



Chronic
Illness
Alliance

Chronic Illness Alliance Inc

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Newsletter April 2009

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.

WELCOME TO NEW MEMBERS

We now have 50 member organisations. Welcome to newest members 'Life Goes On', Stroke Foundation, Polio Network, Huntington's Victoria.

Details and contacts of our member organisations are on our website. While you are reading about our new members please have a look to check we have your organisation's details correctly presented. www.chronicillness.org.au/community.htm

A PERSONAL MESSAGE FROM CHRISTINE

The Alliance tries to issue quarterly newsletters to our members and supporters. Many of you will realise that this newsletter is late due to my personal circumstances. The destruction of Marysville on 7 February this year also led to the loss of my partner Alen. Following the need for the Coroner's Office to follow the international guidelines for identification of disaster victims we are only now able to have a funeral.

There are many people to thank for their compassion and support during this time. Most importantly, they are Jo-Anne Tamlyn and Greg Watson, Stephen Murby, John Berrill, Graeme Shears and all the Management Committee and all our members, who really showed the strength of their commitment to the Alliance and to me personally. It showed me that while there are many improvements we can make to our community to benefit people generally, we have a strong basis on which to build.

SURVEY OF OUR MEMBERS

The Chronic Illness Alliance has circulated its first members' survey. We encourage you all to complete it and to ask any colleagues in the member organisation who know or use our services to also complete it. We will also circulate a CIA individual members and supporters survey in a few weeks. Completing our survey will help us to identify what we do well, what we can improve and to seek funding to address issues you identify, so we can keep on serving our members and people with chronic illnesses generally. Please go to:

http://www.surveymonkey.com/s.aspx?sm=RZ8vJAji78tMvkRLb0xcPg_3d_3d

NEWS ITEMS

New on CIA website

On our Notices page: there is a link to the National Prescribing Service's media releases. Many of these releases contain important information about specific medications and their use, as well as alerts to problems.

On our Reports page: there is a link to an international report put out by The Economist Intelligence Unit in the UK. 'Fixing the Healthcare System' looks at international perspective on health systems. The Chronic Illness Alliance contributed to its views.

Same sex couples now eligible for the Medicare safety net

Reminder from Medicare that a same sex couple is **now defined eligible** to receive the **Medicare Safety Net** program.

All eligible couples should now register. Please inform your clients that if they register, their medical costs are combined so that they are then able to reach the threshold sooner and be entitled to receive a higher benefit.

Registration is free and they will only need to register once, however they may need to confirm the arrangement from time to time when required.

Clients can register in the following ways:

1. Medicare offices
2. www.medicareaustralia.gov.au
3. 132011

Note: The above website has a .pdf explaining the program in full, threshold \$, and savings couples can achieve.

Wanted by the CIA!

The CIA would like the services of a retired volunteer office manager who would work with Christine and Jo-Anne on a very short-term part time basis to upgrade our office administration. A person who can develop position descriptions, templates, standard forms, contracts and who has word processing skills may like to help us.

Melbourne East General Practice Network is looking for consumers to nominate for their Reference Group

Below are some details of the role the consumer representative is expected to fill. If you would like to nominate please contact me on cwalker@chronicillness.org.au and I will send out the contact details.

Melbourne East General Practice Network Reference Group.

Purpose

- To ensure the program is relevant and responsive to General Practice needs.

Function

- To support program development, evaluation, monitoring and implementation in a timely manner.
- To work within the boundaries set by the Board of Management and its Sub- committees.
- To work towards achieving the goals of the Strategic and Business Plans.
- To work within the budget of the Business Plan and where expenditure is likely to exceed this to get prior approval from the CEO and/or relevant Sub-committee.

Membership

- 3-5 GP's (including GP Clinical Advisor)
- 1- 2 Practice Nurses
- 1-2 Practice Managers/Staff
- Relevant staff members
- 1-2 community agency representatives where helpful
- 1-2 consumers as available
- Tenure 2 years (08/09 – 10/11)

Meetings

- Frequency: 3-5 Meetings per year, other meetings may be required from time to time
- Facilitator/Co-chair- Designated staff member responsible for preparing meeting schedules, paperwork and reports to sub-committees
- Minutes

Reporting

- To the Sub-Committee by GP (as required) and /or designated staff member on a regular basis
- Reports to include relevant strategic highlights from the meeting notes, development proposals, program reports and expenditures, (prior to expenditure, unless already approved through the current business plan)

Payments

- Consumers recruited to the GP Network for a particular group shall be paid the sum of \$40 per hour.

CURRENT PROJECTS AND WORKSHOPS

Chronic Illness Peer Support Network

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 meets bi-monthly with the last meeting held on the 1st April at Carer's Vic. Thanks to Judith Oliver for arranging three excellent presentations around peer support for carers of veterans, members of CALD communities and young carers.

The next meeting will be held on the 3rd June. The Network will be discussing peer volunteers – why the role is different and what motivates a peer volunteer. Peer volunteers will be invited and their interest in establishing their own network will be investigated.

The development of a best practice set of guidelines is progressing thanks to pro bono volunteers, Jan Hayes and Mary Cahill from Oxfam Skillshare. These two project workers have been diligently collecting information from Network members. Their report and recommended framework is due late in May.

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.

Thank you to the Ian Potter Foundation for its support.

'Invisible Illness'

Funds from the Jack Brockoff Foundation have enabled us to update and increase the entries on the Invisible Illness resource for schools. We are also working with the RCH Education Institute, ChIPS reference committee, Department of Education & Early Childhood Development and the Catholic Education Office to develop a video clip which addresses generic issues around better management of chronic illness in schools. The clip will be accessed through the Invisible Illness site.

Workwelfarewills

A new topic 'Workplace Discrimination' is about to be launched onto the Workwelfarewills web resource. This material was written specifically for people who have a chronic illness and are facing difficulties in the workplace. The content was written by Middletons Lawyers who will be hosting the launch in coming weeks. We will keep you informed about the arrangements as we will be encouraging our members to come along, meet and connect with the various authorities and agencies that are available to assist clients who experience discrimination and/or harassment.

Chronic disease self-management special interest group

This group continues to meet on a bi-monthly basis. 2009 got off to a great start with presentations concerning the growth of consumer participation in the health system.

The next meeting is 23 April and features Felicity Sloman who will talk on a new Canadian new model of transition from paediatric to adult services for young people with chronic illnesses.

Already planned are several sessions in regional Victoria including a presentation to update people on the Flinders Model, a presentation on consumer participation in health services and a chronic pain workshop. Details of these will be out soon.

In March Christine attended the Australian General Practice Network workshop on self-management in chronic disease for general practice. At this workshop, workers from community health and networks presented the results of their various projects to work with people with chronic illnesses in the community. Christine informed them about consumer perspectives as well as the Chronic Disease Self-management Special Interest Group which is open to all interested health professionals and consumers.

Multiple conditions project

Despite all the delays this year, there has been some small progress on this project. In late January we had a research assistant who searched databases for literature on

this topic and the results have provided us with a good start for a literature review and a discussion paper. We will progress slowly with this over the next few months.

For your interest.

So, now we are all CULPRITS!

Below is a press release from the Australian Healthcare Association website:

Calling people who take time off work or who are unable to work at all due to a chronic illness 'culprits' is a most unfortunate term. It is precisely this form of denigration of people with chronic illnesses that makes it very difficult for them to get employment in the first place and to retain their positions in a time of economic downturn. Wouldn't it be nice if instead of 'bagging' people for take time off to attend appointments or to cope with a flare up of their illness such people were rewarded for managing to work in the face of illness?

Words like 'culprits' are socially excluding and discriminatory. They are ultimately extremely damaging. They do not assist the health or the quality of life of those to whom they are directed.

The full report, which is more measured in its tone, may be viewed on:

<http://www.aihw.gov.au/publications/index.cfm/title/10442>

People with chronic disease work less-depression, arthritis and asthma key culprits

Spokesperson: Australian Institute of Health and Welfare
Date: Wednesday, 11 February 2009
Category: Reports

A report released today by the Australian Institute of Health and Welfare shows that chronic diseases are associated with more days off work and/or being out of the workforce, and some of the biggest culprits are depression, arthritis and asthma.

The report, *Chronic disease and participation in work*, looked at selected chronic diseases to provide an estimate of the loss to the Australian economy due to reduced participation in work among people who have chronic disease.

Report author, Karen Bishop, said, 'As one might expect, chronic diseases are associated with lower participation in the labour force and more missed days of work.'

'Even after adjusting for age, people with chronic disease were 60% more likely to not be in the labour force than people without chronic disease. They were also less likely to be employed full-time, and more likely to be unemployed,' she said.

People with chronic disease who were in the labour force had, on average, about a half a day off work in the previous fortnight due to illness, compared with about a quarter of a day on average for those without chronic disease.

Of approximately 10.5 million Australians aged 25-64 years, about 33% reported at least one of the following chronic diseases: arthritis, asthma, heart disease, chronic obstructive pulmonary disease (COPD), depression, diabetes and osteoporosis.

The report also found that men with chronic disease were more than twice as likely to be out of the labour force, whereas women with chronic disease were 20% more likely not participate in the labour force.

'This difference may reflect the different labour force distribution for males and females. Males are more

likely to be in the labour force, and females more likely to be out of the labour force for a number of reasons, including caring and parenting,' Ms Bishop said.

Deaths of working age people from chronic disease also decreased the potential workforce.

Loss due to deaths could be primarily attributed to cancers (52%) and heart attacks (19%).

The report estimates a loss of nearly 540,000 full-time workers associated with the presence of chronic disease.

'Given that in 2004-05 the Australian full-time workforce numbered 5.7 million, a loss of half a million people represents nearly 10% of the full-time workforce,' she said.

National Health and Hospitals Reform Commission

Media Release

2 April 2009

INTERIM REPORT SUBMISSIONS NOW AVAILABLE ON NHHRC WEBSITE

The National Health and Hospitals Reform Commission (NHHRC) has received more than 240 submissions from individuals and organisations in response to its Interim Report, which was released in February.

From today, 163 submissions can be viewed on the Commission's website at www.nhhrc.org.au

More submissions will be posted on the website soon.

The Commission's final report is due to be completed in June 2009.

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