

Chronic Illness Alliance

Response to the National Health and Hospitals Reform Commission

Report: "A Healthier Future for All Australians"

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The Chronic Illness Alliance congratulates the National Health and Hospitals Reform Commission on its national plan for the health of all Australians. The Alliance supports the platform of reform which is to maintain and extend universal entitlement to health care. The Alliance applauds attempts to improve access and equality.

The Chronic Illness Alliance represents fifty organisations, some of which are state-based while others are national, working with people with a range of chronic illnesses (see Appendix A). The Alliance aims to build a better focus in health policy and health services for all people with chronic illnesses through education of community members, health consumers and health professionals. The Alliance notes that the report argues that the health system requires redesign in order to better respond to emerging challenges. The Alliance considers that one of those challenges relates to the emergence of chronic illnesses as a major focus for the health system.

The Alliance considers that the problem of chronic illnesses is poorly dealt with in this report with the consequence that the health system will not meet the needs of people with chronic illnesses as well as it could, following this reform process.

Experiences of chronic illnesses

People with chronic illnesses are not necessarily elderly people, neither are they only those with preventable 'lifestyle' conditions such as type 2 diabetes, lung and bowel cancers, although all these people fit the category of chronic illnesses (Fortin et al 2005a). There are now many people surviving with illnesses that were once terminal including HIV/AIDS, breast cancer, cystic fibrosis, cardiomyopathy, thalassaemia and type 1 diabetes. Schools and universities have increasing numbers of young people with chronic illnesses.

People with the less 'glamorous' conditions such as epilepsy, hepatitis C, asthma and arthritis face particular challenges relating to poor community understanding which creates barrier for them to access both community and health services.

More people with chronic illnesses now have more than one chronic illness, with the number of illnesses a person may have increasing with age. Illnesses may be related to an index disease, as in the case of advanced type 2 diabetes leading to retinopathy; or an illness may be a direct consequence of the treatment they receive such as chronic pulmonary disease following a bone marrow transplant, or related to adverse events in the health system (Smith 2007). People with a chronic illness are more at risk of having a co-existing mental disorder, than people without a chronic illness.

In some cases, people suffer from rare disorders for which there is little treatment and few services. These are likely to be increasingly recognised through genetic testing, creating another level of complexity.

The current hospital and primary health care system, including diagnosis, treatment and clinical teaching of health professionals is premised on treatment of a single disease (Fortin et al 2005b). It is experienced as a fragmented system by people with multiple and complex chronic illnesses because they must see different practitioners for different single diseases. This increases the risk for people with two or more illnesses to experience adverse events and to receive uncoordinated and potentially risky treatment. Currently, general practitioners may not have the training or experience to provide an appropriate coordinated service, but the responsibility is likely to fall to them.

The Alliance is concerned that this level of complexity receives no attention in the report, although it is a well documented phenomenon in international literature. Medical education, changes to the workforce and the systemic change to the delivery of health services is required to engage with such complexity.

Chronic Illness Alliance response on behalf of people with chronic illnesses

This is not a comprehensive response to the full report and its recommendations. It is mainly concerned that health reform engage with the needs of all people with chronic illnesses. The Alliance is a member of the Australian Health Care Reform Alliance and Consumers' Health Forum and has also participated in the responses they have provided.

Universal entitlement:

The Chronic Illness Alliance supports the continued policy of universal entitlement which will be strengthened through targeted services for those who are still disadvantaged. The Alliance would like to suggest that disadvantages do not always relate to population groups and regional areas but are also experienced by many people with rare or poorly-understood illnesses. However, we acknowledge that for those people with chronic illnesses in areas of low socioeconomic status or regional Australia this disadvantage is greatly compounded. These disadvantages relate to lack of knowledge by clinicians, lack of services tailored to the needs of the person, lack of coordination of services and poor community understanding of the condition and the abilities of the person.

An important barrier to access to services relates to the entrenchment of competition in the report, for example under 'Medicare Select' where 'Health Plan Organisations' are likely to compete for services. Such organisations will operate where there are already larger populations and more services to package rather than creating access where more isolated and poorer people reside.

Co-payments also limit access of people with chronic illnesses to services. People with chronic illnesses pay a large number of co-payments for the many and varied services they require to lead an optimal life. These can significantly reduce their income and force them into living below the poverty line (Chronic Illness Alliance 2004).

The Alliance welcomes the recommendation to improve patient travel assistance schemes. The Alliance would prefer that there was a national scheme rather than state based ones. A national scheme would remove barriers to those people living on state borders to access services interstate. Currently the Victorian scheme is a bureaucratic nightmare and the amount of paperwork and evidence required to apply for the funds creates a strong deterrent for both consumers and general practitioners to apply for refunds.

“When you are really sick and you need to travel as well, the last thing you want to do is deal with all the red tape and form-filling out.”

Woman with cancer travelling for chemotherapy.

Creating strong primary health care services for everyone:

The Chronic Illness Alliance supports this recommendation, particularly with regard to Primary Health Care Centres. The Alliance would like to add that these Centres need to recognise and work with all people with chronic illnesses, not just those conditions that constitute the greatest burden of disease such as diabetes and cardiovascular conditions in order to ensure that universal access is put into practice. As all people with chronic illnesses require far more than health services, the Alliance recommends that coordinated services at the primary health care level be expanded to include welfare services, employment and training services and access to the services provided by the State-based organisations.

“People with thalassaemia attend specialists for care of their thalassaemia but they still need to see a GP for other things, like the common cold and referrals but because GPs don’t understand about thalassaemia it can become risky. Thalassaemia Victoria has worked hard with GP divisions to explain what it is and how people are cared for.”

Community worker with Thalassaemia Australia.

Another important aspect of primary care for all people with chronic illnesses is derived from lay-led support groups and peer-support /education services. The Alliance regards the lack of acknowledgement of the value of these services for which there is now a great deal of evidence as a major gap in the reform to primary health care being put forward. Support groups and peer-support/education services are an important means of integrating consumer needs into services. They also offer a pathway of communication between health consumers and their services. They are also a very cost-effective means for health professionals to communicate with groups of people with chronic illnesses. Peer-support and peer education fill similar roles and provide a cost-effective means to provide self-management programmes and information.

Ensuring timely access to hospitals:

Many people with chronic illnesses have acute episodes or ‘flare-ups’ requiring hospital admission or attendance at emergency departments. In some instances, attendance at emergency departments is incurred by adverse reactions to treatment or wrongly administered treatment. For many people with chronic illnesses the long waits in emergency departments are the result of their conditions not being well understood, which may be compounded by the lack of available specialist care. Long waits can lead to poor outcomes. A national access target, which includes an access plan to specialist services for the full range of chronic illnesses is required to reduce the times between presentation at an emergency department and access to effective care.

“It’s dangerous going to an emergency department these days because many of the staff confuse Type 1 diabetes with Type 2 diabetes. That’s because there is such a lot of emphasis on Type 2 these days. If you treat a Type 1 person as you would Type 2 diabetes, then you are placing them at great risk.”

Young woman with T1 diabetes.

“I was recently admitted to hospital due to complications with my MS. I had to go into the cardiac ward where there was little understanding of MS. The ward was kept very warm for the benefit of the cardiac patients. People with MS are heat intolerant and staff could not understand why I needed

a fan on me all the time and they kept on turning it off.”

Man with MS

Improved access to dental care:

The Chronic Illness Alliance welcomes the reform to improve access to dental care. People with chronic illnesses face deteriorating oral health which is often related to medication use and may be related to their overall declining health. Because of the costs they face for healthcare including co-payments for medication and other services they have to prioritise which services they will access. The cost of dental care is usually prohibitive, while waits for public dental services are so long that oral health continues to deteriorate.

The Alliance would like to recommend that the access to dental care be kept as uncomplicated as possible. The current recommendations of the two tier system appear cumbersome and possibly have many hidden costs, as does the current two-tier system of private health insurance underpinned by the 30% tax rebate and Medicare. Co-payments and waiting lists create barriers to access for people with chronic illnesses who are already spending substantial amounts of their income on their health care and require attention to deteriorating oral health as part of the overall chronic illness care.

“I take medication for epilepsy. It has affected my gums and I have lost many of my teeth. I didn’t have the money to go to a private dentist and my teeth continued to deteriorate while I was on the waiting list for the dental hospital.”

Young woman with epilepsy

Next generation of Medicare:

The Chronic Illness Alliance objects to the phrase ‘tsunami of chronic disease’ which we understand is not used with the intention of being derogatory but which will come to be used in this manner. Many people have chronic illnesses; many of them are serious and life-threatening; however many people with chronic illnesses still work and still pay taxes; others contribute extensively to their communities. Using such a phrase as the one above stereotypes people with chronic illnesses as excessive burdens on other Australians, which is by no means proven.

“When I went for job interviews I thought I should tell them (potential employers) that I had diabetes. It meant they asked me lots of questions about my ability to drive even though driving was not part of the job description.”

Man with type 2 diabetes

“People think you are drunk or a bit gone in the head when they see you are unsteady, so I don’t go out anymore.”

Man with Parkinson’s disease

The Alliance has conducted surveys on the personal costs associated with living with chronic illnesses and we would strongly urge the Government to resist the imposition of further co-payments for services which reduce the living standards of all people with chronic illnesses and act as a deterrent to working (see Appendix B).

The Alliance welcomes the recognition of the need for non-medical services as well as the change from ‘fee for service’, as well as supporting the design of better models of care and payment for people with complex and multiple conditions.

Strengthening consumer engagement and choice:

As the representative voice of organisations working with people with chronic illnesses, the Alliance would welcome participation in these processes. The Alliance would also suggest that support groups and peer support/education are existing and valuable pathways to include, as well as hear from, people with chronic illnesses. There are already valuable models of consumer engagement, for example the National Prescribing Service Community Quality Use of Medicines Working Group; Consumers Health Forum; Medicare Australia Community Consultative Committee and the Chronic Illness Alliance, which has been underutilised by the current government. These models are a ready-made means to engage with consumers whereas citizen's juries and health literacy approaches will require significant work.

APPENDIX A

Members of the Chronic Illness Alliance as at June 2009.

1. AIDS HOUSING ACTION GROUP
2. ARTHRITIS VICTORIA
3. ASTHMA FOUNDATION OF VICTORIA
4. AUSTRALIAN LEUKODYSTROPHY SUPPORT GROUP INC
5. BENDIGO COMMUNITY HEALTH SERVICE
6. BEYONDBLUE-THE NATIONAL DEPRESSION INITIATIVE
7. BRAINLINK
8. CANCER COUNCIL OF VICTORIA
9. CANCER VOICES NSW
10. CARDIOMYOPATHY ASSOCIATION OF AUSTRALIA INC.
11. CARERS VICTORIA
12. CROHNS & COLITIS ASSOCIATION
13. COCHRANE CONSUMER NETWORK
14. CHRONIC ILLNESS PEER SUPPORT PROGRAM
15. CONTINENCE FOUNDATION OF AUSTRALIA
16. CYSTIC FIBROSIS SOUTH AUSTRALIA
17. CYSTIC FIBROSIS VICTORIA INC.
18. DIABETES AUSTRALIA-VICTORIA
19. EPILEPSY AUSTRALIA
20. EPILEPSY FOUNDATION VICTORIA

21. FRANKSTON COMMUNITY HEALTH SERVICE
22. GENETIC SUPPORT NETWORK VICTORIA
23. HAEMOPHILIA FOUNDATION VICTORIA
24. HEALTH ISSUES CENTRE
25. HEPATITIS C COUNCIL OF VIC
26. HUNTINGTON'S VICTORIA
27. KIDNEY HEALTH AUSTRALIA
28. KNOX COMMUNITY HEALTH SERVICE
29. LEUKAEMIA FOUNDATION OF VIC
30. ME/CFS SOCIETY OF VIC
31. MENIERE'S SUPPORT GROUP OF VICTORIA INC
32. MS SOCIETY OF AUSTRALIA -ACT/NSW/VIC
33. MYELOMA FOUNDATION OF AUSTRALIA INC
34. PAEDIATRIC CONTINENCE FOUNDATION OF AUSTRALIA
35. PALLIATIVE CARE VICTORIA
36. PARKINSON'S VICTORIA INC
37. PASS PROGRAM, BARWON HEALTH
38. PEOPLE LIVING WITH HIV/AIDS VICTORIA
39. PHARMACY GUILD OF AUSTRALIA, VICTORIAN BRANCH
40. POLIO NETWORK VICTORIA
41. POSITIVE WOMEN VICTORIA
42. PRO-ABILITY CONSULTANCY SERVICE
43. PROSTATE CANCER FOUNDATION OF AUSTRALIA
44. ROYAL DISTRICT NURSING SERVICE
45. SCLERODERMA VICTORIA
46. THALASSAEMIA AUSTRALIA
47. TYPE 1 DIABETES NETWORK
48. THYROID AUSTRALIA
49. VICTORIAN ABORIGINAL COMMUNITY CONTROLLED HEALTH ORGANISATION
50. VICTORIAN AIDS COUNCIL/GAY MEN'S HEALTH CENTRE

APPENDIX B:

Costs of Chronic Illness for Rural and Regional Victorians (2004) www.chronicillness.org.au/reports

Executive Summary

The Report of the Costs of Chronic Illness in Regional Victoria includes the results of consultations held in three regional areas of Victoria.

The results of these consultations were used to design a survey, which was then distributed with the assistance of the member organisations of the Chronic Illness Alliance.

More than four hundred households responded, with three hundred and eighty one surveys being usable. The surveyed households had 1,626 people of whom 507 had chronic illnesses.

This is a unique survey since it captured the full range of costs associated with caring for chronic illnesses in rural and regional Victoria.

The results show

- a significant level of poverty and financial distress in the households surveyed
- a majority of households considered themselves worse off under the new tax system
- that households paid for their health needs regardless of their incomes
- the value of a concession card to households where a large range of health care supports and services are needed
- medications, both PBS medications and over-the-counter medications were the greatest cost the majority of households faced
- access to a bulk-billing general practitioner was greatly valued
- that the rural and regional families in this survey required more access to information, allied health and support services, and finally, that

- travel costs, despite the patient transport assistance schemes, and telephone and utility charges are still issues for regional households in this survey.

The Chronic Illness Alliance recommends that

- governments provide greater, better targeted assistance to regional households where there is chronic illness;
- concession cards be available to households where there is a chronic illness to assist with the extensive costs households face, and this be based on need rather than income;
- further research into issues facing households where there is chronic illness be funded and encouraged.

References

Chronic Illness Alliance 2004 Costs of Chronic Illness for Rural and Regional Victorians

www.chronicillness.org.au/reports

Fortin M, Lapointe L, Hudon C & Vanasse A 2005a Multimorbidity is common to family practice: Is it commonly researched? *Can Fam Physician*. February 10; 51(2): 245.

Fortin M, Bravo G, Hudon C, Vanasse A, Lapointe L 2005b Prevalence of Multimorbidity Among Adults Seen in Family Practice *Ann Fam Med*. 3: 223-22

Smith S 2007 Chronic Diseases: what happens when they come in multiples? *Br J Gen Pract*. 200April 1; 57(537): 268-270