

Service and Support Requirements for People with Younger Onset Dementia and their Families

Literature Review

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Review for: Alzheimer's Australia NSW

Social Policy Research Centre
University of New South Wales
August 2011



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ISSN: 1446-4179
ISBN:

Published: August 2011

The views expressed in this publication do not represent any official position on the part of the Social Policy Research Centre, but the views of the individual authors.

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Suggested Citation

Thmpson D., (2011), 'Service and Support Requirements for People with Younger Onset Dementia and their Families, Literature Review', prepared for Alzheimer's Australia NSW, September 2011.

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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.

Section 2 Numbers. YOD is defined as dementia which occurs before the age of 65 years.¹ 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.

Section 3 Policy context in Australia. 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.

Section 4 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

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.

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.

Section 5 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.

Section 6 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 WarningTM’, 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.

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.

1 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,² 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.

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.

2 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)³ 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.

Table 1 Projected number of younger people with dementia, 2003 to 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

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).

3. <http://www.health.gov.au/internet/main/publishing.nsf/Content/Dementia-1>

3 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.⁴ 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

4. <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr08-je-je172.htm>

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).

4 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,⁵ 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 WarningTM – 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.

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.

Alzheimer's Australia's website,⁶ 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

6. <http://www.alzheimers.org.au/services/further-reading-and-resources.aspx>

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.⁷

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;

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>

- 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 had 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).⁸

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.

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.

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 Vic'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.⁹

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:

⁹. See also: Armstrong, 2003; Allen et al, 2009; Chaston, 2010.

- *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.¹⁰ 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

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.

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.¹¹ 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. Piguet 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

11. Kaiser and Panegyres, 2007; Rosness et al, 2008; McLean, 2009; Withall and Draper, 2009; Rinfrette, 2010.

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).

5 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 Hammond Care 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.¹²

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

12. Adapted from the Alzheimer’s Australia SA website – <http://www.alzheimers.org.au/south-australia/living-with-memory-loss-program-sa.aspx>

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:¹³

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:

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.

- 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)¹⁴ Program, 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 behaviors 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).¹⁵

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

14. <http://www.ella.org.au/SERVICES/RespiteandRecreation/YoungerOnsetDementiaSocialSupport/tabid/72/Default.aspx>

15. <http://www.hammond.com.au/pages/default.asp?pid=259#>

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.¹⁶

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.¹⁷

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 Vic 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).

16. <http://www.health.vic.gov.au/subacute/cdams.htm>

17. Alzheimer Café UK – <http://www.alzheimercafe.co.uk/home.htm>

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:

- an 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;
- a 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;
- a Links Café, similar to Alzheimer's Australia Vic's Memory Lane Café), which provides opportunities for informal semi-structured information-sharing and socialisation; and

- 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 had 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;
 - a 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:

18. <http://www.alzheimers.org.au/research-publications/hope-newsletter.aspx>

- a 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;
- a 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;
- a 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.¹⁹

19. <http://dementia.uow.edu.au/understandingdementiacare/index.htmlb>

6 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.²⁰

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)

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.

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 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.²¹

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.

²¹. <http://www.youngdementiauk.org/>

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 that 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*²²

The Croydon Memory Service (CMS) 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

22. <http://www.communitycare.co.uk/Articles/2008/07/29/108997/croydons-memory-service-leads-the-way-on-dementia.htm>

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.²³

'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.²⁴

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 service²⁵ found that the key elements of good care were the use of observation and negotiation, responses

23. <http://dementia.ion.ucl.ac.uk/candid.html>

24. 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.

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.²⁶

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 program²⁷ 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

26. http://www.alz.org/professionals_and_researchers_early_onset.asp

27. Details of these sessions are reported in Logsdon et al, 2007: 11.

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 WarningTM' 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 website²⁸ 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*.²⁹

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

COGKNOW³⁰ was originally an eInclusion 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

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

does not even come with a keyboard) with the COGKNOW application maintained on top of everything so nothing else is visible to the user.³¹

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.³²

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

31. http://www.cogknow.eu/1/FP6_COGKNOW/blog/cogknow-ict-results.html

32. For another Dutch study, see: Bakker et al, 2010.

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.

7 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.

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