Talking Pump

2002 Issue 4 Official Journal of the M.E./C.F.S. Society (SA) Inc..

Your Society

forget-ME-not

Office Ph: (08) 8410 8929 Fax: (08) 8410 8931
Support & Information Line City Callers: 8410 8930 Country Callers: 1800 136 626

www.sacfs.asn.au

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

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 people with ME/CFS and their families

Patron

Her Excellency Marjorie Jackson-Nelson, AC, CVO, MBE, Governor of South Australia.

Medical Advisor

Dr P.Del Fante : GP, BSc DipCompSc MBBS (Hons) MSc (Public Health Medicine), 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.)

Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed about 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 any products or services (including those appearing in paid advertisements) or treatments — always consult your medical practitioners before commencing any new treatments.

Deadline for Next Issue
March 10th 2003

Talking Point Subscriptions:

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

Management Committee 2001/2002

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

President: Paul Leverenz
Vice-President: Peter Cahalan
Secretary: Peter Worsley
Treasurer: Geoff Wilson
Management Committee Members:
Margaret Wing, Peter Evans, Kirsty Cordingley, Glenn Domeika, Adrian Hill & Rebecca Cordingley.

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.

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.
At the time of printing the office hours are:
Monday, Tuesday & Thursday 10 am — 3 pm. (Subject to Volunteer Availability)
Our email address is: sacfs@sacfs.asn.au

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.

Donations

CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

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.

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.

EDITORIAL


Welcome to our final edition of Talking Point for 2002. This edition is running a little late, but you will see it has been worth it.

In this issue we have an extensive news section with many happenings in the wider CFS community and in our group. The *Commotion on the Murray* expedition went well, and we have a report from what ensued there; we give you an update on writings in the Medical Journal of Australia; we have the full speech by Sandra Kanck about MCS given to the legislative council; and we also provide information about grants received by the Society.

We have a feature article on 'School and kids with Chronic Fatigue Syndrome' by Mary Campbell. In the medical section we introduce you to some of Dr David Torpy's thoughts as he writes on "Neuroendocrinology, Genetics and Chronic Fatigue Syndrome." Dr Torpy is our keynote speaker for our planned May 2003 Awareness Seminar.

We hope you enjoy some of the personal stories and tips provided by some of the articles, and, as always, encourage you to submit your story and submit it for publication.

Paul Leverenz
Farrah Tate
Editors

Contents

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

President's end of year reports 2002

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

I believe it is important for the membership to be kept fully informed as to the state of their Society. Because of this I have decided to provide effectively three reports beginning with a look at the future. This is followed by my President's Report presented at the AGM of November 9th 2002. I have taken the liberty of expanding on some of the points made at the AGM, for the sake of clarity, but not added new ones. They appear in the final report which rectifies some omission from my AGM report, and brings you up to date with events up until late December.

2003: Keeping up the momentum

By way of introduction I will say that 2002 has been a year in which we have stabilized the Society, and I want to re-iterate some of the reasons why. The cornerstone has been developing an office team which, largely, has operated independently of the Management Committee. To do this we have increased our number of volunteers and spread the work around. This has released the Management Committee to be able to do what it should be doing—and that's writing grants, planning fundraising activites, lobbying the government etc… If we lose this office team, the Society can easily go backwards, and quickly …. So my main priority is to add this team, so it continues on into 2004 and beyond.

The second biggest reason for improvement is good recruiting. We have been able to get team-players on board, and we have chosen to not do some things if there is not a person available with the skills to do them. Our focus, too, is on building a team. Appointments are therefore not made just on the individual, but how that person will work with the existing team.

And the third main reason for our improvement is a change in organizational culture. We have made a point of establishing an unwritten rule that volunteers are not 'flogged to death'. Those who come on board are not pressured into doing more and more. We also operate on mutual trust and seek to give team members a chance to show initiative, and do our best to encourage and affirm other team members.

We now have good momentum—with all but one of the Management Committee continuing on from 2002—and I see my job as making sure this continues in 2003.

Now is the time to talk to us about getting involved. My promise to everyone is that should you volunteer for a specific task, or a certain number of hours per week, that is all you will have to do. No-one will get sucked into the 'vortex' that often happens at volunteer-based organizations.

Now, whilst we have momentum, is the time to involve yourself, but I will qualify that. We *mostly* (but not always) require people who can make long-term commitments—even if its just 5 hours a week—rather than short term commitments. It takes a lot of time and effort to train people, and the organization will grow best, if we can build up a team of people who understand the organization and 'have been around for a while.'

So, if you—or someone you know—are healthy enough, and have the time, then maybe you fancy working a day a week in the office, or maybe joining the support line team to do one day a week on the phone from home—or maybe you would like to write to some schools or businesses to ask for support?

2003 looks to being a good year for the Society. And the more the work is spread around, the more enjoyment and satisfaction there is for everyone involved.

Paul Leverenz

President's Report: AGM, November 9th 2002

The struggle for recognition of ME/CFS continues. Progress is at times frustratingly slow. But given the resources we have, we can be proud once again with what we have achieved this year.

It can also be frustrating for the management committee because we would like to be putting more effort into advocacy, services and developing information resources, but we once we have taken care of the administration, running meetings, fundraising and Talking Point that there is little left over.

Management Committee

Glen Domeika, Adrian Hill, Penny Cahalan & Peter Worseley were co-opted to the Management Committee during the course of this year. Rebeeca Cordingley has also helped us a minutes secretary. Four of those people are continuing on.

Achievements this Year

We have achieved many important things this year.

- Responses before and after the release of Royal Australasian College of Practitioners Guidelines on CFS which had some positive effect on their content, and provided a good context for us to put our point of view across
- May 12th - Public Awareness Meeting with 400 in attendance. Excellent support and collaboration with Fibromyalgia SA.
- Development of Drs Notes (Version 1)
- Badge Day – May 31st. Raised over $3000
- President speaking on chemical sensitivities at Public Health Association of Australia meeting, Sept 26th

- Members Meeting on Sunday October 20th, 45 attended
- First meeting of the ME/CFS (and related conditions) Clinical and Research Network – this is a forum (facilitated by the Society) for ME/CFS Researchers/Clinicians to get together and exchange ideas. First meeting in October was very successful.
- Interaction with Department of Human Services – although we haven't made the progress we would have liked by now, the DHS certainly know we exist
- Development of Office Procedure Manual
- Development (in progress) of Training materials for new office workers
- Revision of Support Line Workers Manual
- Information Pack for new members

Projects that are underway but not yet completed:

- ·Education Support Group – development of Notes for Schools / Teachers / Pavements of children with ME/CFS
- ·Self Management Course – delayed till April / May 2003
- ·Re-working of constitution – yet to be completed

Grants

We have been successful in obtaining several grants in the last 12 months:

1. Sunshine Foundation: $2800 – Self-Management Course
2. Community Benefit: $3080 for SAYME
3. Foundation for Young Australians grant. $5000 – for SAYME website development/upgrade
4. Morialta Trust: $3300 – Information Kits, youth orientated, for parents, schools and doctors.

Thanks to Kirsty and Rebecca Cordingley and others for their work on these grants.

Lowlights

- the passing of Tracey Ash; a lovely, young, energy-filled person cut-down by this terrible illness.
- the closure of the Allergy and Chemical Sensitivity Association of South Australia.

Finances

We life on a knife edge when it comes to finances. Membership accounts for only one quarter to one third of our income. The balance must be found by donations and fundraising.

The committee has discussed how we can reduce expenditure and increase income.

There are limited ways of reducing expenditure. One is obtaining cheaper rent. We have asked the government if they have any space they could rent us cheaply but they claim to not even have enough space for themselves. Another way is to reduce the cost of Talking Point by reducing its size. We can save postage and printing costs by making Talking Point available for download from our website. Such a download would have to be in a password-protected area, so only members could access it. This requires upgrades to our website which we are considering. We are also investigating alternative phone companies, to see if we can reduce our phone bill.

To increase income we believe Badge days are a simple way

(Continued on page 6)

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

(Continued from page 5)
of collecting funds. We have researched their effectiveness and consulted people experienced in running them. All we need is a team of 6-8 people who could do 2-4 days a year of collecting and we could easily raise an extra $3000 that way. And if we could get 40 collectors on our main CBD badge day (instead of 20) we could easily get in an extra $3000. Thanks especially to Adrian Hill who has been instrumental in organising our Badge Days.

I want to give special mention to Geoff Wilson and Margaret Wing, who between them, have kept our books on track over the last 12 months – being on top of our finances means we can budget and plan ahead much more easily.

Office

Since last year we have built up to being open 3 days a week – with 2 people rostered on each day. This has worked brilliantly. Even during the busy time of membership renewals, this was adequate.

This has been possible with the assistance of 5 fantastic people: Patricia Smith, Diana Fleet, Christine Hickmann, Trisha Moores and Ling. These people are putting in total 30 hours a week between them.

Without this help the President can honestly say he wouldn't have lasted the year out. The now fully functioning office has taken a substantial load of his shoulders.

Thankyous

To all the people who make this organization tick. There are many people including the support group leaders, support line workers and the management committee. Special thanks to Bill Daniels for co-ordinating the support groups (despite quite poor health) – he continues to be a faithful servant of this organisation - and to Peter Scott who has been fantastic with the website. Final thanks go to Jon & Vicki Foote for their work co-ordinating the Support and Information Line.

Concerns

- Whilst we have a full Management Committee, we have not been able to develop sub-committees or expand our team much beyond the committee.
- Lack of volunteers for the Support and Information Line
- Poor attendance at Support Groups
- Income
- Talking Point helpers

Closing Remarks

Please continue to support the Society, not just for yourself, but for everyone who has this condition. It is important, for all those people who are suffering with this condition, that we persist in our mission, and that we push on as an organization. We will continue to do what we can, and especially continue to lobby the government.

Paul Leverenz

Beyond the AGM

I would like to add to my AGM report—thanks must also be extended to Tracey Woods who has helped with General Practitioner liaison.

Joint Awareness Seminar

I am pleased to announce (see page 35) that we, together with Fibromyalgia SA, are planning an Awareness Seminar on May 10th at the Norwood Concert Hall. It is going to be an exciting event with Dr David Torpy, endocrinologist based at the RAH, as our keynote speaker. There will be a cost involved (member will get reasonable discounts) as we can no longer afford to subsidize such events. More details in the next Talking Point.

Badge Day: Friday 31st May 2003

Mark down this date in your diary. If you can't participate yourself, you've got plenty of time to work on your friends and relatives, and you can be involved by collecting all that loose change that builds up, and donating it to us for our badge day.

Keep you hopes Up!

I see every day as being one step closer to the time when ME/CFS is given the recognition and attention it deserves as a serious health issue. Hang in there.

Paul Leverenz

Late Breaking News:

Adelaide Bank Charitable Foundation does it again!

Good News! Talking Point will continue in its current form for 2003. This service, like all others, is dependent on funding, and whilst we will always have a journal in some form or another, the current size and standard cannot be guaranteed.

A grant from the Adelaide Bank Charitable Foundation will fund the 4 editions for next year. This funding was received just after the committee had decided to cut back Talking Point in size in order for us to keep to our budget! More about that in the next issue.

Online donations:

We now have the capacity to accept donations by credit card online. This is made possible through *Our Community* (see www.ourcommunity.com.au).

In 2003 we are pitching our fundraising to improving our information services—primarily our *Support and Information* Line but including our websites.
http://www.ourcommunity.com.au/giving/appeal_details.do?appealId=165

More details to follow.

Letters to the Editor

Air Cleaner for Sale

Honeywell Enviracaire air cleaner 13500 model—all metal—well run in (no oil odours etc.). Plus 1 new charcoal filter plus 1 new HEPA filter (spare)

Phone Sue: (08) 8555 2361

Treatment Suggestion

Anyone suffering with irritable bowel syndrome and have had no success re: other treatments, try deleting all tea / coffee from your liquid intake. I most certainly resulted in a health improvement for me.

Your sincerely,

Sue Prider

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

CFS discussion in the Medical Journal of Australia

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

1st July 2002
(also reprinted in June 2002 Talking Point)

Mr Simon Molesworth AM, QC
Chairman
ME/Chronic Fatigue Syndrome Association
of Australia

Professor Richard Larkins
Immediate Past-President
Royal Australasian College of Physicians

Dear Sir,

The ME/Chronic Fatigue Syndrome Society of Australia Ltd. has expressed its concern over the content of the Royal Australasian College of Physicians' Chronic Fatigue Syndrome Clinical Practice Guidelines published in the Medical Journal of Australia.(1. Chronic fatigue syndrome. Clinical practice guidelines — 2002. *Med J Aust* 2002; 176 (6 May Suppl): S17-S56.˜)

Recognising a shared objective to overcome the challenges of CFS, neither the ME/Chronic Fatigue Syndrome Society of Australia Ltd nor the Royal Australasian College of Physicians believe that conflict will provide a useful path to future answers. Accordingly, as the Chairman of the ME/Chronic Fatigue Syndrome Association of Australia and the President (at the time of the publication of the Guidelines) of the Royal Australasian College of Physicians we would like to document the common ground that has been identified.

- We acknowledge, as do the Guidelines, that CFS is a serious, disabling illness.
- There is no evidence that the illness is primarily psychological in origin.
- There is significant evidence of a range of biological abnormalities occurring in people with CFS. It remains unclear whether these are primary or secondary.
- Treatment should be personalised according to the symptoms and circumstances of the individual patient. Treatment plans should be worked out by the patient together with a health care professional and designed to be within the capabilities of the patient.
- Scientific evidence concerning aetiology, pathophysiology and treatment is, at this stage, grossly deficient. More research is required to understand the biological mechanisms involved and to clarify the role that genetic, environmental and infectious agents might have in the aetiology and pathophysiology of this complex and debilitating illness.
- The medical community, other health professionals and patients and their families should work together to encourage increased funding and research into the epidemiology, aetiology and pathophysiology of CFS so that we may find more effective treatments for this condition (or these conditions).

All clinical guidelines should be viewed as documents that will, in time, require refinement, rewriting and replacement. Medical practitioners must be cognisant of the limitations of all such guidelines and be aware that the investigation and management of a patient's condition must be determined with the assistance of the best and latest information as it emerges and in all instances be tailored to the needs of the individual patient.

Yours sincerely,

Professor Richard Larkins FRACP
Simon R. Molesworth AM, QC

Larkin RG and Molesworth. **Chronic fatigue syndrome clinical practice guidelines**. MJA 2002; 177:51-52.

4th November 2002

Chronic fatigue syndrome clinical practice guidelines: psychological factors

Ian B Hickie

TO THE EDITOR: The process of destigmatising chronic fatigue syndrome (CFS) is not advanced by either limiting enquiry to "acceptable" sciences or increasing the stigma already experienced by people with other neuropsychiatric disorders. Contrary to its intent, and in contrast to the recently published Royal Australasian College of Physicians (RACP) guidelines,[1] the recent statement by the immediate past president of the RACP and the Chairman of the ME/Chronic Fatigue Syndrome Association of Australia[2] is in danger of *increasing* the stigma for both people with CFS and people with other common mental disorders.

Unfortunately, key propositions in their letter ("There is no evidence that the illness is primarily psychological in origin") are clearly at variance with the tone of the guidelines (see Box 1.5, p.S31; Box 1.7, p.S32; and, "Management" summary, p. S38). Their letter reinforces the classical "dualistic" and rather simplistic "biological" approach (eg, "There is significant evidence of a range of biological abnormalities occurring in people with CFS"). Unwittingly, it colludes with community-based beliefs that mental health problems are "not health",[3] and often imaginary or under the voluntary control of the patient.[4]

There is no doubt that people with CFS share many experiences with people with other neuropsychiatric disorders. They both have daily experiences where their credibility is

(Continued on page 9)

challenged, their disability is minimised and their needs for appropriate medical management are not met.

Australian research and best practice have been recognised internationally for emphasising the integration of psychological, psychiatric and biological factors and respect for the experiences of persons with these debilitating disorders.[5] Unfortunately, the major advances captured in the guidelines may now be undermined if the RACP is perceived to be backing away from supporting appropriate psychological assessment and provision of effective "psychological" treatments (such as cognitive–behavioural therapy and physical rehabilitation approaches). Similar equivocation has left clinical guideline processes in the United Kingdom in disarray.[6]

As demonstrated recently, prolonged fatigue syndromes are common in the Australian community, and the vast majority of those who seek healthcare services have concurrent depression or anxiety.[7] Real progress towards destigmatisation, meaningful research progress and improved health services for people with CFS will only occur when the field is mature enough to deal with the clear relevance of psychological factors. Instead of rejecting "psychological factors" and associated treatments, relevant professional and consumer bodies should now join with the broader community movement towards increased community awareness of common neuropsychiatric disorders, genuine understanding of their (genetic, "biological", psychosocial and personal) causes and provision of effective (pharmacological and psychological) treatments.[8]

References

1. Chronic fatigue syndrome. Clinical practice guidelines – 2002. *Med J Aust* 2002; 176 Suppl May 6: S17-S56.
2. Larkins RG, Molesworth SR. Chronic fatigue syndrome clinical practice guidelines [letter]. *Med J Aust* 2002; 177: 51-52.
3. Highet NJ, Hickie IB, Davenport TA. Monitoring awareness of and attitudes to depression in Australia. *Med J Aust* 2002; 176 Suppl May 20: S63-S68.
4. McNair BG, Highet NJ, Hickie IB, Davenport TA. Exploring the perspectives of people whose lives have been affected by depression. *Med J Aust* 2002; 176 Suppl May 20: S69-S76.
5. Lloyd AR, Hickie IB, Loblay RH. Illness or disease? The case of chronic fatigue syndrome. *Med J Aust* 2000; 172: 471-472.
6. Eaton L. Chronic fatigue report delayed as row breaks out over content. *BMJ* 2002; 324: 7.
7. Hickie I, Davenport T, Issakidis C, Andrews G. Neurasthenia revisited. *Br J Psychiatry* 2002; 181: 56-61.
8. Hickie IB. Responding to the Australian experience of depression. *Med J Aust* 2002; 176 Suppl May 20: S61-S62.

beyondblue: the national depression initiative, Hawthorn West, VIC.
Ian B Hickie, MD, FRANZCP, Chief Executive Officer, *beyondblue: the national depression initiative*.
Correspondence: Professor Ian B Hickie, beyondblue: the national depression initiative, PO Box 6100, Hawthorn West, VIC 3122. ian.hickie@beyondblue.org.au

Ian B Hickie. **Chronic fatigue syndrome clinical practice guidelines**. MJA 2002 177 (9): 526. Copyright 2002. *The Medical Journal of Australia*—reproduced with permission.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

4th November 2002

Donald D Beard

TO THE EDITOR: In the recent letter from Larkins and Molesworth[1] various statements are made on which I would like to comment.

From time to time everyone becomes physically or mentally exhausted, whether or not it is related to activity.

For some people this exhaustion becomes disabling. They deserve understanding and sympathy. We must do everything we possibly can to assist them to recover and to try to find possible causes.

Larkins and Molesworth acknowledge that chronic fatigue syndrome is a serious, disabling illness. When does ordinary exhaustion become disabling?

I would agree that at this stage there is no clinical evidence that the condition is primarily psychological. Nor is there evidence that it is primarily physical. There may be a mixture.

What is the "significant evidence" of a range of biological abnormalities occurring in people with CFS? What are these biological abnormalities and what physiological evidence is there for each one of these abnormalities to produce fatigue?

Larkins and Molesworth state that treatment plans should be "within the capabilities of the patient": is there evidence to indicate that stimulating each patient to do just that little more each day will do harm?

It was stated that scientific evidence of the aetiology, pathology and treatment is grossly deficient. It is in fact absent. There is no evidence at all. Research is certainly required.

One of the problems is that, as soon as a medical advisor informs a patient that investigations have shown no serious abnormality, the patient often goes away and says to himself or herself or family that the "doctor said there is nothing the matter with me and that it is all in my head". Nothing could be further from the truth. Something *is* the matter and it is up to us to find it out.

References

1. Larkins RG, Molesworth SR. Chronic fatigue syndrome clinical practice guidelines [letter]. *Med J Aust* 2002; 177: 51-52.

134 Beulah Road, Norwood, SA.
Donald D Beard, AM, FRACS, Emeritus Surgeon, Modbury Hospital.
Correspondence: Dr Donald D Beard, 134 Beulah Road, Norwood, SA, 5067.

Donald D Beard . **Chronic fatigue syndrome clinical practice guidelines**. MJA 2002 177 (9): 526.

4th November 2002

In reply: Chronic fatigue syndrome clinical practice guidelines: psychological factors

Richard G Larkins and Simon R Molesworth

In reply: We thank the writers for their comments on the CFS guidelines[1] and our joint letter about these guidelines.[2]

Hundertmark remarks on the interplay between physical and psychological factors in morbidity associated with CFS. We trust that our letter in no way contradicts this. Similarly, the inferences that Hickie drew from our letter are not supported by the text of the letter. Far from undermining the guidelines, our letter had the full support of the convenor of the working party responsible for the guidelines.

As clearly discussed in the guidelines, in the absence of specific diagnostic tests it is likely that a range of factors may contribute to the pathogenesis of CFS. Assumption of a primarily "psychological" pathogenesis is as unjustified as assumption of a primary "physical" basis. There are "abnormal" test results in many people with CFS, including abnormalities of the hypothalamic–pituitary–adrenal axis and some abnormalities of immune function. As stated, it is controversial whether such abnormalities are primary or secondary.

While cognitive–behavioural therapy with graded exercise is effective in some patients, the guidelines outline the deficiencies of the evidence which "significantly limit the generalisability of the findings". As the guidelines indicate, and as is supported by our letter, treatment should be designed in partnership with the patient, and tailored according to the patient's capacity and response.

Finally, as implied by Beard's letter, we restate the need for further research into the aetiology, pathology and treatment of CFS.

We believe that effective progress in the management of this complex and mysterious illness will be best achieved by positive and cooperative rather than adversarial relationships between those suffering from the condition and the doctors and researchers attempting to help them.

References

1. Chronic fatigue syndrome. Clinical practice guidelines – 2002. Med J Aust 2002; 176 Suppl May 6: S17-S56.
2. Larkins RG, Molesworth SR. Chronic fatigue syndrome clinical practice guidelines [letter]. Med J Aust 2002; 177: 51-52.

Richard G Larkins, FRACP, Dean. Faculty of Medicine, Dentistry & Health Sciences, The University of Melbourne, Parkville, VIC.
Simon R Molesworth, AM, QC, Chairman, ME/CFS Association of Australia.

Richard G Larkins and Simon R Molesworth. **Chronic fatigue syndrome clinical practice guidelines**
MJA 2002 177 (9): 526-527.

MCS Motion to South Australian Upper House

SANDRA KANCK
Democrats Deputy Parliamentary Leader (SA)
Member of the Legislative Council

13th NOVEMBER 2002

MOTION:- MULTIPLE CHEMICAL SENSITIVITY

The Hon. SANDRA KANCK: I move:

1. That a select committee be appointed to inquire into and report on Multiple Chemical Sensitivity, with particular regard to-
   (a) which chemicals or chemical compounds are responsible for the majority of symptoms of Multiple Chemical Sensitivity and how exposure to them can be minimised;
   (b) the effect of chemical exposure on human fertility;
   (c) the comparative status in other countries of Multiple Chemical Sensitivity as a diagnosed medical condition;
   (d) best practice guidelines in Australia and overseas for the handling of chemicals to reduce chemical exposure;
   (e) current chemical usage practices by local government and state government departments and changes that could be made to reduce chemical exposure to both workers and the public; and
   (f) the ways in which South Australians with Multiple Chemical Sensitivity might more effectively access sources of support through government agencies.
2. That standing order 389 be so far suspended as to enable the chairperson of the committee to have a deliberative vote only.
3. That this council permits the select committee to authorise the disclosure or publication, as it thinks fit, of any evidence presented to the committee prior to such evidence being reported to the council.
4. That standing order 396 be suspended to enable strangers to be admitted when the select committee is examining witnesses unless the committee otherwise resolves, but they shall be excluded when the committee is deliberating.

Multiple Chemical Sensitivity, or MCS, is, in Australia at least, a mostly unrecognised illness, but its incidence is increasing, and it could be that we are on the edge of an epidemic of chemically induced illness in this country. The World Health Organisation acknowledges the existence of MCS and, as a nation, Germany recognises it. Many US states do, and consequently they have strict pesticide legislation. In California, where the Californian Medical Association recognises it, 6 per cent of the citizens of that state are known to have experienced MCS, and it is recognised as a disability in at least 10 Canadian jurisdictions.

I give credit to the former health minister, Dean Brown, who acknowledged in correspondence with Mr Peter Evans of the South Australian Task Force on Chemical Sensitivity that MCS is `emerging as an important environmental health matter that has national implications'. He is right. Our society is experiencing unprecedented rates of auto-immune diseases, infertility, cancer and childhood asthma. Most of us personally know someone who is suffering from chronic fatigue syndrome, ADHD or fibromyalgia syndrome. Many of us know people who have allergies and intolerances to various foods and substances.

Exposure to chemical toxicity can result in symptoms ranging from headaches, poor concentration, diarrhoea, muscle and joint pain, dizziness and irregular heartbeats, through to life-threatening conditions such as auto-immunity. Once acquired, it takes very little exposure to any other chemical to tip those sufferers back into illness. More and more I find people who cannot tolerate the smell of someone's perfume-something which most people would regard as a pleasant smell. I am sure members recall media stories in the 1980s about individuals who were described as having become allergic to the 20th century. While those individual stories were told, many others were not because for the most part those who suffer from MCS are often confined to their homes. They cannot go outside without being hit by one or more of the products to which they are sensitive.

The World Health Organisation has recognised MCS as a growing problem and a serious environmental concern, yet it does not have any status in the Australian medical community. The consequence of this lack of recognition is that the sufferers of MCS are sometimes treated by their GPs as malingerers. Without formal recognition of the condition, it is hard for the sufferers to argue their need to be given the supports to which others with a disability are entitled. It must be tough for them to know that they have a genuine physical affliction and to be treated as if it is something which they are imagining.

What causes MCS? The Multiple Chemical Sensitivity Association specifically sheets home the blame to some building products, pesticides, paints, cleaning products, carpets, plastics and glues, to which I would add substances such as tobacco and fumes from car exhausts. With the number of complex chemicals being released into the environment, problems emerge from the unintended interactions between different substances in the atmosphere. For instance, nitrogen oxide from car exhausts reacts with sunlight to form ozone which is a lifesaver in the upper atmosphere but poisonous when breathed in at ground level; it can impact on the immune system and, in some cases, lead to cancer.

The Multiple Chemical Sensitivity Association argues that, because of the health impacts, what is regarded by the authorities as acceptable limits of toxins in these very commonplace substances and the acceptable exposure limits to people handling them, may no longer be acceptable and must be reviewed. The National Registration Authority sets the standards for chemical additives in food, for instance, and the states themselves do not undertake any investigation as to what are appropriate levels. One has to ask about the need for us to use some of the chemicals we use and the problems that can arise from accidental exposure.

Tobacco is a product that we do not need-although of course some people are addicted to it-and accidental exposure in the

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

form of side stream smoke can have quite disastrous impacts on people. Some members of this place may be aware of a campaigner against tobacco, a former member of the Australian Democrats, Sue Meeuwissen. Sue had no sense of smell, but she was highly allergic to side stream smoke from tobacco. When she was being treated for her condition in the Women's and Children's Hospital, she went outside and inhaled cigarette smoke from smokers outside the Women's and Children's Hospital. That had such a significant impact on her health that it was all downhill from there and, ultimately, it led to her death.

Firefighters are a group in our society who are often exposed to some of these substances without being aware of it, and it can permanently alter their lives. I remember about a decade ago, when I was working for Senator John Coulter, being contacted by the wife of a firefighter who had been exposed to a product called toluene diisocyanate, more commonly known as TDI. In that case the body becomes allergic to itself and attacks itself, and this firefighter had unfortunately, in fighting a fire, been exposed to TDI. Clearly, he had little chance of any sort of life in the long term. TDI is imported into South Australia and is used by just a few manufacturers in this state. In my opinion, this is material is so dangerous that it should have regulations in place for its transport and storage, and those regulations ought to be as tight as any that we have in place for radioactive materials, so much so that I believe that local government authorities should be aware of the route and time of travel of this substance when it is moved from one place to another. One has to question why we need to manufacture products that require the introduction of such materials. Surely we can do away with products that require them.

A committee that can look at the toxic nature of some of these materials will have the opportunity to ask questions of this nature. As this is early days in Australia, the committee will most likely not find all the answers it needs but certainly, throughout the world, when we have become aware of the harmful nature of some chemicals, their use has eventually been restricted, thus showing that we can do without them. When we became aware of the impact of DDT we were able to find some less noxious alternatives. When we became aware of the impact of the ozone hole in our upper atmosphere we were able to find acceptable alternatives to CFCs which were creating that hole.

Surely we need to ask questions about new chemicals before they enter the market; before they can do such catastrophic damage. There are almost always gentler alternatives. For instance, some local government authorities in New South Wales are spraying kerbside weeds with steam rather than herbicides. There is increasing evidence that exposure to particular types of chemicals is leading to decreased fertility. A Danish study published in 1992 found that around the world the average male sperm count had dropped by 50 per cent in the short period of just five decades, from 1940 to 1990. Whereas back in 1940 only six per cent of men had sperm counts classified as extremely low, in 1990 18 per cent of men were in that category. Subsequent studies in other countries have verified those results. The indicators-

The Hon. T.G. Cameron: It might be nature's way of dealing with the population explosion.

The Hon. SANDRA KANCK: I guess that is one rather cynical way of dealing with it. The indicators are that organochlorines mimic oestrogens and disrupt normal hormonal patterns. They exist, for instance, in plastics and detergents which are very common substances that we all use. The finger points at these chemicals as playing a major role in declining fertility and increased prostate cancer in men. It may be that they are responsible for increased levels of endometriosis and breast cancer in women. Exposure to such chemicals is known to disrupt thyroid production with the potential to impact in utero the children of women who have been exposed. It is known that women who experience low thyroid levels in pregnancy are more likely to produce children who are hyperactive. In nature, the impact of these dioxin-like products is producing infertility, miscarriage and birth defects. The warnings for the human species must be very loud.

We know from some catastrophic events around the world that PCB and dioxin exposure lead to low thyroid levels for mothers of unborn children and to mental retardation of those children. Exposure to these same chemicals at supposedly safe levels leads to slightly lower thyroid levels, and this may be responsible for behavioural disorders and learning disabilities in children.

I know that this goes further than the terms of reference that I am suggesting, but if we begin to tackle multiple chemical sensitivity as an issue we are likely to be tackling a range of health-related issues. At the heart of the problem is the powerful influence of chemical drug and tobacco companies. Unfortunately, ordinary people do not have the power to take on these companies, let alone have the wherewithal to question what is being pushed at them. Members might have seen the film *Erin Brockovich* a few years ago, which was based on the true story of one woman who took on one of the big chemical companies and won.

Unfortunately, such stories are few and far between. It is for sure that we will always know about the positive benefits of any new chemical coming onto the market because the PR machines of those companies will ensure that we do, and so often the media obediently complies with feel-good stories masquerading as news. The environment movement advocates the precautionary principle, which basically says that if we do not know all the possible impacts of a proposed practice or product we should not introduce it until we are certain that it will be safe. We must adopt such a principle in relation to our health.

Our governments seem to prefer intervention after the event rather than prevention. They wait until a problem emerges before doing anything about it when they could have prevented it in the first place. The cost of intervening may be much higher than any costs associated with initial prevention of the problem, but the multinational chemical companies have such massive influence and small community groups have so little voice. We should not wait until the damage has occurred before taking any action. The chemical company must always prove that it is safe: it must never be turned the other way, with ordinary consumers expected to prove that a product is harmful.

The reverse onus of proof is already the case with pharmaceuticals and it should be extended to other types of chemicals because, whether or not we like it, we are taking these chemicals into our bodies through the air we breathe, the water we drink and the food we eat. We should expect

hostility from chemical companies-they have a lot to lose: profits and the potential for legal liability. A task force was established in New Mexico to look at multiple chemical sensitivities. That task force reported in January last year-almost two years ago. In an article headed, `Multiple Chemical Sensitivities Under Siege', Ann McCampbell, a medical doctor and chair of that committee, talked about the response of the industry to MCS. Dr McCampbell states:

To that end, the chemical manufacturing industry has launched an anti-MCS campaign designed to create the illusion of controversy about MCS and cast doubt on its existence. What has been said about the tobacco industry could easily apply to the chemical industry regarding MCS, that is, `the only diversity of opinion comes from the authors with. . . industry affiliations'.

It is a credit to the chemical industry's public relations efforts that we frequently hear that multiple chemical sensitivities (MCS) is `controversial' or find journalists who feel obligated to report `both sides' of the MCS story, or attempt to give equal weight to those who say MCS exists and those who say it does not. But this is very misleading, since there are not two legitimate views of MCS. Rather, there is a serious, chronic, and often disabling illness that is under attack by the chemical industry.

The manufacturers of pesticides, carpets, perfumes, and other products associated with the cause or exacerbation of chemical sensitivities adamantly want MCS to go away. Even though a significant and growing portion of the population report being chemically sensitive, chemical manufacturers appear to think that if they can just beat on the illness long enough, it will disappear. To that end, they have launched a multi-pronged attack on MCS that consists of labelling sufferers as `neurotic' and `lazy', doctors who help them as `quacks', scientific studies which support MCS as `flawed', calls for more research as `unnecessary', laboratory tests that document physiologic damage in people with MCS as `unreliable', government assistance programs helping those with MCS `abused' and anyone sympathetic to people with MCS as `cruel' for reinforcing patients' `beliefs' that they are sick. They have also been influential in blocking the admission of MCS testimony in lawsuits through their apparent influence on judges.

Like the tobacco industry, the chemical industry often uses non-profit front groups with pleasant sounding names, neutral-appearing third party spokespeople, and science-for-hire studies to try to convince others of the safety of their products. This helps promote the appearance of scientific objectivity, hide the biased and bottom-line driven agenda of the chemical industry, and create the illusion of scientific `controversy' regarding MCS. But whether anti-MCS statements are made by doctors, researchers, reporters, pest control operators, private organisations or government officials, make no mistake about it-the anti-MCS movement is driven by chemical manufacturers. This is the real story of MCS.

As I say, we need to expect that the chemical industry will probably lead any attacks against this committee. What needs to be done to deal with MCS? Obviously we need to be more assiduous and more wide ranging with data collection so that we can start to make the connections between outbreaks of MCS and exposure to chemicals. Clearly a lot more research needs to be done.

There are issues that need to be investigated about the appropriate labelling of farm chemicals. In the case of some of the agricultural chemicals being used by some of the farmers producing our fruit and vegetables, many of whom speak English as a second language, the labelling would appear to be inadequate. In the book *Our Stolen Future*, written by Colborn, Dumanoski and Myers, the authors say:

We design new technologies at a dizzying pace and deploy them on an unprecedented scale around the world long before we can begin to fathom their possible impact on the global system or ourselves. As we race toward the future, we must never forget the fundamental reality of our situation: we are flying blind. We are all guinea pigs and, to make matters worse, we have no controls to help us understand what these chemicals are doing.

From my perspective and from the perspective of many of the people who suffer from MCS or fertility problems, the impact of chemical exposure is a growing public health problem. It must be treated seriously. The investigation that I propose will begin the process of giving MCS the recognition that it should have in this state. I hope that it will also result in recommendations that will place pressure on government authorities to look twice at some of the practices we tolerate that we ought not to tolerate.

Hon SANDRA KANCK MLC
Parliament House ADELAIDE 5000
Ph 08 8237 9278 fax 08 8410 4171
sandra.kanck@democrats.org.au
www.sa.democrats.org.au

PHAA—letter to NHMRC

This letter followed a Workshop on MCS and CFS organised by the Public Health Association of Australia that took place in Adelaide on September 29th 2002.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

First Assistant Secretary
National Health and Medical
Research Council
MDP 70
GPO Box 9848
CANBERRA ACT 2601

Attention: Research Development Section

The Public Health Association of Australia (PHAA) Environmental Health Special Interest Group and the South Australian Department of Human Services co-hosted a workshop at the 2002 Annual Conference of the PHAA, to explore the aetiology of Chronic Fatigue Syndrome (CFS) and Multiple Chemical Sensitivity (MCS).

The aim of the workshop was to bring together key stakeholders to share information and views and gain an appreciation of the complexities involved in these vexing conditions. Presenters included clinicians with a special interest in / expertise in managing these conditions. They included Rob Loblay and Bruce Wauchope, and researchers Rey Casse and Colin Little. Representatives from advocacy groups, Paul Leverenz and Audrey Brimson, described the experience of living with one of these debilitating conditions and Liz Hanna and Jack Dempsey led discussions on the policy options from the perspective of the PHAA and Commonwealth.
The breadth of perspectives highlighted several factors. Firstly, it was clear that there is intense interest in resolving the questions of aetiology, diagnosis and treatment from diverse array of viewpoints (eg. researchers, clinicians, syndrome sufferers). Secondly, and most strikingly, all participants felt a keen sense of frustration created by the lack of scientific understanding of these syndromes. Nowhere was this frustration more heavily felt than by those who suffer from these syndromes. The sufferers primarily felt the need for scientific evidence to validate the symptoms that they felt and provide a basis for the development of strategies and techniques to alleviate their symptoms and where appropriate introduce appropriate policies for public spaces that to allow them to resume a more normal life. (It has been estimated that up to 1% of the Australian population could be affected by one or other of these conditions.)

Thirdly, the clinicians, voiced frustrations at having to struggle to manage conditions in the absence of an agreed aetiology or understanding of aetiology or pathological process. They are seeking some diagnostic consensus, or the designation of markers to help identify and differentiate cases. Some consensus has been achieved in diagnostic criteria for CFS, however, the same cannot be said for MCS / IEI. (MCS is perhaps better described as Idiopathic Environmental Intolerance (IEI)). The clinicians also noted that little agreement has been achieved in the development and accepted use of best practice in treatment options.

Evidence suggests that environmental exposures contribute to these conditions. Consequently, it is necessary to place research into these syndromes into a coordinated approach, covering research into aetiology through to the development of clinical guidelines and policy development *within a public health framework.* In addition, development of a health and medical response to these syndromes must face the challenge of developing research and policy while ensuring that those who are currently suffering from these syndromes are protected and those, as yet unidentified, who may be at risk from an unidentified agent or agents are also afforded early protection.

Clearly this is a case where there is a need for research to be undertaken as a matter of some urgency. However, it is just as clear that it is also a case where research and policy development must be undertaken within a precautionary approach.

The workshop noted the following key issues:

- CFS and MCS / IEI have a significant health, social and personal impact on individuals and their families;
- the designation of potential risk, prevention strategies, diagnosis and management/treatment are highly complex;
- there are established criteria for CFS diagnosis but not for MCS / IEI; and,
- there is little research effort being extended to develop our understanding of these conditions.

On the basis of this workshop, the PHAA urges the National Health and Medical Research Council (NHMRC) to:

- make the exploration of CFS and MCS / IEI a priority health issue;
- create a collaborative working group, involving key stake holders, to develop strategies to progress future directions about these conditions in Australia; and,
- manage CFS and MCS / IEI using a public health framework.

The PHAA would be happy to discuss these issues further with you, should you feel that it would help progress work in this area. I can be contacted on (02) 62852373 or by e-mail on plaut@phaa.net.au. I look forward to hearing from you about these issues in the near future.

Yours sincerely,

Pieta Laut
Executive Director

Successful Grant Applications for 2002

The Society have been successful in obtaining money to assist SAYME improve its services to members and young people with CFS in general. Community Benefit has given us $3080 to help with the support we can provide for the younger people while Young Australians has donated $5000 for re-developing and maintaining the SAYME website. The Morialta trust has also donated $3, 300 to assist disadvantaged youth with ME/CFS.

Community Benefit

The Community Benefit funding has been allocated to different areas of service. We have been able to purchase some board-games and a Playstation 2 for use at the monthly meetings and some talking books that, along with the PS2, will be loaned out to members between meetings next year (subject to strict conditions). Some money has been allocated to organizing a weekend camp for the younger people (and a family member) which we will try to hold during the mid-year school holidays in 2003. Some money has been allocated to the improvement and cost of producing the quarterly SAYME magazine.

The Foundation for Young Australians

We are looking forward to improvement the information, resources and support that we are able to provide to young people with CFS as well as their family, friends and carers.

Rebecca Cordingley receiving a certificate from Her Excellency, Marjorie Jackson-Nelson, AC, CVO, MBE, Governor of South Australia. Well done Rebecca!

Rebecca Cordingley has boldly taken on the job of upgrading and maintaining the SAYME website which has badly needed a little refreshment after several years of neglect. Additional features such as discussion groups will be added to the site, and it will be promoted nationally. Young people from all around Australia will be invited to participate in and contribute to the website.

'Thanks' to the Foundation for Young Australians who are supporting this project.

Morialta Trust

The Morialta Trust are supporting our Education Support Team's project to improve the educational opportunities of youth with ME/CFS. Penny Cahalan and Sue Heard are working on an information pack about young people and ME/CFS. The packs are intended for distribution to youth, parents, teachers and schools—to raise awareness and explain the needs of young people and ME/CFS. This is one part of our strategy to assist disadvantaged youth with ME/CFS who suffer at the hands of an education system that fails to properly accommodate children with chronic illness—at the core of this is a narrow definition of *disability* which focuses on the permanent physical incapacity. Chronic illness can be equally debilitating and restrictive—yet don't readily fall under the definition of *disability*.

Penny Cahalan receiving a cheque for $3, 300 from Heather Lockheart, of the Morialta Trust

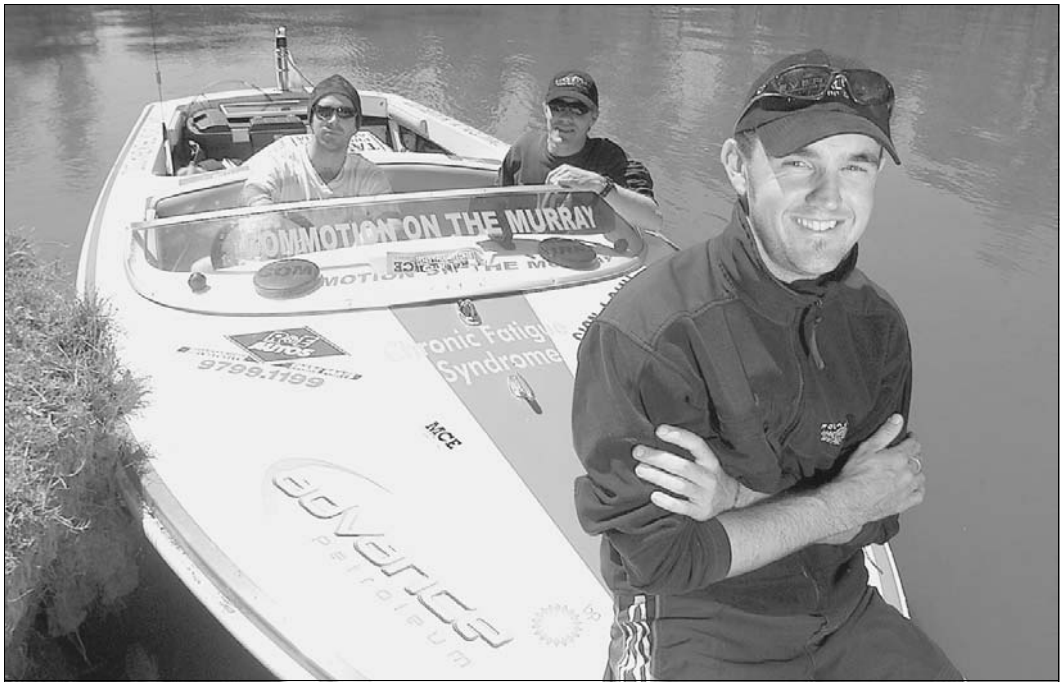
Paul Leverenz / Peter Worsley

Commotion on the Murray

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

raising awareness

Pic. M. Dallinger Front: Ash Thomas Rear Left: Chris Mannering (Support) Rear Right: Nathan Fenton



On Sunday 20th October, we, Ash Thomas and Nathan Fenton, departed on our journey to descend the length of the Murray River, set an unofficial world record for the longest ski biscuit run, and raise awareness for Chronic Fatigue Syndrome. Ash 22, has suffered from Chronic Fatigue Syndrome for 5 years and Nathan, 22, is an adventurous student studying Applied Finance and Investment.

The Murray River is the 3rd longest navigable river in the world, measuring some 2300km, or the equivalent of Melbourne to Brisbane. We were set to travel in a 1978 classic V8 16ft ski boat, designed to be self-sufficient and accommodate the two of us for two weeks. The only modifications we had added were a dual battery setup, UHF radio and solar battery backup. The engine was an original V8 Holden engine, without modification and hopefully up to the job! Our plan included a support crew to assist us with fuel resupply, a role first filled by a mate, then for the second week by our mothers (when you have to rely on someone....) The team all met up for the evenings to camp together on the river bank. The river levels had been kind to us, and would continue to be for the length of the trip.

After starting on the Sunday morning from below the Hume Weir at Albury, after a minor plan alteration, we set off at 6.30am. With our kayak support person, Woody, we made good time. He allowed us to inspect unsafe areas and make the appropriate choice in route, without endangering the boat. Woody stayed with us until we pulled into Albury, a distance of some 30km, before the support crew collected him. From Albury we pushed on to Howlong, where the media awaited to take photos of us. The next stop was Yarrawonga, for a boat portage around the dam wall, hopefully the last time we needed to pull the boat out. With the lake above the wall being rough, it became a real effort to both keep the channel markers on their appropriate sides, and stop the boat taking in water from the waves.

On the Monday, around 3pm, we hit out first real setback. And we do mean setback. We connected with a large submerged log, and stopped abruptly. After paddling to the edge of the river, Ash convinced Nathan that he would in fact have to swim under the boat to check for damage. Foolishly, Nathan believed him, only to discover a

matter of minutes later that the prop could be reached from knee-deep water. After ascertaining there was no fatal damage, we paddled around 2 kms to a beach, where we winched the boat out. 2 hours of winching later, we found that we had indeed smashed a prop, rudder and prop shaft. We tried to get the offending parts out for 4 hours, to no avail. Tocumwal was our next stop to fix these problems, and with the help of Shane and Boots, from Tocumwal Auto & Electrics, it took them 3 minutes and a lead hammer, cast from a jam tin, to get us back in business!

This would prove not to be the only thing we broke. By the time we had the boat in the driveway at home, we had broken 1 prop, 2 prop shafts, 3 rudders, a carburetor, an exhaust manifold, a wheel bearing, and finally the trailer itself. 30km from home (Sunshine) the wheel parted company from the trailer and the boat and trailer ended up on a tow truck! As for the broken trailer blame the tow truck man who managed to break it whilst removing the boat from the truck!. 3000km on the trailer, and it fails in the last 30km... Still, with the help of local mechanics and engineers, we were able to generally make equipment straight enough to be returned into service each time.

The generosity of country people was further evident when we lucked our way onto a 4.5 luxurious houseboat for the night! After a fairly long day, we arrived in Border Cliffs, near the SA/NSW border. Our support team met us with a free beer from the staff at the General Store/ Elura houseboats, and we chatted for a while. In conversation, it came up that Barry and Wendy had a relative who suffered from Chronic Fatigue Syndrome, and 'would we like a night in one of their 5 star houseboats to recharge our batteries, on the house?'. We gratefully accepted and had a very pleasant nights sleep, thanks very much!

Renmark was also a great place, where we met Trevor and Dennis at BP Renmark, and they worked tirelessly acquiring a new exhaust part from Adelaide and fitting it overnight. Without them, we would be both underwater and still in Renmark! In Renmark, we also met Susi Hamilton from ABC Radio, who we took for a ride in the boat while she recorded an interview with us. The interview then went to air the next morning, and we became famous in the area! All the lock masters on the river then knew of our impending arrival, and were looking forward to our brochures and lollies!

Despite hitting a sand bank just out of Renmark, we had quite a pleasant journey through Murray Bridge, and on to Wellington to end our trip. We had been warned of the dangers of the wind, swell and shallow waters on Lake Alexandrina, so decided against crossing it. Upon reaching Wellington we did get curious though, and decided to travel a further 5 kms toward the Great Australian Bite to see just what it looked like! We felt quite relieved to finally see the lake, and realized rather quickly that this lake was not going to be crossed in Commotion II! After a quick self-portrait, we turned around and headed back to Wellington. After 64 hours in the boat, at an average of 33.3km, we had traveled 2037km, crossed 3 states, 3 times zones and had set an unofficial world record! We gave a thought to all those people we spoke to about Chronic Fatigue Syndrome, and enjoyed the lollies from Suga, and realized that this trip had achieved so much more than we planned.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

* * * * * * * *

On the 1st of November, two young Melbourne men completed a descent of the Murray River, the 3rd longest navigable river in the world. Over 13 days, Ash Thomas 22, and Nathan Fenton 22, traveled 2037km in a Classic 16ft V8 Ski boat, raising awareness for Chronic Fatigue Syndrome. The boat traveled from Hume Dam at Albury, to Wellington at the top of Lake Alexandrina in South Australia. "Commotion II" cruised at around 45km/h, with the average speed for the trip coming out at 33.3km/h. During the expedition, they also managed to set an unofficial world record for the longest ski tube ride, with Nathan completing 301 km over 2 days in the tube.

With sunny days for the majority of the trip, the one of the larger problems facing the team was the amount of submerged snags and sandbanks. Over the duration of the adventure, the boat contacted 1 major snag and 2 major sand/ clay banks. These incidents caused considerable damage to the propeller and steering, requiring the boat to be pulled from the water and fixed. The bent components tally, from direct impacts with snags and sand bars, was 1 prop, 2 prop shafts, 3 rudders, and a broken ski pole. Not to be deterred, and with the assistance of Tawco Products Australia, local engineering firms and mechanics, the boat was back on the water quickly.

Nathan's World Record attempt, although not officially recognized by Guinness World Records, was an outstanding achievement. During the 301km, Nathan was subjected to countless snags, tight bends, snakes and freezing conditions, yet persevered to set a new unofficial World Record! He feels that the record shall not be beaten for some time, but welcomes any challengers to extend the record!

Chronic Fatigue Syndrome is a long-term condition, characterized by profound exhaustion. Ash has suffered from CFS for 5 years now, contracted after a long-term virus. The trip was designed to inform and educate as many people as possible about the condition, through an information brochure we provided, and by speaking with Ash and Nathan. Judging by how many people reached for their wallets (we didn't accept donations, please send to CFS/ME Victoria @ 23 Livingstone Close, Burwood), we feel that we have been most successful. What also amazed us was the amount of people that came and found us after hearing about us on the radio. The support was fantastic. More information on CFS/ ME can be found at www.vicnet.net.au/~mecfs

This trip would not have been possible without the support of Advance Petroleum, Evergreen Health, Signarama Moorabbin & Bayside, Suga Confectionary, Tawco Products Australia, R & E Auto's, Kerr & Thomas Solicitors and of course, CFS/ME Vic. Thanks also to the support team, (Chris Mannering, Lyn Thomas and Jan Fenton), Em Broomhall, Elura houseboats, Trevor @ BP Renmark, Tocumwal Auto & Electrical, Susi Hamilton @ ABC Riverland in Renmark, and everyone else involved in this project.

For more information on the expedition, log onto:
http://www.geocities.com/ash_on_mtb/

What gets in the way of being sensible?

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Frankie Campling, author of *CFS/M.E: The Facts*, takes a look at what can get in the way of effective pacing

You can probably relate to knowing what you ought to be doing (or not doing) to best manage your illness, but being diverted from this. At times I'm also guilty of overdoing it, but I'm getting much better at noticing when it's happening. Having talked to hundreds of sufferers while doing telephone counselling, I can recognise many of the things that stop me pacing myself. You might recognise some of them in your own situation.

For many people, doing the minimum just to keep going can make overactivity unavoidable. I think it can help to stand back, look at what needs doing and then ask yourself whether all of it really is essential. It might also be possible to restructure how important stuff is done, breaking it down into smaller bites and stopping for rests between each one.

Speak with authority

It's much easier to follow a regime of balanced rest and activity if you have had a clear-cut diagnosis and authoritative management advice. Nevertheless, if you speak with total confidence, the message is more likely to be received with belief and acceptance. Building up confidence in your own judgement and expertise is vital.

'pride is a luxury I can't afford, but self respect is absolutely vital'

It's only too easy to be sucked into doing too much by other people's expectations, but I think it's worth considering three things:

- Are your ideas about their expectations accurate? It's so easy to do 'mind reading' and believe that they are expecting more of you than they do. Could you check up on this?

- Are their expectations unreasonable? Maybe you could communicate better about what is possible for you, so their ideas are more realistic

- Ask yourself how important it is that you fulfil their expectations. Do you need to please them if they are being unrealistic?

We all have a model of what it means to be a 'good person', which may not be appropriate to the way we are now. It has been useful for me to explore the ways in which I'm valuable for what I *am* rather than for what I *do*. So while I can't always do things with and for my family that I used to, I can be there for them in a way that is probably more appreciated.

I'm working on my tendency to be a perfectionist, which can certainly get in the way of being sensible - but it's still irritating watching someone do something for me that I would have done so much better.

Getting the balance right

When the M.E. eases up after a bad spell, it's very easy to leap into over-activity in sheer relief at feeling better, or to think of it as an opportunity to catch up on all that's been left undone; I can have doubts about my illness and forget just how bad things were last week.

Obviously if our lives are restricted by bad health, it's very tempting to prolong a rare pleasure – 'this is lovely; I want more of it now' – and so move from allowable fatigue into sheer exhaustion. I try to remind myself that by stopping in time, there is a much better chance of having pleasure the next day, instead of being flat out in bed feeling horrible. This applies just as much to my '*I want this finished and out of the way* ***now***' mood.

Often people tell me that they are turning down offers of help because they want to go on doing things for themselves. They may be inconsistent in this, which leads to confusion and possibly anger in those who could lighten the load. I've had to work out for myself what help I can accept, as well as ways of preserving a core of independence. With M.E., pride is a luxury I can't afford, while self-respect is absolutely vital.

Frankie Campling recently won a British Medical Association writers' award in for her book CFS/M.E: The Facts (co-authored by Dr Michael Sharpe; Oxford University Press, £9.99).
In addition, she has co-authored a booklet aimed at the newly diagnosed entitled CFS/M.E: Your questions answered. *To order a copy, send an A5 envelope and cheque payable to Erskine Press (or stamps) worth £1 to Erskine Press, The Old Bakery, Banham, Norwich, NR16 2HW.*

Personal Story:
'An M.E. clinic turned my life around'
By Abigail Owen

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Abigail Owen is living proof that it *is* possible for severely affected sufferers to substantially improve, albeit slowly, given the right specialist support from a multi-disciplinary team. Seven years' illness cost Abigail her career, her marriage, her home and ultimately the will to live. But a referral to the only NHS hospital to offer dedicated M.E. beds turned her life around again. This is her story

My journey through this disease started with a virus, physical and mental stress, and – the last straw - intrusive surgery when I was 36 from which I woke feeling 60 years older. My life was never to be the same again.

Radical and debilitating symptoms included extreme weakness and exhaustion, muscle pain, constant sore throats and headaches, to name but a few. It was if I'd been buried alive and had woken up to find that there was no-one around to help get me out. In my fight or flight reaction I tried to dig myself out, only to find that some joker had buried me upside down and I was digging in the wrong direction.

By 1997, my level of physical suffering meant I was ready to commit suicide – this from someone with no history of psychological dysfunction in her life. I didn't tell anyone because by this point, even talking cost me too much energy.

Turning point

By the time my GP referred me to a counsellor I was sure that the imminent breakdown of my marriage was all my fault: I should not have mood swings, I should try harder to get better. My counsellor listened quietly and then she said, 'Have you heard of the M.E. Centre in Romford, Essex?'

That's when my life changed. The counsellor assured me that I had not caused my own illness, although I was clearly struggling to cope both physically and mentally with the devastation it was wreaking on my life. Both she and my GP suggested that I kept setting myself up to fail, a statement which I took great offence at. After all, I had tried my best to return to work and recover - what else did they expect me to do?

(Continued on page 20)

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

(Continued from page 19)

Pushing too hard

In the first years of illness I had tried changing my career and becoming a hairdresser, which cost me three months bed-bound. Next I tried getting an access certificate to go to university but the effort of gaining this qualification put me back in bed for four months. In fact, by the time I was deemed academically ready to start my degree, I was too ill to read more than two pages.

I finally understood that what my medical practitioner meant by setting myself up to fail was that I was setting my goals too high; that pressure from family, friends and even the medical profession in their desperate attempts to get me 'back to normal' had made me push my body beyond what it was capable of, impeding any chance of recovery.

In the early years of my illness it seemed no-one had the necessary skills to advise me on how to manage my condition. Although my doctor tried to help, he knew very little about M.E. I was advised to conserve energy, but not shown *how* – and felt that I had none to 'bank' in the first place.

Admission to hospital

After the added stress of a horrible divorce in 1999, I was admitted into the CFS unit at Oldchurch Hospital in Essex - an NHS hospital which works closely with the National M. E. Support Centre - for a four-week stay. My reaction initially was that I did not want to go. My condition was getting worse and I was scared of aggravating it further.

Despite my fears I was welcomed into the ward and treated with such gentleness and respect, something I had not encountered for a long time. On the second day Professor Findlay, a counsellor, an occupational therapist and a physiotherapist came to see me, at different times and within my own ability. Their common objective was to help me get my life back.

On my first day walking unsteadily up the corridor to the toilet a nurse came up behind me and said 'If you need help, ask!' This was an experience I'd never been allowed to have, to actually say to someone: I need to go to the toilet, will you help me?

Improving my breathing

There were blood tests and white T cell counts, muscle nerve tests and brain scans to rule out other conditions. During my first consultation with a House doctor I became very defensive after he stated that I had been hyperventilating when I was speaking to him. But the doctor explained that everyone hyperventilated during speech and that part of my recovery programme would be to train myself to breathe from the diaphragm to correct my blood gases immediately after speaking. Since getting ill, I tended to run out of breath and end up gasping for air in the middle of a sentence – I now realised why. Once shown techniques to prevent this happening, I did start to feel the benefit quite quickly.

However, the most significant part of the programme comprised graded activity and disciplined rests, which were to be carried out by ourselves, the patients. To this end, we had to keep a specific diary of our activities for two weeks prior to admission.

Giving the body a chance to heal

Carefully my occupational therapist would go through my day looking at all activity minute by minute. He explained that I had to half the amount of time spent on a particular activity (standing, conversations, watching TV, walking

(Continued on page 21)

etc.). This meant starting activities at my base line, i.e. without provoking symptoms.

He also explained that I must have at least six proper rest periods a day, which I still do. Rest to me now means lying on the couch with a blanket over me, covering my eyes with an eye mask, putting ear plugs in my ears and breathing from the diaphragm to ensure that my blood gasses are correct.

During the next three days in hospital I maintained the disciplines required, not walking any further than I was told, asking for help with personal care, resting, interacting with others and taking medication at set times, while using all the resources of the medical nursing staff, including a wheelchair.

On my fourth day at Romford I woke up without a sore throat or headache for the first time in seven years. The pain in my arms had lessened and although still disabled, I felt so glad that I had not taken my own life when my despair had been at its greatest.

Special friendships an added bonus

As the weeks rolled on, I acquired more knowledge about the illness, and about triggers which caused my shut-downs or a flare up of symptoms. I learned the difference between low, middle and high rate activity, and how to match them in order to manage the condition.

My absence from the family gave me a chance to rest, and not have to handle everyday stresses. By the time I was ready to leave, I had acquired all the skills necessary to live with my illness. As an added bonus, after seven years' isolation, I had made some very special friendships with other M.E. patients on the ward.

As an outpatient, a large part of my programme involved my wheelchair; now a resource and not a shame. Being in a wheelchair meant I could actually enjoy my day and not suffer unmerciful consequences.

A new life

Seven months after my stay in Romford I married my best friend, Frank. Eight months later I managed to visit the magnificent Grand Canyon in America, aided by the specific and calculated use of resource management. I kept rigidly to my programme, making sure that I planned every step of our journey from home, using the airport's wheelchair assistant resources. To maintain a good blood sugar, we bought food every morning and kept it fresh in a 12 volt cool box. Every rest period consisted of a full 30 minutes without light or sound entering my brain. I had the opportunity to witness some of the great wonders on this Earth, that only 15 months earlier would have been impossible.

I still need my carer to come in every day and don't yet have the independence of going far alone, as my brain still reacts badly to such stimulus as the noise of traffic.

Interestingly, I find that so long as I manage the physical side of my illness, the psychological symptoms of depression and despair don't trouble me either.

Living for today

It's now 31 months since my stay in Oldchurch Hospital. While there, friends had sent me flowers and I discovered that I was driven to paint them. A passing neurologist, on seeing my watercolours and the depths and layers of my three-dimensional images, said I had a real gift. This inspired me to gain an occupational therapy myself, so within my rest and activity programme I began developing the skill further, to the extent that I have now launched my own business, making 3D images from personal photographs etc. It means I have fun and if I am fortunate and earn £5 in a week that's a financial buzz too.

The programme is not a magic cure, but it has stopped further deterioration and given me back some quality of life. Not everyone on the ward with me was as lucky; some did not benefit and I witnessed others who actually deteriorated in a hospital environment. Perhaps I flourished because I was used to being assessed, graded and given objectives in my previous career. I was also determined to be open-minded and take anything from the programme that might benefit me.

My carer, Pat Leslie, was so impressed with the benefits of my management programme that she has adapted it for herself. Between us, we have now established a self-help group based in Sedgemoor in Somerset for local people affected by M.E.

Through the fullness of time I hope to make the best recovery I can, but in the meantime the programme and my faith in God have helped me make the most of today. On reflection I would say that despite the disability, my life is now much fuller.

Reprinted with Permission by Action from InterAction Issue 41, the magazine of Action for ME, UK

Www.afme.org.uk

Used with permission

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Special Feature: School and Kids with Chronic Fatigue Syndrome

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

In this society education is important for everyone's future, from a basic understanding of the world, to career prospects. Schooling is also valuable for children because they are given the chance to relate to their peers and teachers. Learning gives young people an interest, a sense of achievement and a purpose.

Complications arise when because of health reasons, kids are unable to attend school and/or complete work in the same way as a normal healthy child. I have struggled with Chronic Fatigue Syndrome since I was 10 years old, and have tried to attend and complete classes since. From trial and error, and with help from my parents and others, I have learnt a great deal. I have learnt information from the school curriculum, but I have also learnt about society, politics, and people, and by the time I attended college (years 11 and 12) I had learnt how to minimise the stress and difficulties that occur when trying to attend school while living with a chronic illness.

The most important advice I can give to kids with Chronic Fatigue Syndrome (CFS) is to be dedicated and diplomatic, and that applies to parents too. Kids, if you want to have an education you have to show your teachers that you are serious. That means asking for work on the days you've missed, turning up to all your classes (unless you are unwell) and behaving in class. You need to respect your teachers and earn their trust. Because you have CFS, you are not an ordinary student and you are asking to be treated with special consideration. Many kids wag school and don't care about their studies and if you are one of those kids it will be hard for teachers to believe you are genuinely ill. Teachers work hard, often marking student's work until late at night and on weekends. They also face many students trying to get out of work or get an extension to an assignment, purely because they are lazy and/or don't want to work.

There is a cloud that is lifting in society in general over whether CFS is a real disease or not. You, as a student, need to make sure you don't give your teacher any reason to believe you are faking. But more than that, teachers work hard and you are asking them to spend extra time on you. This is where there is a need for diplomacy and persistence. 'The system' doesn't easily accommodate people outside the box, or the norm.

For your school to understand absences and acknowledge your illness you will need to have a supportive doctor. A supportive doctor will not only write doctors certificates saying you have Chronic Fatigue Syndrome, but also include on those certificates an explanation of symptoms, what allowances you might need and problems which might arise (such as periods away from school). Also, your doctor will need to advise your school on different strategies at different stages of the illness. A supportive, accepting doctor is essential for any CFS sufferer, and essential for a child to be able to successfully complete their schooling.

The following are strategies that worked for me in Primary School, High School (7-10) and College (11-12), each building upon the other.

Primary School

In primary school, my parents arranged with the school for me to tell my teacher when I was tired and leave class to rest in the library. All I needed was a note to get extensions for assignments. At the time, I saw a doctor who recommended I increase my exercise (which I now believe was the wrong advice) and therefore I still participated in Physical Education (P.E.), and took a note from home on those days I was particularly ill and could not do P.E.

Parents need to take the lead for Primary school children, petition their cause, give them support at home and encourage them to spend time with their friends. It is important for children to have some sort of social interaction. The best thing the kids can do is quite plainly, be good in class. However from what I can gather in most cases this isn't a problem, because kids with CFS are too tired and/or unwell to play up in class. They find it easier to be compliant and do the work asked of them.

High School

My health improved for years 7 and 8 so, while I felt tired constantly and had to rest a little more than my peers, I led a normal active life. In year 9 my health declined again and I was unable to attend school. My teachers and finally the distance education coordinator sent schoolwork home, but even though I tried, it became clear I could not do any schoolwork.

If you are housebound it is important to try to do distance education and work from home without overextending

(Continued on page 23)

(Continued from page 22)

yourself. This will keep your mind busy and give you a sense of achievement with each piece of work you complete. Distance education will help you to continue schooling when you are able. It will decrease the chances of you having to repeat a year and lessen gaps in your general knowledge. No matter how much time you've had off, working from home will make it easier to catch up when you return to school.

When you have been away from the school environment it can be quite daunting to return and gradual steps make this easier. I found the transition smoother because I kept in touch by phone with a couple of school friends, so I knew what to expect when I returned. For the record, school really doesn't change and from a social and managing aspect it was very simple to slot back in to school life.

From a health aspect, don't return to school until you feel you can handle it. And return at the rate you can manage, even if that is only one or two subjects. In some cases only a portion of a subject course will be enough, perhaps learning, but not doing any assessable items. Of course this depends on your condition. Don't jump in head first to a full load, because most likely it will be detrimental for you health, your schooling and your confidence. Push yourself too much, too soon and you will consequently be set back. Having said that, if you do find you are doing too much, too many hours, too much homework or you find the work too difficult, this will be reflected in your symptoms such as tiredness or pain level. Do not hesitate to drop subjects or, if you are only doing one subject, to stop attending school. It is not a failure, you just weren't ready. You can always pick up those subjects when your health improves and you feel ready. Put your health first.

My teacher had an idea that truly helped when I was doing 3 subjects in year 10 and I carried it through to year 12. She recommended I do unfinished classwork, homework and assignments at school if I could, with regular rests. This means you can do school work without distractions such as family, TV etc. This also means that when you are at home you don't have to worry about school. Home will become a place where you can wind down, relax and rest without the pressure of having to do more school work hanging over you.

Another point she made was that a change of subject can be as good as a rest. So when you are doing school work (out of class), alternate work on different subjects to help your concentration. I would tend to rotate, for example Maths homework, an English assignment and resting. Don't try to do big slabs of work in one go, it's best if you do what you can handle, which might only be 10 minutes on each subject. The time you can spend between resting will depend on (be dictated by) your personal health/stamina.

This also applies when deciding on your workload and how many subjects you do. If you are able, it is preferable to do 2 or more subjects, so you are not completely consumed by for example maths, and particular problems you may be having with the maths work or the teacher at that time. Again, you will get some relief from maths while you are in another class or doing homework for another subject. If you can, organize to be excused from less important assessment items for subjects, so you can do more than one subject. I found this beneficial. Basically, if you do more than one subject and you rotate work from each subject and resting, it will mean that you will be less stressed and one subject (in effect all school work) will not become a mountain.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

For your future education's sake, start with core subjects: Maths, Science and English and Social Education (History and Geography). This will give you the basics for future study and life. However, your doctor may recommend you do an elective of a subject you enjoy, again to take the pressure off and keep you motivated towards study.

In particular, if you are doing more than one subject it is important to tailor your timetable as much as possible to your needs. For example, I was stuck with a timetable that meant on Fridays I had one subject first in the morning and then another last in the afternoon. Because I lived out of Canberra this meant I had to stay at school all day and even though I had a room to rest in, it took a toll on my body. This may also be a problem if you have to catch a bus both ways and you find bus rides tiring. The day might take too much out of you. You may also find it difficult to concentrate for two whole subjects in a row without a break (basically 2 hours). Therefore it would be beneficial to organize your timetable so you do one subject and then you have a period off before you do the next. For some people just to have recess (to either rest or chat to your friends) in between classes will be enough. The social aspect of school is also very important. It's important you get a chance to see your friends, to talk to people and have some support and this should also be factored in when deciding your timetable. Of course, your timetable will largely come down to your choice of subject and the school's timetable.

Because for a few years I was only doing 2-3 subjects, my father drove me to school and back. This reduced the toll that school took on my body a great deal and had I not had his help, schooling would have been much more difficult. If it is not possible for a parent to drive you, and school or bus rides are too much, distance schooling is always an option. Talking your situation through with a teacher (for me my counsellor) will give you ideas on solutions.

I recommend from high school age finding a teacher to further/petition/represent your cause. In my case I had a very helpful counsellor who came up with many of the ideas for the logistics of managing school. The person you choose needs to be sympathetic to your situation and willing to push forward your case and put pressure on other teachers if necessary. For this reason it is best to pick a teacher who has some power. Some suggestions are, your counsellor, year co-ordinator, special needs teacher, or a

(Continued on page 24)

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

subject head you have already found helpful. As a rule I wouldn't suggest the principal or deputy principal because most are so busy they won't have the time to help you. Again, you need to work in co-operation with your teachers, basically all your teachers will have to spend extra time on you, and do extra work for you. Because you are not the usual student, they will have to explain their actions in regards to you, to other teachers. Don't abuse the leniency and the trust they give you, as they are under no obligation to make things easy for you.

In High School, if you have a helpful teacher they will talk to other teachers for you (both those listed and your subject teachers), but particularly in College it is important that all the relevant teachers are informed and consulted about your situation.

My counsellor spoke to all my subject teachers about my condition and she also sent them a letter explaining that I might need extensions for work and longer time for tests. She also sent some pamphlets about Chronic Fatigue Syndrome to them. When I went to class, my teachers talked to me and got to know me, so they knew I was serious about learning. This helped as they now had some knowledge of CFS and of my specific condition. When I did need extensions, I found my teachers very reasonable and understanding.

There are many aids you can ask for. You can ask for extensions for assignments and homework, and you can ask for extra time for tests and in class assessment pieces, without losing marks. For instance, I sat a test over three half hour sessions on different days, instead of sitting it in one, hour lesson. If there is a large amount of homework, you may be able to organize with your teacher to do only the most important homework. If this does happen make sure you are not penalized for not handing it in. My science teacher penalized me this way once, so while I received 80% for everything I handed in, he gave me a C.

Both in High School and in College I asked for a room where I could lie down in and rest any time I was not well. This was a quiet, rarely used room in the school. Both in High School and in College I had to ask for a key each time to open the room, and I was rarely disturbed. Ideally you would have a room for yourself, but in most schools this is not possible. Occasionally I had to leave the room because another class wanted to use it. There was a desk in the room, so I often alternated resting with some schoolwork (this was quieter than the library, and I could immediately lie down if I needed to). I bought a beanbag I could lie down on and took my Walkman to school so I had some music to listen to when I was resting. This is better than the sickbay because firstly, sickbays are noisy with people walking in and walking past all the time, and secondly, it is not helpful to be around sick people every day for someone with CFS.

One of my worries about returning to school was that mid-class I would get extremely tired, or be in pain and that the teacher would not let me out of the room. My counsellor said that it shouldn't be a problem with my teachers because she would talk to them. However I was still worried about relief teachers who knew nothing about my situation. My counsellor gave me a card, basically saying that I had Chronic Fatigue Syndrome and that I could leave the class at any time without reason. It had her signature and name down the bottom of the card. I also arranged for one of the teachers in college to give me a similar note. Although I never used the card, I believe it is a great idea, because if you are feeling unwell you do not want to be trying to convince your teacher of that, especially a relief teacher who is likely to think you are lying. Do not abuse this privilege.

I would like to stress the following points. Don't tell other kids you have your room because they are likely to want to go in with you and talk when you need to rest (the teachers therefore may not believe you need it for resting if they find other kids in your room). It's better to join your friends on your terms, in the playground at lunchtime, or recess or before or after school.

Don't tell and especially don't show off to your friends that you get extensions or may not have to do a piece of work. If you do, they may challenge your position and ask why you get an extension and they don't. They could also challenge your grade etc and make life difficult. In this respect it is better to be discrete. The same applies with your note to get out of class. Kids rarely understand this illness and won't want you to have an advantage over them, whether it means getting out of class or getting out of doing homework. If students do challenge your special case, it will be harder for the teachers to cater for your illness. It is a lot easier and causes fewer problems to have a blanket rule for everyone.

There are people in society who do not believe that CFS is real and this also applies to teachers. In year 11, I approached my maths teacher after my first lesson to talk to him about my situation and to explain that I would need extra time for assignments etc. As soon as I said I had CFS he replied sarcastically "Oh everyone seems to be coming down with that", implying that I was faking and I did not have a real illness. This took me back a step. He begrudgingly said "Yeah ok" to my other requests and abruptly left. There were many other maths classes running in my school so I just changed classes. In the end people like that will just cause problems for you so my advice is to avoid them, if possible.

It may be difficult to organize these concessions and ultimately you will have to work around the schools facilities and rules but it is important to organize it, for the best impact on your health, your education, and your social and psychological well being.

College

When it comes to College (years 11 and 12), you are old enough to take your studies largely into your own hands.

(Continued on page 25)

Your teachers will expect you to come to them and explain your situation rather than, or as well as, hearing it from your parents or another teacher. As much as most young people may not want to spend time talking to teachers, it is important to talk to them about your situation, your options and to make general chit chat/small talk. You need to give your teachers respect and not treat them as the enemy. If possible try to be kind, sincere and likeable. As I said, it is advisable to approach teachers yourself. This includes finding a teacher to represent you as well as informing other appropriate teachers of your situation: your subject teachers; counsellor; special needs teacher; year co-ordinator; student programs (the teachers who organize timetables) and school and careers advisor (who will help you work out a plan to complete your Year 12 Certificate, and/or do the HSC and tell you which prerequisite courses you will need if you choose to go to university). There may be other teachers you feel need to be informed. You need to be comfortable in fighting for yourself and telling your story.

You will meet other teachers on the way, and as I've said before, it doesn't hurt to get them on side. For me, when I had a particular requirement, I found out that the teachers had discussed me, and the problem, in the staff room before they came to a decision. One of my subject teachers was able to stand up and support my case because she knew me in class to be a good student. I had previously informed other teachers so no teachers were taken by surprise, or were suspicious of my sincerity. This helped my situation.

However, you may come across teachers who do not respect you as an adult and do not wish to help you. In this instance, you can tell your representative teacher and in most cases they will talk your teacher around. If that does not work or your representative teacher is not helpful, bring your parents in to talk to them. If that doesn't work, arrange a meeting with you, your parents and the principal to talk about your schooling.

As with a normal child or adult, balance is very important for physical and psychological well-being. You need to have a balance between exercise (walking around the corridors at school may be enough), school and mental stimulation, pleasure (whether it is playing a musical instrument, watching TV or playing on the computer), spending time with your family and spending time with friends. Having CFS can be a very isolating disease. As well as the losses incurred when you lose an active life, many children lose friends as well. It is hard particularly for kids to understand CFS, especially when the lifestyle is to stay up all night. Parents and doctors should encourage kids to spend time with their friends, in and out of school.

If you aren't able to go out of the house much, letters and e-mails can help you keep in touch. I found talking on the phone was useful because I could talk to my friends without getting as tired as when I saw them in person. But remember to pace yourself and when you begin to feel tired end the phone call. If your friends don't understand that you have to go because you do not feel well, you can always say your parents need to use the phone. When writing and reading letters, don't feel obliged to finish them in one go, read or write little bits at a time and you won't feel as tired.

Because of the symptoms you suffer due to your condition (such as reduced concentration) and/or if you have missed school, you may not be able to handle the level of work you previously achieved. This may mean making an adjustment to lower standards by accepting lower test scores and marks. It may even mean doing a less advanced level of schoolwork. This is unfortunate, but your health must come first and hopefully as you build up your reserves you will be able to take on more.

In class, sometimes I was well enough to attend, but not work. On these days I listened to the teacher and kept a low profile. Sometimes my concentration ran out part way through class, so I would just sit quietly until I felt a bit better. Then I'd resume my classwork, or wait until the class ended. Because my teachers had some understanding of the illness and because I kept a low profile and wasn't disruptive no eyebrows were raised.

From years nine and ten upwards it is important to be diligent with your studies, even if other kids aren't. Don't be slack and not do homework because you don't want to. If you are away make sure you approach your teachers and get the work you missed. This will prevent you from falling further behind.

Conclusion

Despite all your efforts to be diplomatic and likeable, you are likely to face obstacles during your education and some may be difficult to overcome. Some teachers may treat you unfairly, lower your grade because you have not completed all items, or may not be very lenient. Unfortunately, this is within their rights because they have a set of rules that apply to all students, and they may expect you to abide by those rules even though they may not be realistic for you in your condition. I recommend approaching other teachers who have been helpful and asking them to petition your case, but if they won't or can't make any ground there is little you can do, unless you are outwardly being discriminated against. Most teachers will be helpful and sympathetic as long as you take a mature attitude to your studies. Of course the more CFS is recognized as a valid illness by society the easier schooling for young people with CFS will be.

With hard work and determination it is possible to continue school and do well while living with CFS and in doing so, to gain a feeling of achievement knowing that you have succeeded at schooling despite obstacles you have had to face.

Mary Campbell
ChaMEleon, Spring 2002,
ACT ME/CFS Society
http://masmith.inspired.net.au
Used with Permission

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Thankyou to Microsoft

Microsoft have kindly donated two copies of Windows XP, Microsoft Visio, and Office XP. This is the second time we have benefited from their kindness. These gifts, along with other software donated 2 years ago, are greatly assisting the Society, and are very much appreciated.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

From our Patron: Her Excellency, Marjorie Jackson-Nelson, AC, CVO, MBE, Governor of South Australia

With best wishes for

Christmas and the New Year

from

Marjorie Jackson-Nelson

Marjorie Jackson-Nelson

Government House
Adelaide

Christmas 2002

Her Excellency and four of her grandchildren
at the 2001 Credit Union Christmas Pageant

Medical Matters

Persistent Pain in Patients with Chronic Fatigue Syndrome

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

By Laurence A. Bradley, PhD

University of Alabama at Birmingham

Widespread and persistent pain is very common in people with chronic fatigue syndrome (CFS). A recent population-based study revealed that 94 percent of patients report muscle aches and pains, 84 percent report joint pain or morning stiffness and 19 percent report jaw pain.[1,2] Indeed, there is a high degree of overlap between CFS and other syndromes that are characterized by recurrent or persistent pain.

For example, clinic-based investigations suggest that among people with CFS, 35–70 percent meet criteria for fibromyalgia (FM)[3,4] and 36–63 percent meet criteria for irritable bowel syndrome.[3,5] There also is evidence that four to eight percent of patients with CFS report that they have received diagnoses of interstitial cystitis, chronic tension-type headache, persistent pelvic pain and multiple chemical sensitivities.[3]

The overlap between CFS and FM is especially important because individuals who meet standard diagnostic criteria for both disorders experience debilitating fatigue and widespread pain, and experience allodynia, pain in response to stimuli such as pressure or heat that do not evoke pain in healthy persons.[6] The enhanced pain sensitivity may increase the likelihood of experiencing very high levels of disability and psychological distress.

Unfortunately, little is known regarding the etiopathogenesis of persistent pain or allodynia in people with CFS. Moreover, investigators have not measured changes in pain in studies of medical and behavioral treatments for CFS. This paper will review the current literature concerning factors that may contribute to persistent pain or allodynia in CFS, and will recommend that investigators evaluate various combinations of pharmacological, immunological and behavioral therapies in order to identify the most effective treatment approaches for reducing pain in subgroups of patients with CFS.

Genetic factors

Numerous investigators have proposed that there may be a genetic component to the development of painful symptoms in persons with CFS.[7] However, well-designed investigations of genetic and environmental factors that may contribute to CFS have just begun to appear. While these findings are very exciting, it is not yet known whether there are specific genes that might predispose individuals with CFS to experience allodynia or enhanced sensitivity to pain.

It is interesting to note that a study performed in Germany found that patients with FM, compared to healthy persons, were significantly more likely to exhibit a functional polymorphism in the regulatory region of the serotonin promoter gene.[8] Serotonin is a neurotransmitter that is involved in the pain inhibition system involving the brain and the spinal cord. Thus, the genetic abnormality identified in persons with FM might contribute to the abnormal levels of serotonin and allodynia associated with this disorder. It would be interesting to determine whether a greater number of individuals with both CFS and FM, compared to those with CFS alone, show the same abnormality.

Neuroendocrine and immune functions

Efforts to understand the symptoms of CFS have led researchers to study the neuroendocrine function in samples of patients with CFS. Most of these investigations have

(Continued on page 28)

(Continued from page 27)

focused on the function of the hypothalamic-pituitary-adrenal (HPA) axis, which is activated by stressors such as exhaustion, pain and perceived threats.[9] During exposure to stressors, the hypothalamus increases the production of corticotropin releasing hormone (CRH), which stimulates the pituitary gland to release adrenocorticotropic hormone (ACTH). ACTH, in turn, activates the adrenal gland to release cortisol.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

This sequence of events has important implications for the pain associated with CFS.[10] For example, CRH enhances the actions of descending pathways from the brain to the spinal cord that are involved in pain inhibition through their effects on the sympathetic nervous system and the secretion of opioid peptides in the hypothalamus.[7,10] CRH also may diminish pain through its facilitating effects on production of cortisol and other substances that inhibit pain.[9,10] There is consistent evidence that patients with CFS are characterized by low hypothalamic levels of CRH[11] and some studies indicate that these patients also exhibit low cortisol levels.[12,13]

A number of abnormalities in immune system function have been identified in people with CFS.[14,15] It has been consistently found that patients with CFS tend to exhibit elevated levels of cytokines that promote inflammation, such as interleukin-1-alpha (IL-1 alpha) in blood plasma.[15] These pro-inflammatory cytokines may interact with the central nervous system in ways that have important implications for pain.[15–18]

Neuropeptides related to pain

Serotonin regulates the circadian fluctuations of the HPA axis[19] and probably plays a role in stimulating the release of CRH from the hypothalamus.[20] Moreover, it contributes to the activation of descending antinociceptive pathways from the brain to the spinal dorsal horns.[7] Several investigators have sought to determine whether low serotonin production might be associated with the painful symptoms of CFS. It has generally been found that patients with CFS, compared to healthy controls, show higher blood plasma levels of the serotonin metabolite 5-HIAA[21] and a prolactin response to buspirone indicative of enhanced serotonin neurotransmission.[22] In contrast, patients with FM, compared to controls, show lower blood serum levels of serotonin and lower cerebrospinal fluid (CSF) levels of the serotonin metabolite 5-HIAA.[23]

Psychiatric comorbidity

Many people with CFS experience significant psychological distress. Studies using structured psychiatric interviews indicate that up to one-half of patients with CFS meet standard criteria for major depression.[6]

It does not appear that depression is a major factor in the development of persistent fatigue and pain. However, it is important to acknowledge that depression and other emotional and cognitive factors influence the transmission and modulation of pain in the central nervous system and, thus, affect our perceptions of the intensity, sensory qualities and the unpleasantness of pain.[24]

Treatment implications

Little is known regarding the effects of medical and behavioral interventions for pain in people with CFS. Investigators have focused on fatigue, functional ability and general quality of life as the primary outcomes of controlled trials of these interventions.[25,26] At present, then, it is not possible to make any meaningful conclusions regarding the effects of immunological, behavioral or pharmacological therapies on pain in persons with CFS.

Given the similarities in HPA axis dysregulation among people with CFS and FM, it is worthwhile to examine the outcomes of medical and behavioral interventions on pain in persons with FM. Our laboratory recently reviewed the outcomes of pharmacologic approaches to FM pain and concluded: amitriptyline and cyclo-benzaprine are superior to placebo in producing improvements in pain, sleep quality, and fatigue, although the efficacy of these pharmacologic agents appear to diminish over time; and studies of the effects of selective serotonin reuptake inhibitors (e.g., sertraline hydrochloride, fluoxetine) are limited and have produced both positive and negative results.[27] Given that patients with CFS tend to show normal blood levels of serotonin, the efficacy of these interventions for pain management in CFS may be limited primarily to those individuals who meet criteria for both CFS and FM.

Our review of behavioral approaches to pain management in FM led to conclusions similar to those concerning the effects of behavioral interventions on fatigue and quality of life in the CFS literature.[25] That is, although there is a large amount of variation in the quality of study designs, structured, graded exercise programs that emphasize improvements in aerobic fitness tend to produce significant and sustained reductions in pain among persons with FM.[28] However, in contrast to the literature on patients with CFS, all adequately designed studies of the effects of cognitive-behavioral therapies on pain have shown that these interventions do not produce reductions in pain greater than those achieved by placebo.[29]

Conclusions

Available evidence suggests that there are complex mechanisms underlying persistent pain in persons with CFS. Although little is known about the effects of current treatment interventions on pain in CFS, it is reasonable to suggest that it will be necessary to evaluate various combinations of pharmacological, immunological and behavioral therapies[30] in order to identify the treatment approaches that are most effective for various subgroups of patients (e.g., persons with CFS only vs. those with CFS and FM).

Laurence A. Bradley, PhD, is Professor of Medicine in the Division of Clinical Immunology and Rheumatology at the University of Alabama at Birmingham. Dr. Bradley also serves as the head of the Neurobehavioral Medicine Working Group in the Division's NIH-supportedMultidisciplinaryClinicalResearchCenter.

References

1. Jason LA et al. A community-based study of chronic fatigue syndrome. *Arch Intern Med*. 1999; 159:2129-2137.
2. Jason LA et al. Symptom occurrence in persons with chronic fatigue syndrome. *Biol Psychol*. 2002; 59:15-27.
3. Aaron LA et al. A review of evidence for overlap among unexplained medical conditions. *Ann Intern Med*. 2001; 134:868-881.
4. Bradley LA et al. Pain complaints in patients with fibromyalgia versus chronic fatigue syndrome. *Curr Rev Pain*. 2001; 4:148-157.
5. Gomborone JE et al. Prevalence of irritable bowel syndrome in chronic fatigue. *J R Coll Physicians London* . 1996; 30:512-513.
6. Buchwald D. Fibromyalgia and chronic fatigue syndrome: similarities and differences. *Rheum Dis Clin N Amer*. 1996; 22:219-243.
7. Clauw DJ et al. Chronic pain and fatigue syndromes: Overlapping clinical and neuroendocrine features and potential pathogenic mechanisms. *Neuroimmunomodulation*. 1997; 4:134-153.
8. Offenbaecher M et al. Possible association of fibromyalgia with polymorphism in the serotonin transporter gene regulatory region. *Arthritis Rheum*. 1999; 42:2482-2488.
9. Chrousos GP et al. The concepts of stress and stress symptom disorders. Overview of physical and behavioral homeostasis. *JAMA.* 1992; 267:1244-1252.
10. Lariviere WR et al. The role of corticotrophin-releasing factor in pain and analgesia. *Pain.* 2000; 84:1-12.
11. Demitrack MA, et al. Evidence for impaired activation of the hypothalamic-pituitary-adrenal axis in patients with chronic fatigue syndrome. *J Clin Endocrinol Metab*. 1991; 73:1224-1234.
12. Cleare AS et al. Urine free cortisol in chronic fatigue syndrome. *Amer J Psychiat*. 2001; 158:641-643.
13. Scott LV et al. Urinary free cortisol excretion in chronic fatigue syndrome, major depression, and in healthy volunteers. *J Affect Disord*. 1998; 47:49-54.
14. Vollmer-Conna U et al. Chronic fatigue syndrome: an immunological perspective. *Aus NZ J Psychol*. 1998; 32:523-527.
15. Patarca-Montero R et al. Cytokine and other immunologic markers in chronic fatigue syndrome and their relation to neuropsychological factors. *App Neuropsychol*. 2001; 8:51-64.
16. Besedovsky H et al. Immunoregu-latory feedback between interleukin-1 and glucocorticoid hormones. *Science.* 1986; 233:652-654.
17. Demitrack M et al. Evidence for and pathophysiological implications of hypothalamic-pituitary-adrenal axis dysregulation in fibromyalgia and chronic fatigue syndrome. *Ann NY Acad Sci.* 1998; 840:684-697.
18. Sternberg E. Hypoimmune fatigue syndromes: disease of the stress response? *J. Rheumatol.* 1993; 20:418-421.
19. Krieger DT et al. Serotonin mediation of circadian periodicity of plasma 17 hydroxycorticosteroids. *Am J Physiol.*1969;217:1703-1707.
20. Holmes MC et al. Role of serotonin in the control of secretion of corticotrophin releasing factor. *J Endocrinol.* 1982; 93:151-160.
21. Demitrack MA et al. Plasma and cerebrospinal fluid monoamine metabolism in patients with chronic fatigue syndrome: preliminary findings. *Biol Psychiatry.* 1992; 32:1065 1077.
22. Bakheit AMO et al. Possible upregulation of hypothalamic 5-hydroxytryptamine receptors in patients with postviral fatigue syndrome. *BMJ.* 1992; 304:1010-1012.
23. Russell IJ et al. Cerebrospinal fluid biogenic amine metabolites in fibromyalgia/fibrositis syndrome and rheumatoid arthritis. *Arthritis Rheum.* 1992; 35:550-556.
24. Loeser JD et al. Pain: an overview. *Lancet.* 1999; 353:1607-1609.
25. Whiting P et al. Interventions for the treatment and management of chronic fatigue syndrome: a systematic review. *JAMA.* 2001; 286:1360-1368.
26. Nezu AM et al. Cognitive-behavioral therapy for medically unexplained symptoms: a critical review of the treatment literature. *Behav Ther.* 2001; 32:537-583.
27. Bradley LA et al. Fibromyalgia. In: Koopman WJ, ed. "Arthritis and allied conditions: A textbook of rheumatology." 14th edition. Baltimore, Md. : Williams & Wilkins, 2000; 1811-1844.
28. McCain GA et al. A controlled study of the effects of a supervised cardiovascular fitness training program on the manifestations of primary fibromyalgia. *Arthritis Rheum.* 1988; 31:1135-1141.
29. Bradley LA et al. Central nervous system mechanisms of pain in fibromyalgia and other musculoskeletal disorders: behavioral and psychologic treatment approaches. *Curr Opin Rheumatol.* 2002; 14:45-51.
30. Lloyd AR, et al. Immunologic and psychologic therapy for patients with chronic fatigue syndrome: a double-blind, placebo-controlled trial. *Amer J Med.* 1993; 94:197-203.
31. Lange G et al. Neuroimaging in chronic fatigue syndrome. *Am J Med.* 1998; 105(suppl):50S-53S.
32. Buchwald D et al. A chronic illness characterized by fatigue, neurologic and immunologic disorders, and active human herpesvirus type 6 infection. *Ann Intern Med.* 1992; 116:103-113.
33. Natelson BH et al. A controlled study of brain magnetic imaging in patients with the chronic fatigue syndrome. *J Neurol Sci.* 1993; 120:213-217.
34. Lange G et al. Brain abnormalities exist in a subset of patients with chronic fatigue syndrome. *J Neurolog Sci.* 1999; 171:3-7.
35. Schwartz RB et al. SPECT imaging of the brain: comparison of findings in patients with chronic fatigue syndrome, AIDS dementia complex, and major unipolar depression. *AJR.* 1994; 162:943-951.
36. Costa DC et al. Brainstem perfusion is impaired in chronic fatigue syndrome. *Q J Med.* 1995; 88:767-773.
37. Tirelli U et al. Brain positron emission tomography (PET) in chronic fatigue syndrome: preliminary data. *Am J Med.* 1998; 105 (suppl):54S-58S.
38. Lewis DH et al. Monozygotic twins discordant for chronic fatigue syndrome: regional cerebral blood flow SPECT. *Radiology.* 2001; 219:766-773.
39. Cianfrini LR et al. Pain sensitivity and bilateral activation of brain structures during pressure stimulation of patients with fibromyalgia (FM) is not mediated by major depression (DEP). *Arthritis Rheum.* 2001; 44 (Suppl 9): S395.

This article originally appeared in the Summer 2002 issue of *The CFS Research Review*. It has been reprinted with the permission of The CFIDS Association of America. For more information, call the Association at 800-442-3437 or visit *www.cfids.org*.

Neuroendocrinology, Genetics and Chronic Fatigue Syndrome

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

By David J. Torpy, MBBS, PHD, FRACP,

Neuroendocrinology focuses on the integrated nervous system and hormone release network that links the brain, pituitary and many endocrine glands. A subset of that network is the stress system, which is composed of the pituitary adrenal axis and sympathetic nervous system and coordinates release of cortisol, norepinephrine and epinephrine in response to acute stressors. These systems may play a role in chronic fatigue syndrome (CFS) and other conditions involving fatigue.

A "stress" can be defined as any influence that may disturb the body's inherent natural balance, including infection, trauma or psychological disturbance such as fear or anxiety. Once the stress system is triggered, a flow of hormones such as cortisol helps the body to defend itself by releasing glucose into the blood, increasing blood pressure and moderating the immune system.

A number of disorders with fatigue as their hallmark might be related to abnormalities in the stress system. These have been somewhat arbitrarily separated into syndromes such as: idiopathic chronic fatigue (unexplained fatigue for more than six months); CFS (fatigue plus four or more of a group of eight other features, many of which involve pain)[1]; and fibromyalgia (pain more prominent than in CFS but frequently associated with fatigue).

Research findings

Although there is not yet enough evidence to link specific stressors to neuroendocrine problems in CFS and fibromyalgia (FM), there is accumulating evidence of a defect in the stress system in these patients.[2,3] Highlights of current research include:

- Tendency to low cortisol levels in urine and blood
- Shared features with Addison's disease, including fatigue and low blood pressure
- Altered dynamic responses of the stress system, especially cortisol, to stimuli.[4]

However, there have been variable findings. A panel of experts at a March 2001 research symposium on the neuroendocrine aspects of CFS held by The CFIDS Association of America and the U.S. Centers for Disease Control and Prevention (CDC) noted that low cortisol is not consistent in all CFS patients studied. They hypothesized that some of the discrepancy may come from the relapsing-remitting nature of the illness and differing study designs.

It is not known if the hormonal abnormalities identified by researchers reflect the underlying process of CFS or if they contribute directly to symptoms. To help answer this question there have been two treatment trials of hydrocortisone to treat CFS patients.

One positive therapeutic study was conducted in 32 CFS patients with disease duration <100 months and no evidence of major depression or other co-morbid psychiatric disorders. Five mg or 10 mg of hydrocortisone was administered for 28 days in a placebo-controlled design. Approximately 28 percent of patients experienced a reduction in fatigue scores, such that they became comparable to controls. Only nine percent of CFS patients taking placebo experienced similar improvement.[5]

A study of full-replacement level hydrocortisone (approximately 25-35 mg hydrocortisone daily) in 70 CFS patients for three months resulted in slight improvement on symptom scales, particularly in wellness scores, but there was evidence of suppressed adrenocortical responsiveness on the basis of basal and ACTH-stimulated cortisol levels in 12 patients.[6]

The role of genetics

Genetic research may shed some light on the origins of neuroendocrine abnormalities in CFS. In the last 10 years, studies have described rare genetic mutations of key regulatory components of the stress system, including the glucocorticoid receptor (which "senses" cortisol in the body) and corticosteroid binding globulin (CBG, a transport protein for cortisol), which can lead to CFS-like symptoms.

In the mid-1980s, subjects with altered cortisol receptors were found to have fatigue as their only symptom.[7,8] More recently my research team has discovered a 39-member Italian-Australian family with a newly described loss of function (null) mutation in a gene for CBG, in association with fatigue and relatively low blood pressure.[9]

Plasma CBG was undetectable in family members who are null homozygotes for the mutated CBG gene and reduced by 50 percent of the low-normal range in null heterozygotes. Idiopathic chronic fatigue was present in 12 of 14 adult null heterozygote subjects, and in two of three null homozygotes. Two of the 19 individuals with the null mutation were excluded from assessment for fatigue due to confounding factors related to their associated illnesses.

Significantly, five cases out of the 19 met the CDC criteria for CFS, and other family members had chronic fatigue without associated features, suggesting that these syndromal classifications are not predictive of the mutation. Two other families with milder mutations of the CBG gene, known as the Lyon mutation, have been identified, also in association with fatigue and low blood pressure.[10,11,12]

In the case of the family my research team described, investigations were initiated because of a discrepancy between urine and blood cortisol levels - blood cortisol levels were low and urine cortisol levels were normal. However, it would not have been possible to diagnose these patients with

biochemical findings alone, if they had only one copy of the CBG null mutation.

It should be noted that although multiple family members with chronic fatigue are often recognized in clinical practice, this does not necessarily imply a common genetic factor, as families tend to share a similar environment. However, studies of identical and non-identical twins with CFS have revealed a genetic component, as the identical twins were more likely to share fatigue symptoms than non-identical twins.[13,14]

In addition, as mentioned above, specific mutations in proteins that regulate cortisol transport or action have been found to be associated with fatigue in individual families. It remains to be seen if these alterations of the CBG gene may predispose individuals to the development of CFS.

The mechanism of association between fatigue, relative hypotension and low cortisol has also not been established by these genetic studies. The family we described had lifelong fatigue, albeit variable with time, and did not have postural hypotension. Lack of postural hypotension was also noted in subjects with the glucocorticoid receptor mutation.

Implications for future

There is growing evidence of neuroendocrine disturbances in people with CFS and related disorders. To reinforce this notion, it appears that abnormalities in the proteins for cortisol action or transport may reproduce features of CFS.

In the last 10 years, researchers have discovered specific heritable mutations in cortisol that may lead to fatigue. Although heterogeneity among CFS patient sufferers is the rule, suggesting many potential causes of the illness, the positive findings to date are highly encouraging and should act as an impetus for further work in this field.

It may be that specific "dissection" of the neuroendocrinology of CFS and related disorders may allow us to sub-categorize this enigmatic disease. Such categorization may lead to better diagnosis and treatment of CFS in the not-too-distant future.

References

1. Fukuda et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Ann Intern Med*. 1994; 121:953-959.

2. Torpy DJ et al. Chronic fatigue syndrome. www.endotext.org (In press).

3. Torpy DJ et al. Responses of the sympathetic nervous system and the hypothalamic-pituitary-adrenal axis to interleukin-6 in fibromyalgia: a pilot study. *Arthritis and Rheumatism*. 2000; 43: 872-880.

4. Demitrack M et al. Evidence for impaired activation of the hypothalamic-pituitary-adrenal axis in patients with chronic fatigue syndrome. *J Clin Endocrinol Metab*. 1991; 73:1224-1234.

5. Cleare AJ et al. Low-dose hydrocortisone in chronic fatigue syndrome: a randomised crossover trial. *Lancet*. 1999; 353:455-458.

6. McKenzie R et al. Low-dose hydrocortisone for treatment of chronic fatigue syndrome. *JAMA*. 1998; 280:1061-1066.

7. Bronnegard M et al. Primary cortisol resistance associated with a thermolabile glucocorticoid receptor in a patient with fatigue as the only symptom. *J Clin Invest*. 1986; 78:1270-1278.

8. Chrousos GP et al. Syndromes of glucocorticoid resistance. *Ann Intern Med.*1993;119:1113-1124.

9. Torpy DJ et al. Familial cortico-steroid-binding globulin deficiency due to a novel null mutation: association with fatigue and relative hypotension. *J Clin Endocrinol Metab*. 2001; 86:3692-3700.

10. Emptoz-Bonneton A et al. Novel human corticosteroid-binding globulin variant with low cortisol-binding affinity. *J Clin Endocrinol Metab*. 2000; 85:361-367.

11. Brunner E et al. Molecular characterization of corticosteroid-binding globulin deficiency in a Brazilian kindred. Endocrine Society Annual Scientific Meeting 2001, Denver CO, poster P1-404.

12. Baima J et al. Hereditary corticosteroid binding globulin deficiency

13. Proceedings of the 77th Annual Meeting of the Endocrine Society, Washington DC, 1995, poster 353.

14. Hickie I et al. Unique genetic and environmental determinants of prolonged fatigue: a twin study. *Psychol Med*. 1999; 29:259-268.

15. Hickie I et al. Complex genetic and environmental relationships between psychological distress, fatigue and immune functioning: a twin study. *Psychol Med.* 1999; 29:269-277.

Dr. Torpy is based at the Royal Adelaide Hospital, and is our keynote speaker coming up at our Awareness Seminar in May 2003. He is the lead author of a study on a newly described genetic mutation that has been associated with fatigue and relative hypotension.

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.

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

The effect of a polynutrient supplement on fatigue and physical activity of patients with chronic fatigue syndrome: a double-blind randomized controlled trial.

Brouwers FM, Van Der Werf S, Bleijenberg G, Van Der Zee L, Van Der Meer JW.
Departments of. General Internal Medicine and. Medical Psychology, University Medical Center Nijmegen, The Netherlands.

QJM 2002 Oct;95(10):677-83

BACKGROUND: The efficacy of dietary supplements in chronic fatigue syndrome (CFS) is uncertain, with conflicting evidence.

Aim: To assess the effect of a polynutrient supplement on fatigue and physical activity of patients with CFS.

DESIGN: Prospective randomized placebo-controlled, double-blind trial.

METHODS: Fifty-three patients (16 males, 37 females) fulfilling the CDC criteria of CFS. The entry criteria were a score on the Checklist Individual Strength subscale fatigue severity (CIS fatigue) >or=40 and a weighted sum score of >or=750 for the eight subscales of the Sickness Impact Profile (SIP8) and no use of nutritional supplements in the 4 weeks prior to entry. The exclusion criteria were pregnancy and lactose intolerance. The intervention - a polynutrient supplement containing several vitamins, minerals and (co)enzymes, or placebo, twice daily for 10 weeks - was preceded by 2 weeks of baseline measurements. Outcome measurements took place in week 9 and 10 of the intervention. Five participants dropped out (4 supplement, 1 placebo). The main outcome measures were CIS fatigue score, number of CDC symptoms and SIP8 score. Efficacy analyses were performed on an intention-to-treat basis.

RESULTS: No significant differences were found between the placebo and the treated group on any of the outcome measures: CIS fatigue +2.16 (95%CI -4.3 to +4.39, p=0.984); CDC symptoms +0.42 (95%CI -0.61 to +1.46, p=0.417); SIP8 +182 (95%CI -165 to +529, p=0.297). No patient reported full recovery.

DISCUSSION: The findings do not support the use of a broad-spectrum nutritional supplement in treating CFS-related symptoms.

High prevalence of Mycoplasma infections among European chronic fatigue syndrome patients. Examination of four Mycoplasma species in blood of chronic fatigue syndrome patients.

Nijs J, Nicolson GL, De Becker P, Coomans D, De Meirleir K.
Department of Human Physiology, Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel (VUB), KRO Gebouw-1, Laarbeeklaan 101, 1090, Brussel, Belgium

FEMS Immunol Med Microbiol 2002 Nov 15;34 (3):209-14

Prevalence of Mycoplasma species infections in chronic fatigue syndrome (CFS) has been extensively reported in the scientific literature. However, all previous reports highlighted the presence of Mycoplasmas in American patients. In this prospective study, the presence of Mycoplasma fermentans, M. penetrans, M. pneumoniae and M. hominis in the blood of 261 European CFS patients and 36 healthy volunteers was examined using forensic polymerase chain reaction. One hundred and seventy-nine (68.6%) patients were infected by at least one species of Mycoplasma, compared to two out of 36 (5.6%) in the control sample (P<0.001). Among Mycoplasma-infected patients, M. hominis was the most frequently observed infection (n=96; 36.8% of the overall sample), followed by M. pneumoniae and M. fermentans infections (equal frequencies; n=67; 25.7%). M. penetrans infections were not found. Multiple mycoplasmal infections were detected in 45 patients (17.2%). Compared to American CFS patients (M. pneumoniae>M. hominis>M. penetrans), a slightly different pattern of mycoplasmal infections was found in European CFS patients (M. hominis>M. pneumoniae, M. fermentansz.Gt;M. penetrans).

Hypothalamic-pituitary-adrenal axis reactivity in chronic fatigue syndrome and health under psychological, physiological, and pharmacological stimulation.

Gaab J, Huster D, Peisen R, Engert V, Heitz V, Schad T, Schurmeyer TH, Ehlert U.
Center for Psychobiological and Psychosomatic Research (J. G., D.H., R.P., V.E., V.H., T.S., T.H.S., U.E.), University of Trier, Trier, Germany.

Psychosom Med 2002 Nov-Dec;64(6):951-62

OBJECTIVES: Subtle alterations of the hypothalamic-pituitary-adrenal (HPA) axis in chronic fatigue syndrome (CFS) have been proposed as a shared pathway linking numerous etiological and perpetuating processes with symptoms and observed physiological abnormalities. Because the HPA axis is involved in the adaptive responses to stress and CFS patients experience a worsening of symptoms after physical and psychological stress, we tested HPA axis functioning with three centrally acting stress tests.

METHODS: We used two procedures mimicking real-life stressors and compared them with a standardized pharmacological neuroendocrine challenge test. CFS patients were compared with healthy control subjects regarding their cardiovascular and endocrine reactivity in a psychosocial stress test and a standardized exercise test, and their endocrine response in the insulin tolerance test (ITT).

RESULTS: Controlling for possible confounding variables, we found significantly lower ACTH response levels in the psychosocial stress test and the exercise test, and significantly lower ACTH responses in the ITT, with no differences in plasma total cortisol responses. Also, salivary-free cortisol responses did not differ between the groups in the psychosocial stress test and the exercise test but were significantly higher for the CFS patients in the ITT. In all tests CFS patients had significantly reduced baseline ACTH levels.

CONCLUSIONS: These results suggest that CFS patients are capable of mounting a sufficient cortisol response under different types of stress but that on a central level subtle dysregulations of the HPA axis exist.

Treatment with staphylococcus toxoid in fibromyalgia/chronic fatigue syndrome - a randomised controlled trial.

Zachrisson O, Regland B, Jahreskog M, Jonsson M, Kron M, Gottfries CG.
Psychiatry Section, Institute of Clinical Neuroscience, Goteborg University, Goteborg, Sweden

Eur J Pain 2002 Dec;6(6):455-66

We have previously conducted a small treatment study on staphylococcus toxoid in fibromyalgia (FM) and chronic fatigue syndrome (CFS). The aim of the present study was to further assess the efficacy of the staphylococcus toxoid preparation Staphypan Berna (SB) during 6 months in FM/CFS patients. One hundred consecutively referred patients fulfilling the ACR criteria for FM and the 1994 CDC criteria for CFS were randomised to receive active drug or placebo. Treatment included weekly injections containing 0.1ml, 0.2ml, 0.3ml, 0.4ml, 0.6ml, 0.8ml, 0.9ml, and 1.0ml SB or coloured sterile water, followed by booster doses given 4-weekly until endpoint. Main outcome measures were the proportion of responders according to global ratings and the proportion of patients with a symptom reduction of >/=50% on a 15-item subscale derived from the comprehensive psychopathological rating scale (CPRS). The treatment was well tolerated. Intention-to-treat analysis showed 32/49 (65%) responders in the SB group compared to 9/49 (18%) in the placebo group (P<0.001). Sixteen patients (33%) in the SB group reduced their CPRS scores by at least 50% compared to five patients (10%) in the placebo group (P<0.01). Mean change score on the CPRS (95% confidence interval) was 10.0 (6.7-13.3) in the SB group and 3.9 (1.1-6.6) in the placebo group (P<0.01). An increase in CPRS symptoms at withdrawal was noted in the SB group. In conclusion, treatment with staphylococcus toxoid injections over 6 months led to significant improvement in patients with FM and CFS. Maintenance treatment is required to prevent relapse.

Brain Abnormalities and CFS Pain

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Several investigators have attempted to identify abnormalities in brain structures that might contribute to the painful symptoms of CFS. Their studies have focused on magnetic resonance imaging (MRI) of brain structure and neuroimaging of regional cerebral blood flow (rCBF) in brain structures that process or modulate pain.

MRI studies of brain structure. The results of these studies are difficult to interpret because they are characterized by great variation in research methods that can influence the validity of research findings.[31] Nevertheless, three of four relatively well-designed studies have reported CFS patients, compared to healthy controls, display a significantly greater number of white matter lesions in the cortex of the brain.[32-34] The relationship between these lesions and pain in persons with CFS remains unclear.

Neuroimaging of functional brain activity. Single photon emission computed tomography (SPECT), positron emission tomography (PET) and functional MRI (fMRI) allow investigators to measure activity in brain structures either during rest or during exposure to stimuli that evoke acute pain. All of the peer-reviewed neuroimaging studies performed to date with CFS patients have examined brain activity during rest.[35-38] Six investigations have reported that CFS patients are characterized by low levels of rCBF in numerous brain structures.

There is little agreement regarding the specific brain structures that show low rCBF. Nevertheless, two investigations found that CFS patients, relative to controls, show significantly lower levels of rCBF in the brainstem.[36,37] Low brainstem rCBF levels may contribute to abnormal function of the locus ceruleus-norepinephrine/autonomic nervous system in CFS patients. This abnormality, in turn, may contribute to pain since the locus ceruleus is involved in controlling descending pathways from the brain to the spinal cord that inhibit pain.[14]

It should be noted, however, that Lewis and colleagues[38] recently used SPECT imaging to compare brain rCBF in 22 identical twin pairs in which only one twin met criteria for CFS. There was no difference in the number of brain rCBF abnormalities between twins with CFS and those without the disorder. At present, then, it is not possible to state with confidence whether a relatively large number of resting state abnormalities in brain function are found in persons with CFS, or whether any abnormalities that are found may contribute to persistent pain in persons with CFS.

Despite the inconsistent findings described above, it may be possible to better understand the causes of painful symptoms in CFS by measuring changes in brain rCBF that are produced by noxious stimulation (e.g., pressure, heat, or cold) in persons with CFS and healthy individuals. We recently completed brain SPECT imaging on nine patients with CFS who did not meet criteria for FM and 25 healthy controls.[39] Preliminary analyses indicate that, despite the fact that all of the CFS patients reported experiencing musculoskeletal pain, their pain thresholds for pressure stimulation did not differ from those of the healthy controls.

However, the CFS patients tended to show a different pattern of brain activation than the healthy controls when they were exposed to a five-minute period of repetitive, painful, pressure stimulation. That is, the controls showed the expected pattern of increased activity in brain structures involved in processing the sensory and emotional dimensions of pain located in the cerebral hemisphere opposite to the stimulation site (e.g., right-side stimulation evoked left brain activation). Interestingly, the CFS patients tended to show activation in the same structures in both cerebral hemispheres, despite the fact that there was no difference in the intensity of pressure stimulation delivered to patients and controls. This suggests that the pressure stimulation produced greater transmission of sensory input to the brains of the patients with CFS.

This article originally appeared in the Summer 2002 issue of *The CFS Research Review*. It has been reprinted with the permission of The CFIDS Association of America. For more information, call the Association at 800-442-3437 or visit *www.cfids.org*.

NOTE: See page 29 for references.

Your Society Matters....

Awareness Week 2003
May 10th—May 17th

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Fibromyalgia SA

Arthritis FOUNDATION SA INC.

Awareness Seminar—organised in partnership with Fibromyalgia SA, a branch of the Arthiritis Foundation

Norwood Concert Hall
May 10th, 1 pm — 5 pm

Keynote Speaker: Dr David Torpy*, Endocrinologist, RAH

There will be a number of speakers on various topics, and stalls run by a number of organisations that provide services to people with chronic illness.

Further details including cost of entry to be advised.

* See page 30 for an article by Dr Torpy

SAYME – End of Year Report

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

The year began with Rebecca Cordingley and Elizabeth Cahalan taking over as the SAYME leadership committee and co-producing the first three magazines of the year as well as running the support group and providing ongoing support to members. Despite having no previous experience in such an endeavor and suffering ill health themselves and studying at university, they were responsible for keeping SAYME breathing. It is such an important part of the society's services to its younger members. I joined the team in March and began to familiarize myself with the support group and the immediate and future goals while Elizabeth and Rebecca continued with producing the magazine and keeping in contact with members, with ongoing support and advice from Peter and Penny Cahalan and Kirsty Cordingley.

There have been a few changes and improvements since the beginning of the year with SAYME receiving three grants to help improve our member services, and an increase in people helping to improve and deliver those services. Community Benefit has given us $3080 to help with the support we can provide for the younger people while Young Australians have donated $5000 for developing and maintaining a SAYME website. The Morialta trust has also donated $3, 300 to assist with the development of youth-related education kits.

With the Community Benefit grant we have been able to purchase some board games and a Playstation 2 for use at the monthly meetings and some talking books that, along with the PS2, will be loaned out to members between meetings next year [subject to certain conditions]. Some money has been allocated to organizing a weekend camp for the younger people (and a family member) which we will try to hold during the mid-year school holidays in 2003 and some has been allocated to the improvement and cost of producing the quarterly SAYME magazine. Rebecca is now concentrating all of her efforts on upgrading and maintaining a new-look SAYME website, using the Young Australians grant money. This is a very big and important job and we would like to thank Rebecca for accepting it, as well as thank her for the work she has done throughout the year with the magazine and social aspects of SAYME. I would also like to thank Peter and Penny Cahalan and Kirsty Cordingley for their ongoing support and advice.

The SAYME sub-committee now consists of Elizabeth Cahalan, Kristen Mulvihill and myself with regular contributions towards the magazine from Dan Smith, Briony Hymers, Robert Worsley and Theresa Nicholls. A big *thankyou* to everyone who has contributed to the magazine in any way as without these contributions the already daunting task of producing a magazine every three months would be too much.

During the year we decided to start an older support group that we refer to as the twenties to thirties group but is a broad age range group for those who have finished school. We originally decided to have these meetings at a café, but after having problems with cigarette smoke we have decided to have the summer meetings, starting in January, in parks and gardens such as the Botanical Gardens and Belair National Park. Our most recent meeting was at a member's house with a barbecue. There were twelve of us and everyone left looking forward to the next one.

If anyone would like to speak to Elizabeth, Kristen or myself about the support groups, camp or anything else related to SAYME then contact the office on 84108929, leave your details and we will get in contact with you, or contact us at the email addresses found on the inside cover of the SAYME magazine.

Peter Worsley

Questionnaire 2002

From time to time we include a brief questionnaire along with our membership renewals. (All questions were in a tick-box format)
We received approx 240 responses from 290 renewals. It was interesting to note the average age of the respondents was approx 48 years. (The average age of Society members is likely to be lower with lower than average response rates from younger people.)

Typically our membership has had CFS for over 10 years, and it took nearly five years on average for people to be diagnosed. (Only 62% of respondents answered this question) Many people in the 70s and 80s went for years without recognition or diagnosis. Our job is to lobby governments and health professional, to raise awareness, so that this figure comes right down.

Our members registered 5.5 on average of the 8 core symptoms which comprise the US Centers for Disease Control Research definition of CFS. They self rated themselves on average at 44 on an energy level scale which went from 0 to 100—with 100 being full fit.

As to services, the newsletter, support groups, quarterly meetings and self-management courses are the most desired.

NOTE: An exercise such as this is interesting, but one wouldn't want to draw conclusions from every statistic, because it is unlikely that Society membership is exactly reflective the entire population of people with CFS. It is the longer term sufferers who tend to join Society's such as ours, and that is reflected in the average length of illness being 13 years. I don't want new members to be alarmed by this figure unnecessarily because this figure is too high. One source ('Energy in the Red' by Jacqueline Finch) has suggested the average length of CFS is 7.9 years. Whilst few studies have looked into this figure, and we certainly don't have any good data for Australia, I would suggest this is more accurate. It is important for people to understand that on one hand this illness is chronic, but on the other take heart that some people do get better in 1-2 years.

Results Summary

Number of Respondents in ()

Year Commenced (229) Av 1989 ie average length of illness is 13 years

Gender (239) M 69 F 170

Age Range (248)

0-10	0
11-20	14
21-30	23
31-40	24
41-50	55
51-60	67
61-70	41
71+	19

Ave length of time before diagnosis 4.6 years (155)

Onset (240): Sudden 116—Gradual 124

CDC Research Definition Key Symptoms (241)
People with each symptom
Memory/Concentration Impairment 216—90%
Sort Throat 106—44%
Headache 162—67%
Muscle Pain 193—80%
Tender Lymph nodes 118—49%
Joint Pain 160—66%
Un-refreshing Sleep 211—88%
Post-exertional lethargy 210—88%

Average 5.5 symptoms per person

Other Symptoms (241)
Food Sensitivities 131
Frequent Infections 78
Abdominal Pain 135
Irritable Bowel 158
Chemical Sensitivities 139—58%
Disturbed Menstrual Cycle 47 (out of 170 women) - 28%
Sensitivity to heat/cold 156—65%
Balance difficulties 136—56%
Fever or sensation of fever 105—44%
Sensitivity to noise 146—61%
Light-headedness 156—65%
Depression 137—59%
Difficulty Breathing 83—34%
Orthostatic Intolerance 44—18%
Cold Extremities 139—58%
Blurring of Vision 121—50%
Sensitivity to light 133—55%
Bloating 127—53%
Av. 8.75 symptoms per person with a standard deviation of 4

Support Services Desired (231)
1) Support Groups 83—36%
2) Parent Support Groups 10—4%
3) Newsletter 210—91%
4) SAYME (youth services) 24—10%
5) Carers 11—4%
6) Info Support 74—32%
7) Weekend Support Group 14—6%
8) Email Chat 26—11%
9) Quarterly Meetings 60—26%
10) Male / Female Support Group 3—1%
11) Phone Friendship group 28—12%
12) Library 54—23%
13) Self Management 52—23%)
14) Social Activities 36—16%
15) Advocacy 26—11%

Energy Rating (190 respondents) Average 44 (0-100) standard deviation 28

Volunteer Positions Available: Office

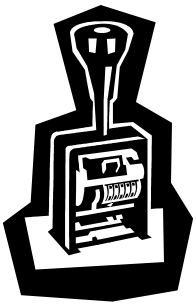
Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

We are looking for people to join our office team in 2003 with a view to the future; we are looking for people who are able to make 'long-term' commitments to assisting the Society.

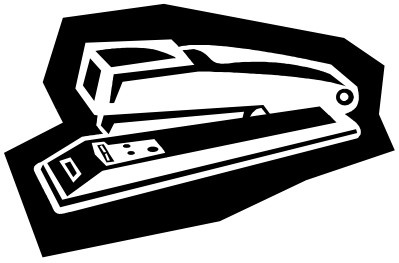
Office shifts are from 10 am to 3 pm and volunteers are expected to undertake one shift per week (perhaps two during the training stage.) Candidates must be team-orientated, be prepared to work with others, and undertake a range of tasks including answering the phone, data entry, tending to correspondence and filing. We would prefer that applicants had basic computer skills, and were familiar with MS Word and email—and are keen to improve those skills.

Joining our office team is rewarding. The work is steady but not overbearing, and it is good fun to work as part of a team.

It is perfect for anyone who would like to fill in some of their time and add meaning to their life. I'm especially keen for healthy parents or spouses of people with ME/CFS to get involved. Such people understand a bit about the illness but without the health concerns.



Along the way you will pick up the following skills amongst others:

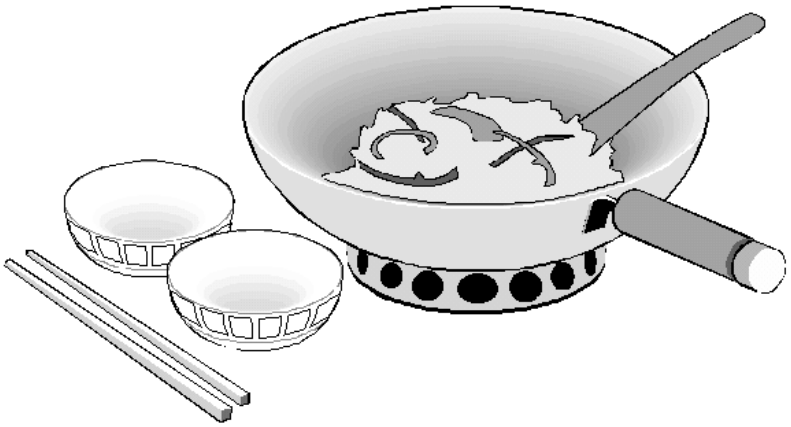


- ⇒ Database entry
- ⇒ Use of email (advanced)
- ⇒ Use of phone system
- ⇒ Maintaining petty cash system
- ⇒ Banking

Over 2003 we would like to train two people with a view to them continuing on in 2004. We also would like to train a 'junior'—either a young member or relative of a member—someone who is keen to go on and seek some sort of clerical employment.

Anyone interested can talk either to Paul Leverenz or to Patricia Smith—call the office on 8410 8929.

Food For Thought



by Dr Bogusha Paks

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Dr Bogusha Paks obtained her degree in the medical/scientific field at the Faculty of Medicine at the University of Glasgow. In Australia she was a university lecturer until she contracted CFS/ME in 1996. Here she discusses various aspects of nutrition, diet, CFS/ME in general and a good place for eating out.

Nutrition….

Mine is a common or garden variety of CFS/ME. By this I mean that it is not any medical wonder (at least inasmuch as CFS/ME can be seen as a "normal" disorder in the situation when the majority of the medical profession is in denial with respect to its very existence and a lot of other doctors are simply puzzled by it). There are a lot of other CFS/ME sufferers who share my problems, but I need to make a few caveats here.

Firstly, there is CFS/ME, CFS/ME and CFS/ME. Therefore I have most in common with people who share my CFS/ME type (although proper classification of CFS/ME is a long way ahead). By this I mean that, if I suffer from chronic diarrhoea, my digestion and absorption are going to be impaired which, in turn, means that I am likely to develop numerous nutritional deficiencies requiring nutritional supplementation in the form of vitamins and minerals, despite the fact that my diet may be quite good. Also, when an infection requires an antibiotic, I may require high doses of it for prolonged periods of time (remember that women on the pill are warned that during a bout of diarrhoea the pill may be ineffective), or even intromuscular injections of antibiotics (especially that, although they are hard on my bum, they do not add to my gastrointestinal problems).

But then there is a group of CFS/ME sufferers without diarrhoea (indeed, some experience constipation) and they will not have any problems arising from it. Therefore what is beneficial in my case (and other cases similar to mine) may be superfluous or even harmful for them.

To finish with caveats I want to add that each and every one of us has our idiosyncrasies, which at least in part are determined by our individual constitutions (read "genes" if you like) and also by our medical history (which, apart from things strictly medical, includes our past nutritional "sins" – or "good deeds" – and other lifestyle or environmental issues).

Diet….

All the above make "one size fits all" advice related to CFS/ME very difficult, if not impossible. This was what I reflected upon when I read the Society's fact sheet on diet (for details of fact sheets see the Spring issue of *Emerge*, Page 7).

Sugar:

At the top of the list of forbidden foods there is sugar. Quite rightly so, for sugar is very had for your immunity: cell-mediated, humorol (i.e. immunity afforded by antibiotics), innate … name it. All kinds of studies have been undertaken and they have come up with the same result: sugar impairs immunity. Since all research that I have seen points towards CFS/ME being primarily an immunological disorder, it would make sense not to put any further stress on one's already impaired immunity wouldn't it? But then you do not have to buy my hunch about the nature of CFS/ME (although I can boast a very good track record there; I vividly remember the icy silence of professors and other medical "big guns" when, during a seminar on AIDS in the mid-eighties, I stood up and said that the epidemiology of AIDS seemed to be very similar to the epidemiology of Hepatitis Type B – but time vindicated me).

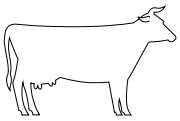
So what about this argument: with CFS/ME there is a good chance that you may have problems with infections. In this case, why add to these problems? And, even if you do not

(Continued on page 40)

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

suffer from recurrent sore throats, enlarged lymph nodes, thrush or any other manifestations of infections, you are already quite sick with ME/CFS, so why take chances with sugar, which could make things worse still? After all, sugar is a non-essential food at best of times and, by eliminating it altogether from our diet, we are not running a risk of any nutritional deficit.

Dairy products:
However, dairy products are also on the proscribed list and the story here is different. It is true that a proportion of adults in the general population (there is no comparative data for the CFS/ME population) suffers from lactose intolerance, but by no means all adults do. However, even if one suffers from lactose intolerance, in most cases fermented milk products (where lactose is largely used up in the process of fermentation) usually are well tolerated. On the other hand, milk products are an important source of calcium (think osteoporosis here and, no, the fact that you are a man does not make you immune from it) and protein, so why give them up if there is no need for it? Although it is true protein can be found in other foodstuffs as well, I feel that CFS/ME alone complicates our lives sufficiently, so we do not need to complicate them any further, when there is no real need for it. After all, one can develop an allergy to anything. There is even this child in England who is allergic to water (I am not kidding!). And there are people allergic to their sexual partners (with problems ranging from infertility to life-threatening symptoms), but nobody calls for blanket sexual abstinence as a precaution for everybody.



It may be all very confusing, but there is light at the end of the tunnel. Before you start making drastic (and often costly, in terms of money, time and/or effort) changes in your diet (lifestyle, dental fillings, etc) first find out whether something is a problem for you.

Wheat:
Wheat is another food on the "to be avoided" list. While two different GPs tested me positive for wheat sensitivity (both of them used kinesiology, although I am aware other methods are also available) and subsequently I excluded wheat from my diet, this greatly increased the energy required for my shopping. In my area wheat-free bread is simply not available and bread happens to be an important part of my culinary culture. Also, although a lot of people suffer from wheat sensitivity, by no means is wheat the only culprit here. So again: isn't it more sensible to test the waters before jumping into the deep end?

Spicy food:
The list also advises that spicy food should be avoided because it will aggravate an already sensitive gut. Well, my first-hand experience happens to be opposite. I suppose that my gut is as sensitive as you want it to be: chronic diarrhoea, abdominal pain, periodic nausea, occasional vomiting and more, yet I enjoy hot curries without any ill after-effects (in fact I seem to be doing better with them that without them). And, no, it is nothing genetic. I have no Asian or German ancestry. I mention German because it is a German (or, more broadly, central European) dietary stereotype that food for the sick and for the convalescent should be bland. And it is just the opposite for me.

Because of my very wasteful digestion and absorption I need to eat a lot. But when my CFS/ME deteriorates I become anorexic. I may lose interest in food altogether and I lose weight which is very bad news for me. (*Editor's note: Bogusha describes herself as being six feet tall*, *blonde and very thin.)* Since spicy food is fun, at least for me, I tend to eat more of it, even when I do not feel like eating.

Conclusion: everybody should find for themselves where they stand with spices.

Fats:
With fats, like with a lot of other things, it is a balanced diet which matters. Unsaturated fats have the same number of calories, or kilojoules, as saturated fats, which is a lot - in fact, more than twice as much as in proteins or carbohydrates (including white sugar) per gram.

Now, saturated fats by the virtue of their saturation are solid while unsaturated facts for the similar reason are liquid. Also, as a general rule, animal fats are saturated, while fats of the plant origin are unsaturated. This claim makes fish, which contain unsaturated fats, "honorary plants" while coconuts are "honorary animals" with their saturated fat content.

Avocados, which have suffered a fair amount of bad publicity among diet-conscious people, are a relative rarity among vegetables, and particularly fruit, in that they contain oil, but it is unsaturated oil, nevertheless.

While I do not feel that there is a case for exclusion of butter from our diet, unless there are very specific medical indications, I am of the opinion that, if you enjoy it, do so in moderation, leaving enough room in your diet for unsaturated fats because "they are good for you".

Fish:


While it is true that we cannot live without so-called essential fatty acids, their excess in our diet will make us obese, but so will the excess of proteins for that matter. "Good oil", i.e. unsaturated and including essential fatty acids, often particularly important in CFS/ME, is commonly found in fish.

Tuna, salmon, mackerel and sardines are regarded as the best sources, both in fresh state and tinned, although after my Tasmanian experience I am inclined to add blue

(Continued on page 41)

SUPPORT GROUP REPORT

How ya' survivin' ? You're not alone.

At a recent General Meeting of the Society, the theme was Coping With ME. The five guest speakers all attested to the significance of the role of the formal Support Groups of the Society and there was a universal feeling amongst the audience that Support Groups offered the chance to come together and share concerns, and knowledge.

Currently there are only a couple of truly active Support Groups. One in the North-East Suburbs with a core of 10 members, the other based at Wallaroo with a core of thirty. The Adelaide Support Group has dwindled to under 10. Other groups meet intermittently, though I have not had any recent reports.

Timing and format have been reviewed but numbers remain low. The Society is only as strong as member involvement. We know some people are house bound.

Remember the other avenues of communication – the phone or email. Some people meet informally for a coffee or a chat or occasionally "do" lunch. These contacts evolved from Support Group contact. Friendship cannot be assumed but common interests often lead to support.

If you are interested in attending an existing Support Group, ring the Support and Information line to check on details or visit the Society's website a couple of days before hand. Details are in the back of Talking Point. If you would like to be a part of establishing a new group in your area, contact the Office. Guidance and support in setting up a group is available. Facilitators need to be aware of the "Aims and Objectives of the Society" and understand the responsibilities and protocol of handling confidential information.

THE ADELAIDE SUPPORT GROUP
Meets in the meeting room on the Ground Floor of the Epworth Building, Pirie Street, on the fourth Tuesday of the month between 12noon and 2pm. Bring your lunch to eat over a chat. Kitchen facilities are available.

Depending on response in Feb [24th] and March [24th], a decision on the frequency, location and timing of meetings will be made.

Owing to acute illness in the past five moths, and an ongoing treatment regime for the foreseeable future, I will not be able to come but the Group's stalwarts: Mandy, Roger and Darryl, intend to continue to provide a warm friendly smile with support and guidance.

Regards
Bill Daniels

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

(Continued from page 40)
eye to my list. Deep sea fish are the preferred choice because they are unlikely to be contaminated with heavy metals, e.g. mercury or cadmium. Heavy metal toxicity results in serious health problems. In fact, some specialists regard it as one of the types of CFS/ME. In any case, heavy metals would aggravate CFS/ME. This is why a flake on our plate is not a good idea. Flake is shark and sharks are scavengers living close to the bottom of the Bay where there is high concentration of heavy metals from the effluent and therefore are at the end of the food chain, helped by the fact that they do not have natural enemies. Organisms, be it mussels, fish, sharks or humans, cannot remove heavy metals once they get into the system, so the last one in the food chain ends up with the highest accumulation of heavy metals - and it could be us!

Travelling and eating out

As CFS/ME dictates that I do not drive and I do not have a devoted carer with a car (in fact, I am a carer myself), I have to rely upon the often unreliable public transport system. (Recently introduced by the Society discounts for taxi fares – page 6 Spring *Emerge* – are of limited assistance to me because of my "car fume allergy".) Moreover I live in Melbourne's Western suburbs (the Wild West!) where the doctors practise good, honest medicine and therefore they have no time for such a nonsense as CFS/ME. As a result, for every medical appointment/treatment I have to take long eastward trips by public transport.

However, like a lot of other CFS/ME sufferers I have been encouraged by my doctors and my naturopath to go organic. Easier said than done when the nearest organic shop is half an hour away by car and impossible by public transport. Therefore I was excited to read in the Spring issue of *Emerge* about Grasslands in Footscray which also provides a delivery service. I decided to pay them a visit in order to look around before committing myself to an order and discovered that, while they are somewhat short on freshness and the range of their produce, they are big on ideology (social justice, not organic ideology, that is). Since I cannot put ideology on my plate and lack of freshness completely negates the benefits of having organic produce, it is off to Victoria Market again for me, at least when I can find enough energy.

However, my time in Footscray was not completely wasted because I discovered Bo De Trai there. It advertises itself as a vegetarian restaurant and take-away and is run by volunteers from a Buddhist temple in the Western suburbs. Their limited English may be something of a challenge sometimes, but they are willing to assist in any way they can and menus are available also in English.

Emerge Autumn 2002
Magazine of the Victorian CFS/ME Society
www.vicnet.net.au/~mecfs

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

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: Pat on 8264 9328 or Julie on 8264 0607

SUPPORT GROUPS: COUNTRY

Northern Yorke Peninsula CFS Support Group
Venue: Community Health Centre Wallaroo
Phone: Jane 8826 2097

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

Central Yorke Peninsula Support group
Carer Support Yorke Peninsula, 48 Elizabeth Street Maitland SA
Phone: Caroline 88374335

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

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
North Eastern	Pat	8264 9328
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

SAYME	Peter	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
Yunta	Gloria	8650 5938

Murray Bridge Group
The Murray Bridge group has been scaled back— there will now just be the occasional special meeting.
Please ring for event times – or to register your interest.
(Next event time not available at time of publication)
Phone: Fran McFaull (Dietician) **8535 6800**

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

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

Talking Point 2002 Issue 4: The Official Journal of the M.E./C.F.S. Society (SA) Inc

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

Print Post Approved:
PP 532154/00023

SURFACE MAIL

POSTAGE PAID AUSTRALIA