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Inquiry into Dementia: Early diagnosis and Intervention
Terms of Reference

House Standing Committee on Health and Ageing

Submission from Silver Chain, May 2, 2012

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Introduction and background

Silver Chain welcomes the opportunity to make the following submission to the House Standing Committee on Health and Ageing on the Terms of Reference for the Inquiry into Dementia: Early diagnosis and intervention.

For more than 100 years, Silver Chain has a rich history in service provision in Western Australia, and is a not-for-profit organization which provides community health and care to people living in metropolitain, rural and remote areas. Today, we are one of the largest providers of community, clinical health care services to the Western Australian and South Australian communities (as Royal District Nursing Service SA Ltd) and a growing entity in Southern Queensland.

Silver Chain provides a diverse range of health and care services, and a high number of clients with dementia are supported in their familiar home environment. As a service provider across a number of States, we believe we have a detailed understanding of a diverse range of care models which support people with dementia and their carers where most people want to be- in their home. It is through this lens of our community based dementia support expertise that we provide a response to the Terms of Reference for the Inquiry into Dementia.

Addressing the Terms of Reference

The Australian population is predicted to age over the next 20 years and as a consequence the number of people with dementia is predicted to more than double. Early diagnosis and intervention has been shown to improve the quality of life for people with dementia, as well as for family members and carers.

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

1. improve quality of life and assist people with dementia to remain independent for as long as possible;
2. increase opportunities for continued social engagement and community participation for people with dementia;
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; and
4. how best to deliver awareness and communication on dementia and dementia-related services into the community.

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

From Silver Chain's experience there is a clear correlation between the resources provided to support large scale integrated community care and the positive outcomes derived for people with dementia and their carers. The focus of this inquiry will need to focus on what intervention is appropriate at what stages of the disease trajectory, and how interventions can be sensitive to context, culture, carer support, capability and capacity and be enablement focused. What elements assist people with dementia to continue to live safely at home is a question that could be asked by the inquiry.

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

Evidence supports that social engagement, community participation and general opportunities for connectedness are important for people living with dementia. Group activities for people with dementia can provide stimulation and socialization that help to slow physical and cognitive deterioration. People with early stage dementia can still retain the comprehension ability to enjoy themselves and the physical strength for gentle walks, while suitable group activities for late-stage patients may include listening to music or stroking pets. Even in advanced stages, caregivers may need education and reminding that the person responds to kindness and human contact and feels rejection and pain.

Evidence has also demonstrated that cognitive exercise can slow the trajectory of cognitive decline. Therefore in order to allow social engagement and community participation it is vital that individual programs aimed at maintaining cognitive function are available. These programs also also allow carers to learn practical methods of engagement even in late stage dementia.

Silver Chain employees are educated and skilled in communication strategies when caring for people with dementia. This is a competency that could be extended across all context of the health and care sector. This education is shared with caregivers and other regular providers so that the optimal communication strategies are employed to allow the individual with dementia to have the greatest chance to be heard and to be understood.

Silver Chain, using it’s expertise in the area of dementia is also able to provide optimal health care delivery. As people experience cognitive decline they are less able to communicate symptoms of ill health such as pain and discomfort. In the older person maintaining physical health status is a vital element of comprehensive health care. As Silver Chain are regular, in home visitors to clients with dementia and their carers they are able to pick up on subtle changes in disposition that warrant investigation – thus providing an early detection mechanism for physical ill health.

Importantly broader community understanding is required to ensure that stigma associated with dementia is reduced and that there is broad knowledge and understanding about how to communicate effecetively and sensitively with people living with dementia.

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*

Australian governments, at all levels, have responded to the needs of people with dementia and their carers and families in a variety of ways. However, the resultant system of community care options can be difficult to navigate, complex and fragmented, with the demand for services far outstripping supply. It can be difficult for people with early stage dementia to know what supports will be required and what supports are available throughout an unpredicatable disease trajectory lived within an individual context.

In addition, Silver Chain urges the inquiry to extend to consideration of planning for palliative care. Dementia is a progressive disease for which there is no cure and a palliative approach should be advocated from the time of diagnosis. Issues concerning palliative care for people with dementia include:

- Decision making, communicating and advance care planning to ensure that the wishes of the person are identified and that appropriate ways of interacting are maintained.
- Pain assessment for people unable to verbalise pain. There are a number of tools that have been identified for this population (some developed in Australia).
- Treatment decisions as the disease progresses such as tube feeding or antibiotic use.
- Recognising issues and concerns of carers and family.

Palliative care had its origins in the care of people dying from cancers. As dementia is not widely recognised as a terminal condition, the need for palliative care services for people with dementia at end-of-life has taken time to be acknowledged and hence, people have died in a high level of distress. Few people at end of life with dementia receive the expert coordination and interventions of palliative care services.

Recent research have suggested that a palliative approach from diagnosis could be beneficial because it addresses people's physical and emotional needs as well as the needs of their families and carers. However, there are issues around how such an approach would be delivered and practical considerations around identification of specific palliative care needs which could be addressed with early planning intervention.

In addition, many people living with dementia have existing co-morbidities which will need to receive appropriate treatment and care. For example, the client may not die from the dementia, but from heart disease. Advance planning and expertise in the treatment of such comorbid conditions is required for people living with dementia.

4. *How best to deliver awareness and communication on dementia and dementia-related services into the community.*

Communication and knowledge about dementia related services is fundamental to effective and efficient health and care service delivery. However, this may be problematic particularly if a diagnosis of dementia is not made in the early stages or if the individual or family does not have a significant degree of organizing capacity. Currently a fragmented system can see people not knowing how to navigate, access and coordinate services, but may also result in duplication of services and resources. Services and support for people with dementia can be diverse depending on need. For example, medication support, continence, respite care, domestic care and financial assistance. Knowledge of a very complex system is required which includes adequate support from a General Practitioner. Currently a single gateway or entry point for coordinated dementia sensitive health and care services is not available.

Our research

In our research conducted with clients and carers of the Royal District Nursing Service in South Australia, Carers found support in a variety of ways, which included informal and formal support groups, from families and counselling. With respect to services received, carers received assistance with activities of daily living, such as showering, feeding and continence, equipment and a range of respite services, which included in-home care, daycare centres and longer term respite in residential facilities. These services were funded by a range of sources, including Commonwealth and State governments and by the people with dementia, themselves. Carers indicated that they needed services tailored to the specific and changing needs of both the person for whom they cared and themselves.

The most exasperating aspect for carers related to the complexity of the aged care system. This complexity was reflected by the number of organizations with which some carers had to deal. Carers, medical professionals and service providers (SPs) expressed their frustrations with the difficulty in locating services, which could cater for these people with dementia. The restrictive eligibility criteria of government-funded programs were lamented by carers and SPs, as they impacted negatively on the ability of these organizations to provide continuity of care for their clients. The need for greater numbers of high level daycare places was acknowledged by SPs. Carers and SPs also commented on the limited numbers of hours available through care packages and that more high level care packages were needed, relative to the numbers of low level care packages that were available. The need for a ‘top up’ palliative care package to respond to higher care needs at end-of-life was also mentioned and should be considered by funders.

On the basis of our findings, it can be said that carers and people with dementia need assistance with activities of daily living, such as showering, feeding, continence, equipment: including hospital beds, shower chairs, hoists, wheel chairs, respite services, both in the home, at day care centres and longer term options, a care manager to co-ordinate care and continuity of care workers. GPs would benefit from access to palliative care expertise and information on services available. SPs need flexible funding arrangements to be able to respond quickly to changes in the needs of clients and carers, information about resources available, information about palliative care services and education about palliative care.
On the basis of these findings, a number of recommendations are made, which include:

- Governments at national and state levels:
    - Continue promotion of need for advance care plans to be in place.
    - Devise an educational strategy to heighten awareness, particularly in the acute sector, of the need for health care professionals to respect patient and carer choices as to location and type of care to be provided.
    - Ensure range of respite options, including high level day care, are provided in line with government policy.
- Commonwealth funding arrangements consideration should be given to:
    - increasing level of funding for high level care packages, i.e. more EACH-D packages
    - reviewing eligibility criteria of government-funded projects with view to increasing access
    - introducing a higher level ‘palliative care’ package, providing more intense resources as needed at end-of-life
    - flexible funding options, such that appropriate services can be acquired in a timely manner.
- Education and training
    - training for health professionals in discussing sensitive subjects with patients and carers
    - training for health professionals about the palliative care needs of people with dementia at end-of-life
    - case managers and care workers to be educated in aspects of palliative care.

In conclusion

Silver Chain is excited by the opportunity of a better system of health, care and support for people with dementia. We believe there is an opportunity to achieve systemic improvements but we need to sieze the opportunity to build more capability in the community sector to significantly improve client care. We urge the Inquiry to use the issues raised in this submission when they consider their terms of reference.