Talking Pump

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

Your Society

forget-ME-not

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.

Advisory Panel

Judy Lovett: Past President of the ME/CFS Society (SA) Inc.
Dr P.Del Fante : GP, BSc DipCompSc MBBS(Hons) MSc (Public Health Medicine) FRACGP FAFPHM MRACMA. Medical Director of the Western Division of General Practitioners.

Membership

Annual membership is from July 1st to June 30th, and includes subscription to the magazine Talking Point. Membership rates for first-time members are as follows (GST included):

New Members:

Single membership……	$32
Single Concession ……..	$22
Professional……	$40
Family ……..……	$38
Family Concession ……	$28
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.
Family Concession applies when the main breadwinners are concession card holders.)

Talking Point Subscriptions:

Professionals:……..	$30
PWME/CFS:……..	$22
Overseas (Asia-Pacific):……..	$32
Overseas (Rest of World): ……..	$38

Management Committee 2001

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

President: Paul Leverenz
Secretary: Penny Cahalan
Treasurer: Geoff Wilson
Management Committee Members:
Margaret Wing, Peter Evans, Peter Cahalan, Kirsty Cordingley, Glenn Domieka and Adrian Hill.

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
March 10th 2002

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, treatments or services (including paid advertisers). 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 Information Officer 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 member information for direct marketing will be investigated and dealt with appropriately. This applies to members and anyone else.

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.

Office

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide. Currently office hours are Tuesday & Thursday 10 am-4 pm.

Our email address is: sacfs@sacfs.asn.au

The ME/CFS Society would like to acknowledge the assistance of the Adelaide Bank Charitable Foundation.

EDITORIAL

Hi,

We hope you are surviving in the Summer weather—our hearts go out to our countrymen in NSW who experienced the rough end of the bushfires.

We hope you'll really enjoy what we've got for you this issue of Talking Point.

You'll have noticed the slightly modified cover. The plastic coated paper we used previously didn't agree with a lot of people, so we thought we try something different.

This issue marks the last instalment of Sheri Connell's work: "Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitation Illness." Lots of people have enjoyed it. It is certainly a valuable resource.

Thanks to Lesley Beasley for her contribution on writing. It is very topical as we'd love for more original articles from members—or anyone for that matter. Is anyone out there keen to write about coping with ME/CFS? Or simply willing to tell their story?

Finally, thanks once again to the Adelaide Bank Charitable Foundation—thanks to them, this edition of Talking Point was produced entirely in our office.

Regards,

Paul Leverenz
Farrah Tate

Contents

SECTION 1: GENERAL

SECTION 2: MEDICAL PAGES

SECTION 3: SOCIETY MATTERS

President's Report December 2001

Welcome

I felt it was important to write an additional President's report to the one I presented at the AGM (That report appears on page 42). A number of issues have come up, that I need to share with you.

Fantastic Fundraising Effort

Before I go on too much I have to say a big thankyou to Rosemary Langley and her team who for the second year in a row organised a successful bridge lunch and raffle. Their magnificent fundraising venture netted approx $2400. We acknowledge a significant contribution by the Frank and Hilda Perry Charity Trust of $500. Thanks also go to Malcolm Creek Wines for their support. Everyone's contributions are very much appreciated by the Society. (Unfortunately no photos are available from the event.)

Adelaide Bank Charitable Fund

I am pleased to announce that for the second time the

Adelaide Bank Charitable Foundation has assisted our Society with a donation. This time round they have generously given us $5300. We have used this to purchase badly needed computer equipment – specifically a desktop publishing setup. We now have a new computer complete with 19-inch monitor, scanner, laser printer and digital camera; we are now able in our office to complete the layout and design of all our publications. More will be revealed in the next edition.

International Conference – Sydney DEC. 2001

I was personally privileged to attend the International ME/CFS Conference in Sydney in December 2001. The conference was outstanding – with a truly international mix of speakers presenting a wide range of material.

We can be very proud as Australians that we were involved in putting together a world-class event. For those of you who didn't catch the September Talking Point—I'm happy to let you know that our Society contributed $4000 to the event.

Dr Rosamund Vallings has written an excellent summary of the event and that has been included in the medical section.

Christine Hunter and her team are truly an inspiration. If you have not done so already, please visit the Alison Hunter Memorial Foundation Website (www.ahmf.org). It is the best resource for ME/CFS in Australia. Take a bit of time to read about the foundation and read about Alison Hunter. You'll see where Christine's drive and motivation comes from.

From my point of view it was great to network with the committee members of other states. I think this is timely as there was a big turnover on the National Exec. The bulk of the National Association board were at the conference and having now met each other it will help us to function as a team. (The National board only meet by phone hookup).

The only disappointment is that the conference made a loss for the AHMF.

Elections

It is my pleasure to report that at the AGM the following

Christine Hunter

National Executive

people were elected to the Management Committee on December 15th 2001: Paul Leverenz, Peter Cahalan, Peter Evans, Kirsty Cordingley and Geoff Wilson. (Marg Wing is continuing on.)

Further positive news is that we co-opted 3 additional members to the committee. They are Penny Cahalan who will serve as Secretary, Adrian Hill and Glenn Domieka.

Fundraising

The policy of the Management Committee of the Society is to refrain from writing to members to ask for donations for project x, or to plea for X-thousand dollars for a Christmas appeal (although we reserve the right to do so in a genuine emergency). This is because so many of our membership do not have the means to assist; similarly many of you are genuinely quite badly off in terms of your heath, and we acknowledge that on top of this illness you do not deserve to have to raise money to help provide services for yourself. Services which others would get without question and with sympathy to boot. In view of this policy we prefer for the people who can contribute to make donations without the letters and pressure—large donations and fundraising efforts will be

noted in Talking Point (unless the contributors ask not to be revealed).

Having established that general point I think it is important from time to time to encourage you to 'remember your Society' when it comes to donations. Many of us give to other charities and we don't even think about it – to door knockers, to street collectors and perhaps even telemarketers. We also participate in lotteries for charity 'hoping we will win the big prize.' This all ads up over the course of a year. It is not my intention to deny the merits of other charities – I will just say that many of them have significant government funding where we have none at present. Because of this fact I won't lose any sleep over encouraging you think about us a little more. Sometimes it is easy to forget 'the cause in our own backyard' which is ME/CFS.

RACP CFS Guidelines

'The guidelines' will be published in the Medical Journal of Australia sometime in late February / early March. A third draft was released for final checks early in 2002. As explained on page 11, this final draft was not distributed to our National Association. We have learned that although there are some changes they are not substantive (as we expected.) In view of the lack of radical change the National President has sent a letter on behalf of us all to the Consumer Health Forum (who have had a representative involved in the process) asking them to reject the guidelines.

It is disappointing that these guidelines will be printed, and especially so as the UK guidelines have just been released—they are far superior. Perhaps this timing will be to our advantage? Time will tell.

Badge Day

On May 31st we'll be holding a badge day in the city. (Done really well we can expect to raise $3000 - $5000.) Our need is to get persons outside of our membership to assist us with the collecting. We would love to hear from you if you have any contacts with any service clubs, social clubs or church youth groups – ones that might be prepared help out with this sort of thing. The more support we can get from such groups the better.

Office Hours

I have great pleasure in announcing that things are looking up with regard to our office hours. For now they have been extended to Tues and Thurs 10-4pm. We hope by May to be open for a third day in the week.

Conclusion

I am looking forward to this year—I expect us to consolidate on the rebuilding year we had last year. Let's hope a successful Awareness Week this year can bring more members into the Society.

Letters to the Editor

Dear Editors,

Thank you for your magazines. The articles 'Sherri L. Connell' had written was extra helpful to those with a misconception re CFS. Plus the article re 'anaesthesia' as I'm due for an op next year so it was most informative and helpful. Thank you.

You may wish to include the enclosed in your next magazine -- I found it extremely good:

1. NON-TOXIC NATURAL FURNITURE POLISH
- Mix equal amounts of cooking oil and the cheapest vinegar in a spray bottle.
- Polish off.
- Gives a non-greasy high polish to timber, furniture.
- Shake well before use

2. DIRECT NUTRITIONAL (Ph. 1300 366 286 for their comprehensive catalogue)
- An economical way to buy your vitamins, minerals, etc., even with $2-25 delivery charge
- They often give 10-15% discount
- Good to deal with, prompt and efficient.
- Will accept bankcard.

3. PHARMACY DIRECT (Ph. 1300 656 245 to ask for catalogue).
- For prescription lines
- Half price -- Claratyne, Zyrtec, etc; even Panamax is cheaper than generic brands from above
- Postage $5-40
- Will accept bankcard
- Good and efficient.

Yours truly,
Sue Prider.

I was (nearly) rude!

After an interesting, but lengthy meeting my husband and I sat in a dinning booth at the club hoping to eat and then go home.

A new acquaintance and her friends came and asked us to move over so they could eat with us. Knowing that one of the ladies was a constant chatterer and that to move again would cause us more pain I said "No, we are in to much pain to be good company" My "energy pennies" were all used up.

My husband was astounded that I had refused, even though he was in greater pain, as usually I am very friendly and try to be gracious. I spoke to this new acquaintance as we left and apologised to her if I'd sounded rude. Her reply was "I'm in pain too so I understand". I was glad she understood.

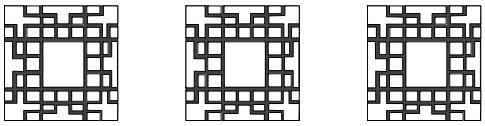
Afterwards I thought-that's the first time I've ever done that! But I've realised with CFS/FM I have to survive with the constant pain and fatigue, so assertiveness, so long as I can be gracious is OK and necessary for my coping. So I felt OK.

Now I can say things like "I'd like to continue this conversation but I have to sit down". So far no one has been offended.

We have to love ourselves as we would love others too.

Barbara S Champion
Wagga Wagga

[EDS—*Well done Barbara!*]



Letter from the Chairman of the National ME/CFS Association: Simon R. Molesworth AM, QC

November 9, 2001

Members will recall that during September 1999 a national association of all the ME/CFS societies in Australia was established as a corporate entity under the name: ME/Chronic Fatigue Syndrome Association of Australia Limited. Judith Lovett from South Australia was elected the first chairman.

On Sunday 14th October 2001, at its Annual General Meeting, I was elected the new (and so second) National Chairman. I am currently the President of the ME/CFS Society in Victoria. Nola Miles, another Victorian, was elected the new National Secretary. All national board positions are honorary, filled by volunteers. New board members were also elected from Queensland, South Australia and the ACT. We owe a debt of gratitude to all those who have now retired from the National board.

Effectively, the National Association is a "federation" of representatives of each of the State and Territory ME/CFS societies in Australia (there being one or more in each Australian jurisdiction with the exception of the Northern Territory). We estimate that the National Association represents at least 150,000 patients and carers in Australia who are experiencing the challenges of CFS on a daily basis.

The National Association has a critically important role to play in Australia to co-ordinate and stimulate nationwide efforts to achieve greater awareness of and then better support services for those with ME/CFS and related illnesses. This role will inevitably require active and persistent lobbying of governments around Australia, but especially in Canberra. I have often used the word "clout" as being the essential ingredient to the make-up of any organization if it wishes to achieve its aims. Politicians and bureaucrats must become aware that there are a very large number of Australians who have been and are affected by ME/CFS - either as sufferers or carers or just concerned friends and family. My role as the new National Chairman will be to ensure that all politicians in the health sector are aware of and supportive of our needs across the Nation. I will be demonstrating that we have clout.

As I write this article the Federal Election has not taken place but as you read it, you will know who is the new Federal health minister. Irrespective of which party has formed government, a new Health Minister was inevitable as Dr Michael Wooldridge voluntarily retired at the Election. I am determined that the National Association, on behalf of all the ME/CFS Societies in Australia, will establish a well trod path to Canberra. The National Association will be demanding a more equitable distribution of medical research dollars; insisting on a greater range of government funded community support facilities; and generally will be insisting on a more pro-active Government-led approach to overcoming the multiplicity of related problems which arise out of CFS; such as insurance issues, superannuation issues, employment issues and education issues. The fact that all these problems are national problems requiring a national response, strengthens my resolve that the new Health Minister needs to become a friend and an ally of the ME/CFS community across Australia. We are looking to the new Federal Minister to take this lead. The time has come to advance: I am pleased to have this new role at such a time of significant change. Times of change are times of opportunity!

The most important project of the National Association (and for that matter of each of the State and Territory societies) over this last year has been seeking the sponsorship of the Third International Clinical & Scientific Meeting on ME/Chronic Fatigue Syndrome that was convened at Manly in Sydney NSW on the 1st and 2nd December. This International Conference, under the auspices of the Alison Hunter Memorial Foundation for Research into ME/CFS, brought to Australia the world's leading specialist researchers into CFS to enable them to share their knowledge with fellow medical practitioners and researchers in Australia. This Conference, being the third in five years, represented the best opportunity for the Australian medical professional to meet and learn from the most significant group of CFS researchers ever brought to Australia.

In closing may I convey to all of you my personal greetings and whole hearted wish that your Christmas and New Year holiday season will be one where you will find renewed health, enjoyment and a sense of fulfilment. Your individual memberships of the State and Territory societies during the last year, along with the support of many others, has underpinned the work of each Society and the National Association: in short, you give us clout. In closing, may I thank each member for what you have done for us and the CFS cause generally. I trust or hope that we will continue to attract your support during 2002.

Simon R. Molesworth AM, QC
Honorary National Chairman

NEW SURVEY REVEALS Chronic Fatigue Syndrome is as Disabling or Debilitating as Lupus, Multiple Sclerosis, and Rheumatoid Arthritis.

~ Lack of Test to Detect the Illness Remains Greatest Barrier to Diagnosis ~

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

CHARLOTTE, NC, November 13, 2001 - Thirteen years after a group of scientists coined the term chronic fatigue syndrome (CFS) to describe a mysterious medical condition, many medical professionals are acknowledging it as a seriously disabling condition in need of treatment, concluded a survey released today by The Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) Association of America.

Three-quarters of medical professionals responding to the survey believe that CFS, also known as CFIDS, is as or more disabling than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis. But despite the severe nature of the illness, diagnosis remains problematic. Half of the survey respondents cited the lack of a proven diagnostic test to be the greatest barrier to accurately identifying CFS. Thirty-five percent feel lack of a known cause of the illness is a barrier to diagnosis and 31% feel there is not enough basic knowledge about CFS among the medical community.

Currently, health care practitioners are using a number of different methods to diagnose CFS. Almost three-quarters (72%) rely on exclusion of other common causes for symptoms; 68% use a patient history; and 25% use laboratory tests. Practitioners also rely on documenting the presence of symptoms other than fatigue. When respondents were asked what one symptom other than fatigue made them more likely to suspect CFS, or without which they would not make a diagnosis, the most common answer was post-exertional malaise (incapacitating fatigue lasting more than 24 hours after physical or mental exertion). Lack of basic knowledge among practitioners and the absence of a diagnostic test means that more research and awareness of CFS is needed. Seventy-seven percent of the medical professionals surveyed felt that the amount of available professional education about CFS is not adequate. In addition, a large majority of respondents (87%) indicated that there should be more funding for research on the illness.

These survey findings confirm that CFS is increasingly recognised as a serious, debilitating illness and medical professionals still lack the core knowledge and tests they need to diagnosis CFS quickly and accurately," stated Kim Kenney, President and Chief Executive Officer of The CFIDS Association of America. "Much has been learned about CFS, but it is now very apparent that there is still a great need for research and education in the medical community."

The four-page survey was mailed to 8,100 medical professionals around the country, with a total of 865 completed surveys returned. The medical professionals polled came from a variety of disciplines including internal medicine, family/ general practice, psychiatry/ psychology, neurology, nursing and medical research.

About CFS (or CFIDS): CFS is a

serious and complex illness that affects many different body systems. There is no known cause. It is characterised by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. CFS can be severely debilitating and can last for many years. CFS is often misdiagnosed because it can resemble other disorders including mononucleosis, multiple sclerosis, fibromyalgia, Lyme disease, post-polio syndrome, and autoimmune diseases such as lupus. CFS is also known as myalgic encephalomyelitis (ME).

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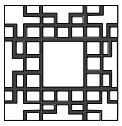
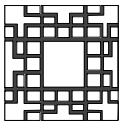
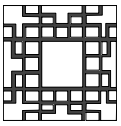
About The CFIDS Association of America: The CFIDS Association of America is the nation's leading organization working to conquer CFS. Since 1987, the Association has invested nearly $12 million in education, public policy, and research programs in its efforts to bring an end to the suffering caused by the illness. For more information on The CFIDS Association of America or CFS, please call 1-800-442-3437 or visit www.cfids.org.

Are You Chemically Sensitive?

Do you hold your breath when walking down the detergent aisle in the supermarket, or avoid the aisle entirely, to keep from feeling sick?
Does the smell of perfume give you a headache or make you feel ill in some other way?
Have you ever gone into a building such as a bank, supermarket, or discount store and felt "spacy" or found that you had difficulty speaking, writing, or remembering things?
Have you suffered headaches or other symptoms at work, or some other place, and later found that they coincided with the spraying of pesticides?
Have you ever had an adverse reaction to a pesticide such as headache, fatigue, respiratory problems, nausea, skin rash, or any other symptom?
Do cleaning products or chemical "deodorizers" give you a headache or any other symptom?
Do you get a rash, headache, dizziness, or any other symptom when you are exposed to carbonless copy paper?
Do you want to hold your breath when entering a public restroom that's just been cleaned?
Do you feel better when you are away from your home, work, or some other environment that bothers you?
Are there foods you avoid because they make you feel ill?
Do you get headaches, eye irritation, feel "spaced out," or have other symptoms when in a fabric or clothing store?
Do you get a headache, eye irritation, cough, or any other symptom when exposed to environmental tobacco smoke?
Does exposure to products or fumes in hair salons make you feel ill in any way?
Have you ever had an unusual reaction to a medication or drug?

http://www.herc.org/hhc/chemsensitive.html

Chemicals Linked to CFS

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

Date: 03/12/2001
Sydney Morning Herald
By Julie Robotham, Medical Writer

Chronic fatigue syndrome (CFS) could be caused by common chemicals such as head lice treatments and insect repellents, a United States expert has told a Sydney conference.

The condition, which affects up to one in 250 adults, has been derided as "yuppie flu" or dismissed as a psychological illness, but doctors are now in general agreement that it is real, an international conference on CFS at Manly heard at the weekend.

Chemicals that were relatively harmless when used independently of each other could become highly toxic to the brain when used together, said Mohamed Abou-Donia, a professor of pharmacology, cancer biology and neurobiology at Duke University Medical Centre.

Rats suffered cell death in the areas of the brain controlling movement and memory when they were exposed through their skin to DEET, used in insect repellents, and permethrin, a popular insecticide, Professor Abou-Donia said. This was "consistent with muscle weakness, joint pain and problems with the central nervous system" reported by CFS patients.

The Sydney Morning Herald Monday, December 3, 2001 | News 7

Chemicals linked to chronic fatigue

Julie Robotham
Medical Writer

Chronic fatigue syndrome (CFS) could be caused by common chemicals such as head lice treatments and insect repellents, a United States expert has told a Sydney conference.

The condition, which affects up to one in 250 adults, has been derided as "yuppie flu" or dismissed as a psychological illness, but doctors are now in general agreement that it is real, an international conference on CFS at Manly heard at the weekend.

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Professor Abou-Donia also presented research which showed that rats were more susceptible to such chemical exposures if they were also under stress. Stress seemed to "cause minor breakdown of the blood-brain barrier", allowing chemicals to permeate the brain more easily.

"It seems to me that CFS and Gulf War syndrome have many common characteristics," Professor Abou-Donia said.

He said governments should consider restricting the availability of some household chemicals until more was known about their interaction in the brain with each other and with other substances such as over-the-counter medicines.

A director of general medicine from Harvard Medical School, Anthony Komaroff, said there was "a preponderance of evidence that a variety of abnormalities - objective biological abnormalities - are present" in the brains of CFS patients.

As well, Professor Komaroff said CFS usually involved the activation of the immune system. The fact that twice as many women as men were diagnosed with the condition lent additional weight to the hypothesis that CFS was essentially an immune disorder because all immune diseases, including lupus and rheumatoid arthritis, affected females more frequently than males.

Emerging evidence had also linked CFS to human herpes virus 6, which causes the childhood illness roseola, and to enteroviruses, which could persist in the body indefinitely.

Cognitive behaviour therapy and exercise regimes could help people deal with their illness, Professor Komaroff said, but for those who were most sick, exercise was counter-productive and exacerbated their illness.

Wilhelmina Behan, professor of muscle pathology at Scotland's Glasgow University, said she had collected more than 100 muscle biopsies from people with CFS, and would now analyse them in an attempt to identify any common genetic variations that might make people susceptible.

She said normal muscle tissue was made up of two types of fibres: "fast" fibres, which were used for bursts of activity, and "slow" fibres, associated with endurance tasks. People with CFS had up to 20 per cent fewer slow fibres, she said, which explained why they tired easily.

National Association Response to the RACP Guidelines

The National ME/CFS Association Board formally rejected the RACP ME/CFS Guidelines Draft 2 which were released in June 2001. A final draft has now been released but the National Association was not given access to the document. We have been informed that the guidelines will be published in the Medical Journal of Australia in late Feb / early March. A third party has been able to summarise for us some of the changes made in the third draft. Although some changes have been made for the better these are only minor—not changing the overall feel portrayal of the condition. Therefore the guidelines are still unacceptable to us. The National Association has had no alternative but to ask the Consumer Health Forum to reject the guidelines.

Mr Matthew Blackmore,
Chief Executive Officer,
Consumer Health Forum of Australia,
PO Box 170,
CURTAIN, ACT, 2605.

Attention: Emma Awizen

Friday, 18 January 2002

Dear Mr Blackmore,

R.A.C.P. Chronic Fatigue Syndrome Guidelines Third Revised Draft 2001

This letter is written on behalf of the four health consumer organisations associated with ME/CFS which are members of the Consumer Health Forum namely: the ME/Chronic Fatigue Syndrome Association of Australia and the ME/Chronic Fatigue Syndrome Societies of Victoria, South Australia and the ACT.

The purpose of this letter is to advise that your four member organisations associated with ME/CFS have decided, after careful deliberation, not to endorse the RACP Chronic Fatigue Syndrome Guidelines (as currently submitted for approval). The National Association also has three other ME/CFS societies within its membership: Western Australia, New South Wales and Queensland. It is my understanding that these societies are also of the view that the Guidelines ought not be endorsed..

In these circumstances, we request that CHF advise the RACP that the Forum is unable to endorse the Guidelines.

The Association, on behalf of all our member societies, is in a position to provide a detailed critique of the Guidelines but for our present purposes it is sufficient to make the following observations.

What is wrong with the Guidelines?

1) The *Guidelines* is a highly biased document, which inadequately describes CFS, misrepresents the illness and people with CFS and could lead to inappropriate treatment and widespread misconceptions about the illness.

2) The *Guidelines* predominantly display a psychiatric-psychological approach to the understanding and management for CFS, dismissing and downplaying evidence of biological abnormality and inadequately describing biological hypotheses of the pathophysiology of CFS.

3) The range of biological abnormalities that may occur in people with CFS is not considered as the basis for the management and treatment of CFS.

4) Suggestions for CFS management are made for which there is no or limited evidence of benefit in the CFS context (sleep strategies, CBT/graded exercise, antidepressants) while inconsistently, several major approaches to the management of CFS, with equal or better evidence of benefit, are not mentioned (pacing, gastrointestinal management, treatment for orthostatic intolerance, antibiotics, detoxification and chemical avoidance, use of supplements such as fatty acids, amino acids, vitamins and minerals) or inadequately mentioned (diet and allergy management).

5) The *Guidelines* suggest practices that are not appropriate for many with CFS (CBT and graded exercise), without giving information that will allow the GP or patient to assess the applicability of the suggestions in individual circumstances.

6) The *Guidelines* do not include information on a number of practices that may improve the quality of life for people with CFS (for example, pacing, management of gastrointestinal problems, detoxification and chemical avoidance, use of antibiotics

(Continued from page 11)

and supplements, treatment for orthostatic intolerance, specific details on diet and allergy management).

7) The symptoms and needs of people at the very severe end of the CFS spectrum are not mentioned in the Guidelines. This is a very serious omission as persons in this category are in the greatest need of appropriate support and treatment. One consequence of not including a section on the "very severe" in the present version of the Guidelines could be that doctors will remain uninformed and so be unprepared for, and so dubious of, the more extreme manifestations of the illness.

In the circumstances of these significant problems with the Guidelines, in determining its attitude to them CHF ought to consider some of the ramifications if the Guidelines are published in their current form. Apart from the point made in Point 7 above, the following ramifications have caused the National Association and its member societies to decide not to endorse the Guidelines.

Implications of the publication of the *Guidelines* for people with CFS

1) Incorrect diagnosis. As a result of insufficient and incorrect information, CFS may not be recognised. Psychiatric or psychological disorder may be incorrectly diagnosed because of inadequate differentiation between CFS and psychiatric-psychological disorders, and especially if SPHERE is used.

2) The GP and others in the community (other health workers, representatives of social service and welfare agents, education authorities, legal organisations, insurance and superannuation bodies, employers, friends, relatives) will be both ill-informed and misinformed and yet having read the document they will believe that they are well-informed.

   · The doctor, in his or her innocence, may recommend management proposals that are inappropriate (and even harmful) whilst at the same time is unable to recommend more appropriate approaches of which he or she is unaware, thus denying the person with CFS help that may improve quality of life.

   The most vulnerable are children with CFS. Doctors may prescribe inappropriate regimes. Parents, not knowing otherwise and wishing to do the right thing for their child, may enforce the recommended regime. However, when the parents realise that the regime is doing no good or even harm and start to oppose it, they may then be open to criticism from the medical profession and child welfare authorities, with potentially disastrous consequences (inappropriate hospitalisation possibly with further inappropriate treatment, child removal). This may seem far-fetched but such situations have occurred and are occurring in Australia.

   · Social service and welfare agents, educational bodies, insurance companies, family and friends, not understanding the nature of the illness, may not provide the financial, domestic and other support that is appropriate.

3) Incorrect information may lead to inappropriate allocation of money for future research. Supporting a psychological approach to CFS (and the suggestion, for example, of the use of SPHERE) and downplaying promising leads in the area of biological abnormalities, may lead to yet more research into CBT and a psychiatric-psychological approach to CFS at the expense of research into biological aspects of CFS and alternative treatment regimes.

4) Misinformation takes years to correct.

In conclusion, the National Association and its member societies, three of which are members of your Forum, are strongly of the view that the CHF ought not endorse the Guidelines in their present form. We ask that you accept this recommendation and act accordingly.

Yours sincerely,

Simon R. Molesworth AM, QC
National Chairman
ME/Chronic Fatigue Syndrome Association of Australia

State President
ME/Chronic Fatigue Syndrome Society of Victoria

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

Disability Support Pensioners Australia Inc.

By Judi-Ann Leggetts

It was a life-time ago, at the age of 19, when a flip of my car on my way home from work one morning (after performing three gigs a night as a professional singer) put me in hospital. My gold 'glowmesh' dress saved me, catching in a tree. The 10 peopCle in the other three cars involved in the accident were all dead in the Yarra river. I spent four months in a coma and two years in hospital to learn to walk and talk again-after being told I would never do either again.

In those days it was wonderful care in hospital-good nutritional food, constant care with therapy and strict supervision on medications. But then I was discharged. Discharged to what? I had no money, no home and no clothes except what I had on me from the hospital charity shop. I was well out of my depth.

I had the best of everything when I used to earn top money in my singing career. But now I had to get a letter from the social worker at the hospital outpatients with appointments times when I would get my medications from the hospital pharmacy. And then I would walk to an address, written by the social workers on an envelope, to receive some money so I could eat. In those days medications were free-of-charge if you did not have money.

DSP

Eventually I ended up sleeping on Elwood Beach where I found some other people in the same position as me. Many times I had to crawl on my hands and knees from Elwood Beach to get to my hospital for medical help. I developed nervous asthma and could not walk. I'd had eight plastic surgery operations on my face, a hair-piece fitted and daggy old clothes that I certainly was not used to, nor were the others that I was with. We decided to band together, as it was cold on the beach and we were hungry all the time. We decided to ask some of the people who walked along the beach if they knew anyone who could help us to write letters to the Churches and the Government, so we could get help in the form of weekly money coming in to pay for accommodation and food.

We met a man who had a business and he wrote letters for us and sent them to the local Federal Member

(Continued on page 14)

(Continued from page 13)
of Parliament and also to the Prime Minister. Our letters were heard and one day the man came to tell us that the Government had introduced a new scheme under Social Security called 'invalid pension '.

Once we had an income, our group saved up enough money to share a three bedroom flat in Elwood where we worked to get more services for us to live better. We would get left-over vegetables from the green grocers, some bits of meat and day-old bread to eat with lots of potatoes and stew. But then we found that some of us were eating the wrong foods for our health problems so we had to find chicken or fish and get left-over salad vegetables. We were always lobbying shops for their left- overs so we could eat well for the sake of our health.
We got support from a lot of locals who would donate their unwanted clothes to us and we shared them around so we looked as good as possible. It was possible to live on the 'invalid pension' decently and in dignity.

But not long ago, 'invalid pensioners' name was changed to DSP pensioners and things started to deteriorate. We had to start paying for medications. Rents and the cost of food went up.

DSP Australia Inc, is very concerned at the deterioration of DSP pensioner benefits because young people cannot live decently on this amount.

Today we are fighting the 'Welfare Reform' which threatens everything we fought for to give people a chance to live decently.
Our fight for better living standards for our members is ongoing. Many DSP Australia members have worked hard until the loss of their jobs through illness of injury that now prevents them from earning enough to live a decent and dignified life.

Judi-ann Leggetts is the founder of DSP Australia Inc.

Reprinted from 'The Australian Health Consumer' – journal of the Consumer's Health Forum of Australia Inc.- No 3, Winter 2001; with permission.

"DSP Australia Inc. is a support organization for young pensioners in our society who live on very low fixed incomes, preventing them from being active in their community or even purchase the essential items needed to live a decent lifestyle and regain the self-esteem, confidence, and dignity needed to feel like a worthwhile human being. Being young and on a fixed income is an automatic setback in today's society; those in this situation cannot participate in social activities, afford medical equipment and medicines, or obtain good clothing, appropriate accommodation and easy mobility. With a DSP Pension Concessions Card these individuals can eliminate any discrimination regardless of the physical or financial disabilities that they may suffer. A DSP Australia Inc. Member who carries a DSP Membership card with their DSP pension card has special requirements and needs that little extra understanding and patience to keep up with the fast pace of today's world.

DSP Australia Inc. is a registered charity with the Australian Taxation Office as well as the Australian Securities Commission. Donations of $2.00 and upwards are tax deductible. A receipt is sent promptly to those who donate. "

http://home.vicnet.net.au/~dsp/

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.

Zoë's Story

This was written for the UK government's consultation on M.E. and CFS. It was published in InterAction Issue 37, June 2001
Zoë Williams May –June 2000

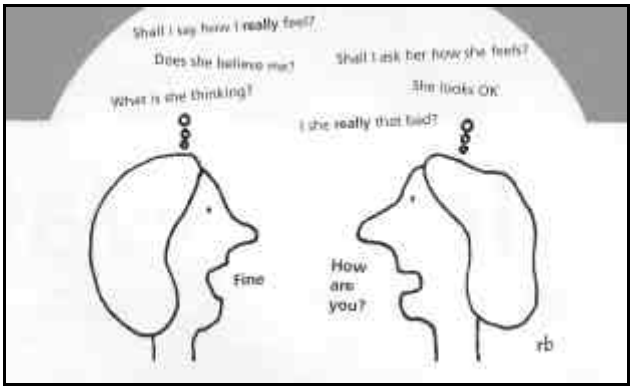
Over my ten years of illness I have had a wide range of experiences of NHS professionals. Although I think the majority had good intentions, their desire to help me has not always prevented them from doing exactly the opposite. A common theme is the belief that people with M. E. would get better if they did a little bit more each week. I can't count the number of times that I have had to explain to a professional that this does not fit my experiences. It can be heart-breaking when this is held up as the effective treatment that I would so love it to be.

In my experience when my health is improving it is very natural to do more. It is important to be self-controlled and not to try and rush the improvement, as it is easy to overdo it. When my health is on a plateau or deteriorating, trying to do more can be positively dangerous. At all times I have to weigh up the risks and benefits of particular activities in relation to my symptoms and health status at that time and my priorities for the week. It is very hard that few professionals respect the risk of deterioration, even though I have had both short-term and permanent deteriorations when I have been encouraged to override my sense of risk and do something that I felt I may not be well enough for.

If I had been encouraged to listen to my body, learning from my experiences, I doubt that I would be as ill as I am. Instead, I was told to do what I knew in my heart was dangerous. It is not merely a case of insensitivity – it is a case of being advised by someone with authority, to do things that predictably make the illness worse. M. E. can be a very serious illness and the risk of a patient with the condition becoming severely ill should be taken seriously. Yet patients expressing concern about possible long-term relapse tend to be treated as if they are over-anxious.

Initially I was treated as if my illness was not at all serious, but I was already too ill to go into school even for an hour in the library (I was 13 when I became ill). Now I tend to be treated as if I am unique in having been in bed for nine years, although I know there are many in a similar situation. There seems to be very little expertise in severe and long-term M.E.

When a person feels that they have been treated badly,



this has an effect even if the problem was unintentional and there is no blame attached. Many people with M.E. have had very difficult experiences with the medical profession and so they are often nervous around doctors. The doctor who helped me the most treated me very gently. She realised that my anxiety was not to do with her, but simply a consequence of my experiences. Although she could not help me physically, she helped to restore my self-respect. One of the hardest things for me has been self-doubt. I didn't really believe my own body because I was continually told things that didn't seem to make sense. It was horribly confusing and it has taken years to build my confidence in the knowledge that it is not my behaviour or attitudes that are keeping me so ill.

When I was less severely ill I went to out-patients appointments. The combination of the journeys, the consultation and the long period spent in the waiting room sitting up in a chair caused me a lot of physical suffering; I also think that it contributed to the major deterioration I was experiencing, from which I have never recovered. The health impact of appointments on moderately severe M.E. would, I think, be lessened if patients had a comfortable, quiet place to lie down while they waited. Home visits should also be provided where travel may be detrimental to the patient's health

If I were to die in the near future, especially if I die of M. E. (as one of my friends did), I would like to leave my body to research into M.E. It seems to me that with any mysterious illness, autopsies would be a good place to start investigating. At present I am not aware of there being anyone willing to carry out such research, and I think this is something that should change.

I would also like to see:

- more scientific rigour and attention to subgroups in research
- equality with other comparable disabilities when it comes to service provision and volume of research
- access to services for people who are housebound (using home visits, telephone consultations, mobile clinics, post, e-mail)
- suitable in-patient facilities for assessment, treatment and respite care (with single, quiet rooms).

Sticks and Stones

Psychotherapist Val Rubie takes a look at the stigma many still associate with having ME

Photo by Audrey Spittal. Caption: How do you see yourself?
Cartoon - attitudes

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

InterAction often hears from people who are concerned about the stigma of having ME. It is also a facet of suffering which often crops up during psychotherapy or counselling.

'The first time the stigma of ME affected me was when I overheard my art teacher saying that I had "terrible trouble with my nerves" adding "she's had some sort of breakdown you know" - just because I'd said I'd rather not use oil paints since suffering from ME'.

A stigma usually gets attached to a type of behaviour or condition which is not fully understood. This makes ME people something of an ideal target for being stigmatised. In spite of all the publicity, education and PR carried out by Action for M.E. and other organisations I am constantly horrified at the extent to which ME is still misunderstood and not recognised. We have all been on the receiving end of being considered lazy, a hypochondriac or simply not trying hard enough to recover. We have all received endless tips and hints on what we *ought* to be doing. Sometimes it seems that anyone and everyone have their own unique and fiercely held beliefs about ME, which can be quite independent of the facts.

Ignoramus or Saint?

When you have ME, meeting someone new is a bit of a lottery. Are they a well-informed, non-judgmental, empathetic saint, a biased, a pig-headed ignoramus or perhaps a well-meaning over-bearing person who will arrive with foul tasting soup every other day? I think this is why ME people can become extremely guarded about revealing their illness. It takes a lot of energy to try and put someone right. This is particularly so when they've got the facts badly wrong and are making judgements based on inaccurate assumptions.

So is it better to keep silent, pretend you are healthy or even claim you have another, better understood illness?

There seem to be two feelings which are associated with stigma: *fear* and *shame*. Fear of what kind of decisions/ actions/assumptions will be made in error because of a misunderstanding about the nature of your condition. Fear that perhaps you will never get back into work, never find a partner and never make new friends.

The shame spectrum

Shame is said to be a bit of a Cinderella emotion, i.e. it's often overlooked by counsellors and therapists in favour of the 'big, serious' feelings like anger and grief. But shame can cause just as many problems. At one end of the spectrum, shame is a mild embarrassment for laughing at the wrong thing. At the other end, it can be a paralysing belief that the way you are and everything you do is totally inadequate and wrong; a wish to keep everything you do, think and feel absolutely secret. Logic of course says that it is not our fault that we have an illness but it's easy to go on feeling ashamed about it. It all boils down to a fear of what other people think of you and believing that they have immense power over you.

For a person who is overwhelmed with shame, to reach out to others or adjust to their illness is a struggle. It is very difficult to rebuild a life if you can't or won't reveal whole chunks of information about yourself. This is the Rip Van Winkle syndrome of ME – if you can't admit to having ME, then how do you explain away years of apparent absence from life.

Hard-line Assertiveness

The hard-line approach to assertiveness says 'don't explain, don't justify, don't placate'. I'm not sure how helpful that is, frankly. If you've managed to reach a place in your development where you are really independent of other's opinions, then that approach might suit you. For the rest of us, it might be better to judge each person's reactions on their own merits. I appreciate this is not easy with ME because it requires decisions and choices. Making clear judgements can require quick thinking which is impossible on a bad ME day.

Generally it is not a good idea to lie about your condition or how you're feeling; it can become a burden and a source of tremendous anxiety. However, I don't say this purely on moral grounds. Telling lies needs a very good

(Continued from page 15)

It seems an omission not to call for more training in M.E. for doctors, nurses, physios and Occupational Therapists, as it is most certainly needed. However, I am concerned about the type of training. I do not want to see 'do-a-bit-more-each-day' training. I would love medical professionals to be told more about the physical abnormalities present in M.E. patients and theories which might explain some of these, and also to learn about how different sub-groups react to different treatments.

memory, a faculty ME people often lack.
Jenny comments: 'I once dated a bloke and the last thing I wanted to do was put him off by telling him I had ME before he got to know me. The problem was, choosing the right time to tell him got harder and harder, and would have meant admitting I'd lied previously. In the end I stopped calling him rather than confess I'd fabricated a career I didn't have.'

The balancing act

On one hand, you could decide to tell everyone everything about yourself, which might make you appear rather tedious and self-obsessed. On the other hand, you tell no one anything and end up feeling totally isolated. The sensible solution is to take a middle course. Sometimes you will get it wrong – but don't feel ashamed about that! Is it a situation where you are hoping to make friends/contacts? In this case, giving a bit more honest information may be worth the risk. However, if it's just a passing nosy stranger, there is no reason why you should feel obliged to give your entire life story.

There are times when we all dread hearing the question 'have you got an illness?' The fact that you may feel reluctant to answer could be because you have sensed you are going to get into a long involved debate. Avoiding a direct answer to a question rates as one of the more difficult assertiveness techniques. A non-committal reply along the lines of 'Oh you don't want to hear all about that, it's very boring' or a vague 'Something like that' may put most people off. Or you could throw the question back to them 'What makes you ask?' This provides thinking time and a chance to discover their assumptions.

The *non-assertive* way to deal with such eventualities is to obsessively monitor your life for any reference or clue to ME and then obliterate all outward signs of it. This takes enormous energy and would be ignoring a very real part of your existence. Whether we like it or not, the experience of ME for most sufferers is of great importance. It has shaped your life, perhaps for many years and may do for years to come. Is it very sensible to completely deny it? Someone with MS put it rather well: 'I don't want my condition to define me – but I do need it acknowledged'.

Stigma or discrimination?

Stigma which is acted upon by official bodies constitutes discrimination. No two ways about it. This is where the fear may be at its worst and perfectly justified. Are we discriminated against in the benefit or medical system? Will years of ME make getting employment impossible? Will insurance companies discriminate against us? The new Disability Discrimination Act is designed to minimise such behaviour but the system is far from perfect and we can sometimes feel powerless, caught within it.

Trying to distinguish past from present is always useful. Is the shame and fear you feel based on what is happening now? Or is it more connected to your past and the way in which you were made to feel ashamed for daring to exist and for having needs. If you are isolated and your past has led you to mistrust others, it is sometimes difficult to get a good perspective on the situation. If you know this may be the case then at least being aware of it is helpful, perhaps by talking your feelings through with an independent person. Or the way ahead may involve longer-term action such as psychotherapy or cognitive behaviour therapy to get rid of such destructive and corrosive beliefs.

In an ideal world we could all refuse to accept any stigma placed upon us.
But even in this world your self-esteem - even your quality of life – are likely to be much higher if you know your own worth irrespective of other's opinions

WHY NOT SHARE YOUR STORY WITH US?

It is very encouraging to hear about others experiences; and quite therapeutic for both reader and writer. If you are interested, then please go for it. Leave you details with the office staff and one of the editors will call you to help you along (If that's what you want.) Otherwise just send your work in to The Editor Talking Point,

PO BOX 383 Adelaide SA 5001. OFFICE PH: 8410 8929.

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

by The Invisible Disabilities Advocate, Sherri L. Connell.

Note: We have been kindly been given permission to print parts 2, 3 and 4 of this booklet. This is our last installment where we look at Part 4.

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

"I Never Know What to Do!" Part 4.

The Balancing Act!

When a person is chronically ill, they have lost various degrees of their ability to complete daily tasks. Some have "good" and "bad" days and may need occasional help on those "bad" days. Others do not have "good" days at all; and, therefore, find it impossible to even keep up with the bare necessities.

Every day is a struggle to choose which 2 or 3 of the 100 chores will get done. Sound like your life? Think again! Try counting all of the tasks you accomplish in a day, including making your bed, taking a shower, running an errand, making a meal, cleaning the house, talking on the phone, writing a letter, paying your bills, etc. For those with a chronic illness simply taking a shower, combing out their hair and getting dressed can be an all day event.

And, imagine spending hour after hour, waiting in doctors' offices, getting blood drawn, having x-rays taken, going through surgeries, all the while knowing your life is rushing by without you; everyone else is out accomplishing their goals and fulfilling their dreams, while you sit watching yours come crashing down around you.

Many people think a person with a chronic illness has a lot of time on their hands, when nothing could be further from the truth. In fact, most chronic illness sufferers do not get the rest they need, because they are so busy spending all day trying to do the things that a "well" person can do in one hour.

For example, it often takes three full days of energy to get one load of groceries or go to a doctor's appointment and one full day to do a load of laundry or to make a meal; and, with most, it is physically impossible to vacuum, mop or even dust.

Dreaded Limitations!

Because of the overwhelming pressure of not being able to complete basic, daily tasks, those suffering from chronic illness, often push themselves beyond their limitations and end up flat on their back with a speeding heart rate, gasping desperately for air and feeling pinned down by a truck. Unlike a "well" person, they cannot simply rest to feel better; instead, they pay a high price of excruciating pain and unbearable fatigue for days and even months.

In order for a chronic illness sufferer to visit with a friend or attend a social gathering, even more daily sacrifices have to be made in order to prepare for the event. They do this by avoiding any other outings or projects around the house for several days, because the energy it takes to sit, smile and talk is incredible! And, by exerting themselves, they will then suffer the consequences for several days, weeks or months and end up even more behind on their daily duties.

So, should you avoid asking them to spend time with you? Absolutely not!
Spending time with friends and family, who care, gives incredible strength and will to keep fighting the battle! Go ahead and invite them, but allow them to say, "no" if they have to, realizing they would if they could. By showing you want to spend time with them, you will make them feel loved and important.

So, Where Do I Start?

First, it is difficult to recognize there is a need, by simply looking at someone with a chronic illness; often they appear physically able to accomplish any task set before them, because their physical challenges and disabilities are invisible.

Unfortunately, most people make the mistake of overlooking what their friend or family member is telling them, because they cannot see the disability.
Therefore, the first thing you must do is to learn to listen to their needs, without discounting them with your eyes.

Second, many people are genuinely willing to help; they just do not know where to begin. They often offer by saying, "call me if you need anything." This is a great effort to reach out, but, unfortunately, it does not work.

When a person has a chronic illness, they are forced to give up countless dreams from losing a career to the inability to complete simple daily tasks. The independence they had all of their lives is suddenly gone and they are left with the struggle of needing help, yet, feeling like a burden if they ask for it; besides, if they do find the courage to call, it will inevitably be a bad time for you.

(Continued on page 19)

So, What Can I Do?

As previously mentioned, a person with a chronic illness will tell you how you can help, if you simply listen. Often, they need rides to doctor appointments or would benefit greatly if you could run an errand for them.

But, how can you help if they will not call you when they need it? Simple... you call them. They know you are busy, overextended and do not have a lot of leisure time; they do not want to add to your pressures. The secret to getting them to accept your much-needed help is to do something that is convenient for you.

You can do this by calling and saying, "I am going to the grocery store, can I pick a few things up for you?" This is an incredible way to save your friend or family member days worth of energy, they know you do not have to make a special trip just for them and it is virtually effortless on your part.

Another way to approach them is to say, "I have some time on Tuesday, can I stop by for a short visit with you? And while I am there, I would love to fold some towels or do a few dishes." Or try, "I need to run some errands, can I take you to a doctor's appointment while I am out?"

Sometimes having company can be quite stressful for someone with a chronic illness, because they are probably behind in household duties; but, if you express that you truly understand their desire and inability to keep up with those things, they will not feel as embarrassed.

What Else Can I Do?

Something that most people do not think about is that many who suffer from illness are very sensitive to chemicals and toxins. When you go to visit your friend, do not smoke or wear perfume. While you know that these things can cause your nose to itch, it may make your loved one extremely ill with headaches, nausea and incredible fatigue that could last for several days.

Another way to ease their housekeeping situation is to organize a few people to chip in for regular cleanings; if you get enough friends to participate, it may only cost you a few dollars a month!

Because getting out is often too exerting, you can bring them a picnic lunch or a cup of tea! If they are not feeling up to the visit, you can drop off a nutritiously prepared meal or a video.

Reading material seems like a good thing to share, but unlike you, if they are sick in bed, they are too fatigued, in pain and nauseous to read; and when they do have the physical energy to read, they must use that energy to do things like sending birthday cards, paying bills or taking a shower.

On the other hand, if others were able to help them with some of these exerting tasks, they would get enormous pleasure out of using their energy to do those things they have dearly missed ... like reading that good book.

In all, remember to listen, believe what you hear, allow them to say, "no" and offer specific help that is convenient for you. Do not worry about making time for hours of strenuous help; what is simple for you could save days of excruciating work for them!

"Just A Little Bit Of Your Time, Can Make A Very Big Difference!"

"I Never Know What to Do" is Part 4 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 Dr. Parker, CO 80138.

Visit IDA's website at www.InvisibleDisabilities.com!

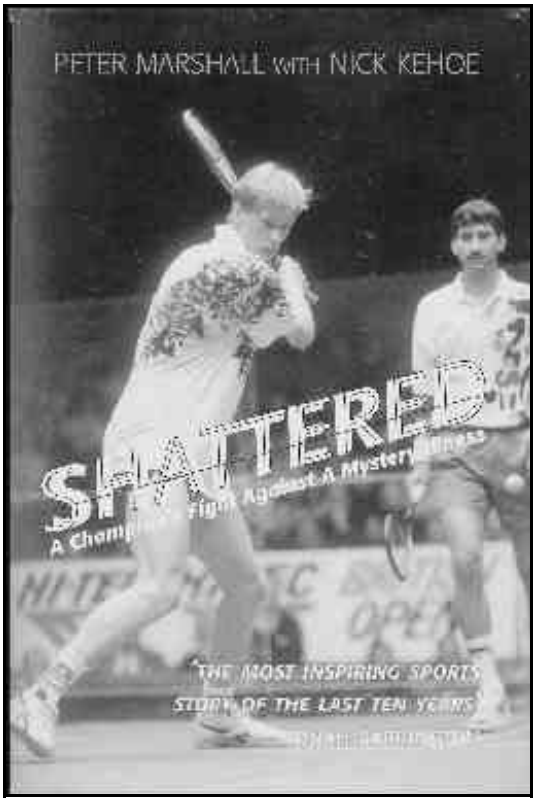
Shattered: A Champion's Fight Against a Mystery Illness. Peter Marshall with Nick Kehoe

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

Book Review by Skye Yuill

Peter Marshall was the second best squash player in the world and poised to take the number one crown when the effects of Chronic Fatigue Syndrome dramatically altered his life.
Together with sports journalist Nick Kehoe, Peter Marshall has put together an autobiographical look at his career in squash and his battle with CFS.

If you are looking for a comprehensive guide to Chronic Fatigue Syndrome that documents research, causes, treatments and self-help techniques then this book is not for you.
However the author does have an excellent understanding of how the illness can effect sufferers and CFS sufferers will be able to relate to many aspects of Peter's journey.
Some of the areas that Peter discusses are the importance and relief of getting a diagnosis, finding a good doctor, self-researching the illness, the problems associated with having a hidden illness, the self doubt and anger associated with being told that what you are suffering from is psychological, the conflicting mental thoughts that arise with receiving conflicting doctors opinions and the loss of faith in the medical community and in making a total recovery.
Peter does a good job of articulating the frustration of having tried numerous alternative and conventional treatment regimes that despite their high cost yielded no benefits.
For instance " I was desperate for a cure. Some of the alternative therapists I had encountered were conscientious and professional, but all to often they would glibly dole out advice and then sting me with a 500-pound bill for something that did no good at all. That's a lot of money when you're not earning. Even more damaging was the frustration of having my hopes built up only to have them come crashing down again"(Marshall and Kehoe, 2001, p. 122).
Peter found nothing that he tried worked. He believed he had to find his own answer and come to some sort of acceptance of the illness.
"With something as uncertain as CFS, you find yourself going round in circles without ever being able to reach a definite conclusion that you can accept and which provides you with any real help."(Ibid, p.137).



I found Peter's comments about the psychology of having CFS to be very insightful and I found that he is very much in tune with what sufferers go through. For example he discussed the difficultly associated with explaining his condition and the reactions he would get, "Ill? You don't look ill. You look really well"(Ibid, p.106) and "You look okay so you must be okay" (Ibid, p.106).

Although CFS plays a major role in the books content, I found a great deal of the book wasn't about CFS.
Marshall has a scholarly knowledge of the game of squash. This is on display throughout the book and is emphasized the most during his anecdotes of historical squash battles. If you are a sports fan or in particular a squash fan I think this book will certainly appeal to you.
I believe the book will also satisfy any reader who wants to be inspired.
Peter Marshall is obviously a very courageous and determined individual and this is no more evident than when he refused to take a quarter of a million compensation payout from his insurance company as a result of his 4 year illness with CFS. Despite still being very limited and restricted by the illness he choose to decline the payout which would have ended any future prospect of him playing professionally. Peter took a huge risk and eventually fought his way back onto the squash court and took the winner's trophy at the British National Championship in 2000.

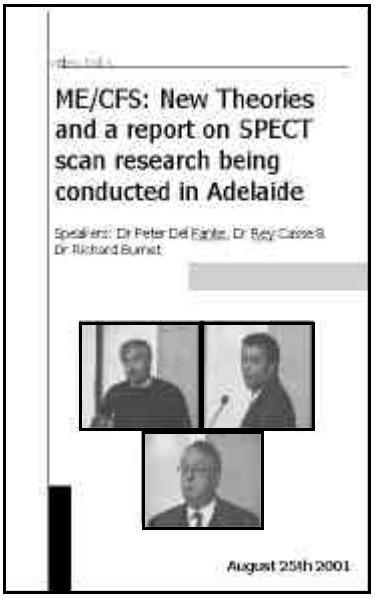
As a sufferer of CFS myself Peter reinforced some truths about having CFS that I am aware of but still learning as I attempt to recover.

With CFS it is important to stop pushing, to take breaks and rest and learn moderation in all aspects of life. It is also important that I accept my current limitations and perceive resting as an essential part of recovery and not some sort of indulgence I should feel guilty about.
In summary the book is easy to read, enjoyable and I found it offers some valuable incites on living with CFS.

* * * * * * * *

The book can be ordered from Australian bookshops if people provide the following information. The title is Shattered, by Peter Marshall and Nick Kehoe.
It's published by Mainstream, Edinburgh and the ISBN number is 1-84018-395-0.

Report From Public Meeting August 25th 2001




Dr Peter De Fante


Dr Rey Casse


Dr Richard Burnet

On a wet and wild day 80 people braved the elements to attend a very informative meeting. Although it was a shame the weather took its toll on the attendance, we had the event professionally taped and have copies for sale.

In this edition we have included two summaries—the talks by Dr Peter Del Fante and Dr Richard Burnet. Dr Rey Casse's talk will appear in the next issue.

Special Price: $16.50 (GST included) + $3.50 P&H
Audio Tapes: $4.40 (GST included) + $2.60 P&H

INTRODUCING ME/CFS

By Dr Peter Del Fante
Medical Director for the Adelaide Western Division of General Practice

Introduction

CFS/ME is not a simple illness, and is not unlike Fibromyalgia (FM) - in fact some people might say that each of these conditions are at one end

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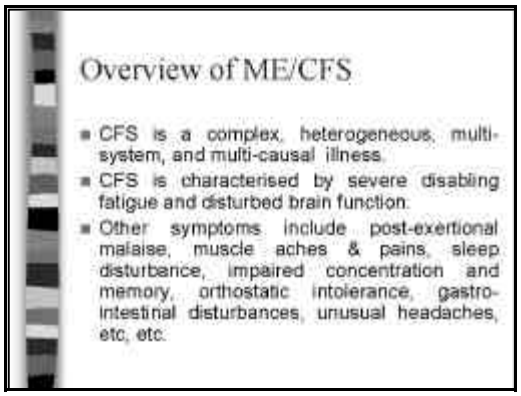
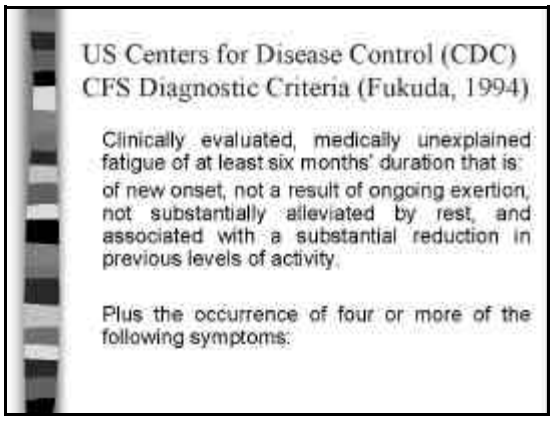


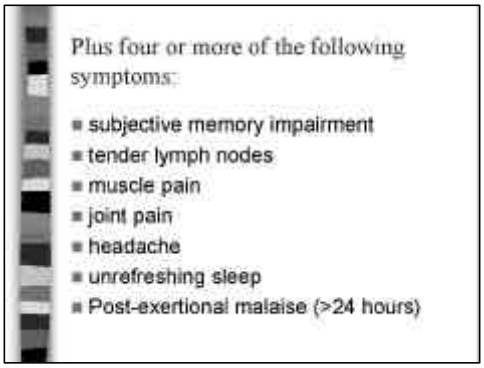
of a continuum, with FM being on the pain end, and CFS/ME being on the fatigue end.

CFS/ME Research Definitions

Although many CFS case definitions or diagnostic criteria have been developed for research purposes, the most widely used case definition of chronic fatigue syndrome is the one developed by Fukuda (1994) at the US Centers for Disease Control (CDC). The main alternative case definition used is the UK Oxford criteria.

The CDC CFS Diagnostic Criteria (Fukuda, 1994)





N.B. There is a considerable subjectivity in interpreting such a criteria because of its descriptive nature. Interestingly, the need for only 4 of the 8 symptoms (above), means a patient can fit the criteria but not have post-exertional malaise. Some would argue that this symptom is a core symptom for CFS/ ME.

The exclusion criteria includes: (NB This list is not intended to be exhaustive):

- Active, unresolved, or suspected other disease* likely to cause fatigue
- Psychotic, melancholic or bipolar depression (but not uncomplicated major depression)
- Psychotic disorders
- Dementia
- Anorexia or bulimia nervosa
- Alcohol misuse or other substance misuse
- Severe obesity

(* Heart disease, kidney disease, sleep apnoea syndrome, Systemic Lupus, occult (hidden) cancers, anaemia, adrenal gland diseases, hypothyroidism, neuromuscular disease, etc).

It is worth noting that uncomplicated major depression is not an exclusion criteria, but alcohol misuse is. Interestingly many people with CFS develop an intolerance to alcohol. You would know that a lot of people with depression tend to use alcohol – so it's a good discriminator when creating a subgroup of patients for research.

The Oxford Criteria

The UK Oxford criteria is not all that dissimilar – again fatigue must be present for 6 months. It brings some of those issues of neurocognitive dysfunction to the main opening sentence of the definition. The fatigue affects both physical and mental functioning, and it needs to be present for 50% of the time for that 6 month period.

Again, how to you actually define this fatigue, and account for it over this time period?" This is can be very subjective.

Also, unlike the CDC definition which has an opening statement then a requirement for 4 out of 8 symptoms to be met, the Oxford criteria simply states that other symptoms may be present, but only gives a few

examples. This is rather inadequate, and hence the international preference for using the CDC criteria.

However, the exclusion criteria are almost similar. Again uncomplicated major depression is not excluded. But, more importantly alcohol misuse is also not excluded in the Oxford criteria.

So you can see that a person with depression and alcohol abuse, and fatigue on top of that would easily fit this criteria, and we would see this as a major problem when trying to sort out what is going on in terms of disturbed brain function in these people.

Problems with current Diagnostic Criteria

As I stated earlier, CFS/ME is a complex illness: multi-causal, multi-factorial. And there is now of lot of evidence and a lot of researchers who are coming to the conclusion that the two criteria I've just outlined tend to be vague and certainly over-inclusive (J of CFS 2000 Vol 7(3) p17-22). More disturbing is that some researchers only use a part of the criteria. In fact some researchers might say they have used a particular criteria, but then not only take out what they don't like, they then broaden it even further with additional (un-warranted) criteria. A lot of the Cognitive Behaviour Therapy (CBT) research in CFS/ME does just that, resulting in very little diagnostic reliability, let alone credible research findings.

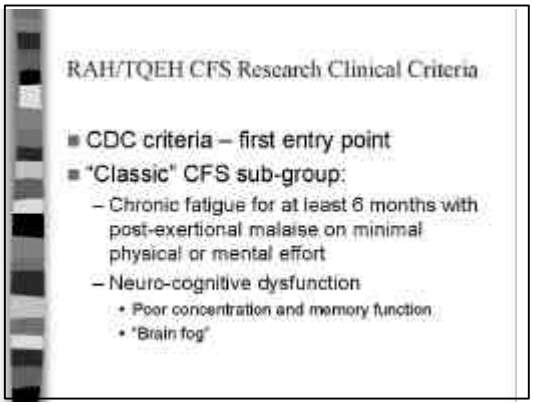
There is now broad acknowledgement by the majority of CFS researchers for the need for CFS patients to be sub-grouped when it comes to research (see US State of the Science Conference on CFS - Oct 2000)

Patients in each subgroup share a common core pattern of defined symptoms, and hence form a more homogeneous group. It is important to note that each subgroup must still meet the current CDC criteria for CFS/ME.

When we start looking at sub-groups I think we can start to get more interesting and meaningful results from the research.

RAH/TQEH Research Clinical Criteria

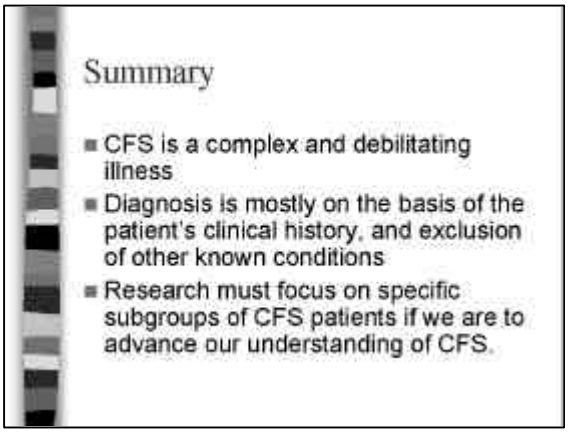
Our criteria (for creating a more homogeneous subgroup of CFS patients) requires us to first meet the CDC criteria and or the Oxford criteria. This is relatively easily met by our "classic" subgroup of CFS patients. They must have had 6 months of fatigue, post-exertional malaise on minimal physical or mental effort, the neuro-cognitive dysfunction. (People sometimes use the term 'brain fog' to explain this dysfunction).



They also must have sleep dysfunction, alcohol intolerance and one or more of the following: orthostatic intolerance, myalgia (though not typically as severe as FM patients), gastro-intestinal symptoms (which tend to be intermittent). It is important to note that many CFS patients develop reactive depression from time to time, due to the frustration and hopelessness that can be associated with their chronic and debilitating condition. However, in this subgroup, patients with major depression and / or alcohol abuse were excluded even though they met the CDC criteria. The RAH/TQEH CFS/ME research team has been using this new subgroup criteria to define a "classic" group of CFS/ME patients. The rest of this seminar will outline some of the research findings to date using this "classic" group of patients.

Summary

- CFS is a complex and debilitating illness
- Diagnosis is mostly on the basis of the patient's clinical history, and exclusion of other known conditions
- Research must focus on specific subgroups of CFS patients if we are to advance our understanding of CFS.



Gastro-Intestinal Research

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

by Dr Richard Burnet, Endocrinologist in private practice, and also with the RAH Endocrinology Dept. He has been active in ME/CFS research for many of years, particularly in collaboration with Dr Garry Scroop in the physiology department of Adelaide Uni.

My views on CFS have changed over the years and I think we are now entering another phase of its improving diagnosis and management. I enter a note of caution and I'd like to use my own set of studies as a way of illustrating the changes that may occur with CFS. It started 15 years ago, with one CFS patient who had another complaint. This patient got better on 'aldactone' and she reported her CFS symptoms had disappeared. After 6 months stopped the aldactone and the CFS symptoms reappeared. Aldactone's main function is as a potassium sparing diuretic. From there I took a total body potassium study found that it was low when her symptoms were worst, put her back on the aldactone, her symptoms got better and her serum potassium went up. I thought that this was easy – I was going to solve CFS with this.

We then went and did more studies on total body potassium using a whole body monitor (which is no longer there) at the RAH. What we found was a wide spectrum between CFS patients and normal. About 2/3 of the CFS patients had low potassium (5-20%) and some of the patients had an increased level of total body potassium – yet all had CFS. These findings have been reproduced overseas.

We then used muscle pain as a discriminator. We found three different groups with the total body potassium. The low potassium group had no muscle pain, the middle group had a mixture of fatigue and muscle pain, and the high potassium group had muscle pain but minimal fatigue.

This certainly explains why only 25% of patients got better [on potassium increasing medication] and 75% were unchanged.

Exercise

After that I then associated with Prof Scroop at the University of Adelaide Exercise Laboratory. [A study was completed where 40 people with CFS and 40 matched controls were exercised to exhaustion.] We found no difference between the production of lactate, the ability to exercise, as well as the amount of work they could do, between CFS patients and controls.

If the CFS can undertake the same amount of work, put out the same amount of lactate, there is nothing wrong with their muscles; there is nothing wrong with their metabolism; there is nothing wrong with their heart. So you have to therefore have a concept that in fact that peripherally the muscles, activity and metabolism is normal.

I was emotionally wedded to the fact there was a metabolic defect, that toxins were produced in the muscles etc… I still can't get over it. But intellectually you have to accept that the muscles are fine. [Don't get me wrong] once the subjects exercise – they were quite sick. Some took 2-3 weeks to recover. [but whilst they exercise] they are no different. They can do it. What that means to me is there is some override button – some sort of emergency override to cope with severe stressful situations.

The group I see in my rooms are tired, lethargic – some have been known to bring their own beds – but they are different to when Garry Scroop gets them. [Garry got the middle of the road group – neither severely disabled or only mildly affected, and all were referred through me.]

My current concept of CFS

- CFS is a condition of severe and prolonged whole body 'shut down'
- It is an abnormal and excessive response and it is prolonged
- It is initiated by one or a number of stimuli regarded by the body as toxic.
- It occurs in a susceptible individual (the extent to which this may or may not be genetic is unknown)
- It is a malfunctioning protective mechanism (possibly why bloods come back normal)

Results from Gastro-Intestinal Questionnaire

[A validated gastro intestinal questionnaire was administered to self-diagnosed CFS subjects. The questionnaire broke symptoms into 3 categories: oesophageal, gastric or large bowel.]

Gastric Symptoms in CFS

SYMPTOMS	CFS	CONTROLS
	Present %	Present %
GASTRIC		
Lack Appetite	88	8
Nausea	48	4
Fullness	95	4
Bloating	100	20
Vomiting	16	0
Abd. Pain	80	8
OESOPHAGEAL		
Swallowing	32	44
Heart Burn	16	10
Acid Reflux	16	40

Frequency of Gastric Symptoms

No. SYMPTOMS	CFS %	CONTROLS %
One Symptom	100	20
Two Symptom	100	15
Three Symptom	90	10
Four Symptom	60	0
Five Symptom	40	0
Six Symptom	5	0

Bowel Symptoms in CFS

No. SYMPTOMS	CFS	CONTROLS
Bowel Movements /day (mean)	2.5	1.2
Constipation (%)	20	30
Consistency. Formed	15	80
Loose	60	20
Watery	25	0
Nocturnal diarrhoea (%)	36	0
Faecal Urgency (%)	22	16

Gastric Emptying Studies (CFS Patients with severe symptoms)

I conducted a study where patients had to eat a meat pattie and consume a drink – each was laced with a radioactive tracer. A camera then tracks the flow of the solids and liquids.

	Females	Males
Number	17	9
Age (years)	32.8	34.4
Weight (kgs)	62.6	78.8
Duration illness (years)	6.8	6.1
Restriction activity (%)	79	68
Oesophageal Emptying (85% solids should empty in 7 – 93 seconds)	62.3	70.4
Solid remaining after 100 minutes should be 4 – 61%	64.4	58.75
Liquid: 50% emptying time should be 6-31 minutes	45.1	39.2

Results were as follows:

Solids: The averages for solid remaining after 100 minutes were at the upper end of the normal scale. Around ½ the CFS patients have longer than normal solid-emptying times.

Liquids: There is a marked prolongation of liquid-emptying. Around 80% of CFS group where above the normal rate.

(Interestingly diabetics have prolonged solid-emptying times – much greater that the CFS group.)

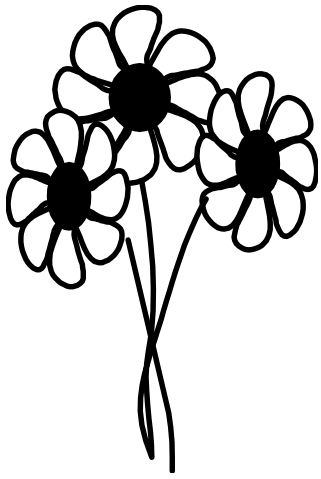
A Working Hypothesis for CFS

- Toxic stimulus in a susceptible individual
- Over-reaction of body (possibly excess cytokine formation)
- Smooth muscle constriction
- Reduction in brain blood flow
  »Disorders of thinking/fatigue/pain
- Peripheral reduction in blood flow
  »Cold extremities
  »Low blood pressure
  »Reduced coronary blood flow
  »Reduced muscle blood flow
- Gastro-Intestinal
  »Reduced Gastric emptying
  »Bowel disorders

NOTE: There is a mechanism to dilate blood vessels under emergency or stressful conditions.

Professor Garry Scroop has been studying blood pressure in CFS patients and can't find anything wrong. It seems that under laboratory conditions the patient responses are different to what we get in our normal consulting rooms.

That is again one of the problems why people get either different results or cannot find anything wrong under these more organised conditions.



Sydney 2001 Conference

Summary by Rosamund Vallings MB BS

108 Ridge Road Howick,
Auckland, New Zealand
Phone/fax: 9 534 3346
E-mail: Vallings@xtra.co.nz

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

From 30/11/01 to 3/12/01, I was privileged to attend the Third International Clinical and Scientific Meeting in Sydney, Australia, convened by the Alison Hunter Memorial Foundation to discuss the Medical Practitioners' Challenge in making an informed and accurate diagnosis of Myalgic Encephalopathy/Chronic Fatigue Syndrome. This conference provided a bringing together of enthusiastic cutting-edge researchers and clinicians from around the world. The first day was spent in informal discussion among those presenting papers, and the following 2 days were filled with fascinating and diverse presentations.

The conference was opened by **Simon Molesworth**, QC, who gave us much food for thought regarding the limited funds available for CFS in Australia, the new clinical guidelines, which are still to be published, but are likely to have a psychological bias, and the need for us all to work together for the common cause of recognition worldwide of this complex illness by education and dedication.

Definition and Epidemiology

The first session was opened by **Anthony Komaroff** (Boston, Mass) who gave an overview of the Biology of Chronic Fatigue Syndrome. Of those people presenting with fatigue (such as accompanying depression, anaemia, hypothyroidism etc) about 2% have Chronic Fatigue Syndrome according to the CDC formal case definition. He described an illness of sudden onset of flu like symptoms in up to 90% of these patients. There are marked differences when comparing CFS with depression, as shown by results of neuro-endocrine studies, treatment studies and formal psychological assessment. There is a low prevalence of past history of psychiatric disorder in those with CFS. However, 50% those with CFS do develop psychological illness in the years after onset.

While there is no single laboratory test specific for CFS, there is a growing body of research reporting distinguishing findings, such as low level circulating immune complexes, elevated total complement, increased activated CD8 cells, elevated IgG, atypical lymphocytes, poorly functioning NK cells, low level ANA and abnormalities in the RNaseL pathway.

A number of abnormalities are found in brain and nervous system studies. Using neuro-imaging techniques, MRI has revealed punctate areas of abnormality in 78% cases, particularly in the subcortical areas. SPECTscans have shown defects in perfusion and metabolism. . However these tests are not diagnostic. However there are differences in cognition, not explained by co-existent psychological disorders, in particular there is abnormal cognitive processing and slowed reaction times. There is evidence of autonomic dysfunction, with sympathetic and parasympathetic neuropathy. 50% patients have signs of neurally-mediated hypotension or postural tachycardia syndromes. Most patients have sleep disorder with alpha intrusion into delta wave sleep. There is evidence of neuro-endocrine dysfunction as shown by changes in the HPA axis. Studies have demonstrated reduced CRH production with smaller adrenal glands and a decreased 24 hour urinary cortisol level. Prolactin and growth hormone levels may also be lower.

The effects on the brain are non-destructive and non-progressive, but cause marked dysfunction.

No one infectious agent has been shown to cause CFS. There is however evidence to suggest reactivation of several viral agents such as HHV6. Infectious mononucleosis, Q fever and Lyme disease are likely precursors of CFS. HHV6 affects most humans, with lifelong infection, but the evidence for reactivation in CFS is higher than in controls. This virus can affect neural cells and the CNS, leading to neural sequelae, encephalopathy in immuno-suppressed individuals, and there is good evidence for a strong association between HHV6 and MS.

Treatment of CFS with low-dose tricyclics has been shown to be efficacious in fibromyalgia, and they are widely used in CFS to improve the sleep disorder. Some improvement in health has been reported with CBT and graded exercise.

Professor Komaroff concluded that in view of the above evidence, CFS has an organic basis, and in many of the patients there are abnormalities of the limbic system in the brain and abnormal regulation of the immune system, which is possibly a result of limbic system abnormalities. A single cause seems unlikely, but multiple triggering agents (infections, toxins, stress) could be involved.

Pascale de Becker (Brussels, Belgium) compared the Holmes and Fukuda definitions used in the diagnosis of CFS, in relation to symptomatology, in European patients. The Holmes definition was more strongly associated with symptoms that differentiated CFS patients from those who did not comply with the CFS definitions. 10 extra symptoms were added and this improved the sensitivity, specificity and accuracy for selection of CFS patients. Those fulfilling the Fukuda criteria were less severely affected and this led to some clinical heterogeneity. A new definition therefore would strengthen the ability to select CFS patients, and the incorporation of a severity index would be beneficial for subcategorization.

Don Lewis, a GP (Melbourne, Vic) had devised a questionnaire sent out to patients prior to consultation at

his specialised CFS clinic. As well as giving the current clinical picture, and saving the doctor time, this also served as a baseline against which future responses to treatment could be assessed. Analysis of 400 patients revealed the most commonly presenting symptoms in order as being: sleep disturbance, fatigue, cognitive dysfunction, neurological symptoms, mood changes and gastro-intestinal problems. Sex, age and illness duration did not alter this incidence.

Prevalence, demography and natural history of paediatric CFS was discussed by **Nigel Speight** (Durham,UK). He considered this in his area in North England over a 10 year period. There had been an increase in incidence over the period studied, peaking in 1995. He had studied 49 patients with a range of age from 19 months to 16 years at onset. In 14% there was a first degree relative with CFS and a past history of migraine in 67%. 57% had a first degree relative with a history of migraine. 12% cases were described as mild, 39% as moderate and 49% as severe. Full recovery was seen in 15 cases (31%) of which 2 had been in the severe category, and 7 others (14%) had improved significantly. Average duration of illness in those recovered was 5.1 years. Of those still ill, 7 were still in the severe category (14%). School loss was considerable and was 1.8 years per child on average. He found that there was enormous unpredictable variation in these cases.

Gastrointestinal Function

Richard Burnet (Adelaide SA) had found that gastro-intestinal symptoms are particularly common in CFS patients, and he noted that they had never been properly assessed. A standard questionnaire with some additional CFS-related questions was given to all CFS-diagnosed patients. Patients were then eliminated from the study if they did not show intolerance to alcohol. 120 patients were suitable for analysis and 56 controls were obtained. 86% CFS and 56% controls had GI symptoms. Abnormalities of oesophagus stomach and bowel were discussed. Bloating and abdominal discomfort after meals was more prominent in CFS patients. Solid and liquid emptying studies were then performed. 91% of the CFS patients had problems of delayed gastric and oesophageal emptying, 89% in the liquid phase and 67% in the solid phase. The main abnormality was delay in the liquid phase, which suggests a central rather than peripheral causation for the gastric delay. Autonomic dysfunction as seen in diabetes tends to cause a delay in the solid phase. The delayed motility may well lead to bacterial overgrowth. The GI problems are unlikely to be due to toxins or mercury poisoning. To treat this condition, care should be taken to separate solids and liquids and nutrition should be looked at carefully. Small frequent solid meals were recommended with fluids given 20 minutes later. Maxolon or cisapride may have a place in treatment.

Bacterial colonosis (BC) was discussed by **Henry Butt** (Newcastle NSW). He had found that patients have multiple gut symptoms with absence of inflammation apparent in faecal samples. Pain and fatigue tended to be more severe in those with BC than without. He has shown a change in the distribution of gut flora in CFS. The E.Coli count was found to be significantly lower than in healthy subjects, and the lactic acid bacteria Enterococcus spp count was significantly higher. There was also marked decrease in Bifidobacterium in CFS. Changes in GI microbial ecology, particularly low E.coli, are significantly associated with fatigue. There are abundant metabolites from E Coli such as serine, alanine and indole. Tryptophan, a precursor of serotonin comes mainly from these metabolites, as well as some from the diet. Serotonin stimulates peristalsis. With the lowered pH associated with increased lactic acid bacteria, the anaerobes have increased proteolytic activity, and this correlates positively with neurocognitive symptoms. There is also deconjugation of bile acids, so fat emulsification is poor and this leads to fat malabsorption.

Cardiovascular Function and Exercise

Wilhelmina Behan (Glasgow, Scotland) presented an update on current research in CFS, which she described as characterised by myalgia and exercise intolerance with unknown pathogenetic mechanisms. Fatigue has central and peripheral components. Fatigue mechanisms are complex, but in disorders such as MS there is significant decrease in muscle phosphocreatine resynthesis after exercise. Patients suffering from MS, COPD and heart failure were studied as well as those with CFS. The muscle chemistry features associated with fatigue all seem to be the same. There is a general manifestation of problems within the muscles, such as changes in enzymes and muscle mass. She described a pathway for exercise from brain, to nerves, to muscle, to muscle metabolism, and from lungs, to circulation, to muscle metabolism. In CFS there seems to be abnormalities in all these processes. She described two kinds of muscle fibres: fast which are used for bursts of energy, and slow which are used for endurance. In

particular she noted that those with CFS had up to 20% less of the slow muscles fibres, which helps to explain why people tire so readily. Deconditioning is not a perpetuating factor in CFS, something else is happening. The muscle involvement includes: weakness, delayed recovery, decreased aerobic activity, mitochondrial abnormalities and metabolic abnormalities. Tests showed that patients are slightly weaker than controls, but they are doing their best. 24 hours after exercise, patients were all worse in strength, and the reduction was most severe after 24 hours. This is because the metabolites are slow at resynthesising. This means that graded exercise is unlikely to be of use. Patients have the metabolites but cannot use them properly, so supplements are unlikely to be of help either.

She discussed the issue of resting energy expenditure (REE). When awake, 30% of energy is devoted to maintaining ion gradients. The REE is elevated in CFS patients unable to exercise, and this may relate to cytokine abnormalities, autonomic dysfunction etc. In relation to cardiovascular involvement, the heart is slow to get going with exercise and remains at a low peak value. This maybe due to increased vagal tone or an intrinsic heart muscle effect. Autonomic function may play a role. CNS involvement has been shown in SPECT and MRI scans, and neuroendocrine studies show HPA axis abnormalities. Medical stress can affect the CNS providing a changed micro-environment in the brain and increased permeability of the blood-brain barrier. This can lead to changes in gene expression, which in turn affects production of neurotransmitters. All these events have an impact on the exercise pathway. The whole process is likely to have been precipitated by a severe insult to the body.

Charlie Sargent (Adelaide SA) presented a study showing that increases in plasma lactate concentration with exercise intensity were no different from controls. Results indicated that the production and clearance of lactic acid in CFS patients is normal, and does not contribute to their earlier fatigue and reduced power output shown in this study. Patients have normal physical fitness and there is no physiological basis for recommending graded exercise in the treatment of CFS.

The issue of effects of acute orthostatic stress on cardiovascular and cognitive function in CFS was addressed by **Adele McGrath** (Adelaide SA). This was a small study on 10 patients and 10 healthy sedentary controls. Blood volume and lean body mass fell within normal limits. It was concluded that postural hypotension did not occur in response to short orthostatic stress in these patients, and acute orthostatic stress did not impair cognitive function.

Infection and Immune Function

The diagnosis and treatment of multiple chronic bacterial and viral infections in CFS, FM and GWI were discussed by **Garth Nicolson** (Huntington Beach, California). These conditions are found to have overlapping symptoms, and a major cause of abnormalities maybe chronic viral or bacterial infections. The infection maybe causative, a co-factor or opportunistic. He is particularly interested in the intracellular bacteria and viruses. Detection is by forensic PCR and gene tracking. He has found that multiple Mycoplasma species are involved in 55% of his CFS/FM patients and the majority have more than one species. These bacteria are also present in other conditions such as GWI and in ALS, there is an 85% incidence. He has also detected reactivated HHV6 in 30% patients with or without Mycoplasma. Some patients were also positive for C.pneumoniae.

Patients with Mycoplasma and/or C.pneumoniae were treated with multiple 6 week cycles of antibiotics (doxycycline, ciprofloxacin, azithromycin or clarithromycin) plus nutritional support. HHV6 patients were treated with immune enhancement. Recovery was slow with 6 cycles being required to provide lasting improvement, at which time those recovered were no longer Mycoplasma positive.

He concludes that subsets of these illnesses have chronic infections, which with appropriate treatment may get a slow recovery. Multiple chemical/biological exposures, including vaccines may be implicated in onset.

Kenny de Meirleir (Brussels, Belgium) gave an overview of the possible immunological pathways that are disrupted in illnesses such as CFS. He presented data suggesting improper activation of 2-5OAS in monocytes in both CFS and chronic MS. (not however in relapsing/remitting MS) This results in inappropriate activation of RNaseL This process ultimately leads to blockade of RNaseL-mediated apoptosis. A complex series of biochemical/immunological events then follows. Resultant RNA fragments are then capable of either activating or down regulating PKR. A subsequent release of NO at high (CFS) rates or low (MS) rates by lymphocytes leads to effects on ion channel, NK cell function, COX2 activation and glutamine release by activated T cells in the brain. The Belgian results suggest that CFS and chronic MS are extremes of an array of dysfunctions in the 2-5A/RNaseL/PKR pathways.

Evidence of active HHV6 infection and its correlation with RNaseL (LMW) protein in CFS patients was presented by Dharam Ablashi (Washington, USA). His team had looked at HHV6 in plasma, CSF and white blood cells. The aim was to correlate HHV6 with presence of the 37KDa protein. The 35 CFS patients studied showed that 65% had active HHV6 infection with varying HHV6 IgM antibody and HHV6 infected PBMCs. In the CSF, 26.7% had HHV6 DNA. Nested PCR showed 34% patients had HHV6 in plasma, but using TaqMan PCR, 48.5% were shown positive in plasma, and 40% in CSF. This test was therefore more sensitive in this assay. HHV6 variant A was identified by TaqMan PCR in almost all positive patients. Variant A tends to be acquired in adult life, variant B in early childhood. Ratio of LMW to HMW(80KDa) protein was detected in 70% PMBC samples. Correlation with HHV6 was significant when the ratio was greater than 4. IgM antibody and PCR correlation was less significant.

Kenny de Meirleir and his group looked at the association between mycoplasmae and the 2-5A/

(Continued on page 29)

RNaseL pathway in CFS. The hypothesis was that there maybe a co-morbid physiopathological mechanism between Mycoplasma infection and the deregulation of the pathway. 182 mainly female patients, free of antibiotic treatment were enrolled. There was significant correlation. He showed that mycoplasmae are active in stimulating some components of the immune system. They can act as polyclonal T cell and B cell activators. Monocytes produce elastase, which can cleave 80kDa RNaseL thus causing deregulation of the antiviral pathway. It has been suggested that LMW RNaseL may reduce Th1 activity, which implicates susceptibility to infections and a suppressed ability to eliminate intracellular antigens.

Wilhelmina Behan then produced strong contradictory evidence that antiviral gene expression is not increased in CFS. 2 interferon-induced antiviral pathways (2-5A/RNaseL and PKR) have previously been shown to be activated in CFS. However, patients with documented viral illnesses were not included in these earlier studies for comparison. 22 CFS patients, 10 with severe gastroenteritis and 21 controls were studied. The mRNA expressions of 4 genes were evaluated in PBMCs using a standard RT-PCR technique. There was no evidence of any significant difference for any of the genes between those with CFS and healthy controls. Patients with infection however, had activation of both pathways: gene expression for PKR was increased by 9.6 compared to controls and that for the inhibitor RLI was higher by a factor of 17 compared to the 2 other groups.

Minor up-regulation in these pathways may persist for several months after a viral illness. Changes seen in CFS patients may therefore be persisting following an earlier infection. When a group of patients with acute infections is included, the changes in CFS are not significant. Antiviral activation cannot therefore be used to form the basis of a rational test for CFS.

Toxic Exposure

Mohamed Abou-Donia (N Carolina,USA) had looked at stress and combined exposure to low daily doses of pyridostigmine, DEET and permethrin in rats. He found that there was blood brain barrier (BBB) disruption and neurochemical and neuropathological alterations in the brain. The experiment simulated the daily exposure to these chemicals experienced by Gulf War veterans. Control groups were used. Animals subjected to stress alone or chemical treatment alone showed no changes in body weight, brain hexamethonium iodide uptake, brain acetylcholinesterase (AChE) or plasma cholinesterase, but exhibited a slight increase in BBB permeability. There was also a decrease in m2-muscarinic Ach receptor ligand binding. In these groups there was no or minimal neuronal cell death. However animals subjected to both chemicals and stress exhibited dramatic increase in BBB permeability, significant decrease in brain AChE activity, decreased m2-muscarinic Ach receptor ligand binding and significant neuronal death. Histological changes were also present in the liver, and were particularly severe when the combination was used. This work showed significant risk in using low doses of these combined chemicals associated with stress. Leakage through the BBB makes the organism vulnerable to entry by toxins, infection etc.

Objective evidence of brain impairment by chemical exposure was presented by **Kaye Kilburn** (S California, USA). He described 4 categories of responses relating to brain function: physiological (eg balance, reaction time, vision), psychological (eg problem solving, recall, memory), emotions, feelings, mood states (eg depression, anxiety) and symptoms (eg headache, sleep disturbance etc). 8 physiological and 11 psychological tests were described to assess brain function, and are usefully applied to those who have been chemically exposed. Illustrative examples were discussed, and computerised measuring tools were demonstrated.

Psychiatry

A psychiatrist who had had CFS, **Nicole Phillips** (Armadale, Vic) expressed concern at the way psychiatrists have approached this illness in the past, angering patients, annoying researchers and focussing on using the terms neurasthenia and somatization interchangeably with CFS. She defined these 2 terms, and pointed out how neurasthenia initially was considered a physical illness, but was coined as a psychological condition by the psychiatrists over time, and was then interchanged with somatization disorder when a psychological disorder presents with the patient attributing symptoms to a physical cause. . There has been a denial of biological abnormalities, with enormously negative implications for CFS patients. She felt strongly that psychiatrists need to better educate themselves about this complex organic illness.

Ellie Stein (Calgary, Canada) produced useful information to differentiate between CFS and psychiatric disorders such as depression and anxiety. All can present with fatigue and there is often clinical overlap. A co-morbid psychiatric disorder should only be considered if the psychiatric symptoms predated the onset of CFS, if the symptoms are generalised beyond health and quality of life issues affected by CFS or if the symptoms are so severe that they prevent a patient from participating in treatment. When treating anxiety and depression in CFS patients, sensitivity to medication must be remembered. SSRIs, treatment of sleep disorder and CBT may all be useful approaches to consider.

Pathophysiology / Symptomatoloty

Pathophysiological mechanisms and CFS were discussed by **Kenny de Meirleir** (Brussels, Belgium). He described this condition as having no single aetiologic agent, but there are a number of predisposing factors leading to abnormalities in the immune system. Viral reactivation and opportunistic

(Continued on page 30)

infections increase. Resultant ankyrin fragments from pathologically cleaved RNaseL interact with ABC transporters, which become dysfunctional, leading to many of the symptoms of CFS. This is described as an acquired channelopathy. 206 CFS patients were studied and 70% were found to be Mycoplasma positive, and these patients had significantly more cleavage fragments of RNaseL.

He also mentioned the Biljmer incident, when following this plane crash, 67% were found to be infected with Mycoplasma, and suffered CFS-like symptoms.

Rey Casse (Adelaide SA) used SPECTscans to study regional cerebral blood flow in CFS. He recommended that a triple headed camera be used for accuracy and reliability. 13 CFS patients' scans were compared with 11 people suffering from other conditions with normal scans. Visually, deficit in regional cerebral blood flow was found in the temporal areas in 7 patients, and equivocal in 3. Statistical Parametric Mapping was applied to show location and amplitude of significant focal deficits. Most deficits were found in the brainstem, temporal lobes, frontal lobe and anterior cingulate gyrus.

Autism and CFS were considered by **Robyn Cosford** (Mona Vale NSW) to be part of the same spectrum of disease, which also included ADHD, in light of her findings of similar neuro-immune and gastro-intestinal dysfunction. Similar trends in urinary amino-acid and organic acid output are typically seen in all these disorders. There are also some similarities in plasma lipid analysis and bacterial faecal studies. She found the children with autism are a more metabolically homogenous group than CFS patients, who typically fall into 5 symptom clusters correlating to metabolic findings. However the subgroup of CFS patients with neuro-cognitive and GI symptoms has similar patterns to autistics, and this could indicate commonality in aetiology. She mentioned the fact that many children with autism have had frequent infections, particularly otitis media prior to diagnosis.

Biochemical anomalies in those with CFS who have visual problems were discussed by **Gregg Robinson** (Newcastle NSW). It has been found that these patients do have biochemical abnormalities similar to those reported as suffering from a visual sub-type of dyslexia, known as Irlen Syndrome (IS). The same visual symptoms occur in both conditions: headaches, photophobia and concentration difficulties. A large percentage have visual processing problems, and there may be a genetic vulnerability. A number of abnormalities of fatty acid metabolism were described. The bacterial fatty acid C17:0 was found to be positively correlated with eye strain and may indicate the presence of a pathogen, and this anomaly was also found in those with CFS.

Greg Tooley (Burwood, Vic) discussed the possibility that disordered circadian time-keeping may contribute to the development and course of CFS. He described a commonality of symptomatology with jetlag and shift-work related syndromes. 3 studies were presented comparing circadian profiles of sleep activity, core temperature and melatonin secretion in CFS. CFS patients' sleep-activity cycles were significantly phase-delayed compared to controls, which led to sleep disturbance and effects on well-being. Circadian rhythms of sleep-wake, core temperature and melatonin secretion were less effectively synchronised in the CFS group. CFS appears to be associated with both internal and external circadian desynchrony.

Neil McGregor (Newcastle NSW) retrospectively reviewed available data to develop a model of disease processes in CFS. Using factor analysis, 4 symptom groups are recognised in CFS: General CFS, neurocognitive, musculo-skeletal and mood changes. The general symptoms are associated with reactivation of viruses, increased RNaseL fragmentation and infectious symptoms. This group are predominantly cytokine-inducing or pathogen associated events. The other groups represent the host's response or cytokine-mediated symptoms. Reactivation of different viruses is associated with symptom variation, while co-morbid infections increase patient morbidity. Pain is associated with increased metabolite excretion and cytokine mediation leads to release of metabolites from the tissues. As amino acids are lost, fatty acids increase and the patient becomes more reactive.

That food intolerance exists as a co-morbidity in CFS was addressed by **Tania Emms** (Newcastle NSW). Food intolerances are a non-immune mechanism with no increase in IgE. Food intolerance appears to be a significant factor in up to 30% CFS patients. A chemical to which an individual is intolerant needs to accumulate and reach a threshold before symptoms develop, so reactions maybe delayed over hours or days, and many symptoms may occur. Patients were studied using food elimination and food challenge. 90% reported positive outcome after elimination, with improvement in a number of symptoms. Bowel symptoms in particular decreased. Food intolerance therefore may be of aetiological significance in the development of IBS symptoms in CFS. She concluded that symptom management involving attention to food intolerances is under-utilised but maybe a useful approach.

Ruud Vermeulen (Amsterdam, Netherlands) had treated 150 CFS patients with oral L-carnitine 1gm bid for 6 months. 69% reported improvement in fatigue, pain and cognition. Several other studies followed and using higher doses was not as effective. However all groups showed significant improvement, and plasma free-carnitine levels correlated positively with improvement. Up to 52% patients relapsed at follow up after ceasing treatment. Carnitine is used by all cells in the body, and it was mentioned that particularly high amounts are found in sperm cells. Carnitine is needed for fatty acid and carbohydrate metabolism, and also protects vessel walls against hypoxia.

The use of Acclydine in CFS had been investigated by **Pascale de Becker** (Brussels, Belgium) Acclydine is a plant sourced alkaloid which has effects on protein structure and metabolism. In particular it leads to the activation of the pituitary to increase release of growth hormone. The GH axis has been shown to be disturbed in CFS, so this alkaloid could be of benefit in CFS. 90 patients were studied and the treatment protocol consisted of 4 weeks Acclydine 250mg qid followed by 4 weeks Acclydine 250mg bid. There was significant improvement in the treatment group with 54% symptom improvement and increased IGF-1. No major adverse events were noted and this could therefore be a safe and useful drug in CFS.

Sociological / Equity Issues

Neville Millen (Deakin, Vic) reviewed the sociological implications of having CFS. The 5 decades of political tensions between ME/CFS sufferers, medical science and State, have created enormous problems and stigma. He argued that the medical profession needs to look beyond set boundaries of its present evidence-based paradigm of care, and adopt a more humane, holistic model of clinical practice for these patients. The government needs to be encouraged to fund research, provide better access to welfare payments and sickness benefits and show more respect for the rights of those with CFS.

Dorothy Morris discussed issues from an educational viewpoint particularly addressing the implications of cognitive dysfunction. She has researched the opportunities afforded those with cognitive dysfunction as part of their CFS in light of their difficulties at tertiary institutions around Australia. The research revealed that no attention had been given to helping those with this condition. There is however some accommodation for fatigue at a tertiary level. It seems that there is a lack of trained personnel in tertiary education who could make assessments and decisions on behalf of those with CFS.

Medico-Legal Implications

Over the last 10 years in the UK, **Nigel Speight** (Durham, UK) has been involved in 14 cases of ME/ CFS in children in which the families have been subjected to Child Abuse proceedings. He feels this is just the tip of the iceberg, as many other families have been threatened. In 13 of the cases the proceedings were reversed, but one boy was kept in psychiatric care for 7 months. Risk factors were noted where parents were more at risk of being accused of neglect, such as single parenthood, failure of child to respond to 'rehabilitation' and confrontational parents. As a result of these actions many of the children lost faith in professionals or even the parents for failing to protect them, and these children had often developed virtual post-traumatic stress disorder.

A father of a severely ill daughter with CFS presented a poignant account of his family's nightmare experiences. Their daughter was subjected to humiliation and intimidation when she did not respond to 'rehabilitation' alongside patients suffering from anorexia. It was suggested she was not suffering a 'real' illness and she was too sick to speak up for herself. When the parents tried to act on her behalf they were accused of interference. The parents were threatened with action from child welfare agencies, and it was suggested that these caring and well-informed parents were not suitable to be looking after their own daughter. They felt they had been grossly abused by the medical profession.

Simon Molesworth,QC (Hampton,Vic) has found that across the world, many ME/CFS patients report unsatisfactory treatment. Serious social, ethical and legal issues were raised. There is now much credible evidence pointing to biophysical and neurological explanations for CFS, and treatment now needs to be shifted away from psychiatry. Doctors need to accept the reality of the physical nature of the illness, chart the case history carefully and determine suitable treatment options. Monitoring and being alert to the stages of the illness all go toward informed decision making, the sharing of responsibilities and liabilities. Patient and medical practitioner need to form a partnership thus sharing the path to recovery.

Clinical Cases / Management

Robyn Cosford (Mona Vale NSW) presented 2 case histories. All patients were assessed routinely and in addition had tests for urinary organic acids, faecal analyses and intestinal permeability testing. Each patient showed abnormalities on these parameters. There was evidence for fibrillar and non-fibrillar catabolism, dysfunction of the TCA cycle, abnormal gut bacteria and increased intestinal permeability. Management was based on lifestyle change, counselling, meditation, graded exercise and dietary manipulation. Wheat, dairy foods, additives and foods to which the individual reacted were removed. Supplements were added where appropriate according to test results, and included vitamins and minerals such as B6, magnesium and essential fatty acids. Some ÒnaturalÓ and prescribed antibiotics were used. There were measurable improvements over 1-5 years.

Richard Schloeffel (Gordon NSW) also presented 2 cases. The first was diagnosed as suffering from CFS and found to be PCR positive for Ch.pneumoniae with positive IgG and IgA antibodies. She was treated with a combination of doxycycline, Nilstat, probiotics, minerals and vitamins for 2 years. She recovered completely and is living a normal life. The second patient had a more complex history with many symptoms, but fitted the CDC definition for CFS. He was suffering diarrhoea up to 40 times daily. He was found to be PCR positive to Mycoplasma fermentens. He was treated similarly, with the addition of tertroxin and thyroxine, as he was hypothyroid after an earlier thyroidectomy. He had persistently low E.coli counts and received 13 donor faecal bacterial infusions per rectum. After 40 years, he is now symptom free with normal bowel function.

The issue of reduced cerebral blood flow was further addressed by **Richard Burnet** (Adelaide, SA). 16 CFS patients were treated with a combination of Hydralazine 25mg 2-4 times daily (starting at _ tablet daily and increasing very slowly), extra salt, 3 litres daily fluid, and supplementation with potassium and magnesium. 10 patients did very well, 3 had no response and 3 stopped treatment because of side effects.

Dan Peterson (USA) discussed immune modulating therapies. He described the immunological model for doing this. Ampligen normalises the abnormal pathways. It is a very safe drug, there appear to be no major side effects and no deaths. It is now in phase 3 in a double-blind trial on 320 patients, and is in fact the only drug for CFS in phase 3. A small phase 3 open label trial is also in progress for 40 very severe patients. He also mentioned several other approaches to treatment which have been tried, including antiviral

agents for those who are HHV6 positive. Oral therapy seems ineffective, but IV treatment has proved very helpful. Transfer factor has also shown some benefit in HHV6 patients, and is available at pharmacies in the US. Modafinil, a stimulant has shown marked improvement in fatigue in MS and fibromyalgia.

Group therapy was suggested by **Rosamund Vallings** (Auckland NZ) as a cost and time effective approach as part of the management of CFS. Some of the difficulties experienced in running such sessions was discussed, and suitable programmes suggested. In NZ these sessions are fully government funded for CFS as long as they have an educational component. Patients have been enthusiastic about this approach and have thus gained coping skills and insight into their illness.

Kenny de Meirleir (Brussels,Belgium) summarised his management approach. He aims to restore immune competence, eliminate or decrease the load of micro-organisms and restore hormonal balance. He is using ampligen on 160 patients, uses antibiotics and occasionally Isoprinosine.

Poster Presentations

10 posters were presented some covering the research presented orally in more detail.

1. Wilhelmina Behan (Glasgow, Scotland) showed preliminary evidence that there is cardiovascular impairment during dynamic exercise in CFS, as judged by the cardiac output response to moderate exercise.

2. Pascale de Becker (Brussels, Belgium) had a poster outlining her department's experience of the aetiology of CFS. Upper respiratory infections do seem to be the most common infections preceding illness in her study. A number of different stressors and consequent immunological and neuro-endocrinological changes can contribute to the onset of CFS.

3. Pascale de Becker had a further poster providing evidence for a channelopathy in a subset of CFS patients, probably induced by the deregulated RNaseL antiviral pathway.

4. She had another poster showing the prevalence of Mycoplasma in Belgian CFS patients. This organism was found in 68.7% of a group of 272 patients. M.hominis was the most frequently observed followed by M. pneumoniae, and 17.3% had multiple infections.

5. Supplementation with serine was shown to have potential for symptom management in CFS by Tania Emms (Newcastle NSW). She indicated that a double-blind placebo controlled trial was warranted after there was significant reduction in symptom expression in 28 patients after 3 months, using 1.3gm L-serine daily.

6. Ann Harvey (Wellington NZ) had done a meta-analysis looking at cortisol levels in CFS patients. She found that patients seen in tertiary care show more endocrine abnormalities and clinical methodologies seem important in assessment procedures.

7. A suspected new chronic roundworm parasite was described by Lawrence Klapow (California,USA). He estimated that in sputum of 63% of the 30 CFS patients studied the worm (cryptostrongylus pulmoni) was identified.

8. C.H.Little (Mt Waverley, Vic) has identified a separate class of immune products (T cell antigen binding molecules) which maybe the basis for the adverse reactions to foods experienced by some CFS patients.

9. A poster presentation by P Clifton Bligh et al (NSW) concluded that the fall in urinary succinic acid seen in CFS patients was associated with deregulation of energy availability and protein synthesis suggestive of a cytokine mediated nitric oxide mediated change in chemistry. These changes relate to the expression of fatigue.

10. W.Tarello (Perugia,Italy), a veterinary surgeon, presented evidence of CFS in a horse from the USA, examined in Dubai. The horse was treated with IV potassium arsenite and made a good recovery.

Summation

The conference was finally summed up by **Peter del Fante** (Adelaide SA). He confirmed that CFS is a legitimate illness although the diagnostic criteria do need refreshing. In particular we must recognise that these patients are not ÒdeconditionedÓ. He presented the GP perspective in saying that one needs to make a positive diagnosis, provide good patient education and supportive therapy should be offered. The doctor should retain ethical boundaries, be a patient-advocate and work with the researchers. Keeping national patient registers and making CFS a notifiable disease are issues to be considered in the future.

Richard Burnet's final words echoed the consensus of the conference that the brain, limbic systems and gut are implicated in CFS with the causation being usually infection plus a predisposition and various trigger factors.

Tim Roberts (Newcastle NSW) stressed the importance of our being ever watchful for new organisms such as strains of Borrelia and Ehlichia not seen before in Australia, which may be implicated in CFS. He thanked Christine Hunter and Ellie Stein for their tremendous energy and enthusiasm which had made this conference possible.

Rest, Pacing and Graded Exercise

Thanks to Action For ME group for the following position paper. Reprinted from www.afme.org.uk

After a thorough period of consultation Action for ME has redefined its statements on the benefits of rest, pacing and graded exercise.

Is rest important?

Action for ME and the ME Association commissioned an independent researcher to survey their members. The survey, to which nearly 350 responded, found that 78% had found complete rest helpful.

What do we mean by rest?

It is unrealistic to try and do what you did before your illness. People need to give themselves permission to be ill, taking time to rest and relax.

Different people find different ways of relaxing. What seems to help one person, another finds stressful. For one, total peace and quiet works best, but for another listening to music, or the radio can be restful. We suggest that you experiment, finding what you find most refreshing.

You should not only plan to rest physically. Rest from mental activity and emotional stress is also very important, particularly in the early days.

Should I go to bed to rest?

Preferably not. Sleep is so important, and bed is better saved for the night time.

Try if you can to find somewhere where you can stretch out and relax other than your bed. Of course this may not be possible, in which case it is better to go to bed than not to rest.

Some people are so badly affected that they have to go to bed. Everyone varies.

Can you rest too much?

Yes. Excessive rest can be harmful.

After any illness your muscles have not been used as much as they are used to and may have become deconditioned (a mild example is of a healthy person taking up cycling after a long break, who will painfully re-discover long forgotten muscles!).

Excessive rest can reduce muscle tone and power and heart and lung function.

People with ME are particularly vulnerable because fatigue and muscle pain are features of the illness. Anxiety and fear about the consequences of exercise can make some over-inclined to rest, making deconditioning more extreme.

We suggest that while rest will remain important throughout the period of recovery, complete rest should be viewed as more frequent during the early period of the illness, with the need for rest periods becoming less frequent as and when you are able to build up your activity levels.

What should I do if I am so ill that I have to go to bed?

If you can, try to get up each day, maybe just to go to the bathroom. Or try to spend some time sitting in a chair.

At the very least try to move your joints regularly. Even this minimum exercise is better than nothing.

What is pacing?

Among those surveyed, nearly 90% reported that pacing had helped them.

The effects of ME generally fluctuate, with days when people feel as though they have some energy. It is good to take advantage of those days to do some of the normal things you used to do before you were ill, but be sure to keep some energy in reserve until you have established your baselines and limitations.

However it is tempting to overdo things on good days, which can lead to a relapse. The effects may be delayed for 24 or 48 hours or even longer! This is sometimes described as 'boom and bust'.

Pacing is about discovering your limitations and learning what degree of activity your body will tolerate without causing a relapse, while taking a positive attitude to your recovery.

We suggest that you keep a diary or a chart, recording how much you have done and how you feel on each day. Remember to record all your activities, not just the physical. This can help to establish a 'baseline' from which you can experiment as you gradually take on more and more activities.

It is impossible to give precise guidance about how much you should do or how long your recovery will take. Every person is different, which is why pacing is a personal programme that each individual develops to establish how much they can do.

But do not be disappointed if it takes time. Overdoing it in a rush to get better may well set your recovery back - and remember that most people significantly improve over time.

Graded exercise - what is it and how can it help?

Graded exercise in its best form is a sensitively applied programme, agreed between the doctor or therapist and the patient. It is sometimes recommended alongside cognitive behavioural therapy (CBT) which can help some people to better manage the consequences of their illness.

Successful programmes do not start by forcing people into exercises beyond their means, but establish a baseline - likely to be different for each person - and start gently. They also stop when patients need a break from the programme because they have reached a limit, and then continue after an agreed pause.

(Continued on page 34)

The best practitioners do not just focus on physical rehabilitation, but take a broader approach to activity. So, stimulating the mind (within sensible limits and with pauses) could also be recorded as a form of graded exercise. For this reason we prefer to talk about 'graded activity'.

In the members' survey we found that nearly 40% of those who tried graded exercise had found it helpful.

Why doesn't graded exercise help everyone?

Our survey found that an equal number of those who tried it felt that it had made them worse. Sadly there is no approach that helps everyone; all approaches seem to help some people but not others.

Some suggest that there are sub-groups within ME and that people's chances of graded exercise working depend on which group they belong to. More research is needed.

Graded exercise has proved harmful for some, we believe, because some practitioners have not recognised the physical limitations of ME and have placed too much emphasis on deconditioning that results from fear and anxiety. Although well-intentioned, they are wrong to push their patients toward a recovery without listening to them and their reactions to the exercise, nor allowing for pauses in the recovery process.

In our experience it is incredibly rare for someone not to want to get better, and our members report more problems from pushing themselves beyond their limits and then 'crashing', than from trying to do too little.

For these reasons, while recognising that graded exercise can be of benefit, we believe it can cause harm if misapplied. We want all practitioners to adopt the best practice, listening to their patients and modifying their recommended activities to the capacity of the individual.

In summary:

* Both rest and activity/exercise are important
* After a period of rest in the initial stages, you should introduce as much activity/exercise into your life as you can within the limits imposed by their illness i.e. without bringing on a relapse
* Graded activity/exercise should not be seen as a treatment for ME but as a form of illness management, helping nearly half who try it to improve significantly, although it is not tolerated by all patients
* We advise against embarking upon a graded exercise programme where the increases in activity are imposed, and are continued with no regard to the patient's reactions

We suggest that you should:

* Rest in the early stages of their illness, but avoid complete bed rest unless absolutely necessary
* Cautiously experiment to determine the level of activity (physical and mental) you can manage without causing a relapse
* Keep within those limits until several days have passed, then if still feeling better gradually increase them
* Keep a diary of your symptoms to see how they fluctuate in relation to your activity levels. This should help you to work out how much you can do without 'payback'
* Do not be deterred by feelings of healthy tiredness (without nausea or prolonged pain) which after unaccustomed activity/exercise are normal and positively beneficial, and should not deter you from moving your activity/exercise to the next level
* You should however stop if you experience feelings described by some as 'flu-like', or if prolonged pain recurs i.e. a flare up of your ME symptoms rather than healthy tiredness
* When you feel that these feelings are well past, start your activities again at a level you can cope with and gradually build up

Members' Tips

Set yourself a programme of rest and activity periods throughout the day. Try and stick to this.

Remember that mental activities like studying or reading can be just as tiring as physical ones.

Try to find somewhere where you can rest other than your bedroom, saving your bed for night-time sleep.

When your energy levels are good, take advantage of this to get back to 'normal' but do not push yourself beyond your limits.

Experiment to find what you find most restful. Is it perhaps listening to music or sitting in total peace and quiet?

Plan to alternate your activities between those that are physically tiring and those that are mentally or emotionally tiring e.g. do the washing up, then have a quiet read, go for a short walk, then watch TV.

Avoid overloading your brain by doing two things at once e.g. studying with the television playing in the background.

Learn to say no.

Prioritise and be realistic. Plan your week ahead as well as each day, making a note of what you want to achieve, and then cross off the less important tasks if these are beyond you.

When you have something to do that is really tiring e.g. going to an outpatient appointment, plan extra rest periods before and after.

Types of physical and mental activities and exercise sufferers have found useful are:

* Short walks (with a stick if needed)
* Hydrotherapy in a warm pool (swimming later)
* Breathing exercises and meditation
* Gentle yoga or stretching

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MULTIPLE CHEMICAL SENSITIVITY - TOXICANT INDUCED LOSS OF TOLERANCE (TILT)

By John Pollak

Thank you for asking me to present a talk on MCS. In my talk I shall discuss the connection between detoxifying enzymes, the CytochromeP450 enzymes, and MCS. I think this is appropriate for me to do, since while I was involved for more than 30 years in the education of medical students, my background is not in medicine but rather in biochemistry. I shall also emphasize the effects that the vast increases of the products of the chemical industry have on the ecology and therefore also on human health in general and MCS in particular.

I am not alone in taking such an approach, as it has been suggested by the Agency for Toxic Substances & Disease Registry, the US EPA, NIOSH, the Center for Disease Control & Prevention and the Institute of Medicine, that "..by integrating environmental medicine into medical education to-day more physicians will be better prepared and able to understand, diagnose and care for people who are exposed to potentially harmful environmental agents." It is not surprising that the problem of chemical intolerance has increased dramatically during the 2nd half of the 20th century and is likely to continue to grow. This is due to the fact that the mass of chemical products has increased exponentially.

The workplace as well as our housing and the ecosphere and therefore also the food we eat, the water we drink and the air we breathe are all part of the environment we live in.

The cause of MCS is considered to be due to a significant exposure to one or more chemicals in the environment, which initiate the sensitization. It is now generally recognized, that this induced sensitivity may become apparent only after an interval of time has elapsed, when subsequent exposures to even quite unrelated chemicals at very low doses (of the order of 1/100 to 1/1000 the dose considered by regulatory authorities to be safe) may produce the symptoms of MCS. Hence a single high level or repeated lower-level exposures to chemicals may cause susceptible people to lose their natural tolerance to various chemicals, foods and drugs. Subsequently ultra-low levels of previously tolerated chemicals may trigger symptoms, thus causing MCS. In some recent work Ashford & Miller (1998) have proposed that because of the two-step process, MCS should be called TOXICANT INDUCED LOSS OF TOLERANCE (TILT). In this context it is relevant to point out that already30 years ago animal studies have shown that low-level chemical exposures may cause sensitization of the brain, while subsequent stress may cause cross-sensitization to unrelated chemicals. This phenomenon is known as **Time Dependent Sensitization (TDS)** (Antelman,1994). As will be pointed out subsequently the function or mal-function of the detoxifying enzymes, the cytochromes P450 (CytoP450) play an important role in this process.

Since the genetic constitution of different people, as well as their life styles may differ significantly it is not surprising that different individuals will exhibit quite different symptoms as a result of exposures to the vast number of chemicals which are nowadays present in the environment . This may be particularly due to the CytoP450 genes, which play such an important role in detoxification. In humans there are 49 genes and 15 pseudo-genes for CytoP450 enzymes. These enzymes are classified according to their amino acid composition and divided into families and sub-families. Most of these CytoP450 enzymes will act on a number of different substrates. However the CytoP450 enzymes are involved not only in the oxidative metabolism of drugs and other xenobiotic chemicals, but they also metabolise endogenous molecules, such as steroids, prostaglandins and biogenic amines. What is more, several xenobiotic compounds will also inhibit some of the CytoP450 enzymes**.**

The name of the detoxifying enzymes, CytoP450, is based on the fact that they are present within cells (hence cyto), they are coloured (hence chrome), P also indicates their pigmentation, and when complexed with CO and they are reduced, they absorb light at 450nm (hence 450). Being enzymes they are naturally proteins. CytoP450 enzymes posses a heme group which is chemically similar to that of hemoglobin of red blood cells.

It is therefore of significance that it has been reported that at least 70% of MCS patients have porphyria disorders, hence limiting heme synthesis (Ziem & McTamney). This obviously would also cause a decrease in the production of CytoP450 enzymes, therefore MCS patients would be less efficient in the detoxification of xenobiotics.

Porphyria also causes liver and bone damage as well as causing other symptoms in common with MCS, such as sensitivity to any estrogen mimicking chemical (Ziem & McTamney, 1997). The estrogen connection may be one of the reasons that females (human and animals) are more susceptible to metabolic disorders, such as MCS and TDS. It is also of interest that it has been shown that chemically sensitive patients with different initiating exposures may have different patterns of porphyrin disturbances (Ziem & McTamney, 1997). Thus MCS patients may have abnormal activities in one or more of the 8 enzymes involved in heme production. It is of interest that in animal experiments it has been shown that heavy metals, petrochemicals and chlorinated benzenes also cause specific patterns of porphyria in rats (Ziem & McTamney, 1997). Thus providing a biochemical explanation for TDS.

CytoP450 enzymes originally evolved as a detoxification system, however under certain circumstances they may also enhance the toxicity of many compounds. There appears to be an association between the impaired detoxification enzymes and diseases, such as cancer, Parkinson's disease, fibromyalgia, CFS and MCS (McFadden, 1996).

(Continued on page 36)

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

(Continued from page 35)

Since it is considered that between 30-200 genes may be involved in coding and regulating the synthesis of different P450 enzymes (Nebert & Gonzales, 1985), it is inevitable that there will be differences in the detoxification mechanism of different individuals. In addition cytoP450 enzymes are inducible, i.e. the presence of a particular xenobiotic will activate a gene to initiate the synthesis of a particular cytoP450. In most cases the chemical which causes the induction of a particular cytoP450 also acts as a substrate for that enzyme, however in some instances a single chemical can increase the concentration and activity of 7 different cytoP450 enzymes, while the level of another cytoP450 is actually decreased (Guengerich & Liebler, 1985). Once cytoP450 is induced and synthesized, its substrate specificity is broad, catalysing the oxidation of a number of different compounds. Therefore it is difficult to predict the outcome of an exposure to a mixture of chemicals, particularly as the increase in enzyme activity may vary between 2-100 times (Guengerich & Liebler, 1985).

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

Prolonged or massive exposures to one or more xenobiotics may excessively stimulate or over-utilize the CytoP450 enzymes so that they may be depleted or even suppressed, causing Chemical Sensitivity (Rae, 1992). Sometimes auto-antibodies against CytoP450 enzymes may also be produced causing their activity to be suppressed or inhibited (Kamataki et al., 1976).

The detoxification process serves to make lipophillic (fat soluble) xenobiotics more water soluble so that they can be excreted in the urine. That process consists of 3 distinct phases. CytoP450enzymes are involved in Phase I : Phase I involves the oxidation or hydroxylation of lipophillic (fat-soluble) compounds. Phase II is catalyzed by enzymes such as glutathione transferase, which catalyzes the conjugation of glutathione with the hydroxylated compound formed in Phase I. Phase III involves the transfer of the conjugate to the kidneys for subsequent excretion.

In many instances the Phase I reaction actually "bioactivates" a relatively non-toxic substrate (e.g. benzo-*a*-pyrene) to produce a much more toxic compound (such as e.g. 7,8-dihydroxy 9,10 epoxy benzo-*a*-pyrene, which is a well-known carcinogen). If for some reason Phase II reaction is slower, then the potentially toxic Reactive Oxygen species, formed by the Phase I enzymes, may give rise to Free Radicals may cause toxic effects (McFadden, 1996)

Since CytoP450 enzymes act on a broad range of substrates, any particular CytoP450 induced by one chemical also has the potential of converting a number of other chemicals into their toxic (hydroxide, peroxide, epoxide) forms. Hence in a mixture, the presence of a relatively non-toxic chemical, which is however a powerful inducer, can bring about the bio-activation of other chemicals, which may be generators of free radicals and therefore the overall toxicity of the mixture is increased.

It is well known that patients suffering from MCS experience a variety of symptoms, such as headaches, dizziness, memory difficulties, nausea, vomiting, diarrhea, joint & muscle pain, sinus problems, asthma, rashes, extreme fatigue, anxiety, cognitive problems, dizziness, mood swings, depression, seizures and irregular heart beats, shortness of breath, irritability, difficulty in focussing eyes and more.

These multi-system health problems tend to confuse the medical profession:

- A rheumatologist observing diffuse muscle pain would concentrate on the diagnosis of myalgia.
- While a neurologist hearing about head pain and nausea would diagnose migrane headaches.
- A pulmonologist would be mainly concerned about asthma,
- While a gastroenterologist noting vomiting and diarrhea would possibly consider the problem as irritable bowel syndrome.
- A psychiatrist would be mainly concerned about mood swings and similar symptoms and may diagnose depression or other psychogenic disorders.
- An allergist may consider that the meaning of the word sensitivity refers particularly to classical IgE mediated allergy.

In MCS IgM and IgG antibodies are involved, while IgE antibodies are not involved, therefore tests for IgE antibodies would turn out to be negative. Hence allergists tend to ascribe the symptoms of MCS sufferers as psychogenic and therefore having a psychological and not a physiological basis. Thus many of the traditional allergists and also toxicologists do not appreciate or accept the two-step process of induction and triggering which characterizes MCS.

On the other hand it was shown that (**POSITRON EMMISION TOMOGRAPHY** (PET) and **SINGLE PHOTON EMMISSION COMPUTED TOMOGRAPHY** (SPECT) brain scans demonstrated debilitating symptoms in MCS patients. These scans showed that blood flow, glucose and oxygen consumption decreased dramatically in particular areas of the brain, the frontal, temporal and parietal lobes, of chemically sensitive patients. These scans closely resembled those of patients with brain damage from toxic chemicals, while differing from those with psychiatric illnesses (Waterhouse, 1999). Hence SPECT brain scans indicate that chemical sensitivity is a physiological and not a psychological disorder.

The chemicals which may cause MCS include compounds present in pesticide formulations, cleaning products, detergents, new carpets, gasoline, building materials, paints, varnishes, adhesives, formaldehyde in new clothes, newsprint, inks, chlorine, air fresheners, perfumes, cosmetics, medications and also some food.

Obviously avoiding exposure to chemicals which may trigger MCS is essential and will permit improvement, yet the large number of chemicals which are encountered in daily life makes this very difficult. Thus it was shown that the induction of MCS or TILT occurred when the US EPA in 1987 installed 27,000 square yards of new carpets, as well as painting their office in Washington D.C.. As a result some 200 employees of the EPA developed sick building syndrome, which is regarded to be a form of MCS (Ashford & Miller, 1998).

The concentration of pollutants is often found to be significantly greater in indoor air samples than in outdoor air samples. This was demonstrated by a

(Continued on page 37)

A closer look at Cognitive Behaviour Therapy

by Stephanie C. Jones

Outside research circles, there has been much debate about the merits of CBT for the sufferers 'on the ground'. The aim in this article is to describe, in a non-scientific way, standard CBT I use to help people with CFS in a routine hospital clinic.

A multi-factorial approach

In order to understand CFS we need to take a multi-factorial approach known as the biopsychosocial model. This model recognises that there are multiple symptoms associated with CFS. Many symptoms are physical, some are psychological and some are social. For example, when you have CFS you are physically unwell (biological**)**; you may feel less like your normal self and more unhappy (psychological); and you may feel like doing less, for example cancelling a date you had with a friend (social). The biological, psychological and social problems CBT aims to address are the result of having had CFS for some time, usually years. These biopsychosocial problems are usually not there at the onset of CFS and do not generally cause CFS. So to improve the overall quality of your life we need to assess all these aspects of your illness, not just the physical symptoms.

Dealing With Stress

When not engaged in normal activities, many people experience changes in their mood (a bit like what happens when unemployed or made redundant). In addition to this, with CFS you have to deal with unpleasant and disabling physical symptoms as well. Sometimes this leads to thoughts such as "I will never be normal again", "Life is hopeless". Often these thoughts lead to more behaviour changes; perhaps you go out even less because your self-esteem is low or not see your friends so much because you have nothing to talk about.

Biological, psychological and social problems interact

(Continued from page 36)

comparison of two gas liquid chromatograms of equal volume air samples that were taken indoors and outdoors near a complaint office building. It is therefore not surprising that the National Academy of Science estimated that INDOOR AIR QUALITY contributes $15-100 billion annually to health costs in the USA.

It is also of interest to point out that a recent study in the Seattle Metropolitan Area provided an indication of the general exposure to organophosphate pesticides (Lu et al. 2001). Urine samples were analysed from 110 children, aged 2-5, from 96 households in the spring and fall in 1998. The analyses were carried out for 6 common metabolites of organophosphates . One metabolite was measured in 99% of all the children and two others in 70-75% of the children. Thus obviously exposure to xenobiotics is unavoidable in the present environment.

It is of interest to point out that just like the tobacco companies who for many years denied the toxicity of tobacco, the members of the chemical industry are now casting doubt that products of the chemical industry may cause MCS or TILT.

On the other hand Germany has listed MCS as a recognized disease in its edition of the WHO International Classification of Diseases and 104 USA and Canadian government agencies recognize MCS as an illness or disability.

In summary it can be stated that evidence is accumulating that exposure levels of chemicals that were thought to be safe, or had negligible risks, have now been shown to be harmful. Thus it has been established that low-level exposures, apart from causing adverse effects such as endocrine disruption and cancer, may also cause MCS (Ashford & Miller, 1998).

> "New theory first is attacked as absurd; then it is admitted to be true, but obvious and insignificant; finally it is seen to be so important that the adversaries claim that they themselves observed it."
>
> *William James*

The general acceptance of MCS will occur eventually ------ unfortunately it often takes time for new ideas to be accepted:

"New theory first is attacked as absurd; then it is admitted to be true, but obvious and insignificant; finally it is seen to be so important that the adversaries claim that they themselves observed it." William James

Further research is still required to develop a better understanding of all the mechanisms involved.

Furthermore, social policy responses should be directed towards those whose health is already affected due to chemical exposures, as well as ensuring that the production of sensitizing chemicals is outlawed or at least limited in future.

This will require significant changes to be made to the manner in which the products of the chemical industry are regulated. It will also require that the chemical industry will have to strengthen its approach to their RESPONSIBLE CARE POLICY.

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

with one another and accumulate to a point of high stress. The demands they put on us outweigh our ability to cope. These demands may come from 'outside' (family, money, work or study) or 'inside'(symptoms of pain, tiredness or low self-esteem). Being human, we cannot avoid stress, but we can learn how best to manage it. If you have a chronic fatigue problem, it is particularly important to manage your stress effectively - otherwise stress can make your symptoms worse.

Thoughts, Feelings and Behaviours

When we are under stress, stress hormones are released and these activate the 'autonomic nervous system'. This then causes certain bodily changes, which individuals experience differently. Changes may include; alterations in breathing, palpitations; excessive sweating; your stomach may feel "knotted"; your muscles may tense; you may feel dizzy or light-headed. When the body is reacting like this and we are frightened, puzzled or irritated, we may deal with it by changing our usual behaviours. This might be to increase the amount we drink, eat too much, do less exercise, sleep more or be less sociable.

Thinking Styles

Catastrophising happens when we face a difficulty and tell ourselves that the probable outcome will be disastrous.
"If I go to that party I will be laid up for at least a month"

All or nothing thinking takes a black or white view of the world**.**
"Unless I am fit and healthy there is no point to life" .

Ignoring the positive is when we tend to overlook all the times in the past when we have coped successfully.
"I might be able to leave the house now but I still have no future"

Over-generalising happens when we translate one negative experience into a general rule of life.
"This tingling in my arms must mean I've got heart disease"

Personalising is when we see ourselves as solely responsible for an external event, which in fact we may have little or no responsibility for.
"If I hadn't have felt unwell perhaps everyone would have enjoyed the picnic much more"

Should's & ought's are those words which sound like 'rules' we have to stick to but when we look more closely at them there is no rule.
"I should do all the ironing today"

Jumping to conclusions is making an interpretation despite not being in full possession of the facts.
"Everyone on the bus thought I was lazy when I asked for a seat"

Turning around unhelpful thinking

Changing thoughts and feelings when under stress may reduce stress and in turn prevent exacerbation of symptoms.

For example; if you are lying in bed at night and hear the sound of broken glass outside the back door you may think "someone is trying to break in the back door". This thought may make your heart beat faster, you palms sweat, you might hold your breath and feel very fearful. However, if the automatic thought is "Oh, silly cat, it's jumped on the milk bottles again", your body will not undergo the same physiological changes it did when you thought it was a burglar.
Certain types of negative automatic thoughts are particularly common. It may help you to monitor your thoughts to see which of these styles are characteristic of your thinking. You may find you have a habit of thinking in one of these particular ways.

Once you have identified a negative automatic thought, the next step is to challenge it. This can be done by asking yourself one of a number of questions (see Box 2) specifically in relation to that thought. For example. you may think "Life is going to go on forever like this", so you need to ask yourself *What evidence do I have that this will happen?*

Challenges to automatic thoughts

What evidence do I have?
Is this an accurate thought?

(Continued on page 39)

Challenges to automatic thoughts

Person A: "Life is going to go on like this forever so what future do I have?"
Therapist: "What makes you say that, what evidence do you have to say that?"
A: "I don't know anyone who has got better from CFS"
T: "You may not know anyone but is it true that no one has ever got better?"
A: "Well I've never met anyone who is better at my ME group"
T: "What about those people who don't come anymore?"
A: "Humm, well yes Jane doesn't come anymore because she is getting on alright"
T: "So if you examine that belief more closely you realise that perhaps some people do get better. So how could you rephrase your first thought?"
A: "Sometimes it *feels* like I'll never get better and I have no future but actually life can and does improve for some people"
T: "How do you feel now?"
A: "Less desperate than I did when I said I had no future"

Awareness Week

The Management Committee is hard at working planning a big Awareness Week. For those who aren't familiar with this: the Awareness Week is held around May 12 which is International ME/CFS/Fibromyalgia Day. You can mark May 13th down in your diaries for now. We're planning a public meeting for the evening. [Details not finalised at time of publication.]

This will be followed by the Badge Day on May 31st. (Badge Day is where we stand on street corners collecting money in tins.)

Full details in the March Talking Point.

Have your say!

Every membership of the ME / CFS Society of SA Inc. says <u>some or all of the following</u>:

- ☑ I believe that ME/CFS is a valid illness
- ☑ I believe that ME/CFS is organically NOT psychologically based
- ☑ I support those trying to help sufferers of this illness
- ☑ I have ME/CFS and need support and information
- ☑ I have had ME/CFS and still have an interest in it and believe those who suffer from it need support and information
- ☑ In my profession I encounter sufferers of ME/CFS and believe they need support and information
- ☑ I am related to or know a ME/CFS sufferer and believe it is a dreadful disease, and wish to help support the cause and the organization

JOIN NOW AND MAKE A DIFFERENCE!!

INTERESTED IN ASSISTING OTHERS WITH ME/CFS?

JOB DESCRIPTION: SUPPORT AND INFORMATION LINE WORKERS

- Take calls between 10 am and 4 pm and give support/non-specific within the guidelines of the society.
- Document all calls made and received.
- Maintain confidentiality at all times.
- Keep up to date on the latest issues relating to ME/CFS.
- Notify the Support line co-coordinator or office of any issues relating to difficult calls etc.
- Ensure adequate supplies of materials for client information.
- Be aware of other agencies which clients can be referred to.
- Be able to attend at least one meeting per quarter (support line workers meet monthly usually on Wednesday).
- Is not required to possess counselling experience or knowledge of ME/CFS but is expected to be willing to learn (training provided if necessary).
- Is expected to undergo a police check and sign confidentiality and code of conduct agreement.

Call the office to register you interest. Volunteers Needed. You can work from home!

(Continued from page 38)

Is it helpful to think this way?
Are there any alternative views?
What would I say to a friend?
What is the effect of thinking the way I do?

Challenging the negative automatic thought might run something like this:

In a nutshell

Cognitive therapy is not about thinking positively - it is about thinking accurately. Behavioural strategies such as pacing, planning, prioritising, balancing activity and rest, setting goals and scheduling pleasurable activities can be made more effective if you keep stress to a minimum and think accurately, not emotionally, about your situation.
This explanation of strategies is necessarily short and succinct. They may need further explanation and should be tailored to your particular needs. This is why it is often helpful to consult a CBT therapist to explore ways in which a programme like this could help you.

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www.afme.org.uk

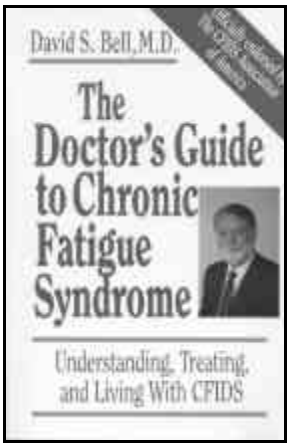
Items Available from the Society

Stock Clearance:
We have Efamol Marine Oil $22 per bottle—or 3 for $60 (GST Included)
Pickup from Office

Lapel Pins $2 each (pins are blue with yellow edging)

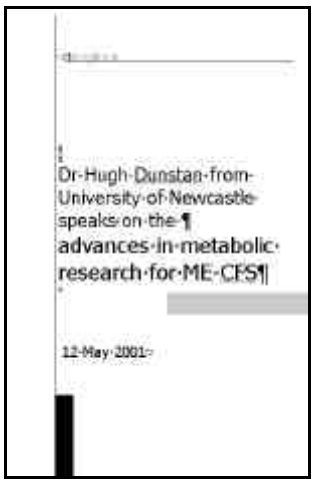
RED by Stephanie McCarthy
Special Price: $12 (GST included) + $2 P&H

The Doctor's Guide to Chronic Fatigue Syndrome $24.00 (inc. GST) + $3.00 Postage and Handling



Video & Audio Tapes

Video Duration 104 mins



Video Duration 96 mins

Special Price: $16.50 (GST included) + $3.50 P&H
Audio Tapes: $4.40 (GST included) + $2.60 P&H

Performing Miracles

■ Lesley Beasiey

Living with a disability is hard. Writing can be almost impossible. But some people do it. One of my heroes is Flannery O'Connor. She was only 25 and had a promising career ahead of her when she developed lupus in 1953. With her first book still only a draft, she had no choice but to retreat to her mother's chicken farm and cut her writing to fit her strength. 'I write only about two hours every day,' she told someone a year later, 'because that's all the energy I have.' By 1956 it was only one hour a day and she was reporting, 'In a sense sickness is a place, more instructive than a long trip to Europe, [but] always a place where there's no company, where nobody can follow.'

And yet, somehow, amidst all that, she kept her sense of humour. People loved to get her letters and it's easy to see why. Being 'afflicted with time', she made them an artform. Even her advice is funny. 'Your ending is too obvious,' she told one fan. 'You can't clobber the reader while he is looking. You divert his attention, then clobber him, and he never knows what happened.'

While Flannery O'Connor kept her private life out of her writing, Dorothy Hewitt is famous for including it. Never one to hide her feelings, she drew on her own experience to write *The Toucher*, teasing us with a mix of fact and fiction about an unconventional, wheelchair-bound novelist who falls for a much younger man.

Others simply skip the fiction and head straight for fact.

Sydney journalist Susan Molloy naturally took a professional approach after finding her own diagnosis of MS so devastating. Most how-to books leave me cold, but *Handling It* is full of interviews with people about how they cope - and sometimes don't cope – with all sorts of disabilities. They lead you to what should be the bleeding obvious but so often isn't: that there is no one way of 'handling' a disability and guess what – your way is probably the best way for you.

On a more personal front, there are countless autobiographies. Some have become classics, such as *I Can Jump Puddles* and *Reach* for *the Sky.* But the personal means something different today. We've changed our definition of strength, and people with disabilities no longer have to measure themselves against Pollyanna and Heidi, or even Douglas Bader.

In *When* I *am Weak* - the title is a joke and she deserves a medal –Melbourne teenager Jacki Schirmer details every moment of her struggle against not only Chronic Fatigue Syndrome, but also a lunatic rehab program that first gave her a wheelchair so she could get out, then when she enjoyed herself, took it away in case she stopped trying to walk.

Another of my treasured possessions is *The Diving Bell and the Butterfly,* by French writer Jean-Dominique Bauby. Immobilised by a stroke, able only to swivel his head and blink one eye, he turned his condition and his body -'these uncooperative deadweight limbs' - into literature.

Bauby didn't have Flannery O'Connor's religion to fall back on, but like her he countered despair with humour - often black humour in his case, that nevertheless gets you thinking about what makes a human being and gives life meaning.

After a harrowing Father's Day, unable to touch or even talk to his kids, Bauby finally decided that 'even a rough sketch, a shadow, a tiny fragment of a Dad is still a Dad.' I'm hoping the same is true of writers, because despite having so much more physical ability than Bauby, there are times when that seems the only way I qualify.

I tell myself that's OK, that I don't need to be a Flannery O'Connor or a Bauby, or even a Jackie Schirmer. I just need to be me, writing my way to one wherever I'm going in whatever small way takes my fancy. Whatever's happening with my writing, there's one. thing I know: I'll want to keep reading.

So if you're out there and you've got the urge, write a book - or a poem or a fragment - for me. Write one for Christopher Reeve, who says, 'Think of the world as an inclusive family, and let's not leave anyone behind.' Write one on what it's like to be you. The world needs to know. There's room for us all and every story counts. We are all making history.

President's Annual Report
AGM, November 24th 2001

I want to start by saying I am very proud of all we have achieved this year despite the continual struggle we face for health and recognition.
As I'll explain more fully later this MC inherited a very difficult situation. I need to make it clear that the Society almost folded in the last 2 years – for lack of human resources. For the second year in a row we struggled to achieve a quorum at the AGM and had to hold meetings in February. When you have to start asking for nominations from the floor 'on the day' you are really struggling - not just numbers wise but, more importantly, in organisational continuity. I think it is important that we, the members, realise this before making assessments of the MC.

There is much positive to report – we have made inroads into several areas, and achieved a lot this year.

- Feb 18th - Public meeting with Dorothy Morris Speaking.
- Feb 24th - MC elected.
- May 11ttth - GP Seminar held at the Chiffley Hotel, with Hugh Dunstan as the speaker, 26 GP's attended.
- May 12th - Public Seminar with Hugh Dunstan as the speaker "Advances in Metabolic Research" at Urrbrae Education Centre. Roughly 200 in attendance.
- July 21st - Members Meeting: Judy Lovett spoke on the National ME/CFS Association / and the MC presented a report on the Royal Australasian College of Practitioners working party Draft Guidelines.
- July: Response to Royal Australasian College of Physicians working party Draft Guidelines sent
- Aug 25th Public Medical Seminar at the University of South Australia. Speakers were Dr Peter Del Fante, Dr Rey Casse, & Dr Richard Burnett. 80 in attendance.
- Sept 22nd GP Seminar. Co-organised with Fibromyalgia SA and the Adelaide Western Division of General Practice. 30 attended.
- Advocacy for National Alison Hunter Memorial Foundation Conference. Letters to Federal and State politicians, and to businesses.
- Advocacy for important issues such as chemical sensitivity
- Improved liaison with other organisations – particularly Fibromyalgia SA and the Allergy and Chemical Sensitivity Association
- Development of an Education Support Group which has made some inroads into a number of issues dealing with secondary schooling

In July, we moved to a reasonable sized office and are on the way to setting it up well. We are in the process of setting up systems and structures that will provide long term benefit to the organisation. Our realistic goal is to have it up and running well by Awareness Week 2002.

We have been working on a lot of things which will take fruition next year. A few of us have attended the Chronic Disease Self-Management Program at the Arthritis Foundation. We plan to train leaders (we have already done one person) and trial the course for ourselves next year. http://www.stanford.edu/group/perc/cdsmp.html

It is also good to note that Bill Daniels has again been asked to run a WEA course on Chronic Fatigue Syndrome. Whilst this is not an 'official' Society event it is good publicity for the condition.

So we have had a productive year, and as I said can be proud of it.

Along the way we've had assistance from a few people. I'd like to extend thankyous: IITAB & SA Training Revelation who donated their old phone system to us. Electrolux – discount on refrigerator. Bank SA a $1000 donation.

Where we started this year

Key Points Relating to the State of the Society Feb 2001

- General State: Constant turnover of MC members has drained our 'knowledge base'. In any organisation operations must be constantly reviewed and improved. Little of this has been able to be done over the last few years and a lot of our materials needed (and still need) review.
  E.g. training programs for Support Line Worker, Support Group Leaders, Job descriptions for MC members. – not to mention key policies.
- We inherited a Society that has just experienced declining membership. From 570 in 1999, we were down to 350 at the end of last year. (We hope to hold at 350 by July 2002.)
- Finances: Inherited a situation where income had to be rapidly increased – we were looking at continued deficits.

Office
I acknowledge from the outset that office hours totalling 6 hours per week are not ideal – and are not consistent with any measure of professionalism. (I will point out that lately we have been open 10am - 4pm on the Tuesday and Thursday, and that we have been very prompt in responding to phone messages.) I believe it has been necessary this year for us to take some short term loss for a long term gain. We have needed to be free to sets things up as we would like. In the new year we will slowly increase the office hours to more acceptable levels.

Finances
Finance is now looming as our biggest concern. With reduced membership and increased costs it was always imperative we increase income this year. Unfortunately we have not been able to achieve that. We simply have not had the human resources to tackle the issue. It is only now at the end of the year that we are at the point where we have together sufficient materials to tackle a lot of the grant applications that need to be made – especially to the Department of Human Services.

Our position demands a strong focus on grantwriting for

the next 6 months. It also demands we look at the issue of fundraising. Up until now it has been the unwritten policy of MCs not to ask for donations for general revenue from members; they have also avoided labour-intensive fundraising activities such as fetes, quiz nights, chocolate / lamington selling. We know none of these are realistic for us to take on. I don't have all the answers but we face some critical times ahead financially, and we may need to call for some help in order to buy a little extra breathing space.

I want to assure you that we will attempt to do these things with the utmost sensitivity. They need to be done in a way where our many members who are financially and energy-challenged do not feel guilty, but provide opportunities for those who are willing and able to help out to do so.

Membership
I think we have arrested the membership downturn. We are badly in need of increasing membership, but I believe in a lot of ways membership is a barometer of how well you are doing. Increases in membership will occur as services improve and as we demonstrate management stability. (It would be nice to get some funding to advertise though).

Professionalism
It has been very much impressed upon this MC that we need to move toward a more professional operation. Without such we will not attract the level of expertise to the organisation which we need to succeed. We are operating in a marketplace where other charities are run professionally.

This starts with treating all volunteer positions (apart from the most very casual) no differently to paid ones. All key volunteers must go through an interview process before being accepted. It is important that we maintain a team, and choose suitable persons to fit into it. I can't stress that enough. Not everyone who volunteers can be accepted.

To be professional we must develop a team that can work together, that has the necessary skills. Starting from late September we have tried to look for people who can come on the MC who have specific expertise such as fundraising, legal or marketing knowledge. In the office we need to have people that can gel together nicely - we won't retain volunteer workers if they don't enjoy coming in and don't feel like they are being productive.

Human Resources
Reflecting previous year's experience we had a turnover of personnel - people were able to give what they could whilst their health allowed it. Throughout the year we had a total of 13 MC members.

However a lot has been left to a few. This is not sustainable – we need people who can be involved for 5 – 10 years not just 1-2 years. It is important we develop a knowledge base.

Despite our good intentions over the years, history has shown we (people with CFS) struggle to have the stamina and energy to see jobs through. The MC has made an important decision that we must pursue 'healthy' people to work in our office. We aim to have a paid person who would look after the banking and processing of memberships, and other key administrative jobs. This would ensure continuity and professionalism in the organisation. We must not expect people with chronic fatigue syndrome to take on the burden of administering the Society. We also see the value in volunteers who are healthy and can make a commitment. We have made good progress, and will continue to work with Volunteering SA.

Moving toward a more professional method of operation involves have a small team of people working in the office (too many cooks spoil the broth).

In September/October the MC made a decision of hiring a temp to assist us with processing memberships / banking / filing. We allocated $5000 for this task. We are actively in the process of seeking funding for that position to continue.

Constitution
As was pointed out last year – our constitution is in need of an overhaul. We have had legal advice and recommendations from several sources to suggest change is needed. The 2001 MC suggest that the Society should make it a priority to review and upgrade the constitution ASAP.

Towards developing a Broader / Better Understanding of our Society and Ourselves
It is very important that we are kind to ourselves. If there is one thing that has been impressed upon me this year, it is that ME/CFS is an emotional illness. Many things compound that to mean we have an 'emotional' Society. It is important we recognise the following things:

1. It's not fair that we have this illness ME/CFS (but we have to deal with it)
2. It's not fair that circumstances conspire against us such that the government is slow to recognise ME/CFS (but we have to keep at them)
3. Its not fair that we have to not only try to help each other, but we have this added burden of convincing the Government and medical practitioners that we are genuine
4. Its not fair (and painfully ironic) that people with an energy draining condition (and debilitating) have to do everything for themselves without government funding (especially when the government does so much for people who voluntarily damage their own health through smoking, drug addiction, alcohol abuse etc…)
5. It is not fair that many of us are financially crippled by ME/CFS, and yet we are having to maintain our Society by our memberships and donations (bigger organisations can offer free membership)

Step one to maintain emotional health is to acknowledge these things. It is easy to fall into the trap of becoming conditioned to abuse, injustice & inequity. Let's not unduly beat ourselves up – life is tough enough as it is.

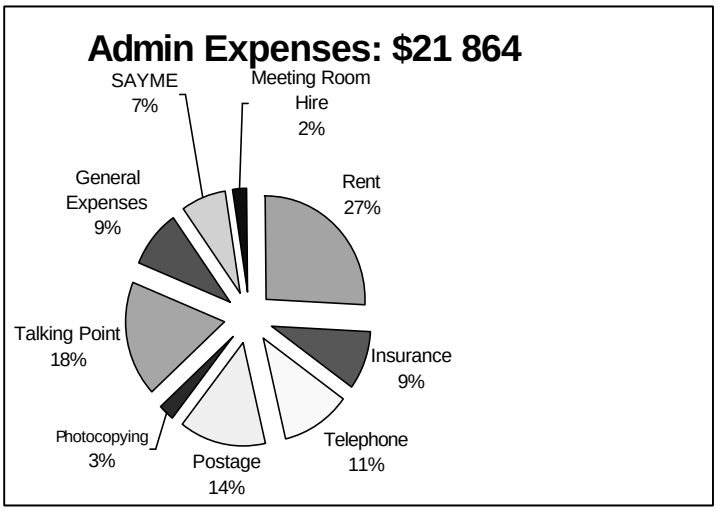
Step two is to channel frustration / anger / pain into the right pathways. This will vary from person to person but whatever the approach the goal must be to take control of our lives in ways appropriate to our situation. We understand that whilst many of our

(Continued on page 45)

ME/CFS Society (SA) Inc. Admin Budget

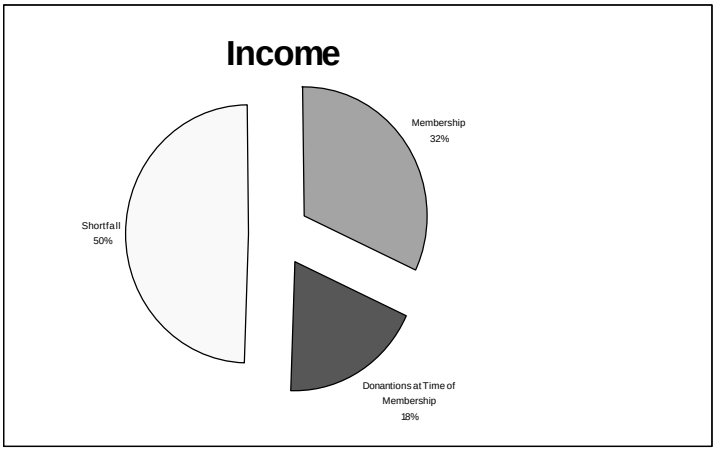
The following document outlines our basic admin expenses; we hope it gives you an idea of what the Management Committee faces. At the moment our cash reserves are low.

Our expenses have gone up considerably in the last year. Up until September 2000 our Society enjoyed inexpensive rent at the Disability Information and Resource Centre. Having moved into Epworth Building our rent has increased from several hundred dollars to $5 600. It's important to note that the accommodation at DIRC could be best described as a 'shoe box' and was never going to be conducive to the development of the Society; our Epworth office is modest but closer to the size we need, and is quite inexpensive in real rent terms.



Basic Admin Expenses	
Rent	$5,664.00
Insurance	$2,000.00
Telephone	$2,500.00
Postage	$3,000.00
Photocopying	$600.00
Talking Point	$4,000.00
General Expenses	$2,000.00
SAYME	$1,600.00
Meeting Room Hire	$500.00
TOTAL	**$21,864.00**

Income has dropped from 3 years ago when we had 570 members. With 300 members at the moment our financial situation naturally comes under strain. Membership fluctuates from time to time but there is not doubt the instability of the organisation's leadership over the last few years has taken its toll. We hope that this year we have 'righted the ship' and can build on this stabilising year. If we can't the Society will not be able to continue to operate.



Basic Income	
Membership	$7,000.00
Donations at Time of Membership	$4,000.00
Shortfall	**$10,864.00**
TOTAL	**$21,864.00**

The bottom line at the moment is that we have to find a minimum of $11 000 each year through fundraising and grants. We are attempting to get grants for Talking Point, SAYME and the Information Support Line. Where we are not successful we must fundraise to make up the difference. So far this year we have not been successful with grants (apart from $1000 from the Bank SA Staff fund), and have not had the human resources to undertake any significant fundraising. We must concentrate on that for the next 6 months.

We hope to obtain some funding from the government. However, even if this met our shortfall, this will not solve all our problems. We still need to improve in the grant writing/fundraising areas, because we feel there is a need to find an additional $15 000 p.a. to employ a clerical worker in our office.

The Management Committee

NOTE: (This paper accompanied the President's report). The Budget figures are approximate in some cases. It is not mentioned that increasing membership will also increase income and reduce the budget deficit—this will be a major goal of the Management Committee.

North Eastern Support Group Report

I would like to take this opportunity to thank all of you who have attended our North Eastern Support Group, "Better Together" meetings during 2001, and let the rest of the CFS Society know what we have been up to.

Our meetings have been informal, with refreshments and a chat. Of course we have spent plenty of time talking about our difficulties, comparing notes about doctors, and our different healing paths. We have also shared our achievements, what we like to do, and looked at the positive side of being slowed down. We had a funny jokes day (keep collecting those jokes!) which was fun, and September 12th when we thought about the world.

There are now seven of is who attend fairly regularly, although with illness and appointments, there will usually be four or five per meeting. Four others of us keep in touch by phone but have been unable to attend meetings. So we have grown, from two at the beginning of the year!

Overall, it has been a very good year. I have experienced how encouraging and comforting it is to spend time with others who understand. Thanks again to all of you, for sharing and caring, and helping to make the group a success.

Thank you very much also, to our Society Management Committee, and all members, who help keep our Society running so that we can be an encouragement to one another. Happy 2002 to everyone.

Julie McGinley.

Five members of the N.E. Support group celebrate Christmas.

(Continued from page 43)

members cannot offer physical or financial support – everyone can offer moral support at the very least, and we'd appreciate that.

Until ME/CFS receives official recognition, and the Society receives Government assistance, I put it to you that we are fighting for a cause as well as running an organisation. And an important one too. It is important that we hold on until the aforementioned relief comes.

Managing the Society
If you feel the Society is not able to do enough for you, and you get frustrated, please bear in mind that the MC is every bit as frustrated as you. People join the MC because they want to make a difference. It can be a very lonely job because we are so under-resourced it is difficult to make the progress we'd like. We know all the wonderful services that members could benefit from – but we just don't have the people and the money. Until we do, we can only do our best.

We need the moral support of every member to give us the hope and energy we need to keep going.

Thankyous
Thanks must first go to Mr Boris Dontscheff who managed the Society over last Summer at great personal cost to him; thanks must also go to those who helped form a caretaker committee to keep the business of the Society going. Thankyou to Rebecca & Gordon Byles, Helen O'Day.

Thankyou to the excellent committee we have had this year. Thankyou to Farrah Tate, Fiona Thompson, Beulah Carter & Margaret Whyatt for their contributions during the year; similar thanks to those MC members who are not continuing on: Marian Hansen, Sue Heard, Luke Pullen & last but not least Stephany Retallick who gave a lot to us this year.

I'd also like to thank all Support and Information Line Workers - who continue to do a great job for the Society. So thanks to John & Vicki Foote, David Andrews, Alex Harris, Elaine Balfort and Rosie Rowland. Special thanks go to Rosie, who has retired from the line after several years service.

It is also important to recognise the work of our Support Group Leaders. Thanks to Jane Gill, Julie McGinley, Marg Turner, Melanie Stratil, Darryl Turner, Bill Daniels, Marian Hansen and Fran McFaull.

Conclusion
We are improving our Society - slowly but surely. Providing we move towards greater professionalism and gain more credibility and respect, I am hopeful that we can secure some Government funding over the next 6 –18 months. The illness is becoming more and more recognised, and more and more medical practitioners are showing an interest. Its a matter of time before the tide turns.

SUPPORT GROUPS: METRO

Adelaide Support Group
4th Tuesday of the month
Venue: ME/CFS Society Office, Room 510, 5th Floor Epworth Building, 33 Pirie St Adelaide
Time: 12:00 pm – 2:00 pm
Best policy is to ring Support Line a few days before to confirm details.

Glenelg Support Group
3rd Wed of the month
Usual Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg
Time: 1 pm
Please ring the Support and Information Line to confirm details: **8410 8930**.

North Eastern Social Group: 'Better Together'
2nd Wednesday of each month
Location: Hope Valley
Time: 1:30 pm – 3:00 pm
Phone: Julie on **8264 0607**

It is good practice to call the information and Support Line for Confirmation: 8410 8930 OR 1800 136 626

SUPPORT GROUPS: COUNTRY

Northern Yorke 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 McFaull (Dietician) **8535 6800**

Southern Fleurieu Support Group
2nd Thursday alternate months
April, June, Aug, Dec
Phone: Melanie Stratil (Dietician) **8552 0600** for venue details.

It is wise for newcomers to phone and confirm meeting times as the regularity of events does change according to demand.

SUPPORT CONTACTS

SA Support Groups

Adelaide City	Support and Info Line	8410 8930
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
North Eastern	Julie	8264 0607
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

Highbury	Pat	8264 9328
SAYME	Paul	0500523500
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 Penisula	Glenys	8837 6375
Yunta	Gloria	8650 5938

YOUTH SUPPORT GROUP: South Australian Youth with ME/ CFS (SAYME)

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

Meetings Each Month. Please call the Information and Support Line for more details or 0500 523 500

MEMBERS MAY PLACE SMALL ADS IN TALKING POINT AT NO CHARGE
(subject to advertising policy on page 3)

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 chronic viral infections, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and auto-immune diseases such as lupus. [In the USA it is 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?

Therapy 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 pharmacological and other interventions.

Lifestyle changes, including increased rest, reduced stress, dietary restrictions & nutritional supplementation may be of benefit. Supportive therapy, such as counselling, can help to identify and develop effective coping strategies.

There is a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake exercise. Most ME/CFS patient groups recommend that sufferers exercise as much as they are able—to pace themselves. It is important to maintain physical fitness if possible, but we recognise that exercise is not always the best possible use of sufferer's limited energy reserves.

DO PERSONS WITH ME/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.

PREVALENCE

ME/CFS strikes people of all age, ethnic and socio-economic groups. ME/CFS is three times more common in women as men; a rate similar to that of many auto-immune diseases such as MS and lupus.

In Australia, very few studies have been undertaken to determine the prevalence of ME/CFS in the community; estimates range from 0.3 to 2.5% or even higher. These studies use different criteria for defining ME/CFS and consequently arrive at widely differing results.

A reasonable[1] figure for the prevalence of ME/CFS is 0.3—0.7% of the population. From these figures we expect that 3000—10 500 people in South Australia have ME/CFS.

1. RACP, 2nd Draft Guidelines for ME/CFS

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

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