

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.



Membership

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

New Members (cheaper rates apply for renewal):

| | |
|-------------------------------|------|
| Single membership | \$35 |
| Single Concession..... | \$25 |
| Professional..... | \$50 |
| Family | \$40 |
| Family Concession | \$35 |
| Overseas – as above plus..... | \$10 |

(Family membership is designed for families with 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.)

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.

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.

Talking Point Subscriptions:

| | |
|---------------------------------|------|
| Professionals:..... | \$35 |
| Persons with ME/CFS: | \$22 |
| Overseas (Asia-Pacific): | \$32 |
| Overseas (Rest of World): | \$38 |

Management Committee 2006/2007

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

President: Peter Cahalan

Vice-President: (vacant)

Honorary Secretary: Peter Mitchell

Treasurer: Geoff Wilson

Management Committee Members: Adrian Hill; Emma Wing; Melanie Cocker

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:

Wednesdays 10am to 3pm (subject to volunteer availability).

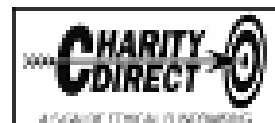
Our email address is: sacfs@sacfs.asn.au.

Our Web site address is: www.sacfs.asn.au.

Our youth Web site address: www.sayme.org.au.

Donations

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



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

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.

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ME & You, ME/CFS Society of NSW Inc., Suite 204, 10 Help Street Chatswood NSW 2067.

Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.

Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.

Chameleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.

ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.

The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.

Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanford le Hope, Essex SS17 OHA, UK.

Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.

Advertising

To advertise your products or services in *Talking Point*, please call the Society office on (08) 8410 8929. Small ads submitted by our members are free subject to the following conditions. *Talking Point* reserves the right to reject any advertisement it considers unsuitable for publication or decline to publish for any reason at its absolute discretion. Advertisements lodged with *Talking Point* must comply with the Advertising Codes of the Media Council of Australia and with the interpretations of the Advertising Standards Council.

President's report

By **Peter Cahalan**, President ME/CFS Society (SA) Inc

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July 2006

Greetings to all our renewing members and especially to any new members.

As I write we've had a terrific inrush of renewals. And what is really heartening is the level of donations which accompany memberships. We've tried to keep our subs low. Your committee's view is that we want the Society to stay inclusive and not to deter people who are really doing it hard financially. So we've figured that if people value the Society and can pay over the odds they will. And the great thing is – they do.

It's worth remembering in this context that to sustain a member is costing us of the order of \$80 or more each, if you divide our operating budget by the number of members. Of course, much of our effort – eg via our wonderful Support Line and our website – goes towards helping people who are not members but who approach us for advice and assistance of one kind or another.

I'll keep the rest of this report crisp. That's because almost all the key readers of this magazine will have received the news below one way or another – either via our weekly e-bulletins or via our more recent efforts to snail-mail to the rest of our members printouts of the bulletins in monthly swatches. Do let us know if you're missing out on both of these avenues of communication (and have not been checking our website, where much useful information is also to be found).

The multiple chemical sensitivity campaign

We've campaigned to get the State government to take some action finally to carry out recommendations made in the parliamentary report on MCS of July 2005. We wrote to the politicians who support the cause and to the Minister for Health. At the end of a year we can report the following achievements:

- The Minister for Health agreed to establish an interagency reference group on MCS in late June.
- The Catholic Education Office agreed to set up a working party with us on making tis schools chemically safer.
- The Department of Administrative and Information Services – which plays a huge role in the development and management of public buildings in SA – has been quite proactive in starting to include considerations about chemical safety in its work.
- The Minister for Disability has been supportive and his department has committed itself to setting a good example in the way it operates.

It's still early days and there could be lots of backsliding. And generating the momentum has fallen to a small handful of about 6 or 7 people so far. So we would be delighted to have more help with this important campaign.

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Communications between us all

Our focus on continuing to build strong communications within our membership and to wider circles of people with ME/CFS has continued to go well. I estimate that for the 2005/06 financial year our website drew around 93 000 unique visits – up from an already strong 30 000 or so such visits about 18 months ago. We've had excellent feedback on the website and weekly e-bulletins from doctors, who tell us that patients are saying that it helps them greatly to be connected to a strong flow of information about everything from developments in medical research to local advocacy efforts. We try to keep our non-emailable members in the loop via sending them regular swatches of printed e-bulletins and via regular telephone contact. It's not perfect, but if you can think of ways to improve this latter work, do let us know.

Seminars

Here things haven't gone so well for us. Our efforts to plan a year's active program of seminars and workshops from as far back as November last year seem to have fallen into a series of holes. No need to bore you with the details. In short, it's clear that we need – as we've known all along – a volunteer or volunteers to take on the task and concentrate on it to the exclusion of other tasks. The committee is just too small and thinly stretched to be able to do this job, important though it is. So as I write we're still hoping for one or more seminars before year's end. But we're not going to stretch ourselves beyond reasonable limits to do so. With luck someone will gallop in out of the sunset to take up the cause!

That's it for now from all of us at the committee, the office, the support line and our various support groups around the State. Thanks to them and to all of you for your support for the cause.

Peter Cahalan
President

History of the Society: can you help?

Here's one for the veterans and it comes out of our recent cleanup day on August 5 (see photos below). We found a framed certificate which obviously accompanied the granting of an Order of Australia medal to Lyn Drysdale in 1992. We think Lyn was one of the founders of the Society. Can anyone advise about Lyn and contact details for her or her family?

As an historian I've long been bothered that I know little about the origins of the Society. I've just been able to guess that it was about 20 years old, but that's about it. It'd be nice to know more.

So if you know something about the Society's early days, feel free to write a few words about it and send it in to us. We'll possibly use it in a future *Talking Point*.

Peter Cahalan, President ME/CFS Society (SA) Inc



Fundraising

By **Peter Cahalan**, President ME/CFS Society (SA) Inc

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Talking Point – 2006 Issue 2

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

Your committee spent some time looking at our short-term and long-term financial situation at its meeting on Tuesday 16 May.

Our position this year is that we might just break even if we can raise several thousand dollars from the annual badge day on 26 May, pull in several small recurrent sponsorships from the State Bank and Adelaide Bank, and whatever else fate throws our way. We dipped into reserves last year and we don't want to do that again this time. We're grateful to the 16 girls from Annesley (courtesy of the energetic Carol Carroll) and the 16 other people who have volunteered in Adelaide. Several country members have once again taken up the cause and they always do a very nice job of pulling in some spondulicks. And to top it all we actually have a member in WA who, when Emma Wing did some phone-trawling for volunteer badge sellers last week, cheerfully said she didn't mind selling badges in Geraldton!! But if there's anyone else out there who could spend an hour or so charming money out of the nice and the flinty-hearted citizens of SA, do call and leave your details.

The long-term situation is the one that we spent a little more time on. The deal is that, through the good fortune of our kind anonymous donor of \$12 000 a year for the last several years, we pulled out of a steady decline in our bank balance and have built it up to around \$45 000. It stood higher a year ago but as noted we had to draw upon the account last financial year.

The nice thing is that, unlike the situation 4 years ago, we don't have to worry that we might go bankrupt in the next year. But \$45 000 is still neither here nor there as a basis for expanding the Society so that it can do more for us all via better services – the kind of services which better-resourced societies can provide to people with other chronic health conditions.

So we've written to hundreds of solicitors and tax consultants and to several targeted businesses in the last two weeks. We're going to reactivate our efforts to get grants from several key granting agencies. And so on. If, by the way, you can help by speaking to business people or Rotarians or whomever and glean some interest from them, let us know and we'll follow up with a letter.

The issue we discussed this week was: if we were able to boost our finances considerably, what would we direct the money to? Our preliminary thoughts are that we would like first a nurse/educator to undertake some home visits and also speak to key groups in the health and school systems (thus making society more empathetic and also hopefully stimulating some increased financial and other support for us). Next would come a part-time support group support officer. Our support groups are extremely important means whereby we assist both members and others. They are kept going by an heroic band of volunteer coordinators. If we can help those people in any way we'd like to (and ditto our unheralded small and longstanding support line team). The ACT CFS society used some of its recent grant from the ACT government for this purpose. And like the ACT and other States with government grants, we'd like to be able to hire an officer worker part-time if we ever could. And we'd like to put money into medical research from time to time. The first use of such funding would probably be to get a survey of CFS sufferers in SA to use as a basis for lobbying for resources from the State and Federal governments.

Those were just first thoughts. We might have other ideas after I've attended a very important meeting in July. The national association of ME/CFS societies has decided to hold what will be the first face-to-face meeting of presidents in as far as I

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Simon Molesworth wins Tattersall's Award for work in CFS

Simon R. Molesworth (pictured below), President of both the National Association of ME/CFS and CFS/ME Victoria, has been given the Tattersall's Award For Enterprise & Achievement. Page 7

Below is a note from Simon to members of the Committee of CFS/ME Victoria:

Dear fellow committee members,

I am both pleased and honoured to advise that today [April 6, 2006] I have been advised by Tattersalls that I have been chosen to receive this month's Award for Enterprise and Achievement in recognition of my voluntary work in the CFS/ME area starting with my family's struggle to assist our son Lachlan. Information regarding the Award is set out below. I have, of course, nominated the Society to receive the \$15,000 prize money. Having visited the Tattersall's website and read about some of the previous winners I am humbled to be amongst such company of incredibly deserving people.

Apart from the Society receiving a significant boost in the immediate future from the \$15,000 prize money, the Award is associated with much publicity with many media opportunities, involving nationwide print media, radio and television in addition to longterm website links setting out my story. There will be a number of media events, not the least being a huge lunch for many, many hundreds on the 3rd August in the Melbourne Grand Hyatt ballroom. At that filmed



event in front of hundreds of dignitaries, the stories through video of each of the 12 monthly winners will be presented, at which time they will then announce the annual winner. Although I am unlikely to be considered more deserving than many of the wonderful people who have won over the course of the last year, I am in there with a chance in which case the Society could again benefit, but this time from a far greater grant from Tattersalls.

I would like to take this opportunity to acknowledge with my warmest appreciation the initiative of Jarrod McDonald, our Society's Immediate Past Treasurer, in nominating me – as that act has now provided the Society with critically needed funds and the opportunity to benefit from nationwide publicity for the CFS/ME cause that we could never dream of affording. I also express my heartfelt thanks to all those who were referees in support of Jarrod's nomination of me.

Kind regards to all,

Simon

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know 7 or 8 years and possibly more. We tend to discuss things by occasional teleconferences and email. They're useful mechanisms – but you can't beat getting to know people and talk to them in depth. We're hoping that we can come back armed with good ideas from the other societies – and a stronger campaigning strategy for boosting the

profile of CFS in all the important areas of Australian society.

The message is that we need everyone's help in building up our resources to the point where we could dare to think that we might be able to do things that are only a dream at present.

SA Task Force on MCS: update

By **Peter Evans**, Convenor SA Task Force on MCS.

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The SA Task Force on MCS has had a real win the Adelaide Dental Hospital implementing fragrance controls in the dental hospital on Frome Road. A sign advising members of the public using the dental service to consider refraining from using strong fragrances when accessing dental services is now displayed in the hospital foyer.

The new policy has been implemented as a result of a complaint to the Human Rights and Equal Opportunity Commission alleging unlawful discrimination against a person with MCS.

Under the Disability Discrimination Act service providers are required to make reasonable accom-

modation for people with MCS. This may include restricting the use of perfumes and fragrances, using non-toxic cleaning products, choosing solvent free paints, or avoiding pesticides, for example.

Anyone with MCS who feels they are being discriminated against in the provision of goods and services, including health care, can lodge a complaint with the federal Human Rights and Equal Opportunity Commission or the state Equal Opportunity Commission.

An explanation of your rights under disability discrimination legislation from the SA Central Community Legal Service is below.



Government of South Australia
Central Northern Adelaide
Health Service

SA DENTAL SERVICE
Frome Road
Adelaide SA 5000
Postal: GPO Box 964, Adelaide SA 5001
Tel: +61 8 8222 8222
Fax: +61 8 8222 8205
email: sadental@health.sa.gov.au
www.sadental.sa.gov.au

FRAGRANCE CONTROLS AT SOUTH AUSTRALIAN DENTAL SERVICE

The South Australian Dental Service is committed to equal access to its services for people with disabilities.

Research indicates that up to 6% of the population may have a medical condition known as **MULTIPLE CHEMICAL SENSITIVITY (MCS)** or environmental illness. People with MCS are made sick by exposure to common chemical products such as perfume, after shave, cleaning agents, air fresheners, fresh paints, new building materials, pesticides, tobacco smoke and others. Symptoms of MCS vary from mild to life threatening and include fatigue, muscle pain, gut problems, asthma and memory loss.

State and federal equal opportunity laws require that patients with MCS are able to access appropriate services and service providers must make reasonable accommodation for people disabled with MCS.

Accordingly, patients and visitors are asked to be aware that the use of highly fragranced personal care products such as perfume, after shave and essential oils can affect the health of other people and prevent them from safely accessing dental services.


Please consider avoiding using these products before your dental appointment.

Thank you for your cooperation. General Manager, Adelaide Dental Hospital (April, 2006)

The MCS Report: we hear from the public servant

We received this letter from the Department of Health re the Interagency Working Group on MCS. It's a few weeks old now, but what has not changed is the actual lack of real action. Read on...

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Government of South Australia
Department of Health

Public Health and
Clinical Coordination
Public Health

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00306/0378

Dr Peter Cahalan
President
ME/CFS Society (S.A.) Inc.
GPO Box 383
ADELAIDE SA 5001

22 June, 2006

Dear Dr Cahalan,

Re: Nomination to MCS Reference Group


From the 04/05 Parliamentary Enquiry into Multiple Chemical Sensitivity (MCS), several recommendations were put to the Government. One of these involved the establishment of an MCS Reference Group by the Department of Health and which would include representatives of relevant Government departments and agencies, professional bodies and organisations, community groups and some local Councils, *'to maintain ongoing communication and provide up-to-date information on developments in the MCS debate.'*

In a tabling in Parliament in November 2005, Cabinet – after gaining agreement from relevant departments – supported this recommendation, and supported in principle a further recommendation that the MCS Reference Group *'work to develop best practice guidelines to enable local Councils to establish No-Spray Registers that identify MCS sufferers, and those with chemical sensitivities generally in local communities. This would include identifying current best practice models of No-Spray Registers among Councils to inform the reference group's best practice guidelines.'*

Having made this commitment, and having reviewed our current priorities and resources, I would like to see the MCS Reference Group commence soon. I have discussed this with Dr David Simon, A/Manager of Scientific Services, and with Dr Jim Fitzgerald, Manager of the Hazardous Substances Section and who will be the convenor of the new group. We envisage this stakeholder group holding 2-hour meetings quarterly. A sitting fee of \$160 is paid to non-Government members of the group.

In the first instance, I wish to seek nominations of appropriate members, and ask if you could nominate someone to represent the ME/CFS Society. If you have any questions about this, please feel free to call Jim Fitzgerald (822 67134).

Yours sincerely,


Dr Kevin Buckett
Director
Public Health

MCS: your rights

Toxic endangerment and access to public premises under disability discrimination law

There is growing awareness in the community of the role of some types of chemicals in making people chronically sick. Multiple Chemical Sensitivity (MCS) is now a recognised disability. People with MCS can be made very sick from exposure to chemicals which are commonly found in urban and agricultural environments, such as perfumes, pesticides, herbicides, solvents and many cleaning products, especially those which have had fragrances added. Symptoms vary widely in severity, but commonly include fatigue, headache, nausea, asthma and pain in the muscles and joints. What is less well understood is the role that such chemicals play in causing the disability in the first place, and possibly causing other related disabilities such as attention deficit and hyperactivity in children, and chronic fatigue syndrome (CFS) and joint and muscle pain in adults. It is in everyone's interest that these likely connections are fully, openly and honestly investigated and reasonable precautions taken now and until the research has been appropriately concluded.

People with MCS who live in our cities and towns have to face the daily threat of being exposed to toxic substances in shops, workplaces, schools, public buildings and even the open streets and parks. Their only alternatives may be to stay at home inside, live in a remote country area, or resign themselves to getting very sick sometimes, perhaps for weeks or months at a time. Current equal opportunity laws do, however, provide a basis for people who have a diagnosed disability to negotiate with the owners and occupiers of publicly accessible premises, including outdoor areas, to minimize the danger of being exposed to toxic chemicals in such places. The relevant law is contained in sections 66, 67 and 76 of the (South Australian) Equal Opportunity Act, and s. 6, 23 and 24 of the (Commonwealth) Disability Discrimination Act and cases decided by the courts involving

those sections. The remainder of this information sheet is about the application of the Commonwealth Act, which has broader application in this area.

The Disability Discrimination Act contains provisions about unlawful discrimination in the limiting of access to premises which are open to the public or in the provision of goods, services and facilities. People with MCS can use these provisions as a basis for negotiation with owners, occupiers and service-providers to ensure their safety. Complaints about the use of toxic building materials, pesticides, herbicides, cleaning agents, solvents, and even personal fragrances in these situations should be addressed to the party concerned in the first instance. If their response is unsatisfactory a complaint can be lodged with the Human Rights and Equal Opportunity Commission. The argument is that by allowing such toxic substances to be present in these situations, the occupier or service provider is imposing an unreasonable condition which impacts unfairly on people with MCS and therefore amounts to indirect discrimination under s.6 of the Act. The complainant can then seek an agreed resolution to the problem in a HREOC conciliation conference.

Indirect Discrimination

To prove indirect discrimination it is necessary to establish the existence of a "requirement or condition" i.e. that some stipulation or set of circumstances must be endured if the complainant is to access the premises or use the facilities. The set of circumstances may comprise the presence of toxic air pollutants. People with MCS are required to comply in that they are required to tolerate or endure the presence of such chemicals if they want access to the premises. Most people in the community are able to tolerate the presence of these chemicals in the environment, but many people with MCS cannot, hence the discrimination.

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The main issue in relation to s.6 is whether the condition is reasonable. Some level of toxic or fragrant chemical presence may be inevitable, depending on the type of premises and the activities that occur there. Complainants can ask that the level of pollutants be reduced to a more optimum level that reflects a fair balance of the interests of the occupier or service provider, the staff, customers with MCS, and the general public. This should also be seen as an occupational health and safety issue for staff. It could even be seen as a potential marketing issue.

Accessible Premises

Disability discrimination is only unlawful in certain situations. One of these is where a condition is imposed on allowing access, or in the means provided for access to premises (s.23). Commissioner Innes in *Francey v. Hilton Hotels* explained: "To be able to have access to, and have the use of, premises, a person must be able to remain in the premises. Therefore a policy which allows environmental tobacco smoke into the atmosphere, and takes no or ineffective action to remove it, is a condition on which a person's access is allowed." By analogy, people with MCS may be unable to remain

in premises or use facilities because of indoor atmosphere pollutants.

Accessible Services

People with MCS can also complain about the provision of goods, services and facilities (s.24). The provider's policies on things like staff wearing fragrances or the use of cleaning agents are arguably conditions on the provision of goods, services and facilities. Customers who are unable to access premises may be able to order goods or access services in other ways, but they may be unable to make use of other facilities such as, in the case of a shop, browsing through products on display, being notified of the availability of new products, and making considered choices.

There may be a defence that implementing special precautions so as to make services and facilities available to the complainants would cause unjustifiable hardship to the service provider (s.24(2)). This will involve questions not only of cost, but the burden or benefit to any interested parties (s.11).

John Steele

Central Community Legal Service

PO Box 962, Prospect East, SA, 5082

Phone 8342 1800

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Christine Hunter now AM

Christine Hunter, founder of the Alison Hunter Memorial Foundation and absolutely dogged campaigner for more research into CFS, became a Member of the Order of Australia (AM) in the Australia Day Honours list.

This is fair recognition for a remarkable person. And of course it's great for us all. It's a bit wearying when of all the honours going seemingly to people who deal with higher-profile conditions such as cancer. So Christine's award is recognition of us all.



The Society has sent her warm congratulations. The citation is as follows:

"For service to the community, particularly for people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and their carers, and through support for biomedical research."

Congratulations, Christine Hunter AM.

Our other high honour holder is Simon Molesworth, our national president, also an AM.

The MCS Report: responses from state Ministers

The Social Development Committee of State Parliament tabled the report of its Inquiry into Multiple Chemical Sensitivity on July 5, 2005.

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Here are the latest letters from state Ministers in response to our enquiries into the report's progress:

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CFS caused by temporary brain injury from glandular fever?

New research into chronic fatigue syndrome suggests that it may be caused by temporary brain injuries resulting from a bout of glandular fever.

Australian scientists have monitored the health of people infected with the Epstein-Barr virus, which causes glandular fever, and found that those who go on to develop chronic fatigue syndrome are likely to have suffered trauma to the brain during their illness.

Professor Andrew Lloyd from the University of New South Wales says their findings show that chronic fatigue syndrome is a real condition.

"I personally have never had a doubt that it's real because there are people who have got a set of symptoms that are unexplained," he said.

"The real versus not real thing is often caught up in the mistaken notion about malingering or it's all depression but really there's no evidence to support that."

"So in a nutshell yes, it clearly supports the argument that it's real."

Professor Lloyd says it seems that some people with glandular fever suffer a brain injury of some kind that leads to chronic fatigue syndrome.

"It's an injury in the sense that it wasn't there, people were perfectly well, something in the acute phase of the illness went wrong and then it slowly recovers like a broken arm or a broken leg, it's just that in this case its taking weeks to months rather than days or quicker," he said.

ABC News Online, March 2, 2006

Badge Day

By **Peter Cahalan**, President ME/CFS Society (SA) Inc

A hardy band of volunteers – including 20 girls from Annesley College – worked the streets of Adelaide on Friday. They raised a neat \$1000 – the exact figure was around \$1018 – and that's a really good result. We're expecting further monies to come in from regional areas and that will boost our accounts.

It wouldn't have happened without the drive of Emma Wing especially. She started at 7:30am and left after 3pm. As anyone with CFS knows, being out and about for hours like that isn't crash hot for the body and I know that she was pretty wrecked on the weekend. So it's thanks from all of us, Emma. Thanks also to Carole Carroll (organiser of the Annesley girls), Freya Thomson, Marg Wing, Libby Hughes (and Jess) and all the other people whom I didn't get to meet.



Margaret and Emma Wing set up at 7:30am – an ungodly hour for most people with CFS.

A new CFS research foundation

By **Peter Cahalan**, President ME/CFS Society (SA) Inc

We've just had news out of the blue that a significant amount of money has been invested in a trust in Victoria to fund research into CFS. The trust has a long name (The Judith Jane Mason & Harold Stannett Williams Memorial Foundation) but its short title is the Mason Foundation. It's been set up by a woman who suffers from CFS and is dedicated to her father who had Alzheimer's and so the funds will be directed to both conditions. But the intent seems to be to direct the lion's share to CFS research.

It's not peanuts either. It looks as if it could direct up to \$500 000 a year into research into the two conditions. We've some excellent researchers in

Adelaide and I vividly recall asking Dr Richard Kwiatek last year what kind of funding would help him to do some further research in his field of SPECT scans at the QEH. He replied that as little as \$20 000 would be a terrific help. That's a big amount for our State society to rustle up but obviously just a teaspoon out of the chalice of this new fund.

It's a reminder that the longer CFS is around as a condition which affects an increasing number of people, the more chance we have of things like this happening. The empire is expanding in good as well as bad ways!

Letter to the Editor

Multiple Chemical Sensitivity

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Talking Point – 2006 Issue 2

Has an awareness flyer about MCS ever been printed – warning the public, about the negative affects of chemicals/pollutions/fumes, on the individual? I think there should be such advertising as this – so simple, but effective. Just an A4 size would do. Flyers should be placed in all work environments, certainly government buildings and offices, and most definitely in schools, universities, child care centres. In fact – wherever children and adults frequent!

Multiple Chemical Sensitivity is a serious problem, and getting worse as the years go by. That doesn't say much for our environment, does it? I moved to Adelaide nine years ago – leaving behind fresh country air, and the petrol fumes have sickened me ever since. This I believe, has caused my system to become sensitive to many other products as well.

Since becoming ill in 2004, with the multi-system disorder of Chronic Fatigue Syndrome, I have become sicker with fumes/chemical sensitivities too. Even the smell of deodorants make me feel nauseous, not to mention perfumes and after-shaves!

Going to the petrol station is quite an ordeal. I'm not game enough to wear a mask there – in case the poor attendant becomes alarmed, but I do place a cloth over my nose and mouth, otherwise I'd become extremely ill. And hey, I do have to put petrol in the car!

In recent years, there has been a review of health and safety regulations. Workplaces must abide by all regulations, with regular 'information' updates for workers' awareness.

Churches too, must abide by the conditions set, with parishioners/volunteers always made aware of the requirements and rules. So too, regular awareness of Multiple Chemical Sensitivity, and it's devastating affect on the human body, is not something to be taken lightly. Not something to be shunned, or put in the too hard basket.

Do we have to wait for a family member of a politician, to be deeply affected by MCS, for anyone to take notice of a life problem such as this? I hope not!

Stop thinking of profits, and put human life/living first. Substances have affected my body, and effected my daily living. Please, make people aware of negative substances, and the disastrous affect that can be had on the individual – even death.

Sincerely,

Christine T. Penglase



A passion for photography

By Carolyn Chase.

This is the story of how the ME Association's magazine cover photographer, Carolyn Chase from Northwich, Cheshire, turned the tables on 16 years of severe illness and came out triumphant.

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The September rain was falling and a light mist heralded the onset of the colder weather. Upon waking and contemplating the usual daily grind, it occurred to me, not for the first time, how the severe problems and harsh realities of the last 16 years of having ME (CFS/ME) have shaped my life, built my character and been instrumental in the success of my favourite passion – nature photography!

Having little mobility I was confined to a life of simply sitting and looking at the world around me. Racing about doing chores, looking after children, pleasing a partner or going to work were not options in my life – a sad fact maybe.

But the world around me took on new meaning as I watched how sunlight played on the leaves, how the birds behaved when enticed with nuts and how droplets clung to flowers after the rain. The textures and colours fascinated me and I noticed how colours became particularly saturated in overcast weather.

More sitting and looking, day after day, became not boring but magical. A beautiful black and white and red bird visited (a great spotted woodpecker) and many other colourful little species such as goldfinch, bluetit, robin and nuthatch, kept me mesmerised.

As time passed I made a canvas hide and sat even closer to the creatures I loved and began to photograph them. I sat for hours and days despite the pain. I built up a collection of photographs which consist of birds, butterflies, leaves, trees, badgers, flowers and many more images of the countryside

and nature.

In 2002 I was as usual mostly housebound and sitting in my small garden in my pyjamas at 4pm was just about all I could manage that day. My new kitten, Hocus, was playing in the cherry tree beside my seat and I was enjoying his antics. I raised my camera and took a photo of him while finding vicarious pleasure from his moments of fun. This photograph went on to win the Cats Protection Photo of the Year 2002 national photo competition out of over 5,000 entries.



The photo was beamed to magazines and newspapers and some of my kitten photos now feature on calendars and other publications. I won a holiday in London all expenses paid. I didn't go on this holiday, courtesy of ME, but it will not take away the pleasure of winning.

Since then I have been granted a Millennium Award to continue my photography and have exhibitions in Cheshire to stimulate interest in the care and preservation of our animals, birds and countryside.

The passion has not waned and today my small back garden hosts the scene for many an opportunist or planned photograph to add to my favourites.

Reprinted from ME Essential, quarterly magazine of the ME Association UK, March 2004.

Editor's Note: There are some delightful photos on Carolyn's website: www.chasephoto.co.uk.

The featured photograph is "Ellie in the Daisies".

My own worst enemy

By Sue Stevenson.

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It was the realisation that I was being my own worst enemy that proved a turning point of sorts. I began to realise that my quest to get well was going to involve a certain amount of learning to be kind to myself. This in turn would lead to listening to my body.

Sometimes it's good that we can't see into the future. It's January 2002 and I don't know it yet but it will be another three and a half years before I will be able to state definitively that I am more well than sick. Right now I'm struggling to come to terms with the different aspects of this horrid illness with such a horrid name. I have trouble even defining what is going on with me a great part of the time.

I'm also in mourning because I had relinquished my tertiary studies the year before. I was overcome by my inability to think straight and remember words, let alone participate in tutorials and write essays. Despite all of this in the back of my mind I have these nagging doubts: if I'm sick as I suspect I am, why can I walk the dog? Or how can I go to a trivia night with my friends fortnightly and behave well enough that no one would know I was sick?

A review of my diary from those years is distressing. How little latitude I gave my illness then (part of this was neurological, part fear – something I wouldn't understand for a long time). Page after page of my diary bemoans my inability to write, wonders why I'm not getting my housework done and why my sex drive is so low.

Just because I could walk the dog, I would suddenly presume I was all right. So when I came back home to be met with filthy floors, a clothes hamper overflowing on to the floor and every surface dusty or covered with something which didn't belong there, I would mentally berate myself. And then I would berate myself for the resulting anxiety!

CFS/ME felt like a surreal dream, not only because I was bone-exhausted and brainfogged, but also because I felt so disconnected from my body that

often I couldn't accurately say with any certainty how bad I was feeling. Someone would ask me how I was. I would say, "Fine." Their response would be that they were not too bad that day except for the horrible brainfog they were feeling. It would dawn on me as they were saying it that my brainfog was actually quite bad when I focused on it.

The CFS/ME roller coaster also means that when you do find yourself with more energy than usual, it's almost impossible to pace yourself and use it wisely. Even though it is a most beautiful commodity, it's difficult to dole out energy in a practical way when you've been starved of it. Who would condemn the prisoner on day release squeezing every ounce of freedom from the time they have left before going back into the cell?

We've all read accounts of the power of positive thinking to help our bodies heal. For me it went even further than that – to the power of honest thinking. At times I was depressed, despondent and suicidal. Admitting it to myself was the most difficult thing. But the harm comes when we pretend we're not feeling those emotions. They have a tendency to fester just below the surface.

There's nothing like a loss of control to help us realise just how much we need to be in control of our lives. Add something as misunderstood and shape shifting as CFS/ME to the mix and this journey becomes one where the psychic pain is almost as bad as the physical and mental pain.

To cope with it all I complained a lot to my long suffering husband, friends and God. But the times

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that helped me the most were talking to fellow sufferers. My family and friends could never understand how difficult it is to do the most mundane things like think straight, no matter how hard they tried to sympathise.

It was the stories other sufferers told about their experience which helped me realise two things that I believe were impeding my getting well. One was how hard I was being on myself. The second was that I needed to learn intuitively to trust what my body was trying to tell me – a difficult thing to learn in the Western world where the mind and body are considered separate. Being hard on myself was something I'd heard other people tell me for years, but I think it struck me finally when I realised how willing I was to undermine myself even when I was sick.

My efforts to control a life that felt precariously out of control meant that I found it really difficult to ask for help. Asking for help would mean there was a problem and that I was lacking somehow.

I even had problems getting a cleaner to come for a couple of hours a fortnight so I could feel the floorboards under my feet instead of dirt. I thought my husband would resent my getting a cleaner, but it wasn't him – I resented getting a cleaner. Never mind the wonderful feeling after she left when I did feel some element of control over my surroundings – my pride felt bruised at having to ask for help.

It all seems slightly bizarre now and it took the disbelieving stare of a friend and fellow sufferer to make me realise that perhaps I was cutting off my nose to spite my face.

I hired a cleaner and maintained the service until I was well. Yes, it was uncomfortable having someone else cleaning my house – I often didn't know what to do while she was there and I felt very strange lying on the couch while she was cleaning up. But the benefits in lowered stress made my discomfort worth it.

It was the realisation that I was being my own worst enemy that proved a turning point of sorts. I began to realise that my quest to get well was going to involve a certain amount of learning to be kind to myself. This in turn would lead to listening to my body.

I began intuitively to suspect, after reading various anecdotes and listening to the conversations of others, that one of the things keeping me sick was infection.

So after much trial and error I was finally diagnosed with several strains of rickettsia. Thus began the last stage of my illness – about twelve months of arduous antibiotic treatment that was in some ways worse than the four years of CFS/ME preceding it.

While fatigue was becoming less of a feature of my days, the die-off effects of the rickettsia antibiotics made me feel for seven days of every month like I was unfit for human consumption.

The happy end to this story is that my rickettsia is under control and I am well. I go to the gym twice a week and I've returned to my studies at university. I'm writing. Slowly, slowly I'm getting a life again. The colours are once again being turned up from palest pastel to vibrancy.

There's a reason why CFS/ME occurs and the reason is as individual as each person. Not only do I believe that with all my heart, but also I believe it is imperative to have the hope that comes with that belief.

It might take longer than you hope or feel you can bear, but the giant jigsaw puzzle will be slowly put back together with every new piece of information you gain about your own personal battle with this illness.

Trust your gut feelings and don't give up hope. It will happen.

Reprinted with permission from Emerge, Winter 2006.

Interview with Leigh Hatcher

By **Meg Beach**.

Page 18 In 1999 Leigh Hatcher (pictured right), a well-known TV journalist, was diagnosed with CFS/ME. Six years on and Leigh has returned to work and started his own media and publishing company.

He kindly took time out from his demanding role as a Sky News presenter to answer a few questions about his CFS/ME journey.

Considering you had CFS/ME, how long did it take to complete the book and what prompted you to write it?

I wrote it from diaries I kept from about three months into my illness. All through my illness a friend who'd been involved in the publishing business urged me to write about my story 'one day'. As soon as my health turned the corner she immediately and wisely said 'wait three years to write the book'. About three years later I was speaking at a church when two women came up in tears, both of whom had known CFS/ME in their family, also urging that I write it. In the preface of the book I've written that it's for all those who don't have a voice in the midst of such a baffling and misunderstood illness. Too often they are driven to silence by all the misunderstandings, misjudgements and even suspicions.

After battling with an "unknown" illness for so long, how did it feel to finally be diagnosed with CFS/ME?

Though the diagnosis might appear grim (as it was), I was hugely relieved to finally have a 'label' and a sense of structure that a diagnosis gives the sufferer. I didn't receive the CFS/ME diagnosis until a year into my illness. One of the most frustrating things about that year was to feel so ill and to lose so much (health, job, relationships) and still not know why!

You had heard of CFS/ME before the diagnosis and felt it had 'dodgy written all over it'. In your opinion why do you think most people have a difficult time understanding CFS/ME?

I think the word 'fatigue' in the title is largely to

blame. Everyone gets fatigued or tired now and then – so inevitably the CFS/ME sufferer is often thought to be one who can't 'get over it', or is a bludger or, worse, a fraud. I also think the fact that there's no scientific marker, as there is for diseases like cancer etc, contributes to the 'dodgy' perception of CFS/ME.

Can you recall your lowest point during the illness?

The powerlessness and alienation of it all hit me near the start of my second year (quite apart from the very significant physical suffering and material loss). I had endured too many difficult and damaging visits and misjudgements from a few people for far too long. Each had brought me to a new low – suffering piled upon suffering.

Guilt is one symptom of CFS/ME, which is often overlooked. Why do you think many people with the illness experience this feeling?

It's easy to feel guilty for two reasons:

First, the response of many, judging you to be either a bludger, a nut case or a fraud. Some even express their envy of 'having time out'!

Second, there's your own inherent need and desire to have a life. 'Having time out' was never my desire or intention. I'm an active activist by nature, revelling in a life on the go. Amid all the misunderstandings, it's easy to feel guilty that you're being seen to have copped out.

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You led a very active life before the onset of CFS/ME. How did you cope with your inability to continue your journalism career?

Though it had so much been part of my life and even identity, surprisingly I didn't experience a crisis of identity and purpose. My Christian faith had much to do with this. Under God I have an identity and hope beyond my job, 'in sickness and in health'. I never wavered in a quiet certainty that, though each diminished day was tough and the future looked so uncertain, God's bigger picture was being played out for my good.

You mentioned in the book that you felt you had learnt things through being ill that you might not have otherwise known. What were some of those things?

1. The incredible gift of good health.
2. The incredible gift of a supportive family.
3. Bad things happen in life.
4. We don't have control over our life.
5. We are not self-sufficient.
6. The largeness and the kindness of God.

What suggestions would you give to a sufferer on how best to describe CFS/ME to any sceptical friends/family?

Hand them 'I'm not crazy, I'm just a little unwell!' I'm only half joking, as there are many (and I encountered many) who, no matter how rationally and logically you explain the reality of CFS/ME, still won't 'get it'. Often it's not as necessary to explain it to immediate family – it's in their face every day. Perhaps a good supportive friend is best to take on the role of explaining the illness to the sceptical. If it continually falls to the sufferer, it can quickly feel like you're bashing your head up against a brick wall. It will only exacerbate the sense of alienation and anger.

What is the best advice you can give to those living with a person who has CFS/ME?

Patience, understanding, acceptance, love. This is often very tough because the illness is a long-term

thing and, with a body and brain running on empty, the sufferer will find it tough dealing with the inevitable 'argy bargy' and 'issues' of relationships. It's a great idea for those living with a sufferer to, where possible, have a life and certainly quality supportive relationships outside of home.

How would you describe your health these days?

My health is good – not 100%. I think there's an extent to which even in 'recovery', the CFS/ME sufferer is never truly 'over it'. I now live a busy, diverse, rewarding life. My work as a newsreader on Sky News Australia is high stress and I revel in it. My turning of the corner in my health identified a metabolic system that had gone haywire so, to cut a long and complex story short, I still eat and exercise like a diabetic. I also need to get a good amount of sleep each day. Life is good!



Dealing with guilt

By **Linnea Smith Noyes**, Guest Contributor, CFIDS Chronicle, Summer 2005.

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People with chronic fatigue syndrome and fibromyalgia are often overwhelmed with guilt. It's important to challenge the cultural and personal belief systems that contribute to guilt because guilt won't make your illness better – and may actually make it worse!

According to psychologist David Richo, guilt has two aspects – appropriate and neurotic guilt. He distinguishes between these two kinds of guilt in his book, *How to be an Adult*. Appropriate guilt, he says, comes from within and is what we refer to as conscience. It's experienced as an internal voice that arises when we have stepped out of our own truth. Neurotic guilt, in contrast, "is a learned response ... to an external injunction of demand that we have internalised. We have stepped out of other's truth."

Guilt is actually a belief or judgment rather than a feeling. In the case of appropriate guilt, the judgment is self-confronting and creates opportunities for resolution. Neurotic guilt, in contrast, is not impacted by acknowledgment or restitution, but hangs on as internal struggle and conflict.

Though everyone experiences both appropriate and neurotic guilt, I believe neurotic guilt is especially challenging for people with chronic fatigue syndrome (CFS) and fibromyalgia (FM). We live in a culture and often come from families that value health, productivity and self-reliance. Being chronically ill flies in the face of these standards and invites the kind of negative self-appraisal referred to as guilt. This guilt is a result of internalising demands to be "normal" in a culture that doesn't include chronically ill people like you in its database. Since self-confrontation is unlikely to impact the fact that you're ill, it becomes important to look for other ways to relate to this particular experience of guilt.

Let's take a look at guilt issues common in people with CFS and FM and then explore ways to minimise the influence of unproductive guilt.

Cultural sources of guilt

It's my fault. One stronghold of guilt resides in the simple fact of being ill. It's not uncommon for people to assume a direct relationship between their worth and what life delivers. You may look to your own character or lifestyle for "explanations" of why the illness arrived at your door.

Your thinking might go something like this: "I brought this on myself; if I'd think positively, I'd get over it." Another common self-assault is this one: "I'm having these problems because I won't exercise, I'm too stressed, I'm too ... whatever." People with CFS or FM have no trouble filling in the blank. A more New Age version of this belief might be: "I create my own reality; if I'm not creating health and wealth, I'm clearly doing something wrong."

Any guilt or self-blame of this type tends to hinge on the assumption that you actually have control over such matters, and that there is a relationship between "goodness" and life events.

Pace and productivity. A second kind of guilt occurs because the United States and many other Western countries put an immense value on fast pace and productivity. Because individuals with CFS and FM are often limited in these capacities, it's easy for guilt to rear its ugly head. A typical issue might involve the inability to work and contribute to the family income. Or there might be huge disappointment around difficulties starting a family, and subsequent guilt for a person who holds herself responsible. Some individuals are unable to cook, clean, shop, and do what they perceive is

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their “fair share” of responsibilities around the home. Needing to prioritise your own needs over commitments to other people is yet another challenging area, often limiting the sense of having a satisfying social life or being dependable.

Guilt about moving at a slow pace and diminished productivity represents beliefs that are learned from role expectations and social convention.

Dependency. Finding ourselves in a receiving rather than giving role is another common source of guilt. Many individuals with CFS and FM cherish being in the role of giver and are very uncomfortable finding themselves in the position of needing to depend on others for physical or financial support.

I practice in Salt Lake City, where I work with many patients in Dr Lucinda Bate-man’s Fatigue Consultation Clinic. A typical comment I hear from clients in my practice is: “I’m constantly disappointing my partner, who gives, gives, gives.” Or, “I feel inadequate as a girlfriend (spouse, friend, etc.) because I have to be selfish with my energy resources to survive being chronically ill.” It’s also common for my chronically ill patients to look back and say, “My old self would have been able to do this task and not rely on others.”

Curiosity about guilt. To diminish the role of guilt in our lives, an attitude of curiosity can be very helpful. What are the beliefs and values upon which our self-judgments are based? Can they be challenged? Can we identify other beliefs and roles that are more appropriate for us and begin to think more creatively?

Challenging beliefs. Challenging our beliefs

about guilt is an important part of the work I do with patients. Linda Milne, one of my clients who has CFS and FM, told a friend she felt “spiritually embarrassed” to be chronically ill. Her friend responded, “I would never have that opinion of you. Why would you have it?” Milne realised she had been equating ill with being a “spiritual failure.” She was able to recognise the faulty belief and release it.

Milne’s experience isn’t uncommon. Just as judgmental and negative comments can feed false beliefs, supportive friends, family and support groups can all act as positive mirrors for us and assist us in seeing through self-limiting beliefs. Surrounding yourself with these positive resources can help you navigate your way through the challenges of living with a chronic illness that is misunderstood by so many people, including health care providers.

You can also challenge beliefs on your own. A very useful question is, “Is that really true? Can I absolutely know that what I believe is true?” For instance, if you believe you’re responsible for being ill, can you actually know that’s true? Not really. It’s impossible to know with certainty exactly

what factors coalesced to create illness. How does it feel when you hold yourself responsible for becoming ill? Who would you be if you didn’t tell yourself that story? (For more on this topic, see Byron Katie’s book, *Loving What Is*.)

In a group session with other CFS and FM patients, Shawn Stupka talked about how it can be a huge relief to let go of the thought, “I’m not supposed to be sick.” Tana Howell agreed: “The key is to ask yourself what beliefs you’re running from. They’re just thoughts. You can choose not to be-

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lieve them anymore."

As you let go of beliefs that are not personally supportive, the guilt associated with these beliefs will abate as well.

Another kind of personal belief you can challenge on your own are assumptions made about how others are experiencing your illness. It's easy to believe other people's feelings of disappointment or anger are worse than they actually are, and to feel deep despair based on these assumptions. But you have essentially made up a story about what another person is thinking or feeling, and then responded to your story as if it were true.

Guilt can be diminished and relationships strengthened when we simply begin asking people directly about their experience. By asking questions, we let others know that we are open to their truth and willing to set our projections aside.

Let's look for a moment at beliefs related to pace and productivity. The cultural expectation to move quickly and be productive is rather like the air we breathe. We are so accustomed to this cultural "press" that we don't even think to question its validity as a lifestyle.

I say question it! In a CFS/FM support group meeting, Rhonda Cassidy did just that, remarking, "We are human beings, not human doings."

In the July/August 2004 issue of *Ode*, an article titled "Going with the Slow" discussed how slowness is supportive to health, mindfulness and a sense of peace. It also described communities in Italy where entire townships are committed to cre-

ating a slower pace of life. Some of the article's recommendations for slowing down the pace make the CFS/ME lifestyle sound very reasonable.

The reality of CFS often requires people to slow down and be less productive. If you let go of the viewpoint that this is a problem, it's possible to see benefits to living life from a more tortoise-like perspective. "Who's to say this isn't a good life, or that society's pace is reasonable?" Howell asked at a recent support group meeting. Milne responded, "Maybe we're the lucky ones. I'm kinder since I've slowed down. I notice others' needs more. I never would have discovered this pace of life if I hadn't become ill."



Thinking out of the box. In addition to challenging the beliefs that drive sensations of guilt, it's useful to notice what we value in a particular belief, and then look for new ways to express that value in our lives. When we think out of the box, we engage creativity to honour what's important to us, while at the same time respecting our physical limitations. We may find ourselves available to new interpretations of what it means to be productive, for instance.

I've noticed that as acceptance grows, clients begin to appreciate the time that's available for inner focus and personal growth, as well as their capacity to be present for others. In *Clear Mind, Wild Heart*, poet David Whyte remarks that individuals moving at rapid velocities literally cannot perceive the people who are moving slower than they are. When our own pace is slow, we can attend to people in a new, more intimate way. This is a good example of reframing and revaluing what we *can* do.

Milne has shifted her focus away from the guilt she

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previously felt about being dependent on other people for support. She has done this by emphasising the concept of exchange over equitable give-and-take. Because generosity is important to her, she looks for opportunities to give to others at a level and pace that is congruent with her limitations. The contributions are usually smaller than the ones she receives and don't necessarily involve the same people.

One of the ways Milne gives back has proven especially powerful – the willingness to talk about chronic fatigue syndrome and fibromyalgia to other patients, family members and anyone else who's interested. "I talk about it everywhere."

A word about therapy. Therapy need not be a lengthy commitment. Most therapists are happy to work with you on a particular issue like guilt or anger for a short period of time. And once you have worked with a therapist on one issue, that supportive relationship is in place for you, enabling you to return on an as-needed basis should other concerns arise.

I encourage clients to trust their own instincts in selecting a therapist who feels "right." Though the work of therapy is sometimes *uncomfortable*, the relationship with the therapist should feel *comfortable* and safe.

Individual therapy is not your only option. Support groups and therapy groups can be very helpful in gaining insight about topics of particular concern to individuals with CFS, FM and related illnesses. While therapy groups support you to explore your personal psychology within the context of the group, support groups tend to be more topic-focused. They are generally facilitated by therapists, although some support groups are run by laypeople with group process expertise.

Either type of group has the advantage of putting you in contact with other individuals who are coping with challenges similar to your own. Sharing personal experiences and discoveries can be very

empowering, especially when there's an intent to grow and be open to a more positive perspective related to being ill, instead of simply venting and complaining.

The gift of guilt. Following neurotic guilt back to its origins permits us to see more clearly the personal and cultural beliefs we hold as standards for ourselves. The opportunity then exists to challenge the appropriateness of those standards and rework them into values that are congruent with our personal ethics. As a result of this process, personal awareness will be enhanced, guilt will begin to diminish, and increasing amounts of energy will be freed for other endeavours. You may even find yourself able to feel increasing acceptance of your limitations and appreciation for experiences you would have missed had the illness not entered your life.

The struggles and imperfect qualities each of us carries through life have an essential role to play in our development. It's by working through the facets of life that are most challenging for us – whether addiction, bad relationships, poor finances or chronic illness – that we discover our true, authentic self.

This process is about being who we truly are and locating ourselves in the company of people, places and activities that call out the best in us, that inspire our grace. It's about allowing and nurturing what is heartfelt and showing kindness toward ourselves by leaving the voices of self-blame and guilt at the door.

Linnea Smith Noyes is a psychologist in private practice in Salt Lake City, Utah. In addition to seeing clients privately, she facilitates a CFS/FM support group. Noyes says she "specialises in supporting people through their major life transitions, often stimulated by divorce, illness, death or any of the 'unwelcome gifts' life may deliver."

Reprinted with permission from Emerge, Winter 2006.

Special thanks to Emerge's Medical Editor, Dr Nicole Phillips for this article.

Is CFS a brain disorder?

The cognitive problems CFS patients report have led to numerous research studies to assess neurocognitive impairments. Although data is not consistent, research confirms both structural and functional brain abnormalities in CFS.

By **Gudrun Lange**, PhD, UMDNJ-New Jersey Medical School
CFIDS Chronicle, Special Edition 2005-2006.

Trouble concentrating. Poor memory. Difficulty processing information. Cognitive difficulties are among the most debilitating of CFS symptoms. These problems, often referred to as “brain fog” by patients, are more than just a nuisance or frustrating. They can be functionally disabling and severely limit school or job performance, even contributing to school failure or loss of career in some patients.

Cognitive problems have been reported in as many as 85-95% of patients, and neurocognitive studies from a significant body of CFS research to date. Researchers have focused both on the anatomy/structure of the brain and the function of the brain in CFS patients to determine if there are abnormalities that might account for the impaired cognitive function.

Although CFS patients describe their cognitive problems as very prominent and disabling, when measured using objective neuropsychological assessment tools, the deficits detected are often labelled as “subtle” or “not statistically significant.” However, statistical significance can’t be equated with clinical significance.

Most researchers now acknowledge that the central nervous system – the brain and spinal cord- somehow plays a role in CFS. The scientific literature, however, is full of conflicting studies, and the exact nature of the neurocognitive impairment is still unclear.

What accounts for conflicting results?

Some of the factors contributing to inconsistent results in neurocognitive research are as follows:

- A standard neuropsychological test battery to assess cognitive function isn’t used across studies, prompting differing interpretations of test results.
- Some studies rely on rater-dependent data analysis techniques that could introduce bias.
- Technological aspects of the studies often differ, affecting results. SPECT cameras can range from single- to triple-head cameras; MRI scanners can have a field strength of either 1.5 or 3.0T.
- Investigators using the SPECT technique often use the cerebellum to normalise their data, assuming that flow in this region of the brain is similar between groups. Based on some reports, this may not be the case.
- Due to technical limitations, some studies only have two image slices available for analysis whose thickness is not always noted, while others are able to analyse contiguous slices of the entire brain.
- When neuroimaging studies are task-dependent, the behavioural paradigms used to evaluate brain function are rarely identical or even similar across studies, so they need to be described thoroughly.

It’s also possible that we haven’t yet discovered what area of the brain to study in CFS, or whether the technology now available can give us the answers we seek.

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Cognitive deficits

In spite of methodological limitations and conflicting studies, there are some consistent findings about brain function from neuropsychological testing. Impairments in numerous cognitive domains – acquiring new information, processing information, attention, concentration, verbal memory, visual memory, reaction time and psychomotor function – can be found in the scientific literature on CFS. The most consistent findings, however, are slower reaction time, poorer performance on complex attentional and memory tasks and slowness in acquiring new information. This suggests that slowed cognitive and motor speed appears to be a basic underpinning of cognitive difficulties in CFS.

Neuroimaging study results

Investigators have used brain imaging technology to examine whether people with CFS have structural and/or functional abnormalities. Both have been found. Here are some of the key findings:

- Several structural MRI studies conducted in the 1990's found abnormalities in cerebral white matter, usually small hyperintensive (bright white spots or lesions). It appears that CFS patients who don't also have a psychiatric disorder like depression are much more likely to have white matter abnormalities than CFS patients with depression.
- Three recent studies have found evidence of cerebral atrophy. This means the brain has decreased in size, possibly due to the death of brain tissue. Our UMDNJ group found indirect evidence for white matter loss, and two recent studies reported a significant reduction in cerebral grey matter (see box No.1).
- Numerous dynamic imaging studies have now shown reduced cerebral blood flow, called hypoperfusion, in CFS patients. Reduced cerebral blood flow has been found globally as well as in the lateral frontal, lateral temporal and medial

Will technology reveal the answer?

New neuroimaging techniques are revealing more and more about CFS. The integrity of the brain of CFS patients is being evaluated using both static and dynamic imaging tools. There is hope that utilising a combination of these tools under strict study protocols may someday give us conclusive answers about the role of the brain in CFS.

MRI, magnetic resonance imaging, is the static technique most often used in CFS. It's used to detect brain lesions, the presence of white and grey matter abnormalities and decreases in brain volume.

fMRI, functional MRI, a newer dynamic technique, is used to assess the functional integrity of the brain in CFS patients.

BOLD fMRI, blood oxygen level dependent functional MRI, is not invasive since no radioligands are involved, so task-related activity can be imaged multiple times.

SPECT, single photon emission computed tomography, is a dynamic technique used to measure global and regional cerebral blood flow either at a resting state or during task performance.

PET, positron emission tomography, has been used to provide data on cerebral blood flow and metabolism in CFS.

H-MRS, proton magnetic spectroscopy, is used to assess the concentration of brain metabolites in CFS patients.

VBM, voxel-based morphometry, is a technique for computational analysis of differences in global and local grey and white matter volume from MRI images. Unlike many morphological assessment tools, which require human observers and subjective ratings. VBM is fully automated, so results are more objective.

temporal lobes. The research suggests that CFS patients, particularly those without concurrent psychiatric conditions, suffer from widespread cerebral hypoperfusion.

- Several studies have found abnormal brain metabolism in CFS patients. Abnormal cerebral glucose metabolism, decreased acetylcarnitine uptake and abnormalities in the serotonergic

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neurotransmitter system are the reported findings.

- Our UMNDJ research team used BOLD fMRI in a 2005 study which found that CFS patients are able to process challenging information, but they utilise more extensive cerebral networks and have to exert greater effort to process auditory information. Brain activation in CFS, particularly in patients without concurrent psychiatric illness, is significantly more diffuse than normal.
- A 2005 study found that 30% of CFS patients had higher protein levels and/or white blood cell counts in spinal fluid than normal. CFS patients without depression or other psychiatric comorbidity were more likely to have abnormal spinal fluid, suggesting that this subset of patients may suffer from central nervous system immune dysfunction.
- Due to work from our research group and many others, it appears that CFS patients who don't have a concurrent psychiatric disorder are the ones with the most severe cognitive difficulties and the most pronounced abnormalities in neuroimaging studies. This suggests subtyping CFS cohorts by the presence or absence of depression and other psychiatric disorders may be very useful in subsequent studies.

What can we say for sure?

We know CFS patients, especially those without concurrent psychiatric illness, are generally slower mentally as well as motorically, but often not to a "statistically significant" degree. This slowness can impact higher cognitive functions, such as memory and executive function.

What we don't know is what causes the slowed latencies observed in CFS patients. Hypotheses abound. Some investigators claim that an infectious process may be responsible, while others suggest cardiovascular problems may be at the root of the

Two studies find grey matter reduction in CFS patients

Cognitive difficulties are found in 85-95% of CFS patients. Now, cutting-edge research from two independent international groups suggests that the volume of grey matter in the brain is significantly decreased in CFS. This decrease in brain tissue, or cerebral atrophy, may be responsible for cognitive problems in some people with CFS.

The most recent of the studies, conducted in 2005 in the Netherlands, used MRI technology to measure brain volume and tissue concentration, finding that the volume of grey matter in CFS patients was significantly decreased. What is especially interesting about this study is that after researchers found structural abnormalities in a first CFS cohort, they repeated the experiment in a second cohort of equal size and found the same results. In all, 28 patients and 28 healthy controls were tested. The researchers, led by Floris de Lange, report that when results from both cohorts were combined, the reduction in grey matter tissue in CFS patients was 8%.

This echoes the 2004 findings of a Japanese research group led by Tomohisa Okada, MD, PhD, which observed "a significant reduction in grey matter volume in the bilateral prefrontal areas of CFS patients". Investigators found an 11.8% volume reduction in the 16 CFS patients compared to the 49 healthy controls.

Both studies used a technique called voxel-based morphology (VBM) to measure the results of the brain scan. Unlike assessment techniques that rely on human observers and rating scales, VBM is an automated procedure that provides unbiased results. While grey matter reduction was found in both studies using VBM, neither study found white matter abnormalities.

Although we don't know if the observed cerebral atrophy is a cause of CFS or a consequence, these findings are alarming some members of the CFS patient community, who are concerned about "brain damage". It's important to note that the studies are small and need to be replicated by other researchers before definite conclusions can be made. And even if the results are confirmed by future investigators, the brain has a remarkable ability to adapt and to "rewire" itself in compensatory ways. Research shows that people with CFS may use more extensive regions of the brain to process tasks and information, perhaps compensating for deficits in specific areas of the brain. There are rehabilitative techniques patients can employ to help with cognitive problems.

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Major depressive disorder in Chronic Fatigue Syndrome: A CDC surveillance study

Eleanor K Axe MD PhD, Paul Satz PhD, Natalia L Rasgon MD PhD, Fawzy MD
Journal of Chronic Fatigue Syndrome, Vol. 12(3) 2004

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SUMMARY:

Background: Controversy continues to exist as to whether Chronic Fatigue Syndrome is a psychological/psychiatric disorder. To further understand this condition the Centres for Disease Control (CDC) conducted a Surveillance Study. The CDC partitioned 565 subjects with fatiguing illnesses into four diagnostic groups, one of which met the 1988 CDC criteria for CFS. The non-CFS groups had either insufficient severity (idiopathic), medical exclusions or prior psychiatric disorders.

Objectives: The present study reports on the psychiatric features in that study, estimates the time of onset of Major Depressive Disorder (MDD) and looks for possible relationships between 1988 CDC criteria for Chronic Fatigue Syndrome and psychiatric disorders.

Methods: The study design is cross-sectional. The Diagnostic Interview Schedule (DIS) assessed for four Axis I psychiatric disorders. Time of onset of MDD was estimated from the DIS and validated by an examination of the medical records. Odds ratios and confidence intervals were calculated as tests of association between 1988 CDC criteria and psychiatric disorders.

Results: Subjects classified as CFS and non-CFS had similar rates of psychiatric disorders. A minority of subjects had preexisting MDD. Three 1988 CDC criteria were associated with current MDD (headache, neurobehavioural and sleep disturbance) whilst no criteria were associated with prior MDD.

Conclusions: CFS subjects did not demonstrate any unique patterns of psychiatric disorders. MDD may not be an important predisposing factor for CFS or the other fatiguing illnesses. Some 1988 CDC criteria may be preferentially endorsed by subjects with current MDD.

Eleanor K Axe, Paul Satz, Natalia L Rasgon, and Fawzy I Fawzy are affiliated with the University of California, Los Angeles, CA 90095

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Los Angeles, CA 90095 (email: eaxe@ucla.edu)

The study utilises the Chronic Fatigue Syndrome Surveillance System data set provided by James G Dobbins, PhD, Chronic Fatigue Syndrome Research Group, Division of Viral and Rickettsial Diseases, National Centre for Infectious Diseases, Centres for Disease Control and Prevention, Atlanta, GA.



CFS/ME definition – 2002 Oxford Concise Medical Dictionary

Page 28 When one looks up the new sixth edition 2002 Oxford Medical Dictionary under Chronic Fatigue Syndrome, ME, Myalgic Encephalomyelitis or Myalgic Encephalopathy you are referred to CFS/ME. It reads as follows:

CFS/ME – The approved name for the condition formerly known as Chronic Fatigue Syndrome, myalgic encephalomyelitis (or encephalopathy) or postviral fatigue syndrome. It is characterised by extreme disabling fatigue that has lasted for at least six months, is made worse by physical or mental exertion, does not resolve with bed rest, and cannot be attributed to other disorders. The fatigue is accompanied by at least some of the following: muscle pain or weakness (fibromyalgia), poor co-ordination, joint pain, recurrent sore throat, slight fever, painful lymph nodes in the neck and armpits, depression, cognitive impairment (especially an inability to concentrate), and general malaise. The cause is unknown but some viral conditions (especially glandular fever) are known to trigger the disease. Treatment is restricted to relieving the symptoms and helping sufferers to plan their lives with a minimum of energy expenditure. Graded physiotherapy and cognitive behavioural therapy may be helpful in some cases.



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cognitive problems. Could the reduced cerebral blood flow found in CFS be linked to the cerebral atrophy and cognitive problems found in some patients? We don't know at this point whether the brain abnormalities observed are caused by underlying immunological or physiological processes or whether these neurological problems are the cause of other abnormalities observed in CFS.

In my opinion, it's premature to conclusively point

to specific brain abnormalities, whether of a structural or functional nature. Better characterisation of study samples and imaging protocols, as well as replicating and combining different techniques, is necessary before we can be conclusive about brain abnormalities in CFS and the role the central nervous system plays in this illness.

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Special thanks to Emerge's Medical Editor, Dr Nicole Phillips for this article.

Information about ME/CFS

What is ME/CFS?

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is characterised by **severe, disabling fatigue and post-exertional malaise**. Fatigue is just one symptom – there are a multitude of others. ME/CFS is a not uncommon medical disorder that causes significant ill health and disability in sufferers.

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is also known by other names such as Post Viral Fatigue Syndrome, Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and Myalgic Encephalomyelitis.

It is now officially recognised by the World Health Organization International Classification of Diseases and by recent international and Australian guidelines on ME/CFS.

Prevalence

ME/CFS affects all social and ethnic groups. There is a predominance of females (2 to 1) and a bimodal distribution with peaks between 15-20 year olds and 33-45 year olds. The prevalence of ME/CFS varies between 0.2% and 0.5% of the total population. In South Australia this translates to between 3,000 and 7,000 cases at any one time.

Main characteristics of ME/CFS

Disabling fatigue for at least 6 months, along with cardinal symptoms such as:

- muscle aches and pain;
- unrefreshing sleep or altered sleep patterns;
- neuro-cognitive dysfunction (e.g. poor concentration and memory);
- gastro-intestinal symptoms (e.g. irritable bowel);
- orthostatic intolerance (e.g. low blood pressure);
- and unusual headaches.

A hallmark of the condition is that symptoms are usually **worsened** with minimal physical and mental exertion.

Diagnosing ME/CFS

Note that there are many *other conditions* which may need exclusion by your doctor before a diagnosis of ME/CFS may be made. These include, Hypothyroidism, Hyperthyroidism, Diabetes Mellitus, Addison's disease and Multiple Sclerosis, just to name a few.

ME/CFS may also *co-exist* with or mimic symptoms associated with: fibromyalgia; multiple chemical sensitivity; Irritable Bowel Syndrome; depression; anxiety disorders; and somatoform disorders.

This can make the diagnosis of ME/CFS and any coexisting conditions difficult.

Definition

There are many definitions of ME/CFS. The Fukuda Criteria (1994) is still considered the international benchmark for use in ME/CFS research, and is often used as a de facto clinical definition. However, many see the criteria as being vague and over inclusive. Furthermore, they downplay (i.e. make optional) post-exertional malaise and other cardinal ME/CFS symptoms.

The term Chronic Fatigue Syndrome may convey the perception that sufferers are simply overtired. However, fatigue is just one of a multitude of symptoms.

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to the Fukuda Criteria, this new definition made it compulsory that to be diagnosed with ME/CFS, a patient must become symptomatically ill after minimal exertion. It also clarified other neurological, neurocognitive, neuroendocrine, autonomic, and immune manifestations of the condition.

A modified tick chart of the Canadian Clinical Criteria is included in the document "ME/CFS Guidelines: Myalgic Encephalopathy (ME)/ Chronic Fatigue Syndrome (CFS): Management Guidelines for General Practitioners – A guideline for the diagnosis and management of ME/CFS in the community or primary care setting", available on our website and distributed to all GPs in SA.

How is ME/CFS treated?

All treatment should be patient-centred and involve supportive counselling, lifestyle management and the setting of realistic goals. There is no known cure for ME/CFS. Management is geared at improving functionality and symptom control through an effective therapeutic alliance between the patient and their GP.

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 may be relieved through the use of medications and other interventions.

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

There is still a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake intentional exercise. Most ME/CFS patient groups recommend that sufferers pace themselves by starting with gentle exercises and slowly increasing levels of exercise without causing a significant relapse of symptoms. 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.

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Support Groups

Adelaide Support Group

The Adelaide Support Group meets on the fourth Tuesday of each month.

Venue: Uniting Pilgrim Church, 14 Flinders Street, Adelaide (behind Adelaide City Council).

Time: 12:00 pm to 2:00 pm.

Contact: Darryl Turner.

Phone: The office on (08) 8410 8929 to confirm attendance.

Glenelg Support Group

The Glenelg Support Group meets on the third Wednesday of each month.

Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg.

Time: 1:00 pm.

Contact: Marion Hansen.

Phone: Marion on (08) 8234 2342.

Northern Metropolitan Support Group

Contact: Merindah Whitby.

Phone: Merindah on (08) 8287 3195.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: David on 8862 1665.

Southern Fleurieu Support Group

Second Thursday alternate months: February, April, June, August, October, December.

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

Murray Bridge Group

The Murray Bridge group is not meeting at present.

Please ring to register your interest.

Phone: Fran McFaul (Dietician) 8535 6800.

Please note that meeting times are subject to change.

If you are attending a meeting for the first time please call the contact or the Information and Support Line for confirmation of meeting days and times:

8410 8930 or 1800 136 626

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Prognosis

The prognosis for ME/CFS patients is variable. Most will generally improve in functionality to some degree over time, usually 3 to 5 years. However, symptoms may fluctuate or relapses may occur from time to time. Early intervention and positive diagnosis often result in a better prognosis. However, a significant proportion of patients will remain quite debilitated for longer periods of time.

Support Contacts

SA Support Groups

| | | |
|--------------------------|----------------|-----------|
| Adelaide City | Office | 8410 8929 |
| Glenelg | Marion | 8234 2342 |
| Murray Bridge | Fran | 8535 6800 |
| Northern Yorke Peninsula | David Shepherd | 8862 1665 |
| Southern Fleurieu | Melanie | 8552 0600 |

Misc. Support Contacts

| | | |
|---------------|-------|-----------|
| North Eastern | Julie | 8264 0607 |
| North Eastern | Pat | 8264 9328 |
| SAYME | Liz | 8278 2093 |
| SAYME Parents | Marg | 8276 5353 |

Country Support Contacts

| | | |
|---------------------------|------------------|---|
| Auburn | Kay Hoskin | 8849 2143 |
| Barossa Valley | Dennis | 8563 2976 |
| Mt. Gambier | Di Lock | 8725 8398 or 0438 358 398 (mobile) |
| Murray Bridge | Fran | 8535 6800 |
| Port Lincoln | Jade and Pauline | 8683 1090 |
| Port Pirie | Marj | 8633 0867 |
| Riverland | Kathy Southeren | 8586 3513 |
| Victor Harbor | Melanie | 8552 0600 |
| Whyalla | Peter | 8644 1897 |
| Yorke Peninsula (central) | Caroline | 88374335 |
| Yunta | Gloria | 8650 5938 |

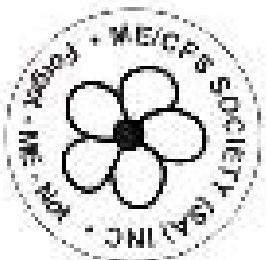
Youth Support: SAYME

South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronic Fatigue Syndrome together at the same place at the same time to relax, chill out, and to have a bit of fun within the limits of their condition and to develop a network of friends with Chronic Fatigue Syndrome that understand the issues we face. Together we can help each other through the tough times.

The Youth group is open to young people up until the age of 30. Please contact Emma Wing in the office on Wednesdays on **8410 8929** for a program of events or if you would like to receive our quarterly magazine. We would love to meet you.

Notes



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

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