



Talking Power

2004 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

Patron

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



Medical Advisor

Dr Peter Del Fante – GP, BSc DipCompSc MBBS (Hons) MSc (Public Health Medicine), Medical Director of the Western Division of General Practitioners.

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

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- Family \$40
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Talking Point

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Management Committee 2004/2005

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:**
Donna Briese, Adrian Hill, Emma Wing, Margaret Wing

Contact Details

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

Note: It is our policy to ignore anonymous correspondence.

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

At the time of printing the office hours are:
Wednesdays and Thursdays 10am to 3pm (subject to volunteer availability).
Our email address is: sacfs@sacfs.asn.au
Our Web site address is: www.sacfs.asn.au

Donations

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



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

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President's report

By **Peter Cahalan**

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It's my pleasure to deliver this annual report. Last year we had not long farewelled my excellent predecessor, Paul Leverenz, and so this is really the first report where I have lived through all that I report on!

It's been a good year. In fact, it's been better than your committee probably had hoped for when it first met after last year's AGM. We were all very conscious then that the Society relies on a handful of people. And we felt pretty daunted by the challenge ahead. Still, we had a go at it and thankfully things have gone fairly well.

Achievements

Our key achievements included:

ME/CFS Guidelines

We contributed to the important new publication aimed at assisting general practitioners to identify and help patients to manage CFS. The ME/CFS Guidelines took two years to develop and resulted from the efforts of a working party of medical practitioners and researchers with two Society representatives. I tender our thanks to the chair, Prof Justin Beilby, and to Associate Prof David Torpy, Dr David Gilles, Dr Richard Burnet, Dr Rey Casse, Dr James Hundertmark, Dr Milton Bowman, Dr Bruce Wauchope, Dr Ian Buttfield, Dr Richard Kwiatak, and the Society representatives Paul Leverenz and Kristin Clark. I also particularly thank Dr Peter Del Fante who assiduously worked on every stage of the drafting. And I thank our partners: the Department of Human Services (now Health) and its representative Mr Bruce Whitby; the Adelaide Western Division of General Practice; and the University of Adelaide Department of General Practice.

The *Guidelines* have now gone out to every GP in the State. We don't expect every one of them to use the document. But we're heartened at stories of doctors very quickly discussing them with patients. And it's great to know that CFS societies in other States have seized on them eagerly. The *Guidelines* are now available for downloading on the NSW Society's website, as it is on our own. Victoria and the ACT have also sought bundles of them. There's no doubt that it's a document of national significance and it's a matter of pride that South Australia has produced it.



Parliamentary inquiry into Multiple Chemical Sensitivity

We used a rare opportunity to get a message across to the State's politicians about an aspect of CFS which affects about half our members. State Parliament in 2003 asked its Social Development Committee to investigate a range of issues associated with what is often called Multiple Chemical Sensitivity. Writing submissions to such committees can be an arduous task. But we were fortunate that member Lorenzo Pizza took on the job and prepared a draft. Former committee member Peter Evans and I then refined it and it went off to the inquiry. I was then called upon to speak to our submission before the Committee on 25 October.

Through this your Society was able to remind State parliamentarians of the large numbers of people suffering from CFS and MCS in South Australia. We stressed the need to make the health-care system more accessible and argued the need for an officer dedicated to dealing with 'chemical injury' to be appointed to the Department of Health.

As part of the process, we co-convened with the Task Force on Chemical Injury a workshop in September. Twenty people attended, the great majority of them members of the Society. It brought out for me especially the huge problem with some highly sensitive people have to gaining safe access to places of health care such as hospitals because of a lack of awareness in management and staff of the need to provide chemically-free zones at least somewhere for them. I was heartened that the MPs on the Social Development Committee were also shocked by this.

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The Committee's report should appear in the first half of 2005. We must then – all of us – work to ensure that it doesn't lie neglected on the shelves whilst more vociferous lobby groups are given priority.

Building alliances

Your committee takes the view that in the long run we need to be more closely aligned to other disability societies. It is utterly clear that we will never get very far in securing the resources which we need from government if we push for them on our own. Even though we speak for between 3000 and 7000 citizens, many of them very sick indeed, we are well down a long queue and vie for attention with formidably organised and better-connected lobby groups. And why should governments support a myriad of small organisations? It's not always the most efficient way to deliver services.

So in the past two years we have kept in touch with Cystic Fibrosis SA regarding possible collocation at some time. Some of the urgency has gone out of this. Our financial position has become more stable and our new landlord at the Epworth Building has raised our rent somewhat but not excessively. But we have to keep the option open for sharing accommodation with CFSA and/or other groups.

We have also tried to develop our profile with other disability organisations by being active members of the Neurological Council of SA. This brings together over 20 organisations. Like everything else it is run by volunteers – in this case mostly the paid employees of larger organisations.

- We have continued our involvement in the Council's joint exercises at agricultural field days. Our thanks go to Denise Stephens and Donna Smedley who staffed our section of the Council stall at the Lucindale Field Days in March. It's really important that the Society has a presence at regional events such as this but it does demand several days' commitment from those concerned. For that reason we chose not to be represented at several other field days this year.
- As well as that, it was at our urging that the Council sent a letter, which we drafted, to the Minister for Health. In it the Council asks for the Department of Health to undertake a review into how it funds disability organisations and to then make public what its criteria are for the massive inequities in the funding available to various organisations.

Because we are at present totally independent of government we can be that much more at liberty to say that which other organisations think. It is quite distressing to read the annual report of, for example, Novita (the former Crippled Children's Association) and to see that the State government grants to it for services to around 1000 clients amount to around \$9m. If just one of those nine million dollars were made available to the rest of us, then there would undoubtedly be some cutback in services to Novita's deserving clients. But our members, also deserving but with virtually no access to services, would at least get something.

As I said, it is not normally seen as polite or good politics to say this sort of thing. But politeness doesn't always get results. We have nothing to lose at this point and perhaps something to gain for our members. But round one is not to ask for money. Round one is to get the government to explain itself. Then we can have a good rational argument.

We will continue to work with our fellow organisations on the Neurological Council for the interests of all those people for whom we collectively fight.

Communications

Our resources are slight. But modern technology means that we can communicate much more readily with our members. So this year we started working on ways to use it. The focus has been on getting the information that comes into the office passed on to members as quickly as possible. So we have posted a regular flow of items on our website (www.sacfs.asn.au). Its webmaster is the jovial and efficient Peter Scott. If you have access to the Internet, please bookmark our site and look at it every week or two. Because that's roughly the rate at which we add new items to it. I think it is now the most actively updated CFS society website in Australia.

We have also taken to sending irregular (but fairly frequent) e-bulletins to those members whose email addresses we have. That's about half. The response from them has been very positive. But we want to bring the other half of our members, who don't have easy access to the internet, into the flow of communications. We aim therefore to recruit several volunteers who are willing to come into our office and just get on the phones to these members to keep them more or less abreast of what their networked co-members are learning. In the meantime our

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thanks go to volunteer Michael Ritter, who handles this and a range of other IT issues for us with good humour and aplomb.

Other activities

- **Awareness Day.** We held our annual Awareness Day seminar at the Burnside Civic Centre on 12 May. Over 100 people attended to hear a panel drawn from the working party on the Guidelines reflect on the publication and what had come out for them from the project. Prof Justin Beilby, Dr Peter Del Fante and Kristin Clark all stuck to their allotted times and so there was plenty of time for an intensive question and answer session afterwards.
- **Badge Day.** A week later we ran our traditional May badge day in the city and at Burnside Village. Our thanks go to the organising committee – Adrian Hill, Bow Thompson, and Bob Griffith – and to the badge sellers, including students from Cabra and Seymour Colleges. Loreto College held two casual clothes days around the same time and the three schools did a great job for us.
- **Talking Point.** Our magazine has come our quarterly, edited by Peter Scott, our webmaster. The arrangement whereby we use articles from the better-resourced Victorian CFS/ME Society's magazine has been very successful. We top and tail it with South Australian material to keep it local and have access to quality articles. We've had excellent feedback from members about it.
- **Country visit.** A personal highlight for me was addressing the North Yorke Peninsula support group in Wallaroo in August. They're a great group and are inspiringly convened by Jane Gill. I'd like to thank her and all other support group leaders for their continuing work over this year. Marion, Fran, Julie, Pat, and Melanie – we thank you and those who work with you city and country support groups.
- **SAYME.** The SAYME group – our support group for younger members – had a good year though a quieter one than previous years. There was a hiatus in the production of its magazine but that was sealed with the publication of the latest magazine in October. It's now back on track thanks to the efforts of Emma

Wing and outgoing editor Elizabeth Cahalan. My thanks go to events coordinator Sarah White and to the person who provided consistent support to SAYME throughout the year, our office coordinator Donna Briese. And I thank Rebecca Cordingley who has retired as SAYME webmaster after revamping the website and overseeing it for several years. More about SAYME below.

- **Research database project.** We have begun work with some of the key players in the Guidelines project on scoping up a proposal for a pilot project to study a group of South Australians with CFS. Around \$30 000 has been raised by interstate supporters for this and we have applied to the Alison Hunter Memorial Foundation for funding. The key drivers will be the University of Adelaide Department of General Practice with Dr Peter Del Fante also involved. Let's hope this one comes off.

Management Committee



The Committee met monthly throughout the year. Its membership changed somewhat. Glenn Domeika, who has been a member for the last three years, resigned in mid term for family reasons. Our honorary secretary Denise Stephens also retired near the end of her term. We thank them both for their efforts. Our numbers were starting to look depleted. But then no less than four

people came on board. Office volunteers Donna Briese and Donna Smedley and SAYME member Emma Wing joined the committee. And in response to our call for an honorary secretary we struck lucky with member Peter Mitchell who had just decided to retire as a high school principal with years of experience as the hon. sec to the principals' association. It's been great to have this new blood on the committee. Unfortunately an onset of ill health has forced Donna Smedley not to continue and I thank her. I also especially thank the ongoing stalwarts of the committee: Marg Wing, Adrian Hill and Geoff Wilson. We have tried to take the approach that people do what they can over a sustained period rather than to burn themselves out in a short time. Each of these people has now served three years and will be continuing. They therefore provide a real stability to the committee.

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Thanks

There are many people who should be thanked for their work for the Society. Some of them are in country and suburban areas and, because I haven't met them, I might be in danger of overlooking them. We hope in 2005 to extend personal contacts from the office with some of these groups.

But I have seen at first hand the work of several people who have provided outstanding service. Patricia Smith was our office coordinator for 2.5 years until she retired early this year. She did an outstanding job of running the office and also taking on a range of projects from time to time. We miss her and I note that somehow or other a long-planned farewell 'do' for her has never happened. Such is life!

After Patricia's departure, the mantle of keeping the office ticking has fallen especially to Donna Briese. Donna has worked tirelessly, despite the ill health she shares with many members, to keep us up to speed with the many day-to-day matters which we must attend to. She has the thanks of the whole committee and to that I add my thanks to her fellow committee-member, Marg Wing, who has regularly come in on Thursdays.

I thank once again the people who coordinate and run our crucially important Support and Information Line: Jon and Vicki Foote, Alex Harris, Elaine Balfort, David Andrews and Marilyn Pennack. I can't overstate the importance of their work and I wish that we could recruit more people to support this devoted team, who have been at it for years.

Future directions

When your committee meets to plan the Society's 2005 program, here are several key things which will be on the table:

- **Continuing to improve our communication with members** – especially with those who don't have access to the Internet.
- **Having a stronger program of lectures and seminars** than we've run in recent years. We'd like to run about four events next years, up from the two which we've averaged of late.

Support Line

Please note that the Support Line will close from Friday December 16, 2004 and re-open on Thursday February 3, 2005.

- **Focusing on young people and their families.** SAYME celebrated its tenth anniversary this year. That caught us by surprise. But we'll honour its achievements and seek to give it particular support in 2005. We plan to hold a workshop for parents of young people with CFS. And a project which went to ground a year or so is being resuscitated. That is to produce a kit for schools on how to deal with students with CFS. We believe that SAYME is a really important enterprise. Its success has always depended on getting new young leaders coming up through the ranks. But most commonly these are young people whose families strongly support their involvement in SAYME. And so we want to give families more support and encouragement.
- **Pushing forward with the research database project.** We hope it will lead to a much bigger program but we want to get Stage One up and running first.

We also want to build our base of volunteers. We'd like several people as office volunteers who can also focus on telephoning our isolated members. We'd like people willing to: help organise our badge day; take on the running of our lecture/workshop program; undertake PR and media relations for us; go to agricultural field days; and take on special project work from time to time when we're asked to provide input to government reviews and so on. Coordinating some of these activities and new volunteers for them might tax the energy of our existing workers. But we'll give it a go. Basically, if people can take on some defined jobs and stick with them for several years, that would be wonderful.

Conclusion

I hope that this report will give you confidence that the Society is serving your interests and those of all people with ME/CFS in South Australia. We have done things in 2004 which we are proud of and which have won us the acclamation of other societies elsewhere in Australia. We hope to build on the good foundations of this year and of the previous years in 2005. I wish you all good health and, if that is not possible, then a strong spirit.

Peter Cahalan

Northern Yorke Peninsula Support Group report

By Jane Gill

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This year we celebrated our fourth birthday! We invited Peter Cahalan and his wife Penny to come and speak to our group also, also Jackie Philips NYP Carer Respite Coordinator.

Peter spoke about the role of the S.A. CFS Society and current activities. Most current being the new ME/CFS Guidelines that the Health Department had put together and were then being distributed – a wonderful correlation of information for GPs. We are grateful to the Health Department for their initiative and commitment to CFS.

Penny Cahalan shared what it was like to have a daughter with CFS diagnosed as early as 12 years of age! Jackie spoke for the benefit of the carers of people with CFS who also have many special needs and we must never forget or overlook our carers. In this meeting there was something for everyone – sufferers and carers.

Earlier in the year we just had two 'get togethers' which we find are great opportunities to be informal, and get down to some 'nitty gritty' issues that we perhaps don't get time to at the more formal meetings with guest speakers etc. We can then talk about our worst symptoms and how they affect us, what helps get us through the day on both good and bad days, even positives they have about having CFS.

We only have our meetings four times a year – in March, May, August and November. We feel fewer meetings are better because of the nature of CFS, then there isn't constant pressure on people to be at meetings when they are under enough pressure anyway – just coping!

We endeavour to bring as many speakers from Adelaide that we can who can inform and educate and therefore encourage and uplift us in our dealing with CFS.

We aim to make the meetings as positive as possible. Over the four years we have been going we have as many as 40 people come or as small as eight. We have never been below eight. All meetings give the opportunity to meet others with CFS, to share – on common ground and be understood! It is empowering to come away knowing you are understood.

Our November meeting was enlightening. We had David Steadman who is the Pharmacist from Wallaroo and

Pauline Johnson who is the Dietician from the Wallaroo Hospital come as guest speakers. They were both so good we are going to have them back – and they were both very happy to come again.

We are always grateful for Community Health at Wallaroo who provide us with a room to meet in for free. They used to provide tea, coffee, etc for free but now are charging – so we have decided to provide our own and at each meeting we take up a gold coin to help cover costs.

Our group is keen to have an information stall at the NYP Field Days at Paskeville again in September – but this decision has to be made and approved by the Adelaide Committee. It was an enormously successful awareness activity in 2003.

We have all our meetings booked for 2005: they are March 9, May 11, August 10, and November 9 and all in the Education Room at Community Health Wallaroo. We always meet on the second Wednesday from 1:30 - 3:30 pm. Afternoons are better than mornings, because most sufferers aren't that good in the mornings.

We have been supported by Clare Rundle, women's health advisor at Wallaroo at all our meetings over the four almost five years. Clare has now retired and looking forward to travel etc. Clare has been a wonderful support – actually taking a couple of meetings for me when once I had a shocking stomach virus and then secondly at the May meeting this year when four days before the meeting we had our home on Kangaroo Island burn to the ground and I wasn't up to running a meeting. We acknowledge the tremendous support and work that Clare has contributed and wish her a wonderful retirement.

I take this opportunity to thank Peter Cahalan who has been very supportive of us this year and also Donna in the office and all the girls/guys who volunteer in the office to keep the Association going. Personally it means a world to me to know there are so many dedicated, selfless, committed workers for the association who are focused on making everyone who suffers with CFS a little more empowered, informed and 'heard'. There is still such a long way to go but hopefully the new year will bring us more media exposure and government financial support, more general public education about CFS and a greater understanding overall.

ME/CFS Society (SA) Inc photos

Northern Yorke Peninsula Support Group 4th birthday



Jane Gill, Clare Rundle, and Penny and Peter Cahalan cutting the birthday cake.



Most of the folk at the meeting gathered around for this photo. One lady travelled from Pt. Vincent and another chap from Stansbury!

Annual General Meeting



Peter Del Fante.



Members of the audience.

Gone in a puff

Peter Cahalan, President of the ME/CFS Society (SA) Inc, sent a quick email contribution on chemical sensitivity of theatre audiences to a national e-forum on the arts. **Rod Lewis**, the editor of the amateur theatre network's magazine in SA, picked it up. And so the result is an article by Rod Lewis entitled *Gone in a puff*, and is about the need for theatre companies to be thoughtful about people with allergies to cigarette smoke, fragrances, and chemicals.

Peter says: "I urge all of our members to take every opportunity to send messages like this to politicians, administrators, the media and anyone who has the power to change things for the better. That goes for any issue affecting the health, education, welfare and comfort of people with CFS. There's a lot of us. We're articulate. We have power! Get started!!"

Do you sometimes unthinkingly create barriers to otherwise willing ticket-buyers? Have you ever had someone in the audience collapse into a sudden or violent attack of coughing and have to leave in the middle of a scene? If so, read on...

In a recent Australia Council-sponsored discussion on risk-taking and the arts, one correspondent noted that theatre companies can put a lot of effort into making first-timers feel comfortable in the strange ambience of their theatre – only to have their committed patrons do everything possible to make the newcomers feel that they are not really welcome!

And then "Lyn", from South Australia, broached the subject of smoke machines. Lyn is a serious asthmatic and she has had more than one bad experience in the theatre. She asked companies to be cautious about using smoke machines and to advertise the fact if they were intending to use one.

Peter Cahalan is State President of the ME/CFS Society for people suffering from Chronic Fatigue Syndrome. There are between 3,000 and 7,000 CFS sufferers in South Australia. In a survey of its members which the Society conducted several years ago, 60% of members indicated that they were chemically sensitive. Some have experienced that near-total collapse of the immune system which puts them into the category of the multiply chemically sensitive. For such people, going to the theatre can be fraught with risks.

Peter endorses Lyn's comments about reducing unnecessary risks to vulnerable audience members from smoke machines and the like, but dares to go one step further.

"We now know that there's been a substantial increase in the numbers of chemically-sensitive people and that the rates of asthma and other respiratory problems are also rising," he says. "So it's both foolish and unethical to do something which will pose a barrier to people's right to

spend money at your performance. I don't think, therefore, that it's good enough to advertise that there'll be smoke effects in a performance – it's like saying 'Sorry, our venue was nice and flat and very accessible to people in wheelchairs. But for artistic reasons we've created a maze of raised platforms and so you needn't bother to come.' Just try that one and see how long it lasts before there's a complaint to the relevant human rights or disability discrimination authority!"

There are related issues: cigarette smoke as part of a performance and the overwhelming use of perfumes and colognes by patrons.

On more than one occasion Peter and his arts-loving daughter Elizabeth have had to leave performances early because she is highly reactive to cigarette smoke. The argument from the companies has been that smoking is sometimes necessary for verisimilitude, but when it comes to sex, companies are not likely to present full-on copulation as a means of achieving dramatic effect. Most cigarettes smoked on stage are there simply for characterisation and not an integral part of the plot.

This issue seems to rate pretty low in the consciousness of arts companies. In a checklist on disability access for arts venues developed a year or two ago in NSW, there was no reference to chemical sensitivities as an issue. There was one about cigarette smoke, asking venue managers to locate bins in a place near the entrance convenient to people in wheelchairs – i.e., in the worst possible place for anyone who reacts to cigarette smoke.

At times, Elizabeth has had to sort out special arrangements to be let into a venue early by a side door – to avoid being trapped in a queue with smokers.

Similar to smoke and smoke machines, many women and some men douse themselves in perfumes and deodorants,

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causing similar reactions from those with a chemical sensitivity. Even *Encore* Editor, Rod Lewis, has been known to dive out of an elevator or change seats in the theatre because of difficulty breathing near someone wearing too much fragrance. But what can be done? Not banning, as is increasingly possible with cigarettes. But increasingly we can expect that there will be moves to raise people's awareness that to wear perfume is not the private act that people commonly assume it is. To send someone reeling from a much-awaited performance before it's finished – or to send them home sick for a week – is to unintentionally commit violence upon them.

Chemical sensitivities are becoming the next big issue in terms of disability access and public health. Arts organisations which ignore it are charting an unnecessarily risky

course. For most of the population, awareness is all it takes. Educating patrons and participants alike about the effects that their everyday behaviour or directorial choices may have on others is usually enough to make them think twice. A steady program of awareness-raising might improve things over time and make our theatres safer for more people, which means more tickets sold to people like Elizabeth.

Here's to an accessible amateur theatre scene in Adelaide for everyone!

Rod Lewis
Editor, *Encore* Magazine
Theatre Association of SA Inc
PO Box 181, Unley BC SA 5061
Phone: 0402 027 891
Fax: (08) 8293 3030

CFS/ME is not chronic fatigue: misnomer causes extra suffering

The following statement was issued by CFS/ME Victoria to MPs, government health departments, media outlets, and other interested parties.

"There is no such illness as Chronic Fatigue," said Simon Molesworth AM QC in a statement issued recently. "The illness is Chronic Fatigue Syndrome, officially known as CFS/ME."

Chronic fatigue is a symptom of many illnesses but is only a symptom, not an illness in itself. As a result of CFS/ME being referred to as 'chronic fatigue,' patients are suffering, not only from the illness, but from the misunderstanding caused by the misrepresentation.

Mr Molesworth, President of CFS/ME Victoria and Chairman of ME/Chronic Fatigue Syndrome Association of Australia, said that, because of the wrong terminology, CFS/ME is perceived as a one-symptom illness – merely extreme tiredness. Therefore sufferers do not attract the understanding of the illness which is their due.

The word 'syndrome' means a collection of symptoms which in CFS/ME are many and varied and are extremely unpleasant. As well as the bone-crunching fatigue, the main symptoms are persistent weakness, post-exertional malaise, dysfunctional sleep, pain and neurological and

cognitive impairment. These are accompanied by other varied symptoms such as orthostatic hypotension and tachycardia, palpitations, gastrointestinal problems, paresis etc.

The Victorian Government's own Better Health Channel explains that fatigue is a symptom rather than a specific disease or disorder and lists causes such as influenza, glandular fever, anaemia, sleep disorders, CFS/ME, hypothyroidism, hepatitis, tuberculosis, chronic pain, coeliac disease, Addison's disease, Parkinson's disease, heart disease, HIV, and cancer.

CFS/ME also causes isolation, as many sufferers have been housebound for years and some are confined to a wheelchair or bed.

There is no known cause or cure for CFS/ME.

More information about the illness can be obtained from CFS/ME Victoria.

Reprinted with permission from Emerge Summer 2004.

A day in the life of Ima Bitovamessovitch

By *M.I. Somaticshertzyn, Ph. D (Philosophical Dag)*

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Talking Point – 2004 Issue 4

I agree with the Beatles. "I'm so tired, I haven't slept a wink, I'm so-o-o ti-i-ired, my mind is on the blink."

My eyes have been rolled in sand during the night and grind in their sockets as I stir. The squeezing sensation covering the soft tissue of my brain is still there. Like a tightening, helmet shaped vice.

I roll and rise awkwardly to the edge of the bed. Sitting, I attempt more connections between body and brain. Like some lower life form I am aware, but not yet of being aware. And, like a combination prize fighter and marathon runner the morning after, I am uncertain as to what will hurt; yet knowing my legs will be weak, strained.

My lower limbs threaten to betray me as I stand slowly and begin the unsteady trek to the bathroom. Frankenstein's monster showed more subtle movement. A freight train of light crashes through the semi-transparent window, smashing into my eyes. Shocked into submission by the daylight, I enter the shower.

The warm water massages my head but the standing and washing is a major effort. Leaning against the shower wall I'm not entirely happy with the legs' underperformance. As usual, the day hits me like a phone book from an interrogation room. Another tune enters my head. "I've been doo-o-ownn, but not like this befo-o-ore..." (In my mind it's the beautiful voice of Linda Ronstadt.) Outside the shower, dry and exhausted, I see a white thing in the corner... white... washing machine... toss towel at it... discover white thing is open toilet bowl... retrieve towel, carefully.

Then like an adrenalin crazed BASE jumper I leap into the day. Well, that's how I'd like it to be. The reality is I'm dressed in tracky daks, t-shirt, windcheater and sheepskin boots. At 12:30 pm I schlep into the kitchen with the express pace of a sloth on valium. (Realise daks are on backwards and change...). Ahh, breakfast. This arduous afternoon ritual will take an hour to work through.

A cocktail of headache negating technology, neuron transmitter enhancers and hopeful supplements rattles down my gullet to swim and disperse with the muesli, toast and tea. After this workout, I need a rest. So I take my finely sculptured body, honed from hours of intensive bed and couch use, over to the couch and relax into the afternoon.

Waking over a couple of hours gradually reveals the colour of this day. Will a body slamming headache emerge? Will I be allowed the privilege of only wearing the brain vice? This vice which dulls and confuses my thoughts and sends occasional hot barbs scorching into my brain?

In the times of the slamming headaches I engage the "bliss bombs." These are my good friends Disprin Max and Disprin Forte. They caress me through the nastiest headaches, working as best they can. If I was cool and hip they'd be D. Max and Forte, but I'm not that cool, or hip.

I've trod the usual remedy path from naturopathy, Chinese herbs and acupuncture, to sportsmen inspired ice-water bath torture and the sweat of an old army sock blessed by the Order of Happiness (Ooh) and the Ancient Absolvers of Horrors (Aah). Pity none of it helped.

I enjoy choices some days. It's just that one or two choices will test my physical and mental abilities almost completely. So is it the challenge of doing some basic shopping? A slow fifteen-minute walk in the sunshine? Or will I attempt to make sense of the week old newspaper's take on the world? Often I don't get a choice, as the Impaired Brain Function manoeuvres me like a marionette.

Lunchtime in cool weather and I am grateful to the inventors of canned soup, plastic wrap and the microwave – a lifesaving combination. I open the fridge to heat the soup and realise that won't work. I've set a place for myself at the table with a knife and fork again, for soup. Innovative I think, and chuckle as I replace them with the more useful spoon.

After lunch I storm into my workout routine which will surely get me into the next Master's Games. A soft foam ball the size of a tennis ball is one strenuous exercise I put myself through. Thirty squeezes with each hand. Pumpin'! I've got my daily walking lap time of the suburban block down to fifteen minutes. And the home triathlon of bed, couch and fit ball is a tough regime. I'm going to be the Mark Spitz of these Games. I'll get one of those 'old man' masks and enter in the over ninety's, just to make it fair.

Frequently I take respite from the world as supplied by the radio and play music to fill my home. A good time for

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this is while cooking dinner. To amuse myself I occasionally indulge in a spot of 'Daggy Dancing.' Daggy Dancing is moving to the music in your own inimitable style. Use the worst dance moves you can remember or create, all jumbled together. Let your imagination go and if you're lucky, partner up with another who sees the playful, care-free, silliness of it all.

I find 30 seconds or so of slow movement is great therapy. I think of it as a cross between tai-chi and the laughing clubs. I will be available for private tutoring (for a small fee) as soon as I can plan more than an hour in advance.

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Is my personality my problem?

Anelie Walsh ponders the question.

Some CFS/ME sufferers get better. Sometimes they take particular supplements or try therapies and other times they experience what doctors would call a 'spontaneous remission' or perhaps a more religious person would call a miracle. In any case, they're well and the rest of us are still sick. Often others try the therapy that apparently cured them and it has little or no effect.

Those still ill are left wondering, "What is the difference between them and me?" Many people conclude the difference is in the mind or personality. Thoughts like, "They got better because they tried harder," "They didn't give up fighting this illness," or "They have better willpower" inevitably lead to "I'm sick because I'm not trying hard enough, I don't fight hard enough, I don't have enough willpower..."

This is incredibly damaging for one's self-esteem and ability to cope with an illness. I do not subscribe to the belief that we are sick because of our attitude, personality or minds.

Trying to pin down the cause of this illness as a personality type (and inferring that people with 'Type A' personalities are more likely to be ill) is a throwback to the 'illness as punishment' mentality, something that was very common in previous centuries and can be detected still in the modern day. There is a somewhat pejorative aura around the word 'over-achiever' and saying that people are sick because they pushed themselves too hard is like saying, "They went too far and now they're getting what they deserve."

From the patient's point of view it's as though we're trying to find where we went wrong and imagine that we could have prevented this illness if we had just seen it coming. But be honest – who saw this coming? It took me

roughly two years to discover this even had a name! After all, when were we supposed to realise we ought to have stopped 'pushing ourselves'? An internal alarm clock did not go off which said, "If you keep striving you'll make yourself sick." It's a situation we've found ourselves in, not one we've created.

We all know one of those irritatingly healthy people who might get the 'flu once every five years, if at all, and when they do they continue to go to work anyway. Yet they do not have CFS/ME. I know plenty of people who thrive on stress, who live a life featuring various degrees of anxiety and who, furthermore, eat badly, smoke and drink high quantities of caffeine. Are they sick? Of course not. There is much more to this illness than our personalities or past actions.

In short: we're not to blame for being sick. No-one enthusiastically received a package from Illnesses Inc which said, "Congratulations! You have won several years of debilitating chronic illness! Just sign here..." While altering our attitudes might help us cope with CFS/ME (or might not – I'm sure it's individual), it is not a cure. After all, if that's all it took, would a bunch of enthusiastic, intelligent, get-up-and-go types like us still be sick? I think not.

It's not our personality to blame, it's some malfunctioning part of our body and, when they narrow down which one it is, we will have THE biggest party during which we will throw darts at effigies of people who have accused us of making it all up in order to avoid life. I can hardly wait.

(Editor's note: Anelie is well on the way to recovery and is now well enough to study part-time and work two days a week. She should be able to throw that party and bombard effigies.)

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Preface to new book on CFS

Author **John Graham** is about to publish *How do we know?: Adventures in stuckness from biological and philosophical perspectives, a new book on chronic fatigue syndrome. Here is the book's preface:*

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In 1977, I was asked to join the Pain management unit at Flinders Medical Centre at Bedford Park in South Australia, principally to help achieve accurate and comprehensive diagnoses in patients who came to the unit with "difficult to manage" chronic pain.

This would surely require relief and healing in the sufferer's life.

I was impressed that this area of medical practice was neither popular with health professionals, nor was it achieving adequate relief for the sufferers.

None the less those professionals are to be admired for doing what they could within the prevailing medical and psychosocial models that were valued at that time.

In time I came to ponder **what would need to happen for people who feel "stuck" to somehow break free of that which constrains them.**

I slowly began to realize that it was not just the patients who were held back.

I remembered the words of Gregory Bateson: "In the world of the living, events take their course or courses because they are restrained from taking other courses."

All of us fall into ways of living, thinking and acting as if we can accept and live with certain patterns and beliefs even when they are not successful.

These ways can constitute traps so that **we can become prisoners of our own linguistic conditioning, and inadvertently we tend to be guardians of our old ways of thinking and of explaining things to others and ourselves.**

The discovery that in South Australia we have some 8,000 sufferers with Chronic Fatigue Syndromes (in a population of about 1.2 million people in the year 2000) was one factor which influenced me to explore this and allied fields, look at the literature and revisit the basic sciences

to understand the disorder as well as the huge morbidity which I saw in the sufferers.

The information which follows includes material, which was originally intended for a lay audience, but was then expanded rather stochastically, as I came across material that intrigued me.

This part became more technical, often with implications for therapy.

At the time of writing the results of treatment are far from satisfactory, but I believe that we are turning important corners.

Things are indeed changing!

Recovery in my patients is no longer a surprise!



We now realize that there are probably at least 5, perhaps 6, different sub categories of the fatigue syndromes, such that therapists will need to specify the abnormalities to get the therapy correct.

Both health professionals and CFS sufferers find it difficult to evaluate the many claims made by people offering remedies for the condition.

I want to reach people, and I hope that they want to reach out to each other.

I strongly hope to be thoroughly honest about what published literature reveals.

Many explanations are offered, yet very often ideas stem from small pieces of work by only one author with conclusions not yet evaluated in a scientific way.

The decision to explore these fields of learning and human exploration has been incredibly rewarding.

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I feel I have been refreshed in my thinking and philosophies, and have a renewed commitment to the ever-continuing learning that is embodied in the scientific method.

I would like to convey this enthusiasm to readers.

You are entitled in your humanness, to open your mind to the two kinds of truth.

The **truth of science** is the reliability of that which stands up to test after test. We call this "objective," in that its validity is used to make it possible for your house appliances, motor vehicles or computer to work time after time.

The second kind of truth is to do with **an integrity which does not hide behind dogma, but with courage faces the field of the inter-subjective domain with compassion and recognition.**

In this domain, it is critical to consider that what is in any human life is the conservation of information that somehow endured in that person's belief system.

I have been inspired by the people who have suffered not only through their illnesses, but also through the unwillingness of health professionals and other people to believe and support them.

One purpose of the material presented here is to invite skeptics to re-evaluate the rich information that is now available.

The document also presents some material that is basic textbook type information, so that those who have a small acquaintance with science and biology have a chance to have this information without having to find such a textbook.

Why will I present the reader with so many mechanisms?

Principally because the group of symptoms that we now call "chronic fatigue syndromes" will have many mechanisms, some of which are particular to specific participating and causative factors.

Indeed there will necessarily be common mechanisms applicable to all fields of medicine.

This is indeed an exploration, **"to leave no stone unturned!"**

Rather ambitiously I will include chapters on our human ways of knowing.

This also embodies a philosophy of approach that addresses epistemology appropriate to the full range of human endeavours.

For those who want much more detail, the expanded information is being continually revisited and revised.

They will themselves seek information in all the ways they wish.

The reader is invited to respond in whichever ways seem most appropriate.

Somehow human beings have been on journeys of discovery and invention aroused by an intense curiosity about all unsolved matters that they encounter.

Unfortunately world gross expenditure on weapons and the systems that support them has gravely decreased the wealth available to solve health problems.

I find myself as a member of a peace seeking and curious band, and invite you, the reader, to be as active as you prefer in these learning adventures.

This is an invitation to increase your self-awareness.

Entering into conversation with other seekers has always been a means for our intelligence to emerge as wisdom.

Creativity matters and we all can have it.

By all means be thoughtful, and even sceptical, but beware of the scepticism which prevents advances being available.

There is an urgent need for consistent, coordinated and financially supported research here in Australia, but for those who are already doing this work I offer my gratitude and support.

*John Graham
September 2004*

A tough act to swallow

The symptoms of M.E. (CFS/ME) can make eating an ordeal for some people. **Zoë Williams** serves up practical advice for those who already have too much on their plate.

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'The sheer effort of eating was exhausting and painful,' writes Diane. 'I used to eat in small achievable chunks with several hours of recovery in between – this took up the entire day. I ate small meals of mashed food with a lightweight plastic spoon. Co-ordination problems meant that I kept digging the utensil into my face, so a spoon was better than a fork.'

Avoid heavy metal!

Adapted cutlery can be obtained, some of which is bent at an angle, or with built-up handles for people with a weak grip. Plastic cutlery makes less noise and is lighter or you may get on better with 'finger foods.' "I make sure I have food I can eat nearby at all times," says Linda.

Other aids that can make life easier include an over-bed table or beanbag tray, a non-slip mat and pillows to go under your arms and legs. For drinks some people use a cup with a spout to avoid spillage or a water bottle with a nozzle lid. Bendy straws can be used while you are lying down, perhaps with a lidded beaker, and you might find a bowl easier to eat from than a plate.

Special dishes are available which can have hot water put inside them to keep food warm. Another tactic if the food takes a while to eat is to divide it into smaller portions to heat up separately. If you are able to eat some chewy foods but find this exhausting, try eating a small amount away from main mealtimes.

Liquid lunch (M.E. style)

'Smoothies' are a good way to get all the nutrients of fresh fruit without the munching. They can be home-made by blending fruit with yoghurt or milk in a liquidiser. John eats a small amount of soup an hour before a main meal to get maximum energy for eating the meal itself. It can also help to have a good quality rest before and after eating.

One woman said she found warm food took less energy to digest than cold and another found it helpful to put a hot water bottle on her stomach after eating. Some people find that food or drink goes down the wrong way more frequently or gets stuck in their throat. If you need to eat lying flat, you may find it helpful to sit up for a few sec-

onds afterwards to release gas (like burping a baby!).

In his book, *Living with M.E.*, Dr Charles Shepherd recommends discussing any gastric problems with your doctor and undergoing tests that seem appropriate to rule out other causes such as Coeliac Disease, Crohn's Disease or Giardia Parasitic Infection. Sue Firth, for instance, experienced bad indigestion-type pain which turned out to be a treatable stomach ulcer. Hypoglycaemia (low blood sugar), Irritable Bowel Syndrome, food sensitivities or an imbalance of gut organisms may be additional problems in some people with M.E.

Appetite loss

"I had no appetite at all," writes Diane. "Food tasted like cotton wool and my throat felt tender and lumpy as though I had a piece of glass down my throat. I talked myself into eating by telling myself that the food would nurture my body." When Alison loses her appetite, the one thing she can manage is celery; she later discovered that celery contains an appetite-promoting substance.

You may find it easier to stomach fruit and vegetables which have been juiced.

When I was more ill, soups and soft foods in small portions helped me to pace myself and avoid collapsing after every meal. I particularly enjoyed trying new recipes at a time when eating was taking up much of my energy.

"I sometimes used baby food when I was finding it too hard to chew," writes Daniel, who was unable to feed himself for six years, and he was often tube-fed. "One problem was that people tended to feed me too fast, which caused stomach problems. It was very painful returning to feeding myself when my health improved. I slowly built up from two mouthfuls per day with the help of careful, passive physiotherapy."

This article reprinted from InterAction No 45, August 2003. The author thanks Dr Charles Shepherd for his assistance.

Editor's note: UK-specific paragraphs have been omitted from the article.

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AACFS Conference report

Press Release
October 7, 2004

American Association for Chronic Fatigue Syndrome (AACFS)

Seventh International Conference on Chronic Fatigue Syndrome, Fibromyalgia and related disorders
October 8-10, 2004
Madison, Wisconsin, USA

Co-sponsored by the Centre for Disease Control and Prevention (CDC) and the National Centre for Infectious Diseases

- CDC researcher Dr William Reeves, Chief of the CFS research program, reported that \$US9.1 billion of earnings and wages are lost annually in the US alone due to the disability caused by CFS.
- CFS patients are more sick and have greater consequent disability than patients with chronic obstructive lung disease, cardiac disease, osteoarthritis and depression, yet fewer than 16% of CFS sufferers in the general population are diagnosed and treated for CFS.
- A CDC collaborative study with Australian researchers found that the strongest predictor of the development of post-infectious (chronic) fatigue syndrome is the severity of the acute illness at onset. Psychological features played no role in the development of CFS following infection.
- The CDC and NIH have proposed the formation of an international collaborative network called the Chronic Fatigue Syndrome Research Network (CRN) to foster collaborative, innovative and incisive research. Such a network will assist in the establishment of diagnosis and therapeutic interventions and bring help to the hundreds of thousands of CFS sufferers and their families worldwide.

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Psychological features play no role in CFS/ME

Christine Hunter of the ME/Chronic Fatigue Syndrome Association of Australia attended the above conference to encourage amendments to the formal criteria for assessing people as having contracted CFS/ME – criteria which could lead to a more 'psychological' approach to be taken.

As you will see from the above press release a collaborative study found that 'psychological features played no role in the development of CFS following infection.'

At the conference Christine Hunter, as a representative of the Alison Hunter Memorial Foundation, was presented with a Distinguished Service Award for the Foundation's outstanding service in furthering the recognition of CFS/ME and for the promotion of scientific research and improved patient care.

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Doubts cast on herbal remedy: Echinacea found to lack enough ingredients to work

Page 18 *The following article appeared in the New Zealand Herald on November 12, 2003 and was reproduced in Meeting Place, the quarterly journal of ANZMES Inc, September 2004 edition.*

It is touted as an immune system booster and a treatment for the common cold, but tests have shown that people who buy the herbal medicine Echinacea may not be getting what they think they are.

Choice magazine tested ten of the most common Echinacea remedies bought off the shelf around Sydney.

The analysis found most of the products did not contain enough of the active ingredients to work.

Despite widespread anecdotal evidence of the benefits of Echinacea, the scientific facts are inconclusive.

Yet *Choice* found manufacturers were advertising the product as a remedy for coughs, catarrh, colds and 'flu, allergies and hay fever, acne, eczema and 'general well-being.'

But scientists have found that Echinacea contains at least two active ingredients – cichoric acid and alkylamides.

The *Choice* analysis found low levels of alkylamides in all the tablets sampled, ranging from 0.001mg to 0.9mg. Cichoric acid levels varied from product to product and one contained no detectable cichoric acid.

"It seems unlikely that the levels of these active ingredients in any of the products we tested are enough to make them worth buying," the report said.

"Nothing on the labels we looked at will help you compare brands or, in most cases, give any hint of how much active ingredient you're getting."

The Australian Consumers Association health policy officer, Marilyn Goddard, said the Federal Government's Therapeutic Goods Administration needed to play a big-

ger role in ensuring consumers got what they paid for.

"The results of our survey are a shocking indictment of the woefully inadequate regulations covering complementary medicines," he said. "The Government must give the TGA the legal tools and resources to police this area."



A spokesman for Federal Parliamentary Health Secretary, Trish Worth, said the Government was considering a report on the herbal and complementary medicine industry handed down by an expert committee last month (October 2003).

"The report called for extensive reforms to the industry and measures to protect consumers from unsafe products," he said.

Choice also found none of the labels provided warnings about the risks of long-term Echinacea use.

The World Health Organisation recommends that people with auto immune diseases like Lupus, HIV/Aids, Tuberculosis and MS should avoid Echinacea. The herb can also cause allergic reactions in some people.

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Regular checkups

Please remember to have regular medical checkups with your doctor. ME/CFS does not confer immunity to other illnesses. New symptoms may not be due to ME/CFS and should be discussed with your doctor.

CFS: Intracellular immune deregulation as a possible aetiology for abnormal exercise response

Nijs J, De Meirleir K, Meeus, M, McGregor NR, Englebienne P

Department of Human Physiology, Faculty of Physical Education and Physical Therapy Science, Vrije Universiteit Brussel, Brussel 1090, Belgium

jo.nijs@vub.ac.be

Med Hypotheses 2004; 62(5): 759-65

(The Role of Nitric Oxide [NO] is discussed in this article.)

The exacerbation of symptoms after exercise differentiates Chronic Fatigue Syndrome (CFS/ME) from several other fatigue-associated disorders. Research data point to an abnormal response to exercise in patients with CFS compared to healthy sedentary controls, and to an increasing amount of evidence pointing to severe intracellular immune deregulations in CFS patients. The manuscript explores the hypothetical interactions between these two separately reported observations. First, it is explained that the deregulation of the 2-5A synthetase/RNase L pathway may be related to a channelopathy capable of initiating both intracellular hypomagnesaemia in skeletal muscle and transient hypoglycaemia. This might explain muscle weak-



ness and the reduction of maximal oxygen uptake, as typically seen in CFS patients. Second, the activation of the protein kinase R enzyme, a characteristic feature in at least subsets of CFS patients, might account for the observed excessive nitric oxide (NO) production in patients with CFS. Elevated NO is known to induce vasodilatation, which may limit CFS patients to increase blood flow during exercise, and may even cause and enhance post-exercise hypotension. Finally, it is explored how several types of infections, frequently identified in CFS patients, fit into these hypothetical pathophysiological interactions.

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Salivary cortisol response to awakening in CFS

Roberts AD, Wessely S, Chalder T, Papadopoulos A, Cleare AJ

Section of General Hospital Psychiatry, Division of Psychological Medicine
Guy's, King's and St Thomas' School of Medicine and Dentistry, London UK
Br J Psychiatry 2004 Feb; 184:136-41

Background: There is accumulating evidence of hypothalamic-pituitary adrenal (HPA) axis disturbances in chronic fatigue syndrome (CFS/ME). The salivary cortisol response to awakening has been described recently as a non-invasive test of the capacity of the HPA axis to respond to stress. The results of this test correlate closely with those of more invasive dynamic tests reported in the literature; furthermore, it can be undertaken in a naturalistic setting.

Aims: To assess the HPA axis using the salivary cortisol response awakening in CFS/ME

Method: We measured salivary cortisol upon awakening and 10, 20, 30 and 60 minutes afterwards in 56 patients with CFS and 35 healthy volunteers.

Results: Patients had a lower cortisol response, on awakening, measured by the area under the curve.

Conclusions: This naturalistic test of the HPA axis response to stress showed impaired HPA axis function in CFS/ME.

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Ambrotose: lifting the lid on an 'essential' supplement

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Ever had a friend or relative come to you with a CURE for all your ills? One such incident leads **Dr Ken Jolly** on the trail of a company selling yet another 'essential' nutritional supplement. The company is called Mannatech and the product is called Ambrotose.

Recently a family member suggested to me yet another 'treatment' that would cure my CFS/ME. I say 'suggested' but bombarded is probably a better description. You might be surprised to hear that even doctors with CFS/ME, like myself, are continually being approached with cures. This is a common experience, of course, for all people with chronic illnesses. The people who bring these 'gospels of cures' feel in their own mind that what they are doing is 'helping you' and this is because they care about you, although I believe their motivation can, and often does, go somewhat deeper than this. There is something about the human psyche that has difficulty accepting that people like us can sometimes not get immediately better and that sometimes we may be sick for very long periods. It is very hard for us to cope with this reality too, of course, but because it is happening to us and we know it is in our bodies it is perhaps easier for us to see the true situation and that sometimes we just have no choice in the matter. These 'well-doers' (a term I made up which is similar to 'do-gooders') on the other hand can sometimes never accept this state of chronic unwellness in others and some even have great difficulty in giving up on their life-long duty to cure us.



This behaviour almost certainly has evolutionary roots for its existence.

Unwell people were a drag on the positive survival of the ancient groups of humans and therefore were often shunned. Nature can be cruel and the importance of the survival of the species tends to over-ride that of the individual. Fortunately humans have to a degree risen above this 'survival at all costs' behaviour and have developed a caring for the weak in society – a behaviour shared by a few other animal groups (according to my late at night information depository – the Discovery Channel!) In my opinion I would go further and say ill people are developing important roles in society. The 'humaneness' that has developed in homo sapiens means that, where possible, unwell people are now fairly well looked after, compared with the situation in the early developing species. However, some individuals still have trouble accepting ill

health in others and this may be a left-over from these earlier behaviours.

Superficially there are many reasons why people react like this, not the least being that it reminds them of their own mortality and morbidity. Seeing us unwell brings out their own fears! If they can make us better then they won't see us sick any more and will feel more secure about their own safety.

Some of this sounds, of course, 'back to front.' Isn't caring for the ill and getting them better being 'humane'? Whilst this is true there are, at times, limits to how far some curing can go. In these situations compassion, solace and symptom management, as proposed by those such as Hippocrates, is more important than the at times unrelenting and usually unbidden enforcement of complete cure upon the severely or the chronically ill. As illnesses progress, what is more helpful to the chronically ill is often support.

Many of you out there will be happy with these people who offer us treatments, especially if giving the appearance of some hope, but as time goes on many will agree that, rather like door-to-door salespeople, some of these people are tedious, selfish and at the very least annoying.

In my situation where I have made it known that I personally do not believe in these unproven cures I have found it an affront to my whole belief system and quite demeaning when I have had such ideas enforced upon me. On one occasion a potion was quite literally forced down my throat. Even the unwell should still be entitled to the dignity of being allowed to make their own decisions.

Anyway back to the story – about the recent incident of a family member trying to get me to take an unproven 'CFS/ME treatment.' This person's belief in its success was so strong they had even paid the initial cost of \$130

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themselves. I may sound ungrateful to some of you because you will feel that this person was merely trying to help but I hope I have explained some of my reasons in the preceding paragraphs as to why I declined this offer. The opposite is that I would not 'force' people who believe in alternative products not to take them either. In the past I have frequently written about alternative products as I do believe people do need to hear both sides of the 'propaganda war' before they make any rational choice. Not only was this product suggested for me and my CFS/ME but for other family members as well because, as is the case with many such products, it is touted as treating most ailments on earth. I decided to refuse the product and investigate it instead in the hope that I might be able to convince my relative to cease spending the thousands of dollars it was costing him at this point which he could ill afford.

The product is called glyconutrients. This was a new one to me but evidently has been around for several years. According to the proponents (from here on called businessmen) there are eight essential glyconutrients (complex sugars or polysaccharides) that the body requires to 'be well' and that we are not getting enough of in our current foods. Components of virtually every food group have been proposed over recent years as being 'essential,' as well as being low in foods and therefore needed as supplements to our diets, e.g. essential fatty acids, vitamins, amino acids (proteins), minerals, etc. It seems sugars were the one food group not yet expounded as necessary for supplementation. This might seem strange to the reader as sugars have generally been thought of as being 'unhealthy' but there is some evidence that certain ones do have important roles as 'between cell messengers.'

Just because science finds a role for something in our bodies does not mean, though, that we immediately need these in extra quantities. Businessmen use recent scientific discoveries to mislead the public into believing or even 'fearing' that they need these constituents and thus create a 'new' product to market. There has been no evidence shown, however, that we are not receiving adequate amounts of these sugars in our foods.

I then researched the main company selling these glyconutrients and found they are a United States based organisation called **Mannatech**. I thank Moira Smith and her Canberra CFS/ME website for much of this information. It appears that numerous suspicious retailing practices have been raised about this company. They call their product **Ambrotose**, a mixture of eight sugars. They are rumoured

to be making about \$US600 million a year from Ambrotose, once again dispelling the myth that these are small companies scraping together a living in order to help people with their health. Much of this money is gained through selling shares in the company and by selling Ambrotose at exorbitant prices and by multi-level marketing. Once one person is convinced of the effectiveness of the product they start buying it but because it is so expensive they convince a network of friends to market below them, thus offsetting some of their costs. This creates a large marketing base for such companies to sell through and therefore the possibility of large profits.

One of the early Mannatech executives, a Dr Darryl See, has been widely discredited. He had claimed that he had proved that the sugars worked in a way positive to health and had done this while working for a prestigious research institution in America and supported by a large government grant. None of this was in fact true. While Mannatech have since distanced themselves from Dr See, they still have problems. Their promotional material reports that Ambrotose is healthful and safe to take but they tell their shareholders that they don't know if either of these statements is true, i.e. they are telling their customers one thing, but their shareholders another.

They also state that they have saturated the American market and that therefore moving offshore to countries such as Australia was now a very feasible proposition. It was suggested that CFS/ME and fibromyalgia were likely areas for sales people to target in this country.

Although I found this quite enlightening about glyconutrients and succeeded in convincing the person involved about the murkiness of the company, the joke also backfired on me somewhat. I had mentioned somewhere along the way that a mixture of these eight sugars could be made quite simply and cheaply from various vegetable and fruit products. Now he is involved in a mass production exercise himself and is producing his own nutrients and annoying even more of the family with his even louder sales pitches. He is blissfully exultant because of the money he is saving. Evidently I was only partly successful in convincing him of the pitfalls!

This article was reprinted from Meeting Place, the quarterly journal of ANZMES Inc, Associated New Zealand Encephalopathy Society Incorporated, Issue No 77, September 2004.

Dr Ken Jolly is a board member of ANZMES Inc and writes medical news and views for Meeting Place.

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Standing up for ME

Dr Vance Spence and Prof Julian Stewart.

Published in *Biologist* 2004 June; 51(2): 65-70.

(The Role of Nitric Oxide [NO] is discussed in this article.)



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Talking Point – 2004 Issue 4

The June 2004 issue of *Biologist* – the prestigious journal of the Institute of Biology, which is the professional body for 14,000 UK biologists – contains the article “Standing up for ME” by Dr Vance Spence (Chairman of Merge & Senior Fellow in Medicine, University of Dundee, UK) and Prof Julian Stewart (Professor of Paediatrics and Physiology, New York Medical College, USA).

The stimulating and authoritative review article – which begins with the plea, “Data, data everywhere and no one stops to think,” examines the problems of orthostatic intolerance in “CFS/ME.” One of the key difficulties that patients face is standing (orthostasis), particularly standing still. Inability to remain standing because of subjective findings (symptoms) or objective findings (signs such as hypotension) is designated “orthostatic intolerance.” Many patients are unaware that something as simple as being upright can trigger a cluster of symptoms, such as dizziness, altered vision, nausea, fatigue, neurocognitive difficulties, headache, sweating and pallor. Orthostatic intolerance is characteristic of so many of these patients that it may very well serve as a definable subset in its own right and might even be seen as diagnostic if the underlying mechanisms could be understood.

For copyright reasons at the Institute of Biology, the full text of this review article cannot be made available.

MERGE comment

This article looks at the various definitions of orthostatic intolerance and the differences between them. It also sets out to explain the specific mechanisms that might underlie the problems that CFS/ME patients have when they are upright. Standing upright provokes major shifts of blood volume in the human body. Without compensatory mechanisms, the pooling of blood in the lower body and the position of the human head well above the heart would combine to produce unconsciousness in us all. In order to maintain blood pressure and consciousness, there are effective compensatory mechanisms.

This article makes clear that what happens in CFS/ME has little to do with cardiovascular deconditioning. Indeed the problems associated with the illness are most likely to

be found in peripheral rather than central mechanisms, although a mixture of both may be applicable to some patients. Much has been written about orthostatic intolerance in CFS/ME but most of this is qualitative; i.e. patients have been subjected to tilt-table testing, most have positive results of one form or other; but very little research has addressed the mechanisms of the problems associated with being upright. Both authors have been studying circulatory problems in CFS/ME patients from different perspectives and this article brings these separate disciplines together.

The central question is what causes orthostatic intolerance in CFS/ME? It is clear that all of the problems cannot be explained by central or autonomic nervous system irregularities, but if CFS/ME is not autonomic dysfunction then what is it? A number of specific yet disparate mechanisms have evolved over time to explain orthostatic intolerance but vascular dysfunction appears to be best supported by the available data.

CFS/ME patients with chronic orthostatic intolerance/postural tachycardia syndrome (POTS) often (but not always) display significant blue discoloration and sometimes swelling (pooling) of the legs, most especially on getting up in the morning. This suggests that vascular abnormalities form the basis for many of the findings of CFS/POTS and fit in well with our knowledge of compensatory mechanisms for orthostatic stress. This has been termed the vascular hypothesis, which includes possible autonomic dysfunction as a subset. Current thinking about both CFS/ME and POTS has emphasised the importance of disturbed blood flow physiology, and some investigators have grouped patients by their patterns of altered blood flow into three groups: “high flow,” “low flow,” and “normal flow” POTS.

It should also be borne in mind that the onset of orthostatic symptoms in many CFS/ME patients is often

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predated by a viral infection. The involvement of inflammatory cytokines such as IL-1, IL-6 and tumour necrosis factor, and nitric oxide (NO) needs to be considered. NO is an obvious candidate for generating orthostatic symptoms, and since there is clearly a problem with local vasodilator and vasoconstrictor mechanisms in these patients, an imbalance between endothelial and immunological-derived NO is an area worthy of further study. Of further interest are potential autoimmune mechanisms and the recent finding that circulating self-antibodies against nicotinic receptors interfere with neurotransmission in patients with problems of the autonomic nervous system, including orthostatic intolerance.

The article concludes that treatment of orthostatic intolerance in CFS/ME will not be possible until the mechanisms underlying the problem are unravelled and quantified. Of specific interest to MERGE is the role of endothelial-dependent vasodilatation and the various pathways surrounding acetylcholine sensitivity in CFS/ME patients. MERGE is currently funding a project examining the relative contributions of endothelial-derived hyperpolarising factor, prostacyclin and NO that are associated with acetylcholine vasodilatation in CFS/ME patients and the first results of this new research study should be available sometime in 2005.

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Exercise therapy for CFS

Edmonds M, McGuire H, Price J

Cochrane Database Syst Rev. 2004;(3)CD003200

Background: Chronic fatigue syndrome (CFS/ME) is an illness characterised by persistent medically unexplained fatigue. CFS/ME is a serious health-care problem with a prevalence of up to 3%. Treatment strategies for CFS/ME include psychological, physical and pharmacological interventions.

Objective: To investigate the relative effectiveness of exercise therapy and control treatments for CFS/ME.

Selection Criteria: Only Randomised Controlled Trials (RCT) including participants with a clinical diagnosis of CFS/ME and of any age were included.

Data Collection and Analysis: The full articles of studies identified were inspected by two reviewers (ME and HMG). Continuous measures of outcome were combined using standardised mean differences. An overall effect size was calculated with each outcome with 95% confidence intervals. One sensitivity analysis was undertaken to test the robustness of the results.

Main Results: Nine studies were identified for possible inclusion in this review and five of the studies were included. At 12 weeks, those receiving exercise therapy were less fatigued than the control participants (SMD – 0.77, 95% CIs – 1.26 to 0.28). Physical functioning was significantly improved in the exercise therapy group (SMD –

0.64, CIs –0.96 to 0.33) but there were more dropouts with exercise therapy (RR 1.73, CIs 0.92 to 3.24). Depression was non-significantly improved in the exercise therapy group compared to the control group at 12 weeks (WMD –0.58, 95% CIs –2.08 to 0.92). Participants receiving exercise therapy were less fatigued than those receiving the antidepressant fluoxetine at 12 weeks (WMD – 1.24, 95% CIs –5.31 to 2.8). Participants receiving the combination of the two interventions exercise and fluoxetine, were less fatigued than those receiving exercise therapy alone at 12 weeks, although again the difference did not reach significance (WMI 3.74, 95% CIs –2.16 to 9.64). When exercise therapy was combined with patient education, those receiving the combination were less fatigued than those receiving exercise therapy alone at 12 weeks (WMD 0.70, 95% CIs 1.48 to 2.88).

Reviewers' Conclusions: There is encouraging evidence that some patients may benefit from exercise therapy and no evidence that exercise therapy may worsen outcomes on average. However, the treatment may be less acceptable to patients than other management approaches, such as rest or pacing. Patients with CFS/ME who are similar to those in these trials should be offered exercise therapy and their progress monitored. Further high quality randomised studies are needed.

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Genes may determine who developed Gulf War Syndrome

Page 24 *Researchers at the University of Buffalo find that a variant in an ACE gene appears to cause susceptibility to environmental triggers*

Talking Point – 2004 Issue 4

Veterans of the first Persian Gulf War suffering from medically unexplained fatigue associated with Gulf War Syndrome may have a genetic predisposition for developing the condition, geneticists at the University at Buffalo have found.

Their research, involving healthy veterans and veterans with severe and chronic fatigue, as well as non-veterans with chronic fatigue syndrome, showed that affected veterans, in comparison with healthy controls, had an increased frequency of a non-beneficial genetic variant in a gene involved in the production of angiotension-converting-enzyme (ACE), an enzyme important in the control of blood pressure and electrolyte balance.

Unexpectedly, the non-beneficial variant was less common among non-veterans with symptoms identical to those of Gulf War Syndrome, indicating that the genetic variant rendered the carriers more susceptible to triggers present in the Gulf-War environment.

Results were reported in the July issue of *Muscle and Nerve*.

“The results of this study are somewhat controversial, because people don't necessarily want to accept the possibility of a genetic predisposition,” said Georgirene Vladutiu, PhD, UB professor of paediatrics, neurology and pathology and first author on the study. “The idea of something external as the cause is much more palatable.”

Vladutiu directs the Robert Guthrie Biochemical Genetics Laboratory at the Women and Children's Hospital of Buffalo and specialises in the laboratory diagnosis of metabolic muscle diseases.

External or environmental factors do play a role in Gulf War Syndrome, said Vladutiu, but likely as triggers in those with a genetic predilection, rather than as the initial cause.

“These triggers may be extreme exertion, heat, chemical exposures, infections, multiple vaccinations, emotional stress and a combination of these conditions or something else entirely. We don't know if the triggers are specific to the first Persian Gulf War,” she noted. “Soldiers serving now are exposed to different environmental triggers. In addition, our sample is small. We need to prove or disprove these findings in a larger group of veterans from different theatres of war.”

Chronic fatigue manifests in two distinct forms. Unexplained fatigue with no other symptoms is diagnosed as idiopathic chronic fatigue (ICF). Fatigue accompanied by infections, painful joints or neuropsychiatric symptoms is called chronic fatigue syndrome (CFS). CFS/ICF is nearly four times as prevalent in veterans of the first Persian Gulf War as in non-veterans, earning the label Gulf War Syndrome in that population.

CFS/ICF has been studied extensively, but the cause remains unknown. Vladutiu and her colleague, Benjamin Natelson, MD, at the War-Related Illness and Injury Study Centre in Washington, DC and the CFS Co-operative Research Centre at the UMDNJ-New Jersey Medical School, set out to determine if genetics may play a role.

Earlier research had shown that persons with an insertion variant (added genetic material) of the ACE gene had higher endurance, appearing to derive a beneficial effect from the variant. Vladutiu theorised that persons with CFS would have a lower prevalence of the insertion variant with a correspondingly higher prevalence of the deletion variant (no added genetic material), which rendered them especially susceptible to a variety of environmental triggers that can bring on the muscle pain and reduced physical abilities characteristic of CFS/ICF.



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To test this theory, Vladutiu and Natelson analysed DNA from banked blood samples from Gulf War veterans and non-veterans who were healthy or had CFS/ICF, looking for differences in the segment of the ACE gene that contains either the insertion or deletion of genetic material, called the I/D polymorphism. The possible combinations of the variants, known as genotypes, are II, ID, and DD. The II and ID genotypes are known to be beneficial, or at least not harmful, while the DD variant is believed to have a potentially negative impact on muscle function and has been associated with a number of other illnesses such as multivessel cardiac disease, said Vladutiu.

The samples were collected from 49 Gulf War veterans with CFS, 61 non-veterans with CFS, 30 healthy veterans and 45 healthy non-veterans.

Results of the genetic analysis showed that the frequency of the II genotype (beneficial) was significantly lower in veterans with Gulf-War Syndrome compared to healthy veterans, and both healthy and ill non-veterans. The II genotype was four times lower in the ill veterans than healthy veterans, results showed.

Moreover, 76 percent of Gulf War veterans with the DD (non-beneficial) genotype had CFS or ICF, compared with only 45 percent of veterans with the ID variant and 27 percent with the II variant. Those with the DD genotype were eight times more likely to have CFS/ICF than those with the II variant, results showed.

"Our genetic make-up determines how we respond to our environment in every sense of the word, including our interior environment," said Vladutiu. "The lower prevalence of the II genotype and the increased prevalence of the DD genotype in Gulf War veterans with medically

unexplained chronic fatigue points to an interaction between these genetic variants and some factor or factors specific to the Persian Gulf."

The next step is to study these and other variants in the ACE gene in a larger group of affected and unaffected veterans of the first Gulf War, and compare the results with studies in veterans of the second Gulf War, as well as in veterans of other wars, such as in Bosnia and Vietnam, said Vladutiu. "If the results of this study are reproducible in terms of the association with the ACE gene variant, then the stresses associated with war activity generally act as an external trigger on the function of a substance (ACE) that has multiple impacts on the physiology of the study."

"If the results show a specific association only in veterans of the first Gulf War," she said, "then there was likely an environmental factor, such as one or more chemical exposures that, combined with variations in the ACE gene, predisposed certain individuals to the development of medically unexplained chronic fatigue." The research was supported by grants from the Muscular Dystrophy Association, the Children's Guild of Buffalo, UB the Veterans Administration and the U.S. Public Health Service.

Contact: John Della Contrada, University of Buffalo Media Relations, dellacon@buffalo.edu or 716 645 500, ext 1409.

Medical Editor's Comment: *Although this paper is a little complicated, it reminds us that in any medical condition, including CFS/ME, it is our underlying genetic makeup that "sets us up" and then interacts with environmental factors leading to protection from or susceptibility to certain illnesses.*

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CFS/ME DEFINITION – 2002 Oxford Concise Medical Dictionary

CFS/ME – The approved name for the condition formerly known as **Chronic Fatigue Syndrome**, **myalgic encephalomyelitis** (or **encephalopathy**) or **postviral fatigue syndrome**. It is characterised by extreme disabling fatigue that has lasted for at least six months, is made worse by physical or mental exertion, does not resolve with bed rest, and cannot be attributed to other disorders. The fatigue is accompanied by at least some of the following: muscle pain or weakness (fibromyalgia), poor co-ordination, joint pain, recurrent sore throat, slight fever, painful lymph nodes in the neck and armpits, depression, cognitive impairment (especially an inability to concentrate), and general malaise. The cause is unknown but some viral conditions (especially glandular fever) are known to trigger the disease. Treatment is restricted to relieving the symptoms and helping sufferers to plan their lives with a minimum of energy expenditure. Graded physiotherapy and cognitive behavioural therapy may be helpful in some cases.

Information about ME/CFS

What is ME/CFS?

ME (myalgic encephalomyelitis) / CFS (chronic fatigue syndrome) is a serious and complex illness that affects many different body systems. The cause has not yet been identified.

It is characterised by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. ME/CFS can be severely debilitating and can last for many years.

ME/CFS is often misdiagnosed because it is frequently unrecognised and can resemble other disorders including chronic viral infections, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and auto-immune diseases such as lupus. [In the USA it is known as CFIDS or Chronic Fatigue and Immune Dysfunction Syndrome.]

How is ME/CFS diagnosed?

Despite more than a decade of research, there is still no definitive diagnostic test for ME/CFS.

According to the CFS case definition published in the December 15, 1994, issue of the *Annals of Internal Medicine*, diagnosing ME/CFS requires a thorough medical history, physical and mental status examinations and laboratory tests to identify underlying or contributing conditions that require treatment.

Clinically evaluated, unexplained chronic fatigue can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.
2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; un-refreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

How is ME/CFS treated?

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 can be relieved through pharmacological and other interventions.

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

There is a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake exercise. Most ME/CFS patient groups recommend that sufferers exercise as much as they are able – to pace themselves. 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.

Do persons with ME/CFS get better?

The course of this illness varies greatly. Some people recover, some cycle between periods of relatively good health and illness, and some gradually worsen over time. Others neither get worse nor better, while some improve gradually but never fully recover.

Prevalence

ME/CFS strikes people of all age, ethnic and socio-economic groups. ME/CFS is three times more common in women as men; a rate similar to that of many auto-immune diseases such as MS and lupus.

In Australia, very few studies have been undertaken to determine the prevalence of ME/CFS in the community; estimates range from 0.2 to 2.5% or even higher depending on definition. These studies use different criteria for defining ME/CFS and consequently arrive at widely differing results.

A reasonable estimate for the prevalence of ME/CFS is 0.2-0.7% of the population. From these figures we expect that 3,000-10,500 people in South Australia have ME/CFS.

RACP, Chronic Fatigue Syndrome Clinical Practise Guidelines 2002., Published in the Medical Journal of Australia May 6, 2002, page S28. See online: www.mja.com.au/public/guides/CFS/CFS2.html.

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

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

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

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

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

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

Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanford le Hope, Essex SS17 0HA, UK.

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

MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.

Support Groups: Metro

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.

Dates

(2005): January 25 (cancelled); February 22; March 22; April 26; May 24; June 28; July 26; August 23; September 27; October 25; November 22; December 27.

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.

Dates

(2005): January 19; February 16; March 16; April 20; May 18; June 15; July 20; August 17; September 21; October 19; November 16; December 21.

Northern Metropolitan Support Group

Contact: Merindah Whitby.

Phone: Merindah on (08) 8287 3195.

Support Groups: Country

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.

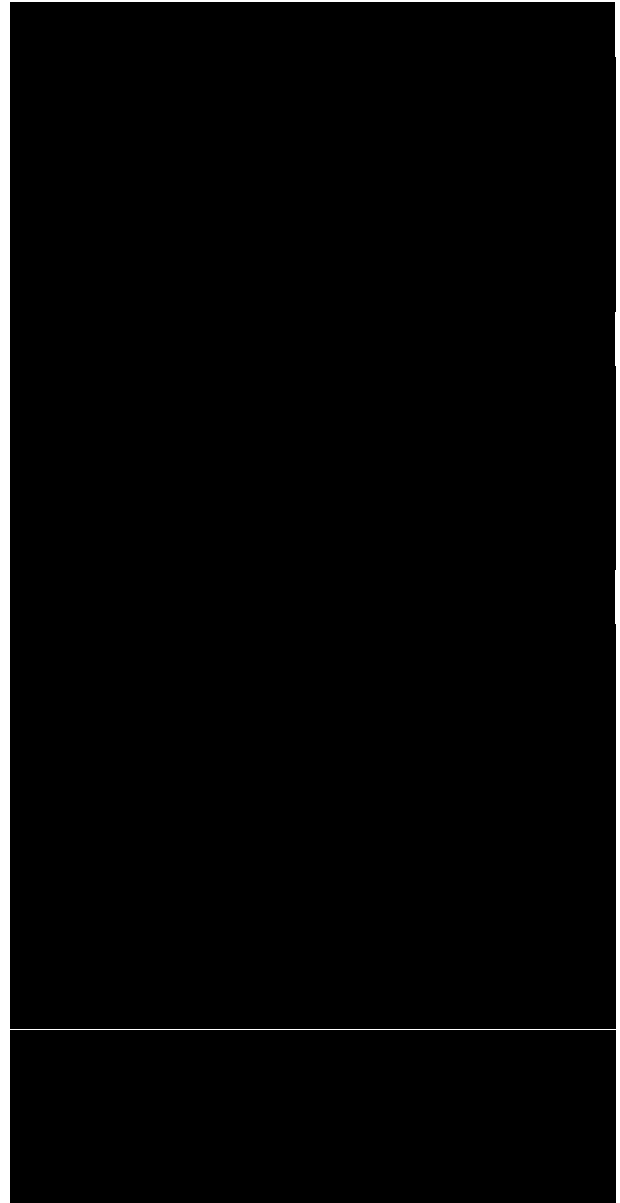
Phone: Fran McFaul (Dietician) 8535 6800.

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

Support Contacts



Youth Support: SAYME

South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronic 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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