



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

We welcome our most recent member, the Continence Foundation of Australia (CFA). CFA is the national peak body for continence management, promotion and advocacy. A not-for-profit organisation, the CFA has branches or representatives in each State and Territory and established Continence Resource Centres in Victoria, New South Wales, South Australia and Western Australia.

The vision of the Continence Foundation of Australia is an Australian community free of the stigma and restrictions of incontinence.

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

INVOLVING PEOPLE IN RESEARCH: A SYMPOSIUM IN WA

On 5 and 6 March this year, the School of Population Health at University of Western Australia presented a symposium 'Involving People in Research'. The aim of the symposium was to workshop issues relating to involving consumers and community members in research. Consumers, consumer representatives, health professionals and researchers gathered together to discuss the benefits of, and barriers to, such involvement. Participants heard about the National Health and Medical Research Council policies to encourage consumer and community involvement in research; similar work being undertaken in the UK; research that was driven by consumer need; consumers as proposal reviewers and the standards that could be adopted nationally to promote beneficial involvement.

This symposium allowed for good debate and at its end the participants produced a communiqué on involving people in research.

While this was the first such event I attended in 2008, I think it will be a highlight of 2008. Its success was largely due to Anne McKenzie's meticulous organization, as well as the visionary approach of the various sponsors.

Christine Walker

A NATIONAL PATIENT CHARTER OF RIGHTS

Consumers' Health Forum conducted a workshop on the National Patient Charter of Rights which has been drafted by the Australian Commission on Safety and Quality in Healthcare. The workshop was organized to gather the views of consumers and carers on the value of a national charter as well as the content of the draft charter. Iva Steinke attended on behalf of the Alliance. Below is part of her report back to the Alliance.

'In general it was agreed that the document was worthwhile. It is to be an "umbrella" Charter from which states can develop their own. However, there will not be any legislation to back it up, so in the end it could prove worthless as implementation cannot be enforced. Concerns were expressed regarding the use of certain words, the meanings of some points etc. It was not clear how the Charter would benefit the average consumer. One participant kept returning to patient responsibilities, which are included in the Principles, but were not part of the discussion points for the day.

Workshop participants thought distribution of the Charter was a major consideration. I think that in the end it was expected that the basic points of the Charter would be displayed in every hospital and medical practitioner's waiting rooms. It will be translated into several languages. It was agreed that an extensive advertising campaign using all available media will be necessary.

The points I made, some of which are already included in the "Principles" section of the Charter, were:

1. Patients should have the right to view their own records and have errors amended.
2. Point no 6 states that: "I am entitled to be included in making decisions and choices about care". This should include that patients have the right to choose the option they prefer. Generally the patient's choice is to accept the doctor's option or refuse treatment altogether.

3. That family and carers be involved in care decisions, including being told the reasons for those decisions.
4. That more consumers should be canvassed regarding their needs and opinions about the Charter, using whatever means are necessary. This may include going to where consumers are rather than hoping to attract them to meetings. Conversations rather than interviews. That greater effort be made to communicate with those consumers who do not feel confident in expressing their needs or whose lack of skills preclude them from participating in usual methods of data collection.
5. Often, consumers do not have an issue with the medical staff, but rather with the attitudes of the Triage nurse, reception and clerical staff. These people set the tone for the establishment and for the experience of the patient.

It was agreed that the Charter should apply to all workers, not only medical staff, in any medical facility.

The meeting was well led and finished on time. Suitable and enjoyable food was provided for the two of us who don't eat 'normally' and Nicola and Alexandra were friendly and helpful. Taxi vouchers were provided although I hadn't asked for them. These were appreciated given the time it takes me to access public transport at the moment.

Thank you for the opportunity to participate on the day.
Regards, Iva.

PS. Since this event, I have been asking everybody I know whether they were aware of the existence of Charters of patient rights. Not one person knew of their existence, even those who have been dealing with medical providers for 30 years or more.'

Thanks Iva for participating on our behalf and for the report back to everyone.

If our members would like to read and comment on the draft National Charter please go to www.safetyandquality.gov.au

CHANGES TO SUPERANNUATION

On the 12th March, Cancer Voices NSW together with Positive Life NSW held a seminar on superannuation in Sydney and invited the CIA to participate. The purpose of the seminar was to discuss the change to super payouts to the terminally ill, passed through Parliament in February 2008. The change allows terminally ill patients (expected not to live beyond 12 months) to claim their superannuation benefit TAX FREE regardless of their age. This was a great win for the cancer groups lobbying for this change but from our perspective we would argue that anyone entitled to a disability payout through a super fund should receive it tax free. We made this point and as a result of this and several other suggestions from the floor, a network is being brought together to lobby the Government for further changes.

John Berrill, a superannuation expert and long time advisor to our members, attended as a representative of the CIA and was invited to speak. He made a number of suggestions about improving the current system. Many of these will be taken up by the new network as priority issues, first and foremost being to lobby Nick Sherry, the Federal Minister for Superannuation & Corporate Law, to add a consumer advisory panel to his collection of industry-based advisory panels. Another priority is to overcome the complexity of financial issues which they identified as being a maze for consumers. The meeting was particularly impressed with the

Alliance's "Workwelfarewills" online resource and recommended that it be adapted to cater for all Australian States (50% of the information relates to Victorian law and this has been on our drawing board for some time now, so with funding it may become a reality).

Anyone who is interested in joining the network should contact Jo-Anne on 9882 4654 or jtamlyn@chronicillness.org.au

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.

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 2007 and planned the first three meetings for 2008. Gayle Homann from MS Victoria/NSW presented on the growth of the MS volunteer program at the meeting in February which was very inspirational to those attending who are currently planning to set up their own programs. Trish Waters from the Cancer Council will be presenting on 'Cancer Connect' at the next meeting on April 16th. 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.

CHRONIC DISEASE SELF-MANAGEMENT SPECIAL INTEREST GROUP

This group continues to meet on a bi-monthly basis. The next meeting is on Tuesday 15 April and is from 2 PM to 4 PM. It is a workshop on Health Coaching and will be held at La Trobe University City Campus, Ground floor lecture room. A meeting on peer support and its role in chronic disease self-management will take place at Bendigo CHS, Eaglehawk, on 8 May from 2 to 4 PM.

NEW ON-LINE HEALTH RECORD.

An innovative new concept to enable carers to keep track of health information has been developed by a leading advocate in NSW. Following the award of a Churchill Fellowship in 2006, Jude Foster, President of the Learning Difficulties Coalition NSW and a registered nurse, investigated how families used technology to share information with professionals involved in their management. Foster found that families around the world are still the messengers between the many professionals involved in their care.

When she returned to Australia, Jude was joined by a team of international professionals and established miVitals Technology to create a secure online Web application that would assist families in managing and accessing their health information from anywhere in the world 24/7. www.mivitals.com is now live and provides free access to a core health module which enables people to record, emergency contact information, allergies, immunisations and all medical conditions. They can even attach appointments (with free SMS reminders), tests and treatments to the record.

"We wanted to develop a system to promote wellness and which I hope will empower individuals and families as advocates." says Foster. Professor William Runciman, author of Safety and Ethics in Healthcare and founder of The Australian Patient Safety Foundation says, "much healthcare associated harm is related to medical records not being available, incomplete and inadequately assimilated. Patients now have access to a powerful safeguard in the form of a medical record which is complete and up to date and they can ensure it is properly understood. Patients can be their own most powerful advocates."

Readers of this newsletter should be aware that there are many similar products being developed throughout the world and the Chronic Illness Alliance does not endorse the above product but advises that those people considering having their own personal health record should check out as many as possible.

A LETTER FROM TIMOR LESTE

Below is a letter from our CIA member, Jan Donovan who is now living and working in Timor Leste.

Friday 21 March 2008

I am currently living and working in Timor Leste with my husband and young daughter. We have packed up our comfortable house in Melbourne and will live here for all of 2008. I am teaching English, English as a Second Language, Science, Maths and Health to the senior and middle school students at the Dili International School.

We have been interested and involved in Timor Leste now for many years and this is my fifth visit here but it is the first time I have lived here for an extended period. I am also an active member of the Chronic Illness Alliance and have been asked by Christine to make a contribution to your newsletter.

There is no part of this country that is not extremely poor. Much of what we take for granted in Australia is simply not available to the people of Timor Leste. What is lacking for most Timorese is access to running water, reliable electricity and fuel for cooking, roads without huge potholes, good quality housing, reliable public transport, good quality schools, TAFEs and Universities, hospitals and health centres and the list goes on.

Many academic studies have told us that poor health and poverty go together. The reverse also applies - good housing, good education, a safe environment and jobs in addition to health services are important contributors to good health. The poor people of Timor Leste have major deficiencies in all of these contributors to better health.

Diseases that were eradicated long ago in countries like Australia such as malaria and TB are significant contributors to major illness and mortality here in Timor Leste. People's lives are short in Timor Leste as a result of these diseases, lack of appropriate and affordable medicines and inability to get to a health service for treatment. Babies and their mothers are also vulnerable to diarrhoea and worms caused by drinking polluted water and living so closely to animals such as pigs, chooks, goats and dogs.

There are no rubbish bins distributed by the local government organisation to individual house holds so people must collect up their weekly rubbish and cart it to a communal rubbish bin. We live opposite one of these communal, blue concrete bins in Dili which are open at the top. If everything is going well the rubbish is collected by a rubbish truck once a week. By this time, however, the bin is overflowing and polystyrene containers, paper and plastic bags are blown along the road and onto the beach opposite. Goats and dogs climb up onto the top of the bins and fossick for food and in the process more rubbish is spilled onto the road and blown along the beach.

Some people live in small houses here with proper roofs and floors but the vast majority live in ramshackle huts constructed out of wood with corrugated iron roofs and very few windows. People cook on open wood fires and there is a constant smell of smoke which I have now adjusted to. I kept thinking something was burning but now realise that people who cannot get their rubbish to a communal bin burn it at the back of their house. Respiratory infections are also common in young children here as a result of this rubbish disposal method the open fire cooking method and also because many men smoke despite their poverty. Cigarettes only cost a dollar a packet.

Having painted this bleak picture I now want to reassure you that there is a lot that is positive happening here. Fundasaun Alola (whose motto is strong women, strong nation) is the Foundation established by the former first Lady of Timor Leste, Kirsty Sword Gusmao in 2002 and is dedicated to empowering women through improved health, education, leadership and employment opportunities. A major program run by Fundasaun Alola is the maternal and child health program. According to the latest Fundasaun Alola newsletter, the program raises awareness of the potential dangers of pregnancy and birth for women, encouraging women to attend antenatal checkups and deliver at a health clinic.

Infant mortality is high at nine deaths for every one hundred births. Maternal mortality is also high with 660 deaths per 100,000 live births. East Timorese families are large

and women have on average seven to eight children. Over 90% of women give birth at home without the assistance of skilled health worker or midwife placing them at high risk in the event of complications during or after the birth.

The success of this particular Alola program relies very much on the local village level commitment and the collaboration of local health staff and “action “networks selected by the community. There are a number of steps taken at the local level to ensure that women have the necessary information including family planning information, community fundraising, transportation and blood group testing network.

Pregnant women are registered by the community networks that also promote the need for antenatal care, identify women with danger signs and develop a birth plan as well as an emergency plan. The fundraising and transport networks ensure the resources needed for rapid transport to a clinic or to collect the midwife are available. One major outcome from this most important project is the establishment of local advocacy for improved midwife services and better road access to isolated communities. If you would like more information about the programs run by Fundasaun Alola please email Vic @alolafoundation.org or info@alolafoundation.org

I could go on and talk about the Internally Displaced Peoples camps but perhaps it is better I leave that to my next letter to Christine and Jo-Anne and all at the CIA.

Jan Donovan