

There's nothing wrong with drinking tea
Disability, memory and language

Disability

e'ssay !
- enteities? say
compound word !

I am writing this from my perspective as a contemporary artist, daughter and carer, October 2017.

I never knew you could induce a stroke from drinking too much tea, but you can, this I learnt from my now 65 year old Mum Jens favourite pastime of drinking up to (on last count) 36 cups of tea a day. For Jen, a cup of tea means she's in control, she knows what she's doing in that precise moment, with the warmth and easy comfort of tea, always black and preferably Dilmah. She loves tea so much my Dad Mike has even taken her to pick tea with the women in the tea plantations of Sri Lanka, a moment so lovely but a memory she is unable to access. lovingly ✓

Jen was diagnosed with breast cancer when she was 52, something I could not fathom because I had never seen her sick a day in my life. She was always a mother lovingly in control, always present and always engaged, with four children in a big, busy and creative household. The night before she went in for surgery I had been as dismissive as a teenage girl could be, a moment I regret most with the benefit of hindsight. I often go back to that moment, when I had the chance to communicate and didn't, I didn't realise what I was forgoing, even over a decade later I hold it in my heart as a moment of regret and guilt. I can see us standing in the kitchen, me desperate to leave and her scared of what will happen tomorrow.

Of what I remember*, Jen had her surgery, came back from the hospital after refusing to stay overnight, and spent a week in bed. This was so unusual and I remember being afraid, four children sat by her bedside trying to get her up to eat something, she had a seizure, and Mike took her back to hospital in the family car. After this she was in the viral ward on a drip. They told us she had a rare virus which was effecting her brain, completely unrelated to the breast cancer, but probably something she had been carrying for some time. The damage was severe.

✓ After this she came home, for six weeks, the wait in between going to a rehab centre for people with Acquired Brain Injury, or ABI. Six weeks was the waiting period at that time for the public health system in Melbourne Australia, and for six weeks she/we hardly slept. She cried and yelled about the missing trees in the backyard and went searching for her children, I and everyone in our family ran after her trying to contain the madness. Her memory had been so severely affected by the virus that she could not access a linear timeline of events, but scenes of her life would flash in and out in different sequences. Being a mother was such an important part of her life that her children were forefront in her confused state, but she could not access the part of her brain that let her know we were right in front of her, or right behind her. Wandering the streets in the night while she looked desperately for her children as we followed trying to keep her safe. She had permanently lost her long and short term memory, not too dissimilar to the effects of advanced Alzheimers. Her short term memory now lasting only a few minutes and long term lasting up until the age of approximately 21 years. She requires 24 hour care and will be on medication for the rest of her life, she has no chance of recovery. despair ?

Jen has never been able to wear watches, not before the virus or after, they just break or stop, this fact now has an acrimonious irony as she does not know what day or year it is, present day time has no meaning for her. She remembers High School and Matriculation, the Vietnam War, The Beatles and the early years with Mike. They married young in the 70's, and Jen has retained that fresh and ✓

*It is interesting in retelling this story because I am reliant on my personal memories, which I'm sure are different to my siblings and to my Dad Mike's and which exist for Jen but are not accessible, and so this story exists and doesn't exist in many different ways.

> look up Cambridge

University

energetic

sometimes demanding affection for him. She loves a chat and regales in her tales of commune life, Marxist hippies in suburban share housing, protesting women's lib, and getting arrested. When Mike returns home from work present day, Jen often gets an excited look in her eye and asks if that's Michael Arnold? We tell her yes, and that they are married with four children, that they own this house and are very happy together, that they have never been separated, that this is not a dream. She will then dart off to the bathroom to check her hair in an excited and proud way. She also gets the same look in her eye when I tell her that I am her daughter, that it is not something she dreamt but a true reality. Because she cannot distinctly remember giving birth, our birthdays and such things, she comes to the reasonable conclusion that she has been fantasising the life she has built. She is never unhappy to see us, there is something deep down no matter how little she remembers that binds us tightly. I often tell her little lies, that she hasn't been sick long, that it is only once in a while that her memory is affected and so she shouldn't worry. These little lies are told every few minutes in between cups of tea, to ease the pain.

look up - fantasizing?

Mike's commitment to Jen is an example of his incredible strength of character. As he told me many years ago he and Jen made a decision on getting married to be together, to be a team, and that decision does not change. He makes it seem simple. He is a family man, the family comes first, *The Godfather* is one of his favourite films, family and culture are incredibly important in their house. Mike has slept in many hospital chairs and taken Jen on overseas University trips over the years she has been sick*. She has travelled with him to Cambridge and Oxford University and attended most of his lectures here at Melbourne University, they do not like being apart. They, as best they can, keep the normal routine of any couple married for now 45 years. Blissful! ♥✓'s x 10

caring

Raising four artist children as she and Mike have, we all manage her in-home care between us, our paid work hours work in harmony with the position of carer and artist. So in a sense we have two unpaid but completely fulfilling professions, contemporary art and caring. In these positions you do not follow a regular or recognised trajectory. There are no promotions, or paid leave, no down payments on homes, no clear markers to indicate time. Sometimes I feel I am in a state of constant adolescence when I lost Jen as a traditional mother, but then I think that is a common feeling, that we all might just pretend to be adults universally, and so, I too try not to worry. Being an artist and a carer for me seem to go hand in hand, the necessary dedication and sacrifice given, the importance of care and art in a community.

Once, in rehab for a dual hip replacement, Jen was placed on a restricted fluid diet, because her legs were swelling with water retention. This did not go down well with the amount of tea she likes to drink and she got her hands on a pen left behind by an unsuspecting nurse. I can only imagine that within a short space of time Jen had started turbulently protesting, as she did against the Vietnam War in her early life, by writing "there's nothing wrong with drinking tea!" and various tea related sentences all over the walls of her small room. We got a call from a very angry nurse asking us if we were aware our mother had been "vandalising" the facility? We wondered if she was aware our mother had a severe brain injury? Situations like these are common when Jen goes into any facility which is not equipped to handle her disability, we are there in tow to control and defend her in equal measure.

disability > vandalizing?

Along with her memory loss Jen has also started to blend language, spoken and written, with what I can decipher as a mixture of French and English. She in earlier years was a Humanities teacher and another one of her pastimes is correcting the paper, or birthday cards, or the packaging in the pantry, any written language she can see, with ticks, crosses, French accents and smiley faces. Rules

* It is a hard word sick, because she is not in a changing state of health more than anyone else's, so in a way she is not sick, but to put more accurately has two intersected but clearly distinctive lives, her life before her Acquired Brain Injury and her life post. But this to her has no meaning as she can not remember and therefore can not be aware of the two, so these markers are for her family, the mother before the ABI and the mother after.

assessment!

like dropping the 'e' before 'ing' have been forgotten, crass words within words, such as 'ass'essment are disliked because it would be rude to spell them in that way. When we go to the National Gallery *Galaxy* in Melbourne I veer her away from attendants at the front of the building because she will tell them they have spelt Gallery wrong on the the signage out the front, because it is spelt how it is pronounced 'Gall a r y'. Words are blended together to create new words and those new words, with our guidance, are written down in an ex^eercise book to send to the Oxford Dictionary. We have about 6 ex^eercise books full of words next to a big new revised copy of the Oxford Dictionary on her shelf. These are prized possessions.

As the years go on, we as a family negotiate who can be with her and when. We arrange travel dates and doctors appointments, she attends all of our art exhibitions and concerts, plays with grandchildren and goes out to dinner most Friday nights with Mike and soon they will be going on a road trip to the desert. They are excited, I am slightly terrified. There is a fear that Jen's language will deteriorate to the point that communication will be difficult, but on the incredible modern medication she takes everyday, she can access her logical mind, and when in conversation if you are not speaking or writing correctly, she will probably just think quietly to herself that you're being a bit silly. ✓

writeing

galaxy = Galant Artistry!

✓

♡ :)_s