

## President's annual report 2006

By **Peter Cahalan**, President ME/CFS Society (SA) Inc. The president delivered this annual report for the year 2006 at the Society's Annual General Meeting on Saturday November 4, 2006.

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I want to begin by acknowledging all those people who are part of our community but unable to join in its affairs because of the severity with which ME/CFS affects them.

The last year was one of fluctuating fortunes for the Society. There were times when your committee wondered if we were making inroads into the many challenges facing us. But it's nice to report at year's end that things have gone generally in the right direction.

### Communications

We continued to focus on strong communications with all members as our main ongoing activity. The key elements were:

- **Our website.** Peter Scott has for another year managed the site wonderfully, adding material sent to him from the committee swiftly and easily. The site's high-energy approach has built our audience to over 95 000 unique visits this year – up from the already respectable 30 000 visits in 2004. One result has been an increasing flow of approaches from international societies, e-magazines and others asking to be linked to us in some way or another. We're particularly pleased with our German linkages on the one hand whilst Cort Johnston, who runs a wonderful e-report on ME/CFS research, tells us that he has tracked his high proportion of Australian visitors to referrals on from our site. The site got so busy this year that we experimented with ways to separate local, Australian and international items of interest.
- **E-bulletins.** We maintained weekly bulletins to members.
- **Talking Point** appeared three times during the year. A blip in mid-year took us down from the planned four which our members expect. Thanks once again to Peter Scott for handling this job as well. It's great that at year's end Jenni Gay, a trained medical librarian, stepped forward to begin assisting Peter by sourcing articles for the website and magazine.
- **SMS messages.** We found these to be quite effective in reminding people to come to various events from time to time.
- **Contacting members not on the internet.** Lynda Brett continued to phone members regularly and we circulated batches of printouts of e-bulletins on several occasions.

Perhaps the nicest feedback we had on the communications strategy came from Dr Peter Del Fante. He remarked some months ago that there was a distinct trend in patients mentioning to him that the website and bulletins were helping them feel better by linking them to the latest research and to a wider community of PWCs (people with CFS).

### Seminars

We had planned to run an increased range of seminars this year but for want of someone to coordinate them and other reasons ended up in fact with a slim program. The highlight was a well-attended meeting where Drs Ian Buttfield and Kerry Callaghan talked as veterans in the treatment of PWCs in this State. At year's end Lorenzo Pizza has stepped forward to take on the coordinating job in 2007. So we're hoping for a stronger program next year – and are off to a great start with the planned workshop with international experts in March.

We did have an interesting variation on the normal meeting format earlier in the year. We planned a meeting for parents of children with ME/CFS. In the event, only one person came along – by telephone. So Marg Wing, my wife Penny and I sat with the phone on loudspeaker at our house and Clytie Siddall from the Riverland had a long and interesting discussion with us. It's interesting that this is the second meeting over the last couple of years where we have tried to target parents – traditionally actively concerned about what to do for their sick children – and yet had a low turnout.

### National Association

The ME/CFS Association of Australia Ltd has been hitherto a frail enterprise. With minimal funds of its own and meeting only two or three times a year by teleconference it has struggled to advance our cause nationally. But things changed this year and for the first time the Board met for two days in Melbourne in October. The directors are mainly State presidents although as company directors we are there to take a national perspective.

We agreed unanimously that we had to develop a stronger and more coordinated approach to supporting people with ME/CFS across Australia. Measures agreed to included developing a common name, logo and other branding material to be used by all State societies; a common website and magazine; common fundraising and other literature; and support for the administrative costs of the Alison Hunter Memorial Foundation, the movement's research fundraising arm. We looked at our basic needs and decided that we would have to seek increased support from State societies – from a present \$1 levy per members to as much (or as little) as \$5 a member.

Your committee endorsed these proposals, including the increased levy, at its October meeting. As I write WA has fol-

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lowed suit and so has Queensland with some qualifications.

The development of a stronger national body will put pressure on our budgets and involve some lessening of our capacity to do our own thing. But the State committee is agreed that we have to take this step. I hope that by this time next year you will have begun to see the impact of the decisions taken at the Board meeting.

## The Multiple Chemical Sensitivity campaign

The campaign to extract the maximum benefit from the parliamentary report on MCS was an active one this year. Key aspects of it included:

- An invitation to the Society to nominate a representative to an interagency reference group to be established under the Department of Health to follow up on the parliamentary report. I am taking on that role. But it is frustrating to have to report that the Department has been extremely slow in actually getting the group to the point of holding a first meeting.
- By contrast the Catholic Education Office has been wonderfully cooperative in responding to a suggestion from us that it develop policies and procedures to make Catholic schools chemically safer for all who use them. Debra Paor and Peter Evans and I have served on an informal working party with CEO representatives Greg Simon and Jayne Ryan.
- Likewise the former Department of Administrative and Information Services, galvanised by Disability Officer Monica Leahy, developed the first Disability Action Plan of any State agency to include a range of actions relating to MCS.
- We also lobbied Spotless, which has major cleaning and facilities management contracts with the State government, to incorporate MCS considerations in its operations. We haven't heard back from Spotless but received a cordial response when we met with a senior manager some time ago.
- Society members were well to the fore at a rally in September on the steps of Parliament House in September. At least 11 of the 25 people present to hear 5 politicians speak were from the Society. It was the largest crowd at one of these rallies and the largest number of politicians ever to join us.

## Advocacy

Peter Mitchell, Peter Del Fante and I met with the Director of Primary Health Services for the Central Northern Region, drawn by an understanding that we might have some hope of getting a project officer appointed to research the needs of PWCs. We came away disappointed. One thing the meeting underlined was that if we could show that PWCs are clustered in one or more particular areas, we might have a better case. Well in fact we're spread thinly across every part of the State. But we are now developing from our membership list a map showing where our members live to give us some idea whether there are cluster areas. If so we'll use it in further negotiations with the health authorities.

We've also maintained our membership of the Physical and Neurological Council, the umbrella body for several dozen disability societies. The PNC secured a Department of Health grant to investigate whether its member societies could deliver shared services which might – only might – enable it to secure some measure of State government support. The Society has been clear for some time that we can't get government support on our own so this hopefully a step in the right direction. The end result, we'd stress, is not to get resources for the Society but to deliver more assistance to our members.



Audience at the Annual General Meeting (November 4, 2006)  
If you look carefully, you'll see all members of the new State committee – plus outgoing Treasurer Geoff Wilson (front right) – listening to the president delivering the annual report

## Pilot research database project

The Society was a partner in a project run by Dr Peter Del Fante and Prof Justin Beilby to develop a small database outlining the history of their condition as recorded by PWCs. The initial database ran to 75 people and the final report of the project, which was for some time bedevilled with delays, came out in mid-year. Kristin Clark, one of our members, was the project officer for the database and did a great job.

We also facilitated research projects undertaken by several graduate students during the year.

## SAYME

SAYME had a quiet year. Coordinators Emma Wing and Sarah White were heavily burdened with other committee work and with fulltime study respectively. Nonetheless several meetings were held and Emma published several copies of the SAYME magazine. Her efforts were admirable given all her

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## ME/CFS Society (SA) Inc.

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

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

## Patron

Her Excellency Marjorie Jackson-Nelson AC, CVO, MBE, Governor of South Australia.



## Membership

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

### New Members (cheaper rates apply for renewal):

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

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

## Talking Point

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

## Talking Point Subscriptions:

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

## Management Committee 2006/2007

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

**President:** Peter Cahalan

**Vice-President:** (vacant)

**Honorary Secretary:** Peter Mitchell

**Treasurer:** Richard Cocker

**Management Committee Members:** Lynda Brett; Adrian Hill; Melanie Cocker; Emma Wing

## Contact Details

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

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

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.

At the time of printing the office hours are:

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

Our email address is: [sacfs@acfs.asn.au](mailto:sacfs@acfs.asn.au).

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

Our youth Web site address: [www.sayme.org.au](http://www.sayme.org.au).

## Donations

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



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

## Disclaimer

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

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

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

Always consult your medical practitioners before commencing any new treatments.

## Notice to Vendors

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

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

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

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

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

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

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

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

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

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

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

### Advertising

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

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other work for the Society and we were all delighted when she was nominated for a Young Australian of the Year Award. The committee hopes to give more attention to ways of sustaining SAYME in 2007. For those of us who have been around the Society for some years, its value is very clear. It has a big impact on the young people and their parents who have participated in it and it has also been a training ground for leaders of the Society generally.

## Thanks

The Society runs on the efforts of a fairly small pool of people around the State. Once a year we get to thank them officially. They include:

- **The committee.** Peter Mitchell, Emma Wing, Adrian Hill, Geoff Wilson, Mel Cocker and, in the last month or so, Richard Cocker, have been a terrific group of people to work with. We pay particular tribute to Geoff Wilson as our long-serving Treasurer as he is standing down today. Geoff has religiously attended to the duties of Treasurer and provided sage advice about what the figures really mean – which is the essence of a good Treasurer.
- **The office team.** Mike Ritter is also someone I'd like to thank especially for staying with us for over two years after coming in to join us with no connection with ME/CFS. He keeps the IT side of things well under control and administers our emails, SMS messages and much besides. Lynda Brett regularly gets on the phone to members. Libby Hughes made a great contribution for some months until new work commitments took her away. Emma faithfully held the fort.
- **Support workers.** The committee has learned to appreciate very much the outstanding work of Elaine Balfort, Vicki Foote and Alex Harris who handle a great range of enquiries week in and week out. My thanks also to all support group leaders across the State. I always feel that we give them less than their full due in sch reports. That's because we on the committee don't see a lot of them and so their work goes on quietly and effectively but somewhat anonymously. It's nice to have two leaders – Marion Hansen and David Shepherd – with us today representing this great group of people. Thank you all.
- **Fundraising.** Thanks especially to Adrian Hill again for our annual badge day and to Carol Carroll for organising a team of Annesley College girls (and a few others) to badge sell at the Railway Station. David Shepherd of Balaklava also generously organised the production and sale of torches and pens for us.
- Peter Greco of Radio 5RPH has been our best media supporter. He actually pursues us for stories and has interviewed Elizabeth Cahalan on a monthly segment on spirituality and chronic illness.

## Reflections and future directions

What did we learn in 2006?

- Our focus on communicating with and between members is working well. Not least, there were heartening signs near year's end that more and more members are taking up the idea of taking on some small advocacy task within their capacities and so increasing our collective political clout. It can't all be done by a few committee members, most of them burdened by the administrative aspects of the Society.
- It's not easy to build our financial reserves and get to a point where we have the resources to employ people to assist with administration and/or undertake specific support and project work. So the support of all members in coming years will be vital as we use all the contacts we can to tap business and philanthropy on the shoulder.
- There's local strength in national unity. I was greatly impressed with the range of skills and experience which the National Association's members have. We'll do better over time to deploy the strength of people from all parts of Australia on delivering services to members and on advocacy for everyone with ME/CFS. To some extent in the short run that could well actually divert State energies from other, more immediate work. But at the least by the end of next year I think our members will be getting a strengthened magazine in their post each quarter. And there'll be more benefits to follow. Meanwhile neither we nor any other State intends to support arrangements which will weaken that sense of local community which our societies offer.
- Lobbying is a slow, hard job. The MCS campaign shows that. If you've got a State health system whose administrators are pursuing priorities which don't include us, it's particularly hard. But the MCS campaign has taught us a lot and got us some wins on the board. We'll continue with it whilst also plugging away at the broader ME/CFS agenda.
- A positive spirit is a great asset. I think we have a positive spirit here in our State society. Goodwill and a certain (often naive!!) hopefulness gets people going tackling things which would not happen where people feel downhearted and isolated. The grim challenges of ME/CFS affect just about everyone who has joined our Society and you can't will them away. But my hope is that in 2007 our members feel even more unified and hopeful and aware that a thousand small, manageable actions can collectively amount to quite a big deal over time.

On behalf of the State committee and all who actively work for our cause, I tender this report to the wider membership.

*Peter Cahalan*  
4 November 2006

## Photos:

### ME/CFS Society (SA) Inc meeting – October 14, 2006

Drs Kerry Callaghan and Ian Buttfeld addressed an audience of over 60 people at a meeting on Saturday, October 14 at the Disability Information and Resource Centre.

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They spoke from their accrued experience in treating people with ME/CFS over many years.



## What happens on Wednesdays in the Society's office?

By **Mike Ritter**, ME/CFS Society (SA) Inc volunteer.

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The day starts with material collected earlier in the week. Incoming email from around the world comes into the office and has to be sorted, read, analysed and passed on to members of the committee and others in the organisation. We receive between 75 and 100 genuine email messages from around the world every week, and the information contained within them has to be gleaned out in a way that would benefit the members of the organisation the most. We listen into people's conversations on CFS in the world during the week 24 hours a day 7 days a week by way of a mailing list.

Did you know that we are considered an international organisation? We get emails from all over the world. One of the latest ones was from Northern Ireland. He asked for a doctor to treat him. Unfortunately I politely turned him away. Half a world away is too far away to be of any use to him. I guess all that could be said is that we're easy to find on the Internet.

There was also the time that a student wanted to do some volunteer work for the CFS – otherwise known as the Country Fire Service (CFS)! I had to explain to him that we are the ME/CFS and to look elsewhere. Fortunately it's only happened to me twice. Then there was the Swede who wanted to know if we could provide a translation of our doctor's guidelines. I guess we are easy to find on the Internet – at least far easier than the Country Fire Service website. With over 93,000 visits a year to our site I'm justified in saying that. The Chronic Fatigue Syndrome Society represents 318 financial members but caters for a lot more – in South Australia, interstate in Australia and internationally. Peter Scott does the job of keeping it fresh and new – from a northern suburb of Adelaide where he too suffers from CFS. There is always something to make you want to come back to the site on a regular basis and it's something for free. I can't think of another site on this side of the planet that does the same thing or even something close to it. People from overseas have an eye on Australia and that's why I'm answering international email. Unfortunately, I can't help them and have to turn them away.

During the week we send out emergency SMS messages, e.g. urging people to tune in to a radio broadcast concerning MCS. Only a third of our members are contactable by way of SMS. SMS is good for small messages that have to be delivered into people's hands at short notice within a very short time before the event occurs. We're so connected it's like having our very own broadcast station. With our messages we could even contact a convalescing yak herder in lower Mongolia with CFS if we had to – providing yak herders have mobile phones! It would have taken ages to phone our members individually and tell them what's going to take place – an impossibility. We simply don't have the people resources.

Despite 80% of Australians carrying mobile phones, we only have mobile numbers for only a third of our members. We'd love to have more, and we will not overuse it. It's a matter of doing more with less people in a very quick way. We can send them from anywhere we have Internet access and the messages will find their own way to the member within 20 seconds no matter whether they're in the state or overseas. The messages are sent on a Monday despite no one being in the office until Wednesday.

### Wednesday

A recent Wednesday went like this:

The Wednesday office ritual starts at 7am. There are 270 people to receive special messages through our bulk email program. Our president has been working on the day's messages up until 11 o'clock last night. He emailed it to me and the office and is unsure whether he has accidentally deleted and lost his work. That's why he rang me at 11 o'clock last night. By the way every thing is OK and we get the document in the pipeline ready to send before all the lunchtime Internet traffic makes it impossible for people to get their mail until much later in the day. Peter finalises the written report. It's all spell-checked, proof-read and grammatically correct before it is offered to people. At the same time Peter is in the office asking if we can do things in parallel. In other words, at the same time as the 270 email messages go out he wants to contact Radio ABC to tell them about the Multiple Chemical Sensitivity Rally on the steps of Parliament House next week. At this stage, the 4 computers on our network start to struggle with all the traffic.

The computer labours under the load as we send the letter to Radio ABC. The computer jams up. The memory is full. The outgoing path into the Internet is narrow and is now grinding to a halt. We'd really like the latest computer with lots of memory and dual CPUs to swiftly take care of the intense workload, but that's not going to happen. We have to make do with what we have. The only thing to do is to walk away from the computer while it is doing all this. Let it sort itself out and do all the jobs before continuing. There's nothing much more we can do with it except move to the next computer and update the members' database. I've calculated we've sent between 20,000 and 22,000 emails since we started with the committee's communication policy.

Emma Wing updates the database. The file server is getting old by today's standard, and just getting on it for the first time

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of the day requires patience. We have to print out membership receipts on the office's laser printer. Not all of our members join up instantly and we've decided to write a reminder notice to them. That's 180 letters to be addressed and sent out. Not a problem, we have Emma's sister in the office and they both get on the database and make labels for 180 people and draft a letter. The laser printer also runs hot. At the same time we answer our incoming snail mail and forward important documents that have been scanned in to the computer and also sent by way of email to the secretary Peter Mitchell. Peter is unable to get into the office because of CFS/fibromyalgia. The computer is still jammed and the emailed pictures of the letter are not helping. The outgoing bandwidth is designed for one computer in a typical home. It is lacking for an office of 3 interactive computers and a file server in the city at peak load times. The trick is to spread the load over several hours if that's possible so things don't grind to such a halt – but that's not always possible.

There have been 27 phone calls since we were in the office last week. For the people who have left a message each one asks for help of some sort. There's never a telemarketer on the answering machine and Emma, who answers all the calls, has a sense of relief as most of these callers hang up in disgust that there is no one in the office to talk to. They simply don't leave a message for us to call back. For the people that do leave a message we find that there are a number of interstate callers who would like to know the name of a doctor who can help them out. The Society only caters for members in South Australia.

Lynda Brett is also at it. She's started at 11 am and has written a letter to the morning radio program asking for help raising funds. Did you know the committee and volunteers raise \$80 for each member to have the Society keep going? By any stretch of the imagination that's a good deal. Invest in a \$25-\$30 membership and have \$80 worth of funds working for you. That's what Lynda's doing. She's trying to raise funds and it's not enough to just write. You have to write well and Lynda has a number of drafts to refine the correspondence. After all, if you don't put in the effort it will get instantly rejected because it's not up to scratch. We'll see how it turns out in the next few weeks. Do we get the cooperation of the radio station or not?

During all this the phone rings. One such caller says she'd like to join. She has two daughters who would like to join the youth group but because it's close to the middle of the year

will hold off until January. She'll save \$12.50, but little does she know we would have spent \$40 for her on the dollars she saves. With the Society's resources and computers used in smart ways to do as much work as possible she's really dealing herself out of a bargain.

Most of the people in the office don't suffer from CFS. People with CFS just can't work for very long periods of time without the threat of relapse and fatigue. There is only one person with CFS in the office regularly, and that's Emma Wing. I've noticed there are two types of people in this world – reactive and proactive. A reactive person wishes there were something better in life without actually doing anything while a proactive person tries to do something. Emma is proactive. Constantly battling fatigue herself, she works with the chronically ill. She works with clerical members that have varying degrees of skills and understanding of Chronic Fatigue Syndrome. She demon-

strates an ability to work with others in a collegial, constructive and productive manner despite her persistent fatigue etc. (you all know the symptoms). She is on the committee and a worker in the office. All our other volunteers don't have CFS – most are carers for people with CFS. No one is paid.

Our Talking Point magazine is running a bit behind its usual publication date. It turns out the magazine has been at the printers for at least two weeks and the printers have been on holidays. People inquire by phone whether they have missed out.

I'm fast coming to the conclusion that we do a lot in the office in a very short space of time. People just don't know it. And if we want more from the Society we will need more volunteer time. We are running clever and

at capacity. We always love to hear from people wanting to offer their time to help others with CFS and their families.

So there you have it. When the next Wednesday comes around, think of us and what goes on in the few short hours. There's a burst of activity in the city office for there's not much more we can really do. And I've done things that only the character of a complete rogue would do. But of course this must be always done with a sense of humour.

*Respectfully,  
Michael John Ritter,  
Volunteer Chronic Fatigue Syndrome Society (SA) Inc., Wednesdays (7 am – 3 pm).  
Office manager and IT Computing Infrastructure Coordinator.*



Mike Ritter

## School and kids with CFS

By **Mary Campbell.**

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In this society education is important for everyone's future, from a basic understanding of the world, to career prospects. Schooling is also valuable for children because they are given the chance to relate to their peers and teachers. Learning gives young people an interest, a sense of achievement and a purpose.

Complications arise when because of health reasons, kids are unable to attend school and/or complete work in the same way as a normal healthy child. I have struggled with Chronic Fatigue Syndrome (CFS) since I was 10 years old, and have tried to attend and complete classes since. From trial and error, and with help from my parents and others, I have learnt a great deal. I have learnt information from the school curriculum, but I have also learnt about society, politics, and people, and by the time I attended college (years 11 and 12) I had learnt how to minimise the stress and difficulties that occur when trying to attend school while living with a chronic illness.

The most important advice I can give to kids with CFS is to be dedicated and diplomatic, and that applies to parents too. Kids: if you want to have an education, you have to show your teachers that you are serious. That means asking for work on the days you've missed, turning up to all your classes (unless you are unwell) and behaving in class. You need to respect your teachers and earn their trust. Because you have CFS, you are not an ordinary student and you are asking to be treated with special consideration. Many kids wag school and don't care about their studies and if you are one of those kids it will be hard for teachers to believe you are genuinely ill. Teachers work hard, often marking student's work until late at night and on weekends. They also face many students trying to get out of work or get an extension to an assignment, purely because they are lazy and/or don't want to work.

There is a cloud that is lifting in society in general over whether CFS is a real disease or not. You, as a student, need to make sure you don't give your teacher any reason to believe you are faking. But more than that, teachers work hard and you are asking them to spend extra time on you. This is where there is a need for diplomacy and persistence. 'The system' doesn't easily accommodate people outside the box, or the norm.

For your school to understand absences and acknowledge your illness you will need to have a supportive doctor. A supportive doctor will not only write doctors certificates saying you have Chronic Fatigue Syndrome, but also include on those certificates an explanation of symptoms, what allowances you might need and problems which might arise (such as periods away from school). Also, your doctor will need to advise your school on different strategies at different stages of the illness. A supportive, accepting doctor is essential for any CFS suf-

ferer, and essential for a child to be able to successfully complete their schooling.

The following are strategies that worked for me in Primary School, High School (7-10) and College (11-12), each building upon the other.

### Primary School

In primary school, my parents arranged with the school for me to tell my teacher when I was tired and leave class to rest in the library. All I needed was a note to get extensions for assignments. At the time, I saw a doctor who recommended I increase my exercise (which I now believe was the wrong advice) and therefore I still participated in Physical Education (P.E.), and took a note from home on those days I was particularly ill and could not do PE.

Parents need to take the lead for Primary school children, petition their cause, give them support at home and encourage them to spend time with their friends. It is important for children to have some sort of social interaction. The best thing the kids can do is quite plainly, be good in class. However from what I can gather in most cases this isn't a problem, because kids with CFS are too tired and/or unwell to play up in class. They find it easier to be compliant and do the work asked of them.

### High School

My health improved for years 7 and 8 so, while I felt tired constantly and had to rest a little more than my peers, I led a normal active life. In year 9 my health declined again and I was unable to attend school. My teachers and finally the distance education coordinator sent schoolwork home, but even though I tried, it became clear I could not do any schoolwork.

If you are housebound it is important to try to do distance education and work from home without overextending yourself. This will keep your mind busy and give you a sense of achievement with each piece of work you complete. Distance education will help you to continue schooling when you are able. It will decrease the chances of you having to repeat a year and lessen gaps in your general knowledge. No matter how much time you've had off, working from home will make it easier to catch up when you return to school.

When you have been away from the school environment it can be quite daunting to return and gradual steps make this easier.

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I found the transition smoother because I kept in touch by phone with a couple of school friends, so I knew what to expect when I returned. For the record, school really doesn't change and from a social and managing aspect it was very simple to slot back in to school life.

From a health aspect, don't return to school until you feel you can handle it. And return at the rate you can manage, even if that is only one or two subjects. In some cases only a portion of a subject course will be enough, perhaps learning, but not doing any assessable items. Of course this depends on your condition. Don't jump in head first to a full load, because most likely it will be detrimental for you health, your schooling and your confidence. Push yourself too much, too soon and you will consequently be set back. Having said that, if you do find you are doing too much, too many hours, too much homework or you find the work too difficult, this will be reflected in your symptoms such as tiredness or pain level. Do not hesitate to drop subjects or, if you are only doing one subject, to stop attending school. It is not a failure, you just weren't ready. You can always pick up those subjects when your health improves and you feel ready. Put your health first.

## Strategies

My teacher had an idea that truly helped when I was doing 3 subjects in year 10 and I carried it through to year 12. She recommended I do unfinished classwork, homework and assignments at school if I could, with regular rests. This means you can do school work without distractions such as family, TV etc. This also means that when you are at home you don't have to worry about school. Home will become a place where you can wind down, relax and rest without the pressure of having to do more school work hanging over you.

Another point she made was that a change of subject can be as good as a rest. So when you are doing school work (out of class), alternate work on different subjects to help your concentration. I would tend to rotate, for example Maths homework, an English assignment and resting. Don't try to do big slabs of work in one go, it's best if you do what you can handle, which might only be 10 minutes on each subject. The time you can spend between resting will depend on (be dictated by) your personal health/stamina.

This also applies when deciding on your workload and how many subjects you do. If you are able, it is preferable to do two or more subjects, so you are not completely consumed by for example maths, and particular problems you may be having with the maths work or the teacher at that time. Again, you will get some relief from maths while you are in another class or doing homework for another subject. If you can, organize to be excused from less important assessment items for subjects, so you can do more than one subject. I found this bene-

ficial. Basically, if you do more than one subject and you rotate work from each subject and resting, it will mean that you will be less stressed and one subject (in effect all school work) will not become a mountain.

For your future education's sake, start with core subjects: Maths, Science and English and Social Education (History and Geography). This will give you the basics for future study and life. However, your doctor may recommend you do an elective of a subject you enjoy, again to take the pressure off and keep you motivated towards study.

In particular, if you are doing more than one subject it is important to tailor your timetable as much as possible to your needs. For example, I was stuck with a timetable that meant on Fridays I had one subject first in the morning and then another last in the afternoon. Because I lived out of Canberra this meant I had to stay at school all day and even though I had a room to rest in, it took a toll on my body. This may also be a problem if you have to catch a bus both ways and you find bus rides tiring. The day might take too much out of you. You may also find it difficult to concentrate for two whole subjects in a row without a break (basically 2 hours). Therefore it would be beneficial to organize your timetable so you do one

subject and then you have a period off before you do the next. For some people just to have recess (to either rest or chat to your friends) in between classes will be enough. The social aspect of school is also very important. It's important you get a chance to see your friends, to talk to people and have some support and this should also be factored in when deciding your timetable. Of course, your timetable will largely come down to your choice of

subject and the school's timetable.

Because for a few years I was only doing 2-3 subjects, my father drove me to school and back. This reduced the toll that school took on my body a great deal and had I not had his help, schooling would have been much more difficult. If it is not possible for a parent to drive you, and school or bus rides are too much, distance schooling is always an option. Talking your situation through with a teacher (for me my counsellor) will give you ideas on solutions.

## Finding an advocate

I recommend from high school age finding a teacher to further/petition/represent your cause. In my case I had a very helpful counsellor who came up with many of the ideas for the logistics of managing school. The person you choose needs to be sympathetic to your situation and willing to push forward your case and put pressure on other teachers if necessary. For this reason it is best to pick a teacher who has some power. Some suggestions are, your counsellor, year co-ordinator, spe-

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cial needs teacher, or a subject head you have already found helpful. As a rule I wouldn't suggest the principal or deputy principal because most are so busy they won't have the time to help you. Again, you need to work in co-operation with your teachers, basically all your teachers will have to spend extra time on you, and do extra work for you. Because you are not the usual student, they will have to explain their actions in regards to you, to other teachers. Don't abuse the leniency and the trust they give you, as they are under no obligation to make things easy for you.

In High School, if you have a helpful teacher they will talk to other teachers for you (both those listed and your subject teachers), but particularly in College it is important that all the relevant teachers are informed and consulted about your situation.

My counsellor spoke to all my subject teachers about my condition and she also sent them a letter explaining that I might need extensions for work and longer time for tests. She also sent some pamphlets about Chronic Fatigue Syndrome to them. When I went to class, my teachers talked to me and got to know me, so they knew I was serious about learning. This helped as they now had some knowledge of CFS and of my specific condition. When I did need extensions, I found my teachers very reasonable and understanding.

### **Accommodations**

There are many aids you can ask for. You can ask for extensions for assignments and homework, and you can ask for extra time for tests and in class assessment pieces, without losing marks. For instance, I sat a test over three half hour sessions on different days, instead of sitting it in one, hour lesson. If there is a large amount of homework, you may be able to organize with your teacher to do only the most important homework. If this does happen make sure you are not penalized for not handing it in. My science teacher penalized me this way once, so while I received 80% for everything I handed in, he gave me a C.

Both in High School and in College I asked for a room where I could lie down in and rest any time I was not well. This was a quiet, rarely used room in the school. Both in High School and in College I had to ask for a key each time to open the room, and I was rarely disturbed. Ideally you would have a room for yourself, but in most schools this is not possible. Occasionally I had to leave the room because another class wanted to use it. There was a desk in the room, so I often alternated resting with some schoolwork (this was quieter than the library, and I could immediately lie down if I needed to). I bought a beanbag I could lie down on and took my Walkman to school so I had some music to listen to when I was resting. This is better than the sickbay because firstly, sickbays are noisy with people walking in and walking past all the time, and secondly, it is not helpful to be around sick people every day for someone with CFS.

One of my worries about returning to school was that mid-class I would get extremely tired, or be in pain and that the teacher would not let me out of the room. My counsellor said that it shouldn't be a problem with my teachers because she would talk to them. However I was still worried about relief teachers who knew nothing about my situation. My counsellor gave me a card, basically saying that I had Chronic Fatigue Syndrome and that I could leave the class at any time without reason. It had her signature and name down the bottom of the card. I also arranged for one of the teachers in college to give me a similar note. Although I never used the card, I believe it is a great idea, because if you are feeling unwell you do not want to be trying to convince your teacher of that, especially a relief teacher who is likely to think you are lying. Do not abuse this privilege.

I would like to stress the following points. Don't tell other kids you have your room because they are likely to want to go in with you and talk when you need to rest (the teachers therefore may not believe you need it for resting if they find other kids in your room). It's better to join your friends on your terms, in the playground at lunchtime, or recess or before or after school.

Don't tell and especially don't show off to your friends that you get extensions or may not have to do a piece of work. If you do, they may challenge your position and ask why you get an extension and they don't. They could also challenge your grade etc and make life difficult. In this respect it is better to be discrete. The same applies with your note to get out of class. Kids rarely understand this illness and won't want you to have an advantage over them, whether it means getting out of class or getting out of doing homework. If students do challenge your special case, it will be harder for the teachers to cater for your illness. It is a lot easier and causes fewer problems to have a blanket rule for everyone.

There are people in society who do not believe that CFS is real and this also applies to teachers. In year 11, I approached my maths teacher after my first lesson to talk to him about my situation and to explain that I would need extra time for assignments etc. As soon as I said I had CFS he replied sarcastically "Oh everyone seems to be coming down with that", implying that I was faking and I did not have a real illness. This took me back a step. He begrudgingly said "Yeah OK" to my other requests and abruptly left. There were many other maths classes running in my school so I just changed classes. In the end people like that will just cause problems for you so my advice is to avoid them, if possible.

It may be difficult to organize these concessions and ultimately you will have to work around the schools facilities and rules but it is important to organize it, for the best impact on your health, your education, and your social and psychological well being.

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## College

When it comes to College (years 11 and 12), you are old enough to take your studies largely into your own hands. Your teachers will expect you to come to them and explain your situation rather than, or as well as, hearing it from your parents or another teacher. As much as most young people may not want to spend time talking to teachers, it is important to talk to them about your situation, your options and to make general chit chat/small talk. You need to give your teachers respect and not treat them as the enemy. If possible try to be kind, sincere and likeable. As I said, it is advisable to approach teachers yourself. This includes finding a teacher to represent you as well as informing other appropriate teachers of your situation: your subject teachers; counsellor; special needs teacher; year coordinator; student programs (the teachers who organize timetables) and school and careers advisor (who will help you work out a plan to complete your Year 12 Certificate, and/or do the HSC and tell you which prerequisite courses you will need if you choose to go to university). There may be other teachers you feel need to be informed. You need to be comfortable in fighting for yourself and telling your story.

You will meet other teachers on the way, and as I've said before, it doesn't hurt to get them on side. For me, when I had a particular requirement, I found out that the teachers had discussed me, and the problem, in the staff room before they came to a decision. One of my subject teachers was able to stand up and support my case because she knew me in class to be a good student. I had previously informed other teachers so no teachers were taken by surprise, or were suspicious of my sincerity. This helped my situation.

However, you may come across teachers who do not respect you as an adult and do not wish to help you. In this instance, you can tell your representative teacher and in most cases they will talk your teacher around. If that does not work or your representative teacher is not helpful, bring your parents in to talk to them. If that doesn't work, arrange a meeting with you, your parents and the principal to talk about your schooling.

As with a normal child or adult, balance is very important for physical and psychological well-being. You need to have a balance between exercise (walking around the corridors at school may be enough), school and mental stimulation, pleasure (whether it is playing a musical instrument, watching TV or playing on the computer), spending time with your family and spending time with friends. Having CFS can be a very isolating disease. As well as the losses incurred when you lose an active life, many children lose friends as well. It is hard particularly for kids to understand CFS, especially when the lifestyle is to stay up all night. Parents and doctors should encourage kids to spend time with their friends, in and out of school.

If you aren't able to go out of the house much, letters and

emails can help you keep in touch. I found talking on the phone was useful because I could talk to my friends without getting as tired as when I saw them in person. But remember to pace yourself and when you begin to feel tired end the phone call. If your friends don't understand that you have to go because you do not feel well, you can always say your parents need to use the phone. When writing and reading letters, don't feel obliged to finish them in one go, read or write little bits at a time and you won't feel as tired.

Because of the symptoms you suffer due to your condition (such as reduced concentration) and/or if you have missed school, you may not be able to handle the level of work you previously achieved. This may mean making an adjustment to lower standards by accepting lower test scores and marks. It may even mean doing a less advanced level of schoolwork. This is unfortunate, but your health must come first and hopefully as you build up your reserves you will be able to take on more.

In class, sometimes I was well enough to attend, but not work. On these days I listened to the teacher and kept a low profile. Sometimes my concentration ran out part way through class, so I would just sit quietly until I felt a bit better. Then I'd resume my classwork, or wait until the class ended. Because my teachers had some understanding of the illness and because I kept a low profile and wasn't disruptive no eyebrows were raised.

From years nine and ten upwards it is important to be diligent with your studies, even if other kids aren't. Don't be slack and not do homework because you don't want to. If you are away make sure you approach your teachers and get the work you missed. This will prevent you from falling further behind.

## Conclusion

Despite all your efforts to be diplomatic and likeable, you are likely to face obstacles during your education and some may be difficult to overcome. Some teachers may treat you unfairly, lower your grade because you have not completed all items, or may not be very lenient. Unfortunately, this is within their rights because they have a set of rules that apply to all students, and they may expect you to abide by those rules even though they may not be realistic for you in your condition. I recommend approaching other teachers who have been helpful and asking them to petition your case, but if they won't or can't make any ground there is little you can do, unless you are outwardly being discriminated against. Most teachers will be helpful and sympathetic as long as you take a mature attitude to your studies. Of course the more CFS is recognized as a valid illness by society the easier schooling for young people with CFS will be.

With hard work and determination it is possible to continue school and do well while living with CFS and in doing so, to gain a feeling of achievement knowing that you have succeeded at schooling despite obstacles you have had to face.

# How hard it is to be me!

By Michelle Lee.

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**My goals: to become a successful photographer; to play basketball at the highest level I can.**

Most people who know me would never know how hard it is for me to be me. I always try to have a smile on my face as, no matter what my problems are, there is always someone else worse off than me.

From a very young age basketball was my life. That's all I cared about. I would train most nights, play the others. The end of my high school years became the changing point. I was never diagnosed with glandular fever but now know that's what it was and, like most people with CFS/ME, I never recovered. My Mum was and is my rock; she believed in me when I said, "Mum there is something wrong" when everyone else said, "But you look fine to me". Doctors soon became my enemies. I hated going to them just to have them tell me that I have an eating disorder, or depression, or there is nothing wrong with me.

My Mum and one of my closest friends took it into their own hands. They jumped on the Internet and looked up all my symptoms and found something called CFS/ME. All I wanted was to be able to play my basketball at the highest level I could and play the full game, like I once could. I have always been very driven and was not going to let my body stop me from doing what I wanted.

I would get up for school an hour before I really needed to, so I could just sit on the couch and push myself for that hour to have a shower. Even talking didn't happen for at least the first thirty minutes. Then getting home from school I would do my homework, if I hadn't finished most of it at school, have dinner and be in bed by 7 - 8pm every night.

When I was about 21 things really became a struggle. I was playing Big V (VBL) basketball and lucky for me I had a very understanding coach at the time, as I was struggling to play two minutes then nearly passing out. I was still nominated for the rookie of the year that year and this was more motivation for me to get better and win an award.

So, once the game was finished, not only was my heart broken from not being able to perform at my best, but my body had the shakes, I felt light headed and barely remembered the game that had just happened. Something was really wrong. At the age of 21 I was diagnosed with ulcers in my stomach and irritable bowel syndrome. My asthma was getting bad and then to top off the year I contracted shingles. This was all to test my will and strength and, boy, did it!

Some days I would train and feel fantastic and think, "There is nothing wrong with me; maybe it's all in my head; yeah I'm

fine". Then the very next session I would struggle so much that I would have to pull out, then go home and the reality would kick in that I do have a problem that won't go away easily and the tears would start. But I never let it beat me down. Part of me would fire up and want to beat this. Nothing can stop what I want – I want to play basketball and I want to be a photographer – that was my drive. I believe that if I didn't have my drive I would have been at the extreme end of CFS/ME, but I refused to let it happen, not me, I'm going to get out of bed, I'm going to work.

I was also very lucky that I had a photography job with a fantastic person who would let me start work at 11am and finish whenever I needed, which most days was around 3 - 4pm. A lady I worked with also became very interested in my problems, so at this stage I had my Mum, my closest friend Kemp and Maree on the case to help me get better.

The season finished and a new coach was appointed. In my head I knew I could play – I should say I was skilled enough to play – but my fitness was nowhere near where it needed to be, so this coach dropped me from the squad. This was a huge wake-up call. I needed to get better, this was my dream and my life was playing basketball and now I'm not good enough.

Mum had researched and found that taking Q10 and vitamin B could really help with my everyday energy levels. I was willing to try anything. I was accepted into another team straight away and was going to prove that I could still play this game I loved so much. My new coach was very understanding and would play me to my strengths, which were short stints on the court. I had the best playing season that year, only averaging 15mins a game, but most games over 10 points. I was so driven to prove that I could beat this and being dropped made me more motivated. I also started to take something called liquid oxygen. It helps with the lactic acid build up in the body, which was one of my major problems. I had figured out that I needed to take it about three hours before a game and I was leaps and bounds ahead of where I was before. I could start to see the changes. This is all with no doctor's diagnosis.

I was still fighting colds and flu, so Kemp said that she had had enough and took me to her doctor who actually believed that my symptoms were real and that it was CFS/ME and sent me to a specialist. This was the greatest thing that could have happened to me. Someone actually believed me.

My first appointment was at 8am – funny for someone with CFS/ME to have an 8am appointment – but I made it. He didn't want to take on any new CFS/ME patients as he now specialises in allergies but due to my age he thought he would

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## Massage: releasing the tension and the fear

By **Mary Campbell.**

I was very apprehensive when I decided to give massage another go. I know of the healing properties, illustrated by the fact that it's a must for any sports person. It's one of those things where you know it's good for you. You know it will loosen up your muscles and that's definitely a good thing when you're tensing them because you are stressed and because you have pain. You know it should be relaxing and most people love getting a massage. But for me, it evoked feelings of fear from last time.

Many years ago I had a massage and the experience was a double edged sword. On the one hand, I relaxed. It increased my circulation and helped release the toxins and in the long term helped my muscles. However, on the other hand, it was painful when I was being massaged, and I was exhausted afterwards. I remember going straight to bed afterwards and it was around three days before I felt I could function again. Despite the positive benefits, it took too much out of me to try again for a few years.

This time I prepared myself. As I knew that it would tax my body, I rested before the massage and cleared my schedule so I could just go home and sleep after. It helped that when I walked into the waiting room they were very professional and took a full history. This included indicating on a diagram where I felt pain (something I've filled out for neurologists and other medical professionals in the past).

It's funny because despite me being so sick I could barely function all those years ago, all the tests from the doctors came back negative. According to the tests I was perfectly healthy. But the masseur last time said she could feel the massive knots in my muscles, she could feel I wasn't well. It was nice to have the recognition.

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take me on. This really opened my eyes to how stereotype my problem was and that I was no different to everyone else who struggles with CFS/ME. The doctor ran a whole bunch of tests and sure enough all the common CFS/ME problems were there. The main one was my magnesium level, well below what it should be. I had also gained new allergies, but not sure what the cause was, so along came the EXTREME diet.

The diet eliminates most food and takes you back to the extreme basics. I learnt a lot about natural foods and the natural chemicals that can also harm us. It took me about eight months to finish the diet and I was feeling fantastic. I was waking up in the morning and able to talk straight away and make myself a decaf coffee. It was very hard to stick to, but

The lady last time was very gentle, and said she was as light on me as she's ever been on anyone, but still half the time it hurt. But I'm no stranger to pain so I didn't worry too much because I could feel it working, but still when I look back at it, it's not something you would want to do often.

This time I lay on the table and explained to the lady that I'd feel more comfortable leaving my jeans on. Before she began the lady this time looked at my chart. She noted my CFS and offered to cut my session short so I didn't get too tired. I said "I think I'll be fine for the full hour, but I'll see how I go." She asked me if there was an area she'd like me to focus on. I could also mention areas that were too sore, so we could skip then. When she began the massage she was careful to get feedback from me, to make sure I was comfortable and was happy to press lighter when it started to hurt a bit. The rest of the time she was very gentle and slowly I relaxed. The massage actually felt great.

She asked if I'd like her to massage my legs, and it was good because the intensity was reduced through my jeans – I have been having a fair bit of pain in my knees lately, but this was just gentle enough.

After the massage I felt relaxed. My muscles and joints felt easier to move. I went home and drank lots of water to flush out my system. I also went to bed as planned. I slept very well that night. And the next day when I woke up I was functioned as per normal, except, with my muscles easier to move. I've decided I'll treat myself to a massage once a month.

I'm glad I didn't let my fear stop me from trying massage again.

again I was driven by getting better, so I can play that full game of basketball and do a full day's work.

I know that this is going to be something I struggle with all my life; I can manage it now, but I know there will always be the chance of slipping back to where I was. If I forget to take all my vitamins or eat the wrong things or party too much I pay for it.

But I'm playing longer minutes now. I actually went for a long jog and didn't need to stop. I am working full days and enjoying life to the fullest. So I have reached my goals; it's just a matter of maintaining them and making new goals to reach.

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# The debate: myalgic encephalomyelitis and chronic fatigue syndrome

By **Dr Charles Shepherd**, Medical Adviser to the ME Association (UK).

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Talking Point – 2006 Issue 3

## Abstract

Almost every aspect of myalgic encephalomyelitis (or encephalopathy) and chronic fatigue syndrome is the subject of disagreement and uncertainty — something that has undoubtedly hampered recognition, understanding and research. Although the pathogenesis remains the subject of intense medical debate, a number of predisposing, precipitating and perpetuating factors are now starting to emerge. Therapeutic nihilism is no longer appropriate as there is a great deal that can be done to alleviate some of the more distressing symptoms and improve quality of Life for these patients.

### Key words:

- Chronic fatigue syndrome
- Myalgic encephalomyelitis

Mention the terms myalgic encephalomyelitis (ME) (or encephalopathy) or chronic fatigue syndrome (CFS) to a group of health professionals and they will produce a variety of opinions on cause, management, and even their very existence as distinct clinical entities.

Controversy and uncertainty surrounding ME/CFS is nothing new and largely dates back to an editorial in the *Lancet* (1956) that introduced ME into medical language as a severe post-infectious illness involving muscle and brain symptomatology. But medical opinion remained sceptical and it was only during the early 1980s that interest was renewed — one result being the redefinition and renaming of ME as CFS.

In 1998, in an attempt to produce a degree of consensus, particularly in relation to diagnosis and management, the Chief Medical Officer (CMO) appointed a Working Group to produce a report (Hutchinson, 2002). The CMO report concluded that ME/CFS is a genuine and disabling illness that imposes a substantial burden on the health of the UK population, and called for a programme of research, education and the availability of multidisciplinary services.

## Nomenclature: a disease of many names

### ***Myalgic encephalomyelitis/encephalopathy (ME)***

As encephalomyelitis describes an unproven pathological

process — namely inflammation in the brain and spinal cord — many doctors have become reluctant to use this term. Some, including the author, have suggested that encephalopathy is a more acceptable way of describing the various neurological abnormalities and symptoms.

### ***Chronic fatigue syndrome***

CFS is a name that makes no firm assumptions about cause. Two major criticisms of the term CFS are that it fails to reflect the symptomatology and severity of the illness — in the same way that chronic forgetfulness syndrome would be a totally inappropriate description for dementia — and that it has become a convenient label for anyone with unexplained chronic fatigue.

### ***Post-viral fatigue syndrome***

PVFS was introduced in the 1980s. While this description is generally acceptable to both doctors and patients, it is obviously not appropriate in the absence of a clear cut viral onset.

Clearly, there needs to be nomenclature upon which both doctors and patients can agree rather than resorting to the ME/CFS compromise — a term that covers a heterogeneous group of patients with differing symptom complexes and responses to treatments.

## Symptoms and definitions

ME/CFS is characterized by severe, disabling physical and mental fatigue, both of which are markedly exacerbated by relatively small amounts of exertion. Fatigue is accompanied by post-exertional malaise whereby there is a delayed impact so that symptoms are often worse later in the day, or the next day, following activity. The way in which patients describe their fatigue is very different to normal everyday tiredness.

Other characteristic symptoms, which also often fluctuate in severity, include (Hutchinson, 2002):

- Cognitive impairment, particularly involving short-term memory, concentration, information processing, ability to plan or organize thoughts and a short attention span
- Pain, which is sometimes persistent and may be severe. The pain can be muscular, arthralgic or neuropathic - where it is described as burning or searing in quality; not all patients have pain
- Neurological disturbance presenting as problems with balance, paraesthesiae, increased sensitivity to various

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stimuli and autonomic dysfunction presenting as postural hypotension or postural tachycardia

- Headaches, which may be migrainous in character
- Sleep disturbance, which may range from hypersomnia (increased requirements) through to insomnia as the illness becomes chronic
- Sore throats, enlarged glands, on-going flu-like feelings
- Disturbances in temperature control with sensitivity to both heat and cold
- Alcohol intolerance, drug and chemical sensitivities.

More serious neurological symptoms may occur in a minority of patients, particularly those at the severe end of the spectrum. These include double vision, blackouts, atypical convulsions, and loss of swallowing ability — which may require assisted feeding. As with any chronic disabling illness, some patients go on to develop clinical depression or other disturbances in mood.

A number of definitions of CFS have been proposed primarily in an attempt at producing an homogenous group of patients for research purposes. The most recent and widely used (Fukuda et al, 1994), requires the presence of:

Six months or more of persistent or relapsing chronic fatigue resulting in a substantial reduction in previous levels of occupational, educational, social or personal activities, plus the concurrent occurrence of four or more of the following symptoms:

- Cognitive dysfunction
- Sore throat
- Tender cervical or axillary lymph nodes
- Muscle pain
- Headaches of new type, pattern or severity
- Unrefreshing sleep
- Post-exertional malaise lasting more than 24 hours
- Multi-joint pain without swelling or redness.

Research criteria for CFS also require the specific exclusion of a number of medical and psychiatric disorders that may cause chronic fatigue.

The introduction of research definitions has undoubtedly helped to stimulate research but in the absence of subgrouping (e.g. the presence or absence of psychiatric comorbidity) the results often leave many questions unanswered.

A major practical problem is that research definitions have not been designed or modified to cover the routine clinical assessment of patients as well. One group of physicians has recently put forward guidelines, the *Canadian Consensus Document*, that are designed to meet clinical rather than research needs (Carruthers et al, 2003).

## Disability assessment and quality of life

Most patients fit into one of four categories of disablement, which are based on an assessment scale devised by Cox and Findley (1998):

- **Mild:** patients are mobile, can care for themselves, and are usually able to perform light domestic tasks. Some will be working full time or be in education; to work, they often have to stop leisure or social pursuits
- **Moderate:** there is significantly reduced mobility and restrictions in all aspects of daily living, often associated with peaks and troughs of activity. Some are able to just about cope with flexible part-time work or education but usually require a prolonged rest period in the afternoon
- **Severe:** Often require assistance with personal care such as washing and are unable to cope with domestic tasks such as cooking. Mobility is severely affected and they may require wheelchair assistance. Some will be largely house-bound
- **Very severe:** Require help with almost all aspects of daily living. Confined to the house and may be bed-bound.

Studies which have examined functional status and quality of life measures (Komaroff et al, 1996) confirm that the impairment of physical and mental activities can be just as great, or greater, than is found in many other chronic medical conditions.

## Epidemiology

Problems with definition, and the lack of any large-scale epidemiological study being carried out here in the UK, mean that estimates of incidence and prevalence have to be viewed with caution. In particular, the use of current case definitions may well be producing an under-estimate of the true prevalence, particularly the numbers with severe ME/CFS.

Overall, the CMO report (Hutchinson, 2002) used current evidence to conclude that:

- The population prevalence is at least 0.2%–0.4%
- The most common age of onset is between early 20s to mid-40s
- In children, the most common age of onset is 13–15, but cases can occur as young as 5
- ME/CFS is about twice as common in women as in men
- It affects all social classes to a similar extent
- It affects all ethnic groups.

## Aetiology, pathogenesis and disease associations

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Research into the possible aetiology (cause) and pathogenesis (underlying disease process) has largely been carried out on patients who meet one of the international research criteria, normally Fukuda et al (1994) for CFS. Although a number of interesting endocrine, immune, infectious, muscular and neurological abnormalities have been reported, none of them are sufficiently consistent or specific enough to act as a diagnostic test. Neither are they robust enough to fully explain a specific symptom or group of symptoms. A consensus is, however, emerging that ME/CFS may be a three-stage illness involving predisposing, precipitating and perpetuating factors.

### Predisposing factors

There is growing evidence, in particular from twin studies being carried out in America (Buchwald et al, 2001), that genetic predisposition plays a role and this may help to explain the slightly higher than expected familial incidence.

### Precipitating factors

A substantial proportion of people with ME/CFS report that their illness followed an infective episode. A wide variety of viral infections, including glandular fever (White et al, 2004), hepatitis (Berelowitz et al, 1995), meningitis (Hotopf et al, 1996), parvovirus (Kerr et al, 2002) and those caused by enteroviruses (Chia et al, 2005) are known to trigger ME/CFS. Non-viral infections such as Coxiella burnetii/ Q fever (Ayres et al, 1998) are occasionally implicated as well. Although infections are a common trigger factor, the majority of current evidence suggests that persisting viral infection is not part of the on-going pathology. Immunizations, organophosphate pesticides, toxins and physical trauma are reported as being the principle trigger in a small minority of cases. About a quarter of all patients report a gradual onset to their ME/CFS with no obvious precipitating factor.

### Perpetuating factors

There is now a considerable amount of evidence, some of it replicated, to indicate that abnormalities in the central and autonomic nervous systems, possibly linked to a viral trigger and on-going immune system dysregulation, play a key role in

the pathophysiology of ME/CFS. Both ME and CFS are therefore classified as neurological disorders by the World Health Organization in section G93.3 of their 10th International Classification of Diseases (ICD 10).

Key neurological findings include:

- Magnetic resonance imaging (MRI) studies demonstrating punctate areas, i.e., small spot-like lesions of no greater than 5 mm in diameter, of high signal intensity in the cerebral white matter (Buchwald et al, 1992). These appear to be more likely in patients who have no psychiatric comorbidity (Keenan, 1999).
- MRI measurements of brain volume, with two independent groups reporting evidence, suggest that the volume of

grey matter is significantly decreased. The study by de Lange et al (2005) reported that the decline in grey matter volume was linked to a reduction in physical activity. Okada et al (2004) reported that the reduction in the right pre-frontal cortex paralleled the severity of fatigue.

- A functional MRI study (de Lange et al, 2004) demonstrating that patients have to exert greater effort to process incoming auditory information and that brain activation, especially in those with no concurrent psychiatric illness, is more diffuse than normal.

- A xenon-computed tomography blood flow study demonstrating a reduction in absolute cortical blood flow (Yoshiuchi et al, 2006) and single photon emission computed tomography (SPECT) hypoperfusion in specific areas of the brain, in particular the brainstem (Costa et al, 1995),

The study by Yoshiuchi found that patients devoid of psychopathology were the group most at risk of developing symptoms due to brain dysfunction.

- Brain metabolism studies demonstrating decreased acetyl-carnitine uptake (Kuratsune et al, 2002), increased choline (Puri et al, 2002; Chaudhuri et al, 2003), fluctuations in serotonin status (Badawy et al, 2005) and abnormalities in dopaminergic modulation (Georgiades et al, 2003).
- Cerebrospinal fluid analysis demonstrating higher levels of some cytokines, protein levels and/or white blood cells (Natelson et al, 2005) - an abnormality which suggests that

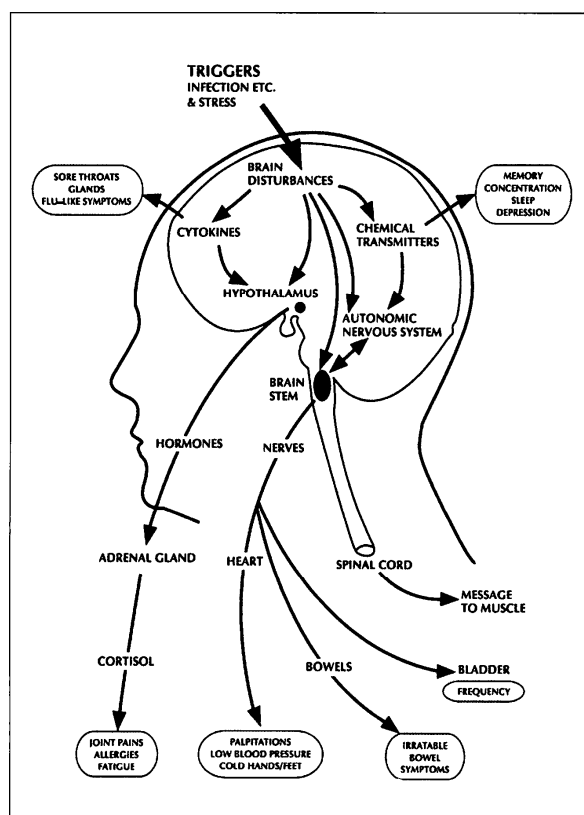


Figure 1: Diagram to illustrate how ME/CFS may involve the central nervous system.

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immune dysregulation within the central nervous system may be involved.

- Evidence of autonomic dysfunction (Freeman and Komaroff, 1997; Freeman, 2002) which may help to explain the neurally mediated hypotension (condition in which the body has difficulty regulating the blood pressure, especially when upright) that occurs in some patients, as may disturbances in peripheral cholinergic transmission (Khan et al, 2003).

Additionally, a wide variety of immune system abnormalities have been reported - some of them being consistent with either activation or suppression of various components. However, no consistent pattern of abnormalities has been identified so far (Lyll et al, 2003). One theory is that following a precipitating infection there is an inappropriate and on-going change in immune system function, which may involve cytokine activation — the component that is partly responsible for flu-like symptoms. Immune system dysregulation may also help to explain the increased incidence of allergic illness in some patients.

Neuroendocrine hypoactivity of the hypothalamic-pituitary-axis, in particular adrenal activity and reduced output of cortisol, has been consistently reported by several research groups (Papanicolaou et al, 2004) as well as adrenal gland atrophy in one small study (Scott et al, 1999). Disturbances at the level of the hypothalamus may help to explain symptoms such as disturbed thermoregulation.

Although current consensus is that the fatigue experienced in ME/CFS is primarily a central problem (i.e. brain), there is some evidence to suggest that in a subgroup of patients there are metabolic (Arnold et al, 1984) and mitochondrial abnormalities (i.e. muscular) (Behan et al, 1991) which cannot simply be explained by deconditioning or a relative lack of activity.

Gene expression research being carried out in both the UK and USA (Whistler et al, 2003) is currently examining how changes in gene expression may contribute to symptomatology and whether these abnormalities could also act as diagnostic biomarkers for ME/CFS.

## Maintaining factors linked to the actual illness

To complicate matters further, a number of symptoms and consequences of the illness may also play a role in maintaining or exacerbating ill health and disability. These include the presence of constant pain, and/or any significant sleep or mood disorder such as depression. The role of inactivity and subsequent deconditioning remains controversial with the most recent research examining exercise capacity failing to support any association (Schmaling et al, 2005). Even so, some researchers have put forward a psychosocial model of causation in which the illness is principally maintained by a vicious circle

of inactivity, mood disturbance and abnormal illness behaviour and beliefs.

## Associated conditions

There are also a number of conditions, including fibromyalgia and irritable bowel syndrome, which appear to be more common in patients with ME/CFS.

## Diagnostic assessment

One of the key recommendations in the CMO report was that patients should, wherever possible, receive an early and accurate diagnosis so that a management plan can be put in place as soon as possible. But a recent survey carried out as part of the preparation for an ME/CFS charities report on early and accurate diagnosis (ME Alliance, 2005) found that 53% of adults were still waiting over a year before being diagnosed. The Alliance report recommended a diagnostic timeframe whereby:

- At 4–6 weeks of persisting undue fatigue and other ME/CFS-like symptoms following an acute infection, a diagnosis of a postviral/infectious fatigue syndrome should be considered
- After 3–4 months of persisting symptoms, and where other possible causes of ME/CFS-like symptoms have been excluded through investigation, a provisional diagnosis should be considered
- By 6 months, if symptoms persist, the provisional diagnosis should have been confirmed, provided all other explanations have been properly excluded, and further advice on management given.

As the symptoms of ME/CFS can sometimes be similar to many other conditions where fatigue is a prominent feature, the diagnostic assessment should always include a detailed clinical history, a full examination, routine investigations and further investigation where appropriate.

The medical history often provides vital clues, not only about possible causation, but also about what sort of management plan is required. In particular, it should explore other possible explanations where there are less common symptoms or where a symptom such as joint pain is particularly prominent.

Physical signs in ME/CFS are limited and often subtle in nature. One fairly common finding is being unable to perform a standard test of balance (i.e. the Romberg test where a patient is asked to stand up still with their eyes closed). Evidence of vestibular dysfunction — using a Fukuda test — can be demonstrated in a smaller number who complain of dysequilibrium (problems with balance). Those with widespread pain may have tender spots at sites where these are commonly found in fibromyalgia.

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The following basic investigations should always be carried out before a diagnosis is confirmed:

- Full blood count and differential
- Erythrocyte sedimentation rate (ESR) or acute phase protein changes
- Blood biochemistry: calcium, sodium, potassium, urea, etc
- Blood glucose
- Creatine kinase (to help exclude muscle disease)
- Thyroid and liver function tests
- Urine tests for renal disease and diabetes.

Second line tests, which may be appropriate in certain circumstances, include:

- Antibody screening tests for specific infections, e.g. hepatitis B/C; Lyme disease; parvovirus
- Screening for coeliac disease if there are irritable bowel-type symptoms or unexplained anaemia (Skowera et al, 2001)
- Autoimmune and rheumatology screen if joint pains are prominent
- MRI scan if another neurological illness seems possible on the basis of symptoms and signs
- Pituitary and endocrine function tests if there are symptoms and signs suggestive of an endocrine disorder.

There is insufficient evidence to justify testing for antiviral activity, the RNaseL test (Gow, et al 2001) or urinary markers (Chalmers, et al 2006).

## Children and adolescents

ME/CFS also occurs in children and adolescents and is one of the most common causes of long-term absence from school (Dowsett and Colby, 1997). Although the main symptoms are very similar to those seen in adults, children may have additional symptoms such as abdominal pain, nausea and sinus congestion. Liaison with the school in relation to home tuition and part-time schooling, where appropriate, forms a key part of any management programme. The Royal College of Paediatrics and Child Health has produced a guideline (2004) on issues relating to diagnosis and management, and there are separate support charities dealing with this area of ME/CFS.

## Management

### General principles

Having established a diagnosis, or provisional diagnosis, patients with ME/CFS require a flexible management plan that is based on both the stage and severity of their illness, as well as the type of symptom complex that is present. In most cases the best person to coordinate such a plan is their GP. Management should be multidisciplinary and may involve dieticians,

**Table 1.**  
**Differential diagnosis of an ME/CFS-like illness**

#### Endocrine and metabolic

Addison's disease  
Fluid retention syndrome  
Haemochromatosis  
Hypercalcaemia and hypocalcaemia  
Hypothyroidism  
Pituitary tumour

#### Gastrointestinal

Coeliac disease  
Crohn's disease  
Irritable bowel syndrome

#### Infections

Brucellosis  
Giardia  
Hepatitis B or C  
HIV  
Lyme disease  
Parvovirus  
Post-polio syndrome  
Q fever  
Toxoplasmosis

#### Malignancy

Hodgkin's lymphoma

#### Neuromuscular

Chiari 1 malformation  
Multiple sclerosis  
Myasthenia gravis  
Narcolepsy  
Rare myopathies

#### Psychiatric

Depression  
Hyperventilation  
Somatisation disorder  
Stress

#### Respiratory

Sarcoidosis  
Sleep apnoea

#### Rheumatology

Fibromyalgia  
Sjogren's syndrome  
Systemic lupus erythematosus

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nurses, occupational therapists, physiotherapists and psychologists.

Important issues such as benefit entitlement, along with negotiations with employers and educational authorities, often form an additional component of any management plan. The Department of Work and Pensions have made it clear that, where appropriate, people with ME/CFS are entitled to the full range of sickness and disability benefits. In relation to employment and services, ME/CFS is an illness that is recognized under the Disability Discrimination Act.

Patients should have access to a local hospital service where further advice can be given on diagnosis and/or management, and where referral to other specialist services is available.

The Department of Health has recently allocated £8.5 million of ring-fenced money to support the establishment of 36 local multidisciplinary teams, 11 specialist teams for children and adolescents, and 13 clinical network coordinating centres throughout England. Some of these new services are able to arrange domiciliary visits for more severely affected patients. Unfortunately, no such initiative has yet taken place in Scotland, Wales or Northern Ireland. The ME Association is collecting feedback on the new services and has a list of their locations and referral requirements.

The management of ME/CFS is currently the subject of a new guideline being prepared by the National Institute for Health and Clinical Excellence. This guideline is due for publication in 2007.

## Pharmacological treatments

A wide variety of drug treatments have been advocated for ME/CFS but no single approach has been shown to significantly affect the underlying disease process. The following interventions have all been assessed, or are being assessed, to some extent in clinical trials:

- Amantadine: a drug for which there is some evidence that it can reduce central fatigue in neurological conditions, such as multiple sclerosis
- Ampligen: an antiviral and immunomodulatory drug currently being tested in America, where a Phase 2 clinical trial has recently been completed
- Central nervous system stimulants, e.g. modafinil (Randall et al, 2005; Turkington et al, 2004) and methylphenidate (Blockmans et al, 2006)
- Eicosapentaenoic acid (EPA): an omega-3 fatty acid supplement (Puri, 2004)
- Hydrocortisone to correct any hypocortisolaemia (McKenzie et al, 1998; Cleare et al, 1999)
- Isoprinosine: partly in relation to the immune dysfunction involving natural killer cell activity (Diaz-Mitoma et al, 2003)

- Midrodine: for neurally mediated hypotension (Naschitz et al, 2004)
- Ondansetron: a 5-HT<sub>3</sub> receptor antagonist which may also have an effect on central fatigue in ME/CFS (Spath et al, 2000) and chronic liver disease (Jones, 1999)
- Oestradiol patches and cyclical progestagens: in those where an oestrogen deficiency state appears to be present (Studd and Panay, 1996)

Although some of these drugs, such as hydrocortisone, have demonstrated some degree of benefit, their use at present remains highly speculative. EPA supplements are available over the counter and are being quite widely used by ME/CFS patients at present. Thyroid supplementation has also been advocated, even in the presence of normal thyroid function tests, but most doctors believe this is unwise and potentially harmful (Shepherd, 1997).

Patients with ME/CFS are often sensitive to the side-effects of drugs, particularly those which act on chemical transmitters systems in the brain and nervous system. Therefore, it is usually advisable to 'start low and go slow', depending on the response.

## Symptomatic relief

With no effective drug treatment currently available, the role of medication is largely confined to symptomatic relief, an approach that should be combined with appropriate self-help strategies and, where safe and appropriate, the use of complementary therapies.

## Pain

Over-the-counter analgesics are seldom adequate where pain is a significant feature of the illness. In this case drugs, such as a low dose of amitriptyline (e.g. 10 mg at night) or gabapentin (again starting with a low dose of 100 mg) may be helpful, especially where the pain has neuropathic features. Other pain relief options that could be considered include the use of acupuncture, a TENS machine, or referral to a hospital pain clinic. The cautious use of antispasmodics, such as baclofen, may be helpful where painful muscle spasms occur.

## Irritable bowel syndrome

Where this co-exists, and conditions such as coeliac disease have been excluded, this should be managed with relief of specific symptoms along with the possibility of trying an exclusion diet to see if there is intolerance to any specific food groups.

## Sleep disturbance

Self-help strategies, such as trying to regulate times of going to bed and getting up, relaxing rather than sleeping during the day, and controlling noise, light and temperature in the bedroom, should be discussed. A low dose of amitriptyline may

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again be helpful, and where someone has difficulty in initiating sleep a course of a short-acting hypnotic may be worth trying (Moldofsky, 2002). Some people with ME/CFS, who have more severe sleep disturbances, claim that melatonin has been helpful, although there is only limited evidence to support this (Van Heukelom et al, 2006).

### **Depression**

Clinical depression, where it occurs, must be taken seriously. For those with mild to moderate depression the options include cognitive therapy, antidepressant medication or St John's Wort. The choice of antidepressant medication will need to take account of the type of depression, the presence of symptoms such as pain or sleep disturbance, and any drug side-effects which may exacerbate existing ME/CFS symptoms. Suicidal intentions, especially where these coexist with social isolation, poor symptom control, financial or relationship difficulties, probably indicate the need for specialist referral.

## **Non-pharmacological management**

### **Energy management: pacing and graded exercise therapy**

The most important aspect of management is achieving the right balance between activity and rest, in relation to both physical and mental activities. Finding the right balance will depend on the stage and severity of the illness as well as the degree of variability of symptoms.

Feedback from patients to the CMO report indicated that over 90% found an approach known as pacing, to be the most helpful. In practice, this means finding a level of activity at which patients feel comfortable. Physical and mental activity can then be gradually increased and interspaced with periods of rest and relaxation, but always keeping within individual limitations.

Graded exercise therapy, which has demonstrated some benefits in some mobile patients in clinical trials (Fulcher and White, 1997; Wearden et al 1998), was reported as only being helpful by 35% in patient feedback with 50% saying that it had made them worse.

Any form of activity programme must therefore be planned with care and the informed consent of the patient (Shepherd, 2001). And from the medico-legal point of view, health professionals who prescribe exercise programmes must do so with just as much caution as would be taken with medication.

There is some limited evidence to suggest that supplements such as carnitine (Vermeulen et al, 2004) and nicotinamide adenine dinucleotide (Forsyth et al, 1999) may be of value in reducing physical fatigue.

### **Nutrition, vitamins, minerals and supplements**

A large amount of sometimes confusing and conflicting information about the value of changes in diet and the use of various supplements is widely available in self-help books and on the internet. However, there is very little evidence to support most of these claims and adding further lifestyle restrictions may cause more harm than good.

Eating a healthy balanced diet, identifying any food intolerance through reputable methods, and maintaining a good fluid intake (especially if postural hypotension is present) are all common sense advice. There is no need to recommend expensive vitamin or mineral supplements and the use of megadose products should be avoided.

### **Psychological therapies**

Cognitive behaviour therapy (CBT) is sometimes advocated as a treatment for ME/CFS but as with graded exercise the feedback from patients to the CMO report did not match the results obtained in clinical trials (Deale, et al 2001; Prins, et al 2001). There is a wide variety of CBT on offer with some therapists basing their programmes on the theory that ME/CFS is perpetuated by abnormal illness beliefs and behaviour whereas for others it is principally about practical ways of coping with key aspects of the illness such as activity, pain and sleep disturbance. CBT may be helpful for people who are having difficulty with developing appropriate self-help strategies or where there are co-existent psychiatric problems or psychosocial distress. As with activity management, any programme must be properly discussed with the patient and based on informed consent.

### **Alternative and complementary therapies**

Although patients often report that alternative and complementary therapies have been helpful, others are persuaded to spend large sums of money on products and services which are dubious at best and fraudulent at worst (Campbell, 1997). Very few of the popular approaches have been subjected to properly controlled clinical trials in ME/CFS, homeopathy being an exception (Weatherley-Jones, et al 2004), but they may be worth a try, especially where someone has faith in what they are doing and they are using a reputable practitioner. Acupuncture, for example may be of help in relieving pain and headaches. There is no evidence to indicate that treatments involving anti-candida programmes are of any value.

### **Prognosis**

As with the epidemiology, sound knowledge about prognosis is limited by the use of different definitions and by a shortage of good quality studies.

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Research findings, as reviewed in the CMO report, indicate that:

- Prognosis is extremely variable
- Most patients will improve to some degree, often over quite a long period of time, but only a small minority fully recover and return to previous levels of health and functioning
- Many patients follow a fluctuating course with relapses and periods of relative remission. Overall, they tend to stabilize at a much lower level of functioning compared to when they were well
- A significant minority become severely and permanently disabled
- Progressive deterioration is unusual and calls for a full clinical review in case another condition has not been recognized
- Children and adolescents have a much better prognosis than adults.

The length of time that people have ME/CFS differs greatly. In some, the illness may resolve within a period of two to three years whereas others remain ill for decades. And where the illness has lasted for more than 5 years, full recovery is unusual.

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## KEY POINTS

- ME/CFS is recognized by the Department of Health as a genuine and disabling illness.
- ME, CFS and PVFS are classified by the World Health Organization as neurological disorders.
- Up to 250 000 people in the UK have ME/CFS — including some children and adolescents.
- Under the umbrella of ME/CFS are patients with a variety of clinical presentations and responses to treatment.
- Abnormalities in endocrine and immune system function, gene expression and neurological function have been identified.
- Management should be multidisciplinary and may involve a combination of drug treatments, self-help strategies and complementary approaches.
- Prognosis is variable and although many patients improve over a period of time, very few return to normal



## Genes and chronic fatigue: how strong is the evidence?

*Results of Centres for Disease Control and Prevention research.*

The U.S. Centres for Disease Control and Prevention (CDC) in Atlanta, Georgia, has announced that it has cracked a medical mystery: chronic fatigue syndrome (CFS) has a biological and genetic basis. CDC Director Julie Gerberding called the study "groundbreaking" and also hailed its novel methodology. These claims have attracted widespread media attention.

But, like most aspects of CFS, the study and its findings are controversial. Some scientists think the agency is overstating the case for a link between the syndrome and genetic mutations. "Most complex-trait geneticists would interpret [these] findings more cautiously than the authors have," says Patrick Sullivan, a psychiatric geneticist at the University of North Carolina, Chapel Hill.

CFS is defined as severe fatigue lasting more than 6 months, accompanied by symptoms such as muscle pain and memory problems. It is thought to afflict at least 1 million Americans, mostly women. The lack of specific diagnostic criteria since CFS was first defined 20 years ago has led to debate over whether the cause could be an infectious agent, psychiatric, or something else - - and made research funding for the disorder highly political. In 2000, a CDC division director lost his job after the agency diverted \$12.9 million that Congress had instructed CDC to spend on CFS research to other infectious disease studies (*Science*, 7 January 2000, p. 22). The agency agreed to restore the money over 4 years and launch a major study.

The new project, led by William Reeves, CDC's lead CFS researcher (who had blown the whistle on the diverted funds), took an unusual approach. Instead of recruiting patients already diagnosed with CFS, CDC surveyed one-quarter of the population of Wichita, Kansas, by phone to find people suffering from severe fatigue. Several thousand then underwent screening at a clinic for CFS.

The population-based aspect is "a big plus" because it avoids the possible bias in tapping a pool of patients seeking treatment for their problems, says Simon Wessely, who studies CFS and a similar disorder, Gulf War illness, at King's College London.

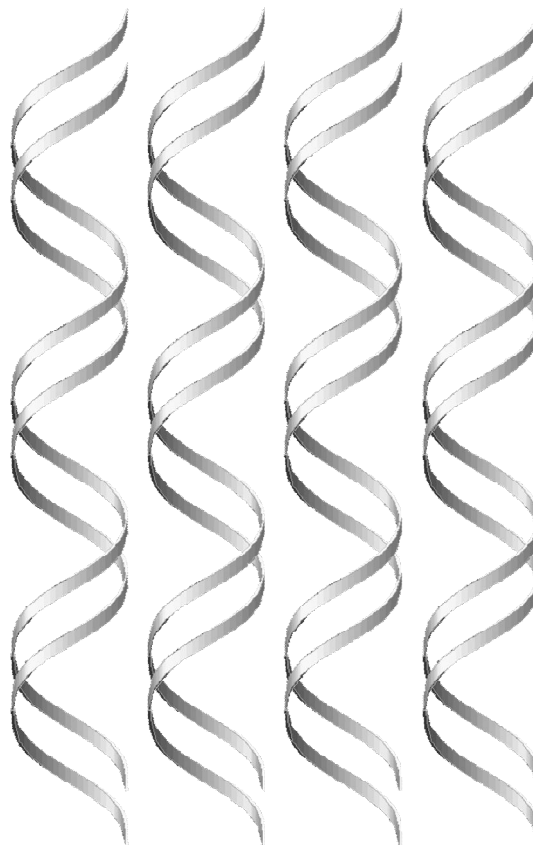
Out of this survey, 172 people, most of them white middle-aged women, were deemed to fit the criteria for CFS (58) or CFS-like illness (114). A total of 227 people, including 55 controls, then underwent an extensive 2-day battery of clinical measurements, including sleep studies, cognitive tests, biochemical analyses, and gene-expression studies on blood cells. This part of the study alone cost upward of \$2 million, says Reeves.

In another unusual step, CDC's Suzanne Vernon then handed this massive data set to four teams of outside epidemiologists, mathematicians, physicists, and other experts. They spent 6 months examining statistical patterns in the data. The culmination of the 6 months work was the CDC organised meeting "From Markers to Models: Integrating Data to Make Sense of Biologic Systems", at the Banbury Centre, Cold Spring Harbour Laboratory, Long Island, New York, September 18-21, 2005.

One group analysed patient characteristics such as obesity, sleep disturbance, and depression and grouped them into four to six distinct subtypes; they also looked for different gene-expression patterns in these categories. Some groups also looked for associations between CFS and 43 common mutations in 11 genes involved in the hypothalamic-pituitary-adrenal axis, which controls the body's reaction to stress. The 14 papers were published in the April issue of the journal *Pharmacogenomics*.

The results, which include the finding that the patterns of expression of about two dozen genes involved in immune function, cell signalling, and other roles are different in CFS patients, provide what Harvard University CFS researcher Anthony Komaroff calls "solid evidence" for a biological basis of CFS. They dispel the notion that "this is a bunch of hysterical upper-class professional white women," says Reeves.

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## Harvard Health Letter: any help on the horizon for chronic fatigue syndrome?

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The following is a letter that appeared in the August 2006 edition of Harvard Health Letter, a monthly publication from Harvard Medical School.

Talking Point – 2006 Issue 3

**Q.** *I would be most grateful for information concerning chronic fatigue syndrome, a disorder from which I have suffered for the past 10 years. Do you see any help on the horizon?*

**A.** Chronic fatigue syndrome is a complex illness that is defined entirely by its symptoms. Profound fatigue is the main one, but the official diagnosis also includes others (muscle pain, sleep that doesn't refresh, feeling especially tired after exertion, to name a few). We don't yet have a way to make the diagnosis by a physical examination or with a lab test. Since anyone can say they have a symptom, some doctors suspect that the syndrome is not a real biological disorder but mainly psychological.

But in my view, since the early 1990s, researchers have found good evidence that chronic fatigue syndrome involves abnormalities of the brain and the autonomic nervous system, which controls functions like body temperature, heart rate, and blood pressure. They've also found that the immune system may get stuck in the "on" position, as if it were engaged in a long-term, low-grade war against some foreign invader.

Laboratories around the world are working on the disease. In

the United States, the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health are supporting much of the research. Results from an interesting CDC-sponsored study were published in April 2006. Four teams of researchers compared genetic and other test results from 58 people with chronic fatigue syndrome with those from "nonfatigued" controls. The researchers found that certain genes important in brain function, immune activation, and energy metabolism were unusually active in people with chronic fatigue syndrome.

We're still a long way from identifying a cause or definitive test for chronic fatigue syndrome, let alone a reliable treatment. But we've made progress in understanding the biological basis of the illness. And that's the first, essential step in fixing any medical condition.

– Anthony L. Komaroff, M.D., Harvard Health Letter Editor in Chief

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Other scientists are much more cautious. The gene-expression results, says Jonathan Kerr of Imperial College London, are "meaningless" because they don't demonstrate conclusively, using the polymerase chain reaction, that the genes' RNA is indeed expressed. After this step, says Kerr, 30% to 40% of genes could drop out.

The most controversial assertion, however, is that the Wichita study has tied CFS to particular mutations in three genes, including the glucocorticoid receptor and one affecting serotonin levels. Genetic epidemiologists are sceptical for two reasons. First, the team looked for associations with just 43 gene variants; some other set of genes might have correlated just as closely, notes Nancy Cox of the University of Chicago in Illinois. Second, the researchers studied no more than 100 or so individuals with fatigue. The results, although they meet the threshold for statistical significance, are "very likely not robust," says Sullivan. (Sullivan himself has co-authored twin studies finding a "modest" genetic component for CFS, although without pointing to a particular gene.)

Reeves doesn't disagree: "One of our caveats is that it is a small study," he says. CDC researchers are now planning to repeat the study with 100 CFS patients. Vernon says her group is also validating the gene-expression results and will hold another computational exercise next month at Duke University in Durham, North Carolina, with a larger data set.

Meanwhile, Gerberding has suggested that the same multi-pronged approach could be applied to seek genetic links to other complex diseases such as autism. That's already being done for many other diseases from cancer to schizophrenia, notes Sullivan, although the studies use much larger samples and search the entire genome for disease markers. That scale may never be possible for relatively uncommon diseases such as CFS, he says. And he and other human geneticists warn that it's unclear whether any conclusions can be drawn from gene hunts carried out on such very small sample sizes.

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## The biology of stress

By **Pamela Young**, Director of Publications.

A four-part series exploring the physical impact of stress. Up first, understanding your stress load (The CFIDS Chronicle, Spring 2006).

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Stress is a word we all know. But it's often easier to describe the stressors than the effects of the stress itself. Stressors can be emotional or physical, acute or chronic and can stem from events we think of as positive (like a wedding) or negative (like a layoff or physical injury). But what are the physical ramifications? The next four issues of the *CFIDS Chronicle* will explore the biology of stress – looking at its impact on various systems of the body. In this first instalment, we examine the overall load stress puts on our bodies.

Scientists increasingly look at stress as an important factor in the origin of illness. Studies show that civil servants in stressful jobs are more prone to high blood pressure and heart disease. People under repeated stress tend to show early memory decline as they age. Through science, we're realising that the phrase "can't handle the pressure" may be more accurately applied to our bodies than our minds.

When threatened or stressed, our bodies mount a chemical response. Though this response can affect our emotions, it begins and ends in the body. Without it, we would be unable to react effectively to danger, infection, hunger, extremes of temperature or other challenges. But the same stress responses that can ensure our immediate survival can also threaten our long-term physical well-being.

Dr Bruce McEwen of Rockefeller University in New York describes the interplay of physical and emotional stress in terms of *allostatic load*. As he explains it, allostatic systems allow the body to respond to stress and work towards a return to balance (allostasis). These systems include the autonomic nervous system (which controls heartbeat, blood pressure and similar functions); the hypothalamus, pituitary and adrenal glands (which work together to produce a hormonal response); and the cardiovascular, metabolic and immune systems.

Under normal circumstances, we react or adapt to stressors and our body returns to routine functioning. But when stressful events persist or recur frequently, the allostatic load on these systems can become too burdensome to process effectively. This accumulated load creates wear and tear – essentially becoming the price the body pays for doing its job less efficiently or being overwhelmed by too many challenges.

What makes up our individual allostatic load is far from simple. Genetics play a role, as does what happens to us in life – trauma, good or bad fortune, caring or neglectful parents, failure or success in our goals. Even boredom can add to the load. How we live, what we eat, whether we smoke or not and

### HOW TO DECREASE THE LOAD

Lifestyle changes, including proper diet, mild exercise, plenty of rest and the development of positive coping skills, can make a difference in the body's ability to minimise the effects of chronic stress.

#### Increase your fibre, decrease your sugar

Many people reach for potato chips or sweets when feeling stressed. Although this provides short-term comfort, the resulting insulin elevation can combine with increased stress hormones to process the calories into abdominal fat, which puts even further stress on your system. It's a vicious circle. Choosing a more prudent diet can have a counterbalancing effect on stress hormones and insulin levels. Higher fibre, fewer carbs, less processed sugar and fresh vegetables can help.

#### Get consistent exercise and generous rest

Mild but regular exercise can help regulate stress hormones and blood pressure as well as improve cognitive functioning. But, as always, people with CFS should exercise gently for brief intervals alternated with longer rest periods. Adequate sleep is also important to reducing allostatic load.

#### Make choices that reduce sources of anxiety

Some stressors can be mitigated by your own actions. When possible, take steps to reduce financial burdens. Try to remove yourself from chaotic or dangerous surroundings. Scale back commitments that leave you exhausted or anxious. Try thinking of new ways to view things you cannot change, but with you could. Each reduction can help lower the load.

#### Strengthen social connections

Strikingly, people with more social ties have lower allostatic load scores, making social interaction an important factor in reducing the physical effects of stress. Fortunately for people with CFS, the strength and quality of the *connections* matter as much or more than the number of events you attend. Meaningful conversations, keeping in touch by phone and acknowledging the support of loved ones all have a positive effect.

(Continued on page 28)

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whether we are active or sedentary are all part of the package. And chronic illness, like CFS, both contributes to allostatic load and may be intensified by it.

Although the causative factors are complex, the results are traceable. For example, stress-induced hormone secretion (cortisol) and overactivity of the autonomic nervous system can produce elevated levels of sugar in the blood (hyperglycaemia). If prolonged, this can result in a rise of insulin and ultimately lead to Type 2 diabetes. In a sort of cascading cardiovascular effect, elevated autonomic activity and too much insulin promotes hypertension.

On another front, when the immune system is under chronic stress, it's unable to function at sufficient levels making it harder for the body to fight infection and to heal itself. And for people who produce too little cortisol, as is often the case in CFS, there is nothing to contain the release of inflammatory agents, which can quickly go from aiding healing to putting more wear on the body. In short, high allostatic load prevents the body from regaining balance and the resulting state can grind down our systems.

Allostatic load can be evaluated by measuring a number of physiologic factors, including blood pressure, heart rate, glucose control and the level of stress hormones in urine. Waist-hip ratios and deposits of abdominal fat are also indicators of overactive stress hormone production. According to McEwen, the higher the load, the harsher the effects of stress and the more illness you may experience. For this reason he believes allostatic load should be a factor physicians consider when diagnosing and treating illness.

Research has long shown correlations between stress and health – from a 1998 study showing that people with lifelong economic hardship experience early signs of physical and mental decline to a 2005 Montreal study finding that people with an accumulation of stress hormones tend to experience spatial and memory problems. The idea of allostatic load provides a framework for understanding the health implications of stress and evaluating a course of action.

*Medical Editor's comments: Since this article was written, CDC research has uncovered connections between CFS and high allostatic load. This data, published in the April issue of Pharmacogenomics, also suggests that the genetic makeup of CFS patients may affect the body's ability to physically process stressors from injury, illness and other traumas.*

## CFS blood test?

First published on [www.immunesupport.com](http://www.immunesupport.com) on 10/7/06, and reprinted with permission of the ImmuneSupport.com Editor, the following article is heartening for everyone hoping for a diagnostic test for CFS:

### Blood Test Shows Distinct Promise as Tool for Diagnosing CFS

Recent tests using spectroscopic blood serum analysis successfully sorted the blood of healthy subjects from that of diagnosed Chronic Fatigue Syndrome patients with a 97 percent accuracy rate, according to a study by virologists at Japan's Osaka University and Osaka City University School of Medicine.

First, the researchers analyzed the serum of 77 known CFS patients and 71 healthy subjects using a visible and near-infrared (Vis-NIR) spectroscopy analysis. (Spectroscopy arrays molecular energy frequencies along a spectrum to depict the composition of complex substances.)

They found that the CFS blood samples and the healthy samples seemed to produce two different profiles, or models.

Next, they ran a test to see if they could use these models to sort out CFS serum samples from healthy samples. Working with a masked group of 99 subjects, they found that the spectroscopy analysis correctly classified the blood samples for all 54 of the 54 healthy subjects, and for 42 of the 45 CFS patients.



The study report, *Spectroscopic diagnosis of Chronic Fatigue Syndrome by visible and nearinfrared spectroscopy in serum samples*, by Akikazu Sakudo, et al., is published in the July 14, 2006 issue of *Biochemical and Biophysical Research Communications* at [www.sciencedirect.com](http://www.sciencedirect.com).

## Information about ME/CFS

### What is ME/CFS?

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

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

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

### Prevalence

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

### Main characteristics of ME/CFS

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

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

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

### Diagnosing ME/CFS

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

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

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

### Definition

There are many definitions of ME/CFS. The Fukuda Criteria (1994) is still considered the international benchmark for use in ME/CFS research, and is often used as a de facto clinical definition. However,

many see the criteria as being vague and over inclusive. Furthermore, they downplay (i.e. make optional) post-exertional malaise and other cardinal ME/CFS symptoms.

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

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

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

### How is ME/CFS treated?

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

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

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

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

### 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

### Adelaide Support Group

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

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

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

Contact: Darryl Turner.

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

### Glenelg Support Group

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

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

Time: 1:00 pm.

Contact: Marion Hansen.

Phone: Marion on (08) 8234 2342.

### Northern Metropolitan Support Group

Contact: Merindah Whitby.

Phone: Merindah on (08) 8287 3195.

### Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: David on 8862 1665.

### Southern Fleurieu Support Group

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

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

### Murray Bridge Group

The Murray Bridge group is not meeting at present.

Please ring to register your interest.

Phone: Fran McFaull (Dietician) 8535 6800.

## Support Contacts

### SA Support Groups

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

### Misc. Support Contacts

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

### Country Support Contacts

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

## Youth Support: SAYME

### South Australian Youth with ME/CFS

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

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

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**.

## Notes



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