



## DTA Guest Lecture: Living their Best Lives: Best Practice Support for People Living with Younger Onset Dementia - 24 September, 2020

### Audience Q&A's

| QUESTIONS   | ANSWERS   |
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| Is physical activity beneficial for someone who has dementia?   | Absolutely! There is a lot of evidence that regular exercise can help a person with dementia to maintain their independence for longer. It's also very beneficial for mood and overall health, just like for people without dementia              |
| Do I have permission to share the YOD resource with my students?  | Absolutely. We want to share as wide as possible  |
| Can a plan be done by a diagnosing doctor/health team?  | Assessments are done by the NDIA. Planning meetings can be done by the NDIA or local area coordinators.   |
| Which languages is the book available in?   | Currently English only. Happy to receive funding to make available in other languages   |
| Can we include dementia in the disability category?   | Dementia causes a range of disabilities. In Australia young people with dementia are eligible for the National Disability Insurance Scheme.   |
| Is the ebook confined to younger onset of dementia or dementia in general?  | It is suitable for care providers/family of any age of person living with dementia  |
| What is the most common age diagnosed in young onset dementia?  | Overall, the majority of young people with dementia have their symptom onset between 60 and 64 years. However some types of dementia (for example, frontotemporal dementia) often onset in a person's 50s   |
| I am a personal trainer, I would like more understanding, knowledge on how I can help people with YOD   | Please access Prescription for Life YOD through the ECU website   |
| Me and my husband both are in our mid 40's. Is there any test to find out if we are heading towards dementia or not?  | There is no simple test. Remember that dementia in your 40s is incredibly rare and you are unlikely to have dementia now. If you notice significant changes to your thinking or memory, see your GP. They can send you to a specialist if needed. |
| I would really like a contact for someone that could help with looking for respite care for a 55 male with YOD. Unable to speak/communicate but very active - walks all day. Asking on behalf of his wife who is struggling to find help as all respite seems to be aimed at aged care which is not suitable. | This is such a common challenge. There aren't many suitable respite services for young people with dementia. It depends where he lives - if he has NDIS support, perhaps contact the Local Area Coordinator to see if they have advice?           |
| I know someone who has dementia at the age of 57 years. With this age, they cannot access MY AGED CARE service, so what is the alternative service for them to get support?   | This person should be eligible for the National Disability Insurance Scheme   |
| I work with a resident in aged care who is 66 but has no insight she has dementia and is not sure why she is living in aged care. She feels a little isolated. Any suggestions on how to help her feel more settled and happy in the environment she finds herself?   | Try working through the Prescription for Life YOD resource to see some ideas for inclusion in her care.   |
| Is there a blood test for dementia? Both mum and sister had and have dementia. I'm 72. Thank you.   | Unfortunately no, there is no blood test for dementia. If you start to notice changes to your thinking and memory, see your GP. They can do some screening and refer you to see a specialist if needed.   |
| Did you use a standardised attitudes and knowledge questionnaire, or did you develop your own?  | We used The Dementia Attitudes Scale O'Connor & McFadden and the DKAT 2   |
| My hubby was under 65 when diagnosed. He is now 68 so do I still consider him to be "younger onset"?  | Yes, if a person had symptom onset before 65 we continue to consider them a person with young onset dementia forever. However, he would NOT be eligible for the NDIS unless he made an access request prior to turning 65 years old               |
| Can a person with younger onset dementia have the same deteriorations as an older person living with dementia?  | Yes, symptoms will progress for both older and younger people with dementia.  |

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| John, as a new chef in aged care, just enquiring about your diet, throughout your life. Was it a balanced diet?   | I ate a typical male Aussie diet. Fat, sugar and meat! I did eat a huge amount of fruit and vegetables as well. About the time I was diagnosed with Dementia my sugar cravings increased and increased and increased again. Very hard to fight the urge to eat anything sweet. I have heard/noticed that many people with dementia get sugar cravings.  |
| John did you experience friends suggesting you might have a problem that required visiting a Neurologist?   | No. My GP recommended the neurology line. Friends had no suggestions really.  |
| Are you still teaching in some way or form John?  | I can't teach anymore but I do love to be involved with education. I help some adults I know with their educational pathways and continue learning daily.   |
| John, how do you deal with frustration with family and friends who don't understand?  | My family and friends are amazing and very supportive of me. When people don't "get it" I try to back away and give them some space. I try to "teach" them about dementia without being a pain. Sometimes it works!!!   |
| John, I want to know, when you heard the news about your dementia, what were your thoughts? Are you planning things for your day to day tasks?  | When it was suggested and then I was diagnosed that I had dementia I was relieved and very happy that I had a label. It made me feel GREAT. Truly. I know that dementia is a terminal condition but so is life! Now I had a way to understand my own types of peculiarities.  |
| John, do you follow any physical exercises and a proper diet?   | I so very much want to say "yes" and I know that these are the two aspects of my life that I can control and will make make day to day life better. I am becoming increasingly lazy. I also have reduced my intake of food significantly. This not a positive as I am not eating enough and am losing weight too much. I fluctuate with my feelings of guilt which alters/increases the exercise for a short while. It is honestly harder to exercise and eat properly but I do try....sometimes! |
| Hi John, just wondering what types of activities do you find useful to keep mentally stimulated?  | I love listening to books e.g. Audible. I also watch at least one lecture per day (often 3 or 4) from The Great Courses. Audible is a few cents to dollars a week on subscription and The Great Course is about \$30 AUD for 3 months (unlimited!) Both products are from the US but they are worth giving a try. I visit friends and grandchildren throughout the week.  |
| Thank you for sharing your story John. Were your cholesterol levels high to warrant a heart problem too? Do you think the two are related?  | I had Rheumatic fever as a child 5 years in a row. That led to Aorta valve problems. My Aussie diet didn't help. I did have high cholesterol levels which were truly under control by the time I was diagnosed. High cholesterol and heart problems are clearly linked. I think my strokes were the major factor in my dementia especially with FTD and Neurological dementias.   |
| Hi my son has been diagnosed with dementia and Parkinson's aged 33 any suggestions for him please?  | Please access Prescription for Life YOD through the ECU website. Encourage him to maintain/develop a group of close friends.  |
| John, What kind of activities or things do you do apart from listening to music.? What kind of activities would you look to be doing that wasn't demeaning? I'm a lifestyle coordinator in aged care. | I love listening to books e.g. Audible. I also watch at least one lecture per day (often 3 or 4) from The Great Courses. Audible is a few cents to dollars a week on subscription and The Great Course is about \$30 AUD for 3 months (unlimited!) Both products are from the US but they are worth having a try. I visit friends and grandchildren throughout the week. I am still looking to extend my range of activities.   |
| John how do you stay positive as consistently as possible? Do you have mood swings often?   | I am a positive person. I do think about the people who don't have life as good as me and try to help other people as much as I can.  |
| Do people suffering with dementia show aggression as a means to fight the irritability with loss of memory?   | I think my irritation levels are on a short wick. I get VERY Frustrated with my loss of short term memory.  |

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| John, in your opinion, is your community is Dementia Friendly?   | I think my community is Dementia neutral. I think most people (including me) know very little about Dementia. If huge percentages of people have dementia where are they all? Invisible. The word Dementia used to conjure a picture of a blithering idiot when I was younger and later I could not create an image because I never saw anyone who I KNEW had Dementia. I really think that needs to change. Having said all the above I live in an amazing community and I believe that People will become even more supportive. The Prescription for Life (free) Resource is fantastic. The Dementia library is wonderful. The more people know the better. |
| Could there be any limitations to upskilling due to cognitive impairment?  | Being a crazy optimist I think every human being I have ever met is capable of more. Of course there are limitations but until a person reaches their limit who is to say what it is. (Aside) I keep tinkering of the chicken who had its head chopped off in America but lived for years afterward. No one told the chicken it was supposed to stop thinking and die. Apparently people who are shot fall down wounded and dying because this is what is expected of them. Messgae: Don't do what is expected - live up to your potential!   |
| What are the tests for early onset dementia? and what kind of changes and conditions should i anticipate?  | All the various specialists are important. I found neurologists and geriatricians very helpful with their cavalcade of tests. MRI was very important for me.  |
| Monica, is there anything that can be done to expedite the process in availing the services?   | Making an access request as soon as the person is diagnosed is a good idea. Speak to Dementia Australia about whether they can provide any pre-planning support, to ensure the person has the best chance of receiving the funding they need.   |
| Do you have examples of some great supported housing models for people living with YOD in Australia?   | There are a number of proposals and facilities being built at the moment. There is one YOD-specific residential aged care facility in Sydney, hosted by Hammond Care. It has a good reputation, though it is not supported disability accommodation.  |
| Getting information to residents in residential aged care on what NDIS can pay for/supply can be lifechanging. Can anyone provide information on this as I feel some feel only their facility can provide? | I absolutely agree, and there is a significant lack of resources and information available out there. The Summer Foundation may be able to help, but I don't know of any other good resources I'm sorry. Others may know!   |