



## Diagnosis of Dementia.

There are huge problems for those who have been affected by "Younger onset Dementia". Diagnosis and help can take years in some cases.

It can also be very difficult with older patients; Doctors can be very patronising e.g. "Well, at your age...." Or a sympathetic pat on the shoulder and to be told "Well there isn't any cure you know!" and then be shown the door.

It is very important to be able to get prompt, early diagnosis as medication is available to help slow down the progression and reduce some symptoms. This is so important and gives those affected a better chance to plan for their future and to make every day count. The Doctors should refer patients on to a Specialist and also to hand out information and encourage contact with the Alzheimer's Association.

More must be done to Educate our G.P.'s as they are our first line of contact.

Consumer Directed Respite Care Packages.

Sound good but are wrongly named! These packages went on trial nearly 2 yrs. ago. In July 2011, I was fortunate to be offered one of these packages and I was able to access overnight stays at Norman House with money from this package. As my husband is up 5 – 8 times during the night, this is one of the ways I am helped most- with overnight care and having the money to help cover costs.

This year, although receiving the CDRC package, I was not able to use this money for respite at Norman House. It is now seen as “double dipping” according to Wesley Bowden Uniting Care. In July 2012 I contacted my MP Mr. Steve Georganas, also the Minister of health Mr. Butler. I received a reply from Mr. Butler in September 2012. In this letter he said “I can confirm that you are able to access overnight respite services from Norman House using funds from your CDRC Package.” Since then the Health Department on Sept. 28<sup>th</sup> advised that if I use the CDRC for Norman House I would be paying over \$300 a night instead of the \$40 that I usually pay. This means that instead of paying \$160 for 4 nights respite, I would pay over \$1200 for 4 nights. The entire package is only a total of \$4200 so you do not need to be a mathematician that there is no joy here!

Wesley Bowden Uniting Care who handles this package for me seems unable to anything. They did however make the “helpful” suggestion that I seek care elsewhere!!!!!!!!!!!!!! My husband has been attending Norman House for day respite for several years. The girls are all wonderful and my husband feels safe, secure and very happy there. He has made new friends and just loves the activities provided. If this package is “consumer directed” I feel that I and others should be able to use the money in a way which is the most help to us. Isn't that what Consumer Directed means?

Standard of some Agency Carers.

Agency carers seem often to not have any particular “standards” to meet. The conditions of some vehicles are not good, dress codes do not seem to exist and some do not seem to really understand the needs of people with Dementia. Luckily there are also some very excellent people but carers never know the person that is rostered to them until they arrive and have no background on their capabilities. It seems impossible, even when booking weeks ahead with the Respite Centre to be able to get a person that you have had before.

In conclusion, I would like to thank you for this opportunity to bring our concerns to your notice. Unfortunately, any changes to happen in the future are unlikely to be of assistance to many of us, but we can hope and pray that maybe the road can be a little easier for those carer's walking in our footprints in the future.

## Residential Care.

Firstly, paper work needs to be standardised. Carers do not have the time or energy to wade through mountains of paper work. Every Residential Care facility seems to require different paperwork. This is so time consuming and I feel very unnecessary! When we start this process, it is suggested that we need to put our names down at about 10 different centres. Carer's are time poor and often sleep deprived, and this sounds all just all too hard.

Some Residential care centres do not allow you to visit their facility until a position is available. All this wasted work, time, stress and paper if this centre is not suitable or too expensive. Others open once a month for a short time, more stress as we try and juggle this step – not just once but perhaps 10 times!

When Residential care has it accreditation, is the entire area inspected or only certain areas? I find it difficult to believe that entire facilities are checked, unfortunately by personal experience.

**CARERS ALLOWANCE:** The Carers Allowance is payed to assist carers to look after the loved ones at home saving the government billions of dollars a year in nursing home costs. I have been caring for 11 years, the allowance has gone from \$98 per fortnight to \$115.40 pf, an increase of \$17.40 it equates to 34c per hour a total insult to the value of carers. Carers bonus that is payed once a year to carers and the person they are caring for also has not increased for some time ,time carers where looked after ! Money for respite, holiday visit family.

**ACAT:** To get an acat assessment is very difficult and stressful being told it could take years, the acat is needed so we can access our 63 days residential respite a year plus put name down for permanent residential care. Having to get angry and tearful to get heard.

**RESPITE FUNDING:**The number of respite houses need to be increased and given more funding so they can increase the quantity and length of time they can offer. In the early days of someone having dementia it is distressing to be put in nursing homes for respite with people who are far more advanced than they are. Halfway house between home and residential care.

Garry Leith, Carer.

Today Garry Leith was keen to come and present to the inquiry. He cares for his wife who is 59 years old and she was diagnosed at the age of 57 with YOD however symptoms were noted for 2 ½ years prior. Due to a family emergency and the ongoing complexity of his working and caring roles, he is unfortunately unable to attend today. On his behalf, as well as for carers of individuals with YOD, I would like to relay some of the issues that they face every day.

### **The path from symptoms to diagnosis**

The path from personal concerns about a loved one's memory and behaviour to the actual diagnosis of YOD has been described as complex, overwhelming and insulting. The majority of carers of individuals with YOD talk about a destructive path of miss-diagnosis where they feel dismissed and ignored. Depression, anxiety and general mental health issues are common diagnosis in the initial stages. Doctors do not seem to be aware of YOD and its presentation, which can be quite different to that of an older individual with dementia. The loss of employment occurs as the inability to cope or manage tasks become apparent, so then individuals have to also deal with the stigma of being sacked, retrenched or forced into retirement. Often by this stage friends and colleagues have started to become distant as they also do not understand what is occurring. The financial burden begins, as the feelings of isolation and inadequacy set in.

The stress on relationships is immense. Often there are children at home who are also trying to cope with the changing behaviours that are being exhibited. They stop asking friends home and the financial pressures impact on the children's lives. Stories of the need to leave private schools due to financial pressures as well as the need to sell the family home have an impact on children that are dealing with more than we can imagine.

A 2 year delay in diagnosis is commonly reported and when it arrives it is often a relief which brings fear and pre conceived ideas.

### **Intervention**

Support networks for YOD are minimal in SA, and with an estimated 1255 individuals in SA in 2011, representing 5% of those with dementia the numbers are not excessive. It is estimated to increase to approximately 1700 by 2050. These numbers are not high, but the complex scenario and the needs for this group have been highlighted in Living Longer, Living Better. The state is in need of specific programs to provide support for the individual with YOD as well as their families.

Traditional respite models are not suitable for this group if we are aiming to promote cognitive and physical wellbeing. Their needs are different due to their physical state, the progression of the disease, age appropriate desires and also their preconceived image of an individual with dementia is not conducive to acceptance. Programs that are age appropriate and provide a respectful model of support and stimulation are currently limited and have waiting lists

YOD respite models need to be flexible and able to support working partners. 9 – 5 models do not enable partners to continue in the workforce and therefore they resort to relying on pensions. Funding needs to ensure some flexibility for families living with YOD

YOD carers need a wide range of support including counselling, financial advice, counselling and support for children.

Access to intervention is often limited due to the age of the individual. Being under 65 years of age excludes individuals from an ACAT which is the access point for community packages, residential care and respite. There is a struggle for access to be obtained and due to the complexity of the disease process and the funding implications, providers are at times reluctant to support individuals with YOD.

As the disease progresses and the need for increased support becomes apparent, this proves to be a very difficult stage. Residential facilities are reluctant to offer support due to funding issues and the complexity of the individual's needs. Residential facilities are also overwhelming for younger children as they struggle to cope with their parents declining health.

Managing the complexities of dementia is amplified for individuals with YOD and their families. LLLB has identified that there is a gap in service provision for this group, and now we need to work towards specific programs and intervention that can be implemented within Adelaide.