

### Newsletter September Quarter Issue 3. 2009



Self Help Queensland Inc, Sunnybank Community Hall, 121 Lister Street (PO Box 353) SUNNYBANK 4109

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

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 all

I recently read the recent A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission – June 2009 <a href="http://www.health.gov.au/internet/main/publishing.nsf/Content/nhhrc-report">http://www.health.gov.au/internet/main/publishing.nsf/Content/nhhrc-report</a>

Here are some of the recommendations that would particularly affect the self help sector:

We recommend the development of accessible information on the health of local communities. This information should take a broad view of the factors contributing to healthy communities, including the 'wellness footprint' of communities and issues such as urban planning, public transport, community connectedness, and a sustainable environment....(I think this means prepare to be counted)

We support strategies that help people take greater personal responsibility for improving their health through policies that 'make healthy choices easy choices'. This includes individual and collective action to improve health by people, families, communities, health professionals, health (Continued on Page 3)



### Please Celebrate With Us!

A warm welcome is extended to all members and friends to join us.

# 2009 AGM & Thank you to Sue Smyllie

Sue is stepping down after 12 years at SHQ. Anyone who knows Sue will appreciate her commitment to the Self Help Sector, to democratic processes, openness and transparency, ongoing dialogue, trust in relationships and encouragement of leadership in others.

With Sue's vision, wisdom, gentle guidance and great sense of humour, SHQ has evolved from a small relatively unknown organisation to a well respected peak body for the Sector in Queensland.

It's a fair way off, but please put this date in your diary now!

### Wednesday 4th November 2009 at 9.30am

Join us for a light lunch, help say thank you to Sue, celebrate with us, network with other groups, have fun and elect new people to carry on the good work!

**RSVP** to SHQ office by Mon 2nd Nov **Venue:** Sunnybank Sub Branch, RSL, Gager St Sunnybank (next door to SHQ)

### **Self Help Queensland Management Committee Members**

President Sue Smyllie
Secretary Thea Biesheuvel
Kathleen Zarubin

Members Alan Noller

Joe Soda Bob Wyborn

#### **Committee Meetings**

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

#### **Project Officer**

Trish Fallon

#### **Mental Health Project Officer**

Diana East

#### **Administration Officer**

Janice Nankivell

#### 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
 www.selfhelpqld.org.au

### Self Help Leaders Online Social Network

**URL:** www.selfhelpleaders.ning.com

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.





#### Suicide Call Back Service 1300 659 467

#### 10am to 8.30pm seven days a week

The Suicide Call Back Service is a free, nationwide telephone service that offers **short to medium term support** for people at risk of suicide, their carers, and those bereaved by suicide.

The Suicide Call Back Service supports callers (18 years of age +) through a series of six 50-minute telephone counselling sessions, scheduled to suit you.

Professional counsellors, with specialist skills in working with suicide-related issues, will assist you in working through difficult emotions.

Parents of youth at risk are encouraged to call for support. It is not a Crisis Line.

(For 24 hr Suicide and Crisis Counselling Queensland wide call 1300 363 622)

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insurers, employers and governments. Further investigation and development of such strategies should form part of NHP&PA work on the Healthy Australia 2020 Goals, targeting cross portfolio and cross industry action....(I think this means prepare to be trained)

We urge all relevant groups (including health services, health professionals, non-government organisations, media, private health insurers, food manufacturers and retailers, employers and governments) to provide access to evidence-based, consumer-friendly information that supports people in making healthy choices and in better understanding and making decisions about their use of health services.....(I think this means prepare to be assessed)

While this is just a report at the moment and not policy there are a number of other recommendations which will affect us all. I urge you to have a look at them and comment if you agree or disagree. My concern is not necessarily with the statements but with the way in which these will be interpreted. Past experience tells me it is easier to count things than experience things and further decisions will be based on the information collected.

For a more detailed look at this issue you may like to venture into the highly academic world of the Cochran Review <a href="http://www.joannabriggs.edu.au/carma/about.html">http://www.joannabriggs.edu.au/carma/about.html</a>

There may be scope for a better way of interacting with government if the National compact acts as good as it sounds. The National Compact will be an agreement between the Government and representatives of the third Sector. It establishes a standard to which the government and the sector will be accountable. It states the principles or values that need to underpin every aspect of the relationship between these two parties. Again I would urge you to have a look at it and decided what you think and let people know.

http://www.qcoss.org.au/upload/6085 Final%20draft%20Compact%20Principl es.pdf

I particularly like the value placed on diversity and the right to advocate without losing government funding. Againbe prepared to be counted, trained and assessed as the draft says:-

"The government and the sector will work together over the next 12 months to establish governance and implementation arrangements for the Compact. In the next phase of Compact development a monitoring and reporting system will be developed that could include regular reporting to Ministers on the progress of Compact actions and initiatives and the development of codes or action plans relating to priorities that affect the sector and the government."

The self help philosophy works because people build from their own needs in the way they want and they learn along the way then they move beyond their own needs to the common good and share their learning with others. There is no policy that can make this happen, they can't be imposed and won't work if they are. They are the greenshoots of wellbeing and need to be nurtured not harnessed. The capacity exists - it is the expression of it which is hampered by a lack of opportunity or a diversion to the needs of an increasingly complex planning, consultation and accountability process.

SHQ has direct knowledge of and contact with over 700 self help groups in the health and welfare sectors and we know there are many more out there. A conservative estimate could therefore claim over 2000 groups in Queensland alone. Groups can have as many as 1000 participants and as few as 3 – if we estimate a conservative average of 20 / group. Potentially over 40,000 people in Queensland are members of self help groups.

Each group member has social and economic networks. The ability to work, to support families, (Continued on Page 4)

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to participate in society etc has far reaching consequences. Self help groups ameliorate these effects. If 40,000 people in Queensland are directly involved in a self help group, up to 10% of the Queensland population or over 840,000 people, may be positively affected by the existence of self help groups. Nationally the figure would be highly significant.

By any measure, this diverse and committed population of people, active in their own well being represent not only a significant contribution to the community and the health sector but also a potentially powerful political force. Self help groups and their impacts represent savings to the health and community public service sector alone of many millions of dollars.

The great strength of this sector is its diversity. The greatest weakness it has is the lack of sufficient investment in a communication, networking and support infrastructure. SHQ supplies a service which applies the fundamental principles of the self help philosophy across the sector. Our lack of critical mass decreases the benefits which could be achieved on a community scale. At SHQ we have been able to see the outcomes of sufficient investment through the Mercury Rising Project.

What are my recommendations for the future?

- 1. A freehold "Self Help House" with shared meeting rooms, 'hot desk' type offices and computers, copiers and storage spaces so that groups that only need this infrastructure a few hours a week can benefit from economies of scale and won't be turfed out when the government changes.
- A better funded SHQ which has the capacity to really serve the State. I think a critical mass is perpetual funding to support 3 FTE community development workers (one based in Townsville) and admin support, a ratio of wages to funding of

- at least 50:50 and costs such as insurance and auditing external to the main agreement. This is so we don't end up having to reduce staff hours so we can pay our insurance bills.
- 3. A research program which investigates the social and economic impact of the self help sector.

Over the 12 years I have been involved with the self help sector my great sadness has been that we remain unrecognised and underfunded because we 'don't provide services'. Self help groups provide much more.....an opportunity for people to become themselves again, to share their knowledge and experience and to contribute to society. My greatest joy has been the rich diversity of the sector and the grace, warmth and courage of the people I've met.

Sue

#### Heard of the Policy Bank?

There is no need for community organisations to re-invent the wheel — just visit the Policy Bank instead.

The Policy Bank is a great place to find free policies and procedures for non profit groups. There are close to 100 policies to choose from a range of policy categories. It's easy! There are just a few very simple steps to follow.

- **1** Look through the list to see which policies/procedures your group needs.
- **2** Download the policy you want click on the name save it to your computer.
- **3** Adapt the policy to suit group needs:
- Modify or delete irrelevant clauses
- If the policy refers to a Human Resources Department and your group doesn't have one, then who is responsible?
- Substitute "Management Committee" for "Board" if relevant.
- 4 Adopt new policy at next meeting.

ww.ourcommunity.com.au/boards/boards\_article.jsp?articleId=1453

(Source: Our Community Matters May 2009)

#### Genetic Matters

by Kim Summers PhD

#### The butler did it!

Numerous detective stories and family sagas over the years have been based on the idea that individuals and their family members can be identified from a blood sample. In the early days, a key component of the story was to "type the blood". This meant testing for certain proteins found in red blood cells which varied from person to person, variation which was inherited from the parents. Possible test results (genotypes) were A, B, AB or O. Often the plot revolved around the fact that two O parents could not have an A, B or AB child, or that an O person could not leave A, B or AB blood at the scene of the crime. The genetics of the ABO system is simple (for an explanation, see:

http://manual.transfusion.com.au/Transfusion-Medicine-Science/Blood-Groups-and-Antibodies/Inheritance.aspx). Now the equally simple genetics of DNA variants has allowed much more extensive testing of inherited variation and genetic "fingerprinting" for victims and suspects of crime.

DNA is our genetic blueprint, the set of recipes which provide instructions to cells so that they can perform their duties in the body. All cells have the same DNA, but different cell types use different sets of instructions to carry out different functions: for example to be muscle, nerve, blood or liver cells. Imagine a set of 23 books with recipes for Italian, Chinese, Moroccan and all other possible kinds of food, arranged in no particular order and interspersed with instructions about where and when to start and stop, advertisements, blank pages, repeated sections and incomplete recipes and other misleading information. Since particular cell types only needs a subset of the recipes, there has to be a mechanism to allow them to sort through all the pages to find only those recipes, and to make entrees for the beginning of the meal and sweets

for the end. That's how each cell or cell type is able to be different from the others and make up the complex set of tissues and organs that is a human being, a fly, a tree fern or a bacterium.

If there is a printing flaw like a blob of ink in a recipe book, it might cause the food to taste awful (if it covered an important measurement or ingredient and made you use sugar instead of salt), or it might cover a word which is not really necessary to the recipe, or is in an advertisement and doesn't have much impact. In the same way, our DNA can have alterations which cause devastating genetic diseases, or which go unnoticed through the lifetime of the individual. The DNA recipes are made of four letters: A, C, G and T, and there are about 3,000,000000 (3 billion) of these letters making up about 25,000 different recipes in a single copy of our DNA. Changing any one of these letters for another of the four, or deleting one or more out of the DNA, is called a mutation. No two people are the same: overall we probably have one change every 1,000 letters. That is the basis for DNA fingerprinting, parent testing and other uses of the DNA information.

Almost all cells have two copies of the 23 recipe books (chromosomes). So for each letter in the DNA of one copy there is a matching letter in the other copy. Mostly the two copies will have the same letter at that place, but sometimes they won't. So one copy might have an A and the other a G. At that point in the DNA the person would have two possibilities, depending on which copy was consulted. The person would be AG, called a heterozygote. Other people would have A or G on both copies (AA or GG), called a homozygote. Since one copy of the DNA is transmitted from parent to offspring, an AA parent can only transmit an A, a GG parent can only transmit a G, but an AG parent can transmit either an A or a G with equal chance. So all the children of two AA parents will also be AA, all the children of one AA and one GG parent will be AG, but the (Continued on Page 6)

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children of two AG parents could be AA, AG or GG depending on which DNA variant they inherit.

Now imagine doing a similar test for 2 different letters. Let's say the possibilities at the first are A or G and at the second are C or T. Then people could be AA CC, AA TT, AA CT, GG CT, AG CC, AG TT, or AG CT. Two people who are both AA CC can only have AA CC children, an AA CC and a GG TT can only have AG CT children, but other combinations can give a range of offspring DNA combinations. If you add a third set of letters, the range of combinations in total becomes even greater. This is the basis of DNA fingerprinting, because the more different letter pairs you check, the more possibilities there are for each person, so the greater the variation in the population. If you do enough tests, each person will have a unique combination of DNA letters. However, the range for children of each couple is still limited by their parents' own combinations, and the more tests that are done, the more likely that the parents and their offspring will have unique patterns. This is the basis for testing paternity and relatedness.

A key aspect of DNA testing is that people can be ruled out without any doubt, because it is not possible to change a DNA letter: an AA person will always be AA in all cells, so could not have a hair sample which is GG. But there are likely to be lots of people who are AA, so seeing an AA result doesn't mean that the AA suspect has to be guilty, it just increases the chance. This is why, when a DNA test result is received, it will usually give a probability that the hair found at the crime scene comes from the same person as the suspect's blood sample. This probability (chance) is calculated from the population frequency of the DNA variants (how many people in the population have the different genotypes for each set of letters tested). The more DNA letters tested, the lower the likelihood that two people will have the same combination by

chance. With modern DNA testing, probabilities of 1 in a million of two people having the same combination are routinely given, and almost all suspects can be ruled out completely because they have the wrong DNA fingerprint. For someone with the matching fingerprint the calculated chance of two people being identical may determine whether he or she is found guilty.

When it comes to relationship testing, the same applies. It is possible to rule out a potential parent because there is no shared DNA pattern between parent and child, but not possible to say that one candidate is definitely the parent, because there is a small possibility of two people being identical, depending on the number of DNA letter sets tested. A probability will be issued based on the same calculation and taking into account the genetic result for the other parent or relatives.

There are a couple of exceptions to the rule that each person has a unique DNA pattern which doesn't change through life, and these have been exploited by the writers of fiction. One case is identical twins. These are two people who came from the same fertilized egg and so share the same DNA fingerprint pattern. There are a few people who are genetic mosaics, with different DNA fingerprints in different cells. This can arise through alterations in the DNA early in development, giving two different cell types. Occasionally non-identical twins (who are only as similar as non-twin siblings) share a blood supply in the womb and can end up with some of each other's blood and hence DNA type.

People who have had successful transfusions or transplants always have a residue of the donor's cells amongst their own, or even a whole tissue made up of cells from someone else. These people can also give confusing results for DNA testing. And criminals are inventive in discovering ways to minimize, destroy or change the DNA they leave behind. Most of these scenarios have been used in fiction since the (Continued on Page 7)

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concept of DNA testing became well known.

In spite of these exceptions, DNA testing has had some remarkable successes. In the famous first case using DNA in the United Kingdom, a suspect persuaded a friend to give a blood sample in his name. His DNA was subsequently tested again and found to match the crime sample.

The Innocence Project is an initiative of student lawyers all over the world, which reopens old cases for forensic testing using the new technologies. A number of people who were imprisoned for years have been freed following DNA testing which showed they were not at the scene of the crime.

A group of geneticists in North America have been helping Argentinean authorities to reunite children born in captivity to subsequently executed parents with their grandparents. A colleague in Edinburgh uses DNA testing to identify animals and birds illegally imported into the country and is developing the information required to DNA test dog samples, so that a suspect might now be identified on the basis of the hair of his dog left behind at the crime scene. Perhaps in future, the catch phrase won't be "The butler did it", but "The beagle did it"!

Kim is a Senior Scientist at the Roslin Institute, University of Edinburgh and a member of the School of Molecular and Microbial Sciences at UQ. Kim is also a valued past member of the SHQ management committee.

#### Telegram from George Bernard Shaw inviting Winston Churchill to the opening night of Pygmalion:

"Am reserving two tickets for you for my premiere. Come and bring a friend — if you have one."

#### Churchill wired back:

"Impossible to be present for the first performance. Will attend the second if there is one."



# SHQ Directory Update

As you are probably aware, SHQ is in the process of developing a new, free, online searchable directory of self help and support groups.

While it is taking longer than we would like, it is progressing well and should be worth the wait. We are keen to get it right!

A feature of the new website will be a series of 'fact sheets' we have developed in response to specific requests for information over the years.

We will be sending a form to your group soon. It will be able to be filled out online, emailed, faxed or posted back. It will contain specific questions designed to deliver accurate information to people looking for a particular group. Hopefully this will contribute to more appropriate referrals to groups - with less drain on group resources stemming from totally unrelated enquiries.

# Volunteer Grants Open Now Quick and Easy to Apply!

Funding of between \$1000 and \$5000 is available now to non-profit groups to buy practical and tangible small equipment items or to assist with re-imbursement of volunteer's fuel costs.

The application form and guidelines are available from the Department of Families, Housing Community Services and Indigenous Affairs (FaHcsia) website at www.fahcsia.gov.au or phone the toll free hotline on 1800 183 374. Applications can be made online. There is a very quick and easy method of applying. Alternatively a paper form can be requested.

Closing date 5pm 25th September 2009



#### **Invitation**

to

### Retina Australia National Congress Brisbane 2009

#### 23rd to 25th October

The Retina Australia National congress will give you the opportunity to engage with researchers of international renown. You will hear all the latest news in retinal research as well as on topics of interest to the visually impaired community. All this will be in an atmosphere of fun and learning and great opportunities to socialise.

The program of speakers (researchers) is wide-ranging, and the opportunity to hear first-hand from the leaders of the Inherited Retinal Disease Register and DNA Bank is an opportunity which should not be missed.

Keynote speaker Professor Elizabeth Racokzy, Research Director, Centre for Opthamology and Visual Science, University of WA said recently "after taking my gene therapy research targeting AMD to Human trials I am back to focus on Retinitis Pigmentosa again". She also spoke about the future, saying, "I am learning new computational techniques that can assist us to design new methods that might offer general treatment strategies for RP. It is a very exciting new direction!"

#### Register online at:

www.retinagld.org.au

#### For further information contact:

Retina Australia (Queensland)

Ph: (07) 300 300 65 Fax: (07) 300 300 65 Toll Free: 1800 000 999

**Venue:** Royal on the Park

Cnr Alice and Albert Streets, Brisbane



Does it Run in the Family?

#### **Take Charge of Your Health**

# Customise family health history materials for your family, organisation and community!

Thanks to the Genetic Alliance for their development of a family health history tool which is **FREE**, adaptable, and available to be used by people anywhere in the world.

'This tool helps you create personalized booklets to start conversations about health in your family and community.

The sooner we understand the link between our family's health and our own, the sooner we can make changes and take steps to live longer, healthier lives. A peek into the past can reveal a lot about your future.'

#### www.familyhealthhistory.org

(Source: Genetic Alliance Bulletin 25 Aug 2009)

Said one oyster to a neighbouring oyster, "I have a very great pain within me. It is heavy and round and I am in distress."

And the other oyster replied with haughty complacence, "Praise be to the heavens and to the sea, I have no pain within me. I am well and whole both within and without."

At that moment a crab was passing by and heard the two oysters, and he said to the one who was well and whole both within and without, "Yes, you are well and whole; but the pain that your neighbour bears is a pearl of exceeding beauty."

Kahlil Gibran Lebanese Novelist, Essayist, Poet, Artist

1883 - 1931

#### Beaudesert Support Group Welcomes Anyone Affected by Cancer

Beaudesert Cancer Support Group is supported by the Queensland Cancer Council and welcomes anyone who has been affected by a cancer diagnosis – patients, carers, family and friends. The group meets on the fourth Thursday of each month – January through to November at Blue Care, 7 Duckett St Beaudesert. 10am – 12 noon.

### A cancer support group can be useful at all stages of cancer:

- Coping with a cancer diagnosis and treatment
- Coping with living with cancer
- Adaptation to life after cancer

#### Cancer support groups offer:

- Shared experiences and the freedom to speak openly
- Reinforcement of the normalcy of reactions and feelings
- Development of new friendships and socialisation, often at a time of isolation
- Opportunities to learn from each other
- Opportunities for cancer education from professionals
- Support, encouragement and hope
- A sense of belonging

#### Meets on Fourth Thursday of Each Month

For more information, please contact Carmel O'Neill, Community Health Nurse

64 Tina Street, BEAUDESERT QLD 4285

"I often quote myself. It adds spice to my conversation."

George Bernard Shaw British Novelist, Playwright, Theatre and Music Critic, Satirist Nobel Prize for Literature 1925 1856 - 1950

#### Beaudesert Carers' Support Group Open to all Carers

#### Who are Carers?

Carers are usually but not always, family members who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged.

Carers can be parents, partners, brothers, sisters, friends or children.

Some carers are eligible for government benefits while others are employed or have a private income.

They all provide unpaid, informal care.

A Carers' Support Group is a chance for you as a carer to:

- Take some time out for yourself
- Share in the support that comes from chatting with others doing the same job
- Acquire information and skills that may help in your caring role
- Have a say about supports or services that you need

### Meets on Third Wednesday of Each month

**Venue:** Community Hall at Beaudesert Garden Estate

339-347 Brisbane St Beaudesert

Time: 10am to 12noon

For more information about the Beaudesert Group call Carmel O'Neill at Beaudesert Community Health on 07 5541 9231

#### Go Green - Read the Screen!

Are you willing to receive this newsletter by email rather than post? It would be a big cost saving to SHQ as well as the environment.

We are still happy to send it by post to small groups or individuals who do not have their own computer. Please let us know at 07 3344 6919 or email self-help@gil.com.au If you no longer wish to receive the newsletter we would appreciate hearing from you also.





# The Queensland Police Service (QPS) is committed to ensuring policing services are accessible to all members of the community.

Improved liaison with the Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) communities will assist in the development of partnerships as well as an awareness and understanding of issues impacting on LGBTI communities.

The QPS initiated the LGBTI project in 1997 at a metropolitan level. In 2001 the QPS expanded the LGBTI Program state wide. Police and staff member liaison officers have been trained to assist LGBTI communities. This role is voluntary and performed in conjunction with their normal roles and responsibilities. The purpose of this program is to provide a professional, non-discriminatory, accessible policing service to members of the LGBTI communities.

The LGBTI liaison officers are situated throughout the state. An up-to-date contact list for liaison officers can be found on the QPS Internet site <a href="http://www.police.qld.gov.au/programs/community/lgbti/">http://www.police.qld.gov.au/programs/community/lgbti/</a> under "Contact Officers". This network provides an important link between the QPS and the LGBTI communities.

Each police region has an important role in the establishment and maintenance of a network of regional and district liaison officers, provide support to the LGBTI communities, formulation of LGBTI community consultative committees and continued liaison within the community and community service providers.

The State Coordinator of the LGBTI program is located at the QPS, Community

Safety & Crime Prevention Branch and can be contacted on 3234 2111.

The QPS is committed to high standards of service delivery for clients and members of the LGBTI communities who should expect to be treated with dignity and respect regardless of their gender preferences.

I would invite you to visit the QPS LGBTI Internet site and should you have further inquiries please contact a liaison officer in your area or telephone:

#### Senior Sergeant Monica O'Mara State Coordinator 07 3234 2111

http://www.police.qld.gov.au/programs/community/lgbti/

## men's health & wellbeing

#### **Invitation**

to

### Men Who Want to Unleash Their Potential!

Manhood 2009 Men's Gathering

Friday 13th (6pm) to Sunday 15th (3pm) November 2009

Great workshops, abundant food, inspired company

Minimum age 16. Men only. Alcohol, drug and pet free

**Venue:** Camp Bornhoffen (near Nerang in the Gold Coast hinterland). Contact: Ph: Brendan on 0413 856 320 www.mhwaq.org.au

### New on the ATO Website! - about Gift Funds

This web page answers frequently asked questions about gift funds including who must have a gift fund and how to set up, maintain and wind up a gift fund. http://www.ato.gov.au/distributor.asp? doc=/content/Content/32068.htm



#### New!

Much Needed Pain Support Group Started In Queensland

### Australian Pain Management Association (APMA)

Many people are livina with chronic/persistent pain, managing the best they can on their own at home. Our Brisbane based Australian Pain Management Association was formed by a group of individuals who were doing just this. Wishing for a better way, we have formed APMA to provide peer support, information, advice and advocacy. "Persistent pain" and "chronic pain" are terms which have the same medical meaning. However, persistent pain is the term of choice used overseas to describe ongoing pain, partly as a response to the negative stigma associated with the label 'chronic pain'.

#### What is Persistent Pain?

Persistent pain is pain that persists beyond the usual healing time, usually three months. Persistent pain covers 200 conditions and is felt as severe to disabling which interferes with daily functioning. It impacts physically, psychologically and environmentally. In 2009 there is no medical cure.

The combination of central nervous system physiological changes, psychological and environmental changes have been characterized as a 'disease entity' - in other words, the experience and process of chronic pain becomes the principal problem. For the large majority of people with long term chronic pain, all avenues of treatment of the underlying cause(s) have been exhausted, or have proven ineffective. The pain itself, and associated neuroplasticity changes in the nervous system, psychological seguelae and environmental alterations have become self sustaining resulting in persistent pain.

### What is the impact of persistent pain on individuals?

The impact of persistent pain is felt every day, in all daily functions. It severely restricts an individual's ability to participate in family, social and workplace environments and their overall quality of life.

Sufferers experience significant economic disadvantage as a result of persistent pain. The burden in terms of suffering and lifestyle impacts attributed to persistent pain is high. In addition to the daily pain, common adverse physical and psychological effects of chronic pain include:

- Insomnia
- adverse drug effects such as nausea, dizziness, loss of concentration
- disability, difficulty undertaking home duties, social and leisure activities
- loss of employment, underemployment, interference with work
- family and relationship disruption
- psychological distress eg anxiety and depression
- physical deconditioning eg muscle wasting, joint stiffening
- premature death;
- suicide

### Pain related disability is a real and common feature of persistent pain.

In a major recent Australian study the prevalence and causes of chronic pain were:

- 23% of the population sample experienced chronic pain and more than 25% of those had pain related disability
- 44%, chronic pain resulted from injury
- 14% attributed their pain to workplace factors

The greater levels of pain-related disability were associated with higher

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health care expenses, such as high levels of medication and health care use, including multiple doctor and allied health professional visits, x-rays and hospital admissions.

#### How big is the problem?

It has been estimated that in Australia there are 3.2 million individuals with persistent pain. As there are no Queensland data available, an assumption of similar rates in Queensland (representing 20% of the Australian population) would suggest that at least 640,000 individuals suffer chronic pain. Overall the **prevalence of chronic** pain is higher in women (20.0%) than in men (17.1%), and is more prevalent amongst age groups in excess of 50 years. As the population is aging rapidly, the prevalence and cost of chronic pain is projected to increase markedly. The table below provides a snapshot of incidence of chronic pain by age and gender.

### Summary of Baseline Prevalence Rates by Age and Gender (%)

The vulnerable and more marginalized groups in society tend to be over-

Age group	Males	Females
15 - 29	10.1	12.4
30 - 44	16.2	15.1
45 - 59	22.0	26.8
60 - 74	23.4	28.1
75 - 90+	19.3	24.2

represented in persistent pain statistics. People from rural and remote areas, and from culturally and linguistically diverse backgrounds, are especially vulnerable to being left out of medical services and to having more significantly interrupted working lives and lower quality of life. Sufferers from ATSI backgrounds are amongst the most vulnerable.

Chronic pain is not listed as a National Health Priority Area (NHPA) despite its widespread prevalence in the Australian community and burden of disease.

There is a greater incidence of chronic pain in Australia than a number of current National Health Priority Areas including:

- Asthma
- Mental and behavioural disorders
- Diabetes
- Neoplasms (benign, pre-malignant, malignant tumors)

Chronic pain needs to be given the status of a NHPA which fairly represents its prevalence and burden of disease in the Australian community. The Burden of Disease is a term used to describe the loss of quality of life that is the daily pain, premature death and loss of life quality that result from chronic pain.

The direct healthcare costs of medical treatment for individuals with chronic pain are high. Patients see medical specialists, GPs, psychologists, physiotherapists etc., and incur fees for each visit, often incurring costs for ineffective treatments.

The one dimensional medical treatment of chronic pain is inferior and more costly than the model of multidimensional assessment and treatment with co-ordinated treatment plans.

Multidisciplinary Pain Centres (MPCs) need to be appropriately funded to assess and treat the numbers of individuals in pain requiring their services. Because of the complexity of chronic pain problems, MPC's have been developed in major teaching hospitals throughout Australia. Such centres harness the talents of specialist medical and allied health professionals to assess the multidimensional aspects of chronic pain and to formulate co-ordinated treatment programs aimed at managing pain including rehabilitation and improving functional outcomes.

However, the average waiting time for patients to access multi-disciplinary pain centres is in excess of 6 months and, anecdotally, is much higher in Queensland – between 10 and 18 months.

(Continued on Page 13)

(Continued from Page 12)

#### How APMA can help?

#### **Our Mission**

To enhance the wellbeing of all Australians living with persistent pain through supported self efficacy.

#### **Our Vision**

Pain relief is a human right and achievable in the 21st Century. All Australians living with persistent pain or in caring roles are entitled to life quality such as:

- Respectful and knowledgeable societal attitudes toward persistent pain.
- Safe high quality healthcare.
- Empowerment to manage own care.
- Social and workplace advocacy.
- Education and training to develop the skill set needed to best manage ongoing pain.

#### **Our Objectives**

- Social networking and peer support
- Best practice persistent pain information and advice
- Information and training for community groups supporting those living with chronic pain
- Persistent pain personal development courses – a.c.t.w.e.l.l.
- Social and activity based opportunities
- Workplace awareness and supportive workplace practices
- Influence government, employer bodies and others about the needs of affected individuals and their families to facilitate positive attitudes supporting health and community resources being deployed to further life quality for affected individuals

#### **Our Activities**

APMA seeks to provide specialised community support such as:

- Reliable, current and accessible information about persistent pain management
- Continuing community education for

developing and maintaining healthy lifestyles for people with persistent pain

- Peer support
- Ongoing social activity
- Supporting persistent pain based research by quantifying the demand of persistent pain issues
- Lobbying government/s for improved health services affordable safe and effective treatment options

#### How you can help?

It is only with the assistance of other self help groups that APMA will be able to build a representative Association with a strong community voice.

- Become a member and encourage others to become members.
- Challenge discriminatory attitudes about people with persistent pain in your community.
- Direct individuals with persistent pain and their carers and families to APMA for information or support.
- Invite APMA to come and speak to your staff or client base.

For further information or to contact APMA:

Elizabeth (Lil) Carrigan (07) 3391 6629 Annette Rijnbout (07) 3359 2275

Email secretary.apma@bigpond.com www.painmanagement.org.au/

### **Gastric Bypass Surgery V Electrical Implant Device for Type 2 Diabetes?**

Some people with poorly controlled Type 2 Diabetes turn to gastric bypass surgery to lose weight. But an implanted device may do the job much less invasively, sending electric signals to make the person feel full.

Volunteers who got the Tantalus System lost an average of 5 kg and lowered their blood sugar enough to cut the risk of many complications by 40% It will be widely available in 5 years.

(Source: 'New Scientist' June 2009)



#### Ten Facts About Persistent Pain in the Australian community

- 1. 3.2 million individuals with persistent pain.
- 2. There is no cure.
- 3. Persistent pain is NOT listed as a Na tional Health Priority Area (NHPA)
- 4. Persistent pain carries a greater burden of disease than diabetes and asthma.
- 5. There is a greater incidence of chronic pain than:
  - a. Asthma
  - b. Mental & behavioural disorders
  - c. Diabetes
  - d. Non-malignant & malignant tumours
  - e. Hearing loss
- 6. 40% of individuals with persistent pain also suffer depression with high levels of psychological distress.
- 7. 25% of individuals with persistent pain also suffer a pain related disability.
- 8. Individually the burden of disease was \$10,847 in 2007
- 9. The economic costs of persistent pain to the Australian economy was \$34 billion in 2007
- 10. Costs to workplaces was \$5.1 billion annually, 2007

#### References:

- 1. Application for Specialty Recognition, Faculty of Pain Medicine to the Australian Medical Council, 2003
- 2. The High Price of Pain: The Economic Impact of Persistent Pain in Australia, 2007

"Muddy water, let stand, becomes clear."

#### Lao Tzu

Chinese Teacher and Philosopher Lived 25 hundred years ago - dates of birth and death disputed.

#### 'Livewire Siblings'

Livewire Siblings is a free, safe and supportive online community for young people (aged over 10 and under 21) who have a brother or sister living with a serious illness, chronic health condition or disability. It is a place for them to meet other siblings, share experiences with people who understand what they are going through, and gain the skills and knowledge to help them feel more in control of their situation.

Many families struggle to cope with a child living with a serious illness or disability. The brothers and sisters of young people living with a serious illness or disability face unique teenage challenges. These siblings suffer a heavy emotional burden - they experience feelings of isolation from the rest of their family and their peers; guilt, confusion, anger, jealousy and often receive less parental attention than their ill siblings.

Livewire Siblings aims to facilitate connection, empathy and understanding between siblings who are experiencing similar situations. Young people can:

- Chat online and meet other siblings who understand what they are going through
- Create a blog about themselves or stuff they are interested in
- Enter competitions and win awesome prizes
- Read content and information created just for them
- Check out the latest music and games
- Post in forums and have their say!

Chat hosts and moderators trained in adolescent health are online 7 days a week to ensure that Livewire remains a supportive and fun place. Livewire works with the Australian Federal Police to ensure members remain safe while engaging with the community.

www.livewire.org.au/siblings

(Subsidiary of the Starlight Children's Foundation)

(Source: Mackay Autism SG Newsletter No 9, '09)





### NPS Medicine Name Finder A Free Tool for Consumers!

Knowing the active ingredient in your medicine can be critical to avoiding accidentally taking more medicine than you need. The active ingredient in a medicine is what provides the therapeutic effect, i.e. what makes the medicine work in the body. Most medicines are known by the brand name rather than the active ingredient, and can be marketed under several different brand names.

Many people identify their medicines by colour and shape, but if you switch brands and the medicine doesn't look exactly the same, you could mistakenly think it's something different. By not identifying the active ingredient you might accidentally end up taking a double dose or not enough of it.

To help people quickly identify the active ingredient in prescription medicines, NPS has developed the NPS Medicine Name Finder<a href="http://www.nps.org.au/consumers/tools\_\_and\_\_tips/medicine\_name\_finder">http://www.nps.org.au/consumers/tools\_\_and\_\_tips/medicine\_name\_finder</a>.

When a PBS-listed medicine is entered into the online tool, the active ingredient name appears, and when the active ingredient is entered its brand names appear. People are then prompted to record their medicine details on a downloadable Medicines List<a href="http://www.nps.org.au/consumers/tools\_and\_tips/medicines\_list">http://www.nps.org.au/consumers/tools\_and\_tips/medicines\_list</a> or print the information. A link is also provided to the Consumer Medicine Information <a href="http://www.nps.org.au/search\_by\_medicine\_name">http://www.nps.org.au/search\_by\_medicine\_name</a> (CMI) leaflet which contains more details about the medicine.

NPS Medicines Lists and the NPS Medicine Name Finder are available to download for free at www.nps.org.au/activeingredient>

### Male Reproductive Health Fact Sheets Available Free

Fact sheets are produced by Andrology Australia (Australian Centre of Excellence in Male Reproductive Health) to provide answers to questions on specific issues in male reproductive health.

Dowload, print or view any of the following fact sheets from the A A website:

- Osteoporosis
- Gynaecomastia
- Male pattern hair loss
- Blood in Semen
- Penis Problems
- Erectile Dysfunction
- PSA Test
- Problems of the Testes
- Testosterone Deficiency
- Undescended Testes
- Peyronie's Disease
- Prostate Enlargement (BPH)
- Prostatitis
- Sexual Difficulties
- Klinefelter's Syndrome
- Male Infertility
- Prostate Cancer
- Psychosocial Issues
- Testicular Cancer
- Testicular Self-examination
- Understanding Vasectomy

Information from the above fact sheets has been translated into 12 languages. Compiled into "A User's Guide: What Every Man Needs to Know", it is also available from the website in the following languages:

Arabic Bosnian Chinese
Dari Farsi Greek
Italian Khmer Korean
Serbian Turkish Vietnamese

Ph: 1300 303 878

Email: info@andrologyaustralia.org URL: www.andrologyaustralia.org

"Take rest; a field that has rested gives a beautiful crop."

Publius Ovidius Naso Ovid Italian Poet 43BC - AD17



#### Queensland Police Develop Online Resource Package for Survivors of Adult Sexual Abuse

The Queensland Police Service (QPS) acknowledges that many survivors of rape and sexual assault have reasons for not officially reporting the crime or not wanting to go through the court process. Recently detectives from the Cold Case and Serial Sex Crime Team, State Crime Operations Command, Brisbane developed an online resource package for survivors of adult sexual assault.

There are many myths and untruths about rape and sexual assault that contribute to the difficulty in survivors speaking out about their experience. It is important for survivors to understand that they have options. Research by the Australian Institute of Criminology in 2003 identified a number of personal and Justice system barriers to reporting rape and sexual assault including:

#### **Personal barriers:**

- perceptions on seriousness
- shame
- embarrassment
- fear reprisal
- self blame
- protect offender
- protect an existing relationship
- protect children

#### **Justice System barriers:**

- inaction by Police
- fear of not being believed
- fear of hostile treatment by Police
- fear of hostile treatment by justice system
- fear of legal processes
- fear of lack of proof

The online resource package aims to provide information about all options should you be the survivor of rape or sexual assault. It is aimed at assisting

the person in making an informed decision and covers important topics such as:

- reporting to police
- Alternative Reporting Options (ARO)
- myths and facts
- the court process
- support services

The package describes in detail the role police play in the investigation of reported rapes and sexual assaults, the gathering of evidence and dealing with the offender. It also explains the court process through both the Magistrate and District Court and provides survivors of rape or sexual assault a link to a variety of support agencies in their local area.

Detective Inspector Cameron Harsley of the Sexual Crime Investigation Unit said the resource package is important and could help police solve or prevent further offences.

"It is understandable that some people may prefer not to officially report to police. The Alternative Reporting Option provides survivors the option to provide information to police about what happened to them. This type of information could help us investigate other crimes," Detective Inspector Harsley said.

The process of ARO involves filling out the details of your assault on a sexual crime survey form, available on the QPS website, under the Adult Sexual Assault link. The option does not involve court and you can remain anonymous if you wish.

The Adult Sexual Assault package can be accessed via the QPS webpage at <a href="https://www.police.qld.gov.au">www.police.qld.gov.au</a> by following the Adult Sexual Assault link.

Should you require further information regarding this project please contact a member of the Cold Case and Serial Sex Crime Team:

State Crime Operations Command Police Headquarters Brisbane

Ph: 07 3364 6430

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#### Happiness and Its Causes Conference 2009: Happiness is a fundamental human quality that is within the reach of us all

#### By Diana East

How to improve our happiness and overall quality of life is the big issue of our time. The question, what does it take to be happy, is the universal great leveller because all of us - comfortably off or financially struggling, single or in a relationship, awkwardly overweight or elegantly slim, gaining some sense of achievement from the work we do or hating each and every aspect of it - are equal in our desire to achieve true happiness. Not the happiness we have all experienced which comes and goes depending on circumstances, but a happiness which endures regardless of change - a happiness we feel deep down inside.

Recently, along with about 2,000 other delegates, I attended the 4th Annual Conference on Happiness and Its Causes and was thoroughly entranced (and more than slightly overwhelmed) by all the information provided by 50+ speakers. Together we spent 2 days exploring many and varied facets of the science, psychology and philosophy of human happiness. As promised by the conference organisers, it was a veritable smorgasbord of tools and techniques for a happier life. The following is a brief overview of some of the happiness highlights.

Sonja Lyubomirsky (author of 'The How of Happiness') provided a great overview of her research reminding us that although some of happiness is genetically determined there's also a significant percentage (40%) that is under our control. We must invest time and energy in implementing happiness-enhancing strategies that fit with our individual personality, goals, strengths, etc, and make those strategies habitual.

She quoted an old Chinese proverb: 'to find happiness for an hour – take a nap; for a day – go fishing; for a month – get married; for a year – inherit a fortune; for a lifetime – help someone else.'

Robina Courtin, Buddhist Nun and Founder of the Liberation Prison Project (Australia and USA), advised that we can mould our mind into any shape we like. We are all different packages but we all have this potential. By becoming our own therapist we can gradually learn skills to know what's going on in our mind so that we can unravel it, deconstruct it, understand it, change it. As said to a young man in prison: 'Your prison is nothing in comparison with the inner prison of ordinary people: the prison of anger, the prison of attachment, the prison of depression.'

Marva Collins, a black woman from Alabama, was truly inspirational. She spoke passionately about applying the principles of positive psychology in education and about how, with the right approach, any child can achieve happiness and success in life: 'I am really practicing my own excellence and helping them to develop their own excellence.... I am only responsible for my own integrity... I am not happy when I am not following my own excellence.'

Ingrid Poulson provided an awesome personal account of resilience and how to find happiness after an extremely traumatic event, using her own tragedy as a catalyst to help others. Instead of allowing herself to feel the victim of a cruel god or indifferent universe, she moved on from the past with something very positive, having the resilience that allows you to go down into the negative emotions, accepting the full palette of our emotional landscape, and bouncing back: 'It is better to be wire than steel'.

Norman Doidge (author of 'The Brain that Changes Itself' about the neuro-plasticity revolution) told how the brain can actually change itself, its very structure and function, with the use of thought. Thus we can overcome bad habits and cure all (Continued on Page 18)

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manner of physical and psychological deficits, making new neural connections and finding new resourcefulness to achieve happiness and recovery: 'The adult human brain, rather than being fixed or hard-wired, can not only change itself but works by changing itself.'

Daniel Siegel spoke about social intelligence and how the development of insight, compassion and empathy in individuals, families and communities can be enhanced by examining how our interactions shape our emotional habits and sculpt our brain. Our negative feelings don't have to be us; they originate from one part of our brain but can be controlled by another part through the practice of mindfulness, actually altering what we think: 'Connections in the brain shape the way you think, but the flip side is true, too. The way you think can change your brain. Neural firing changes neural connections – if you pay attention.'

Professor Irving Kirsch discussed some fascinating research questioning the myth of the chemical imbalance, the use of antidepressant medications, placebo effects and the need to change the social conditions that put many people at risk of experiencing depression. This was followed by a panel discussion in which the primary topic was the overmedicalisation of unhappiness: 'Keep taking medication if that works (for you) but also have a whole bunch of nonmedical therapies you can access (as these are often the best prescription for depression and anxiety)' – Ian Hickie.

After hearing Marci Shimoff (author of 'Chicken Soup for the Women's Soul' and 'Happy for No Reason') advocate cultivating the habits of happy people, Tony Buzan (author of 98 books!) then walked us through a wonderful overview of mind-mapping, the new age we are currently in (the age of multiple intelligences) and its relevance to happiness. 'You must realise that, in some way, everything connects with something else (Leonardo da Vinci).'

John Gottman presented, in a thoroughly entertaining way, his decades of brilliant and influential research into couples and marriages and happiness, the importance of building 'love maps' and...how to determine who should hold the remote control when you're watching TV: "A man can think highly of himself unless he is married (GB Shaw)."

Another panel discussed how to increase our social and emotional intelligence and be better parents, better spouses, better people. Several speakers/ panelists looked at ways of teaching our children well, inspiring young people to have happy, meaningful lives. Dr Tim Sharp, founder of the Sydney-based Happiness Institute, moderated a panel focusing on using the proven principles of Positive Psychology to increase happiness at work. Panel members included the founder of Lentil as Anything, Renata Consiglio from Camp Quality and representatives from the Mental Health Council of Australia and BUPA/MBF: 'Many businesses are extremely disciplined in other areas but they ignore the cognitive and emotional lives of their most valuable asset at their peril' and 'anyone can be a singing bus driver' (now that quotation refers to a great story!).

Well-known Journalist, Ruth Ostrow, described 'clan people' (those who nourish us, share our values, etc) and the happiness of a simpler lifestyle: 'It's our separation from the natural world that distorts reality... We get an exaggerated view of our own precious importance from the top of tall buildings.'

I haven't even begun to tell you the half of it but, all in all, this was a conference jam-packed with fascinating insights and wonderfully practical advice about how to find and maintain happiness in life. And yes, I'm intent on practicing some of it, remembering that we can make big changes by taking small steps.

Diana East Mental Health Project Worker Self Help Queensland June 2009

#### Have You Heard of CICADA?



#### Cochlear Implant Club and Advisory Association

"No-one can explain better what it is like to have a cochlear implant than a person who uses one"

#### CICADA exists to make this happen.

Self Help Queensland recently learned about a self help group in Queensland called CICADA. Thanks to Katie Paulsen, 'cochlear implantee' and supporter of CICADA, for filling us in on cochlear implants, and how CICADA can help.

Katie kindly responded to our request to provide an article for this newsletter about her experience of receiving a cochlear implant. She also wrote:

"For more information on cochlear implants, questions about anything at all, hospitals, who to talk to in hospitals, or just who to talk to, believe me Shirley Edwards, Qld Cicada Secretary/Editor can fix you up for anything. She can be contacted at:

#### **CICADA Queensland**

Secretary: Shirley Edwards Phone/Fax: 07 3824 5003 Email: lee14@tpg.com.au www.cicada.org.au Website:

For those with TTY's, ring the National Relay Service on 133 677 and leave a message. Shirley will get back to you ASAP.

My C.I. has completely changed my life, if you are contemplating one, just want more info for you or a friend or just have a question, Shirley can help you. Cicada Qld has groups all over Queensland. Shirley is lovely and you could not receive a warmer welcome."

#### I Have a Cochlear Implant

#### - what I would like others to know By Katie Paulsen

This article is largely based on my own experiences as a cochlear implantee. No implantee is truly alike as we all have different expectations, outcomes and experiences with our implants.

My experiences with cochlear implants (CI for short) and the hardware (the outside bits) have been quite varied. As technology improved, my hearing improved. Out of all of the 6 different processors available over the years since 1982 I have become used to four including the latest technology, the Freedom implant.

On June 13th this year, at Queensland Cicada's (Cochlear Implant Club and Advisory Association) 20th birthday luncheon I was one of the five people to receive an award for having reached the milestone of having had a cochlear implant for 20 years. Incidentally, I was the 5th person and the 2nd woman in Queensland to receive a cochlear implant at the Mater Adult Hospital in Brisbane in 1989.

As a matter of interest, did you know there are over 120,000 people around the world who have the Australian Cochlear implant designed and developed by our own Australian Professor Graeme Clark in Melbourne. (Dowell, R. 2009).

I would like to re-iterate that no cochlear implantee is the same. Nor is there such a thing as the "perfect cochlear implantee". Everyone has their strengths and weaknesses. The same with implantees. Some can use the phone (maybe in a limited way with family) and some cannot, some can hear more speech than others. However, many factors have to be taken into account eg length of time between hearing loss and implantation; the placement of the software inside the (Continued on Page 20)

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skull (surgeon's job); how many nerves in the cochlea are still working, and how well. The list is endless and a lot of it is beyond the implantee's control.

Nonetheless, if you fit the criteria, pass all of the tests and have the operation you then face the hard work with your Audiologist and Cochlear Implant Team to aim for what we call a comfortable "map". That is a range of noises (not unlike a piano scale - high to low) that sounds comfortable to you. That is not too loud and not too soft. It is not a walk in the park, but I will stress that in the last 20 years, despite all the highs and lows of CI life, there is no way on earth that I would give up on my cochlear implants. They are not perfect, but to me they are pretty close!!

# So, what would I like you to know? Here goes (someone did ask me to write this!)

Please don't put things in, on or around your mouth when speaking to me. It hinders lip-reading. Further, it is not a pretty sight trying to lip-read a mouth full of half-chewed food.

I dislike loud music and noise. Sounds get distorted and I cannot distinguished between different sounds. I cannot understand what anybody says in this situation, even by lip-reading, because I find it a massive distraction and cannot 'tune it out' and just lip-read.

I love talking to people, but if they keep looking away whilst talking to me, this disrupts my lip-reading and comprehension of 'the story". (I lip-read and listen, not one or the other) and I get hugely frustrated. People get frustrated with hearing impaired/deaf people. That would probably occur much less if you gave them your full attention, faced them in good light and repeated everything succinctly and clearly. If that doesn't work, write it down.

I have a fantastic quote that I identify with 100%. Matilda Rose (2009) now 11, says: "What my implant does is

make me hear really well when there is just one person talking to me, but in group conversations it sounds like a hundred voices at once and feels overwhelming, and sometimes I feel left out. I don't like to feel left out as it hurts my feelings. I am not asking for sympathy just a bit of consideration."

This does not mean I avoid all group situations. There are times where I'm just happy to sit back, watch and soak up the ambience, realising that I can't get some of the conversation all of the time. A lot of this is compromise, especially in regular commitments such as family get-togethers. On the other hand, you might have to find what I call "my" people. Those who love and care enough for you to make the compromise mentioned above; to face you when talking; to be considerate when you are around; to make the status quo.

This brings me to the term "bionic ear". Unfortunately C.I.'s don't work like that – think Lee Majors in the Bionic Man. Next year I will have been deaf for 30 years. The first ten years I had to learn to lip-read fast as that was the only communication I had. You cannot tell by my voice that I am deaf and have a C.I. If only I had a dollar for every comment, "But you don't look deaf!"

Cochlear Implants can't, unlike surgery to remove cataracts, restore someone back to nearly perfect sight! My 86 year-old Grandmother had a cataract removed and could read the telephone book without her glasses for the first time in decades. Unfortunately, some C.I.'s don't work like that. That can also come down to unrealistic expectations after "switch-on" (when the Audiologist matches you to your hardware and connects you to the computer to commence the process of mapping - leading you to the commencement of hearing with a cochlear implant.

The biggest question I get asked once it is established that I have an implant is "Can you hear now?"

(Continued on Page 21)

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I know what they mean. Can I hear like them now? I have to be careful. Depending on the situation if it's a "quick" encounter I might probably just say "Yeah, it's great! Wouldn't be without it!" Other times I clarify that I need to see faces so I can lip-read; that this helps me communicate. I explain that the implant is great, but for me it works in tandem with lip-reading.

Another dislike is messy, overgrown moustaches and beards! They hide facial movement crucial to lip-reading. I get information from as far as the end of a person's nose down to mid-chest level.

People need to know that C.I.'s who lipread need the light on the speaker's face. Light shining in my eyes is the equivalent to a torch shining in your eyes - how much can you see then? The same goes for strong sunlight and strong glare. If possible, I try to move to where it is more comfortable to observe and lip-read.

I have always believed that if you can hear one sound you couldn't hear before the implant then the cochlear implant is a success. Before I got my implants I was totally deaf. C.I's revolutionised my life. I liken it a bit to a University degree (I couldn't have gotten mine without my C.I.!) If it was easy everyone would do it!

C.I 's are a special breed. If you want it, and are prepared to put in the work for it, then you will reap the rewards. It's like most things in life, it it's worth doing it's worth doing well.

I have never regretted any step in the C.I. process - good or bad. Because it means I can still listen to my 70's music!!!! ( I may not remember all the words - but that is a work in progress!) Incidentally, if anyone know where I can obtain lyrics on the line please email me on <a href="mailto:dpa35094@bigpond.net.au">dpa35094@bigpond.net.au</a> - many thanks-I'm desperate!

I can also hear the jug boiling (aaargh)

my dog bark, birds singing, and right up there with my music – are the waves crashing onto the shore at Moffat Beach, Caloundra, Queensland (Moffat Beach because it usually has BIG dumping waves that I can hear. Every Christmas holiday was spent at Caloundra hence the wave fetish!)

### My Cochlear Implant has completely changed my life!

#### References

Cochlear Limited. (2009). Hear always: News and advice from the world leader in hearing implants: Moving toward: Phasing out the MSP, spectra, ESPrit and ESPrit 22 support. June. Lane Cove, NSW: Cochlear Limited

Dowell,R.(2009) Head of Otolaryngoly, Professor of Audiology and Speech Science at the University of Melbourne, Director of Audiological Services at the Royal Victorian Eye and Ear Hospital (also where implant surgery is done. Guest Speaker at the Cicada Queensland 20th Celebration Luncheon, 12 noon, 13 June 2009. Information available from Shirley Edwards at <a href="mailto:lee14@tpq.com.au">lee14@tpq.com.au</a>

Rose,M (2009). Matilda's story: Imagine going deaf for a day. (p.1.) Australia Inc. Winter. South Turramurra, NSW Cicada Australia Inc.

#### New Eating Disorder Support Groups on Sunshine Coast

Self Help / Support group are now available for parents and friends of people with eating disorders in Maleny and Mooloolaba.

Their aim is to offer support in strengthening thoughts, feelings and actions to assist in coping. Meetings are held on Thursdays once a month at Mary Cairncross Park in Maleny from 1 to 3pm, and every 3rd Friday at Gloria Jeans in Mooloolaba from 9.30 to 11.30am.

Contact Contact Gill on 5478 2854 or Sonya on 0411 530 764 for more information. Both these groups are free of charge.

"The best things in life aren't things."

John Ruskin English Author, Critic, Poet, Artist 1819 - 1900 An Excerpt from the Abstract 'Mercury Rising: Mental Health Self Help Support Groups and the Recovery Process'

### Presented at the Queensland Alliance 2009 Conference

#### By Diana East, Margie Maddison, Karen Ruhl

### The following is Karen's part of the presentation.

My name is Karen and I facilitate a, Depression and Anxiety support group in Townsville. This group is run by Hand-Up, a small non-profit organisation made up of people who experience mental illness, people just like me.

In Hand Up support groups we share our personal stories and by doing so, we find and offer understanding acceptance and friendship. So in the spirit of Hand Up, I would like to share the story of how the Mercury rising project has helped our support groups to grow.

This story begins in August last year, when Hand up had only one support group that had been meeting weekly, on a Tuesday morning for 2 years. Unfortunately, at this point in time the support group was experiencing some serious group problems, problems that were threatening to tear the group apart.

The reality was, we were a group of people who experienced mental illness. We were not mental health professionals and we did not know how to fix this group problem, on our own.

Fortunately the North Queensland mental illness fellowship came to our aid and helped us get back on track.

By December, our support group was recovering. It was then that myself and John, another Hand Up committee member attended the Mercury rising consultation meeting in Townsville.

I must admit the Hand up group still felt quite vulnerable. That was... until we realised that the mercury was rising in the Hand Up mental health barometer signalling, a good change was on the way. A change that said "other people valued our support group"; A change that offered us ongoing training, some small grants and continued support; A change that would connect us with like minded people.

Now being told that other people valued our support group was empowering; and we gained the confidence to start a second group. A night group, because we knew there were people out there who experienced depression, anxiety and other mental illnesses, who worked and could not attend a day group. And also some people preferred to meet at night. People like me who have trouble getting out of bed in the morning. So we decided to start a night meeting.

The mental illness fellowship offered us a free meeting room, we put some free adds in the papers, and on the radio. And by the time of the next Mercury rising consultation meeting (three months later) we were averaging 5 people each week. Now six months later we are averaging 10 people each week.

The ongoing training has also strengthened our support groups. Our facilitators and co facilitators are more confident, enthusiastic and have become better group facilitators.

In the training we learnt some creative facilitation activities that we could use in our groups. For example we learnt to use strength cards, which we were later able to purchase with our small grant.

Now the first time that the group used the strength cards was an incredible experience. That night, each person was asked to select 2 cards. One card with a strength that they had and another card with a strength that they wanted to develop.

First, each person shared about the strength they had and after they shared, every other member agreed that yes, that group member did have that strength. Then each member talked about a strength (Continued on Page 23)

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that they wanted to develop.

But the amazing thing was that after each member talked about the strength that they wanted to have, the other group members said "but you already have that strength". And by the time we were half way round the group we all began to realise that we were already developing the strengths that we wanted to have.

We laughed a lot that night. It was an extraordinary meeting and we gained the insight that what we were doing was working for us.

Incidentally, we now have 3 different types of cards to help guide our mental health recovery journeys.

Here is a photo of the Thursday night Depression and Anxiety Group enjoying their cards.

The small grants have gone a long way. They have allowed us to purchase resources for our groups and to produce some flyers. And we are also in the process of becoming incorporated and will use the small grants money to register our incorporation. Once we are incorporated we will be able to apply for small council grants, which in turn will keep Hand-Up going into the future. It is amazing how much value we have gotten for such a little grant!

But the value does not stop there, because the continued support from Diana East, which includes one on one contact, both on the phone and face to face, is invaluable as sometimes support groups need support too.

And finally, the project has connected the Hand Up support groups with like minded people. For example, at the last Mercury rising network meeting the Mental Illness fellowship told the support groups about an upcoming Rotary Forum.

Eight people from Hand up attended that forum and I spoke about the Hand Up support groups and we gave out some flyers. Then one week later a

lady walked into our Thursday night group and said that she had heard about the support group from her son, who had attended the forum.

We welcomed her, and we shared our experiences. That night we used the Language of letting go cards to help with our self acceptance. Everyone took something home that night and the group was strengthened by the connections that led this wonderful lady to our door.

I'd like to finish now by saying that the Mercury rising project has helped our support groups in many ways. We have gained confidence, skills and momentum.

However this is not the end of our story, because now we are connected to a network of like-minded people, a network of possibilities, a network that is growing and each of these connections will bring a new chapter to our story.

\*The presenters of the abstract were:

Diana East, Mental Health Project Worker, Self Help Queensland

Margie Maddison, Mental Health Branch, Disability Services Queensland

Karen Ruhl, Support Group Facilitator

To receive the full abstract by the three presenters, (Diana, Margie and Karen) please contact Trish at Self Help Queensland on 07 3344 6919 or email selfhelp@gil.com.au

To discuss the abstract, or to find out more about the Mercury Rising project, please contact Diana East on 07 3880 3501

#### Tribunals Amalgamating

From 1 December 2009 more than 15 Queensland tribunals will amalgamate to form the Queensland Civil and Administrative Tribunal (QCAT).

Tribunals such as the Anti-Discrimination Tribunal; Children Services Tribunal; Guardianship and Administration Tribunal and Health Practitioners Tribunal will cease to exist and QCAT will deal with the matters these tribunals would have handled. Visit:

www.trinunalsreview.gld.gov.au

#### Life and Human Relations

by Mary Matthews

Life and Human Relations (LHR) is a non-profit organization providing caring support for individuals and families through counselling and courses in relationship education, parenting and personal development.

'There are many dimensions within a human being. The mind the emotions, the physical body as well as another less tangible dimension some would call the spirit or soul, but at Life and Human Relations (LHR) this dimension is called Inner Being.

Inner Being is the term used for the dynamic core of every person, the place of each ones goodness, wisdom, power, and potential.

Today's world is one of materialistic values. We are lead to believe that our possessions are the true path to happiness, but many people still feel empty when what they have strived for materialistically comes to fruition.

Life and Human Relations' Unique approach focuses on the psychological and the spiritual path to inner peace. We all accumulate baggage along the road of life and unless we deal with this baggage we could end up wearing it on our hips, as extra weight, or in our bones as pain or in our emotions in the form of anger, anxiety, depression, low self esteem to name just a few. This baggage can weigh us down on our life journey unless we deal with it. So at LHR the focus is holistic looking at mind emotions spirit and the physical body.

At the moment you may be feeling very balanced and in good health but still feel a void in your life. This is where the Inner Being comes in because everyone at some point in their life wants to find purpose, meaning and passion. Getting to know your inner being, trusting your inner being and living through your inner being can really assist with these bigger questions and set you on a path

Because you are a vital person you will be able to touch other people's lives, which in turn gives you meaning on your own journey.

LHR has been operating as a non-profit organization since 1984 and is celebrating it's 25th anniversary in October. The work was inspired initially by the French educator Andre Rochais and further developed by the late visionary Marist Brother Paul Maranta. The organization comprises a small group of skilled counselors, course facilitators and other voluntary office staff. Every one works in a voluntary capacity because they believe and love the work and it also enables the organization to offer very affordable fees for counseling and the courses.

LHR offer individual, family and couples counselling and a series of workshops that can set you on the path to a baggage free journey.

The first workshop is called "DISCOVERING WHO I AM" It runs over 2 weekends and helps you to understand and love yourself for who you are and not what others think of you. You will learn to see your unique gifts with clarity and embrace your limitations.

The workshop 'HOW TO LOVE AND BE LOVED' again runs over 2 weekends and explores your relationships. It looks at how to improve or enrich existing relationships and how to develop your capacity to be loved and to love.

The third workshop is called "MY LIFE WITH GOD" this again runs over 2 weekends and is a retreat away from your earthly worries and commitments. It is a journey into your spiritual self your Inner Being and look at your life with God. This course is still applicable if you have no belief in God as you will be able to explore your own belief the spiritual core that rest within everyone.

L.H.R.'s approach springs from several convictions:-

 that we are intrinsically good and full of potential.

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- that this potential yearns to be developed for the betterment of ourselves, society and the world.
- that it is possible to heal past wounds in our psyche and enjoy greater peace and contentment.
- that our happiness is closely tied to our capacity:-
- (1) to be open to and stick to reality and truth
- (2) to believe we are lovable and can love
- (3) to choose love rather than non-love
- (4) to create and sustain quality relationships
- (5) to develop our spiritual nature
- that our destiny is to become in a personal, relational and spiritual sense, the person the Creator intended us to be.

I went to my first workshop to keep a friend company, having none of my own baggage (complete denial) but found I had a few suitcases worth. Having taken the workshops many of them more than once and 8 years down the path I am a lot lighter with my luggage and am able to help others on the same journey.'

For further information please contact: Life and Human Relations, RED HILL Ph 33692124

<u>lifeandhumanrelations@dodo.com.au</u> www.lifeandhumanrelations.com

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# Dr Ian Gawler - In Brisbane for 3 sessions at Relaxation Centre in September

Ian Gawler, cancer survivor of 30 years, renowned author and presenter, says these seminars are great for all people, not just those whose lives have been touched by cancer.

Ian focuses on life and living, and what he offers is full of common sense and wisdom for all people wishing to lead fuller, empowered and more fulfilling lives.

#### **Thursday 10 September**

'Medicine of the Mind'

#### Saturday 12 September 2009

'Meditation: A Complete Path'

#### **Sunday 13 September 2009**

'Health, Healing and Wellbeing'

For times, further information and bookings please contact the Relaxation Centre Ph 07 3856 3733

Email: relaxcetreofqld@powerup.com.au

#### Check Out SCAMwatch

SCAMwatch is a website to help you recognise, report and protect yourself from scams.

Owned and maintained by the Australian Competition and Consumer Commission, it is also the campaign portal for the Australasian Consumer Fraud Taskforce.

Find out more about how scams work and how to protect yourself. Check out victim's stories from fellow Australians who have been stung by scams.

- Identity theft scams
- Mobile phone scams
- Health and medical scams
- Job and employment scams
- Investment scams
- Chain letters and pyramid scams
- Banking and online account scams
- Lottery and competition scams
- Money transfer requests

Register for free SCAMwatch email alerts. You can also report scams to the Australian Competition and Consumer Commission (ACCC) and other government agencies through SCAMwatch.

Go to: www.scamwatch.gov.au

"Dancing is the poetry of the foot."

John Dryden

English poet, Literary Critic, Dramatist and leader in Restoration comedy

1631 - 1700



### Diary Dates

12th - 13th September 2009: Albinism Fellowship of Australia Brisbane 2009 Conference "Shining the Light on Albinism"

**Ph:** 0425 229 799

albinismnsw@albinismaustralia.org **URL:** www.albinismaustralia.org **Venue:** Chifley at Lennons, BRISBANE

29th - 30th September 2009: National Hepatitis Health Promotion Conference "Grass Roots to National

Action"

**URL:** www.hepatitisaustralia.com

Venue: Hobart

30th September - 2nd October 2009: Australia's Disability Employment Network Conference 2009
Website: www.acenational.org.au

**Venue:** Gold Coast Convention and Ex-

hibition Centre

**10th October 2009: Narcolepsy Community Conference 2009.** For people with narcolepsy, families, interested professionals and community. Presented by Narcolepsy and Overwhelming Daytime Sleep Society of Australia (NODSS) **Ph:** 03 9432 9669

**Email:** info@nodss.org.au **URL:** www.nodss.org.au **Venue:** MELBOURNE VIC

#### 14th - 17th October 2009: Be Active '09 Conference

A comprehensive scientific forum on all facets of sports medicine, sports science, and physical activity from elite sports performance to community participation in physical activity and their impact on individual and community health.

URL: www.beactive09.com

Venue: BRISBANE

28th - 30th October 2009: 4th World Congress on Mental Health and Deafness

**Email**: info@mhd2009.org **URL**: http://www.mhd2009.org/ **Venue**: Brisbane Convention Centre

18th - 20th November 2009: 2nd National Siblings Australia Confer-

ence "Creating Connections"

**Ph:** 08 83571214 **Mob:** 0408 720 558 **Email:** kate@siblingsaustralia.org.au **URL:** www.siblingsaustralia.org.au

Venue: ADELAIDE SA

#### **Invitation**

#### Fabry Support Group Australia

#### **Sunday 18th October 2009**

#### National Program for Fabry Disease Treatment in Australia

Presentation by Clinical Professor Jack Goldblatt, Director Genetic Services & Familial Cancer Program of WA, member Fabry Disease Advisory Group of LSDP.

### Replacing Enzymes - 'The Long Journey Home'

Presentation by Andrew Komjathy, VP, General Manager North American and Asia Pacific Regions for Shire Human Genetic Therapies.

**Venue:** The Hawthorn Room, Amora Hotel Riverwalk Melbourne 649 Bridge Rd Richmond Vic

For further information:

Rachael: rbjgclan@gmail.com or Megan: meganfookes@ozemail.com.au

#### **Crisis Counselling Service**

1300 363 622

#### Queensland Wide 24 hours Suicide and Crisis Counselling Line

The views expressed in this publication are those of the individual authors and not necessarily those of Self Help Qld

The material supplied is for information purposes only, and is not to be used for diagnosis/treatment, or as legal, tax, accounting or any other type of advice. Self Help Qld reserves the right to edit contributed articles.

SHQ's Policies and Procedures Manual is reviewed annually, and may be seen at the office by contacting 07 3344 6919.