

Before I forget: Christine Bryden's struggle with early-onset dementia

Tuesday 22 December 2015 10:14AM

Lynne Malcolm and Olivia Willis



IMAGE: CHRISTINE BRYDEN, LEFT, WAS DIAGNOSED WITH EARLY-ONSET DEMENTIA OVER 20 YEARS AGO. (ALZHEIMER'S AUSTRALIA/SUPPLIED)

Imagine being in your forties and receiving a diagnosis of dementia. Twenty years ago, this happened to Christine Bryden. Despite having difficulty remembering what she's doing, she's applied her extraordinary insight for the benefit of others. **Lynne Malcolm** and **Olivia Willis** report.

At the age of just 46, Christine Bryden was diagnosed with early-onset dementia.

'The doctor said, "You've got about five years until you are demented, and then another three until you die."'

'It was,' Bryden says, 'just unbelievably cruel.'

It was 1995, and Bryden was a successful biochemist and adviser to the prime minister. She was married

It's a toxicity of the medical model; that we are nothing

with three children, but suffering at the hands of a violent and abusive partner. **but a disappearing brain.** **CHRISTINE BRYDEN**

'It was just gruesome. When I try and

look back at all of that, I wonder how on earth I survived, but I did.'

Under an enormous amount of stress from a difficult home life, Bryden began to experience 'thundering migraines'.

'I thought it was just because of work life, home life and stresses and trying to keep everything going. I was just ignoring them and taking tablets, as you do.'

Eventually, the migraines became so bad Bryden was forced to see a doctor, but she concedes the headaches weren't the first sign that something was wrong.

'I recall in my late thirties getting confused and lost in the middle of Sydney on a familiar drive to CSIRO laboratories. I couldn't remember which way to turn to get out of the laboratories.

'And then getting names a little bit muddled—it was abnormal for me. I knew something was wrong, but I kept on putting it down to stress.'

Bryden eventually left her husband, but her symptoms of stress remained. A visit to the GP led to a series of brain scans, which later revealed the devastating diagnosis.

'It was the beginning of a new life for us all. I was feeling on cloud nine and just quickly whipped into the neurologist to get my migraines fixed. Instead, my whole planet tilted on its axis.

'It felt like an earthquake under my feet. It was just horrific. I couldn't think of the future without horrible fear.'

Read more: Using music to reawaken memory

Bryden, who had developed anorexia nervosa and associated mental health concerns as a teenager, became deeply depressed.

'At the beginning it was dreadful, it was just so miserable, there was no support, and I couldn't rise above and think positively.'

Two decades later, Bryden is the first to admit that she's been lucky; the progression of her dementia has been unusually slow.

'I'm still here after 20 years for several reasons. Presumably one of them is that the brain disappearing trick is actually not quite as fast as might be expected, about 4 or 5 per cent a year apparently, but also it's giving me time to try and counteract it.'

Over the years, Bryden has been buoyed by science's relatively new understanding of neuroplasticity—the brain's ability to heal itself—and she tries to live her life guided by that knowledge.

The progression of her dementia continues, however.

'Word-finding is much harder, and my vocabulary is less. My pronunciation of long words is much harder.'

'But also my levels of anxiety: I don't cope very well at all with the day. And my memory has got a lot worse.'

'I don't really recall the past, and I can't work out what is happening in the future.'

'What I did last week? I don't know. What am I going to do next week? I don't know. I have to use more and more aids.'

Perhaps Bryden's most important aid is her husband and 'care partner' Paul, who she married some years after receiving her initial diagnosis.

'He's still here, still supporting me, still being my enabler, helping me do as much as possible ... telling me what day it is, and what it's going to be tomorrow, and what I did yesterday.'

'He just keeps me oriented so I can keep going. He is helping me right the way through to do as much as I can, while I can.'



IMAGE: CHRISTINE BRYDEN HAS WORKED TO REMOVE THE STIGMA ASSOCIATED WITH DEMENTIA. (SUPPLIED/ALZHEIMER'S AUSTRALIA)

Together, Christine and Paul have become passionate advocates for people living with dementia all over the world. In 2003, Christine became the first person with dementia to be elected to the board of Alzheimer's Disease International.

She says she's determined to break down the stereotype about dementia; the idea that once you're diagnosed, you immediately become an 'empty shell'.

'To me, the toxic lie of dementia is what you are told at the beginning. It's a prescription; "Oh, you've got dementia, you've got about five years until you are totally demented, and then another three until you die."

Bryden believes such diagnoses become self-fulfilling prophecies, and ultimately lead people to retreat into depression and despair.

'It's a toxicity of the medical model; that we are nothing but a disappearing brain.'

Instead, Bryden believes people living with dementia should turn their attention to the present.

'We need to just live every day as if it's our best day, even if it is our last day, and make the most of every moment in the day, and make it a moment full of wellbeing.'

In what Bryden describes as 'the journey from diagnosis to death', she says people living with dementia become increasingly 'present' in the moment.

'I always say to people who are looking after us, try and just be present with us, because by being present, you can truly connect with us, just by eye contact or touch.'

'Just let us know that you are there with us, not negating our feelings or in some way patronising us, but that you are on an equal level with us and that you are also truly present.'

Read more: [Dementia can impair our ability to imagine the future](#)

In addition to focusing one's attention on the present, Bryden encourages people living with dementia to use a calendar to mark down what they can, when they can.

'If you have a thought, whatever you might want to do, like buy something or write someone a card, write it down in the calendar for maybe tomorrow or the day when you know you've got a bit of time.'

'Just capture everything in writing somewhere.'

Bryden stresses the importance of remaining calm in otherwise overwhelming situations, and encourages people to take anti-dementia medication if they can.

'There are five things to prevent dementia ... they are to eat healthily, look after your heart, undertake moderate exercise, enjoy socialising and mentally challenge your brain.'

When asked about the future of care for people living with dementia, Bryden says there are more things that could be done to enable people to settle into 'more comfortable, present' moments.

'First of all let me say that the people who care for people with dementia are wonderful. I think it's a thankless and underpaid task, and often there's just not enough time.'

Through her advocacy work, Bryden is hoping to shift what she perceives as the broad attitude towards people living with dementia; from 'physical objects of care', to people who are 'fully human and fully present'.

'I'm not going to be just Mrs So-and-so sitting over there in the corner who needs a shower, I'm going to be someone with a life story, someone who can be connected with, even if I've got no words.'

When there are no words, Bryden says any signs of non-verbal expression should be seen as an effort to communicate, with which we must engage.

'I often say, listen with your eyes, look at us, what are we trying to say?'



Before I forget

Down

Sunday 13 December 2015

Listen to the full episode of *All in the Mind*.

[More](#)

An exploration of all things mental, All in the Mind is about the brain and behaviour, and the fascinating connections between them.

Share

Tweet

Print

Email

More

Comments (3) Comments for this story are closed. No new comments can be added.

DAVID BOYD :**22 Dec 2015 3:10:55pm**

I have just read your wonderful article about a brave & beautiful women with dementia.

first thing that struck me was, no comments. well I have to say that I am one of those carers, who appreciates what you have said & done. it is so difficult to support & help someone you love through this terrible journey. great medical advanced are close, but not close enough for some. I will not say everything I feel except that the government & the general public need to learn & support those with dementia & their carers. we are not good enough in helping those in need. thanks david boyd

Alert moderator

Suzanne :**22 Dec 2015 6:10:05pm**

Thank you Christine for sharing your remarkable story. I read the text of the story and then listened to your voice telling us about how you deal with your life. I've recently had a close relative die from this terrible disease. It was difficult for our family to cope as our loved one deteriorated. I hope you will live and enjoy one day at a time long into the future.

Alert moderator

Wendy White :**22 Dec 2015 7:57:05pm**