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Dementia: Early Diagnosis and Intervention

Submission by HammondCare

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HammondCare
An independent Christian charity

About HammondCare

Established in the 1930s, today HammondCare is an independent Christian charity specialising in dementia care, palliative care, rehabilitation, older persons' mental health and other health and aged services. HammondCare has a particular commitment to dementia care and research as well as to people who are financially disadvantaged.

Introduction: diagnosis and intervention practices in Australia

Strategies aimed at promoting early diagnosis and intervention for people with dementia have the potential to improve quality of life and increase opportunities for planning and preparation. However, it is important to stress that diagnosis and intervention need to be linked closely; a dementia diagnosis must be seen as a first step that connects people to support and services which help them to adjust to and live with the condition.[1] Without adequate follow up, an early dementia diagnosis could actually result in negative consequences.

There is considerable evidence which suggests that GPs are reluctant to pursue an early dementia diagnosis for their patients. A recent Australian study found that many GPs felt an early diagnosis provided no real benefit to patients because they did not believe there were enough effective treatment options. [2] Their lack of confidence in current ‘intervention’ strategies meant they were less likely to make a formal diagnosis. Some even believed an early diagnosis can be harmful because it may lead to increased stigma without increasing the possibility of finding a cure. Numerous clients have also told HammondCare that they did not receive sufficient assistance and information after being diagnosed with dementia.

It is crucial that any strategy or policy to promote early diagnosis of dementia be matched by an equal effort to provide timely and appropriate assistance and guidance. Receiving a dementia diagnosis can be a traumatic experience and people with dementia and their families need to have the opportunity to grieve and adjust to their changing circumstances, as well as being provided with information about interventions and care programs. HammondCare’s clients and their families have said that it is often best to have some to process their emotions between the initial diagnosis and when they receive information. Clients and their families also report that they would benefit from a continuum of personalised support and assistance as the disease journey progresses. One way to meet this need is through a dedicated, key contact person who would form a relationship with the person with dementia and their family at the time of diagnosis and provide ongoing support, advocacy and case management. The Dementia Advisory Service goes some way to meeting this need but the service is limited in its scope and its programs vary from region to region. A useful model for a key contact person is the dedicated breast care nurse, who provides support, information and referral advice to women with breast cancer and their families throughout their disease journey.

Recommendation 1: *A full review of the DA model to identify the strengths of the model and the distribution of existing resources. This review should also examine how to move towards the introduction of a consistent and personalised key contact person model.*

Younger onset dementia (YOD)

There are also shortcomings in current practices around the diagnosis of younger onset dementia (YOD). HammondCare has recently appointed a YOD Partnership Advisor, who works with younger people with dementia and their family carers to help them identify needs and develop strategies. In her conversations with these clients, the Partnership Advisor has repeatedly heard that it is common for GPs to treat patients under 65 for depression, sometimes for years, before considering the possibility of dementia.

The interventions for YOD also need to be considered separately from other forms of dementia. Younger people with dementia have a different set of needs as they are heavily involved in complex professional and family relationships. They tend to be much more physically active than older people with more conventional forms of dementia and are more likely to have a form of dementia that is associated with higher levels of behaviours of concern, such as fronto-temporal lobe dementia.[3] This means that traditional residential aged care services are not well-equipped to support younger people with dementia.

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[1] Brodaty, Henry Et al., ‘Six reasons why early diagnosis of dementia does not occur and ten reasons why it should,’ *Les cahiers de la Fondation Mederic Alzheimer* 1(1), May 2005, 12-17, p.14

[2] Hansen , Emily C., Hughes, Clarissa, ‘General practitioners’ experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis’, *Social Science & Medicine*, 67 (2008) 1776–1783, p.1777.

[3] *Quality Dementia Care: Understanding Younger Onset Dementia,* Commissioned by Alzheimer’s Australia and Prepared by Melbourne Neuropsychiatry Centre, April 2008, pg.20

HammondCare has established a pioneering cottage for younger people with dementia within its residential facility at Horsley in the Illawarra region of NSW. The cottage has a strong emphasis on maintaining meaningful community connections and its domestic, small-scale design supports residents to be involved in normal daily activities, such as cooking and gardening. Through its Dementia Centre, HammondCare has also provided staff with workplace support and a formal training program to improve their understanding of the needs of younger people with dementia, along with their family and friends

Recommendation 2: *That further training be provided to GPs, neurologists and medical students about the nature of dementia in general and younger onset dementia, specifically.*

Improving quality of life and maintaining independence

Early diagnosis coupled with well-targeted intervention and support does not remove the challenges or the pain of dementia but it does allow the person with dementia and their family to preserve and build on existing capacities as much as possible. This is crucial if the person with dementia is going to maintain their independence and a sense of control.

Work and independence

For younger people with dementia, independence is closely related to preserving continuity in family and work arrangements for as long as possible. As the average retirement age continues to increase, general issues around employment and dementia will also become more common. With proper support and information, the person with dementia and their family are able to discuss their current situation other key stakeholders, such as work managers, colleagues community and social groups. This enables them to discuss their abilities, changing needs and, if necessary, to arrange flexible work conditions.

Despite this, there are few pathways and options at the moment to assist people who have recently been diagnosed with dementia to continue working. A premature end to meaningful vocational activity adds to the stigma of dementia and can impact on a person’s wellbeing and sense of self. The Commonwealth Rehabilitation Service provides comprehensive support to people whose jobs are in jeopardy as a result of a disability, injury or health condition, however, this program is not necessarily suitable for people with degenerative conditions, such as dementia, and it is only available for people aged between 14 and 65.

Case study

John is an engineer in his early 60s who was diagnosed with vascular dementia after he began arriving late for work on a regular basis with no apparent reason. While at work, John is still able to function well but his employer is concerned about his unreliable attendance. As the morning commute is the major issue affecting John’s ability to work at the moment, an appropriate strategy would be to arrange for a car pool or community transport service to take him to and from work. This strategy would enable John to continue working for longer, supporting his family and maintaining a sense of independence and identity. If this early transport support was not available, John would probably have to stop working immediately.

Recommendation 3: *The introduction of more effective, individualised support and care pathways be developed to meet the specific needs of younger people with dementia. Due to the challenging behaviour of some younger people with dementia, there is also a need for high level care for people with younger onset dementia.*

Recommendation 4: *The development of a program to assist people in the workforce who have received a dementia diagnosis. Such a program would help people with dementia to develop creative strategies and to negotiate with their employers, as well as providing assistance to family carers who are still working.*

Social engagement and community participation

Current initiatives aimed at promoting social engagement and community participation for people with dementia, such as day centres, have a greater focus on providing respite for carers than maintaining the social life of the person with dementia. While carer respite is important, there is also a need for early intervention strategies which assist the person with dementia to continue to participate in the community groups and clubs where they have existing connections.

An early diagnosis allows people to maintain their existing social networks as it gives them a way to explain and manage the changes in their behaviour and develop strategies for ongoing participation. However, it can be difficult to break the news or talk about the implications of a diagnosis to a group of friends or acquaintances in a sporting club, craft group or a faith community.

Case study

Aged in her mid-70s, Jan is a dedicated lawn bowler who has been actively involved in her club for decades. Jan was recently diagnosed with dementia and she and her husband are still coming to terms with this. The future seems very uncertain but Jan is sure of one thing: she doesn't want to stop playing bowls. At the moment, even though she gets distracted from time to time, Jan is still able to play fairly well. She wants to talk about her diagnosis to the rest of her team but she doesn't know how to broach the topic. What she wants is someone else, who understands dementia and knows how to talk about it, to come and speak to her team on her behalf.

Recommendation 5: *Greater funding for coordinated programs that provide information and support to friends, families, social clubs and community groups to help them include people with dementia, following a diagnosis. Such programs would consist of information packs and a telephone inquiry service, in conjunction with face-to-face consultations who would hold face-to-face meetings with the groups.*

Financial, legal and care planning

The enhanced key contact person (outlined in Recommendation 1) would be well positioned to play a crucial role in supporting people with dementia to make plans for their future. A useful model for collaborative planning was established by Advocacy Tasmania as part of its 2008 project on advocacy and the rights of the person with dementia. [4] Under this model, the client drives the planning process, by identifying their existing strengths and capabilities and outlining their concerns about the future. The advocate then provides a series of suggestions to help the client set their own goals and to develop strategies. The project found that using this method, clients were better able to articulate their own choices and preferences.[5]

A major impediment to effective planning at the moment is the confusion around legal capacity or competence, which varies from state to state. With the exception of Queensland, there are no legal definitions of capacity in Australia so a number of tests are used to assess capacity. If the definition of capacity was expressed more clearly and consistently, it would assist people with dementia and their families to make critical plans about future legal, financial and care decisions.

While there is a general consensus throughout Australia that no diagnosis automatically signals incapacity, we believe this message needs to be communicated more effectively in a way that emphasises the rights and citizenship of the person with dementia (see Recommendation 7).

One of the most useful resources currently available is the 'Capacity Toolkit',[6] developed by the NSW Department of Attorney General and Justice, which sets out six fundamental principles for assessing capacity. The toolkit stresses that when assessing capacity, it should always be presumed that a person has capacity, that the same person may have different levels of capacity in relation to different decisions and that substitute decision making should only be adopted as a last resort.

In the UK, these same principles are clearly articulated in the Mental Capacity Act 2005[7], which establishes a legislative framework designed to protect the rights of people with impaired capacity. The Act establishes a flexible, decision-specific test for assessing capacity and sets out the provisions for advance care decisions and the requirements for establishing powers of attorney.

Recommendation 6: *A review of current arrangements for assessing capacity and making arrangements for subsequent decision making to assess the benefits of national consistency in this area.*

Communicating dementia to the community

In order to provide real benefits, strategies to promote the early diagnosis and intervention of dementia need to be supported by broader efforts to dispel myths and improve general attitudes to dementia. Efforts to improve the quality of life are still hampered by the stigma associated with dementia and, if not adequately

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[4] Advocacy Tasmania Incorporated, 'Rights of People with Dementia and Advocacy Project', 2008, p.18.
[5] Advocacy Tasmania Incorporated, 'Rights of People with Dementia and Advocacy Project', 2008, p.29.
[6] http://www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_DiversitySrvces.nsf/vwFiles/CAPACITY_TOOLKIT0609.pdf/$file/CAPACITY_TOOLKIT0609.pdf (Viewed 2/5/2012)
[7] http://www.legislation.gov.uk/ukpga/2005/9/contents (Viewed 2/5/2012)

addressed, this problem will not go away.[8]

The key messages that need to be communicated are that a dementia diagnosis should not deprive a person of their citizenship or their rights. The tone of such messages should be positive but realistic.

Following a diagnosis, people with dementia and their carers also need access to simpler information. Several HammondCare clients have reported that current information, available in brochures and on the internet, is full of jargon and medical terms, like impairment and dysfunction, which are confusing and alienating, adding to the stigma of dementia.

Recommendation 7: *That the Australian Government considers developing a public education campaign emphasising the citizenship of people with dementia.*

Recommendation 8: *A review of the appropriateness and usefulness of existing brochures and websites providing information about dementia.*

Contact

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[8] Brodaty, Henry, Breteler, Monique Et al., 'The World of Dementia Beyond 2020', *Journal of the American Geriatrics Society*, 59, 2011, 923-927, p.926.