# Final Report: Literature Review and Needs and Feasibility Assessment of Services for People with Younger Onset Dementia

## Executive summary

**July 2014**

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## Executive summary

This report documents the key findings of the major activities associated with the Literature Review and Needs and Feasibility Assessment of Services for People with Younger Onset Dementia project funded by the Commonwealth Government. The project was conducted between July 2013 and January 2014, and comprised two key elements: an international literature review, and a needs and feasibility assessment of services for people with younger onset dementia.

This report brings together findings from a comprehensive review of the international literature, and those of a national consultation process that included face to face meetings, an online survey and email and telephone discussions  with people with younger onset dementia, carers, service providers, researchers, policy and program advisers. In summary, we:

- reviewed over 300 journal articles, reports, presentations and websites out of 425 identified from the search strategy;

- interviewed 215 people, including 33 people with dementia and carers, 54 from special interest groups; 77 service providers; 19 peak body representatives; 11 researchers and 21 policy and program advisers (state and territory government representatives); and

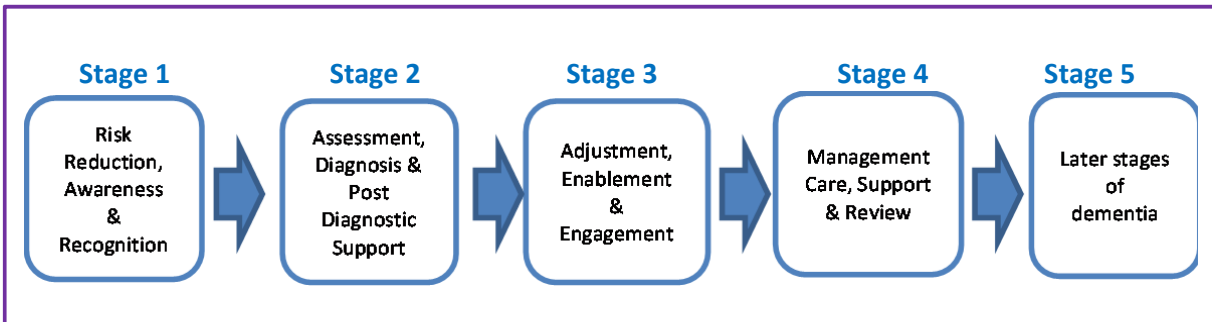- received 29 completed survey responses, out of a total of 97 received.

In recognition of the relatively low level of younger onset dementia specific services that currently exist, the project sought to identify models from other sectors that may be transferable to meet the needs of people at this life stage. Our approach from the outset was to assign a broad definition of 'younger onset dementia' to ensure we captured the more well-known diagnostic groups e.g. Alzheimer's Disease, fronto-temporal dementia, as well as those who may have developed a dementia as a secondary condition associated with another primary diagnosis e.g. HIV/AIDS, Parkinson's disease, alcohol or drug abuse etc. We also considered the different contextual factors associated with dementia, such as living arrangements, and the social, economic and environmental factors that enable and support people with younger onset dementia.

## Conceptual approach

Traditional dementia service models do not sufficiently take into account the life stage at which symptoms of early onset dementia emerge, and therefore are not well equipped to support people with younger onset dementia. Additional supports are required to maximise people's capacities for participation in the activities that generally occur at this time of life, for example, paid employment, family responsibilities, and social and community activities.
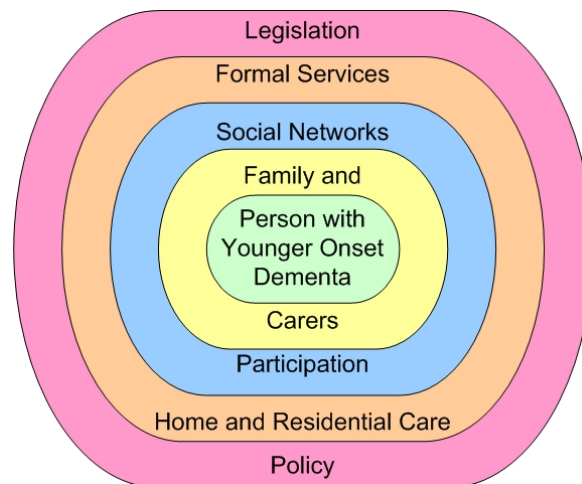
We conceptualised the project across two dimensions: longitudinally as well as systemically. In the first instance we considered the 'dementia journey', describing the different stages of the lived experience of dementia and identifying the types of supports and services that may be required. This is depicted in the following diagram:

**Five Stages of Younger Onset Dementia**

| Stage 1 | | Stage 2 | | Stage 3 | | Stage 4 | | Stage 5 |
|---|---|---|---|---|---|---|---|---|
| Risk Reduction, Awareness & Recognition | → | Assessment, Diagnosis & Post Diagnostic Support | → | Adjustment, Enablement & Engagement | → | Management Care, Support & Review | → | Later stages of dementia |

We also took a systems approach to understanding the context within which people with younger onset dementia live and the groups that are influenced by, and have influence on them. This is depicted in the following diagram:

**Circles of impact of younger onset dementia**

Legislation
Formal Services
Social Networks
Family and
Person with Younger Onset Dementa
Carers
Participation
Home and Residential Care
Policy

**Findings**

The service delivery models that offer the strongest evidence for good practice are those that address all elements of the 'circles of impact', starting with a focus on the person with younger onset dementia and working outwards to facilitate the enablers within the surrounding spheres of influence. This requires different emphases of effort across the five stages of dementia support.

There was strong alignment of the major issues and practices raised in both elements of the project. In one sense this was a very positive outcome – there seems to be a number of service models that are exhibiting the good practices identified in the literature, including some 'cutting edge' examples; however, the systemic deficits identified in the literature appear to be equally evident in the Australian context.

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The literature provided revealed a number of Key Service Attributes that facilitate good outcomes for people with younger onset dementia, which were subsequently tested within the context of the Needs Assessment. In the main, there was strong alignment with the attributes identified in the literature; the final Key Service Attributes includes a small number of refinements accordingly. The final list of attributes are summarised in the box below.

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**Younger onset dementia service attributes**

### Individualised model of service

- Listen to people with younger onset dementia and their carers
- Individualised service planning / person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Recognise and respond to the different diagnostic groups and their needs

### Staff attributes

- Appropriate skills and attitude
- Holistic approach to care and support
- Enabling and consumer centred approach
- Care co-ordination / case management skills
- Effective communication and interpersonal skills
- Flexibility
- Capacity building

### Organisational attributes

- Integrated specialist diagnostic and ongoing symptom management services
- Organisational change capabilities
- Regionally based, integrated and coordinated interagency partnerships and pathways
- Timely service provision
- Dementia friendly environments
- Cost effective and flexible fees policy
- Cultural Safety
- Cater for needs of people in rural and remote communities
- Individualised service planning / person centred approach / continuity
- Respect and consideration for staff and clients
- Manage risk effectively
- Effective exit policies: re suspension and withdrawal of services.

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These attributes have been used to make a judgement about the current services available, as well as service models from other sectors that have the potential to be adapted to meet the needs of people with younger onset dementia.

The majority of services used by people with younger onset dementia are those that have emerged from within an aged care context, with a smaller number being delivered by the disability and health sectors. Most of the well-targeted and responsive models of support are those that use a combination of disability and aged care program funding, applied in a flexible manner. For example, some organisations pool respite funding with transport services to create flexible peer group options that included outings as well as centre-based activities.

The Feasibility Assessment (Section 5) contains details of services that meet, or have the potential to meet, Younger Onset Dementia Key Service Attributes. Despite our broad search strategy, both in terms of the literature and the consultation process, the overall number of models in practice are quite small. Overall, the service types include modifications of respite and peer support groups, health and fitness initiatives, employment and vocational options, inter-sectoral partnerships, diagnostic and health pathways, accommodation and residential aged care models. Examples of some of the innovative and potential service models include:

- **Gardening on the Tram Tracks:** A collaboration between LifeCare's Norman House and the local Council of Unley, this is an eight week program in which men with younger onset dementia are supported and supervised by a council worker and a volunteer to beautify the nearby Black Forest Tram Stop gardens. As well as providing the men with a meaningful and rewarding activity it also provides an opportunity for them to speak to commuters about the issues relating to younger onset dementia.

- **Safe2Walk:** The Safe2Walk system was developed to support people with dementia being able to choose the timing and duration of their walking activities, as opposed to a traditional service delivery which dictates to the person depending on the availability of the worker and the resources available to pay for that service. The program uses a small mobile phone like device with a Global Positioning System (GPS) function that can locate a person to within 10 metres. It has one large button which, when pressed, calls and connects with one of three pre-programmed numbers; it also acts as an SOS as when pressed the location data is sent to the carer's mobile phone via SMS, enabling carers to log on to a secure website to locate the person. Pilot studies conducted by Alzheimer's Australia WA and Vic found positive outcomes for many of those who participated. It is possible that people with younger onset dementia may be more likely to benefit from this type of assistive technology, given the increased likelihood of their familiarity with using mobile phones, GPS technology and computer-based programs.

- **Circles of Support:** This is an informal support network whereby a group of people form a network or circle of support, to provide support to a person and their family, work alongside the formal service provider and agree to 'make time to look out' for the

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person. Currently used within a number of disability services nationally, including Western Australia by Planned Individual Networks (PIN), Victoria by UnitingCare Community Options (UCCO) and in NSW by Down Syndrome NSW in partnership with UnitingCare Disability Services as part of the Independent Living Support Initiative (ILSI).

- **BANCPASS:** A collaboration between Baptcare Northern, Northwest Aged Care Assessment Service (ACAS) and the Neuropsychiatry Unit (Royal Melbourne Hospital North West Adult Mental Health), BANCPASS is designed to support people with younger onset dementia and their families navigate the health system and initiate service provision from the point of diagnosis of younger onset dementia through to community support and care.

- **The Home Occupiers Mutual Enterprise (HOME):** A proposed 'intentional community' in the Sydney's Inner West, where 'people with a disability and people without a disability live in a collaborative and supportive way'. The HOME group is currently seeking finance for a purpose built apartment block of approximately 40 dwellings, of which 15% would be allocated for people with disabilities who have significant support needs which would be met by a partner provider (in this case, UnitingCare Supported Living).

## Key Messages for ongoing service development

A number of recurring themes emerged across all aspects of this project, and provide a range of lessons for those involved in developing and delivering health, care and support services for people with younger onset dementia, their families and carers:

### Focus on the individual
Good practice models are those that have a sound understanding of who the person is, including their personal attributes, goals and interests; includes the person in service planning; provides holistic and ongoing assessment of need; is flexible in terms of service delivery; is accessible and affordable; and, works alongside the person in a respectful and considerate manner.

### Timely and accurate diagnosis
Good practice models include a broad community education and awareness activities; targeted information for primary health care professionals; access to multidisciplinary teams that can provide holistic assessment, treatment and management options.

### Appropriate services
Good practice models include services which are individually tailored to the needs and interests of the person with dementia, their carer and family; are underpinned with an enabling and well-being approach to service provision; provide ongoing assessment to monitor changes and adapt services accordingly; are accessible in terms of location, transport and cost; are flexible and able to deal with change; have appropriately skilled staff who are supported by a sound business framework that includes ongoing education and risk management policies; and, are culturally appropriate and accommodating of special needs groups.

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*Integrated care*

Good practice models are those that are based on an understanding of the individual's capacities and preferences and the needs of their immediate support network; have a capacity building approach that draws on personal, social and community networks as well as formal services; are flexible regarding their service provision according to changing needs of the client; have the appropriate skills, education and attitude; and are networked into specialist services and able to draw on expertise as needed.

*Continuity of care*

Good practice models are those that have an identified 'case manager' or 'care coordinator' who fully understands the needs and aspirations of the person with dementia and those of their immediate care support network; can work across different services and sectors to build capacity within support and care services, as well as the person's social and community networks; facilitates the involvement of carers and families across the continuum of the dementia journey, including palliative care and death, for as long as is desired.

*Service specific issues – respite care*

Good practice models are those that, in addition to the attributes identified above, take into account the specific needs of both the person with dementia as well as the carer; provide meaningful activities that cater for the interests of the person with dementia; are offered in 'blocks' of sufficient time to enable carers to engage in their desired activities.

*Service specific issues – peer support*

Good practice models are those that are those that are designed around the needs of carers as well as people with dementia, in terms of timing, and the nature of activities; are self-directed as much as possible by group members; are accessible in terms of transport and cost; offer opportunities for meaningful engagement amongst one another, and with their local community; and do not enforce arbitrary age thresholds of programs which disadvantage clients.

*Policy and program issues*

Good policy design is that which does not arbitrarily require people with a diagnosis of dementia to cease particular activities; includes provision for targeted assessment of attributes and capacity pertaining to the relevant activities, e.g. driving, paid employment; acknowledges the interdependence of people with dementia and their carers when considering program eligibility and funding; and, facilitates cross-sector and inter-jurisdictional approaches to supporting people with dual diagnoses and complex health, care and accommodation needs.

## Conclusion and recommendations

It is clear that the current service system is not well placed to meet the needs of people with younger onset dementia to remain living and participating in the community. In part, the ability to develop responsive policies and service models has been hindered by a lack of evidence regarding prevalence, presentation and appropriate management strategies;

consequently, the default service option has been the aged care system which has dependency and frailty as its operating paradigms. This report includes a large number of personal stories and experiences that reinforce the need for a new paradigm in terms of the way services are funded, developed and delivered. Paradoxically, this context has also provided the stimulus for the emergence of a number of new and innovative models of health, care, support and employment opportunities that more appropriately take into account the life stage, circumstances and expectations of people with younger onset dementia.

The Key Service Attributes and the key messages arising from this project are, on the whole, not new; many have been present within disability services sector for some time. That sector is underpinned by a philosophy of enablement and engagement, which in turn requires an individualised approach to support and service delivery. A number of the new and innovative models described in the feasibility assessment are drawn from, either directly or in part, developments that have been emerging from within disability services.

While these new initiatives hold promise, their ongoing delivery remains precarious; there are uncertainties around future funding and relevance of the models, particularly in light of the implementation of the National Disability Insurance Scheme (NDIS). Many of the more innovative models are driven by the commitment of a few individuals within an organisation, and therefore subject to the vagaries of staff and management changes. The major barriers to implementing good practice services arise from a mix of personal, cultural, organisational and attitudinal factors. Addressing these barriers will require ongoing commitment and collaboration across and between: individuals and their families and support networks; the formal health and community care services; and, the broader political, jurisdictional and community levels.

## Recommendations

In order to address the critical issues identified in this report, and encourage the continuation of the positive developments that have occurred within the research, service delivery and policy sectors, the following recommendations are made:

1. Increase community awareness of younger onset dementia to encourage greater awareness of the continuing contribution that people can make, e.g., the 'Don't Dis my Ability campaign'.
2. Develop an inter-jurisdictional working group to address the issues identified in the report, in particular: development of integrated assessment, diagnostic and care pathways; improved employment options; and, removal of local policies currently being employed that restrict access to appropriate services in a timely manner.
3. Convene a panel of cross-sector representatives to further develop service delivery models identified in the Feasibility Assessment.
4. Work with relevant health and medical colleges to identify opportunities to increase awareness and improve access to specialist assessment, diagnostic and ongoing management of younger onset dementia.

5. Enhance the opportunity for people with younger onset dementia to be involved in the design, development and delivery of services and policies that affect them through the development of appropriate resources and/or financial incentives.

6. Make this Final Report, and the Literature Review on Younger Onset Dementia, publicly available to encourage the continued development of research, service and policy initiatives that will benefit people with younger onset dementia.

*The complete report can be found at:*
http://ahsri.uow.edu.au/chsd/projects/yod/index.html