

Beyond hospitals

Caring for people with a chronic illness



Chronic Illness Alliance of NSW

February 2003

Introduction

This document has been prepared by the Chronic Illness Alliance of NSW to highlight issues of concern to people with a chronic illness living in NSW, and their families.

In recent years, media debate about health care has focussed very strongly on the hospital system. For people with a chronic illness and their families, this is not the critical issue. The greatest improvements in the quality of life of people with a chronic illness is gained from improving the network of services which support people living in the community, and improving the coordination between these services and the hospital system.

Meeting the needs of people with a chronic illness requires NSW Health and the Department of Ageing, Disability and HomeCare to overcome the historical divisions in their responsibilities, and collaborate to fill gaps in care. There are insufficient resources for community care services, and the active program of reducing length of stay in hospitals is adding to existing demands. Many people with a chronic illness require aids such as wheelchairs and hoists to assist them to live in the community, and there are insufficient public funds available to provide these. There are also insufficient resources available for respite care and to assist with transport to access health services.

Many people with a chronic illness require support from a range of Government agencies, and they face a fragmented system which is difficult to negotiate. Improved coordination between Government agencies is required.

For people with a chronic illness, there are grave dangers in developing a health system which assumes that individuals with moderate to high incomes have private health insurance coverage. The cost of living with a chronic illness can be very high, and many people with a chronic illness cannot afford the additional cost of private health insurance.

The community organisations that support people with a chronic illness are profoundly under-resourced to assist their communities, and require additional funding. These organisations are well-placed to provide informed input into planning and policy development processes within NSW Health, and should have opportunities to do so.

The Alliance recognises that NSW Health has allocated substantial funds to chronic illness initiatives over the past three years, and welcomes this attention to the issue. The Alliance is, however, concerned that the primary statewide measures of success of these initiatives are reduction in hospital usage. The Alliance is particularly committed to ensuring that the additional financial and personal burdens on consumers and carers of shorter hospital stays are accurately documented and that appropriate support services are well resourced.

The Alliance considers it essential that people with a chronic illness have accommodation which is appropriate to their needs, and is concerned at the ongoing placement of young and middle-aged people in aged care facilities.

In this document, the Chronic Illness Alliance has made recommendations for State Government about improving the quality of life of people with a chronic illness and their families. These cover:

- More community care services
- Improved coordination between Government agencies
- Better access to equipment
- More respite care

- Adequate health-related transport
- Health initiatives to focus on consumers
- Improved participation in decision making
- More funding for community organisations
- The role of private health insurance
- More allied health services
- Appropriate accommodation

About the Chronic Illness Alliance of NSW

The Chronic Illness Alliance of NSW is a network of community organisations working to improve the quality of life of people with a chronic illness.

The role of the Alliance is to:

- advocate for changes which would assist people with a chronic illness, both in Government policies and in the private sector
- promote information exchange between individuals and organisations with an interest in chronic illness
- promote coordination between the different services working to assist people with a chronic illness

Organisations involved in the Alliance include self help groups, advocacy organisations, charitable organisations, and other community based agencies. Many of the organisations involved in the Alliance are focussed on a specific illness or a group of similar conditions.

Some of the issues the Alliance has pursued are:

- costs of medication
- ensuring private health insurance meets the needs of people with a chronic illness
- community care for people with a chronic illness, including the Commonwealth Enhanced Primary Care Medicare item numbers
- adequacy of funding for equipment through the PADP scheme

The Alliance keeps its network informed through an e-forum, which is supplemented by mailouts to organisations which are not on the net. The Alliance also runs forums on burning issues for people with a chronic illness.

The Alliance is in the process of establishing a website which will contain a directory of organisations working on chronic illness and information on issues and events:
www.ncoss.org/cia

As at February 2003, the Alliance management committee consisted of representatives from:

Alzheimers Association, Arthritis Foundation of NSW, Australian Kidney Foundation, Carers NSW, Council of Social Service of NSW, Cystic Fibrosis NSW, Diabetes NSW, Epilepsy Association, Hepatitis C Council of NSW, Huntington's Disease Association, Motor Neurone Disease Association, MS Society, Parkinson's NSW

For further information, please contact the chairperson, Ros Bragg, on <cia@ncoss.org.au> or (02) 9211 2599 ext 112.

About chronic illness

The Chronic Illness Alliance defines chronic illness as:

A chronic illness is an illness that is permanent or lasts a long time. Effective treatment may be developed, it may finally go away, or it may lead to death. It may cause permanent changes to the body. It will certainly affect the person's quality of life.

Historically, the health system in NSW has not responded well to the needs of people with a chronic illness. The health system caters primarily for people who have acute illnesses, or people with disabilities. Chronic illness falls between the two. People with a chronic illness are often more frequent users of the health system. This was acknowledged in the report of the NSW Health Council in 2000.

The provision of health care for people with chronic and complex conditions is often more complicated than for other people in the community. This is not only because they have more frequent and unplanned hospital admissions (including urgent admissions through Emergency Departments), but because they need to interact with a number of health care providers and health services and other Government services at any given time. This includes GPs, specialists, community health workers, mental health workers, allied health and Home and Community Care. Patients are often required to coordinate their own care, putting them at risk of receiving different advice from different providers...

People with a chronic illness often require a more coordinated response from a range of health services and other human agencies. Coordination between different Government agencies in responding to the needs of people with a chronic illness is particularly poor.

Living with a chronic illness can be expensive. Additional costs include prescriptions, over the counter medicines, special foods, medical consultations, complementary therapies, special equipment and additional transport costs. These costs should not be underestimated. For example, many people with a chronic illness need to try several different medications before they identify the one which works best for them. The costs of chronic illness are a huge burden for people on low incomes, and can also be a crippling expense for people on medium incomes.

The NSW Health Council emphasised that people with a chronic illness often experience severe disadvantage:

Improving health care for people with chronic and complex conditions is a fundamental issue of social justice. Individuals with these health conditions are often unable to work, have to meet additional expenses associated with their illness, suffer with chronic pain, and require a great deal of support from their carers and families...

Recommendations

More community care services

There are insufficient community care services to meet the needs of people with a chronic illness. There are 300 people with very high support needs who are waiting for services through the Virtual Pool (Home Care Service High Needs Pool), and the Alliance is constantly hearing reports of individuals unable to obtain basic support services.

Community care services include assistance with tasks of daily living such as showering and meals, through to support services for people with severe disabilities. These are not health services, but they are essential to maintain the health of many people with a chronic illness. These services are the critical factor in determining whether a person is able to live in the community or is institutionalised.

Recommendation: That people with a chronic illness should have ready access to community care services to support them to live in the community. This requires a substantial injection of funds.

(Spending on community care for people with a chronic illness is not separately identified by the Department of Ageing, Disability and Home Care. To partly address unmet need for people with a chronic illness, people with a disability and frail older people, the Alliance considers that an additional \$28 million is required.)

The current system of planning for community care and for health services is divided between NSW Health and the Department of Ageing, Disability and Home Care. There are gaps in services for people with a chronic illness where agencies claim the other is responsible. Planning processes which involve both NSW Health and the Department of Ageing, Disability and HomeCare are essential to support the development of service systems which are based on consumer needs, rather than departmental silos.

Recommendation: That the planning and provision of community care services should meet the needs of people with a chronic illness. This requires NSW Health and DADHC to develop a statewide plan for community care which clearly delineates each agency's responsibility in relation to people with a chronic illness and ensures that gaps in services are addressed.

Improved coordination between Government agencies

Effectively responding to the needs of a person with a chronic illness often requires coordination between a range of Government agencies. In addition to health and community care services, people with a chronic illness may require affordable, appropriate housing; accessible transport services; or family support. At present, people with a chronic illness face enormous difficulty in obtaining appropriate services.

The Chronic Illness Alliance is calling upon Government to develop a whole of Government action plan for people with a chronic illness. This would involve NSW Health, Department of Aboriginal Affairs, Department of Ageing, Disability and HomeCare, Department of Community Services, Department of Housing, and Department of Transport. It would provide a framework within which Government

agencies would coordinate their response to the complex needs of people with a chronic illness.

Recommendation: That services for people with a chronic illness should be effectively coordinated. This requires the NSW Government to develop a whole of Government action plan for people with a chronic illness.

Better access to equipment

People with a chronic illness often require equipment to assist them to live in the community. These may consist of wheelchairs, hoists, shower chairs, or a range of other items.

The Alliance receives consistent reports of long waiting lists for essential equipment through the Program of Appliances for Disabled People (PADP) program. This is increasing pressure on chronic illness organisations to seek funds from service clubs and other charitable sources, which is an unreliable and extremely time consuming process.

Delays in obtaining equipment have a direct impact on the lives of people with a chronic illness and their carers. An eleven month wait for a wheelchair, for example, is eleven months in which a person with a chronic illness has no mobility.

Community organisations are reporting difficulties in resolving issues of access to respiratory equipment, following changes to the PADP guidelines. They are also reporting that high cost items, such as communication equipment, are generally not available.

Food for enteral feeding is not available through the program, and community organisations report that consumers are facing high costs to purchase this privately. The Alliance considers it appropriate for this food to be made available at cost through Area Health Services.

Recommendation: That people with a chronic illness should have speedy access to equipment which is essential to support them to live in the community. This requires a substantial injection of funds to the PADP program. .

(Funding for people with a chronic illness is not separately identified in PADP figures. To partly meet unmet need for people with a chronic illness and people with a disability, the Alliance recommends that funding for the Program of Appliances for Disabled People program be immediately increased by \$4 million.)

More respite care

The Alliance is constantly hearing of families struggling to obtain respite care for a family member with a chronic illness. Respite care is an essential support for carers of people with a chronic illness, and can be a key factor in determining whether an individual will continue to be cared for in the community or in a nursing home. Respite care is funded through Commonwealth and State programs, and the Alliance is aware that additional Commonwealth funds are also required.

Recommendation: That people with a chronic illness and their families should have access to adequate respite care. This requires a substantial injection of funds into respite care services.

(Funding for respite for people with a chronic illness is not separately identified in agency figures. To meet the needs of people with a chronic illness and other individuals requiring respite care, State funding for respite care be immediately increased by \$3 million.)

Adequate health-related transport

People with a chronic illness are facing an increasing number of trips to obtain health services, and are facing increasing difficulties in obtaining assistance to make these journeys.

While in previous years an individual might be hospitalised for tests, it is now more common for the tests to be conducted on an outpatient basis and to require multiple visits to different practitioners. Similarly, many procedures which previously involved several days hospitalisation are undertaken on a 'same day' basis, with the consumer required to attend hospital very early in the morning and sent home when they are still very unwell.

NSW Health has announced \$2.5 million for health-related transport and is developing a policy framework. While extremely welcome, the funding is focussed exclusively on rural areas and falls far short of the amount required.

Recommendation: That comprehensive health-related transport services be available to people with a chronic illness, whether they live in rural or metropolitan areas. This requires a substantial injection of funds.

(Funding for people with a chronic illness is not separately identified. To meet the needs of people with a chronic illness and for all other individuals, the Alliance recommends that funding for health-related transport for be increased by \$5 million.)

Health initiatives to focus on consumers

The Alliance considers it essential that the health outcomes and quality of life of people with a chronic illness and their carers be the fundamental reference points for any chronic illness initiatives.

NSW Health has completed the first three years of its Chronic and Complex Care Programs, which received \$45 million over three years. These programs focussed on three conditions, which were selected on the basis of high consumer usage of hospital services.

NSW Health recently released the personal health record, 'My health record', which is described as 'a special folder that holds information about your health all in one place'. This is a small but welcome assistance for people with a chronic illness.

The Alliance is concerned that data collection for the Chronic and Complex Care Programs has focussed on reductions in unplanned admissions to hospital and in length of stay in hospital. There has been no statewide data collection on the impact of these initiatives on the health outcomes or quality of life of people with a chronic illness or their carers.

The Alliance is adamant that the financial imperatives of reducing hospital usage should not outweigh the needs of people with a chronic illness and their carers. The Alliance is particularly concerned that the additional financial and personal burdens on consumers and carers of shorter hospital stays is accurately documented and that appropriate support services are well resourced.

Recommendation: That health initiatives targeting people with a chronic illness should take as their starting point that they are to improve the health outcomes and quality of life of people with a chronic illness and their carers. For this to be effective, statewide data collections need to focus on these issues.

Improved participation in decision making

Consumer participation in health decision making is stated Government policy. As well as being an essential component of a democratic system, it also promotes better health planning, better community understanding of challenges in health service management (such as resource limitations), and better health outcomes for the community.

Despite stated Government policy, people with a chronic illness have minimal opportunity to participate in the health system decisions which affect their lives. Community organisations working with people with a chronic illness report that they are rarely, if ever, invited to contribute to planning for specialist health services for their client group, or to broader Area Health Service planning.

People with a chronic illness and their families are often very busy managing their lives. They rely heavily on community organisations to represent their interests. Community organisations working with people with a chronic illness are extremely well placed to comment on the gaps and limitations of the existing care system. They are also able to synthesise the comments and frustrations of many people with a chronic illness and their carers, and feed this information into the appropriate health decision making processes.

Recommendation: That both Area Health Service planning and statewide policy development should have the benefit of active participation from community organisations which represent people with a chronic illness. This requires a significant shift in practice within NSW Health to create opportunities for effective community participation across the system.

More funding for community organisations

The Chronic Illness Alliance has identified 90 community organisations across NSW that are working to improve the quality of life of people with a chronic illness. These organisations provide people with a chronic illness and their families with a wide range of services, including: community care, support and counselling, self-help groups, assistance to obtain housing, accessible transport, social events, activities for children, information about treatments, equipment, and advocacy. Many of these community organisations are highly professional operations.

These organisations are profoundly under-resourced. While a number receive Government funding, many report that obtaining Government funding is virtually impossible. This is a particular problem for new organisations. Many organisations already in receipt of funding have reported that they have been unable to obtain any

increases. The NSW Health NGO Program, which funds community organisations working in health, currently has no growth funds available.

The planning structure for the NSW Health NGO Program is problematic for chronic illness organisations. Many chronic illness organisations operate on a statewide basis, however, all community organisations are required to seek funding through their local Area Health Service. As the Area Health Service prioritises according to local need, statewide services are rarely recommended for funding.

Recommendation: That community organisations working on chronic illness should be adequately resourced to support their communities. This requires a substantial additional funds and changes within the NSW Health NGO Program to facilitate funding of organisations with a statewide brief.

(The Alliance recommends an immediate allocation of \$3 million to fund community organisations working on chronic illness.)

The role of private health insurance

The Chronic Illness Alliance has noted with concern the growing emphasis on private health insurance and private provision of health care.

In a recent survey on chronic illness and insurance issues, the Chronic Illness Alliance received reports of a number of individuals who were refused private health insurance after disclosing their medical conditions. The Alliance is also aware that many people with a chronic illness are unable to afford private health insurance either because of low incomes or because of the additional costs of prescription drugs, special food, over-the-counter medications, complementary therapies, special equipment, and additional transport costs.

The Chronic Illness Alliance considers access to a comprehensive network of public health services to be a basic issues of equity.

Recommendation: That people with a chronic illness should have access to a comprehensive range of health services through the public system. This requires that health service development take into account the substantial number of people with a chronic illness who do not have private health insurance.

More allied health services

The Alliance has received numerous reports of people with a chronic illness having difficulty accessing allied health. There are reports of Area Health Services not replacing allied health positions when staff leave, and of extensive delays in recruitment where a replacement is sought. Chronic illness organisations are reporting that many allied health staff in the public system have large workloads, and that waiting times are growing.

Access to allied health service is important for improving the health of people with a chronic illness. It can also impact on access to other services. For example, an assessment by an Occupation Therapist is required before a person with a chronic illness can obtain a hoist. The hoist is, in turn, a requirement for Home Care to commence personal care services.

The Alliance would like to see a range of strategies developed to improve access to allied health services for people with a chronic illness. The Alliance has received positive reports about multidisciplinary clinics which bring a range of allied health practitioners together, and support specialist services for people with conditions such as progressive neuromuscular conditions.

Recommendation: That people with a chronic illness should have access to appropriate allied health services through the public health system. This requires development of a range of strategies to improve access to allied health services for people with a chronic illness, and additional resources.

Appropriate accommodation

The Alliance considers it essential that people with a chronic illness have accommodation which is appropriate to their needs. Many young and middle-aged people who require a high level of care are inappropriately accommodated in aged care facilities. Aged care facilities are not focussed on the needs of younger people, and offer poor quality of life for this client group.

A range of accommodation options need to be developed and adequately resourced to ensure people with a chronic illness have access to services which are age-appropriate, address individual needs, and promote quality of life.

Care in the community is an appropriate form of accommodation for younger people with a chronic illness. For this to be a real option, there needs to be a substantial injection of funds, and the development of appropriate pathways and services. It also requires effective coordination between various State agencies.

Aged care facilities are a Commonwealth responsibility, and disability services are a State responsibility. As a result, addressing the problem of younger people in nursing homes will require cooperation between these two tiers of Government. The Alliance is keen to see a speedy clarification of respective Government responsibilities so that the matter can progress.

Recommendation: That people with a chronic illness have access to accommodation and support which is appropriate to their age and support needs. This requires effective advocacy by the State Government to resolve inter-governmental issues surrounding the inappropriate placement of younger people in nursing homes, and the allocation of appropriate funds.

End