



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

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Submission to the National Health Committee on: People with Chronic Conditions

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 41 nationally organised societies. It has 33 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.

The comments contained in this submission are collated from members of the Health Standing Committee and other interested parties.

NCWNZ has, over many years, addressed the problems associated with chronic conditions. In 1899 a resolution was passed stating, "That special homes or hospitals for the reception of chronic cases be established in centres in the colony." Several resolutions were passed with regard to traumatised soldiers returning home and how they were to be cared for. In 1988 a resolution was passed, "That NCW urge the Minister of Health to ensure that an adequate proportion of the funds allocated to Area Health Boards be available for community-based support services." It would appear that many of these issues are still with us and at some time they must be addressed.

Earlier this year NCWNZ completed a submission to the Ministry of Health on: "Ageing New Zealand and Health and Disability Services Demand Projections and Workforce Implications 2001 - 2021." Many of the issues addressed in this submission are very similar to those being addressed in this submission. It should be possible to address many of the issues jointly.

SPECIFIC COMMENTS

Definition of People with Chronic Conditions

Do you agree with the NHC's definition of people with chronic conditions?

NCWNZ agrees with the definition, *"including people with any ongoing, long term or recurring condition that can have a significant impact on a person's life."*

NCWNZ is pleased to note that the discussion paper recognises that some people have more than one chronic condition, and others live with multiple conditions. The National Health Committee (NHC) should also be commended for recognising the need to address the spiritual well being as well as the physical health of people with chronic conditions.





Section 2: Approaches to Supporting People with Chronic Conditions

What are your views on the best way/s to approach chronic conditions in New Zealand?

NCWNZ believes that early identification of chronic conditions has a significant bearing on improving outcomes and assists individuals in coming to terms with prognoses.

Supporting people with chronic conditions in a 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.

What lessons can we learn from existing models to improve how people with chronic conditions are supported?

Primary health care services need to be adequately resourced to be able to focus more on the prevention of some chronic conditions and their complications. In the recent past the General Medical Subsidy payment has been severely eroded, making access to services for many people with chronic conditions very difficult.

The Leading for Outcomes programme, as outlined on page 15, is praise-worthy in that it uses a population health approach that identifies patterns. An example of this occurred a number of years ago when Dr Sandy Milne identified the need for hepatitis treatment in the Bay of Plenty region. This study also showed that identification of a condition without the persistent follow-up that Dr Milne pursued is useless.

The Counties/Manukau chronic care management programme is also praiseworthy but it is questionable as to whether a busy GP would have time to chase up patients who don't bother to seek the on-going treatment/supervision that they require. It could also be argued that some individuals must be made aware that they have responsibility for their own well being, e.g. people with heart conditions who, against medical advice, continue to smoke.

It was surprising to note that the Counties/Manukau chronic care management programme does not include the psychiatric group as well as the neurological disease groups, such as MS and Parkinsons. These groups would also require similar services to those provided for the groups listed, e.g. congestive heart failure, diabetes, asthma, etc.

The Counties/Manukau chronic care management programme has a strong emphasis on cultural competence. It should be noted that in the case of people with diabetes and those who suffer from cardiovascular disease, many also have an obesity problem. These problems occur across all cultures. The Manukau Branch of NCWNZ has made several submissions to the Manukau City Council to have more time made available to these people to have sessions in the swimming pool as part of their exercise programme. These sessions may need to be held in the mornings and evenings to allow those who work to be able to take part. Further, there should be more swimming pools built to ensure people with chronic conditions have a chance to take part in regular exercise.



NCWNZ believes it is essential that whatever model is used, it is necessary to use opportunities to positively reinforce those that self-manage well and not just leave them to get on by themselves, or take them for granted.

Continuous rather than episodic care is more likely to result in positive outcomes for the person and their family.

Existing models have gaps because of a lack of seamless referral systems. People fall through the gaps between providers. Providers and professionals who do not talk to each other are thus unaware of what other providers do.

What other key initiatives are going on around New Zealand (that are not included in Appendix 2)?

Implementation of the Primary Health Care Strategy and importantly, adequately resourcing the implementation, is a very important step forward in providing better care for people with chronic conditions

One way to approach the management of chronic conditions is to coordinate the primary and secondary healthcare systems with the community/patient/family support networks, including educational services.

Cultural issues sometimes impede appropriate health care access and having the appropriate community support networks in place will improve timely access. An example of a successful initiative in the Manawatu is the implementation of The Palliative Care Strategy. Over the last 2 years there has been a memorandum of understanding agreed between the specialist hospice service and the IPA GPs resulting in a coordination of services. More specialist nurse Care Coordinators have been appointed. Increased training for GPs, rest home nurses and practice nurses has been extremely successful. A social worker and chaplain were appointed to the hospice team and are proving invaluable.

Support for self-managing chronic conditions

Do you agree with the National Health Committee's definition of self-management?

NCWNZ agrees with the NHC definition of self management, i.e. "*people with chronic conditions having greater control in looking after themselves, with the support of their families/whanau (where desired), and in partnership with health professionals and community resources.*"

One respondent expressed concern that the wording 'shared care' or 'shared management' should be included in the definition

What role do you think self-management has in living with chronic conditions?

NCWNZ agrees that self-management with support and training should provide important benefits for participants. It is vital the programme be well supervised and must never be a way for authorities to off-load the responsibility onto the shoulders of family/whanau or the community.

In any self-management programme the following should be remembered:

- Empowerment is an important component of self-management.
- The programme needs to be tailor-made for each individual.
- A range of options should be available and the best one selected by or for the individual.
- Psychological support may be required to enable a person to make an appropriate decision about the elements of self-management that could be beneficial.

Do you think self-management should be better encouraged and supported in New Zealand, and if so, how?



NCWNZ recognises that most primary health care services encourage self-management as much as possible and that this is a vital part of the service. However, some people with a chronic condition require more support than is usually available in general practice and having other community service options is therefore necessary.

Ways to encourage and support self-management could include:

- Education of health professionals as well as identified patients and their families.
- Ensuring that funding is available to support self-management options.
- Ensuring that staffing levels are appropriate and available.
- Monitoring and support for delivery personnel.

Role of Complementary and Alternative Care

What role do you think complementary and alternative medicine has in living with chronic conditions?

Although there is very little evidence-based research to show that many of these treatments are effective, respondents were open-minded to the potential value of complementary and alternative medicine (CAM). If appropriate decisions are to be made about CAM, patients, GPs and others need to have access to quality information about alternative treatments, their possible benefits and adverse effects. It is important that patients keep their GPs/lead care providers informed about alternative treatments they have chosen to use.

Do you think complementary and alternative medicine should be better encouraged and supported in New Zealand, and if so, how?

In 2003 NCWNZ, in its submission to the Ministry of Health on, “Complementary and Alternative Medicine in Current Policies and Policy Issues in New Zealand and Selected Countries” stated, “that integration of CAM modalities into mainstream medicine should be carried out slowly and selectively.” At the time there was not enough evidence-based research done to show the efficacy of these treatments, or their adverse effects. To date there would appear to be no great advances in the research, or registration of practitioners of CAM under the Health Practitioners Competence Assurance Act 2003 for NCWNZ to change their recommendation.

If, and when, CAM modalities are proven to be beneficial they should receive appropriate funding to ensure that they don’t become an option only for those people who can afford them.

Section 3: Summary of Issues - People with Chronic Conditions

Do you agree that these are within the main factors that help people with chronic conditions?

The factors listed were as follows:

- Support from others and self-help groups.
- Relationships with health professionals and NGO’s.
- Income, employment and transport assistance.
- Individual factors.
- Spiritual health.

Respondents generally agreed that all the factors mentioned are important for people with chronic conditions.

If not, what other factors are important?

Other factors that respondents considered important included:

- Suitable housing.
- Improving access to quality primary health care.
- Remaining as part of the community as an aid to maintaining or improving socialisation.



- Regular training for providers and for them to come under an Accreditation programme in line with other professional health workers.

What suggestions would you make to help improve the ways that people with chronic conditions are supported?

Respondents suggested the following:

- People living alone could be connected to a telephone be-riender service.
- Support for self-care management.
- Care-plan where the person concerned sets their own goals.
- Management of medication.
- Use of teams, including allied health professionals.
- Trained volunteers for some tasks.
- Shared information across all relevant health providers.
- Collaboration with other services such as housing, employment, transport, etc.

What is the role of spiritual beliefs and practices in helping people live with chronic conditions? How can these be better addressed by health and other services?

Spiritual beliefs are important in holistic care and improving awareness of their importance would help. Awareness of different cultural practices would also help.

The work of the Hospital Chaplains should have the full support of the Health Authorities and perhaps the service could be extended to include patients living in the community, especially those who have no access to a church. The same support could apply to kaumatua and spiritual leaders of other cultures.

Part 2: Factors that hinder people with chronic conditions

Do you agree that these are the main factors that hinder people with chronic conditions?

The factors listed were as follows:

- Lack of coordination (within health and between health and other agencies)
- Societal attitudes and myths about chronic conditions.
- Inadequate information for patients.
- Transport.
- Income/employment.
- Problems with support services to help in the home.
- Access to services and facilities.
- Mental health and emotional factors.

Respondents agree that the factors mentioned are the main factors hindering people with chronic conditions.

If not, what other factors are important?

Other factors that respondents considered important included:

- Education of health professionals.
- Improving primary health care health services, especially with financial support, would go a long way to meeting some of the needs mentioned.
- Provision of social workers and counsellors in the primary health team would provide a more holistic approach.
- Advocates to assist and support the patient and carer especially over holidays and weekends.
- High cost of medication. One respondent gave an example of a relative who was at risk of losing her home as a result of the high cost of her own medication. The medication for her condition is expensive. She gave up her job and went on a benefit to look after a 90-year-old father, who had arthritis and post prostate cancer symptoms, requiring 24-hour home care.



Social Welfare advised her to sell her home to pay for her medication. This would leave her homeless when her father died and she would have to spend all the proceeds of the house sale before she would be entitled to a benefit. In the meantime she would continue to look after her father.

What suggestions would you make to help improve the ways that people with chronic conditions are supported?

NCWNZ agrees that home support carers are often inadequately trained and certainly underpaid. Respondents' suggestions for improving the ways that people with chronic conditions are supported, include:

- Better access to respite care available.
- Financial support for family members caring for people with chronic conditions.
- Carers who can be flexible, who are trained and are paid at a reasonable rate.
- Clarity about entitlements and the processes to access these.
- Creation of a trusting environment with regard to accessing services.
- Reducing waiting times to consult medical specialists.
- Ensuring people are able to communicate clearly and concisely with GPs and/or consultants. Assistance could be provided by making available prepared lists of questions, for example.
- Long term care facilities for the elderly.
- Entitlements for those with chronic conditions should be similar, or at the same level as those provided by ACC for people who have sustained an accident.
- Advocacy services for those who are unable to speak for themselves. Advocates should have knowledge of entitlements and care should be taken to not unduly increase expectations of the person with a chronic condition.
- Consideration needs to be given to the cost of specialists, doctors, medication, allied health professionals and CAMs.
- Ensuring physical access does not constitute a barrier.
- Grief management as well as care about a person's spirituality.
- Where changes need to be made in the home these should be government funded.
- The mentally ill need special places to live and be assisted with ongoing support from appropriately trained health workers. Currently, there appears to be very little support in this area.

Section 4: Summary of Issues - Practitioners and Agencies

Element 1: Improved Interactions between People and Professionals

Do you have any comments on the issues raised in this section?

Issues in this section were listed as follows:

- Interactions between people and professionals
- Self-management support

Respondents agreed with the issues raised.

What other issues do you think are important to add?

Respondents had no comments to add.

What suggestions do you have to improve the ways that people with chronic conditions are supported?

Feedback or evaluation forms could be used by patients to comment on the provision and quality of services. Issues raised could then be managed using a problem-solving approach

Element 2: Redesign of Delivery System and Processes

**Do you have any comments on the issues raised in this section?**

Issues in this section were listed as follows:

- Funding.
- Primary Health Organisations (PHOs).
- Barrier to accessing services.

Respondents generally agreed with the issues raised. However, it was pointed out by one respondent, that not all chronic conditions are preventable and therefore funding should be carefully targeted.

One respondent made particular mention of the Care Plus initiative to fund one-hour assessments for people with chronic conditions. This should lead to improvements in the primary care service. Allowing more consultation time to assess people's needs and finding solutions would help improve the support for people with chronic conditions.

What other issues do you think are important to add here?

NCWNZ believes that good communication by well-qualified and capable front line staff is regarded as extremely important. More should be done to enable hospital staff, who have knowledge and experience across a number of areas dealing with chronic conditions, should also be able to work in the field. This would provide some continuity of service. It may also serve to address the very real problem for people with chronic conditions, when the current "disease silo" approach is used and services become fragmented.

What suggestions do you have to help improve the ways that people with chronic conditions are supported?

Respondents agree that:

- There needs to be more funding to allow for adequate rehabilitation before discharge from hospital. Discharge too early may result in poor outcomes or even readmissions.
- There should be early intervention for chronic conditions.
- Professionals should be encouraged/supported to make home visits. It is acknowledged that health professionals from a hospital setting are unsuited to home visiting. Linked to this is the need for some hospital treatments to be modified from that which is appropriate in the hospital setting to that which is appropriate in the domestic situation.
- Continuity of care is vital.
- The cost of dental health is prohibitive for many people on benefits. Tooth decay not only affects the mouth but nutrition and general health. Decay may also compound other conditions.
- A programme that is available in some places, e.g. Hamilton and Auckland, known as the Accredited Visitor Service, should be more widely available. This service provides a friendly, volunteer, social visitor who has been checked out, approved and trained.

Element 3: Workforce Planning and Development**Do you have any comments on the issues raised in this section?**

Issues in this section were listed as follows:

- Need for improved workforce capacity.
- Need for change and innovation in workforce roles.
- Role of nurses in supporting people with chronic conditions.
- Role of community health workers in supporting people with chronic conditions.

Respondents agreed with the issues raised.

What other issues do you think are important to add here?

Respondents had no further comments to make.

**What suggestions do you have to help improve the ways that people with chronic conditions are supported?**

Respondents suggested the following:

- The need for more support workers is paramount.
- There need to be more nurses in primary health care in order to effectively deliver comprehensive support for people with chronic conditions.
- There needs to be a larger workforce of trained caregivers.

Element 4: Knowledge Management**Do you have any comments on the issues raised in this section?**

Members agreed with the need for decision support and quality technical support, as they are crucial to effective care for people with chronic conditions. It is likely that some rural nurses do not have computer access. In a field where knowledge of adverse reactions and the side effects of medications is critical, quick access to information makes ready access to computer technology invaluable.

Multi-disciplinary teams rarely work properly as it is difficult to bring them all together for meetings. Greater emphasis on “teamwork” structure needs to be adhered to. Better information for the caregiver from knowledgeable people would greatly assist instead of the makeshift arrangements as members have reported happen at present.

What other issues do you think are important to add here?

There needs to be greater support for the family caregiver as his/her own needs need to be met as well.

What suggestions do you have to help improve the ways that people with chronic conditions are supported?

More use may need to be made of the internet, websites and TV, rather than relying on pamphlets to provide information for people with chronic conditions.

Element 5: Partnerships Within Health, and Between Health and the Community**Do you have any comments on the issues raised in this section?**

Issues in this section were listed as follows:

- Need for leadership and coordination - partnerships within health.
- Partnerships between health and the community.

Respondents generally agreed with the issues raised. However, as one respondent pointed out, the criticism of schools not working with other agencies for the good of the children leaving school is unfair. The role of the teacher is to educate. All too often they are being required to do the work of social workers as well.

What other issues do you think are important to add here?

Respondents had no further comments to make.

What suggestions do you have to help improve the ways that people with chronic conditions are supported?

Respondents made no further suggestions.



GENERAL COMMENTS

One respondent has made the comment that, "... the time has come when all these groups who have Field Officers (Parkinson Society, Multiple Sclerosis Society, Alzheimer's Society, Asthma Society, Arthritis Foundation, etc) and all struggling for the mighty dollar, should come together under one roof, their Field Officers expand their roles and knowledge into 'High Risk Nurses' and be PHO funded."

NCWNZ thanks you for this opportunity to make comment and looks forward to seeing the programme put into place.

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National President

Catherine Gurnsey
Convener, Health Standing Committee