

Services that will benefit carers of sufferers of younger onset dementia during the later stages of the illness

Younger Onset Dementia Summit

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Tony Walsh

I have been asked to speak to you today about services that will benefit carers of sufferers of younger onset dementia during the later stages of the illness. I have based my talk on that which I have learned as Chairman of the Younger Onset Reference Group in Victoria and from people in similar situations I have met on this journey.

Just a bit of my history

I can remember the exact moment that my partner told me in 2003 that he had been referred to a memory clinic by our GP. I remember thinking what a load of nonsense. A few months later I also remember sitting in on a consultation with a specialist and it dawning on me that yes there is a problem and I had taken over at home without realising it. It was at this point I knew the issues had become difficult at work and that is why he had sought the referral.

The next moment I remember was in 2006 when a psychiatrist diagnosed Alzheimer's disease. I noticed a tremor in his arm in 2007 and Parkinson's was added to the diagnosis. It was not until 2011 that he began to hallucinate and had very exciting delusions that the final diagnosis of Lewy Bodies Dementia was made. This will be a familiar story for many of you - we attended the Alzheimer's Australia Living With Memory Loss course and made friends with seven other couples who have remained in regular social contact since; a valuable resource to have during this journey. I also attended another course, this time aimed at the carers of people with younger onset dementia. During this early part of the journey I must say the education available was excellent and the resulting collection of pens, we got a new one at each session, was impressive.

A few more years passed whilst we continued to see the world before it was too late. We completed 15 cruises before 2011 when Paul deteriorated quickly and had to be moved into care. Although I had to select quickly I think I did it well and both Paul and I are very happy with the care being provided. Suddenly this person who I lived with for 22 years who since his retirement was my constant companion for 5 years was no longer in this big house. What was worse, I realised that I had not fully taken in the information that had been so expertly provided in the early years. Looking

back I am not surprised that all that talk of end of life documents, nursing home fees, wills and powers of attorney had only been absorbed and acted on in a limited fashion. We had written our wills and nominated our powers of attorney probably as a result of a recognition that we were getting older more than an acceptance of the diagnoses that had been pronounced could possibly lead to situations where they were needed. I am sure that much of the information was treated very lightly; I was in the constant company of this lively partner who could not wait to do the next trip and whilst I had to plan days with a sleep in the afternoon and not too much activity he was still there, still great company and the thought that this diagnosis would progress was difficult to accept.

Suddenly I was faced with a large house with no-one but me in it; the need to travel daily to see the person I had cared for so long and the gradual loss of a meaningful connection because of the diseases progress. Very few friends visited more than once and I began to understand why people had said to me, "you will know who your real friends are when things get tough". Worst of all, I found that there was no-one and nowhere I could go for help and the pen collection was shrinking as they ran dry. I must say that the nursing home did offer a couple of visits to a counsellor but I think his lack of knowledge of the difficulties that carers of younger onset patients face was not as deep as one would have hoped. Given that probably over 90% of the residents are over 80 that is not surprising.

Before I tell you about what I think can be done, I would like to share with you some comments I received from others in a similar situation.

A friend of mine who cared for a partner with terminal cancer told me, "it was easier for me, he did not lose his marbles."

Another said, "I remember when my husband went into permanent care I was in mourning for months, it was like he died. No counselling was offered but luckily my family found some and it helped."

Dementia is different, the patient is still there but you lose contact with them: children, siblings, favourite close relatives and friends all find this difficult. I think this

is the main cause of the low visitor rate to people in dementia units. The behavioural issues of other residents probably also play a part.

Another told me, "Hardly anyone of my husband's friends visit and they all live around the corner. They tell me they want to visit but they never do. Some say they want to remember him the way he was. Some have visited once and never again. I think it is too confronting for them coming face to face with the reality of the situation and seeing all the other older residents."

In the same vein someone else said, "There were 450 people at my partner's funeral...only one friend had visited him (twice) in the 11 weeks that he was in care. I think people are afraid to face the reality of later stage dementia. It is confronting for us, especially when younger people like our partners are placed among much older residents. So no wonder it's even more confronting for our children, grandchildren and friends.

And now what to do about it

I think there are three groups of people that need help:

- The carer
- family and friends
- the staff at the facility.

Let's start with the facility. I am told that the more people who visit the happier the resident. I also observe this to be the case. The happier the resident, the happier the staff and the less pressure they are under. So let's get people visiting more often. As a first step I think we need to understand that visiting a dementia wing is well outside the comfort zone of most people. We need to provide help to those who wish to visit and tell them about the how, when and where to visit. It is a matter of education. It's a bit like helping people to overcome the fear of flying. You have to do it before they take off in a less confronting environment.

How to visit includes signing in, knowing the staff and knowing who has what responsibility, how to react to the other residents and how to deal with difficult situations. It also includes knowing how to plan the visit, do you need to come

equipped with something more than talk? Know the fall back position if your plans cannot be brought to fruition because the resident is not well enough or the weather is bad. Answers to simple questions like where you make a cup of tea or coffee, the location of the loos, where the sanitiser is located and how to use it are valuable when visiting such a confronting place; when to visit is to know to keep clear of mealtimes and when the person you're seeing is at their most active and receptive to visits; where to visit includes learning where you can go for a walk or a trip (the shops, local parks suitable cafes), who to advise before you venture out, who to advise when you return. If you do not choose to leave the premises what can you do on site? Do you have access to the recreational facilities away from the unit?

Which brings us to the carer, we have all heard of the saying, "The carer goes first." That is something it is in all our interests to ensure does not happen. Family carers are, I believe, one of a nursing home's assets. We need to understand that much of the education we provided at the beginning of this journey was not absorbed and there comes a time when we need to run over it again. Perhaps there is more to be added at this point. This is probably best done on the basis that a problem shared is a problem halved so counselling either on a one to one basis or in a group will be valuable. It does, I think, need to be led by someone with some experience who can suggest strategies. For myself I have found a counsellor from the AIDS council who, of course, deals with many people in our age bracket and thus with similar issues. Although, of course, most of them do not have dementia to deal with.

In short, counselling for the carer and education for friends and relatives could probably fill the gaps.