



Newsletter

March Quarter

Issue 1. 2006

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

From the President

Sue Smyllie

We at SHQ had our first committee meeting for the year in February and as usual I really enjoyed the opportunity to talk and discuss the meaning of life, the universe, self help and everything with such a lovely group of people (no one ever suggests that 42 is the answer!). Anne, Bob and Jill are new committee members and we are benefiting so much from their wisdom, experience and commitment. We are so lucky to have them!

I was feeling a little sorry for myself after a particularly harrowing holiday season. We always start our meeting with a round robin sharing whatever is of interest, new or pressing on our minds at the moment – sometimes this leads to personal, political or practical discussions. Not only is this a way for everyone to contribute it also a way of making the term 'network' live in practice, not just in thought.

After our talk I felt:

- Listened to, accepted and soothed
- Not the only one with a problem
- That there are happy things happening too
- That I had a few ideas about what to do next
- That I could cope much better with the rest of my day, week and month.

Funny, this is just what the research says happens in a self help group!

I wanted to take this opportunity to add my fanfare to the general hubbub about our

new Directory of Self Help Groups. It looks really wonderful and is easy to follow. We are filling orders fast so don't miss out. Congratulations again to Ann and Trish for a job so well done and for the support of the Greater Brisbane Area Consultative Committee and Department of Transport and Regional Services.

Also I would like to draw your attention to the information on Dynamic Facilitation (Page 10), a process which will be used during the Wellbeing Councils, Deep Democracy Project we are pulling together. This Project is for you if you are tired of being consulted but not listened to and would like a different experience. We are planning to start with 3 communities and invite you to let us know if you would like to be involved. We don't care where they are but they do need to be defined by some sort of existing boundary eg. a council ward, a town, a post code. If you would like to be a community champion for this project please let me know at ssmyllie@bigpond.net.au.

And so we are off and running for the new year...don't forget that our committee meetings are open to anyone who would like to come and listen in and contribute...the next one is scheduled for May 10th at 9.30 am in our office at Sunnybank. Please let Trish know if you plan to come, just so we have enough morning tea to share!

Till next time

Sue

Please let us know if your details have changed, or if you would prefer to receive the newsletter by email rather than post.

Self Help Queensland Inc Management Committee Members

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

Committee Meetings

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

Project Officer

Trish Fallon

Office

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

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

Office Location:

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

Postal Address

P.O. Box 353
Sunnybank QLD 4109
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Email: selfhelp@gil.com.au

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



Apology

Due to an editing error while conducting a global spell check on the new SHQ Directory, email addresses that began with "info@..." were converted to "information@..." We apologise to any organisations whose email addresses may have been altered and wrongly published in the Directory due to this editing error.

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SHQ Confidentiality and Privacy Policy

Self Help Queensland continues to review and update its Policies and Procedures Manual. Openness and accountability are an important part of SHQ, and anyone is welcome to contact the office to view the Confidentiality and Privacy Policy.

Tell us what you think!

We would appreciate feedback about any aspect of our service. Please tell us what you think so we can try to do things better.

SHQ Website

The saga of the website is nearly over! It should be up by the end of April 2006. Thanks to all who have contributed their skills over time to help us finish the site.

Suggestions for additions/changes to the site welcome.

Contents

President's Message	1
SHQ Committee & How to Contact Us	2
Genetic Matters	3
Charcot-Marie-Tooth Conference	4
Just for Dads	4
Trichotillomania	5
Self Help Queensland Directory Information	7
Phoenix House - Burns Survivor Group	8
Brain Injury Survivor Network	8
Saviour Siblings	9
Committee's Lament	9
What is Dynamic Facilitation?	10
Link Line	11
Letter to those who do not have RSD	12
Recently Formed Groups	13
Diary Dates	14

Genetic Matters

by Kim Summers PhD

Reading

- a genetic condition?

Dyslexia involves problems in word recognition and difficulties in learning to read and spell. Compared with people who read normally, individuals with dyslexia use different parts of the brain to process information and have different responses in the brain when they have to perform a reading task. Dyslexia is not associated with reduced intelligence.

Genetically, dyslexia tends to run in families, with up to half of the parents, offspring and siblings of a dyslexic individual likely to be affected as well. This has led to a search for genes which might be involved in development of the parts of the brain which control the functions necessary for reading. Large scale studies of genetic variation in families with dyslexia have found at least 10 regions on the chromosomes which may contribute to determining whether a person develops dyslexia or not. Now two research teams have identified a gene in one of those regions which seems to regulate brain development. Variation in this gene is, at least in part, responsible for development of dyslexia in some people.

Genes are stretches of DNA (part of a chromosome) which carry information telling cells how to make specific proteins, rather like a set of recipes with instructions for cooking a range of different foods. The proteins then carry out the functions of the cell. Some proteins are enzymes which carry out chemical reactions, like the breakdown of food into useful molecules. Other proteins instruct the cell to multiply and assist in this process. Some proteins provide support for collections of cells forming tissues like the muscles or brain. One class of protein is involved in guiding the migration of cells to specific areas in the developing fetus. All cells have genes and most of the genes contain an accurate set of instructions for their proteins. Sometimes there is a change in the information and that can cause a problem with the resulting protein (like using plain flour instead of self raising flour in a recipe).

People with dyslexia have unusual patterns

of cells in parts of the brain known to be associated with reading skills. The gene discovered by the dyslexia researchers contains instructions for a protein which is involved in the movement of cells into these regions of the brain before birth. Many dyslexics have a large portion of the gene missing. In them, the protein would be incomplete and unlikely to be able to do its job properly. The researchers suggest that this would result in failure of the cells to migrate to the proper places in the brain. They showed that variation of this gene contributes to differing abilities to read and explains at least some cases of dyslexia.

This discovery won't lead to a "cure" for dyslexia. Other factors as well as variation in this gene are involved in the development of dyslexia. The genetic variant was only found in some dyslexics, particularly those with a more severe form, so only a subset of patients could be helped by this knowledge. The gene acts before birth, during the time when this group of cells is migrating into the brain and becoming specialized brain nerve cells, and it would be hard to administer a drug or other treatment at that time.

However this discovery does tell us more about brain development and the critical importance of specific cells in the functions of the brain which are required for reading comprehension and related activities. This knowledge should lead to greater understanding of the process normal process of reading as well as the abnormalities associated with dyslexia and hence to better strategies for coping with the condition.

Knowing about the role of this gene might also enable families with a susceptibility to dyslexia to identify those children who are most at risk and could benefit from starting a program very early in life to minimize the impact. The success of this approach will encourage researchers to look for more genes associated with reading, so that the full picture of this unique human ability will soon emerge.

SPELD Qld Inc has an advisory line where people who need help with Specific Learning Disabilities can obtain support and information. Ph: 1800 671 114

(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.)

Townsville to Host First Ever Charcot-Marie-Tooth Awareness Day Seminar in North Qld

Saturday 27th May 2006

The Charcot-Marie-Tooth Association of Australia would like to invite CMT sufferers, their families or carers and health professionals to attend the first ever CMT Seminar in North Queensland.

The purpose of the Seminar is to provide information and support to people in rural and remote areas. It will also be an occasion for people to get together, meet others with the same condition, make new contacts and establish future support networks.

The principal speaker will be Associate Professor John MacMillan from the Queensland Clinical Genetics Service.

The CMT Association was successful in securing funding for the Seminar from the Queensland Government's Gambling Community Benefit Fund. Self Help Queensland Inc was pleased to provide support for the Association's grant submission.

For further information and registration pack please contact the CMT Queensland Co-ordinator:

Margaret Burke

Phone: 07 3886 2492

Date: 27 May 2006

Venue: Townsville General Hospital

Do you belong to a Self Help or Support Group?

If your group is new or you think we may not know about it please email/call/leave a message and we will get back to you. We would really appreciate hearing from you.

There are probably many groups we are still unaware of throughout Queensland, particularly in rural and regional areas. We would like to be able to help someone find yours.

Please call Trish at Self Help Queensland
Ph: 07 3344 6919
Email: selfhelp@gil.com.au

Just for Dads **of children with disABILITY** (Sunshine Coast)

A monthly informal get together for fathers of children with disability is now under way in the Sunshine Coast Region.

Are you a father of a child with a disABILITY?

Do you find that due to work commitments you can't always attend special events, workshops or sessions to learn more about how to meet your child's/children's needs?

Do you find that you don't often get the opportunity to speak to other fathers who have a child with a disABILITY?

Do you sometimes feel left out of discussions with professionals, experts and others 'in the know' because it's often perceived that Mums are the primary carers?

Well "Just for DADS" could be for you! Remember you are not alone as there are many Dads out there who would like the opportunity to meet together with other Dads from time to time, to talk about their kids and families, listen to guest speakers and to relax in an accepting, friendly and non judgmental environment.

When: Last Tuesday evening of each month from 7pm to 8.30pm.

Cost: \$2 per meeting to cover supper

Venue

Sunshine Coast Children's Therapy Centre
70 Windsor Rd
NAMBOUR 4560

Contact

Phone: 07 5441 7199

Fax: 07 5441 7905

E-mail: carolinem@scctc.org.au

Is your Support Group Applying for Funding Grants?

Self Help Queensland is happy to provide letters of support for member groups applying for funding grants. If you would like to talk over your ideas with someone, feel free to call Trish at the office on Ph 07 3344 6919.

Trichotillomania

(The urge to pull one's own hair out)

"The Lonely Epidemic"

Trichotillomania, or trich as many sufferers call it, is one of the most misunderstood and most under-treated chronic conditions. It causes the urge to pull out one's own hair. It has been around a long time, even being mentioned in the Bible. A French physician, Francois Hallopeau, who had a patient who pulled out his hair, invented the name in 1889.

Derivation

Trich - from the Greek Thrix, hair

Tillein - to pull

Mania - craving or excessive activity, (not madness)

The Definition of Trich by The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV):

- Recurrent pulling of one's hair resulting in noticeable hair loss (balding or general thinning)
- An increasing sense of tension before pulling or when trying to resist followed by a sense of relief after the hair is pulled
- The disturbance is not better accounted for by another disorder or medical condition
- It causes clinically significant distress or impairment in the individual's functioning.

NB. *This official description is somewhat limited and may change as more is learned about trich. Noteably, the tension before and relief after pulling may not always be experienced.*

People pull from any place or places on the body and to varying degrees. Scalp pulling is the most common, followed by eyelashes and eyebrows. It can occur both consciously and subconsciously, but frequently in response to an irresistible urge. Imagine a fly walking over your lips – to resist the impulse to wave the fly away is almost impossible. The urge to pull is similar. Trich can be episodic, so people can experience short and even long periods of remission. However there is no cure.

Who gets trich?

Men, women and children of all ages, cultures and intelligence are affected, including babies. It is usually activated in childhood by the age of puberty.

Trich is surprisingly common. It is already estimated that trich affects as many as 2% to 4% of the US population. (Christenson 1991) A much higher rate of trich in the population, possibly as high as 15% has been found, when the tension and relief criteria are not included in the definition. It is not known how many suffer in Australia alone.

What are the consequences of trich?

Trich causes considerable trauma. The few studies into other disorders which occur with trich agree that major depression is the most common disorder accompanying trich, affecting more than half of trich sufferers.

The emotional impacts can be enormous - such as isolation, frustration and helplessness, low self esteem, shame, poor self image, social anxiety due to the hair loss, the guilt of a self-inflicted problem, and problems with relationships. This can be especially traumatic in adolescence.

Hair loss occurs to varying degrees. Hair regrows more slowly over time, and can become white and coarse. Some people need a wig or other ways to cover their hair loss. Extensive hair loss can lead to permanent thinning of hair. Repetitive strain injuries may also result.

What causes trich?

The cause of trich is unknown, and research is in its infancy. However trich appears to be a distinct and complex neurobiological disorder, much more than just a habit, which can manifest in many ways. While a genetic cause is likely, there is no evidence yet that trich is hereditary.

Trich was officially classified as an impulse control disorder in 1987, probably because no one knew where else to put it. It has little in common with the other ICD's (kleptomania, pyromania and compulsive gambling) apart from having impulses which may be preceded by tension and can be pleasurable. It is definitely distinct from, yet probably related in some ways to Obsessive Compulsive Disorder.

(Continued Page 6)

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Research also suggests that there is a higher incidence of OCD amongst trich sufferers. Trich has more recently been categorised as a Body Focused Repetitive Disorder along with nail biting and skin picking.

Why is it so little is known?

Trich has been called “the lonely epidemic”. It has been largely a hidden disorder due to the extent of shame and guilt felt by sufferers who often go to extreme lengths for much of their lives to hide their disorder, even from parents, partners and families. Most sufferers still think that they are the only one who pull out their hair. Thankfully, this is beginning to change.

Common myths about trich, none of which are true

- Caused by stress, depression, family trauma etc
- It is just a bad habit, which can be stopped at free will
- Punishment will help stop the behaviour
- Medications can cure trich
- Hair is pulled because the trich sufferer hates him/herself, or his/her hair
- Trich is a self-harm/ self mutilation behaviour or an addiction
- The sufferer doesn't want to stop

Treatment

Professional treatment is available from psychologists and psychiatrists. No specialised trich services are available in Australia and few have experience or expertise in treating trich. However, trich can respond well to a cognitive behaviour therapy approach, which uses habit reversal techniques adapted to individual sufferer's behaviours.

Benefits of a Support Group for people with trich

Support groups and self help strategies are currently the main source of assistance accessed by sufferers. Support groups provide a great opportunity for people to find they are not alone or crazy. They can share their experiences freely, in an atmosphere of understanding and acceptance not often possible for them otherwise.

Where to find support in Australia

TTM In OZ is an online support group and source of information for trich sufferers throughout Australia and New Zealand.

The group offers support for self help strategies, a website with a message board, weekly chat, a database of useful information and State based support group meetings. It also aims to develop greatly needed awareness and assistance in the community. If you would like information, a brochure, or would like to join the group, please contact the website at: <http://groups.msn.com.au/ttminoz> or email ttminoz@groups.msn.com *

Further information on trich

The central source of current information, support and advocacy is the Trichotillomania Learning Center, a non-profit organisation in the US. Their website is at: www.trich.org

The Hair Pulling Problem, A Complete Guide by Fred Penzel, published by Oxford University Press, is highly recommended as the most comprehensive book on trich for sufferers.

*** If you are a trich sufferer and don't have internet access, please ring Trish at Self Help Queensland Inc on Ph 07 3344 6919 for information and assistance.**

(Source: TTM in OZ - information sourced from “The Hair Pulling Problem, A Complete Guide” by Fred Penzel.)

Can you Help?

The Stroke Association of Queensland Inc aims to improve the quality of life of stroke sufferers, their carers and families.

The Association is facing similar challenges to many other community groups. A limited number of volunteers, who themselves have suffered a stroke, are needing some extra help.

A paid position exists for an Office Manager, and a volunteer Treasurer's position is up for grabs. If you can help please phone the President, Ian, on 07 3277 3838.

If you know anyone who might like to receive the SHQ newsletter (by email or post) please invite them to contact Trish on Ph: 07 33446919 or email selfhelp@gil.com.au.

SHQ Directory Project Receives Honourable Mention in Australian Parliament!

The Self Help Queensland Directory was one of four Queensland projects to receive an honourable mention in a 2005 Senate Inquiry into the Regional Partnerships Program.

Projects in each state were chosen for recommendation by the Senate Finance and Public Administration Committee.

http://www.aph.gov.au/Senate/committee/fapa_ctte/reg_partner_prog/report/d04.htm
(See Chapter 4.12)



Newsletter Circulation Hits 1600!

Thanks to an increased awareness of Self Help Queensland through the success of the Directory Project, our newsletter circulation has now reached 1600. Quarterly editions reach support groups, hospitals, community health centres, divisions of general practice, neighbourhood centres, social workers, health professionals, politicians and various other interested individuals throughout Queensland. A number are also sent to Interstate groups.

Newsletter articles and advertisements for upcoming events etc are very welcome from groups, along with any suggestions or issues you would like addressed in future editions. If you belong to a self help or support group, anywhere in Queensland or Interstate, we would love to hear from you.

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

(The email version is in PDF format and you will need Adobe Acrobat Reader to read it.)

Directory Feedback Welcome!

We would really like to know what you think about the Directory! Please turn to page 14 if you would like to help us.

Have you ordered a copy yet?

Self Help Queensland Directory of Self Help and Support Groups 2006/07 Inaugural Edition

Self Help Queensland Inc recently launched a hard copy Directory which contains contact details and information for approximately 600 self help and support groups throughout Queensland - across a very broad range of health conditions and well being issues eg chronic illness, genetic conditions, mental health, grief and loss, disability, sexual health and others.

An order form may be obtained by contacting the SHQ office and we will post, fax or email you a form. Alternatively, please feel free to complete/copy the form below.

Organisation.....
Contact name.....
Mailing address.....
Town/suburb.....
State.....Postcode.....
Phone.....Fax.....
Email.....

Please send (No of copies).....@ \$38.50 ea
(Includes \$5.00 Postage/Handling and \$3.50 GST)

Payment details

Please make cheques/money orders payable to "Self Help Qld Directory". (Sorry no credit card facility.) Purchase orders and EFT accepted. Post to:

Self Help Queensland Inc
PO Box 353 SUNNYBANK QLD 4109
Ph/Fax: 07 3344 6919
Email: selfhelp@gil.com.au

Yes I would also like to receive the **Free** SHQ newsletter by Post or Email

Phoenix House

- a peaceful place that aims to provide support and information for burns survivors.

Phoenix House is the home of burns survivor, Steven Fennell, and his family. Plans for renovating the house are currently underway to enable burns survivors to have a place of respite where they can stay for a few days, share experiences and recuperate in a relaxing environment.

Situated on peaceful Macleay Island, the second largest of the Southern Moreton Bay Islands, it is only a short trip by fast Water Taxi from Redland Bay. Guests and Visitors of Phoenix House are picked up at the jetty.

The Phoenix House Project aims to offer practical assistance and information to enable families to better cope with the traumas that follow burn accidents.

While the building project is taking up a great deal of Steven's time, he is still available to answer enquiries, provide emotional support, information and resource material relating to the damage caused by burns.

Home visits (by other burns survivors) can be arranged on request, along with referrals to specialist Solicitors trained in personal injury compensation claims. For further information, or if you would like to assist the project, please contact Steven:

Ph: 07 3409 4263
Fax: 07 3409 4601
Mob: 0412 060 764
Email: islandlife59@yahoo.com.au
URL: <http://phoenix-house.netfirms.com/page6.html>

Welcome to all our new readers!



Hello and welcome to everyone who is receiving the SHQ newsletter for the first time.

Our readership is quite broad, so we invite you to contribute articles of interest, or just let us know what you think!

Brain Injury Survivor Network

...Liberating you for a whole life again...

Sustainable Solutions for life which will continue to work in the years to come.

The Brain Injury Survivor Network is an international e-mail cyberspace community whose objective is to provide a sense of connection and belonging via the internet for brain injury survivors.

The whole focus of the Brain Injury Survivor Network is about HOPE hope for restoration and being a valued member of the community again. This focus is by the experience of a sustainable life. Such a life has the ability to be continually maintained every day.

It is the belief and personal experience of those who facilitate this network that there are three important components in recovering from a brain injury and maintaining an ongoing life. These are: Structure, Social Network and Spirituality, and each of the components acts to support a sustainable life.

The Brain Injury Survivor Network website and e-mail broadcasts emanate from Queensland, and are increasingly touching many people around the world.

Facilitator:

Ken AITKEN (B.Sc.): PH: 07-3297 0069
E-mail: kaitken@iprimus.com.au
1606 Chambers Flat Rd. CHAMBERS FLAT
QLD. 4133 AUSTRALIA

(Ken is a brain injury survivor from December 1995.)

Consultant:

Dr. Mark Sherry (Ph.D.)

markdsherry@yahoo.com

(Mark is a brain injury survivor from 1992.)

See both Ken's and Mark's stories on :
www.brain-injury-survivors.org/

Please let us know if you have changed your contact details.

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

Saviour Siblings

A book review by Kim Summers PhD

If you need a transplant, your best chance of success is to obtain the organ or cells from your identical twin. Then you know that all the genes match and there should be no problem with rejection. Since less than 1% of us are identical twins, most of us have to rely on other family members or unrelated donors if we need a transplant. But what if we could order up a perfectly matched donor to supply whatever spare parts we need?

One of the promises of cloning is that we could create cell lines which would allow the generation of organs for transplantation which would be exactly matched because they were derived from our own tissues. But until those techniques can be made to work reproducibly for humans and the ethical issues can be resolved, and failing an identical twin, the best hope is to create a sibling who has the matched tissue type.

That is the theme of the novel by Jodi Picoult called *My Sister's Keeper* (Hodder and Stroughton, London, 2004). Kate was diagnosed with acute promyelocytic anaemia at the age of 2. Anna is her younger sister, produced by in vitro fertilization followed by genetic testing of embryos to implant only those whose tissues matched to Kate's. This is the process of preimplantation genetic diagnosis which was discussed in a previous newsletter (September 2003).

In her short life Anna has had a succession of medical procedures, not because she is ill but because her sister needs her cells. Anna is now 13 years old and has been asked to donate one of her two functioning kidneys to her sister whose own kidneys are failing due to the stress of her cancer. Her parents have always made the medical decisions for her but now she has asked the legal system to give her the right to control her own body.

This book provides a good summary of the issues and consequences of creating a child as a reservoir of spare parts for another. There is no doubt that Anna is loved by her parents and brother or that she is a valued member of the family and her community. But her life is tied to her sister's and her own

wishes are submerged in the need to keep her sister alive.

The book gives a lucid and interesting examination of the issues of saviour siblings. Essential reading for anyone contemplating this approach to health management.

If you are contemplating preimplantation genetic diagnosis discuss it with your GP who may refer you to a fertility clinic or the Queensland Clinical Genetics Service at:

Ph: 07 3636 1987
Email: qcgs@health.qld.gov.au

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

New Groups Update

Thyroid

The Queensland Co-ordinator of Thyroid Australia has advised the formation of several new support groups. Queensland groups are as follows:

Warwick:
Tracie 07 4667 0535

Gold Coast/Tweed Heads:
Lisa 07 5529 9840

Sunshine Coast:
Patricia & Geoff 07 5439 9208 beginning mid year

Brisbane North (Central):
Valerie 07 3863 3257

Brisbane South (Central):
Rick 07 3808 4961

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Tourette Syndrome Group

Following earlier meetings in Brisbane and on the Sunshine Coast in March 2006, a morning tea/get together for people with Tourette Syndrome and their families is planned for Wednesday 3rd May at 10.30am. Depending on numbers, the proposed venue is the Self Help Queensland meeting room at Sunnybank. If you are interested in attending please contact Sue:

Ph: 0428 108 458
Email: camlin1@bigpond.com

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What Is Dynamic Facilitation?

Jim Rough and Associates, Inc. has been teaching public seminars in Dynamic Facilitation Skills since 1990.

With Dynamic Facilitation skills you empower people to solve impossible-to-solve issues because you bring out a quality of thinking where people operate at their best. The facilitator structures the dynamic flow of conversation so each comment becomes an asset to the group and builds to a breakthrough.

The dynamic facilitator establishes a “zone” of thinking and talking known as “choice-creating,” where shifts and breakthroughs are normal. It is like when people face a collective challenge and pull together to creatively overcome it. Sometimes these shifts take the form of new ideas, other times they bring a new sense of what the “real problem” is, and other times there is a change of heart.

Some Benefits Of Dynamic Facilitation:

- Meetings arrive at better solutions to problems, faster, with more consensus
- Groups achieve breakthroughs on impossible-to-solve issues
- People determine and resolve what's really on their minds
- The process builds trust, respect, and the spirit of community
- Everyone is engaged, enthused and committed to the results
- People grow in personal creativity and capability

How Is It Different?

Rather than seeking to manage change, the facilitator elicits, sustains, and enhances the self-organizing dynamic of change. He or she helps people to figure out what they want and to get it themselves. The Dynamic Facilitator works more completely with self-organizing change than the traditional facilitator.

The traditional facilitator elicits self-organizing change in the realm of what people think, talk and decide about, but uses the methods of control to manage how they think, talk and decide. The Dynamic

Facilitator assures a self-organizing dynamic both in what people talk about and how they talk. It leads to a creative thinking process known as “choice-creating” instead of “decision-making.” This approach maximizes what might go right instead of minimizing what might go wrong.

How Dynamic Facilitation Works

The dynamic facilitator focuses on group energy more than the agenda, helping people to determine an issue they care about deeply. Then he or she helps people to speak their minds and hearts.

The dynamic facilitator assures that each comment is appreciated, using four lists: 1) Solutions, 2) Concerns, 3) Data, and 4) Problem-statements. The high-quality of dialogue that results yields spontaneous conclusions, which are placed on a fifth list: 5) DECISIONS.

When To Apply Dynamic Facilitation?

Most meetings aim to help people be logical and reasonable. But this emphasis limits the potential of people to solve problems and form community. Dynamic facilitation takes on bigger issues, while helping people to think creatively together.

Dynamic Facilitation is appropriate for:

- Big-issue meetings
- Heart issues - resolving conflict, building shared values, building community and teams
- Dialogues - coachings, trainings, and personal development
- Straightforward meetings - quality improvement meetings, staff meetings, simple decisions, presentations, planning, etc

In your next meeting notice

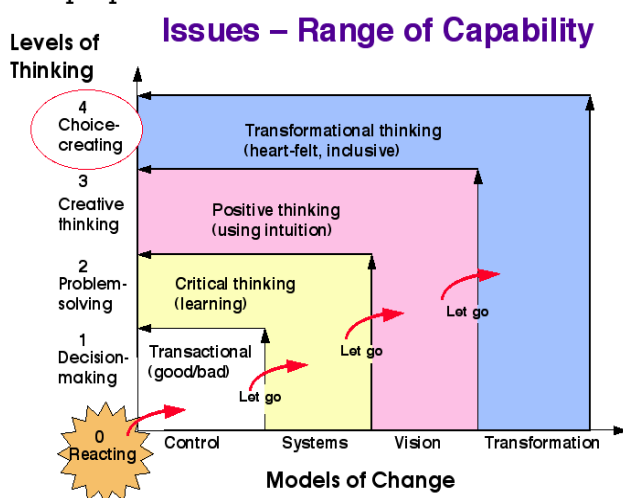
- Do people say what they really think, or do they hold back?
- Is the group addressing the real issue efficiently, or caught in a minor topic? or over-analyzing?
- Are people being creative and seeking win/win solutions, or trying to persuade others?
- Do people leave the meeting with enthusiasm and commitment?

(Continued Page 11)

(Continued from Page 10)

Dynamic Facilitation uses the appropriate Level of Thinking

Four levels of thinking capability are shown in the chart below. Each is associated with a particular model for how change happens. Often, facilitators focus on one style of thinking and one model of change, unknowingly limiting the capabilities of the group. The Dynamic Facilitator starts from the highest level, helping people to address the most pressing issue, but can downshift to the appropriate level if smaller issues are chosen.



Levels of Thinking : Models of Change

Level 0: Reacting ... Here, the circumstances determine the situation. There is no model of change, just avoiding pain and pursuing pleasure.

Level 1: Decision making ... Here the idea is to establish options, and then to choose the best according to preset standards.

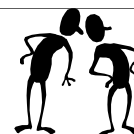
Level 2: Problem solving ... In this case one seeks to understand the underlying causes to problems and to determine high leverage solutions. This is systems thinking.

Level 3: Creative thinking ... Here one uses the unconscious, creative mind to envision a desired future and to bring this future into being. Brainstorming and appreciative inquiry are examples.

Level 4: Choice creating ... This is where important, big issues are addressed creatively, with open minds and hearts. Win/win breakthroughs are the natural result as well as increased trust and the spirit of community.

(Information reproduced from www.ToBe.net
Jim Rough & Assoc, Inc. 1040 Taylor Street, Port Townsend, WASHINGTON 98368 - Phone: (360) 385-7118-)

Link Line



Link Line has returned by popular request!

The purpose of this column is to connect individuals and families for whom no known support group exists.

Self Help Qld will endeavour to facilitate contact wherever possible - *in a mutually respectful, sensitive and confidential manner* - though we are unable to determine the suitability or compatibility of linked individuals and families.

Do you or anyone you know have one of the following conditions?

Cauda Equina Syndrome
Incontinentia Pigmenti
Vitiligo
Hypotonia
Hypospadias
Tick Syndrome

If you would like to be in touch with someone in the same situation please call Trish at the Self Help Qld Office Ph: 07 3344 6919 to facilitate contact.

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Did You Know?

Your group can apply for Free Microsoft Software!

Your not for profit group may be eligible for Free Software through Microsoft's Community Assistance Scheme. (Many groups have taken advantage of this excellent scheme over the years.)

For further information or to make an application please contact:

Rod Fitzgerald
Barbara Bridges & Associates
Level 2, 263 Liverpool Street
DARLINGHURST NSW 2010
Ph: 02 9360 1966 Fax: 02 9361 6698
Email: rfitzgerald@wildchile.com.au

To read the guidelines and eligibility criteria, or to download the very user friendly application form go to:
<http://www.communitybuilders.nsw.gov.au/download/caidetails.pdf>

Letter to those who do not have RSD

RSD is the very painful and debilitating condition, Reflex Sympathetic Dystrophy.

The author of this letter, who remains anonymous, has given permission for it to be used if it can be of help. It came to Self Help Qld via the Queensland Reflex Sympathetic Dystrophy/Complex Regional Pain Support Group. (Sent from Tom Barnes, Director, Maryland RSD & Pain Support Network, USA.)

Having grown to know many members of support groups over the years, we thought this letter might ring true for large numbers of people whose health conditions are accompanied by chronic pain and fatigue.

“Having RSD means many things change, and a lot of them are invisible. Unlike having cancer or being hurt in an accident most people do not know even a little about RSD and of those who think they do, many are actually misinformed.

In the spirit of informing those who wish to understand, these are the things I would like you to understand about me before you judge me.

Please understand that being in pain doesn't mean that I am not still a human being. I have to spend most of my days in incredible pain and exhaustion and if you visit I probably don't seem like much fun to be with. But, I'm still me stuck inside this body. I still worry about school and work and my family and friends and most of the time I'd still like to hear you talk about yours too.

Please understand the difference between "happy" and "healthy". When you've got the flu, you probably feel miserable with it, but I've been in pain for years. I can't be miserable all the time and, in fact, I work hard at not being miserable. So if you're talking to me and I sound happy, it means I am happy. That's it.....it doesn't mean that I am not in a lot of pain, or extremely tired, or that I am getting better or any of those things. Please don't say "oh, you sound better!" I am not sounding better. I am sounding happy. If you want to comment on that, you're welcome to do so.

Please understand that being able to stand up for 10 minutes doesn't necessarily mean that I can stand for 20 minutes or an hour. And, just because I managed to stand up for 30 minutes yesterday doesn't mean I can do the same today. With many diseases you're either paralysed or you can move: with this one it gets more confusing.

Please repeat the above paragraph substituting "sitting", "walking", "thinking", "being sociable" and so on.....it applies to everything. That's what RSD does to you.

Please understand that RSD is variable. It's quite possible (for me it's common) that one day I'll be able to walk to the park and back, while the next I'll have trouble getting to the kitchen. Please don't attack me when I'm hurting by saying "but you did it before!" If you want me to do something then ask if I can. In a similar vein, I may need to cancel an invitation at the last minute. If that happens, please do not take it personally.

Please understand that "getting out and doing things" does not make me feel better, and can often make me seriously worse. Telling me that I need a treadmill, or that I just need to lose (or gain) weight, get this exercise machine, join this gym, or try these classes, may frustrate me to tears and is NOT correct. I am working with my doctor and physical therapist and am already doing the diet and exercise I am supposed to do. Another statement that hurts is "you just need to push yourself more, work harder..." RSD deals with nerves and circulation, and our bodies don't repair themselves the way yours do; pushing myself can do far more damage than good and could result in recovery time of days, weeks or months.

Please understand that RSD may cause secondary depression (wouldn't you get depressed if you were hurting for months and years on end?) but it is NOT created by depression.

Please understand that if I say I have to sit down/lie down/take pills now, I have to do it RIGHT NOW--it can't be put off or forgotten just because I am out for the day (or whatever). RSD does not forgive.

Please understand that I don't want you to suggest a cure to me. It's not because I don't

(Continued Page 13)

(Continued from Page 12)

appreciate the thought and it's not because I don't want to get well. It's because I have had almost every one of my friends suggest one at some point. At first, I tried them all, but then I realized I was making myself sicker, not better.

If there were something that cured, or even helped, all people with RSD would know about it. This is not a drug company conspiracy; there is world wide networking (both on and off the Internet) among people with RSD, and if something worked we would KNOW. If, after reading this, you still want to suggest a cure, then do it, but please don't expect me to rush right out and try it. I'll take what you say and discuss it with my doctor.

In many ways I depend on you -- people who are not in pain. I need you to visit me when I am in too much pain to go out. Sometimes I may need you to help me with the shopping or the cooking. I may need you to take me to the doctor or the physical therapist. You're my link to the outside world.

And as much as possible, I need you to understand me."

Tom Barnes (TomRSDMdSupport@aol.com)
Director, Maryland RSD & Pain Support Network, PO Box 1397 ABINGDON, MD 21009

Queensland Reflex Sympathetic Dystrophy/
Complex Regional Pain Support Group
17 Margaret Street
ROCKHAMPTON QLD 4700
Ph/Fax: 07 4922 1405
Email: sunnyandsam@cqnet.com.au
URL: www.cqnet.com.au/~user/rj.white

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Congratulations Motor Neurone Disease Assoc of Qld Inc

The Motor Neurone Disease Assoc works hard to support families living with this terminal illness. SHQ was very pleased to learn of the Association's successful application for funding for patient aids and facility improvements through the Gambling Community Benefit Fund. We were pleased to offer our letter of Support, and happily extend this offer to other SHQ member groups.



Australian Tinnitus Association

Do you have noises in your ears or head?

Tinnitus is the medical term for the constant ringing, hissing or other distressing noises that people hear in their ears or head. An unpleasant noise that sometimes never stops can be hard to take. People with Tinnitus can have trouble sleeping, concentrating on their work and enjoying recreational activities. Some people with severe Tinnitus are in great distress from the unending noise, which in some cases may lead to anxiety and depression.

Who has Tinnitus?

Tinnitus is often associated with older people. People from all age groups have reported Tinnitus; seniors, adolescents, those in midlife (both men and women) even children. Approximately 20% of the Australian population experience Tinnitus.

What are the causes?

Exposure to very loud noise is not the only cause of Tinnitus but is the most common and one we can control. As the noise in our world becomes louder, more people complain of Tinnitus.

There are other causes: head injury, under active thyroid, stress, ear disorders, neck or jaw disorders, some drugs, cardiovascular disease, the aging process and in rare cases a tumour.

What are the treatments?

There are many treatments that help relieve Tinnitus: Tinnitus Retraining Therapy, Auditory therapies with hearing aid-style and tabletop devices, biofeedback, hearing aids, cognitive behavioural therapy, counseling, conventional and naturopathic medicines, relaxation techniques, hypnosis and others.

Contact: Australian Tinnitus Association (NSW) Limited on (02) 8382 3331/Fax (02) 8382 3333

Email: info@tinnitus.asn.au

URL: www.tinnitus.asn.au

Or

Contact: Rod Murphy at the Brisbane Self Help Group on (07) 3289 2835 or Bruce Smith on (07) 3217 3658 for details of the next group meeting.



Diary Dates

30th April 2006: Thyroid Gland Disorders Seminar presented by Throid Australia (Brisbane) Speaker - Robyn Koumourou, author of "Running on Empty Hypothyroidism"
Ph: 07 3808 4961
Email: bermere@bigpond.net.au
Venue: Chermside Library, Brisbane

17th - 19th May 2006: Lock "Them" Up? Disability and Mental Illness Aren't Crimes Conference
URL: www.sistersinside.com.au/
Venue: Mercure Hotel, Brisbane

17th - 19th May 2006: "Walkabout" 2nd International Conference in Special Care Dentistry (Pre-Congress Seminar for Professions Complimentary to Denistry)
 Topics include:
 Cancer and hospital dentistry
 Geriatrics - more than just growing old
 Laser treatment in dentistry
 Aroma therapy - good scents
 Depression and aggression disorders
URL: www.ada.org.au/societies/asscid/_asscid.asp
Venue: Westmead Hospital, Sydney

3rd - 5th July 2006: 19th Australian Winter School. Annual inter-sectoral conference on alcohol, tobacco and other drugs and addictions. Presented by the Alcohol and Drug Foundation, Queensland.
Email: winterschool@adf.org
URL: www.winterschool.info
Venue: Brisbane

6th - 10th August 2006: 11th International Conference of Human Genetics
URL: http://www.ichg2006.com/
Venue: Brisbane Convention and Exhibition Centre

2nd - 4th November 2006: Velo Cardio Facial Syndrome International Conference 2006. Hosted by VCFS Foundation (Qld) Inc. World professionals will present papers, tutorials and give clinics.
Phone: 07 3857 1073
Email: mail@vcfs.com.au
URL: www.vcfs.com.au
Venue: Carlton Crest Hotel, Brisbane

Thank You!

Self Help Queensland would again like to acknowledge and thank everyone who kindly agreed to be included in the 2006 Self Help Queensland Directory of Self Help and Support Groups, along with those who have supported us through purchasing the Directory and providing positive feedback.



An Australian Government Initiative

Thanks to the Department of Transport and Regional Services for Funding Under the Regional Partnerships Program

Directory Feedback Needed



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

We are particularly interested to know:

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

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

Important News!

Health Quality and Complaints Commission Bill 2006

This proposed bill is being drafted to replace the Health Rights Commission Act 1991. It may have implications for self-help groups. Keep an eye out for announcements and keep informed.