



# Talking Point

Official Journal of ME/CFS Australia (SA) Inc

**2009 Issue 1**

*Your  
Society*

*forget-ME-not*

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## ME/CFS Australia (SA) Inc.

ME/CFS Australia (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 Australia (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](mailto:sacfs@sacfs.asn.au).

Our Web site address is: [www.sacfs.asn.au](http://www.sacfs.asn.au).

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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):

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Single membership.....	\$38
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Family.....	\$45
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Overseas – as above plus .....	\$10

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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; James Hackett; Adrian Hill; Spen Langman; Emma Wing.

## Talking Point

*Talking Point* is the official journal of ME/CFS Australia (SA) Inc. It is published quarterly, and is financed primarily by member subscriptions.

**Editor:** Peter Scott ([pmrscott@tpg.com.au](mailto:pmrscott@tpg.com.au)).

**Assistant Editor:** Judy Rhodes ([dustyrhodes@dodo.com.au](mailto:dustyrhodes@dodo.com.au)).

## Talking Point subscriptions

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.

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



## Disclaimer

ME/CFS Australia (SA) Inc. aims to keep members informed about research projects, diets, medications, therapies etc.

All communication both verbal and written is merely to disseminate information and not to make recommendations or directives.

Unless otherwise stated, the views expressed in *Talking Point* are not necessarily the official views of the Society or its Management Committee and do not imply endorsement of any products or services (including those appearing in paid advertisements) or treatments.

Always consult your medical practitioners before commencing any new treatments.

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# President's report

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

Greetings from all of us at the Society. We hope that 2009 has started well enough for you and that it gets better.

## The last Talking Point

Yes, this is a poignant moment. After all so many years, the Society's faithful quarterly magazine will cease its separate journey after this issue [see page 6]. Instead we will follow the example of our sibling societies in NSW and the ACT and join with the excellent Victorian society's magazine *Emerge*.

The idea of building towards one national magazine has been discussed between the State societies during the last few years. Perhaps nothing more than inertia has kept us from doing this earlier. We all recognised that much effort goes into the journals and with limited resources it would make sense to pool our efforts.

So your next magazine in the post in several months' time will come in the shape of *Emerge* with several pages dedicated to SA news. That actually will not mean much, if any, decrease of our local content as most of *Talking Point* has been dedicated to international and national content for some time.

This is a moment nonetheless to acknowledge all those people who have edited and contributed to getting *Talking Point* out over the years. Our thanks especially go to Peter Scott who has done a fabulous job over all the years that I've been on the committee. His cheerful and obliging approach has always buoyed the rest of us. Thanks, Peter. [*You're welcome.* – Ed.]

## Young bikers are to be cherished

Nick Lawless, son of our member Sue Lawless, has got together with three mates to ride a huge distance through the Flinders Ranges in April. They're doing it as a fundraiser – for us. They've set themselves a target of \$12 000. If they get this or any thousands of dollars between it and nothing, we'll be absolutely delighted.

We'd like you to get behind this brave and generous venture and do all that you can to encourage people to sponsor the boys. You can read about their planned epic on page 7 and can keep in touch with developments via our website.

## We have to move

We moved to the Epworth Building in Pirie St seven or so years ago after our previous office (free) in DIRC had become far too cramped. Our landlord was the kind Uniting Church at first and we enjoyed a quite favourable rental arrangement. But we've had new, commercial landlords for the past several years. And they've just told us that they want to raise our rent by several thousand dollars a year.

We had already been reviewing the cost of our offices given that our expenditure now well and truly exceeds income. (Unless benefactors like Nick and his mates heave into view with a nice regularity.) So as I write, the committee, spearheaded by Spen Langman who has a strong background in the building industry, is looking for a new and cheaper home for us.

Wish us luck. I think actually that those of us who have worked in the old offices these past few years have felt that their 'karma' hasn't been as good as it used to be. Maybe a shift will revitalise us and in particular attract new volunteers.

## The MCS campaign continues

Late last year I attended a national summit in Canberra to look at a draft report by the Federal Office of Chemical Safety on the state of research into multiple chemical sensitivity. The report is a potentially important milestone for people in Australia who are chemically sensitive. There has been and is a continuing strong vein of cynicism or scepticism about MCS within the medical and research establishments and there have been some particularly loud, obnoxious and well-placed opponents in Australia.

Since the meeting the community/consumer representatives who attended have worked at times feverishly via email to debate how to ensure that the final report really does accept that MCS is a real condition and not psychosomatic. Peter Evans of our Society attended too and has done another amazing job writing a long and detailed critique of the original document. (By the way, it had lots of positive material about MCS as 'real' but that was countered by the amount of attention it gave to the other side. And there were lots of little stylistic touches in it which

*Continued on page 7*



ME/CFS Australia (SA) Inc  
GPO Box 383, Adelaide,  
South Australia 5001

## MEMBERSHIP APPLICATION FORM

Full Name: (Mr / Mrs / Ms / Miss / Dr) \_\_\_\_\_

(Please only provide address, phone number and email below if this has changed in the last twelve months)

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\_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: (H) \_\_\_\_\_ (W) \_\_\_\_\_

Mobile: \_\_\_\_\_ Email: \_\_\_\_\_

Date of Birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

### Annual Subscription Rates

(Rates are due on 1 July each year)

- |                    |   |  |
|--------------------|---|--|
| Membership         | <input type="checkbox"/> <b>\$38</b> (incl. GST)  | Single                                   |
| Subscriptions      | <input type="checkbox"/> <b>\$25</b> (inc GST)    | Single (concession)                      |
| (includes Journal) | Please circle one:                                | DSP / Student / Unemployed / Age Pension |
|                    | <input type="checkbox"/> <b>\$45</b> (inc GST)    | Family                                   |
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| ADD                | <input type="checkbox"/> <b>\$10.00</b>           | Overseas members                         |

Plus Donation \$ \_\_\_\_\_ Your donation will greatly assist the Society's work.

All donations of \$2 or more are tax-deductible and a receipt will be posted to you.

Total enclosed \$ \_\_\_\_\_ Payable to "ME/CFS Australia (SA) Inc."

Send to: ME/CFS Society,  
GPO Box 383,  
Adelaide, SA 5001  
(please don't send cash in the mail)

### Miscellaneous

I agree to uphold and abide by the constitution of the ME/CFS Australia (SA) Inc. The constitution can be found on our website at <http://sacfs.asn.au/society/member/index.htm>.

Signed: \_\_\_\_\_ Dated: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

- ☐ I would like to receive Society notices by email.  
☐ I would like to receive Society notices by SMS.

### Credit Card Payment

Name on Card \_\_\_\_\_

VISA / MasterCard / Bankcard EXP \_\_\_\_ / \_\_\_\_

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Signature \_\_\_\_\_



*Continued from page 4*

I – as a non-scientist but someone whose career has been in communications – could tell suggested that the author is nervously looking over his shoulder at the sceptics.)

Anyway, we have offered to be the place where submissions on the report are posted. The network was concerned that the only reference to their individual submissions might be a one-liner noting their name on the OCS website. So if you're interested in this then you should be able to go to our MCS News section of our website and find some of these submissions as and when their authors send them in to us.

Peter Evans and I also attended the first meeting of the State Government Reference Group on MCS in early February. Things grind on slowly and we later met with Dr Ian Buttfield, who is on the committee and is impatient for faster progress, to discuss how we can more systematically prod the government agencies around the table to do more. We are particularly concerned that the Department of Families and Communities has not had a representative at the last few meetings. DFC is meant to be with Health one of the two main agencies on the committee, as it deals with disability issues.

Dr Buttfield, Peter and I agreed that, whilst progress is slow, there is progress on developing policies such as the guidelines for local government on pesticide use which we reviewed at the February meeting. We would rather have a slow-moving inter-agency committee than no committee at all! But we'll still push it to move faster on a broader front.

## **The website powers on**

Late last year webmaster Peter Scott decided that he'd change tack. In the past we would sometimes have two or three items posted on one day and then a gap of a few days. He set himself the goal of posting one new item – no more and no less – each day. And by gum he's stuck to his task through thick and thin. We've had one new item a day – no more and no less – for several months now. If you're not a regular user or don't access it at all, we urge you to start ac-

cessing it more often. I find that reading the steady flow of items about new research into ME/CFS, Fibromyalgia and MCS has tended to make me feel more positive about the state of play for our conditions. Of course there are no magic answers yet and the enemies of fair play for us are still powerfully entrenched in medical and bureaucratic establishments. But you ought to go and scroll down the articles just for the last month or so. You'll be astounded, I think, at how rich a resource our website is. And once again all thanks to Peter Scott.

Meanwhile our Facebook group has steadily increased its membership to over 140 as I write this. There are quite a range of discussion threads from alcohol usage and its impact to hives to safely travelling by air to where can I find a good doctor. Not every query is responded to immediately and it's not yet at

a stage where it's bursting with new postings every day. But what an important service it is. In fact if I can use a service station analogy: in the old days you needed an attendant (someone from the Society's office or support line) to fill your tank. Now we have self-service – in this case someone else who knows perhaps more about hives, the impact of particular medications and treatments and so on than anyone might who has an official role in the Society.

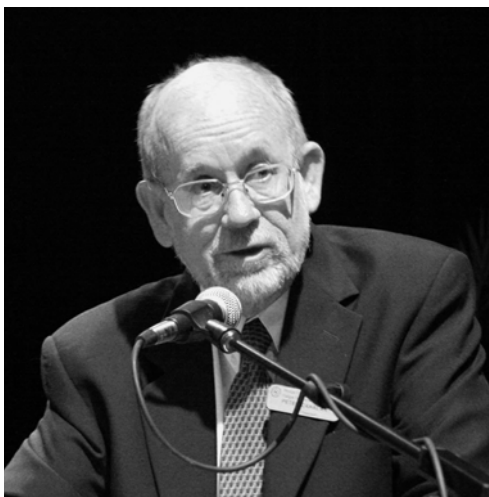
So hop into our self-service information filling station. Join our Facebook group. You can access it most easily off our website. There's a link near the top left corner of the home page.

## **Quorn – the alternative home base of the movement?**

I will be based in Quorn for my work for a few months. As it happens our only country member on the committee is James Hackett – of Quorn! We're thinking of moving a motion at a coming committee meeting to shift the meeting venue a few hundred kilometres north of Adelaide. Sadly, we probably don't have the numbers for moving away from our very pleasant venue at the home of the Wing family of Trott Park.

That's it for now. We battle on at the Society and we hope that you're battling on too. We wish you better health and inner strength.

*Peter Cahalan*



Peter Cahalan

## The last *Talking Point*

Unfortunately, we've had to cease publishing *Talking Point*.

On a personal note, I've thoroughly enjoyed messing about with *TP*, choosing articles, pictures, layout etc, and having friends find the mistakes I had a habit of missing before we went to publication.

Thanks to everyone who suggested or supplied articles for *TP*. And an extra special thanks to assistant editor Judy Rhodes (and before her, Jenni Gay). Thanks for tolerating the bad jokes in all those emails.

Despite the departure of *Talking Point*, you can still catch up with Society shenanigans on the website ([sacfs.asn.au](http://sacfs.asn.au)) and in our sister publication, *Emerge*.

Well, it's a 'sayonara' from me, and I hope we all meet again sometime.

Have fun!

Peter Scott (ex-Editor, *Talking Point*).



Your (almost) humble editor

## Society meetings for the rest of 2009

**Date:** Saturday 2 May 2008

**Speaker:** John Steele, disability discrimination lawyer

**Topic:** Due to an increase in employment-related problems since the economic downturn, John will discuss CFS and problems in the workplace that are of special interest to people with CFS.

**Time:** 1pm start.

**Venue:** Ellen Gowan Hall,  
St Peters Hall, 80 Payneham Rd, Stepney.

**Date:** Saturday 13 June 2009

**Speaker:** Dr Ross Philpot

**Topic:** Dr Philpot will discuss Rickettsia and CFS. Specifically, the symptoms, the research, the causes, the management and the treatments.

**Time:** 1pm start.

**Venue:** Ellen Gowan Hall,  
St Peters Hall, 80 Payneham Rd, Stepney.

**Date:** Saturday 18 July 2009

**Speaker:** Liz Vaskin, psychologist

**Topic:** "Mindfulness meditation and ME/CFS"

Liz will discuss the benefits of meditation and give participants an introduction to some simple meditation techniques.

**Time:** Note: 11am start.

**Venue:** Sofia conference room,  
225 Cross Rd, Cumberland Park.

**Date:** Saturday 5 September 2009

**Speaker:** Belle McCaleb, naturopath

**Topic:** Belle will review dietary, nutritional medicine and herbal medicine approaches to treating CFS and enhancing health. She will review some of the scientific research/rationale supporting these approaches, the role of detoxification, lifestyle considerations and recommended nutritional and herbal remedies.

**Time:** 1pm start.

**Venue:** Ellen Gowan Hall,  
St Peters Hall, 80 Payneham Rd, Stepney.

**Date:** Saturday 7 November 2009  
**Annual General Meeting**

**Speaker:** Dr Ian Buttfield

**Topic:** Dr Buttfield will discuss the lactic acid and ME/CFS research project.

**Time:** 1pm start.

**Venue:** Ellen Gowan Hall,  
St Peters Hall, 80 Payneham Rd, Stepney.

The cost for each meeting is a gold coin for members, \$5 for non-members.

Please refrain from wearing aftershaves, perfumes etc, and please refrain from smoking at the meetings.

# Riders for Chronic Fatigue Syndrome

Nick Lawless, son of Society member Sue Lawless, has taken on the challenge of a big bike ride as a project for his studies.

Nick and three mates – Codey Ellison, David Chadwick and Jack Rivers-Dixon – are going to ride 380km off-road through the Flinders Ranges for a week in April 2009.

Their aim is to raise money for our Society and to publicise ME/CFS.

Here's a message from Nick about the ride (taken from his *MySpace* page – [http://www.myspace.com/CFS\\_riders](http://www.myspace.com/CFS_riders)):

## About me

For my personal project (a year-long assignment at school) I am riding 380kms off-road along the Mawson Trail in April 2009 with 3 friends to raise money for the ME/CFS Australia (SA) Inc. society as my mum has had chronic fatigue syndrome now for more than 7 years. We will all be 15 or under when we undertake the challenge, and none of us have ever done anything anywhere near this big before.

## Donations

If you are kind enough to want to donate something, go on to any bank website and enter

- 105159 as the BSB
- and 022779240 as the account number

You can donate directly into the ride account anonymously. You can also make a donation by following the links at [www.ourcommunity.com.au](http://www.ourcommunity.com.au).

If you would not like to remain anonymous and want to show the world that you gave to this worthy cause leave your name in a comment there.

Any help you can give is GREATLY appreciated :)

## Who I'd like to meet on the ride

Anybody willing to support our worthy cause! ☘



# CFS Checklist

By **Dr Sarah Myhill**.

(Editor's note: This article is an edited version of "CFS Checklist – start off and check your treatment regime here" which originally appeared here: <http://www.drmyhill.co.uk/article.cfm?id=5>.)

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Chronic fatigue syndrome is not a diagnosis – merely a group of symptoms which may have many causes. By the time someone has been ill for several years there are often several causes. The best results are obtained by identifying as many different causes as possible and tackling them all at once.

Serious disease must first be excluded. By the time people come to see me they have already had a series of blood tests. If you have not had tests done recently, then I strongly recommend doing the disease screening group of tests.

I used to do things one at a time in order to see what does and does not work. I now do things the other way round – treat everything I think to be important, get the patient better, then relax the regime and hope they stay well. If they don't, work out "backwards" what is wrong.

The following is the programme of treatment I go through with every patient. If I try to cut corners, I often end up missing important problems. The patient who thinks about their illness and works out things for themselves has the best chance of getting better. I can point you in the right direction, but you have to do the donkey work!

Don't go on to the next stage until the earlier ones have been fully explored.

## Stage 1: Make sure it's CFS

- Is the diagnosis right – has serious pathology been excluded? e.g. cancer, MS, autoimmune disorders.
- Is the fatigue delayed? i.e. do you pay for any exertion 1-4 days later. If you do, you have CFS and must pace all activities carefully. If not (i.e. you just feel tired that evening but are better by the next day), then you should do a graded activity programme.

- Have a careful think about what caused your CFS as this will give a guide to treatment. Think about the time building up to the start of the illness, what the trigger was, which illnesses run in the family?
- CFS is a diagnosis of exclusion. Tests to exclude serious disease may be helpful, but even if they are all normal, you could still have other serious disease. The opinion of a good physician should always be taken to make the diagnosis. Recent onset of symptoms which may be worsening would suggest serious underlying disease.

## Stage 2: Observe six fundamental rules



This applies to all CFS sufferers:

**Rest:** 80% rule, pacing, mental and physical rest. Get organised. Accept help. Arrange for deliveries to house. Delegate work. Prioritise: list the 10 most important things in your life, then ignore the last five. You can't do everything.

**Sleep:** quality sleep is essential to life. Don't be afraid to use tablets to restore the normal day/night diurnal rhythm. Sleep disorders. Avoid caffeine after 4pm – it will interfere with sleep.

**Supplements:** it takes at least 6 months for body stores

to replete. Supplements are for life.

**Avoid infections** whenever possible. At the first sign of a cough, cold or sore throat use vitamin A (not if pregnant), vitamin C, zinc, selenium and propolis. If you don't believe you could have any deficiencies, then do the disease prevention screening tests.

**Diet:** you are what you eat, but everybody is different. Everything in moderation but use as wide a variety of quality foods as possible. Avoid sugar and

*Continued next page*

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“junk foods”. Avoid any one thing in excess. Don’t drink tea at meal-times: it blocks absorption of trace elements. Use mineral water to drink – at least 2 pints daily. Eat salt, ideally SOLO sea salt (full of essential minerals). Eat foods as raw and unprocessed as possible. Organic foods where possible. Use beans (flagollets, chick peas etc) hot and cold in salads to increase variety and fibre, they can be bought in bulk and store well. At some stage you must do the DIET for CFS.

**Do a chemical clean up:** throw out all the smellies in your house, keep the house well ventilated, avoid sprays, polishes, aerosols, new paints, new carpets, gas cookers and heaters etc..

### Stage 3: Fighting and nurturing

You need to start to tackle some, or all, of the underlying causes. Also, you need to do the other things which support the body.

Some interventions work for a high proportion of sufferers (B12, antidepressants, magnesium injections etc). Do as many of these things at the same time as you can. By the time you have been ill for several years, more than one thing will be wrong – you need to tackle them all at the same time to see improvement. The priority is to get well. Once you are better, these things can be knocked off one at a time to find out which is important.

The manoeuvres to try, in order of importance:

1. **Magnesium levels:** get your magnesium levels checked.
2. **Painkillers:** for pain.
3. **B12 injections** should be tried at some stage. Don’t waste money measuring B12 levels, they are irrelevant. It is the response to injections which is important. Make sure you are on a multivitamin containing folic acid when you have injections.
4. **Elimination diet:** do a good elimination diet. Grains (wheat, barley, rye, oat) are the commonest allergic cause of fatigue.
5. **Correct hormonal disturbances:** adrenal gland dysfunction; hypothyroidism.
6. **Gut symptoms:** getting gut symptoms right is central to getting the CFS right. Consider gut fermentation, *helicobacter pylori*, gut parasites (e.g. symptoms following travel abroad), food intolerance, lactose intolerance
7. **Care with female sex hormones.** The Pill and HRT worsen CFS in the long term and certainly predispose to getting CFS because

they suppress the immune system and induce nutritional deficiencies.

8. **Low-dose antidepressants:** many CFSs do well on tiny doses of tricyclic antidepressants such as amitriptyline 10mgs, dothiepin 10mgs, trimipramine 10mgs at night. In these doses I would not expect much effect on depression.
9. **Chronic low grade undiagnosed infection:** *helicobacter pylori*, pelvic infections, chronic prostatitis, skin and nail infections.
10. **Hyperventilation** can cause fatigue. Often driven by food intolerance and low magnesium levels. Helped by relaxation techniques.
11. **Chemical poisoning:** exposure at work to organophosphates (farmers), dog and cat flea treatments, human head lice treatments, Vapona fly blocks/sprays, woodworm treatments. Contaminated water. Any silicone implants – siliconosis? Gulf War Syndrome? Chemical poisoning often leads on to MCS.
12. **MCS (Multiple Chemical Sensitivity).** Suspect if symptoms better out of doors, better in the summer, better away on holiday. Do chemical clean-up. Eat organic where possible.

### Stage 4: Allergy

If you are still struggling despite having tried all the above, then it is likely your problems are caused by multiple allergy to foods, to chemicals or to moulds.

- Get mould allergy tested: either by skin tests or by going abroad to a warm dry climate, ideally for one month, but two weeks may give you an idea. Make sure that the holiday house is chemically clean. I know it is not easy, but it is important.
- Consider desensitisation such as neutralisation or my preferred technique, enzyme potentiated desensitisation (EPD) for foods and possibly chemicals. EPD does not work so well for mould allergy.

### Conclusion

Everybody gets better from CFS in a different way: often a combination of the above. Tackle your illness from every angle you can. Always have a plan. Always keep a light at the end of the tunnel. Keep talking with other sufferers: they will give you ideas and inspiration. ☸

*Dr. Sarah Myhill is a UK-based specialist in fatigue-related illnesses. Reprinted with permission.*

# Mitochondrial dysfunction in ME/CFS

**Dr Sarah Myhill, MD** offers her views on the role mitochondrial dysfunction plays in ME/CFS.

Please note: Although some of the testing Dr Myhill mentions is unfortunately unavailable in Australia, we thought the article of sufficient interest for inclusion in Talking Point.

*Mitochondria are the engine of the car – they supply energy to every cell in the body. When mitochondria goes slow, everything goes slow!*

I think this is one of the most important ideas I have come up with in terms of my understanding of CFS and what to do in order to recover! So please read this very carefully and several times over because for many sufferers it contains the keys to unlock their illness!

We are made up of lots of different cells – heart, blood, muscle nerve cells etc. All these cells are different because they all have a different job of work to do. To do this job of work requires energy. But the way in which energy is supplied is the same for every cell in the body. Indeed all animals share this same system. The mitochondria in my dog, my cat and my horse are exactly the same as mine. Mitochondria are a common biological unit across the animal kingdom. Energy is supplied to cells by mitochondria which I think of as little engines which power every cell in the body.

Chronic fatigue syndrome is the symptom caused by mitochondrial failure. The job of mitochondria is to supply energy in the form of ATP (adenosine triphosphate). This is the universal currency of energy. It can be used for all sorts of biochemical jobs from muscle contraction to hormone production. When mitochondria fail, this results in poor supply of ATP, so cells go slow because they do not have the energy supply to function at a normal speed. This means that all bodily functions go slow.

Chronic fatigue syndrome therefore is a symptom of mitochondrial failure and every cell in the body can be affected.

## Mitochondrion

ATP (3 phosphates) is converted to ADP (2 phos-

phates) with the release of energy for work. ADP passes into the mitochondria where ATP is remade by oxidative phosphorylation (ie a phosphate group is stuck on). ATP recycles approximately every 10 seconds in a normal person – if this goes slow, then the cell goes slow and so the person goes slow and clinically has poor stamina ie CFS.

Problems arise when the system is stressed. If the CFS sufferer asks for energy faster than he can supply it, (and actually most CFS sufferers are doing this most of the time!) ATP is converted to ADP faster than it can be recycled. This means there is a build up of ADP. Some ADP is inevitably shunted into adenosine monophosphate (AMP -1 phosphate). But this creates a real problem, indeed a metabolic disaster, because AMP, largely speaking, cannot be recycled and is lost in urine.

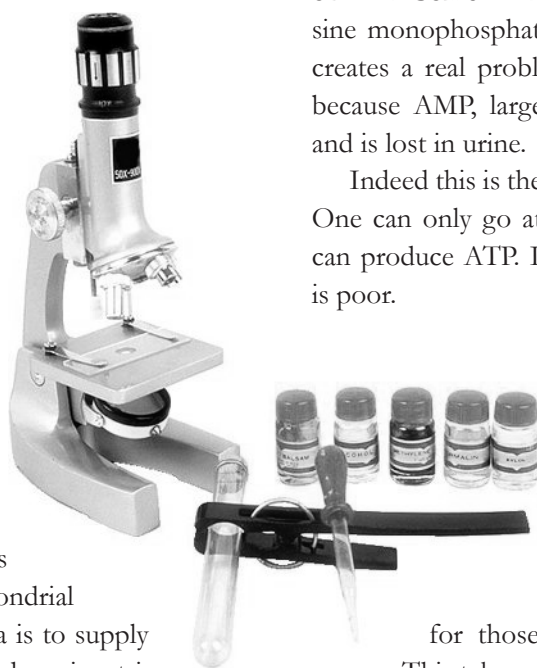
Indeed this is the biological basis of poor stamina. One can only go at the rate at which mitochondria can produce ATP. If mitochondria go slow, stamina is poor.

If ATP levels drop as a result of leakage of AMP, the body then has to make brand new ATP. ATP can be made very quickly from a sugar D-ribose, but D-ribose is only slowly made from glucose (via the pentose phosphate shunt

for those clever biochemists out there!).

This takes anything from one to four days. So this is the biological basis for delayed fatigue.

However there is another problem. If the body is very short of ATP, it can make a very small amount of ATP directly from glucose by converting it into lactic acid. This is exactly what many CFS sufferers do and indeed we know that CFS sufferers readily switch into anaerobic metabolism. However this results in two serious problems – lactic acid quickly builds up especially in muscles to cause pain, heaviness, aching and soreness (“lactic acid burn”), secondly no glucose is available in order to make D-ribose! So new ATP cannot be easily made when you are really run down.



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Recovery takes days!

Worse than that, lactic acid has to be converted back to pyruvate – but this requires a lot of energy (ATP) to do this. So lactic acid hangs about for a long time causing pain.

The biological basis of treatment is therefore explained:

**1. PACE** – do not use up energy faster than your mitos can supply it.

**2. FEED THE MITOCHONDRIA** – supply the raw material necessary for the mitochondria to heal themselves and work efficiently. This means feeding the mitos correctly so they can heal and repair.

**3. ADDRESS THE UNDERLYING CAUSES** – as to why mitochondria have been damaged. This must also be put in place to prevent ongoing damage to mitos. In order of importance this involves:

**A-** Pacing activities to avoid undue stress to mitos

**B-** Getting excellent sleep so mitos can repair

**C-** Excellent nutrition with respect to: taking a good range of micronutrient supplements, stabilising blood sugar levels, identifying allergies to foods

**D-** Detoxifying to unload heavy metals, pesticides, drugs, social poisons (alcohol, tobacco etc) and volatile organic compounds, all of which poison mitos.

**E-** Optimising gut fermentation – HYPOCHLORHYDRIA and PANCREATIC FUNCTION, GUT DYSBIOSIS

**F-** Addressing the common problem of hyperventilation

**4. ADDRESS THE SECONDARY DAMAGE** – partly caused by mitochondrial failure such as immune disturbances resulting in allergies and autoimmunity, poor digestive function, hormone gland failure, slow liver detoxification.

## The Perfect Test for Chronic Fatigue Syndrome

The central problem of chronic fatigue syndrome is mitochondrial failure resulting in poor production of ATP. ATP is the currency of energy in the body and if the production of this is impaired then all cellular processes will go slow. It is not good enough to measure absolute levels of ATP in cells since this will sim-

ply reflect how well rested the sufferer is. The perfect test is to measure the rate at which ATP is recycled in cells and this test has now been developed by the brilliant medical biochemist Dr John McLaren Howard. He calls it “ATP profiles”. It is a test of mitochondrial function.

Not only does this test measure the rate at which ATP is made, it also looks at where the problem lies. Production of ATP is highly dependent on magnesium status and the first part of the test studies this aspect (A).

The second aspect of the test (B) measures the efficiency with which ATP is made from ADP. If this is abnormal then this could be as a result of magnesium deficiency, of low levels of Co-enzyme Q10, low levels of vitamin B3 (NAD) or of acetyl L-carnitine.

The third possibility (C) is that the protein which transports ATP and ADP across mitochondrial membrane is impaired and this is also measured.

The joy of the ATP profiles test is that we now have an objective test of chronic fatigue syndrome which clearly shows this illness has a physical basis. This test clearly shows that cognitive behaviour therapy, graded exercise and anti-depressants are irrelevant in addressing the root cause of this illness.

To get the full picture I recommend combining this test with measuring levels anti-oxidants such as Co-enzyme Q10, superoxide dismutase (SODase), and glutathione peroxidase together with NAD (an element in the process of energy production).

Cell free DNA is very useful because it measures severity of the illness. When cells are damaged and die, they release their contents into the blood stream – cell free DNA measures the extent of this damage. The levels which come back are similar to those from patients recovering from major infections, trauma, surgery or chemotherapy – so this test puts CFS firmly in the realms of major organic pathology. SODase is an important antioxidant which mops up the free radicals produced in all the inefficient chemical reactions in the cells. Dr McLaren Howard also looks at the genes which code for the different types of SODase! It is common to find blockage or polymorphisms typical of toxic stress.

In fact, all of these blood tests have now been combined as a MITOCHONDRIAL FUNCTION PROFILE (which combines the “ATP profiles” and tests of antioxidant levels) and can be ordered from my practice – see details below.

The two other important co-factors in the production of energy in cells are L-carnitine and D-ribose.

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The latter is used up so quickly by cells that measuring levels is unhelpful, but low levels of ATP imply low levels of D-ribose. Acetyl L Carnitine is supplemented as routine.

The cost of the Mitochondrial Function Profile, which will now include the mitochondrial function studies (ATP profiles), levels of Co-enzyme Q10, glutathione peroxidase, zinc copper SODase, manganese SODase and extracellular SODase together with NAD levels and cell-free DNA is £195, plus £50.00 for the letter of interpretation to the GP.

John McLaren Howard now has specialist equipment to refine these tests further, particularly in respect of oxidative phosphorylation.

### **Severe CFS is also low cardiac output secondary to mitochondrial malfunction**

Two papers have come to my notice recently, which make great sense of both my clinical observations and also the idea that CFS is a symptom of mitochondrial failure. The two symptoms I am looking for in CFS to make the diagnosis is firstly very poor stamina and secondly delayed fatigue. I think I can now explain these in terms of what is going on inside cells and the effects on major organs of the body. More importantly, there are major implications for a test for CFS and of course management and recovery.

If mitochondria (the little batteries found inside every cell in the body) do not work properly, then the energy supply to every cell in the body will be impaired. This includes the heart. Many of the symptoms of CFS could be explained by low cardiac output because the heart muscle cannot work properly. Cardiologists and other doctors are used to dealing with low cardiac output due to poor blood supply to the heart itself. In CFS the low cardiac output is caused by poor muscle function and therefore strictly speaking is a cardiomyopathy. This means the function of the heart will be very abnormal, but traditional tests of heart failure, such as ECG, ECHOs, angiograms etc, will be normal.

Firstly MicroRespiratory studies which look at oxidative phosphorylation (conversion to ADP to ATP) in more detail. Secondly translocator protein studies which look in more detail at how well ATP and ADP move across mitochondrial membrane. The point is that the blood supply to the heart is fine (fuel and oxygen adequate) but the mitochondria cannot convert this to ATP which is the currency of energy for

muscle contraction.

Research by Dr Arnold Peckerman (<http://www.cfids-cab.org/cfs-inform/Coicfs/peckerman.etal.03.pdf>) shows that cardiac output in CFS patients is impaired. Furthermore the level of impairment correlates very closely to the level of disability in patients. Dr Peckerman was asked by the US National Institutes of Health to develop a test for CFS in order to help them to judge the level of disability in patients claiming Social Security benefits. Peckerman is a cardiologist and on the basis that CFS patients suffer low blood pressure, low blood volume and perfusion defects, he surmised CFS patients were in a low cardiac output state. To test this he came up with Q scores.

“Q” stands for cardiac output in litres per minute and this can be measured using a totally non-invasive method called Impedence Cardiography. This allows one to accurately measure cardiac output by measuring the electrical impedance across the chest wall. The greater the blood flow the less the impedance. This can be adjusted according to chest and body size to produce a reliable measurement (this is done using a standard algorithm). It is important to do this test when supine and again in the upright position. This is because cardiac output in healthy people will vary from 7 litres per min when lying down to 5 litres per min when standing. In healthy people this drop is not enough to affect function. But in CFS sufferers the drop may be from 5 litres lying down to 3.5 litres standing up. At this level the sufferer has a cardiac output which causes borderline organ failure.

This explains why CFS patients feel much better lying down. They have acceptable cardiac output lying down, but standing up they are in borderline heart and organ failure. CFS is therefore the symptom which prevents the patient developing complete heart failure. Actually, everyone feels more rested when they are sitting down with their feet up! The subconscious has worked out that the heart has to work less hard when you are sitting down with your feet up – so we do so because we feel more comfortable!

### **Low cardiac output explains the symptoms of CFS**

The job of the heart is to maintain blood pressure. If the blood pressure falls, organs start to fail. If the heart is working inadequately as a pump then the only way blood pressure can be sustained is by shutting down blood supply to organs. Organs are shut down in terms of priority, i.e. the skin first, then muscles,

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followed by liver, gut, brain and finally the heart, lung and kidney. As these organ systems shut down, this creates further problems for the body in terms of toxic overload, susceptibility to viruses which damage mitochondria further, thus exacerbating all the problems of the CFS sufferer.

### **1. Effects on the Skin**

If you shut down the blood supply to the skin, this has two main effects. The first is that the skin is responsible for controlling the temperature of the body. This means that CFS patients become intolerant of heat. If the body gets too hot then it cannot lose heat through the skin (because it has no blood supply) and the core temperature increases. The only way the body can compensate for this is by switching off the thyroid gland (which is responsible for the level of metabolic activity in the body and hence heat generation) and so one could get a compensatory under active thyroid. This alone worsens the problems of fatigue.

The second problem is that if the micro-circulation in the skin is shut down, then the body cannot sweat. This is a major way through which toxins, particularly heavy metals, pesticides and volatile organic compounds are excreted. Therefore the CFS sufferer's body is much better at accumulating toxins, which of course further damage mitochondria

### **2. Symptoms in Muscles**

If the blood supply to muscles is impaired, then muscles quickly run out of oxygen when one starts to exercise. With no oxygen in the muscles the cells switch over to anaerobic metabolism, which produces lactic acid and it is this that makes muscles ache and fatigue so much.

As well as the above problem, muscles in the CFS patient have very poor stamina because the mitochondria which supply them with energy are malfunctioning.

When we do translocator protein function tests it is common to find lactic acid stuck onto mitochondrial membranes – this illustrates one of the many vicious cycles in CFS – if TL protein is blocked by lactic acid, mitochondria work less efficiently and therefore one is more likely to switch into anaerobic metabolism and produce more lactic acid!

### **3. Symptoms in the Liver and Gut**

Poor blood supply to the gut results in inefficient digestion, poor production of digestive juices and leaky gut syndrome. Leaky gut syndrome causes many other problems such as hypochlorhydria, allergies, autoimmunity, malabsorption, etc., which further compound the problems of CFS.

If liver circulation is inadequate, this will result in poor detoxification, not just of heavy metals, pesticides and volatile organic compounds, but also toxins produced as a result of fermentation in the gut again further poisoning the mitochondria.

### **4. Effects on the Brain**

Last October I attended a conference sponsored by the late Dr John Richardson. A Canadian physician Dr Byron Hyde showed us some functional scans of the brains of CFS patients. If I had not known the diagnosis, I would have diagnosed strokes. This is because the blood supply to some area of the brain was so impaired. The default

is temporary and with rest, blood supply recovers. However, this explains the multiplicity of brain symptoms suffered from, such as poor short term memory, difficulty multi-tasking, slow mental processing and so on. Furthermore brain cells are not particularly well stocked with mitochondria and therefore they run out of energy very quickly. Brain mitochondria are particularly dependent on blood sugar levels. Many brain symptoms are caused by HYPOGLYCAEMIA.

### **5. Effects on the Heart**

There are two effects on the heart. The first effect of poor micro-circulation to the heart is disturbance of



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the electrical conductivity which causes dysrhythmias. Many patients with chronic fatigue syndrome complain of palpitations, missed heart beats or whatever. This is particularly the case in patients with poisoning by chemicals since the chemicals are also directly toxic to nerve cells.

The second obvious result is poor exercise tolerance. Heart muscle fatigues in just the same way that other muscles fatigue. Symptomatically this causes chest pain and fatigue. In the longer term it can cause heart valve defects because the muscles which normally hold the mitral valve open also fatigue.

THIS APPROACH TO TREATING HEART DISEASE IS EXACTLY THE SAME REGARDLESS OF THE CONVENTIONAL DIAGNOSIS. So patients with angina, high blood pressure, heart failure, cardiomyopathy, some valve defects as well as patients with cardiac dysrhythmias often also have mitochondrial problems and will respond in the same way to nutritional therapies and detox therapies.

## 6. Effects on Lung and Kidney

The lung and kidney are relatively protected against poor micro-circulation because they have the largest rennin-angiotensin system, which keeps the blood pressure up in these vital organs. Therefore clinically one does not see CFS patients with kidney failure or pulmonary hypoperfusion.

## Explanation of the Fatigue Problems in CFS Patients

Energy to the body is supplied by mitochondria, which firstly produce NAD (nicotinamide adenosine diphosphate) from Kreb's citric acid cycle and this is used to power oxidative phosphorylation which generates ATP (adenosine triphosphate). These molecules are the "currency" of energy in the body. Almost all energy requiring processes in the body have to be "paid for" with NAD and ATP, but largely ATP. The reserves of ATP in cells are very small. At any one moment in heart muscle cells there is only enough ATP to last about ten contractions. Thus the mitochondria have to be extremely good at re-cycling ATP to keep the cell constantly supplied with energy.

If the cell is not very efficient at re-cycling ATP, then the cell runs out of energy very quickly and this causes the symptoms of weakness and poor stamina. The cell literally has to "hibernate" and wait until more ATP has been manufactured.

In producing energy, ATP (three phosphates) is converted into ADP (two phosphates) and ADP is recycled back through mitochondria to produce ATP. However, if the cell is pushed (ie stressed) when there is no ATP about, then it will start to use ADP instead. The body can create energy from ADP to AMP (one phosphate), but the trouble is that AMP cannot be recycled. The only way that ADP can be regenerated is by making from fresh ingredients, but this takes days to do. This explains the delayed fatigue seen in chronic fatigue syndrome.

So to summarise, the basic pathology in CFS is slow re-cycling of ATP to ADP and back to ATP again. If patients push themselves and make more energy demands, then ADP is converted to AMP which cannot be recycled and it is this which is responsible for the delayed fatigue. This is because it takes the body several days to make fresh ATP from new ingredients. When patients overdo things and "hit a brick wall" this is because they have no ATP or ADP to function at all.

## Implications for Treatment

Many patients I see get well with my standard work up with respect to vitamins and minerals, diet, pacing and sleep. All these things must be put in place to repair and prevent ongoing damage to mitochondria so allowing them to recover. For mitochondria to recover they need all the essential vitamins, minerals, essential fatty acids and amino acids to manufacture the cellular machinery to restore normal function. The mitochondrial function tests then allow us to identify lesions which can be corrected by attention to nutritional supplements, improving antioxidant status, detoxing, hyperventilation or whatever. CFS sufferers have limited reserves of physical, mental and emotional energy and this test allows us to direct those energies into the most fruitful line of approach. ☸

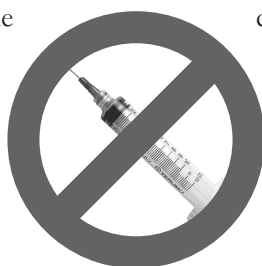
*The scientific paper entitled 'Chronic Fatigue Syndrome and Mitochondrial Dysfunction' is available here <http://www.ijcem.com/files/IJCEM812001.pdf>, Int J Clin Exp Med (2009) 2, 1-16*

*For more information about mitochondria and their clinical reference, see extract from the online book, free for anyone to download, written by Dr Sarah Myhill (<http://www.drmyhill.co.uk>).*

# CFS treatments which are not worth trying

By **Dr Sarah Myhill**.

- **Graded exercise.** This is positively harmful when CFS is active. I find it quite extraordinary that so many doctors seem to advocate this as a treatment. It is as if they are unable to distinguish between CFS and lack of fitness! Let's face it, if graded exercise worked then the diagnosis could not possibly be CFS. The only possible explanation I can think of as to why this has stuck in the medical folklore is that after a physician has recommended this to the CFS patient, the latter never bothers to attend again for useless advice. The doctor then believes he has cured the patient because they don't come back. Has anybody else got any better explanation?
- **Cognitive behaviour therapy.** The idea behind this is that the CFS patient does not exercise because he is afraid to because it makes him ill. CBT is all about getting round this fear. The trouble is that the patient is right – he is fearful of exercise because it really does make him ill! CBT might help the patient who is recovered from the acute phase of CFS, but on the law of averages it is far more likely to make patients worse. Patients can tolerate so much CBT because they do the exercises at the expense of other activities, not in addition to and this makes the results of trials look impressive.
- **Cold water therapy.** This was advocated as a treatment for fatigue by Kakkar. It probably works because it gives the adrenal glands a huge "kick". However, if the adrenal glands are not working properly, as in CFS, then the patient feels awful. I don't recommend cold baths.
- **Amino acids.** I tried these after reading a paper about amino acid deficiencies in CFS. The tests are expensive, the amino acids expensive and the results very disappointing.
- **Glutathione/ATP injections.** Again, the initial paper looked promising. I tried these on 4 patients, twice a week over six months but no response from any, so I gave up. Glutathione and ATP are often deficient but one just cannot get the amount in by injection to make a difference. I find levels of glutathione in the blood correct reliably well with oral supplements. Similarly ATP levels come up with d-ribose.
- **Enada.** Enada is the activated version of niaci-



namide or NAD. NAD is an essential part of the mitochondrial package and considerably less expensive.

- **Cocktails of Low Dose Antidepressants and Treatment of CFS.** At the British Society for Allergy, Environmental and Nutritional Medicine meeting in April 1998, Dr David Smith presented his views on the treatment of CFS using cocktails of low dose antidepressants. His theory is that CFS patients have low levels of neurotransmitters across the board, namely acetylcholine, noradrenaline, adrenaline, dopamine, GABA, serotonin and probably others. It is this which causes the multiplicity of symptoms including fatigue. He has concluded from his studies and his experience with patients that the fatigue in CFS is central – that is to say the cause is within the brain. These abnormalities are within the mid-brain, thalamus and hypothalamus and are neurological in origin. I tried these cocktails for several patients, but they just developed the side effects that I see in most of my patients with any one antidepressant. I was not impressed by this approach and would not particularly recommend this line.
- **Fludrocortisone.** The idea here (Dr David Bell) was that the fatigue in CFS is caused by low circulating blood volume and low blood pressure. He certainly demonstrated that this was the case and is probably due to autonomic disturbance. The question is what can one do about it? In theory by using a mineralocorticoid blood volume could be increased. In practice I found that the fludrocortisone simply caused swollen ankles and the blood pressure was unchanged.
- **Heparin by injection.** Work by Dr David Berg suggests CFS may be caused by being in a state of hypercoagulability – this means CFSs get tiny clots in their capillaries which impair blood supply. This would certainly explain the multiplicity of symptoms in CFS and theoretically could be treated by heparin injections. I've tried these in 4 patients with no success. ☹

*Dr. Sarah Myhill is a UK-based specialist in fatigue-related illnesses and has worked in healthcare for over 20 years. Reprinted with permission.*

# How your doctor can help if you have CFS/ME

By **Charles W Lapp, MD.**

*Editor's Note: Dr. Lapp, Director of the Hunter-Hopkins Center in Charlotte, is one of the few CFS specialists in the United States.*

TALKING POINT – 2009 ISSUE 1

If you are not able to access a provider who is expert on CFS/ME, your next best bet is to find a doctor who is empathetic and willing to help. This person may be your existing primary care doctor or someone else you find who either knows about CFS/ME or is willing to learn about it.

There are four ways your doctor can help:

1. Establish a diagnosis
2. Treat major symptoms
3. Treat other conditions that often accompany CFS/ME
4. Provide usual primary care

While your doctor's role is important, you should recognize that there is no known cure for CFS/ME, so there are limits to what your doctor can do. Medical treatment does not treat the disease; it only palliates the symptoms. Medical treatment will not even speed your recovery, but it will make recovery more comfortable. The key to recovery in CFS/ME is acceptance of the illness and adaptation to it by means of lifestyle changes, for which medical treatment is no substitute.

## Diagnosing CFS/ME

We at the Hunter-Hopkins clinic have developed materials for physicians to use to diagnose and manage CFS/ME. The Quick Start Guide provides all information needed to establish a diagnosis and rule out other possible causes for your symptoms. It is available at: [www.cfstreatment.info/quick\\_start\\_guide\\_for\\_practitioner.htm](http://www.cfstreatment.info/quick_start_guide_for_practitioner.htm). Similar material for diagnosing and managing CFS/ME is available at the website of the Centers for Disease Control (CDC): <http://www.cdc.gov/cfs/toolkit.htm>.

## Treating Major Symptoms

There is no known cure for CFS/ME, so currently the goal of treatment is to reduce those symptoms that make your life miserable. Top among these are

sleep disruption, fatigue, and pain. The treatment recommendations below also apply to fibromyalgia, with the qualification that people with “pure” FM (minimal fatigue and cognitive impairment) usually tolerate higher levels of exertion and can push somewhat harder.

## Treating Sleep

Sleep problems of PWCs [People with CFS] include difficulty falling asleep, difficulty staying asleep, restlessness at night, vivid dreams, and – most importantly – non-restorative sleep. Whether you sleep 4 hours or 14 you probably will not awaken feeling refreshed. CFS specialists agree that sleep is THE most important symptom to address. Poor sleep has widespread effects. Treating sleep can improve quality of life and reduce other symptoms.

The first principle for improving sleep is to practice good “sleep hygiene.” This includes: (1) using your bed for sleeping only; (2) avoiding stimulant foods and beverages at night; (3) keeping a regular sleep schedule by getting up every morning at the same time; (4) avoiding daytime naps (although short rest periods are

fine); (5) not watching TV or using a computer in the bed at night (instead, try reading, soft music, or relaxation tapes); and (6) hiding the clock from view. Another practice that is often very helpful is to have a “wind-down period” before going to bed. Beginning about an hour before you want to retire, change your activity level and environment.

If you have frequent sleep problems, consider a simple over the counter sleep aid such as diphenhydramine (Benadryl™ 25-50mg), Tylenol PM™, melatonin (3-9 mg 2-3 hours before bedtime), or doxylamine (12.5 to 25mg), which is the sleep-inducing agent in “Nyquil.” Sometimes herbal sleep aids (which usually contain valerian, chamomile, passion



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flower, or similar) can be helpful.

If your sleep problem is resistant to such simple remedies, talk to your doctor about prescription medications such as zaleplon (Sonata™), eszopiclone (Lunesta™), or ramelteon (Rozerem™) to help you fall asleep. If you have trouble staying asleep, however, ask your doctor to add 5-10mg of cyclobenzaprine (Flexeril), 2-8mg of tizanidine (Zanaflex™), 2-25mg of doxepin elixir, 10-50mg of amitriptyline (Elavil), or 25-50mg of trazadone (Desyrel). The latter is favored because it has the fewest adverse effects and actually increases the depth of deep sleep.

Zolpidem (Ambien™) and benzodiazepines like Restoril™, Dalmane™, ProSom™, and Ativan™ are not generally recommended because they may be associated with sleepwalking and amnesia or may actually interfere with deep sleep, respectively.

If these measures do not help your sleep problem, ask your doctor for a referral to a good sleep specialist. These experts can recommend more powerful sleep aides, but they can also check for sleep apnea and other serious sleep disturbances. Sleep disorders are present in over 60% of PWCs, but are frequently overlooked by the primary physician.

## Treating Fatigue

Fatigue is extremely hard to overcome. Self-help techniques are frequently effective. Perhaps the most important is pacing, which involves honoring the body's limits and balancing activity and rest. Also helpful are relaxation and other stress management strategies, modest exercise to counteract deconditioning and checking medications for the side effect of sedation.

Stress and blue mood also draw down neurotransmitters in the brain that can interfere with sleep, cause irritability, and magnify both pain and fatigue. For this reason, we frequently recommend a trial of a low dose stimulating-type antidepressant -- not so much for anxiety or depression as to replace those necessary brain chemicals! Favorites include 5-20mg of fluoxetine (Prozac™), 50-150mg of sertraline (Zoloft™), 30-60mg of duloxetine (Cymbalta™), or 150-300mg of bupropion (Wellbutrin™). Bupropion has the fewest side effects and is most activating; but duloxetine is very effective when both depression and pain are problems together.

If you are sleepy during the day (that is, you fall asleep reading, watching TV or riding in the car), then a stimulant medication might be in order. Have your doctor consider modafinil (Provigil™) at 50-200mg each morning to help you stay more alert and focused. Another possibility would be amphetamine salts (Adderall™) at 5-20mg each morning or methylphenidate (Ritalin) at 5-20mg each morning, if your doctor is comfortable prescribing these medications. Remember, stimulants are only helpful if you have excessive sleepiness, not just tiredness or fatigue, which is common to all PWCs.

## Treating Pain

Short of anesthesia, there is no drug that will totally alleviate the pain of CFS/ME or FM, so the first step in pain management is the recognition that you will probably always have some pain.

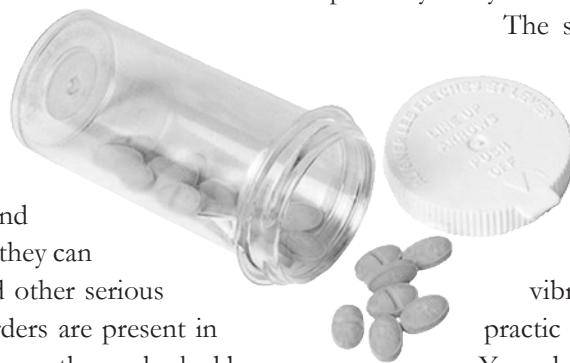
The second step is to employ non-pharmacological therapies such as cool packs, hot packs, liniments (such as over-the-counter Deep Heat, Icy Hot, Aspercream, etc.), warm tub or shower soaks, massage, a vibrating massager, perhaps chiropractic treatment or even acupuncture.

Your doctor could consider prescribing a TENS unit or a muscle stimulator, both of which are available on the internet for very reasonable fees.

Pharmacologically, see if you can manage pain with over-the-counter products such as acetaminophen (Tylenol™ and others), ibuprofen (Advil™, Motrin™, and others), naproxen (Aleve™ and others), magnesium salicylate (Dones Pills™) or aspirin. Your doctor will need to be sure you don't use too much, and he/she will need to check liver and kidney function regularly if you use these medications.

Non-narcotic medications that can markedly reduce pain should be tried next, if needed. These include duloxetine (Cymbalta™), which can be especially helpful if pain and depression run together; gabapentin (Neurontin™); or pregabalin (Lyrica™).

Failing other pain control methods, tramadol (Ultram™, Ultracet™, and others) is the next best choice because it provides codeine-strength pain relief but is well tolerated and is thought to have little or no addiction potential. Doses of up to 100 mg four times daily can be used (although an overdose condition called



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“serotonin syndrome” can occur if you are taking certain antidepressants or other drugs).

Narcotic medications are generally not recommended for chronic pain unless absolutely necessary. If you need narcotic-level pain relief your doctor will probably refer you to a pain specialist.

Pain in the lower back can be improved with chiropractic treatment or physical therapy in some cases. Localized heat, liniments, and over-the-counter analgesics such as ibuprofen, naproxen, or magnesium salicylate may also help. Lidoderm Patches can be extremely helpful. You can cut the patches to an appropriate size and apply them to the areas of localized pain.

## Treating Related Conditions

Most persons with CFS/ME have additional medical conditions that we refer to as “overlap syndromes” or “shadow syndromes.” Probably the most common is fibromyalgia. A majority of people diagnosed with CFS/ME also meet the diagnostic criteria for FM. Besides fibromyalgia, the most common overlapping conditions are:

- Irritable bowel and irritable bladder
- Temporomandibular joint disorder (TMJ)
- Migraine headaches
- Restless leg syndrome (while awake) or periodic leg movements (during sleep)
- Sleep apnea
- Vasomotor (autonomic or non-allergic) rhinitis
- Digestive problems such as gut motility disorder with trouble swallowing, early satiety, nausea, and/or constipation
- Autonomic dysfunction with low blood pressure
- Multiple chemical or food sensitivities
- Gluten (wheat or grain) intolerance or celiac sprue-like symptoms
- Lactose (milk) or fructose (fruit sugar) intolerance
- Orthostatic symptoms or fainting
- Dry eyes and mouth (sicca complex)
- Vulvodynia or vulvar vestibulitis (vulvar / vaginal pain)
- Joint hyperlaxity (hyperextensible or “trick” joints, frequently associated with low blood pressure and autonomic symptoms)
- Metabolic syndrome (a pre-diabetic condition characterized by elevated blood sugar and triglyceride levels, a protuberant or pear-shaped abdomen, and insulin resistance)

Your doctor probably already knows how to han-

dle these problems, if present. Just ask him or her to address them ... but one at a time!

## Four General Treatment Rules

In considering drugs and other treatments, there are four general rules that your doctor must know:

1. PWCs are extremely sensitive to medications (especially sedating ones), so your doctor should start with low doses and increase slowly. Start low and go slow!
2. CFS/ME and FM are very complex conditions and may require multiple medications to address the numerous symptoms. This “rational polypharmacy” is not unusual or unexpected, and should not deter your doctor from helping you.
3. Your doctor may have to replace medications periodically, since it is not unusual for PWCs to develop tolerance to medications.
4. No medication works for everybody, so you and your doctor will probably have to experiment to find what works for you.

## In Conclusion

Even though there is so far no cure for CFS/ME, there are many treatments. The most important is acceptance of the illness and adaptation to it. Good medical care can play a role. While it cannot cure CFS/ME, medical care can help alleviate its symptoms and further reduce suffering by treating other medical problems. ❀

Reprinted from *The CFIDS & Fibromyalgia Self-Help Program* ([www.cfidsselfhelp.org](http://www.cfidsselfhelp.org)).



# Virus is passed from parent to child in the DNA

By **Maggie Fox**, Health and Science Editor, Reuters, 2 September 2008.

WASHINGTON (Reuters) – A virus that causes a universal childhood infection is often passed from parent to child at birth, not in the blood but in the DNA, US researchers have found.

They found that most babies infected with the HHV-6 virus, which causes roseola, had the virus integrated into their chromosomes. Not only that, but either the father or mother also had the virus in the chromosomes, suggesting it was a so-called germ line transmission – passed on in egg or sperm.

“This is really a unique mechanism for congenital infections,” said Dr. Caroline Breese Hall, a pediatrician at the University of Rochester Medical Center in New York who led the study published in the journal *Pediatrics*.

Her team is now investigating what this means for the children.

“If you have a chromosome that has got a virus integrated into it, what does it mean? What does it do? Can it activate again? Can it start spewing out virus and cause problems? Can you get an immune response to it?” she said in a telephone interview.

The questions are critical because nearly everybody is infected with HHV-6. It is a herpes virus that can cause roseola – an infection marked by high fever and the usual vague virus symptoms that may include respiratory or stomach problems.

About 20 percent of children also have a characteristic sudden rash that appears just as the fever breaks.

Hall’s team studied 250 infants, 85 with HHV-6. Of those infants, 43 were born with the virus and 42 were infected later.

Most of the babies born with the virus – a congenital infection – had the virus in the chromosome. Hall

said the assumption had been that the virus somehow crossed the placenta from the mother to the child but in 86 percent of cases, it was inherited directly in the genetic material.

Just 14 percent were infected across the placenta.

Tests showed either the mother or the father – but not both – also had HHV-6 in the chromosomes.

“Because we know a parent already had the virus in the chromosome, we know that it didn’t spontaneously wiggle its way in once the baby got it”, Hall said.

There were several spots where the virus integrated into the DNA, but usually right at the end of the chromosome, where a key structure called the telomere is found. Telomeres protect the chromosome and are involved in aging and immune response.

The virus is everywhere in people who inherit it, Hall said. “In your hair, your nails, your skin, your blood, and at very high titers (levels),” she said.

The babies infected this way did not appear ill but Hall wants to follow them as they grow up to see if they develop normally. They all had antibodies to HHV-6, which is evidence of an immune reaction of some sort.

Other viruses are known to integrate into the DNA and pass on from parent to child, but these so-called human endogenous retroviruses have never been known to cause symptoms or activate an immune response.



*Comment from Medical Editor, Nicole Phillips: This is fascinating information and may provide clues into cases of familial transmission of ME/CFS.*



# Taking action helps defeat negative emotions

By Sally Price.

After years of dealing with arthritic pain and fibromyalgia, Nancy Fortner has become an expert in turning negative emotions into positive ones. Instead of looking for or expecting big changes in her life, she has learned to congratulate herself on the small victories.

When she feels angry or frustrated about her physical limitations, Nancy focuses on aspects of her life where she has taken control and made life easier. "It takes discipline," says the 60 year old Rio Vista, California resident, "but it pays off."

Nancy recalls when she began a computerized sign business in order to help her husband take an early retirement. "I soon realized that I had been in denial about my illness," she says, noting that severely increased symptoms forced her to give up the business. "I felt guilty about it," says Nancy, "but instead of blaming myself for no longer doing it, I started congratulating myself for having done it at all."

Another time the mounting clutter in her home discouraged her from inviting friends over, increasing the social isolation that often occurs with chronic pain. She says, "I was blaming myself and saying, 'Oh, you're just lazy.'"

Instead of dwelling on negative emotions, Nancy searched for one small area she could improve, and found her bathroom vanity. "In a moment of insight I realized that I don't use these things every day," she says, and resolved to keep the vanity clear. Feeling encouraged by that success, she slowly worked through the whole house, gradually disposing of things she didn't use daily. She disciplined herself to keep the areas clear of clutter, and adopted neater habits, such as sorting the mail right away. In time, she had an organized house, a happier husband, and a solution to what seemed an overwhelming problem.

"I congratulated myself because these are household chores I'm still able to do; chores I don't have to ask my husband to take over for me," she says. "It does much to improve my mood – and his, too – to come home to a clean house every day."

## Turning Negatives Into Positives

Keeping on top of negative emotions so they don't overtake us is especially important for people with chronic pain. If stressful feelings aren't dealt with, they can increase our pain, and decrease our ability to manage the pain. As Nancy says, "Everything is interactive. If I have bad pain it tends to bring my emotions down, and it works the other way too."

Her daily strategy is to find interesting things to do, "so I don't think about the pain," she says. A creative person, she turned to painting and pottery making when she had to give up her teaching job. When the osteoarthritis in her knees made it too hard to stand at an easel or sit at a potter's wheel, she started making jewelry from semi-precious stones, a hobby she continues today.

When her circumstances changed, Nancy didn't bemoan the fact that she could no longer do something that she loved. Instead, she would congratulate herself on finding something she still could do. It made a lot of difference in her moods, she says.

Nancy is familiar with the damaging effects of negative emotions from her childhood. "I had a lot

of anger. My parents divorced, my mother died, and each sibling was adopted by different relatives, and raised separately. There were other events that came up later in my life. I realized that this anger was doing me harm. It was zapping my energy," she says.

When she realized that holding onto anger was only hurting her, she was able to release it. Living in the present also helps to deal with pain and fear. I realize there's nothing I can do, so I redirect (myself) to today," she says. "If we live in the past or are always looking at the future, we're missing what we have, and that's the present."



Continued from previous page

## Alternative Ways to Deal With Pain

Meditation also helps Nancy deal with her emotions and pain. She says, "I meditate two times a day for 15 minutes with my eyes closed. I try not to think of anything. I sort of blank out and go into a state of deep relaxation."

Getting regular gentle exercise also helps, Nancy says. She swims laps and does aqua aerobics several times a week. "If I start feeling my mood kind of low, I start moving my muscles in some way," she says, recalling how taking long walks helped her through the intense grief of losing a sister.

Reaching out to other people is another wonderful antidote to a depressed mood. When she wasn't able to get to meetings of the various ACPA groups she had started, Nancy found help from online support groups. She is currently a trained moderator for courses offered on the CFIDS/Fibromyalgia Self-Help website ([www.cfidselfhelp.org](http://www.cfidselfhelp.org)).

Nancy is not one to sit and stew in her emotions. She looks for solutions. When learning to use a C-PAP (Continuous Positive Airway Pressure) machine for her sleep apnea, she became intensely frustrated, so went to a psychologist for help with her emotional state.

When she encountered stiff joints after sitting, a solution came to her at a concert. She felt much better after "swaying to the music." So now when sitting for a prolonged time she tries to move slightly, "like rocking a baby," she says. "I praised myself for coming up

with another idea for handling my pain." Nancy has learned how to take control of the little things she can control and not get hung up on big solutions. "When you have a chronic illness you are not going to make it all better."

Another little thing that has been a big help is to rest before she gets tired, something most people with fibromyalgia don't do. "Usually they push themselves until it is too late and they get a flare," she says.

Nancy says her biggest obstacle to dealing with her feelings was her belief in the "shoulds." "I was a very conscientious, hard-working person. I had to learn that a job that wasn't done perfectly was still valuable," she says. "I also had to learn to delegate, and if others didn't do it my way, that's still okay."

Nancy focuses on the benefits of chronic pain, like finding pleasure in a quadruple rainbow or her two dogs. "People think it's amazing to see me in an electric scooter with two dogs on leashes," she says with a hearty laugh.

Her pain has helped her be more aware of other people, she says. "Dealing with suffering has made me feel more a part of the human race. It helps me if I think, 'how would I feel toward someone in the same situation [as me]?' I would be very sympathetic. So why don't I do the same with myself?" ❀

*Reprinted from The CFIDS & Fibromyalgia Self-Help Program ([www.cfidselfhelp.org](http://www.cfidselfhelp.org)). This article originally appeared (with permission) from "The ACPA Chronicle," the magazine of the American Chronic Pain Association ([www.theacpa.org](http://www.theacpa.org)). Nancy Fortner is a moderator for the CFIDS/FM Self-Help program.*



### Excerpts from "A Dog's Life"

(From: *Voice of the Seniors* No. 77, Aug 2008, p 9 and reprinted in the Wollongong ME/CFS/FM Support Group Newsletter)

If a dog was the teacher you would learn stuff like:

- Take naps every day.
- Stretch before rising.
- On warm days, stop to lie on your back in the grass.
- On hot days, drink lots of water and lie under a shady tree.
- When you're happy, dance around and wag your entire body.
- Be loyal. Never pretend to be something you're not.
- When someone is having a bad day, be silent, sit close by and nuzzle them gently.

# The first federally approved drug for ME/CFS?

By **Cort Johnson**.

## Ampligen

There can't be many more frustrating subjects than Ampligen. Chronic fatigue syndrome (ME/CFS) advocates hoped that the FDA would 'fast-track' Ampligen twenty years ago and yet its fate is still in limbo. At the 2007 IACFS/ME conference Ampligen representatives seemed excited over their chances at the upcoming FDA review. Ampligen did not, however, pass muster and the FDA, citing numerous problems, kicked the application back to the company.

What is it with Ampligen? We know Ampligen works very well and has even been something of a lifesaver for some patients. Federal advisory committee (CFSAC) members were recently treated to impassioned testimony from a man with CFS and his wife regarding his decline after he had to stop Ampligen. Annette Whittemore's daughter and Mary Schweitzer are two prominent figures who've benefited greatly from Ampligen. Yet here we are 20 years later and this drug is still available only to study participants. What's going on here? Is it the FDA? Is it the company? Is it the drug?

It's probably everything but in this case we are indeed unlucky in our friends. Hemispherx has been embroiled in financial intrigues and lawsuits for much of its existence. The founder of the company is a hard working but at times very contentious eighty-something figure who some believe might have done the drug better by remaining more in the background.

Why was Ampligen's latest (last?) bid rejected? The FDA said it was missing information. Apparently the information was there but it was in an unusual format that the FDA had trouble understanding; Ampligen has been in the works long enough that Hemispherx has been stuck using an old statistical package the FDA was not familiar with. Due to the long time frame, Hemispherx is also reportedly stuck using the old Holmes definition chronic fatigue syndrome (ME/CFS). Questions have also been raised whether they're measuring the right endpoints and why different study sites reportedly had very different success rates... Despite all these questions Hemispherx appears to remain quite optimistic about Ampligen's future.

## Good News

Dr. Carter almost oozed confidence in a recent conference call on Ampligen's prospects. The FDA accepted Hemispherx's revision and will make a determination on the drug's suitability for chronic fatigue syndrome (ME/CFS) probably in the first half of 2009.

According to Dr. Carter, just getting past the first round with FDA was a huge step. The FDA is now taking a very hard look at drug applications early in the process – if a drug survives that scrutiny, Dr. Carter reported, it has an 80 percent chance of approval.

## Filling a Hole

Ampligen also gains points with the FDA because it is categorized as filling an 'unmet need'. (Yes 'need' does seem to register with at least one government agency – would that it would with others.) The FDA does care enough about underserved diseases to give drug companies something of a break when they build a drug for one. That 'unmet need' reportedly gives Ampligen another 10-15% boost. (Could we really be talking a 90-95% chance of approval?)

## A Safe Drug

Dr. Carter believes Ampligen has some other aces up its sleeves. The FDA is very interested in immune stimulation but is scared to death of approving an immune enhancing drug that pushes immune performance to the point where a monster – an autoimmune disease – is created.

## The Fading Question of Legitimacy

Another point in Ampligen's favor is the increasing legitimization of the disease. Having the head of the Centers For Disease Control (CDC) stand up at a national press conference and publicly state that this is a real, serious disease apparently really did open many people's eyes. The CAA's media campaign also provided a substantial boost. (Indeed it's difficult now to find a mainstream website that does not treat this disease respectfully).

# Get a better night's sleep

By **Elisabeth Deffner**. This article was originally written about fibromyalgia.

We all know that sleeping troubles go hand-in-hand with fibromyalgia. But did you know there are some simple ways you can help yourself ease those troubles? Try these tips, straight from the FM patients who have benefitted from following them.

- Check your sleeping surface. At a friend's suggestion, Susan Kuske of Eagan, Minnesota, replaced her 20-year-old mattress with a new one that had extra padding. It has "helped significantly for morning stiffness." Mattress pads have proven helpful for some patients, too. Heated pads are also available.
- Consider a sleep study. Maybe your difficulty sleeping is simply part of your FM symptoms – but maybe the trouble stems from a different disorder altogether, like sleep apnea. Pinpointing the exact cause of your sleep troubles, and the ways they manifest themselves, will make it easier for you to manage them.
- Talk with your doctor about medications that may help – and try doing some homework beforehand. For instance, Paula Reid takes melatonin, a naturally-occurring hormone that regulates the wake-sleep cycle. "I do not only take the melatonin during the evening for retiring, but also during the daytime," she says, "and find that it is helpful to some extent with the pain."
- Set up the bedroom for sleep success. Make sure to eliminate sources of light – not just lamps, but also television screens – that may be cuing your brain to stay awake. Try an eye-mask, earplugs, or a sound machine that plays ocean waves or birdsong for extra assistance in blocking out disturbances. Lila Peck sprays her bedding with a linen spray she makes herself, scenting the sheets with lavender and sandalwood to help her fall asleep.
- Pay attention to what you're paying attention to! Does the nightly news make you feel anxious or sad? Consider getting your news from a different source earlier in the day. Do crime dramas tense you up? Try eliminating them for a while.
- Exercise. FM patients are used to hearing about the benefits of exercise – but you may not realize it can also help your sleeping patterns. Studies indicate that moderate exercise helps improve quality of sleep. "I walk at least 30 minutes a day and feel that it is an important factor overall, but also for sleep," says Kuske. "I often use my break at

work to walk. Clears my head and helps my body!"

- Maintain a consistent sleep schedule. Try to go to sleep at the same time every night, and to wake up at the same time every morning (even on weekends!). This will get your body into the habit of resting during those same hours each day.
- Eliminate caffeine, alcohol, and other stimulants including tobacco.
- Develop a bedtime routine. Kuske likes to read the Bible or another book with a positive message before she goes to sleep. Other patients may play relaxing music or make lists of things they are grateful for. Using a self-massage machine, or getting a massage from a loved one, can also make it easier to relax and fall asleep.
- Margaret McGing recommends keeping a "sleep journal." "Include the times you go to sleep, wake up, what you ate/drank that day, when you ate/drank, when/what forms of exercise [you did], and record how often and what times you might wake up during the night," she suggests. Yes, it's tedious – but very helpful to a neurologist if one should continue to have problems and seek help," she says.
- Restrict your daytime napping. Even if you feel tired, try to nap for only 20 minutes or so – otherwise when it's time to hit the hay that night, you may have trouble falling asleep. ❀

Reprinted from FMAware.



# The Whittemore-Peterson Institute comes out of the closet

By **Cort Johnson**.

*"I believe that the Whittemore Peterson Institute is the beginning of new hope for the millions who suffer from neuro-immune diseases such as ME/CFS, fibromyalgia, atypical MS and other similar diseases that have a life long impact on both the immune system and the brain of those afflicted."*

— Annette Whittemore, President of the Whittemore Peterson Institute For Neuro-Immune Diseases

They said they'd be different, that they'd be filling in gaps in the research agenda and that it was time for a fresh approach to this disease ... and they weren't blowing smoke. The Whittemore Peterson Institute (WPI) website is up and this organization is different.

## ME/CFS

The first hint of something new came in the 'About Us' section. Chronic fatigue syndrome is gone! Instead there's this disease called 'ME/CFS' and what a change that is; instead of that fatigue word staring you in the face there's just ME/CFS – a symbol for a difficult disease, nothing more.

It's actually a bit jolting to see ME/CFS dot a professional organizations website and it's probably intended that way; the WPI, after all, is not focusing on chronic fatigue syndrome. The disease they're studying – called 'ME/CFS' – appears to bear little resemblance to the chronic fatigue syndrome our federal agencies are studying.

## Frequently Asked Questions: Very Different Answers

The WPI's conception of this disease really begins to emerge in the FAQ's.

**A Different Definition** – The diagnosis section refers not to the CDC produced International Definition but to the Canadian Consensus Definition (CCD) – a startling change for an organization of this prominence. The CCD with its tighter diagnostic parameters and its emphasis on post-exertional malaise has been a big hit with many researchers but the WPI is the first prominent Research Institute to specifically endorse it.

**A Contagious Disease** – Similarly it's almost become dogma that ME/CFS is not infectious but the researchers at the WPI aren't so sure. When asked if the disease is contagious the WPI, citing various 'outbreaks' and several pathogens that may be associated with the disease, simply says "Quite possibly".

**New Prevalence Figures** – How many people does this possibly contagious disease with a new name and definition strike? In what appears to be a dig at the CDC's latest figure of 4 million Americans with CFS – which was based on their controversial Empirical Definition – the WPI states 4 million people worldwide have ME/CFS.

**Prognosis** – Most ME/CFS experts say full recovery is rare and the WPI agrees but the general consensus seems to be that many if not most ME/CFS patients do get better over time. Here the WPI goes its own way, rather startlingly stating that the vast majority of ME/CFS patients, fully 80% of them, "do not get better" over time.

## A New Emphasis Indeed

A possibly contagious disease with a different definition, a different name, different prevalence figures and different outcomes? The WPI has not pulled their punches on their website; this disease – this 'ME/CFS' – is different from what we're used to seeing portrayed by professional organizations.

## A True Research Center

The rubber really meets the road with the research component. In order for the WPI to make the difference they want to make they're going to have to do research and lots of it. Building a building is one thing but raising money for a strong research program is a much more nebulous enterprise. Could they do it?

The answer appears to be an emphatic yes. The WPI lists 14 ongoing research projects – the same number as the NIH did in 2007 – suggesting that their effort may be on par money wise with the NIH, CDC and Japanese efforts. It clearly dwarfs any other research programs on ME/CFS.

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This isn't your ordinary bag of research projects either; for one thing they're completely focused on the immune system (no 'neuro' projects yet). Not surprisingly a significant number of projects focus at better elucidating the pathogenic component of ME/CFS (HHV-6, enterovirus, HCMV) but the biggest focus is on elucidating the immune problems (cytokines, RNase L, NK & T cells) these researchers clearly believe play a big role in this disease.

One particularly interesting study will try to determine why some patients respond to Valcyte and other anti-virals and others do not. Another seeks to uncover the immune imbalances that may be allowing chronic infections to persist. Another involving enteroviruses with its emphasis on 'leaky gut' appears to be piggybacking on Dr. Chia's work. Two are examining a possible cancer (T-cell lymphoma) subset. Two more are searching for biomarkers.

## A New Player in Town

Thus far everything we've heard from Annette Whittemore about the WPI is true. With its focus on a new name, a different definition and a different research slant – the WPI clearly aims to shake up the CFS research world. ME/CFS is a complex disease that has not yielded its secrets easily and it'll take time to tell if their new approach will pay off. In the meantime one can only admire and applaud the Whittemores' and Dr. Peterson's determination to bring this facility to fruition. As federal programs decline its nothing short of astonishing to see an Institute of this size (focused on this disease!) spring up almost overnight. ☘

*Reprinted with permission. This article originally appeared in Cort Johnson's newsletter, Phoenix Rising.*

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The federal advisory committee on CFS (CFSAC) gives Ampligen another arrow in its quiver. It's been stated before but it's true (and rather startling) that while the NIH has over a hundred advisory committees only a handful are focused specifically on one disease and CFS is one of them. (How did that happen??). An FDA representative sits on the CFSAC panel and he interacts with ME/CFS physicians on the panel, some of whom have been involved in the Ampligen trials. He also hears the patients' stories – some of which have concerned their relapses after being deprived on Ampligen. His presence on the panel can only help.

## Insurance

Ampligen is expensive, expensive enough that one wonders if insurance companies would be willing to pay for it. But even here Dr. Carter had good news. He reported that Hemispherx has studies showing that because chronic fatigue syndrome (ME/CFS) patients on the drug require fewer doctor's visits, hospitalizations, etc. that if insurance companies commit to this drug their costs should go down, not up; i.e. ME/CFS patients on Ampligen will cost their insurance companies less.

## Length of treatment

Dr. Carter said they were working very closely with the FDA about 'labeling'. Despite having done studies of all sorts of different lengths (6, 20, 40, 75 weeks) he couldn't give a hard and fast time about how long a patient would have to be on the drug. Patients with a more severe illness or who've had the disease longer might need to take it for longer periods. He said the length of treatment would be a 'doctor-patient' decision.

## Approval?

Only 16 drugs were approved in all of 2007. Will Ampligen join that select club? Will the first FDA approved drug for ME/CFS be an immune modulator? FDA approval of an immune enhancing drug would cause many in the medical establishment to reassess their ideas about the disease and, of course, help ME/CFS's legitimacy. Have the stars aligned for both Ampligen and chronic fatigue syndrome (ME/CFS)? We'll know within the next six months. ☘

*Reprinted with permission. This article originally appeared in Cort Johnson's newsletter, Phoenix Rising.*

# Swimming in the ocean

By **Glynis Scrivens.**

*“You’re too young to be living like this,” I was told yesterday by a very well-meaning niece. My social armour had slipped and allowed in a chink of light to give her a glimpse of what it means to live with ME/CFS.*

What does a holiday at the beach mean to you? I always benefit from the sea air and the refreshment that change brings. Access to shops is so much easier too. My husband can usually park right outside them, something often not possible in the busy inner city of Brisbane where I live. Life moves at a slower pace at the beach so people like you and I don’t stick out like sore thumbs there.

Anyway, my niece simply asked if I’d gone swimming in the ocean every day while I was there. Well, maybe in my dreams that might still be possible – but inside this body of mine at this time of year? If only!

*(Editor’s Note: This article was written last Spring.)*

My body slumps every year from August to November. No doctor has found a reason for this other than springtime hay fever or a virus. It’s not in their textbooks, is it? Yet it happens as regular as clockwork. I’ve read in quite a few books that a regular annual slump is common with ME/CFS but this knowledge seems to be confined to sufferers.

A slump – and swimming in the ocean – the words don’t belong in the same sentence do they?

During my holiday I sat on an embankment every day watching the ocean and wishing with all my heart that my legs were strong enough to get me in there for a paddle. There was a chicken hawk arcing above the cliffs and plenty of holiday makers swimming between the flags. One day the surf was so flat that the ocean looked like an enormous lake. That day nobody bothered swimming. Instead, about a dozen people rowed about in all manner of small boats. How I longed to join them.

My best effort was to walk as far as the fine dry sand on the main beach one day and sit there – and I did manage to put my feet in the ocean.

We drove to Mooloolaba and found an access point between dunes where there was a reasonably short flat walk. And it was high tide, saving me long stretches of wet sand to negotiate. Our local beach at Coolum has a steep slope which I can only manage during my better periods and, if it’s low tide, there’s a vast expanse of sand.

Perhaps mistakenly I told my niece that I’d put my feet in the ocean at Mooloolaba and that it’d felt abso-

lutely wonderful. I guess I was trying to point out that it’s not for lack of motivation. There was a tone in her voice that made me feel defensive.

What followed was a conversation we’ve all had, and it can leave you feeling very flat and misunderstood.

*“This business about you not being able to walk to the ocean,” she began. “You need to work on this. Start with baby steps, and walk a bit further every day.”*

If only it were that simple. Does nobody remember that I was an athlete? I do know how bodies are meant to function and for quite a long time I tried to make mine conform. But ME/CFS doesn’t follow the usual rules, does it?

I didn’t have an answer for her. I regularly read articles about what we’re supposed to say in these circumstances but, when faced with one of these pep-talks late in the day when I’m tired, my heart just sinks. I hope you’re tougher than me.

The conversation followed the usual pattern. She kindly pointed out that my body is deconditioned from lack of exercise. If I could only deal with that – by increasingly longer walks – I might find the underlying illness more manageable. The unsaid message here was that perhaps deconditioning was the actual problem.

Sound familiar?

I can see that my niece means well. I’m not sure I’d be any more understanding if the shoes were on the other foot and she’d succumbed to a weird debilitating malady that doctors regarded sceptically.

Some of the mud sticks. Just wash it off and keep going. This is our own private journey. Our bodies let us know what the rules are and they certainly let us know when we’ve broken any of them. Don’t waste energy trying to make other people understand. Save it for yourself.

Summer’s coming. My body’s always stronger in the hot weather. Come January or February I’m going back to the beach. This time I expect that I’ll be able to go for a paddle when the tide is full and cool myself in that amazing ocean that’s been tantalising me. It’ll be all the sweeter for having been earned.

Yes, I’m too young to be living like this but it wasn’t my choice. ❀

*Reprinted with permission from Emerge Autumn 2009.*



## Beautiful Big Red Balloons

by Christine Benson



*Gone are the days of confusion and pain  
When I suffered inside my head,  
Gone are the days I lay like death  
Buried deep within my bed.*

*Gone are the days when I fought for words  
Wrong ones coming out, back to front,  
When names hovered just out of reach  
Through my address book, I'd have to hunt.*

*Gone are the days when touch would so hurt  
And 'doing' was a dream for me,  
When collapse seemed ever close  
And quiet, things had to be.*

*Gone are the days of dreading the phone  
And when print defied my eyes,  
Of my head jammed under a cushion  
No-one aware of my silent cries.*

*Gone are the days of wrestling with life  
The 'nuts and bolts' all come apart,  
Gone are the days of ME-  
I've been given a brand new start!*

*Never give up hope of wellness  
Don't let defeat get a toe in the door,  
You cannot know what the future holds  
Of that, I'm very sure!*

*Rest when you must, just do what you can  
Choose your company with care,  
Welcome help and loving kindness  
Of trials, you've had more than your share.*

*I got well, why, so might you!  
There'll be answer one day, my friend,  
I implore you. You must believe  
ME will come to an end!*

*Then gone will be the days of troubles of pain  
When you suffered inside your head,  
And you, too, will take your leave, of life  
"Through a window," viewed from your bed.  
never give up hope of a new beginning  
I got one, so might you!  
Till then, go gently, take care  
And be kind to yourself, too.*

*God doesn't make mistakes  
There'll be a reason for your ME,  
And there'll be an answer, just right for you  
Just as one was for me.*

*So send beautiful big red balloons  
And pop them away in a drawer,  
You might want to celebrate some time  
When ME slips away, out the door!*



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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, neuro-cognitive, 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

### Clare Valley ME/CFS Support Group

Venue: 20 Beare St, Clare.  
 Contact: David Shepherd.  
 Phone: 8862 1665.  
 Email: dcshepherd@dodo.com.au.

### Northern Yorke Peninsula CFS Support Group

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

### Riverland CFS Support Group

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

### SAYME Support Group

Time: 7:30 pm  
 Date: First Friday of each month.  
 Phone: 0500 523 500 for more details.  
 Website: [www.sayme.org.au](http://www.sayme.org.au).

## 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	Andrea and Mark	8552 9857
Whyalla	Peter	8644 1897
Yorke Peninsula (central)	Caroline	8837 4335
Yorke Peninsula (northern)	David	8862 1668
Yunta	Gloria	8650 5938

### 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](mailto:pmrscott@tpg.com.au).

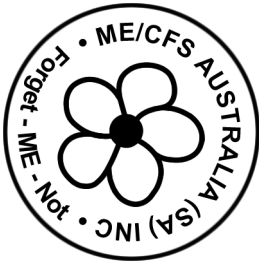
### Disclaimer

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.





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