Talking Point

Official Journal of the ME/CFS Society (SA) Inc

2007 Issue 3

Your Society

forget-ME-not

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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.

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:
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Our Web site address is: www.sacfs.asn.au.
Our youth Web site address: www.sayme.org.au.

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.)

Management Committee – 2007/2008

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:** Richard Cocker
- **Management Committee Members:** Lynda Brett; Melanie Cocker; Adrian Hill; Spen Langman; Emma Wing

Patron

The role of patron to the ME/CFS Society (SA) Inc is currently unfilled.

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.
Editor: Peter Scott (pmrscott@tpg.com.au).
Assistant Editor: Jenni Gay (jrgay@iprimus.com.au).

Talking Point subscriptions

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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.

The ME/CFS Society (SA) Inc is a member of *Charity Direct*.

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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.

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.

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From the President

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

I write this as we've all just passed through the middle, darkest months of the year. It's been a busy time and we have continuing work to do with the looming Federal election.

Our seminar program

It's great to have had our busiest year for some time with seminars. There was of course the monumental public meeting and closed experts' forum in March. Since then we've had several meetings.

- Our April non-meeting. We'd planned to have a feedback session from local participants in the March forum. In the event none of them could make the advertised time. But we improvised and the fourteen or so people who rolled up, not having heard of the cancellation, enjoyed what one called an excellent support group encounter.
- In May we had an impressive performance from Emeritus Professor Barrie Marmion AO, one of those people better known internationally than in his own city. Prof Marmion is a world authority on Q Fever and national moves are in train to attempt to maintain the momentum of his research into a virus which can trigger ME/CFS. Although in his 80s. Prof Marmion spoke and answered questions standing for over two hours – and then revealed he was recovering from bronchitis!
- In July we heard about two alternative therapies used by a number of our members. Tim White spoke on kinesiology and Dr Andrew Barrie discussed bioresonance therapy. It was interesting to find that there were many overlaps between the two therapies.
- In August we had another interesting time of it when our scheduled speaker, psychologist Liana Taylor, fell sick at the last moment. We thought for a moment that it was going to be another case of improvising, as in April. But at the last moment member and psychologist Liz Vaskin stepped forward. Liz did a great job despite suffering the usual effects of having to put out an unexpected burst of energy at the end of a busy week. Thanks Liz. We're hoping that Liana can speak to us early in 2008.
- Our September meeting – on diet – will have been held by the time you get this.
- Our October meeting on physiotherapy has had to be cancelled. After that it's our AGM on 17 November.

Lorenzo Pizza put the program together. Lorenzo's so efficient that our August committee meeting was able to review a proposed schedule of speakers for 2008 – down to exact dates!! We'll hear from experts in physiotherapy, occupational therapy and psychology and we'll have a session open to members who have done their own research into treatments for ME/CFS to speak on a panel. We regretfully decided not to explore at this stage talks on meditation and naturopathy, simply for want of time. We think that six meetings a year is about right at this stage.

Our country members

Last year was great for memberships, which rose to 310. However, we've noted that the numbers of country members are somewhat lower proportionally than they should be against city numbers. Yet country members are sometimes quite isolated in terms of having supportive medicos and other people with ME/CFS around. Previously, all we could offer them was *Talking Point*. Now we can send those with access to the Internet a regular flow of bulletins and a great website with frequently added new material. Those with mobile phones can get our SMS alerts re media segments on ME/CFS; and those without access to the Internet are contacted by phone as often as we can via volunteers in the office when they're not flat out on other tasks.

If you know of country people with ME/CFS who might not be members, how about getting on to them and encouraging them to join? We're not in it for the money, by the way! *Talking Point* costs us (around $20 a member); so do our costs of communicating with you; and so do the costs of simply maintaining an office. And that's not all our costs. In simple terms, we subsidise all members who pay a basic membership. It's now great to note that many of our members have been extraordinarily generous in sending in donations with their memberships. One even kindly paid for the memberships of five people on pensions and five lucky people had their names drawn out of a hat. Our reason for wanting members? Well, we want to help as many people as possible. And as the voice of

people with ME/CFS in this State, we want a strong membership base to fight from.

So let's hope that we can boost our country memberships this year.

The Multiple Chemical Sensitivity campaign

The Health Department's reference group on MCS plods on. It's had one meeting in the last several months. On the positive side, we have two local government representatives now who both have personal experience of chemical sensitivities. And one of our participating agencies has appointed a staff member to work full time for eight months on developing policies and procedures on chemical health and safety-especially regarding the use of herbicides and pesticides.

We held a meeting of people interested in the campaign in July. Eleven people attended. Frankly, I'd hoped for more. The same few people can't sustain a campaign which offers many targets and much potential. Certainly I have to note that I've been able to give it little attention these last few months. I'd encourage anyone out there with an interest in it and some energy to come forward to take on some specific aspect of the campaign. It's good that the Australian Democrats sent two staff members along and we're hopeful that they will take up some issues with the Democrat Senators in Canberra. You never know. Small meetings can often produce greater results than large ones. That's certainly been the message of the often lonely struggle of the few heroes who have plugged away on this issue for the last decade.

Finances

We ended the year, thank goodness, in the black by several thousand dollars. The outstanding feature was the terrific number of generous donations received from members, as noted above. On the debit side, we failed in several attempts to get grants to cover our most significant program – our communications strategy. We suspect that grants committees simply see it as a request for equipment etc and so pass us over for more 'interesting' projects. It's a pity. Mike Ritter told us recently that he's been scouring the web looking at ME/CFS websites around the world. He rates ours as perhaps the best in the southern hemisphere and up there with some of the best in the northern hemisphere. It'd be nice to get funding to support it and our other work. Meanwhile, thanks for your support.

Volunteers

We could always do with more! I'd love to see more help in the office-doing mailouts, keeping in touch with members by phone or taking on specific project work. Or perhaps you'd like to husband your energies for now but commit some of them in the crucial weeks of the (official) election campaign. Of which more below…

The Federal elections

Several things are clear:

- ME/CFS does not rate highly as an issue for the Australian medical, bureaucratic or political establishments.
- Nothing we do right now in this election will improve our rating much, if anything.
- But if we do nothing now then we have no base to build upon in the next few years.
- And we will therefore be right where we are now when the next election comes around.

To which I'd add:

- Your committee is a group of seven people – and they're flat out with the routine stuff.
- There are over 300 members – at least some of them with morsels of time to give to a burst of politicking.
- If we can get good examples of lobbying efforts – letters to local candidates, for example – we can post them on our website and thereby inspire the literally thousands of people who are accessing it. (Yes: the numbers keep rising.)

We've started getting ready. Member James Hackett has mapped where our members live in terms of Federal electorates. Of 280 SA members whose electorates he could be sure of, the numbers work out at: Adelaide 33; Barker 14; Boothby 37; Grey 22; Hindmarsh 23; Kingston 19; Makin 19; Mayo 31: Pt Adelaide 14; Sturt 32; and Wakefield 22.

We've done some calculations. Wild guesses really – but then one of our basic needs is for better statistics. We've noted that there are between 3000 and 7000 people with ME/CFS in our State. That means you can multiply each of our members by roughly 10 to 20 to get an overall figure per electorate. Then add all the family and closely related persons of voting

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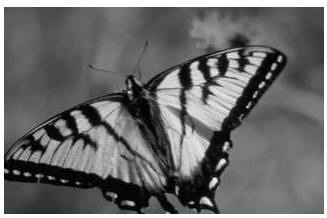
Patiently Progressing with MCS

*A short report by **Peter Evans**, Convenor, SA Task Force on MCS.*

State Progress

Despite the positive recommendations of the Parliamentary Inquiry into MCS in 2005, progress on MCS reforms has remained slow. However, the state government is starting to consider the needs of people with MCS in various policies and plans. Some positive developments include:

- MCS disability access has been included in the state government's Disability Action Plan for government buildings, particularly in the area of renovating materials, cleaning products, deodorizers, and emergency evacuation. MCS has also been included in the state government's Safety and Quality Framework and Strategy document for health care services.
- The Department of Health has convened an MCS Reference Group to oversee the implementation of the Inquiry into MCS recommendations. The Group has met several times this year and enthusiasm amongst individual Group members is high. The Group is currently working on the development of herbicide No-Spray Registers with local councils to help identify MCS sufferers in the community. But a broader action plan for the Group still needs work.



- The Department of Primary Industries has dedicated resources to develop herbicide use guidelines in relation to the No-Spray Register. The aim includes ensuring best practice for those using herbicides and reducing herbicide use as much as possible.
- The Department of Health has set up a separate working group to develop hospital protocols for patients with MCS. The Minister for Health has advised that work on the protocols is progressing well but no documentation is available for public comment at the present time and the working group has not made contact with community representatives, despite a request to do so.
- The City of Adelaide has included MCS in its Disability Action Plan.

On a less positive note, a review of Recommendation 9.2 from the Inquiry into MCS, which advised the establishment of a working group to enable greater MCS disability access to community based health care services, was again rejected by the government. This is a particularly serious problem as most people with MCS access their services in the community rather than public hospitals. Agreeing to develop MCS hospital protocols, then refusing to develop the same protocols for access to health care services in the community seems rather contradictory. This issue needs further discussion with the MCS Reference Group.

National Progress

On a national level progress on MCS is even slower. The promised national review of MCS by the Office of Chemical Safety has still not materialized, despite continuing assurances that a community consultation is to take place soon. The results of a clinical consultation, which invited participation from doctors only, have not been made public and there is growing concern in the national MCS community that the views of people with MCS are not being taken seriously enough. A letter to the Office of Chemical Safety protesting against the way the review process is being conducted is currently being drafted by a coalition of MCS community groups.

Protest Action

Given the extraordinary delays and other problems associated with the national MCS review the SA Task Force on MCS has decided to hold a protest rally in late September targeting the Office of Chemical Safety and the Commonwealth Department of Health and Ageing.

National MCS Peak Body

There was a recent proposal to form a national peak body of MCS community groups, which was followed by discussions amongst existing state groups, with various opinions on what an MCS peak groups might look like and how it would be constituted. However, despite agreeing that a national group would be ideal,

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the parties were unable move forward mainly due to the lack of personal and financial resources. The good news from this proposal is that the existing national groups are now in closer communication.

Local Progress on MCS

There is progress in the area of MCS disability access at a local level. The disability sector in South Australia has started making accommodations for people with MCS. The Disability Advocacy and Complaints Service of SA has developed a disability access policy that now includes MCS. The Disability and Rehabilitation Professionals Association has started requesting fragrance controls at its public meetings. The Disability Information and Resource Centre, which often hosts public meetings attended by people with MCS, has had an MCS disability access policy for several years now. Also, Relationships Australia has acknowledged MCS in its disability action plan.

Catholic Education Office

The Catholic Education Office, working with representatives from the ME/CFS Society and the SA Task Force on MCS, has set up a committee to develop safer chemical use guidelines in schools which include MCS. The next step is to publish a policy document which can then be taken to the public school system to apply some influence for MCS awareness in public schools.

Conclusion

Despite ongoing efforts to develop public policy on MCS there is still a lot of work to be done in convincing authorities that MCS needs urgent action as a public health issue. Although progress is happening it is much too slow. The bottom line is that many people with MCS are still struggling to access basic services that most people take for granted. Hopefully this will change but only with continued effort. ❀

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age. These will vary. But I've reviewed people whom I know have ME/CFS within their family and find from two voters to five each per person with ME/CFS. Let's average it as 3 affected voters per person with ME/CFS. So we're going for something like this: take each member of our Society and multiply by 30 to 60 and that gives you a fair idea of how many relevant voters there are in an electorate.

In my own electorate of Boothby the small group of 37 members might thus represent between 1 000 and 2 000 voters. There are 95 000 electors in Boothby. We thus can speak for up to 2% of them. The seat is held by the Liberal Party with a margin of 5%. Of course not all our notional supporters are going to be swayed to vote on the basis of considering ME/CFS issues alone. But we do have figures which can grab the attention of politicians in a swinging seat.

So: take heart. If you write to or speak to your local candidates, you can honestly claim to be speaking for a lot of other voters!

That's it for this time. On behalf of us all at the Society, I wish you wellness and tons of determination.

Peter Cahalan ❀

Thank you to our Patron

We'd like to wish our immediate past patron, Mrs Marjorie Jackson-Nelson AC CVO MBE, all the best in her recent retirement from the Governorship of SA.

We have appreciated her support of our Society during her years as Governor.

Single, with child and ME

Raising a child is hard. Being a single parent is harder. Being a single parent with ME/CFS is just about impossible. ***Luca Clark*** *found herself in this situation and managed to find the strength to get through it. In this article, she looks back on her struggle.*

It has taken me several months to write this article, not because I was tired but because writing this has brought back so many disturbing memories. Was I a good parent? I certainly did some horrible things as I swam the rollercoaster of my emotions and dealt with regular childhood behaviour through a clouded veil of physical, mental and emotional exhaustion. Even today – when my child has left home, I cannot clearly answer the question 'would my son have been better off in care?'

Imagine trying to raise a child while you have a chronic illness, and you are:

- always exhausted
- in bed most of the day, for years on end
- financially strapped
- your brain doesn't work; you can't logically work through problems and you don't remember things
- mentally overloaded
- sensory overloaded: sight, sound and smell
- on an emotional roller coaster and
- physically in pain

Couple this with being a single parent with little support, mix in an extremely active son that doesn't need much sleep and is prone to accidents, and who, as time passed, I realised had learning difficulties and behavioural issues, and you had the situation I was in.

Looking back I am not sure how I survived mentally, emotionally or physically or how my son did. The key word here is survive and for most of the time that is what we did.

When my son was at school it was easier to get by as I was able to establish a survival routine. After some trial and error I realised I needed at least 3 hours sleep before he came home for me to be able to mentally and emotionally cope.

School holidays were a disaster. It was a constant struggle between me wanting to sleep and me needing to be awake for my son.

Despite looking for help I had no success. The difficulty was that the more I spiralled down the harder it was to see help when it was offered. I was so exhausted that it became just survival, one breath at a time. Emotionally I just shut down until it became the norm.

Being exhausted and having a brain that didn't work made consistent parenting impossible. I remember my son saying to me – 'you won't remember' when I was trying to establish some consequences, and he was right. It took everything I had to make sure the bills were paid and there were groceries in the house.

Meal preparation was another major problem area. On days that I couldn't get out of bed my son ate Weet Bix – and he ate a lot of Weet Bix over the years.

The isolation that many people with CFS/ME experience was extended to my son. Being regularly unable to go to places and to socialise meant he missed out on many developmental experiences that are taken for granted, including walking in the bush, picnics, skiing, sports, camping, going swimming at the beach, shopping, having friends over, eating out – even walking in town and learning how to cross the street.

As my son was accident prone I learned early on that I always needed an energy reserve in case I needed to take him to the doctor. I remember one time being at the hospital and looking longingly at the hospital beds – I so badly wanted to crawl into one!

During his teenage years, following a couple of nights walking the streets at 1 am and not finding him I just gave up and went to bed leaving the door open.

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OzME Internet Mailing List

OzME is an Internet mailing list for people with CFS/CFIDS/ME, FMS, MPS, or any other related illness like MCS. People who have some interest in these diseases – such as parents, children, spouses and carers – are also very welcome. The focus is on Australia and New Zealand, but people overseas can apply if they have Aus/NZ links.

The group is for support, information sharing, and discussion of medical issues, activism etc.

OzME is a private list. Only members may post and receive mail. Only members can read the archives. The List is owned/moderated by Vicki (member of the SA ME/CFS Society), Sally (member of the Victorian ME/CFS Society), Lynda (Qld).

To apply to join, go to: http://www.mecfscanberra.org.au/aus_info/ozme.htm.

Before your membership is accepted, you will get an email from the list administrator asking for some very basic information to confirm your eligibility. This is to protect list members – so you can be assured that only people who belong on OzME can join, and you will find yourself in the company of kindred spirits who understand what you are going through.

It is not necessary to have a Yahoo! Mail email address to join – mail can go to whatever email address you prefer. It is a good idea to have a Yahoo! Mail ID though, because once you are an OzME member, it allows you to read the archives online. ❀

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Having CFS/ME meant that I was not able to advocate for him well with the education system, or with his father to provide support. He missed out big time on both.

There were some people who helped me and my son; friends, neighbours, some of my family members, and sport coaches. Without these people we wouldn't have made it at all.

To try and create a positive outcome from my experiences I have put together a list of things that would have made a difference. I have done this with the hope that others will not have to experience what we had to.

- help in and outside the home, so that I wasn't pushing myself until I was exhausted.
- regular breaks from parenting – especially during the school holidays.
- local, knowledgeable field workers that can suss out and tap into the services that are available within the community – and that can advocate on behalf of the person with CFS/ME.
- a higher profile for CFS/ME as an illness and a better understanding of its implications – in the medical community, the support agencies and the general public (which includes schools, our family members, friends and neighbours).
- a diagnosis test for CFS/ME. This would enable an earlier diagnosis and remedies such as rest, lifestyle changes and support structure could be put in place before the long spiral down begins and before one's financial assets are depleted.
- and of course a cure!

My son is now 18 and has left home.

I now have the luxury of thinking only of myself and resting when I need to. However I do miss my son. I miss his crazy sense of humour and his energy, and I love him. In this way I am like all parents. ❀

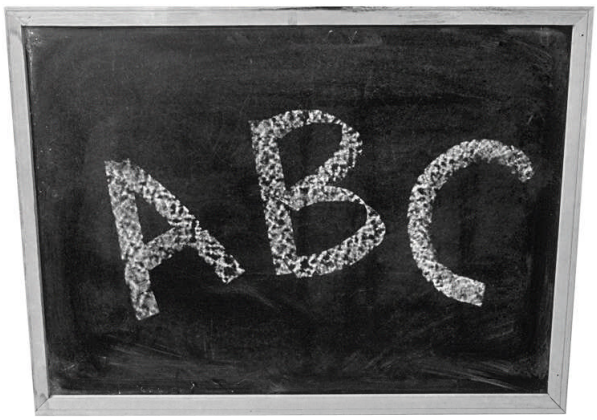
Reprinted with permission from Meeting Place*, Issue 88 June 2007.*

Learning

By ***Maureen Jepson***.

I seem to have been learning new strategies for living since I was born.

I had to learn to be a redhead at school where the teachers always picked me out in a sea of brunette – that had its difficulties because I was the first to be blamed for every class misdemeanour. Learning a new language when I came to Australia forty two years ago had its fun and peculiar moments. I learnt golf, and that is a very frustrating experience, and then the editor of the district's newspaper decided he wanted me to report on the local events, including Council meetings. I was given a notebook, a camera, some pencils, a business card which said I was a journalist and told to get on with it – on the job training, but it was fun.



And then, twelve years ago, I was forced to learn to live with ME/CFS which is no fun at all.

You'd think that, coming from England, I would have no difficulty with language – not so. At the time I arrived in 1964 the only English program on TV was *Steptoe and Son* and I was useful at the office in translating all the cockney slang.

However, for the first few months in Australia I was always putting my foot in it. One day footy was discussed – to make conversation I asked one young lady who she rooted for and realised that 'root' here means something different, or did then, and there was a very long silence. In fact an Australian colleague of mine went to the US to attend a wedding and the first notice she saw in the church was 'Root for Jesus'. It made her feel very uncomfortable! 'Root' in England then meant 'barrack' and 'barrack' meant 'heckle'.

When tramping up Collins Street with my boss on a very hot afternoon, he asked whether I would knock back a beer. "Too right", I said and I didn't get my beer. He thought I had refused the offer and I meant that I would knock it back in one go.

At school I reasonably successfully learnt to be a redhead – out of 650 girls there were only two of us. I had fun learning the Australian language with a few embarrassing hiccups, I learnt to be a fairly good journalist, even winning a couple of awards, I didn't learn to play golf properly (no-one does unless they are a budding Tiger Woods) but the big hurdle came when I had to learn to live with ME/CFS and, like you, I am still learning.

It takes a year or two to learn how to have a life with ME/CFS; to learn how to get things done with the minimum of effort; to pace oneself; to try to ignore pain; to ignore those delightful people who make those silly comments, or at least to learn the smart answers; how to 'train' friends to make appointments so that I can get my proper rest and how to gracefully accept help.

Managing one's limited energy is an administrative challenge, the like of which I have never had before. Funny moments are few and far between, but they are there, usually when one's ambitions far outweigh one's abilities. I once spent ten minutes lying on my back on the lawn, having fallen over while adjusting a hose. It was very peaceful studying the cloud formation until my husband missed me and rescued me. "What are you doing down there?" he asked. "Waiting for someone to pick me up," I said.

And we all have some amusing moments using the wrong words – like 'root' instead of 'barrack'.

However, above all things, I have learnt that I have to keep my sense of humour. ❀

Reprinted from Emerge *Spring 2007 with permission.*

CFS Advisory Committee testimony

***Mary Schweitzer**, PhD, gave testimony to the Chronic Fatigue Syndrome Advisory Committee of the US Department of Health & Human Services on 17 May 2007.*

"There are no tests and there are no treatments": What does that mean?

Testimony to the Chronic Fatigue Syndrome Advisory Committee of the U.S. Department of Health and Human Services, Washington, DC
Mary M. Schweitzer, Ph.D.
May 17, 2007

No matter how pretty the glossy handouts, no matter how lengthy the website, in the end we keep coming back to this single short statement. EVERYTHING that CDC sends out about CFS includes this sentence: "There are no tests and there are no treatments."

That single, bleak sentence is very costly – in terms of disability denied, healthcare reimbursement refused, and the sheer difficulty getting pharmaceuticals interested in finding drugs that will treat our disease.

As I understand it, CDC does not consider anything useful as a test or treatment unless it works for every single person they have classified as having 'chronic fatigue syndrome'. That has been difficult enough with the CFS (Fukuda, 1994) definition. As CDC shifts to a definition based primary on the single symptom 'chronic fatigue', it will be impossible.

CONSEQUENCES OF CDC'S DECISION TO INSIST "THERE ARE NO TESTS AND THERE ARE NO TREATMENTS"

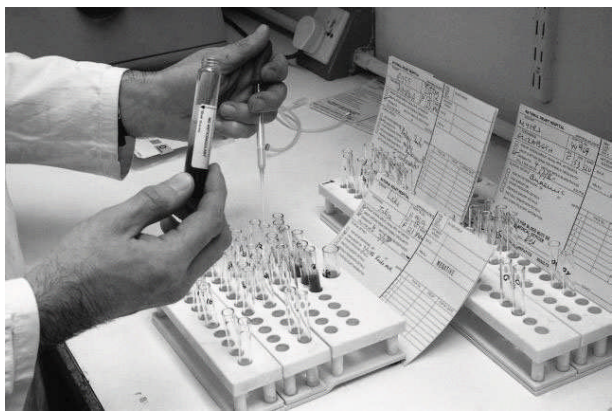
There are perhaps unintended but nevertheless very real consequences to the CDC's longstanding position that "there are no tests or treatments" for 'CFS'.

It makes it harder to get disability, and it makes it harder to get medical coverage from your insurance company.

The default option in a 'medically unexplained disease' is psychiatry. All somatic syndromes require that there be no evidence of physical causation of the symptoms experienced by the patient. Somehow that has been turned into the stronger transitive: If it cannot be proven that a symptom is caused by physical abnormalities, then it is open season for diagnosis by psychiatry. In England, the preferred psychiatric diagnosis is 'neurasthenia' – in the United States, CDC tends to use the language of 'handling stress' instead. Either way, the disease becomes reduced to a neurosis, a character flaw.

Pharmaceuticals are reluctant to spend the large amounts of money necessary to pass the FDA's rigorous approval process when there is no objective measure of the positive impact of the drug on the patient. FDA judges far more harshly the possibility of placebo effect and/or mild adverse reactions when it is not clear that the benefits of the drug clearly outweigh the potential costs in terms of the health of the patient. If there "are no tests," it makes it much more difficult to come up with treatments.

Ultimately, researchers are denied information that would help push knowledge about this secretive disease further; physicians are frustrated with high-maintenance patients whom they cannot seem to help; and patients are left bereft of medical care.



Let's look at a case where both CDC and NIH agreed there was a test that, in general, was abnormal in patients with CFS (Fukuda, 1994). Stephen Straus and Mark Demitrack found that, when compared to controls, CFS patients had lower-than-average levels of the hormone cortisol. This was considered an important finding at the time because patients with major melancholic depression have higher-than-average levels of cortisol. After a cursory study concluding that hormone replacement therapy was too risky for the level of benefit (and not controlling for the patients; continuing problems with sleep), the cortisol thread was dropped.

Normally, when a patient presents to a doctor with abnormally low levels of cortisol, there will be

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a discussion of the condition called Addison's Disease. According to Medline Plus, Addison's Disease is a hormone deficiency caused by damage to the outer layer of the adrenal gland (the part known as the adrenal cortex). In one form, Addison's Disease may be an autoimmune condition. That's interesting, because usually patients with CFS (Fukuda, 1994) have an unusual number of comorbid autoimmune conditions.

The discussion might not center on Addison's Disease per se, but perhaps a version of it unique to patients with CFS (Fukuda, 1994). A disinterested observer might think that would be the most obvious place to start.

When I tested positive for hypothyroidism and Hashimoto's thyroiditis, we discussed the known treatments for the disorders. As it turned out, I have an unusual form of hypothyroidism in which my body fails to convert T4 (the hormone made by the thyroid and stored in the thyroid gland) to T3 (the hormone that is actually used by the body, most of the time). So I have to take Cytomel, which is T3 – the usual remedies for hypothyroidism, levithroid and synthroid, do not work. Thyroid replacement did not cure M.E./CFS – but it significantly helped my symptoms. Furthermore, there is always a danger that Hashimoto's thyroiditis can lead to cancer. Appropriate treatment (focusing on TSH levels and T3) not only improved my quality of life, but also perhaps prevented a dangerous complication of the disease.

However, in the world of CFS at CDC, NIH, and the Royal Colleges in London, the discovery of abnormal levels of cortisol did not lead to discussions of existing information about Addison's Disease – or even use of the terminology.

At first, the information was anathema because it had disproved a previous hypothesis that many patients with 'CFS' were actually suffering from a mental illness. Then it became incorporated into an advanced model involving the entire HPA axis (hypothyroid, pituitary, and adrenal) axis. According to this theory, an abnormal HPA response is critical to understanding CFS. Some authors suggested that the disease itself caused the abnormal response – others that earlier events in a patient's life (such as parental abuse) had stretched the HPA axis response beyond repair, and the result was CFS.

Either way, the HPA axis theories quickly developed a large superstructure built upon a very slim foundation. When pressed, it appeared that the main source of evidence for these theories was the single observation that one of the glands – the adrenal gland – failed to produce sufficient output of a single hormone, cortisol.

The U.S. CDC was so convinced of the power of this theory that when human genome studies sponsored in large part by CDC were conducted in 2005, using a sample of 43 patients gathered in a still-unclear manner [the reader is referred to the December 2005 description of the two-day Wichita hospital stay in Reeves *et al*, "Chronic fatigue syndrome – a clinically empirical approach to its definition and study," BMC Medicine 3:19, 2005, available in full text at http://www.biomedcentral.com/1741-7015/3/19], researchers were asked to use only genomes already known to be connected to the HPA axis. No alternate possibilities were allowed.

Physicians were never asked to check their CFS patients for hypocortisolism; never alerted to the possibility that some CFS patients might develop a form of Addison's Disease; and never given the opportunity to decide for themselves whether the patient's personal level of hypocortisolism was sufficiently severe to warrant treatment.

The evidence of hypocortisolism was torn from the realm of normal medicine, and a disease (Addison's) accessible to most physicians. Ironically, given that the early research on hypocortisolism had failed to prove a relationship between a known major mental illness (major depression) and CFS, when subsumed into the large HPA theory, it enabled those government officials so disposed to reposition CFS as a type of neurosis: the inability to handle modern-day stress.

Focusing on an abnormal HPA response, instead of the stronger evidence of a form of Addison's Disease, enabled a transition to the fuzzy world of neo-psychiatry. A physical disorder was thereby transformed into a character flaw with a behavioral solution. Once again it could be claimed that there was simply something wrong within the patients themselves – in this case, that they were suffering from a type of post-traumatic stress disorder. The evidence for PTSD in CFS-Fukuda patients is slim. Once again, CDC used a single sample of 43 patients (only 6 of whom had actually been diagnosed with CFS-Fukuda during the 3-year Wichita surveillance study).

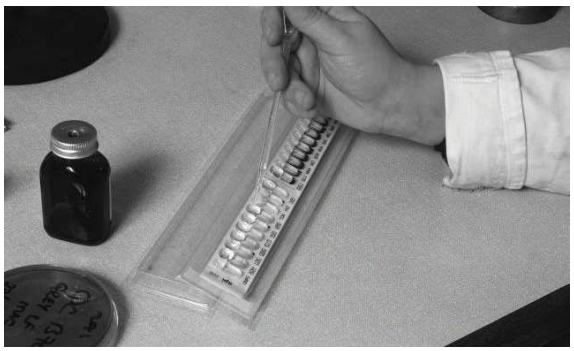
In 1999, I asked a representative from CDC why no one ever spoke to the media about the severity of the disease. I was told at the time that to do so would be irresponsible. Until the BEHAVIORS associated with DEVELOPING chronic fatigue syndrome could be identified, there was no reason to tell the public about it. CDC could only inform the public when they could also tell the public how to avoid coming

down with CFS. Apparently it occurred to no one that 'CFS' might be a disease that did not have a behavioral component. If you could not tell patients not to smoke, not to have unsafe sex, and to put your seatbelt on when driving, what was the point? I thought that a most peculiar (if revealing) response.

Now, eight years later, CDC has its behaviorist slant: CFS is either caused by, or creates, an inability on the patient's part to 'handle stress'. Of course, this has been Dr. William Reeves' theory about the disease for some time. The addition of the 'childhood trauma' and 'post-traumatic stress' theories remain simply that – theories.

So now we had the prize: evidence that CFS was a character flaw (physical in nature) that could be corrected by behavior modification (don't get so stressed).

I consider that to be a most bizarre approach to the scientific study of a disease about which little is known, except that it impacts roughly one million Americans and the majority of them are undiagnosed; of those who are diagnosed, a majority cannot work full time. This is not a minor illness. Yet we could not discuss it in public without being able to offer some type of personal behavior modification.



KNOWN TESTS FOR CFS (FUKUDA, 1994) AND M.E.

How can CDC remain so convinced there exist "no tests and no treatments" for CFS? I have been given tests and receiving treatments for some time. Most of you may not remember when I would come here in a wheelchair – sometimes pushed by my aging mother – barely able to do anything except present my short little paper that had taken weeks to write.

Here are tests which my own doctors used that were positive in my case:

- Simple office tests: Romberg test; subtracting from 100 by 7's; remembering 3 items with a distractor
- NMH/POTS
- Hashimito's thyroiditis/hypothyroidism
- Oxygen reuptake during a treadmill test
- Intestinal permeability
- Low natural killer cell function
- 37kDa Rnase-L; abnormally high levels of Rnase-L
- Chronically reactivated Epstein-Barr Virus
- Active HHV-6A

Cheney uses a different test for exercise tolerance – bicycle ergometry with gas analysis – but the purpose is the same as the one Peterson uses (oxygen reuptake during a treadmill test). Cheney found that most of his patients shifted to anaerobic metabolism within minutes of beginning the test. When I did the test for Peterson, my oxygen reuptake was 19, below the legal disability limit of 20 (that is, on the basis of that test alone I was disabled). Thankfully it is better than that now, because I have had treatment. However, any exercise program had to be tailored to my obvious disability – and my prior improvement with pharmaceutical treatment.

If we are telling physicians to start exercise therapy for their CFS patients (as CDC does in the toolkit and on the website), should we not also tell them how to measure the impact of exercise on the patient? As a bare minimum, shouldn't the physician have some idea about the ability of the patient to conduct normal aerobic exercise?

Other tests exist that have led to successful treatment (that alleviated symptoms and/or suggested a direction to head). Many tests that have helped others did not have positive results in my case. This is a disease that must be approached on an individual basis. But is that not true of most severe illnesses? Does every cancer patient receive the same treatment?

For example, recently specialists have added more cardiological testing as evidence has appeared supporting a higher incidence in cardiological abnormalities in ME/CFS.

I'm certain Dr Nancy Klimas (on the current CFSAC) can provide a list of other immunological tests and how physicians can use that information – cell aptosis, natural killer cell counts and measures of killer cell function, T-cell ratios, alpha and beta cell measures, for example. Here is Dr. Klimas, sitting at the table, a longstanding researcher on the immunology of CFS and AIDS, yet there is no reference to her work at the CDC website or the content of her work in the CDC's suggestions for physicians and patients.

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Over the years I have watched as numerous physician/researchers either participated in or presented evidence to the CFSAC (formally the CFSCC and the CFS-ICC) – Dr. Robert Suhadolnik on the Rnase-L Factor, Dr. David Bell on childhood CFS, Harvard researcher Anthony Komaroff on neurological testing. Komaroff has been a frequent member of this committee, yet his pathbreaking Journal of American Medicine article (2000) giving a brief survey of the biological testing available for CFS, has never been referenced in a CDC publication.

Returning to my own case, should not doctors be informed about treatments that physicians who are part of the CFSAC use in their own practice? If controversial, that can be acknowledged. In the case of a finding such as a low natural killer cell function, is there actually disagreement on the implications of those results?

Why are we withholding this information, simply on the basis that it cannot be proven (and never will be) that every patient who has one or another of these abnormalities fits the ever-broadening description of CFS by Dr. Reeves at CDC?

Finally, although I tested negative for these conditions, it was important to be tested for them anyway: tests for HHV-7 and 8, mycoplasma, Chlamydia pneumonae, cytomegalovirus, coxsackie viruses, adenoviruses. The toolkit does suggest that some diseases be ruled out: mononucleosis (glandular fever), Lyme disease, lupus, multiple sclerosis, primary sleep disorders, hypothyroidism, severe obesity, and major depressive disorders. My own physicians also ruled out leukemia, untreated anemia and diabetes, and heart disorders. I was given PET, SPECT, and MRI scans to rule out brain tumors and M.S., and to detect the impact of the disease on my brain – because of the expense of those tests, CDC does not recommend them, but I would think physicians should at least make certain that patients are not suffering from a containable brain tumor.

Because I have private insurance and because my extended family was willing to chip in and help pay for whatever testing was available, I was able to find out that I had some things and not others, and I have received treatment for what I have. If I need more treatment, my physician looks for what is available and we do the best we can getting it and paying for it. We are still finding abnormalities and trying to treat them.

Should patients be denied testing and treatment because insurance companies and Medicare don't want to have to pay for the testing?

Should CDC be in the business of assisting insurance companies and Medicare in denying tests and treatments to patients?

QUESTIONNAIRES AS "TESTS"

CDC might respond that their questionnaires are a kind of "test". Keep in mind that although questionnaires can provide a comparatively quick way of beginning the diagnostic process, they are and will always be subjective. They may provide a numerical result that can be poured into a computer to crank out statistical results, but the information remains subjective. As for the CDC's own packet of questionnaires, I've had to answer most of them every other month since 1999 (as part of the Ampligen study I am on), and I do not believe they can pick up the severity of the symptoms that many of us experience. If it were up to me, I would add the following questions:

- Do you have trouble with balance?
- Can you cross the street unassisted? Can you cross the room unassisted?
- Do you use a wheelchair and/or a cane? Can you stand up from a chair unassisted?
- How many steps can you take up a stepladder without something to hold on to?
- Can you read the newspaper or understand the evening news?
- Can you follow a simple sitcom plot?
- How often have you mixed up where to put items away (e.g., milk in the cabinet, sugar bowel in the refrigerator)?
- Can you drive a car?
- Do you experience blackouts?
- Do you pause in the middle of a sentence, unable to remember how to complete it?
- Do you use the wrong word for things, or have so much trouble with word retrieval that you are blocked from being able to finish the sentence?
- Do you speak in a halting, slow manner?
- Do you walk in a halting, slow manner?
- Was this questionnaire difficult for you to fill out?
- Did you require assistance in filling it out?

Of course, these questionnaires are designed to be filled out in person, with a nurse or other medical practitioner directly asking the questions to the patient – but in practice, the patient is generally handed questionnaires and told to fill them out himself/herself. In that case, it might be helpful to ask a family member, when possible, to help fill out the questionnaire.

A QUESTIONNAIRE FOR M.E.

Previously I have given testimony about Myalgic Encephalomyelitis (M.E.), the disease that was also called atypical polio and, in the United States, Epidemic Neuromyesthenia. When the Holmes committee came together in 1987, they rejected the notion that there was any relationship between M.E. and any of the cluster outbreaks that had occurred in the U.S. in the mid-1980s. However, by 1991 NIH had published a booklet stating that M.E. was an outdated term for CFS.

More recently, CDC has added a sentence to the website that states M.E., like fibromyalgia, overlaps somewhat with CFS, but is not the same disease.

Perhaps what we need is not yet another series of tests on "fatiguing diseases that are medically unexplainable," but a questionnaire for M.E. The Canadian consensus criteria for ME/CFS, adopted in 2003, offer an excellent set of criteria for clinicians – and researchers – to diagnose this illness in all its complexity. They should be at least mentioned in the information handed out to physicians and patients. I guess not – they include tests and treatments.

CONCLUSION

"There are no tests and there are no treatments".

Twenty years after the Holmes meeting in 1987 chose the name CFS and the Holmes definition to go with it, that's ALL CDC and NIH have been able to come up with?

Roughly one million people in the United States have 'CFS'. The vast majority have no idea what is wrong with them, and few of those who do have the diagnosis have access to a physician with the slightest idea of how to treat them.

After twenty years, that's a pretty sad state of affairs. ❀

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Some terminology

The terminology surrounding this illness can be somewhat confusing due to the large number of different terms and acronyms used to describe the illness. In fact, the naming of this illness is a very controversial subject. In this magazine we prefer to use the term ME/CFS. However, as our articles come from many different sources, you will come across many other terms. The following is a list of some of the most common ones.

CFS – **Chronic Fatigue Syndrome**: Term introduced in 1988 in the USA; preferred by many doctors and researchers; not preferred by many people with ME because it focuses on only a single aspect of the illness (fatigue) and is seen by many to trivialise the illness.

ME – **Myalgic Encephalomyelitis**: Original name, introduced in the UK; the acronym 'ME' is preferred by many people with ME worldwide but not doctors and researchers because it is now considered by many to be a scientifically inaccurate description of the illness.

– **Myalgic Encephalopathy**: variation of the original UK name in attempt to make the acronym 'ME' more acceptable scientifically ; used by many people with ME worldwide but not adopted by many doctors and researchers.

CFIDS – **Chronic Fatigue Immune Dysfunction Syndrome**: Term used by some people with ME, particularly in the USA.

PV(F)S – **Post-viral (Fatigue) Syndrome**: term used to refer to the subset of the illness in which the onset is following a viral infection; considered a separate, but related, illness by some.

FM(S) – **Fibromyalgia (Syndrome)**: a related illness characterised by widespread musculoskeletal pain and fatigue; many symptoms overlap with ME/CFS.

PWC – **Person/People with CFS/CFIDS**: often used as an alternate term for people with ME/CFS, particularly in the USA.

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Acceptance, Discipline, and Hope

*"Acceptance, Discipline, and Hope" is the title of a talk given by clinical psychologist **Elizabeth Vaskin** to ME/CFS Society (SA) members at a Society meeting on 4 August 2007. The following article is a report by **Peter Mitchell** on Liz's talk.*

Introduction

Liz Vaskin is a clinical psychologist who has had ME/CFS for the past decade. She took many years to complete her Master's degree in psychology because of the illness, and has learnt many lessons along the way.

Liz based her discussion primarily on Dr Bruce Campbell's work on the self-management of CFS/FM. His website[1] has some very useful information, including an on-line version of his book[2] and tips for managing various symptoms and difficulties arising from the illness (e.g., tips when travelling). The eight-week course is also run throughout South Australia for a fee of $40 which includes a copy of the book[3].

The role of psychologists in ME/CFS

Psychologists can play a useful role in helping ME/CFS patients, particularly if the psychologist has an understanding of the illness and what they should not be suggesting. A psychologist can assist with related issues such as anxiety and depression. For instance, depression related to reactive grief due to loss of health, social connections, family support, financial capability, career and uncertainty re all of these; biological change in mood/cognition as part of the disorder; co-existing depressive disorder; and mood change due to medication or food or withdrawal from either. Similarly, anxiety and panic attacks can be related to concerns about health (e.g. prognosis, cause of symptoms, or unpredictability of symptoms); as a result of the impact of having ME/CFS (e.g. loss of social connections, loss of family support, financial hardship, and loss of career); anxiety about being denied disability payments; co-existing anxiety disorders (such as generalised anxiety disorder and social anxiety); and in those who also have Multiple Chemical Sensitivity, anxiety can be in reaction to drug or volatile organic exposure or fear of such exposures. (From Eleanor Stein's guidelines[4]).

Notes from discussion: Eleanor Stein's guidelines for psychiatrists in treating people with ME/CFS might be a useful resource to share with treating psychologists (these guidelines are helpful even for lay people). A member of the audience also praised the role of both psychiatrists and psychologists in helping patients through medico-legal issues, especially by their written reports.

Source: Bruce Campbell,
CFIDS and Fibromyalgia Self-Help website

Grief and Loss

Through ME/CFS we can feel that we lose the person we used to be and the person we had hoped to become. The person with ME/CFS has to respond to loss, and be helped to move through grief and beyond the sense of loss. One of the stages they go through is denial. This process of denial can actually help with adaptation to loss. Another phase involves guilt: some people blame themselves for causing the illness, eg through over-work. These feelings can certainly lead to sadness and depression, which may need treatment.

It is important for patients to recognise that acceptance is not resignation: you do not need to be resigned to always being as you currently are. Acceptance needs to include hope.

Coping Strategies

1. Keep a structure or routine in your life: this helps to avoid stress.
2. Avoid stressful situations, stressful people where you can.
3. You will need to let go of friends who cause your

stress levels to rise, but keep those you can trust and who support you.
4. Connect with others, help others where you can.
5. Focus on what you can do, not on what you can't.
6. Prioritise: use your limited resources efficiently.
7. Nourish yourself.
8. Find new interests that you can do within your new limitations.
9. Embrace solitude at times, for the calmness and relaxation it brings.

What is a psychologist?

Psychologists study the way people feel, think, act and interact. Through a range of strategies and therapies they aim to reduce distress and to enhance and promote emotional wellbeing. Psychologists are experts in human behaviour, and have studied the brain, memory, learning and human development. Psychologists can assist people who are having difficulty controlling their emotions, thinking and behaviour, including those with mental health problems such as anxiety and depression, serious and enduring mental illness, addictive behaviours and childhood behaviour disorders.

Clients experiencing mental health problems such as panic attacks, anxiety and depression can access very loss cost psychological services through their general practitioner (http://www.psychology.org.au/Assets/Files/Medicare_Fact_Sheet1.pdf). It may be useful to take the fact sheet along to your general practitioner. There is also a team care plan that your general practitioner can utilise to access psychological treatments for chronic illness management, if you do not have a mental health condition.

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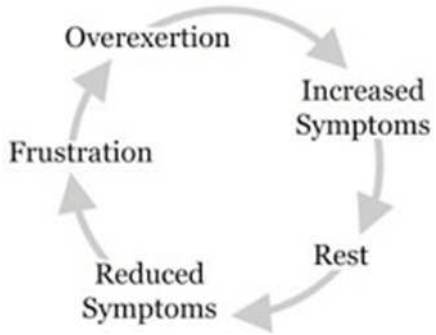
Discussion: The issue of cost in seeking out therapy was raised. It is possible to get referrals to psychologists from your GP/physician, in order to access Medicare support. A health care plan including provision of mental health (eg dealing with anxiety/depression) may be useful in this.

The Energy Envelope

People with ME/CFS need new ways of imaging their energy reserves, which are no longer very deep. The following diagram illustrates this:



Source: Bruce Campbell,
CFIDS and Fibromyalgia Self-Help website

Strategies for coping with the depleted energy reserves include:

1. Developing a detailed understanding of what impacts on your energy reserves and how much energy you have at best and worst.
2. Learning through experiments e.g. about rest periods through the day or week. A useful lesson for all people with ME/CFS to learn is to stop yourself and rest when you are going well.
3. Expanding the Envelope.

Keeping Records

Many people with ME/CFS may find it useful to keep records of their illness. There are templates for this, e.g. on the CFIDS and Fibromyalgia Self-Help website[5].

In essence, the process is as follows:

1. Linking cause and effect: what causes me to crash, what seems to promote more energy?
2. The record-keeping shapes behaviour.
3. Records can become motivators.

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But even then, with careful record-keeping, the illness can be unpredictable. The strategy of record-keeping helps reduce but not eliminate unpredictability. A coping strategy for those with ME/CFS is to accept that this is so, and will be so, no matter what you do. Your goal should be to reduce crashes, but also to accept those that do occur from time to time.

Remember that something good may also be stressful, so avoiding or coping with stress may mean coping with good things as well as bad.

Discussion: led to a shared understanding that there are times with ME/CFS where you have to accept that you will be "in debt" because you have over-exerted (e.g. because of a family celebration that you really want to be involved in, even though you know it will lead to a crash), but the rewards (and the memories) are worth it. On the other hand, coping with ME/CFS also involves saying "no", and accepting that sometimes some people will not understand your refusal, no matter how hard you try to explain.

Pacing

It is important to recognise that ME/CFS leads to de-conditioning. At the same time, over-exercising will lead to relapses. People with ME/CFS need to find that balance. One coping strategy is to build in pre-emptive, planned rest in your day, ie to take rest even when you don't feel you need it – and rest is not sitting watching TV, it's lying down in a quiet place, or maybe meditating, maybe listening to calming music.

1. With exercise, find your limits: what leads to (delayed) fatigue and/or pain. Stick within those limits.
2. Try to discover the time of day when you operate best and plan for more normal activities then. This may involve experimentation.
3. Remember that "exercise" includes house-work, gardening, making a meal, even getting out of bed.
4. Break up exercise with rest periods.
5. Know that your recovery from exercise may be uneven.

Minimising Relapses

In order to minimise relapses, you need specific strategies:

1. Prevention of setbacks: learn what causes them and try to avoid.
2. Personal guidelines; what works for you.
3. Gaining control of your personal situation: this includes writing down actions that work for you.

Emotions

ME/CFS makes you feel more emotional. Understand yourself and what triggers emotional issues for you. This has a positive side: eg recognise the importance of fun in coping with illness: comedy, jokes, laughing are very beneficial for you.

Support

It is critical that you have acceptance from family and friends. It's also important to seek out support from others with ME/CFS and a sympathetic doctor if you can. And you can get inspiration from reading about, speaking to, watching, stories of others who have recovered from ME/CFS.

Summary

Six strategies for successfully coping with life with ME/CFS:

1. Using multiple techniques
2. Experimentation
3. Pacing
4. Controlling stress
5. Addressing emotions and relationships
6. Building a new life. ❀

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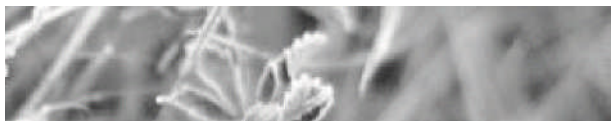

Study: dealing with the effects of brain fog

*By **David Lindsey**.*

One of the things that make study difficult for people with ME/CFS is that it operates to a schedule. Assignments have to be done on time, lectures are held regularly and inflexibly, presentations have to be given on the appointed day and time and exams are sat at the prescribed time whether you are feeling up to it or not. This is difficult both physically and mentally. For me, brain fog prevents me from operating at my best in an environment that is intellectual by definition.

Because sometimes I am feeling well and other times I am not, my performance fluctuates. In off-times I am often mistaken for being lazy, uncooperative or disinterested, but it is simply because I can't use my brain in the required fashion. I am judged in this manner all the more so because in my on-times I am known to be an exceptional student.

My brain fog prevents me from stringing concepts together. This means that I can't think things through very easily and also I can't follow conversations because I lose the thread of the argument. My responses are slow, sluggish and dull. Brain fog also impairs my memory so that I can't remember what was just said, what was actually meant, or what I wanted to say myself!

Brain fog is very frustrating. Knowing that you can do so much more than you are tries my patience, but I have had to just accept the situation and work within it. It is, of course, impossible to say how much my grades have suffered, but it is clear that they must have.

It has taught me to be thankful for what I have, however, and never to take good health for granted.

To cope with this situation, the strategies I have adopted are:

- Working like crazy when I feel well in order to make up for the times I'm not. I'm not sure if this is a good idea in the long term, but ME/CFS makes me want to overcome the odds and show everyone I can do it.

- Placing a lot of emphasis on relationship building rather than just on academic performance. This means getting to know the lecturer so that it is known that I am interested and not lazy, even when I am having an off day.

- Doing assignments at any time of the day or night when I feel up to it. The early evenings are a good time for me, although I have been known to write great essays at 3am!

- Having an alternative activity to go to when my brain is not up to the task I have set myself. This might be something in the garden, a chore around the house, reading a novel or walking the dog – hard for someone who is physically weak, I know, but whatever you can cope with at the time – do that. Come back to the study later when the fog has cleared a little.

- Making sure I start assignments well in advance so that I have plenty of "up-times" to get it done; being well prepared for oral presentations, etc.

- Persevering – knowing that the bad times come when everything seems too much and being able to ride it out and wait for it to pass. Remember that others have been through it too and have succeeded.

- Relaxing – enjoy the journey as much as the destination. Know that your worth does not depend upon your success. Doing your best is succeeding.

- Looking after myself physically, including staying warm and eating a healthy diet.

- Having supportive family, spouse, friends, etc. is very helpful. Having a buddy to share with is also helpful. Being a member of an ME/CFS Society and/or support group is also important so you know you are not alone. ❀

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Accen-chu-ate the positive

Challenged by the idea of writing something positive about living with ME/CFS, ***Vicki Bailey*** *has written a few short pieces which she hopes you will find entertaining. "*The movie buff*" is one of them.*

The movie buff

I have never watched so many films as I have since I became ill with ME/ CFS ten long years ago. Of course, as I am housebound, I have to wait for them to come out on DVD, but this affords me the opportunity to watch them in the comfort of my own home, without the presence of obnoxious people to have to share the cinema with. No popcorn munching, no slurping of drinks, no-one with nasty personal habits, no talking through the good bits, no mobile phones going off (and ensuing conversations), no-one's head in the way, no-one throwing Jaffas from the back row (never mind down the aisle) and hitting me on the head. This did happen one awful Saturday afternoon many years ago pre-CFS (what an inadvisable time to choose to go to the movies!), and we spent half the time dodging the missiles and the other half complaining to the usher. Don't remember much of the film, and we had to pay for the joy of this experience!?! My advice: wait for the video!

At home I can have the sound at a volume I can bear, the brightness and contrast of the picture at a level I can tolerate, and best of all, I can watch whenever I want. I can have intermission when I need to (more than once even), I can be comfortable in my own chair and I can skip the ads. If I miss a bit I can go back; if I don't get the plot I can check out the special features to see if they can tell me what the film was supposed to be about; and I can learn much interesting, but most likely ultimately useless, information from those same special features and feel like I am an expert. I can then knowledgeably inform members of my family of these bits of information (whether they are interested or not) and feel I am contributing to their general education.

The cost of seeing a film is an important issue, too. To hire a new release is less than half the cost of buying a cinema ticket, and you can watch the film as many times as you like, or you can spread your viewing over a couple of days in instalments if your concentration span is short (hopefully your memory lasts long enough to remember what you've already seen!). For a new release I do admit that your time is limited, but for something not quite as new you can even have the pleasure of watching it more than once, if you wish, for the same price – that's value for money all right.

The other good thing about CFS is that, if you have problems with memory, you can watch a film (or read a book) and then several months or years later come back to the same film or book and not remember the ending, or indeed the whole thing. If you happen to have purchased said film or book, you can really get your money's worth! **And** it can become a whole new experience!

So, today's movie is… ❀

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Annual General Meeting

Saturday 17 November 2007
1 pm
DIRC Building
195 Gilles St Adelaide

CFS research study

An Exploration of the Chronic Fatigue Syndrome Experience: A Qualitative Study *is a thesis by* ***Janice Sutton***. *The thesis was completed as part of the requirements for the award of the Degree of Masters of Counselling at the College of Counselling, within The School of Medicine at The University of Notre Dame, Fremantle, Western Australia. It was completed in November 2006.*

Abstract

"It feels like a tsunami hit me one day – came out of nowhere and receded to nowhere, barely witnessed, yet left such a long lasting devastation to me and to those close to me".

Chronic Fatigue Syndrome (CFS) remains a controversial and baffling illness. However, its impact can be profound, threatening everything that is vital to a person. Life stories are a set of meanings: our stories help us to make 'sense of the world' – 'it is as if nothing has happened until a story is told about it' (Schank, 1990).

This qualitative research study explores the personal stories and experiences of ten women living with Chronic Fatigue Syndrome. It explores concepts of individual experience, intuitive knowledge and embracing the wisdom of the body as potentially important components for understanding illness and healing.

The study also provides a brief outline of the current issues and research literature pertaining to CFS, and explores the implications for counselling clients with CFS.

This is not – nor does it pretend to be – a definitive study on Chronic Fatigue Syndrome. ❀

Exercise and chronic fatigue syndrome

Full title: A real-time assessment of the effect of exercise in chronic fatigue syndrome.
Journal: Physiol Behav. *2007 Jul 24; [Epub ahead of print]*
Authors: Yoshiuchi K, Cook DB, Ohashi K, Kumano H, Kuboki T, Yamamoto Y, Natelson BH.
Affiliation: Department of Neurosciences, University of Medicine and Dentistry of New Jersey New Jersey Medical School, United States; Department of Psychosomatic Medicine, Faculty of Medicine, the University of Tokyo, Japan.

Patients with chronic fatigue syndrome (CFS) report substantial symptom worsening after exercise. However, the time course over which this develops has not been explored.

Therefore, the objective of this study was to investigate the influence of exercise on subjective symptoms and on cognitive function in CFS patients in natural settings using a computerized ecological momentary assessment method, which allowed us to track the effects of exercise within and across days.

Subjects were 9 female patients with CFS and 9 healthy women. A watch-type computer was used to collect real-time data on physical and psychological symptoms and cognitive function for 1 week before and 2 weeks after a maximal exercise test. For each variable, we investigated temporal changes after exercise using multilevel modeling.

Following exercise, physical symptoms did get worse but not until a five-day delay in CFS patients. Despite this, there was no difference in the temporal pattern of changes in psychological symptoms or in cognitive function after exercise between CFS patients and controls.

In conclusion, physical symptoms worsened after several days delay in patients with CFS following exercise while psychological symptoms or cognitive function did not change after exercise. ❀

Amitriptyline

In this article from the UK ME Association's ME Essential *magazine,* ***Dr Charles Shepherd****, their medical- adviser, takes a look at amitriptyline, a medicine commonly prescribed for the management of ME.*

This article is reprinted from by kind permission of Dr Shepherd.

What is amitriptyline?

amitriptyline is one of the oldest members of a group of anti-depressant drugs known as tricyclics. They can be of benefit in some people with depression because they alter the levels of brain chemical transmitters – noradrenaline and serotonin in particular – that may be reduced in depression.

Although amitriptyline was developed for treating depression, its use has decreased in recent years – mainly because new types of antidepressant medication are just as effective, or more effective, and tend to cause less problems with side-effects. Newer types of antidepressants may also be safer if an overdose is taken.

So amitriptyline is not usually a first choice drug for someone with ME/CFS who needs treatment for depression.

Why might amitriptyline be used in ME/ CFS?

Firstly, for pain – because even at very low doses amitriptyline can be very effective at relieving pain that affects the muscles, joints or nerves. So it is sometimes recommended for pain relief when first line analgesics such as aspirin, paracetamol or ibuprofen aren't effective.

Secondly, for sleep disturbance – because one of the side-effects of amitriptyline is sedation. So it can be very helpful for people who are waking during the night and not getting a solid block of at least five hours. A low dose of amitriptyline taken mid evening might be prescribed in this situation.

When amitriptyline is being taken for either pain relief or sleep disturbance, a dose of 10mg or 25mg may be all that is required. At this dose, which is much lower than the normal anti-depressant dose, side-effects are less likely. Amitriptyline can also be prescribed in liquid form.

An important practical point is that amitriptyline doesn't usually start to produce any beneficial effects immediately – this may take several weeks of use to achieve.

What are the possible side-effects?

Common side-effects can include:

- blurred vision
- constipation
- dry mouth
- gastric upsets
- postural hypotension (a fall in blood pressure on standing)
- palpitations and tachycardia
- sweating and tremor
- urinary retention
- weight change

Other side-effects can include:

- allergic skin reactions
- blood sugar changes
- heart rhythm disturbances
- liver function abnormalities and jaundice
- sexual problems

Two important points about side-effects. First is that they are less likely at the lower doses used for pain relief and sleep disturbance. Second is that they tend to be worse when the drug is first started and then often diminish over a period of weeks.

Are there any contra-indications?

If you have any of the following medical conditions in addition to ME/ CFS, this will mean that amitriptyline must only be used with great care or not at all.

- epilepsy
- glaucoma
- heart disease and low blood pressure
- liver disease
- mania, psychosis or schizophrenia
- pregnancy or breast-feeding
- thyroid disease
- urinary retention – 'prostate problems'

Can amitriptyline be given to children?

All drugs have to be used with care when given to children, especially in the case of ME/CFS. Amitriptyline

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is sometimes prescribed by paediatricians for pain relief and sleep disturbance in children and adolescents – provided there are no specific contra-indications.

Does amitriptyline interact with other drugs?

amitriptyline can interact with a number of other drugs to sometimes cause problems.

Examples include:

- other types of antidepressants, including St John's Wort
- antihypertensive drugs (for high blood pressure)
- cimetidine (for stomach problems)
- local anaesthetics
- thyroid treatments
- tramadol (for pain)

Your doctor and pharmacist will be aware of all of the possible interactions. Do check if in doubt.

Is there anything else I should do whilst taking amitriptyline?

- If a low dose of amitriptyline for pain or sleep disturbance has not produced any benefits after a few weeks, go back and see your doctor. It may be worth trying a cautious increase in dose or switching to another type of sedating tricyclic drug (eg trimipramine) before concluding that this approach is not going to help
- Don't combine amitriptyline with alcohol – this will enhance the sedative effect.
- Take care when driving or operating machinery because amitriptyline will have a sedative effect.
- If the dose is going to be increased this should be done slowly because people with ME/CFS tend to be very sensitive to drugs that affect brain chemical transmitters.
- If a higher dose of amitriptyline is going to be stopped, this should be done by gradually reducing the dose. This should help to reduce the chances of any withdrawal symptoms.

Further information

There is more information on depression and all the different types of antidepressant medication on pages 231 - 242 of my book *Living with ME*. ❀

Fibromyalgia/ME

By ***Linda Deakin***

You wouldn't know
looking at me
I have an illness
no one can see
No wheelchair,
walking aid
on me can be
found
I look so well
as I drive
about town...
So walk a while
in my shoes
and you'll know
why …
Sometimes I get the blues
muscles so sore
this disease
will test
the one thing that helps
is rest and more rest
Please don't ask more
than I feel I can give
I know what's best for me
to live …
With this horrible illness
to do what I can,
to live for today
is my best plan
So fellow sufferers
join in my prayer
to continue to educate
friends and family
and the world out there
No matter how ill
tell the world of our
plight
It will take a long time …
Just don't give up …
Fight!

From Brainstorm, *May 2006. Reprinted from* Meeting Place *Issue 88, June 2007.*

Can vaccinations induce CFS?

The following article is excerpted from Infection and vaccination in chronic fatigue syndrome: Myth or reality? *Autoimmunity. 2007 Feb;40(1):48-53.*

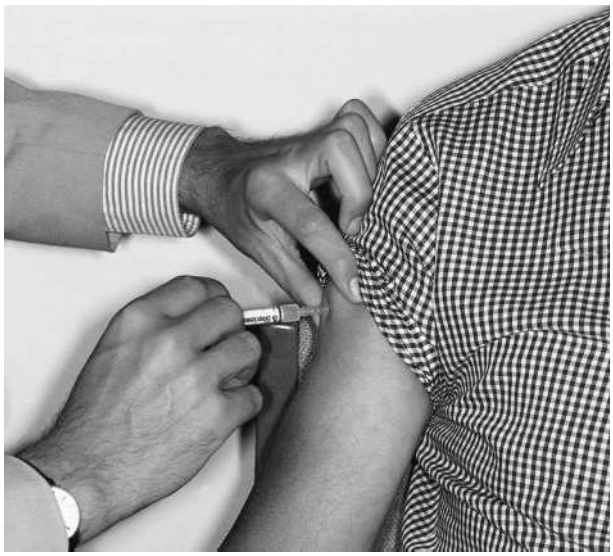
Authors: Appel S, Chapman J, Shoenfeld Y.
Affiliation: Department of Neurology, Sheba Medical Center. hashomer. Israel.

The exact pathogen of CFS is unknown, but the leading theory is that an aberrant immunological response to infection causes a chronic activation biased toward a Th-2 dominant reaction.

This theory raises the suspicion that vaccinations that are given in order to trigger an immunological defense reaction, may cause in distinct cases an aberrant reaction that will be expressed as CFS by the mechanism discussed above.

The main adverse reactions to vaccinations are usually local at the site of injection (erhythema and pruritus) but systemic flu-like reaction (fever, myalgia, fatigue and lymph nodes tenderness) and allergy may occur. Those adverse reactions are usually mild and self-limited.

Several reports associate distinct vaccinations with the induction of autoimmune disease. Rheumatoid arthritis, reactive arthritis, vasculitis, encephalitis, thrombocytopenia and multiple sclerosis relapse have been documented after hepatitis B virus (HBV) vaccination. Acute arthritis or arthralgia, chronic arthritis and thrombocytopenia appeared after mumps and rubella vaccine (MMR). Guillain–Barre syndrome (GBS) and vasculitis after influenza, and GBS that appeared after polio-immunization.



Several syndromes that are related to vaccinations contain chronic fatigue as a part of the syndrome. The Gulf war syndrome was described in 4–8% of the soldiers who participated in the Gulf war and few months–years later suffered from illness that included impaired cognition (distractibility, memory problems), fatigue, arthromyoneuropahy (joints and muscle pains) and post-traumatic stress disorder.

The syndrome was related to chronic Th-2 biased immune response. Rook and Zumla raised the hypothesis that the multiple vaccinations given to the troops during their deployment induced a systemic Th-1 to Th-2 switched immune response and cause to the symptoms above. Four features of the vaccination protocol used in this war led them to this theory:

1. The vaccination against anthrax that was given to the soldiers used Pertussis derivate as an adjuvant agent, which is known to induce a Th-2 dominant response.
2. The soldiers were exposed to large burden of vaccinations which tend to shift the immune response to a Th-2 dominant response.
3. The vaccinations were given after the deployment of the troops, while being in stressful condition. Under this condition the cortisol level is reduced, the DHEA level is increased and the immune response is shifted to Th-2 dominant profile.
4. The troops were exposed to carbamate and organophosphate insecticides which inhibits IL- 2 – a pivot cytokine of Th-1 response.

Support for this theory came from a cross sectional study of 923 UK Gulf war veterans who still had their vaccinations records. The study found an association between multiple vaccinations given during the conflict and later evolution of Gulf war syndrome.

Another syndrome that was related to vaccinations is macrophagic myofasciitis. This syndrome is a post-vaccination disorder characterized by stereotypic lesion on the deltoid muscle (site of injection) associated with prominent fatigue that fulfills the CFS criteria. Electron microscopy and experimental studies show that the lesion is due to persistent immune reaction to aluminum hydroxyl used in different vaccination as an adjuvant agent including HAV, HBV and toxoid vaccinations. The aluminum hydroxyl is known to induce a shift of the immune response toward a Th-2 profile

reaction and if it persists – a chronic inflammatory activation may occur. The persistent elevated levels of the Th-2 cytokines induce the systemic symptoms of chronic fatigue, muscle and joints pain.

An association between vaccination and CFS is much less documented. In 1992 several reports were published in Canada that claimed CFS had evolved after immunization to HBV. A working group of the Laboratory Center for Disease Control (LCDC) of the Canadian National Health and Welfare (NHW) was founded in order to examine the suspected association between anti-HBV vaccination and CFS.

The working group gathered 30 cases of patients with CFS that appeared within 3 months after immunization against HBV – the great majority after the first dose of the vaccine. The working group examined several studies dealing with this question. A retrospective study on 134 CFS patients found that 2.2% of them received anti-HBV vaccine within the 3 months before the beginning of the disease. When they compared this figure to the occurrence of anti-HBV vaccination in the matched Canadian population (1.9%), no significant different was found.

A prospective study followed after 700 students who were vaccinated with anti-HBV vaccine. About 12% of the students complained of tiredness that was self-limited and none of them evolved to CFS. Those studies brought the members of the working group to the conclusion that there is no evidence to show an association between CFS and anti-HBV vaccine. Updated studies that checked the relationship between CFS and vaccination came to the same conclusion.

The use of vaccinations in CFS patients did not exacerbate their symptoms. A study that examined CFS patients vaccinated with anti-influenza vaccination found no significant difference between the CFS patients and the control healthy group. Although CFS patients reported on adverse affects four times more than the healthy vaccines, those adverse effects were related to common post-influenza vaccination symptoms and to constitutional CFS symptoms.

We can summarize carefully that except for several case-reports, there is no study that found induction of CFS by vaccination, but only few studies concerning this issue have been published. Further studies examining this question should be carried out and the physician's index of suspicion should be raised because this possibility of vaccination-induced CFS is reasonable in view of the ability of vaccinations to cause Th-2 dominant response. ❀

Reprinted from the Co-Cure Mailing List.

Recall of Prexige

The federal Therapeutic Goods Administration has recalled the drug Prexige because of its side effects.

Society member Suzanne McCusker, who has been affected, has drawn our attention to it for members who might have taken it for joint pain relief.

Read on…

It may be worth alerting members to the recall of Prexige, the joint pain relief medication some CFS suffering members (including myself). Prexige is being withdrawn due to liver problems – two identified deaths and two awaiting liver transplants.

If members have suffered liver problems they need to alert the Therapeutic Goods Administration (TGA) to monitor the significance of this.

I have been very ill since end of June with toxic hepatitis and now jaundice. I had all the tests available to test the liver including three hospitalisations. It has been difficult for our family of 5 (children aged 3,6 and 9), both financially and logistically. It is a serious matter and the TGA has told me I am not out of the woods yet. I feel better, though, knowing what we have to work with. Prexige comes in 100mg, 200mg and 400mg doses. I was on 200mg since December 2006.

I am not sure if you were aware, I do know my CFS physician Ian Buttfield is.

With kind regards,

Suzanne McCusker ❀

Q Fever, Rickettsia and CFS

*A report by Committee member **Melanie Cocker** on Professor Barrie Marmion's lecture on Q Fever, Rickettsia and ME/CFS held at the Disability Information and Resource Centre in Adelaide on Saturday 12 May 2007.*

Peter Cahalan (President of the ME/CFS Society SA) welcomed approximately 40 people to the first official seminar of the year; 'Q Fever, Rickettsia and CFS' presented by Emeritus Professor Barrie Marmion. It was noted that the 12th May is Florence Nightingale's birthday, and ME/CFS awareness day. Also marking the occasion was a 10 minute segment on CFS, aired on JTV Friday 11th May. The segment is available for viewing on the Society's website or ABC website.

Peter encouraged all to continue distributing copies of the guidelines to their GP's. Members were reminded that a copy of the guidelines can be obtained free of charge from the office, and additional copies are available at a cost of $2 for SA guidelines and $4 for Canadian guidelines (plus 50c postage for each).

Lorenzo Pizza (seminar organiser) thanked all for attending, and introduced Emeritus Professor Barrie Marmion, a world renowned researcher on Q Fever and Rickettsia.

Professor Marmion started by saying that although he is not an expert on CFS, his main focus has been the running of a Q Fever research group, aiming to find a vaccine. Q Fever is a disease that comes from cattle and goats, caused by a small bacterium that has to live inside a body of cells. Q Fever has been an incredible drain on mainly the farming and meat processing industries.

Trials of the vaccine were conducted in 4 South Australian abattoirs (where many people are affected). The research group kept hearing stories of people who 'had Q Fever and never quite got over it' or 'recovered from it and then it started up again'. Conventional wisdom at the time was you fell ill with Q Fever then got over it; this was not true.

Professor Marmion presented an overhead transparency on signs and symptoms of Q Fever:

Presentations of acute primary Q Fever

Systemic*	**Organ based**
Fever	Lung/pleura
Headache	Liver (LFT↑) (Liver Function Test)
Sweats	Bone marrow (granuloma)
Myalgia	Brain
Arthralgia	Ovary
Fatigue	Testis/epidymis

Cerebral dysfunction

*(cytokine, cascades : autoantibodies : thrombocytopenia)

So how does the organism grow? The organism itself isn't toxic; signs and symptoms are caused by the immune system's reaction to the organism, not the organism itself. As shown above, Q Fever systematic symptoms are similar to influenza. In order to make a diagnosis, a laboratory test is needed to detect which agents are involved.

The research group decided to look further into cases where abattoir workers had never gotten over the illness. These cases were people who had laboratory proven Q Fever in the past, and they were compared with those vaccinated against the illness, and those who were infected but never complained of symptoms.

Professor Marmion showed another overhead transparency detailing the above findings. The conclusion was that there may be something in what the patients were saying!

Another overhead was shown which compared people with Q Fever in the past with control subjects. The Q Fever patients showed symptoms including fatigue, a general feeling of illness, muscle pain and also

muscle fasciculation (or twitches). This was the most discriminating feature.

Diminished ethanol use was also a feature; working in an abattoir is an unpleasant job, and alcohol use can increase as a result. However, with Q Fever, if alcohol is consumed an exaggerated hangover is experienced the next day. Night sweats were also a marked feature in patients with Q Fever in the past, compared with control subjects.

Constant re-exposure to the organism can have an effect; even if a person is immune to a 2nd clinical attack, re-exposure to the organism in the air can reactivate symptoms.

Question:

An audience member asked if Rickettsia is a subgroup of Q Fever.

Professor Marmion answered no, and that the two are genetically quite different even though they look the same in smears and slides and lead the same lifestyle. The clinical presentation of the two is also much the same.

Question:

Another audience member asked how people who do not work in abattoirs contract the illness.

Professor Marmion explained that the illness can be passed onto cats etc. At the end of animal pregnancy, Q Fever is contained in the placenta, and people can be infected by breathing in the air around the birth product. Those who work with stock and cattle are at increased risk; however not every herd is infected. When the infection becomes airborne, others are often exposed.

A group in Birmingham that was studied had the following story; right next to one of the motorways are extensive pastures, and the sheep all lamb around the same time. In this particular incident, high winds blew over the birthing sheep and 147 cases of Q Fever were recorded in a large 'wedge' surrounding the motorway.

An outbreak in Germany also occurred; an agricultural fair had ewes giving birth (so the children could observe) and 299 cases of Q Fever were found in those who had passed through the fair.

Therefore, the general population can be affected. Human to human infection is very rare. The primary way of infection is aerosol (from the placenta).

The research group thought the problem was the continuation of the acute phase cytokine responses, downsized (cytokine disregulation). They collected blood samples from those who had post Q Fever fatigue then simulated the samples with various antigens.

The result was that people with post Q Fever fatigue syndrome had much more of one cytokine (IL1) than others. IL2 was downgraded and less efficient in these patients. It appeared that those with post Q Fever fatigue syndrome had hypersensitivity in their immune system.

The next thing the research group moved onto was the cause of the persistent cytokine disregulation. The theory was that it's due to the organism itself; either still challenging the immune system as an antigen (even though the organism is dead) or the organism itself was still alive.

An overhead was shown:

Reappraisal of Coxiella burnett-host relationships – importance of persistent infection

Propositions

- Most humans or animals don't completely clear coxiella after an infection.
- Low level of infection is controlled to a varying degree by continuing cellular and humoral immune responses.
- Recrudescence of persistent infection to a detectable clinical or cerebral (culture/PCR) may be induced by pregnancy, immunosuppression, or immunomodulation by the coxiella.

The results of further study are that a large proportion of people with Q Fever had the organism present in their bone marrow. The research group then joined forces with a group in Birmingham. Studies showed that some people, 12 years after exposure, were still carrying the organism. The group then looked in the bone marrow and 10 of 12 tested returned positive results for the presence of products of the organism.

The question then was why were patients with continuing post Q Fever fatigue syndrome reacting differently to those who made a recovery? Genetic factors may be involved; 35% of patients with post Q Fever fatigue syndrome had a genetic marker compared with only 9% in the control group. It's the host's background which also determines the condition.

In conclusion, Professor Marmion said that in his opinion the illness has been greatly clouded by psychiatric opinions. Psychiatrists were focused on cerebral

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confusion and ignored other symptoms that make up the condition.

We are swinging back to the notion that much of CFS is based on infection and the disposition of the host handles the infection in different ways.

Antibiotics as treatment don't seem to work; this is a problem currently being battled; perhaps we are dealing with an organism that is not affected by antibiotics. Researchers need to find out what state the immune system is in, in those with post Q Fever fatigue syndrome. Professor Marmion finished by saying that post Q Fever fatigue syndrome is not a separate entity; it is all part of the same pathophysiological response in the body, linked to the original infection.

Peter Cahalan asked the audience who believed that Rickettsia or Q Fever are responsible for their illness. Approximately 7 people raised their hands. Professor Marmion continued to answer audience questions for 15 minutes, after which, he was presented with a bottle of wine from the Society as a token of thanks. Peter mentioned that Christine Hunter (of the Alison Hunter Memorial Foundation) had said a lot of research has come out of Adelaide, unheralded, by Professor Marmion.

Professor Marmion said he is now 87 and wants to retire! However a facility is being opened next week where the vaccine can be created (level 3 biocontainment facilities were needed), but we really need a reference and research centre. It was put to the audience that if anyone knows a friendly millionaire, perhaps they would like to donate to this cause!

Peter closed with some final comments:

- News from Dan Peterson (who presented at the forum in March) is that the Nevada Institute is now under threat from politicians. Supporters are urged to contribute in any way to the American CFS committee's efforts to reverse this. Dan Peterson has also said that generally CFS societies around the world are focused on a support group model; this is great but the game is politics. Peter Cahalan mentioned that even if each member sends one letter a year to a politician that would equate to 310.
- MCS Reference Group; a form letter will be on the website directly for people to send to Tony Abbott.

Lorenzo Pizza drew the audience's attention to the meeting program for 2007 available for download on the website.

The CFS committee is trying to vary its start times for the speakers this year based on feedback obtained from members. Please check all times and locations of meetings beforehand in case of changes. New members were encouraged to introduce themselves to members of the committee; the Society is about being part of a community and not being isolated.

On that note, the meeting concluded, with participants staying for refreshments and conversation with others present. A very informative and enjoyable afternoon! ❀

Let me be me!

*By **Christine Benson***

Pain and fatigue, shove off, go away!
And come back again, not, *night or day,*
Brain fog and forgetfulness, leave me be
I want to think clearly, understand. (Don't you see?)

Struggles and difficulties get lost, *I say!*
(I'm so tired of M.E. day after day),
Frustration, restriction, be on your way
My shout's but a whisper, but hear what I say!

Allergies, sensitivities, just let me go
I want to breathe and eat, normally, don't you know.
Headaches and pounding heart, oh, leave me alone
No more do I want to wrestle and groan!

Stumbling and bumbling, hands off, *I say*
Let me with: speed, strength and grace, move each day,
Giddiness and near faints, I've just had enough
Don't pick on me to do your stuff!

Confusion and malaise, oh, no more, no more
I've had enough of feeling unable and poor,
Eye and ear problems, you're just a pain
Too familiar *are you, again and again!*

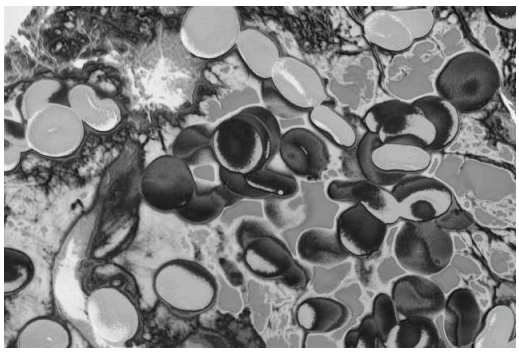
I want to do more, than just get by:
"To leap with hind's feet", "Like an eagle, fly"!
To purpose, to action, to victorious be
That's *what I want, Lord,* I want to be me!

Reprinted from Meeting Place *Issue 88, June 2007.*

CFS: not in the mind but in the cell nucleus

For decades, CFS patients were – and still are – dismissed as lazybones or hypochondriacs. Since 1994, the baffling illness has received recognition by the introduction of diagnostic criteria (the CDC criteria).

Many medical doctors and insurance companies still assert that CFS is a mental condition. The mainstream treatment for CFS is cognitive behavioural therapy, which means that patients with CFS are being treated as having a mental illness with "treatments" that do not treat any underlying cause.



Doctors who treat CFS patients as suffering from an organic disorder and scientists who examine the biological causes of CFS are often considered quacks by their colleagues, insurance companies and anti-quack societies, which sometimes are even officially supported by governments (eg the Dutch government) in their attempts to eliminate the scientific view that CFS is an organic disorder. The official acceptance of the latter obviously would mean that the national health care systems are obliged to financially support those patients who now are considered hypochondriacs and, therefore, may easily be suspended from the national health care systems.

There is, however, evidence that CFS is a severe immune disorder with inflammatory reactions and increased oxidative stress, which has caused a significant damage to functional lipids and proteins in the cells.

Maes *et al* (2007), in a new published study, show that patients with CFS show very high levels of nuclear factor kappa beta (NFkB) in their immune cells. NFkB is the major mechanism which – in the cell – regulates inflammation and oxidative stress. Thus, the increased production of NFkB in the white blood cells of patients with CFS is the cause of the inflammation and oxidative stress which reportedly occurs in CFS.

Maes *et al* also report that the high levels of NFkB predict more severe symptoms, such as aches and pain, muscular tension, fatigue, irritability, sadness, and the subjective feeling of infection.

Maes and coworkers show that inflammation and oxidative stress may cause aches and pain, muscular tension, fatigue, and sadness. Phrased differently, the increased production of NFkB may cause chronic fatigue and the key symptoms of this illness.

Maes *et al* assert that the factors which increase the production of NFkB are also causes of CFS. Thus, viral infections, bacterial infections, leaky gut, psychological stress and physical exhaustion are all able to increase the production of NFkB and are known trigger factors for CFS. In other words, NFkB functions as a "smoke sensor" which detects threats to the body such as viral and bacterial infections, leaky gut, psychological stress and physical exhaustion, and it acts as a switch to turn inflammation and oxidative stress on and off in the cell and, consequently, may cause CFS when the above threats are severe enough or have become chronic.

Finally, the findings of Maes *et al* open new vistas in the treatment of CFS: new drug development in CFS should target NFkB. Maes *et al. Neuroendocrinology Letters*, 2007. ❀

This article originally appeared on the Co-Cure Mailing List: http://listserv.nodak.edu/archives/co-cure.html.

No one knows, no-one cares

By ***Alan Stephen Jones***

Sitting, lying down, standing up
There is no place, no position to ease the pain,
The feelings of a knife plunging deep inside,
But no blood, no knife – just the pain,
People look, people stare, not believing,
Only thinking what you plan to gain.
The pain increases, as someone turns the knife,
But no-one sees, no-one feels the pain you feel.
Thinking you're a fake, your friends evade,
Not knowing the horror that stalks you daily,
Isolated loneliness while you wait for friends,
But no-one comes, no-one cares,
The pain is all that comes for you,
No-one comes, no-one cares, no-one shares,
Just you and the pain at home alone.

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.

Definition

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to earlier sets of 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. The Canadian Consensus criteria are wholly supported by ME/CFS SA and by the National Board of ME/CFS Australia. Copies are available from the ME/CFS SA website.

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.

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.

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. ❀

Contact numbers

Miscellaneous Support Contacts

North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
SAYME	Emma	8381 4417
SAYME Parents	Marg	8381 4417

Country Support Contacts

Auburn	Kay Hoskin	8849 2143
Barossa Valley	Dennis	8563 2976
Mt. Gambier	Di Lock	8725 8398 or 0438 358 398 (mobile)
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	8837 4335
Yorke Peninsula (northern)	David	8862 1668
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.

Support groups

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 Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: David on 8862 1665.

Disclaimer

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.

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

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