



Newsletter

September Quarter

Issue 3. 2006

Self Help Queensland Inc 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

The committee and staff at SHQ recently developed a poster presented at the 2006 Genetic Counselors conference, held in Brisbane in August. The theme of our poster was the relationship between professionals and self help groups and had some great information which I thought would be useful to share.

Contemporary comprehensive patient care requires not only expert clinical intervention but also an understanding of and support for the psychological and social impacts of diagnosis. Self help groups often see professionals as an "expert", and therefore not equal to the members. "Professionals" are often involved with self help groups because of their job, not because they share the same issue or condition. They may start a group because they know several people with the same condition, and see a group as a way to provide information, coping skills, and break down feelings of isolation. The threat this power imbalance represents requires the careful development of a good working relationship between professionals and groups so that they can complement each other and gain mutual benefits.

Some groups will never form a relationship with professionals as their history and aims take energy from a confrontational approach. Some groups, often mental health groups, can't function effectively without the support of a professional because people are not well consistently enough to support the practical things that need to be done.

For yet other groups the relationship can develop if professionals build capacity without dependency by sharing their range of skills with the group from the sideline, acting as a kind of "consultant". This allows the group to grow, develop and ultimately take charge of its own affairs.

For professionals who work with self help groups it is important to be able to recognise which sort of group you are working with to help action and expectations.

A recipe for success for Professional's involved with self help groups

- Develop skills and knowledge in group theory and practice before you approach or work with a group
- Leave narrow clinical conceptions of 'illness' at the door
- Understand the powerful position your knowledge places you in and pursue equality in participation and perspective.
- Respond to and support group decision making

Some practical ways Professionals can be involved in self help groups

- Provide resources eg meeting rooms, help with photocopying, transport.
- Use your networks for connecting groups to other organisations, resources.
- Help group members develop skills such as facilitating meetings, keeping records, producing flyers/newsletters on computer, debriefing, conflict resolution.

(Continued on Page 3)

**Self Help Queensland Inc
Management Committee Members**

President Sue Smyllie
Secretary Thea Biesheuvel
Treasurer Kathleen Zarubin
Members Jill Metcalfe
Ann Sprought
Kim Summers
Bob Wyborn

Committee Meetings

If you would like to attend our meetings, please contact the office for dates and times. Everyone is welcome to attend.

Project Officer

Trish Fallon

Office

The office is attended Monday to Friday, 9am to 4.30pm. However, staff are sometimes required to liaise with groups or attend meetings away from the office.

If you wish to call in to use the office facilities or talk to the project officer, please phone first to ensure that someone will be available to meet with you.

Office Location:

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

Postal Address

P.O. Box 353
Sunnybank QLD 4109
Phone/Fax: (07) 3344 6919
Email: selfhelp@gil.com.au

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Thanks to Queensland Health for providing funding to Self Help Queensland to help carry out its activities, and for supporting the publication of this quarterly Newsletter.



About the SHQ Newsletter

- 1700 newsletters are posted or emailed each quarter to support groups, health professionals, hospitals, community health centres, neighbourhood centres, divisions of general practice, social workers, psychologists, politicians and other interested individuals and groups.
- Past quarterly newsletters from 2005 are on the website www.selfhelpqld.org.au
- By contributing articles of interest, or letting us know what you think, you can help us provide a better newsletter.
- Letting us know if you have moved will ensure you receive your quarterly copy of the newsletter and directory updates.

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Pick up from SHQ, Sunnybank Ph: 3344 6919

SHQ Confidentiality & Privacy

SHQ continues to review and update its Policies and Procedures Manual. Anyone is welcome to contact us to view the Manual.

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- Try to locate a group that has been running well for a long time and find out why.
- Act as a guest speaker.
- Be someone for the group to test out ideas on.
- Encourage group members to take responsibility – everyone has a job.
- Use strategies such as a telephone tree amongst the members to let each other know of changes to meetings etc.
- Help members decide what their common goal is, the group rules etc.

A recipe for success for self help groups: successful groups have answers to these questions

- Why are we here, what are we trying to do, why is it important to us?
- What values are we going to hold ourselves accountable to?
- How are we going to make decisions?
- How will we learn?
- How are we going to support the participation of others?
- What relationships do we need to develop (including those with health and other professionals)
- How well are we doing at all of the above?

Collaborative relationships between professionals and self help groups are often highly productive and supportive. Paying attention to the power balance is very important if groups are to deliver the health and well being outcomes research indicates are possible.

Happy communicating!

Sue

Have you got your copy of the 2006/07 Self Help Queensland Directory of Self Help and Support Groups yet?

(Approx 600 groups covering a broad range of health conditions and related issues)



Ph: 07 3344 6919 URL: www.selfhelpqld.org.au



Invitation Self Help Queensland Inc

AGM



A warm welcome is extended to all members and interested friends to come along and meet other members of your network, management and staff. A good opportunity to put a face to the names and enjoy Self Help Queensland's hospitality!

Thursday 9th November at 9.30am

Note it down in your Diary now!

Venue: Self Help Queensland
Sunnybank Community Hall
121 Lister St (Cnr Gager St)
SUNNYBANK

RSVP to Trish by Friday 3rd November
Ph/Fax 07 3344 6919
Email: selfhelp@gil.com.au

Does Your Group Have a Newsletter?

Thank you to all the groups who send us their newsletter. We appreciate receiving each one of them, and can assure you that they are all read from cover to cover!

We realize most groups receive no funding, and newsletters cost money. However, we would be really grateful to those who could afford to send us one so that we can hear about upcoming events, know about the good things that are happening with groups and become more aware of the issues facing the Sector.

As email is a lot cheaper, we would be happy to receive newsletters at:
selfhelp@gil.com.au

or by post to:
PO Box 353 SUNNYBANK QLD 4109

(Unfortunately we are unable to pay membership fees to the many hundreds of groups that make up the Network, but would hope that we could exchange newsletters. Please let us know if you require a contribution towards the cost of postage).

-oOo-

Free Counselling Available Online

*- for anyone concerned about
alcohol or drug use*

<https://www.counsellingonline.org.au>

CounsellingOnline is a new website recently launched by Turning Point Alcohol and Drug Centre.

The site supports existing alcohol and drug counselling and treatment services by offering free, text-based, confidential support and referral.

Completely secure, immediate and anonymous if preferred, this new service is particularly suited to clients not yet ready for face-to-face sessions, or who find it difficult to access services due to location or hours of work. Clients will be supported to discuss their concerns and then referred to on-ground services as appropriate.

CounsellingOnline is staffed by trained counsellors and operates 24 hours per day, 7 days per week. **It can be used by anyone in Australia** who has a concern about their drug or alcohol use, or who is concerned about the drug or alcohol use of someone close to them.

Specialist services for Vietnamese speaking clients are planned for launch on the next few months.

Features of the service include:

- Live and immediate counselling via webchat
- Easy-to-use website
- Anonymous
- Confidential
- Free
- Available 24/7

If you would like to distribute information about CounsellingOnline to your clients, contact DrugInfo Clearinghouse on tel. 1300 85 85 84 or email druginfo@adf.org.au for a pack of posters and wallet cards.

(This initiative is funded by the Commonwealth Department of Health and Ageing as part of the National Illicit Drugs Strategy.)

Invitation

Polycystic Ovarian Syndrome Support Meeting

"Naturopathic Insight into PCOS"

The Queensland Branch of the Polycystic Ovarian Syndrome Association of Australia (POSAA) is hosting a support meeting in Brisbane with a focus on naturopathy.

Jon Wardle is a Naturopath practicing in Brisbane and regional Queensland with a specific interest in the treatment of PCOS. Jon and his associate Michelle Keel will be giving a brief understanding of the condition from a naturopathic perspective and discussing the herbal, nutritional and naturopathic treatment options for PCOS.

Date: Monday 25th September, 6.30pm

Venue: Brisbane City Council Library
Indooroopilly Shopping Town

(Library is at bus terminal + cinema end of shopping centre. Road entrance from Grave Rd. Car Park Gate No:5. Conference room entrance is via car park.)

RSVP: to Franca by 22nd Sept

Email: qld@posaa.asn.au

Wattle

By Thea Biesheuvel

It is her yellow pom-poms

When winter is still here

Turning to the westerlies

A defiant tossing jeer

It is her dotted sunspots

Her bright and lively head

That whispers to the dormant plots

'Winter is now dead'

(Thea wears many hats - writer, poet, member of the Self Help Queensland Management Committee. This is another of her published poems. Very timely!)

All information collected by Self Help Queensland is treated confidentially and no details are released without permission.

Genetic Matters

by Kim Summers PhD

Marfan mice and men

Marfan syndrome affects a protein called fibrillin-1 which makes up fibres used in many parts of the body. As a consequence of this problem many tissues lose their elasticity. The fibres attached to the lens of the eye are not strong enough to keep the lens in place behind the pupil. Bones, especially the long bones of the arms and legs and the finger and toe bones, grow more than they should. The skin and the ligaments can be stretchy and the lungs may collapse. The most life-threatening symptom is the affect on the "glue" between cells making up the aorta, the large artery leading from the heart to all parts of the body. Each beat of the heart tends to stretch the tissue. Eventually one of the layers in this tube may split (a dissection) or all three layers may break so that blood flows into the chest cavity (a rupture).

Since the discovery that the gene for fibrillin-1 has been changed in people with Marfan syndrome, researchers have speculated about whether drug or gene therapy might be possible. The problem is that replacing the abnormal protein would be very difficult. It would be like trying to replace all the mortar between every brick in a brick house. Missing just one bit could leave the patient susceptible to all the problems of Marfan syndrome. Some high blood pressure drugs have been found to slow the rate of widening of the aorta and reduce the risk of the aorta splitting, but they did not help the other symptoms, like the bone overgrowth and the eye problems.

Now researchers have made a discovery about the role of fibrillin-1 in the life of a cell which may change all that. They found that this protein is important in regulating levels of another protein, called TGF- β , which itself controls many activities of the cell. When there are low levels of functional fibrillin-1, as in Marfan syndrome, TGF- β levels may become too high. This has many consequences, depending on the type of tissue. Now one research group has used a mouse version of Marfan syndrome to study the effects of reducing the level of TGF- β back to

normal. The Marfan mice develop enlargement of their aortas and lung problems similar to humans with Marfan syndrome. Amazingly, the Marfan mice which were treated with the drug had normal aortas and minimal lung problems.

Suddenly there is the possibility of a treatment for Marfan syndrome which may stop many of the consequences of the abnormal fibrillin-1 by blocking its effect on TGF- β . The exciting thing is that the drug is already approved for use in people with high blood pressure. Before it can be used routinely, there are still a number of clinical trials to be done to make sure it is safe for adults and children with Marfan syndrome, because mice are not men and their bodies operate in a different way from ours. But this discovery gives hope to families that a treatment might be possible.

Contact the Marfan Association Qld at:
PO Box 294
SUMNER PARK QLD 4074
PH: 07 3376 6160
Email: marfanaustralia@hotmail.com

Kim wrote about connective tissue diseases in the December 2003 issue of our Newsletter. Copies available from Self Help Qld.

(Kim Summers is a member of the School of Molecular and Microbial Sciences of The University of Queensland and a member of the SHQ Management Committee.)

New! National Support Network Formed for Jeune Syndrome

Jeune Syndrome is a rare genetic multi-system disorder that affects the growth of the rib cage, thereby restricting growth of the lungs. Jeune Syndrome may also affect other parts of the skeleton, as well as the eyes, kidneys, liver and pancreas. Due to the rarity of this genetic condition, no other Jeune's organisation or support network currently exists within Australia. You can find out more about Jeune Syndrome and the Association by contacting:

Claudine Spinner, President
Australian Jeune Syndrome Association Inc.
C/- 7 Cathcart Street
MAIDSTONE VIC 3012
Email: claudinespinner@optusnet.com.au
<http://home.vicnet.net.au/~jeunesyn>



Multicap invites expressions of interest in:

A Community Choir For People with Disabilities

The purpose of the choir is to share interests and form friendships in a fun and safe environment.

All you need is a love of music!

Age range: 14-50 years
When: Saturday afternoons, 1 – 4pm
Where: 269 Padstow Road, Eight Mile Plains 4113
Who: Anyone with a disability who lives on the Southside of Brisbane
Estimated cost: \$2.50 per hour
Contact: Maree Stenson
Ph: (07) 3340 9018
Email: marees@multicap.asn.au

-oOo-

The Chromosome 18 Registry & Research Society (Aust)

Invitation to Annual Family Meeting

Health professionals will discuss topics including bipolar/depression as well as family/sibling issues.

For more information please contact:
Marlene, Australasian Coordinator
The Chromosome 18 Registry & Research Society(Aust) Inc

Phone: 02 9580-5707
Email: chromosome18@optusnet.com.au
or contact Ruth:
Email: drmcrac@xtra.co.nz
Venue: Auckland, New Zealand
Date: Saturday 30th September and Sunday 1st October 2006.

-oOo-

Cornelia de Lange Syndrome Association Australasia Inc Presents

"Making Waves"
at
Surfers Paradise
on
30 September 2006

This one-day Conference will be of interest to families and caregivers of people with **Cornelia de Lange, Cri du Chat and Angelman Syndromes**. Professionals will also gain valuable information(from the excellent Keynote Speakers) which can be adapted to suit the wider disability community they serve. The Conference explores four main areas:

Genetics - following the recent genetic research findings of a second cause for CdLS, Dr Meredith Wilson will explain what this means for families.

Behaviour - often complex and challenging can strain families to their emotional limits. Professor Chris Oliver presents findings of his unique and ongoing research "Behaviour Disorder and Family Adjustment in Cornelia de Lange, Cri du Chat and Angelman Syndromes".

Siblings - often overlooked and whose unmet needs can manifest in school, social and emotional issues. Kate Strohm will hold "siblings only" workshops in a safe and nurturing setting.

Building Support Networks - Sharon Bourke will present a workshop which is about strengthening families' capacities by future planning and exploring the importance of relationships in the lives of our sons and daughters.

For more information or to register please contact the Cornelia de Lange Syndrome Association Inc:

Jenny Rollo (Secretary, CdLSA) 02 9809 0287
Rose Humphrey (Qld Contact) 07 3353 3470

URL: www.cldsaus.org
Date: 30 September 2006
Venue: Watermark Hotel, Surfers Paradise

**** Register by 30th August 2006****

Red Alert for Fish Lovers

by Deneice Tronc B.A.; MTASA
Director, Queensland Ciguatera Fund

Red tides, which are only one indicator of the presence of toxins in the waters and in fish/seafood, are caused when toxins leak into the water when algal cells burst open. They can cause nose, throat and lung irritation if breathed in from the air (R.Pierce).

These and other toxins, which are often present in fish/seafood at dangerous levels, are cumulative in the system, and far too many deaths have already occurred world-wide, over centuries. The usual cause of death from marine toxins is by pulmonary-cardiac disorders or respiratory paralysis.

Small fish can be just as toxic as large fish. Even a toxic sardine is capable of killing a grown man within two minutes (Dr R. Bagnis). Canned fish can be just as toxic as fresh or dried fish. The toxins are heat stable, so canning is no safeguard. Dr Banner wrote that, in some instances, muscles around the lungs have slowly constricted the lungs, causing death.

.....even a toxic sardine is capable of killing a grown man within two minutes

Some advertising campaigns insist that we have to eat fish to get essential Omega-3 fatty acid. Not so. According to the Medical Benefits Fund, other excellent sources of Omega-3 are: dark green vegetables, walnuts, game meat, and lean beef. Flaxseed and flaxseed oil are also excellent sources.

Be wary of diets that rely too heavily on fish/seafood. Fish poisoning can cause havoc with the body's metabolism. Neither will eating fish necessarily make you slim. For over 30 years I have consistently found that victims of fish/seafood poisoning who were naturally plump put on large amounts of weight, while those victims who were previously quite slim took off weight.

Worldwide, thousands of people die annually from ingesting fish/seafood toxins, while thousands more survive and suffer the less disastrous consequences of unknowingly eating toxic fish/seafood. The effects can take from a few seconds to several

months to become evident, so sometimes diagnosis can be difficult. Already sensitised people can become ill not just if they eat fish/seafood again, but also from eating anything which has been near fish/seafood, or cooked in the same medium. Sometimes these people can find themselves quite suddenly in a life-threatening situation and

.....other excellent sources of Omega-3 are: dark green vegetables, walnuts, game meat, and lean beef.....

need urgent medical attention. Any fish in the sea can become toxic (Dr Bruce W. Halstead). Toxic fish can be found in waters from the Tropics to the Arctic, the highly toxic Greenland shark being a good example. Once established in an area, the toxins can affect all fish in those waters.

The possible symptoms are many and varied, so anyone becoming ill after eating fish/seafood should seek medical assistance. If no doctor is handy, make the victim vomit, and other persons who have eaten the offending fish/seafood but who have not displayed symptoms should also be made to vomit either with Syrup of Ipecac or by fingers down the throat method. Some of the common symptoms are: vomiting, diarrhoea, severe headaches, paralysis, and reversal of sensations of heat and cold and/or out of character depression or aggression. However, the absence of any particular symptoms does not preclude a diagnosis of poisoning.

Deneice's book, "the Fish Lover's Guide to Ciguatera and Related Forms of Ichthyosarcotoxism" contains lists of symptoms, as well as some treatments. Some are written in medical language and some in lay language used by victims.

.....any fish in the sea can become toxic.....

The book also contains other useful and interesting information, and is available by writing to Deneice and enclosing \$16 which includes postage, packaging and handling. Proceeds are donated to the Queensland Ciguatera Fund.

**The Queensland Ciguatera Fund
PO Box 554
ROCHDALE SOUTH QLD 4123**

15 Myths About Recovery from Mental Illness

1. People with psychiatric disabilities cannot be successfully rehabilitated nor can they recover.
2. Increasing compliance with drug treatment can singularly affect rehabilitation outcome.
3. Traditional inpatient therapies, such as psychotherapy, group therapy and drug therapy, positively affect rehabilitation outcome.
4. Inpatient therapies, such as milieu therapy, token economics, and attitude therapy, positively affect rehabilitation outcome.
5. Hospital based work therapy positively affects employment outcomes.
6. Time limited community based treatment produces better rehabilitation outcomes than does time limited hospital based treatment.
7. Community based treatment settings are well used by persons with psychiatric disabilities.
8. Where a person is treated is more important than how a person is treated.
9. Psychiatric symptomatology is highly correlated with future rehabilitation outcomes.
10. A person's diagnostic label provides significant information relevant to a person's future rehabilitation outcome.
11. A strong correlation exists between a person's symptomatology and a person's skills.
12. A person's ability to function in one type of environment (eg a residential setting) is predictive of a person's ability to function in a different type of environment (eg a vocational setting).
13. Rehabilitation outcome can be accurately predicted by professionals.
14. A person's rehabilitation outcome is directly related to the credentials of the mental health professional with whom the person interacts.
15. A positive relationship exists between rehabilitation outcome and the cost of the intervention.

(Anthony, W. "Psychiatric Rehabilitation" 2nd Ed Ch "Review of the Research: Historical Myths." Available online at Queensland Alliance www.qldalliance.org.au)

Technical Support & Low Cost Internet Service Available to Disabled in Queensland

Technical Aid to the Disabled, Queensland Inc (TADQ) is a not-for-profit organisation that provides technical support for people with disabilities.

TADQ takes requests from therapists and individuals to adapt or modify existing items, or to fully create new ones. Project work is done by highly-skilled Technical Volunteers for the cost of materials only. Recent TADQ projects include grocery winches, fold-down shower seats, hair-dryer stands, writing aids; tricycle modifications, extended easels, and tactile floor modules for children.

TADQ's service is unique in the State. 200 Technical and non-technical Volunteers are located in 22 regions across Queensland.

Regional co-ordinators are located in: Atherton Tableland, Bundaberg, Cairns, Chinchilla, Emerald, Gladstone, Gold Coast, Goondiwindi, Gympie, Kingaroy, South Burnett, Longreach, Maryborough, Harvey Bay, Mt Isa, Rockhampton, Yeppoon, Stanthorpe, Sunshine Coast, Toowoomba, Crows Nest, Warwick.

Technical Aid to the Disabled, Queensland Freecall (Regional Qld) 1300 663 243
Phone: 07 3216 1733 Fax: 07 3216 1744
Email: tadq@technicalaidqld.org.au
10 Waterloo Street, NEWSTEAD QLD 4006

Low Cost Internet Service

Technical Aid to the Disabled Australia (TADAust) is the national body that represents each of the State TADs, and is the Dial up Internet Service Provider for people with Disabilities, the Aged and Veterans.

For just \$5.50 per Month you can be connected if you hold a Pension Card*!
Local Connect call anywhere in Australia+

TADAust Dial up connection offers:

- No Download limit
- No Setup Fee
- No Annual Fee

Call 1300 735 439 (toll free Australia wide)
Email signup@tadaustconnect.org.au

*Conditions apply
+ Remote areas need to be checked

Common Colds Need Common Sense, They Don't Need Antibiotics.

Common colds are caused by viruses and usually get better on their own in 5 – 7 days.

Antibiotics work on bacteria, not the viruses which cause common colds. Antibiotics won't help a cold get better faster or stop it from getting worse, and they won't stop a cold from spreading to others. The best treatment is to rest, treat the symptoms, and see your doctor or pharmacist if it gets worse.

Common colds are infections of the respiratory tract. Symptoms can include sneezing, coughing, a sore throat and a blocked or runny nose. Fever is generally mild when it does occur.

Colds are common. In fact:

- Children can get 5-10 colds per year while adults can get 2-4 colds per year.
- Children get more colds than adults because they don't have the same immunity to many cold viruses as adults do.
- More than 200 different viruses can cause common colds.

Common colds usually get better in 5-7 days. A cough is often the last thing to improve and can last 1-2 weeks longer than other symptoms. Green or yellow mucus may come from the nose. It is a sign that the immune system is fighting the infection and does not mean the cold is getting worse.

Common colds rarely cause serious harm. Children with colds can go to childcare, preschool and school as long as they feel well enough to participate.

Colds are not flu

Influenza (or flu) is a serious illness. A 'common cold' is often called the 'flu', but they are different. Flu symptoms usually start suddenly with a high fever and you may feel sick enough to go to bed. Symptoms can also include irritation in the throat or lungs, a dry cough, shivering, sweating and severe muscle aches. The flu tends to make the whole body ache, whereas the common cold usually affects the nose and throat only.

Influenza vaccine is recommended for older people, people with chronic conditions, some pregnant women, people who live in nursing homes and Aboriginal and Torres Strait Islander people who are 50 years of age or over. See your doctor for more information.

Will antibiotics help?

Common colds, flu and most coughs are caused by viruses and get better on their own. Antibiotics work only on infections caused by bacteria and have no effect on viruses. The immune system can fight and overcome these viruses.

Antibiotics:

- Won't help a cold get better faster.
- Won't stop a cold from getting worse.
- Won't stop a cold spreading to other people.

Using antibiotics when they are not needed may make them less effective when they are needed. They can cause unwanted side effects like stomach upsets, diarrhoea, thrush and allergic reactions.

How to clear mucus, relieve blocked sinuses, dry a runny nose

- Saline (salt water) sprays or drops can help clear mucus.
- Inhale steam from the shower or put a towel over your head and breathe in steam from a bowl of hot water (not boiling). Steam from a bowl of hot water can burn the lining of a child's nose and the hot water can be spilled, so only allow children to inhale steam from a shower.
- Decongestants for the nose can help dry a runny nose or relieve blocked sinuses. These are available as drops, sprays, tablets or a mixture. Check the label to see if it is safe to use a decongestant.

> Children under 2 years old should avoid using decongestants given by mouth.

> Children over 6 months old can use some decongestant nose drops or sprays.

> Children under 6 months old should generally avoid all decongestant products, whether given by mouth or as nose drops or spray.

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> Do not use decongestant nose drops or sprays for more than five days; using them for longer can make congestion worse.

> Do not use some decongestant products if you're pregnant or breast feeding, are being treated for high blood pressure, or have heart problems, glaucoma, or some other medical conditions; read the label and ask your doctor or pharmacist for advice.

- Use an ointment to soothe dry and chapped skin around the nose.

How to soothe a sore throat

Some adults and older children find it soothing to gargle warm salty water, or to suck on ice or a throat lozenge.

Some common pain relief medicines can ease the pain of a sore throat. The active ingredient in these medicines is paracetamol, ibuprofen or aspirin. Read the label to find what is in the medicine you choose.

- Don't use ibuprofen in babies under 6 months of age.
- Don't give aspirin to anyone under 18 years of age unless prescribed by your doctor as it can cause serious harm in viral illness.
- Talk to your doctor before using either ibuprofen or aspirin if you or your child:
 - > Has kidney problems
 - > Is allergic to either ibuprofen or aspirin (e.g. some people with asthma)

or if you:

- > Are pregnant.
- > Have ever had a stomach ulcer.
- Do not take aspirin if you are breast feeding unless advised by your doctor

Using vitamin or mineral supplements, herbal and natural medicines

All medicines, including herbal and natural medicines, can cause unwanted effects and may interact with other medicines. The benefits and harms of herbal and natural medicines are often based on traditional use and they may not have been tested in the same way as prescription medicines, however they are often used to treat or prevent common colds.

For children

There is not enough information from quality clinical trials to show that vitamin or mineral supplements or herbal medicines help treat or prevent colds in children. Children can have side effects from these medicines.

For adults

Vitamin C may shorten the length of a cold and severity of symptoms. For most people, vitamin C does not seem to prevent colds. Zinc lozenges have not been shown to shorten the length of a cold or the severity of symptoms. They can have side effects. Echinacea purpurea, a specific variety of the plant, might help to shorten the length of a cold or the severity of symptoms in adults. Most clinical trials have not shown echinacea helps to prevent a cold.

See your doctor if it gets worse

Common colds may cause problems with other health conditions (e.g. asthma or diabetes). See your doctor if other health conditions worsen during a cold.

Some serious diseases may initially appear like a cold or flu but may require urgent medical attention. The best thing is to see your doctor if the symptoms come on suddenly, are severe or last longer than usual.

(Source: National Prescribing Service News June 2006 www.nps.org.au)

A Laugh Borrowed from the Older Women's Network

(It may be a joke but it rings soooo true!!)

The bus overturned killing the women returning from a bowls carnival. An embarrassed St Peter greeted them from the Pearly Gates, explained that Heaven was full and he'd have to put them in Hell until the new subdivision was completed.

Three weeks later a frantic Satan called Peter, begging that he take the women back.

"But I'm still having housing troubles", St Peter replied.

"Troubles? You don't know what trouble is!" Satan roared. "What with their cake stalls, garage sales and fetes, do you know those women are only \$50 short of air conditioning this place!"

(Source: OWN Newsletter July 2006)

Alzheimer's Disease

Is there a Role for Herbal Medicine & Alternative Therapies?

Herbs contain powerful, biologically active substances, and the earliest medical texts make references to herbal substances to treat disorders of the mind. In recognition of this, much research is being conducted to discover just what the role herbs, vitamins and minerals play in the prevention and treatment of Alzheimer's disease.

Low levels of folic acid and vitamin B12 are now recognized as risk factors in the development of Alzheimer's disease. Antioxidants such as vitamins E, A and C, and the herb Ginko biloba, destroy oxygen radicals (by-products of metabolism) that are known to damage brain proteins, fats and DNA. In Germany, Ginko biloba is routinely used within treatment regimes for Alzheimer's.

Some herbs are known to act as anticholinesterases. That is, these herbs have similar actions to Aricept, Exelon and Reminyl, but are not as potent. That herbs, vitamins and minerals play an important role in the maintenance of health is not disputed. But their exact benefit in the treatment of Alzheimer's disease or other forms of dementia has yet to be determined, and they are not a cure for these diseases.

Herbs, vitamins and minerals will interact with medications. So if you do decide to use herb and vitamin supplements as well as conventional medications, please check with your doctor first.

Other alternative therapies that have been trialed as possible preventions or treatments for Alzheimer's disease include oestrogen therapy and non-steroidal anti-inflammatory drugs (NSAID's).

To date, oestrogen therapy trials have yielded inconclusive and often contradictory results as to their benefits in the prevention and treatment of Alzheimer's disease. Non-steroidal anti-inflammatory drugs have a wide range of potentially serious side effects, so their use in prevention and treatment of Alzheimer's is not recommended.

Dementia Help Line 1800 639 331.
URL: www.alzheimeronline.org

(Source: "Dementia Matters" Autumn 2006 Page 2)

New Initiative to Support Young Carers

The Australian Government has funded a new initiative to support young people who are the main carer of a friend or relative. This includes people under the age of 26 who support someone with an ongoing health problem, disability, drug/alcohol issue or mental illness.

To be eligible the young person would need to be the main carer, can be studying at school, TAFE, or University, or undertaking an apprenticeship or traineeship. The support is flexible and based on the needs of the young carer. Assistance includes:

- Basic housework, cooking and cleaning
- Support with training and education eg one on one tutor
- Giving the young carer a break from their caring role
- Ensuring correct Centrelink payments
- Activities and outings with other young carers
- Advocacy and counselling
- Referral to other services

The Australia wide contact number is 1800 059 059. This will put you in contact with the nearest service in your area.

Summary of 34 Peer Run Support Groups for People with Mental Illness

An excellent table of research papers has been compiled by Jean Campbell, PhD. "The Emerging Research Base of Peer-Run Support Groups" can be found on the website of the National Empowerment Centre Inc. Encouraging reading for people interested in setting up such groups.

The website is also filled with practical information aimed at helping the recovery of people labelled with a mental illness.

National Empowerment Center Inc
599 Canal Street
Lawrence, MA 01840
Correspondence: info4@power2u.org
www.power2u.org

Life Could Become Easier for Smaller Organisations in QLD

The Queensland Government is proposing amendments to the [Associations Incorporation Act 1981](#).

Under the proposals, organisations with both total income and total current assets of \$20,000 or less would supply to the Office of Fair Trading those financial statements provided to their annual general meeting, together with a statement by the President or Treasurer that the association's books are kept in an appropriate manner.

Associations with either total income or total current assets between \$20,001 and \$100,000 would have to lodge the financial statements provided to their annual general meeting plus a statement by an accountant that the financial records are kept in accordance with good accounting practice.

Those organisations who have either total income or total current assets over \$100,000 would continue to lodge formally audited accounts in the same way as always.

The amendments are yet to be considered by Parliament and until the laws are altered, current provisions of the Associations Incorporation Act 1981 apply.

The Government is also proposing to remove the current public liability requirements of the Act to reduce the financial burden imposed upon low risk associations.

The proposed provisions would require management committees to give appropriate consideration to the need for, and the level of public liability insurance with respect to their association and report to the membership on these decisions.

Insurance would be a matter for associations to decide relevant to their individual circumstances. However, the Government wishes to ensure associations give proper consideration to their legal liability responsibilities.

For a **free copy** of the **Incorporated Associations Good Business Guide** or information on the proposed amendments, contact the Office of Fair Trading :

Ph: 13 13 04 www.fairtrading.qld.gov.au

Important!

Directory "Updates"

2006/07 Inaugural Edition



To keep the Directory as current as possible (until we undertake the 2nd edition in 2008) "updates" are being included with our quarterly newsletter.

The second "update" is included with this edition, and the first "update" is available from the SHQ office for those who may have missed out. If you or someone you know is not receiving our newsletter plus "updates" please let us know and we will fix it!

If you are happy with the Directory please help us by spreading the word among your colleagues throughout Queensland.

-oOo-



Directory Feedback Would Help Us!

We would really like to know what you think about the Directory.

We are particularly interested to know:

- If you are happy with the Directory format or not.
- If you find it easy or hard to find what you are looking for in the Directory.
- If being listed in the Directory has had any consequences for your group, more members or enquiries for example.
- If the Directory has made it easier to do your work or to help people.
- If you would like the next Directory to have more or different information included.

We will be collecting this information all the time so feel free to phone, fax or email your feedback to us at SHQ.

Please let Self Help Queensland know:

- **If your group is no longer running**
- **If the contact details have changed**

Support Groups

an undervalued community resource

by Dorothy M. Bowes

(Dorothy is the President of Allergy, Sensitivity & Environmental Health Association Qld Inc - ASEHA - a volunteer community organisation providing support for people with allergy, food and chemical sensitivity. Dorothy has strongly advocated on behalf of ASEHA for many years, and has been a passionate supporter of the Sector in general.)

“Support groups are working models of primary health care. They are an essential and important community resource as they are usually actively involved in systems advocacy and often take on individual advocacy as required. They assist people to make necessary lifestyle alterations, to manage their illnesses, provide information, emotional support and contribute to improved wellbeing. They are instrumental in keeping people out of expensive levels of care in the health system.

Special need

The existence of a support group usually indicates that there is a gap in health care services and is most likely signalling:

- an area of special need
- poor understanding of an issue by the health care profession
- poor service delivery
- no services at all

Size not relevant

Overall numbers in support groups are not a good indicator of the need for the existence of a support group, or for service provision. Support groups are an important resource in the community and many people only see them as that, not realising that the group may be an unfunded, voluntary agency. Most enquiries are initiated by non-members who:

- only want specific information
- only want to tap into the information base when they have a need
- do not want to pay for the service provided
- do not want to join a support group

Difficult conditions

Support groups often function under extremely difficult conditions and under unusual circumstances. Those who run support groups are usually sufferers of a specific medical condition who can assist others with the practicalities of living with their disorder. This is what they do best. They are often not professional people and do not offer professional services.

It is difficult for support groups to function because:

- they lack physical resources
- financial resources
- their capacity to raise funds for their group is often diminished by their personal circumstances
- the energy in the groups is often low
- they are usually run by sick people - by sufferers, for sufferers
- those who are actively involved in running the groups are often bogged down responding to members in crisis - mostly medical but sometimes in other areas such as disability services, allied health care, or welfare services
- those running support groups often do this to their own detriment financially, and at great physical and emotional expense to themselves

Structural difficulties

Support groups often run their service out of somebody's home, which contributes to their struggle to establish a strong support group base. It is difficult for them to function efficiently, as they need financial resourcing in the form of establishment costs and administrative support to provide:

- office space
- infrastructure
- paid staff to ensure good energy and a better standard of efficiency
- a greater range of services
- constant upgrading of information and re-skilling

Assistance to grow necessary

Professional input into research and report writing would expedite their issues into service provision much faster,

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adding to knowledge of the specific disorder in the community and improved quality of life for sufferers. A lack of resources, office space, structure and good energy:

- prevents groups from growing
- limits their ability to keep adequate records
- limits their overall output and their capacity to achieve their aims
- prevents them from demonstrating a need for their existence
- prevents them from demonstrating a need for health services in their area of interest
- means that they can't measure outcomes

This makes it difficult for groups to argue their case for funding as the current funding model is outcome focussed.

Models of Primary Health Care

However, support groups are models of primary health care that provide essential human needs for their client group. They provide:

- emotional support in the form of listening and a voice on the end of the phone to reinforce that other people have similar problems
- understanding and experience of the problem
- empathy
- practical hands-on information to assist with self-care and the maintenance of wellbeing

Poor acceptance

Lack of available resources for support groups:

- disempowers and disadvantages them in the health care system
- they are not on equal footing with government and the health industry
- they are usually not able to attend conferences or to acquire material to allow for education, upgrading of information to do research in their area of interest, and re-skilling
- their issues are lost in professional interpretations of their needs

Physical and Financial Assistance needed

Adequate resourcing in the form of recurrent funding needs to be available to groups whose illnesses are not well known or routinely diagnosed. This funding needs to include assistance from professional people to establish a firm base for support groups and to assist them to become self-funding over a period of time. Every assistance should be given to support groups to:

- allow them to establish a strong support base for their client group
- allow them to undertake systems and individual advocacy to an effective level
- respond to members in crisis where possible
- acquire appropriate information, skills and expertise
- be on an equal footing with government and the health industry
- ensure that they have a strong voice
- ensure that they are heard
- ensure that their special needs are not missed in health policy making and when health services are being planned
- allow support groups to become equal partners in the planning and development of health services

Need for a funding model to be developed

A model needs to be developed to fund support groups to allow for their sustained growth and increased effectiveness. Support groups should be recognised for their contribution to health care and a budget for them included in health planning. They should be given a high level of assistance by government to achieve recognition and equality. Support groups should not be ignored because they do not have professional status or low numbers. Low numbers may well indicate a new or emerging disease that is not routinely diagnosed.

Support groups are not bureaucracies

Care should be taken with funding for support groups not to disrupt the main function of the support group, which is to support sufferers. They are not professional organisations and should not have to be treated as such. They should not be bogged down with reporting requirements that take them away

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from their primary aim - which is hands-on support for sufferers.

Useful to planners also

Support groups are in a unique position to gather useful information for planners of health services. They are directly in contact with the public, the issues involved and should be regarded as a resource to health service planners to:

- indicate gaps in service provision
- identify areas of special need
- improve the range of services available
- provide services that are truly in tune with the needs of the community

Primary Health Care policy not working

According to Primary Health Care Policy, small groups of people with special needs should not be disadvantaged in health care. Some groups provide a free 24 hour service to the community. They are volunteers who are compassionate enough to forego their lifestyle, their family life and sacrifice their own health for the good and wellbeing of the wider community.

Many groups work with diseases that are not recognised, included or well entrenched in health care services. While many people need to be under the care of the medical profession, the health care system often neglects them. People may be disadvantaged by not being able to claim expenses associated with their illness from Medicare, or have access to necessary medical and disability aids. In the case of the income disadvantaged who cannot afford private doctors or natural therapists they have no treatment at all - falling through all the safety nets and consistently neglected in health care.

Social justice should work for all in a meaningful way and support groups are instrumental in pursuing this for the sub section of the community they represent."

Revised 20 April 2005

(Excerpts taken from original hard copy article available in full from Self Help Queensland Ph 07 3344 6919)

ASEHA Qld Inc

PO Box 96 MARGATE, QLD 4019

Phone: 07 3284 8742

Email: asehaqld@powerup.com.au

URL: www.asehaqld.org.au

Institution Reunions

- not for everyone, but can be a positive experience for some

While it isn't for everyone, many people who have attended "institution reunions" have found it a positive experience. If you would like to be involved in a reunion for the resident's of your childhood institution please contact Vicki at the Aftercare Resource Centre (ARC) on 1800 501 560
32 Thomas Street
WEST END QLD 4101
Phone: 3255 2848
Email: aftercare@relateqld.com.au
www.relationships.com.au/qld/qld_arc.asp

(The Aftercare Resource Centre (ARC) was established in response to the Forde Commission of Inquiry into Child Abuse in Queensland Institutions and offers services for survivors of institutional abuse, or abuse in foster homes.)

Cancer Support Group Facilitator Training



Queensland Cancer Fund

For North Queensland in 2007!

After a very successful pilot training program launched in Brisbane in May 2006, the Queensland Cancer Fund is now offering Support Group training to facilitators of cancer and cancer related support groups who reside in north Queensland. Topics included in training are:

- Cancer and Cancer Treatments
- Privacy and Confidentiality
- Grief and Loss
- Group Facilitation
- Practical considerations when setting up a Support Group

The Cancer Fund is now taking applications from Support Group Facilitators in northern Queensland (from Rockhampton to Cairns).

Training will take place in Townsville, at a date to be announced. To enquire about the application process, please contact Tracey Ward at the Queensland Cancer Fund.

Phone: 07 3258 2257

Email traceyward@qldcancer.com.au

Attention all Community Sector Organisations & Workers

Do you want to have your say on issues your organisation experiences ?
Do you want the community services sector as a whole to be more proactive?
rather than reactive to government agendas?

Creating a Future for our Sector: A Consultation

A collaboration of state-wide peaks and networks are currently working on a project to strengthen the position of the community services sector and enable us to speak with a strong collective voice – **The Creating a Future for our Sector** project.

Through a statewide consultation, community organisations across Queensland are being invited to take part in the development of a Community Services Sector Charter.

The consultation aims to find out from community not-for-profit services:

- Common values that unite us
- How we can collaborate to achieve common goals
- Key issues of concern.

The consultation offers an opportunity for all organisations working within the community services sector:

- To work together to gain recognition of the value that we contribute
- To strengthen our position to achieve greater outcomes for the communities we serve.

Your organisation's contribution is extremely important!!

This consultation process offers a unique opportunity for all organisations working within the community sector to work together to gain recognition of the value that we contribute, and strengthen our position to achieve greater outcomes for our communities .

Please ensure that information about **Creating a Future for the Sector** project is shared with your CEO or board of management for their consideration.

To have your say simply complete the survey on the Queensland Council of Social Service (QCOSS) website or print the survey, write in

your responses and fax or post to to Tanyah Hall by 10th September 2006.

QCOSS

PO Box 306, RED HILL QLD 4059

Phone: 07 3832 1266 Fax:07 3832 4119

Email: tanyah@qcross.org.au.

URL: www.qcross.org.au

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Telling it Like it is Helps Break Down Barriers

People with a disability, their family, friends and carers are invited to share their stories to help improve community insight into living with a disability.

12 stories will be chosen to appear in Disability Services Queensland's calendar "**Share Your Story**".

Submission categories are:

- Just like me
- Overcoming a challenge
- Work and education
- Making communities a better place for everyone
- Focus on ability
- Working with people with a disability
- Breaking down the barriers
- Family and friends
- My story/our story

Submissions should be 250 words or less and can be posted or emailed to:

Share Your Story

Marketing and Communication Branch

Disability Services Queensland

PO Box 806, BRISBANE QLD 4001

Email: dsqmail@disability.qld.gov.au

URL: www.disability.qld.gov.au

Closes 8th September 2006!

Self Help and Support Groups receive little or no funding. Paying a membership fee helps them to keep going.

Junk Food is Cheaper than Fresh Fruit and Vegies in many Aboriginal Communities

Sister Joan Healy of the Josephite Leaders' Social Action Group, has just returned from a visit to the Anangu Pitjanjatjara Yakunytjatjara Lands in South Australia.

She said that after listening to many mothers and grandmothers concerned about their children, she was surprised and distressed to find that the most frequently mentioned need was affordable, nourishing food.

Aboriginal women were angry about comments made by Health Minister Tony Abbott, reported in the Australian, where he said that while he would not rule out subsidising the cost of fresh food, it would happen only if communities committed to changing their diet, eating less and exercising.

The women said their children need more to eat, not less. But they need the right kind of food.

"Junk food is cheaper than fresh fruit and vegies in many communities," Sr Healy said.

"Chicken and chips cost \$3 a serve, but broccoli is \$3 for a single floret and apples and oranges are up to \$2 each. Fruit and vegetables are priced by the piece.

Poor quality mince is \$18 a kilo and stewing steak is around \$25 a kilo. Baby formula is beyond the budget of most families, but breast feeding mothers need nourishing food," Sr Healy said.

It's not a matter of not knowing the facts. These women know what is best for their children. They don't want to feed their children 'rubbish food'. But when their children are hungry they feed them whatever they can afford.

But good things are happening in the APY Lands. The women talked about the music shed where young people gather to play music and have a feed. One woman said the young ones used to break school windows, but now when they can play music and dance and have a feed there is much less trouble. The band shed closes at 9.00 pm

and the women say there is much less petrol sniffing. They say 'people not hungry, and not bored - that's the answer'.

Sr Healy said a regular supply of affordable, good quality, fresh fruit and vegetables is a much cheaper alternative to kidney dialysis and the other health complications caused by inadequate diet.

CONTACT:

Joan Healy, 02 8912 4872 / 0417 681 145
Judith Tolley, Public Affairs, Catholic Social Services Australia 0408 824 306

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Osteoarthritis Clinical Trial

The Australian Centre for Complementary Medicine Education and Research (ACCMER) is a joint venture of the University of Queensland and Southern Cross University.

ACCMER is currently conducting a study which aims to determine if BSP-201 Sheabutter extract is effective and safe for the treatment of osteoarthritis.

Osteoarthritis (OA) is the most common joint disorder and is among the most frequent and symptomatic health problems for middle aged and older people.

Nonsteroidal anti-inflammatory drugs (NSAIDs) are among the world's most commonly prescribed medications for OA and work principally as pain relievers but do not stop the progression of the disorder.

* Sheabutter is made out of shea nuts harvested in the African savanna.

For further information contact:

ACCMER
Mater Health Services
Level 2, Community Services Building
39 Annerley Road
Brisbane QLD 4101
Phone: 07 3840 6112

"To me, one of the great benefits of the group is finding out you're not alone.

Whatever you're thinking/deciding/experiencing, you're not the only person who's been there"



Diary Dates

4th September 2006: Learning Café. Education: It's a Journey not a Destination. A Professional Development and Networking event with Pru Goward Sex Discrimination Commissioner & Commissioner Responsible for Age Discrimination, Australian Human Rights and Equal Opportunity Commission.

RSVP to Lifelong Learning Council, West End

Registration: Free

Email: secretary@LLCQ.org

Venue: Footsteps Gallery, Brisbane

7th September 2006: Annual Prostate Cancer Phone In. Talk to an expert from the Cancer Council Team - urologist, radiation oncologist, urology nurse, specialist educator about Prostate Cancer.

Phone: 13 11 20

21st - 22nd September 2006: Shared Visions Disability Conference 2006. Bringing together people with a disability, families and carers, disability service providers, the government and corporate sectors.

Phone: 1800 302 510

URL: www.disability.qld.gov.au

Venue: Conrad Jupiters, Gold Coast

29th September - 1st October 2006: 11th National MPS Conference "Strengthening Partnerships". Presented by Mucopolysaccharide & Related Diseases Soc Aust. Key speaker Dr Ed Wraith, Consult Paediatrician Royal Manchester Children's Hospital.

Phone: 02 9476 8411

URL: www.mpsociety.org.au

Venue: Brisbane

29th September 2006: PCOS 6th Annual National Conference. Presented by the Polycystic Ovarian Syndrome Association of Australia. The theme for this year's conference is "POSSAively managing PCOS". Includes a special one hour forum "Ask the Doctors" Ask any question you have to Professor John Eden, Dr Warren Kidson, Professor Helena Teede, Dr Anne Clark or Dr Mac Talbot.

Phone: 02 8250 0222

Email: info@posaa.asn.au

URL: www.possa.asn.au

Venue: Sydney - Tattersalls Club

30th September 2006: Cornelia de Lange Syndrome Association Australasia Inc Conference: Making Waves

Details Page 6 of this newsletter

30th September 2006: Chromosome 18 Registry & Research Society (Aust) Annual Family Meeting.

Details Page 6 of this newsletter

23rd - 25th October 2006: 3rd Indigenous Road Safety Forum - to share resources and information, maintain an ongoing national commitment to indigenous road safety. Make recommendations to produce practical and locally relevant initiatives to address indigenous road safety problems.

Contact Australian Transport Safety Bureau

Phone: 02 6274 7131 **Fax:** 02 6274 7922

Email: annette.bartlett@atsb.gov.au

Venue: Broome, WA

28th October 2006: Kabuki Syndrome Family Day. Indoor and outdoor areas, fully enclosed. Catered lunch and snacks,

toys and activities provided for the kids. Geneticist, Dr Sue White, has a keen interest in Kabuki Syndrome and may be attending. Please RSVP as soon as possible. Contact Darrin or Stacey

Phone: 03 5275 1542, or 0408 552 914, or

Email: dsmckiernan@dodo.com.au

Venue: Geelong, VIC

2nd - 4th November 2006: Velo Cardio Facial Syndrome International Conference 2006. Hosted by VCFS Foundation (Qld) Inc. World professionals will present papers, tutorials and give clinics.

Phone: 07 3857 1073

Email: mail@vcfs.com.au

URL: www.vcfs.com.au

Venue: Carlton Crest Hotel, Brisbane

11th - 12th November 2006: MDDA Conference "Rising to the Challenge" Metabolic Dietary Disorders Assoc

Phone: 1800 288 460

Venue: Melbourne

7th - 10th March 2007: 9th National Rural Health Conference. "Standing up for Rural Health: Learning from the Past, Action for the Future."

Phone: 02 6285 4660

Email: conference@ruralhealthorg.au

URL: www.ruralhealth.org.au

Venue: Albury