Talking Point

2005 Issue 4 Official Journal of the M.E./C.F.S. Society (SA) Inc.

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forget-ME-not

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ME/CFS Society (SA) Inc.

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

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

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Talking Point

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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: Geoff Wilson
Management Committee Members: Adrian Hill; Emma Wing

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Note: It is our policy to ignore anonymous correspondence.

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Wednesdays 10am to 3pm (subject to volunteer availability).
Our email address is: sacfs@sacfs.asn.au.
Our Web site address is: www.sacfs.asn.au.
Our youth Web site address: www.sayme.org.au.

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

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President's Report

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

(The photos in this report are from the November 12 Annual General Meeting.)

I am writing this not long after leaving a small but productive bit of political lobbying. I thought it had some things to tell us about the value of putting a bit of effort into politics (whilst waiting for the medicos to come up with the cures for ME/CFS).

Some productive lobbying at Local Government Association House

Our indefatigable member Peter Evans (aka convenor of the SA Task Force on Multiple Chemical Sensitivity) organised another annual No Pesticides Rally on December 2 [*see article on page 6*]. The venue was LGA House in Hutt St. The LGA was targeted because the Social Development Committee's report on Multiple Chemical Sensitivity had some critical things to say about the poor performance of many councils in SA with regards to protecting chemically sensitive ratepayers from their spraying of herbicides and pesticides.

How many rolled up? Not many – in fact, 19.

But:

- Two politicians attended: one sitting MP (Sandra Kanck MLC, Australian Democrats) and one aspiring member of the Legislative Council (Mark Parnell, Greens).
- The executive director of the LGA, Wendy Campana, came down to speak to us. The LGA had previously sent a 'can't-do-much' response to us previously. But I'd been able to get hold of a contact on its staff and speak to him at length that morning and clearly he'd spoken to her. Because she spoke of perhaps investing some effort in producing some guidelines for local councils on how they can perform better in this field. One option my contact had mentioned was spending a small amount from the LGA's research and development fund to employ a consultant to draft guidelines.
- The president of the Soils Association of SA attended, keen to link her society's lobbying efforts with ours. They're actually the organic growers of the State. She happens to know at least one internationally-regarded local expert who might be able to prepare guidelines for local councils if the LGA decides to go that way.
- Finally, I was delighted that several of our members came along. Wendy Begg brought an MCS friend Aviva; Freya Thompson brought her boyfriend; Helen O'Day struggled there on public transport to support the cause; and Michael Ritter, our IT coordinator, rolled up and found himself turned into a paparazzo, snapping shots of the event. That these members attended is in part an outcome of our efforts to keep reminding members – at least those on email and mobile phone – in the weeks leading up to it.

So it was a neat little sample of grassroots politics at work. Not many activists but an attentive political establishment and some excellent alliance-building between various interest groups. And of course further vindication of our efforts to boost our communications with our members.

However, there was one big sour note for me from the day. Peter Evans showed me the response of the Minister for Health, the Hon John Hill, to the various recommendations of the Social Development Committee on MCS. The Minister – or his Department – has in effect refused to do anything about a number of the recommendations, arguing that since the causes of MCS as not fully understood it is too hard and not a priority.

Your committee will be in touch with you over the next month or so to let you know what we all collectively might do to put pressure on the State government to be more positive about a problem that affects half our membership. After all, it's election time in March and if we just sit back doing nothing, we'll continue to be ignored. We might well be ignored anyway! But as the rally outside LGA House

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showed, a few people can achieve a lot with a bit of effort.

Our communications efforts bear fruit

Michael Ritter drew to my attention on the day of the rally the statistics relating to our website. If you're on the web you can access them at www.sacfs.asn.au/stats . Not being that literate on such matters, I could get the fascinating array of graphs open but wasn't sure what they meant. Michael has previously estimated that we get about 30 000 'unique' visitors (unique as opposed to the same visitor coming back more than once to 'hit' the site at one time) a year. The new figures suggest that we are heading for a 2005 total of almost 80 000 'visitors' this year. I can't figure the difference between unique visitors and visitors but the inference is that we're doing even better than we last estimated. We are certainly averaging over 200 visits a day. You can check monthly pie-charts showing where people came from. The figures fluctuate. But over half the visitors are from outside Australia with a lot of Americans.

That said, I was interested to learn from Wendy Begg when were chatting outside LGA House that she rarely opens up the Society's website but always reads our weekly e-bulletins. These started as simply a device to promote the website but now have a life and readership of their own. And as I write we're waiting for member #100 to give us their mobile phone number to receive our occasional text messages about 'stop press' items.

So the big question is: how can we assist more members to access the powerful tool which is the World Wide Web? I'd be grateful for your advice on this. Meanwhile, I am also grateful to Lynda Brett for coming in every week and telephoning members who are not on the internet. It's a different form of support and of course for some people even better than getting regular bouts of information.

The Annual General Meeting

Our AGM was held on November 12 at the Disability Information Resource Centre. We had 21 people in attendance, down from last year but with an amazing number of formal apologies. We'd rather have people there on the day – but that people bothered to apologise was most appreciated and suggested real interest in the event. All went smoothly and we had a good talk from Phil Calvert, a senior physiotherapist who discussed his recent study tour of ME/CFS clinics in Britain. One of the points to emerge from discussion with him was the lack of status accorded to conditions such as CFS and fibromyalgia within the medical establishment. This in turn means that those professionals who want to address the conditions are not given the same recognition for it that accorded to professionals dealing with more high-profile conditions (eg cranio-facial disorders). This theme also emerged during the June De Merleir workshop. It is very much in our interest to raise the public and political profile of ME/CFS. That way we create a positive feedback loop where more professionals become interested in us because they know their careers will be helped by it. Phil Calvert himself is an altruist who amongst other things dedicates himself to Cystic Fibrosis SA as its vice-president. But we need to be aware of this simple fact that there are fashionable and unfashionable conditions and ours is not yet fashionable. The medicos alone can't change that. We can. Once again, the message is that we need to keep working on the political and public relations aspects of our work. And that's a job for every member.

And thanks

There are many people I should thank as we end 2005. I thanked most of them in my president's report at the AGM. Here I'd like especially to record my thanks to a departing member of the State Committee. Marg Wing has been a rock for us all for years now. She has come regularly into the office each week to deal with the paperwork, assisted our Treasurer Geoff Wilson with our finances, been there to help organise every event and on it goes. We will miss her contribution to the committee though we fully expect, knowing Margaret, that she will still be there helping out. Thanks again from all of us on the committee, Margaret, for your years of great service.

And now I wish all of you a happy Christmas and a year of growth in health and spirits in 2006.

PS: For all those people interested in the major forum in June between Professor Kenny De Meirleir and Australian researchers and clinicians, do make sure you read the really excellent summary of it in this issue (see page 14). It's by the Victorian CFS/ME Society's medical advisor, Dr Nicole Phillips.

Talking Point – 2005 Issue 4

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Herbicide protest

*By **Peter Evans**, Convenor, SA Task Force on MCS.*

Around twenty people attended a public health protest rally recognizing multiple chemical sensitivity (MCS) outside Local Government House on Friday, December 2. The protest called on local governments in South Australia to end the routine use of herbicide in residential areas. The call for local reforms in herbicide use was based on the findings of a parliamentary inquiry into MCS, which found that "MCS is very real," that "up to 6% of the population may have MCS," that "herbicides such as glyphosate are associated with the condition," and that Department of Health records show that glyphosate is "frequently cited" as a chemical that can trigger symptoms of MCS.

The inquiry referred to glyphosate as "particularly pernicious" for people with MCS and recommended that local governments establish No-Spray Registers to identify people with MCS in the community, and that the federal government undertake research to identify safer methods of weed control.

Speakers at the rally included the Hon Sandra Kanck, MLC, Democrat's Spokesperson for Health, Mr Mark Parnell, Greens Senate Candidate and Executive Office of the Environmental Defenders Office, Dr Peter Cahalan, President of the ME/Chronic Fatigue Syndrome Society, Ms Wendy Campana, Executive Director of the Local Government Association, Mr Peter Evans, Convenor of the SA Task Force on MCS and Mr Andy Alcock, from the United Trades and Labour Council's Occupational Health And Safety Committee.

Although at present the Local Government Association has refused to discontinue the use of chemical herbicides in street maintenance, the President of the Association has agreed to meet with rally organisers, the SA Task Force on MCS, to discuss their concerns.

The rally represents the beginning of a long term community campaign for safer herbicide use. The emerging scientific data on the herbicides used commonly by local governments show that they are associated with a wide range of public health problems including multiple chemical sensitivity, asthma, birth defects, spontaneous abortion, reproductive problems, attention deficit disorder, skin diseases and cancer.

More information on international pesticide reforms and what local governments are doing to address the public health problems associated with herbicides and pesticides can be found at: www.beyondpesticides.org/lawn/activist/index.htm.

Not so macho

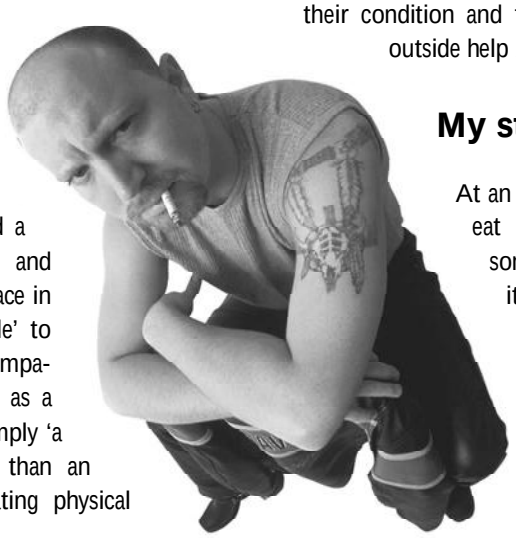
A male perspective on ME

***Dave Lamont**, although now at university, has had ME (CFS/ME) since childhood. Having heard from other men with the illness, he examines the challenges it poses to traditional notions of masculinity.*

The dictionary defines masculinity as: 'something traditionally considered to be characteristic of a male'. But, when certain characteristics are dampened down as a result of having ME, what effect does this have on our sense of happiness and identity?

A blow to my self-image

Steve, who developed the condition in his late teens, describes the plight of men with ME: "Having a chronic disabling illness, which isn't accepted as even existing by some, deals a hammer blow to a guy's self-image and masculinity." A martial arts enthusiast prior to developing ME, Steve explains that, for him, knowing he was able to defend himself and being physically fit and strong was an important part of his identity. He contrasts the change in his physical condition since becoming ill saying, "Instead of being able to do 100 press-ups every morning, I could barely walk 100 metres."



Andrew believes the illness has had a negative effect on his self-esteem and highlights the problem many of us face in that the condition is often 'invisible' to others, making it harder to obtain sympathy or understanding. He says that as a result he feels he is often seen as simply 'a weak, inferior, feeble man' rather than an individual suffering with a debilitating physical condition.

However, Jo has found a way to tackle this issue head-on: "I've had to rethink my need to be useful and productive," he writes. "If it's true that men's self-worth is often tied up with success, then maybe ME challenges us to find other sources of self-worth: in being strong enough to cope with illness and in recognising the small pleasures of life. If I can just enjoy watching clouds outside the window instead of measuring how much I have achieved, that's a good day."

Hard to 'open up'

Clearly the loss of traditionally male attributes such as physical strength and fitness is one of the hardest hitting effects for men with ME. It's also clear that for many men not feeling comfortable discussing their problems can intensify the effect the condition has upon their lives, whereas women do not seem to find talking about their health and emotions so difficult.

It's very hard when you're a teenage boy to sit down and explain your condition to friends and open yourself up in that way. Indeed it's often far easier to blame obvious moments of weakness on a fictional hangover, a late night or to simply cite laziness. It basically boils down to male pride and issues relating to one's self-image.

In a recent members' survey conducted by Action for M.E., 82% of respondents were female, even though the ratio of female to male sufferers is known to be between 2:1 and 3:1. This suggests that men may find it harder to accept their condition and that many remain reluctant to seek outside help by joining support groups.

My story

At an all-boys' school there is often a 'dog eat dog' competitive atmosphere and sometimes a bully or be bullied mentality exists. Having ME was certainly a big disadvantage to me during my school life as it prevented me from keeping up physically and so made me more of a target for the mindless bully. I know of female friends who were ill in various ways during their time at school and their experiences and the treatment they received differ greatly. Girls generally seem to be more compassionate and caring towards others.

As anyone with ME will tell you, having the condition soon helps you to discover who your real friends are. These are the mates who would understand when you had to pull out of a trip to the cinema at the last minute, who you felt you could talk to and who didn't poke fun if you couldn't keep up on the sports field.

My advice based on experience is that so-called friends who fail to offer support and understanding are not the kind of people you want to surround yourself with in any case. One

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of the most positive things to come out of all this for me is to discover that I have a good group of close and loyal friends and I know who those people are.

What women want

Steve shares a similar view: "I got ill at around 19 and most friends soon lost interest when I couldn't go out drinking or clubbing any more. But luckily for me there were a handful who stuck around." He says that fellow men with ME whom he met through support groups have often proved to be the most valuable and understanding friends.

I wasn't the only one who felt that ME can prove a huge barrier to forming and maintaining relationships. It can often be hard to meet new people when affected by the illness as you may be unable to go out and socialise regularly. Steve comments, "This is one area that becomes a hundred times more difficult, especially for guys." He explains that prior to becoming ill he never found meeting and dating women a major problem. Things changed dramatically for him with the onset of ME though. He explains, "Dating is an incredibly hard thing to do when your entire body aches and you're feeling so ill. You just don't feel as though you have the same right to put yourself forward as a viable candidate."

In sickness and in health

In some cases ME can even contribute to the breakdown of an existing relationship. I was fortunate to find a partner who understood and sympathised with my condition, although at times it did present a few problems.

Richard was very hard on himself in his letter to *InterAction*, though he's grateful for a wonderful partner. "When I became ill we lost the house, the cars and all that we'd worked for … my wife, Sue, was very confused and had to adapt to a dependent, disabled failure – the opposite to the man she'd married." But adapt she did. "I have photos of both my daughters' weddings with their mum instead of me walking them down the aisle." Richard's doctors grudgingly accepted that he may have suffered insecticide poisoning from his work in farming, but have no helpful treatments to offer. Despite feeling "…a deep sadness at the loss of a decent physical relationship," Richard appreciates his wife's love and support. "We cope together with the crashing relapses. She is braver than me, having to take a new responsibility for us both as the only one able to work."

Ultimately I believe that ME can be a barrier when seeking relationships but by no means is it a closed door. Nobody in life is perfect and everyone comes with their own problems. If you meet someone who genuinely cares and loves you for who you are, ME shouldn't stand in the way.

A family affair

Having a support network, whether of close friends, family or through an organisation, is a vital tool in the fight against ME. Gary, 48, was disappointed by the way his employer treated him when he became sick. Although he found it hard to face the consequences of no longer being the main breadwinner, he says his wife and friends have been a wonderful support. Even so, seeing the effect on his family has been hard. "The sudden lack of independence from being the only breadwinner to relying on income support – not to mention the effect on our boys when having to apply for free school meals and uniforms – has been very tough." Gary also talks about how bad he felt watching his wife having to undertake household chores and DIY jobs he would have liked to do himself.

For men like Richard becoming a 'house husband' rather than the conventional breadwinner has had a negative effect on their self-confidence and led them to question their identity. However, Jo, also a father, has had a happier experience. "For some men ME can bring about a chance to rethink traditional gender roles. I've spent so much more time with my daughter than I would have done if I'd been working during this period, had time to chat to her when she came home from school and been available if there was a crisis. I've loved every minute of that."

Moving towards acceptance

Feeling that you can't live up to society and other individuals' expectations of you is a tough battle to face and one most men with ME unfortunately must face. My advice would be to set aside these expectations and only judge yourself against the new goals you set and believe in, appropriately adjusted for someone who's chronically ill.

Steve now measures success in a different way "…not by outcomes, but by whether I can look back and say that I gave something my best shot." He adds, "I'd love to go back to being this strong, successful, popular young man who seemed to have the world at his feet. But it's a waste of life to live in such a dream world. Instead I think it's better to own your current situation for the good and bad. So okay I might be ill, but that doesn't mean I can't have friends, a social life and interests."

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Number plate: CFS001

*By **Sandra Cowan**.*

I was trying to explain to a male friend what it's like living with CFS/ME. Knowing how blokes love their cars, I thought this might do the trick…

Imagine a car:

- It's not a new car so there's a bit of rust around the edges.
- It hasn't had a grease and oil change for a while so it creaks and squeaks and its moving parts are a bit stiff and slow.
- The radiator leaks so it continually has a bit of a high temperature and the oil leaks too.
- There's not much air in the tyres and the steering is a bit out so it's wonky on the road.
- The timing is a bit out too and you're never sure if it will suddenly conk out on you.
- The battery is running low, there's very little spark in the spark plugs and the engine is firing on only one cylinder.
- The power is minimal and the car sounds pretty sick, but it still goes.

- Most mechanics that you take it to say there's nothing wrong with it and they just tell you to take it on longer trips and drive it a bit harder and it'll be fine.
- Others say there are no major problems and they give you some additives which are supposed to make it go better, but these mixtures don't help at all.
- So, occasionally it receives a cup of water in the radiator, a small amount of low-grade oil in the sump and a couple of dollars' worth of petrol.
- It's a bit sluggish because of all the mechanical troubles but it eventually starts up, manages to thump and rattle its way around town, goes where it has to go and does what has to be done.
- Then it puffs and chugs its way back home as it runs out of fuel, oil and water and it coughs and splutters and comes to a grinding halt, slumping into a heap in its garage where it can rest until it drags itself out again for its next short journey.

Pretty much like my day, really!

Reprinted with permission from Emerge *Summer 2005.*

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I've personally gone through infinite ups and downs over the years as a result of the illness but believe that, while my physical strength has often been lagging, my inner strength and self-belief have been reinforced by my experiences. I've learned to accept who I am and worry less about what others think and say. This is something I found impossible when I was younger and at school – I felt that I had to constantly question myself and try to justify how I felt.

ME has given me a great insight into myself and taught me to appreciate certain things which I may otherwise have taken for granted. Yes there were times when I felt like chucking in the towel but, thanks to the loving support of those close to me, I've been able to pull through and am now on an upward curve, studying a course I love at uni.

This article reprinted from InterAction*, November 2004, the quarterly magazine for Action for M.E. (UK).*

Chronic Fatigue Syndrome is a Real Pain...

Linda Wylie *has published a book entitled* Chronic Fatigue Syndrome is a Real Pain….

The following article contains an introduction by Linda and excerpts from her book.

My name is Linda Wylie, I was born in Scotland but have lived in Australia for the past seventeen years. My son, Gary, was diagnosed with CFS/ME at nine years of age. He never attended school from this age and totally missed out on going to high school. He is now nineteen and his health continues to improve. At present he is attending college and hopes to work as a counsellor to help other youths who have suffered some trauma in their lives.

I was Gary's main carer for ten years. Four years ago I had a virus from which I have not recovered and was diagnosed with CFS/ME about three years ago.

I found it almost impossible to find information about children suffering from this most debilitating illness. This has led me to write a book about our experience living with CFS/ME and how it changed our lives. It will be in print by December 1, 2005 and is titled Chronic Fatigue Syndrome is a Real Pain… .

If you would like any more information about my book you can contact me on my email address: linda.wylie@bigpond.com.

If you would be interested in purchasing a copy, I will be giving a substantial discount to support groups, sufferers of CFS/ME and their carers.

Here are some excerpts from the book:

It is extremely difficult for anyone who has not endured C.F.S. to understand the limitations it places on sufferers and their carers. One of the purposes of this book is, hopefully, to help people and families coping with C.F.S. to be better understood. I also hope that it will help non-sufferers to be more sympathetic and understanding when judging the many thousands of very brave people who have to limit their lives because of this illness.

Gary before C.F.S.

During the bad periods it is even difficult to talk to others, as your body is so exhausted just trying to deal with the pain. Anything else like processing noise or conversation is just too much to cope with. This is why it is important to have somewhere quiet to where you can retreat. The physical and mental drain on the body is such that it is a matter of getting through it minute by minute and hoping it will soon pass. The fatigue is very debilitating and during times of extreme fatigue, just doing the normal everyday chores like bathing or dressing is too much of an effort. Just thinking about doing anything that involves physical movement is too much to cope with and can leave you in tears. It has an impact on all aspects of the sufferer and their families' life from employment, education, financial, social and both mental and physical abilities. Fighting this horrible illness is so difficult and exhausting that you have very limited energy to do anything that the 'normal' population would take for granted.

The paediatrician now recommended that I force Gary to attend school; he is sure that after a couple of weeks everything will be back to normal. How wonderful it would be to have such faith. Forcing Gary to go to school, in the early days of C.F.S., is one of my biggest regrets in life. At the time, we had no knowledge of this illness and trusted doctors to know best.

After forcing Gary to school for about a week, I could not do it anymore. I could see that he was suffering. The paediatrician was wrong. School was not the cause of the prob-

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Gary when he first became ill at the age of nine.
(This photo appears on the front cover of
Chronic Fatigue Syndrome is a Real Pain...)

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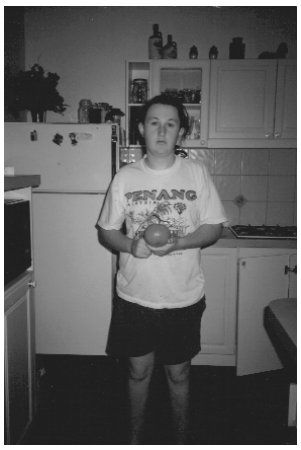
lem; it was most definitely not and act. There was something physically wrong with him.

The following paragraph explains one of the difficulties we had with getting Gary diagnosed. How many children suffer because of this type of attitude?

By now, we had vaguely heard about C.F.S. and asked if Gary could be suffering from this. The paediatrician told us that C.F.S. is a psychological illness (his words not mine; I have this in his own handwriting). He stated that as Gary was very sick, he did not have a psychological illness, therefore he did not have C.F.S.!

As a mother, and I would say to any parent reading this, YOU know your children best, trust them, they are very vulnerable, be there for them and really listen to what they have to say.

If you think your child could be suffering from this, it is very important get the opinion of doctors you trust but first and foremost if your child does not feel up to doing something please, please do not force them. Let them set their own pace, believe in their pain, it is very real and very frightening for children. The uncertainty of C.F.S., even as an adult, is extremely difficult to come to terms with. Children do not understand what is wrong with them. They get scared that others may perceive them as being different or as not normal. They feel very vulnerable as their world, as they know it, has collapsed and there is no logical explanation as to why this has happened. They sometimes feel that they must have done something that they are being punished for but do not know what. They can find it very difficult to express their feelings. They are in a situation that they have not been prepared for and can become very confused. They need constant reassurance, lots of family support and understanding, give it unconditionally. Fighting this illness is hard enough without having any added stress. Do as much as you can without pushing but above all do what makes you both happy and it will help ease the hardship of dealing with C.F.S. If this advice helps even one child and family cope better with C.F.S., it will be worth it.



Gary with his first home-grown tomato. 2000

I would highly recommend to anyone with C.F.S. or family and carers of anyone with C.F.S. to get in touch with your nearest support group. It is the best way to keep up to date with information relating to C.F.S. Having someone, who understands what you are going through and to discuss any problems with really does help. We certainly learned a lot from talking to other people in a similar situation to our own.

Gary with our fostered Joey. 2000

One of the most difficult aspects of C.F.S. for other people to understand is that although the sufferer may seem to be well in their own environment it does not necessarily mean they are well enough for outings.

Finally, in April 1999, I had another breakdown. I was so emotionally and physically drained, that I could not cope for one more day. I needed a break. The events that occurred during this break helped us to make the decision that would transform our lives. No! We did not decide to sell Gary! It was something much more exciting for all of us.

You'll have to read the book to find what that decision was! I have to keep some suspense going. (Ha! Ha!)

I kept my emotions on such a tight rein that it would just get to the stage that the dam would be at bursting point and nothing could stop it . I had no reserves left. I found it very hard to ask for help; I thought that I should be able to cope. If anyone reading this is a carer and has ever felt this way PLEASE, PLEASE ASK FOR HELP. I know it is easier said than done but do not feel guilty. You too have rights, wants and needs and to deny yourself is the biggest cause of stress. No one can be expected to keep going indefinitely. You are entitled to some time out. You need it to build up your strength and stamina to enable you to return to your job with renewed vigour. I know finding it can be very difficult but please try, you and the person you care for will both benefit from a change in routine.

10 things I hate about C.F.S.:

1. *I HATE that my life has been changed without my consent*
2. *I HATE the restrictions that have been forced on me by C.F.S.*
3. *I HATE that no one understands me and what I am going through except Gary.*
4. *I HATE being in pain.*
5. *I HATE the days I have to spend in bed.*
6. *I HATE missing mornings.*
7. *I HATE not being in control of my life.*
8. *I HATE not being able to plan ahead.*
9. *I HATE not working*
10. *I HATE BEING ILL!*

Off-White and the Seven Dwarfs

Tod Whitehouse *with a male view of the CFS/ME predicament.*

A couple of years ago I bumped into an old girlfriend I had not seen since my bell-bottoms and kipper-tie days. "I remember you," she sniffed condescendingly, "You were that fake macho man."

One of the positive things CFS/ME has done to me is to make me more gentle. I just don't have the energy to fake anything, let alone the whole complex of hand-me-down masculinity. And I guess it must be the same for most sufferers.

The illness came on me slowly. I barely noticed it at first. The analogy springs to mind of a pair of pristine white underpants thrown all too frequently into the wrong wash and gradually changing the colour through various deepening shades of off-white to a grisly, irredeemable grey.

Inner struggles

The eight of us whose experience has contributed to this article may have had vastly different triggers to our illness but the inner struggles to cope and survive it psychologically display significant similarities. We feel profoundly diminished. We are dwarves not men, unable to participate in the various male bonding rituals that underpin the practice of masculinity, unable to cast aside our instinctive roles as hunter-gatherers until the disease has become so deeply embedded that we are severely disabled and have no other choice.

DOPEY, for example, remained manacled to his job at Comet long after he first crashed. After all, he had two young children, a large mortgage and a hunter-gatherer addiction to feed. His penance has been to spend the last two-and-a-half years confined to a wheelchair.

But DOPEY can speak for himself: "Little things worry me…

- My wife walking the dogs late at night is scary. I can't rest until she's home.
- I feel like I'm not a man when my wife or the nurse has to wash me. It's degrading.
- Being driven by my wife when I'm not drunk!
- I never cried in front of my wife, not even when my father died, but now it just happens. Mostly I cry when I get frustrated in anger and I punch things – doors, walls, etc – never any person. God forbid. It's a man thing – we like to hit things when we get upset.
- Also, when I've been unable to have sex with my wife for a long time, like a typical man I think because she hasn't said anything for some time she's getting it from somewhere else, so I accuse her of having an affair. What an idiot! The person who does the most for me! She is used to it now and knows it's a cry for help, that I'm feeling insecure and we have a cuddle and a chat. Stupid isn't it, but I bet I'm not the only one."

Loss of libido

No, he is certainly not. Loss of sexual libido has been a problem for all of us and impotence or erective dysfunction for half of us. GRUMPY "Couldn't imagine why InterAction would want a separate article about men with CFS/ME unless it were about the single thing that a man has that a woman hasn't!"
BASHFUL did not have an erection for the first three years of his illness. "All my mature life I've been used to waking up with a hard-on," he reveals. "It was the first thing I felt and looked for. Suddenly it no longer happened. I was a changed person. No longer capable or desirable.

DOC has counselled many male fellow victims and is convinced that impotence is not a physiological symptom of the illness. It is likely to be caused by low self-esteem, loss of role status and the related depression, although he cautioned that blood circulation problems could be a contributory factor.

GRUMPY puts it down to 'classic double-blind anxiety' noting that, "Any exertion beyond the very gentle is likely to bring on the throbbing, crushing 'I must have a brain tumour' kind of headache." Even on the rare occasions he managed to achieve penetrative sex, the fear of failed contraception haunts him.

"Getting the thing to work at all is asking a lot, but expecting it to stand up in the cold while trying to put on a rather unappealing little overcoat is asking the next to impossible."

Courage reconsidered

DOC says that prostatitis is another common but rarely discussed problem – severe red-hot pains during ejacula-

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tion, also manifested in swollen lumps in the scrotum. It is thought by some doctors to be caused by candida but must always be checked out thoroughly. Unlike women, whose gynaecological problems are well documented, men find such confessions of vulnerability virtually impossible, especially in male company.

"You're expected to be big, beefy and strong," says BASHFUL, "and never whinge about your problems. Men are shockingly emotionally constipated. They're scared of being thought weak. They'll cut you dead if you don't conform, even your best friends – and this is just as true of the gay community."

Yes, BASHFUL is gay – which made his testimony much more compelling for me, exploding a stereotyped myth.

"CFS/ME has made me rethink my view of courage," reveals SLEEPY, who demonises the Douglas Bader model of toughness in which, he believes, all boys become quickly indoctrinated. "Real Bader-like men push themselves against pain, exhaustion and fear until at the end they collapse into the arms of an adoring woman as the credits roll and we assume everything will be all right from now on."

The shackles of this ideology have to be broken. Courage has to be redefined. "Throughout my working life I pushed myself against fatigue and illness to keep working and to break this deeply ingrained habit of behaviour brings me face to face with the awfulness of my loss. How much easier it is to keep doing something even when I know I will be terribly ill later! What really takes guts is to stop, to rest and to cherish myself before I reach this point of collapse."

The house-husband

Similar messages are delivered by HAPPY, a high-achieving financial expert since become reluctant house-husband who silently squirms when his friends snipe: "Isn't your wife working hard nowadays?" And by SNEEZY, whose main friendship base is now primarily women because they are "less one-dimensional than men in their sensitivity." He adds pointedly that: "When seeking new partners women seem to be just as ruthless as men in getting what's right for them.

I'm not trying to plead a special case for men or instigate competition. Women have their biologically and culturally determined crosses to bear. They are, for instance, as CFS/ME sufferers, much more likely to get dumped by their partners than men are. And once men have accepted they are ill they do find it easier to rest, whereas women locked into the nurturing, home-based roles of mother or wife struggle to surrender.

What I like about my dwarves is their honesty. They are all on a learning curve. They have begun to see beyond the brittle mirror images of the given world. They are on a journey. Personally I have come to think of my illness as an opportunity given, not one taken away.

Editor's Note: This article is reprinted from InterAction*, March 1999 (the magazine of Action for ME, UK) and first appeared in Emerge in the Winter 1999 issue. I enjoyed this article so much that I decided to give it another airing for those members who may not have read it.*

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Talking Point – 2005 Issue 4

The Official Journal of the M.E./C.F.S. Society (SA) Inc

CFS/ME Forum – the Victorian report

This feature will focus on the proceedings from the CFS/ME forum held at the University of Adelaide on June 3 and 4, 2005. It was compiled by the Victorian CFS/ME Society's medical advisor, ***Dr Nicole Phillips****.*

This forum was initiated and organised by the inspirational Christine Hunter from the Alison Hunter Memorial Foundation in New South Wales. As many of you are aware, Christine has been a tireless campaigner in the area of CFS/ME/ since her daughter Alison died of complications of CFS/ME in her late teens. Christine contacted a number of researchers and clinicians throughout Australia, as well as Kenny De Meirlier from the University of Brussels, to workshop over two days to exchange ideas with two primary goals – firstly to assess the current diagnostic criteria and, secondly, discuss the establishment of a tissue bank.

The proceedings of the forum are presented by chronology of the presenter, with day two's discussion being summarised at the end.

CFS/ME research overview

Kenny De Meirlier
University of Brussels, Belgium

Kenny began by optimistically stating that this condition is now understood at a cellular level, and that this understanding explains the symptoms of the condition. He described CFS/ME as an immunovigilant disorder in which the immune barrier is broken, either from chronic infection or chronic low grade sepsis. He stated that he has data now on a few thousand patients.

Kenny presented work that he has presented previously looking at RNase L. He stated that present in CFS/ME and absent in depression, is a low molecular weight (LMW) (37kDa) RNase L. This low molecular weight RNase L correlates with functional capacity, cognitive function deficits and the number and activity of natural killer cells (NK cells). He stated that this has been confirmed by five groups in the USA, one in Belgium, one in Japan, and one in Spain. He mentioned work by Jo Nijs who looked at 16 CFS/ME patients, and found that the leukocyte elastase activity is universally correlated with exercise activity which is lower in patients. Work by Knox et al showed that 32% of patients vs 4% of controls have deficient STAT1 protein. These proteins mediate cell response to cytokines. Harrison et al showed procoagulent genetic factors play a role in that an abnormality of genes that control coagulability are three times higher in patients (probably related to chronic inflammation). Kuratsume et al showed on PET scans of brains that there is a decrease in serotonin transporter molecules in CFS/ME. Garcia - Quintana et al have shown in CFS/ME a decreased aerobic work capacity on bicycle ergometry. There is also a decrease in upper body work capacity. Kenny stated clearly that this is not deconditioning, it is a metabolic dysfunction. Work by Strayer et al using ampligen and double blind placebo controlled cross over studies on 234 patients showed that exercise duration was 16.1% greater in the treated group. There is a question which subgroup in particular responds to ampligen.

Also shown was LMW RNase L and an increase in RNase L activity in 90%. PKR activity is activated in about 50%. There is a low intramonocyte nitric oxide. There is peripheral resistance to T3 (one of the thyroid hormones), and there is a switch to the Th2 state in 70% due to a decrease in Th1 immunity. Work by Schwartz et al looking at Lyme diseased questioned whether Lyme disease was a form of CFS/ME, and due to either an unresolved infection or due to immune abnormalities. Kondo et al looking at herpes virus 6 (HHV-6) showed reactivation during work-induced fatigue, which could perhaps be an objective marker for fatigue. Other workers have shown macrophage activation with phagocytosis of apoptotic neutrophils, and that there is a suppression of natural killer cells and alpha T-cell receptors.

Work in Sweden on 60,000 twins showed only a weak genetic trait in CFS/ME (15-30%). Chaudhuri et al showed an abnormality of ion channels and transporter function, which may explain some of the clinical symptoms. Work by Natelson et al showed 20% of patients will have a chronic low grade encephalopathy. Spinal taps have shown increased evidence of infection, such as increased white blood cells and protein. Alegre et al in their work in 74 CFS/ME patients have shown basic antiviral pathways are abnormal. Takahashu et al have shown that turnover of dopamine is high in the amydala and lower in the insula cortex and cingulate gyrus, and that there was a lower uptake of serotonin in the temporal region of the brain. PET scans have shown decreased activity in the frontal and anterior temporal lobes and cingulate cortex, and increased

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activity in the occipital lobe.

Dr Anthony Komaroff from the Harvard School of Medicine has shown that there is a substantial reduction of function in CFS/ME patients. He showed that CFS/ME symptoms improve in one third during pregnancy, but in one third worsen and in one third stay about the same. Kenny felt that the majority do improve during pregnancy but have a big relapse after. It was also felt that the course in most people waxes and wanes, but only 10% will achieve a complete remission. Central nervous system involvement is evidenced by decreased CRH, ACTH, and cortisol, increased prolactin response to serotonin stimulaters, decreased growth hormone and the abnormal brain imaging studies. Cognitive studies have shown a decrease in the ability to process complex information, slower speed, difficulties with acquiring new information and learning and difficulties recalling complex material. There has been shown to be a decrease in blood volume (red cell mass), and a prolonged acetylcholine mediated vasodilation of microcirculation. Sleep has been proven to be less efficient. There are sleep study abnormalities in up to 50%. Activating circulating lymphocytes are increased and can cross the blood-brain barrier to activate other lymphocytes and dendritic cells. This may persist for years. Activated microgliae secrete proinflammatory cytokines and nitric oxide, which cause low level injury. There is increased apoptosis (cell death) in white blood cells. Inflammatory cytokines are increased. At the onset, persistent fatigue correlates with increased gamma interferon in a small subgroup. A large proportion of sufferers have at least one species of micoplasma and this is significantly different to the control group. There are persistent deficiencies in oxidative phosphorylation, glycolysis, and glucose metabolism. There is decreased vitamin D, which correlates with muscle pain. There is increased substance P in fibromyalgia, but not in CFS/ME patients. There are decreased omega 3 fatty acids, which are associated with increased inflammatory mediators and decreased antiviral activity. Overall there is a low grade inflammation with a defective immune system in the gut and blood-brain barrier.

Medical Editor's Comments:

Don't worry if you didn't understand most of this. All of this research is way above the heads of most medical practitioners! I guess the overall take-home message is that there is more and more evidence mounting that CFS/ME patients have multiple abnormalities at many biological levels and within many systems of the body. The evidence can no longer be disputed.

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Q Fever

Dr Barry Marmion
Royal Adelaide Hospital

Barry has had a huge degree of experience in Q Fever and believes that we have a lot to learn from Q Fever and the fatigue-like state that follows in a subset of patients. Q Fever follows infection with a small intracellular bacteria which grows in the macrophage and works at low pH. Broad spectrum antibiotics are used but the organism is not necessarily eliminated. It is common in Queensland and northern New South Wales. Often people recover from the initial illness and then become ill again, and this can be called "the anniversary syndrome". There was a letter published in The Lancet in 1996 by John Ayres from Birmingham who discussed an outbreak of 148 cases of patients who were exposed to a wind-borne infection from sheep. There was subgroup of patients that did not recover and Barry believes that this was due to long term persistence of the organism, and was linked to abnormal cytokine stimulation. In these patients there was an increased liberation of interleuken 6 (Il-6), tumour necrosis factor (TNF) was slightly raised, TGFB was raised and 12 years later 10% of the group of original patients remained ill. Barry said that in common with CFS/ME patients there is a failure of homeostasis to infection rather than a particular infection being causative of the illness. Barry stated that the original cytokine response was not down regulated, and so the organism can persist in the bone marrow. He also stated that organisms could colonise heart muscle even 2 to 5 years after the original infection.

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MRI

Dr Richard Kwiatek
Queen Elizabeth and Lyell McEwen Hospitals, Adelaide

Richard has done work looking at structural MRI scans in fibromyalgia. This is a condition in which the symptom is total body pain and the sign is total body tenderness. He believes that there is biological evidence particular to fibromyalgia, in that there is a deficit in regional cerebral blood flow, particularly a decreased blood flow in the thalami more so on the right. He also found a diffuse area of decreased signal in the orbitofrontal cortex. He stated that the non-dominant hemisphere is more involved in pain processing.

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Vasoactive neuropeptides

Dr Don Staines
From the Gold Coast Public Health Unit

Don presented a novel explanation for chronic fatigue syndrome, questioning whether it is an autoimmune disorder of endogenous vasoactive peptides.

Vasoactive neuropeptides including vasoactive intestinal peptide (VIP) and pituitary adenylate activating polypeptide (PACAP) belong to the secretin/glucagons super family and act as hormones, neurotransmitters, immune modulators and neurotrophes. They are readily catalysed to smaller peptides fragments by antibody hydrolysis. They and their binding cytes are immunogenic and are known to be associated with a range of autoimmune conditions.

Vasoactive peptides are widely distributed in the body, particularly in the central, autonomic, and peripheral nervous systems, and have been identified in the gut, adrenal gland, reproductive organs, vasculature, blood cells and other tissues. They have a vital role in maintaining vascular flow in organs and in thermoregulation, memory and concentrations. They are co-transmitters for acetylcholine, nitric oxide, endogenous opioids, and insulin. Are potent immune regulators, with primarily anti-inflammatory activity, and have a significant role in protection of the nervous system to toxic assault, promotion of neural development, and the maintenance of homeostasis.

Dr Staines described a biologically plausible mechanism for the development of CFS/ME based on loss of immunological tolerance to the vasoactive neuropeptides following infection, significant physical exercise, or other assaults. He proposed that the release of these substances is accompanied by a loss of tolerance either to them or to their receptor binding sites in CFS/ME. He believes that all the documented symptoms of CFS/ME are explained by vasoactive neuropeptides compromised, namely fatigue and nervous system dysfunction through impaired acetylcholine activity, myalgia through nitric oxide and endogenous opioid dysfunction, chemical sensitivity through peroxynitrite and adenosine dysfunction, and immunological disturbance through changes in immune modulation. Perverse immunological memory established, against these substances or their receptors, may be the reason for the retractive nature of the condition.

Dr Staines also discussed the role of vasoactive neuropeptides in thermoregulation, and postulated a novel theory in sudden infant death syndrome, that vasoactive neuropeptides may be involved. He commented that babies had no shivering response until they are one year, and that probably sudden infant death syndrome is not in fact "sudden" but that it is an impaired immune response happening over a few days.

He also commented at the end of his presentation that perhaps new vaccines may be able to be discovered to protect against vasoactive neuropeptide disorders.

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Five case histories

Dr Richard Schloeffel
General Practitioner NSW

Dr Schloeffel has had a vast experience treating CFS/ME, stating that he has seen over 2500 patients. He has a number of patients at the severe end of the spectrum and presented 5 patients who are so severely ill he believes that some of them may be at risk of dying.

Richard discussed MNGIE (Mitochondrial Neurogastrointestinal Encephalomyopathy), this being a disorder of mitochondria and he believes although rare should be excluded in severe cases of CFS/ME. (MNGIE will be discussed in Dr Duley's presentation).

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CFS/ME and metabolic disorders

Dr John Duley
Chemical Pathology, Misericodiae Hospital, Brisbane

Dr Duley has an interest in mitochondria (the energy factories of cells), and stated that mitochondrial disorders can be inherited, for example MNGIE, or acquired, for example environmental pollutants.

He stated that there were three main ways to look for metabolic diseases. Firstly, you could look for a mutation in the gene, but this is difficult if it is not known. Secondly, you can measure the activity of a protein (enzyme), for this you need a blood sample or a biopsy, and usually a muscle biopsy is the best way to do this. Thirdly, he stated you could look for an accumulation or loss of metabolic chemicals in body fluids. He spoke about MNGIE (mentioned previously in Dr Schloeffel's talk), this being an inherited mitochondrial disorder. MNGIE is diagnosed by the following symptoms: loss of eye muscle control, droopy eyelids, limb weakness, cramps, gastrointestinal and digestive problems

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including chronic diarrhoea and constipation and abdominal pain. In this condition, which is a recessive condition and inherited from both parents, there is a blockage in one of the metabolic pathways leading to a build up of abnormal metabolites (d urid and d thymid), and this build up leads to damage in the DNA in the mitochondria, causing a mitochondrial deficiency. This can be diagnosed by seeing a build up in the urine of two abnormal pryimidine metabolites.

In CFS/ME Dr Duley believes there is a problem with adenosine which is a purine metabolite. This is a powerful alarm signal in the body, and signal breakdown of the energy molecule ATP. When oxygen is low or mitochondrial function is compromised, ATP gets converted to adenosine. Adenosine is multifunctional in the body, it regulates sleep, blood pressure, heart rate, immune response, kidney function, and wound healing. He stated that high adenosine levels have been found in some CFS/ME families in the UK, possibly due to adenylate deaminase deficiency (there are two forms of this enzyme, one in the muscle, and one in the blood).

Dr Duley stated that it was important to exclude mitochondrial disorders such as MNGIE from CFS/ME. Dr Duley stated that mitochondrial function is assisted by creatine which can be bought in health food stores, heptoin oil which is produced in Belgium or France and used in cosmetics, folic acid (folinic acid if there is no response to folic acid), and SAMe (S adenosylmethionine).

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Gastric emptying

Dr Richard Burnet
Endocrine and Metabolic Unit, Royal Adelaide Hospital

Dr Burnet has studied the gut and gastric emptying in CFS/ME patients. He has looked at a group of CFS/ME patients (183) compared to 56 controls. He used the Fukuda criteria and divided the groups into positive or negative for gastric symptoms and undertook gastric emptying studies.

He also looked at lower GI symptoms, looking at the number of bowel motions a day, their consistency, whether constipation was there and also symptoms of nocturnal diarrhoea and faecal urgency, and CFS/ME patients did show some differences here as well with increased numbers of bowel motions and increased nocturnal diarrhoea.

In summary Dr Burnet has found a marked delay in CFS/ME patients in gastric emptying, markedly seen with the emptying of liquids, a less dramatically delay seen with solids. There was no difference in oesophageal symptoms, and no significant differences in oesophageal clearance.

	CFS/ME %	CONTROLS %
Abdominal discomfort	86	46
Fullness	78	31
Nausea	76	15
Abdominal pain	73	27
Loss of appetite	58	12
Vomiting	23	4
Acid regurgitation	58	38
Heartburn	55	38
Swallowing problems	43	12

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Approach to management

Kenny De Meirlier

Kenny spoke about the significance of the herpes virus (HHV6) in CFS/ME. He stated that this is a virus we all contract between 0-18 months. HHV6B gives a short-lived illness with a high fever and a rash for 3 days, and if you get B this protects you from A. A infects you when you are older than 18 months. He stated that, in an animal model, if you get A, which was infected into 11 Macaque monkeys, 5 of these monkeys developed multiple sclerosis, and 6 developed symptoms of CFS/ME. The B strain is latent and can be reactivated when there is damage to the immune system, whereas A is lytic which destroys cells and causes scar tissue. He did state than in cerebrospinal fluid in a number of CFS/ME patients studied, that there has been a positive viral culture and that you see an increase in opening pressure in a lumbar puncture, increased protein, and lymphocytosis (increased white blood cells).

Kenny then went on to talk about anti-viral treatment and mentioned that ampligen is an immune modulating treatment, but that there are also anti-viral treatments. He mentioned several, but stated that there are currently no good anti-virals to treat HHV6A but that there has been an anti-viral studied called Cidovar (Vistide) in which T and natural killer cell function seems to improve in studied patients. Kenny mentioned Dan Peterson in the USA who has a large experience with this particular virus.

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Kenny went on to also talk about other infections. He mentioned micoplasma and stated that antibiotics must be continued for 36 weeks to 1 year. In Gulf War Syndrome, in which micoplasma has been thought to play a role, he mentioned 2 studies in which 78-80% of people were "cured" with antibiotics. In 3 studies of CFS/ME patients, with a total example of more than 700, there was improvement in 60-80%, with a cure in 47-50%. The treatment of choice for chlamydia pneumonii is azithromycin.

He also about rickettsia, bartonella, and coxiella, seen in 8-10% of CFS/ME patients, and went on to discuss Cecile Jadin's work on rickettsia using antibiotics over a 12-18 month period.

He also spoke about looking for heavy metals with a metal ELISA test (MELISA). This tests for metals in the tissues.

He spoke about mycotoxins which are neurotoxins, and mentioned aspergillus niger requiring antifungal treatment if high antibody levels (IgG) are found. He also mentioned Candida for which antifungal treatment and diet is used, if high antibody levels (IgG) are found. He did mention that Candida is found in the digestive tract as part of a normal immune system. He also briefly mentioned leaky gut, peripheral resistance to thyroid hormone treated with low dose T3 (Cynomel) starting with 25mcg and titrating the dose up every 2-3 weeks to 37.5mcg.

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The Marshall Protocol

Dr John Graham
Adelaide

Dr Graham stated that of his 611 CFS/ME patients, 337 were found positive for rickettsia (mainly spotted fever). Dr Graham spoke about the Marshall protocol, which is considered a therapy for Th1 inflammatory diseases. The pleomorphic intracellular bacteria which cause Th1 diseases seem to be resistant to most antibiotics. Only the immune system can kill these bacteria. The Marshall protocol weakens the bacteria so that the immune system can then kill them. The killing of these bacteria always elicits an inflammatory cytokine release from the cells they have parasitised. This results in a temporary exacerbation of the symptoms, a phenomenon often referred to as the Herxheimer reaction. This will continue until all the bacteria are eliminated. The Marshall protocol minimises this reaction by allowing the patient to control the severity of the Herxheimer reaction by controlling the antibiotic dose.

As this protocol is quite complicated, if anybody is interested in looking into this further I suggest they do their own research. Most of the work has been done in the area of sarcoidosis and involves restricting vitamin D.

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Psychiatric assessment in CFS/ME

Dr Nicole Philips
Psychiatrist, Melbourne

My presentation was divided into three sections. Firstly I introduced a paper by a Canadian psychiatrist, Dr Eleanor Stein. This looked at differentiating depression and anxiety from Chronic Fatigue Syndrome. Dr Stein spoke about the difficulty in using a number of diagnostic instruments in diagnosing depression in physically ill people, and suggested the HAD (Hospital and Anxiety Depression Scale), which is a self-screening questionnaire for depression and anxiety, be used in CFS/ME as it tends not to focus so much on the importance of somatic symptoms. Her paper suggested that a diagnosis of co-morbid depression in CFS/ME be considered when the depressive symptoms pre-dated the physical disorder, when pessimism is generalised beyond health and illness related issues, and when the patient seems stuck in depression and it is having a negative effect on treatment. She listed the DSM IV criteria to diagnose major depression, and importantly as there are a number of somatic or physical symptoms in the diagnostic list, it is important to have either depressed mood or loss of interest or pleasure as a must before depression is diagnosed with all the other physical symptoms. This does seem to be forgotten in things like sleep disturbance, fatigue, and cognitive disturbance, as seen in both illnesses. When diagnosing anxiety she stated that a co morbid anxiety disorder should be considered when anxiety pre-dated the physical disorder, and anxiety is generalised and not limited to health and healthcare related issues, and when the patient is unable to cope with or resolve anxiety over the long term. Importantly with the DSM IV diagnostic criteria it clearly states that symptoms of anxiety should not be due to direct physiological effects of a medical condition.

My presentation went on to emphasise that depression is a major medical illness and by the year 2020 is estimated to be the second major cause of disability world wide under ischaemic heart disease. I emphasised that physical signs and symptoms in major depression are the norm, with tiredness and lack of energy being described in at least 85% of patients with depression, headache and head pains in

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64%, dizziness or faintness in 60%, parts of the body feeling weak in 57%, muscle aches and pains in 53%, stomach pains in 51%, and chest pains in 46%. When depression is being treated most of the residual symptoms are physical and I also made the point that most physical complaints that people experience are not ever linked to an identifiable cause. With this understanding it is easy to see how Chronic Fatigue Syndrome and depression could be easily confused. I felt that in differentiating the conditions, the following eight points were important:

1. Fatigue should be considered secondary rather than primary. It is secondary to many other symptoms, for example chronic inflammation. When we de-emphasise the importance of fatigue we will actually progress much further in this condition.

2. CFS/ME has been seen in epidemics. I believe there has been at least 30 epidemics between 1934 and 1977. This does not occur in depression.

3. As Dr Stein mentioned, it is important to consider the temporal order of psychiatric and physical symptoms, and what you see in CFS/ME is that depression usually follows the illness rather than pre-dates it.

4. There are differences in the somatic symptoms between the two. In particular, the relationship to activity is important in that it is not just the fatigue that worsens after activity, other symptoms are also made worse, as exercise-induced fatigue is also seen in depression.

5. Although the somatic symptoms are similar, the cognitive symptoms do differentiate the two conditions. In CFS/ME you see less low self esteem, less suicidal ideation, less hopelessness, less loss of pleasure. In depression you get loss of pleasure both in anticipation of the act and after its fulfilment vs CFS/ME where there is more a frustration that things can't be done. Also in depression there is often a worse mood in the morning.

6. It is important to focus in CFS/ME on the early symptoms vs the chronic symptoms. These are often infective in nature, for example night sweats, enlarged glands and sore throat. These symptoms may not be seen in the latter stages of the illness.

7. It is important to focus on the variability of the symptoms, both within and between episodes of CFS/ME. This does differ to what is seen in depression.

8. It is important to focus on the biology that we do understand that is clearly different to depression, for example in CFS/ME we see neurally mediated hypotension, this is not seen in depression. In CFS/ME we see a disturbance of the HPA axis but it is opposite to what is seen in depression. In CFS/ME you see a decrease in CRH leading to a decrease in cortisol and there is no abnormality of the dexamethasone suppression test. In depression you see an increased CRH leading to an increased ACTH and an increased cortisol and a failure of suppression with dexamethasone.

I also gave an update on what is currently the thinking in psychiatry about CFS/ME. The previous week to the forum, the Royal Australian and New Zealand College of Psychiatry held a Congress. I attended a lecture given by Professor Ian Hickey, who spoke about chronic fatigue as opposed to Chronic Fatigue Syndrome. He used this term interchangeably with neurasthenia, fatigue states, and neuropsychiatric disorders, and stated that chronic fatigue was "a culture bound syndrome" which was becoming international. He stated that in cross cultural studies of "somatic syndromes", Sydney and Manchester seemed to have the highest incidence. He presented a slide looking at the prevalence of these conditions but did not compare "apples with apples". He stated that a WHO primary test study of neurasthenia showed a 5.4% incidence. An Indian study presented in the British Medical Journal this year by Patel et al showed a 12.1% incidence in women (of what I am not sure). He then went on to state that the USA, using CDC criteria for "chronic fatigue" with "limited psychiatric input", showed a 0.5-2.5% incidence (this is much closer to the Chronic Fatigue Syndrome incidence that we would expect world wide). He also commented on the fact that cognitive behaviour therapy trials have shown that they are a "highly effective" treatment.

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Children and adolescents

Dr Kathy Rowe
Royal Childrens Hospital, Melbourne

Dr Rowe's experience is with CFS/ME and adolescents. She has concerns that the symptoms may be different to those experienced by adults and stated that the symptoms experienced by more than 80% of the clinic group are the following: fatigue, headaches, sleep disturbance, myalgia after activity, and "lost for the word". She stated that pro-

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longed fatigue and headache are nearly universal, and divided groups of symptoms into: a) muscle pain and fatigue, which involves muscle pain after activity and muscle pain after doing nothing; b) neurocognitive, which includes poor concentration, speech problems, memory loss, vivid dreams, and nightmares; c) abdominal and chest pain; and d) neurophysiological, which involves recurrent chest pain and the need to sleep longer, e) immunological symptoms. She stressed that there were no abnormalities in parental bonding, as parents of CFS/ME children and adolescents have often been considered to be over protective. She stated that parental bonding is identical to that of the control group. She found 28% of her adolescents with CFS/ME had depression vs 20% seen in "normal" adolescents. Depression is associated with the severity of the CFS/ME, a delay in diagnosis, not being believed, school difficulties, and family problems, and sexual abuse. She found that 80% of her sample had an onset following a viral or febrile illness. Others followed immunisation, surgery, or perhaps had a subclinical infection.

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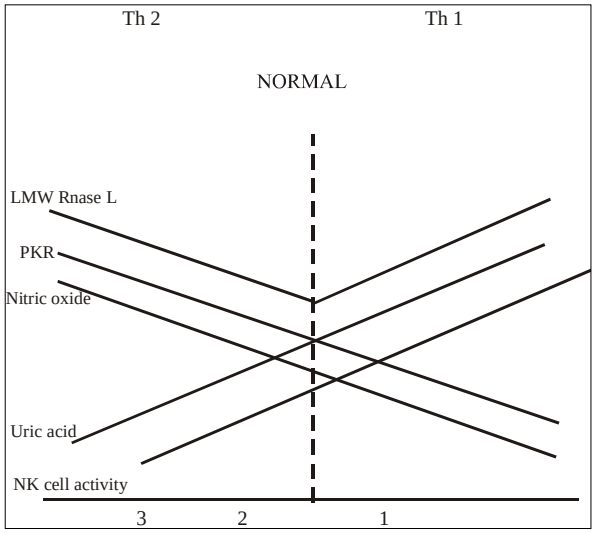
Day two

The second day of the forum revolved around discussing diagnostic criteria and also the establishment of a tissue bank. Kenny De Meirleir stated that if symptoms were present in more than 80% of patients that they should be included in diagnostic criteria. The following diagram, which Kenny drew, I personally found to be one of the most exciting outcomes from the forum, because this then leads the way for some kind of battery of diagnostic testing and a possibility to subgroup different groups of CFS/ME patients.



This diagram [above right] shows that there is a very severe group (number 3) who are likely to have significant bowel problems and to have almost no natural killer cell activity, very low uric acid, a very high PKR, a lot of fragmentation with a high amount of elastase and a very high nitric oxide. A less severe group (number 2), which is probably the largest CFS/ME group, have decreased natural killer cell activity, average or a bit low uric acid, increased PKR, some fragmentation of RNase L, and a slightly increased nitric oxide. Both of these groups had Th2 illnesses. On the other side of the line are Th1 illnesses like multiple sclerosis. This group are immune activated, they have high natural killer cell activity, high uric acid, low nitric oxide, low PKR activity, and high low molecular weight Rnase L.

Other than uric acid, these tests are not standard tests done in Australia, so Kenny is currently in discussions with a laboratory in Australia to perhaps get these tests off the ground.

The group as a whole discussed the pros and cons of the different diagnostic criteria that have been used currently. Obviously because of the differences in diagnostic criteria, different groups of research subjects are being studied making a lot of the research quite meaningless. Although the Fukuda criteria are primarily used in Australia, we reviewed the more comprehensive Canadian criteria which Kenny was involved in putting together. The Canadian guidelines were developed by a committee following input from invited world leaders in the research and clinical management if CFS/ME. It was felt that the Canadian guidelines represent evidence-based clinical practice guidelines developed from the best available research evidence. The forum agreed unanimously to propose that the Canadian criteria be used in world wide discussions of this illness. See below.

Although it is unlikely that a single disease model will account for every case of CFS/ME, there are common clusters of symptoms that allows a clinical diagnosis.

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Clinical Working Case Definition of CFS/ME

General Considerations in Applying the Clinical Case Definition to the Individual Patient:

1. *Assess Patient's Total Illness:* The diagnosis of CFS/ME is not arrived at by simply fitting a patient to a template but rather by observing and obtaining a complete description of their symptoms and interactions, as well as the total illness burden of the patient.

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Clinical Working Case Definition of CFS/ME

A patient with CFS/ME will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7.

1. Fatigue*:* The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

2. *Post-Exertional Malaise and/or Fatigue:* There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period - usually 24 hours or longer.

3. Sleep *Dysfunction:** There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

4. Pain*:** There is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints, and is often widespread and migratory in nature. Often there are significant *headaches* of new type, pattern or severity.

5. *Neurological/Cognitive Manifestations: Two or more* of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorising and word retrieval, and perceptual and sensory disturbances – e.g. spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload1 phenomena: cognitive, sensory e.g. photophobia and hypersensitivity to noise – and/or emotional overload, which may lead to "crash"2 periods and/or anxiety.

6. At *Least One Symptom from Two of the Following Categories:*
   a. *Autonomic Manifestations:* orthostatic intolerance – neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.
   b. *Neuroendocrine Manifestations:* loss of thermostatic stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change – anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.
   c. *Immune Manifestations:* tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, mediations and/or chemicals.

7. The illness *persists for at least six months. It usually has a distinct onset, **although it may be gradual.* Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

*To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day. *There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except CFS/ME. A diagnosis of CFS/ME can be entertained when this group has infectious illness type onset. **Some patients have been unhealthy for other reasons prior to the onset of CFS/ME and lack detectable triggers at onset and/or have more gradual or insidious onset.*

Exclusions: Exclude *active* disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anaemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnoea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis and polymyalgia rheumatica; immune disorders such as AIDS; neurological disorders such as multiple sclerosis (MS), Parkinsonism, myasthenia gravis and B12 deficiency; infectious diseases such as tuberculosis, chronic hepatitis, Lyme disease, etc.; primary psychiatric disorders and substance abuse. *Exclusions of other diagnoses, which cannot be reasonably excluded by the patient's history and physical examination, is achieved by laboratory testing and imaging. If a potentially confounding medical condition is under control, then the diagnosis of CFS/ME can be entertained if patients meet the criteria otherwise.*

Co-Morbid Entities: Fibromyalgia Syndrome (FMS), Myofascial Pain Syndrome (MPS), Temporomandibular Joint Syndrome (TMJ), Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud's Phenomenon, Prolapsed Mitral Valve, Depression, Migraine, Allergies, Multiple Chemical Sensitivities (MCS), Hashimoto's thyroiditis, Sicca Syndrome, etc. *Such co-morbid entities may occur in the setting of CFS/ME. Others such as IBS may precede the development of CFS/ME by many years, but then become associated with it. The same holds true for migraines and depression. Their association is thus loose than between the symptoms within the syndrome. CFS/ME and FMS often closely connect and should be considered to be "overlap syndromes."*

Idiopathic Chronic Fatigue: If the patient has unexplained prolonged fatigue (6 months or more) but has insufficient symptoms to meet the criteria for CFS/ME, it should be classified as idiopathic chronic fatigue.

(Continued from page 20)

2. *Variability and Coherence of Symptoms:* Patients are expected to exhibit symptoms from within the symptom group as indicated, however a given patient will suffer from a cluster of symptoms often unique to him/her. The widely distributed symptoms are connected as a coherent entity through the temporal and causal relationships revealed in the history. If this coherence of symptoms is absent, the diagnosis is in doubt.

***

Tissue Bank

With respect to the establishment of a tissue bank, Christine Hunter gave a heart rending story of what she personally went through with her daughter Alison when Alison died as she tried to get tissue saved for future study. It was felt that electron microscopy must be done in order to see the mitochondria. Someone commented that when autopsies are performed there is only a 30% concordance with what the clinical diagnosis was. Someone else mentioned that even tissue done from such procedures as endoscopies could be used positively to look for clues in this difficult illness.

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Conclusions

Simon Molesworth concluded the forum by stating that he had felt that this had been a great coming together and that the crisis of credibility that he has always spoken of has "come a hell of a long way." We spoke about how important it was to disseminate the information from the forum to wide reaching areas medically and politically, and that hopefully such forums will be repeated bi-annually.

Dr Peter Cahalan chats with Simon Molesworth

Adelaide Forum – June 3 and 4, 2005

Participants, by invitation

***** – informal presentation to Forum

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Jim Chambers Vice President CFS/ME Victoria
Dr Peter Cahalan PhD President ME/CFS Society of SA
Annette Leggo Alison Hunter Memorial Foundation
Christine Hunter Alison Hunter Memorial Foundation

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The ultra-comprehensive ME/CFS symptom list

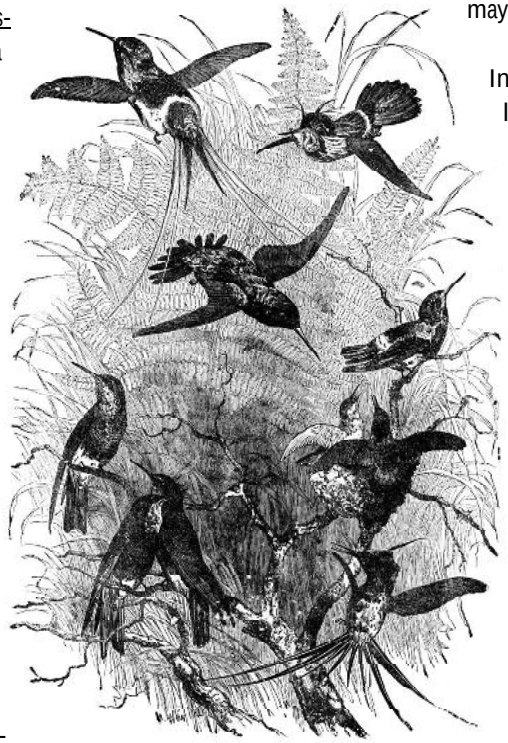
*Written and compiled by **Jodi Bassett**.*

Introduction

Before reading the symptom list please note:

The symptom list is also NOT a diagnostic tool. It cannot be assumed that because you may have some of the symptoms on the list that you necessarily have ME/CFS – some of them are common in a variety of other disorders and it is the pattern of symptoms which enables a ME/CFS diagnosis to be made, as well as the presence of a number of core characteristics/symptoms which are always present in the illness (and without which a diagnosis of ME/CFS should not be made).

The Canadian Criteria (www.cfids-cab.org/MESA/ccpc.html) are a much more useful tool for ME/CFS diagnosis.



Also note that if you find a symptom of yours listed here it does NOT mean that you don't still have to tell your doctor about it and get it checked out. 'Just' because it's a ME/CFS* symptom it does not mean it can't be serious. Cardiac problems in particular should always be investigated, as should lymph node pain (among many other things).

Never assume that everything is 'just' ME/CFS either, having ME/CFS does not mean you are immune from catching or developing other illnesses as well unfortunately.

So make sure you get every new symptom checked out by your doctor.

The symptoms are listed in no particular order (common ones are listed right near the rarer ones) and of course, remember that nobody will get *every* symptom.

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The defining characteristic of ME/CFS is exercise intolerance. Physical exertion causes relapse and continued physical exertion causes disease progression.

The effects of exercise are post-exertional muscle weakness, generalised weakness, faintness and pain; as well as the exacerbation of other symptoms. The level of activity which precedes post-exertional symptoms can be extremely trivial compared to a patients level of function pre-illness and varies greatly between patients

Post-exertional symptoms range from mild to severe, or may be life-threatening (seizures and cardiac events). The onset of post-exertional symptoms may also be delayed by 12-24 or even 48 hours and may then persist for hours, weeks or months afterward. Symptoms may or may not abate with rest.

In addition to physical exertion, relapses in symptoms can also be caused by mental exertion, sensory overload, mental stress and orthostatic stress.

Another of the core characteristics which clearly differentiates strictly defined ME/CFS from many other seemingly similar illnesses is, as Dr Melvin Ramsay explains 'the striking variability of the symptoms not only in the course of a day but often within the hour. This variability of the intensity of the symptoms is not found in post viral fatigue states.' (1989)

Another doctor makes the observation that 'a [ME/CFS] patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day.' (Jain, 1992)

As is the case with exercise intolerance, the unpredictable fluctuation of the variety and severity of symptoms from each hour, day or week to the next; is also diagnostic of ME/CFS.

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From the book by David S. Bell, M.D., *The Disease of a Thousand Names*:

> "A list of [ME/CFS] symptoms is misleading. At first glance it appears that almost every symptom possible is part of the list. This is another reason many physicians have not accepted the reality of [ME/CFS] – there are simply too many symptoms. But a patient relating these symptoms does not list them in a random manner. They fit a precise pattern that is nearly identical from one patient to the next. The pattern of symptoms is so reproducible in the usual case that patients are able to diagnose [ME/CFS] in others in an instant."

***

The ultra-comprehensive ME/CFS symptom list

This list has been compiled using the following sources:

- *CFS – A Treatment Guide*, by Verillo and Gellman;
- *ME/CFS: Clinical Working Case Definition* (Canadian definition) Carruthers *et al*;

The Doctor's Guide to Chronic *Fatigue Syndrome*, by Dr David S Bell. Myalgic Encephalomyelitis Society of America (online); and

- *M.E.: The New Plague*, by Jane Colby.

Symptoms are not presented as direct quotes from these sources (and are instead paraphrased) to aid readability. No extra anecdotal symptoms have been added.

Cardiac and cardiovascular symptoms

- Sensations of chest pain, chest pressure or fluttering sensations in the mid-chest.
- Light-headedness and/or syncope (fainting), lower than normal blood volume, low blood pressure – hypotension.
- Reduced maximum heart rate and/or an elevated resting heart rate.
- Extreme pallor or edema (swelling of the hands and feet).
- Neurally Mediated Hypotension (NMH): low blood pressure which occurs when there is an abnormal reflex interaction between the heart and the brain) which can also occur with Delayed Postural Hypotension (usually delays are around 10 minutes or more).
- Postural Orthostatic Tachycardia Syndrome – POTS (a heart rate increase of 30 bpm or more from the supine to the standing position within ten minutes or less) which can also occur with Delayed Postural Orthostatic Tachycardia Syndrome (usually delays are around 10 minutes or more).
- Palpitations (skipped heart beats), tachycardia (rapid heart beat – up to 150bpm), premature atrial and ventricular contractions (early or extra heartbeats), various arrhythmias (abnormal heart rhythms) or ectopic heart beats (a contraction of the heart that occurs out of its normal rhythmic pattern, it may feel like a thumping sensation in the chest) can all occur.

Cognitive and emotional symptoms

- Slowed retrieval of long term memories and difficulty making and consolidating memories (particularly short-term memories).
- Prosopagnosia – not being able to recognize faces, even those of close friends and family, (facial agnosia) and also a difficulty associating faces with names.
- Multitasking problems and an inability to learn to perform new tasks (as well as forgetting how to perform routine tasks).
- Volitional problems; difficulty starting or stopping tasks and/or cognitive slowing (tasks can take much longer than usual).
- Impairment of concentration.
- Difficulty with visual and aural comprehension; Difficulty following oral or written directions, trouble distinguishing figure from ground and delayed speech comprehension. Greater difficulty with auditory than visual memory is common.
- Paraphasia – incorrect word selection, such as using the wrong word from the right category or using a word that sounds similar to the correct word but has a different meaning.
- Word blindness – inability to recognize words.
- Word, letter and short term ordering problems, for example; transposition – reversal of letters or numbers, or words when speaking or writing (pseudodyslexia).
- Difficulty/inability to understand speech (Wernicke's Aphasia) and/or an inability to express language i.e. speak (Broca's Aphasia). Difficulty pronouncing words intelligibly (Dysarthria).
- Inability to locate the words for writing (Agraphia) and/or problems with reading (Alexia).

Loss of arithmetic skills, inability to do simple addition, count money etc (Dyscalculia).

- Perceptual and sensory disturbances e.g. spatial instability and disorientation and an inability to focus vision.

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- Altered time perception (losing time), feeling 'spaced out' or 'cloudy' or not quite real somehow.
- Disorders of colour perception – recognizing colors but forgetting what they mean, at traffic lights for example.
- Hypersensitivity to noise and/or emotional overload.
- An exaggerated response to even small amounts of additional input, incoming messages become scrambled or blurred resulting in distorted signals and odd sensations.
- Difficulty organizing, integrating, and evaluating information to form conclusions or make decisions.
- Personality change – usually intensification of a previous tendency, mood swings (emotional lability), crying easily, excessive irritability etc or intense emotions such as rage, terror, overwhelming grief, anxiety, depression and guilt or sometimes there can be emotional flattening or situations may be erroneously interpreted as novel (due to prefrontal cortex dysfunctions).
- Anxiety and panic attacks (often not tied to environmental triggers).

Digestive disturbances

- Esophageal spasms (felt as extreme pain in the centre of the chest that sometimes radiates to the chest or mid-back).
- Difficulty swallowing (or an inability to swallow altogether) or esophageal reflux (heartburn).
- Great thirst and/or increased appetite and/or food cravings or lack of appetite.
- Inability to tolerate much fat in the diet (gallbladder problems).
- Changes in taste and smell, an increased sense of smell or bizarre smells. Strange taste in mouth (bitter, metallic).
- Multiple new food allergies and intolerances.
- Bloating, abdominal pain, nausea, indigestion or vomiting.
- Intense gallbladder pain (in the upper right quadrant of the abdomen) or liver pain, tenderness or discomfort. Liver problems can lead to a poisoned feeling, and alcohol intolerance is extremely common.
- Diarrhea, constipation or an alternation between the two.

Endocrine and neuroendocrine disturbances

- Thyroid pain, inflammation and/or dysfunction (usually secondary hypothyroidism) and/or adrenal gland dysfunction (aspects of both overactive and underactive adrenal function) and/or pituitary dysfunctions.
- Loss of thermostatic stability – subnormal body temperature and marked diurnal fluctuation (temperature fluctuation throughout the day) and/or poor temperature regulation – suddenly feeling cold in warm weather and/or recurrent feelings of feverishness and/or hot flashes particularly involving the upper body.
- Sweating episodes (profuse sweating, sometimes even when cold) – with the sweat often having quite a sour smell.
- Cold hands and feet, sometimes on only one side.
- Swelling of the extremities or eyelids.
- Loss of adaptability and worsening of symptoms with stress.

Exercise and stamina

- A feeling of agitated exhaustion (feeling 'tired but wired') is common.
- A sudden unexpected feeling of being 'high' can occur (due to neurological malfunctions) leading to (usually short) bouts of physical hyperactivity.

Impaired cognitive processing when engaged in physical exertion and/or a reduced maximum heart rate and/or a drop in body temperature and/or dyspnea (shortness of breath) with exertion.

- Severe muscle weakness and/or paralysis. (Problems arise from sustained muscle use – it is a delayed or impaired recovery of muscle after exercise. They often may function normally to start with, but pain and weakness (or paralysis) develop after very short periods of use and often come on very suddenly. It is a problem involving the metabolism of the muscles.)
- Loss of the natural antidepressant effect of exercise.

***

The defining characteristic of ME/CFS is exercise intolerance. Physical exertion causes relapse and continued physical exertion causes disease progression.

The effect of exercise is post-exertional muscle weakness, generalised weakness, faintness and pain; as well as the exacerbation of other symptoms. The level of activity which precedes post-exertional symptoms can be extremely trivial compared to a patients level of function pre-illness and varies greatly between patients.

Post-exertional symptoms range from mild to severe, or may be life-threatening (seizures and cardiac events). The onset of post-exertional symptoms may also be delayed by 12 – 24 or even 48 hours and may

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then persist for hours, weeks or months afterward. Symptoms may or may not abate with rest.

In addition to physical exertion, relapses in symptoms may also be caused by; mental exertion, sensory overload, mental stress and orthostatic stress. (As with physical exertion, the levels of each of these stimuli required to produce symptoms may be trivial compared to a patient's tolerances pre-illness; and the severity, duration and type of symptoms triggered will also vary widely between patients).

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Headaches

- Onset of a new type, severity or pattern of headaches is common. These can be experienced as a feeling of extreme pressure felt at the base of the skull and/or severe pain or sensation of pressure behind the eyes (or ears). Sinus, pressure or tension headaches (dull continual headaches which are not actually caused by anxiety as the name may suggest) can occur, as can hypoglycemia headaches (generalized prickly ache over the top of the head, sleepiness) .

Hearing, vestibular and speech problems

- Hyperacuity – an intolerance to normal sound volume and range, but particularly sounds in the higher frequencies. Sudden loud noises can also cause a startle response (flushing and a rapid heart beat) and there can also be an extreme intolerance to vibration.
- Tinnitus – ringing, buzzing, humming, clicking, popping and squeaking noises generated in the ear.
- Hearing loss – sound can be muffled or indistinct or sound strangely flat.
- Sharp transient ear pain, deep itching in the ears and/or swelling of the nasal passages.
- Dizziness or vertigo – a sensation that your surroundings (or you) are spinning wildly (can cause vomiting).
- Acute profound ataxia (balance problems) and/or a sensitivity to motion/movement (which can affect balance).
- Nystagmus – a rapid involuntary oscillation of the eyeballs (eyes rolling back in your head).
- The voice may become very weak, hoarse or fall to a whisper, and then there can be total loss of speech.

Slowed rate of speech, sometimes with stammering, stuttering, muddled or slurred speech.

- Difficulty moving the tongue to speak and/or difficulty getting enough air to speak more than a few words at a time.

Hypoglycemia

- Hypoglycemia or hypoglycemia-like symptoms (low blood sugar).

Immune system problems

- Painful/swollen lymph nodes especially on the neck, underarms and/or groin, particularly on the left side, and recurrent flu-like symptoms (general malaise, fever and chills, sweats, cough, night sweats, low grade fever, sore throat, feeling hot often and low body temperature).
- Throat pain, scratchiness and tenderness which often worsens with exercise, exertion, or before relapses. Throat may feel clogged and require constant clearing. Throat may appear red or have characteristic 'crimson crescents' around the tonsillar membranes of the upper throat.
- Increased susceptibility to secondary infections or a decreased susceptibility to secondary infections. (There is a tendency to catch either every virus going around or none of them).
- A worsening of existing allergies and/or new severe sensitivities/allergies/intolerances to airborne allergens: pollen mould, animal dander, fur and feathers, dust. Food. Chemical sensitivities: indoor and outdoor chemical air contaminants, drugs and medications, clothing and personal care products.

Allergy symptoms

- **Skin:** pallor, itching, burning, tingling, flushing, warmth or coldness, sweating behind the neck, hives, blisters, blotches, red spots, pimples, dermatitis, eczema.
- **Eyes:** blurred vision, itching, pain, watering, eyelid twitching, redness of inner angle of lower lid, drooping or swollen eyelids.
- **Ears:** earache, recurring ear infections, dizziness, tinnitus, imbalance.
- **Nose:** nasal discharge or congestion, sneezing.
- **Mouth:** dry mouth, increased salivation, stinging tongue, itching palate, toothache.
- **Throat:** tickling or clearing, difficulty swallowing.
- **Lungs:** shortness of breath, air hunger, wheezing, cough, mucous or recurrent bronchial infections.
- **Heart:** pounding or skipped heartbeats, chest tightness.
- **Gastrointestinal tract:** burping, heartburn, indigestion, nausea, vomiting, abdominal pain, gas, cramping, diarrhea, constipation, mucus in stool; frequent, urgent or

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painful urination, bedwetting (in children).

- **Muscular system:** muscle fatigue, weakness, pain, stiffness, soreness.
- **Central nervous system:** headache, migraine, vertigo, drowsiness, sluggishness, giddiness.
- **Cognition:** lack of concentration, feeling of 'separateness', forgetting words or names, anxiety, tension, panic, overactivity, restlessness, jitteriness, depression, PMS.

Joint problems

- Significant myalgia (pain) in joints is often widespread. The most common joints affected are knees, ankles, elbows, hips but pain in the fingers also occurs as does aching in the joints.
- Gelling (stiffness) in the joints that develops after holding a position for awhile, usually sitting or upon awakening or be caused by changes in temperature or humidity.
- Stiff slow gait (often with legs quite wide apart) Difficulty with tandem gait.

Muscle problems

- Significant myalgia in muscles is often widespread (sharp, shooting, burning or aching pain).

Transient tingling, numbness and/or burning sensations (or other odd sensations) in the face or extremities (paresthisias).

- There is sometimes atrophy of specific muscle groups (a shrinking in size visible to the eye).
- Inability to form facial expressions leading to a 'slack' facial appearance and/or a loss of ability to chew/swallow.
- Paresis – severe muscle weakness. (Note that problems arise from sustained muscle use, they may function normally to start with but pain and weakness develop after very short periods of use and often come on very suddenly) or paralysis.
- Tremors and twitches of the muscles (involuntary movements), muscle spasms, which can be extremely severe and painful or there may be spasms of the hands and feet, which can lead to 'clawed' deformities.
- Loss of co-ordination/clumsiness – difficulty in judging distance, placement and relative velocity (caused by proprioception disturbances, proprioception being the perception of stimuli relating to your own position, posture, equilibrium, or internal condition) Extension or quick rotation of the neck can cause dizziness (also due to proprioception disturbances).
- Slight hesitation in movement or 'cogwheel' effect with movements.
- Skin is very sensitive to the touch, there can be also be allodynia – a pain response to stimuli not usually painful and/or spontaneous bruising

Oral problems

- Dental decay and periodontal disease (gum disease) are much more common than in the general population.
- Frequent canker sores (painful sores in the mouth which look like small bumps with white heads).
- Loose teeth and endodontal (the soft tissue in the centre of the tooth) problems.
- Temperature sensitivity in the teeth and/or pain.

Reproductive symptoms

- Menstrual cycles may become shorter, longer or irregular. Periods may also become lighter or disappear altogether (when illness is severe usually).
- Intensification of ME/CFS symptoms before and during a period.
- Lowered libido.
- Impotence.

Respiratory symptoms

- Erratic breathing pattern and/or episodic hyperventilation.
- Dyspnea – air hunger, (often on waking or exertion), which can be severe.
- Persistent coughing and wheezing can occur.

Seizures and seizure activity

- Grand Mal seizures (where there is loss of consciousness and motor disturbances), Petit Mal seizures – absence seizures (where you are conscious but unaware of

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your actions, a person may continue with an activity as though asleep) or Simple Partial seizures (do not involve loss of consciousness but produce altered sensations, perception, mood or bodily sensation) can occur. (Note: 6% of ME/CFS patients have seizures as part of the illness).

- Sensory storms/overload phenomena (hypersensitivity to light, sound, vibration, speed, odours and/or mixed sensory modalities).
- Myoclonus (strong involuntary jerks of the arms, legs or entire body).

Skin, hair and nails

- **Skin:** extreme pallor, rashes, dry and peeling skin, acne, spontaneous bruising, fungal infections, butterfly rash on face, flushing of face, fingerpads may be atrophic so that the fingerprints are hard to see, skin may become red and shiny (after a substantial period of illness usually).
- **Hair:** loss and poor quality regrowth.

Nails: vertical ridges, bluish nail bed, brittleness, fungal infections.

Sleep problems

- Unrefreshing sleep (waking up feeling worse than when you went to bed).
- Reversed or chaotic diurnal sleep rhythms (i.e., your body clock resets itself inappropriately).
- Insomnia – difficulty initiating or maintaining sleep or Hyposomnia – lack of sleep.
- Hypersomnia – excessive sleeping (in the earlier stages of the illness only).
- Very light sleep.
- Unusually vivid nightmares.
- Dysania (morning fog).
- Temporary paralysis after sleeping (also called waking paralysis, can last from minutes to hours) and/or early waking states (where you are neither asleep nor awake which can last for minutes or many hours).
- In severe illness, patients can become unconscious, comatose for up to 23, 24 hours a day (the brain becomes unable to maintain wakefulness).

Urinary tract problems

- Urinary frequency and bladder dysfunction, uncomfortable or painful/burning urination (Dysuria), difficulty passing urine or incontinence and/or nocturia (excessive urinating at night).

Vision and eye problems

- Photophobia (extreme sensitivity to light). Oscillating or diminished pupillary accommodation responses with retention of reaction to light.
- Pain or burning sensations in the eyes, floaters, spots and scratchiness in vision, sluggish focus, an inability to focus or accommodation difficulty (difficulty switching from one focus to another) can all occur as can double, tunnel or blurred vision, night blindness and/or a transient loss of vision and/or loss of depth of field, less ability to make figure/ground distinctions.
- Nystagmus – a rapid involuntary oscillation of the eyeballs (eyes rolling back in your head).
- Tearing and dry eye.

Weather sensitivity

- Intolerance of extremes of hot and cold (exacerbation of symptoms during temperature extremes). Insomnia, migraines, irritability or generally 'feeling off' a day or two before the weather changes. Changes in temperature or humidity can cause stiffness or increased aching or pain in the muscles. Changes in barometric pressure can cause night sweats and spontaneous sweating during the day.

Weight changes

- Marked weight gain (often independent of dietary changes) or marked weight loss (often independent of dietary changes), rapid weight loss can also occur despite copious amounts of food being eaten.

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ME/CFS is a severe acquired systemic illness, it manifests symptoms predominately based on neurological, immunological and endocrinological dysfunction and occurs in both epidemic and sporadic forms. The severity of symptoms varies unpredictably from week to week, day to day, even hour to hour. Some symptoms can be extremely severe, and in rare instances ME/CFS can also be fatal.

Characteristics of ME/CFS include: Physical as well as cognitive exertions exacerbate all other symptoms. Activity rhythms in the physical, cognitive and emotional realms are unpredictable. Significantly lower peak oxygen consumption. Low cardiac reactivity to cognitive stress. There is clinical evidence of immune system activation in the absence of viral exposure and/or associated with inappropriate events such as physical exercise and stress. Severe and

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prolonged exacerbation of illness if activity limits are transgressed too deeply or too often.

ME/CFS Fatalities: Most deaths from ME/CFS, around two thirds, are due to organ failure (according to the National CFIDS Association). Death can also occur as a result of secondary infections in a similar way to AIDS, or be due to severe cardiac irregularities or problems with maintaining breathing.

Co-morbid entities (note that some conditions, such as NMH for example, are instead included in the general symptoms list because they are so central to ME/CFS):

- Increased tendency for Mitral Valve Prolapse, especially in children (breathlessness, fatigue, edema)
- Viral myocarditis – inflammation of the heart (usually of little consequence but which can sometimes lead to substantial cardiac damage and severe acute heart failure. It can also evolve into the progressive syndrome of chronic heart failure. There have been sudden deaths associated with exceptional physical exertion in patients with viral illnesses);
- Pericarditis (the outer layer of the heart, pericardium, is inflamed. Symptoms include chest pain, shortness of breath, and rapid, shallow respiration);
- Secondary or reactive depression (as with any other chronic illness) or organic depression;
- Irritable Bowel Syndrome;
- Raynauds phenomenon (poor circulation);
- Shingles;
- Systemic yeast/fungal infections are common (e.g., Candida);
- Multiple Chemical Sensitivity Syndrome;
- Carpal tunnel syndrome (weakness, pain, and disturbances of sensation in the hand);
- Pyriform muscle syndrome causing sciatica;
- Positive Fibromyalgia tender points (FMS) and Myofascial trigger points (MPS) are common;
- Temporomandibular Joint Syndrome TMJ (spasms of the jaw muscles causing intense pain);
- Hashimoto's thyroiditis;
- Sicca Syndrome;
- Endometriosis (the presence and growth of functioning endometrial tissue in places other than the uterus that often results in severe pain and infertility) may be more common in ME/CFS;
- Dysmenorrhea – menstrual pain experienced a week before, during and a few days after periods (other symptoms include; headache, suprapubic cramping, backache, pain radiating down to anterior thigh, nausea and vomiting, diarrhea, syncope);
- More severe or new onset PMS;
- Migraines (nausea, vomiting, head pain, light and noise sensitivity which can last for hours or days);
- Restless Legs Syndrome;
- Sleep apnea;
- Irritable Bladder Syndrome Cystitis (inflammation of the urinary bladder);
- Prostatitis (inflammation of the prostate gland);
- Sjogrens syndrome (autoimmune disorder affecting moisture producing glands in the body).

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If you'd like to see more of my ME/CFS writings just go to www.ahummingbirdsguide.com.

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References

(All symptoms/signs are taken from the following ME/CFS books – I've just put them all in the one place. The headings and groupings of symptoms are my own, so any faults with which symptom is in which category is mine alone (and there was quite a bit of room for error as many symptoms fit into more than one sub-heading). Please note that I haven't included any personal or anecdotal symptoms.)

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Information about ME/CFS

What is ME/CFS?

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

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

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

Prevalence

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

Main characteristics of ME/CFS

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

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

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

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.

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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: Jane on 8826 2097.

Southern Fleurieu Support Group
Second Thursday alternate months: April, June, August, 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.

Please note that meeting times are subject to change.

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

8410 8930 or 1800 136 626

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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 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

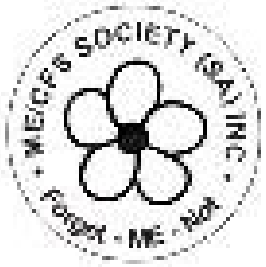
Auburn	Kay Hoskin	8849 2143
Barossa Valley	Dennis	8563 2976
Mt. Gambier	Di Lock	8725 8398 or 0438 358 398 (mobile)
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Kathy Southeren	8586 3513
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897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



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