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Submission No. 064

(Dementia)

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Mr Steve Georganas MP
C/- Committee Secretary
Standing Committee on Health and Ageing
House of Representatives
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Mr Georganas,

Re: House Standing Committee on Health and Ageing Inquiry into Dementia Early Diagnosis and Intervention

The City of Darebin encompasses a total land area of about 53 square kilometres and includes the suburbs of Northcote, Preston, Reservoir, Thornbury and parts of Alphington, Bundoora, Fairfield, Kingsbury and Macleod. Population forecasts predict Darebin's population at 142, 905 for 2011. The municipality is characterised by a municipality that is ageing, has a high proportion of people living with a disability and is diverse in a range of characteristics including culture, levels of socio and economic advantage and prevalence of health issues.

Darebin Council has a strong connection with its community through programs offered by the Aged and Disability Department which includes the Home and Community Care (HACC) program. Darebin Council's Dementia Care Unit provides social support and recreation through activity based programs which aim to safeguard and enhance the skills of participants. It simultaneously provides respite for carers and families. A monthly support group provides carers with social and emotional support in addition to formal education sessions which focus on understanding dementia and carer wellbeing.

Darebin Council has strong links with the community sector, including local Aged Care Assessment Services. In November 2011 the Aged and Disability Department conducted its bi-annual survey of Residential Aged Care providers and Community Care providers located in Darebin. The purpose of this survey is to monitor trends relating to aged care and this includes a focus on monitoring issues concerning people with dementia and their carers.

In responding to the terms of reference, views represent carers who use the Dementia Care Unit, observations of staff employed at the Dementia Care Unit as well as feedback from service providers and Aged Care Assessment Services who participated in the survey.

The recent study commissioned by Alzheimer's Australia estimates the prevalence of dementia is expected to increase significantly between 2010 and 2050. Across the eight Department of Health Regions, the study identified that the North and West Metropolitan Region is anticipated to rank first in both dementia prevalence and incidence.

It is estimated that by 2010 there were 2000 people living with dementia in Darebin. In comparison with Local Government Areas (LGA) in both metropolitan and non-metropolitan regions, Darebin is ranked 8th meaning that compared to other LGAs across Department of Health Regions, Darebin has a significantly higher proportion of people with dementia. Projections continue to increase over time with the prevalence estimated to be 3,540 in 2030 and 5591 in 2050. (Source: Projections of dementia prevalence and incidence in Victoria 2010 – 2050, Alzheimer's Australia Vic, 2010).

Given these projections combined with our knowledge of the numbers of residents with a dementia on the Centralised Waitlist, we welcome the House Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention.

Should you have any further questions in relation to this submission please contact Gillian Damonze, Coordinator Planning and Advocacy

Yours sincerely

Shadi Hanna
Acting Manager
Aged and Disability Services

Improve quality of life and assist people with dementia to remain as independent for as long as possible.

Early intervention, access to information and support for carers and families

- People newly diagnosed with dementia and their families need information that is accessible to them regardless of their literacy or ethnicity.
- Improved communication from health practitioners about dementia in addition to practical assistance to 'walk' people through the maze of services
- There is a need for better integration between services and health practitioners. The Commonwealth Carelink and Respite centre is a good example of a service which provides vital information and practical assistance through carer support workers to help the carer navigate the residential respite system. However there still remains a dis-connect between services that play an important role in carer support and other agencies such as GPs and hospitals who have capacity to refer people for support following diagnosis.

Carers who attend the monthly support group through Darebin Council's Dementia Care Unit shared some of their own experiences. Common themes include:

- At the point of diagnosis carers were provided with very little information about the type of dementia the person had been diagnosed with and how the dementia would effect the person
- Not knowing what supports the person and the carer could access
- For others finding support through the Commonwealth Carelink and Respite Centre occurred by stumbling across the website while googling on the internet.

Recognizing quality of life of the carer is synonymous with the quality of life of the person with dementia.

- The quality of life of the person with dementia and their capacity to remain at home is often dependant on the capacity of the carer to enable this. The extent to which the carer can access good supports in addition to flexible services are strong factors in improving quality of life of the person with dementia and their capacity to remain independent and connected to their community.
- Equal and ongoing access to support and services for both the person with dementia and their carer. Some carers have described experiences of having good support through carer support agencies up until their loved one is able to access formal support through a community care packages such as an Extended Aged Care in the Home Dementia (EACHD) package. Once this occurs they are no longer eligible to access the resources of the carer support agency. Rapid cognitive changes in a person with dementia means access to services and supports when it is needed is vital to carer wellbeing.

Flexible Respite Options

Data collected through the bi-annual survey undertaken with residential aged care providers located in Darebin indicate that since 2008 there has been a downward trend in the number of high care residential respite places available while there are a higher number of low care residential places available.

At November 2011 there were only 6 High Care residential respite places on offer and 14 respite places offered in Darebin. The total number of high and low care places reported by 20 residential aged care providers through the survey was equivalent to 1163 places.

The percentage of booked respite places (20) as a proportion of the total places available (1163) is 1.7 %. This is very low considering the number of people who are supported at home through a Community Care Package in addition to the numbers of people in Darebin waiting for an EACHD package.

For the period 1 July 2010 – 30 June 2011, Darebin had the highest number of people with dementia waiting for an EACHD package on the Centralised Waitlist. For the Bundoora catchment area only there were 67 people with dementia waiting for a package.

Further work is needed to explore:

- The availability of flexible, overnight, short stay or day residential respite is vital in safeguarding the relationship between the person with dementia and their carer as well as supporting carer wellbeing and reducing social isolation.
- Flexibility in the type of residential respite should extend to carers and families having the option to try residential respite on a weekend or a day at a time to encourage the person and the carer to try out different options that may suit their situation.
- Capacity of the aged care sector to attract more funding to upgrade residential care facilities that could better suit the needs of people with dementia.

Lengthy waiting periods and insufficient supports = reduced quality of life

Darebin has the highest number of residents on the Centralised Waitlist waiting for an EACHD package. There are 27 providers of Community Care Packages (CACPS, EACH, EACHD*) and 23 providers submitted their responses through the survey. Feedback from these providers indicate that a person wait between 6 months – 24 months for an EACHD package to become available.

Without access to vital case management and brokerage funds to purchase the necessary supports to help the person remain independent, the quality of life of the person and their carer is significantly diminished.

There is currently no formal process for monitoring people on the Centralised Waitlist, although some Aged Care Assessment Services attempt to build in monitoring processes with no additional resources to do so. There are no mechanisms to monitor carer stress, particularly where carers themselves are frail.

Increase opportunities for continued social engagement and community participation for people with dementia

Individualised planning for community connectedness

There is a need for people diagnosed with dementia and their carers to explore meaningful opportunities that will encourage the person to remain connected and engaged with their community particularly for people with early onset dementia. Exploration of these opportunities need to take into consideration the individual's needs and preferences and respond to people who may choose not to engage in a group setting. Planning also needs to explore supports and services that are culturally relevant to the person.

Community connectedness in residential care

Feedback from residential aged care providers indicate residents with mobility issues and those with advanced dementia who may have a tendency to wander or where there are behaviours deemed difficult to manage, are the least likely to access the community. Other issues that contribute to lack of social connectedness is lack of reliable and accessible public transport that can help elderly family members remain connected to the person when they move to a residential aged care facility.

Planning for diversity in our communities

Emphasis on understanding the diversity of local communities that extends beyond cultural difference will help those pockets of the community who struggle to connect with mainstream services because of their perceived difference or fear of discrimination.

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

- Development of resources that contain information about specialist services can help people with dementia and their carers to plan for their futures soon after diagnosis as well as managing longer term financial and legal affairs.
- Setting up Guardianship and Power of Attorney while the person still has cognitive capacity to make decisions can ease the burden on family members and the immediate carer.
- Health services and specialist dementia specialists can also help the person and their carer to develop advanced care plans depending on the nature of the dementia and the care required.

How best to deliver awareness and communication on dementia and dementia related services into the community

Feedback from carers suggest there is a 'hit and miss' approach that people experience at the point of diagnosis only fuels stress, anxiety and confusion.

Multi – levelled awareness raising campaigns

Creation of smaller information hubs that is based on Local Government Areas or similar to Medicare Local boundaries. The benefits of smaller information hubs include:

- Each Hub could have staff with relevant expertise in dementia such as a local community dementia consultant that would assist in developing the capacity of the local community through helping people navigate the service system and understanding dementia.
- Hubs could have a mandate to organise information sessions targeting GPs and other health practitioners – keeping everyone abreast of current practice and process
- Hubs could have responsibility for monitoring the training needs of GPs and other health practitioners
- Information hubs would have better knowledge of the cultural and other diverse needs of the community and therefore may be more culturally sensitive in provision of support.
- People in need of information or services may feel less intimidated if they can access resources locally. Alternatively, where there is stigma felt and where a person may be less inclined to access local services; there would be at least several other alternatives they could access by going to other hubs.

Development of resources that provide consistent messages about dementia

Development of step by step FACT Sheets that focus on different topics may be useful for the person diagnosed with dementia and their family as well as health services providers such as GPs. Fact Sheets may include information that focuses on:

- Information about the type of dementia that is relevant to the person's diagnosis
- Key contacts and services that can be contacted for more information and support
- Organisations that can help organise financial and legal affairs

Fact sheets could also focus on outlining the next steps to assist the person and the carer to navigate the service system. Other topics may include: accessing Advocacy Services, Power of Attorney, Advance Care Planning, Accessing Respite, Residential Aged Care.

Workforce planning

- Provision of funding that can address the shortage of staff in the human services field but particularly in aged care
- Development of professional development that focuses on up- skilling staff at all levels of the human services spectrum including GPs, residential aged care workers and home carers.