

Presented by Helen James October 4 2017 at International Carers Convention in Adelaide

WHY DEMENTIA CARE IS DIFFERENT. THE RELATIONSHIP IMPACTS OF DEMENTIA ON FAMILY CARERS.

Everyone has the right to die with dignity and free of pain.

To-day I will share my views and experiences in three areas: **firstly**, how I coped with managing my husband when, aged 64, he was diagnosed with Fronto Temporal Dementia with the variant of Semantic Dementia; **secondly** - how I was always searching for what I call “the windows of joy”; and **thirdly**, the difficulties we experienced at end of life despite him being lovingly cared for in a care facility.

Nothing ever prepares you when you are both told about a terminal dementia diagnosis. You feel your whole world is collapsing around you.

When I was thinking about my presentation today, I realised the enormity of the subject. Everyone develops different strategies and we are all such different personalities, and have different relationships.

There are so many different elements to the dementia journey – from early diagnosis to transitioning into residential care, and end of life. Not one dementia is the same. Every aspect of decline and adjustment is a story in itself.

Before Gordon’s diagnosis, I had heard about Dementia, but had no idea of the complexity of the disease.

It was something “other” people got, and something to do with the brain and memory loss.

But back to Gordon. We met in 1994. Gordon was English, had an outstanding career in London as an Insurance Broker at Lloyds, and in the early 80’s came to Sydney and set up his own successful business as an Insurance Broker. I teamed up with him in the latter years before retiring in 2006.

It was in that last year we were working that I detected changes in him. His spelling had deteriorated; he forgot client's names after he had just spoken with them; and he became easily agitated – all very abnormal for Gordon.

He was accurately diagnosed with Fronto Temporal Dementia, with the variants of SEMANTIC AND BEHAVIOURAL DEMENTIA - a rare and progressive dementia with the symptoms worsening over time. It is predominantly the loss of comprehension and the meaning of words.

But it was the personality changes, lack of empathy and behavioural issues which were difficult.

He became inflexible and less concerned for the feelings for others as well as socially unacceptable behaviour. He became preoccupied with a few activities, had a fixed daily routine and liked to do things at the same time each day.

He wouldn't recognise people he didn't see all the time. He would use words incorrectly, for example "sheets or my pleasure" for wine; "trees" for trousers and the labels would change. You had to be a mind reader and observe body language closely.

But he could remember to do things at the right time, and remember certain events, and of course, he knew the way to the shops – he was a daily visitor at Vinnies, and was always bringing home dolls for me and all sorts of bits and pieces which he proudly displayed at home.

So, how does one cope with a diagnosis?

For me, I decided I needed to educate myself on managing the disease. I was fortunate to attend an intense carer education programme to learn skills on managing FTD behavioural problems as part of a research programme.

These were invaluable skills; I learnt to retrain my brain in order to manage Gordon.

This is a time when it would have been helpful to have a mentor or coach to help me through this period.

So I was so pleased to learn of the formation of The Stronger Carers Programme back in September 2013, launched by Baptist Community Services in New South Wales, and funded by the Federal Government. It was free of charge to the carer.

It was a 10 week programme involving an in-house coaching model using skilled carer coaches that worked directly with the carer. They were focused on **caring for the carer**, and supporting them in what can be a long term and stressful situation.

The first six weeks of the programme were in-home sessions between the carer of the person with dementia and their carer coach. The carer coach discussed carer expectations, goals and better strategies to manage the person with dementia.

In the last four weeks, this involved the coach to follow up with the carer via phone or e.mail to ensure they were supported or referred to other appropriate services in their local area.

I was the consumer representing Alzheimers Australia NSW on the steering committee and after the two year trial, in my view this model was so successful it should have been launched nationally.

Unfortunately, funding was not granted again to continue the service.

In actual fact, Baptist Care now fund a modification of the programme with a different name involving a program facilitator and volunteer coaches, who have experienced caring for a loved one with dementia.

Alzheimers Australia NSW also use a modified programme called "Better Life" using a coach from the original concept. "Better Life" consists of 8 free weekly or fortnightly sessions by phone or video chat.

I strongly believe if people with dementia, as well as family carers gain early acceptance of this disease, and have access to a mentoring programme, this prepares them for the ongoing declining stages, and if necessary, residential care.

A dementia diagnosis has a big impact on family and friends. You feel helpless.

For me, the only way I could manage was to treat it as a project; dealing with the emotions on one hand, and the management of the disease on the other. Gordon couldn't change, but I could. As far as he was concerned, there was nothing wrong with him. His common phrase was "it's perfectly alright".

And his type of dementia needed to be managed differently to someone with Alzheimers Disease, which is a different type of memory loss.

Also I would never have survived if I hadn't firstly attended the Memory Loss Workshop at Alzheimers Australia NSW and subsequently joined a Support Group. I learnt from other family carers.

I had three goals; to make sure Gordon had the best possible life; for us both to enjoy a life together while we could; and for me to have a life, and remain healthy to be his carer and advocate.

For me, I needed to turn a negative into something positive to share the 12 year dementia journey with Gordon.

So I joined my local Probus Group, played tennis, and kept up my social life with friends and family as well as becoming an advocate for Alzheimers Australia NSW to make more people aware of dementia, and reduce the stigma.

Additionally, I was constantly searching for what I call "the windows of joy" so Gordon could find enjoyment in his life at every stage. We have always celebrated each day. But of course, as Gordon's dementia symptoms changed – we kept on making adjustments. While we were able, we travelled to England and Europe to visit Gordon's family and friends; attended concerts, picnics, visited friends and generally did whatever was possible.

Gordon loved gardening, he attended a fortnightly activity group, played scrabble with a volunteer – weird words appeared I can assure you – and a weekly paid carer took Gordon bushwalking. The bonding with a male carers was also important for him – and gave him a break from me as well.

Also, when Gordon went into residential care, during the early days, we were able to go on walks; drive to a park, where he loved watching the seagulls and boats, or we'd have lunch or afternoon tea, with or without friends, always focusing on what we could do rather than what we couldn't.

We discovered Gordon loved Art. This was an opportunity for him to express his creative side in safety and he didn't have to communicate with anyone. He loved it .

But one of the biggest difficulties was the fact that Gordon looked so healthy and normal. He had an invisible disease.

I remember comparing myself with another carer whose husband had a visible disability and was in a wheel chair. We were both assisting our husbands to get onto a bus.

Help was readily available for her as her husband's problem was visible. But I had to explain my husband's socially unacceptable behaviour. It is stressful. You walk on egg shells.

Then - the transition to a Care Facility was, one of the toughest experiences I had to adjust to.

In my view, support is vital and I believe family carers and paid carers within the Residential Care Facility need to understand each other's roles to work together as a team, to get the best outcomes.

Which brings me to my next point of good Palliative Care for those with Advanced Dementia. It would be remiss of me if I was not a voice for people as my husband in this area.

Because, nothing had prepared me for the advanced stages of Gordon's dementia. Physically, he was a strong man, but mentally like a 1 year old; he has been a good, gentle man; through his life he has been resilient, and just got on with things without fuss; however, he became **mute**. He had no quality of life, he didn't really know me, and he sat and stared into space, or slept.

I have no idea what it would be like walking in his shoes.

But it was obvious he was in severe pain. We didn't know where the pain was coming from. He couldn't tell us.

However, because he shuffled around, was still eating (he had no taste and would eat anything, including paper) could swallow, and did not have an infectious disease, he didn't fit the definition of "palliative care". He was on low doses of morphine to keep him calm and pain free.

No one wants to see their loved ones suffer. This topic always seems to be "the elephant in the room" – especially the choice to die with dignity, which is a sensitive topic.

In the end the Palliative Care Team were called in for advice and to manage the pain; but his doctor struggled to understand Palliative Care with the symptoms Gordon presented.

As I was still distressed about the situation, I appointed another doctor who understood. Finally Gordon became more comfortable with increased medication and passed away in February this year.

Advanced Dementia should be no different to a patient suffering pain with cancer or other terminal diseases.

Understandably, doctors may find this difficult as the complexities around dementia can be complicated as the patient is unable to articulate what they are experiencing.

It is really important that GPs, Registered Nurses and staff in residential care facilities have appropriate training in providing Palliative Care and end of life issues for all patients with advanced dementia, to avoid suffering.

No one needs to suffer at the end of their life; it is delaying the inevitable, and it is inhumane and lacking in dignity. I mirrored his pain, as did everyone around him, all trying to assist him.

I have since learnt from the AMA - "that all dying patients have the right to receive relief from pain and suffering, so long as it's undertaken in accordance with good medication practice, the administration of treatment or other action intended to relieve symptoms, which may have a secondary consequence of hastening death.

"It is often referred to as the "principle of double effect" and is an ethically and legally acceptable form of palliative care if given with good medical practice – with appropriate consent, in good faith and without negligence, in accordance with medical guidelines."

The AMA also believes there should be more community education and awareness of palliative care and the principle of double effect so that health professionals and the wider community are aware of, and understand, what can be done to help alleviate suffering at the end of life.

You may wonder why I am telling you this. Well I want to advocate for a better world for people as my husband without a voice, because you know what? This could happen to any of us. I certainly do not want to end my life in the same way as Gordon.

But you know, all through Gordon's dementia, he still inspired me by his strength of character in coping with the complexities of his disease where he had some awareness, but could not communicate.

However, looking beyond the dementia symptoms, there was still a beautiful, gentle soul there, and soft eyes, which were saying "thank you to anyone who assisted him".

I will now conclude by sharing a recent quote I saw about Life:

It's a journey – no one is ahead of you or behind you. You are not more "advanced" or less enlightened. You are exactly where you need to be. It's not a contest.

It's LIFE. We are ALL teachers and we are ALL students.

