SELF HELP QUEENSLAND

December Newsletter Issue 4. 2004

Self Help Queensland is a network of self help organisations and groups in Queensland. The network was formed by self help organisations to share resources, support each other, assist in the development of new groups, raise community awareness of the importance of self help and provide a strong united voice on issues which affect our members.

From the President

Sue Smyllie

Part of my life long learning lately has been concerned with finding out more about co-operatives. According to the International Co-operative Alliance a co-operative is 'an autonomous association of persons united voluntarily to meet their common economic, social and cultural needs and aspirations through a jointly owned and democratically controlled enterprise.' Sounds like a self-help group doesn't it? I have been learning about them because I am very curious as to how we may be able to concurrently support economic and social goals. Too often these days the social aspects of groups are overshadowed by economic demands. These demands may be self generated in order to exist, or funder generated in order to account.

The co-operative model has been around for a long time, since 1750 in fact. It is practiced in various ways in various situations. Perhaps the most well know co-operatives are those associated with agriculture. Across the world co-operative members number in the billions as do profits. Co-operatives focus on generating benefits which may or may not be profits and these benefits often spill over into the non-member community.

It seems to me that co-operatives are a possible way in which the non-government sector could build capacity for the future. I know the model is often associated with failed market gardens and fierce personal and political battles….but name me a corporate model that isn't! The difference is a set of founding principles which insist on equitable participation in decision making and a built-in recognition of the value of non-economic goals, two battles at least which would not have to be re-fought.

How I would love to see self-help co-operatives, or women's co-operatives or public health co-operatives or job seekers co-operatives ..self funded and accountable! I know there must be lots in existence even just in Queensland. I'd be very interested in hearing of your experience just email me at ssmylie@bigpond.net.au. Or perhaps you'd like to share your story in our newsletter…a very special self-help section.

As the end of the year approaches it is again time to send you all my best wishes for a safe and happy future.

Regards
Sue

Self Help Queensland Inc 2005 Planning Afternoon

A warm welcome is extended to all to attend our 2005 Planning Afternoon at SHQ:

When: Tuesday 1 February 2005 at 3pm
Where: 121 Lister Street, Sunnybank.
Ph/Fax: 07 3344 6919
Email: selfhelp@gil.com.au
RSVP: Trish by Wednesday 26 Jan

Refreshments Provided

Holiday Office Closure

The SHQ office will close on Thursday 23/12/04 and re-open on Monday 24/1/05

Management & Staff of Self Help Queensland Wish all our Members and Friends a Very Happy and Safe Holiday Season.

Self Help Qld Management Committee Members

President	Sue Smyllie
Treasurer	Kathleen Zarubin
Secretary	Cheryl Russell
Member	Kim Summers
Member	Thea Biesheuvel
Member	Glenis Charlton

Committee Meetings

If you would like to attend our meetings, please contact the office for dates and times. Everyone is welcome to attend and we look forward to seeing some of you at our meetings. We are always on the lookout for new committee members!

Project Officer

Trish Fallon

Office

The office is attended (unless our staff are at meetings) from Monday to Friday from 9am to 4.00pm each week.

If you wish to call in to use the facilities at the office or talk to our project officer please phone first and check that there will be someone in the office.

Office Location:

Sunnybank Community Centre
121 Lister Street (Cnr Gager Street)
Sunnybank 4109

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P.O. Box 353
Sunnybank QLD 4109

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The material supplied is for information purposes only, and is not to be used for diagnosis/treatment, or as legal, tax, accounting or any other type of advice.

Thanks to Queensland Health for providing funding to Self Help Queensland for publication of the Self Help Queensland quarterly Newsletter.

Student Drug Use

Assessment and Treatment for Students and Families

The recent news in the media over expulsion of high school students for drug use has been cause for concern among principals, teachers, students and parents. When a student has been excluded from school for drug use, it's important the student and their family get professional help immediately.

Parents and families play a significant role in alcohol or other drug use and how they deal with it now, could make all the difference in the future. The Holyoake service offers confidential assessment and treatment programs to students and families involved in a drug related incident. Appointments can be made on (07) 3831 4094.

Holyoake is a not-for-profit organisation providing both individual counselling and group workshop programs for family members of those with an alcohol and/or drug problem. Holyoake is affiliated with the Alcohol and Drug Foundation, Queensland, and receives funding from Qld Health.

Contact: Holyoake - The Queensland Institute on Alcohol and Addictions Inc
Ph: 07 3834 0214 Fax: 07 3832 5625
Email: holyoake@adfg.org
URL: www.adfg.org/holyoake.html

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Genetic Matters

by Kim Summers PhD

Medicine in 2020

Biotechnology is the process of using living organisms to achieve an endpoint which is desirable to humans. As part of the recent Aus Biotech conference in Brisbane, speakers at a public forum discussed the impact that biotechnology is likely to have by the year 2020. One of the speakers was Professor David Hume from The University of Queensland's Institute for Molecular Biosciences, who spoke about how developments in biotechnology will impact on the practice of medicine.

David focused on three areas: genetics, organ regeneration and drug design.

We are constantly hearing about the Human Genome Project and its likely impact on medicine. Sequencing of the whole human genome has increased our understanding of the way genes work, how genes and proteins interact with each other and what happens when there is a problem with a gene. We are now able to detect a disease-causing genetic change well before any symptoms appear (presymptomatic or predictive testing, for example for Huntington disease) and classify the risk of developing a disease on the basis of genetic makeup (susceptibility testing, eg for breast cancer).

A few years ago I used to predict that eventually parents would leave hospital with a baby in a basket and a CD of the baby's genotype in their hands. With the rapid pace of technological change, David feels they are more likely to be given a bar code unique to their baby. By logging on to a website they will be able to download all the genetic information for their baby, telling them what diseases are high risk and how to modify the baby's environment and life style to minimize those risks. There are social and ethical implications to this prediction.

Do parents have the right to know this information about their child, to consent to the genetic testing on the child's behalf? If we can prevent diseases which are a cost to the society, should we force parents to minimize the risks to their child? Who should have access to this information?

Knowledge of genetic variation may also be used in the future to adjust drug therapy so that it suits the genetic makeup of the individual. There are a number of diseases where different causes are predominant in different people. For some people with high blood pressure, ACE inhibitors are the best treatment but for others they don't work, presumably because different genetic or environmental variation is involved in producing the elevated blood pressure. Pharmacogenetics is the process of matching drugs and genes, so that each person takes only the medicine which is most likely to control their condition.

Another aspect of biotechnology which is frequently discussed is stem cell therapy. Stem cells are cells which have the capacity to divide and differentiate into a number of different cell types. These cells can go on to become specialised types which may be used to treat diseases. Bone marrow transplants rely on the presence of stem cells which divide and replace the different types of blood cells in the patient. There are already moves to use nerve stem cells to assist people with spinal cord injuries and other nerve problems such as multiple sclerosis and brain disorders like Parkinson disease. Liver stem cells injected into the blood stream are transported to the liver where they may increase liver function. Muscle stem cells may be able to differentiate into heart muscle to replace dead tissue caused by a heart attack.

Stem cells also offer the possibility of creating whole organs in a bottle, to avoid problems of donor availability and rejection. David pointed out that the technology already exists to provide scaffolds on which cells can grow in a defined shape. Some cell types are self-organising: kidney stem cells will form tubules to make primitive kidneys in a Petri dish and cardiac muscle cells start to beat spontaneously when grown in a culture flask. By 2020 we will understand much more about the factors which are needed to induce stem cells to begin the process of differentiating into specific tissues, and the support needed to provide appropriate shapes for replacement organs.

There are also ethical issues about the use of stem cells. The most versatile cells are found in early embryos. At present, experi-

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ments can be done on embryos which are not needed for in vitro fertilization. These will allow researchers to develop the necessary techniques. However, to ensure that the new organ is not rejected (and to avoid harsh anti-rejection drugs) it would be best to use the patient's own stem cells. In animals, embryos have been created from the cells of an adult using the process called cloning. These are almost identical to the adult and grow into creatures whose organs are entirely compatible with that adult. But waiting for your clone to be old enough to provide a liver for transplant is not realistic in human disease. And there are ethical issues involved in allowing a clone of oneself to be created for the purpose of providing an organ. One alternative would be to create the embryos and harvest the stem cells, and then grow the organs in a bottle. But would this process be ethical in humans?

Finally David talked about drug design. Almost all of the drugs we use today were discovered by chance, based on traditional medicine, chance events or trial and error chemistry. Chewing willow bark was a folk remedy for headache. We now know it works because willow bark contains the active ingredient of aspirin. We've all heard how penicillin was discovered because of an experimental accident where some bacterial culture plates were contaminated with a mould which stopped the bacteria growing. Many newer treatments developed by making minor changes to the structure of established drugs in a more or less random way.

One impact of all the genome projects should be to allow the rational design of drugs. This has been called pharmacogenomics. Genome information (including the expanded knowledge of how genes and their products interact) should allow researchers to create therapeutic molecules which have a very specific and well understood interaction with their target molecule and other molecules in the cell. Unfortunately, it takes something like 14 years to go from initial drug design to the chemist's shelves or doctor's surgery, so the drugs which will be newly on the market in 2020 are already being developed. Some of these will be the result of rational drug design; many more will still result from traditional serendipity.

Other topics at the forum included biotechnology and agriculture, problems raised by genetic engineered organisms, and the importance of water management biotechnologies. David and the other speakers provided an interesting vision of life in 2020 where biotechnology has made a significant contribution to our lives. After his talk David asked participants whether they would like to live to be 120 if it was possible and half answered yes. If we do reach that age in comfort, it will be because of developments permitted by the biotechnology revolution of the early 21st century.

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2005/2006 Queensland Directory of Self Help & Support Groups

- for Health Conditions & Related Issues

As mentioned in our last newsletter, Self Help Queensland will be undertaking an important/exciting project in the New Year to produce a much requested hard copy "Directory of Self Help and Support Groups for Queensland", with the prospect of web access in the future. To our knowledge, this will be the first of its kind for the State. The Directory will be sold to cover costs and updates and represents an important infrastructure support for the sector.

Please Tell us about Your Group

If you belong to a self help or support group anywhere in Queensland, we would love to hear from you so we can make contact, learn more about your group and hopefully establish a mutually supportive relationship.

We will be contacting known groups in the New Year to see if they wish to be included in the Directory and to check on the accuracy of our information. We are very thankful to the Commonwealth Dept of Transport and Regional Services, and Qld Health for seed funding for this Project.

Contact: Trish at the SHQ office:
Ph/Fax: (07) 3344 6919
Email: selfhelp@gil.com.au

Support Available for Sex and Love Addicts

Hi my name is Rick and I am in recovery from sex and love addiction. Don't be scared, I'm only human! When I first heard of the term sex and love addiction, it conjured up all sorts of thoughts and images. I was concerned that I would be labelled as one of society's outcasts. I really had no understanding of what this addiction was all about, even though it had me in its grip for a large part of my life. It was as a result of my own sessions with a psychotherapist and subsequent attendance of the 12 step program of recovery that helped me to further understand this addiction and how it played out in my own life.

I write this article to hopefully give you some idea of what sex and love addiction is about. We hear about alcohol and drug dependencies and yet there are many addictions that are not necessarily related to substances. Sex and love addiction is one of these. Behaviours that stem from underlying issues are varied. A sex and love addict may have one or more of these presenting behaviours. Here are some of the documented characteristics of sex and love addiction. (Sourced from Sex and Love Addicts Anonymous literature)

- Having few healthy boundaries, we become sexually involved with and/or emotionally attached to people without knowing them.
- Fearing abandonment and loneliness, we stay in or return to painful destructive relationships, concealing our dependency needs from ourselves and others, growing more isolated and alienated from ourselves, and loved ones.
- Fearing emotional and/or sexual deprivation, we compulsively pursue and involve ourselves in one relationship after another, sometimes having more than one sexual or emotional liaison at a time.
- We confuse love with neediness, physical and sexual attraction, pity and or the need to rescue or be rescued.
- We stay enslaved to emotional dependency, romantic intrigue or compulsive sexual activities. Our lives become unmanageable.
- We assign magical qualities to others. We idealise and pursue them, then blame them for not fulfilling our fantasies and expectations.
- To avoid feeling vulnerable, we retreat from all intimate involvement, mistaking sexual and emotional anorexia for recovery.
- We use sex and emotional involvement to manipulate and control others.

These are only some of the characteristics that sex and love addicts may experience.

Being in recovery from my own sex and love addiction, I have learnt that underlying these characteristics have been feelings of low self worth, issues of abandonment in relation to my family of origin, rage and anger in relation to issues of discrimination and bullying, and the list goes on. So sex and love addiction is a manifestation of presenting behaviours, resulting from underlying issues that often remain unconscious until we begin our journey of self discovery, and that is very much an individual pathway.

Fortunately for me, my pathway of recovery introduced me to other sex and love addicts through the twelve step program of Sex and Love Addicts Anonymous. I no longer felt all alone on my sometimes challenging pathway towards self understanding and healing. I am grateful today for all of my addictions as they brought me to this point of knowing that I no longer have to be the victim to their destination of inevitable destruction.

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Tell Us What You Think

We would like to receive feedback about the newsletter and invite you to contact us about content, quality, format, or any issues you would like addressed in future editions.

Please contact Trish at the SHQ Office:

Ph/Fax 07 3344 6919
Email: selfhelp@gil.com.au

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In fact, admitting powerlessness around any addiction begins the change to true empowerment, which is a very wonderful gift to my life. I am no longer at the mercy of these feelings or behaviours that tell me that I need them in order to survive.

I could probably write a book about my personal experiences in relation to my life and my issues of addiction and maybe one day I will, but for now I share this much with you, in the hope that if there is one person out there reading this and relating, that this may be of some help to you. If this is the case please know that you are not alone.

If you would like further information on Sex and Love Addiction meetings you could contact me (Rick) on 07 4635 8590.

Sincerely
Rick Ireland

SLAA Membership

The only requirement for SLAA membership is the desire to stop living out a pattern of sex and love addiction. All meetings are open to all adults of any gender except for "closed" meetings which are open only to SLAA members. Our meetings are usually in two parts - a formal part of approximately 90 minutes followed by an informal part of about 30 minutes.

SLAA Meetings

Brisbane Metropolitan
Thursday, 6pm, Red Hill Paddington Community Centre, 180 Jubilee Terrace, Bardon

Saturday, 4.30pm, "Biala" (Floor 3, Group Room) 270 Roma Street, Brisbane

Queensland Regional
Thursday, 2pm, St Patrick's Cathedral Centre, 123 Neil Street, Toowoomba (building between Cathedral and Paddy's Café - enter Via Conference Room door)

For further information or details of remote/ country meetings contact head office:

SLAA
PO Box 1253
MAROUBRA
NSW 2035
Phone: (02) 9358 6605

Community Tool Box

Supporting Your Work in Promoting Community Health and Development.

The Tool Box is a web site which provides over 6,000 pages of practical skill-building information on over 250 different topics. Topic sections include step-by-step instruction, examples, check-lists, and related resources. The site is created and maintained by the Work Group on Health Promotion and Community Development at the University of Kansas (U.S.A). It has been on line since 1995, and continues to grow weekly.

The core of the Tool Box is the "topic sections" that include practical guidance for the different tasks necessary to promote community health and development eg. there are sections on leadership, strategic planning, community assessment, grant writing, and evaluation to give just a few examples. Each section includes a description of the task, advantages of doing it, step-by-step guidelines, examples, checklists of points to review, and training materials.

Learn a Skill: A "Table of Contents" links you to 46 Chapters and over 250 Sections that provide training in specific skills of community work.

Plan the Work: Toolkits provide outlines for tasks, examples, and links to how-to information for 16 core competencies involved in doing this work.

Solve a Problem: "Trouble-Shooting Guides" list common dilemmas you face in this work, questions for analysis, and links to relevant supports for solving them.

Explore Best Practices and Processes: Evidence, examples, and links to tools help you make the case for a set of key mechanisms that advance your work.

Connect with Others: Learn with others about this work in on-line forums, ask a question of an advisor, and find links to other on-line resources.

Contact: Work Group on Health Promotion & Community Development.
Email: Toolbox@ku.edu
URL: http://ctb.ku.edu/

ECZEMA ASSOCIATION

OF AUSTRALASIA INC

bee eczema educated!

The **ECZEMA ASSOCIATION OF AUSTRALASIA INC** (EAA) is an independent Australasian wide organisation founded in Cleveland, Queensland, in January 1994 as a non-profit registered charity.

The EAA supports and educates eczema sufferers & carers, along with the wider community, in all aspects of eczema & its impact. To achieve this, the Association relies on memberships and donations along with corporate sponsorship.

The EAA has a good working relationship with Australian & International Dermatologists, Natural Therapists, other Medical Practitioners, Pharmaceutical Companies, Political Representatives from various parties and many companies who manufacture products which may be beneficial to eczema sufferers.

As well as supporting and educating Eczema sufferers, their carers and the wider community, the EAA also aims to:

- greatly increase public awareness of Eczema
- ensure the improved treatment of sufferers and carers in public situations
- improve and broaden the availability of medical treatments and supplies for Eczema sufferers
- maintain links with medical professionals to ensure continuance of up to date information
- conduct specialised research into the causes and effects of Eczema

Eczema, which affects up to 30% of the Australian population at some time of life, is a disorder which results in dry, inflamed and sometimes weeping or infected skin.

Although there is no known cure for eczema, the condition can be controlled.

The main type is Atopic Eczema, which is usually inherited, and often allied to asthma and hay fever. Other forms of Eczema include Contact (Allergic) Eczema, Contact (Irritant) Eczema, Discoid Eczema, Light Sensitive Eczema, Pompholyx Eczema, Seborrhoeic Eczema & Varicose Eczema.

As Eczema is a very individual condition, finding the right products to treat it is a trial and error process. Fortunately, there are many ways to ease the suffering and a huge number of products on the market especially formulated for treating the condition.

The Association has a free information pack which it sends to people who make enquiries and members are entitled to many more benefits such as the following:

- quarterly newsletter with tips, information, members letters and details of the latest products on the market
- free product samples which may be beneficial for Eczema sufferers
- optional social register for members to contact others on the register
- information sheets on a wide range of Eczema topics
- help and information from Dermatologists and Natural Therapists via the EAA
- availability of staff to discuss the condition, its difficulties and impact

For further information please contact the Eczema Association:
Phone: 1300 300 182
Email: itchy@eczema.org.au
URL: www.eczema.org.au

What Else is in the Tablet?

Medicinal tablets, capsules, mixtures and creams usually contain a variety of substances in addition to the medicine itself. The additional substances are known as excipients or fillers.

Excipients have many purposes. Often, they bind the medicine together so it can be picked up and swallowed. Sometimes, they increase the stability of the medicine so it can be stored for months or years. Sometimes, they form pleasant-tasting coating that hides the medicine's offensive taste.

Most excipients in tablets and capsules are ordinary substances like starch, lactose, sugar and talc that almost everybody can ingest without ill effects. Therefore, most people are not concerned about them. However, people who are allergic or very sensitive to certain substances, or who must avoid certain products for ethical or religious reasons need to know about the excipients in their medicines.

Every Consumer Medicine Information (CMI) leaflet (where available) includes a comprehensive list of excipients. If you may need to know about the excipients in your medicine, ask your doctor or pharmacist to check the CMI leaflet when they prescribe or dispense the medicine for you.

In most cases, the information provided in the CMI leaflet will be adequate. However, occasionally, it may be ambiguous. For example, "gluten free" may mean that the tablet contains no gluten containing starches such as wheat, rye or barley, or it may mean that the wheat starch in the tablet has been deglutinated (>95% of the gluten removed). Such information is important for people with severe gluten intolerance. Similarly, the CMI leaflet may not say whether the gelatin capsule comes from pork or beef, which is important information for Jewish and Muslim people who want to avoid even traces of pork products.

If the CMI leaflet does not provide enough information or the medicine does not have a CMI leaflet, seek the information from your pharmacist or doctor, Medicines Line (1300 888 763), or the medicine's manufacturer.

(Source: Medicines Talk Newsletter No 10 Winter 2004)

Invitation to Join

Sunnybank Arthritis Support Group

The Sunnybank Arthritis Support Group extends a friendly welcome to all new people interested in attending. The group offers:

- Mutual support
- Information sharing
- Monthly, interesting guest speakers
- A friendly "cuppa"

Where: St Barnabas Church Hall
189 Lister Street
SUNNYBANK
When: 4th Wednesday of the Month
Time: 9.30am
Contact: (07) 3345 6669

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10 Tips for Safer Health Care

The Australian Council for Safety and Quality in Health Care has produced a consumer booklet "10 Tips for Safety Health Care": what everyone needs to know" which is being distributed around Australia. Earlier this year all Health Ministers agreed that all public hospital patients would receive a copy of the booklet at or before the time of admission.

The booklet has also been translated into 15 community languages. The English and translated versions of the booklet are available on the Council's website: www.safetyandquality.org

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Pilot of the National Medication Chart

Different medication charts are currently used in hospitals across Australia and this is not optimal for patient safety. Building on work done in Queensland, the Australian Council for Safety and Quality in Health Care has developed a national medication chart for use in all public and private health care facilities in Australia.

A national medication chart includes design features that help prevent known types of errors. A national pilot of the chart started with workshops in Sydney and Adelaide during October.

(Source: "Consumer Update" Sept/Oct 2004)

Remunerating and Reimbursing Consumer Representatives

by Darlene Cox

Have you ever sat on a committee as a consumer representative and been the only person not paid to be there?

Governments around the world are inviting consumers (particularly health consumers) to participate in service delivery, policy and planning. In the UK, for example, the 'NHS Plan sets out to establish a new system of patient and public involvement ...to enable patients and the public to influence and work with those who make decisions about health'(www.nhs.uk/england/aboutTheNHS/getinvolved/default.cmsx).

In the ACT, the current government has stated their commitment to strengthening consumer participation in key documents such as the ACT Social Plan, Social Compact and Health Action Plan.

Increasing consumer participation means increasing amounts of consumer time and effort going into the design and delivery of services. At lease a hundred committees and advisory groups in the ACT have consumer and carer representatives sitting on them, not to mention consumer participation in specific working groups, focus groups, and other forums. This means real people giving up time and income, and incurring costs to sit on committees, consult with their constituents etc etc.

There is currently no consistent policy across the ACT Government regarding how to remunerate consumer representatives for their time and contribution. In many cases there is no remuneration available at all, nor are the consumers reimbursed for expenses such as transport. In some cases consumers are reimbursed for out of pocket expenses. In a few instances consumers are paid a sitting fee. By contrast, many other 'professional' groups receive significant remuneration for participating in advisory groups.

The Commonwealth Consumers Affairs Advisory Council (CCAAC) guidelines on the appointment of consumer representatives to government and industry decision making and advisory bodies clearly sets out principles to ensure that such representation is valued as an essential part of decision making process in government agencies. The CCAAC consider that to adequately fulfil their roles, consumer representatives require adequate resourcing. This involves the reimbursement of expenses, remuneration and access to ongoing training and professional development needs.

Barriers to Involving Consumers.

There are personal, systemic and philosophical barriers to engaging consumers. Removing these barriers to consumer involvement is necessary in order to achieve effective consumer participation. The unequal distribution of power and resources can undermine confidence and the capacity of consumers to participate.

Consumer representatives face time and cost restraints in performing their role. For some consumers the costs of childcare, respite care, transport and their own health issues may prevent them from participating or considering representation. Some sacrifice other pursuits (including paid employment) in order to make a commitment to being a consumer representative.

Reimbursing and remunerating consumer representatives enables participation from people who would otherwise be constrained financially and offers encouragement to those who may not normally participate.

Resourcing consumers can also be an important way of acknowledging and respecting the value of the unique 'expertise' and knowledge which consumers bring to the table. Consumer representatives are not just representing their individual needs or making an individual contribution to the common good - as with volunteers. They are advocating for a collective community benefit. This contribution needs to be recognised and valued in a different way to the way we value volunteers.

Remuneration also demonstrates the commitment of management to involve consumers. Consumer representation which takes place in government agencies, providing input which would require considerable resources to collect in other ways, should not automatically be relegated to designated volunteer positions.

Remuneration levels the playing field and is a way of minimizing (Continued Page 10)

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'tokenism', where consumers are involved only to 'tick a box'. There is a strongly held perception that advice you pay for is often more valued than that which is provided for free.

It is well recognized that power imbalances exist between service providers, health professionals, public servants and community and consumer representatives. Most notable is the financial inequality in having paid professionals and unpaid consumers on the same committee.

Broader Support

Consumer organisations also play an important role and need to be resourced appropriately so that they can meet the challenge of recruiting, training and providing ongoing support to consumer representatives. This matter needs to be addressed in the broader context of consumer participation across government agencies.

All members of an organization need skill development including members of Boards, advisory committees and similar bodies. In particular, organisations appointing consumer representatives can attend appropriate seminars, workshops and conferences. Many of these events provide opportunities for consumer representatives to share information, to access specific training and consider industry wide or systemic issues arising from their roles. This training will strengthen the contribution consumer representatives are able to make.

Summary

Consumer representatives play a vital role on government committees and advisory groups. By ensuring that these bodies have access to the views of consumers, the group most likely to be affected by these decisions, the resulting advice or decisions will be better balanced, more informed and more likely to be accepted by stakeholders.

It should be beyond contention that no person should be 'out of pocket' as a result of their role as consumer representative. However, remuneration for consumer representatives also sends a strong message. It expresses both value and the seriousness of the role played by representatives in bringing a unique perspective to decision making forums. While representatives take their role seriously without payment, remuneration is another incentive to commitment, consistency and accountability.

(Article based on a paper prepared by HCCA and ACTCOSS with advice, input and support from the broader community sector. It was presented to the Joint Community Govt Reference Group in August 2004 and referred to the Community Engagement Unit, ACT Chief Minister's Dept.)
Source:HCCA Newsletter "Communicator" Winter 2004

Finding Good Health Information on the Internet

Use well known and recommended sites
When looking for information, don't rely solely on search engines such as Google. Use well known sites, and sites recommended by health professionals and consumer groups. Some larger sites, such as HealthInsite and Better Health Channel, primarily provide links to specialised websites that meet their quality standards. In effect, they direct you to quality information by doing some of the checking for you.

Health and Medical Sites

HealthInsite
www.healthinsite.gov.au

Better Health Channel
www.betterhealth.vic.gov.au

MedlinePlus
www.medlineplus.gov

Mayo Clinic
www.mayoclinic.com

My Doctor Health Information
www.mydr.com.au (click on health information search)

Informed Health Online
www.informedhealthonline.org

ABC Health matters
www.abc.net.au/health

Medicines Sites

NPS Medicines Information
www.nps.org.au (click on consumers, then medicines information CMI)

Better Health Medicines Guide
www.betterhealth.vic.gov.au (click on library, then medicines guide)

My Doctor Medication Search
www.mydr.com.au (click on medication search)

(Source: Medicines Talk Newsletter No 11 Spring 2004)

Inflammatory Bowel Disease & Coeliac Disease. What is the Difference?

By Sue Shepherd - Dietitian, and Professor Peter Gibson - Gastroenterologist

Coeliac (pronounced "seal-i-ac") disease and IBD both affect the bowels and have many similar symptoms, but they are different conditions. This article aims to sort out the differences between coeliac disease and IBD, discussing coeliac disease in detail, to help you understand it further.

What is coeliac disease?
Coeliac disease is a medically diagnosed condition of an intolerance to gluten in the diet. Gluten is the protein component of wheat, rye, oats and barley, and is found in derivatives of these including triticale and malt.

In people with coeliac disease, gluten causes damage to the lining of the small intestine (villi). Normally the villi lining of the small intestine looks like long fingers under the microscope. However in people with coeliac disease, these fingers become flattened. This causes a reduced surface area into which the goodness in the foods eaten can be absorbed. As a result, the nutrients in food are poorly absorbed, and this can cause ill health.

How common is coeliac disease?
We do not know accurately the prevelence of coeliac disease in the general population. It may be as high as 1 in 100. It can be diagnosed at any age, although more adults are diagnosed than children. One in 10 first degree relatives of people with coeliac disease can also have the condition, and it is recommended that all immediate relatives be screened. The cause of coeliac disease is unknown, but it is thought that both genetic and environmental factors are involved.

Coeliac disease is a completely different condition to Crohn's disease and also Ulcerative Colitis. However, diseases can occur together, and sometimes people with IBD can have coeliac disease too.

What are the symptoms of coeliac disease?
Many of the symptoms of coeliac disease relate to the damaged villi lining of the small intestine. Some common symptoms can include:

- Diarrhoea or constipation , or a combination of both
- Reduced iron, folate & vitamin B12
- Fatigue, weakness, lethargy
- Weight loss
- Abdominal bloating and/or pain
- Flatulence
- Reflux (heartburn)

Interestingly, people can differ remarkably with their symptoms. Some people diagnosed with coeliac disease may not even have any symptoms (asymptomatic).

Symptoms of coeliac disease can be similar to those experienced by people with active IBD. If you have ongoing symptoms even when your IBD is clinically well controlled, it may be worth discussing with your GP or gastroenterologist about the possibility of co-existing coeliac disease. Screening for coeliac disease is described below. Irritable bowel syndrome is another possible cause of these symptoms.

How is coeliac disease detected?
We screen people for coeliac disease by doing special blood tests that look for the presence of particular antibodies. These antibodies are called endomysial, transglutiminase and gliadin antibodies. Not all need to be done to screen for coeliac disease. Most people who have coeliac disease will be detected using these tests, but sometimes they are positive but coeliac disease is not present. For this reason, a further test is needed to diagnose coeliac disease.

Coeliac disease is diagnosed with a small bowel biopsy. This is done at gastroscopy and involves an instrument (like a long flexible hose with a camera) being passed from the mouth to the beginning of the small intestine, where several very small samples (biopsies) of the lining are taken. These samples are examined under the microscope for the flattened appearance that is characteristic of coeliac disease. Small bowel biopsy is the only recognised way of diagnosing celiac disease.

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What is the treatment for celiac disease?
The only treatment for celiac disease is a strict gluten-free diet. By removing gluten from the diet, it allows the villi to heal and return to normal. In most people with celiac disease, symptoms resolve when they are commenced on the gluten free diet.

Gluten is found in wheat, rye, oats and barley. This therefore includes regular bread, pasta, breakfast cereals, cakes, biscuits, noodles. Ingredients that contain only minute amounts of wheat, rye, oats and barley can also still contain gluten. These can include foods such as many sausages and deli meats, sauces, gravies, confectionery and many other foods.

Gluten-free alternatives include: rice, corn, soy, potato, arrowroot, sago, tapioca, lentil, amaranth, lupin, buckwheat, sorghum, and millet. These can be used to make alternative pastas, bread, crispbreads, biscuits, cakes and other foods suitable for people with celiac disease. All fresh meat, fish, chicken, eggs, nuts, milk, cheese fresh fruits and vegetables are also gluten free. The gluten free diet must be strict, and it is lifelong. There is no cure for celiac disease, it is only treated with the gluten free diet.

Crohn's disease and ulcerative colitis, however, may rely on a number of treatment options. Types of medications used and alternative therapies vary from person to person. You are encouraged to understand your disease by talking to your doctor or gastroenterologist, and take any medications as prescribed.

Do not start a gluten-free diet in an attempt to diagnose celiac disease.
It is essential that people suspecting they have a celiac disease do not commence the gluten-free diet until they have a confirmed diagnosis. It is not recommended to trial a gluten-free diet to attempt to diagnose celiac disease. If the gluten-free diet is commenced before a small bowel biopsy is taken, the villi may begin to grow back, making diagnosis difficult. Your doctor or gastroenterologist can provide you with more information.

Some people with IBD may trial a gluten free diet to assist with symptom relief. The gluten free diet is effective for celiac disease, but it is not a recognized therapy for either Crohn's disease or ulcerative colitis. Good nutritional intake is the cornerstone of dietary therapy for IBD - and people should only avoid foods if they notice they cause aggravation (eg low residue diet is recommended for small bowel strictures, a reduced lactose diet is recommended for lactose intolerance, etc.) It is inappropriate for anyone to be restricted to a gluten-free diet unless they really need it!

Are you about to have a gastroscopy?
If you have ongoing symptoms, and are going to have a gastroscopy to investigate, ask your doctor if he/she can also check you for coeliac disease. Having biopsies of the small bowel will in most cases give a definite answer as to whether you do or do not have coeliac disease. Remember, it is only a small proportion (less than 1 in 100) of people with IBD who have coeliac disease.

If you have coeliac disease, how can you learn about the gluten-free diet?
The gluten-free diet is quite involved, but is certainly still manageable. It is recommended that people with coeliac disease see an experienced dietician. For expert nutrition advice, contact an Accredited Practising Dietitian (APD) on 1800 812 942. Dietitians can also be recommended by state Coeliac Societies. Although overwhelming at first, the diagnosis can be a relief for patients who now have an explanation and effective management for their symptoms.

For more information on coeliac disease, see the following sites:

Coeliac Society of Australia
www.coeliac.org.au

Gastroenterological Society of Australia
www.gesa.org.au

(Reprinted with permission of the Australian Crohn's & Colitis Association (ACCA) National Newsletter, Edition 1, Autumn 2004.)

Related Sites

Austrlaian Crohns & Colitis Association Inc
www.accaq.org.au

Irritable Bowel Information & Support Association of Australia Inc
www.ibis-australia.org

The above sites provide contact details for Queensland support groups/associations.

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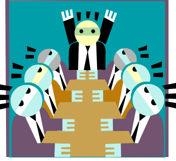

What's Up With Your Board?

Identifying The Most Common Signs Of Board Dysfunction.

For many people, joining a non-profit or community board or committee is a prime chance to make a real difference to their local community. Not only do they get the opportunity to volunteer for a group that they feel passionately about but they also have the chance to assist in setting the direction of the group.

The downside is that while many boards operate in a unified, co-ordinated, positive and innovative manner, there are others that are dysfunctional and provide ongoing frustration for Board members. Instead of feeling positive about their contribution, they find that little gets done.

It is a problem that must be addressed but some board members are not sure how to read the signs. Our Community has developed a Mayors Fellowship Program that provides resources and workshops to assist local groups to acquire skills necessary to ensure they are more effective and efficient.

One of the resources specifically looks at the common characteristics of a dysfunctional Board and how to avoid them.

1. Board meetings are unspeakably boring and/or interminably long.

Probably the number one reason for a Board's ineffectiveness, this problem is usually caused by a poor meeting structure and lack of discipline.

Remedies

- Ensure agendas are brief, relevant, logically presented and distributed well before meetings. Try allocating set times for items to be discussed and start meetings on time.
- Ensure all Board members know the meeting rules and are committed to following them and set time limits for individual speakers to avoid rambling Board members.
- If the chair is unable to keep order or keep the meeting on track, consider training.

2. Board members are unclear about their responsibilities.

It is frighteningly common for people to begin their role as a Board member without being clear of their roles and responsibilities. This is not only legally dangerous but is almost sure to impede the effectiveness of the Board.

Remedies

- Fully brief all new Board members about the contribution and commitment required of them and give them a written job description.
- Establish an induction process for all new Board members.
- Carry out annual training sessions for the Board.

3. Board members don't take their role seriously.

This is a similar problem to Number 2 above, but a more difficult one to tackle as it involves dealing with attitudes, rather than a mere lack of information. There is an alarming tendency for some not for profit Board members to take their roles less seriously than they would a company Board position - despite the fact that the legal requirements for each are identical.

Remedies

- Ensure that all new and existing Board members are aware of their roles and responsibilities, particularly when it comes to financial and legal obligations. Our Community's handbook, **"Surviving and Thriving as a Safe, Effective Board Member",** is a good place to start.
- Pay for Board members to attend an outside training course on Board responsibilities, or put in place your own training session.

4. Board meetings are enjoyable but decisions are rarely made; things are always being deferred.

This problem can be caused by a number of factors, including structural and operational deficiencies.

Remedies

- Ensure that the Board is being provided

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with enough information before and during meetings to allow it to make a thoughtful decision.

- Think about the Board's size and structure and whether it may be too big and ungainly to be effective.
- Examine the conduct of your Board meetings to see if improvements need to be made.
- Ensure the Board's mission and vision are regularly reviewed so members are focused on the future direction of the organisation.

5. Decisions are made but they aren't followed through/implemented.

Again, there could be structural and operational problems at play here.

Remedies

- Review the Board's committees and subcommittees. Do they meet regularly? Are their meetings conducted efficiently? Are committee members committed to their roles? Are they led by an effective committee Chair? Is everyone aware of their responsibilities?
- Ensure that tasks are assigned and that minutes record to whom all tasks have been assigned. Follow up on the progress of assigned tasks during every regular meeting.

6. The Board's decisions are inconsistent.

Boards are often accused of being inconsistent in their decision making - approving one course of action one month and rejecting a similar proposal the next. This can lead to uncertainty and frustration among the community group's staff, members and other stakeholders.

Remedies

- Ensure all Board members are conversant with and committed to the mission and vision of the community group, as well as its long and short term goals.
- Ensure the Board has developed a range of well-articulated, clearly understood policies to guide Board members in their conduct and decision making. Policies could cover issues such as ethics and conduct, volunteer management, financial management, accountability, and so on.

7. Board members do not get along; conflicts are common.

Some conflict within a Board is not only inevitable but is actually desirable - the most effective Boards are those that invite differences of opinion. However, too much conflict can become a destructive force in a Board.

Remedies

- Consider the root cause of the conflict and try to treat that - for example, does one party feel others are not pulling their weight? Does someone feel they are not being listened to? Is there a personality clash?
- Consider holding a retreat or social event to allow Board members to interact outside the pressures of the boardroom environment. Talk about the need for all members to focus on the organisation's overall mission, rather than the interests of individuals.

8. The Board is dominated by a clique.

While it is common for similar minded individuals to join forces on particular issues, it can become quite damaging to the Board dynamics if the remaining members are consistently having their opinions overruled. Constantly defeated Board members are likely to lose interest in their role and conflicts could result.

Remedies

- The Chair must take the lead in ensuring that all members' opinions are heard during debates and that all members are given an equal vote. Of course, if one group has the numbers, they will always win the vote; that's democracy.
- Think about purring in place subcommittees to deal with specific issues so that the power structures of the full Board can be diluted, or at least shared.

(Source: Re-printed with permission of "Our Community Matters" Newsletter November Edition 2004 www.ourcommunity.com.au)

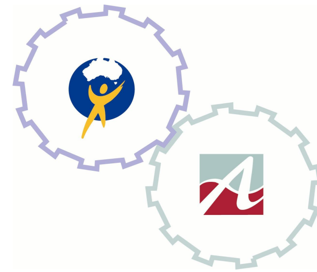
Tell us about Your Group

If you belong to a self help or support group we would love to hear about it so we can include you in the wider QLD network.

Please contact Self Help Queensland Inc
Ph/Fax : 07 3344 6919
Email: selfhelp@gil.com.au

COTA NATIONAL SENIORS

WORKING IN PARTNERSHIP



Be Up-front With Your Doctor and Pharmacist: Have A COTA National Seniors Peer Educator Talk to Your Group

Did you know that currently 140,000 plus people in Australia are admitted to hospital each year through mix-ups of medicines?? And that a recent Griffith University study revealed that a sizeable proportion of Queenslanders are not up-front with their doctors and find that their GP appointments do not quite go as planned?

As an avid reader of our newsletter you will be aware that twice this year we have featured an article to encourage groups to learn more about medicines and their wise use (our March issue asked if you are thinking of getting a speaker for your group and our September issue promoted the Medimate for 'medicines without the mix-ups' brochure)?

If these articles have aroused your interest you will be pleased to know that COTA National Seniors has been contracted by the National Prescribing Service (Inc) to head up the Seniors Quality Use of Medicines program, incorporating the 'Medimate' brochure and aiming to make consumers aware that they can be more assertive in their communication with their doctors and pharmacists and become 'active partners' in their choice of medicines.

COTA National Seniors have trained Peer Educators who are ready NOW to visit groups of seniors (people 50 plus) in various parts of Queensland (including Brisbane, Logan, Gold Coast, Ipswich, Sunshine Coast, Townsville and Cairns). They will facilitate a lively, interactive session on the benefits of becoming an active partner with your doctor and pharmacist, thereby getting better results from the medicines you take, avoiding medicine mix-ups and enjoying better health.

All groups who include older people, or carers of older people, in their membership are encouraged to take advantage of this opportunity. COTA National Seniors are currently taking bookings for the whole of 2005. Their peer educators have a wealth of knowledge to share with groups of older people about becoming a more active medicines partner and the sessions are free of charge.

So do take this opportunity and contact COTA National Seniors to have a peer educator attend one of your meetings.
Phone: Jill or Diana on 3221 6822
Email: dianaeast@cotaq.org.au

Invitation To Join

New Self Help Group

"Living Alone With Physical Disabilities Or Chronic Illness "

We are forming a self help group for people who have physical disabilities and/or a chronic illness, who live alone and are unable to fully participate in the workforce.

We are looking for new members; people who would like to participate in:

- Companionship - through meetings, social outings, phone contact
- Moral support - we understand our difficulties more than anyone
- Problem solving - people in similar circumstances may have found answers
- Inclusiveness - our activities will be planned to fit everyone's needs
- Personal contact - especially during periods of illness and disability
- Being active - without the stress of feeling you can't keep up

The group currently meets at the East Brisbane Community Centre, 538 Vulture Street, East Brisbane, with a view to enabling access to information and services that will be helpful to all members.

To discuss the group, or for further information about meeting times etc please contact founding member, Jan, Ph: (07) 3342 6049.

Diary Dates

10 - 13 March 2005: 8th National Rural Health Conference
Phone: (02) 6285 4660
Fax: (02) 6285 4670
Email: friends@ruralhealth.org.au
URL: www.ruralhealth.org.au
Venue: Alice Springs

11 March 2005: "A Hypothetical for Carers" Presented by ARAFMI Qld Inc.
Contact: Ph (07) 3254 1881
URL: www.arafmiqld.org
Venue: Merthyr Centre, New Farm

13 - 16 March 2005: Australian Health Promotion Association 15th Annual Conference. "20/20 Vision - 20 years since Ottawa, 20 years from now."
Email: ahpa@confco.com.au
Venue: Canberra

20 - 22 April 2005: 5th Women's Health 2005 Conference. A forum for individuals, organisations and services involved and concerned with women's health. This conference will examine the evidence from the perspective of gender as a determinant of women's health, in all its dimensions.
URL: www.awhn.org.au
Venue: Melbourne

4 - 7 July 2005: The 2005 Australian Winter School. Presented by the Alcohol and Drug Foundation Queensland, the Winter School will address Drugs, Lifestyles & Culture in the context of the practical application of research and policy for those working in service delivery agencies. International keynote speakers, practical workshops, posters and presentations.
Phone: (07) 3834 0211
URL: www.winterschool.info
Venue: Carlton Crest Hotel, Brisbane

18 August 2005: Partners in Pain: Patients, Clinicians and Pain Management. This is a satellite meeting immediately preceding the 11th World Congress on Pain. (21 - 26 August 2005).
Phone: (02) 9954 4400
Email: pinp2005@dcconferences.com.au
URL: www.dcconferences.com.au/pinp2005

DISCOVER THE LILT EXPERIENCE

The Mental Health Association (Qld) Inc. recently established a Registered Training Organisation – Leap into Life Training College (LILT College).

LILT College provides nationally recognised training in Community Services across Queensland.

Certificate IV in Mental Health Work (Non-Clinical) (CHC41102)
No pre-requisites needed
Gold Coast Brisbane Ipswich
Commencing February 2005

Certificate IV Course covers:

- Client service
- Community service
- Communication and counseling skills
- Community development
- Advocacy
- Mental health practice and philosophy
- Systems, policy, law, ethics.

Nationally recognised training.
Attracts Austudy, Pensioner Education Supplement etc
A training philosophy centred on fun, experience and quality.

For further information contact Pam:
Phone 07 3271 6812
Email: assoction@mentalhealth.org.au.

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Parentline

1300 30 1300

- **Any Parent**
- **Any Day**
- **Any Issue**
- **Confidential**
- **Anonymous**

Parentline is a confidential telephone counselling service aimed at providing professional counselling and support for parents and all who have the care of children.

8am - 10pm

Seven days a week

Phone: 1300 30 1300 (Cost of local call)
Email: parentline@kidshelp.com.au
Url: www.parentline.com.au
Post: PO Box 376, RED HILL QLD 4059