

Sean's Story:

My five tips for living well with frontotemporal dementia



By Sean Kelly
with Deborah Moore

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Important: Dementia care knowledge and research is continually changing and as new understanding develops, so too does the support provided for people with dementia. All care has been taken by the authors and publishers, as far as possible at time of publication, to ensure information is accurate and up-to-date.

The Dementia Centre HammondCare is committed to providing excellence in dementia care. Older and younger people living with dementia deserve services that are designed and delivered based on evidence and practice knowledge of what works. This is achieved through providing research, training and education, publications and information, consultancy and conferences.

Thank you to everyone who supported the publication of *Sean's Story: My five tips for living well with frontotemporal dementia*.

About this book

Sean's Story is the result of conversations between Sean Kelly, who lives with frontotemporal dementia (FTD), and Deborah Moore, a Dementia Consultant with the Dementia Centre. Sean and Deborah have known each other for many years and have spent many hours talking about his journey with FTD. They share a trusting relationship and friendship. In 2018, Sean and Deborah presented 'Sean's Story: Living with frontotemporal dementia' at the International Dementia Conference.

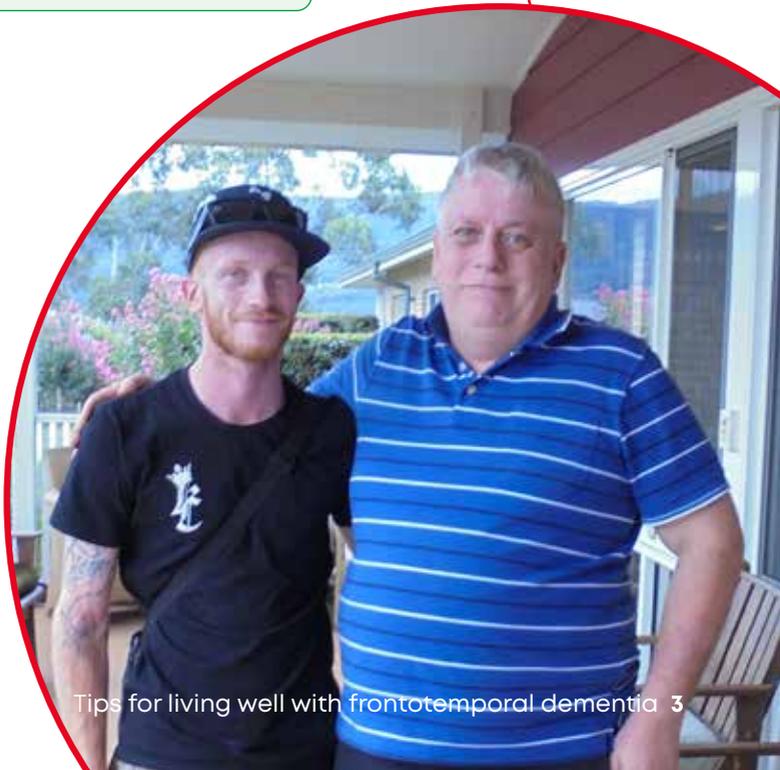
To start a conversation with Sean, you can reach him on:



@SeanPKelly3



<https://www.facebook.com/groups/125434488163324/about/>



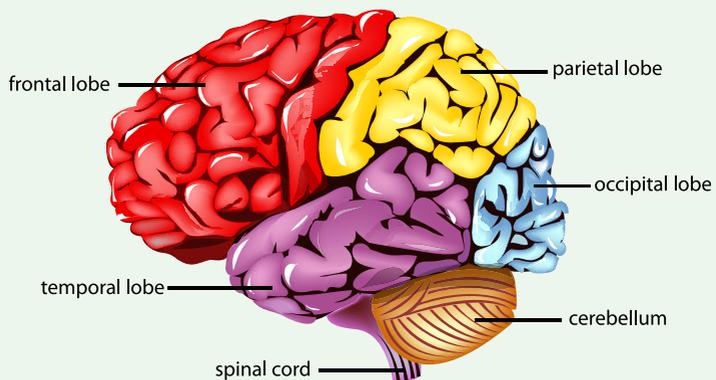
What is frontotemporal dementia?

Frontotemporal dementia (FTD) is the second most common form of dementia in younger adults in their 50s and 60s, and is the commonest form of dementia in those under 50 years old. The name comes from describing the area of the brain that is impacted, the frontal and temporal (side) lobes of the brain.

The symptoms of the condition can differ depending on the extent and area of the brain that is damaged. Some people with FTD may experience changes in behaviour, personality, mood, or have difficulty understanding or expressing language. While memory is often only minimally affected in the early stages, there is invariable involvement of memory as the condition progresses.

While younger and late onset dementias can have similar symptoms, there are often differences in people's perceptions. As dementia is commonly associated with old age, there is an increased likelihood for those affected to be misdiagnosed with depression or a psychiatric condition. An added challenge of dealing with younger onset FTD is that a person will likely be employed, raising a family or have financial responsibilities. This has a major impact not only for the individual but on those around them.

While there is no cure for FTD, there are supports that can help a person understand and better manage their condition. These include psychological therapy, speech therapy, occupational therapy and some medications.



About Sean

After many years of misdiagnosis, I was diagnosed with younger onset frontotemporal dementia (FTD) at the age of 44. I wanted to tell my story and share some tips that allowed me to live well with FTD, which I hope will help others with dementia to enjoy life too.

I was born in the United Kingdom and lived in Singapore before moving to Australia in about 1972. I had a colourful childhood and referred to myself as a 'latchkey kid'. My two older sisters, Linda and Wendy, moved out when I was young and my parents were never there, so I quickly learned to fend for myself.

Living across the road from Maroubra beach, I spent time surfing with friends and getting into mischief. I believe that the challenges I faced in my childhood led me to become a youth worker. I wasn't much older than the kids I helped out. Later I moved to Canberra, found love, got married and had two sons, Rhys and Lachlan.

When the boys were in their teens, my family noticed I had started to act differently. My moods changed, I was withdrawn and would get angry easily. I could be sad, happy and angry all in the one day. I wasn't myself. The doctor thought I had carer stress, as I had been looking after my wife after an accident, and he referred me to a neurologist who had previously diagnosed my sister Linda with FTD. He told me that I might have dementia like my sister, but I didn't pay much attention to it at the time.

I had some troubled times during this period. I received a diagnosis of schizophrenia, was prescribed numerous medications and separated from my wife. The turning point was when I moved in with my sister Wendy and brother-in-law Jeff; I really believe they saved me. We talked about the possibility of dementia, and everything changed.

Here are my top five tips for living well with FTD.

1

Chase the right diagnosis

Seek out medical advice to confirm the right diagnosis

People often say to me: 'You don't look like you have dementia.' I usually ask them, 'Well, what am I supposed to look like?' I guess because I'm younger, people find it harder to believe that I have something that is meant to be an older person's disease.

In 2012, after being misdiagnosed with schizophrenia, my sister Wendy and I went to the Frontier (Frontotemporal Dementia) Research Group, which was initially with Neuroscience Research Australia. Following a lot of testing, I was diagnosed with FTD in 2012 and Wendy was diagnosed in 2015. This was very hard for both of us, as we had seen how quickly our other sister, Linda, had been affected by FTD.

A year before, studies found that changes to the C9orf72 gene was the most common cause of hereditary FTD. Wendy and I have been a part of an FTD longitudinal study since 2012. We get tested every year in November, and the most



recent test showed that my FTD symptoms have plateaued. Wendy's have too.

I believe getting the right diagnosis has helped me and others to understand what I am experiencing and has given me the best chance to access the right support and manage my symptoms.

An early or 'timely' diagnosis of dementia, especially for younger adults, can be difficult. There are many barriers to an early diagnosis such as the perceived stigma of dementia, lack of a standard diagnostic test, and the likelihood of misinterpretation by medical professionals of the individual's changes in behaviour and cognition.

However, an early diagnosis enables people to plan for their future and investigate possible alternate treatments that may slow down the progression of the condition and improve quality of life.

Resources

Dementia Australia www.dementia.org.au

Diagnosis, treatment and care for people with dementia:
A consumer companion guide www.cdpc.sydney.edu.au

Eastern Cognitive Disorders Clinic www.ecdc.org.au

Neuroscience Research Australia (NeuRA) www.neura.edu.au

The Australian Frontotemporal Dementia Association
www.theaftd.org.au



“ Getting the right diagnosis has given me the best chance to access the right support.”



2

Find a place to live that fits you

Keep looking until you find somewhere to call home

I was so grateful when Wendy and her husband Jeff took me in, but I needed to find somewhere to stay long term. I did some respite in an aged care home, but this didn't suit me. I had nothing in common with the other residents and the food was awful. I was in and out of places; I stayed at a boarding house for six months, then moved to a share house and ended up in another boarding house, which was terrible. It had 50 men to one worker, it wasn't a place where I felt safe, and although I was lucky enough to have my own room it wasn't somewhere I was proud to call 'home'.

When you have dementia at a young age, it's not easy to find a place to live where you feel good about being. In 2015, while

I was still living at the boarding house, Wendy had arranged for me to do two week's respite at HammondCare Horsley's younger onset dementia Streeton Cottage. As soon as I walked in, I thought I was in paradise. I knew this was where I wanted to stay. It wasn't crowded like the boarding houses, I felt like I could have my own space, there were beautiful gardens and places for cooking meals, and it felt safe.

There need to be more cottages and services to support people with younger onset dementia. There's just not enough around. I know how lucky I was to find a place in Streeton Cottage. It's a stable and supportive environment, and I've found peace there.



For a person living with dementia, a safe environment that promotes independence and wellbeing supports their ability to live as normal a life as possible.

Recent studies have shown that living in small, domestic-style aged care homes with access to outdoors is perceived by the person with dementia and their families to improve their quality of life, reduces inappropriate medication use, and leads to fewer hospitalisations.

Resources

Clustered domestic residential care in Australia: fewer hospitalisations and better quality of life (journal article)

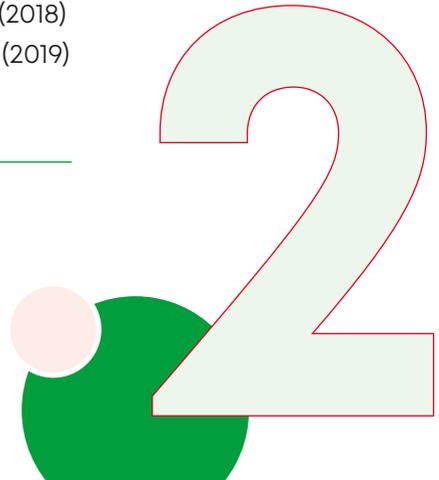
Dyer and colleagues (2018)

My Aged Care www.myagedcare.gov.au

My Home, My Life (book) Colm Cunningham, Natalie Duggan and Agnes Houston (2018)

Talking Murals (book) Mary Marshall (2019)

Younger Onset Dementia Hub
www.yod.dementia.org.au



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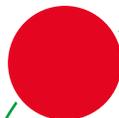
Be cared about, not just cared for

Being supported by people who care about who you are is just as important as them caring about what you need

When I was living in the boarding house, I became very depressed and was prescribed medication. I didn't feel like I was seen as a person, but more as a 'patient'. What I needed as a person did not seem to be a consideration. There were all sorts of rules, there was nothing to enjoy about being there. With only one staff member to 50 men, they had no chance to find out who I was.

When I moved to Streeton Cottage, my life changed. My medications were slowly reduced. I'm off all of them now and I've lost weight. Although I'm living in a care home, I am able to make my own choices that the staff support. I'm now treated like an individual and I feel respected by the care staff. They know who I am, they know my family and my background, and they always go out of their way to help me if I need it. They don't just meet my needs; they make me feel as though I belong.

“With one staff member to fifty men, they had no chance to find out who I was.”



Caring for a person has never been about getting through daily routines of showering, meals and sleep. The new Aged Care Quality Standards have defined what good care should be, with the person being cared for at the centre of these standards.

Dignity and choice are central to the new standards, meaning that care providers spend time getting to know the person they care for by talking to them and their families to understand their preferences, needs and values, and to support them to live the life they choose.

Resources

Dementia Support Australia www.dementia.com.au

My Home, My Life (book) Colm Cunningham, Natalie Duggan and Agnes Houston (2018)

Talking Sense (book) Agnes Houston and Julie Christie (2019)



4

Stay connected to the community

Keeping in touch with the community can help you to feel less isolated or alone

In the cottage, I have access to a computer and the Internet, which is my connection to the world. I like to share information about FTD and started a Facebook group for people with younger onset dementia, which has almost 400 members and am on Twitter with over 650 followers. It's important to spread the word about younger onset dementia, because a lot of people don't realise that younger people can also be diagnosed with the condition. Raising awareness gives me a sense of purpose.

Socially, I am able to do different things each week like walking, going out for breakfast, and visiting the lake, beach, zoo and, most importantly, the footy! (Go the South Sydney Rabbitohs!)

I also go on twice-weekly bus trips with Streeton Cottage and attend Men's Shed gatherings and barbeques. I was able to go on my first cruise with my family in July 2019. I'm glad to have the opportunity to get out and do things. Besides helping me to stay connected to the community, it's good for my mental health.

“ Raising awareness gives me a sense of purpose. ”

Many people who are diagnosed with dementia become socially isolated from the community, friends and family. Often this is due to a lack of awareness in the general public as well as the stigma associated with dementia. Loneliness and isolation for the person with dementia negatively affects their quality of life.

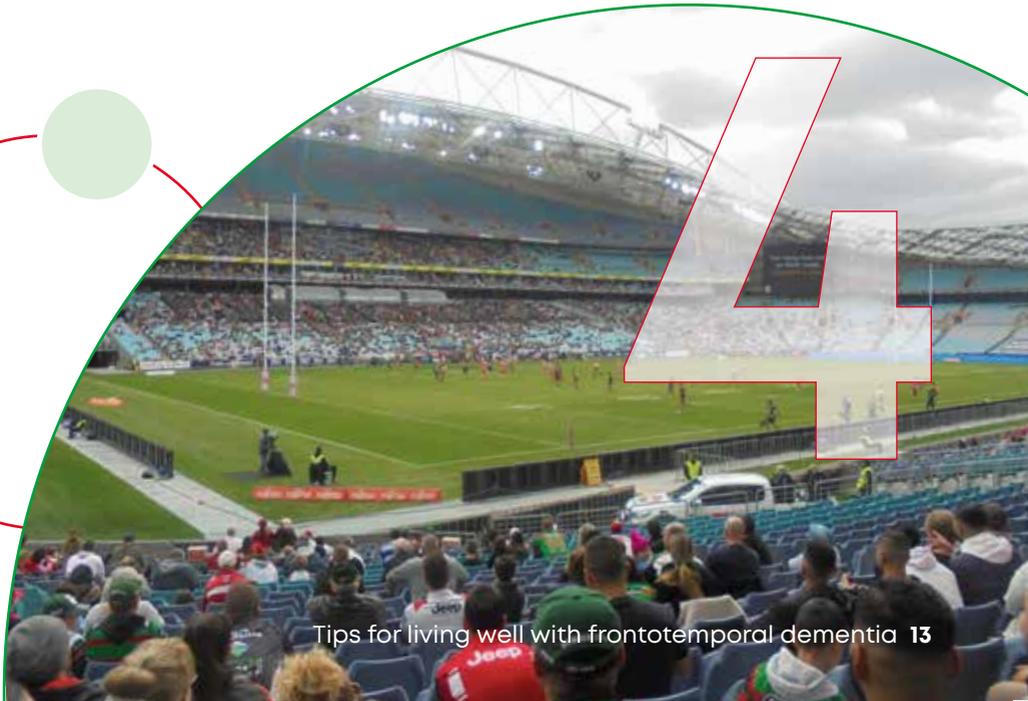
Keeping socially active, continuing to be involved in activities that the person and carer enjoy is important for both to maintain their quality of life, health and wellbeing. There are a number of government and community engagement services that are available to support the person with dementia and their carer.

Resources

Australian Men's Shed Association www.mensshed.org

Dementia Australia www.dementia.org.au

HammondCare at Home (provides information and services for a person to remain at home, socially active and as independent as possible) www.hammond.com.au/services/home-care/



5

Happy heart, happy mind

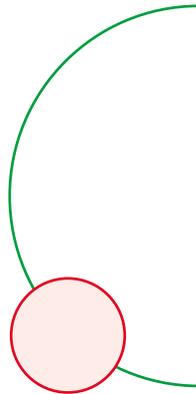
If you do what makes your heart happy, your mind will follow

I sometimes wonder what my life would look like if I didn't get the help I received in the early days before and after my FTD diagnosis. What would I be like if I still had a diagnosis of schizophrenia? What if I'd stayed homeless? What if I'd stayed at the boarding house? What and how many medications would I still be taking, and what would my mental state be like? My guess is I'd be very depressed, angry and still on many medications.

Last November, I was told my symptoms had plateaued. I think this is because of how happy I am now. I look back on my early life in Maroubra, feeling like no one cared about where I was or what I was doing. Now it feels like everyone cares! I have the support of my family and carers, and I live in a great environment where I feel safe and secure. I have friends, am able to go out and do things and stay connected to the community. I'm medication-free, healthy and happy.

Having a diagnosis of FTD at a young age is not ideal, but I feel as though I'm living the best life possible. I'm happy and content where I am, and I believe this has helped to keep my moods and mind on an even keel.

“ I have friends and I'm able to go out and do things and stay connected to the community. ”



Happiness and what makes people feel happy is different for everyone. Although a diagnosis of dementia can be distressing it doesn't mean a person stops enjoying life. It is possible to live well with a diagnosis of dementia, and what constitutes living well is dependent on the individual and stage of dementia.

Engaging in social interactions and enjoyable activities as well as a healthy lifestyle with exercise and a good diet have shown to improve a person's wellbeing. Understanding the person with dementia, knowing their story and likes and dislikes, can inform how to best care for a person with dementia and maintain or improve their quality of life.

Resources

Live and Laugh with Dementia: The essential guide to maximizing quality of life (book) Lee-Fay Low (2014)

Living well with dementia

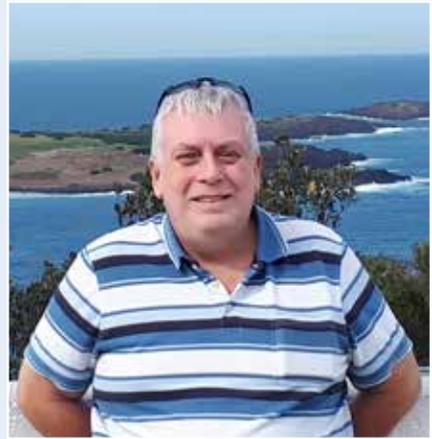
www.livingwellwithdementia.org.au



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Sean's Story is about Sean Kelly's experience with FTD and what he did on his journey to be in a place where he is now happy and content with life. As everyone experiences dementia differently, each person's story of living with the condition will be personal and unique to them. Sean hopes that by telling his story others may find happiness and peace.



**The
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