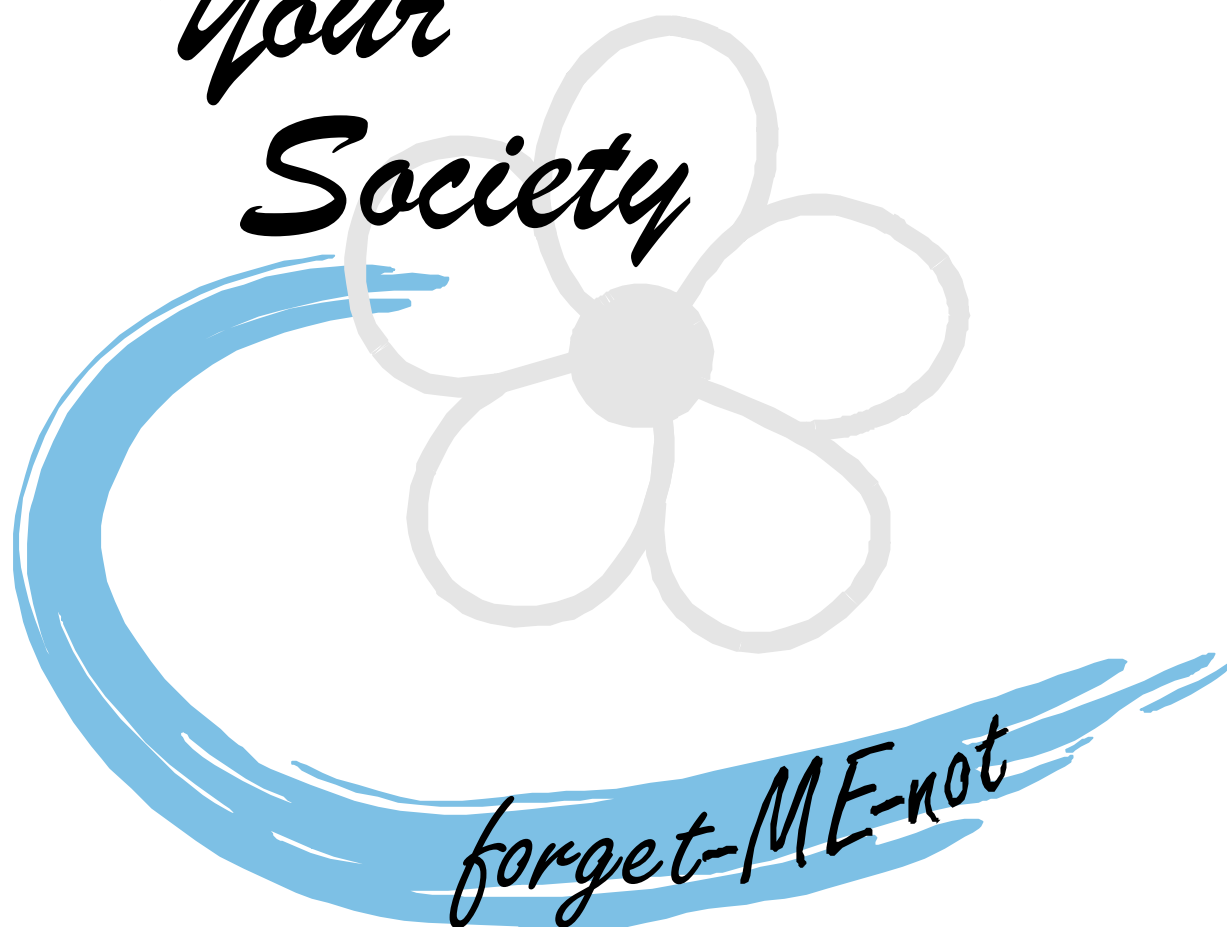


Talking *Point*

March 2001 Official Journal of the M.E./C.F.S. Society (SA) Inc.

*Your
Society*



Office Ph: (08) 84108929 Fax: (08) 8410 8931

Support & Information Line City Callers: 84108930 Country Callers: 1800136 626

www.sacfs.asn.au

ME/CFS Society (SA) Inc.

The ME/CFS Society (SA) Inc. is a non-profit organisation (Registered Charity 698) which aims to:

- Promote recognition and understanding of the disease among the medical profession and the wider community;
- Provide information and support for sufferers; and
- Promote and foster research towards a more effective treatment and cure.

Page 2

Patron:

Lady Neal



Advisory Panel:

Judy Lovett: Past President of the ME/CFS Society (SA) Inc., Chairperson of the ME/CFS Association of Australia Ltd.

Dr P. Del Fante : GP, Medical Director of the Western Division of General Practitioners.

Membership

Annual membership is from July to the following June, and includes subscription to the magazine Talking Point. Membership rates are as follows (GST included):

Regular membership.....	\$30
Pensioner/Student/Unemployed.....	\$22
Family/Professional.....	\$35
Overseas – as above plus.....	\$10

(Family membership is designed for families with more than one sufferer, or more than one person who will directly benefit from the membership at the same place of residence; it enables each person in a family to have membership status and voting rights, but there is in total only one vote for each family membership at AGMs and Special General Meetings.)

Management Committee 2000

The Society is directly administered by a voluntary committee elected at the Annual General Meeting.

President: Boris Dontscheff
Vice-President: Paul Leverenz
Secretary: Steph Retallick
Treasurer: Marion Hansen
Management Committee Members:
Margaret Whyatt, Farrah Tate, Beulah Carter, & Margaret Wing

Contact Details

Any correspondence should be directed to:
ME/CFS Society (SA) Inc.
PO BOX 383
Adelaide
SA 5001

Note: It is our policy to ignore anonymous correspondence.

Deadline for Next Issue May 31st

Talking Point

Talking Point is the official journal of the ME/CFS Society (SA) Inc. It is published quarterly, and is financed primarily by member subscriptions.

Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed of the various research projects, diets, medications, therapies etc. All communication both verbal and written is merely to disseminate information and not to make recommendations or directives. Unless otherwise stated, the views expressed in Talking Point are not necessarily the official views of the Society or its Management Committee and do not imply endorsement of products or services. Always consult your medical practitioners before commencing any new treatments.

Notice to Vendors

The ME/CFS Society (SA) Inc. does not permit direct marketing of products to our members. This includes distributing promotional literature, providing demonstrations of products or approaching members at any of our events.

If you have information about products which you wish to bring to the attention of the Society, you should direct it to the Society GPO Box 383, Adelaide 5001.

In particular, you should note that members give their contact details to the Society in trust and misuse of those is a breach of confidentiality. Any use of our membership list for direct marketing will be investigated and dealt with appropriately.

Advertising

To advertise your products or services in Talking Point, please call the Society office on 8410 8929.

Small ads submitted by our members are free subject to the policy below.

Talking Point reserves the right to reject any advertisement it considers unsuitable for publication or decline to publish for any reason at its absolute discretion. Advertisements lodged with Talking Point must comply with the Advertising Codes of the Media Council of Australia and with the interpretations of the Advertising Standards Council.

Donations

Donations are an important source of income for the Society and are welcome at all times.

All donations of \$2.00 or over are tax deductible and a receipt will be issued.



ME/CFS Blue Ribbon Stick Pins: Do you have one?



Available from the society for only \$2.

EDITORIAL



Hi there, welcome to the latest edition of Talking Point. Yes we've had a change of editor - thank you so much to Lyn Rossitor for her many, many years of proficient and tireless service as the Editor of Talking Point. Your efforts over the years have not gone unnoticed - Talking Point has been one of the most loved, core services of this Society. We hope we can follow in your footsteps.

This edition heads up a New Year with new aspirations and much activity already. Details of recent events such as the Special General Meeting, Election General Meeting and session with Guest Speaker Dorothy Morris are provided in the "Society News" section of this issue.

We hope you like the new-look format of the journal. With members input and help we can continue to improve on the size and content of it.

One major aim of the editorial team is to achieve greater interaction between members and those involved in producing this publication. We would very much appreciate your feedback - we welcome responses to articles, general suggestions for improvement, or even ideas for specific articles and regular columns/items. For this purpose, we have instituted a forum page, so please do not hesitate to put your thoughts to paper.

We currently have vacant positions on our editorial team and are keen to form a team comprising a number of members from diverse backgrounds. We feel that this is the best way to collate material that is broad in interest and knowledge. We also feel that this is necessary to minimise the workload for each individual. Please also note that additional volunteer positions are vacant in the Society - please call the office for further details.

As a final note - but certainly not an afterthought - we thank the current members for their support and encouragement for the new management committee.

Farah Tate / Paul Leverenz
Editors

Contents

SECTION 1: GENERAL

4. Management Committee Report
5. FORUM PAGE: Poem included
6. NEWS: "Five Years Funding for Sydney Researchers" by Moira Smith
9. NEWS: "The Latest on the CFS Name Game" by Lisa Lorden
11. Call for participants in new study
12. Dietary Corner: "Dietary hints for managing hypoglycaemia" by Melanie Stratil
14. Coping: Don't Give Up Your Dreams
15. Helpful Hints by Sherri Connell
17. Maintaining Self-Esteem by Val Rubie
18. Humour: CFS Happens

SECTION 2: MEDICAL PAGES

19. Obituary: Dr Mukherjee
20. Neurocognitive impairment in CFS
21. Fludrocortisone acetate to treat neurally mediated hypotension in chronic fatigue syndrome
22. Childbearing and CFIDs: *Making a Difficult Decision*
23. Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome.
24. Graded Exercise Therapy for ME/CFS?
A response to: Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome.
26. Media Watch: ABC Health Report: Graded Exercise For Chronic Fatigue Syndrome
Exercise Capacity in Chronic Fatigue Syndrome

SECTION 3: SOCIETY MATTERS

27. Awareness Week
28. Report on General Meetings 10th Feb 2001
29. Report from Tertiary Education Meeting 18th Feb 2001
30. Report from Election General Meeting 24th Feb 2001
31. Chronic Illness on the Web
32. Members Talk: Jon Foote
Volunteer Positions Available
33. Book Review: "Adolescence and Myalgic Encephalomyelitis / Chronic Fatigue Syndrome" by Naida Edgar Brotherton
34. Handy Hints
35. Report on Support Groups
36. Youth Outlook
37. Vice-President's report ctd...
38. Support Groups and Contact Numbers

**GREAT SPOT FOR AN AD, ISN'T IT?
CAN YOU SUGGEST A BUSINESS THAT MIGHT BE INTERESTED
IN ADVERTISING HERE?**



Introduction

(With illness hitting our president, Boris Dontscheff, I've undertaken to write this report.)

I'm sure you will agree that ME/CFS is a dreadful illness. It's chronic, it's invisible, and it's poorly understood. We certainly have a lot of things that appear to conspire against us at times.

I'll give you a classic example of how tough it is. A person with ME/CFS recently went to court to dispute his rejected Centrelink application for the Disability Support Pension. He decided to represent himself on the advice of legal counsel. His appeal was rejected – one of the reasons given was that he represented himself so well. By doing a good job they thought he couldn't possibly be sick enough to warrant the pension.

Ironical isn't it? We all know we can gear ourselves up to perform for a short period of time, but it is not indicative of how we are the other 6.5 days of the week. Yes, we face an uphill battle to increase, understanding don't we?

ME/CFS is a dreadful disease. It's chronic, it's invisible, and it's poorly understood.

Who's going to look out for us?

Unfortunately no-one. If we are going to make progress we are the ones who will have to forge the way ahead. I know it's tough, but it's time for us to pull together, and for 'the tough to get-going'. We must actively seek to shape our destiny.

The people who shape world history, and actually make a difference are the determined ones - people willing to make a sacrifice. It's not necessarily the ones who are the smartest, most-gifted or enjoy full health. I never met her but I hear our founding President, Lyn Drysdale, was a remarkable person. She would organise the society and counsel people from her sick-bed; and at all hours of the day and night. She wouldn't let her poor health be a barrier to helping others – she is a great example to us all.

We have a big task ahead of us, and we are at a critical point in ME/CFS history in Australia – the revised clinical guidelines are due out sometime soon. We need to be ready to debate and critique them strongly. (They guide GPs in how to treat ME/CFS.) More about them in the next issue.

To move ahead we mustn't ignore the difficulties we face in our society. Membership is down (and even when it's been higher we had only the tip of the iceberg) and that places a financial strain on the society – especially as we now have to pay more rent for our office. And, as most members who take an interest in the running of the society would know, we have had a constant turnover of management committee members over the last few years.

This has meant a lack of continuity. I can't express strongly enough how difficult it is for an organisation to grow/develop if every year its management committee has to re-invent the wheel. Frankly, whilst that wheel is getting re-invented, so much other stuff is not being worked on. And so this new management committee finds itself slowly working its way out of a big hole. Having been elected in Feb. it will take several months for us to come to terms with

our roles and responsibilities. It's not an ideal situation.

Why a high turnover?

The single biggest problem we face too much is always left to too few, and either people burn out, or the team burns out (disintegrates) because of stress. And because some have burnt out, we are reluctant to 'put up our hand' for fear of overwork. As an organisation I estimate we have only half the number of people needed to safely carry out the core business of the society. I can honestly say things do need to change – there are only so many people in the society left – and I hope we can face the issue together and work to recreate the culture of our society from the ground up.

Until you get involved in committee, you just don't appreciate how much work there is. It fast becomes a lonely occupation. Being an incorporated body and a registered charity involves many responsibilities: to other charities, to our patron, to charity direct and other organisations we work with (eg SACOSS, Volunteering SA), to our members, and all our volunteers. Volunteer organisations have the same legal responsibilities as professional 'for-profit' businesses, and increasingly the expectation is that volunteers be treated no differently than paid employees. There is a lot to think about, and it's all new stuff to most of us.

So, please understand that the management committee has a big job and it needs your support. Together we can really build up this society – we have a great team of people involved at the moment. I'm not just referring to the management committee, but to the support line workers and to the support group leaders. We just need to expand that team in numbers, and develop expertise together.

Working towards independent Admin and Office Teams

Every management committee is swamped with admin – and this inevitably impairs its ability to focus on the things it should be doing such as forward/strategic planning. Our aim is to develop an office admin team separate to the management committee. This team would run the office and ensure the society's basic administration is carried out eg mailouts, correspondence & phone calls properly dealt with. This would leave the management committee free to concentrate on governing (the big picture) the society. I can already say that having to do both is already taking its toll on me. It's just too much.

To achieve this goal I believe our society needs to recruit a minimum of 6-10 extra people who can do 3-4 hours a week each.

Immediate Issues to Address

The biggest issue we face – and I'm going to say it right out – is this committee going to burn out? Ultimately that is the management committee's responsibility BUT I suggest there is also a corporate responsibility to ensure this doesn't happen. As I said earlier I think we have a great team, and I

(Continued on page 37)



THIS SPACE RESERVED FOR YOUR LETTERS!!

Please write to us – tell us what you like or tell us what you don't like about the new format. Did you enjoy any particular article that appeared in this issue? Do you have any strong

opinions on anything said in this issue? Have you got some helpful information you'd like to add to one of our articles?

We'd love to hear from you – Eds.



A Flock of Birds

- by K. M. Gwisdalla

"Your mind is sluggish and won't work. You struggle to coordinate your ideas...but it's useless: a complete fog! Don't force yourself, and don't worry either. Listen closely: it is the hour for your heart."

- Josemaria Escriva (1902-1975)

In the midst of what often seems unbearable isolation can be found tiny joys which, when viewed with an open heart, a mind not trying to struggle for words, become magnificent treasures bringing with them strengths that fill the soul.

Today I saw a flock of starlings, a very common bird, on a wire, for some reason reminding me of old men in dark coats bunched together in the gloom of a long winter. Something beyond my perception caused them to rise as one, swirling into the sky. No more were they old men in long coats huddled against a grey sky. Rather, they had become graceful dancers, choreographed without flaw, against a stage set to show them at their best. I wonder if anyone else noticed.

Today I saw the drops of snow-melt falling from the edge of my roof. Perfect in their symmetry. Each drop a tiny

rounded reflection holding the world around it. Tiny harbingers of a springtime to come. Hitting the pavement below, creating starbursts of droplets, coming together to create the life-giving puddles that will nourish the ground as it thaws. Am I the only one smiling at them today?

Today there was a small break in the cloud cover, which let the sun shine through. How crystalline blue the sky appears in back of the clouds. Still there it seems, even when I couldn't see it. The light shafts in through the window, casting gold in its path, a spot of warmth on the floor no furnace can duplicate. The cat finds it quickly, rolling luxuriously in it, enjoying this small, unexpected pleasure without reserve. She has much to teach me.

I remember when I was a child, a very solitary child, walking to school in the rain, noticing the textures of the cement squares of the sidewalk. How they varied. Some with large stones containing glints of minerals, some with stones so tiny I had to bend to see them better. Noticing that only near a certain type of tree did a certain type of worm appear on the ground in the rain. I wonder if any of the other kids in their chattering groups ever noticed.

I remember walking home from the city bus stop when I was in high school, seeing a robin on someone's lawn. The first I'd seen that spring. I remember watching it a moment and smiling, saying right out loud "Thank you for showing me that", certain that I was indeed being shown small treasures throughout my childhood solitude.

I remember getting terrible news as an adult and, walking out into my backyard to sit and cry, seeing a hummingbird suddenly dart toward me as if to land, then hover, magnificent jewel, within a foot of me, refreshing himself with the nectar of a flower. My troubles were not gone, but my spirit was as bejeweled as that tiny gift of nature.

I remember sitting on the lounge chair in the yard one summer, so very ill, so very hopeless. A tiny beetle of a type I'd never seen before caught my eye, and I was lost in watching his journey, trying to discern his mission among the leaves that surrounded him. Perhaps it was simply to distract me from my dark despair.

Oh, how wonderful has Nature been to me, to show me tiny treasures others have no time to see. To renew my spirit when all was dark, with hidden-in-plain-sight treasures, from the shape of the tallest tree, to the tiniest textures of its bark.

Today I saw a flock of starlings dance in the sky.

http://chronicfatigue.about.com/health/chronicfatigue/library/uc/uc_flockofbirds.htm

⇒ **Your Health**

⇒ **Your Home**

⇒ **BIO Paints**



Indoor pollution is a growing concern. A main contributor are conventional paint products.

But here is the good news for You. Bio's natural and non toxic paints will create a healthier home.

Do You want to use these environmental responsible products? They are easy to use, of high quality and have no bad smell.

Phone us on our Freecall Number

1800 809 448

and we'll send you FREE Toxic Information and a coloured Brochure, which tells you the different applications for each product and surfaces. This is invaluable for anyone looking at painting.

Bio Products Australia Pty. Ltd.
25 Aldgate Tce., Bridgewater S.A. 5155





Five years' funding for Sydney CFS researchers by Moira Smith

Disappointing news from the NHMRC

For years, the government's National Health and Medical Research Council has been funding a particular group of researchers who increasingly favour labelling people with ME/CFS as psychiatrically ill. In recent consultations, sufferers made it very clear this is not what they want. However, now that the 2001 grants have been made public, it seems nothing has changed.

Grants announced

A November 2000 press release from Health Minister Wooldridge about National Health and Medical Research Council (NH&MRC) funding announced:

Dr Ian Hickie of the University of New South Wales has been granted \$100,000 for the first year of a five-year study of chronic fatigue syndrome (CFS), its links with two viral illnesses, Glandular fever and Ross River Virus and with a non-viral illness, Q Fever. . . . Dr Hickie's study will take place in Western NSW where infections such as Glandular Fever, Ross River Virus and Q Fever are common and have been associated with prolonged states of fatigue. The study is the central component of a larger set of studies which will investigate psychiatric, immunological and infective causes of CFS. [1]

Hickie is Professor of Community Psychiatry at the University of New South Wales and now heads up the

government's new National Depression Initiative "Beyond Blue". Publicity for the initiative mentioned his "research expertise in ... physical health consequences of depression, somatic presentations of mood disorders and chronic fatigue states." [2]

While the press release singled out Dr Hickie, details of the grant on the NH&MRC website show Associate Professor Andrew Lloyd and Prof Denis Wakefield as co-recipients of the grant. Lloyd has also received a separate but obviously related grant of 120,000 two years running to study Q fever. Together, the new grants amount to nearly a quarter of a million dollars over the next five years.

Grant details

The grant details as shown on pages 8 and 84 of the document "Project Grants results for funding in 2001" on the NH&MRC website: <http://www.health.gov.au:80/nhmrc/research/project/results.pdf> page 8:

Standard Projects

University of New South Wales

CI Name/s: A/Pr Andrew R Lloyd, E/Pr Barrie P Marmion, Dr Ray J Harris

Application ID 157092

Title: Microbiological and immunological determinants of prolonged illness following Q fever.

(\$) Funding 2001 120,000

Future Support 2 year(s)

page 84:

Epidemiology Grants

New South Wales

University of New South Wales

CI Name/s: Prof Ian B Hickie, A/Pr Andrew R Lloyd, Ms Tracey A Davenport, Prof Denis Wakefield

Application ID 157052

Title: A prospective study of the psychiatric & medical characteristics of post-infective fatigue & chronic fatigue syndrome.

(\$) Funding 2001 100,000

Future Support 4 year(s)

The Sydney Researchers

Hickie, Lloyd and Wakefield have been publishing together on CFS for some time. They belong to the group, associated with the Prince Henry Hospital and University of New South Wales, sometimes referred to as "the Sydney researchers". Their early work in the late eighties on immunological abnormalities gave great hope to Australian ME/CFS sufferers. In particular their work at that stage showed that depression was a result of the illness and not a cause of it. In a 1990 paper they concluded:

... we have demonstrated that while depression and anxiety are common symptoms in patients suffering from CFS, there is no evidence from our well defined sample to support the hypothesis that CFS is

(Continued on page 7)

from the earth.

NATURAL FOOD SUPERMARKET

195 Magill Road, Maylands 5069

Ph: 8363 1911 Fax: 8363 0007

- Adelaide's specialists in macrobiotic products
- Large selection of local and interstate special dietary breads
- Organic fruit and vegetables, eggs, meat and chickens
- Dried fruit and nuts (organic and naturally dried where possible)



- Organic and biodynamic flours and grains
- Cold pressed oils, natural honeys, malts (organic where possible)
- Nutritional supplements
- Natural hair and skin care products

**10% discount
for ME/CFS members
on production of current membership
card for cash purchases of \$10.00 and
over (excluding bread and specials).**

(Continued from page 6)

a somatic presentation of an underlying psychological disorder. Instead, our study supports the hypothesis that the current psychological symptoms of patients with CFS are a consequence of the disorder, rather than evidence of antecedent vulnerability." [3]

Around 1994-95, however, they changed their tune. A 1995 paper dismissed immunological findings in CFS as of little significance and stated their new position:

"Poor long term outcome appears to be predicted by psychological factors (past or current psychiatric disorder, a rigid belief in an 'infective' aetiology) and behavioural factors (decreased activity and social isolation) rather than immunological or infective factors." [4]

They continue to subscribe to the view that the physical symptoms of ME/CFS are due to somatization - psychological problems manifesting in physical form - and deconditioning. They have joined in an international effort by some psychiatrists and others to put physical aspects of ME/CFS into the "too hard basket" and focus on patients' attitudes, beliefs and "coping styles" instead.

Hickie, Lloyd and Wakefield were influential members of the Working Group that produced the 1997 Draft CFS Clinical Practice Guidelines [5] that dismayed so many ME sufferers and advocates. These guidelines largely ignored international and Australian scientific evidence of physical abnormalities in ME/CFS. They repeated the idea that CFS is caused by believing one is ill, and recommended graded exercise programs and cognitive behavioural therapy as the mainstay of treatment. (The guidelines are still in draft at the date of writing, but have been said for some time to be on the verge of being finalised. All work on them was funded by the government.)

Also in 1997, Hickie published an editorial in the journal *Psychological Medicine* [6] arguing that the diagnosis of "neurasthenia" should be reintroduced as a psychiatric diagnosis for fatigue, and appear in a future editions of the DSM - the psychiatrists' handbook. If that were to come about, anyone whose ME/CFS could not be clearly linked to a physical cause, such as a specific chronic infection, would by definition be suffering from a psychiatric disorder.

Research priorities

The very predictability of yet more funding for the Hickie, Lloyd and Wakefield team is especially disappointing as this round of grants was allocated under a new system that had

promised change. In the past, funding by the NH&MRC has been submission-based. In 1999, recognising that "research driven by academic, scientific or marketing interests might not be headed in the directions consumers need" [7], the NH&MRC set up a Strategic Research Development Committee to identify priority areas for funding. The Consumers' Health Forum (CHF) was one of three organisations asked to consult with the community and report back.

The Consumers' Health Forum sent out a questionnaire to support groups and societies. Organisations and individual CFS patients responded arguing the case for physical, not psychiatric research, pointing out that research teams such as those in Adelaide and Newcastle were doing promising work that deserved funding.

The ACT ME/CFS Society said in its covering letter:

"our members are not interested in any research into psychiatric aspects of ME/CFS and related conditions. We do not wish to see ME/CFS becoming a psychiatric diagnosis. While psychological interventions should remain an aspect of patient support, as for anyone with a serious or chronic illness, we do not wish to see funds being directed to research into cognitive behavioural therapy, graded exercise, and other inappropriate treatments that take no account of the reality of our illnesses."

At first these efforts seemed to have borne fruit. The Consumers' Health Forum, at least, represented our views strongly. They singled out CFS in their report as a special "case for concern", noting that they had had a "significant number of responses" from sufferers and their representatives. The authors spelt our names wrong ["chronic fatigue syndrome, myeloencephalitis and neuralgia"] but got our aims right:

"These people have been trying to raise awareness of their plight and their research needs with an illness that is hard to define and with no effective treatment or management strategies, for a number of years. Many responses identified that the main research need was for an understanding of the causes and processes of the illness, developing accepted assessment criteria, such as a mapping of the physical dimensions of the condition(s) and effects, or diagnostic tools, so that treatments could be developed. Some of the problems of people with CFS were common to other conditions without a clear diagnosis, such as not having their health needs recognised, or misdiagnosis and inappropriate

(Continued on page 8)

BIOSCREEN

Available tests



Bioscreen tests can assist your health practitioner in providing you with treatment options in the management of Chronic Pain and Fatigue

BIOSCREEN PTY LTD
P.O. Box 145
Jesmond, NSW 2299
Ph: 02 4961 6467
FAX: 02 4961 6513
Email: bioscreen@bioscreen.com.au

SPECIALITY TESTING

- URINE
- BLOOD LIPIDS
- MICROBIAL PCR
- FAECES ANALYSIS
- ORGANOCHLORINES
- STAPHYLOCOCCAL TOXINS

Bioscreen tests are backed by over 10 years of research

For more information, visit our website: www.bioscreen.com.au

treatment, including symptoms being attributed to mental illness." [8]

In the event, not only have Hickie and his colleagues received another five years' funding, but I understand that applications from the Newcastle and Adelaide researchers were unsuccessful.

Does the newly funded Sydney study fit in with whatever research priorities were identified by the NH&MRC's Strategic Research Development Committee? Presumably it must. However the Sydney researchers have apparently been planning their project for some time. The grant documentation states the funding is for research into "the psychiatric & medical characteristics of post-infective fatigue & chronic fatigue syndrome" and the press release quoted at the beginning of this article mentions glandular fever (Epstein Barr virus) Ross River Virus and Q Fever. As long ago as 1996, Andrew Lloyd told a meeting of the Victorian ME/CFS Society that he and his team were planning to study people with glandular fever, Ross River Virus or Q fever to find out what immunological and psychological differences there are between those who recover and those who develop chronic fatigue [9].

He said it would be an ambitious study, but one that could answer a lot of questions about CFS. We can only hope this will prove to be true.

Moir Smith
January 2001

References

[1] Media release by Federal Health Minister, Dr Michael

Wooldridge, dated 21 Nov 2000 <http://www.health.gov.au:80/mediarel/yr2000/mw/mw20114.htm>

[2] National Depression Initiative official fact sheet #4 <http://www.health.gov.au/depression/infosheet.htm>

[3] "The Psychiatric Status of Patients with the Chronic Fatigue Syndrome" by Ian Hickie, Andrew Lloyd, Denis Wakefield and Gordon Parker, published in the British Journal of Psychiatry. Abstract

[4] Hickie IB, Lloyd AR, Wakefield D. "Chronic fatigue syndrome: current perspectives on evaluation and management". The Medical Journal of Australia 1995; 163; 314-318. Abstract

[5] *Draft Clinical Practice Guidelines on the evaluation of prolonged fatigue and diagnosis and management of CFS*, December 1997; developed by a Working Group convened by the Royal Australasian College of Physicians, at <http://www.mja.com.au/public/guides/cfs/cfs1.html> on The Medical Journal of Australia website

[6] Hickie I, Hadzi-Pavlovic D, Ricci C. "Reviving the diagnosis of neurasthenia" Editorial: Psychological Medicine Volume 27 Issue 5 (1997) pp 989-994 Abstract

[7] "Please tell us YOUR health and medical research priorities", Consumers' Health Forum questionnaire publicity, 1999

[8] Summary Paper: Input into the Strategic Research Priorities Discussion Groups " by Helen Hopkins and Matthew Blackmore, Consumers' Health Forum, October 1999 www.chf.org.au/chf_submissions/strategic_research_priorities_di.htm

[9] An International Perspective on CFS Research - talk given to the ME/CFS Society of Victoria's Annual General Meeting Nov 23 1996 by Associate Professor Andrew Lloyd. Originally reported in the Society's magazine *Emerge* Autumn 1997; now on their website

Background and further reading:

Draft Clinical Practice Guidelines information and comments on this website Ted Shaw's article "A critique of the Sydney researchers" describes the early work of Lloyd, Hickie and Wakefield, and contains links to more information.

Moir Smith is involved in the ACT ME/CFS Society Inc. This article appeared in their newsletter *ChAMEleon*.

Moir maintains an excellent website at: <http://www.masmith.inspired.net.au/>
This article can be found specifically at: <http://www.masmith.inspired.net.au/docs/newgrant.htm>

VITAMINS

Are you paying too much?

Buy direct and save!

10% discount to all ME/CFS Society Members

Direct Nutritional Supplies Pty Ltd offers a direct mail service for all your vitamin, mineral, herbal and Aloe Vera products. Savings are passed directly to you as there are no middle men to mark up prices.
Remember No Obligation - Just Savings.

For a FREE 48 page Colour Catalogue

Ph: 1800 633 106

(Free Call)

Direct Nutritional Supplies Pty Ltd





By Lisa Lorden

Report from the AACFS Conference in Seattle January 26-29, 2001

What's in a name? Plenty. At least that was the consensus among attendees at the Name Change Working Group's open forum during the recent American Association for Chronic Fatigue Syndrome's bi-annual conference.

One by one, participants (mostly from the patient community) took the microphone and shared their views about how the name "chronic fatigue syndrome (CFS)" had negatively affected them in their quest for understanding, recognition, and adequate treatment. Some spoke eloquently, and a few quite angrily.

Their concerns reflected both personal experience and the status of CFS patients as a whole. Many shared frustration about the response commonly elicited when patients reveal they suffer from CFS: "Chronic fatigue? Well, I'm tired too." Other attendees explained how the trivializing name has had a negative impact on doctor's attitudes, research funding, and the ability to obtain disability benefits for so many patients who are unable to work.

Evidence of a Name's Impact

New scientific evidence now supports the claim that the name CFS influences attitudes toward sufferers of the illness. An abstract presented at the AACFS conference by researcher Leonard Jason and others described a series of studies that explored the impact of different "diagnostic labels." The researchers' goal was to determine the effects of certain illness names upon the conclusions of medical trainees and college undergraduates regarding cause, nature, severity, contagion, prognosis, and treatment.

The three labels tested were: chronic fatigue syndrome, Florence Nightingale Disease, and myalgic encephalopathy. Participants were divided into three groups and given a case study to read, the only difference between the groups being the type of diagnostic label given. Afterward, participants completed a questionnaire measuring their various judgments about the illness described in the case study.

Results showed that the myalgic encephalopathy label was associated with the poorest prognosis and the attribution of a physiological cause. These results indicate that the name "myalgic encephalopathy" is more likely to be seen as a serious condition with a physical basis than the current name "chronic fatigue syndrome."

The Task at Hand

The Name Change Working Group was established by the U.S. Department of Health and Human Services and is charged with exploring alternatives and making recommendations for changing the name chronic fatigue syndrome. At the open forum in Seattle, Nancy Klimas--a CFIDS researcher and clinician, reported taking a "straw poll" during one of the conference sessions. She asked physicians and researchers in attendance how many believed that the name CFS should be changed *this year*. The hands that went up in the room revealed nearly unanimous support for a name change in the very near

future. This is in stark contrast to a similar poll taken by Klimas at the last AACFS conference two years ago, in which she says about 85% did not support a name change that year.

For the first time, patients and doctors alike are committed to supporting a name change, sharing the belief that the name "chronic fatigue syndrome" is not only inadequate, but stigmatizing. But that's where the consensus ends. Not everyone agrees about just what the new name should be.

Overview of Alternate Names

At the open forum in Seattle, the members of the Name Change Working Group objectively presented four names, representing the various schools of thought:

Myalgic Encephalomyelitis or Myalgic Encephalopathy (M.E.)

The largest group of patients in attendance at the open forum favor the "restoration" of the name M.E., already recognized as the name for a similar condition in the United Kingdom and many countries around the world. Myalgic Encephalomyelitis was first used in the 1950s and is widely recognized as a "synonym" for CFS. Therein lies one of the problems, however. As the criteria for M.E. are somewhat more specific and stringent than those for CFS, some believe this will only make it more difficult for those around the world who have achieved recognition and a clear definition for their condition. Roger Burns, a long-time CFIDS patient advocate for a name change and an attendee at the open forum, pointed out that many European M.E. leaders are saying that in 1988 the U.S., in effect, "exported" the damaging name CFS to other countries; the decision now to appropriate "their" name--M.E.--without adopting the M.E. definition may not be well-received.

Nevertheless, many patients and doctors in the United Kingdom and elsewhere *do* support the use of the name M.E. Using an already recognized name would be much less confusing to both the research community and the public. More importantly, as Leonard Jason's study showed, a condition with the label M.E. is seen as serious and debilitating. Jean Harrison, another advocate working to "restore" the name M.E., points out that "using a name which is very nearly 50 years old will dispel the false perception that M.E. is a new, fad illness; a disease du jour."

One other objection to the name M.E. is that there is no evidence of inflammation of the brain, which "encephalomyelitis" implies; thus, "encephalopathy" is seen by some as preferable. Dr Charles Shepherd, Medical Director of the UK M.E. Association agreed, and he further proposed an interesting solution to the argument that even muscle pain (myalgia) is not universal in cases of CFS; he therefore advocates the name "Myoencephalopathy," which can still maintain the acronym "M.E."

Neuroendocrine Immune Disorder (NEID)

A smaller number of attendees at the open forum supported this name, which is another attempt at a "scientific-sounding" label, and reflects the current state of knowledge about the body systems that have shown documented

dysfunction in CFS: the neurologic, endocrine, and immune systems. One question about this name is how the acronym "NEID" would be pronounced when spoken. Just as concern as been expressed over whether the name M.E. may result in the media declaring it "the me-disease," there could be problems with "need"-oriented misconceptions and stereotypes.

Polyalgic Asthenia

A common objection to changing the name has always been the fact that a scientifically-oriented name implies knowledge of the etiology or pathogenesis of the condition, which remains elusive. A proposed solution to this problem is a name that reflects common symptoms of CFS other than fatigue. Illnesses like lupus and diabetes are examples of this strategy. Polyalgic asthenia, which means "many pains and widespread weakness," has been proposed for the purposes of discussion, but little support was expressed for this name at the open forum.

Ramsay's Disorder

Some illnesses, such as Lou Gehrig's Disease (ALS), are widely recognized by the name of a person associated with the illness in some way. Melvin Ramsay is the British researcher credited with first describing M.E. in the medical literature. A name like Ramsay's Disorder would eliminate the need to achieve an understanding of etiology before renaming the illness. However, this name adds no clarification and may be taken less seriously than "scientific-sounding" names, as Jason's research demonstrated.

A New Name Now

Most patients at the open forum stressed the importance of the name being changed right away. John Herd, name-change advocate and patient representative member of the Name Change Working Group emphasizes "that the belittlement, blaming the victim, and derogatory treatment people face when they say they have CFS can be more traumatic than the condition itself."

The majority of CFS sufferers feel that the name has been an insurmountable obstacle to getting the recognition they need to obtain diagnosis and appropriate treatment, not to mention the ability to claim benefits from Social Security and private disability companies. In addition, many people feel that the trivializing name is a real detriment to achieving necessary research funding that will lead to what patients *really* want: a cure, and the opportunity to get their lives back. In the meantime, patients seek acknowledgment of their suffering rather than the frequent degradation and even ridicule that is typically a part of any CFS sufferer's life.

Most of the patients who spoke out at the open forum blame the name CFS, at least in part, for all this and more. "Get rid of the F-word!" is the most oft-heard battle-cry. But Dr. Fred Friedberg, Ph.D., CFS sufferer and author of *Coping With Chronic Fatigue Syndrome: Nine Things You Can Do*, argued that perhaps people were being overly optimistic about what a name change might accomplish. He correctly pointed out that fibromyalgia is a "scientific-sounding name," yet struggles with similar issues of legitimacy and recognition.

But the vast majority of CFS patients and clinicians believe

(Continued on page 17)

BECAUSE YOUR BODY IS 75% WATER THE PURE WATER SHOP IS 100% WATER!

Try REVERSE OSMOSIS water!

Our reverse osmosis systems produce clean, refreshing, non-carbonated, low sodium drinking water by using state of the art non-chemical purification technology based on the principal of osmosis, a process which occurs naturally in all living cells.

Reverse osmosis water is high in oxygen content with a unique 'sweet clean' taste all of its own.

It's the ideal drink for today's health or fitness conscious person demanding a pollutant-free, organically pure drinking water to complement their lifestyle and well being.

We have a full range of filters and reverse osmosis systems from small portable units for those who rent, to installed under-sink types for those in their own homes.

JUST ARRIVED! A new range of exotic herbal table waters imported from Europe. Ideal for non-alcoholic entertaining.

15 litre bottles of Purelle, factory bottled for \$5.50 ea.

16 litre high grade, de-ionised, de-mineralised \$7.50 ea.

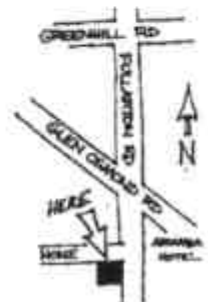
**THE PURE WATER SHOP
259 FULLARTON ROAD
PARKSIDE PH: 8373 5500**

**Visit our new shop at
4A WESTERN ROADWAY
ADELAIDE CENTRAL MARKET
PH: 8231 3311**



AT YOUR LOCAL
PURE WATER SHOP, WE
HAVE ALL YOUR WATER
REQUIREMENTS....

- THE PUREST WATER
- WATER PURIFIERS
- WATER FILTERS
- SHOWER FILTERS
- THE BEST ADVICE ON YOUR HOUSEHOLD



Call for volunteers to participate in a CFS/chronic fatigue investigation



In December 1998 a paper was published in the Journal of the Australasian College of Nutritional & Environmental Medicine examining evidence that prolonged exposure to excessive 50 Hz (powerline frequency) electromagnetic fields (EMF) may act as an immune system stressor. The authors suggest the possibility that this exposure may give rise to symptoms similar to those reported in CFS or chronic fatigue. The paper concludes with the recommendation that medical practitioners working with CFS patients need to consider this possibility and take action to determine that their patients are not overly exposed to this factor.

The paper is available on the Internet at:
http://www.acnem.org/journal/17-2_december_1998/cfs-emfs.htm

This paper was based on a number of actual case histories which indicated that EMF exposure was a contributing factor in the ill health of particularly susceptible people. In most cases, where high exposures were found, reducing these levels was a relatively easy step to take.

Details on these cases are available at:
<http://www.tassie.net.au/emfacts/case-studies.html>

The authors of the above paper now wish to test the paper's hypothesis by conducting a small scale pilot investigation of the weekly EMF exposures of a group of 60 people, who are suffering CFS or ongoing chronic fatigue.

This investigation is planned for both Adelaide and Melbourne and will start in Adelaide in May 2001. We are seeking at least 20 people to volunteer as subjects from the Adelaide area.

Subjects will be sent a questionnaire (in April) and later this

will be followed (in May) by a field survey of all subject's home EMF levels. Where appropriate, workplace exposure levels would be taken as well. For the group (A) where it is found that their exposures are in excess of a set "benchmark" level, they will be notified immediately and advice and assistance will be given to reduce these exposures to below that level as soon as possible. There will be no cost for participation in this investigation, but if any building electrical faults are found, there may be a charge for an electrician or plumber to come in and carry out repairs.

It is totally at the discretion of the participant whether or not any repairs are done. For the group (B) who have exposures below the benchmark level, no advice will therefore need to be given and they will serve as the "control group" for the investigation. The health status of both groups will be monitored for a period of one year to determine any significant differences that may become apparent.

It must be emphasised that exposures over the benchmark level DOES NOT mean that there will be a negative health effect as it may only be in particularly susceptible people that this is of concern.

For further information and enrolment forms please contact:
Don Maisch, PO Box 96, North Hobart, Tasmania.
ph: (03)6243 0195, Fax: (03) 6243 0340
E-MAIL : emfacts@trump.net.au

(Continued from page 10)

adopting a more representative name for the illness is, at the very least, a necessary start. No name can be expected to carry the full weight of responsibility for the perception and understanding of the condition, and strong educational efforts will need to be implemented to promote the acceptance of both the new name, and the illness itself. Definitive action is needed to begin the process.

As John Herd said, "By default all those who allow the name CFS to continue, will in turn be contributing to patients' future suffering. The scars of history cannot be healed, but new ones can be prevented."

(c) 2000-2001 Lisa Lorden
(<http://chronicfatigue.about.com>), About, Inc. Used by permission of About, Inc. which can be found on the Web at www.About.com. All rights reserved.

About.com is on of the best ME/CFS websites online with practical information on coping with the illness.
This article is can be found at:
<http://chronicfatigue.about.com/health/chronicfatigue/library/weekly/aa020601a.htm>

GOOD NEWS

[This is an edited version of an email announcement]
April 2, 2001
NEWS FLASH
Re: CANADIAN EXPERT CONSENSUS PANELS
MYALGIC ENCEPHALOMYELITIS/CHRONIC
FATIGUE SYNDROME AND FIBROMYALGIA -
MARCH 30TH TO APRIL 1, 2001

The National ME/FM Action Network is pleased to announce that as a result of the current Peer Review Meeting in Toronto, the National ME/FM Action Network is pleased to announce that we have a UNANIMOUS CONSENSUS for BOTH ME/CFS & FM Clinical Definitions & Treatment Protocols!!

This means that the ALL the General Practitioners and Rheumatologists will all be able to diagnose and treat Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia.

The National ME/FM Action Network wants to congratulate all of you as WE HAVE ARRIVED!!!!!!
Doctors and Patients will now be empowered.
<http://www3.sympatico.ca/me-fm.action/>

Lydia Neilson
President/C.E.O.
The National ME/FM Action Network
3836 Carling Avenue



DIETARY HINTS FOR MANAGING HYPOGLYCAEMIA

By Melanie Stratil, Senior Dietitian, Southern Fleurieu Health Service, Victor Harbor, S.A.

In my clinical experience, I have found that some clients with Chronic Fatigue Syndrome can be troubled by episodes of hypoglycaemia (low blood sugar level), with symptoms that may include:

- Feeling dizzy or light-headed
- Pallor
- Fatigue or weakness
- Hunger
- Trembling or shaking
- Palpitations
- Headache
- Sweating
- Blurry vision

Blood sugar (glucose) is one of the 2 important fuels for the body, and the main fuel for the brain and nervous system. Because it is so important, the blood glucose level is normally kept within a strict range of 3.5 to 7.8 millimoles per litre, by the balancing act of several hormones, particularly insulin (which lowers blood glucose levels), and glucagon (which raises blood glucose levels). Insulin is released when our blood glucose levels start to rise, after we eat carbohydrate-containing foods (see table below for a list of carbohydrate foods). Insulin acts as the key that allows glucose to enter the cells of the body, where it is either used for energy, or converted to fat for storage. Glucagon is a hormone that allows us to gradually release stored glucose (in the form of glycogen) from our liver, when we are in a fasting state, such as overnight. Another hormone, adrenalin, can also release glucose from the liver. It is part of the body's response to danger, allowing us to prepare for peak physical performance to help us run away or fight the danger (flight or fight response). In this situation, we need a good supply of readily available fuel (glucose) in the blood to supply our muscles.

Sometimes this balancing act doesn't work properly. If there is insufficient insulin, or insulin doesn't work properly, blood glucose cannot get into the cells and the blood glucose level rises too high (hyperglycaemia). This is called either impaired glucose tolerance (if slightly raised) or diabetes (if levels are higher). If too much insulin is released, the opposite effect occurs - the blood glucose level can drop below normal levels, ie. below 3.5 mmol/l. This is called hypoglycaemia. If this happens in response to a high carbohydrate meal, it is called "reactive hypoglycaemia", and occurs 1 to 5 hours after the meal. Fasting hypoglycaemia refers to a blood glucose level below 3.5 mmol/l after an 8 hour fast.

Hypoglycaemia is diagnosed by a Glucose Tolerance Test (GTT), in which blood glucose levels are measured at regular intervals after a test-load of glucose is consumed, if there is a rapid and prolonged drop in blood glucose below 3.5 mmol/l. In practice, I also find that some people are troubled by symptoms if their blood glucose drops rapidly to the low end of the normal range, and others feel hypoglycaemic at slightly higher blood glucose levels.

The symptoms of hypoglycaemia are not specific to low blood glucose levels. If blood glucose levels are found to be normal after a GTT, other causes for the symptoms need to

be found. Food intolerance reactions, for example, can mimic hypoglycaemia symptoms, as too can panic or anxiety attacks. If possible, the cause of hypoglycaemia should be established.

Some of the symptoms of hypoglycaemia are due to the brain and nervous system not getting enough glucose, its primary energy source (eg tiredness, weakness, dizziness). Others are caused by the release of adrenalin "coming to the rescue" to release extra glucose from the liver (eg sweating, trembling, palpitations). Anyone who has been in a frightening situation will recognise these effects of adrenalin!

I'm not sure why some people with Chronic Fatigue Syndrome are prone to hypoglycaemia, but it may have something to do with disturbances in the normal energy pathways in the body. Some people also have restricted diets due to food intolerances, and may be relying on those carbohydrate-containing foods which are not very sustaining, and which boost blood glucose levels too quickly (thereby triggering an excessive response of insulin).

Dietary management of hypoglycaemia

Dietary management aims to stabilise blood glucose levels over the day, avoiding surges and drops. It means eating regularly, and listening to your body for signals indicating the need to "top up" with food.

- **Have moderate quantities of carbohydrate-containing foods at regular times throughout the day.**

*Try not to go more than 3 or 4 hours without a meal or a snack. Generally, at least 3 meals plus 2 or 3 mid-meal snacks will be helpful, making sure to include carbohydrate-containing foods each time. Some people have found that they need to eat small amounts every 2 to 3 hours.

*Generally limit quantities of foods that are concentrated in sugar (eg soft drinks, cordials, confectionary), and other carbohydrate foods that are "quick-release" (high G.I.)—see Glycaemic Index information below. If blood glucose rises too rapidly, it may trigger an excessive release of insulin, which then leads to an excessive drop in blood glucose.

However, these quick-release (high G.I.) foods may be helpful as a short-term measure to quickly boost blood glucose, if it has already dropped too low. If used in this situation, they need to be followed up soon afterwards, by eating something more sustaining.

- **If possible, include more "slow release", sustaining carbohydrate-containing food choices.**

These are the ones with a low "Glycaemic Index"—see below. Ideally, include one low G.I. food at each meal, although food intolerances may restrict some of your options.

- **Include moderate amounts of protein-containing foods with meals.**

Protein slows down stomach emptying time, and will help to make meals more sustaining.

Protein foods include meat, chicken, fish, eggs, milk, cheese, dried beans and lentils, soy drinks, tofu, nuts and seeds.

- **Limit or avoid alcohol**

Most, if not all, people with Chronic Fatigue Syndrome

DIETARY CORNER

do not tolerate alcohol very well anyway! Alcohol can cause hypoglycaemia, if consumed on an empty stomach, as it interferes with the release of glucose from the liver. If you do drink alcohol, make sure to eat before or with your drink.

The Glycaemic Index of Carbohydrate-containing Foods

Research over the past 20 years or so has lead to a better understanding of which carbohydrate foods are digested quickly, thereby causing a more rapid rise in blood glucose, and those that are digested more slowly, leading to a slower and more sustained blood glucose response. This has been formalised in the concept of Glycaemic Index (G.I.)

Basically, the glycaemic index of a food is a rating of that food's blood glucose effect compared to a reference food, usually glucose. Glucose is defined as having a G.I. of 100. Foods that have a G.I. of 70 or more are defined as high G.I., indicating that they are "quick release". Foods that have a G.I. of below 55 are defined as low G.I., indicating that they are "slow-release", and therefore more sustaining. Foods with a GI between 55 and 70 are moderate G.I.

The Glycaemic Index is based on comparing quantities of foods that gave an equal load of carbohydrate in a meal (usually a 50gm carbohydrate load). If you eat a smaller amount of a food, it will, of course, give you a smaller rise in blood glucose level; a larger amount will give a larger rise

in blood glucose. Please note that I am not suggesting that anyone with a hypoglycaemia problem needs to avoid high G.I. foods altogether, but just to be aware that they are quick release, and so be more careful about the quantities eaten at any one time (in fact, they can be used as part of the treatment of a hypoglycaemic episode, as noted above). Making more use of low G.I. foods can be one strategy to stabilise blood glucose better, so that hypoglycaemic episodes can be avoided.

Further information about the glycaemic index of foods can be found in books such as "The G.I. Factor" by Dr Jennie Brand-Miller et al, or on internet sites such as <http://www.glycemicindex.com/>

It is also likely, in the near future, that some food labels of carbohydrate-containing foods will include information about the food's glycaemic index.

This article is for general information only. If you need more specific dietary advice, it is recommended that you seek the assistance of a qualified dietitian.

Page 13

March 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Glycaemic Index Table of Some Common Carbohydrate Foods

G.I. below 55 (slow release)	G.I. between 55 and 70	G.I. over 70 (quick release)
Oats, muesli	Vitabrits	Ricebubbles
Allbran	Weetbix	Cornflakes
Kellogg's Guardian TM	Kellogg's TM Just Right	
Kellogg's Special K TM	Shredded wheat	Wonderwhite TM bread
Pumpnickel bread	Wholemeal bread	Baguettes and Bagels
Wholegrain bread	White bread	Gluten-free bread
Barley or oatbran breads	Pita bread	Calrose rice
Barley	Basmati and Doongara rice	Rice pasta
Pasta (wheat-based)	Brown rice	Coffee biscuits
Plain sponge	Digestive biscuits	Puffed crispbreads
	Shredded wheatmeal biscuits	Rice cakes
Milk, Soy drinks	Icecream	
Yoghurt, custard		Potato
Sweet potato	Sweetcorn	
Dried beans and lentils		Dates
Pome fruit (apples, pears)	Apricots (fresh)	Watermelon
Citrus (oranges, mandarins)	Soft bananas	
Dried apricots	Mango	
Peaches, plums	Pineapple	
Cherries	Sultanas, raisins	
Firm bananas	Rockmelon	



REGULAR CHECKUPS

Please remember to have regular medical checkups with your doctor.



ME/CFS does not confer immunity to other illnesses.



New Symptoms may not be due to ME/CFS and should be discussed with your doctor.



Don't Give Up Your Dreams by Patti Schmidt

Page 14

Like many CFIDS patients, my emotions go up and down along with my symptoms. So far this year, I've been at the top of my personal health curve, working full-time and feeling good. I've also been bedridden, the lowest end of my curve. I've been everywhere in-between, too.

Along with the physical roller-coaster ride, my emotions have also travelled some peaks and valleys. That has been tough on me and on those around me. But I learned some other lessons during my last relapse. Next time, I won't be caught off-guard.

In the battle against this disease, which humbles you, humiliates you, and limits even your pursuit of happiness, you've got to have an arsenal of patience and persistence to be able to weather the storm. You've got to believe deep in your gut, where there's no room for bull, that you can have a life despite this illness and its current severity.

You simply can't give up hope for some kind of happiness.

Patience and Persistence

Patience means that on my sickest days, I have to force myself to believe that this, too, shall pass. I know sometimes that's not easy. I have lain in my bed and despaired that I would ever get out of it again. In spite of those really horrible days, I try very hard to limit self-pity and to employ a matter-of-factness that seems to lessen those days' impact on my overall well-being.

"You've got to believe deep in your gut, where there's no room for bull, that you can have a life despite this illness and its current severity...."

Nowadays, if I have a really bad day, when my husband comes home, I simply tell him I had a bad day. I don't dwell on it. I don't bug him for hours with talk of the 'what ifs' (What if this is another relapse? What if I'll be like this for the rest of my life? What if you catch this? What if we run out of money?).

Most of all, I don't let myself think of myself as that person stuck in bed. She's me alright, but she's not the best of me. She's just a part of who I am. So was the 'well' me. One isn't better or worse, it all just is. What I've got is some bad days, some middle-of-the-road days, and some good days. Who doesn't?

I have learned a few things that helped get me through those bad days. Maybe they'll help you, too.

- **Remember the better days.** I remember the better days and realize that I will have some of those again soon. I knew I'd gotten somewhere when I subconsciously began having "good day" things to do and "bad day" things to do. I know I'll have some bad days, so why not plan for them? Then when they arrive, I'm not scared or disappointed.
- **Plan for the bad days.** I plan for a bad day by imagining it as a day off from work. (I am working on recuperating, after all). Just like I did when I was well and had a day off but it was raining outside, I curl up in front of a fire and read a good book. I take naps. I try like hell not to feel guilty that I'm basically doing nothing. (That's what I'm supposed to be doing, I'm sick!) I have things put aside for my bad days: some very easy puzzle books, some trashy magazines. I write the occasional letter to a friend or call someone else with CFIDS and we commiserate together. I watch

Oprah, eat simple, healthy things I can grab right out of the frig or cabinet. Give yourself permission to take it easy.

- **Allow an occasional bout of private self-pity.** On my absolute worst-of-all-days, I allow myself a short period of time to really get into feeling sorry for myself. I cry. I wail. I hold my dog and wonder if this is all worth it. I get very angry. I think about all the useful, fun things I could be doing with my life. Even though I don't actually believe it for a minute, I even imagine that if I weren't sick I'd be everything I'd hoped I'd be (thin, beautiful, successful, etc. I'm 35 now and none of those). Then I let it all go. There isn't much point staying in that mood for longer than a few hours. I don't share those moods with anyone anymore. They're mine and I use them to diffuse the worst effects of this disease on my life. I'm persistent in believing that my life is still worth something. I'm still worth something.

Good Days Are Part of This, Too

On the other hand, no matter how severe the relapse, I do have the occasional good day. I make the best use of those as well. I've learned not to squander the little energy I have.

- **Use the 50-percent solution.** On a good day, I try to do about 50-60 percent of whatever I can manage. It is the hardest thing I've ever had to do. It's hard to learn the intricate way your body will tell you when to rest and when to do. You have to play it by ear and pay attention to what your physical and mental needs are. Persistence pays off; don't let yourself get carried away.
- **Just do a little.** On those days when I felt lucid and mildly energetic, there were so many things I hadn't been able to do that I wanted to do that I tended to crowd too much in. Naturally, the next day or so, I paid for it with increased needs for bedrest. Once the pattern emerged, I slowed down. Now I allow myself to just do a little. Then I lay low for a few hours.
- **Schedule time for rest.** Even on a good day, I schedule time for rest each day. It's a fact I hate but have been forced to heed.
- **Don't give up your dreams.** Just because you're sick doesn't mean you can't have a nice life. Okay, so you can't have your old life. Make a new one. For example, although I used to run a newspaper office, now I can only write a column every other month. I don't dwell much on what I can't do. Instead, I spend time trying to figure out how I can be happy doing what I can do.

The bottom line: life is not a dress rehearsal. This is your life, and it's the only one you'll ever have. CFIDS or not, don't forget to live it.

Patti Schmidt is a member of the Board of Directors of the CFIDS Association of America and has been a PWC since 1979. This article originally appeared in the association's publication The CFIDS Chronicle.

This article can be found online at:

http://chronicfatigue.about.com/health/chronicfatigue/library/uc/uc_pschmidt.htm



"Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitating Illness."

written by The Invisible Disabilities Advocate, Sherri L. Connell. Copyright 1996

EDITOR'S NOTE

We have been kindly given permission to print part 2, 3 and 4 of this booklet. These 3 parts will be spread over 4 editions of Talking Point. So stay tuned for more!

Part 2: "But You LOOK Good!"

What Is A Chronic Illness, Anyway?

A chronic illness is a disease or disorder that a person has to cope with on a continuous basis. Many people become so ill, they are unable to work and are forced to give up activities they have always enjoyed. Often their illness goes undiagnosed for years, leaving thousands of people frustrated, depressed and without answers to why their bodies will not cooperate with their desires.

But, They "LOOK" Fine! How Can They Be Ill?

Many chronic illnesses such as: *Arthritis, Chemical Depression, Crohn's Disease, CFIDS, Cystic Fibrosis, Diabetes, Fibromyalgia, Heart Disorders, Hypothyroidism, IBS, Lyme Disease, Lupus, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Parkinson's, RSD, Women's Chronic Disorders and many, many others cannot be seen with the naked eye, but are nevertheless persistently keeping the person from enjoying life the way they once knew.

Unfortunately, their families and friends are rarely supportive and understanding, because they do not see a broken bone or bleeding head to confirm the complaints. However, do not expect to see a disease that lives below the skin, because most illnesses are invisible until the person has had chemo or organ failure! Your friend or family member needs you to believe what they are saying is true, without judgment or question.

*This is only a very small sample of the hundreds of chronic illnesses which can be disabling; it is not intended to be a complete list of all debilitating disorders.

So, They Have "Good" & "Bad" Days, Right?

Actually, not everyone with a chronic illness has the same symptoms or degree of symptoms; yet, there are basically three stages in any chronic illness:

1) THE EARLY STAGE: This person may notice occasional symptoms or lack of energy. They start experiencing setbacks from activities which previously never took a thought. If diagnosed in this stage, which is rare, many can get help from their doctors and proper nutrition to cure or prevent further progression of the disease. This person has mostly "good" days with occasional "bad" days.

2) THE MIDDLE STAGE (or the Relapsing/Remitting Stage): This person may have frequent bouts of symptoms and is forced to make limitations for themselves in order to avoid extreme fatigue and relapse of illness. They reluctantly begin discovering that the simple things they

used to enjoy, now must be done with care or sacrificed completely. In this stage, some can lower the frequency of relapse and progression of the disease with help from their doctors and proper nutrition. This person has both "good" and "bad" days, depending on activity and stress.

3) THE LATE STAGE (or the Chronic/Progressive Stage): This person's disease has progressed to the point where it does not remit. They live each and every day with symptoms that feel much like having the stomach flu, complete with extreme to unimaginable fatigue, muscle aches, weakness, nausea, cognitive difficulties, dizziness and/or pain.

When they push themselves to do what used to be easy, like dusting a piece of furniture, going to a relative's house or doing a load of laundry, they pay a high price, because their symptoms worsen to an unbearable level for days and even months. In cases like Multiple Sclerosis, the treating drugs available are affective only for persons in stages 1 and 2. This person does not have "good" days, only "bad" days and "horrific" days.

Well, I Still Don't Understand!

At least once in your life, you have probably experienced having to stay home from work or school, because you were too sick to go; incidentally, I have yet to meet someone who has a cold or the flu, tell me they are having the time of their lives and enjoying every minute of it! Or, you may have been hurt in an accident and were forced to give up activities you loved for weeks or even months; so, you know how stressful, depressing and frustrating being unable to do what you want to do can be!

Now, when I refer to being sick, I am not talking about feeling just a little "under the weather" or just not "up to" going to work that day. I am talking about being so sick you can barely sit up or talk, having a fever that makes every muscle ache and your bones feel like they are being crushed. Then, when you try to get up to go to the bathroom, your head pounds, your body feels like it weighs a ton and you become dizzy and nauseous.

Just imagine feeling that way every single day, week after week and year after year. True, some chronic illness sufferers have a few "good days" in between, but many do not have any at all! So, if you see them out and smiling, does that mean they are having a "good day?" Not necessarily! Many times they cannot wait for a "good day" to get out, because they do not have them; thus, they make the sacrifice, sitting there in horrible agony and knowing they will pay dearly for it later!

No human being can be at peace with being sick day in and day out! In fact, most people become very frustrated and impatient after just a few hours; then, if it lasts a few days, they become panicked and angry about missing work, school or other activities; next, they become depressed and act like

(Continued on page 16)

(Continued from page 15)

a week out of their busy lives is the end of the world! Yet, they often treat their loved ones like losing months and years out of their lives is no big deal! So, why would you expect your loved one to be happy with losing years of their lives, when you cannot stand to even lose a few days?

It is true, you will never fully comprehend what it is like to be chronically ill, with all of the loss and pain it poses. You will never know what it is like to feel horrible every day and you will never have a grasp at what it is like to watch your lifetime dreams come crashing down forever. So, stop using the excuse that you do not have understanding and start focusing on whether or not you have compassion!

In all, your loved one just wants you see their courage in enduring a life of feeling sick, achy and exhausted all of the time; and, you have the capacity to know you would not want to feel this way every day yourself! You know how horrible it is to be sick and forced to put your life on hold for a while, so why don't you tell them how amazed you are at their strength and perseverance!

But, What If They "Give In" To The Illness?

When a young ice skater named, Nancy Karrigan was assaulted and suffered a leg injury, she faced the possibility of losing all of which she had dreamed; the whole world cried with Nancy, because it could have meant the end of her skating career! Yet, when a person loses their job or is forced to give up their career due to illness, for some reason, people often treat them like they are choosing to do so; and, they are often insensitive to the fact that the sufferer has lost all for which they have worked, planned and hoped for their future.

Most people do not "give in" to illness; in fact, it is ingrained in our nature to fight to survive as hard and as long as humanly possibly. If you believe that your loved one is "giving in" to the illness, because they have given up their usual activities, this is just your perception of how they are handling their limitations.

When a person first experiences the effects of a chronic illness, they have a fantastic attitude about conquering it; they feel strong and invincible to its grip. Even if the disease progresses, they will continue to fight for their right to live the way they planned their lives to be; and, they will stay persistent in the battle until their bodies force them to make limitations.

Creating limitations for oneself is one of the hardest things a person can do. It goes against everything we are and everything we ever hoped to be. No one wants to be sick and no one ever chooses to give up those things in life which bring such joy. Yet, these limitations are mandatory in managing a chronic illness; so, respect their new boundaries by acknowledging their losses and supporting their need to say, "No."

It Seems like I Am Always Saying The Wrong Thing!

What can sometimes be even harder to bear than the illness itself, is feeling alone in the daily struggle and mourning of lifelong dreams. As pieces of oneself die off bit by bit, isolation consumes them when others refuse to affirm their pain. By repeatedly trying to "cheer them up" and make

them see the "bright side" you are not validating their pain, but instead saying, "I don't want to hear the truth" or "your losses don't matter." On the other hand, if you acknowledge their losses, they will no longer be compelled to gain your belief by having to explain their situation over and over again.

Resist the temptation to make a visual diagnosis by saying, "gee, you look you're feeling good today" or "hey, you must be doing well." They may look like they are feeling well, because there is joy in their face from seeing you; however, your comment will only make them realize they are alone in their battle, since you are evidently unaware of their insurmountable hurdles.

In other words, by rebutting their answers with, "But you LOOK good," your friend really hears, "But, I don't believe you, because you look fine to me." Instead try, "I am so glad to see you," "wow, I can't imagine what you go through, you are amazing!" "you look nice today," or "how can I pray for you?"

Encourage your loved one by affirming your trust in them, loving them and showing them that they are still just as valuable to you even if they can no longer do the things they used to do; your willingness to acknowledge their losses will give them the strength and positive attitude they need to fight the illness, instead of wasting their energy fighting with you to believe. They are not seeking your pity or sympathy, they simply want your compassion; some will need your help, just listen, they will tell you how.

We, as chronic illness sufferers, do not want to give up; we want to laugh, smile, look our best and enjoy life; after all, it is our incredible courage, perseverance and persistence to fight for our lives which make our painful disabilities seem invisible to the naked eye.

"Learn to See With Your Ears!"

"But You LOOK Good" was written by The Invisible Disabilities Advocate, Sherri L. Connell. It is Part 2 of Sherri's 40 page booklet, "Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitating Illness." To order this booklet, please send \$5.00 each (includes postage from the US, discounts available for 15 or more). Make the check payable to W. Connell and send to: IDA 41553 Madrid Drive, Parker, CO 80138. Visit IDA's website at www.InvisibleDisabilities.com!

EDITORS:

Tell us what you think of this article. Did you relate to it? Has it helped you explain things better to friends/relatives? Are there additional points you can think of? If so, please send them in to us.



Repairing Self Esteem By Val Rubie

One of the most common worries I hear from people with ME is about their lack of confidence or self-esteem. Most of us treat these words as interchangeable but I think there is a slight difference. Confidence seems to be more about assurance, poise and self-reliance. Self-esteem could be seen as going far deeper in that it is about how you value yourself; that you believe you have an intrinsic worth as a human being.

Lost identity

It is not surprising that both of these attributes take a severe bashing during the course of the illness. ME often means losing your job or education and therefore ability to earn money. It can also mean losing roles in your life such as friend, lover, partner, employee and parent. With the loss of a job or school often comes the loss of a public persona. During our working or school life it is as if we get up each morning and put on a professional face, whether we are a pupil, hairdresser, solicitor, gardener or child minder. We interact with many people in the course of a day, even if only on the phone or by email. Some of these interactions will be difficult, some will be pleasant and some will be plain indifferent. When not working it is easy to get 'out of practice', resulting in loss of confidence and this applies to anyone away from their job (ask any Mum who's been on maternity leave). People with ME often have the additional problem of physical symptoms such as failing memory, difficulty in sustaining conversations and so on, which can further drain confidence. After all, if you can't be sure that the words will come out of your mouth in the right order you are not going to feel confident about communicating clearly.

Mirror mirror on the wall

These interactions are also one of the ways in which we reaffirm our sense of who we are. To my mind this is where the going gets really tough. We need to be mirrored as individuals to know how we are doing or even who we are. It is useful to be able to see oneself through another's eyes. Without this we can almost believe we cease to exist. We make people laugh so we know we are fun, they thank us for listening and we know we are thoughtful. We snap at someone, they look hurt and we know we are irritable. We smile and someone smiles back and we know we are there and we matter in the world. Take this away and it is hard for even the most confident people to believe in themselves.

If because of your ME you are isolated, spending many hours alone each week then you will find your confidence and self-esteem plummet until it seems there is nothing left. As I have mentioned before in these articles, this will be made even more likely if you didn't have "good enough" experiences during your early life or if you have been unfortunate enough to get ME before your adult life has really begun. Recent theories on child development¹ state that if we get good attunement from birth then as early as two to three months old we begin to create a SELF. Attunement means that we have caring people with whom we can interact. We carry through our life the need to be with others and share experiences with them.

Who needs others?

Sometimes when this isn't happening it is tempting to convince yourself that you don't really need anyone or don't care that you are alone. This can feel better than owning up to the dreadful overwhelming loneliness but it may also mean losing your belief that you have a rightful place in the world. ME



sometimes means that not only are you alone much of the time, but when you do see someone they say things which make you feel even worse. For some people their only significant contact is with professionals such as GPs or Carers who may not fully appreciate their condition and feelings. So they are left alone with the anguish of not being understood or heard.

The best way to counteract loss of self-esteem and confidence is to try and increase the amount of good contact you have with others. I know for some of you this may seem impossible but believe it is vital even if you feel too ill for most of the time. When you are deciding how to use that precious bit of energy you have I know it is easy to think only of the practical things, which must be done — like getting yourself fed and clean. But it's dangerous to overlook your emotional needs. In its most basic form, the occasional sound of a human voice, even from the radio or talking books and for very short periods, is better than never-ending silence. Moving up a notch, trying to talk or write to someone for only a few words may be comforting, if you can manage to interact face to face then it may be worth doing even if it leaves you wanting so much more when you are alone again.

Warm fuzzies and cold slimies

My favourite theory about all of this is the one which says we all need so many positive strokes a day². A positive stroke might just be someone saying hello to you in the corner shop or it may be a full-blown hear to hear with your best friend. We grow up believing we are entitled to a certain number of strokes. If we've been lucky, we know we are worth hundreds of strokes a day. If not, we may think we only deserve one or two. If we've been lucky, we know we are worth hundreds of strokes a day. If not, we may think we only deserve one or two. If this is the case then we block out other strokes people may give us. For instance we may say in our head when we have been paid a compliment "They're just saying that — they don't mean it" and a positive stroke is turned into a negative one. Many ME people are stroke hungry!!

A long time ago someone told me this story. Once upon a time there was a land where everyone was happy, healthy and confident. All the people had bags of warm fuzzies which they handed out to everyone they met. The more they handed out, the more the bag was full. Then one day the Wicked Witch of the North told them they were silly to keep handing them out, they should keep them for themselves because after all they might run out. So sadly this is what everyone did until one day

You Know You Have CFS When...

CFS HAPPENS

- You know you have CFS when you are cautioned to slow down by your doctor instead of by the police.
- CFS is having a choice of two temptations and choosing the one that will get you home earlier.
- You know you have CFS when you realize that caution is the only thing you care to exercise.
- Don't worry about avoiding temptation. With CFS, it will avoid you.
- You know you have CFS when getting lucky means you found your car in the parking lot.
- You know you have CFS when you're sitting in a rocker and you can't get it started.
- You know you have CFS when you don't care where your wife goes, just so you don't have to go along.
- You know you have CFS when you wake up with that morning-after feeling, and you didn't do anything the night before.
- Doctor to patient: "I have good news and bad news -- the good news is that you are not a hypochondriac."
- You know you have CFS when you know how to spell gastroenterologist, chiropractor, etc.
- You know you have CFS when you go to make toast and nothing happens. You've plugged in the can opener.
- You know you have CFS when you say to your wife, "Good morning, Mary"...and her name is Sharon.
- You know you have CFS when you have to sit down to brush your teeth in the morning.
- You know you have CFS when you become exhausted from the effort to blow out the candles on your birthday cake.
- You know you have CFS when you forget your twin sister's birthday.
- You know you have CFS when you realize that you just sprayed spot remover under your arms instead of deodorant.
- You know you have CFS when you put both contact lenses in the same eye.
- You know you have CFS when you realize the marriage vows you took about sickness and health meant HIS sickness not YOURS.
- You know you have CFS when you have to take a nap because chewing your dinner wore you out.
- You know you have CFS when you have trouble adding single digit numbers.
- You know you have CFS when you get up to change the TV channel and decide as long as you're up, you might as well go to bed.
- You know you have CFS when one of the throw pillows on your bed is a hot-water bottle.
- You know you have CFS when everything that works hurts, and what doesn't hurt doesn't work.
- You know you have CFS when you reach the toilet, but forgot what you wanted to do.

(Continued from page 17)

they discovered there were no more warm fuzzies only cold slimies. And the land became cold and ark and miserable and no one believed in themselves anymore. One day many, many long years later, a little child made a warm fuzzy and gave it to a stranger who gave it away that minute and before long everyone was busy giving out warm fuzzies and the land became a happy place again.

As we know when you have ME you often get far more cold slimies than warm fuzzies. So it's very important to encourage even one warm fuzzy a day and make sure you

- You know you have CFS when you can't finish a conversation, because you don't remember what you were talking about.
- You know you have CFS when your top three favorite pastimes involve sleep.
- You know you have CFS when you have to get rid of your dog; he kept trying to drag you to the yard to bury you.
- You know you have CFS when Medicare states that you're too sick for their coverage.
- You know you have CFS when everyone is happy to give you a ride because they don't want you behind the wheel.
- You know you have CFS when a passing funeral procession pauses to see if you need a lift.
- You know you have CFS when people are constantly putting a mirror under your nose while you nap to see if you're breathing.
- You know you have CFS when you know "where it's at", but forgot why it's there.
- You know you have CFS when at 25, your colleagues that are 15+ years your senior and have kids, manage to do more on the weekends than you.
- You know you have CFS when you get the vacuum out because, by golly, today's the day your going to DO SOMETHING, and then you have to lay down and get hubby to put the stupid thing away. Unused.
- It's hard to be nostalgic when you can't remember anything.

And from the FMS side, Kathleen Scott adds "You know you have Fibro Fog when . . ."

- You boil the kettle dry three times to get one cup of tea.
- You read a note you wrote to yourself to pay a bill, and you wonder who the heck is Bill.
- You call the school twice, to let them know your child is at home sick.
- You can't disconnect the dishwasher from the kitchen tap, because you didn't turn the water off first to release the pressure.
- You read 100 e-mails from your online support group, then realize you're in the trash folder.
- You feed the dog twice, because she has learned how to trick you into thinking you forgot.

I have done all of the above.

<http://www.geocities.com/cfsdays/uhavecfs.htm>

Bill Jackson, © 1998-2000.

Any comments? Send them to Bill Jackson at cfsdays@yahoo.com

hear it.

- (1) Dr Daniel N. Stern, Professor of Psychiatry, Cornell University Medical Centre, USA
- (2) Dr Eric Berne, Transactional Analysis

This article was taken from InterAction No. 34, August 2000.
Photo © Karen Wilson merryrat@hotmail.com



OBITUARY



Dr Tapendra Mohan Mukerjee

**Born 30th September 1933 India
Died 2nd February 2001 Adelaide**

It was with great sadness that I recently attended the funeral of Dr Tapen Mukerjee, one of Australia's first researchers to make significant scientific discoveries into the disease ME/CFS. The funeral was an incredibly moving and spiritual experience combining both Hindu and Christian elements – a true reflection of how Dr Tapen lived his life.

Dr Mukherjee was born in Dehra Dun, India and from an early age had a keen sense of passion about whatever he did. He was determined and courageous and always believed that one should be the very best that they could be.

He graduated from the University of Calcutta in 1955 with a medical degree and followed by a Diploma in Gynecology and Obstetrics. He then entered the field of electron microscopy, which became the focus of his life's work. Tapen travelled to various parts of the world on fellowships and in 1965 he travelled to New Zealand where he took up the position of Head of Electron Microscopy at the University of Otago.

During the course of his career he made many scientific discoveries and was the first to describe the presence of tight junctions between cells which serve as mechanisms of cell communication. In 1969 Dr Tapen came to Adelaide and became a pioneer researcher in Ultrastructural Pathology. A research discovery that he was very passionate about was the finding of structural abnormalities existing in the red blood cells of patients with chronic fatigue syndrome. This was a significant discovery because it showed for the first time that patients with this disease had a definite organic pathology. This work drew world attention when it was published in Time magazine. Dr Mukherjee worked very closely with Dr Kathy Maros in this research and travelled overseas to establish links with other researchers interested in CFS. The South Australian Society in the 80's, led by Lyn Drysdale also worked together with Dr Mukherjee and lobbied for equipment and funding for ME/ CFS research. Tapen was one of the first Doctors to seek R&D funding from the private sector for ME/ CFS research.

Sport, and especially cricket and golf were his great loves, and allowed him to express his competitive nature. He also loved music and played a wide variety of instruments. Dr Mukherjee supported many community groups and ME / CFS sufferers were always close to his heart. He always wished to be able to do more.

Dr Mukherjee, a very committed family man, is survived by his wife and two daughters, Sutapa and Jini both of whom followed in his footsteps and joined the medical profession.

He is fondly remembered as a gracious gentleman by all who knew him.

JUDY LOVETT

With special thanks to Dr Jini Mukherjee-Gray

JOIN THE TALKING POINT TEAM

We are looking to expand our Talking Point team. We need the following: 1. health professionals to act as advisors and/or write articles for Talking Point. 2. Someone who is able to track down journal articles for us. 3. someone with some medical background who can do background research on specific topics, and prepare materials for our planned medical advisory team. 4. people to scour the internet for interesting articles and to look out for developments in the ME/CFS world.

IF YOU ARE INTERESTED THEN PLEASE CALL THE OFFICE: 8410 8929.



By Dr. DeLuca Taken from The CFS Research Review, The Quarterly Publication of the Chronic Fatigue and Immune Dysfunction Syndrome Association of America. Summer 2000 Volume 1 Issue 3

Page 20

Studies assessing structural and functional neuroimaging, autonomic activity and neuroendocrine abnormalities all point to neuro-pathology in chronic fatigue syndrome (CFS) patients. While the nature and the extent of neuropathologic involvement in CFS is still unclear, neurocognitive studies make up a very high body of CFS research.

This is an important area for clinicians to familiarize themselves with, as cognitive problems have been cited as one of the most disruptive and functionally disabling symptoms of CFS, with up to 85% of patients reporting impairments in attention, concentration and memory abilities.

This article provides an overview of neurocognitive findings in CFS patients and the possible underlying structural changes in the brain.

Cognitive Problems Observed

Neuropsychological testing confirms cognitive abnormalities, although the data is not consistent as to their nature and testing abnormalities may be subtle in contrast to patients' descriptions of day-to-day problems.

Several formal neuropsychological studies report impairments in attention, verbal memory, visual memory, reaction time and complex auditory information processing.²⁻⁵ However, others have not found memory or attentional deficits.⁶⁻⁷

Despite methodology limitations, research with CFS patients is fairly consistent in showing the neuropsychological impairments are primarily in the area of complex information processing efficiency, verbal processing difficulties or susceptibility to interference are important questions that were addressed in a recent study. Patients were found to be susceptible to brief distraction, which resulted in impaired immediate and delayed recall.⁸

Another important question for neuropsychological research in CFS is the relationship between self-reported fatigue, perceived cognitive impairment, and objective neuropsychological performance. Some research findings have demonstrated that fatigue brought about by mental challenges did not universally impair performance.

A study at the NIH-funded New Jersey Cooperative Research Centre found that after exhaustive treadmill exercise, CFS patients demonstrated impaired cognitive processing compared to healthy controls, suggesting that physical fatigue may be a crucial variable in explaining impaired cognition.⁹ Several other studies have arrived at similar conclusions.

It is important to note that the impaired cognition experienced by many CFS patients may not necessarily be explained by an underlying psychiatric condition. In at least one study, CFS patients without psychiatric comorbidity were impaired relative to controls and patients without CFS with concurrent psychiatric disease on tests of memory, attention and information processing.¹⁰

Neuroimaging Study Findings

It has been postulated that some of the Symptoms of CFS, such as impaired cognition, may result from brain abnormalities. Several studies have been reported significantly more abnormalities on MRI among CFS subjects relative to controls.

Overall, MRI studies are generally consistent in demonstrating T2 signal hyperintensities in the subcortical white matter, often in the frontal lobes. One study found that CFS patients without depression had a significantly larger number of small, punctate subcortical white matter hyperintensities compared to CFS patients with depression or sedentary controls.¹¹

Another approach to neuroimaging is assessing cerebral blood flow via single-photon emission computed tomography (SPECT). Most SPECT studies have shown significantly decreased blood flow. This technique has demonstrated change in some patients' brains that were not apparent on MRI.

In one study, decreases in regional cerebral blood flow throughout the brain have been reported on SPECT in a CFS group relative to healthy controls, and abnormalities were observed in 80% of the CFS patients. CFS patients could be distinguished from controls with unipolar depression based on the pattern of SPECT abnormalities.¹²

In addition, significant brain stem hypoperfusion on SPECT was found in patients with CFS relative to controls and depressed patients.¹³

At least one research group reported a positive correlation between frontal blood flow (on SPECT) and cognitive impairment. They hypothesised that the blood flow abnormalities may play a pathophysiological role in cognitive impairment and physical limitations in CFS patients.¹⁴

There have been few published reports of positron emission tomography (PET) scans in CFS patients. One research group reported hypometabolism on PET in the brain stem of 18 CFS patients which was not found in six depression patients or six healthy controls.¹⁵

How Does CFS Differ From Depression?

CFS symptoms rely on subjective report, which fuels the controversy over an organic versus emotional aetiology of the illness. Some practitioners confuse clinical depression, which may also cause difficulty in cognitive processing, with CFS.

High diagnosis rates of depression in CFS patients may result from overlapping symptomatology, reaction to disability imposed by fatigue or viral/immune changes in the brain. However, as has already been pointed out, studies have shown that some of the brain abnormalities found in CFS may be differentiated from patients who are psychiatrically depressed. However, this research is in its infancy, and more studies are needed. In addition, one recent study showed that the pattern of depressive symptoms in CFS patients is dissimilar to that observed in clinically depressed patients.¹⁶

(Continued on page 21)

Fludrocortisone acetate to treat neurally mediated hypotension in chronic fatigue syndrome: A randomized controlled trial.



JAMA 285(1): 52-9 (Jan 3 2001)

F -- GF (Medical Library) -- 610.5 A53

Rowe PC, Calkins H, DeBusk K, McKenzie R, Anand R, Sharma G, Cuccherini BA, Soto N, Hohman P, Snader S, Lucas KE, Wolff M, Straus SE
Brady 212, Johns Hopkins Hospital, 600 N Wolfe St, Baltimore, MD 21287, USA.

[Medline record in process]

CONTEXT: Patients with chronic fatigue syndrome (CFS) are more likely than healthy persons to develop neurally mediated hypotension (NMH) in response to prolonged orthostatic stress. OBJECTIVE: To examine the efficacy of fludrocortisone acetate as monotherapy for adults with both CFS and NMH.

DESIGN: Randomized, double-blind, placebo-controlled trial conducted between March 1996 and February 1999.

SETTING: Two tertiary referral centers in the United States. PATIENTS: One hundred individuals aged 18 to 50 years who satisfied Centers for Disease Control and Prevention criteria for CFS and had NMH provoked during a 2-stage tilt-table test. Eighty-three subjects had adequate outcome data to assess efficacy.

INTERVENTION: Subjects were randomly assigned to receive fludrocortisone acetate, titrated to 0.1 mg/d (n = 50)

(Continued from page 20)

depressed patients and more closely resembles the pattern observed in patients with multiple sclerosis (MS).¹⁶

Implications for Treatment

Much of the data on brain abnormalities in CFS is still too preliminary to use in practice. Although the MRI and SPECT findings of the brain in CFS patients are intriguing, more carefully designed and controlled studies still need to be undertaken.

However, physicians and other health care professionals could still make use of the information that neuroimaging provides. Some patients with apparent CFS and brain lesions on MRI may actually have mild presentation of other neurological illnesses, such as MS.

Clinicians should also keep in mind that patients' diminished neurocognitive processing can be addressed through rehabilitation.

Clinicians should also take patients' impaired cognition into account during office visits. Patients may need assistance in completing complex tasks, such as filling out medical forms.

They may also have difficulty expressing themselves verbally and understanding questions during exams. One way to help patients is to make questions very specific and to state them one at a time, rather than as an uninterrupted series, since slowed processing speed is a major problem in patients with CFS.

or matching placebo (n = 50) for 9 weeks, followed by 2 weeks of observation after discontinuation of therapy.

MAIN OUTCOME MEASURE: Proportion of subjects in each group with at least a 15-point improvement on a 100-point global wellness scale.

RESULTS: Baseline demographic and illness characteristics between the groups were similar; CFS had been present for at least 3 years in 71%. Using an intention-to-treat analysis, 7 subjects (14%) treated with fludrocortisone experienced at least a 15-point improvement in their wellness scores compared with 5 (10%) among placebo recipients (P = .76). No differences were observed in several other symptom scores or in the proportion with normal follow-up tilt test results at the end of the treatment period.

CONCLUSIONS: In our study of adults with CFS, fludrocortisone as monotherapy for NMH was no more efficacious than placebo for amelioration of symptoms. Failure to identify symptomatic improvement with fludrocortisone does not disprove the hypothesis that NMH could be contributing to some of the symptoms of CFS. Further studies are needed to determine whether other medications or combination therapy are more effective in treating orthostatic intolerance in patients with CFS. PMID: 11150109, UI: 20583385



References

1. Grafman J. In: Straus SE. ed. Chronic Fatigue Syndrome. N.Y.; Marcel Dekker, 1994; 263-84.
2. DeLuca, J et al. J Neurol Neurosurg Psych. 1995; 58;38-43.
3. Riccio M et al. Brit J Clin Psych. 1992; 31:111-120.
4. Grafman J et al. J Neurol Neurosurg Psych. 1993; 56; 684-9.
5. Scheffers MK et al. Nerol. 1992; 42;1667-75.
6. Johnson SK et al. Clin Infect Dis. 1994; 18; S84-S85.
7. Krupp lb et al. Arch Neurol. 1994; 51; 705-10.
8. Johnson SK et al. Cog Neuropsych. 1998; 3; 269-285.
9. LaManca J et al. Am J Med. 1998; 105; 59S-65S.
10. DeLuca J et al. J Neurol Neurosurg Psych. 1997; 62; 151-55.
11. Natelson BH et al. J Neurol Sci. 1993; 120; 213-7.
12. Ichise M et al. Nuclear Med Commun. 1992; 13; 767-72.
13. Costa DC et al. Quartyerly J Med. 1995; 88; 767-73.
14. Fischler B et al. Neuropsychobiol. 1996; 34;175-83.
15. Tirelli U et al. Am J Med. 1998; 105; 54S -58S.
16. Johnson SK et al. J Affect Dis. 1996; 39; 21-30.

Dr. DeLuca is Director of Neuroscience Research, Kessler Medical Rehabilitation and Education Corporation, and Professor of Physical Medicine, Rehabilitation and Neurosciences, University of Medicine and Dentistry of New Jersey (UMDNJ) - New Jersey Medical School.





Childbearing and CFIDs: Making a Difficult Decision

The CFIDS Chronicle, Summer 2000, Volume 13, Issue 3.

Deciding to have children is a central event in many individuals' lives. Having chronic fatigue and immune dysfunction syndrome (CFIDS) makes the decision more difficult. Pregnancy and parenthood for individuals with CFIDS can seem daunting, and it is hard to find good information on the risks. Unfortunately, there is very little formal research on pregnancy and CFIDS, so most of what is known is medical opinion rather than fact.

This article aims to provide some general advice, but women who have CFIDS and are thinking about becoming pregnant need to talk through the issues carefully with their partners and with their physicians. Countless couples with CFIDS have successfully borne and reared children. Careful advance planning can help make the experience easier and more enjoyable.

Deciding whether to get pregnant

Clinical experience with CFIDS patients who have become pregnant suggest that the majority either stay the same or actually feel somewhat better during their pregnancies. This has been true in my own practice. A recent review of medical charts for 27 women who became pregnant while they had CFIDS revealed 25 felt better during pregnancy. On the other hand, approximately one-third of CFIDS patients experience a worsening of their original symptoms after giving birth—almost like a bad relapse.

The reason for this may have to do with the immune system. A similar lessening of symptoms during pregnancy occurs with other autoimmune conditions such as multiple sclerosis. The theory is that the body "turns off" parts of the immune system to prevent the woman's body from attacking the baby as it would a virus or anything else that is not an original part of itself.

The improvement may also have something to do with hormones produced during pregnancy. A few physicians have treated CFIDS patients with oxytocin, a hormone that women produce when breast feeding. CFIDS physician Dr. Jay Goldstein reported improvement in about one-fifth of the patients studied.

CFIDS patients trying to get pregnant should be aware that they might be at higher risk for first-trimester miscarriage, although this is based on clinical experience, not formal research.

A study published in the September 28, 1998 issue of *The American Journal of Medicine* did not find that a higher percentage of women with CFIDS experienced irregular menstrual cycles, hormone imbalances affecting menstruation and ovarian cysts, which may affect their ability to get pregnant and successfully complete a pregnancy. However, in my chart review of CFIDS mothers, I did not find a rate of miscarriages in excess of the expected limits for the general population. Only 4 of the 27 had experienced one or more miscarriages.

Possible effects on the baby's health

The majority of women with CFIDS seem to have normal, healthy children. There have been no formal reports of a child being born with CFIDS. However, there is no definitive proof on whether parents can transmit the illness to their babies or whether children can inherit the ability to contract CFIDS later in life.

Pregnet

www.pregnet.org

THE ACTION FOR M.E./C.F.S. PREGNANCY NETWORK

A good resource for information on ME/CFS and pregnancy. This site includes case studies and helpful information.

The question of whether CFIDS is inheritable is often raised, as the illness does seem to run in some families. Dr. David Bell found that during an outbreak in Lyndonville, N.Y. in 1985, more than 15% of individuals diagnosed had another family member ill with CFIDS as well. However, this does not necessarily mean that CFIDS is genetically linked.

Some physicians and researchers believe that CFIDS is caused by an unidentified infectious agent or triggered by a known virus in patients who have a vulnerable immune system. This "vulnerability" could be genetic and inherited, or it could be due to damage to the immune system from various environmental hazards to which the entire family is exposed.

If the illness is caused by a virus, it could be transmitted to an unborn baby as it travels through the birth canal or to a newborn through breast feeding. The chances of this are low, but if parents-to-be are concerned, they may want to consider bottle feeding rather than breast feeding to help lower the chances of passing on an infectious agent.

To breastfeed or not is a personal choice that should be based on what is best for the mother and baby's health. Breast feeding does provide the baby with an important source of antibodies and cuts down on the work of preparing formula and bottles. However, bottle feeding means that the mother's medications will not have to be restricted after the baby's birth and other people can help with the feeding (especially at night) to allow the mother to get more rest.

Special considerations for pregnancy and delivery

It is advisable for CFIDS patients to stop most of their over-the-counter and prescription medications before they get pregnant because they may be harmful to the fetus. Some drugs, such as antidepressants and pain medications, need to be tapered off slowly, so talk to a physician first.

Women with CFIDS who are planning to get pregnant should also stop taking herbal preparations and nutritional supplements (aside from prenatal vitamins or other supplements recommended by their physicians). In most cases, there is just not enough data to show how they will impact the baby.

An epidural can help conserve a woman's energy during birth and speed recovery afterwards. Pain relief options should be discussed with the obstetrician or midwife well in advance of the baby's due date.

(Continued on page 23)

Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome.



Pauline Powell, Richard P Bentall, Fred J Nye, and Richard H T Edwards (2001), *British Medical Journal* 322: 387

Objective: To assess the efficacy of an educational intervention explaining symptoms to encourage graded exercise in patients with chronic fatigue syndrome.

Design: Randomised controlled trial.

Setting: Chronic fatigue clinic and infectious diseases outpatient clinic.

Subjects: 148 consecutively referred patients fulfilling Oxford criteria for chronic fatigue syndrome.

Interventions: Patients randomised to the control group received standardised medical care. Patients randomised to intervention received two individual treatment sessions and two telephone followup calls, supported by a comprehensive educational pack, describing the role of disrupted physiological regulation in fatigue symptoms and encouraging home based graded exercise. The minimum intervention group had no further treatment, but the telephone intervention group received an additional seven follow up calls and the maximum intervention group an additional seven face to face sessions over

four months.

Main outcome measure: A score of ≥ 25 or an increase of ≥ 10 on the SF-36 physical functioning subscale (range 10 to 30) 12 months after randomisation.

Results: 21 patients dropped out, mainly from the intervention groups. Intention to treat analysis showed 79 (69%) of patients in the intervention groups achieved a satisfactory outcome in physical functioning compared with two (6%) of controls, who received standardised medical care ($P < 0.0001$). Similar improvements were observed in fatigue, sleep, disability, and mood. No significant differences were found between the three intervention groups.

Conclusions: Treatment incorporating evidence based physiological explanations for symptoms was effective in encouraging self managed graded exercise. This resulted in substantial improvement compared with standardised medical care.

Page 23

March 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

This paper was published on-line at: <http://bmj.com/cgi/content/full/322/7283/387> with the facility for people to post responses onto the internet. It has received many 'Rapid Responses' (<http://bmj.com/cgi/content/full/322/7283/387#responses>) from ME/CFS groups, researchers and advocates from around the world. It is difficult for people with ME/CFS to see this kind of treatment heralded as an answer to our problems, when we know that exercise is not the answer – in fact it may frequently be the exact opposite of what most of us need. Over the page we summarise some of the key criticisms that have been made in the responses to this paper, and provide some thoughts on graded exercise.

(Continued from page 22)

Also keep in mind that PWC mothers may spend a longer time in the hospital following delivery than healthy new mothers. A British survey of 27 women with CFIDS showed that half spent extra time in the hospital after delivery because of their CFIDS symptoms. You should discuss this possibility with your doctor during pregnancy so he/she is prepared to advocate for you if your insurance provider denies extra time in hospital.

Coping after the baby is born

Taking care of babies and toddlers requires a considerable amount of emotional and physical energy, and for many women and men with CFIDS, coping with childcare is the largest factor in deciding whether or not to have a baby.

having a good support network of parents, grandparents, neighbors and friends can help. Couples who do not have a network to fall back on may have to hire extra help, which something to take into consideration early on. Families with tight budgets might want to contact local universities about hiring a nursing or early education student.

One way to conserve energy is by sitting or lying down to change diapers or feed the baby. Most young babies can only stay awake for about two hours, so anticipating when the baby will be tired and encouraging him or her to sleep will help establish a regular schedule and help new mothers get more rest.

For additional tips, contact a local support group to find out if there are other parents with CFIDS nearby who would be willing to share their experiences and lessons learned.

Dr Charles Lapp is head of the Hunter-Hopkins Center in Charlotte, NC and Clinical Associate Professor of Family and Community Medicine at Duke University.

The CFIDS Chronicle is a publication of the CFIDS Association. <http://www.cfids.org>



Graded Exercise Therapy for ME/CFS?

Few patients and practitioners alike would dispute that some exercise is beneficial for ME/CFS patients. Certainly, in a brief literature review White (2000) provides substantial evidence for the significant effect of inactivity on several physiological parameters, both endocrine and autonomic, thought by some to be contributing factors to the illness. However, the reality for many ME/CFS patients is that regular "exercise" is impossible and contrary to popular belief and psychiatric stereotype this certainly is in opposition to their willingness and desire.

In 1989 Wessely and colleagues (as cited by Bazelmans et al, 2001) infamously hypothesised that physical deconditioning may play an important role in CFS, their rationale being that because CFS patients experience a worsening of complaints after activity, they learn to avoid activity in order to prevent this from occurring. However, being inactive then leads to a decrease in physical fitness, and correspondingly complaints get worse at an increasingly lower level of physical activity, establishing a vicious cycle of deconditioning. This led to patients being psychiatrically coined as having "a low threshold for certain somatic perceptions" (Lawrie et al, 1997 as cited by Fulcher, 2000) and adherence to the Cognitive Behaviour Therapy (CBT)/ Graded Exercise Therapy (GET) models has become popular amongst psychiatric CFS researchers. These therapies are aimed at the re-establishment of beneficial behaviour; this alone has been purported to return optimal functioning through apparently improved perceptions of well-being, strength and exercise capacity (Russell, 2000).

However, the theory of CBT has not been well received by patient advocates, supportive physicians and physiological ME/CFS researchers. The controversial organic vs psychological debate still rages with much argument over the preceding cause of physical deconditioning (De Becker, 2000; Russell, 2000; Fulcher, 2000). Psychiatric researchers use to their advantage the inconsistency of muscle histological and metabolic muscle research findings. Physiology researchers continue to defend this assertion by claiming that ME/CFS is a heterogeneous illness and differences in patient populations and muscles studied may account for discrepancies (Russell 2000; De Becker 2000).

The current study by Powell et al (abstract on previous page) has incited much open comment and debate (<http://bmj.com/cgi/content/full/322/7283/387#responses>), as this publication has been made available to the public free of charge (<http://bmj.com/cgi/content/full/322/7283/387>.) Although the authors claim a victory over CFS via their treatment, their conclusions have been criticised by numerous claims that the methodology employed to generate the results was significantly flawed.

Type of patients used

The criteria used to recruit ME/CFS sufferers was the Oxford criteria. This criteria does not diagnose ME/CFS patients exclusively, but rather may allow inclusion of patients who have the symptom of "chronic fatigue" as a result of various other illnesses and disorders. Particularly, patients with mental and primary depressive orders may be mistakenly "diagnosed" as ME/CFS sufferers by these criteria. As Gurli Bagnall suggests (2001), this is evidenced in the present study by the number of patients who were excluded from the trial for various reasons, including psychiatric exclusions. Moreover, only one consultant physician confirmed the

diagnosis, and we are not told whether this physician has background knowledge of, and experience with, the illness of ME/CFS. We find it difficult to accept that one individual alone (per patient) could constitute such a major diagnosis, particularly when the criteria are so subjective. A panel of ME/CFS experienced physicians (and possibly other health professionals) may ensure a more accurate diagnosis.

Perhaps the title of the paper should be renamed to "Randomised controlled trial of patient education to encourage graded exercise in patients with chronic fatigue as a symptom" or "... patients with symptomology meeting the Oxford diagnostic criteria."

Sarah David (2001) provides an interesting discussion of the diagnostic criteria in her Rapid Response, and reminds us that an expert CDC diagnostic criteria working group (1994) rejected the Oxford criteria. Of course, there has also been much discussion regarding the effectiveness of the CDC criteria. David observes that the Oxford criteria is conveniently used and "widely accepted" by adherents to the CBT model. That is, psychiatric researchers selectively use the Oxford criteria as it suits their purpose.

David goes on to state "This definition is used for one reason and for one reason only. In practice, they tend to exclude people with any kind of disease process (ongoing infections, neurological problems etc.), leaving psychiatrists and psychologists with a sample dominated by individuals whose health is likely to improve with CBT." As demonstrated by this study and another recent study by Fulcher & White (2000) we can begin to see that authors supporting the behavioural therapy of graded exercise programs may also prefer to use the Oxford criteria to their benefit.

We also agree with the following comment from Clark (2001): "Those with the severest symptoms have been consistently ignored in research and are least likely to access the few specialist services that do exist. We call for clinicians to take responsibility for those most profoundly affected." Certainly the sickest individuals (long term and acute in the initial stages of the illness) are significantly marginalised. Surely this contributes to, and continues to perpetuate, the myth that there is no organic basis to illness of ME/CFS. What is more, the exclusion from the study of patients confined to wheel-chair or bed shows complete ignorance of the illness. Researchers must acknowledge the extreme degree of fluctuation in severity of illness. Patients attain different degrees of limited mobility on a monthly or even weekly basis, as often paradoxically adversely affected by their level of physical and mental exertion and other various exposures detrimental to health outcome.

What caused the improvement?

The interesting thing about this study is that the three 'intervention' groups showed similar improvements. What do we conclude from this? Is it simply possible that any personal follow up provides encouragement to the sufferers? And does this contact and encouragement keep the subjects motivated and feeling better about themselves such that fatigue, sleep, disability and mood are rated better? The authors disagree "Our current study has several limitations, including the lack of a placebo control group that received equivalent therapist time and attention. However, other investigators have found that therapist time alone does not result in positive outcomes. After treatment, most patients attributed their improvement to

changes of behaviour brought about by the physiological explanations they were given for their symptoms." So can it be postulated that education was the key? This is somewhat puzzling as Clark points out: "Had education itself been the significant intervention at least some differences between the groups could have been expected." This does not persuade the authors who instead optimistically suggest that only a minimum of education/followup may be necessary for significant improvement. In this respect, the graded exercise intervention may appeal to governments as a *seemingly* cost-effective treatment strategy. And the concern is that governments will be tempted to skew funding toward research that seems to suggest low-cost solutions.

The results cast doubt on whether we can ignore the lack of a proper control group – one which received some sort of followup, but without reference to symptoms or to graded exercise. If this were done it would eliminate the doubt that followup itself produced improvement. It would show that indeed it was the education about symptoms, and the encouragement to keep active and keep up with the exercise programme that makes the difference. Certainly, sound scientific protocol only allows for one variable between comparison groups.

Underlying Assumptions about ME/CFS

We do not believe the authors properly understand ME/CFS. On one hand the authors were quick to point out that they do not believe that CFS is just in our head. They are prepared to acknowledge there is a physiological disturbance there too. That is fine, but the authors believe the physiological disturbances are psychologically based, or so we conclude from the following statement: "escape from the vicious circle maintaining the disorder can often be achieved by the gradual resumption of normal patterns of activity." We do not believe this is the case. True ME/CFS is organically based. We would argue that individuals who recover in this way are unlikely to have experienced ME/CFS (certainly not severe ME/CFS) in the first place, or they are already on the way to recovery.

Lack of Respect

Probably one of the most controversial aspects of the paper is the lack of respect shown towards patients with ME/CFS. The BMJ press release opens with: "Many patients with chronic fatigue syndrome have inaccurate illness beliefs that may perpetuate their condition." The authors certainly make it quite clear that they believe patients need to be *re-educated* that physical deconditioning alone is the cause of their chronic symptoms. What's more, the authors frequently use unnecessarily emotive language, such as that ME/CFS patients are "... Fearful of contact with mental health workers". Is this a deliberate attempt to portray ME/CFS patients as damaged emotionally, or is it yet another example and indication of their poor scientific protocol?

Other Considerations

There are other important issues that we do not have space to elaborate on – such as how do we actually measure a person's health and then go on to say they have improved or declined. To view a more detailed summary of the criticisms of the full paper, please go to our website: www.sacfs.asn.au where Farrah provides a more detailed discussion on this paper.

Conclusions

It is disappointing that such a study has been allowed to be published because of lack of a properly setup control group.

inappropriately selected patients and various other important methodological flaws. It hard for ME/CFS sufferers not to think that an unequal amount of attention is given to papers advocating cognitive behaviour therapies because they seem to offer a quick-fix solution to the problem. It is very difficult to draw definitive conclusions from this particular study. Was it the graded exercise, the education about symptoms or just the fact that they were followed up that improved patients? And were these people suffering from ME/CFS or just chronic fatigue?

We ask that criteria that are more rigorous be used to ensure genuine ME/CFS sufferers appear in these trials, and that they are designed to include a range of severity of the illness. We believe results may be different under these conditions.

Far be it for us to decry any treatment that helps any individual in any way. Clearly there are some people out there with some sort of chronic fatigue that are in need of this kind of support and/or treatment. We acknowledge that unhelpful psychological habits may develop in the chronically ill, and in some case these may need to be addressed. Nor do we wish to say that exercise is a bad thing - we should try to do as much as possible without aggravating our symptoms and condition. But we also must firmly state that *graded exercise is not the principal solution to genuine sufferers of ME/CFS, and that for some sufferers exercise may exacerbate their condition.*

Whatever is researched, whatever is reported, we know ourselves that the majority of ME/CFS sufferers are not people caught in a destructive, hopeless mindset that a pep talk and some support can get us out of. We have a genuine organic illness that robs us of significant quality of life – an illness that we cannot simply fight away, but one that we must respect and learn to manage.

References:

- Bagnall G (2001), Medical accountability. <http://www.bmj.com/cgi/eletters/322/7283/387#EL1>
- Bazelmans E, Bleijenberg G, Van der Meer J & Folgering H (2001), Is physical deconditioning a perpetuating factor in chronic fatigue syndrome? A controlled study on maximal exercise performance and relations with fatigue, impairment and physical activity. *Psychological Medicine* **31**(1): 107-114.
- Clark C (2001), The importance of a therapeutic partnership with M.E. (CFS) patients <http://www.bmj.com/cgi/eletters/322/7283/387#EL5>
- David S (2001), Unfair response is most revealing. <http://www.bmj.com/cgi/eletters/322/7283/387#EL9>
- De Becker P, Roeykens J, Reynders M, McGregor N, & De Meirleir K (2000), Exercise Capacity in Chronic Fatigue Syndrome. *Archives of Internal Medicine* **160**: 3270-3277.
- Fulcher K & White P (2000), Strength and physiological response to exercise in patients with chronic fatigue syndrome. *Journal of Neurology, Neurosurgery and Psychiatry* **69**(3): 302-307.
- Powell P, Bentall R, Nye F & Edwards R, (2001), Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome. *British Medical Journal* **322**: 1-5. : <http://bmj.com/cgi/content/full/322/7283/387>.
- Russell L (2000), Chronic Fatigue Syndrome: is it physical? *Journal of Neurology, Neurosurgery and Psychiatry* **69**(3): 289.
- White P, (2000), The role of physical inactivity in the chronic fatigue syndrome. *Journal of Psychosomatic Research* **49**(5): 283-284.

Paul Leverenz (B.Sc.) and Farrah Tate (B.Sc.)



ABC HEALTH REPORT: Graded Exercise For Chronic Fatigue Syndrome

Broadcast Monday 26 February 2001

Rae Fry interviews one of the researchers on this paper, **Richard Bentall**. To read the full transcript go to: <http://www.abc.net.au/rn/talks/8.30/helthrt/stories/s252103.htm>

In this interview Bentall discusses the graded exercise findings of his team. It is interesting to note that the title states "Graded exercise for chronic fatigue syndrome, but the article summary says "A British study has found that gradual, graded exercise for treating chronic fatigue has benefits." Then the next line uses the terminology: "Chronic Fatigue Syndrome". Throughout the article Bentall and Fry use the terminology "chronic fatigue." So there is an inconsistency in the naming of the illness being discussed. Are we talking about Chronic Fatigue Syndrome or Chronic Fatigue?

This radio interview featured a lady who had suffered from "chronic fatigue" for 20 years. She had undergone a form of graded exercise program and improved from it. It was reported she improved her mobility over a period of two years from being able to walk 12 metres to being able to walk from a car park to her doctors rooms several floors up in a building. What is overlooked is why is such a person only able to do such a little amount even after two years? Regardless of whether she has full-blown ME/CFS or just chronic fatigue, the therapy only marginally improved her mobility, but it clearly hasn't treated the real cause of the

problem, and doesn't explain why she is impaired to such a degree. The attention is solely on the improvement, and we hope that governments aren't blinded by this kind of selling a pragmatic product which forgets to ask why such a person is so sick.

We ask ourselves why this kind of research that seems to get all the attention? The first line of the press release for Powell, Bentall et al. says "Many patients with chronic fatigue syndrome have inaccurate illness beliefs that may perpetuate their condition." This kind of claim touches upon a raw nerve in the Australian psyche – it suggests that the ultimate cause of our fatigue is not organic but psychological. This puts us in the category of bludgers or malingerers – the worst kind of. This claim will always be heard, because it is easier to believe this than deal with an illness that can't easily be defined, tested for or seen with the naked eye.

We maintain that the large majority of ME/CFS sufferers are neither malingerers. We have a genuine, organic illness (in origin) that is not powered/perpetuated by our psychology, and ultimately all research that is undertaken with this patronising belief will be judged by history as misconceived.



Exercise Capacity in Chronic Fatigue Syndrome

Pascale De Becker, PhD; Johan Roeykens, PT; Masha Reynders, PT; Neil McGregor, MD, PhD; Kenny De Meirleir, MD, PhD

Background

Patients with chronic fatigue syndrome (CFS) suffer from various symptoms, including debilitating fatigue, muscle pain, and muscle weakness. Patients with CFS can experience marked functional impairment. In this study, we evaluated the exercise capacity in a large cohort of female patients with CFS.

Methods

Patients with CFS and matched sedentary control subjects performed a maximal test with graded increase on a bicycle ergometer. Gas exchange ratio was continuously measured. In a second stage, we examined only those persons who achieved a maximal effort as defined by 2 end points: a respiratory quotient of at least 1.0 and an age-predicted target heart rate of at least 85%. Data were assessed using univariate and multivariate statistical methods.

The resting heart rate of the patient group was higher, but the maximal heart rate at exhaustion was lower, relative to the control subjects. The maximal workload and maximal oxygen uptake attained by the patients with CFS were almost half those achieved by the control subjects. Analyzing only those persons who performed a maximal exercise test, similar findings were observed.

Conclusions

When compared with healthy sedentary women, female patients with CFS show a significantly decreased exercise capacity. This could affect their physical abilities to a moderate or severe extent. Reaching the age-predicted target heart rate seemed to be a limiting factor of the patients with CFS in achieving maximal effort, which could be due to autonomic disturbances.

Arch Intern Med. 2000; 160: 3270-3277

Results

IS YOUR HEALTH PRACTITIONER KNOWLEDGEABLE ABOUT ME / CHRONIC FATIGUE SYNDROME?

If your doctor understands ME/CFS and you find he/she helpful in dealing with your condition, then please tell us (8410 8929). Ask he/she if they would like to be on our mailing list.

AWARENESS WEEK: PUBLIC MEDICAL LECTURE BY DR. HUGH DUNSTAN



The ME/CFS Society (SA) Inc.
invites you to a:

PUBLIC MEDICAL SEMINAR

Advances in Metabolic Research for ME/Chronic Fatigue Syndrome: an update on research being conducted at the University of Newcastle
by Dr. Hugh Dunstan, Senior Lecturer School of Biological and Chemical Sciences, University of Newcastle

International ME/CFS Awareness Day
SAT. MAY 12th 2001, 1:30 pm



Details
Location: Urrbrae Education Centre, Cnr Fullarton Rd and Cross Rd Fullarton
Entrance via gate B on Fullarton Rd (see map)
(A friendly environment for those with chemical sensitivities.)

Costs
Members: \$5 (GST inc.)
Non-members: \$7 (GST inc.)
Members will need to show their 2000-2001 membership card to obtain discount.
There will be facilities to join the society on the day.

IMPORTANT NOTE:
Please refrain from wearing hair spray, aftershave, and other perfumed products, to ensure this is a safe environment for those with chemical sensitivities.



BUS DETAILS
171: City to Mitham
alight stop 12
1:10pm
Return to City
3:47pm, 4:47pm
Circle Line: stop 160

Members: Please support your society by inviting interested friends and health practitioners along to this event!

Dr Hugh Dunstan is a member of a world recognised chronic pain and chronic fatigue disorders research team. Two of its members are editors of the American Journal of Chronic Fatigue Syndrome and one holds a place on the international medical advisory board for the Chronic Syndrome Support Association. In 1999 he presented a paper at the Oxford Conference of Sustainable Medicine, and in 1999 he presented at the Second World Congress on CFS in Brussels.

***Please support your Society by coming to this event**

Dr Dunstan is last came to Adelaide to speak to us in 1995 at the exact same venue. The meeting was packed out with over 300 people present.

The Urrbrae Education Centre Hall is friendly for those with chemical sensitivities, but total safety in this regard is only possible if people in attendance refrain from wearing perfumed products such as hair spray and after-shave.

This event will be a good chance to catch up with others in the society, and for you to meet the new management committee.

There will be opportunities for people to become members on the day.

Please invite along your friends, family and health practitioners. With your help we can make this event a great success.

The Year to Date

We have already had several meetings this year. Starting on Feb. 10th we had 2 general meetings where members had a chance to express concerns over issues in the society.

This was followed on Feb. 18th with a public meeting where Dorothy Morris spoke on her research on **"The Lived Experiences of ME/CFS:**

A study into human rights and equity in tertiary education."

Then, on Feb. 24th we had our Election General Meeting where we able to elect a management committee for this year. (This meeting was called after there proved to be insufficient nominess to form a management committee quorum at our AGM on November 25th, 2000.)

Reports on these meetings follow.

SOCIETY MATTERS

- Awareness Week
- Report: Special General Meetings
- Report: Public Meeting on Tertiary Education
- Chronic Illness on the Web
- Election General Meeting
- Meet our members
- Volunteer Positions Available
- Book Review
- Handy Hints
- Support Groups Report
- Youth Report
- Vice-president's report ctd. from page 4
- Support Group times and contact numbers

Know anyone who has ME/CFS but isn't a member of the society?

Invite them along to the May 12th event and let them see what the society can do for them.

The larger our membership, the greater our clout! Clout means funding, and funding means services.

We would like a minimum of 500 members to have a significant voice. Help us raise this membership by telling family and friends – convince them to stand with us in our cause and have them become members too.

SPECIAL GENERAL MEETING: 10TH FEB 2001

The group discussed past problems in the society, and sought to clarify the key issues facing us. Along the way we thought of ways we might prevent such things from happening in the future. Mr Steel helped us to categorise the issues and we have 4 main sections under which matters are headed.

1. FUNCTION / MODEL / STYLE / TASK SHARING (HOW WE OPERATE)

The meeting acknowledged that the recent history of the society had been volatile. Boris introduced some terms which explained it really well. The Society had been going from a stage of 'forming' to 'storming' and back to 'forming' again.

A key jobs was therefore to make the society stable and safe and therefore attractive to volunteers; we need to develop a new culture.

Suggestions

- (1) Because of the peculiar needs of ME/CFS sufferers perhaps we could include a clause in our mission statement which was a "committee protection" statement. This would basically state that the committee was to undertake the business of the society it was not to injure its own health in the process.
- (2) Rotating the chair at meetings so everyone learnt about the process and developed respect for it, and so no one particular person can bear undue influence
- (3) Having standing agenda items to important matters are not forgotten
- (4) That we list all the tasks that need doing and divide them up between committee and sub-committee members.

2. COMMON PRIORITIES (DIRECTION/ COHERENCE)

We need to re-examine mission statements, keep them to the forefront of our focus.

We must agree on common goals and stick to them – not have individuals going off in all directions.

3. RECOGNITION OF GRIEVANCE PROCEDURE (CONFLICT RESOLUTION)

It was suggested the grievance procedures of the society should have a higher profile, that when conflicts arise they are dealt with properly.

We acknowledged that mutual value and respect is what we all want from others.

That all processes should be ME/CFS tolerant.

That proper training of chairpersons may help to keep meetings more focused and orderly

Suggestions:

- (i) Form a mediation sub-committee, not involving portfolio management committee members, to whom conflicts can be referred. This neutrality is essential for successful resolutions to be brought about.
- (ii) Committee meetings should start with a brief time for all to say how they are going.
- (iii) We need to develop a document that outlines the special considerations we need to show each other as ME/CFS sufferers; examples given were that our short term memory issues mean we may but in at times for fear of forgetting our point, we feel very guilt when we can't complete tasks we have said we will do them.
- (iv) That we work towards have full-fledged 'shadow' positions for committee members. 'Shadow' members can proxy for their committee member partner.

4. BALANCE OF BUDGET (FINANCE)

It was emphasised that it was any committees' responsibility to balance income and expenditure. Obviously a detailed review of the financial position must be undertaken.

CONCLUSIONS

In all things we must have safety limits / measures built into everything.

Paul Leverenz



SPECIAL GENERAL MEETING: 10TH FEB 2001

Guest Speaker: Policy & Process Issues for Community Organisations.

Malcolm Downes, Senior Project Officer (SACOSS).

Mr Downes gave a short presentation on principles and issues for the management of community organisations.

He outlined key Principles for Organisations as involving a focus on:

- **people**, eg members;
- **objectives**, to move forward as an organisation; and
- **history**, the previous efforts of members.

Key points for Governing Bodies were outlined as:

- **Transparency of Process.** Engagement of all members. Information distributed to all members.
- **Declaration of Interest by members.** Financial or personal to avoid a perceived conflict of interest.
- **Clarity of Process**, eg chairing, status of decisions etc.
- **Communication & Consultation.** Actively maintain interest of members.

Review Operations & Services.

Education for Self. Provide members and volunteers with skills development, eg. Treasurer given time with bookkeeper.

Questions to Guest Speaker

Malcolm supplied the following answers to questions from members.

1. **Induction Process** - possible outside facilitator, look at norms, expectations, anxieties of group.
2. **Can Only Deal with People in Room** -
3. **Building Volunteer Team** - Professional model for campaigning, training and supervision. Make people feel that it's a good place to be!
4. **Decisions about how to Manage Volunteers** - Create sub-committee to manage this. Recruit, Induct (interview). Be assertive about what is needed.
5. **Recruit** - Value the efforts of members and volunteers.
6. **Making a Change of title** from president to convener - Change behaviours as well as title.

"The Lived Experiences of ME/CFS: A study into human rights and equity in tertiary education."

Dorothy I.W. Morris, TSTC., HDTS., B.VET., Dip. RBM., Ph.D. student

Research Abstract

The research analysis into the lived stories of Australian tertiary students with ME/CFS has revealed that there are four major areas of concern which have arisen. These are:

- the effects of the illness experience, especially the cognitive dysfunction;
- accommodations: rules, practical access issues, equity issues weighed against the Federal Disability Discrimination Act (1992) and the Students with Disabilities: Code of Practice for Australian Tertiary Institutions (O'Connor et al., 1998);
- the disempowerment through the political/medical/psychiatric constructs and the name; and
- the emotional and social effects on the ME/CFS tertiary student which arise from the first three issues.

These become important quality of life issues for the ME/CFS students, as well as impinging on their student life and academic success.

Please note that these findings are discussed in detail in the paper entitled "The Conduct of the Research and Preliminary Findings and Discussion," (Morris 2001a).



On Sunday the 18th of February **Dorothy Morris**, Ph.D. student Deakin University, addressed the above-mentioned topic, before our members.

Dorothy's motivation to conduct this research stemmed from the experience of having her own University enrolment

cancelled because of "incorrect knowledge" about her "capabilities as a student with ME/CFS" (Morris 2001a).

According to preliminary research results, Dorothy has suggested it imperative that alternative assessment procedures to typical set-date tests/exams (written, oral and practical) be investigated by educators and support staff. One appropriate option is the "writing of small essay/exercises during the course of the semester", which would allow ME/CFS students to work within their "window of opportunity" on their "hopefully, better days", (Morris 2001a). Dorothy acknowledges that this suggestion may not be appropriate for all students with ME/CFS. Therefore she otherwise recommends that "any decisions regarding the form of assessment be made with the ME/CFS student" after they have weighed up all explained options and engaged in discussion with other ME/CFS experienced students (Morris 2001a). Of particular interest and emphasis, Dorothy writes in her reference paper (2001 a): "Flexibility will be important if the spirit of the Draft Guidelines for Education is to be achieved for ME/CFS students."

Dorothy discussed, in varying contexts, the issue of the commonly used name of our illness: Chronic Fatigue Syndrome. Dorothy advised students to use the term ME/CFS, rather than Chronic Fatigue Syndrome, when needing to name the condition, as she feels that this lends greater

authenticity to the condition. Dorothy also discussed the need, when negotiating assessment/learning accommodations, to take into consideration the heterogeneous, multi-factorial, and fluctuating nature of the ME/CFS illness. She feels that each student should negotiate based on his or her individual ME/CFS symptoms. For example students may negotiate, based on the symptom of low blood pressure and/or orthostatic hypotension, for appropriate accommodations for tasks that require prolonged standing or alternative arrangements and support services for mobility constraints (Morris 2001b). Naturally, accommodations useful to one student may not be applicable to another, if their physiological experience is different or varies substantially over time, and this is something that must be acknowledged by all staff involved with the student.

Dorothy suggests that the individual student should "do their research" before their appointment with their Disability Liaison Officer (DLO). Dorothy has collated a list of scientific references explaining and verifying major symptoms of ME/CFS, which could be printed and presented to the person with whom the student is negotiating (perhaps with the most relevant points highlighted), (Morris 2001b). Providing this information seems pertinent as Dorothy mentioned that documents commonly accessed by DLOs, principally address the fatigue aspect of the illness whilst largely overlooking the other symptoms of the illness, and particularly cognitive dysfunction, (Morris 2001c). It is also largely presumed that extra time in written assessments is a sufficient accommodation for this fatigue (Morris 2001c), again demonstrating ignorance of the multi-factorial nature of ME/CFS.

Relating to the standards for education practise in Australia, Dorothy briefly mentioned and discussed the Federal Disability Discrimination Act (FDDA 1992), the Draft Education Guidelines for Disability (2000) and the Code of Practice for tertiary students in Australia (O'Connor et al. 1998, as cited by Morris 2001d). Dorothy addressed the two most important sections of the DDA as relating to

(Continued from page 29)

education, Sections 22 and 6 (see Box below). Dorothy suggested that "whilst academics and institutions are aware of the implications of Section 22, many have remained blinded to Indirect Discrimination and how this impacts on students", (Morris 2001d).

Indirect discrimination by educators/assessors is often not intentional, and certainly may stem predominantly from a lack of awareness and understanding of the symptomatology of ME/CFS. This often means that student's disability is assessed rather than their true ability, as is otherwise intended and desired. Educating DLOs about the symptomatology of ME/CFS may also help to allay indirect discrimination. One practical suggestion is for students to use their University Internet account to obtain a copy of the sections 6 and 22 of the Federal DDA. This knowledge may better assist them towards negotiating equitable accommodations.

In addition to discussion regarding education, Dorothy also provided members with an account of her personal experiences with the illness. Many members commended her for her courage and tenacity through illness. The account of her efforts to learn embroidery, and create in 1990 (through a lengthy bedridden patch), a large number of works to be successfully published in her name was considered both inspiring and encouraging.

NOTE: The Video (70 mins) of this event is available for purchase from the office for \$10.

A broad spectrum of age and interest groups attended the event, all embracing the opportunity to meet and mingle. A number of students have since agreed to undertake the task of writing an article providing some generalised, practical advice for tertiary students with ME/CFS.

Thank you to those in attendance for your generous donations towards hosting this event and the photocopying costs associated with providing Dorothy's papers on the day.

Please note: articles provided by Dorothy to supplement her talk are now available on-line:

http://www.sayme.org.au/cfs/cfs_tertiary.htm

Morris D.I.W. (2001 a) Part 1: The Conduct of the Research and Preliminary Findings and Discussion.

Morris D.I.W. (2001 b) Part 4: The symptomatology of ME/CFS.

Morris D.I.W. (2001 c) Part 3: A brief review of related literature.

[Also note: A useful reference list of ME/CFS tertiary and other student support documents is provided in this paper.]

Morris D.I.W. (2001 d) Part 2: Standards for education practice in Australia.



Chronic Illness on the Web

What does CFS have in common with HIV, cancer, MS, and arthritis? Biological and scientific differences divide these illnesses, but remarkably there are important similarities between them that bring them together. To answer the question they are all chronic debilitating illnesses.

Chronic illness share many characteristics, including: misunderstanding, discrimination, physical limitations, financial setbacks, and inability to continue working. These and other similarities give us as sufferers of ME/CFS the opportunity to share and relate to the lives and stories of people suffering from other types of illness.

In addition, we can use general resources created to help and support sufferers, and also those designed to bring understanding about chronic illness into the community.

To find out more about your membership in the chronic illness community, and to access information on chronic illness, and useful resources, log on to the internet sites listed below.

<http://www.invisibledisabilities.com/>

The Invisible Disabilities Advocate (IDA) has some great articles to read from her booklet "Helpful Hints: Guide to understanding, supporting and encouraging people with

debilitating illness".

<http://funrsc.fairfield.edu/~jfleitas/contents.html>

A fantastic resource for kids, teens and adults. Covers a wide range of issues concerned with growing up and coping with a medical problem.

<http://www-hsl.mcmaster.ca/tomflem/top.html>

A site containing links to information on almost any chronic illness. There are also resources on health sites, alternate medicine, wellness, and disciplines and education.

<http://www.coloradohealthnet.org/>

Go to the chronic illness link for comprehensive information on a range of chronic illnesses, covering both medical and personal aspects.

<http://victorian.fortunecity.com/cezanne/518/index.htm>

Lots of everyday tips for coping with chronic illness. Including tips for self-care, household tasks, energy conservation, pain and relaxation, and inspiration.

By Andrea O'Brien

NIAGRA MASSAGER MACHINE 'MISSING'

The society owns a Niagra Massager which was donated to the young adolescent group. This unit has a heat and massage pad, as well as a hand held massaging device that goes with it. We have lost track of its whereabouts and would like to know where it is.

Could whoever has either one of the components (or both) please let us know ASAP?

ELECTION GENERAL MEETING: 24TH FEB 2001

A new management committee was elected at this meeting. A couple of changes had to be made from the original nominees for that meeting. Helen O'Day withdrew her nomination (thanks Helen for being part of the Caretaker committee over the summer), and Fiona Thompson withdrew from the Treasurer's position, but still nominated as a general committee member.

The elected committee was as follows:

President: Boris Dontscheff

Vice-President: Paul Leverenz

Secretary: Stephanie Retallick

Treasurer: **NO NOMINATION**

Committee Members: Margaret Whyatt, Farrah Tate, Beulah Carter, Fiona Thompson & Margaret Wing

[Subsequent to that meeting, Fiona Thompson has withdrawn from the management committee, and Marion Hansen has been appointed Treasurer.]

Our EGM guest speaker was Robyn Moss, who led us through a workshop: Volunteer Rights / Responsibilities



This is what we came up with.

Organisation Rights (What it expects from Volunteers)

Commitment

Confidentiality

'Professional' Approach

Notify - Progress

Problems

Need to Bail Out

Undergo training

Promote a consistent / corporate image of organisation & and its values (not personal opinions)

Accountability to organisation/co-ordinator (or relevant supervisor)

Manage time / take time out (pace themselves)

Take a Duty of Care to themselves and co-workers

Organisation Responsibilities (What it need to provide Volunteers)

Clear Vision / Planning Process / Policies

Respect Volunteers

Comply with Occupational Health & Safety regulations

Clear Guidance – Job Descriptions

Well organised - eg rosters

Match Volunteers skills with tasks

Orientation

Communication

Volunteer Rights (What Volunteers would expect from an organisation)

Same work conditions as paid employees

Respected / Valued

Training – appropriate support

Policies to be followed

Equal Opportunity / Conflict Resolution – Grievance process

Statement of Ethics / Values

Duty Statement

Out of Pocket Expenses

Volunteer Responsibilities

Co-operation – willingness to follow OHS and other regulations/procedures

Perform duties to maximum of ability – working to duty statement / job description

Provide feedback about job – reporting

Provide liaison support between management committee and members

Support Management Committee – not allow themselves to become the 'meat in the sandwich'

Willingness to learn

Maintain the values of the society

Robyn Moss is a former trainer of Volunteer Managers with Volunteering SA, and now runs her own consultancy business.

WANTED: YOUR EXPERIENCES ON PAPER

**HAS ANY PARTICULAR TREATMENT HELPED YOU?
HAVE YOU DEVELOPED ANY INTERESTING WAYS TO COPE
WITH THIS ILLNESS?
HAVE YOU DEVELOPED WAYS TO DEAL WITH PEOPLE WHO
DON'T UNDERSTAND THIS ILLNESS?
WHAT HOBBIES / ACTIVITIES DO YOU FIND THERAPEUTIC?**

Please send in details of your experiences so we can share them with others. Talking Point GPO Box 383 Adelaide SA 5001



Hi. My name is Jonathon Foote. I'm one of the support line workers within the CFS society.

I was first diagnosed in February 1994 after contracting an unspecified viral illness in September 1993.

I was a nurse at the time so I often wonder whether or not it was a result of my work environment with all the various chemicals/drugs etc. It would appear as though health care workers are over-represented I was quite ill for another 4 years or so but finally went back to part time work as a research officer in December 1998 where I still work part time.

My wife (Vicki) and I currently administer the support line and I have been a support line worker for about 6 years.

When first diagnosed I rang the support line and found it a great comfort just to speak with someone who had been where I had been so I thought when I became well enough I should return the favour!!!

I see the support line as the shopfront of the society (I may be biased!!) and as such believe it accurately reflects the commitment of all within the society to raise awareness of the issues surrounding ME/ CFS and provide help for those struggling with the enormous sense of grief/loss/guilt associated with such a dramatic change of life.

My hobbies/interests include tropical fish keeping/breeding, biology/palaeontology, the creation/evolution debate and mindlessly fiddling with computers (my wife told me to put that in).

All you need to remember is that we're always there if you feeling a bit down or overwhelmed or need to know a bit more about the disease.

VOLUNTEER POSITIONS AVAILABLE

Expand/develop your skills!!

Financial Assistant (total 1-2 hours per week)

We require someone to assist the Treasurer with the bookkeeping/reporting. We would prefer applicants to be computer literate as we explore ways of computerising our accounts. An applicant must obviously be good with figures, and be able to do budgeting and forward planning. Please be aware that the job is not that arduous as our small society doesn't have a huge volume of transactions per month.

Media Liaison (average only 1-2 hour per week)

The society needs someone with skills / or willing to develop skills in writing media releases. Anyone interested in this job must be able to write well. Lack of experience is not an obstacle – we are prepared to arrange training for anyone willing take on this job for 18 months – 2 years, and train others at the end of this time. A great opportunity to expand your CV!

Membership Officer (2-3 hours per week)

We require a volunteer with enthusiasm and ideas for this position. As well as keeping a record of new memberships each membership year, this job requires someone willing to explore ways to increase our membership, and who is prepared to follow up people who do not renew to find out why they haven't done so.

Advertising Consultant (2 hours week)

We require someone to sell advertising space in Talking Point, and on our websites. Such a job requires someone who is positive, who has a good phone manner and who is willing to cold-call businesses. The role could expand as much as the person wanted it to. No experience necessary.

IF YOU WOULD LIKE TO HELP THE SOCIETY IN SOME WAY WE CAN MATCH YOU TO A TASK THAT YOU ARE SUITED TO BOTH IN TERMS OF SKILLS AND TIME COMMITMENT.

Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Journeys with the Dragon By Naida Edgar Brotherston, Copyright 2001 The Haworth Medical Press.

By Skye Yuill

Naida Edgar Brotherston's book explores many issues that surround ME/CFS. She takes a multifaceted look at the illness and considers the wide range of problems that sufferers of this debilitating disease may encounter.

One of the book's strengths lies in the author's efforts to make the voices and experiences of her research participants a central aspect of the book. Chapter 3 and the biographies section in the appendix deliver the words of Brotherston's research participants to full effect showing the severe impact ME/CFS has had and continues to have on their lives. These two sections of the book are the easiest to digest and probably the most validating for those who have the illness.

The book documents the academic research of Brotherston and as a result, at times, it is heavily laden with theoretical rhetoric. Whilst it is always informative and tackles the issues with depth and a good understanding of what ME/CFS means to sufferers, it is possibly most valuable for health professionals who are wishing to learn how they can improve services and assistance for sufferers.

The conventions of academic writing that are present throughout the text make reading for the lay person a little difficult however this is paradoxically a strength as the book is constructed in such a fashion that it will only increase the veracity of ME/CFS and further the acceptance of the disease in medical circles.

The content is excellent with discussion moving around topics such as the stigma that goes with the illness and how this stigma is perpetuated through society by the media and in the health professions, coping mechanisms employed by sufferers, the metamorphosis of being ill, relationships and problems with friends, family, health professionals, social security/welfare agencies and educational institutions.

The author places a particularly strong emphasis on the psychosocial effects of having a debilitating physiological disease that has and continues to struggle to gain acceptance and understanding throughout society.

Brotherston believes the study she conducted indicates: "that adjustment to living with ME/CFS began to occur as the participants learned to honor their own lived experience and to maintain their own personal illness narrative, rather than accepting societal beliefs about the disease and persons who have the disease. As participants developed the capacity to honor their own experiences, they were able to rebuild their essence of self and to acknowledge and work with their reality of illness experience." (2001,p.127)

The sample size was small for the study, and not representative of the population of ME/CFS sufferers (4 young females). Nevertheless, a substantial amount of the subject's accounts are immediately recognisable and generalize well. While a male voice amongst the participants would have provided greater balance and perhaps strength to

the research the four young women are insightful, eloquent and inspiring in each of their accounts.

Gemma and Marina speak of their dissatisfaction with the name:

"It was a joke in the media; you just...didn't tell people. It was taboo"(Brotherston 2001,p.31).

"Chronic Fatigue Syndrome was the new name, and I just thought, you know to have such a flimsy name for something that is doing this to me."(Ibid, p.148)

Val speaks of the uncertainty that goes along with the illness:

"I wouldn't write my future now. I'm just very play it by ear now. Like, I'm not...I don't make long term, long range plans, long-term commitments. I have a vague idea of directions that I want to go, but I can't..."(Ibid, p.66).

Bailey mentions the importance of living spaces to be functional and aesthetically pleasing:

"I check to see, Are there stairs? Is the sink close? How easy is it to clean? Light and air and warmth are really important, and I like lots of color...not pink or white...too many hospitals use pink or white."(Ibid, p.62).

Marina talks about her illness process:

"You go through your disbelief, your acceptance, your crisis, and...frustration, you get frustrated trying to get better, your crisis, and then just your overall acceptance or peace. And that was my crisis, and it lasted for a long time. So you know, now I feel that I'm out of it, and now I just have to deal with the everyday conflicts that

affect my health."(Ibid,p.150).

"In summing up her experience with ME/CFS, Val stated:

...it has changed my life. It's not been a lot of fun. It's been a lot of hard work, and it's been very scary and...but in a sense, I'm glad for it. Because I really like who I am. And if that's what I had to go through to become who I am, it's worth it."(Ibid,p.153).

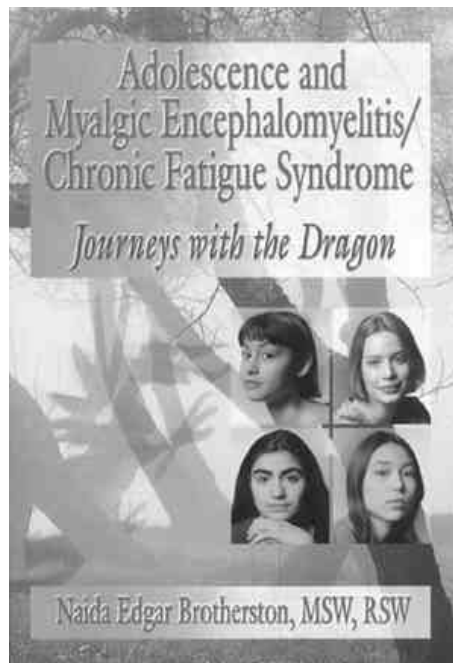
I feel the book could be extremely useful for health professionals who want to gain insight into the illness and a greater respect for sufferers. It could also be helpful for families dealing with chronic illness. The book is validating for sufferers of ME/CFS and can possibly make living with the illness more understandable and manageable particularly through the insights it offers on coping and management strategies for those who live with the illness.

The author has a daughter with ME/CFS and although she spends very little time discussing her experiences with ME/CFS one can feel that the illness has touched her life even through the sections of the text that have been sterilized by the detached rhetoric of academia.

I think that it is worth reading. I'll probably even buy it.

Reference

Brotherston, N.E., 2001. Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Journeys with the Dragon, The Haworth Medical Press, New York.



Local Government News Flash

If you live in the following councils, or know of someone who does, this information may be of interest. The Community Services Departments of the **Onkaparinga, Marion, Holdfast Bay, Unley and Mitcham Councils** have recently received HACC Funding. The funding is specifically targeting specific groups - carers, frail aged, and people on a disability or people who have mental health issues. It is designed for people who can manage all of their life skills, but may have one area of "single need" in which they are struggling ie. cleaning or transport, and this is placing their independence and accommodation at risk. It is designed to fill a gap for people who are not eligible for services such as Domiciliary Care etc. However, it is always worth inquiring as some current service providers may not be able to meet the need ie. (Options, Mental Health, IDSC) etc. It is for people who have long term needs, and who cannot afford to purchase private services. The maximum cost is \$10 per hour on a sliding scale.

Each council carries out an assessment which is to determine eligibility for the service.

This assessment is based on HACC funding guidelines, and will establish whether there are other people who can meet the need ie. families, neighbours etc, or if people are isolated and cannot access such services. The length of time the service is likely to be required is also considered, and the capacity of the person to undertake the task will be assessed. Some consumers have reported that services have been offered for a few months only, whilst others have received services on an annual basis. All services are subject to a review.

Contact numbers
Onkaparinga 8384 0065
Marion 8375 2263
Holdfast Bay 8229 9964
Unley 8372 5144
Mitcham 8272 8888

HANDY HINTS

Centrelink

1. It is possible for a young sufferers to receive Youth Allowance even if they are unable to study the 2/3 workload normally required. Some families have been able to obtain this benefit by providing 3 monthly doctor's certificates outlining the sufferer's inability to carry out such a workload.

2. Note that the latest Centrelink mailout explained how "Social Workers are there to help." Call 13 1021 to make an appointment with a Centrelink Social Worker. They are offering to provide counselling and support for any personal or family concerns."

University Entrance: Don't Panic

Student ME/CFS sufferers needn't push themselves to complete a full 5 year 12 subjects. Parents please be aware that a fully completed year 12 is not necessary to gain immediate entrance to university. One of our members was able to sit a STAT test at age 19, having only completed 2 year twelve subjects. That member is now studying at Flinders University.

Home Assist Programmes

Local Government Home Assist Programmes, can also be useful for residents. Anyone considered "older" – people over 50 have received help, although the frail aged are targeted again. Can provide up to 5 hours cleaning home help, after a hospital stay at a cost of \$5.00 per hour. Other home assist council services can provide for eligible residents (people who are without support and who cannot afford private services) are hand rail installation (consumer meets cost of rail) at similar rates, and also gutter cleaning (own home, not rental, or SAHT, sometimes strata units), as well as small handyman jobs –and plumbing.

Community Buses – some councils will provide a pick at the door for people who have medical conditions and are not able to access public transport- generally for older people but each council may have its own priorities, and it is worth a try. Generally buses go to fixed locations ie. shopping centers, and libraries etc.

Trade Registers – councils keep lists of trades people who have current insurance – available to all residents –some trades people supposed to give a pensioner discount.

**IF YOU TRY ANY OF
THESE SERVICES PLEASE
RATE THEM FOR US –
TELL US HOW THEY
BENEFITED YOU.**

**IF YOU KNOW OF OTHER
SERVICES THEN PLEASE
LET US KNOW.**

**IF YOU HAVE LEARNT
SOMETHING FROM
DEALING WITH
ORGANISATIONS SUCH
AS CENTRELINK OR THE
HOUSING TRUST, THEN
PLEASE SHARE THAT
WITH US.**

**YOUR FEEDBACK WILL
HELP OTHER MEMBERS.**

SUPPORT GROUP/ RURAL CONTACTS REPORT March 2001

How are you surviving?

Your Society tries to provide a range of services for members, newly diagnosed patients, medical/health care workers and the public in general.

The strength of these services often falls on sufferers.



Jane, Bill, Glenys and Rosemary at the Wallaroo meeting

People willing to provide a service because they believe, or are committed to helping fellow sufferers etc.

Often the provider of the service may be having a down day, but they push themselves to accommodate the perceived need. It must be remembered that they are



turning up in a voluntary capacity.

The strength and value of Support Groups depends on a degree of consistency and in number of attendees. A number of urban groups are teetering – people are voting by not turning up. The Adelaide Support Group has been down to single figures for some time, and the Southern Suburbs group has only two or three. Those that attend are encouraged to participate in the running and decision making for the group. A variety of activities are possible – last year there was a successful structure for the Adelaide Group, but recently no one feels like doing anything but sitting. The Glenelg Group on the other hand has made a conscious decision to call themselves a Social Club – they meet to have a coffee and provide “only” moral support.

A diverse range of activities has been suggested in addition to guest speakers and workshops: “Picnic in the Park”, visiting Heimiji Gardens, going to the movies, Popeye ride - but support has been lacking.

What is the answer to poor attendances? Meet less frequently? Abandon meetings? A number of people reportedly have formed small informal groups which is encouraging. They may have a hotel lunch occasionally, chat over the phone or have social visits.

Requests often come in asking if there are support groups in particular areas, but unless people are willing to help organise and run a group then the opportunity is lost. We have not had a Support Group in the SE for a number of years, despite a ring around. The Society will provide guidelines for the establishment and the running of a



group.

One Support Group that is flourishing is the Upper Yorke Peninsula group. Jane, Rosemary and their group meet quarterly in the Wallaroo Community Health Centre. The issues of isolation, correct diagnosis, community acceptance, and advocacy due to discrimination are very real. My family and I were able to attend the March meeting and found it a rewarding experience. It was good to share experiences and indicate first hand, the role of the Society.

It is a big challenge to meet everyone's demands/needs.

The directory in Talking Point lists the other groups and people willing to be contact people/ facilitators. Ring them, give them your support and encouragement.

Let the Society know what you want, what you can



provide. Not everything can be done – time has to be allowed for development to occur.

Without our volunteers, there would be no services.

Bill Daniels
Support Group Coordinator



Youth Report

With Farrah Tate and myself joining the management committee, there is a need for other people to have a go at helping out with SAYME – perhaps we may need some parents to step in a be a bit more involved?

In Dec. last year we had an end-of-year event – a sleepover – which went really well. We hope to be able to do more such events in the future. Included is a photo.

sent over from NZ to check out SAYME with a view to starting a group over there. Good luck Libby, we hope you guys over there can get something happening!

This year we planned to have a picnic at the beach in March, but when we decided on the date we didn't quite factor in the 'old daylight saving time factor. Our picnic was in the dark by the time the few of us got together at 6:45 pm – and it was freezing cold. It was a good idea at the time.

Over summer we were pleased to meet Libby grant who was

Paul Leverenz

'ME has taken over my daughter's life'

BBC NEWS ONLINE: Wednesday, 21 March, 2001

Kay Gilderdale, whose 23-year-old daughter Lynn is severely ill with ME tells BBC News Online how the illness has affected her family over the last nine years.

Lynn Gilderdale, from Tunbridge Wells in Kent, was a happy 14-year-old when she fell ill.

She had been an active teenager; sailing, dancing, playing the clarinet and piano and going out with her friends.

After a BCG vaccination for TB, she felt unwell. She then went on to have bronchitis, tonsillitis and glandular fever in quick succession.

Kay said: "Our GP told us she was developing a post-viral infection. But she began to get very ill and we knew that there was something very serious going on."

She was diagnosed then as having ME.

The family followed their GP's advice and encouraged Lynn to take as much exercise as possible.

But that proved to be the worst course of action, says Kay. "We would walk her down the road and she would get back to the house and collapse.

"It got to the point where she was totally bed-ridden and she couldn't sit up without going unconscious.

"She couldn't swallow anything at all. She was in terrible pain, with muscle spasms and she had swollen glands and lymph nodes.

"We were very frightened by the whole thing and we went to the medical profession to try to get some help."

But she says: "We came up against a brick wall because nobody seemed to realise ME could be that serious."

'Lack of help'

A short stay in a psychiatric ward, the only place available, proved to make Lynn's health worse.

So for the last nine years, Kay has cared for her daughter at home, giving up work to do so.

She says she gets extremely angry when people dismiss ME.

"Lynn knew she was very ill. We knew she was very ill, but she had doctors and nurses telling her that she was pretending and that she could do more.

"We get very very mad if we see anyone who doesn't believe ME is an illness, and if people just think its a very minor illness.

"If I could bring people here each day and make them see what Lynn has put up with... It's taken over her whole life."

When she came home, Lynn could do nothing for herself. She could not even speak.

Over the last nine years, she has suffered a number of complaints.

Last year she had a clot on her lung. And she has suffered from low cortisol levels, which could have led to her adrenal glands failing.

In the course of treating that, doctors looked at the hypothalamus in the brain, and found that was where the problem lay. She is now on steroids to correct the problem.

Lynn also has osteoporosis because of low oestrogen levels.

Her health has improved a lot over the last nine years. She still cannot speak, but can communicate through sign language, and she is bed-ridden, but can mover her arms and the top half of her body.

Her memory is still bad, and she has to be fed through tubes because she us unable to swallow.

Kay says the family's life has changed dramatically since Lynn got ill, though the family have no way of knowing when she might get better.

But she is determined to do so. Kay says: "Lynn always says to us that she hasn't given up so much not to get better."

Over the years she has had to watch her friends, and her older brother go through the normal stages of growing up, and hearing their news makes her happy.

Kay says: "But sometimes I read letters to her and there are tears in her eyes because she can't do any

"If I could bring people here each day and make them see what Lynn has put up with... It's taken over her whole life"

Kay Gilderdale

(Continued from page 4)

think it needs to be valued, encouraged and supported.

You may have been surprised by our mailout in March, outlining drastically reduced office hours. We have been finding it difficult even to meet these obligations. Our new management committee is faced with many tasks: orientation, updating job descriptions, writing policies, doing a financial audit and financial planning, upgrading our office, grant writing, improving our core services, making up doctors and new member packs, making a brochure to go into doctor's surgeries, as well as restarting the volunteer project. There really is a lot.

You may say "We need to scale back what we are doing with the society" - but it is very hard to see where we can cut back in terms of our responsibilities - we are doing a bare minimum as it is now. Support groups, the support line, Talking Point, SAYME, public meetings and awareness week are all valuable. To cut back services would be disastrous. I believe we actually need to spend even more time improving each of these core services, as well as offer more things for the long term sufferers. The latter is needed to help retain members long-term. I believe we have simple choice right now: curl up and die (scale back), or have a crack at improving what we do (with a view to expanding). And I'm not one to give up easily.

So what is the way forward?

Well, we must be careful to not be like our friend Egbert in the cartoon. Whatever work we do must be well



thought out and planned. Activity doesn't equate to productivity. We are looking at updating the office computers, installing a network and putting in place systems which will streamline the admin tasks of the society.

We are building up ties with Volunteering SA, and part of the reason for updating the office, is that we need to make our office a great place for volunteers to work. A place that is organised and has good use of technology is appealing, and will enable us to attract more interest from outside volunteers.

The previous management committee instigated an important process - it developed a list of the day to day jobs in our society. This information was passed on to members in the form of a volunteer recruitment form which was sent out in Oct. last year. (Thankyou to those who responded.)

The idea is simple. Break all the jobs of the society into manageable bits. People who would like to help out a bit with the society, can then be matched to their nominated skills/interests and to the workload they can undertake. Some have been overwhelmed by this list, but that is the very opposite of what was intended. Yes, the list of jobs required is long, but please keep in mind that we are not asking anyone to do them all - just one.

In order to break up the running of the society into more manageable pieces we have set up several sub-committees. These will research and explore issues and make recommendations back to the management committee, as well having specific oversight over certain service areas within the society. This immediately opens up opportunities for more people to be involved in running the society (This may involve only 5-6 hours a month.) Over time sub-committees will reduce the management committees' workload, and this is step in the right direction toward retaining management committee members.

CONCLUSION

Do you believe ME/CFS is a terrible illness? It's time for all who believe this to roll up their sleeves to have a go at making this society really work. This is the year of the volunteer and I reckon we deserve our fair share.

Maybe you can help, but if not - perhaps you have a friend or family member who can, or perhaps you

An Anthology of Creative Writing

By people with ME/CFS/FM

Hi! We are two writers with ME/CFS/FM who are putting together an anthology of creative writing by Australian and New Zealand CFS sufferers and their carers. Our plan is to have it ready for launching by May 2002.

If you write fiction or poetry, we would love to see your work. The most important thing to remember is that it must reflect the experience of CFS in some way. Other than that, style, theme, subject matter, word choice, genre, technique and point of view are open and unrestricted. The word limit is 2000 words for fiction and 60 lines for poetry.

Previously published work is still eligible, as long as you let us know where and when it appeared. We will consider personal stories of literary merit or exceptional interest. We definitely don't want to see anything resembling advertising or propaganda. Artists, cartoonists and photographers are welcome to submit their work in black and white.

Send a stamped, self-addressed envelope so that manuscripts can later be returned. Let us know if you would like notification of publication or comments on your work. Please include with your submission a short biographical note about yourself, your illness, family, interests or anything else that seems relevant.

Send your work to:

Libbie Hughes and Sue O'Loughlin

C/o SHOUT Office

PO Box 717

Mawson ACT 2607

Phone: (02) 6294 5470 or (02) 6296 1845

Email: libhug@regards.net

Skol@dynamite.net.au

belong to a community group where you could advertise for voluntary help?

There are many small jobs, and a number of big jobs. Even if you can only do a little, we need people to take on specific tasks and be prepared to stick at them. Remember that volunteering has its benefits - it gets you out of the house mixing with others, it provides opportunities to develop skills, and we can give anyone a reference who requires it.

Finally, it would be great to see as many of you as possible come along to our 'Public Medical Lecture' on International ME/CFS Awareness Day, May 12th. It will be a great day, and it will be a chance for you to meet the new management committee.

Paul Leverenz

SOCIETY MATTERS: SUPPORT GROUPS AND CONTACT NUMBERS

SUPPORT GROUPS: METRO



CONTACTS

Adelaide Support Group

Venue: DIRC, 195 Gilles St, Adelaide.

Time: 1:15 pm – 3:15 pm

Dates: April 26th (This is a Thursday due to Anzac Day), Wednesdays: 23rd May, 27th June, 25th July

Phone: the office on **8410 8929** for more details.

Glenelg Social Group

Venue: Cinema Centre Coffee Lounge, Jetty Road,

Glenelg

Dates: 25th April, 30th May, 27th June

Time: 1 pm

Check the Guardian for details, or phone the Support and Information Line for details:

8410 8930.

North Eastern Social & Support Group: 'Better Together'

Location: Hope Valley

Date: 1st Wednesday of each month

Time: 1:30 pm – 3 pm

Phone: Julie on **8264 0607**

Southern Suburbs Support Group

Venue: Happy Valley Church of Christ (Cnr Windebanks Rd and Hub Drive, Aberfoyle Park)

Date: 4th Monday each month

Time: 1 pm-2:30 pm

Phone: Daryl **8322 0329** for more details.

Western Support Group

Venue: Findon Community Health Centre

Date: 1st Monday of each month

Time: 1 pm- 3 pm

Phone: The office **8410 8929.**

SA Support Groups

Adelaide City	Office	8410 8929
---------------	--------	-----------

Aberfoyle Park	Darryl	8322 0329
----------------	--------	-----------

Glenelg	Support and Info Line	8410 8930
---------	-----------------------	-----------

Murray Bridge	Fran	8535 6800
---------------	------	-----------

North Eastern	Julie	8264 0607
---------------	-------	-----------

Northern Yorke Peninsula	Jane	8826 2097
--------------------------	------	-----------

Southern Fleurieu	Melanie	8552 0600
-------------------	---------	-----------

Western	Office	8410 8929
---------	--------	-----------

Misc. Support Contacts

Highbury	Pat	8264 9328
----------	-----	-----------

SAYME	Paul	0500 523 500
-------	------	--------------

SAYME Parents	Marg	8276 5353
---------------	------	-----------

Country Support Contacts

Barossa Valley	Dennis	8563 2976
----------------	--------	-----------

Murray Bridge	Fran	8535 6800
---------------	------	-----------

Port Lincoln	Jade and Pauline	8683 1090
--------------	------------------	-----------

Port Pirie	Marj	8633 0867
------------	------	-----------

Riverland	Ros	8588 2583
-----------	-----	-----------

Northern Yorke Peninsula	Jane	8826 2097
--------------------------	------	-----------

Victor Harbor	Melanie	8552 0600
---------------	---------	-----------

Whyalla	Peter	8644 1897
---------	-------	-----------

Yorke Peninsula	Glenys	8837 6375
-----------------	--------	-----------

Yunta	Gloria	8650 5938
-------	--------	-----------

SUPPORT GROUPS: COUNTRY

Northern Yourke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo

Phone: Jane 8826 2097

Murray Bridge Support Group

Venue: Murray Mallee Community Health Centre

Date: 1st Wednesday of the month 10:30am.

Phone: Fran McFaul (Dietician) **8535 6800**

Southern Fleurieu Support Group

2nd Thursday alternate months

April, June, Aug, Dec

Phone: Melanie Stratil (Dietician) **8552 0600** for venue details.

YOUTH SUPPORT GROUP: SAYME

Parents Welcome

SAYME meetings are actually 2 meetings in one – one for youth, one for parents. Two separate rooms are provide at each venue – one for each of these groups to chat away independently of the other.

Last Friday of the Month 7:30 pm

PH: **0500 523 500** for more details

BAR FRIDGE NEEDED

Do you have a bar fridge you could give or sell cheaply to the society? We desperately need one in the office.

WHEEL CHAIR FOR HIRE

The society has a wheel chair that can be hired for a nominal fee. Please – someone – take us up on this offer, as it is taking up valuable space in the office.

**MEMBERS MAY PLACE
SMALL ADS IN TALKING
POINT AT NO CHARGE**

(subject to advertising policy on page 2)

WHAT IS ME/CFS?

(M.E.) myalgic encephalomyelitis / (CFS) chronic fatigue syndrome is a serious and complex illness that affects many different body systems. The cause has not yet been identified. It is characterised by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. ME/CFS can be severely debilitating and can last for many years. ME/CFS is often misdiagnosed because it is frequently unrecognised and can resemble other disorders including mononucleosis, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and auto-immune diseases such as lupus. [The illness is also known as CFIDS or Chronic Fatigue and Immune Dysfunction Syndrome.]

HOW IS ME/CFS DIAGNOSED?

Despite more than a decade of research, there is still no definitive diagnostic test for ME/CFS.

According to the CFS case definition published in the Dec. 15, 1994, issue of the Annals of Internal Medicine, diagnosing ME/CFS requires a thorough medical history, physical and mental status examinations and laboratory tests to identify underlying or contributing conditions that require treatment. Clinically evaluated, unexplained chronic fatigue can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.
2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

HOW IS ME/CFS TREATED?

Treatment for ME/CFS is intended primarily to relieve specific symptoms. It must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies and depression are some of the symptoms which can be relieved through the use of prescription drugs, over-the-counter medications and other interventions such as physical therapy. Persons with this

illness **may have** unusual responses to medications, so extremely low dosages should be tried first and gradually **increased as appropriate**.

Lifestyle changes, including increased rest, reduced stress, dietary restrictions, nutritional supplementation and minimal exercise are recommended frequently. Supportive therapy, such as counselling, can help to identify and develop effective coping strategies.

ME/CFS strikes people of all age, ethnic and socio-economic groups.

Carefully designed studies have yielded estimates that more than 800,000 adults in the U.S. have ME/CFS. In women, ME/CFS is more common than multiple sclerosis, **lupus, HIV infection, lung cancer and many** other well-known illnesses.

DO PWCs [persons with CFS] GET BETTER?

The course of this illness varies greatly. Some people recover, some cycle between periods of relatively good health and illness, and some gradually worsen over time. Others neither get worse nor better, while some improve gradually but never fully recover.

The CDC [USA Center for Disease Control] is conducting a long-term study of PWCs to learn more about the course of illness. CDC investigators have reported that the greatest chance of recovery appears to be within the first five years of illness, although individuals may recover at any stage of illness. Investigators have also found an apparent difference in recovery rate based upon type of onset. PWCs with sudden onset reported recovery nearly twice as often as those with gradual onset. This study is ongoing and observations about the course of illness are likely to change as more data is collected.

*This document is based on another appearing in the CFIDS Chronicle – itself an *abridged and up-to-date* version of "Understanding CFIDS," a comprehensive, 16-page *booklet about ME/CFS published by The CFIDS Association of America*. Minor changes have been made to replace 'CFIDS' with 'ME/CFS' in several places.*

We are working towards producing our own document relevant to Australia. As more studies are conducted in Australia we will be able to provide numbers of sufferers, average length of illness and demographic breakdowns specific to our country.

Copyright © 2001 ME/CFS SOCIETY (SA) Inc. Copies of [original articles](#) may be used by similar non-profit organizations if accompanied by clear acknowledgment of each item and the inclusion of the ME/CFS Society (SA) Inc.'s postal address.

ME & You, ME/CFS Society of NSW Inc., Royal South Sydney Community Health Complex Joynton Ave., Zetland. NSW 2017.
Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.
Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.
ChAMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.
The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.
Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, Hight Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.



If undeliverable return to:
ME/CFS Society (SA) Inc.
GPO Box 383
ADELAIDE SA 5001

Print Post Approved:
PP 532154/00023

