



Chronic
Illness
Alliance

Chronic Illness Alliance Inc

Ph: 9805 9126

E-mail: christine@chronicillness.org.au

Newsletter June 2006

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.

Some of the year's achievements

It is the end of the financial year and we thought you would like to know some of the things the Alliance has achieved over the year, apart from the projects we have undertaken to bring in an income. We have held forums for our members: a driving and medications forum in June 2005 and a chronic pain and medications forum in October 2005; a forum on utilities (gas, water and electricity) and consumer rights in April 2006. We have held regular meetings of the Chronic Disease Self-Management Special Interest Group in Melbourne and two more in regional Victoria.

We have updated and redesigned the website and have launched Utilitease as a new web-based resource.

We have presented at national and international conferences on the needs of people with chronic illnesses.

Building partnerships

This year, through its memberships and partnerships the Chronic Illness Alliance continues to contribute to the following:

National Prescribing Service Community Quality Use of Medicines Project; Dept of Human Services Emergency Demand Programs; Medicare Australia Consumer

Communication Group; Dept of Human Services Statewide Paediatric Rehabilitation Service Reference Group; Westbay HARP Diabetes Project; Centre for General Practice Integrated Studies (UNSW) projects; Consumers' Health Forum and the Victorian Council of Social Service.

CIA membership renewals

As you will realise your membership is important to us. We hope you will renew your membership for the coming year, 2006-7. Jo-Anne will send out renewals form next week. If you know of others who would like to join the Alliance then please direct them to our membership form on our website after 1 July.



Work, Welfare, Wills:

A plain English web guide to legal issues around health and life changes.

We are now ready to launch this new resource which was created for people whose health has brought about life changes, and in particular their ability to stay in the workforce. It will be a very useful resource for our member organisations and their members/clients if they are:

- Exploring alternative income especially Centrelink and superannuation entitlements.
- Planning their future financial, medical and lifestyle decisions.
- Wanting to know more about health privacy rights. Who has to be told and who doesn't?

'Work, Welfare, Wills' will be launched Thursday 6th July at the Victoria Law Foundation offices in Hardware Lane, Melbourne. We strongly recommend you view the new site after the 6th July and let your members know about it through your own newsletters. We will give you the URL address as soon as it is launched and online. For further details on the launch contact jtamlyn@chronicillness.org.au

Utilit Ease

The Chronic Illness Alliance has undertaken community forums to give people information about their gas, electricity and water supplies which now comes through private companies. All this information is on our new web pages called Utilit Ease which explains people's rights and responsibilities in relation to the companies supplying their gas, electricity and water. There are also details of the concessions people with chronic illnesses are eligible to receive and advice on what to do if illness means someone has difficulties paying their bills. Refer your clients to these pages and use them as a reference to help clients who are having financial difficulties.



Following recommendations of the Committee of Inquiry in to Financial Hardship of Energy Consumers, the Victorian Government has allocated more funding to mitigate financial hardship of consumers in meeting their bills. More low income households will be able to access Energy Relief Grants provided by the Dept of Human Services. This ensures that households facing genuine financial hardship retain their gas and electricity services. An additional 3,000 should have access to financial assistance to pay their bills and/or to replace essential items.

Researching the Impact of Epilepsy in Australia

Following its discussion paper on applied research in epilepsy, the Chronic Illness Alliance in partnership with the Epilepsy Foundation of Victoria applied for a grant

from William Buckland Foundation to consult on the needs that people with epilepsy would like to see researched first. We are now consulting with people across Victoria and have run workshops in Melbourne, Shepparton and Bendigo. Another one is planned for Geelong in July with young people with epilepsy. The Epilepsy Foundation of Victoria will use the results of the consultations to plan its research strategy.

These workshops have been well attended and thanks are due to the staff at EFV who have enthusiastically recruited participants. Many of the participants have travelled long distances, especially in regional Victoria, so they can have their say. At the workshops, people gather in groups to discuss what is most important to themselves and their families. They then feed the results of their discussions back to the larger group which generally results in more animated discussion. The workshops have also given regional people an opportunity to meet Dr Kevin Brown, the new research officer at EFV.

We have learned about the difficulties of travel in regions where there is little public transport; how hard it is for young people to complete their education and that while the broader community is often ill-informed of the needs of people with epilepsy there are many families and local communities that are very supportive.

PEACH Project

PEACH stands for Patient Engagement and Coaching for Health (PEACH). This project is being undertaken by the Dept of General Practice of the University of Melbourne, and is funded by the NHMRC. The Chronic Illness Alliance is a partner in the project which consists of a randomised controlled trial of a telephone coaching self-management program for people with Type 2 diabetes in Melbourne's northern and north-western suburbs. Focus groups have been run with people with Type 2 diabetes. Two of the groups were with English-speaking people and there were groups with Turkish and Arabic-speaking people.

Most recently the Chronic Illness Alliance has assisted the project to establish a Consumer Advisory Committee consisting of English, Arabic and Turkish speakers who will assist the research team to develop resources and survey tools that everyone understands.

Therapeutic Patient Education Conference Florence 2006

In April-May 2006, Christine was fortunate to be able to attend the Therapeutic Patient Education conference in Florence. At this conference the Chronic Illness Alliance presented three posters. One detailed the work of the Westbay Alliance which has undertaken a project to approach diabetes care more systematically for people with diabetes in Melbourne's western suburbs. Westbay has developed a toolkit to ensure all people with diabetes receive a high standard of care, and has developed self-management programs to sustain this care. Another poster detailed a toolkit developed by the National Health and Medical Research Council (NHMRC) Health Advisory Council which assist clinicians and consumers to communicate better with one another. The third poster gave the results of the Peer-Led Self-Management of Chronic Illness Project undertaken with the Greek, Italian, Chinese and Vietnamese communities in Melbourne's north-eastern suburbs. The Chronic Illness Alliance has been a partner in all these projects.

There will be a full report from this conference available on our website shortly, but the main take-home message was that living with long-term illnesses means social and emotional costs that health professionals largely neglect. This conference presented a range of programs and models to address these matters.

And yes! Spring in Florence is very nice!

News from our members

Positive Women and the play “In the Family”

Real stories about real women in our
community living with HIV/AIDS


told by some of our leading performers including
Robyn Arthur, Sally Cooper, Anne Phelan, Greg Stone,
Sonya Suarez, Alison Whyte & Anne Wood.

In the Family

Written by Craham Pitts · Directed by Terence O'Connell





In The Family is on the 2006 VCE Theatre Studies Playlist

St Martin's Youth Theatre
44 St Martin's Lane off Park Street South Yarra



Session times
Tuesday 1 August at 2pm
Wednesday 2 August at 11am & 2pm
Thursday 3 August at 2pm & 8pm
Friday 4 August 2pm & 8pm
Saturday 5 August at 5pm

Admission Adults \$20 · Students and Concession \$15
Bookings on www.positivewomen.org.au or 03 9276 6526

Proudly presented by  Supported by   

Cardiomyopathy Association of Australia

Looking into the crystal ball: a seminar
August 19th at Norman Nock Lecture Theatre, Royal North Shore Hospital, NSW.

For more information please visit www.cmaa.org.au