



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.

In March 2007, the Alliance was awarded Deductible Gift Recipient status as a charitable institution with aims to promote the prevention and control of disease. Our Management Committee now has a Gifts Committee and is actively exploring partnerships and sponsorships with like-minded businesses.

Welcome to new members

The most recent organisation to join the Alliance is the South East Healthy Communities Partnership in Dandenong, Victoria. 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 are updated on our website. Please have a look to check we have your organisation's details correctly presented.

www.chronicillness.org.au/community.htm

INTERESTING NEW WEBSITES

At a recent e-health presentation I learnt about some interesting US websites. They provide good models of support for people with chronic illness. The first one Patients Like Me could be a wonderful support resource if it were reproduced specifically for Australians.

www.patientslikeme.com

www.revolutionhealth.com

www.whoissick.org

NEW ON OUR WEBSITE

Annual Report 2007

Publications of Christine Walker

Multiple Conditions Working Party

CURRENT PROJECTS AND WORKSHOPS

Multiple Conditions Working Party

In August 2007, the Committee of Management of the Chronic Illness Alliance in Australia established the Multiple Conditions Working Group.

The basis for this new working group is that the Alliance recognises that many people have more than one chronic illness; that when a person has one chronic illness they may be at greater risk of developing other chronic illnesses.

The Alliance ran an exploratory workshop in August and participants reported that as well as their primary conditions some people had Type 2 Diabetes, depression, asthma and musculoskeletal conditions. Many of those participating had three or four conditions. In some instances, participants had developed a condition as a direct result of their primary condition, while in other instances it was a side-effect of the long-term treatment they were on. For another group, participants had developed a condition as an adverse event.

In some cases multiple chronic conditions are a consequence of improved treatments and care. People with cystic fibrosis and thalassaemia, for example, are now living much longer than was anticipated even a few years ago. While they value this improved life expectancy, it is sometimes accompanied by the development of other conditions such as Type 2 Diabetes and renal failure in the case of thalassaemia or CF-related diabetes in the case of cystic fibrosis.

Depression was a problem for many of the participants. While there may be a well-documented relationship between having depression and Type 2 Diabetes there was also a strong relationship between living with a rare chronic illness such as thalassaemia and living with uncertainty about one's life expectancy or living on low incomes due to incapacity to work. Depression was also likely to be significant when a person's quality of life was reduced due to an adverse event.

Participants believed that many people with multiple conditions missed out on services because they did not fit some of the guidelines; they were treated for a

primary condition and the other conditions were not considered as important. Some people with multiple conditions could not afford the time or expense of travelling between the various services. Most importantly where rarer conditions were concerned, health professionals did not always have the experience of the complex interrelationship of conditions.

The workshop developed its own draft definitions of 'multiple conditions'. These definitions are not clinical ones but ones that provide directions for the Working Group to pursue a program that will lead to improved understanding of what it is like to live with multiple conditions.

Draft set of definitions

A cluster of health conditions that create a complex relationship between individuals and the health system;

A cluster of health conditions that require negotiating systemic barriers to achieve the best outcomes for individuals with these conditions.

Draft aims

To identify those organisational and political conditions that together create complexity of service management for people with multiple conditions;

To identify those systemic barriers to optimal care for people with multiple conditions.

The Multiple Conditions Working Group will develop a discussion paper which will provide direction on removing some of those barriers and ultimately assist people with multiple conditions to achieve a better quality of life.

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 held its first meeting in October and planned the first three meetings for 2008. Gayle Homann from MS Victoria/NSW will present on the growth of the MS volunteer program at the first meeting in February and a peer support volunteer from the MS program will present on the role of the volunteer in March. If you are interested in being part of this network or just attending the meeting, please contact Jo-Anne Tamlyn on 9882 4654 or email jtamlyn@chronicillness.org.au.

Healthwest project

The Chronic Illness Alliance was pleased to undertake a project with Healthwest (a partnership between Westbay Alliance and Brimbank-Melton PCP) to explore the needs of people living with chronic illnesses in the Western suburbs of Melbourne. We ran four focus groups, two with English-speaking participants and one each with Italian and Vietnamese participants. The report entitled Consumer Perspectives on

Managing Chronic Illnesses has been submitted and will soon be available through Westbay Alliance.

CHRONIC DISEASE SELF-MANAGEMENT SPECIAL INTEREST GROUP

This group continues to meet on a bi-monthly basis. The next meeting is on Thursday 21 February. The topic will be 'The Emerging Value of Peer Support and Support Groups in Managing Chronic Illnesses'. The venue and the speakers will be confirmed in January 2008.

MEDICINES TALK ARTICLE

The following article is a timely one and taken from the Summer edition of Medicines Talk, a consumer publication of the National Prescribing Service. You may like to read the full edition of Medicines Talk on www.nps.org.au or subscribe for regular editions following the information below.

Going away? Keep your medicines cool

Keeping medicines cool and away from sunlight is important when travelling. Heat and sunlight can make medicines deteriorate. This can result in them not working properly, or losing their effectiveness well before the expiry date.

Keep cool and away from light

Most medicines are designed to be kept at 'room temperature', that is, between 20-25°C. Keeping them at temperatures cooler than this is not usually a problem, so the instructions for most medicines will tell you to keep them below 25°C or below 30°C. Such medicines are unlikely to be affected by one hot day. But, if you will be travelling in temperatures above 30°C for more than a day or you know it will be very hot, you will need to protect them from the heat. Possibilities include placing them in a thermos, insulated bag, polystyrene container or small esky. You might also like to take a thermometer (from a camping or hardware store), so you can keep an eye on the container's temperature.

Don't leave your medicines in a hot car, and never in the glove box or on the dashboard. Keep medicines out of sunlight by, for example, putting them in a bag.

In the fridge

Some medicines, such as some eye drops and injections, need to be kept at lower temperatures, so they are normally kept in the fridge. In this case, the fridge means the main compartment of the fridge, not the freezer.

If your medicines are normally kept in the fridge, you should minimise the time they are out of a fridge while travelling. An insulated bag or esky with an ice-brick may be an answer. Ask your pharmacist for advice on where to keep them while travelling.

Medicines are like mushrooms. They need to be kept cool and dark...not on the dashboard! What is the right temperature?

The medicine's Consumer Medicine Information (CMI) leaflet will tell you at which temperature your medicine should be kept. If a medicine needs to be kept in the fridge, this will also be on the label.

Take enough

Take enough medicines and prescriptions to last the trip, along with some extra supplies in case your return is delayed. Also, don't forget to take a complete and up-to-date Medicines List (see back page).

And, last but not least, have a good trip!

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The information in *MedicinesTalk* is not medical advice, so seek professional help before making any decisions based on this information.

This article was accurate and up-to-date when it was published. The evidence or context for this article might have changed since then.

MedicinesTalk is a free quarterly newsletter for consumers written by consumers about using medicines wisely. Subscribe to the hard copy version using our [online ordering system](#), or write to MedicinesTalk, National Prescribing Service Limited, PO Box 1147, Strawberry Hills, NSW 2012.

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Have a safe and happy holiday.

Seasons Greetings from Christine and Jo-Anne