


SUBMISSION TO THE INQUIRY INTO DEMENTIA, EARLY DIAGNOSIS AND INTERVENTION

While the person with dementia is the subject of this Inquiry, many challenges facing the patient are also thrust upon family carers who share the journey with them, sometimes falling into the frail aged category themselves.

Financial strain, the loss of independence, behavioural changes, altered marital relationships and social isolation have far reaching effects on the quality of life for family carers as well.

When considering people with dementia, it is vital to take into account the pressures faced by family carers who are the other half of the equation. Without their carer acting as an enabler, the person with dementia would have limited opportunity to access necessary services, participate in social activities or remain in their own homes.

Quality of Life and Independence

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If dementia is diagnosed early, the patient has a starting point for medication and coming to grips with the situation while they are still able to understand the changes taking place. When medication works to alleviate the symptoms, even for a limited time, that person's quality of life has to improve.

As many spousal carers are elderly, early intervention may also help them to accept the situation before their partner's needs accelerate to a point where they are unable to cope.

In situations where the person with dementia manages household finances and household maintenance, or cooking and domestic duties, an early diagnosis gives them the opportunity to gradually hand over these tasks to their partner. A couple may decide to bring forward a holiday or some other event they had planned for later on.

Day centres and cottage care provide much needed time out, giving the carer a break so they can cope with their loved one remaining at home for longer. Short periods of respite may be more attractive to both the patient and their carer than blocks of residential respite. The current shortage of flexible, short -term overnight and age appropriate respite needs to be urgently rectified.

Early diagnosis could assist in investigating alternative modes of transport. If the person with dementia knows he/she will lose their drivers licence eventually, they may learn to drive a gopher while their brain is still receptive to learning new skills. Perhaps their carer may need to refresh driving skills if they are used to being the passenger. Using public transport would be easier for passengers who have time to get used to the system, rather than needing to learn about it when their dementia had advanced.

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Social Engagement and Community Participation

Sometimes friends from a former life lose touch or mixing with them becomes too hard. Meeting other people with memory loss or dementia in the early stages promotes a gentle way of acceptance. New friends with similar challenges may step in to fill the void. This is also true for carers of people with dementia, who often form lasting friendships with their peers.

Attendance at day centres that incorporate physical exercise and memory training helps keep brains active in the fight against dementia. The benefits of social interaction via clubs, activities and friendship groups are well documented. People who attend cottage respite and day centres are more amenable in accepting longer term respite or permanent placement when it becomes inevitable.

When a diagnosis is made at an early stage of dementia, it gives them the opportunity to seek out day centres and respite options that offer activities they would like to participate in. Some programs run by day centres record aspects of the person's life, either through digital media (DVDs) or in book form. As well as being an enjoyable and positive experience, the record can also serve as a memory tool further down the track.

Planning for the Future

The world we live in increasingly requires documentation for our medical and lifestyle needs. Power of Attorney, Guardianship and Wills are also an imperative. Early diagnosis allows the patient to put plans in place while they are still able to understand the outcomes. When there are no written directions, the stress on families and potential legal fees create enormous problems.

An early diagnosis may encourage couples to move into retirement complexes catering to their progressing needs, thus avoiding traumatic upheaval at a later stage. As well as providing familiarity for the person with dementia as they progress, it also sets the stage for their partner to form new friendships with neighbours.

Some people may wish to live in a purpose built house and an early diagnosis allows them time to design suitable accommodation. Others may want to move closer to family or medical centres, or explore alternative housing options such as Home Share or community living.

A person with younger onset dementia has unique needs, especially under the age of 65 and not eligible for aged care services. They may still be employed, have a working spouse and/or children still attending school. Early diagnosis can help in planning for the family's future direction and security. The current lack of services, and difficulty in finding those that

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do exist, needs to be urgently addressed. It is devastating for younger onset dementia patients to be housed in residential facilities where neighbours are the age of their parents, or even grandparents.

Communication and awareness of dementia-related services

I think the biggest obstacle to dementia awareness is the perceived stigma attached to the disease. Many people consider dementia to be a mental illness or those living with it to be dangerous. Education, through print, media and word of mouth is vital to reduce the perception of shame. With intelligent marketing, acceptance of, and compassion for, people with dementia could reach the same level as say, people suffering from other incurable conditions.

As Carers are the main drivers in seeking out dementia-related services, they are an obvious group to approach with information. Understandably, GPs these days are often too busy to keep abreast of current services and entitlements, but the Practice Manager may have a display rack for leaflets or noticeboard where brochures can be prominently displayed. Displaying brochures in locations such as Community Centres, Council Chambers, recreational venues and on public transport is also logical.

Alzheimers Australia is dedicated to spreading awareness about dementia and provides education and support for people whose lives have become affected by the disease. They run support groups, resource centres and emergency services and are available for home visits. Their lead in having well known people involved and championing dementia (eg, Ita Buttrose and Sue Pieters-Hawke) lends gravitas to the cause.

Carer organisations help sustain carers in their role, providing information, support services and opportunities for carers to meet others who experience similar challenges. Outings, activities and events are sometimes a lifeline to carers who may be overwhelmed by their dementia journey.

Services to the community are often hard to find, but introducing the My Aged Care website, national call centres and a network of Carer Support Centres will provide greater assistance with home support. It is heartening to see that increased funding has become available for better and more flexible services in the future.

We need to break down the barriers when it comes to understanding dementia so that our ageing population is not fearful if they are diagnosed, but actively seek out positive ways of fighting the disease. Early diagnosis and intervention is the best way this can be achieved.

