

Quality services available to people with younger onset dementia

Younger Onset Dementia Summit

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Most people with younger onset dementia do not have access to appropriate services and supports that can improve their quality of life and help their carer. There needs to be an increase in the number, flexibility and variety of age appropriate services for people with younger onset dementia within the community. The newly funded Younger Onset Key Workers may help provide more support for people to access services.

Services for younger onset dementia that are well designed and support social engagement and participation in society are essential because these people need to be a part of life and have a purpose. I am fortunate because I have access to multiple services, which help me in my every day life. Today I am going to tell you about some of these wonderful people and services, which I appreciate and enjoy.

I was diagnosed with Alzheimer's in September, 2010 by a neuropsychiatrist in Melbourne after having had a neuropsychological assessment in Ballarat. I first observed symptoms in 2005 and it then took 5 years until I received a diagnosis. It is very important for people to be diagnosed as early as possible as it enables access to medication, time to plan finances, time with the family and support from dementia specialist services at the earliest stage. These specialist services are important for both the person with dementia and their partner and family.

I am fortunate to have great medical professionals whom my partner, Anne, and I can rely on. I continue to see the neuropsychiatrist, who gave me my diagnosis, every 2-3 months as he monitors my medication and where things are at. Our GP is also a great support to us both, as she keeps a watchful eye on us with regular appointments once every 6 weeks. We also see a Social Worker who specialises in younger onset dementia. This helps us talk through some of the issues which arise and provides us with invaluable information and support.

I also appreciate the support my local hospitals provide me. It is important for hospitals to know about the diagnosis and have information in writing to put on medical files, to ensure all hospital staff are aware of the special issues for someone with dementia.

After diagnosis of dementia, Alzheimer's Australia offers a three day program for the person with dementia and their carer, partner and family. This is an excellent way of introducing a broad range of discussions and issues about dementia. I recommend this

program, although it can be confronting, it is also a great way to meet new people in the same situation. This was where many significant relationships were forged and the beginning of us accepting our situation.

We have continued to receive support from Alzheimer's Australia through their younger onset dementia group. We have three main people that provide support to us: Glenda, the coordinator of services; Sandra, a social worker; and Mary. Glenda negotiates with service providers on behalf of the younger onset dementia group and is in regular communication with them to get the best possible outcome for the group. Glenda maintains a personal relationship with all those involved with younger onset dementia in the region. The ages of the younger onset dementia group range from 32-62 and there are 4 females & 5 males. Tuesdays are the days we spend together as a group. We get out and about and go to interesting places in our 12-seater bus and have frequent catch-ups at various cafes. The group is very supportive of each other and we have a lot of input into what we do.

Providing activities in a group outside the home is important because it decreases social isolation, provides opportunities for communication and laughter, and helps others to understand the issues of someone living with younger onset dementia by being visible and active as a group in the community. The activities I participate in help me forget about the problems associated with dementia and provide me with a sense of belonging that comes from being a member of a group. Activities which I enjoy outside home include Eyres House Day Centre and Art Classes at the Salvation Army Community House.

Eyres House Day Centre is the base for the Alzheimer's Australia younger onset dementia group and it also provides a meeting place for partners and families. The centre organises 3 to 4 family barbeques a year and respite care on weekends. We are currently trying to organise occasional respite weekends that are exclusive to people with younger onset dementia. We have a lot of fun at Eyres House Day Centre, it is such a beautiful, gracious mansion and we all love it.

The other activity I enjoy outside of home is art classes at the Salvation Army Community House. I pay a small fee to attend these classes, which are lead by artists and run for approximately six weeks, four times a year, using different art mediums and ideas. They encourage people to bring personal and meaningful photos, poems, books and ideas to create something of value to the individual to keep as a reminder. The Salvation Army

House also ran a series of computer classes for the group as a way of telling their stories. Some of the vignettes were uploaded to the ABC Open Program website.

Younger onset dementia activities outside home are important because apart from improving the quality of life of those with dementia, they also provide respite for carers. My loving partner is my major carer but I also have additional carers who come fortnightly or weekly. Ballarat City Council provides a carer who comes once a fortnight for 3 hours. Usually these visits involve cooking up a storm together to provide the evening meal and fitting in a walk with my two dogs. VISTA also provides a carer for a small fee. Julie comes over once a week for four hours and we go shopping, play tennis and have lunch together. I view her visits as my play day and I love it!

In addition, Carer's Victoria allocated us a Case Manager, Faith, when I was first diagnosed. We have found her very helpful, especially when she negotiated the support we got from VISTA when I had a hip revision. Anne can contact Faith for support anytime and if there was an emergency. Faith also runs a monthly luncheon for local younger onset dementia couples, which is greatly enjoyed by all.

I am very grateful for the support and services my partner and I receive, but we still need more help so I can live at home for as long as possible, for example, increasing carer hours over time and more regular and flexible respite.

As I have mentioned in this talk, it is crucial that people with younger onset dementia have access to appropriate services and support. Service providers need to acknowledge the medical, physical, social, emotional, psychological, financial and respite needs of both the person with younger onset dementia, their partner and family. They must endeavor to make sure these needs are met.

If it takes a village to raise a child, you need a community to support & meet the needs of someone with younger onset dementia and their partner & family.

Thank you.