



# **SERVICE AND SUPPORT REQUIREMENTS OF PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR FAMILIES FINAL REPORT, AUGUST, 2012**

**FOR AGEING, DISABILITY AND HOME CARE  
DEPARTMENT OF FAMILY AND COMMUNITY SERVICES, NSW**

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Thank you to the research team, the Steering Committee and participants for their advice on the research.

Alzheimer's Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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## **ABBREVIATIONS**

ACAT	Aged Care Assessment Team
ADHC	Ageing, Disability and Home Care
ADL	Activity of Daily Living
AlzNSW	Alzheimer's Australia NSW
CACP	Community Aged Care Package
CALD	Culturally and Linguistically Diverse
CNC	Clinical Nurse Consultant
COAG	Council of Australian Governments
COTA	Council On The Ageing
DAS	Dementia Advisory Service
DBMAS	Dementia Behaviour Management Advisory Service
DCRC	Dementia Collaborative Research Centre
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
FTD	Fronto Temporal Dementia
GLBTI	Gay Lesbian Bisexual Transgender Intersex
HACC	Home And Community Care
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
LHD	Local Health District
LWML	Living With Memory Loss
GP	General Practitioner
MS	Multiple Sclerosis
NRCP	National Respite for Carers Program
NSW	New South Wales
RACF	Residential Aged Care Facility
RACPG	Royal Australian College of General Practitioners
SPRC	Social Policy Research Centre
SPSS	Statistics Package for Social Sciences
UK	United Kingdom
UNSW	University of New South Wales
YOD	Younger Onset Dementia

## **CONTENTS**

<b>1</b>	<b>Executive Summary</b>	<b>6</b>
<b>2</b>	<b>Introduction</b>	<b>12</b>
2.1	What is younger onset dementia?	12
2.2	Research, policy and service background	13
2.3	Research scope and approach	14
<b>3</b>	<b>Methodology</b>	<b>15</b>
3.1	Research design	15
3.2	Research stages and methods	15
3.3	Participants	18
<b>4</b>	<b>Identifying younger onset dementia</b>	<b>21</b>
4.1	Recognition of symptoms	21
4.2	Diagnosis process	22
4.3	Diagnostic practitioners	23
4.4	Diagnosis for specific groups	25
4.5	Effect of having a diagnosis	26
4.6	Understanding and stigma	27
<b>5</b>	<b>Experience of support services</b>	<b>28</b>
5.1	Early intervention	28
5.2	Community participation and social engagement	33
5.3	Family and relationship support	39
5.4	Informal support	42
5.5	Respite support	43
5.6	Employment, financial and legal support	47
5.7	Services for people from CALD backgrounds	49
5.8	Services for people with other disability and health conditions	49
<b>6</b>	<b>Support in the later stages of younger onset dementia</b>	<b>51</b>
6.1	Access to ACAT assessment and aged care packages	51
6.2	Residential respite	53
6.3	Residential care	55
6.4	Palliative care options	58
<b>7</b>	<b>Principles to guide the provision of services and support</b>	<b>58</b>

<b>8</b>	<b>Policy implications</b>	<b>61</b>
8.1	Service and funding approaches	61
8.2	Integrated service delivery	62
8.3	Collaboration and capacity building	63
8.4	Workforce skills	64
8.5	Evidence based practice	65
<b>9</b>	<b>Strategies to address key areas of need</b>	<b>66</b>
9.1	Timely diagnosis	66
9.2	Diagnosis and referral	66
9.3	Early intervention	67
9.4	Support for transition points	68
9.5	Behaviour management	69
9.6	Supporting people to remain at home	70
9.7	People with additional needs	71
	<b>Appendix 1: Report research instruments</b>	<b>75</b>
	<b>Appendix 2: Report endnotes</b>	<b>107</b>
	<b>Appendix 3: Report references</b>	<b>108</b>
	<b>Appendix 4: Report literature review</b>	<b>110</b>
	<b>Tables and figures:</b>	
T 3.1:	Sample size	18
T 4.1:	Source of diagnosis	23
T 5.1:	Time first used services for person with younger onset dementia	29
T 5.2:	Time first used family support services	29
T 5.3:	Focus of services for people with younger onset dementia and their families	40
T 5.4:	Family benefit from one to one respite, personal care or domestic assistance	44
T 6.1:	Family members and carers would benefit from residential respite	53
T 6.2:	Person with younger onset dementia would benefit from residential respite	53
T 6.3:	Benefit of residential care for the person with younger onset dementia	55
T 6.4:	Benefit of residential care for the family member/carer	55
F 7:	Principles for best practice in person-centred approaches for people with younger-onset dementia and their families	60
F 9:	Summary of vision, principles and implications for service system development	73



## I EXECUTIVE SUMMARY

### BACKGROUND

In 2011, Alzheimer's Australia NSW (AlzNSW) was engaged by Ageing, Disability and Home Care (ADHC) to research the service and support requirements of people with younger onset dementia and their families in New South Wales. AlzNSW partnered with the Social Policy Research Centre (SPRC) and UnitingCare Ageing to conduct the research. This report outlines the methods, findings and policy implications of the research.

Dementia is a major cause of disability amongst older people and some younger people aged under 65 years, causing 'progressive change and degeneration in cognitive mental functions, such as memory, language, rational thinking and social skills, as well as behaviour, emotion and personality' (Mocellin, Scholes and Velakoulis, 2008:1). Younger onset dementia is defined as dementia which occurs before the age of 65 years and under 50 years for Aboriginal people.

The social context of people with younger onset dementia, their family and carers differs compared to older people with dementia. The consequences of having dementia at a younger age may mean that they are still in paid employment, raising or financially responsible for a family and physically strong and healthy while developing and living with dementia<sup>1</sup>. For family members/carers, younger onset dementia can be associated with additional stress for those who are still working, cannot find services appropriate for younger age groups (McLean, 2009), must change retirement and travel plans and have multiple caring responsibilities (AlzNSW, 2010).

These considerations mean that the support and service needs for younger people, their family and carers can be different to people who develop dementia at an older age. Service providers need to consider the different needs associated with better physical health, earlier family, work and financial responsibilities and other life stage plans than older people with dementia services in the aged care context. The aim of this research is therefore to explore these different service and support requirements.

Younger onset dementia has received increased attention in Australian policy and service provision in recent years. Historically, service and support requirements of people with younger onset dementia and their families and carers were addressed through generalist dementia services, which had limited capacity to provide for individualised needs or the specificity of having dementia at a younger stage in the life course.

More recently, there has also been reflection of the policy implications of having dementia at a younger stage in the life course within broader dementia and disability policies and frameworks being developed and implemented. Australian states and territories have been working towards developments in dementia services. The *NSW Dementia Services Framework 2010-2015* sets the direction for improving the quality of life for people with dementia and their family members/carers in NSW. It is underpinned by principles that emphasise quality dementia care and is contingent on being responsive to the needs and experiences of people with dementia, carers and families. Key principles include timeliness and choice between services, as well as detailed consideration of individuals, families and communities in determining approaches to care for people with dementia. Younger onset dementia is identified as a specific population group within the Framework. Dementia support spans the health, aged care and disability sectors, and services for people with younger onset dementia and their family members/carers are also being addressed within the context of developments in the disability sector. The NSW government's responsibility for disability support, summarised in *Stronger Together II*, emphasises person-centred, individualised approaches and funding for people aged under 65 years.

## **RESEARCH SCOPE AND METHODS**

The research examines:

- Good practice community based service models reported in the literature that are both nationally and internationally applicable for people with younger onset dementia and their carers
- The barriers to timely diagnosis of younger onset dementia
- The experience of people with younger onset dementia and their families in accessing the service system in NSW
- The service and social support requirements of people with younger onset dementia and their family members/carers
- Appropriate service models for early intervention community support services, accommodation and respite, including development of innovative flexible models to assist providers to increase access to services and achieve greater effectiveness and efficiency in the service system
- Service models to facilitate quality of life, community living and minimisation of risk of premature entry to residential aged care.

The report distinguishes between formal services and informal support. Formal services include funded medical services, assessments and programs, such as respite, day programs, support groups or accommodation services. Informal support includes assistance from family, carers, neighbours or friends, community groups and volunteers. Informal support often includes people who may have been important in people's lives prior to the onset of dementia, and continue to be a source of assistance after onset.

The research included a literature review; qualitative data from roundtables, in-depth interviews with people with younger onset dementia, family members/carers and service providers; and questionnaires with people with younger onset dementia and family members/carers. Each method built on findings from earlier data collection. The data collection included a total of 170 contributions across the roundtables, interviews and surveys (over 150 participants, some contributing through more than one method). Participants in the research were people with younger onset dementia and their family members/carers, as well as service providers with people with younger onset dementia within their services.

The research also included formative advice from a Steering Committee, including service providers, policy representatives and people with younger onset dementia and family members. Including people with younger onset dementia and family members/carers in roundtables and on the Steering Committee was an opportunity to include their advice in the formative stages of the research.

Findings about experiences of people with younger onset dementia, their family and carers are in three parts: identifying younger onset dementia, experience of support services and services in the later stages of dementia. The implications of these findings are analysed in the last part of the report.

## **IDENTIFYING YOUNGER ONSET DEMENTIA**

The findings discuss their experiences identifying that they have younger onset dementia, including the early recognition of symptoms, experiences with diagnostic practitioners and the poor understanding and the stigma surrounding younger onset dementia. Key findings about identifying younger onset dementia include:

- Misrecognition of symptoms and lengthy diagnosis process
- Poor delivery of diagnosis and information about dementia
- Poor follow-up appointments and referrals to support services
- Link between acceptance of diagnosis and accessing support
- Poor understanding and stigma surrounding younger onset dementia.

## **EXPERIENCE OF SUPPORT SERVICES**

The findings explore the support services available in the community to assist people with younger onset dementia, family and carers to continue to live at home and participate in family and community life. The support services are grouped into early intervention, community participation and social engagement, family and relationship support, informal support, respite support, employment and financial support, services for people with Culturally and Linguistically Diverse (CALD) backgrounds and services for people with other disability and health conditions.

### **EARLY INTERVENTION KEY FINDINGS**

- The immediate impact of diagnosis is significant for both people with younger onset dementia and family members/carers
- People with younger onset dementia and their families/carers need for timely information and resourcing about dementia and what lies ahead
- People with younger onset dementia and their families/carers need emotional support, education and tips on daily functional support
- Non-acceptance of the diagnosis can be a barrier to support services

### **COMMUNITY PARTICIPATION AND SOCIAL ENGAGEMENT KEY FINDINGS**

- Cost and transport can be barriers to community activities
- People with younger onset dementia want to feel valued, have stimulation, worthwhile occupation and physical activity
- Social connections in the community with friends and family is important for the person with younger onset dementia
- Activities that are meaningful and person-centred meet the needs of people with younger onset dementia
- Changes in verbal communication and behaviours of dementia can be a barrier to participation for the person with younger onset dementia

### **FAMILY AND RELATIONSHIP SUPPORT KEY FINDINGS**

- Family members and carers' health is often good at the time of diagnoses, but the stress of caring can lead to a need for social and emotional support
- Marriage difficulty or breakdown due to changes and behaviours of dementia
- Families/carers need to manage financial and emotional stress
- Difficulty for school age children who are living with a parent with younger onset dementia
- Support for young people with a parent with younger onset dementia
- Multiple interdependent care roles with partner, children and parents

### **INFORMAL SUPPORT KEY FINDINGS**

- People with younger onset dementia often have active social lives with broad networks of friends and neighbours they can draw on for support
- Some CALD communities can have strong trusting relationships with community leaders
- Strong informal support networks can support ongoing participation in social and community life for people with younger onset dementia



### **RESPIRE SUPPORT KEY FINDINGS**

- Some working carers need respite to continue employment and take time out
- Trained workers and suitable activities are necessary for safe and meaningful respite
- Respite support can relieve strain on family members/carers, including from behaviours of dementia
- Some GPs and service providers have poor understanding about the cause of these behaviours and strategies to manage them
- Behaviours of dementia can be a barrier to support and service delivery

### **EMPLOYMENT, FINANCIAL AND LEGAL SUPPORT KEY FINDINGS**

- Impact of premature loss of income
- Difficulties transitioning out of paid employment
- Impact of loss of employment on self-esteem
- Importance of executing legal documents to plan ahead while the person still has the cognitive capacity to participate

### **SERVICES FOR PEOPLE FROM CALD BACKGROUNDS KEY FINDINGS**

- Stigma of younger onset dementia in some culturally and linguistically diverse communities
- Some family members are expected to take on most of the caring role, especially personal care

### **SERVICES FOR PEOPLE WITH OTHER DISABILITY AND HEALTH CONDITIONS KEY FINDINGS**

- Access to supports through existing disability or health services
- Importance of person-centred and self-directed care
- Need for supports to families and carers
- Need to explore younger onset dementia in disability sector support services
- Younger onset dementia is sometimes ignored in care plans for other conditions

### **SUPPORT IN THE LATER STAGES OF YOUNGER ONSET DEMENTIA**

The last set of findings are about the issues facing people with younger onset dementia, their families and carers during the later stages of dementia, including accessing appropriate support to assist people with younger onset dementia living at home for as long as is suitable; using residential respite services; and decisions concerning residential care placement. The key findings are:

- Inconsistent access to Australian Government funded aged care and State funded disability packages of support
- Different interpretations and application of Aged Care Assessment Program (ACAP) policy by Aged Care Assessment Teams on assessing people with younger onset dementia
- Some residential respite staff have poor understanding of younger onset dementia and there is a lack of capability in supporting people with behaviour and psychological symptoms of dementia (BPSD)
- Shortage of younger onset specific residential respite facilities
- Shortage of appropriate residential care facilities for people with younger onset dementia
- Some family members and carers feel guilty about moving the person with younger onset dementia to residential care

## **PRINCIPLES TO GUIDE THE PROVISION OF SERVICES AND SUPPORT**

The findings from the first half of the report about the particular needs of people with younger onset dementia, their families and carers that need to be addressed in their support arrangements include:

- People with younger onset dementia are often physically strong and healthy
- People with younger onset dementia often have family responsibilities
- People with younger onset dementia may have a primary carer who may still be working
- People with younger onset dementia and their families will make adjustments to their expectations in their daily lives, including work, finances, living arrangements, social and sexual relationships, independence and responsibility for others
- The kind of dementia maybe a rarer form than in older people with dementia, with implications for pathways, support and treatment
- People with younger onset dementia may have significant financial commitments.

To guide the development and provision of effective services for people with younger onset dementia and their family members/carers the research highlighted the following principles within the framework of a person-centred approach to service delivery: holistic, enabling, whole of family, timely, flexible, coordinated, dementia-friendly environment, effective communication, skilled staff and cost effective. Each principle is defined in the report.

## **POLICY IMPLICATIONS**

The research findings have implications for policy and the provision of services and support to people with younger onset dementia and their family members/carers. Drawing on the principles above, the report outlines policy implications to inform the development of a services sector that is responsive to and can meet the key areas of need in younger onset dementia. To achieve this goal, five features can inform service system development for younger onset dementia: service and funding approaches; integrated service delivery; collaboration between sectors and capacity building; workforce skills and evidence based practice.

### **SERVICE AND FUNDING APPROACHES**

- Implement approaches that incorporate person-centred services, enablement, wellness and restorative models of care; early intervention; whole of family support and communication in planning, delivery and transition points
- Provide information in various formats to people with younger onset dementia, families, carers and community members to inform decisions and awareness about the condition, personal and family implications, planning ahead, support and opportunities
- Provide responsive flexible approaches such as a key worker function for proactive follow up and support and individualised funding approaches

### **INTEGRATED SERVICE DELIVERY**

- Integrate service delivery initiatives within and between service sectors, including health, aged care and disability sectors at national, state and local levels to increase the range of local service options and simplify referral processes
- Inform mainstream service providers about younger onset dementia so they understand and respond to the needs of people with younger onset dementia

- Integrate care assessment, planning and delivery processes across agencies to refer to specialist and mainstream services and local community support opportunities
- Plan for consistent, coordinated and timely approaches to changes in service delivery across the transitions as the impact of the dementia changes to achieve responsive continuity of care

### **COLLABORATION AND CAPACITY BUILDING**

- Identify, define and build collaborative pathways throughout the progression of dementia to supply timely services and support, with clear protocols to support their implementation, including key workers
- Coordinate communication and partnerships between government, non-government, community and informal support to contribute to opportunities for social support and participation of people with younger onset dementia and their family members/carers, including community awareness and information
- Combine service improvement experiences from the aged care, health and disability sectors

### **WORKFORCE SKILLS**

- Improve knowledge, skill development and training, and ongoing support for service providers and frontline workers
- Improve working conditions, supervision and peer support for staff working with people with younger onset dementia
- Implement staff and team reflective practice in order to improve quality and continuity of care
- Arrange cross sector (health, aged care and disability) sharing of experience and skills

### **EVIDENCE-BASED PRACTICE**

- Promote innovation and development of new evidence-based and responsive models of support
- Evaluate services for program improvement, accountability and generalised good practice
- Replicate good practice services in other locations
- Provide cross sector development opportunities to facilitate collaboration between health, disability and aged care providers and consumers.
- Research the social and medical implications of younger onset dementia

### **SUMMARY OF VISION, PRINCIPLES AND STRATEGIES FOR IMPLEMENTING SERVICE CHANGE**

The report concludes with strategies that follow from the policy implications for service system development to inform implementation. It groups the strategies into the key areas of need for people with younger onset dementia and their families/carers. The strategies address the following needs: timely diagnosis; diagnosis and referral; early intervention, support for transition points; behaviour management; supporting people to remain at home; and people with additional needs.

The figures summarise the relationship between the vision for person-centred approaches for people with younger onset dementia, their families and carers; the principles to guide the provision of services; implications for service system development; and strategies to implement change.

## **2 INTRODUCTION**

In 2011, Alzheimer's Australia NSW (AlzNSW) was engaged by Ageing, Disability and Home Care (ADHC) to research the service and support requirements of people with younger onset dementia and their families in New South Wales. AlzNSW partnered with the Social Policy Research Centre (SPRC) and UnitingCare Ageing to conduct the research. This report outlines the methods, findings and policy implications of the research.

### **2.1 WHAT IS YOUNGER ONSET DEMENTIA?**

Dementia is a major cause of disability amongst older people and some younger people aged under 65 years, causing 'progressive change and degeneration in cognitive mental functions, such as memory, language, rational thinking and social skills, as well as behaviour, emotion and personality' (Mocellin, Scholes and Velakoulis, 2008:1).

Younger onset dementia is defined as dementia which occurs before the age of 65 years and under 50 years for Aboriginal people. Approximately 70 per cent of people with younger onset dementia are aged 59 to 64 years (Community Care Directorate, 2012). It is rare before the age of 45 years, but it can begin in the early 30s and earlier if associated with other conditions (Rinfrette, 2010). It is estimated that younger onset dementia affects 16,000 people in Australia, which is about 4 per cent of the total population with dementia (Access Economics, 2009:121). Approximately one third of those people live in New South Wales.

The causes of younger onset dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, fronto-temporal dementia and dementia linked to other primary conditions, such as Parkinson's disease, Huntington's disease, Multiple Sclerosis, HIV/AIDS, Down Syndrome and alcohol related dementia (Mocellin et al., 2008). Each type of younger onset dementia is associated with slightly different symptoms related to changes in mental functions, behaviour, emotion and personality. For example, fronto-temporal dementia includes behavioural changes related to increased aggression and decreased inhibition, whereas dementia with Lewy bodies may cause particular fluctuations in mental state (Mocellin et al., 2008). Where younger onset dementia presents with other medical conditions, such as Parkinson's or Multiple Sclerosis, this may result in complex cases where diagnosis, degree and progression of the dementia may be hard to determine or distinguish from other conditions.

The social context of both people with younger onset dementia and family members/carers differs compared to older people with dementia. For people with younger onset dementia, the consequences of having dementia at a younger age may mean that they are still in paid employment, raising or financially responsible for a family and physically strong and healthy while developing and living with dementia<sup>2</sup>. For family members/carers, younger onset dementia can be associated with higher stress for those who are still working, have a lack of services appropriate for younger age groups (McLean, 2009), changed retirement and travel plans and multiple caring responsibilities (AlzNSW, 2010).

These considerations are more likely for younger people and mean that the support and service needs for them and their family and carers can be different to people who develop dementia at an older age. Service providers need to consider the different needs associated with better physical health, earlier family, work and financial responsibilities and other life stage plans than older people with dementia services in the aged care context. The aim of this research is therefore to explore these different service and support requirements.

## 2.2 RESEARCH, POLICY AND SERVICE BACKGROUND

Younger onset dementia has received increased attention in Australian policy and service provision in recent years. Historically, service and support requirements of people with younger onset dementia and their families and carers were addressed through generalist dementia services, which took less account of individualised needs or the specificity of having dementia at a younger stage in the life course.

Over time, however, there has been increasing attention to the individualised needs of particular groups of people with younger onset dementia, such as people with difficult behaviour associated with dementia (Alt Beatty Consulting, 2007) or people with younger onset dementia from Aboriginal and culturally and linguistically diverse backgrounds (Alt Beatty Consulting, 2008). Such developments highlight movement towards more flexible, collaborative and culturally informed dementia services over time.

More recently, there has also been reflection of the policy implications of having dementia at a younger stage in the life course within broader dementia policies and frameworks being developed and implemented. In February 2009, a Younger Onset Dementia Summit was held in Canberra, funded by the Australian Government and organised by Alzheimer's Australia, following a number of recent conference presentations specifically on the issue of younger onset dementia. In 2010, the Council of Australian Governments (COAG) agreed to reorganise services under the COAG reforms, with the Commonwealth becoming responsible for all services for people aged over 65 years and the States and Territories overseeing the support sector for people aged under 65 years (or 50 years for Aboriginal Australians). This means the States now carry full responsibility for the care of people with younger onset dementia.

In response, Australian states and territories have been working towards developments in dementia services. In late 2009, the NSW Government, with the input of AlzNSW, began work on the development of the *NSW Dementia Services Framework* in order to set the direction for quality dementia care in NSW. The *NSW Dementia Services Framework 2010-2015* was released by the Deputy Premier/Minister for Health and Minister for Ageing/Disability Services/ Volunteering/Youth during Dementia Awareness Week 2010.

The *NSW Dementia Services Framework 2010-2015* sets the direction for improving the quality of life for people with dementia and their family members/carers in NSW. It is underpinned by principles that emphasise quality dementia care and is contingent on being responsive to the needs and experiences of people with dementia, carers and families. Key principles include timeliness and choice between services, as well as detailed consideration of individuals, families and communities in determining approaches to care for people with dementia.

Younger onset dementia is identified as a specific population group within the *Framework* and both general references and recommended actions on good practice are made for addressing the needs and access to services for this group. These include addressing work and employment issues; addressing access to services for this group; designing services that emphasise physical activity, community participation and flexibility to the hours of working carers; having appropriately targeted support groups; and specifically addressing the needs of children of people with younger onset dementia. The implementation of the *Framework* in NSW is in final stages of development.

Dementia support spans the health, aged care and disability sectors, and services for people with younger onset dementia and their family members/carers are also within the context of developments in the disability sector. The NSW Government's *Stronger Together Plan (2006-2016)* (NSW Government, 2006) is its strategy to support people with a disability. It includes principles about goals to support people to participate in work, education and community life. It is underpinned by principles to ensure access to services is fairer and more transparent; to help people remain in their own home;

to link services to need; to provide more options in specialist support; and to make the service system more sustainable.

The second phase of *Stronger Together* (NSW Government, 2010) increases the focus on having the right interventions at each point in a person's life to build their strengths and enable increased independence and community participation. Early intervention and prevention principles apply at opportunities across the person's life-span especially at diagnosis and at key transition points. *Stronger Together II* recognises that consumers are to be at the centre of decision-making about how the specialist disability system supports them, including determining the application of their support resources. This reflects an increased focus on the importance and implementation of person-centred services.

The *NSW Dementia Services Framework* and *Stronger Together* both emphasise principles of choice, person-centredness, consideration of families and flexibility to respond to the life-stage of people with younger onset dementia. They both set out steps for movement towards the implementation of a person-centred approach. This approach is beginning to be applied to service models for people with younger onset dementia and their family members/carers. For example, the *Draft Guidelines on Younger Onset Dementia Person Centred Packages*, released in February 2012, is a pilot project for implementing a person-centred and individualised funded approach to younger onset dementia services. This is a pilot of a case management and brokerage model intended to improve the quality of life of people with younger onset dementia and their families, through person-centred support based on choice in what support is provided, how and when it is received and who the provider is (Community Care Directorate, 2012). The pilot reflects an approach based on person-centred planning; appropriateness to age and life stage needs; flexibility and choice; social inclusion; healthy and fulfilling lifestyles; cultural appropriateness and accessibility; integrated and collaborative practice; evidence based practice; and efficiency and cost effectiveness (Community Care Directorate, 2012). It draws together the new developments in the aged care and disability sectors to test a new approach in practice. Piloting such approaches is important in supporting the continued implementation of the new approaches supported by the *Dementia Services Framework* and *Stronger Together*.

The initiation of such pilots reflects a context of policy research and new practice to explore how the policy developments and recent principles in health, aged care and disability service provision can be further translated into innovative, flexible and responsive service models and support for people with younger onset dementia and their family members/carers. In July 2010, the NSW Premier announced a grant for AlzNSW to research the service and support needs of people with younger onset dementia and their family members/carers and how services can best address those needs (AlzNSW, 2010:10). This grant led to the current research, which is intended to explore possible future directions for younger onset dementia services.

### **2.3 RESEARCH SCOPE AND APPROACH**

AlzNSW partnered with SPRC and UnitingCare Ageing to conduct research about younger onset dementia services. The research draws on data collected from people with younger onset dementia, their family members/carers and service providers. It reflects the experiences of these groups in order to clarify options for future development of younger onset dementia services. The research examines:

- Good practice community based service models reported in the literature that are both nationally and internationally applicable for people with younger onset dementia and their carers
- The barriers to timely diagnosis of younger onset dementia
- The experience of people with younger onset dementia and their families in accessing the service system in NSW



- The service and social support requirements of people with younger onset dementia and their family members/carers
- Appropriate service models for early intervention community support services, accommodation and respite, including development of innovative flexible models to assist providers to increase access to services and achieve greater effectiveness and efficiency in the service system
- Service models to facilitate quality of life, community living and minimisation of risk of premature entry to residential aged care.

The report distinguishes between formal services and informal support. Formal services include funded medical services, assessments and programs, such as respite, day programs, support groups or accommodation services. Informal support includes assistance from family, carers, neighbours or friends, community groups and volunteers. Informal support often includes people who may have been important in people's lives prior to the onset of dementia, and continue to be a source of assistance after onset. Making this distinction is an opportunity to reflect on how younger onset dementia services can be best positioned to maintain and strengthen informal support within people with younger onset dementia's existing living arrangements and communities.

The findings are intended to inform decisions about priorities, responsibilities and roles in younger onset dementia services, address service gaps through promoting policy change, promote partnering between organisations and support people and their families to use services and support in a way that promotes choice, flexibility and community living. This is drawn out in the policy implications of the research detailed in the final sections.

## **3 METHODOLOGY**

### **3.1 RESEARCH DESIGN**

The research was designed to provide a comprehensive account of the service and support needs of people with younger onset dementia and their family members/carers. The research included a literature review; qualitative data from roundtables, in-depth interviews with people with younger onset dementia, family members/carers and service providers; and questionnaires with people with younger onset dementia and family members/carers. Each method built on findings from earlier data collection.

The research also included formative advice from a Steering Committee, including service providers, policy representatives and people with younger onset dementia and family members. Including people with younger onset dementia and family members/carers in roundtables and on the Steering Committee was an opportunity to include their advice in the formative stages of the research.

The research was a partnership project. The research team included researchers from AlzNSW, SPRC and UnitingCare Ageing. This brought together specialist knowledge and experience related to dementia service provision, younger onset dementia and research processes and methods. Researchers from AlzNSW and SPRC took part in all research activities, across planning, fieldwork, analysis and reporting, with advice from UnitingCare Ageing. The partnership approach of the research represents a capacity building approach to research, where peak organisations and research centres can draw on each other's skills and expertise to further build their own practice.

### **3.2 RESEARCH STAGES AND METHODS**

The research was conducted in five phases, which overlapped during implementation.

## **PHASE 1: RESEARCH PLANNING**

The initial stages of the research involved planning and refining the scope and focus of the research questions and methodology, based on consultation with the Steering Committee for the research and the initial stages of the literature review (Phase 2). Roundtables were conducted with people with younger onset dementia, family members/carers and service providers to inform the content of the interview questions and to ensure that the research design was specific to the NSW service and support context and the needs of interested stakeholders (Phase 3). These research design considerations were discussed with the Steering Committee to ensure that the design took account of organisational, member, network and policy interests. Ethics approval was obtained from the UNSW Human Research Ethics Committee, and a Research Plan was finalised.

## **PHASE 2: LITERATURE REVIEW**

A focused review of Australian and international literature was conducted to identify recent research and development in community-based best-practice service models for people with younger onset dementia and their family members/carers. The literature review identified good practice service models, based on the practical experiences of people with younger onset dementia, family members/carers and service providers. It also examined and reviewed current programs available in NSW and other states and territories, as well as international examples of good practice. This was with a focus on innovative, flexible and age appropriate service models, including person-centred and multi-disciplinary models. The process of doing the literature review and its findings were used to inform research planning during Phase 1, and to inform fieldwork approaches and instruments in Phase 3.

The literature review is available online at [www.sprc.unsw.edu.au/media/File/1Alzheimers\\_YOD\\_lit\\_rev\\_FINAL\\_DT\\_Oct11final.pdf](http://www.sprc.unsw.edu.au/media/File/1Alzheimers_YOD_lit_rev_FINAL_DT_Oct11final.pdf)

## **PHASE 3: FIELDWORK**

Fieldwork focused on the lived and service experiences of people with younger onset dementia and their family members/carers in NSW. This included the experience of diagnosis and entry to services; positive and negatives experiences in existing services; remaining needs; and key differences between the lifestyle and service considerations for younger onset dementia compared to dementia at older ages. Information provided covered the family and support context, life choices and quality of life; service and support needs, including met and unmet needs, daily difficulties and changes in needs based on the progressive stages of dementia; and perceptions of positive, negative and ideal service experiences, including through all stages from pre-diagnosis, diagnosis, community support and residential care; barriers to timely access to services; and gaps in available services. Fieldwork included roundtables, in-depth interviews and surveys, described below. The research instruments are included in Appendix 1.

### *Roundtables*

Roundtables were conducted with key informants at the start and end of the fieldwork to draw on expertise about younger onset dementia based on lived and professional experience. The roundtables were conducted with separate groups for people with young onset dementia, family members/carers and service providers (Table 3.1). The first roundtables were based on the research scoping, Steering Committee feedback and initial stages of the literature review. The findings informed the design of the fieldwork instruments. This was important to ensure the focus of the research matched the lived experience.

A second set of roundtables were conducted with key informants at the end of the fieldwork. Family members/carers, service providers and the Steering Committee were included in separate groups. These roundtables included discussion of the preliminary findings of the research and provided family members/carers, service providers and the Steering Committee an opportunity to provide feedback on some of the key findings and policy implications. These roundtables also aimed to gain further

information on gaps and remaining questions from the fieldwork. These roundtables were important for ensuring the clarity and practical application of the research findings.

### *In-depth interviews*

In-depth semi-structured interviews were conducted with people with younger onset dementia, family members/carers and service providers (Table 3.1). These were designed to capture in-depth information about how people with younger onset dementia and family members/carers' received a diagnosis and came to access services, their service experiences and further needs, as well as about their family and support context, life choices and quality of life particularly in relation to having a diagnosis of dementia at a younger age. The interviews also aimed to capture service providers' experiences of working with people with younger onset dementia to inform future services. The questions drew on the findings of the commencement roundtables, literature review and input of the Steering Committee.

A purposeful sample was used for all stakeholder groups. For people with younger onset dementia and family members/carers, this aimed to include men and women, people with different lengths of time since diagnosis, different types of dementia, and from different cultural and socioeconomic backgrounds and metropolitan and regional areas. The purposeful sample was selected through third party introductions initiated by service providers and Dementia Advisory Service workers across NSW, combined with advertising in newsletters and network distribution lists. Based on these introductions and advertisements, participants from across NSW then self-selected for participation. Multiple Sclerosis Australia organised a group interview with nine members. People with younger onset dementia and family members/carers who participated in an interview all received a gift voucher.

Language and communication were key considerations in the interview context for people with younger onset dementia. Semi-structured face-to-face interviews were chosen for their adaptability and choices between easier and more complex interview questions. People with younger onset dementia and family members/carers chose to participate in the interview either separately or together, based on preference and communication needs. These strategies were intended to be flexible to the needs of participants, encouraging as many as possible to participate. Fifteen interviews were conducted together (n=30), with 5 people with younger onset dementia and 19 family members/carers participating separately or individually.

For service providers, the purposeful sample aimed to include staff working in key younger onset dementia services associated with elements of good practice identified in the literature review or staff working specifically with people with younger onset dementia with other specific characteristics, such as co-occurring disability or from a culturally or linguistically diverse background. The recruitment of service providers was through contacts with AlzNSW and Dementia Advisory Service workers, and interviews were mostly conducted face-to-face and some by telephone.

### *Questionnaires*

Questionnaires were conducted with people with younger onset dementia and their family members/carers (Table 3.1). These were to explore, clarify and confirm the findings of the interviews, address gaps and reach people who did not wish to participate in an in-depth interview.

Three questionnaires were available. Separate, but comparable, questionnaires were available to people with younger onset dementia and family members/carers, asking about experiences and satisfaction with existing services, day to day difficulties and perceptions of ideal services. Both people with younger onset dementia and family members/carers were given the opportunity to answer about themselves and each other. A shortened survey was also available for people with younger onset dementia asking only key questions. The choice between two surveys for this group was designed to allow people at both the early and middle stages of dementia progression to participate accessibly. Surveys were advertised through Dementia Advisory Service workers, local dementia newsletters and networks, and newsletters and distribution lists in the broader disability sector, and people from across NSW self-selected to participate.

#### PHASE 4: ANALYSIS AND REPORTING

Thematic analysis was used for the qualitative data, based on a combined deductive and inductive process drawing on both the aims of the research and the themes and issues evident from the data. The analysis was conducted in conjunction with the final roundtables in order to confirm and clarify the emerging findings before the final analysis was completed. Survey data were analysed using SPSS and incorporated with the qualitative findings during write up, based on the research aims and findings. As the survey was designed based on the interview findings, the quantitative data for the report fitted with the qualitative findings and analysis.

The report was tabled and discussed with the Steering Committee prior to finalisation, to further clarify the details of the findings and implications.

#### PHASE 5: PRESENTATION ABOUT THE IMPLICATIONS OF THE RESEARCH FINDINGS

After the finalisation of the report, the findings were presented to the Steering Committee and other key stakeholders to inform potential directions for using the findings to promote policy change, partnership between organisations providing younger onset dementia services and new service approaches to facilitate quality of life, community living and minimisation of risk of premature entry to residential aged care. This aimed to maximise the impact of research findings for AlzNSW, service providers and government, by engaging in detailed discussion of the application, utility and value of the findings, and by linking and working across how the report would be used by multiple stakeholders. By engaging the varied experience of these groups, the report and project findings are well placed to have a key role in supporting the continued implementation of improved services and support for people with younger onset dementia and their families and carers.

### 3.3 PARTICIPANTS

#### SAMPLE SIZE

The research included a total of 170 contributions across the roundtables, interviews and surveys. This included a total of over 150 participants, with some contributing through more than one method. Participants in the research were people with younger onset dementia and their family members/carers, as well as service providers with people with younger onset dementia within their services.

**Table 3.1: Sample size**

Method	People with younger onset dementia	Family members/carers	Service providers
Roundtables start	6	7	6
Roundtables end		12	9
Interviews*	20	34	10
Questionnaire	18**	48	N/A
<b>Total</b>	<b>44</b>	<b>101</b>	<b>25</b>

Notes: \* The interview participant numbers include nine people who responded to the interview questions in a focus group and two people who responded to the interview questions through a written response.

\*\* A further 10 people with younger onset dementia attempted to fill in the survey, but did not complete the questions. These 10 people are not included in the numbers reported here.

## **PARTICIPANT CHARACTERISTICS**

People with younger onset dementia and family members/carers who participated in the research reflected a range of demographic characteristics. Both men and women who were people with younger onset dementia or family members and carers participated. Most people who participated were in spousal relationships, with the addition of some single people with younger onset dementia. The family members and carers also reflected a range of other relationships to the person with younger onset dementia, including adult children, parents and siblings; and two family members and carers of a person with younger onset dementia who had died recently. The scope of family relationships included thus covers many of the relational ways that younger onset dementia may affect families.

People with a number of different types of younger onset dementia participated, including Alzheimer's disease and other types of dementia. For example, several people with fronto-temporal dementia participated, contributing information about the behavioural changes associated with this type of dementia. People with rare genetic forms of vascular dementia also participated, as well as dementia associated with other primary conditions, such as Multiple Sclerosis and Parkinson's symptoms. This ensured that the experience described covered both common and more complex presentations of younger onset dementia.

By including both people with younger onset dementia and family members/carers, the sample also included those who could discuss the experience and support needs in the variety of stages of the progression of dementia, including the process of awaiting diagnosis, recent diagnosis, living with dementia over a number of years, entering residential care or palliative care and dying.

People from both metropolitan and regional areas were specifically included. Most interviews were conducted in the Sydney metropolitan area, with the addition of five trips to regional areas including the mid, north and south coast of NSW. Other interviews were conducted by telephone, after purposive sampling through key regional service providers. Including people from these areas allowed reflection of service experiences/availability and support needs, based on the living situation and geographical location. While harder to reach and identify, people from a range of socioeconomic backgrounds also participated and reflected in their discussions of the role of financial considerations, housing and job-role changes in their younger onset dementia experience.

The sample for this study reflects variety on a number of key issues that make up the scope and diversity of living with younger onset dementia, thus placing the research in a good position to assess the service and support needs of a range of people associated with this condition.

## **HARD TO REACH GROUPS**

Some groups were more difficult to reach in the research. This was anticipated, and addressed with purposive sampling through key service providers, networks and contacts. These efforts were not fully successful, as consistent with other social research (Brackertz, 2005).

Few people from culturally and linguistically diverse (CALD) and Aboriginal backgrounds<sup>3</sup> wanted to participate, even when contact was made with service providers that worked with them. Feedback from these service provider contacts suggested that stigma about dementia in some cultural groups and not identifying with dementia terminology may have been reasons people did not want to participate. Future research could work with key service providers to adapt the language, terminology and methods to reach these groups.

Other people who were hard to reach were those who had younger onset dementia with another primary condition, such as Down syndrome, HIV/AIDS, drug or alcohol dependency or fully-diagnosed Parkinson's. Contact was similarly made with key service providers, but only a few participants with these types of conditions chose to participate, including a focus group with people with Multiple Sclerosis. A reason might have been that they receive services and support for their primary condition, rather than for younger onset dementia, and so did not identify with the research topic. In other

instances, the service providers for people with the primary condition did not keep records about who had younger onset dementia, so it was difficult for them to approach people with an interest.

Future research strategies could include working with service providers over a longer time to identify and approach people with younger onset dementia and another condition to participate or other options that do not rely on recruitment through a service provider.

In addition, although the researchers worked with service providers in a number of locations across the state to find participants, certain areas of NSW were poorly represented in the research. This included people in Western Sydney and Western NSW. Future research could confirm the findings for people with younger onset dementia and their family members/carers living in these areas.

## **LIMITATIONS AND GENERALISABILITY**

This project used a qualitative sample tailored to the needs of the study, relying on an open and self-selected sampling strategy. The qualitative nature of the sample has benefits for operating a flexible and broadly inclusive research process. It presents some limitations for the diversity of participants and for the generalisability of the research findings.

Information about the exact proportion of participants with various demographic characteristics was not available. Throughout different research methods, participants gave different descriptions of, for example, their type of dementia, the relevance of their cultural or socio-economic background and of the types of caring or family relationships they engage in. These descriptions involved more or less detail, contextualised or brief descriptions, different classifications and situations in which relevant demographic characteristics may have been omitted entirely at the choice of participants. The variety in these descriptions means it is difficult to report consistent demographic information for all relevant demographic characteristics. For this reason, this report discusses the broad and various experiences of participants with specific reference to key demographic features such as gender, cultural background and specific behaviours of concern, but does not attempt to report the profile of participants in any numerical way against these characteristics.

The report has also taken the approach of looking broadly at the particular life-stage needs of younger onset dementia, rather than reporting against specific sub-types of dementia. This is in recognition of the focus on the service and support context for people with younger onset dementia and their families and carers, where people with different types of dementia often use the same services. Other factors, such as their younger age, family responsibilities and the continuing workforce and financial responsibilities, have a direct impact on their service and support needs. In this context, this research has examined the other factors that contextualise service and support requirements, rather than examining the specific experiences associated with different sub-types of dementia. Where the features of specific sub-types of dementia, such as behaviours of concern, affect service and support needs, these have been drawn out in detail in the report.

The findings from these research design choices provide broad and important information on demographic considerations and on the service and support context for a younger age group, however they also have some limitations on the generalisability of the findings. The report generalises to the extent of suggesting common service and support experiences and using these to suggest appropriate principles and policy implications for service provision. Further research into the relevance and applicability of these findings to specific communities or groups with other specific characteristics (Aboriginal communities; culturally and linguistically diverse communities; people with other primary health conditions; type of dementia; caring status; socio-economic background and location) would be required in order to make any further generalisation, for example, to a clinical, cultural or socioeconomically informed level. The intent of this study is to identify the broad range of experiences and issues, which could then be used as a basis for supporting research into younger onset dementia in association with other key groups, communities or issues.



## **4 IDENTIFYING YOUNGER ONSET DEMENTIA**

This section discusses the experiences of people and their family members/carers in identifying that they have younger onset dementia. The early recognition of symptoms, experiences with diagnostic practitioners and the lack of understanding and the stigma surrounding younger onset dementia are covered.

### **KEY POINTS**

- Misrecognition of symptoms and lengthy diagnosis process
- Poor delivery of diagnosis and information about dementia
- Poor follow-up appointments and referrals to support services
- Link between acceptance of diagnosis and accessing support
- Poor understanding and stigma surrounding younger onset dementia.

### **IMPLICATIONS**

- Develop standardised clinical processes or a referral pathway for younger onset dementia for health professionals
- Promote the addition of a Medicare billing item to allow for longer GP consultations with carers and families of people with younger onset dementia
- Promote information for greater awareness and reduction of stigma about younger onset dementia in the community
- Publicise the barriers to services and support resulting from misdiagnosis, stigma and non-acceptance of the condition.

### **4.1 RECOGNITION OF SYMPTOMS**

People with younger onset dementia and their family members/carers reported a variety of early symptoms they noticed prior to receiving a diagnosis:

- Unable to tell the time
- Getting lost
- Misplacing items
- Speech difficulties
- Aggressive behaviour
- Short-term memory loss
- Forgetting to pay bills
- Difficulties at work
- Personality changes
- Missing appointments
- Dangerous driving
- Poor spatial perception
- Loss of confidence
- Paranoia
- Return to first language
- Irrational behaviour
- Poor financial decisions
- Telling stories from the past constantly
- Forgetting to eat.

At first, they rarely considered these changes as symptoms of younger onset dementia. During the roundtable discussions and interviews, service providers highlighted that people may not recognise symptoms as a problem for several years resulting in a lengthy process of identifying dementia. Service providers also spoke about the impact of this period on families and relationships. They reported that often family members, friends and colleagues do not realise the explanation for the person's behaviour, which can lead to relationship and family breakdown.

Interview participants reported medical professionals ruling out other conditions – such as depression, menopause, and brain tumours – before dementia was considered a possibility. Many of the people interviewed acknowledged they had little or no awareness of younger onset dementia prior to diagnosis.

### **Case study about recognising symptoms**

*Carol's\* husband, Don\*, started doing some 'strange things' such as forgetting appointments, losing items, and getting traffic tickets. Friends were telling Carol that their husband did weird things too so she put it down to stress. A few months later Don's behaviour was worse and his family had noticed personality changes. They became very concerned when they realised that Don was struggling at work. Don and Carol went to their local GP and Don was sent for a CT scan but nothing showed up. The GP told them not to worry because he was still holding down his job and put the odd behaviour down to stress. Following this Carol and their children began to notice instances when Don lacked judgement and serious problems with his driving. However it was not until Don's boss called Carol and told her not to let him come back to work the next week that their GP finally took their concerns seriously. The GP suspected that Don had a tumour; certainly no one considered earlier that Don, at 55 years of age, had fronto-temporal dementia.*

## **4.2 DIAGNOSIS PROCESS**

*There is no simple test for the diagnosis of dementia. Diagnosis is made on clinical assessment and supported by investigation results. This includes a comprehensive assessment to ensure that other conditions that show similar symptoms are identified or eliminated. (Workman, Dickson and Green, 2010: 723)*

As found in the literature review (Thompson, 2011), diagnosing younger onset dementia is difficult for a number of reasons, such as lack of understanding of younger onset dementia and the large number of tests required to determine a correct diagnosis. The variation in causes of younger onset dementia also makes it more difficult to diagnosis than late onset dementia. In addition, because dementia under the age of 65 years is not common, it is often misdiagnosed as depression or other mental illness, which not only delays correct diagnosis and access to services and support, but can also lead to the incorrect prescription of anti-depressants and other medications.

For the participants in the research, difficulties surrounding diagnosis were a major barrier to accessing support services. Most people experienced a lengthy diagnosis process that often involved convincing their GP that something was wrong, followed by misdiagnosis, before younger onset dementia was confirmed. Very rarely was the diagnosis process simple. People with younger onset dementia expressed concern about the poor way in which their diagnosis was communicated, the lack of information they were given about dementia, often a lack of compassion, empathy and respect displayed in the delivery of the diagnosis, and the perceived inappropriateness of some assessment tools, such as the 'mini-mental' examination. They also expressed their disappointment at the lack of follow-up appointments and referrals to support services.

\* All names have been changed for de-identification and reporting purposes.

### Case study about the diagnosis process

*Trevor was experiencing difficulties at work and had lost his sense of direction. He and his wife, Ann, went to their local GP who took their concerns seriously. The GP conducted a mini-mental examination and tests to rule out other conditions. She suspected a cognitive impairment, possibly Alzheimer’s disease, and referred Trevor to a neurologist. Of the neurologist, Trevor said, ‘He was efficient, I could say. We didn’t actually feel him as a person, we knew him as a technician, not as a person like we did the GP.’*

*The neurologist conducted more testing, including an MRI scan, and then referred Trevor to a neuropsychologist. Ann explained the confusing and exhausting process that continued from there, moving between many different medical professionals in search of a diagnosis...*

*“[The neuropsychologist] was lovely but she said Trevor was still able to learn new things, so it wasn’t Alzheimer’s ... And that was true ... but there were a lot of things falling by the way ... And then the neurologist would not let us look at the neuro-psych report. He said it was confidential. But it’s confidential to us! That was very awkward. So then he said that this woman said that Trevor must be depressed because of how he was that day; but after five hours of tests, and he couldn’t have done well on all of them ... and after he just got in the car and just sobbed. He was exhausted ... The neurologist then referred Trevor to a psychiatrist. And she said to him ... after a lot of testing, ‘Do you think you’re depressed?’ and he said ‘No.’ And then she said to me ‘Do you think he’s depressed?’ and I said ‘No.’ And she said ‘No, I don’t think he’s depressed’ ... Then she said, ‘Well, the neurologist wants me to give you antidepressants’ and Trevor said, ‘I’ll take them.’ And she ... wrote out the prescription ... the antidepressants ... didn’t really make any difference because he wasn’t depressed.” Ann.*

*Two years on and Trevor’s neurologist has still yet to say the ‘D’ word. Ann received confirmation of his diagnosis via email from a research assistant of a drug trial study in which Trevor was involved.*

### 4.3 DIAGNOSTIC PRACTITIONERS

The most common source of diagnosis was from a neurologist (49 per cent), followed by a geriatrician (29 per cent; family member/carer survey; Table 4.1).

**Table 4.1: Source of diagnosis**

Diagnosis	Respondents	Per cent
Neurologist	22	48.9
Geriatrician	13	28.9
Other health professional	6	13.3
GP	2	4.4
Unsure	1	2.2
No confirmed diagnosis yet	1	2.2
Did not respond	3	
Total	48	

Source: Family member/carer Survey, Q. Who diagnosed your family member with younger onset dementia?

A few family members/carers told of how their family member with younger onset dementia was initially diagnosed by a neurologist and then transferred to the care of a geriatrician for follow up appointments.

One man with younger onset dementia explained how he does not mind seeing his geriatrician, because he believes that clinical dementia is best treated by practitioners from aged care. Participants said geriatricians have specialist knowledge of dementia and tend to approach diagnosis and treatment as part of an ongoing process.

In contrast, some participants said that neurologists sometimes consider their job complete once they make a diagnosis. Many participants provided examples of the poor manner in which their diagnosis was delivered by a neurologist (box below). Their key concerns included poor inter-personal skills, empathy, information, follow-up or referral to support services.

### **Examples of poor communication of diagnosis**

*'He said: diagnosis to death, seven to ten years, then he turned around to make a phone call' [wife].*

*'Both neurologists were extremely unhelpful and useless, if I could dare to be so bold' [wife].*

*'I wasn't particularly impressed with the gentleman who gave us the diagnosis because he basically bluntly said 'yes, you've got Alzheimer's, go back to your own doctor and they'll look after you.' I felt it could have been a little bit more sympathetic, a little bit gentler' [wife].*

*'The experience to me was appalling...there was no empathy when giving the diagnosis and the lack of information made things particularly difficult, as I had no idea what I was dealing with and no idea how to explain it to the family and Mum's friends' [adult child carer].*

One couple told of how they left the neurologist because of his personal manner. They then went back to their GP who sent him to a geriatrician, who they described as a 'young doctor who is lovely and easy to talk to.' Similar comments were made by a range of other family members/carers.

In comparison, the research demonstrated the positive impact that a good local GP can have on the experience of diagnosis and treatment:

"Our GP was amazing! It's because of him that we've got the diagnosis ... second visit he went away with a referral [to a specialist]. He was on to it straight away," said one wife.

### **EXAMPLES OF REPORTED GOOD GP PRACTICE**

- Knowledge of younger onset dementia and the effect it has on the lives of those diagnosed and their families
- Hearing the concerns of the family member/carer before and after diagnosis
- Acknowledging the diagnosis of dementia when the person with younger onset dementia or the family member/carer visit the GP for other reasons
- Referring the person and the family member/carer to support services at appropriate times
- Assisting the person and the family member/carer to make transitions from one stage to another, such as driver to non-driver, employed to unemployed, and living at home to living in residential care.

GPs are often gatekeepers to service provision and the point of contact with the health system for people with dementia and their carers, yet GPs have reported that the most difficult problem with the management of dementia is the communication and disclosure of the dementia diagnosis (Paterson et al., 2010).

This current research project demonstrates the importance of including the families and carers in diagnosing younger onset dementia. Similarly, health professionals are arguing the case for a Medicare billing item number for GPs to meet with carers to be able to fully assess and review the primary health care and treatment of people with dementia.

**EXAMPLE OF GOOD PRACTICE: Hunter clinical pathway for the management of Younger Onset Dementia**

*A Younger Onset Dementia working group – an interagency collaboration in the Hunter region (Newcastle and Lake Macquarie) – has developed a clinical pathway for the management of younger onset dementia. The pathway is designed to facilitate early and timely diagnosis and appropriate management, planning and referral options. It gives primary care providers, particularly GPs, an algorithm that enables people aged under 65 years who present with cognitive and/or functional decline to be appropriately identified and assessed. It ensures not only timely dementia diagnosis (if that is the case), but promotes independence and quality of life through early intervention, monitoring of health and connection with support services.*

#### **4.4 DIAGNOSIS FOR SPECIFIC GROUPS**

The additional needs or context of some people with younger onset dementia are also relevant during the process of assessment and diagnosis, such as people from Aboriginal or culturally or linguistically diverse backgrounds or people with other conditions, such as Multiple Sclerosis, discussed below.

##### **ABORIGINAL COMMUNITIES**

Dementia can affect Aboriginal Australians at an earlier age than in the general population, with greater proportions of Aboriginal Australians in the 45-69 years age group affected compared to the general Australian population (Arkles et al, 2010).

An Aboriginal service provider discussed how younger onset dementia is sometimes undiagnosed in Aboriginal communities. She reflected that some reasons may be because some Aboriginal health workers are not trained to recognise dementia and some GPs are not referring to specialists for diagnosis. In her experience, some Aboriginal people diagnosed with or undergoing diagnosis of younger onset dementia are not accessing mainstream dementia support services (younger onset specific or otherwise), because they do not identify with the language or conceptualisation of dementia. Further research is required on the service and support needs of people with younger onset dementia in Aboriginal communities.

##### **PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES**

A service provider working in culturally and linguistically diverse (CALD) communities reported that an increasing number of the people aged under 65 years who they work with have memory loss and other symptoms of younger onset dementia but have not been diagnosed. She suggested that some of the reasons they were not seeking a diagnosis included a lack of knowledge about dementia and stigma for the person and the family if they were diagnosed. As a result, some people from CALD backgrounds present late for both medical and community care, sometimes close to or at crisis point.

CALD service providers reported that the multiple assessment process is confusing and access to interpreters is not consistent. There is generally no language support provided when people from

CALD backgrounds are assessed and diagnosed by specialists. Information and diagnosis needs to be delivered in a culturally sensitive and streamlined way.

Service providers also advised that some GPs, religious and community leaders who work with particular communities need information about dementia, as this is where some members of CALD communities seek advice. They said that some GPs reportedly do not refer patients to specialists for diagnosis and deal with dementia needs themselves. They said that the needs of hidden carers within the family from stigma following diagnosis or avoiding diagnosis should be considered. Information about younger onset dementia in the context of cultural implications is required to ensure that assessments and referrals are delivered in a culturally appropriate manner.

## **PEOPLE WITH MULTIPLE SCLEROSIS**

Approximately 50 per cent of people with Multiple Sclerosis (MS) will experience memory loss and mild cognitive impairment as a symptom of MS, with 30 per cent of people having memory, concentration, and/or focus problems as a symptom at diagnosis; however only about 10 per cent of people with MS develop dementia (Longley, 2007). It is only in recent years that the term dementia has been used in the MS community and some professionals continue to resist using the language of dementia, due to stigma.

The people with MS related younger onset dementia and their family/carers who participated in this research reported difficulties distinguishing between symptoms of MS and dementia. They also spoke of the shock they felt on receiving a diagnosis of younger onset dementia.

## **OTHER CONDITIONS**

Younger onset dementia is also associated with other conditions, such as for people with intellectual disabilities and people with alcohol or drug related dementia. For these people, diagnosis can be additionally complicated by the multiple conditions. As a result, their needs might be misdiagnosed or ignored (Chaston, 2010, Mendez, 2006). This research was not able to reach participants from these groups to examine their experiences.

## **4.5 EFFECT OF HAVING A DIAGNOSIS**

### **IMPACT OF DELAYED DIAGNOSIS**

Delayed diagnosis of younger onset dementia results in delayed referrals to early intervention support services and can have profound emotional and practical impacts for the person and their family. Some family members/carers spoke about the impact a delayed diagnosis, including financial implications:

*“Because my husband is younger and because it wasn’t picked as early as I really felt it should have been ... and where my husband ... was self-employed, he made lots of financial decisions that were really bad, and because of that we’re pretty deep in debt ... I’m still working and struggling to keep us where we are, pay off the debt,” [wife].*

One young man told of how fortunate he was to sort out power of attorney and enduring guardianship as soon his father’s diagnosis was confirmed. However, the delay receiving a diagnosis could have caused major dilemmas for the family had they not been quick to act to contact a solicitor, as he acknowledges, ‘Luckily the solicitor authorised it; if I’d left it another couple of weeks later ... because it was a late diagnosis I was against the clock.’ Most service providers spoke about the impact a delayed diagnosis can have on relationships and family dynamics. One service provider said:

*Not all marriages are great when people come to the point of diagnosis. A lot of people have gone through some pretty horrendous times reaching that diagnosis, so it’s those problems around misdiagnosis and the time it takes to reach a diagnosis and in the meantime often marriages are really strained to breaking point.*



## ACCEPTANCE OF DIAGNOSIS

For some people, receiving a diagnosis of younger onset dementia is a relief as they finally have an explanation for the difficulties they have been experiencing. Other people struggle to accept the diagnosis of dementia and can be unaware of the impact of their symptoms, as illustrated in this dialogue,

*Husband: When you first get involved with the nice people who look after people, you think 'woah, I don't think I need that.'*

*Wife: But with this disease you have good days and bad days.*

*Husband: Yes, but so does everyone...if I experienced difficulties, I would know. (To his wife) I know you don't think so.*

The time taken to accept a diagnosis can impact on the timeliness of people with younger onset dementia accepting assistance from support services. It may not be until they reach a crisis situation that they are willing to accept information and support, by which time they have lost the opportunity for early intervention.

## 4.6 UNDERSTANDING AND STIGMA

Younger onset dementia is not a visible condition and often people with a diagnosis are still physically well. As a result, the community may not recognise the difficulties that a person with younger onset dementia faces. This man with younger onset dementia explained his frustration:

*People don't seem to realise what you go through – other people. They think, 'Oh, it happens to me too' and I hate that, because it's not the same sort of thing. Like my mother is 91 years old today and she's better than I am, but to you or anyone else I appear fine.*

People with younger onset dementia agreed in the roundtable discussion that the public do not have enough understanding about younger onset dementia and they view dementia as an old ladies' disease. Family members and carers agreed about the lack of understanding in the community and amongst health professionals. A wife and an adult daughter said,

*In the community I've found that with a person with older dementia ... people seem to have an understanding, 'Okay, they've got dementia', so they make allowances. But people with younger onset dementia ... there's not the same understanding ... They don't seem to recognise that this person has Alzheimer's or dementia.*

*We get questioned more as people have never heard of younger onset dementia. I've found even some medical professionals fall into this category, particularly emergency departments. This makes it hard to get assistance sometimes, because it seems they don't believe the diagnosis when you tell them your parent's age.*

Some family members told of extended family who refuse to accept the diagnosis, and who blame them for the person's problems. Two wives said,

*We've had family problems with my husband's brother and his wife who believe that if I did certain things, then my husband would be cured of Alzheimer's. So they basically have said that it's my fault that he's got Alzheimer's.*

*His mother thinks the reason her son does not remember and is not good with executive function is because I have taken control and taken away his ability to use these faculties.*

As a result of the poor understanding, some participants said they could not get the social and practical support they needed from family and friends. A wife said,

*We can't keep going like this, we need to tell people. It's not going to go away, it's going to get worse and we need the support of our family and friends. If they are intimidated by it then that's their problem!*

Most participants spoke about the need to increase community understanding of younger onset dementia. Many told of how they advocate for their family members and others with younger onset dementia, taking advantage of opportunities to tell people about the condition and increasing community awareness and understanding of younger onset dementia. A daughter of a man with younger onset dementia told of how she is, 'all about educating people about dementia and what it means' for the whole family.

*I'm telling anyone who even looks at us sideways, because I figure the more people who hear, the more they're going to think about ... because I think there is no awareness of it ... I'm wanting everyone to know about the condition...and I don't want sympathy [wife].*

Dementia is a condition that carries a lot of stigma. People's attitudes, perceptions and understanding of the nature of dementia determine how a person diagnosed with dementia and how their family and carers accept and live with the condition.

*I think that younger onset dementia is more prevalent than people realise; that there are families out there who are really struggling with great difficulties [service provider].*

The cost of stigma is profound; it can affect a person's ability to seek help and support, including assessment and timely diagnosis, as well as referral to services (Alzheimer's Australia NSW, 2010). A man with younger onset dementia said,

*One of my sisters said that we shouldn't be delving into that at all [accessing support services]. It was too early, 'you shouldn't be doing this, you'll put a stigma on my forehead or something' ... I think her response is old fashioned.*

## **5 EXPERIENCE OF SUPPORT SERVICES**

This section discusses support services available in the community to assist people with younger onset dementia, family and carers to continue to live at home and participate in family and community life. It highlights the strengths of these services, acknowledges the gaps in delivery and describes the barriers that prevent people from using support services. The support services are grouped into early intervention, community participation and social engagement, family and relationship support, informal support, respite support, employment and financial support, services for people with CALD backgrounds and services for people with other disability and health conditions.

### **5.1 EARLY INTERVENTION**

#### **KEY POINTS**

- The immediate impact of diagnosis is significant for both people with younger onset dementia and family members/carers
- People with younger onset dementia and their families/carers need for timely information and resourcing about dementia and what lies ahead
- People with younger onset dementia and their families/carers need emotional support, education and tips on daily functional support
- Non-acceptance of the diagnosis can be a barrier to support services

#### **IMPLICATIONS**

- Provide timely information, education and following up, that includes staged information and appropriate resourcing managed by a case manager or key worker

- Provide Information in formats that meet the needs of the person with younger onset dementia, their family member/carer and their extended families and friends
- Encourage generalist counselling services to include dementia as a specialist area of practice
- Incorporate an enablement approach in early intervention support services to reinforce the idea of maximising the remaining capacities of the person with younger onset dementia

The impact of a diagnosis of dementia for someone aged under 65 years and their families can be significant. This impact during the post diagnosis period is distinct in its difference to people with older age dementia, as the diagnosis is very often unexpected, the person with younger onset dementia often has dependent family members, is often still in employment and financing debts based on their prior income, they have made plans for a future beyond employment and often, in all other aspects of their health and wellbeing, they feel well.

### REFERRAL AND INFORMATION

Due to the significant impact that a diagnosis of dementia brings, people need appropriate information after diagnosis and proactive follow up. Support may be required immediately to counsel and reassure the person with younger onset dementia and their family members that support services are available to assist them.

However, many people with younger onset dementia and family members/carers said they were left 'stranded' after diagnosis, not knowing where to go for assistance. Nearly as many people with younger onset dementia received services long after diagnosis as did those shortly after diagnosis (Table 5.1 and Table 5.2).

**Table 5.1: Time first used services for person with younger onset dementia**

Timeframe	Respondents	Per cent
Before diagnosis	4	8.3
At the same time as diagnosis	4	8.3
Shortly after diagnosis	16	35.6
Long after diagnosis	14	31.1
No services received yet	7	15.6
Did not respond	3	6.3
Total	48	

Source: Family members/carers questionnaire, Q. Family members/carers – at what stage did your family member with younger onset dementia first receive services?

**Table 5.2: Time first used family support services**

Timeframe	Respondents	Per cent
Before diagnosis	4	10.0
At the same time as diagnosis	4	10.0
Shortly after diagnosis	14	35.0
Long after diagnosis	11	27.5
No services received yet	7	17.5
Did not respond	7	14.6
Total	48	

Source: Family members/carers questionnaire, Q. Family members/carers – at what stage did you first use services for carers?

As a husband explained,

*The whole process for somebody who has never been ill, never used any social services of any description or any government services, it's a complete mess trying to navigate through ... especially in the early days, you don't know ... for someone who is an outsider ... doesn't understand it, it's very confusing.*

While neurologists most often gave the diagnosis of dementia, people with younger onset dementia and carers reported that neurologists often offered nothing further by way of referral, assistance or access to services (Section 4.3). People with younger onset dementia and family members/carers said that for those that did receive support soon after the diagnosis, it was often via their GP. The informative GPs contributed to successful and timely service access. Alternatively, people who received little support or referral about the management of dementia from their usual GP were disadvantaged as they often presented for support and service delivery in emergency situations or when it was too late. A service provider said,

*People get their diagnosis through the health system ... and getting health [care] to recognise that the community care services can actually help is still problematic ... it's very frustrating to think that people are missing out because a health professional has made a diagnosis but then not sent them on anywhere else.*

Information at this early stage was linked to the referral process. Many family members/carers stated they would have appreciated information given to them as soon as possible after the person was diagnosed with dementia. Some family members/carers reported finding most of their information about dementia on the internet, via websites both from Australia and overseas. This was particularly the case if it was a distinct type of dementia, such as fronto-temporal dementia.

Conversely, some family members/carers were aware of support services available to them, but did not feel they needed to use them at first. Many said that they did not immediately look for information and support following their partner's diagnosis, because they thought they could cope. A husband and his wife with younger onset dementia were unwilling to seek out information and support services in case her dependency on support increased, resulting in a faster progression of her symptoms of dementia.

Family members/carers also reported that in the early stages both the person with a diagnosis and the family members can feel overwhelmed and did not feel that they had the time to seek out information. This indicates that information about dementia and support services needs to be provided in a 'staged' manner. Family members/carers also believed that GPs and specialists should refer people with younger onset dementia and their families to support services, such as Alzheimer's Australia NSW.

## **DEMENTIA ADVISORY SERVICES**

Dementia Advisory Services (DAS) were cited by family members/carers as a good source of information and support. These services provide advice on the management of dementia, organise support for people with younger onset dementia and family members/carers and provide referrals to other sources of assistance.

Generally referral to a DAS came from a GP. Consistent contact with the same one or two workers appeared to be effective, as the workers grew to know the needs of the person with younger onset dementia and the family member/carers. A family member said that an outreach worker approached her in the supermarket, quietly passed her card and simply said, 'Call me if you need some help.'

## CASE MANAGER OR KEY WORKER

*I didn't have the mental energy to sort it all out [wife].*

Many family members/carers reported benefit from having one person such as a Dementia Advisor or a good GP to support them. They also expressed the desire for information from someone such as a case manager or key worker to provide proactive dementia management following the diagnosis – someone with specific knowledge of the impact of younger onset dementia and available services; who would know them well and refer them to appropriate services; and who could take them from diagnosis to residential care. Two wives said,

*A case manager would be ideal but I think that's probably impossible. I don't think the Health budget is going to stretch to that.*

*I think a case manager would be nice. Someone to ring up. Not just about problems, but just about your actual circumstances ... You probably just need a friend, someone to talk to and say 'What should I do!?'*

Case managers or key workers manage instances where needs of the person with younger onset dementia and the carer differ, where needs change and where the situation is complex. Case managers and key workers can also provide invaluable support to a person with younger onset dementia and their family in co-ordinating, organising and encouraging use of appropriate services and support from the initial diagnosis and throughout the progression of dementia.

### EXAMPLE OF GOOD PRACTICE CASE MANAGEMENT – Community Options

*A Community Options case manager assisted a man caring for his wife who had younger onset dementia. Following a comprehensive assessment and development of a care plan, the case manager arranged domestic assistance and in-home respite for the man to assist with his care responsibilities and provide meaningful activity for his wife at home.*

## COUNSELLING

Emotional support is often needed to deal with the adjustment and distress experienced by the person with younger onset dementia and their family member/carers following the diagnosis of younger onset dementia. The need can continue during the process of readjustment and change that comes with the progression of dementia. The person with younger onset dementia often relies heavily on the family member/carer for emotional support, who is mostly commonly a partner, but often an adult child or less commonly a parent or sibling. The family member/carer also has their own emotional support needs as they manage the needs of the person with younger onset dementia alongside their own needs and sometimes those of other family members as well.

Sometimes people with younger onset dementia and their families do not seek counselling in the early stages of dementia due to the stigma of dementia and the low acceptance or understanding about the cognitive impairment. Families and carers indicated that counselling for the person with younger onset dementia would have helped the person to accept the diagnosis and acknowledge their strengths and remaining capacities.

One man with younger onset dementia, who lives alone, indicated that while he accepted his diagnosis, he would like the opportunity to talk to someone who understands,

*Maybe just talking to somebody would probably help. You know, I can talk to my mother or father or brother, but they're different. I don't know how to say it. They just say 'get over it.'*

Similarly, a woman with younger onset dementia said,

*My main problem is that what I am feeling and what I am saying comes out differently to what you are hearing. What I am trying to convey to someone is always misunderstood.*

Alzheimer's Australia NSW provides dementia counselling via the National Dementia Helpline and AlzNSW regional offices across NSW. Counselling is also available from other dementia services around the state, such as Memory Clinics. Some family members/carers found this beneficial, particularly immediately after the diagnosis. Others had been offered this service, but had not taken it up as they felt they were coping. A wife who did not use counselling stated, 'I felt they were more interested in his dementia than [in] me.'

Counselling is required at different times for a range of reasons. Some people found it helpful after diagnosis, while others needed to use a counselling service when some behaviours of dementia were difficult to manage and caused emotional stress. A wife whose husband with younger onset dementia had died reported that in hindsight she should have made use of counselling services when her husband was first admitted into residential care, as she felt she 'could have gone and driven off [a cliff]' such was her distress.

### **PSYCHO-EDUCATIONAL SUPPORT**

*The carer role for me is very lonely, you've got no one to talk to ... Loneliness is an issue. I've got lots of other stuff in my life, but at the end of the day, there's a person you've been with for most of your life, and now you're not going to be together ... Most of the time I'm strong, but sometimes it just catches you [husband].*

A service provider said,

*I don't think there's ever enough [support] for someone; because it's so fast in its progression often there's never enough to be able to cope with those changing needs, those increasing needs ... But certainly at the moment the support is really quite limited for both the carer and the person with dementia.*

The Alzheimer's Australia Living with Memory Loss Program (LWML) was an early intervention program cited by carers that met their psycho-educational needs. They cited the LWML program, particularly the version for younger onset dementia, as a helpful early stage initiative that provides information and education about dementia and support services available. Access to the LWML program is often via Dementia Advisory Services (DAS), which are operated by a range of health and non-government organisations. Some people with younger onset dementia and family members/carers also considered the generic LWML for all ages helpful. A wife said,

*In terms of receiving support ... it's wonderful, absolutely wonderful. I now get counselling through Alzheimer's [and] that's been an amazing help along the way ... being inspired by people who care so lovingly.*

#### **EXAMPLE OF GOOD PRACTICE PSYCHO-EDUCATIONAL SUPPORT**

##### **– Younger Onset Dementia Living with Memory Loss Program**

*The Younger Onset Dementia LWML Program runs for eight weeks, which is one week longer than the generic program. This week is included to provide extra time for a problem solving session in recognition of the additional needs related to younger onset dementia. On completion of the program a social support group is conducted for six months. People with younger onset dementia and family members/carers, who participated in the program are able to meet others in similar circumstances and often make friends. The program also has a process of referral to other services appropriate to people with younger onset dementia in their local area.*



## DAILY FUNCTIONAL SUPPORT

Assessment of people with younger onset dementia's cognitive ability is recommended (Hodges et al., 2009) in order to use their strengths to overcome other losses. An enablement approach such as this can enable timely strategies to psychologically reinforce the idea of maximising the remaining capacities of the person with younger onset dementia.

### EXAMPLES OF GOOD PRACTICE FOR MEMORY TRIGGERS

*Memory triggers can remind the person about activities such as to take medication or how to make a cup of tea. This allows the person to retain some independence and support their family members and carers, especially when they are at home alone. This assistance can be by way of technological assistance or simple strategies, such as using a white board to remind the person of their activities for the day. One man with dementia reported he used his Smartphone to record the list of things his wife asked him to buy at the shops, including photographs of items as a visual aid, and he found this useful.*

Family members/carers were asked their perspective on allied health services (such as occupational therapists) providing assistance with daily functioning for the person with younger onset dementia. Some family members/carers believed the value of the time spent setting up memory strategies would quickly be lost as the person's cognitive capacity decreases due to the rapid progression of younger onset dementia.

The discrepancy here implies the need for timely assistance with daily functional support, which is assessed and implemented as soon as possible after diagnosis and reassessed to cater to rapid changes in the progression of younger onset dementia. This would allow the person with younger onset dementia and their family member/carer to gain the optimum and longest-possible effect from the functional support.

## 5.2 COMMUNITY PARTICIPATION AND SOCIAL ENGAGEMENT

### KEY POINTS

- Cost and transport can be barriers to community activities
- People with younger onset dementia want to feel valued, have stimulation, worthwhile occupation and physical activity
- Social connections in the community with friends and family is important for the person with younger onset dementia
- Activities that are meaningful and person-centred meet the needs of people with younger onset dementia
- Changes in verbal communication and behaviours of dementia can be a barrier to participation for the person with younger onset dementia

### IMPLICATIONS

- Provide opportunities for people with younger onset dementia to participate in meaningful occupation, including work as volunteers
- Provide flexible person-centred support services to meet the individual needs of the person with younger onset dementia
- Encourage an enablement approach to increase the self-worth of the person with dementia and highlight the remaining capacity of the person to contribute socially and emotionally

- Provide a range of service types to enable choice for people with younger onset dementia, including transport and cost considerations
- Provide high staff-to-client ratios in centre-based day programs to enable active programs
- Provide services that address the need for physical activity suited to younger people as part of a person-centred approach, particularly men
- Provide joint opportunities for peer support for people with younger onset dementia and family members and carers
- Provide education and training, including effective communication, to service providers and family members

The people with younger onset dementia emphasised a need to remain engaged in the community for as long as possible and to keep up relationships with family and friends. It is important to find a fit between the needs of the person with younger onset dementia and their family members/carers. Many of the family members/carers interviewed emphasised the need for information, community awareness about dementia and good care for the person with younger onset dementia to promote community participation. Other examples are discussed in Sections 5.4 and 5.5.

Good community participation and social engagement can incorporate an enablement approach when providing services and support to people with younger onset dementia. An enabling approach focuses on what the person can do, not what they are currently unable to do. It facilitates a person to actively identify and pursue goals that are important and meaningful to them. Having appropriate service structures and assistance to identify and pursue these personally important and meaningful goals is also the approach of a person-centred model, focused on facilitating decision-making and choice by people with younger onset dementia themselves. An enabling and person-centred approach builds confidence and self esteem and empowers people to participate in decision making about their care needs, which in turn enhances their autonomy and independence and improves their wellbeing and quality of life.

### **BARRIERS TO COMMUNITY ACTIVITIES**

The cost of community activities sometimes precluded people from participating, particularly those who were not in receipt of any government payments, such as a Disability Payment or Carers Payment, or not eligible for benefits that come with older age. A wife said,

*I'm aware that there's a fishing group and an artist's group up here, which I think would be great for my husband, especially just the fishing, socialising and that, but I know again, there's a cost involved in that, how much it is, I don't know.*

Travel to social activities can also be a barrier, since people with younger onset dementia eventually lose the capacity to drive safely and many have their driver's licence revoked soon after diagnosis. This is often distressing, particularly for men and people who reside in regional or rural areas where public transport is not readily available. People with younger onset dementia want to remain mobile, but community transport is often only available to older, less mobile people with dementia. Younger people with dementia cannot always afford a commercial taxi service. Friends and family members often fill this gap and assist with transport requirements.

Transport can be a daily issue for people with younger onset dementia and their family members/carers. It can also be a problem for getting to support services, such as social and community participation programs, so some service providers said they needed to provide transport as part of the service arrangements.

## PEOPLE WITH YOUNGER ONSET DEMENTIA AS VOLUNTEERS

People with younger onset dementia expressed a desire to remain active in the community and some felt that volunteering filled that need. Transition out of work can be distressing for many people with younger onset dementia, because they feel the loss of regular meaningful activity and still want to contribute to their community. In the early stages of dementia, volunteering can be a good way for a person to make the transition out of paid employment.

One service provider reported that the RSPCA enlisted the help of a volunteer with younger onset dementia to assist with grooming and bathing the dogs. A man with younger onset dementia said,

*I have been thinking of doing some community work, some volunteer work, but I just don't know how to get into it, at the moment. I wouldn't mind doing something for dementia people. I haven't actually tried to do anything, got in touch with anyone, but I would do something if I was asked.*

### Case study about people with younger onset dementia volunteering

*Jenny explained that her husband Bob had volunteered for some time alongside her at a local health agency, but that once Bob could no longer assist her, a local service provider asked him to volunteer at the centre-based day program. Here he eventually became a regular visitor and then a client of the service. Jenny felt that Bob's smooth transition into the day centre was assisted by the cooperation of the service provider to include him as a valued volunteer first, then a client later.*

## PEER SUPPORT FOR PEOPLE WITH YOUNGER ONSET DEMENTIA

A good example of peer support for the person with younger onset dementia is the 'buddy' system of support. This type of support service is a professionally-led volunteer service that is usually part of an overall support program and provides a one-on-one, person-centred approach to social support services.

Buddy programs are particularly beneficial for people with younger onset dementia who live alone. Apart from the provision of physical and social activities, the buddy can provide support to undertake daily activities such as shopping, catching a bus and meal preparation skills, which enables the person to maintain their independence for as long as possible.

A program coordinator said that it is difficult to match a buddy to someone when communication is limited, so it is easier to access this type of support closer to diagnosis.

### EXAMPLE OF GOOD PRACTICE WITH BUDDY VOLUNTEERS

*One social support service described a program whereby trained volunteers and support workers are 'buddied up' with a person with younger onset dementia to provide social support and respite for their family member/carer once a week. During the assessment for the program, a personal history or background, previous occupation and hobbies is given to the coordinator and the match with a buddy is made accordingly.*

*The volunteers are given dementia specific training, such as how to communicate with a person with younger onset dementia, the unpredictable nature of dementia and what to expect as the dementia progresses. The coordinator touches base with the volunteer after each weekly visit and any changes or concerns are addressed. This provides a flexible person-centred service approach to meet the needs of each person with a buddy.*

## CENTRE-BASED DAY PROGRAMS

Centre-based day programs can benefit family members/carers by way of respite and at the same time provide meaningful activities and social engagement for the person with younger onset dementia. Some people with younger onset dementia who were naturally social said they enjoyed attending a centre-based day program. Some family members/carers reported that these people enjoyed their time and they were happy to attend if they felt valued at the centre, were allowed to contribute to the organisation of activities or were able to provide assistance to other people with dementia. Some day centres provide specific programs for younger onset participants, including age appropriate physical, social and musical activities.

Some CALD service providers said that some people from some CALD backgrounds with younger onset dementia use centre-based day programs as a social group. Word of mouth is a common source of referral. A service provider reported that some people of all ages with dementia from some CALD backgrounds present younger at mainstream and ethno-specific centre-based programs and often do not wait until health or frailty issues arise. This finding is interesting in its contrast to other reports below about participants who do not want to attend centre-based day programs. Perhaps the group programs meet the social needs of some people with dementia from some CALD backgrounds and their family members/carers, without the stigma associated with dementia.

However, many centre-based day programs for people with dementia often support frail, older participants and do not meet the needs of someone with younger onset dementia. Inappropriate sedentary activities, old fashioned music and being treated as children were common complaints about centre-based day programs. A service provider said,

*Normalise their life...need something that is going to give them some sort of meaning and connection, rather than being isolated out of the community, which is what happens when you go to a bricks and mortar day care centre.*

A wife said her husband refused to get in the bus that came to pick him up as it was full of old women. Another man with dementia joined a day program to participate in their walking group only to find that it was made up of people using walking frames who constantly needed to stop for a toilet break. The same man reported, 'I think the only thing I enjoyed were the lamingtons!'

Some participants described some centre-based day programs as lacking flexibility and unable or unwilling to meet the individual needs of people with younger onset dementia. In this environment, some people refuse to participate, it is not a stimulating environment and it prevents respite for their carer. A man with younger onset dementia said,

*Every now and then [I've been to a group], but you end up sitting around with people who just sit there and look at you and then you try and talk to them and nothing happens, but anyway, so it's a bit depressing basically – I'm not real keen on being, well, I put up with it anyway.*

Often the staff are not skilled enough to understand and manage the challenging behaviours of a person with younger onset dementia and resort to phoning the family or carer to say the person can no longer stay. Both service providers and family members/carers of people with younger onset dementia said they believe that workers at these centres need not only the appropriate skill base, but also the personality to support a younger and more active group attending the service. Appropriate service models and programs need to be developed that meet the needs, interests and abilities of the younger members, and service management needs to provide leadership and mentoring for staff and volunteers.

## EXCURSION GROUPS

Excursion groups that take people with younger onset dementia out for the day to different locations hold appeal for some people with younger onset dementia and family members/carers. The excursions are usually outdoors and include some sort of physical activity, such as walking or bowling.

### EXAMPLE OF GOOD PRACTICE IN AN EXCURSION GROUP

*One service picked up and dropped off up to three people with younger onset dementia, at a cost of \$10 on an outing from 9am-3pm. The excursions occurred every two or three weeks and included ferry trips and walks in the National Park with lunch provided.*

Unfortunately the example cited was a pilot program with nonrecurrent funding. A wife said,

*It was so sad that they finished it ... that they didn't get the funding ... it showed how many people there are ... with younger onset dementia, there's a need here. And I don't understand why they stopped it when there's a need.*

A man with younger onset dementia enjoyed an excursion group and spoke about it with his wife,

*Wife: But your most favourite thing is going out on the bus, isn't it?*

*Husband: Definitely.*

*Interviewer: You go out and have lunch somewhere?*

*Husband: Yes. And it's all so nice. We go to good places.*

*Wife: He likes going on Tuesday, because it's an older men's group, not dementia.*

*Interviewer: So it's a bit like a Men's Shed type arrangement, is it?*

*Wife: Yes, but it's not the actual Men Shed.*

*Husband: I'm the only person.*

*Wife: With dementia?*

*Husband: Yep.*

## PHYSICAL ACTIVITY

Many people with younger onset dementia were used to a high level of activity pre-diagnosis, compared to someone older have a greater physical capacity, particularly men. Consequently, it is important to find meaningful activity to meet their physical needs.

This requires a person-centred approach that caters to gendered variations within dementia care options. Centre-based day programs and social support programs that meet the range of gendered needs include younger staff, male and female staff and physical activities, such as bowls, walking and sailing, rather than just the more sedentary and female-oriented activities often offered by older dementia programs.

Models such as Men's Sheds are options for some men with younger onset dementia that have been successful with supervision. A man with younger onset dementia said, 'I find if I've got something to do, something to make, and I'm occupied, I am a lot happier.' The success of these models depends on the skills and knowledge of the organisers and other participants about dementia. The use of power tools, for instance, requires constant monitoring due to the unpredictable nature of dementia and the risk of injury to the person and other participants.

### **EXAMPLE OF GOOD PRACTICE OF SOCIAL SUPPORT FOR MEN**

*A good model of social support to meet the physical needs of men with younger onset dementia operates in regional NSW, based on a Men's Shed model. It is open to all people with dementia, but has a good component for younger participants. It specifically caters to the needs of people with dementia and provides trained staff and mentoring. Amongst the program's range of activities is its recent work with a local high school to develop a sensory garden.*

A 'buddy' system approach, that provides one-on-one attention to the person with younger onset dementia, can incorporate male-oriented activities, such as golf, cycling, surfing, walks and fishing to allow younger people to continue to engage in physical activity.

### **SOCIAL SUPPORT BENEFITS FROM PARTICIPATION IN DRUG TRIALS AND RESEARCH**

Drug trials and clinical research projects are conducted with people with rare and diverse types of dementia, mostly in Sydney. Some people with younger onset dementia and family members/carers attend these trials; some said that whenever they are accepted into the trials, they feel hope that they may be cured.

The trials primarily conduct clinical investigation, and this research also revealed an unintended consequence of social engagement for the person with younger onset dementia, increasing a person's self-worth and meeting the need to feel valued. One man with dementia said that he enjoyed the camaraderie and social engagement he found with the staff at the hospital and found the setting a place where he could be himself. He said,

*They have a very good way of dealing with people with dementia with sensitivity, humour and understanding, while still conducting their tests.*

Another man with younger onset dementia also reported that he felt participating in the trials was a 'reciprocal thing' and stated, 'I think I have something to offer others in the same situation.' Their participation in drug trials also indicates their capacity to seek and absorb as much information as possible about younger onset dementia.

### **JOINT ACTIVITIES FOR PEOPLE WITH YOUNGER ONSET DEMENTIA AND FAMILIES/CARERS**

Positive reports were given about activities that involve both the person with younger onset dementia and the family member/carers, such as dementia cafes, combined group outings, retreats and the AlzNSW Ad Hoc group. Some family members/carers thought activities together were a good idea because some people with dementia get anxious about going places by themselves and would be more willing to participate and socially engage if a family member was also able to participate. Other family members and carers valued a break away from their person with dementia and stated that if their respite time was limited they would prefer to do something on their own (Section 5.5). Such findings imply the need for a range of individual and combined service options.

### **EXAMPLE OF GOOD PRACTICE IN GROUP FAMILY SUPPORT**

*One DAS provides a regular get together for people with younger onset dementia and their family members/carers, which the participants are reported to enjoy. The same provider also organises retreats for both the person with younger onset dementia and the family member/carers. People who attend the get together stated that while the person with younger onset dementia was often apprehensive at first, it was enjoyable for everyone. The people with younger onset dementia are able to enjoy activities and mix socially with others their own age. The family members/carers felt that it was an opportunity to socialise in a safe environment and at the same time provide some respite from their daily concerns about caring for someone with dementia.*



## Dementia cafés

The dementia café model is a popular model of social support and engagement for both the person with younger onset dementia and their family member/carer. A dementia cafe is a place where people with younger onset dementia and their family members/carers can meet. They are usually run on a monthly or weekly basis by a health care worker or other workers who are trained in dementia care knowledge. Dementia cafes provide a social outlet and friendships are often made that continue beyond the group. Some cafés use other names to avoid the stigma associated with dementia.

### EXAMPLE OF GOOD PRACTICE OF SUPPORT WITH A CAFÉ MODEL

*One social support program holds a younger onset dementia specific Coffee Club meeting once a month in a large sport and leisure club. The Coffee Club is centrally located in the club and apart from the immediate contact with other people around the table, the location means that the people attending feel part of the club's overall activities. In this program, the club provides funding each month, as part of its community service allocation, to cover the cost of coffee and cake for the group.*

Another younger onset specific dementia café in western Sydney was also cited as beneficial to all attendees and the work of the coordinator was highlighted as integral to its success. A wife said,

*[The coordinator] does such a good job, she's so active. There's stuff for us to do every week; there's something we could go to every week and that's younger onset specific. And my worry is if we don't support it, it will go away.*

## Family retreats

In Sydney and regional areas, family members/carers said they and their family member with younger onset dementia had benefited from participating in joint retreats. The retreats combined respite and pampering for the family member/carer, social and active group activities for the people with younger onset dementia and, for both, the chance to make social connections with other people in the same circumstances. For couples, it was time to spend together without the care responsibilities felt by many families in their daily activities with the person with younger onset dementia.

Barriers to attending these retreats include the initial reluctance of the person with younger onset dementia for social engagement; funding; the time required; and availability of people to assist.

## 5.3 FAMILY AND RELATIONSHIP SUPPORT

### KEY POINTS

- Family members and carers' health is often good at the time of diagnoses, but the stress of caring can lead to a need for social and emotional support
- Marriage difficulty or breakdown due to changes and behaviours of dementia
- Families/carers need to manage financial and emotional stress
- Difficulty for school age children who are living with a parent with younger onset dementia
- Support for young people with a parent with younger onset dementia
- Multiple interdependent care roles with partner, children and parents

## IMPLICATIONS

- Promote a whole of family approach to practical, emotional support and social support
- Provide information to community members with whom families of people with dementia have a relationship, such as teachers and employers
- Encourage family counsellors to enhance their professional capacity for dementia specific education and training
- Inform service providers about ways to address the needs relating to the younger 'life stage' of family members/carers and people with younger onset dementia and their multiple care responsibilities, such as ageing parents and dependent children

## FAMILY RELATIONS

People with younger onset dementia showed concern for the wellbeing of their partners and families. For some, the anxiety about the future wellbeing of their family in the light of their own deterioration was their main concern. One man described his concern about his wife worrying about him doing work on their large property given his increasing symptoms of dementia, and highlighted that domestic or property assistance would be of key benefit to his wife for this reason. Such concern was also reflected in the survey data, where people with younger onset dementia overwhelmingly identified that younger onset dementia services should also focus on their partners or their whole family, as well as themselves (Table 5.3).

**Table 5.3: Focus of services for people with younger onset dementia and their families**

Whose needs should younger onset dementia services focus on?	Respondents	Per cent
On the needs of the person with younger onset dementia	1	5.9
On the needs of the person with younger onset dementia and the family/carer	10	58.8
On the needs of the whole family	6	35.3
Did not respond	1	
<b>Total</b>	<b>18</b>	

Source: Person with younger onset dementia questionnaire, Q. People with younger onset dementia – Whose needs should younger onset dementia services focus on?

Family conflict can be a significant consequence of younger onset dementia (Allen et al., 2009). A diagnosis of dementia can affect the person's partner and children, and other extended family relationships. Service providers explained that the strain on partner relationships can be intense,

*They might have been thinking 'Oh, I'm going to pull the plug on this and now I've got to take this on again because they're sick' and it can be a very difficult time for people ... that takes a huge amount of adjustment if you've been thinking of going.*

For some marital partners, along with the added responsibility of raising children, caring for ageing parents and maintaining a career, can be the added stress of maintaining a marriage relationship with someone with younger onset dementia, including the loss, expressed by some spousal carers, of a close sexual relationship. Some partners felt anger at the lost opportunities that they had

planned with the person with younger onset dementia and felt guilty about negative feelings they sometimes had toward their partner as the cause of their lost career, income, social life, holidays and/or companionship. A wife said,

*It's not just about services for the person with dementia. It is also about the impact on the children and the spouse. We need support too. If dementia was not in the picture, what we experience would be seen as child abuse or domestic violence. Because it is seen as coming from the dementia we are expected to simply suck it up. The cause of it doesn't change what we experience, especially so for the children.*

## **CARER SUPPORT GROUPS**

Carer support groups can be a source of good peer support and a way of meeting the emotional and psycho-educational needs of family members/carers. Some family members/carers stated they did not like attending a group that was not specifically for carers of people with younger onset dementia, as they felt they had little in common with the other members and 'our problems are a lot different.'

### **EXAMPLE OF GOOD PRACTICE FOR CARER SUPPORT GROUPS**

*Younger onset specific carer support groups are rare, but for family members/carers who attended these types of groups, they provided good social, educational, informational and emotional benefits, through exchange and a skilled and informative leader. The members could relate to each other and good referrals were made based on personal experience for respite accommodation and other support services.*

Family members/carers who participated in carer support groups reported that they received good emotional support from the group. Previous research by Alzheimer's Australia NSW (2009) highlights the importance of the 'uncelebrated capacity of group members to provide mutual aid in support of each other in the safe and trusting environment of the carer groups.'

Family members/carers in this research who had gone to support groups spoke about the peer support they received – 'no one's embarrassed, you help each other.' When asked what is required to support people to continue to care for a family member with younger onset dementia for as long as possible, many family members/carers highlighted the need for carer support groups.

## **SUPPORT FOR FAMILIES WITH CHILDREN OF PEOPLE WITH YOUNGER ONSET DEMENTIA**

Children often experience their parents' grief and loss and may feel shame about their parent's behaviour, anxiety about stress in the parents' relationship, loneliness because the healthy parent needs to devote added attention to the person with younger onset dementia and worry about developing dementia themselves (Rosenthal Gelman and Greer, 2011).

Family members/carers were concerned for children still living at home, especially if they were still at school. In some cases, husbands or wives of people with younger onset dementia felt they were parenting their children and their spouse and felt protective of both. A wife said, 'My kids are confronted with it daily, like twenty four hours. And they're really, really good with him. They're amazing with him.'

Some families still had adult children living with them and generally these children were a source of support to their parent with the main care responsibilities. One woman had a night out each week to attend a craft session, while her son stayed at home to care for his father with younger onset dementia.

The prevalence of young people as primary carers may rise with the increasing number of single parent families<sup>4</sup>. These young people will need to be equipped with support services to assist them at the beginning of their adult life.

### **Case study of adult children carers**

*James who was aged 28 years old cares for his father, Sam. Sam was diagnosed with dementia by a neurologist and given some information and referral to support, but none of the information was specifically for younger onset dementia. Initially Sam was supported by another family member, getting advance planning documents in order, but eventually James decided to give up work to look after his father.*

*James said the care responsibilities are stressful and coordinating the services for Sam are difficult, 'It's like pass the parcel.' James would appreciate a case manager to help him coordinate information and services. He said it would be in the government's interest to support family member/carers of people with younger onset dementia because 'You're not just losing one person out of the community – you're losing two.'*

### **EXAMPLES OF GOOD PRACTICE FOR SUPPORTING ADULT CHILDREN AND YOUNGER CHILDREN**

*Alzheimer's Australia NSW has a blog to reach young people who have, or know someone, with younger onset dementia in their family, as well as a specific young people's support group to assist the sons and daughters, aged over 18 years, of people with younger onset dementia. One group member claimed, 'I wouldn't have survived without that group!'*

*A social support service on the Central Coast of NSW organised a Bowling Day at the local bowling alley and many of the children of the people with younger onset dementia attended with their parents. Apart from the shared enjoyment experienced amongst the participants, the service provider stated that it was a great initiative for the children to get together and know there were others with similar experiences.*

Consideration of children of people with younger onset dementia implies that a whole of family approach needs to be developed within the sector to enable a coordinated approach to supporting all family members. Families need to have the necessary resources to allow them to live together for as long as possible, at home and as active participants in the community.

## **5.4 INFORMAL SUPPORT**

### **KEY POINTS**

- People with younger onset dementia often have active social lives with broad networks of friends and neighbours they can draw on for support
- Some CALD communities can have strong trusting relationships with community leaders
- Strong informal support networks can support ongoing participation in social and community life for people with younger onset dementia

### **IMPLICATIONS**

- Provide information to strengthen awareness and understanding of dementia in the community to encourage support from informal sources
- Provide education to informal support persons with a focus on practical strategies, including effective communication

Many people under the age of 65 years have active social lives such as with neighbours, family and friends, from which they can often call on for informal support for assistance. Family members/carers reported that even when the person with younger onset dementia had not accepted their diagnosis, caring neighbours or extended family members would covertly assist by keeping an eye on the person with younger onset dementia, for instance, if the family member/carer needed to leave the person at home to go to work.

#### **EXAMPLES OF GOOD SOCIAL SUPPORT**

*Family members/carers told of how friends from the beach or the coffee shop continued to include the person with younger onset dementia in their activities, thus maintaining social connections and worth for the person and respite support for the family.*

*One man with younger onset dementia reported that he still rides his bike to the coffee shop each morning to socialise with his male companions.*

*A family member/carer who had injured her arm badly and could not drive was assisted by a neighbour when she or the person she cares for needed to be taken to appointments, sometimes quite a distance away, as the person with younger onset dementia no longer had his driver licence.*

Service providers supporting people from culturally and linguistically diverse backgrounds reported that informal networks amongst the family are often utilised. However like other communities, other informal networks, such as friends and neighbours, are not always available due to the stigma related to poor information about dementia and some cultural beliefs that the family should be the sole carers.

A CALD service provider explained that sometimes the community or religious leader is often a valuable informal support to the person with younger onset dementia and their family. Some people from a CALD background may be suspicious of government services due to their background, such as that of asylum seekers and refugees, yet a community leader is considered authoritative and respected and can provide support and comfort for this reason. These informal supporters are of most value if they are informed about dementia and able to refer the person concerned onto other support services that may be able to assist them.

Strong informal support networks can reduce reliance on paid services and promote social inclusion for people with younger onset dementia, while at the same time enhancing their mental health. To strengthen informal support, community awareness and understanding of dementia needs to be increased so that the stigma associated with dementia is reduced.

## **5.5 RESPITE SUPPORT**

*I picked up a book for the first time in three years [a wife]*

### **KEY POINTS**

- Some working carers need respite to continue employment and take time out
- Trained workers and suitable activities are necessary for safe and meaningful respite
- Respite support can relieve strain on family members/carers, including from behaviours of dementia
- Some GPs and service providers have poor understanding about the cause of these behaviours and strategies to manage them
- Behaviours of dementia can be a barrier to support and service delivery

## IMPLICATIONS

- Provide flexible respite models to meet the needs of working family members/carers
- Provide training, education and support for service providers to manage behaviours of dementia
- Encourage person-centred activities in respite for people with dementia to match their age and interests
- Provide education and training to service providers of in-home respite about the needs of people with younger onset dementia and models for appropriate engagement, to support continued living at home and to avoid premature entry to residential care
- Encourage service providers to utilise available specialist support services including DBMAS when needed to support a person with behaviours of dementia

Some family members sought respite services to continue working and/or to provide some relief from the physical and emotional strain of caring, particularly if the person with younger onset dementia displayed behaviours of concern. Respite can be accessed via centre-based day programs, in-home respite and community based programs, such as the 'buddy' system of support, which provide peer support to the person with younger onset dementia but also an opportunity for respite for the carer (Section 5.2). At later stages, some people also use residential respite (Section 6.2).

Most family members/carers indicated in the survey that they felt they would benefit from respite services and other similar assistance (Table 5.4). This was confirmed in qualitative comments from people with younger onset dementia, identifying respite as a support service that would assist and benefit their other family members. The survey for people with younger onset dementia also indicated this finding, although the response was too small to be conclusive.

**Table 5.4: Family benefit from one to one respite, personal care or domestic assistance**

	Respondents	Per cent
I would benefit	31	81.6
I would not benefit	5	13.2
Don't know	2	5.3
Did not respond	10	
Total	48	

Source: Family/carer questionnaire, Q. Would you benefit from one-to-one respite, personal care or domestic assistance?

## RESPIRE FOR WORKING CARERS

Some families and carers needed respite to help them to continue to work. Some family/carers and service providers suggested that longer centre-based day programs could address this. One woman had used her five hours of respite to engage a worker to come in each morning to help with breakfast and personal care with her husband while she got ready for work. Another carer, who worked from home, said she would like someone to provide respite, either at home or elsewhere, so that she could continue working in another room at home without disruption.



### **EXAMPLES OF GOOD PRACTICE FOR DAY RESPITE FOR WORKING CARERS**

*A respite service operates in an area of Sydney to provide five hours of respite per week specifically for working carers and particularly those that want to retrain for entry back into the workforce. This service is currently only available for carers of frail older people with dementia and while the number of hours is relatively small, it is encouraging that it recognises the needs of working carers.*

*Another service in Sydney provides centre based support Monday to Friday from 7am-7pm. The service is open for people of all ages and accommodates between 10-15 people at a time. The centre advertises a program that offers 'a variety of structured activities such as group outings, theme and culture days, gentle exercise, entertainment activities and various other recreational activities. Individual care plans with flexible respite can be organised if required and the centre provides meals and refreshments throughout the day.'*

### **RESPITE FOR BEHAVIOURS OF DEMENTIA**

*If I give him one-on-one attention, sit beside him and stroke his hand, he is OK. But if I complain or am not available, he loses it [wife].*

Some behaviour associated with dementia can be disturbing and have a significant effect on the emotional and physical health of family members/carers and are often the reason that they seek respite care for the person with younger onset dementia. These behaviours can include wandering, sleeplessness at night, uninhibited sexual behaviour, incontinence, aggression and violence.

Some people with younger onset dementia who displayed such behaviours of concern had not received appropriate specialist support and would sometimes be prematurely placed in a high care residential facility or psychiatric hospital. Antipsychotic medications were sometimes prescribed and little attention was paid to the cause of the person's actions or consulting with the family member/carer to try to seek out the cause of the behaviour.

Sometimes a barrier to good services for these people with behaviours of concern and their family members/carers was the person's non-acceptance or lack of insight into their condition. Some family members reported not being able to even talk about dementia in the presence of the person.

Another barrier to support was a lack of understanding by GPs and service providers about the cause of these behaviours and strategies to manage them. Some of these challenging behaviours can be reduced with active, stimulating and meaningful activity that requires active participation. Some people with younger onset dementia need to be supported by a higher staff-to-client ratio than traditionally found in dementia or aged care programs, to meet the need for a higher level of physical activity and stimulation. Past research cites a dementia behavioural advisor who states 'many people look to abscond from social programs, because they are not active and engaged' (Tyson, 2007:26).

When service providers were asked about appropriate training for staff caring for people with younger onset dementia, they cited managing behaviours of concern as a common problem that requires specific training to seek out and address the cause, rather than constant medicating. This requires a high level of support, knowledge and skill for the workers in support services for people with these behaviours.

### **IN-HOME RESPITE**

Some family members and carers explained that they did not need to use in-home respite until the person with younger onset dementia could not be left alone in the house. They used in-home respite

to attend meetings, catch up with outside tasks or to enjoy a social event alone. An adult child caring for her mother said,

*The ladies who visit Mum and take her to her appointments or for her weekly shop and coffee outing are wonderful! They've been able to match Mum with people who are humorous and fun to be around, which is what Mum responds well to at the moment. They are never demeaning and seem to have a good grasp of her dementia and how to communicate with her without leaving her feel like she's been put down.*

One service provider was currently advocating for younger onset dementia specific overnight respite in a home setting in her local area, stating that,

*Younger onset dementia clients should not be forced to do a respite program in a [large] group situation, because dementia is very confronting and often they don't want to see or socialise with other people with more advanced impairments than they have.*

A barrier to in-home respite can sometimes be the reluctance of the person with younger onset dementia to have a stranger in the home. Some family members/carers said that if the same support worker visits over time this allows the person to get to know and trust the worker.

#### **EXAMPLE OF GOOD PRACTICE IN HOME RESPITE**

*A respite worker comes from 10.30am to 1.00pm on a Tuesday to relieve Sue who cares for her husband Robert. The worker takes Robert and the dog walking by the ocean and then they have a coffee at one of the local coffee shops. The respite worker introduced herself slowly to Robert by coming first as a helper for Sue and doing the ironing so that Robert could get to know her slowly. Once they worked out how they would get along, the respite worker introduced the idea of having an outing. If Sue does not go out, she stays at home for some quiet time.*

Another barrier to in-home respite was that some workers did not have the skills to cope with the person's challenging behaviours, especially if the person was worried about the absence of the family member/carer. A wife told of leaving her husband in the care of a respite worker overnight with disastrous consequences. She said,

*Jim became quite confused and annoyed with the worker and verbally abused him. The worker left the house and never came back. He left at around midnight and left Jim on his own until the next morning around 10.30 when the next worker arrived [to take over]. I was furious!*

Some family members/carers who wanted to maintain their involvement in outside activities and social lives with friends and family requested in-home respite at night or on weekends but were refused. They said this would have supported them to maintain social connections and would have been beneficial to their emotional health and wellbeing. A wife said,

*My husband has severe younger onset dementia. Whilst I still care for him at home and I have an EACHD [Extended Aged Care at Home Dementia package], it is not flexible at all. Unless you want respite Monday-Friday 9-5 they can't help you. It is extremely hard as a younger carer to try to keep up some sort of social life.*

## **5.6 EMPLOYMENT, FINANCIAL AND LEGAL SUPPORT**

*The challenge is money, especially with a large mortgage [wife].*

### **KEY POINTS**

- Impact of premature loss of income
- Difficulties transitioning out of paid employment
- Impact of loss of employment on self-esteem
- Importance of executing legal documents to plan ahead while the person still has the cognitive capacity to participate

### **IMPLICATIONS**

- Promote knowledge of financial and employment rights and entitlements from advisors and welfare agents, such as social workers, case managers or Centrelink or human resources personnel
- Increase awareness and education about dementia for employers and coworkers; and front line staff providing financial services and advice to people with younger onset dementia
- Promote an enablement approach amongst employers to ensure people with dementia are employed for as long as possible using their retained capacities

### **PAID EMPLOYMENT**

The impact of younger onset dementia on the experience of work for the person diagnosed and the family member/carer was an important finding. Many of the people with younger onset dementia were still working when their diagnosis was confirmed, however they all resigned soon afterwards. For some, their employer cited poor performance and recommended they resign or made them redundant. For others, they recognised their inability to continue to work productively in their specified role. They strongly felt their loss of financial security, their attachment to their profession and the stimulation that work provides.

A man whose profession had won him awards in Australia and internationally was still very proud of his achievements and spent time perusing books that depicted his career highlights. Employment and a steady income had enabled another person with younger onset dementia to care for dependants and repay debts, such as a mortgage, credit cards and loans for cars and holidays. Alternative participation through volunteering is discussed in Section 5.2.

### **FAMILY AND CARER PAID EMPLOYMENT**

Many family members/carers were working when the person they care for was diagnosed and some continued to work part time after diagnosis. Some carers needed to keep working to provide an income for the family, especially because their partner had stopped working; to have some social and intellectual stimulation outside their caring role; and to at least work minimal hours so that they had continuity of employment when the person with younger onset dementia was no longer living with them.

In addition to income loss, the impact for family and carers who resigned early was that it reduced their future workforce capacity, changed collegial relationships and disrupted financial expectations. The tension between caring for someone now and planning for the future for young family member/carers was evident. A husband said,

*I'm only 56. Let's say in another five years [my wife] is either dead or in a nursing home ... I'll have to go back to work ... that transition back into the workforce ... really it's in between, if the ... government could provide employment opportunities for carers, work from home, specifically online, and you know, I could be home here. And I've done it in the past, worked from home.*

Most carers reported their employers were understanding but others explained that they had used all their leave or felt they could not continue to ask for favours of their employer. Some carers were able to leave the person with younger onset dementia at home alone, but once that was not a possibility they usually resigned.

## **FINANCIAL AND LEGAL PLANNING**

The loss of household income caused significant financial difficulties for some people, especially if the partner was also unable to remain in the workforce due to caring responsibilities. Some family members/carers reported failed business ventures, mismanagement of the family's financial investments resulting in lost income for their retirement years and an inability to deal with money and payment of bills on the part of the person with younger onset dementia. An adult child caring for their father with dementia said,

*My father was financially abused by a neighbour prior to me obtaining a power of attorney. I wish someone had given me advice on how to protect Dad's financial position in the early stages.*

The consequent financial loss felt by many people with younger onset dementia and their family members/carers requires financial advice and assistance at the point of diagnosis. This includes advice about matters such as rights of the worker with dementia to benefits via insurance or superannuation schemes and low cost finance. Often people with younger onset dementia stopped working before they had investigated their rights as employees or had not accepted their diagnosis and were therefore unable to pursue any available benefits.

Tools for planning ahead, such as enduring power of attorney, a will, enduring guardianship and advance care directives, need to be urgently addressed after diagnosis, while the person still has capacity to be involved in making these plans. Welfare services such as Centrelink and commercial services, such as accountants, financial planners and lawyers should be skilled in this area of assistance. Some family members/carers reported that they were helped by another family member, lawyer or accountant, but others told of not receiving appropriate assistance from workers who were unskilled in knowledge of dementia, especially younger onset dementia, in both the welfare and commercial service areas.

They also made some unfavourable reports about the inadequate skill level of particular staff at Centrelink, with one couple being advised to separate for the sake of financial assistance. Inconsistent information about entitlements was given to different family members/carers in different regions and staff knowledge of dementia was not always good. State and local level information and training to Centrelink front line staff about younger onset dementia could address some of these problems.

A participant suggested that perhaps facilities for temporary suspension of payments to banks on debts such as mortgages could be negotiated. This could be for a limited amount of time to alleviate the financial and emotional strain on the family member/carer until they are able to return to work. A wife said,

*There must be a lot of people in our situation with younger onset Alzheimer's, and who've been self-employed and who are in just an absolute mess. If there was some scheme out there where you could access a lower interest rate home loan rate that you could get into, that would be fantastic.*

## **5.7 SERVICES FOR PEOPLE FROM CALD BACKGROUNDS**

### **KEY POINTS**

- Stigma of younger onset dementia in some culturally and linguistically diverse communities
- Some family members are expected to take on most of the caring role, especially personal care

### **IMPLICATIONS**

- Provide information and support to family members/carers about younger onset dementia in a safe environment without stigma
- Provide information and education to CALD specific GPs and community leaders about the nature of younger onset dementia and support services to assist them
- Adopt a whole of family approach to address the needs of the whole family in the context of particular CALD communities
- Encourage further research about the needs of people from CALD backgrounds with younger onset dementia and their family members/carers

In addition to comments already made on centre based day programs, information specific to services for people with younger onset dementia from CALD background was reported in the research. Some service providers reported that some CALD communities are receptive to general information sessions where they are not singled out, due to the stigma associated with dementia and the shame it can bring to the person and the family.

The research suggested a high degree of stress for some family members and carers if cultural attitudes in some groups reinforce that the care rests solely with the family and often with one family member. Care can be emotionally and physically stressful, particularly alongside the barriers to service that cultural understandings and implications of a diagnosis, poor information and stigma can create.

In some areas, language specific support groups and counselling services are helpful and provide information about dementia and services to suit the needs of the family member/carer. There were however few reports of services specifically for people with younger onset dementia and their family members/carers.

## **5.8 SERVICES FOR PEOPLE WITH OTHER DISABILITY AND HEALTH CONDITIONS**

### **KEY POINTS**

- Access to supports through existing disability or health services
- Importance of person-centred and self-directed care
- Need for supports to families and carers
- Need to explore younger onset dementia in disability sector support services
- Younger onset dementia is sometimes ignored in care plans for other conditions

### **IMPLICATIONS**

- Encourage collaboration amongst health and other service providers in the development of a person with younger onset dementia's individualised care plan
- Incorporate a person-centred approach to provide choice and self-directed care
- Provide education on dementia to the disability sector for both physical and intellectual disability

Some service providers explained that where there is another disability or health condition, the diagnosis of dementia is sometimes overlooked as a focus for treatment and support. Collaboration between disability and health professionals is required so that the symptoms of dementia are incorporated in the care plan for the person concerned.

Some people with other primary conditions, however, found it was easier to access services because they were already in the system. These people already had experience with service delivery and their rights as a person with a disability and so they were able to apply this information to finding appropriate dementia services as soon as the needs arose. Some people with a disability also often have services managed by a case worker, who sometimes with the right skill set, can adjust the support to also address the dementia related needs and so alleviate the need to bring in more service providers to assist.

**Case study about a person with dementia and other health conditions**

*Michael explained he has had severe health problems since birth and been the recipient of various services and supports that have continued through his life. He said this life experience has enabled him to realise the potential for his contribution to participate in decision making about his own care. Michael and his partner have been able to access HACC and respite services and feel they are more aware of the range of support services available to them due to the knowledge they have accrued over time.*

Self-directed and person-centred care are preferred service models for people with a disability – models which are currently also promoted for people with young onset dementia (Community Care Directorate, 2012). Self-directed care services enable the person with younger onset dementia and their family member/carer to choose what they need when they need it. An added benefit is the person with younger onset dementia can be given the opportunity to participate in the decision making process, if they still have cognitive capacity, and so the service is more appropriate and timely in matching the needs of both people.

Amongst the disability sector recognition is also given to the need for respite for carers and its positive effects. Service providers are often already aware of the complexity of family dynamics in the case of disability and so offer assistance to families and support to children, such as programs with Carers NSW and the Young Carers program. A neuro-psychologist spoke of the benefits of a program called “Flexi-Rest”. With links to Muscular Dystrophy, Motor Neurone and MS Associations, the program is funded by ADHC and provides self-directed funding for broader respite options as determined by family members/carers.

A service provider in the disability sector reported that dementia and cognitive impairment had only been paid lip service in the past and that service delivery to people with other conditions, that included younger onset dementia, had not developed well in disability services and support. This implies that there is still further development to be made in providing services to people with younger onset dementia as well as another primary health condition.



## **6 SUPPORT IN THE LATER STAGES OF YOUNGER ONSET DEMENTIA**

This section discusses the main issues facing people with younger onset dementia, their families and carers during the later stages of dementia. This includes accessing appropriate support to keep people with younger onset dementia living at home for as long as is suitable; using residential respite services; and decisions concerning residential care placement.

### **KEY POINTS**

- Inconsistent access to Australian Government funded aged care and disability packages of support
- Different interpretations and application of Aged Care Assessment Team (ACAT) policy about assisting people with younger onset dementia
- Some residential respite staff have poor understanding of younger onset dementia and have difficulty dealing with behaviours of dementia
- Shortage of younger onset specific residential respite facilities
- Shortage of appropriate residential care facilities for people with younger onset dementia
- Some family members and carers feel guilty about moving the person with younger onset dementia to residential care

### **IMPLICATIONS**

- Clarify eligibility criteria for assessment and access to packages of support
- Promote interaction and collaboration between service providers to proactively manage changing needs, including between specialist and mainstream professionals, family, carers and people with younger onset dementia
- Increase younger onset dementia specific training opportunities for staff working in residential care facilities
- Develop alternative models to traditional residential care and accommodation for people with younger onset dementia
- Develop protocols for planned and supportive transition to residential care when it is required
- Improve the range of palliative care services in the home

### **6.1 ACCESS TO ACAT ASSESSMENT AND AGED CARE PACKAGES**

State and Commonwealth responsibility for funding and delivery of aged care and disability support services was reformed during the period of this research. From 1 July, 2012 the State government is financially responsible for disability support and the Commonwealth government is financially responsible for aged care services. Contracted service providers are likely to continue to deliver support to both groups of people through aged and disability sector funding.

Services that assist people with dementia to continue to live in the community are funded primarily by the Home and Community Care (HACC) program and other Commonwealth Government programs including Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), Extended Aged Care at Home Dementia (EACHD) and the National Respite for Carers Program (NRCP).

The HACC Program provides basic maintenance and support services that promote independence at home and in the community. CACPs are planned and managed packages of community care for people with complex low-level care needs, who can still live in their own homes. EACH is another planned and

managed package for high-level care at home for people who need more assistance than in a CACP. EACHD packages are for people who need extra assistance including nursing, because of behaviours associated with dementia, including periods of changes in behaviour or other disturbances (Australian Government, 2012). The Australian Government's Aged Care Reforms outlined in 'Living Longer. Living Better' increase the range of packages and change the way that packages of care are delivered<sup>5</sup>.

Access to Commonwealth funded packages of support, respite in residential aged care facilities and permanent placement in residential aged care require that people are assessed by an Aged Care Assessment Team (ACAT). Most family members/carers who had received an ACAT assessment for the person they cared for were satisfied with the experience. However, some families, carers and service providers reported that sometimes people with younger onset dementia were refused access to an ACAT assessment.

The barrier to accessing ACAT in some areas was due to the criterion imposed in those areas that the person needs to be aged over 70 years for assessment. As a consequence, some people with younger onset dementia cannot access to services at require an ACAT assessment in those areas. One family member/carer was told by an ACAT assessor that she should not be ringing the ACAT team even though the service provider said her husband's dementia is regarded as an aged related illness for assessment. The ACAT told the woman she had to exhaust all HACC services before she would be entitled to an ACAT assessment. Although an ACAT assessment is deemed a last resort for people under the age of 70 years (NSW Department of Health, 2007), the policy states that people with younger onset dementia may access services, such as respite and accommodation in residential age care facilities (RACFs), and therefore require an assessment.

#### **Case study about access to ACAT**

*Laura told how she had to be persistent in order to get ACAT to assess her husband, Kevin. She explained that the actual assessment process was good, however when she initially requested an assessment, ACAT said they could not have one because it was too soon to be asking for an assessment. Laura asked again and ACAT again said no, they were too young. She persisted and eventually Kevin was assessed because they had to have an ACAT assessment to access the respite services they needed. ACAT would not assess his eligibility for residential care.*

A service provider reported that sometimes when clients with younger onset dementia have been assessed by ACAT, they are offered community service support, which comes at a cost and not as part of a package. She explained that this is particularly difficult, as these clients have already experienced a loss of income and, if not in receipt of a disability payment, struggle to meet their everyday expenses (see also Section 5.2). Another service provider spoke of the shortage of EACHD packages for people with younger onset dementia, stating that she has 'seen people die waiting for a package and a higher level of care.'

This research found some confusion amongst family members/carers about when and how they can use the ACAT team. One family participant told of how he received no follow-up referrals or support package after an ACAT assessment and in order to meet his wife's increasing care needs he ended up sourcing and paying for private services. Some people were unable to access an assessment and some could access an assessment but were unable to receive the support for which they were deemed eligible, either due to service providers not accepting younger clients or services lacking the flexibility to meet their needs.

In summary, accessing an ACAT assessment as a person with younger onset dementia appears to vary according to where they live in NSW. The ACAT policy, process and procedures for people with younger onset dementia were inconsistently interpreted and applied, and as a result, people are prevented from accessing some services that require the assessment to determine eligibility.

ACAT is an Australian Government responsibility, but concerns about the assessment process and access to aged care services for people with younger onset dementia need to be considered by the NSW Government, due to their recent responsibility for services and support to all people under 65 years. Either a separate assessment process for people with younger onset dementia is needed or the NSW Government must advocate for consistent recognition of younger onset dementia by ACAT teams throughout NSW.

## 6.2 RESIDENTIAL RESPITE

Residential respite care provides short-term care as needed to give family members/carers a break. Residential respite care may be used on a planned or emergency basis. As identified in the literature review (Thompson, 2011), previous research indicates that family members/carers of people with younger onset dementia are reluctant to access residential respite, as the services are usually designed for aged care and do not meet the needs of younger people.

The survey data highlight that family members/carers felt they would benefit more often from residential respite than the people with younger onset dementia (Table 6.1 and Table 6.2). Residential respite decisions confronts tensions between the needs of family members/carers and people with younger onset dementia.

**Table 6.1: Family members and carers would benefit from residential respite**

Opinion	Respondents	Per cent*
I would benefit	24	64.9
I would not benefit	9	24.3
Don't know	4	10.8
Did not respond	11	
Total	48	

Source: Family members/carers questionnaire, Q. I think I would benefit from my family member using residential respite

Note: \*of those who responded

**Table 6.2: Person with younger onset dementia would benefit from residential respite**

Opinion	Respondents	Per cent*
They would benefit	20	55.6
They would not benefit	3	8.3
Don't know	13	36.1
Did not respond	12	
Total	48	

Source: Family members/carers questionnaire, Q.I think my family member with younger onset dementia would benefit from residential respite

Note: \*of those who responded

The families and carers in the research had few positive experiences of residential respite facilities. One woman told of her experience when her husband went to residential respite – they ‘kicked him out’ on the grounds that his behaviour was too aggressive and they had a duty of care to other patients.

### **Case study about residential respite**

*Rose stated that, 'Respite is disastrous for younger people', after explaining her difficult experience with respite. Staff called her to come and collect her husband, Nathan, after one hour because the staff could not manage his behaviour. He was banging on the walls and was aggressive, as he was distressed. They did not give him an opportunity to settle in and get used to the respite facility. Nathan was labelled as too difficult and Rose was forced to give up her respite at a time when she most needed a break.*

Some service providers also told distressing stories about the experiences of people with younger onset dementia in residential respite facilities. They identified poor understanding of younger onset dementia as the reason some residential respite staff could not deal well with younger people. One service provider reported poor care practices, such as restraining people and instances where the family member/carer was called to return from holidays to take the person with younger onset dementia home when staff were unable to deal with challenging behaviours. This added to family member/carer stress, rather than relieved it.

Some people had positive respite experiences in respite cottages, rather than larger residential aged care facilities. One service provider contrasted good experiences of residential respite in a cottage, rather than a larger setting. A spouse said,

*[We need] more respite centres for people with younger onset dementia – not in a nursing home. Some sort of group house, as a respite service e.g. a week's stay ... the houses could be used as retreats for both carers and sufferers.*

### **EXAMPLE OF GOOD PRACTICE IN COTTAGE RESPITE**

*A cottage style respite operates on the NSW Central Coast. It is suitable for younger onset clients as it is located in a house. Each respite resident has their own bedroom, the living areas are cosy and homely, and the backyard is large and secure. Residents are encouraged to treat the home as their own for the duration of their stay.*

Some family members/carers of older people with dementia use residential respite as a way to ease the transition into residential care. However, negative experiences for younger people with residential respite services may have implications for family members/carers' attitudes towards full-time residential care, creating barriers that may negate their inclination to take up permanent placement in residential care.

Family and carers of people with younger onset dementia agreed they would be more willing to use residential respite services if the service was flexible and age-appropriate to the needs of younger people. They also said that if they had a trusting relationship with a service provider, they would consider allowing a care worker to stay in their home for a length of time with the person with younger onset dementia so that they could go away for a holiday. This implies the need for service providers to build trust through continuity of care to be able to provide in-home respite (Section 5.5).

### 6.3 RESIDENTIAL CARE

Although this research focused on community-based services and models to prevent premature entry into residential aged care facilities, some families and carers also discussed decisions about the use of residential care. The topic was too sensitive to discuss with other family members/carers and most people with younger onset dementia.

Some families and carers said that they need services and support to enable them to continue to care for the person with younger onset dementia at home and to prevent premature entry into residential care. Many family members and carers were determined to keep caring for their person with younger onset dementia for as long as possible in their home. However, some people recognised this may not be possible or appropriate in some instances and discussed the care and accommodation options available and ideas for alternative options.

More than half of the family members/carers surveyed believed that the person they care for would benefit from permanent residential care at some stage (Table 6.3). They were less sure about the benefit to themselves, although over 40 per cent thought they would benefit too (Table 6.4).

**Table 6.3: Benefit of residential care for the person with younger onset dementia**

	Respondents	Per cent*
My family member would benefit	20	55.6
My family member would not benefit	3	8.3
I don't know	13	36.1
Did not respond	12	
Total	48	

Source: Family members/carers questionnaire, Q. I think my family member would benefit from using residential care

Note: \*of those who responded

**Table 6.4: Benefit of residential care for the family member/carers**

	Respondents	Per cent*
I would benefit	15	41.7
I would not benefit	9	25.0
I don't know	12	33.3
Did not respond	11	
Total	48	

Source: Family members/carers questionnaire, Q. I think I would benefit from my family member using residential care

Note: \*of those who responded

Some family members/carers discussed their future plans for using residential care. Some husbands defined incontinence as a point at which they would need to consider moving their partner into residential care. Two husbands said,

*I think everyone tries to keep their partner at home for as long as possible ... but once they become incontinent, how much cleaning up can you really do? How much can you take before you snap, you know?*

*I think the turning point for me will be incontinence ... it's a bit of selfish thing and I have huge difficulties with it, but I think in many ways we'll see when the time comes, but that seems to me to be time in my head that I will need help ... and even with her weight, manhandling her will be difficult; I've always had back problems.*

The wives who had moved their partners into residential care said the point at which they felt that residential placement was necessary was when their husband became aggressive and they had safety concerns and had extreme carer stress. A wife told of how she was forced to move her husband into residential care after he was hospitalised. She asked if they could have a package of support so her husband could remain at home, but this was denied and she was told that he must go into a residential aged care facility. She said,

*When he ended up in hospital that was the end of road. The social workers said to me, 'You can't take him home.' I felt like I wanted to continue fighting it. Like I felt that if they could sort of get his medication and behaviours under control, I would have like to have had him at home for as long as possible ... They told me that I wouldn't be able to cope anymore, you know, the social workers said we know best ... I was really quite prepared to continue looking after him, but I wasn't given that option. They found a place, but as they say, you wouldn't put your dog in it.*

She later found another place for her husband in a dementia specific unit and was able to move him there.

#### **Case study about residential care**

*Julie explained about when her husband, Craig, moved from home to residential care. Julie reached the point when it was increasingly difficult to care for Craig at home. His spatial perception was affected and he was having lots of falls. Julie called people to come over to help him up. Service providers advised her to call an ambulance to help get him up, but she didn't feel comfortable doing that. Craig became incontinent and Julie had difficulties when changing him and he became aggressive. She also had to feed him. Julie received in-home assistance to shower him, but did not have any help at night when he would not sleep well. 'I hated the night; I'd nearly end up in tears.'*

*The emotional toll on Julie was considerable. Prior to moving Craig into residential care, Julie was seeing a psychologist regularly, because she was struggling to cope. When she decided Craig needed to move into residential care, they used up their remaining respite hours before he moved permanently. Craig's geriatrician was helpful and phoned facilities on Julie's behalf, requesting that he be placed at the top of waiting lists. Craig moved into a high care dementia unit and although he has settled in well, he is the youngest resident. Julie visits Craig every day and continues to care for him.*

Some family and carers noted concerns about the financial impact of residential care placement, including accommodation bonds and daily care fees. Others felt they were abandoning their family member and felt guilty for not continuing to care for them at home.

Other people did not consider they would use residential care. One woman whose husband still lives at home spoke about how, although her husband is heading toward the later stages of dementia, he is still part of the family. Despite needing constant care and heavy nursing to keep him at home, she could not consider moving him into a residential care facility. She has put his name on the waiting list of one facility, because she was told that she should, however she was told by the facility manager that they would medicate her husband because he is still active and physically strong. She said,

*I couldn't imagine him being in a residential situation apart from his home ... I want him to be at home. I want to look after him. I want him to be here for his children, he's still their dad ... I'm fortunate to be able to do that. I don't have to work; we don't have a mortgage to pay off.*



Some service providers reported that some CALD communities have shame about using residential care. They wish to remain at home, with their family and cultural community for as long as possible. Familial and cultural obligations to care for family are strong in some of these communities.

Some parent carers expressed fears about what will happen to their children with younger onset dementia when they are no longer able or alive to care for them. A mother said, 'I'm worried about where he will go when we're gone? What's to happen? That's our biggest fear.'

The shortage of younger onset dementia specific accommodation was a concern for some people, as was the attitude of some residential aged care facility staff to people with younger onset dementia. A wife and a husband said,

*[We need] access to residential care that is not aged care. Some services will not assist with future care needs and planning as my husband is under 65. They say he is not suitable despite having a diagnosis of Alzheimer's. Other services stated a Board would have to give permission for entry into the facility.*

*A biggie is the lack of nursing home facilities for younger onset people ... I think [a service provider] is experimenting with one where it's all younger onset. But that's a waste of space for us; there's no way we're ever going there [because we live too far away], but something might come of it. But that's the only one. Otherwise they're in with old people ... we haven't got critical mass to have younger onset specific nursing homes.*

Some family and carers spoke about the distances they would have to travel if they were to place their partner in a younger onset dementia specific facility. Some said they would be willing to use a similar facility if it was near their home, particularly if they knew the group of people with younger onset dementia living there. These carers highlighted their need to be able to re-create a social network and sense of community in a residential care facility.

They also said the shortage of high care facilities for people with younger onset dementia was a problem. A carer told of how she visited a younger onset specific facility and was very impressed. However, she was disappointed that it was only a low care facility, she said,

*I was so elated when I was there and then when I left I was so deflated, because there's no way I'm putting him in there when he's low care.*

Some service providers also spoke about the need for high care facilities, which were either younger onset specific or at least suitable and catering to the unique needs of younger clients with dementia.

## **ALTERNATIVE ACCOMMODATION OPTIONS TO RESIDENTIAL AGED CARE FACILITIES**

Some service providers made suggestions about what could be done to support people with younger onset dementia and their families in alternative accommodation settings to both home and residential care. One suggestion was for social housing designed for people with younger onset dementia, collocated with a drop-in community centre.

Some service providers raised the suggestion of clustering younger people within an aged facility. They reported that one residential aged care facility has already become a facility suitable for younger onset dementia, due to a cluster of younger onset residents who have moved there.

Secure cottage style accommodation for people with younger onset dementia was suggested as another option. This would provide a homelike environment with a high staff-to-client ratio to cater to the different needs of younger people, similar to the respite cottages (Section 6.2).

## **6.4 PALLIATIVE CARE OPTIONS**

Some people are preferring to remain living in the community for as long as possible with support, which has an impact that more people with younger onset dementia die at home, rather than in residential aged care facilities or hospitals. A service provider reported that some palliative care for people with younger onset dementia is inappropriate and that they were not yet adequately supported to die at home, because 'of a preconceived idea that people with dementia die in residential aged care facilities.' They said that people with younger onset dementia and their family members/carers need to be provided with better palliative care services and support in the home to enable their wishes to be carried out. Further research is needed about good practice in palliative care for people with younger onset dementia.

## **7 PRINCIPLES TO GUIDE THE PROVISION OF SERVICES AND SUPPORT**

In summary, the findings from the first half of the report about the particular needs of people with younger onset dementia, their families and carers that need to be addressed in their support arrangements include:

- People with younger onset dementia are often physically strong and healthy
- People with younger onset dementia often have family responsibilities
- People with younger onset dementia may have a primary carer who may still be working
- People with younger onset dementia and their families will make adjustments to their expectations in their daily lives, including work, finances, living arrangements, social and sexual relationships, independence and responsibility for others
- The kind of dementia maybe a rarer form than in older people, with implications for pathways, support and treatment
- People with younger onset dementia may have significant financial commitments.

A person-centred approach is required to address these considerations and to enable people with younger onset dementia to shape the support and service arrangements that address their needs and preferences. A person-centred approach provides informed, supported decision-making opportunities for people with younger onset dementia and their families to plan and manage services and support to best suit their specific lifestyle, interests and demographic characteristics, such as age, gender and cultural background.

A person-centred approach includes the provision of appropriate, timely, easily understood information and resources. It supports the person with younger onset dementia as well as their family members/carers to live as independently as possible, sustain healthy relationships and participate in community life.

To guide the development and provision of effective services for people with younger onset dementia and their family members/carers the research highlighted the following principles within the framework of a person-centred approach to service delivery: holistic, enabling, whole of family, timely, flexible, coordinated, dementia-friendly environment, effective communication, skilled staff and cost effective (summarised in Figure 10.1). These principles are described below.

### **HOLISTIC**

Plan and deliver services and support that take account of physical, emotional, social, economic, and spiritual domains in the lives of people with younger onset dementia and their family members/carers, including needs for housing, transport, financial and legal assistance.

## **ENABLING**

Recognise and build on the individual strengths, abilities and priorities of people with younger onset dementia to maximise and promote their wellbeing and independence. Support services and activities should foster a sense of enablement and empowerment, which facilitates social and emotional participation in family and community life.

## **WHOLE OF FAMILY**

Acknowledge the impact of younger onset dementia on the lives of primary carers and other family members. This means providing practical and emotional support to the whole family, and includes supporting the formation and strength of social networks if these are weak. Recognise that effective communication with family members and carers can support information sharing and resourcing of families.

## **TIMELY**

Offer services and support that are responsive to the progression and complexities of dementia, from early identification, early intervention, referral, family support and increasing services to support people to live in their own home and avoid premature entry into residential care.

## **FLEXIBLE**

Recognise that dementia is a progressive condition that often advances more quickly in younger people. Life stage changes for people with younger onset dementia, spouses in their middle years and younger children in the family can be diverse in the areas of employment, family responsibilities, financial commitments, study, housing, family mobility and travel. Different approaches may be needed at transition points to support people with younger onset dementia and their family. Flexible and timely service responses are key at these points, alongside coordinated transition between services to ensure continuum of care.

## **COORDINATED**

Manage services in a way that promotes coordination between people involved in service provision, including specialist professionals, providers of social and community support, family/carers and people with younger onset dementia. Good coordination and information sharing can improve access, proactively address needs, avoid service overlap and fill service gaps.

## **DEMENTIA-FRIENDLY ENVIRONMENTS**

Create environments that support social connection, a sense of self and maximise independence for the person with younger onset dementia in their home, community and places of service delivery. Recognise the importance of physical, organisational and cultural environments to enable staff to be person-centred in the way that they interact with people and their families.

## **EFFECTIVE COMMUNICATION**

Communication can be impaired due to dementia. Recognise that effective communication improves the quality of life of people with dementia. Communicate in ways that support meaningful interaction and enable mutual understanding. Effective communication with a person with younger onset dementia can also assist in managing behaviours, where these may be a consequence of confusion, frustration or anxiety.

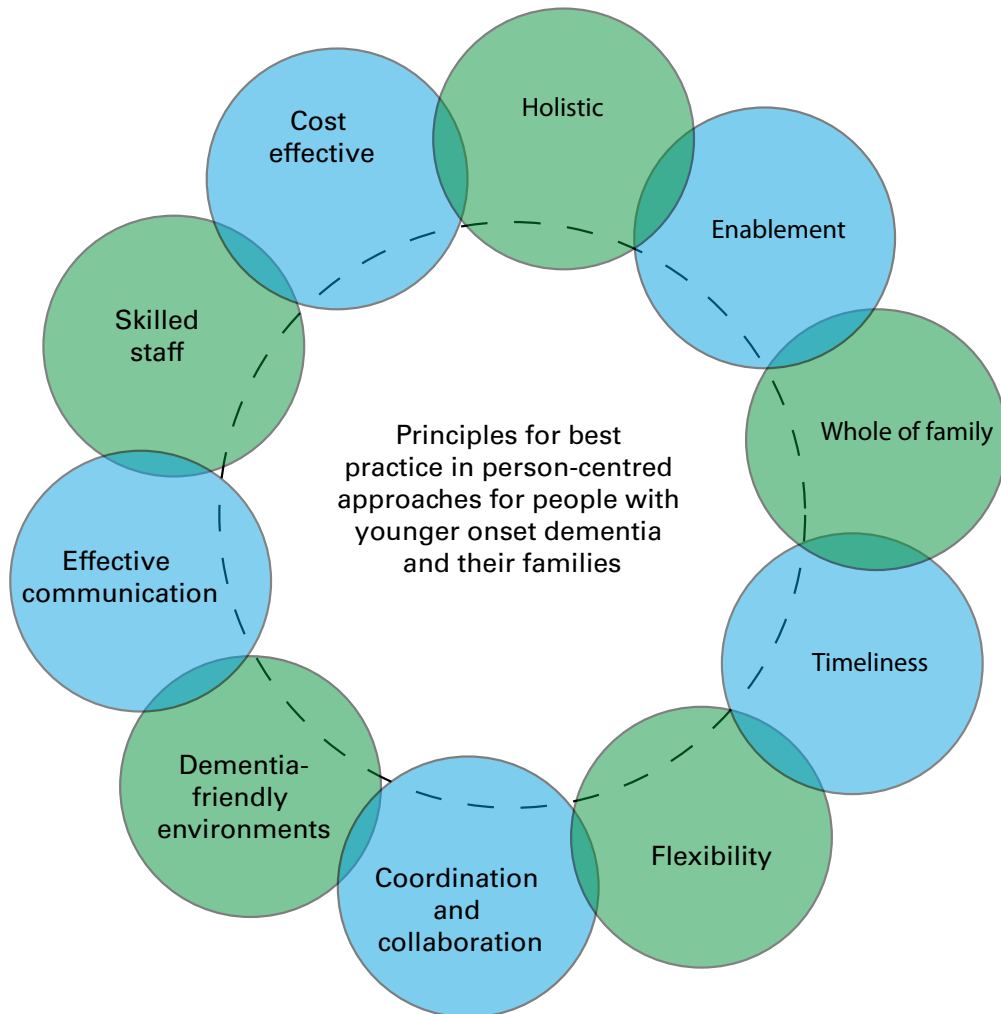
**SKILLED STAFF**

Ensure that staff are appropriately trained, qualified, experienced and supervised in the provision of care and support for people with younger onset dementia, families and carers. This includes training and reflective practice in enabling, person-centred approaches and effective communication. Ensure staff are well supported to respond confidently to the changing needs of people with younger onset dementia, families and carers.

**COST EFFECTIVE**

Maximise the cost effectiveness of service approaches by monitoring outcomes and considering the opportunity costs of any financial and resource commitments to service types. Coordinate with families and carers, other informal support and social networks to maximise return on formal service support.

**FIGURE 7: PRINCIPLES FOR BEST PRACTICE IN PERSON-CENTRED APPROACHES FOR PEOPLE WITH YOUNGER-ONSET DEMENTIA AND THEIR FAMILIES**



## **8 POLICY IMPLICATIONS**

The research findings have implications for policy and the provision of services and support to people with younger onset dementia and their family members/carers. Drawing on the principles in the previous section, this section outlines policy implications to inform the development of a services sector that is responsive to and can meet the key areas of need in younger onset dementia (the links are summarised in Figure 10.1). To achieve this goal, the following features can inform service system development for younger onset dementia: service and funding approaches; integrated service delivery; collaboration between sectors and capacity building; workforce skills and evidence based practice. Section 9 details strategies to implement these implications. The five sets of policy implications are listed and explained further in this section.

### **8.1 SERVICE AND FUNDING APPROACHES**

#### **KEY POINTS**

- Implement approaches that incorporate person-centred services, enablement, wellness and restorative models of care; early intervention; whole of family support and communication in planning, delivery and transition points
- Provide information in various formats to people with younger onset dementia, families, carers and community members to inform decisions and awareness about the condition, personal and family implications, support and opportunities
- Provide responsive flexible approaches such as a key worker function for proactive follow up and support and individualised funding approaches

#### **HOLISTIC SERVICES**

Approaches to promote responsive flexible services include holistic services, information, key workers and individualised funding. As described in the principles (Section 7), service provision should include person-centred and enablement approaches that encourage informed choice, flexibility and social and emotional participation of people with younger onset dementia and their family members/carers in family and community life. Holistic and broad based approaches to assessment of care and support needs ensure that appropriate interventions can be introduced earlier, improving opportunities for social participation and promoting improved quality of life for people with younger onset dementia and their families. In addition to their life domains, important areas to be addressed are psychological and behavioural needs.

Concerns about relationships and the welfare of family members were expressed by people with younger onset dementia and their family members/carers. A policy implication is the need for a whole of family approach for service and funding models to recognise the distinct and different service and support requirements for all family members. Communication and partnership between family members and carers with formal service providers can enhance service plans to strengthen informal and formal support for the person and family members.

#### **INFORMATION**

People with younger onset dementia and their family members/carers described a need for information about younger onset dementia and the services and support available. Some people also felt overwhelmed at times by the quantity and disparate information. A policy implication is the need for a consistent, coordinated and timely approach to the provision of information and education to these groups, which is closely managed and tailored to their particular stage of dementia and their current and future needs.

## **KEY WORKERS**

Key workers are an example of responsive information provision. Some people with younger onset dementia and their families described the benefit of having a single point of contact to help them access appropriate information and advice about their condition and the services available along the dementia pathway. A key worker is defined in the NSW Dementia Services Framework 2010-2015 as,

*Responsible for provision of direct care services and care coordination for people with dementia, their carers and families. This will often involve maintaining continuing contact with a person and their carer over long periods of time, providing intensive support during periods of crisis.*

Skilled key workers ensure appropriate information and education is given when it is needed and tailored to inform the immediate concerns of the person and their family members/carers. They support the primary carer and other family members, particularly school age children and young adult children who provide care. Good key workers use a whole of family approach to determine appropriate service delivery to support family relationships and address the personal needs of family members experiencing changed relationships and responsibilities.

## **INDIVIDUAL FUNDING PACKAGES**

A second approach for flexible services is to organise them through individualised funding packages, which means that funding is allocated to the person rather than a service provider, program or place. They can choose to spend the funding within specialised or mainstream services or in an open market.

The goal is to enable greater control by the person, family and carers about how, what and when services are provided. They are supported to make informed choices to suit their individual lifestyle, priorities and social context. One way of managing the choices, planning and funding is with the support of a key worker, who is informed about the options. The NSW government policy is to offer the option of individualised funding for all disability support by 2014 (Stronger Together II).

## **8.2 INTEGRATED SERVICE DELIVERY**

### **KEY POINTS**

- Integrate service delivery initiatives within and between service sectors, including health, aged care and disability sectors at national, state and local levels to increase the range of local service options and simplify referral processes
- Inform mainstream service providers about younger onset dementia so they understand and respond to the needs of people with younger onset dementia
- Integrate care assessment, planning and delivery processes across agencies to refer to specialist and mainstream services and local community support opportunities
- Plan for consistent, coordinated and timely approaches to changes in service delivery across the transitions as the impact of the dementia changes to achieve responsive continuity of care

People with younger onset dementia and their family members/carers described using a range of different types of services and support. The use of a particular service or support depended on the stage of dementia, the circumstances of the family and carers, such as working carers, and the preferences people had about the activities and the relationships in which they wished to engage. Patterns of service use changed as the dementia progressed, and services and support that suited some people with younger onset dementia and their family members/carers did not suit others. External reasons for which services they used depended on local variation in availability, eligibility rules and referral processes.



Good support services need to respond to their diverse experiences which can require particular attention. These included people with younger onset dementia and their family members/carers from Aboriginal communities, people from CALD backgrounds, people with other health conditions, people living in rural and regional areas, people from GLBTI communities and those people with younger onset dementia who live alone.

People with younger onset dementia who exhibit behaviours of concern and their family members/carers also require responsive service delivery that seeks out the cause of the behaviour and provides alternative management options to alleviate the effects of the behaviour for the person and their family/carer.

A policy implication of this variation is the need for integrated service delivery, within and between service sectors to ensure responsiveness to the different needs of people with younger onset and their families. Care assessment and planning processes should ensure that appropriate services are mobilised to provide support for transitions and enable people with younger onset dementia to receive continuity of care, for example when they move between health, aged care and disability services or across geographical service boundaries. A range of services and support need to be available, so people can make informed choices and can move between services as their needs change. In practical terms, the availability of transport is an important consideration to enable access to services.

### **8.3 COLLABORATION AND CAPACITY BUILDING**

#### **KEY POINTS**

- Identify, define and build collaborative pathways throughout the progression of dementia to supply timely services and support, with clear protocols to support their implementation, including key workers
- Coordinate communication and partnerships between government, non-government, community and informal support to contribute to opportunities for social support and participation of people with younger onset dementia and their family members/carers, including community awareness and information
- Combine service improvement experiences from the aged care, health and disability sectors

In addition to direct information and service delivery for a person and their family/carers described in Sections 8.1 and 8.2, service system level coordination is necessary to improve the way service providers work together. Three policy implications at this level are pathways to services and support; partnerships to increase service and support options; and sharing good practices across the service sectors.

People with younger onset dementia, families and carers discussed their range of experiences accessing services and support, and their confusion about entry and entitlements. They had followed many different paths. A system level policy implication is the need to identify and define pathways from diagnosis and through the progression of dementia to access timely services and support, with protocols to support the implementation of pathways.

Implementing pathways requires inter-agency collaboration and multi-disciplinary practice to improve interaction and cooperation among different agencies, increase the transfer of knowledge and build capacity across the services sectors. Responsive approaches discussed above, such as key workers, individualised funding (Section 8.1) and integrated service delivery (Section 8.2) complement a pathway approach and have the potential to improve the efficiency and cost effectiveness of service delivery.

Communication and partnerships between formal and informal support can enhance the opportunity for community engagement for people with younger onset dementia and their family members/carers. The people with younger onset dementia, their families and carers also stated that poor community understanding about younger onset dementia hampered their quality of life, community participation and

capacity to adjust to changes in their personal, family and community relationships. A policy implication is the need to increase community awareness about younger onset dementia through explanatory information in various forms for distribution by individuals, families, service providers and government.

Collaborative service initiatives across health, aged care and disability at Commonwealth, State, and local levels can develop flexible, innovative and locally based solutions through sharing service improvements. At a State level, this may be an Expert Advisory Group for Younger Onset Dementia as part of the implementation of the NSW Dementia Services Framework 2010-2015.

At a local level, it may be dementia and service networks working together to achieve integrated approaches to service planning, service pathways and coordinated service delivery. Networks such as the Hunter Younger Onset Dementia Network have demonstrated successful integrated service approaches with the development of a Hunter Clinical Pathway for the Management of Younger Onset Dementia.

## **8.4 WORKFORCE SKILLS**

### **KEY POINTS**

- Improve knowledge, skill development and training, and ongoing support for service providers and frontline workers
- Improve working conditions, supervision and peer support for staff working with people with younger onset dementia
- Implement staff and team reflective practice in order to improve quality and continuity of care
- Arrange cross sector (health, aged care and disability) sharing of experience and skills

Across the sectors, workforce skill development was identified as a priority to improve service delivery and to implement preferred service approaches. Family members/carers and service providers described variable levels of knowledge amongst service providers and frontline workers about younger onset dementia. A policy implication is the need for ongoing knowledge improvement, skill development, training, supervision and reflection for service providers and frontline workers.

Education and training about younger onset dementia needs to include knowledge of the differences in social context for people who experience dementia at a younger age, as well as knowledge of current developments in professional practice, care service delivery and styles of case management for timely information and individualised funding.

Service providers and family members/carers need training and education about specific areas of difficulty, including current, effective and evidence based strategies for managing behaviours of dementia in a way that recognises the communication, contextual and personal factors associated with this behaviour, such as frustration and sadness.

Workforce skill development involves exploring new modes for training, as well as including components about younger onset dementia in existing training modules, such as community services, disability and aged care certificates, and further promoting other training opportunities provided by universities, service providers and peers.

Family members/carers emphasised the importance of developing rapport, continuity of care and trusting relationships with frontline workers, and the difficulty when staff were not understanding or personable. Family members/carers wanted continuing relationships with caring and compassionate workers. These comments are made about sectors that have high staff turnover due to poor pay and working conditions.

Policy implications include the need to improve working conditions, supervision and peer support for staff working with people with younger onset dementia; encourage reflective practice in order to

improve continuity of care; and share the experience and skills of staff and people receiving services across the aged care, health and disability sectors.

Forums and workshops such as the Younger Onset Dementia Forum organised by AlzNSW in April 2012, provide opportunities for service providers across sectors to come together and focus on younger onset dementia service development and capacity building.

## **8.5 EVIDENCE BASED PRACTICE**

### **KEY POINTS**

- Promote innovation and development of new evidence based and responsive models of support
- Evaluate services for program improvement, accountability and generalised good practice
- Replicate good practice services in other locations
- Provide cross sector development opportunities to facilitate collaboration between health, disability and aged care providers and consumers.
- Research the social and medical implications of younger onset dementia

The final set of policy implications is to develop an evidence base to inform improvements to service approaches. Few programs for people with younger onset dementia have been formally evaluated. However, some people with younger onset and their family members/ carers and service providers cited some good, valuable outcomes in younger onset services and support.

The policy implication is the need to build a foundation of evidence based good practice, from which to build quality, appropriate services and support to meet the needs of people with younger onset dementia and their family members/carers.

Evaluation of pilot studies via seed funding or other means should be encouraged to develop a strong evidence base of good practice. This would encourage innovation as well as replication of other services that demonstrate the implementation of evidence based approaches or good practice standards. Service and support outcomes for people with younger onset dementia will be strengthened and further development of the younger onset service sector consequently enhanced as a result.

Examples that encourage the development of an evidence base are pilot projects that apply person-centred, individualised funding or other flexible approaches, such as the NSW *Younger Onset Dementia Person Centred Packages Pilot*. Similarly, promoting, updating and applying resources such as the ADHC funded younger onset dementia mapping project undertaken by the Ella Centre encourage the sharing of good practices.

Academic enquiry to establish evidence based research should be encouraged and promoted. Research that combines both social and medical components of younger onset dementia such as the INSPIRED Study, an epidemiological study at the University of NSW enable a greater understanding of younger onset dementia and its prevalence in Australia.

Events such as the AlzNSW Younger Onset Dementia Forum held in Sydney in April 2012 should continue as a regular opportunity to showcase new and valuable service options and provide an opportunity for service providers, people with younger onset dementia and their family members/ carers to network and exchange ideas.

## **9 STRATEGIES TO ADDRESS KEY AREAS OF NEED**

This section of strategies follows on from the policy implications for service system development in Section 8 to inform implementation. It groups the strategies into the key areas of need for people with younger onset dementia and their families/carers. The strategies address the following needs: timely diagnosis; diagnosis and referral; early intervention, support for transition points; behaviour management; supporting people to remain at home; and people with additional needs (summarised in Figure 10.1).

### **9.1 TIMELY DIAGNOSIS**

Barriers to a timely diagnosis of younger onset dementia were identified in the research. The key barriers are the poor awareness and understanding of younger onset dementia, the stigma surrounding dementia and delays in GPs and other professionals recognising and acknowledging symptoms of dementia in younger people and referring to specialists for testing and diagnosis.

#### **STRATEGIES**

- Conduct a community education campaign to increase awareness and understanding of younger onset dementia and reduce stigma, including simple information cards to help people explain their dementia to friends and extended family.
- Include a younger onset dementia focus in annual Dementia Awareness Week activities.
- Conduct a GP education campaign which includes how to recognise the symptoms of younger onset dementia, where to refer patients to for diagnosis and the provision of local support services brochures.
- Engage Medicare Locals to work with GPs and other primary health providers to increase awareness of younger onset dementia and improve the experience of the diagnosis process for people with younger onset dementia.
- Provide GP practice nurses with training opportunities and incentives to undertake dementia assessment, diagnosis and ongoing management of younger onset dementia.
- Include a younger onset dementia component in TAFE and university studies, such as that developed by the NSW/ACT Dementia Study Training Centre.
- Support local Aboriginal Medical Services to provide information and assessment for younger onset dementia in Aboriginal communities.

### **9.2 DIAGNOSIS AND REFERRAL**

A diagnosis of younger onset dementia is often delayed and the diagnosis delivered in an insensitive manner with little information provided about the dementia and likely progression. Some people did not receive information about follow-up appointments with specialists or referral to services for support and advice. In addition, the key role of the family or carer in the diagnosis process was not always acknowledged.

#### **STRATEGIES**

- Improve the process of diagnosis and referral by increased use of diagnosis and referral pathways documents for GPs, neurologists and geriatricians and the development of younger onset dementia specific pathways. Current models of good practice include the Hunter Younger Onset

Dementia Network Clinical Referral Pathway and the 14 Essentials for Good Dementia in General Practice developed by the Royal Australian College of General Practitioners (RACGP) and Dementia Collaborative Research Centre (DCRC). This supports Section 2.1 in the NSW Dementia Services Framework to promote diagnosis and assessment referral protocols to key health services.

- Provide 'breaking bad news' training for neurologists and GPs to improve the way in which a diagnosis of younger onset dementia is delivered. Similar literature for other chronic and terminal conditions, such as cancer is available<sup>6</sup>.
- Include younger onset dementia guidelines, screening instruments and referral forms in software used by GPs.
- Remunerate GPs via specific Medicare item numbers for time spent conducting assessment and diagnosis, carer consultations, referrals and care planning for people with younger onset dementia.
- Include the family or carer in the diagnosis process to provide important information and support. GPs should also monitor the health and wellbeing of the primary carer throughout the progression of dementia and provide referrals to support where required.
- Improve the navigation of the service system for people with younger onset dementia and their carers through the implementation of younger onset dementia key worker position. Key workers support people with younger onset dementia and their families by providing information, such as what the diagnosis means, anticipated prognosis and progression, information and referral to support services, and planning for future needs. Aboriginal and CALD specific key worker positions are also required. They can be situated in specialist or mainstream services for people with dementia, disability, health or other needs.
- Promote Alzheimer's Australia NSW as a resource for information, education and counselling for people with younger onset dementia and their families and service providers.
- Provide timely information about services, support and resources in formats accessible to people with cognitive impairment, low literacy or English as a second language.

### **9.3 EARLY INTERVENTION**

The importance of early intervention for people with younger onset dementia and their families was identified by the research. Early intervention includes the provision of timely information; referral to appropriate support services; and planning for and reviewing of needs and support services as required.

#### **STRATEGIES**

- Provide proactive follow-up after diagnosis by a key worker to develop, monitor and review individual service and support plans in recognition of the changing needs of people with younger onset dementia and their families associated with the progression of dementia.
- Provide opportunities for peer support and mentoring for people with younger onset dementia, carers and families. Utilise new technologies to connect people, including internet forums.
- Refer people with younger onset dementia and their families to psycho-social education and support. A current model of good practice is AlzNSW's younger onset dementia specific Living with Memory Loss (LWML) program.
- Extend the operation of the younger onset dementia specific LWML program to include a program conducted over a series of Saturdays to cater for working carers.
- Ensure transport options are available to enable community participation for people with younger onset dementia.

- Support the remaining capacities, functional independence, social participation, community engagement and quality of life of people with younger onset dementia.
- Encourage dignity of risk for people with younger onset dementia to improve their confidence in their remaining capacities and abilities.
- Promote the use of assistive technologies to enable independence and continued community participation.
- Provide support which engages the whole of family not just the person with a diagnosis of younger onset dementia and the primary carer.
- Provide counselling for people with younger onset dementia, primary carers and family members, especially younger children.
- Include younger onset dementia as a specialist area of practice for counsellors and psychologists, as exists for other chronic health conditions such as diabetes.
- Increase the availability of support for children, especially for those under the age of 18 years. Current models of good practice for adult children include the AlzNSW 'Younger Onset and Me' blog and 'Young People' support group.
- Develop a model of support that includes teachers, parents and children to provide support and monitor the well-being of children with parents with younger onset dementia in the school setting.
- Provide camps and retreats for people with younger onset dementia and their families, including younger children. These could be modelled off Carers NSW and CanTeen camps for young carers and families affected by chronic health conditions.
- Increase the availability of younger onset dementia specific carer support groups. Utilise web enabled technologies to connect people who may be geographically or socially isolated.
- Initiate planning ahead processes while the person with younger onset dementia still has the capacity to be involved in the decision making process.
- Promote the use of the NSW Government Planning Ahead Tools website [www.planningaheadtools.com.au](http://www.planningaheadtools.com.au) for people with younger onset dementia and their families.
- Ensure that advance care planning positions established in Local Health Districts (LHDs) have an understanding of the context and special needs of people with younger onset dementia and their families.
- Provide information about younger onset dementia to professionals such as lawyers and accountants to assist them when working with clients with younger onset dementia and their families to plan their legal and financial affairs.

#### **9.4 SUPPORT FOR TRANSITION POINTS**

Transition points for people with younger onset dementia and their carers and families were identified as times when increased support and services are required. Such points include: transitioning out of employment; transitioning from driver to non-driver; and transitions for carers, especially in relation to work, as the dementia progresses and care needs increase. These transition points for people with younger onset dementia and their families differ compared to the experiences of most older people with dementia due to their life-stage and responsibilities.

#### **STRATEGIES**

- Establish key workers to provide timely information and services to support people during these transition periods to achieve the goal of person-centred support.



- Provide a younger onset dementia specific helpline as part of the Australian Government funded National Dementia Helpline currently operated by Alzheimer's Australia.
- Deliver a continuity of care at transitions between services to provide flexible and appropriate support as needed for people with younger onset dementia and their families.
- Provide education for employers of people with younger onset dementia and carers to facilitate flexible work arrangements and supported transitions out of the workforce.
- Support carers who want or need to continue to work through the provision of long day program models which operate from 8am-6pm for people with younger onset dementia.
- Provide volunteer opportunities for people with younger onset dementia to support their transition out of the workforce and partake in alternative meaningful activities. A current model of good practice is the South Australian Bunnings' volunteer program for people with younger onset dementia.
- Fund 'community builders' programs such as Men's Sheds and community gardens to enable the inclusion of people with younger onset dementia.
- Increase community awareness of younger onset dementia and build the capacity of informal networks by providing information in formats that people with younger onset dementia and their families can give to extended family, friends and other community contacts such as employers, coworkers and teachers.
- Encourage the use of volunteers and buddies in mentoring and support programs for people with younger onset dementia. A current model of good practice is the UnitingCare Ageing Younger Onset Support Services Program on the NSW Central Coast.
- Implement the recommendations of the AlzNSW (2010) discussion paper 'Driving and Dementia' to support people with younger onset dementia to transition from driver to non-driver via planning, education and the accessibility of alternative forms of transport.

## **9.5 BEHAVIOUR MANAGEMENT**

Managing challenging behaviours of dementia was a key issue for some family members, carers and service providers in this research. Behaviours of dementia, such as aggression, are possibly more acute for younger people and their families due to the person with younger onset dementia still being physically active and mobile, feeling a higher level of frustration, and the incidence of fronto-temporal dementia. Challenging behaviours may impact on access to services for people with younger onset dementia and carers, such as social support programs, day centres, and residential respite. Instances of behaviour mismanagement were identified such as inappropriate medication, the use of restraint and staff unable to understand the possible causes of certain behaviours. At its most extreme, mismanagement of behaviours of dementia results in premature or inappropriate placement in residential care facilities.

### **STRATEGIES**

- Encourage the use of alternative methods of communication when needed to understand people with younger onset dementia. For example, if verbal communication is limited, encourage families and service providers to learn to understand non-verbal cues and communication.
- Educate families and service providers to understand the possible reasons for challenging behaviours and manage the underlying causes. This includes providing alternative management options instead of anti-psychotic medications.
- Train community care, day respite and residential respite staff in effective, evidence based

strategies for communication and management of behaviours. For example, expand the use of the Dementia Training Study Centre Younger Onset Dementia module and the NSW Health e-learning dementia module.

- Provide dementia friendly environments to reduce anxiety, agitation and aggression in people with younger onset dementia.
- Provide appropriate day and residential respite options, with well-trained and qualified staff, for people with younger onset dementia to ensure carers receive regular breaks from their carer role.
- Ensure day programs for people with younger onset dementia have younger care workers, a higher staff to client ratio, and a greater proportion of male staff.
- Provide respite accommodation for people with dementia and their carers which provide strategies to help carers manage difficult behaviours. This could be similar to a retreat which rejuvenates the carer and provides person-centred care for the person with younger onset dementia.
- Facilitate access to specialist dementia services, for example the Dementia Behaviour Management Advisory Service (DBMAS) consultants and 24 hour helpline, for people with younger onset dementia to ensure behaviours are managed appropriately.
- Provide flexible community-based service models which cater to the needs of physically active clients to reduce agitation and anxiety.

## **9.6 SUPPORTING PEOPLE TO REMAIN AT HOME**

A general goal of person-centred support for most people with younger onset dementia, their families and carers is to support people to remain in their own home and avoid premature entry to residential care facilities. Premature placement in residential care may occur due to inadequate support to challenging behaviours of dementia, significant carer stress and burden, and as a transfer straight from hospital. In some instances however, residential accommodation and care for people with younger onset dementia is required but the lack of suitable facilities for younger people can lead to inappropriate placement in a residential aged care facility. Also, as people with younger onset dementia are increasingly encouraged to live at home for as long as is appropriate, the need to provide for palliative care support in the home will also increase.

### **STRATEGIES**

- Promote strategies to alleviate and reduce carer stress and burden to prevent premature entry to residential care.
- Increase the number of younger onset dementia specific carer support groups.
- Include younger onset dementia specific training in the AlzNSW Carer Support Group Leadership Program.
- Provide family and carer coaching and wellness programs aimed at building carer capacity and resilience
- Facilitate consistent access to care packages to support families and carers to continue to care at home for as long as is appropriate.
- Clarify the eligibility of people with younger onset dementia for ACAT assessment and ensure consistent access to assessment packages throughout NSW.
- Provide training for hospital staff to increase their understanding of younger onset dementia.
- Develop younger onset specific clinical nurse consultant (CNC) positions to provide clinical support and education to reduce the risk of premature entry into residential care following hospital stays.

- Provide support to people with younger onset dementia and carers during and following hospital admissions to ensure they can return home if appropriate, rather than transfer to residential care.
- Develop processes for planning the transition to residential care for people with younger onset dementia and their families in the event that it is required.
- Provide alternative care and accommodation options, for example, apartment style accommodation with staff available 24 hours a day, for people with younger onset dementia. This could also include on-site accommodation for carers and families if required.
- Provide appropriate palliative care options for people with younger onset dementia to support them to die in their own home, rather than a hospital or residential aged facility should this be their wish.
- Increase the knowledge and skill base of palliative care specialists about younger onset dementia.

## **9.7 PEOPLE WITH ADDITIONAL NEEDS**

Further research is required into the specific needs of people with younger onset dementia associated with the following additional contextual experiences that might affect their service and support needs. A person-centred approach guided by the principles discussed in the previous section is a starting point to address the needs of particular groups, and the earlier findings sections included examples of good practice. The research also identified some strategies needed for policy and service provision as outlined below.

### **PEOPLE WITH YOUNGER ONSET DEMENTIA WHO LIVE ALONE**

- Increase access to dementia monitoring and social support programs for people with younger onset dementia who live alone.
- Build the capacity of informal networks to assist people with younger onset dementia who live alone to maintain their independence and participate in their local community for as long as is appropriate.

### **PEOPLE WITH YOUNGER ONSET DEMENTIA AND CARERS FROM ABORIGINAL COMMUNITIES**

- Develop culturally appropriate younger onset dementia information specific to local Aboriginal communities in NSW.
- Provide culturally appropriate support services for people with younger onset dementia and carers from Aboriginal communities.
- Provide cultural competency training for staff working with people with younger onset dementia and carers from Aboriginal communities.
- Conduct further research into the different understandings and perceptions of dementia and needs of people with younger onset dementia and their families from local Aboriginal communities in NSW.

### **PEOPLE WITH YOUNGER ONSET DEMENTIA AND CARERS FROM CALD COMMUNITIES**

- Develop culturally appropriate younger onset dementia information specific to CALD communities.
- Provide culturally appropriate, or where possible ethno-specific, support services for people with younger onset dementia and carers from CALD communities.
- Provide cultural competency training for staff working with people with younger onset dementia and carers from CALD communities.

- Conduct further research into the different understandings and perceptions of dementia and needs of people with younger onset dementia and their families from CALD backgrounds.

#### **PEOPLE WITH YOUNGER ONSET DEMENTIA AND CARERS LIVING IN RURAL AND REMOTE NSW**

- Develop and/or expand the provision of web-based online support and access to internet facilities.
- Build the capacity of informal networks to support people with younger onset dementia and carers in rural and remote NSW.
- Improve the availability of diagnostic practitioners for people living in rural and remote areas, such as locally trained practitioners, visiting practitioners or tele-video support to local practitioners.

#### **PEOPLE FROM GAY LESBIAN BISEXUAL TRANSGENDER INTERSEX (GLBTI) COMMUNITIES WITH YOUNGER ONSET DEMENTIA AND CARERS**

- Develop culturally appropriate younger onset dementia information specific to GLBTI groups
- Implement inclusive and person-centred practices in service provision.
- Conduct further research into the specific needs of people with younger onset dementia who are GLBTI.

#### **PEOPLE WITH YOUNGER ONSET DEMENTIA AND WITH A DISABILITY OR OTHER HEALTH CONDITIONS**

- Promote the role of allied health in addressing clinical needs related to younger onset dementia.
- Conduct further research into the specific needs of people with younger onset dementia other health conditions and their families.

#### **PEOPLE WITH YOUNGER ONSET DEMENTIA AND INTELLECTUAL DISABILITY**

- Provide education and training to disability service providers about dementia and the need for integrated management of the disability and dementia, particularly in relation to changed behaviours
- Build the capacity of the disability sector to support people with intellectual disability who are living at home so that they can maintain their independence and participate in their local community for as long as is appropriate.
- Build capacity of providers of residential disability services to support the changing and increasing needs of people with intellectual disability and to allow them to maintain their independence and community participation for as long as is appropriate.
- Work with self-advocacy organisations providing accessible health information to people with an

**FIGURE 9: SUMMARY OF VISION, PRINCIPLES AND IMPLICATIONS FOR SERVICE SYSTEM DEVELOPMENT**



This figure summarises the relationship between the vision for person-centred approaches for people with younger onset dementia, their families and carers; the principles to guide the provision of services; implications for service system development; and strategies to implement change, as outlined in Sections 7-9.

## KEY AREAS OF FOCUS

## STRATEGIES

### 1. Barriers to timely diagnosis

- Conduct a community education campaign to increase understanding of younger onset dementia and reduce stigma
- Engage Medicare Locals to work collaboratively with GPs and other primary health providers to raise awareness of younger onset dementia
- Conduct a GP education campaign about younger onset dementia
- Train GP practice nurses to screen for younger onset dementia

### 2. Diagnosis and referral

- Streamline the process of diagnosis and referral to services through the use of clinical and referral pathway documents
- Encourage GPs to include the carer in the diagnosis process to provide important information
- Improve access to and navigation of the NSW service system for people with younger onset dementia and their families through the implementation of a key worker model
- Provide a 'one-stop-shop' for information about younger onset dementia

### 3. Early intervention

- Proactive follow-up after diagnosis by key worker to develop individual service and support plans
- Use whole of family approach to provide opportunities for peer support and counselling
- Acknowledge and promote remaining capacities, functional independence, community engagement and quality of life of the person with younger onset dementia
- Instigate planning ahead processes to ensure inclusion of person with younger onset dementia in the decision making while they still have capacity

### 4. Support for transition periods

- Support people with younger onset dementia to transition out of employment with education for employers and opportunities to partake in meaningful alternatives
- Support working carers via the provision of long day program models and promote the importance workplace flexibility
- Support the person with younger onset dementia and their carer to transition from driver to non-driver via planning, education and provision of transport options
- Increase community awareness to strengthen community capacity building

### 5. Behaviour management

- Develop an understanding of the causes of behaviours and increase the use of effective communication and dementia-friendly environments
- Provide appropriate and timely carer respite and in-home support with younger onset dementia trained staff
- Provide access to specialised multi-disciplinary support services to assist the management of behaviours of dementia

### 6. Avoiding premature entry to residential care

- Promote strategies to alleviate or reduce carer stress to prevent premature entry to residential care
- Develop processes and protocols for a planned transition to residential care if required
- Provide alternative care and accommodation options for people with younger onset dementia
- Train hospital staff to support people with younger onset dementia and their families to enable them to return home if appropriate rather than placed in residential care

### 7. People with additional needs

- Aboriginal communities
- CALD communities
- Co-morbidities
- Rural and remote
- GLBTI
- Living alone



## **APPENDIX I: RESEARCH REPORT RESEARCH INSTRUMENTS**

### **Roundtable start questions**

#### *People with younger onset dementia*

1. Please tell us about yourself. What is your name? Why did you come today?
2. What services or support (other help) you use? Can you give examples?
  - What dementia services and support do you use?
  - What other services and support do you use?
  - What makes these services or support good for you?
  - What made you want to use these services or support?
  - What makes these services or support bad for you?
  - What made you not want to use these services or support?
  - Have the services or support been able to meet your changing needs?
3. Can you tell us what other services or support you still really want or need? (Now that you are living with dementia, what are some of the things you most want to do or have in your life? How can services or support help you get this?)
4. What are the most important things services and support should help you with?
5. What would make your services or support better? What would make them better for you? What would make them better for your family? What would the best service be like?

#### *Family and carers*

1. What was your experience in the lead up to a formal diagnosis?
2. Who gave your person with dementia the formal diagnosis?
3. Were you referred to support services? (Were they appropriate for a person with YOD? Were they appropriate for you and your lifestyle?)
4. Has the diagnosis of dementia for your person affected your financial position?
5. Have you accessed respite care services? (If so were they appropriate? If not, why not?)
6. What suggestions would you make to improve service provision for people with YOD?
7. Has the unpredictable nature of dementia affected your capacity to make plans for the future? (Financial, with family, lifestyle-related)
8. What do you see as the main differences between someone caring for a person with YOD and caring for an older person with dementia?

#### *Service providers*

1. Is there a clear understanding of YOD amongst health professionals generally? (Is specific support/training required?)
2. Is there sufficient/appropriate service delivery for carers of people with dementia and their families?
3. Is developing appropriate services for people with YOD difficult?

4. What are your greatest concerns regarding current service delivery for people with YOD?
5. If resources were endless what would be the one thing you would do for people with YOD?
6. What impact do you believe the current changes to federal and state government responsibility will have on funding for services for people with YOD?

### **Roundtable end questions**

#### *Family and carers*

1. We have found that lots of people would like better information about younger onset dementia services. What would good quality coordinated information be like? What has worked well for you in your services? What type of information do your clients say they want?
  - What format?
  - How/where would people access it?
  - Who from e.g. case manager, GP, peer support, ACAT
  - What information is needed?
  - Who needs what info? (PYOD, carer, extended family, friends, community groups, service providers)
2. Our findings have shown a need for diversifying younger onset dementia training for direct support workers and sector development more generally. From your experience, what training and development options would be most useful or appropriate?
  - Target (who is the training for?)
  - Coverage (what should it be about?)
  - Channel (how is it best delivered?)
3. Family members and carers have said that they are reluctant to have their family member with dementia attend long day centres, residential respite or use residential care. We are interested to know whether this is due to the quality/appropriateness of how these services currently are.
  - Are there examples you know of these services, where these have been used more willingly? If so, what distinguishes these services from others? What makes them different and/or more appropriate?
  - What alternatives have worked well and what are the characteristics?
4. Our findings have shown a number of service qualities that people would like to see further developed in younger onset dementia services. What are practical strategies by which the following qualities could be implemented?
  - Flexibility of services (timing, location, scheduling etc.).
  - Person centred services (in the context of younger families).
  - Individualised services.

### *Service providers*

1. As people with younger onset dementia often have families and/or young working partners, the upheaval of an unexpected diagnosis of dementia is intense.
  - How best can families be assisted to cope within the emotional and financial impact of a diagnosis?
  - How might family members with different extents of caring responsibilities be assisted?
2. Our findings have shown that people would like to see person centred and enablement approaches used in younger onset dementia services.
  - As service providers, how can you implement such qualities?
  - And what resources and support do you need to do so?
3. Family members and carers have said that they are reluctant to have their family member with dementia attend long day centres, residential respite or use residential care. We are interested to know whether this is due to the quality/appropriateness of these services.
  - What do you think would make people more willing to use such services? Do you think people would be more willing to use such services if they were YOD appropriate and/or specific?
  - Do you know of examples that work well for younger people with dementia? If so, what distinguishes these services from others? What makes them different and/or more appropriate?
  - Can you think of any alternative accommodation options (non-traditional residential respite or permanent care) for younger people with dementia? E.g. co-located housing
4. Our findings have shown a need for improving awareness and understanding of younger onset dementia for direct support workers.
  - From your experience, what training is most needed and is most useful?
  - How can the sector be developed to improve outcomes for people with younger onset dementia and their families?

### **Interview questions**

#### *People with younger onset dementia*

1. Tell me about yourself and your experience with dementia.
2. What support have you used already? How have you found that? What's been working well? (What's been good?) What's been working not as well? (What's been bad?) What could make this better?

3. What do you still need? (At the moment, what extra help do you need?) What does your family still need? (At the moment, what extra help does your family need?) How has what you both need changed?

4. What do you need to help you \_\_\_\_\_?

Prompting options:

- Help you keep in control and doing things yourself (keep independent)?
- Help you be involved (take part) in the community?
- Help you do things you enjoy or care about?
- Help you manage at home?
- Help you stay at home for longer?
- Help you with practical things like planning and money?
- Help you keep up the relationships that are important to you (including with your partner)?
- Help you deal with your feelings about having dementia?
- Help your family, friends and other people understand more about younger onset dementia?
- Help you find out about support?
- Help you use support?

5. Have you heard of any support that would help you with this?

6. What do you think are the main differences between what you need and what an older person with dementia needs?

7. Is there anything else you want to say?

#### *Family and carers*

1. Tell me about yourself and [family member] and your experience with dementia.

2. What types of support have you and [family member] used already, and what has your experience been? What's been working well? What's been working poorly? What do you think would improve this?

3. What do you still need? What does [family member] still need? Thinking back over the last few years, how have these needs changed?

4. What do you need to help you \_\_\_\_\_? If individual or group support could assist you with that, what would you want the support to be like? What would the best support be like for you?

- Help you and [family member] remain independent?
- Help you and [family member] participate in the community?
- Help you and [family member] do things you enjoy or care about?
- Help you manage at home?
- Help [family member] stay at home for longer?

- Help you with practical things like planning and finances (loss of income)?
  - Help you keep working?
  - Help you address your and [family member's] needs (e.g. practical, emotional, medical, care, service coordination)?
  - Help you balance [family member's] needs with your other responsibilities?
  - Help you and [family member] keep up the relationships that are important to you (including with each other)?
  - Help you with the emotional impact of dementia?
  - Help your family, friends and other people understand about younger onset dementia?
  - Help you find out about support?
  - Help you use support?
5. Have you heard of any support that would help you with this?
  6. What do you think are the main differences between what [family member] needs and what an older person with dementia needs? What are the main differences between what you need and what an older carer needs?
  7. Is there anything else you want to say?

*Service providers*

1. Tell me about your role in dementia services.
2. What types of support have you been involved in providing? What other support do you know of or work closely with? What's works well? What's works poorly? What do you think would improve this?
3. From your work, what do you understand as people with dementia and their family/carers' main needs? How do these needs change as the dementia progresses?
4. What would optimal support be like to \_\_\_\_\_? What are some good practice examples you've heard of to address this? Or what are new ideas you would like to see happen?
  - Help people with dementia and family/carers remain independent?
  - Help people with dementia and family/carers participate in the community?
  - Help people with dementia and family/carers do things they enjoy or care about?
  - Help people with dementia and family/carers manage at home?
  - Help people with dementia stay at home for longer?
  - Help people with dementia and family/carers with practical things like planning and finances (loss of income)?
  - Help family/carers keep working?

- Help address people with dementia and family/carers' practical, emotional, medical, care and service coordination needs?
  - Help family/carers balance people with dementia's needs with their other responsibilities?
  - Help people with dementia and family/carers keep up the relationships that are important to them (including with each other)?
  - Help people with dementia and family/carers with the emotional impact of dementia?
  - Help family, friends and other people understand about younger onset dementia?
  - Help people with dementia and family/carers find out about support?
  - Help people with dementia and family/carers use support?
5. What do you think are the main differences between what people with younger onset dementia needs and what an older person with dementia needs? What are the main differences between what a younger family/carer needs and what an older carer needs?
  6. Where should younger onset dementia support sit in relation to disability and aged care service systems? What is the optimal placement for good outcomes? What is the optimal way to manage transitions between the two?
  7. Is there anything else you want to say?





**Short version:** Survey for people with younger onset dementia

## Service and support requirements for people with younger onset dementia and their family/carers

This survey is **only** for people currently living in NSW who have been diagnosed with or are being assessed for younger onset dementia.

If you need it, you can have assistance in filling in the survey. It is better to fill in the survey with help than not at all. One to one assistance could be from:

- A family member or friend to explain the questions.
- Someone from Alzheimer's Australia will assist if you phone (02) 8875 4636.

### Services for younger onset dementia include:

- **Funded programs.**
- **Medical services.**
- **Assessments.**

**Services do not include informal forms of support from family or friends.**

### Question 1

This question is about using services. Please tick **ONE** box in each row.

Either now or in the future, I think I would benefit or not benefit from...

	I would benefit	I would NOT benefit	Don't know
One to one social support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One to one respite, personal care or domestic assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Permanent residential care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Support or educational groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure and activity/therapy based programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modification and equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case management and assistance with planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 2 (OPTIONAL)**

**Which of these services might your family/carer benefit from, as well as or instead of you?**

**Question 3**

**How should younger onset dementia services be provided? Please tick ONE box only.**

- Younger onset dementia services should be for younger people only
- Younger onset dementia services should be with other people with dementia

**Question 4**

**Whose needs should younger onset dementia services focus on? Please tick ONE box only.**

- On the needs of the person with younger onset dementia
- On the needs of the family/carer
- On the needs of the person with younger onset dementia and the family/carer
- On the needs of the whole family

**Question 5**

**What features of younger onset dementia services are important to you? Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Choice between services is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services that are flexible to changing needs are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A range of activities is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clear information about services is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services that need minimal payment from clients are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services appropriate to the age of younger people are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 6 (OPTIONAL)**

**Do you have anything else you want to say about services for younger onset dementia? If so, please write your comments in the space below.**

**Information about you**

**Question 7**

**I am...**

Male

Female

**Question 8**

**How old are you?**

Age: \_\_\_\_\_ years

**Question 9**

**I have the following type of dementia. Please tick ONE box only:**

Alzheimer's disease

Fronto-temporal dementia

Dementia with Lewy Bodies

Vascular dementia

Unspecified type

Unconfirmed diagnosis

Other (please specify)

\_\_\_\_\_

**Question 10**

**I live... Please tick ONE box only:**

- At home alone
- At home with spouse/partner
- At home with spouse/partner and children
- At home with children only
- With parent/s
- With other relative or friend
- In residential care/supported accommodation
- Other (please specify) \_\_\_\_\_

**Question 11**

**My postcode is...** \_\_\_\_\_



**Standard version:** Survey for people with younger onset dementia

## **Service and support requirements for people with younger onset dementia and their family/carers**

This survey is **only** for people currently living in NSW who have been diagnosed with or are being assessed for younger onset dementia. If you are a family member or carer, please fill in the other survey.

**In this survey:**

- **There are questions about you and about your ideal services.**
- **There are questions at the end of the survey about families/carers. You can choose whether or not to fill these in.**

If you need it, we encourage you to have assistance in filling in the survey. It is better to fill in the survey with help than not at all. One to one assistance could be from:

- A family member or friend to explain the questions.
- Someone from Alzheimer's Australia will assist if you phone (02) 8875 4636.

**Services for younger onset dementia include:**

- **Funded programs to assist people with younger onset dementia and their family/carers (e.g. respite, day programs, support groups).**
- **Medical services (e.g. diagnostic services).**
- **Assessments (e.g. driving or ACAT assessments).**

**Services do not include informal forms of support, like community groups (e.g. church groups), volunteer work or support from family or friends – even though these may also assist you.**

## Section A: My experience of services for younger onset dementia

This section is about your own experiences of younger onset dementia services.

### Question 1

Who gave you your dementia diagnosis? Please tick ONE box only.

- Geriatrician
- Neurologist
- General practitioner
- Other health professional
- Unsure
- No confirmed diagnosis yet

### Question 2

At what stage did you first start to receive services? Please tick ONE box only.

- Before diagnosis
- At the same time as diagnosis
- Shortly after diagnosis
- Long after diagnosis
- No services received yet

### Question 3

What is the MAIN way you have been linked to services? Please tick ONE box only.

- Referred by health/diagnostic practitioner
- Referred by local dementia advisor
- Referred by Alzheimer's Australia
- Found out from someone else with dementia/their family
- Found out about services ourselves
- Combination of the above
- Not currently linked to any services



**Question 4**

**This question is about using services. Please tick ONE box in each row.**

**Either now or in the future, I think I would benefit or not benefit from...**

	I would benefit	I would NOT benefit	Don't know
One to one social support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One to one respite, personal care or domestic assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Permanent residential care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support or educational groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure and activity/therapy based programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modification and equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case management and assistance with planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 5**

**This question is about your satisfaction with services. Please tick one box to show how strongly you agree or disagree with the following statement.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A – have not used services
Overall, I am satisfied with services I have used for people with younger onset dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 6**

**This question is about difficulties you may have had since experiencing symptoms of younger onset dementia. Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I find it hard to keep doing my usual activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard dealing with the emotional impact of younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard dealing with the financial impact of younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to make plans for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to understand or explain younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to get information and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to organise my day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to complete practical tasks at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 7**

**Do you have anything else you want to say about services for people with younger onset dementia? If so, please write your comments in the space below.**

**Section B: Ideal younger onset dementia services**

**Question 8**

**How should younger onset dementia services be provided? Please tick ONE box only.**

- Younger onset dementia services should be part of disability services
- Younger onset dementia services should be part of aged care services
- Younger onset dementia services should be part of both of these services
- Don't mind
- Don't know

**Question 9**

**How should younger onset dementia services be provided? Please tick ONE box only.**

Younger onset dementia services should be for younger people only

Younger onset dementia services should be with other people with dementia

**Question 10**

**Whose needs should younger onset dementia services focus on? Please tick ONE box only.**

On the needs of the person with younger onset dementia

On the needs of the family/carer

On the needs of the person with younger onset dementia and the family/carer

On the needs of the whole family

**Question 11**

**What features of younger onset dementia services are important to you? Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Choice between services is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services that are flexible to changing needs are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A range of activities is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clear information about services is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services that need minimal payment from clients are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services appropriate to the age of younger people are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 12**

**What needs to be considered when planning services for people with younger onset dementia? Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
A range of activities for the person with younger onset dementia to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The circumstances of younger families, such as working carers or responsibilities to children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stigma and a lack of understanding that dementia can impact younger people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The lack of knowledge of younger onset dementia among general health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nothing extra should be considered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 13**

**Do you have anything else you want to say about ideal services for younger onset dementia? If so, please write your comments in the space below.**

**Section C: Information about you**

**Question 14**

**I am...**

Male

Female

**Question 15**

**How old are you?**

Age: \_\_\_\_\_ years

**Question 16**

**I have the following type of dementia. Please tick ONE box only:**

- Alzheimer's disease
- Fronto-temporal dementia
- Dementia with Lewy Bodies
- Vascular dementia
- Unspecified type
- Unconfirmed diagnosis
- Other (please specify)   
\_\_\_\_\_

**Question 17**

**How many years has it been since:**

You first noticed symptoms of dementia \_\_\_\_\_years

(please answer in the nearest whole year)

You received a diagnosis of dementia \_\_\_\_\_years

(please answer in the nearest whole year)

**Question 18**

**I have significant medical condition/s other than dementia. Please tick as many as apply:**

- Multiple Sclerosis
- Parkinson's
- Diabetes
- Down Syndrome
- AIDS
- Drug/alcohol addiction or dependency
- None
- Other (please specify)   
\_\_\_\_\_

**Question 19**

**I live... Please tick ONE box only:**

- At home alone
- At home with spouse/partner
- At home with spouse/partner and children
- At home with children only
- With parent/s
- With other relative or friend
- In residential care/supported accommodation
- Other (please specify) \_\_\_\_\_

**Question 20**

**I am of Aboriginal or Torres Strait Islander origin:**

- Yes
- No

**Question 21**

**I speak a language other than English at home:**

- Yes
- No

**Question 22**

**I was born in Australia:**

- Yes
- No

**Question 23**

**My postcode is... \_\_\_\_\_**



## Section D: My family/carer's experience of services for younger onset dementia

This section asks about your family/carer's experiences of younger onset dementia.

This section is optional. You can choose to fill in this section or not.

### Question 24

Are you filling in this section? Please tick ONE box only.

I am filling in this section about my family/carer

I am not filling in this section because I don't have family/carers

I have family/carers, but I have chosen NOT to fill in this section

### Question 25

Is your family/carer receiving carer services for younger onset dementia?

Yes

No

Not sure

### Question 26

This question is about your family/carer using services for carers. Please tick ONE box in each row.

Either now or in the future, I think my family/carer would benefit or not benefit from...

	They would benefit	They would NOT benefit	Don't know
One to one social support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One to one respite, personal care or domestic assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Permanent residential care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support or educational groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure and activity/therapy based programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modification and equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case management and assistance with planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 28**

This question is about your satisfaction with services for your family/carer. Please tick one box to show how strongly you agree or disagree with the following statement.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A – has not used services
Overall, I am satisfied with services available to family/carers of people with younger onset dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 30**

Do you have anything else you want to say about services for families/carers of people with younger onset dementia? If so, please write your comments in the space below.

**Section E: Information about your family/carer**

**Question 31**

The main person who helps me is my...

Spouse/partner	<input type="checkbox"/>
Son/daughter or son/daughter in law	<input type="checkbox"/>
Parent	<input type="checkbox"/>
Friend	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

**Question 32**

The main person who helps me is:

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

**Question 33**

How old is the main person who helps you?

Age: \_\_\_\_\_ years

Thank you for completing this survey.

To contact the National Dementia Helpline, please phone 1800 100 500.



Survey for family/carers of people with younger onset dementia

## **Service and support requirements for people with younger onset dementia and their family/carers**

This survey is **only for people currently living in NSW** who are the family member or carer of someone who has been diagnosed with or are being assessed for younger onset dementia.

If you are a person with younger onset dementia, please fill in the other survey.

### **Services for younger onset dementia include:**

- **Funded programs to assist people with younger onset dementia and their family/carers (e.g. respite, day programs, support groups).**
- **Medical services (e.g. diagnostic services).**
- **Assessments (e.g. driving or ACAT assessments).**

**Services do not include informal forms of support, like community groups (e.g. church groups), volunteer work or support from family or friends – even though these may also assist you.**

### **Section A: The experience of my family member with services for younger onset dementia**

**This section is about the experiences of your family member with services for younger onset dementia. Please answer from your perspective about your family member's experience.**

**Question 1**

**Who gave your family member their dementia diagnosis? Please tick ONE box only.**

- Geriatrician
- Neurologist
- General practitioner
- Other health professional
- Unsure
- No confirmed diagnosis yet

**Question 2**

**At what stage did your family member with younger onset dementia first receive services? Please tick ONE box only.**

- Before diagnosis
- At the same time as diagnosis
- Shortly after diagnosis
- Long after diagnosis
- No services received yet

**Question 3**

**What is the MAIN way your family member with younger onset dementia has been linked to services? Please tick ONE box only.**

- Referred by health/diagnostic practitioner
- Referred by local dementia advisor
- Referred by Alzheimer's Australia
- Found out from someone else with dementia/their family
- Found out about services ourselves
- Combination of the above
- Not currently linked to any services

**Question 4**

This question is about using services. Please tick **ONE** box in each row.

Either now or in the future, I think my family member with younger onset dementia would benefit or not benefit from...

	My family member would benefit	My family member would NOT benefit	Don't know
One to one social support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One to one respite, personal care or domestic assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential respite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Permanent residential care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support or educational groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure and activity/therapy based programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modification and equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case management and assistance with planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 5**

This question is about your satisfaction with services for your family member with younger onset dementia. Please tick one box to show how strongly you agree or disagree with the following statement.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A – has not used services
Overall, I am satisfied with services that are available for my family member with younger onset dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 6**

**This question is about difficulties your family member with younger onset dementia may have had since experiencing symptoms of dementia. Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I think my family member finds it hard to keep doing his or her usual activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to deal with the emotional impact of younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to deal with the financial impact of younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to make plans for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to understand or explain younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to get information and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to organise their day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my family member finds it hard to complete practical tasks at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 7**

**Do you have anything else you want to say about services for people with younger onset dementia? If so, please write your comments in the space below.**

## Section B: My own experience of services for younger onset dementia

This section is about **your own** experiences of younger onset dementia services. Please answer from your own perspective, **not** that of your family member with younger onset dementia.

### Question 8

At what stage did **you** first start to use services for carers? Please tick ONE box only.

- Before diagnosis
- At the same time as diagnosis
- Shortly after diagnosis
- Long after diagnosis
- No services received yet

### Question 9

What is the MAIN way **you** have been linked to services for carers? Please tick ONE box only.

- Referred by health/diagnostic practitioner
- Referred by local dementia advisor
- Referred by Alzheimer's Australia
- Found out from someone else with dementia/their family
- Found out about services ourselves
- Combination of the above
- Not currently linked to any services

### Question 10

This question is about using services. Please tick one box in each row. Either now or in the future, I think I would benefit or not benefit from...

- |  | I would benefit          | I would NOT benefit      | Don't know               |
|--|--------------------------|--------------------------|--------------------------|
| One to one social support services                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| One to one respite, personal care or domestic assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Residential respite                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Permanent residential care                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Support or educational groups                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Leisure and activity/therapy based programs              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Home modification and equipment                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Case management and assistance with planning             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Information about services                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



**Question 11**

**This question is about your satisfaction with services for you as a carer. Please tick one box to show how strongly you agree or disagree with the following statement.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A – haven't used services
Overall, I am satisfied with services that are available to me for families/carers of people with younger onset dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 12**

**This question is about difficulties you may have had since your family member has experienced symptoms of younger onset dementia. Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I find it hard to keep doing my usual activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard dealing with the emotional impact of younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard dealing with the financial impact of younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to make plans for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to understand or explain younger onset dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to get information and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to do practical and care tasks at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to find someone to take over my practical and care tasks when I can't do them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 13**

**Do you have anything else you want to say about services for families/carers of people with younger onset dementia? If so, please write your comments in the space below.**

**Section C: Ideal younger onset dementia services**

**Question 14**

**How should younger onset dementia services be provided? Please tick ONE box only.**

- Younger onset dementia services should be part of disability services
- Younger onset dementia services should be part of aged care services
- Younger onset dementia services should be part of both of these services
- Don't mind
- Don't know

**Question 15**

**How should younger onset dementia services be provided? Please tick ONE box only.**

- Younger onset dementia services should be for younger people only
- Younger onset dementia services should be with other people with dementia

**Question 16**

**Whose needs should younger onset dementia services focus on? Please tick ONE box only.**

- On the needs of the person with younger onset dementia
- On the needs of the family/carer
- On the needs of the person with younger onset dementia and the family/carer
- On the needs of the whole family

**Question 17**

**What features of younger onset dementia services are important to you? Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Choice between services is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services that are flexible to changing needs are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A choice and range of activities is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clear information about services is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services that need minimal payment from clients are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services appropriate to the age of younger people are important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 18**

**What needs to be considered when planning younger onset dementia services? Please tick one box in each row to show how strongly you agree or disagree with the following statements.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
A range of activities for the person with younger onset dementia to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The circumstances of younger families, such as working carers or responsibilities to children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stigma and a lack of understanding that dementia can impact younger people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The lack of knowledge of younger onset dementia among general health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nothing extra should be considered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Question 19**

**Do you have anything else you want to say about ideal younger onset services? If so, please write your comments in the space below.**

## Section D: Information about your family member with younger onset dementia

### Question 20

**My family member with younger onset dementia is...**

Male

Female

### Question 21

**How old is your family member with younger onset dementia?**

Age: \_\_\_\_\_ years

### Question 22

**My family member has the following type of dementia. Please tick ONE box only:**

Alzheimer's disease

Fronto-temporal dementia

Dementia with Lewy Bodies

Vascular dementia

Unspecified type

Unconfirmed diagnosis

Other (please specify)

\_\_\_\_\_

### Question 23

**How many years has it been since:**

You first noticed symptoms of your family member's younger onset dementia \_\_\_\_\_ years  
(please answer in the nearest whole year)

Your family member received a diagnosis of dementia (please answer in the \_\_\_\_\_ years  
nearest whole year)

### Question 24

**My family member has significant medical condition/s other than dementia. Please tick as many as apply:**

Multiple Sclerosis

Parkinson's

Diabetes

Down Syndrome

AIDS

Drug/alcohol addiction or dependency

None

Other (please specify)

\_\_\_\_\_

**Question 25**

**My family member lives... Please tick ONE box only:**

- At home alone
- At home with spouse/partner
- At home with spouse/partner and children
- At home with children only
- With parent/s
- With other relative or friend
- In residential care/supported accommodation
- Other (please specify)

\_\_\_\_\_

**Section E: Information about you**

**Question 26**

**My family member with dementia is my...**

- Spouse/partner
- Son/daughter or son/daughter in law
- Parent
- Friend
- Other (please specify)

\_\_\_\_\_

**Question 27**

**I am...**

- Male
- Female

**Question 28**

**How old are you?**

Age: \_\_\_\_\_ years

**Question 29**

**I am of Aboriginal or Torres Strait Islander origin:**

Yes

No

**Question 30**

**I speak a language other than English at home:**

Yes

No

**Question 31**

**I was born in Australia:**

Yes

No

**Question 32**

**My postcode is...**

---

**Thank you for completing this survey.**

**To contact the National Dementia Helpline, please phone 1800 100 500.**



## **APPENDIX 2: REPORT ENDNOTES**

1. <http://www.alzheimers.org.au/services/early-or-younger-onset-dementia.aspx>
2. <http://www.alzheimers.org.au/services/early-or-younger-onset-dementia.aspx>
3. 'People from Aboriginal backgrounds' has been used as this is the preferred terminology in NSW, however people from Torres Strait Islander backgrounds might also need the services and support.
4. <http://www.abs.gov.au/ausstats/abs@.nsf/0/F4B15709EC89CB1ECA25732C002079B2?opendocument>
5. Two new levels of packages have been introduced in the reforms - a basic package, at a level lower than the current CACP, and an intermediate package between CACPs and EACH. The two new packages will be piloted and evaluated from 2012/13. From July 2013 EACHD packages cease and will be replaced by a new behaviour supplement (10% of the package value) for people with dementia receiving any of the packages. All new Home Care packages will be offered as consumer directed care packages after 1 July 2013. Over time, all packages will convert to consumer directed packages. In the longer term, people will be able to purchase additional or extra services above the minimum services in the packages (COTA, 2012; Australian Government, 2012).
6. See, for example, P Harvey (2005) Guidelines on the Breaking of Bad News, Yorkshire Cancer Network

## APPENDIX 3: REPORT REFERENCES

ACCESS ECONOMICS. 2009. *Making Choices: Future Dementia Care: Projections, Problems and Preferences report for Alzheimer's Australia* [Online]. Available: <http://www.alzheimers.org.au/research-publications/access-economics-reports.aspx>

ALLEN, J., OYEBODE, J. R. & ALLEN, J. 2009. Having a father with young onset dementia: the impact on wellbeing of young people. *Dementia* 8, 455.

ALT BEATTY CONSULTING 2007. Appropriate HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern. Report for for the NSW Department of Ageing, Disability & Home Care Metro North.

ALT BEATTY CONSULTING 2008. HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern: Issues for Aboriginal and Torres Strait Islander People and People from Culturally and Linguistically Diverse Backgrounds. Sydney: Report for Community Care (Northern Beaches) Inc.

ALZHEIMER'S AUSTRALIA NSW 2009. Quality Support Groups Research Project

ALZHEIMER'S AUSTRALIA NSW 2010. Addressing the Stigma Associated with Dementia. *Discussion Paper 2*. September 2010.

ALZHEIMER'S AUSTRALIA NSW 2010. Grant boots YOD research. *In Touch: The Quarterly Newsletter of Alzheimer's Australia NSW*.

ARKLES RS, JACKSON PULVER LR, ROBERTSON H, DRAPER B, CHALKLEY S AND BROE GA. 2010. *Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples*. Neuroscience Research Australia and Muru Marri Indigenous Health Unit, University of New South Wales. June 2010.

AUSTRALIAN GOVERNMENT. 2012. *Help with Dementia* [Online]. Available: <http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Dementia-3> [Accessed 13 May 2012].

BRACKERTZ, N. 2005. *Community Consultation and the 'Hard to Reach': Concepts and Practice in Victorian Local Government*. Melbourne: Swinburne Institute for Social Research, Swinburne University of Technology.

CHASTON, D. 2010. Younger adults with dementia: a strategy to promote awareness and transform perceptions. *Contemporary Nurse*, 34, 221-229.

COMMUNITY CARE DIRECTORATE 2012. *Younger Onset Dementia Person centred Packages: Draft Guidelines*. Sydney: Community Care Directorate, Ageing, Disability and Home Care, Department of Family and Community Services NSW.

COTA AUSTRALIA 2012. Policy Alert No. 6.

HARVEY, P. 2005. *Guidelines on the Breaking of Bad News*, Yorkshire Cancer Network

HODGES, J., GREGORY, C., MCKINNON, C., KELSO, W., MIOSHI, E. & PIGUET, O. 2009. Quality Dementia Care Series: Younger Onset Dementia a practical guide. *Alzheimers Australia*, February 2009.

- LONGLEY, W. A. 2007. Multiple Sclerosis-related Dementia: Relatively rare and often misunderstood. *Brain Impairment*, 8, 154-167.
- MCLEAN, A. 2009. Younger onset: the move towards specialist services and support. *Alzheimer's Australia 2009 Conference, 'The Power is Now: Moving on Dementia'*. Adelaide, June 205, 2009: Alzheimer's Australia WA.
- MENDEZ, M. F. 2006. The accurate diagnosis of early-onset dementia. *International Journal of Psychiatry in Medicine*, 36, 401-412.
- MOCELLIN, R., A. , SCHOLE, A. & VELAKOULIS, D. 2008. *Quality Dementia Care: Understanding Younger Onset Dementia* [Online]. Melbourne: Neuropsychiatry Centre, Royal Melbourne Hospital. Available: [http://www.alzheimers.org.au/common/files/NAT/20080400\\_Nat\\_QDC\\_QDC4UnderstandYOD.pdf](http://www.alzheimers.org.au/common/files/NAT/20080400_Nat_QDC_QDC4UnderstandYOD.pdf)
- NSW DEPARTMENT OF HEALTH 2007. *Protocols and Procedures Manual for Aged Care Assessment Teams in NSW*. NSW Department of Health and Aged Care Integration Unit Inter-Government and Funding Strategies Branch.
- NSW DEPARTMENT OF HEALTH 2010. *The NSW Dementia Services Framework 2010-2015*.
- NSW DEPARTMENT OF HEALTH 2011. *Draft Implementation Plan for the NSW Dementia Services Framework 2010-2015*.
- NSW GOVERNMENT 2006. *Stronger Together: A New Direction for Disability Services in NSW 2006-2016*. Sydney: NSW Department of Ageing Disability and Home Care.
- NSW GOVERNMENT 2010. *Stronger Together, The Second Phase: A New Direction for Disability Services in NSW 2006-2016*. Sydney: Department of Ageing, Disability and Home Care NSW.
- PATERSON, N., PHILLIPS, J. & POND, D. 2010. Early diagnosis of dementia and diagnostic disclosure in primary care: A qualitative study into the barriers and enablers. *National Conference of Emerging Researchers in Ageing*
- RINFRETTE, E. S. 2010. *Impact on Informal Caregivers of Caring for those with Early Onset Dementia*. PhD, State University of New York.
- ROSENTHAL GELMAN, C. & GREER, C. 2011. Young Children in Early-Onset Alzheimer's Disease Families: research gaps and emerging service needs. *American Journal of Alzheimer's Disease and other Dementias*, 26, 29.
- THOMPSON, D. 2011. *Service and Support Requirements for People with Younger Onset Dementia and Their Families*. Social Policy Research Centre, University of New South Wales.
- TYSON, M. 2007. *Exploring the Needs of Younger People with Dementia in Australia. A report to Australian Government Department of Health and Ageing*, Alzheimer's Australia, <http://www.alzheimers.org.au/common/files/NAT/20101027-Nat-YOD-Exploring-needs-Australia.pdf>.
- WORKMAN, B.; DICKSON, F. & S. GREEN 2010. Early Dementia: Optimal management in general practice, *Australian Family Physician* 39(10): 722-726

## **APPENDIX 4: SERVICE AND SUPPORT REQUIREMENTS OF PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR FAMILIES - LITERATURE REVIEW**

### **CONTENTS**

Executive Summary	112
Introduction	115
Numbers of people with younger onset dementia	116
Australian policy context	117
What is necessary for good practice	120
Australian examples of good practice	135
International examples of good practice	145
Conclusion	154
Literature review endnotes	155
Literature review references	157

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## **ABBREVIATIONS**

AA	Alzheimer's Australia
ACAS	Aged Care Assessment Service
ACAT	Aged Care Assessment Team
ADHC	(NSW Department of) Ageing, Disability and Home Care
AHMC	Australian Health Ministers' Conference
AIHW	Australian Institute of Health and Welfare
AlzNSW	Alzheimer's Australia NSW
CACP	Community Aged Care Package
CALD	culturally and linguistically diverse
CDAMS	Cognitive, Dementia and Memory Service
CDN	Cogknow Day Navigator
COPS	Community Options Service
DADHC	(NSW) Department of Ageing, Disability and Home Care
ESML	early-stage memory loss
FTD	fronto-temporal dementia
HACC	Home and Community Care
LWML	Living with Memory Loss (program)
MRRT	Mobile Respite Response Team
NHHRC	National Health and Hospital Reform Commission
NHS	National Health Service (UK)
SPRC	Social Policy Research Centre
YOD	younger onset dementia
YODSSR	Younger Onset Dementia Social Support and Respite

## **EXECUTIVE SUMMARY**

### **INTRODUCTION**

The literature review was focused on identifying recent research and development in community-based best-practice service models, both nationally and internationally, appropriate for people with younger onset dementia (YOD) and their families and carers.

### **NUMBERS OF PEOPLE WITH YOUNGER ONSET DEMENTIA**

YOD is defined as dementia which occurs before the age of 65 years<sup>1</sup>. Its prevalence and incidence are unknown as no epidemiological studies have been conducted anywhere in the world. The consensus in Australia is that currently around 10,000 people have YOD.

### **AUSTRALIAN POLICY CONTEXT**

Alzheimer's Australia, through its state-based affiliates, and other providers currently offer ongoing support for people with YOD and their families and carers in all states and territories. There is also increasing recognition from the federal government and most state and territory governments. The level of recognition within the health and disability departments of the Australian states and territories varies from one jurisdiction to another. NSW and Victoria appear to be the states with the most services specifically designed for people with YOD.

There are still unresolved problems in relation to policy. The chief of these involves the allocation of responsibility for aged-care services to the Commonwealth and of disability services to the states and territories. Services for people with YOD belong in both streams, although they are not completely covered by either. Other problems involved the short-term nature of the funding, its competitiveness (which created difficulties for cooperation between service providers), and tying funding to particular geographical areas.

### **WHAT IS NECESSARY FOR GOOD PRACTICE**

The review did not uncover many examples of 'best practice' in the strict sense of programs that had been evaluated. The focus instead was on good practice service models, assessments of which were based on the practical experiences of professionals, carers and people with YOD themselves. Based on this kind of evidence, the literature does contain clear guidelines for what constitutes good practice:

- diagnosis – timely, accurate, sensitive and informative, with prompt referral to needed ongoing services;
- information – sufficient information (what people are told) and delivered sensitively (the way they are told it);
- differences – recognition of the differences between YOD and dementia that develops later in life, chiefly the greater likelihood of responsibility for dependent children, employment and financial commitments;
- services – both YOD-specific and generic, multi-disciplinary, and person- and family-centred;
- carers – recognition of the specific difficulties faced by carers of people with YOD, largely as a result of the time of life when the disease appeared, but also because of the higher incidence of frontotemporal dementia and its behavioural symptoms among people with YOD; and
- respite – age-appropriate with provision for the greater physical health and strength of people with YOD.

## **AUSTRALIAN EXAMPLES OF GOOD PRACTICE**

While accessibility to services appropriate for people with YOD in Australia still appears to be ad hoc and variable, there have been a number of programs, services and other initiatives. The list of programs below is based on the published evidence.

Nationally the Living with Memory Loss program is designed for people in the early stages of dementia. Although the program itself does not specifically focus on people with YOD, some groups do.

### **IN NSW**

- four Home and Community Care (HACC) services designed around the specific needs of people with YOD in the Sydney Metro North region of the Department of Ageing, Disability and Home Care – the Mercy Community Care Younger Onset social support service (Waitara), the Chesalon Younger Onset social support (Avalon), the Hope Healthcare Horizons program (North Sydney), and the Mercy Day Program (Waitara);
- the Younger Onset Dementia Social Support and Respite (YODSSR) Program – The Ella Centre – in the inner west of Sydney;
- a pilot residential and respite service opened by HammondCare in Horsley, near Wollongong, south of Sydney in April 2010;
- a number of initiatives in the Hunter region of NSW, including the new Alzheimer’s Australia NSW Hunter Dementia and Memory Resource Centre in Hamilton, various groups for people with YOD and for carers run by the Dementia Advisory Service, and the Hunter Younger Onset Working Group, which plays a coordinating role;
- the Ritz Nursing Home in the Blue Mountains NSW;
- two YOD support groups for carers and one group for children of YOD parents, all in Sydney; and
- a blog for the young people called Younger Onset Dementia and Me.

### **IN VICTORIA**

- the Cognitive, Dementia and Memory Services – not YOD-specific but recommended by Alzheimer’s Australia;
- Memory Lane cafés, as a continuation of the Living with Memory Loss programs – again, not YOD-specific;
- a one-year pilot Linking Lives program – specifically for people with YOD and their carers; and
- other initiatives described in less detail.

South Australia had Connexus and the Sundowner Club, but neither of these is still operating.

The ACT had a Mobile Respite Response Team providing short-term in-home interventions, which ended after 12 sessions. Currently a YOD-specific respite program was funded in 2010, which provides one group for women and another mixed-sex group.



## **INTERNATIONAL EXAMPLES OF GOOD PRACTICE**

This section describes a number of international examples of good practice.

Most of the examples came from the UK:

- the Clive Project, named after the husband of the author of *Losing Clive to Younger Onset Dementia* – now called YoungDementia UK;
- the Birmingham Working Age Dementia service;
- the ACE club, also called the Glen Devon Day Club in Denbighshire in North Wales, also YOD-specific;
- the Croydon Memory Service, with a stated goal of 10 per cent of referrals of people with YOD (18 per cent in the first 18 months);
- PROP (People Relying on People), a self-help group for people with YOD and their carers based in Doncaster, South Yorkshire;
- CANDID (Counselling and Diagnosis in Dementia), a telephone helpline providing information for people with YOD, their families and carers, and the professionals caring for them – alternatively, a nurse-led information and advice service at the Dementia Research Centre, Queen Square, London, part of the National Hospital for Neurology and Neurosurgery;
- an 'Out and About' group, which provided social activities for four women with YOD in South Warwickshire; and
- other initiatives mentioned although with no details.

In the US, a number of community organisations, including local chapters of the Alzheimer's Association, have begun providing education and support programs for people with early-stage memory loss. Although these are not YOD-specific, the programs are aware of the issue and of some of the difficulties. Researchers in the area agreed that there are limited services for people with YOD, although a report of a support group for people with YOD in Chicago, 'Without Warning™', indicated that the necessary experience and expertise in supporting people with YOD was being developed.

The review also came across a number of initiatives elsewhere in the world. Alzheimers New Zealand is very active, with contact details for a number of YOD support groups. A PROP group has also been established for people in rural and regional areas. In Europe there is COGKNOW, an assistive cognitive prosthetic to support people with mild dementia in their daily lives. Originally funded by the European Union, it is in the process of being developed commercially. In the Netherlands, a longitudinal observational study, the NeedYD-study, is following 217 people with YOD and their carers, although to date there are no results from this study. In Japan, a longitudinal study of people with dementia (although not younger onset) found a number of benefits from a cognitive rehabilitation program.

## **CONCLUSION**

In sum, there is general agreement in the literature that too little is known about the support needs of people with YOD; that their needs are under-researched; and that specific services are rare. However, that situation is changing and YOD is increasingly a focus of policy and research interest.

## INTRODUCTION

The Social Policy Research Centre (SPRC) is collaborating with Alzheimer's Australia NSW (AlzNSW) in a research project to identify service and support requirements for people with younger onset dementia (YOD) (aged under 65 years) and their families and carers. The research is intended to identify appropriate service models for early intervention services providing support in the community, and the development of innovative flexible models to assist providers to increase access to services and achieve greater effectiveness and efficiency in the service system.

The initial step in the research project was a literature review specifically focused on identifying recent research and development in community-based best-practice service models, both nationally and internationally, appropriate for people with YOD and their families and carers.

An extensive review of the literature on YOD (Tyson, 2007) was published recently. Commissioned by Alzheimer's Australia and funded by the Australian Government, its emphasis differed from this present review in that it was not mainly focused on models of service provision, but rather on the differences between people with YOD and older people with dementia, and the resultant unique needs of people with YOD. As well as reviewing the literature, this earlier study incorporated information from consultations with people with YOD, primary family carers and other family members, Alzheimer's Australia service providers and other service providers, and special interest groups. Although its investigation included issues of relevance to best practice in community-based service models, that was not its specific focus.

In contrast, this present review largely focuses on issues around best practice in service provision (or rather, good practice – see the discussion in section 4 below), especially the literature published since that earlier review. It includes information about what is seen to be necessary for good practice in this area, and provides examples of programs either currently available or available in the recent past in states and territories across Australia, as well as of programs in other countries. The review was confined to information available on the internet, both the academic and the 'grey' literature (any books mentioned were sourced from information on the internet), and is not exhaustive although some generalisations can be drawn from the results.

With one exception, the review was not concerned with the different forms and causes of YOD, e.g. alcohol or drug abuse, HIV/AIDS, Parkinson's disease, Huntington's chorea, Down syndrome, multiple sclerosis. While each of these can have different service requirements from the others, as well as from the main cause of YOD, early-onset Alzheimer's disease, the limited timeframe of this review prohibited dealing them as particular issues. Instead, the review focuses on the needs of people with YOD in general terms without addressing the particularities of different kinds of dementia. In practice, this has meant that the focus of this review, as of the literature more generally, is largely on the needs of people with younger-onset Alzheimer's disease, since that is the most common form. The exception is frontotemporal dementia (FTD), and it is discussed because of the effects on carers of its behavioural manifestations.

Neither is this review concerned with clinical services or medical issues more generally<sup>2</sup>, which are outside its scope. Clinical services and other types of support services sometimes overlap, especially in relation to diagnosis and the importance of identifying the disease in its early stages. Delays in making an accurate diagnosis can mean that the disease is inappropriately managed and that the therapeutic intervention is at best ineffective, or at worst, has significant adverse effects. However, in the research we are looking at people's experiences of receiving a diagnosis, and the barriers to accurate diagnosis, because that can impact on service referrals, etc. To the extent that it was possible, this review distinguished between clinical/medical issues on the one hand, and community-support services on the other, with the aim of focusing only on the latter.

There is general agreement in the literature that not enough is known about YOD, that there is a limited evidence-base and the people with YOD are continually under-represented in the literature, and that specifically dedicated services are rare. The 2010 World Alzheimer report (Wimo and Prince, 2010), released by Alzheimer's Disease International, for example, does not discuss YOD (although two of the people illustrated in the report were diagnosed with younger onset Alzheimer's). A UK review of the literature (Roach et al, 2009) found that most of the published accounts of YOD came either from government and NGO 'grey literature', or from first-hand accounts by people with YOD themselves and their families and carers both professional and informal, with little published primary academic research of high quality. The literature that reports on services for people with dementia tends to mention younger people specifically at the outset, and then make no further reference to them in the rest of the publication (Stalker et al, 2005). Such issues as prevalence estimates and the understanding of the care responsibilities and service-use needs are still markedly under-researched. The consequence of this relative lack of information is that planning how best to help people with YOD and their families is hampered (Withall and Draper, 2009).

However, as the prevalence of dementia increases overall, the condition among younger people is starting to receive increased attention from national and international policymakers (Roach et al, 2009). If the academic literature is any guide, younger onset dementia is no longer being ignored but has become an important issue in its own right. Increasing efforts are being devoted to studying it, and it is no longer being assumed that dementia occurs only among people aged 65 years and over. Research is still in its early stages, and there is a need to expand it with the aim of leading to more effective diagnosis and management of YOD, as well as making a case for the allocation of funds and the development of services appropriate to the unique needs of people with YOD (Werner et al, 2009). But the process has begun and YOD is increasingly a focus of policy and research interest.

## **NUMBERS OF PEOPLE WITH YOUNGER ONSET DEMENTIA**

YOD is defined as dementia which occurs before the age of 65 years. It is very rare before the age of 45 years, but it can begin in the early 30s, even in the form of Alzheimer's disease, and there have even been reports of onset in those who are in the mid-20s (Rinfrette, 2010). Its prevalence and incidence are unknown as there has been no epidemiological study anywhere in the world (Rinfrette, 2010; Alt Beatty, 2007). Nonetheless, there are a number of 'best guesses'.

In Australia, estimates vary between 9,600 people Australia-wide (in 2005)<sup>3</sup> to 15,000 (In touch, Issue 74 Spring 2010) or even 16,000 (Alzheimer's Australia website), although the consensus seems to be that there are currently around 10,000 people with YOD (e.g. Hodges et al, 2009), as estimated by Access Economics in 2009 (Access Economics, 2009a). The Australian Institute of Health and Welfare's national data analysis of dementia (AIHW, 2007) gave the following estimates (Table 1) of the projected numbers of people aged 0-64 with dementia from 2003 to 2031. The research project investigating HACC service models (Alt Beatty, 2007) added the percentage of the total population represented by the numbers of people with YOD.

The AIHW report (2007: 58) noted that the increases were not due to increases in the rate of the disease, but entirely to demographic factors, that is, to projected increases in the numbers of older people over this period. The incidence of younger onset dementia has only a slight relationship to the ageing of the population. It increases marginally with the older age groups, but not as markedly as in the population over the age of 65. Most of the increase in numbers would be the result of increases in the population overall, as well as improvements in assessment and diagnosis, not simply of older people.

A recent prevalence study in the South Eastern Sydney and Illawarra Area Health Service found a rate of 1 in 750 people aged 45 to 64 years of age with YOD (NSW Health, 2011), while a study in the Hunter Valley region estimated there were 8,000 people with dementia in the area, approximately 10 per cent (700-800) of whom were aged under 65 years (Merl, 2010).

**Table 1. Projected number of younger people with dementia, 2003-2031**

	2003	2006	2011	2021	2031
Persons with YOD aged 0-64 years	8,100	8,800	10,000	11,400	12,000
Total population aged 0-64 years	17,326,223	17,820,200	18,527,500	19,399,300	19,992,700
Per cent of population aged 0-64 years	0.05%	0.05%	0.05%	0.06%	0.06%

Source: AIHW, 2007: 59, Table 4.5; Alt Beatty, 2007: 7, Table 2.1

## AUSTRALIAN POLICY CONTEXT

There is ongoing support for people with YOD and their families and carers offered by Alzheimer's Australia in all states and territories through its state-based affiliates. As Brodaty and Cumming (2009) have pointed out, Alzheimer's Australia continues to be a powerful advocate for improvement in services. Many of the people with YOD and their family members who were consulted as part of the earlier project (Tyson, 2007) were clients of Alzheimer's Australia. The author commented that, although this might have meant that the results were favourably biased towards Alzheimer's Australia's services, it was still legitimate to highlight the support the organisation has provided for people with YOD.

There is increasing recognition from the federal government and most state/territory governments (McLean, 2009). The main policy document from the federal government, the National Framework for Action on Dementia (AHMC, 2006), which provides the blueprint for services for people of all ages with dementia, acknowledges the need for YOD-specific services, care, education and research. Prepared under the auspices of the Australian Health Ministers' Conference (AHMC), it identifies people with YOD as a distinct group with unique needs that are not met through current service arrangements, and indicates that significant progress has been made towards acknowledging their unmet needs (Tyson, 2007).

The Australian Government Department of Health and Ageing has issued a Dementia Resource Guide (DHHA, 2009), with a section containing information for people with YOD as a 'specific community group', as well as a brochure called, 'Younger onset dementia – know the signs'.

One of three new dementia training resources launched by the Minister for Ageing in September 2008 as part of Dementia Awareness Week, included a program to assist in supporting the care of those with YOD. Called '2 young 4 dementia – meeting the needs of people with younger onset dementia', it aimed to support improved dementia awareness and care for people with YOD and their carers and families, in a variety of work and care environments<sup>4</sup>. This program was mentioned favourably in a US case report of a person with frontotemporal dementia, as a training resource for health professionals and carers (Chemali et al, 2010, citing Kaiser and Panygeres, 2007). The Australian government also funds Living with Memory Loss programs in each state and territory.

However, the level of concern with YOD within the health departments of the Australian states and territories varies from one jurisdiction to another. A search of the health department websites of all jurisdictions in Australia, using the keywords 'younger onset dementia' and 'early onset dementia',

found no mention in the Tasmanian Department of Health and Human Services, Northern Territory Department of Health, or ACT Department of Health. However, all jurisdictions have Living with Memory Loss programs as well as links to Alzheimer's Australia resources; and in the case of the ACT, a number of projects have been initiated by Alzheimer's Australia ACT (Section 5). The health departments in the other jurisdictions are aware of the issue and show varying degrees of interest in it (at least insofar as it appears on their websites).

In Victoria, the Department of Health website has a link to Alzheimer's Australia website for the booklet, *Understanding Younger Onset Dementia* (Mocellin et al, 2008), and both the government's *Dementia Framework for Victoria Implementation Plan 2006–08* (Victorian Government, 2006), and the earlier *Consultation Paper for the Dementia Framework for Victoria* (Victorian Government, 2004) acknowledge people with YOD as special needs group. The Alzheimer's Australia Background Paper to the 2009 Summit on Younger Onset Dementia (Alzheimer's Australia, 2009a) recommended to professionals the Cognitive, Dementia and Memory Services (CDAMS) (see below) in Victoria as a useful model to which to refer people with YOD. The report of a research project investigating Home and Community Care (HACC) service models in the Sydney Metro North area, for their appropriateness for people with YOD (Alt Beatty, 2007), found that HACC authorities believed that Victoria was the state which had made the most progress in addressing the needs of these people.

In Queensland, the Queensland Health Dementia Framework 2010-2014 (Queensland Health, 2010: 7) notes the existence of younger onset dementia, acknowledges that the needs of people with YOD are very different from those of older people, and estimates that there are probably around 1,700 Queenslanders with YOD. The Framework also says that Queensland Health will explore opportunities for the development of more flexible service models for people with YOD and their carers, which link to specialist NGOs and peak bodies.

In Western Australia, the Department of Health's Dementia Action Plan contains no mention of YOD (WA Department of Health, 2006). However, Western Australia has a Younger Onset Dementia Project (McLean, 2009) aimed at meeting the needs of People with YOD, through case management, advocacy, Dementia Behaviour Management Advisory Services, carer support groups, Living with Memory Loss programs, respite and social support, counselling, assistive technologies and education.

In South Australia, the Department for Families and Communities' South Australia's Dementia Action Plan 2009-2012 (SA Government, 2009) says that people with YOD require uniquely tailored responses and that, because of its rarity, the disease is difficult to diagnose accurately and people can be misdiagnosed at first and appropriate treatment and care delayed. Among the dementia-specific service models to be expanded, the Plan mentions 'Connexus Younger Onset' (see below).

The NSW Dementia Services Framework (NSW Health, 2011) has the most detailed information of all the Frameworks and Plans across the states and territories. It recognises people with YOD as a specific population group with particular needs and experiences and notes that, although age is the primary risk factor for dementia and it is uncommon under the age of 60, it can occur in people in their 40s or even younger. The Framework also notes that Alzheimer's disease is the most common form of dementia both in people over the age of 65 and in younger people, although it is less prevalent among the latter. It recognises that there are differences between people with YOD and older people with dementia, largely because people with YOD are at a different stage in their lives, still physically and socially active, still working and driving, with young partners and children, and with significant financial commitments. As well, the Framework recognises that they do not fit into mainstream dementia services and that they have added difficulties with getting a diagnosis.

There are many important issues still outstanding. For example, the Alzheimer's Australia Annual Report (Alzheimer's Australia, 2010a) raised a number of pressing questions which have not been resolved. The most pressing of these was people's access to appropriate services, especially in

light of the confusion between state and federal responsibilities in relation to YOD, given that it does not fall neatly into the disability sector (a state responsibility) or the aged-care sector (a federal responsibility). The report also identified other concerns expressed by consumers, involving questions about how the disability sector understood the care and support needs of people with YOD, what resources were available to develop appropriate services, and what the federal government required of current initiatives in the states and territories for including people with YOD. Nonetheless, awareness of younger onset dementia on the part of the Australian government is slowly increasing.

In his submission to the Productivity Commission, Brodaty (2010) also referred to the lack of congruence between state and federal responsibilities, pointing out that the issue had not been resolved through the National Hospital and Health Reform process. On the contrary, the reforms would place people with YOD wholly within disability services and exclude them from aged-care services. While services within aged care are not always appropriate, that is where services for people with dementia are organised, and there is very little on the disability side to assist them. Younger people with dementia, he said, should be eligible for generic dementia services.

The earlier review (Tyson, 2007) also found that the division between state and federal responsibilities made it difficult for people with YOD to fit into the service system. While their disease is catered for by the aged-care sector funded by the commonwealth, their age means that they fall within the disability sector funded by each state and territory. Many people, service providers and others relevant to this field as well as people with YOD themselves and their families, had found this state/commonwealth divide to be a stumbling block in terms of funding arrangements and entitlements. Its rigidity has meant that no one has clear responsibility for people with YOD, and consequently they tend to fall into the gaps in the services. (See also: Alzheimer's Australia, 2009a: 8).

The earlier review (Tyson, 2007) uncovered other funding arrangements which created difficulties of service provision for people with YOD. Most of the service providers interviewed felt that programs were not sustainable because of the government's short-term approach to funding. While program sustainability was made difficult by the rapidly changing progressive nature of the condition, having to re-apply for funding every year increased the difficulties of maintaining services. As well, the requirement that funding applications be competitive hindered the collaboration between service providers that funding bodies supposedly encouraged. It led providers to be protective of their work so that no one could compete with their program in the next round of funding. Moreover, tying funding to particular geographical areas excluded people from outside the area from accessing the services. In sum, the call was for more flexible funding arrangements which allowed people with YOD to access services in both the disability and aged-care sectors, according to need. (See also: Alzheimer's Australia, 2009a: 8-10).



## WHAT IS NECESSARY FOR GOOD PRACTICE

As already mentioned, the primary purpose of this review was a focus on community-based best-practice service models for people with YOD. The review did not uncover many examples of 'best practice' in the strict sense of programs which had been subjected to a process of evaluation or a random controlled trial process, so most of what follows discusses projects for which there is less rigorous support. In that sense these are good practice service models (based on the available evidence), rather than best practice (as shown by the results of evaluations). A large proportion of the literature consists of stories, biographies, autobiographies and testimonies<sup>5</sup>, which are a vital source of experiential information, an important guide for practice and a resource for evaluations. But unless they are collected systematically, they are not the kind of data required by a process for evaluating best practice. Much of the assessment of good practice is based on this kind of evidence arising out of the practical experience of professionals, carers and people with YOD themselves, rather than on anything that might qualify as scientific evidence.

For example, the organisers of a support group for people with YOD in Boston (Without Warning™ – see below) based their belief in the efficacy of the program on what the group participants said. 'These benefits', they said, 'can best be expressed by those individuals with [younger onset Alzheimer's disease] themselves' (Arends and Frick, 2009: 38). Similarly, the initiator of the ACE club in North Wales (see below) said that she believed that their success could be judged by what the members said about whether they felt personally effective and by their perceptions of their own well-being (Davies-Quarrel et al, 2004: 20). Again, Tyson (2007) cited an earlier English-language literature review (Beattie et al, 2002) whose recommendations for a person-centred model of care was largely based on the practical experience of professionals and paid carers, rather than on scientific evidence. And further, a scoping study on the needs of younger people with disabilities in the UK (including people with YOD) (Stalker et al, 2005) found that much of what had been written about YOD was confined to anecdotal accounts from practitioners about the benefits of their services.

Client satisfaction is, of course, the best evidence for success, and taking account of it is standard operating procedure in any evaluation process, no matter how informal. Moreover, if the criterion of good practice is that which offers client-responsive services (Alt Beatty, 2007), the initiatives described below qualify, even though for the most part that assessment is not based on results produced by a rigorous methodology.

Even though the literature contains few examples of programs that have been systematically evaluated, it does contain clear guidelines for what constitutes good practice.

Alzheimer's Australia's website<sup>6</sup>, for example, has a number of Help Sheets setting out information for people with YOD and their carers. On the information contained in *Help Sheet No.1*, 'What is younger onset dementia?', the best practice would include early and accurate diagnosis involving a number of physical and psychological tests, together with detailed information about the disease and what to expect, and the reassurance that 'You are not alone'. *Help Sheet No.2*, 'Early planning', emphasises the importance of planning financial and legal affairs; *No.3*, 'Next steps', describes the services that will be needed and that are available; and *No.4*, 'Employment', discusses decisions that need to be made about people's employment situations. Taken together, these *Help Sheets* illustrate many of the elements that go into ensuring appropriate services for people with YOD and those who care for them.

The *HACC National Service Standards* are another example of guidelines for good practice (Alt Beatty, 2007: 72, Appendix D). While not specifically devised for people with YOD, they relate to what is already accepted as good practice in service provision, even though that might not actually be achieved in the face of resource constraints or competing demands. Similarly, researchers in the UK (Roach et al, 2009) identified Standard 7 of the UK National Service Framework for Older People as



the relevant section making recommendations about reviewing service provision for those with YOD, and locating it within specialist care-settings and primary care. The report of the HACC evaluation noted that good practice is that which helps to meet the needs of the less common or more challenging clients (Alt Beatty, 2007: 39).

In their submission to the National Health and Hospital Reform Commission (NHHRC), Alzheimer's Australia (2008: 12) listed five major issues that would need to be incorporated into service provision for Australians with YOD:

- the need for appropriate services, both community and residential care, which take in to account the fact that people with YOD are often physically strong and otherwise healthy;
- the recognition of people's family responsibilities, including the fact that they could be still actively raising a family;
- the recognition that people will need to revise their expectations of their daily lives, including work, finances, living arrangements, social and sexual relationships, and independence and responsibility for others;
- awareness that the kind of dementia is likely to be a rarer form than in older people; and
- the recognition that people are likely to have significant financial commitments.

The earlier review (Tyson, 2007: 4-5) summarised a set of nine key factors emerging from the literature which needed to be taken into account in any policy changes for improving Australia's service system for people with YOD:

1. *Minority group:*

The first of these involved the recognition that people with YOD were a minority, and hence tended to be a hidden group of clients both to the dementia-specific care services and to the general health services. Because of their age they are not automatically recognised by the aged-care sector, although dementia is typically associated with old age. For that reason, they do not fit into the disability or health sectors either. This is particularly the case in rural and remote areas where even mainstream services may be scarce or lacking altogether. The low numbers should not mean, however, lack of access to services, and to the extent that their needs are unique, that should be taken into account in providing services.

2. *Access to services:*

The situation whereby people with YOD have to access services across the health, aged-care and disability sectors is not ideal. It is difficult to find anything appropriate to meet their needs, it is a lengthy and frustrating process, and it often means that the condition has worsened before they are able to get knowledgeable help. This takes an emotional toll in the face of inadequate services or services that are denied altogether because the person is deemed 'not eligible'. Residential care facilities in particular can be reluctant to offer long-term respite to people with YOD.

3. *Social circle:*

People with YOD have different kinds of social relationships from those of older people in their 70s, 80s or 90s, such as children still living at home, a spouse and friends who are still employed, friends in complex marital arrangements, or elderly parents with dementia. Services for these clients need a holistic approach in order to take in the additional needs, demands or pressures of a wider circle friends and acquaintances. This would include the provision of social support services, such as counselling, for the children. Moreover, people of pre-retirement age are less likely to be already involved in social clubs than older people who have retired. This means they might not have immediate access to appropriate activities and would need to be specifically referred to such services.

4. *Financial commitments:*

The person with YOD will sooner or later be forced to give up work, even though the family is dependent on those earnings. This can place a significant financial burden on the family, as it may also become impossible for the person's carer to remain in the workforce, especially as they become more reliant on respite services. The financial situation is worsened if people are still paying off mortgages and/or managing the costs of their children's education and upbringing. Financing residential care while maintaining a family home is another concern, especially as the person with YOD is too young to qualify for an aged pension but, having been forced to retire early, has too little superannuation. In the light of these complicated financial pressures, there is a need to establish good referral pathways to appropriate bodies for advice and/or financial assistance. Legal and other types of planning, e.g. an up-to-date will, enduring power of attorney, health and care plans, need to be urgently addressed as well. Centrelink and other welfare services also have a role to play, and there is a need for more consistent information process nationally.

5. *Diagnosis:*

Given how crucial early diagnosis is, the issue of delays in the diagnosis of dementia is of vital importance for younger people (see below).

6. *Huge emotional impact:*

People have reported varying emotional reactions to the initial diagnosis. Shock, grief and denial are common, but so is relief at finally having an explanation. Many people felt dismayed at the changes to their relationships, both socially with friends and family, and intimately with their partners. The onset of dementia is wholly unexpected for younger people, and they are unlikely to have had the opportunity to achieve lifelong goals and wishes for the future. As a consequence, counselling support is important, especially to help the person decide what they can still realistically achieve. They also need to revise their expectations of everyday life, as they gradually lose their abilities to carry out their usual activities.

7. *Reluctance to access respite services:*

Some carers are reluctant to access respite services, either because the services are inappropriate for active, younger people who could feel isolated among much older clients, or because the carer feels guilty about not looking after their loved one.

8. *Engaging activities:*

Services need to take account of the kinds of activities that would engage the interest of people with YOD by allowing them to use existing skills and increase their self-esteem. Most of the activities available, whether in respite and residential facilities or at home, have been found to lack interest for younger people. Examples of appropriate activities are going for walks, visits to museums and art galleries, and having lunch out with a group, although these require a higher staff-client ratio than for older, frailer clients. Consideration needs to be given to transport, especially when people have given up driving. Caring for younger people can be more demanding than caring for older people because they usually have more energy and would rather get out and about than be involved in sedentary activities. This could make it difficult to find the staff capable of caring for younger people, who may require a higher staff/client ratio than older people. This is expensive unless it is possible to use volunteer staff. Another factor to be taken into consideration when designing engaging activities for people with YOD is that aged-care facilities, and hence dementia services, are generally designed for women rather than men, and this can pose problems for younger, agile men. There are some good programs for people with YOD, both in Australia and overseas, examples of these are described below.

9. *Range of causes of dementia among younger people:*

There is a higher proportion of rarer dementias among younger people than among people over 65, and service providers need to be aware of the range of different causes of dementia among younger people. Different causes give rise to different patterns of symptoms and behaviour changes. For example, fronto-temporal lobar degeneration, which is more common among younger people, usually involves behaviours of concern such as aggression, anger, rudeness and loss of sexual inhibition. Because these are physically healthy and active people, they can pose a physical threat to people around them, as well as being emotionally confronting and intimidating. Services need to provide appropriate methods to deal with this behaviour, and carers need extra support services in order to reduce the risk of burnout. However, staffing and cost implications mean that many services are unwilling to offer this additional support as behaviours change. Other causes of dementia more common among younger people are those that are alcohol-related, and connected to HIV/AIDS, Down syndrome, Huntington's or multiple sclerosis.

The background paper to the evaluation of HACC services in Sydney (Alt Beatty, 2007) listed some key characteristics of service models for meeting the needs of people with YOD. These differed somewhat from the factors identified by Alzheimer's Australia (2008) and Tyson (2007), while adding extra dimensions to any model of what constitutes good practice. Most of the characteristics listed related to person-centred care involving a service response based on individual needs:

- by seeking input from people with YOD and their carers from the time of the service's initial design phase;
- by identifying people's strengths, maintaining their existing skills, supporting their individuality, enabling individual choice, and providing opportunities for client-focused and client-initiated community activities;
- by promoting people's community participation and their existing links in the community (community group, club, church), and encouraging socialisation and other active forms of social support; and
- by valuing and understanding each person's life stage, interests, history and relationships;
- in short, through services that were 'flexible, holistic and strengths-based'.

As well as these person-centred characteristics, the HACC evaluation report (Alt Beatty, 2007) listed other factors appropriate for services for people with YOD. Ideally, services should:

- provide opportunities for one-to-one support as well as for group activities;
- have staff with specific training in working with people with YOD;
- draw on people's existing community links or on their desire to participate in existing community groups as a way of meeting needs and reducing isolation;
- assist carers and family members, including teenagers and young adults, to meet others in similar situations, and to access education and counselling if they want to;
- provide case coordination, including assistance for working carers;
- actively seek referrals of clients, who can easily become lost in the service system; and
- recognise the needs of emerging groups of people with YOD, particularly people with intellectual disabilities.

The study also contained a number of suggestions (Alt Beatty, 2007: 62) about ways in which HACC could improve services for people with YOD:

In the case of generalist HACC services by:

- training service managers, care workers and volunteers in awareness of and competency in YOD, the services available, and ways of communicating with people with YOD and their carers (although there is a challenge in maintaining a balance between service delivery and training of staff);
- strengthening workers' knowledge of existing services and ensuring that they are fully aware of what is available, in order to make appropriate referrals and the best use of advice, support, training and information, and to promote effective care coordination, problem-solving and case management (because referrals tend to be slow due to late diagnosis and confusion about what is available);
- recognising that in-home respite is often particularly appropriate for people with YOD;
- creating support options for carers in paid employment;
- using the social support model;
- introducing more flexibility in the hours of operation of services, especially respite services;
- learning from the disability sector's models of service delivery, especially individualised services that focus on people's abilities rather than deficits;
- reassessing the Service Description Sheets for the extent to which they are overly targeting the frail aged and limiting funding flexibility; and
- clarifying where people with YOD fit within the different sectors (aged and community care and disability), so that they do not continue to fall through the gaps.

In the case of specialist services by:

- funding more specialist services across the Metro North region, using the social support projects auspiced by Mercy Community Care and Anglicare as a model (see below);
- identifying a key worker in each agency to be the specialist referral point;
- introducing a specialist team to assist service providers, the person with YOD and their carer from the time the dementia is identified;
- earmarking flexible brokerage funds for people with YOD to be used to purchase individualised support;
- exploring alternative models targeting the needs of this group and sub-groups within it; and
- making overnight respite available through the community house model rather than aged-care homes.

While each of these sources lists different service requirements, a number of common themes emerge<sup>7</sup>.

## Diagnosis

Although not always the first issue mentioned in any listing of issues of concern for people with YOD, difficulty with diagnosis is one of the most pressing problems. It is true that timely and accurate diagnosis is vitally important for identifying dementia at any age. As Phillips et al (2010: 12) pointed out, in relation to diagnosis everyone has the right to:

- a thorough and prompt assessment by medical professionals;
- sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis; and
- sufficient information to make choices about the future.

The executive officer of the Ella Centre (Easton, 2011), which runs the Younger Onset Dementia Social Support and Respite (YODSSR) program in the inner city in Sydney (see below), listed a number of elements she considered essential for a dignified delivery of a diagnosis:

- sensitivity in delivering the diagnosis;
- clear verbal information about the illness and the expected progression of the disease;
- written information that can be taken away and read later;
- timely referrals to health services and other agencies for the ongoing management of the disease; and
- information on community services to support both the person with YOD and their carer(s).

In the case of people with YOD, there are a number of reasons why diagnosis is more difficult than for older people. The earlier review of the literature (Tyson, 2007) found that among those reasons was the lack of awareness of YOD both among the general public and on the part of the GPs to whom people usually first present. There is also the large number of tests and scans needed in determining the correct diagnosis, the reasons for which aren't always clearly explained. Because dementia under the age of 65 is uncommon, it is often misdiagnosed as depression or another mental health disorder, which results not only in considerable delays, but also in the inappropriate use of anti-depressants or other medication. Delays in diagnosis mean that referrals are also delayed, and this can have a profound emotional impact on the person with YOD and their family, not to mention their trust in the health system. The delays can also have serious consequences for setting in place legal issues such as wills and powers-of-attorney.

Another reason why YOD is more difficult to diagnose than late-onset dementia involves the variety of causes. People with YOD are more likely to have atypical dementias than older people, e.g. fronto-temporal dementia (FTD), primary progressive aphasia, dementias resulting from infections, metabolic disorders and neurological conditions (Parkinson's disease; HIV/AIDS), and those resulting from misuse of alcohol. Memory problems may not be the presenting problem, and other symptoms such as behaviour and personality changes and language disturbance may occur first (Chaston, 2010).

The report of a longitudinal study in the Netherlands (van Vliet et al, 2010a), the NeedYD study (Needs in Younger Onset Dementia), also mentioned the wider range of causes of YOD among the reasons why it was more difficult to recognise, along with its lower prevalence rate and the fact that people tended to use mental health services (e.g. community mental health teams) rather than dementia services. These authors also pointed out that YOD can have different clinical manifestations due to the relatively high prevalence rate of FTD, where problem behaviour is more common as the presenting sign than it is in late-onset dementia (see below).

A US study of people with rapidly progressive YOD (Kelley et al, 2009) found that, in a small number of cases, the cause of the dementia could not be decided. Six of the people in the cohort had indeterminate etiologies despite extensive clinical evaluation. In one case, the cause could not even be ascertained through autopsy. The authors commented that understanding of YOD was clearly incomplete, and that for some people even the most thorough evaluation might not establish a definitive diagnosis.

Despite the difficulties, there are reasons why early diagnosis is somewhat more urgent for younger people. One is the fact that the development of the disease is generally more rapid than for older populations. This makes early diagnosis critical to improving quality of life (Alzheimer's Australia, 2009a). As the evaluation of a YOD-specific NHS service in Newcastle (UK) found (Reed et al, 2007), for many people, by the time the diagnosis is made they are beyond the point where they are able to understand the implications.

Bentham and La Fontaine (2007), writing in the UK, said that a small proportion of the causes of dementia in younger people were potentially reversible, and that this was another reason why early and comprehensive assessment was important (see also: Panegyres and Frencham, 2007; Hodges et al, 2009; Rossor et al, 2010). These authors emphasised the need for people with YOD to be thoroughly investigated in specialist medical units with multi-professional input. But they also pointed out that a diagnostic assessment should incorporate a broader approach including the experiences of both the person themselves and their families and carers. This latter could be provided by other professionals such as nurses, social workers and occupational therapists, and would require collaboration to support the person throughout the process of diagnosis.

Another reason for the greater urgency of the question of diagnosis for younger people is the greater possibility of misdiagnosis. Mendez (2006) discusses a number of reasons why YOD is more likely to be misdiagnosed than dementia that occurs later in life. One reason is that YOD has more varied causes than late-onset dementia, with Alzheimer's disease making up only a third of the cases, the rest being due to many other conditions such as frontotemporal lobar degeneration, vascular dementia, traumatic head injury and alcohol-related dementia. A second reason is that, because of the variety of causes, the presenting symptoms can differ from those of late-onset dementia. Whereas memory loss is the primary presenting symptom in Alzheimer's disease, other dementias present as challenging behaviours, spasticity or seizures. The third reason is the wide variety of symptoms which can be behavioural, cognitive, psychiatric or neurological. The author notes that there is a high likelihood of dementia when someone develops new psychiatric symptoms in mid-life.

In sum, Bakker et al (2010) in the Netherlands concluded that obtaining a diagnosis was especially problematic for people with YOD, and the difficulties prolonged the period of uncertainty and adversely affected the relationship between person and their family members. YOD was often not recognised by health care professionals, for all the reasons noted above – it was not as prevalent as late onset dementia, and had different clinical manifestations (predominantly behavioural rather than memory loss), and different cognitive symptoms.

The report of the US Alzheimer's Association study of younger onset dementia (Maslow, 2006) suggested two steps that could be taken to reduce the difficulty in getting an accurate diagnosis. Both involved information and education: raising awareness among doctors about younger onset dementia and the importance of accurate diagnosis; and providing training for doctors about how to diagnose it. (For another recommendation about educating health care professionals, see also: Hayter, 2008). Since for most people the GP is the first medical professional they visit, this advice is especially relevant in the case of GPs. The earlier review (Tyson, 2007) recommended that GPs be provided with dementia education throughout their medical training and as part of their continuing professional development, in order to develop an understanding of dementia and to help them recognise the indicators in a person.

In the light of all these issues, Alzheimer's Australia's submission to the National Health and Hospital Reform Commission (Alzheimer's Australia, 2008) strongly recommended that measures be introduced to achieve early diagnosis for people with YOD, since the process of diagnosis can be even more protracted and traumatic for them than for people who develop dementia later in life.



## **Information**

The question of information, both what people are told and the way they are told, is another issue of pressing importance. The Alzheimer's Disease International website notes that people with YOD and their carers find it difficult to access information, support and services. The carers interviewed in the Newcastle (UK) study (Reed et al, 2007) were critical of the methods of disclosure used by some clinicians and of the limitations of the information that was available. They believed there should be psycho-educational support and information available throughout the whole course of the illness, both for the person with YOD and for their carer.

The executive officer of the Ella Centre (Easton, 2011) concurred. 'Carers are left to find their own way through the maze after their spouse receives a diagnosis', she said. In her experience, people were given little information about the disease or about how it would progress, and medical professionals at the initial stage of diagnosis gave little input about how people might get access to the information and support they desperately needed, either for the person with the diagnosis or for the carer. She argued that a diagnosis of dementia should be made by a knowledgeable health-care professional, in an empathetic and supportive manner, who could ensure that appropriate information was provided both verbally and in printed form, as well as opportunities for asking questions.

The UK scoping study (Stalker et al, 2005) found that there was a great deal of information available from both statutory and voluntary bodies, and that there was an identifiable demand for that information. Unfortunately, there was little provision for bringing the two together in an easy and efficient way.

## **Differences**

The question of the ways in which developing dementia at a younger age is different from developing it later in life, is widely discussed in the literature (e.g. AlzNSW, 2010; Alzheimer's Society (UK), 2010; van Vliet et al, 2010a). As the Alzheimer's Australia NHHRC submission (2008) said, people with YOD and their families have unique (and complex) needs due to the stage in life in which they developed the disease. Unlike older people, they could be still bringing up children and still financially supporting a family.

Alzheimer's Australia summed up the differences in their pamphlet containing the stories of some of the people who live with YOD (Alzheimer's Australia, 2009b). Demotion, early retirement and diminished superannuation are more likely among those of prime workforce age, as are mortgages, significant levels of debt and a lack of legal planning. Younger people are also more likely to have young and adolescent children still at home and to be physically fit, and the unexpected nature of dementia at such an early age is more likely to lead to relationship breakdown. The pamphlet also notes that partner carers of people with YOD tend to have greater levels of psychological distress and carer responsibility, while the children a parent with YOD face different challenges from those faced by the adult children of people with late-onset dementia (See also: Alzheimer's Australia, 2008).

The main reason for the differences is the stage in life at which the disease occurs. People aged in their 40s and 50s, and even in their 60s, could normally expect years of productive activity ahead of them. Instead, with the onset of dementia they have to radically revise their expectations of life and what they can do.

Over ten years ago, Cox and Keady (1999: 293-4) listed a number of factors relevant to people with YOD. Although not all of these factors are exclusive to younger people, in combination and taken as a whole they can have a significant impact on the ways in which younger people and those close to them experience the disease. The first factor listed was the life stage with its own particular history and current roles, responsibilities and concerns. The next factor involved the enforced lifestyle changes to what people viewed as significant and meaningful. The other factors were:



- continued mobility and physical strength;
- the presence of dependent children – infants, teenagers and grandchildren;
- financial commitments;
- genetic issues (because early-onset dementias are more likely than later-onset dementias to have a familial component) (Rossor et al, 2010);
- the expectations of acceptable behaviour on the part of family and friends and the wider society;
- different patterns of social contact and networks from older people;
- having to face loss, death and the meaning of their condition;
- having to revise their expectations of everyday life and issues such as work, money, living arrangements, social relationships and sexuality, independence and responsibility for others; and
- having to come to terms with an altered body image.

Other factors mentioned in the literature (e.g. Tyson, 2007; Alzheimer’s Australia, 2008, 2009a) are:

- the greater likelihood of having a rare form of dementia; and
- the greater likelihood of a more rapid progression of the disease.

The main differences were that people with YOD were more likely than older people to have dependent children still living at home, to be in employment, and to have significant financial obligations. Another factor that was often mentioned (although not discussed at any length) was the greater physical fitness and strength of younger people.

#### *Children and family responsibilities*

One of the chief ways in which the impact of YOD can differ from the impact of dementia which develops at later ages is the presence of dependent children. As NSW Health’s Dementia Services Framework 2010-2015 (NSW Health, 2011) points out, children can have strong reactions when a parent becomes unwell, especially if the parent behaves strangely. An Australian study (Luscombe et al, 1998) found that only 8 per cent of the carers surveyed considered that their children had experienced no problems because of the dementia. Half the carers said that their children had been in conflict with the affected parent, more often with a father than with a mother, and the younger the parent the more likely there was to be conflict. Children were more likely to have problems at home or at school if the parent with dementia was less than 50 years old.

It is often assumed that people with younger onset dementia will be cared for by their families. What is less often realised is that, in the case of YOD, some of that care-giving is likely to be performed by young children (Stalker et al, 2005). Luscombe et al (1998) found that carers who were children of the person tended to report being psychologically or emotionally affected by the disease more often than other carers (although the survey did not ask the age of the children or whether they were living at home).

A recent review of the literature on children as carers (Gelman and Greer, 2011) found that there had been very little written about the experience and needs of the children of people with YOD. (The Luscombe et al study had found none in 1998). The authors suggested, however, that the children of people with YOD could sometimes be very young, not only because the disease could develop in people who were comparatively young, but also because of the increasing tendency to postpone childbirth. This means that children experience their parent’s loss of cognitive function and self-care abilities throughout their crucial developmental years. Moreover, there was evidence of a triple responsibility for many carers of people with YOD, who were also caring for their own or their spouse’s ageing parents as well as their children. As a result of this additional responsibility on primary carers, young children were often called upon to help with care-giving tasks. The literature

on child care-giving more generally suggests that, while it can be a positive experience, caring for a parent as a child can be a significant source of stress. The stresses can be even greater for the young children of a parent with YOD. As well as confusion about the role reversal (which they share with all child carers), they could feel shame about their parent's strange behaviour, anxiety about difficulties in their parents' relationship, fear of and grief for the losses the parent is going through, loneliness because the healthy parent has to focus more attention on the YOD parent, and worry about the chances of themselves getting dementia in the future.

Shame appears to be a common reaction on the part of young children of people with YOD. Research into the impact of diagnosis on the children of people with YOD found that, while the young people usually told their friends about the diagnosis, they rarely invited them home, and their reactions included shame as well as feelings of hopelessness, embarrassment and irritation. There was also a negative impact on relationships between parents and children (cited in Stalker et al, 2005)<sup>8</sup>.

The report of the Newcastle (UK) study (Reed et al, 2007) said that the need to improve services for young people with dementia was widely recognised in the UK. The authors cited the recommendation in the Robertson (1996) report concerning the use of a family-systems approach from the diagnosis on, which would involve children from the outset. The evaluation report of Alzheimer's Australia Victoria's Linking Lives program (Moore and Renehan, 2011) recommended a state-wide Living with Memory Loss program for people with young children, which included a specialised education program for children about dementia combined with meeting other children. Tyson (2007) found that most of the people consulted would welcome such a program. They felt it would be valuable to offer counselling to the whole family, including the children, as soon as possible after diagnosis, because that was the time when life was most chaotic and the changes in the family were having an immense impact<sup>9</sup>.

### *Employment*

Employment can be a significant issue for people with YOD, in a way in which it is not for older people past the conventional retirement age. People with YOD are more likely to be in work at the time of diagnosis. If their diagnosis has been delayed, they can be put under great pressure to improve their work and then dismissed when they don't improve (Chaston, 2010).

Alzheimer's Australia's Background Paper to the 2009 Summit on Younger Onset Dementia (2009a) listed a number of the issues in relation to employment. The paper pointed out:

- it was often in the workplace where the signs of dementia were first noticed;
- that people would prefer to remain in the workforce as long as possible;
- a lack of understanding by employers can lead to discrimination;
- sickness or disability benefits may be difficult to access, both workplace-related and Centrelink;
- there are difficulties in accessing superannuation; and
- carers too can find employment difficult because of inflexible workplace practices.

The report of the US Alzheimer's Association study of younger onset dementia (Maslow, 2006) suggested that what was needed was to raise awareness of YOD among employers and human resources personnel, and to disseminate information about ways in which workplaces could accommodate people with YOD and about the legal requirements for workplace accommodation.

The report on the Newcastle (UK) study (Reed et al, 2007) advocated the development of 'work-assisted schemes' either in conventional workplaces or in sheltered environments, as one aspect of a broad range of services for people with YOD. Cox and Keady (1999) said that at the time of writing there were some supported employment initiatives in the UK which included people with YOD (giving the example of the Kite Employment Services in Kent). The authors discussed a number of characteristics of work schemes:

- work support, whereby employers and colleagues can be helped to understand YOD through a case-management approach advising them about issues such as safety aspects, ways in which the person can still do their work, retraining, retirement and pension prospects;
- alternative types of work, which would need to be client-centred, near the person's home, could involve coaching and one-to-one work to help the person adjust;
- meaningful leisure and recreation, whereby people access community-based activities and maintain or rediscover old skills; and
- valued roles and responsibilities, e.g. helping the staff in day centres, supporting people who are more frail, volunteer work, further education.

Employment can also be an problem for carers, who have difficulty getting services that will support them to continue working full-time, and in juggling care and work commitments (Hayter, 2008; Easton, 2009). Carers have to struggle to combine employment with the demands of caring, and many eventually give up paid work to care full-time for their partners (Chaston, 2010).

#### *Financial issues*

The issue of financial problems associated with YOD is connected to the issue of employment. People who are no longer able to work lose their job-related income along with their job. The literature frequently stresses the importance of the financial consequences of forced retirement. People with YOD may have been financially responsible for supporting their families before they had to leave work. They may have had significant financial commitments, such as a mortgage and a young family, based on their previous earnings. But beyond these brief mentions, there is little discussion of financial matters in the literature.

There is even less discussion of the financial costs of providing care for people with YOD, although it is mentioned briefly (Hayter, 2008; Easton, 2009).

#### **Services, specific and otherwise**

As a result of these differences, the need for appropriate services for people with YOD is a recurring theme in the literature (e.g. Alzheimer's Australia, 2008; Challis et al, 2010). Mainstream dementia services can at times be problematic for people with YOD. Assessment instruments, for example, are not always sensitive to younger-onset dementia as they have been designed for people over 65 (Stalker et al, 2005). Researchers in Lothian, Scotland, found that the instruments they used to measure change in a group of people with YOD of varying aetiologies produced contradictory results. They showed improvements in some areas while also showing the expected deterioration in others. In most cases the improvements did not fit with the clinical picture (with the exception of the alcohol-related dementia). The total neurological change score was unable to distinguish between alcohol-related dementia and the other forms, although other scores indicated that it generally had a milder profile of impairment and that there were some areas of improvement in the follow-up period. The authors pointed out that, with the development of new agents to treat cognitive decline, it is important to have instruments that can reliably detect change (Woodburn and Johnstone, 1999).

Chaston (2010) gives a number of reasons why conventional dementia services might be inappropriate for people with YOD. In contrast to older people, they are likely to be physically fitter, and more likely to be sexually active, to have different interests, and to identify more closely with staff. The report of the HACC evaluation (Alt Beatty, 2007) pointed out that people with YOD are outside the norm for a HACC client, i.e. a very frail woman aged over 80. They did not see themselves, the report said, as aged-care clients because they were younger, sometimes much younger, than the usual clients, and because their retirement was not age-related but early, unplanned and forced. This report also noted the greater physical strength of people with YOD, and their greater capacity and their need for high levels of exercise. This need, the report said, can strain traditional models of

day-centre respite which are usually designed around fairly sedentary activities. It also meant that a service needed transport capable of accommodating tall and large people. Hence, people with YOD needed services and workers who understood their very different life stage.

There is also some agreement that what people with YOD require are specialist services able to meet their particular needs<sup>10</sup>. The earlier review (Tyson, 2007) said that an appropriate service system for respite and day-care would involve acknowledging that the needs of younger people are different from those of older people in aged-care facilities, and provide for separate premises designated specifically for people with YOD. The review also said that those consulted in the study were in favour of more in-home support so that the younger person could be cared for longer in their own home.

Bentham and La Fontaine (2007) cited research in the UK indicating that most of the people with YOD who attended day centres providing age-appropriate activities found the experience positive, and the uptake in these centres was high.

However, the same authors (Bentham and La Fontaine, 2007) also pointed out that the low prevalence of YOD, together with the diversity of these people's needs, made it impracticable to provide specialist day-care and respite units. They suggested instead services promoting independence and participation in enjoyable leisure activities, that were home- and community-based.

Moreover, the Newcastle (UK) study (Reed et al, 2002, 2007) found that, although the NHS service being evaluated was YOD-specific, clients' responses did not necessarily highlight age-specific needs. People's comments more often referred to the service's sensitivity to individual needs. The researchers suggested that the ways in which the team responded could be a model for all services for people with dementia, regardless of age, and indeed across all client groups.

The evaluation of the Linking Lives program (Moore and Renehan, 2011) found that there were some difficulties with the use of age as a criterion for receiving services. The authors noted that it failed to account for differences within the age groupings and similarities across them. Moreover, requiring clients to leave a service when they turn 65 disrupts continuity of care. And while there were benefits to having a single point of contact for people with YOD, these benefits could also apply to older people. Older people, too, can be struggling financially, and have difficulty accessing services and receiving a diagnosis. The authors cited the Beattie et al (2002) review, which had found that services specifically for younger people could have unfortunate implications, e.g. 'that older people aren't physical fit, that they have no sexuality, that their carers do not work during the day, that they don't live with their children, and that they are satisfied with the services that provide little in the way of activities or opportunities for physical exercise'. One of the most worrying of these implications is the implicit assumption that people of different generations should not socialise with each other. The authors of the earlier review (Beattie et al, 2002) had also pointed out that many of the issues raised in the context of YOD-specific services were also highly relevant for older people, e.g. the over-emphasis on the later stages of the disease, problems accessing services, the need to incorporate a multi-disciplinary approach, and inadequate care and assessment.

Considerations such as these have led some researchers to the conclusion that people with YOD need both specialist and generalist services. Age-appropriate services are often stressed as the way to develop good practice for YOD, but people need other services that are not necessarily age-specific, e.g. day care, pre- and post-diagnosis counselling, ongoing assessment (Stalker et al, 2005). Moreover, mainstream services tend to be already well-established and based on recognised expertise. The Newcastle (UK) study (Reed et al, 2007) found that, through the old-age psychiatry route, people with YOD could access social work, psychology, occupational therapy and community psychiatric nursing, and subsequently day care, respite and residential care.

A UK study of community support services for people with dementia (Challis et al, 2010) found that there was a lack of services for people with YOD. But they also noted that it did not particularly matter in terms of effectiveness whether domiciliary care for people with dementia was organised on a

specialist or a generic basis. What mattered most was the extent to which the service conformed to quality standards for dementia care, and the evidence suggested that both kinds of providers could offer such care.

One interesting finding from the Newcastle (UK) study (Reed et al, 2007) was that the case-load of the YOD-specific service had a much higher proportion of male clients than was usual among older people with dementia. This had an impact on the appropriateness of existing services. In particular, it was found that some of the male clients felt uncomfortable spending time with female staff, and preferred male staff, particularly in public activities.

Nonetheless, whether the services for people with YOD are specific or generic, it is generally agreed that they need to be person-centred and multi-disciplinary.

#### *Person-centred*

The need for person-centred services is echoed through the literature. This largely means people with YOD and their families involved in the decision-making. As Davies-Quarrel et al (2010) pointed out, people with dementia need to feel that the services belong to them. Service choice needs to be financially supported so that people with dementia and their families can make real choices and decisions that invest in their future.

Chaston (2010) found that, when people with YOD were asked about their needs, their overwhelming desire was for purposeful age-related activities and the opportunity to remain in employment for as long as possible. This researcher emphasised people's need for the maintenance of their personhood, and said that staff could contribute to this by using the experience and knowledge of people with YOD themselves. After all, she pointed out (citing the UK Department of Health), anyone with a long-term condition becomes an expert in that area and they don't have to become simply a beneficiary of care delivery. Unfortunately, there was a limited amount of literature available on the topic of people with dementia as educators.

Person-centred care does not mean that the needs of family and carers can be ignored. As Bentham and La Fontaine (2007) concluded, services should be underpinned by both person- and family-centred practice. Bakker et al (2010) in the Netherlands said that there was a special need in the case of YOD, because of their particular stage in life, to understand the effect of the disease on the family members' functioning and roles, as well as on the person's. The researchers gave the example of one carer who, besides the care of her husband, was having to deal with issues concerning work, financial problems and the household, as well as his increasing difficulties with his roles as husband and financial provider. These difficulties, the authors said, were much more likely in a younger, active life phase than later in life. There was also the dilemma of a comparatively young carer dedicated to the care of her family member at the expense of her own future perspective.

Clare et al (2011) said that there were many kinds of intervention strategies for helping family members cope, although there were still very few that targeted both the carer and the person with dementia as a dyad. This was not because such interventions had been shown to be ineffective, but because such research and intervention design had lagged behind research which focused separately on the person with dementia and the family.

There is a recognition among service providers that families need support, too. The Birmingham Working Age Dementia Service (La Fontaine, 2004; Bentham and La Fontaine, 2007) (see below), for example, had separate workers for the family and for the person with YOD. Another example concerns the ACE club in North Wales (Davies-Quarrel et al, 2004, 2010; Daniel, 2004) (see below). Here, staff took a relationship-centred approach which sometimes meant that the needs of the carer took precedence.



### *Multi-disciplinary*

Texts discussing YOD often have 'multi-disciplinary' in the title (e.g. Hodges, ed., 2001; Baldwin and Murray, eds, 2003). The latter argues that people with YOD need skills best delivered by a team using a multi-disciplinary approach because they do not readily fit into any of the conventional mental health services categories, either for adults of working age or for older adults.

A group of counsellors from Alzheimer's Australia interviewed for the earlier review (Tyson, 2007) unanimously called for a suite of service options, including counselling and information, to be offered to people at the point of diagnosis. The counsellors argued that this holistic approach would be more likely to take into account the more varied social circle of people of pre-retirement age, including children still living at home and a spouse and friends who were still employed. In an article discussing practical issues in the management of people with dementia, Gregory and Lough (2001) stressed the importance of multi-disciplinary assessment as a way of teasing out the various factors behind people's behaviour (although their focus was not confined to people with YOD).

In the Croydon Memory Service model (Willis et al, 2009), the team is multi-disciplinary, made up of staff with backgrounds in nursing, psychiatry, social care and psychology, and they devise the diagnosis and management plan jointly. At the same time, they also have a generic team approach, which enables staff from any discipline to conduct the initial assessment or take the key worker role.

### **Carers**

An overview of the literature on the impact of YOD on informal carers (and on the children) (van Vliet et al, 2010b) concluded that it was 'still unclear' whether or not there were any differences between caring for someone with YOD and caring for someone with later-onset dementia. The reason was that the studies reported in the literature were too limited methodologically to be able to give any definitive answer to the question. The studies certainly found that carers of people with YOD had high levels of responsibility, that they experienced depressive symptoms, and that they had a number of problems such as relational difficulties, family conflict, and employment and financial issues, not to mention negative experiences with the diagnostic process. However, although studies comparing the two kinds of carers did find higher levels of responsibility in YOD carers, the differences were not statistically significant. Only one study (Freyne et al, 1999) found a significant difference, but it was not clear whether this difference was the result of YOD per se or of the longer duration of care. Longer care duration is associated with higher responsibility levels among carers of older people, too.

Nonetheless, these authors believed (van Vliet et al, 2010b) that YOD carers did experience specific problems related to their phase in life and that, for that reason, it was likely that YOD had a greater impact on person and their family than late-onset dementia. Work-related problems, financial problems, problems with children, and diagnostic uncertainty and delays in referral occur less often in the case of late-onset dementia. Moreover, YOD has a different clinical manifestation from late-onset dementia, being more often characterised by neuro-psychiatric symptoms such as alterations in socio-emotional behaviour and insight due to the higher prevalence of fronto-temporal dementia (FTD).

In younger adults with dementia, FTD is more common than it is in the case of older people (Kaiser and Panegyres, 2007; van Vliet et al, 2010b). Studies have estimated that FTD is the second most common cause of YOD (after AD). A study in the UK found that FTD accounted for between 15 and 20 per cent of the people with dementia in the age group under 65 years (Rosness et al, 2008). Chemali et al (2010) in the US said that people with FTD were commonly in their 40s and 50s. They estimated that up to 70 per cent of YOD cases were initially misdiagnosed because people presented with the neuro-psychiatric and behavioural symptoms typical of FTD, rather than with the cognitive impairment typical of AD. Combined with the fact that people with YOD are often fit and physically healthy, behaviour change can have a profound impact on the lives of those who care for them. The Alzheimer's Disease International website links the issue of challenging behaviours with the greater physical fitness of younger people.

Overall, the consensus in the literature is that the responsibility for carers of people with YOD more generally is greater than for carers of people who develop dementia later in life<sup>11</sup>. A study in Norway (Rosness et al, 2011) of carers aged 49 to 70 found that the youngest carers reported the poorest quality of life, suggesting that it was these couples who experienced the most problems. Freyne et al (1999) found significantly higher levels of stress among carers of people with YOD than among carers of older people. They also found that the level of stress was not associated with either the severity of the dementia or the level of disturbance in the person's behaviour. Other research has found, however, that having to cope constantly with challenging behaviours is a major cause of carer stress (Gregory and Lough, 2001). There is evidence of higher levels of depression in spouses of people with FTD (Kaiser and Panegyres, 2007). Often it is the challenging behaviour that brings the carer into contact with medical services, and the management of challenging behaviour poses a major challenge for clinical services involved in dementia care (Gregory and Lough, 2001).

Behavioural disturbances have been found to be more worrying in YOD than in late-onset dementia, partly because of the person's greater strength and physical ability, and partly because of the higher prevalence of FTD among people with YOD. Piquet et al (2011) cite a number of recent studies showing that the carer responsibility in FTD is much greater than in Alzheimer's disease (AD). It seems that it is the behavioural changes rather than the disability in itself that causes the carers' distress and burden, although the authors note that very few studies have been done.

An Australian study (Nicolaou et al, 2010) investigated needs, burden, and depression and anxiety, in two groups of 30 carers each, one caring for people with FTD and one caring for people with AD. No significant differences were found between the two groups on carers' levels of burden, depression or anxiety. But the study's findings indicated that the needs of the FTD carers were significantly higher than those of the carers of people with AD, due to the younger onset of the FTD, the characteristics typical of FTD, difficulties with access to services, information and support, and financial problems. The study also found that women carers were more likely than men to report the disruptive symptoms associated with FTD. The authors concluded that FTD carers were likely to be particularly distressed because behavioural problems are more pronounced in FTD. Again in relation to sex differences between carers, other studies have found that husbands caring for their wives report less emotional distress than wives caring for their husbands (Luscombe et al, 1998; Kaiser and Panegyres, 2007).

The report of a study in the US (Chemali et al, 2010) highlighted three areas of intervention that could lead to better awareness, diagnosis, management and care for younger people with FTD and other dementias. While the third of these recommendations was specific to the funding of health care in the US, the other two suggestions have a wider relevance. The first referred to an education campaign raising public awareness of the fact that dementia can occur across the lifespan, affecting not only elderly persons but also much younger persons. Such a campaign could encourage people with YOD and their carers to present for timely assessment at appropriate centres. The second suggestion involved the need for resources to improve the availability and quality of post-diagnostic care. Legislators should reward innovative programs that successfully meet people's needs, and health providers should not hesitate to rethink and restructure programs that fail to do so.

Family members consulted as part of the earlier review (Tyson, 2007) commented that health professionals often did not take into account the spouses and children who were the primary carers of the person with dementia. There were reports of professionals who were caring, who gave straightforward information, and who knew of the problems with diagnosis and were keen to refer people to social supports such as Alzheimer's Australia. But informants had also had experience of health professionals who did not fully explain what was going on, and who were unsupportive, dismissive and patronising, and who were deliberately evasive.



The background paper to the consultations involved in the HACC evaluation (Alt Beatty, 2007) listed a number of requirements of carers for people with YOD:

- more intensive help and support than older carers throughout the whole duration of their care-giving (because those caring for people with YOD report higher levels of stress);
- workers from ethno-specific organisations to assist carers from CALD communities to access relevant services;
- companionship and support from carers in a similar situation (because they may have lost their earlier friends, or no longer feel comfortable with them);
- assistance which supports and strengthens their relationship with their partner; and
- the recognition that carers aged under 50 years may have to place the person with YOD into care sooner rather than later (because of the other commitments in their lives).

### **Respite**

It has been pointed out (Alt Beatty, 2007) that what people with YOD require of respite services can strain traditional models which may be designed around fairly sedentary activities. Younger people are likely to be physically stronger than older people, and to need activities that allow them to get exercise. They do not identify as aged-care clients, and they need staff who understand their different life stage.

The Newcastle (UK) study (Reed et al, 2007) found that carers were reluctant to use respite care, despite the fact that they needed a break, because in their view the services were inappropriate. They also felt that their relative would deteriorate in a strange environment, and that they might have problems resettling at home.

The earlier review (Tyson, 2007) also found a reluctance among carers to access respite, believing that their loved one would feel isolated because they did not fit in with the older clients. The author commented that improvements in respite services for people with YOD would need to be creative, and involve collaborating both with carers and with people with YOD. She suggested that respite should not only be viewed as a service for the carer, but also as an opportunity for younger people to get together and participate in activities that gave them self-esteem and a sense of capability. It was also important for services to work with carers to familiarise them with what was being offered, so that they would be willing to take up the service. She gave as examples of innovative approaches: the Mobile Respite Response Team (MRRT) in the ACT; The Sundowner Club; and the Ritz Nursing Home, Blue Mountains NSW (all of which are described below).

## **AUSTRALIAN EXAMPLES OF GOOD PRACTICE**

The report of the evaluation of the Linking Lives project (Moore and Renehan, 2011) said that, despite increased awareness of the needs of people with YOD, there were still very few programs around Australia. The report mentioned Connexus in SA (see below), the two initiatives in the ACT (see below), and the HammondCare residential facility in Horsley near Wollongong (see below). While acknowledging that this was not an exhaustive list of initiatives, the report noted that accessibility to services appropriate for people with YOD still appeared to be ad hoc and variable.

Nonetheless, there are in Australia a number of programs, services and other initiatives either specifically devoted to the needs and interests of people with YOD, or appropriate for them, with or without adaptation. Not all of these are currently active, being pilot programs which reached the end of the funding period. They are described below. This list of programs is based on the published evidence. Other programs also exist but this review was unable to access information about them from the public domain.

## **NATIONAL**

### **Living with Memory Loss**

The Living with Memory Loss (LWML) programs are funded by the Australian government, and operate in both regional and metropolitan areas in each state and territory in Australia. (There are similar programs in other countries around the world). The programs are designed for people in the early stage of dementia (although not specifically for people with YOD), together with a family member or friend, and are free of charge to the participants. Two groups are conducted in each session, one for the person with dementia and the other for their carer/friend, although the person with dementia can attend by themselves if they wish. There are usually six weekly two-hour sessions. Topics discussed include: symptoms and diagnosis; adapting to changes; research and new drug treatments; practical strategies; relationships with family and friends; looking after yourself; planning for the future; community services; legal issues; and: Where to from here? People who attend can obtain information, have their questions answered, talk confidentially with others in a similar situation, discuss their experiences and express their feelings in a safe environment, maintain and even enhance their abilities, and explore ways of managing<sup>12</sup>.

The design of LWML is loosely based on the successful program developed by Brodaty et al (Brodaty and Cumming, 2009). The earlier review (Tyson, 2007: 22) described the LWML program as 'a psycho-educational program which aims to maximise the health and well-being of people living with early stage dementia and their family carers'. It provides early intervention and ongoing support for people of any age, although it is not available to people who have progressed past the early stage of dementia because it is felt that they would not have sufficient insight to benefit from the program. As a result, those who are not diagnosed early enough or informed early enough about LWML miss the opportunity to participate. The solution is to implement policies to reduce delays in diagnosis and to promote services early (see also: Alt Beatty, 2007: 60).

## **NEW SOUTH WALES**

### *AlzNSW*

Alzheimer's Australia NSW provide or are involved in a range of services and support options, e.g. a website for information about dementia and the services available, material in community languages, carer stories, publications, education and events. They provide leadership in dementia policy and services, encourage and participate in research initiatives, and provide education, knowledge, skills and risk-reduction strategies to people with dementia and their families and carers. Their services are not only for people living with dementia, their carers, family and friends, but also for health and care workers, service providers, researchers, volunteers, business and community organisations and the general public. AlzNSW has shown a particular interest in YOD with its initiation of this present research project and its close involvement with the earlier review (Tyson, 2007).

### *Services in the Sydney Metro North region of the Department of Ageing, Disability and Home Care (DADHC)*

A research project in the Sydney Metro North region of the Department of Ageing, Disability and Home Care (DADHC) (Alt Beatty, 2007) found four Home and Community Care (HACC) services containing key elements of service models appropriate for the expressed needs of people with YOD. Two were social support services and two were day centres offering excursions: Mercy Community Care Younger Onset social support; Chesalon Barrenjoey Younger Onset social support; Hope Healthcare Saturday Horizons program for 'early age, early stage' dementia; and Mercy Day Centre. These are described below<sup>13</sup>:

### **MERCY COMMUNITY CARE YOUNGER ONSET SOCIAL SUPPORT SERVICE (WAITARA)**

The innovative features of this service:

- the recognition that people with YOD have social needs and interests and are physically able to participate in activities;
- dealing with social isolation through regular, planned and innovative activities supporting individual interests;
- staff trained to support people with YOD in their differences from frail aged clients; and
- a service integrated with other services, e.g. carer support groups, counselling, dementia day-care program and pastoral care.

The features most appropriate for replication in other HACC services:

- the fact that the model was based on individual needs;
- its emphasis on community activities which were client-focused and client-initiated;
- its use of natural community supports whilst maintaining existing supports such as friendships, church groups, etc.;
- its provision of both individual and group programming; and
- the YOD-specific staff training.

Difficulties and areas for improvement:

- the amount of time required to market the program to potential service users and develop referral pathways (Alt Beatty, 2007: 14).

### **CHESALON YOUNGER ONSET SOCIAL SUPPORT (AVALON)**

The innovative features of this service:

- clients' active participation in planning the outings;
- discussions about what was safe for them to do and what was no longer safe; and
- the provision of a positive social network and a good peer support group who helped each other through the life stage changes.

The features for replication in HACC:

- the social support, which was general but which was constantly reaffirmed to assist people as they worked through the rapid changes of the disease.

Difficulties and areas for improvement:

- difficulties finding clients, largely because there is too little awareness of YOD both in the general community and among general practitioners and other primary health providers;
- the scarcity of transport and its cost, given the service's geographical area;
- client sensitivities around being labelled 'disabled' and hence around how the service is named and presented to them;
- a need for longer respite periods in order to accommodate spouses' working hours;
- services close to where the clients live or where their spouses work (Alt Beatty, 2007: 12-13).

### **HOPE HEALTHCARE HORIZONS PROGRAM (NORTH SYDNEY)**

Innovative features:

- client decision-making about outings and activities;
- staff facilitation of these decisions;
- staff member trained in conflict resolution;
- the club-like atmosphere of the program;
- access to same-day in-home respite when client refuses to attend program; and
- evaluation via quarterly quality reviews, annual surveys of clients and carers, dementia-care mapping, and the HACC *Integrated Monitoring Framework*.

The features for replication in HACC:

- staff training in client decision-making and in working with clients with difficult behaviours;
- the social club model of care in a therapeutic environment; and
- the regular evaluation.

Difficulties and areas for improvement:

- funding needed to expand to three days per week (the service operated only on Saturday);
- difficult to get staff to work on Saturdays;
- staff need bus driver's licence;
- funding needed for transport resources for carers (e.g. taxi vouchers, staff picking up clients);
- the demanding nature of the work with this particular target group; and
- the extra stress on these carers (Alt Beatty, 2007: 11).

### **MERCY DAY PROGRAM (WAITARA)**

Innovative features:

- client access to the community in a comfortable and supportive group;
- DVDs for the family with photos of clients participating in activities;
- high attendance and no withdrawal;
- clients sharing experiences, building social relationships, and maintaining or increasing physical activity levels;
- carers' appreciation of being kept informed and given regular feedback about participation levels;
- a back-up venue for bad weather; and
- integration with other support services such as counselling for carers, carer support groups, individual social support program, and pastoral care.

The features for replication in HACC:

- flexible, regular weekly activities;
- close liaison with and support of family carers;
- social interaction within the group and between clients and people in the community; and
- provision of staff training specific to YOD.

Difficulties and areas for improvement:

- limited funding which restricts the type of activity and the number of times the service can be provided (one day a week within a three-day day care service).

The researchers recommended that the model included in the two social support projects auspiced by Mercy Community Care and Anglicare be replicated in any plans to expand services for people with YOD. The model involves a YOD-specific program backed up by a Dementia Advisory Service, Community Options Services (COPS), Community Aged Care Packages (CACPs), carer support groups and individual counselling, personal care and domestic assistance, in-home respite, and a day centre allocating funding of one day a week (Alt Beatty, 2007: 63).

#### ***Younger Onset Dementia Social Support and Respite (YODSSR) Program – The Ella Centre***

The Younger Onset Dementia Social Support and Respite (YODSSR) Program<sup>14</sup>, operated by The Ella Centre, is small social group for people with YOD diagnosed between the ages of 50 and 70, who live in Sydney's Inner West, are mobile, and can manage their own personal care and administer their own medication. It provides five hours of activities twice a week (Easton, 2009), on Monday and Thursday mornings. Activities and outings are age-appropriate, and there are opportunities for social interaction and making new friends, physical activity to maintain general health and well-being, and respite for carers. It is funded by ADHC and by grants from local business and the local council, and fund-raising.

An evaluation in 2008 (Hayter, 2008) found the following strengths: flexibility in meeting people's individual needs; cost-effectiveness; potential for significant further expansion if sufficient funding were to be provided; extremely committed and caring staff prepared to do everything necessary for clients; and the provision of a peer group and a valued role for people with YOD. Areas identified for improvement at the time included: the need for recurrent government funding; additional funding for increased staff ratios for extended support of people with changing needs and those with behaviours of concern; more days of operation (since expanded from one day a week to two); and increased funding for a greater variety of activities. (See also: Easton, 2011).

#### ***HammondCare Horsley***

In early April 2010, HammondCare opened a pilot residential and respite service in Horsley, near Wollongong, south of Sydney, specifically for people with YOD, the first of its kind nationwide. Called Streeton Cottage, it is a 15-bed residence, with four beds being allocated for respite care. It began as a pilot project funded through the usual aged-care funding arrangement, although additional funding is being sought from various sources, with the assistance of Alzheimer's Australia. The cottage is designed and operates as a domestic home, families and friends are welcome, and residents are supported to become engaged in the local community. Although in the Illawarra in NSW, the service is available to any person with YOD nation-wide, following an assessment by HammondCare. Residents also need to have approval for Residential Aged Care by an Aged Care Assessment Team (ACAT or ACAS) prior to admission (*HOPE Newsletter* 2010, Issue 5: 5; Moore and Renehan, 2011: 7)<sup>15</sup>.

#### ***The Hunter region of NSW***

The Hunter region has acquired an excellent reputation for organisations working together to support people with YOD. The Hunter Younger Onset Working Group, which held its inaugural meeting in May 2009, meets monthly as a forum of consumers, stakeholders and professionals to tackle the issues surrounding service provision. It is very active in identifying existing services for people with YOD, developing a database of people in the area, and encouraging services to nominate staff specifically devoted to helping plan new YOD services. Organisations which have worked together to devise ways of better utilising existing services for people with YOD include AlzNSW, Hunter New England Health (HNEAH), HammondCare, UnitingCare Ageing, Nova Care, and Eastlakes Dementia Services.

The new Hunter Dementia and Memory Resource Centre in Hamilton has a special YOD focus, and offers a first point of contact with dementia services that is welcoming and easily accessed. The HNEAH Community Dementia Nurse program, with its aim to provide quality person-centred care, is also aware of YOD issues. There are plans to set up a LWML program for people under 65 when sufficient people have been identified locally. It will be run through a partnership between AlzNSW and the Dementia Advisory Service. The latter already provides a counselling service for people with YOD and care partners, as well as hosting many carer support groups across the region (Merl, 2010; *HOPE Newsletter* July 2010, Issue 5)

### ***The Ritz Nursing Home in the Blue Mountains, NSW***

The earlier review (Tyson, 2007) also described a residential care facility which, although not catering specifically for people with YOD, was willing to provide for them and capable of doing so. The facility was the Ritz Nursing Home in the Blue Mountains NSW. A significant proportion of residents were people with YOD, including those with dementias other than Alzheimer's disease. Although other facilities had considered these people too difficult to manage, the Ritz made provision for them with its high security fence, adequately trained staff, and information and counselling for clients.

## **VICTORIA**

### ***Cognitive, Dementia and Memory Services***

Although not specifically designed for people with YOD, the Cognitive, Dementia and Memory Services (CDAMS) in Victoria have been recommended by Alzheimer's Australia as a useful program to which GPs can refer younger people concerned about changes in their cognitive abilities. In the view of Alzheimer's Australia, extending such services would help people to get timely and accurate diagnoses in what is an often complex and needlessly drawn out process (Alzheimer's Australia, 2009a).

CDAMS is a specialist diagnostic clinic which assists people with memory loss or other changes in their thinking, and their families and carers. It provides expert clinical diagnosis, education, information on appropriate treatments and on dealing with day-to-day issues, direction in planning for the future, and links to other service providers and community supports. It was developed by the Victorian Government as a specialist multi-disciplinary diagnostic, referral and educational service, in recognition of the importance of early diagnosis for determining appropriate treatment needs and planning for the future. It provides people with a timely opportunity to learn about their condition, and to understand changes as they occur and how to cope with the day-to-day issues of cognitive impairment. Referrals can be made through general practitioners or community agencies, or people can approach the service directly<sup>16</sup>.

### ***Memory Lane cafés***

While not catering specifically for people with YOD, cafés are seen as an option which may particularly appeal to this group and their carers (Alt Beatty, 2007; Jolley and Moniz-Cook, 2009). First set up in 1997 in Leiden in the Netherlands, by Dr. Bère Miesen, a dementia specialist and clinical psychologist, they were called 'Alzheimer's cafés'. The first Alzheimer's café in the UK was opened in 2000, others quickly followed, and their spread throughout the UK continues. Since 2008, the Alzheimer's Café UK has been a registered charity<sup>17</sup>.

A brief evaluation of an Alzheimer's Café in the UK (Capus, 2005), in which six carers were interviewed, found that it was an important venue for helping carers to normalise the experience of caring and the changes in their relationships. For families who find themselves becoming socially isolated, the café can provide a secure base and a new and different social network. With its emphasis on a non-clinical, non-didactic, non-pathologising, non-stressful and unstructured ambience, the café offered a unique environment for carers and those living with dementia to meet as equals, share understanding and insights, and work together towards solutions.



In 2002, Alzheimer's Australia Victoria adapted the Alzheimer's café model for the Memory Lane Cafés in Victoria. These are available for people with dementia and their carers after having completed the LWML program together. This had the advantage that the group had already got to know each other and established a group dynamic to carry over to their meetings in the cafés (Moore and Renehan, 2011). An evaluation of three Memory Lane Cafés (Dow et al, 2011) found that the cafés did promote social inclusion, prevent isolation and improve the social and emotional well-being of attendees. They did not meet the needs of everyone, especially people from CALD backgrounds and Indigenous people. Other people could not attend because of distance and transport problems, and others because of the requirement that attendees had completed the LWML program. Nonetheless, the evaluators recommended that the existing cafés be continued and possibilities for extending them be explored. As a result of the evaluation, the Department of Health Victoria provided funding for four additional pilot programs in four different regions of Victoria.

The evaluation found that peer support was one of the key benefits of the cafés, which provided an opportunity for people with dementia and their carers to socialise with others with similar experiences in an environment where the behavioural symptoms of dementia were familiar. Sometimes people socialised outside the cafés as well. Alzheimer's Australia Vic staff were able to educate people about other services and link them with local service providers. There were opportunities to learn about and gain access to the broader service system, although links between the cafés and these services were limited (Dow et al, 2011).

The guidelines for the four new pilot Memory Lane Cafés were based on the recommendations from the evaluation, namely:

- allowing a range of entry points (rather than simply through LWML);
- ensuring accessible and usable venues;
- partnership with other organisations with dementia expertise;
- meeting diverse needs including CALD and Indigenous people;
- ensuring that entertainment, information and refreshments met the needs and preferences of attendees;
- clarification of staff roles; and
- the involvement of people with dementia and their carers in annual evaluations (Dow et al, 2011. See also: Mather, 2006).

The key worker for Linking Lives (see below) felt that a model similar to the Memory Lane Cafés would be of benefit for that program, too (Moore and Renehan, 2011).

### ***Linking Lives program***

The Linking Lives project is a one-year pilot established by Alzheimer's Australia Vic. Funded by a small grant, it is intended to address the particular issues faced by people with YOD and their families and carers. The program commenced in April 2010 and involved a key worker supporting 14 people living with YOD, together with their families and carers (Moore and Renehan, 2011).

The principles on which the project is based are:

- consumer-directed care: people with YOD and their carers influence and control the support they receive;
- partnerships between services and people with YOD and their carers, because the participants are the best judges of their own needs; and
- positive living that builds on people's strengths and capabilities, not limitations.



There are three interrelated objectives:

- individually-based, person-centred support;
- peer support: opportunities for participants to share their experiences; and
- resource-informed decision-making: information to assist people to make decisions.

The project has four components:

1. informal Linking Lives Project Group consisting of people with YOD and their families, with flexible membership and participation, which uses people's experiences and knowledge to shape the activities to be undertaken;
2. Linking Lives Facilitator, a 'key worker' who works with the participants as a resource and a mentor and who establishes a relationship with the participants – not case management, nor does it include contacting providers or monitoring service provision;
3. Links Café, similar to Alzheimer's Australia Vic's Memory Lane Café), which provides opportunities for informal semi-structured information-sharing and socialisation; and
4. resource development, in particular a YOD service directory and web-based strategy TIP sheets (*HOPE Newsletter* 2010, Issue 5: 4)18.

An evaluation of the program (Moore and Renehan, 2011) found that it had experienced some difficulty trying to meet everyone's diverse needs. This suggested that there was a need for a range of programs to address needs of particular clients, e.g. at different stages of the progression of the disease, still involved in the workforce, still physically active, with dependent children. One of the main issues to come out of the evaluation was the question of whether or not to continue restricting the service to people under the age of 65. The evaluators recommended continuing the program and maintaining the key worker position, with a number of modifications, among them:

- splitting the key worker role into two positions, one to work directly with clients, the other to deal with strategic and developmental work;
- considering the possibility of running the program as crisis intervention;
- incorporating the kind of continuity developed for the LWML/Memory Lane Cafés model, given what appeared to be a lack of cohesion among clients;
- developing web-based communication and support strategies; and
- further exploration of the specific information needs people have.

The Linking Lives project is currently funded until October 2011 (Bevilacqua, 2011).

### **Other**

The report on HACC services in the Sydney Metro North area (Alt Beatty, 2007: 61) described a number of services that existed in Victoria at the time of writing:

- **Carinya Respite Service in Melbourne, with links to the Living with Memory Loss program (LWML), was running an 'Out and About' Group on Mondays for eight men with YOD.**  
The program was planned around activities of interest to the men, including good weather programs and wet /cold weather programs, e.g. fishing, BBQs, walks, lunches in pubs. The service was planning another men's group, and there were a number of women ready to start a 'Chat and Chew' program based around the women's interests. The service has overnight accommodation and was considering one weekend a month for younger people to stay to give families a break.

- **Alzheimer's Australia Victoria was running a number of different groups:**
  - \* three-day LWML residential retreats funded by National Respite for Carers Program, for 11 people with YOD and their carers, aiming to bring people and their partners together to share their experiences of life and of dementia, to discuss the complexity of living with dementia, and to form new social relationships and provide people with positive social and recreational experiences;
  - \* Partners Group, a regular discussion group for partners of people with younger onset dementia; and
  - \* a monthly Art Therapy class specifically for people diagnosed with YOD.
- **Carer Links West, Melbourne, was also providing a number of different groups:**
  - \* fortnightly recreational program on a Saturday initially designed for people with YOD who were not able to access appropriate group activities – over time, though, the group needed to take in older people too, because there were too few new YOD referrals;
  - \* group getaway to Daylesford for 12 people with YOD a month, specifically matched to people with similar care issues – available to each carer once a year;
  - \* fortnightly weekend Outings Program, suitable for people with YOD because it has a travel component and an emphasis on socialisation.

## **SOUTH AUSTRALIA**

### ***Connexus***

'Connexus' was a social support program for people with YOD and their families in Adelaide, established by Alzheimer's Australia SA in 2007 with funding from the Australian Government Department of Health and Ageing (Moore and Renehan, 2011). Originally an 18-month pilot program, the program was funded again in 2009. It offered a range of information and education, as well as lifestyle opportunities, and used a person-centred approach by identifying individual needs for participation in new or ongoing age-appropriate activities. It also provided opportunities for interpersonal relationships and engagement through peer-support groups, and one-on-one support to increase social interaction in community activities and groups and increase social confidence and self-esteem (Alzheimer's Australia SA, 2009; Alford et al, 2009).

It is not clear whether or not the program is still in existence. The search term 'Connexus' found no results on the Alzheimer's Australia SA website.

### ***The Sundowner Club***

The earlier review (Tyson, 2007) described a program in Adelaide called 'the Sundowner Club'. Although not specifically designed for people with YOD, it had sufficient flexibility to meet their needs. The club's name is a reference to what has become known as 'sundowning' behaviour, i.e. symptoms such as a tendency to wander or become agitated that worsen in the late afternoon and early evening. As these behaviours occur after business hours, they are not catered for by conventional respite services. The Sundowner Club provided an evening meal and a program of social activity for clients between 3:00 and 8:00 pm, Monday to Friday, at two locations in Adelaide, as well as transport by bus from clients' homes. Clients helped prepare the meal and dined with the other members in a small-group setting (maximum eight clients). The program aimed to benefit carers who were still working, where current respite services were not provided late enough.

One of the initiatives under the Innovative Pool Dementia Pilot program, the club started in April 2004 and was evaluated from June to September 2004 and in September 2005 (AIHW, 2006: 82-7). The evaluation, which involved interviews with the carers, found a number of positive outcomes:

- the small group model, which reassured clients who felt overwhelmed in large groups;
- the out-of-home respite, which enabled carers to have time to themselves or participate in social contacts and valued social activities, and contributed to their ability to continue caring;
- social participation for the person with dementia;
- respectful, flexible and responsive staff; and
- the fact that the clients enjoyed themselves participating in activities which they did not perceive to be demeaning or infantile.

The club was a pilot program and is no longer in operation.

## **ACT**

The earlier review (Tyson, 2007) described a respite program developed by Alzheimer's Australia ACT. Called the Mobile Respite Response Team (MRRT), it was a short-term in-home intervention tailored to meet the needs of people with YOD and their families. It provided respite, education and strategies for behaviour management for carers, and assistance in accessing appropriate services. The program also offered couples the opportunity to go away together on weekends accompanied by MRRT staff. This gave carers had the chance to observe how staff interacted with their partners and how their partners coped, and to let go of some of their caring tasks for three days. The program ended after 12 episodes, partly due to the difficulties of running on an extremely limited budget. Nevertheless, it provided a good example of how to organise respite services suitable for people with YOD.

In 2010, Alzheimer's Australia ACT received a grant from Australian Government Department of Health and Ageing to develop a YOD program that would respond to the increasing demand for respite care. Two weekly programs were established: a social group for women and a walking group for both sexes. Both programs were intended to promote social interaction and exercise for clients, as well as respite for their carers. Transport was provided. Alzheimer's Australia ACT are also exploring other possibilities for extending social and recreational programs for people with YOD, as well as opportunities for service partnerships to foster services that meet their needs (Moore and Renehan, 2011).

## **OTHER**

Tyson (2007) also mentioned favourably a number of informative documents. The first was called *Signposts*, and had been published in 2002 by the former Alzheimer's Association of NSW. It was aimed at the families of people with YOD and health professionals working in the field, providing basic information about the main issues, and giving telephone numbers and further sources of information that could be accessed when needed. Although now out of date, it could be updated and distributed to memory clinics, GPs' surgeries and Alzheimer's Australia offices across the country. Another policy document recommended by Tyson (2007) was *The Young Mind – Issues in relation to young people with dementia* by Freeth, published by the Alzheimer's Association in Sydney in 1995. While it is difficult to obtain now, it would still be useful in that describes in detail a research project about issues in relation to people with YOD, and provides a good overview of their needs. Tyson also recommended Alzheimer's Australia's 2003 document called *The Long and Lonely Road*.

The two key workers interviewed for the evaluation of the Linking Lives project (Moore and Renehan, 2011) had a number of innovative suggestions for service provision. One suggested that more telephone client contact with occasional outreach as required would be a more realistic model for this particular project. The other worker suggested that web-based communications might be beneficial for this population. She said that a pilot Internet program run by Alzheimer's Australia for people with YOD found that the online chat room was the most successful component, while the topic-based discussions were not as popular. The evaluators said that online counselling was also being piloted and could be another resource for the Linking Lives program. They noted that web-based options

had the advantage of being accessible at any time of day, and that this solved some of problems of programs operating only during business hours.

The NSW/ACT Dementia Training Study Centre is a resource which offers dementia training online. It is a learning unit made up of six modules of which the 5th relates to YOD. This learning module is built around four content areas: prevalence and causes; screening and diagnosis; behavioural symptoms; and service provision<sup>19</sup>.

## **INTERNATIONAL EXAMPLES OF GOOD PRACTICE**

This section describes a number of examples of good practice elsewhere in the world. It covers only English-language resources (or resources which have been reported in English), and it cannot claim to be exhaustive or even representative. However, it does give a sense of what is available.

### **DEMENTIA ADVOCACY SUPPORT NETWORK INTERNATIONAL (DASNI)**

This organisation is a not-for-profit corporation which was established in 2000. Although not devised specifically for people with YOD, its aims are nonetheless appropriate, namely:

- to promote respect and dignity for persons with dementia;
- to provide a forum for the exchange of information;
- to encourage support mechanisms such as local groups, counselling groups and internet linkages;
- to appeal for services for people with dementia; and
- to assist people to connect with their local Alzheimer's organisation (Tyson, 2007: 45).

### **UNITED KINGDOM**

The earlier review (Tyson, 2007: 64-72) contains a detailed discussion of the situation of service provision for people with YOD in the UK, and in Ireland (pp.72-3), as well as the UK Alzheimer's Society Charter for younger people with dementia and their carers. The author noted that, at the time, most of the literature about YOD she found had been produced in the UK. This present review will not reproduce Tyson's work, but rather, update and extend it with examples of what has developed since then<sup>20</sup>.

The Alzheimer's Society in London has had a strategy for people with YOD since 1996 (Alt Beatty, 2007). They have also worked with the Royal College of Psychiatrists (2005) to develop policies focused on increasing awareness, establishing services specifically for YOD, promoting cooperation between specialist groups, and providing pathways of care (Chemali et al, 2010).

The 2001 UK National Service Framework for Older People referred to the need for specialist services for people with YOD (Allen et al, 2009), and the 2009 National Dementia Strategy recognized that not all people with dementia are late stage and incapable of functioning relatively normally (Milne, 2010). Nonetheless, there is a consensus in the literature that services for people with YOD in the UK are scarce, even 'woefully inadequate' (Harris and Keady, 2009), and that they are usually included in services for older people. This situation is not unique to the UK, but occurs also in the US and Australia (Harris and Keady, 2009). Werner et al (2009) suggested that one reason for the scarcity of services for people with YOD might be that staff in general psychiatric services lacked adequate knowledge and training<sup>20</sup> to recognise and treat the disorder. Existing services for people with YOD include community/home support, day care, residential and nursing care, and the number of support groups for carers and people with YOD is growing. However, the availability of these services is not always recognised. A study of people with YOD in Ireland found that fewer than two-fifths of the study participants had used any of the available services.

### ***The Clive Project***

The Clive Project started in April 1998. It was named after Helen Beaumont's husband, whose experiences with YOD and those of his family are described in her book, *Losing Clive to Younger Onset Dementia* (Arie, 2010). The name has since been changed to YoungDementia UK<sup>21</sup>.

Based in Oxfordshire, the project's model of support has been adopted in areas beyond, and the organisers are exploring a next phase of development involving ways to reach out to people with YOD. The service is for people who developed dementia before the age of 65, and live in the relevant area. They can continue until they no longer benefit from the service. They can also be referred by someone else, with their agreement. The program has four components: a one-on-one service for the person with YOD; a family service; a club; and a café.

The one-on-one service offers the person with YOD a choice of activities, involving a trained support worker who partners the person to develop a trusting relationship. There are fourteen trained staff in the team, who delivered 7500 hours of support to over 50 people with YOD between the age of 36 and the late 60s (average age 56). There is an hourly charge for the service, which can be paid for through people's individual budgets, and there are also costs for mileage and some activities.

The family service started in April 2005. There are three staff, who give intensive support throughout the year to over 50 family members between the ages of 8 to 80. The team provides individual and group support, a program of information discussions called the Exchange, and regular social events throughout the region. Team members visit people at home or anywhere else they specify. There is a variety of support services, such as: further visits from a designated support worker; telephone and email contact; providing information; identifying other useful services and agencies; help in contacting other services and professionals; ongoing practical and emotional support; and most of all, the opportunity to talk. There are plenty of opportunities to get to know people living with the same problems, a newsletter is published three times a year, and there is a Resource library available to members. The family service is free.

The club involves social events held throughout the year in locations across the region. They are relaxed and informal, and provide opportunities for the people with YOD and their partners and families to enjoy time together, supported by the team.

The café is on the fourth Thursday evening each month, excluding December, always in the same location. Supper, music, games and occasional live entertainment are provided, as well as the opportunity to meet up with others in similar circumstances, and easy access to information and to the team.

YoungDementia UK is planning a number of projects for the future. These are: a YoungDementia Homes project which will offer short breaks and long-term accommodation as a high quality alternative to home when it is needed; working with health and social services in the region to develop a comprehensive service for people with YOD and their families; working with other organisations involved in dementia care; and campaigning for coherence and collaboration between the specialist YOD services that are gradually being established across the UK.

### ***Birmingham Working Age Dementia Service***

The Birmingham Working Age Dementia Service is a specialist community service dedicated to people with YOD and their families and carers. It became operational in 2002 as a result of campaigning from carers, the Alzheimer's Society and committed professionals. The team is made up of professionals from three different agencies, working both full-time and part-time in collaboration with the person and their family, and includes a psychologist, a consultant psychiatrist, a project manager, an occupational therapist, a senior social worker, a team administrator, a community support worker and a consultant nurse. The approach is intended to be enabling and rehabilitative, and involves counselling, early and ongoing assessment, multi-disciplinary interventions, training and supervision,

and service development. The care is person-centred, although the team have found that this has its challenges, two of which are discussed by the researcher. The first of these involves delivering person-centred care in a community setting (as opposed to an institutional setting), where it is necessary to respond to the needs of the family as well. The team resolved this by having different workers for different people in the family, rather than one worker for the whole family. The second challenge is the effect on the staff, who can sometimes be ill-prepared for the emotional impact of working full-time with people with YOD and their families. This highlights the importance of support for staff without which, working with people with dementia can become too painful. For this reason, the original team had monthly psycho-therapeutic group supervision (La Fontaine, 2004; Bentham and La Fontaine, 2007).

### **ACE club**

The ACE club, also called the Glen Devon Day Club in Denbighshire in North Wales, was a peer-support, relationship-centred day service for people with YOD, which commenced in January 2002. It was pioneered by a mental health nurse working independently in the community, who was commissioned by the local branch of the Alzheimer's Society to design a dedicated service for people with YOD that would also provide a period of respite for the family carer. This nurse had found that working in the independent sector, rather than in public health, allowed more freedom to innovate and develop ideas. Her experience had been that the demands associated with risk assessments in the health trusts and departments was constraining what could be done by nurses trying to improve the quality of life of those in their care. The ACE philosophy, she said, 'is to enable people to take risks, not to actively disable people for fear of litigation' (Daniel, 2004).

A steering group was formed of key professional stakeholders, as a way of ensuring collaboration and partnership across agencies and of establishing and maintaining appropriate referrals. The steering group consisted of representatives of health, social services, nurse education and research, and the Dementia Service Development Centre, Wales. The club was not a stand-alone service, but had reciprocal arrangements with statutory agencies as well as a named point of contact with each agency. This group met quarterly with the club itself to report on progress, referrals and developments.

ACE variously stands for: Autonomous, Confident and Empowered; Activity, Companionship and Enjoyment; and Awareness, Care and Education. The club's formation was based on the assumption that much of the withdrawal and the decline in activity and abilities was due to the combination of a lack of confidence, a decrease in self-esteem and an increase in anxiety, rather than solely to the effects of dementia. If these areas could be addressed through appropriate support both for the person and for their carer, then they could develop strategies that would partly compensate for any actual decline in abilities. Staff took a facilitative, educative and supportive role in the activities, which were chosen by the ACE club members themselves. The relationship-centred approach taken by staff was intended to challenge the belief that the person with YOD always had to be at the centre of any model of support. It recognised that the needs of the family carer might have to take precedence, for example, if the carer was exhausted after being unable to sleep. At the same time, ACE welcomed the involvement of family and friends, so that family members could see for themselves how much enjoyment their partner was having and the progress that was being made. Bringing together people in similar situations reduced the sense of isolation and provided an environment where new relationships and friendships could flourish without the anxieties so many people had experienced.

ACE was also actively involved in raising awareness locally. It aimed to reach others in similar situations by informing care practice, research, education and service development.

An independent evaluation during the first year of operation showed that the philosophy of empowerment did lead to a person-centred service that contributed positively to the well-being



both of members and of their families (Davies-Quarrel et al, 2004: 20). A further evaluation was conducted by the club members themselves. As a result of that evaluation and the success of the ACE approach locally, older people with dementia requested a similar service. Launched in 2009, it was called ACE Active. However, as one commentator put it, 'securing core funding is an on-going challenge' (Daniel, 2004). Despite the belief that the ACE approach had revolutionised dementia care for younger people in Wales (Daniel, 2004), funding for both clubs ceased in April 2010 (Davies-Quarrel et al, 2010). The website is still accessible (<http://ace.glendevon-care.com/>), but there are no 'upcoming events' (see also: Davies-Quarrell et al, 2007).

### ***Croydon Memory Service***

The Croydon Memory Service (CMS)<sup>22</sup> model was developed to fill a gap in service delivery for people in the early stages of dementia and to provide them with the treatment they needed. It involved the introduction into the local care system of a low-cost, generic service additional to the existing system. One of the stated aims against which the success of the multi-agency group was to be judged was engagement with people with YOD, with a goal of 10 per cent of clients under 65. It started in November 2002, and an evaluation of its first 18 months of operation found that it exceeded this goal, with 18 per cent of referrals being people with YOD (Banerjee et al, 2007). A later evaluation conducted in 2004 (Willis et al, 2009) found that the services provided were not always appropriate for people with YOD. However, the sample was small (16 people with dementia and 15 carers), and the report of the evaluation concluded with recommendations for ensuring the services was appropriate for people with YOD. Moreover, there are aspects of the CMS – its focus on early intervention, its cost-effectiveness, its aim of enabling people to plan for the future and of providing a continuum of care – which are already relevant to the particular needs of people with YOD.

CMS is a development of the memory clinic model, designed to maximise service effectiveness while providing broadly-based care and assessment in people's own homes (Banerjee et al, 2007). It involves a multi-disciplinary team of staff with backgrounds in nursing, psychiatry, social care and psychology, who jointly devise the diagnosis and management plan, and any one of whom can conduct initial assessments and take on the role of key worker. Along with anti-dementia medication and pharmacological management of symptoms, the team provides:

- case management through the key worker role, which lasts as long as needed;
- systematic feedback of diagnosis to both clients and carers;
- individual and group psychological therapies (memory retraining for clients and carers together, and a support group for carers only);
- psycho-social management of the behavioural symptoms of dementia;
- access to social services support (e.g. day care, respite, home care);
- advice on benefits; and
- contact with voluntary agencies.

The CMS is an integrated service incorporating the local mental health trust, local social services and the local Alzheimer's Society branch. Because the team is integrated with social services there is no need for any further assessment for packages of care. Referrals to the service come from primary care, secondary care and social services (Willis et al, 2009. See also: Szymczynska et al, 2011).

### ***PROP***

People Relying on People (PROP) is a self-help group for people with YOD and their carers based in Doncaster, South Yorkshire. Initiated in 1999, it was facilitated by a nurse with personal experience of caring for a relative with YOD. Over five years, the group evolved into a constituted service with its own committee with both people with YOD and their carers as members. One of the aims of PROP



was to portray the person as an educator, a strategy intended to challenge traditional assumptions about people with dementia as incapable of participating in their care or expressing their own views. Another aim was to ensure that service users had a say in the care they received. The group produced a DVD with an accompanying booklet, as a resource to help the general public understand the condition and needs of people with YOD and generally to promote a positive attitude towards them. The DVD has had a wide distribution to countries around the world, including New Zealand and the US (Chaston, 2010).

PROP works with service users to increase their self-determination and enable them to direct their own affairs wherever possible. They have helped to redesign care-plan documents and demystify the terminology, devised their own information leaflets, and participated in devising templates for care needs when people are no longer able to make decisions. They are independent and self-organised and not aligned with a health care trust or a charity such as the Alzheimer's Society. Members use their disability as an asset to open doors to new opportunities for themselves in ways that health professionals cannot, constrained as they are by service rules. The group enables people with YOD to develop ways of meeting their own requirements, rather than relying solely on provision by the health community. PROP also reaches out to other local disadvantaged groups, such as deaf people (Chaston, Pollard and Jubb, 2004).

### **CANDID**

CANDID (Counselling and Diagnosis in Dementia) was a telephone helpline providing information for people with YOD, their families and carers, and the professionals caring for them (Harvey et al, 1998). It offered direct telephone and e-mail access to a specially trained nurse or counsellor who recorded the query and provided emotional support and practical advice. If the people wanted to, they could register with the service which would hold their clinical details so that the advice given could be tailored to their specific needs and forwarded to their GP for action. All advice given was reviewed by a consultant neurologist and a psychiatrist. It was the first UK telemedicine project in the field of dementia, although telemedicine had already become established in other areas such as radiology, pathology, dermatology and cardiology. CANDID was not just a simple helpline – the advice given could be based on specific knowledge of the person's disease, and the service aimed to be active in improving management of their needs.

A retrospective review of all calls received by the helpline over the first two years found that it had become rapidly accepted and used by families and members of the public, although less so by professionals. Only 5 per cent of calls were from doctors and only 13 per cent from nurses and social workers. The evaluators said that CANDID offered 'an exceptionally scaleable model of care' for people with YOD, with possibilities for expanding it nationally and throughout Europe. Callers need not be confined to any particular locality, and information technology can be used to route complex queries back to a central CANDID hub (Harvey et al, 1998).

It is not clear what happened to the service. It is not mentioned on the Alzheimer's Society website, although it may have been incorporated into a nurse-led information and advice service at the Dementia Research Centre, Queen Square, London, part of the National Hospital for Neurology and Neurosurgery. A program called CANDID is run by the Consultant Nurse and Clinical Nurse Specialist, for patients and families registered with the NHS Specialist Cognitive Disorders clinic at the National Hospital, as well as for associated healthcare professionals. The program involves a telephone helpline service before the first appointment, between appointments and following discharge to local services, as well as face-to-face consultations at clinic appointments<sup>23</sup>.

### ***'Out and About' group***

The 'Out and About' group provided social activities for four women with YOD in South Warwickshire (Casey, 2004). The group met weekly on Tuesdays for outings such as picnics, walks during the summer and visits to shopping centres in the winter, with planned excursions to the cinema and concerts. The participants took photographs and collected leaflets which were made up into an album to use as a memory jogger for the evaluation. There were three group facilitators – an occupational therapist, a mental health nurse and an Alzheimer's worker. Not all three were present on every occasion, but three workers were necessary to provide continuity in case of eventualities such as holidays or sickness. The first meeting was in June 2001, and at a meeting just before Christmas the group was evaluated by means of a semi-structured questionnaire. The evaluation found that people had enjoyed the outings and that they wished to continue with them.

### ***Other***

The literature also contained brief references to a number of other initiatives for people with YOD in the UK without, however, going into any detail. For example, the Alzheimer's Society website contains a link to a video, and accompanying transcript, about The Limes, a day support service for people with YOD based in Bristol<sup>24</sup>.

The scoping study on the needs of younger people with disabilities in the UK (Stalker et al, 2005) gave as an example of an innovative service for people with YOD an independent supported living house in Newcastle. The project aimed to respond to the changing needs of residents and manage their moods and behaviour, as well as providing them with physical comfort, personal care and security, and the maximum of pleasure and achievement. An independent evaluation of this service<sup>25</sup> found that the key elements of good care were the use of observation and negotiation, responses specific to the individual concerned, and encouragement by staff. The care was of good quality partly because both the staff and the family members were committed to the project.

## **UNITED STATES**

According to the authors of a study using both UK and US data on selfhood in YOD, the first public acknowledgement of YOD by the US national office of the Alzheimer's Association came with the release in 2006 of a comprehensive report on the incidence, prevalence and special needs of people with YOD (Harris and Keady, 2009). Called *Early Onset Dementia: A National Challenge, A Future Crisis* (Maslow, 2006), this publication used information from the 2000 national Health and Retirement Study, together with other studies, to provide a first view of the extent of unmet need among Americans with YOD and their families<sup>26</sup>.

A number of community organisations, including local chapters of the Alzheimer's Association, have begun providing education and support programs for people with early-stage memory loss (ESML), where they can meet other people in their community who have been newly diagnosed, and share experiences, learn more about the disease, reduce isolation, and help each other to cope with lifestyle changes and long-term care planning. A study in Washington (Logsdon et al, 2010) evaluated one of these programs in one of the few randomised controlled trials in the clinical area of dementia (people in the program versus those on a waiting list). The study was not specific to YOD, and in fact the researchers acknowledged that people with YOD faced a different set of problems from people with later onset. However, the study found that those who participated in nine sessions of an ESML program<sup>27</sup> reported fewer depressive symptoms than those on the waiting list, as well as a better quality of life associated with improved mental health, family communication and self-efficacy. The differences were minor, but they were statistically significant. The researchers commented that their findings were consistent with other reports of the benefits of early-stage support groups based on qualitative research, and provided empirical confirmation of

the efficacy of these groups. Given these findings, there is no reason why ESML programs should not also be efficacious for people with YOD.

An earlier report (Logsdon et al, 2007) on preliminary outcome data said that, as well as improved quality of life, results to that point also suggested that participation decreased family conflict (although this was not mentioned in the later report). The earlier report had also commented on the fact that support groups did not appeal to everyone, while making the same point as the later report – that people with YOD might not feel comfortable in a group where the other participants were so much older.

A study in Massachusetts in 2008 (Silverstein et al, 2010) investigated the services provided by adult day health care, through an electronic survey of providers (of whom 93 or 60 per cent responded) and in-person interviews at eight sites. The purpose of the research was to document how providers were addressing the needs of participants with Alzheimer's disease and related disorders, with a specific focus on YOD (as well as early, late and end stages of the disease at any age). The study found that, although providers were adapting well to the cognitive and physical limitations of their participants, there were limited services for people with YOD (as well as for participants at later stages of the disease). However, staff at those sites which did serve people with YOD said that one of their chief needs was to maintain their self-esteem. Some providers said that younger participants got satisfaction from undertaking responsibilities at the centre, e.g. washing dishes, sweeping, helping to put out the garbage, because that made them feel more like volunteer workers than participants.

'Without Warning™' is a support group for people with YOD in Chicago, offering a program of education and support to the whole family unit, including sessions for children under 18 and adult children (Arends and Frick, 2009). It has been meeting monthly since June 2004. The average attendance increased from 10 to 40 in the four years from 2004 to 2008, and there are currently four to five separate groups meeting at the same time. As is the case with all the initiatives described here, the driving force has been people with YOD and their families. A number of practical issues have come up during the life of the program:

- meeting location – venues that were too medically focused or too far to travel were rejected in favour of space donated by a church, that was easily accessible by car and easy to navigate inside (well-lit rooms, hallways and stairs, with an elevator);
- meeting schedules and structure – 10:00 am to noon because mornings are better for people with YOD, with an initial half hour for announcements and social time, followed by one hour of sessions held separately for people with YOD and for their families, and then a final half hour of combined social time;
- the importance of consistency of location, meeting time and food;
- two kinds of groups for people with YOD – a verbal group for people with insight into their problems, a music therapy group for those less verbal, with movement allowed between the two;
- optimal size for the family group – eight to ten;
- attendance of people with YOD limited to those with mild to moderate impairment;
- at least two staff members for each group of people with YOD (as well as a facilitator for each family group) – in case anyone needs to leave the room, one staff member can go with them and the other can stay with the group;
- name tags colour-coded to indicate which group the person is going to;
- ensuring the family groups end at the same time as the YOD groups (so that staff are not wholly responsible for making sure people don't wander off); and
- no observers allowed in meetings, e.g. media, students, health care professionals.

There were other support options suggested by US researchers. For example, a student researcher reported in her Honours thesis (Trela, 2009) that the use of a memory book improved communication and increased positive statements about self-identity on the part of a single participant with moderate dementia. Another example concerns teleconferencing. An article advising social workers in the US on ways of implementing teleconferencing among carers (Toseland and Larkin, 2011) suggested that telephone groups might be a way of forming support groups for people who were geographically dispersed. The authors gave the specific example of YOD which, because it is comparatively rare, often means that people with YOD and their carers are scattered over a wide area. Use of the telephone could enable them to establish and maintain contact despite the geographical distances.

## **NEW ZEALAND**

The Alzheimers New Zealand website<sup>28</sup> has a section devoted to 'Younger people with dementia (early onset)'. Contact details are provided for a number of a number of support groups, including a bi-monthly 'Younger onset social group' in Hastings. Alzheimers New Zealand have also produced a Dementia Booklet (Alzheimers New Zealand, 2006), which contains a section on 'Younger-onset dementia'. Moreover, the fifth Strategic Goal of *Alzheimers New Zealand's National Dementia Strategy 2010-2015* (Alzheimers New Zealand, 2010), which relates to Appropriate Services, has as its fourth Objective: to 'Identify and establish early on-set dementia programmes nationwide to accommodate the under 65 years age group'. The needs of people with dementia aged under 65 years of age are also mentioned in the *Dementia Manifesto*<sup>29</sup>.

A PROP group (see above) has been established in response to requests from members in rural areas in New Zealand. The group has organised a telephone advice and support service, and a newsletter to which both people with YOD and their carers contribute and which provides information about social activities in local areas. This model is an attempt to address the social isolation experienced by people with YOD, which is compounded by their location. Chaston (2010) argues that the Competencies for Registered Nurses of the Nursing Council of New Zealand, based as they are on the Treaty of Waitangi concepts of participation, partnership and protection, provide an appropriate model of culturally safe nursing care for the empowerment of people with YOD.

## **EUROPE**

COGKNOW<sup>30</sup> was originally an e-Inclusion project funded under the Information Society Technologies (IST) program, which is one of seven major thematic priorities of the European Union's Sixth Framework Programme (FP6) for Research and Development. It started in 2006. Although not specifically for people with YOD, the project aimed to create an assistive cognitive prosthetic to support people with mild dementia in their daily lives in the community. It set out to create two user-friendly devices, one home-based and one mobile, that would feature needs identified as high-priority by people with mild dementia and their carers, as well as by the dementia experts. Touch-screen technology was deemed to be the best way for people with dementia to use the computer-based assistive functions. The necessary hardware devices could be bought off the shelf and the software could be installed on them. The end result is a flat-screen monitor for the home and a mobile smart phone with a simplified user-interface. Both devices are controlled by touch screen (the monitor does not even come with a keyboard) with the COGKNOW application maintained on top of everything so nothing else is visible to the user<sup>31</sup>.

A prototype, the COGKNOW Day Navigator (CDN), was developed and will be available commercially in 2011. The CDN was field-tested and evaluated by 42 users in Sweden, the Netherlands and Northern Ireland (Mulvenna et al, 2007) (although the results are not publicly available).

The main functionalities are:

- time indication
- remotely configurable reminders
- music
- radio
- picture dialing
- activity assistance
- house alerts for safety
- mobile navigation for going home.

CDN uses mainstream IT equipment with software especially designed for people with dementia. It can be used with most touchscreen-equipped computers and with mobile devices using the Android operating system.

## **NETHERLANDS**

In the Netherlands, a longitudinal observational study, the NeedYD-study (Needs in Young Onset Dementia), is following 217 people with YOD and their carers (van Vliet et al, 2010a). The study is a prospective cohort study in which people and their families, including children older than 14 living at home, are followed up every six months for a period of two years. It aims to delineate the course of the disease, the functional characteristics and needs of people and their caregivers, the risk factors for institutionalisation, and the interaction with the caring environment. One of the main aims is to document the level of unmet need. To date, there are no results from the study<sup>32</sup>.

## **JAPAN**

A study in Japan (Nomura et al, 2009) evaluated the process of a cognitive rehabilitation program which aimed to empower a group of elderly people with early dementia, and to provide education and counselling for their carers. It was a monthly activity-based program developed specifically to improve cognitive function. The research participants were not people with YOD – its focus was on the early stages of dementia, whatever the age of the person. It has been included here because it is one of the few dementia management programs to be evaluated longitudinally. The study, which lasted for five years, used a community health action research model of participatory research, involving 37 elderly with early or mild dementia living in the community and 31 carers in a rural town in Japan. The program did help the participants to regain lost procedural skills and acquire confidence. Recognition that they did have skills seemed to be the most important element of empowerment. The education and counselling aspect of the program for carers was also successful in that it promoted coping skills and improved family relationships. The research group also gained recognition in the community because it actively participated in community events.

## **CONCLUSION**

This literature review focused on good practice in service provision for supporting people with younger onset dementia (YOD) in the community. It investigated both academic and 'grey' literature for information about the policy context in Australia, what is deemed necessary for good practice in this area, and examples of community-service initiatives both in Australia and overseas.

In relation to the policy context in Australia (section 3), most jurisdictions acknowledge the existence and the importance of YOD, although there are wide variations in the extent to which each jurisdiction does so. In some cases, the relevant health department website may not mention YOD, but there are services available, especially through each state affiliate of Alzheimer's Australia. NSW and Victoria appear to be the states with the most programs for people with YOD.

A number of general themes about what is needed for good practice emerged from the literature. The difficulties people had experienced with diagnosis were frequently discussed, and attributed largely to the lack of knowledge of the existence of YOD, even among health professionals. Information was another important issue, both what people were told and the way they were told. But the themes that recurred most often were the differences between YOD and developing dementia later in life, and the consequent need for appropriate services for people with YOD. The main differences involved the greater likelihood of having dependent children, of still being in employment, and of having significant financial responsibilities.

The question of whether those services should be YOD-specific or generic was resolved in favour of both, although the question of the balance between the two remained open.

There was general agreement that services needed to be multi-disciplinary (and a number of the programs discussed were deliberately devised with this in mind) and person-centred. The latter requirement did not mean that the focus was always exclusively on the person with YOD. The fact that the family also had needs was stressed, even to the extent that those needs sometimes took precedence.

There was a consensus that caring for someone with YOD could be more stressful than caring for an older person with dementia, although the literature was unclear on this issue, largely because of the methodological limitations of the studies. The main reason why this might be the case centrally revolved around the unexpected disruptive effects of acquiring the disease at this early stage in life. Another reason was the higher prevalence in YOD of dementias characterised by challenging behaviours.

Respite services were found to be problematic to the extent that they were organised around the needs of older people. Conventionally designed respite tends to be sedentary whereas people with YOD are still physically strong and healthy; they were also reluctant to see themselves as aged-care clients.

The final two sections of this part of the report give details of initiatives that are either YOD-specific or relevant to people with YOD and their carers and families, both in Australia (section 5) and overseas (section 6).

In sum it can be said that, while there is still too little awareness of younger onset dementia, that situation is changing. There is increased interest being shown by policy makers, service providers and researchers, and it is possible for people with YOD and their families to see themselves as an identifiable group, with particular wants and needs and specific requirements for service provision. That does not translate directly into adequate and appropriate services, but it is a step in the right direction.



## LITERATURE REVIEW ENDNOTES

1. This report uses the term 'younger onset' to refer to first onset before the age of 65 years, rather than 'early onset', which is also sometimes used to refer to the early stages of dementia at any age.
2. For example: Panegyres and Frencham, 2007; Piguet et al, 2007; Kaiser and Panegyres, 2007; Koedam et al, 2008, 2010; Hodges et al, 2009; Hornberger et al, 2009; Piguet et al, 2009, 2011; Werner et al, 2009; Gauthier et al, 2010; Phillips et al, 2010.
3. <http://www.health.gov.au/internet/main/publishing.nsf/Content/Dementia-1>
4. <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr08-je-je172.htm>
5. See, for example: Anderson, 2007; Ramshaw, 2007; Grant, 2008; Parsons-Suhl et al, 2008; Allen et al, 2009; Harris and Keady, 2009; Alemán and Helfrich, 2010; Alzheimer's Australia, 2009b, 2010b; Brown and Roach, 2010; Page and Keady, 2010; Rose et al, 2010; Zimmerman, 2010; Bevilacqua, 2011; Withall et al, 2011.
6. <http://www.alzheimers.org.au/services/further-reading-and-resources.aspx>
7. These themes are echoed throughout the literature: Shinagawa et al, 2007; Snyder, 2007; Tyson, 2007; Hayter, 2008; Access Economics, 2009a, b; McLean, 2009; Bakker et al, 2010; Brodaty and Cumming, 2010; Merl, 2010; Moore and Renehan, 2011; NSW Health, 2011. See also: Alzheimer's Disease International – <http://www.alz.co.uk/withdementia/younger-dementia>; Alzheimer's Australia – <http://www.alzheimers.org.au/services/early-or-younger-onset-dementia.aspx>
8. The research cited was reported in Robertson, S. (1996) *Younger People with Dementia: The Impact on Their Children* University of Stirling: Dementia Services Development Centre. It was not possible to get a copy of this report in the time available.
9. See also: Armstrong, 2003; Allen et al, 2009; Chaston, 2010.
10. e.g. Davies-Quarrell et al, 2007; Panegyres and Frencham, 2007; Hayter, 2008; Alzheimer's Australia, 2009c; Easton, 2009; Roach et al, 2009; Willis et al, 2009; Alzheimer's Society (UK), 2010; Silverstein et al, 2010.
11. Kaiser and Panegyres, 2007; Rosness et al, 2008; McLean, 2009; Withall and Draper, 2009; Rinfrette, 2010.
12. Adapted from the Alzheimer's Australia SA website – <http://www.alzheimers.org.au/south-australia/living-with-memory-loss-program-sa.aspx>
13. The program was assessed in an earlier research project, reported in: E. Pross (2006) *Two Years On: Findings from the Younger Onset Dementia Social Support Program 2004-2006* A Report for Mercy Community Care, June 2006. This report is not accessible on the Mercy Community Care website, and it is not kept in any library in Australia.
14. <http://www.ella.org.au/SERVICES/RespiteandRecreation/YoungerOnsetDementiaSocialSupport/tabid/72/Default.aspx>
15. <http://www.hammond.com.au/pages/default.asp?pid=259#>
16. <http://www.health.vic.gov.au/subacute/cdams.htm>
17. Alzheimer Café UK – <http://www.alzheimercafe.co.uk/home.htm>
18. <http://www.alzheimers.org.au/research-publications/hope-newsletter.aspx>
19. <http://dementia.uow.edu.au/understandingdementiacare/index.htmlb>



20. See also the UK Alzheimer's Society's website: <http://www.alzheimers.org.au/services/further-reading-and-resources.aspx>. Tyson (2007) refers to the Society's policy document, *Younger people with dementia: an approach for the future*, their *Charter for Younger People with Dementia*, and a publication, *Younger people with dementia – a guide to service development and provision* (also cited in Alt Beatty, 2007). These are not currently available on the Society's website, although the Charter is reproduced as Attachment 1 to Tyson, 2007.
21. <http://www.youngdementiauk.org/>
22. <http://www.communitycare.co.uk/Articles/2008/07/29/108997/croydons-memory-service-leads-the-way-on-dementia.htm>
23. <http://dementia.ion.ucl.ac.uk/candid.html>
24. [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1361](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1361)
25. Cantley, C and Smith, M (2000) *An Independent Supported Living House for People with Early Onset Dementia: An Evaluation of A Dementia Care Initiative Project*, Newcastle: Dementia North. It was not possible to get a copy of this report in the time available.
26. [http://www.alz.org/professionals\\_and\\_researchers\\_early\\_onset.asp](http://www.alz.org/professionals_and_researchers_early_onset.asp)
27. Details of these sessions are reported in Logsdon et al, 2007: 11.
28. <http://www.alzheimers.org.nz/>
29. <http://www.alzheimers.org.nz/assets/Resources/Dementia-Manifesto.pdf>
30. [http://www.cogknow.eu/index.php?option=com\\_content&view=article&id=18&Itemid=3](http://www.cogknow.eu/index.php?option=com_content&view=article&id=18&Itemid=3)
31. [http://www.cogknow.eu/1/FP6\\_COGKNOW/blog/cogknow-ict-results.html](http://www.cogknow.eu/1/FP6_COGKNOW/blog/cogknow-ict-results.html)
32. For another Dutch study, see: Bakker et al, 2010.

## LITERATURE REVIEW REFERENCES

- Access Economics (2009a) *Making Choices: Future Dementia Care: Projections, Problems and Preferences* report for Alzheimer's Australia  
– <http://www.alzheimers.org.au/research-publications/access-economics-reports.aspx>
- Access Economics (2009b) *Keeping Dementia Front of Mind: Incidence and Prevalence* report for Alzheimer's Australia  
– <http://www.alzheimers.org.au/research-publications/access-economics-reports.aspx>
- AHMC (2006) *National Framework for Action on Dementia 2006-2020* Australian Health Ministers Conference – <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-nfad-0610.htm>
- AIHW (2006) *National evaluation of the Aged Care Innovative Pool Dementia Pilot: Final Report* Cat. No. AGE 48. Canberra: Australian Institute of Health and Welfare  
– <http://www.aihw.gov.au/publication-detail?id=6442467871>
- AIHW (2007) *Dementia in Australia: National Data Analysis and Development* AIHW Cat. No. AGE 53. Canberra: Australian Institute of Health and Welfare  
– <http://www.aihw.gov.au/publication-detail?id=6442467941>
- Alemán, M. W. and K. W. Helfrich (2010) 'Inheriting the narratives of dementia: a collaborative tale of a daughter and mother' *Journal of Family Communication* 10(1): 7-23
- Alford, M. and Alzheimer's Australia SA (2009) *CONNEXUS – Assisting Younger People with Dementia to Live Life to the Max* HammondCare, Sydney – <http://www.hammond.com.au/resource/Alford-Connexus,assistingpeoplewithyoungeronsetedemen%5BRead-Only%5D.pdf>
- Allen, J., J. R. Oyebode and J. Allen (2009) 'Having a father with young onset dementia: the impact on well-being of young people' *Dementia* 8(4): 455-80
- Alt Beatty Consulting (2007) *Appropriate HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern: Issues for Aboriginal and Torres Strait Islander People and People from Culturally and Linguistically Diverse Backgrounds* Alt Beatty Consulting for Community Care (Northern Beaches) Inc., commissioned by Community Care (Northern Beaches) Inc. on behalf of the NSW Department of Ageing, Disability & Home Care, Metro North Region – [http://www.adhc.nsw.gov.au/\\_\\_data/assets/file/0003/228162/AltBeatty\\_Dementia\\_Models\\_Report.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0003/228162/AltBeatty_Dementia_Models_Report.pdf)
- Alzheimer's Australia (2008) 'Submission to the National Health and Hospital Reform Commission' – [http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/215/\\$FILE/Submission%20215%20-%20Alzheimers%20Australia%20Submission.pdf](http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/215/$FILE/Submission%20215%20-%20Alzheimers%20Australia%20Submission.pdf)
- Alzheimer's Australia (2009a) 'Background paper: 2009 Summit on Younger Onset Dementia' – <http://www.alzheimers.org.au/services/2009-younger-onset-dementia-summit.aspx>
- Alzheimer's Australia (2009b) 'In our own words: A collection of very personal stories Younger Onset Dementia'  
– <http://www.alzheimers.org.au/common/files/NAT/20101027-Nat-YOD-InOurOwnWords.pdf>
- Alzheimer's Australia (2009c) 'National Consumer Summit Younger Onset Dementia: Not too young for dementia – Communiqué'  
– <http://www.alzheimers.org.au/services/2009-younger-onset-dementia-summit.aspx>

- Alzheimer's Australia (2010a) *Annual Report 2009 – 2010* – <http://www.alzheimers.org.au/common/files/NAT/20110120-Nat-AR-Alzheimers-Australia--annual-report-2009-2010.pdf>
- Alzheimer's Australia (2010b) 'The long and lonely road: insights into living with younger onset dementia' – <http://www.alzheimers.org.au/common/files/NAT/20101027-Nat-YOD-LongLonelyRoad-resource.pdf>
- Alzheimer's Australia SA Newsletter* August 2009  
– [www.alzheimers.org.au/common/files/SA/SA\\_Aug09News.pdf](http://www.alzheimers.org.au/common/files/SA/SA_Aug09News.pdf)
- Alzheimers New Zealand (2006) *The Dementia Booklet: Information for carers, family and whanau following a diagnosis of dementia*  
– <http://www.alzheimers.org.nz/assets/Resources/The-Dementia-Booklet.pdf>
- Alzheimers New Zealand (2010) *National Dementia Strategy 2010-2015* – <http://www.alzheimers.org.nz/assets/Reports/National-Dementia-Strategy-Alzheimers-New-Zealand.pdf>
- AlzNSW (2010) 'Addressing the stigma associated with dementia' Discussion Paper 2  
– <http://www.alzheimers.org.au/new-south-wales/research-nsw.aspx>
- Alzheimer's Society (UK) (2010) 'Younger people with dementia' Fact Sheet 440  
– [http://www.alzheimers.org.uk/site/scripts/document\\_pdf.php?documentID=164](http://www.alzheimers.org.uk/site/scripts/document_pdf.php?documentID=164)
- Anderson, D. (2007) 'Positive images of life with younger onset dementia', a presentation at the Alzheimer's Australia 2007 Conference, 'A journey of passion and purpose', Perth WA  
– <http://www.alzheimers.org.au/research-publications/alzheimers-australia-2007-conference.aspx>
- Arends, D. and S. Frick (2009) 'Without Warning(TM): lessons learned in the development and implementation of an early-onset Alzheimer's disease program'  
*Alzheimer's Care Today* 10(1): 31-8
- Arie, T. (2010) 'Book review: Losing Clive to Younger Onset Dementia'  
*International Journal of Geriatric Psychiatry* 25: 216
- Bakker, C., M. E. de Vugt, M. Vernooij-Dassen, D. van Vliet, F. R. J. Verhey and R. T. C. M. Koopmans (2010) 'Needs in early onset dementia: a qualitative case from the NeedYD study'  
*American Journal of Alzheimer's Disease & Other Dementias* 25(8): 634-40
- Baldwin, R. C. and M. Murray, eds (2003) *Younger People with Dementia: A Multidisciplinary Approach* London: Informa Healthcare
- Banerjee, S., R. Willis, D. Matthews, F. Contell, J. Chan and J. Murray (2007) 'Improving the quality of dementia care – an evaluation of the Croydon Memory Service Model' *International Journal of Geriatric Psychiatry* 22(8): 782-8
- Beattie, A. M., G. Daker-White, J. Gilliard and R. Means (2002) 'Younger people in dementia care: a review of service needs, service provision and models of good practice'  
*Aging & Mental Health* 6(3): 205-12
- Bentham, P. and J. La Fontaine (2007) 'Services for younger people with dementia'  
*Psychiatry* 7(2): 84-7
- Bevilacqua, J. (2011) 'Younger onset dementia the linking lives project, Victoria 2010', a presentation at the Alzheimer's Australia National Conference, Brisbane, 17-20 May  
– <http://www.alzheimers2011.com/>

- Brodady, H. (2010) 'Submission to the Productivity Commission'  
– [http://www.pc.gov.au/\\_data/assets/pdf\\_file/0012/99867/sub045.pdf](http://www.pc.gov.au/_data/assets/pdf_file/0012/99867/sub045.pdf)
- Brodady, H. and A. Cumming (2010) 'Dementia services in Australia' *International Journal of Geriatric Psychiatry* 25: 887-95
- Brown, A. and P. Roach (2010) 'My husband has young-onset dementia: A daughter, wife and mother's story' *Dementia* 9(4): 451-3
- Capus, J. (2005) 'The Kingston Dementia Café: The benefits of establishing an Alzheimer café for carers and people with dementia' *Dementia* 4(4): 588-91
- Casey, J. (2004) 'Early-onset dementia: getting out and about' *Journal of Dementia Care* 12: 12-13
- Challis, D., P. Clarkson, J. Hughes, H. Chester, S. Davies, C. Sutcliffe, C. Xie, M. Abendstern, R. Jasper, D. Jolley, B. Roe, S. Tucker and M. Wilberforce (2010) *Community Support Services for People with Dementia: The Relative Costs and Benefits of Specialist and Generic Domiciliary Care Services* Discussion Paper M245-3. Personal Social Services Research Unit, University of Manchester/Department of Health, UK Government – [http://www.dementia.dh.gov.uk/\\_library/Dementia\\_and\\_domiciliary\\_care\\_-\\_PSSRU\\_full\\_report.pdf](http://www.dementia.dh.gov.uk/_library/Dementia_and_domiciliary_care_-_PSSRU_full_report.pdf)
- Chaston, D. (2010) 'Younger adults with dementia: a strategy to promote awareness and transform perceptions' *Contemporary Nurse* 34(2): 221-9
- Chaston, D., N. Pollard and D. Jubb (2004) 'Young onset dementia: A case for real empowerment' *Journal of Dementia Care* 12(6): 24-6
- Chemali, Z., A. Withall and K.R. Daffner (2010) 'The plight of caring for young patients with frontotemporal dementia' *American Journal of Alzheimer's Disease & Other Dementias* 25(2):109-15
- Clare, L., G. J. Kinsella, R. Logsdon, C. Whitlatch and S. H. Zarit (2011) 'Building resilience in mild cognitive impairment and early-stage dementia: innovative approaches to intervention and outcome evaluation', in B. Resnick et al, eds *Resilience in Aging: Concepts, Research, and Outcomes* New York: Springer, pp.245-59
- Cox, S. and J. Keady (1999) 'Changing the mind-set: developing an agenda for change', in S. Cox and J. Keady, eds. *Younger People with Dementia: Planning, Practice and Development* London: Jessica Kingsley Publishers, 292-304
- Daniel, Karen (2004) 'Dementia and younger people' *Community Practitioners* 77(10): 369-70  
– <http://ace.glendevon-care.com/wp-content/uploads/2009/09/Dementia-and-Younger-People.pdf>
- Davies-Quarrell, V. (2004) 'The ACE approach: facilitating well-being for younger people with dementia and their families' *Signpost Journal* 9(2): 18-23  
– <http://ace.glendevon-care.com/wp-content/uploads/2009/09/ACE-Approach.pdf>
- Davies-Quarrell, V., A. Higgins, J. Higgins, P. Quinn, M. Quinn, G. Jones, L. Jones, A. Foy, V. Foy, R. Marland, P. Marland, A. Powell and J. Keady (2010) 'The ACE approach: promoting well-being and peer support for younger people with dementia' *The Journal of Mental Health Training, Education and Practice* 5(3): 41-50
- Davies-Quarrell, V., L. Jones and G. Jones (2007) 'Beyond respite: working in collaboration with younger people with dementia and their families in designing support services that "enhance life"', in J. Keady et al, eds, pp.40-7

- DHHA (2009) *Dementia Resource Guide* Australian Government Department of Health and Ageing – <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm>
- Dow, B., B. Haralambous, C. Hempton, S. Hunt and D. Calleja (2011) 'Evaluation of Alzheimer's Australia Vic Memory Lane Cafés' *International Psychogeriatrics* 23(2): 246-55
- Easton, A. (2009) 'The value of age appropriate services for those with younger onset dementia' The Ella Centre, a presentation at the Alzheimer's Australia 2009 Conference, 'The Power is Now: Moving on Dementia', Adelaide, 2-5 June  
<http://www.alzheimers.org.au/research-publications/alzheimers-australia-2009-conference.aspx>
- Easton, A. (2011) 'Are younger people with dementia and their carers being informed and supported appropriately at the time of diagnosis?' a presentation at the Alzheimer's Australia National Conference, Brisbane, 17-20 May – <http://www.alzheimers2011.com/>
- Freyne, A., N. Kidd, R. Coen and B. A. Lawlor (1999) 'Burden in carers of dementia patients: higher levels in carers of younger sufferers' *International Journal of Geriatric Psychiatry* 14(9):784-8
- Gelman, C. R. and C. Greer (2011) 'Young children in early-onset Alzheimer's disease families: research gaps and emerging service needs' *American Journal of Alzheimer's Disease & Other Dementias* 26(1): 29-35
- Grant, S. (2008) *A Qualitative Study of the Way in which Male Carers of Spouses with a Working Age Dementia Experience and Perceive Their Role* submitted to the University of Leicester, School of Psychology, in partial fulfilment of the Doctorate of Clinical Psychology  
– <https://lra.le.ac.uk/bitstream/2381/4143/1/2008GrantSDDClinPsy.pdf>
- Gregory, C. A. and S. Lough (2001) 'Practical issues in the management of early onset dementia', in Hodges, ed., pp.449-68
- Harris, P. B. and J. Keady (2009) 'Selfhood in younger onset dementia: transitions and testimonies' *Aging & Mental Health* 13(3): 437-44
- Harvey, R. J., P. K. Roques, N. C. Fox and M. N. Rossor (1998) 'CANDID – Counselling and Diagnosis in Dementia: a national telemedicine service supporting the care of younger patients with dementia' *International Journal of Geriatric Psychiatry* 13(6): 381-8
- Hayter, C. (2008) *Flexible and Responsive: Evaluation of the Younger Onset Dementia Social Support and Respite Program Final Report*, commissioned by The Ella Centre  
– <http://www.ella.org.au/LinkClick.aspx?fileticket=uJNNFRa%2FHKE%3D&tabid=86&mid=530>
- Hodges, J. R., ed. (2001) *Early-Onset Dementia: A multidisciplinary Approach* Oxford and New York: Oxford University Press
- Hodges, J. R., C. Gregory, C. McKinnon, W. Kelso, E. Mioshi and O. Piguet (2009) *Quality Dementia Care Younger Onset Dementia: A Practical Guide* commissioned by Alzheimer's Australia, prepared by Frontier, Frontotemporal Dementia Research Group, Prince of Wales Medical Research Institute, in association with Cognitive Disorders Clinic  
– <http://www.ftdrg.org/wp-content/uploads/yod-practical.pdf>
- Jolley, D. and E. Moniz-Cook (2009) 'Memory clinics in context' *Indian Journal of Psychiatry* 51(Suppl1): S70-S76
- Kaiser S. and P. Panygeres (2007) 'The psychosocial impact of young onset dementia on spouses' *American Journal of Alzheimer's Disease & Other Dementias* 21(6): 398-402

- Keady, J., C. L. Clarke and S. Page, eds (2007) *Partnerships in Community Mental Health Nursing and Dementia Care: Practice and Perspectives* Maidenhead: Open University Press
- Kelley, B. J., B. F. Boeve and K. A. Josephs (2009) 'Rapidly progressive young-onset dementia' *Cognitive and Behavioral Neurology* 22(1): 22-7
- Koedam, E. L. G. E., V. Lauffer, A. E. van der Vlies, W. M. van der Flier, P. Scheltens and Y. A. L. Pijnenburg (2010) 'Early-versus late-onset Alzheimer's disease: more than age alone' *Journal of Alzheimer's Disease* 19(4): 1401-8
- La Fontaine, J. (2004) 'Providing person-centred care for younger people with dementia' *Journal of Dementia Care* 12: 18-20
- Logsdon, R. G., S. M. McCurry and L. Teri (2007) 'Time-limited support groups for individuals with early stage dementia and their care partners' *Clinical Gerontologist* 30(): 5-19
- Logsdon, R.G., K.C. Pike, S.M. McCurry, P. Hunter, J. Maher, L. Snyder and L. Teri (2010) 'Early-stage memory loss support groups: outcomes from a randomized controlled clinical trial' *Journal of Gerontology: Psychological Sciences*, 65B(6): 691-7
- Luscombe, G., H. Brodaty and S. Freeth (1998) 'Younger people with dementia: diagnostic issues, effects on carers and use of services' *International Journal of Geriatric Psychiatry* 13: 323-30
- Maslow, K. (2006) *Early Onset Dementia: A National Challenge, A Future Crisis* Washington, DC: Alzheimer's Association – [http://www.alz.org/national/documents/report\\_earlyonset\\_full.pdf](http://www.alz.org/national/documents/report_earlyonset_full.pdf)
- Mather, L. (2006) 'Memory Lane Café: follow-up support for people with early stage dementia and their families and carers' *Dementia* 5(2): 290-3
- McLean, A. (2009) 'Younger onset: the move towards specialist services and support' Alzheimer's Australia WA, a presentation at the Alzheimer's Australia 2009 Conference, 'The Power is Now: Moving on Dementia', Adelaide, 2-5 June – <http://www.alzheimers.org.au/research-publications/alzheimers-australia-2009-conference.aspx>
- Mendez, M. F. (2006) 'The accurate diagnosis of early-onset dementia' *The International Journal of Psychiatry in Medicine* 36(4): 401-12
- Merl, H. (2010) 'Hunter Dementia Interagency Younger Onset Dementia Working Group' *HOPE* Issue 5, July: 2-3 – [http://www.alzheimers.org.au/common/files/NAT/20100600\\_Nat\\_NSL\\_HOPE5July10.pdf](http://www.alzheimers.org.au/common/files/NAT/20100600_Nat_NSL_HOPE5July10.pdf)
- Milne, A. (2010) 'The "D" word: reflections on the relationship between stigma, discrimination and dementia' *Journal of Mental Health* 19(3): 227-33
- Mocellin, R., A. Scholes and D. Velakoulis (2008) *Quality Dementia Care: Understanding Younger Onset Dementia* Melbourne Neuropsychiatry Centre, Royal Melbourne Hospital – [http://www.alzheimers.org.au/common/files/NAT/20080400\\_Nat\\_QDC\\_QDC4UnderstandYOD.pdf](http://www.alzheimers.org.au/common/files/NAT/20080400_Nat_QDC_QDC4UnderstandYOD.pdf)
- Moore, K. and E. Renehan (2011) *Evaluation of the Linking Lives Pilot: Supporting younger people with dementia* Draft report, National Ageing Research Institute, For Alzheimer's Australia Victoria
- Mulvenna, M., F. Meiland, F. Moelaert, R. Castellot, J. Wallace, C. Nugent, S. Martin, R. Davies and S. Devlin (2007) 'COGKNOW: translating research innovation into products and services' University of Ulster – [http://eprints.ulster.ac.uk/11520/1/eChallenges\\_ref\\_75\\_doc\\_3154.pdf](http://eprints.ulster.ac.uk/11520/1/eChallenges_ref_75_doc_3154.pdf)



- Nicolaou, P. L. S. J. Egan, N. Gasson and R. T. Kane (2010) 'Identifying needs, burden, and distress of carers of people with Frontotemporal dementia compared to Alzheimer's disease' *Dementia* 9(2): 215-35
- Nomura, M., K. Makimoto, M. Kato, T. Shiba, C. Matsuura, K. Shigenobu, T. Ishikawa, N. Matsumoto and M. Ikeda (2009) 'Empowering older people with early dementia and family caregivers: a participatory action research study' *International Journal of Nursing Studies* 46(4): 431-41
- NSW Health (2011) *The NSW Dementia Services Framework 2010-2015*  
– [http://www.health.nsw.gov.au/policies/gl/2011/GL2011\\_004.html](http://www.health.nsw.gov.au/policies/gl/2011/GL2011_004.html)
- Page, S. and J. Keady (2010) 'Sharing stories: a meta-ethnographic analysis of 12 autobiographies written by people with dementia between 1989 and 2007' *Ageing & Society* 30: 511-26
- Panegyres, P. K. and K. Frencham (2007) 'Course and causes of suspected dementia in young adults: a longitudinal study' *American Journal of Alzheimer's Disease & Other Dementias* 22(1): 48-
- Parsons-Suhl, K., M. E. Johnson, J. J. McCann and S. Solberg (2008) 'Losing one's memory in early Alzheimer's disease' *Qualitative Health Research* 18(1): 31-42
- Phillips, J., D. Pond and A. Shell (2010) *Quality Dementia Care Standards: No Time Like the Present: The Importance of a Timely Dementia Diagnosis* Alzheimer's Australia  
– [http://www.aag.asn.au/filelib/No\\_time\\_like\\_the\\_present.pdf](http://www.aag.asn.au/filelib/No_time_like_the_present.pdf)
- Piguet, O., M. Hornberger, E. Mioshi and J. R. Hodges (2011) 'Behavioural-variant frontotemporal dementia: diagnosis, clinical staging, and management' *Lancet Neurology* 10(2): 162-72
- Queensland Health (2010) Queensland Health Dementia Framework 2010-2014  
– [http://www.health.qld.gov.au/cpic/documents/dementia\\_framework.pdf](http://www.health.qld.gov.au/cpic/documents/dementia_framework.pdf)
- Ramshaw, T. (2007) 'Caring for a younger person with dementia', a presentation at the Alzheimer's Australia 2007 Conference, 'A journey of passion and purpose', Perth WA  
– <http://www.alzheimers.org.au/research-publications/alzheimers-australia-2007-conference.aspx>
- Reed, J., C. L. Clarke, C. Cantley and D. Stanley (2007) 'Younger people with dementia: emerging needs, multi-disciplinarity and the CMHN', in J. Keady et al, eds, pp.152-68
- Rinfrette, E. S. (2010) *Impact on Informal Caregivers of Caring for those with Early Onset Dementia* Ph.D., State University of New York at Buffalo – <http://gradworks.umi.com/34/07/3407981.html>
- Roach, P., J. Keady, P. Bee and K. Hope (2009) 'Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice' *Reviews in Clinical Gerontology* 18: 165-74
- Rose, K., F. Yu, F. J. L. Palmer, N. E. Richeson and S. C. Burgener (2010) 'Care considerations for persons with early-onset dementia: a case studies analysis' *Alzheimer's Care Today* 11(3): 151-61
- Rosness, T. A., P. K. Haugen and K. Engedal (2008) 'Support to family carers of patients with frontotemporal dementia' *Aging & Mental Health* 12(4): 462-6
- Rosness, T. A., M. Mjørud and K. Engedal (2011) 'Quality of life and depression in carers of patients with early onset dementia' *Aging & Mental Health* 15(3): 299-306
- Rossor, M. N., N. C. Fox, C. J. Mummery, J. M. Schott, and J. D. Warren (2010) 'The diagnosis of young-onset dementia' *Lancet Neurology* 9(8): 793-806



- Royal College of Psychiatrists (2005) 'Services for younger people with Alzheimer's disease and other dementias', a policy paper prepared by the Faculty of Old Age Psychiatry, Royal College of Psychiatrists, in conjunction with the Alzheimer's Society – <http://www.rcpsych.ac.uk/pdf/servicesforyoung.pdf>
- SA Government (2009) *South Australia's Dementia Action Plan 2009-2012: Facing the Challenges Together* Office for the Ageing, Department for Families and Communities – <http://www.sa.gov.au/>
- Shinagawa, S., M. Ikeda, Y. Toyota, T. Matsumoto, N. Matsumoto, T. Mori, T. Ishikawa, R. Fukuhara, K. Komori, K. Hokoishi and Hirotaka Tanabe (2007) 'Frequency and clinical characteristics of early-onset dementia in consecutive patients in a memory clinic' *Dementia and Geriatric Cognitive Disorders* 24:42-7
- Silverstein, N. M., C. M. Wong and K. E. Brueck (2010) 'Adult day health care for participants with Alzheimer's disease' *American Journal of Alzheimer's Disease & Other Dementias* 25(3): 276-83
- Snyder, L. (2007) 'The experiences and needs of people with early-stage dementia', in Carole B. Cox, ed. (2007) *Dementia and Social Work in Practice: Research and Interventions* New York: Springer, pp.93-110
- Stalker, K., J. Davidson, C. MacDonald and A. Innes (2005) *A Scoping Study on the Needs of, and Services to, Younger Disabled People including those with Early Onset Dementia in Scotland* final report for The Analytical Services Division, Scottish Executive Health Department. Social Work Research Centre, Department of Applied Social Science, University of Stirling
- Szymczynska, P., A. Innes, A. Mason and C. Stark (2011) 'A review of diagnostic process and postdiagnostic support for people with dementia in rural areas' *Journal of Primary Care & Community Health* published online 4 May DOI: 10.1177/2150131911404705
- Toseland, R. W. and H. Larkin (2011) 'Developing and leading telephone groups' *Social Work with Groups* 34(1): 21-34
- Trela, M. J. (2009) *Using Memory Books to Enhance Sense of Self* a Senior Honors Thesis, The Ohio State University – [https://kb.osu.edu/dspace/bitstream/handle/1811/44566/Trela\\_Margaret\\_Thesis.pdf?sequence=1](https://kb.osu.edu/dspace/bitstream/handle/1811/44566/Trela_Margaret_Thesis.pdf?sequence=1)
- Tyson, M. (2007) *Exploring the Needs of Younger People with Dementia in Australia* a report to Australian Government Department of Health and Ageing, Alzheimer's Australia – <http://www.alzheimers.org.au/common/files/NAT/20101027-Nat-YOD-Exploring-needs-Australia.pdf>
- van Vliet, D., C. Bakker, R. T. C. M. Koopmans, M. J. F. J. Vernooij-Dassen, F. R. J. Verhey and M. E. de Vugt (2010a) 'Research protocol of the NeedYD-study (Needs in Young onset Dementia): a prospective cohort study on the needs and course of early onset dementia' *BMC Geriatrics* 10: 13(8 pages)
- van Vliet, D., M. E. de Vugt, C. Bakker, R. T. C. M. Koopmans and F. R. J. Verhey (2010b) 'Impact of early onset dementia on caregivers: a review' *International Journal of Geriatric Psychiatry* 25(11): 1091-100
- Victorian Government (2004) *Dementia Framework for Victoria, 2005 and Beyond Consultation Paper* Victorian Dementia Reference Group, Aged Care Branch, Department of Human Services – [http://www.health.vic.gov.au/agedcare/downloads/dementia\\_framework.pdf](http://www.health.vic.gov.au/agedcare/downloads/dementia_framework.pdf)

- Victorian Government (2006) *Pathways to the Future, 2006 and Beyond: Dementia Framework for Victoria Implementation Plan 2006-08*  
– [http://www.health.vic.gov.au/agedcare/downloads/dementia\\_framework\\_implemtn.pdf](http://www.health.vic.gov.au/agedcare/downloads/dementia_framework_implemtn.pdf)
- WA Department of Health (2006) *The Dementia Action Plan for Western Australia 2003-2006* –  
[http://www.health.wa.gov.au/publications/documents/Dementia\\_web.pdf](http://www.health.wa.gov.au/publications/documents/Dementia_web.pdf)
- Werner, P., I. Stein-Shvachman and A. D. Korczyn (2009) 'Early onset dementia: clinical and social aspects' *International Psychogeriatrics* 21(4): 631-6
- Willis, R., J. Chan, J. Murray, D. Matthews and S. Banerjee (2009) 'People with dementia and their family carers' satisfaction with a memory service: a qualitative evaluation generating quality indicators for dementia care' *Journal of Mental Health* 18(1): 26-37
- Wimo, A. and M. Prince (2010) *World Alzheimer Report 2010: The Global Economic Impact of Dementia* Alzheimer's Disease International – <http://www.alz.co.uk/research/files/WorldAlzheimerReport2010.pdf>
- Withall, A. and B. Draper (2009) 'What is the burden of younger onset dementia in Australia?' *International Psychogeriatrics* 21 (Suppl.2): S26-7
- Withall, A., V. Traynor and S. Bromhead (2011) 'Younger onset dementia: understanding the story of survival', a presentation at the Alzheimer's Australia National Conference, Brisbane, 17-20 May – <http://www.alzheimers2011.com/>
- Woodburn, K. and E. Johnstone (1999) 'Measuring the decline of a population of people with early-onset dementia in Lothian, Scotland' *International Journal of Geriatric Psychiatry* 14: 355-61
- Zimmermann, M. (2010) 'Dementia in life writing: our health care system in the words of the sufferer' *Neurological Sciences* 123: (6 pages)