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BAPTISTCARE INC

Submission into the

Inquiry into Dementia: Early diagnosis and Intervention.

House of Representatives
House Standing Committee on Health and Ageing

2nd May 2012

BACKGROUND

About Baptistcare

Baptistcare is a Christian faith-based, not-for-profit organisation, established in 1972.

Baptistcare provides a broad range of services across a wide geographic area within Western Australia. While providing services predominantly to older Australians, Baptistcare also provides services to those living with a disability and those struggling with mental health illnesses, together with support for their families.

All three client groups access residential, home and community-based services.

Baptistcare operates in the Perth metropolitan area, in rural and regional Western Australia, often in remote locations. Approximately 65% of our activity is in regional WA.

We employ 1400 people and have over 20 different service locations. Baptistcare is Western Australian and is an active member of a national board, Baptist Care Australia (BCA), which acts as a representative and advocacy body at a national level.

Our current activities include:

- Residential Aged Care – 880 approved beds within 13 Residential Aged Care Facilities. Six of these are in the Perth Metropolitan area and seven located in rural and regional Western Australia.
- Community Aged Care Packages – 223 CACP, 35 EACH, 46 EACHD.
- Disability Services - 222 packages through our Partners in Purpose Programme, 34 beds in Supported Accommodation in Perth.
- Mental Health and Counselling Services, including Mental Health Recovery Services, Supported Accommodation (Geraldton) and Counselling Services.

Given the scope of our activity and the issues facing our clients and their families around dementia, opportunities in relation to the early diagnosis of dementia and intervention is of particular interest to Baptistcare.

ISSUES APPARENT TO BAPTISTCARE

1. Impact of a Shift Toward Community Care

The aged care system has, in the past, often received residents into Residential Aged Care Services via a pathway involving low care entry, with residents progressing through to high care as their care needs change. Entry into a low care situation has enabled dementia screening for many to occur at that point, very often at a relatively early stage or where a diagnosis of dementia has not been made previously.

With a trend toward choosing community care, we will not be seeing people coming into low care facilities as we did previously and these people will now generally be seen in the home. This is a significant change and there will be a greater potential for those with early onset dementia, whose symptoms might otherwise have been identified on entry into an aged care facility, to be missed.

The importance of effective and proactive screening in the community to maximise opportunities for the individual and his/her carer and family will be even more important given this.

2. Younger People with Dementia

Younger people with a diagnosis of dementia generally experience a more rapid decline than those diagnosed later in life.

Most dementia service screening and service delivery is directed at the aged (for example, the Aged Care Assessment Team).

A significant gap exists in the early diagnosis of younger people with dementia and it is important to maximise intervention opportunities to improve outcomes for these people as early as possible.

In addition, when younger people do suffer dementia and can no longer live in the community, they are admitted into a Residential Aged Care Facility, which is inappropriate given that the needs (including care) of the individual can differ significantly from that of older residents.

Similarly, many community-based options are targeted to meet the needs of seniors and not younger people and their carers who may still be active in the workforce.

3. Reluctance to Recognise Dementia/Loss of Rights.

Symptoms of early onset dementia are often masked or ignored by the individual, his/her family and other health professionals, including General Practitioners. There are a number of reasons for this, which may include:

- Fear of loss of independence, rights to manage one’s own affairs (including finances) and individual freedoms are often lost at the point of diagnosis. This contributes to significant reluctance by all parties to recognise the onset of dementia.
- Ignorance of both the symptoms and that intervention and treatment options are multi-dimensional and available. Early warning signs are often missed as people in early stages can present as managing well in their familiar home environment and it may only become more apparent as the condition progresses or the environment they live in changes. Often, it is the family that notices changes first, but because of ignorance and a lack of understanding, they may choose to ignore the situation.
- Misdiagnosis, of depression for example, which frequently manifests with the onset of dementia.
- Avoidance, borne of fear, stigmatisation and a lack of understanding in relation to symptoms and treatment/intervention options.
- Normalising short term memory loss in the aged is often considered to be expected with ageing, which delays the response and offers an “excuse”.

These are significant issues. It is clear that even Medical Practitioners are often reluctant to formalise a diagnosis of dementia and this is a major obstacle in maximising opportunities that may present for the individual through early diagnosis and intervention.

4. Potential for Abuse

People with dementia are more likely to be the victims of a range of different abuses, including physical assault, financial and emotional abuse.

5. Impact on Families and Carers

Caring for a person with dementia can be very demanding for carers and families.

It is important that families and carers receive a high level of support so as to avoid family breakdown, carer burnout and social isolation themselves.

Particular issues frequently arise when the primary carer takes ill and is unable to fulfil the role of carer for a period of time.

Support requirements include in-home support, respite (including in the home and outside of the home), adult day centres, support for when a carer is in a crisis, and financial support.

The tipping point where families struggle to care for a person with dementia is very often around continence management, when behaviours deteriorate and costs of care increase.

6. Financial Costs of Aids to Assist People Live in the Community

The costs of providing aids, which assist the individual to live independently and in the community, can be expensive and burdensome.

Aids and modifications to maximise function and independent living, such as gas or electricity isolation devices for cookers, kettles and irons to stop them being left on and unattended, GPS to assist finding those who have wandered away or been unable to get themselves home, and emergency call systems and alarm/monitoring systems, are currently met by individuals and their families, with little financial assistance available.

These costs need to be recognised in any planning around early intervention, given an increase in care provided at home and in a community setting.

7. Workers supporting people with dementia require specialist skills.

Dementia Care workers require a broad range of skills and knowledge to meet the complex and highly personal needs of people with dementia and their families effectively. In the community, these workers mostly work in isolation without the direct support of a supervisor or colleagues. Pay rates are acknowledged to be low given the skill level required and the need to keep updating skills as the sector's knowledge of best practice and research increases and better informs how we care.

The cost of post-graduate training programs for professional staff (nursing and allied health) is prohibitive and salary packages are lower than in other fields of employment (including public health). It is therefore difficult to recruit and retain professional staff.

SUGGESTIONS AND RECOMMENDATIONS

The following suggestions are offered as strategies to assist with the aforementioned issues:

1. The role and proactive engagement by the General Practitioner is critical in early diagnosis:

- Working with the Divisions of General Practitioners regarding positive aspects of early diagnosis.
- Ensuring General Practitioners are familiar with the range of Medicare Schedule items that will support the complex care activities for GPs around diagnosis, care planning and coordination, liaison with other members of the service provision team.
- Recognition by GPs and other stakeholders of the importance of the health and wellbeing of the family Carer and actively encouraging regular check ups and attention to the range of conditions that may manifest in the stress of caring for a loved one with dementia.

2. Dementia is a condition that requires specialised support and knowledge:

- Increased geriatricians – introduction of community based geriatricians with referral pathways. Currently geriatricians are mostly employed in major hospitals and referrals are made via the GP. We would suggest that making more geriatricians available/accessible, locating them in the community and enabling referrals from allied health practitioners as well as GPs would improve the diagnosis and access to early intervention programmes and medications. The geriatrician's skill and expert knowledge of 'normal' functioning in our seniors would ensure that the person with signs of dementia is viewed in their totality with a focus on differential diagnosis and wellbeing.
- Competency framework established recognising dementia as a specialty with appropriate reward at any certificated level (e.g. Carers, Enrolled Nurses and Support Staff).
- Subsidised post graduate courses for health professionals.

- Competitive salary packages for professional staff (such as registered nurses, occupational therapists and physiotherapists)

3. **A diagnosis of dementia carries enormous implications in terms of grief and loss for the individual and carer/families, requiring greater support to assist with innumerable challenges:**

- There is a need for counselling programmes and support for the individual and family to assist with the grief and loss experienced.

  Medicare Schedule items for counselling have undergone some restrictions recently and could be opened up to ensure that the person with dementia and their family are able to access the number of sessions they need to be able to adequately deal with the current situation and prepare for the future.
- Enabling access through GPs for the individual, family and carer to counselling and support to address life decisions, grief, and Carer stress for example.
- Functional definitions for competency that enables people with dementia to retain legal rights for as long as possible thus reducing the stigma and complications associated with earlier diagnosis. This will require the determination of and access to appropriate assessment and advisory services.
- Education campaign, with focus on younger people and people living in rural areas.

4. **Support needs to be extended for carers and their families in the community:**

- Subsidies for aids, equipment and modifications to make the home safe and maintain independence as long as possible.
- Support programmes in the community extended beyond personal care and domiciliary assistance e.g. specialised Social Work programmes to assist with general planning, loss of rights, crisis planning, etc.
- Ready access to free information sessions and training for families once a diagnosis is made. Training needs to be accessible, and ‘endorsed’ to ensure quality and consistency of information provided.
- Day Respite – there is a need for increased provision of day respite; possibly expanding alternative models such as day care in a home setting.
- Increased research into the support needs of people with dementia, their families and carers which will clearly identify evidence-based best practice.

Conclusion

The benefits of early diagnosis and intervention of dementia are clear in terms of opportunities to improve the quality of life and to maintain independence of a person suffering dementia for as long as possible.

Options in relation to dementia intervention are less restricted the earlier the diagnosis. In addition, the earlier the diagnosis and intervention and more consistent and familiar the service delivery, the better the outcomes for the individual in terms of acceptance of personal care and other services as their condition changes.

With the growth in numbers of people with a diagnosis of dementia, the tendency for more care to be delivered in the home/community and changing profiles in Residential Aged Care, there is a need for increased access to screening and dementia services in the community. Importantly, this is not just for older people, but also a younger cohort.

Whilst there is reluctance for individuals, families and practitioners to recognise a diagnosis of dementia, the benefit of early diagnosis in enabling people with dementia to plan for the future is also clear. However, there do need to be changes that recognise dementia is a progressive disease and to ensure that everyone with dementia is not grouped into a single category, which diminishes independence and rights once there is a diagnosis.

Baptistcare believes that a multi-faceted approach focusing on increasing the knowledge, support and proactive engagement of the General Practitioner, along with education, increasing access to specialist services in the community and greater support for the family and carers, will assist to improve outcomes for those diagnosed with dementia.

The range of strategies listed above is derived from Baptistcare's experience and knowledge working both within the community care sector and in residential aged care.

I hope this is of assistance to the inquiry.

Dr Lucy Morris
Chief Executive Officer
Baptistcare