

online
DisAbility

**New Writing from
Western Australia**
Creative Non-Fiction
Poetry
Essay

In this Issue
Jane Monson
Jessica White
Andy Jackson
Heather Taylor-Johnson

Westerly



'Erstwhile: On Water'
Heather Taylor-Johnson

Something has died,
is missing, and then you find
it again, like a ghost sign,
and then it is something new;
you are something new.

Westerly

Online Special Issue 7,
'DisAbility', 2019

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Design: Chil3

Typesetting: Lasertype

Print: UniPrint, The University of Western Australia

Front cover: Design: Chil3

Image: Oliver Mills, *Oliver's Choice*, 2014. Photograph of the hands of Oliver Mills taken on completion of the artwork *Walking on Air* (oliverschoice.net). Photography Kerri Mills.

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Westerly is published biannually with assistance from the State Government of WA by an investment in this project through the Culture and the Arts (WA) division of the Department of Local Government, Sport and Cultural Industries. The opinions expressed in *Westerly* are those of individual contributors and not of the Editors or Editorial Advisors.

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irondark vials spinning syncopated data tapping
sympathetic impulse
they say they don't know but the body knows and it won't teleprint
secrets
for the bad power man the Axis man thumbing out blisters
punch card middleman.
Daughter telegraphic obscure prognosis girl
Heliographic organs playing parlour songs like
Who's that knocking at my door? double-bass suicide
fenland hysteria pyromancing sisters
lunatic drunk barn eye-droop milkmaids' grip
aunt delivered sleeping.
Close throat synovial floods come
benedictions for the unborn the notborn
son will be. a one-time walnut shell her alpha-beta séance child.
nothing's gone just hidden.

'Fighting Time'
Family dialogue on ageing,
disability, death
Suzanne Ingelbrecht

Suzanne Ingelbrecht is a performed and published award-winning Western Australian playwright, whose extended family comes from New Zealand. She is founder and director of *Fragmented Artists*, a WA professional theatre ensemble that actively engages performing artists and communities of disability and/or disadvantage.

As we get older, our bodies inevitably change. Grey hair; age spots, wrinkles and lines erupting on our skin; more pronounced signs of impairment, or disabling conditions such as arthritis or osteoporosis. Researchers Laura Hurd Clarke and Alexandra Korotchenko remind us that 'in and through our bodies [...] we most immediately experience the social and physical realities of growing older' (495). Yet mostly, we are woefully unprepared for the reality of our own corporeal fragility and the bodily disintegration of those we love most: our grandparents, parents, aunts, uncles, partners, friends. How can independence and our desire to age well reconcile, or not, with stooped and straining bodies, pain sweeping through nerves and tissues, and the increasing need for support and care? How can the existential dilemma of asking who would want to continue like this be responded to pragmatically, positively, ethically, in an individual, family and societal context?

This essay takes a personal and reflective approach to such rhetorical questions through dialogue and bearing witness with my aunt Marie and my uncle Des over a period of several months. Both are now severely physically impaired, the result of creeping old age and the accrual of various debilitating illnesses, including rheumatoid arthritis. Des is in an aged care home, and visits Marie every Sunday; Marie still lives independently at their home in Waikanae, New Zealand. In a series of online Messenger chats over a period of several months, I explore with them what their lives have become and how they find the will and impetus to carry on. As a playwright and former journalist, I use dialogue—the actual words spoken by individuals in question-answer, action-reaction context—at intervals throughout this essay. For me, dialogue interviews are a particularly immediate form of reflective process, bringing remembrances into present time. Marie is also keeping a diary of her daily life—what happens, what she feels—to share with others. Such acts

witness and respond to the current condition of two individuals for whom life has become an ever-decreasing circle, but for whom living still very much matters: for each other, for their family and for their friends.

Bearing witness in a professional caring context is highly regarded, writes Sandra Bunkers. Nurse theorists such as Rosemarie Parse discuss the concept as ‘true presence’ or an ‘intentional reflective love’ (*Human Becoming* 71), recognising that each person in a witnessing situation knows their own way, ‘which is both alike and different from the ways of others’. True presence is lived in ‘face-to-face discussions, silent immersions and lingering presence’ (Parse ‘Humanbecoming’ 84). As Bunkers extrapolates, ‘witnessing speaks to the power of humanuniverse cocreation’; of the ‘response-ability’ to embrace the suffering and joy of others (194). It is also, I believe, an appropriate ethical response to the notions of lack, limitation and negativity that ageing, illness and disability implicitly suggest.

Ageing and disability: the notion of ‘biographical disruption’

Uncle Des has been trawling back through time, remembering his past. It’s a favourite occupation, and quite often happens in that relaxed hiatus between wakefulness and sleep. Since our last online chat, I’ve been asking him to try and keep a mental note of what pops up for him in memory (unworkable hands mean he can no longer write).

His daughter Rosemary wheels him in from the next-door room to chat, props the iPad into position on his knees so that I can see him. Sometimes the iPad slides down and all that is visible is the top of his head. Des is oblivious to such vicarious technical machinations. He continues talking regardless—until the moment I tell him I can’t see him anymore!

So, what came up for you in memory this week?

I went back to Seddon [in the Marlborough region of New Zealand’s South Island]. I must have been about three, going on four. I was talking and walking down to the shops and wanting to buy things. I had a big collection of cars and always wanted more. When we left Seddon, I was pissed off that I had to leave my cars behind.

What else did you remember?

The time the family cow got into my parents’ bedroom [chuckles]. And I remembered when a workman threw a sack full of newborn kittens into the river because the old man [Des’s father] told him to get rid of them. I remember thinking ‘why?’.

Were you a free spirit?

I think I was more of a free spirit when I was in Dunedin. I flew kites in Dunedin.

I ask Des to describe what flying a kite used to be like. He’s only too happy to oblige. It is 1936, he is nine years old, the wind lifting his white pine and brown paper kite high into the sky at the Forbury Park racecourse, where his grandfather has allowed him to roam free on this weekend afternoon. There are no crowds, no trotting horses—only Des on the grassy oval in the middle of the horse track, running solo. The wind arcs the kite across the sandhills ringing St Clair beach, sends it soaring out to sea.

How high could it fly?

I don’t know.

He screws up his eyes, thinking.

It went bloody high!

Des’s son-in-law Ian shows me a Google Earth photo of Forbury Park today.

Wow!

The Pacific Ocean, which in Des’s memory lay just beyond the dunes, is clearly visible. Meanwhile, the sandhills themselves have been turned into the grassy mounds of a public golf course. Time marches on, even if one’s memories remain on rewind and repeat.

These days, Des’s memories very often blur into his sleeping dreams, where he’s working the family farms at Tikokino and Waipawa, with his (dead) brother Bill usually beside him. Marie’s dreams are more anxiety ridden: being late for teaching or wandering through some mysterious house trying to find her way out. Separately, I ask them whether they are disabled in their dreams. (I have to speak to them separately because their physical incapacities mean they can’t cuddle up together in front of the tiny eye of the iPad webcam.) I tell them I’ve been reading a paper on the dreams of amputees that reveal their bodies as intact entities, despite the sometimes lengthy passage of time that has elapsed from the loss of their limb(s) (Mulder et al.). Marie and Des are fascinated. The amputees’ experiences correlate exactly with their own dreams of being abled and moving around, empowered, beings with purpose and agency. Perhaps, I muse, it’s part of the optimism one needs to continue inside a body that will no longer do what you want it to.

The sociologist Michael Bury has written that the sudden onset of chronic illness is akin to a kind of 'biographical disruption' (169). In a 1982 paper, Bury described three aspects of such disruption: the disruption to taken-for-granted assumptions and behaviours; the disruption to one's self-concept; and the necessary mobilisation of resources to face an altered personal situation. Such notions of disruption to selfhood don't necessarily apply merely to those with chronic illness, however. They are just as relatable to anyone living through the sudden or gradual loss of faculties previously taken for granted: hearing, sight, smell, movement. When they were young, neither Des nor Marie gave a second thought to potentially losing the use of their ears or legs or any other physical capacity. Only through acquiring disability over the course of their advancing years has the extent of the disruption to their lives become apparent and their adaptability to change become tested. In 1982, Bury wrote of how little was known about the 'limits of tolerance' within families and workplaces, and how these might vary between different social groups and settings (180).

If there is one trend that links my family's members, apart from their tenacity, it is tolerance: their ability to endure unpleasant circumstances. It is emblematic of the ancient philosophy of the Stoics that one should submit without complaint to unavoidable necessity. Both Marie and Des have proved adept at pushing against the limits of tolerance that the disabling properties of rheumatoid arthritis have imposed upon their physical lives. Des has had the illness since the 1990s, but its effects have become more profound and pronounced as he has aged. Nowadays his hands splay outwards like a seal's flippers, and the fine motor skills that once enabled him to hold pencils or unscrew jam jars have faded into memory. The wonder drug methotrexate, so powerful that the dosage is just one tablet once a week, used to be 'bloody good' in keeping Des mobile and able to work as a builder. But along the way it may also have clogged up his lungs. In 2011, a diagnosis of pulmonary fibrosis revealed lungs apparently so damaged and scarred, his oxygen intake so low that he'd become the equivalent of a deep-sea diver. Then three years ago, in the aftermath of a gall bladder operation, he suddenly found himself unable to walk.

How did you feel about that?

I thought it would go away. I thought, she'll be right. I don't know. It always has been in the past. But it didn't work this time.

His voice trails off as he remembers, and discovers he doesn't actually want to remember—not at this time, not at this moment.

I change tack: **What do you think about your life now?**

I don't like to think of it. Too morbid. Life is still pretty good.

Do you mean life was pretty good or life now is pretty good?

Now, it's pretty good.

Rosemary adjusts the tubes that connect him to a machine pumping oxygen into his depleted airways. His wife of sixty-eight years picks up the baton, patiently relaying her own debilitating conditions. Since her mid-thirties, Marie has been taking one tablet twice a day to keep 'the silent killer' (high blood pressure) and its migraine fallout at bay. In 1977, viral pneumonia and a collapsed lung kept her in hospital for a month. She was diagnosed with rheumatoid arthritis nine years ago. Blood tests confirmed the presence of the chronic progressive illness that inflames joints and deforms body parts.

I ask her what she has noticed most about her changing body.

My biggest challenge is that I can't walk as much as I used to. Everything is an effort.

Tell me what your usual day is like.

Well, I get up about eight, shower, dress, make my bed, do the crossword, do any ringing that might be necessary. At eleven I'll have a coffee and have lunch and then at about two or half past I come down to the [care] home and see Des. I stay a couple of hours. Sometimes I drop off to sleep in the chair and then I come home, make my dinner, watch television. I try to do something every day. So, I'll bake sometimes; and Rosemary and Ian come over every Thursday night. Sometimes I think routine is the grave of the soul. But it also disciplines me, keeps me going.

Marie reveals how at times she must make Herculean efforts to make sure she doesn't lose any more physicality. Sometimes she has to make herself get out of bed, and the inflammation of the rheumatoid arthritis and the pain she's in because of it (she has to take four to six Panadol a day) impedes her walking.

I have a pusher and I still walk. I'm not giving up. As long as I can walk I can stay on my own.

As long as she can walk she is independent.

As long as she can walk she won't have to follow Des into care.

Disability and Death: Turning negative(s) into positive(s)

We've been discussing another 'D' word today.

Des cracks a joke about all the people dying at the care home: 'Happens fairly regularly. They try to hide the body bags so as not to upset people.' Marie is more whimsical, more personally philosophical about dying: 'If I die, I won't know what's going to happen to my children, or the grandchildren.'

I ask her: ***So living is preferable to dying?***

Oh yes, as long as I don't get any worse.

Even if you're locked inside your body—like Des?

Not like that.

Marie quite often berates her uselessness, unconsciously mirroring the official geriatric medical opinion of the 20th century that seemingly had no patience for the elderly. The father of geriatric medicine, Ignaz Nascher, wrote in the first geriatric medicine textbook of 1914 that the aged 'are often a burden to themselves, their families and the community at large' (O'Neill 440). Negative characteristics leak into contemporary geriatric medical literature, according to Desmond O'Neill; or conversely in idealised stereotypes of the ageing human, 'a form of gero-eugenics that does not readily incorporate the existential vulnerability of old age and the adaptation and life satisfaction of older people with varying states of physical and cognitive disability' (440).

John Rowe and Robert Kahn's still widely referenced health model of 'successful ageing' (Successful Aging 433), which denotes an actively engaged individual who has low probability of disease and disease-related disability coupled with high cognitive and physical functional capacity, is manifestly problematic for people with severe disabilities (Minkler and Fadem 229). As Sandra Richardson, Sathya Karunanantham and Howard Bergman also suggest, the Rowe and Kahn model implicitly makes vulnerability and frailty an incompatible part of any successful ageing process: 'Many investigators, as well as older persons themselves, would disagree' (26).

In recent years, some critical disability studies debate has more forcefully challenged the prism of 'ableism' which makes the disabled person 'other' and the ableist agenda dominant (Goodley 637). Notably, in this arena, disability researcher and activist Fiona Kumari Campbell has spoken against the notion of disability as something to be overcome:

Impairment is the foreign invader, an injury or parasite that replaces the authentic self—no wonder many seek non-envelopment and are encouraged to partition impairment from the rest of our *relevant* selves. (216)

More useful, Kumari Campbell suggests, would be a counter-ableist version of impairment that could 'explore what the experience of impairment produces and ask how does disability *productively colour* our lives' (216).

With World Health Organisation figures showing that the world's proportion of older people is growing dramatically and correlatively their likelihood of developing some sort of disability (2015), a different approach to acknowledging the power of physical disintegration over the ageing human spirit seems appropriate. Learning to adapt and grow into disability as my uncle Des has, rather than partitioning it off from his individuality, may be crucial to continued well-being and happiness.

What have you been up to today?

I've been home [to see Marie]. Came [back here] at eleven, watched television, had a Subway lunch. Now? Not much. I'm watching the Secret Army on television at the moment.

He loves travel shows—Joanna Lumley cruising down the Nile is the latest. He reads a lot, part of his still voracious curiosity for knowledge. He doesn't need glasses since an operation to remove a cataract from his left eye five years ago. He doesn't need large script writing either, just a normal book propped up on the bedside table, on his abled side.

What's the best part of living now?

I come home on [Sundays]. I get some freedom in this vehicle.

Des has a new electric wheelchair now, which allows him some mobile independence.

What would you most like to be able to do now, if you could?

I'd like to walk again... a little bit.

How about a lot!

Marie rolls her eyes. She finds Des's will to live extraordinary—even the fact that he finds the thought of fish and chips on Fridays exciting.

I ask her: **What makes life worth living even when you're in chronic pain?**

What makes you carry on?

She thinks for a moment. In an earlier chat, she has coined the expression 'fighting time' to manifest her determination to live.

Probably my optimism, hoping that tomorrow it'll all be gone and I'll be all right. I know I'm not going to get better, but I hope I'm not going to get a lot worse. I'll probably die before that. Well at ninety you don't have too many options.

An ethics of care and caregiving: a family perspective

Des has established a warm, interested relationship with the staff who look after him in the care home. He knows them by name, asks them about their families, listens to their stories.

Do you enjoy being looked after by other people?

Not particularly. I've got a lot of Filipina girls looking after me... and from Kiribati.

I know... and you like them. You like them a lot.

They're bloody good. Can't fault them.

Today, Rosemary has taken Des for a walk, leaving Marie to try and work out the technology of the iPad so she can chat to me. At one point, she does something (neither of us know what) and a figuratively decorative armchair suddenly fills the frame. Marie has disappeared.

I try and help her autocorrect from my office in Western Australia. The technology is as complex as its user and I realise it's useless attempting to work out what has happened. I may as well accept Marie's wonderfully hilarious inability to troubleshoot the unfathomable. I feel her vulnerability, her sense of stupidity in that moment. But it should not, need not matter. As the critical disability studies theorist Rosemarie Garland-Thomson reminds us, disability should be the 'essential characteristic' of being human: 'Our bodies need care; we need assistance to live; we are fragile, limited, and pliable in the face of life itself' (342).

Our frailty begins at birth. The human baby is utterly dependent on its mother and other adults to live and to grow; impaired and vulnerable within that dependency. Reimagining dependency and interdependency as natural, essential elements of being human—as individually, familiarly and societally acceptable across one's lifetime—should be part of human progress, and part of a process therefore of mutual caregiving throughout

life. When Rosemary returns from her walk, she gently takes the iPad from her mother's hands, reverses the frame so that Marie and I can once again see each other as we talk. Our moment of incapacity has passed. But there are many other moments in our lifetimes, when compassion, when care is as natural as sleep and is as gladly given as received.

I remember when I received the news of Des's pulmonary fibrosis diagnosis. It was 2011 and I was in Dunedin as the William Evans Playwriting Fellow at Otago University, in the kind of job that could give me compassionate leave when I asked for it. I wrote to my head of school, explaining that the woman I regard as like a mother to me and who herself had recently been diagnosed with rheumatoid arthritis was finding it difficult to cope with domestic tasks.

I flew to Wellington and caught a bus to Masterton, and for the following week Marie and I shared the camaraderie of familiar connection, while Des was laid up in hospital. She regaled me with stories—the time my grandmother 'encouraged' the pathetic-looking copper beech tree at the family farm to grow by weeing in a chamber pot and scattering the urine round its roots. Or, nearer to home, that her friends number 'a Noreen, a Doreen and two Maureens!' We laughed and hugged a lot, and reminisced about the births of both my sons in the Masterton maternity hospital. When my husband Nick couldn't make it for our second son's birth, because Jack was premature, Marie was there, of course she was, to hold my hand when I pushed Jack scared and howling into the world.

These family events, one from a possible end-of-life scene, one from a beginning-of-life tableau, reinforce caregiving within the family unit as normative (Bailey and Gordon 229): that our family members will step up to help and support one another when needed. Nowadays, support for Marie and Des is multi-faceted and genuine. A few months before Des got his electric wheelchair, he and Marie made—by any standard—a journey of epic proportions to view Peter Jackson's Great War Exhibition at the Dominion Museum in Wellington. Rosemary and Ian brought Marie up to Des's care home and all four of them went by wheelchair taxi from Waikanae to Wellington.

Marie wrote in her diary: *We were quite a procession at the exhibition. Ian [first] pushing Des in the wheelchair, Rosemary next wheeling the oxygen, while I was in the rear pushing my walking frame!! Desperately tired and sore at the end of it all, but it was well worth it.*

Marie and I discuss interdependency and how, at a societal level, we are all interdependent upon each other.

What does that word interdependence mean for you?

Probably being dependent on my family, depending on their support I suppose.

Anything else?

I don't know. I like going out and meeting people, doing things. You know I play mahjong and I go to afternoon tea parties.

I know.

I visit Des every day and I need to do those things. But when you get old, Suzanne, you need to make yourself do them. I could quite easily just lie in bed all day or all morning and do nothing. The minute I start feeling like that, I say 'get out of that bed, and into the bathroom!'

I'm sure it'll get harder and harder, but at the moment I'm still winning the fight.

She smiles wryly. Marie has always acknowledged the backdrop importance of family to enable her and Des to continue doing things together, maintain their psychosocial balance of wellbeing and their worthiness to be part of the world. Literature on ageing highlights the importance of individuals finding resilience, 'from emotional support from others, a sense of personal worthiness, self-efficacy, trust in others, hope for the future, appraising things positively, a sense of humour and having a sense of purpose' (Hochhalter et al. 21). Marie and Des's resilience clearly stems in large part from family and the emotional love and care both get from family interaction.

Family care comes in many guises. Rosemary and Ian dine with Marie every Thursday, son Mark does Marie's cleaning for her, son Ricky and daughter-in-law Sarndra visit from Auckland for long periods whenever they can. Then there's the procession of siblings, grandchildren, nieces, nephews, cousins that stop by for a chat, quite often on a Sunday afternoon when Des is home for the day: part of the fabric of an active social life that maintains their purpose and positivity.

At around 5pm on Sunday, the wheelchair taxi arrives to collect Des and take him back to the care home. Marie accompanies him onto their driveway, leans over his wheelchair to kiss him on the lips, pats him on the shoulder. There's an emotional connection between these two that is touching, and which marks this moment of physical departure, as it has all their many other moments of departure.

See you tomorrow.

See you tomorrow.

The wheelchair taxi pulls away into the quiet residential street.

Marie waves after it.

It's impossible to know whether Des can see her or not. His hat is veiling his eyes. But Marie is smiling, looking forward to another tomorrow, and quite possibly also to the brandy and soda she can enjoy in the here and now.

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