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(Dementia)
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Baptcare
Bringing care to life

Baptcare submission to:

House of Representatives Standing Committee on Health and Ageing, Inquiry into Dementia: Early Diagnosis and Intervention

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Special thanks to the clients, families and staff that have assisted in shaping Baptcare's Dementia Care. Additional thanks to Baptcare's Dementia Reference Committee in the preparation of this document.

Introduction

For over 65 years, Baptcare has been committed to meeting community needs, caring for the elderly, families, youth, people with disabilities, financially disadvantaged people, people from culturally diverse communities and asylum seekers. We are the largest provider of community packaged care in Victoria and provide a range of community and residential aged care services within Victoria and Tasmania. This submission is made in the context of local and international research that supports the early diagnosis of dementia and timely intervention.

Through our work in aged care we daily see first-hand the fractured impact that dementia can have on families and the effect that delayed diagnosis and treatment can have on a person's capacity to maintain quality of life and independence.

Quality of life and the independence of the person with dementia and their family are significantly impacted by delayed diagnosis as this:

- Robs the person and their family of the time required to plan together for the future;
- Negatively impacts meaningful and important relationships as symptoms of dementia such as anxiety, social withdrawal, mood changes and changed behaviour are misinterpreted;
- Intensifies the frustration and hopelessness felt by the person with dementia as there is no identified 'cause' for what they are experiencing;
- Prevents the commencement of treatment options that may delay the progression of the dementia; and
- Denies access to services and supports only available to persons with a diagnosis of dementia.

Term of Reference 1: Improving quality of life and assisting people with dementia to remain independent as long as possible

The World Health Organization defines quality of life as 'an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns' (WHOQOL Group, 1994). The capacity to remain independent and exercise control and choice over one's life is considered a significant factor in achieving quality of life.

The Productivity Commission Inquiry Report 'Caring for Older Australians' noted "Older Australians generally want to remain independent and in control of how and where they live; to stay connected and relevant to their families and communities; and be able to exercise some measure of choice over their care" (Productivity Commission, 2011, p. XIX).

An early diagnosis of dementia enables individuals to exercise control regarding treatment options and begin to make choices regarding what treatment or care may be required in the future. It is also widely recognised that informed people have better health outcomes.

Baptcare has found that barriers to an early diagnosis and treatment include:

- General Practitioner (GP) understanding of dementia including:
    - The early warning signs and how to differentiate dementia from other diagnosis;
    - Underlying assumptions that nothing can be done;
    - Advances in the treatment of dementia and the importance of early intervention in delaying its progress;
    - The significance of undertaking further investigations and identifying the underlying cause of the dementia;
    - Referral, treatment and service support pathways; and
    - How to communicate a diagnosis of dementia.
- Limited access to diagnostic services such as the Cognitive, Dementia and Memory Service (CDAMS) due to referral processes, waiting lists and geographical location and / or access to health professionals able to provide a formal diagnosis;
- Financial barriers including the cost of diagnostic services for individuals but also the capacity for the health community to seek appropriate remuneration for pursuing a diagnosis and cause of dementia (such as through the Medicare Benefits Schedule - MBS);
- Poor public awareness of dementia and what to do if they experience the signs and symptoms of dementia:
    - Many people who have signs and symptoms of dementia misinterpret them as normal signs of ageing when they are not;
    - Often when medical advice is sought, a diagnosis of dementia is not considered or is dismissed by the general practitioner, and a second medical opinion is not sought; and
    - Limited understanding of medical terminology can result in individuals misunderstanding the communication of a diagnosis of dementia and the importance of seeking further treatment.
- There is often fear associated with a diagnosis of dementia due to the powerful negative stigma associated with it. The word dementia comes from Latin and literally translated means ‘without mind’. History shows us that people with dementia were often given the label of ‘mad’, ‘lunatic, ‘insane’, ‘senile’ and ‘demented’ and as such were institutionalised and hidden away;
- Embarrassment and shame associated with some of the symptoms of dementia causes some people to hide their symptoms rather than have them diagnosed; and
- Belief and acceptance by GPs and the general public that there is no treatment for dementia and therefore no point in pursuing a diagnosis or cause.

Quality of life and independence can be considerably enhanced if an early diagnosis is achieved and treatment commenced in a timely manner. However this needs to be undertaken in a person-centred holistic context. The current approach to dementia care is still quite fragmented with diagnosis, treatment and service provision often undertaken separately and without any collaboration between health care providers.

Individuals from Culturally and Linguistically Diverse (CALD) Communities

Culture and language impact the way an individual experiences dementia. Cultural attitudes towards dementia also impact when and how they access treatment and support services. It is Baptcare's experience that people from a CALD background generally have a lower level of service utilisation and if services are accessed they are often not culturally appropriate.

This trend unfortunately means that people from non-English speaking backgrounds (NESB) are less likely to be diagnosed and/or less likely to receive treatment in a timely manner. Even if a diagnosis is obtained there are often difficulties in accessing treatment and complications surrounding the accuracy of monitoring due to communication difficulties. In addition information for individuals from a non-English speaking background is not often available.

Recommendations:

- *That ongoing education for General Practitioner's includes mandatory updates in dementia diagnosis and treatment;*
- *The MBS be expanded to include diagnosis of dementia by health professionals such as nurse practitioners;*
- *Funding for diagnostic services be expanded to improve timely access with special consideration for services to be delivered to rural and remote areas and individuals from a culturally and linguistically diverse (CALD) background;*
- *Bulk billing options be available for diagnostic and treatment services where a diagnosis of dementia is suspected or confirmed;*
- *An holistic person-centred approach to care (as provide to persons diagnosed with cancer) be adopted;*
- *Special consideration be made of the needs of CALD community members including:*
    - *Additional funding be made available for services aimed at supporting members of the CALD community;*
    - *Further ethno-specific dementia information and education materials be developed;*
- *That a public awareness campaign be undertaken and maintained to ensure the public remains fully informed regarding dementia*[1] *and the importance of early intervention.*

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[1] For further detail refer to recommendations listed under "How best to deliver awareness and communication on dementia and dementia-related services into the community".

Term of Reference 2: Increase opportunities for continued social engagement and community participation for people with dementia

A study conducted by Alzheimer's Australia NSW in 2010 found that 'People with dementia called for recognition of their retained abilities to increase their capacity for social inclusion' (p. 5). It is Baptcare's experience that it is important for people with dementia and their families to maintain existing social connections as much as possible as these can often provide the greatest meaning and support to individuals and their families. These connections are significant as they are more likely to be with persons / groups who know the individual well, can support retained abilities and who wish to maintain a significant relationship with the person diagnosed. However the capacity to preserve existing social connections is difficult due to the disabling nature of dementia and the stigma associated with it.

Access to Transport

As dementia progresses cognitive and other physical disabilities emerge that create barriers for maintaining independence. In Baptcare's experience one of the greatest of these is access to transport. Although a diagnosis of dementia may not affect driving in the early stages of the disease, the complex visuospatial skills required and the need for quick decision making means that this task can become unsafe. Other options such as public transport become unfeasible due to symptoms such as short-term memory loss and the inability to learn new things impacting the capacity to negotiate the public transport system. Options such as taxis often cannot be accessed due to the cost and issues surrounding reliability.

Recommendations:

- *That transport provision be a primary consideration of funded dementia programs; and*
- *That subsidised transport be provided in a manner that does not require the person diagnosed with dementia to onerously demonstrate financial hardship in order to gain eligibility.*

Financial Barriers

There is evidence that suggests that low income (such as the aged pension) is a barrier to accessing specialist medical practitioner and ancillary health services as these are less likely to be bulk-billed (Schofield, 1998). An undiagnosed cause of dementia can also limit access to medication which would otherwise be available on the Pharmaceutical Benefits Scheme. At the same time the capacity to increase family income is often inhibited by family members needing to undertake an increasingly active caring role as the care needs of the individual with dementia increase.

Increased costs hinder the capacity to remain socially connected as many social activities also attract a financial burden.

Recommendations:

- *That age restrictions applying to Concession Card (Seniors Card) status be removed for those with a diagnosis of dementia.*

The Stigma associated with Dementia

In discussing dementia with clients we often find that the signs and symptoms were recognised long before they sought medical advice. Australian research shows that families first notice symptoms up to 1.9 years before the first health professional consultation (Alzheimer's Australia, 2012). One of the primary reasons for this is they fear what others may say about them because of the stigma attached. Similarly they may know of people with dementia who were sent 'away' from family and friends into 'institutions'. This stigma and the presence of dementia symptoms contribute to social isolation.

Recommendations:

- *That a public awareness campaign be undertaken and maintained to ensure the public remains fully informed regarding dementia*[2] *and the importance of early intervention.*

Term of Reference 3: Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements

Baptcare has been witness to many family breakdowns as a result of family members trying to enact what they believe to be the wishes of their loved one, often in direct opposition to other family members trying to do the same. We have seen clients with dementia suffer financial abuse at the hands of significant others as a result of poorly thought through financial and legal planning. We have also seen clients suffer physical abuse as family members try to keep clients with dementia 'safe' by restricting mobility due to poor understanding of how to manage the behavioural and psychological symptoms of dementia (BPSD).

Advanced Care Planning

Baptcare supports the beliefs espoused by Palliative Care Australia in their Position Statement on Advanced Care Planning. In particular that:

- Quality end of life care is realised when it meets the person's needs and upholds their care preferences;

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[2] For further detail refer to recommendations listed under "How best to deliver awareness and communication on dementia and dementia-related services into the community".

- Advance care planning provides a mechanism to improve the quality of end of life care for people. It enables the coordination of their desired access to resources and services, to match their anticipated care needs;
- Advance care planning offers everyone, and especially people living with a terminal condition, their families and significant others the opportunity to take control of decisions which affect their care; and
- Advance care planning should not be considered only relevant to people nearing the end of life but be considered by everyone. It should be considered as an ongoing conversation between the individual, their care team and as appropriate their family, significant others and carers.

(Palliative Care Australia Incorporated, 2011)

Planning for the future should not be limited to future *care* preferences. It should also include ensuring that appropriate legal and financial planning has occurred and provisions such as an enduring power of attorney are investigated whilst a person is able to do so.

Recommendations:

- *That publications such as "Dementia – the Caring Experience" and "Australian Government Directory of Services for Older People" produced by the Australian Government Department of Health and Ageing be updated to include detailed information on advanced care, legal and financial planning;*
- *That a publication outlining the importance of 'Advanced Care, Financial and Legal Planning' be sent to all Australian's when they reach the age of 50; and*
- *Three free legal sessions be available to all Australians when they reach the age of 50 to assist in independent informed planning.*

Carer Burden and Planning for Intensive Care Requirements

Another significant factor in family breakdown is the impact of the caring role. This is particularly the case where there is dementia as many of the symptoms of cognitive decline can be emotionally challenging. In addition the caring role is often unappreciated as the person being cared for loses the capacity to recognise the carer and / or their symptoms.

An understanding of the prognosis of dementia and likely care requirements can assist individuals and their families to make choices regarding care that may be required in the future. The importance of respite can also be discussed and agreed so that guilt felt by carers can be reduced when respite is required. However our experience is that access to respite is often limited by geography, the capacity of a service agency to accommodate the needs of someone with dementia or the limits placed on the amount of respite that can be accessed – resulting in the respite required to provide appropriate carer support not being available.

Is it also worth noting that there is a severe lack of overnight high level care respite and facility based 'day programs' for those individuals requiring high care. Access to planned respite in high level care services is also limited – if you don't book well in advance you often cannot find respite and when you do book early it cannot confirmed until the 'last minute'.

Respite, in our experience can also be very 'regimented' in terms of service hours and is generally not person-centred. As dementia and its symptoms are quite individualised, respite can often be too inflexible and inappropriate for some families.

Recommendations:

- *Access to centre-based and in-home respite options be expanded and be made more widely available to ensure adequate access to respite;*
- *Widen the support and funding for new innovative approaches to respite; and*
- *Respite models be required to reflect a person-centred approach that demonstrates flexibility aimed at meeting the needs of people with dementia and their families.*

Younger Onset Dementia

It is important to recognise that the experience of individuals diagnosed with Younger Onset Dementia and their families is often different to a diagnosis obtained later in life due to the stage in life in which they are in. Issues faced include:

- Obtaining a diagnosis of dementia for those under the age of 65 is often a complex medical process, requiring extensive 'investigation'. The process can be quite lengthy, often taking several years, resulting in profound anxiety for individuals and their families. Some General Practitioners have had little or no experience with Younger Onset Dementia; There is a higher incidence of the rarer causes of dementia often resulting in personality, behaviour and mood changes as well as language difficulties;
- Underplaying the importance of how the diagnosis is communicated. For people who are told 'sensitively' this is helpful in coming to terms with the diagnosis. For those who are not told 'sensitively' there is often a feeling of anger towards the diagnosing doctor and the impersonal way with which their health is dealt. This often causes difficulties in coming to terms with the reality of the diagnosis;
- Many younger people are still working at the time of diagnosis. Some find all of a sudden they 'can't cope' with certain aspects of their work. If changes are made in the workplace, many find they can't learn new things or adapt to new technology. Work colleagues start to notice changes. Some people leave work without realising what is happening to them and then find six or twelve months or more there is a diagnosis of dementia. Some leave work without realising they are entitled to superannuation or disability insurance;

- Grieving associated with diagnosis and dreams for the future. The area of ‘loss’ is obviously a significant issue. People talk openly about the double loss - loss of their minds and loss of aspects of their life that are highly valuable to them;
- Financial burden related to loss of income due to progression of symptoms or the need to undertake a caring role;
- Increased carer burden where there are children to be care for;
- Psychological impact on children; and
- Locating respite services relevant to the persons age group.

Recommendations:

- *A Younger Onset Dementia education kit be developed to support persons diagnosed and their families;*
- *Access to centre-based and in-home respite options that are age sensitive and take into account the physical strong and healthy nature of persons with Younger Onset Dementia be made available to ensure adequate access to respite;*
- *Free information sessions be made available for teenage and young adult children of people diagnosed with Younger Onset Dementia.*

Term of Reference 4: How best to deliver awareness and communication on dementia and dementia-related services into the community

Much of the information available to the public focuses on how to prevent dementia or how to access support once a diagnosis has been made. Information regarding prevention often causes people to look for ‘cures’ associated with preventative practices instead of seeking an early diagnosis and treatment when symptoms have appeared.

The importance of early diagnosis and intervention needs to be a major focus of future campaigns.

Recommendations:

- *A multi-media public awareness campaign be commenced which focuses on:*
    - *recognition that memory loss is not a normal part of ageing;*
    - *the symptoms and early warning signs of dementia so people know what to look for and what to report to their GP or health professional;*
    - *the importance of early diagnosis and treatment so people seek advice early;*
    - *what dementia is to assist in reducing the stigma attached to a diagnosis of dementia; and*

  - *that promotes the concept of referral for identification of the cause of the dementia and for support.*
- *That education be targeted at all age groups including the commencement of a high school campaign.*

Conclusion

It has been noted that dementia is now the single greatest cause of disability within Australia. Early diagnosis and treatment can improve the quality of life of those diagnosed with dementia and assist in providing them with the opportunity to plan for future treatment and care requirements. Baptcare supports the aims espoused in the Terms of Reference of the Inquiry into Dementia: Early Diagnosis and Intervention and we look forward to reviewing the Inquiry Report from the House of Representatives Standing Committee on Health and Ageing.

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