



Chronic  
Illness  
Alliance



## Chronic Illness Alliance Inc

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### Newsletter December 2005

A big thank you to all our members, supporters and friends for your assistance and support over the year. We wish you all a happy festive season and a peaceful holiday. We look forward to a busy and productive New Year.

Best wishes,  
Christine and Jo-Anne

**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.

**Making a contribution**

This year, through its memberships and partnerships the Chronic Illness Alliance has contributed to the following:

National Prescribing Service Community Quality Use of Medicines Project; Health Insurance Commission Consumer Communication Group; National Health and Medical Research Council Health Advisory Committee; Dept of Human Services Statewide Paediatric Rehabilitation Service Reference Group; Westbay HARP Diabetes Project; Centre for General Practice Integrated Studies (UNSW) projects; Royal Children's Hospital Community Advisory Committee; Cancer Council of NSW Public Health Advocacy Conference.

We enjoyed it all and there was more but there is too much to list!

**Consumer Utility Advocacy Centre Grant**

This grant has allowed us to run a forum on the rights of people with chronic illness to maintaining their gas, water and electricity supplies and to develop webpages that provide everyone with information on their rights and where to access help. In 2006, we will run another forum and will officially launch the webpages.

**National Institute of Clinical Studies Project**

This year we undertook a project on behalf of NICS, where we explored the reasons some people in high risk groups did not have influenza immunisations. The focus groups were run nationally and the results have contributed to a larger project being undertaken by NICS.

**Discussion Paper on Applied Research in Epilepsy**

The Chronic Illness Alliance was privileged to write a discussion paper regarding the need for applied and social research in epilepsy. The paper looked at how applied research could assist in improving the quality of life of people with epilepsy and how applied research could best be undertaken by the Epilepsy Foundation of Victoria. This discussion paper was followed by a workshop to explore the options and the Epilepsy Foundation of Victoria will employ a research officer to implement a research program.

**CIA Policy Forums**

In 2005 we ran forums on the implications of driving while using common medications; the impact of welfare reforms; and pain management for people with chronic illnesses. More forums are planned for 2006, including the launch of the new webpages to assist people with chronic illnesses when they leave paid employment.

We are also going regional with some of our self-management forums.

**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 north-eastern suburbs.

**Children's and Young People's Working Party (CYPWP)**

[RCH Community Advisory Committee](#): We continue to contribute to this committee and argue the case for greater consumer participation in all facets of hospital service planning and delivery. Contact Jo-Anne Tamlyn at the office if you have queries or feedback re RCH.

### **Welfare. Work and wills: A Resource for People with Chronic Illness**

Jo-Anne continues to work on developing this new on-line legal resource which will provide information on superannuation and insurance including disability and death insurance entitlements; discrimination and equal opportunity and in particular workplace discrimination; privacy, disclosure and confidentiality; guardianship, power of attorney and wills; and social security entitlements for people with chronic illness. Judging by the growing number of queries we receive about some of these issues the resource will be well-used.

Watch our website for its launch in early 2006!

### **Self-management of chronic illnesses**

At present the Chronic Illness Alliance facilitates a Chronic Disease Self-Management Special Interest Group. We are now going regional with this group and will hold meetings in 3 regional areas during 2006. Chronic Illness Alliance members, consumers and anyone interested in participating in discussions about self-management programs are welcome to attend. Please see the website [www.chronicillness.org.au](http://www.chronicillness.org.au) for information and reports from the meetings.

The next metropolitan meeting of the Chronic Disease Self-Management Special Interest Group is Thursday 16 February, 2006. Meetings are between 10 am and 12 noon, with the venue to be confirmed. The presenter is Jackie Beckmann from Bayside Health who will present on **ConnectED**-Integrated care for people with complex needs.

## **ARTICLE**

**Working Carers Support Gateway**

*Helping you juggle work and care*

## **Christine Casey**

People who juggle paid work with caring for a relative or friend in need of help because they are ill, frail or have a disability are able to get useful, relevant information and support via the Internet site, the *Working Carers Support Gateway*.

The *Gateway* website [www.workingcarers.org.au](http://www.workingcarers.org.au) is now online for New South Wales carers generally, and low-income and isolated carers in particular, who have both caring and workplace responsibilities.

Developed by the Disability & Aged Information Service (DAISI), the website provides direct information support State-wide for busy working carers. The vision for the *Gateway* project is that working carers are valued, respected and supported to achieve balance in their work and home life. The project is funded by NSW Health's Carers Unit.

### **Who is a working carer?**

Working carers are defined as those who do caring work for two or more hours per week and also hold down casual, part-time or full-time paid work, as distinct from 'at-home' carers.

Given that the number of people who combine paid work and caring is expected to rise, the project is timely. It provides a one-stop-shop of practical information that busy working carers can access via the *Gateway* website 24 hours a day, seven days a week.

The website focuses on industrial relations advocacy and financial planning advice. It contains lists of services for working carers; information - including medical information; fact sheets; advice and links. Working carers are able to subscribe free to a weekly electronic newsletter, join an online discussion group for added support, and contribute stories that reflect on their experiences with employers, services and families. They can also join a *Gateway* reference group to contribute to the website's development.

For those working carers who do not have access to a computer, the *Gateway* provides information about a number of programs and organisations that provide low cost computers, free/subsidised internet access and computer training.

Send your submissions, comments, queries or interest in joining the reference group to the *Working Carers Support Gateway* team at [info@workingcarers.org.au](mailto:info@workingcarers.org.au).

