Chapter 7
Younger Onset Dementia

> I think for younger people in particular there is a sense of loss. There is a sense of loss with dementia anyway but for younger people it is a little more acute because they are seen as not having had a bite at living their life yet. That sense of loss for their immediate family is often not addressed.
>
> – Dr Morkham, Young People in Nursing Homes National Alliance

7.1 The issues faced by people with Younger Onset Dementia (YOD) have many parallels with those faced by older people with dementia. Issues around staff training, the use of restraints, assistance for carers, and other matters previously discussed in this report all hold true for people with YOD. The purpose of this chapter is to highlight some of the unique challenges faced by people with YOD.

7.2 Although dementia is often seen as a disease of the elderly, an estimated 23 900 Australians under the aged of 65 suffer from YOD. YOD typically refers to the onset of dementia before the aged of 65.[1] The progression of the disease is reported to be faster in YOD than in other forms of dementia.[2] It was reported by the Royal Australia and New Zealand College of Psychiatrists (RANZCP) that:

> Younger onset dementia has a more diverse range of causes than later onset dementia. Alzheimer's disease is less common. Frontotemporal dementia is more frequent, and 'secondary dementias' due to issues such as alcohol, traumatic brain injury, HIV, multiple sclerosis and a large range of metabolic, infection, neoplastic and autoimmune disorders. Current epidemiology regarding the prevalence of younger onset dementia from all causes is poor.[3]

7.3 The Australian Institute of Health and Welfare (AIHW) reported that over seventy per cent of those with dementia under the age of 65 were profoundly limited in core activities and needed substantial support.[4] Around 6800 young Australians presently occupy around five per cent of residential aged care beds nationally with the majority of these being classified as high dependency.[5] Behavioural and Psychological Symptoms of Dementia (BPSD) is also more prevalent in YOD.[6]

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1 Young People in Nursing Homes National Alliance, *Submission 48*, p. 4.

2 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 19.

3 *Submission 49*, p. 7.

4 Young People in Nursing Homes National Alliance, *Submission 48*, p. 5.

5 Young People in Nursing Homes National Alliance, *Submission 48*, p. 4.

6 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 7.

7.4 Due to both a lack of understanding of dementia and the prevalent notion that it is an ailment of the aged, diagnosing YOD can be slower than ideal.[7] The long process and difficulties involved in a diagnosis of YOD was related to the committee:

> There is still a considerable gap in terms of younger people getting access to diagnosis and into services. It is similar to older onset but has a few key differences. If you are a younger person who presents with symptoms that may be related to dementia, we try and eliminate every other possible cause first. That makes sense but it complicates the journey for those individuals. It is not uncommon for people with YOD to have unusual forms of dementia as well as the garden variety, for want of a better phrase, so it can be more difficult to determine what the actual diagnosis is. But a key problem is that we do not think people under 65 will have dementia.[8]

Interaction between Acute-, Disability-, and Aged-care

7.5 Due to their age and diagnosis, YOD tend to fall between the responsibilities of the aged- and disability-care sectors. The Young People in Nursing Homes National Alliance (YPINH) expressed their frustration at the lack of coordination between the aged-, community- and disability-care sectors:

> Young people with dementia continue to enter an endless merry-go-round of bureaucratic avoidance where various arms of the service system not only diminish their responsibility for the care and support these young people require, but actively shift their responsibility to other sectors.[9]

7.6 National Disability Services (NDS) similarly noted the impact on service delivery created by the present administrative demarcations:

> At present the needs of this group we believe are not well met, in part because they do not fit neatly into any of the existing service systems: the disability system, the health system, the mental health system or indeed the aged-care system.[10]

7.7 The interaction between State, Territory and Commonwealth systems can cause additional problems for people with YOD. The committee was informed that before a person under 65 can receive a Commonwealth Aged Care Assessment Team (ACAT) assessment (in Queensland, Victoria and South Australia) they need a letter from the State disability services 'stating that there is no suitable disability support for this person. Obtaining this letter can be a complicated, lengthy process.'[11] The delays in gaining access to ACAT and the services they can provide, at a time when people are 'in need of urgent assistance', may contribute to people being admitted into acute

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7 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 7.

8 Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 32.

9 *Submission 48*, pp 5–6.

10 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

11 Alzheimer's Australia, *Submission 42.2, p. 3.*

care or a residential aged care facility (RACF).[12] The committee heard evidence that ACAT often do not see YOD as part of their responsibilities and refer people back to the disability sector.[13] Such are the difficulties of accessing services, it was reported to the committee that some people end up homeless due to a lack of support.[14]

7.8 The committee heard that providers of acute care (hospitals, mainly) are often the first port of call when a crisis develops in the health of a person with YOD. Once a patient's health has stabilised or is being managed appropriately, the acute care provider will look to discharge the patient. If the person with YOD has informal care in the community they will return there. If community care is not available, the acute care provider will look to discharge the patient either to the disability- or aged-care system.[15]

7.9 Neither the disability- nor aged-care sectors appear to be appropriately equipped to deal with YOD. It was reported that:

> Disability Services' funding limitations and its design of funding rules thus means that the YOD group – like those with progressive neurological conditions more generally – continues to struggle to access increasing levels of service in a timely manner.[16]

7.10 In addition to accessing the available care, it was reported that the disability sector more generally does not have the expertise to deal with YOD.[17] When the limits of this assistance are reached, the person is often sent back to acute care.[18] The other 'exit' from acute care is to the aged-care sector. Evidence provided by YPINH highlights the problems associated with this outcome:

> Resource for a very different cohort of frail older Australians in the end stages of life, aged care services are ill prepared to manage the different and dynamic health and other supports needed by [young people in nursing homes] generally and individuals with YOD especially. While their aged dementia services provide some assistance, these services are not geared to the different requirements of those with YOD.
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> …

12 Alzheimer's Australia, *Submission 42.2, p. 3.*

13 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 9; Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 27; Mercy Health, *Submission 29*, p. 4; Consumers Health Forum of Australia, *Submission 35*, p. 2.

14 Royal District Nursing Service, *Submission 24*, p. 4.

15 Young People in Nursing Homes National Alliance, *Submission 48*, p. 7.

16 Young People in Nursing Homes National Alliance, *Submission 48*, p. 7.

17 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

18 Young People in Nursing Homes National Alliance, *Submission 48*, p. 7.

> The result is often the start of a revolving door of hospital admissions involving discharge from acute care to aged care to acute care again to aged care again and so on, none of which provides an enduring solution, but consumes significant health and aged care resources in the process as it fails.[19]

7.11 The acute care sector creates a trio of administrative divisions unable to meet the needs of YOD:

> For the acute care service, it is a disaster. Already struggling with inadequate funding, sky rocketing demand for health services and the escalating cost of providing health care, hospitals are now increasingly facing provision of long term accommodation to growing numbers of young people they are unable to discharge to other services.[20]

7.12 As evidenced by the above discussion, each sector holds a portion of the expertise required to address the needs of YOD: they need to be brought together.[21] In the opinion of the Productivity Commission and some service providers, the aged-care sector will remain the key provider of services to this group of people.[22]

Caring for people with younger onset dementia

7.13 It was reported to the committee that there is a general lack of appropriate services for people with YOD, with YPINH reporting:

> …a distinct lack of specialised services for this group remains and the dedicated accommodation, clinical or other services these young people require are nowhere to be found. Even services that, while not necessarily YOD specific, are still capable of providing targeted responses are extremely rare.[23]

7.14 Mercy Health highlighted that community care is most appropriate for YOD:

> For those with YOD, care provided in the community setting is most appropriate (ideally consumer directed care). This allows them to remain with their family, and eliminates the additional stress to themselves and their family involved in moving into a residential aged care facility.[24]

7.15 The carers of YOD tend to be younger including working carers and children living with the person.[25] Many families have to meet a significant financial burden from providing consumables such as incontinence aids, as well as deal with the financial costs associated with foregone labour and one member of the family out of

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19 *Submission 48*, p. 8.

20 Young People in Nursing Homes National Alliance, *Submission 48*, p. 9.

21 Young People in Nursing Homes National Alliance, *Submission 48*, p. 9.

22 Productivity Commission, *Caring for Older Australians*, Canberra, 2011, p. 46; HammondCare, *Submission 25*, p. 6.

23 *Submission 48*, p. 5.

24 *Submission 29*, p. 4.

25 Helping Hand, *Submission 11*, p. 1.

the workforce.[26] The RANZCP argued that more supports need to be available for carers of people with YOD, noting that: 'carer depression and other psychological issues are common in this group of people'.[27]

7.16 Social and support programs for people with dementia are typically targeted at the elderly. People living with YOD may feel isolated as 'they commonly know few others with the same condition and often cope primarily within their own resources'.[28] The committee heard that 'there really was not anything around for younger people'.[29] YPINH and Mercy Health reported that the lack of age-appropriate care is a problem across Australia.[30] While there is no reason why older and younger people should not engage in activities together[31], there does appear to be a significant shortfall in the provision of social activities that specifically cater to YOD.

7.17 Younger people with dementia are also physically different from older sufferers. The committee heard that YOD experiencing BPSD:

> …are not be able to be managed at home because of either violent outbursts or challenging physical abilities where people are younger and stronger, and that can cause real problems for families.[32]

7.18 When BPSD manifests, families report difficulties organising income support and 'respite options are almost non-existent'.[33] The committee was given a glimpse of the challenges of providing care at home for someone experiencing BPSD:

> For the whole week he was up 24 hours a day – all week. He dozed on the chairs but would not go to bed. He wanted to break out of the house and break windows, and he jumped on me and dived on me. By that stage he had gone for my neck and I knew that I just could not have him back home, and there was nowhere else for him to go except into an aged-care facility.[34]

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26 Helping Hand, *Submission 11*, p. 1; Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 11.

27 *Submission 49*, p. 8.

28 Mercy Health, *Submission 29*, p. 5.

29 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 22.

30 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 32; Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 27.

31 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 37.

32 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 19.

33 National Disability Services, *Submission 43*, p. 3.

34 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 21.

7.19 Evidence provided by Alzheimer's Australia highlighted that access to respite care is often limited as service providers are reluctant to take on the care of people who are 'fitter and younger than other residents'.[35]

7.20 HammondCare similarly highlighted the challenges faced by YOD in relation to respite care:

> What we have found in that service is that the [respite] service options for people with younger onset dementia are not adequate to meet the needs that people have. There is a large gap in terms of what is provided out in the community for people with younger onset dementia. It is a different set of needs to those of people who are older. Respite services in particular are different; their family members still need to be in full-time work because there are still mortgages to pay. The person with dementia does not need an hour of personal care in the morning and an hour of personal care in the evening—the person needs eight hours during the day when their spouse is going to work and making sure that the world goes around for the family. Those services are not adequate at the moment.[36]

7.21 Carers Australia noted that day care is particularly important for carers of YOD, but the hours of operation do not take into account carers having a full time job or significant other responsibilities such as children.[37]

7.22 As well as different hours, people with YOD have different requirements for respite care that are not presently met:

> Younger people and their carers require different types of respite services than older people and their carers do. They are at greater risk of boredom and isolation and need activities to keep the connected and motivated. For instance, they may be in the early stages of a relationship and what to have time alone over a weekend with their partner.[38]

7.23 The majority of people with YOD receive services through the aged-care system.[39] The residential care they are offered however—designed as it is to cater for the elderly—is different from what they need:

> …people need to be given the opportunity to continue to engage in normal life in a broader sense, and have more personal freedoms – which also comes with more personal risks.[40]

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35 *Submission 42*, p. 7.

36 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.

37 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

38 Carers Australia, *Submission 46*, pp 12–13.

39 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

40 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 14.

7.24 The committee also heard that it is more expensive to provide accommodation infrastructure for YOD:

> Younger people have different accommodation requirements for example to providers to adequately accommodate younger people there is a significant capital cost, younger people require greater access to open space, these people often need to move around freely.[41]

7.25 Families with people with YOD in residential care still want that time to be a quality life where they can do things together they would have done at home.[42] It was suggested to the committee that YOD should be provided with areas that provide 'opportunities for families to come together if they are not staying there all the time'.[43]

7.26 The institutionalisation of people with YOD with residents who are 20 or 30 years older, with no common interests, may exacerbate their BPSD.[44] It was explained to the committee that residential aged-care facilities (RACFs) are not equipped to deal with YOD[45]:

> Younger people with young onset dementia present a particular conundrum for aged-care providers, who, with the best intend and best will in the world, are not resources for them. Younger people are bigger, heavier and more demanding.[46]

7.27 The evidence received by the committee highlighted that the residential care model as it exists for dementia, even what is considered best practice, may not be suitable for YOD exhibiting BPSD:

> Even residential care services dedicated to younger people with dementia may not be appropriate for residents if they are based on existing models. HammondCare began pioneering a 15-place (14 permanent beds and one respite) cottage for young people with dementia. However, this cottage model, based on our cottages for older people with dementia, is not suitable for people with very severe and persistent BPSD.
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> HammondCare is currently reviewing a smaller house-based model that would cater for five to six younger people with dementia. As part of this review, we are exploring the possibility of adapting a number of group living models used to support people with intellectual disabilities.[47]

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41 Helping Hand, *Submission 11*, p. 1.

42 Mercy Health, *Submission 29*, p. 5.

43 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 37.

44 BlueCare, *Submission 32*, p. 3.

45 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 53.

46 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 33.

47 HammondCare, *Submission 25*, p. 5.

7.28 Due to facilities not being appropriately staffed or equipped to deal with YOD, chemical and physical restraints are more likely to be used as YOD 'are more active and can be physically strong.'[48] There is also the potential for YOD to make other residents in RACFs feel uncomfortable.[49]

Recommendation 17

7.29 The committee recommends that a review of the adequacy of respite facilities for Younger Onset Dementia patients be carried out urgently.

Recommendation 18

7.30 The committee recommends that the Commonwealth fund the development of a pilot Younger Onset Dementia specific respite facility at either the Barwon or Hunter area National Disability Insurance Scheme trial sites.

Improving care for people with younger onset dementia

7.31 HammondCare recommended two macro-level changes to caring for younger people:

> So I think one of the things we need to look at in the younger onset context is being able to make sure that, firstly, the services are available and appropriate to their needs and that, secondly, we are able to respond to those needs.[50]

7.32 There is a need to ensure there are services available, and that those services must proactively manage YOD, rather than waiting until a crisis point is reached. Professor Draper emphasised that there is a need to address the shortfalls across community-, acute-, and residential-care as services will be provided by all of them.[51]

7.33 As part of the Commonwealth's *Living Longer, Living Better* reforms Younger Onset Dementia Key Workers (key workers) are being trialled in order to improve coordination of services for people with YOD. As of 18 February 2014 there are 40 key workers operating nationally.[52] The key worker pilot will be an important step in this direction provided that they can achieve their stated objectives:

> The younger onset dementia key worker acts as a primary point of contact for people with younger onset dementia, their families and carers. The key worker provides information, support, counselling, advice and helps consumers effectively engage with service appropriate to their individual needs.

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48 Alzheimer's Australia, *Submission 42, p. 8.*

49 Ms Small, General Manager of Operations, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 7.

50 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 19.

51 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 53.

52 Department of Social Services, *2013–14 Supplementary Estimates*, answer to question on notice (written): 433, (received 18 February 2014).

> This program ensures that the needs of people with younger onset dementia are being met in the community by increasing awareness and education, building capacity in the disability, aged care, community and residential care sectors and improving coordination of services across agencies. Key workers identify and address gaps in services and build capacity through consultation, networking and collaboration with service providers and consumers.[53]

7.34 Although there are doubtless benefits in providing information, support, counselling and advice, it is unclear how many of the service gaps identified by the contributors to this inquiry can be met through the better coordination of services when those services do not appear to exist. Whereas dementia services for older Australians may be insufficient, especially for people with BPSD, they seem to be non-existent for YOD.

7.35 Brightwater Care Group highlighted a model of support they have developed to provide services to people with Huntington's disease that they suggested may be applied to YOD:

> Brightwater has provided support for those families from point of diagnosis. They were working quite closely with the Huntington's Disease Association and with the neurosciences to almost providing a case management model identifying where the person is on their journey, when there are challenges in the family in providing support, and looking at education, and we carry that through when those people require residential accommodation and support. We certainly provide education and training to staff in supporting those people with Huntington's disease and we see that potentially that could be a good model for supporting people with younger onset dementia.[54]

7.36 Mercy Health reported they are working on a similar YOD-specific initiative involving their organisation, Alzheimer's Australia Victoria and the Lovell Foundation. As they explain: 'This consortium has been formed with the intent of developing a leading edge service for those living with younger onset dementia'.[55] These approaches appear to have many parallels between the key worker pilot, with the added benefit that the service provider has the ability to improve staff training and minimise disruption for the person with the illness as there is greater continuity of care. The committee notes that this model appears highly applicable to all dementia sufferers.

7.37 Many stakeholders appeared positive that *National Disability Insurance Scheme* (NDIS) could facilitate improved access to

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53 Alzheimer's Australia, *National Younger Onset Dementia Key Worker Program*, http://www.fightdementia.org.au/services/younger-onset-dementia-key-worker-program.aspx, (accessed: 19 February 2013).

54 Ms Hudson, Wellbeing and Dementia Support Coordinator, Brightwater Care Group, *Committee Hansard*, 14 February 2014, p. 33.

55 *Submission 29*, p. 2.

YOD specific services as the market begins to cater those needs.[56] It will take time for the necessary skills to develop in the disability sector. As NDS explained:

> The disability service system is at present not well equipped to support this group of people. Although there is experience in supporting people, for example, with Down syndrome who acquire dementia and early-onset dementia is more probable among people with Down syndrome than the general population, there is not wide experience within the sector of supporting people with dementia.[57]

7.38 There is capacity under NDIS to purchase expertise from the aged-care sector where much of the necessary expertise resides.[58] Mercy Health noted that consumer directed care will improve YOD care:

> Consumer Directed Care will provide significant benefits for those with YOD and their family. Support received in the home may not be direct care for the consumer, but be the provision of home support or respite which allows the spouse to leave the house to shop, or attend children's sporting events. For the children of those with YOD, counselling could be provided.[59]

7.39 NDS cautioned however that although participants in NDIS will have greater choice over the service they could receive, organisations may not wish to provide services to this group; as is often the case presently.[60]

7.40 As YOD cross over the boundaries of several areas, advanced care planning is of crucial importance to ensure that immediate and future needs can be prepared for.[61] It was noted by the Office of the Public Advocate Queensland that: 'In addition to empowering the person, this may also be a cost-effective way to enhance quality of care.'[62] The committee was informed that there was insufficient emphasis on the importance of advanced care planning:

> I believe that there is not enough being done in this area. First and foremost, we completely support [advanced care planning]. We think it is very

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56 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 38; Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 38; Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 27.

57 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

58 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 10.

59 *Submission 29*, p. 5.

60 National Disability Services, *Submission 43*, p. 5.

61 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 2.

62 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 2.

> important, particularly with people who have early onset dementia. But the issue is that there is not a lot of awareness about it. That needs to be augmented so that people know what it is about, how they can do it and how they can get their wishes recorded.[63]

7.41 Engaging the person with the illness in their care planning while they are still able to will make it easier for service providers to understand and meet the goals and needs of that person in the future. Providing the person-centred approach previously discussed in this report relies on having an understanding of who the person is, what their preferences are, and how they want to live out their life. Advanced care planning is a key tool to facilitate this care approach.

Committee view

7.42 Australia's disability sector, aged care sector, and acute care facilities are, through no fault of their own, systematically failing younger people diagnosed with dementia. The changes emerging from NDIS and *Living Longer, Living Better* should improve access and availability of services for people with YOD. Improving coordination between the aged- and disability-sectors through the key worker program is an important initiative, and the advent of person directed care through NDIS will create a marketplace of services.

7.43 As has been seen throughout this inquiry however, the most promising trends often come from the service providers themselves who go out of their way to create innovative and effective models to provide care for all Australians. Brightwater Care Group's and Mercy Health's model of working with patients, peak bodies, carers and staff to provide holistic and appropriate support is one that needs to be applied more broadly. HammondCare's efforts to provide YOD specific housing similarly stands out as a model of care with great potential. The Commonwealth has an important role to play in advertises these successes to allow other providers to emulate that successful care.

63 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 9.