

Living in dying

by Hannah Rachel Bell

We will all surely die; leave our bodies, end as dust.

But how would you react to knowing with considerable certainty that you will leave this life within two years? Where would your mind take you?

I have a condition that has no known cause, is incurable, and is always terminal; a mysterious and rapidly progressing bodily decline from leading an active, full, healthy life to death in an average time of 27 months. I want my leaving to be as healthy as my living.

Motor Neurone Disease (MND) takes roughly six months to diagnose through a process of exclusion of every other neuropathy. MND is what's left after all conditions are explored for any symptom that might be treatable, only to find near perfect health in its chosen ones. I use the expression 'chosen ones' deliberately, because the usual nouns 'sufferers' or 'victims' carry specific sickness meanings. Infuriating? Yes. And, I repeat, mysterious.

Living with this prognosis is challenging to say the least. The challenges that confront the chosen ones lie largely in two basic expressions of the condition. While there are no rules with MND because it expresses itself in a plethora of ways, the two common categories are Limb onset of the Lower Motor Neurone system, and Bulbar, or Upper Motor Neurone onset. In Limb onset, the one I have, you lose your mobility, but can still breathe, talk, and swallow. For Bulbar onset MND individuals, you keep your mobility, but lose speech, swallowing, and breathing, and generally have a shorter life expectancy. Both MND expressions take you out in a predictably progressive way, with only the timing

being a little flexible. Few of us endure the lifespan of Steven Hawking. And miracles are always possible.

At my first visit to the neurologist I was confronted unexpectedly by the attendance of a team of professionals. These included health workers in palliative care and occupational therapy, representatives from the Motor Neurone Association, and two more that I've now forgotten. It felt ominous, as though they all knew something I didn't. Interestingly, there was no psychologist or spiritual counsellor present. So my first statement to the neurologist was that I firmly believed in the concept of a prismatic body/mind/spirit view of the condition, and queried from whom and where I could find research in this field. It was impossible to believe that someone whose tests showed perfect health in every way could be disappearing bodily without warning. In my thinking, the trigger that turned something on or off in my brain/psyche relationship had to have a psychological/spiritual foundation.

Alas, no research anywhere was focused on this perspective. Research focuses on the knowable and controllable – nerve cells and their behaviours, chemistry of denervation, genetics, and so on: the measurable and the manageable.

Meanwhile, the second most challenging experience was the reaction of colleagues, family, and friends. The shocking news evoked disbelief, and a subsequent outpouring of grief and sympathy. As if my own anger, grief, and self-persecution were somehow insufficient, others poured theirs into the cocktail of bewilderment. I found myself becoming 'the counsellor' to others' reactions, pacifying and comforting

WRITERS' AWARD VII

them in their anticipation of their (and my) loss. Some even spoke to me in the past tense until I reminded them that I was sitting there with them, very much alive and in the present! It took about six months for people to normalise their attitudes and behaviours, and for us to return to enjoyable discourse, fun, laughter, and shared experiences. And my work continued, and continues, as normal.

My work did change. Until MND I travelled and worked for 40 years with Countrymen in remote Kimberley and Northern Territory communities, and in the past five years on Moa Island in the Torres Strait. Frequent travel all but stopped as mobility progressively left me. However the decades of learning from the original knowledge holders of remote Australia gave me a different future. I could consolidate and pass on the ancient philosophies and templates of living culture to anyone who wanted to listen. I continue in this work.

With visitors – friends, academics and seekers who want to share perspectives on their own lives and works and mine – arriving from all over Australia and the world, my diary is constantly full. I love sharing with them.

Then there are healers: concerned, loving, and skilled individuals whose special offerings include shamanic

healing, kinesiology, acupuncture, reiki, pipe smoking, instrument playing, stone power signifying, dietary, vitamin and elemental supplementation, chanting, collective praying to name a few. I accept and appreciate them all.

About eight months after diagnosis I decided to align my perception of the MND condition with a long-held belief that everything within the prism of my body/mind/spirit entity expresses a human potential and has function. In nature, nothing exists without a functional purpose. In chaos there is coherence, an order that we continue to explore and discover. Yes, there are mistakes or mis-takes, usually genetic, often caused by environmental factors. I now ask, do these also have a function? From this question comes another. What has MND given me – and others – that otherwise we would not have experienced?

From this perspective, MND in fact has been a gift of health and healing. It has allowed, even forced, me to focus on a different set of achievable projects, reconcile long-standing family dysfunction, consolidate decades of knowledge in retrievable forms. It has exposed me to a range of academic possibilities and collaborations, and reduced the stresses of the physically exhausting demands of working in

tropical and arid Australia. None of these would have eventuated without MND, so for this opportunity I am grateful. But there's more.

The MND experience has slowed me down, deepened my understanding and awareness of being human, given me time, solitude, and desire to reflect on the process of living and leaving, and to explore the meaning of life. As I accept the fact that my body is leaving rather more quickly than I might have expected, a kind of compressed 30-year ageing process into two years, I have now become comfortable with the journey. This flies in the face of conventional cultural expectations and values where MND is seen as a 'sickness' that deserves and demands every stop pulled out to fix it. A major driver of this healing urge in others – the professional medical industry and alternative therapeutic practices – is to prolong living regardless of the natural cycle of birth, life and death, and regardless of an individual's acceptance of their experience of the process.

Some healers – conventional and alternative – believe that it is an absolute imperative and responsibility of a terminally-conditioned person to try everything to stay alive, and that includes full participation in their healing offerings. Call it hope. If



Photo: 'Wondjina', Graeme Churcard

betterment and wellbeing are not the products of the intervention, an amazing judgement is sometimes made: I did not believe or have enough faith in their hope and idea of healing.

One healer of whom I am very fond assumed I would want to recover, so pressed on with her ministrations. I said to her, "You haven't asked me the right question. You haven't asked me, if you could recover to your former self, would you now want to?"

There is an assumption at large that the response to this question would and should be "yes" because saying "no" would indicate depression or despair, a giving up of hope. But there is also the possibility that the process in MND of rapid ageing or physical fading is experienced as a time of completion,

enlightenment, amplified awareness, release, and fulfilment. In my journey in MND, experience is condensed, heightened, concentrated, focused, and given rich meaning. Hope is irrelevant. I see hope and fear as two sides of a coin, and I have neither.

This is a story of healthy acceptance of destiny, and the inevitability of death through self-awareness that appears in mythologies the world over. From Christians to Buddhists, and through the lives of people on death row to saints, there is an internal process of acceptance that at some stage walks with the drive to stay alive. This actually enhances the journey of leaving. Hope never dominates because fear dissolves. The drive to heal doesn't consume daily life as a desperate

struggle to live. Seizing the day on the journey to death can be much more challenging and exciting.

This acceptance of impending and foreseeable departure confronts us with our own cultural values and attitudes: our fears around death and dying, our hopes, our anticipation and/or avoidance of grief and loss, and our capacity to respectfully share the journey of the departing.

It also offers everyone the opportunity to seize the day, to share the journey, to express and receive compassion, empathy and sympathy with grace, to share stories and laughter, and to reconcile meaning in our own lives. In this light, MND has the potential to be redemptive. Surely this is also what health means? ■