The Lived Temporalities of Prognosis

Fixing and Unfixing Futures

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Abstract
In this article, we explore the ways in which a man with motor neurone disease, Gareth, and his wife and carer, Maggie, enact different temporal orientations, when the expected future, an early death, does not arrive. We attend to the tensions between everyday priorities and uncertain futures to discuss the ways Gareth and Maggie negotiate action to deal with problems that are yet to come, but, despite this, already matter. We argue that prognosis thrusts people towards multiple presents and futures; while the future is fixed in time through prognosis and repaired through present action, it is also unfixed as lived experience unfolds over time. What emerges is a dialogue between multiple futures, pre-determined *and* uncertain, and practices that aim to repair the future, even if they cannot do so.

Keywords: anticipation, care, death, illness, prognosis, temporality

> **Maggie:** Now, going to the toilet is getting difficult. So, whether there are any aids about that we can have to help Gareth…clean himself up. I mean, I'll do it, but he doesn't like it.
> **Gareth:** Difficult now, because I'm losing the feeling in all my fingers, you know.
> **Maggie:** The same with cleaning his ears out. You don't realise, do you, when you…?
> **Dikaios:** No, because you need really fine movement.
> **Maggie:** Yes, yes. And he's got none of that, so…I am gonna have to get in touch with the occupational therapy and ask them to suggest something.
> **Gareth:** You take for granted and then it suddenly don't happen.
> **Maggie:** Suddenly it's taken away and it's not likely to come back.
> **Gareth:** Crazy world.

Diagnosis and prognosis are closely related practices mobilised in biomedicine to name disease and anticipate its course (Risør and Nissen 2018). Upon diagnosis with a long-term disease, people often rely upon information given to them by health care professionals about the stage and timing of their illness course, what to

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expect, and when this might occur; these temporal aspects of illness are collectively referred to as *prognosis*. While the future is uncertain for all people, whether they live with a disease or not, prognosis serves to allay some of that uncertainty by foregrounding some possibilities regarding disease course as more probable, even certain, than others. Prognosis thrusts people into the future. It gives a sense of reassurance to the person that the future, no matter how undesirable it might be, is determined, and at the same time, relieves the uncertainty that accompanies diagnostic practices and processes (Risør and Nissen 2018). Yet, there is tension between this foregrounding of epidemiologically more probable scenarios and lived experience, where certainty is elusive. Further, this tension is complicated by structural and historical forces that act upon people.

For Maggie,[1] a Welsh woman in her early seventies, and her husband Gareth, who lived with motor neurone disease (MND), these tensions were foregrounded when the biomedically prognosticated early death did not arrive, highlighting both the reach of biomedicine as the hegemonic regulatory framework in the UK governing health-related perceptions and actions and its limits. The deferral of a certain future, death, called other futures into existence, requiring action in the present. The ensuing shifting prognostic landscape brought with it new challenges and demanded action to address the loss of abilities, such as decreased control over the body and paralysis, leading to changes in daily activities.

Incurability and an early death are often communicated to people with MND and their families as the only certainties, either at the point of diagnosis or soon after (Seeber et al. 2019). In this article, we explore the ways in which Maggie and Gareth enacted different temporal orientations, when the expected future—Gareth's early death—failed to arrive. Rather than critiquing the reach of the biomedical practice of prognosis, and its effects, important as such a focus might be, in this article we turn our attention to the ways in which Maggie and Gareth tried to not only imagine multiple futures but also to act upon those imagined futures in the present. We argue that the lived experience of prognosis demands a temporal orientation towards multiple presents and futures, mutually exclusive and yet all possible, involving not only imagining what those futures might be like but also acting in the present to address the problems these futures hold. Further complicating this are the lived realities of gender, generation, and social class, which permeated Gareth and Maggie's understanding of the prognosis and its implications. In the next paragraphs, we will first explore what living in prognosis entails, both in terms of temporal orientations and actions taken, before exploring the ways Maggie and Gareth took action in the present to address future problems.

Living in prognosis

When something with their bodies is not working the way it is supposed to, people subject to the regulatory power of biomedicine first seek a diagnosis, for themselves or for the people they care about; the 'second step is to search for a cure' (Manderson 2016: 242). MND, also known as amyotrophic lateral sclerosis or Lou

Gehrig's disease, however, is one of those conditions for which no cure is currently available. It is an incurable, neurodegenerative disease of unknown aetiology (Eisen 2009). People with MND are 'not just sick, but inexplicably sick' (Wikan 2000: 215). MND can lead to the complete paralysis of voluntary muscles, affecting functions such as walking, eating, talking, and breathing. The average survival expectancy after diagnosis is three to five years; however, this can be up to thirty or more years depending on the type of MND.

The power of the performative utterance of diagnosis and the ensuing prognosis can interpellate people to a specific kind of subjectivity, that of a *sick* person, and, in the case of people with MND, that of someone who can and in fact ought to, expect to die within a few years. People diagnosed with MND learn that a future without MND is no longer possible; they live in prognosis.

Drawing on ethnographic work with people living with cancer, Sarah Jain argued (2007) that people 'living in prognosis' make decisions in the present based on what might, or might not, happen in the future, in a constant and irresolvable tension between the factuals—the predicted outcome—and the counterfactuals—alternative outcomes—of prognosis. Living in prognosis for people with MND holds together both the fact of a radically reduced life span, constituted through the ramifications of prognosis and prevailing media imagery,[2] and its counterfactual, the possibility of unexpected survival, due to, for example, a changed diagnosis or the development of disease-modifying therapies. Prognosis 'projects a future as it acts as a container for a present' (Jain 2007: 79), while at the same time allowing the existence of a variety of future possibilities, drawing not only from a biomedical discourse of diagnosis and treatment regimes but also from lived experience. Living *in* prognosis calls for a temporal orientation towards a subjunctive future tied to disease progress and possible technological developments, creating presents that 'are necessarily understood as contingent upon an ever-changing astral future that may or may not be known for certain, but still must be acted on nonetheless' (Adams et al. 2009: 247). While those so affected cannot know the future, anticipating it allows people to produce potential futures (Adams et al. 2009; Lemos Dekker 2020).

Anticipating the future requires imagination, which Lisa Stevenson (2014) argues is an important methodological tool allowing access to the uncertainties of life. People construct images of what was, what is, and what has yet to be, linking them together with fears and hopes, what has been and what might have been, what will be and what might be. Such an imaginative horizon involves imagining what might lie beyond the present, what possibilities might emerge in the future (within the realm of what is culturally imaginable), and what these might look like (Crapanzano 2004). This may also include what Natashe Lemos Dekker called an 'unwanted future' (2020: 1), that is, a future that is feared and undesirable.

Anticipating the future requires action in the present. The process of making concrete decisions in the here and now—informed by the diagnosis and the resulting prognosis, by what is and what may be—is complicated by the fact that the future is unknowable. Although people living in prognosis may act as if the future is already taking place in the present, there is always room for other, alternative futures that counter prognostic norms; Maggie and Gareth can only know what *might* happen but not what *will* happen. This means they need to make decisions based on possible futures which may not arrive. While they may be in suspense waiting for what might happen, decisions still need to be made to address the future, and by so doing, certain possibilities are foregrounded, fixing the future in time, through acting as if it has already arrived, while at the same time remaining open to other outcomes.

Everyday experiments in living

In this article, we conceptualise *living in prognosis* as a lived experience, rather than as a universal category, unfolding as people seek to contend with ways to reconcile the unknowability of the future with the need to do something about it in the present, to address problems that have not manifested yet but which may do so. People living with serious illness, together with other people significant in their lives who perform practices of care, engage in intensive future-orientated decision-making; this process involves decisions on medication and palliative care, advance care directives, living wills, finances, preferred place of death, and beyond. It is not only such big decisions that matter. The seemingly mundane and often taken-for-granted activities of everyday life can emerge as sites of uncertainty: deciding on a holiday a week or a few months in advance, planning to meet a friend, or going out shopping, can all become sites of tension and experimentation.

Cheryl Mattingly (2014) introduced the metaphor of a moral laboratory as an imaginary illustrating how people try to create a life for themselves and for those they care about. The moral laboratory for Maggie and Gareth was everyday life itself, and through that they tried to achieve a notion of normality that worked for them. These were experiments in constructing a good, or better, life and, like all experiments, some were successful, and some were not. Maggie and Gareth had to experiment with everyday activities and sometimes modify them. These experiments did not happen somewhere outside of everyday life, in a controlled space, but rather they were accomplished in their kitchen, in their garden, and in their bathroom, among other settings; they were the product of a vulnerability of established practices (Criado and Callén 2013) and were about being able to go for a walk, eat, participate in social gatherings, or share a bed, now and in the future.

Unplanned survival can also be part of that future. One aspect of this is that people who previously expected to die within a short period of time can now expect to live, moving from a planned death to an unplanned survival (Block 2020). Introducing this term, Pamela Block (2020) called attention to the social and bio-technological advances that are widely available, even expected, within biomedicine and which have made possible the survival of people with severe impairments. Unplanned survival, tied with a politics of hope, occurs when people who expected to die do not die when prognosticated; this could be because of misdiagnosis, a slower disease progress than expected, new treatments being made available, a cure, or for reasons that are not always apparent.

For people with MND and other neurodegenerative conditions, incurability and imminent death often emerge as the two certainties that guide decisions, such as early retirement. Living in prognosis holds together both the facts of incurability and deterioration and the counterfactual of unplanned survival, as we show in this article. A new disease-modifying drug, or a cure, may emerge, or the disease's progress may slow down or even halt, making hope possible, despite the future constituted by the prognostic interpellation. If unplanned survival can postpone death, it also unsettles plans and highlights tensions between multiple presents and futures.

The study

This article is based on a study conducted between 2011 and 2013 in Wales, UK. We used narratives to foreground what was at stake for specific people as they sought to create a life *with* MND (Mattingly 2014; Murphy 1990; Kleinman 1988). We were guided by a first-person perspective (Mattingly 2014), privileging lived experiences and attending to the minutia of everydayness. While our analytical focus was drawn to experience and how people made sense of it, we acknowledge the broader discourse within which the prognostic utterance shapes the emergence of specific kinds of futures, entailing gendered practices of care and attitudes towards disease and death.

Long-term engagement with our interlocutors facilitated the creation of stories of life with MND, which not only highlighted that 'illness and reality are open to mystery, potency and change' (Good et al. 1994: 837) but also, more importantly, allowed us to follow the changing narrative as the certainties of Maggie and Gareth's future changed over time. Narratives revealed not only what the interlocutors who participated in the study did to the world, their actions, but also what the world did to them and how they interacted with the world around them (Mattingly 1998), as they orientated themselves towards multiple possible futures, some of them desired and some of them dreaded. What emerged here was not dissimilar to the narrative subjunctivising tactics described by Byron Good (1994): the recognition of multiple perspectives within the narratives ensured that multiple possibilities were kept open, imagined and, to some extent, made possible, demonstrating how Maggie and Gareth worked to overcome the incommensurability of possibilities, both disparate and uncertain.

The first author conducted twenty-one interviews with seven people (four diagnosed with MND and three partners of those so diagnosed) over the duration of the study. Each interlocutor was involved in the study for an average of twelve months, allowing several opportunities for observations, interviews with key informants from the MND Association, and phone calls. The first author conducted five joint interviews with Maggie and Gareth over the course of fifteen months, complemented by several phone conversations with Maggie. All interviews were conducted at their kitchen table, where they spent a large part of their day.

When, early in the study, it was suggested to Gareth and Maggie that they be interviewed separately, they expressed a strong desire to be interviewed together. They viewed living with MND as a shared, intersubjective experience; their first-person perspective moved between a singular *I* to a *we*, fragmented as this was at times. Consequently, they were interviewed jointly (Sakellariou et al. 2013), acknowledging that the 'coupled relationship will influence how the course of the illness is negotiated by the patient' (Taylor and de Vocht 2011: 1576). Interviews were constructed as multivocal occasions between three interlocutors: Gareth, Maggie, and the interviewer. These interwoven and co-created narrative threads themselves underscore the subjunctive nature of their stories (Good et al. 1994).

The relatively long involvement of Gareth and Maggie in the study allowed the development of rapport, facilitating a degree of deep sharing, and an exploration of the couple's shifting orientations to temporality. This included a shift from a joint story to privileging Maggie's story. As Gareth's health declined, Maggie took on the task of imagining the future for herself, for Gareth, and for both as a couple taking action in the present. The material presented below reflects this shift, moving from an initial focus on Gareth and Maggie to a foregrounding of Maggie's voice later on, mirroring Gareth's declining communicative abilities and Maggie's increasing responsibilities as his carer. This study was approved by the Research Ethics Committee of the School of Healthcare Sciences at Cardiff University.

A *different* kind of MND: Fixing unfixed futures

Maggie and Gareth were both in their early seventies at the time of the study and had been married for more than forty years. They grew up in working class villages in South Wales and married in their twenties. Domestic life was strongly shaped by gendered roles and expectations,[3] with Gareth being the main income earner; Maggie worked but was responsible for the bulk of domestic work and care in their family. Having worked hard all their lives, they were able to buy a house in a coastal village, in what only later became a very affluent area, as they were both quick to point out when we first met. Gareth was diagnosed with MND nine years before our first meeting. Prior to Gareth's MND diagnosis, they had anticipated a long retirement travelling, playing golf, spending more time with their grandchildren, and just having a good time. The MND diagnosis and the ensuing prognosis changed this, thrusting them into other futures.

Most people diagnosed with MND have a fast-progressing variant of the disease and at the point of diagnosis are often told they have three to five years to live. Gareth kept on working for one year after he was diagnosed and then he retired as he felt he could no longer cope with the demands of the job. Maggie decided to stop working as soon as they got the diagnosis in order to care for Gareth, as they both thought they would have only a few more years together. The prognosis called into existence a specific kind of future, anticipating not only what would happen but also when, thus *fixing the future* in time, providing a specific temporal horizon; death was scheduled to arrive at a rather specific point in the future: within three years. It was not just an early death that was called into existence but a specific future that was anchored in that undesired, yet certain to arrive within three years, death.

Fixing the future simultaneously operated in a second way, allowing Maggie and Gareth to make plans for their future, informing decisions which were predicated on that particular future. If the first way fixing the future worked was by setting in time, this second way orientated them towards ways to address problems that had not yet appeared and was thus concerned with repairing and remedying rather than setting. Both can be seen in the following excerpt:

> **Maggie:** Yes, yeah. And, uhm, and then of course as soon as we got this diagnosis, I gave up work, more or less straight away, because we thought…you know, Gareth wasn't going to be around for very long. So, I gave up work to look after him and that's what I do. And that [is how] our day is filled then, with me looking after him.

However, Gareth was consequently re-diagnosed with a slow progressing form of MND, which entailed a more extended life together and necessitated a longer period of caregiving than Maggie was led to believe based on the initial prognosis they were given. At the time of initial diagnosis, the anticipated future demanded decisions; they took the one they thought would allow them to be together longer, for the limited time they thought they had left; everything else receded into the background. However, that dreaded yet expected future failed to materialise, contesting the definitive character of prognosis, and indeed, diagnosis (Risør and Nissen 2018; Warren and Manderson 2015). Gareth's unplanned survival unfixed the future and required different temporal orientations: one future got postponed and other futures approached.

Maggie and Gareth prepared for a future anchored in an early death, which was experienced as a certainty; that is what they were told at the point of diagnosis, and that is how they 'thought it was going to be'. They made decisions based on future possibilities that they lived as if they were certain, guided by the social power of prognosis as incontestable fact. The power of prognosis here is influenced by the cultural context in the United Kingdom in which people expect to be in control over their future. This agentic patienthood is reflected (and deterministic of) the shift to responsibilisation in health (Armstrong 2014; Pickard and Rogers 2012). There is an expectation that biomedicine provides an indication of what that future might look like, how things might develop over time with regards to bodily symptoms and changes, and how people might live and care during that period.

When the anticipated future did not materialise and became unfixed, another narrative was required, something that would help them construct a liveable life into a now extended future. Gareth had a *different* kind of MND, which was associated with other futures and social expectations. What emerged was a constant dialogue between the fixings (setting the future but also remedying it) which were desired by Maggie and Gareth and offered by prognosis, and the unfixings which occurred as their lived experience unfolds over time, contesting various prognostic elements. We illustrate this further in this article.

Known effects and unknowable futures

Soon after our first interview, Gareth's legs became weaker and he found walking difficult and had to reluctantly stop going out for coastal walks. A few months into the study, Gareth started using a wheelchair when outdoors, enabling them to go out for walks again, although no longer on the beach. However, the wheelchair had to be put into and out of the car. It needed to be lifted, collapsed, and pushed open again. And it had to be propelled. Gareth could not self-propel, so Maggie had to do that, and although she enjoyed being able to go out for walks with Gareth, she found all these accompanying tasks tiring. Having lived in the same neighbourhood for many years and having an extended local network of friends, Maggie and Gareth often accepted help from friends. Their three grown-up children also supported them, as commonly expected in tight-knit families in Wales, although they did not live locally. Friends and family helped with rides to hospital appointments, carrying luggage when travelling, or helping to lift Gareth when he had a fall.

As they both aged and Gareth's MND progressed during the course of the study, Maggie had to offer help for a growing number of activities, orientating themselves to the present, and the day-to-day practicalities of living with neurodegeneration. Driving, paying the bills, propelling the wheelchair, and more intimate activities, such as toileting, bathing, and dressing, demanded the attention of both.[4] Maggie was there to offer help when Gareth could not do something or when he found an activity challenging. In brief, she carried out what Arthur Kleinman and Sjaak van der Geest (2009) called the *technical/practical* elements of caring. She did more than that though, as she was also engaged emotionally in the process of caring for Gareth and also caring for all that held them together.[5]

Three days before their fortieth wedding anniversary, instead of getting ready for a holiday to Turkey (an almost annual getaway to the sun), they were at home waiting for a wheelchair to be delivered. Gareth could no longer walk safely without holding on to objects, and holidays overseas were just getting to be too difficult to organise, as they involved help from friends and family, airport and airline employees, and hotel staff.

For Maggie and Gareth, their space shrunk while time expanded; they experienced a shrinking repertoire of activities, as more and more spaces, like airports, were no longer accessible over an (unexpectedly) longer life.[6] Over the course of the study, Gareth stopped going to a choir he had been part of for many years, could no longer tend to his garden, and by the time of our last meeting, he considered no longer going to the local pub, something he had been doing regularly for many years with his friends.

This spatial and temporal reconfiguration of their lives brought about more changes:

> **Maggie:** I have to pay all the bills. Just do everything that most husbands do, plus what a wife does, all the cooking and cleaning…the driving. It has made a big difference.
> **Gareth:** We've changed now. I do the beds and the ironing [he laughs].
> **Maggie:** Yes…so…life has changed…drastically.

'Life has changed drastically' means that the roles they had learned to perform and the positions they occupied in their relationship had shifted. The spatial reorganisation of their lives in response to the temporal reconfigurations, necessitated new ways of being. Nancy Fraser (1989) argues that care is located within local contexts and is part of peoples' lives and their structures of interdependence. Through four decades of shared living in what Maggie called 'an old fashioned marriage', with clearly defined gender roles, Maggie and Gareth had established a repertoire of activities and constructed social identities that were closely related to these activities; Gareth was the avid gardener and prize-winning vegetable grower; Maggie viewed herself as a wife and mother, who worked and ran a household that included three children, and later on several grandchildren.

In that drastically changed life, it was a notion of normality, not defined by disease but shaped by everyday life and all its exigencies with which Maggie experimented. Maggie's hoped-for future excluded the things she wanted to avoid, while the process of planning for that future gave her an element of control over it, reflecting the constant swaying between having things done to her and Gareth by the world around them and doing things to that world.

Gareth and Maggie's practices point to the ways people can become affordances for each other (Dokumaci 2020), unravelling the fiction of an autonomous, independent subject and instead highlighting the ways that people are interdependent as they seek to care now for the future, repairing problems that although have yet to manifest, already matter. The same practices leave open the possibility for their failure; Maggie could not know if she would still be able to help Gareth in the future. Living with a progressive disease, Maggie and Gareth did not have a way of knowing how things would unfold in the future. While, for example, several people with MND have breathing problems or are unable to eat because of weakened chewing and swallowing musculature, these problems do not affect everybody, and there is no way to known when they might appear. Will Gareth still be able to walk, and if not, will Maggie be able to push the wheelchair? Will their group of friends, also ageing and living with illness, be able to be there with and for them? Will Gareth need a percutaneous endoscopic gastrostomy or non-invasive positive pressure ventilation, and if so, will Maggie cope with this extra caring responsibility? And if she can cope with it, for how long will she be able to hold it all together?

Preparing for the future

An unexpectedly longer life requires a new orientation towards a different yet unknown and unknowable future. This unknowability was both desirable and undesirable: knowing can bring its own set of challenges, just as not knowing does:

> **Maggie:** When we ask, they say everybody is different. So, in a way, it would be nice to know how things are going to go, but on the other hand, I don't know whether I want to know, or just rather go blindly forward, because you can't do anything about it, you can't do.…If somebody said you could take multivitamins, you [could] do all that, change your diet, you'd do all to make him not suffer…but we can't.

Although biomedical discourse creates the illusion that prognosis only or mostly communicates certainties and facts, it often also communicates the opposite: the wide variability in manifestations of MND symptoms means that nobody knows how MND will progress for specific people; the best a prognosis can do is offer probabilities[7] (Jain 2007; Puar 2009). These, however, can be of little use as they lack the specificity of the everyday. It is a crazy world, as Gareth says in the opening quotation, a world where things that one expected to be able to do, are no longer possible. In the absence of personalised information, Maggie did not know what to do in the present to make things better for and in the future, oscillating between different actions, in the space of uncertainty. This uncertainty led to multiple temporal orientations, going from long-term visions of the future to short-term ones, or even present-focused ones:

> Gareth just thinks these are the cards that we have been dealt and we've got to deal with it [Gareth nods].…All the plans that you've made all through your marriage, the children are grown up, are off your hands, retirement, you know…but of course that all came to…you go from having a wide horizon to having one that is very close to you. You don't think much further ahead than, uhm, a month or two really, if that.

The unfixing of the future, first through the MND diagnosis and then through the unplanned survival but still within a horizon of a limited life, required new ways to relate to what might come. What happens when the orientation towards a long-term future may no longer be possible, or desirable? While Gareth tried to focus on the present, Maggie maintained a future orientation, informed by the prognosis and trying to prepare for the future:

> **Maggie:** Yes, we've been in touch with the social services, since that meeting, and they all said, 'had we applied for any help?', and we hadn't, but since that meeting, because the meeting was mainly about anticipation with MND, sort of trying to get things in place before, before you come to a crisis, I got in touch with the, uhm, critical illness nurse at out surgery, and she arranged for a social worker to come and we are now putting in place, uhm, no, hang on, the occupational therapy people have been out and have made an assessment and are drawing up a plan.

Maggie took actions in the present to shape the future; it was about 'drawing up a plan' to ensure a liveable future. Since the future held the possibility of things suddenly being taken away from them, never to come back, as the excerpt at the beginning of the article shows, Maggie could prepare for some of the anticipated losses by optimising the future, through, for example, having a care plan in place for when/if it was needed and acted in the present as a way of addressing these potential, yet *real* because they mattered, difficulties. While they had to wait, since nobody knew what the future would bring, Maggie and Gareth were also called to take action for that uncertain future, in ways reminiscent of Michael Jackson's (2016: 25) discussion of negotiations between 'agency and patiency'.

Stories about what might have been or might yet be are closely related to the stories people enact in relation to what they hope for and what they are afraid of:

> **Dikaios:** Are you always aware of MND, since the word was first mentioned nine years ago, has it ever left your mind?
> **Maggie:** No, no, every day. Especially now, it's affecting us all the time. It can't, you can't put it to the back of your mind. Gareth does [with emphasis]. He, he, he just sort of, I don't think he thinks about it, he never talks about it.
> **Dikaios:** How do you think he manages to do that?
> **Maggie:** I think it's ignorance, I don't think he knows. I haven't told him what, what he is going to be like. I know what he is going to be like, which is not good. So, he doesn't worry about it. And with his memory loss as well, I think he just lives in the day. He's got no, he can't remember the past and, because he's got no imagination, he can't imagine what the future is going to be like, so he just lives in the day, which is good for him, I suppose. I am the one who…but then, I don't think about it. Uuuh [sigh]. A friend of ours died with MND, living up the top of the village, three years ago. I remember his wife taking me on one side and saying, 'oh Maggie, I feel so sorry for you, because', she said, 'Eddie's death was horrendous, [he was] choking and couldn't breathe'.

And later on, during the same interview:

> I got this picture in my mind that…it's coming in a couple of years' time, you won't be able to get out of bed and I think…whilst you can get out of bed, we should be doing…going somewhere and doing…that's why we go out every day.

Maggie anticipated what might come, exploring not only future factuals and counterfactuals but also past ones: could they have done something to prevent MND? Was it somehow their fault, or was it just bad luck? Such past factuals and counterfactuals helped Maggie make sense of a future where anything can be taken away without warning, including Gareth's life. After all, unplanned survival cannot ward off death, it just delays it. Maggie sees the future 'coming', and this shapes her, and Gareth's, present. For Maggie, MND evokes a future where her husband will not be able to get out of bed and might choke to death, like their friend did.[8] Going to support groups organised by the local branch of the MND Association, Maggie was up to date with information showing that most people with MND die peacefully due to respiratory failure, losing consciousness, rather than by choking. Yet, the image of the future that MND takes her to is that of her husband choking to death. Living in prognosis then, for Maggie, allowed a rehearsal of the possible futures—including her fears related to these.

Maggie appeared to take responsibility for imagining the future and organising her and Gareth's life in preparation for what might come, in an effort to create an inhabitable world (Friedner and Cohen 2015), a world with disability where they could keep on living, retaining a sense of who they were; in other words, a world not dominated by the exigencies of neurodegeneration but guided by Gareth and Maggie's desires and needs. While Gareth, according to Maggie, did not think (or, perhaps could not think in a way recognised as valid[9]) about a future that was unknown, orientating more towards the present rather than the future, Maggie anticipated difficulties to come and did not know how they would cope with these new, but yet unmanifested, challenges. She made choices in the present, in anticipation of problems that had not yet arrived, and she could not know how her/their choices would turn out. As she put it, 'how life is going to be in the future, how difficult it will get, we don't know'. Indeed, Gareth's unplanned survival, unsettled the future, demanding their attention and action.

Final remarks

Gareth's unplanned survival offered a narrative countering existing prognosis. It subjunctivised his and Maggie's futures, deferring death and leaving room for alternative futures to unfold. In this article, we explored what happens when those potential futures are themselves both limited, in terms of the months and years of life yet to be lived, and indeterminate. Maggie and Gareth oscillated between multiple presents and futures, as they worked to create a desired or *best possible* life (Rose 2007), or anything in between, seeking to fix an unfixable future—unfixable because neither death nor neurodegeneration could be warded off. We argue that, for Gareth and Maggie, prognosis demanded a temporal orientation towards multiple presents and futures, creating tensions between what is and what might be, and between fixing the future in time through the expectations associated with a prognosis of an early death and taking action to make things better (now and in the future) through daily engagements towards an uncertain future, just as that future became unfixed, and in fact unfixable. If for Jain prognosis can be seen 'as a technology of mourning, holding together the future and the past' (2007: 90), in Maggie and Gareth's story, prognosis called into existence a different kind of technology, fixing a future that cannot be fixed.

While uncertainty is a feature of life, with or without illness, Maggie and Gareth were called by the prognostic interpellation to foreground specific possibilities as certainties and take action in the present to address those problems that were yet to materialise. When these problems, however, did not arrive, the future was unfixed, leading to new futures being imagined and other actions taken to address those other futures. Fixing and unfixing the future refers to allaying the uncertainties of living, by using prognosis as an anchor that creates a certain horizon of possibilities and desires, while at the same time contending with the subjunctive nature of prognosis, whereby the anticipated future might not arrive, or might not arrive when expected. The story presented illustrates the ways in which the concept of 'fixing' is both temporal and remedial and is anchored in a specific historical and structural context.

Neurodegenerative disease complicates what fixings can be mobilised depending on life stage, gendered relations of care, and imaginaries of biomedical possibilities. While diagnosis can appear to communicate an incontestable fact, this belies the uncertainty inherent in prognosis; several possible futures can co-exist, including unplanned survival *and* an early, or earlier, death. Past, present, and future are inextricably entangled, leaking into each other. For Mattingly, '"actuality" consists not simply of things that happen but also of things that might happen…as well as things that might have happened' (2014: 28). These stories that could have been or might yet be, are closely related to the stories people enact in relation to what they hope for and what they are afraid of. Thinking about worst scenarios, or about the best possible outcome, can steer people into action. If the future includes both the things we hope to happen *and* the things we try to avoid or are afraid of, we often plan in order to go from an unpleasant now to a hoped-for future (Crapanzano 2004). In other words, 'we act in order to bring certain endings about, to realise certain futures, and to avoid others' (Mattingly 1998: 93).

Maggie orientated herself temporally in relation to Gareth's illness, anticipating what might come. This temporal orientation, however, was neither static nor morally neutral; Devin Flaherty (2019) discussed how different modes of anticipating, including *not* anticipating a future that includes an early death, can be seen as forms of moral willing, whereby people seek to shape the imagined future and construct alternative outcomes. Such 'kinds of "endings"' (Mattingly 2019: 20) may or may not be informed by the diagnosis and its associated prognosis.

Anticipation is a lived experience, drawing people's attention to different temporalities, past, future, and present linked to disease progress, hope, of fear, and caring (Stephan and Flaherty 2019), leading to experimentation in response to an unknown future that matters; it also requires action (Lemos Dekker 2020). For Vincanne Adams and her colleagues (2009: 249) 'anticipation…is a moral economy in which the future sets the conditions of possibility for action in the present, in which the future is inhabited in the present. Through anticipation, the future arrives as already formed in the present', and something must be done about it. The present, then, becomes contingent upon an unknown future, one that is both uncertain and inevitable.

Living in prognosis includes both what is seen as a future that has already arrived and alternative scenarios: the information that Maggie and Gareth had was that while most people with MND will require mechanical ventilation, some will not and although informed predictions can be made, the future includes both possibilities. Holding these different, seemingly mutually exclusive, futures together calls for ways of anticipating, or not, what might come and what to do now about these yet unmanifested problems. This new temporality draws attention to 'bodies and events that confound attempts to fold easily into and out of the distinctions between living and dying, and to reflect shifting, capacious, porous and contradictory parameters of bio and necro politics' (Puar 2009: 163). Who is let to live and who is let to die, and their opposites, point to the ways biopolitics shape experiences of life and death, intersecting with the availability of and access to treatment, and subjects' recognition as worthy of affective and medical care.

The actions Gareth and Maggie took, alone and together, and the stories they enacted about their intersubjective life, were all, to some degree, tied to a future that was both uncertain and inevitable (Warren and Sakellariou 2020). For people who have received a diagnosis of an incurable and life-limiting disease, the future includes an expected death. While resistance is possible, the social currency of prognosis in many societies is such that once uttered it often becomes inescapable and needs to be acted upon. Gareth and Maggie were asked to do something, whether it was planning for a future with MND or for death, accommodating that future, accepting it, denying it, or fighting it. What emerges is a constant dialogue between multiple futures, pre-determined and uncertain, and practices that aim to repair the future, even if they cannot do so.

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Notes

1. We use pseudonyms for our two interlocutors.
2. Recent MND awareness campaigns have used fast-moving bullets to refers to the illness (campaign by the ALS Association, USA, https://www.youtube.com/watch?v=DAQrUDAhoz0) and represented MND as something that can strike unexpectedly, quickly leaving people helpless on the ground (campaign by the MND Association, UK, https://www.youtube.com/watch?v=4b-h_XBArC4).
3. Gender roles in rural South Wales tend to be more fixed than dynamic, especially among people of Maggie and Gareth's generation. Women are not only expected to carry out the domestic chores but they also believe this to be their role. See Dawn Mannay (2014) for a fuller discussion of the ideology of the Welsh Mam, a woman who has the moral responsibility to take care of her family. See also Rogers and Weller (2012) for a critical discussion of care as a gendered practice.
4. Care is conceptualized as a moral, political, and ethical orientation in which the concerns of another are prioritized (Puig de la Bellacasa 2011). Originating in the obligations that people have towards one another, care is produced in interactions between people and operates through assemblages—comprised of human and non-human parts—that facilitate the practice of everyday living. Arseli Dokumaci (2020) discusses how people can become affordances for others through their bodies, realising possibilities through coming together in ways that not only appear to be but sometimes are also experienced as ingrained in daily routines, and thus performed as a matter of course. Care can be seen as an affective, embodied, and intersubjective practice that reflects and is reflected in relations between bodies but also between bodies and formal structures and institutions. It is also a resource that can be used (or not used) to reduce or create power relations (see Warren 2021).
5. See Hilary Graham (1983) for a discussion of caring as a labour of love.
6. Writing on living with breathlessness due to lymphangioleiomyomatosis, a rare and incurable lung condition, Havi Carel (2016) describes how the progression of the disease is accompanied by a shrinking social environment of daily activities, and how such a smaller repertoire becomes a new normal. As social worlds contract, people's capacity to make decisions changes and largely puts the possibility of reversing this social transformation increasingly out of reach, leading to a recursive process whereby increasing challenges start to outweigh creative imagining of the future (Manderson and Warren 2016).
7. For Jasbir Puar, prognosis is inherently tied with hope through the articulations between 'prevailing notions of chance, risk, accident, luck, and probability, as well as with bodily limits, incapacity, disability, and debility' (2009: 163).
8. Vincent Crapanzano (2004) wrote about how the use of a place-name can act as an anchor to a past event, evoking a situation; mere reference to that name can then take the people who recognise it to that event, conjuring emotions and memories, linking these to unfolding events. Illness names can function in a similar, yet drastically different, way. Whereas place-names take people to a lived, or sometimes imagined, past, illness-names, like motor neuron disease, conjure images of the future, informed by existing knowledge and reminding people of problems yet to come.
9. While only a small number of people with MND develop frontotemporal dementia, evidence indicates that a much larger number of people develop milder frontotempoeral dysfunction, affecting executive functions, including memory, organisation, and planning (Lillo and Hodges 2009).

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