

Newsletter

December Quarter

Issue 4. 2005

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 Smylie

As we enter the gravitational field of December - January ready to be flung into the coming year, as always it is time to reflect on the past and plan for the future. 2005 has been an extremely busy year for SHQ.

Along with our usual services, information sharing and support work we have been busily developing the Directory of Self Help Groups. Ably managed by Anne Meehan and Trish Fallon, this has been a huge project and a timely one. The Directory contains over 600 groups and organizations and represents hundreds of hours of patient data gathering, checking, rechecking and sleuthing.

I would like to congratulate Anne and Trish on a job well done and thank the committee, especially Thea, who spent countless hours providing support and editing and Kim who brought her considerable Directory development experience to the fray in so many practical ways.

Of course none of this would have been possible without funding from DOTARS and the support of their staff.

Our other major task for the year was to update policies and procedures. We have updated an orientation manual which includes lots of who, where and what information, a privacy policy and a workplace health and safety policy.

I would also like to report on the Insurance Auspicing Protocol which was discussed at last year's AGM. As expected this has not been an easy row to hoe. Communication with Insurance companies seems to be fraught with confusion, jargon, suspicion and terror. Not to mention the way things change so rapidly in the industry...It seems like a full time job just keeping up with it. As the protocol states, we intend to develop specific protocols with each organization wishing to explore this opportunity, individually - until there are enough groups involved for inclusion criteria, processes and accountabilities to be developed collectively. We remain committed to providing what ever support we can through this protocol but I ask you to bear with us through the insurance communication nightmare. It may become far too unwieldy, but I hope not - it was meant to help not harm so I will keep you informed of our progress.

As I look forward to 2006 I remain concerned about the need for dialogue and discussion across the community sector. I think it's time the community sector took the deepening of democracy and the development of 'social capital' into its own hands.

(Continued Page 4)



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

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



Newsletter Circulation Up 16%

Newsletter circulation has grown to 1400, an increase of 16% since June. Quarterly editions are sent to 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.

If you would prefer to receive the newsletter by email rather than post, please let us know. We would also appreciate feedback about our service. Please feel free to pass on any suggestions you may have that might help us to do better.

Newsletter articles from groups are very welcome, 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. As an information and referral service for the Self Help Sector, we greatly value knowing what groups are available where, so we can provide better information to those seeking our assistance. For any of the above please contact Trish at the 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.)

Contents

President's Message	1
SHQ Committee & How to Contact Us	2
Genetic Matters	3
Learn to Manage your own Health Problems	4
Cairns & District Grandparents Group	5
Velo Cardio Facial Syndrome	5
Developing Strong Foundations	6
Self Help Queensland Directory Information	7
Health Consumers Network	8
Never Underestimate Parent Power	8
He's not Lazy - He is Dyspraxic	9
Medicines for Headache and Migraine	10
Self Help Queensland Invitation	11
Solace Association	12
Living Life in the Tropics with CFS	12
Cushing's Syndrome	13
Diary Dates	14

Genetic Matters

by Kim Summers PhD

Blowflies - Friend or Foe?

Canberra people have perfected the characteristic wave of the hand required to flip away the pesky little black houseflies which make outdoor life a misery there. But the ACT harbours a greater pest, the sheep blowfly, which is rarely seen in the city but costs the sheep industry millions of dollars each year through blowfly strike.

Fly strike

Lucilia cuprina is a secondary miaisis blowfly. This means that it attacks living skin which already has a superficial wound due to continued dampness or mild bacterial infestation. The female flies



lay eggs on the damaged skin. After a day or so the eggs hatch into larvae (maggots) about 1 mm long. Over the next few days the maggots feed voraciously on the living flesh of the sheep and grow to 1cm or longer. At that stage they drop from the sheep, burrow into the soil and form a cocoon (pupa). A week or so later, flies hatch from the pupae and the cycle begins again.

Maggot therapy

Sheep which are badly infested with blowflies suffer extreme pain, as well as damage to tissue and wool. If untreated, the flystrike will kill the sheep. But blowflies can also be used to clean wounds which have resisted all other treatments including surgery and antibiotics. This is because the fly larvae preferentially attack dead tissue in humans. When placed on a wound, the larvae produce a number of chemicals which kill bacteria and liquefy the dead tissue so that it can be consumed.

Doctors are now deliberately infesting wounds with fly larvae to clean and heal them. This maggot therapy has been practices for thousands of years but the first report in Western medicine is from the American Civil War. Two soldiers had abdominal wounds covered in maggots and healed better than their comrades who had surgery. There are similar reports from the Boer and First World Wars. In Australia *L. cuprina* is used; other countries use its relative *L. sericata*. Overcoming the initial yuck factor is

the main hazard of maggot therapy which is particularly useful for patients who can't be anaesthetised and for wounds which may be difficult to treat.

Forensic flies

Patricia Cornwall's book *Blow Fly* (Putnam Adult, 2003) details the decay of a corpse due to fly infestation. Forensic scientist use the age of fly larvae to estimate how long a body has been lying in the open. But because flies are insects, their development rate is dependent on temperature. The cunning murderers in *Blow Fly* killed their target, released some blowflies into the room and then turned the heaters up high so that the fly life cycle would be completed faster than expected from the outside temperature.

A range of insects can be used to estimate the age of a corpse. Different species favour different stages of decomposition. Blowflies are the first to colonise a body. Usually the time since the corpse was exposed to the insects is estimated using eggs, third instar larvae (ie the last stage before pupation) and adults, because it is easier to identify the species and hence the appropriate duration of the life cycle. L. cuprina is commonly found in Australia. Other blowflies, such as Sarcophaga, Calliphora and Chrysomya species feed on carcasses and can also be used for forensic investigations.

Flies in the garbage

L. cuprina is usually found in sheep farming areas, with a high number of pupae where sheep commonly cluster, such as at waterholes and sleeping sites. Brisbane is the only major city where L. cuprina is the main domestic pest fly. The shiny green flies you may find hovering around your garbage bin or intruding on the evening meal are L. cuprina. They are likely to feed on meat scraps within the wheelie bin and the larvae will form pupae at the bottom.

Next time you are annoyed by the flies hovering around the family barbeque remember that these pesky creatures can actually be useful to us.

(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. This article was first published in the Bright Minds Newsletter in September 2005.)

http://www.brightminds.uq.edu.au/teachers/news/ne wsletters/past_issues.html

(Continued from Page 1)

I have been involved with SHQ for nearly 9 years now. The only time I meet or see others involved in other groups (other than at the AGM) is when we have been called together at the behest of either a government body or a research institute. We are consulted, focused grouped and surveyed and we are trained – every time a reporting process or application or evaluation framework changes, to develop our 'ownership'. Others put the framework around what will be discussed, others interpret, collate and use or discard our contributions.

There is even greater potential for this as the Forster Inquiry calls for involvement of community in area health plans and service profiles based on community values about health and health care service.¹

I would like to suggest that the community sector takes some positive steps towards strengthening our relationships, links and networks through conversation. I know we are all busy people and often we can't justify our time if there are no "outcomes" predicted before hand. However I think we need to show some leadership and explore highly communicative relationships, getting to know each other, sharing our issues, challenges and disappointments – not just once but regularly and sustainably.

This is not necessarily about speaking with 'one' voice. It may be speaking with 'knowing' voices. SHQ is happy to take a step in this direction. I would like to invite any who are interested to a *conversation café* next year. I am hoping that our friends in rural areas will hold similar events and we will be able to share our discussions in some way.

If you would like to be involved in planning this, or you would like to come or you have a question about the proposal, please let me know ssmylie@bigpond.net.au

For now it only remains to wish you all a happy and safe holiday season and hope that we are about to take a quantum leap into a new, collaborative era of well being in Oueensland.

Regards Sue

 1 On first read I can't discern any impact on the Inquiry due to the SHQ submission recommendations.

Learn to Manage Your Own Health Problems!

If you suffer from any long term health problems, then you could benefit from learning how to manage them better.

In 2006, Brisbane South Community Health Service will be running self management courses to help people address their health issues. These will be run out of QEII Hospital, Inala Community Health Centre and Coorparoo Community Health Centre.

The courses are one morning a week (2-3 hours) for 4, or 6 weeks depending on the course you choose to attend.

The courses are as follows:

- Chronic Disease Self Management (CDSM) – Suitable for any long term health condition such as:- past stroke, heart disease, arthritis, diabetes, lung conditions, fibromyalgia, chronic fatigue etc, or for people who have more than one specific health condition.
- Arthritis Self Management (ASM) Similar information To CDSM but more specific to Arthritis.
- Osteoporosis Prevention and Self Management (OPSM) again similar to CDSM but more specific to osteoporosis.
- Diabetes Education Group (DEG) specific diabetes education sessions
- Breathe Easy specific education for people suffering lung conditions such as emphysema, COAD and any other Lung complaints.
- Lighten Up program emphasizing making healthy food choices, being physically active and making healthy lifestyle changes including setting realistic goals, overcoming negative behaviours and managing stress.

Cost: Course is Free. Course Manual \$45, but in case of hardship, may be loaned free.

Anyone with any of the above conditions is welcome to participate. To find out more information, or to register for a course please phone 07 3710 2222 and ask for Maria.

(For other areas in Queensland please contact your local Community Health Centre for information about the above courses).

Cairns and District Grandparents Support Group

- Providing support and information to Grandparents and extended family members.

The birth of a child is a wonderous occasion for Parents, Families and Friends, yet many Grandparents are denied this experience and pleasure through relationship breakdowns, distance and other factors. Even those rearing Grandchildren can't enjoy the delight of Grandparenting as they have to assume parenting roles. This is why Grandparent Support Groups have been formed throughout the country - to provide support and information to Grandparents and extended family members.

The Cairns and District Grandparents Support Group was formed in 2004 when a group of like minded people got together after seeing a story in a local newspaper about a Grandmother wishing to form a support group to help other Grandparents in similar situations. The group was set up with the help of Mr Nev Abbey from the Townsville Grandparents Group and TRCOTA and now operates under their auspices.

As yet, the group is a small non profit organisation which receives no funding. However, it is able to function with help from Hambledon House Community Centre and dedicated members who print and distribute brochures and newsletters. This information helps the group to keep in contact with those who are unable to attend meetings, or may just want phone contact.

The aim of the group is to allow, where possible, all Grandchildren, Grandparents and family members to be able to:

- enjoy the special bond they share
- give them a sense of belonging
- know their family heritage
- experience the special love Grandparents and extended family can provide

The Cairns and District Grandparents Support Group meet on the first Wednesday of each month at Hambledon House Community Centre, Edmonton, at 9.30am. All Grandparents, family members and friends are welcome to join us for a cup of tea and a chat, or just give Janet or John Goessling a call on 07 4055 5161.

Support for Queensland Families Affected by Velo Cardio Facial Syndrome

Velo Cardio Facial Syndrome is a genetic condition. It is caused by the deletion of some genetic material from Number 22 chromosome (referred to as the 22q11 deletion).

Velo - refers to palate. VCFS people either have submucous cleft or a cleft palate,

Cardio - the heart is affected.

Facial - they have similar facial features, elongated face and slightly almond eyes.

Syndrome - is a collection of similar findings.

VCFS is characterised by - these features, learning difficulties, speech delay, behavioural problems, up to 186 other physical findings, widely varying in degrees of severity. VCFS affects one in 3,000 births. VCFS was first described by Dr Robert Shprintzen at the Montefiore Hospital & Medical Centre in New York in 1978. VCFS can sometimes be known as Shprintzen Syndrome.

VCFS Qld was established in 1997 by Stephen & Kathy Russell. As parents of a child with VCFS they wanted to learn more, and meet other families. Foundation Qld will open the first VCFS Centre later this year at the Mater Children's Hospital, Brisbane.

The 2006 VCFS International Conference will be hosted in Brisbane from Thursday 2nd to Saturday 4th November 2006, and will be attended by an international consortium of professionals and lay people.

If you would like to speak to someone who has experience of the condition, or to receive further information please contact:

VCFS Foundation Qld 1 Milman Street CLAYFIELD QLD 4011

Phone: 07 3857 1073 Fax: 07 3857 3444

Email: dinnes@vcfs.com.au
URL: www.vcfs.com.au
Membership: \$22 per annum

Developing Strong Foundations

Language and Literacy Development in the Home

By Jane Heyden B.Ed (Early Childhood) M.Ed.St

Self Help Queensland recently spoke to some self help groups for parents of children with learning difficulties. The groups were searching for practical information to share, so SHQ approached Jane Heyden, an Early Intervention Language and Literacy Teacher, who kindly agreed to pass on some of her valuable knowledge of 3 to 6 yr olds.

'There are many opportunities in daily routines at home where you can encourage your child's language and literacy development.

In the Kitchen

I found it amazing the other day when my three-year-old nephew saw a pineapple and asked me "What is that"? Although he loves to eat pineapple, it was the first time that he had seen a pineapple that hadn't been sliced. He had many opportunities to learn new vocabulary when he could see the whole pineapple.

"Look at the spikes on the pineapple!".

"Feel the skin. Is it rough or smooth?"

Getting Dressed

When getting dressed in the morning, you could play describing games. By using words such as stripes, spotty, checked, patterns, you are adding new words to your child's vocabulary.

Story Time

When reading a story to children you can help their comprehension skills by asking questions about the book. Start questions off with words like: What, where, who, why and how. "How do you think the boy felt when he was pushed over into the mud"?

Outside in Nature

Observation and language skills can be encouraged in many different ways. Going for walks with children can create opportunities to extend your child's understanding of basic concepts.

Choose any two things in the environment to compare: "Look at those two Jacaranda trees, they have the same purple flowers". Encourage your child's awareness of the differences and similarities between trees, leaves and flowers In the garden when filling up a wheelbarrow, use language to describe what you're doing. "This wheelbarrow is so heavy, how can I make it lighter"?

In the Bath

There are many opportunities in the bath to practise naming body parts. Practise listening skills with simple games like Simon says. You can give directions in a sequence: "Can you touch your stomach and then your head"?

Pre-Reading Activities

Visual memory is an essential skill to develop for reading. Children have to remember the shapes of the letters and numbers from one day to the next. Depending on the age of your child, use two to five everyday objects.

- 1. Tell the child what the objects are.
- 2. Cover the objects up with a towel.
- 3. Take one object away.
- 4. Ask the child "What is missing"? The child has to remember and tell you what is missing.

Phonetic skills (or sound awareness skills) are essential for reading. Parents can help to develop these foundations by encouraging children to become aware of sounds in their environment. Describing the sounds that children hear encourages their interest in sounds. "Gosh that dog is barking loudly". "Those breaks made a squealing sound".

For older children you can make up little rhymes to emphasise the initial sounds of their name: "Sammy the slimy slug likes slithering in the soil". "Animalia" written by Graeme Base is great for developing children's awareness of the initial sounds in words.

Enjoy time with your children!'

To contact Jane:

Phone: 3876 7824 or 0418712569.

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.



Directory

of

Self Help and Support Groups

2006/07 Inaugural Edition



The Directory contains entries for self help and support groups all over 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.

How to order the Self Help Queensland inaugural, comprehensive Directory of Queensland Self Help and Support Groups.



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.

Organistion		
Contact name		
Mailing Address		
Town/SuburbStatePostcode		
PhoneFax		
Email		
Please send (No of copies)@ \$30.00 ea	Payment details Please make cheques/money orders payable to "Self Help Qld Directory". Post to:	
Cost including GST (+ \$3.00 ea)\$ Postage & handling (+ \$5.50 ea) \$	Self Help Queensland Inc PO Box 353 SUNNYBANK QLD 4109	
TOTAL enclosed \$	Ph/Fax: 07 3344 6919 Email: selfhelp@gil.com.au	

Health Consumers Network Urges Citizen Involvement

- for a Better Health Care System for all

Health Consumers Network (HCN) is non party political - grassroots, unfunded, and community based. We provide a consumer perspective on health policy, planning, and service delivery. Initially launched by Consumers' Health Forum in the early 1990's, volunteers have continued operating HCN at various levels of activity since that time.

HCN lobbies government, health professions, and the wider health system to promote a consumer perspective in health planning and service delivery. We work with other organizations to promote our key project areas: safety and quality in the health system; the WHO's human rights perspective on health; a framework for patient centered compassionate care; and a sustainable universal Medicare system.

In order to control health costs, HCN believes that one of the strategies needed to be adopted is a solid commitment to primary health care which embraces the community's participation in illness prevention and health promotion.

This requires a process for enabling people to take more control in making improvements to their health. It requires building healthy public policy; creating supportive environments; strengthening community action; developing citizens' personal skills; and reorienting health services away from treating patients as passive recipients of care to active participants.

HCN believes only a broadly consultative process supported by all political parties has any chance of overcoming the obstacles to progress that have frustrated efforts to provide Australians with the reforms needed to sustain excellence, equity and efficiency.

To be effective in promoting this to our governments, HCN urges community health organisations to join the Australian Health Care Reform Alliance (AHCRA) and support its recommendations for government to hold a nationwide consultation and engagement with citizens to determine the values and principles we as a nation want to underpin our county's health system.

AHCRA is currently composed of more than fifty health professional and consumer organizations who speak with one voice on the need for citizen engagement in major restructuring of our health system.

If you have any questions about AHCRA, or would like copies of AHCRA's statement of principles, history and communiqué which was presented to the federal government in 2003, please contact Kathy on 07 5497 5786 or hcm@aapt.net.au. Alternatively, you may contact the Chair of AHCRA, Mr. John Dwyer on email <a href="https://j.ichair.org/j.chair.

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Never Underestimate Parent Power (NUPP)

NUPP is a group of parents and carers who offer support to other parents who have children with special needs owing to disability, illness or life circumstance.

NUPP's activities take place within the context of a child's Educational life. The group endeavours to assist parents to overcome obstacles caused by red tape and difficulties in understanding relevant Government policy as it applies to Education..

As well as assisting parents with personal support and the provision of information, NUPP endeavours to work at a grass roots level, through the use of dialogue, to facilitate the changes it deems necessary to achiever a fairer education system for all.

By gathering stories, with due recognition of the need for privacy and confidentiality, NUPP also hopes to achieve change through the strength of numbers.

Individualised Behaviour Management Plans, Respite Care, Safe Zones/rooms in schools for students experiencing difficulties, abolition of cards given as punishment for poor behaviour and lack of support funding are examples of some of the issues NUPP has in its sights.

For further information please write or phone NUPP representatives:

Debbie 3293 1170 **Jeanette** 3285 5671 **Jeanine** 3423 0064 **Greta** 3876 8034

PO Box 154 INDOOROOPILLY QLD 4068

He's Not Lazy - He is Dyspraxic

Developmental What is Dyspraxia?

Developmental Dyspraxia is a motor planning disability, which is present from birth. It is an impairment or immaturity of the organisation of movement. This affects the way in which the brain processes information, resulting in messages not being properly or fully transmitted. In other words a child knows what he wants his body to do but can't get his body to do it!

Dyspraxia affects up to 10% of the population and statistics show that males are four times more likely to be affected than females. Children with Dyspraxia appear outwardly like all other children yet this hidden disability can lead to severe educational, behavioural and social problems for the

There are three types of Dyspraxia

A child with ORAL DYSPRAXIA has difficulty with planning and executing non-speech sounds, such as blowing, sucking or individual tongue / lip movements. This may indirectly affect speech and / or swallowing skills.

A child with VERBAL DYSPRAXIA knows what he/she wants to say, but is unable to organise the lips, tongue, palate and vocal cords for the voluntary production of speech, i.e. they have difficulty initiating sounds and sequencing these sounds into words. Young children with verbal dyspraxia often use gestures in order to communicate.

A child with MOTOR DYSPRAXIA may not know what they want to do, and will appear clumsy and disorganised. They find it hard to plan and organise the body movements needed to carry out age appropriate motor skills in a smooth co-ordinated manner, i.e. skipping, riding a bike (gross motor skills), tying shoe laces, writing (fine motor skills).

Who can provide help?

Early diagnosis and therapy is very important. So if you know a child that is clumsy, or age appropriate motor skills, please contact a Speech Pathologist for advice on Oral and Verbal Dyspraxia and an Occupational Therapist for Motor Dyspraxia.

These professionals are available through private practice, your local community health centre, or hospital. No referral is required but waiting lists may apply.

If you would like further information, support or assistance on Dyspraxia, please contact Christine Meredith - National Coordina-

Australian Dyspraxia Support Group & **Resource Centre Inc**

PO Box 5519 SOUTH WINDSOR

NSW 2756

Email: information@dyspraxia.com.au

Website: www.dyspraxia.com.au

Ph: 0245 776220 Fax: 0245 776088

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Welcome to all our new readers!



Welcome to everyone who is receiving the SHQ newsletter for the first time.

Our newsletter circulation is on the increase! Through the Directory project we have been fortunate in locating many and varied groups in all parts of the State - as well as some National groups for rarer conditions.

We invite all new readers to contribute articles about your groups, or upcoming events you need advertised. If you would like to network with other like groups please let us know and we will try to assist. Call us on 07 3344 6919 or email selfhelp@gil.com.au.

Do You Know Anyone with Polycythemia Rubra Vera?

A Brisbane man who has been diagnosed with PRV would like to make contact with others with the condition. Please contact SHO on Ph: 07 3344 6919.

Medicines for Headache and Migraine

Many of us use the terms headache and migraine interchangeably. However, in reality, they are different conditions, even though it's often quite difficult to distinguish between them.

Headache or migraine?

If your headache is on both sides of the head, and is not made worse by going about normal activities, and is accompanied by nausea, vomiting or sensitivity to light and noise, then it's more likely to be a migraine.

In addition, if it's a migraine, the headache may be preceded or accompanied by an "aura". The symptoms of an aura include seeing lights or spots, losing your vision, or suffering pins and needles, numbness or speech disturbances.

If you suffer frequent or persistent headaches, it's important that you see a doctor. Don't be tempted to self-treat them by taking more than the recommended dosage of painkillers. Your headaches may not be ordinary headaches: they may be due to an underlying condition, or they may need specific treatment.

In addition, paradoxically, if you're using painkillers frequently, your headaches may be caused by the painkillers, particularly if they occur on most days or every day. These medication overuse headaches can be caused by any of the painkillers used to treat headache and migraine, but are more likely when using combination painkillers.

Treating headache

Occasional headaches can be alleviated with simple painkillers, such as paracetamol, ibuprofen and aspirin. Avoid preparations containing codeine.

Massaging and stretching the head and neck muscles may alleviate occasional headaches. There is also some evidence that spinal manipulation by a physiotherapist, chiropractor or osteopath can reduce headache pain.

Preventing headache

Reducing stress and managing stress better using relaxation techniques and specialised counselling may help prevent headaches.

Treating migraine

It generally takes time to work out the best way to control migraine attacks. Simple painkillers, such as aspirin or ibuprofen, are usually tried first. In many cases, these medicines eliminate mild to moderate migraine headaches, or reduce their severity. If you can't use aspirin or ibuprofen, try paracetamol. If you have nausea or vomiting, think about using tablets that can be dissolved in water.

If your migraines are severe or disabling, or if you find that simple painkillers don't work, talk to your GP about trying a specific migraine medication. Several preparations are available, so you will need to work with your GP until you find the best medication and dose for you.

If you use a specific migraine medication, use it as soon as you feel the migraine headache coming on. Using the medication that works for you right from the start means that you're more likely to alleviate the migraine before it becomes severe. If your medication doesn't work, it's probably best to retreat to bed in a quiet and darkened room.

Preventing migraine

Some people can reduce their frequency of migraine attacks by recognising and avoiding the things that trigger them. The most common triggers appear to be stress, irregular sleep, skipping meals, smoking, and some foods such as chocolate, cheese, citrus fruits and wine.

While it's generally not possible to avoid stress completely, you may be able to manage it better by undertaking relaxation training or specialised counselling. Other techniques that may be useful include yoga, massage and exercise.

Keeping a pain diary each time you have a migraine may help you recognise the things that trigger and resolve them. Later, you can use the diary to monitor the success of your treatment. A pain diary can be found at www.clininfo.health.nsw.gov.au/nswtag/publications/guidelines/migraine_patient.pdf.

If you suffer more than three severe migraines a month, your doctor may suggest taking a medicine to reduce their frequency. These medicines often cause side effects, so you and your GP will (Continued on Page 11)

(Continued from Page 10)

need to weigh up the benefits and side effects before making a decision whether or not to try one.

Avoid codeine preparations

Avoid painkillers containing more than one medicine, especially those containing aspirin, ibuprofen or paracetamol *plus* codeine. These painkillers are often called combination painkillers.

The codeine in combination painkillers can slow down the absorption of other medications being used, and may make any nausea and/or vomiting worse.

Combination painkillers are also often implicated in cases of medication overuse. Instead, use painkillers that contain only one medicine, such as paracetamol, ibuprofen or aspirin, to alleviate headache. These are often called simple painkillers.

Simple Painkillers

Aspirin Aspro, Aspro Clear, Bayer Aspirin, Disprin, Herron

Aspirin, Solprin

Ibuprofen Actiprofen, Advil, Brufen,

Bugesic, Nurofen, Tri-Profen

Paracetamol Dymadon, Herron Paraceta-

mol, Lemsip, Panadol, Panamax, Parahexal, Paralgin,

Setamol, Tylenol

Combination Painkillers

Aspirin & Codeine

Aspalgin, Codiphen, Codis, Codral Forte, Disprin Forte,

Veganin

Ibuprofen & Codeine

Nurofen Plus

Paracetamol & Codeine

Codalgin, Codapane, Codral Pain Relief, Dolaforte, Dymadon, Febricod, Hexal Comfarol Plus, Mersyndol Day Strength, Painstop, Panadeine, Panamax Co,

Prodeine

Paracetamol & Codeine & Doxylamine

Codalgin Plus, Fiorinal, Mersyndol, Panalgesic

The above list is not exhaustive. There are over 300 paracetamol preparations.

(Medicines Talk Newsletter No 15 Spring 2005)



Invitation

SHQ would like to apply for some funding to support our Conversation Cafés. We would like to include some training in Dynamic Facilitation to people interested, with particular emphasis on making it accessible (ie free) to community people from rural areas. We would like to link this training with Conversation Cafés in rural and urban areas and would like to invite expressions of interest from communities and participants in the training and the cafés

At this stage we would like you to let us know if you would like to be involved and if you are prepared to support our funding application. If you would like to know more about Dynamic Facilitation you can see details at:

http://www.tobe.net/

If you would like to know more about the ideas behind the Conversation Café approach have a look at:

http://www.co-intelligence.org/

Please talk to your community about this and let us know if you want to be involved. Ring Trish on 33446019 or email Sue Smyllie on: ssmyllie@bigpond.net.au

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SOLACE Association Inc

Solace Brisbane offers understanding and friendship for widows and widowers.

The group meets twice a month at Garden City Library at 1pm. Next meeting December 1st 2005.

After a Christmas break, the group will again meet on 16th January 2006, and meetings will take place on the first and third Mondays of the month during 2006.

For further information please phone Kathy on 3341 4643.

Living Life in the Tropics with Chronic Fatigue Syndrome.

The rise of CFS support groups in 11 North Queensland locations!

Hi!

My name is Neil Reynolds. I used to live in Perth, Western Australia. In 1994 I was prematurely retired after contracting Chronic Fatigue Syndrome through a viral infection. I had struggled to work with the illness since 1985.

It felt like I was dragging a two ton lead weight to my desk each day. The fog in my head was always about eye level, and my brain felt like it was wrapped in cotton wool. Restful sleep was a luxury I never experienced. My eyelids had to be permanently propped up with coffee, aches and pains were my constant companions. I had a permanent flu, elevated temperature, swollen lymph glands, and intermittent cognitive failure.

My life had come to a natural pause - work having become a long faded memory. I decided to move closer to my ageing family in North Queensland. Mareeba was my first port of call.

Mareeba is normally hot, dry and dusty (300 sunny days a year!). After a few weeks in a hot timber house, I was starting to melt, and the first signs of hay fever came. The next move was 30km away. The Atherton Tablelands being what it is, the climate was entirely different: higher up the mountain, cooler, wetter, greener, and a breeze!

Now I have been in Atherton for over 3 years, and I must say the climate has done me good. There are no extremes of temperature - either hot or cold (not like Perth!), but you do watch the humidity. The wardrobes here are open affairs so that the humidity doesn't build up and rot your clothes. My library of books has to be guarded against insects, and the humidity controlled. At least the temperatures are so constant that you can wear shorts and T shirt for 9 months of the year. Just avoid any exertion during times of the day that may raise perspiration.

Another big challenge are the agricultural chemicals. There are crop dusters spraying all sorts of evil onto the crops around here, and they don't wait for the breeze to stop. Half an hour later we start coughing! Congested lungs are now part of the landscape. You learn to close the windows or go for a drive.

A meeting with an interested journalist from the local free newspaper in Atherton led to an interview about Chronic Fatigue Syndrome. I had no idea how far the paper was distributed. One small article produced over 100 phone calls, one from 300km away.

Another article in a Cairns paper brought another flurry of calls. But the people were all tired, and some could not travel. So the decision was made that we would have to take the meetings to the people!

Out of that has arisen a support group that collects people from an area the size of Tasmania. We have regular meetings in 11 locations, each with a local contact person. We distribute information packs and pamphlets about Chronic Fatigue Syndrome, Fibromyalgia Syndrome, Multiple Chemical Sensitivity, and Allergies.

We have Kits for Doctors, and offer support to carers and other community groups. We also provide public information sessions open to the community. We now have contact with over 270 sufferers, and 300 other "interested parties".

All our people are volunteers. We are entirely unfunded, but we do advocate membership of the Queensland Association. The ME/CFS/FM Support Association Qld Inc State office is now located in Toowoomba, and can be contacted as follows:

ME/CFS/FM Support Association Qld Inc 27 Scott Street

TOOWOOMBA 4350 Phone: 07 4632 8173 Fax: 07 4632 8173

Email: mefmtba@bigpond.com

URL: www.users.bigpond.com/mefmtba

How can we help YOU?

Neil Reynolds CFS Support Group Co-ordinator ATHERTON

Phone: 07 4091 2970

Cushing's Syndrome

New Group Emerging in Queensland!

Cushing's Syndrome is a rare endocrine or hormonal disorder affecting approximately one in 250,000 people. It occurs when the adrenal glands release too much of the hormone cortisol into the body for long periods of time.

Cortisol is essential to many of the body's cardiovascular and metabolic functions. But perhaps its most important job is to help the body respond to stress. Normally the adrenal gland releases the exact amount necessary to meet our daily needs. However, sometimes the process goes wrong and an excess of cortisol is produced.

The malfunction may be caused by:

- A pituitary tumour, which causes the pituitary gland (at the base of the brain) to stimulate the adrenal glands to secrete high levels of cortisol (Cushing's Disease)
- A tumour of the adrenal gland (located above the kidney)
- A tumour in other parts of the body (thyroid, thymus, lungs, pancreas, ovaries)
- Medications given to treat other conditions, such as Prednisone, commonly prescribed for asthma, rheumatoid arthritis or lupus

There is no single symptom shared by everyone with Cushing's Syndrome. The effects of excess cortisol include:

Upper body obesity with thin arms and legs
Red, round face
High blood sugar
High blood pressure
Muscle weakness
Acne
Female balding
Menstrual irregularities
Thin skin and bruising
Poor wound healing
Increased body or facial hair
Depression
Cognitive difficulties
Emotional instability
Sleep disorders

Fatique

Diagnosis can be long, difficult and frustrating. The process can take many months as tests are performed to identify the cause. Treatment will depend on the diagnosis, and could take the form of medication, surgery or radiotherapy.

Recovery from Cushing's is also a long process as your body gets used to not having excess amounts of cortisol.

If you require any further information, or if you would like to talk to someone in the same situation, or you are interested in becoming part of an emerging support group in Queensland, please contact Annie:

Phone: 07 3720 1402

Email: amugridge@hotmail.com.

(Source: Cushing's Support & Research Foundation

2005 www.csrf.net)

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Supporting Siblings: When a Brother or Sister has a Disability or Chronic Illness



This booklet, published by the Australian Association for Families of Children with a Disability (AAFCD), is designed to assist parents and service providers with sibling issues. It outlines common sibling responses from early childhood through to adolescence.

"Supporting Siblings" focuses on strategies that promote coping and resilience in siblings. Social factors that impact on life experiences are also considered in terms of how they contribute to the ability of siblings to cope with their situation.

AAFCD is a not for profit organisation run by parents in Victoria. Very generously, a hard copy of "Supporting Siblings" is available **FREE** to parents in Queensland. Contact AAFCD on Ph: 03 9500 1232 or 1800 654 013 or email: mail@acd.org.au.

A printable version of "Supporting Siblings", along with other valuable information and support, is also available on the Association website: www.acd.org.au

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Diary Dates

8th - 10th February 2006: 7th Annual VALID Self Advocacy Conference - Having a Say 2006. My Life! My Voice! My Choice!

For further information please contact VALID:

Phone: 03 9416 4003 Email: office@valid.org.au, URL: www.valid.org.au

Venue: Costa Hall, Deakin University, Water-

front Campus, Geelong

19th February and 21st February 2006: Menopause the Musical. Celebrating life after 40, Menopause the Musical is a hilarious celebration of women and "The Change". Laugh out loud, sing out loud, and enjoy your journey with the Sisters. Organised by Children by Choice Association.

Phone: 07 3357 9933

Email: info@childrenbychoice.org.au URL: www.childrenbychoice.org.au **Venue:** Twelfth Night Theatre, Brisbane

29th March - 2nd April 2006: Ideas Festival

Celebration, discussion and debate of ideas and innovation - with lectures, demonstrations, debates, panels and exhibitions. Open to all. Presented by Qld Govt, Griffith University and BAC Australia.

Phone: 07 3875 3238

Email: info@ideasfestival.com.au URL: www.ideasfestival.com.au **Venue:** Southbank, Brisbane

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@adfq.org URL: www.winterschool.info

Venue: Brisbane

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

Thanks Again!



Self Help Queensland would like to thank everyone who kindly agreed to be included in the 2006 Self Help Queensland Directory of Self Help and Support Groups - for health conditions and wellbeing issues.

We have endeavoured to include as many regional groups as we could find, and if we have missed your group we would be very happy to hear about it and make sure it is included in the next edition.

We've have a few hiccups and fallen a little behind, but hope that the Directory will be launched some time in December, and will prove to be a valuable community resource. It is certainly a reflection of all the marvellous work carried out by community support organisations in Queensland.

Thank you once again from all at SHQ.

Urgent! Volunteer Treasurer Needed

The Stroke Association of Queensland Inc is a not for profit community organisation which works to improve the quality of life of Queensland stroke survivors, their carers and families.

The Association, run mostly by volunteers, is desperately in need of an accomplished Treasurer - someone who is willing to donate some time to manage the financial accounts in a professional manner. (Software used is MYOB).

If you have some time on your hands and would like to help out, the Association President, Ian Murdoch, would love to hear from you on Ph: 3277 3838.

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Active, participant directed communities are healthier places to live than insular ones

Sue Smyllie 2005