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# WAITING, STAYING AND ENDURING IN GENERAL PRACTICE

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Submitted for the degree of Doctor of Philosophy

Birkbeck, University of London, November 2022

### **Abstract**

My thesis asks the question, 'what forms of care can issue from time in general practice, in situations in which nothing appears to improve, or get better?' With its attention increasingly turned towards intractable, complicated, long term and medically unexplained health conditions, NHS general practice is becoming more defined by situations that are demanding in terms of time and effort, but unproductive in terms of obvious clinical outcomes. Yet, there seem to be fewer ways now than ever for thinking about care outside of productionist modes. This is a problem because if we are only able to think about caring for health as an accretive, future making activity, then we risk cutting it off in response to those situations that seem the most demanding and the least promising. My research considers the claim that there are certain 'practices' of care in the NHS that only really begin at the point where progress in medicine drops off, giving rise to the potential for waiting (or not), staying (or not) and enduring (or not) for both practitioner and patient. I establish a method of testing this claim through a series of ethnographically derived 'cases' depicting seemingly unproductive episodes of care in general practice. They are crafted from material collected over the course of one year of observing physical and digital sites of general practice during the coronavirus pandemic in England. This includes interviews with healthcare workers in clinical and non-clinical roles, observations of routine GP appointments, observations of Balint group meetings and personal testimonies of general practitioners made publicly available online. I take an interdisciplinary, interpretive approach to handling this material, combining narrative and theoretical modes, not as a way of yielding a definitive explanation of what happens when the activity of care becomes detached from any definable notion of progress, but, as a way of unfolding the tensions and uncertainties of unproductive episodes and of keeping open the forms that care can take within them. In chapter one, I present close readings of pre-pandemic policy documents addressing the perennial problem of not having enough time in the NHS and offer

different entry points to thinking about how this problem has shaped the relationship between time and care in contemporary general practice. In chapters two and three, I discuss the difficulties involved in observing something as elusive as non-progressive time. Then, I examine Michael Balint's psychoanalytic method of 'making cases' in association with 'difficult' patients, so as to rework this as my own method of using the case as a mode of representation. In chapters four to seven, I test the claim that care can form in non-progressive ways in situations that show how practitioners have tried to offer care in response to inevitable decline, chronic illness, failing infrastructure and ongoing crises in the healthcare system. My findings based on this material, show general practice to be a site where the very possibility for care can rest on the willingness of patients and practitioners to refuse the categories of the epic and heroic in favour of finding other ways of 'getting through'. My conclusion summarises what has emerged from these case studies on the question of how do we narrate the history of pandemic care, and argues for an approach to thinking about time in general practice that looks beyond progress, to the precarious world-making that comes afterwards.

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# I. Introduction

The aim of this research study is to track the forms of care and attention that can emerge out of situations where care as an activity has become detached from any definable notion of progress. In order to do this, I have observed sites of NHS general practice in England, and I have collected accounts of caring in relation to stalled chronic realities. The first half of this introduction is dedicated to setting out and framing the research problem. In the second half, I review the critical theoretical engagements with time and care that have provided me with the conceptual resources needed to imagine a study about non-progressive experiences of care.

#### **Overview**

Between Spring 2020 and Spring 2021, I conducted what began as an ethnographic study of waiting in two NHS general practices. I spoke to practitioners, administrators, and receptionists. I observed meetings and clinical discussions. I watched people waiting in waiting rooms and in consultations. Even though waiting was spoken about mainly in terms of something that only patients did, usually when they were on the outside of care, 'waiting' to get in, I encountered another kind of waiting on the inside of general practice and this form of waiting from within the episode of care as it is happening has become the focus of my study. As many of the most ordinary conditions cared for were chronic, 'complex' or self-limiting (resolving in their own time), it was common for whole episodes to revolve around situations that patients and practitioners were unable either to change, or to move on from. Whilst they were not exactly 'waiting' for something to change or to get better, both practitioner and patient could be caught up in what might be described as 'non-progressive time'. These were long or short durations of time in which nothing seemed to happen of enough decisive significance to bring about a definitive

break in the situation. When a hoped for sign of improvement or turning point failed to materialise, the waiting that predated a person's contact with the NHS did not necessarily come to an end just because an episode of care had begun.

The people I observed during appointments or whose cases I heard being discussed did not all suffer from chronic conditions, although many of them did. To some extent, this reflects the new ordinary of NHS general practice, which is that more than half of all GP consultations are dedicated to the care of long-term conditions (Williams and Law, 2018). The number of those with multiple long-term conditions is also rising and it is becoming the norm for older people, particularly those whose lives have been made more difficult through poverty and other kinds of hardship, to be living for many years with clusters of long-term conditions in different combinations (Powell, 2021; Marmot et al., 2020; Dugravot et al., 2020; Kingston et al, 2018). At the last annual survey of disease prevalence in general practice, the condition with the greatest increase in recorded prevalence was for depression (NHS Digital, 2021), an illness that often exceeds the attempts of general practitioners to treat it with medicine (Sforzini et al, 2022; Thomas et al, 2013). Appointments involving symptoms that do not lead to any organic diagnosis (medically unexplained symptoms) are also often associated with reports of chronic, recurring 'somatization' and they are estimated to account for between 10 to 45% of all general practice consultations (Chew-Graham et al., 2017). Long term conditions can be a source of frustration for practitioners making them acutely aware of the limitations of medicine and leading to feelings of failure when no response to treatment is forthcoming. Ongoing mental health conditions such as depression are known to cause GPs conceptual, practical and emotional difficulties (McPherson & Armstrong, 2012; Johnston et al, 2007; Chew-Graham et al, 2000). GPs can also struggle to know how to respond to unexplained conditions that cannot be named or treated, causing them to feel hopeless and uncertain about whether they are doing the right thing, or fostering resentment towards the patient for placing them in a difficult situation (Shattock et al. 2013; Howman et al. 2016).

<sup>&</sup>lt;sup>1</sup> Somatization is a contested term. See, Noyes, R., Stuart, S. P., & Watson, D. B. (2008). A Reconceptualization of the Somatoform Disorders. *Psychosomatics*, 49(1), 14–22.

What has emerged in my work is a focus on this difficult in-between space that not progressing in the context of medicine opens up. This is where the work of caring for and about chronic, terminal or untreatable problems which refuse to resolve in response to repeated attempts to prevent and manage them, can mean having to stay in the contradiction between 'today's hope and the defeat that comes in the end' (Canguilhem, 1989/2012, p. 66). In making this the focus of my study of general practice, one of my aims has been to try to narrate this labour of persisting in holding on to what feels worthwhile about going on with such a care arrangement, specifically through the engagement with time.

#### Writing about Care during a Time of Crisis

In recent years, a lot of attention has been paid to 'the crisis of care', and to its origins in defensive cultures of self-interest becoming entrenched and self-sustaining under the influence of capitalist, neoliberal and nationalist ideologies (Fraser, 2016; The Care Collective, 2020; Dowling, 2021; Bunting, 2020). As a catalyst for these arguments, the pandemic has provided plenty of evidence of just how reliant we have always been for our shared survival on countless others being willing to carry out poorly remunerated material labours of care and maintenance (Allen, Jenkins and Howard, 2020). Understandably, one of the common themes cutting across this literature has been the correction of an inherited notion of care as exploitable, racialised, devalued, 'women's work', and several of the authors who have worked on this as a problem have offered visions of a more caring world coming out of crisis. For example, Bunting, Dowling and the Care Collective have all wanted to redress the lack of care by stressing its centrality to the reproduction of society, and how it forms part of the fundamental infrastructure that holds society together (Bunting, 2020, Dowling, 2021, The Care Collective, 2020). They argue for the indispensability of infrastructure that is capable of supporting forms of interdependent life, where care is put at the 'front and centre' of a politics of the present (The Care Collective, 2020, p. 6). As an extension of this emphasis on the intrinsic but devalued worth of care, these authors have argued that care is necessary to securing life, survival, and the future. The Care Manifesto for instance, formulates care as 'active' and 'necessary' across every domain of life, and endows it with life-saving potential for bringing 'our world back from the brink of catastrophe' (The Care Collective, 2020, p. 67). In spite of its apparent mundanity and routinisation in everyday life, care is ultimately understood here as holding the key to delivering us from a world in which 'carelessness reigns' (The Care Collective, 2020, p. 6). I understand this need to emphasise the relationship between care and survival, especially at a time when our awareness of our own vulnerability is heightened, but this thesis stands apart from the crisis of care literature in some important respects. My reluctance to write about care through the valorising narrative of crisis comes in part from seeing for myself how the concept of survival mobilised through crisis can be undermining of actual attempts to care.

My own lived experience of care work from the mid 2000's onwards; first as a home care worker, then as a social worker, mainly involved offering support to people whose social problems and mental health conditions were inextricable, ongoing and often intergenerational. In these contexts, it could be impossible to know whether 'care', or what we thought of as care, could be having any effect in the ways that we hoped that it would. Sometimes there might seem to be a correlation between the amount of time spent with a person and the likelihood that some good would come of it. A person who was being cared for may be more likely for instance, to remember to take medication, pay their bills, or attend an appointment with their GP. But these small efforts at maintaining the appearance of some kind of order would often have little or no bearing on the bigger picture of their life. By orientating the work of care towards the possibility of transcending what is most bewildering, unsatisfying, open-ended and sometimes doomed about it, the focus on survival can screen over the ambiguities that make care what it is. It can also harden lines between what is, and what is not worthy of being an object of care. In my experience, this can undermine the project of trying to care about the things that are the most demanding in terms of time and effort whilst being the least promising in terms of their chances of either thriving or surviving. In the community mental health setting where I was employed as a social worker, care work would routinely involve calling somebody three times a week when it was obvious that they did not want to speak to me. It could involve spending more time with somebody as they slid predictably into their third acute psychotic episode of the year. Quite often it would require me to make repeat visits to see a person whose current level of drug use foretold the likelihood of an early death regardless of anything that I might do, or say to change that. The experience of offering care in situations like this, where no clear line of progression exists that could lead to anything like health, independence, survival or a longer life, could be characterised by feelings of failure, anxiety, indecision, occasionally anger or irritation, occasionally boredom, resignation and ambivalence.<sup>2</sup>

As Fiona Wright has observed, there is a 'temporal knot' at the heart of an ethics of care in crisis (Wright, 2022, p.316). Mobilisations of crisis narratives in the NHS need to be placed within the wider paradox of crisis as a mode of organising experience into events. This is the paradox that, although crisis (krino) signifies a singular, decisive moment – one that reveals the truth of a situation, sets the scene for a transformation, and offers a temporality upon which one can act and consequently bring about change, crisis in 'our time' refuses to culminate in the decisive event that we have been led to expect (Roitman, 2013). Whilst the NHS's long-standing adherence to a crisis narrative implies a gathering of forces at critical, decisive moments, it denies the fulfilment of the hope for any end to this crisis. This can have the effect of further weakening our capacity to engage in tenuous attempts to care for things that may or may not benefit, because when care is read 'through' crisis, or through the spectrum of emergency, a particular kind of present is produced. To use Ben Anderson's term for this, an 'emergency present' is produced in association with particular temporalities - exceptionality, urgency, interval and hope (Anderson, 2017, p. 466). Crisis produces hope but in a way that requires that the demands of the present be put on hold.

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<sup>&</sup>lt;sup>2</sup> This is different to the kind of ambivalence that comes from being reminded of our own mortality through 'the handling of 'abject' flesh' that can be involved in 'hands on' caring (The Care Collective, 2020, p. 25).

So, whilst making a crisis out of care may go some way towards achieving the rhetorical aim of injecting optimism and energy into what can sometimes feel like a losing battle, there is also a perpetuation of 'cruelty' (Berlant 2011) entailed when care is lifted out of the obscurity of everyday life and imbued with the magical telos that it may seem to have been lacking. Crisis narratives tend to invest care work with a kind of heroic agency, whereas in reality it can often feel more like an 'ongoing failure to reach the desired critical turning point' (Wright, 2022, p. 32). In other words, care work defined as active, hopeful and efficacious in response to an emergency present simply does not match up with the embodied experience of caring for chronic realities.

Another decade of crisis has passed since Roitman asked her speculative question, 'what are the possibilities generated by suspending crisis as the foundation of narration and critique?' (Roitman, 2013, p. 72). Without seeking to undermine a belief in the ability to manage or overcome that it might take a crisis to mobilise, this thesis joins her in reaching for alternatives that look for a different starting place from which to posit a relationship to time and the future. As you will see, this has meant to some extent having to try intentionally to fall 'out of step' with the anticipatory, future orientated temporalities of crisis, without really knowing where this will lead.

#### Situating the Research

This research forms part of a wider research project<sup>3</sup> that has investigated experiences of waiting and delay forming a part of healthcare but under conceptualised, in part because they are so mired in crisis narratives of failure, survival and impending disaster (Baraitser and Salisbury, 2020a). One of the

<sup>&</sup>lt;sup>3</sup> The 'Waiting Times' Project was a multi-stranded research project on the temporalities of healthcare. It ran from 2017 to 2022 and was supported with funding from the Wellcome Trust [Project number 205400].

theoretical differences setting this work apart from the care in crisis literature is the decision not to read care solely through the role that crisis can bestow on its essential functions. This is part of a collective endeavour to know about healthcare through its embodied, durational temporalities, and also to find ways of knowing about the crisis in healthcare, that have the potential to produce different futures, i.e., those that do not depend on crisis in order to understand themselves. I see this effort to avoid reading care out of crisis as part of an attempt to avoid the trap of responding with an 'anti-crisis' of care (Roitman, 2013). It alters the orientation of the work from finding solutions and offering alternatives, to experimenting with what it might mean to begin to 'narrate a future without crisis' (Baraitser and Brook, 2021). For me, this has involved having to learn how to be speculative to some extent, and to 'jump with both feet' (Stengers, 2009) out of a world in which the only public conversation to be had about time and care in the NHS is the one that has been made possible by a crisis notion of time, i.e., a notion of time as something that can be acted upon, and of change as something that is always possible.

The Waiting Times project was interdisciplinary and this is reflected in the different approaches taken to thinking and writing about non-progressive temporalities of healthcare. By giving us the histories of the NHS through its record of being an institution that has always required waiting of some kind, the historian Martin Moore's work complicates the familiar crisis narrative of waiting as an exceptional sign of things breaking down in the present (Moore, 2021, 2022a, 2022b). He shows us that some experiences of waiting would probably not be imaginable without the existence of a National Health Service. These include certain experiences of delay, for instance those built into NHS appointment systems and waiting rooms which have been made necessary by the shared temporal economy of a collectively funded healthcare system. Moore's cultural histories of waiting suggest not only that the tensions and paradoxes of non-progressive temporalities have recurred in the NHS ever since its inception, but also that they belong in some way to the same orderings as those that have enabled the practices of care that have come to define it. More pronounced tensions come to the fore in his work on the wider historical questions of who the NHS has historically been willing to wait for, who it has not considered worthy of waiting for, and who has been doing the work of waiting all this time. In connection with this, Moore reminds us that there is a history in the NHS of prioritising care and resources 'towards those who might be considered productive or reproductive, and...seen to be reproductive of particular national subjects' (Moore, 2020).

In other NHS intersecting strands of the project, researchers have engaged with how non-progressive temporalities adhere to particular sites of clinical care. In the strand of the research focusing on end-of-life care for example, Kelechi Anucha encounters a form of something like non-progressive time in the stretch between diagnosis and death which, as she writes, 'emerges as a time to be endured...'. She describes this experience as having qualities that make it 'untimely' because it is 'out of sync with dominant linear narratives of recovery and heroism'.4 Also, in her NHS based work with adolescents in crisis, the psychotherapist and researcher Jocelyn Catty encounters another form of time that must be endured in the adolescent 'protestation against the seemingly relentless temporal thrust towards the future: an attempt to halt progress, even at a terrible cost' (Catty, 2021, p. 189). It is not that the temporalities of crisis are bracketed off from these narrations of time losing its flow. It is more that the focus is turned towards how crisis is experienced in affective life as a crisis of time in which the present has become distended, having lost its facility for passing into the future. When trying for example, to understand the reasons for why the idea of time passing might be felt to be so unbearable for a young person living now, Catty reminds us that those born at the turn of the 21st century are members of a generation that has already been disadvantaged in terms of the ability to project a future life with any certainty. Whilst on the one hand, these young people have been kept 'forever active' due to the relentless pace of modernity and technology, most of them do not have the resources that they would need to be able to predict or to plan for what will happen to them in the time to come. They cannot know whether they will have a home, a job, or a chance to retire. So, they find

<sup>&</sup>lt;sup>4</sup> Anucha, K. (2022) Out of time: temporality, form and fugitive care in contemporary literature and culture. *Waiting Times*. Retrieved Oct 2022 from https://waitingtimes.exeter.ac.uk/the-work/out-of-time-temporality-form-and-fugitive-care-in-contemporary-literature-and-culture/

themselves 'waiting for an uncertain future' (Catty, 2021, p.190). From within this temporal predicament Catty suggests, it is perhaps not so surprising that some young people might feel something like rage. Rage against the 'apparently relentless march of time that propels the adolescent towards a troubled, uncertain, or even apparently cancelled future, perhaps even while they feel frozen in a traumatic past' (Catty, 2021, p. 194). Thought about in this way, a young person's act of suicide or deliberate self-harm may be understood at least in part as an act expressing the refusal to progress, and as an attempt whether in fantasy or reality, to 'stop time altogether' (Catty, 2021, p. 194).

Running like an undercurrent through all of this work on waiting is the notion that states of waiting and delay might hold within themselves the possibility for care, as conceptualised by Lisa Baraitser in her book, Enduring Time (Baraitser, 2017). Developed out of psychoanalytic theory in conversation with feminist thought, Black thought and queer thought, Baraitser theorises a way to understand what it means to care for others in terms of the making of a claim, 'a small theoretical gesture, that may turn out to be the gesture that gives time' (Baraitser, 2017, p. 17). One of the shared endeavours of the collective project been to somehow put these understandings about the relationship between time and care into contact with the realities of an NHS in crisis. Ideas about what clinical form this might take, how and for whom the time of not progressing might be expected to play out and with what sort of results, have developed along different lines. One of the directions this has taken is to have thought about how the NHS may still be able to care from within crisis by helping to create situations in which the passing of (crisis) time is made 'less threatening' (Catty, 2021, p. 202). Staying broadly within the theoretical framing of psychoanalysis, this assumes that within the context of an ongoing relation of care, it might still be possible to live with, and through, the painful experience of not being able to imagine any future beyond an irreparable present. This is a postive orientation to the idea of having to wait for an uncertain future; one in which the NHS, by offering to wait with, and for, its patients, could allow something like 'a slowing of time, even in the midst of crisis' (Catty, 2021, p. 200).

#### The Focus of my Research

My own engagement with non-progressive time follows the same vein of hope, that waiting time might also be 'a time of care in and for the present' (Baraitser & Salisbury, 2020b), but the direction I have taken with this, has been to make what might be described as a phenomenological study of what such an experience might entail. In my observations of general practice, people did not necessarily share the optimism that through their efforts, they were helping to make an unbearable present more endurable, either for themselves or for their patients. When the assuredness that comes with the psychoanalytical investment in time's therapeutic potential is frayed or absent, the experience of offering time to chronic or untreatable conditions may be divorced from the promise of things getting any better. Baraitser & Brook touch on this in their account of an episode in general practice where the practitioner describes 'bending the books' so to stay in contact with a patient, without knowing exactly what could be achieved by this.

There appears to be some attempt by patient and doctor to go on being in contact, even as the dependency is hated, as the overt offer of care is experienced as intrusive, patronizing, inappropriate. 'Bending the rules' to stay on the books neither responds, nor does not respond to the current crisis, but could be understood as a commitment to going on without decision or judgement about the right course of action.

(Baraitser & Brook, 2021, Chapter 11)

From this description as the authors point out, the fact of 'going on' without quite knowing why, cannot really be described as waiting *for* something in particular. Any resemblance to what we might usually think of as care is hard to define. Even the possibility of something good forming out of a relationship is doubtful, in a context where 'relationship may be only relevant in the loosest sense' (Baraitser & Brook, 2021, Chapter 11). Yet, in a setting where speed, outcome and movement are

assigned the highest values, to keep offering time 'without decision or judgement', does imply its own form of unplanned and unthought out endurance. Alongside the work of consciously turning this gesture of delaying or suspending the move to act decisively, towards its potential as a temporal mode of care in the NHS (Baraitser and Brook, 2021; Baraitser and Salisbury, 2020; Catty, 2021), I have wanted to look at what it means to make the offer of time in light of what is seemingly hopeless about such a gesture. This would need to include for example, a weakened investment in the idea that the 'chronic thing', whether that is a problem of embodiment or the beleaguered NHS itself, will eventually subside, give way, or recover. This does sometimes happen. People do sometimes get better. Catty describes for instance how holding 'an authentically hopeful image in mind, alongside the violence' may be what helps to sustain an offer of time during a long wait for somebody to get better (Catty, 2021). But for some, the experience of offering this kind of care in the processual present may be more defined by the feeling of going on, sometimes anxiously, sometimes with ambivalence, but crucially, without expectation of anything ever getting better, at least not to the extent that it represents a break with the past or the start of something new. This suggests that there are spaces of endurance in NHS workplaces that do not always know why they endure and that cannot be grasped in the language of progress, duty or even of care narrowly defined. Trying to understand them through the overdetermined traditions and practices of the NHS tends to collapse us back into heroic narratives of medicine that have little in common with how it can feel to actually stay, wait or endure (or not) in relation to chronic conditions. One reason for wanting to put these experiences into dialogue with critical theories of time and temporality is to see what critical perspectives they can provide on the formation of late liberal power (Povinelli, 2011). This work is also a continuation of a wider conceptual effort to shift the orientation of collective attempts to organise care from centring around matters of fact in biomedicine that want to preserve, prolong or perfect biological life, to a kind of care that does not try to cure us of death or interdependence, but that understands its own limits, possibles and consequences (Kaufman, 2015, Clare, 2017).

## II. Review of the Literature

With its onus on productivity, capacity and the linear movement from appointment to outcome, the prevailing model of time in contemporary general practice has not been able to provide me with the conceptual resources needed to understand non-progressive experiences of care. In this introductory section, I look further afield to bring together strands of work across disciplines that have been some of the most influential in providing me with ways of understanding the experience of not being able to move on from the present. In the first part, I look at the contribution of feminist and queer critical engagements with theories of durational time, reproductive labour and time that unfolds away from futurity. In the second part, I look at the theorisation and representation of temporal modes that engage with the experience of a protracted present, through their relationship to care, time, the body and the NHS.

#### **Overview**

In this introductory overview of work on critical engagements with time and temporality from the past few decades, I look at some of the different formulations of non-progressive time that have been so influential over my own psychosocial approach to understanding the relationship between time and care. I begin by looking at some of the feminist configurations of durational time that have been developed in association with a corporeal experience of time lived through the body. Then, I turn to queer theorising about time and particularly in relation to the critical work on the future that has characterised the temporal turn in queer theory. Following this are some examples of phenomenological inquiries into waiting as a mode of being in 'time without value' (Schweizer, 2008). The final sections give a summary of some anthropological studies of crisis in late capitalist time and its

undersides in chronicity, exhaustion and waiting. When referring to non-progressive time, I sometimes refer to waiting (Hage, 2009; Bissell, 2007), at other times to confinement in time (Mbembe, 2020), at other times to a state of suspension. In doing this, I do not mean to suggest that these modes are interchangeable. In fact, I hope to show that there are qualitative differences between and within them. However, my aim is not to provide a typology of non-progressive time, but to look at how the experience in general, of not being able to move on from the present, might be understood through its relationship to care.

#### Feminist Theories of Durational Time

Feminist engagements with temporality have tended to emphasise the body and gender in time, the complexities that derive from being immersed in time, and time as constituted in and through relationships. At different points within the last seventy years, calls have been made for a feminist account of time (Beauvoir, 1949; Kristeva, 1981; Grosz, 2004). Julia Kristeva for instance, argued that the female subject has not yet found a language to describe its irreducible differences of 'intrasubjective and corporeal experience' (Kristeva, 1981). In her landmark essay in which she provides the impetus for other feminists to 'untime' progressive, linear history, female modalities of being in time are defined expressly against the time of 'epic' history which she associates with masculine subjectivity (Kristeva, 1981). Engaging with the idea of a feminist account of time, Elizabeth Grosz draws on the philosophical work on time of Henri Bergson (1889/2008; 1922/1999), Gilles Deleuze and Félix Guattari (1968; 1980; 1991) to develop a theory of temporality understood as both continuous and discontinuous, enduring and changing (Grosz, 1999; 2004; 2005). In another strand of feminist work on time, postcolonial and Black feminist theorists including Gayatri Chakravorty Spivak (2012), Saidiya Hartman (2007) and Christina Sharpe (2016) have engaged temporality through the subaltern themes of continuity, erasure, pathos and living on. These developments have all been influential over how I have come to understand non-progressive temporalities and their implications for why time in late modernity might feel a

certain way. In this discussion however, I focus on the idea of processual and durational time based on the work of Elizabeth Grosz and Lisa Baraitser, its difference from time understood as forward linear progression and the relationship between this non-progressive notion of durational time, and the reproductive labour of keeping something going (Arendt, 1958; Beauvoir, 1948; Diprose 2002; Tronto and Fisher, 1990; Frederici, 2004).

To convey how non-progressive time might be lived in and through the body requires a way of speaking about time as an interiority rather than as an outwardly extending space. For Bergson, whose theory of time has been important for feminist philosophy including, arguably, for the work of Hannah Arendt (1958) and Luce Irigaray (1985a; 1985b; 2017), the passing of time is sensed through our awareness of the perpetual movement of one conscious state succeeding another. Bergson's usefulness for feminist thinking on time is that he makes explicit the bodily and conceptual cost of reducing time mathematically into numbers and spaces. In grasping time in terms of its 'qualities', its 'states of becoming' (1889/2008, p.128) or as 'a qualitative multiplicity with no resemblance to number' (1889/2008, p.105), Bergson provides an alternative conceptual framework. For Grosz, these are the conceptualisations of time that have enabled the human subject to think of themselves as being in time in a new way, '...it is we who are in time, rather than time that is in us; it is time which inhabits us, subsists or inheres within and beyond us as the milieu of the living and as the order and historicity of the universe itself' (Grosz, 2005, p. 3).

Deleuze's contribution to the development of a feminist notion of time is to have understood time not only as a passive unfolding or wearing away, but as a process of dynamic becoming; the duration of life and history proceeding 'not through accumulation, gradual accretion or the unfolding of a blueprint that was already worked out, but 'through division, bifurcation, dissociation – by difference' (Grosz, 2005, p. 111). Also influential for a feminist understanding of time and the present, is Deleuze's notion of 'the event' as 'coextensive with becoming' (Deleuze 1968/2004, p. 18) which I will return to later. Conceptions of feminist temporality

based on Bergson and Deleuze's philosophies of time and becoming are those in which the future is unknown, in which we are 'present to the present' (Badiou, 2007, p. 39), where the temporal movement forward is more of a leap, loaded with potential, as distinct from a progression through linear time.

Working with this notion of time as durational, Lisa Baraitser theorises what it means to substitute our own time for the future of somebody or something else as a practice of care. In her words, this implies a willingness to endure as 'a modality of being in time where I am not the site of the work of time passing' (Baraitser, 2017). In *Enduring Time* (2017), this is formulated as a 'durational practice of care' in reference to how the time of one person is used up in the activity of maintaining and keeping 'things' going for another. 'These practices are (usually hidden) forms of labour that maintain the material conditions of ourselves and others, maintain connections between people, people and things, things and things, people and places, and social and public institutions, along with the anachronistic ideals that often underpin them, and that constitute the systems of sustenance and renewal that support 'life' (Baraitser, 2017, p. 49).

Durational practices of enduring time provide a model for thinking about other, similar kinds of practices in which something or someone is maintained, supported or enabled to persist as a result of somebody else's willingness to remain in a situation of nothing happening. My research looks at how this might work in everyday life healthcare contexts where practitioners do often find themselves having to work out a way of continuing to care in relation to 'the *non-event*, the not-yet-happening...' (Baraitser, 2017, p. 15), but where it may not be clear at all what, if anything, is really being maintained, supported or enabled to persist as result of their fidelity to remaining in situations of enduring time. To live non-progressive time in this sense could mean having to live without a project of my own, to be 'without project' (Baraitser, 2017, p. 61), and yet to still not have any guarantees as to whether this is helping to support or sustain anything as a result.

Feminised labours of care that have no masculine telos, no 'project' to speak of, are described by Hannah Arendt as reproductive labours because they entail the daily repetition of tasks that reproduce life, but without producing any artifice of durable value (Arendt, 1958). Arising out of the necessity to cope with birth, growth and decay, the purpose of this kind of labour is usually to support life, or in Arendt's words, to use one's own body to 'minister to the needs of life', by maintaining the conditions needed to keep it going (Arendt, 1958, p. 73). As Arendt observes, the temporalities of this kind of reproductive labour are endless and potentially depletive. This type of labour 'uses up durability, wears it down, makes it disappear' (Arendt, 1958, p. 96). Simone de Beauvoir makes a similar distinction between productive and reproductive labour in her own work on the temporalities of labours of maintaining. She writes that whereas man's project is not to repeat himself in time, but rather to 'reign over' the instant and to 'forge' the future, women who are subordinated to domestic roles are not called upon to build a better world (Beauvoir, 1949/1989). In a life that is dedicated to reproducing the conditions needed for life to persist, there is no 'scattering of instants' (Beauvoir, 1949/1989, p. 53) or what we might call, 'events', because one moment of maintaining is impossible to differentiate from another. It goes on for as long as life makes this necessary.

In her well-known definition of care as 'a species activity that includes every-thing that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible' (Fisher & Tronto, 1990, p. 40), Joan Tronto also puts the labour of maintaining at the centre of what it means to care. In theories of social reproduction, organised forms of care maintenance work can be associated with cyclical temporalities of ongoingness leading to exhaustion and organised wearing out. When we consider all of the reproductive care labour required to support collective forms of life, this also has to extend to all of the paid and unpaid labour in its many different forms that is needed today to sustain and maintain social institutions including the NHS. Depletion of the reproductive labour force can happen through organised neglect. As Silvia Federici argues, social institutions have been assigned many of the reproductive labours that might formally have been expected to come

from the family, and this has resulted in divisions of labour along classed, gendered, racialized, and colonial lines (Federici, 2004; 2018).

Feminist theorisations of time as something that must be endured can help us to understand what might be difficult but also necessary about caring for chronic things, but in general practice where the boundaries between productive and reproductive labour are blurred, the situation is more complicated. Where, for instance, do we look to find care's 'non-event' and 'not-yet-happening...' (Baraitser, 2017, p. 15), within a system in which every minute of caring activity is assigned a purpose and an outcome? How does the reproductive labour of healthcare co-exist with the predictive, linear narratives of scientific-bureaucratic medicine? One of my aims is to look at what constitutes the durational labour of healthcare in this slower domain of medicine where timeframes tend to be longer, and to acknowledge its similarities and differences from reproductive labours of maintaining and sustaining.

#### **Queer Temporalities**

Three of the main strands of thought in queer theory have been influential over my own development of a language for time in the context of care and medicine. One is the examination of queer subjects in relation to the inexorably progressing linearity of 'straight time' marked by the graduation to heterosexuality, family and reproduction (Halberstam, 2005; Ahmed, 2006). A second strand running on from this is the association of productivity and progressiveness with the movement towards, and reproduction of, the future at the expense of the present. Elizabeth Freeman's term, 'chrononormativity' to mean 'the use of time to organize individual human bodies toward maximum productivity', is one of the most well-known formulations of this (Freeman, 2010, p. 3). Another is the rejection, or in some cases, the affirmation of a failure to progress, or to reproduce the temporality of futurity that keeps us firmly orientated towards the future (Edelman, 2004).

In their articulations of crip temporalities, theorists including Alison Kafer (2013; 2021), Leah Lakshmi Piepzna-Samarasinha (2018) and Moya Bailey (2019), have extended this intervention of queer theory into the realm of disability studies, forming critical engagements with time and disability that go beyond the problem of needing more time. An important aspect of this work of queering 'crip time', has been to work out how it unfolds away from futurity framed in curative terms (Clare, 2017; Hedva, 2016; 2022). Timeframes that are governed by curative imaginaries tend to cast disabled people as out of time, or as obstacles to progress. Kafer writes that this is because within the temporalities of curative time, 'the only appropriate disabled body/mind is one cured, or moving towards cure', and the effect of this is that 'disabled bodies are held outside of narratives of progress until they are in some way, 'cured', at which point they become the 'sign' itself, of progress' (Kafer, 2013, p. 41). As Clare points out, the problem with cure, is that it always 'operates in relationship to violence' seeking to eradicate the sick body in preference for another, healthier body (Clare, 2017, p. 28). One of the defining characteristics of queer theorising about time along these lines is the will to actually desire non-progressive, finite temporalities, and the way that this brings us back endlessly to the incurably demanding body and to presence, even when it might not be clear where such a desire will take us, or whether it can realistically be borne out in ways that can ensure the care of the body, or its survival.

Temporalities of suspension, especially those that arrest productive temporal rhythms can bring relief from notions of progression as the default mode of the body. Ellen Samuels and Elizabeth Freeman found this to be true during the pandemic in which they saw the potential for catabolically sloughing off chrononormative capitalist structures and taking back the time that they had stolen. 'What if we all simply took as much of our time as possible back from late capitalism? What if we developed new forms of punctuality centering on presence, simultaneity, and concurrence: new ways of being together in time—perhaps even ones that valued stasis and the present rather than motion and the future?' (Samuels & Freeman, 2020, p. 252). These questions also underlie Hil Malatino's paper in which he laments 'future fatigue' in the lives of trans people who are stuck in the lag

preceding a desired future of a present lived as the period of trial and potential duress (Malatino, 2019). Malatino asks about what would happen if people who are waiting for gender transition were to stop subscribing to narratives of 'it gets better' in which the promise is implicit that, 'as one takes steps to bring their embodiment in line with their gender identity, a radical metamorphosis takes place that makes the rhythms and patterns of everyday life easier, more bearable, and less traumatic'? (Malatino, 2019, p. 639). In these accounts that posit a dwelling together in 'lag time', linear narratives of getting better can actually be an impediment to flourishing. This poses a problem for the kinds of medicine that depend upon linear categories like prognosis, remission, recurrence, and pre- and post-transition, as a way of conceiving disability and transness (see Jain 2007; Kafer 2013; Samuels 2017; Clare, 2017). In suggesting that it might be possible to desire 'crip time' (Kafer, 2013), or to live out a whole life in 'lag time' (Malatino, 2019), queer theorising is not asking that progressive temporality is rejected or dispensed with altogether. Its proposal is for other, more realistic ways of thinking about what it means to be stuck together in a protracted present, with all of the difficult demanding, desirous, dealing with 'presence', that this inevitably entails. If formulations of care in queer and crip studies of time tend to be imperfect, open-ended, makeshift, awkward, this is because there are no solutions put forward for how to care in relation to such a presence (Piepzna-Samarasinha, 2018). The NHS is a problematic place to experiment with being stuck together in the way that these authors describe. As Kafer and Malatino have pointed out, queer commitment to the present is unpredictable in its consequences and it sometimes relies upon people being willing and able to tolerate the intense demands of being beholden to one another with no end in sight. General practitioners have been accused in the past of exempting themselves from having to absorb the negative effects and threats to autonomy that can ensue from being in demanding long term patient relations (Frankenberg, 1988). But in their routine clinical lives, whether they want to be or not, practitioners are repeatedly brought back to the body with all of the frustrations, fatigue, struggle, disappointment and enmeshment that this can entail. Queer and crip perspectives on time have tended to define themselves against normative understandings of health (Clare, 2017; Hedva, 2016), but this suggests that the

protracted, lagging temporalities that characterise some of these perspectives on care, may also need to emerge somehow within institutional spaces of healthcare.

#### Care and Time in Science and Technology Studies

Technoscientific, environmental and biomedical engagements with time and matter in the life sciences are taken up in the work of Georges Canguilhem (1966; 1989) and Donna Haraway (1997), and in quantum physics by Karen Barad (2007). Here, I am focusing on recent feminist engagements with time and care in Science and Technology Studies and their reliance on temporalities of everyday life (Certeau, 1984). In this field, where the discourse around care has grown over the last decade, (Despret, 2004; Mol, 2008; Mol et al., 2015; Myers, 2015; Bellacasa, 2011; 2017), researchers have turned away from care as a timeless abstraction that claims to possess some kind of absolute value. The emphasis is more on the work of care; not the moral work, but the 'layers of labour that get us through the day' (Bellacasa, 2012, p. 210). STS temporalities are those that come from below, attuned to what lies 'beneath technology and disturbs its operation' (Certeau, 1984, p. 200). This is time that cannot be calculated using the temporal logic of technoscientific accounting in that it not 'governed by market temporalities and demands, and it is not synonymous with productivity' (Martin, Myers & Viseu, 2015, p. 6). When looked at from 'without', it might appear only as 'a lacunae in production' or as 'the darkness that leads up to an accident', rather than as ubiquitous and as constituting a constantly active totality holding up the surface (Certeau, 1984, p. 201).

Some STS research has also focused on the ontologization of care out of 'messy substances' (Mol, 2008), 'mundane material cultures' (Buse, Martin, and Nettleton, 2018) or 'laborious and devalued material doings' (Bellacasa, 2011, p.95). Unravelling the 'true social content of good healthcare', for instance, is one of the objectives that Anne-Marie Mol sets for herself in, *The logic of Care: Health and the Problem of Patient Choice* (2008). From her close observations of how diabetes care is being 'done' in practice, she finds that this consists in materialities that perform

care when faithful to the right kind of logic. They involve the sort of 'doctoring' as she calls it, that breaks down into 'fragile bodies and not quite predictable machines' (Mol, 2008, p. 105). Within this perspective, the logic of care relies on a willingness to deviate from the static models for making healthcare by being 'transgressive' – which for Mol, means engaging in the concealed practices that can still materialise good healthcare regardless of what is protocol for the institution. This implies deviation from sequential linearity, and a refusal of 'key moments' to allow for the 'twisting and turning' trajectories of care (Mol, 2008, p. 62).

Whilst the focus on material things can lead to time becoming a neglected area of study in STS work on care, this is not always the case. Maria Puig de la Bellacasa restores time to matters of care by attending in scientific detail to what is necessarily relational about our engagements with matter. 'Care time' in Bellacasa's definition is 'time consecrated to the reproduction, maintenance and repair of ecological life' (Bellacasa, 2017). It arises out of a relation of care and it depends upon this relation being sustained against the likelihood of time wearing, disrupting, displacing or depleting. STS engagements with networks of caring relations can also provide us with a way to speak about ambivalence and contingency in environments where care is seen as standardised. Evidence of the radical indeterminacy of heterogeneous interdependent forms and processes of life and matter are inconvenient for technoscientific modes of producing care on a massive scale. For one thing, an ecological understanding of care entails having to know that it is not something that can be 'forced upon living beings by a moral order' (Bellacasa, 2011, p. 198). Also, whilst we depend on it for our survival, care is full of contingencies. For instance, even in those cases where a caring relation does exist, its effects on the other cannot be calculated, 'one does not know in advance where this attention will lead' (Martin, Myers & Viseu, 2015, p. 6). STS formulations of care show us exactly why its activities can never go on without interruption, and why it is unscientific to try to think care in terms of its potential to either make progress or not, but in human care environments, these approaches have so far tended to exclude or minimise the relational dimension so as to focus on the minutiae of the materials and orderings needed to make 'good' health care. One of the problems with doing this is that it runs

the risk of reducing all caring activity to processes of production which leaves very little scope for understanding how care might be formed in situations where there is no visible production outside of what happens within the care relation itself.

#### Phenomenological Accounts of Time Without Value

In the growing fields of affect theory and for theorists of new materialities and object-orientated ontologies, the privileging of Whiteheadian methods of grasping entities as 'presence', and Deleuze inspired notions about the dynamic potential of being in time, has meant that even the most uneventful activities can be regarded as totally generative. The state of simply waiting for instance, can be seen as buzzing with potential when envisioned as taking place in a field of infinite possibilities as to where it might lead and what forces might be set in motion through it. In this section, I look at four accounts of waiting as a mode of being in time 'without value' (Schweizer, 2008), focusing on their representation as unwilled embodied states which nevertheless, are still seen as lively and dynamic. They suggest that non-progressive time is not synonymous with unproductive time, but that there are also reasons to be cautious about this tendency to want to extract value and purpose from waiting-like states which are defined in part by their quality of keeping the body suspended, passive or enthralled to something else.

In Kathleen Stewart's anthropological work on 'ordinary affects' (Stewart, 2007), waiting is one of the default modes of the affective human subject. It describes the condition of being latent — of not yet having caught up with what is happening but of needing to, and of not yet knowing but of needing to know, what we are in the process of becoming. A person who waits is, 'one who learns to sense out what's coming and what forms it might take, one who aims to notice what crystallizes and how things ricochet and rebound in a social-natural-aesthetic ecology of compositions and thresholds of expressivity' (Stewart, 2017, p. 194). In these accounts, waiting is construed as a heightened state of receptivity, made even more vital by the fact that it cannot ever be fully grasped or known about by the one

waiting. The body is a conductor of the present charged with anticipation about what is coming next. Berlant and Stewart compare the experience to '...feeling the electricity without knowing where it comes from or having an intention' (Berlant and Stewart, 2019, p. 65/66).

For the geographer David Bissell, waiting is conceptualised as an event and as a 'complex' — 'a variegated affective complex where experience folds through and emerges from a multitude of different planes' (Bissell, 2007, p. 278). This would seem to suggest that whilst not instrumental in bringing something about that has been willed, waiting as a way of being in time is productive in terms of how the body is animated or induced into experiences of being moved about on an affective level. Though taking place in time during which the future is being withheld from us, waiting is still conceived as a mobility, happening 'within the space of flows' (Castells, 1996, p.411).

In Harold Schweizer's reading of what it means to 'simply wait', in waiting, we are submerged in time that is essentially without any ostensible value, but through this, we are opened up to a qualitatively different experience of being in time, one where we live the present, not less, but more intensely in an existential sense. He articulates this through Bergson as an experience of time entering our bodies, so that 'we are the time that passes' (Schweizer, 2008, p. 128). Again, waiting is understood to hold the potential for a more than usually productive time in terms of how it has the capacity to affect us. For Schweizer, certain experiences of waiting can be profound as they allow us to fall into the intimacy of lived time which we would usually be trying to escape from.

One of the conceptual problems with emphasising what is teeming, busy and mobile about the body in states of inactivity or suspense is that other aspects of human experience may be being neglected or denied in the process. For instance, how are we to reconcile a statement such as, 'everyone lives the historical present intensely' (Berlant, 2011, p. 54) with modes of being in time that do not feel at all intense? In contrast to the expanding field of work on embodiment that wants to see the body

as being always knowingly or unknowingly active or productive in some way, Paul Harrison's work on embodied states of stillness, vulnerability and non-affirmation (Harrison, 2008; 2009; 2015) enables questions about the qualitative differences between dynamic and sedate ways of being in time. Staying wary of depictions of the human body in which no sense is given, of the 'effort, exertion, and the accordant happenstance which are inherent to all corporeal action' (Harrison, 2009, p. 994), requires that more thought be given to the problem of how to describe the negative capacities of waiting-like states. In my project's concern with a kind of sociality that is conspicuously unproductive, at least from a capitalist economic point of view, this raises an important question about how to write about waiting, staying and enduring bodies in ways that do not only succeed in erasing them further. Thinking corporeal existence through those aspects of experience which take more the form of a falling away from the present than of an intense living of it, means having to actively avoid reconstituting these experiences along productivist lines.

#### The Temporal Modes of Late Capitalism

There is now a growing number of anthropological studies and theoretical works investigating the landscapes and temporal modes<sup>5</sup> characterising the historical present referred to at different points in this discussion as 'late capitalism' (Roitman, 2013; Cazdyn, 2012; Sharma, 2014; Povinelli, 2011; Hage, 2009; Tsing, 2017; Vigh, 2008). I share their interest in questions that have been foreclosed by decades of crisis being posited 'as the very condition of contemporary situations' (Roitman,

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<sup>&</sup>lt;sup>5</sup> Temporal modes offer categories through which to think and to feel a certain time more intuitively and perhaps also more sympathetically. They work by configuring the histories through which things are figured into existence or to put it another way, they modulate how we experience the time of events. 'Modes of eventfulness' like crisis, emergency and waiting (Berlant, 2011; Anderson, 2017; Hage, 2009) are what constitute 'the affective-ideational resources available to make sense of how existing states of affairs fall apart as harms, damages and losses materialize' (Anderson, 2017, p. 465). They can organise our experience of time by offering particular ways of relating past, present and future, as well as specific assumptions about how those events will play out and what they might mean. For example, the assumption that a crisis will lead to demands for things to be different in the future can make the time as lived through the mode of crisis, feel more urgent, intense, precipitous (Roitman, 2013; Mbembe and Roitman, 1995).

2013, p. 10). I also share the concern expressed by some of them, with what happens when states of emergency become ongoing, protracted, ordinary, and an accepted means of stabilizing an existing condition (Masco, 2017; Anderson, 2021). More particularly, I am concerned with what lies beneath ongoing states of crisis and emergency, in the experiences of exhaustion and waiting for things to get better that can come to characterise everyday life amidst crisis (Hage, 2009; Povinelli, 2011). In this section, I look first at the conceptualisation of temporal modes as a method of categorising different experiences of late capitalist time, before and during the pandemic. I go on to summarise contributions from anthropologists who have studied different aspects of the temporal mode of waiting, said to be characteristic of late capitalist time with its temporalities of 'stuckedness' (Hage. 2009). In the final section, I come back to the context of my own research in reference to Sophie Day's anthropological study of that exemplary experience of being in non-progressive time known as 'waiting in the NHS' (Day, 2015).

#### The Everyday Life of Crisis

The mode of 'waiting out' a crisis that the anthropologist, Ghassan Hage introduces in his anthropological work on waiting and governmentality takes the counterintuitive form of inactivity. This is what Hage refers to as 'stuckedness', where the wait for the crisis to be over represents a period of forced immobility which must somehow be endured. Crisis understood this way, through the experience of waiting can modulate or materialise events differently to how we might expect. Hage observes this when he writes that 'the analytical power of waiting amidst crisis derives from its capacity to highlight certain features of a social process that might have hitherto been foreshadowed by others or entirely hidden' (Hage, 2009, p. 4). In his view, this kind of waiting is endemic now and we seem to have been living through social and historical conditions of permanent crisis for so long that many of us have become adept to the point of taking pride in our ability to go on enduring it.

...to 'wait out' the crisis is perceived as something that one is proud to do. It is a mark of a deepening of the civilisation process. It is civilised to know how to endure a crisis and act in an orderly, self-governed, restrained fashion. It is the uncivilised 'third world-looking masses' that are imagined to be running amok in the face of crisis.

(Hage, 2009, p. 105)

For Hage, there are different kinds of waiting in a crisis. Civilised, mannered 'waiting out' is just one of them, but there are other collective forms for waiting that can form in response to new crises with their own effects, affects and modalities.

When addressing the need for temporal frames, other than those of crisis for materialising the everyday life of the poor American subject under late capitalism, Lauren Berlant also finds that temporal modes of everyday life are better able to convey the sense of the situation in terms of its real duration, 'as managed in the context of living' (Berlant, 2007, p. 101). Berlant's approach to modulating harm and 'decomposition' by watching how they take place in ordinary time, works to extend definitions of crisis, to make them take in its durative and everyday effects by zoning in on the everyday and on the reproductive work of 'getting through it' (Berlant, 2007, p. 764). In this way, the genre of 'crisis ordinariness' tries to be a corrective to the limits and obfuscations of momentary and catastrophic representations of the fall-out from capitalist modes of living. In detailed renderings of the accumulative harms or the 'slow deaths' that accrue in spaces of the ordinary where crisis is not so much an event as a defining fact of life, crisis ordinariness makes itself sensible as the hard domain of living on, of surviving and of slowly dying.<sup>6</sup>

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<sup>&</sup>lt;sup>6</sup> 'Slow death prospers not in traumatic events, as discrete time-framed phenomena like military encounters and genocides can appear to do, but in temporal environments whose qualities and whose contours in time and space are often identified with the presentness of ordinariness itself, that domain of living on, in which everyday activity; memory, needs, and desires; diverse temporalities and horizons of the taken-for-granted are brought into proximity' (Berlant, 2007, p. 759).

## Confinement in Time

Non-progressive time has a more specific meaning in situations where it comes to define the embodied experience of many people all at once. Writing during the lockdown period of the pandemic, Archilles Mbembe observed the arresting of time that had been brought about by the virus (Mbembe, 2020). He wrote about how it seemed to have forced people who might ordinarily have imagined that they could defer or delegate their own death, to be 'living towards their own death', perhaps for the first time. In his meditation on the effects of what he called 'the great confinement' caused by the spread of the virus, Mbembe imagines this time not as a time of care, but as a 'a catabolic period par excellence', when the brevity and perishability of the human body becomes common knowledge. 'Try as we might to rid ourselves of it, in the end everything brings us back to the body' (Mbembe, 2020). This is also a 'pathogenic' period, when the body has been literally shut up in time and when the greatest terror is that all we have left in common with every other living person on the earth, is the time remaining to us. The constraints that nonprogressive time applies to our ability to project into the future can, in this case, bar any escape from the body and its finitude, forcing the realisation that we are in 'it' together, 'inescapably in relation with other beings and the world...continuously adjusting to them' (Berlant, 2022). This is another example of non-progressive time allowing things to break down in ways that are bracketed off from any caring response, but which can act as an injunction, to 'answer here and now for our life on Earth with others (including viruses) and our shared fate' (Mbembe, 2020).

# Living On After Progress

In their discussion of collateral afterworlds, anthropologists Zoë Wool and Julie Livingston address all those contexts especially marked by the temporality of a present that has come 'unhinged from the pervasive hope for a better tomorrow' (Wool and Livingstone, 2017, p. 2).

Our effort here is to convey something of the lives and worlds that endure out of the way of such redemptive possibilities not beyond their reach but that roll along off to the side of efforts to stabilize, repair, and improve any collective lot in the name of the future.

(Wool and Livingstone, 2017, p. 2)

By concentrating on the chronic, ongoing experience of everyday life and not on the turning points from which a better tomorrow might be expected to arrive, a space is delineated marking the time that comes *after* progress. The temporalities of living on here tend to be circular, repetitive, dwindling or stalling. Elizabeth Povinelli gives a good example of this in her close reading of a scene from Charles Burnett's 1977 film, *Killer of Sheep*. In her description of Stan, the film's protagonist, she attempts to relate the particular mode of exhaustion that comes from having to continuously endure an atmosphere of enervation and of nothing happening.

Something and yet nothing has happened to cause Stan to be so exhausted—it is hard to point to anything as the event in relation to which his exhaustion is the effect. Instead, his hope and despair are conjured through the endurance of the exhaustion of numerous small quasi-events. Little things pile up. But these "little things" don't recursively enclose or intensify in such a way that a thisness is easily formed. It is hard to pull a thisness out of the ongoing flow of the everyday because so much decomposition happens below the threshold of awareness and theorization.

(Povinelli, 2011, p. 132)

This concept of a collateral afterworld draws on an understanding of crisis in which there is no longer any belief in either a progressive or redemptive telos but where the crisis narrative perpetually fails to come to an end. It describes more accurately than crisis, the temporality of 'living on' in shared social worlds that cannot be assumed to cohere, or to be knowable or durable (Duclos and Criado, 2019), 'in which sociality fails to redeem experiences of injury, vulnerability, and loss' (Wool & Livingston, 2017, p. 2).

For Isabelle Stengers, the present is characterised by a temporality of waiting and suspense because for those who live there, a new history is beginning, and they cannot know what will happen next. 'We live in strange times, a little as if we were suspended between two histories...' (Stengers, 2015, p.17). For those who are suspended here, the question is not about how to invent new ways to save the things that need saving. This would take us back to a time of, 'on the one hand, binding necessities from which there is no escape...on the other, boundless possibilities coupled with a total indifference for their long-term consequences' (Latour, 2014, p. 3). Stengers is more concerned with what are the modes of assembling that will bring out the capacity to do what people are usually incapable of doing in response to what is happening. In other words, 'what 'possibles' are there?' (Conley, 2016, p. 340). To restore the space for 'possibles', at a time when the capacity to be affected by events as they are unfolding has been enveloped or 'primed' by capitalist temporalities of expansion, growth and venture, requires that the time of suspension not be allowed to fold back into what came before it. Whilst this complicates care as an idea, leaving it with no obvious way of latching on to the problems that it cannot solve, and preventing us from deriving satisfaction from trying to solve them, for Stengers, this is the complication that also makes something like care possible. One of the things that makes NHS general practice such an intriguing site for studying the temporalities of living on, is the position that it occupies in relation to the 'collateral' of everyday life. Its practitioners are already bound up with trying to care for the possible in the form of scientifically elongated lives and the intricate, unpredictable effects of more medical interventions. This means that rather than asking about how to restore the space for concern over what might be the consequences of having 'experimented' without thinking ahead, I have looked to general practice more in the hope of learning something about what it means to be already immersed in trying to stabilize and repair lives, bodies and NHS

worlds which may be 'out of the way' of redemptive possibilities, but not quite beyond their reach (Wool and Livingstone, 2017, p. 2).

## Living On in the NHS

In 2005, the breakdown of the welfare state was already spoken of as a past event. In *Borderline Welfare: Feeling and Fear of Feeling in Modern Welfare*, Andrew Cooper and Julian Lousada explain how over a certain period, '...the original post-war welfare state, began to break down...'. Their book is an attempt to 'feel out' the terrain of living on after it.

The structures of feeling that we believe have now replaced the psychic settlement achieved during the initial decades of the post-war welfare state are the outcome of definite historical and political processes, and are still evolving. These processes have ushered in what we think of as a new social topography, a revised set of conditions in which we now work and transact our relationships with clients, patients, colleagues, policy makers, and our own organizations, communities, and families.

(Cooper & Lousada, 2005, p. 194)

This idea of coming after the NHS, whilst finding yourself somehow still within it has evolved over time. In Fiona Wright's more recent work on the temporalities of care in NHS mental health services, living on in the NHS now also entails living with the 'collateral' of chronic and enduring crisis: its cruel promises of salvation and the 'toxic or precarious circumstances that persist, whilst being neither meaningless nor transformative' (Wright, 2022, p. 316).

If the concept of a collateral afterworld sounds remote from the National Health Service, it sounds even stranger when applied to general practice with its immersion in mundane concerns and problems of living which rarely, if ever, reach the point of being catastrophic. And yet, in another way, the notion of having outlived its own project attaches very easily to the NHS, engaged as it is in trying to fulfil the promise of social democratic ideals for medicine, whilst struggling with the consequences of having helped to lengthen human life. But more than this, in a world of many such collateral afterworlds, all potentially in need of repair in a material, social, affective and existential sense, the NHS retains a moral responsibility for continuing to offer care at the point where it is most needed. This is perhaps even more relevant for general practice than it is for the NHS as a whole, because general practice specialises in caring for the fall out from those modes of living on, in which chronic, ongoing experiences are often, at least in part, the result of a sociality that has failed to redeem experiences of injury, vulnerability, and loss. This includes the experiences of NHS caregivers themselves who, during the pandemic, tended to be perceived as heroic and as saviours of the NHS, whilst in reality, many had been thinking about leaving their jobs when it happened. This is particularly true of general practice where the numbers of practitioners leaving, or thinking of leaving practice are still higher than in other parts of the NHS (Palmer and Rolewicz, 2022; Odebiyi et al., 2022),<sup>7</sup> and where one of the main reasons cited for leaving has consistently been that the particular kind of care that general practice offers, is neither valued, nor understood, within the wider healthcare system (Doran et al, 2016; Sansom et al, 2017).

Some GP authors who have touched on the subject of time when writing about their experiences of working in the NHS have regretted the loss of the longer, continuous timeframes for care, so much a part of how this branch of medicine has historically defined itself. In a recent long article written for the Guardian on how English general practice had changed over the course of her thirty year career, GP and spokesperson for the profession, Clare Gerada writes about the erosion of general

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<sup>&</sup>lt;sup>7</sup> Findings from the most recent GP worklife survey showed that 33% of GPs are likely to quit direct patient care within five years. Policy Research Unit in Commissioning and the Healthcare System. (2021) The Eleventh National GP Work life Survey. Retrieved October 30 2022 from https://prucomm.ac.uk/eleventh-national-gp-worklife-survey-2021.html.

practice which she believes has been due, in part, to the breakdown of the conditions needed for a continuity of care. Thinking about how this has changed what it feels like to carry out a home visit to see older people who are now more likely to be suffering from several serious chronic conditions simultaneously, she writes that, whereas as in the past, 'one felt that 'something could be done', even if it were only to offer compassion...there is nothing much I can offer to the patients I attend to nowadays. I cannot make them better or reverse the effects of old age or serious illness with simple painkillers or antibiotics'.8 Another long serving London GP9 Iona Heath, writes about this in terms of general practice having lost the time for care due its adherence to the belief that all clinical time should be spent on trying to prevent the onset or progression of ill health. 'When is the time to care for the sick and dying instead of preventing the healthy from becoming sick, or the sick from getting more sick? What is the right time to be sick or to die?' (Heath, 2014). Just as the linear rationality of preventative medicine does not make time for being sick and dying, neither does it make time for an appropriate response to the experiences of suffering that these experiences usually entail. Heath's argument is that in losing its sense of timeliness, medicine loses its capacity for care, because without the sensibility to know when medicine is timely and when it is better for clinicians to 'do nothing', the practice of medicine is liable to produce more harm than benefit (Heath, 2012).

<sup>&</sup>lt;sup>8</sup> Gerada, C. (2022, February 22). 'In my 30 years as a GP, the profession has been horribly eroded'. The Guardian. Retrieved 13 March 2022 from

https://www.theguardian.com/society/2022/feb/22/my-30-years-as-gp-profession-horribly-eroded-clare-gerada.

<sup>&</sup>lt;sup>9</sup> These examples are based on the experiences of GPs working in London, but a recent survey of the decline in care continuity in primary care in England recorded a steady and significant decline in continuity in all types of practices, irrespective of geographic location, or level of deprivation. Continuity was defined in the study as 'patients having a preferred GP and seeing this GP 'usually" See, Tammes, P., Morris, R. W., Murphy, M., & Salisbury, C. (2021). Is continuity of primary care declining in England? Practice-level longitudinal study from 2012 to 2017. *British Journal of General Practice*, 71(707).

### Waiting in the NHS

Waiting may be the mode of time that is most closely intertwined with the National Health Service. Certain modes of waiting seem to belong specifically to it, so much so that Martin Moore writes about the 'NHS-ness' of some kinds of waiting, where the political promises of inclusion and service, meet with individual experiences of using the NHS at different points in its history and with different results (Moore, 2021). Whilst the necessity of having to wait has been shown to be a common feature of all public health systems (Sheard, 2018), the anthropologist Sophie Day, makes the argument that ongoing occupation of NHS 'worlds of waiting' implies a shared recognition that those who wait, still belong to the NHS in some way. She likens this to 'an intense form of occupying the NHS and being held in place, which can approximate to a process of articulation between those who wait together and the worlds in which they wait' (Day, 2015, p. 180). As the hyphen that links the promise with the reality of being looked after by the state (Day, 2015), waiting in the NHS is understood not only through its negative connotations of a failure to deliver on time, but also through what it says about the intensity of vital participation and investment in the 'promise' of a universal healthcare system. Those who wait together here, recognise one another as still belonging to 'cradle to grave', whilst at the same time, they recognise in one another the potential to be humiliated and demeaned by their condition of dependency on the state. Day points to the historical identity of such a project describing it as socialist in its aspirations, bureaucratic in its ways of working and as imperfect for all the reasons that we already know about. In continuing to give our assent to waiting within the NHS, we retain a risky investment in the flawed project of trying to prevent the world to which it belongs from disappearing altogether. When we stop waiting or when we lose all of our willingness to wait in the belief that perhaps the need for it will be dissolved by the introduction of technological solutions or market mechanisms, then there will be nobody left to care about the memory of this other world with its different sensibilities and its unfulfilled promise. Following Day's line of reasoning,

that waiting is 'a material occupation' (Day, 2015, p. 180) in recognition of the world to which we want to belong, ceasing to wait means losing any stake that we had, causing the NHS to become impoverished through neglect. '...the end of waiting will empty out or eviscerate the NHS' (Day, 2015, p. 168). Understood in this way, waiting is an expression of care for an endangered world, one in which the temporalities of delay arising from a collective project of healthcare may be in need of defending. This helps to locate a practice of waiting that is historically and institutionally aligned to the National Health Service, but abstract notions of waiting as a gesture of belonging do not really speak to the experience itself, of what it can feel like to wait in this context. By bringing an ethnographic attention to bear on this question, this work sets out to observe how NHS healthcare workers reconcile the potential of waiting as a practice of belonging, with its potential for cruelty and exploitation.

### **Conclusion**

As Maria Puig de la Bellacasa helpfully reminds us, whilst it is certainly true that care is necessary to life, we cannot be forced to care about something or somebody. How then, do we measure the value of a continuous voluntary effort to care that keeps going on its own time, even when doing so probably won't resolve a problem, cure a condition, stop a pandemic, or save the NHS? One of the aims of this research is to find a way to think about what it means to keep up a caring relation that depends on a willingness to go on without expecting that this will achieve anything in the end. In this overview of developments in critical engagements with time, care and non-progressive temporalities, researchers working across disciplines have begun to address the need to think experimentally about the realities of sharing time that we do not have the option to transcend. Critical accounts of time are no longer defined only in opposition to linear, epic temporal arrangements, but have been shown to possess qualities and capacities of their own. They emerge in theorisations of durational time and in waiting together without expectation, especially in relation to long, uneventful modes of engaging in political struggle and in the embodied

endurance of time as a labour of care that eludes definition in terms of either productivity or progression.

What does it mean to care in relation to a non-event, or in relation to a continuous flow of small 'quasi-events' where there is nothing to get hold of, no clear aim, no way of knowing when to begin, or when to end? In common with many of the longterm problems of embodiment that require the ongoing attention of those in caregiving roles, the heightened exposure to threat that comes from living crisis in ordinary time, cannot be grasped and manipulated or moved on from using direct modes of helping along progressive timelines. Care in these contexts becomes more like a problem than a response, which makes it align more closely with the original meaning of care as a form of serious attention, a burdened state of mind, or an object of concern. Not all these authors are interested in theorising how non-progressive time might somehow lend itself to 'practices of care'. But, by allowing the fall out of ordinary harms to materialise in ways that trouble us because they are out of reach of the usual liberal correctives, some of them create exigencies for something like care, or support, or for something that 'enables enduring' (Berlant, 2011, p. 225). Through their sustained attention to how conditions of living are endured rather than being managed, dealt with, or cared for, they are evocative in the way that they constrain any ideas that we might have about how to help, whilst nevertheless still demanding a moral response.

### III. March 2020 10

Written immediately following the suspension (due to the pandemic) of an ethnographic investigation of waiting in a general practice in London, in this preface to the research, I track the first signs that working definitions of time would struggle to survive the onset of a temporality of acute crisis in the NHS. This section views the coronavirus crisis in terms of its unpredictable effects on the interior life of the National Health Service (NHS) workforce and considers what it might mean for healthcare practitioners at this particular moment in the NHS's history to be living through an experience of 'the ordinary' breaking down. It also follows hints of new temporal modes of care appearing during this same period, when one kind of crisis in the NHS has been put on hold, and another (the crisis of coronavirus) is just getting underway.

I was a researcher undertaking an investigation of waiting in a London general practice when I heard the news that the virus, seemingly so far away, had arrived, having entered literally through the front door. In the hours that followed the first suspected case, all thoughts were immediately drawn towards the virus, siphoned off from wherever they had happened to be only an hour before and, after having being relied upon for so long to replenish everyday life in the surgery with its essential quality of 'everydayness', many long established orderings of time and space – meeting times, consultation times, waiting room times, lunch-time, opening and closing times, patterns of movement through the building - were reduced to just the remainders of what was left over after the coronavirus had taken hold. So too were the ordinary patterns of behaviour and identification that had belonged to them; of employees knowing how to compose themselves as those who 'work for

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<sup>&</sup>lt;sup>10</sup> This piece of writing was originally published in *Wellcome Open Research* with the title 'The politics of staying behind the frontline of coronavirus.' I chose to reproduce the original version with only very minor changes as it better captures the feel of the time. It was intended as a contribution to the Waiting in Pandemic Times project Collection in response to COVID-19-19. Davies, S. (2020). The politics of staying behind the frontline of coronavirus. https://doi.org/10.12688/wellcomeopenres.15964.2.

the National Health Service'. Through rapid modes of improvisation and with an intensity that might have come from the combined energies of so many people all furiously channelling what was going on around them, they very quickly began to reconstitute themselves as those who work for a different kind of NHS, one still in the process of being formed out of a time of national emergency. This all seemed to take place over the course of a single morning, just a day after the first suspected case of coronavirus had entered the building.

The original research questions I had just then begun to investigate had sought to grasp waiting in healthcare in its everyday aspect — as a circumstance so taken for granted that many of its lesser known functions for general practice were being completely overlooked. I had watched for the details of how waiting happens in general practice, out of necessity, by accident. I wanted to know 'what do people do with waiting in primary healthcare?', 'how do they use or consume it?', 'how is waiting 'made' or engineered out of the things available and at hand in care work of this sort?', 'what does it look like to wait?'. And 'how is waiting made 'readable' or 'unreadable' for the NHS or for this particular organisation?' When the virus had struck without warning just as observations had begun, the regular rhythms of care had collapsed including those I had been watching up to that point. During a crisis on the scale of coronavirus, the invisible forces holding an institution's 'time' in place (Hammer, 2011)<sup>11</sup> can seem to collapse as they suddenly lose their power to regulate the institution's everyday life in the drastically altered situation. Almost at once, the structures that had supported everyday forms of waiting appeared to fall away, carrying my original research questions along with them. In place of my old investigation of waiting at its most ordinary, the new questions arising had corresponded to an altered reality — one not at all orderable by the standards of the everyday.

The orderings of time in healthcare that are usually seen to be of utmost importance for the future – recording, inspecting, reviewing for instance – are suddenly made to

<sup>&</sup>lt;sup>11</sup> The time 'kept in place' refers to the local arrangements for inferring time from structures imposed or engendered; the 'specific temporal economy' of an institution (Hammer, 2011, p. 26).

appear extremely relative alongside the infinitely more pressing and immediate demands of the present: the saving of life, the protecting of one's own life, and the need to survive the crisis. At such a moment, a person might get caught up in the end of one set of working conceptions of time, before another has even begun to circulate. Yet, for those healthcare workers who might now be experiencing something like this in their own NHS workplaces, the failure of the ordinary to assimilate the fears, risks and demands connected with an unknown virus, is an event that they have had no choice but to find some way of working through. So how are they keeping time in such a crisis? (Catty, 2020).

### The Hidden Life of Crisis

The interior life of the workplace is said by Christophe Dejours to hardly ever be allowed to show itself, except in very rare situations (Dejours, 2007). The hiddenness of its invisible inner workings and affective economies is believed to be partly due to a lack of interest by the public whose currency is mainly that of the name or brand of the organisation (the part that faces outwards), but also because the workers themselves are thought to be complicit in secreting the innerfunctioning of their own institution with whom they are required, at least in part, to identify. At a time of great public interest in watching the collision of coronavirus with healthcare systems all over the world, the growing intensity of collective identification with the aims of the NHS and its projection onto the workforce, could mean that the privately felt realities for NHS staff, of becoming part of a temporality of crisis, are even more likely than usual to remain hidden from view.

On the surface, the crisis appears to have prompted new modes of agency that have begun to emerge in NHS settings, and a shift in the perspectives of its workforce. They are made visible in practices that might have seemed unreasonable, odd or out of place before now, such as those that involve taking risks or making personal sacrifices — for example, in the images and testimonials depicting doctors and nurses remaining steadfast at their posts, 'heedless of their own health as they work

tirelessly to care for people in the face of the Coronavirus pandemic'. <sup>12</sup> It is not clear whether such practices (of staying to care for others) correspond to the experiences of frontline NHS employees as a multiplicity, or whether they are imposed from elsewhere, or a combination of both. But because they are seen to be working on behalf of others at their own risk, and often in a way that requires them to withstand the most concentrated and contagious parts of the pandemic over an indefinite length of time, NHS staff who stay in post, or return to posts they had previously left, appear to be choosing to exercise a form of altruistic endurance. The outward forms for this kind of 'extreme' care work — of duty, self-sacrifice and a commitment to 'staying with, in spite of' may seem on the one hand, to have been closed off to present day NHS employees. But they can also be read as the signs of a new orientation to the present — one characterised by the 'making of promises'.

In social media bearing the message, 'we stay here for you – please stay home for us', promises are not being made in the usual sense. Instead, there is the impression of a collective promise. It is made through a shared identification with the NHS, as a subject who promises 'to wait for citizens in their time of need' (Moore, 2020). In Paul Ricoeur's hermeneutic philosophy of time, the promise describes the public act of putting myself under an obligation of doing something — for someone. It is 'the projection of a horizon of expectation' made possible through the inscription of dialogue onto the public space where historical responsibility for it can be assumed' (Ricoeur, 1990, p. 234). No matter how unbelievable or fleeting the experiences of the present might turn out to be in the longer term, they are prolonged and substantiated by the making of a promise. As jarring and anomalous as they might be, the experience of living and working through the first days of the outbreak, are turned into something real and lasting when they must be remembered as a condition of the promise-maker's fidelity.

<sup>&</sup>lt;sup>12</sup> The full quote from the website is: 'From cradle to grave, the National Health Service, and the incredible professionals within it who care for us, is a part of British life. Today, more than ever, we should cherish those who dedicate themselves to our care, 'heedless of own health as they work tirelessly to care for people in the face of the Coronavirus pandemic' (NHS Heroes, 2020).

There is something not quite right however, about the promise implied by such messages as 'we stay here for you – please stay home for us'. When glimpsed from below the level of image and identification, practices of staying and of 'being here for you' need to be understood as coming after a much longer, drawn out time in which the normal working day has been organised around the assumption that care is something that can only be apprehended at the specular level of the organisation, and where time is reduced to being just one of the costs of its production. They hint at modes of care that have been inspired by affective investments in what is 'real' about care work during a pandemic - its resistance to appropriation as, just 'a task to be accomplished' (Dejours & Deranty, 2010, p. 451). 13 Considering that healthcare of all kinds has, until now, tended to be seen as synchronic output; as happening all at once, with little attention to how a particular labour of care might evolve over time, or how a continued engagement with it might help to 'sustain interdependent worlds' (Bellacasa, 2012, p. 198), the appearance of an unconditional promise to 'stay here for you' is an anomaly, pushing in the opposite direction to the one that healthcare had been going in.

This is strange, considering that unpredictable, prolonged and intermittent timeframes are to be expected in the NHS, particularly in relation to chronic, multiple or undiagnosable illness of the kind that now makes up most of its workload. Intuitive practices that can be receptive to the effects of time passing on the world of the patient might actually be required more than anything else during the attendant long periods of suspense, observance or endurance that are so central to healthcare. It is the continuation of an older formulation of care as synchronic, that has made staying with the idea that the activity of care might still be worthwhile in and of itself, increasingly difficult to justify (Latimer, 2000). Though outwardly they may be focused on making more 'time for care' (NHS England, 2019), policy initiatives that have sought to curtail the patient's and the practitioner's experience

<sup>&</sup>lt;sup>13</sup> For Dejours, 'to work is, first, to experience the real, that is to say, experience the breakdown of technical know-how' (Dejours & Deranty, 2010, p. 170).

of time passing<sup>14</sup> have tended to result in many temporal practices of care being rendered as obsolete. This is not to say that discretional practices of offering more time to some patients are not one of the inevitable consequences of making the offer to care in the first place, or that they haven't always gone on and won't continue to do so. But nevertheless, the growing concern amongst clinicians over finding themselves unable to spend time on the things that matter most to themselves and their patients, has been met until now with a response that questions their ability ever to have really known what it was worth their while having cared about in the first place. As one NHS England consultant put it, 'we wondered how health and care systems could design services that would improve peoples' lives, if the people running the system didn't understand what matters most?'.

Kathleen Stewart observes that 'there's a politics to being/feeling connected (or not), to affective contagion, and to all the forms of attunement and attachment' (Stewart, 2007, p. 16). It changes the way we think about the politics of staying at the frontline of a pandemic, if we remember that many of the most experienced members of the NHS workforce, those who have stayed or returned, and who are still working on 'our' behalf, bring with them a decades long history of attachment to the institution in relation to the slow collapse of a former symbolic order. This is an order they worked hard to delay the future collapse of, even though they might well have wished to be released from it. It is a situation that has proven to be unendurable for many, as the annual problem of how to fill all the vacancies in British general practice affirms. Each year, a steady stream of doctors under the age of fifty have made the decision not to stay, not to carry on. More than just a feeling of exhaustion from overwork, by the time they have left, many of these people, described quite tragically in one study as the 'lost to the NHS' (Doran *et al.*, 2016)

<sup>&</sup>lt;sup>14</sup> Of the ten actions included the Time for Care programme, all of which are based on time looked at 'from the outside' so to speak, the majority can be described as attempts to deflect or deter face-to-face GP consultations wherever possible and to speed up the everyday activity of practitioners with the aim of producing more 'care' in the least amount of time (NHS England, 2019).

<sup>&</sup>lt;sup>15</sup> 'The institutional and linguistic network (the province of duties, roles and obligations) and the values of a given culture'. Dashtipour, P. (2014). Freedom through Work: The Psychosocial, Affect and Work. In K. Kenny & M. Fotaki (Eds.), *The Psychosocial and Organization Studies: Affect at Work* (pp. 104–125). Palgrave Macmillan, (p. 5).

have reached the point of feeling that they had in some way been locked out from the time when *real* care was taking place.

Superficially, it would be difficult to imagine a more complete reversal of the recent past than what we are seeing on this new frontline, where virtually everything that the NHS does is seen as extremely valuable, heroic even, in its relation to a future that has yet to unfold. One of the most contagious forms of agency that a temporality of acute crisis seems to be able to offer us now, is a capacity to become so immersed in the doings of the present that nothing else seems to matter. In this respect, coronavirus appears to have achieved in hours, what official long form strategies for 'releasing time' never could, which is to have forced the making of more time for care into the present. In fact, an orientation to this time - as care, has not so much been offered to the workforce as required of them, just as to a lesser extent, it has been required of everybody whose time is having to be lived out firmly in the present (in quarantine), so that others might have more time to live on.

As with the politics of any 'surge', the afterlife of this crisis and all the time for care that miraculously bubbled up around it, may depend on events that have yet to come to pass — on where the surge 'might go, what happens, how it plays itself out and in whose hands' (Stewart, 2007, p. 15). As my own observations of general practice were cut short, I was one of those who couldn't stay to follow the energy, to see where it might go, but from what I did see of the frontline after the first shock, there was something very fragile and forgetful about the forms taken by the ordinary and what they had the power to release during this time. In retrospect, I can say that it would not be long before many of the old routines returned to general practice. But like the waiting practices I had been observing only months ago, for better or for worse, they will never coincide exactly with their pre-covid predecessors.

<sup>&</sup>lt;sup>16</sup> The resulting tendency to see everything only in relation to the virus carries its own risks for those who are dependent on health and social care services at a time when their needs may have increased whilst the availability and integrity of care and support has been reduced overall. An example of this is the impact of the Coronavirus Bill on the integrity of existing legal safeguards for adults with care and support needs and their carers.

The simple, stark statement that 'general practice is crisis' is almost as old as the NHS itself (Moore, 2022a). But at the start of the pandemic, the synchronous outward forms of carrying on with the work of reproducing general practice were suspended, causing its interior life in the present to become freshly exposed. In describing and examining this present in terms of the urgent relationships that I see beginning to form between care, productivity, crisis and suspension, the themes of this project begin to emerge. They can be seen in references to the hidden, everyday life of the general practice, and in the 'fabrications of universality' (Certeau, 1984, p. 28) that seem to attach to crisis so easily. Also, in the figuring of embodied care as the elusive source of time on the one hand, and as the main threat to the survival of the institution on the other.

### IV. Overview of the Thesis

Partly because of strange circumstances and partly in consequence of having taken up 'time' as a subject matter, this thesis has developed along lines that were unforeseen and unpredictable. This was not originally envisaged as a theoretical piece of work and yet it has become more theoretical in the course of its construction. It still claims an identification with ethnography and yet its methods are hybrid and difficult to categorise. If I maintain that the thesis is ethnographic in its orientation to 'knowing' something about time and its relationship to care, then this is because it tries to offer specific, methodologically, and epistemologically grounded descriptions of how 'real subjects, in real conditions of everyday life, possessed by real interests' are making sense of their own reality (Hymes, 1964: xiii). But as ethnographic attempts at representation always originate in theorised attempts at cohering realities (Law, 2004), perhaps it is unnecessary to draw such a hard lined distinction. The best description of the aims of the thesis, and the simplest, might be that it enquires into the experience of trying to keep care going after hope as I see this being played out in the NHS every day. The more minor theoretical themes that run throughout the thesis include the reassessment of NHS temporalities through an engagement with critical temporal theorisations of time, an exploration of the interior 'everyday life' of the NHS during the coronavirus pandemic, and the methodological question of how to represent and narrate time without progression. The main areas covered in each individual chapter are as follows:

**Chapter 1** opens with an introduction to the temporal scene of general practice before the pandemic. It follows the recent debate within the National Health Service in England over which sorts of policies ought to be being pursued to better adapt the general practice workplace for a future of precarity. I show how the problem of not having enough time for care is linked to the dominance of crisis, capitalist and progressivist modes in this setting. This provides a justification for why, when responding to problems of time and care in the NHS, and in general practice in

particular, we might want to search for modes other than those of crisis. This account serves as an introduction to the compositions of time in this setting, and their disruption during the research period. It marks the beginning of a dialogue between critical theories of time and NHS orderings of time to be continued and expanded upon in the chapters to follow.

**Chapters 2 and 3,** describe the research process and discuss the methods used in the study. **Chapter 2** gives an account of the research design and how it responded to the transformation of general practice during the pandemic. The ethnographic framework of the project is set out disclosing the influence of STS researchers including John Law, Anne Marie Mol and Bruno Latour. The speculative philosophical orientations to the production of knowledge are also articulated through the influences of thinkers including Isabelle Stengers and Alfred North Whitehead. Particular attention is paid to the methodological challenges of conceptualising 'time' as an object of research, and to the ethical considerations involved in collecting accounts of patients who are 'not getting better'. The speculative strands within the project are discussed and some of the tentative findings from the early stages of coding and interpretating the material are shared. **Chapter 3** discusses the use of the case as a mode of representation with a particular focus on Michael Balint's psychoanalytic device of case making which he used to introduce new ways of thinking about time into general practice. This short chapter serves as a preface for the four case-based chapters that follow, several of which go on to discuss Balint's cases in more detail.

**Chapters 4, 5, 6 and 7**, are based on my analyses of observations, interviews and accounts of general practice workers offering care in relation to things that are not getting better. Each of these chapters represents one of four temporal modes of care in non-progressive time. They should be taken together as cases of care forming in non-progressive ways with material from the study serving as illustrations. **Chapter 4** is based upon close interpretations of Balint group discussions taking place remotely out of a Practice in East London between December 2020 and March 2021. The influence of Balint's work runs all through the thesis and this chapter provides

an observer account of the Balint group which is one of his most lasting legacies to general practice. I offer evidence to support the claim that the Balint group has the potential to disrupt narratives of restitution and repair by practising a non-progressive form of care. This chapter draws on work that looks at the power to be affected by things that cannot be acted upon as this has been articulated in the work of authors including Todd Meyers and Astrid Schrader.

Chapter 5, looks at the case for 'temporal drag' as a mode of caring for what is in danger of being neglected or left behind in a crisis. This chapter is framed by the work of Sara Ahmed, Elizabeth Freeman, Lisa Baraitser and Laura Salisbury who have all written about drag or delay in the context of a refusal, a disinclination or an inability to move on from the present. The evidence for drag as something from which care might issue here, is based on the testimonies of three long serving general practice staff. I assess their reasons for refusing to shift completely into a crisis mode at a such critical time, when a refusal could be seen as 'being a drag' on others' attempts to rush forwards to do battle with the pandemic. A revised understanding of the important figure of the frequent attender begins to emerge in this chapter based on a receptionist's account of presiding over an empty waiting room during the lockdown. This carries forward the work begun in chapter three, of studying the phenomenon of frequent attending in more detail and reconceptualising the figure from being one that poses a threat to the organisation, to one that actually has the potential to make time for care in conditions of scarcity.

**Chapter 6,** is based on practitioner accounts of overseeing unstoppable decline or deterioration in a patient's condition. In an interpretation of their experiences, I revaluate assumptions about the role that healthcare can play in relation to inevitable realities of death and degeneration over time. This chapter revisits the theme of 'the ordinary' through the work of Georges Canguilhem, Lauren Berlant and Alison Kafer, amongst others. It considers the case that there are certain forms of care that are only available to those who are watched over, as they 'wear out'. A new understanding of waiting from within the NHS emerges in this chapter, one in

which people can be thought of as waiting not for cure, but for the next stage of pain or physical decline, or death.

Chapter 7, offers an alternative account of what it was like to be on the frontline during the coronavirus pandemic based on close readings of GP testimonies posted online. It draws on the work of theorists including Ghassan Hage, and researchers of race in the NHS including Roberta Bivins and Satnam Virdee to track a history of ambivalence, one that often intersects with the experiences of a migrant workforce. The analysis is used to make the claim that 'being between' provides a third 'place' to be as an NHS worker who finds themselves on the frontline in the midst of a national healthcare crisis. This is a further development of the argument that temporalities of suspension, whilst dampening the opportunity for heroic agency, can be responsive to the needs of a complicated present in ways that the temporalities of crisis tend to neglect.

In the **conclusion,** I summarise the argument for an approach to thinking about time in general practice that looks beyond progress. Based on what emerges in the case studies, I offer an account of care that ties it to failure, finitude, and temporalities of waiting. Finally, I return to Isabelle Stengers to frame an afterword discussion about 'taking care of the event' in the context of the NHS during the coronavirus pandemic.

# Chapter One

# **Time and Crisis in English General Practice**

This chapter provides an introduction to the pre-pandemic composition of time in contemporary English General Practice. Rather than offering a general overview of the relevant policy frameworks, I analyse discourses emerging from recent debates about the specific problem of not having enough time for care in this setting. Michael Balint's work on the relationship between time and general practice is also discussed here for the first time.

# 1.1. The Problem of Time

In May 2015, the Royal College of General Practitioners issued a formal request to the government for increased investment so that more time could be made available for care. Not long after this, a report commissioned by NHS England appeared in response offering a series of recommendations for how this time could be made. In my survey of the temporal scene of general practice at this juncture, I concentrate on two interpretative operations in particular and on what they might mean for practices of care whose efficacy rests on assumptions of time possessing a value beyond what might be useful or justifiable from the point of view of an institution in crisis. One of these operations makes possible a perception of a time being dynamically 'released' in the service of the organisation. The other apprehends time being locked into wasteful practices of care and makes it appear redundant or 'out of use' to the organisation. Don Ihde used the term 'macro perception' to mean 'disembodied perception not based on sensory-bodily capacities but made possible by a cultural or hermeneutic interpretive 'text' or device – it interprets phenomena in place of the body and the body perceives the world based on its interpretation' (Ihde, 1990, p. 29). By inquiring into the logics of 'macro perceptual' devices adopted, my aim is to survey this scene without losing sight of the interpretive moves that have helped to make such a vision possible in the first place.<sup>17</sup> To help me with this, I turn to authors including Michel de Certeau (1984) and Maria Puig de la Bellacasa (2017), whose work provides resources for reading time and matter back in to the everyday processes and practices from which they have been made absent.

The first of these reports to be published in May 2015 by the Royal College of General Practitioners (RCGP, 2015)<sup>18</sup> was 'Blueprint for Building the New Deal for General Practice' which I will refer to from now on as the 'New Deal report'. The New Deal report was timed to coincide with the start of a new government. It was an attempt to influence the direction of policy and to change the way that general practices were being organised. The report begins by announcing that there is a crisis in general practice.

The scale of the challenge is huge. England's GP practices are under massive strain, providing an estimated 370m consultations every year to a growing and ageing population — more than 60m more than they were five years ago.

(RCGP, 2015, p.2).

Practices were said to be 'overstretched' for three main reasons. Firstly because of the rising numbers of patient consultations needed to cope with the ageing population. Secondly, because of all the 'barriers to effective patient care' faced by GPs. Thirdly, because the workforce of general practice was (still is) itself, ageing, and an increasing number of practitioners had already left or were planning to retire

<sup>&</sup>lt;sup>17</sup> As Ihde goes on to explain, 'both micro and macro perception belong equally to 'life world'. And both dimensions of perception are closely linked and intertwined. There is no micro-perception (sensory-bodily) without its location within a field of macro-perception and no macro-perception without its micro-perceptual foci' (Ihde, 1990, p. 29).

<sup>&</sup>lt;sup>18</sup> The Royal College of General Practitioners are the professional body for general practitioners. <sup>19</sup> In 2015, more than one in five GPs was aged over 55 and likely to retire in the next few years (Royal College of General Practitioners, 2015).

early. In more ways than one, general practice was running out of time. At the heart of the Report's appeal for a change in this worsening situation, was the idea of wanting to make more time for care. The government were urged to 'give GPs time to focus on patient care', 'allow GPs time to innovate', aspire for 'longer consultation times', and to 'conduct a full-scale urgent review into how the bureaucracy...currently faced by GPs can be reduced, and their time freed up to focus on delivering high quality patient care' (RCGP, 2015, p.7).

One of the recurring messages from the Report addressed to the government is the appeal for sensitivity to the already existing burden of administrative work attached to care and the need for moderation in the introduction of yet more new policy. 'Barriers to care' in this context mainly refers to the 'bureaucracy, red tape and unnecessary workload' that are said to be locking away the time that ought to have been available for patient care (RCGP, 2015, p.7). The impression is one of having to continuously meet an excessive demand, and of practitioners feeling exhausted by the effort of producing nothing worthwhile in return. On this issue, the Report specifically requests NHS England not to 'do anything that will lead to major top down structural reorganisation which could lead to the setting up of new bureaucratic structures', and suggests a policy of testing every new NHS initiative against how it will impact on GPs' time and workload. 'A 'one in, one out' approach...' (RCGP, 2015, p.7). It also stresses the need for GPs and politicians to 'work together to ensure that new and existing policy initiatives relating to general practice do not have unintended consequences for patient care' (RCGP, 2015, p.7). The policy to introduce a seven day week surgery, for instance, whilst theoretically appealing for politicians who wanted to appear to be taking action on waiting times, had actually led to a number of adverse consequences. The depletion of in-hours staffing had led to longer waiting times for patients during the week. As so few people wanted to attend an appointment at the weekend, practitioners had felt that their time was being wasted. The overall effect was to have made the situation worse as well as

compounding misconceptions about what really lay behind the waiting times in the NHS (Sheard, 2018).  $^{20}$ 

Published just five months later in the year, the 'Making Time in General Practice Report' (to be referred to from now on as the 'Making Time report'), was compiled by a partnership of two consultancy organisations, NHS Alliance, and The Primary Care Foundation. It contained the findings of the urgent review that the Royal College of General Practitioners had requested, and NHS England had commissioned. Based on these findings, the Making Time report makes recommendations for what it describes at different points as 'saving practices time and money', 'reducing avoidable demand for GP appointments', 'using GP time in different ways', and 'unlocking', 'releasing' or 'freeing up' GPs' time through the creation of 'more efficient systems' (NHS Alliance, Primary Care Foundation, 2015).

The strength of British general practice is its personal response to a dedicated patient list; its weakness is its failure to develop consistent systems that free up time and resources to devote on improving care for patients... This report offers a series of suggestions for how emerging practice groups and federations can create more efficient systems and free up clinical time, for example, by reducing the need for repeat visits rather than creating yet more activity in an over-heating system.

(NHS Alliance/Primary Care Foundation, 2015, p. 8)

In keeping with the familiar cultural logic of late capitalism, in which 'anything and everything seems possible' (Hunter, 2015, p.4), the Making Time report is concerned with methods that claim to be able to 'make time' in NHS general practice. This involves the development of systems to redirect patients so as to keep them

<sup>&</sup>lt;sup>20</sup> Sally Sheard points out that waiting has always been a necessary feature of tax funded) health systems, but rather than being transparent about who waits longest, and why, policy makers have used the monitoring of waiting to create the superficial and temporary impression of a resolution (Sheard, 2018).

moving through the service, preventing people from getting too stuck, or too 'attached' to long term projects (Fisher, 2009).<sup>21</sup> The rest of this chapter is dedicated to looking at how this works in more detail.

### 1.2. New Models of Care

For the authors of the New Deal report, articulations of care are closely bound up with time scarcity. Care is something that GPs want to spend more time 'developing', but are unable to, due to current 'pressure levels' (RCGP, 2015, p. 7). The report is missing any clear definition of care, but it envisions 'new models', better equipped for the 21st century. For example, there are references to future integrated systems that will move general practice 'away from the traditional NHS focus on single-disease pathways and individual episodes of care', so as to enable GPs to treat multiple morbidities in the same patient.

It is vital...that these emerging models build on the strengths of general practice, including the 'local' nature of GP services, their generalist scope, the continuity of care they provide to individuals and families and the population-level perspective they are able to take through the registered patient list.

(RCGP, 2015, p.8)

One of the most noticeable things about these 'emerging models' is how obviously reliant they are on older practices of care in general practice. The local nature of GP services, their generalist scope, the continuity of care provided to individuals and families, 'responding to the needs of the individual', and acting as 'independent advocate'; these are some of general practice's longest standing-standing attributes

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<sup>&</sup>lt;sup>21</sup> Mark Fisher singles out the problem of attachment in workplaces where attachments and ties have become unsustainable, superseded by 'permanent instability', and an arrangement where the employees are like 'interchangeable machine parts', prevented from engaging in any long-term project (Fisher, 2009, p. 32).

used to formally identify what it is and what it does. The classic principles of generalist medicine that set it apart from hospital doctoring, with its long, humanist tradition of holistic and patient-centred care, are reintroduced in the report as though they were new ideas, if not for the people practising them, then for the terrain they are being (re)introduced or 'hardwired' back into (RCGP, 2015, p. 8). Some GPs have taken issue with this on the grounds that the requirement to develop care practices that are rooted in a philosophy of people as 'purposeful, thinking, feeling, emotional, reflective, relational, responsive beings' (Harding, Wait and Scrutton, 2015) are simply not compatible with the technoscientific models of care that have come to define contemporary medicine. A manifesto for 'recovering the self' in primary care published in 2016 is one example of this. It was written collaboratively by Christopher Dowrick, Iona Heath and colleagues with many years of experience working in general practice.

GPs are encouraged to work collaboratively with patients, fostering shared decision-making and promoting self-management. This assumes that patients (and doctors) have agency and capacity, the ability to make their own choices and decisions and the power to take action in a given situation. But these assumptions are problematic when you are running 15 minutes late during a morning surgery with 18 patients, most of whom are unknown to you, and your QOF screen pop-up urges you to update the patient's CVD risk assessment score and take action to reduce their HbA1c levels.

(Dowrick et al, 2016, p. 582)

The manifesto argues that humanist perspectives are missing from the physical sciences and that as GPs have both an instrumental and a moral need to take personhood seriously, 'an academic model is required that includes human consciousness as a valid and significant entity' (Dowrick et al, 2016, p. 583). In effect, they are arguing that the practitioner's sense of self is being eroded in a way that parallels the erosion of self in those seeking care, and that what is needed is a model

of health care that has at its centre, two or more temporal beings both of whom have the capacity to suffer.

## 1.3. Making Time for Care

The Making Time report subscribes wholly to the belief that the solution to the problem of time scarcity in this setting is to invest in strategies of managing demand. This is summed up by the (then) Health Secretary, Jeremy Hunt, whose words set the tone for rest of the Report.

Put simply, if we do not find better, smarter ways to help our growing elderly population remain healthy and independent our hospitals will be overwhelmed – which is why we need effective, strong and expanding general practice more than ever before in the history of the NHS.

(NHS Alliance/Primary Care Foundation, 2015, p. 13)

In taking seriously the idea that more might be done to make time by tapping into a surplus believed to be lying dormant within general practice and its established ways of doing healthcare, the report suggests that with the right kind of technology and the most efficacious ordering of all the pieces involved in doing healthcare, it should be possible to source and spring time from one part of the system and to 'release' it, into another. On this basis, 'ten high impact actions' are devised to address the concerns of practitioners over not having enough time for care (RCGP, 2018). Five of the ten actions measure the success of their initiatives by how effective they can be at deflecting or deterring practice-based GP consultations in cases where they might be avoided ('Signposting', 'New Consultation Types', 'Partnership Working', 'Social Prescribing', 'Supporting Self Care'). This includes the diversion from the Practice of 60-70% of consultations that 'could be handled entirely on the phone in an average of 4-6 minutes' (NHS England, 2016). Of the remaining five high impact actions, two address speeding up the everyday activity

of practitioners ('Personal Productivity' and 'Productive Workflows'). Two others address how to reduce the number of non-attendances and how to apply the principle of specialism in general practice where doctors are encouraged to protect their time by limiting themselves to the types of healthcare work that only they can do, redistributing the rest amongst other members of the team. The final action tries to solve the problem of establishing the primacy of the strategic perspective which stresses the need for an overhead view of time in the surgery. GPs are encouraged to establish a 'different perspective' on what they are doing, from where they are expected to discover the potential to make 'completely new improvements', unseen before (NHS England, 2016).

Taken all altogether, the report and the recommendations represent just such a vantage point from which to look out over the operations of their workplaces. They contain what might be described as their own technology of perception (Ihde, 1995), a disembodied way of looking at healthcare labour that works by providing practitioners with the conceptual means to transcend the sedimented temporalities of their own care work and to see themselves differently in relation to it. Through a rereading of the original problem of time scarcity from this position, a range of opportunities for expanding the time available might present themselves, but in order to take advantage of them, practitioners need to adhere to a productionist temporal regime that has the safeguarding of the future as its ultimate aim. As the authors express this, 'the sector can and must reform to meet evolving needs. GP capacity must be freed up' (NHS Alliance/Primary Care Foundation, 2015, p. 13).

The challenge that this represents for practitioners is to reconceive care as an act of calculation. As Bellacasa painstakingly explains, the work involved in managing anticipation and calculation is characteristic of late capitalist fears about regression in the face of uncertain futures and its regimes for managing this (Bellacasa, 2017). By reducing what counts as care —for instance, to a managerial "conduct" of tasks to follow, we inhibit the possibility for 'developing other relations of care that fall out of its constricted targets' (Bellacasa, 2017, p. 186). The effects of such a regime are antithetical to making time for care, because care is reduced 'from a

coconstructed interdependent relation into mere control of the object of care' (Bellacasa, 2017, p. 186).

In the 1950's, the Hungarian psychoanalyst Michael Balint and his collaborator, Enid Balint, proposed an alternative method of continuing to offer care under conditions of time scarcity (Balint and Norell, 1973). For the Balints, whose work in general practice led to them having to rethink the relationship between time and therapeutic practices of care, the element of continuity was believed to define the very possibility of a particular kind of care in this setting. In their psychoanalytic imaginary of general practice, the doing of care and the time when this activity could be expected to take effect, were not expected to happen synchronously as has generally been assumed to be the case in these more recent attempts to organise time in general practice. If they happened at all, they happened at different times. Their method works by using a temporal practice of waiting to exceed the small amounts of time apportioned to the consultation itself.

The idea is that your relationship with the patient goes on for years, and if each time you can do a little, one little step, it can add up to enormous amounts...

(Balint and Norell, 1973, p.149)

Here too, was a sense in which time could be released from a frustrated care situation in the hope that it would become more productive if applied elsewhere, but whereas the Making Time initiatives appear to want to disambiguate the care relation, assigning a productive value to every unit of time dedicated to care, for the Balints and their doctor colleagues, the six minute GP consultation<sup>22</sup> represented the chance of working on care continuously by doing a little each time, in the hope that something unpredictable but potentially 'enormous' might eventually come out of it.

<sup>&</sup>lt;sup>22</sup> An average 'six minutes for the patient' in general practice was the working assumption of the group formed by Balint who believed that 'intermittent therapeutic influencing can have an effect in spite of the short time periods available for each intervention' (Balint and Norell, 1973, p. 149).

### 1.4. Time Saving

After just one year from its launch date, the Making Time recommendations were calculated by NHS England to have saved 257,662 hours of clinical time. These were hours that were either already realised in practice or 'highly likely to happen due to the changes made' (NHS England, 2016). The GP consultation itself was one of the sites singled out for its potential to waste time unnecessarily. In spite of many GPs having expressed reservations about the use of phone triage and remote consultations around this time (Brant, Atherton and Salisbury, 2016), the use of these technologies to reduce the time spent on being with a patient in person is strongly recommended:

From a starting point of treating phone contacts as brief triage encounters, practices are increasingly recognising the feasibility and value of fully addressing the patient's need in a single phone contact where appropriate. Experienced consulters generally find phone consultations are half the length of face-to-face ones, and that approximately 75% of consultations can be fully concluded on the phone.

(NHS England, 2016)

The strategy of avoiding or shortening the GP consultation wherever possible suggests an emerging view of this classic site of care in general practice as a place where nothing happens anymore that can justify the time being used to sustain it. Many of the practices with which general practice has long been associated, including listening to the patient and achieving a holistic understanding of their needs, are seen as untenable mainly because, at just ten minutes in length, the duration of the consultation is deemed too short for them to achieve anything worthwhile.

Evidence suggests that one-to-one consultations may not be working for GPs nor for patients. Ten-minute appointments are a high pressure way of

working and organising care in this way may impact on job satisfaction and GPs' personal wellbeing... to sustain primary care and the clinical teams who provide it, we need to find new and better ways of delivering care that energise clinicians and leave people feeling better able to cope, care for themselves and keep well. When we achieve this, people will self-care with confidence and may need their practice team less.

(NHS Alliance/Primary Care Foundation, 2015, p. 64)

From a strategic perspective, the modes of production afforded by an in-person consultation are also perceived as unmeasurable and unmanageable. Being in the presence of the other person and seeing how their health problems are interconnected with other areas of their life makes it more difficult for the doctor to stay limited to doing 'what only a doctor can do'. The conditions created by face to face contact may also be more conducive to the patient's staying and coming back, and the absence of any definite cut off point offers no assurances that patients with chronic illnesses in particular will not just keep coming back again and again without there being anything to show for it from a clinical or organisational point of view.

The Making Time report had little to say on the subject of continuity, or about the patterns of regular or intermittent attendance over long periods that are so typical of the timelines for chronic illness. If mentioned at all, the practice of the patient coming back tends to take either the form of a repetition or a malfunction. Either the patient is coming back to replay the same event again and again, or they are coming back because the consultation is not working properly. This notion of an unnecessary repetition of care also forms part of the strategy for how more time will be made – through 'the reduction of the need for repeat visits' (NHS Alliance/Primary Care Foundation, 2015, p. 9).

Some practices find that there is enormous pressure on appointments, but the solution comes from looking at what it is about the way the practice works that means that patients are coming back so often compared to the norm.

(NHS Alliance/Primary Care Foundation, 2015, p. 41)

'Repetition' is the term that the authors use to describe what is happening when a patient 'comes back' for something, as when repeat prescriptions are issued requiring 'repeat visits', or when a 'repeat attendance' is needed to enable a GP to refer for another hospital appointment after a cancellation, or when a patient is compelled to 'repeat a consultation' to acquire a sickness certificate, or a 'no cause for concern' blood test result, something that the authors intimate could probably be acquired in another way (NHS Alliance/Primary Care Foundation, 2015, p. 8-10). This suggests a high frequency of wasteful appointments where the same possibilities and outcomes of the previous appointment are only ever replicated. Any follow up contact not sufficiently able to account for its own use of the surgery's time, can be viewed as time repeating itself in a system described as 'already overheating' (NHS Alliance/Primary Care Foundation, 2015, p. 8). When care is defined primarily by its potential to deplete essential resources, there is no way of justifying spending more time on it, other than by showing how this will ultimately lead to less time being spent on care in the future.

'Returning' describes the event of coming back differently. Whatever the reason for it, to return which mean literally 'to turn back again', describes a continuation of the timeline for care, not just its repetition. Whereas to repeat implies a quantitative memory of having made all the same 'moves' on at least one previous occasion, to return suggests remembering and preserving the history of the care relation up to that point, including its variance across the separate instances of attending: what was tried on one occasion, what had changed by the next, how things have developed looking back. In these examples, practices of care that involve returning to something or somebody, are at odds with linear orderings of time and with the proposition that there could ever be such a thing as a repeat visit in a workplace of care. In place of 'the monotonous return of the same, self-identical, noise' (Lefebvre,

2004, p. 78) practices of returning to work on care operate on the assumption that some movement will happen, but only as time passes.

### 1.5. Keeping People Moving

The activity of movement and mobility in general is a recurrent feature of the ten high impact actions recommended by NHS England. The recommendation to consider group consultations, for instance, as a replacement for the GP appointment, are calculated to save time by moving patients with chronic conditions away from practice-based GP appointments where they could become fixed in cycles of repetition in which 'basically, no-one is winning' (NHS Alliance, Primary Care Foundation, 2015, p. 64).

Ten minutes is not long enough to have the kind of discussions people want to have. This leaves professionals feeling frustrated and powerless because they can't deliver the kind of care they want to.... group consultations usually run for six months by which time people are often ready to move on and support themselves; sometimes maintaining contact and becoming a self-managing group.

(NHS Alliance, Primary Care Foundation, 2015, p. 65)

The group consultation takes the form of a series of shared appointments offered as a replacement, not as an addition to the one-to-one appointment. In them, patients are expected to progress steadily towards the goal of self-care. Running through each session is the strategic aim of moving along towards a future of managing a chronic condition independently, or at least to the point that less outside help is needed overall compared to what they might have needed, had they attended a series of one to one appointments with a clinician or with a team of clinicians.

The strategic hope of all of these recommendations is that at the same moment in which care is consumed by a patient with a chronic condition, an investment is being

made. The time they consume will be repaid when at some future point, the same patient falls back on their own resources rather than approaching their general practice for help once again. This ability to be able to produce self-care out of care is one of the magical solutions offered to the problem of too much demand for care. It takes effect when extra time or capacity is released in the future as a result of the work carried out in advance. This is the meaning of the mantra running through the report, reminding people of the 'time that repays itself' (NHS Alliance/Primary Care Foundation, 2015, p. 36).

In this formulation, there is no longer any need for temporal practices of care that outlive the moment. When self-caring takes effect, the practitioner is relieved of their former responsibility for watching over the patient or for keeping them in mind. For those involved in the activity of giving and receiving chronic or ongoing care however, the need to be seen to be always moving forwards could be at odds with the temporalities of care associated with long-standing conditions (Samuels & Freeman, 2021; Clare 2017). If the nature of time in chronic care tends to be more stumbling and oscillating than moving and flowing, where 'problems emerge and as they are tackled new problems arise' (Mol, 2008, p. 67), then it is unclear what 'moving forward' might mean in terms of the work that general practices do, or what might be expected to happen to the chronically unwell patient for whom forward movement is not an option. The perception of care as the work of keeping things going progressively in one direction - away from the circumstances that led to the need for it in the first place, suggests a synchronicity of temporalities all working to the same rhythm. However, for patients and practitioners whose being in the world of chronic care and illness means that they may not be in a position to see or to experience time as this synchronous force compelling all movement towards a future of wellness, the image of an ever, onward movement of care could represent yet another unrealistic timeframe to have to contend with, extraneous to the work itself, of care.

Michel de Certeau describes strategies as the means whereby functions which would usually be reserved for living subjects (the function 'to care' for instance), are

attributed to institutions created in the image of a universal and anonymous subject. Though they often aim to restrict the freedom of the inhabitants of these exteriorities, Certeau sees strategies of governance as necessary to cohere everyday life, or at least for maintaining a fantasy of its coherence. Irrespective of how seemingly grounded in the institution and its values they might appear to be, strategic articulations always have to remain at a distance from their object, in 'a place that can be delimited as their own to serve as a base from which relations with an exteriority composed of targets or threats... can be managed' (Certeau, 1984, p. 36). Within this definition, the strategic can only ever be theoretical 'creating places in conformity with abstract models', no matter how alike the functions attributed to the institution are to the activity taking place within it (Certeau, 1984, p.29). Grasped in this way, the views on time contained in the New Deal report and the Making Time report represent look out points from which to see their shared object. In a phenomenological sense, they are imaginary or theoretical because what they claim to have 'seen', does not correspond directly to any sensory perception of anything that has actually been seen, heard or sensed by them through the body. They map time onto care from somewhere 'foreign' to the experience of those who are living in it. In this way, practitioners are invited to see things from a perspective where their very embeddedness in the worlds they are supposed to be caring for, presents a major stumbling block to their ever being able to achieve the 'headroom' needed to make time for care.23

### 1.6. Conclusion

Temporal reorganisation in response to time scarcity in the NHS goes back much further than 2015. The invention of the appointment system is an earlier example of the reworkings of the offer of time that have been at the heart of NHS general practice in its attempts to assert temporal control (Moore, 2022a). The imperative to keep people moving through the system and the use of clinical justifications to

<sup>&</sup>lt;sup>23</sup> Finding the headroom to see care from a more strategic position is an idea that recurs in the Making Time report (NHS Alliance, Primary Care Foundation, 2015, p. 36).

achieve this is also not new in the NHS. More than twenty years has passed since Joanne Latimer linked the acceleration of hospital discharges to the growing insistence on medicine as a 'success story of completed diagnostic episodes and clinical pathways' (Latimer, 2000, p.126). In Latimer's view, the care that patients were being provided with in the years before 2000 was already of a kind that served mainly to reproduce organisational aims to keep patients moving through the hospital and on towards discharge. Through a perception of time as pure capacity at the total disposal of the organisation, as empty until filled, and as incapable of ever being made full with anything except more productive capacity, the temporal scene of general practice is made to look empty and unoccupied, at the same time as it is made to appear full of potential for a reenergised future. From being a source of fear and despair over how care and the working life of the institution is in danger of getting consumed too quickly, time is re-envisioned by those who have no embodied relation to it, through a perspective which 'continues to impose itself as the only conceivable horizon' — that of growth identified with progress (Stengers, 2015, p. 21). The composition of time in general practice between 2015 to 2020 might best be understood as a prolongation of these agendas for growth, against a background of devastation in the NHS. The modes of making time that they offer are based on an imperative of moving forward in a futuristic drive whereby any impediments, including those associated with the demands of care, are made to seem as obstacles to be overcome.

# **Chapter Two**

# **Research Process and Methodology**

This chapter describes the development of a methodology that was designed to investigate forms of care that issue from non-progressive time in general practice in England. It narrates the process of adjusting to the new conditions for carrying out research in general practice during a pandemic. The first section gives an overview the research design before introducing some of the difficulties involved in defining and observing an object as elusive as non-progressive time. The second section addresses the altered context of the study during the 2020 Covid-19 pandemic and how I responded to the loss of the general practice itself as a spatial site for data collection. The middle sections summarise the working methods used throughout the research process, including details of how participants were recruited and consented, and some of the considerations involved in using speculative research techniques. In the final part of the chapter, I discuss some of the hidden parts of the research process and provide an overview of my approach to interpreting and analysing the data.

### 2.1. Introduction

This project began as an ethnographic study of waiting as a temporal practice in general practice. Then, it evolved into a study of the relationship between care and time in situations in which nothing appears to improve, or get better. This happened in part because the coronavirus pandemic and the subsequent lockdown of private and public life as a response to the virus, made it impossible to keep to my first research design which relied heavily on the freedom to observe areas of the surgery over long durations, but it was also partly in response to a sharpening focus on what

it could mean to wait in the NHS under certain conditions. The study retains its original STS-informed ethnographic engagement with how the realities of caring for things that do not get better are 'done' in this setting (Mol, 2008). It also retains most of its original sites: the Balint group, the GP consultation, and the Waiting room, which were chosen for their association with stuck time, chronic time and uneventful time. Practitioner accounts of offering care at these points still do make up the primary data for the study, but my observations of care at these sites have been complicated and contextualised by online accounts of non-progressive time in NHS general practice collected over the course of the same period, between Spring 2020 and Spring 2021.

In what follows, I outline the details of a working method which both is and is not, a product of the unexpected. It is, in the sense that I did not expect a global pandemic to happen during the first week of my fieldwork precipitating the onset of time 'lived differently' (Nieuwenhuis, 2020). It is not, in that crisis is exactly what I had expected to find in the NHS, and if anything, the intensity of this particular crisis seems to have led to an even deeper aporia between the temporalities of crisis management and temporalities of care in the NHS and in general practice. Anand Pandian writes that it is almost a truism and cliché to say that anthropology lands us in the midst of things unexpected, but that this is as it should be, because anthropology happens in the place between truth and accident, where insights of enduring value are 'stumbled over' (Pandian, 2019, p.46). But it would be wrong to say that this research method is the product of what Fiona Wright calls 'making good of crisis' (Wright, 2022). As she observes, to do this without also attempting to 'sit with' the trouble of crisis, could risk sealing over the harm that has been done in order to make it into a launchpad for ideas and theories that are not fully capable of seeing or responding to the violence in crisis. An alternative reading might be that the pandemic represents an interruption that takes place within a continuation — 'the last in a longer series of crises' (Nieuwenhuis, 2020), and perhaps this helps to explain why my research process has been allowed to endure, in spite of yet another iteration of crisis, albeit this time on a more catastrophic scale.

### 2.2. Overview

The study of general practice as a site of waiting, staying and enduring forms part of a wider Wellcome Trust-funded 'Waiting Times' research project<sup>24</sup> which looks at what it means to wait in, and for healthcare by examining lived experiences, representations and histories of delayed and impeded time. This work has definitely benefited from the resources of the wider project. Intellectually, it has been heavily influenced by the thought and engagement of the eleven other members of the Waiting Times research team, most of whom had already worked for years on interdisciplinary questions relating to time, care and/or general practice before starting work on the Waiting Times strands of research. It has also benefited from the wider project in practical ways including from access to pre-existing connections to general practice. The two general practitioners who were the main contributors, participants and points of contact within their own NHS organisations over a threeyear period had already committed to participating in the study in advance of my arrival. This laid the groundwork for me to form a research partnership with their two surgeries and to draw up a local research contract based on guidance provided by the NHS Research & Development Office for Central and North West London. When working out the finer details of how these research activities would be carried out in practice, I took the advice of practice managers from both sites, and was guided by the helpful suggestions of the two general practitioners who were also my main participants.

This is a three-year doctoral research study which was extended to four years. The extension of one year was to make up for the time lost due to the pandemic, but this time was not lost exactly. With the exception of a few months in 2020, when it was my turn to be sick with the virus, I never really stopped working on the project. It might be more accurate to say that the study was held in suspense across successive lockdowns, to be reimagined and revised at regular intervals based on what might

<sup>&</sup>lt;sup>24</sup> https://waitingtimes.exeter.ac.uk/ [Project number 205400].

have seemed possible at any given time. From suspension, I found other ways to assemble sites of general practice so as to be able to observe them remotely, which I will go on to explain.

### 2.3. Defining the Parameters of the Field

Prior to March 2020, before I had ever heard of such a thing as a lockdown, I had already spent some time at the two participating surgeries which were to have been my field sites for an ethnographic study of waiting as a temporal practice; the one in East London, the other in rural Devon. The practice managers from both sites had generously guaranteed their own support and that of others from the wider teams in helping me to disseminate information about the study, recruit participants, access certain areas and schedule a timeframe for observations and informal interviews. By February 2020, we had signed an agreement putting our research partnership on a more secure footing.

Earlier on during this period of planning and negotiating access, I had made several visits to the East London Practice to speak with staff about the study and to enlist their help with defining the parameters of the field for a study of time and care in this setting. On one occasion, I consulted with the GPs when they were all together. On another occasion, I consulted with the receptionists when they were all together. I also formally consulted with three practitioners when they were on their own.<sup>25</sup> My initial aim during these consultations had been to distance myself from this 'thought-object' which I was provisionally calling waiting, and to try to cultivate the ethnographic sensibility towards it, of 'unknowing what I thought I knew before beginning' (McGranahan, 2014). I had wanted to create a situation in which people were free to interpret what waiting time could be in relation to care, and to articulate this in their own words. As a way of losing some control over the forms that this might yet take, I tried to keep the terms of definition as open as possible by asking

<sup>&</sup>lt;sup>25</sup> The purpose of these individual consultations was to refine my research questions and approach. The data from these consultations do not form part of the data set for the study.

very general questions such as, 'what, in your experience is the relationship between time and care?' Or, 'where do you see waiting happening?' Responses were varied. As expected, some of them focussed on time as something that practitioners did not have enough of, and on waiting as something that only patients do. Or, waiting as something that happens between the moment of needing care and the moment of 'accessing' it. One practitioner described this type of waiting as being like a form of 'bad care', comparable to a bad customer service, the implication being that waiting should always be minimised wherever possible. Other responses were more unexpected, particularly those that revolved around a notion of timeliness and its importance to the craft of generalist medicine. For example, one general practitioner told me about how he had delayed diagnosing a patient because a diagnosis would not have been considered timely under the circumstances. He had not known enough about the patient at to feel confident about offering an explanation of her symptoms at the time, so had protracted the period of assessment by inventing reasons to keep her coming back to see him. What I noticed when listening to these practitioners speak about waiting time from their own experience was that, even after having orchestrated it themselves for sound clinical reasons, as in this example, waiting was almost always associated with unproductive time. If 'seen' at all in the surgery, it tended to be seen as time wasted, or as the failure to get to an outcome quickly enough. Yet in a very real sense, the whole idea of getting to an outcome quickly could be totally at odds with the temporalities of care in general practice. Symptoms sometimes took time to emerge, unwell patients often did not get better, or if they did, this might be due as much to the effects of time passing as it was to the effects of any medical intervention. Situations in which time could be made to force an event; a cure for example, or a recovery, or a longer life, or better health overall; appeared more as the exception than the rule.

# 2.4. Early methodological considerations

The language of object assemblage that I have been using to describe these early stages of my research, places this study partially within the contemporary wave of

theorising about method from a material semiotic, or actor network perspective (Law, 2004; Latour, 2005; Mol, 2010). By focusing on the ontological dimensions of how realities are represented, enacted or assembled, these theories want to take more seriously the implications of the belief that the world is not 'out there', waiting to be known once and for all. For experimenters in this perspective, this has meant having to look for methods, 'after method' (Law, 2004), that avoid reproducing or collapsing back into the disciplining practices that always seem to lead back to the same old modes of knowing about something. In an ethnographic context, this implies a shift from representation as a technique of mediating between object and image where the goal is to reflect the world in its proper form, to representation as more of an ontological commitment to a writing practice which has the potential to 'world' the realities that it writes about. I also want to acknowledge here the influence of speculative thought and philosophy over how I have come to understand what it is that I am trying to achieve by doing this research, in terms of what kinds of experiences, if not those of simply knowing, I am aiming for. I have wanted to do the kind of research that works more towards the emergence of novelty and to the potentiality of experiences, than towards those that are repeatable and that confirm what was always probable, based on what has come before. To borrow an expression from Isabelle Stengers (Stengers, 2017, p.7), this is to emphasise that I am more concerned with the 'possibles' of care, than I am with the foreclosure of its possibilities through the offer of guarantees, explanations, causes or effects. In this respect, the speculative notion of the 'research technique' (Wilkie, Savransky and Rosengarten, 2017, p.113) as opposed to the research method, may actually be a better description of what I am trying to do.

One of the main constraints of speculative thought, traceable to the writings of Alfred North Whitehead (Whitehead, 1978), is that the epistemic cannot be separated from the ethical. Or, to put it another way, methodologies cannot be thought of apart from what makes them possible and from what they, in turn, make possible. Whilst social sciences often require of researchers that they situate themselves in relation to their research in a realm of sociality (through gender, race, class etc.), situatedness in speculative research has more to do with 'recognising that

which generates a philosophical problem and the ground from which our thinking of this problem departs' (Halewood, 2017, p.56). In this respect, I mean to situate the problem enabling this research within the long, intersecting histories of thinking time through the salvific, capitalist telos of progress. This shared history is operative in medicine in the form of curative narratives, and in the NHS, it takes the form of narratives of social progress. For inheritors of it, including myself, this is arguably what has brought us to where we are — to where expansion and growth are imposed as 'the only conceivable horizons' (Stengers, 2015, p.21). And, as this may also be the only way that we have of thinking the future, it works as a constraint on my ability to think outside of capitalist time. Whilst speculation implies an openness of mind, and a 'jumping' off the solid ground of agreed conventions for what should and should not be allowed to be made possible, 'it also demands that the thinker not aim at what would transcend the conventions that give its consistency to this ground' (Stengers, 2009, p.18). Whilst I might want to reject curative imaginaries and the abstract ideal of progress as a way of organising what is good about the NHS, speculative techniques need to stay faithful to the empirical realities<sup>26</sup> and to the problems that enable them to jump, which in this case, means staying faithful to the actual context for care in NHS general practice in a late capitalist present.

The other constraint that I want to mention is that speculative research is risky. It looks to evoke and incite a response, though without being able to provide any guarantees as to whether this is right or wrong. Stengers likens this to the pharmacological art of 'gathering around a question to produce a heterogeneity of response' (Stengers, 2015, p.140). As there is no 'right' or 'wrong', 'good' or 'bad', only what happens next' (Halewood, 2017, p.62), this implies the need to keep paying attention so as to be able to respond to what does happen. As with the forms of care that concern this project, speculative research entails staying with the possibles that the research enables beyond the moment of their production, and then resisting the temptation to think of them as the solutions to the problem of a 'crisis in care'.

<sup>&</sup>lt;sup>26</sup> I use the term empirical here to refer to the existence of a provable relationship between experience and knowledge.

# 2.5. Summary of Research Activity and Working Methods

After March 2020, my plans for carrying out observations had to be remade, but whilst this was happening, the ground of general practice was itself shifting. My original sites: the consulting rooms, waiting rooms and meeting rooms of two English surgeries, had been chosen for their quality of 'ordinariness'. This was in keeping with my speculative premise, or 'lure' to use Whitehead's expression for this (Whitehead, 1978, p.25), that non-progressive time in everyday general practice was not the exception, but the rule. However, during the first few months of the pandemic, between March and May 2020, the number of GP appointments across the country had fallen dramatically. Many patients stayed away of their own accord, only to come back in greater numbers after the lockdown had been lifted. For a time, the surgeries themselves were almost empty and it no longer made sense to privilege this site as a field site for a study of care. The move from observing sites of the ordinary to collecting the material to author 'sitings' of the ordinary (as they appear in the thesis), was partly result of the enforced constraint of having to stay at home and partly the result of the migration of huge swathes of everyday life in general practice to more or less virtual environments. But it was also a reaction to the break up, during the lockdown, of many formerly stable, if relentlessly under threat 'worlds', including those within the NHS that I had been occupying and studying up to that point. At the time, I felt that I was witnessing the makeshift enactment of general practice under radically altered circumstances; an experience which sensitised me to the Actor Network Theory insight that clinical sites are not stable, but enacted (Mol, 2008). The ordinary of general practice was having to be improvised by those who were tasked with continuing to 'carry on' with it, no matter what. This changed the way that I understood what it might mean to try to represent experiences of offering care at these sites, and I began to see this more in terms of what Emily Yates-Doerr describes as 'refiguring the empirical as a practice of siting it' (Yates-Doerr, 2017, p.382).

Researchers who followed the migration of everyday life into online spaces (myself included), were led into encounters with different, but related versions of 'the local' in the form of digital socialities. Online forums were used by some English GPs to engage in what was described at the time as 'pandemic imaginings' (Saxena and Johnson, 2020). They took the form of blogs in which questions along the lines of, 'what has led to this?'; 'what will come afterwards?'; 'how will we carry on?', were asked, argued and pondered over. Non-progressive time in these blog testimonies would often, though not always, take the form of an annoying impediment preventing a shared project from unfolding, usually the project of NHS general practice itself. For example, one GP blog author laments that she is not able to do 'what matters most' for her patients, because a day in general practice has become like, 'dancing on the perpetual hamster wheel'.<sup>27</sup> There were also examples of GPs who described impediments to care lifting as a result of them having being forced to come to a standstill, most notably those writing in the early months of the lockdown. One GP described how the experience of self-isolating at home had moved her from a position of apathy and weariness towards her work ('was I flogging a dead horse?'), to a 'renaissance of thought' in which she and other 'unwell doctors' found that their capacity to care about many things had renewed. 'We existed on social media support groups and signed petitions, over-analysed symptoms and dreamt of knowing our formal immune status to better care for patients and our families'.28

What follows is a description of all the research activities used in this study to author multiple, connected sitings of non-progressive time in general practice. As this suggests, the field is not bound by geographic contexts,<sup>29</sup> but is figured as temporal rather than spatial. It fits into the growing scene of anthropological studies which might be said to prioritise fields of time over fields of space as in Anne Allison's study

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<sup>&</sup>lt;sup>27</sup> Finnikin, L. (2021, February 26). Burnout revisited—But it's not my fault. Pulse Today. Retrieved February 2021 from https://www.pulsetoday.co.uk/views/workload/burnout-revisited-but-its-not-my-fault/

<sup>&</sup>lt;sup>28</sup> Parihar, A. (2020, May 22). Doing the day's work well—My unlikely COVID-19 renaissance – BJGP Life. BJGP Life. Retrieved May 2020 from https://bjgplife.com/doing-the-days-work-well-my-unlikely-covid-19-renaissance/

<sup>&</sup>lt;sup>29</sup> The one geographical context that still applies is the national. All of the material is collected from sites of general practice in England.

of Japan's current 'moment of precarity' (Allison, 2014), or Todd Meyer's study of the 'afterlife of therapy' (Meyers, 2013). All of the material used for the study is ethnographically derived in the sense that it was collected and interpreted with an ethnographic sensibility as to what would be lost or gained by scientific interpretations of the same material, rather than as 'stable objects to be seamlessly moved from perspective to paper' (Yates-Doerr, 2017, p. 394).

### Observations of the virtual Balint group<sup>30</sup>

Balint groups are the continuation of a practice that began in the late 1950's, when the psychoanalyst Michael and Enid Balint began holding seminars for GPs in London. They invited doctors to bring cases of 'difficult patients' to discuss at the seminars, particularly those ongoing, unresolvable cases where patients had 'offered' the doctor an illness that it was not possible to treat using the usual methods of generalist medicine (Balint, 1957). Most of the present day Balint groups have retained this practice of discussing cases. They are not exclusively dedicated to 'difficult patients' but they often do become a forum for practitioners to speak about the challenges of being a doctor with a focus on the patient relationship (Salinksy, 2002).

I attended four meetings of a virtual Balint group between December 2020 and March 2021 where I observed the presentation and discussion of several patient cases. There were usually between 10 and 13 GPs in remote attendance, all with their cameras switched on, although it was rare for more than five of them to speak during the course of one meeting. The group leader opened each meeting (in what I afterwards learned was the conventional way), by asking whether anybody, 'has any cases that they want to discuss?' After a case had been suggested and the presenter invited to go on, the speaker would give an overview of their current situation with a patient and its recent history. On each occasion that I had the chance to observe

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 $<sup>^{30}</sup>$  It was quite typical during these discussions for the doctor to express a feeling of being stuck and of not being sure of how to proceed with a patient.

this, the case being presented took the form of a problem or a dilemma, most often an ongoing, immoveable problem in which a limit had been reached in terms of what it was possible to do to help a patient using the resources available to a general practitioner. Nobody would speak during the presentation except to ask a question or to clarify a detail. After they had finished speaking, the group leader would invite others to share their thoughts on the case. Three or four of the other doctors might offer a response. Somebody would usually try to solve the problem by diagnosing it and recommending treatments. When they did this, the group leader would step in and remind them that this was not the purpose of the meeting. As far as I know, this was the only forum where practitioners would come together to discuss their work with patients in this way. At the end of the allotted time, the meeting would end at whatever stage of the discussion had been reached, so that whatever difficult situation had just been unravelling over the last half hour, it was left in its original open-ended, unresolved state. I took detailed notes during each meeting and transcribed them afterwards.

### Observations of GP consultations

I observed eight GP consultations during the same week that the lockdown was announced, and I observed four meetings before social distancing came into force. Both types of observation took place at the East London Surgery as my original plan had been to spend three months observing this site before moving my research to the other general practice site in rural Devon. These observations all took place in the same room of the practice and with the same GP. They were routine appointments with patients who were from all different backgrounds, of various ages and mainly female whose reasons for coming in that day were as follows: fatigue; a general feeling of being stuck in a rut; concern about a baby who was having restless nights; no reason, just wanting to check in with the doctor; on advice from the diabetes nurse; spinal tingling; feeling depressed; a lump on the neck. I took notes as the appointments were happening but they were brief as most of the appointments lasted no longer than seven or eight minutes. The notes record the

problem in the patient's own words and fragments of their conversation with the doctor, plus anything else that I thought was relevant. I give an example below.

### Patient seeking help for: fatigue

Patient: "I'm exhausted all the time".

**Doctor:** "What do you do as a job?"

Patient: "I'm a chef".

**Doctor**: "Is it a hard job?"

**Patient:** "Yes..." (explains why the job has got more demanding recently).

**Doctor:** "The thing about fatigue - is that it can be caused by anything. It could just be the result of a hard life. Different doctors would do different

things".

The doctor goes on to explain that there are lots of tests that could be carried out, but that nothing was certain.

I have explained the process of gaining informed from patients consent prior to these observations, but whilst all the steps were followed and the consent sheets read and signed during the 2 or 3 minutes before an appointment, the actual experience of gaining informed consent was not always so straightforward as the paperwork might seem to imply. Whereas in legal and administrative terms, the process is made to appear watertight, in reality, my brief conversations with patients in the waiting room just as they were waiting to be called up for their appointments could be ambiguous in their content making it difficult to know whether somebody had really consented or not. In one exchange for example, a patient did give verbal consent to being observed during her consultation, but she also expressed concern about the idea of being physically close to me at a time before social distancing measures had been formally introduced even going so far as to ask me if I could sign the consent form on her behalf so that she would not have to use my pen. Her anxiety about the risk of infection was visible and her reluctance

to be close to me undermined her consent to be observed in a small room with a third person present.

Bester, Cole and Kodish (2016) describe informed consent as 'the victim of its own success' in that it can be foregrounded to the extent that people sometimes stop noticing when people's ability to give or withhold it in any meaningful way is being compromised. One of the factors compromising the integrity of consent in this case was the shortness of time available in which to speak to the participant and to answer any questions they might have. GPs have tight schedules with back-to-back appointments and even just a very short delay of only a few minutes between appointments runs the risk of lengthening patient waiting times for the rest of the day. The need to rush through information made it difficult not to question the extent of a person's real willingness to be involved. In certain cases, instead of allaying my concern, the signing of a consent form only increased it when I thought I could detect signs that the participant might be feeling overwhelmed by what was going on. I tried to compensate for this by emphasising to participants, that they were able withdraw their consent at any time with immediate effect, and also by remaining alert for any signs that they might be uncomfortable with my presence particularly in the event of a physical examination. None of the participants did withdraw their consent and no circumstances arose to cause me to leave the room midway through an observation.

### Observations of routine meetings

In addition to the observation of patient consultations, I had the chance to observe four staff meetings and one long observation of the waiting room. These all took place during the last weeks of February and the first weeks of March 2020. The four meetings were for all different purposes. Two of them were for a weekly journal club described to me as 'another, smaller kind of clinical meeting, a place for people who've been 'on' updates to share what they've learned, an opportunity to discuss a complex condition and then perhaps to consider it in relation to a patient'. One was a weekly general meeting attended by the whole team. The other meeting was an

unplanned emergency session. This took place on Thursday 13th March 2020, the morning after the surgery had received its first suspected case of a patient with Covid-19. Later that same morning, I carried out an observation of the waiting room from behind the reception. These were my last hours inside the physical space of the surgery and they were the last few hours of anything like 'normality' for the surgery for some time to come. By the 13th March 2020, the government had begun issuing announcements about the need to isolate in the event of a cough. Some patients had begun to show signs of panic. The receptionists were having to improvise their responses to routine requests and queries because they did not know what the future might hold. The surgery's structures of the ordinary had seemed to be breaking down. This marks the point in the research process when my original plan to undertake a more conventional ethnography using observational methods had to be deferred, and then later abandoned.

#### Interviews

I carried out 15 interviews with general practice workers between June 2020 and April 2021, all remotely and using password protected zoom video conferencing. These included a series of planned informal interviews with two general practitioners which took place on a more or less monthly basis over a five month period in the second half of 2020. Later on, in the first months of 2021, I carried out some other informal interviews with reception, managerial and administration workers from the surgery in East London. Separately to this, I also interviewed the leader of the Balint group who is himself a retired GP with many years of experience of working at the same surgery. I did not record these interviews electronically (with the exception of the first two), because this research was dependent upon participants feeling able to speak openly about potentially exposing aspects of their work, often hidden from view of the organisation. Also, I realised that a lot of clinical detail would build up during the interview and a verbatim recording would have made it too easy to identify the individuals involved. I decided instead that I would take notes as we spoke and then transcribe these notes afterwards. The interviews took place in the middle or at the end of the working day. Time was often short with conversations usually lasting for around half an hour. I would be seated at my desk from the spare room in my flat. GP participants would almost always be seated in their consulting rooms, sometimes eating lunch at the same time. Other interviewees spoke to me from their homes. My aim throughout all of my research activity at this stage was to collect the details of how care was being enacted in relation to things or people or situations that were not improving or moving on, or getting better.

#### Monitoring GP pandemic blogs

Between March 2020 and March 2021, I monitored three GP publicly available online forums every week and I read hundreds of blogs and comments pages all authored by GPs. In keeping with the conventions of the blog form, many of them were used didactically as a way of sharing a lesson about how best to adapt to the new situation. Others were used to carry a moral message about the direction that general practice was taking and how it was changing, or ought to change. In addition to these uses however, some practitioners used the blog to offer personal testimony about aspects of their day to day lives, and to share experiences of what it was like to be trying to carry on with community healthcare during a global pandemic. This was the blog type that I was interested in collecting data from.

I have listed the three digital forums monitored most closely:

- *BJGP Life,* which is the section of the British Journal of General Practice reserved for 'personal opinions on topics relevant to primary care'.
- Pulse online magazine (specifically the 'views' section of the magazine),
   which publishes the comment and opinion of a rotating cohort of authors
   most of whom are practising GPs based in surgeries in England.
- A better NHS blog, which is the personal blogging site of an NHS GP working in London who writes posts mainly 'about the relationships between GPs and patients and how health policy impacts on that'.

These blog sites were chosen for two reasons primarily. Firstly, because they share an interest in testimonial style accounts of the everyday world of NHS healthcare. Secondly, because they made it possible for me to verify that every author was a registered general practitioner, blogging from their own lived experience. By the end of the monitoring period in March 2021, I had collected 27 GP authored blog testimonies as potential material for the study. The narrow selection reflects the inclusion and exclusion criteria which ruled out the great majority of blogs on the grounds that they were more concerned with making a contribution to medicine than they were with the day-to-day experience of working in NHS general practice. The two requirements of the inclusion criteria were that blogs must be authored by, and based upon the experiences of general practitioners working in England and that they must narrate in however small or fleeting a way, some aspect of a lived experience of caring for something 'incurable'.

In the spirit of remaining curious about how 'the local is being done' (Yates-Doerr, 2017, p.383), I saw no reason to exclude blogs in which time and care were narrated in a context other than the clinical. When I refer to the local as being 'done' or 'enacted' by the digital blog, as opposed to 'constructed', this is to emphasise that I regarded these digital accounts of general practice as not simply made from ideas, beliefs and 'imaginaries', but as enacted through material-semiotic practices, with world-building effects. This is based on an understanding of digital sociality as somehow layered into other lived encounters with sociality and infrastructure, in which 'different platforms, different algorithms, and different people may enact distinct versions (of a shared experience) in ways that are simultaneously ideational and material' (Saxena and Johnson, 2020).

By the end of the data collection period, I had carried out 14 interviews with workers in clinical and non-clinical roles, 8 observations of routine GP appointments, 4 observations of Balint group meetings, 4 observations of clinical or other types of meetings, 1 direct observation of the waiting room and I had collected 27 personal testimonies of general practitioners made publicly available online. I calculated the number of hours spent engaged in either directly or remotely observing sites of

general practice as being around 300 hours, although the total amount of time that I spent ethnographizing general practice exceeds this when I take into account other activity including online monitoring of other GP forums and remote attendance at general practice themed events and conferences.

# 2.6. Recruitment of Participants, Consent and Confidentiality

Recruitment of practitioners in the early stages of the study happened through selfselection. After an initial meeting in which I addressed all the GPs and explained what the study was about, the lead contact shared an email with instructions about how to participate. GPs were asked to contact me to arrange either a consultation or to agree a date during a morning or an afternoon surgery when I could sit in and observe them with patients. Several GPs did get in touch and I carried out eight observations of GP consultations before having to abandon this method due to advice on social distancing. Other participants in the study including administrators and managerial staff, were also self-selecting. Some had agreed informally to participate, at an earlier stage. I contacted them individually to invite them to speak with me remotely. In the case of those staff whose informal interviews took place later on in the study, recruitment was more spontaneous and opportunistic, coming about through word of mouth or during the course of other observations. Patient participants in observations were also self-selecting. I invited all eligible patients to participate who were due to attend an appointment with the GP whose surgery I was observing that day. Only one patient out of nine declined their consent to take part.

### **Informed Consent**

Prior to the start of any clinical observation, each patient needed to 'opt in'. This required me to seek their consent before they entered their GP's consulting room on each occasion. During the few days when I had the chance to carry out these

observations, I would go out to meet the patient in the waiting room in the minutes just prior to their appointment. Patients were made aware of the study by leaflets at the surgery reception and messages screened on the digital waiting room display. I would sit down and introduce myself briefly and speak to them about the study. Then, I would explain that it was their right to consent or to decline to participate and to withdraw from the study at any point. Each patient would be offered an information sheet and invited to sign a consent form agreeing to the researcher being present during their consultation and taking notes. I also sought and obtained the consent of all of those general practice workers who agreed to take part in interviews with me. This happened by email days in advance of the interview day to give them time to read through the information and decide before signing.

### **Confidentiality**

To avoid building an overly detailed clinical picture, in the written notes from the meetings and the patient consultations, I swapped some details for others. I did not record the names of patients or anything that might easily identify them as individuals. Balint groups are confidential and sensitive both for the practitioners who are presenting cases and for the patients who are the unknowing subjects of these cases. I attended with the prior agreement of the group leader only after all the GPs had been written to, their consent checked once in advance, and once again on the morning of the meeting. For publications and presentations, the names of patients, practitioners and surgeries have been anonymised or replaced with pseudonyms in line with the research activity agreement. Patients and practitioners were offered a leaflet informing them of how they could withdraw their information from the study at a later date if they chose to. I have not anonymised the authorship of any blogs used as material for the study. Their names were freely given by the authors and made publicly available at the time of publication.

### 2.7. Ethics

This study gained the approval of a university ethics committee whose members oversaw that the steps I had taken to address issues of consent, risk and confidentiality were safe and proportionate. Although the research site is an NHS primary healthcare centre with its own internal ethics approval process, the formal route of applying for NHS ethics approval was deemed unnecessary by the Health Research Authority.<sup>31</sup> In its place, I was advised to make separate arrangements with each participating primary care site. With assistance from the local NHS Primary Care Research and Development Office whose role is to oversee research activity at primary care sites in Central and North West London, I drafted a local agreement documenting all of the planned activity and a confidentiality agreement binding me to adhere to legal requirements in relation to any patient data. These documents were signed off by the practice manager in advance of any formal research activity going ahead. I was conscious of making use of my status as a social worker when seeking permission to carry out observations and when applying for ethics approval to conduct research activity in an NHS patient setting. This may have been an attempt to persuade people that I could be trusted to uphold laws around consent and to incline my research (as well as my self), to be 'sensitive' in its approach to patients who tend to be construed as vulnerable by research ethics committees (Borgstrom and Ellis, 2021). The process of obtaining ethics approval and gaining access did go surprisingly smoothly, but whether the decision to share this information with decision makers made any difference to the outcome is impossible for me to say.

Ethnographers of healthcare who have written about the experience of being a researcher who is also a practitioner (most of them nurses) have tended to think

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<sup>&</sup>lt;sup>31</sup> The fact that my study did not require formal approval by the Health Research Authority reflects the focus of NHS research agendas which are heavily weighted towards clinical trials. The decision was based on a 3 point criteria that focused on the following: 1) whether participants in the study are randomised to different groups; 2) whether the study includes a protocol demanding that patients depart from normal treatment or care; 3) whether the findings are going to be generalizable. I answered no to all three.

about this in terms of the dilemmas of performing a dual identity. They have written in particular, about the dilemma of being simultaneously an insider and outsider in their own workplaces (Allen, 2004), and about the difficulty of having to maintain particular ways of positioning themselves in relation to patients and colleagues, so as to not to be seen to take advantage of their professional status (Wood, 2018). My own experience as a researcher-practitioner differed from most of the accounts that I read, perhaps because there is something about the social worker role that makes the experience of being simultaneously inside and outside feel not so unfamiliar. This might be because social workers are often called upon to perform the role of a mediator between individuals and institutions and the people they serve. It also made a difference that I was not employed by any of the Practices where I was carrying out research. In fact, no social worker was employed by them directly, so I did not have the problem of having to renegotiate my own, and others' expectations of my professional identity. Nevertheless, throughout the study, I was very conscious of my own 'dual identity', perhaps because I could not help seeing the general practice as an extension of the NHS worlds that I had occupied myself as an NHS social worker. This probably made me more inclined to be sympathetic towards practitioners whose experiences I recognised in my own. The experience of trying and failing to make somebody better. It might also have made me less sympathetic to accounts of the NHS that I recognised but could not share, in particular those that I saw as gamifying the challenges of the NHS's weak position in a competitive marketplace of healthcare. So, whilst I did not feel the need to discipline myself to make sure that I was not being 'the social worker' when I was being 'the researcher' (Wood, 2018), I might have needed to make myself more open to the different ways of occupying and investing in the NHS including those that I have no stake in. Other researchers of the NHS have attempted to open up and interpret these worlds (Hunter, 2015), but as they tend to narrate publicly funded healthcare almost exclusively in terms of achieving, surviving, expanding and winning, they have not been the focus of my study.

At certain moments, I was made more aware of my specific identity as a mental health social worker by how others responded to my presence in clinical discussions. Sometimes I would be asked for my opinion on a patient related issue which I would decline. This was interesting to me not only because it revealed the extent to which practitioners were remembering me as a mental health professional (or forgetting me as a researcher), but because it made me aware of the kinds of problems that people might be moved to ask with for help for in a general practice. These tended to be the sort that there were no straightforward medical solutions for. They were often mental health related, though not always. A more detailed account of this happening is provided in the next section where I relate my experience of being an observer practitioner in the Balint group during discussions of difficult cases.

In choosing to narrate a kind of labour that produces the appearance of care but without anything being repaired or maintained by it, I am opening up the potential for provoking violent responses. This is intentional and is part of a wider attempt in the critical medical humanities to engage with ontological questions that look at the constitution of notions of 'care', 'cure' and 'the medical' at multiple levels (Viney, Callard, Woods, 2015, p. 2). I have purposefully avoided using statistical figures to represent the materialities of general practice during this period. Statistics are good for if you want to prove that something is happening, i.e., to eke out an event from an intuition, but they can be misleading as a way of making something that is durational and complicated into the appearance of an event. By appearing to capture a worrying phenomenon on the spot, so that something can be 'done' about it, they tend to distort what is ongoing and sometimes inevitable about what is happening. They also represent human life and suffering in biomedical ways that can preclude the ability to respond with care.

From an early stage of the study, I chose not to interview patients about their experiences of care in general practice. The absence of a patient perspective is a very noticeable omission from a study of care, especially at a time when the task of upholding standards of care is arguably heavily outsourced to the patient. My reason for choosing not to interview patients was in part to address this imbalance. I wanted to maintain the tension between knowing and not-knowing what the effects

of care may turn out to be. In my observations, the predicament of not knowing what the other person might want or need, or how they might be helped, was not resolved simply by asking them, 'what do you want?'; 'how can I can help you?'. It felt important to acknowledge that there are these limits to what practitioners and patients can know in advance about how they will effect one another in ways that shape what is to come. Monica Greco describes this as the condition of 'knowing that you can give, without knowing the positive content of the aim of that giving' (Greco, 2008, p. 102).

My inclusion of online blog posts as data to be analysed also needs to be accounted for in terms of its ethical implications. The processes that are in place to safeguard the rights of human research participants do not extend to the authors of online material who have chosen to make their data public, yet much of this material is of a personal nature and in some ways the authors are left more exposed because their identities are already disclosed. My own use of this material for research purposes is particularly sensitive because I have discussed selected blog posts in detail, contextualising the author's experience in ways that may not have been intended by them. Some researchers have argued for an approach to this that recognises blog authors as agential actors who have chosen to offer up their self-published writing for use in the public domain in exactly the same way that any other published author might do (von Benzon, 2019). In my own approach to decision-making around the use of online posts, I have not assumed this to be the case. When considering what may have been the probable intentions and expectations of authors in terms of who they anticipated might be reading their online posts, and what they expected might be the consequences of sharing the material, I have formed individual judgements on a case by case basis. This approximates more closely to a contextualised approach to the use of unsolicited online material that takes account of the status of the blog and the blogger and of how each blog is situated online (Snee, 2013). Within this approach, ethical engagement does not end after a judgement has been made about whether the blog is intended to be public or private. The researcher is required to maintain their accountability to the author throughout the process of analysis. In my case, this has involved making a concerted effort to avoid attributing motives or intentions not explicitly acknowledged by the bloggers themselves, and trying to follow their intended meanings within their own frames of reference, holding interpretive effort apart from the author's reality as far as possible.

### 2.8. Hidden Parts of the Research Process

Going back to my experiences of selecting and interpreting the material collected from general practice in all of its forms, in this section, I want to look more closely at the hidden parts of the research process, where text and speech is transformed into data. I discuss this firstly in relation to my early experiences of trying to speak to GPs about time and waiting. Then, I look at the hidden parts of observing Balint groups and reflect in more detail on my experience of recording speech whilst 'sitting in' on discussions about 'difficult' cases.

### Speaking to doctors about time

During my earliest experiences of speaking to GPs about time and its relevance to care generally, one of the most common responses had been to grasp time through the organisational structures used to 'manage' it. I give an example of this below:

**GP:** "Timeliness is what we do.... But do you know about 'managed care'? Managed care replaced doctors being able to make these decisions about time within the context of a stable, trusting relationship between the doctor and the patient. Now we are required to apply clinical pathways. We decide when to start them and stop them".

In these initial conversations, the durational life of time in the surgery rarely came to the surface, making it difficult to see how connections might be made between time and the work of care and medicine. Within the meaning that the philosopher Michel De Certeau ascribes to these terms, it was as though the time of everyday life had to be 'repressed' (Certeau, 1984, p. 71) in order for clearly defined linear clinical

timelines to appear. Despite underlying everything, the flow of ongoing time would only be allowed to appear as the 'obscure background' to meaningful activity, or as what Certeau refers to as the institution's 'night-side', '... a night longer than their day, a dark sea from which successive institutions emerge, a maritime immensity on which socioeconomic and political structures appear as ephemeral islands' (Certeau, 1984, p.41).

In research terms, the conclusion I drew from this was that data about time in the surgery was not going to be recoverable by any straightforward means, and that discussions of durational time may even be in tension with a self-image of general practice as a forward moving, evidence-based force for change and improvement. Further compounding the problem was the fear that I learned could be inspired in some doctors by the thought of failing to progress a patient to a clinical pathway on time. The relationship between time and care was a more sensitive subject than I had expected it to be. Some practitioners associated it with untimeliness in a clinical sense, and with the failure to adhere to set pathways with all of the risks of being accused of clinical negligence that this could entail. Below is an example of this from a conversation that took place during the consultation stage.

**SD:** "Do you think there's an element of fear driving your activity sometimes?"

**GP1:** "The onus is on not to screw up, yes."

**GP2**: "Sometimes, I'll make them fit the two-week timeframe.<sup>32</sup> Does anybody else do that? Or am I the only one?" (*Looks around the room nervously*.)

<sup>32</sup> The Two-Week Wait appointment system was introduced so that anyone with symptoms that might indicate cancer could be seen by a specialist as quickly as possible. There are national guidelines indicating when a GP should, and should not refer a patient for a two week wait appointment.

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**GP1**: "But don't you do it because you have a gut feeling that's it the right thing to do?"

**GP2**: (Superficially agreeing) "Yes, that's the reason. Exactly what you've described".

These doctors tended to place a high value on their ability to do things quickly and to start and stop processes in a timely way. As GPs work almost exclusively by themselves, it also occurred to me that they may have been understandably reluctant to share personal experiences of deviating from clinical pathways or, as in the last example, of admitting to using tactics to make them more flexible. I tried to avoid asking questions that might place them in the difficult position of having to decide whether or not to disclose something to me that could expose them to the judgement of their peers, but this was not always within my control. In response to being asked open questions about their experiences of being in a non-moving clinical situation, there was always the possibility that a GP would unravel a case that ended with them judging themselves harshly for not being able to do more with the time that they had with a patient. No matter what I said to doctors in an attempt to frame forms of non-progressive time as neutral, in this time pressured environment, any allusion to it could carry negative associations.

Later on in the research, when interviewing practitioners by themselves, I tried to keep the parameters of my questions very open so as to invite interviewees to narrate their time with patients in their own words. I found that the easiest way to do this was just to ask them about their most recent appointments and contacts with patients, paying attention to the specifics of speech, context, response. 'What had taken place during these latest episodes?'; 'how exactly had the situation improved, or not?'; 'what had it meant to attempt 'care' in this case?'. This seemed to work better, I think because it allowed GPs to narrate non-progressive time in its situated context of everyday relations of care. One of my concerns about doing this though, was that by inviting practitioners to talk so freely about their work without having explained to them beforehand exactly what I was looking for (as I did not always

know myself what I was looking for), they might feel at a disadvantage. They did not know in advance which criteria to use to decide what might be important to disclose, or to hold back. This made me conscious of my own responsibility around the handling of this free ranging, highly sensitive material. Whilst curious about the ways that open and uncensored accounts of care could show the fragility of care in a scientific environment, I was very aware of the potential for exploiting fragility that might easily be made to look like clinical failure or wastes of time.

### Sitting in on discussions about 'difficult' cases

During my observations of group meetings, I was privy to detailed narratives in which practitioners offered to share experiences of struggling to perform medicine smoothly, or to the satisfaction of either themselves, or their patients. Whereas in other clinical forums, the frustrations of durational labour that inevitably accompany this type of work might have been repressed or concealed, in the Balint group, they were allowed to form and come to the fore. Whilst in many ways the Balint group was an ideal site for my study as it was so rich in these examples of care without progress, this was not a context in which data could be lifted out or extracted in any kind of straightforward way. Several participants, particularly the younger doctors, seemed reluctant to speak. There was sometimes an atmosphere of awkwardness and heaviness which might have been intensified by the fact that this was taking place remotely and during a pandemic, when it seemed quite normal to feel exhausted and bewildered by everything that was going on. I was also conscious of how, in relating these experiences of caring for 'difficult' patients, practitioners were making themselves vulnerable to one another, and to me, in a way that I thought was probably quite exceptional within the culture of contemporary medicine.

In my work as a mental health social worker, I also have experience of presenting cases, discussing the most intimate details of patients' lives, trying and probably failing to solve their problems based on what I think I know about them. However, as a remote observer of the Balint group who was not there as a participant, I was

sensitised differently to the ethical considerations involved in speaking about a person who is absent in such great detail and without their knowledge. Whereas in my own work for the NHS, I had authorised myself to do this within what I had believed to be a context of care and accountability towards the absent person, as a researcher whose access to other people's lives was not directly 'in the name' of care, I realised that I might have lacked crucial justifications for being there. During case presentations describing hopeless sounding situations, this feeling became more troubling. If I was useless to the patient and to the practitioners, then what authorised me to stay, listen and even to record the details of another person's life; their pains, sorrows and sources of ongoing strife? At the time, the acquisition of knowledge did not seem a good enough reason. For one thing, it was not clear to me how I would be able to make knowledge out of these cases. Experiences as complex as 'care' and 'suffering', do not always cohere in ways that would even allow us to 'say' them, still less to make social science out of them (Harrison, 2007). Apart from any ethical concerns, attempts to do this have ended in ontological humiliation because, as Law & Singleton discovered in their failed ethnography of a care system for patients diagnosed with alcoholic liver disease, 'the lust to map creates its blindness. That which it cannot see – it simply cannot see it' (Law and Singleton, 2003, p.23). When I noticed however, that doctors from the group sometimes responded to the case presentations in a similar way to me (although they might have articulated this in another way), I began to think differently about the situation. I began to think that perhaps the feeling of having no good enough solution to offer to the situation might be in common with the group. This was the response, for example, following a presentation in which a practitioner described feeling powerless to help a young learning disabled patient whose life had changed drastically following the death of his mother.

Long silence...

**GP1:** "It's situations like these that make realise that we don't have that many tools to work with".

**GP2:** "Yes, I often sit and listen to people telling me about all their social problems and I never know what to do about any of them. I usually just refer them to our social prescriber".

**GP1**: "These things are just sort of thrown into our laps. We don't do anything about them".

Hearing these accounts of trying, and failing to make something or somebody better, not only disturbed the operations of smooth productive medicine. They drew attention to the problem of unrelieved human suffering in such a way that the question of how to respond, gaped open in need of a response. Something about the case as a form of telling these stories in the Balint group, made the potential for people (myself included) to be moved by the medical encounter, in a way that they probably would not have been had the non-progressive parts of the experience been edited out or passed over as clinically irrelevant. Rather than bracketing off my own responses as those of a researcher whose proper place is on the outside of care, I came to understand my own feelings of helplessness as being part of the dynamic that I was trying to describe, of becoming more sensible to accumulating harms that I was unable to do anything about.

### Synthesising Data from Multiple Sites

Between March 2020 to April 2021 was a very particular time for NHS practitioners to be posting publicly to online forums from the frontline. As well as sharing day-to-day experiences of working in the novel conditions produced by the pandemic, many GPs also shared their speculations about what they thought might be in the process of happening to their workplaces and what this could mean for the future of their profession and for the future of the NHS. It would have been easier for me to have limited my digital data to only include general practice blogs about non-progression in everyday and clinical contexts,<sup>33</sup> but it seemed important just at this time not to

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<sup>&</sup>lt;sup>33</sup> Jonathon Tomlinson's blogging on his experience of caring for patients with chronic pain and depression is a good example of what I mean by this. https://abetternhs.net/

exclude the other narrations of living through this episode of being 'stuck' in NHS general practice during the lockdown. One of the problems though, of including online posts on a variety of subjects in terms of the data generated, was that doing this made my data more disparate. It meant having to jump between different worlds of NHS general practice. Not only between those that are digital and those that are not, but also between the various genres of general practice blog, from the irreverent and idiosyncratic, to the serious and panoramic. In practice, this has often led to me having to move from tragi-comic accounts of working as a doctor in the present, like this one:

...my workstation (should I still, hopefully, call it a consulting room?) has become – I imagine – like a command post in a submarine or nuclear fall-out bunker: I am planted there to receive and process signals and data from a world beyond that I must distance myself from...So there I sit, often for many hours, with screen or phone. There are endless emails. The increasing number from institutions – informing and instructing about innumerable things – are so many, long and bureaucratic as to defy my sustained consciousness. Those from anxious patients are often nervously chaotic beyond ready comprehension. I often feel like an exhausted traveller trudging for survival against a driving, blinding blizzard. <sup>34</sup>

To serious, incendiary posts like this one, in which a GP shares the realisation that the NHS in its current form, has lost the ability to improve.

Why has our health service been incapable of adapting to a moderate increase in demand, for which it should have been prepared? How on earth will the NHS ever regain control of surgical or outpatient waiting times?

<sup>&</sup>lt;sup>34</sup> Zigmond, D. (2021, January 4). Human contact: Do we need it in medical practice? BJGP Life. Retrieved October 2021 from https://bjgplife.com/human-contact-do-we-need-it-in-medical-practice/

Make no mistake, our health service was already on the brink of collapse. Covid was simply the final straw.<sup>35</sup>

Initially, I had tried to make connections across these sites, but the disparities in scale and proportion meant that this always seemed to end in the production of synthetic configurations of time and care taken out of context. Not wanting to engage with social media posts in isolation (Winter and Lavis, 2020), or to engage in 'the (doomed) holist, realist fantasy of mapping endless entanglements' (Yates-Doerr, 2017, p.393), I changed my approach. My intention had never been to try to produce any kind of definitive representation of English general practice anyway. For me, it made more sense to think of all the data as 'local' (Loukissas, 2019), as 'self-scaling' (Strathern, 2004), and as containing configurations of time and care only made possible through 'the relations that hold them in place' (Strathern, 2020, p.16). I began to treat each online posting as its own distinctive 'siting' of general practice, and to practice a more sustained engagement with the blog and what surrounded it in terms of the captions, comments, and loops and webs of conversations that ensued from it, giving it meaning. Winter and Lavis describe this as a form of 'listening' to digital culture (Winter and Lavis, 2020).

# 2.9. Interpreting and analysing

I used different techniques to interpret the material during the research process. At a general level, three dimensions capture my approach to the interpretation and analysis of data:

- 1. experimenting with/inquiring into temporal modes of experience;
- 2. analysing the relationship between these modes of experience and care in general practice; and,

<sup>&</sup>lt;sup>35</sup> Musgrave, K. (2021, February 24). But... Hasn't our NHS always been overwhelmed? Pulse Today. Retrieved May 2021 from https://www.pulsetoday.co.uk/views/katie-musgrave/but-hasnt-our-nhs-always-been-overwhelmed/

3. understanding the extent to which any mode of non-progressive time (waiting, staying, delaying, enduring) may be implicated in certain 'practices' of care.

### Experimenting with/inquiring into temporal modes of experience

At the start of this research, I had no predefined notion of what non-progressive time might look or feel like in a healthcare context. From the very beginning, part of the process of analysis has involved me in ongoing attempts to inquire into this as a valid temporal mode of experience. In fact, the term, 'non-progressive time' was brought into the research as part of this process. I introduced it as a way of trying to create a conceptual field or 'frame' through which durational experiences of caring for, or about things that do not get better in these places, might become intelligible as an object of study.

A first step towards interpretating data was to begin a system of manual coding when recording and transcribing material. I read and re-read each account making notes on the contexts for experiences of repetition, immobility, circularity or stuckedness. As I was doing this, I flagged up any instances in the data of things getting stuck or having to be repeated for any reason. This led me to make some early observations about the types of situations where people might be likely to find themselves in a waiting like state from which they were unable to move on for a time.

From this point onwards, I chose to begin analysing the data manually rather than using a coding software because coding software works by extracting and reordering data into hierarchies, and I wanted to keep each account in its original, singular context. This was partly to resist what Whitehead calls a 'bifurcation of nature' (Whitehead, 1920) resulting in the production of bland data cut out from any world to which it might properly belong, but it was also important for me to be able to get a sense of how non-progressive time might feel in different situations. I learned for instance, that it was often associated with frustration and failure for those in caregiving roles, whereas for those in administrational roles, it might be

seen purely in terms of a gap in production and as a factor in making the surgery less competitive. I was also able to begin to understand why this might be the case, by seeing how individual instances of caring for things without much hope of improvement, could deepen a person's commitment to persisting with a labour that takes time, despite a wider NHS context of ongoing crisis and relentless drives to save time. Given that this process of reading and re-reading required me to handle data manually and in a way that took time, I would have taken steps to limit the amount of material that I was producing in observations and interviews had social distancing not intervened and narrowed my field of observation in a different way.

# Analysing the relationship between modes of experience and care in general practice

As more data was transcribed, certain themes, figures and places began to emerge in my notes suggesting several sites, often overlapping, with strong links to non-progressive time. I listed the themes and looked for connections within the data more widely, expanding on the different categories and finding illustrative examples in the material. One of the first of these themes to emerge from my conversations with practitioners and from my observations of patient consultations, was the notion of non-progression as somehow ordinary in general practice, as in, part of the routine, everyday type of contact with patients which often did not result in any direct action to intervene decisively in a bodily process. Based on the data, non-progression could appear as ordinary, because it suggested that much of the work carried out in general practices could be described in these terms, as not resulting in in any action to change the situation decisively. As one GP said to me, most of the illnesses he sees are of a kind that will clear up by themselves over time, and many others are outside of the scope of medicine to cure, or to intervene in.

We don't get people better! A lot of what we do, is deflection: sifting through and separating out what needs something urgently, medically; from what doesn't. Doing what we need to do to keep them functioning.<sup>36</sup>

The concept of the ordinary is well established in feminist theories of care. It belongs to the domain of the everyday where the most routine material practices — those needed to reproduce everyday life, are neglected or made to seem immaterial precisely because they are so ordinary and mundane. As Joanne Latimer argues, 'attention to the ordinary can help illuminate how existential and clinical efficacy are actually deeply entwined' (Latimer, 2018). The connections between themes drawn from the data and conceptual frameworks like this one helped me to find an orientation to the material and to compare what was ordinary in general practice with formulations from other studies of the neglected ordinary in environments where care is needed (Mol, 2008; Bellacasa, 2011).

Another of the recurring themes that came to my attention this way, assuming more importance for the study as time went on, was the figure of the *frequent attender*, or rather, a particular version of this figure. Of all the attributes that most defined how this type of patient was able to disturb the identity of general practice, the one that featured most prominently in my conversations with staff, was the frequent attender's lack of respect for borders, typically demonstrated by their tendency to keep coming back even after all the avenues for treatment had been exhausted. For some staff, this figure could represent the prospect of having to remain in a relation in which there was little hope of ever being able to move on or achieve a satisfying outcome. This was a problem for some, as this interview with a non-clinical worker demonstrates.

S: "What feels different about working at the practice when its quiet?"

**R:** "Less stress ...the day-to-day stress of people calling and not being able to get an appointment. That's the main stress. Lack of capacity is the main

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<sup>&</sup>lt;sup>36</sup> From an interview with a General Practitioner, December 2020.

problem. During the first part of the pandemic, people stopped calling...or they only called when necessary. That's how it should be all the time. If you look at the frequent attenders list, they're not the people who are most in need of medicine. They are lonely..., or bad at managing medication. They're the offenders. It's the same everywhere".

**S:** "Is the list of frequent attenders a long list?"

**R:** "Not really, it only takes a few people. Some want to see their GP a couple of times a month. With some it's every week. For some it's every other day. Recently, it's been busier than usual because there's been a surge in demand across the entire borough. I don't know why".

I went back through the data, listing all the instances where a variation of this figure would appear and looking at what ways specifically, they could come to represent time without value within this setting. I ended up thinking of her (she was invariably female) as the 'abject' patient, partly in reference to Julia Kristeva's use of the term to denote that which disturbs, by threatening the loss of the distinction between subject and object, or between self and other, causing us to want to cast it out (Kristeva, 1982).

In addition to the themes of the Ordinary and the Frequent Attender, the third theme pulled from my notes on the data, was that of *carrying on* in contemporary general practice. This is different to the popular heroic notion, coined during wartime, of 'keeping calm and carrying on' against a backdrop of things falling apart. It means something like continuing to offer time, despite not really knowing whether this is having any good effect on the patient. At a more general level, I used this term to categorise examples of continuing to offer time to a project or an idea, but without the expectation of any return on this investment of time and labour. This category was the most relevant when thinking about how to identify the forms of non-progressive time appearing in GP authored online blogs, as in this example where a GP shares her frustration about having all her time taken up with tasks that do not amount to anything meaningful.

It matters not one jot to the patient in front of me that I've slogged my guts out, not eaten or visited the bathroom that day, but have successfully completed every task assigned to me. I believe what matters to my patient is that they have had a meaningful interaction with me, that they feel listened to and that they feel their concerns have been addressed. It matters to me that I'm able to use my hard-earned skills as a GP to the best of my ability. I want to make sound clinical decisions for my patients, and sometimes that means allowing myself time to think about a problem...<sup>37</sup>

Again, I drew on conceptual frameworks from anthropology and critical theory to make sense of carrying on and what it might mean to stay invested in a project like NHS general practice after it has ceased to be a site of hope or promise of a better future. In particular, Lauren Berlant (2011), Elizabeth Povinelli (2011) and Isabelle Stengers (2015) helped me to arrive at a theoretical understanding of this as having something to do with an ongoing investment in sustaining life, relations, ideas, practices, but without this being conditional to the survival of what was at stake, whether that was the future of the organisation, or the institution or a cherished ideal.

The activity of organising the data into categories allowed me to move within and between distinct but overlapping accounts of living and working within this other mode of time. It also provided me with a coding frame for sorting and interpreting new data. I used this coding frame to loosely guide areas of further inquiry for the remaining interviews. These were not the only themes and figures emerging from the data but they were the most influential in allowing me to break it down schematically into concepts with a connection to non-progressive time. From here, I was able to begin to follow my own theoretical hunches leading to the formulation of critical questions which I could then put to the data.

<sup>&</sup>lt;sup>37</sup> Finnikin, L. (2021, February 26). Burnout revisited—But it's not my fault. Pulse, Views. Retrieved March 2021 from https://www.pulsetoday.co.uk/views/workload/burnout-revisited-but-its-not-my-fault/

### Understanding the extent to which a mode of non-progressive time may be implicated in a practice of care

Towards the end of 2020, after all of the material had been transcribed, sorted and coded, and the most intense period of the pandemic had passed, I found that my data resembled what might be described as a small, uneven and unusual archive of general practice in England during a strange period. 'Unusual' is how Ann Cvetkovich describes her own archive from her book, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Cvetkovich, 2003). She writes about this collection that its contents of oral and video testimonies, memoirs, letters, and journals, photographs and other objects invested with emotional value, might be considered 'too fleeting, contingent or unstable, to be put to work as containers' (Cvetkovich, 2003, p.17). The same might be said of my data. Narrations of time passing without culminating are by their very nature, contingent, unstable, subjective and inconclusive. This might have something to do with the nature of non-progressive time which shares certain affinities with trauma and has the same capacity to 'put pressure on conventional forms of documentation, representation, and commemoration...' (Cvetkovich, 2003, p.17).

There is a tension in the data between the marginal and the ordinary. Marginal figures, perspectives and experiences came to characterise large parts of the data, which might seem to contradict my claim that non-progression is in fact ordinary in general practice. Thinking about this another way, it was perhaps inevitable that in seeking to uncover the role of non-progressive time in contemporary healthcare, I would also be uncovering the role of the marginal. Experiences of waiting, staying, and enduring are made marginal by capitalist and scientific temporalities of advancement and progress — the main ways of organising time in general practice.

Some of my earliest assumptions and theories about uneventful time in this setting were contested in response to new data. One example of this had to do with the extent to which care, time and clinical efficacy might be expected to coincide in this

setting. An early assumption had been that in evolving situations where a quick fix was not an option, offering more time to a patient situation might just be the most clinically efficacious thing to do under the circumstances. However, I had cause to amend this assumption in response to data suggesting that practitioners who offered time in the knowledge that it probably would not lead to anything, often did not know whether or not it was clinically efficacious for them to do so. This helped me to draw distinctions between caring, clinical and other types of engagements (i.e., business), and to see how the tensions between them might be brought to a head in situations where there was a perceived failure to keep pushing forwards and meeting outcomes as expected. In this way, using smaller bits of material from across the range of online, observation and interview data, my initial themes were revised along the way as I tried to work out the relationship between time and care in more detail. Four superordinate themes emerged out of this process of going back and forth between coded data, the conceptual framework that had built up around it, and my ongoing attempts at interpretation.<sup>38</sup> They reflected my revised understanding of the relationship between non-progressive time and care, and they were used to begin the process of organising the material into cases.

The case making model that has been used to represent the data<sup>39</sup> is highly selective in terms of decision-making about what to include and what to leave out. As with every other decision that I made during the research process, I was led by subjective, theoretical and methodological considerations. The criteria that I used when doing this looked at the potential of a given narrative for illustrating different aspects of non-progressive time and for inquiring into its relationship to care at a theoretical level. I selected cases based on their capacity to give this relationship a form which might allow it to 'fulfil its destiny in time'. As this would require access to the different contexts of general practice including its new technologies of care, the strange time of the pandemic, and the physical and psychological transformation of the NHS over the last seventy years, I chose material from across all of the sites where I had collected data.

<sup>&</sup>lt;sup>38</sup> Not Going Anywhere; Being a Drag; Being Between; Wearing Out.

<sup>&</sup>lt;sup>39</sup> I discuss this use of the case as a mode of representation in detail in the next chapter.

Whilst the constraints of using a case making model has meant that I have only been able to present a small amount of the material that I collected, the cases do overlap with the content of other accounts, and they often include detail that has been drafted in from elsewhere in the data. Certain concessions have had to be made because of my decision to concentrate on only a small number of accounts of non-progressive time. For instance, the experience of administrators and managers is almost entirely absent from my representations of general practice. This is despite the fact that several administrators and three managerial staff did participate in interviews or consultations. There are reasons for this that relate to my focus on the embodied care relation and its capacity to frustrate and delay the satisfaction of care, but virtuality in care is an important area of study in its own right, especially as general practice is moving more towards remote methods, and the distinction between administrational and embodied practices of care seem to be becoming more blurred.

### 2.10. Conclusion

In clinical settings, where the clinical trial is still the default method of choice, a speculative, ethnographic approach to research is not just unusual. It can be regarded with suspicion. From a medical point of view, my research might not have been sufficiently scientific or concerned with the advancement of knowledge to gain the trust of some of the doctors. From the point of view of the knowledge industry, I was not offering anything marketable like a solution or a discovery 'in the mode of, 'we had believed, but now we know. . .'. (Stengers, 2018, p.57). Neither did I have an agenda to reform some aspect of the NHS, or to draw attention to yet another failing of the healthcare system. At different points during the research process, I have sometimes wondered who I was producing this knowledge for, which became another way of asking myself about the feasibility of any project lacking in any clear progressive aim. This is one of the reasons why I describe my research process as having speculative sensibilities, because rather than pre-empting the need for an

answer in relation to a well-defined problem, it seeks to engage with the possibilities that are latent in the present but passed over as perhaps too irrelevant or inconvenient to want know about. Its aim is to respond to what Stengers describes as the 'the sense of a possible to be activated' by sensing 'the virtualities present within this situation' (Stengers, 2015, p. 18), however incapable the situation may be of validating them.

## **Chapter Three**

### The Case as a Mode of Representation

Having described the research process and outlined the design of a method, this short chapter discusses the use of the case as a mode of representation. Intended as a kind of preface to the four chapters that follow, it examines the potential and the shortcomings of 'making cases' in general practice. As part of the process of working out how to narrate non-progressive episodes in a way that also enquires into their possibilities as an opening for care, I take a critical look at Michael Balint's psychoanalytic device of case making in association with 'difficult patients'.

### 3.1. Uses of the Case in Ethnography and Medicine

"What are our modes of abstraction doing to us?

What are they blinding us against?"

(Stengers, 2008, p. 50)

As this thesis is interested in what happens when practitioners open themselves up in a willed or an unwilled way, to suffering they are unable to either treat or to alleviate, I have needed to look for a method that opens up 'the case' to objects of concern that do not respond to the attempts of practitioners to act upon them. In looking for a precedent for this in Michael Balint's method of case making, I turn to a different, older version of the NHS to try to recover, rather than to invent a form through which to grasp how this might be done. It feels appropriate to look to the past for this rather than the present, because the notion that care might be an

activity that takes time in this setting, feels out of touch with a present that is moving towards a future, in which care is envisioned as a totally productive labour.

The case as a narrative form already lends itself to the assembling of problems to provoke thought about how they might be solved. It does this through its convention of drawing attention to what is enigmatic about the phenomena that it claims to represent; 'any enigma could do—a symptom, a crime, a causal variable, a situation, a stranger, or any irritating obstacle to clarity' (Berlant, 2007a, p. 663). My reason for turning to the Balints' use of the case<sup>40</sup> in their work with general practitioners is because they use it specifically for the purpose of narrating how doctors go about trying to treat illnesses that resist their attempts to cure them in the usual way. As Shaul Bar-Haim reminds us in his discussion of Balint's relationship with the case as method, case studies were Balint's main tool in building his theoretical apparatus for studying the relationships of GPs and their patients. 'Balintian notions like the 'drug "doctor", 'collusion of anonymity', and 'apostolic function' emerged from actual case studies, taken from GPs' consulting rooms' (Bar-Haim, 2020, p. 52).

As a mode of representing problem-events involving clinical activity, the case has a history of use both in ethnography (Mol, 2008; Meyers, 2021; Callon & Rabeharisoa, 2004), and in medicine (Forrester, 1996, 2016). In ethnography, detailed case making has been used to slow down medical reasoning, to redefine what counts as a proper object of clinical concern (Mol, 2008), to extend clinical timeframes (Gunaratnam, 2013), and to find a method of looking at a clinical reality that 'agitate(s) as much as looks' (Meyers, 2021, p. 9). In medicine, case histories from the twentieth century onwards have been used by the profession as a way of making

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<sup>&</sup>lt;sup>40</sup> Whilst Michael Balint is credited with this particular conceptualisation of the case, the influence of Enid Balint's social work approach to case making is discernible throughout the *Doctor, His Patient, and the Illness,* especially in relation to how the role of the public service in the newly formed welfare state is envisaged, and in theorisations of how general practitioners can function as pastoral role models. For an insight into Enid Balint's work on the case before the Balint groups. See, Eichholz, Enid (1951) The Development of Family Discussion Bureaux Work. *Social Work* (1939-1970) 8(1). Oxford University Press: 495–500. Shaul Bar-Haim also points out that the idea to establish a peer group for general practitioners (GPs) to discuss case studies of a psychosocial nature came from Enid Balint. Bar-Haim, Shaul 2018 "The Drug Doctor": Michael Balint and the Revival of General Practice in Postwar Britain. *History Workshop Journal* 86(1). Oxford University Press: 114–132.

knowledge based on experience which can then be duplicated or repeated (Forrester 1996). The medical case as the accidental record of a singular life is traced by Forrester as far back as Hippocrates, whose physicians' case notes, many of which were taken down during times of epidemics, attend closely to what is happening to the subject of the case, sometimes during hour by hour observations of what often turns out to be the final days of their life. General practice has evolved its own uses of the case which differ from specialist medicine in how they grasp the logic, the history and the science of medicine in the context of family and community (Pickles, 1939; Huygen, 1990). But the case as a record of everyday life is perhaps most closely associated with Freud (Forrester, 1996), who elevates mundane details of the everyday by finding what is hidden in it and then using this as material for constructing elaborate psychoanalytic cases in which he is not so much an observer of what is happening, as a protagonist. As a way of narrating the unfolding of long episodes of care or treatment, case-making in English general practice in the early years of the NHS was heavily influenced by psychoanalysis through the involvement of Balint (Loudon, Horder & Webster, 1998). The sub-genre of the case history that developed out of this association tended to affirm the general practitioner's own methods of listening to the patient, observing over time, encountering 'difficult patients', and seeing health in its social and historical context. It is with this method of case-making as a form of representation that I am concerned.

### 3.2. Time in the Case

The desire to control time and to avoid having to respond to the uncontrollable demands of the patient body is something that general practitioners in particular have often been accused of in the past (Horobin and McIntosh, 1983; Armstrong, 1985). The medical anthropologist Ronald Frankenberg referred to this as the 'special position in relation to time' (Frankenberg, 1988, p.11) that practitioners have been able to cultivate as a way of protecting themselves from 'bad' experiences of offering care. Frankenberg believed that case making enabled the healthcare worker to distance themselves from the continuous time of living with an illness, so

that whatever might be the patient's reality of being sick or in need, the clinician would still be allowed to feel that they were at least still moving towards a resolution of some kind. He describes for instance, how the process of taking a case history from a patient could produce the impression of disease as timeless, so that the ordeal of actually having to endure the time of being sick could be assigned solely to the patient and those around them.

...medicine as it is at present practiced in industrial society inevitably requires health workers and especially physicians to distance themselves in time from the experience of their patients by taking the present-tense account of perceived illness (the history), which they initially share, and translating it into timeless, almost disembodied, disease.

(Frankenberg, 1988, p. 11)

Similarly, for the physician and bioethicist Eric Cassell, adhering to the medical case as a story about the progression of something, even if that something is the progression of the illness itself, can be a way of shielding the clinician from submergence in endless accounts of unrelieved pain, misery, and suffering of the kind 'no one enjoys hearing about' (Cassell, 1999, p. 532). He argued that by individualising the patient's problems and excluding anything that could not be acted upon by the practitioner, thinking in terms of medical case histories could limit what was allowed to develop into an object of clinical concern. Like Frankenberg, Cassell also seemed to believe that this was intentional avoidance on the part of the physician. He suspected them of wilfully excluding aspects of a patient's suffering about which nothing could be done as a way of protecting themselves from the feeling of helplessness that would follow from leaving themselves too exposed. Urging clinicians to overcome this aversion, he advised them to ask their patients directly, "are you suffering?"; 'I know you have pain, but are there things that are even worse than just the pain?'; 'are you frightened by all this?'; 'what exactly are you frightened of?'; 'what do you worry (are afraid) is going to happen to you?' 'What is the worst thing about all this?" (Cassells, 1999, p. 532). This was part of an ambitious attempt to get them to think less in terms of what they

thought they knew was happening to the patient's body in a biological sense, and more in terms of what they did not know about the patient's experience of having to live through this time.

Unlike the traditional model of the medical case, Michael Balint's case-making begins at the point where medical progress stops and all of its attention is turned towards the nature of the specific relationship between the doctor and the patient (Bar-Haim, 2020, p. 59). The interesting thing about this from the perspective of my own study, is that this use of the case as a method relies to some extent on practitioners allowing themselves to be elected into the kinds of experience that they have so often been accused of trying to avoid because of their potential to be energy depleting and a drag on medical ambition. By zoning in on the shared experience in this setting, of finding yourself stuck in a dissatisfying care arrangement from which you are unable to move on, Balint's cases draw attention to what was always known about general practice, but not always spoken of, which is that for a certain type of patient, the usual methods of treating an illness do not work. We see this in Balint's opening address from *The Doctor*, his Patient and the *Illness* (Balint, 1957/2000) where he uses cases to demonstrate how the problem of people not getting better, was there all along.

These four case histories convincingly illustrate our first thesis, which, I am afraid, will sound rather startling to some of my colleagues. But we can quote innumerable case histories in support of it. The four selected here are only a small sample. We think that some of the people who, for some reason or other, find it difficult to cope with the problems of their lives resort to becoming ill. If the doctor has the opportunity of seeing them in their first phases of becoming ill, i.e., before they settle down to a definite "unorganized" illness, he may observe that these patients, so to speak, offer or propose various illnesses, and that they have to go offering various new illnesses, until between doctor and patient, an agreement can be reached, resulting in the acceptance by both of them of one of the illnesses as justified.

Casting doubt on the effectiveness of diagnosis for ever arriving at a 'true' or 'factual' understanding of what is really wrong with the patient, Balint invites his audience to consider the possibility that their most trusted methods for 'getting somewhere' in medicine have actually been the means whereby they have been kept going round in circles. As each of his cases pushes this thesis further by providing us with yet another illustration of a case history that fails to follow the linear timelines of perfectible medicine, they establish the existence of another temporality of care in general practice made sensible through the language and concepts of psychoanalysis. As a form of cure, it can be characterised by what Salisbury and Baraitser refer to as, the 'specifically chronic cure – the offer of time and care, and of remembering, repeating and working through - to contain, understand, and ameliorate the chronic condition of mental distress' (Salisbury & Baraitser, 2020, p. 106). What makes this approach to case making of especial interest to me in my own search for a form of representation is that through introducing the cyclic or nonmoving clinical situation (which often takes the form of the 'difficult patient'), as a new object of concern in this setting, these cases assemble non-progressive time as the focus of ongoing attention and perhaps also to a lesser extent, of something like care.

#### 3.3. Balint's Cases

By inviting GPs to participate in this practice of making cases, and by allowing them 'the discomfort of abandoning their own ideas of what should be happening' (Gill, 1973/1986, p. 39), Balint engages them in thinking from the in-between space that not progressing in the context of medicine opens up. We can see this in the formulation of questions more interested in the possibilities of the encounter than they are in demonstrating a solution to the presenting problem: 'what does the patient need from his doctor, and what does he actually get?'; 'what is it that the patient cannot get from his doctor, so that he must keep coming back?'; 'what is it

that the doctor gives the patient that the patient neither wants nor needs?' (Balint, 1957/2000, p. 20). At the level of the everyday, we see the unsettling effects of this sort of questioning in the personal accounts of general practitioners who are describing their experiences of trying, often with doubt and trepidation, to treat patients using psychotherapeutic methods they are still not sure of. In case discussions from *The Doctor, His Patient and The Illness*, we hear for instance, accounts of how Doctor G has 'come to a dead end' with a woman seeking help with 'waves of depression' (Balint, 1957/2000, p. 123); of Doctor M's experience of 'not getting very far' over the course of seven sessions with a young woman whose trembling attacks he cannot explain (Balint, 1957/2000, p. 163); and of Doctor D's admission that he 'might have tried harder' with a woman whose chronic tongue pain he is unable to find any physiological cause for (Balint, 1957/2000, p. 60). These everyday accounts of breaks in the flow of medicine draw us into a world where impasses, misunderstandings, suspicions and partial perspectives are a part of what it means to follow up on an offer of care in NHS general practice.

As I have tried to explain, what enables Balint's cases to 'hold rather than migrate' temporalities of endurance (Berlant & Povinelli, 2014), is his knack of animating the problem of what it means to be in a caring relation to somebody whose illness is inaccessible to all initial attempts to understand or to treat it. The practices that he makes cases for, for example, that of delaying a diagnosis, or of carrying out 'a long interview' (Balint, 1957/2000), tend to be based on the experiences of those practitioners whose sense of knowing how best to treat or manage a 'difficult patient', has been replaced by finding themselves in a relationship whose meaning they must now try their best to interpret. This has influenced some of my own attempts to make cases that illustrate episodes of care consisting in repeating or circling round, dragging and delaying or in coming to a stop. I also follow Balint in using cases as a way of elucidating concepts and practices. However, unlike Balint who crafts his 'techniques' with a view to scientizing them, the singular, everyday 'practices of care' that appear in my cases are not perfectible or exemplary of anything. They are meant to be understood as figurative practices whose purpose is to configure a set of possible relations between care and non-progressive time.

Figuration is an action that holds the material and the semiotic together in ways that become naturalized over time. The action of configuring or 'materialized refiguring' to use one of Donna Haraway's names for this (Haraway, 1994), stages an interference in how we expect things will 'naturally' materialise. 'The point is not just to read the webs of knowledge production; the point is to reconfigure what counts as knowledge in the interests of reconstituting the generative forces of embodiment' (Haraway, 1994, p. 3). Thinking practices of care in these terms, as the crafting of provisional, shapeless material realities, or in Bruno Latour's formulation, as the 'reassembling of the social' (Latour, 2005), is a way of thinking more ontologically about care's potentialities.

When it comes to the question of how to represent such realities including what is non-coherent, incomprehensible or incomplete about them, John Law suggests that some modes are better at doing this than others. He distinguishes between those practising a form of denial, i.e., the biomedical representations that refuse to register what is messy about scientific practices, and those that try to assemble realities without forcing them to cohere. Interestingly, Law chooses to define this mode as 'care', referring to 'the need to handle unfolding uncertainties that are also in tension in a way that holds them together imperfectly, provisionally, adaptably, and responsively, which strikes balances, but balances that are constantly being rebalanced' (Law et al., 2013, p. 183).

Forrester reminds us that the particular figuration of the world that is offered through the case depends on 'who is the thinker?' – 'who is the thinker in cases?' (Forrester, 1996). During the post-war years, the possibilities of the NHS were still in the process of being worked out, and Balint's approach to the representation of everyday life in a GP surgery may have been influenced by his concern to establish something like a pastoral ethos for the new health service. He believed, for example, that the doctor's technique ought to have both a medical and human aspect. 'He is a doctor and missionary who converts people towards a more realistic form of

adjustment to life' (Balint, 1951, p. 6).<sup>41</sup> This is relevant for why his cases dwell so much on theories about the psychological 'immaturity' of patients, and how this can be remedied or regulated. But also for why, despite having offered an account of the chronic case as 'a matter of concern' in which chronic illness is gathered around, supported, cared for, worried over (Latour, 1993, 1999), Balint's cases are essentially demonstrations of how, with time and effort, GPs may be able to heroically overcome a patient's resistance to getting better.

### 3.4. Conclusion

Although Balint's cases eventually do assemble chrononormative narratives (Freeman, 2010) of growing up, and being cured against the odds, I believe that they still have a potential for holding non-progressive time usually absent in the medical case as a form of representation. Over the next four chapters, I try to develop this potential by using the case as a way of narrating repeated attempts at 'making something better' over the course of an episode. Rather than seeing non-progressive time in the NHS as something to be mastered and resolved once and for all, my own approach to thinking in cases is more interested in what caring from within this time helps to make possible. I try to narrate modes of endurance which, though they are unheroic in the sense that they do not 'save lives', are nevertheless signed up to a kind of work that tries to keep making life more liveable, without the incentives that crisis can offer of eventually overcoming. My version of the Balint case tries to be a form that allows non-progressive time to build up by remaining in the nonhappening place of care, prior to its foreclosure as a medical or care event. It does this by holding and keeping apart the relation that links an attempt at cure to the production of an outcome, leaving open the question of whether or not care is ever really happening.

<sup>&</sup>lt;sup>41</sup> I am indebted to Shaul Bar-Haim for this reference which I came across in his paper, Bar-Haim, Shaul (2018) "The Drug Doctor": Michael Balint and the Revival of General Practice in Postwar Britain. *History Workshop Journal* 86(1). Oxford University Press: 114–132.

## Chapter 4

# Chronicity, the Balint Group, and Cases of Not Going Anywhere

The following four chapters centre around a collection of ethnographically derived cases depicting unproductive episodes of care in general practice. In the first of these chapters, I begin by presenting two Balint group cases which I use to illustrate a clinical labour that consists in 'not going anywhere'. In the second part, I make the argument that by inclining one another towards what is irrelevant to going 'somewhere', Balint group case discussions cultivate a shared vulnerability to those aspects of living with pain or other intolerable states that cannot be transcended. This chapter also deepens the project's engagement with the theme of 'carrying on' in chronic contexts.

### 4.1. Meera and Sara

It is the 9<sup>th</sup> December 2020, exactly one week after the first Covid-19 vaccine in the world has been approved for use in the UK.<sup>42</sup> Practices all over the country are inundated with calls from people asking when they can come in for an injection. Some respond by issuing online announcements asking patients to please 'wait your turn...'.<sup>43</sup> ("Please Wait Your Turn", 2020). In a surgery in East London, around eight healthcare workers are meeting remotely before the start of the working day. All of the staff are isolating in their own rooms either by themselves or with as few others

<sup>&</sup>lt;sup>42</sup> The Pfizer-BioNTech covid-19 vaccine.

<sup>&</sup>lt;sup>43</sup> The message goes on to say, 'although it's great news about the vaccine can we please ask that you don't call your GP practice asking when you'll be able to receive it" ("Please Wait Your Turn", 2020).

as possible, still trying to keep contact to a minimum. I am present in the meeting as an observer.

Meera, a general practitioner, sits by herself in a consulting room. She is saying to the others how difficult she is finding it to be 'in the moment' for this conversation. This is partly because there are two screens on her desk and one of them keeps flashing at her. Also, if her phone rings, she will have to answer it because she is on duty, and all the calls that come through to her must be treated as urgent. Another inconvenience is that she is having to lean forwards to be close to the computer monitor in order to make herself heard. This means having to move out of any position that would allow her sit back and relax into thinking. Not everybody is against the idea of remote working. The practice manager at the surgery has spoken to me of his optimism about the fact that 'all of a sudden, every GP has access to this technology'. For him, this means that they will finally be able to compete with the other practices who have been 'scooping' all the younger, fitter, wealthier patients with no long-term conditions or complex health concerns. This makes good business sense because, as he explains to me, 'if you can get these patients on your register, you get a lot of money and not as much work'. Private providers of general practice also have reasons to feel optimistic about the future during this time. As NHS waiting times increase, the number of people who are willing to pay for a GP consultation appears to be going up.44 They often use this in their marketing messages to show why it makes sense to pay for a private consultation; because 'going to see the doctor isn't the most convenient thing', so if 'you don't want to 'sit in a waiting room. Or wait ages to be seen', then why not skip the waiting, and pay?<sup>45</sup>

The homepage for the private remote practice, *Doctor Care Anywhere*, promises a 'modern family doctor who is *always there* to give you that reassurance and peace

<sup>&</sup>lt;sup>44</sup> NHS waiting times are having a direct impact on the demand for self-pay in a way 'that hasn't been seen in recent years' according to a report published by health data firm LaingBuisson in April 2021. Heath, L. (2021) *Private Healthcare Self-Pay UK Market Report*, 3<sup>rd</sup> Edition. LaingBuisson. https://www.laingbuisson.com/shop/private-healthcare-self-pay-uk-market-report-4ed/
<sup>45</sup> Doctor Care Anywhere. "Mission, Vision, Purpose." *Doctor Care Anywhere*. Retrieved 28 March 2022 from https://doctorcareanywhere.com/about-us/our-vision/

of mind you need'.46 The website is full of images of youthful people in perfect health, with conspicuously able bodies. Oddly, there does not appear to be any reference made to ageing or dying. Amongst the conditions that patients are advised to see their NHS GP for, I see that 'severe mental health problems' is listed, alongside 'severe pain'. Doctor Care Anywhere do not offer treatment for some of the most severe chronic conditions, it seems. Another section of the website is dedicated to uplifting testimonials from patients and doctors who have made the move to private healthcare. 'Dr Glass' who is one of those featured, writes about how she had always wanted to do a job where she could help people, but as a Partner working for a busy Practice in Islington, she had not been able to. 'I felt like I didn't have the resource or time to do what patients wanted and needed. It wasn't how I wanted to practice medicine and I felt like I was constantly letting people down'. She says that leaving her old Practice to work for Doctor Care Anywhere, has enabled her to become the kind of doctor that she always wanted to be. Her ultimate dream now: to look after 'a set number of patients throughout their lives...from when they're babies, to when they're looking to start a family of their own',47 echoes the original mission statement of the NHS.48

Back in the NHS, Meera has been trying to explain to the others in the group why she is feeling so weighed down by the thought of having to see a certain person, a long-term patient of hers 'Sara', who she has not seen for some time.<sup>49</sup> Until recently, Sara had been in hospital staying there as an inpatient. Then, she was discharged. When a patient is discharged from hospital, there is an official handing over of care back to the GP. Other people might be involved too; mental health workers for instance, or district nurses, but the GP is there to come back to if all else fails. On leaving the

<sup>&</sup>lt;sup>46</sup> Doctor Care Anywhere. "Mission, Vision, Purpose." *Doctor Care Anywhere*. Retrieved 28 March 2022 from https://doctorcareanywhere.com/about-us/our-vision/

<sup>&</sup>lt;sup>47</sup> Doctor Care Anywhere. "Dr. Glass' Story." *Doctor Care Anywhere*. Retrieved 28 March 2022 from https://doctorcareanywhere.com/about-us/user-stories/dr-glass-story/

<sup>&</sup>lt;sup>48</sup> This is a reference to William Beveridge's 'cradle to the grave' social programme which called for more than just a free national health service, but the term 'cradle to grave' has since become strongly associated with the NHS. Beveridge, W., (1942). *Social Insurance and Allied Services* (The Beveridge Report). London: HMSO

<sup>&</sup>lt;sup>49</sup> All of the unattributed extracts in this case and the one that follows are verbatim quotes from notes taken down during remote observations of Balint group meetings. A sample of these notes is included in the appendices.

hospital, Sara will be handed back over to the care of the Practice but mainly and in the formal sense she will be coming back to Meera. At this point Meera says that she does not know how as a practice, 'we are going to manage this'. The thought of having to still be there when Sara comes back is overwhelming. When she had first taken over from Sara's last GP, she had wanted Sara to be able to open up during their time together. She had even made more time available for this reason specifically. It had worked because after a while, Sara had wanted to talk. But with more talking, there unravelled more problems, all consuming, intractable pains and problems which Meera had been unable to do anything about. Sara's 'horrendous' history of abuse for instance, her lifelong addictions, her endless domestic troubles. Suddenly, it was as though Meera had become 'part of the family'; that network of people who, far from being able to intervene in Sara's life in helpful ways, had gotten enmeshed. If Sara would not stop unravelling, or if she would not settle - there would be nothing that Meera could do about it. Meera remembers that before the hospital admission, actually being in the room with Sara had sometimes felt more manageable in practice than it had felt as a prospect. For example, when they were able to be together in person, it had been possible to put 'virtual-metaphorical arms' around her. This was not a method that had yielded any results, but it seems to have enabled them to 'budge along' for a while at least. She is hoping that they can 'get through this time so that they can back to something like that, but then there is Covid-19 and social distancing to have to think about as well.

In his famous paper, 'The Doctor, His Patient, and the Illness', published in the Lancet in 1955, Michael Balint sets out the case of a man of fifty-eight who comes to see his general practitioner every Friday (Balint, 1955, p. 687). He has lots of symptoms, but none of the referrals made to innumerable specialists over the years appear to have made any difference. Every time he comes to the see the doctor he says, 'nobody can do me any good' (Balint, 1955, p. 686). Balint writes about this case that the patient and doctor had drifted along together for sixteen years in what he refers to as 'a rather difficult situation'. For Balint though, the case 'bristles with puzzling problems' (Balint, 1955, p. 686). What, for instance, is the doctor able to offer a patient whose suffering he knows he can not relieve? In his opinion, practitioners

should not succumb to the temptation to try everything possible in the attempt to 'be a good and helpful doctor'. They should find the compromise that offers the best prospect of therapeutic help. In this case, the compromise seems to have been that the doctor would continue to prescribe whatever medicine he was asked for and the patient would come by every Friday evening to collect it. A relationship was established in which they both more or less accepted that there was nothing that the doctor could do to bring about a change in the situation. The doctor summarises it in these terms: 'I accept that nothing will do him any good and commiserate with him; we metaphorically slap each other on the back more or less cheerfully when he comes for his weekly bottle of medicine, which we both agree will not do him any good' (Balint, 1955, p. 686).

Therapeutic compromises have also been a feature of Meera and Sara's relationship. Although instead of 'a bottle of medicine', what has tended to happen is that Sara would seek out Meera's help in securing a prescription for benzodiazepines. They are medications for use in situations of extreme anxiety that usually effect people in a similar way to alcohol; a fuzzy feeling, everything is basically 'ok' and even if the anxiety is still there, it has no direct bearing. Benzodiazepines are not recommended as a treatment for chronic conditions, and they are known to be addictive but some GPs will offer to prescribe them in the absence of any alternative ways for helping somebody whose problems are of the 'unspecified psychosocial' kind. The offer of medicine complies with the expectations associated with 'the role of a doctor' (Anthierens et al., 2007). When presented with 'things that are unbearable', a prescription can make an opening to do something, that feels like more than doing nothing. It can also be a way out of the feeling of overwhelm that can accompany being appealed to for help to solve an insoluble problem. Meera has struggled in the past to loosen Sara's dependency on benzodiazepines and today she has discovered that a hospital nurse had given the drug to Sara during her stay on the ward, simply in response to being asked for it. She feels angry that the cycle of being asked and of refusing and of having to work out a compromise over them has been started up all over again by somebody whose passing encounter with Sara makes it easier for her

just to say 'yes', to avoid being in the position that Sara is in, of not having anything to offer.

At this point, the decision about whether to offer a face to face or a remote appointment is based on a clinical judgement about the benefits weighed against the risk of spreading the virus, which can feel like yet another barrier, '…every relationship now is having to be negotiated through somebody or something else'. Inevitably, Covid-19 does sometimes make its way into the case discussions. It is absorbed into the mundane details of the clinical encounter. One of the doctors mentions a patient who has complained about her to the manager. She thinks it must have been because she was wearing a mask. 'I said all the right words but maybe it had something to do with my eyes? She read something into them, maybe?'

There is a sense of the face to face relation 'trickling away'. Some GPs are protective of it; 'I know I drone on about this, but I really do think it makes a difference to see patients face to face'. For others, it is difficult to imagine general practice without it. I also get the impression that some of the GPs just do not feel up to doing the kind of work that requires them to keep returning to a general practice that feels as though everything is still in a state of freefall. The day to day is already hard, the future is blank, and the prospect of having to anchor another person, might be the thing that takes them 'over the edge'.

Meera is of the opinion that Sara is one of those patients who it will be better to see in person. She believes that 'sometimes, it helps to be in the room'. One of the other doctors asks her whether there will be any mental health support for Sara after she leaves the unit? Meera thinks, yes, there probably will be some involvement, '…but then, there were plans in place last time too'. The specialist support for Sara's mental health is there in theory, but this does not necessarily mean that the same disaster will be prevented from happening all over again.

### 4.2. Daniel and Camille

It is half past eight in the morning of March 2021. A group of around ten tired looking practitioners are sat in front of their screens again, waiting for this month's Balint group meeting to begin. 'Does anybody have a case?' There is silence. Some time passes. Daniel a GP offers a case for discussion involving a woman who suffers from intractable pain. He looks unsure about whether to go on, but nobody objects so he begins to lay out some of the background. He is careful about how he does this, speaking slowly, avoiding assumptions and correcting any misrepresentations. The woman whose name is Camille, is described as a 'strong character', 'Spanish, I think'. She lives with her adult daughter who Camille says spends most of her time watching television and being depressed. Three years ago, Camille's life had changed drastically when she began to suffer from severe back pain followed by a 'slow descent into disability'. Before this, she had been a swimming teacher who had loved her job.

Daniel looks uncomfortable talking about Camille in her absence. He stays as close as possible to the words that she has used herself when speaking about her condition. During their consultations together, Camille has continued to express deep despair over her condition. Daniel recalls that the very first thing she had said when she walked into his consulting room had been, 'I cannot live with this pain'. At first, they had tried going down the standard medication route, but nothing had worked. Then, after exhausting the pharmaceutical options, he had referred her to a specialist, and they had agreed to try waiting 'to see if this clinic can come up with something'. His overall impression is that Camille's life is on hold until the day when she gets to be able to live once again without debilitating pain. He had hoped that by going through all the options, eventually, something might be done. But her condition had been 'kind of medically unexplained'.<sup>50</sup> There had been lots of underlying medical issues but nothing to pinpoint the underlying cause.

<sup>&</sup>lt;sup>50</sup> Chronic primary pain is defined by NICE as 'pain that persists or recurs for more than three months which has no clear underlying cause or is out of proportion to any observable injury or

A few weeks forwards in time from this meeting, on the 7th of April, a new standard route for patients suffering with chronic primary pain would be formally introduced by the National Institute for Health and Care Excellence (NICE). Healthcare practitioners will be instructed to 'recognise and treat a person's pain as valid and unique to them' (NICE, 2021). In the guidance, they are told not to prescribe painkillers or opioids anymore, because there is little evidence that they help, and opioids can induce dependency. Instead, they should consider antidepressants and engage in 'shared decision-making' around pain.<sup>51</sup> I wondered, what 'shared decision-making' might mean in relation to Daniel and Camille? Daniel says that for a while, there had been a pattern of Camille using the appointment as a way to 'offload'. She would tell him about all the worst things about her situation. There would be despair, tears, and, in the moment, this had seemed like it might be enough and that 'things were getting better'. But the next week it would happen all over again. If anything, it had felt as though things were getting worse because the crying offloading had progressed into a 'prescribing more medication' sort of an offloading. Decisions had been made to prescribe as a last resort, but they had been more like concessions to a desperate situation. They were not based on any shared clinical understanding, because that had not been possible. They were more like spontaneous ways of responding to a pressured situation in which there were no good options and very little time. When Daniel thought that an understanding might have been reached, it turned out that he must have been wrong, because their agreements never seemed to last beyond a week. From Daniel's perspective, it was

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disease'. Recommended treatments are antidepressants, an exercise programme, a short course of acceptance and commitment therapy, acupuncture or dry needling lasting no more than 5 hours of healthcare professional time. NICE Recommendations (7th April 2021) Chronic Pain (Primary and Secondary) in over 16s: Assessment of All Chronic Pain and Management of Chronic Primary Pain, Retrieved 28 April 2021 from

https://www.nice.org.uk/guidance/ng193/chapter/Recommendations#managing-chronic-primary-pain.

<sup>&</sup>lt;sup>51</sup> Martin Marshall, the then chair of the Royal College of GPs and a practising GP himself, wrote in his response to the consultation on the new guideline for chronic primary pain that 'most patients in pain do not want to take medication long-term, and GPs do not want this either, but sometimes medication has been the only thing that brings relief.' Chronic Pain: Antidepressants Not Painkillers Recommended. *BBC News*, August 4. Retrieved March 31, 2022, from https://www.bbc.com/news/health-53649189

always as if Camille had no memory of the previous appointments having happened at all. Each appointment, she would always be 'just as distressed as the last time'. But when he had suggested a referral to therapy, she had rejected the offer outright saying that therapy would only make her feel worse, insisting, 'it's a physical problem!' She would keep repeating, 'I cannot live with this pain'.

Writing about his own experience of being asked for help by a woman suffering with chronic pain, the GP Jonathan Tomlinson describes moving through almost exactly the same stages as Daniel.

'I had spent the last 30 minutes listening to Sharon describe her pains, which shifted from the somatic – how they feel, to despair – how she feels, and anger – how she feels about me. Why didn't I know what was wrong with her? Why didn't I refer her for more investigations? Why didn't I send her to a [another] specialist? Why didn't I listen?' At some point I tried to introduce the idea that perhaps a pain-psychologist might help but this merely ignited the oil I'd been trying to pour on troubled waters. "You don't even know what's wrong with me and now you're trying to tell me it's all in my head, you're not listening to me!" she all but screamed at me, tears welling up in her eyes.'52

He is left feeling exhausted but more than that, he feels useless, demoralized, and angry. 'I felt angry, really pissed off'. The appointment was only supposed to have lasted for ten minutes, but had gone on for half an hour. Jonathon still has another seventeen patients to see. He wants to help but instead, he is filled with anguish. 'Why does she keep coming back? What can I possibly do.' Later, going back over what had happened, motivated as he says, by the despair that he always feels when he sees that Sharon is on his appointment list, Jonathon reflects on what has been so hard about trying, as a general practitioner, to care for people whose illnesses

Tomlinson, Jonathon. "How Doctors Respond to Chronic Pain." *A Better NHS*, 7 Sept. 2013, Retrieved August 2021 from https://abetternhs.net/2013/09/07/pain/

cannot be overcome and whose health will probably never be 'restored'. He thinks that it must have something to do with how 'naturally solution-focussed' GPs tend to be. In their desire to make restitution in the future, they always look for ways of intervening in the present, but this only works in relation to conditions where lasting change is possible. In a situation where this is not the case for whatever reason, perhaps for reasons unknown to all, the doctor can be at a loss to know what to do, or what to say. He believes that those who find themselves in this situation can suffer from 'crises of identity and purpose'. When they cannot make their patients better or even relieve their symptoms, they may find their sense of themselves as GPs faltering. They don't like the way that it feels to be with a patient to whom they have 'nothing to offer,' so they avoid situations that make them feel like this. And yet, as Jonathon points out, 'our patients still come back to us. And then what happens?'

In the Balint meeting, Daniel brings his opening case summary to a close by saying, 'so...what to do now?' He says this quietly to himself as though he does not really expect there to be any answer. There is a silence, and then another practitioner speaks. This doctor describes a recent duty telephone call with Camille lasting twenty-five minutes. She had come away feeling terribly struck by Camille's 'awful descent into pain'. During the phone call, Camile had sounded desperate, so the doctor had made the offer of a referral to the crisis team, but this had been rejected in anger and indignance. 'What can the crisis team possibly do for me?', Camille had shouted. 'They don't even know me!' After her offer of a referral had been rejected, the practitioner had stayed on the phone for some time, listening to Camille talk about how much pain she was in. She had tried to sympathise. She had not known what else she could do. Thinking of it now makes her feel 'awful'.

A third doctor who has been listening to this, floats a theory of his own. 'My fantasy is that Camille's health is stopping her from having a partner.' The person saying this is wondering whether, in the absence of a confiding relationship with another person, Camille might be using the Practice as some sort of substitute. Daniel thinks not. Camille does have a partner he says, but they don't talk about him much. There

is a lot that he does not know about her. He says that she is not really the kind of person to volunteer information about her private life. Maybe he ought to find a way of asking her about these sorts of things?

A fourth GP thinks that that there must be something positive about all this. Afterall, Camille has not stopped coming back to see Daniel during this whole episode despite all the referrals that have not led to anything. She thinks that it is a good sign that she keeps coming back. 'She's obviously found something supportive about your relationship along the way.' Daniel does not seem particularly reassured by this. Camille had not said anything to him to suggest that she did value their relationship. Their frequent meetings have not stopped her from seeking the advice of other doctors in the private sector. 'She's not dismissive. She's seen a lot of people as part of looking for a solution.' His firm belief is that she is in serious pain and doing whatever she can to get this sorted out.

Another doctor voices his strong opinion that Camille is definitely looking for a cure. 'This is a very solution focussed patient', he says. 'We've been unable to provide that solution'. He is speaking with more conviction than anybody else. There is a personal element to this because he understands what it feels like to suffer with pain relentlessly. He is convinced that by always adopting a biopsychosocial approach, '...we are looking at it through two completely different lenses'. To be told in a case like this, that your problem is about acceptance rather than about pain, 'it feels invidious!' he exclaims loudly. 'Patients can feel frustrated when they are looking for cure and doctors are trying to move them towards acceptance.' Daniel does not disagree with him.

The final contribution comes from somebody who thinks that perhaps what Camille really wants is 'understanding'. 'There is a real feeling isn't there, that doctors can't help?' 'Yes... often, doctors can't help', but she questions whether Camille's anger might be mainly due to her feeling that doctors do not truly *understand* her pain. Perhaps Camille feels alone in what she is going through, and wants to be in some

way, understood. Turning to Daniel, she says 'that's a bit of a theme, isn't it — not being understood?' Daniel seems unsure about this. His own experience has been that Camille definitely wants relief in any form more than she wants understanding. He thinks that something needs to be done about how much pain she is in, but he just does not know what. This is how things are left hanging when the meeting is brought to an end.

### 4.3. Chronicity and Cases of Not Going Anywhere

References to the pandemic are made only very rarely in these meetings, but it was during this time — between December and March 2021— that the first vaccines for Covid-19 were introduced in the UK. As the pace of clinical activity needed to accelerate to match the speed with which a new variant of the virus spread, the temporalities of care production in the NHS outwardly appeared to be speeding up. For the government, this quickly became synonymous with the ambition of getting ahead of other nations in the race to be the first to vaccinate the population.<sup>53</sup> Ministers boasted about having always had the confidence and the foresight to have 'moved fast and early' towards the goal of getting out of the pandemic and returning to normal life.<sup>54</sup> The discovery of a vaccine was the proof that no state of suspension could last forever, and that scientific advancement plus the right sort of investment would always eventually restore the world 'back to normal'. By comparison with the mood of heightened suspense during the pandemic, in the Balint group meetings, I am privy to some of the parallel realities of the NHS during the pandemic — human lives stalled by Covid-19, but not only by Covid-19. They are also stalled in a more permanent way by ordinary chronic conditions and circumstances which are

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<sup>&</sup>lt;sup>53</sup> Ministers credited the government for getting ahead of other European nations by accelerating the pace of the vaccine's delivery in the UK. In his address to the nation on 4th January 2021, the Prime Minister announced that the UK had already vaccinated 'more people than the rest of Europe combined'. Retrieved March 2022 from https://www.gov.uk/government/speeches/primeministers-address-to-the-nation-4-january-2021.

<sup>&</sup>lt;sup>54</sup> The Ministerial Forward to the Vaccines Delivery Plan opened with a statement about how 'we have always known that vaccines would be our best way out of this pandemic'. Retrieved March 2022 from https://www.gov.uk/government/publications/uk-covid-19-vaccines-delivery-plan/uk-covid-19-vaccines-delivery-plan.

keeping them in a temporal loop of not being able to 'get out', 'get ahead' or 'return to normal'.

'Chronic living', is a term used to describe the state of suspension that a person can find themselves in when they are cut off from both curative and palliative care and, 'life itself turns pathological' (Keimig, 2020, p.17). As an experience, chronicity might pass through stages of being more or less affecting, feeling at one time like a weakening resolve, at another time as something more intense; but what defines an experience of illness as chronic according to Aditya Bharadwaj, is that it is typified by a refusal: 'a refusal to abandon that which it afflicts' (Bharadwaj, 2022). These readings show general practitioners caught up in trying to work out, not so much what to do about these illnesses in terms of what to prescribe or to advise, as how to be somebody who cares in a doctorly way for patients whose lives are held up in states of chronic living. With its focus on the continuity of care, general practice is supposed to have an aptitude for 'managing' the chronic but in the Balint group, I learned that as well as refusing to respond to attempts to change them, chronic conditions can also refuse all attempts to make them more manageable. From a healthcare perspective, this limits what the practitioner is able to 'do' when presented again and again with the imperative that 'something needs to be done' and yet, even after practitioners have stopped having anything tangible to offer, the dynamic that keeps bringing their patients back to them, apparently remains unbroken. These are the realities that I want to acknowledge in this chapter and to offer support for if I can, of trying to care in situations where more time and effort will probably not result in the long-awaited release from the tight spring of waiting. I have tried to do this by collecting evidence of the 'practices' of not going anywhere that proliferate in Balint group case discussions around the question of how to care for something or someone, who is dangling indefinitely in a state that does not preclude being in crisis.

When I write about not going anywhere in the context of chronicity and NHS general practice, I use the expression in the first instance to refer to how some people might experience the labour of caring for chronic states in an outcome orientated

healthcare setting. In this respect, it is a description of how it might feel to keep trying and failing to do the impossible by producing clinical outcomes in relation to an illness which, because it is more like an 'illness of time' (Biehl, 2005, p. 107), does not have any desirable 'outcomes' to speak of. I also use the term to refer to the positioning of a workforce whose motto during the pandemic was 'we are still here for you'.55 As well as being another way of saying, we are not going anywhere, the message that we are still here for you, points to the existence of an abstract but enduring relationship between a protective NHS and an inherently vulnerable public. Severe chronic illness can account for the presence in general practice of bodies that because they are stalled 'in the very dynamic of their lives' (Bharadwaj, 2022), refuse to be moved on, or shaken off. But chronicity in a system that is obsessed with making 'fit for the future' (NHS, 2019), can also stand in for any condition that threatens to jam, delay, or bring that system a standstill. This includes disability or any other ordinary state of dependency to which we are necessarily predisposed as human beings — 'puny, vulnerable', 'profoundly interdependent creatures' that we are (Crosby, 2016, p. 4). In the case discussions, I saw how the efforts of practitioners could be disturbed by real chronic states of personality disorder and intractable back pain amongst others, but I have also used the term 'chronicity' in a more figurative sense, to mean the embodiment of a negative drive<sup>56</sup> comparable to Lee Edelman's figure of the queer, as the embodiment of a relentlessly future-negating drive (Edelman, 2004).

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<sup>&</sup>lt;sup>55</sup> City and Hackney Council. (2020, May 6). *The NHS in City and Hackney is still here for you*. The NHS in City and Hackney Is Still Here for You. Retrieved November 2020 from https://bit.ly/3ccbytM

<sup>&</sup>lt;sup>56</sup> I am using the same device that has been used by queer theorists following Lee Edelman and crip theorists after Robert McRuer, to figure the queer and the crip as 'future negating drives' from the perspective of normative, idealised futures: Edelman, Lee (2004) *No Future: Queer Theory and the Death Drive.* Duke University Press; McRuer, Robert (2017) No Future for Crips: Disorderly Conduct in the New World Order; or Disability Studies on the Verge of a Nervous Breakdown, In *Culture - Theory – Disability*, (Eds) Anne Waldschmidt, Hanjo Berressem, Moritz Ingwersen. Transcript Verlag (Pp. 63–78).

### 4.4. The Balint Group

One way of describing the Balint group is to say that it is a psychoanalytically informed practice of disciplining practitioners to reflect not on solutions, but on the experience itself, of being with the patient. Its method of 'staying with the relation' is slow and open-ended, working against the tendency to want to look for solutions or to believe that somebody else (i.e., a specialist), might hold the answers. Meditations on the relationship with the patient do not resolve the practitioner's doubts and questions over how to progress a case. Instead, they circulate around the patient and their situation, adding yet more layers of interpretation, generating more questions. Conversations stop and start, go round in circles and end all of a sudden and without getting to the point. Any detail can be lingered over no matter how small. High risk patients are not prioritised. The case is shared out, passed around, commented upon, expanded on, and handed back. Attempts to 'solve' it are pushed back on, usually by the group leader. In the tightly controlled world of contemporary NHS general practice with its strict temporal regimes that map each unit of time to a subsidised outcome, the Balint group makes time for the parts of NHS care labour that have no outcome.

The original model for the Balint group dates to the 1950's, when Michael and Enid Balint began holding psychological training seminars for GPs in London (Balint, 1957/2000). At that time, Michael Balint had believed that at least a quarter of the general practitioner's work was taken up by patients whose problems were not be physical in origin, but psychological — the 'psychologically ill', and that these tended to be the patients who took up most of the GP's time because they could not be 'settled' into any of the cures on offer (Balint, 1957/2000, p. 284). Initially, the aim had been to save time by getting to the root cause of the problem. He argued against the doctor simply accepting whatever physical illness or problem a patient 'offered' to him on the grounds that without knowing it, he might be helping to 'organise' a physical illness for which there was no cure. By temporarily delaying the standard general practice type of response to these illnesses, and by looking to see what might

be underlying them, the practitioner's patience and attention would eventually be repaid when it became clearer to him 'what to treat' (Balint, 1957/2000, p. 287). Cases that refused to resolve using the biomedical method were still moved towards the goal of restitution, only by another method — psychotherapy.

For Balint and his doctor associates, not all forms of 'carrying on' with an unproductive patient relationship were seen as bad, but a distinction is made between those that are tolerable and those that are not. A desirable ongoing relationship is one where the patient 'has grown away 'from an infantile dependency on the doctor, but still needs him for something' (Balint, 1957/2000, p. 169).<sup>57</sup> A bad ongoing relationship is one where the patient still feels actively dependent on the doctor for help. It might seem strange to us that there is no proper place assigned to chronic illness within this system, but then chronicity as a problem category in general practice did not really exist at the time that Balint was delivering his seminars. This comes later in the 1960's, when the temporalisation of illness in a common space emerges as an idea in association with the new concept of early diagnosis. 'By, as it were, intervening in the past, the future could be made secure because the past and future were directly linked' (Armstrong, 1985, p. 664). This also marks the origin of ideas about 'community' in healthcare<sup>58</sup> and of the practices of anticipatory and preventative care, and care in continuity, for which general practices are still known today.

Modes of relating to the incurable patient may have changed over the years, but the basic method of the Balint group is still 'to look at the relationship that the presenting doctor has with a patient – with a view to helping the patient'. The obstacles to achieving this are also roughly the same today as they were sixty years ago. Now as then, the group leader must try to dissuade GPs from going straight to

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<sup>&</sup>lt;sup>57</sup> A 'more mature, more satisfactory' form for a continuing patient relationship, is one where the patient 'has grown away 'from an infantile dependency on the doctor, but still needs him for something' (Balint, 1957/2000, p.169).

<sup>&</sup>lt;sup>58</sup> 'The word 'community' only became a medical subject heading in Index Medicus in 1967 when the terms 'Community health services' and 'Community mental health services' were introduced to replace the old 'Public health' (Armstrong, David (1985) Space and Time in British General Practice. *Social Science & Medicine* 20(7): 659–666. (p. 665).

finding solutions.<sup>59</sup> But what interests me is the difference in what gets produced by this more recent practice of reflectively being with the patient in general practice what aspect of their labour as NHS practitioners does the Balint group help to assemble? What they are doing cannot really be described as therapy, or as therapeutic in the sense that Balint implies when he writes about 'therapy which offers the best possible chances for the patient's future life' (Balint, 1957/2000, p. 267). Though they might be aiming at producing healing affects, and though there may be the occasional sense of a connection between cause and effect, the presenters never really know for certain whether their attempts have landed as care or as violence, or whether they have simply evaporated, 'into the ether'.<sup>60</sup> When it does seem as though healing might be going on, this is intermittent and happens almost by accident. The good moments, when it feels to Daniel and Meera as though they might be doing something helpful, do not supply any formula that can be repeated or serve as the foundations for anything to come. Either they come and go, or circle back on themselves, or fall apart. When Meera is reflecting on her ongoing struggle to manage being in the room with Sara, or when Daniel describes his standoff with Camille after she refuses to leave the consulting room without getting some pain relief, what we see being assembled is not a practice of care so much it is as a practice of *trying* to care in relation to something chronic, and of making multiple attempts at it.

<sup>&</sup>lt;sup>59</sup> The doctors who attended Balint's seminars are said to have wanted to solve their patient's problems in the style of a 'great detective'. Their desire for 'understanding' clashed with his strategy of 'following the patient's lead' (Balint, 1973, p. 8). In my observations, new technologies were only adding to the difficulty of maintaining the right conditions for not looking for solutions. One of the recurring problems has to do with practitioners having access to electronic patient records during the meeting. As the group leader told me in an interview. They have this tendency to go 'zipping into the records' to check for facts and accuracy [Interview with Balint Group Leader]. <sup>60</sup> [GP Interview, 9th Nov 2020] 'We tend to defer to concrete things - medical things. What can I do in twenty minutes? I can give her my time, my absolute attention – a kind of relational healthcare. She might say something – I listen to it – it goes inside – has meaning: it's not just transactional. I don't want to use psychoanalytic words, but it's [a kind of care] that's modelled more around transference - you have terrible problems, but I can give you myself. Sometimes it doesn't work. It goes into the ether'.

### 4.5. Having nothing to Offer

Persistence in the readings does not lead to practitioners getting to the root of the problem, as it almost always does in Balint's own case discussions. We hear for instance about how the Practice accumulates details of Sara and Camille's chronic states over time; assigning more names to them, adding people to the network of those who need to be informed about them, growing more, or sometimes less concerned about them as circumstances change, speculating over what remains unknown about them. The passing of time appears only to deepen the Practice's involvement in their lives, allowing them to expand into whatever is offered up by way of a response. Though not a clinician himself, Todd Meyers writes a parallel account of his own 'undoing' during his attempt to grasp 'a life marked by the real threat of persistent, unrelenting chronic illness' (Meyers, 2021, p. 10). Meyers had originally set out to ethnographize the life of 'a middle-aged black woman' -'Beverly', whose precarious life is bounded by the realities of poverty, racism and illness. He begins by focusing on her chronicity: 'Arthritis, Migraines, "Dizziness", Chronic Obstructive Pulmonary Disease, "Confusion", Depression, Substance Abuse, Type 2 Diabetes Mellitus, Hypertension, Hepatitis C, Obesity, Kidney Disease, "Voices", Chronic Pain' (Meyers, 2021, p. 47). But during the long hours that he, as a young white anthropologist spends 'observing' Beverly, Meyers' project and his identity begin to lose their coherence. As well as feeling that he was wrong to have scrutinised her body and her life for signs of chronic living; 'honestly, what was I doing anyway, besides prying?'; he finds that he cannot maintain distinctions between all the different harms that permeate her world, making anything that comes 'pouring' out of them, including care, more like 'the product of exhaustion...' (Meyers, 2021, p. 172). A doctor, it might be assumed, is somebody whose work on caring for a life marked by chronic illness has already been carved out for them in advance. But in her account of being a doctor to Sara, Meera relates a similar experience of having to let go of the project that had made their relationship one that could be managed from a safe distance. When she talks about 'hoping' that Sara will 'come out (of this difficult phase) ...we'll get through this time and things will

just calm down and she'll settle down', there is nothing anymore to remind us that she is a general practitioner, and that Sara is her patient. All of Meera's early efforts to gain Sara's trust have been repaid more by the undoing of all of her attempts at 'doctoring', leading her to doubt that 'this' (Sara? her incurable illness? the assemblage of Sara, her illness, the here, the now?) is something that can ever be 'managed'. As Meyers observes about Beverly's life, 'care is a resource that keeps getting depleted' — Meera responds repeatedly to the need for care in Sara's turbulent life, but her resources of 'hoping' and 'getting through', are no different to those that anybody else might reach for in the same situation. They may be more the product of mutual exhaustion than of anything else.

### 4.6. A Non-Progressive Temporality of Care

The Balint group is an obvious site for observing practices of not going anywhere because of the way that it allows these chronic realities to assemble without dissolving them back into a story that ends differently to how it began, but I would also like to claim the Balint group as its own practice of not going anywhere. I am thinking particularly of this group's practice of trying to nudge doctors out of their automatic reactions back into caring for the ordinary. In my observations, one of the ways that the doctors can be inclined towards this, is by looking to the side of the main events of a treatment (suicide attempts, diagnosis, hospital admissions) which, in clinical ledgers, tend to become the markers of whether things are progressing in the right, or the wrong direction. This happens in part through the asking of questions about the relational aspects of the encounter which would not usually be asked in this setting, including those that 'envisage a face'.61 Questions such as, 'how would you describe the patient?'; 'how do you know her?'; 'why are you bringing this up now?' By inclining one another towards what is irrelevant to going 'somewhere' — towards the 'who' rather than the 'what', other ways of articulating a relation to

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<sup>&</sup>lt;sup>61</sup> 'The question who? envisages a face. The notion of the face differs from every other represented content'. Levinas, Emmanuel. (1961/1979) *Totality and Infinity: An Essay on Exteriority*. Translated by Alphonso Lingis. Duquesne University Press, Pittsburgh (p. 177).

the patient are taken up, including those that that easily overflow the categories used to make sense of clinical labour as productive or progressive. Sara's retoxing during her stay in hospital and Camille's pattern of doing all the same things in each appointment 'all over again', are troubling for an account of care that wants to see it as an accessory to progress. And yet chronic states where 'symptoms appear, disappear and reappear, return, arrest time, and efface it' (Meyers, 2016, p. 361) are characterised more by these experiences of backsliding and repetition than they are by those of progression and moving on. One way of describing what the Balint group does, or has the potential to do, is to say that it practices a non-progressive temporality of care, through which people can speak about not going anywhere not only as a form of neglect or as the failure to make progress, but as shared vulnerability to those aspects of living with pain or other intolerable states that cannot be transcended. Adopting a mode of attention similar to that described by Astrid Schrader as 'abyssal intimacy', practitioners are sometimes caught up in activity that requires them to put their own selves on hold whilst they register realities that are as unassailable for them as they are for the absent patient. They find themselves 'suspended in a zone of indeterminacy, hesitating, slowing down, not exactly knowing what to do, confused, listening intently to what might still be hidden...but also desiring (sometimes) to act with passion'.<sup>62</sup>

### 4.7. The Undertow of Illness

In late 2020, Long Covid had already begun appearing more frequently on appointment lists across the country<sup>63</sup> but it was still a new disease, and very little

<sup>&</sup>lt;sup>62</sup> Astrid Schrader writes about how care, and the capacity for it, is limited as a possibility when associated with progressive temporalities. In cases where caring does not translate directly into helping action, she suggests a way to think about it as 'abyssal intimacy'. 'Abyssal intimacy does not require recognition but describes a creative engagement that relies on the withdrawal of the self, a passivity that enables active listening, an opening to surprises'. Schrader, Astrid (2015, p. 683) <sup>63</sup> It was estimated that in the last week of November 2020, around 186,000 people in England were living with symptoms of covid-19 that had persisted for between 5 and 12 weeks. The Prevalence of Long COVID Symptoms and COVID-19 Complications - Office for National Statistics (16 December 2020). Retrieved April 18, 2022 from

was known about it. Initial guidance suggested that for those not hospitalised, the illness would be short lived, and its symptoms would be mild, but this did not reflect the realities for the very many people who were suffering from it (Callard, 2020). Patient stories of Long Covid from this time are characterised more by 'strange and unpredictable' symptoms of varying severity and disrupted chronologies where 'the trajectory of recovery in which they had been led to believe (an uncomplicated restitution narrative), was unexpectedly upset' (Rushforth et al., 2021). The NHS was felt to be absent from many of these stories (Baz et al., 2021), but in certain cases, patients did describe feeling cared for by their GPs, often despite knowing that there was nothing they could do for them. As one Long Covid patient said, 'it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing' (Taylor et al., 2021). In these cases, care is not something recognisable that can be worked towards over time. Instead, it issues from the practice of being in the same place as the patient, 'one step forward, one step back', of 'crashing', of being 'stuck' (Rushforth et al., 2021), and of sharing their anticipation for a future recovered state in the full transparency that there is nothing they can do as doctors, to make this happen. This relates to the practice of not going anywhere that can involve having to endure the patient's own articulation of their condition, even when this means having to sustain the loss of identity, agency and mobility that comes from not knowing exactly how to respond to it. 'Whereas, restitution stories attempt to outdistance mortality by rendering illness transitory, chaos stories are sucked into the undertow of illness and the disasters that attend it' (Frank, 1995, p. 115). The Balint group provides practitioners with lots of opportunity for bringing order to the chaos, as when Daniel is invited to think paternalistically<sup>64</sup> about what it is that Camille *really* wants or needs, as distinct from what she herself has 'offered' him: physical pain that cannot be lived with. To this end, theories are put forward in the pursuit of a more satisfying ending: that Camille is really looking for 'someone to understand her pain' for

<sup>&</sup>lt;sup>64</sup> Shaul Bar-Haim observes that for Balint, the doctor represents a kind of parent figure, one 'who should not always listen to his or her child's will, as the child does not really know the potential dangers of his or her behaviour'. Bar-Haim, Shaul 2018"The Drug Doctor": Michael Balint and the Revival of General Practice in Postwar Britain. *History Workshop Journal* 86(1). Oxford University Press: 114–132 (p. 17).

instance, or that her pain is a symptom of loneliness and a dissatisfied life. But Daniel resists the temptation to accept an alternative explanation that will allow him to move on from Camille's stultifying reality. He only reiterates her point of view: 'it's a physical problem'; 'she's not going to accept the pain'; 'she's very angry' and 'I am stuck'.

### 4.8. Conclusion

On 6th January 2021, the surgery had just begun administering their second round of Covid-19 vaccinations for the 975 older people who were the first in the area to be vaccinated. All the clinical staff and some of the non-clinical staff, were recruited to help with the injections. An official letter from NHS England congratulated GPs on their 'rapid mobilisation' and on how they were 'managing the ongoing needs' of their 'population'.65 Under the heading, 'freeing up practices to support covid vaccinations', military style plans were laid out for a new prioritisation of work with the aim of refocusing all attention towards Covid-19 vaccinations and other Covid-19-related support. Interestingly, in the Balint group meeting taking place on the same day, there is very little mention of the vaccination programme. Instead, the discussion revolves around two patients. One is a man who has pushed his way into through the closely monitored doors of the surgery just as the meeting is about to begin. His angry shouting can be heard from two floors up to where the doctors are sat socially distancing in their consulting rooms. Two GPs leave their rooms to go down and speak to him. When they come back twenty minutes later, they explain that this is an ongoing situation. The man has a long-term condition. He feels angry a lot of the time. On this occasion, they say, 'he was angry with everybody, and his neighbours were driving him mad and we just... listened'. The other patient is a man in his thirties who nobody seems to know very well. Until very recently, he had

<sup>&</sup>lt;sup>65</sup> Commissioning for other services locally had been suspended except for those that were helping to provide Covid-19-related support to the local system. NHS England (7 January 2021) Freeing up practices to support COVID vaccination. Retrieved April 2021 from https://www.england.nhs.uk/coronavirus/wp-

always been taken care of by his grandmother. There is a suggestion that he might have a learning disability, but no diagnosis has ever been made because his family came to the UK seeking asylum when he was a child. Presumably, there were just too many other things back then to worry about. But now his grandmother has died, and his GP is worried that he might be struggling without her. A referral has been made to the learning disability service, but the GP does not really believe that this referral will actually go anywhere: 'he needs to be cared for but there's nothing for him'. He says that 'it's as though this edifice, the NHS, that we all rely on, isn't really there'. The GP resigns himself to 'budging along' with the man which, 'if you don't know whether you've got anything to offer' can be difficult, he says.

How do people respond to these daily realities of chronic living that cannot be outsourced, deferred, or redirected within the NHS beyond a certain point? Budging along without really going anywhere is exactly the sort of labour that is increasingly coming to be regarded as inessential and unsupportable in the temporal economy of an NHS in crisis. And yet, as we are often reminded, chronic disease (wistfully renamed 'preventable disease' in the NHS long term plan (NHS, 2019), is now the definitive disease of general practice. The work involved in caring for long term conditions is what counts as 'ordinary'. To be working within and against a public sector that is forced to stagnate at the same time that it is forced to speed up, is 'ordinary' now too it appears.

In place of the GP who 'prescribes himself, his medical and social authority, and his very own existence as psychosocial guide' (Bar-Haim, 2018, p. 132), the clinicians I observed in the Balint group were often perplexed, self-doubting and unable to establish a position ahead of their patients, from where they could instruct them on how to get better. In this respect, the present day Balint group may be said to produce the undertow temporality of crisis and capitalism in the NHS, but not its solution. As against the celebrated feat, during the pandemic, of 'rapid mobilisation', these practitioners describe finding themselves to be stuck, not knowing what will come next, nor whether any of their investments in treatments and interventions will endure into the future. This chapter makes use of Balint's vision of general

practice for how it interrupts the fantasy of relation-less health care, but Balint's 'drug doctor'<sup>66</sup> is notably absent from this later, more chronic age of the British welfare state' (Bar-Haim, 2018, p. 132). In making the case for a practice of not going anywhere, I have suggested that a shared sense of passivity before the future might generate other modes of scientific attention to the problems of chronic living, providing practitioners with reasons to keep on responding without this needing to lead to a solution necessarily, or to a way out of the crisis.

<sup>&</sup>lt;sup>66</sup> The drug doctor is one of Balint's most famous cases. He uses it to illustrate the lesson that 'the most frequently used drug in general practice was the doctor himself'. In Balint (1957/2000).

## Chapter 5

## Temporal Drag and Falling Behind in an Emergency

In the first weeks and months of the coronavirus pandemic, healthcare workers were required to move to ways of working that would prioritise survival above all else. This chapter examines three cases of general practice workers refusing to leave behind old practices or to break with the past at the risk of being accused of slowing down collective efforts to act on imperatives set by crisis. I also return to the figure of the frequent attender who has long been accused of being a source of drag in this setting. The first part of the chapter looks briefly at the concept of temporal drag as it has been worked out in feminist and queer theories of time and delay. The middle section presents three cases which are based on a combination of interview and blog testimony collected during the research period. The chapter ends with a discussion of what forms of care, if any, may be afforded by lagging behind. I offer the outlines of an account of temporal drag that has a specific meaning for those working in non-emergency departments of the NHS amidst temporalities of crisis.

#### 5.1, Overview

This chapter is about what sort of forms, a refusal to move on from the past can take in general practice. It builds on the testimonies of three long serving staff members whose failure to shift completely into a crisis mode during the first Covid-19 lockdown is what enables them to stay in contact with what is in danger of being neglected or left behind. I use the concept of temporal drag developed by Sara Ahmed (2016), Elizabeth Freeman (2010), Lisa Baraitser and Laura Salisbury

(2020) to understand a mode of care arising out of the refusal of these healthcare workers to adapt to the changed situation of general practice during the pandemic. In the concluding part of the chapter, I ask what sort of case, if any, do these accounts make for drag as a necessary mode of care in contemporary general practice.

The first testimony is based on an interview with 'Eunice', a general practice receptionist of many years standing. It concerns Eunice's experience of trying to stay available to a small cohort of patients whose habit of frequenting the surgery and checking in with her on a regular basis, has resulted in the waiting room being used as an informal place of care in addition to its more mundane use as a place to sit and wait for your name to be called. As the interview takes place at a time when the surgery is still operating a closed-door policy in compliance with social distancing rules, the reception as a social space is out of bounds, but Eunice is refusing to switch completely to a remote system of online triage as she has been told to do. The second and third testimonies are both based on pandemic blogs shared by GPs and made publicly available online. In one of the blogs, a GP tries to make sense of his own reluctance to join colleagues in rushing headlong into remote or socially distanced ways of working. In another, a retired GP talks about the ordinary work during a pandemic, of caring for those who are dying ordinary deaths. She wants other GPs to see why it is not appropriate to grasp all dying from Covid-19 through the mode of emergency and why certain exceptions need to be made.

## 5.2. Temporal Drag

The idea of a temporal drag can be useful when thinking about what it might mean to refuse to move on at a time when this could be seen as a blocking or delaying the future for others. It gives a name to the insight that just because somebody declares a time to be over, doesn't mean that it is. Sara Ahmed gets behind this when she advocates for being a killjoy (another name for drag), by not being willing to get over histories that are not over. Ahmed's 'feminist killjoy' earns their name by 'becoming the problem' that they insist on talking about (Ahmed, 2016, p. 9). 'She is doing more

than saying the wrong thing: she is getting in the way of something, the achievement or accomplishment of the family or of some we or another, which is created by what is not said' (Ahmed, 2016, p. 9). Elizabeth Freeman uses the term to describe what might be happening when a future-orientated present is feeling the rub of histories which, though they have been cancelled or omitted, are still carrying us back to them in the undertow (Freeman, 2010, p. 65). This refers to the way that successive political generations and the collective fantasies that travel with them, pull backward even as they only ever seem to be moving progressively forwards. Freeman's 'practice of temporal drag' in response to this, is 'a counter-genealogical practice of archiving culture's throwaway objects, including the outmoded masculinities and femininities from which useable pasts might be extracted' (Freeman, 2010, p, xxiii).<sup>67</sup> In a paper intended as a response to the conditions of lockdown during the first year of the pandemic, Lisa Baraitser and Laura Salisbury write about how in an emergency, a willingness to stay with the temporal drag can be a possible form of care. They formulate being 'inside of delay' as a way of getting behind those who are being cared for, 'so that their needs can be responded to and they become the future towards one which is inclined' (Baraitser and Salisbury, 2020, para 21). In this practice of dragging or delaying, it is the capacity to hang back at a time of being propelled forwards, that makes time for care.

This last formulation of what it might mean 'to think in, and with delay' (Baraitser and Salisbury, 2020, para 1) may have come during a weird moment for the NHS, of waiting all together during a time of great uncertainty, but its relevance for general practice is not limited to just this time. Ever since its absorption into a national health service in 1948, there have been tensions in general practice over the question of what to do about those parts of healthcare work which cannot be easily avoided or delegated and that do not conform to the idea that healthcare is about making progress. A lot of this type of care work which we would describe now as chronic in kind, is said to only have come to light after the introduction of a

<sup>&</sup>lt;sup>67</sup> Freeman's practice of temporal drag is proposed in part as a response to the disavowal of the radical feminist temporalities that can act as a normative 'deadweight' on a queer theory and politics that privileges transformative differences (Freeman, 2010).

continuing offer of healthcare allowed recurring conditions to manifest as being in need of an ongoing response and a different approach.<sup>68</sup> The sociologist of general practice David Armstrong wrote that the clinical problems that come to general practice cannot be localised to specific and immediate lesions because they are biographical. They take in how 'the past informs the present and pervades the future' (Armstrong, 2002, p. 44). This means that practitioners might be tasked with the strategic aim to prevent or to deflect crisis in the future by making an early diagnosis based on a patient's medical history, but the work involved in actually trying to achieve this aim is more likely to take the form of mitigating and delaying harm that unravels slowly and over the course of years. This brings us back to the notion of staying in the delay which requires of care workers that they remain willing to stick around for the unravelling, even sometimes at the cost of being a drag on wider projects, of saving the NHS for example, or of making an NHS 'fit for the future' (NHS, 2019).

How do people stay attuned to what they continue to feel responsible towards, even as it is in the process of being left behind by the organisation or by the health service as a whole? What do care workers do in a practical sense to try and stay binded in time to those they care for? This is a bind in the sense that Elizabeth Freeman uses the term which I think captures better than commitment how still being inclined to another's future, however frustrating that may be in relation to your own future, could be viewed as both an attachment and a problem. It conveys how staying in the delay of a difficult reality as it unfolds is likely to generate a certain kind of work for the practitioner, work that they may not want to take on but which they feel they have to as a condition of being able to carry on doing their job. Without exactly searching for evidence in the contemporary scene of general practice of a willingness to drag behind, I am interested in the ways that people in this setting

<sup>&</sup>lt;sup>68</sup> The idea that a continuity of care between one doctor and one patient is necessary to the health of the individual has been in circulation in NHS general practice since the 1950's. In the Central Health Services Council Report of 1954, Lord Cohen, who was the president of the General Medical Council from 1961 to 1973, spelled out the connection between the need for continuity in healthcare with his belief that general practice was 'the key' to the NHS. In, Clark, S. G. N., & Briggs, A. (1964). *A History of the Royal College of Physicians of London*. Clarendon Press for the Royal College of Physicians.

notice when there is a danger of falling out of whatever it is that binds them in time to those they are supposed to be 'looking after'. Over the next three sections, I look more closely at this phenomenon of temporal drag in the cases of Eunice, Jonathon, and Iona.

## 5.3. Eunice: Staying Behind

Eunice told me that with the arrival of Covid-19, the practice's open-door policy was one of the first things to go.69 It was replaced in March 2020 by a new policy of keeping the door to the surgery locked and only admitting one person at a time. A year and a month later, things had still not gone back to the way they were before. The door is always locked now. Visitors have to buzz to get a response and reception staff have to respond by saying 'no, book an appointment'. This is a momentous change because ever since they were first opened to the public, generations of people have walked freely through the surgery doors. Over the course of years of being thought of, frequented, spoken about by the people who live in the surrounding area, the surgery had gotten wedged into the scenery of people's daily London lives and had come to form an essential part of hundreds of little taken for granted routines. It was a good place to keep dry when it rained because of the shelter at the entrance. It was also a useful place to mention when giving directions because it stands out in an area mostly made up of residential houses and flats. People would usually come to see a GP, but they might be visiting for other reasons too. Local community groups had made use of the building for meetings, classes, workshops, support sessions. It had featured as part of regular journeys to pick up prescriptions and attend appointments. People passed it when walking to the shops, some might have stopped there on occasion to break up the distance. There was a time when everybody with an appointment needed to sign in at the reception on their arrival into the main building. Even after the recent introduction of self-service machines, most visitors would still find themselves drifting through the waiting

<sup>&</sup>lt;sup>69</sup> All the unattributed extracts in this section are taken from the transcript of an online Interview with F, an administrative worker at a London GP Surgery. The interview took place in April 2021.

room towards the main desk to speak to the staff who would still have to respond to them even if this was no longer their main job.

Eunice a receptionist, tells me that before the pandemic, they would still be seeing the "same old faces" every week, many of whom would pass time in the waiting rooms, falling in and out of conversation with one another or, as was more often the case, with the reception staff who were mostly women and who were sitting directly opposite to them. Some of these people would belong to the patient group known collectively in the general practice as 'frequent attenders'. The figure of the frequent attender has been around ever since the healthcare system first became free for all and from the very beginning, she was seen as a threat to the viability of the general practice as a public institution. As early as 1954, she was perceived as a source of discouragement amongst the doctors, preventing them from deriving a sense of satisfaction from their work (Backett et al, 1954). Her main characteristics have changed over time, but she still tends to be female, will likely be over sixty and have been diagnosed with multiple long-term conditions (depression being one of the most common). Crucially, she will visit the surgery many times more than the average person, around once every two weeks or more (Barker, 2017). Debates are ongoing internationally as to the real identity of the frequent attender. The stakes are high because she is implicated in huge potential losses for the NHS in terms of time, money and morale all of which are already in short supply. Even just as a thought-object, she has the potential to provoke intense emotions across the whole spectrum of the service. This can spill out into arguments over whether her repeat attendances are due to her unreasonable determination to get what she believes she is still entitled to. Or, to her insecure attachment style predisposing her to fixate. Or, to the fact that she has endeared herself to the staff too much so that they find it difficult to keep her at a distance. Most recently, her habit of coming back has become the target of disciplining tactics that try to break it on the pretext that this is one of the main ways that time for care is wasted (NHS England, 2017). I have noticed that in almost all these different lines of questioning, the trait of hers that we are invited to be bothered by the most, is her tendency, portrayed as pathological, to repeat herself. But, aside from all the inquisitiveness about what

could be the secret motive behind her compulsion to make repeat visits to the practice, what little we know of the details of her everyday life and of her personal and social history, suggests that there might be some more banal reasons for why she attends the surgery on a regular basis. For one thing, she is said to be more likely than others to live very close by (Scaife et al., 2000). She is also said to be more likely to live alone or to be in some way isolated from others in her living arrangement. She is often unemployed if she is not already past the time in her life when she would be seeking employment. She is usually in the process of getting poorer and living a life that is not mobile in either the social or the spatial sense. Her body does carry more than the average amount of chronicity and she does feel unwell for much of the time. She might also have lost a person with whom she had been in the habit of intimacy through death or separation (Kivelä, Elo, & Kääriäinen, 2018). Her resources have always been pretty low. She gets ground down by the demands of everyday life and the daily ordeal of having to endure this is built up over years. In other words, she is exactly the kind of person who you might expect would be open to an arrangement with public services that takes the form of something more like a routine, rather than just a one-off contact. Responsibility for keeping her going needs to be spread out both in a relational and a temporal sense. Yet, medically speaking, she will typically come across as a questionable candidate for continuous doctoring. I have seen her reviled in the British Medical Journal as 'the practitioner's everyday life hell' because she represents 'fears and expectations' going beyond anything that can be dealt with in a clinical way (Carelli and Ferdinando, 2002). But it is not quite true to say that the clinician is alone in having to deal with this, at least not here, in this particular general practice. Besides the GPs, there are others working within the surgery who may also be caught up in caring type relations with those who fit the description of the frequent attender.

Eunice's job as a receptionist has always required her to operate from within the other life of the institution, what you might call its 'social life'. Frequent attenders recognise her. Some would ask for her specifically by name, especially if there was a problem and they couldn't reach their GP. In their everyday conversations about what they need and how they are getting on, she gets to know things about them —

who their GP is and what they tend to need help with. She might also find out whether they live alone, what sort of life they live, how they get by from one hour to the next. "I'd ask them, "how are you?" And they'd have a chat with me about what they'd been doing — "I've just been shopping..." ". She does not make the usual distinctions between her time and theirs. So far as she is concerned, they are always just picking up from where they last left off. Administrators and service managers might be able to tell you the percentage of asthmatic patients in whom there is a record of smoking status in the preceding 12 months and where to look to find the number of patients aged 40 years and over with a blood pressure measurement recorded in the preceding 5 years, but they will probably never have passed the time of day with any of these people or spoken to them in the consciousness of being possibly the only person they might speak to for the rest of the day. In the digital general practice, there are no recesses for shared time to be allowed to settle which means that no matter how many times a staff member has met with the same person in the past, each encounter is envisioned as though it is happening for the first time and will never happen again. It is as though all bodies are to be regarded as bodies fresh to the scene and always on the move.

For Eustice however, working at the practice has always entailed continuing to remain in a relation of coevality with slow familiar faces in rotation. She has passed a lot of hours with familiar faces sitting in the same room, in addition to the hours accumulated speaking with them on the phone. She has been used to certain people making the same onerous journeys back and forth, stopping by on their way home from the shops. They used to come by on a whim, sometimes "with cake and biscuits." Occasionally (and this still happens) she will be stopped by them on the street to talk before moving on, only to resume their conversation a few days later in the waiting room or over the phone. They will often be in a state of waiting for something or someone: an appointment, a prescription, a pain, a lift. These topics of conversation make up the typical background for an encounter with Eunice, but this has never led to her feeling as though she was being slowed down or held up. It is all part of the job of overseeing that these people are still there, still being accommodated and checked in with. Her job is to reconnect them with the parts of

the practice that keeps them in the loop of being picked up again, remembered, or relieved of having to wait, if only for a short while. She feels responsible for assuring them that even if nothing much appears to be happening, they are still where they need to be, that they are still being held in mind and that the connection has not been totally lost.

This habit of offering comfort to regular patients, and of 'looking after' them, could be perceived as a source of drag on the surgery's ambition to move patients quickly through a treatment pathway and to see them disappear at the end of it. To really lag back with those whose needs no longer number amongst the possible or eligible or urgent, Eunice must be prepared to fall out of step with those around her and to find herself amongst people who are actively being left behind. Having to be receptive to the fallout from this can place her in an uncomfortable position. When, for example, in the later months of the pandemic, some frequent attenders showed up without appointments and were denied entry because the front door of the surgery remained closed in accordance with a policy to only allow access to one patient at a time, Eunice is tormented by the thought of them standing there, waiting with nowhere to sit down. "You just see them...at the door". After having known them for so long, she is unable to suddenly stop thinking about how they are getting by, especially not now at the end of a long stretch of weeks and months in lock down. She worries about how uncomfortable they must be in their vulnerable suspended states of being poised to ask for the same kind of reception as they are used to getting, only to be turned away. As she says, "it's hard to do that because they've walked all the way there, and we have to say no." She also worries about the people who call up the practice to make an appointment only to be redirected online to complete a self-assessment. She doesn't think that they will understand why they can't make a routine appointment anymore. The pace of everything is faster, "everything happens on the day now" and many of those who can't keep up are never quite able to arrive or to settle or to find a comfortable way to stand in a place that they had been used to thinking of as open to them. "I honestly don't think patients can understand". Her reflex is to want to accommodate these still waiting bodies wherever they happen to be but the resources that she has at her disposal for

making this happen are all about diversion, referral and forwarding on; of not allowing them to stay where they are. This includes those technologies that want to 'shape demand' by shedding patient attachments formed around other, earlier expectations and understandings that have since become outdated. In small gestures like keeping the option open for patients to speak to her over the phone "if they need help to fill in the triage form", I see Eunice refusing to keep them on the move, even if all that amounts to in the end, is holding their place within a system that can no longer be said to exist in any material sense (if it ever did). She stubbornly tries to stay within reachable distance to them — to their pace, their longevity, their relational claims on her as a historical person; not because she chooses to necessarily, but because unlike some people who have never met them, she cannot, not be conscious of who and what she would be leaving behind if she were to just cut them off now. Doing the upkeep work needed to maintain the expectation that these bonds are still intact, even when others are trying hard to shake them off, is part of her own activity of reproducing a world that bears some resemblance to the one that was there yesterday and the day before that. Stopping would be like becoming "a different person", something that she cannot imagine herself doing, "I can't become a person that I'm not...", "It's difficult, I can't". In a sense, these people are her contemporaries, and as contemporaries, they go on sharing the same time, as before, waiting for the same things as before, managing the ebbs and flows of their long-term health conditions. It is all part of the same thing. Even when this may seem to defy the logics that are deemed necessary for the organisation's survival, Eunice does not share the optimism of the surgery that they will ever find the right kind of solution to the problems of frequent attenders. For her, they are tired, uncategorisable but familiar bodies, waiting to come back in to a place where they can be accommodated just as they were, just as they still are.

## 5.4. Jonathon: Sticking to the Old Ways

It is 24th April 2020. Jonathon Tomlinson is recording his experience of general practice during the first months of lockdown during Covid-19.70 He reflects in some detail on what feels different about the GP consultation, a scenario that he thinks of as having barely changed 'in hundreds of years'. That was before the outbreak of the virus. A different mood is setting the tone now and there are new rules to adhere to. Ever since the rules about social distancing were applied, activities as routine as just sitting together in the consultation room have gotten complicated. He describes the potential problems caused by a three-metre apart seating arrangement. 'I sat with my back to the window which meant that her face was lit by the sun while mine was masked by the shade. It wasn't a deliberate ploy to expose and conceal, but we noticed it as soon as we looked up at one another. I apologised as she winced in the light, and I moved my chair around 90 degrees.' Jonathon misses what he refers to as 'the old ways' - conventions of style and scenery that had always seemed to come together in the past to support the main effect of the consultation as a piece of general practice. He tells us that he was already used to thinking of medicine as a performance but in the past, he had enjoyed the work that had gone in to keeping it going. 'In the old days I liked to imagine good consultations like performance art with my consulting room as the backdrop to a drama performed by patient and doctor improvising with one another'. Now, the whole ecology of healthcare has been shaken up causing all iterations of it to feel unstable. People are having to improvise subtle conventions of timing and position, a task he compares the task to navigating unchartered territory together without a map.

In Jonathon's account of what it is like to go into work as usual during the pandemic, he tries to explain what is involved in carrying on with routine healthcare in the absence of the sort of ambience that he has always taken for granted before now. He

<sup>&</sup>lt;sup>70</sup> All of the unattributed extracts in this section are taken from Jonathon's pandemic blog which can still be accessed online: Tomlinson, Jonathon (2020a) *Consulting during Covid.* Retrieved March 2022 from https://abetternhs.net/2020/04/24/consulting-during-covid/.

has spent the last 20 years working at the same arms-length distance, 'learning how to judge how much touch is appropriate, and how to 'harvest the richness of multisensory exposure' in order to unpack 'heartaches', 'headaches', 'bellyaches' and more'. He had not known it at the time, but he realises now that a divide between himself and the patient of an arms-length was 'the perfect length' – 'the length of a stethoscope'. It established exactly the right amount of distance from where he could 'inspect hands for signs of disease or reach over to hold them in comfort or pass a tissue to catch the tears'. He realises that without knowing it, the atmosphere of the consulting room, its lighting, the character of the event, its flow and its geography had combined to provide the ideal conditions for being able to form sound clinical judgements at the same time as being able to offer comfort when needed.

At the time of his writing this account however, the three-metre distance rule and the move to seeing people remotely for appointments have become compulsory requirements for all practices. Jonathan finds that when the distance is suddenly increased and touch is ruled out, this does more than just interrupt the flow of healthcare by slowing it down or speeding it up. It interferes with the logistics that had ensured just the right amount of contact, exposure, and consent. The incoming logistics do not provide the same structure for the raw material of the encounter between the person who is seeking help and the person who is offering it. Whereas before, he had sometimes walked out to meet patients in the waiting room, now, patients 'appear from nowhere'. Whereas before, he had sometimes walked them back again after the appointment, now they 'disappear in an instant'. Without the little intermissions of waiting, talking and dawdling, the GP appointment is whittled down to its most basic components of showing, looking and telling. The substance of it is diminishing. Jonathon describes how yesterday, he physically recoiled from the monitor when one patient 'wanted to show me a rash on their abdomen and they thrust their phone right up against it'. He is discovering that the sparseness and the clumsiness of the medical encounter by itself can be a bit brutal for everyone involved.

Now that technology is making it easier for practitioners to eject themselves out of the awkwardness of these situations, or not to enter them in the first place, Jonathon is conscious of having to choose to keep putting himself through the ordeal of being in a position of responsibility towards another human being at a time when he feels that they are all amateurs at making this work again. The guidance for how people should go on in this way is felt by him to be counterintuitive. It is not only Jonathon who is left feeling exposed in situations where all the conventions are out of joint. He observes the patient looking as though they too, may be struggling to know how to conduct themselves so as to make the right moves appropriate to the delicate situation. He hints at the effort needed to keep the consultation from slipping into bad territory. Some aspects of remote consulting are felt to be intrusive. For example, the patient and their surroundings can easily become over exposed to what he refers to as 'the clinical gaze', which he says is a kind of looking that 'is full of moral judgement whether it is intended or not'. In the past, it was different because most patients had the choice of declining a home visit. If they accepted, they would have the time to prepare themselves before the doctor could lay 'his judgemental eyes upon them'. He also finds that high levels of concentration are required to maintain the connection with a patient through a screen where, as he explains, 'if I look at her then I am gazing off to the left, if I look at the camera then it looks as if I am looking at her, but I'm not. If I look at myself (I can't help it) then I'm looking somewhere else'. He objects that it feels unnatural for him to try to mediate care like this, using technology; 'we weren't made for this'. The framing for classic scenes of sympathetic medicine has been jerked away.

Another way of thinking about what Jonathon and his patients are having to do to keep things going in a socially distanced world is to imagine general practice during this period as not so much a place where intimacy has been driven out, as a place where there is a surplus of unstructured anxious feeling streaming in from all sides and having nowhere to go. Though they may be more distance between them in spatial terms, Jonathon's encounters with patients are not lacking in intimacy so much as they seem to have become problematically intimate. He likens their confused, bumbling bodies to 'clumsy teenage lovers trying to work out where to

start' or 'cowardly boxers' circling one another in the ring. There is a need for collaborative effort just to protect one another in the most minimal ways from making a sudden swerve into the inappropriate or the violent. It is an ordeal for him to have to be at the centre of all this, acting as though he still knows what he is doing.

## 5.5. Iona: Pointing out the Obvious

In a video blog posted to the online platform for the British Journal of General Practice on 11th April 2020,<sup>71</sup> Iona Heath, a retired London based GP, addresses GPs on the subject of care for the dying. She is speaking, presumably from her home, as this was less than a month after the first lockdown was announced when everybody had been instructed to stay indoors. The central message of the video focuses on the problem with our attitude towards death; specifically, 'how we're handling dying'. She is saying that we have already begun seeing death as a kind of 'technical issue' rather than as the end of a life, and that since the start of the pandemic, we have taken this further, to a point where the event of death is hardly being allowed to happen at all anymore. Iona is thinking in particular of people who she describes as 'older' and 'vulnerable' who have contracted the virus at a time when they were already approaching the end of their lives. For them, the prospect of dying at this particular moment and of this particular virus (as opposed to dying from another similar virus), might be thought of not as a tragedy but as timely and sometimes even as 'extremely timely'. As she puts this, 'some of the deaths that are happening are extremely timely, some are not, some are very tragic, but some are very timely and evoke the old adage of pneumonia being the old man's friend... not the worst way to go when you're very old'. As she is saying these words, the idea of dying in a non-traumatic way already seems to have lost its reality. Iona predicts a legacy of traumatic bereavements of the kind you get 'after an earthquake or a bombing or something where there was no chance to say goodbye'. A veto on all physical contact,

<sup>&</sup>lt;sup>71</sup> All of the unattributed extracts in this section are taken from Iona Heath's pandemic video blog which can still be accessed online: Heath, Iona (2020) Death, Dying, and Love with Iona Heath. BIGP Life. Retrieved March 2022 from https://bjgplife.com/death-dying-love-with-iona-heath/

and the logistics of caring for people with so few ventilators, and the need not to allow people to die of this particular virus, means that for a person who is dying of it, an ordinary death from Covid-19 is almost unimaginable. A situation seems to have been created in which, as Iona observes, 'suddenly, nobody must die'.

The first person to respond to the video in the comments section is mildly irritated by what Iona is saying. They complain that 'she only says the blindingly obvious'. This is true. Iona is making a case for something that is in one sense quite obvious: dying as a commonplace, relatable human experience, 'all snot and coughing'. But she is doing it at a time when all death from the virus is regarded as catastrophic and an offence against life. She is describing dying in terms that make it seem somehow manageable, even in an unmanageable situation. 'There's a space where this could be happening' — death as a continuation of the everyday life that a person has lived up to that point and as a stretch of lived time, not so very different to any other. In a way which feels very typical of the sort of care that general practitioners might be said to specialise in, she tries to get us to look (and touch) the facts about what is going to happen — about what is in fact already in the process of happening; so that we can work out a way of living through it rather than trying desperately to stop it from coming to pass. In order to do this though, first, she has to assemble certain facts about 'what old age is about', including things that may not be obvious at all, like what counts as a life worth living. Iona's experience as a GP seems to be what authorises her to make the controversial judgement for example that, 'of course you shouldn't resuscitate anybody when they're living in a care home...if you're over eighty then your chances of surviving and returning to a 'normal life' after resuscitation are practically zero'.

By drawing us back to dying as an inevitable event that must happen ('we all have to die'), and not only when there is a massive threat to life, Iona appears to want to put us back in touch with it. She argues that we should literally keep touching the person who is dying and not stop just because of the risk of infection because otherwise, 'what are we saying? We're saying: risk of infection, is more important than human love in this context'. Iona mentions love on more than one occasion and

does not say what she means by it. Just that it 'cannot be right' not to put love first at such a time. Touch as a way of 'continuing to communicate' is one of the main ways that people can keep the love relation going, even when all thoughts of prolonging a person's life have come to an end and they are no longer conscious. Her advice about how we might find a way of living out our own dying and that of others for whom we care, is to 'be with' one another — 'to hold their hand, to talk to them; to say those crucial last things that you need to say to people when they're dying'. The problem right now as she puts it is that death is 'the most contagious kind of event', but even more pressing than this is the problem that 'love is being prevented from being in the equation'. A fixation on warding off the possibility of all death means that ordinary human dying is not being allowed to unfold in the proper way. Rebuffing the trend for chronicling every death from the virus as a tragic failed attempt to save life, Iona seems to be asking that we hold in mind two difficult realities at once. Yes, that life needs to be protected from the threat of being cut short, but also that life needs to be able to come to an end when this is appropriate. If we let go of the opening for this as part of our emergency measure to protect ourselves against the virus, then the only kind of waiting we have left is the tense waiting alone for news of what cannot be delayed any longer. In situations where death is protracted, 'an opening' is created for a different sort of waiting based on something like 'love', where people can wait with the dying rather than just waiting for their death to happen. Iona is suggesting that that we need to make time for this event that just needs to be allowed to happen in its own time, even if all of our collective energy is committed to forcefully resisting it in principle.

## 5.6. Drag as a Possible Mode of Care

In these accounts, no life is saved necessarily, the benefit to self and others of dragging behind are questionable and the decision not to prioritise dealing with a crisis may even be considered medically and morally reprehensible. Motives for doing this are often the focus of suspicion. David Armstrong was suspicious of GPs who refused to modernise their Practices in 1990, interpreting this as an attempt to

cling to professional dominance (Armstrong, 1990, p. 693). UK newspapers tend to interpret any kind of delay or holding back in this setting as further evidence of GP's 'unwillingness to work hard' (Barry & Greenhalgh, 2019). What interests me about this way of taking a stance, especially in this part of the healthcare system, is how it can make us see what might be generative and protective about some healthcare workers refusing to move into an emergency mode. These testimonies depict temporal drag as being more like something lived, than thought. What they describe only really makes sense in the context of relational worlds where, as Bellacasa observes, caring is more than an affective-ethical state, involving 'material engagement in labours to sustain interdependent worlds, labours that are often associated with exploitation and domination' (Bellacasa, 2012, p. 198). Durability rather than drag might be a better word for describing this. It conveys more accurately how practitioners are engaged in sustaining not just ideas or practices to which they have become attached, but the very existence of the interdependent worlds that have formed spontaneously in response to the common plight of having to get through everyday life. For the authors, the way to go on is not always to move forward, because moving forward in this setting can imply dropping the material engagement that has been needed to sustain such a scene of care in general practice.

When Jonathon Tomlinson, who is describing what it was like to gaze at himself on the computer screen in place of seeing a patient in person writes, 'we wanted to go back to the old ways', we can hear something of how he might be feeling responsible for material realities of healthcare in the process of coming apart under the pressure of the measures being taken to deal with Covid-19. His adherence to a pre-pandemic mode of seeing patients face-to-face is happening in the context of feeling aggrieved over the loss of a scene of medicine that he identifies as being the only one possible. This has nothing to do with the desire for productivity without interruption in a setting where lots of interruptions are to be expected anyway. It comes more from his belief that without some dragging on his part, the capacity for keeping certain forms of care going will probably be permanently lost. This is more like a reluctance to move on from the spot where he still insists that he needs to be if he is to stay in

touch with certain realities of healthcare: how 'being with and being around people is as important as talking' for instance, or how consent is gradually conceded (or withdrawn) according to how comfortable people feel, 'which in turn depends on body language, which is lost when we are not together'. Whatever is being held onto to and carried along here, it manages to retain the things about it that had made it so inconvenient for the present in the first place. For Jonathon, this might be something like the unspoken contract that exists between the doctor and the patient and how it allows for the continuation of what he refers to as, 'a safe and symbolic space'. For Eunice, it is the sociality of the surgery and its serviceability as a place where local people, herself included, can be assured of an atmosphere of hospitality going beyond what is functional, clinical and impersonal.

General practice receptionists can embody the expectations and frustrations that an open offer of care inevitably gives rise to.<sup>72</sup> In ethnographic studies of their role in the smooth running of repeat prescribing processes in UK general practice, reception staff have been observed making many hidden contributions as part of trying to meet patient expectations (Swinglehurst et al., 2011). Trisha Greenhalgh and Deborah Swinglehurst found that despite not having formal accountability for the clinical aspects of these processes and despite not being remunerated for them, the receptionists could see, as other staff could not always see, all of the minor ways in which clinicians and technology will regularly fail to do all of what they need to do to get the job done. In additional to their own work, receptionists did the work of picking up the pieces and seeing the prescription process through to its completion because they considered themselves 'informally accountable to the patient' (Swinglehurst et al., 2011). This comes close to Eunice's own stance towards reception work, except that whereas her voluntary feelings of accountability might have been useful to the organisation before the lockdown, they outlast their former

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<sup>&</sup>lt;sup>72</sup> General practice receptionists often find themselves on the receiving end of the anger that comes from feeling that expectations of being cared for by the NHS are being failed. In 2015, they were responsible for nearly half of upheld complaints in primary care, the largest figure of any staff group. Based on data from the Health and Social Care Information Centre. (2015). *Data on written complaints in the NHS - 2014-15*. National Statistics. Retrieved March 2022 from https://www.gov.uk/government/statistics/data-on-written-complaints-in-the-nhs-2014-15-ns

use value. Identifying the persistence of a habit as a case of drag, changes how we think about her ongoing embodiment of patient expectations and makes us see this as the continuation of the same instinct to step in and pick up the pieces after an offer of care has been made, only for some of those who turn up to accept it to be left hanging, i.e., the regular attenders and those patients who she knows will probably struggle to get what they need from anonymous online interactions.

Another aspect of temporal drag from these accounts is the repetitive work of pointing out the obvious that can be involved in bringing up to the surface of the present again and again, something that seems irrelevant, unimportant or out of place within the wider scheme of what's going on at any given time. In Ben Anderson's work on emergency as a temporal mode (Anderson, 2017), he writes about how a state of emergency (for those not already living in a constant state of emergency), can change how we let the future form for us. Instead of seeing it as a time in which history can continue to unfold and transform, when grasped through this mode, the future takes the form of something strange, temporary but also perhaps, hopeful. The declaration of the emergency is the cue for a response that will bring to an end 'the unbearable present of systematic and eventual harms' (Anderson, 2017, p. 464). Iona Heath's testimony alerts us to some of the problems that can ensue when we stop being able to grasp harms, damages and losses, through any mode other than those that 'being in an emergency' or 'being in crisis', can offer us. This has a particular relevance for those parts of the NHS specialising in non-urgent care where harm, loss and damage sometimes needs to be able to work itself out to the end, prompting quite different responses to those that are required in an emergency. Her main concern seems to be about how, in the case of those who are dying because they are at the end of their lives, this can mean that we stop being able to grasp their dying as necessary, relatable and final. Before the discovery of a vaccine, coronavirus still represented an incalculable threat to human life and in this context, the message that we sometimes need to be able to let death happen, feels particularly risky because of its untimeliness. What suggests this intervention as a form of drag, is the insistence on a prior attunement to dying that sees it as painful and unparalleled in its own way, not as strange or exceptional or imbued with hope as it can be made to seem when grasped as the unfolding of a bigger crisis. In order to make herself heard over the noise though, Iona has to keep dredging back up to the surface something that may seem not only too insignificant to warrant worrying about at such a time but possibly also inappropriate. What she is saying resembles dragging because she is having to keep bringing back realties of ordinary dying that predate the present to a time when the end of a human life might be 'protracted', 'contagious', but never preventable and not tragic. That she is having to materialise what she thinks of as normal death, as though these were the exceptional and not the ordinary realities of dying, is a sign that something that ought to be commonplace in healthcare is having to be forced back into contact with the present as a way of stopping it from falling out of public consciousness. This could be why it feels to other GPs like Iona is only saying what is already obvious.

There are more idealised versions of this from the history of doctoring; scenes where the authoritative physician remains calm, whilst everybody around them panics and loses their grip on reality. This is the quality that John Berger's Dr. Sassall most admires in the doctor figure remembered from his own childhood; 'a man who was all-knowing but looking haggard... came in the middle of the night... his pyjama trousers were poking out through the bottom of his trousers. But above all I remember he was in command and composed — whereas everybody else was fussing and agitated' (Berger, 1967/1997, p. 53). The heroic stance of doctors keeping their heads when all about them are losing theirs, implies taking a position ahead of those for whom they care, from where they can stoically face up to what their patient is unable to, due to their vulnerable condition. From her description, Iona Heath's understanding of where the carer should be positioned in relation to the dying person, is not ahead of them, showing them the way, but in touch with them, holding their hand. This comes closer to the definition of 'looking after' suggested by Lisa Baraitser and Laura Salisbury as 'a process of putting the object of one's care ahead of one's own position at the very moment one is positioned ahead' (Baraitser & Salisbury, 2020, para 21). Emergency is rejected as an appropriate mode through which to try to understand the situation or to prioritise what is important.

For Jonathon Tomlinson, one of the consequences of delaying moving to remote methods of seeing patients, is that it deepens the divisions between those who will leave the old scene of general practice and those who, like him, will insist on staying. He is sure that for some doctors and for some patients, 'the new world is a welcome relief from the intensity of physical proximity'. This points to another negative aspect of drag from the testimonies. Recalling Sara Ahmed's words of warning about the consequences of being a killjoy (Ahmed, 2016), this is that by staying in contact with something that is hard or inconvenient, care workers risk endangering themselves by becoming identified with what is hard and inconvenient. Jonathon is already envisioning such a scenario. His refusal to let go of the necessity for multisensory exposure at close proximity, even when this sometimes results in overexposure and absorption 'in a black hole of despair', could cause him to become a drag on others who would rather escape from this. The rising numbers of depressed, anxious, stressed, burnt out or emotionally distressed GPs suggests that perhaps they might really need to find ways of escaping from this.

#### 5.7. Conclusion

These testimonies suggest that there are ways of being attached to what gets formed through healthcare work over time; expectations, practices, shared understandings, that can make the prospect of becoming suddenly unattached to them, feel like giving up on the care aspect of care work altogether. To refuse to relinquish such a relation is neither good nor bad in itself, but what I think these accounts show is how their durability in general practice might help to mitigate some of the more harmful effects of what Carol Roitman refers to as crisis's 'blind spot' (Roitman, 2013, p. 11).

<sup>&</sup>lt;sup>73</sup> A British Medical Association Survey of GP work life balance recorded that out of the 2030 practitioners who responded, just over half said they were currently suffering from depression, anxiety, stress, burnout, emotional distress or another mental health condition. Of these, one in five said they were suffering 'worse than before the start of the pandemic'. High levels of attrition in the general practice workforce are a long-standing problem. Dyson, M. (2021). *Pressures in general practice*. The British Medical Association. Retrieved 10 December 2021 from https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice

This is the insight that crisis represents a point of view which is often not viewed or observed itself. Staying in contact with what is missing from this point of view might enable healthcare workers to make judgements that question the appropriateness of organising all healthcare around the imperatives set by crisis. For example, Iona Heath's insistence on staying in touch with ordinary dying frames a needful but difficult question about what we are willing to keep losing in exchange for another round of survival at all costs. Seeing drag as generative can also lead to multidimensional ways of thinking about delay and waiting in healthcare. For instance, delays in referring patients for cancer tests during the lockdown could also have been a way for doctors and patients to collude together in not having to enter the fray of another grand survival saga in addition to the one that was already playing out. This might mean that to hang back or not, when faced with the prospect of having to move on, is not a straightforward choice. There is more at stake than life or death. This is more suggestive of a type of hold like the one described by Isabelle Stengers, 'it involves a body-to-body relation to the world, which has a relative truth' (Stengers, 2015, p. 15). If we can talk about drag as a hold that endures over time, then perhaps we can also talk about the qualities that a body-to-body relation would need to have in general practice, to survive the destabilising effects of crisis-like states in the healthcare system.

## Chapter 6

# Wearing Out, Care at the Limits of what Medicine can do

This chapter looks at the forms of care that are available to practitioners in situations where medicine is limited in what it can do to intervene in a person's wearing out of their own resources for life. It expands on the concept of the ordinary introduced at an earlier stage of the study in association with nonprogressive time. The first part of the chapter conceptualises what it means to wear out the body, drawing on the work of Georges Canquilhem, Lauren Berlant and Alison Kafer, amongst others. I go on to describe the unique historical context for exploring what it means to care at the limits of what medicine can do. The remainder of the chapter is given over to the discussion of cases based on practitioner accounts of overseeing unstoppable decline or deterioration in a patient's condition. These cases adhere closely to the accounts of two general practitioners, Peter and Ben, and are drawn from a series of interviews carried out during the lockdown period of the pandemic. They offer a new understanding of waiting from within the NHS, one in which people can be thought of as waiting not for cure, but for the next stage of pain or physical decline, or death. When defined in relation to this kind of waiting, care describes a practice of watching over, as people are 'wearing out'.

#### 6.1. Introduction

Seth has lung cancer, bowel problems, vascular malformation, a severe kind of knee pain amongst other kinds of chronic pain. Ben says, "it's as though his body is torturing him." Seth is not very old but in recent years, his health

problems have been mounting up. There is only so much that Ben, his GP, can do. He had wanted to arrange for Seth to go to the hospice for a while, "not because this is end of life, but because they are so good at symptom control". Seth is strongly opposed to the idea. Time goes on. Ben visits Seth at home every few weeks. He registers and records all the signs and symptoms, notices when there has been a deterioration, follows the cancer updates after each hospital appointment, sees the overall picture of decline and does what he can to help to bring the pain down. On each occasion of visiting Seth, he sees that the pain is not within manageable limits, but all he can do is to keep exhausting the options, and offering the option of the hospice if things get worse.

(Based on a GP's recollection shared during an interview, Winter 2020)

In medical terms, breakdown in a body is usually viewed as an exceptional event. It can be a sign of health crisis which breaks with the ordinary, alerting us that help is coming too late, or not early enough, or a sign that something has suddenly become unsustainable in its current form. However in their routine, everyday work with patients, the breaking down of a body over time, made perceptible as a long process of 'wearing out', can be something that practitioners are aware of, not necessarily as a disaster to be averted but as a predictable ongoing event. In this chapter, two practitioners describe inevitable wearing out happening as the result of circumstances beyond the reach of medicine, but also as the result of living and of 'life-making gestures' which 'wear on life, sometimes dangerously' (Garcia, 2015, p. 388). They show general practice sometimes having to position itself neither for, or against death and degeneration, but within the machinations of ordinary 'death in life' (Garcia, 2015, p. 316). As a condition worsens, they make episodic attempts at mitigating symptoms and slowing down deterioration, but they might also watch over, bear witness, or accompany patients into the unknown, after medicine has reached the limit of what it is able to do.

My focus is not the clinical or existential quandaries that are opened up by what Sharon Kaufman names as the 'ordinary medicine' complicating our approach to the inevitable (Kaufman, 2015, p. 199), but on how generalist medicine can be complicated by what is normal in the form of people who are dying or who are permanently fatigued by life, or who keep on relapsing, or who do things that are bad for their health. I use the term ordinary in this context to refer to what Lauren Berlant names as 'the long-term problems of embodiment' (Berlant, 2007, p. 764) that can defy the unrealistic expectation that health systems, even when run properly, will be able to prevent disease and dying. 74 This could include individual cases like Seth's, where conditions accumulate without anybody being able to stop them from getting worse, but it could also include the collective conditions of being worn out or broken down that have long been the norm in general practice consultation rooms, like the 'gradual slow wearing out that comes with having to endure everyday hardship' (Wilkinson and Ortega-Alcázar. 2019), 'Ordinary' for the NHS also includes the present-day condition of the NHS itself, whose collective, racially diverse 'body' materialised during the pandemic as exhausted, overworked, and sometimes dying or fleeing the workplace. Based on the experiences of two general practitioners, of carrying on with their routine work during this time, my aim is to look closely, if fleetingly at what it has meant for them to oversee and to try to organise unstoppable decline or deterioration on behalf of a healthcare system that derives most of its authority from scientific practices which claim to be able to ward off death and breakdown. If it is true that the NHS, in addition to improving health, is looked to unconsciously to 'keep death at bay' (Obholzer, 1994) especially at a time of crisis, then this might represent a small attempt to reinsert the temporalities of dying back into general practice in order to reclaim their ordinariness.

<sup>&</sup>lt;sup>74</sup> For Anton Obhlozer, the demand that the health system should prevent disease and dying is one of the unconscious social demands fuelling unrealistic policies. This is the reason he refers to the NHS as the 'keep death at bay service' (Obholzer, 1994, p. 171).

## 6.2. Wearing Out

The provisional term of 'wearing out' draws on the idea of human life as biological life, sensitising us to how we are handling (and wearing on) living matter. But it is also intended to serve as a reminder that to be physically worn out by life and by time, is a relentless, unavoidable experience. In their work on the embodied wearing away of the poor American subject under capitalism, Lauren Berlant offers us a language (which includes the term 'wearing out') for speaking about the relationship between time materialised as living on, and the gradual attrition of the human subject. Amongst the different arrangements of this relationship that Berlant experiments with, is their concept of slow death. Slow death accounts for how the deterioration of a population can be a defining condition of the experience of living on under late capitalism, but because it can take effect so slowly and in such mundane contexts, we can fail to recognise and to be alarmed by the violence of what is unfolding before our eyes. It prospers, in what Berlant describes as 'that domain of living on, in which everyday activity; memory, needs, and desires; diverse temporalities and horizons of the taken-for-granted are brought into proximity' (Berlant, 2007, p. 759). The causes and effects of slow death can be so enmeshed in the ordinary activity of just getting on with life, that it does not take the form of anything that we might understand as a traumatic event. Its precise forms have been worked out with reference to American lives, environments, memories, habits and desires, but as Berlant points out, this is only in so far as it takes on specific shapes in present day USA. The dynamic of wearing out slowly but fatally, is locatable not only in the United States at the turn of the twentieth century but in any domain, including in the UK where 'dying and the ordinary reproduction of life are coextensive' (Berlant, 2007, p. 759).

The existence of a national healthcare system which is at least in principle still free at the point of access, does not significantly alter the climate for slow death in the UK. Here, as in America, sickness is defined as the inability to work. Whole populations are made dispensable by capital's labour regimes. Poorer bodies live

shorter lives and show signs of what Berlant refers to as 'structurally motivated attrition' (Berlant, 2007, p. 759). General practice is still an interesting proposition to place alongside the conceptual event of slow death, perhaps because it claims to be concerned with the whole life of the patient and not only their symptoms. A historical commitment to 'Cum Scientia Caritas' (science with compassion)<sup>75</sup> means that its practitioners have always been positioned somewhere between regarding life as an object of science and regarding life in this more anthropological sense, as what Didier Fassin refers to as the matter of an existence, delimited by birth and death—life as it is lived by human beings (Fassin, 2015).

## 6.3. Life Before a Vaccine

Between July 2020 and March 2021, most general practices (or those that could) stayed open, though with restricted access to limit the ongoing risk of infection. Not knowing how long this new socially distanced way of life would last, and as a way of trying to stay in contact with the day to day, I continued to speak remotely with the two general practitioners whose surgeries would have been the ethnographic sites for my study had the pandemic not intervened when it did. In snatches of time during lunch or between appointments, and often following several failed attempts, I spoke with Ben from where he was based in his large inner-city East London Practice, and with Peter from where he sat in the consulting room of his smaller Practice in rural Devon. This was during the period which began just as the first shock of the pandemic was subsiding, and which ended during the first months of living in the cross currents of the virus, the vaccine and their innumerable aftermaths. It would have been easy for these conversations to have been swallowed up by the most recent news about Covid-19 and I tried to keep the focus on the processual present, not steering towards or away from pandemic related matters. This sometimes required me to trip myself out of my own fascination with the crisisinspired view of NHS general practice from this time. So when Ben asked, 'would

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<sup>75 &#</sup>x27;Cum Scientia Caritas' is the official motto of the Royal College of General Practitioners

you like to hear about covid patients, or non-covid patients?', my answer was that I just wanted to hear about whatever had become normal, routine and ordinary right now. I wanted to know what it was like to be carrying on amidst a general feeling of not knowing how, and to conceive of a space for 'ongoingness and ordinariness' (Berlant, 2007) — to see what might come into it.

Having visited both of these Practices at a time when I was still able to, I was aware of how differently situated they were. The surgery where Peter works is located just steps away from the only bus stop on the main street of a tiny village in rural Devon. It stands out as being larger than the other buildings on the street and more modern. Many of the people who go there are local people who were born in the surrounding area and have lived there ever since. They are usually financially secure, often (though not always) seeking help with caring for age-related conditions, either their own or somebody else's. The catchment area is large and sparsely populated, and the team of practitioners and administrators is relatively small, four doctors and two practice nurses. The reception doubles as a dispensary and many of the administrative staff are also trained as medicine dispensers. By contrast, the surgery where Ben works sits halfway down a crammed residential street in East inner-city London; a large business-like building with tall glass fronts and edgy modern design. In the part of this Practice that is open to the public, there are two floors with light filled waiting rooms on both. The patients who used to be sat in them whilst they waited for their appointments were from all different backgrounds and nationalities: English, African, Caribbean, Eastern European, Turkish, Kurdish, Vietnamese. Most were not wealthy. Many would be probably be classed as being in poverty, particularly if they happened to be Black. <sup>76</sup> At the time these conversations were taking place, both waiting rooms would have been virtually empty. The people who would usually have been sat in them, were sat in their homes, calling up to speak to practitioners over the phone as they had been told to do.

<sup>&</sup>lt;sup>76</sup> This is partly based on a survey of poverty in this London Borough showing that almost half of all the children living here are classed as being in poverty after housing costs, and these children are significantly more likely to be Black. Trust for London. (2022). *Poverty and Inequality Data for Hackney*. Retrieved October 2022 from

https://www.trustforlondon.org.uk/data/boroughs/hackney-poverty-and-inequality-indicators/

In the Summer of 2020, lockdown measures had been eased against the advice of scientists. As predicted, within only a short time, the numbers of those testing positive and dying from Covid-19 soon started to creep up again.<sup>77</sup> In his address to the nation on the 31st October, the Prime Minister deployed all the conventions of crisis as the preferred mode of narrating ongoing events. The "medical and moral disaster in the NHS" was said to be imminent but still avoidable.<sup>78</sup> Reaching for the oldest devices of his profession, he announces that what is called for is a singular moment of decisive judgment between the alternatives of life and death.<sup>79</sup> If we go back into lockdown now, he says, we can bide ourselves more time in the "realistic hope of a vaccine in the first quarter of next year". 80 The alternative is that Covid-19 continues to spread, hospitals are overrun, and oxygen supplies eventually run out. In the speech, care is only thinkable as that which ensures our best chances of survival. As a resource, it cuts off at the exact moment when the oxygen runs out. After this, there is only the terrible end game of doctors and nurses choosing which patients to treat: "who would get oxygen and who wouldn't. Who would live and who would die?" In the Prime Minister's words, when this happens, "for the first time in our lives, our NHS will not be there for us".81

Writing during the pandemic, Isabelle Stengers objected to what she called 'the refrain of this time': that 'until the scientists prove it, everyone has to say, 'we don't know' (Stengers, 2021). Whereas the time of waiting for another lockdown to end might be an opening for what Lisa Baraitser and Laura Salisbury describe as, '-

<sup>&</sup>lt;sup>77</sup> On the 28th October 2020, eleven European countries reported that they had recorded more cases and deaths from coronavirus in the last 24 hours than since the pandemic began. Aspinall, Evie (2020) COVID-19 Timeline. British Foreign Policy Group. Retrieved May 15 2022 from https://bfpg.co.uk/2020/04/covid-19-timeline/

<sup>&</sup>lt;sup>78</sup> Johnson, B. (2020, October 31). Prime Minister's statement on coronavirus (COVID-19): 31 October 2020. Prime Minister's Office. Retrieved March 2022 from https://www.gov.uk/government/speeches/prime-ministers-statement-on-coronavirus-covid-19-

<sup>31-</sup>october-2020 (line 33).

79 The *calling* for a singular moment of decisive judgment between alternatives is one of the

narrative devices of crisis that Janet Roitman identifies in her book, Anti-Crisis. (2013, p.15).

80 Johnson, R. (2020, October 31), Prime Minister's statement on coronavirus (COVID-19): 31

<sup>&</sup>lt;sup>80</sup> Johnson, B. (2020, October 31). Prime Minister's statement on coronavirus (COVID-19): 31 October 2020. Prime Minister's Office, (line 106).

<sup>&</sup>lt;sup>81</sup> As above, (line 47).

waiting that is the management and mitigation of a future threat, but also a time of care in and for the present' (Baraitser and Salisbury, 2020, para 1), Stengers warns that by making science the arbiter of hope for the future, we risk rendering ourselves incapable and unauthorised to respond to the needs of the present (Stengers, 2021). Waiting on these terms inclines us to wait for care to happen. We wait to become the beneficiaries of the life-saving potential of innovation and public/private partnerships. Or, we wait to be given assignments that enact responsibility on behalf of something or somebody else. Stengers wants us to understand that this is not a struggle against the sciences and their practices, but against science as an institution that takes upon itself the authority to enlighten others about their own capacity to respond.

One of the poets of the lockdown, Gonçalo M. Tavares, visualises global epidemic temporality in his description of 'a century with its mouth agape'. In this poem dated 13<sup>th</sup> April 2020, Tavares conveys the sense of a world future that might not form, and of waiting for a solution to fall down to earth from above.

'They are talking about three vaccines and about the impossibility of a vaccine.

We ought to stop and look at that doctor Christ in Rio de Janeiro.

The whole century, as if it were a person, sitting mouth agape looking at Christ dressed as if the city below him were a hospital.

The century with its mouth agape.

(...)

If a new Christ comes let him be a doctor, they're asking these days.

They're asking for a medicine or a vaccine.

We cannot bear to stay home any longer'.

(Gonçalo M Tavares, 2020, 13th April 2020)

The doctor Christ who appears in the poem is a reference to the Christ the Redeemer statue in Rio de Janeiro and to its illumination on Easter day in 2020, adorned with

a doctor's white coat and stethoscope. This was intended as a tribute to the healthcare workers who were putting their lives at risk by going to work in hospitals, but as Tavares notices, the image can also be associated with a kind of waiting that actually delays care for the present. In the poem, the statue does not inspire the city to pay attention to what is happening. It compels them to look up in expectation; to keep asking for a vaccine; to fixate on whatever they think might make the future unfold; to fixate in particular on the figure of the doctor in a white coat. In contrast to this, situated between science and the everyday, the figure of the general practitioner is at odds with the idea that science, or medicine can ever fully deliver us from an unbearable present. These doctors are not spokespersons for Science, nor are they actively associated with 'arrangements decided in high places' writes Stengers. Rather, they are 'close mediators' who are 'first and foremost caregivers' (Stengers, 2021). As mediators between medical ways of knowing and embodied experience, they might be in a position to gage the possibilities of medical science for slowing down or preventing the inevitable in the form of sickness, decline, breakdown, or death, but their embeddedness in everyday life means that they are often in situations where the potential of medicine is limited, or nonexistent even. Their authority in these sitations is supposed to derive from the trust of their patients.

#### 6.4. The Disabled Present

Disability theorist Alison Kafer has thought and written at length about time and disability, the lived present, and disabled futures in the making (Kafer, 2013, 2021). Along with others including Ellen Samuels and Elizabeth Freeman (2021), Sarah Lochlann Jain (2007), Eli Clare (2017), she has written from personal experience about how the progressive temporalities offered to disabled people tend to conceive of disability and illness in linear temporal terms. A 'cure-driven future' may be well intentioned, but it imposes a temporality that has the effect of pushing disabled bodies and minds out of time, positioning them as 'always on hold, in limbo, waiting for the cure to arrive, and as not fully existing in the present' (Kafer, 2013, p. 44).

Crip theory offers another way to think about the time of living on in a present that is frustrating in part because it has forced us to experience our bodies as limiting, slow to adapt, inconvenient and caught in limbo. As a counterpoint to the kind of waiting that places its hopes in the idea that disability is temporary and correctible, Elizabeth Freeman, writing from this perspective, offers another way to remember the pandemic before the vaccine as the moment when we were all living in crip time. This was when 'those who had lived previously with the privilege of normative ability began to learn what sick and disabled people have known forever: that crip time isn't easy, it isn't fair, it cannot be reasoned with' (Samuels and Freeman, 2021, p. 247).

Without rushing towards the expectation of a future of no cure, crip time normalises the state of having no vaccine and no other, more masterly body to return to. This might be part of what makes crip time 'not easy' to live in that there is nothing to wait for except more of the same. In Kafer's work however, this is the temporality in which the disabled present can begin to fully exist. In her meditation on this, again written during the pandemic, she invites us to consider experiences of waiting as the time of slowly wearing down as one waits for even more violence to come. 'For many the waiting is not for treatment but for (additional) injury, for (more) trauma, for (quicker or slower) death—waiting for the disability that is coming, unfolding, already under way....' (Kafer, 2021, p. 421). Most of the general practice encounters described by Peter and Ben do contain elements of this other kind of waiting in which they seem to be expecting and planning for the likelihood of more incapacity, more injury and more dying.

In this next section, I turn to the cases of Giulia and Rita. Giulia has a diagnosis of chronic depression and Rita's health has been declining steadily for some time. Both are long term patients of the Devon Practice where Peter has worked for many years. These summaries are based on his words to me during our interviews in which he relates some of what had taken place in their most recent appointments.

## 6.5. Giulia and Rita: Seeing many Afterlives

When Giulia called Peter at the surgery this morning it was to tell him, "I've been cured!" She had been on an NLP (neurolinguistics programming) course and "it had worked!" So now she wanted to know, could they stop her medication straightaway? When Peter hears about the cure, he is "impressed". He tells me, "NLP has changed her mind-set completely. It sounds good. So that might improve things, for a while". He is wary though, of the idea of stopping Giulia's medication altogether. "We talked about it. You don't question why you might take medication for a long-term health condition like diabetes, so why question taking anti-depressants? It's the same". When I ask him how long Giulia has been coming to see him, he says, "oh, years. She goes through episodes – she will have crisis moments, like when family die... This is the kind of thing that brings on a crisis. Then she gets better for a while". He talks about that part of his work that involves "watching an episode unfold" and learning to read the signs so as to avoid making the same mistakes again the next time it happens. "When people go to see their GP, they're cross referencing with you. They want to know "is this the same? Is it different? Do we do what we did last time? Or is it different this time?" You want to be able to reassure somebody that they've been through this before". I ask him how he feels about the prospect of carrying on with this approach to caring for Giulia indefinitely, watching one crisis episode unfold after another. He says, "that's what makes the work rewarding. The repetition of a cycle is reassuring. You know what to expect and how to help because you've seen it play itself out before".

Peter describes watching as Giulia's depression unfolds - learning from what happens, storing it in his memory for future reference. I picture him going along with her through another mood cycle, reflecting the past back to her, looking at what stage they are at now, compared with 'how this has played itself before'. One of the assumptions built into his own practices of care is that most people get better, or go

on, not forever, but for only 'for a while', suggesting that there are always more episodes of care to come, if not straightaway then in a few weeks, months or at most, after an interval of years. This relates to the aspect of wearing out which has to do with the consideration given to the question of what happens 'afterwards?' What futures are made possible by the latest episode of care, medication, therapy? What contingencies are likely to arise in association with them? Not all therapeutic practices are inclined to think about what happens 'afterwards'. The operative assumption of NLP 82 for instance, is that human beings already have everything that they need to make a full recovery, and that getting better is just a case of activating these potentials. As 'impressed' as Peter is with the positive mindset that this seems to have inspired in Giulia ('it sounds good, so that might improve things for a while'), his inclination is still to be wary in relation to her future and to stay open about what she may still yet have need of. He thinks cautiously for instance, about what could happen if she were to stop taking antidepressant medication altogether and he advises her against this. 'We had a long chat about it, and about stopping the medication not necessarily being an aim...'. Ultimately, Giulia may decide that she has no further use for any of these long-term practices. At any point, she might stop taking her tablets, break ties with Peter and lose contact with the surgery altogether. But then, another episode can start back up again whenever Giulia feels the need for it. In theory there is no end to how many episodes of wearing out might be required but the vulnerability of this as a practice is exposed when it becomes apparent that Giulia, who is the intended beneficiary of all this careful attention, has been waiting all along for a treatment that 'works'.

Episodes of care in general practice can erratically fall apart and come back together again and there is usually no way of measuring how much of an endeavour has gone 'into the ether', and how much 'has gone inside'. In *The Clinic and Elsewhere*, Todd

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<sup>&</sup>lt;sup>82</sup> Neurolinguistic programming. This is a therapy mostly used for personal development purposes but sometimes also to treat health conditions including depression without the need for continuity of care. It rests on the claim that there is a connection between neurological processes, language and acquired behavioural patterns, and that these can be changed to achieve desired goals in life. Bandler, R., & Grinder, J. (1975). *The Structure of Magic*. Science and Behavior Books.

Meyers uses the term 'afterlives' to refer to the places 'at the epistemological threshold of therapeutics, where knowing ends' (Meyers, 2013, p. 34).

'This concerns the notion and limits of cure, of healing, and what stakes (and claims) are at work in defining success and failure—and, fundamentally, how the question of time relates to evidence'

(Meyers, 2013, p. 35).

Peter is already asking himself about the afterlife of NLP in Giulia's case, and what will happen in the weeks, months and years following the 'damascene moment' that it has helped to bring about. He cannot know in advance what will be needed when the time comes, if anything, but he anticipates that the resources of the moment will exhaust themselves and that he will still be there when they do. If there is such a thing as a 'bedrock' quality to NHS general practice, perhaps this is it. Giulia can always return to make use of its practices of accompanying, remembering, reflecting, 'tinkering' (Mol, 2008), after the potential of all the other options for total healing have been exhausted.

One of the accusations levelled at private general practice is that it has lost the habit of needing to care about what happens 'afterwards'. GPs in East London have spoken recently about how in private practice, where patients can always be told to go back to their NHS GP for following -up, monitoring, reviewing, starting over, there is not the same obligation to consider the consequences of making a prescription, a diagnosis or a recommendation (Carter, 2022). Unable to wait any longer in the NHS queue, patients might decide to save or borrow the money to pay for a private assessment, but once a diagnosis has been made and drugs<sup>83</sup> have been prescribed, they will need following up, sometimes with 'regular ECGs, blood tests and monitoring'. As a result of their private consultant deciding not to know about what

<sup>&</sup>lt;sup>83</sup> NHS GPs draw particular attention to their role in monitoring the side-effects of amphetamine based drugs which tend to only be prescribed by private doctors following a diagnosis of ADHD. See *Private Providers Making the Most of the Pandemic* (2022) Pulse Today. Retrieved Sep 2022 from https://www.pulsetoday.co.uk/analysis/cover-feature/private-providers-making-the-most-of-the-pandemic/

the consequences of their practices may have been, the patient returns to the NHS with healthcare needs that they did not have before. Allowing an episode of healthcare to be cut off like this just, at the point where it begins to have unforeseeable consequences, is like making an attempt at healing but then deciding to abandon it half way through. By comparison, Peter's modest claim might be that he takes responsibility for continuing to know about the effects of care, on care.

Peter is seeing Rita this afternoon. He describes her as "a little old lady – in her late eighties. She looks very small but this is because she has back problems, osteoporosis". For a long time, Rita has been the sole carer for her husband. He is dependent on her for getting him up, dressing him, feeding him, and helping him to walk and bathe. She has always declined any offers of outside help. She has wanted to do it all herself, "...she'd get up, work all day; dressing him, helping him to walk, feeding him. Then she'd go to bed, get up and do it all over again the next day." In recent months, Peter has noticed that Rita is getting more visibly worn out. She has lost weight. Her back pain is very bad, and there are other, more worrying symptoms. They may be pointing to something underlying. They are in the process of ruling out possibilities. Peter says if it turns out that her problems have an underlying physical cause requiring surgery, then he suspects that her health will decline further and she won't be able to care for her husband anymore. This is her sole concern. "All she wants is to hold their life together for as long it takes – for her to outlive him. She accepts the support that makes that possible". Today, they are sending off blood tests to check for cancer, following up on signs of anything that looked like it might be serious and trying to prolong Rita's life, but as far as she is concerned, this is only with the aim of enabling her to keep doing the work of caring for her husband — "she wouldn't accept anything else". I ask Peter if he has thought about what will happen after Rita loses her husband. He says, "GPs see many afterlives. That what GPs do".

In these scenarios, general practice seems to take place from within an understanding of human life as a continuity requiring daily effort, sometimes with dangerous and disastrous consequences for health. In her work following the lives of families struggling with heroin addiction in northern New Mexico's Española Valley, Angela Garcia observes the 'wearing on life' that happens as 'the articulation of daily efforts to maintain and increase one's hold on life, while acknowledging the uncertainty and risk such efforts entail' (Garcia, 2015, p. 318). 'This wearing is not, in my view, a form of "cruel optimism" to borrow Laurent Berlant's evocative term for relations of attachment that diminish conditions of possibility. It is the means whereby somebody "holds on to the possibility of life — but with the knowledge that there is no assurance that their efforts will succeed' (Garcia, 2015, p. 316). Peter is too close to what is happening in Rita's world to fail to understand that what is most at stake for her is not life as it resides in the cells or the genes, but life in particular, as 'a matter of existence' (Fassin, 2009). The work that he is doing to try to strengthen Rita's hold on her life, alongside attending to the strain that this puts on her already tired body, is part of this practice that I am trying to describe of staying watchful over how a person wears themselves out, allowing for their 'life's meaningful unfolding' (Garcia, 2015, p. 316). His focus is not only on how she might be supported to manage risks to her health to increase the longevity of her life and wellbeing, but on how to withstand the wearing that might be necessary if she is to keep the 'hold on life' that is the key to its continuity (Garcia, 2015, p. 318).

In this next section, I turn to two different cases concerning patients of the London Practice where continuity is more erratic and it is not unusual for people to move between GPs even within the same episode of care. They are the cases of Joe who is in the process of dying of cancer, and Carrie, who often calls up the Practice to ask for help to deal with problems in multiple areas of her life. These cases are based on my interviews with Ben and they include some of his own words.

## 6.6. Joe and Carrie: Being There, Being of Use

Ben is speaking about his recent visit to see Joe, a man in his sixties who is dying at home. Over the last few months, Joe's body has grown weaker from the metastatic cancer. The signs are visible. When Ben arrives and sees him lying in his bed, he thinks "right, we're in a new phase — the dying phase". There are a lot of practical things to be doing; "...drugs, things like that". He likens this to "gathering the threads" and speaks about trying "to get hold of my final position – of taking responsibility, keeping an eye on him." It can sometimes feel, he says, as though "everyone is a little bit, out there, in my consciousness as a physician. But then you can be thrown into these situations, where the context for what you are doing is suddenly very grave". There is also the reality, which nobody has yet spoken of, that Joe is going to die. They discuss palliative care drugs and Ben describes feeling close to Joe during these moments and wanting to be more involved between now and the time of death. "I feel a kinship with him... a great sense of privilege to be his doctor. To be trying to hold on to his sense of autonomy and ownership over decisions." He hopes that Joe will still be at home when he comes back for follow up in ten days' time. "There is something about bearing witness... trying to get hold of the weight of it – the symbolic quality of it.... I can bear witness... be around for if he wants to talk". Ben says that he feels responsible for bringing the subject of death up in the presence of others. In the end, he finds that on this occasion, for some reason he is unable to. "I don't know whether it was for lack of courage, or for lack of resolve I couldn't bring it up....". There are still treatment options to defer to; one other chemotherapy drug left to try, and the oncologist will be in touch to discuss this, but before he leaves, Ben advises Joe privately that "the moment for this drug might have passed".

When I ask Ben what he believes his patients are expecting from him in situations where they have reached the limits of what more medicine is able to do for them, he

describes feeling as though he has been thrown on to a scene, and of having to make sense of what he is there to do. He wants to be of use, but whether he can be or not depends on the potential for others to take up his offer to 'use me'. In the case of Joe, a 'white working-class man' who is dying of cancer, the experience of being a doctor who is 'thrown' into a so a 'grave context' as the home of a dying man, sets up an encounter in which Ben feels as though he is playing out a 'centuries old' role. You are 'the representative of a profession for whom this is very well trodden ground'. The scene itself — of dying, seems to have the effect for him, of activating some kind of deeper potential for a mode of care that cannot be articulated as the practice of anything in particular. John Berger also places this form of care in the medical tradition of 'witnessing'; '...when we call for a doctor, we are asking him to cure us, and to relieve our suffering, but, if he cannot cure us, we are also asking him to witness our dying' (Berger, 1967/1997).84 But for Ben, the purpose of the visit is far more elusive than this suggests. After reaching the limits of what more science has been able to offer to the situation, it is not what he knows or what he can do that can be of use to Joe and those around him, but more just the fact of his being there, inhabiting the role of somebody whose usefulness is not in question. The experience is one of being passively 'imaged' into a role that he must wait to be given, and then of not being able to say how exactly he is owning that role. It is an offer of use, in the hope that this will be picked up and transmuted into something genuinely helpful and meaningful in some unquantifiable way.

Ben is speaking over the phone to Carrie. She is not his patient but it fell to him to take the call today as he was on duty. He knows Carrie does not stay with one doctor. Ben says that this is because her life is so chaotic that sticking with just one is difficult. In her case, he says, "there is no 'conventional use' of the NHS". "You try to build continuity back in, but it

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<sup>&</sup>lt;sup>84</sup> The full quote alluded to by Ben when reflecting on what happens during witnessing: 'when we call for a doctor, we are asking him to cure us, and to relieve our suffering, but, if he cannot cure us, we are also asking him to witness our dying. The value of the witness is that he has seen so many others die … He is the living intermediary between us and the multitudinous dead. He belongs to us and he has belonged to them. And the hard but real comfort which they offer through him is still that of fraternity' (Berger, 1967/1997, p. 62).

will often be thwarted". Carrie is diagnosed with depression but she usually has more than one problem to discuss. Telephone conversations tend to be long and unfocussed. The call might be regarding her children's health, or her own "mental health things" as Ben puts it. This might be why, when he thinks of her, "there's just this blizzard of problems." I ask him, "why do you think Carrie calls the Practice so often? What is it that you think she wants or needs from you?" Ben says that this is "a really difficult question to answer". He speculates about what this could be, "...a better life? A lift in the heaviness of her mood? For me to stop her children from being ill?" On this particular day, Carrie has a specific request. She has asked him to forward a letter of evidence to the council confirming her family's vulnerable status. Her hope is that the letter might help to delay or put off the eviction that has been hanging over her for months now. Once this has been agreed, she has other things that she would like to discuss. Most of them are problems with life in general. They include: a bad relationship, dealing with social workers, rent arrears, childcare. I ask Ben if he can remember any of his actual words to Carrie during this phone call. Ben thinks he might have said something like, "let's unpack it then - these multiple things. Right, let's separate them out." As he is saying this though, he is not sure what he is going to do with all the information. "What can I do in twenty minutes? I can give her my time, my absolute attention.... She might say something – I listen to it – it goes inside – has meaning: it's not just transactional". He describes their encounters as "having the emotional temperature of somebody depleted in every way".

What does it mean in practice, to go on 'being responsible for the problem' in those areas of a person's life where medicine is either falling short, or where it has run out of potential to intervene in the forces that wear on one or more lives? In the case of Carrie, whose problems are believed to exceed what more medicine is able to do for herself and her family, the offer of another episode of care, this time to screen her son for symptoms of ADHD, is just one of the ways that Ben tries to enact what it means to be capable of responding. If this feels to him like deferring to concrete,

medical things', perhaps this is because in reality, he does not really know exactly what it is that Carrie wants or hopes for from their encounter, 'a better life...?' His commitment to doing something (anything) for her seems to stem more from his sense of her as somebody who will continue to need help, who is 'really just clinging on by her fingertips'. In a situation of such protracted desperation, the medical justification for more involvement is only one of the factors in the equation. For Ben, it seems to be more a question of how Carrie can make use of the encounter to get some small part of what she needs. The clearest indication of this is when he formulates his response as a practice of giving her 'myself', but with no guarantee that this will 'work'. In effect, he is saying to Carrie, '...you have terrible problems, but I can give you myself. Sometimes it doesn't work'.

'Use' as an idea in general practice is a problem for medicine understood as the application of scientific knowledge, although it has its own small tradition within the NHS carried over from psychoanalysis. Michael Balint's advice to general practitioners for instance, was always to 'let the patient use you!' (Balint, 1957/2000).<sup>85</sup> But in these case scenarios, Ben's inclination to be of 'use', seems to be as much the result of his not knowing what else he can do, as it is the enactment of a certain commitment to go on 'being there'. He speaks about this in terms of a sense of 'ownership', or of 'feeling responsible' in relation to the 'all the other things that are going on' in a person's life, not just the things that show up when you look at them 'in a purely medical light'. This is one of the qualities that he thinks distinguishes his orientation as a GP from that of a vascular surgeon or a respiratory consultant. 'Specialists can apply their medical know-how to patient information and decide not to respond to a request without feeling in any way responsible for the problem of what to do about the situation'.

'Use' also implies wear, as in the wearing on a person or a workforce that happens when they are used or employed for purposes not necessarily their own. During this

<sup>&</sup>lt;sup>85</sup> Balint was echoing Donald Winnicott's request to his patients to 'use me'. Winnicott, D. W. (1969) The Use of an Object. *The International Journal of Psychoanalysis* 50(4). United Kingdom: Institute of Psycho-Analysis: 711–716.

time, when many more people than usual were dying at home and every physical contact carried a risk of infection, the delegation of most home visits to practice nurses and healthcare assistants was perceived by some of these nurses as being akin to offering them up for use in place of a doctor. A few have since spoken of their resentment towards GPs for 'hiding in their offices' whilst they had no choice but to 'be there', carrying out the material labours needed to keep people alive. As one nurse expressed this; '...it kind of makes me feel like, well, their lives matter but mine doesn't, you know?' (Russell et al., 2022, p. 5).86 To be in a position to ask, 'how may I be of use?' may be a luxury reserved for the few NHS workers who can afford to be theoretical about what use might be made of them by a patient.

#### 6.7. Episodes of Wearing Out

During these conversations with Peter and Ben between June 2020 and early 2021, I learned that much of what counted for them as routine healthcare work fell outside of anything that could be described as practices of medicine. Though many of the patients they consulted with already had more than one diagnosis with treatment plans that included the long-term use of pharmaceutical drugs, there were often other, stronger forces in play, complicating their successive attempts to provide healthcare in the shape of prescriptions or advice. Sometimes, these other forces would spill over from other domains of a patient's life cancelling out the promise of therapies in advance. In other cases, they might issue from the nature of the condition itself which it could just be beyond the scope of pharmaceutical remedies to suppress or to contain. These limits tended to be taken for granted by the practitioners. When they did register that the potential of medicine for preventing further decline and deterioration had been exhausted, it was as something to be expected and lived with. They registered it as an everyday event ingrained into

<sup>&</sup>lt;sup>86</sup> The practical nature of nursing consultations meant that a large proportion remained face to face during the pandemic. When interviewed, a significant number of practice nurses in England questioned why they were made to go to see patients in their homes during the pandemic whilst GPs were able to stay in the Practice. They worried about the potential for getting infected and becoming sick themselves (Russell et al. 2022).

general practice and expressed casually as a fact of life. 'They come with problems that can't be resolved'.87 Sharon Kaufman makes the observation that 'potential and possibility are what organises how we engage with medicine and the future' (Kaufman, 2015). However, when I spoke to these practitioners about their own practices of medicine, they did not always share this belief in its potential for 'possibilizing' other, better futures. Having followed patients as they passed through one stage of worsening health only to enter another, the promise of general practice sometimes seemed to consist more in its potential for offering to accompany a person through the various stages of a long term illness.

These healthcare encounters are taking place in epidemic time, when all of us were liable to be considered as either 'a sick person or a potential sick person with no third option', which was how Gonçalo Tavares described the situation (Tavares, 2020),88 but when speaking with Ben and Peter, the presence or absence of a pathology in any given case, was almost always inconclusive. Their patients would rarely be either sick, or not sick, dying or not dying, but they might be going through an episode or entering a stage. They tended to speak more in terms of what *stage* of cancer, dementia, or depression was about to be entered into, or about how to handle an episode in a way that might help to mitigate a person's suffering.

'Episodes' in general practice did not only refer to the aggressive surges of positive symptoms that characterised a relapse or a health crisis. They could encompass what Jain refers to as 'the folds of various representations of time' (Jain, 2007, p. 80) that follow on from a prognosis. In the case of Rita, this could include the present time of holding a life together with difficulty, but it could also take in the projected future time of having to live in the aftermath of that life. For Joe, a patient who is

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<sup>&</sup>lt;sup>87</sup> From an interview with a GP, Winter 2020.

<sup>&</sup>lt;sup>88</sup> 'The sickness overtakes the sick person, the doctor, the medical instruments, the hospital, the neighbourhood, the city and the country.

And your head.

The status of observer disappears.

Sick person or potential sick person. There is no third option' (Taveras, 2020).

approaching the end of his life, it refers to the final stretch of time that cannot be deferred any longer, but must be lived out somehow. As a way to organise care over time, the episode has its own internal logic. Through it, medicine, care and contact are modulated in a way that allows medicine to be non-progressive, up to a point. A genre for time that has not yet been made into an event, the episode comes, or 'falls' into everyday life as an interruption. Unlike some other ways of organising care in the NHS, 'pathways' for instance, it has no destination, and its success or failure does not hinge on whether a patient has been moved through to the end or not. It is an addition, a new thread bracketed off from the rest of a person's life. Berlant defines episodes as 'occasions that make experiences while not changing much of anything' (Berlant, 2007, p. 760). Their temporality is digressive which might explain why it is difficult to imagine waiting to access an 'episode of care', but all too easy to imagine waiting to access 'care' as a standalone, self-actualising event. When Giulia finds for instance that more episodes and more digressions are all that general practice can realistically offer her as a treatment for recurring depression, she turns to a different therapeutic practice, one that claims to able to force the event of arriving at a destination. One way to think the episode as a mode of care might be to see it as a method (hodos) for digressing. It can be offered as a kind of enclosure in situations where people find that they are falling out of continuity with themselves, or falling out of continuity with an old life. As nobody really knows in advance where exactly an episode will lead, or what will materialise from it, the practitioner can be somebody who offers to 'hold the thread', as when Giulia's episodes are watched, remembered, recorded by her Practice.

How do these practitioners care from within this time 'of slowly wearing down as one waits for more violence to come?' (Kafer, 2021, p.421). In his formulation that 'to heal is to pay the price for slowing the process of degradation', Canguilhem (1989/2012) suggests that the existence of temporalities in healthcare that unfold away from productivity and calculated progression are 'normal'.

...should we really try so hard to hide from people that it is normal to fall ill from the moment one is alive, that it is normal to heal,

with or without the help of medicine, that disease and healing are inscribed within the limits and powers of biological regulation?

Canguilhem (1989/2012, p. 61)

Likewise, in their attempts to formulate crip time, Kafer, Khúc and others have elaborated on how an experience of waiting for disability, rather than a return to health, might unfold 'beyond, away from askance of productivity, capacity, self-sufficiency, independence, achievement' (Kafer, 2021, p. 421).

The failure of personhood, as we've already learned, is endless. But if unwellness were not failure, if it were not measured by productivity and societal contribution but simply by how unlivable life feels, then perhaps we would be allowed to be as unwell as we need to be —.

Khúc, (2021, p. 384)

This is also how I understand what is so routine about these scenes in general practice. The best intentions of medicine are always being sidetracked by the drama of bodies returning continuously to incapacity, disability and death. In these scenes where we see vulnerability intricately imbricated with hope, practitioners implicate themselves in both the vulnerability and the hopefulness of trying to care for what they cannot repair. They gesture towards what is hopeful about the future, even when there is reason to doubt whether this future will ever come to pass. Quite often for these doctors, it is a case of just 'doing what we can to keep them (the people) functioning'.

When trying to make sense of these scenes, clinical categories that rely on a distinction between the pathological and the normal can be misleading. They hinge on the assumption that to be healthy is to be normal and that episodes of care begin with sickness and end with a return to health and the normal. This presupposes health as the natural state to which we will eventually return, but in conversations

with practitioners, my impression was always that they were waiting for the resources of the moment, however weak or strong they may have seemed at the time, to wear themselves out at some point. This is not the same as saying that practitioners are waiting *for* life to wear itself out. Peter is not waiting for Giulia to relapse or for Rita to break down. But they do commit themselves to following up on whatever happens afterwards in the knowledge that with more living — more 'wearing' and more decline will inevitably follow. In this, they are adherents to Canguillhem's view of the able body as always only temporary, and of an idea of health as totally contingent on forces beyond the reach of medicine (Canguillhem, 1966/2012). This is a perspective shared in part with some crip theorists who have deployed 'as threat, as looming reminder, as the weight of everyday life', the concept of the temporarily able-bodied (Kafer, 2021, p. 421).

#### 6.8. Conclusion

The practices of care that I have wanted to tap into and to draw out of this material are unclean and uncertain, perhaps because they are linked to the tenuous nature of the hold that a general practice can have on its patients. These are all situated practices (Stengers, 2008, p. 44). They represent habituated attempts over time, to respond to the questions raised by finding yourself responsible for how another person is wearing out. Questions like, 'what does this situation demand?', 'which kinds of attention, concern and care are required?' This attention to wearing out is not a replacement for the question of how do we prevent or reverse the violence or the injury or disability to come. It is the mobilisation of a different sort of response to the same predicaments. The practitioners I spoke with were too close to the give and take of living to engage in practices that can only ever affirm life and health. Episodically watching over their patients and hoping to strengthen their hold on life were ways of trying to be of use to them in an atmosphere of depletion and exhaustion whilst accepting the limits of medicine as a practice. The question of how

do we live and die (and wear out) well,<sup>89</sup> held more relevance for them than the prevailing scientific question of how do we prevent wearing out so as to live better or longer?

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 $<sup>^{89}</sup>$  This is also the question that arises out of Kaufman's study of the consequences of having 'made' more time for ourselves in which we are able to wear out more slowly now, than in the past (Kaufman, 2015).

# **Chapter 7**

# Cases of Being Between in the NHS during Times of Crisis

Based on close readings of pandemic blogs authored by general practitioners, this chapter offers an alternative account of what it was like to be on the frontline during this period. It draws on the work of theorists including Ghassan Hage and researchers of race in the NHS including Roberta Bivins and Satnam Virdee, to track a history of ambivalence in the NHS, one that often intersects with the experiences of a migrant workforce. In the main part of the chapter, I investigate two cases of what I refer to as cases of 'being between' in the NHS. Then, in the analysis that follows I make the claim that there is a third 'place' to be as an NHS worker who finds themselves on the frontline in the midst of a national healthcare crisis. This is a further development of the argument that temporalities of suspension, whilst dampening the opportunity for heroic agency can be responsive to the needs of a 'crisis ridden' present in ways that the temporalities of crisis tend to neglect.

#### 7.1. Introduction

In this chapter, I look at two cases of being neither for nor against the NHS but 'in between'. I offer an understanding of this position in terms of how it tries to break with destructive modes of endurance in the NHS and the desire to either normalise them or to become free of them. Based on testimony and with contributions from historians and researchers from the field, the cases assembled here both arise out of the interstitial time of NHS general practice during the pandemic. They are drawn

from the online posts of London practitioner, Dr Roghieh Dehghan Zaklaki and Devon based GP, Dr Katie Musgrave. In one, Roghieh is explaining why, as an NHS doctor who is also an Iranian migrant, she feels unable to share in the hope that seems to have been inspired by the mood of emergency that is sweeping the nation. In the other, Katie is trying to make sense of the recent swelling of support for 'our NHS' coming after more than a decade of political neglect and indifference. By placing these two accounts alongside each other in a discussion about GP experiences of ambivalence towards the National Health Service, I look at the relationship between waiting for the NHS and the different modes for enduring this waiting time afforded to practitioners depending on who they are and where they come from. Towards the end of the chapter, I ask about the forms of care that might issue from Roghieh and Katie's being simultaneously for and against the NHS at a time when they are expected to make personal sacrifices to secure its future. These sources are different from the other sources that feature in this study in that they relate to forms of non-progressive time that are historical rather than clinical.

## 7.2. Being Between

From around April 2020, after the first shock of the pandemic had passed, the visceral feeling of having broken with the past seemed to heal over quickly. However, this did not lead to life in general practice returning to 'normal'. Instead, it felt like something of an in-between time, or a 'hiatus'. For some Practice staff, administrative workers in particular, this period was remembered primarily for its quietness. So quiet and peaceful... it was really nice'. For the general practitioners I spoke to though, the year seems to have passed through three distinct stages. First

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<sup>&</sup>lt;sup>90</sup> This comment was made during an observation of a primary care seminar attended by GPs on 19th June 2021 on the subject of 'primary care before and after the impact of Covid-19'. In fact, general practices remained open during the pandemic but in Spring 2020, the number of face-to-face appointments declined and all the public facing general practice workers I have spoken to about this period comment on the break in the continuity of a routine and the sensation of there being something like a hiatus.

<sup>&</sup>lt;sup>91</sup> The full quote: 'It was really quiet – for us, those that remained. It was really nice. So quiet and peaceful. I really enjoyed working. It sounds bad, but for me personally, it was nice' (From an Interview with a general practice administrative worker, April 2021).

came action, planning and a desire to be at the 'epicentre' of the crisis, volunteering for the newly formed 'covid hubs'92 or doing whatever they could do to help out. Then came the summer lull and a growing feeling of estrangement from patients, some of whom were believed to be isolated with no support. By October, the mood in the surgery had become flat and subdued. Practitioners spent all day on the phone and in meetings which they discovered could be more exhausting and depleting than seeing patients in person for back-to-back appointments. The thought of such an arrangement becoming permanent was felt by some doctors to be depressing; 'blitz spirit fatigue' was how one GP put it. But at the time, it had felt like a flattened out 'new normal,' as though this might just be how things were going to work from now on.

In certain respects, these experiences are characteristic of the temporalities of the pandemic and its strange effects on time. Nobody could predict at this point whether the situation was going to be temporary, or if what some people were describing as 'the break' would forge an opening into 'an entirely new temporality' (Nieuwenhuis, 2020). There was no reason to believe that the suspension constituted by Covid-19's relentless unfolding might not just go on indefinitely. Such questions were unanswerable at a time when people were still waiting to see what would happen. The temporality of the pandemic could make things appear 'in pause' (Nieuwenhuis, 2020), causing the present to feel uncompromisingly stuck and impassable. Getting beyond it was not only a logistical challenge. In a very real but quite inexplicable way, the future had been inaccessible to thought.

The anthropologist Ghassan Hage uses the term 'stuckedness' when writing about the experience of being wedged between progress and immobility. Hage's account of what he refers to as 'a heroism of the stuck' (Hage, 2009) is linked to the human need to find ways of living in a world where opportunities for upward social and spatial mobility become barred to them instigating a crisis of agency. People get

<sup>&</sup>lt;sup>92</sup> Covid-19 hubs were introduced in March 2020 as a way for GPs to offer care and advice to patients with possible symptoms of coronavirus or who were self-isolating as part of a household and needed to urgently see a GP in person.

stuck when social, legal, economic or other long-term, endemic obstacles stop them from being able to imagine that they might be 'going somewhere' (Hage, 2009, p. 97). This leads to the predicament of going nowhere becoming almost like a fact of life, giving rise to the need to learn ways of enduring the non-progressive time that this generates every day. According to Hage, one of the main ways that people are managing to adapt to living in a world where a crisis of agency has become the normal state of things, is through learning how to derive heroic agency from the condition itself, of being stuck.

...it is not what you actively or creatively achieve that makes you a hero but your capacity to stick it out and 'get stuck well', so to speak. To be a hero under such circumstances means to be resilient enough to endure and to wait out your stuckedness. It is the achievement of being able to wait for deliverance so as to come out as a survivor and start 'moving' again.

(Hage, 2009, p.100)

Hage warns that there are consequences for how people adapt to living without forward movement. Those who try to normalise it or to turn it into some kind of achievement, 'as something that one is proud to do' (Hage, 2009, p. 105), might be overlooking what is self-defeating and doomed about it. They may unknowingly be making life harder for those who are unable or unwilling to join in with the endurance test of waiting something out. Failing to adhere to, or stay the course could mark them out as people 'who do not know how to wait out and endure ...like everyone else' (Hage, 2009, p. 105). This way of confronting crisis implies that the condition of being between the stuck present and an unattainable future is the problem of the individual, to be got through in isolation by those who are strong and single-minded enough.

Another writer who has thought a lot about states of being between and how to survive them is the theorist of transgender temporalities, Hil Malatino. In a way that is characteristic of queer interventions into liberal modes of endurance as an

individual achievement, Malatino does not attempt to offer a solution to, or a denial of, what can feel like the 'lag time' of being stuck between genders whilst waiting for medical technologies to be offered. 93 What he proposes instead is that we look to see what other modes of endurance might be afforded by rethinking the time that falls between states of passing and not passing; 'what possibilities open up when we cease to run toward promissory futures from pasts that we're (sometimes, literally) dying to leave behind?' (Malatino, 2019, p. 644). In this trans-specific critique of narratives of progress, Malatino suggests that the time between might not be so hazardous if allowed to form in ways that do not overload the moment of a trans person's 'passing' with so much false promise. It might fill up with qualities of its own to form what he calls an 'interregnum', defined not as a midpoint of a linear narrative but as 'a kind of nowness that shuttles transversally between different imaginaries of pasts and futures and remains malleable and differentially molded by these imaginaries' (Malatino, 2019, p. 640). This may sound promising and alive with new ways to be in 'it' together, but as Malatino himself reminds us, the consequences of relinquishing the attachment to 'passing' as an orientation to the present are not known about in advance. To choose to occupy lag time more fully means to some extent to confront what is so difficult about it; for example, that it involves 'grappling with the negativity that doesn't ever seem to stay planted firmly in the past...' (Malatino, 2019, p. 645).

In the next section, I return to Roghieh and to her account of being an NHS doctor in March 2020, just when the future of universal healthcare that she had hoped to see unfolding appears to be coming instead to a dead-end. Roghieh describes herself as a 'European GP of Middle Eastern background'<sup>94</sup> who has always had a strong sense

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<sup>&</sup>lt;sup>93</sup> A contentious relationship between the NHS and transgender understandings of what it means to 'be between' has come to the fore in recent years. A synergy of long waiting times, plus the waiting that has formed a part of the NHS's therapeutic response to young people experiencing issues of gender identity has placed the NHS at the centre of debates about its own role in the production of a crisis of stuckedness in their lives. For an overview and discussion of the issues: Osserman, Jordan, and Hannah Wallerstein (2022) Transgender Children: From Controversy to Dialogue. *The Psychoanalytic Study of the Child* 75(1). Routledge: 159–172.

 $<sup>^{94}</sup>$  Dehghan, R. Z. (2017). Roghieh Dehghan: A migrant GP on upfront NHS charges. The BMJ. Retrieved August 2022 from https://blogs.bmj.com/bmj/2017/11/10/roghieh-dehghan-a-migrant-gp-on-upfront-nhs-charges/

of ownership of the NHS, but this changed in 2016 when the NHS started to close its doors to some people under the influence of policies of suspicion and scrutiny towards patients on the basis of their nationality. As a migrant herself, Roghieh uses her blog post to describe the experience of being pushed further into the 'in between' during the febrile early days of the coronavirus pandemic.

#### 7.3. Falling Out of Time with the NHS

On the 23<sup>rd</sup> March 2020 just days into the first lockdown, Doctor Roghieh Dehghan Zaklaki explains that only a week ago she was hit with 'a long spell of disorientation and agitation'95 with symptoms of apathy, nausea and weakness. She tells us that she was self-isolating but not because of coronavirus which at that time was the single cause of most employee absences in NHS workplaces. There was no risk of contagion. But her illness was still serious enough to need time for it to take its course. Some time passes, 'a long spell'. This time is not accounted for in the medical sense since it produces no diagnosable illness or infectious symptoms. Yet it must be time in which something is happening because at the critical moment, just as the NHS is being idealised for its capacity to care equally for all who need it, her ability to care for her own patients has been interrupted.

It all started when, like many other times before, I went to my friendly local café for a black Americano and round of toast. Except this time, my breakfast came with an extra serving of 'go-back-home-foreigner' from one of the other patrons. He was convinced that 'foreigners' and 'migrants coming in boats' were responsible for coronavirus as well as for all of the other infections in the UK.

Roghieh does not need to tell us much of the detail of what the man said. We know

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<sup>&</sup>lt;sup>95</sup> All of the unattributed extracts in this section are taken from Roghieh's pandemic blog which as of September 2022 can still be accessed online: Dehghan Zaklaki, Roghieh (2020) Love in the Time of Corona. British Journal of General Practice - Life. <a href="https://bjgplife.com/2020/03/23/love-in-the-time-of-corona/">https://bjgplife.com/2020/03/23/love-in-the-time-of-corona/</a>. The whole blog is also available to view in the Appendices.

that at least some of the time that followed this incident must have passed in her feeling the effects of rage because it was only after 'the haze of rage had receded' that she was able to think and feel differently about going back to work. There was the fall out that an event of this kind will inevitably have in a coffee shop in London that Roghieh an NHS doctor, visits on a regular basis. This includes the immediate reactions of the other customers, some of whom know her. One of them comes rushing to her defence, '...no, no. This lady is doing good work in this country'. But this only leads to one painful contradiction being overlaid with another. 'Who I am is worth nothing, but what I do is worth everything'. These initial feelings of 'rage' might be understood as a reaction to racist practices and experiences during a synthetic moment of national unity, but in its very focus and its energy, Roghieh's anger is productive of more than just practices of 'naming'. To borrow from Audre Lorde's formulation of anger that has its origins in racial injustice, her rage is 'loaded with information and energy' (Lorde, 1984, p. 127). As Lorde goes on to tell us, this anger has potential because it can push a person to think not only about what has made them angry (what they are against), but also about how they might use this feeling in the service of something else, 'anger expressed and translated into action' (Lorde, 1984, p. 127). Sara Ahmed develops this thought in her expansion on the concept of anger as an emotion that is usually characterised by 'against-ness' in relation to something from the past, but that can also be turned towards the future through its demand to be translated.

Anger does not necessarily become 'stuck' on its object, although that object may remain sticky and compelling. Being against something is also being for something, but something that has yet to be articulated or is not yet.

(Ahmed, 2004, p. 175)

In Roghieh's case, the clarifying force of her rage is apparently what pushes her to draw the line between her own definition of 'care', and that of the National Health Service. In attempting to translate the meaning of this for her own future, she formulates the question (an unusual question in general practice), of – 'how do I

love?'

There are some wounds and fractures within the NHS that never seem to reach the point of becoming an emergency. Instead, they turn into something more permanent and in need of ongoing attention and restoration. The experience of being addressed simultaneously as the foreigner and as the NHS doctor 'splits' Roghieh into two. One part of her is resented and regarded with hostility and fear, whilst the other is trusted and reached for by the public in their hour of need.

Those who love half of you do not love half of you, they do not love you at all. They want to split and trim you, they want to amputate and mutilate you. $^{96}$ 

When describing the suffering caused by being loved only in halves, Roghieh is not only writing from her experience of being perceived as an outsider, she is writing directly from her experience of working for many years as a general practitioner. Her hopes for a different ethical code within the NHS have been profoundly disappointed after its leaders opened up the healthcare system to the same unimaginative moves of splitting, fragmentation and exclusion as those that she experiences first-hand in the café.<sup>97</sup> Yet Roghieh's attachment to the NHS may be partly what keeps allowing her to get hurt. If she did not 'cherish' her patients or attach value to the work of the NHS and invest hope in it for the future, then presumably there would be no need for her to endure the 'slaps', 'pushes' and 'disappointments' that staying with it entails. The sting of the slap is that that it seems to hurt and 'push' more in proportion to how much she has invested in it. 'Our political leaders slap me on one cheek and kiss me on the other', 'I cherish my

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<sup>&</sup>lt;sup>96</sup> Roghieh is quoting here a line from the poem 'You' by Erich Fried (1983/2012) In 'Love Poems'. Translated by Stuart Hood. Reprint edition. Richmond, Surrey England: Alma Classics.

<sup>&</sup>lt;sup>97</sup> The 2013 Immigration Bill introduced measures that aimed to make it more difficult for people who do not have the legal status of a UK resident to access secondary healthcare. 'The Immigration Bill will tighten immigration law, strengthen our enforcement powers and clamp down on those from overseas who try to abuse our public services'. Home Office (2013) *Immigration Bill Factsheet: National Health Service* (Clauses 33-34). Retrieved March 2022 from <a href="https://ec.europa.eu/migrant-integration/library-document/immigration-bill-factsheet-national-health-service-clauses-33-34">https://ec.europa.eu/migrant-integration/library-document/immigration-bill-factsheet-national-health-service-clauses-33-34</a> en.

patients, but I am profoundly disappointed in our leaders'.

It would be easy to forget that this is happening during a time when people are more anxious than usual about their own health and about the capacity of others to provide healthcare should they, or those they care for fall ill with the virus. What Roghieh would really like to be doing — what she 'cherishes' the ability to do, is to be able to return to her work as a GP. 'The minute I stepped into the surgery, I could sense a mix of exhilaration, determination, and composure'. The state that she finds herself in now however is one of estrangement and dislocation. All of her earlier optimism about the idea of NHS as a good place to work has rested on the belief that here was an institution that would not deny, 'amputate' or 'mutilate' people who came to it, for the universally understandable reason that they needed caring for. Yet even with the added value that comes with being an 'NHS doctor', she feels that she can no longer rely on the same care being extended to her as she would like to extend to her own patients. 'I have been pushed to the margins before corona and I will almost certainly be kept there during and after corona, too'. As she explains in the post, this is not a new situation that she is having to take time out to learn how to manage. 'To be sure, the bond between me and the NHS started loosening when we started excluding some of the most needy and vulnerable in our society from universal healthcare, when we let the Home Office branch out into our health services'. From her position outside of the centre, Roghieh cannot feel unequivocally proud of the NHS like some of the other healthcare workers. 'The foreigner in me should 'go home,' and the doctor in me should continue to help in the NHS. I am both the beast and the beauty.' But it is from here that she finds that she is able to continue offering the only kind of care that she believes is worthwhile, which is founded on a 'mutual recognition of intrinsic self-worth, '...when the ties with systems loosen, I find myself where it matters most and with those who alone should matter.'

The optimism and attachment needed to sustain the NHS has historically always been harder for some to sustain than it has been for others. In the 1980's, Beverley Bryan, Stella Dadzie and Suzanne Scafe collected the testimonies of Afro-Caribbean women workers for the NHS, many of whom had arrived in the United Kingdom in

response to the call to help to build the new National Health Service after the Second World War. They had arrived in the hope of something; but it is a hope which turns to out to be 'hard to realise' (Bryan, Dadzie and Scafe, 1985, p. 16). In their testimonies, they do not resemble the 'smiling black women in white' who were highly visible in newspaper photographs of NHS scenes from the 1950's onwards (Bivins, 2017, p. 96). They make themselves visible as women whose work is to restore others to health often at the cost of their own health which gets worn down in the process. 'We came into this service, not as potential clients, but as workers' (Bryan, Dadzie and Scafe, 1985, p. 89). They have not been provided with the basic care (time, rest, shelter, security) that anybody would need to be able to realistically sustain themselves through years of hard caring and cleaning work or to tide them over in the time remaining after their retirement from 'the frontline'. Still, Bryan, Dadzie and Scafe continue to be hopeful that the NHS will be preserved, in part because having built it, they believed that Black women had a stake in it and also because in a situation where the NHS is still the only option for essential healthcare, they don't have the luxury of being able to give up on it, '...because we are women, the National Health Service is central to our lives. We cannot avoid using it' (Bryan, Dadzie and Scafe, 1985, p. 90).

We meet Roghieh in a moment of growing concern over which direction the NHS is headed in following the proposal of a Bill (since passed into law) that wants to create further barriers to health care services for people seeking asylum in the UK. As others have shown (Simpson, 2018; Haynes, 2017; Kyriakides and Virdee, 2003; Simpson, Esmail, Kalra, & Snow, 2010), this is not so much a bitter twist in the back story of the NHS as the continuation of a push coming from within the medical profession itself. The NHS has always depended upon migrant and racialised labour to keep it going, particularly in those areas of medicine with the lowest status such as general practice and in those parts of the country with the highest rates of deprivation (Simpson 2018).

'Passing' as a migrant doctor in the NHS has been made consistently more difficult due to the imposition of national and imperial barriers to being received into the

NHS. The fact that most of these barriers seem to have originated from within the British medical profession suggests a different context in which to understand Roghieh's experience as a woman who is positioned one way as an Iranian migrant and in a different way as an NHS doctor. Historically and institutionally, it appears that migrant doctors like her, have not always been wholly 'wanted' by the very people who have most needed and relied upon them as colleagues and collaborators (Kyriakides and Virdee, 2003, Haynes, 2017). Roghieh's experience of being 'slapped' on one cheek and 'kissed' on the other by those in positions of power over the NHS is foreshadowed in the use of internal and external immigration controls by medical authorities. Douglas Hayes writes for instance about how the General Medical Council (GMC) have previously engaged in lobbying for more, not less obstacles to be put in the way of allowing doctors from outside of Europe to practice in Britain (Haynes, 2017). As well as increasing the difficulty level of language tests and clinical examinations at the point of entry, the GMC has repeatedly used its powers of discretion to privilege domestic graduates over those from colonial and other non-European territories, citing differences in the integrity of medical training outside of the United Kingdom (Haynes, 2017, p. 204). Overseas doctors have been regarded with suspicion not only because of doubts over their fitness to practice but also because of doubts over their eligibility to inherit and take forward the aggregated projects of medicine and nation state building. Across the decades and successive waves of migration into the NHS, this suggests a deeper significance to Roghieh's resolve to 'loosen ties with the system'.

In the next section, I move on to Katie's account which she wrote towards the end of the lockdown period for publication on an online GP forum.<sup>98</sup> In this pandemic blog post, Katie shares her reasons for not wanting to join in with 'saving the NHS', after having being a part of a Health Service under threat for so long.

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<sup>&</sup>lt;sup>98</sup> All the unattributed extracts in this section are taken from Katie's blog which, as of September 2022 can still be accessed online. Musgrave, Katie (2021) *But... Hasn't Our NHS Always Been Overwhelmed?* Pulse Today. https://www.pulsetoday.co.uk/views/katie-musgrave/but-hasnt-our-nhs-always-been-overwhelmed/

#### 7.4. Quitting the Battlefield

It is the 24th of February 2021. The UK is in its third national lockdown. The mood in general practice feels very different now from what it was eleven months ago. Patients are filling up all the appointment slots again. Remote consultations are becoming normalised. Clinical and non-clinical workers alike are rolling up their sleeves and helping to administer the first round of vaccinations. Online, a GP from Oxfordshire wonders whether Primary Care will 'after all become one of the pandemic's heroes, the restorers of 'normality'.99 From a surgery in Devon, Katie Musgrave is reflecting on ten years of working for the NHS. She can see that the government is serious in its efforts to prevent the Health Service from becoming 'overwhelmed'. She also sees that there is no line of continuity between what is being done about this now (a lockdown, closures, restrictions), compared to what has been done in the past (in her opinion, denial, silence, neglect). You see, the NHS I've worked in for the last decade appeared – by all accounts – to have been overwhelmed long ago'. She has found herself 'repeatedly pondering' the idea that this particular crisis could really be so extraordinary. Being overwhelmed hadn't felt very extraordinary before the pandemic. Nobody had paid much attention to the damage it did then, so why now? She wants to know what has happened to the other NHS? The one that she had worked hard to 'keep afloat' before the pandemic?

In her blog, we meet Katie in a melancholic, not a battling frame of mind, weighing up the collective costs of having endured 'working beyond safe levels' for so long. She wants to be able to belong to the NHS wholeheartedly. She calls it 'our NHS', 'our beloved NHS'. It clearly is precious to her. But she also sees in it the potential for neglect and a growing indifference to its own capacity to do harm. The only practical response to this that seems to have made any sense to her up to now has been to 'battle'. She writes that, 'long before covid, our health service battled'. For Katie, one

<sup>&</sup>lt;sup>99</sup> Ladds, E. (2021, February 18). *Despite Coronavirus, General Practice is still the best job in the world*. British Journal of General Practice – Life. Retrieved February 2021 from https://bjgplife.com/despite-coronavirus-general-practice-is-still-the-best-job-in-the-world/

of the consequences of having been pitted against crisis in the NHS for years as though it were 'an inevitable pathological state which has to be endured' (Hage, 2009, p. 97) has been the loss of the ability to imagine what might be being missed or overlooked in the meantime. Before the pandemic, healthcare workers were unable to imagine what it might have been possible to care for if things had been otherwise; '...it's felt too hard. We've lacked the capacity to imagine something better'. This war-like way of talking about the NHS through the violent language of battling and resisting defeat goes back a long way. Historian of the NHS, Roberta Bivins reminds us that the exhortations to the public to 'fight' to 'save the NHS', are a continuation of a trope that originated in the 1950's when working in the National Health Service was equated with doing military service (Bivins, 2020). The association with nation building and nation defending have refused to disappear and sacrifice is still arguably one of its main modes of endurance. Bivins writes that the NHS has been a site for sacrifice and public service ever since it first opened its doors up to the public. From the very beginning, its workforce has struggled to catch up with the volumes of 'pent-up ill health' that had awaited it (Bivins, 2020, p.155); ill-health resulting from a combination of mass health and income inequalities exacerbated by the war (Webster, 1998).

From Katie's descriptions, the task of being someone who has battled in the NHS has been to persevere with an ever-increasing workload to the point that they are 'collapsing' out of a sense of duty. In her view, this has been the main mode of getting through the endless stretches of the healthcare system being 'on the brink of collapse'. The amount of work required has been 'unmanageable'. GPs across the country have 'collapsed under the weight' of it. But they had felt that if by working harder and by being more 'dutiful' — that they would somehow 'keep the system afloat', then this would be reason enough to persevere. She writes that 'the comparison to war zone medicine isn't far from the mark'. This is not an evocation of the 'blitz spirit' of the NHS as has so often been the case in popular imagery of the NHS under threat (Bivins, 2020). In fact, it is the opposite. Katie wants us to know that practitioners had not come into this latest crisis as strong bodies with surplus energy and thriving attachments to their work, poised to throw themselves into new

defensive action, but as battle-worn GPs many of whom had considered leaving the NHS long before the arrival of coronavirus (Walker et al. 2019). They had already carried on in conditions that more than half of them had felt were not even minimally good enough. The only reason that the healthcare workforce had stuck with it for as long as they had was because they were so exhausted by the effort required to keep going that they did not have the mental energy to think about how the future might be made differently.

In Katie's blog, the period before the pandemic assumes the aspect of a delayed catastrophic event that has been going on for a long time without anybody seeing it for what it was: 'historic scandals involving other avoidable public deaths...'. She inserts herself and her contemporaries into this scandalous picture of a health service whose willingness to carry on in a mode of helpless endurance has backfired by contributing to the causing of harm. This places the healthcare workforce in an invidious position (when writing about the healthcare workforce, she writes as 'we'). '...we, the UK medical profession, have found ourselves ground down into a position of learned helplessness. There's been too much to change, and it's felt too hard'. Just like in a war, they had needed to put the idea of a good enough NHS on hold whilst they got on with the more pressing task of just surviving. She writes that there were times when it would have seemed 'heretical' to ask whether the NHS was 'good enough'. This might be why it had seemed necessary just then, not to imagine straightaway how things could be better. So, the truth had 'remained unspoken'.

Now, Katie is looking back and taking the long view of how the healthcare system has declined over the course of decades. She regrets that the NHS has had a hard life. It has 'suffered from afflictions' and has had 'deep-seated issues.' Yet as a British GP, she won't allow herself the option of envisioning a future in healthcare without it. Her dream of a fully restored, benevolent NHS is what she imagines herself to be

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<sup>&</sup>lt;sup>100</sup> According to The Tenth 2019 GP Worklife Survey, the number of GPs who said they were likely to quit direct patient care within five years was 37% (Walker et al., 2019). Interestingly, the proportion of staff leaving the NHS improved during the pandemic only to revert to higher levels of attrition after 2021 (Palmer & Rolewicz, 2022).

moving towards. It is a prerequisite for the only type of care that she wants to offer, 'decent medical care to the whole population'. What is more, it might represent for her the only possibility that there is for making a virtuous living out of practising medicine. But, as she has already pointed out, the NHS is replete with 'deep-seated issues', failings and afflictions, that 'cannot be solved by throwing money at the problem'.

There is a long history of people waiting for the NHS to return at some point to what Katie refers to as 'the things that matter'. Perhaps this is because of how it first landed in the public imagination, as a set of promises. In his speech to parliament about the National Health Service Bill in 1946, Aneurin Bevan was adamant that a free to access Health Service mattered more in the long term than any objections based on present day concerns about costs or logistics; "...it will lift the shadow from millions of homes. It will keep very many people alive who might otherwise be dead. It will relieve suffering. It will produce higher standards for the medical profession. It will be a great contribution towards the wellbeing of the common people of Great Britain" (Bevan, 1946). For Katie, maintaining a durable relation to this vision has been something that she has had to work on. This has sometimes been about looking back to an NHS that had seemed 'good enough'. At the time of writing, she is picturing the workforce 'walking away from the burning embers' of a version of this that she no longer believes is worth waiting for. At other times, the promise of the NHS is thrown further into the future and she seems to be imagining what it might take to wait for it to finally arrive. The idea of the National Health Service is where she goes when she wants to 'go back to providing the basics of decent medical care', but it also has the aspect of something that is yet to be built and is always having to be remade, 'I cannot help dreaming of building something...'.

Not everybody believes that the NHS is worth waiting for. The problem of retaining people in general practice, is a very old problem. There seems to be something about the combination of this type of medical care work and successive arrangements of it by a centralised system which, from as far back as the 1950's has made the prospect of doing this work an unappealing one for many, for different reasons.

Dissatisfaction with the constraints of working for a universal healthcare system was one of the main reasons cited by British trained doctors for why they decided to migrate to Canada in the 1960's (Wright, Mullaly and Cordukes, 2010). For many of these doctors, the experience of working for the NHS was one that they wanted to escape from rather than commit to. It meant having no choice but to respond to the constant needy demands of others. This extract from an oral history interview is revealing for how one doctor describes this as being like a form of enslavement. This physician trained in Oxford before emigrating in the 1960's to work in a practice in Nova Scotia.

You were very much the slaves of your patients... there were huge clinics and a lot of house calls and lots of bureaucracy. It wasn't like practice in Nova Scotia which was very free. You could do it the way you wanted to do it. Moreover, in terms of pay there was no comparison, I was much better paid here [Nova Scotia] ... [and] you were nobody else's servant, it was more, you were more able to control your destiny.

(Wright, Mullaly and Cordukes, 2010, p. 565)

Contempt towards the idea of having to work under the state was not marginal within the British medical profession at this time (Seaton, 2015). Many British doctors did not want to be elected into a system that would require them to sacrifice their personal and professional freedom in order to attend to the demands of more and more patients. Thousands are calculated to have emigrated to Canada, Australia, or the United States, many seeking to avoid having to be drafted into the NHS, a fate compared by one of these doctors to 'being married' (Wright, Mullaly and Cordukes, 2010). They wanted the freedom to practice medicine on their own terms and on their own time. The historical significance of this for those who were recruited to fill their vacant positions, most of whom during this period were Indian or Caribbean doctors, is presumably that they would go on to do the years of work on building and sustaining the NHS that many white British doctors preferred not to do, at least

in part because they did not want to make the sacrifices of financial and personal freedom that this would have required of them.

National and colonial histories of worker discontent with the National Health Service are intersecting. For white British trained practitioners, the hard parts of working for the NHS may have been made more tolerable by the belief in their necessity for realising its moral objectives in the longer term. But when contextualised in terms of the rise and decline of the British Empire, their commitment to making sacrifices in order to ensure a virtuous destiny for the NHS carries a hidden cost for those whose labour has been relied upon to help with the realisation of such a destiny. Kyriakides and Virdee argue that whereas British practitioners can inherit the NHS as a 'moral construct' inviting them to make necessary sacrifices to keep the Great British 'dream' of universal healthcare alive, migrant workers have been 'pulled in' as saviours, and 'pushed out' as pariahs, as required.

...migrants and British-born 'non-whites' entering the British medical profession are forced to negotiate 'saviour/pariah' ascriptions indicative of discriminatory but contradictory processes specific to the operation of the British National Health Service as a normative institution.

(Kyriakides and Virdee, 2003, p. 283)

The positioning of migrants as inferior doctors would have consequences not just for the type of medical labour that tended to be assigned to them, but also for what modes of endurance might be available to them. Esmail (2007) uses the term 'indentured labour' to describe how Asian doctors have historically become 'indentured' into the system of the NHS, both in a financial sense and in terms of the

work they have been required to do.<sup>101</sup> He writes that part of the reason for this is that after having being recruited in India to move to the UK to fill vacant positions when they arrived, they found they were consigned to work in areas of medicine usually avoided by white British doctors, where they were paid such poor wages that they could never afford to pay back the money they borrowed to get there in the first place.

'So, the Asian doctors ended up being tied to the UK and the NHS, because returning without fulfilling your aspirations was not an option. They always hoped that they would break out of the cycle but in the end they did not but stayed on and made the most of it. They were indentured to the system'

(Esmail, 2007, p. 830).

Tellingly, alongside mental health rehabilitation, psychiatry and geriatrics, Esmail includes general practice in the list of careers that the NHS wanted them for, all areas of medicine in which the opportunity for deriving quick satisfaction through expert medical intervention are limited by the ongoing nature of the need.

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More recently, a series of reports on race in the NHS have found that if you are Black, Asian, not white or trained outside of the UK, there is a higher likelihood that you will be recruited into deprived areas where you are more likely to be caring for chronic conditions with social determinants in isolation from other practitioners and as part of a heavier workload. Your options for mobility within the NHS will probably be more limited than those of white practitioners who received their medical training in Britain. Also, your Practice will probably receive less funding from the government and there is a significantly higher chance that you will be referred to the General Medical Council over concerns about your fitness to practice which, if it happens, will lead to sanctions and other kinds of cyclic disadvantage further limiting your options for moving on in the future. Esmail, A., Panagioti, M., & Kontopantelis, E. (2017). The potential impact of Brexit and immigration policies on the GP workforce in England: A cross-sectional observational study of GP qualification region and the characteristics of the areas and population they served in September 2016. *BMC Medicine*, 15(1), 191; Fisher, R., Dunn, P., Asaria, M., & Thorlby, R. (2020). *Level or not?* - The Health Foundation. Retrieved September 2022 from

https://www.health.org.uk/publications/reports/level-or-not; Atewologun, D., Ochieng, M., & Roger, K. (2019). *Fair to refer?* General Medical Council. Retrieved September 2022 from https://www.gmc-uk.org/about/what-we-do-and-why/data-and-research/research-and-insight-archive/fair-to-refer

If anything, the NHS's long-standing associations with duty and the greater good have only been heightened since its earliest days when it was first positioned as 'a precious but threatened resource...' to which doctors, nurses and patients owed their loyalty (Bivins, 2020, p. 155). The protective 'we' that is mobilised when somebody 'feels' the NHS defensively tends to resurface in timely evocations of blitz spirit and might imply many things: a shared history of struggle; the inheritance of a vulnerable (national) institution; a commitment to keep it going. During the pandemic, an appeal to a national fantasy of the NHS might have helped to produce forms of solidarity and of hope, but it could be used in other ways as well. It could be used for instance, to position certain patients and practitioners as a threat, on the basis of their visible, ineradicable difference from a white British norm that was only ever imaginary (Bivins, 2015, p. 2). It has arguably been used in a cynical way by politicians to justify requiring personal sacrifices from NHS workers and patients. For Katie, it has inspired waiting and perseverance even when she no longer knew what she was waiting and persevering for. Afterall, as Hage reminds us, 'it is civilised to know how to endure a crisis and to act in an orderly, self-governed, restrained fashion' (Hage, 2009, p. 105).

#### 7.5. Conclusion

The unfolding of universal healthcare is deeply implicated in the realisation of a Great British nation-state that relies heavily on a migrant workforce to do some of its hardest work, whilst denying them equal status as doctors and full citizenship (Simpson, 2018). Yet Roghieh's experience of racism and disappointment in the NHS is not reducible to these histories. Neither is Katie's struggle to survive in the NHS cancelled out by them. Part of the value of the case study is that it defies assumptions based on generalities. Roghieh and Katie's accounts cannot be made to fit the moulds of either 'the migrant subject' of the NHS or that of its 'white British' counterpart. Though in some ways, their different experiences are recognisable for how they seem to align with histories of white heroic endurance and racialised surviving, in other respects, they fall outside of the normative parameters of migrant and non-

migrant experiences.<sup>102</sup> By placing them alongside one other, I have tried to maintain their differences whilst looking for the points where they intersect or interact. I look at for instance, how nationalised forms of waiting courageously for the NHS might be aligned with modes of endurance that wear disproportionately on a migrant workforce. But also, at other ways of enduring waiting in the NHS that are not teleological, where there is the potential for those who have fallen out of time with it to gather around an idea of universal healthcare articulatable in the present. By loosening their loyalty to the goal of saving 'our' NHS, Katie and Roghieh are not liberated from their respective impasses, but they both loosen their adherence to a regime that has the potential to desensitise people to its costs and its consequences.

In Katie's case, I have maintained that her refusal to go on waiting for the NHS constitutes a break with the kind of heroic waiting that individualises problems, sacrifices the present for the future and confers blame on those who, for whatever reason are unable, or unwilling to wait. At the time of writing her blog, she appears to be trying to adjust to waiting for the practices that she wants to preserve, rather than for the institution that may have made those practices possible in the first place. Roghieh's testimony suggests that the temporalities of care and crisis in general practice are different for those who find that they have been made to become temporally other to the political project of the NHS. At a time when national interests are allowed to take precedence over almost every other interest, her invention of 'the margins' for migrant patients and practitioners follows in the Black radical tradition of creatively recasting the fate of those whose destiny it is to be the

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One of the most noticeable ways they both fall outside the normative parameters of NHS general practice in a historical sense is that they are GPs who express a strong sense of belonging to the NHS. Ever since the inception of the NHS, GPs and their representative bodies have engaged in disputes with the government over working conditions, but until quite recently much of this activity was undertaken without much attachment to the NHS and sometimes it was undertaken in opposition to the principle of universal healthcare. I have Martin Moore to thank for this insight. The other way that Roghieh and Katie are marginal within the history of general practice is that they are both women. This is important and relevant to what is being discussed here but it is not the focus of this particular chapter.

<sup>&</sup>lt;sup>103</sup> Hage calls attention to how this mode of waiting has formed part of a racialised civilisational discourse through its of 'the uncivilised third-world masses' as those who do not know how to wait and who 'run amok in crisis' Hage, 2009, p. 105). This is mobilised in the UK in the vilification of migrants and refugees as queue jumpers and as those who interfere with the citizen system of deriving virtue from waiting.

broken parts of a totalising system (Harney and Moten, 2013). The specific form that this seems to have taken for Roghieh, is to have occupied the time that is 'out of time' with the NHS. This means that instead of either abandoning it altogether or organising her life around the hope of things getting better eventually (which would mean having to constantly defer the arrival of what may never arrive), her intention seems to be to remain (for now), but to remain with others, as 'other' in time. To be in the margins of the NHS is to break with its straight timelines and old modes of getting through that have always been about ensuring its fate as a national destiny. The Margins are 'interregnum-like' (Malatino, 2019), in that they offer a way to go on being in relation to a future ideal of the NHS, that does not depend on us making it our future.

<sup>&</sup>lt;sup>104</sup> In another sense, Roghieh's decision to commit herself to caring for what is pushed into the margins of the NHS, by the NHS, might be seen to represent a continuation of migrant experiences of working in the NHS throughout history (Simpson, 2018; Esmail, 2007; Kyriakides and Virdee, 2003).

# **Chapter Eight**

### **Conclusions**

In this concluding section, I return to my original aim of inquiring into the forms of care that emerge out of situations in which nothing appears to improve or get better. I discuss some of the main points from each of the preceding chapters before going on to offer some closing remarks on my decision to narrate this chapter of NHS history through the temporalities of staying, waiting and enduring.

### 8.1. Care After Progress

At the start of this thesis, I set out to track the forms of care and attention that can emerge out of situations where care as an activity has become detached from any definable notion of progress. NHS general practice seemed a good site to carry out such a study because of its deepening ongoing involvement with chronic realities that manifest in ways that defy attempts either to move them on or to allow practitioners to fully move on from them. The forms of care I have observed here are described under the headings of waiting, staying or enduring, but they do not lend themselves to lists or categories and they cannot really be described either as science or care within the usual definitions of these terms. In an environment that measures care by what it can produce, I find that they are untenable and incapable of transcending the moment. Yet, during a time when NHS general practice is intensely preoccupied with its own survival, my claim is that there are practices of care that persist in assembling chronic realities in ways that make it seem necessary to care about them, even when to do this can constitute a threat to the viability and competitiveness of the organisation. I sometimes refer to them as practices, but a

more accurate way to describe them might be modes of response arising from the body which are lacking any direct route to their object of care. If a commitment to waiting or staying can be said to have any potential in regard to this object, this might be that it inclines somebody more towards care in than away from it. Vincianne Despret captures something of this in her formulation of an indirect relationship between waiting and care, where she writes that 'those who wait and those who wait on (or attend) sometimes become attuned and learn to be affected—that is, to care' (Despret 2004, 131). Given the inevitability of the rise in long term health conditions combined with a steady withdrawal of other types of long term support, there is a case for arguing that these are the modes or the practices of care most needed in general practice today, rather than those that are associated with the ability to manage a crisis.

Contemporary general practice is a place where the material labours and temporalities of healthcare must somehow coexist with technoscientific orderings of them and with temporalities of crisis. By re-reading the body and lived time back into some of the most recent technologies for managing crisis in this setting, I have sought to disturb the logic of such practices as 'releasing time' from unproductive areas of medicine as a way of addressing the crisis of not having enough time for care.

My earliest conversations with practitioners were influential in showing me where to look for non-progressive time in the surgery in the form of certain places, themes and figures. This included the figure of the frequent attender as a interrupter of progress, the notion of non-progression as somehow ordinary in a setting where caring for long-term conditions is the norm, and a particularly hopeless version of 'carrying on', in which trying to care for something keeps going without the expectation of any return on the investment of time and effort this implies. They reappear throughout the thesis, anchoring the content of each chapter to empirical realities of care in situations where care seems to have no outcome.

By introducing a psychoanalytic attention to the past, the Balint approach to case making in generalist medicine assigns value to the work of persisting with perplexing ongoing cases in general practice, widening the scope for what can become a proper object of concern in this setting. In a development of this idea, I have attended closely to the non-progressive temporalities of general practice in everyday life as a way of opening up the medical case to objects of concern that do not respond to the attempts of practitioners to act upon them. The cases that feature in this study question the assumption of ready-made solutions claiming to be able to 'manage' chronic illnesses. In place of an abstract notion of care management, they narrate how practitioners have been required to respond to stalled chronic pain or illness even after having run out of things to do in response. The persistence I sometimes observed in practitioners who would try out different treatments, open 'door after door', go on seeking answers and refuse to give up on somebody who has come to them for help, is one of the ways I claim that care can form discreetly, or as endless searching activity. This is understood as the willingness to be affected by the daily realities of chronic living that cannot be outsourced, deferred, or redirected within the NHS beyond a certain point.

This thesis challenges the idea that care is always compatible with rushing in to save lives, or with doing what it takes to ensure that there will be more future to come. It interprets staying behind in an emergency not as a sacrificial gesture for the common good, but as a prerequisite for staying 'situated by the situation so as to understand what the situation demands', and which kinds of attention, concern and care are required (Stengers, 2008, p. 44). I have argued that this could have a particular relevance for those parts of the NHS specialising in non-urgent care where the right way of responding to a presenting need is often not pre-known but must unfold with the phenomena that it seeks to respond to.

Practitioner accounts of overseeing unstoppable or cyclic decline and deterioration in a patient's condition can force us to revaluate normative assumptions about the role that intermittent healthcare can realistically play in relation to inevitable physical realities. *Wearing out* is a term that I borrow from Lauren Berlant and use

to describe the care adjacent acts of watching as another person's resources for living are worn out and offering to be of use to them in some indefinable way. Drawing on Alison Kafer's work on disability and time, I make sense of this as a practice of care coming from within the time 'of slowly wearing down as one waits for more violence to come' (Kafer, 2021, p.421). I have claimed that this can offer us new understanding of waiting from within the NHS, one in which people can be thought of as waiting not for recovery or renewal, but for the next stage of physical or institutional decline and the exigencies that this will inevitably give rise to.

The insight that there is a third 'place' in the NHS between holding on and letting go, which I refer to as 'being between', interferes with the idea that carrying on in the NHS is always a good thing. Drawing attention to how a historical willingness to wait and to endure has been exploited, especially during times of crisis, I interpret the decision to stop waiting for the National Health Service not as a decision to stop waiting altogether, but as coming from a desire for different modes of waiting and enduring, less coercive and more responsive to the needs of the present.

In the next section, I come back to some of these discussions to interpret their overarching meanings and to look at what they might be able to tell us about the relationship between time and care in the NHS more generally.

#### 8.2. Discussion

In some ways, general practice might be described as a place that specialises in caring for things that do not get better, but throughout my time observing practitioners and listening to them talk about their work, I have often been struck by all the ambivalence surrounding the very idea of care in medicine. I thought that this might be because for some of them, the labour of care seemed to begin at the point that effective, scientific medicine stopped, and perhaps they would rather stay on the side of this line that held the most promise. In retrospect, I suspect that my talk about care might have inadvertently called attention to those parts of the

clinical work intuitively felt to be the most vulnerable and perhaps also the most threatening. Understood as the risky private activity whereby one person extends to another the chance of something that may or may not be the thing that is needed or wanted, the offer of care (which is inseparable from the offer of medicine or therapy), has the potential to fail, to be rejected, to complicate things or to prolong an ordeal, undermining everything felt to be self-evidently good about medicine, the NHS and general practice.

Finding the language needed to speak about what it could mean to persist in making such an offer has not been easy. For the reasons just described, asking healthcare workers about their experiences of caring for things that do not get better has sometimes felt as though I was criticising their practices by intentionally pointing out the parts of their work that link to failure. But rather than trying to avoid this, I have claimed that there is a relationship between practices of care and experiences of failing in medicine. One of the recurring messages of the research is that there are certain forms of care in the national healthcare system that feel like pessimism, as they only seem to really begin at the point where all sense of moving towards a hopeful destination comes to an end, after all affirmative plans for action have fallen away.

In their 2005 assessment of the changing nature of the welfare state project in Britain, Andrew Cooper and Julian Lousada arrive at a comparable understanding of care as a wounder of optimism (Cooper and Lousada, 2005). In their interpretation, the achievement of the welfare state is not to have solved the problem of social and health inequalities. In fact, one of the arguments they make is that 'over a certain period... the original post-war welfare state, began to break down' (Cooper and Lousada, 2005, p. 11). Its real achievement is to have disclosed aspects of the inner workings of organised care, suffering and neglect that had quite literally been 'unthought' before. They compare the lived experience of welfare state relationships in 2005 to that of the psychotherapy patient who embarks hopefully and willingly on a treatment, 'only to encounter a profound sense of anxiety and despair as the depth and apparently bottomless nature of their internal as well as external

difficulties make themselves known, together with the potential and actual limitations of their therapist' (Cooper and Lousada, 2005, p. 29). What Cooper and Lousada term 'the predicament of the borderline' refers to the confrontation that ensues after realising that the more care that is offered to people, the more care they threaten to need. Anticipating the themes of my own research, they write that when faced with this knowledge, people can either persist, or they can flee (Cooper and Lousada, 2005. P. 16).

The analytic that I have tried to open up to study what it means to have persisted in the NHS up to this point engages what Biehl refers to as 'the negative space' inhabited by chronic things, in which people are able to excuse themselves from caring. Biehl writes that this is '...a space of disregard...that points to the limits of care' (Biehl, 2005, p. 248). I would add, based on what I have observed, that this is also the space in which something like care might be allowed to begin. This is not the same as saying that non-progression in healthcare constitutes a space of potentiality rife with possibility. In NHS general practice, where people are often not getting any better, the effects of persisting in a negative space can be difficult to tell apart from the feeling of having excused yourself from it. It speaks to the 'moral agony' as one GP described it, of having to do too much for too many in too little time, without support while repeatedly suffering the guilt of having done too little in too much of a hurry'. 105 When thinking about what it means to care in this setting now, it feels more appropriate to think in terms of the invisible temporal practices that do not emerge in opposition to the neglect of chronic realities, so much as they describe the effects of not having fled from them, yet. This gives a new meaning to the endless refrain coming out of the NHS that 'we don't have enough time for care'. 106 In their aim to invent more ways to divert the needs of patients in the hope

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<sup>&</sup>lt;sup>105</sup> Tomlinson, J. (2020, November 15). *The Art of Not Running Away*. A Better NHS. Retrieved December 2020 from https://abetternhs.net/2020/11/15/the-art-of-not-running-away/.

<sup>&</sup>lt;sup>106</sup>Not having enough time for care has been at the centre of recent disputes about worker satisfaction in general practice. In 2015, NHS England commissioned an investigation into the causes of the problem and made recommendations that targeted the least productive areas of general practice for reform. See, NHS Alliance, Primary Care Foundation. (2015, October). *Making Time in General Practice*. Retrieved April 2020 from

https://www.primarycarefoundation.co.uk/making-time3.html

that they might be better met elsewhere, or to speed up the progress of treatments so as to hand them back to the patient at the earliest opportunity, recent policies that claim to have been able to make more time for care in general practice by removing disruptions to a practitioners' 'personal and productive workflows' (NHS England, 2016, p. 2), obscure the ongoing nature of the kind of needs that find their way into general practices, many of which may never realistically be met. This will not work as a strategy if, as this research suggests, caring for chronic conditions involves carrying on in the absence of any such 'flow'. To choose to make a crisis of productivity out of the growing feeling of disconnection from anything that can be described as care, ignores that those clinical activities which are the least productive in terms of outcomes, may actually be the most productive in terms of care. This includes the ultimate disruption of having nothing to show for the effort expended, an activity for which no time appears to be being made, despite that as people live long lives with less support to maintain these lives, this is becoming more of an ordinary experience in general practice.

In personal accounts of routine clinical activity, embodiment can be what makes the care component of healthcare labour most disruptive, time consuming and depleting, but it can also be what makes this labour actual and endurable, both for the patient and the practitioner. This is overlooked by national strategies that try to use crisis as a way to justify wanting to reduce the amount of time spent on care, for example by diverting face to face contact wherever possible. In light of this, perhaps a more valid question for strategists of time in the NHS is not how to 'make time for care', but how to protect the conditions needed to endure the disruption that caring for chronic conditions makes necessary, and the unaccountable labours that make this labour 'liveable' (Bellacasa, 2014, p. 16).

During the pandemic, Boris Johnson spoke about how the NHS was a system 'powered by love', 107 but today, one of the most pressing problems that it faces, is

<sup>&</sup>lt;sup>107</sup> Johnson, Boris [@BorisJohnson]. (2020, April 12). *It is hard to find the words to express my debt to the NHS for saving my life.* [Tweet]. Twitter. Retrieved October 2022 from https://twitter.com/BorisJohnson/status/1249336590482243585

that of getting people to stay. This is most apparent in general practice whose workforce has continued to ebb away over the last ten years, particularly in the most deprived areas of the country where chronic, complex health make up a greater proportion of the work (Parisi et al., 2021). In this thesis, I have argued that problems of how to wait and endure, 'after progress' are directly linked to the problem of staying in the NHS today. Who stays? Who has no choice but to stay? What kind of general practice is needed to support these people who, whether voluntarily or involuntarily, find themselves staying behind together? For some practitioners and patients, it is no longer possible (if it ever was) to go on believing that 'the slow incremental expansion of the health services, with an increasing degree of public investment will gradually but surely overcome the problems which we associate with inequalities' (Webster, 1992). Neither can they subscribe to the idea of the NHS as a source of 'social growth' for the UK – a growth that 'cannot be measured, cannot be quantified, but relates to the texture of relationships between human beings' (Titmuss, 1974, p. 150). Instead, some practitioners see themselves as having stayed not because of the good that the NHS will bring about, but rather in spite of the disappointments, betrayals and losses that a long-term attachment to it, has brought them.

It has been instructive, in this respect, to watch what can happen in situations where a patient waits for access to care, only to find that their waiting does not come to an end after an episode of care has begun. In these cases, care does not stop forming just because the longed for sign of improvement or turning point fails to materialise. It forms more as the willingness of the practitioner and the patient to stay bound in time to a project that only one of them may have the luxury of being able to decide to move on from. I trace this phenomenon of a 'care-filled' notion of non-progressive time back to NHS temporalities of care which have always revolved around the shared waiting that requires each person to allow themselves to be delayed so as not to leave others behind.

'There are modes of assembling', writes Isabelle Stengers, 'that bring out the capacity to do what people are usually incapable of doing. We have to invent a

capacity to act and struggle collectively without concocting a simulacrum of salvation or a truth for one and all' (Stengers, 2021, p. 357). When writing this thesis, I was conscious that of all the different narratives available during the pandemic for telling the story of the NHS, the one that seems to have stuck from very early on is about how the NHS mobilised its innate capacity for self-sacrifice in order to fulfil its historic mission of overcoming and getting us through the crisis. As one author expressed this in his chronicle of general practice during the Covid-19 pandemic; 'the clinical encounter, with its alliance of science, kindness and intensive care would endure and... humanity would recover from this pandemic, as it has from so many in the past' (Francis, 2021, p. 198). The lesson that I think I am being taught by this story is about keeping faith in science and waiting patiently for progress to take its course. Its message is to hold the course because crisis is only a moment in time and whilst the situation may look hopeless now, ultimately, scientific knowledge will advance, medicine will do its work, the NHS will endure, and we will eventually get better. In an effort to heed Stenger's warning to care for the consequences of events that we have helped to create (Stengers, 2011), my own aim is to lure the potentiality of an experience of care in the NHS that stays in the ambivalent in-between space afforded by a temporality of suspension. Conceptions of time as always ultimately drifting towards a future when humanity will eventually recover (even if that means having to cut its losses along the way) are those that ground the liberal subject, but they do not support the modes of endurance needed for liberal subjects to maintain such a project. This is why I am more interested in chronicling the experiences of GPs, administrators, and receptionists who, whilst submerged in forms of waiting that adhere more or less to the belief that things will improve, also sometimes allow themselves to be worn down by the collateral of everyday life in the NHS. They tell a different story about waiting during this period; one in which people allow their time to be used up by those who need it, in the hope of something, but for reasons that have nothing to do with saving time, the NHS, the world, or anything else.

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# Appendix A

### **Source Material**

This appendix contains a sample of the source material used in this study. It includes data from four of the sites of general practice that I engaged at different points during the research period: the GP Consultation, the Balint Group Meeting and the Online GP Forum. The data has been anonymised and some details have been redacted to protect the privacy of individuals.

#### **GP Consultation Observation Notes**

| Observation type: GP appointment             |  |
|--|--|
| Site: / Date:                                |  |
| Patient seeking help with: feeling depressed |  |

In response to the doctor's opening question about what he could help her with today, the patient gestured that they didn't really know. Then they listed exhaustion, a previous overdose, a wish to self-harm and being raped as a child as possible reasons for being in need of help.

Dr. L: 'You'll have to get hold of just a few of these.

As usual, the patient is asked to narrow down their concerns to the one thing that they want the doctor to help them with today and to stick with that. Other issues can be dealt with next time.

So, after being asked what *one* thing they wanted help with from the doctor today, the patient's response, as though picking something from out of the air, was to say 'depression'.

Dr. L asks about medication which the patient says she has not tried. She tells him that she's 'been through' a few counsellors, but that she always ends up feeling that she's being judged and becomes 'paranoid'. The most recent of these was last month.

Dr. L: 'what are you hoping for today?'.

Pt: 'I just feel exhausted. My body feels like it's going to shut down'.

In response to questions about her health, the patient tells the doctor that she hasn't had a period for some time but is certain that she's not pregnant as she's had a negative test. She makes reference to an abusive past and then waits to see how the doctor will respond as though inviting him to make sense of her situation.

Reiterating his last question, Dr. L asks the patient 'what's the help you would like to get from me?'

Pt: 'Whatever's best...like I said, I'm paranoid'.

Dr. L has been searching through the patient's electronic record during this time. He remarks that he is surprised that no medication has been offered before now.

Dr. L: 'Medication is not the answer to life's problems but some people find it helpful. It takes some time to take effect, about a month. It's not meant to transform your life, just to lift some of the worst effects of the depression'. Then he says, 'how about I give you a prescription and you come back in 2 weeks' time?'

The patient agrees to this and then Dr. L asks her: 'Do you have someone to speak to if you feel you're going to self-harm?'

Afterwards, I asked Dr. L what he thought about all of this patient's concerns and whether he worried about all the things they wouldn't get the chance to talk about today. He said that he didn't worry about them too much because they were likely to be self-limiting (resolving with time). He'd prescribed mirtazapine as the patient had never been prescribed an anti-depressant before and it would 'kill two birds with one stone' because it would also help with their sleeping problems (mirtazapine has a sedative effect).

This patient had seen several different doctors from the Practice before today. Dr. L told me that it was a case of exhausting the options. 'There are doors that open and some that are closed'. He reflected that he just had to take the patient at face value. If she was suffering from depression, they could do a PHQ-9\*. About this he said, 'here's the concrete thing, it's not about my spin'.

We talked about the need to 'economise' with the time in general practice. He told me that he would just attempt a 'single intervention today'. This was one of the reasons why the patient list (of concerns) could feel like 'a declaration of war'. He said something that he has said before, that 'the patient gives you what's most important just before they leave'.

\*A PHQ-9 is a self-administered diagnostic questionnaire used to make a tentative diagnosis of depression.

## **Sample Balint Group Observation Notes**

#### Balint group observation

Date:

The meeting opened with a disclaimer by the group leader. He wanted to address something that had been bothering him ever since the meetings had moved online. He had noticed that some GPs had begun scrolling patient histories on their screens as they were being discussed. He knew they were doing this to help try to solve a problem or to be more accurate about the details but he wanted to remind them that a Balint discussion is not about being right or wrong. He said that in a Practice, like this one, where lots of people have seen the patient, information from their patient record can detract from thinking about their situation. He ended with the question, 'what do people think about that?'

- 1. L: 'I agree. It's ok to look up facts at the start of a conversation to check the facts about a patient but if we carry on as we're talking, it can detract from the discussion about the feelings and the relation to the patient'.
  - P: 'Taking the long view (taking too much history into account), we can lose our focus on what it is to live the relation with the patient. It might be better if you sit on your hands and try to stay with the patient relation.'
  - H: 'I'll make one observation. This is an atypical balint group. In a group (like this one, which is made up) of the people you work with, you tend to fall into sharing information about the patient (as part of your job as a GP).'
  - P: '(I feel that) when we've sat here (in this meeting) face to face, there's been much more respect for the presenter and their view. You put your notes aside (when you're speaking to people in person). What you forget and what you don't say can be just as important as what you do say. What you suddenly remember can be important...does that make sense?'
  - [...] There is a long silence before anybody speaks again.
  - P: 'I suppose that the reason Balint wanted to do that, had to do with psychoanalytic reasons. ...as doctors, we're not taught to do that. ...we're taught to be measured and right'.
  - [...] more silence.
  - ...any other thoughts?
  - L: 'I'm just grateful that we have you [P], to keep us on track. It's very easy to go into fact finding mode.'
  - P: 'It's a way of going into the unconscious...refining our ability to observe our patient for the benefit of the patient, and to refine our ability (as doctors) to observe.'

[...]

'It's a very strange world (we're living in right now). And it's quite difficult to get a hold on reality.'

1. E: 'I see a woman with intractable pain' (whose case I thought of bringing up for discussion).' is someone who used to be a but who has had a descent into disability (so her life has changed a great deal and this is something that she's finding very difficult. When she walked into my room, the first thing she said to me was, 'it's been vears, months and 5 days that I've been in pain.'. From my point of view, something needs to be done. (She often communicates despair over her situation, and she'll say things like,) 'I can't live with this pain'. 'She lives with her -old son (who, she says, spends most of his time) moping around the house. (Her condition) is kind of medically unexplained. We went down the standard medication route (which didn't work. So, then I referred her to a specialist and we agreed) to try waiting to see if this clinic can come up with something. 'It's unsatisfactory, prescribing something you don't want to prescribe – opiates. (Recently,) it's got to more of a crisis point. She had some surgery from neurosurgery (but they made a mistake so that) the pain just moved from one part of her body to another, I'm stuck, She's angry. We have this pattern of offloading, (which) seems to make things better) in the moment. But it doesn't last. And the next time I see her it's as if none of it ever happened, because she's just as distressed as the last time)'. 'It used to be a sort of crying offloading. Now it's a 'prescribing more medication' sort of an offloading. She used to have some domestic abuse ... I think things are more stable now. (Other GPs have worked with her.) She told (Dr.) J. that she'd tried to herself (in the past)'. 'So, what to do now? She's had therapy in the past. She said it made her feel worse so she doesn't want to do that. From her point of view, it's a physical problem'. 2. '...It can be quite intense. Once, she refused to leave the room until something had been done (about her pain) so I gave her a injection. Then, the week after, I suppositories (but there were adverse effects), so that put me on prescribed the back foot. She's quite a strong character'. (P: 'Can I ask why you're bringing this case up for discussion now? – Is there something in particular you'd like the group to discuss?). E: 'I'm not quite sure why I'm presenting it...but J. reminded me (of the case recently. And so, I thought, as I'm stuck and not much has changed, that this might be a good place to discuss it.) 3. (P: 'how do you know the patient J?') J: 'We spoke for 25 minutes on a duty call - this was when she told me about the attempted hanging. I wanted the crisis team to pick her up and take her to hospital but she said they had no right to do that. I wanted to explore it more but there was so much transference. She was held in this state of anger and pain – anger at her year-old son because he wanted to keep her alive. (On this point, feeling was, 'how dare he keep her alive?'. *Her* mum had died when she was (the same age).'

"...ok, so whose got a case?"

by her – and this awful descent into pain'.

'I feel awful, she's been on my mind, as I'm sure she's been on E's mind. I feel very struck

| 1. | L: 'I'm very struck by the dichotomy of going from being an being disabled.'  |
|----|---|
|    | H: 'I'm struck by what she said to you [E] when she walked in the room: 'it's been years, months and 5 days that I've been in pain.'  |
|    | F: 'My first thought was (that) her son is the protective factor. He is stopping her from killing herself. I can also see it from the patient's perspective – I (too) have been in so much pain that I've been parasuicidal. I think patients can feel frustrated when doctors are trying to move them towards acceptance and the patient is looking for cure.' |
|    | "The patient is bringing the timeline – 'I've been in pain years, months and 5 days', she is asking 'what is wrong with me?' 'How did this start?' I think we're hamstrung by the biopsychosocial model of back painI really feel for her as a patient.'  |
|    | J: 'Can I just add in some more layers of complexity?   |
|    | - she's looking for the solution. (This is the context fo looking to us for help- she is saying) - 'the pain started then, and I want somebody to sort it out'.'  |
|    | 'She's not going to accept the pain. I'm worried about her. She's very angry. I think she's seeing somebody privately.'   |
| 2. | P: 'What does she look like?'   |
|    | []  |
|    | E: her anger is what makes the strongest impression.'   |
|    | H: "There is a real feeling isn't there, that doctors can't help? Often, doctors can't help. But the anger at doctors for not understanding the pain, that's a bit of a theme?"   |
|    | E: 'She's not dismissive. She's seen a lot of people (as part of) looking for a solution.'  |
|    | J: 'She wants a grafting of a nerve. She thinks it's her right, and something that can cure her.'   |
|    | F: '(This) is a very solution focussed patient. We've been unable to provide that solution Our approach – the biopsychosocial, feels invidious. She's depressed because she can't accept the pain! This is particularly true for patients with MSK*** We're looking at it through two completely different lenses.'   |
| 3. | E: 'What don't we know?'  |
|    | []  |
|    | J: 'What about what she can do, about how she manages?'   |

E: `She has help from her immediate and extended family. On good days...she does what she can ...we've had conversations about her mood and how it can amplify pain ...I think

she recognises that we've not really talked about her son. Maybe I should initiate that conversation...'

- H: 'Despite all of this, she's obviously getting something positive out of her relationship with E. He's made lots of referrals to specialists who haven't been able to help yet but along the way, she's obviously found something supportive (about their relationship.)'
- 1. L: 'Has she tried any non-medical approaches?'
  - E: 'I think she'd like massage but she can't afford massage.'
  - L: 'I think it's interesting that she feels let down by medical interventions, but she's prepared to stick with it.'
  - E: 'I think she feels she's got no other options and that she's willing to try anything to help with the pain.'
- 2. F: 'My fantasy is that her health is stopping her from having a partner...I wondered whether the practice might be acting as a substitute?'
  - E: 'She does have a partner, but we don't really speak about that ...maybe that's a conversation we need to have.'
  - C: 'She seems a very private person. Maybe there are things she doesn't want to tell us? (Didn't she say) when she tried to kill herself, that it was no-one's business?'

Discussion brought to an end

- \*Myelogram: A myelogram is a diagnostic imaging test generally done by a radiologist. It uses a contrast dye and X-rays or computed tomography (CT) to look for problems in the spinal canal. The contrast dye is injected into the spinal column before the procedure. The contrast dye appears on an X-ray screen allowing the radiologist to see the spinal cord, subarachnoid space, and other nearby structures more clearly than with standard X-rays of the spine.
- \*\* MRI: a medical examination performed using magnetic resonance imaging
- \*\*\*MSK: Musculoskeletal. This includes injuries and diseases affecting the muscles, bones and joints of the limbs and spine. Approximately 30% of all GP consultations relate to problems with the musculoskeletal system.

## **Sample Interview Data**

#### Notes from an online Interview with Dr P, 25th Nov 2020

Before any questions are asked, P reissues me the invitation to attend the Balint Group next week and we have a short conversation about the Group and how it works. On being asked, I remind P of the prompt for the interview which is to try to use the time as an opportunity to reflect in some depth on any recent everyday experience of caring for a patient.

|    | ny recent everyday experience of caring for a patient.  |
|----|---|
| 1. | P: 'the first chap [I wanted to speak about – is one of two older, bachelor brothers [and be both my patients]. had] a cancer diagnosis [was in] terrible health [- they both were]. [I've known] for years. [not so long, but recently I saw more of him because he had] cancer around the mouth and jaw.'   |
|    | 'I got a call from the ambulance: had died. I went round to show my face.'  |
|    | 'This was followed immediately by a palliative care visit'  |
| 2. | P: 'This second visit [for palliative care] was a man [ ], around, dying of cancer He was infirm, lying in his bed. [Looking at him, I thought] 'right, we're in a new phase'. [ ] had always been what I would describe as a] discreet [man] – never demanding. [You might describe him as a] 'burnt out schizophrenic' [although I don' like that term – 'burnt out']. [He hadn't had any active symptoms for years, but he'd had] bad luck. [After he was diagnosed with cancer], the chemo[therapy] set off a psychotic reaction [and he'd] been admitted to a [psychiatric] inpatient unit [where he'd been ever since]. |
|    | '[ 's main] story [in physical healthcare terms] was weakness [from the] metastatic cancer. His private life is complicated. He got back with an ex some time agothey all lived together, with her daughter.'   |
| 3. | P: 'It's a curious thing – visits like that. There's a lot of practical thingsdrugs, things like that. The elephant in the room is that this man ( is going to die. [Though the subject] feels very present [even if it's] not actually talked about.'  |
|    | '[I don't know whether it was] for lack of courage, or for lack of resolve I couldn't bring it up[but] on this occasion, it was fine [not to].'   |
|    | 'This [probably] sounds weird, but I like these encounters [of the kind], why? [I suppose] it feels a great privilege. There's a grave context for what you're doing.'  |
| 4. | P: 'In our exchange ( and ), s family had suggested going away - you know, to get away from the doctor. I suppose [during my conversation with ], I had [allowed] him to think, you know – [that he could change his mind about going if he wanted to]. And then, we got into the palliative drugs But throughout it all, it felt that there was something unspoken going on.'  |

'I feel a kinship with him...a great sense of privilege to be his doctor. [To be] trying to hold on to [his] sense of autonomy and ownership over decisions.'

'...there's this chemo[therapy] drug [that would have been prescribed as a drug of last resort - if searcer specialist had believed he might still benefit from it, but] in the heat of the moment, I had to tell him: 'I think the moment for this drug might have passed [knowing all that this] also implied.'

'[I told :] 'I'll communicate with the oncologist, it's their decision. ...The wife was worried [that] if we stop the drug, he won't live'.

SD: 'Do you think he understood the implication of this drug not being prescribed?'
 P: 'Yes. [That's how we left it, and I'll be] seeing him in ten days' time [for follow up]'.

SD: 'What do you hope to be able to do for a shis GP] during this time?'.

P: '[I'm] not an expert on the drug...it's relational. [I learned a lot from the patient testimony of Kieran Sweeney – a Senior Medic who gives his own patient testimony on cancer. He talks about the relational parts of receiving his diagnosis [and about how disappointed he was with the way this was handled when his own test results were found to be positive for terminal cancer. His point was that even where everything happens as it ought to in a procedural sense, if the relational parts of sharing a diagnosis are disavowed by those whose responsibility it is to confront them - as they were in his case, then the consequences for the patient can be devastating].'

'I hope to be able to concentrate on the relational. [We're often] split between the relational and the transactional. ...I can bear witness...be around for if he wants to talk.'

'One outcome could be if he goes downhill very quickly... [and then] dies in the hospice [where I wouldn't get to see him]. I'd be very sorry [not to get the chance]. It's very selfish. I want more...I want a little more sense of ownership in the process. - I hope I can help him to die at home'.

2. P: '[When I arrived at some, after he had just recently died] – the dead brother was [still] in the house. I [hadn't] needed to go round. The death was already certified [a nurse can do this], and [what's more] there was a [whole company] of people [already there] - palliative care nurses, family etc. My presence there didn't help anyone. [They were waiting for the funeral director to come and remove the body to a funeral home]'.

'[It's true that paying a visit after the death] can make some of the paperwork easier... you're [actually] asked [in the form]: 'did you see the body after the death?'. After somebody dies, a whole machining [of the death] takes place. It [can be] quite confusing [even] for medics.'

SD: 'What do you feel others expect from you at the scene of a patient who is dying?'

P: 'I think it's symbolic. [It makes me think of this section from] John Berger's *A Fortunate Man* – he's trying to get hold of the weight of it – the symbolic quality of it. It's [something about] bearing witness. Even if you haven't seen any people die [before], you're a representative of a profession for whom this is very well trodden ground...if you're canny, you can draw on that.'

'...just that ability to be the grown-up in the room, maybe [it's a kind of] dissociation – not relational [at all]. It's [as though] 'imaged' into the role you're given. I can't say how you do, 'own' that role'.

'It's quite an abstract side of medicine. It's about historizing our role. It's a centuries old history. [As a doctor who is thrown into these situations, you need to] have some sense of having this lineage.'

1. SD: 'Do you feel that the same expectations are at work regardless of the differences (racial or otherwise) that exist between yourself and the patient or the patient's family?'

P: 'I'm tempted to say yes, but I can't say how. It cuts across culture, class, race'.

'With the two brothers [ and ], both white, working class; they're very deferential. I always feel out of my depth, yes…'.

9. P: 'a is [also] a complex care case – he has throat cancer, drank heavily, [had] chronic pain, bowel problems, painkiller havoc, vascular malformation – complicated surgery, [a severe kind of] pelvic anal pain, the blood vessels in his leg are ruined: a nightmare'.

'It's as though his body is torturing him. One option is to think about the hospice, not because this is end of life, but because they are so good at symptom control. [When I suggested this to him], he saw it as a betrayal – as though I was saying something not transparent'.

- 10. 'I received a long letter from his respiratory consultant [basically declining a referral for assessment on the grounds that he didn't think it was appropriate. He didn't make any other suggestions as to what might be more appropriate. Specialists can do this apply their medical know-how to patient information and decide not to respond to a request without feeling in any way responsible for the problem of what to do about the situation. Michael Balint had this term for it 'the collusion of anonymity'.
- 11. SD: 'I'd be interested to hear what's like to be the General Practitioner in a situation like this, knowing that you will have not have the same option [as the specialist] of declining to stay involved in the patient's care.'

P: 'A vascular surgeon can do a fantastic job on [all things] vascular and ignore all the other things that are going on for this man. Meanwhile, his life is an absolute car crash'.

'It's [a kind of] non-ownership [made possible by seeing everything in a purely medical light. The patient is] a non-person.'

'GPs do it as well. The patient comes in with six things [that they want to talk to the doctor about and the GP] picks [the] one [that they want to deal with]. [But you know] the door's always open...the patient can sack the doctor, but the doctor can't sack the patient.

[text inside of the square brackets designates words not originally written into the notes that may have been added either because they were remembered to have been spoken along those lines or to better convey the spoken meaning].

## **Sample Blog Post Data**

Subject: How do I love?

Posted by: Roghieh Dehghan (Practicing London-based GP)

Posted to: BJGP Life

**Source:** https://bjgplife.com/2020/03/23/love-in-the-time-of-corona/

Date published or posted: 23 Mar 2020

- 1. It was my first day back after a week of self-isolation, and I cherished the ability to return to my work as a GP. The minute I stepped into the surgery, I could sense a mix of exhilaration, determination, and composure. From the receptionists to the doctors, all of our ordinary activities took on a new meaning. It was the energy of we-are-in-it-together, the energy of solidarity.
- 2. Only a week ago, I spent the day in bed feeling apathetic, nauseous, and weak. I experienced a long spell of disorientation and agitation it was not coronavirus though.
- 3. Let me go back a little bit. It all started when, like many other times before, I went to my friendly local café for a black Americano and round of toast. Except this time, my breakfast came with an extra serving of 'go-back-home-foreigner' from one of the other patrons. He was convinced that 'foreigners' and 'migrants coming in boats' were responsible for coronavirus as well as for all of the other infections in the UK. To make sure that I understood the depth of his feelings for those like me, he added: 'You wanna hear it in English? Piss off!'
- 4. One of the other customers, a regular like me who knew I was a doctor, rushed in to save me: 'No, no. This lady is doing good work in this country.' I surely am. I work for the NHS during the COVID-19 pandemic.
- 5. Still, both men were right. The foreigner in me should 'go home', and the doctor in me should continue to help in the NHS. I am both the beast and the beauty. Who I am is worth nothing, but what I do is worth everything. That is the narrative that has been woven together by the UK government for some years.

Perhaps now you have some sense of my feelings of disorientation and confusion? Having our political leaders slap me on one cheek and kiss me on the other, I cannot feel unequivocally proud of the NHS like other members of the staff might. Erich Fried° once

- 1. wrote: 'Those who love half of you do not love half of you, they do not love you at all. They want to split and trim you, they want to amputate and mutilate you.'
- 2. To be sure, the bond between me and the NHS started loosening when we started excluding some of the most needy and vulnerable in our society from universal healthcare, ° when we let the Home Office branch out into our health services. And again, there is the rub I cherish my patients, but I am profoundly disappointed in our leaders. I say this to the relevant decision makers: You should have mobilised more strongly to resist policies that fragment the NHS and jeopardise social cohesion and solidarity.
- 3. Whether it manifests itself in a local café or in a set of deceptively-worded national policies, the upsurge of racism is personal to me.
- 4. In times of crisis, we rely on social capital. However, solidarity is not a switch you can simply turn on and off at whim. Solidarity as 'shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional and otherwise) to assist others' requires nurturing and maintaining through trust. '[T]rust is a form of mutual recognition of intrinsic self-worth'. Recognition, in effect, is a form of love.
- 5. Ultimately, I was forced to consider a single fundamental question: How do I love? How do I love in times of a pandemic when I have been pushed to the margins before corona and I will almost certainly be kept there during and after corona, too?
- 6. Once the haze of rage receded within me following the incident in the café, I realised that I can still love from the margins; in fact, I can love more forcefully, more passionately, more clearly from the margins. When I am pushed away by hate, when the ties with systems loosen, I find myself where it matters most and with those who alone should matter.
- 7. I remember my oath to medicine as an art of healing. I remember my commitment to the ethics of justice and care that will survive politicians, governments, and transient policies. I remember my enduring love and gratitude for those patients who, day in and day out, humble me with their trust.
- 8. I call on you to speak up now. Demand that government suspends the NHS charging regulations of 2015 and 2017 that restrict access to the NHS for anyone suspected of having an irregular immigration status.
- 9. We are redeemed by solidarity. We are redeemed by love in the time of Corona.

# **Appendix B**

# **Data Coding**

A first step towards interpretating the data was to begin a system of manual coding when recording and transcribing new material. Below is a sample section of the data coding table used for the process of finding out what forms non-progression might conceivably take in general practice. I used it to record practitioner experiences of trying to care in situations where this activity was detached from any clear idea of making progress. This sample is taken from the section of data that I collected during interviews.

| Experiences of care  | Data                     | Source material   | <b>Emergent Themes</b>   |
|--|--------------------------|---|--|
| Caring through one crisis after another, through one cure after another – supporting the interim episodes of being ok  | Interview 3 with Dr B    | 'Psychodynamic therapy happens with a GP, but just in a different way. It develops over a longer time but all the little bits will [eventually] have therapeutic benefit'  'We don't get people better (!).   | Carrying on in spite of relapse and breakdown  The ordinariness of crisis repeating itself             |
| Never having the answer - recognising the limits of the human body to heal itself but never really knowing for sure what might be possible. Having to refrain from knowing | Interview 2<br>with Dr B | 'People tend to come to see<br>GPs with problems that<br>can't be resolved' 'They<br>can't do what they used to<br>do. It's a purely practical<br>issue. It's not as though<br>there's a medical solution. A<br>diagnosis would be fairly<br>pointless' | Absorbing or holding  Carrying on in spite of not knowing what to do                                   |
| Not caring towards death either – providing somebody with the support that keeps a life, a world, two people's world, going for as long as possible.                       | Interview 4<br>with Dr B | All she wants] is to hold their life together [for as it takes] – for her to outlive him. She accepts the support that makes that possible.'  | The ordinariness of people living in ways that predispose them to sickness and hasten their own deaths |

|  |  |   | The futility of caring for health when every other area of a person's life is exposed to neglect.   |
|--|--|---|---|
| Dealing with the administrational work generated by repeat attenders. Responding to their extra demands. Being stopped by them (even sometimes on the street) and allowing yourself to be slowed down. | Interview with receptionist, F.  Interview with Assistant Manager, D  Interview with Administration Worker, B  Interview with Manager, S | 'It used to be that) you'd see the same old faces (every week). (We were like) a comfort blanket (to them). (They'd pop by on their way home from the shops or come in for a chat and to pick up their prescription.) If they're on their own, they (might) have no-one else to talk to (so they would come and talk to us because they'd got to know us). (Some of them) used to bring cakes in and biscuits".  'If you look at the frequent attenders list, (they're not the people who are most in need of medicine. They are) lonelyor bad at managing medication. They're the offenders. It's the same everywhere.'  'In some cases, there is [something more personal happening] – like when you get to know some of the patients – [there are some patients who call again and again and everybody in the surgery knows who they are].'  [Before the pandemic], what they'd been left with, were all those patients with high demands – mental health, long term conditions[they] cost lots of money. If you take out the well people, the Practice can't cope.' | The relational labour of working in an NHS general practice.  The frequent attender as a site of care but also of neglect.  The easy exhaustibility of an open offer of care in general practice. |

# Appendix C

### Information and Consent Forms



#### Carrying on in General Practice: Ethnographic Sitings of Caring for the Unresolvable

Stephanie Davies



#### **About the Study**

The study looks at how time and care be thought in general practice where the labour of caring goes on and on but appears to lead to no outcome. Its aim is to grasp this form of care historically, affectively, socially, materially - in ways that can be sensitive to time.

#### **Agreeing to Participate**

If you agree to participate, I will ask you to complete a consent form and to take part in an online or phone interview lasting between 30 minutes and 1 hour.

surgery is a public partner of the Waiting Times Project but any data relating to you will be kept anonymous as far as possible. Data will be transcribed and anonymised before being stored in a secure password protected electronic file. Following this, any handwritten notes or video recordings will be destroyed. An analysis of your participation in this study will be written up in a report of the study.

No information that could be used to identify you (other than the name of your organisation) will be used in the write up or any publication which might ensue. The research is supervised by Professor Lisa Baraitser who may be contacted at the above address and telephone number.

This study is being undertaken as part of Waiting Times, a multi-stranded research project on the temporalities of healthcare supported by funding from the Wellcome Trust. It also forms part of the requirements for my Psychosocial Studies PhD at Birkbeck, University of London. Ethical approval has been given.

#### **Agreeing to Participate**

If you are over the age of 16 years and able to sign your consent to take part, then you can participate in this study

If you agree to participate, you will be agreeing to a researcher being present during your consultation

You will be free to withdraw and to ask them to leave the room at any time during the appointment

#### **How to Give your Consent**

You can consent by signing a consent form confirming that you give your permission for a researcher to observe your healthcare appointment

#### **Good to Know**

The Surgery is a public partner of the Waiting Times Project but any data relating to you will be kept anonymous as far as possible. Data will be anonymised before being stored in a secure password protected electronic file.

An analysis of your participation in this study will be written up in a report of the study. No information that could be used to identify you will be used in the write up or any publication which might ensue.

The research is supervised by Professor Lisa Baraitser who may be contacted at the address and telephone number below.

You can find out more about the Waiting Times Project at http://waitingtimes.exeter.ac.uk

For information about Birkbeck's data protection policies, please visit: <a href="http://www.bbk.ac.uk/downloads/policies/privacy-research.pdf">http://www.bbk.ac.uk/downloads/policies/privacy-research.pdf</a>

If you have concerns about this study, please contact the School's Ethics Officer: sshpethics@bbk.ac.uk

You also have the right to submit a complaint to the Information Commissioner's Office https://ico.org.uk/

Department of Psychosocial Studies BIRKBECK University of London Malet Street, London WC1E 7HX 020 7631 6000

### **Consent Form (participant copy)**

| I understand that Surgery will be identified as one of the two general practices participating in the research and that any contribution I make could be used as data for the study.  I understand that I may withdraw from the study at any time by making my wishes known to the researcher triggering her to leave the consultation room immediately.  I understand that I may withdraw my data before it has been anonymised and combined with other data by contacting the researcher by email: sdavie16@mail.bbk.ac.uk  I understand that the anonymised form of the data I have provided will be made available to other researchers through publications and by being deposited in the Birkbeck data repository.  I am over 16 years of age.  Name  Signed  Date  Date | I have been informed about the nature of this study and willingly consent to take part in it |  |  |
|--|--|--|--|
| I understand that I may withdraw my data before it has been anonymised and combined with other data by contacting the researcher by email: sdavie16@mail.bbk.ac.uk  I understand that the anonymised form of the data I have provided will be made available to other researchers through publications and by being deposited in the Birkbeck data repository  I am over 16 years of age.  Name  Signed  Signed  |  |  |  |
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| researchers through publications and by being deposited in the Birkbeck data repository  I am over 16 years of age.  Name  Signed  |  |  |  |
| Name   | ·  |  |  |
| Signed   | I am over 16 years of age.   |  |  |
|  | Name   |  |  |
| Date   | Signed   |  |  |
|  | Date   |  |  |
|  |  |  |  |

As two copies are needed, one for the participant and one for researcher, please could you also sign the consent form overleaf