

Talking Point

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

2008 Issue 2

*Your
Society*

forget-ME-not

Proudly Supported By:



OFFICE

Phone: (08) 8410 8929
Fax: 8410 8931

SUPPORT & INFORMATION LINE

City Callers (Mondays & Thursdays) (10am-4pm): (08) 8410 8930
Country Callers: 1800 136 626

www.sacfs.asn.au

ME/CFS Society (SA) Inc.

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

- promote recognition and understanding of the disease among the medical profession and the wider community.
- provide information and support for people with ME/CFS and their families.

Contact details

Any correspondence should be directed to:
ME/CFS Society (SA) Inc. PO Box 383, Adelaide, SA 5001.

Note: *It is our policy to ignore anonymous correspondence.*

The Society has an office:
Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.
At the time of printing the office hours are:
Wednesdays 10am to 3pm (subject to volunteer availability).
Ph: (08) 8410 8929; Fax 8410 8931.
Our email address is: sacfs@sacfs.asn.au.
Our Web site address is: www.sacfs.asn.au.

Membership

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

New Members (cheaper rates apply for renewal):

- Single membership.....\$38
- Single Concession\$25
- Family.....\$45
- Family Concession\$38
- Overseas – as above plus\$10

(Family membership is designed for families with more than one person who will directly benefit from the membership at the same place of residence. Family Concession applies when the main breadwinners are concession card holders.)

Notice to Vendors

The ME/CFS Society (SA) Inc. does not permit direct marketing of products to our members. This includes distributing promotional literature, providing demonstrations of products or approaching members at any of our events.

If you have information about products which you wish to bring to the attention of the Society, you should direct it to the Secretary, GPO Box 383, Adelaide 5001.

In particular, you should note that members give their contact details to the Society in trust and misuse of those is a breach of confidentiality. Any use of member information for direct marketing will be investigated and dealt with appropriately.

See notice regarding Advertising on page 3.

Management Committee – 2008/2009

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

- **President:** Peter Cahalan.
- **Vice-President:** (vacant)
- **Honorary Secretary:** Peter Mitchell.
- **Treasurer:** Richard Cocker.
- **Management Committee Members:** Lynda Brett; Melanie Cocker; James Hackett; Adrian Hill; Spen Langman; Emma Wing.

Patron

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

Talking Point

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

Editor: Peter Scott (pmrscott@tpg.com.au).

Assistant Editor: Judy Rhodes (dustyrhodes@dodo.com.au).

Donations

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

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

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



Disclaimer

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

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

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

Always consult your medical practitioners before commencing any new treatments.

Contents

4 Society matters

- 4 President's report
By Peter Cahalan
- 5 Talking Point: old issues
By Jenni Gay

6 Medical pages

- 6 M.E.: All in the Brain?
Interview with Dr Abhijit Chaudhuri

10 Articles

- 10 Travelling with ME/CFS
By Peter Mitchell
- 12 My Travels with ME/CFS
By Julie Gilbert
- 13 ME/CFS Awareness in Hospital
By Maureen Jepson
- 14 My Little Lucky Life
By Mary Edwards

- 16 Managing My Illness
By Mary Campbell
- 17 Book Review
By Barbara Seccombe
- 18 Do What You Can
By Glynis Scrivens
- 19 Society meetings for 2008
- 20 'Liar liar pants on fire!': Coping with Disbelief
By Val Rubie
- 22 Using Self-Help to Recover from CFIDS
By Bruce Campbell
- 26 Healthy Lifestyle Guide

30 Miscellaneous

- 30 Information about ME/CFS
- 31 Support groups
- 31 Contact numbers

Copyright

Copyright © 2008 ME/CFS Society (SA) Inc. Copies of articles copyrighted to the ME/CFS Society (SA) Inc. may be used by similar non-profit organizations if accompanied by clear acknowledgment of each item and the inclusion of the ME/CFS Society (SA) Inc.'s postal address PO Box 383, Adelaide South Australia 5001 and website address www.sacfs.asn.au.

Advertising

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

President's report

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

It's my pleasure to report to you on developments over the last few months.

Death of our most generous donor

For the last seven years our society – totally unsupported by government, unlike many disability societies – has been the beneficiary of an annual and untied gift of \$12 000. It came from a person with no known connection to ME/CFS and whom we came to call The Nice Lady – though we came to know that she was Miss J Miller. That was all we ever knew. But her generosity meant that the Society was able to stay solvent and to take a positive approach to building a stronger national Association and to supporting several research projects.

We were deeply saddened a month ago to hear that Ms Miller died in April. We have since been able to learn that she was

Joy Miller, born in Quorn, a devout Baptist who worked for her mother's family business Fricker Construction. She was a generous donor to a range of causes, of which we were lucky to be one. We salute her memory. We will benefit from a final bequest of \$5000 when her estate is wound up soon.

A new approach to sustaining our work

Several months ago, even before we found that the person who had provided us with over one third of annual budget had died, your committee started looking at ways to improve our sources of earned income. We have steadfastly kept subscriptions at the same level for years but this year had to raise them slightly. Nevertheless we resolved to keep the crucial single concession rate unchanged for yet another year.

So far so noble. But then how to fund the shortfall left between the roughly \$7000 we raise from our members and the roughly \$30 000 a year it costs us? We decided to try to exploit our greatest strength – our distinctively strong use of the new technologies to communicate to our members and to ME/CFS people around the world. So we're well-advanced now on sorting the technical details to enable us to set up an on-line store. We don't expect it to be a big money-spinner at first. But we do hope that it will build. And it will help us to learn by doing just what the com-

mercial potential of our excellent position within the global ME/CFS community is. Amongst other things, we've already been asked by one doctor if we'll sell a particular supplement which he recommends.

The online store, when opened, will introduce an interesting new phase for us. My own hope is that we can also use the internet to generate financial contributions from the many active users of our website who aren't members.

People can in fact already donate online to us. We are connected to Our Community, a national philanthropic body which acts as an umbrella fundraising conduit for charities of all sizes. If you check the top of our website home page you'll regularly see a small box appear which links you to www.ourcommunity.com.au. We receive \$20 a month from Our Community so clearly one or more people have decided to have small amounts automatically debited from their account and paid in to Our Community for sending on to us. Last month the figure jumped to a princely \$130. You can see that if more actively draw our web-readers' attention to Our Community, we might well be able to build a steady stream of financial support which in some way makes up for the loss of that wonderful annual gift of \$12 000 from one kind person.

The National Association cranks up

The ME/CFS Association of Australia ran out of puff during 2007. To be honest, we found ourselves embroiled in a somewhat fruitless but energy-sapping debate about whether 'CFS' should be got rid of. The view which I took, endorsed by the State committee, was that whatever the downside of the term 'chronic fatigue syndrome', we had more urgent things to do than to debate names. That also was the view of the majority of the Association's board. But the debate depleted the energies of a group of people who not only mostly run ME/CFS societies but all either have ME/CFS or are carers.

We were also affected by the resignation of our outstanding president, Simon Molesworth QC AM because of new and arduous business commitments. So things went quiet for a while. But we've got into gear again. We have a new president – our former SA president Paul Leverenz. Paul is simply amazing when he gets going and he's been energetically leading us into a renewed period of consolidating the national

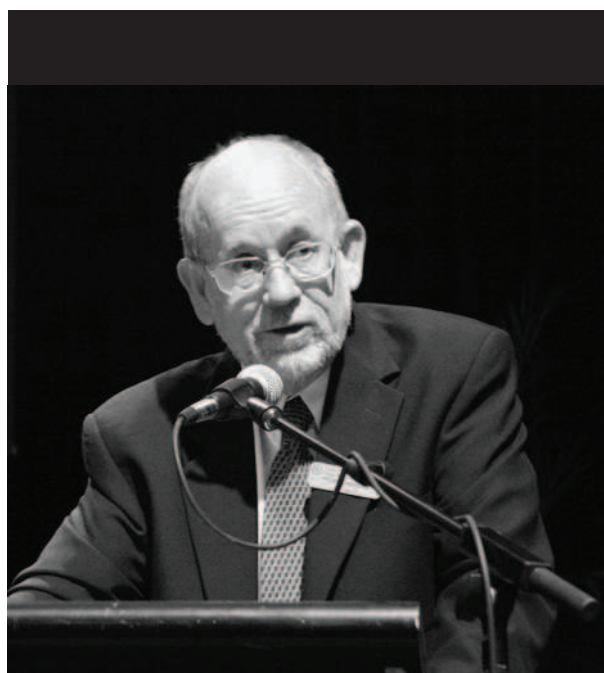
effort. He's supported very ably by one of our members, Jenni Gay, who has been assiduous in filling the role of company secretary. I'm a director and Peter Mitchell is my alternate when I can't participate in our regular teleconferences. So there's a strong SA presence on the board.

We are focusing efforts on strengthening our national website and working out how it links to State websites such as ours. We'll also be reviving discussion of whether we should move towards a national magazine. Several States now use the Victorian Society's *Emerge* as their magazine and this is something which we've discussed in the past with a lot of goodwill on all sides. Watch this space over the next year.

That's it for this quarter. On behalf of the great band of volunteers who work to sustain us as a community of positive and gritty people, I wish you improved health and spirits over the months ahead. Go well.

Peter Cahalan

President



Peter Cahalan

Talking Point: old issues

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

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

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

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

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

Please contact me:

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



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

M.E.: All in the Brain?

Glasgow-based neurologist **Dr Abhijit Chaudhuri** draws parallels between MS and M.E. – and explains why a new type of brain scan might shed light on previously unanswered questions... Interview by **Theresa Coe**. This article is taken from Action for M.E.'s InterAction magazine.

Tell us about your clinical experience – how did you come to be interested in M.E.?

Professor Peter Behan introduced me to the problem of chronic fatiguing disorders in neurology while I was working with him as a clinical lecturer. Fatigue symptoms in MS, Parkinson's disease and stroke are also remarkably similar to the fatigue experienced in ME/CFS. Like pain, fatigue is a complex neurological symptom. MS and ME patients both experience symptoms of focal and generalised fatigue that fluctuate and are influenced by physical or psychological stress and temperature extremes. The clinical similarities of fatigue and also the fact that both MS and M.E. may follow a viral infection stimulated me to take a special interest in M.E./CFS.

You're probably aware that some neurologists view M.E. as psychological rather than neurological...

I am aware of this view and think it is rather unfortunate. I say this because M.E. is classified as a neurological disease by the World Health Organisation and the disabilities in M.E. patients are comparable to those experienced by patients with chronic neurological diseases like MS.

I think the example of pain may be useful here because human response to pain has a behavioural component. Depending on how bad your migraine headache is, you may choose to work at a slower pace or go to a dark room and sleep it off. This is also true for fatigue.

But to dismiss fatigue as a largely psychological problem would be very similar to the rejection of the sensation of pain itself and to suggest that your migraine headache did not exist in the first place. This is a rather simplistic argument but I think the overemphasis on psychology and behaviour therapy in M.E. in the past has not really helped our understanding of chronic fatigue.

Their argument would seem to be that while with MS, you can see clear evidence of damage from brain lesions that gives rise to symptoms, there aren't any such clear markers indicating a neuro-

logical basis for M.E.

There is little evidence that the changes you get in MRI brain scans of MS patients are the markers of fatigue. There are papers to suggest that some M.E./CFS patients with more severe cognitive symptoms may have MRI brain scan changes showing small areas of increased signals. But the fatigue they experience is very similar to that of other patients who do not show these abnormalities. Conventional MRI brain scans in MS or M.E. therefore seldom identify the specific brain changes that may contribute to the genesis of fatigue.

I agree that there aren't at present any clear neurological markers for M.E., just as we do not have a 'painometer' to measure pain or any laboratory tests for migraine. However, neuroscience is advancing at an amazing speed and we are experimenting with newer types of brain scanning that were previously considered impossible in a living brain. We've only made progress in MS research by way of new brain scanning in the last twenty years. Before that, many MS patients were also considered to have a psychological cause for their symptoms. I think M.E. is a very young problem to neuroscientists – we're only just beginning to understand it.

Given the apparent similarities, can the field of M.E. benefit from research done on fatigue in MS?

Yes, I certainly believe so. Take the anti-influenza virus drug amantadine, for instance. This was noted as effective in Parkinson's disease and was then researched in MS patients to see if it could alleviate their fatigue. A good response was noted in about half these patients and amantadine still remains the best available treatment for MS fatigue.

My clinical experience suggests that it also helps a minority of M.E. patients at smaller doses. We have used a combination of low dose amitriptyline (an antidepressant) and amantadine with a degree of success in some M.E. patients but I don't think a randomised controlled trial has been done yet, which is a shame.

Similarly, a paper presented at last year's CFS conference in Seattle suggested that central stimulant

drug Modafinil (intended for narcolepsy but also effective in alleviating MS fatigue at 200mg daily) may be helpful in some cases of M.E./CFS – especially for those who continue to sleep in excess.

All these drugs are about symptom control rather than treating any underlying problem though, aren't they?

That's right. Unfortunately, this is also true of most chronic neurological disorders. We all know there is still no cure for M.E./CFS, MS or Parkinson's disease. As physicians, all we can do is try to treat the symptoms and improve quality of life with advice on lifestyle changes. In my experience, antidepressants are being used far more liberally in M.E./CFS than in other neurological conditions, with a false hope that they will work for fatigue even if the patient is not depressed or anxious.

But isn't there a difference with other chronic illnesses, in that some people with M.E. can improve or even recover?

I don't think there is ever 100% improvement in most adult patients if they have been symptomatic for over a year. What does happen is that some will get substantially better to a point where they may be able to continue with their normal daily activities. Most who will recover fully tend to be younger and do so spontaneously in the first one to two years after symptom onset.

Are there any neurological tests which may be useful in diagnosing M.E.?

Not yet. What you can do with neurological tests and other assessments is firstly exclude other conditions and then perhaps use them as a tool to aid understanding of the problem. It's very often a case of looking at the broad symptom complex. If you see someone with joint swelling and pain in addition to fatigue, for instance, you might check the blood for possible rheumatological problems. On the other hand, if your patient has fatigue and neurological symptoms such as balance problems, you might wonder if it could be MS. Quite a few MS patients talked about having 'M.E.-type fatigue' until an MRI scan showed the true cause of their particular set of symptoms.

Many M.E. patients can't understand why blood test results come back as normal when they feel so desperately ill. Why is this?

It's because what we test is based on what we already know and clearly we don't have sufficiently sensitive tests for M.E. There are some subtle abnormalities in M.E. patients, but nothing that is really unique to this illness. Put simply, fatigue in M.E. (or MS) is not due to an abnormality in immunity, liver, kidney or thyroid functions so these tests may all come back as normal. It's more likely to do with alteration in the level of brain activity. However, M.E. isn't the only condition where diagnosis needs to be clinical. Blood tests won't show a change in migraine patients for example, yet we know they are genuinely ill. You can't dismiss the pain they are experiencing.

What problems do you think are caused in both research and treatment by 'lumping together' all CFS and M.E. patients?

We have to define what we're dealing with. If we use the broad term CFS which does not exclude all patients with psychological fatigue then there will be a subset of patients who would benefit from an entirely different kind of approach. A good comparison again is chronic headache. If you don't distinguish migraine sufferers from those that have simple anxiety or tension headaches you cannot treat them effectively. That's where clinicians are important and scans or reports will not help.

We sit down and try to work out what is more likely to be the cause of a patient's symptoms, accepting that sometimes we might get it wrong – and that in some cases there will be overlaps. For some conditions there are tests that may confirm your clinical diagnosis, and in other cases there aren't – you just have to make an informed judgement, listening carefully to the patient.

When I have a patient with chronic fatigue, I always try to make out whether they're suffering primary depression and associated fatigue or a post-viral M.E.-type fatigue. For the latter I use the term 'M.E./CFS'. I had a letter published in the Lancet some time back regarding the need to separate out neurological versus psychogenic chronic fatigue, in the same way as we clinically distinguish between different types of headaches or Parkinsonian disorders.

There has already been some work done using SPECT brain scans which have shown a lack of oxygen to the brain stem in many M.E. patients studied.

Continued on next page

Continued from previous page

Yes, Costa's studies have shown changes in blood flow through the brain stem and we have shown here that blood flow changes are present in the cerebral cortex. However, patterns of blood flow changes in M.E./CFS are not specific. Cerebral blood flow is influenced by a number of factors including the rate of brain activity (metabolism). I think SPECT scans in this illness only provide indirect evidence that there are changes in brain function as compared to a normal brain. By themselves, altered SPECT blood flow patterns do not generally identify a specific disease.

What particular research would you like to see investigated further?

Currently, my main interest is in new forms of brain scanning in chronically fatiguing neurological disorders and I would like to apply this tool to both M.E. and MS. We're also trying to experiment with some form of laboratory markers that may indicate proneness (susceptibility) to M.E./CFS.

We have been able to identify fairly robust abnormalities showing up in the specialist brain scans of a small number M.E. patients whom we have studied so far. However, we also need to look at these changes over time. Equally at a more basic level we need to understand why some patients develop M.E. after infections and some not. I think part of the answer lies in genetics. If you can identify pathways between genetic predisposition to viruses and subsequent neurological disorders and fatigue that would be a major advance in science.

How would you treat a patient that may have some degree of mood disorder but who primarily has what you consider to be neurological M.E.?

It would be important to identify whether the mood disorder is primary or reactive to the illness. For M.E., we'd offer basic symptomatic management of fatigue and advice on lifestyle changes to minimise relapses, just as we would to a patient with MS. Our advice would also include treatments to alleviate pain, sleep problems, physiotherapy to address any joint problems and where indicated, antidepressants for depression or mood disorders.

Why do you think the role of depression in M.E. is given so much emphasis in this country?

The role of depression in M.E. is perhaps no more important than that in any other chronic medical mess where it may exist as a co-morbid factor. If you match MS or heart disease patients with healthy controls they will have substantially higher risks for depression and suicide than healthy people. I don't think M.E. is any exception. However, because depression can be more easily treated than the underlying neurological problem in M.E., it has received more attention.

Sadly, few neurologists have shown any special interest in the neurology of chronic fatigue, despite it being a very common problem in clinical practice. Instead it has been with the psychiatrists and psychologists for a while who have used their own methods to try and find an answer to this problem. Naturally, every speciality approaches a clinical problem from its own area of expertise and the psychiatrists have developed a theory that they believe may apply to chronic fatigue as a medically unexplained symptom.

Some physicians may confuse reactive or secondary psychiatric complications in a medical disease with primary depression and so feel compelled to use psychological interventions without fully assessing their appropriateness. There is also an increasing trend to use a psychological paradigm to explain symptoms that are hard to quantify, like fibromyalgia or irritable bowel. In my view, that's probably more convenient than scientific.

Is the field changing now?

I think so. I have been referred M.E./CFS patients seen by psychiatrists who confirm that they did not have a primary depressive or psychiatric illness. I'm sure many have come to realise that the conventional psychiatric model for this illness as a depressive, somatising disorder is perhaps too naive and no longer valid.

Perhaps a tendency to focus on the mind in these patients has been influenced by the fact that their tests and scan reports are normal. Maybe we have to ask ourselves if we should pay more attention to patients rather than reports. We need a return to traditional practice of medicine that makes use of the technology to understand, rather than to reject, what the patient is telling us.

Do you have concerns about the NHS mainstay of treatment for M.E./CFS which seems to revolve around graded exercise therapy and cognitive behaviour therapy (CBT)?

CBT and graded exercise therapy are two of the pos-

sible options in the management of M.E./CFS – but these interventions do not cure M.E. and are not suitable for every patient.

Let's take the issue of graded exercise. In any form of neurological disorder if physical inactivity is present for some time, that will lead to muscle wasting and deconditioning which of course will compound the problem. To overcome that, within their limitations, patients need some degree of exercise. But you can't 'beat' M.E. by pushing yourself to your limit because one of the core problems is post-exertional malaise. On the other hand, if you use physical activities as part of a rehabilitative strategy to maintain muscle condition, this can be very helpful so long as you pace yourself and don't overdo it.

And what's your view of CBT?

Well, research certainly demonstrates that it does help a proportion of patients, but we aren't sure why. It's very interesting that psychiatrists believe CBT is effective because it challenges 'unhelpful' illness beliefs, but this is entirely hypothetical – I don't think that the effectiveness of CBT in a patient implies that his or her M.E./CFS was due to abnormal illness behaviour. In depression, interpersonal therapy seems to be effective in changing brain metabolism and blood flow where antidepressants have failed. You obviously have an explanation for CBT that is nothing to do with

simply 'challenging beliefs'. That's where my reservations about the psychologisation of M.E. come in. I think more research is required in this area.

Any final advice for patients?

Trust yourself rather than anyone who says you do not have a disease or who advises you to push yourself harder even if that makes you feel worse. Make sure your lifestyle is regulated and try to keep to a flexible programme of physical and mental activities on a regular basis.

Always remain positive and take measures that can improve the quality of your life, but don't be entirely dependent on the advice of doctors – it's you who has to live with your condition. ❀

About the interviewee:

Dr Abhijit Chaudhuri is a senior clinical lecturer in neurology at Glasgow University and a consultant neurologist at the Institute of Neurological Sciences Glasgow where he sees up to 200 M.E. patients a mostly from the West of Scotland (physician referral essential; no private appointments).

Reprinted with permission from InterAction, the quarterly magazine of Action for M.E. (www.afme.org.uk), Issue 42 (Oct 2002).

HOW TO MAKE YOURSELF MISERABLE

1. Forget the good things in life and concentrate on the bad.
2. Put an excessive value on money.
3. Think that you are indispensable to your job, your community, and your friends.
4. Think that you are overburdened with work and that people tend to take advantage of you.
5. Think that you are exceptional and entitled to special privileges.
6. Think that you can control your nervous system by sheer willpower.
7. Forget the feelings and rights of other people.
8. Cultivate a consistently pessimistic outlook.
9. Never overlook a slight or forget a grudge.
10. And don't forget to feel sorry for yourself.

Travelling with ME/CFS

By **Peter Mitchell**, Honorary Secretary ME/CFS Society (SA) Inc.

This article started out as a series of tips in the Society's weekly ebuletin. We have now expanded it, taking on board further experiences and suggestions of others.

By road

Out of painful experience I have realised that my limit for road travel is about 5 hours, so we tend to do our travel in 5-hour chunks now. I also realised in more recent years that bumping around in a car on the road put pressure on my spine, which was reflected in strong neck-aches/headaches. I now lay the seat back and use a pillow to relax in a more prone position. I take a water bottle and force myself to drink regularly. I find that I am far better if I follow those steps religiously. I would imagine that the same would apply to coach travel: I'd try to do it in manageable bits if possible. As to driving, I have discovered the joys of cruise control. For those of us with muscle pain, this is a fantastic invention, which has allowed me to comfortably do some of the driving on country/interstate trips. Not having to hold down an accelerator pedal for kilometre after kilometre is a blessing. If you have cruise control in your car, and you do any sort of long-distance trips, you must try it.

By air with mobility scooter

These comments are purely about domestic travel,

since I have not been able to travel internationally yet. (I almost got to China once, but they had a SARS epidemic, so I had to cancel). I am indebted to a couple of people, but especially Jenni Gay, for this advice. Jenni was our *Talking Point* assistant editor last year and is currently the company secretary of ME/CFS Australia. She tackled air travel with a mobility scooter well before me, and gave me vital advice before I tried it.

First, airlines are required to carry your mobility scooter or wheelchair. This is without charge, a fact that stunned my GP when I told him recently. It's all about equity: the airlines can't charge you more because you happen to need a mobility device. However, your device needs to be within size and weight parameters: most modern "travel scooters" are fine.

What I do now is to book my flight as normal, which allows me to make use of discount flights. Then, closer to the flight date, I ring the airline and inform them that I will be travelling with a mobility scooter. Whenever I say that, they ask what size and weight it is, and sometimes an engineer will ring back to check that it will fit in the hold of the particular aircraft being used, and has a safe battery. Warning: if you follow the directions on airline web pages to the



letter, you may find yourself ringing the airline before you book your flight – and paying a lot extra for the privilege. I did this the first time I flew with a scooter, and they charged an extra forty dollars, not only for me but also for my wife flying with me: eighty dollars for a phone call! So now I book first and tell later.

As to dealing with the rigours of flight itself, I have no magic recipe, other than the importance of being hydrated: take your own water and ask for more if given a choice of drinks. I tend to wear a compression garment called “skins” these days, although I couldn’t say that they make much difference. And of course try to get a seat where you can lay back without causing a battle with the person behind you. (That’s not easy, in fact it’s virtually impossible on a busy flight.)

I have only travelled with Qantas thus far: after observing the sordid legal battle put up by the “maiden primary colour” airline to get out of taking any passengers in wheelchairs, I haven’t trusted them, and one budget airline’s flights to Melbourne end up at Avalon, halfway to Geelong, so they are not in consideration for us. I would be delighted to hear of other people’s positive experiences with the non-Qantas fleets. With Qantas, I have found it valuable to have a Frequent Flyer number: while it costs initially to join, the FF number helps their computers keep track of you and your special needs, and allows them to automatically allocate appropriate seats to you before you even check-in online.

By air without your own mobility device

When I was still working full-time with ME/CFS, and didn’t use a scooter, I travelled to Victoria, Queensland, ACT, WA (twice) and Tasmania by air. I found then that the real issue was not the flying but the walking involved: especially the huge distances airlines expect you to walk inside terminals or across the tarmac (this was before the days of air-bridges in Adelaide!). To reduce the walking, there are wheelchairs available at check-in. So, if you have a companion travelling with you, s/he could push you at least as far as the departure gate. But that leaves you both to sort things out at the other end. I would suggest that you act as above: book your ticket first; then, closer to flight date, ring and let the airline know you require a wheelchair at check-in and at your destination. This gives you the opportunity to request a staff member be available to help wheel you, and you can request they wheel you to the cabin for departure and meet you either at the cabin in or at the arrival gate. If you are really lucky, there’ll be several people on your flight needing

assistance, and you can get to ride one of those cute electric buggies in the terminal.

Taxis

Taxis can be great when you have a disability, but they have two disadvantages compared to driving yourself: cost and reliability. If your disability is significant enough that your GP will support it, the cost issue can be addressed by having Access cab vouchers, which are usable interstate. The vouchers generally give you 50% off the cost of the cab fare. And they entitle you to use Access cabs, which can be necessary if you have a large scooter or electric wheelchair. That helps with the cost issue. Reliability is another matter. Having been badly let down on the occasions when we needed an Access cab to get us to Adelaide airport, we have given up on them in this state, and use the mainstream cab companies. And now after a recent trip to Sydney, I found that they can be just as unreliable there. We simply ask for a station wagon which can take my travel scooter. If any of you have a friend or relative who works for Access cabs, my apologies, but if they can’t deliver a reliable service, it is not a service I can use.

Buses and trains

This is a whole separate item to address, I suspect. I have lots of experience in getting a mobility scooter onto the Football Express bus, and now that I’ve caught buses in Sydney too, I can verify that some of their services there are wheelchair buses. The first thing to do is to be sure that the service you need will take wheelchairs/scooters. Buses which do take chairs are usually labelled front left with the international wheelie symbol. They have the capacity to “tilt” towards the footpath, and then the driver flips out a ramp. Once you’re on, there should be dedicated seats where you can sit and leave your scooter/chair. I say “should” because we live in a society where many people seem to ignore obvious signs and want to sit where the sign tells them the seat is allocated to age/disability. I have learnt to be politely assertive about this and simply say “I’m afraid I need that spot”. I’ve only once caught a train with a scooter. And I tried a tram in Melbourne, but discovered (a) there’s a gap between the tram and platform that a scooter’s wheels fit down nicely and (b) once you’re on the tram there is no area for you to put your mobility device, nor any disability seat to sit in! I think that’s one of a number of reasons that you don’t see many people in wheelchairs or scooters in the Melbourne CBD. ☸

My Travels with ME/CFS

*Travelling with ME/CFS doesn't always work out, as ME/CFS Society (SA) Inc member **Julie Gilbert** tells us her story.*

My travels with CFS can't be put into the category of helpful, but may be mildly interesting.

Our son lives in London and my husband and I were desperate to go and see him. Not knowing how I would react to a long international flight I devised a test flight: Adelaide to Perth and back immediately, thus simulating an Adelaide-Singapore leg. If I passed that test with ease, I felt more confident about the longer Singapore-London flight. First step, ask our GP for advice. His reply, oxygen required. Went through the rigmarole of booking an oxygen tank from BOC, and informing the airline that it would be accompanying me. Couldn't book the ticket online as the computer didn't believe I'd fly there and back on the same day. When I presented myself, the tank wouldn't fit under the seat in front of me (the connecting tube wasn't long enough) so the airline wanted to charge me for an extra seat for the tank. Luckily they relented. This was 9:00 am. The flight was long and boring. Cat-napped the whole way to save energy, the only noise my irregular breathing and the hiss of the tank. Sipped a lot of water, refused all food and drink. Got to Perth 3 hours or so later. The

cabin crew were amused/bemused that I'd be returning with them; no one had ever done this before. They kindly allowed me to leave the tank in the seat, whilst I disembarked during refuelling. Had time to refill my water bottle, stretch my legs, then back on the plane for the return flight. Arrived home in Adelaide about 6:00 pm, and felt fine. Yahoo, London here we come!! Next morning drove across town to return the oxygen cylinder, got home... and crashed. Took 3 months to recover. So London was ruled out.

Not long after a special event came up with family in Sydney. Well, an hour flight isn't a six hour flight is it, so I gave it a go. Same rigmarole with forms and doctors letters to get the oxygen. My husband is a paraplegic and has his own special needs. Picture us arriving at Adelaide airport, me laden like a pack horse

with 3 suitcases, a bathchair and an oxygen cylinder. The sympathetic staff enquired kindly but casually if the oxygen was for my husband, and were quite taken aback to be told it was mine. We obviously looked like terrorists because we were both singled out for a spot security check. They even took Ralph's ugg boots off, in case there was a bomb in the bottom of them. Not our fault that by the time they finished their searching and had loaded us on the plane with the forklift (pre air-bridge days) the flight was late departing.

Arrived in Sydney an hour later, were met by family, collected our gear and set off for a short walk to the car. Just managed that. When we arrived at our hotel I had the dreaded "shuffle", where the exhaustion has set in and I can barely walk. We stayed a week, and I managed about 8 good hours out of 110. But

I did make it through the important family events. On the return to Adelaide I again had "the shuffle" and the airline staff got tired of waiting for me to walk oh so slowly, so they stuffed me in a wheelchair and wheeled me to our car. Another month recovering.

Next trip was a year later, to Melbourne. Not risking a flight this time,

I sat in the back seat, with pillows and walkman, relaxed, stretched my legs when I could, and left the driving to Ralph and a friend. Next day I could barely walk 200 metres to a deli for breakfast milk. A week's stay. Fell asleep at a dinner with friends. Lay on the bed in the motel feeling dreadful most of the time. Happy but dreadful, if you know what I mean. We went to see a friend who was ill. We saw him. So, goal achieved – even if there was a price to pay.

So, sad conclusion: travel just doesn't agree with me. Have tried various shorter trips, such as Victor Harbor. Sometimes it works, sometimes it doesn't. Haven't given up all hope of travelling overseas though. Miracles happen. Maybe the next trip will be perfectly OK.



ME/CFS Awareness in Hospital

By **Maureen Jepson.**

Imagine my delight when fronting up to the local regional base hospital for pre-op checks at the end of January to discover that all six health practitioners I saw had not only heard of ME/CFS but accepted it as an illness. I went armed with a list of my symptoms which was added to my file. The anaesthetist even suggested an epidural for post-op pain management which would cut out the ME/CFS pain in my legs while confined to ICU for nearly five days.

Seven years ago when I had similarly fronted up to the same hospital for pre-op checks the attitude to ME/CFS was similar to that of the possibility of the existence of life on Mars. Therefore there was a vast improvement in the seven years.

While in hospital for 19 days – 16 at the large base hospital and three at the local country hospital – the illness was accepted as real but there was a variety of interpretations of it.

The surgeon said that ME/CFS was my history and not the reason for my admittance to hospital. I explained that the illness will not just go away and that it would be very likely to adversely affect my recovery. He accepted that.

Most of those treating me, while accepting ME/CFS as a real illness, had not looked beyond the fatigue and, of course, had not had the time or had not bothered to look at the list of symptoms on my file.

My colostomy bag had to be changed every four days and I found it almost impossible to explain that my cognitive and co-ordination problems, occasional dyslexia and inability to absorb new information would make the procedure impossible for me to cope with. (My husband changes the bag for me.) One of the nurses began to understand when she watched me attempt to pour milk into a glass. Had she not intervened it would have landed all over the table.

There was the physiotherapist who thought ME/

CFS ‘was only transitory’ and her colleague who suggested I abandon my walking stick for a walker on wheels with a seat, which turned out to be a good idea. However, she also said that she could treat me so that I would be able to dispense with the walker and my wheelchair and she would have me walking round the block ‘in no time’. I just laughed at her.

One doesn’t have complete conversations in hospital. Everyone, including the patient, is very busy so I was unable to discuss a lot of points raised. Also, I did not feel well enough to keep explaining or I would fall asleep.

At the local country hospital the senior nurse who checked me in said that they all knew about my illness and understood ‘chronic fatigue’. I corrected her. “No,” she said, “Here we have a policy of calling it chronic fatigue,” She was very surprised at the list of symptoms I gave her.

The GP in charge of my case at the local country hospital seemed to have a complete understanding of ME/CFS and we did have some very good discussions about it.

After being discharged I was in the hands of the local district nurses who also had a good understanding of the illness,

but, at the same time, were surprised at all the symptoms over and above fatigue.

So, the good news is that ME/CFS was accepted as an illness at the two hospitals I attended. However, the understanding that there are numerous symptoms over and above fatigue was not good.

There was a big improvement in the seven years since my previous hospital visit. To have the illness accepted is a big plus. However, we now have to spread the word that there’s more to it than just plain fatigue.



Reprinted with permission from Emerge, Winter 2008.



My Little Lucky Life

By **Mary Edwards.**

Fall ill with ME/CFS then have a baby. Not what one would usually recommend, let alone expect, but that's what I did – well, sort of.

My story about ME/CFS starts very much like many of the ones that have appeared on the pages of this journal before.

At the end of my thirties, married with no kids, enjoying a successful career and active social life I contracted glandular fever. Cutting a long story short, I simply never got better – at least never fully better again. I was nonetheless very fortunate in that I was never totally bed-ridden with ME/CFS as are many others.

Over many years I did manage to get rid of most of the brain fog, could exercise gently and regularly – if very carefully – accepted that my memory, once almost flawless, was now unreliable and sorted out the painful cracked finger tips and the sleep and thrush problems by cutting out the heaps of sugar and starchy foods that I had always loved and often craved. I now accept it as normal that I will have days, or sometimes weeks, when I am only 20% functional and that if I try to push myself at those times I will relapse for twice as long.

But early on, just after it became clear that this wasn't like another virus where I'd get well again, I started rethinking many of my earlier values. I had loved my career and my financial independence and it dawned on me that this chronic illness could very possibly end my career. I realised that I could be left without a career, a family or much of anything else that I valued.

So at about 40 years of age I decided that I wanted children. Doctors didn't hold out much hope – not because of ME/CFS (most didn't even acknowledge that this existed



anyway) but because of my age. At this stage I was still struggling to continue with work, albeit punctuated with regular absences to recover from yet another relapse. This went on for about two years with more relapses and no baby either.

Then my husband was offered a stint working overseas. Having a wonderful husband, we sorted out the financial aspects of my loss of income so that it felt as if I was still independent and indeed contributing to our little family. Of my husband's many strengths, his ability to help me feel worthwhile then and now is perhaps his greatest. So off we set.

I had been off work for only a few months when I became pregnant, although I miscarried at about six weeks. I was optimistic and I continued on my merry way, setting my own timetable instead of being driven by someone else's, sleeping whenever I felt like it, often in different places around the house just for a change of scenery. Surprisingly enough, six months later I was pregnant, had an uneventful pregnancy and delivered a healthy baby boy. I was 43 at this time and as I hadn't resorted to IVF I felt pretty pleased with myself.

And yes, babies, breast feeding, etc., are very tiring but I had become used to managing fatigue with five years of trial and error behind me. In a strange way I think it was even beneficial for me to slow my life rhythms to fit a baby's sleep, eat and gurgle patterns. And my husband was there helping with the baby, constantly reminding me not to overdo it and to forget the clutter, the paperwork that didn't get put away and the



gardening that didn't get attended to and our shrinking circle of friends. The fact that we were able to afford help with cleaning and babysitting proved to be a real life saver for me. After another miscarriage, and against the odds, when I was 46 I had a daughter. Having two children under three was a challenge, but luckily they were very healthy and there were no major problems to worry about.

The children are 12 and 9 now. They are used to seeing me napping on the couch or heading off to bed. I try to use my minimal energy to be available to the family, do some volunteer work and have a small social life. Sometimes I can do more, sometimes I do less. When I have a relapse, then it's a lot less. I try not to compare what I am able to do as a wife and mother with what I'd like to be able to do, nor what I used to be able to do. Although, even after having ME/CFS for 17 years, it is still frustrating to be living a very little life.

I have many regrets about getting ME/CFS. I regret not paying more attention to my body and not simply telling the doctors that I really needed more than a couple of weeks away from work to recover. I regret that I felt that I always needed to do more, even when it was obvious to my body, if not my mind, that



I really, really needed to do much less.

But I must have learnt something in those 17 years because now when I hear friends saying how much they are doing and how little rest they are getting I don't feel envious, I just feel nauseous. I resent the loss of spontaneity in life and having to carefully sift

and space activities days or weeks apart. I am very aware of the loss of social status that comes from being out of the full-time workforce, not to mention the peculiar looks one gets if one is ever game enough to mention ME/CFS. Then having acknowledged ME/CFS I am still both angry and despondent when I am glibly told, "It's just a question of mind over matter."

But all in all I am hugely lucky. I have a supportive partner who has carried a disproportionate load of work and responsibility for 17 years. I have two terrific children. They have given me warmth, love and joy. My daughter has magic little fingers and when I am looking really exhausted she sits behind me and quietly massages my shoulders and head. It may not cure ME/CFS but it reminds me that life is still wonderful. ❀

Reprinted with permission from Emerge, Autumn 2008.

YOU KNOW YOU HAVE CFS WHEN...

1. You try to put the kettle back in the fridge – twice.
2. You get increasingly frustrated with trying to change channels on the VCR with the remote control, and the TV channels keep changing instead. When you complain of this to the family, you are asked "Is the remote set to 'TV' or 'VCR'?"
3. You haven't got enough puff to blow out the one candle on your birthday cake.
4. Your doctor asks you why you haven't seen him for a while and you tell him you didn't feel well enough to see him.
5. You are accused of faking illness by people who will never know how hard you try to fake acting normal.

Reprinted with permission from the ME/CFS Society of NSW.

Managing My Illness

By **Mary Campbell**. This article by Mary also includes a review of *The CFIDS & Fibromyalgia Self-Help Book* by Dr Bruce Campbell (no relation).

My story

As is the usual story, when I became ill with ME/CFS & FMS there were many tests, and visits to doctors and specialists before diagnosis. Then it was a matter of trying this or that treatment. Each time I hoped I would get better. Every time when there was limited improvement or it made me worse, my heart fell a little more. My sadness turned into anger toward the illness and my body. I developed a determination to fight it all the way regardless of whether it would help me in the long run. Eventually I had to accept that my life has changed. I cannot reclaim my childhood years. I worked out what I can do is have the best quality of life now.

At my worst I was close to bed ridden, dependant on all those around me. In my case through managing my health, and with some luck on my side I have been able to stabilise and slowly increase my activity level. Now after many years I am able to work part time, study part time, help out the ACT ME/CFS & FMS Society and even socialise. I am by no means perfect at managing, but I'd like to share some of my ideas and hopefully help some readers.

Limitations

I know myself, the more I learn to manage my illness, the better my quality of life. One great tool for this I found is *The CFIDS & Fibromyalgia Self-Help Book* by Bruce Campbell (no relation) [see page 22 for a related article by Bruce Campbell entitled "Using Self-Help to Recover from CFIDS"]. For example, "Living within limits means not being able to do everything you want to do." Page 82 hits home. While this is obvious, it's a trap I constantly fall into. My eyes are bigger than my stomach. I compare myself to a 'healthy' person (usually a high achiever). The funny thing I know inside is that even they have to live within their limits. They have to take time out and rest. Often they don't have perfect health (they may have an old sporting injury or need glasses). Ultimately, they aren't necessarily doing everything they want to do, there are always restrictions, whether financial, qualifications, experience or

connections. Each of us has our own path to walk, and our own limitations. And yes, like many people reading this, proportionately I do have to spend a larger amount of time in pain and tired and resting compared to a healthy person. But the point of management is so I can maximise the amount of 'good' times I have.

Pacing

One key area of the book is pacing and management. When I was very sick it meant resting so I could manage a five minute phone conversation to a friend every couple of nights. Other times meant pacing myself and resting before (and after) so I could visit the local botanical gardens, walk the 10 metres from the car to the chair and sit in the beautiful surroundings for half an hour.

Dancing

A few years ago it meant managing my health so I could dance again. Dance you say? You must be very well to do that! Granted, I was lucky enough to have the health to dance, but I chose dancing with modification, not physically demanding ballet. Some of these ideas may help you to return to an activity you love. I pay as I go with no pressure to attend, so if I'm unwell I can skip a week. On days I intend to dance I don't do much and I make sure I sleep before I go. I dance for a song and then rest for a while until I'm up to dancing again. I drink lots of water and when I'm tired I leave and then go straight to bed. I spend the next morning recovering. It doesn't affect me for days, or leave me in bed for a week. On the health side, my circulation improves and my muscles are less tight. When I dance I have to stand up straight so my posture improves as does my breathing and my oxygen intake. Most importantly I get to dance, something I've loved my whole life, spinning and flying and enjoying the music.



Continued from previous page

Choices and Emotions

Another area covered in the book is emotions, and as my Dad said when I first became sick “Do you really want to spend all your limited energy being angry/frustrated/upset? Just think of all the happy things you could be spending your energy on.” As annoying as that comment was at the time, it’s very true. We often wear ourselves out with the negative emotions, when we could be spending that energy doing something that builds our spirits. Sometimes we get carried away with the stress of the event rather than seeing this big picture that can be so vital in terms of quality of life especially when you have a chronic illness. It’s something this book reminds me of and gives me strategies to work on.

Some management techniques I learnt years ago and they are second nature for me. I still greatly ben-

efit from them. Other people who may not have received the same guidance could through reading this book fast track some management strategies rather than learn the hard way.

Forgetting

I find there are management strategies I forget, or choose to forget (I say cheekily because I’m not sensible all the time). I have to swallow my pride and put on my learning hat and realise that no matter where I am in my life or illness I can always learn to manage better.

You can purchase the book at cost for \$15 plus postage from the ACT ME/CFS Society. The book is also available as an audio book on CD (with an Australian accent) for those who have difficulty reading. For further details call (02) 6290 1984 or email admin@mecfscanberra.org.au. ☘

Book Review

Barbara Seccombe offers a review of *Chronic Fatigue Syndrome / ME Turning, Disability Toward Ability* by Dr Don Lewis.

Dr Lewis recently appeared on Australian television. He was interviewed, along with ME/CFSer Imogen Newhouse, on Channel 10’s morning program 9am with David & Kim on Thursday 15 May 2008. You can view the interview in its entirety on the ME/CFS Society (SA) Inc’s website: http://sacfs.asn.au/news/2008/05/05_16_9am_david_kim.htm. The book can be purchased at Dr Lewis’s website: <http://www.cfsdiscovery.com.au/book.html>.

A thoroughly knowledgeable, well-researched and comprehensive specialist account of the whole syndrome. I think every sufferer of this horrible illness should read what Dr Lewis has to say.

His central contention is that, on the one hand, the illness is due to an over-activation of one aspect of the immune system, and on the other, a suppression or under-activation of another ‘pathway’ on the other is crucial to our understanding of this complex and baffling syndrome. I often wondered why my sinuses and glands seemed to be working overtime when I experienced a relapse and yet my resistance to infection and recurring viral-type symptoms was always down. Now it’s clear – thanks to Dr Lewis!

The book gets a bit scientific with its medical terminology, diagrams, graphs and expert descriptions of theories and treatment, but there are case studies

and very readable comments on various aspects of the illness scattered throughout the text. If you feel you’re lost, read it two or three times. It’s well worth it. I can’t imagine anyone knowing more than Dr Lewis on this subject nor dedicating themselves unstintingly to its cause.

One last comment: Dr Lewis’s correlation of cardiac arrhythmias, bladder dysfunction and orthostatic intolerance (inability to maintain while in the upright position for more than twenty minutes) throws a lot of light on my own problems with an unexplained fibrillating heartbeat, attacks of cystitis not due to bacterial infection and why I often feel like passing out in dressing rooms at shopping centres! ☘

Reprinted with permission from Emerge, Autumn 2008.

Do What You Can

By **Glynis Scrivens.**

"Do what you can, with what you've got, where you are."

– Theodore Roosevelt (pictured)

I stumbled upon this quote quite a few years ago. It seemed to say exactly what I needed to hear. I have no idea of the historical context of Roosevelt's words, but I needed them – and maybe you could benefit from them, too.

I've had ME/CFS since late 1992. It's so easy and the most natural thing in the world to fall into the trap of focusing on what we've lost. Let's face it, it's a LOT. But the path back to a useful, engaging life lies in focusing on what we have.. It took me a while to realise that.

Here's a brief list of what I still have and what I do with it. Make your own list – you'll surprise yourself.

1. Time

Yes, time, day and night – hours of it – and it's been a real eye-opener to discover how many people need my time: time to listen when my children and their friends need to pour out some problems or plan their future; time to plant seeds and watch them grow; time to phone elderly relatives who live on their own; time to listen to music.

Some years ago I gave English lessons at my home. A Vietnamese boy who was getting a D for English at school told me, "No teacher has ever listened to me before. They've never had the time." This boy's grade improved to an A minus over the following three years. I hadn't been able to go for walks or get much housework done during that time, but I used his tuition fees to pay for a cleaner and we were both better off.

Spending so much time at home has also been a bonus in terms of pets. My younger daughter loves animals. We have goldfish, guinea pigs, chickens and two dogs and have also nursed injured birdlife.

2. Experience

Being chronically unwell teaches us more than we wanted to know about life, the medical profession and the school of hard knocks, but it does give us a wealth of experience and even wisdom – something we can offer other people when they're going through a rough patch.

3. Creativity

I'm well enough these days to enjoy using my brain, but don't have the physical stamina to manage work outside home. So I write.

For the past five years I've been writing fiction for women's magazines both here and overseas. It gives me a huge buzz to see my stories in print, and to share something of my experiences of life with so many other people.

I've joined two on-line writing groups and have made a few close friends and sometimes we find we have ME/CFS in common – one friend has a son with the illness. Others have debilitating physical conditions but these conditions no longer define who we are – we are writers.



4. Faith

I'm Christian and have been able to keep my faith. Going to church is often not possible – too much standing up, too many steps etc. but, using Roosevelt's principle, I'm doing what I can. Services mightn't be feasible but I've joined a small book club at my church and can often manage the meetings. It gives me fellowship and an opportunity to see life from other perspectives.

Continued on next page

Continued from previous page

5. Family

I've put family at the end of this list but, in terms of what I've learnt to value, they're at the very top. They're in this position here because if you have the first three or four things on my list but aren't fortunate enough to have a supportive family, you'll still be able to create a valuable and viable existence within the limiting framework of ME/CFS. I'm blessed with a loving husband and three great kids (a son and two daughters). They provide incentive every day for me to "do what you can, with what you've got, where you are".

Do what you can...

Keep putting one foot in front of the other, however slowly. It's surprising where it can lead and you un-

earth new interests. In the early days of my ME/CFS when I was essentially house-bound – the only thing I was able to share with my son was watching Sunday afternoon rugby league. Till then the only football in my vocabulary was soccer. These days I'm an avid Broncos fan and never miss a match – on TV, that is. I'm still looking forward to the day I'll be able to go to a match. This enjoyment is a gift ME/CFS unexpectedly handed me.

As is my interest in magazines, which started with buying *Family Circle* for my older daughter and me to do the crosswords together. We never won any prizes but it was fun.

When I was a young girl I read and re-read *What Katy Did* and *What Katy Did Next* – the story of a girl unable to walk who had to decide how to live. She learnt to focus on the positive. So can we. ❀

Reprinted with permission from Emerge, Autumn 2008.

Society meetings for 2008

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

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

Date: Saturday 14 June 2008

Speaker: Edwina Shannon, occupational therapist

Topic: Edwina will be covering equipment, activity planning and energy conservation.

Date: Saturday 2 August 2008

Speaker: Dr Anne-Marie Southcott, President of the Sleep Disorders Association of SA

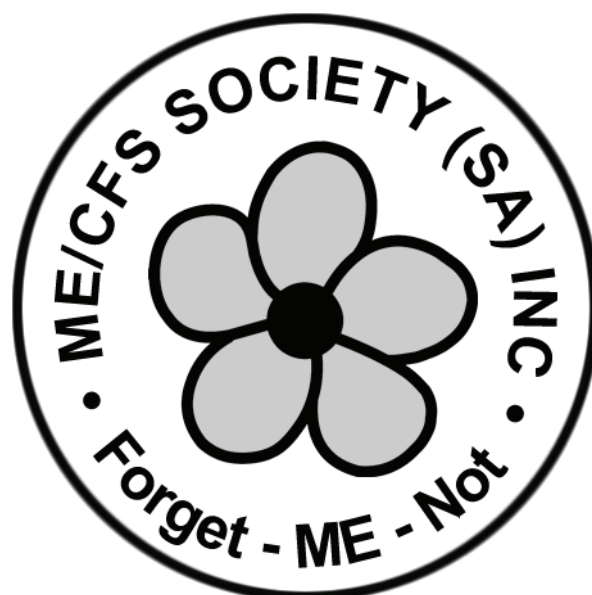
Date: Saturday 4 October 2008

Speaker: Katie Behlau, naturopath

Date: Saturday 8 November 2008

Speaker: (speaker to be confirmed)

Topic: Annual General Meeting



'Liar liar pants on fire!': Coping with Disbelief

In this article from Action for M.E.'s InterAction magazine, **Val Rubie** takes a look at disbelief, its effects on people with M.E. and how to cope with it.

This article is about being disbelieved.

Although the pantomime season is a long way off, I've been thinking about Tinkerbell and Peter Pan. For those who haven't seen the play, there is a poignant moment when the fairy Tinkerbell is fading, her bell is barely audible and her mischievous presence is disappearing.

All the children in the audience are asked to shout, 'We believe in fairies!'. As their voices swell, so Tinkerbell's jingling gets louder, her light gets brighter and soon she is zooming around as naughty as ever. I love this image of the power of belief. The fact that children identify with it so easily suggests that being disbelieved is one of our earliest experiences and we recognise that it can threaten the very core of our being.

How you describe it

Despite atrocious symptoms, some people with M.E. still hear a chorus of voices telling them they are imagining, exaggerating or being plain pathetic. Eventually they start to feel like the disappearing Tinkerbell. From my work with people with M.E. I am aware that being disbelieved is one of the most hurtful aspects of the illness. Feedback sent into Action for M.E. by members includes the following:

- 'Disbelief has caused as much pain as the illness.'
- 'It made me feel I was impotent and destroyed my self-esteem, which was already battered by guilt at not being able to work and be a useful member of society.'
- 'At its most insidious it can lead to time of disbelieving oneself and hence denial, depression or simply mad bouts of overdoing things in a wild attempt to fight it off or prove something.'
- 'The disbelief seems to increase in a relapse. If you report worse symptoms to those of the original acute phase you are less believed... the circle of friends seems to go into a decreasing spiral.'
- 'After five years of M.E. even I still have problems believing I'm ill... one of the reasons I overdo it.'

Add to this comments such as: a G.P. asking "Is it really that bad?" when a patient asked for help adapting her home; a brother saying 'So you're still claiming



to be disabled'; and a doctor replying 'You're basically healthy' to a query about post-operative recovery.

Why does it hurt so much?

I often speak in these articles about the fundamental human need particularly during infancy for 'mirroring'. When experiences and thoughts are reflected back by attentive, loving individuals, we come to learn that those experiences are real and have a meaning in the world. Inevitably, there are times when this doesn't happen and there is a conflict between what we think happened and what others seem to be suggesting. This is the origin of the confusion we feel when we are disbelieved.

Most of the time such lack of mirroring is not deliberate – it's about parents and other adults not being perfect. Sometimes of course it is deliberate (remember those old spy films when this was used as a torture technique) and we are then in the realms of abuse.

I was reminded of this graphically during an exercise on a course about the long-term effects of abuse on children. Half of us were asked to kneel so we were child-height. We were then asked to tell a genuine secret in a quiet voice to a standing person. Those standing were asked to disbelieve the 'kneelers', to look disinterested or walk away.

We all remembered what it was like to be a child again with a small voice and stature.

This story encapsulates why most of us find the pain of being disbelieved so searing. M.E. puts you on your knees, robs you of adequate words and many people don't listen to you with an open mind. Sometimes they have already decided, like the big powerful adults we once encountered, that they know best and have all the answers.

Retaining self-belief

Do we need to remain prisoners of past experiences or can we learn to treat disbelief as inconvenient rather than annihilating? This is easier in some situations

than others.

Many have felt supported by various agencies but others have pointed out how the disbelief of benefit agencies and medical services can withdraw our income, deprive us of treatment, cause dangerous relapses, and at its worst bring people to the brink of suicide. One talked about 'the hopelessness and cruel pain caused by institutionalised disbelief.' This is the kind of situation that cannot just be shrugged off. A long slow fight may be on the cards but many people with M.E. do win through in the end.

There is also disbelief from people who are supposed to be on your side. Feedback does suggest that anyone with 'believing' friends and family will cope much better. While there are many members who talk of steadfast support from families, others have less fortunate experiences, like the member whose father physically threw him out of bed. Life is very difficult for those feeling trapped in an uncaring and even hostile environment.

Strategies for fighting back

It helps to understand why people choose not to believe. For instance, those lacking insight into their own feelings may get angry when something makes them feel uncomfortable and they don't understand why – for instance when they see someone in a terrible state and they can't do anything to help. They can't bear to feel helpless so they get angry instead.

Also, many people hate the idea of life being out of their control. The 'disbeliever' has in front of them evidence that you can't control everything in life. If this makes them too frightened, they will tell themselves that it is the person with M.E. who is to blame for being ill and this way can convince themselves it will never happen to them.

The feedback you sent includes a range of options for dealing with disbelief:

- 'Reduce the hurt by discussing problems with others affected by M.E., perhaps using email lists if you find talking tiring.'
- 'Don't be afraid of walking away from a tiring, unimportant conversation if you need to.'
- 'If I run into anyone believing it's psychological, I explain that it's a disease of the immune system. That tends to shut them up. After all, who's the expert – me or them?'
- 'Ask for help and accept it.'
- 'Understand your illness. Research it.'
- 'Choose not to think about it all when you are very tired; wait until you're having a good day.'

- 'Don't waste energy on working out someone's motivation. If they don't believe, give up on them and find someone else who does.'
- 'The best way to feel OK and make the most of your day is to let go of expectations.'
- 'Re-evaluate friendships. Work on your own acceptance of other people.'
- 'If you feel trapped in a situation, investigate how others got out. Talk to severely affected people who live alone and find out how they do it.'
- 'Believe in yourself and then it matters less if others don't understand.'

Choosing not to care

It's worth remembering the following from the Assertive Bill of Rights*:

- You have the right to offer no reasons or excuses to justify your behaviour
- You have the right to be independent of the goodwill of others

And the one which most people have problems accepting:

- You have the right to say 'I don't care'

You may wish to care about certain people not believing you but with others you really can decide not to care what they think. It's about choosing when to fight and when to walk away. Both are equally valid depending on the circumstances. Endless seething about something you can't change can be self-destructive.

If you find yourself stuck in that position, professional help might be necessary to help you let go of these feelings so they no longer have control over you. ☘

*From "When I say no I feel guilty" by Manuel J Smith

Val Rubie is a counselor and psychotherapist whose private practice includes counselling people with M.E./C.F.S. and their carers. However she wishes to point out that work undertaken in this setting is entirely confidential and not used for the purposes of her articles in InterAction or any other publication.

Reprinted with permission from InterAction, the quarterly magazine of Action for M.E. (www.afme.org.uk), Issue 45 (Aug 2003).

Using Self-Help to Recover from CFIDS

By **Bruce Campbell.**

The following is an article published in the CFIDS Chronicle as a two-part series in Spring and Summer 2002. For an updated and expanded account, see *Recovery from Chronic Fatigue Syndrome: One Person's Story* (<http://www.recoveryfromcfs.org/>).

(Note: Shortly after I became ill in 1997, I found an article in the CFIDS Chronicle with an account of a patient's recovery. In it, Dean Anderson described his successful eight-year struggle with the illness. Turning away from medical treatments, he instead focused on figuring out what he could do to make himself better. Now that several years have passed and I have improved greatly using a similar approach, I thought I would describe my own recovery in the hope that a second account of the power of self-help might provide encouragement to other patients. — BC)

When I received the diagnosis of CFIDS in November, 1997, I had been sick for four months with a flu-like illness. During that period I gradually reduced my time at work to 15 hours a week, then stopped working entirely. Neither strategy reduced my symptoms. I functioned at about 25% of my pre-illness level.

Today, four years later, I have returned to a nearly normal life. My improvement has been very gradual but steady, about one or two percent a month. I now rate myself at about 90% and I am still improving. While I still have limits and experience mild symptoms at times, I have an activity level that is similar to others of my age. I don't know whether my improvement will last, but I am encouraged by the fact that my progress has been steady with no major setbacks.

Setting a Self-Management Strategy

Before CFIDS, I had learned to ask myself two questions when facing a health problem: 1) what help does the medical system offer? and 2) how can I help myself? After getting my diagnosis, I read everything I could find about CFIDS. I learned that the medical resources were quite limited; there was no medical cure for CFIDS and no standard treatment. It seemed that the best a medical approach had to offer was modest symptom improvement, probably requiring a long period of experimentation.

On the other hand, it appeared that some people, including Dean Anderson, had success with a self-management approach. I was attracted to this option in part because of my professional experience before becoming ill. I had been a consultant to self-help programs at the Stanford University Medical School and

seen some impressive results from people's participation in self-help groups for other chronic illnesses. That experience convinced me that how one lives with chronic illness can change its effects and may even change the course of illness.

Based on my research and my prior experience, I decided to forego experimenting with medical treatments and instead utilize exclusively a self-help approach. I felt confident that I could find many things that would help me improve. I have not had a medical appointment for CFIDS since. This decision does not imply a rejection of medicine in general or of my doctor. I checked in with him monthly by phone to keep him apprised of my progress and continued to see him for other medical problems. He was supportive of my approach to CFIDS.

Listing Assets

I believe that all patients have resources that can help them cope with their illness. The resources vary from person to person. Looking back, I can see several assets I possessed.

First, I was fortunate to have a moderate case of CFIDS. Though significantly limited by the illness, I believe I was somewhat better off than the average patient in the severity of my symptoms.

Second, my life circumstances were favorable. As a person in his early 50's, I was old enough to have created a financial cushion for myself, so that I was not stressed by the financial pressures that many CFIDS patients face. Also, I received understanding and support from my family and closest friends. They accepted my illness as real and agreed with my decision to pursue a self-management approach. Finally, I lived alone. Although it could be frightening on the days when I was too sick to get to the grocery store, living alone gave me the freedom to live my life as I thought necessary for my recovery.

Third, my personality and disposition lent themselves to a self-help approach. I enjoy solitude, and have often used discipline and patience to achieve my goals.

Lastly, I had a cancer in the 1970's that was treated

successfully, so my life already included an experience of recovery from serious illness.

Accepting the Illness

For the first year or more that I was sick with CFIDS, I wondered whether I should make recovery my goal. Sometimes I thought I should, but that standard was hard to live with. Like Dean Anderson, I found having the goal of recovery condemned me to an emotional roller coaster, in which I was encouraged by my progress but devastated by the inevitable setbacks.

The dilemma helped me to understand the distinction between those things I could control and those I couldn't. I finally concluded that whether I recovered was out of my hands, but that there were many things I could do to improve my quality of life. By suspending expectations about recovery, I could focus on what I could do to make my life better.

I found inspiration in Dean Anderson's description of how he combined acceptance of being ill with hope for a better life. He described acceptance not as resignation, but rather "an acceptance of the reality of the illness and of the need to lead a different kind of life, perhaps for the rest of my life." I adopted his formulation as my own approach to CFIDS.

Using Multiple Coping Strategies

Chronic illness is comprehensive in its effects, touching many aspects of our lives: how much we can do, our ability to work, our moods, our relationships, our finances, our hopes and dreams, our sense of who we are. In response, I used a variety of self-management strategies. Seven were particularly helpful.

1) Keeping Records

I was confident that making notes about my life would enable me to see patterns, to identify links between my actions and my symptoms. I experimented with a variety of logs, most requiring only a few minutes a day to fill out. I was greatly rewarded by the effort. Record keeping enabled me to recognize fluctuations in symptoms by showing me that my CFIDS was worse in the morning and better in the evening, and that the effects of exertion were cumulative during a week. Also, logging showed me the connection between standing and symptoms, documented how much exercise was safe, and showed me my vulnerability to stress.

Logging was also a good motivating tool. After noticing that some days were better than others, I fo-

cused on trying to find what I was doing that created good days so I could expand them. I also used my records to chart my progress over time. At the end of each month, I rated myself using a 0 to 100 rating scale. Seeing written evidence of improvement gave me hope, motivating me to continue my self-management program.

Perhaps the most dramatic use of logging was the two hours I spent at the end of 1998 trying to understand the relapses I had experienced that year. Reviewing my daily logs, I found eight instances in which my symptoms had been so intense that I had spent at least one day in bed. Looking for common causes, I found that almost all of the relapses were associated either with travel or with having a secondary illness. I then developed strategies to minimize the effects of travel and other illnesses, mostly taking more rest at those times than usual. I believe the strategies were successful, as I have had no relapses since.

2) Finding Limits: The Energy Envelope

To give my body a chance to recover, I had to accept living within the limits imposed by the illness. I was helped by the concept of the Energy Envelope. This is the idea that people with CFIDS have less energy than when healthy and that they can improve their quality of life by staying within the limits of their available energy.

For some time, I used this idea in a very general way. I would ask myself whether doing something would take me "outside the envelope" or whether I was living "inside the envelope." By reminding me of my limits, the concept of the Envelope helped me gain some control over symptoms.

Then I asked myself what were my limits in different areas of my life. I wondered how much sleep I needed at night, how much daytime rest, how much time I could safely spend on the computer, how long could I stand at one time before triggering symptoms, how far could I walk. Thinking of my energy envelope in terms of different aspects of my life led to a detailed understanding of my limits. I ended up with a list of about fifteen items. In addition to those just mentioned, I included activity limits (how long I could do various activities like driving, standing, housework, reading, and spending time with people), stressors in my life, food sensitivities, sensitivity to light and noise, and emotions. It took me at least a year to develop this more detailed understanding, but I felt rewarded all along the way because every insight I had helped

Continued on page 24

Continued from page 23

me gain more control.

3) Pacing: Rest and Routine

In my first several months with CFIDS, I was on a roller coaster. I rested when my symptoms were intense, then was overactive when the symptoms declined. Doing too much led to high symptoms again and the demoralizing cycle started over. I was living in response to my symptoms, which left me feeling my life was out of control. The idea of pacing offered an alternative. Pacing meant finding the right balance of activity and rest, and applying that balance on an everyday basis.

The key was to live a life that was planned, with a similar amount of activity and rest every day. Having a consistent level of activity made sense, but I resisted the idea of scheduling rest every day. It was hard to accept the idea that I would lie down voluntarily regardless of how I felt. I decided to try it by having a fifteen minute rest every afternoon. Much to my surprise, the rest helped, reducing my symptoms and making my life more stable. After a while I added a morning rest as well. I also experimented with how I structured my rests, finally defining rest as “lying down in a quiet place with my eyes closed.”

I found that taking these “pre-emptive rests,” as a friend called them, enabled me to reduce the time I spent in “recuperative rest” or resting in response to symptoms. The result was that my total rest time was reduced. Looking back, I think the two daily rests were the most important thing I did to aid my recovery. Resting on a planned schedule greatly stabilized my life, enabling me to get off the roller coaster and giving me a much greater sense of control.

4) Trying Experiments & Making Small Changes

I adopted the attitude that CFIDS had imposed severe and largely inflexible limits on me. To improve my quality of life, I had to find and adhere to those limits. Then, if I was lucky, I might be able to extend the limits gradually through making small changes. I came to view living with CFIDS as a series of experiments that I called being my own “CFIDS scientist.”

I learned a lot through my experiments, especially my attempts to exercise. Early on I was able to do only a fraction of what I could before becoming ill, walking fifteen minutes to half an hour most days. Through experimenting with walking at different

times of day, I discovered that exercising in the afternoon was much less likely to lead to higher symptoms. The realization led to a general realization that when I did something could be as important as how much. When I tried extending my walks, I observed that I sometimes felt fine during the walk but experienced strong symptoms afterwards or had to take a nap later in the day. That experience helped me to realize that the effects of activity might be delayed.

I was finally able to expand my exercise in a significant way when I incorporated pre-emptive rests into my walks. I would walk for 20 minutes, then sit down for a similar time, then walk some more. Planned rests also enabled me to begin walking again in areas with uphill stretches.

My progress was very slow. Often I extended the length of my walks by only one or two minutes every several weeks. Also, I backed off and I returned to my previous length if I experienced increased symptoms. But the discipline and patience paid off over time. By extending my exercise very gradually as I could tolerate it, I have returned now to a level of exercise close to what I had before becoming ill. In Fall, 2001, I had a four and a half day hiking trip in which I walked 60 miles.

5) Getting Support and Helping Others

Within weeks of receiving my diagnosis, I joined two local support groups. The experience was especially useful for the friends I made. I found there is something powerfully healing about feeling understood, all the more so for a stigmatized disease that some don't believe is real. Illness is isolating; feeling connected to others gave me a sense of belonging. Also, fellow patients were tremendous sources of information and perspective, helping me to understand CFIDS much more quickly than I could have on my own.

Because I stopped working and dropped out of my volunteer commitments shortly after becoming ill, fellow patients became perhaps my most important community. I think that served me well. I took CFIDS patients to be my peers, not healthy people. That meant that I measured myself in comparison to them, not to my peers from work. That comparison took a lot of pressure off.

A few months after receiving my diagnosis, I started a self-help class for myself and other patients I had met. (Over time it has become the CFIDS/Fibromyalgia Self-Help program.) Even though I didn't realize it at the time, leading the class helped me deal with one of the greatest challenges of chronic illness: finding new meaning in response to massive loss. By

developing new goals and focusing on what I was still able to do, I found a way to feel useful even when previous roles had fallen away.

6) Controlling Stress

I was surprised at how easily I was upset by stress. Even modest amounts of stress greatly intensified my symptoms, creating a feedback loop in which my symptoms and my response to them intensified one another. Once I realized how vulnerable to stress I had become, I decided that dealing with stress sensitivity had to be a big part of my effort to manage CFIDS.

My first reaction was to try various strategies for stress reduction. The most helpful proved to be a regular relaxation/meditation practice, which I included in my daily rests. Relaxing my mind while relaxing my body had a dramatic effect on my anxiety level, thus reducing my tendency to over-produce adrenalin.

Stress avoidance proved to be even more helpful. I learned that I could prevent stress by avoiding those things that caused it. The most useful strategy in that regard was routine: living my life as much as I could according to a plan. Having a daily schedule of activity, rest, exercise and socializing at set times gave structure and predictability to my life. With routine I had less pressure, and fewer surprises and emotional shocks.

I also learned to identify stress triggers, those situations and even specific people that set off symptoms. I learned, for example, that I was vulnerable to sensory overload after observing how noisy situations quickly led to intense symptoms. I also observed that situations of conflict were much more stressful than before. I then tried to avoid or minimize these stress triggers.

7) Managing Emotions

I knew from my work at Stanford that strong emotions are normal reactions to having a chronic illness. Serious illness turns people's lives upside down, upsetting their hopes and goals, and creating frustration and uncertainty. So I knew intellectually that managing emotions could be just as challenging as managing the physical aspects of the illness. I don't think this background prepared me, however, for the strength of the feelings associated with CFIDS and their apparent connection with the physiology of the illness. I felt less in control of my emotions than at almost any time in my life.

I developed a number of strategies in response, all

based on recognition that I was much more emotionally vulnerable than usual. First, I observed that the strength of my emotions was often associated with the strength of my physical symptoms, and that the strategies used to control symptoms also helped moderate my emotions. In particular, resting seemed to reduce the intensity of emotions while alleviating my fatigue and brain fog.

Second, I observed that I had an exaggerated initial reaction to relapses, often seeing them as evidence I would never improve. So I learned to talk in reassuring tones to myself. I consoled myself by saying things like "you've always bounced back from other setbacks" or "remember how life looks better after you've rested."

Third, I trained myself to mute my emotions after observing the toll that strong emotions took on me, whether positive or negative. It seemed that experiences that triggered the release of adrenalin led to an increase in symptoms. As a way to avoid symptoms, I tried to cultivate a Zen-like calmness and to construct a life that emphasized routine.

The Power of Self-Help

My approach to CFIDS was very similar to Dean Anderson's. I began with an acceptance that my life had changed, perhaps forever and certainly for an extended period. Second, I acknowledged that my illness imposed limits on me, and decided that living a disciplined life consistent with those limits offered the best chance of controlling symptoms and improving my quality of life. Third, I had confidence that I could find things that would help me get better and committed myself to experimenting to find what worked.

My approach of using self-help exclusively was different from that taken by most patients. Under different circumstances, I might have combined a self-management approach with a medical one. But self-help served me well, enabling me to regain most of my lost health gradually over a period of four years, using techniques I believed were safe and prudent, focusing as they did on living within limits and extending those limits very gradually as allowed by the illness. I hope my experience, in combination with that of Dean Anderson, will suggest to other patients that attitude and behavior can have powerful effects on health. ☸

This article originally appeared on the following web page: http://www.cfidselfhelp.org/artcl_success_bruce.htm. Reprinted with permission from CFIDS & Fibromyalgia Self-Help (www.cfidselfhelp.org).

Healthy Lifestyle Guide

The following is a list of healthy lifestyle-related stores in South Australia. We hope you find it helpful.



1342 Organics and More

Phone: 8264 7865

Organic fruit and vegetable store located in Tea Tree Gully.

Adelaide Hills Gourmet Foods

Phone: 0411 076 525

Email: petertilker@iprimus.com.au

Custom-designed gluten-free, dairy-free and soy-free foods. Wholesale or at Adelaide Showground Farmers Market on Saturdays.

Affordable Organics

Phone: 8333 4325

Website: www.affordableorganics.com.au

Email: affordableorganics@iprimus.com.au

Wide range of health foods including fruit and vegetables, meat, dairy, breads and grains. Located in Magill.

AllergEase

Phone: 0403 759 416

Website: www.allergease.com.au

Email: info@allergease.com.au

Online supermarket for allergy-free products.

Baby Moov

Phone: 0413 977 287

Website: www.roseandlily.com.au

Bébédélance appliance. Prepare fresh, nutritious blended baby food in 11 minutes.

Bellamy's Organic Farm

Phone: 1800 010 460

Website: www.bellamysorganic.com.au

Email: sales@bellamysorganic.com.au

100% Australian-owned-and-operated company providing organic baby food and snack food.

Betterlife Organics

Phone: 0404 828 171

Website: www.betterlifeorganics.com.au

Email: dominic@betterlifeorganics.com.au

Free-range, organic chickens, turkeys and spatch-cocks.

Biodynamic Farm Paris Creek

Phone: 8388 3339

Website: www.bdfarmpariscreek.com.au

Email: info@bdfarmpariscreek.com.au

Fresh, organic biodynamic dairy products.

Bridgewater Greengrocer and Cafe

Phone: 8339 6753

Website: www.bridgewatergreengrocer.com.au

Email: daniel@bridgewatergreengrocer.com.au

Organic greengrocer, supplying organic fruit and vegetables and gluten-free bread, plus organic cafe. Located in Bridgewater.

Central Organic

Phone: 8211 8526

Organic and biodynamic fruit and vegetables, groceries and dry goods located in the Central Market.

Chocolate World

Phone: 8223 3837

Website: www.chocolateworld.com.au

Email: info@chocolateworld.com.au

Dairy-free, sugar-free and organic chocolate ranges available. Located in Adelaide Arcade.

Eclipse Cleaning

Phone: 8258 6371

Website: www.eclipsecleaningproducts.com.au

A wide range of natural, environmentally friendly house-cleaning products.

Continued on next page

Continued from previous page

Eco Direct

Phone: 1300 767 065

Website: www.ecodirect.com.au

Email: info@ecodirect.com.au

Moltex Eco Nappies.

Ecokid

Phone: 1800 882 174

Website: www.ecokid.com.au

Australian-made, organic hair-care range for kids. Specialising in protection against lice.

Enviro Choice Cleaning

Phone: 0434 420 305

Effective cleaning service without the use of toxic chemicals.

Free – the best things in life

Phone: 8357 0094

A range of sugar-free, gluten-free and dairy-free products. Located in Unley.

Fruit to Boot

Phone: 8341 6000

Organic retailer supplying in-season, organically grown fruit and vegetables located in Semaphore.

Gluten Free Travel Company

Phone: (03) 9823 5222

Website: www.glutenfreetravel.com.au

Email: info@glutenfreetravel.com.au

Specialises in international holidays for coeliacs and the gluten intolerant.



Goodies and Grains

Phone: 8212 2324

Email: goodies55@optusnet.com.au

Organic and locally sourced products including nuts, cereals, cakes, teas and biscuits located in Gouger Street, Adelaide.

Heidelberg Cakes

Phone: 8362 5111

Website: www.heidelbergcakes.com.au

Email: info@heidelbergcakes.com.au

Gluten-free cakes for all occasions. Located in Stepney.

Imperial Carpet and Upholstery Cleaning

Phone: 0416 115 866

Website: www.imperialcarpetcleaning.com.au

Allergy-free carpet and rug cleaning.

Island Beehive

Phone: 8553 0080

Website: www.island-beehive.com.au

Organic honey.

Kylie's Gluten Free Bakery

Phone: 8293 4407

Website: www.kyliesglutenfree.com.au

Email: kyliesglutenfree@hotmail.com.au

Forestville store selling gluten-free pies, pastries, wedding and birthday cakes.

Leda Nutrition

Phone: 1800 353 896

Website: www.ledanutrition.com.au

Email: info@ledanutrition.com.au

Health bars with no gluten, wheat, lactose, dairy, eggs or yeast.

Lifetime Health

Phone: (02) 9907 2377

Website: www.lifetimehealth.com.au

Email: info@lifetimehealth.com.au

Australian-made supplements made with pure, natural ingredients.

Mary's Organic Patch

Phone: 8523 4466

Gawler East market, selling fresh organic produce.

Continued on next page

Continued from previous page

Mega Health

Phone: 8332 0066
Website: www.megahealth.com.au
Email: admin@megahealth.com.au
 Health-food retail chain.

Mite-Y-Fresh

Phone: (02) 9986 3432
Website: www.miteyfresh.com.au
Email: info@miteyfresh.com.au
 Allergy-free products including bedding.

Mother Meg's

Phone: 8354 1622
Website: www.mothermegs.com.au
Email: sales@foodnation.com.au
 Gluten-free biscuits.

Nature's Care

Phone: (02) 9485 8888
Website: www.naturescare.com.au
 Specialises in health-food supplements, baby skin-care products and cosmetics.

Nature's Cradle

Phone: 8358 3308
Website: www.naturescradle.com.au
Email: nurturing@naturescradle.com.au
 Natural and organic pregnancy, baby and toddler products available from Brighton store.

Nip Naps

Phone: 1800 215 148
Website: www.nipnaps.com.au
Email: info@nipnaps.com.au
 Leading supplier of cloth nappies.

Nirvana Organic Produce and Farm

Phone: 8339 2519
 South Adelaide organic fruit farm, educational farm walks for schools also available.

Non-Toxic Life

Phone: 1300 887 153
Website: www.nontoxiclife.com.au
Email: sales@nontoxiclife.com.au
 Naturally organic products including bath and hair products, gifts, baby wipes and clothes detergents.

Nordic Nappies

Phone: 1300 725 876
Website: www.nordicnappies.com.au
Email: info@nordicnappies.com.au
 Eco-disposable nappies, and organic skincare and products for pregnant and new mums.

Nui Organics

Phone: 0402 230 000
Website: www.nuiorganics.com.au
Email: sales@nuiorganics.com.au
 100% organic New Zealand merino-wool baby clothing and blankets.

Olive Leaf Australia

Phone: (07) 5424 6771
Website: www.olea.com.au
Email: scott@olea.com.au
 Olive-leaf extract multi-use tonic.

Organic Solutions

Phone: 8172 0422
Website: www.organicsolutions.com.au
Email: info@organicsolutions.com.au
 Organic food, beverages, health and beauty products. Store located in Malvern.

Out of Eden

Phone: 8272 1703
Website: www.outofeden.com.au
Email: belinda@outofeden.com.au
 Organic bath and body products for babies and adults.

Pure Organic Produce

Phone: 0411 117 578
 Organic-produce mobile wholesaler.



Continued on next page

Continued from previous page

Pyramid Organics

Phone: 8524 3677

Email: pyramidorganics@baonline.com.au

South Australia's oldest organic wholesale business specialising in fresh local produce. Located in Lewis-
ton.

Real Organics

Phone: 8363 1911

Website: www.realorganics.com.au

Health-food grocer and butcher located in Norwood. Gluten-free and vegan-friendly goods available.

San Remo Macaroni Co Pty Ltd

Phone: 8261 0555

Website: www.sanremo.com.au

Email: info@sanremo.com.au

Specialty pastas including wholemeal, organic and gluten-free pasta.

Star Allergy Alerts

Phone: 0418 846 490

Website: www.starallergyalerts.com.au

Email: contact@starallergyalerts.com.au

Allergy-awareness badges, stickers, bracelets, EpiPen pouches and children's clothing.

Taralee Orchards

Phone: 8668 4343

Website: www.taralee.com.au

Email: info@taralee.com.au

Eco-friendly accommodation on a biodynamic stone-fruit orchard located in Wirrabarra Forest.

The Coeliac Society of South Australia

Phone: 8365 1488

Website: http://sacoeleliacsociety.com.au

Email: sa@coeliacsociety.com.au

Assistance and advice for people with coeliac disease. Also sells a range of gluten-free foods, such as bread and pasta.

The Gluten Free Beauty Spot

Website: www.theglutenfreebeauty-spot.com.au

100% gluten-free foods, organics and natural beauty products.



The Organic Market and Cafe

Phone: 8339 4835

Website: www.organicmarket.com.au

Email: organics@ozemail.com.au

Certified organic and biodynamic produce and cafe. Dairy-free, sugar-free and gluten-free products available. Located in Stirling.

The Organic Pasta Shop

Phone: 8388 4566

Store supplying organic pasta, located in Balhannah.

The Organik Store

Phone: 8295 7767

Website: www.theorganikstore.com.au

Email: info@theorganikstore.com.au

Store selling organic and biodynamic produce, located in Glenelg South.

Waterco Solutions

Phone: 1300 651 837

Website: www.watercosolutions.com.au

Water-filtration systems.

Wild Thyme

Phone: 8361 8888

Website: www.wildthyme.com.au

Organic market, cafe and wellness centre located in North Adelaide. A range of gluten-free products are available.

Wild Walnut

Phone: 1300 725 987

Website: www.wildwalnut.com.au

Email: customerservice@wildwalnut.com.au

Organic and environmentally friendly products from babies, toddlers and mums.

This article first appeared in the April 2008 edition of Adelaide's Child. Reprinted with permission.

Information about ME/CFS

What is ME/CFS?

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

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

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

Prevalence

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

Main characteristics of ME/CFS

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

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

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

Definition

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to earlier sets of criteria, this new definition made it compulsory that to be diagnosed with ME/CFS, a patient must become symptomatically ill after minimal exertion. It also clarified other neurological, neurocognitive, neuroendocrine, autonomic, and immune manifestations of the condition. The Canadian Consensus criteria are wholly supported by ME/CFS SA and by the National Board of ME/CFS Australia. Copies are available from the ME/CFS SA website.

Diagnosing ME/CFS

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

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

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

How is ME/CFS treated?

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

Therapy for ME/CFS is intended primarily to relieve specific symptoms. It must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies and depression are some of the symptoms which may be relieved through the use of medications and other interventions.

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

There is still a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake intentional exercise. Most ME/CFS patient groups recommend that sufferers pace themselves by starting with gentle exercises and slowly increasing levels of exercise without causing a significant relapse of symptoms. It is important to maintain physical fitness if possible, but we recognise that exercise is not always the best possible use of sufferer's limited energy reserves.

Prognosis

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



Support groups

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.

Contact numbers

Miscellaneous Support Contacts

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

Country Support Contacts

Auburn	Kay Hoskin	8849 2143
Barossa Valley	Dennis	8563 2976
Mt. Gambier	Di Lock	8725 8398 or 0438 358 398 (mobile)
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yorke Peninsula (central)	Caroline	8837 4335
Yorke Peninsula (northern)	David	8862 1668
Yunta	Gloria	8650 5938

Changes

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

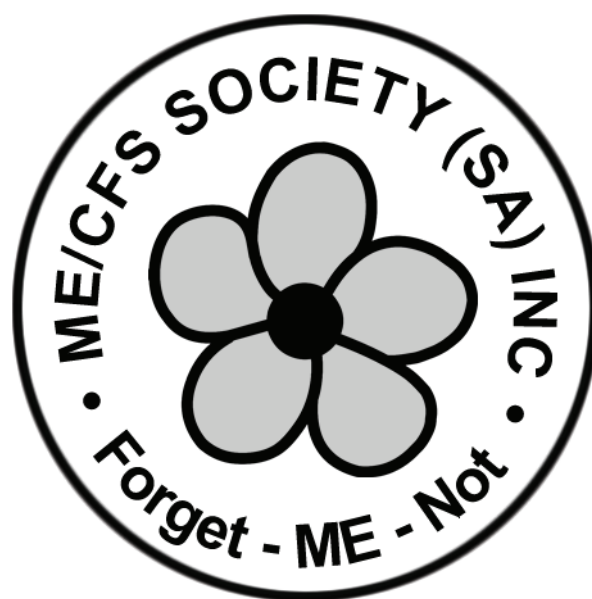
- Mail: GPO Box 383, Adelaide 5001.
- Email: pmrscott@tpg.com.au.

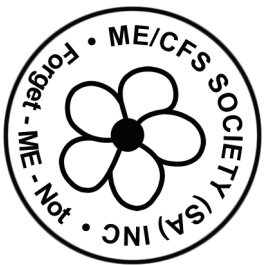
Disclaimer

Please note that meeting times are subject to change.

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

- 8410 8930; or
- 1800 136 626.





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

Print Post Approved:
PP 532154 / 00023

SURFACE
MAIL

POSTAGE
PAID
AUSTRALIA