

# H O P E

helping other possibilities emerge

Welcome to the third and final edition of **HOPE** for 2009.

As you prepare for the Christmas season our wish is that it is a time which brings you many of life's pleasures. Try not to get caught in the 'busyness' of the season but rather enjoy the simple pleasures of spending time with family and friends. Enjoy and we look forward to hearing from you in 2010.

Our feature article this issue gives a glance at Youngcare apartments in Brisbane. During 2010 let's hope that we can move towards more positive options for long term care for younger people with dementia.

Our next edition will be scheduled for March 2010 and it would be helpful to have your contributions by the end of February.

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## What's On

?

### 1. Dementia: Lesbians and Gay Men

Alzheimer's Australia, in association with Aids Council of NSW and Aged & Community Services Association of NSW & ACT, invites you to attend the launch by Hon Michael Kirby of the publication

## 'Dementia: Lesbians and Gay Men'

Thursday 19 November 2009,  
7 pm – 9 pm  
Rex Convention Centre  
50-58 Macleay Street,  
Potts Point NSW 2011



Michael Kirby

Speakers:  
**Dr Jo Harrison** School of Health Sciences, **Mark Orr** President ACON  
University of South Australia

Bookings are essential. Enquiries and registration contact Deb Gavan Email: DGavan@acon.org.au Tel: 02 9206 2000 RSVP by Friday 13 November 2009 Funded by the Australian Government Department of Health and Ageing.

## **2. Talking to children about your illness**

Dealing with your diagnosis is hard – not just for you but also for those around you. In some ways, it may be easier not to talk about it. ... But talking to children may seem a particularly daunting prospect.

Thus begins a short publication of 8 pages from Alzheimer's Society UK has some good hints about talking to children. It has strategies and tips for talking to preschool children, school children and teenagers.

It can be printed from the website at [Living with dementia booklet - Talking to children about your illness - Downloads](#) - Alzheimer's Society

## **3. Lovell Foundation (to be confirmed – subject to permission)**

From the web site:

**Our ambition.**

**Creating services for people with Younger Onset Dementia**

The recently established Lovell Foundation aims to provide long term accommodation services for people diagnosed with Younger Onset Dementia and their families.

The Lovell Foundation wishes to establish facilities that allow for a stimulating, age appropriate environment. We aim for a place where residents can maintain independent, rewarding lives and receive a variety of therapies that will perpetuate health, stimulate intellectual capabilities and encourage emotional well being.

Our dream is to provide a retreat style accommodation and activity centre which will be a family friendly and inclusive environment.



## A Tip for the Reader:

Try re-reading the books you enjoyed as a younger person



## Reader's contribution



I have always enjoyed reading. However, with the progression of my Alzheimer's I began to find reading less of a pleasure and more a demanding chore. I found that reading placed a significant demand on my short-term memory and as my capacities decreased in this regard I began to find current novels very unrewarding. I had difficulty in retaining the details of the many characters in such stories and found the intricacies of the multiple sub-plots very challenging.

Then my granddaughter arrived and, with this blessed event, I started to keep an eye out for suitable children's books to interest her during her future visits.

It was while browsing for infants books in a favourite second-hand bookshop that I noticed an 'old friend' in the adolescent/young adult section: *A Little Bush Maid*, a book I had received for my ninth birthday. The author was Mary Grant Bruce. The book had been first published in 1910 and the story was set in this period in rural Australia. A key character in the story was Norah – the little bush maid – along with brother Jim and her father, family and friends. The second-hand copy I saw (with

dust jacket still reasonably intact) was the post-war republished edition I had received on that birthday fifty years ago.

Surprised as I was to see the book again, the real satisfaction came when I began to read it. I found the main characters to be refreshingly familiar, no doubt because they remained embedded in my long-term memory. Also I was pleased to find the story line simple, the Queen's English in use and the ambience created to be something special.

I now find myself searching for more literary treasures from my younger reading days knowing that literature of this genre, vintage and prior exposure will allow me once again to experience the joy of reading.

For those who are finding their reading brings diminished rewards, my tip to you is to try re-reading those books you enjoyed as a younger person.

Annette Altree-Williams  
Member, ACT Branch, Alzheimer's Aust  
6 September 2009

Right now, there are over 6500 young Australians living in aged care - simply because there are very limited alternatives (Senate Community Reference Committee 2004).

## Youngcare Apartments - Brisbane Visit

In addition, there are a further 700 000 more struggling at home with support from family, friends and a range of community groups. In September I visited the Youngcare apartments in South Brisbane along with Trish and Leonie. Trish has younger onset dementia and was invited to look at the apartments after spending some time with Mike Munroe for an interview on Chanel seven's Sunday Night program.

Youngcare is a not-for-profit organisation whose goal is to 'Create change in the way we care for young people with 24/7 care needs by providing relevant and dignified lifestyles.' The organisation raised over \$10 million in cash and in-kind support to build the first ever Youngcare apartments, located in Western Brisbane.

The apartments in Sinnamon Park are home to 16 young people with 24/7 care needs. Each apartment is fully self-contained, featuring individual kitchens, living rooms, bedrooms, bathrooms and outdoor decks or patios for every resident. Other features in the apartments include ceiling mounted track hoists for increased independence and mobility; and emergency call buttons to facilitate the provision of high level care.

There are no restrictions on visiting hours and friends and family are free to stay overnight in adjoining guest rooms complete, with individual ensuites. On the day we visited some of the resident's children were staying for the first week of school holidays and they had a Hawaiian themed barbeque the night before for all the families who were able to come along.

Outside of the resident's individual apartments, other features of the complex include communal entertainment rooms complete with



Above: Apartment lounge area Below: Bedroom

Nintendo Wii and big screen plasmas; a commercial kitchen and dining room; BBQ areas and a spacious deck.

The Youngcare Apartments also offer a unique model of 24/7 care, administered by Wesley Mission Brisbane. With one carer to every two residents, the care model specifically caters to the exact needs of the residents, ranging from conditions such as Acquired Brain Injury to Multiple Sclerosis. There were no residents with younger onset dementia, when we asked about the process to take up an apartment the eligibility

guidelines are established by Disability Services Queensland, not Youngcare themselves, which Trish found a little disheartening as she has had little recognition from the department so far in her journey. But as Trish said a goal like this gives her something to work towards.

Little things in the apartments like colourful feature walls and modern practical furnishings alongside personal items and photographs made the apartments feel like a home.



Left: Common area for indoor/outdoor entertaining Right: Apartment bathroom

The next phase of Youngcare's future planning includes three key projects:

**Gold Coast – Target: \$5 million**

Construction due to commence  
Dec 2009

**Sydney – Target \$11 million**

Construction due to commence  
Dec 2010

**Melbourne – Target \$7 million**

Construction due to commence  
Nov 2010

The Gold Coast, Sydney and Melbourne apartment projects will be based on the model of the Brisbane apartments. The apartments will provide more alternatives for young people who are facing the prospect of having to reside in aged care facilities. There is currently nothing else like the apartments in Australia and Youngcare hopes that these models will be adopted and successfully replicated through national policy and systems changes.

For more information about Youngcare visit their website at [www.youngcare.com.au](http://www.youngcare.com.au) there are more images of the apartments, peoples stories and updates on the progress of the new projects coming up.

## AA ACT

We had 7 couples all under 65 yrs of age with the carer still working full time. They were invited to a dinner we at the Premier Inn Belconnen. It was an opportunity to get together and keep socially engaged with other couples who are in similar situations.

Our feedback indicates it was a success and both carer and their partner got a lot out of the social support. We plan to make it more regular event. Hopefully this will be driven by the carers eventually. If there is another group of people compatible we will look to supporting them to do the same thing.

I am sorry we didn't take any photographs this time.

Kaye Teague  
Key Dementia Worker  
Alzheimer's Australia ACT

## AA NSW

AANSW has invited providers of YOD specific services to an inaugural meeting on Friday 27th November. This meeting will aim to develop a register of services and identify gaps; facilitate cross referral and discuss policy and advocacy issues in a collaborative environment.

RSVP to [mcole@alznsw.asn.au](mailto:mcole@alznsw.asn.au) or phone 02 8875 4682

## YOD in OZ

Over the last quarter I have been collating a list of Younger Onset Dementia Services that currently exist in Australia. May be in 10 years we'll reflect back and see how far we have advanced!!

As the document runs to 9 pages, it will be attached as a second document along with this newsletter. If you know of a service that should be included please ask them to write to me [sue.bromhead@alzheimers.org.au](mailto:sue.bromhead@alzheimers.org.au)

The following table has been collated from data in the Access Economics Report *'Keeping Dementia Front of*

*Mind: Incidence and Prevalence 2009 -2050'*.

Figures below represent base case capital city populations and BOS (balance of state i.e. outside capital city) prevalence projections for people with dementia aged 0-64.

Detailed findings for Australian Capital Territory cannot be presented due to a lack of data projections from the ABS. However the total number of persons with dementia in ACT is estimated at 2,917 in 2009 and 5,389 in 2020

Area	2009	2020
Australia (capital cities)	9,385	11,387
other	5,963	7,418
NSW (Sydney)	2,976	3,482
Balance of state	2001	2,408
QLD (Brisbane)	1,320	1,654
Balance of state	1,808	2,385
SA Adelaide	844	962
Balance of state	346	409
TAS Hobart	153	184
Balance of state	233	264
VIC Melbourne	2,648	3,257
Balance of state	1,095	1,304
WA Perth	1,127	1,459
Balance of state	422	576
NT Darwin	82	115
Balance of state	55	69
ACT	2,917	5,389

## AA WA

Alzheimers Australia WA Education Officer Linda Taylor recently delivered a workshop to volunteers, support workers, students, assistant co-ordinators and social workers who provide support services to clients with younger onset dementia in Western Australia.

The one-day workshop was conducted using the *2 Young 4 Dementia* resource developed by Alzheimer's Australia ACT with funding from the Department of Health and Ageing.

The group looked into the difficulties faced by a younger person when trying to gain a diagnosis of dementia, the impact on the person and others when they receive a diagnosis and the lack of appropriate services available in WA.

A few participants shared their experiences from their professional background that enabled the group to discuss relevant concerns and differences faced by service providers when supporting a younger person with dementia.

The participants were extremely interactive in looking for possible solutions for change that would benefit younger people with dementia living in WA.

An evaluation of the workshop by the participants provided positive and constructive feedback such as what they found useful and what should be included for future workshops.

The general consensus from participants was that although the DVDs in the package provided good insight, they were not of people living in WA.

Alzheimers Australia WA is hoping to obtain funding to develop a DVD resource specifically targeting issues affecting younger Western Australians living with dementia.

For free copies of the resource *2 Young 4 Dementia* contact [dementia@health.gov.au](mailto:dementia@health.gov.au)

## AAV

AAV has identified a Younger Onset Dementia Responsiveness Project as a key objective for AAV for 2009 and a small staff working group has been established to lead the project.

A Younger Onset Dementia Reference Group of 8 consumers chaired by Tony Walsh, a carer, is providing overall input and advice.

Key strategies are:

- Younger Onset Dementia Summit implementations (information dissemination)
- Younger Onset Dementia Registrar in Training position (Neuropsychiatry Unit Royal Melbourne Hospital)
- Younger Onset Dementia hospital service model enhancement (Royal Melbourne Hospital and Box Hill Hospital)
- E-resource funding and development of strategies for younger people living with dementia
- Education programs relating Younger Onset Dementia
- Enhancing Alzheimer's Australia Vic services

To date Younger Onset Dementia information has been distributed to all Divisions of General Practice across Victoria and other key stakeholders.

A **Petition** is being prepared to be presented to the Spring session of the Legislative Assembly and Legislative Council and members of the Younger Onset Dementia Reference Group will be meeting with their State and Federal MPs to promote awareness of the condition.

**The Younger Onset Dementia Registrar** commences at the Royal Melbourne Hospital in August and Alzheimer's Australia Vic is working with the hospital team on an orientation and education program.

Alzheimer's Australia Vic has translated the **strategies for people with younger onset dementia** into 20 draft tip sheets which have been distributed for comment by consumers through all States and Territories.

**Twenty Five Councils** have been contacted to identify if any services offered to younger people with dementia.

**Dementia specific carer groups** across Victoria have been identified to source any younger onset dementia contacts/services.

Many months of work came to fruition on October 20th when ADAHPS was able to stage its first Carers Day event. The recognition of the support of carers expressed at the National Consumer Summit on Younger Onset Dementia in February this year added impetus to our planning of this day.

Being an organisation managing many young people with HIV/AIDS related dementia, it is often difficult to effectively support the carers of our clients.

This day was planned to support carers of HIV positive people by offering training, information and entertainment as one way of recognising their untiring and often unrecognised efforts. By making a range of respite care services available to

the clients and transport available to the carers assisted greatly in the success of the day.

A peak of 24 carers and several service providers attended a day for carers of People Living with HIV/AIDS and HIV positive people with caring responsibilities, at the Tree of Hope, Surry Hills, NSW on National Carers Day. The activities of the day combined information, relaxation and pampering activities aimed at meeting the needs of the diverse group of carers in attendance.

Peter Canavan from NAPWA (the peak body representing people with HIV/AIDS) presented an informative session on HIV treatments which was received extremely well by those in attendance and a session

facilitated by staff from South-Eastern Sydney Commonwealth Respite and Carelink Centre was greatly appreciated by carers and workers who attended.

Overall the event represented a very successful day involving enthusiasm and cooperation from a range of services working with people living with HIV/AIDS and carers. Formal and informal feedback from carers identified high levels of satisfaction with every aspect of the day, from the information sessions to taking part in relaxing activities and particularly enjoyed the opportunity to be recognised as carers.

Thanks Geoff for this article.



### 1. MANA (Memory Appointment and Navigation Agent)

Alzheimer's Australia SA is proud to be associated with the MANA project. MANA is a form of computerised artificial intelligence designed by researchers at the Flinders University of South Australia. The purpose of MANA is to help make life easier for people with dementia by using a computer system that reminds them about their daily appointments and activities. MANA consists of a computer generated face, or talking head, which can talk, recognise faces and turn itself on when someone enters a room. Appointment times, important dates and reminders are entered into the system by carers via the internet and this may include information about medication reminders.

People with younger onset dementia are very interested in MANA to help assist them with the many and commitments specifically associated with their younger age. This includes managing an active household around working partners and children's extra curricular activities, as well as remembering everyday appointments and functions such as school meetings, gym sessions, essential shopping or meeting up with friends.

People with younger onset dementia are participating in a research trial for this project.

### 2. New Alzheimer's Australia Update Sheet – BRAIN DONATION

In order to understand brain diseases, researchers need access to brain tissue from people generous enough to donate their brain after death. This process is organised through brain donor programs which register participants and collect medical details to assist with research into dementia that will improve our understanding of the underlying

mechanisms and lead to better treatments. In Australia, the brain tissues if stored in 'brain banks' which coordinate its collection, storage and distribution for research.

This update sheet provides information to help you make a decision about donating your brain and how to go about it. [http://www.alzheimers.org.au/upload/Update\\_Sheet\\_17\\_%20Brain\\_donation.pdf](http://www.alzheimers.org.au/upload/Update_Sheet_17_%20Brain_donation.pdf)

More detailed information can be obtained from the Brain Donor Coordinators listed on the update sheet.



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