



# Newsletter

March Quarter Issue 1. 2007

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*

Hello everyone

You may remember that at the AGM last year, the committee's interest in a Deep Democracy project and a mental health project were confirmed and supported by our constituents. Since then one of our new committee members, Diana East has volunteered to manage the mental health project. If you would like to be involved please contact her through our office.

The deep democracy project is still active and although lots of people think it's a great idea, few have energy to spare for it. This is a familiar story and the best thing to do is regroup and revamp. The committee is having lots of discussion on these projects and your views and participation are very welcome. As with all community development work, it is the action based on the value that counts. In this instance if there is no participation the project won't proceed. This would not be a tragedy, just an opportunity to find out what people are interested enough in to act about. As a friend and very skilled community development practitioner used to say 'people with passion participate'.

Talking about values in action, I wanted to let you all know that SHQ was recently approached by Qld Health's Health Contact Centre in relation to the large database they are developing. A request was made for an electronic copy of the data base that serves our Directory. We were also subsequently contacted on two occasions with the same request by CAS-Asia Services, the firm

contracted to provide the technology and services to create and maintain Qld Health's Service Provider Directory.

We informed the Contact Centre and CAS-Asia Services that we have no authority to provide this information and that furthermore, the information is just a tip of a community development iceberg which represents dedicated relationship building, sector knowledge development, nurturing and human support. It seems likely however that the information in the Directory may be used to contact organisations and groups in order to get permission to include them in the new data base. We understand that this data base is to be made freely available. I would like to assure all Directory participants that we have not breached our agreements concerning the confidential information you supplied to us.

The SHQ committee will be seriously considering the implications of this development for future Directory versions and would welcome any comments you may have.

I would like to take this opportunity to welcome Dr Fran Boyle as a new contributor to the newsletter. Many of you will know Fran and her significant and important body of research in the self help sector. Fran will keep us informed as to the latest research concerning self help and the challenges of community-led health programs and organisations. Fran is currently the Chief Investigator for a Queensland study to evaluate the benefits of self-help organisations to people who suffer chronic diseases and to examine ways to improve links between the groups and GPs.

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**Self Help Queensland Inc  
Management Committee Members**

President Sue Smyllie  
Secretary Thea Biesheuvel  
Treasurer Kathleen Zarubin  
Members Jill Metcalfe  
Kim Summers  
Penny Threlfall  
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

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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.



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The researchers will conduct Australia's first comprehensive survey of people who contact self-help organisations focused on chronic illness. They will also trial an education strategy with GPs designed to improve awareness of and access to such organisations.

As for me, I have been surfing the net (after the approach from Queensland Health) just to re-acquaint myself with the information about self help that is available. Many thousands and thousands of sites respond to a self help query so I refined my search to pick up the information presented on Queensland Health and the Commonwealth Government policy sites. Again the number of hits is staggering but I was concerned at the interpretation of the term 'self help' in many of the documents I opened. Rather than an understanding of the value of sharing experience, working together and expanding social and helping networks that underpins our work, there was a lot of 'do it yourself' type articles, 'how to' lists and self care on everything from 'achieving your goals' to dealing with 'vicarious violence'.

*Sue Smyllie*

SHQ's Policies and Procedures Manual is reviewed annually, and may be seen at the office by contacting Trish on 3344 6919.

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# Genetic Matters

by Kim Summers PhD

## The Thousand Dollar DNA Sequence

It may only be a few years before our personal DNA sequence (our genome) may be available to each of us. The only man to have his DNA sequenced now, J. Craig Venter in the USA, has offered a \$US10 million prize to the first person who can get the cost of sequencing a human genome down to \$US1,000. So for about the cost of a washing machine or fridge, you would be able to obtain a listing of As, Ts, Cs and Gs, the building blocks of your DNA, in the very specific arrangement which makes you you. Last year an issue of *New Scientist* featured articles on the latest studies of individuality and asked what makes us different from each other, and what will knowing our own genomes tell us about ourselves.

The first promise of the vastly increased genetic knowledge is already being met to a limited extent. That is the promise that we will be able to predict who is most at risk of certain diseases and therefore reduce the risk using lifestyle changes, drugs and other approaches. There are currently a number of DNA tests which ascertain whether certain drugs will be helpful or harmful for people of particular genetic makeup. We also know some of the genetic risk factors for some cancers and cardiovascular diseases. We are beginning to understand the complex interactions between genes and environment which determine who gets diabetes and we know that even infections are influenced by the genetic variability of people who are exposed.

As we continue to study the DNA of numerous humans, and to link genetic variants, as well as environmental changes, to particular diseases, the ability to predict those people most at risk and to modify their lives to minimize the risk will increase. This is unlikely to be precise: many diseases are caused by a number of genetic variants interacting with the environment and at most we may be given a rough guide to the level of risk.

The print out of your genome might tell you which scents, tastes or foods you will like and prevent you from excessive use of a

perfume you think is mild but others find strong and offensive. We can identify genes involved in the sense of smell and correlate the ability to smell specific odours with genetic variants of those genes. Some people can't look up and smell the roses because they lack the rose scent receptor. Others are unable to eat broccoli and cabbage because they have a taste receptor which detects an unpleasant compound made by green leafy vegetables. Still others have a strong physical reaction to milk products because they lack an enzyme which breaks down milk sugar which is then fermented in the gut. Understanding your children's genomes may help you provide a healthy diet which they won't refuse to eat.

Beyond health risk assessment, genomic science may give us some insight into our personalities and abilities. The problems there are as great as for disease susceptibility. Genius is largely due to hard work building on a level of innate ability. Top musicians, sportspeople and scientists have all put in many hours developing their skills. Many are not gifted as children and only become accomplished when in an environment which suits their temperament and talents. It may be possible to tailor educational programs to individual learning styles, skills and deficits. But teachers, tutors and trainers may not have the time or the understanding to interpret a genomic printout so that each pupil can get optimal tuition. Knowledge of the genome may only reinforce what we already know: that the best learning happens in the best environment for learning, when the teacher is enthusiastic and committed and the pupil is interested and rewarded for achievement. And maybe knowing that your genome predicts high intelligence or an aptitude for maths may make you reconsider your career choices.

What about information you didn't want to know? Genetic studies are likely to reveal cases where one or both of the social parents is not the biological parent. You may find you have an untreatable genetic condition or that you once had a twin who has left some of his cells in your tissues. You genome might suggest that your ethnic background is different from what you have always believed. Knowing you have genetic variants found in risk-takers may encourage you to indulge in increasingly risky behaviour or alternatively make (Continued Page 4)

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you timid and unable to experiment. And knowing that your genetic status predicts that you won't do well at school, running or playing the violin may be enough to make you give up trying.

Your genetic sequence will tell you some things about yourself which you don't know now. You might like what you find out, but the chances are that you will also find things which don't please you, and knowing what's in your genome may put unrealistic pressure on you to preserve your health and maximize your potential. So think carefully before ordering your \$1,000 genome.

(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.)

**Sound  
Good?**



I want to live my next life backwards.

You start out dead and get that out of the way.

Then you wake up in an old age home feeling better every day.

You get kicked out for being too healthy; go collect your pension, then when you start work, you get a gold watch on your first day.

You work 40 years until you're young enough to enjoy your retirement.

You drink alcohol, you party, you're generally promiscuous and you get ready for High School.

You go to primary school, you become a kid, you play, you have no responsibilities, you become a baby, and then...

You spend your last 9 months floating peacefully in luxurious spa-like conditions with central heating, room service on tap, larger quarters every day, and then, you finish off as an orgasm!

Author unknown



**Australian Pituitary  
Foundation Ltd**

## **Inaugural National Seminar Saturday 18<sup>th</sup> August 2007 at 9am**

The Seminar will focus on **both children and adults** who have been diagnosed with a pituitary condition.

This event will provide an excellent opportunity to converse with fellow members, carers and medical experts regarding pituitary related topics

The objective of the day is to:

- Provide education on pituitary illness and associated conditions
- Enhance quality of life and assist people in getting on with it
- Assist those who care for a loved one or dependant.

Keynote presentations throughout the day on such topics as:

- Growth Hormone Replacement for Children & Adults
- Reproductive Health & Fertility
- Weight Issues
- Dealing with Stress
- Osteoporosis
- Hormone Replacement & Suppressants
- Mental Health

**Registration:** includes morning tea, lunch, afternoon tea and light refreshments at the social function upon conclusion of the seminar (4pm to 6pm). It does NOT include accommodation or transport.

**Venue:** Westmead Hospital, Sydney - a specialised tertiary referral hospital within walking distance of Westmead railway station and five minute drive or train ride from Parramatta CBD.

For further information or enquiries please contact:

Sue (07) 3376 2083

[sue.pituitary@ozemail.com.au](mailto:sue.pituitary@ozemail.com.au)

Catherine (02) 9594 5550

[pituitary@bigpond.com](mailto:pituitary@bigpond.com)

URL: [www.pituitary.asn.au](http://www.pituitary.asn.au)



## Supporting Aussie Kids with Kabuki Syndrome (SAKKS)

Kabuki Syndrome (Also known as Niikawa-Kuroki syndrome) is a rare disorder. There are more than 300 individual cases published worldwide, but many more that are not published. It was first described in 1981 by Niikawa and Kuroki who observed several children with similar characteristics.

There are many features which can occur in Kabuki syndrome but not all are seen in every child. Features seen in Kabuki syndrome are:

- Unusual facial features  
wide eyes with arched, interrupted eye brows  
large and low-set ears  
depressed nasal tip
- Short stature. Most children with Kabuki syndrome are below the 50th centile for height for their age. Occasionally, growth hormone deficiency has been found.
- Skeletal abnormalities such as short fingers, loose joints
- Intellectual disability, which varies from mild to severe. Most individuals with Kabuki syndrome have a mild to moderate intellectual disability.
- Many other abnormalities are sometimes seen:  
Cleft lip and palate  
cardiac abnormalities  
urogenital and kidney problems  
ano rectal and intestinal problems  
immune abnormalities  
ear infections and hearing loss

The cause of Kabuki syndrome is not known. It is thought to be a genetic problem and research is ongoing to try to identify the cause. In most cases of Kabuki syndrome, there is no family history of the syndrome. Kabuki syndrome is found in males and females equally.

There is no cure for Kabuki syndrome but there is a lot that can be done to ensure

good health in a person with Kabuki syndrome, and to make sure that each person with Kabuki syndrome achieves their full potential.

Health care professionals that are likely to be involved include a paediatrician, geneticist, and other specialists depending on the problems in the child. Most children will require the input of speech therapists, physiotherapists and other allied health professionals.

SAKKS is an Australian, online support group aimed at providing information, connecting families and supporting children with Kabuki Syndrome. SAKKS membership is free, and open to families to join via the very user friendly and informative website.

People have the opportunity to give consent to being included on a SAKKS register which will be provided to members bi-annually. This will assist in making contact with other families, and sharing knowledge and experiences. In one month alone, 25 members joined the register - 21 Australian and 4 International.

Your participation in SAKKS will assist in the further development of the group, hopefully allowing new information and discoveries to be made available to members.

A National Family Day is held annually. To date, the Family Day has been held in SA, VIC, and NSW. The day is an excellent opportunity for families to meet, have fun, share their stories, and meet professionals.

To become a member, or to learn more about Kabuki Syndrome please contact Peta:  
Email: [petal@sakks.org](mailto:petal@sakks.org)  
URL: [www.sakks.org](http://www.sakks.org)

### Kabuki Syndrome Family Day 2007

Date: 15th September 2007  
Venue: Varsity Lakes, QLD  
Enquiries: [petal@sakks.org](mailto:petal@sakks.org)

(Sourced from the article "What is Kabuki Syndrome" with permission of the author, Peta Colton, and edited by genetics researcher into KS, Dr Sue White.)

*"Why repeat the old errors if there are so many new errors to commit."*

**Bertrand Russell**

## Queensland Advocacy Incorporated

### Human Rights E-Consultation & On-Line Discussion Forum

Queensland Advocacy Inc (QAI) is working on a human rights project for people with disability. This project aims to tell you about your human rights. The project also aims to find out if your human rights are being respected.

Human rights are the most important rights. Human rights belong to every person.

We want to find out if the human rights of people with disability in Queensland are being respected.

We want to ask you what you think about this, and find out about your experiences.

The information you give us will help QAI work out what changes we need to push for to make things better for people with disability in Queensland.

You are invited to talk about your human rights by E-Consultation. We will send you E-Bulletins every week for 6-8 weeks. We want you to think about the issues raised in each bulletin, and respond to some questions by email. You can do this in just a few minutes, or take as much time as you want. Your emails will be private and confidential and the information you tell us will be recorded in a de-identified form. You don't have to worry about anyone finding what you said to us. Please email Melinda Ewin [melinda@qai.org.au](mailto:melinda@qai.org.au) to be placed on the E-Bulletin email list.

If you would like to join an on-line discussion forum where you can discuss the E-Bulletins with other people please join via the QAI website [www.qai.org.au](http://www.qai.org.au).

Queensland Advocacy Incorporated  
Suite G2, Ground Floor  
Brisbane Transit Centre  
151 Roma Street, BRISBANE QLD 4000  
Ph: 07 3236 1122 07 3236 1590

If your contact details change or you no longer wish to receive our newsletter, we would love you to let us know. Ph: 07 3344 6919 or [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au) Thank you!

## "Yes We Care" Campaign 2007

- volunteers offer practical assistance in your home on 2nd June 2007

The "Yes We Care" campaign will take place in Brisbane again this year. It is run by volunteers from Brisbane Churches with the support of the Brisbane Lord Mayor and the Brisbane City Council Resourcing Team.

Last year the campaign arranged for 600 volunteers to go to 300 homes across Brisbane to provide assistance by mowing lawns, cleaning, gardening and spring cleaning among other things.

The campaign is aimed at assisting people who may be sick, elderly, disabled or frail, or a sole parent. The preferred time frame is for jobs that do not go beyond a half day's work for each home. Someone may need help to move some furniture, clean out the garage or just help tidy up hard to reach places.

As there is a great deal of organisation involved it would be appreciated if people needing assistance could make contact ASAP. Please phone Bernice Callanan on 3378 3595 or 0416 344 064 if you would like someone to call and help you in your home on the day.

-oOo-

## New Health Community Councils in Queensland to be sounding board for the community.

Recruitment for new Health Community Councils in Queensland is currently under way by the Health Quality and Complaints Commission. Councils will be responsible for talking to the community about public health issues and then telling Queensland Health what they are hearing.

The statutory responsibilities of the Councils include community engagement, providing community input and oversight about the safety and quality of local health care and assist with community education about public health services.

Contact: Brad Smith, Manager  
Health Community Council Coordination  
Ph: 07 3234 1561  
Email: [brad\\_smith@health.qld.gov.au](mailto:brad_smith@health.qld.gov.au)

# Does Queensland Need a Self Help Group for Survivors of Electric Shock?

*By a Queensland Survivor*

Did you know that the non-fatal effects of electric shock (ES) have the international classification, ICD Code: 994.8<sup>1</sup>? The Australian Department of Veteran's Affairs considers such damages as "the deleterious effects to the body caused by exposure to electricity but does not include the effects of lightning"<sup>1</sup>. This discussion also excludes electroconvulsive therapy (RST or ECT).

Authorities require "sound medical-scientific evidence" for acceptance of a final diagnosis of electric shock injury (ESI) by a GP or specialist<sup>1</sup>. "Unconfirmed" or "provisional" diagnoses demand more costly "examinations, referrals and special investigations"<sup>1</sup>. At least one Brisbane survivor has found that local medical professionals tend to tag low voltage ESI as too "uncommon" or "complex" to warrant personal investment and repeatedly, they treat it with the unverified opinion that "they can't do anything for it anyway". So does assistance really exist for survivors of electric shock in Queensland?

In Australia, high voltage power lines over 1000 volts supply an alternating current (AC) to low voltage electrical outlets of less than 1000 volts like the 240 Vac of a household power point. Direct current (DC) sources do about one third of the damage that AC sources do<sup>1</sup>. An extremely short duration shock of less than 500 V may initially produce "minimal or no observable evidence" of harmful changes<sup>9</sup>. People have survived voltages as high as 100,000 V and died from contact with 50 V<sup>1</sup>. Fifty percent of low voltage ESIs occur in the home, mainly to children<sup>1</sup>. With the medical emphasis on visible injuries, many cases do not receive hospitalisation and appear unlikely to develop other problems.

Electrical trauma can present in 4 stages<sup>7</sup>. Stage 1 appears immediately at the accident site and may or may not include unconsciousness, burns and heart or respiratory failure<sup>7</sup>. Stage 2 or hospitalisation phase only treats damages to external and internal organs, some of which takes several days to identify<sup>11</sup>. Stage 3 or rehabilitation phase

starts from the first few weeks to 6 months and manages things like chronic pain, tremors, blood pressure problems, gait abnormalities, sleep disorders, emotional and neuropsychological effects<sup>7</sup>. Stage 4 occurs after 6 months where long-term damage can arrive as degenerative brain and heart disorders, often years later<sup>7</sup>.

ESI literature tends to focus on treating the first two emergency Stages<sup>11</sup>. As early as Stage 2, permanent symptoms can surface that resemble several syndromes such as Parkinsonism, cerebellar disorders, myelopathy, spinal muscular atrophy, or sensorimotor peripheral neuropathy<sup>3</sup>. In rare cases, contact with cables up to 380 V can increase the chance of developing Motor Neurone Disease<sup>2</sup>. In Queensland, one adult survivor with no known family history has presented with symptoms of Friedrich's Ataxia, even though DNA tests only verify a carrier status. This raises the question that something may "switch" a DNA weakness<sup>5</sup>.

**This discussion does not include the effects of lightning or electroconvulsive therapy.**

Some long-term ESIs defy explanation<sup>8</sup>. Test results or neurobiological theories "fail to explain" neuropsychological problems<sup>9</sup>. Contact conditions or prior injuries do not account for "disproportionate" diffuse electrical injuries (DEIs)<sup>9</sup>. Even though a distinct "symptomology fingerprint" exists, these DEIs continue to attract "non-organic" diagnoses<sup>9</sup> from mental health professionals.

Considering that medical tests rarely provide evidence<sup>7</sup> and Stage 3 and 4 symptoms prove unpredictable<sup>9</sup>, a domino effect arises for survivors as they fail to prove damages for employers, insurance companies, justice systems and government services.

Unfortunately in Queensland, the high potential for long, lengthy litigation surrounding ESI, often dictates the tone of the limited

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health services offered to ES survivors, especially those with long-term DEIs. Who knows how many ES survivors require more support?

Placing the onus on the injured innocent to supply non-existent medical evidence increases post-traumatic stress and isolated survivors fade into statistical obscurity as they retreat from systemic doubt. It does not seem surprising that a high number of survivors suffer deep depression and lose their jobs and spouses<sup>7</sup>.

As long as the mechanisms that cause DEIs remain unidentified<sup>8</sup>, social structures, including health systems in Queensland, offer only very limited aid to survivors, so individually, they already take care of themselves.

**Fifty percent of low voltage ESIs occur in the home, mainly to children<sup>1</sup>.**

Self Help Queensland can assist isolated survivors interested in starting up a support group. The aims of such a group might include gathering and sharing useful knowledge, monitoring and aiding new research or simply connecting people. Those interested can phone Trish on 07 3344 6919 for further information.

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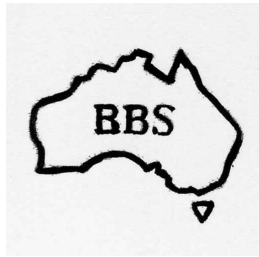
## References:

1. AUSTRALIAN GOVERNMENT, Department of Veteran's Affairs, S007, Statement of Principles, "Non-Fatal Effects of Electric Shock and Death from Electrocution", ICD CODE: 994.8, Veteran's Entitlements Act 1986, subsection 196B(2-3), <http://www.dva.gov.au/pensions/statemnt/s007.htm>  
Sited: 13 March, 2007; Last modified: Unknown.
2. BBC1, BBC News, HEALTH, Lightning Link to Muscle Disease, 91% relevance, <http://news.bbc.co.uk/2/hi/health/1444045.stm>  
Sited: 9 March, 2004; Last modified: 19 July 2001.
3. BRAIN INJURY .COM, Electrical and Lightning Injury, <http://www.braininjury.com/electricalandlightninginjury.html>  
Sited: 17 March, 2006; Last modified: Unknown.
4. CHEN, Chin-Tu, LEE, Raphael C., SHIH, Ji-Xiang, ZHONG, Min-Hua, (Editors), Annals of the New York Academy of Sciences, Volume 888, "Occupational Electrical Injury: An International Symposium", Oct 30 1999.
5. DAVIDSON, Michael W., Florida State University, "Magnetic Field Alignment of the Unwinding region", <http://micro.magnet.fsu.edu/dna/pages/magneticfield1.html>  
"Magnetic Field Effects on the Cholesteric Helical Pitch", <http://micro.magnet.fsu.edu/dna/pages/magneticfield2.html>  
"Ordered High Density Phase Growth in Magnetic Fields", <http://micro.magnet.fsu.edu/dna/pages/magneticfield14.html>  
Sited: 13 March 2007; Last modified: 26 February 2004
6. FISH, Raymond M., Ph.D., M.D., FACEP & GEDDES, LESLIE, B.S., M.S., Ph.D., "Medical and Bioengineering Aspects of Electrical Injuries", Med League Support Services, Inc, 2003, Lawyers and Judges, [http://www.medleague.com/webstore/lawyersandjudges/electrical\\_injury\\_mba.htm](http://www.medleague.com/webstore/lawyersandjudges/electrical_injury_mba.htm)  
Sited: 24 May, 2006; Last modified: Unknown
7. HOOSHMAND, M.D. Neurological Associates Pain Management Center, Vero Beach, Florida. Electrical Injuries, [http://www.rsdrx.com/electrical\\_injuries.htm](http://www.rsdrx.com/electrical_injuries.htm)  
Sited: 9 January, 2007; Last modified: 9 January, 2000.
8. MORSE, M.S., BERG J.S., TEN WOLDE, R.L., "Diffuse Electrical Injury - A Study of 136 Subjects", Department of Electrical Engineering, University of San Diego, San Diego, CA, USA. San Diego Naval medical Center, San Diego, CA, USA. (Presented at the 25th IEEE Engineering in Medicine and Biology Conference, Cancun, September 2003.)
9. MORSE, M. Steven, WEISS, Diana, University of San Diego, "An Evaluation Protocol for Electric Shock Injury Supported by Minimal Diagnostic Evidence", Department of Electrical Engineering, University of San Diego, San Deigo, CA, USA. San Diego Naval Medical Center, San Diego, CA, USA. (Presented at IEEE .EMBS, San Diego, 1993.)
10. PRICE, Timothy G., COOPER, Mary Ann: "Electrical and Lightning Injuries", Rosen's Emergency Medicine, Concepts and Clinical Practices, 6th Edition, 2006. <http://tigger.uic.edu/labs/lightninginjury/pub4.html>  
Sited: 13 March, 2007; Last modified: Unknown.
11. UNIVERSITY OF CHICAGO ELECTRICAL TRAUMA PROGRAM, Division of Biological Sciences, The University of Chicago, Mission, <http://etp.bsd.uchicago.edu/mission.html>  
Sited: 9 March, 2004; Last modified: Unknown.

## OFFICE FOR RENT

3.45m x 6.4m carpeted office, would suit 1- 2 employees. The office is situated in New Farm- plenty of street parking available. Included in rent is the use of a meeting room, electricity and some tea/coffee facilities. Three support organisations share the building. Please contact Liz Davis at SANDS on 07 3254 3422 for further details.





## Newly Formed Bardet-Biedl Syndrome Support Group a first for Australia

### Bardet-Biedl Australia

Bardet-Biedl Syndrome, also known as BBS, is a rare genetic syndrome. (A syndrome being a group of features that occur together to characterise a medical condition.)

Although researched in the UK and USA, BBS remains mainly unknown throughout Australia. This also includes the medical profession. Based on statistics from other countries it is estimated there are at least 200 sufferers of BBS in Australia. The actual official rate of inheritance for BBS is stated as, 1 in 160,000 people. This support group BBS Australia is being established for a number of reasons; the first to find the sufferers in Australia.

BBS is not a common syndrome as it is a recessively inherited condition. Recessive genetic conditions only occur when a person receives the defective gene for the same condition from both parents. They have to have 2 copies of the gene to have the condition. Researchers of BBS from overseas have been leading the way in the possibility that with some BBS a new triallelic inheritance is occurring revolutionising the genetics field. In very basic terms in addition to the 2 identical defective genes causing BBS, sometimes there is another gene also involved in causing the condition.

BBS is a multi-systems disorder as it affects so many parts of the body. Diagnosis of BBS is still dependent on the physical presence of features of the disorder. Features are classed in primary and secondary features. An affected individual has either 4 primary features or 3 primary features and at least 2 secondary features.

#### Primary Features

- Rod – cone dystrophy / Retinitis Pigmentosa with early vision loss
- Polydactyly (extra digits hands & feet)
- Obesity

- Learning disabilities
- Hypogonadism in Males
- Kidney disease & abnormalities

#### Secondary Features

- Polyuria/polydipsia
- Hearing loss/sensitivity
- Speech deficit
- Liver disease
- Congenital heart defects
- Hypertension
- Diabetes
- Hypothyroidism
- Female reproductive abnormalities & hormones
- Developmental Delay
- Behavioural difficulties
- Epilepsy
- Clumsiness and Poor co-ordination
- Short Stature
- Brachydactyly

Diagnosis of BBS is usually delayed, as most features are not present from birth. With so many features part of the syndrome this also complicates the diagnosis, as great variation can occur in the expression of the syndrome.

In 2001 the first gene responsible for BBS was discovered. Since then research teams in the UK and USA have now found 12 BBS genes. Geneticists now believe that there may possibly be up to 30 genes involved in the inheritance of BBS, explaining the variations and the complexity of the condition. From these advancements DNA testing now exists in the UK, USA and Germany but not in Australia. One of BBS Australia's long-term goals is to lobby for the introduction of DNA testing for BBS in Australia.

Further ground breaking research with BBS that has been published is that of the effect of dysfunctional cilia. At the UK Laurence-Moon-Bardet-Biedl Society (LMBBS) Conference, Professor Phil Beales, Consultant Clinical Geneticist, Gt. Ormond Street Hospital & President of LMBBS explained that, "Cilia are little hairs that present themselves on the surface of most cells of the body. They come in two varieties, those that beat to get rid of the mucous from our lungs, and those that sense the surroundings in the environment around the cell..."

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some of the work that has been published confirms that in some way the dysfunction of cilia gives rise to BBS".

BBS was initially known as Laurence-Moon-Bardet-Biedl Syndrome (LMBBS) after John Laurence, Robert Moon, George Bardet and Artur Biedl who each discovered people exhibiting features of LMBBS. For some time it has been recognised that within LMBBS two separate conditions exist. Therefore the conditions are now correctly known as either Laurence-Moon Syndrome (LMS) or Bardet-Biedl Syndrome (BBS). The distinguishing features of BBS are the extra digits on the hands or feet, called polydactyly, obesity and kidney disease.

The diagnosis of BBS can be truly devastating and overwhelming. As a sufferer of BBS I know firsthand the need of having the support of other sufferers, as BBS is a unique condition. At present we only know of a handful of people in Australia with the condition although from statistics we know that this should not be the case.

People need to know about BBS as there is a poor rate of diagnosis. With many of the conditions such as hypertension, diabetes, obesity common society illnesses, doctors and the community need to be aware of the other features in case they could have BBS. In establishing BBS Australia, hopefully BBS will be known throughout Australia.

BBS Australia asks people to contact them to help establish this new support group either via email or phone. Contact with other BBS sufferers does help in coping, just knowing that you are not alone. We really need your help in finding those affected by BBS and once we receive that contact the support group will set up a forum in which members can establish contact with other BBS sufferers. For further enquiries to BBS Australia:

Ph: Kathryn 07 3279 0763

Email: [bbs.Australia@yahoo.com.au](mailto:bbs.Australia@yahoo.com.au)

### Tell Us What You Think!

We value feedback about any aspect of the services we provide. Please assist us by letting us know how you think we may be able to do things better. Ph 07 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)

## Peer Support Program on offer to Amputees in Qld

Have you, (or someone you care about), recently had an amputation, or are you about to undergo surgery?

The **Amputees and Families Support Group Queensland Inc** offers a peer support program which endeavours to link you with an amputee who has experienced similar challenges to yourself.

Peer support volunteers are available in various regional and rural areas of Queensland as well as the South East corner. The service is free and confidential. Please phone 07 3290 4293 if you would like more information or email [admin@afsg.org.au](mailto:admin@afsg.org.au)

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## Miscarriage Memorial Services Helpful to Many

Many hospitals throughout Queensland hold non-denominational memorial services in memory of all babies born before 20 weeks of gestation. All parents, families, friends and staff are welcome to these services. Your baby does not have to have died at the hospital at which the service is being held. Parents, families and friends of babies who died at any gestation many years ago, before assistance was given with creating memories may find these services helpful and are very welcome.

### Memorial Services known to be conducted in Queensland Hospitals:

Redcliffe-Caboolture Hospital  
Ipswich Hospital,  
Mackay Base Hospital  
Gold Coast Hospital  
Royal Women's Hospital (Brisbane)  
Townsville SANDS/SIDS Memorial Services in co-operation with Townsville Hospital, Wesley Hospital Townsville and Mater Misericordiae Hospital  
Redland Hospital  
Toowoomba SANDS Rock of Remembrance Memorial Service

(Source: SANDS (Qld) Inc Newsletter April 2007, Issue 250. [www.sandsqld.com](http://www.sandsqld.com))

# Resolving Grief

## - To “be strong” or to “have courage”?

*By Bob Wyborn*

We are very often told to be “**strong**” when in times of great emotional challenge and in particular when grief is that challenge. It has always struck me as a very easy piece of meaningless advice and it invariably comes from those who have never been in the current predicament we are experiencing. I have often pondered the use of that word and its intended meaning by the user. Is it chosen and then totally misinterpreted because the English language often lacks specificity? After all on a hot Queensland summer day almost all of us would “love” to have a cool, refreshing ice cream.

On the other hand do our mostly well intended advisors choose a clichéd word without understanding its significance and power to have exactly the opposite affect to that which it was intended?

It became apparent to me some time ago that part of a successful resolution to our grief required the use and engagement of another word and we needed to bring it into play much earlier than we often felt inclined. That word is “**Courage**”. Observation confirms that it comes as an almost obligatory action in our grief journey and not, most often, as a welcome visitor. We are “forced” to display it firstly at the funeral, then many times thereafter for many different reasons; - because other family members rely upon us for their daily welfare, at the workplace from which we cannot hide, the shops, the neighbours, our spouse, the very act of leaving the cocoon of our bed and entering the shower is often a monumental task requiring great pain. The list goes on and on. I think perhaps the toughest task which requires our utmost courage is to be able to face and accept ourselves for what we are in that “eternal moment” of truth and absolute exposure.

Perhaps a quick look at what is meant by the two words in question may allow us to understand and hopefully influence others to choose their words with more deliberation and thereby cause less pain than they continue to do.

- We are strong if we have the muscular capacity to lift heavy weights – we are courageous if those weights are emotional pain and its many visitors.
- We are strong if we can exert great physical or mechanical power – we are courageous when we use that power to face reality.
- We can have a strong voice which can be heard at a distance – we are courageous when we listen to the still, quiet voice.
- The economy is strong when it is stable and thriving – we are courageous when our emotional bank shows a healthy balance of deposits and withdrawals.
- A sporting crowd can be 50,000 strong – we are courageous when we can stand as the sole participant and can cheer our own on field achievements.
- We can have a strong likeness to a family member – we are courageous when that likeness resembles who we really are.
- The oceans have very strong currents – we are courageous when the tides of our injured emotions are allowed to wash over our Soul.

There are many more examples that could be made to highlight this belief. It seems to me that the word “strong” is often used to denote an instruction given by a non-participant in the communal action that is grief. Someone for whom the advice is not relevant or needed and indeed it is given as a tacit order. It therefore must be obeyed as it has some omniscient prerequisite to moral character and courage. The insidious component of the use of the word “strong” in the context of grief is its glaring comparative and polar nature. ‘If you are not **strong** you must therefore be **weak**.’ It is a very tough call under which to rally.

“Be strong” can also mean some of the following:-

- “I do not know how to handle this situation but surely you can get over it as it has been 8 weeks now”
- “I have no real understanding of your situation but as I currently feel this is the solution”

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- “ I am uncomfortable with this and my words of advice have fulfilled my moral obligations to you, so get over it!”
- “ I am very genuine in my belief that this is the best for you”

The desire to offer help to those in grief is most genuine for nearly all people however those who often hurt us the most are those who are the closest to us. Is this because of our nearly non-existent training on the subject and our poor understanding of death? How much does our Western dominated thinking of permanence and procrastination contribute to this circumstance? Do we simply not have any idea what to say? Do we need to develop a grief specific language?

I would suggest that when we look at offering advice to those in grief that we learn to understand that grief is an active and participatory process. Whilst it is very true that it is also a learning experience and probably **the** ultimate learning experience it does not need a series of “Professors” instructing those who know their pain. If grief is anything it surely can be well described as **the absolute pain**. Grief comes to us because we have had someone, most loved, die. The attached love and its myriad of memories stay whilst their physical presence leaves. There has never been a situation like this before and we have no reference point to help us make sense of the apparent senselessness.

We are then catapulted onto a one way road with no clear sign post or road map. Amongst the mixture of all the emotional feelings and total uncertainty comes the companion of the unknown – fear. The secret to overcoming grief is not obedience to a command to be strong but rather to have the state of mind, body and spirit that will allow you to face the pain, feel its force and thus strip fear of its power. We need to encourage such a course of action as it brings into play the healing energy of courage.

I suspect those that mourn do not often acknowledge their own courage as they do not feel very brave most of the time. However I would suggest that we must take time out to recognise and become “aware” of what it is that we are experiencing and what actions we are undertaking ; those by deliberation

or rote. Courage is a doing thing not engendered by obedience to a cliché or command. The courage that is shown in grief is an essential part of the journey towards resolution and acceptance of what has occurred. As Mary Anne Radmacher has said; “Courage doesn’t always roar. Sometimes courage is a little voice at the end of the day that says I’ll try again tomorrow”

The significant role that courage plays can not be overstated. Perhaps before we offer the “be strong” advice we should place ourselves in the shoes of the grieved person and recognise that the emotional turmoil that is their unwelcomed lot is already extracting its long term pain. The day to day course of their life is requiring courage whether it is volitional or not. We need to acknowledge their current achievements and encourage their progress. Just like a long distance road sign they need to see that this sign has the destinations of Imagination, Hope and Resolution upon it.

The danger of quelling courage is that it leads to another road which is sign marked with such destinations as Snagged, Hopelessness, Bitterness and Clinical Depression.

Courage should not be misinterpreted as an action requiring super human feats but rather be seen and understood for what it is – the act of facing your fears. Fears are generated by the mind. They do not exist but they are nevertheless very powerful. The same source that generates fear produces hope and in equal amounts. Courage is the converting catalyst. We need to gently and lovingly encourage this wonderful and essential quality.

I have included a few quotations that may help expand this subject.

- “Courage is resistance to fear, mastery of fear – not absence of fear. Except a creature be part coward it is not a compliment to say it is brave” ~ Mark Twain
- “For without belittling the courage with which men have died, we should not forget those acts of courage with which men have lived.” ~ John F. Kennedy
- “Life shrinks or expands in proportion to one’s courage” ~ Anais Nin

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- “Courage is doing what you’re afraid to do. There can be no courage unless you’re scared” ~ Eddie Rickenbacker
- “Courage is the art of being the only person who knows you’re scared to death” ~ Harold Wilson
- “Courage and perseverance have a magical talisman, before which difficulties disappear and obstacles vanish into air” ~ John Quincy Adams

(Bob Wyborn is a grief facilitator for the Redcliffe Chapter of The Compassionate Friends and is passionate about the healing of those on their grief journey. He wrote this as a result of observations and feed back from the many family members who were confronted by the use of the word “strong”. Bob is also the Queensland contact for the Australian Leukodystrophy Support Group and a member of the Self Help Queensland Management Committee.)

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## Free Chronic Disease Self-Management Course



The Hepatitis Council of Queensland is offering a free course on self-management for people with chronic conditions and families/carers.

Topics covered will be:

- Managing symptoms
- Fighting fatigues and frustration
- Living with depression
- Making daily tasks easier
- Medications - responsibilities and usage
- Communicating with healthcare providers
- How to get more out of life!

Courses will be held:

Monday evenings for 6 consecutive weeks from 6pm - 8pm starting 14th May 2007 at:

New Farm Neighbourhood Centre  
967 Brunswick Street, NEW FARM

If you would like to register, contact:

Hepatitis Council of Qld Inc

Ph: 07 3236 0610 or 1300 437 222

Email: [development@hepqld.asn.au](mailto:development@hepqld.asn.au)

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## Carers!

Want to get back into the workforce?  
Don't know where to start?

You may need a little.....  
Momentum!

Trying to get back to work after a long absence can be very daunting. The workforce changes so quickly, it's hard to know if the work you once did still exists, whether your skills are relevant or up to date, or even where to begin in trying to find a suitable job....let alone actually writing an application.

This is where Momentum can help. Momentum is a Back to Work program primarily aimed at carers needing help navigating the path back to paid work or continuing education. Carers Qld has received a state government grant to conduct the Momentum program in the Brisbane area over the next 12 months. Up to 50 carers will be enrolled in three intakes, with the first group beginning in May.

Momentum offers:

- Individual career support and advice
- Counselling
- Job ready training
- Vocation specific training
- Placement and post placement support
- Assistance with respite, transport, clothing and/or childcare

To be eligible you must have been unemployed for the past 12 months. All carers are multi-skilled and can offer employers a lot. Momentum can help you reach your potential.

To register your interest in Momentum contact Carers Qld on 07 3421 5900 or drop into their office at 972 Logan Road, Holland Park.

*“There are people who speak to us and we do not listen to them; there are people who hurt us and they don't leave a scar, but there are people who simply appear in our life and they mark us for ever.”*

**Cecilia Meireles**

## New Medicare Items Give Better Access to Mental Health Services

On November 1 2006, the Federal Government introduced a number of new Medicare rebates under the Better Access to Psychiatrists, Psychologists and GPs through the Medicare Benefits Schedule (MBS) initiative. These changes will hopefully allow people with mental health issues to receive the assistance they require and at an earlier stage.

There has already been a large take-up in the new rebates, including consultations to create individual mental health plans, therapy sessions delivered by GPs and clinical psychologists, focused psychological strategy services provided by psychologists, occupational therapists and social workers.

Conditions classified for the purpose of the rebate are informed by the World Health Organisation's Diagnostic and Management Guidelines for Mental Disorders in Primary Care (1996). It includes:

- Psychotic disorders
- Schizophrenia
- Bipolar disorders
- Phobic disorders
- Generalised anxiety disorder
- Adjustment disorder
- Unexplained somatic complaints
- Depression
- Sexual disorders
- Conduct disorders
- Bereavement disorders
- Post-traumatic stress disorder
- Eating disorders
- Panic disorder
- Alcohol use disorders
- Drug use disorders
- Mixed anxiety and depression
- Dissociative (conversion) disorder
- Neurasthenia
- Enuresis (non-organic)
- Sleep problems
- Hyperkinetic (attention deficit) disorder
- Obsessive compulsive disorder
- Co-occurring anxiety and depression

Dementia, delirium, tobacco use disorder and mental retardation are not regarded as a mental disorder for rebate purposes.

The most significant of the new Medicare items is the introduction of a rebate for psychological therapy services. Previously,

many people could not afford to access these services. A person can claim up to 12 individual allied mental health services in a calendar year. These services include:

- Psychological therapy services - provided by eligible clinical psychologists.
- Focused psychological strategies - provided by eligible psychologists, occupational therapists and social workers.

(Source: Women's Health Queensland Wide Inc Newsletter, "Health Journey", Vol 1. 2007.)

For further information see:

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/mental-boimhc>

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## Peer Mentor Program needs Volunteers across Queensland

An excellent initiative of the Spinal Injuries Association is its Peer Mentor Program. The Association sees a peer mentor as "someone who has a spinal cord injury (SCI), is living successfully with it, and has experience with handling the same or similar situations that people may encounter upon their discharge from the spinal unit. They are knowledgeable about living with SCI, and they would like to pass this knowledge on to people who are newly injured."

Currently there are 24 Peer Mentors in Queensland, and the Association is hoping to greatly increase this number so that everyone leaving the spinal unit has someone close by to assist them adjust to SCI.

Peer Mentors provide information and practical advice gained from their own personal knowledge and experiences. They are not health care professionals, professional counsellors or personal assistants/carers.

A training package is currently being developed to assist mentors. Peer Support Coordinators will be available in Brisbane and Townsville to support and guide the new mentors. For further information contact: Peer Mentor Program, Spinal Injuries Assn Townsville 1800 024 422 Brisbane 1800 810 513

(Source: "Imprint" Newsletter of the Spinal Injuries Association March - April 2007)

## Mentors Needed for Drug Arm "Get Set" Initiative in Logan

Get Set is a new youth initiative designed to reduce the risks of alcohol and other drug use amongst young people in Logan. It will work with 10-15 young people aged 13-17yrs 'at risk' from alcohol and drug use.

The young people will be involved in a weekend camp where they will be motivated to engage in life, work as a team, explore issues of concern and develop leadership skills. This will be followed by a series of weekly meetings where they will design and create their own community projects aimed to educate their peers about the risks and harms associated with alcohol and drug use. These projects may involve making a DVD, music CD or organizing an event.

Volunteer mentors will be involved in the project to provide ongoing support to the young people throughout the process, being a role model and adult friend. They will be required to attend the weekend camp in May, attend the weekly meetings (evenings or weekends) and once the formal part of the project is finished they are encouraged to keep in contact with their mentee, with a minimum of a phone call a week for the rest of the year. Training will be provided.

Mentors can be any age over 18, they need to be able to apply for a Blue Card. They can have a history of drug use but need to be at least 2 years drug free to be involved. They need to be able to access transport to Logan.

Contact Clare Thomas, Get Set Co-ordinator at DRUG ARM Logan on 3290 3531, 0411 022 293 or [claret@drugarm.com.au](mailto:claret@drugarm.com.au).

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### Help us help your group

If your group needs help to get its message out to the Sector please feel free to submit an article for publication in this newsletter.



## Mental Health Project

SHQ continues to receive many calls from people who are looking for a mental health support group/mental health peer support and yet there still does not seem to be many such groups in existence. At our last AGM it was agreed that our organisation would look at a small project that focuses on this issue during 2007 but the scope of such a project has not been defined.

One of our new committee members, Diana East (who has a wealth of experience in the community mental health field), is keen to meet with anyone who would like to be part of an informal get-together to explore the issue a bit further and help to shape a small project.

If you are interested in being part of this get-together with Diana, or would like more information, please phone Trish at SHQ or Diana on 3880 3501.

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## Critical need in QLD for Foster Carers from a diverse range of backgrounds and cultures

For children from culturally and linguistically diverse backgrounds, their cultural needs are just as important as their physical and emotional needs.

The Queensland Department of Child Safety is urging people to consider taking on the challenging but rewarding role of Foster Carer.

For further information:  
Ph: 1300 550 877  
[www.childsafety.qld.gov.au](http://www.childsafety.qld.gov.au)

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## Albinism Support Goes National



The Albinism Friends and Family Support Group (Qld) has amalgamated with several other small support groups across all the States of Australia. The group now forms part of a national organisation and is called the Albinism Fellowship of Australia Inc (Qld Branch)

**Email:** [albinismqld@yahoo.com.au](mailto:albinismqld@yahoo.com.au) **URL:** [www.albinismaustralia.org](http://www.albinismaustralia.org)

## Community Building: Critical Voices, Alternative Strategies

National Symposium, 19 June 2007

Governments around the country are currently throwing money and officials at 'community building' objectives, often with little conceptual or strategic clarity about what they are doing or what they are aiming to achieve. Highly bureaucratised initiatives, excessive amounts of hype, and low levels of actual community participation tend to characterise most of these initiatives. Debate and critical thinking about these processes has largely been forced underground, since open, public critique is not favoured by governments or encouraged by government-funded agencies in receipt of community building dollars.

This conference aims to gather community leaders, activists, researchers, policy makers, social entrepreneurs and workers in community agencies who are interested in authentic community building, critiques of government sponsored community building programs and models, and alternative community building strategies which have a stronger emphasis on empowerment, devolution, subsidiarity and self-determination.

Papers, presentations and workshops have been invited which address one or more of the following symposium themes:

- analysis of the current 'community building' trend, its origins and philosophical underpinnings
- evaluation of actual practice, participation and outcomes
- use and misuse of concepts of social capital, participation, civil society
- the relationship between service delivery agencies and community building processes
- the relationship between local government and community building processes
- critiques of place management
- communities and institutions: whose capacity is being built?
- elaboration and refinement of 'civil society' vs 'managerial' approaches to community building
- comparative critique of indigenous and non-indigenous approaches to community building;

This Symposium is hosted by the Centre for Civil Society, a public policy and social innovation think tank. The Centre is a non-party organisation that welcomes participants from all social and political backgrounds in strengthening civil society and empowering people in families, communities, associations and small businesses.

The program will run from 9.00am till 5.00pm with a mix of key presentations, concurrent workshops, and two strategic plenaries. It will be oriented to ongoing work in shaping alternative community building strategies and approaches. Venue: Darebin Arts & Entertainment Centre, Melbourne  
<http://www.civilsociety.org.au>

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## 2007 NAB Volunteer Awards Nominations Now Open

The National Australia Bank Awards recognise the commitment of volunteers around Australia and reward the organisations who demonstrate best practice in their management of this workforce.

The NAB Volunteer Awards are now in their 10th year and are a partnership with Volunteering Australia. There are over \$200,000 in prizes, with State winners receiving \$10,000 and national winners \$20,000.

Nomination forms can be completed online or forms picked up from any National Australia Bank and posted to:

NAB Volunteer Awards Manager  
PO Box 784  
Milsons Point  
NSW 1565  
[www.nab.com.au/volunteering](http://www.nab.com.au/volunteering)  
1800 807 121

**Nominations close 8th June 2007**

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**Still Available!**  
**Inaugural Queensland Directory of Self Help and Support Groups**

Copies of our Self Help Queensland Directory of Self Help and Support Groups are still available for sale through the office. Updates are sent quarterly to all who purchase the Directory. Enquiries 07 3344 6919



## The Loneliness of Living Alone

Loneliness or aloneness is a problem that most widowed people have difficulty with as they endeavour to come to terms with the loss of their partner. Here are some suggestions given by a number of widows and widowers to assist with this problem. It can only be someone that has already "been there" who can "know" the intense loneliness of being alone in the midst of caring and supportive family and friends.

### Make your Home your Haven

Set your home up the way it suits **you**. Your home that is so much part of you should become your "haven" - your **own** place where you can be **yourself**. Take the time to arrange your home just the way you want it to be comfortable.

Invite friends into your home to join you for meals. Others who are in the same position will appreciate the company. It also gives you the opportunity to try your "culinary delights" and prepare meals again.

### Substitute Aimlessness with Supportive Activity

If you take the time to sit down and plan out your day's activities - to plan your week, your jobs and projects as well as your social calendar, you will find a great deal of satisfaction at the "end" of each day when you realize that you have achieved a great deal rather than just "existing".

### Maintain Close Ties with Family and Friends

We need the closeness of family and friends when we are grieving - people whom we love and trust. People who **know you** and will **allow you** to be **yourself** without the need to explain, or to have to be continually justifying your actions or reactions when you are coping with the loss of your loved one.

### Be Good to Yourself

Each person is a unique individual and will grieve in his or her own way. As such, each individual is responsible for their own selves. While there are many people who can and will help the widow or widower in their grieving, nobody should be forced to do that which they are not ready for. Every widowed person should be allowed to grieve in their own unique way. Each one should be encouraged to be responsible for

their own selves, both emotionally and physically. Part of the healing in the grieving process is to "be good to oneself" - "to really take care of one's self."

### Make use of the Benefits of your Church, Club or Support Group

There are many activities that are available to help those that have lost a partner. Seek out those that meet your own particular needs and make use of them. Those who are widowed need a "safe environment" where they can begin to build a new life again. Do not be slow in asking for help. We are all dependant - there are people who like to help. Allow others to help when you need it. There will come a time in your healing and growth in your grieving when you will be the one to offer someone else help when they have lost their partner. The saying "you help yourself when you are helping others" is true, but only when you are ready and feel comfortable in the helping of others.

As you go through this article take from it anything that will "work" for you and discard that which does not. These suggestions have helped many and it could be that you have others which could help widowed people learn to cope with the "loneliness of living alone".

(Source: Information supplied by a Widows and Widowers Support Group, QLD. Author/s unknown)

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## Extra 20,000 Australians to benefit from new changes to Continence Aids Assistance Scheme (CAAS)

From 1 July 2007, more people will be helped with the cost of purchasing continence aids. Under the new arrangements, people over 5yrs with permanent incontinence as a result of a neurological condition are eligible. The changes will approximately double the number of Australians who will benefit from the scheme, from around 20,000 to 40,000 people per year.

People who received CAAS but left the scheme after they turned 65 are eligible to reapply for funding from 1 July 2007. The previous requirement for people over 65 to be in employment will no longer apply. For more information contact the CAAS Helpline on 1300 366 455.



## Diary Dates

**4th - 7th May 2007: Manshine 2007 Mens Gathering.** Now in its 15th year, Manshine is well organised, professionally run, and rich with opportunities for men to replenish their masculine essence in a relaxed, safe and supportive way.

Contact Chris Johnson Ph: 0411 415 527

[www.mhwaq.org.au](http://www.mhwaq.org.au)

**Venue:** Ewen Maddock Dam, near Landsborough, behind Sunshine Coast, QLD

**11th May 2007: Breakfast to celebrate International Nurses' Day and International Day of the Midwife:** "Learning a thing or two from the bush about innovations in nursing and midwifery". Speaker is Katie Jefford, Director of Nursing at Goondiwindi Health Service.

**Ph:** QNC 07 3223 5140 or QNU 07 3840 1445

**Email:** [cbly@qnu.org.au](mailto:cbly@qnu.org.au)

**Venue:** Carlton Crest Hotel, Brisbane

**24th - 25th May 2007: Cerebral Palsy Australia 2007 National Conference: "Thinking Outside the Chair."** Innovation, Creativity and Collaboration. The Future of Disability Services. Guest Speakers: Phillip Adams, Dr Norman Swan, Marayke Jonkers, Ric Thompson.

**Email:** [info@iamevents.com.au](mailto:info@iamevents.com.au)

**URL:** [www.cp2007.iamevents.com.au](http://www.cp2007.iamevents.com.au)

**Venue:** Jupiters Casino, Gold Coast, QLD

**4th - 5th June 2007: Communities in Control Conference. "From Advocacy to Policy; Communities Driving Change."** Speakers includes High Court of Australia Judge The Honourable Justice Michael Kirby AC CMG; American social change trailblazer Angela Glover Blackwell; social forecaster Bernard Salt; revered green bans organiser Jack Munday AO; social capital guru Eva Cox AO; and many, many more.

**Ph:** 03 9320 6800

**Email:** [lisar@ourcommunity.com.au](mailto:lisar@ourcommunity.com.au)

**URL:** [www.ourcommunity.com.au](http://www.ourcommunity.com.au)

**Venue:** Moonee Ponds, Melbourne, VIC

**14th - 15th June 2007: Health in Difference Conference 2007 Changing Spaces, Changing Faces: 6th National LGBT Conference** - exploring change, new ideas on health, spirituality, emotional & psychologi-

cal lives, physical and of course sexual issues, legal rights, relationships, families, and parenting.

**Ph:** 07 3211 7178

**URL:** [www.healthindifference07.org.au](http://www.healthindifference07.org.au)

**Venue:** Rydges Conf Centre, Brisbane

**28th - 29th June 2007: Altering States, Creating Futures Conference: A Mental Health System for the 21st Century.** Presented by the Queensland Alliance of Mental Illness and Psychiatric Disability Groups

**URL:** [www.qldalliance.iamevents.com.au](http://www.qldalliance.iamevents.com.au)

**Venue:** Sofitel Hotel, Brisbane

**28th, 29th 30th June 2007: Sister's Inside 4th International Conference "Is Prison Obsolete?"** The Conference will address crucial issues relating to the criminalisation of women, their experience of prison and post release. Free to women who have been in prison.

**Ph :** 07 3844 5066

**URL:** [www.sistersinside.com.au](http://www.sistersinside.com.au)

**Venue:** Crown Plaza, Darwin, NT

**4th July - 7th July 2007: 18th Annual Australian Winter School on Alcohol and Other Drugs "Drugs, Lifestyles and Culture - Innovation and Evidence".**

**Phone:** 07 3834 0211

**Fax:** 07 3832 5625

**Email:** [winterschool@adfq.org](mailto:winterschool@adfq.org)

**URL:** [www.winterschool.info/](http://www.winterschool.info/)

**Venue:** Carlton Crest Hotel, Brisbane

**17th - 20th July 2007: International Feminist Summit - "Women of Ideas: Feminist Thinking for a New Era"** Organised by the Coalition for a Feminist Agenda and the Women's Studies Centre, James Cook University, and Townsville Women's Services.

**URL:** [www.feministagenda.org.au/Summit/summitIndex.html](http://www.feministagenda.org.au/Summit/summitIndex.html)

**Venue:** Townsville, QLD

**30th - 31st July 2007: Health Care Reform Summit "Reform in the Australian Health Sector".** Conveyned by the Australian Health Care Reform Alliance.

**URL:** [www.healthreform.org.au](http://www.healthreform.org.au)

**Venue:** Old Parliament House, Canberra

If your group would like to advertise an event on this page (free) please contact Trish at the Self Help Queensland office Ph 07 3344 6919 or email [selfhelp@gil.com.au](mailto:selfhelp@gil.com.au)