IN THE SPOTLIGHT
YOUNGER ONSET DEMENTIA FORUM REPORT 2016
**Background**

Younger onset dementia (YOD) refers to a diagnosis of dementia before the age of 65. People may be diagnosed as young as in their 30s and experience unique and profound impacts on their everyday functioning, relationships and livelihood.

In 2013, Alzheimer’s Australia Tasmania launched a national program aimed at providing individualised support, information and advice to people living with YOD. The Younger Onset Dementia Key Worker Program is now in its third year in Tasmania and continues to go from strength to strength.

A key component of the Key Worker Program is to promote awareness and understanding of YOD in the community. This includes the dissemination of information to and collaboration with community services, to increase the number of dementia friendly services available to people living with YOD.

The program focuses on gathering the experiences of community members (e.g., carers, service providers and people living with YOD) in order to identify the needs and successful support stories of people, impacted by YOD. It was in this vain that the, In the Spotlight: Younger Onset Dementia Forums were held in Hobart and Launceston in August 2016.

The forums incorporated information on:

- the causes, symptoms and impacts of YOD
- the impact of dementia on those diagnosed with YOD
- the experience of caring for someone living with YOD
- the Younger Onset Dementia Key Worker Program and Buddy Program
- a workshop on the key issues of those impacted by YOD and how we can address gaps in services to meet those needs.

---

**Key Speakers**

**Dr Wendy Kelso**
Neuropsychologist
The Royal Melbourne Hospital, Neurological Unit

**Connie Alomes**
YOD Key Worker
YOD Key Worker Program Team Leader

**Alex Good**
Counsellor
YOD Key Worker
Buddy Program Coordinator

**David Guinane**
Past-carer of his wife Andrea

**Jennifer Quill**
YOD Key Worker Program Participant

**John Hiller**
YOD Key Worker Program Participant

**Graham Wright**
YOD Key Worker Program Participant

*Report written by Alex Good*
Summary

The forums were well attended by professionals and community members alike. More than 45 people attended the forum held in Hobart and in excess of 35 people came to join the discussion in Launceston.

The audience included carers, people living with younger onset dementia, friends and family members. Professionals from multiple organisations and services also attended including nurses, support workers, residential care workers, case managers, respite coordinators, support service managers and allied health professionals.

The forums have provided the Younger Onset Dementia Key Worker Program with new directions to focus on going into the future. The most crucial areas of need are identified as:

1. Age and needs appropriate accommodation for people living with YOD.
2. Education and awareness of YOD in the community.
3. The provision of quality social support and carer support services which include the engagement of volunteers.
4. Preparation for the National Disability Insurance Scheme (NDIS) roll out in Tasmania.

Graham Wright - Since being diagnosed, I am now more outgoing and outspoken than I ever was before. This has been a positive change for me. There is a lot of life to live after a diagnosis.

David Guinane - There needs to be care for the carer. This involves the gradual inclusion of a team of people that you choose and trust to help you look after someone living with younger onset dementia. They can help you through multiple transition points.
Workshop

The workshop was designed to create collaboration between consumers and services providers about the needs of people living with younger onset dementia. It was envisioned that by increasing the understanding of YOD and facilitation of group discussion, solutions to gaps in services and unmet needs could be identified.

Workshop Questions

1. What has been useful/supportive for you so far (in relation to YOD)?
2. What are the gaps in services? What needs are not being filled?
3. What are some solutions to meet these unmet needs?

Things that are useful/supportive

- Forums which provide educational opportunities to increase community understanding and awareness of YOD, its impacts and the needs of people impacted by the disease.
- Listening to the personal stories of those who have been diagnosed with YOD.
- Having a key worker to provide information, advice and support to people impacted by YOD, throughout the progression of the disease and duration of their needs.
- Awareness raising in the community about YOD and its impacts.
- Awareness of Alzheimer’s Australia’s support services in the community and for professionals.
- Training for staff in community and residential care facilities regarding the early symptoms and signs of dementia and behaviour management strategies.
- The use of media and social media to increase community awareness of YOD e.g., the movie Still Alice.
- The availability of free online learning courses about dementia (e.g., Massive Open Online Courses) which provide understanding about dementia in “plain English” instead of professional jargon.
- Having a timely diagnosis by qualified specialists in Younger Onset Dementia.
- Information and support groups to know that you are not alone in having the disease or in caring for someone with YOD.
- Information about how to maintain good brain health.
- Age-appropriate, enjoyable social activities and outings that provide variety and a break from routine.
Identified Gaps in Services

- The need for age-appropriate social support options which are sensitive to the needs of people with YOD in the community.
- Services which reach rural and remote areas.
- Education to family, service providers and school-age children needs to be increased.
- Education of general practitioners and nurses about YOD and support services available for those impacted by YOD.
- A need for education of emergency services such as police, ambulance and fire services about YOD.
- A lack of appropriate accommodation for people who need full-time care – people with YOD often end up living in residential care facilities at young ages.
- Financial support services for those impacted by YOD.
- Training for specialised carers e.g., support workers.
- A lack of the use of the arts in dementia care in the community and residential care facilities.
- Support systems to prevent early retirement and/or to replace work with something that provides purpose and structure (e.g., volunteering).
- Lack of continuity of care, of support workers in the home – assigned staff changes from week to week which may cause confusion and distress for a person living with YOD and their carer.
- Lack of sensory activities for people with YOD in residential care facilities.
- Support and resources for young people caring for someone living with YOD.
- Language and cultural difficulties for migrant families. There may be trust issues and difficulty understanding written information provided.

Recommendations for Solutions

- Community visits by volunteers to people living alone with dementia.
- Group homes or models of accommodation for younger people which involve a continuity of care for all stages of disease progression.
- Sensory rooms in organisations and residential care facilities to help them to become more dementia friendly.
- Consumer directed care (such as the NDIS) and individualised support plans.
- Positive media attention regarding YOD and the support services that are available.
- A guide map or flow chat to help carers navigate services.
- Development of a school program to teach about dementia and YOD at an early age to change social stigmas and improve support for children at school who may be impacted by dementia in their family.
- Collaborations with diversional therapists and/or art therapists to deliver music, dance and art programs for people living with YOD.
• Volunteering opportunities for people living with YOD when they can no longer work.
• The use of social media to support children and young people who are caring for someone living with YOD.
• A national awareness program about YOD (e.g., TV advertisements and radio announcements).
• Development of YOD help sheets in multiple languages and those which are culturally relevant for multiple minority groups in Tasmania.

Current programs, innovations and directions supported by the YOD Key Worker Program at Alzheimer’s Australia Tasmania

Younger Onset Dementia Social Group (Hobart)

Buddy Program
• Befriending and volunteering program for people living with YOD.
• Currently operating in the south with intended expansion to the north.
• Volunteers are matched with people based on their interest, skills, hobbies, values and culture.
• Buddies [https://www.youtube.com/watch?v=Ck1LAzrHtEA&feature=share](https://www.youtube.com/watch?v=Ck1LAzrHtEA&feature=share)

Artist in Residence Program

Men’s Carer Support Group
• Peer support for men caring for people living with dementia.
• The program is offered to people of all ages.

Care Mentor Program
• Suggested by David Guinane.
• Similar to the Buddy Program but for carers.
• Past carers volunteer to provide weekly/fortnightly visits to current carers to offer emotional support, advice and information from their lived experience of caring for a person with YOD.
• The program will be offered to people of all ages.
• Expected to be trialled early 2017.

Stretching and Walking Group
• Collaboration with a community service provider and exercise physiologist.
• The program will be offered to people of all ages.
• Likely to begin early 2017.

**Group Cognitive Stimulation for people living with YOD**

**Individual Cognitive Stimulation for people living with YOD**

• Sessions run by volunteers with a person living with YOD.
• Once or twice a week.
• The program will be offered to people of all ages.
• The program will be trialled in 2017.

**Capacity building**

• A current focus on education and awareness regarding YOD in local emergency and transport services (e.g., metro, taxis, police, ambulance and fire services.
• Ongoing capacity building in disability and special needs organisations.
• Dissemination of YOD information to general practitioner surgeries and community organisations in rural and remote areas (utilising innovative techniques, where possible).

**Age-appropriate accommodation**

• Establishing a relationship with a residential care provider who is looking to expand their services.
• The model of care would be based on that which is provided at the Old Vicarage, through Alzheimer’s Australia Tasmania.
• This respite centre would most likely be group home style accommodation.
• The facility would provide a continuity of care throughout the progression of a person’s illness and changes in their care needs.

**Social media**

• Facebook and Instagram YOD awareness and fundraising campaign (likely to begin in November 2016).
• A Young Carer Connect Tasmania Facebook group to help support young people caring for those living with YOD.

**Preparation for the NDIS**

• Consumer focus groups to be held in 2017 regarding the availability and effectiveness of current services being offered through Alzheimer’s Australia Tasmania and in the community.
• This information will inform the services which will be provided under the NDIS fee for service, consumer directed care, through the YOD Key Worker Program.
• Direction from Alzheimer’s Australia’s national office regarding best practice strategies to ensure the Key Worker program provides quality, consumer focused services.

Information and Support

Are you, or someone you know, experiencing the impacts of younger onset dementia? Contact one of the services below for more information, advice and support.

National Dementia Helpline 1800 100 500

Alzheimer’s Australia Tasmania - Younger Onset Dementia Key worker Program

Hobart: (03) 6279 1100
Launceston: (03) 6325 4608
Email: tas.admin@alzheimers.org.au

24 Hour information and advice: fightdementia.org.au