Kate's Story: My Disappearing World

Kate wrote her own story.

My name is Kate Swaffer, I have a younger onset frontal temporal dementia, and I am here to tell you my deeply personal story.

I am married and have two sons 21 and 22. I was born in 1958 in a small country hospital and grew up in a farming community on Eyre Peninsula. My first career was nursing, which brought me to Adelaide and a career specialising in operating theatres.

After a marriage breakup, I decided to change careers and became a chef, owning and managing my own food businesses for almost 10 years. Finally I worked in health care sales selling into hospitals and nursing homes. In 2004, I was working full time, studying a double degree, caring for our school-age children and running our home with my husband.

I also volunteered for various organisations, including *The Bereaved Through Suicide Support Group*, the children's schools doing tuck shop, reading and fundraising, and as a community visitor to the elderly in a nursing home at Norwood. My life was interesting, busy and very fulfilling.

Then along came the opportunity for new way of living. Late in 2004 I was diagnosed with a Type 1 Arnold Chiari brain malformation, which required neurosurgery early in 2005, followed in the same year by a cervical discectomy, a fractured hip and a right carpal tunnel operation.

In 2008 I was diagnosed with Semantic Dementia, a rare and debilitating terminal illness that is trying to steal the very essence of who I am. To say it has been a roller coaster ride is probably an understatement!

My life has changed in ways that are challenging to understand and live with, and yet somehow I have managed to use these things to strengthen my resilience and drive me to achieve more of my goals; to live every day as if it is my last, just in case it is!

I urge you to, "*live with urgency, before the emergency*". (Robyn Moore, Alzheimer's Australia national conference, 2011).

In spite of my illnesses, I managed to complete a Bachelor of Arts in Writing and Creative Communication in 2008, and then a Bachelor of Psychology in 2009. My energy and resolve to complete the Bachelor of Arts Honours degree waned after the possible diagnosis of Motor Neurone Disease, but after another year deferred, and a plateau in my health, I am now attempting to complete this degree.

The changes brought on by dementia are relentless, yet most people don't see them as disabilities rather as external symptoms. Many also think it is a mental illness, which it is not.

And so, we are regularly defined by the symptoms of our disease—forgetful, confused, aggressive, odd behaviour, absconders, mute or refusing to communicate—rather than the people we still are—mothers, fathers, lovers, daughters, wives or husbands, employees or employers, grandmothers, aunties.

It is a tragedy that so many just see our deficits. The feeling that my life is slipping away from me is almost tangible and I do sometimes feel cheated. Losing my legs and arms or my sight or hearing, or even contracting AIDS might be better than this hideous disease.

When I was first diagnosed, the tears ran down my cheeks, the tang of salt a permanent fixture on the taste buds of my lips. The only solace then was I occasionally would forget why I'd been crying. I cried, almost nonstop, for about three weeks.

I used to think, "if only someone would tell me it is just depression or some bizarre mental illness—anything other than dementia". I know the diagnosis is real but it has not been easy to come to terms with. It feels as if my soul is being sucked out, little bit by little bit, as my world slowly disappears.

I wrote an article published in 2008. This is one of the things I said back then:

"My high functioning mind has slipped away, sometimes showing itself like a ghost, trying to tease me into believing it will be okay, but now outside of my reach. My thoughts fly around inside my head like helium balloons high inside an auditorium, also out of my reach."

Speaking and thinking is more difficult; the search for words, the meaning of words, numbers and equations are now a major challenge. I am seeing words in strange ways—not as whole words any more but as if they are split into two, for example, castle now appears to my mind as 'cast' and 'lee'; imperialism as 'imp' and 'era', leaving out the 'ism' entirely.

The acquired dyslexia is changing terms like *Hamish and Andy* into *Amish and Handy*, and colours like purple into orange, or numbers like 89 into 98. It is much harder to hide the symptoms, or to rely on the inner voice I have been using to help me to think and to find the right words to speak.

It is harder to process information, to know how to act and to respond, how to behave appropriately and to know what to do in normal everyday situations. There are many more moments where the slips of my tongue or mind are evident and my tongue is 'twisting' as it struggles with the effort of finding the right words.

Studying and writing has been greatly impacted, as it takes many more hours to not only to understand what it is I am meant to do, but then to actually do it. For example, it can take up to an hour to make a short email legible.

My ability to process information or to understand simple words or things is damaged and my photographic memory is dead and buried! I read then I forget… I read then I forget… I read, I take notes, and then I forget…

Hallucinations sometimes take over my mind, as strangers and wild cats stalk me. The feeling that these things are real is momentary, but startling none the less and they increase the feeling of madness creeping into my soul.

I am hearing phones and doorbells ringing when they are not. I am becoming fixated on things, and adopting strange behaviours, like making tea towel tents over a hot cake instead of putting it onto a cooling rack.

There are times when I pour myself a glass of water, then drink from the bottle. It is no longer possible to be sure of what I will do or how I will behave, reducing my desire and enthusiasm to go out to socialise or to do simple things like shopping.

Money and how to manage it has become problematic. I have now closed all of my personal bank accounts as I cannot trust myself to spend wisely. We also transfer the majority of our funds into an account that cannot be accessed by me, leaving just enough money for shopping and emergencies in an everyday joint account.

I blow dry my hair less often as I sometimes forget how to. I sometimes cannot name a pair of socks. I am forgetting how to cook—even simple things like potatoes. This story has taken me many weeks to write.

Christine Bryden in her book *Dancing with Dementia*, describes perfectly how it looks to others—like a swan, calm and serene on the surface, but legs paddling a thousand times faster below the surface to make things “look ok” to others. It feels humiliating and demoralising to show my symptoms, and I am often very fatigued as I spend a large amount of energy trying to hide them.

As each day deals out a new challenge, a new loss, a renewed fear of what is happening to my brain, I fight to rise above it. I am getting used to what is unfolding in front of me, and now alarmingly unfolding in front of my close family and friends. It is trying to degrade my existence and it tempts me to feel less like a human being.

One of the regular features of my life now is the fear of not remembering my close family and friends. Each time I meet with them, I walk away wondering will I recognise them the next time we are together. I still know that I know them, but now I often feel disconnected, as if I have been overseas for years, as many things they talk about seem new to me.

I need the comfort of their reassurance and of being believed. As my new world evolves and the old one slowly disappears, the trepidation grows. It is as if I am drowning, with everyone looking on and me just out of their reach.

The intensity of my fears and grief is hard to ignore as my world slowly disappears, a world which is spinning past me, taunting me to remember, to recognise it, teasing my mind in its capacity to function.

The hard drive I had is slowly evaporating. The lapses of memory are intermittent; sometimes short term, sometimes long term, but happening more often. On the good days I am tempted into believing nothing is wrong when it seems as if it is just a memory loss normal for my age.

The multi-tasking I was so good at has gone, and sometimes I can barely cope with one function, getting distracted part way through a simple task, then forgetting what it was I had been doing. As these things worsen, I am often confronted with the ‘sour lemon look’ from people who are young enough or well enough to still feel invincible; so few have tolerance for human incapacity.

My relationships have changed, especially with those very close to me. My children mostly act as if nothing is wrong, and manage any obvious changes as best they can.

Our way of coping is to use humour; for example they introduce me to their friends as the ‘dementer’ in the family (from the Harry Potter books). In fact if you have seen those movies, the dementers perfectly represent in a visual way how it feels inside, as if the dementia is sucking the life and goodness out of my soul.

Our intimacy and sex life has changed; our socialising has decreased as I now struggle with groups and large crowds. Going to the movies is pointless as I can no longer keep up with a fast moving story, no longer cope with a scary one, and no longer watch my favourite European movies, as by the time I’ve read the subtitles, the screen has moved on.

My philosophy is to try and live in the now and be happy and enjoy every single moment, to hang onto our love rather than waste our time now being sad and fretful. There will be plenty of time for that later on!

There are many days when I am tempted to hate having dementia and what it is inflicting on me, and I fight against the deep sadness that seeks to envelop me like a shroud of darkness.

Being fearful and sad is not an option I can afford to indulge in as it will erode my ability to achieve and enjoy the now, while I still can. I also know this will change, and I won’t be able to stop the downward slide.

Continuing to study in the pursuit of my academic goals, writing creative nonfiction stories and poetry, and volunteering for others has sustained my motivation and sense of wellbeing.

I am about to publish a book of poems, and am working on a second volume. This has also given me a sense of purpose, and enabled me to define myself in positive ways, rather than by illness.

Getting involved with The Big Issue, an organisation that supports the homeless by giving them a “hand up, not a hand out” and the Hutt Street Centre for the homeless has helped me rise above the negatives of my own situation, to be grateful for what I still have.

These wonderful brave people have inspired me to be positive, and given me the drive to be strong and to try to be a better person. I manage my health with a regime of transcendental meditation, prayer, self-hypnosis, gentle exercise and stretching, learning, positive thinking and a healthy diet and lifestyle. The other keys for me are to create as much fun as possible, and in some ways, try to live in denial.

Studying means I need to use a lot of strategies to be productive. For example, I need assistance finding library books, need to take copious amounts of notes to compensate for the memory loss, have pictures of my lecturers and supervisor to remind me of what they look like, and use the campus map to find my way around, even though I’ve been there so many years.

I start my days like a preschooler, planned to the very last detail. My husband and the disability advisers on campus have allowed me to maintain as much independence as possible and supply me with encouragement and support to make my goals achievable.

My advice to others is to never give up, to utilise as much support as possible without allowing it to erode your self-worth, and finally, ignore those who seek to minimise you or your disabilities.

So now I must learn to separate what is left of my mind, learn to live without restraint, free of the fear of madness and of death. I must focus my energy on what is good in life, as if there is nothing wrong with me, to give myself every chance to find the energy to continue to pursue my goals and dreams, to spend good and happy times with my loved ones, and to look beyond myself.

I strive every moment of every day to develop a more welcoming approach to illness, disability, dementia and death, and to see them as the gifts that they have become. My life continues to be interesting, busy and very fulfilling.

Finally I made a digital story not long after diagnosis, available on YouTube http://www.youtube.com/watch?v=9ZUyIRq5DAs and two of my poems are published here:

Stolen dreams

stolen dreams smashed against a solid brick wall
disappearing into nothingness
feeling cheated   angry   deeply sad
the six words that created my new world
what bad luck you have dementia
this train is racing down a one way lane
no chance to get off   no chance of anyone getting on
never to return to the place i once knew
tears escaping from swollen eyes down blotchy cheeks
the taste of salt   a permanent flavour
my soul mate   angry and crying   both feeling cheated
we were two sides of the same coin
knowing each other intimately and completely
best mates and passionately in love
aware of each other's thoughts before they were spoken
conscious of each other's inner worlds   sadness or joy
our new world is collapsing into one of fear and trepidation
somehow we must find the good in yet another crisis
our love will get us through it has before
but the effort will be gigantic
the world at the other end is too scary to think about
he said he will hate it when i forget who he is
then he said with a sense of despair
please don't call me by your ex-husbands name
and at this we laughed out loud

even though the gravity of this new world
hit us between the eyes like a piercing hot needle

Kate Swaffer © 2008

Losing my mind

I'm losing my mind
Down dementia lane
Life is leaving me behind

So unfair, so unkind
And so little to gain
I'm losing my mind

Somehow I must find
An end to this pain
Life is leaving me behind

Everyone's so kind
And though I seem sane
I'm losing my mind

To find a way to rewind
The direction of this train
Life is leaving me behind

I pray they will find
A cure for my brain
I'm losing my mind
Life is leaving me behind

Kate Swaffer © 2008
(This poem won a University of SA prize in 2008)

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