



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.

Annual General Meeting 2006

The Alliance held its AGM in 2006. At the meeting we were able to report that the Alliance is in a healthy state financially (at least in the short term). The AGM also voted to change the Constitution to make the Alliance conform with the new ATO rulings so as to apply for Deductible Gift Recipient (DGR) status. The new Committee of Management is: Mr Stephen Murby (Cystic Fibrosis Vic), Ms Francesca Manglaviti (Australian Crohn's and Colitis Association), Mr Mike Kennedy (Victorian AIDS Council), Mr Alistair Kerr (Cardiomyopathy Association Australia), Ms Susanne Baxandall (Diabetes Australia-Victoria), Neil Blenkiron (Community Rep), Mr Russell Pollard (Epilepsy Foundation of Victoria), Mr Alan Blackwood (MS Society, Victoria and NSW). If there are members who are interested in being part of the Committee please let us know as there is the opportunity to co-opt members.

CURRENT PROJECTS

Community Educator appointed

With the assistance of the Law Foundation of Victoria, we launched the [WorkWelfareWills](#) resource on 6th July 2007. Thanks to support from DHS, we now have a community educator, Jan Donovan, who will be contacting many of you and other community groups to explain the value of the web guide for your clients,

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especially those who need to find alternative forms of income because their health is affecting their ability to work. Jan will also be encouraging you, where appropriate, to link to the site so that your clients will have direct access to this resource.

In December, the Leukaemia Foundation held an information day for country clients at the Warragul Arts Centre. For the first session, they invited the Alliance to present on the [WorkWelfareWills](#) site. We included a representative from Centrelink and John Berrill from Maurice Blackburn Cashman to talk about superannuation and insurance issues. John's presentation was very well regarded judging by the huge applause he received at the end and the queue of people wanting to ask him questions. One of the evaluations remarked that "*John Berrill was just great and spoke in a language and a way we could all understand*".

We are now planning a **forum** about WorkWelfareWills for all our members that will include presentations from the Health Services Commissioner and the Welfare Rights Unit as well as John. We plan to hold it sometime in June and will advise the date and venue soon.

In the meantime, we strongly recommend you make a link to this resource on your website. www.chronicillness.org.au/workwelfarewills

Consultation on behalf of Knox Community Health Service

Over the last few months the Chronic Illness Alliance has been privileged to work with the Knox Community Health Service. We have conducted focus groups on access to services for people with chronic conditions in the Knox locality. The broad aim has been to provide the health service with consumer feedback on the services people need to care for themselves with a chronic condition. Focus groups have shown us the value of community health services in providing people with chronic illnesses with the sustained support they require to care for themselves over many years.

'Welfare to work' forum held in October 2006

In association with MS Australia and Diabetes Australia Victoria, the Chronic Illness Alliance held a forum on the implications of the recently introduced 'welfare to work' policies. While many people with chronic illnesses welcome a return to work, some of the problems they face, including their capacity to work a certain number of hours need more attention. This forum was chaired by Mr. Ralph Willis whose previous experience in government and with the ACTU gave the forum useful insights. There were speakers from TAC, MS Australia, Diabetes Australia-Victoria and Epilepsy Foundation of Victoria. The forum agreed there was a need for a better understanding of chronic illnesses by job capacity assessors. The Victorian Council of Social Service has agreed to assist us further this issue. The full report is available on the website www.chronicillness.org.au under 'What's New.'

It is interesting to note that following this forum the Alliance received a phone call from a young man who was working as a job capacity assessor in NSW. He had just seen a woman with Chronic Fatigue Syndrome and depression. He was clearly distressed by his inability to offer her any kind of help to improve her life, and he thought that returning to work was not an option for her. He was ringing as he was looking for services to assist her rather than just telling her she was unsuitable for employment and then abandoning her. There must be many stories out there like

this one. If you have them please let us know as they are a means to highlight the problems and try to improve the system.

PEACH research project

Christine Walker is a chief investigator on this NHMRC-funded research project being undertaken in the Dept of General Practice at University of Melbourne. This research is testing a model of telephone coaching to assist people with diabetes to self-manage better. People with diabetes in the northern suburbs of Melbourne who consent to participate in the research will be phoned several times over 18 months by a practice nurse who will assist them with the problems they face in controlling blood glucose through diet and exercise or medication. At this stage, the team is up to training practice nurses in the coaching program and recruiting people to participate.

Epilepsy Foundation Project

Last year the Epilepsy Foundation of Victoria and the Alliance received funding from the William Buckland Foundation to undertake a project with people with epilepsy. In this project we have asked people to inform us of how epilepsy impacts on their lives and what they would most like the EFV to research on their behalf with a view to improving their lives. The report is now being written and demonstrates that many people with epilepsy have to cope with underlying prejudice and misunderstanding of epilepsy in the wider community.

Medicare Consumer Consultative Group

The Alliance continues to represent people with chronic illness at Medicare consumer consultation meetings held quarterly in Canberra. Medicare offices and services are undergoing substantial changes. While their core function of rebating medical bills remains unchanged, the way they process the rebates is changing and their offices are now being used for a number of other social security functions.

Already you may have noticed that revamped Medicare offices now have a Family Assistance counter and it is intended that more social security benefit payments will be transferred from Centrelink to Medicare. Conversely, in some rural and remote areas Centrelink is trialling Medicare processing where the Medicare does not have an office.

Later in the year [possibly June/July] it is planned that doctors will be able to process rebates immediately via electronic funds transfer (EFT) at the same time as the doctor's bill is paid. This will save a visit to the Medicare office or the time it takes to make a claim by mail. If you have any comments to make about any of the changes that you want passed on to Medicare, please reply by email or contact Jo-Anne Tamlyn on 9805 9126 Tuesday/Wednesday.

The most controversial change that Medicare is involved in is the new 'Access Card'. Medicare will be the agent for registering for the card, an anticipated 33,000 registrations per day. As you may have learnt from the publicity and debate surrounding the passing of its legislation recently, the card will replace all other Centrelink cards. It is a single card for people to receive health and social services. The immediate response is that most people will be pleased to have their lives simplified by having all their information on the one card and to have additional health information for emergency purposes. However, there is much controversy about the detail and what exactly is recorded on the cards. The following report outlines some of the more serious concerns that are currently held.

Access Card Workshop Canberra December 2006

One of our members, Robert Pask, represented the Alliance at a Federal DHS workshop on the new Access Card, held in Canberra in December 2006. Robert is from MS Australia. Here is his report.

Report by Robert Pask [MS Australia]

The Federal Department of Human Services held a workshop in Canberra to go over the Access Card (Smart Card), and concerns different sectors of the community may have with its introduction and content.

These consultations were supposed to continue into 2007 but the Minister decided during the Christmas New Year break that there were to be no more of these held.

The Government has during this session of Parliament put forward the legislation to bring the Access card into existence. The opposition Shadow Minister (Tanya Plibersek) has put forward amendments to the legislation.

Personally I think it is a disgrace that the consultations have stopped as in my opinion there are many concerns about this card being put into circulation and that is beside the cost of the exercise.

To me this is an identification card that will invade people's privacy. It is said that it will not be compulsory to apply for the card but if a person does not have the card they will not get services such as Medicare.

The card will have two sections, one with the information the government requires such as Medicare number, pension number and a photo. Then there is the part of the card where people can put their own information such as if they suffer an illness, their doctor's name, medication etc and this part of the card can be protected by a PIN number if the consumer wishes. If there is an emergency situation, for example where an ambulance is called, a paramedic can override the personal PIN.

This is an area I have a problem with and so did many of the people at the December workshop I attended. If a paramedic can access the information others will be able to as well and that is a major problem. People with illnesses such as HIV, mental illness and many other chronic illnesses will, through fear of prejudice not want to have this information on a card that could be accessed by so many and be at risk of involuntary disclosure.

Another of the many concerns others and I have is if the wrong information is keyed onto the card like wrong spelling of a medication, could spell another medication that could be harmful and even cause death. As medications change the card information will need to be updated. There are many very vulnerable people in our community who have had bad experiences with bureaucracies such as Centrelink, They avoid contact with them so their information will not be updated.

Another concern of mine is what happens to privacy if data input goes off-shore so that we lose control of our private data.

Robert Pask.

Planning Paediatric Services

The Alliance is currently representing families of children on two service planning committees. The Paediatric Rehabilitation Reference Group has been meeting for over two years and in that time has developed a new model of care for treating children requiring a multidisciplinary approach to rehabilitation. As a direct result of our advocacy for genuine consumer input, the State government engaged the services of a research company (IPSOS) to undertake a series of family interviews and focus groups. Their interview work is complete and a report will be ready soon. While the results are not yet released, it is anticipated that the report may well influence other DHS projects as the issues raised are important to consider in good service planning.

The Alliance is also working at the Royal Children's Hospital with a group working towards a much improved obesity and weight management clinic. Any member interested in either of these projects is welcome to contact the Alliance for more information.

For more information about the RCH projects, please contact Jo-Anne on 03 9805 9126.

Finally, we have not included any of our members' activities in this edition. This is because we are aware that we have not distributed a newsletter since last year. We wanted to get one out quickly! However, we love circulating information about our members' activities and we will return to this in the next newsletter.

Best wishes,

Christine and Jo-Anne.