Welcome to Issue 15 of HOPE.

HOPE is Alzheimer’s Australia’s national newsletter for younger people with dementia, their care partners, family and friends, health professionals, care staff and everybody with an interest in younger onset dementia.

In this issue I’m very pleased to be able to bring you reports on two significant recent events involving the younger onset dementia community – well one ‘event’ and one ‘program’ actually.

The event is the “Younger Onset Dementia: A New Horizon” National Summit. The photo above shows the consumers – people with younger onset dementia, family members and carers – who kindly travelled from all four corners of Australia to Melbourne on March 19 to discuss the issues they face, from care and support to diagnosis and social participation. Over 350 delegates on day two of the Summit, March 20, heard not only the outcomes of the consumer discussions, but also from 15 Australian and international speakers. You can read more about the Summit, including a summary of the consumer deliberations, on pages 2 to 4.

The program is the National Younger Onset Dementia Key Worker Program. Funded by the Australian Government under the Living Long. Living Better. aged care reform, Alzheimer’s Australia has been tasked with establishing a national network of Key Workers. These Key Workers will act as a single point of contact to assist younger people with dementia and their families to navigate through the complex pathways of existing systems and available supports. I recently spoke with Rob Woolley, Alzheimer’s Australia’s National Program Manager, and asked him to explain the Program and how consumers can benefit by having access to a Key Worker.

I look forward to bringing you regular updates on the Key Worker Program in future issues of HOPE.

This issue also contains three items in Our Stories. One from carer and regular contributor, Bob Leicester brings some happy news! Kate Thompson and Glenda Hipwell have shared stories of the Alzheimer’s Australia younger onset dementia social and support groups they coordinate in Canberra and Ballarat.

Our Stories such as these are most welcome and are always popular with our readers, so feel free to contact me if you would like to tell everyone about your group, network or social event.

I hope you enjoy reading this issue of HOPE.

Jenny Warren
Editor
While this 2013 Summit followed up on some of the themes from the previous National Younger Onset Dementia Summit held in 2009, it was a very different landscape for people with younger onset dementia at this Summit.

Since 2009, dementia has been listed as a National Health Priority, recognising the impact the disease has on families and society more broadly.

There have also been significant reform announcements in both the aged care and disability sectors.

First, the Living Longer. Living Better. aged care reform announced in April 2012, included a program to help people with younger onset dementia to access age-appropriate services and supports.

Second, the roll out of the National Disability Insurance Scheme (now known as DisabilityCare Australia) will bring with it the biggest ever change to disability funding and services with a shift towards individualised support for eligible people. It was confirmed that people with younger onset dementia will be eligible for support through DisabilityCare Australia, an announcement that was welcomed by Alzheimer’s Australia on behalf of Australians under 65 living with dementia.

These changes in the service and support arena may have contributed to the level of interest in the National Summit.

It was the largest meeting of the Australian younger onset dementia community to date, with over 350 delegates attending from across the aged care and disability sectors as well as people with dementia, their families and carers.

The Summit also presented an opportunity for a number of Australian, if not international “firsts”, such as the Day 1 program where all delegates (pictured above at left) were younger people with dementia or those who care for someone with younger onset dementia; and on Day 2, a press conference given entirely by people living with younger onset dementia and chaired by Alzheimer’s Australia’s National President and 2013 Australian of the Year, Ms Ita Buttrose AO OBE (pictured above at right).

Day 1 delegates travelled from across Australia – from rural South Australia, regional Western Australia and Victoria, Tasmania, the New South Wales Central Coast, Sydney, Brisbane and Melbourne.

They were brought together to talk about key policy, funding and service provision gaps and were asked to share their stories – good and bad...
Day 2 participants came from a broad cross section of the community with an interest in improving the lives of people living with younger onset dementia. Younger people with dementia, carers, family members, service providers, health professionals, policy makers from the aged care, disability and mental health sectors, among others, heard from expert speakers from Australia and overseas on topics ranging from diagnosis to service provision. Regional, national and international experiences were described, including comparisons of support services available to people with younger onset dementia in communities as diverse as the Hunter region of NSW and Mariahoeve in The Netherlands.

Alzheimer’s Australia’s National President and the 2013 Australian of the Year, Ms Ita Buttrose AO OBE, opened Day 2 of the conference with a speech entitled “A New Future For People With Younger Onset Dementia?”

In her opening comments, Ms Buttrose summarised the purpose of the Summit by saying “Today brings together consumers and service providers to better understand how we can ensure we provide the services and support that people with younger onset dementia are seeking so they can enjoy a good quality of life.”

Additionally, she outlined the current status of the National Disability Insurance Scheme and how people with younger onset dementia may receive support under the scheme. Ms Buttrose highlighted the challenges faced by all stakeholders in the reform process – government, service providers and consumers. “There will also be multiple interfaces between the National Disability Insurance Scheme and the health and aged care systems, particularly in terms of diagnosis, assessment and services. Therefore, the rules that will govern the scheme will be complex.” she said.

The Summit would not have been possible without the support of Nich and Rosemary Rogers, the (Melbourne) Lord Mayor’s Charitable Foundation and the Australian Government, to whom we extend our thanks.

Alzheimer’s Australia would also like to thank the consumers who travelled from distant corners of Australia, for their energetic and optimistic participation in the discussions on Day 1, which resulted in the identification of six priority areas (see page 4), providing a focus for action in the coming months and years.

And thank you to our Day 2 guest speakers, for sharing their knowledge and experience, their successes and challenges.

And finally, thank you to all who attended Day 2. Whether you are a person with younger onset dementia or a carer, whether you work for a service provider, a government agency, or you are a clinician or other health professional, Alzheimer’s Australia hopes you found the program interesting, relevant and that you left the Summit with a renewed sense of optimism for the future.

...............continued overleaf
Following a full day of sometimes challenging discussions, Day 1 delegates identified the need for priority action in six areas:

1. **AWARENESS**
   Increased awareness to reduce stigma and to improve the opportunity for social participation by individuals in their local community.

2. **TIMELY AND ACCURATE ASSESSMENT AND DIAGNOSIS**
   Timely and accurate diagnosis with access to specialist services as needed.

3. **NATIONAL DISABILITY INSURANCE SCHEME AND YOUNGER ONSET DEMENTIA KEY WORKERS**
   A National Disability Insurance Scheme that places the person with younger onset dementia and their families at the centre and supports their choice and control over their future and the services and supports they require.

4. **REDESIGN OF SERVICES**
   Action by service providers to redesign their services so they can respond flexibly to the goals, aspirations and plans of younger people with dementia.

5. **PARTICIPATION**
   Opportunities to participate in society with access to employment and adequate income security.

6. **DEMENTIA RESEARCH**
   A greater investment in research into cause, cure and care of younger onset dementia if there is to be a better understanding of the condition.

These six priority areas are each explored in detail in the Summit Report with recommendations and actions outlined across all six areas. The recommendations are targeted at the development of better responses to the needs of people with younger onset dementia, their carers and their families.

Some examples of the recommendations are:

**AWARENESS**
Alzheimer’s Australia establish a national advisory group of people with dementia (*) of all ages to advocate on behalf of people with dementia and in particular to contribute to shaping a national awareness program, evaluating the work of the Younger Onset Dementia Key Workers, and raising the profile of people with younger onset dementia in DisabilityCare Australia.

**TIMELY AND ACCURATE ASSESSMENT AND DIAGNOSIS**
The funding contained in Living Longer. Living Better. to achieve timely diagnosis should also include younger onset dementia in the development of training programs for general practitioners and other health professionals.

**REDESIGN OF SERVICES**
A training program is developed for the disability sector to up skill workers on the specific needs of people with younger onset dementia.


(*) See page 6 of this issue Call for Expressions of Interest, Alzheimer’s Australia’s Dementia Advisory Group

A NEW HORIZON? - YOUNGER ONSET DEMENTIA NATIONAL SUMMIT

continued
**National Summit – “Younger Onset Dementia: A New Horizon?”**

The Summit was held in Melbourne on March 19 and 20.

The feedback I have received from consumers and other attendees confirms that the event was not only worthwhile, but for some, life changing.

We invited 15 people with dementia to day one of the Summit, asking them to open up about their circumstances, their lives and the challenges they and their families face, particularly on the subject of access and availability of age-appropriate support and services.

These people and their carers gave us more than we could have hoped for. They spoke of their experience with younger onset dementia specific services and support in their communities, or the lack thereof.

Whilst the day one participants agreed that there have been improvements in some areas, everyone agreed there is still a lot of work to be done to improve the lives of younger people living with dementia.

You can read more about the Summit on pages 2 to 4 of this issue, including the six priority areas and associated recommendations identified by the consumers. The full Summit Report is also available on our website.

**Key Worker Program**

The National Younger Onset Dementia Key Worker Program, which was announced by the Australian Government in April 2012 as part of the Living Longer. Living Better. aged care reforms, is now up and running.

Under the Program, a national network of Key Workers will be supported through Alzheimer’s Australia.

The Key Worker role will be to support the achievement of short and long term goals identified by the person with younger onset dementia and their family.

The Younger Onset Dementia Key Worker Program is a direct outcome of consumer consultations and feedback received since the 2009 National Younger Onset Dementia Summit.

**National Conference**

Alzheimer’s Australia’s 15th National Conference, The Tiles of Life - Colouring the Future was held in Hobart, Tasmania from May 14 to 17.

The biennial conference is a significant event on the international dementia advocacy and research calendar, bringing together world leaders in social and medical dementia research.

Key speakers from Australia, New Zealand, the United Kingdom, the United States and Germany challenged participants on how we can be positive in addressing dementia through promoting awareness, rehabilitation, social engagement, creativity and self-expression.

They also discussed the critical role investment in dementia research can play in identifying the cause of, and treatments and preventative health measures for dementia.

I would like to draw your attention to three important publications launched at the Conference by Alzheimer’s Australia’s National President and Australian of the Year 2013, Ita Buttrose.

They are:

1. Dementia Friendly Societies
2. Cognitive Impairment Symbol: creating dementia friendly organisations
3. Respite Care for People Living with Dementia.

All three publications are directed at changing community attitudes towards dementia.


Glenn Rees AM
Chief Executive Officer
Alzheimer’s Australia
CALL FOR EXPRESSIONS OF INTEREST

Alzheimer’s Australia’s Dementia Advisory Group

Alzheimer’s Australia is seeking individuals with dementia of all ages who are interested in having a say about the needs of people with dementia in Australia. We are looking for people who are interested in being actively involved in advocating for the needs of people with dementia through Alzheimer’s Australia.

The Alzheimer’s Australia’s Dementia Advisory Group is a new group that will aim to:

- Determine the priorities of people with dementia
- Contribute to policy and advocacy work
- Promote dialogue between those with dementia and service providers with a view to promoting a better understanding of their social and care needs
- Assist in refining and evaluating Alzheimer’s Australia’s national programs

Communication will be via email and teleconferences and the group may meet face to face one to two times per year.

Members of the group may be supported by their partners or carers to participate in meetings.

New members are being sought from around Australia and experience in a similar role is not necessary.

To express your interest or find out more information, please contact

Samantha Blake, Policy Officer, Alzheimer’s Australia
Email: samantha.blake@alzheimers.org.au
Phone: (02) 6278 8909
NEW SERVICES AND PILOT PROJECTS

YOUNGER ONSET DEMENTIA KEY WORKER PROGRAM

Jenny Warren, Editor, HOPE

For all Australians living with dementia it has long been a dream to have one-on-one support from a person who can provide advice and support on a consistent basis to assist in finding a pathway through the maze of care, support and health services.

On 20 April 2012 the then Prime Minister, Julia Gillard, and the then Minister for Mental Health and Ageing, Mark Butler, announced as part of the Living Longer. Living Better, aged care reform, an investment of $268.4 million over 5 years to tackle dementia. One component of the package is funding of $23.6 million over 5 years to enable younger people with dementia to access better coordinated care and support.

Part of this funding will support the new National Younger Onset Dementia Key Worker Program.

Rob Woolley is Alzheimer's Australia's National Program Manager with responsibility for the new National Younger Onset Dementia Key Worker Program.

I recently spoke with Rob in Canberra and asked him to explain the Program and how consumers can benefit by having access to a Younger Onset Dementia Key Worker.

**Question:**
What is the role of a Younger Onset Dementia Key Worker?

**Answer:**
There are an estimated 24,000 people living with younger onset dementia in Australia. Yet availability of and access to age-appropriate care and support is extremely limited and many people with younger onset dementia don’t know where to start when it comes to accessing support and services in the health, community support and care sectors.

In response, the role of the Younger Onset Dementia Key Workers has a dual focus.

First and foremost, the Younger Onset Dementia Key Worker’s role is to provide information, advice and support to individuals and families living with younger onset dementia, to help meet their needs and improve their access to available care and support services, thereby enhancing their quality of life.

Secondly, to address the lack of age-appropriate services and support mechanisms, the Younger Onset Dementia Key Workers will work with service providers, health professionals and support organisations across the spectrum of the community, health and residential care sectors in order to contribute to the development of a service sector that is responsive to and can meet the needs of people living with younger onset dementia. This will also involve increasing awareness of the needs of people living with younger onset dementia within existing services and organisations, encouraging them to improve the scale and scope of the service they offer to consumers.

**Question:**
What does that actually mean for consumers?

**Answer:**
The Younger Onset Dementia Key Worker acts as a single point of contact for people with dementia, their carer and family members. They will help to coordinate care, not only within the healthcare system, but also across systems including legal, education, social services, financial resources, recreation and transportation, among others.

This activity is accomplished by a variety of means which may include:

- working with the person with dementia, their family and carers to identify individual goals and ways to achieve them;
- helping people with dementia, carers and family members to understand and navigate systems;
- being present at various meetings/appointments as necessary;
- assisting with the interpretation of assessment results or outcomes of meetings;

...continued overleaf
• helping people with dementia, their carer and family members to develop their skills, and providing additional tools to facilitate empowerment.

Additionally, they may provide counselling in groups or one-to-one, and facilitation of support groups where necessary.

In essence, from the point of view of the consumer, the Younger Onset Dementia Key Worker supports them and their family members to navigate and link to existing services, agencies and activities that meet their individual goal and needs, promoting wellness, independence, community engagement and improving their quality of life.

**Question:**
That sounds similar to Case Management. **What’s the difference?**

**Answer:**
The principle underpinning key working is consumer or self-directed care. That is that people accessing the service are the people best able to make decisions regarding the services that they need and wish to receive.

Traditional case management is a process that matches the client’s health care needs with the available services and resources. Case management, in most cases, does not involve coordination across all systems, individualising approaches for different families based on their specific needs, or taking steps towards empowering consumers/clients.

**Question:**
**What skills and experience do Younger Onset Dementia Key Workers have?**

**Answer:**
A lengthy and rigorous recruitment process has ensured that all Key Workers have excellent communication skills and experience in delivering and coordinating services that comply with relevant standards, regulatory requirements and policies. In addition to this, each Key Worker brings a wide range of relevant skills and experience from a broad range of backgrounds including relevant qualifications and/or experience in the delivery of a community, health or disability based service.

Counselling skills have also been a major focus during the recruitment process, as has experience in coordinating other support services.

Importantly, we have sought people who have the ability to network with, consult and respond to the needs of a diverse group of stakeholders. We believe the best outcomes will come from service providers and agencies talking to each other and coordinating the support of people with younger onset dementia.

**Question:**
**How many Younger Onset Dementia Key Workers will there be across Australia?**

**Answer:**
Forty (40) Younger Onset Dementia Key Workers have been recruited.

**Question:**
**Where will the Younger Onset Dementia Key Workers be located?**

**Answer:**
The best way to answer that is to refer to the accompanying map (please see next page).

The cities, towns and regions marked on the map are where the Younger Onset Dementia Key Workers will be based. There will be more than one Younger Onset Dementia Key Worker in the larger capital cities.

Younger Onset Dementia Key Workers will have the capability to work with clients face-to-face and remotely via telephone and other available technologies such as Skype, email etc.

Just because there isn’t a Younger Onset Dementia Key Worker in your town or region, doesn’t mean you won’t have access to the Program. Key Workers based in regional centres will be offering support to people across a larger geographic region. For example, the Key Worker based in Bendigo, Victoria, will also cover the cities and towns of Castlemaine, Echuca, Mildura and Swan Hill and others in the Loddon-Mallee region.

The number of Younger Onset Dementia Key Workers per state and territory was determined based on the most recent dementia prevalence and population statistics.

**Question:**
**How can consumers access the services of a Younger Onset Dementia Key Worker?**

**Answer:**
There are a number of ways that consumers can engage with the Younger Onset Dementia Key Worker Program.

Some consumers will be referred to a Younger Onset Dementia Key Worker by their GP or other health professional. Others will be referred by community service and support organisations, including existing clients of Alzheimer’s Australia.

Other consumers who may not currently be receiving support from existing services may call the National
Dementia Helpline on 1800 100 500 to make an initial enquiry.

Alternatively, consumers can contact their Alzheimer’s Australia State Office to find out more about the Program.

The important thing is that consumers are made aware of the Younger Onset Dementia Key Worker Program and the support it offers, whether that be by their GP or medical specialist, hospital or allied health service, or by calling the National Dementia Helpline.

Question: Do consumers have to have a diagnosis of dementia to access the Younger Onset Dementia Key Worker Program?

Answer: No.

One of the issues identified at both the 2009 and 2013 National Younger Onset Dementia Summits was the delay in receiving a proper diagnosis that so many people experience.

The Younger Onset Dementia Key Worker Program acknowledges that barrier and has been designed so that having an actual diagnosis of dementia is not a pre-requisite to engage with the Program.

One of the primary roles of the Younger Onset Dementia Key Worker will be to assist people with dementia and their families who engage with the Program without a diagnosis, to navigate the health system with a view to receiving a timely and accurate diagnosis.

Question: Is there a charge to access the Younger Onset Dementia Key Worker Program?

Answer: No.

The Program is fully funded by the Australian Government. There is no cost to consumers for support provided by a Younger Onset Dementia Key Worker. This also applies to consumers accessing the program in the National Disability Insurance Scheme/DisabilityCare Australia trial sites of Barwon (Vic) and Hunter (NSW).

Normal charges may still apply to activities, services and supports outside of the Younger Onset Dementia Key Worker Program, such as respite, transport, in-home support.
NEW SERVICES AND PILOT PROJECTS

ADVANCE CARE PLANNING AND DEMENTIA

- PROJECT UPDATE

Advance care planning is the process of thinking about and communicating how you would like health and lifestyle decisions to be made for you if you could not speak for yourself at some time in the future. One reason this happens is if a person develops dementia and gradually loses the capacity to make his or her own decisions.

In the October 2012 issue of HOPE you will have read about a project funded by the Consumer Dementia Research Network within Alzheimer’s Australia, to develop a nationally-focused website and campaign to promote advance care planning and other aspects of planning ahead. This funding is part of the National Quality Dementia Care Initiative.

HOPE readers and all interested people were invited to respond to an online survey as part of the project team’s extensive consultation with people with early stage dementia, carers, healthcare and other professionals as well as staff of state and territory health and guardianship authorities.

The Project Manager, Dr Chris Shanley, has provided this project update to HOPE readers.

I would like to thank everyone who responded to our survey or participated in our nationwide consultations. These consultations have informed the style and content of the website that has been developed.

Content for the website has been finalised and the designers are hard at work on completing the build of the site. It is expected to be launched in August or September this year.

The website and associated campaign to promote it will be called start2talk.

While there are a number of websites related to planning ahead available, there are aspects of this new start2talk website that will add value to existing resources.

• It uses a consumer-focused model that seeks to address the issues raised by consumers during extensive consultations.

• It moves beyond providing information to include a number of worksheets that promote communication and help users take action related to planning ahead.

• It includes the ability for users to register with the website and store their worksheets online if they want to.

• While not being restricted to persons with dementia, it has sections that are clearly focused on people with dementia and their families.

• It has comprehensive information and links relevant for all States and Territories as well as a section for health and community care professionals.

• The website will be widely promoted through collaborations with a number of consumer and professional organisations.

This new website will be a practical and comprehensive resource for members of the community across Australia who are interested in planning ahead as well as people with dementia and their families.

As mentioned above, the website launch will be advertised via a range of consumer and professional organisations and via the regular communication channels of Alzheimer’s Australia including HOPE and the twice-monthly Dementia News.

To get more information about the project or the website, contact the Project Manager, Chris Shanley on 0423 842 781 or via email at Christopher.Shanley@sswahs.nsw.gov.au
OUR STORIES

SOME HAPPY NEWS

By regular contributor, Bob Leicester, carer.

In two previous issues of **HOPE** (Issues 5 and 11) we have presented news items on our little “A-team”, a support group of eight Alzheimer’s sufferers and their carers. We first met at a YOD Living with Memory Loss course run by Alzheimer’s Australia Victoria in 2007. We have continued to meet socially about every 6 weeks since and with time, the shared news has become increasingly difficult.

However at our recent picnic lunch on the cliffs of Hampton in Melbourne, two of our carer members broke the happy news of their engagement.

The engaged couple are Bernie O’Brien and Sandra Mast who, together with their respective spouses Cath and Trevor, completed the YOD Living With Memory Loss Course together in 2007.

Sadly they both lost their partners during the past two years but have provided great support to each other during that time.

They plan to marry in the next few months and will celebrate with their combined families totalling 9 children and 16 grandchildren.

Bernie and Sandra are both active members of the Alzheimer’s Australia Victoria YOD Consumer Reference Group and also the Lovell Foundation Committee.

HELP SHEET UPDATE

Some readers may be aware of the **LEWY BODY DISEASE** series of 10 Help Sheets released in November 2012. The first of that series is Help Sheet 20 in the Alzheimer’s Australia **ABOUT DEMENTIA** Help Sheet series.

Help Sheet 22, **POSTERIOR CORTICAL ATROPHY** (PCA), has recently been released.

This Help Sheet is available in both hard copy and electronically.

To find all Alzheimer’s Australia Help Sheets, go to our website [www.fightdementia.org.au](http://www.fightdementia.org.au), click on "Understanding Dementia and Memory Loss", then on "Helpsheets".

You can also refer to the new **DEMENTIA Q&A** section of the Help Sheet page of our website.

The information in our Q&A section is more detailed than the general Help Sheets and new topics are added regularly.

Questions range from "PBS subsidies for cholinesterase inhibitors: What are the conditions?" to “Rights to Health Information" and “Safer walking for people with dementia: Approaches and technologies".
OUR STORIES

CONTINUED

YOUNGER ONSET DEMENTIA DINNER
AT THE CANBERRA YACHT CLUB

By Kate Thompson, Dementia Advisor and Projects Facilitator, Alzheimer’s Australia ACT

Canberra is a beautiful city with many hidden gems. It’s fair to say that the Canberra Yacht Club in Yarralumla, the location of our most recent social dinner for younger people with dementia and their families, is one of these.

We arrived to a private room overlooking the grassy shore of Lake Burley Griffin as the sun was slowly lowering in the sky. It was nice to have our own room, not just for the view, but also because it meant that people could feel relaxed and safe, away from the hustle and bustle of the restaurant.

As people arrived and took their seats, the conversation flowed freely. Some people recognised one another from previous dinners; others were new faces making new friends. The tables were set along a large window so we didn’t have to turn our heads to admire the view; it was just naturally in our sights. It was a great turn out, with about 32 people, including one very well behaved, charming 6 year old. It was lovely to see some of the children attend with their parents, as a family dinner out is not a regular occurrence for some families affected by dementia.

Later in the night, one guest commented to a staff member that she had been admiring the amazing sunset happening just outside, the beautiful pinks and purples swirled through the sky and the lake shimmering as the sun dropped behind Black Mountain. She had turned to see whether people on other tables were taking the time to admire such a view, but she quickly realised that everyone was too engrossed in their conversations, laughing and joking, to be paying too much attention. This, after all, was what we were here for.

The service and food were divine and everyone was commenting on the meals – especially the entrée salt and pepper squid, which was absolutely delicious. People stayed until the last bit of dessert had been eaten. Everyone left with a smile on their face and a very full, satisfied feeling, not necessarily from the food.

I’d like to thank all the people who came along to make the YOD dinner such a successful night. I’d also like to acknowledge the service and support of the Canberra Southern Cross Yacht Club for hosting the dinner.

USEFUL 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 OR WWW.DBMAS.ORG.AU

COMMONWEALTH RESPITE AND CARELINK CENTRE
1800 052 222

EMERGENCY RESPITE (AFTER HOURS)
1800 059 059
ALZHEIMER’S AUSTRALIA VICTORIA’S BALLARAT YOUNGER ONSET DEMENTIA GROUP

Submitted on behalf of the group by Glenda Hipwell, Dementia Consultant - Ballarat, Alzheimer’s Australia Victoria

Since launching in 2011, the Ballarat Younger Onset Dementia group has gone from strength to strength.

At the time of the group’s inception, Dementia Consultant Glenda Hipwell had eight clients with younger onset dementia and identified an opportunity to bring them together in a supportive environment.

“I spoke with each one of these people individually to see what they thought about the idea of starting a support group that could meet on a regular basis for fun, friendship and activity,” Glenda explained.

“They all embraced the idea. Along with our local health service which runs a dementia day program we met to discuss the structure, preferred days, times and activities.”

Members worked closely with the group Coordinator to discuss and develop a program of activities based on their goals and, in a matter of weeks, the group was operating regular sessions.

Member achievements to date have been incredibly diverse and have included the development of digital life stories, participating in art programs across a multitude of different media platforms (pictured are two of the wonderful works created by members of the group), making scarecrows for the Ballarat centre’s garden, taking day trips to places of interest and rummaging through antique and second hand stores for treasures.

The group now has 10 members who, together with their support people, families, friends, carers and Alzheimer’s Australia Vic staff, meet quarterly for a BBQ or pizza night where they share stories, listen to guest speakers and generally relax, socialise and enjoy each other’s company.

In addition, the support people of group members have also recently begun meeting monthly to discuss ways in which they can raise awareness and funds.

“The Salvation Army Community House has provided a fantastic resource for running art sessions and digital programs,” Glenda added. “We have had wonderful support and encouragement from them.”

“Each week these amazing people enter into our lives and enrich it far beyond they realise,” said Salvation Army Neighbourhood House Coordinator, Alison Demuth. “Their enthusiasm and their courage is inspiring. We enjoy the conversations over coffee and we enjoy watching the smiles on their faces as they create art from pieces of paper, photos, water colour, acrylic and from their memories.”

Alzheimer’s Australia Vic recently opened its new Grampians regional hub in Ballarat. The centre’s team of three provides counselling, information, support and family carer education. The office also has a dedicated space for group meetings, program activity and education. Its development is the result of a funding increase of $400,000 per year from Commonwealth and Victorian governments, through the Home and Community Care program, to expand services in the Grampians, Loddon Mallee and Barwon regions.
What’s On

Love, Loss and Laughter - Photographic Exhibition

Between May and November 2013, The Love, Loss and Laughter exhibition will be touring Australia. The exhibition is the work of photographer and sociologist, Cathy Greenblat, whose aim is to convey the message that life goes on after a diagnosis of dementia. For more information about the artist, the photographs, exhibition locations and dates, and how to submit your own photo and story, go to the exhibition website, http://exhibition.fightdementia.org.au/

Upcoming Dates:
- Canberra 16 – 26 July
- Perth 8 – 27 August
- Adelaide 5 -17 September
- Brisbane 3 – 11 October
- Sydney 7 – 27 November

Dementia Awareness Week

When?

16 – 23 September 2013, including World Alzheimer’s Day on September 21.

The theme will be continued from 2012, Brain Health: Making the Connections.

Dementia Awareness Week (DAW) is the national centrepiece for Alzheimer’s Australia’s community awareness activities each year. Local DAW activities and events will be announced throughout the year. Check your state or territory page of the Alzheimer’s Australia website as September approaches.

For more information on how you can get involved, contact your local Alzheimer’s Australia Office via the National Dementia Helpline 1800 100 500.

Who Reads Hope?

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

Each reader has their own reason for wanting to learn more about the community affected by younger onset dementia, whether it be the personal stories from people with dementia and their carers, current scientific or social policy research, advocacy, or simply finding out about available services and support.

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 readers, old and new, in the coming months.

Jenny Warren
Editor, Hope News
Alzheimer’s Australia
E: hope.news@alzheimers.org.au
STATE AND TERRITORY EVENTS

Alzheimer’s Australia organises events, courses, support groups and many other activities in all capital cities and many regional centres.

Check your State or Territory page on our website, www.fightdementia.org.au or call the National Dementia Helpline on 1800 100 500 for information on activities in your area.

Here’s a selection of upcoming Alzheimer’s Australia regular and special events, along with relevant events presented by other organisations.

SOUTH AUSTRALIA

Connexus Evening Meeting
Join us for an evening of information and discussion groups. People who live in the community with a diagnosis of younger onset dementia and their support person/s are welcome.
When 4th Wednesday, bi-monthly, 6:00 – 8:00pm (28 August, 23 October, 4 December 2013 etc)
Where Broadview Baptist Church, Cnr Collingrove Ave & Howard St, Broadview or other locations in metropolitan Adelaide
Cost Free
Enquiries & Registration: 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 (except January)
Where The Chapel Room, The Corner Church, Cnr Diagonal and Oaklands Roads, Warradale, (Adelaide)
Cost Free, refreshments provided
Enquiries & Registration: Please register via the National Dementia Helpline on 1800 100 500.

ACT

Walking Group
The walking group’s quote is “friendship doubles our joy and divides our sorrow”. An active social group, for people with younger onset dementia to meet, socialise and exercise. This group participates in the National Heart Foundation quality of life measure, “active body active brain” project as funded by Alzheimer’s Australia National Quality Dementia Care Initiative.
When Weekly, Tuesday morning, 10:00 - 11:30am
Where Alzheimer’s Australia ACT, 159 Maribyrnong Ave, Kaleen
Cost Free, buy own refreshments at Kaleen Sports Club
Enquiries: All attendees need to meet with a staff member of Alzheimer’s Australia ACT prior to joining the 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.

VICTORIA

Younger onset dementia Café
Alzheimer’s Australia Vic run a café style support program for people living with Younger Onset Dementia and their family members and friends. The events are held at our Hawthorn office and will reflect the needs of the Younger Onset Dementia core group. The cafés are a fantastic place to meet other people, share experiences, offer each other support and receive resources and information relating to younger onset dementia.
Upcoming Dates: Sunday 14 July, 12:00noon – 2:00pm
Thursday 22 August, 12:00noon – 2:00pm
Sunday 6 October, 12:00noon - 2:00pm
Where Alzheimer’s Australia Victoria, 98-104 Riversdale Rd, Hawthorn, 3122
Cost Free
Enquiries: For further information please contact Belinda Nixon on (03) 9815 7800 or call the National Dementia Helpline on 1800100 500.

The Younger Onset Dementia Café is proudly supported by the Wood Family Foundation.

The Caring Role - A compassionate approach
Suitable for family carers who are ready to reflect on their new role and relationship with their family member living with dementia, and who can participate in a longer (4 week) group program. While this program includes information about dementia, changes and communication, it also incorporates the loss and grief associated with becoming a carer. We talk about how to create an environment to facilitate the caring role as well as maintaining and getting support as a carer.
When Held over 4 weeks, each Monday in October (7, 14, 21 & 28 October), 1:30 - 4:30pm
Where Alzheimer’s Australia Victoria 98-104 Riversdale Rd, Hawthorn, Vic 3122
Cost Free
Enquiries: For registration or further information please contact Lisa Reed on (03) 9816 5722 or call the National Dementia Helpline on 1800 100 500.
STATE AND TERRITORY EVENTS

Coping with Carer Stress
When  Held over 8 Thursdays, 10:00am - 12:30pm  
  September 26, October 3, 10, 17, 24, 31, 
  November 7, 14
Where  Alzheimer’s Australia Victoria  
  98-104 Riversdale Rd, Hawthorn, Vic 3122
Cost  Free
Enquiries and further information: In order to join this program, participants will need to complete an assessment interview with a counsellor. Call the Gateway Counsellor on (03) 9815 7800.

An invitation from Villa Maria in conjunction with Alzheimer’s Australia Vic to a Younger Onset Dementia Carers Support Group
The Carer Support Groups is targeted toward those caring for someone with younger onset dementia in the Outer East. We invite you to attend this group to participate in the conversation, meet others in the same caring situation and to receive support from and provide support to others in the group.
When  Once a month on the following Mondays  
  4:30 - 6:00pm  
  8 July, 12 August, 9 September, 14 October, 
  11 November, 9 December
Where  Orana Neighbourhood House (multi purpose room)  
  62 Coleman Road, Wantirna South, 3152
Cost  Free, afternoon tea supplied
Registration: Please confirm attendance with Cyndie Fox on (03) 9538 4300 no later than three days prior to your meeting. All service providers are requested to make a referral prior to participants attending. New Carers contact the facilitator, Cyndie Fox on (03) 9538 4300.

TASMANIA

YOD Support Group
Fun and Friendship. Lunch included.
When  Weekly, Mondays 10:30am – 2:00pm
Where  The Old Vicarage Respite House, St Johns Avenue, New Town, 7008
Enquiries: For further information, please call Rhonda Vickery or Pat Baines on (03) 6279 1101 or call the National Dementia Helpline on 1800 100 500.

Social Luncheon Group
A monthly lunch for people with younger onset dementia. Come along, make new friends, try a different venue each month!
Enquiries and further information: Please call Rhonda Vickery (03) 6279 1100.

Opals Support Group
A group for carers of people with younger onset dementia. Our monthly chats provide an opportunity to share experiences, challenges, humorous happenings and information. Provides contact with other carers in a confidential and caring group.
When  1st Thursday of each month  
  10:30am – 12:30pm
Where  The Old Vicarage Respite House, St Johns Avenue, New Town, 7008
Cost  Free. Tea & coffee provided. A morning tea plate to share would be appreciated.
Enquiries: For further information, please call Rhonda Vickery or Pat Baines on (03) 6279 1100 or call the National Dementia Helpline on 1800 100 500.

QUEENSLAND

Living With Memory Loss
Educational and informative course specifically for people who have recently been diagnosed with younger onset dementia and their support person/s.
When  26 - 27 August 2013, 10:00am - 2:30pm
Where  Labrador (Gold Coast)
Cost  Free. refreshments supplied
Enquiries: Please call Alzheimer’s Australia QLD for more information on (07) 3895 8200 or call the National Dementia Helpline 1800 100 500.

YOD Memory Lane Cafe Group
Our social support group for people with younger onset dementia and their carers. Come along and chat, make new friends and socialise!
When  3rd Sunday of each month, 2:00 - 4:00pm
Where  Labrador (Gold Coast)
Cost  Free, refreshments supplied
Enquiries: It is necessary to have attended a Living With Memory Loss program prior to attendance. Please call Alzheimer’s Australia QLD for more information and to ensure it’s the most suitable group for you. You can contact us on (07) 3895 8200 or call the National Dementia Helpline 1800 100 500 or email qld.registrations@alzheimers.org.au

YOD Social Group
When  3rd Friday of each month, 10:00am - 12:00noon
Where  Woolloongabba
Cost  Free, refreshments supplied
Enquiries: Please call Alzheimer’s Australia QLD for more information and to ensure it’s the most suitable group for you. You can contact us on (07) 3895 8200 or call the National Dementia Helpline 1800 100 500 or email qld.registrations@alzheimers.org.au

Townsville DMCC
(Dementia and Memory Community Centre)
Our social support group for people with younger onset dementia and their carers, including education from a guest speaker.
STATE AND TERRITORY EVENTS

When 3rd Monday of each month, 10:00am-12:00noon
Where Townsville
Cost Free, refreshments supplied
Enquiries: Please call Alzheimer’s Australia QLD for more information and to ensure it’s the most suitable group for you. You can contact us on (07) 3895 8200 or call the National Dementia Helpline 1800 100 500 or email qld.registrations@alzheimers.org.au

Wide Bay DMCC (Dementia and Memory Community Centre)
Our social support group for people with dementia and their carers, including activities that stimulate brain function.
When Every 2nd Monday, 10:30am - 12:00noon Upcoming 2013 dates: 8 July, 22 July etc
Where Maryborough
Cost Free, refreshments supplied
Enquiries: Please call Alzheimer’s Australia QLD for more information and to ensure it’s the most suitable group for you. Whilst this group is not exclusively for people with younger onset dementia, a number of participants are living with, or supporting someone living with younger onset dementia. You can contact us on (07) 3895 8200 or call the National Dementia Helpline 1800 100 500 or email qld.registrations@alzheimers.org.au

NORTHERN TERRITORY

Please call the National Dementia Helpline on 1800 100 500 for information.

WA

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 2013 dates: 10 July, 24 July etc
Where Suite 9, Lotteries House, 80 Civic Boulevarde, Rockingham
Cost $8 plus spending money
Enquiries & Registration of Interest: Julie Twyford, Alzheimer’s Australia WA on (08) 9535 8772 or email julie.twyford@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

The Saturday Club
This program enables younger people with dementia to continue engaging with the local community through outings decided by club members.
When Every Saturday, 10:00am – 3:00pm
Where Mary Chester Centre, 9 Bedbrook Place, Shenton Park
Cost $8 plus spending money
Enquiries & Registration of Interest: Marlene Grogan, Alzheimer’s Australia WA on (08) 9388 2800 or email marlene.grogan@alzheimers.org.au or call the National Dementia Helpline 1800 100 500.

NSW

Support groups
Social Days (Far North Coast)
Run by Far North Coast Dementia Outreach Service
When Quarterly, 2013 dates TBC
Enquiries: Atosha Clancy (02) 6620 6283.

Port Macquarie/Macleay Valley (Kempsey) region
YOD social support group for people with dementia and carers meets monthly, usually first Wednesday of the month.
Enquiries: Linda Grant (02) 6584 7444.

North Ryde
YOD afternoon carers group
When 1st Tuesday of the month, 2:00 – 4:00pm

YOD evening carers group
When 2nd Tuesday of the month, 6:30 – 8:30pm

Young People’s Support group
A bi-monthly group for adult children (18 and over) who have a parent with younger onset dementia.
When 3rd Wednesday of every second month from 6:30 – 8:30pm
Enquiries for the three North Ryde groups: All enquiries to Lyndell Huskins on (02) 8875 4615 or contact the National Dementia Helpline on 1800 100 500.

HOW TO SUBSCRIBE AND UNSUBSCRIBE FROM HOPE

We want to ensure HOPE is getting to the right people. 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/content/hope-newsletter.aspx

Jenny Warren
Editor, HOPE
Alzheimer’s Australia