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NAVIGATING MEANDERING THREADS

A critical and creative thesis delivered in
partial fulfilment of the requirements for the
degree of
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of Creative Writing

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Abstract

This Master of Creative Writing thesis consists of two sections: a critical essay which analyses features of the braided form in 'Time and Distance Overcome' by Eula Biss and 'The Fourth State of Matter' by Jo Ann Beard, and a collection of personal essays recording my experience of living with motor neurone disease.

Being diagnosed with motor neurone disease fractured my world and has raised many unanswerable questions. I knew that I needed to tell my story, but parts of it seemed too painful to tell. I was interested to see how other writers attempt to make meaning of a world that becomes fractured for them, and after reading a selection of lyric essays, I discovered the fragmented form of the braided essay. Made up of several seemingly unrelated topics or narrative threads, the braided essay provides space for the writer to approach painful or complex material indirectly, blending it with other material to draw the focus away from what Brenda Miller refers to as the "emotional center" (69) of the piece.

Eula Biss and Jo Ann Beard are two essayists who use features of the braided form in their essays in an attempt to make sense of a complex world, Biss to explore racial violence in the United States and Beard to confront her own grief after a workplace shooting that killed six of her colleagues. With its use of fragmentation and white space, and the repetition of details that unite each strand, the form of the braided essay seems to reflect its content, making it well suited to writing about a broken self and a broken world.

In approaching my own personal essays, I drew on the features of style and structure employed by Biss and Beard, and in doing so I was able to navigate around my grief and fear and frustration and see that woven through it all was the importance of family and friends,

the importance of love. I have been able to confront my own mortality by taking refuge in the braided form, while hopefully leading my reader in leaps and sidesteps towards an understanding of motor neurone disease and living while dying.

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Navigating Meandering Threads

Introduction

In her essay 'The White Album', Joan Didion stated, "We tell ourselves stories in order to live" (185), but in order to live we need to make meaning of ourselves and the world we inhabit. This would be straightforward if the world and our place in it wasn't so complex. Although we progress chronologically through the world, living in it seems to be more haphazard than linear, and more often than not, we struggle to make meaning of it at all. How do we make meaning of a mass shooting, for example? or racial violence? or a diagnosis of motor neurone disease? For writers of the lyric essay, one way to make meaning is to look at it "from a distance ... but with a sidelong glance" (Michel de Montaigne), a sentiment shared by Deborah Tall and John D'Agata who felt it was "less possible (and rewarding) to approach the world through the front door". To write about ourselves or our world from a different angle - through a side door, a back door or even a window - may be a less daunting way to approach writing about a subject that is too complex, or too painful, to explore in a conventionally linear manner.

The use of the braided form of the lyric essay enables the writer to take refuge behind the essay's structure while writing her way towards an understanding of material she might otherwise be unable to look at directly. Made up of several topics or narrative threads woven together, these essays employ what Brenda Miller refers to as "peripheral vision" (69), as they draw the gaze away from what she describes as the "emotional center" (69) of the subject. Miller compares the braided essay to challah, describing the strands of dough that make up this neatly plaited loaf of bread as having "a sense of weaving about it, interruption and continuation" (47). The analogy is fitting, but I would argue that the intertwining strands of a plait of challah are too neat and precise for the meandering structure of the braided essay and the complexities being explored within it. I prefer to think

of the braided essay as being more like the braided rivers of New Zealand's Canterbury Plains. These rivers spill down from the upper reaches of the Southern Alps to the expanse of the plains, where they become multiple channels that repeatedly branch and rejoin, shaping and reshaping the landscape before draining into the Pacific Ocean. Like these rivers, the braided essay, with its multiple meandering threads that meet and divide, alters the landscape of meaning for the reader as well as the writer by offering what Eula Biss described as "a kaleidoscopic look at a question or a problem" (Susan Lerner). The narrative braids, and their use of fragmentation and white space, fracture the text, disrupting its continuity, but in doing so "bring the reader into an arena where questions are asked" (Miller and Paola 121). The reader is drawn into the writing process and invited to "piece together possible answers and interpretations" (Miller and Paola 121), joining the writer in making sense of her fractured world.

Both Eula Biss and Jo Ann Beard use the discontinuous structure of the braided essay in an attempt to make meaning of their own fractured world. In 'Time and Distance Overcome', Biss uses the invention of the telephone to reflect on the threat to human connectedness in the world while Beard uses her dying dog and dying marriage in 'The Fourth State of Matter' to come to terms with the workplace shooting of six colleagues. Both essays fulfill Nicole Walker's belief that the essay "tries to see something others can't see. It tries to believe something others don't yet believe. The essay says, Look at what's happening. It says, Do not look away until you see the things you didn't want to see. Then the essay says, Look until you figure out how to make it better." By approaching her essay with the "peripheral vision" of multiple meandering threads, each essayist is able to 'figure it out' and create new meaning for herself and for her reader.

Only Connect

In 'Time and Distance Overcome', Biss interweaves three seemingly disparate ideas to reflect on the threat to human connectedness in America. The essay was written in 2008 and appears in her collection of essays, *Notes from No Man's Land*, which won the 2010 National Book Critics Circle Award in Criticism and the Graywolf Press Nonfiction Prize. What begins as a meditation on the invention of the telephone and the subsequent proliferation of telephone poles across the United States leads to an observation on the use of these poles as gallows to lynch thousands of black men during the late nineteenth and early twentieth centuries. Biss incorporates her personal connection to the telephone pole, inviting the reader to examine her own attentiveness towards issues of race and contemplate the role of each of us in shaping history. Using features of the braided form, such as fragmentation and white space, her essay "move[s] by association, leaping from one path of thought to another" (John D'Agata and Deborah Tall) and in doing so Biss highlights how human connectedness can and has become "distorted" (Biss 7).

Biss shapes her essay using fragments of text separated by white space, each fragment communicating with the other to illuminate her concerns about how we try, and fail, to connect. It is the telephone pole that ties these threads together, but Biss enriches the meaning by including other details in each narrative thread that work in opposition to each other, adding to the essay's cohesiveness and allowing the reader to "see it whole" (D'Agata and Tall). The fragments describing Bell's invention, for example, reveal his intent that every home in the country be "connected" (Biss 3) by wires and "joined" (Biss 4) by a cable, uniting communities. Biss repeats the words "connect", "communicate", "join" and "unite" many times throughout these fragments to underscore Bell's vision, but it is only

when reading the fragments of text describing the lynchings that the reader is able to make the associative leap and understand how telephone poles have been used and misused. What began as a tool to unite the country has become a symbol of division. Biss juxtaposes society's responses to the invention of the telephone with the lynchings to highlight this division. When they were originally installed, the telephone poles were viewed as "urban blight" (Biss 5) that "marred" (Biss 5) the landscape and property owners "defend[ed] their sidewalks with rifles" (Biss 4) to stop them being erected. The public opposed their installation by "sawing" (Biss 4) and "chopping" (Biss 5) and cutting them down, the repeated verbs highlighting their active resistance, while their actions were supported legally by a judge who ruled that a man who chopped down a telephone pole was not guilty of malicious intent. Opposition was so strong that the *New York Times* described it as a "war" (Biss 4). By contrast, Biss presents the lynchings as public entertainment, conveying just how disconnected society had become. As well as emphasising the very public nature of the hangings that took place not only from telephone poles but "from bridges, from arches, from trees" (Biss 7), she includes details of men and women standing in cars to witness the killings, and describes postcards created from photos of charred and mutilated bodies hanging from telephone poles. And she again references the *New York Times*, this time quoting its response to a black man who was hanged, burned, shot, and stoned with bricks - an indifferent "before he was hanged he begged hard for his life" (Biss 9). Judges and law enforcers who are seen to support those that opposed the telephone poles, stood by as "one man was dragged out of the courtroom by a mob and another was dragged out of jail" (Biss 7) to be lynched. Biss juxtaposes these details between the two braids of the essay, creating "patterns of resemblance in parallel" (Rebecca Solnit) and leaves the reader with the understanding that it is people who are the real urban blight.

The use of fragmentation makes reading Biss's essay an "associative process" (Chelsey Clammer), the disparity between the fragments challenging the reader to figure out what the associations mean. Central to the reader's experience in making the connection between the telephone and the lynchings is a fragment describing the children's game of 'Telephone'. Biss states that the game "depends on the fact that a message passed quietly from one ear to another to another will get distorted at some point along the line" (7). On its own, the fragment is not revelatory - many of us have played the game of 'Telephone' and seen for ourselves how garbled the message becomes as it's passed from person to person. But by reading this fragment alongside the others, the reader is able to draw associations between them. The braided essay is a process of discovery with each fragment providing space to reveal its complexities, reshaping the landscape for the reader. The reference to the game of 'Telephone' in the context of the lynchings leaves us to ponder our own role in ensuring human connections do not become distorted.

It is the white space between fragments that communicates much of Biss's meaning about human connectedness, reflecting Brenda Miller's view, shared in an interview published on her website, that "sometimes what cannot be spoken is more truthful than what is verbalized". The unspoken dialogue that occurs in the white space in Biss's essay enables what Donna Haraway describes as a "thinking between" (34), inviting the reader to reflect on society's failure to connect. Perhaps the most powerful use of white space occurs at the end of the first section in a fragment that celebrates the success of the telephone. Despite the initial suspicion and hostility towards Bell's invention, the fragment closes with the words of Thomas Edison announcing that the telephone has "bought the human family in closer touch" (Biss 6). Biss then begins the next fragment: "In 1898, in Lake Cormorant, Mississippi, a black man was hanged from a telephone pole" (6). The silence created by the

white space allows the two fragments of text to comment on each other as Biss takes the reader from celebration to desolation. The effect is jarring and Biss amplifies this by using short, simple sentences to list other episodes where telephone poles have been used as gallows to 'crucify' thousands of black men. Biss has fragmented these lists into small blocks of text, perhaps using the white space as a 'non-thinking' space for the reader, a pause to exhale our held breath before the next assault. One can almost imagine Biss herself needing these breaks as she read the 2,354 references to lynchings in the *New York Times* that formed her research for this essay. In another fragment, Biss quotes from Herbert Casson's *History of the Telephone*, ending the fragment with his description of the "spluttering and bubbling, jerking and rasping, whistling and screaming" (8) noises that accompanied early telephone calls. These sounds are chillingly juxtaposed in the next fragment with the description of yet another black man "hanged from a telephone pole" (Biss 8), the white space becoming an echo chamber to highlight the man's torturous death. According to Biss, literature is "transformation you have to participate in" (Lerner), and by punctuating the fragments of text with white space, she makes sure we are attuned to the silence and ready to extract meaning by "thinking between" the fragments.

Biss's language is sparse, but the matter-of-fact tone and crude simplicity of her prose style doesn't lessen the impact of her writing. Much like the 'unspoken words' of the white spaces, what's left unsaid says so much more. She writes in short, simple sentences using concrete language to convey the stark horror of the killings, as if, like Michel de Montaigne, she needs to view this horror "from a distance". When she does write more lyrically, her meaning becomes highly evocative. Her use of a simile to describe bodies hanging "like flags in still air" (Biss 9) highlights the stagnation of American values and identity; the alliteration of the plosive 'b' in the description of a man who, while "his body

was burning, the mob beat [...] with clubs" (Biss 7), emphasises the violent brutality of the killing; the image of bodies "silhouetted against the sky" (Biss 9) as they hang is incongruous in its sibilant beauty. These richly descriptive moments propel the reader towards a new way of knowing and feeling, creating a shift in our perspective on the disconnectedness of our world.

The final section of the essay, its third braid, turns to Biss's childhood, a time when she regarded telephone wires as "beautiful" (Biss 11), telephone poles "glorious" (Biss 11) and the telephone itself "a miracle" (Biss 11). Once again, the reader is compelled to participate in this narrative when she reflects that "now [...] nothing is innocent" (Biss 11) and we are forced to confront our own place in the complexity of history. The word "now" brings the essay full circle as the reader makes the connection between this and an opening paragraph of the essay, "Even now it is an impossible idea, that we are all connected, all of us" (Biss 3). Her use of the personal pronouns "we" and "us" are a reminder that we are all complicit in this racial violence, something that is endorsed in Ira Sukrungruang's essay, 'Because, the Ferguson Verdict': "We share this body of history, which joins – never separates – us" (281). We are all interconnected, and each of us must take responsibility for ensuring we remain so. Biss seems to make sense of this fractured world for herself and the reader, for despite the threats to human connectedness, she suggests that we are capable of repairing what is broken for "nothing [...] remains unrepentant", (Biss 11) and she ends her essay with the hopeful image of telephone poles in Nebraska growing "small leafy branches" (Biss 11) to illustrate this.

Biss said, "When I write from information I'm [...] not writing about that information, I'm writing through it to get to other questions" (Lerner), and this is reflected in the process she undertook to craft her essay, explained in the Notes included at the back of the

collection. Functioning almost as a fourth braid, the notes outline how she originally set out to write an essay about telephone poles and telephones but after reading article after article about lynchings, realised there was a more complex story to be told. By braiding her essay and interweaving three seemingly disparate threads she is able to “write through” her material to take a “kaleidoscopic look” at the question of human connectedness. And while the emotional centre of the essay is still confronting – nothing can or should dissipate the shock of the lynchings – she is able to guide us to an understanding of our personal responsibility to ensure this doesn’t happen again.

Traces Remain

First published in ‘The New Yorker’ in 1996, Jo Ann Beard’s essay, ‘The Fourth State of Matter’, is her attempt to make meaning of the deaths of six colleagues in a workplace shooting. To do so, Beard interweaves four distinct braids - her dying dog, her dying marriage, squirrels that have taken over a bedroom in her house, and the shooting. The discontinuous structure of the braiding allows Beard, like Biss, to approach the “emotional center” of the essay “in a sideways fashion”, as she described it in an interview with Yvonne Conza. As the essay progresses, these braids branch and rejoin, with each braid or fragment becoming a ‘thinking through’ space as she tries to process these losses. Beard connects the fragments by “patterns of thought and points of intersection” (Mary Heather Noble), repeated ideas and images that lead both reader and writer to a more nuanced understanding of loss. Nicole Walker suggests that “as you stitch an essay together, you stitch yourself into the world”, which is pertinent to an examination of Beard’s writing as we

get the sense that for Beard, the coming together of these stories is a way of “plumbing ... [her] own depths” (Conza). It becomes a reparative process as she figures out how to explain the inexplicable, and by stitching herself into the world, Beard creates unifying threads that enable her to help herself and her reader make sense of its complexities.

These complexities are given shape and meaning through the repetition of images throughout the essay that connect each of the braids. Beard signals the interconnectedness of these braids from the start of the essay by incorporating elements of each in the essay’s opening fragment. There is the collie that wakes her in the night; the squirrels turning over in their sleep; the marriage separation, hinted at in the use of the plural and past tense, “we used to” (Beard 308); and her colleagues “whose own lives are ticking like alarm clocks getting ready to go off” (Beard 309). From here, the braids divide, but Beard connects them by using repetitions, or echoes, that reverberate through the essay in a unifying rhythm. These echoes in images, words, lighting and sound create a sense of familiarity, so that in her losses we recognise our own. The “clenched” (Beard 308) toenails of the collie are echoed in the sound of the “scrabbling toenails” (Beard 310) of squirrels in the room upstairs; the dogs that settle between the narrator’s “elbows and legs” (Beard 310) as they sleep on the blue vinyl couch are echoed in the disembodied “elbows and legs” (Beard 323) of people as they try to escape the shooter; the “mute” (Beard 321) eyes of the dog are echoed in the “expressionless eyes” (Beard 320) of the killer: and the plasma that the narrator refers to as “blood” (Beard 314) in a conversation with Chris is later echoed in her description of the bloodshed in the seminar room as “broken and red” (Beard 323). Beard makes explicit the link between her dying dog and the victims of the shooting by referring to her dog as “my peer, my colleague” (Beard 329), but the connection is made more meaningful through other details repeated in each braid. She describes the collie sleeping in

“an unnatural position” (Beard 320) after falling down the stairs, and later describes the “unnatural angle” (Beard 323) of Chris’s head after being shot. And in a more subtle echo, she uses rhyme to connect the collie’s “gazing eyes” (Beard 308) with the “glazed over” (Beard 322) look of the scientists gathered for the Friday-afternoon seminar. Each echo acts as a stitch between braids and it is only when we “see it whole” that we understand that Beard is using her dying dog and dying marriage to help her understand the inexplicable deaths of her colleagues.

Perhaps the most significant echo in the reparative process of the braiding is the blackboard, which becomes a symbol of impermanence as well as a space to ‘figure things out’, much like the process of writing the essay. Pictures are doodled on it and erased, scientific diagrams and equations are written on it and also erased. On the morning of the shooting, the narrator draws a picture of her collie on the blackboard, with “Xs where her eyes should be” (Beard 321). She seems to be contemplating the fate of the collie, aware that they are “breaking each other’s heart” (Beard 321), and the Xs suggest her decision to euthanise. As she is leaving the office however, she stands at the blackboard “thinking” (Beard 321) before erasing the Xs and replacing them with the collie’s almond-shaped eyes. For now, the collie lives, but the act of erasing what she has drawn makes us aware that nothing is permanent. This impermanence is poignantly illustrated in the next fragment in which she describes the shooting of six of her colleagues that same afternoon. Beard juxtaposes the narrator’s choice of life for her dog with Guan Lu’s choice of death for his colleagues, suggesting how arbitrary death can be. Despite life’s impermanence however, Beard seems to suggest that memories cannot be erased, something that is reinforced in the visit, two months after the shootings, of a friend of one of the victims, Bob Smith. When shown to his office, it is his “scribbles and arrows and equations” (Beard 319) on the

blackboard that upset the friend, but despite the narrator erasing the blackboard when she returns to his office, the numbers, “ghostly and blurred” (Beard 319), can still be seen.

Traces remain. Similarly, in the opening paragraphs, Beard describes The Milky Way as “a long smear on the sky, like something erased on a blackboard” (Beard 308) and she closes the essay looking up at the stars, describing them as “dead men, drifting in the blackness” (Beard 328). Even if they only remain as a distant blur, memories cannot be fully erased.

The blackboard therefore acts as a “point of intersection”, that guides Beard and her reader to a deeper understanding of loss.

Images of light also reverberate through the essay, signifying Beard’s struggle to process each of these losses. Overarching all four threads in the opening fragment is the “dim, complicated dream” (Beard 308) highlighting the difficulty she has in making sense of it all. The narrator appears to be in a state of suspension, “hiding from [her] life” (Beard 321), unable or unwilling to move on. She cannot bring herself to get rid of the possessions of the “vanished husband” (Beard 309) from the spare room, remaining hopeful that he will return. She cannot bring herself to euthanise her dying dog, despite the advice of friends and her own heartbreak. And she cannot bring herself to accept that her friend and colleague, Chris Goertz, has been killed in the shooting. Each narrative thread is connected by this lack of clarity: after she has “evicted” (Beard 318) the squirrels, she sits with her collie “in the dimness” (Beard 318), perhaps contemplating their loss as well as the impending loss of her dog; in the aftermath of the shooting she sits in the “terrible dimness” (Beard 326) as she is waiting to hear confirmation of those killed. She is unable to “remember what anything means” (Beard 326) and the dimness in each braid reflects her search for clarity. She is aware that she can “either understand or not understand. There’s a choice to be made” (Beard 325) and it is only when she is sitting in the bathroom with her

dying dog and looks at her reflection in the mirror that she can accept “what happened has happened” (Beard 327). It is only when she realises her husband looks at her “the way he looks at the dog on the blanket” (Beard 328), the dog whose face they “used to call [...] the face of love” (Beard 308), that she can accept the end of her marriage. And it is only in the silence of the “cavernous and dead” (Beard 329) living room that she can accept that “they never come back once they’re gone” (Beard 329). By using the discontinuous structure of the braided essay and repeating ideas and images throughout, Beard is able to move back and forth between narrative threads as she works her way towards an understanding of each loss and an acceptance of its permanence.

The emotional centre of the essay is the shooting, and Beard, like Biss, approaches it from “a distance”, employing a starkly simple prose style to reflect the cold, calculated moves of the killer. Despite its simplicity, the writing is highly charged, and, like water forced through a narrow channel, gathers speed in the short sentences that describe the mapped-out route of the killer as he walks the university in search of his victims. These are the depths Beard needed to plumb and she needs to adopt a dispassionate tone in order to write her way through it.

The response to the shooting of six colleagues is undoubtedly painful, but by allowing each braid to meander back and forth, joining and separating, Beard is able to use her marriage breakdown and dying dog to help her navigate that loss. Beard has described her writing as “a chance to figure something out that I didn’t know, or couldn’t quite see, before” (Conza). By using the braided form to weave each of her “current turmoils” (Beard 313) together, she is able to figure out that although loss is permanent, traces do remain and memories are preserved, much like the fly wings in the piece of amber Chris brought

back from Poland. As the essay closes, we get the sense that although she might not be able to explain each loss, she has at least reached a point of understanding, as has her reader.

Conclusion

Both Beard and Biss use the braided form as a way to “look at what’s happening” in their fractured world, Biss as she examines her position as a white woman complicit in America’s racial violence and Beard as she confronts her own grief in the face of loss. Neither look away until they “figure out how to make it better” and nor does the reader, compelled as we are to follow each meandering braid, moving forward in leaps and sidesteps as if navigating a path across a braided river. The narrative threads allow the emotional centre to be viewed from different perspectives, and although we may never make sense of a mass shooting or racial violence or a diagnosis of motor neurone disease, the braided essay does help the essayist write her way towards a more coherent understanding of her world and transform the landscape of meaning for her reader.

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Living, Not Dying

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

Susan Sontag, 'Illness as Metaphor'

1 Then

I missed the call. I'd been teaching period 3, and with exams around the corner had offered a lunchtime tutorial. Ngugi wa Thiong'o, *Petals of Blood*. The voicemail message simply said, "Dr Hill has had a 5pm cancellation this evening. Let me know if you would like it." It was a Friday.

Prepared, but not prepared at all.

My husband, Rob, and I arrived separately. Rob was waiting in the carpark when I arrived. We were both early. We'd been through this before in 2020 when we had sat together in Dr Rose's office and been told that Rob had cancer. We'd had the dress rehearsal and knew the script. But I had forgotten my lines.

Prepared, but not prepared, because nothing at all prepares you. "Motor Neurone Disease," she said. "We're worried about how quickly it's advancing." I watched her words swirl in the air and tried to catch them, but they drifted to the floor. "You might want to consider giving up work," she said. "You'll need a wheelchair," she said. I wanted to leave them there to be swept up and disposed of by someone else, but her words were now my words and I had to try to make sense of them. "It's untreatable."

*

My leg had been weird for a while, but I had either ignored it or been distracted by more pressing matters, like Rob's cancer and Covid-lockdowns.

I heard it before I felt it. As I walked, I could hear the slap, slap, of my right foot, like a rubbery jandal tapping on a lino floor. I heard it through the hush of the community taking

a breath from their locked-down lives to thread their way around carless streets on their daily walks. The slap turned into a limp, barely perceptible at first, but then it became more pronounced so that it was an effort to lift my right leg up the stairs. Step left, swing right. I was Mr Teabag from The Ministry of Silly Walks - without the bowler hat.

I fell a few times, but kept that to myself, convinced that I was just off-balance or that the cleaners had over-polished the concrete floor in the cafeteria. Then, just before Christmas, I tripped and fell in the mall fracturing my fibula and it was clear that something more serious was going on.

I did my own research. Google told me I might have Motor Neurone Disease (MND) or Amyotrophic Lateral Sclerosis (ALS), its American equivalent. I didn't want to believe it, but Google kept giving me the same response to my ceaseless questions.

I limped from specialist to specialist until eventually I got a referral to a second neurologist, Dr Hill. I didn't like the first one. He was creepy and made me sit on his consulting room bed in my bra and knickers for a long time while he silently examined me. Is this normal? I don't know. Dr Hill revealed my diagnosis. She never asked me to remove my clothes.

There is no cure for MND. There are no pills to take, no bits to cut out, nothing to zap. This is what I might expect:

I will no longer be able to walk or move my arms.

I will no longer be able to talk.

I will no longer be able to swallow.

I will no longer be able to breathe.

I will die.

Worldwide, between 4 and 5 million people now alive today will die from MND, so my risk of developing the disease was 1 in 300. In New Zealand, about 400 people are living with MND, a small but select group, but it felt like the worst club in the world, a club where you don't want to meet its other members. To do so would be too confronting. Who wants to see your future self? It is a lonely club and I feel isolated, adrift, and scarily ill-equipped, despite the team that quietly gathers around me – two physios, an MND support person, occupational therapist, speech language therapist, neurologist. My GP is supposed to be there somewhere but he is missing in action.

We left Dr Hill's office and made our way home. I don't remember anything about what we did next, apart from having a glass of wine, and then another, and then another ... because the neurologist said I could.

A week later my inbox delivered the words I had left scattered on her office floor.

Unfortunately, I think it is likely that this will prove to be a form of motor neurone degeneration. I have assured Robyn that the diagnosis will be reconsidered if there are any unexpected developments. For the time being we will manage her as though motor neurone disease is a possibility.

Over the next few weeks, I tried to digest what I knew, what I didn't know and what I didn't want to know.

What I knew from various medical websites was this:

Motor neurone disease is a progressive, degenerative, neurological condition with no known cure. MND is the name given to a group of diseases in which the nerve cells (neurons) controlling the muscles that enable us to move, speak, breathe and swallow degenerate and die. With no nerves to activate the muscles, they gradually weaken and waste. The effects of MND vary significantly from person to person. The average life expectancy after diagnosis is two to three years.

What I didn't know was its emotional impact. My initial searches online revealed a surprising lack of information; what I did find I struggled to absorb. It was bleak. People spoke of being "destroyed" by their diagnosis, "unfairly robbed of a future" and likened the development of the illness to "disappearing in quicksand." But a common thread was the importance of family. One man, diagnosed in July 2015 at age 48, wrote: *"It is love that sustains us through it and nothing reflects that love more than the care of our families when the chips are down."* He died in July 2021.

What I didn't want to know is which muscles my brain would choose as their next target. The MND New Zealand website gave me one prediction:

MND can cause weakness in the tongue, lips, vocal cords and chest, causing speech to become faint, slurred or unclear. It can also affect gesture and facial expression. This means communication can become increasingly difficult as your symptoms progress.

What might I want to say when I can no longer say anything at all? The thought of being silenced filled me with horror. I had stories to tell, opinions to share, wine to order. I had devoted an entire career to communicating with others. My voice was me.

But the diagnosis itself had already silenced me. In the same way that we reach for the remote to silence the ads on TV, I muted my diagnosis. We told only family, a few close friends and my boss. Apart from that, I did not want to give voice to my condition. Giving it air meant giving it life.

Months after, I still struggled to say those three words out loud. I found myself snatching at euphemisms when questioned about my immobility by strangers – and it happens more often than you'd think. *'Have you just had [hip/knee/insert here whatever medical issue the speaker is afflicted with] surgery?'* *'No, I have a muscular condition.'* Vague but true. And easier than dealing with the awkward response that would inevitably follow.

There was silence, too, in the struggle of friends and colleagues as they searched for an appropriate response: *'No words.'* *'I don't know what to say.'* This was in fact the right thing to say. I didn't know what to say to myself. In lieu of words, I received hugs, many hugs, which induced tears but which did not require an answer. I kept a mental list of those who cared enough to offer some sort of acknowledgement of this shitty news. I was surprised by some names that did not make the list. You learn a lot about people.

I did not want to allow MND to silence me. Already I could hear changes in my speech: a stumble over the odd word during leadership meetings, lazy pronunciation when I read aloud to my students, the occasional sober slur on the letter 's'. My ability to communicate with clarity was deteriorating. Thankfully, I was introduced by a colleague to a lecturer in Speech Language Therapy at Massey University, who put me in touch with TalkLink and the voice-banking software Acapela.

To 'bank' my voice, I began to write down the words and phrases I unthinkingly use every day, knowing that I needed to get these recorded before my speech became too slurred or unintelligible. 150 words and phrases are apparently all it takes for the computer programme to make me sound more Robyn Pryor and less Stephen Hawking.

I love you, Rob.

I'd like a glass of wine, please.

This is shit.

When I finished, my recorded voice lay dormant in a cloud somewhere ready to engage in scintillating conversation with the world. I was excited but also vaguely unsettled. A bit like Victor Frankenstein, I was unsure about what I had just created and reluctant to bring it to life. When I eventually did, it didn't sound like Stephen Hawking but it wasn't me either. I

shared it with Rob, bleakly amused by the metallic twang of my voice, but when I realised he was crying, I silenced her. We weren't ready. Prepared, but not prepared.

*

These are the things I'm scared of:

Being imprisoned in my own body, strait-jacketed by an illness I did not invite into my life.

Losing my independence and being fed, showered, dressed and toileted by strangers.

That people will look at me and think I'm a freak or listen to me and think I am simple.

Dying, and the bleak black nothingness of whatever comes next.

Not being here while everyone else carries on living life.

That Rob will find someone else to love.



2 Six Months

The screensaver on my iPhone shows Rob and I sitting on a lava-red kilim rug beneath the olive trees at Casita Miro where we are celebrating my sister's 60th birthday. It is November 2020 and our glasses are raised in yet another silent toast, our faces warmed by the wine and the mid-November sun, our smiles not yet aware of the illnesses festering within.

Just one week after my sister's 60th, Rob was diagnosed with oesophageal cancer.

His treatment was scheduled to begin before Christmas and initially we thought about putting it off. We thought we might enjoy Christmas with Guy and Hugo. We thought we might fly to Christchurch as planned to attend a family 90th. We thought we would still take the train north to Picton to walk the Queen Charlotte Track. Only two months before we had thought we were healthy and well.

Instead, four days before Christmas, Rob began eight weeks of chemotherapy followed by an eight-hour operation to remove his oesophagus and then another eight weeks of chemo.

His surgery was scheduled for 19th March and he was admitted to hospital the day before. I stayed with him into the evening, painfully failing in my attempt to distract us both from the next day's ordeal. There were two others with him in the ward, both also awaiting surgery, and all that separated these three fused stories was a thin mustard-blue curtain, a flimsy preserver of privacy and dignity. We tried not to listen to the small team of surgeons that visited the woman in the bed opposite, but we knew this was our conversation too.

Yes, she did want to keep the cancer-curdled pieces that they would cut from her body.

Yes, she did understand that she might die during the operation.

Rob had understood that too. He had walked with this 'knowing' for some time: knowing that led him to see the doctor when lockdowns were lifted; knowing as he underwent a gastroscopy; knowing when Dr Rose said he was sure everything was fine but there was a slight anomaly that he thought they should investigate further.

Rob knew. So, unbeknownst to me, in the top drawer of our dresser he had left a folder of instructions in case he died during surgery. Bank details, insurance information, funeral arrangements, even instructions on how we should toast his life. With Veuve of course. In that moment, as the cancer was trying to negotiate a path around his body, Rob knew the fragility of life and the threat of death.

We didn't need the folder, but it's still there, both of us more morbidly aware of how life changes in an instant. Now I too have a folder in the top drawer. My funeral is planned, my florist chosen, my pallbearers named. I have written letters for Rob and the boys, and there is a growing collection of cards in my bottom drawer, my voiceless words of love and gratitude to Rob.

*

It was inevitable that we would have to move. It was becoming more difficult for me to manage the four flights of stairs, and the concrete bones of our house meant it would be impossible to make alterations. We investigated a stair lift, resigned to meeting the \$23,000 cost after my occupational therapist told me the Ministry would not fund it. She spoke clinically, well-trained in District Health Board-speak, as she explained that I was "not sustainable" and then, deciding I needed clarification, told me that I was not expected to live for more than three years.

The reality was that a stair lift would only ever be a temporary solution, so we made the decision to lease our house and live elsewhere while we contemplated our next move.

In 1967, psychiatrists Thomas Holmes and Richard Rahe identified the five most stressful events a person can face in life:

1. Death of a spouse or loved one
2. Divorce or separation
3. Moving home
4. Personal injury or illness
5. Job loss

Of these five stressors, I had already experienced numbers 4 and 5, Rob was contemplating the first and we were about to embark on number 3.

Unable to help, I became a bystander, looking on as Rob crammed ten years and four storeys of our lives into suitcases and boxes and rubbish bags labelled DALDY ST, STORAGE and HOSPICE. I looked on as Rob dismantled our home, dismantled our memories, dismantled our dreams. The hydrangeas, gardenias and lime tree; the island bench, weekend baking and Christmas drinks; working from home, the rooftop bar and orchids. This was the home where we had lived as a family for ten years; the home where we had celebrated my 50th, our marriage, Rob's 60th and the boys' 21sts.

On the day of the move, we stood at the bottom of the stairs staring at the empty shelves that lined the garage walls opposite and at the dozens of storage boxes that tightly cocooned our lives, sealed and neatly stacked on the garage floor.

"A new chapter," my brother-in-law said.

The final chapter, I thought.

My dictionary tells me that *moving* (verb) means the action of going to a different place to live while *moving* (adjective) means causing strong feelings of sadness.

*

Every day I am reminded that the human body really is a miracle of engineering. Take walking for instance – the complex technology that triggers the brain to send a signal through the spinal cord to the nerves to enable us to put one well leg in front of the other. From the window of our rented 8th floor apartment, I marvel as people saunter, run, plod, amble and stride around the streets below. Sometimes, during my ‘low mood moments’, I am resentful of these people who are able to do the things I can no longer do, the things that Rob describes as now being ‘off the menu’. Most times, however, I can appreciate the things my disabled self is still able to do.

In her book, *Waist-High in the World*, MS sufferer Nancy Mairs explores the language used to define those of us who are ‘physically challenged’. We are variously described as crippled, handicapped, differently abled, mobility impaired, or more commonly (and some would argue, correctly) disabled. But Mairs, quite rightly, is reluctant to use this word, regarding it, like all ‘binary’ terms, as “existing in relation to a privileged opposite”. The prefix *Dis-* connotes negativity so, by definition, I am not able, or lacking in ability. This might be true of my legs, and more progressively my speech, but I am certainly able to function in many other ways. I am able to bake biscuits for the boys, read a book and enjoy a meal out at Soul. I am able to hear, taste, see, smell and feel. I am able. So if anything, I’ve come to prefer the word cripple. Not for any rational reason other than it fits well with our

tragic list of C challenges we have endured over the last three years – Covid, Cancer, Crippled. A neatly alliterative threesome.

Instead of regarding myself as *disabled* (and believe me, there are many occasions when I still do), mostly I do appreciate my good fortune to have things that *enable* me: my crutches, my wheelchairs, my shower and perching stools, my grab rails, my sit-to-stand chair. All have enabled me to move, cook, shower and stand upright. Along with equipment, I have my family, friends, colleagues, physios, and most importantly my husband, who have enabled me to keep taking one figurative step at a time. And they continue to enable me to face my very certain future with more strength than I think I can muster sometimes.

My enabling equipment has not always brought me great joy. My crutches are the graceless appendages of Anthony Sher's "lump of foul deformity" that is Shakespeare's Richard III; my wheelchair is the "wheeled chair" of Wilfred Owen's poem, 'Disabled'. I actually cried when we bought it: "It's not an Audi," I sobbed. The DHB-supplied equipment is unforgiving in its rest-home functionality, its steel-grey sterility implying that my condition has also crippled my sense of style. Despite this, these things have enabled my disabled self, and for that I am grateful.

But I have all too often been dis-abled by the thoughtlessness of others – airport staff, roading engineers, architects, bureaucrats. The weight and hang of the door on our apartment mean that I am physically unable to open it. The long, sloping path from the disabled carpark to my office means I am unable to walk it with my crutches. Our first trip to Sydney post-diagnosis, designed to stick a very erect finger at MND, left me without wheels for the first 32 hours after an airport baggage-handler neglected to load my wheelchair. My frustration echoed around the empty baggage hall and continued to echo in the very terse exchange of emails on our return as I tried to convey why the offer of flowers

as compensation for their incompetence and complete lack of communication was woefully inadequate.

To: Air New Zealand customer complaints

cc: Greg Foran CEO

... I can only liken what I was put through to an able-bodied person having their legs chopped off as they boarded an aircraft and returned to them 32 hours later with no apology and no explanation for why they were chopped off in the first place...

I received 500 Airpoints instead, along with a generous 30-minute stay in the Koru Lounge.

Further dis-abling includes the wheelchair access to our favourite local restaurant which, as an appetiser, takes me down a narrow potholed path along the outside of the building, nose-to-lid with the rubbish bins.

And then there's Auckland Transport and the lack of thought that has gone into the design and placement of the city's disabled carparks. The two local disability spaces I would commonly use have obstacles that make it almost impossible to open my passenger door and transfer to my wheelchair: one is hugged by a tree and the other is blocked by two rubbish bins. We have so far avoided putting dents in the car door, but I've suffered a few dents to my pride inching along the length of the car, fingertips clinging to the roof, to 'safely' reach my chair.

Even the more recently developed Wynyard Quarter needs a rethink. We were delighted to see a double disabled parking space on Jellicoe Street. But with the front park taken, we were left to park in the space behind which forced us to navigate my chair across a dubiously positioned rain garden to reach the pavement. Beautifully impractical.

Frustration aside – and there have been many – I continue to feel great fortune to have a husband who every day makes me feel whole. Who enables me to be me.

But who is me? When I was first diagnosed, I received a text from a friend reassuring me that *“this is part of you but not all of you.”* So true, and I try hard not to let this illness define me. But sometimes I’m not sure who ‘me’ is.

I know who I was. I was a teacher, a wife, a parent, a daughter, a sister, an aunt, a friend. I was active, independent, a planner, an optimist, healthy, confident. Who am I now? I look in the mirror and don’t even recognise my smile. The weakening muscles in my right cheek have slackened to produce what I can only refer to as a ‘grinace’.

Every day I need to remind myself that who I am is irrevocably bound to who I was, no matter how loose the ties may seem at times. I was a teacher, past tense, but occasionally I will bump into past students and realise that I am still a teacher in their eyes. And I still carry a red pen in my head to correct the errors in spelling and punctuation I read in the newspaper and other media. I do know who I am; I just need reminding now and then.

I may not be able to complete a 10km run, but I can take part actively and passively in physio twice a week and take ‘walks’ with Rob each weekend.

I may have lost some of my independence, but I can buy a fabulous St Laurent handbag online and meet friends for coffee across the road.

I may not want to look too far into the future, but I can still plan one season at a time: a July escape to Melbourne, my next hair appointment, a birthday dinner at Onslow.

I am still a wife, parent, daughter, sister, aunt and friend – and these people know who I am.

*

“It is easy to see the beginnings of things, and harder to see the ends,” Joan Didion observes in her essay, ‘Goodbye to All That’, and I tend to agree. We often see beginnings with a great deal more clarity. The ‘new’ is met with anticipatory nerves or excitement, whether it be a new job, a new place to visit or a new relationship.

I remember our beginnings well. The first text [he had the flu, *nothing porcine*], the first date [lunch at the Stone House in Mission Bay], the first meal he cooked for me [mushroom risotto], the first gift he bought [a lemon tree, left on my front porch with a tag attached – *Looking forward to G&Ts on the new deck!*], the first dinner out [Japanese], the first time I met the boys [at his house – they were warm, curious, well-mannered, welcoming], the first piece of art we bought together [Dick Frizzel’s ‘Red Roses’], the first time he told me he loved me.

It’s hard to say goodbye to all that.

*

I sometimes wonder about the mess we leave behind. The boxes of photographs of 1980s hairdos, drunken farewells and failed relationships. A lace handkerchief, never used, but bought on a trip to Belgium. The cookbooks of recipes I have never made. Earrings purchased and never worn because I am too lazy and sentimental to wear anything other than the diamond studs Rob bought me one Christmas.

I have an attic filled with stuff. My stuff and I have co-existed amicably for many years. It has sat there demanding nothing of me but space. I staged a brief intervention during one of the many Covid lockdowns. With a chance to pause and purge, I cleared my

closet of ill-fitting shoes and seldom-worn clothes. We de-boxed crockery, linen, books and toys, taking a moment to enjoy the memories of Temuka pottery, school reports and old LPs. We gave our stuff a chance to breathe again, then happily sent it off to hospice to become someone else's stuff. I sometimes wonder if the Instagram generation will know the burden of collecting stuff, or is their attic a cloud to be decluttered by pressing delete? I have been more ruthless lately, forced out of necessity to declutter my clutter.

When my auntie passed away, she left behind a spare room stacked high with newspapers and magazines collected over the many years she had lived in her small unit. There was an ironing board that had never been used, expired tins in kitchen cupboards, Christmas cards unopened. Her spartan life was not spartan at all. My parents and brother and sister decluttered for her and despaired at the mess she'd left behind.

I have discarded and donated and have created a succession plan for my grandfather's books and the Drummond tartan kilt. I am emptying my own nest so that no one else will have to do it for me.

Apparently, there is a name for this. Swedish Death Cleaning, or *Döstädning*. *Dö* means death and *städning* means cleaning. Someone has even written a book about it – *The Gentle Art of Swedish Death Cleaning: How to Make Your Loved Ones' Lives Easier and Your Own Life More Pleasant* by Margareta Magnusson. Magnusson describes the process as “surprising and invigorating” and she's right. Rather than feeling guilty or sentimental, I felt liberated.

*

A google search will tell me the things I should be doing right now:

Bucket List: 101 Things to do Before you Die

71 Bucket List Ideas to Change Your Life

67 Incredible Bucket List Ideas for 2023

The Bucket List. I have come to loath the load these words now carry. It implies that there is a limit to what I can achieve – that I can only do what it takes to fill my bucket and no more.

I have lived a full life. I've travelled to 17 countries, stood at the top of the Burj Khalifa, been on safari in Tanzania, walked the Milford Track, attended an FA Cup final at Wembley, watched Ian McKellan perform on stage as King Lear, run a half marathon, lunched at the Dorchester, been up the Empire State Building. But I know that it's not what you do or where you go in life that's most important, it's who you share life with. I have seen lots of places and achieved lots of things, but only in the last 14 years have I been truly loved. So, I don't care where I am or what I'm doing, as long as I'm with Rob. Simply.

We are not on a mission to tick off any sort of list. I don't need to swim with the sharks or get a tattoo. We simply want to continue to create memories and enjoy doing things together. And while we are both keenly aware of the implications of each trip and each experience, we are having fun in the now.

"How do I not see everything we do as the last?" Rob asked the counsellor at our first session.

"By being mindful of each moment and staying in the present," she replied.

Despite my scorn for the word, being 'mindful' is how I have always lived my life. I have tried to live according to my father's adage, wisely but irritatingly imparted to me in my youth when I had complained about not being able to do something or go somewhere.

'But these are the best years of my life,' I had wailed.

'Every year is the best year of your life,' he replied.

At 92, my father is still alive and still imparting wisdom. And it is to him that I mentally turn since becoming ill. A post-polio sufferer, he inspires me every day with his uncomplaining and patient endurance; with his ability to keep seeing the fullness of his cup. And he was right, every year continues to be the best year of my life.

So, I will keep living life fully, if not wholly, and enjoy each moment spent with Rob. We have created some wonderful memories and will go on to create many more, even if from a different menu and even if that menu is seasonal.

*

As a child we lived on a hill. Our family home was perched on the urban-rural divide and beyond the farmland to the west, the Tasman Sea stretched and swelled. On a clear day we could see Kapiti Island adrift on the horizon and sometimes the shadow of Te Wai Pounamu where D'Urville Island reaches out to touch the North. Today my view is a volcano. Rangitoto rises proudly from the depths of the Waitemata as it did violently and bloodily 500 years ago. I have climbed it many times, clambering to the top to stand at the viewpoint and look back towards the Auckland skyline and the Waitakere Ranges beyond.

Views are an inhalation, a pause to consider the possibilities beyond the here and now. I am determined to inhale and keep my eyes lifted towards the view.



3 Twelve Months

Eleanor Gehrig said of her husband, Lou, who died of motor neurone disease in 1941, that he was “like a great clock winding down.” I bought Rob a watch in August 2021 to celebrate being cancer-free, to celebrate his life. Time ticks more slowly on his wrist now, but the months pass apace.

*

I am suffering from mourning sickness, grieving the loss of so many things. My loss of mobility has put a stop to walks on the beach, morning runs and driving my car; the gradual weakening of my hands means I can no longer twirl pasta on a fork, whisk an egg or tie my hair back; the lack of clarity in my speech prevents me from ordering a coffee, singing happy birthday or chatting to strangers in the lift. At 25 and 21, the boys have graduated from their mute adolescence and are engaging and interesting and articulate. Both are flatting now, but we come together each week for Sunday family dinner, and I listen as they discuss house prices, trips abroad and the election.

When I consider all the things my brain will steal from me, the loss of my speech is the worst, and the shroud of silence is already beginning its hushed descent. I feel it as my tongue loosens its hold on my words, hear it in my claggy consonants and see it in the way people lean in to snatch at my vowels as they try to knit together a sentence. I am being silenced.

I do still have my back-up plan - my banked voice languishes in a cloud, its discordant twangs waiting to be invited to join my conversations.

How was your day, Rob?

I'll have a pinot gris, please.

English historian, Tony Judt, wrote of his experience living with motor neurone disease in his essay, 'Night':

In effect, [MND] constitutes progressive imprisonment without parole. First you lose the use of a digit or two; then a limb; then and almost inevitably, all four [...] In the more extreme variants of the disease, associated with dysfunction of the upper motor neurons (the rest of the body is driven by the so-called lower motor neurons), swallowing, speaking, and even controlling the jaw and head become impossible [...] Having no use of my arms, I cannot scratch an itch, adjust my spectacles, remove food particles from my teeth, or anything else that—as a moment's reflection will confirm—we all do dozens of times a day.

I am afraid of this knowledge of what I will become. In May 2023, I watched as former English rugby league player, Rob Burrow, was unstrapped from his wheelchair and carried over the finish line of the Leeds marathon, an event held in his honour to raise awareness and funds for MND which he was diagnosed with in 2019. He inspired with his determination and courage, but I watched as he was lifted from his chair and I saw his non-compliant body flop and his sunglasses slide from his nose and come to rest uncomfortably askew across his face, digging into his cheek.

Sometimes my own body fast-forwards me to my future MND-self and this is when I feel the fear of grief: when my sluggish right foot becomes glued to the floor as I try to take a step, for example, or when my legs behave like a petulant teenager and refuse to swing themselves out of bed in the morning. More recently, I found myself stuck in the bathroom, holding the voluminous pleats of my skirt in one hand and my walking frame in the other while my knickers bunched ungracefully around my ankles. Rob rescued my dignity. He said he didn't mind. But I did. I sobbed for two hours and wondered at what stage husband and wife had become parent and child and I tried to recall whether I voted yes in David

Seymour's End-of-Life referendum and I remembered reading Lesley Martin's *To Die Like a Dog*, because I went to school with her and I was curious to know how she could choose to end her mother's life like that.

I am afraid. I am afraid of death, but I am also afraid of the knowingness of life. My body will shut down, muscle by withering muscle, while my brain remains alert.

I will know I have a feeding tube in my abdomen.

I will know I have an oxygen mask attached to my face.

I will know I am being lifted on and off the toilet.

And I will know the shame and gratitude of it all.

*

According to the literature, my death should be peaceful. I am likely to die of respiratory failure, probably in my sleep, my diaphragmatic muscles too weak to expand my lungs.

Inhale. Exhale.

My breath has sustained me, twenty-five thousand times a day, since the red rope that attached me to my mother was cut to release my first gasp – whether of pain at separation or joy for freedom I will never know. Since then, the act of breathing has barely registered, my lungs inflating and deflating of their own accord. Lately I have been forced to focus more intently, aware of the need to exercise this thin, dome-shaped muscle. I inhale slowly, expanding my lungs for a count of five seconds, hold, then slowly, deliberately exhale for a count of five. New research suggests that practising this for 20 minutes a day, several times a week can help prevent the onset of Alzheimer's disease. This seems the least of my concerns.

Every three months I attend the Respiratory Laboratory at the Greenlane Clinical Centre, Building 4, Level 1, Reception J, where my respiratory function is measured. The building itself does not inspire confidence. Dating back to the 1890s, the site has been home to the Aged Poor, a Female Infirmary, National Women's Hospital, a tuberculosis shelter, nurses' home and Greenlane Hospital, where in 1958 Bryan Barratt-Boyes performed New Zealand's first open-heart surgery on an 11-year-old girl. Surgical techniques have advanced significantly since then. The buildings have not.

Each time I visit, I am transported to February 2021 when we attended the Clinic for Rob's pre-surgery check. Of the many tests he had to do that day, the one that stands out is the 'beep test' which would determine if he was fit enough to cope with the anaesthetic. I took a photo as he ran up and down the length of a public corridor, the beeps urging him to go faster and faster with each 'lap'. He is holding his slow-release chemo bag in one hand and trying to fend off perambulating medical staff with the other. It seemed an unfair test at the time, as though they wanted him to fail.

Pulmonary function seems to be a critical indicator of the progression of MND. So far, my respiratory function is "reassuringly still within normal limits". What adverb will they use when it drops below normal limits? Discouragingly? Distressingly? Fatally?

As children we made a game of not-breathing. Swimming under water at the Durie Hill School baths became a test of endurance as we skimmed or flailed beneath the buoyant surface, traversing first the width then the length of the pool to complete this rite of passage. Bridges and tunnels on road trips also became competitions in breath-holding. A family outing to Castlecliff Beach, for example, would take us along Taupo Quay, hugging the Whanganui River towards where its gaping mouth spews its brackish bile into the

Tasman Sea. Passing under the Cobham Bridge, we would duck our heads and hold our breath for the few seconds it took for us to pop out the other side. Another time, on a road trip to Christchurch to celebrate my grandmother's 70th birthday, we held our breath and tooted the horn through the tunnels south of Kaikoura - a fun game until my sister ended up in hospital after a severe asthma attack. That took the not-breathing game too far.

The best by far though was the old Manawatu River bridge, just south of Foxton. An exhilarating 600 metres of not-breathing. As we left the township we would inhale great stomachfuls of air, certain that the more we inhaled, the longer our breath would last. Then, at the point where the road leaves the safety of the earth and takes off on pillared feet over grassland and the braids of the Manawatu River, the competition would begin: lips sealed, cheeks apple-ing, eyes widening, you're cheating ... until the explosive gasp of air as we reached land again.

I would store all those moments of held air to let my breath linger longer now. In the meantime, each visit to the clinic induces anxiety. It is a death test. A test that will determine when my time is up. Perhaps it's no accident that breath rhymes with death.

*

Would contemplating the end of life be easier if I understood what comes next? Surely, we can't simply cease to exist. This is what I fear: the unknowingness of what happens when we die. Will a window open, like a scene from Jim Carey's *A Christmas Carol*, inviting me to join the hundreds of drifting spirits weighed down by the chains of their burdensome pasts? Are we reunited with other deadly departed, adorned in our funereal finery, toasting our lives

well-lived? Maybe we get a second chance to relive our lives, as ourselves, or someone else. Or is there a God who is warming a seat for me in heaven, a place to rest while I wait for Rob? I envy those whose faith provides them more certainty. Death can't simply be a full stop.

Rob and I have always taken journeys together, deciding on a destination, choosing what to wear, planning what to do. This is a journey I must take on my own and I have no idea where I am heading or what I will do when I get there.

I do know that I will be cremated. Burial is not for me - the thought of being lowered into the ground and covered in soil unsettles me. I'm not sure I care for the worms, those blind, writhing creatures seeking out any orifice in which to cast their fecal trail. And I'm haunted by Gillian Clarke's poem, 'Lunchtime Lecture', in which she describes a skeleton that has been unearthed by a farmer, the remains of a young Stone-age woman. She had lain undisturbed for centuries; now her bones lie exposed on a table, the subject of a talk given by an archaeologist at a museum.

*Left, only her bone
Purity, the light and shade beauty that her man
Was denied sight of*

What if I too was to be dug up many years from now? Would I want to be laid out, vulnerable and exposed, stripped of my flesh and leered at by curious strangers? Would I want to reveal the secrets of my body that even Rob hasn't seen?

No. Cremation seems to me to be the best way to exit this world. Far better to endure the 700°C furnace for four hours than a deathtime of composting. Ashes to ashes.

We went to an open home on Sunday and this week we purchased our final piece of real estate – our forever home. \$3300 for a plot.

*

I rarely answer the phone these days. I pick up for family and close friends, people who I know will be patient as I attempt to voice each guttural 'g' and sibilant 's'. When it rings, I let it go to voice mail, preferring to avoid the endurance test of faceless communication. Unless it's 09 3670009. This, I know, is the DHB, scheduler of appointments with the OT, SLT or Respiratory Clinic. Healthcare professionals.

So, when the scheduler called to book my next lung function test I picked up, expecting her to listen patiently as I confirmed the time of my appointment and to clarify my one question carefully and caringly before wishing me a lovely day and hanging up. Instead, she asked if there was someone else at home she could talk to, repeated the appointment time twice to make sure I understood, responded with silence to my one question and when I repeated it, she hung up on me. So, when the confirmation text came through five minutes later

LUNG FUNTION APPT ON:

30/08/23@10.20AM

I texted back to let her know that function has a C.

*

Unlike most other neuro-muscular diseases, motor neurone disease does not affect the senses. It is also relatively pain-free, and, although my brain may be to blame for sending mixed messages to my muscles, in all other respects it is functioning well. This is both a blessing and a curse. On the one hand, I am fully aware of the progression of the disease and the deterioration in my capabilities, particularly as the more anti-social aspects of the illness show themselves – the pools of drooling saliva, the sip of wine that escapes from the weakening seal of my lips, the spontaneous laughter that takes hold at the most inappropriate times (while the hospice nurse explains palliative care support, for example). But there is also joy. I cherish time spent with family and friends, holidays with Rob to Noosa, Melbourne and Lake Hayes, and my university studies. Robbed of what would have been five more years of teaching literature to high school students, I have become a student myself and enrolled in distance learning papers at University. My months are richer for it. One paper, then another, has become a goal to complete my Master's degree by the end of next year.

There are some days when I let the darkness in. This morning my sister and brother-in-law left to ride the Otago Rail Trail, a trip that Rob and I were to take in April 2021 until cancer and covid curtailed our plans. These are the days when I feel like a bystander, watching from the sidelines as others fulfill my stolen dreams. I had promised to grow old with Rob, knowing his head was already haunted by loss. Our imagined future now lies shattered at my feet: trips to Italy and New York, celebrations of life events, grandparenting, an active retirement.

In *Holding Tight, Letting Go*, UK journalist, Sarah Hughes, wrote of her experience living with terminal cancer. In the final chapter of the book, her husband contemplates life without her:

One of the things that has been brought into sharp focus since her death is that when people use the term 'other half' it really means exactly what it says: the other half of every conversation you want to have is missing; the other half of your bed is empty every morning and every night; there is a hole in the other half of every single event in your children's lives.

This, I think, is how Rob must feel. We have always been two halves of a whole, but now Rob's other half is absent, unable to fill the void of conversation or take part in the events we had planned. I am a missing partner in the ship of marriage.

Despite the mess, we pick up each shard and attempt to piece our life back together, to reshape it. And even though the image may be cracked and distorted, a life still reflects back at us.

When revealing his truth of living with motor neurone disease, Tony Judt described it as "hell. Because there is no hope, no help ...". Perhaps as my illness progresses, I too will share his despair. But for now, there has to be hope. To believe otherwise is to invite the darkness to stay.



4

Eighteen Months

To take a photograph is to participate in another person's mortality, vulnerability and mutability. By slicing out a moment and freezing it, all photographs testify to time's relentless melt.
Susan Sontag (On Photography)

All I wanted was a photograph. I had the perfect image framed. Portrait, not landscape. A line of purple gladioli coloured-in the foreground and the stone dairy sat immutable behind. Beyond loomed the peaks of the Crown Range, icing-sugared with snow from last night's autumnal freeze. I imagined the photograph added to my Instagram story. An attempt to capture the moment, preserve it, immortalise it.

But the image was anything but immortal. The vibrant hue of the flowers would soon fade as each stem loosened its grip on its petals. And within 48 hours, the March sun, determinedly clinging to summer, would thaw the light dusting of snow. Time's relentless melt.

I rediscovered my old photographs when we cleared the attic before our move. Greying albums that had long since lost their stick released the Kodak instamatics of my 4th form school camp at Curious Cove in the Marlborough Sounds and family summers in the caravan at Athenree. Another box held packs of glossy images along with their transparent shadows from travels in Europe and Africa, too many to ever find their way to an album. I shuffled through each pack at speed, not stopping to negotiate with nostalgia, and tossed them into the discard pile. Who would want to look at them when I'm gone? I kept a few, including a black and white of me and Rob, framed. But I am aware that this too won't last. I should not expect it to stay on his shelf for long.

French essayist and philosopher, Roland Barthes, believed that one of the things that should move us about a photograph is the knowledge that everything depicted in it would die. I consider the photographs that my mother clings to, branches of a sepia-starched family tree, cracked and time-stained. These flat figures that once wept, laughed and loved have achieved an immortality that they never had in life. My parents will be added to that album and I will join them - or will they join me? – in the generations of still lives.

I feel the urgency in others lately to capture my image. Each celebration, holiday and dinner out is accompanied by the flash of an iPhone, and I know the haunting image is destined to appear embalmed in a silver frame, a Facebook album or pinned to a corkboard. I will live, still.

*

It was a pleasure to see Robyn this afternoon with her husband, Rob. As expected, she has noticed a further deterioration in her speech which is inevitably frustrating. She still makes herself understood verbally and Rob has no real difficulty understanding what she says, though others find it difficult. She had good vocal volume but struggled to cough on request. Speech was severely slurred but I was able to understand what she said provided I was looking at her.

These days I find myself playing a mental game of ‘Articulate’ as I thumb through the thesaurus in my head, searching for alternative ways of saying *charger, job, shorts* - words that I know my tongue will scramble as they escape my mouth. Sometimes I allow each synonym to somersault inelegantly into the conversation – *jeans, pants, trousers, denim* - until I hear the spark of recognition – or relief – in my listener’s voice. Other times I just laugh out loud, both startled and amused by the verbal carnage. I find myself gesticulating a lot: a thumbs up for ‘yes’ or ‘I’m fine’; hand on heart for ‘thank you’; passing my hand across my throat for ‘no, thanks’ or ‘I give up trying to tell you what I wanted to say because it’s

actually not that interesting or it's too hard so I'm going to bury my head in a corner and cry.' And sometimes I have cried. Slobbering tears of frustration, despair and self-pity. But mostly I laugh. I considered learning sign language, but given MND will eventually take control of my hands and arms, that seemed a pointless exercise.

I think the most difficult has been the phone calls to my parents. I now sit mute while Rob asks after their health and fills them in on our week. The girl whose school reports consistently mentioned how talkative she was is now barely able to talk at all.

*

Our parents teach us what it is to grow old. My father is now 93, my mother is 86. Born in 1930 and 1937, they have lived through World War Two, my mother watching as uncles returned home, hollow and twitching, or failed to return home at all. They survived a polio epidemic, my father forever scarred with a limp and a dislike for carrots after being hospitalised, separated from his parents, for three Christmases. They watched man walk on the moon on the black and white TV in the lounge on Durie Hill, the same TV that had a chunk taken out of it after the window shattered during the Wahine storm. Their years have been enriched by children, grandchildren and great grandchildren, strong and loyal friendships and a long-lasting love – 65 years married last September. Now, with Dad in and out of hospital dampening the flames of one infection after another, and Mum being scanned for cancerous tumors after already having one breast removed last year, they are teaching us resilience, stubborn determination, tenacity – human frailty.

At my first appointment post-diagnosis, my new GP spoke of another patient with MND who was “only 40”. I am 60. Should I feel grateful that I have had 20 more years of

life? Only 40. Only 60. At what age should I be satisfied that I have lived a 'long life'?

Statistics New Zealand tells me I should expect to live long enough to celebrate my 89th birthday. I should have a third of my life left to live. Thirty more years to grow old with Rob.

As I watch their lives flicker and spark, my parents are teaching me that I would give anything for those extra thirty years.

*

On examination, Robyn was beautifully presented. She did not exhibit any pseudobulbar affect today. Tongue movements were very slow and she was not able to put her tongue into her cheek on either side. The jaw jerk was exaggerated. She had marked spasticity, lower limbs more than upper, with pyramidal weakness in both legs and much better preserved strength in her arms. Reflexes were all pathologically brisk and both plantars were extensor.

There is no medication I can take to cure me of MND, or even to extend my life significantly.

Within weeks of being diagnosed, a friend's research came up with the drug Riluzole. It was a glimmer of hope in an otherwise bleak outlook, but further investigation showed that while the drug might slow down the progression of the disease, it would only increase survival by several months. It was not a cure, nor would it reverse damage to motor neurons which have already been affected. Then, at the age of 59, several months did not seem to me to add much value to my life. And the further I progress into this disease the less inclined I am to spend any more time than I have to locked inside this body. There are, however, a number of drugs available to treat some of the symptoms.

1 I drool. Weakening muscles around my mouth mean that I can't close my lips properly. Thin, watery saliva slips from the corners of my mouth, or pools on my bottom lip before falling in a thin viscous stream, like a spider spinning its web. I speak to my

neurologist who tells me we produce about 2 litres of saliva a day. This is a fascinating fact but does not seem to me to be a suitable solution to my problem. She prescribes scopolamine patches to be worn discreetly behind the ear. I develop an itchy rash. I have to stop using the patches. I drool.

2 When I was at primary school and innocently ignorant of the weight of words, we would casually toss insults like knives at whoever happened to be the target of our childish humour or wrath.

Dumb.

Lame.

Spastic.

Careless cruelty at the expense of the physically or intellectually challenged. Now I am the dumb, lame, spastic one. My legs stiffen and refuse to bend at the knees, while a crack or lump in the pavement will dislodge the weak hold my feet have on the footrest of my wheelchair, shunting my legs forward stiffly to pierce the air like a blunt missile.

According to my latest neurologist's report I have spasticity in the lower and upper limbs. She prescribes baclofen to relax the muscles. Within 10 hours the muscles in my right leg are so relaxed I can't move it. Within 48 hours my left leg can barely shuffle. The pills come with a warning: *Abruptly stopping this medication can cause seizures.* I stop taking the medication. I wait.

3 When MND weakens the muscles around the throat, mouth and tongue, it can become difficult to chew and swallow. This is already proving to be a problem - the chewing at least. My tongue can't move the food around my mouth so whatever I am eating gets

lodged to the roof of my mouth or along my gums and I have to use a finger to hook it within chewing distance of my teeth. I am determined to continue eating as normally as possible but some things are definitely off the menu. Anything small and slippery, like grapes or cherry tomatoes, slide around my mouth, slickly evading my tongue, and end up being swallowed whole. Leafy greens like lettuce are just as evasive and dangle loosely at the back of my throat threatening to choke. I can still eat chicken and steak, but only at home where I don't feel embarrassed about the marathon that chewing has become.

I've been told that as my condition progresses, eating and drinking will become more difficult which may lead to weight loss, malnutrition or dehydration. Many MND patients choose to have a gastrostomy, most commonly a **percutaneous endoscopic gastrostomy (PEG)** which involves a tube being inserted through the abdominal wall into the stomach so that food and drink can be injected directly. This is suggested as an option for me to consider with some urgency. If left too long the procedure can become too risky.

I am sold the benefits - the convenience of 'topping up' before dining out, or being able to inject wine directly into the stomach. Hardly a selling point; I don't understand the appeal in a Central Otago pinot gris if I can't taste it.

Rob had a PEG inserted after his surgery to allow his body to adjust to its new oesophagus. Despite keeping it clean, thick yellow ooziings of pus began congealing around the entry point. He was hospitalised for five days. His PEG was there to save his life; my life can't be saved. I decide against the procedure.

*

It's ironic that I first noticed my symptoms while doing something I loved. A walk around the Orakei Basin had become a regular weekend thing, 90 minutes to sweep away any dust that had gathered during the week. Down Brighton and along Shore Road past the avocado man and the house where a woman was stabbed on her morning run; past the rapidly rising new girls' school and across the boardwalk that skims the mangroves; down Ngapipi Road past the boatsheds, their backs turned as they watch the ins and outs of the tides; along Tamaki Drive past the runners, the walkers, the cyclists and the fishermen with their always-empty lines, and back home. Rob took that walk the day after I was diagnosed. A need to be alone to shout at the clouds and swear it's unfair and scream fuck to a god who does this to nice people.

I recall other walks. The Milford Track with my ex and my mother and her friend when they wanted to take apples and we said they'd be too heavy for us to carry in our backpacks. Rain on day three, swollen rivers and spectacular waterfalls. Sandflies, my first kiwi and more sandflies. No posh lodge for us. *We freedom walked it you know*, Mum would boast to anyone she met.

And others: the Tora Walk, the Abel Tasman, the Tongariro Crossing, the Bream Head Coast walk, and the many urban walks of lockdown, observing the city with new eyes and ears. The Great Lake Relay and Round the Bays, team walks where we started as colleagues and finished as friends. And the competitive walks, quarter marathons over the harbour bridge and through the vineyards of Hawkes Bay, after my knees finally screamed 'Enough!' to running - or when I finally listened.

We still walk, me in my wheeled chair and Rob pushing behind. Explorations of our new neighbourhood: past Peter Gordon's 'Homeland', soon to be demolished to make way for a new development in luxury retirement living; along the walkway that edges the

motorway to Westhaven Marina and its tethered flotilla of the moneyed, *Xanadu*, *Idle Hour*, *Liberty*; turning back when we reach the yacht clubs that squat in the shadow of the harbour bridge. And as we walk we still attempt to clear some of the dust that has gathered during the week - it just lies thicker now.

*

In *Blue Nights*, Joan Didion observed, "Memories are by definition of times past, things gone." Didion found no solace in memories. For her, they were a reminder of the things she didn't want to remember – the sudden death of her husband after nearly forty years of marriage, the death of her daughter eighteen months later, aged only 39. Memories fade - time's relentless melt makes sure of that - but however time-washed they might be, they can still provide comfort, inviting us to linger longer on love as well as loss.

Rob proposing to me at The French Cafe and later celebrating our marriage there with family and close friends.

Summer holidays with the boys in Waiheke, Tata Beach, Cable Bay, Whangapoua.

Rob and '*Ice, Ice Baby*' urging me on as I cross the finish line of the North Shore half-marathon.

Like a photograph, these things remain in soft focus, but like a photograph, they are a reminder of things gone.

A year after being forced to move from our family home, we finally ventured back, this time to prepare the house for sale. We had bought elsewhere, and our home was no longer ours. I knew this because the gardenias had died.

*

The hospice nurse is obsessed with my poo. I tell her I am too. She visits every four weeks. I don't have the courage to query the frequency. She produces a chart and asks me to rate my poo. The 'Bristol Stool Chart' lists seven types of poo, each helpfully illustrated with brown pictures. At one end of the scale is Type 1, an image of small sheep-like poo pellets, described as 'Separate hard lumps, like nuts (hard to pass)' and at the other extreme is Type 7, a runny mess resembling spilt chocolate milk, described as 'Watery, no solid pieces. Entirely liquid'.

I tell her it's a 4: 'Like a sausage or snake, smooth and soft'.

She tells me that's perfect.

Like a sausage or snake, smooth and soft. I ponder the use of sibilance and the way it mirrors the serpent-like shape of my poo and echoes the hushed slither as it exits my body. I also like the rhythm and its suggestion that my body is in harmony, balanced.

*

I read recently of a study being conducted by researchers at the University of Auckland:

University of Auckland scientists lead the first big trial of wastewater sampling to monitor alcohol consumption.

Researchers took samples from Auckland, Palmerston North, Wairoa, Dunedin, Queenstown, Westport and Christchurch. They found that

- South Islanders consumed more alcohol than North Islanders
- Smaller settlements had higher consumption than bigger ones

- South Aucklanders drank the least of any place studied
- Drinking spiked during special events like rugby and cricket matches

It seems to me that the conclusions they have drawn are self-evident, and I wonder what they thought their findings could contribute to making this world a better place. Research should save lives. It should find a cure for cancer or MND.

“Charity founded by Doddie Weir passes £11m milestone for MND research”

The Independent, 24 November 2023

Google his name and you will find hundreds of articles dedicated to Doddie Weir. He was a former Scotland international rugby player who was diagnosed with MND in 2016 and subsequently set up a foundation in his name in a bid to see the world free of the disease. Weir died in 2022, but by late 2023 his foundation had committed more than £11 million to fund 40 research projects focussed on finding effective treatments, and ultimately a cure, for the disease.

Rob Burrow, who played rugby league for Leeds and England, is another prominent UK sportsman having an impact on the search for a cure. He was diagnosed with MND in December 2019, aged 37, and together with fellow Leeds player, Kevin Sinfield, has gone on to raise over £15 million to fund research into the disease. Burrow and Sinfield each received a Commander of the Order of the British Empire award in January 2024 for services to motor neurone disease awareness.

Research will cure MND but research needs money. So, on a grey Sunday morning in February, 350 strangers, each connected by the ghostly thread of MND, gathered at Silo Park in Auckland to raise money for research. There was the woman who had just watched her brother die of cancer and was about to welcome her sister’s return from Australia. Her sister had MND. She was coming home to end her life. There was Jean, wearing the blue-

yellow tartan plaid of Doddie Weir over her left shoulder. Her husband had had MND. He died in December. And there were those like me, supported by family and otherwise helpless friends and colleagues, who seemed grateful that they could do something, anything.

Walk to Defeat MND is an annual fundraising event held in a number of cities around the country. Last year I didn't take part. It was too raw, too soon, too remote. This year I signed up. I attached a profile picture of Rob and I to my sponsorship page. We are at a vineyard in Gibbston Valley, wine in hand. I am in my wheelchair. I shared the link to Instagram and Facebook. I came out.

It was a walk of love. I was supported by a team of past and present colleagues, students and parents as well as four of my Miss Daisies, two dear friends of Rob's who each have faced their own health challenges, employees and their families, including the CEO, from the Auckland office of the company my brother works for, old friends from uni, my niece, and, of course, Rob and Hugo. Together we raised \$22,771.00 of a total \$123,348.00.

Most cases of MND, about 90%, are sporadic; it's believed that people develop the disease due to a combination of factors amounting to 'bad luck', rather than because of a single major lifestyle factor, such as their occupation or diet. Dr Hill had been very clear about that when she gave me her prognosis back in July, 2022. "It's not like getting lung cancer and wishing you hadn't smoked for all those years," she assured me. "There is nothing you could have done differently to prevent this." But how can she be sure when they haven't found a cause? What if I got too close to the dust dropped from the Aeroworks' top-dressing planes that swooped over the neighbouring farm when I was a child? What if I hadn't chosen to live in large polluted cities for much of my life? What if I

hadn't liked wine so much? What if? What if? What if? Someday somebody will find the answers to my questions.

The researchers at The University of Auckland are trying. They are investigating the other 10%, those that have a close family member with the disease; understanding the genetic causes of MND should help in understanding the sporadic causes. Led by Dr Emma Scotter, the research team has been examining the genes, blood, skin cells and brain tissue of individuals affected by motor neurone disease to learn about how motor neurons are damaged and how to prevent or reverse that damage. Familial MND is caused by a mistake in the genetic code that holds instructions for making each protein in our bodies. This mistake then has a one in two chance of being passed down from parent to child. Scientists have identified about 70% of the gene mutations that are responsible for inherited MND, and genetic testing means people can now determine whether they are at risk of developing MND later in life. But would you want to know that you carried that mutant gene and that sometime in the not too distant future it would begin its slow deathly invasion of your body? Would it make you live more fully or more fearfully? Would you want to start your own family knowing the risk your children would be inheriting? And what are the implications for life insurance, health insurance, travel insurance? Familial MND must be terrifying.

One man who we've met since our move has a family history of MND. He has lost a number of family members to the disease including his mother, a sister and his brother. He does not have the gene.

Familial MND must be lonely.

*

On learning of my diagnosis, one of my colleagues asked what he could do to help. I told him he could wipe my arse when I lost the use of my hands. Back then it seemed incomprehensible, distant, so it was easy to be flippant.

Now, as my fingers jump over the keyboard like an abseiler, finger pads touching down on random letters, I realise that time's slow march is dragging me closer to this inevitability. There is an intimacy involved in bottom-wiping that I don't believe should be shared. I shudder at the indignity.

Growing up, we were a family of six living in a three-bedroom stucco house my parents had built in 1962. There was one toilet with purple-papered walls, halfway down the hallway, first door on the left. It was within sniffing distance of the living room and bedrooms. Every morning after breakfast my father would lock himself in and stay there for the length of time it took for him to smoke one cigarette. A slim white Pall Mall laxative. That was intimate enough.

On 13 December last year I emailed my OT and suggested it was time to have a bidet fitted to my toilet. This would not have come as a surprise as it was an option we'd discussed when the toilet was installed earlier that year. It is now April, and after eight emails and several home visits I am no closer to having the bidet installed.

*

I have become familiar with (but certainly not immune to) the bureaucratic blockades placed in my path as I have tried to navigate my way through this disease. The DHB has been the most frequent target of my wrath, but there have been several other organisations that

have allowed their red tape to throw a noose around common sense and strangle the life out of it.

Knowing the expenses we would be facing with my illness, and the fact that I was unlikely to make it to 65, we decided to withdraw my Kiwisaver funds. Kiwisaver is one of the better legacies of the Labour Government, and has allowed me to build some modest savings almost by stealth, much needed after the 'here for a good time, not a long time' frivolity of my 20s and 30s.

The process seemed simple enough. Complete the serious illness withdrawal application and provide a medical report from the neurologist in support of my claim. I expected the wheels to grind slowly so was delighted to receive a response within 24 hours.

Feb 3, 2023, 9.43AM

*Dear Mrs Robyn PRYOR and Doctor Alison,
ASB KiwiSaver Scheme – Serious Illness Request for further information
We can confirm we are in the process of assessing your Serious Illness withdrawal application.
For us to proceed with your request could you please provide:*

- *Registered Medical Attendants report stamped by your doctor as we are unable to verify your current and future health situation*

*Once we have received this, we will be able to continue assessing your application. Please contact them to ensure this is provided promptly as this may hold up your application. We have requested they provide us with this information at latest by **17/02/2023***

We're here to help

If you have any questions regarding your application or the information required, please reply directly to this email, or contact us on the details below.

*Kind regards,
C*

Feb 3, 2023, 11.12AM

Hi C

Thanks for your response. The verified medical statement is included in the final pages of the scanned pdf I sent through yesterday. Can you confirm please?

*Thanks
Robyn*

Feb 7, 2023, 11.04AM

Dear Robyn

As stated by C and shown in the screenshot provided, your Registered Medical Attendant needs to stamp the form where it is [sic] been highlighted. We have asked for this as we did not see this. Looking forward to hearing from you. If you have any further questions please contact us on the details below or simply reply to this email.

*Kind regards,
S*

Despite having her signature and handwritten responses on the form, they wanted a rubber stamp. I found out later she doesn't even have a stamp. I persevered.

Feb 8, 2023, 2.59PM

Dear S

Thanks for clarifying the fact that the stamp is missing. I have contacted my specialist, Dr Alison Charleston, and she is on leave until 20 February. I note in the first email that C has provided a deadline of 17 Feb to receive the stamped document. Can you ensure this date is extended please to allow your request to be followed up.

*Thanks and regards
Robyn*

Feb 9, 2023, 10.18AM

Dear Robyn

Thank yo [sic] for your email. We can try to extend member's application deadline until 20/02. But member will need to send the stamped RMA form to us on the 20/02/2023 as we are unable to extend member's application any further. Thank you for your understanding. If you have any further questions please contact us on the details below or simply reply to this email.

*Kind regards
C*

Feb 9, 2023, 10.41AM
CC: VITTORIA SHORTT CEO

Dear C

Your email does not offer much flexibility or support for someone who has banked with ASB for over 30 years and who has now been diagnosed with a terminal illness. However, I will do my best

*to communicate your deadline to my neurologist and hope she is able to arrange to stamp and return my RMA on her first day back from leave.
Can I ask that in future emails you refer to me by name or use the personal pronouns 'you' and 'your' rather than referring to me as 'member' - it makes me sound like I am not a person!*

*Regards
Robyn*

By midday I had received a very apologetic phone call from someone with the authority to rescue the common sense from its noose and find other ways of verifying the credentials of my specialist other than a rubber stamp, such as a phone call to her rooms. Five days later the money was in my account.

I have had similar exchanges with various personnel from the DHB and I've become embarrassed by how quickly my anger and frustration now escalates the tone of my emails. Most recently I sent an email to my speech language therapist after reading the handwritten notes she left on the coffee table recording her visit.

<p>SWALLOWING RECOMMENDATIONS FOR Robyn Pryor</p> <p>Level of Assistance: full supervision Medication Delivery: no medications</p>
--

*Hi J
Thanks for the visit yesterday and it was lovely to meet S. I was impressed with her ability to translate my speech on first meeting.
I just want to clarify something you recorded on my notes. You wrote that I required "full supervision". What does this mean exactly?
Thanks
Robyn*

Morena Robyn,

*Lovely to see you Monday, so glad you enjoyed meeting S. She's great!
Sorry I didn't explain this during the session. We usually recommend a level of supervision for clients based on their dysphagia severity and level of risk. This is usually 'full supervision, distant supervision or independent with eating and drinking'.
I would recommend that you have someone with you when you eat and drink (full supervision or distant supervision), as your opting to have solid textures, chewing is now more effortful and your cough is reduced in strength, these factors increase choking risk. Overall I totally understand that*

you would like to continue having foods you enjoy for pleasure! (rather than softer options) and i think you seem really tuned into monitoring your dysphagia and managing the level of risk safely.

Happy to chat through further!

Hi J

Gosh, that is a pretty heavyweight recommendation to throw in without discussion! At this stage I will continue as normal, thanks, without the babysitter .

Robyn

Hi,

Apologies if this wasn't covered in the session, distant supervision would require someone to be in the same room/ close by whilst you're eating but not necessarily directly next to you. Full supervision would be having someone sitting with you whilst you're eating. Often people manage this by having whanau or a caregiver present with them. I totally understand and acknowledge your wish to continue as normal though. It's our job to provide safest recommendations and provide you with the information to make an informed decision but ultimately it is your choice.

Happy to arrange a follow up session to chat through further if you'd like.

Morning J

I have to say that I am extremely disappointed in the manner in which you delivered the news that my condition has deteriorated to the extent that I am on the highest level of need when it comes to eating and drinking. I will not require a follow up session thank you - your explanation below is adequate - but I do think your apology for not discussing this in our session a bit weak. As you were writing "full supervision" on my sheet, did you not think that this was a prognosis more sensitively delivered verbally? Once again, I am left dismayed at the lack of dignity and respect afforded someone who every day is acutely aware of the deterioration in their capabilities. By not engaging in discussion about key aspects of my healthcare plan, you show little consideration for my feelings or intelligence.

Regards

Robyn

And then there was the battle I had with disability healthcare providers after we needed to move my Aerolet toilet from our rented apartment into our new home six floors below. Four weeks of emails resulted in both AccessAble and Able Tech refusing to assist with its removal and reinstalment, provoking more emails.

This is so frustrating. All I want is to be able to go to the toilet in our new home. I raised this early in January to ensure we had plenty of time to get organised. Now we are 6 working days away from me having to pee in my chair. AccessAble and now AbleTech clearly have little regard for the people they claim to care for. They more suitably should be called UnAccessAble and UnableTech.

Even Rob reached the edge of his patience, teetered there for a moment, and then released his own frustration.

*Can you please prioritise this – this is quite unbelievable.
Without the toilet seat Robyn will be unable to perform her functions and will probably have to end up in a care facility. We cannot believe the lack of attention and care that we have received from the DHB over the course of her illness. What more can we do? We may have to take this up with the Disability Commissioner and see if we can get some action.*

I do not feel proud or smug when I re-read my responses. It is not a version of me I admire. It is not a version of me that I want to portray to others. But it has become a version of me out of necessity, as I attempt to jump the hurdles of carelessness, ignorance or poor communication from some of those I have had to deal with.

I was not always this reactive. As a child I was meek and compliant. I even thoughtfully timed my arrival into the world to ensure Dad was able to eat Mum's hospital lunch. Chops. And at the age of ten, when my brother gave me the harmonica to play after he had put it down the toilet, I didn't tell on him. My sisters did though. I had my mouth washed out with disinfectant. He was a naughty little shit. If it had been a thing back then he would have been labelled ADHD and had his naughtiness medicated away. Today he is a fine man. Gentle, considerate, loyal. Whereas I have become stroppily intolerant of those who can't see beyond the rubber stamp or section 5.6.1 of the rule book to empathise with the person standing behind the Perspex barrier. All I ask is that they walk in my shoes.

The good news is that four months, seventeen days and three pooey hands later, I finally have a bidet.

*

Why is it that we are always in search of bodily perfection? We shave, pluck, bleach and wax; we pierce, dye, tattoo and tan; we diet, exercise, medicate and meditate; we plump, lift, implant and inject. What does all of this suggest about how we perceive bodies which are imperfect? What does it suggest about me?

I once stood tall, my 5 foot 7 inch body more often than not in heels, shoulders drawn back by the invisible hand of my highland dancing teacher prodding the space between each shoulder blade. I went to the gym three times a week, walked every Saturday, and on Sunday I would stretch my body into unfamiliar shapes with familiar names like cobra, cat-cow and downward dog. I shaved, plucked, waxed, lasered, dyed and tanned. I even had Botox. Once. Now I sit short, my 4 foot 2 inch body most commonly in sneakers, shoulders rounded by the visible hand of MND. I can no longer shave my legs or under my arms and I've done away with fake tans. I do still cling to a sliver of vanity: I visit the beautician once a month to have my eyebrows plucked and dyed, and every week I visit the hairdresser to have my hair washed, dried and straightened. I am trying still to perfect my body despite its imperfections.

I do not question this quest for perfection. It seems we have long been victims of fashion. In Elizabethan times, pale skin was seen as a sign of wealth and beauty, so women would cover their face in a mixture of white lead and vinegar in an effort to achieve an alabaster glow. Deadly nightshade was used to dilate the pupils while urine was used to bleach hair to a fashionable blonde or red. Of course, the price of perfection then was deadly with many ending up with permanent hair loss, and skin that was grey and pock-marked. Or they died. Interestingly, I find some familiar ailments among the symptoms of lead poisoning: wrist or foot drop, loss of co-ordination, limb weakness, fatigue, weight loss and slurred speech. All are symptoms of MND.

So what of the Elizabethans' attitude to disability? In a letter to his sister-in-law in the late 16th century, Sir Robert Cecil, chief minister to Queen Elizabeth I, observed that it was "the fashion of the court and London [...] to laugh at all deformities". Cecil suffered from scoliosis, a deformity of the spine which made him short in stature, and was frequently the object of ridicule at court. Shakespeare's portrayal of Richard III supports another Elizabethan view, that bodily disfigurement reflects an inner monstrosity. In the opening lines of the play, Richard describes himself as so "[d]eformed [and] unfinished" that "dogs bark at me as I halt by them." He declares that because his deformity prevents him from succeeding as a lover, he will succeed as a villain. His disability therefore becomes the motivating factor for his villainy. This distorted view of disability remains evident today in literature and film. Darth Vader in Star Wars, the Joker in Batman, Voldemort in Harry Potter, Captain Hook in Peter Pan, and any number of Bond villains, all have a disfigurement or impairment which is seen as a reflection of their moral character. They are portrayed as evil and corrupt and we feel relieved when they finally succumb to the moral superiority of the unimpaired, able-bodied 'good guy'. In many cases there is a prevailing sense that the villain is deserving of his disability, that in some way he is paying for past sins. Perhaps this explains the brand name of my DHB-issue wheelchair - 'Karma'.



5
Twenty-four months

“I may wish to be free from torture, but if the time comes for me to endure it, I’ll wish to bear it courageously with bravery and honour. Wouldn’t I prefer not to fall into war? But if war does befall me, I’ll wish to carry nobly the wounds, starvation, and other necessities of war. Neither am I so crazy as to desire illness, but if I must suffer illness, I’ll wish to do nothing rash or dishonourable. The point is not to wish for these adversities, but for the virtue that make adversities bearable.”

Seneca, Moral Letters, 67.4

It’s my arms and hands that are now in MND’s cross hairs, placing things just beyond my reach and out of my grasp. I feel a numbness, not as a physical sensation, more a sense of detachment. I stretch my arms above my head and it’s as if someone’s forgotten to oil my hinges. More tasks are becoming a challenge. I can no longer tie my shoelaces. I am unable to pick up my laptop with my right hand. I cannot cut my finger nails. I struggle to balance food on a fork. Once again I have to find new ways to navigate through this changing bodyscape and once again I find myself digging a deep hole of cannots. I now know the true meaning of being ‘all fingers and thumbs’ as I clumsily attempt to clasp a pen between my thumb and forefinger, reducing my handwriting, once neat and fluid, to a spidery scrawl. Wrapping gifts, once accomplished with care and finesse, feels like a masterclass in origami. Who will write my words of love to Rob and tenderly wrap his gifts on his birthday and at Christmas?

My handwriting has always been a source of pride, stemming, I’m sure, from when I was in standard 3 or 4 at primary school and achieved perfect scores in handwriting exercises. It became a hobby of sorts, joining circular loops of teddy bears, their bottoms perched precisely on the lines of my 2B5. I was such an expert that Mr Smith would give me the exercise books of the entire class to mark, and I would gladly sit with the pile of thirty-something books on the corner of my desk drawing little red crosses where a pencil had

crossed the line or the bar of the 't' was not perfectly aligned. I was proud. Mr Smith was lazy.

My friend Ali says I have the handwriting of an architect. She is mocking my early career plans when I spent my first year of university enrolled in a Bachelor of Architecture degree and studied physics and maths before switching to a Bachelor of Arts in English. The maths papers weren't wasted. They allowed me to teach the occasional Maths class when timetablers struggled to fill a gap, much to the hilarity, and horror, of colleagues. I much prefer to teach English. I love the potential of language to instruct, persuade, inform, entertain. If I had my time again, I would still be an English teacher.

My weakening hands and arms have raised other pressing concerns.

Who will hook my bra strap back when it slips from my left shoulder?

Who will floss the gap I have between my two upper left molars?

Who will deal to those pesky hairs, a legacy from my mother's side of the family, that occasionally sprout from under my chin?

These are just some of the big questions that I do not find answers to on the MNDNZ website.

It takes renewed effort to reset my mind to those things I am still able to do. I recall my MND support person pulling me up on this just seven months after diagnosis when I was bemoaning my lot. "*You can still stand,*" she'd said. I felt admonished, but she was right. And I can still stand now, even though I lean heavily on my walker and grip my hands ever harder on the handles. So when I start to slip into self-pity, I remind myself, *I can still stand* and I take another faltering step forward.

*

I have to choose my going away outfit. I have never been short on things to wear but what one thing do I choose to wear for the rest of time? I have always favoured black, which would be fitting for a funeral, but I do have a beautiful Knueferman dress in navy which I could wear. The Knueferman website describes it as “sophisticated in its simplicity” and “suitable for black tie events, formal functions, weddings, bridesmaids, mother of the bride / groom and special occasion wear.” No mention of funerals. It has short sleeves. Will I be cold?

Nowadays my wardrobe is half what it used to be. My workwear went to the hospice shop the summer MND forced me to retire, along with many clothes and shoes that I decided did not have a place in my new life. In hindsight I should have kept my heels.

My first attempt to cull my clothes ended in tears. I started with dresses, believing that I'd have little need for formality as a cripple, but each dress I attempted to discard was woven with memories and the memories induced tears. Rob made me stop. I wasn't ready.

My second attempt two months later proved more successful. I was ruthless and bitter and determined to rid myself of the memories of my old life, a life I was no longer able to live. The discard pile grew far bigger than it should have, although Rob would beg to differ. In Alexandra Shulman's *Clothes ... and other things that matter*, the former editor of Vogue magazine began by listing all the items in her closet. It was a lengthy list. I realise that if I was to write a similar list, it too would be lengthy, despite the number of bulging bags that filled the back seat of the car for their journey to the hospice shop.

I have added more items since then – including 12 new pairs of knickers so as not to bring shame on my mother in front of the carers that I knew would soon be entering my life. But there is not the same pleasure in shopping now that I'm in a wheelchair. In most stores,

I am unable to navigate the narrow aisles that separate display racks and shelves; I fear being approached by the cheerful assistant who will invariably ask if I need help and then look horrified or perplexed as MND pinches my nose and grabs hold of my tongue to let her know I am 'nghz lukng, thkoo'; I feel embarrassed that my chair and I are blocking the aisle and stopping others from their own 'just looking, thank you' experience; I am unable to reach the clothes hanging from the racks so end up being pushed by Rob who, despite being a willing and patient shopper, would no doubt soon tire of me making him pull out every item of clothing to check the colour or fabric or cut or size; and the changing rooms in most stores are not designed to accommodate chair, me and Rob.

In 2018, Apparel Magazine NZ published an article highlighting the lack of accessibility in New Zealand clothing stores.

One of the most common problems people with disabilities face when shopping for clothes is the size and shape of changing rooms. Many shoppers need a friend or partner to accompany them into the changing room, and most rooms are too small for two people to fit comfortably.

There's also a lack of bars, which many people living with disabilities would like to hold on to while getting changed, as well as the common complaint that store aisles are too narrow for mobility aids.

Despite this, I have yet to discover a women's clothing store in this country that caters for the needs of a disabled shopper. The closest I get to an authentic shopping experience these days is watching as my sister tries on and models the clothes for me. It helps that we are about the same size and wear clothes of a similar style. In fact, one summer we bought the same swimsuit in the same colour from the same shop on the same day, none the wiser until we met up later that evening. These days I tend to shop virtually, scrolling websites, assessing sizes, anticipating delivery. It seems to me to be a good way to pass the months. I live life differently now, sedentary, static, and my body is changing. My

trousers no longer fit snugly to my body: my calf muscles are now empty pockets of flesh and when seated my thighs look like half-baked loaves of ciabatta. Vertical lines of flesh gather at my core and my upper arms resemble the tightly closed folds of an accordion. I hate to think what my bum looks like.

Yes, I am filling my wardrobe again, knowing that some month soon Rob will again fill the back seat of the car with bulging bags destined for the hospice shop, including the items I could never give away. The purple Moochi top that I wore on our first date at the cafe in Mission Bay where he proved he was a keeper by ordering a second glass of wine. The black dress Jude bought me back from the UK which I wore the day after our wedding and the Yves Saint Laurent skirt she gifted me from her own wardrobe the year before she died. The Kate Sylvester dress I wore for my sister-in-law's 70th birthday in Christchurch, bought the day of the party when the temperature suddenly dropped to long sleeves. And, of course, my Yvonne Bennetti wedding dress, the day I bought it and the day I wore it both occasions that add to the warp and weft of my happiest memories. I may never wear these things again, but I will not discard them. They are part of the fabric of my life. Their fate can be someone else's decision. And maybe my going away outfit can be someone else's decision too. There is enough to choose from. For now, I settle on the black.

*

It weighs about 1.4kg, feels a bit like firm jelly and makes up only 2% of our body weight, yet it is the most powerful organ in the human body. The brain is the body's command centre, controlling our thoughts, feelings and actions. An adult brain contains about 100 billion microscopic cells called neurons and these neurons are connected by billions of neuron

pathways that send messages around the body. In fact, our neurons create and send more messages than all the phones in the world.

We have two types of neurons: sensory neurons and motor neurons. If you touched a hot element with your hand, for example, sensory neurons in that hand would travel at 240km/h to your brain which would register the pain. The brain would then respond by sending motor neurons back at more than 320km/h with the message to get your hand off the element, now. It is these motor neurons that stop working in MND. For some reason they start to deteriorate so the messages do not get through to the muscles and these muscles progressively waste away. And even though researchers are still trying to figure out why, I imagine mine have simply taken a wrong turn, poured a G&T and said, "Fuck it."

I don't understand why my brain has turned on me like this, especially after all the years I've spent nurturing it and feeding it with knowledge. Despite my care, my brain has become a weapon of self-destruction, killing off each muscle one neuron at a time. No wonder illness is often described metaphorically, using military or hostile language. Cancer cells 'invade' the body and treatment can be 'aggressive'. Obituaries refer to the deceased as 'losing their fight' or describe illness as a 'battle'. Even during the coronavirus pandemic the government referred to healthcare professionals as 'frontline workers'. But to my mind, this sort of metaphorical language isn't appropriate for MND. A military battle implies two parties at war with one another, enemies that are equally equipped and equally determined to win. My battle is one-sided; MND will always win. It's the Goliath to my David, and I don't even have a slingshot.

The journey is another common metaphor used to describe chronic or long-term illness, and no doubt for many it is a journey - of self-discovery, perhaps, or spiritual enlightenment. But this is not the sort of journey I'm used to. Yes, there is a great deal of

planning involved, we've had to fork out a lot of money and I've had the normal angst about what I'm going to wear, but I'm not filled with anticipatory excitement, only anticipatory dread. I can think of better places to travel to.

I'm also curious about the adjectives used to describe the terminally ill. As Susan Sontag notes in her essay, 'Illness as Metaphor', "Fatal illness has always been viewed as a test of moral character." The unwell are often referred to as 'brave' or 'courageous' in their suffering, so much so that these moral attributes have become the yardstick for how the ill should respond to their terminal diagnosis. So I too put on a brave face, in public at least, for fear I will be viewed as weak. But I am not brave.

Rob was brave. He was brave as he lay on the bed at Canopy Cancer Care for hours at a time, being drip-fed the toxic chemicals that we hoped would cure him, chemicals so toxic that he was told to flush twice after using the toilet in case I was poisoned too. He was brave as we watched his hair thin and disappear from his head, his arms, his groin. He was brave when the nurse knocked out his epidural the day after his surgery. He was brave, and he wore superhero socks every day of his treatment to prove it, a gift from a friend in Christchurch.

I am not brave. I have sobbed, I have howled, I have thrown things. I have been bitter, resentful and sullen. I am not brave. I'm just trying to find a way to get through each day.

*

Rob and I meet with the neurologist every 3 or 4 months. The routine of these appointments allows me time to admire the Stanley Palmer artwork in the waiting room

that I had barely noticed on our first visit. Usually there are one or two others in the waiting room with us and I wonder if they too are about to hear news that will atomise their lives. Or is that sort of news only delivered at 5pm on a Friday?

We chat for an hour - about me, the health system, my writing. She always asks how Rob is, aware that the passenger has an equally turbulent ride. I know she is observing me closely, assessing the progress of the disease since we last met. There are no MRIs or CAT scans to study. I have become a specimen in a petri dish that is observed, recorded, resealed, set aside. She looks in my mouth, watches as my tongue tries unsuccessfully to probe the inside of my cheek, checks my reflexes with a hammer – knees, wrists, elbows - and instructs me to sniff and cough and shout. I ask her how I am progressing. “*Uniquely,*” she says.

After each appointment I greet the arrival of the consultation letter in my inbox with a slight amount of dread. Occasionally her notes rankle. In response to my tearful concern for how this was affecting Rob, she wrote: *I have pointed out that patients with motor neurone disease quite often become depressed but usually respond well to conventional treatments.* A benign observation, but it did seem to be an extreme response to my public grief, and it spoke to my fear that MND was just the tipping point for a raft of other issues.

Each consultation letter begins with the confirmation that I still have motor neurone disease, the words as jarring as the day of diagnosis. I read the ‘problems’ I present with - *motor neurone disease with spastic paraparesis and pseudobulbar palsy* - and mentally highlight the words *deteriorated, challenging, more difficult, decline.* I read the confirmed list of MND’s successful hits to my body - lower limbs, upper limbs, speech, salivation – and I read the additional paragraph.

Robyn's recent respiratory function testing showed a decline in her inspiratory and expiratory pressures. I have explained to Robyn and Rob that this may be causing some CO₂ retention especially at night. This is the rationale for considering assisted ventilation with BiPAP. This involves wearing a mask overnight with a machine by the bed which assists breathing to improve CO₂ expulsion. Without it, CO₂ levels can increase in the bloodstream, leading to frequent awakenings overnight and daytime sleepiness, headache and loss of clarity of thinking. I will send a referral to the Sleep Service at Auckland Hospital for an assessment.

MND has found its next target.

*

"I that have examined the parts of man, and know upon what tender filaments that Fabrick hangs, doe wonder that we are not alwayes so [sick]; and considering the thousand dores that lead to death doe thanke my God that we can die but once."

Thomas Browne, *Religio Medici* (1643)

Of the "thousand dores" that lead to death each year in New Zealand, about 30% are caused by some form of cancer, while about 20% are due to heart disease. The chances were high then that it would be one of these that would cause my demise, especially given my family history. My maternal grandmother died with cancer. It's not what caused her death, but for the last fifteen years of her life the cancer feasted hungrily on her breast. My maternal aunt died of breast cancer and her daughter, my cousin, underwent a double mastectomy in her 40s after the results of her mammogram, detailing the presence of a cancerous tumour, languished for 18 months in a filing cabinet at Whanganui Base Hospital. My eldest sister also died of cancer, not of the breast but the lungs, no doubt as a result of smoking unfiltered cigarettes for much of her life. She was 59. Since then, my mother has had a breast removed after being diagnosed with cancer at the start of last year and is now facing surgery to have her gall bladder removed after the presence of something malignant or benign was confirmed last week. Because of its prevalence in my family, I have always been vigilant, undergoing regular mammograms, smears and skin cancer checks in my

determination to catch my killer before it attacked. These, I thought, would be certain protection against early death.

Cancer has also haunted Rob. As well as his own brush with the disease, it killed both his parents, as well as his late wife. It's the disease most of us fear, perhaps because it's the disease that has forced its way into the lives of so many of us. We have all witnessed its devastating impact, the pain and suffering, often endured over a prolonged period of time.

I did not want to die of cancer, or even with cancer. In fact, I always believed that a sudden death would be the best way to die. Not violently in the mangled wreckage of a car, or as the victim of a rogue gunman, but something relatively quick and uncomplicated. Like a heart attack. In 'Illness as Metaphor', Susan Sontag states that "cancer is more feared than heart disease [...] because [heart disease] can be instantaneous, an easy death." An easy death means not having to wait and watch as death stakes its claim.

But is a sudden death really easy? Now that my own door to death has been revealed I am appreciating the benefits of knowing in advance that I now have between 12 and 18 months left to live. My death won't be instantaneous, and it will certainly not be easy. But as I face its inevitability, there is some comfort to be had in having time to prepare. Time to reflect on my life, create lasting memories, write my story and say my goodbyes. Time to let life be more precious and purposeful. To let life be. And I won't be alone. This, I think, is a 'good' death.

Western culture does not do death well. Death has become mysterious, unfamiliar, something to be feared, which is perhaps why many of us regard a sudden death as an easy way to go. Until early last century, dying was most likely to occur at home surrounded by those we love, and for several days after death the body would remain in the home for friends and family to view and bid their final farewells. Death was normal, known, familiar.

Now, with advances in medicine and technology, we are more likely to die within the cold white walls of a hospital or care facility, the fading beeps of machinery uttering a mournful eulogy. When my sister died, her body was collected from hospice within hours of her last out breath and whisked away to a funeral home to be viewed by appointment only. This stark portrayal of death was illustrated most poignantly during the Covid-19 pandemic in the images of people dying in the isolated sterility of hospital rooms and mourned in solitude at virtual funerals. We have been removed from the process of dying. For many of us, this has resulted in death being something we dread, kept at arm's length so as not to remind us of our own mortality. We seek to avoid death, and to "[r]age, rage against the dying of the light" as urged by Dylan Thomas. I agree that we shouldn't go passively to our graves, but none of us can resist death so we might as well make sure it's a good one.

Researchers from the University of California, San Diego School of Medicine, identified eleven factors that constituted a 'good' death, the three most valued of which were having some control over what happened, such as where we will die and who will be with us, having control over pain relief and having some quality of life in the time we have left. I want to die surrounded by the people I love. I want to hear them share gossip and laugh raucously. I want to feel Rob's hand in mine.

We only have one life and we only have one death, and although we have little choice over which door will lead to our death, we can choose to die well. I would not choose to die of MND, but as much as I fear its slow strangulation of my body, I at least have the gift of time, something I wouldn't have if I was to die suddenly. I will have a good death.

*

In late April we took a family holiday to Arrowtown. There were fourteen of us, and those four days were a reminder of what's important in life, spending time with those you love. While we were there, my great nephew, Billy, had his first birthday, and we lunched at Ayrburn where he was treated to his first fluffy and entertained us by plunging his whole face in the cup, emerging jubilant with his nose and mouth covered in a pillow of froth. He was equally delighted at teething his three teeth on the bone of a lamb chop gripped tightly in his fist. I watched him eat and drink and drool and move and was intrigued by how similar we were. It is only later, when I read Plunket's stages of child development, that I realise we are traversing the same path, just in different directions.

According to Plunket New Zealand, a child in its first year will cry when there's a loud noise, need help getting dressed and communicate by babbling. He will progress from holding his head up to rolling over, sitting up, crawling and eventually walking; from being fed, to drinking from a cup and eating from a spoon.

I am reaching my own milestones with MND. In the space of a month I have gone from being unable to tie my right shoe lace to needing help getting dressed and undressed. My speech is increasingly an inarticulate babble and I am more reliant on typing words on my iPhone to make myself understood. I spend most of my time on my bottom and even rolling over in bed has become an effort. And, like Billy, I find it much easier to pick up my food and eat it from my fingers. I also startle at loud noises. In fact, only three months after being diagnosed I fell from my crutches onto the concrete floor of the gym carpark after being startled when a workman sent a wooden pallet clanging to the ground.

Billy's sister, Alex, wants to know what's wrong with me. 'Nonnie's brain is being naughty,' my niece replies. How else do you explain MND to a four year old?

Arrowtown wears autumn well. The planes and ash and maples are cloaked in a flame of colour when we are there, and nature is beginning to create a temporary red carpet at their feet. Later in the season, the trees will be stripped of their coat, leaving their bareness exposed to winter's cruel chill. But for now, despite its impermanence, we admire the splendour. In 'To Autumn', John Keats describes these autumnal days as "soft-dying" but he recognises that autumn has its "music" too. In spite of, or perhaps because of, the signs of winter's approach, autumn is a season of beauty, a season of plenitude, as though nature is gleaning the most from life before putting herself to sleep. We can learn a lot from nature.

Like Keats' autumn, I have my own music. I have an abundance of love and support from my husband and our boys, but there's also my sister and brother-in-law who make regular visits to Auckland to support Rob as much as me and who say yes to every request we make of them, especially if it involves wine; there's my niece who shares work stories as well as a love of rosé with me, and is so very generous in gifting me her family's love; there's the friend from my first year at university who takes three hours out of her day every Tuesday to lug me and my wheelchair to physio and back; there's my former boss / always friend who visits and messages and supports and makes me laugh; and there are my two physios who have bolstered my body as well as my spirits every week for the last two years. There are the visits and texts and emails from friends, colleagues, former students and parents; comments of like or love when I change my profile picture on Facebook; photographs and messages from family and friends on WhatsApp, or a simple heart emoji. All make me feel connected, all tell me that in that specific moment I am in their thoughts, that I am cushioned with love. And that has its music too.

*

In their 2022 research paper on palliative caregiving, Mary James and Kate Reid made the following observation:

“For couples, caring for an unwell spouse can be all-consuming. It is love with gumboots on, entering new terrain on a regular basis, committed, loving, laughing, honouring, and trusting one another, knowing that decisions made are for the best interests of each other. It is in the tiny gestures: a look, a smile, a whispered “thank you”; it is in the companionship, the quiet moments, the being present, the knowing and being known. It is choosing to look heartbreak in the eye and continuing on, step by step. It is the work of the soul and spirit, the essence of themselves that drives their desire to care for one another.”

MND has certainly tested us. At times, it has stretched our relationship so taut that I can see each emotional thread that connects us ache in fear, creating space for a new anxiety to burrow into the gaps in my head.

As my condition worsens I have become more needy, more reliant now on Rob to cook for me, dress and undress me, talk for me, lift my legs into bed each night. At a time when he so desperately needs it, I am unable to lean in and wrap my arms around him in a spontaneous gesture of love and reassurance and support. We cannot walk side by side, hand in hand as we face this challenge and I don't have the words to soothe my fears about what this is doing to him.

Rob is patient and kind, but occasionally he too loses his words and allows his own burden of care to settle on his shoulders. Sorrow, impatience and frustration pull those emotional threads that much tighter, and I wonder, does he still view me through a husband's eyes? Certainly, he is upholding the promises we made on 7th March 2015, in sickness and in health until death do us part, but will he feel relief when he is finally released from this “onerous citizenship”?

In an interview with *The Guardian*, Rob Burrow and his wife Lindsey said they had agreed early on in his illness that they would adopt a 'no-tears policy'. I understand why, but I don't understand how. Rob and I have shed and shared many tears, each tear a reminder that we feel and we love. Love is a way of being, and I am sometimes so consumed by my anxieties that I forget Rob has his own to endure and I must remind myself that love remains love even if its shape shifts and changes.

We will continue to laugh, honour and trust one another; we will continue to appreciate the companionship, the quiet moments, the being present; and we will continue to love, gumboots and all.



In her essay 'On Being Ill', Virginia Woolf wrote that when you are sick "the lights of health go down" while Susan Sontag used a similar comparison in 'Illness as Metaphor', describing illness as "the night-side of life". To Woolf and Sontag, the oppositions are distinct: wellness is light, illness is dark. Their images draw on the common associations that equate light with life and darkness with death. But now that I am on Sontag's "night-side of life", I would argue that this approach to describing the well and the sick is far too simplistic.

There's no denying that illness has a dark side; it is, as Sontag describes, an "onerous citizenship". Illness, especially when it is labelled terminal, can take you to a dark place. Along with the physical burden of enduring the various symptoms of an invasive disease and having to find new ways to navigate an alien bodyscape, there are the mental, emotional and spiritual challenges: the mental anxiety of not being in control of your own body, of losing your independence and being a burden to others; the sadness, anger, despair, self-pity, loss of hope and fear; and the soul-searching that comes with re-evaluating or reaffirming the meaning or purpose of life.

Of course there are days when I would prefer to bury my head under the duvet and remain in darkness rather than face the crippling reality of MND. But the suggestion that to become ill is to descend into a pit of darkness ignores the fact that I am still living. And I will continue to live until I die.

In the weeks following my diagnosis I believed that I would die within the year. I mentally gathered the evidence:

My neurologist only validated my disability parking permit for one year.

I was advised to give up work.

I was told not to wait until May to fulfil the things I wanted to achieve in life.

Plans were made for the whole family to come together to celebrate Christmas.

Rob insisted we purchase our wedding anniversary gift four months early.

So I took care of my end-of-life: my power of attorney, my advanced care plan, my will, my funeral, my insurances. For a short time I was so preoccupied by the epilogue that I forgot about what was happening on the stage.

Clare Madge coined the term “livingdying” to convey the complex duality of living with a life-limiting disease. By running the words together, Madge is signifying the connectedness of life and death, one cannot exist without the other. But the fact that she has prioritised life by placing the word ‘living’ first is significant to how we should perceive our experience of being ill, an experience which can and should be infused with light and joy and hope.

Early on, I was advised that I won’t feel any better tomorrow than I do today, so I have been forced to make the most of each today, to enjoy what I am still able to do. I still plan a season at a time: birthday celebrations, visits from family, Hugo’s graduation – these are my joy and love and light. And as long as there is light there is life. I choose living, not dying.



“In examining disease, we gain wisdom about anatomy and physiology and biology. In examining the person with disease, we gain wisdom about life.”

Oliver Sacks MD, Island of the Colourblind

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