



Chronic
Illness
Alliance

Chronic Illness Alliance Inc

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The Chronic Illness Alliance undertakes a range of educational and information projects aimed at minimising the social impact of chronic illness by developing a better focus in health policy and health services. We rely on the participation of our members in our activities to help achieve our goals. This newsletter presents some of the current work that is being undertaken in this manner.

Welcome to new members

The most recent organisation to join the Alliance is the Prostate Cancer Foundation of Australia. We now have many national organisations as members. As with all our members, we look forward to a long and rewarding partnership where the Alliance is able to learn about your clients' needs and represent those needs in our research, policies and presentations. Member organisations details have been updated on our website. Please have a look to check we have your organisations details correctly presented. www.chronicillness.org.au/community.htm

Best wishes

Best wishes to our colleague and long term supporter Twanny Farrugia for a safe and speedy recovery.

CURRENT PROJECTS AND WORKSHOPS

Multiple Conditions Working Party

The Chronic Illness Alliance held its inaugural meeting of the Multiple Conditions Working Party on Thursday, 16 August. There were 8 people present and the aims of the first meeting were to 'brainstorm' the need for such a working party, its aims and future ways of working. Most of the people present had rare and very complex

conditions that had led to other complications. The group identified that depression often played a part in chronic conditions and that issues relating to lack of community understanding made their lives more difficult.

Another problem some people faced was that they were often not eligible for services since these were reserved for more elderly people. The point was made that many people with multiple conditions fall through the gaps in services.

The working party's draft working definitions are:

- **Cluster of conditions that create complex relationship between the individual and the health system or:**
- **Cluster of conditions that require negotiating systemic barriers to achieve the best outcome for the individual with multiple conditions.**

As this working party meets and refines its work the definitions may change. The next steps are to develop up a working plan; identify partners interested in working with us and to gather any statistics related to multiple conditions.

Next meeting is at 2 PM, Tuesday 16 October at EFV, 818 Burke Road Camberwell. All CIA members are welcome to attend. If some people are not well enough to attend please email me and let me know if there are views you would like to contribute.

Chronic Illness Peer Support Network

A new initiative of the Alliance is the Chronic Illness Peer Support Network. Based on a similar model to the Chronic Disease Self-management Special Interest Group, the network will meet bi-monthly and include both program managers and peer support volunteers in all its activities.

The main objective of the network is to progressively improve the quality and quantity of the network members' peer support programs through sharing knowledge and collectively adding to that body of knowledge; from learning from each other's presentations and from other experts about how to build better and stronger programs.

The network has already attracted a great deal of interest from members who have well developed programs through to those at the planning stages. If you want to know more about the network, please contact Jo-Anne Tamlyn on 9882 4654 or email jtamlyn@chronicillness.org.au.

Chronic Disease Self-management Special Interest Group

The Chronic Disease Self-management Special Interest Group is attended by service providers and consumers who have a strong interest in research and projects related to self-management strategies and programs. Attendees from all over Victoria regularly travel to the forums. With funding assistance from DHS we hold 5 to 6 workshops a year in Melbourne and 3 a year in regional Victoria. So far in 2007, we have had workshops on 'Embedding Self-Management in Chronic Disease Care' in Melbourne and Latrobe Regional Hospital; workshops on 'Consumer Participation in Self-Management' in Melbourne and Bendigo and a workshop on early intervention strategies held in Melbourne.

In August in Melbourne we ran a session on managing multiple conditions, where Louisa Di Pietro from Thalassaemia Society of Victoria gave a moving presentation of the complexities of living with thalassaemia and its associated problems.

October's meeting will feature presentations on new projects in partnership with indigenous communities for achieving better health outcomes through chronic disease management. It is on 18 October, between 10 am and 12 noon in Room 138, 215 Franklin St, City (nr Vic Market).

Interested SIG members who cannot attend all the meetings continue to access the information from the workshops that we place on the SIG website. Chronic Illness Alliance members are welcome to do so as well. www.chronicillness.org.au/sig

CIA POLICY ON MANAGING CHRONIC DISEASE

Below is a draft of the CIA policy on managing chronic illness. This has been developed in association with Alan Blackwood of MS Australia (Deputy Chair of the Chronic Illness Alliance) and Robert Pask of MS Australia. The policy will assist CIA argue for better services for all people with chronic illnesses both during the Federal election and in the future.

The chronic illness epidemic facing Australia is well documented. While some chronic diseases are preventable through public health measures, not all chronic diseases are lifestyle-related, nor are they preventable. Many of these, such as multiple sclerosis, Type 1 diabetes, epilepsy, Cystic Fibrosis and Crohn's Disease are disabling, incurable and result in reduced quality of life and productivity.

Many chronic diseases cannot be managed by the health system alone, as their main impacts are in the community on employment, income levels and relationships. A comprehensive chronic disease policy must focus on quality of life through health promotion, affordable pharmaceuticals and coordinated continuous care services.

While Health Policy is increasingly being targeted at chronic illness through prevention and other targeted measures, the comprehensive management of non preventable illnesses is critical to quality of life and community participation for those living with these conditions. To maintain good health across the life cycle, health programs should focus on effective interventions aimed at delivering good health and lifestyle outcomes **for all citizens**. Good health is not only important to people with chronic illness; it is vital to ensuring that they manage other areas of life impacted by these diseases including family integration, life/work interfaces and emotional and psychological health as well.

1. Coordinated Care

Effective chronic disease management requires a person centred approach that coordinates programs around individuals and families and needs to be directed at sustaining wellness, maintaining productivity and promoting self management. People need support services across the life cycle.

What is required:

A dedicated chronic illness continuous care program is required that can co-ordinate services across current jurisdictional boundaries (including services from the private and public sectors) to deliver more timely and better targeted services to people.

2. Pharmaceuticals – PBS reform

Many breakthrough drugs for chronic illnesses are coming to market, but are being evaluated via a cost benefit model without the full lifetime impact of disability on the individual and on the wider health system being taken into account.

What is required:

Greater flexibility is needed with these drugs due to the disease modifying outcomes and the potential relieving effects on Government funding programs and quality of life outcomes for individuals and families. The introduction of a cost-utility methodology for assessing new drugs by the PBAC that values community and health outcomes from new drugs will encourage better allocative efficiency across the health and community care sectors.

3. Aids and equipment

This is a major area of need for people with chronic illness and the current arrangements are unwieldy. Some disability aids are underfunded by State systems and some essential devices, such as **Baclofen pumps** (to relieve muscle spasticity in MS and brain injury) and **insulin pumps** (for people with Diabetes 1) are not available as funded items, although their use would have great quality of life benefits in terms of good health and productivity.

What is required:

Ensure that life-enhancing medical devices are evaluated and funded with the systemic benefit model needed to deliver the best health outcome. Overall, a national aids and equipment program is needed to rationalise all equipment schemes operated by Governments, compensation schemes and hospitals. This will deliver savings through buying power and will improve service levels.

4. Employment and Financial Security

Many people with chronic illnesses are able to lead productive lives if supported to do so, however part time work and early retirement are workforce realities. People with chronic illnesses generally live with lower incomes, and many experience health related poverty, spending over 20% of their incomes on medications.

What is required:

- *People with chronic illness on part-time incomes outside concession thresholds need additional assistance with the cost of medications. The current concession arrangements have only 2 points (\$4.90 with a health care card or \$30.70 without). However a **sliding concessional scale** is needed to allow greater fairness for those who are living on part time incomes but have high medicine requirements.*
- *The threshold for the safety net for pharmaceuticals needs to be restored to 52 scripts per year, and should include private scripts for non-PBS medicines*
- *The establishment of employment retention programs in the labour market sector for people with chronic disease and their carers preventing early exit from the workforce*
- *Tax deductibility for disability home modifications and aids and equipment purchased by individuals and families outside Government schemes.*

The Welfare to Work program is not sensitive to the situations of people with episodic or degenerative conditions. W2W has the same intake and obligations for job seekers and people with partial but diminishing capacity, and the 15 hour per week threshold is poorly targeted at people with chronic illness who can keep working with income top up.

What is required:

- *People with chronic illness and partial capacity that meet the DSP impairment criteria are eligible for DSP income support to complement part time work.*
- *Due to the lower benefit and crippling marginal tax rates, remove the current Newstart stream for people with chronic illness and disability who require partial income support*

5. Health Workforce

The stresses on the health workforce are well documented, and have serious implications for people living with chronic illness.

What is required:

Actively develop the capacity of the health workforce to ensure it has the requisite skills to manage the complexity of chronic illness. This includes enhancing the vocational training programs of GPs and allied health professionals.

Review the MBS schedule to enable GPs to perform some specialist procedures and implement nurse practitioners to undertake some tasks currently restricted to GPs.'

MEETINGS, MEETINGS, MEETINGS...

There are too many meetings to report on but just to give you an idea...Christine attended a meeting of the national reference group for Carers Australia in August while Jan Donovan represented the CIA at the recent National Prescribing Service Stakeholder Reference Group meeting on improving health outcomes. The outcomes of the meeting will assist NPS to develop their programs and plans for the future. In August, Jo-Anne attended the Consumer, Consultative Group of Medicare Australia in August.

Scroll down for more messages from CIA and its members

Has Cardiomyopathy Touched Your Life?

If you, a friend or relative have been diagnosed with Cardiomyopathy (heart muscle disease) you will understand the value of a support group in your time of need.

The Cardiomyopathy Association of Australia Ltd (CMAA Ltd.) offers that necessary support. .

Many of our members tell of their dismay and even anger they were not advised of the support available. Because of medical improvements and a better understanding of the condition, fewer patients these days are placed on a heart transplant list and lead relatively normal lives albeit with some lifestyle modification.

Many become aware of the Cardiomyopathy Association through the Heart Foundation (Heartline) or our website www.cmaa.org.au. This identifies contact persons in each State, Territory and New Zealand and tells about the services we provide.

Alternatively you can phone our message bank 1300 552 622 to receive additional information.

Cardiomyopathy can strike at any time, any age, anywhere.

Take Great Strides for CF

Sunday, October 21st is Great Strides Day.

This is a family – office – team fun day and a fun way to raise much needed money to support the work of Cystic Fibrosis Victoria. Last year's Great Strides Walkathon was a tremendous success with over 450 people participating. This year the venue is Princes Park in Parkville and there is the choice of the 3km or 6 km RUN or WALK.

**There'll be music and magic and giveaways and sausage sizzles and lots, lots more!
We'll even have a "Cloaking Tent" where you can check-in your picnic baskets and travel rugs for an afternoon in the park afterwards.**

Enter as a family or a team or individually and get behind this super Sunday in Spring event!

Finishing touches are being put to the brochures and the website and full details will follow in due course. In the meantime, mark the date in your diary. We would love you to get behind CFV and support Great Strides.

It takes a whole community to care for CF....

Hope to see you there. Stephen Murby.

Positive Women, Victoria

Our Patron, Annie Phelan's upcoming show, "An Accidental Actress" is showing at the Kyneton Town Hall, 129 Mollison Street, Kyneton on 8:00pm Thursday 18th October 2007.

The cost of tickets is \$27.50. Please see attached flyer for more details.

To book contact the Kyneton Town Hall on 1300 88 88 02.