Talking Point

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

2008 Issue 1

Your Society

forget-ME-not

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www.sacfs.asn.au

ME/CFS Society (SA) Inc.

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

- promote recognition and understanding of the disease among the medical profession and the wider community.
- provide information and support for 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:
Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.
At the time of printing the office hours are:
Wednesdays 10am to 3pm (subject to volunteer availability).
Ph: (08) 8410 8929.; Fax 8410 8931.
Our email address is: sacfs@sacfs.asn.au.
Our Web site address is: www.sacfs.asn.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.)

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 Secretary, 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.

See notice regarding Advertising on page 3.

Management Committee – 2008/2009

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; James Hackett; 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:** Position currently unfilled

Talking Point subscriptions

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

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.

Contents

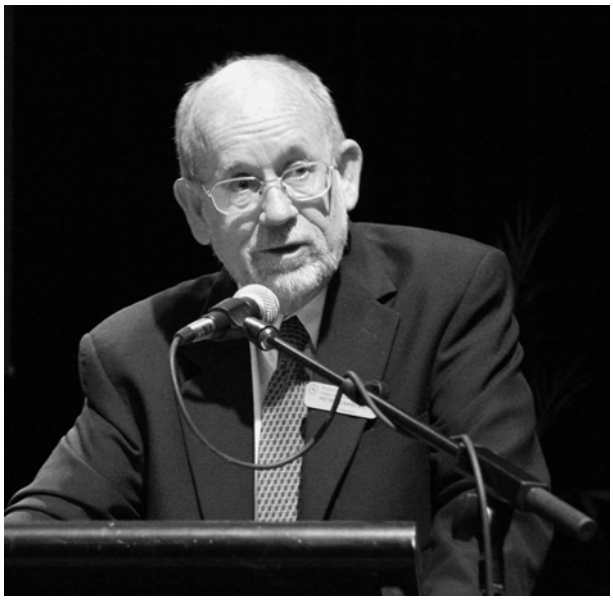
President's report

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

Greetings for 2008. Well advanced though it is by the time you get this, it is actually only early in the year for the Society. The committee and volunteer team enjoyed their summer break in January, and then when we started getting the game rolling late in that month, we ran into a series of snags which meant that we really only got underway fully in mid-February.

Listing health providers

Our most frequently asked question is: "Can you tell me what doctor or other health professional I can go to?" We get such queries through our support line, emails and office telephone. The Society has laboured to keep lists of good health providers over all its years. But our last attempt to update the list a year ago seemed to leave us with a shorter list, as doctors asked to be taken off it for one reason or another.



Peter Cahalan

We decided it was time to really focus on getting a better list of providers. And we were delighted when long-time member Jayne Warwick volunteered to take on the task. Jayne has been working as and when she can over the last several months. We've asked members on our e-bulletin list to send us recommendations and some have responded. But we'd like to hear from more of you. We're interested in any provider of health support from doctors and physiotherapists to complementary and alternative health providers. It's politically easier, mind you, to deal with the accepted list of classic health providers, and our own members are split on whether we should be seen to endorse methods which they regard as unproven. We take the view that we should act as a pool of the shared wisdom of our membership and will take all comment.

We need to boost the numbers on our list, if only because many queries not surprisingly relate to health providers in a particular area. So we need to know who's out there in the way of sympathetic GPs, for instance, who have shown themselves to be willing to work hard with patients to find answers. I urge you to contribute to this work in progress. Or perhaps I should correct that. It's easier for us if it's not entirely a work in progress. It would be better were we able to draw a line at the end of April and say that this is the 2008 list. Further consolidations of it will be undertaken in subsequent years.

A brochure for schools and students with ME/CFS

Some years ago we secured a grant to publish an advisory resource for students with ME/CFS and their schools. Young people with ME/CFS often struggle against considerable obstacles in seeking to access fairly normal schooling. Their peers are usually uncomprehending – and therefore often judgemental – and so, regrettably, are some of their teachers. This usually varies depending on whether the other student or teacher has had to confront the illness among his/her own family or friends. And of course, school communities are not just composed of students and teachers. In the case of one of our members, the principal and the teachers were fine, but the office secretary – first port of call when a child sought to leave early – took some delight in humiliating someone she seemed to have regarded as a malingerer.

Our first volunteers on this made a start but were unable to complete it. So the project was in limbo for several years. Then our honorary secretary Peter Mitchell, who was a long-serving school principal before retiring, undertook to complete the task. We could not have asked for a better person to take it on. As the rest of the core team in the Society can testify, he's a person of wide-ranging abilities and has

the sharpest of minds. Even so it took him a while too. Even the last stage – getting it designed – took more time than expected with computer glitches and the like.

Anyway, the job is now done. The two brochures have been printed. The Independent Schools Board has already taken them for distribution to schools on its courier list. And we have begun negotiations with the State and Catholic education systems to get them out to their schools.

We have limited stocks of the brochures in the office. If you know of a school student with ME/CFS, you can contact us and we'll get a copy to you.

The first seminar of the year

We have a good program of speakers for this year, as you can see on page 7 of this issue. Our thanks go to Lorenzo Pizza who has organised the program for the second year in a row. This takes a huge weight off the committee. It's not easy pulling together the ideas as to what topics and speakers should be on the list and then pinning down the speakers to agree to our invitation and to naming a date. Thanks, Lorenzo.

The first meeting was held in early February. Perhaps too early. We did send out information on the website and e-bulletins and it was, as I recall, advertised in the last *Talking Point* for 2007. Still, we accepted that people with email might have forgotten that and had intended to contact them by phone. But our office team was unable to make it on several successive Wednesdays when we had intended to do a phone-around.

Perhaps for that reason only 14 people rolled up – our smallest attendance in a long while – which was a real pity, because physiotherapist Julie Peacock gave a fabulous talk. She was thoroughly prepared and brought with her two colleagues to assist with her PowerPoint presentation and her demonstrations. She had everyone up practising simple exercises and self-massage techniques and I for one, as a generally well but now somewhat unfit 60-year-old male, found it personally really helpful.

It was so good that we will probably ask Julie whether she would be kind enough to reprise it next year. We'll have to promise her of course that there'll be a better crowd!

We have in the past year or so filmed most of our talks and for several we've published DVDs. However, our volunteer camera person – who happens to be one of our leading committee members – signed off late last year. These days you can mostly capture the essence of talks with any PowerPoint and other materials which speakers can provide. Thus Melanie Reid's superb talk on diet last September was not filmed. But she provided us with a range of resource materials for our website. I checked recently. During February no less than 3800 people visited one article and 780 another. That's months after a talk which as I recall about 40 people heard. It's quite astonishing, really. But for people without the Internet it'd be good to have each talk recorded. And even more, we need a few willing persons to come forward each year to offer to write a report of each talk for our readership. So, if you've a video camera, how about helping out? And if you feel that you have the time and energy to attend one meeting and write up notes from it as and when you'd can, we'd really like to hear from you.

Lactic acid research project

On page 8 of this issue you'll see a call for volunteers for a very interesting project. Dr Ian Buttfield, one of our key medical supporters, has partnered researchers from Victoria in the past in projects dealing with ME/CFS. The team has regathered to look at lactic acid uptake in people with ME/CFS.

The Society is strongly committed to supporting research into ME/CFS. (We've even given positive support to psychologically-focused projects on the basis that we can thereby give some guidance early on to the researchers and hopefully steer them away from the cruder assumptions which have given the psychological sciences a bad name amongst us.) In this case we've gladly said that we'd do all we can to encourage members to volunteer. The process is not intrusive and it's a great chance to help a network of Australian researchers to advance knowledge about the condition.

The Society has also decided to contribute $2000 to the project. Our funds are actually depleting somewhat at the moment, I have to say, after a period of building up. But we take the view that we just have to commit resources to moving things ahead now rather than husbanding resources for bigger things at some future date. The Society has raised funds specifically for research in the past. In recent years it has taken the view that most such fundraising should be through the national Alison Hunter Memorial Foundation. But as in this case we see the value of modest support for good local projects.

Do check the notice about this project and sign on for it.

Continued on next page

Continued from previous page

Other matters

On other fronts the year is getting into gear slowly and steadily. They include:

- **The Multiple Chemical Sensitivity campaign.** The first meeting of the MCS Reference Group convened by the Health Department was cancelled because of a series of apologies. I was one, so in that sense I was pleased. But with the other 'consumer' representatives Peter Evans and Cathie Powell I remain concerned at the slow progress that the group is making. We expect to see a draft policy on No Spray Registers at the rescheduled meeting. The Health Department is looking at hospital protocols for MCS patients, and the Department of Families and Communities at a policy on government agencies booking venues that are accessible to MCS persons. (The latter came out of a DFC conference on accessible housing held at a hotel which had been renovated recently and thus our intended delegate could not attend.)

  I want to pay tribute to a great parliamentary supporter for this campaign. Sandra Kanck's office was in touch with us about her campaigning for stronger controls on smoking in public places – itself very much part of the effort for a fairer society for chemically sensitive persons. Her officer asked what other questions she should be pursuing and we answered that anything which prompted faster effort from agencies on the MCS reference group would be great. Within days Ms Kanck had sent two letters to the Minister for Health. She is not the only politician on our side on MCS issues. But she is certainly the most assiduous and has been campaigning the longest. Let's hope that others are willing to vie for top honours with her!

- **Recruiting a new generation of doctors.** Some of our key medical supporters have expressed their concern about the lack of a new generation of specialists and GPs coming through with an expressed interest in ME/CFS issues. Dr Ian Buttfield, for one, is retiring right about now, leaving a further gap. A group of doctors and I met last September and agreed on several actions. However, the pressure of other business has made it hard for me to get to this one since. In particular the committee has been trying to address nuts-and-bolts issues about servicing our members more efficiently via better databases and via the not insignificant step of recruiting a few more volunteers to ensure that the office is always fully staffed on Wednesdays. We're making inroads on this basic issue at present, and once it's all settled we'll get back to addressing more actively this pivotal issue of regenerating the supply of health service providers for people with ME/CFS.

As always, I encourage you to keep in touch with us regularly via the Internet. If you don't have direct access to the Internet, you might know a family member or friend who does have access. That way you can get them to check the Society's website (http://sacfs.asn.au) for you. And we can get you our weekly bulletins which many members say are of considerable benefit to them. In making contact with a number of members and ex-members over recent weeks, I've been surprised at how many who do have email somehow or other haven't passed the details on to us or don't remember to check the website. For all our scarce resources, this Society has managed to distinguish itself for the excellence of its communications with members. We'd hate to think that you might be missing out on the continuous stream of information which we are providing to the several hundred people who are hooked onto the system. So if all you get is *Talking Point* four times a year and you'd like to be catching up weekly or more often, send us the details and find a way to make the link.

Finally, and on behalf of all the committee and other volunteer leaders, I wish you a good year in 2008.

Peter Cahalan ❀

Society meetings for 2008

The time for all talks is 1pm. The venue for each meeting will be announced prior to the meeting. The cost for each meeting is a gold coin for members, $5 for non-members. Please note that this program is subject to variation so please re-check the website (http://sacfs.asn.au) before each meeting.

Many people with ME/CFS are chemically sensitive, so please refrain from wearing aftershaves, perfumes etc, and please refrain from smoking at the meetings.

Date: **Saturday 5 April 2008**
Speaker: *Liana Taylor, psychologist*
Topic: "A guide to managing CFS": covering "mindfulness for bringing calm and presence and awareness and nurturance of the body and its current needs". Also, "creating a positive vision for the future, a vision that sits out in front of us shining the light on our path forward."

Date: **Saturday 14 June 2008**
Speaker: *Edwina Shannon, occupational therapist*
Topic: Edwina will be covering equipment, activity planning and energy conservation.

Date: **Saturday 2 August 2008**
Speaker: *Dr Anne-Marie Southcott, President of the Sleep Disorders Association of South Australia*

Date: **Saturday 4 October 2008**
Speaker: *Katie Behlau, naturopath*

Date: **Saturday 8 November 2008**
Speaker: *(speaker to be confirmed)*
Topic: **Annual General Meeting**

Talking Point: old issues

Jenni Gay *is calling on anyone who may have old issues of* Talking Point.

We are keen to preserve our Society's history before it is too late and would appreciate hearing from people who were around in the late 80's when the Society started.

Our first president and founder was Lyn Drysdale of West Lakes Shore. The first committee consisted of:

President	Lyn Drysdale
Secretary	Simon Fisher
Treasurer	Kay Botroff
Committee	Brian Caire
	Colleen Harris
	Chris Hughes
	Phil Kirk
	Jeff Gregory

We need to compile 3 complete collections of *Talking Point* as they are an important record of our Society's activities. We have some early issues but need the following issues to complete this project.

Please contact me:

- by email jrgay@iprimus.com.au
- write to me c/- of the Office
- phone the Office on Wednesdays: 8410 8929 ❀

Volume	Issue	No. needed
Volume 1	Issue 1	3
Volume 1	Issue 2	2
Volume 2	Issue 1	3
Volume 2	Issue 2	3
Volume 2	Issue 3	3
Volume 2	Issue 4	2
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Volume 3	Issue 3	2
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Volume 4	Issue 1	2
Volume 4	Issue 2	2
Volume 4	Issue 3	2
Volume 4	Issue 4	2
Volume 5	Issue 1	2
Volume 5	Issue 2	2
Volume 5	Issue 3	2
Volume 5	Issue 4	2
1992	Only have Dec	3 of any issues
1993	Only have Jun	3 of any issues
1994 - 2000		3 of all issues
2000 - present		3 of all issues

Free DVD with your Talking Point

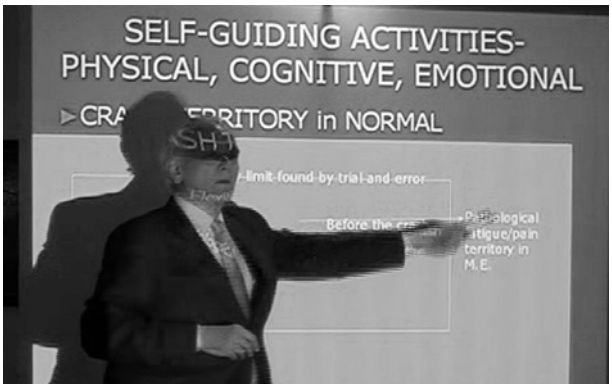
You will notice that this issue of Talking Point includes a free DVD. This is another exclusive benefit available only to our members. We are continually seeking ways in which we can bring benefits to members, and members only. Those benefits currently include weekly ebulletins, special mailouts, SMS messages, and discounts to our seminars.

The DVD is in DVD-R format, which we have found is the most compatible format for all our members.

Its title is *Uncovering Significant Patterns in M.E.*, and it records a session with Dr Bruce Carruthers (pictured), the key writer behind the *Canadian Consensus* document on ME/CFS.

The seminar, which occurred a couple of years ago in the UK, is easy to follow, highly relevant, and has been well-filmed. There are the usual searching questions from the ME audience, which we see locally too – and Dr Carruthers answers them well.

We thank M.E. Support-Norfolk for the licence to distribute this DVD. If you have any problems with your DVD, please contact the office for a replacement. ❀



Lactic acid study

*The following is information provided by **Dr Henry Butt** about a study on bacteria produced by lactic acid. The study is being conducted by Dr Ian Buttfield (Adelaide), Dr Henry Butt (Melbourne) and A/Prof. Paul Gooley (Melbourne).*

D-Lactic acid and D-lactic acid producing bacteria in patients with chronic fatigue syndrome

Please read the following information carefully and take home with you for future reference.

If you wish to participate in this study please make an appointment to see Dr Ian Buttfield as soon as possible to commence arrangements.

Purpose of the Study

This is a research project. The purpose of this study is to identify changes in CFS patients by measuring levels of specific chemicals in urine, blood and faeces in a clearly defined group of sufferers. The specific chemicals are "organic acids", especially lactic acid. A further aim of this study is to see if the changes in these organic acids can be related to changes in the bacteria in the gut. Studying and comparing these changes in patients against those from individuals with little or no symptoms may further help to understand the disease.

The ultimate aim is to understand these changes so that they can be corrected with specific treatments which will help improve symptoms for patients.

It must be understood that agreement or refusal to participate in this study will not affect your medical care. The study is under the direction of Dr Ian Buttfield (Adelaide), Dr Henry Butt (Melbourne), and A/Professor Paul Gooley (Melbourne).

Description of Study

If you wish to participate in the study it is necessary for you to undergo a medical examination. A urine, blood and a faecal sample will be collected for analysis during the course of the study. The suitability of you as part of the study will depend both on the medical examination and laboratory results.

If you consent to participate in this study you will be asked to attend Dr Buttfield's clinic (90 Unley Rd, Unley, SA, 5061) for a medical examination. If you are accepted in the study by Dr Buttfield you will need to provide a urine, faecal and blood sample and to complete and return a 86-point questionnaire at a date suitable to you and Dr Buttfield. Dr Buttfield will be responsible for collecting your blood sample on that date. The questionnaire can be completed, and the urine and faecal sample to be collected the day before your appointment for the blood test.

There should be no recognized risk in taking part in the study.

General Points

The data from this study will be reviewed by the investigators and by the staff of Bio 21, Molecular Science and Biotechnology Institute, University of Melbourne. Data obtained from the investigation will also form part of a study by a post-graduate student (Mr Chris Armstrong) and may be published in medical journals and presented at International Meetings. In such cases your name will not be included and confidentiality will be maintained.

All medical examinations, and laboratory tests are cost free to you. Results from the urine, faecal and blood tests will be made available to you after the study.

Please read the consent form carefully. Having signed the consent form you do not have to participate in the study and may withdraw at any time. The investigators reserve the right to withdraw you from the study at any time. If you have any questions concerning the study please do not hesitate to ask.

The University requires that all participants are informed that if they have any complaints concerning the manner in which a research project is conducted, they may be given to the researcher, or if an independent person is preferred, to the Executive Officer, Human Research Ethics, The University of Melbourne, ph: 8344 2073; fax 9347 6739.

Telephone Contact of Investigators

Dr Ian Buttfield (MBBS, MD, FRACP)	(08) 8272 4822
A/Professor Paul Gooley (PhD)	(03) 8344 2273
Dr David Stapleton (PhD)	(03) 8344 2258
Mr Chris Armstrong (BSc)	(03) 8344 2275
Dr Neil McGregor (MDS, PhD)	(03) 9509 6939
Dr Henry Butt (MSc, PhD)	(03) 9349 5933

Yours Sincerely,
Henry Butt, Senior Fellow (Hon)
Bio 21 Molecular Science & Biotechnology Institute
University of Melbourne

2 February meeting photos

The Society held a meeting at 1pm on Saturday 2 February 2008 at the Ellangowan Hall in the St Peters Holy Name Church, Stepney. The guest speaker was physiotherapist Julie Peacock.

Here are some photos from the meeting:


ELLENGOWAN
HALL
FIRE HOSE


ELLENGOWAN
HALL


FIRE HOSE

Profile: Dr David S Bell

*By **Kristy Katzmann**, ImmuneSupport.com. A profile of David Bell, MD – part of a series highlighting the accomplishments of ME/CFS New Name Implementation Committee (NNIC) members.*

Dr. David S. Bell, MD – Dedicated to the Plight of Chronic Fatigue Syndrome Patients Since 1985

Dr. David Bell, MD, is a renowned specialist in pediatric ME/CFS with a private practice in Lyndonville, New York. He serves on the Board of the International Association for Chronic Fatigue Syndrome/ME (IACFS/ME), and in recent years was appointed chair of the Chronic Fatigue Syndrome Advisory Committee, which advises the Secretary of Health and Human Services. Dr. Bell was one of the first doctors to recognize ME/CFS as a legitimate medical condition, and has spent more than 20 years dedicated to patient care and the ME/CFS cause.

In 1985, David Bell, MD, was an established pediatrician with his own successful practice in Lyndonville, New York, when his life unexpectedly took on new meaning. A mysterious illness ripped through his rural community affecting an unprecedented 216 people, 16 of whom were children. "It was fairly striking. At first it looked like mononucleosis, but we tested them for that and it was negative," Dr. Bell recalls. "I assumed they were going to get better, but then they never did."

Dr David S Bell

"We studied (the kids), we referred them, we called the Centers for Disease Control, we sent them to all sorts of infectious disease specialists, and no satisfactory answer was ever forthcoming," he says. Determined to find answers, Dr. Bell began his life-long work with this devastating illness, now known as ME/CFS, by doing his own extensive medical work-ups on the affected children.

What he found shocked the medical community. His diagnostic testing concluded that Epstein Barr Virus (EBV) was not the cause of the outbreak, and therefore debunked the widely held belief at the time that EBV is the cause of ME/CFS. "While EBV can still be a trigger, the illness has evolved into a post-infectious phenomenon," explains Dr. Bell. He continues his "1985 Lyndonville Outbreak" study today, making it the longest running continuous ME/CFS follow-up study ever conducted.

Whether ME/CFS chose him or he chose ME/CFS is unclear. What is clear, however, is Dr. Bell's dedication to ME/CFS patients and their difficult plight. "I can remember one moment where it sort of fell into place. In the initial outbreak there were several children who I sent to an infectious disease specialist, and the report came back that they were hysterical, that they were nuts…I knew these kids weren't nuts," he says. "That was the first time it ever hit me so clearly that there was a complete misunderstanding of this illness."

According to Dr. Bell, this gross misunderstanding is largely due to the name (Chronic Fatigue Syndrome) itself. "I feel that (the name) disrespects patients and is one of the reasons that the illness is not taken seriously, and this is a very serious illness," he says. "This is a major, major problem, and one of the worst things about it is the name."

Ever since its inception in 1988, the name has wreaked havoc within the patient, medical, political and public communities. Issues such as disregard, disrespect, lack of credibility, inadequate medical treatment and ignorance run rampant. "This is the reason why so many adults refuse to acknowledge that they have Chronic Fatigue Syndrome. They don't know whether they're sick or they're crazy, and they don't want to talk to anybody about it because it's such a threatening subject," Dr. Bell says.

So why is the name itself so crucial to the ME/CFS movement? Dr. Bell believes it boils down to one thing: respect. "If the illness becomes recognized appropriately, (patients) will start getting the respect of their family and of their primary care physicians. They will start being treated with dignity which is a very important step," he explains. "As soon as patients with this illness are treated with dignity, it will remove one huge burden from their shoulders."

While most everyone can agree that the name needs to be changed, fierce debate persists when deciding on the most fitting name for this illness. Although he has suggestions of his own, Dr. Bell backs the use of the name ME/CFS (Myalgic Encephalopathy/Chronic Fatigue Syndrome). "I think going to ME/CFS is a fairly good first step, but I still think that it needs to go even further than that," he says.

Dr. Bell stresses the use of the acronym "ME/CFS" because it satisfies many different parties, while also providing an umbrella term that can be further differentiated down the line. Although he says both "Encephalopathy" and "Encephalomyelitis" are medically correct, he thinks a universal consensus is necessary for progress to be made. He supports the move to "Myalgic Encephalopathy-Chronic Fatigue Syndrome," and is optimistic that others will get on board to effect positive change.

But the name, in Dr. Bell's opinion, is not the only obstacle standing in the way of progress. He believes that the perception and clinical treatment of ME/CFS are also major roadblocks. In his new book, *Cellular Hypoxia and Neuro-Immune Fatigue*, Dr. Bell offers a new focus. "The area that I feel is becoming more important in the research, is that instead of (ME/CFS) being isolated to a single organ, it's found in practically every cell of the body. This is a disease of cellular energetics, of cellular energy production," explains Dr. Bell. "That toxic feeling you get is a cellular issue."

His excitement is evident as he talks about this new strategy and its boundless possibilities. "If in fact this is correct, then it has very direct implications for treatment, which would be absolutely huge," says Dr. Bell. "We are doing some things here in the office that I'm very excited about, but it's much too early to say that they're working." It's a massive undertaking, but one he feels is essential to making progress. "At first I thought, it's too complicated, I'm too old for this. But now I've gotten very excited and I expect to spend the next 10 years of my life reading (about it)."

Although it is a journey he never could have planned to take, Dr. Bell is immensely grateful for his work with ME/CFS and remains unfailingly dedicated to the cause. His voyage has been ripe with surprises, struggles and rewards, and he wouldn't have it any other way. "I've learned an incredible amount of medicine I never would have learned the same way," he says. "If a person is interested in something, and they're willing to just keep plugging away at it, then good things can happen.

"Whether or not that's going to happen in this illness for myself or for any of the other people who have been doing it remains to be seen, but it's an important lesson of life – everybody needs to take on a project that's good for themselves, and good for the world, and then stick with it for the long-haul," Dr. Bell explains.

In the end, amidst his mountains of research and stacks of writing, with hundreds of lectures and interviews under his belt, one thing matters more than anything else to Dr. Bell: his patients. "Perhaps my greatest contribution has been that I have stuck by (my patients) for a long time," he says. "Even though I haven't been able to remove all of their symptoms, I've never lost faith in those particular people. I've never given up on them, and that's the only thing that I feel really proud of." ❀

Reproduced with permission from the September 19, 2007 issue of ProHealth's ME/CFS Treatment & Research News *bulletin, archived at www.immunesupport.com/bulletins.*

Drained by the brain

The following article appeared in the January 29, 2007 issue of The Australian *newspaper.*

Yuppie flu is real and may be caused by disruption in the brain. Clara Pirani investigates the disease, which is costing the country $525 million a year

January 29, 2007

LYN Wilson has a blunt message for anyone who doubts that chronic fatigue syndrome is a debilitating physical illness. "Why would anyone want to give up their life and their income, for nothing? People who think we're not sick don't have a clue."

The 54-year-old Queensland woman was 37 when she suddenly developed gastroenteritis and began to have trouble staying awake. She was admitted to hospital but doctors were baffled by her symptoms, which included loss of feeling in her legs and difficulty concentrating.

During the next 16 months, Wilson was misdiagnosed with multiple sclerosis and lupus, and was told by one doctor that she only needed to start taking aerobics classes to get fit. "I finally went to a diagnostic specialist who diagnosed me with chronic fatigue."

By then, Wilson was experiencing crippling headaches and neck pain, had trouble following conversations and had to quit her job as a teacher's aide at a kindergarten. "I was devastated. I absolutely loved my job."

Wilson, who wears a neck brace to reduce headaches and walks with a frame, works as a volunteer when she can, helping people with CFS. "Most people I meet, when I tell them what I have, will say, 'Yeah, I get tired like that.' They have no idea. Wearing a neck brace is painful, it's hot, very uncomfortable and it's hardly a fashion statement.

"My daughter's wedding is coming up and I'm dreading having to wear it. Why would I do this if I didn't have to?"

Wilson, like many of the 140,000 Australians who suffer from the affliction, is fed up with people who question whether CFS, sometimes known as myalgic encephalomyelitis, is a real condition.

In the 1980s it became known as the yuppie flu, a vague illness that affected high achievers. Its seemingly unconnected symptoms - including fatigue, joint and muscle pain, disrupted sleep and an inability to concentrate - were questioned by doctors and employers who accused sufferers of being hypochondriacs or malingerers.

Even doctors who believed that the symptoms were real dismissed the condition as a psychological disorder.

In the past five years, however, research by some of the world's leading medical organisations has shown CFS is a crippling, physical condition that affects people of all ages.

The US Centres for Disease Control and Prevention this month launched a campaign to convince the public and medical profession that CFS is a serious illness.

CFS costs the Australian community $525million a year, according to research published in The Medical Journal of Australia. Many sufferers are unable to work and between 25,000 and 35,000 are housebound.

However, doctors and researchers remain deeply divided on how to diagnose and treat the condition.

CFS usually begins with flu-like symptoms but progresses to chronic fatigue. It is not improved by bed rest and exhaustion follows any sort of physical activity.

Most people with CFS develop it after a viral infection such as from the Epstein-Barr virus, which causes glandular fever.

In 2002 the World Health Organisation classified CFS as a neurological disorder and research conducted in the past five years supports the theory that the illness is caused by a disruption in the brain. Anthony Komaroff, a professor of medicine at Harvard Medical School and a spokesman for the CDC campaign, says brain functioning and cell energy metabolism appear impaired in those with CFS.

Last year, James Baraniuk, a researcher at the

Georgetown University Medical Centre in Washington, DC, reported that CFS patients have a series of proteins in their spinal cord fluid that are not present in people without the condition. "Our research provides initial evidence that it may be a legitimate neurological disease and that at least part of the pathology involves the central nervous system," Baraniuk says.

Andrew Lloyd, professor of infectious diseases at the University of NSW's school of medical sciences, says researchers are starting to reject previously accepted theories that CFS was caused by an infection or some form of abnormal immune response to an infection.

"Disorders of blood flow, metabolism or muscles have also been crossed off the list. The current thinking is that it's a disorder of the brain. We just don't know where in the brain or exactly what sort of brain chemical disturbance occurs," Lloyd says.

Peter Del Fante, an Adelaide GP who has treated more than 300 patients with CFS, says researchers are increasingly finding physical abnormalities that are only present in people with CFS: "For example, researchers in Japan have found molecular differences in the blood of people with CFS," he says.

While Colin Neathercoat, director of the ME/CFS Association of Australia, welcomes the research, he wants doctors to focus on better ways of treating the condition.

Neathercoat accuses many Australian doctors of advocating outdated and potentially dangerous treatments.

Since 2002, doctors have used treatment guidelines set up by the Royal Australasian College of Physicians, which advocate cognitive behavioural therapy to help patients to cope with the condition, and graded exercise to build up their strength.

Lloyd says CBT helps patients deal with their physical and mental limitations. "CBT is a package deal based on helping patients to understand the pragmatic approach to day-to-day management of fatigue. One of the typical things in CFS is that patients find the stuff that they used to do easily, like running for a couple of kilometres, is not possible. They find that if they walk around the block they feel buggered and it takes them hours or even days to recuperate. That phenomenon often drives patients to think it's a bad idea to do anything physical."

Lloyd says that encouraging patients to perform short bouts of exercise prevents them from pushing themselves too hard. "They need to learn how to avoid that boom-bust cycle, dividing physical and

Continued on next page

SICK AND TIRED

Chronic fatigue syndrome, also called CFS/ME (chronic fatigue syndrome/myalgic encephalomyelitis) is an illness characterised by extreme exhaustion. It can strike at any age. The cause is unknown and recovery can take years. Some people don't recover at all and some suffer relapses for the rest of their lives.

Symptoms

Persistent profound weakness, extreme tiredness after any form of exertion, disrupted sleep, pain and neurological and cognitive problems.

Other symptoms include: orthostatic hypotension (a sudden drop in blood pressure when you stand up); orthostatic tachycardia (increased heart rate when you stand up); palpitations; shortness of breath with exertion; muscle twitching; nausea; gastrointestinal and urinary problems; sore throat and tender lymph nodes; marked weight change, extreme loss or gain.

Cause

The cause is unknown but there are avenues under investigation including: an abnormal response from the central nervous system; an unusual response to a virus; blood pressure abnormalities; viruses or bacteria in the intestines.

Other issues

Lack of community understanding can lead to depression.

Some sufferers are too ill to work, study or socialise. As with other disabilities, depression is common, particularly when other people don't take the condition seriously.

Source: Victorian Government

Continued from previous page

other activities into smaller, short segments."

Neathercoat, however, warns that approach can cause more harm than good. "For some people, they get up and have a shower and that's all they can manage. The more you push these people with work or recreationally, the more severe those symptoms become."

Jim Chambers agrees. Eleven years ago his son Jeremy, a 23-year-old student, developed CFS after a bout of glandular fever.

His condition deteriorated and he spent three years at home, almost bedridden. "On a good day he was able to make his breakfast and not much else," Chambers says. "His quality of life was zero, he just focused on what he had to do to stay alive."

Jeremy remains at home and is unable to work or study. "The prognosis is pretty bleak," Chambers says. "He was a vibrant young man who was a high-distinction student working on his honours. His short-term memory is definitely affected and it's just terribly distressing to have to say goodbye to your dreams as a young person."

Chambers says Jeremy suffered relapses whenever he tried to push himself physically or mentally. "The message we have to get out to parents and teachers is to back off and stop telling kids and teenagers to just push on when they are sick.

"If a kid is usually a go-getter and suddenly they are not performing and they've got nothing left in the tank, then obviously something is wrong. It's better that they take 12 months off to recover rather than pushing on and becoming critically ill and bedridden."

Lloyd admits that graded exercise does not work for all patients. "A lot of GPs looked at the guidelines that were sent out and thought that graded exercise meant that if patients could walk around the block a few times, they should try to walk around the block 10 times the next week. That sort of simplistic formula doesn't work. I have patients who are elite athletes from the Institute of Sport who can still ride for kilometres, but they used to ride for hundreds of kilometres. At the other end of the scale, I have patients who are housebound and their exercise program is a walk to the letterbox and back."

Neathercoat and GPs such as Del Fante are also critical of the way the Australian guidelines define CFS. "The Royal Australasian College of Physicians' guidelines set up in 2002 are so vague that basically anyone with a little bit of fatigue would fit into it," Neathercoat says.

CFS organisations want Australian doctors to follow the Canadian guidelines. Launched in 2003, they diagnose people with CFS only if they have experienced six symptoms including general fatigue, post-exertion fatigue, sleep dysfunction, pain, cognitive impairment and immune or neuroendocrine problems for more than six months.

"We are approaching the Government to adopt the Canadian guidelines, which are also critical of graded exercise as a form of treatment," Neathercoat says.

Del Fante says South Australia has developed its own version of the Canadian guidelines, using post-exertion malaise as the identifying symptom of CFS.

"If they have to lie down in bed, sometimes for days, to recover from physical exertion, that's CFS. There is nothing else that does that to you but CFS. And if you put those people on an exercise program, unless it is very, very slow and minimal, it's extremely dangerous."

ME/CFS Australia is also calling on the medical profession to stop referring to the condition as chronic fatigue syndrome and to adopt the name myalgic encephalomyelitis.

"The view of most patient advocacy groups around the world is that not only does the name chronic fatigue syndrome trivialise the condition, but the principal symptom may not be fatigue," Neathercoat says.

"There are so many more symptoms to the illness. Changing the name will help people to finally accept that this condition is very real and very serious."

Clara Pirani is The Australian's health reporter. ❀

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Poetry

The fex and deds

By ***Christine Penglase***

An intruder invaded my life,
it has infected my whole body.
It affected every system of my body,
and it has effected my daily living.

The 'fects (fex) of the invisible illness
lay deep in the pit of dark stillness
Awakening hours are few . activities less.

Insensitive comments of the uneducated
sadden the heart once so elated.
To think of those more incapacitated
is what we need in a world so desiccated.

A glimmer of hope arises I see,
today I sense the before me.
What! no more fex?
Oh yes! let's flex the pecs.
go here, go there, do this, do that!

Alarm bells ring, inner shakes begin.
Those darn fex!
'Rest awhile' cries the weary me.

I rest, I listen, my body pleads.
don't be like the deds,
please treat me with respect.
I need compassion, caring,
some sense of daily order.

So walk with me gently one day at a time,
let me live each hour of mine.
And later let's help those on the border,
with signs of . deficient empathy disorder.

The fex and deds - our daily dread
Thank God for God - my Life-giving Bread!

Christine T. Penglase ©2007

Gone Walkabout!

(The way of an ME Sufferer)

By ***Christine Benson***

Oh it's a beautiful day
I want to be out and about!
So much I might do –
But my get-up-and-go
Has gone 'walkabout'.

Life is for the living!
There is no doubt,
But I'm forced to be quiet –
Since my get-up-and-go
Has gone 'walkabout'.

Oh! Better than a good outing
There simply is not,
Alas, I'm often left behind –
Now my get-up-and-go
Has gone 'walkabout'.

Well, it doesn't help to get mad
And scream and shout,
I just do what I can –
(Sigh) 'Cos my get-up-and-go
Has gone 'walkabout!'

So I rest off and on, sometimes
Even under a shady tree,
One day, I am hoping –
That my get-up-and-go
Will come back to me!

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

Coping with depression

ME/CFS is certainty not 'just depression'. However, people with ME/CFS can often be depressed; who wouldn't be with having to face the loss of so much in their lives? In this article from Action for ME's InterAction *magazine,* ***Jackie Fenwick*** *takes a look at how some AfME members cope with having both depression and ME/CFS.*

(***Editor's note:*** If you are struggling with depression, whether caused by ME/CFS or not, you should know that there are people who can help. Here are some numbers that you can call: Lifeline on 13 11 14; Beyond Blue on 1300 22 4636; and Kids Help Line on 1800 55 1800. You should also discuss your situation with your GP, and ask for a referral to a psychiatrist. Depression and anxiety are quite common in our society; untreated, they can cause distress to the sufferer and their carer/s.)

For those unlucky enough to suffer both M.E. and depression, the hardest challenge is learning to manage depression within the strait jacket which M.E. imposes on us. Houdini may have been clever but those of us juggling this are geniuses!

Having heard the stories of over fifty readers, there seems to be a marked difference between depression as a result of the loss, disability and loneliness that M.E. can bring, and clinical depression resulting from chemical changes in the brain.

The latter have been described to me in frightening terms and it would be wrong not to give weight to the extreme and hellish battle some folk fight when something in their brain goes out of balance.

Many of us will not know that struggle but can relate to the day-to-day challenge of feeling emotionally low, with limited energy to distract ourselves. What follows is a range of stories from people with M.E. about how they've learned to cope.

Losing a loved one

Jane's illness began with flu. She explains: 'I kept hoping to get better but the more I pushed myself, the worse I got. My husband was able to shop, cook and support me but four years ago he died. While I had previously had bouts of depression and mood swings, these have now become severe. I didn't just lose my husband, I lost my carer. It has been so stressful, on top of everything, to have to fight for the help I need to cope each day. Twice, the anxiety and depression have been so severe that I have been hospitalised.'

How does Jane cope by herself? 'I break the day into slots: a TV programme, the radio, an audio book, a phone call – it's easier to face the next hour than to face a whole day. Moving about does help shift my mood but this is only possible on good days when I am physically strong enough. It's extremely difficult to lift the depression if you know that doing something will distract you now but you'll pay a physical price later.'

However, there was an unexpected outcome from one of her hospital stays, in that Jane was introduced to watercolour painting. 'Losing myself in music or watercolours is what helps to get me through but it's still hard,' she reflects. 'My psychiatrist is sympathetic, tries to understand M.E. and is always respectful of it.

'He recommended cognitive behavioural therapy, which taught me to observe and change negative patterns of thought and I found it helpful for this. Even so, I feel very strongly that I also need counselling support for all the effects of the illness. I have never had this and always end up instructing health professionals in all the difficulties, losses and battles which it presents.'

When the drugs don't work

Robbie suffered terrible nightmares when he first got M.E. 'I felt anxious because I was unable to cope with the most basic tasks and couldn't control any part of my life. I lay in bed feeling so ill that at times I thought I would die.'

How did he handle the anxiety and depression that swept in? 'Sadly I have been unable to tolerate most drugs, but in the end I think it has helped me because it means I've had to pay even closer attention to my thoughts, habits and lifestyle.

`No-one can rely on drugs forever and as there is no drug simply for feeling grief and sadness, it's probably just as well that I've learnt to be proactive outside of any medication.'

He continues: 'M.E. is so limiting – sometimes I wish I had the energy to thump the pillow or get my frustrations out by yelling or whacking a tennis ball, but I don't. Instead, when I am most ill, I use a dictaphone and speak my worries into it. It's my way of saying: "I will worry about this in 48 hours when I feel a bit stronger."

'In fact, I usually find that as my physical strength picks up, my emotions level out and what was nag-

ging me previously feels manageable again. I've learnt to let negative thoughts flow through me. I recognise I'm in a very weakened state and don't take them seriously.'

Has counselling helped? 'In the main I avoided the psychiatric route because, as the triggers had been Hepatitis and Glandular Fever, itseemed so inappropriate – my low mood was a direct response to the profound limits M.E. had put on my life.

'However, I did value one counsellor who gave me space to say the worst of how I felt. I find that if I bottle up feelings they build up, but if I have a place to say: "I don't think I can bear this much longer" the truth is that I don't go insane and I do bear it.'

As my physical strength picks up, my emotions level out and what was nagging me previously feels manageable again'

So would that be Robbie's top tip? 'No, my best advice would be to get spiritual! Becoming a Christian turned my life around. My faith enables me to let go of many worries and negative emotions I previously carried. It gives me a purpose beyond any physical achievements. It is certainly my strongest recommendation for coping and finding the peace and patience needed to manage the illness.'

'I set a date to die'

Another long-term M.E. sufferer, Amy became so profoundly depressed after a series of bereavements that she planned to take her own life.

She explains: 'There are different kinds of depression, and mine felt as though it ran a course of its own, outside of my control. Certainly, when I dramatically improved after six months, I didn't feel this was because of anything I had done. I had tried visualisation and breathing techniques, and had spoken by phone to various helplines. I had seen a psychiatrist and a clinical psychologist, but none of this brought relief. It was a question of riding it out.

'M.E. made this difficult to do because exercise was impossible, and I was too weak to make the most of better moments. But I had the telephone on one side of my bed and the television on the other, so that I could keep in touch with friends and the outside world whenever the hell inside me let up a bit. I also made a mental list of things I aimed to do before I died and was determined to hang on until I had done them.'

Is there any advice she can give to others? 'Yes – I didn't know that a recognised danger-point for suicide is when depression is on the turn: you still feel terrible, but recover some power to make decisions. I was imminently planning suicide two days before feeling amazingly better. Nobody told me about this.

'Also, I now know that most of these intense episodes do eventually remit of their own accord. You can return to yourself. This is scant comfort for someone who feels unable to get through the next five minutes – but maybe this knowledge could just help someone to bear it. I hope so.'

So how is she now? 'My progress was uneven and I am aware things may recur, but it has been three years now since the worst times and I am largely recovered from the depression side of things.'

'Keep taking the tablets'

'I welcomed the diagnosis of both my M.E. and the depression by an immunologist,' Carol writes. 'Beware of those who tell you that you don't need antidepressants. I feel strongly that because I'm not able to exercise or keep busy with hobbies, I've needed the clinical help the tablets give.

'In addition I try to have a daily routine and plan things to look forward to. This is difficult as my health is so unreliable, but I have found any change or even possibly a holiday is so useful to focus on. I often ask my mum to visit and play Scrabble with me. Keeping my mind occupied and slightly distracted from the depression and other symptoms is better than just sitting around feeling awful.'

Carol is lucky enough to have a supportive GP whom she sees regularly. She has also had cognitive behavioural therapy. Did it help? She writes, 'What I most valued about it was a place to offload my concerns onto a non-family member.

'Initially the sessions were extremely difficult because the therapist had their own ideas about M.E. I needed to explain at length that my negative thoughts didn't always correlate with low energy levels, as the therapist presumed. Once this was understood we were able to discuss energy management and thinking strategies and these were helpful.

Overall what helped most though was having a friend who had also suffered from depression. I cannot overstate the value of being able to talk to someone who knows exactly what you're going through and with whom there's no need to try to conceal things.'

Summary of your management tips:

- Get a friend who understands depression.
- See your GP. If you can tolerate tablets, take them. Try different types and strengths – don't give up too soon and consider trying again.
- Seek out a supportive place to unload the sadness

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On a fairground ride

Andy Brown *lives with ME. Here he talks about the downs of being labelled as 'depressed' and the ups of finally gaining a diagnosis.*

My whole world seemed to change dramatically in 1992 when I was retired from my work as a nurse on ill-health grounds. My main health problem was cervical spondylosis, a condition that causes wear and tear on the neck vertebrae. I had also been diagnosed with asthma and a hiatus hernia (when the upper part of your stomach pushes upwards into the opening of your diaphragm). The spondylosis affected my spine and I would suffer from low back pain, which in turn affected my mobility.

I was suddenly faced with questions: how was I going to keep up with my mortgage payments? OK my partner worked as a nurse, but how would we cope living on one salary and me on benefits? We didn't and eventually we had to move home, letting the mortgage provider put the house up for sale.

Thankfully we found another three-bedroom house owned by a private landlord and we managed to rent the property. I felt relieved, as though a heavy weight had been lifted from my shoulders. We still had financial problems, but a Citizens' Advice Bureau worker helped us by writing to the building society and explaining the situation. There was no way they could recover any of the mortgage from us at that time and things seemed slightly better.

I was determined to try to be of some use within society so I got involved with Age Concern and became an unpaid client advocate. My nursing experience stood me in good stead as I had specialised in care of the elderly and I thoroughly enjoyed it.

I still felt unwell, however, and I seemed to be totally fatigued some days, as though the very essence of my being had been drained from me. Never one to give up, I continued with the advocacy work.

The tiredness got no better. In fact some days it was extremely difficult to drag myself out of bed, what with my pain and fatigue. I took myself back to my GP and asked for advice. He thought I was depressed and prescribed Prozac – I refused to take it. I insisted on seeing a neurologist as I had started to get dizziness problems too – and a feeling of disorientation.

The neurologist saw me and ordered an MRI scan. He decided that everything was fine and put it down to being over-anxious. In his letter to my GP, which I read, he said I was suffering from 'paramedic syndrome' – I was furious! First, I had been a nurse not a paramedic and, secondly, probably THE most important point, was that he felt I was imagining things – that they were all in my mind!

My GP was very sympathetic and reassured me that he didn't think I was imagining my symptoms but he definitely thought I was depressed and heading for some sort of breakdown. I did not know then that I had ME but I knew my problem was neurological. I would spend hours on the telephone speaking to friends and relatives. It helped me a lot just to talk.

Things went on; sometime I felt better, some days were bad. I developed muscle and joint pain but thought, "Oh well, must be all the heavy lifting I did while at work." Back then we didn't have the luxury of hoists to lift the patients – we had to lift them bodily.

This went on month after month, year after year. I would see my GP at regular intervals just so he could keep a check on me. Then through a disagreement with another doctor at the practice I was removed from the panel list in 2000 and had to find a new GP. Luckily my new GP was a welcoming breath of fresh air; he would listen to what I had to say.

In 2001 a most bizarre thing happened. I had taken a bath and after drying off I leaned over the bath to start to clean it out. As I leaned over my vision suddenly went black, my hearing went and the sweat was pouring from me. Fortunately my partner was nearby and got me onto a seat and held me. I thought I was going to die. I couldn't keep still. I was unaware of what was happening and was very frightened. My first thought was that I had suffered a stroke or a brain haemorrhage. After about twenty minutes I started to pull round. My partner gave me some water to sip but I felt very weak. I took myself to bed but the weakness lingered.

After Christmas I decided to go back to the GP and explain the whole thing. I didn't see my own doctor but another one who told me plainly and simply I would have to live with it, that he couldn't do anything for me. I was mortified and came home where I went to bed. Apart from getting up to go to the bathroom I remained there for ten weeks. My partner was frustrated because I was showing no signs of improvement. My doctor was called and came to see me on a

Continued on next page

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regular basis.

Over the next two years life was a complete hell. I saw about sixteen consultants, all of different specialities. I had numerous tests, most of which I paid for. I couldn't possibly wait to be seen on the NHS – I thought time was running out. I thought I had something sinister wrong with me, from a brain tumour to mad cow disease. I thought I was going to die.

Finally I saw a consultant who specialised in stroke services. From then on things started to move forward. I was referred on to another neurologist who decided that there was definitely something neurological going on, but all the tests were inconclusive.

To date I have had at least five MRI scans, four CT scans on head and neck, eye tests and ear tests. My dizziness and lack of co-ordination are unbelievably distressing, but thanks to this guy I am learning to live with it – I have to.

It has been over five years now and some days are fairly good, some days are bad. No medication that I've taken to control the dizziness works; it feels constantly as though I'm on a fairground ride. Some days I stumble and fall, other days I don't, but I do have faith in the neurologist and my GP now. They both think that ME is the problem and although I haven't really accepted the diagnosis I have learnt to live with the symptoms. Maybe one day they will find a cure, but until then I wake every day and thank God I am still alive.

About the Author:

Andy lives in the West Midlands area of the UK with his partner Kevin. He is the volunteer chair for the disability advisory group at Walsaw's Hospital NHS Trust and a public and patient involvement forum member for Walsaw teaching primary care trust. ❀

This article reprinted from InterAction*, the journal of Action for M.E., March 2007 www.afme.org.uk.*

Myalgic Encephomyelitis – what does it mean?

MYA	muscles
ALGIC	painful
ENCEPHALO	brain
MYEL	nerve
ITIS	inflammation

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and effects of your M.E.

- Know yourself. Be strong. Don't let psychological issues dominate your treatment unless you want them to.
- Consider any offers of CBT – contributors to this article said that while they hadn't found it helpful for their M.E. they did find it useful for observing and changing their thought patterns.
- If well enough, join a depression support group.
- Keep a 'happy book' and concentrate on remembering and writing down good things.
- Find something to distract you – a hobby, some music, books on tape.
- Be kind to yourself.
- Develop a spiritual side to your life.
- Keep making sure you have small things to look forward to.
- If necessary, consider making changes so that you are less isolated.
- Would company help? Would it be a distraction?

And your advice to others who may feel suicidal:

- Remember previous occasions when you felt couldn't go on. Life has seasons. Recognise even this will pass – you could be days away from relief.
- Is your mind lying to you? – 'Events do not kill us as much as the view we take of them' – kill your thoughts, not yourself. Are you sure you are seeing it all clearly?
- Will it help to tell someone? Sometimes talking openly about the option of suicide helps, rather than just thinking about it. Call a telephone helpline such as Lifeline.
- Has all else failed? Call your GP surgery or go to an A&E clinic/hospital. If you are going to harm yourself then you must take that seriously. It may get you the help you need.

While all names have been changed to ensure confidentiality, we'd like to thank everyone who shared their experiences. ❀

Reprinted with permission from InterAction*, quarterly magazine of UK charity Action for M.E., Issue 46 (Nov 2003).*

To B12 or not to B12?

That is the question (apologies to the Great Bard)

In this article from Action for ME's InterAction magazine, AfME member and former nurse ***Jacki Carter*** *explains how a simple vitamin injection has improved her M.E. symptoms – particularly 'brain fog' – and looks at the rationale behind this.*

Now 46, I've been medically retired for over ten years with M.E./C.F.S. While I have the usual range of symptoms, the one I found incredibly hard to come to terms with was 'brain fog'. I had been a Registered Nurse used to running a busy medical ward, but after becoming ill, I found that most days I could barely remember my own telephone number or whether a green traffic light meant stop or go!

Two years ago I began vitamin B12 injections. Within hours of the first injection the log' began to clear and I have not looked back since. My overall wellbeing seems to have improved too.

Interestingly, before blood tests were available for vitamin B12, GPs prescribed this treatment for the majority of patients complaining of fatigue, with very good results. While B12 is not approved by the NHS for use in CFS/ M.E., some doctors may be willing to prescribe it, once the objectives of the treatment are explained.

My own GP would not consider prescribing the injections as my serum (blood) B12 levels were within normal parameters at 380 picograms per ml (normal levels being 180 - 800 pg/ml in UK). However, 'normal' B12 levels are set at the baseline that prevents pernicious anaemia, which may not be the same as those needed for optimum biochemical function throughout our bodies (*see refs 1 and 2*). This meant that to even begin a trial I had to seek private medical treatment, for which I consulted Dr. Sarah Myhill, Secretary to the British Society for Ecological Medicine, who is based in Wales.

What does B12 do?

This nutrient:

- is a powerful scavenger of nitric oxide (*ref 3*; more about this later)
- helps in formation of red blood cells
- is essential for the formation of the myelin sheath (substance that surrounds and protects nerves)
- has a role in energy metabolism and cell replication
- helps creation of DNA and RNA (genetic material in cells)
- aids chemical detoxification of the liver
- assists clearance of the harmful amino acid homocysteine from the body (see later on)

How might it help M.E./C.F.S.?

Many people with M.E. appear to have high levels of the neurotransmitter nitric oxide and its oxidant peroxynitrite (*ref 4*). These are substances released in response to stress - be it physical, chemical, infectious or emotional.

Nitric oxide has a detrimental effect on brain function. It can cause:

- pain sensitivity
- fatigue
- muscle weakness
- brain 'fog'
- mood change
- ataxia (lack of co-ordination)
- parasthesia (pins and needles)
- sore tongue

Sound familiar? Two studies have successfully illustrated that vitamin B12 is a very powerful scavenger of nitric oxide. One looked at cases of B12 deficiency (*ref 5*) and the other at patients with ongoing tiredness (*ref 6*). Both found that difficulty thinking clearly, poor short-term memory, and difficulty multi-tasking were improved after treatment with B12 injections.

Where to get B12

Rich in foods such as wheat and cereal, vitamin B12 is also found in significant quantities in oily fish, red meat and dairy products. This can be a problem if you need to follow a wheat/grain-free diet as I do, or are vegetarian, and doctors advise limited consumption of oily fish due to concerns about levels of mercury contamination.

B12 can be supplemented in the following ways:

- tablet, 1 to 2mg dissolved under tongue daily (available from health food stores/chemists)
- spray, 1 mg daily, as above (via Internet sites, mainly based in the USA, or from private doctors)
- injections, starting dose 2mgs weekly (via your GP

or with a private medical prescription)

If B12 supplementation is something you want to try, it's worth asking your GP if they will consider a trial of injections. I'd advise taking copies of published research to back up your request (see useful contacts list at end for extracts of published research). It may also help to point out the research article indicating that blood serum levels as tested for on the NHS may not be the levels that are present in brain cells – i.e: that 'normal' levels may not be adequate to pass the blood-brain barrier. This was the finding of Scandinavian researchers in 1997 who found that the twelve CFS patients they tested had normal B12 levels in blood but extremely low or undetectable levels in spinal fluid, and by inference, in their brains (*ref 7*).

Dosage and self-injection

Research recommends that the dosage of B12 needed to treat M.E./CFS is generally higher than that suggested for treatment of other conditions such as pernicious anaemia (*ref 8*).

Professor Findley, Consultant Neurologist and CFS/M.E. specialist at Oldchurch hospital in Romford, prescribes 1 mg intra-muscular injections of hydroxycyanocobalamine weekly for three months, then monthly for one year. He says that in the USA B12 is used as routine treatment for CFS, where as much as 50mgs a day is given for six months.

Fortunately, large amounts of this vitamin do not appear to have any adverse reactions on the body. as any excess is excreted in the urine (which may have a pinkish colouration). This makes it fairly safe to try, whether it helps your symptoms or not.

I started on 2mg weekly, which I continued with for around 12 months, gradually lengthening the period between injections. I now inject once every two to three weeks. I know when I need to top up my B12 levels: my tongue becomes sore and I feel edgy and clumsy but worst of all the brain fog starts drifting back. I also take a multivitamin and mineral supplement every day.

Being a nurse made it easy for me to self-inject, but unless you're squeamish, it isn't difficult to learn how to do this and the needles and syringes can often be supplied by the prescriber. It's easier if you have someone to show you the method and perhaps your GP surgery's nurse could advise or may be prepared to inject for you. (They might want to charge!)

This is a relatively inexpensive treatment, with my private prescription consisting of the B12, syringes and needles costing around £1.60 per injection.

What the experts say

Professor Leslie Findley states that amongst his patients about 50% show a good response to B12 and stresses there can be a depletion of central B12 even with 'normal' blood levels.

Dr. George Lewith, a leading researcher in complementary medicine based at the Centre for Complementary Medicine in Southampton, says: 'My feeling is that B12 injections are something worth trying over a couple of months. If you find it beneficial, keep going; if not, leave it alone. Many people do report benefits. The material being injected is not harmful although giving an injection isn't entirely harmless.'

Dr. Charles Shepherd, a former GP and author of Living with M.E., feels differently: 'It's not a form of treatment that I personally recommend or prescribe. Firstly, it may mask the onset of pernicious anaemia, and secondly for the lack of laboratory evidence.'

However, he continues: 'I do feel that this is an area of treatment worthy of further investigation because there is some evidence in medical literature that the elevated levels of homocysteine in the cerebrospinal fluid of ME/CFS patients could be linked to a subtle B12 deficiency.' (*ref 7*). He explains that homocysteine is a harmful by-product of early B12 depletion, but that it is also produced in people with M.E., as well as those with metabolic problems, lack of folate or low vitamin B6.

Dr. Sarah Myhill finds that oral supplementation is less effective than injections due to problems with absorption. She says: 'I suggest B12 injections to all my CFS patients because so many see benefit from this simple, safe, non-toxic intervention.' She recommends trying one injection of 2mgs weekly for ten weeks, stopping if no improvement is seen.

Prof. Florian Thomas (Associate Professor of Neurology at St. Louis University, USA) is calling for improved B12 testing. 'A further test is needed. If GPs think their patients may be suffering symptoms of B12 deficiency but their blood levels are "normal", they should test for methylmalonic acid (MMA), a natural compound in the body which increases when B12 is lacking.'

Labs may differ slightly but the cut-off level for B12 deficiency is MMA serum levels above 0.376pmol/17. So it might be worth asking your GP to test for this if your B12 levels are normal. An informal study of more than 100 people with CFS showed an elevation of urinary MMA in over 30% of cases (*ref 8*). Biolab

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offer a urine test for MMA.

Patient feedback

Cheryl, whose B12 injections were prescribed by Prof Leslie Findley at the National M.E. Centre in Essex, says: 'The effect of B12 is like a soothing balm on my nerves giving me less twitching and less pain... after two years I feel normal most of the time.' However, Andrew (also a Prof Findley patient) says, 'I've just had the seventh injection and can't say I've noticed much difference. I thought I had more energy but then did too much and had my worst week this year.'

`My mood is better... I have less pain,' writes Katherine. But Kate says: 'Made no difference.'

Maggie has been able to return to work after using B12 as part of her treatment and Gill, who has been having injections for seven years, also saw improvement and now has a maintenance dose fortnightly.

Another reader states that her GP started giving her the injections back in 1998. She began to improve after the first dose and continues to do so. Previously she was virtually housebound, spending most of her time lying on the settee, but now she feels well enough to have a limited social life and read 'non-fluff' books. She writes: `It is a huge improvement, but not a cure'.

Alan has tried taking B12 orally for six months (sub-lingual methylcobalamin tablets) but cannot notice any difference. Interestingly, I tried a vitamin B12 sub-lingual spray but found that after two months it was not working for me and returned to the injections with immediate effect.

InterAction commentator Dr Kelly Morris concludes:

The relationship between homocysteine, B12, and nitric oxide remains far from clear. For example, high homocysteine leads to reduced nitric oxide function, which is now thought important in producing cardiovascular disease. Vitamins B12 and folate reduce homocysteine levels, except in dialysis patients in whom high levels of both B12 and homocysteine have been detected after supplementation.

With this in mind, it's important to remember that mega- dosing with any nutrient could potentially have unwanted effects by upsetting the balance of other chemicals in the body – human toxicity from high-dose B12 has been suggested but not proven to my knowledge.

On the other hand, some experts suggest that normal levels of total B12 in blood may not be sufficient in all people to maintain healthy brain function.

The large numbers of case reports of improvement of M.E./C.F.S. following B12 injections indicates that a randomised trial is urgently needed. Since B12 injections are not licensed for treating this illness, currently doctors must take the responsibility of prescribing 'off-label' for what is called an 'n=1' trial – i.e. giving a therapy for a defined time to judge improvement in symptoms in an individual. If you and your doctor do decide to embark on such a trial. three months of injections seems a sufficient time to determine whether any improvement is likely to occur.

Further information

Dr. Sarah Myhill's website (www.drmyhill.co.uk) quotes Prof Pall's research and Ellis & Nasser (*refs 3, 4, 6*) plus other research work as a rationale for using B12.

See conclusion of research document: 'B12 testing in all patients with cognitive dysfunction' at www3.interscience.wiley.com/cgi-bin/abstract/70500054/ABSTRACT.

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[This article has been modified slightly to make it relevant to the local situation] ❀

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A real-time assessment of the effect of exercise in chronic fatigue syndrome

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[B]Department of Psychosomatic Medicine, Faculty Medicine, the University of Tokyo, Japan
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[D]Educational Physiology Laboratory, Graduate School of Education, the University of Tokyo, Japan

Summary

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 computerised ecological momentary assessment method, which allowed us to track the effects of exercise within and across the 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 modelling. 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 patient 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.

In Conclusion

Physical symptoms did not change following exertion until 5 days later. This prolonged delay appears strikingly different from the sort of post-exertional symptom worsening that occurs in cardiopulmonary disease. This delay may distinguish CFS from other fatiguing illness. In addition, psychological symptoms did not get worse over time. This dissociation between physical and psychological symptoms is important because it suggests that physical symptom worsening is not associated with altered mood. ❀

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Majority of ME/CFS patients negatively affected by Cognitive Behaviour Therapy

A recent pilot study (Koolhaas, et al., 2008, Netherlands) reports that only 2% of ME/CFS patients are cured by CBT, while the greatest share (38%) are adversely affected – most reporting substantial deterioration. It is especially notable that employment and education are negatively affected. This is in sharp contrast to the claims of psychiatrists and the Dutch Health Council who claim that as many as 70% of patients significantly improve with CBT.

Previous studies have also ignored or denied the negative affects of CBT on ME/CFS patients. The pilot study, recently published in the Dutch medical magazine, Medisch Contact, *concludes that the previously reported claims of 70% improvement in ME/CFS patients receiving CBT are vastly overstated and misleading.*

The following summary is from page 4 of the Dutch-language study:

Cognitieve gedragstherapie bij het chronische vermoeidheidssyndroom (ME/CVS) vanuit het perspectief van de patiënt

Drs. M.P. Koolhaas, H. de Boorder, Prof. dr. E. van Hoof
Date: February 2008
ISBN: 978-90-812658-1-2
The Netherlands

SUMMARY

Background

In recent years, Chronic Fatigue Syndrome, also known as Myalgic Encephalomyelitis (ME/CFS), has been getting a lot of attention in scientific literature. However, its aetiology remains unclear and it has yet to be clarified why some people are more prone to this condition than others. Furthermore, there is as yet no consensus about the treatment of ME/CFS. The different treatments can be subdivided into two groups, the pharmacological and the psychosocial therapies. Most of the scientific articles on treatment emphasize the psychosocial approach.

The most intensively studied psychological therapeutic intervention for ME/CFS is cognitive behaviour therapy (CBT). In recent years several publications on this subject have been published. These studies report that this intervention can lead to significant improvements in 30% to 70% of patients, though rarely include details of adverse effects. This pilot study was undertaken to find out whether patients' experiences with this therapy confirm the stated percentages. Furthermore, we examined whether this therapy does influence the employment rates, and could possibly increase the number of patients receiving educational training, engaged in sports, maintaining social contacts and doing household tasks.

Method

By means of a questionnaire posted at various newsgroups on the internet, the reported subjective experiences of 100 respondents who underwent this therapy were collected. These experiences were subsequently analysed.

Results

Only 2% of respondents reported that they considered themselves to be completely cured upon finishing the therapy. Thirty per cent reported 'an improvement' as a result of the therapy and the same percentage reported no change. Thirty-eight percent said the therapy had affected them adversely, the majority of them even reporting substantial deterioration. Participating in CBT proved to have little impact on the number of hours people were capable of maintaining social contacts or doing household tasks. A striking outcome is that the number of those respondents who were in paid employment or who were studying while taking part in CBT was adversely affected. The negative outcome in paid employment

Continued on next page

Cellular and genetic studies under way

Here's a summary of three of the five American CFIDS Association-funded studies under way at the present time.

Brigitte T. Huber, PhD, of Tufts University School of Medicine in Boston is exploring the presence of human endogenous retrovirus k18 (HERV – K18) as a risk factor for CFS. Results from Huber's pilot study have shown a strong correlation between infectious agents and CFS. The study also identified the presence of a specific HERV – K18 allele-a superantigen from within the cell – that may prove to be a predictor for postinfectious CFS.

Superantigens constitute a class of proteins capable of deregulating the immune system.

Huber has expanded the size of the patient group to examine this relationship, furthering the collective understanding of the diverse interactions that take place between an infectious virus and the immune system of its host. She also hopes to confirm whether a correlation exists between the presence of a particular HERV – K18 allele and the development of CFS. If so, this could provide a viable diagnostic biomarker for the illness in at least a subset of patients.

Nancy Klimas, MD, of the University of Miami is investigating possible mechanisms of immune system dysfunction and working to match those findings with CFS symptom clusters and severity. Her research team is focusing on a key neuropeptide (neuropeptide Y) and a membrane associated with converting peptides to amino acids (known as CD26) and how these two elements may relate to cell damage in CFS. Elevated levels of neuropeptide Y have been demonstrated to cause defects in the function of immune system cells like natural killer (NK) cells and T cells. It also plays a role in the inflammatory process, cardiorespiratory system, nervous system and endocrine system. Preliminary data indicates that CD26 is depleted in CFS, most likely through chronic cellular activation, resulting in immune dysfunction and, ultimately, the symptoms of CFS.

Lastly, a study led by **Ronald Glaser, PhD**, of Ohio State University is just beginning with support from the CFIDS Association. Dr. Glaser and his team, including three clinical collaborators – Dr. Nancy Klimas, Dr. Debra Buchwald and Dr. Gailen Marshall – will provide patient samples that will be tested for the presence of incomplete viral proteins that may be responsible for increasing the production of certain cytokines capable of inducing some of the characteristics CFS symptoms. This research is particularly timely given the renewed interest in the role of various viruses in CFS. ❀

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was statistically significant. CBT did, however, lead to an increase in the number of patients taking up sports.

A subgroup analysis showed that those patients who were involved in legal proceedings in order to obtain disability benefit while participating in CBT did not score worse than those who were not. Cases where a stated objective of the therapy was a complete cure, did not have a better outcome. Moreover, the length of the therapy did not affect the results.

Conclusions

This pilot study, based on subjective experiences of ME/CFS sufferers, does not confirm the high success rates regularly claimed by research into the effectiveness of CBT for ME/CFS. Overall, CBT for ME/CFS does not improve patients' well-being: more patients report deterioration of their condition rather than improvement.

Our conclusion is that the claims in scientific publications about the effectiveness of this therapy based on trials in strictly controlled settings within universities, has been overstated and are therefore misleading. The findings of a subgroup analysis also contradict reported findings from research in strictly regulated settings.

For more information, please contact:
Dr. M.P. Koolhaas
Email: m.p.koolhaas@consunet.nl. ❀

Neuroimaging tracks mental fatigue in CFS

Cook, D.B., et al., Functional neuroimaging correlates of mental fatigue induced by cognition among chronic fatigue syndrome patiens and controls, *NeuroImage (2007), doi: 10.1016/j,neroimage. 2007.02.033.*

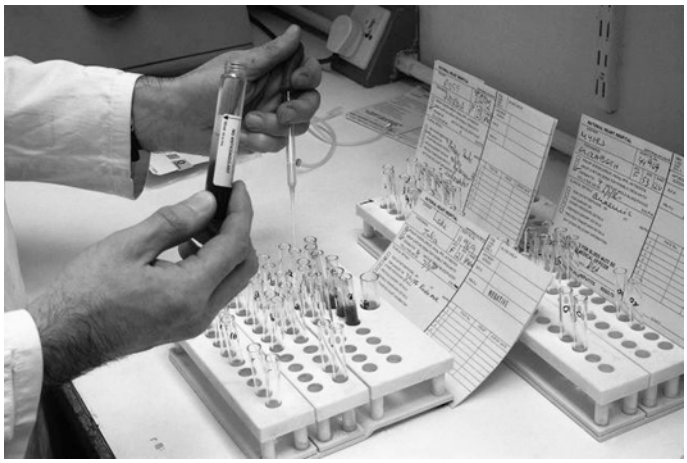
The neural mechanisms underlying feelings of mental fatigue are poorly understood.

Though neuroimaging has been used to show differences in brain responses to movement and motor skills, less attention has been paid to understanding the brain responses to demanding cognitive tasks that produce mental fatigue.

The relative lack of research in this area is surprising because a primary complaint of individuals reporting ongoing fatigue is the perceived inability to adequately perform cognitive tasks.

This spurred a well-known CFS brain researcher, Gudrun Lange, PhD, and her team of researchers led by Dane Cook, PhD, to use functional magnetic resonance imaging (fMRI) to determine the association between feelings of mental fatigue and brain response in people with CFS.

Functional magnetic resonance imaging is one of the most recently developed forms of neuroimaging. When nerve cells are activated they consume oxygen carried by red blood cells from local capillaries. The local response to this use of oxygen is increased blood flow to regions of the brain with increased neural activity. An fMRI scan allows researchers to track neural activity by detecting these changes in blood flow and oxygenation. So this scan looks at the way the brain works, rather than its physical anatomy, as a traditional MRI does.



In the study by Cook, Lange and colleagues, published in *NeuroImage*, small groups of healthy non-fatigued control subjects and subjects with CFS performed three types of tests: a fatiguing cognitive test, a non-fatiguing cognitive test and a non-fatiguing motor test. FMRI scans were conducted with each of the three tests. Each participant's fatigue was measured prior to scanning and following each task during the fMRI data collection.

The researchers hypothesised that mental fatigue would be significantly related to the brain activity during the fatiguing cognitive task, but not during the other tasks. Did the test and fMRI scans bear that out?

Indeed, the results showed that mental fatigue was related to brain activity. The participants with CFS didn't differ from control subjects for either of the non-fatiguing tasks, but exhibited significantly greater activity in several regions of the brain during the fatiguing cognitive task.

This suggests a direct association between subjectively reported feelings of mental fatigue and brain responses during fatiguing cognition – in essence validating that CFS patients' complaints of mental fatigue have a verifiable physiologiccomponent. With replication by other research groups and against other types of control groups, this type of study could have important applications in documenting both the diagnosis of CFS and disability associated with it. ❀

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CFS heart rate dysfunction persists in sleep

Boneva RS, Decker MJ, Maloney EM, Lir J, Jones J, Helgason HG, Heim C, Rye DB, Reeves WC. Higher heart rate and reduced heart rate variability persists during sleep in chronic fatigue syndrome: A population-based study. Auton Neurosci 2007 Sep 10.

A study published in *Autonomic Neuroscience* found that increased heart rate and reduced heart rate variability in CFS patients was also present during sleep, suggesting an ongoing state of sympathetic autonomic dysfunction.

The autonomic nervous system (ANS) is the part of the nervous system that controls involuntary bodily functions such as heart rate, digestion, respiration rate, salivation, perspiration, diameter of the pupils and urinary secretion. Heart rate, blood pressure and breathing, among other things, are part of the *sympathetic* ANS.

Disorders of the ANS share many clinical features of CFS and are present in many people with the illness. Several studies have found differences in heart rate and heart rate variability in CFS cases. All of these studies, however, were conducted while subjects were awake and usually performing some type of challenge such as treadmill activity, head-up tilt test or forced/paced breathing. While these studies shed light on valuable elements of CFS pathophysiology, the role of the induced stress response, anxiety and other environmental conditions cannot be completely ruled out as contributing to altered ANS function.

Researchers Roumiana Boneva and colleagues from the CDC, the Department of Neurology at Emory University and the Department of Psychiatry and Behavioural Sciences at Emory University hypothesised that some of the ANS dysfunctions observed in CFS – particularly increased heart rate and decreased heart rate variability – might reflect an ongoing perturbation in autonomic function that would persist during sleep. They explored their hypothesis by studying 43 people with CFS, 61 people with medically-unexplained fatigue but not enough other symptoms to diagnose CFS and 60 healthy control subjects. All subjects were part of a massive study referred to as "Wichita Clinical".

The heart rate of all study participants was monitored overnight and levels of the adrenal hormones norepinephrine (aka noradrenalin) and aldosterone were also measured. Compared to the control subjects, the study participants with CFS had slightly higher mean heart rate (71.4 beats per minute vs. 64.8 beats per minute in control subjects) and reduced heart rate variability. CFS patients also had significantly lower plasma aldosterone and tended to have higher plasma norepinephrine levels. Limitation in moderate physical activity was strongly associated with the increased heart rate and decreased variability in the CFS patients. Nevertheless, among 42 study subjects with similar physical activity limitations, the subjects with CFS still displayed a higher heart rate than the respective controls, suggesting that reduced physical activity could not fully explain the CFS-associated differences in ANS function. The researchers conclude that the observation of heart rate and variability differences observed during sleep, coupled with higher baseline plasma norepinephrine and lower aldosterone, suggest a state of ANS dysfunction with perturbed neuroendocrine activity. ❀

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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. ❀

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.
Phone: Marion Hansen on (08) 8234 2342.

Riverland CFS Support Group

Venue: Riverland Community Health Resource Centre, 9-11 Seekamp Street, Berri.
Phone: Raelene or Simon on 0449 120 715.
Email: riverlandcfssupport@gmail.com.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.
Phone: David on 8862 1665.

Changes

In order to keep us up to date, please send any alterations, additions or deletions to the Editor:

- Mail: GPO Box 383, Adelaide 5001.
- Email: pmrscott@tpg.com.au.

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.

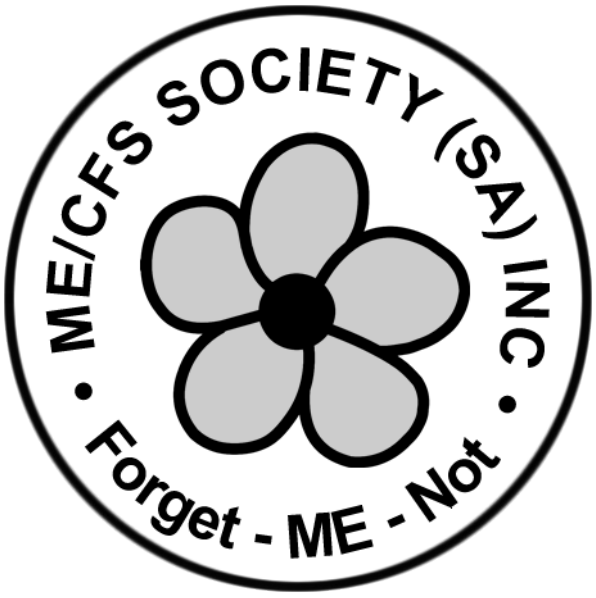
Contact numbers

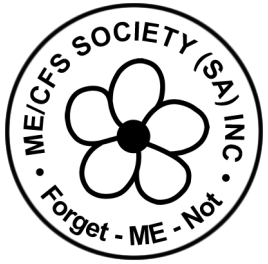
Miscellaneous Support Contacts

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
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





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