

5. INQUIRY REGARDING DEMENTIA CARE

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The purpose of this report is to advise the Council of a proposed inquiry into the standard of care for people with dementia (Dyson 6/601). The report recommends that the Council write a letter supporting a full scale review, requesting the development of a national strategy and seeking Council input into the review and strategy.

INTRODUCTION

Dementia is a problem that affects a substantial number of people and has major social and economic implications.

The Council has an interest in this issue due to its concern for and role as advocate¹ for the well-being of the people of Christchurch. The Council's experience in housing of the elderly and in developing, implementing and advocating for quality standards in other areas of care such as childcare, out of school care and community facilities means that it could add value to an inquiry and strategy.

The Council is a provider, funder or part-funder of a wide range of social and community services that contribute to the health and well-being of residents. It can therefore contribute to an integrated approach to service provision, particularly community based service, for those with dementia and their caregivers and family. It also has a potential role in health promotion and public awareness programmes.

The issue aligns with the Council's Strategic Goal of "advocating for quality health and disability services" and "providing or facilitating the delivery of services and opportunities in order to enhance the safety, health and well-being of Christchurch people". It also aligns with Council policies, such as the Social Well-being, Disability and Older Persons policies.

BACKGROUND

Over the last year The Press has reported that there is a 'growing crisis' in the standard of care in many rest homes and specialist dementia units. These reports were prompted by the killing of a 93-year-old dementia patient by another patient at a Christchurch rest home in September last year. This incident also motivated the Ministry of Health to undertake an audit of 12 Canterbury rest homes. "Those investigations revealed problems ranging from poorly trained, overworked staff, and lack of individual care, to shoddy medication practices." (The Press, 6 June 2001).

Alzheimers New Zealand have argued that the problems identified at those 12 rest homes are likely to be evident elsewhere. Alzheimers New Zealand is calling for an inquiry into the standard of care in rest homes and dementia units.

Associate Minister of Health Ruth Dyson has expressed concern regarding the care of older people in rest homes and dementia units. She said it was unacceptable that elderly people in vulnerable situations are being left without the support and care they deserved.

"I am very concerned about what is happening. If it was happening to our children there would probably be a nationwide outcry. It is of comparable concern to me that it is happening to our older people because they are just as vulnerable." (Dyson, 9 June 2001)

Hon Ruth Dyson has asked the Ministry of Health for an urgent report on audit processes and other related matters.

Professor of Older Persons' Health at the Christchurch School of Medicine, Dick Sainsbury, is backing calls for an inquiry into the standard of care in rest homes and dementia units. Professor Sainsbury stated that " a large number of rest homes are doing a good job and providing good care – but there are some that are failing in their duty to provide care and protection for our vulnerable elderly." (The Press, 9 June 2001.)

Dementia services have traditionally fallen between the gaps of mental health services, health of elderly and disability support.

¹ Council's advocacy role is particularly important since people with dementia are not usually able to advocate for themselves.

The Government is in the process of introducing the Health and Disability Services (Safety) Bill, which would replace the existing licensing regime with a new process of certifying and auditing rest homes against a single set of revised service standards. The New Zealand Health Strategy 2000 has ten goals and 61 key objectives. Under the goal of 'Better Mental Health', the strategy has an objective of "reducing the impact of dementia". A review of services and national dementia care strategy would aid the implementation of the bill and the 'Better Mental Health' goal.

IMPACT OF DEMENTIA

Dementia constitutes a public health problem of considerable magnitude. It not only has a significant impact on the life of the person affected, but also their families, the community and the health and social services.

The dementias are a group of disorders characterised by deficits in cognition, of sufficient severity to cause a decline in social, occupational and personal functioning. "The dementias are devastating illnesses and responsible for considerable morbidity and mortality" (Ellis and Collings 1997:412). The most common causes are multi infarct and Alzheimer type.

Dementia disorders most commonly affect the elderly population, but some, such as AIDS dementia complex, Huntington's disease, Pick's disease, alcohol-related dementia and hereditary presenile dementia, affect younger people (Ellis and Collings 1997).

All the dementias have complications that reach beyond the sufferer. Expensive facilities and services at substantial social and financial cost are needed for their management. While many of the dementias are incurable, to some extent their complications may be preventable (Sainsbury et al 1997).

Irrespective of the cause of the dementia, there are substantial risks for complications that cause greater disability and increase the need for care. These are often treatable and preventable. Social factors such as the amount of support given, social stimulation or isolation, and anxiety or depression can all influence the impact of dementia (Ellis and Collings 1997, Sainsbury et al 1997).

Dementia affects people's physical, emotional and intellectual capacity. People's capacity to protect themselves decreases as their judgement declines, for example, they may attempt to pick up a hot element because it is glowing, do not recognise scolding water, and do not understand traffic safety.

"Cognitive impairment, memory loss and failure to attend to their personal care always occur in dementia, which has a deteriorating, progressive course.... The behavioural and psychiatric complications of dementia are many. They include features of psychosis such as hallucinations and delusions, depression, anxiety, agitation, wandering, challenging vocalisation and diurnal rhythm disturbances." (Burns et al 1990a, 1990b, 1990c, 1990d; Becker et al 1994; Lykestos and Rabins 1994). (Ellis and Collings 1997:413.)

About 38,000 people in New Zealand suffer from dementia, and that number is expected to double in the next 20 years. New Zealanders over 65 years have a one in twenty chance of developing dementia, or a one in five chance if they are over 80 years (Sainsbury et al 1997). The growing absolute number and increasing proportion of elderly people in the population mean that disorders affecting older people will have a greater impact on society, for example, dementia. The proportion of the population aged 65 years or over is projected to double over the next 50 years.

In Christchurch, both the number and proportion of children is expected to shrink while the city's elderly population will continue to swell. The wide-ranging effects of Christchurch's ageing population will become much more pronounced from 2011, when the baby boomers start to reach retirement age. As the absolute number of people with dementia increases, services to support both sufferers and their caregivers will be necessary (Update 2000).

Christchurch Projected Population



Source: Statistics New Zealand, Population Projections (Adjusted 1996 Base).

SCOPE OF REVIEW

While the issues surrounding residential care are of critical concern, there is a need for a national strategy on dementia. A national strategy should take an integrated approach and include public health initiatives, primary health care, community-based services and research as well as tertiary services and rest home care.

Approximately 80% of people with dementia are cared for at home; only 10-20% reside in institutions. As a result of the increasing absolute numbers and the capping of expenditure on hospital or health service-based services, there has been an increasing trend worldwide as well as in New Zealand for more reliance on informal caregiving. Cost-shifting from the health to the community sector is not without impact on the community in terms of caregiver morbidity. The literature on caregiver stress indicates that services for the patients alone are insufficient and that services need to be designed with caregiver needs in mind as well (Ellis and Collings 1997).

Primary health care and community-based services are therefore central to ensuring appropriate care for people with dementia and support for caregivers (including support groups, counselling services, social work services, day care, sitter services, night care and information services).

Similarly, programmes promoting public awareness and understanding are also important. Health promotion can reduce problems. Early detection and treatment could reverse impairments or modify subsequent morbidity of disability from some types of dementia. Scientific and treatment studies of biological, psychological and social effects of dementia are needed.

It is critical that any review of care for people with dementia takes a broad approach and a strategy is developed that includes all services, including primary health care, community services and caregiver services.

BASIS FOR COUNCIL INVOLVEMENT IN REVIEW

The Council has a number of reasons for wishing to be involved in the review of care for people with dementia.

1. **Concern for well-being of residents** – the Council prides itself in its concern for the quality of life of its residents. It has a national and international reputation for being a progressive local authority based on its active involvement in social issues. It is important that the Council work to ensure the city's most vulnerable members receive the care they need. Because dementia can also cause morbidity in others and there is considerable carer and family stress, this will be an issue affecting an increasing number of residents.

2. **Experience in advocacy for quality standards** – the Council has played an active role in advocating for the development and implementation of quality standards in early childhood education, out of school programmes and in community facilities. Advocacy in these other areas has set a precedent for advocacy for quality standards in this area. The experience of developing, promoting and implementing standards also means that the Council could add value to an inquiry.
3. **Expertise in housing for elderly** – the Council’s experience in housing of the elderly means that it has developed a level of expertise in housing provision and in the integration of support services with housing services.
4. **Community-based services** – the Council is a provider, funder or part-funder of a wide range of social and community services that contribute to the health and well-being of our people. Given that approximately 80% of people with dementia are cared for at home, community-based services are central to ensuring appropriate care for people with dementia and support for caregivers (including support groups, counselling services, social work services, day care, sitter services, night care, and information services). As a funder of and adviser on community services the Council has a role contributing to an integrated approach to service provision for those with dementia and their caregivers and family.
5. **Experience in health promotion and public education** – the Council is actively involved in health promotion. It also has expertise in public education and awareness programmes. This experience means that the Council is in a good position to identify appropriate public health strategies related to risk factors that influence dementia and in developing strategies to increase community understanding.

STRATEGIC FIT WITH THE COUNCIL’S OBJECTIVES AND ROLES

1. **Strategic Statement** - The Council’s vision identifies that *“Everyone has access to good housing and health care ... and ...the elderly are respected”*. The Council’s Strategic Goal of Community Cohesion and Well-being identifies *“providing or facilitating the delivery of services and opportunities in order to enhance the safety, health and well-being of Christchurch people”*. It also states that the Council will *“advocating for quality health and disability services.”*
2. **Social Well-being Policy** - The issue aligns with key Council policies including the Social Well-being Policy. For example, a policy priority is *“ensuring services are appropriate to community needs”*.
3. **Disability Policy** – the Council recently developed an Equity and Access Policy for people with disabilities (including mental health conditions). Dementia is one of the major causes of disability in the elderly, affecting personal care, everyday cognitive activities, and social behaviour (Jorm, 1994). Prevention of dementia would make a major contribution to the postponement of disability in old age. Irrespective of the cause of the dementia, there are substantial risks for complications that cause greater disability and increase the need for care.
4. **Healthy Christchurch (Public Health) Strategy** - There is an important role for education of the general public on risk factors that influence dementia. Channels for this include the media as well as specific health promotion programmes. There are several community groups and agencies whose main interest is the quality of life of the people with dementia (eg, Alzheimer’s Society and Age Concern), which could have a role in disseminating health information. Health promotion can also reduce the risks that cause greater disability and increase the need for care.
5. **Older Persons’ Policy** – the vision of the Older Persons Policy states that
“Christchurch is a city where older persons are valued and respected; are safe and secure ... and where diversity among older people is recognised and respected”
6. **Third Age** – discussions with the Third Age Co-ordinator confirmed that this issue does not fit within the scope of the Third Age Project.

Recommendation:

That the Council write to the Minister of Health and Associate Minister of Health seeking:

- (a) A full-scale review of dementia services (including residential care, primary health care, community services and caregiver services)
- (b) The development of a national strategy for dealing with dementia and
- (c) The Council's involvement in such a review.