CATHOLIC HEALTH
Australia

Catholic Health Australia

Submission to Senate Community Affairs Inquiry

Care and management of younger people and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

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Catholic Health Australia

21 public hospitals, 54 private hospitals, and 660 aged care services are operated by different bodies of the Catholic Church within Australia. These health and aged care services are operated in fulfilment of the mission of the Church to provide care and healing to all those who seek it. Catholic Health Australia is the peak member organisation of these health and aged care services. Further detail on Catholic Health Australia can be obtained at www.cha.org.au.

1. Introduction

Catholic Health Australia (CHA) is the largest owner grouping of health and aged care services in Australia advocating on behalf of the 75 hospitals covering 21 public and 54 private, plus 660 aged care services.

Our members are significant providers of health and aged care services, employing around 35,000 people. Their aged care services comprise some 19,000 aged care beds; 8,000 home care packages; home support services for over 6,000 people each year; and over 6,000 retirement and independent living units and serviced apartments. These services are provided in fulfilment of the mission of the Catholic Church to provide care to all those who seek it.

2. Background

It is estimated there are 266,574 people with dementia in Australia in 2011. This is projected to increase to 553,285 people by 2030, and 942,624 people by 2050. Dementia prevalence is greatest in the age bracket 85-89 years throughout the projected period, increasing from 65,471 in 2011 to 225,898 in 2050. As prevalence rates are not the highest in this age bracket, the large dementia prevalence is due to the relatively large number of people. That is, although dementia prevalence rates are higher for people 90 years and older, mortality rates are also higher and the net effect is a lower dementia prevalence.

Due to the relatively large growth in the older population in Australia, people with younger onset dementia (those aged less than 65 years with dementia) will make up a smaller proportion of total dementia prevalence in the future. It is projected to decline from around 6.1% in 2011 to 2.9% in 2050. There will be 75,000 baby boomers with dementia by 2020 and dementia will be the third largest source of health and residential care costs by 2030.

People with dementia have special needs. They require particular care and deserve the best of practice. Catholic health and aged care services are increasingly catering for people with dementia whether in an acute setting, the community or in aged care homes. The services strive to meet the highest standards and aim for optimal results based on the preservation of human dignity.

The future challenges for policy makers and service providers in the care and management of people with dementia is now clearly understood. Current service examples of better practice offer a way forward by being translated into everyday service delivery. Catholic Health Australia's (CHA) submission focuses on better practice Case study examples across the Catholic acute, sub-acute, residential and community aged sectors.

3. Acute and Sub-acute Care

In 2010–11, there were over 4.6 million acute care separations for women and girls compared with 4.2 million separations for men and boys (52.4% and 47.6% of separations respectively. People aged 65 and over accounted for 38% of separations and 48% of patient days.

Separations increased for both males and females between 2006–07 and 2010–11. These increases were very marked for both men and women aged 55 and over. For persons aged 85 and over, there was an overall increase of 41% in separations between 2006–07 and 2010–11, an average increase of 9% each year. (AIHW).

People with dementia stay longer in hospital and have higher associated costs of care, according to the Australian Institute of Health and Welfare (AIHW). Their report, *Dementia care in hospitals: costs and*

strategies, estimates the average cost of hospital care for people with dementia is generally higher than for people without dementia ($7,720 compared with $5,010 per episode).

3.1 Case Study 1: Quality Care for people with Cognitive Impairment in the acute care setting

It has been reported that people with dementia have relatively high rates of hospitalisation and casemix complexity (AIHW, 2011) and are generally admitted for a different primary diagnosis. Non recognition of their cognitive status may well hinder the quality of care they receive in hospital, increase length of stay along with a discharge to inappropriate destinations.

The hospital environment is an overwhelming place even for people whose cognitive function is intact. For those who may be cognitively impaired it can be distressing for both the patient and the next of kin. Very often hospitals witness a patient on admission to hospital or post operatively become agitated, confused or demonstrate behavioural problems, yet the tendency is to focus on the primary diagnosis with limited consideration for or understanding of an underlying cause.

The care of people with cognitive impairment (inclusive of dementia and delirium) in the acute care setting is poor because it is often unrecognized and hospitals are not well equipped to manage such patients. Findings of the Dementia Care in Hospitals Program (Ballarat Health Services, Victoria), which involved 16 Victorian public hospitals, has identified that on any one day 30% of patients in hospital over the age of 65 years have cognitive impairment and that for 20% of these patients the hospital is unaware of this. The number is expected to grow along with the ageing of the population and it has been said that 'dementia is an acute problem for the acute setting' (Minister's Acute Care Advisory Group, 2012)

St John of God Hospital (SJOG) Bendigo was one of 2 private hospitals in Victoria who participated in a research project investigating the translation of the Dementia Care in Hospitals Program from the public to the private health sector. Initial findings were consistent with the public sector, i.e. on any one day 30% of patients aged over 65 years have cognitive impairment.

The research project was conducted in two phases. Firstly, the establishment of the processes and polices required to introduce routine cognitive assessment for patients over 65 admitted for an overnight episode, followed by the auditing and evaluation to determine the effectiveness of cognitive screening.

The second phase involved a whole of hospital education program to introduce the Cognitive Impairment identifier (CII) to clinical and non-clinical caregivers along with the Cognitive Risk Assessment tool and associated policies and procedures.

Prior to the introduction of routine cognitive assessment, whilst utilising screening tools such as falls risk and pressure injury risk assessment, the hospital did not have a distinct process for the identification of patients experiencing memory or thinking problems. Therefore the number of patients suffering with a cognitive impairment was unknown, along with any relationship between patient incidents, such as falls, medication errors, length of stay or re-admission rates.

By introducing a Cognitive Impairment assessment process the hospital has demonstrated a true commitment to the Mission and Values as well as moved towards more successfully meeting the requirements of the National Safety and Quality Health Service Standards which include, Partnering with Consumers, Medication Safety, and Managing Falls.

3.2 Case Study 2: A Sub-acute Cognition Clinic and Jim's Story

Jim is a 68 year old gentleman who presented to the Cognition Clinic with a two year history of declining memory and increasing difficulties performing in his role as a Pastor and Church Counsellor. He lives with his wife of fourteen years, who was concerned about his poor memory, and that people of the Church had

begun noticing this too. Jim and his wife were increasingly concerned as his mother was still alive and suffering from dementia.

Jim was diagnosed with a form of dementia, but he and his wife were very anxious about the diagnosis – what this meant for the future and how they were going to be able to plan for this.

The Social Worker was able to provide vital extensive grief and loss counselling to Jim and his wife. They were able to make plans about the future together, which was important to Jim as he wanted to be able to begin making changes while he was "still in control." They were able to make plans about his work, finances and housing.

The Cognition Clinic has allowed for Jim and his wife to receive a difficult diagnosis in a supportive and caring environment. They were able to make changes to their lives on their "own terms" and in their "own time" without being forced into a time of crisis. This was Jim's primary wish.

This model provides a "one stop shop" for patients living with dementia in the community with a timely multidisciplinary geriatric assessment and management of medical, functional and social issues due to their dementia. The management of behavioural issues can be optimised and the capacity and confidence of family carers to provide optimal care can be built.

Demand on Ambulances and Emergency Departments is reduced with a corresponding drop in acute admissions.

4. Aged and Community Care

At 30 June 2011, 70% of permanent residents were female. Of all female residents, 63% were aged 85 and over, compared with 43% of their male counterparts. This can be attributed to the greater proportion of females among older age groups in the general population, a factor usually attributed to increased life expectancy.

At 30 June 2011, 57% of permanent residents were aged 85 and over. This proportion has gradually increased since 2000, when 50% of residents were in this age group. Those residents in the 85–89 grouping represent the largest number of permanent residents, accounting for 30% of the total. At 95 and over, 10% of permanent residents were female (11,810) and 4.5% (2,238) were male. By contrast, 4% of residents were aged under 65. Male residents generally had a younger age profile than female residents with 7% (3,434) entering residential aged care at age 65 or under compared with 2.5% of females (2,937).

Over three-quarters of residents (78%) were reported to have a mental illness. More than half (52%) of the 164,116 permanent residents with an ACFI (Aged Care Funding Instrument) appraisal had a diagnosis of dementia recorded. Over two-fifths of residents with dementia also had a diagnosis of a mental illness. A further 26% of residents had a diagnosis of mental illness without a diagnosis of dementia. (AIHW).

4.1 Case Study 3: Interaction Based Care

This NSW residential aged care service has 120 high and low care beds including a seven bed high care dementia unit. Staff have developed a model of care delivery known as Interaction Based Care. The model was developed from observations of daily life in a residential aged care facility and is based on the simple premise that every human interaction is unique. These interactions occur within an ever changing framework which incorporates:

- **Physical design** – shape and layout of building; size and location of various units; location of support resources.
- **Human design** – numbers, skill mix and distribution of staff. This also includes management systems, such as case management and program management.

- **Social and emotional factors** – the need for comfort, understanding and affection.
- **Professional and clinical factors.**

This framework is multi-factorial and responsive which means that staff are supported to provide the best possible care for residents through high quality interactions. Quality interactions are built upon three major themes:

1. **Consistency** – this doesn't mean staff acting in the same way with every resident. It means that staff must consistently be professional in providing individualised care.
2. **Flexibility and responsiveness** – staff demonstrate sensitivity to the needs and preferences of the resident. Staff do not impose rigid work routines but engage in individualised interactions marked by flexibility and responsiveness.
3. **Focus upon organisational practices and values** – this relates to the management framework and support systems. The organisation also provides guidance towards preferred values, such as empathy and ethical conduct.

Interaction Based Care describes a supportive culture that embeds a caring relationship as the basis of all interactions and thereby creates opportunities to deliver the very best care.

4.2 Case Study 4: A Model of Community Care

Traditionally, community care services have focused on supporting people who are frail and elderly. There has been a standard range of interventions that are appropriate in supporting people with physical limitations, and this care often tends to be task focused.

Such a standard community care approach does not work well for people with a dementia. While people with dementia may have health issues that need to be managed, other issues such as memory loss, confusion, impaired judgement and impaired interpersonal skills are the major risk factors in their lives.

Community Care Services need to do the following to be effective:

- Shift from a task focused style of care to a person-centred style, so that client needs and carers needs are responded to on a day to day basis rather than following methodical work routines that might allow for easier staff rostering.
- Ensure that clients have very regular contact and monitoring, including on weekends.
- Where there is a live-in carer, the timing of visits fits with the concerns of the carer and that practical help is delivered wherever possible.
- Minimise the number of staff in regular contact with the client.
- Ensure that the program has staff that are committed to the program and the clients, who are problem-solvers, and who enjoy a degree of responsibility and autonomy.
- Ensure that Coordinators are Registered Nurses and can capably assess when a client's needs have changed, and can work well with psycho-geriatric and mental health teams.

Those people with dementia living at home alone are the ones most at risk. Usually these people have become increasingly dysfunctional if they have not been receiving appropriate support. Most are not eating well and have become malnourished; usually they have been taking prescribed medication incorrectly, wavering between under medicating and over medicating. They often have few supportive social networks and because of their dementia they need practical support more than ever.

On an emotional level they are likely to be either worried and agitated, or depressed and withdrawn. In more severe cases they may have developed quite paranoid delusions and they may be in conflict with their neighbours.

Initially the Community Care Service will set out to address three key factors:

- Inadequate diet;
- Poor medication management, and
- Lack of social, emotional and practical support.

Whilst meals on wheels can be a basis for a healthy diet, it's typical that a person with dementia who is living alone will forget to eat the meal, or they feed it to pets or eat it many days later when it is no longer safe to do so.

The Community Care Service will need to find other ways of ensuring that the client is having a healthy diet. This may mean a staff member needs to sit down with the client and share a meal. Finger food may also be left in the refrigerator that the client can have later in the day when they feel hungry. The client's medication needs to be simplified and better managed in a way that can be tracked. Finding ways to do this will require the cooperation of the client's GP and Pharmacist.

Within six to eight weeks of addressing these issues there is generally a marked improvement in the client's functioning and mental state. The client becomes more trusting and this enables the service provider to begin to look at how they can help the person get some enjoyment back in their lives.

Where clients live with carers, the service needs to target support to those issues and times of the day that are most problematic. This may be when the live in carer tries to shower the client in the morning. If this is a point of conflict, the service's staff member will need to be there at that time of the day. The service needs to find ways to engage with the client and change the pattern of problematic behaviours so that practical support as well as emotional support can be provided to the carers.

4.3 Case Study 5: Social Support for Younger People with Dementia

Younger onset dementia refers to people under the age of 65 with dementia. People may be in the early, middle or later stages of the disease and the dementia may be caused by a range of conditions. It results in difficulties with work and social activities, rather than dependency. Younger people usually have greater occupational demands, financial obligations and may have greater social responsibilities. The person may no longer be able to work, to assist their teenage children with school work or drive children to weekend sport.

The ideology of the program centres on not creating dependence, or taking away or substituting the role and work of the carer and family or friends, but assisting the carer in their role and minimising depression and social isolation for the person. An outcome of the program is that it supports family and spousal relationships, and is a link into more formal and medical supports, as well as providing advocacy support.

The service aims to meet people's individual needs, maintain their abilities and encourage and support them to have fun. Many clients are still otherwise healthy and like to be out in the community. The program may assist people with continuing a regime of playing golf, or going fishing, shopping or to attend a concert as well as providing in-home visits.

Carers are supported throughout the process and are recognised as providing a vital role in maintaining a person's quality of life. Carers are encouraged to network with each other either face to face or through email, and to access a local carers' support group.

4.4 Case Study 6: The Chantal Program

Max (94) lives with his wife Peggy. Max has a diagnosis of dementia (including memory loss), hearing and vision impairment. He requires supervision with showering and medications and has a history of falls resulting in a fracture. Mr M served as an Air force intelligent officer and after WW2 – worked as a fashion buyer travelling around Europe and Asia. His wife, Peggy, has been a nurse and as the sole carer for Max, Peggy has begun to struggle in providing care due to her own health issues.

Although Max was approved for a CACP the couple declined assistance offered by the Packaged Care Coordinator; he was referred to HACC Case Management . In September 2012 Mrs M accepted support offered by HACC Case Management service and agreed to a referral for a Day respite at Chantal Centre. The assessment took place soon after but Max did not agree to attending to the service.

After regular monitoring phone calls and encouraged by the HACC Case Manager Mr M agreed to visit Chantal again in November 2012. He has been provided with an opportunity to participate in the program several times before but Max wasn't ready and kept resisting, postponing, finding some excuses not to attend. It took a lot of encouragement and perseverance from his wife Peggy who decided to go ahead with the day program.

Prior to Max's first visit his preferences and interests were discussed with all Support staff. Examples of the objectives are: to provide Max with opportunities to share his stories; encourage active participation in preparation of social activities which interest Max, such as history and geography; contribute to sense of achievement for Max by providing him with positive feedback.

During the first visit on November 2012 Max was offered individual assistance through a volunteer to make him feel comfortable while meeting other clients and when participating in activities. The Day Centre used history books and music to create a calm and welcoming atmosphere.

In December 2012 Max and Peggy accepted an invitation to celebrate Christmas at Chantal with the staff and other care recipients and carers. Early this year Peggy informed that Max would like to continue with participating in our Tuesday program.

Recently Max was asked for a feedback about assistance provided at Chantal and this is what he said. "I think it's tremendous, part of a good dream. Everything is good, the outings, program the food and the company. I look forward to the group. Staff could not be better. My hope is that I can continue. It' the highlight of the week"

Chantal provides a unique opportunity for the clients who are interested in attending day and overnight respite. Clients familiarise themselves with Chantal environment and staff during the day programs and often are more comfortable when invited to participate in the overnight respite. Careful client matching and booking clients with the similar interests and skills- ensure positive respite experience for all.

4.5 Case Study 7: Dementia Support & Monitoring Program

Edith (82 years) spent a short period in hospital in July last year before coming to the Dementia Support & Monitoring Program. Although her GP was very helpful, her medications had become confusing, her diet was slipping a little, she was forgetting appointments and she was unsure about who to talk to about things that confused her. Her stay in hospital had sorted out her medications and boosted her health but she felt her confidence in managing at home had declined since her husband Laurie had passed away 7 years ago. Although initially Edith declined to accept assistance from community services, the Aged Care Assessment Team (ACAT) had recommended a referral to the Catholic Aged Care Provider's Dementia Support & Monitoring Program for assessment. Edith was visited at home by an assessor following her discharge from hospital.

Edith revealed during the assessment that sometimes she found her bills confusing and she wasn't getting out as often as she would like and although her cat Beasley was great company, she felt lonely and worried about things. At first Edith felt uncomfortable about strangers coming into her home but agreed to the Dementia Support & Monitoring Program providing a dementia trained community worker, Kerry, to visit once a week just to see how Edith was travelling. In time the service increased to twice weekly to prompt medications and provide Edith with some social contact.

"I only need a little bit of help and I like to do things myself, but I feel more confident that I can manage now"

Recently, an additional community worker now assists Edith to go shopping for groceries, pay her bills and attend the meals service at the Community Centre where she had not been for nearly a year prior.

"I stopped going because couldn't remember the day. It was hard to get to and I thought I wouldn't know anyone anymore. It was surprising to see some familiar faces and we have a nice lunch there"

When assessed by the ACAT, Edith was noted as very resistant to accepting services but now said that she didn't mind the visits. Assistance continues for Edith and the relationship with the service is stable.

Contact and services must be delivered at the pace the client is comfortable with. Clients are often referred to the Dementia Monitoring Program over the case management program as the timeframe to establishing a trusted relationship to even assess the client can take months. The DMP has the scope and flexibility to take all the time needed to establish trust and familiarity with the client with which to make forward progress.

5. Conclusion

The future challenges for policy makers and service providers in the care and management of people with dementia is now clearly understood. Current service examples of better practice offer a way forward by being translated into everyday service delivery.

The Case Studies cited in CHA's submission rely on ongoing funding for survival. Funding for acute and sub-acute examples may be one-off or just not translated into wider practice. CHA considers that all acute services should routinely conduct during admission of patients a cognitive assessment using a standardised Cognitive Assessment Tool.

In residential care, the current funding model, the ACFI, does include a Behavioural Supplement but as the assessment instrument is geared to recognising and funding behavioural management interventions, it's not geared to funding more specialised dementia service models as outlined in above Case Studies.

Current funding for community programs may be provided under a low level Social Support model for community connectedness to combat social isolation. While this can become a function and role of the program, the impact of dementia behaviours is not adequately taken into account in achieving the desired outcome of a traditional social support model.

There is a need for recognition in the acute, sub-acute and aged care funding approaches by governments that specific targeted intervention programs can achieve significant health and aged care expenditure savings by reducing admissions to acute care, unnecessary utilisation of Ambulance and Emergency Department services and admissions to residential aged care.

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