



**National Council of
Women of New Zealand**
Te Kaunihera
Wahine O Aotearoa

National Office
Level 4 Central House
26 Brandon Street
PO Box 25-498
Wellington 6146
(04) 473 7623
www.ncwnz.org.nz

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**Submission to Standards New Zealand on DZ8134.6
Guidance for Community Services
for People with Dementia and Audit Workbook**

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 40 nationally organised societies. It has 32 branches throughout the country attended by representatives of those societies and some 150 other societies. The Council's function is to serve women, the family and the community at local, national and international levels through research, study, discussion and action. NCWNZ has a longstanding history of encouraging the promotion of social and health issues, particularly as they affect women.

NCWNZ has in recent times addressed similar questions and proposals relating to the management of people with dementia.

In 2004, in a submission to Standards New Zealand, "DZ 8163 Staffing Effectiveness Indicators for Residential Aged and Dementia Care" the comment was made that, "There needs to be adequate provision for the safety, in terms of training and numbers of staff available to handle aggressive residents." NCWNZ believes that this is likely to be more difficult to handle in the community situation.

In 2005 a submission to the Ministry of Health, entitled "Ageing New Zealand and Health and Disability Services Demand Projections and Workforce Implications 2001 - 2021" contained the following, " In 1995 a submission to the National Advisory Committee on Core Health and Disability Support Services stated, "Older people are staying in the community longer and we welcome this trend. However, this puts an increasing burden on the carer and family members. Many carers, spouse or family members, are older people themselves and their own health could be jeopardised by the burden of care. The stress of caring for an older person in a family situation can be high. Increasing demands on finances can sometimes result in physical or emotional abuse and neglect and we would hope that planning ensures support for carers, that their needs are met and respite care is available."

Also in 2005, NCWNZ wrote to the National Health Committee, in a submission entitled, "People with Chronic Conditions" that, "Supporting people with chronic conditions in an holistic way has always been an important part of primary health care services. Such an approach is essential, as patients need to be able to access a range of services on an ongoing basis to give them the best possible quality of life. They also need the support of family and the community. The patient and the support team require access to appropriate information, resources and financial support. Traditionally primary health care nursing has been under-resourced. It has also been noted that there is very little resourcing of social workers and counsellors in the primary health care services.

Education of the person and the family/whanau and empowerment of the person to be involved in health decisions is important. This is best managed if there can be home visiting at some stage in the assessment. An assessor or advisor who interviews only from a clinic/office may not





appreciate the problems and obstacles in living with a chronic condition. By home visiting those close to the client can be included in the education process and gain a greater understanding of the support needed. “

All these observations would seem to be as equally appropriate for those with dementia as for the aged and those with chronic conditions. NCWNZ recognises that the aged, those with chronic conditions and those with dementia may well be the same people, although not always.

Branches and other interested parties were asked to comment on the following information provided by Standards New Zealand.

Community Care Services

In order to achieve a high-quality standard of care, people living with dementia in the community and their families/whanau need:

- (a) Access to appropriate, professional assessment, early identification and diagnosis;
- (b) Education and training for family/whanau, carers and health professionals in the specialised area of assessing the needs of people with dementia to ensure access to appropriate and timely services;
- (c) Active partnerships between family carers, people with dementia, professionals and service providers in the planning and provision of services;
- (d) Education and support for family/whanau carers and service providers in care giving and the management of issues arising during the course of dementia;
- (e) Flexible, coordinated and individual care routines and individualised care-plans;
- (f) Appropriate intervention through therapies, activities, advice and support;
- (g) Protection from abuse or exploitation;
- (h) Environmental adaptations to optimise home care;
- (i) Special attention to the needs of younger people with dementia (under 65 years of age) and people with pre-existing disabilities;
- (j) Special recognition of the needs of Maori, Pacific and Asian people, and people with dementia from other ethnic groups; and
- (k) Good governance, dynamic leadership and a supportive management culture in the home care service providers.

Questions

- 1 Are there any issues that you believe have been omitted from the list above?
- 2 If yes, please elaborate.
- 3 Are there any issues arising from the list above that you feel need to be addressed?
- 4 If so, please elaborate.

Based on the 4 questions above, the following is a summary of their comments.

Questions 1 and 2

Are there any issues that you believe have been omitted from the list above?

Respondents regarded all the issues as relevant to dementia. The issues that need targeting are;

- (a) Access to appropriate, professional assessment, early identification and diagnosis;
- (c) Active partnerships between family carers, people with dementia, professionals and service providers in the planning and provision of services;
- (d) Education and support for family/whanau carers and service providers in care giving and the management of issues arising during the course of dementia;
- (k) Good governance, dynamic leadership and a supportive management culture in the home care service providers.



Other issues that were regarded as not being sufficiently covered are:

Enduring Powers of Attorney need to be discussed with the family, and especially the person with dementia, before they get to a stage where they cannot understand what is being proposed.

One respondent noted, that while the Community Care Services listed seem entirely appropriate, it is important for people who become care givers to know how to access what help is available. Such help is available through GP's, hospital clinics, Disability Support Services, Alzheimers Association, etc. The critical point here is that there must be good communications between all of these agencies if the job of the care giver is not to be made even more difficult.

Care givers going into homes are often not fully trained. Sometimes care givers are not able to cope with difficult or aggressive situations. In some areas training options are not being taken up by people who might have considered this as a field of work. There also appears to be a real lack of education in the area of rehabilitation/habilitation that includes injury prevention for both the care giver and the person being cared for.

Questions 3 and 4

Are there any issues arising from the list above that you feel need to be addressed?

Appropriate education must be implemented for assessors.

Plans for regular periods for 'time out' or respite care for home care givers need to be part of the assessment process and put into the subsequent individualised care plan of the person with dementia. The individual care plan needs to include a 'transfer plan' for the time when home care is no longer possible. It is important that the options for this plan are explored and worked out before the situation requires it. The individual care plan should be made from a 'strengths base' rather than from a 'problem base.'

There also needs to be more public recognition of dementia and other related conditions so that people know how they could support a family trying to deal with a family member with dementia. The message needs to be got out to the community. The mental health advertisements are very powerful and they help to demystify the issue for many people. There needs to be advertising of the no shame message and encourage care givers to get early help. Because of this not knowing, some cultural groups continue to keep their relative at home because of the shame factor.

More adequate financial assistance is needed for those who give up work to become home carers of family members with dementia. Access to funding to assist with care, household modifications, legal advice, etc should be taken into consideration. There also needs to be a better way of ensuring that people who need the newer, and undoubtedly, more expensive medications, are assisted in some way to get these.

All agreed that home care is desirable for as long as the family/whanau can cope, but patient safety has to be balanced with the care giver's physical and mental health and safety. Spouses and families are not trained to look after dementia patients. It is possible that care givers are putting themselves at risk of stress related conditions, because they feel that they cannot cope. No one should be made to feel guilty about admitting they cannot cope and having to admit a family member to round the clock professional care.

Residential homes need to be more attractive places, where relatives will feel happy leaving the person suffering from dementia. They should have areas where visitors can be alone with the



patient in a pleasant environment. Unfortunately, in some areas there are not even enough residential homes, so choice is very limited.

As one respondent put it, “The crying need is for carer relief to be provided in both the home of the demented person and dementia residential facilities. It is all very well to set high standards but the amount of allocated support is severely limited by government needs assessment policies and insufficient funds. The threshold limit for receiving home support is a lot higher now than it used to be, and it is getting increasingly harder to get carers because they are paid so poorly, and no petrol allowance!!!. The family (usually the woman) carries a 24/7 load in looking after a stranger who looks like their husband/relative, but doesn’t recognise them or respond to them. The majority of dementia sufferers are cared for by their families. Are families going to be subject to these standards? A quality service is no good if there is not enough to go round.”

Rural Women who are also members of NCWNZ have stated, “For good stable home based care training must be available to carers, as well as a career path and adequate remuneration for travel costs. Those with dementia react poorly to disjointed services and changing support people. It is often forgotten, when looking at a problem, that not all clients live in rural areas and this needs to be reflected in providing for those in more remote areas, e.g. Northland, King Country, West Coast, South Island.”

Specific Comment.

The UN Principles 5 and 10 were clear and succinct.

(b) and (d) Respondents were generally positive about the need for education of family/whanau, care givers, professionals and other service providers. However, the question still remains about where we are going to get these care givers, both in the community and in residential care facilities.

(g) Protection from abuse or exploitation. Protection from abuse is a three-way problem, namely abuse by the patient, by the care giver and the mental health system. This section should thus be widened to include protection from the care giver and protection for the care giver from the person with dementia.

(h) This was looked at in conjunction with the UN Principles. Respondents preferred the wording, “an environment adapted to optimise home care.” To some people the phrase, “environmental adaptations” could be confused with chemical and climatic environments.

(i) It was unclear if it was the disabled who develop dementia or those who, because of being under 65 years of age fall through the system where neither dementia care or disability services will care for both problems. NCWNZ understands that there are different funding criteria for disability services for those under the age of 65.

(i) and (j) It was suggested that instead of “*special attention*” and “*special recognition*” a change should be made to “*attention to/recognition of any special needs of ...*” thus focussing on the needs rather than the attention or recognition.

(j) Cultural sensitivity should cover everyone. Each person is an individual who requires kindness and consideration as well as health and physical care 24 hours a day.

(k) “...supportive management culture in homecare services provider.” This needs to be supported by adequate hourly rates. At present pay is by the hour over 7 days, but the Holidays Act requires extra pay for public holidays. While this has been promised by the Ministry of Health (MoH), it is



slow to arrive. Management costs have to be squeezed out of the low hourly rate given by the District Health Boards (DHB) and MoH, for the assessed person. This together with increasing petrol costs mean that many good people are leaving the sector and so we are losing professional experience.

NCWNZ finds that the setting of standards for care of people with dementia, particularly in the community to be laudable. Our concern is that some of these services are already available but that there is not enough flexibility to fully realise the unique needs of the individual and their family/whanau, or care givers.

NCWNZ recognises the need for standards to protect both those providing the service and those receiving these services. However, it is how these standards are managed into the system that concerns us. This sector is already losing care givers, for reasons already mentioned. Together with a decreasing numbers of residential care facilities able to cope with people with dementia, it may well seem that standards will seem to be imposed rather than taken up. The end result could be that there are even fewer resources available to family/whanau and care givers.

NCWNZ thanks you for this opportunity to comment and looks forward with interest to the outcome of this consultation.

Christine Low
National President

Catherine Gurnsey
Convener, Health Standing Committee