



Ms Kate Swaffer, co-founder and chair of Dementia Alliance International, was in town recently to speak at the Young Onset Dementia Symposium. Besides her two bachelor degrees from the University of South Australia, she has also completed a master's in dementia care at the University of Wollongong and is now working on her PhD. ST PHOTO: NG SOR LUAN

ItChangedMyLife

Author, activist and poet living with dementia

Kate Swaffer's initial despair at her diagnosis became a defiance in beating the condition



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It started in 2006, when Ms Kate Swaffer was 47.

Every now and then, the former nurse who was then doing a double degree in psychology and creative writing would find herself not knowing how to spell simple words like "that".

She'd also mix up her colours and get lost in places she used to know like the back of her hand.

She went to a neurologist, suspecting that it might have something to do with the neurosurgery she had the year before to correct a condition called chiari malformations, where brain tissue extends into the spinal canal.

The neurologist asked if she wanted memory testing to determine if she had dementia. She refused at first but relented when things did not improve several months down the road.

One year and a couple more tests later, she was diagnosed with semantic dementia, a type of frontotemporal dementia. It is a progressive disorder of the brain which can affect behaviour, language skills and movement. Those afflicted with semantic dementia progressively lose semantic and conceptual knowledge.

What healthcare professionals told her next was not encouraging: "Get your end-of-life affairs in order and get acquainted with aged care."

For months after she was diagnosed, she bawled her eyes out and moped. But then defiance set in and she started finding out all she could about her condition.

Now, nearly 10 years later, Ms Swaffer is one of the world's feistiest and most active dementia activists. She is the co-founder and chair of Dementia Alliance International (DAI), an international non-profit organisation which represents and supports those living with the disease.

Besides her two bachelor degrees from the University of South Australia, she also completed a master's in dementia care at the University of Wollongong and is working on her PhD.

She has also authored several books including *What The Hell*

Happened To My Brain?: Living Beyond Dementia, and Diagnosed With Alzheimer's Or Another Dementia.

It is hard to believe that the 59-year-old has dementia as she sits in the lobby lounge of the Marina Mandarin fielding questions articulately and cogently.

Then again, people with semantic dementia have been known to retain the ability to speak fluently even as they progressively lose the ability to match words with their images or meanings.

"I had a good sleep, I meditated as well, that's really helpful," says Ms Swaffer, who was in town recently to speak at the Young Onset Dementia Symposium organised by Alzheimer's Disease Association and Lien Foundation.

Often, she feels like a swan – calm on the surface but paddling furiously to stay afloat.

Named South Australia's Australian of the Year 2016, Ms Swaffer is the second-youngest of four daughters of farmers.

She grew up on a remote 2023ha farm with no running water or flushing toilets, near Cleve, a small town that is about a six-hour drive from Adelaide.

"We didn't get electricity until I was 12. It took me 1½ hours to get to school on the school bus," she says.

Her father didn't believe in education for girls so she left school at 16 and went to a nursing school in Cleve.

"I actually wanted to be a vet but nursing was the easiest option to leave home. It gave you accommodation, money in the bank and a career. What my father wanted me to do was to marry a local farmer and have babies. And that wasn't high on my list of priorities at 16," she says.

After completing her training, she left for Adelaide where, ironically, she worked in the city's first dedicated dementia unit in a residential nursing home.

"When I trained, I don't think we got more than 10 minutes of education on dementia. It was known as senile dementia or pre-senile dementia then. I only thought old people got dementia. And a lot of people today still think it's only an old person's disease."

She left after a year, because she loved it too much.



Ms Swaffer has been tirelessly lobbying for awareness about dementia, even as the disease affects her cognitive abilities. PHOTO: COURTESY OF KATE SWAFFER



"I was too soft and wanted to spend my days off with the patients because they were isolated; many had families who didn't visit them," she says.

For the next two decades, she worked in the emergency operating theatre of a public hospital.

When she was 27, her boyfriend of six years killed himself. An anaesthetist, he suffered from schizophrenia.

"Now I see that him taking his life was actually his greatest gift to me ever, because I wouldn't have left him. And he knew he was never going to get well. That's when I started to do a lot of self-help, reading books about being positive, optimistic and resilient."

Not long after, she married a colleague with whom she had a son. It ended in divorce several years later – she reckons, because she had not recovered from her grief.

Because her former husband also worked in the operating theatre, she decided to leave nursing and become a chef.

A foodie, she was a big fan of famous Malaysian chef Cheong Liew and had taken lessons under him at a cooking school for three months.

She set up Kate Swaffer Catering and started catering boardroom lunches. Before long, she was running, and cooking at, a centre for weddings and funerals; she bought a cake business too.

By then, her second husband Peter Watt, a businessman, had come into her life. Like her, he was a single parent with a son.

"I thought he was the biggest bore I'd ever met. We found each other attractive only many months later; our kids kept dragging us together. Next year, we would have been married for 20 years," she says with a laugh.

Her food business kept her busy but she gave it up after 10 years because of health issues.

Since going to university was a childhood dream, she decided to do a double degree at the University of South Australia while holding down a job selling, first, operating

theatre equipment and later, wound care products.

Her health woes, however, continued with neurosurgery for chiari malformation in 2005.

"By the time I was diagnosed, the brain stem had grown down the spinal canal, so it was compressing the nerves," she says, adding that the surgery probably prevented her from becoming a quadriplegic.

When she first started having problems with spelling, she didn't think much of it because she could easily compensate for it with the help of technology.

"I just thought, this is weird. But spellcheck on a computer corrects words for you if you misspell. It was when I started getting lost in the car in familiar places, and having trouble finding my way in the university that I started getting worried."

Her diagnosis, and the less-than-encouraging prognosis of health professionals, made her cry for weeks. The only solace, she says, was that she sometimes forgot what it was she was crying about.

"I was pretty gloomy about the future... I actually thought that I would be like the late-stage patients I nursed and (deteriorate) really quickly," recalls Ms Swaffer, whose cognitive problems caused her to lose her job and her driving licence.

But being in university at this critical period in her life was a blessing and changed her life in a positive way, she says.

A lecturer told her: "Oh, you're just a student with acquired disabilities. We've got a whole disability support team. I'll make an appointment for you."

Her disability adviser gave all her lecturers a Dictaphone so that Ms Swaffer could listen to her lectures. She also had buddies who helped her navigate her way around campus, and note-takers to help her.

Determined not to be shackled by naysayers, she read up all she could about her disease. She was especially inspired by Dr Richard Taylor, an American psychologist who was diagnosed with younger onset dementia and who believed in writing as therapy.

That led to her blog *What The Hell Happened To My Brain*. After striking up an online friendship with Dr Taylor, she met him in London at an Alzheimer's Disease International Conference two years later.

That was when they started talking about setting up DAI with five other academics.

Although three of the co-founders, including Dr Taylor, have died, Ms Swaffer now leads the organisation which has a presence in nearly 40 countries.

Her journey as an advocate started when she wrote a piece, *Dementia Inside My Head*, for her creative writing course. She also sent it to the editor of *Link Disability* magazine who published it. Not long after, she was asked by Alzheimer's South Australia to give a talk to its nursing staff.

One thing led to another, and she was soon attending international conferences on dementia, sitting on different boards, advisory groups and national health panels providing an academic as well as consumer perspective for the disease.

The only Australian to be a full member of the World Dementia Council, she is the first person with dementia to give a keynote presentation at the World Health Organisation's first ministerial conference in Geneva in 2015.

"I asked for better post-diagnostic service, including rehabilitation and disability support. I asked for balance in research, research for not only a cure but for care," says Ms Swaffer, who also asked for the inclusion of people with dementia in the Convention on the Rights of Persons with Disabilities.

It is not all hunky-dory. The disease is progressively chipping away at her cognitive abilities. Studying and writing have become increasingly difficult; composing a simple e-mail can take her 45 minutes.

Ms Swaffer, who is also a published poet, counts herself blessed to have her husband, whom she calls her "BUB" or "Back Up Brain".

"Some days I struggle dressing, some days I struggle making a cup of coffee or I'll make five cups and not drink any of them. Some days I feel like the doctors are wrong, there's nothing wrong with me," she says, adding that having a sense of humour helps her cope with her condition.

She shakes her head when asked if she fears the day when her illness will not allow her to continue doing what she does now.

"I'm way past that. I feel that every day while I can still speak, I have a moral and ethical responsibility to speak out.

"One day, I will die too and that's all I ever thought about, I would have a really shitty life."

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