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Promoting women's health and wellbeing
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SUBMISSION TO THE ENQUIRY INTO DEMENTIA: EARLY DIAGNOSIS AND INTERVENTION

being conducted by

The House of Representatives Standing Committee on Health and Ageing

Introduction.

The Australian Women's Health Network (WA), in conjunction with Community Vision, welcomes the opportunity to make a submission into the enquiry into ‘Dementia: Early Diagnosis and Intervention.’ As two non-government, not-for-profit organisations serving at the national level and the State level in Western Australia, we are very familiar with the impact that dementia has on persons themselves, their family members and the wider community support network.

AWHN is an advocacy organisation that provides a national voice on women’s health, based on informed consultation with members. Through the application of a social view of health, it provides a woman-centred analysis of all models of health and medical care and research. It maintains that women’s health is a key social and political issue and must be allocated adequate resources to make a real difference.

It aims to foster the development of women’s health services and advocates working in partnership with others on issues affecting women’s health. It coordinates the sharing of information, skills and resources to empower members and maximise their effectiveness. The coalition of groups that comprises the organisation aims to promote equity within the health system and equitable access to services for all women, in particular those women disadvantaged by race, class, education, age, poverty, sexuality, disability, geographical location, cultural isolation and language.

Currently, AWHN has 95 organisational members and 119 individual members, allowing it to engage with women across a broad range of health and well-being issues. Through member organisations, especially women’s health centres and services, it reaches smaller or poorly represented groups, members of which may be socially excluded and marginalised.

Community Vision Inc. is a not-for-profit community service organisation based in the northern suburbs of Perth offering support to seniors, people with disabilities, youth, children and families. Our services provide a variety of options to maintain and enhance quality of life in ways that are meaningful to each individual. All programs are inclusive of people of all ages, with disabilities and also from culturally and linguistically diverse backgrounds.

With dedicated staff, supported by volunteers, Community Vision is committed to delivering accredited high quality services to clients and their families. As an organisation, it prides itself in flexible teamwork which includes listening to and responding to people seeking support to achieve their personal goals and aspirations, thus actively demonstrating the strapline *"What Matters to You Matters to Us"*

The ultimate aim is to empower individuals to be active citizens, exercising their rights in caring communities. It provides a range of services including home and community care services, community aged care packages, veteran's home care, adult day centre care, podiatry and an extensive range of services for people with disabilities, including intensive family support, post-school options, out-of-school care and child and youth respite care.

From our joint perspectives and experience, the Australian Women's Health Network and community vision submit the following underpinning rationale, identified issues and recommendations.

Underpinning Rationale:

Dementia is an umbrella term for the range of currently irreversible changes within the brain resulting in a progressive deterioration of cortical function which impacts on the person's capacity to function independently and is ultimately terminal.

However, the ways that that these changes manifest themselves may be very different in each individual and can be seen as result of a combination of influencing factors, which include:

- the actual changes in the brain itself and the specific areas affected
- the overall physical health and wellbeing of the person and any other pre-existing or new health issues
- a person's previous coping style and reactions to stress
- a person's social history, lifestyle and experience
- the influence of the social and physical environments within which a person is now living.

All these factors combine to influence how people with a diagnosis of dementia will respond to the changes confronting them. How these factors are understood, managed and supported will influence the ongoing wellbeing of the person.

A balanced approach will ensure the best outcome. Likewise, an imbalance in the support available will have an adverse effect on the wellbeing of the person, their families and in some incidences the wider community.

The following issues are seen as the most significant barriers facing people with dementia and the families as they try to adjust to the inevitable changes in their lifestyles.

Issue 1: Early Diagnosis

There are a number of barriers to the timely diagnosis of dementia. These include:

- the current shortage of accessible, reliable information about advanced care planning and advanced care directives

- the current lack of central distribution points at which all relevant information could be made available

- the current lack of appropriate support and counselling services to deal with the emotional stress that may follow from a diagnosis of dementia

- the current shortage of culturally appropriate support and counselling services for members of those communities in which the diagnosis of dementia carries stigma

- the current shortage of strong and comprehensive primary health care services where early diagnosis would be facilitated and where appropriate support and information services could be provided.

Recommendation 1:

That a range of mechanisms, discussed below, be put in place to ensure that adequate and appropriate, non-stigmatising information is readily available in all health settings and online.

Issue 2: Social Isolation and Stigma

Australian society attaches great significance and status to intellectual achievement and physical prowess. An unfortunate consequence of this societal attitude is the sense of shame, social stigma and marginalisation that emerges with decline in cognitive ability.

The ensuing isolation and loss of social supports experienced by people living with dementia is an issue both Community Vision and the members of the Australian Women's Health Network confront on a daily basis. The high risk of increasing isolation at a time of highest need has significant social and economic consequences for the whole Australian society.

Both organisations applaud the work of Alzheimer’s Australia to raise awareness of dementia within our society. However, with the predicted increase in numbers of people diagnosed, we believe a greater emphasis needs to be placed on changing the attitudes of the Australian community.

Recommendation 2:

- That a major National Awareness Programme be funded, developed and implemented. This programme should be similar in intent to the HIV awareness programme or the Prostate Cancer awareness programme. Both programmes were partly successful in changing the attitudes of people towards a disease process previously associated with shame, embarrassment and stigma.
- This programme should be led by Alzheimer’s Australia
- The language used in the programme should be carefully chosen to reflect the inherent value of all people. For example, the WHO term ‘burden of disease’ should be replaced by a term such as ‘effects of disease’. One of the greatest fears expressed by people as they age is that of becoming a burden to others. The WHO term reinforces this fear and associated feelings of shame

Issue 3: The Limits of Social Marketing

We are aware, however, that social marketing, while useful, often fails to benefit those who need information the most, such as low income and marginalised people. The place where most Australians currently receive their primary medical care is in a general practitioners surgery. However, there are serious barriers to the provision of appropriate information in this setting. In the first place, general practitioners are busy and the provision of information is time-consuming. In the second place, the fee-for-service medical practice that we have in Australia encourages fast, high throughput medical care which may be appropriate for treating ailments. But it is quite inappropriate for the lengthy discussions and explanations across multiple visits that people with dementia may need. Moreover, general practitioners are not necessarily well versed in the intricacies of advanced care planning and directives and such work may be a waste of their valuable expertise in treating diseases. We see the community-based health sector as a more appropriate locus for the provision of information and support. There are networks of women's health, Aboriginal health and community health centres spread across Australia, albeit too thinly. In these settings, time can be taken for the lengthy discussions, for information provision and to help connect sufferers and their families with appropriate local services.

Recommendation 3:

We recommend that the non-profit, community-based health sector, including service providing agencies, be expanded and strengthened as an appropriate site for the provision of information and support for people with dementia and their families. This would also vastly increased the capacity of the health system to provide preventive health services and health advice.

Issue 4: The Need for a Gender Perspective.

A quick search of the research literature and public policy discussion shows that "people", "patients" and "sufferers" are affected by dementia. There is generally no mention of "men" and "women". Yet it is well documented that all diseases impact upon men and women differently and also that the different social and economic conditions in the lives of men and women mean that they are in very different positions when facing a diagnosis like dementia.

Especially in the older age group, that Australian women have fewer economic resources and lower social status. Such a situation means that women are less able to purchase support services, such as counselling and advice that are so critical in the early stages. It also influences the capacity to arrange appropriate future care needs because of lack of resources. Older women are still one of the poorest groups in Australian society.

The latest national data on dementia was produced by Australian Institute of Health and Welfare in 2007. [1] The findings were that "people with dementia are mostly older women" (p xiii). In 2003, 64% of people with dementia were female and 81% of those were aged 75 years or more. Approximately 37,000 new cases of dementia are diagnosed each year, of which 23,000 are female and 14,000 are male.

Moreover, the research found that "the carers of people with dementia are mostly older women" (p xiv). About three quarters of carers were in a partnership or married arrangement with those for whom they cared. Because women live longer than men, they are not only more likely to develop dementia but they are far less likely to have a partner to care for them if they do.

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[1] Australian Institute of Health and Welfare (2007) *Dementia in Australia, national data analysis and development*, available at www.AIHW.gov.au.

A further complication of this situation is that many women reduce their workforce participation at an earlier age than men in order to carry out caring, further undermining their capacity for economic independence. Carers (predominantly women) have also reported feeling weary, tired, depressed and socially isolated due to their caring duties (AIHW 2007: xv).

Conversely, while the more specific needs of women have been researched, those of men living dementia themselves or in a caring role do not appear to have received the same scrutiny. From our experience men tend to find it more difficult to express their emotional needs but may find it easier to seek out support services.

What is clear is there is a lack of awareness of the differing needs of men and women both as carers and as sufferers of dementia.

Further information in this area may lead to a more effective focus of available services.

Recommendation 4:

That a gender lens be employed in all research and public policy on dementia, given that the condition affects the sexes differently.

Issue 5: The Need for Coordinated Comprehensive Support Partnerships

There is strong evidence that early diagnosis with planned support and intervention can greatly influence the overall wellbeing and continuing independence of persons with dementia and their families.

However, early diagnosis alone without ongoing support can be devastating.

Significant resources have been committed to improving the diagnostic skills of general practitioners in this area of health. However, the workload of general practitioners rarely allows time for the critical issue of future lifestyle planning.

Explanation of and support in planning an advanced care directive requires time and sensitivity to ensure full understanding. While this needs to be done with support from general practitioners, a better model is where early diagnosis from a medical practitioner can be combined with sensitive, skilled, support from well trained professionals. This will enable people to maintain greater control of their lives and plan ahead more effectively and without feeling pressured.

The key factor in this process is time. Time is needed to allow people to ask questions, to discuss their fears and to begin the emotional adjustment required.

Community Vision and the Australian Women's Health Network are aware that the key issues of concern to people are a combination of both medical and social issues. These include the following:

- Uncertainty about how the diagnosis this affect future lives? (including advanced care directives)
- Uncertainty about medication and treatments are available?
- Financial concerns and advice about future lifestyle needs

- The need to have time to express fears, grief, anger and we emotional stress that may follow from a diagnosis of dementia
- The need to establish a consistent ongoing relationship with 1 or 2 support people to create a focal point and sense of security
- The knowledge that support workers are in close liaison with all members of the support team, including medical practitioners.

Early automatic connection to a structured, coordinated, ongoing support service has the potential to become the most effective intervention strategy to assist people to maintain their overall wellbeing and decrease dependency.

In the short term, the community-based health sector, the networks of women's health, Aboriginal health and community health centres that are strung across Australia, albeit too thinly, are seen as the most appropriate site for the provision of information and support for people with dementia and their families. In these settings, time can be taken for the lengthy discussions, for information provision and to help connect the person with dementia and their families with appropriate local services.

In the longer term, a more proactive, structured, collaborative and accessible support network needs to be put in place, under the combined umbrellas of community-based primary health care teams and relevant medical practitioners.

Recommendation 5:

- That an approved, collaborative, support service framework be developed to respond to identified customer needs.
- That these needs be identified through direct feedback from the customer groups concerned, either from survey or representative focus groups.
- That general practitioners and other primary health care providers be required to establish a formal link with an approved support service staffed by health professionals specifically trained in the social and economic consequences of dementia.
- That the existence of this service be widely advertised.
- That support services have established links with general practitioners and/or community-based health care services, even in far-flung geographic locations.
- That funding to significantly subsidise this service be approved so that all people have equal access.

Issue 6: The Need for a Culturally Sensitive Perspective.

Research has shown that attitudes towards dementia differ between people from differing cultural backgrounds.

In some communities, a dementia diagnosis carries with it a great deal of stigma. Such attitudes may impose a wall of silence around symptoms of dementia and around diagnosis, thus erecting barriers to obtaining the appropriate information and to putting into place advanced care plans and directives.

The AIHW found that between 16% and 18% of people living with dementia had been born overseas in non-English speaking countries (AIHW 2007: xiii). Additionally, a "significant proportion" of dementia carers have been born in non-English speaking countries (AIHW 2007: vix).

Research and public policy should also be especially sensitive to the position and needs of Aboriginal Australians who develop dementia.

Recommendation 6:

The Australian Women's Health Network and Community Vision recommend that a culturally sensitive lens be employed in all research and public policy on dementia.

Issue 7: The Need for a Lens which Recognises Previously Existing Disability.

One of the most disadvantaged groups in the Australian community is people who have experienced or are experiencing disability. Such people are generally in less secure positions, physically, financially and socially and are thus have reduced capacity to cope with the ramifications of a diagnosis of dementia. People experiencing a disability have less chance of obtaining relevant information in a timely way and have fewer resources which might be allocated to future caring needs.

Recommendation 7:

That special attention be paid to the position of people with pre-existing disability in all research and public policy discussions on dementia.

Summary

Overall, people living with dementia have a heightened need for strong connections and stable consistent relationships with others within a community environment, where they can maintain a sense of personal identity, purpose and belonging. Ideally, people would benefit from access to comprehensive, community based primary health care services. She

Without this strong community support network both people and their carers are at high risk of social isolation with the ensuing risks of a crisis situation developing, necessitating high cost and labour intensive interventions. Such crises are detrimental to the person, the carer and to the community as a whole.
This enquiry into the early diagnosis and intervention services, both current and potential, available within Australia is extremely timely and is welcomed by both the Australian Women’s Health Network (WA) and Community Vision.

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