

My Story

Younger Onset Dementia Summit

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Chontell Johnson

It's 11 o'clock in the morning, I'm lying beside my 47 year old mother on a soft mattress on the floor of the room she shares with a woman who appears to be twice her age. Mum awakes every so often, petrified, her body writhing in pain.

At no more than 35kg she is in the final stages of Alzheimer's disease. Her body is slowly ceasing to function and there is nothing more anyone can do, except to manage her pain and try to ensure there is no undue discomfort. I am curled in beside her, holding her and trying to comfort her through the terror, reminding her that she is not alone and that it's ok for her to let go, that this is not the place for her anymore.

I was 28 years old.

I had been both fearing and praying for this moment for years.

My mother, Shelly, was a bright vivaciously engaging woman, always moving, always exploring. You had to be pretty quick to keep up. For most of my life she was bold and brave, strong, seemingly fearless and infinitely compassionate. However, for almost $\frac{1}{4}$ of her life my Mum's vibrant energy and fiery nature were subdued by Alzheimer's disease. Mum's assumed onset has been calculated back to around the age of 36, young....even for younger onset. I was 17 and preparing to sit my HSC, aware of my Mum's mood swings, but oblivious to her condition. It must have been so frightening, I couldn't possibly imagine. There is such a common misconception that Alzheimer's is just people "forgetting things", but there are so many more cruel attributes to this disease. Mood swings and self -alienation are a couple that come to mind, but the most prominent sign for Mum was when she stopped being able to write, she could speak well and read but when it came to putting something down on paper, the communication just wasn't getting there. This made it especially difficult when a signature was required at the bank.

At this point my Mum didn't have a diagnosis of Dementia. All the usual suspects were thrown around over the years; depression, nervous breakdown, silent stroke, hormonal imbalances etc. People don't look at a 36 year old and see Alzheimer's Dementia; in fact, I doubt that it was even on the GP's radar.

While I will acknowledge that our family's genetic predisposition to Younger Onset Alzheimer's is rare, it certainly does exist. A truth to which, I am certain, everyone here today will attest.

However, it's not just Alzheimer's disease or "genetic predisposition" that causes young people, as young as I am today, to suffer the effects of Dementia. Conditions such as Huntington's, Parkinson's, Pick's Disease, Stroke disorders, Creutzfeldt-Jakob disease, to name a few, are all conditions that can burden people as young as their 20's or even younger in some cases. These are all conditions that can affect a person's capacity to function socially, professionally, physically, emotionally and mentally, often compromising the cohesive bonds established within their own family units.

While most Dementia related conditions individually, have relatively low percentages of younger onset when compared with onset in over 65's, in collaboration as dementia related illnesses, they contribute to a frighteningly high proportion of a widely underrepresented people within our communities. These communities are already lacking in basic dementia support and dementia specific care facilities, much less access to providers and facilities whom are adequately equipped with the understanding and flexibility to care for the differing requirements of a person with Younger Onset Dementia.

I, like many people I have met, belong to a family line with a devastating history of Younger Onset Alzheimer's Disease. I don't know where it came from or what tripped the circuit, but as far back as I can see on my family tree, people have suffered as a result of this cruel condition.

Imagine

The 1800's a young mother with Alzheimer's Disease would simply have been considered "mentally affected", probably hidden away, lonely, afraid, an overwhelmed husband, caring for the children, while working to provide for his family, dealing with the social stigma, watching the love of his life degenerate into a stranger. No community support, no financial aid, no counselling.

Fast forward 100 years plus 4 generations of poor diagnosis, misdiagnosis, no diagnosis. 4 generations raised under extreme stress emotionally, mentally and most certainly financially...

My Great Grandfather Bert Maher, separated from his siblings, misdiagnosed with Huntington's Disease (a symptomatic diagnosis due to lack of facility or knowledge), his wife (a child of German immigrants who came to Australia for a better future), a strong woman, raised their 2 children and cared for her husband alone, providing for her family alone, still with the social stigma, still with the lack of community support, still without adequate medical care or respite facility.

Fast forward

60 years later there I am, in that room, with my Mum. Holding her tiny frail body, feeling unbelievably helpless, thinking of the previous 10 years, wishing I could have helped her more, supported her better, understood her pain and her fear more empathically... 10 years of improper medication, misdiagnosis, loss of good friends because the social stigma is still there, self medicating, shock therapy, homelessness, abuse, bad care facility's ...

160 years later and we are still facing the same obstacles, while somewhat better, we still have a distinct lack of social awareness... 160 years later there is still misdiagnosis, we are still fighting for adequate facilities, health care professionals are still asking for better education and tools to care for people with Younger Onset Dementia. There is still an appalling lack of counselling and community support for carers and the children of people with Younger Onset Dementia. Many of these children are by default, carers themselves..... 160 years later families are still burdened financially, limiting opportunities for future education, health care and social growth.

Fast Forward 6 years

My name is Chontell Johnson and this is my story.

I am a 33 year old woman. I am as professionally successful as I would like to be. I am incredibly social and I have a magnificent network of friends and family. I don't enjoy routine. I am terrible with appointments, so I rarely make them. I like the freedom to change my mind if I want to. I love the ocean, but not the beach. In fact I feel a little unsettled when I am too far from the sea. I love storms and walking in the rain. I love children and hope someday to have a couple of my own, if I am so blessed. I do not like to wear shoes. I have never had short hair and I hope I never have to.

I am a massive communicator, though as I grow older I am learning that people don't have to talk all the time to connect with each other (had I learned this earlier in life I would have save my Mum a fortune in "hush money" otherwise known as "if you just shut up for 5 mins ill give you \$1" money). I am unnaturally patient with people and life. I am empathic to a fault. I have been told that I am brave, but I think that is just a combination of patience and empathy. These are not unique achievements, just life tools I am grateful to have been given.

When I was 26, I lost the love of my life to a motor cycle accident. I thought this was the most devastating thing that would ever happen in my life... a month later I was diagnosed with a genetic mutation that promised I would develop Alzheimer's disease before I reached 50, most likely in my 30's if history had any say in the future. It was at this point that I came to realise that nothing is "THE most devastating moment in a persons' life" and that the only truly devastating thing would be to fail to appreciate what you have in your hands RIGHT NOW at this moment. That for all the time we can spend obsessing over what hasn't happened yet or worse, what has happened that cannot be changed, we are sacrificing precious moments in the present. I would also come to realise some time later that it is possible to have more than one love in your life without betraying the other and if you find that, you should embrace it.

Perhaps some of you are wondering how any of this is relevant to the NDIS or Younger Onset Dementia care and why you should you be concerned with my footwear preference or how I prefer the weather.

It is relevant because I am a part of your broader community.

I am telling you this now because I have the capacity to tell you, because right now in this moment I have the luxury of expressing myself, my likes, my dislikes and my needs. I have the luxury of making my own decisions and planning or not planning as and when I choose.

Because one day I may not have this luxury and I am relying on people like you all to make the right decisions. To create and follow the right policies, to provide the right support and facility, to impart proper knowledge to care providers, to listen to carers and nurses when they speak; they are the ones who are in the trenches, they have valuable experiences to share.

I want to form a part of adequate support networks so that consideration is given to who I am.

I need to know if a cure is not found in time for me that I won't become lost in the antiquated notion that Alzheimer's is for "old people" or that it's just a "normal part of ageing".

I want peace of mind that rather than facing social stigma, I am welcomed as a result of social awareness leading to acceptance. I want to know that provisions are made for me to continue functioning as a member of a society that is informed and empathic and that I am able to remain as I have always been, independent for as long as I possibly am able.

I need the assurance that when the time comes and I cannot be entirely independent, that I will not have to be a burden on my friends and family. I want the promise that I will be able to maintain my integrity as a functioning contributing member of society to whatever capacity I am able.

I want the assurance that I need not fear the possibility of being dumped in a substandard nursing home because my family don't have access to information on where is appropriate.

I hope when the time comes, that I am cared for by people who are educated on my condition and capacity and not resentful of the changes they might have to make to accommodate my individual needs.

I want consideration given to dementia specific facilities like the Garrawarra Centre in Waterfall NSW, where upon my mum's enrolment; I was asked "what did your mum like to do when she was able to speak for herself?" Where she could walk all day if she wanted to and listen to music that she liked. Where it was acceptable for us to tango up the corridor and she could flirt with men passing by. Most importantly, where she was loved and cared for compassionately and with dignity right through the stages of her palliative care, until the day she decided it was time for her to let go.....consistency of care, genuine care, specific to the specific type of dementia because this is the training that these amazing people have undertaken and the area in which they are highly skilled.

I have dealt with and seen the alternative and it is simply not acceptable.

I have been independent since I was 15 years old. Right at this moment I am strong and determined. I am diplomatic and articulate. I approach my life with passion and positivity and I am open minded.... All these things are luxuries.

I had genetic testing for a hereditary form of Alzheimer's disease because I considered it to be my responsibility.

I have a 98% probability of developing Alzheimer's disease.

I am taking responsibility for my future by participating in the DIAN study with NeuRA so they can use this rare mutation in the hope of finding a cure for many forms of Dementia. This means MRI's, Pet Scans, Lumbar Punctures, Cognitive and NeuroPsych assessments – all a part of a blind study, none of which do I receive

feedback for. Paul, whom some of you may have met this week was my partner in life and is now still my partner in the study. We separated more than a year ago but he still left his job early, gave up his vacation time and flew from England to be here in time so he could participate in and support us in the study.

I have paused my career this year purely with the intention of making myself available to Alzheimer's Australia and NeuRA and anyone else who needs my help in the hope of raising awareness of the importance of Dementia research, care and support services. In 6 months or so I will embark on a clinical trial to find a cure for Alzheimer's, which I'm sure you all understand, has risks which are impossible to anticipate entirely.

Everyone here for this summit has taken themselves out of their daily routine and comfort zone to share their story. They have been strong and courageous and unselfish in the hope that they will be able to communicate the need for change, to advocate for those who, for whatever reason, can no longer advocate for themselves.

We are here today and doing our part to help ourselves and those we care for. We are being transparent and brave. I hope the NDIS is the tool that enables us to continue to be functioning, courageous members of our communities and society as a whole and we hope our input is heard and considered respectfully.

Thank you