Talking Point

2005 Issue 3 Official Journal of the ME/CFS Society (SA) Inc.

Your Society

for get-ME-not

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ME/CFS Society (SA) Inc.

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

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

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Talking Point

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Adrian Hill, Emma Wing, Margaret Wing

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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
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From the president

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

President Peter Cahalan with Professor Kenny De Meirleir at Mount Lofty Summit

September 2005

Greetings to all our renewing members and especially to our new members. I hope that you all gain from your membership in the coming year. And thanks everyone for your support for our common endeavour to improve the lives of everyone with CFS.

Professor Kenny De Meirleir

The highlight of 2005 so far has been the visit of Prof Kenny De Meirleir, the internationally renowned CFS researcher. Prof De Meirleir:

- spoke to 300 people at his evening lecture on 2 June at the Norwood Town Hall;
- was key speaker at a forum held on 3-4 June at the University of Adelaide for 25 Australian researchers and physicians and key lay leaders of the Australian CFS movement; and
- was interviewed on the ABC, 5AA and 5RPH. (We tried unsuccessfully to get *The Advertiser* to interview him.)

The visit from many angles was a great success and I think the two-day forum fostered a greater sense of common purpose and common awareness of new developments in testing and treating people with ME/CFS.

We followed up with a public meeting on 30 July. Drs Richard Kwiatek, David Gillis and John Graham took the audience of 120 keenly interested listeners through what they had gained from the forum. Was it all easy to explain? No. The developments in the field are complex and wide-ranging. My own' take' on it as a lay listener is that the researchers have come a long way in identifying a series of 'markers' for CFS which can be tested. There is not yet full agreement on either markers or tests but we're getting there. For anyone who has not been to a mainstream medico for some considerable time, I suggest that you return and seek to be tested. As noted, the problem there is to work out which test from what doctor. But I'm hoping that over the next year there will be developments in this area in Australia.

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Meanwhile for those of you impatiently wanting to know the full score from the forum – please be patient for the publication of the formal report by the Alison Hunter Memorial Foundation. I expect that out in the next few months.

I want to record my admiration for the great work of the Foundation in brining Prof De Meirleir to Australia and in convening the forum. In speaking to Christine Hunter and attending the forum I came to have a much better understanding of what a tenacious battle she has had to fight to promote the cause of research into CFS and better treatment for those suffering it. Christine and Annette Leggo, who works with her, are amazing people, as is Simon Molesworth, our national president.

Parliamentary report on Multiple Chemical Sensitivity

The Social development Committee of State Parliament brought out the report of its inquiry into MCS in July. I personally found the report somewhat disappointing. It's got some solid recommendations for action by various Ministers and by local government, of which it was critical for the lack of systems for managing the use of pesticides and herbicides around people. But it could have done more to drive South Australia towards becoming a world leader in the field rather than just one of the better Australian States playing some sort of catch-up with the more advanced Canadian provinces and American States.

Anyway, it should lead to some improvements for citizens with MCS. To help that to happen, we are organising with several other groups a public meeting on 22 October at 2pm at the Catholic church hall, 80 Payneham Rd Stepney. Three members of the Legislative Council – Gail Gago, Michelle Lensinck and Sandra Kanck – will address us on the report and you can put your point of view to them. Please come. We've got to become highly organised and very vocal as a lobby on all matters affecting our health and lifestyle. And this for many of us is one of the big ones. See you there.

By the way: I'm now telling everyone I meet who wants to go to a chemically-safe place to have a holiday to try the Quorn caravan park. Managers Bronwyn and Gary are working hard to eliminate all nasty practices because Bronwyn herself is chemically sensitive. Let me know of other safe places like that, will you?

The committee

Your committee has lost one person and gained one person in the last couple of months. Donna Briese – she who ran the office and looked after many of you with your enquiries – left us in June. She made a great contribution to our work over several years and I know will be missed especially by support group organisers around the State. On the up side, we have gained Michael Ritter. Michael came to us as a volunteer in 2004 and has made a big impact on our IT work and our communications strategy. His latest effort has been to bring the SAYME website back on line after it had been on vacation for over a year.

Of course, that still leaves only a small committee and a few volunteers to run everything. At the moment we are getting lots of plaudits from both members and from an amazing number of out-of-State people. That's mainly because our website is generally regarded as one of the best anywhere in the world. We're getting about 600 visitors a week to it, thanks to the efforts of our webmaster Peter Scott and the diligence of our committee in feeding him new items just about every week. For those of you on email, the weekly bulletins also seem to have increased our members' loyalty to 'brand ME/CFS (SA) Inc.' (Sorry, I'm spending too long in marketing seminars at work!!) We are increasingly concerned to find ways to assist many more members to get access to our communications efforts and encourage any of you without email at home to find ways to access it – even via a family member or neighbour who might monitor our bulletins for you. Just send us their e-address and we'll add them to our growing e-address book.

Anyway: the real point is that people think things are going well. And they are. But it remains a Thin Red Line affair. We continue to encourage you to offer yourself for a bit of work with us as and when you can – and as and when we can find appropriate work for you. If you can't volunteer your time regularly, you might just lobby someone you know to do a fundraiser at their work; or write to a pollie about a matter of concern; or attend a relevant forum or conference on our behalf and do your best to get our concerns on the agenda. It's more productive if we think of ourselves not as a "Society" with paid-up members who consume newsletters and lectures but as a movement of activists each doing a little bit to make a big impact. Because there's lots to do!!

And now: I hope that you stay hopeful and that you have solid grounds for hope that things will improve for you and those you love over the months ahead. May good things come your way.

Peter Cahalan
President

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CFS researchers conference

Professor Kenny De Meirleir was the keynote speaker at a two-day workshop of leading CFS researchers and clinicians at the University of Adelaide on June 3-4, 2005.

Many members attended a public meeting on June 2. There, Prof De Meirleir gave a rapid-fire and highly technical report on the most recent findings on the causes of and treatments for CFS. During that meeting and the forum, one message emerged: this is a condition with organic causes which researchers are now beginning to understand. It is not a psychiatric or psychosomatic condition.

To help general readers make sense of what was a very technical discussion at the forum, the Society has asked the experts attending it to provide short reflections on what they got out of it.

CFS researchers conference participants

Rear (l to r): Jim Chambers (Vic); Dr Richard Burnet (SA); Dr John Graham (SA); Dr Richard Schloeffel (NSW); Dr Michael Barratt (NSW); Dr Neil McGregor; Dr David Gillis (SA) (partly obscured); Jan Jolly (Vic); Dr Nicole Phillips (Vic); Simon Molesworth (Vic).

Middle: Prof Kenny De Meirleir (Belgium); Cathie Powell (SA); Christine Hunter (NSW); Annette Leggo (NSW); Dr Don Lewis (Vic).

Kneeling: Dr Don Staines (Qld); and Dr Peter Cahalan (SA).

Absent: Emeritus Prof Barry Marmion (SA); Dr Peter Del Fante (SA); Dr John Duley (Qld); Susan Brookes (Vic); Dr Wendy Scheil (SA); Dr Jim Fitzgerald (SA); Kristin Clark (SA).

CFS researchers conference: Where to now?

*By **Michael Barratt** MBBS FRCPA, Medical Adviser, Alison Hunter Memorial Foundation.*

In the early years of ME/CFS societies in Australia our motto seems to have been, "We don't know where we're going, but we are on our way."

After the Adelaide Forum, for the first time I believe, we are able to say, "Don't give up now, big advances coming, finally!"

Various attempts to define Chronic Fatigue Syndrome have foundered on the vagueness of the word "fatigue." Everybody gets fatigue, physically and mentally, from time to time. It is found as well in "serious illnesses" including heart disease and major depression. Rather than making "fatigue" the main compulsory symptom, in a new attempt at a "case definition" of ME/CFS, the Canadian Clinical Case definition, 2003 has brilliantly rewritten the guidelines to capture, at last, what ME/CFS is really all about. It is not that patients are fatigued. Healthy people get fatigued. Rather, the definition specifically selects patients who worsen with exercise. This takes the emphasis away from the subjective sensation of "fatigue" and forces one to clearly describe the connection between fatigue and activity. This also embraces mental fatigue (loss of cognitive function and alertness) as well as physical fatigue (lack of energy and strength, often felt in the muscles). The patient must become symptomatically ill after exercise and must also have evidence of neurocognitive, neuroendocrine, dysautonomic (e.g. orthostatic intolerance) and immune malfunction.

The Adelaide Forum unanimously agreed to embrace the Canadian case definition with a strong recommendation that it also be taken up by ME/CFS societies.

The obfuscation, deliberate I believe, of the previous case definitions resulted in the lumping together of numerous diseases that have little or nothing to do with each other, apart from exhibiting "fatigue" to some degree. This has been corrected. The Canadian definition states that "patients become worse after exercise rather than better." There are pathologically slow recovery periods – usually 24 hours or longer.

Professor Kenny De Meirleir, who incidentally helped to frame the Canadian definition, gave a wonderful exposition summarizing the research enshrined in over 5000 scientific papers. His own immense contribution and modesty were inspirational. Briefly, he and others have elucidated a whole battery of biochemical tests that reflect the great complexity of CFS. Settling for the moment on a panel of five or six basic tests, mostly unavailable in Australia for the moment, he is able to separate ME/CFS patients into three separate groups, each with different causes, therapies and (sometimes) outcomes. His clinic in Brussels sees 800 CFS patients every three months.

Interestingly, given the biochemical results of these tests, without seeing the patient he is now able to predict into which group the patient falls, correctly in 95% of cases. This would be impossible if ME/CFS is a psychiatric illness. It is also highly significant that these tests can discriminate between ME/CFS and normal, or non-CFS patients.

He told us of an encouraging story of a girl who was bedbound from the age of 12 to 19 with ME/CFS. She is now running European marathons.

The take home message of the forum is, "do not give up, and hang on. The greyness is not that of evening before the dark night, it is the greyness of the dawn before a bright new day of hope for the sufferers of this hideous disease."

There was also discussion about encouraging laboratories of excellence to make readily available some or all of these tests so that the exciting work done in Belgium, Spain, Japan, Canada and the USA will soon be available in Australia.

To all those who supported the forum financially – thank you.

Dr Michæl Barratt

The Forum was convened by the Alison Hunter Memorial Foundation, with the financial assistance of:

- ME/Chronic Fatigue Syndrome Society of South Australia
- ME/Chronic Fatigue Syndrome Society of Victoria
- CFS/ME Special Fundraising Committee Victoria
- ME/CFS Support Group Western Australia
- ME/Chronic Fatigue Syndrome Society of New South Wales

CFS researchers conference: Report by Valerie McKeown

*Note by **Valerie McKeown**: This report is an attempt to put together, in layman's language, an outline of the information given about CFS by Professor Kenny De Meirleir as I understood it.*

Also included is information from Drs Richard Kwiatek, John Graham and David Gillis, all speakers from the meeting on Saturday July 30. However, I have decided not to endeavour to attempt to rewrite Drs Kwiatek's and Graham's talks in layman's language. Instead, I am including written information from these, which they so kindly sent me, following this meeting. To clarify the medical jargon I have provided, where possible a glossary of medical definitions procured from the Medline Plus Medical Dictionary *at the end.*

A layman's interpretation of Professor De Meirleir's talk

From the bones of De Meirleir's talk this is what I gained as the important factors:

Many viruses have at times seemed to play some role in CFS and related illnesses.

There is a virus from the herpes family, which most of us have before the age of eighteen months and successfully rid ourselves of at that time. This virus is called HHV6B and we usually get lifetime immunity from this exposure

In those prone to CFS however, it appears that this may not be the case and that the closely related HHV6A virus appears in the body until some time later when symptoms of CFS appear.

This virus enters specific cells and evokes changes causing other changes, which bring about CFS. Several researchers have found evidence of HHV6 in CFS with neurological features. In some persons cytomegalovirus (HHV5) appears to play a role.

Often there is also a change in the gut as well. This appears to include increased gut permeability, leaky gut syndrome.

Changes in the brain, muscle tissue, cellular electrical changes (called channelopathy) and other areas of the body may also occur.

However, each individual has their own specific variations in the above-mentioned, which creates the wide variance in the level of CFS and symptoms.

Therefore, it is important to arrive at the right program of treatment for each and every individual.

This appears to be the key to curing this disorder and the reason why in the past some people have been lucky and others have not. It appears to me, that what the doctors are saying is that rather than look for something new they need to look at how to be sure that they correctly understand in which submodality the patient belongs and apply treatment according to that specific modality.

This would entail using some similar forms of treatment for every patient but applying the arrangement of treatment according to the sub-modality in which the individual sits. It is how they discover the arrangement of treatment, which they are working on now and have great hope of discovering in the coming few months.

Dr Richard Kwiatek

(i) CFS seems to involve (to varying degrees and with yet to be understood interactions) dysfunction of at least: (a) the bowel (ie bacterial flora); (b) the innate (ie primitive) immune system; and (c) the brain.

(ii) Rheumatologist Dr Richard Kwiatek, of The Queen Elizabeth Hospital, concentrated on (c) the brain. This was with regards to the closely linked to CFS disorder of fibromyalgia (FM). His research team's preliminary results showed subtle (too small to be visible to the naked eye) structural changes in the brain in FM, derived from standard clinical magnetic resonance imaging (MRI), but analysed with a highly sensitive and accurate new automatic technique which his team have developed. This technique compares the MRI scan intensity at all sites within the brain between groups of different subjects.

(iii) FM is a condition which overlaps with CFS, but in general tends to occur later in life. It tends to have a greater female to male ratio (10:1) and, whilst being triggered by many of the causative factors of CFS, can also be triggered by factors such as chronic biomechanical stress and inflammatory autoimmune disease, such as rheumatoid arthritis. Like CFS, the manifestations of FM would appear to be somewhat heterogeneous, and so the label of FM may actually encompass more than one underlying disorder.

(iv) FM denotes the clinical condition of chronic peripher-

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CFS researchers conference audience members

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ally unexplained widespread (total body) pain associated with peripherally unexplained widespread (total body) tenderness. Two percent of the population meet this (research) definition, and roughly another 10% would seem to have patchy (in distribution) or incomplete FM. Consequently, full blown FM would appear to occur more commonly than (research defined) CFS. However, both disorders are important members of the "chronic multisystem illness" group of disorders (which also includes MCS), all members of which seem to varying degrees involve: (a) musculoskeletal pain; (b) fatigue, (c) cognitive dysfunction; (d) psychological distress; and (e) sleep disturbance.

(v) Dr Kwiatek's team have detected MRI signal changes in predominantly the right hippocampus in FM. However, maximal signal difference here was only 3%, between research subjects with FM and healthy controls. Slightly less significant changes were detected in the right orbitofrontal cortex. The pattern of distribution of these changes was not consistent with either tissue shrinkage (atrophy) or swelling (proliferation). These results would seem to constitute the first direct evidence of structural changes within the brains of patients with FM, but (a) a longitudinal study is needed to assess if they are primary to the FM disorder or secondary to it, and (b) they need to be confirmed by a completely independent technique, such as magnetic resonance spectroscopy.

(vi) If the findings are confirmed, they may provide an at least partial explanation for many of the clinical features of FM, such as pain. (Injection of the general anaesthetic ketamine directly into the hippocampi of rodents significantly reduces experimental pain perception. Early evidence suggests that ketamine can provide prolonged pain relief in a subgroup of patients with FM, These patients suffer memory dysfunction (the hippocampi have long been known to play a critical role in memory), and even associated psychological distress (given the evolving understanding of the link between the hippocampi and the orbitofrontal cortex).

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Recent research in CFS as written by Dr John Graham

Chronic fatigue syndrome (CFS) is a disorder characterized by debilitating fatigue associated with immunological abnormalities.

The etiology has remained unclear.

However, Professor Kenny De Meirleir, from Brussels, suggests that research on CFS between the Belgian and the American scientists "has uncovered a series of hidden mechanisms."

Professor Kenny De Meirleir has made remarkable and scientifically verifiable steps, in these post-infection illnesses.

Many microorganisms can lie dormant despite antibiotic treatment, and the evidence is good that in at least three subgroups, HLA status and other factors operate to evoke chronic consequences. Organisms which live in cells are prominent in these studies.

These organisms include bacteria such as chlamydia, mycoplasma, rickettsiae, borrelia, coxiella and other bacteria with deficient cell wall and other pleomorphisms. They have in common intracellular location and capacity to avoid macrophage phagolysomal dissolution. What we need to recognize is the difficulty in identifying the presence of intracelluar cell wall deficient bacteria.

The strange forms were exceedingly difficult to find, but use of EM, magnification to 7-10,000x, special strains and immunofluorescence eventually confirmed that the odd forms were indeed borrelia, albeit L forms

Barrie Marmion has found the coxiella in bone marrow of Q fever patients who remained in chronic ill health despite antibiotics. They had elevated levels of IL6, and HLA haplotyping showed them to have DR11 markers.

HLA is the logo for human major histocompatibility complexes [genes and products] and variations [polymorphisms] determine how antigen processing and presentation occur.

These diseases have measurable physical abnormalities, contrasting with the dearth of adequate science in psychiatric claims. We need about six new tests to become available in Australia to get the therapy right for each person.

Kenny[1]s research is around activation of the TH2 pathway using cytokines interferon alpha and beta, which are part of the 2,5 oligoa pathway.

Kenny's research is impressive, showing a ratio of RNAseL 37kDa/83 kDa is very high in >90% of CFS, but only 1% of controls or persons with depression. This pathway is well known to research immunologists, and is a response to certain microorganisms.

Bear in mind that there is a subset of CFS with TH2 lymphocyte setting, but some CFS cases are set differently.

Bernard Le Bleu in Montpellier in France sent me a chapter on IFN alpha and beta and the 2,5 oligo A pathways, while Kenny has passed on many papers and the full range of tests which he undertakes! This is verified research, with 2 US researchers confirming the findings.

He measures the above plus PMC elastase, PKR activity, NK cells activity, uric acid and PCRs for various organisms.

He tests gut permeability and MELISA for evidence that in leaky gut syndromes, some heavy metals are absorbed. He is very sure that gut abnormalities are important, and I am convinced. Our Australian Newcastle researchers have long been able to demonstrate gut flora and other changes, but Australian doctors seem to have been too sceptical to use this work properly.

De Meirleir documents T3 (tri-iodothyronine is the active thyroid hormone) resistance [change in T3 receptors] as well. He places CFS into three categories, based upon these results.

Most of the tests are not available in Australia, yet! Without these measurements many therapies are very "hit and miss."

I have been in dialogue with Trevor Marshall, PhD, who is slowly unravelling information about cell wall deficient and L form bacteria, which both evade immune mechanisms and may bring on unwanted responses.

One effect is this macrophage activation.

Macrophages also possess angiotension 2 receptors on their cell membranes, and these are altered in TH1 set diseases. The theme is a range of cell wall deficient or L forms of bacteria, which evade immune mechanisms and bring on either TH1 or TH2 responses. [This theme seems to in-

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clude intracellular bacteria such as rickettsiae, coxiella and borrelia, which evade the phagolysosome.]

We perhaps should look for L forms of bacteria by live blood examinations at 8-10,000x magnifications, [ear lobe blood] and by special stains as well as immunofluorescence. Ear lobe blood, seems to allow better numbers of bacteria to be seen than venous or finger tip blood. If white cells are positive, then PCR for specific organisms could be added.

Activated macrophages possess the enzyme 1 alpha hydroxylase to turn 25 hydroxy D3 into the 1,25 dihydroxy D3, and Marshall claims that this aids the survival of the bacteria. I have already encountered some severe CFS cases with high I,25 dihydroxy D3 where avoiding daylight and wearing shades was associated with striking improvement. Marshall states that this is very significant in marking a TH1 type immune response and claims they are responses to these cell wall deficient bacteria located in macrophages.

Another fascinating finding is that Marshall finds that the use of olmesartan, an angiotensin 2-receptor blocker seems to improve some cases of CFS and sarcoidosis. Olmesartan rapidly reduces 1,25 dihydroxy D3 levels, when they have been elevated Angiotensin 2 receptor blockers [ARBs] are vasodilators, but A2 receptors are used by some organisms as entry points. [see note below]

Much depends on the molecular configuration of the A2 receptor.

Olmesartan works the best and is definitely able to stop NF kappa beta activation, thus decreasing transcription of the TNF alpha gene, and decreasing this inflammatory cytokine. Other A2R blockers have very little PPAR actions.

Inflammatory cytokines like TNF alpha and IF gamma down regulate the PPAR gene, but Marshall says that of the A2R blockers available in Australia only irbesartan has some anti-inflammatory action in his patient group, and it has almost no PPAR agonist action.

What do T3 receptors, sex hormone receptors, PPARs and 1,25 dihydroxy D3 receptors have in common? They are all intranuclear receptors with polymorphisms, with emerging evidence that they can alter in disease states.

Minocycline and azithromycin are better than doxycycline, in dealing with cell wall deficient bacteria, because of better intra cellular penetration. The dose is remarkably low. Minocycline 25 mg alternative days for thirty days, then azithromycin 250 mg every third day for twenty one days, then review. Minocycline enters 30S ribosomal locations, while azithromycin does the same at 23S locations within the 50S area.

Every antibiotic molecule locating in ribosomes decreases peptide assembly in these organisms!

Each of these medications has the capacity to decrease matrix metalloproteinase activity as well.

I regard probiotics as essential!

We all need to be cautious about the Marshall claims for the following reasons:

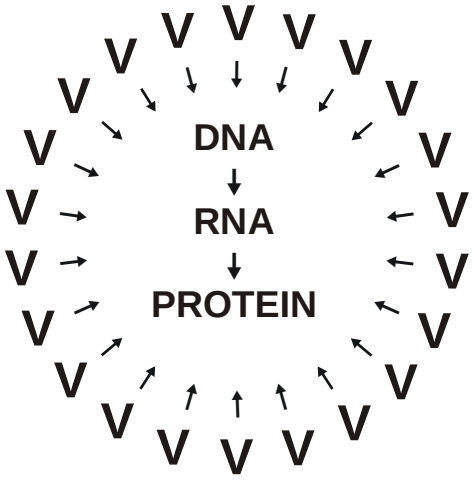
1. So far no confirmation has come from independent researchers;
2. Vitamin D3 deficiency is serious and all patients undertaking the Marshall protocol should have follow-up D3, 1,25D3 and PTH monitoring;
3. The olmesratan dose is about 4-8x the usual antihypertensive dose and may be risky in some people. Close monitoring of adequate fluid intakes, BP and renal function is important.

Points outlining talk by Dr David Gillis

CFS frequently follows a viral infection.

Kenny De Meirleir's test is about how the immune system has gone wrong with response to virus and has led to CFS. That is :-

DNA [all cells have this]



Viruses are either DNA or RNA and when they enter cells

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their genes use cell mechanisms to replicate the virus, and this may badly injure the cell.

The Immune System

The innate immune system (this means macrophages and dendritic cells) reacts in hours. Toll like receptors can recognize the virus or bacteria and the cells make specific cytokines.

The adaptive immune system (T and B lymphocytes) is what kicks in after several days to weeks, eg T cells making cytokines and B cells making antibodies.

In chronic fatigue, the problem is with the innate immune system following infection with a virus, plus TH2 set T cells generate cytokines called Alpha and Beta interferon (called TH2 cytokines) which target receptors on cells containing viruses, allowing those cells to make RNAse-L. (83kDa).

Normally RNAse-L is produced for only a very short time] & destroys RNA in the virus.

In chronic fatigue a particular funny RNAse-L (37kDa)[5] persists for longer than required and interferes with our muscles, immune system and a whole lot of other body functions. People who are tired have more RNaseL

This is very interesting but has to be confirmed by more studies.

Glossary

Adaptive Immune System: Lymphocyte activations, specific cytokines and antibodies, etc.

Acyl: [noun] A radical* derived usually from an organic acid by removal of the hydroxyl* from all acid groups.
**Radical: [noun] FREE RADICAL. Also: a group of atoms bounded together that is considered an entity in various kinds of reactions. Highly reactive and able to injure cell membranes.*
**Hydroxyl: An unisolated compound radical of one atom of hydrogen and one oxygen.*

Amide: [noun] An organic compound derived from ammonia or any amine by replacement of an atom of hydrogen with an acyle* group.

Angiotensin 2: [noun] A naturally synthetisized amide derivative of angiotensin 11*. This is an 8 amino acid peptide, and constricts smooth muscle in arterioles, as well as stimulating the adrenal glands to make aldosterone; bocking agents are used to treat some forms of hypertension.

Coxiella: [noun] A genus of small pleomorphic bacteria occurring intra cellularly in the cytoplasm of the vertebrates and including the causative organism [C. burnetti] of Q fever.

Cytokine: [noun] Literally "cell mover." Any of various plant and animal signalling substances that are usually derivates of adenine.

DNA: [noun] Any of various nucleic acids that are usually the molecular basis of heredity, are localised especially in cell nuclei, and are constructed of a double helix held together by hydrogen bonds between purine* and pyrimidine* basis which project inwards from two chains containing alternative links of deoxyribose* and phosphate – called also deoxyribonucleic acid*.
**Purines: Adenine and guanine.*
**Pyrimidines: Cytosine and thymine (in RNA uracil instead of thymine)*
**Deoxyribose: A sugar.*
**Deoxyribonucleic acid: Variant.*

Etiology: The truth about the cause of a disease.

Heterogeneous: [adjective] Not uniform in structure or composition. ("Tumours which have a heterogeneous composition by reason of structure and presence of the necrosis*" – *Year Book of Endocrinology*.) ("The beam of X-ray is not monochromatic but heterogeneous, containing wavelengths over a large range" – *Medical Physics*.)
*Necrosis: - death of tissue.

Hippocampus: [noun] A curved elongated ridge that is an important part of the limbic* system, extends over the floor of the descending horn of each lateral ventricle* of the brain, and consists of gray matter covered on the ventricular* surface with white matter.
**Limbic system: A group of cubcortical structures of the brain that are concerned especially with emotion and motivation.*
**Ventricle: One of the system of communicating cavities in the brain that are continuous with the central canal of the spinal cord, that like it are derived from the medullary canal of the embryo, that are lined with an epithelial ependyma, and that contain a serous fluid.*

HLA: 1. The major histocompatibility complex in humans; 2. A genetic locus, gene, or antigen of the major histocompatibility complex in humans – often used attributively – often used with one or more letters to designate a locus or with letters and a number to designate an allele at the locus or the antigen corresponding to the locus and allele. ("Relationship ... between HLA-B27 antigen and ankylos-

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ing spondylitis." – G. E. Ehrlich.)

Immunofluorescence: Labelling of antibodies so that when they join with antigens the product fluoresces and can be seen in the test specimen.

Innate immune system: Our earliest detection and response immune system.

Intracellular: [adjective] Existing, occurring, or functioning within a cell.

Kinin: [noun] Any of various polypeptide hormones that are formed locally in the tissues and causes dilation of blood vessel and contractions of smooth muscle.

Macrophage: A phagocytic* tissue cell of the mononuclear phagocyte* system that may be fixed or freely motile, is derived from a monocyte and function in the protection of the body against infection and noxious substances.

**Phagocytic: [adjective] Having the ability to engulf by phagocytosis; capable of functioning as a phagocyte.*

**Phagocytic Index: [noun] A measure of phagocytic activity determined by counting the number of bacteria ingested per phagocyte during a limited period of incubation of a suspension of bacterie and phagocytes in serum.*

**Plagocyte: [noun] A cell [as white blood cell] that engulfs and consumes foreign material [as microorganisms] and debris.*

Phagolysosome: [noun] A digestive vesicle formed within a cell by the fusion of a phagosome containing ingested material and a lysosome containing hydrolytic enzymes.

Polymorphism: [noun] The quality or state of existing in or assuming different forms, as (a) [1] the existence of a species in several forms independent of the variations of sex, [2] the existence of a gene in several allelic forms, [3] the existence of a molecule [as an enzyme] in several forms in a single species; or (b) the property of crystallising in two or more forms with distinct structure.

Macrophage phagolysomal dissolution: A white corpuscle that engulfs and consumes foreign material [as microorganisms] and debris that maybe fixed or freely mobile, dissolving and killing any bacteria that attacks noxious bacteria or formations.

Monocyclic: [adjective] Containing one ring in the molecular structure.

Permeability: Quality state of being permeable; having pores or openings that permit liquids or gases through.

Pleomorphisms: In biology, the occurrence at the same time and in the same place of independent forms or types of structure of the same organism. Sometimes extended to the consideration of all the various genera of bacteria as polymorphous forms of certain species. The quality or state of having or assuming various forms

PMC elastase: [noun] an enzyme able to digest or hydrolyse certain elastins and related proteins. Elastins are the chief constituents of elastic fibers.

Receptors: A chemical group or module [as a protein] on the cell surface or in the cell interior that has an affinity for specific chemical group, molecule, or virus.

**Affinity: An attractive force between substances or particles that cause them to enter into and remain in chemical combination; a relation between biological groups involving resemblance in structural plan and indicating a common origin.*

RNA: [noun] Any of various nucleic acids that contain ribose and uracil as structural components and are associated with the control of cellular chemical activities - called also 'ribonucleid' acid.

RNaseL: An enzyme*.

**Enzyme: A complex organic substance, which in solution produces fermentation and chemical change in other substances apparently without undergoing any changes itself; a form of catalyst; digestive ferment.*

TH1: Cell or fiber set diseases.

T3 (Triiodothyronine): [noun] A crystalline iodine-containing hormone C15H12I3NO4 that is an amino acid derived from thyroxine is used especially in the form of its soluable sodium salt in the treatment of hydrothyroidism & metabolic insufficience – also called liothyronine T3.

Talking Point – 2005 Issue 3

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

CFS researchers conference: Report by John Duley

John Duley *is a specialist in purine and pyrimidine metabolic diseases at Mater Hospital, Brisbane.*

Metabolic disease: The body's chemistry runs on a huge series of chemical pathways, producing the chemicals it needs for energy, growth, repair, reproduction etc etc. You could imagine these pathways to be like the processes in a chemical factory, producing nutrients and hormones etc etc and carrying them around to where they are needed. The chemicals are called metabolites, and the process is called metabolism. We have energy metabolism, and growth metabolism, etc. It all works reasonably well for most people.

Most of us have genetic mutations (or changes to our genetic makeup/DNA), because the pathways that maintain (reproduce and repair errors) the huge DNA code in each cell cannot work to 100% perfection. Most of the mutations we have are probably harmless, but some mutations can affect important functions, and then we develop a disease or a pathology. If a mutation affects a chemical pathway, it produces a 'metabolic disease.' Then it is like a blockage in the production line somewhere in the factory.

There can be a rapid build-up of a natural chemical that normally is just a part of a process in the body and never normally reaches high concentrations, but when there is a blockage such a chemical can become toxic to cells because it builds up to unnatural levels. Or the blockage can produce a lack of a chemical downstream in the process line, and there is 'starvation' of cells for the necessary chemicals.

Quite a few neurological diseases are caused by inheriting a mutation from parents. The one I discussed was a metabolic disease called 'MNGIE' – it arises from a mutation that affects the energy production line (the mitochondria) in cells: a single chemical step has a mutation and this causes toxic build-up of a metabolite that eventually kills the mitochondria.

The most highly energy-dependant cells in the body are the nerves (including the brain), the muscles and the retina. Mitochondrial diseases thus usually affect multiple organs: The nerves and brain suffer, usually first causing 'peripheral neuropathy' or loss of sensation in the peripheral parts of the body, the legs and arms; The muscles not only lose power and fatigue is experienced but also there are severe gastric problems because the digestive system uses a lot of muscle power, and the eye muscles also weaken – the eyelids droop (ptosis) and it is difficult to turn the eyeballs (ophthalmoplegia); The retina can weaken so there is loss of eyesight.

Metabolic diseases are typically 'progressive' – they get worse with age, because there is a continual build-up of toxic chemicals/metabolites or starvation of cells. I pointed out it is necessary to exclude known metabolic diseases where a ME/CFS patient has appropriate symptoms, because we could be trying to treat the wrong problem (and mitochondrial and some other metabolic diseases mimic ME/CFS). But I was also of the opinion that ME/CFS patients might be suffering from metabolic problems (eg, build-up of toxic chemicals). I admit I may be wrong…

Toxicological disease: Most of us are aware of what can happen if we get a bacterial 'infection' in a cut or in the throat following a flu virus. There is an increasing inflammation of the affected area, and eventually the bacteria can cause cell death, destruction of tissue and even get into the blood stream (sepsis). The bacteria cause this destruction by producing nasty chemicals that kills cells – these are not normal chemicals that our bodies produce but foreign chemicals that are toxic to us. 'Antibiotics' are simply another form of toxic chemical, but they are toxic to bacteria, not our cells (antibiotics are mostly produced by fungi/moulds, which compete with bacteria in the wild). Typical nasty bacteria are streptococcus and staphylococcus, but there are lots of others.

However, not all bacteria are bad. We have zillions of them living on and inside our bodies (mainly inside the gut – and the digestive system is strictly speaking 'outside' the body – it has a thick protective layer that shelters the 'inside' of our body from the things that we eat, absorbing just the bits it wants). A typical 'good' bacterium in the gut is 'E. coli.' Our gut also likes the bacteria in yoghurt, etc. We actually depend on some gut bacteria to provide us with chemicals that our body needs but can't make for itself (we call these 'vitamins'). If we get a nasty bacteria in the gut, eg, 'food poisoning', there can be severe problems because the bad bacteria are producing toxic chemicals that either kill the protective layer (eg, cholera bacteria) in the gut, or the gut mistakenly absorbs the toxins and they cause havoc elsewhere in the body (some bacteria can produce toxins that affect nerve cells, producing paralysis etc). These severe infections in the gut usually subside after a few days – the gut clears itself (by diarrhoea/vomiting).

But if we get a sneaky bacterium that lives in the gut and produces toxins but doesn't produce a response by the body to get rid of it, then we are stuck with living with a continual flow of bacterial toxin from the gut into our body. This seems to be what Kenny De Meirleir and Richard Schloeffel were saying: that ME/CFS is the result of

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abnormal gut bacteria or 'microflora.' These abnormal bacteria are producing continual low-dose toxins that leave the ME/CFS sufferer fatigued, disoriented etc. Gut problems are common. Similar to mitochondrial problems, many organs are affected, especially the nerves and muscles. Do the toxins target the mitochondria? We don't know – there has been so little research of ME/CFS!

But I think ME/CFS sufferers don't usually get the full mitochondrial range of symptoms – they don't usually get peripheral neuropathy or ptosis, for example. Should antibiotics work? Many bacteria are unaffected by antibiotics because they were made by moulds to attack just certain bacteria that they compete with, not all bacteria.

Tetracycline antibiotics are very powerful and are 'wide spectrum' – they attack many bacteria types – and seem to help with some cases of ME/CFS but not all (I think the minority). And tetracyclines are so powerful that they are also toxic to our cells and cause severe side effects – the cure can be worse than the disease!

I understand that Richard and Kenny find success by trying to replace the bad gut bacteria with good ones, in two ways – giving good bacteria in the diet (yoghurt, supplements etc) which will compete with the bad bacteria and hopefully replace them; and changing the diet to provide an environment in the gut that suits friendly bacteria and removes any unsuitable foods that may weaken the body in other ways. Not everyone responds – some sufferers still go gradually downhill. My wife is a 'lucky' one – she has had ME/CFS for almost 20 years but is slowly getting better year by year, not worse, and of course her age will also be offsetting any gradual improvement – we lose mitochondria as we grow older, that's why we grow weaker etc!

OK, sorry this has been long-winded, but it's not an easy concept to grasp, but I hope it helps.

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

Book review

Chronic Fatigue Syndrome: A Biological Approach

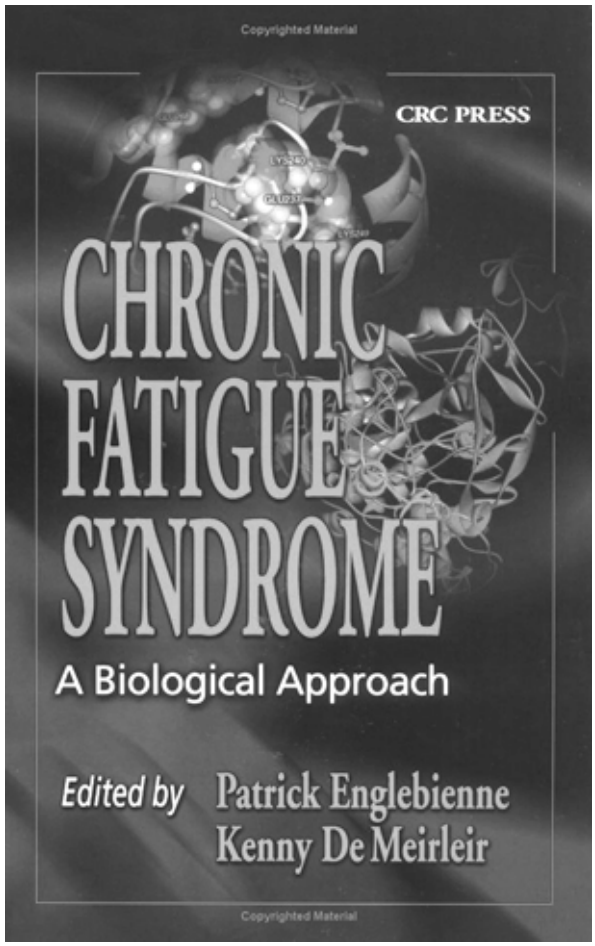
Edited by Patrick Englebienne, PhD, and Kenny DeMeirleir, MD, PhD

ISBN: 0849310466

*Review by **Peter Mitchell**.*

This is, I suspect, a seminal text in the literature of ME/CFS. It contains articles from Professor De Meirleir and his fellow editor Dr Englebienne, doctors Garth Nicholson and Neil McGregor from Australia, Dan Peterson and Robert Suhaldolnik from the US and a number of other key researchers. The topic is the biology of the illness, and the focus is very much on what happens in the body of a person with ME/CFS. This book created a deal of interest, particularly in relation to the role of RnaseL in the illness. Members attending Professor De Meirleir's session or the recent follow-up at St. Peter's will note the importance of that work on RnaseL. However, the book is mostly aimed at fellow medicos and researchers. I quote this passage from the second chapter as an instance of how technical it can be:

> "*1.2 THE 2-5A/RNase L PATHWAY: AN OVERVIEW*
> IFNα/β and γ induce the transcription of several 2-5A synthetase isozymes. In human cells, the low molecular weight (40 and 46 kDa) 2-5A synthetases are produced by alternative splicing of a single gene. The medium size (69 kDa) isoforms and the high molecular weight (100 kDa) form are synthesized from separate genes. The 2-5A synthetase isoforms differ in intracellular localization, in enzymatic properties (for instance, in their requirements for dsRNA activation), in oligomeric structure, and in length of the synthesized 2-5A oligomers. However, the physiological relevance of these differences is not understood. Activated 2-5A synthetases polymerize ATP into 2'-5' linked oligomers of various lengths (Figure 1.4), except for the p100 isoform which primarily synthesizes 2-5A dimers which do not activate RnaseL. It is worth mentioning that 2-5A immunoreactive material (2-5A dimer cores) has been detected in nonmammalian tissues using a 2 -5A core-specific radioimmunassay, thus suggesting alternative roles for 2-5A synthetases."



Not easy reading for most of us, and much of the early part of the book is similarly technical.

On the other hand, some of the later chapters are more accessible to the lay reader, especially Chapter 9, which covers the field of recent advances in CFS therapy. It is this chapter on which local researcher Dr Neil McGregor collaborated.

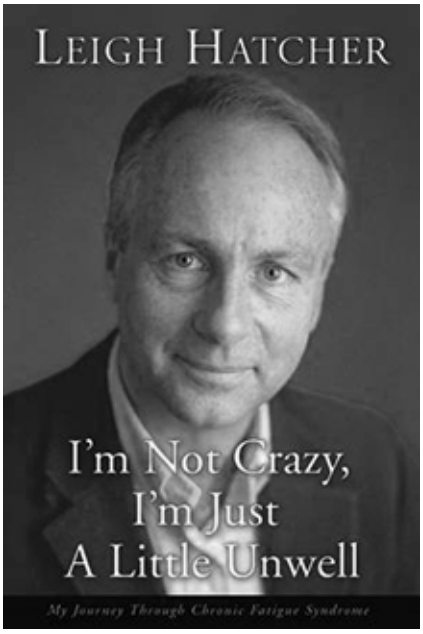
The book costs a little over $120AU in the US, and considerably more here, reflecting its small specialist audience. It is fairly readily available on www.amazon.com, including second hand copies, which can bring the price down closer to $100AU. We have checked, and the State Library does not currently have a copy.

Profile: Leigh Hatcher

Leigh Hatcher, who is a presenter on SKY NEWS (pay television) and has now recovered from a severe bout of ME (Myalgic Encephalomyelitis)/CFS (Chronic Fatigue Syndrome), is also Vice-Patron of the NSW ME/Chronic Fatigue Syndrome Society of New South Wales and a frequent advocate for people with ME/CFS. He spoke about his personal experience of living with, and recovering from, ME/CFS to an audience of 70 on May 14, 2004 for Awareness Week. This article is a synopsis of Leigh's talk.

Leigh can remember exactly when he got ME/CFS – at 3pm on January 19, 1998 whilst on holidays with his family. His feelings at that time: like being "run over by a truck"; and being "toxic". Prior to this date, Leigh led an extremely active and successful life balancing his favourite recreational activities – "plenty of surf, sun and sleep" with his very busy television life (10 years of stressful deadlines and travelling across time zones working for Channel 7).

He was first diagnosed with an unusual viral hepatitis (not A, B or C) as his liver function tests were initially very abnormal. He stated he was fortunate to link up with Dr. Robert Loblay of Royal Prince Alfred Hospital, and Dr. John Darcy, whom, Leigh believes saved him "months of time" searching for diagnosis and appropriate treatment. Leigh's diagnosis from Dr. Loblay: a 'Post-Viral Fatigue' state. When finally diagnosed, Leigh stated he felt "liberated" by now having a label for his chronic ill-health.



Leigh lost 1-2 stone in 3-4 months with his viral hepatitis. He stated that, for him, rest did help in the early stages. He suffered daily "crashes", very poor temperature regulation (high summer was worse for him than winter), irritability, 1-2 hour "flashes" of feeling normal and testing that went "on and on".

However, Leigh's greatest suffering, and the "worse part of the illness," was the "all too often misunderstandings and misjudgements" of people with whom he usually associated. He was told by a number of different acquaintances that "he can't or won't cope;" that his job, which he loved, was to blame; that he was really a "fraud" and not sick at all; that his illness was due to some "unconfessed sin" not yet dealt with. Leigh's advice to the audience in how to deal with any similar negative comments: "unfortunately you need to find new friends." Despite such negativity, Leigh remained hopeful, optimistic, purposeful and occupied throughout his illness, studying theology full-time for a year as he did not suffer the "brain fog" which affects many people with CFS.

In his first year of illness, he did not have depression ("by a number of specific measurements"). However, 13-14 months post-onset, Leigh accepted that he might be suffering a reactive depression to being chronically ill with no idea of when recovery may occur. He started to take antidepressants (SSRIs), to which he "reacted very badly", he told his audience.

One Saturday morning, after he had collapsed with acute abdominal pain and became unconscious, Leigh decided it was "well past the time to take ownership" of his illness – a decision which was a significant turning point. He learnt to recognise, respect and manage his own energy limits; to "not go crackers with the occasional good day, and just blow it". After a 5-hour glucose tolerance test had revealed abnormal sugar and insulin levels, Leigh commenced a 'diabetic lifestyle' with graded exercise. His health improved within two weeks, and became significantly better, but not totally well, over time, returning to free-lance work within two months and then to his old job reporting for the Channel 7 Network within five months to cover the Sydney Olympics full-time from August to October 2000. On October 21 2000, he read his first news bulletin with SKY NEWS, a position he retains to this day.

Leigh has turned the 0.5 million words recorded in his diaries over his three years of chronic illness into a book, *I'm Not Crazy, I'm Just A Little Unwell*, which he intends to be published and released as part of 2005 Chronic Fatigue Syndrome Awareness Week. He has also recorded it as a 'Talking Book', for those sufferers who battle to read. Both are available at www.notcrazy.net.

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Getting the best out of a chronic illness

*By **Jennifer Tosolini**.*

I have lived with ME/CFS for many years and have been through all of the ups and downs from seeming to be in remission and living a so-called normal life, to being house-bound for a period of about 4 years.

This is not a Pollyanna story. I have experienced the humiliation of not being able to work, sliding down the financial ladder, losing most of my old friends, my husband, my house, my ability to drive a car, to travel and move around freely. And having been my own carer throughout the illness, I have felt deeply the isolation that ME/CFS can bring. I know about touch deprivation which is usually only discussed in relation to the elderly, but you don't have to be elderly to experience it.

I have been on the emotional roller-coaster; asked myself "Why did this happen to me?"; thought seriously about suicide; felt resentful that my friends were continuing with their lives, but over a period of years, my life, which I know is far from normal, is now the only life I know. This is it – and I wring every drop of enjoyment out of it that I can.

During my period of being house-bound, when life hardly seemed worth living, and I was looking at little patches of the world through my windows, I constantly thought about how I could become a part of the community again, and how I could make myself important to at least one other person. After many telephone calls I discovered the Home Tutor Scheme. Due to my varied work background and travel experiences I was accepted as a Home Tutor (this is voluntary work) and due to my inability to move around in the community or to drive a car, instead of going to the home of my students which is the usual arrangement, my students were perfectly happy to come to me.

I began with one student a week, she was a young woman from China, an artist, who was studying English with professional teachers, but needed tutoring by way of extra individual support and a place where she could make mistakes and not feel uncomfortable. I had never done anything like this before, so it was a huge learning curve for me.

Over a period of time I realised that I had become very important to Mei-Mei because her mother and sisters still lived in China, so I was like an aunt. She would often bring me gifts; flowers, a beautifully hand-carved bracelet, embroidered handkerchiefs, things which were obviously her personal possessions, but she wanted to let me know how much she appreciated me. I had achieved my need to be an important part of someone's life.

There were times when I had to cancel lessons with Mei-Mei because I was too ill to get out of bed, but she didn't seem to mind. She knew I had a serious health problem, and although she understood little of the complicated ramifications, that didn't make me any less of a person in her eyes. Through her, I recovered my self-worth.

What was very important about becoming a Home Tutor, was that not only did it take me in a completely new direction, it gave me the opportunity to meet people from different countries and to learn about their way of life. It was also a way of becoming involved with people who were also on the margins of the society. I could relate in some ways to these fellow human-beings due to my experience with ME/CFS. I too had lost my peer-group support network, my ability to work, been cast out of the mainstream, ejected from my tribe and I had experienced ridicule, not because I was in a country where I was unable to speak the language, but because people didn't believe the story I was telling them about ME/CFS.

Then something really wonderfully happened, I was lucky enough to have several political refugees from a Latin American country. They were struggling so hard to learn English that I decided I was going to study Spanish, thus making my communication with them a little easier, and also giving them the opportunity to laugh with me at my attempts to speak their language, instead of being constantly ridiculed by people here at their attempts to speak English. I began studying Spanish as an external student.

Prior to my Spanish studies, I had already completed a 3-year part-time Freelance Writing Certificate course as an external student with TAFE Adelaide and from that experience wrote 2 film scripts. That was something else I didn't know I was capable of! However, due to the enormous amount of energy required to get scripts from the page onto the screen, they remain on the page, but I am happy with that.

At some stage, I became aware of the danger of actually becoming the illness rather than a person with the illness. The thought of becoming a helpless victim to the illness kept me searching for ways to reinvent myself. I learnt to

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let go of the things I could no longer manage to do and realised that I could not simply sit (or lie) around waiting for researchers to out how to change my state of constant sickness. It was up to me to work within the boundaries of my available energy and to make my life as interesting as possible.

I continued to be active in a political sense regarding the appalling treatment of people with ME/CFS and wrote letters to politicians, journalists and loud-mouthed radio broadcasters who I considered knew very little about anything except how to display their appalling ignorance about the illness through their use of vitriol and hatred.

But back to Spanish. Wanting to go further with my studies, I completed a 3 year certificate course, once again as an external student, then I began studying French. The marvellous thing about studying languages is that it allows me to travel without all the drama of actually leaving home, and watching the news daily on SBS direct from Paris and Madrid, gives me an enormous insight into the world at large, thereby enriching my life.

Another powerful insight into the world was becoming a member of Amnesty International about 11 years ago. I am a member of the Urgent Action Letterwriting Network. Reading constantly about the cruel treatment of people in many countries of the world, has helped put my life and ME/CFS into perspective, and I know that when thousands of Amnesty members around the world are asked to target certain government leaders on behalf of other human beings, it can mean the difference between life and death.

Something else I became involved in in order to take the focus off me and my life, was to become a penfriend to refugees who are imprisoned in detention centres. Learning about their stories made me realise, that although ME/CFS has made my life difficult, it was nothing when I compared it with what my penfriends had not only been through, but continue to experience whilst in detention. When I had a bad day, or night, I thought about the fact that I was safe and comfortable in my own bed and I was not at the mercy of strangers. It made me feel very humble to realise that even in the depths of their horrendous surroundings, my penfriends would send me their heartfelt thanks and blessings, and one of them, a man isolated in the camps in Nauru, was upset one Christmas because he was unable to go to the 'bazaar' to buy me a card. That he was able to think of me despite his circumstances, taught me a lot about the expectations I had for my own life, which I now believe is idyllic compared with millions of others in the world.

In 2001 I decided to really go for broke and study for a Bachelor of Arts degree. Having left school many, many years ago, without formal qualifications, I had to write an essay about myself convincing enough to get me a place. I consider it one of my great achievements that I have now completed four years as an undergraduate external student and hope to complete my degree this year. I have already been asked to consider doing Honours and then to think about a PhD because one of my unit coordinators considers that I am capable of both. This was excellent news for someone who is still considered by certain members of the medical profession to be displaying "learned helplessness".

The situation as an external student has certainly had its challenges. I chose subjects which did not have mandatory attendance at residentials (the university is in country NSW) and consider that when I am actually well enough to get on a plane, I'll be flying to Madrid!

For the first two years I was able to arrange, with medical certificate evidence, to sit examinations at home with a suitably qualified person as my supervisor. However, eventually the strain of examinations saw me going in a ME/CFS 'meltdown' within about 8 minutes of starting a paper, and it took about 16 days to recover. My GP thought that this was not only putting me at a severe disadvantage trying to work under this conditions, but also that it was reckless of me to do this to myself. More negotiations went on, and I am now able to do a special assignment instead of sitting exams. There have been many instances when I have felt totally humiliated having to request special consideration, but one can recover from humiliation!

Some of you may be wondering how I manage to do any studying. The answer is that I pay scrupulous attention to what I eat and to my physical energy output. I have found that the only way to keep my energy levels from zooming between feeling I can take on the world, to ending up in a coma-like sleep for two hours after eating a meal, is to stay away from too much complex carbohydrate. I feel much better on a high-protein diet and this also helps my brain function well. I know the foods which will bring me undone within about 30 minutes of eating them, and as far as I am concerned, I am not interested in doing that to myself. However, I am fully aware that we are all different, and what brings relief to one person will not work for another.

The fact that I live alone means that I can target my energy expenditure on what is beneficial to me. It allows me to focus on myself, and make decisions about what is important and has to be done, and what can be left for another day. However, as with most things in life, there are down-

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Getting sucked in

*By **Lenny DeRoma**.*

For most of us CFS sufferers, we exhaust every avenue in the quest to get better: various doctors, multiple naturopaths, countless diets, and every known form of alternative medicine etc etc. The list goes on. You name it, we've tried it.

It is important to raise awareness that this can become a costly exercise to sufferers and their families. Recent reports have shown that certain medical professionals are entirely focused on the financial side of their business, rather than effectively treating the patient. By advertising their proclaimed miracle cures to distressed patients, they structure a series of irrelevant on-going maintenance appointments, and prescribe excessive amounts of marked up products and supplementation.

To provide an example, the Chiropractors Board of South Australia have received a number of complaints from members of the public about a small percentage of chiropractors using pay in advance contracted treatment plans. The CBSA placed a warning notice to the public in a June copy of The Advertiser regarding these issues.

The offending Chiropractors market their treatment to achieve optimal health and prevent many symptoms of ill health, including all those involved with CFS. Patients that sign up are subjected to a production line style of treatment, and very quickly lose faith in way their medical professional goes about the process. Despite this, they are pressured into commitment, and struggle to receive refunds on the remainder of services not provided.

The CBSA has recently revised its Code of Professional Conduct and Practice to ensure:

- patients are not pressured or coerced into entering such plans;
- patients' rights are respected;
- patients receive services which meet their particular needs;
- patients are able to withdraw from such plans at any time and receive a refund;
- patients have clear and accurate information about their treatment needs and options.

Chiropractors are obliged to comply with these requirements.

Research and doctor's advice suggest that Chiropractic treatment will not cure symptoms of CFS. It is best to find a reputable medical professional that understands CFS, and genuinely cares for the improvement of their patient's health … not their wallet. If you wish to discuss anything further, please feel free to contact Lenny DeRoma on 8358 6693.

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sides to living alone, one of which is that if I am too ill to get out of bed to prepare a meal, I simply don't eat!

Living with ME/CFS is not easy, I would rather be well, however I am not, so I am doing the best I can under extraordinarily difficult circumstances and try only to do things which enrich my life. I realised many years ago that I am a person with ME/CFS I am not ME/CFS. I have spoken to people who can talk about nothing but the illness however this is an excellent way to lose friends and I prefer not to get involved in such limiting conversation.

I have learnt not to use the term 'fatigue' because this invites the response that the other person knows how I feel, because they get tired too! I find it less stressful to simply say I have a post-viral problem. This is immediately accepted and I am not then required to justify my illness or the limitations it places on my life.

Do I want my old life back? The answer is that now, I would not fit into it. The opportunities I have had to broaden myself and enrich my life during the period I have lived with ME/CFS have added extra dimensions to me as a person. I intend to continue in a forward movement, however slow that may be!

Keeping an open mind

*By **Rose Mercer**.*

I believe myself to be reasonably intelligent, educated, prudent. I make an effort to keep myself well informed. Although it took a while for my GP to convince me of the possibility I may have CFS/ME in addition to fibromyalgia (yes, I'm one of those few lucky ones who stumbled on a GP who believes… but that's another story), I continued soldiering on. I've diligently read copious material about FM and CFS/ME and am aware that sometimes alternative medicines cost much but do little. I've never really been too alternative, so I saw myself as reasonably safe from such risks.

Imagine, then, a warm summer's day just before New Year's Eve when one of my best friends phones me urgently with exciting news. His sister-in-law, who also battles with FM and CFS/ME, had found a kinesiologist in Melbourne for a couple of weeks before he returns overseas to teach. One visit and she was just about over all the debilitating yuckness we all know about.

Well, I was about ready for recovery and due to the shortness of time I rushed to make an appointment. Fortunately for me, he fitted me in on New Year's Eve, so off I rushed, optimistic, cheque in hand.

On my arrival, he explained that he would work to balance my energies and that will solve my difficulties. I came with an open mind, so I lay on the bed and heard some rattling and murmuring, but… I was keeping an open mind, right?

There was some tapping on my head some pushing and pulling on my left arm and leg, more murmuring and more rattling and tapping. I kept working hard at keeping my mind open. He placed a bottle of magnesium tablets on my belly, told me I did present him with an interesting challenge, then hooked me up to a machine. This told him I am severely low on magnesium and the most dehydrated person he'd met. Huh? Okay, back to keeping an open mind.

Then there was some curious pushing and pulling on my jaw, followed by placing his hands on my shoulders. "Can you feel the heat?" he asked. "Yes" – remember I'm keeping an open mind here and his hands are warm… therefore I'm feeling it. "This is the deepest type of healing," he assured me. I apologise to those of you who I'm now probably insulting but, just about then, a loud voice in my head yelled "C**P!" But my other voice reminded me to… keep an open mind, he'd fixed my friend's relative.

By now you've got the picture. The final thing the kinesiologist did was stretch my neck several times in various directions, told me I may feel a little off for a couple of days, but my energies are now aligned and I shall be over my CFS/ME and FM. Hooray, I thought, and with my open mind I paid him $70. Being on a disability pension meant I could ill afford it but, once recovered, I could get a job again (I justified).

By that night my back was very sore, so I took some painkillers and went back to bed. Next morning I couldn't even take a deep breath. My husband had to lift me in and out of bed, my whole back and neck being one massive spasm. Luckily I had some Panadeine that barely touched the pain, and diazepam which is one of the strongest antispasmodics about. I did the best I knew how until the public holidays were over then rushed (well, all right, shuffled and groaned) to my GP who showed nothing but kindness and understanding. She fixed me up with a medication regime so I could at least cope and rolled me into the physiotherapist's rooms.

I am recovering slowly, though recently I had a day when I felt so wretched I even lost my sense of humour. I still have pain more than two months later, but can at least take deep breaths and wash/dry myself. I still don't have full use of my left arm with three fingers (middle, ring and little) feeling like they belong to someone else – they certainly seem to get few messages from me.

I've returned to my massage therapist who is brilliant and together we're finally making some headway.

So, dear fellow CFSers/FMers no matter how smart and well informed I am, I too have been taken in and am now paying very dearly for it.

Beware – don't despair. As a good and smart friend told me recently, if professors of medicine can't work it out, how can anybody else?

Please note this is my story, and my story only. I am merely sharing my experience and I am not for one moment suggesting the kinesiologist hurt me on purpose.

Editor's Note: kinesiology *– the study of the mechanics and anatomy of human muscles. (Collins English Dictionary)*

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Von's jigsaw puzzle

*By **Von Dubbeld**.*

It's been two years and three months since I 'came down' with CFS/ME and I must say it's been 'interesting' trying to find my way back 'up' to something a little more normal. As I write this, my husband and I have just begun our biggest jigsaw puzzle yet and I'm struck by how my experience with CFS/ME has been like putting together an enormous jigsaw.

Finding the corner pieces

It took me only four months to be diagnosed. You see, I knew two people who had CFS/ME and I recognised myself in their stories. So, after three months of feeling awful, I called up one such CFS/ME sufferer to see if she might validate my suspicions. This she did, as well as drop by a little pile of books she had collected on the subject.

My reading equipped me with a list of symptoms and triggers that paralleled with mine and, when my regular GP didn't give me the time of day, I found the contact number for CFS/ME Victoria who referred me on to a GP who would.

I was able to shuffle in, plonk into the chair and toss my prepared list of symptoms on to his desk. He read the list and agreed with me, although he told me then and there that officially it wouldn't be CFS/ME for another two months! I thank God for my friends – Dr Charles Shepherd's Living with M.E., CFS/ME Victoria and my new GP – the corner pieces I needed to start my CFS/ME puzzle

Connecting the frame

Having the corner pieces doesn't give you any idea how big a jigsaw puzzle will be – for this you need to construct the edges. Although my swift diagnosis has increased my chances of recovery, it was not enough to stop my downhill spiral for another six months. I had already quit my studies, my part-time job, stopped driving, slept incredible chunks of my day away and was leaving more and more of the care of our toddling son to my husband. But eventually I was bedridden, in terrible pain, in constant dark and quiet, moving and socialising only minimally and needing my husband's support to shower, eat and get to the toilet.

This was a terrifying time. I felt as though my body was giving up on me; I had no way of knowing how far downhill I was going, didn't know what to prepare myself for and was running out of places to turn to for answers and support.

But thankfully things stopped spiralling downwards. I underwent a huge screen of blood tests, producing only two pieces of evidence: my wheat antibodies were up and I was otherwise healthy (yeah, right!). I was referred to an allergy specialist who revealed a host of food and airborne chemical intolerances (e.g. mould, smoke, petrol fumes, perfumes).

The picture emerges

And so, before I knew the overall size of it, I started on the guts of my puzzle. We eliminated lots of problem foods from my diet and all fragrances from our home. We shifted our bedroom out of a room which was mould-prone which also meant I was next to both the living area and the bathroom, letting me feel much more a part of things.

I stopped wearing certain clothes and using my hot water

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bottle and switched to a woollen pillow. I wrote a letter to friends and family, explaining where I was at, what I could cope with socially and asking them to avoid exposing me to things like smoke and perfume if they visited. We couldn't stop the neighbours from mowing or lighting their wood fires, so we bought an air purifier. And, once I was able to get out again, I wore a carbon mask when exposed to traffic fumes. I also completed the counselling I had been receiving for depression (well before the CFS/ME onset), eliminated my sleep disorder (a medication side effect), acquired glasses and had my wisdom teeth removed.

This all took nearly two years, but I now have my framework and much of the picture. It is not complete, but it's enough to give me an idea of how big the puzzle is. And at times it's overwhelmingly huge. I dreaded each visit to the allergy clinic because of what else I may have to eliminate from my life. I feared each and every food challenge, jumping at the slightest sense that I was having a food reaction and that I was actually making myself sick. I still battle with both hope and scepticism as I listen to each new specialist claim that their treatment may bring a cure.

But I now understand my body a lot more; previously unexplained itches, cravings and 'breathing bothers' now make sense. And I've developed patience for my mental limitations, skills for times of emotional struggle and a greater reliance upon God. I have never paid this much attention to my health before!

Some critical connections

In the last few months I have made a number of critical connections between pieces of my CFS/ME jigsaw. Our little family has moved to the rural coast where the milder weather, slower lifestyle and purer air are all bringing a steady improvement to my energy levels.

I have also been receiving Advanced Allergy Elimination (AAE) treatment for both my chemical and food intolerances. I am now able to breathe freely amidst city traffic and smoke and can eat many foods that I have been avoiding for more than a year, including dairy and wheat products.

My energy levels are still poor; I dare not start up any kind of exercise program just yet. I still have one- to three-day spells of the fluey aches, sensory overload and/or memory loss, but I also now have ten- to thirty-minute spells where I joyfully proclaim, "I actually feel healthy right now!" and have to forcefully prevent myself from doing cartwheels!

And just like jigsaw puzzling, there is a fine line between frustration and satisfaction as my CFS/ME puzzle comes together. And forever the question, "Do I have all the pieces to finish this thing?" At least with a jigsaw you can always give up and pack it away, even choose not to begin it in the first place! "Just remember, Von, life is the act of puzzling, not just a puzzle display!"

More information on AAE can be found at: www.aaeclinics.com.au.

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Mission possible

This delightful cartoon was drawn by Margaret (Peggy) Lowell who is one of the many overseas contacts with whom our members correspond.

Peggy lives in River Falls, Wisconsin, USA, has had FM and CFS/ME since 1990 and before that was an administrative secretary. Her cartoons have been published in various magazines.

She now runs a cottage industry making and selling soap – she says she takes things very slowly because of her illness. Peggy has a website: www.splendidsoap.com.

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A lady's companion

*By **Selina O'Brien**.*

Life is good – even if a little quiet. I lounge in bed until about mid-morning and then wander out to the kitchen, have a light breakfast and continue on to the back verandah. This is a lovely spot, sheltered from the wind and warming up as the sun soaks into the old wooden floorboards. It has a pleasant outlook and I can watch the native birds forage for the seed She occasionally puts out for them. A leisurely life with companionship and comfort.

Life is good and not as lonely as it once was. I used to spend most of my time by myself looking after the house and waiting for Her to come home. She was the breadwinner and I was the stay-at-home house mate. And then, one day, about eight years ago that all changed.

I was still in bed – you would have noted that I am not an early riser – when She came back from work and laid down on the bed. She had been spending more and more time resting over the last few months but had never come home this early. I tried to find out what had happened but She could not tell me. She did not know herself. All She could say was that She felt awful and She was so tired.

Eventually, She staggered to the bathroom, with my help, changed Her clothes and returned to bed. Later in the day we went to the kitchen and had some dinner and then She went back to bed. I tried to keep to my normal routine. This went on for several weeks and I grew really worried about Her. But She kept saying that She just had the 'flu and would be better soon. I was troubled, however, and gradually assumed more and more nursing duties. Fortunately, I have a natural aptitude.

Weeks turned into months and my nursing skills proved very useful. I watched Her carefully and became aware of Her needs and offered all the support and empathy I could.

One day She came back from the most recent of a growing number of visits to doctors, this time seemingly relieved instead of upset. She told me that the doctor had said that She had CFS/ME. She was relieved, as was I – a diagnosis of this weirdness we have been living in for the last months: exhausting days; wide-awake nights; dim lights; emotional roller-coasters; pain, recumbent in a chair in front of the TV or on a mat and now the frequently used back verandah – finally a diagnosis. I would start to treat Her and She would get better. If only I had known what a naive belief that was!

Eight years later and things have changed considerably around here. The beloved back verandah has been made over and the trendy metal coffee table and chairs have been bartered for a very comfortable recliner. The microwave has gone. We now have a young girl who comes in occasionally to do some heavy housework under my supervision. There seem to be fewer papers and documents around the place for me to rearrange. Her court shoes, stockings, leather briefcase and suits have been replaced by inexpensive shorts and T-shirts, or track suits when it gets cold. However, I notice that She still tries to colour co-ordinate! Some traits die hard.

Things move more slowly. There are fewer visitors, but I like the ones who come now. They seem more genuine. She has begun to read more lately and the books appear more complicated than the simple magazines She used to read when She first became ill. I enjoyed them, however; I could look at the pictures. I miss that. I also miss the take-away food She used to bring home when She was working late. I like pizza. The food She eats nowadays is much blander. However, She says it helps. I can't see it myself. Fortunately, She still prepares tasty food for me – even if it is only opening up a tin of something.

The stories I could tell: times when She came home full of hope at the prospect of a new treatment; eventual realisation that the promise was not being fulfilled; relapses; small achievements; multitudes of so-called remedies, mainstream and alternative; periods of mental confusion; embarrassed colleagues; well-intentioned friends; attacks on Her self-respect; loss of employment; restructured budgets. So much has happened in the last eight years while, to the outside world, so little appears to have happened.

I am no longer a nurse. Nowadays I am more of a lady's companion and we are both eight years older. I lie on the back verandah and watch Her as She potters around in the small back yard. She is planting some bulbs that She was given in the hope that they will come up in Spring. Really! Bulbs in Queensland in this drought? I ask you! However, She tries to be an optimist. She has forced herself to be.

Life is good here. However, I do not get around as much as I used to and when I pass over I would like to come back and see how She is progressing.

Fortunately, I have a choice as I have nine lives.

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Communicating with free email

*By **Mike Ritter**, Information Technology Infrastructure Coordinator for the ME/CFS Society.*

Did you know the most popular use of the internet is to communicate using electronic mail, also known as email? For most of us email is within reach. You don't need to own a computer yourself. By making use of the local council library and the help of the librarians, the state library facilities or any Internet café (if you can afford an Internet cafe) and an email account provided by more than one source you too can communicate with any one around the world. Did you know they are free and can be accessed anywhere around the world? Can I convince you to open an account?

The ME/CFS Society, your society, is interested in introducing as many members as possible to the free email accounts and Internet access because we send out email to more than 250 people within five minutes, each week telling them of the activities and current information. It started off with the facilities of a dial up Internet access that is commonly found in the home. It was nothing very special but grew into broadband higher capacity access and since its inception has sent approximately 11,000 messages.

It is part of the society's communication strategy that intends to make all of the South Australian ME/CFS community stronger by arming them with information. The South Australian society is fast becoming known as one of the more active societies in Australia. It often happens on Wednesdays when Mike Ritter is in the office.

Some people who are on our email list are not even in the state. They feel it is so important. It's just a great way of communicating and it's much faster than the postal service. Imagine sending mail to Canberra, to the Prime Minister John Howard, and have it arrive within 4 minutes. Similarly delivery to anywhere on the planet is very fast.

How do you get a free account? Firstly there are a few ways of getting an account and the first one is called Yahoo mail.

Yahoo Mail!

Yahoo! Mail gives you 1 Gigabyte of storage including attachments. (http://mail.yahoo.com). It offers you an address book, calendar and notepad. You first have to open a free account and provided that you visit your email account on a regular basis it won't be deactivated. You have to not visit your email account for four months before it becomes deactivated.

Ninemsn Hotmail

Hotmail is located at http://hotmail.com and gives you 25M on setup and 250M after 30 days of use. You can send and receive email up to 10M including attachments and that's a whopping amount in anyone's language. Every time you log in you are taken to you 'Today' page where it gives you the overview of new email you have received.

Your account becomes inactive if you do not sign in for 30 days of first signing up. If the account stays inactive for a further 90 days, the account name is permanently deleted. There's only so much storage their computer can allocate and this is one way of making sure that the space allocated will be used.

Netscape Mail

Netscape offers a nice clean interface that is easy to navigate (http://mail.netscape.com). Storage limit is 250M and can receive and send messages of up to 16 M, including attachments.

If you do not log in for more than 30 consecutive days, your account becomes inactive and your email is deleted, however you can reactivate it by signing in again. Netscape mail is simple, straightforward with no bells or whistles and has no ads. It is easy to use and the help section is ideal for people who are not familiar with email.

What to do next

Once you open an account with one of the above mentioned services, send us some email at sacfs@sacfs.asn.au and tell us that you're a member, include your full name so we might update you email details on our data base. For no charge, we will send you one email packed with juicy information once a week.

You will be the most informed people in the state of South Australia and possibly all of Australia, as our offices receive important information weekly from around the world, interstate and around the state of South Australia. All for free.

Poetry

*By **Pamela Du-Valle** (home.iprimus.com.au/tahu007/Tah's~1/HOME_PAGEx.html). All poems are copyright 2005.*

WHY OH WHY?

(Chronic Fatigue Syndrome & Fibromyalgia)

January 20, 2004

I open my eyes in the morning light
Then wonder if I will be alright
My body aches in spite of a long night sleep
I feel so tired, so exhausted, to even weep

I lay and hope I can get out of bed
Then I sit up and hold my head
Next I try to go to the loo
Hoping I will make it through

Staggering to the kitchen to get my drink
Waiting, leaning on the kitchen sink
Hoping I can make it through another day
Feeling so alone, and what can I say?

Last week I managed to go for a walk
So happy I could and to my dogs did I talk
Then another day out where I had some fun
Making crafts and feeling my day had begun

Then the next four days I could hardly walk
Laying around on my lounge and unable to talk
Not having the energy to do anything.
So listen to radio hoping someone would ring

I lay day after day in pain and so very tired
I wish I had money to have some one hired
To make my meals and clean my house
Helping me and being quiet as a mouse

I would rather have for this illness a cure
So I could be functional in life and very sure
To be able to just jump out of bed into life
Instead of a physical battle from morning to night

I try so hard to be happy and not to cry
Realizing this illness is not terminal like some are and I will not die
Yet as I lay day after day and hour after hour
Trying to get the energy to have my daily shower

I wonder how much longer I can take these dam disease
Will I ever be able to have some peace and feel at ease?
The days I go out and I look made up and good
People say wow you look so well, yet misunderstood?

I have years of this illness to take day after day
Please God please help us find a way
To find a cure for this illness of fatigue and pain
So we can live life and not feel we are going insane

I just want to be able to get up and go out into the world
To be involved in doing something and feeling hopeful and fulfilled
I want to be able to look after myself with ease
To get rid of this bloody disease

So when you see me out and about
Don't make assumptions I am well and shout
I will let you all know when a cure is found
Everyone will know, as I will make sure it gets around

I just ask that those of you in world of this terrible illness
Will take a moment to help those of us who lay in pain and with stillness
To understand we do not want to lie day after day
Not being able to go out into life and play

Please help us find hope and a cure
So we can have life and be sure
That we can have quality in our life each day
So we can help others and have our say
I promise I will help others until I die
Once a cure is found, I smile with a sigh

I will try to be positive and pray for a miracle to be found
So quality of life can help us and make us jump up and bound
That very soon we can know a cure has happened and will help us through
So I can hug you and help others and we no longer feel so misunderstood and blue.

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CHRONIC FATIGUE SYNDROME AND ME

(Dedicated to those who have ME and to those who care for them)

September 1998

As I sit alone day after day
Not being able to have my say
To live with pain and fatigue year after year
Not being able to do the things I hold near and dear

Living alone with myself and ME
Is not how I wanted life to be
Yet this dam disease has no boundary limits
We just have to sometimes grin and bear it

Yet I try to remain positive, helpful and be
To live my life as best as I can to be open and free
When others say why don't you go out for a walk
Inside I say," I wish I could," as well as I bloody well talk

Others who don't have FMS and ME
Don't really understand how *it can be*
Unless you walk in somebody else's shoes
You need to know this isn't the life we wanted to choose

I would love to go out day after day
Instead of resting and having at home to stay
Living alone is not much fun
Trying to do things and get things done

Yet I try to be happy and learn to help myself and be glad
No letting the emotions of life make me resentful or sad
I am thankful for all I can say and do
To myself, be authentic and true

As we come to acknowledge the ME/FMS day 12th of May
May we educate others and have our big say
Letting others know that this is a dam disease
Without a cure right now to give us some ease

May we never give up the fight to educate and tell
So that a cure be found and we can get free from this hell
Reach out to others and make yourself free
By supporting each other and helping us to just be

I will never give up the fight for ME
Hoping one day we can be wellish and free
Help each other, touching each others hand
As together we fight for ME to be learned and to understand

Never give up, take strength in your spirit inside
Never let your inner feelings hide
Let go of the hurt and the pain
By doing this we will not go insane

To be true to ourselves is the best advise I can give
To be happy and free with ME and to live
Days of freedom and loving each day
Not caring about others will say

So take my hand and reach out to all who have ME
Understand each other and one day we will be free
Free from pain and fatigue and all that it brings
We will be able to shout out and sing
With love and joy in our hearts
Being free and loving each other is a great start.

Talking Point – 2005 Issue 3

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

Wisdom from the Rose Pavilion

*By **Sharon Stormer Cherry**.*

The setting for my daughter's 1995 wedding was a beautiful one – the Rose Pavilion at the Royal Botanic Gardens in Melbourne, Australia. Because I was in my second year of CFIDS (CFS/ME), I couldn't be there. It wasn't possible to contemplate the travelling from the US to Australia and we had no idea when I might be well enough for a wedding at home. She and I made arrangements over the phone selecting flowers for her bouquet, talking about music and food and discussing all the details. Then I went back to sleep in my Providence, Rhode Island home. The day came and went without my presence. It was a bad time.

Nine years later in December 2003 my husband and I stood in that rose pavilion on a soft, sunny day with the former bride and groom, now the parents of our three gorgeous grandsons. The little Aussie Americans were running around with bounding energy. It was a glorious experience, poignant and proud.

Our belated but wonderful trip to Australia has caused me to reflect on my long journey with CFIDS. Here's what I have learned in the past eleven years, which may be helpful to fellow travellers.

When I was in my third year of the illness I suffered a great deal over 'not being able to do anything'. I was still living in the context of my past life which was chockful of career, community service and many varied activities. I knew enough, however, to recognise my daughter's wisdom when she said to me from half way around the world, "Mother, you have to stop thinking of yourself as a commodity which isn't being used." For people with CFIDS this thinking is disastrous and I believe fighting this tendency is one of the most powerful ways to treat the disease.

I recently had a conversation with my stepson who commented that Laura Hillenbrand must be an inspiration for her extraordinary accomplishment of writing *Seasbiscuit* while having CFIDS. We had both read her article in the *New Yorker* which powerfully described her experience with the disease. Millions of people have now heard her story and have a greater understanding of CFIDS. I believe so strongly that public awareness of this illness helps everyone who has it. Being sick is awful, but being suspiciously sick and considered deficient in the personal characteristics necessary to overcome the illness is disastrous. The widespread misunderstandings about this illness continue to need to be dispelled. The consequences of its disabling aspects need to be widely recognised. We need to foster treatment – find both the cause and the cure. In the meantime, it needs to be respected and vigorously attacked.

That's a role some CFIDS sufferers like Hillenbrand can take on. But I've learned you don't have to rise like the phoenix, discover a cure for cardiac disease or provide inspiration for others. Whatever your circumstances are, value positively whatever you can do. The main thing *is* to stay in a state of self-harmony. Managing this illness to your benefit is your job and an essential treatment. Have goals that are yours and realistic. Fight despair as symptoms wax and wane. Avoid the darkness of "I was doing so well and here I am, sick again." This is evil mud that crawls in your brain and weighs you down. I confess I can't avoid the evil mud all the time, even now.

I haven't written a book, but I have kept a life going that includes attention to family and special people who are very dear to me. I have moved to a better climate and made friends while trying to keep in touch with cherished people in other places. We have built a house and moved three times. I have watched our children become admirable adults and welcomed their spouses and children into our lives.

Although the eleven-year accumulation of life events isn't as full as it would have been without CFIDS, I can make a long list of ways in which my life is rich. Somewhere along this mysterious road as I look back I can see that I have learned to prioritise. Continuing to learn in different ways

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gives me purpose. My family, friends and community get my best days in ways I can manage. The basket of eleven years is very full.

Adjusting to lost vigour, accepting what is possible with gratitude and altering expectations is such hard work. Sometimes I get scared that living a quieter life than most of my friends means there is something wrong with me; it is my fault somehow. Here is where we all need our own positive reinforcement. After all, for me and perhaps for you, not going out too much, not hiking or biking and not going to events are some of my best techniques in symptom control. Moderation in all things is something I rail about. Anger and sadness for things I cannot do is sometimes crushing. I am not, however, giving in *to* these negative emotions or to this illness.

There is a bit of a battle necessary to keep the fire going. But now I can always remind myself that at Christmas 2003 I travelled for five weeks to Australia and New Zealand. We moved around and saw many unforgettable things. It wasn't easy. I got very tired and I was sick some of the time. But I saw three of my grandchildren every day for more than three weeks. I felt giddy with joy. We didn't know what the trip might do to me, but with the help of my generous husband and family it was wonderful. The trip, combined with a visit from my son and his family before we left, expanded my world with complete happiness. I am so grateful.

For whatever degree of health you have, live from your heart. Give what you can of yourself to what makes you feel good. Learn new things. Rely on your faith. Keep company with people who live a true course. Avoid people who can't handle your real situation. There are books, music, gardens, walks, art and yoga for the days when you can manage such activities.

There is the love of a child or a pet to enjoy or a friend you can write to or call for a long chat. Pour in a lot of that. The point is: do whatever you can. Just that. Don't become the victim of this disease or the life you have because of it. A changed life it certainly is for most of us, but we can all be our own producer and director.

Stimulate yourself with beauty and be glad you know yourself better when you slow down and watch what's happening. Be generous with your thoughts and deeds, especially to yourself and to the people you love most. That's the deal with this illness; kindness is the best medicine and courage is your best friend.

Be glad for those times when someone writes or comments, "Why would anyone invent an illness as bad as this?" That question means that at least one more person recognises that CFIDS takes away careers, independence and enjoyment of everyday and major events. It causes family havoc and pares down life's fire to very low embers. It is painful, expensive and limiting. It fiddles with intelligence and memory and exposes a vulnerability you never imagined you could feel.

Live with imagination for there is hope and possibility and remember that you have much to offer because you are on a different road. Who is to know why this happened or whether the disease will go away, but it's yours to manage as best you can. When the illness turns your world upside down, try with all your might to make it right side up, with help from your point of view.

In New Zealand I saw a map with the Southern Hemisphere as the top of the world – truth from a different perspective.

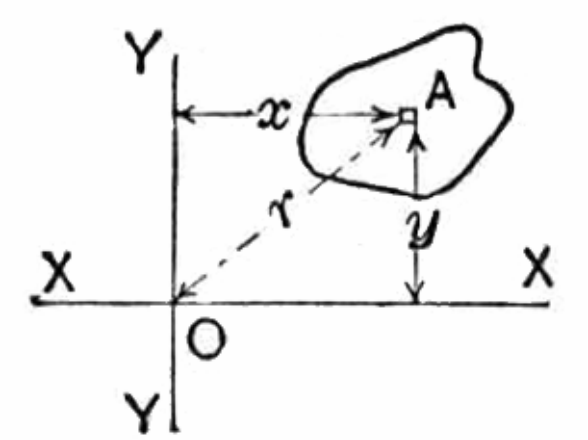
This article reprinted from CFIDS Chronicle*, Spring 2004.*

The role of the HPA axis in perpetuating CFS

Anthony Cleare, MRCPsych, of the Institute of Psychiatry in London, and one of the authors of the HPA study mentioned above, provides his perspective on "HPA axis and the genesis of chronic fatigue syndrome," in the March 2004 issue of TRENDS in Endocrinology and Metabolism.

He argues that current evidence suggests that neuroendocrine changes occur later in the illness, partly in response to certain features of CFS/ME, such as sleep disturbances and physical deconditioning, and there is evidence that, once established, HPA axis changes might play a role in perpetuating the illness. If one accepts this theory, it may be hypothesised that modification of these features would lead to reversal of HPA axis changes.

In assessing the HPA axis, Cleare notes that this physiological mechanism does not exist in isolation and interacts with many body systems. He says most tests of the HPA axis assess only part of the system in isolation, and evaluating the significance of results of such tests needs to be seen



in this context. He proposes that researchers in the future use a multidimensional assessment of CFS/ME components and confounding factors at various stages of the illness.

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Non-invasive test for distinguishing HPA axis function

Researchers at Guys, King and St Thomas School of Medicine in London conducted a non-invasive trial on 56 CFS/ME patients and 35 healthy control subjects. This test, the salivary cortisol response to awakening, has been described as a measure of the capacity of the HPA axis in response to stress. Awakening is a natural physiological stressor.

The testing method has obvious advantages because it uses saliva as the biological sampling material, which is simple, painless and easily obtainable in any setting. The researchers found that the test results correlated closely with those of more invasive tests that have been reported in scientific literature.

Study results showed that CFS/ME patients had a lower cortisol response to awakening, indicative of HPA axis dysfunction.

Several variables were considered in the study population, including comorbid depression vs. no depression, smokers vs. nonsmokers, medications vs. no medications, female vs. male, body mass index and awakening times. Test results were not statistically different between the groups.

Some limitations of the trial included the relatively small size of the study group and the fact that the group consisted of patients who were recruited from a clinic population that may not be representative of the general population. The study was unable to ascertain if HPA axis changes cause CFS/ME, or if they occur as a consequence of the illness. However, it did strengthen the findings of previous studies indicating that changes to the HPA axis may represent one of the biological factors that contribute to ongoing fatigue and CFS/ME symptoms.

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Altered central nervous system signals in CFS/ME

***Vlokek Siemionow**, **Yin Fang**, **Leonard Calabrese**, **Vinod Sahgal**, **Guang H. Yue**.* Altered Central nervous system signal during motor performance in chronic fatigue syndrome*. Clinical Neurophysiology 2004: 115(10):2372-81.*

A study conducted at the Cleveland Clinic, and partially funded by a National Institutes of Health grant, sought to determine whether brain signals of CFS/ME patients for controlling handgrip motor actions are different from those of healthy individuals.

Past motor performance tests have been unable to examine motor output, muscle activation, fatigability and brain signals simultaneously. In this study researchers characterised electroencephalogram-recorded (EEG) brain signals in eight medication-free CFS/ME patients and eight age- and gender-matched healthy controls during handgrip exercises involving moderate to relatively high levels of muscle fatigue by simultaneously recording scalp EEG, surface electromyographic signals and mechanical output (force) signals.

The study concluded that CFS/ME patients displayed a lesser ability to perform the motor tasks, especially those requiring maximum muscle exertion and that caused greater fatigue; the relative power of brain signal frequency while performing the motor tasks was altered in the patients compared to the controls; and the magnitude of the control signal was greater in the patients than in the controls, indicating the necessity for stronger voluntary efforts to perform the same motor tasks.

The results, which suggest that CFS/ME patients are weaker and more easily fatigued than healthy controls, support the theory that CFS/ME involves altered central nervous system signals in controlling voluntary muscle actions. Biological markers for more objective diagnosis of CFS/ME may be found in one or all of the demonstrated abnormalities (reduced motor-performance ability, increased power of the theta frequency and greater voluntary effort needed for motor performance).

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Abnormal immune cells in CFS/ME

***G Kennedy**, **V Spence**, **C Underwood**, **JJF Belch**.* Increased neutrophil apoptosis in chronic fatigue syndrome*. Journal of Clinical Pathology 2004; 57(8): 891-893.*

Researchers from the United Kingdom have completed a study suggesting there is a detectable abnormality in the behaviour of the immune cells in some CFS patients. This underlying behaviour is consistent with an activated inflammatory process.

According to the study, neutrophils, which are short-lived, reactive cells fundamental to an intact immune system, make up 50 to 60 percent of total circulating white blood cells. Amplification of the inflammatory response and the production of cytokines are among the immunilogical consequences that can result from even minor changes to the neutrophil function. The process of apoptosis helps to reduce inflammation by eliminating unwanted or damaged cells, such as accumulated neutrophils, without releasing their toxic contents and increasing the inflammatory response.

The study found that the 47 CFS/ME patients had higher numbers of apoptotic neutrophils, lower numbers of viable neutrophils, increased annexin V binding and increased expression of the death receptor, tumour necrosis factor receptor1, on their neutrophils than the 34 healthy controls. The study also found higher concentrations of active transforming growth factor in the CFS/ME patients.

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Paradoxical Stress Response Test

The ME/CFS Society of NSW had an interesting email from one of its members, and with her permission, we have decided to share some of her correspondence.

K. and several of her adult children suffer from CFS/ME. Recently, she read a book by Andrew Cutler PhD from the USA. He designed a test called the Paradoxical Stress Response Test. We know clearly that there is a problem with the HPA axis in CFS/ME and many symptoms fit in with "adrenal exhaustion" or cortisol deficiency. ACTH and cortisol should rise after exercise. Cutler has found a non-rise or a fall in some patients with CFS/ME.

K. and her family had the following test performed. They had blood samples taken to measure ACTH and cortisol between 8 and 9am. Within 15 minutes of blood being taken they exercised (walked) for half an hour, then rested for 15 minutes, then had blood samples taken again to measure ACTH and cortisol. (This must be done within 30 minutes of cessation of exercise.) In their case there was a pathological drop in both ACTH and cortisol.

Prior to this test, it was supposed that because we might have an essentially normal response in the ACTH stimulation test (low and normal indicating some adrenal fatigue), that there wasn't too much wrong in the HPA axis. A test like this certainly helps "mimic" what is happening clinically more than resting tests.

Certainly the endocrine system needs much more attention. As K. writes, it would be interesting "to measure aldosterone post exercise, given its close relationship to ACTH. Aldosterone regulates sodium and potassium in the body" and blood pressure – of significance because of neurally-mediated hypotension or POTS.

If anyone can get their lab to do this test, we would be most interested in gathering further results and publishing them in *Talking Point* and/or in the medical literature.

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Cognitive performance slow in CFS/ME

De Lange FP, Kalkman JS, Bleijenberg G, Hagoort P, Vd Werf SP, Van Der Meer JW, Toni I. Neural correlates of the chronic fatigue syndrome – an fMRI study. *Brain. 2004 July 7.*

A recent study suggests a new explanation for the memory and concentration problems common in CFS/ME. Prior research has pinned the blame on general problems with complex information processing, but the new research suggests that the cause may be a specific impairment in the brain's ability to plan a response to stimuli.

The researchers used functional MRI (fMRI) to examine brain activity and cognitive performance in 16 nondepressed CFS/ME patients and 16 matched healthy controls. While both groups had similar rates of errors on timed visual and motor imagery tasks, the CFS/ME patients were considerably slower to respond and had more missed responses. The CFS/ME patients used visual processes on nonvisual tasks to a greater degree than healthy controls, suggesting that the brain was trying to compensate for problems in motor performance. Finally, when they made errors, the CFS/ME group was nonresponsive in the part of the brain responsible for assessing the accuracy of emotional/motivational information and regulation of emotional responses.

The researchers propose that impaired motor planning could also be responsible for CFS/ME patients' low levels of physical activity, since this area is also responsible for the brain's ability to plan movement. They also suggest that disturbances in the motivational area of the brain a central aspect of the CFS pathophysiology.

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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.

ME & You, ME/CFS Society of NSW Inc., Suite 204, 10 Help Street Chatswood NSW 2067.
Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.
Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.
ChaMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.
The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.
Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.

Talking Point – 2005 Issue 3

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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 McFaull (Dietician) 8535 6800.

Please note that meeting times are subject to change.

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

8410 8930 or 1800 136 626

Support Contacts

SA Support Groups

Adelaide City	Office	8410 8929
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

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

Country Support Contacts

Auburn	Kay Hoskin	8849 2143
Barossa Valley	Dennis	8563 2976
Mt. Gambier	Di Lock	8725 8398 or 0438 358 398 (mobile)
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Kathy Southeren	8586 3513
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yorke Peninsula (central)	Caroline	88374335
Yorke Peninsula (northern)	David Shepherd	8862 1665
Yunta	Gloria	8650 5938

Youth Support: SAYME

South Australian Youth with ME/CFS

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

Notes

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

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