YOD has never been a focus for policy, nor has it been easy to gain recognition of the issues. The decision of COAG to lump YOD under disability funding agreements was made without consultation with Alzheimer’s Australia, and there is concern as to how much research was done into whether this was the best option.

On the 26th of May 2010 Glenn Rees, Anne Eayrs, myself and Angela Reguz from HammondCare met in Bill Shorten’s office with members of his staff. This was followed by a meeting with Minister Elliot’s office on the 31st May 2010 with a larger group, including Alzheimer’s Australia HammondCare (Angela Reguz and Kate Sarkodee) and a younger person with dementia. The consumer came along with his sister and brother in law as support, to share his story privately with the Minister. A number of issues were discussed and YOD broken up further into three main categories:

1. Those with disabilities who develop dementia
2. Those who develop YOD in their 30’s and 40’s
3. Those who develop later, in their 50’s or 60’s.

Under the recent COAG decision all three categories are covered under disability funding/services. Issues surround the transition from disability services before the age of 65 into aged care after the age of 65. Other issues include:

- Disability sector may need to buy in dementia skill sets including dementia
- The length of the dementia journey varies a great deal
- Continuity of care
- This is not a small group of people
- People wish to stay in their own homes
- Services will need to focus on keeping younger people engaged in their community
- Where will the funds come from?
- There is a need for consistency with regard to the role of disability and aged care services across Australia in access to services for younger people with dementia
- Aged care should provide a stand alone service for people new to disability while offering sensitivity to those with existing disabilities
- ACAT & Disability services are not necessarily providing the same services in each state/territory; there needs to be a consistent approach to service provision.

Glenn Rees has suggested the ‘Grit in the Oyster’ approach: encouraging community service providers to put forward submissions on demonstration projects so that we are able to assess what models work, what funding sources exist and to “tease out” the needs of consumers.

Glenn has also expressed Alzheimer’s Australia’s support of the HammondCare project (featured in the 5th edition of HOPE).

Angela Raguz explained that the service which HammondCare have proposed:

- Approaches from the back end of service delivery
- Will not succeed without the community services to back it up
- HammondCare have proven in the past that they are able to work with the states, as is essential to success.

During the course of the meetings, we agreed that the discussion might be followed up in three ways:

1. The development of a paper that traverses the issues in providing care for people with younger onset dementia including identifying the different target groups (people with disabilities who develop dementia, those who develop younger onset dementia with no
Dementia and the long term effects of alcohol abuse

Wintringham is a not-for-profit welfare company providing an extensive range of advocacy, support and aged care services to elderly homeless men and women, and to financially disadvantaged elderly people who are at risk of homelessness. Working exclusively with financially disadvantaged older people has given Wintringham a unique perspective on issues associated with homelessness and the aged.

Currently Australia has a well developed aged care service system. Comprehensive aged care services are generally effective in delivering appropriate care and support to the majority of the aged population. Yet despite the richness of services available, there are still groups of people in the community who are not gaining access to these services or not utilising them to their full potential to meet individual needs. There are also some people for whom the services available lack the specialised skills or resources required to adequately address these needs.

Alcohol problems in older people are increasingly common.1,2 It has been found that a significant number of people aged over 65 drink at levels that exceed recommended drinking limits.3 The frequency of under-diagnosis of alcohol problems in older people is significant. When the effects of excessive or inappropriate alcohol consumption are considered in an aging population, alcohol-related ill-health is a compounding factor. The body changes that occur with aging leave the body more vulnerable to the effects of alcohol along with the increased risk of mixing alcohol with prescribed medication.

Although the effects of alcohol abuse can be felt across the far reaches of our community, the relationship between alcohol and homelessness4 is well documented in that it can be both a cause and an effect of homelessness.4 In a study undertaken by Wintringham in 2003, 43% of an elderly homeless population self-reported having issues with alcohol.5 However, when case workers were questioned as to their client’s level of alcohol consumption, estimates were 77% were reported. Alcohol related brain injury (ARBI) is caused by long-term heavy drinking leading to a combination of Thiamine (vitamin B1) deficiency, general shrinkage of brain matter, and a range of other insults to the brain including repeated head injury or assault.

For people recovering from ARBI, there is evidence of improved brain functioning and possibly recovery of some damaged brain cells over the first two weeks of abstinence, especially in younger people, but conflicting evidence as to the possibility of further improvement over a longer period of abstinence, because a person living with ARBI characteristically experiences behavioural changes such as being more impulsive and unable to appropriately link actions to consequences, it is very unlikely that a person who has ARBI will stop drinking and thus improve brain function. Continued heavy drinking subsequently leads to further brain injury and deterioration in brain functions. ARBI rarely occurs in isolation with a significant proportion of sufferers having both a substance abuse disorder (alcohol and/or other drugs) and a mental illness or psychiatric disability (referred to as ‘dual diagnosis’), or age-related dementia and other forms of acquired brain injuries. Homeless persons living with multiple diagnoses constitute a particularly vulnerable subgroup within the community and present with extremely complex service needs. It is very common for older people with multiple needs to be particularly unwilling to seek and utilise specialist or mainstream services.

The outcomes of the recently completed research project offer new hope to adults living with alcohol related dementia.

The findings show that compared with the control group, Wicking participants demonstrated considerable cost-saving per capita and statistically significant reductions in levels of anxiety, depression and the amount of alcohol consumed (down by 62%). Levels of productivity also increased significantly. Nearly all outcome measures and life quality indicators experienced positive change within the intervention group.

Based on the success of the Wicking Project this specialised model has shown potential to deliver an appropriate, cost-effective and dignified care solution to older people living with ARBI and challenging behaviours. The model could potentially be promoted as an intensive transitional care strategy designed to facilitate a step-down transition from a congested hospital or crisis driven service system into long-term aged care residential solutions. With additional funding we hope to investigate these possibilities further over the next couple of years.

The highly specialised nature of Wintringham’s work, has given a greater understanding of the special needs of those who are socially and financially disadvantaged, some of whom may have alcohol-related brain damage, chronic illness or unresolved psychiatric issues. Many of these needs have resulted from premature aging which is reflected in the high and early incidence of chronic illnesses. We believe that treating each person as an individual and planning care on this basis provides the best and most effective method of meeting a person’s physical and emotional support needs. Wintringham’s service delivery model has evolved to incorporate flexible, tolerant and non-judgmental strategies to address a myriad of unique and diverse care needs.
Welcome boost for Younger Onset Dementia care

Alzheimer’s Australia NSW warmly welcomes a $250,000 NSW Government grant for a two-year research project on Younger Onset Dementia.

The grant was announced by the Premier of NSW, The Hon. Kristina Keneally MP, during the official opening of Alzheimer’s Australia NSW’s Gibson-Denney Centre at North Ryde today. The Minister for Ageing, The Hon. Peter Primrose MLC, was also present at the opening.

“This NSW Government funded research project will address the different types of support people with younger onset dementia need to maintain their quality of life,” Premier Keneally said.

“People with younger onset dementia require different support measures to people who are diagnosed over the age of 65 and this study will look at the how we can address the needs of those people.”

The CEO of Alzheimer’s Australia NSW, The Hon. John Watkins, said the needs of people with Younger Onset Dementia – dementia diagnosed in people under the age of 65 – were very different to older people diagnosed with dementia and that there were very little age-appropriate services available for them.

“We warmly welcome this grant as it gives us an opportunity to focus on the special needs of those with Younger Onset Dementia,” Mr Watkins said.

“Many are still pursuing their careers and are paying mortgages, while others may still be raising children, caring for grandchildren, or pursuing lifelong dreams to travel and enjoy their retirement.”

The project will identify the barriers to timely diagnosis and access to appropriate services, as well as identify appropriate models for early intervention.

“A diagnosis of dementia at this stage in their life can be an unexpected and devastating shock,” Mr Watkins said.

“As well, many of the services available for those with dementia have been designed to accommodate people over the age of 65 and are not at all suitable for younger people.”

Stephen Jones was just 51 when he was diagnosed with Younger Onset Dementia, which affects an estimated 15,000 Australians.

It was a devastating diagnosis made all the more complex by the lack of services available that were appropriate for Mr Jones’s age.

His wife, Rosemary, said the lack of appropriate respite services meant she could no longer carry on in her part-time job as she had to be available to care for him around the clock.

“There is nothing around for this age to go to,” Mrs Jones said.

“When he did go to a respite centre, all the other people there were in their 80s. It’s like putting a person in their 20s in a room with someone in their 50s – it was completely inappropriate and Stephen hated it.”

Mrs Jones said she welcomed the focus on the special needs of people with Younger Onset Dementia.

The funding announcement came at the official opening of Alzheimer’s Australia NSW’s Gibson-Denney Centre in North Ryde.

The State Government, through the Department of Health, generously assisted with the new Centre by provision of the building and rental assistance and with a $17,000 grant for capital upgrade through the NSW Government 2009 Community Building Partnership Program.

The refurbishment of the Centre was also made possible thanks to a generous bequest from the late Dora “Bunty” Gibson and her sister the late Margaret Denney.

“This new centre is a significant step forward in the ability of Alzheimer’s Australia NSW to help tackle the dementia epidemic that is coming our way,” Mr Watkins said.

“Being able to bring all our Sydney-based staff on to the one site will allow us to continue to deliver vital support and services to the nearly 90,000 people in NSW who have dementia, and their families and carers.

“Because of the ageing population, dementia is a growing concern for the entire community, with predictions is it going to hit 341,000 people in NSW by 2050.

“That means 341,000 families – husbands, wives, sons, daughters and friends – will be caring for a loved one with dementia who will also need support and care and we need to be able to be there to help provide that for those living with the illness and for those caring for them.

“On behalf of all our members, I would like to thank the State Government for their support and acknowledge the generosity of the late Dora Gibson and the late Margaret Denney.”

On the same day, the Premier of NSW also officially opened new offices of Parkinson’s NSW, which is in the same building. These new offices will enable Parkinson’s NSW to continue to deliver high-quality services to their clients across NSW.

An estimated 257,000 Australians live with dementia and without a significant medical breakthrough, that is expected to soar to 1.13 million by 2050.

The Younger Onset Dementia Online Community commenced as a pilot on the 1st of June 2010, and ran for three months.

The pilot has been developed in response to the YOD community expressing a desire to be connected to others in a similar situation. As YOD makes up approximately one percent of the population the demographics make it difficult for the connection to be in person. It is hoped that the online medium will reduce the barriers of isolation in a more accessible opportunity that eliminates time and distance issues.

The online pilot was designed to provide peer to peer support in the model of a forum and chat room. The forum enables participants to post comments, thoughts and advice at any time on various headings; the chat is open twice a week (once in the morning and once in the evening) and this provides an opportunity to connect with others in real time by text mode.

130 people from the Vic YOD mailing list were invited to participate. It was a closed site with access by invitation only.

To date there have been 30 people registered as users on the forum; approximately 8 of whom were regular users. Users of the forum have posted under the following headings:

• Younger Onset Dementia: types, symptoms, progression and medication
• I have Dementia – What that means for me...
• Everyday life: Coping Mechanisms and Strategies
• Driving
• Employment
• Financial/Legal Issues: Referral, Centrelink, Superannuation, EPoA, Financial counseling, etc.
• Respite and residential care
• Information sharing on services, support groups and activities

In total these comments have been viewed 297 times by registered users.

Successworks (the external agency chosen to assess the success of the project) have conducted an initial assessment of the project, participants and reference group and the initial response is overwhelmingly positive; particularly in regard to the forum. The chat room has only been occupied by two participants at the same time on one occasion – this may be a limitation of numbers rather than its usefulness.

We look forward to hearing further results of this pilot study and seeing where this could lead in the future.

Dementia News is a bimonthly newsletter which aims to provide an overview of research featured in the media with detailed analysis and links to further reading. It is designed to keep individuals with dementia, their families and carers up-to-date on research developments.

Dementia News is a convenient way for people seeking to broaden their knowledge of dementia to extend their knowledge-base.

The newsletter is distributed by email, and current and previous editions are available online from the Alzheimer’s Australia website, www.alzheimers.org.au/content.cfm?infoaged=5404.

If you would like any more information or would like to be added to the distribution list, please contact Ashley Lamont at ashley.lamont@alzheimers.org.au or by phone on (02) 6278 8909.

Young people standing up to say “we care”

The Forget-Me-Not Girls are four young Sydney women who have joined together to hold a fundraising event for the Hazel Hawke Alzheimer’s Research and Care Fund. Their first initiative is a cocktail evening to be held during Dementia Awareness Week, on 25 September at the Museum of Contemporary Art, Circular Quay. They are expecting 250 young people and are hoping to raise awareness about the different issues that face younger carers of people with dementia as well as providing a space for them to share their stories and experiences.

Mark Rimmer, a consumer involved with Alzheimer’s Australia, Tasmania, has contributed the following:

**True Contentment**

Rest and contentment. Oh what bliss,
When you’re home is restful and dear,
The storms of life may shock and dismay,
But all is right if you have a home of care.

Together we labour, together we are one,
Facing each day, looking for the sun,
All of the promises in life are true,
As long as there is love at home.

It is said the woman of your life makes the home, Better still by far if both hands and lives work as one, The walls of your home are only as strong as the love, that is the true foundation of all.

Live to love as if each day could be the last,
Dance in your heart to the music of love,
Let it guide your action, fill your mind,
Energize your senses and motivate your heart.

With its precepts guiding you, reach out in response to love demands,
Sharing, caring, crying, daring,
Living each moment with more fulfilment your heart energized by hope,
Looking to share the vision with those who care.

In my life there has been sadness, yet as I love I feel such gladness, lighting our lives and the way ahead,
I feel that the cup of my life is filled to overflowing, My heart cannot contain such gladness, The little things of life are sweet when there is love at home.

Mark Rimmer

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**Ged Fogarty – RIP**

Ged lost his battle with early onset dementia on the 27th of June 2010. Ged was diagnosed with dementia in 2007 at the age of 36. At the time, Ged was one of Melbourne’s “hottest jewellery designers” and had a successful jewellery store on Collins Street, he had a beautiful new home which he shared with his wife and two children, aged just one and four. Ged was supported by a team of dedicated friends and family and resided in his parents’ home up until his passing. Unfortunately Ged’s disease progressed quickly, and the past few years have been tough on those around him. Ged’s family have been heavily involved with Alzheimer’s Australia, and we extend our deepest sympathy to them at this sad time. Below is a poem written by Ged’s grandmother and included in one of his Newsletters, at the time of her passing;

“This day comes with sad regrets,
It brings a day I will never forget,
Close to my heart you will stay,
Loved and remembered every day.

Silent thoughts and tears unseen,
Wishing your absence was only a dream.

Mark Rimmer

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