Welcome to Issue 11 of HOPE, Alzheimer’s Australia’s newsletter for younger people with dementia, their care partners, family, friends, health professionals, care staff and everybody with an interest in younger onset dementia.

People with younger onset dementia are obviously at a very different stage of life at the onset of the illness when compared with older people. They may still have a mortgage on the family home or property, or significant other business and financial commitments. They may have young or young-adult children, and in some cases, are also caring for their own ageing relatives. Typically, they are very physically and socially active, and often at the pinnacle of their careers.

But then they, their family and friends, their work colleagues or manager may notice changes to memory, behaviour, relationships, organisational capability, confidence – all the aspects of life that dementia challenges.

This issue’s Feature Articles are on the subject of younger onset dementia and employment.

First, in a very honest view of the impact of younger onset dementia on his own career, Wayne Sawyer shares his story. I think this comment from Wayne explains where he found himself in his career when he was diagnosed with dementia in his mid-forties. “There appeared to be no regard for employee feelings by employers who had no idea how to manage a worker with dementia.” Wayne has orchestrated his own transformation and now works in a number of volunteer and part-time jobs, finding that his past experiences, professional and personal, are enabling him to stay focused and optimistic in his new work places.

Our second story describes a South Australian partnership project, Side by Side, which is giving people diagnosed with younger onset dementia who are no longer working, an opportunity to re-engage in a work environment. As you’ll read in the article, carers of Side By Side participants report their partners have improved self esteem, interact more effectively with their loved ones and everyone’s even sleeping better!

The third story is from a regular contributor to HOPE, Judy Woolstencroft, who describes the impact of dementia on the career of her partner, Chris Wylks, a high school maths teacher for more than 30 years. Chris was lucky that his boss, the school principal, understood that the decline in Chris’s performance was possibly the result of an undiagnosed health issue, rather than purely a performance issue, which could have resulted in Chris’ dismissal.

Alzheimer’s Australia is talking to governments at all levels about the employment related needs of people affected by younger onset dementia. We advocate for long day-care programs, to allow younger carers of people with younger onset dementia to continue to work full time. We talk about the financial impact on a family of going from two wages to one, or one to none. We talk about the lack of knowledge of dementia in the community - but specifically in workplaces - which can result in a person’s employment being terminated for the wrong reasons. We advocate for people whose career comes to a sudden end, particularly those who are unable to access their superannuation or other income support.

And of course we talk about the delays in diagnosis experienced by all age groups, but particularly by younger age groups.

Since our last issue of HOPE was published in March 2012, there have been significant announcements from the Australian Government in relation to aged care and disability reform. In his “From the CEO” column, Alzheimer’s Australia’s CEO Glenn Rees welcomes the Government’s aged care reforms, specifically the Living Longer. Living Better, package, which promises $268.4 million over five years to address the issue of dementia, including a number of plans specifically addressing the requirements of people with younger onset dementia.

Thank you for your interest in younger onset dementia. I hope you enjoy reading Issue 11 of HOPE.

Jenny Warren
Alzheimer’s Australia
WAYNE’S STORY

WAYNE SAWYER WAS DIAGNOSED WITH YOUNGER ONSET DEMENTIA AROUND THE AGE OF 45 YEARS. HE UNDERSTANDS VERY WELL JUST HOW HAVING DEMENTIA IMPACTS ON EMPLOYMENT. AFTER EXPERIENCING THE DIFFICULTIES OF MAINTAINING EMPLOYMENT, WAYNE HAS MADE POSITIVE AND ENABLING DECISIONS WHICH HELP TO KEEP HIM FOCUSED AND OPTIMISTIC.

Wayne told his story to Clare Beard, Alzheimer’s Australia South Australia.

After a variety of employment experiences, Wayne had focused on working in a community setting assisting people with disability. He had also begun specific tertiary studies to enhance his job opportunities. Wayne talks about his time working in the disability sector very positively, as an experience he felt was personally valuable, where he felt good and where he could give something back to the community. Then along came the memory loss and organisational difficulties which impacted on Wayne’s employment as well as his studies, and this took away all his future plans.

The irony for Wayne was that although he worked in a very caring environment, when he needed some help or support to maintain his employment, it was hard to find.

Wayne highlights some of the issues which affected him. Firstly, he describes “the struggle of maintaining employment when your memory isn’t working well”.

Then, along with the diagnosis, “there was a loss of driving licence, which meant there were significant limitations on what I could do, on how I was able meet the workplace expectations and created practical difficulties in getting to and from work”.

Wayne felt that there was a significant lack of understanding around dementia in younger people, and very little knowledge of how his role may be adapted to accommodate his changing situation. This lead to Wayne deciding that it was easier to give up working all together. However this created its own problems, and made Wayne feel that he was not contributing or worthwhile.

The loss of employment is significant in itself. Wayne also describes feelings of loss of self and loss of dignity. Wayne said “There appeared to be little regard for employee feelings by employers who had no idea how to manage a worker with dementia.” For Wayne, there was no salvage of employability, but a haste to disconnect.

Unemployment created feelings of dependency and worthlessness; it disempowered and reduced choice. Wayne found it hard to adjust to unemployment and was left to initiate his own opportunities. He has done this through a combination of volunteer roles and paid work roles. “I have to be accepting of the diagnosis and understand the limitations that it may bring”, Wayne said.

Wayne now openly discloses his diagnosis. In doing this, he finds that people are more willing to assist him, to consider him for volunteer roles, to work with him to recognise needed supports, and to assist him to overcome any limitations or difficulties.

Currently Wayne works three days each week across two residential care facilities, including assisting the lifestyle coordinator in a dementia unit. He finds that his past experience and qualifications are embraced in his volunteer roles. Wayne also works at The Phoenix Society of South Australia which provides him with a small income and a change in work environment.

Wayne is also looking to consolidate his previous TAFE studies by undertaking further modules in disability. Whilst being realistic about his long term employment opportunities, he remains optimistic that he can continue with his current arrangements for a long time yet.

There also has been an added bonus for Wayne. He is sure that by keeping active and engaged, by continuing to use and improve his skills, and by maintaining a positive outlook, he has slowed the progression of his dementia. “My specialist told me that whatever it was that I was doing, I should continue to do it,” Wayne says. While he might not be on a full-time salary or in a full-time role, he does now feel employed and valued.

Wayne is continually improving his computer skills.
Younger onset dementia can leave individuals in their forties and fifties unemployed and isolated from their families and society.

However, South Australian aged care provider Life Care is providing an opportunity for people with the condition to re-engage with the community helping them to maintain skills and self-esteem.

The Side By Side project is a partnership between Life Care and the Australian Government’s Dementia Community Support Grants Program with support from Alzheimer’s Australia and Bunnings.

The project works by supporting people with younger onset dementia to spend time in a working environment and to meaningfully interact with others in everyday activities while allowing their regular carers to have some much-needed respite.

Bunnings is the first company in Adelaide to support the project. They welcome individuals with younger onset dementia from Life Care’s specialist respite care facility, Norman House, to work with team members at its Mile End store near the city.

Life Care’s Chief Executive Officer, Allen Candy, said “It is important to build community awareness of younger onset dementia.”

“With the Federal Government and our supporting organisations, we are proud to have developed an innovative program that broadens Life Care’s services to the community by assisting people with younger onset dementia and their families,” he said.

Jacinta Robertson, Community Coordinator of Respite Programs for Life Care, said “each participant was partnered with a “buddy” from Bunnings to undertake a range of different tasks.”

“It is about putting people with younger onset dementia back into the workplace on a weekly basis to perform meaningful tasks,” she said. “A Life Care staff member or volunteer is always on hand during these times.”

“The outcomes to date have exceeded expectations among the participants themselves along with their carers and Bunnings buddies.”

“It is a socialisation process through which the participants are developing new task skills while having a valued workplace role.”

Carers of Side By Side participants report their partners have improved self esteem, interact more effectively with their family and friends and sleep better. The participants enjoy being able to undertake meaningful tasks in a real workplace and the positive effects provide genuine relief for their carers.

The University of South Australia is working with Life Care to evaluate the impact of the Side By Side program on the participants and their regular carers.

Carolyn Daly’s husband, Terry, was diagnosed with dementia late last year.

“Before that I felt something was not right with Terry because he was forgetting things and losing his sense of logic,” she said.

“In a sense, it was a relief for me when the condition was diagnosed because it confirmed my feelings. Our two sons were also expecting the diagnosis.”

“We did a course through Alzheimer’s Australia and heard about Norman House. We found it provided a wonderfully safe and caring environment where Terry could spend a meaningful day with people in similar circumstances.”

“The Side By Side program is great for him. To have the opportunity of a full and active day in a workplace communicating with others is fantastic.”

Further Information:
Jacinta Robertson, Community Coordinator of Respite Programs, Life Care
Phone: (08) 8293 5924
MY PARTNER, CHRIS WYLKS, WAS 56 WHEN HE WAS DIAGNOSED WITH ALZHEIMER’S DISEASE IN DECEMBER 2007.

Chris was a high school maths teacher with a successful career of over thirty years. He really enjoyed being a teacher and felt that his work was fulfilling and he liked to make a difference. The last two years of his career was spent teaching high school children who had learning difficulties, in a Learning Centre.

About three years before diagnosis, Chris began to have problems at work. He became more disorganised, was having trouble getting started on marking assignments and planning lessons. As things progressed he was also having trouble remembering names, marking the roll and complained he was unable to track along the lines when entering test results. Putting together reports was a nightmare.

For the last couple of years, Chris had an Assistant assigned to him as he was teaching in a Learning Centre. As time and his disease progressed, the Assistant was doing more in the classroom, more preparation, and taking more responsibility. At one point Chris was sent to a counsellor to obtain some organisational skills. Of course that didn’t work and often he forgot to turn up for appointments. At the same time, I was urging Chris to take some time off and seek medical advice.

However it wasn’t until March 2007, when the school principal asked him to take sick leave and find out what was wrong, that he went to his GP. Chris was lucky that the principal understood he had a health issue as his performance issues could have lead to his dismissal.

Then started the round of doctors and testing that led to his diagnosis. That took another nine months. Chris was fortunate that up until then he was very healthy and had accrued sick leave that allowed him to be paid in full for twelve months.

Chris was invalided out from work after receiving a very confronting report on his performance at work and a medical report. We were both shocked at the extent that his work performance had suffered.

Chris was one of the lucky ones that had a sympathetic employer. However, as a relatively young man who expected to work for at least another five years and who loved teaching, this was a difficult time and led to him feeling pretty depressed and wondering about the next stage of his life. He was also socially isolated from his peers, who were of course, still working.

Counselling from Alzheimer's Australia ACT, the Living with Memory Loss course and getting involved with appropriate activities, enabled Chris over time to accept his diagnosis and to find joy and satisfaction outside his career. This was a process that he could not have gone through without the great support he received. It was a very upsetting time for us both.

We had planned for retirement for some time and Chris was able to access his superannuation. However, leaving work early has meant that his financial position isn’t as good as it would have been had he remained working as planned. In addition in May 2010, I left work to take a more active role in his care. I had planned to work for another 5 years. I was able to access my superannuation as well, but at a reduced amount.

ADVANCE NOTICE! ALZHEIMER’S AUSTRALIA NATIONAL CONFERENCE - HOBART, 14-17 MAY, 2013

The theme for the 15th national conference is The Tiles of Life – Colouring the Future. It is about making memories when the very thing that brings us together is memory loss.

You may wish to contribute to the conference either by submitting an extract or by creating a memory on a ceramic tile, helping us to capture moving, personal reflections of what Alzheimer’s and dementia means to all the artists. See the conference website for more details.

Click here to visit the Conference website or enter http://www.alzheimers2013.com or call the National Dementia Helpline 1800 100 500.
FROM THE CEO

LIVING LONGER. LIVING BETTER.

Alzheimer’s Australia welcomes the Australian Government’s Aged Care Reforms and their plan to tackle dementia.

Whilst the April 20 announcement of the Living Longer. Living Better. package is made under the banner of Aged Care Reform, it promises $268.4 million over five years to address the issue of dementia.

Importantly, especially for readers of this newsletter, it includes a number of plans specifically addressing the requirements of people with younger onset dementia.

$23.6 million will be provided over five years to enable younger people with dementia to access better coordinated care and support, assisted by what the announcement calls “dementia key workers”. This funding will also help younger people with dementia continue to actively participate in the community through the development and dissemination of information about dementia for community groups. Topically for this issue of HOPE, this will include funding for a program to increase dementia awareness in the workplace.

The Australian Government will also take a proposal to the next meeting of Commonwealth, State and Territory Health Ministers, requesting that dementia be added to the existing list of eight National Health Priority Areas. This is a positive outcome and will help focus attention nationally and drive collaborative efforts in the fight against dementia. We are looking forward to a favourable response.

The Living Longer. Living Better. announcement responds to the advocacy of Alzheimer’s Australia in five important ways.

Firstly, the reforms hold out the promise of strengthening the community care system to make it possible for people with dementia to stay at home longer. There will be more community care packages and more funding for respite care. This is central to any strategy for consumer choice in order to avoid premature entry to residential care.

Secondly, the reforms to empower consumers through adopting consumer directed care in all care packages will enable consumers to have more say over the services they need, when they need them and who delivers them.

Thirdly, the approach to funding will embrace the principle of supplementary funding to meet the extra costs of dementia care in both residential and community settings. In other words there is a focus on dementia in the aged care reforms.

Fourthly, there are measures that should help reassure consumers that there will be greater transparency in the quality of aged care service provision through the independent Aged Care Financing Authority, the new Australian Aged Care Quality Agency, My Aged Care website and greater independence of the Aged Care Complaints Scheme.

Finally, there is a plan to tackle dementia. The Government’s proposals for tackling dementia address the key priorities in Alzheimer’s Australia’s Fight Dementia Campaign, particularly:

- **Improved support for people with younger onset dementia ($23.6 million).** The National Dementia Support Program will be expanded to improve access to better coordinated services. A national network of specialist key workers will provide a single point of contact to assist younger people with dementia and their carers at every stage of the journey following diagnosis.

- **Supporting people with dementia across the health system** including improved hospital services for people with dementia, such as by expansion of the Dementia Behaviour Management Advisory Service to include primary care and hospital settings.

- **Support for more timely diagnosis** to improve the quality of life for people with dementia, to provide earlier medical and social interventions and reduce hospital admissions. GPs and practice nurses will receive much needed training and education programs and improved support to help them diagnose dementia more effectively.

- **New Dementia Supplement** for the provision of additional financial assistance for dementia care in recognition of the additional costs involved.

- **Better care for Australians with severe behavioural and psychological problems** associated with dementia in residential or home care environments.

For more information please refer to the Australian Government Department of Health and Ageing website. 

Not all our priorities have been addressed. Research in dementia is important if we are to reduce the future numbers of people with dementia. Alzheimer’s Australia is concerned about the very low level of investment in dementia research. This is an issue we will be pursuing vigorously through the Minister’s review of Scientific and Medical Funding in Australia. Research is vital if we are to inform practice.

The reforms will be reviewed at the end of five years, and the Government has rightly taken the view that the full impact of the reforms will take ten years to have an impact. This is because the reforms are not just a question of funding, but of changing the way services are delivered.

Alzheimer’s Australia is committed to working in partnership with the Australian Government to ensure that people with dementia and their carers, regardless of their age, background or lifestyle, receive timely and appropriate support to meet their needs in all stages of their journey through dementia.

Glenn Rees
Chief Executive Officer, Alzheimer’s Australia
Alzheimer’s Australia WA acknowledges that it can be difficult for younger people with dementia to access age appropriate services. Due to the general assumption that dementia is an “older person’s” disease, dementia-specific services are usually designed for people who fall into the older age brackets and often do not meet the needs of younger people who are at a different stage of life.

A particular area of concern for younger people is availability of age-appropriate residential respite. When the family carer reaches a stage where they need to have a break from caring for more than just a day, they often find that their only option is to place their family member into a facility where most of the residents are 20 or 30 years their senior. Daily routines and activities in these facilities are usually designed for the frail elderly and, on the whole, do not meet the needs of younger people with dementia who tend to be more active, mobile and physically capable. The lack of an engaging environment can lead to boredom, distress and/ or behavioural problems in the person with younger onset dementia.

In an effort to address this issue, Alzheimer’s Australia WA (AAWA), in partnership with Uniting Church Homes (UCH), decided to trial an alternative model of residential respite for younger people with dementia. A pilot program, called “The Holiday Program”, was developed and delivered on 19th to 26th March 2012, at Hakea Respite Facility in Bentley.

“The Holiday Program” was so named because the aim of the program was to not only give the carer a break from caring, but to give the person with dementia a holiday as well. This meant that the clients were the ones making the decisions about what they wanted to do during the week and the staff’s role was to support the clients to engage in the activities they chose. The program was well-resourced with a staff to client ratio of 2:5 and a vehicle that could be used to take the clients off-site. This allowed flexibility in terms of what the clients were practically able to do.

There were five people with younger onset dementia who participated in the pilot (four women and one man) ranging in age from 34 to 67 years old. The group did lots of different activities during the week, including going to Kings Park, having a movie night, art activities, going to the cinema, having a BBQ with the clients’ families and going shopping at a local shopping centre. A number of clients had family visit them during the week, and this also added to the atmosphere of being on a holiday.

The feedback from clients and carers after the program was overwhelmingly positive. One client said “I enjoyed all the new experiences and just had such a good time.” Another lady was so excited about the great time she had, that she told her Support Worker and one of the AAWA Respite Coordinators all about it. “I have never heard a client that has gone into residential respite come out raving about it, the way

that I have heard my clients rave about the Holiday Program” said the Respite Coordinator.

Feedback from the carers was equally complimentary. “I felt assured that my mum was cared for in a friendly, secure environment as this was our first experience at residential respite” one carer said. Another carer commented “The Holiday Program was so well organised and the staff from Alzheimer’s and Hakea were so friendly and comforting to my wife and myself.” All clients and carers identified that given the opportunity, they would like to participate in the Holiday Program again.

**In the future, Alzheimer’s Australia WA would like to schedule another Younger Onset Dementia Holiday Program. However, this will be dependent on finding resources to support the delivery of the program. For further enquiries regarding this project, please contact Alzheimer’s Australia WA’s Younger Onset Dementia Services Coordinator, on (08) 9388 2800 or (from WA) on 1800 100 500.**
**The Fifth Anniversary of the A-team**

Well, it is now two years since we introduced the "A-team" in Issue 5 of HOPE (July 2010). We were then a group of eight people with younger onset dementia and their carer/partner counterparts. Although we had an idea of the rough road to come, we enjoyed good fellowship, even to the extent of spending weekends away together. We met regularly every couple of months, and swapped information on methods for handling the looming crisis in our lives. To some extent we all felt that we had the monster under control.

A month ago it was the fifth anniversary of the A-team, and we decided that we would choose an upmarket restaurant to “celebrate” the event. It was a beautiful day and our restaurant provided a spectacular view of Port Phillip Bay. The food and wine were excellent, and in a touching gesture, one of our A-team members, Bernie, handed out long-stemmed roses to each one of us. It would be fair to say that we thoroughly enjoyed the occasion. But everything had changed in the past few years. Two of our team have died, three are now in permanent residential care, and only one sufferer was able to attend the luncheon. The statistics on the progress of Alzheimer’s disease are relentless.

There is no doubt that staying together as a group has been an immense comfort for us. It has given us companions who understand our concerns and emotions. Furthermore, even though several of us are involved with specialist groups such as the Alzheimer’s Australia YOD Reference Group, action committees and research projects, it has proven to be very useful to have access to advice from other members of the A-team when searching for answers. We will probably still be together for the 10th anniversary.

Bob Leicester, Victoria

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**Dinner at The Pavilion on Northbourne**

We could have been anywhere…… the Whitsundays, Cairns or wherever we wanted to be…… We were in fact, in the atrium of a beautiful hotel on a wet, cold May night in Canberra.

There were 37 of us, out for a special night with those living with younger onset dementia. It was lovely to see familiar faces and to put faces-to-the-names of the new families as everyone arrived. It was also lovely to see the warmth of familiarity between friends as they greeted each other.

We were treated to first class service, being waited on by the hotel staff bringing wine and nibbles. We then enjoyed a beautiful two course meal. After much chatter, laughter, and with everyone complaining about having eaten too much, we headed off, very satisfied with the evening.

We’re looking forward to the next time we can get together in a private setting in a public space, where we all feel safe from potentially critical eyes, because we may not hold our cutlery correctly, or we may say the wrong thing.

Whether it’s because we get a break from cooking, or because it allows us to enjoy time together as a family, or simply because we get to spend a few hours talking and laughing with old friends, events such as this Alzheimer’s Australia ACT’s Younger Onset Dementia Family Dinner are appreciated by all.

Deanne Ballard, Manager Family Services
Alzheimer’s Australia ACT

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Alzheimer’s Australia organises regular social functions, such as the Canberra dinner described in Deanne’s article (left) for people with younger onset dementia, their carers and other family members. Contact your local Alzheimer’s Australia office via the National Dementia Helpline, 1800 100 500.
On April 11, 2012, the World Health Organisation (WHO) and Alzheimer’s Disease International (ADI) released a joint report entitled “Dementia: A public health priority”.

Among other key statistics, the report predicts that global dementia prevalence is likely to triple in the next thirty years, from an estimated 35.6 million people today to 115.4 million by 2050. This global projection of growth in dementia numbers mirrors projections for Australia, where prevalence is predicted to double from 280,000 people now to over 500,000 by 2030, and again to almost 1 million by 2050.

Alzheimer’s Australia is a member of ADI and a number of our staff, including national CEO, Glenn Rees, provided technical contributions and reviews of the report during its development.

I spoke to Glenn about the report, which recommends that Governments around the world commit to a public health approach to dementia that focuses on prevention and risk reduction, better assessment and diagnosis, management of people with the condition, and increased research funding to develop treatments and interventions.

Glenn agrees that these priorities must be addressed by the Australian Government if we are to provide both better care and support for people with dementia. “In our Fight Dementia Campaign, Alzheimer’s Australia asked the Australian Government to invest in a five-year, $500 million dementia action plan in the 2012-13 Federal Budget,” Glenn said.

“We were very pleased to see that many of these elements were included in the Government’s announcement of the Living Longer, Living Better, aged care reform package on 20 April. "However, there was no new money for dementia research, which is something that Alzheimer’s Australia will be pursuing vigorously through the Minister’s review of Scientific and Medical Funding in Australia.”

Here are links to WHO-ADIs’ Report “Dementia: a public health priority” Via Alzheimer’s Australia’s website or Via World Health Organisation’s website

The report recognises the different experience of younger people with dementia. Page 59 of the report says “From a social perspective, a person who develops dementia before normal retirement age is differently placed in the lifespan compared with a person who develops dementia when older. Persons with YOD may still be working or may have recently left the workforce, they may have children still in the home or of university age, and they may not have the additional chronic conditions that the older population general acquires.”

Further, the report goes on to say “From a policy perspective, the younger onset population requires specific consideration because eligibility for social/medical supports or old age pensions is frequently based on an attained age, and younger persons may not be able to access financial support”.

Many readers will relate to the role people with younger onset dementia are playing, as described in this paragraph, also from page 59 of the report. “People with YOD and those in the early stage of dementia are often engaged by dementia advocacy groups as spokespersons and advocates, and they frequently play a role in the governance of their organisations.”

“This inclusion has led to positive policy recommendations in recognition of this niche population. To the extent that they engage in public activities and share their experiences, these younger faces of dementia can also provide a positive dissonance that helps mitigate the ageism that is associated with dementia.”
CHAPTER 2, “EPIDEMIOLOGY OF DEMENTIA”

In this chapter, the report states that younger onset dementia is a rare condition. However it goes on to acknowledge that “Few population-based surveys have been carried out, since large sample sizes are needed to estimate prevalence with precision, instead, researchers typically conduct registry-based studies, reporting prevalence calculated as the number of cases known to local service providers divided by the total local population from the census. The assumption is that all of those with YOD seek help early in the disease course. This is not always the case, and therefore such studies will underestimate the true prevalence of dementia.”

The expert consensus was that prevalence increases exponentially with increasing age, roughly doubling every five years from 9 per 100,000 at age 30, to 156 per 100,000 at age 60-64. Two-thirds (68%) of all young onset cases were aged 55 and over. Among this large, middle-aged group of people with YOD, males predominated over females with a gender ratio of 1.7:1.

On pages 18-19, there is an analysis of dementia subtypes including a review of a Dementia UK report, which the WHO report acknowledges as the most sophisticated analysis of studies of dementia subtypes available. This section discusses the most common subtypes across the whole population, and goes on to describe the results of two UK YOD studies which indicated that frontotemporal dementia (FTD) is a common subtype in YOD, particularly among men, among whom it is the commonest subtype up to age 55. Vascular dementia (VaD) is also relatively more common among men aged 45-75 years of age.

On page 21 of the report there are two interesting graphs which demonstrate the gender difference. In the case of women with a diagnosis of dementia, the UK study identified Alzheimer’s disease as the commonest form across all age categories, with FTD increasing in prevalence in the 45-59 age group, before declining again.

The picture for men is quite different, with FTD as the most common subtype for those aged 30-54 years. VaD appears as the most common form from 55 to 69 years of age, and from 70 years of age onwards, Alzheimer’s disease is the predominant form.

For more information click on the links below:
WHO-ADI’s Report “Dementia: a public health priority”
via Alzheimer’s Australia’s website
via World Health Organisation’s website

Who reads the HOPE Newsletter?

Since Issue 10 of HOPE was published in March 2012, I have received many requests from new readers to be added to our email distribution list. So thank you to those of you who send HOPE to your networks and contacts.

HOPE is read by people with younger onset dementia and their carers and family. But it is also read by people working in a wide range of community based organisations, health and residential care service providers, hospitals, government agencies (local, state and federal) and the media.

To give you an idea of the variety of lifestyles, professions and backgrounds of HOPE readers, I recently had a request from a couple of ‘grey nomads’, who want to receive the newsletter by email as they travel Australia. HOPE is emailed to readers both in Australia and overseas. In fact, just prior to publication, I received a request from two Aussies living in Italy who had received the last issue of HOPE via a family member (buon giorno...you know who you are!)

You can help make HOPE more interesting for your fellow readers by sending your story or suggesting a topic that you think will interest readers. I look forward to hearing from more of our readers in the coming months.

If you know someone who would like to receive HOPE via email, please ask them to contact me at hope.news@alzheimers.org.au

If you no longer wish to receive HOPE by email, please contact me and ask to be removed from our mailing list.

This and all previous issues of HOPE are published on Alzheimer’s Australia’s website at http://www.fightdementia.org.au/research-publications/hope-newsletter.aspx

Jenny Warren, Editor
Alzheimer’s Australia
E: hope.news@alzheimers.org.au
SUPPORT FOR PEOPLE WITH YOUNGER ONSET DEMENTIA IN NSW

ON APRIL 18TH THE NSW GOVERNMENT ANNOUNCED A $1 MILLION, THREE YEAR PILOT THAT WILL COMMENCE IN LATE 2012 AND PROVIDE FLEXIBLE PERSON CENTRED PACKAGES TO SUPPORT PEOPLE WITH YOUNGER ONSET DEMENTIA IN NSW.

The announcement was made by Andrew Constance, NSW Minister for Ageing and Disability Services, immediately after he attended a forum on younger onset dementia hosted by Alzheimer’s Australia NSW for the community care sector in Sydney.

“The aim is to improve quality of life for younger people with dementia and their carers living at home, by promoting active lifestyles, maintaining social networks, and providing support to navigate the care support network,” Mr Constance said.

“An important issue for younger people with dementia is that they may still be raising children. The unexpected diagnosis of dementia has an impact on family relationships, employment and financial security, emotions and friendships – not just for the person with dementia, but for their partner and children.”

“Younger people with dementia have particular difficulties accessing the right kind of services because their age means they have different needs and different lifestyles.”

(Source: Press Release)

Alzheimer’s Australia NSW’s General Manager, Policy, Research and Information, Brendan Moore, told HOPE that Alzheimer’s Australia NSW welcomes the announcement. He says that people diagnosed with younger onset dementia and their carers tell Alzheimer’s Australia NSW that access to appropriate services is currently difficult, if not impossible. This is particularly the case in rural and regional areas. “There is strong evidence that those with younger onset dementia are not currently well served by aged care services” Brendan said. “Additionally, the person diagnosed with younger onset dementia, their carers, and family can become increasingly isolated from support services, extended family, and friends. This pilot program will provide much needed support to identify and coordinate services available to assist the person with younger onset dementia, their carer and family.”

RESEARCH ON CARER WELLBEING

A team at Griffith University is conducting research on the Physical and Emotional Wellbeing of Carers of People with Dementia. If you are currently the main provider of care or support for a family member, friend or spouse with dementia, they would like to hear about your experiences.

If you previously provided care or support for a person with dementia who is now in a residential care facility or who passed away within the last two years, they would also like to hear from you. Through this research project, the team are seeking to explore the physical and emotional wellbeing of carers and the factors which distinguish carers who experience positive outcomes from those who experience negative outcomes.

You can get involved by completing an anonymous survey on the type of care or support you provide, your health and your emotional wellbeing. To be sent a paper copy of the survey, please contact Dr Siobhan O’Dwyer on s.odwyer@griffith.edu.au or (07) 3735 6619.

To complete the survey online, please click on this link https://prodsurvey.rcs.griffith.edu.au/dementiacaresurvey
New DISCUSSFORUM

The new DISCUSSFORUM is an Alzheimer’s Australia initiative in response to feedback from readers of Alzheimer’s Australia’s fortnightly national electronic newsletter ‘Dementia News’.

The forum can be used to clarify science terms and themes, to express your opinion, or even highlight research you may want more information about.

Here’s a quick link to Discuss Forum or go via http://dementianewsforum.com

All past copies of Dementia News are published on the Alzheimer’s Australia website. Click on this link to go there.

If you would like to subscribe to receive Dementia News fortnightly by email, please send an email request to dementia.news@alzheimers.org.au

CONTACT NUMBERS

NATIONAL DEMENTIA HELPLINE
1800 100 500

ALZHEIMER’S AUSTRALIA
1800 100 500 OR
WWW.FIGHTDEMENTIA.ORG.AU

DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICE (DBMAS)
1800 699 799

COMMONWEALTH RESPITE AND CARELINK CENTRE
1800 052 222

EMERGENCY RESPITE (AFTER HOURS)
1800 059 059

An Australian Government Initiative: helping people with memory concerns

This issue of HOPE was supported with funding from the Australian Government Department of Health and Ageing as part of the Australian Government’s Dementia Initiative.

The views expressed in this work are the views of its author(s) and not necessarily those of the Australian Government.
UPCOMING EVENTS

DEMENTIA AWARENESS WEEK

DATE: 21 – 28 SEPTEMBER 2012
THEME: BRAIN HEALTH - MAKING THE CONNECTIONS

Dementia Awareness Week (DAW) is the national centrepiece for Alzheimer’s Australia’s community awareness activities each year. It kicks off on September 21st, which is the annual, international “World Alzheimer’s Day”, a day on which Alzheimer’s organisations around the world concentrate their efforts on raising awareness about Alzheimer’s and dementia.

This year’s Australian DAW program is headlined by a national tour by Dr Serge Gauthier, Director, Alzheimer’s Disease Research Unit, McGill Center1 for Studies in Aging2, Canada. You can read about Dr Gauthier and his work by going to the website http://aging.mcgill.ca/gauthier.htm. [1, 2 North American spelling]

During his talks in all Australian capital cities, Dr Gauthier will speak about:

• The possible causes of dementia and the prospects of new treatments.
• The links between dementia and other chronic diseases, and their management.
• The potential to include dementia in existing health prevention programs.
• The evidence base for reducing the risk of dementia.
• Slowing the progression of the disease and reducing prevalence of dementia.

OTHER LOCAL DAW ACTIVITIES AND EVENTS WILL BE ANNOUNCED THROUGHOUT THE YEAR.
FOR MORE INFORMATION ON HOW YOU CAN GET INVOLVED, CONTACT YOUR LOCAL ALZHEIMER’S AUSTRALIA OFFICE VIA THE NATIONAL DEMENTIA HELPLINE 1800 100 500 OR CHECK YOUR STATE OR TERRITORY PAGE OF THE ALZHEIMER’S AUSTRALIA WEBSITE.

MOVIE NEWS “DEMENTIA - TAKING THE NEXT STEP”

ADVICE ON WHAT TO DO IF YOU RECEIVE A DIAGNOSIS OF DEMENTIA FROM THE VOICES OF EXPERIENCE IS THE FOCUS OF A GROUNDBREAKING FILM DEVELOPED BY ALZHEIMER’S AUSTRALIA.

The brainchild of Alzheimer’s Australia Victoria client, Carol Liavas who cares for her father, the film has been developed to help those feeling confronted by the diagnosis of dementia by sharing the stories of three families who have been through this experience.

One of the couples who appear in the 26 minute film, Garry and Mandy Lovell, featured in the November 2011 issue of HOPE. Garry has younger onset Alzheimer’s disease.

The film also features medical comments by dementia specialist, Associate Professor Michael Woodward, who provides an overview of dementia in terms of how to understand what is happening, how to make adjustments to deal with the diagnosis and how to get help.

"A lot of people are quite unsure of what they need to do once a diagnosis has been made and who they can talk to about it," Assoc Prof Woodward said.

"After the diagnosis from a doctor we encourage people who have been diagnosed, or their family members and friends, to contact Alzheimer’s Australia (via the National Dementia Helpline) on 1800 100 500 to discuss what has happened and to find out what services would benefit them.

"What we are trying to achieve with the film is to remind our communities that there is help out there and they don’t have to deal with their diagnosis, or that of their loved ones, by themselves."

The movie is available on YouTube, enter “Dementia: Taking the Next Step (full version)” to locate it. To order the film on DVD, contact Diana Fayle at Alzheimer’s Australia Victoria, dfayle@alzvic.asn.au or (03) 98165792.
MEMOry walks

A record number of people took part in the 2012 Memory Walk & Jog at the Bay Run in Lilyfield on Sunday 6th May (see photo). Supporters have so far raised more than $103,000 which will go towards supporting Alzheimer’s Australia NSW’s Memory Vans, a mobile service which provides people with dementia and their families with information, and allows AlzNSW to reach out to people across the state. This is an especially important resource in regions where services are scarce.

REgional nsw

More Memory Walks and Jogs are scheduled around regional NSW in September. Further information can be found at http://www.memorywalk.com.au/ or call the National Dementia Helpline 1800 100 500.

The Hunter The Illawarra Tweed Heads Port Macquarie
Speers Point Park Stuart Park Chris Cunningham Park Westport Park
Lake Macquarie North Wollongong Tweed Heads Port Macquarie
Sunday 9 September Saturday 15 September Sunday 23 September Sunday 30 September

WA

The Western Australian Memory Walk is scheduled for 21 October 2012, 9.30am to 4.00pm at Edinburgh Oval, Curtin University, Kent Street, Bentley, WA. Entry fee is $20 for members of Alzheimer’s Australia WA, $30 for non-members. Further information can be found at http://www.memorywalkwa.com.au or call the National Dementia Helpline 1800 100 500.

REHABILITATIVE THERAPIES MONTESsORI METHODS FOR DEMENTIA PROFESSIONAL DEMENTIA EDUCATION FOR AGED, COMMUNITY, DISABILITY AND HEALTH CARE WORKERS

Unit 1 – ALRTO1 Develop & deliver Montessori based activities as part of a cognitive rehabilitative therapy model

This first unit is one of a two unit course that on completion will equip participants with the required knowledge & skills required to provide rehabilitative therapies for people living with dementia.

Who should attend? Individuals who are interested in learning about Montessori Methods for Dementia are invited to attend. Montessori for Dementia principles can be implemented by a range of people including diversional therapists, nurses, support workers, paid carers, lifestyle and leisure staff, family members and community support workers.

ENTRY REQUIREMENTS Participants should have completed CHCAC319A Dementia Competency or equivalent training
FACILITATORS Anne Kelly, Training, Development & Consultancy Alzheimer’s Australia Tasmania & Linda Graham, Education Manager, Nurse Educator Alzheimer’s Australia Tasmania.
COST $600 (Lunch is provided)
DURATION 2 x 7 hour workshop days + assessment day

Queensland Woolloongabba (Anne Kelly)
Assessment: 2nd October, 2012
Contact Alzheimer’s Australia QLD to book your place on (07) 3895 8200 or email qld.general@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

Tasmania Hobart (Linda Graham) Launceston (Linda Graham)
Assessment: 8th November, 2012 7th November, 2012
Contact Alzheimer’s Australia Tasmania to book your place on (03) 6279 1100 or email linda.graham@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.
ALZHEIMER’S AUSTRALIA STATE AND TERRITORY EVENTS

Alzheimer’s Australia organises events, courses and support groups for people with dementia and their family, carers and professionals working in dementia care and support roles. Events are organised in all states and territories, in all capital cities and many regional centres.

For information on upcoming events near you, go to Alzheimer’s Australia’s website www.fightdementiA.org.au and click on ‘Choose your state’, then select your state or territory from the list.

Here’s a selection of upcoming events that may be of interest to readers of HoPE.

QUEENSLAND

Dining for Dementia Fundraising Dinner
Alzheimer’s Australia Queensland’s first fundraising gala dinner, a night of dinner dancing and old Hollywood glamour, auctions, prizes and more.

When  Friday 3 August 2012 from 6.30pm
Where  Princeton Room, Bond University Gold Coast
Cost  $125 per person or $1025 for a table of ten
Enquiries & Registration of Interest:
Julie Samuels at Alzheimer’s Australia Queensland, (07) 3895 8200 or email qld.general@alzheimers.org.au

ACT

Coffee Group
A social support group, for people with younger onset dementia to meet and socialise, organised by Alzheimer’s Australia ACT.

When  Weekly, Thursday afternoons, 1:30 - 3:30pm
Where  Gungahlin Lakes Golf Club
Cost  Free, buy own refreshments
Enquiries:
All attendees need to meet with a member of Alzheimer’s Australia ACT staff prior to the coffee group, to ensure it’s the most suitable group for them. For more information, please call Alzheimer’s Australia ACT on (02) 6255 0722 or call the National Dementia Helpline 1800 100 500.

NSW

Living with Memory Loss evening program for people with YOD
The program is an early intervention program for people in the early stages of dementia and their support person and covers a range of topics including but not limited to; relationships and communication, symptoms and diagnosis and planning for the future. The program focuses on maintaining and enhancing skills and abilities.

Benefits include the opportunity to discuss experiences in a safe supportive environment and to meet others in a similar situation. The program will be run in the evening to cater to working carers.

When  8 Wednesdays, 3rd October to 21st November 6:30 – 8:30pm
Where  Alzheimer’s Australia NSW, Vincent Fairfax Centre, Cnr Cox’s and Norton Roads, North Ryde
Cost  Free, bookings are essential
Enquiries & Registration of Interest:
Lyndell Huskins, Coordinator, Early Intervention Group Programs, Alzheimer’s Australia NSW, (02) 8875 4615 or email Lyndell.huskins@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

Carer Courses
Are you caring for a person with dementia? If so, you are invited to attend one of the FREE course for family carers and friends, conducted by Alzheimer’s Australia NSW.

Course 1 - Carss Park
When  3 Tuesdays – 14th, 21st & 28th August 2012
Where  Keystone Community Solutions, 72 Carwar Avenue, Carss Park (St George area, Sydney)
Cost  Free
Enquiries & Registration of Interest:
Alzheimer’s Australia NSW, Education Team on (02) 8875 4640 or (02) 8875 4651 or email nsw.education@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

Course 2 - North Ryde
When  3 Tuesdays – 11th, 18th & 25th September 2012
Where  NSW Vincent Fairfax Family Resource Centre Cnr Coxs and Norton Roads, North Ryde
Cost  Free
Enquiries & Registration of Interest:
Alzheimer’s Australia NSW, Education Team on (02) 8875 4640 or (02) 8875 4651 or email nsw.education@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.
**WESTERN AUSTRALIA**

**Caring for a Younger Person with Dementia**

This free course, offered over four sessions, has been specifically designed to assist families and friends who are supporting a younger person (under 65) with dementia.

**When**
- Session 1: Tuesday, 4th September, 6:00 - 8:00pm
- Session 2: Tuesday, 11th September, 6:00 - 8:00pm
- Session 3: Tuesday, 18th September, 6:00 - 8:00pm
- Session 4: Tuesday, 15th September, 6:00 - 8:00pm

**Where** Alzheimer’s Australia WA, 9 Bedbrook Place, Shenton Park

**Cost** Free

**Enquiries & Registration:**
Sheila Haywood, Alzheimer’s Australia WA on (08) 9388 2800 or email sheila.haywood@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

**Younger Onset Dementia Workshop**

This workshop is for care staff who interact with younger people (under 65) diagnosed with dementia. Participants will gain an understanding of the unique needs of younger people with dementia and will explore ways to adapt their care and service provision.

**When** Monday 17th September, 9:00am to 12:00 noon

**Where** Alzheimer’s Australia WA, 9 Bedbrook Place, Shenton Park

**Cost** $77

**Enquiries & Registration of Interest:**
Sheila Haywood, Alzheimer’s Australia WA on (08) 9388 2800 or email sheila.haywood@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

**Rockingham Younger Onset Dementia Associates (YODA) Group**

This social group meets fortnightly and caters for people with dementia under the age of 65 and their support person. The group regularly attends activities and outings such as trips to Serpentine Falls, barbeque lunches and lawn bowling.

**When** Every 2nd Wednesday, 9:30am - 2:30pm
(Upcoming meeting dates: 25th July, 8th August etc.)

**Where** Suite 9, Lotteries House, 80 Civic Boulevarde, Rockingham

**Cost** $8 plus spending money

**Enquiries & Registration of Interest:**
Barry Garnham, Alzheimer’s Australia WA on (08) 9535 8772 or email barry.garnham@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

**SOUTH AUSTRALIA**

**Younger Onset Dementia Evening Groups**

A suite of evening information and support groups for people with a diagnosis of younger onset dementia and their family members. The evening also includes a support group for family members living with younger family members in residential care.

**When** 3rd Wednesday of each month, 6:00 – 8:00pm

**Where** Alzheimer’s Australia SA, 27 Conyngham Street, Glenside 5065 or other locations in metropolitan Adelaide

**Cost** Free

**Enquiries & Registration of Interest:**
Please register via the National Dementia Helpline on 1800 100 500.

**South Metropolitan Younger Onset Dementia support group**

**When** 2nd Tuesday of each month, 1:00 – 3:00pm

**Where** The Chapel Room, The Corner Church, Cnr Diagonal and Oaklands Roads, Warradale, Adelaide 5046

**Cost** Free

**Enquiries & Registration of Interest:**
Please register via the National Dementia Helpline on 1800 100 500.