Talking Point

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

2008 Issue 3

Your Society

forget-ME-not

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ME/CFS Society (SA) Inc.

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

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

Contact details

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

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

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

Membership

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

New Members (cheaper rates apply for renewal):

Single membership..... $38
Single (concession)..... $25
Family..... $45
Family (concession) $38
Overseas – as above plus .. $10

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

Notice to Vendors

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

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

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

See notice regarding Advertising on page 3.

Management Committee – 2008/2009

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

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

Talking Point

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Editor: Peter Scott (pmrscott@tpg.com.au).
Assistant Editor: Judy Rhodes (dustyrhodes@dodo.com.au).

Talking Point subscriptions

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Overseas (Asia-Pacific)..... $32
Overseas (Rest of World) . $38

Donations

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

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

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Disclaimer

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

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

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

Always consult your medical practitioners before commencing any new treatments.

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President's report

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

Greetings once again.

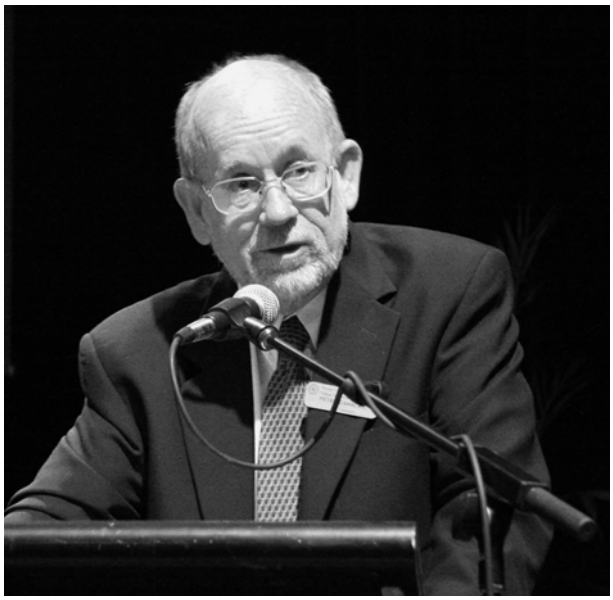
The Society has had a quieter time during 2008 than in recent years. The third quarter has continued this trend.

1. New energies

Quite a few of the Committee's members and other key volunteers have been absorbed in health, family, work and other issues. Inevitably this has meant that we've jogged along doing what we could. But it seems one of those cosmic laws that, as one set of leaders sag in their energy levels, new people come forward with fresh energy.

I can think of two such cases in particular this year:

- Lorenzo Pizza has not only continued his great job of organising our seminar series for the second year in a row (and he's on the case for 2009 already) but he's also recently taken on the role of membership officer. We've felt plagued by difficulties with our membership system for some time. You don't need to know the gory details! Suffice it to say that Lorenzo has been going into the office for hours at a time processing renewals, sorting out the database, dealing with enquiries and complaints and so on. His mandate is to be not just an administrator but also a members' advocate. That is, it's his role to look at what we do and what we offer from your perspective and to keep us focused on ensuring that membership offers real advantages over non-membership. The committee is heartily grateful to Lorenzo for taking on this role.
- Simon and Raelene Jackson have energetically shaped the first year of a new support group in the Riverland. They've held a number of meetings and have organised a stand at the September Riverland Field Days. It's a real lift to have someone on the phone or email asking for banners, brochures or other support and swiftly sending in photos of the latest meeting. Thanks to you both, Simon and Raelene.



Peter Cahalan

2. Health practitioners list

Jayne Warwick has continued to build our database of health professionals of all kinds. Like the membership issue, this was one of those areas which had been bothering us for some time. So many people contact us regularly asking for advice on good, or at least sympathetic, practitioners to whom to turn. Our existing database had gone badly out of date. The new one is not complete – because it never can be. Practitioners retire, get too busy or come on line. So it's a continuing task and one which we're grateful to Jayne for sticking at.

We've had several discussions about how to manage the database. Some of us have argued for posting it on the website and making it freely available. On balance we've decided to make it available only to key volunteers who are most likely to be fielding the questions. We haven't set our minds against a more open policy, but there are some delicacies involved. For instance, what if we were to remove a name from the list after more than one member had complained about a practitioner and that person were to discover that fact? We just don't want to get embroiled in health politics in that and other ways. Furthermore, we felt that we can gain richer and more informative interactions with members and enquirers if they have to come through us to access the information. Volunteers who've worked with the database can attest that they often pick up really useful information about who's doing what out there when people phone in for advice.

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Anyway, we're not setting that policy in stone. But we are sticking with it for the next year and we'll see how it goes. Meanwhile, if you have recommendations about good doctors, physios, naturopaths or any kind of practitioner, do let us know.

3. National politics

Peter Mitchell and I have been absorbed in a range of work for the ME/CFS Association of Australia. The board meets in Canberra at the end of November – it's only the second ever such meeting, as we traditionally meet via teleconferences. President Paul Leverenz has been setting a fast pace and we've had monthly board teleconferences. Peter and I are on a working group on a national website and one way or another it is quite busy work.

Your committee resolved at its September meeting to communicate to the board that above all it seeks from the board the development of a national political agenda. We've actually been fairly successful here in encouraging individual members to get involved in lobbying politicians. But it would be much easier for more people to go political if only they felt clearer about what to ask for. So we're hoping that the two-day meeting will shape a list of proposals which we can all harass the political establishment about.

As I write I'm very aware that two related national policy reviews are being undertaken. One is for the creation of a National Disability Strategy. The other is the review of pensions. Both of these have huge practical relevance to many of us in the case of pensions and all of us in the case of the Strategy. I urge you to write in to both reviews and/or attend public consultative meetings.

4. Multiple Chemical Sensitivity

The State reference group will have met again by the time you read this – after another rather long hiatus. I wax and wane in my optimism about it, although overall I've been pleasantly surprised that a number of policies and draft policies have been shaped.

I also expect to represent the Society at a national consultative meeting in Canberra some time in October. It's being convened by the Office of Chemical Safety which several years ago commissioned a review of issues relating to MCS persons. There has been the sound of dragging feet on this one and the OCS has finally had to respond to sustained pressure from 'consumers'. (Don't you love this way of describing people affected by health conditions?!) Peter Evans also will attend.

That's it for this time round. I extend the best wishes of the Society to you.

Peter Cahalan ❀

Society meetings 2008

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

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

Date: **Saturday 4 October 2008**
Speaker: *Katie Behlau, naturopath*

Date: **Saturday 8 November 2008**
Speaker: *(speaker to be confirmed)*
Topic: ***Annual General Meeting***

Riverland Support Group meeting

The Riverland CFS Support Group held their regular 6 week meeting on the 1st of August 2008 at the Riverland Resource centre in Berri. Eleven people attended – two of these were new members.

A group discussion took place with members chatting about their medication and what works for them.

Brenda McHugh Wilkinson, a grief councilor with Riverland Regional Community Health Service, was our well received guest speaker.

Brenda spoke on what grief reactions we have when dealing with any illness, including ME/CFS, and how to try and cope; she said that each person reacts differently to loss and grief. Our members put forward their feelings of what grief meant to them – these included disbelief, anger, helplessness, a feeling of loss of self worth and other emotions.

Brenda also spoke on ways of taking 'care of yourself', expressing your feelings by writing or through art, or by poetry and joining a support group like ours. Our members all agreed that they could relate to this.

Thanks to Brenda for an informative and thought provoking session.

It was decided by all members present to have a Mental Health Support person attend and speak to the group in our final meeting for the year on Friday 5th of December.

Raelene Jackson (Support Group coordinator) ❀

Brenda McHugh Wilkinson

Riverland Field Days

Riverland Field Days: 17 & 18 September 2008

The Riverland ME/CFS support group was given a big hand with financial support to attend the 2008 Riverland Field Days.

Held each year at a permanent site just out of Barmera (230kms east of Adelaide) it is one of the larger country agriculture shows in the state.

It is an agricultural and horticultural expo and is broadly based with many exhibits of interest to the whole community.

Each year all sorts of exhibitors flock to the site for two days to promote their business, be it cars, tractors, trucks or harvesters.

However these are but a few that attend, all sorts are found at the show from allied health, to rain water tanks, food stalls to colleges, crafts, home improvements, personal care and financial institutions and of course it is fully catered.

Our financial sponsor who wishes to remain anonymous saved us a few hundred dollars in site fees for an under cover site in the permanent pavilion.

We decided on the permanent pavilion because there is always one of the two days that it either rains or is very windy. So a big thank you to our sponsors as it has helped to get the word out about ME/CFS.

Even though we weren't overly busy the response was positive as was the feedback.

We were approached by Carers S.A. on the Thursday and asked if they could take some of our pamphlets back to their site, they also wanted us to keep them informed as to our meetings and any other relevant info. Along the way we picked up a couple of new group members.

The idea for the Field Days came from David Shepherd from the Northern Yorke Peninsula & Clare Valley ME/CFS Support Groups

We would like to thank, Cheryl Martin, Liz and Corrado Angeletti for helping us on the two days so we could have a bit of a look around the Field Days.

Also thanks to the Society and Lorenzo Pizza for organising to make available the Society banner. Thank you one and all.

Raelene & Simon Jackson
Riverland ME/CFS Support Group ❀

Letters to the Editor

Multiple Chemical Sensitivity & the hospital environment: a recent experience

My wife suffers from Chronic Fatigue and Multiple Chemical Sensitivity and, after delaying the inevitable for about four years, recently needed to be hospitalised for surgery.

Fortunately, she was able to restrict her admission to just one night, but still we were filled with dread because of previous bad experiences that arose simply visiting a relative in hospital.

On those occasions the chemical laden air within the wards had made her ill and we had been forced to leave after about twenty minutes.

Mindful of her intolerance, we set up a meeting with a hospital representative two weeks before the scheduled admission to discuss what measures could be adopted to minimise the anticipated effects.

We requested a number of strategies, all of which were received with an open mind and which subsequently were implemented for us, resulting in a safe overnight stay more comfortable than my wife could have hoped for.

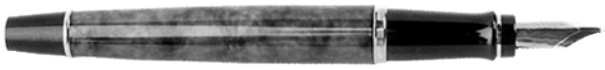
Among the specific actions implemented were the following:

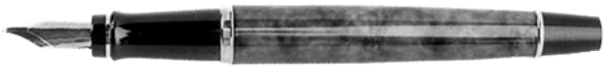
- Private room with ensuite, located as far away as possible from ward reception and work rooms generating cleaning smells (disinfectants, etc).
- Kept the room door closed as much as possible.
- Cleaned the room with clean water only – no chemicals.
- Supplied our own bed linen and soap.
- The catering manager personally prepared meals after consulting with my wife to ensure she could tolerate all food presented.
- One ward nurse was allocated as my wife's dedicated carer after surgery and she made a point of not wearing any perfumed personal products.

The hospital is The North-Eastern Community Hospital on Lower NE Road, Campbelltown SA and we think their efforts should be acknowledged.

We are very grateful for their efforts.

Colin Northey
June 2008





Parainfluenza-5 virus

Dear Talking Point,

When the National Forum announced the involvement of the parainfluenza-5 virus in CFS/ME, it confirmed as an animal-mutated virus it is heavily implicated in brain dysfunction. The supporting publicity material with Dr Leonard Horowitz's book published some time ago, Emerging Viruses: Ebola – Nature, Accident or Intentional?, mentioned that when animal cells are transferred from one species to another it creates brain dysfunction, a topic explored in great depth in Dr Jay Goldstein's books published by Hanworth Medical Press.

The virus previously known as the simian-5 virus is linked to a form of epilepsy and MS (the lesions of the brains of patients with CFS/ME are similar to that of MS). This virus has jumped species and when a researcher moved the virus around on different parts of the brain on the mice used in research it created the three conditions.

The National Forum's web site can be located by googling "National CFIDS Foundation" (without the quotes) and clicking on "NCF Medical Discoveries". In addition, if you search for "Goldstein Sherkey Betrayal By The Brain" (without the quotes) in Google, the first result is a doctor's view.

You can also google "Dr Jay Goldstein Kathy Collett" (without the quotes) for articles I have previously written.

Kathy Collett
[address supplied]

ME/CFS Society (SA) Inc

Annual General Meeting

Saturday 8 November 2008 at 1pm

at the

Disability Information Resource Centre, 195 Gilles St, Adelaide.

Guest speaker:

Dr Richard Burnet

Dr Burnet is an endocrinologist at the Royal Adelaide Hospital. He has been researching ME/CFS for many years and is one of the Society's key medical supporters in South Australia.

Dr Burnet will report on his latest research into ME/CFS. We have not featured research-focused presentations much in our seminar series in recent years, so this is a great opportunity to catch up with what's going on.

This is a smoke- and fragrance-free event

Out of respect for people with multiple chemical sensitivity please avoid wearing strong personal fragrances such as perfume, after-shave and essential oils when attending this meeting.

International ME/CFS Conference Report

*A report from the International Conference on ME/CFS Biomedical Research, Cambridge, England 6 May 2008, by **Dr Ros Vallings** MNZM, MB BS.*

Introduction

On 6th May 2008 I attended the International conference on ME/CFS Biomedical Research at Hinxton, Cambridge, UK. 130 people attended and cutting edge research was presented from around the globe.

A review of the clinical aspects of ME/CFS

The first presentation was given by Professor Nancy Klimas (Florida, USA). She explained how we needed to get away from clinical case definitions towards biomedical sub-grouping and described the Canadian definition as more clinical by including autonomic, neuroendocrine and immune dysfunction. She feels the most important symptom of all is post–exertional relapse and stressed the importance now of having a paediatric case definition. Children can have a diagnosis made after three months of illness.

Various other symptoms are included, such as rhythm disturbances of sleep as well as non-restoration, more widespread and migratory pain and the inclusion of two or more of a neuroendocrine or immunological nature.

A number of overlapping conditions such as Fibromyalgia, Gulf War Syndrome and Multiple Chemical Sensitivity were also mentioned. Epidemiologically: this illness in the USA has as incidence of 522 per 100,000 females and 291 per 100,000 males. This leads to a 50% reduction in household income, and a $9 billion US loss in productivity. There are probably 1,000,000 sufferers in the USA of an illness, which can be as severe as congestive heart failure. In the UK, 44% of physicians lack confidence in making the diagnosis and those that do make the diagnosis more usually have had a family member with the illness. The pathogenesis involves a combination of genetic susceptibility coupled with a trigger event and /or infection, then mediators (immune, endocrine, neuroendocrine, psychological) lead to persistence of illness.

In this illness there is an immune cascade leading to chronic immune activation, with a shift from Th1 to Th2 dominance. The immune activation leads to functional defects. The level of severity depends on the pro–inflammatory cytokines. Viral persistence and reactivation was discussed with references to studies on HHV6, Enterovirus and EBV. In HHV6 studies, 79% of patients were found to have HHV6 activity (compared to 22 – 54% of controls) and 28 out of 144 were found to have HHV6 in the spinal fluid and 7 out of 35 in another group. Clearing the spinal fluid led to great improvement in 5 out of 8 people, but the antiviral agents used are potent and toxic. Enterovirus was found in 13% of muscle biopsies and in 60% of gastric biopsies in those with gastric symptoms.

Endocrinologically, there is reduced cortisol output due to various mechanisms, such as heightened negative feedback, heightened receptor function and impaired ACTH and cortisol responses to challenge. There is a possibility of DHEA abnormality.

There are many symptoms of autonomic dysfunction. These occur as a result of parasympathetic dysfunction with sympathetic over activation. Neurally mediated hypotension, orthostatic hypotension, slow gastric emptying, heart rate variability, haemodynamic instability (shown on tilt table), decline in cognitive function after treadmill, abnormal perfusion in cerebellum, reduced perfusion in mid cerebral region, and a drop in BP causing relapse are among the many effects.

In the central nervous system, tryptophan abnormalities in the cerebrospinal fluid result from abnormalities in levels of serotonin and its precursors. PET scans have shown that 5HTP binding is reduced. There is pronounced reduction of serotonic transporters in the anterior cingulate. Reduction of grey matter in the more severely affected is evident. There is utilisation of more extensive regions of the brain to process tasks than normal. Sleep is usually abnormal with intrusion of alpha waves, altered hormonal releases and lowering of NK cell count. There is also a decrease in exercise induced pain threshold. Gene studies are very exciting. 35 genes have been differentially expressed, which relate to T cell activation, and neuronal and mitochondrial regulatory abnormalities.

Up to 6 subgroups have been identified. ME / CFS is a complex illness and the subgroups must be further defined.

Many treatments were discussed

Immunomodulatory:
- Ampligen.
- Isoprinosine, thalidomide, AntiTNFa, monoclonal antibodies.
- Autologous lymphocyte study.

Antimicrobial:
- Antivirals such as foscanet, valganciclovir.

Endocrine:
- Florinef (failed when used alone)
- Erythropoietin (very modest benefit).

Autonomic:
- Beta-blockers to regulate the pump.
- HPA drugs (not particularly useful).

Sleep:
- Sleep routine.
- Tricyclics.
- Sodium oxybate (must have sleep study to eliminate apnoea).
- Pregabilin.
- Melatonin (mixed results).

Cell Metabolism

CNS directed medication

Nutrition:
- CoQ10 alpha lipoic acid, NADH etc

Reconditioning

Short 5-minute spells of upright exercise, followed by 5 minutes of flat flexibility work can be more manageable. Exercises to increase flexibility and muscle bulk should be encouraged. Studies of gene expression using micro-array techniques will help direct us to which drugs will be suitable for which sub group, with the eventual aim being a preventative approach. Quality of life is improved with multidisciplinary approach and compassionate care.

Intracellular immune dysfunction in ME/CFS

Dr Jo Nijs (Brussels) gave an overview of intracellular immune dysfunction in ME/CFS. He described dysregulation of intracellular immunity and upregulation of the RNaseL pathway (due to proteolytic cleavage of native RNaseL), and immune cell apoptosis. The virus in a cell leads to release of interferon, with change in the activity of the host cell, affecting the enzymes, (PKR, RNaseL). Apoptotic neutrophils are increased, leading to cell suicide, which is overactive in ME/CFS.

TNF alpha-receptors are increased, RNaseL cleavage is equivalent to caspase activity and there is G – actin cleavage. There is interplay between NK cells and infections. Conflicting data of the functioning of the PKR enzyme in the blood cells may reflect stages of the illness or distinct subgroups. The clinical importance of this is a reduction in quality of life and a reduction in exercise capacity, both of which are affected by intracellular activity. Elastase over-activity may be an important consideration and neutrophil elastase inhibitors may prove useful, as elastase may only be important and needed when the body is fighting massive infection.

Drug trials are needed in combination with exercise intervention, as drugs may diminish the side effects of exercise intervention leading to improved effectiveness. Drugs to fight exercise-induced oxidative stress and subsequent post-exertional malaise may prove useful. Drugs targeting the 2.5A synthetase / RNaseL pathway in combination with careful exercise intervention may also be of future interest.

The development of clinical services for those with ME/CFS

Dr Gregor Purdie (Scotland) as a GP advisor to the UK NHS looked at the development of clinical services for those with ME/CFS. He stressed that knowledge comes from patient contact. There has been some positive progress this year. There is still great need for clinical services, education and training. Re-

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search should be supported and translated into clinical tools. We need to ask ourselves who is to do this, when and how?

Most of the work is done by voluntary organiations. Work needs to be done at all levels: local, regional, national and international. The personnel involved should include a multidisciplinary approach with specialist consults, GPs, nurses, physios, OTs etc. All have a niche role and the eventual aim should be for specialist Centres of Excellence.

Patient-centred research and clinical aspects

Dr Byron Hyde (Ottawa, Canada) looked at various patient-centred research and clinical aspects and presented his view that CFS and ME are not the same thing. He described ME as resulting from chronic brain injury, usually as a result of infection, often during an epidemic. The injury is measurable and most often in the limbic area. He demonstrated with a number of brain scans.

The long viral phase of herpes and EBV has been studied and he feels these are not likely to be the primary cause of the illness. Echoviruses maybe more important. Echoviruses have been recovered in some patients up to three years after falling ill. In another study in 2008 he found that hepatitis B vaccination led to 22% of cases of ME. Mention was made of the high incidence of enteroviruses in China now.

In another study, he found that mercury, lead, zinc, copper and aluminium were elevated in 11 out of 52 patients. Generally patients suffered poor sleep, which led to poor short-term memory and inadequate production of human growth hormone. Only 1 out of 53 of patients had normal sleep pattern with resultant normal brain scan. Brain oxygen saturation was generally low at 88% or less. He concluded with a case study of an Olympic athlete who seemed to have classical ME, and was eventually found to have a tumour in the atrium of the heart. He used this as an illustration of the importance of thorough investigation.

Treatments targeting the methylation cycle

Dr Derek Englander (New York) looked at treatments targeting the methylation cycle. The methylation cycle is complex and part of general metabolism.

He presented a most complicated slide to demonstrate to us just how complex is the biochemistry associated with this illness. His team has developed a protocol over the past 15 years after treating 800 patients, 65% of whom have benefited. Initially weekly IM injections of Kutapressin were used. It was subsequently theorised that there was a defect in the methylation cycle, which maybe due to genome defect. A wider protocol has now been developed using glutathione, B vitamins, zinc, magnesium, and a number of amino acids.

The care pathways adopted in clinical practice

Dr Gavin Spickett (Newcastle upon Tyne) discussed the care pathways adopted in clinical practice in the North of England. The diagnosis is one of exclusion; looking at other causes of fatigue, such as infection, connective tissue diseases, and auto-immune disease, sleep problems and organic brain disease. There is overlap with IBS, POTS, FM, overtraining etc.

Everything is being stored on a database. There is encouragement to refer children early (at 6 weeks). Pre-screening blood tests are recommended to eliminate other causes, such as coeliac disease, which has been found to be common. Despite this, 17% patients are still found to have other conditions. Older, retired patients need more intensive investigation looking for other conditions.

To increase awareness a number of GP training days were set up and there was no uptake initially, but now these are heavily subscribed. Of note, 57% of patients relapsed with graded exercise.

Clinical studies focusing on autonomic issues

Dr Julia Newton (Newcastle) discussed clinical studies focusing on autonomic issues, with particular refer-

ence to heart rate and BP regulation. Autonomic dysfunction is strongly associated with fatigue in many ME/CFS patients.

There is a problem with synchronicity between the sympathetic and parasympathetic systems. 90% ME/CFS patients have Orthostatic Intolerance (OI). 52% patients experience a drop in BP on tilt table. MRI scans have shown that there is impaired proton removal from muscle during exercise in patients, so it is hypothesised that the fatigue arises due to impaired pH run-off from muscle during exercise, which may be influenced by the autonomic dysfunction.

Research is now focusing on how to help patients reset the parasympathetic / sympathetic balance.

A centre of excellence

Annette Whittemore, (Nevada, USA) who is president of the Whittemore – Petersen Institute for Neuro-immune Disease was unable to be present, so her address was given on her behalf by Dr Dan Petersen (Nevada, USA). This exciting development is to be a centre of excellence comprising 80,000sq ft at a cost of $US 78 million. It will be a comprehensive patient-friendly research facility devoted to patients with Neuro-immune Disease such as ME/CFS, FM, atypical MS and other similar presenting illness. Location is within the Centre for Molecular medicine, University of Nevada.

Research is already being established and currently looking for bio-immune markers which could lead to more effective treatments, and also looking at those ME/CFS patients who go on to develop cancer.

Current research taking place in Nevada

Dr Dan Petersen then gave an overview of the current research taking place in Nevada. He began by stating that in the US 10% of the patients consume 70% of the healthcare dollars, and chronic disease diagnosis and management accounts for a significant proportion.

Patient-centred, cost effective approaches are being designed and implemented. Oxidative impairment is evident in ME/CFS and there is a need to demonstrate this to insurers. Exercise tolerance testing with expired gas exchange is widely recommended, but paired tests are needed as performance is significantly decreased on the second test over a two day interval. Other research to be furthered will be identifying subsets, looking at the role of viruses in the development of neoplasia in chronically affected patients, looking at bone marrow as a reservoir for HHV6, and collaborative studies utilising viral array to identify potential patients who may be amenable to specific antiviral therapy will be undertaken. One study presented analysed cytokines and chemokines in a controlled trial and found chemokines dramatically high with Th1 / Th2 dysregulation.

Vascular and inflammatory aspects of ME/CFS

Vascular and inflammatory aspects of ME/CFS were presented by Dr Faisel Khan (Dundee).

There is increasing evidence that ME/CFS patients have associated cardiovascular symptoms. Endothelial function is an important regulator of vascular function and a well-established marker of cardiovascular events. ME/CFS patients have significantly enhanced vascular responses to acetylcholine (Ach) compared with control subjects. This may be a consequence of free radical attack on acetylcholinesterase expression on the vascular endothelium, giving rise to a reduced expression of the enzyme, resulting in the prolongation of the ACh response.

Arterial stiffness is also significantly elevated in ME/CFS compared to controls, and this is associated with elevation of CPR, pointing to low-grade inflammation and oxidative stress.

All this may result in unfavourable haemodynamics and increased risks of cardiovascular events in ME/CFS patients.

Increased arterial stiffness and inflammation may be regulated by levels of Vitamin D. Other risk fac-

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tors for ME/CFS patients may be a tendency to lower HDL cholesterol and higher LDL. Isoprostane is a maker for oxidative stress, and in ME/CFS this goes up with exercise intolerance. Oxidative stress can lead to endothelial damage.

A review of molecular studies in ME/CFS

Dr John Kerr (London) gave a review of the molecular studies in ME/CFS at his centre. 88 genes have been identified of which only 3 were down-regulated. The others were all up-regulated. The highly represented functions were haematological disease and function, immunological disease and function, cancer, cell death, immune response and infection. 13 transcription factors were over-represented. Data from ME/CFS patients revealed 7 subtypes with distinct differences in SF – 36 scores, clinical phenotypes and severity. 12 genes have been linked with EBV. It is now important to determine what these subtypes represent, as they appear to be biologically meaningful.

Possibilities for treatment with 5 potential drugs to target these genes should provide rationale for treatment. The study needs to be confirmed and replicated, and specificity of the genes needs to be tested. Eventual diagnostic test sub typing should be possible.

The Swedish Twin registry – looking for a biomarker

Professor Birgitta Evengard presented her team's work with the Swedish Twin registry looking for biomarker.

31.406 individual twins, comprising 12,407 complete pairs, responded to a telephone interview and 1 in 5 claimed to be tired. 2.36% had fatigue with symptoms suggestive of ME/CFS of at least 6 months duration.

33 pairs of monozygotic twins discordant for ME/CFS were identified and 1,779 individual twins were identified for ongoing study. There were no sex differences in symptoms, but the females had more severe symptoms.

There was no association with age, education or occupation. The mean number of symptoms was 2.4. The commonest symptoms were sleep difficulties, cognitive impairment, myalgia and joint pain. Estrogens may be the key regulator. It is a regulator of growth and differentiation in the reproductive tract, breasts, CNS and skeletal system.

There was also HPA axis disturbance, immune dysfunction (with abnormal cytokine dynamics), abnormal blood / brain communication and a background of infection. 75% improved with valganciclovir. Genes were identified in 20 of the women and 2 more viruses were detected (orphan viruses).

Q fever, Rickettsia and ME/CFS

Q fever, Rickettsia and ME/CFS was the topic discussed by Dr Stephan Graves (NSW, Australia).

Rickettsia is gram-negative bacteria transmitted by arthropod vector. It was named after Ricketts, the microbiologist, and is nothing to do with rickets due to malnutrition.

Patients respond in different ways:

- Death.
- Infection, then recovery
- Autoimmune illness
- ME/CFS
- (10% – 20%) illness due to Rickettsia honei and Q fever caused by Coxiella burnetii both has similar sequelae.

ME/CFS is largely a post-infectious condition, and Q fever and Rickettsia can be precipitants. The microbial antigen may persist. These bacteria have an intracellular lifestyle.

Post Q fever, the microbial antigen persists in the bone marrow. The microbe C. burnetii is not viable because a cell-mediated response had killed it, but it may persist as undegraded cells with some DNA. The antigen is only found in the more virulent form.

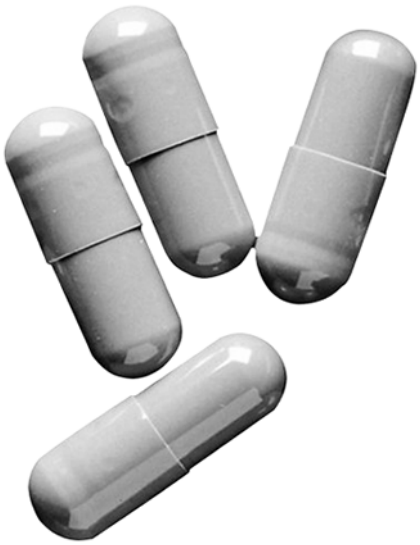
The persistence of the microbial antigen appears to cause dysregulation of the cytokine cascade leading to ongoing fatigue in a genetically predisposed subpopulation. The relevance of this could mean the Q fever vaccination could have a positive impact on the incidence of ME/CFS in Australia. ❀

Reprinted with permission from Emerge*, Spring 2008.*

What a Pain!

*By **Alan Spanos**, MD, MA.*

Pain figures in no less than five of the nine "official" criteria for chronic fatigue syndrome used in the United States. This is no news to most CFS sufferers, for many of whom pain is at least as important as fatigue in limiting what they can do. But the spectrum of pain in CFS is very wide. A few people with CFS (PWCs) have little or no pain, only exhaustion and difficulty concentrating. On the other end of the spectrum are the unfortunate ones who, in addition to these symptoms, have pain everywhere, all the time. Despite this, pain has been largely neglected in research on CFS and is routinely undertreated by doctors who treat PWCs. This is a pity because pain can usually be reduced substantially with proper treatment. Sometimes the reduction is sufficient to allow a previously disabled person to return to work and to active participation in family life.



The mechanism of pain in chronic fatigue syndrome is thought to be a disorder in the nervous system, rather than in the organs or tissues where the pain is felt. So pain in a muscle doesn't mean there's something wrong with the muscle; the problem is with the nerves between the muscle and the brain, and in the brain itself. But this emphatically does not mean that the pain is "all in the mind!" Rather, it's a disorder of the information transmission through the nerves and spinal cord to the brain, causing information that would normally result in a nonpainful sensation (such as the movement of a joint, the pressure of clothing or the sensation of a full bladder) to be "processed" or "amplified" and provoke a feeling of pain. The pathways through which the information travels have been changed or "sensitized," like a stereo system that has become prone to producing feedback noises instead of just reproducing the music as it ought to.

This pain mechanism is referred to by scientists as a disorder of pain amplification, as pain processing or as central sensitization. Since this represents a change (plasticity) in the way the nervous system works, it is also referred to as a kind of neuroplasticity. These terms are confusing at first, but when readers come across them, they should just remember that they all refer roughly to the same process: messages traveling in nerves to the brain have become "turned up" so they cause pain, instead of mild nonpainful sensations.

The underlying cause of this process is unknown. The current favorite theory is that proinflammatory cytokines, which are chemicals released in the body in response to infections, become excessive and uncontrolled in CFS and irritate cells in the nervous system, producing pain amplification and other CFS symptoms. In favor of this theory is the fact that such chemicals, when injected intravenously into fit volunteers, do produce widespread pain and exhaustion, similar to illnesses like influenza – and CFS. However, this is still just a theory. So far it has few implications for treatment, but this may change in the next few years if specific drugs can be developed to inhibit damage by cytokines. Whatever the mechanism is for the pain, it must be quite variable from one person to another to account for the very divergent responses to particular pain medications from one PWC to another.

Thankfully, treatment of pain need not wait upon such research, since it depends not on theories about the underlying cause of the pain, but on the observation that a wide variety of pain treatments each help a few patients with CFS, but no single one of them helps a majority. The conclusion is obvious: if you want to treat pain in CFS, you have to be prepared to try a number of different remedies in order to arrive at one that might work for you. We have no reliable guides to match treatments with particular patients, or even with particular kinds of pain. It makes sense to try each of the main contenders, with as brief a trial as is necessary to establish if the treatment helps or not.

This is rarely done. Most doctors try one or two treatments, then give up if neither worked, and patients understandably quickly get discouraged when trying one thing after another.

Another problem, which enormously hinders the

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process of finding out what helps and what doesn't, is the practice of having a patient take a drug (or try a treatment such as acupuncture or biofeedback) for far too long as a trial period, even when it could – and should – have been assessed much more quickly. For instance, many pain medications have their full effect within two days, so the trial period is exactly that – two days. To require the patient to stay on the treatment for a month, then come back to see the doctor, is quite wrongheaded, since it wastes time that should have been spent exploring a number of different treatments, and it exposes the patient to unnecessary side effects.

Medications

The list below shows some of the main pain medications, each of which helps a number of PWCs. This list is based on my own experience of working with CFS patients over almost two decades, and on informal surveys that have been done of doctors specializing in CFS. Proper scientific studies have simply not been done. The closest we have are studies of such treatments used for fibromyalgia (FM), a condition which overlaps so much with CFS that we assume that treatments for FM will help at least some patients with CFS as well.

There are also pharmacologic pain treatments that don't involve taking tablets. One is to apply medications locally, right where the pain is, in the form of creams or patches. The Lidoderm patch (which requires a prescription), contains lidocaine and is often especially helpful for localized pains. Patches that deliver heat often help back pain, and the newer nonprescription ones can last all day.

Nutritional supplements

PWCs are very familiar with supplements touted to improve energy, but some supplements are also used to treat pain. None of them helps more than a minority of patients. When I suggest to my patients that they try stopping their supplements, most are no worse off for this. But there are exceptions. If you stop taking several supplements and you do feel worse, then it may be best to reintroduce them, one at a time, to try to find out which one was helping.

Other pain treatments

Acupuncture, massage and other "hands-on treatments" sometimes help, but they are costly, inconvenient and very much dependent on the skill of the practitioner. Unfortunately, competent practitioners are not common. To find good ones, I suggest two simple criteria. First, do you know people the practitioner has clearly helped? And second, does he or she promise that only four or five treatments will be needed to tell if it helps? The best practitioners get results very quickly, so beware the ones who want you to sign up for 10 or more sessions even if nothing is getting better after the first few.

The underlying rule for these alternative treatments is the same as for medications: only a minority of PWCs gets a worthwhile response. So if you try one, only do so for a short trial period and only continue if it's clearly helping. Finally, remember that advertisements for these treatments are not legally controlled, so their promoters are free to make highly exaggerated claims for them.

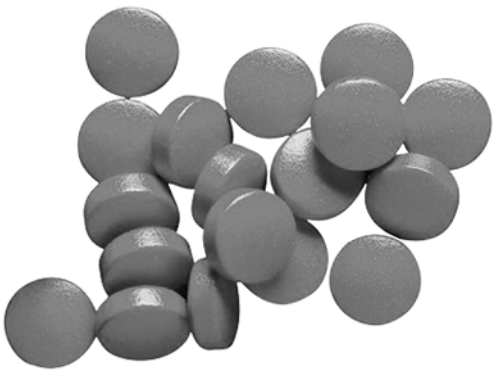
The bottom line for CFS sufferers is that the best chance for pain relief comes by working patiently through a number of drug and nondrug treatments until you find something that helps. And since many doctors are unfamiliar with this process, you'll probably have to push to get the doctor to persist with it. You may wish to show the drug and nondrug treatment lists accompanying this article to your doctor to use as a basis for that enterprise.

Drugs For Treating Pain In CFS Patients

- **Acetaminophen:** Sometimes helps a little; try adding to other treatments, especially during pain flare-ups.
- **Tramadol:** Sometimes helps dramatically. To minimize side effects, work up to a full dose in one to two weeks.
- **Nonsteroidal anti-inflammatory drugs (NSAIDS), such as ibuprofen, naproxen, Celebrex:** Rarely help much, but are worth trying; nearly all the full effect occurs within a day, so a trial consists simply of one day on a low dose, then one day on a high dose. Long-term use carries small but serious side effects, so this treatment

should be discussed with your doctor.

- **Tricyclic antidepressants (TCAs), such as amitriptyline, doxepin, nortriptyline:** Often help sleep as well as pain, but a rather wide dose range has to be explored slowly to minimize side effects, so a trial usually takes about two weeks.
- **Other antidepressants (SSRIs such as Prozac, Zoloft, Paxil), Effexor, Cymbalt:** These antidepressants have been touted for pain, but with low success rates. They probably take several weeks to have full effect, so trying several of them is very time-consuming.
- **Opioids (hydrocodone, oxycodone, hydromorphone, morphine, methadone, fentanyl):** Our strongest pain medications, these are very safe when used properly. Many doctors wrongly withhold them from PWCs because of needless fears of inducing addiction. This is the only group of pain medicines that commonly benefits PWCs sufficiently to make big changes in their lifestyle, such as returning to work. Both benefits and adverse reactions vary from one opioid to another, so it's generally worth trying several.
- **Medications for "nerve pain" such as Neurontin, Topamax, Lamictal:** Sometimes helpful for shooting, tingling or burning pains. Neurontin is also sometimes helpful when sleep is disturbed by pain, and a trial can be as short as a week. The others take several weeks to work up to the effective dose.



- **Lidoderm patches:** Postcard-sized patches which stick to the skin and deliver lidocaine, a local anesthetic that can help even with quite deep pain, such as pain over the hips that makes it hard to lie on them.
- **Muscle relaxants, such as Skelaxin, baclofen, Flexeril, Soma, Parafon Forte, Robaxin, Norflex, Zanaflex:** Each of these is chemically distinct, so one may work well when the others don't help at all. For each one, the trial period lasts only one to three days, so trying sample packs from the doctor is worthwhile.
- **Other medications:** Various other medications certainly help a few CFS patients. The rule for all of them should be to try them and observe the results carefully to find out as quickly as possible whether they help. This usually takes only a few days.

Non-Drug Treatments For Pain In CFS Patients

- **Acupuncture:** Helps some patients, but few find it worth the time and expense to continue long-term. More often used as a brief course during pain crises. Because of wide variance in the styles and the competence of acupuncturists, word-of-mouth recommendations are probably best when selecting a practitioner.
- **Massage:** Helps some patients during acute pain crises, but may not work as a long-term strategy to control chronic pain. The competency and efficacy of individual massage therapists varies dramatically, so referrals are helpful. Massage can actually exacerbate pain symptoms in some patients.
- **TENS (Transcutaneous Electrical Nerve Stimulation):** A tiny battery-powered gadget delivers small "buzzing" sensations that sometimes mask a nearby pain. Often used for well-localized pains, such as pain over the hips. Patient rents or buys the device and learns how to use it from a physical therapist.
- **Heat or cold:** Either heat or cold can sometimes help, or worsen, pain in CFS patients. It's quite safe to experiment on your own with hot and cold packs and stick with whatever clearly helps.
- **Nutritional supplements:** Disappointing to date. Supplements that are touted for pain-relieving properties often don't work, or only help a small percentage of people, or have such a small effect that patients don't find them worth the expense. Wildly overpromoted by health food stores, supplement manufacturers and many Internet sites. ❀

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Scepticism in CFS/ME

Scepticism has been a problem for people with ME for a very long time. In this article, ***Dr Ros Vallings****, a New Zealand GP who specializes in ME/CFS, takes a look at scepticism and disbelief in ME from a medical practitioner's point of view.*

One of the hardest things for those with CFS/ME has been the issue of "no-one seems to believe I am ill". Fortunately I am hearing this less and less these days because I think this illness is becoming better understood and validated by current research. One of the problems of course has been the historical issue of some psychiatrists who claimed that Royal Free Disease was "all in the mind". Royal Free Disease was a result of a recognized epidemic of a flu-like illness affecting many medical and nursing staff at the Royal Free Hospital in London. Many remained chronically ill for a very long time, with what we now call CFS/ME. I was at medical school soon after this in London, and clearly remember seeing patients from that hospital epidemic who were very ill, hospitalized and being investigated for clues. However there was no question that these people were genuinely physically very sick. The illness was described in the textbooks clearly. When the psychiatric reports came out some time later, I am sure many people did ask that question – "Was this in fact a psychological illness or mass hysteria?" So of course thinking did change, as we entered the era of mind-body medicine. Previously psychology was an almost "hidden" branch of medicine, with the psychologists and psychiatrists relegated to the basement in the bowels of the hospital or attached to mental institutions still known as "lunatic asylums". I think this is not the only illness that has been questioned in this way – there was a long phase when Multiple Sclerosis was thought to be of psychological origin.

Thankfully with the emergence and development of sciences such as immunology, genetics and biochemistry, illnesses such as CFS/ME are becoming validated and acknowledged by the wider medical and research community. Any chronic illness has psychological effects and we no longer separate mind and body (the psychologists no longer reside in the basement). So issues of depression and anxiety inevitably become part of the illness and need to be diagnosed and treated as part of the whole. This will enhance chances of making a recovery. But this certainly does not mean we are labeling this as a purely psychological illness. It is just like any other illness with physical and mental aspects.

So why do patients still have problems with convincing doctors and others in their lives that they have a "real" illness and are seriously afflicted? Firstly there is very little space in the medical curriculum to teach detail about any illness, so medical students only get a very brief introduction. It is usually after medical school that detail is achieved, as the newly qualified doctor moves into the real world and moves in directions of particular interest, some acquiring post graduate qualifications on the way. Secondly, CFS/ME does not exactly as yet fit into a particular speciality – it extends between immunology, neurology, rheumatology, psychiatry, cardiology and more recently genetics. So it may be an illness in which many medical specialists may only 'dabble' unless they develop a particular interest in it. Some of the older doctors too may have been at medical school during the CFS/ME "psychiatric" era and have been taught that it did indeed fit the psychiatric mode. Thankfully medical education is now encompassing the illness more accurately and there are many research papers now available online and being regularly published in the recognized, peer-reviewed medical journals from prestigious institutions.

As yet there is no specific test to make a firm diagnosis and doctors do rely on their experience and expertise in making this diagnosis from careful history taking and examination. Again this is not unique to CFS, as many diseases have no specific diagnostic test. There is a set of criteria (recently updated) by which a doctor will make the CFS/ME diagnosis, but this is not usually something the regular GP would have at his fingertips – there are just too many diseases!! This is becoming easier however, with access to the Internet.

There are other difficulties for the doctor too and these may stem unknowingly from the patient. For a

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start these patients usually do look well. This is partly because they are not usually seen when they are really ill – they tend to come to the doctor on a "good" day. Or those who are very ill, may rarely see a doctor anyway – they are just too sick to get out. Human nature is such that we always try to put on a good front anyway, so people will often smile and say they are fine, when in fact they are not well at all. Many people have said to me that no-one ever sees them when they are at their worst. There is also that deep-seated fear of being labelled as a psychiatric case – so there is a great effort to appear "normal" and deny any references to anything with a vaguely psychological tone. For example, I often ask a patient if he has any stress issues – to be then faced with an angry looking person gripping the chair and declaring, often shouting "I am never stressed" – that is abnormal as we all face stress every day!

Many patients I see have often been the rounds of many doctors with no firm diagnosis, so feel they have been ignored or maltreated, so are often very angry at the medical profession as a whole. This can certainly make it hard for the doctor when faced with an aggressive person in combative mode. Patients are angry too because so often they are told that all their tests are normal. How can the tests be normal, when one is so ill? They cannot understand why the doctor wants to do more and more tests if everything is so normal. Of course the doctor is trying hard to look at as many potential causes as he can, and hope to reassure the patient that certain possibilities have been eliminated.

Sometimes too, the story the patient gives is quite bizarre, and the doctor, in his mind, maybe questioning the patient's sanity, particularly if this is tempered by anger, mood swings and wandering thoughts during the consultation. Patients do also find it very hard to describe their fatigue and other symptoms accurately. This is understandable, for although they are very expert at their own symptomatology, they are not experts in medical terminology and description. The short time allowable for consultations is a barrier too, and it is often only when a doctor gets to know the patient well, that the true story and genuineness emerges. Doctor shopping and flitting from doctor to doctor does not allow for development of rapport.

Many doctors may give advice, and feel frustrated when the patient does not stick to the suggestions – the advice may of course have been inappropriate. But some people do not stick to treatment because of ill effects, which if they had persevered may have settled down. Patients often arrive with their own diagnosis and sheaves of information off the internet and this can put the doctor off a bit – particularly if the information is non-scientific, and it is hard for lay people to work out what may or not be valid research. Some so-called pseudoscience may seem very convincing. Sometimes too patients have had the diagnosis made by an alternative practitioner, which may be fine, but can sometimes be nonsensical, as there are many charlatans around who prey on the vulnerable. And it is then hard for the doctor to convince the patient that this may not be correct.

Unfortunately patients are often told they do not seem to want to help themselves, or maybe just bone lazy – this may come from health professionals, teachers, family, friends etc. Again it may be hard to verbalise the very real ill effects of say, going to the gym. A person with CFS may seem to look good and do well at the gym, and feel good because of endorphin release, but no-one sees them the next day when they are lying in bed in pain trying to recover from doing too much. Thankfully, recent research is showing that one exercise test is not useful in this illness – the telling time is the second exercise test 24 hours or more later when the ill effects show up. The opposite can of course occur with the striving person just pushing themselves too hard all the time, despite everyone telling them to slow down.

Social welfare agencies and insurance companies get caught up with this illness too. Patients are often poorly treated by lay staff who have no medical knowledge at all, let alone knowledge of this illness. But usually these people are keen to learn, and there is really no question that the term CFS/ME should be acceptable, and if the doctor uses this term on medical certificates, no further questions should need to be asked, any more than they would be for diabetes or cancer. Children at school are often the butt of much skepticism. Teachers may think of the child

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Disabled Persons Parking Permits

Who can apply?

A **person**

(a) whose ability to use public transport is significantly impeded by the impairment
and
(b) whose speed of movement is severely restricted because of the impairment.

Organisations that provide services including transport to at least **4 persons** with disabilities may also be eligible for the issue of a Disabled Person's Parking Permit.

A **Temporary Disabled Person's Parking Permit** may be issued to a person whose disability is likely to last for **more than 6 months** but is not permanent.

What do you need to do?

- Obtain an Application for a Disabled Person's Parking Permit form from any Customer Service Centre or by telephoning the Call Centre on 13 10 84 or
- Download a printable version of the Disabled Person's Parking Permit form.
- Your **doctor** must fill in the form.
- **Post** or **take** the application form to any Customer Service Centre along with the required fee.

If you are from an organisation

An **authorised representative** from the organisation must

- Obtain an Application for Permit to Park in Zones Reserved for the Disabled form from any Customer Service Centre or by telephoning the Call Centre on 13 10 84.
- Complete the application form.
- Declare that the permit will only be used when transporting persons who fit the above definition.

Post or **take** the application form to any Customer Service Centre along with the required fee.

How long is the permit valid for?

A permit can be issued for up to **five** years.

A **Temporary** Disabled Person's Parking Permit can not be issued for **more than 1 year**.

Disabled Person's Parking Permit Conditions

A Disabled Person's Parking Permit

- is valid if the vehicle is being used for the transportation of the person, who is the holder of a permit
- enables the vehicle to be parked for twice the period indicated on the sign, or for the period indicated on the sign and a further 90 minutes, whichever is the greater
- allows the vehicle to be parked in parking spaces which are sign posted and have the people with disabilities symbol painted on the road surface (if a sign indicates that a time limit applies to disabled parking space there is no additional time allowed)
- only needs to be displayed when parking in the above conditions. The permit must be displayed on the inside the vehicle of the windscreen on the side opposite to the drivers position so that it is easily legible to a person standing beside the vehicle.
- must be displayed inside the vehicle as near as practical to the side opposite the to the driver's position (or, if the vehicle does not have a windscreen, in some other prominent position) so that the permit is easily legible to a person standing beside the vehicle.

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with CFS/ME as lazy or playing up. Parents may have been told the child has a school phobia, or may even feel threatened if the child is not regularly attending school. The cognitive difficulties may mean the child is not achieving to his ability, and may end up being put down a class or left behind by his peers. Other children cannot be expected to understand and may be cruel towards one who is sick but with no obvious disability to "see". In our sports-orientated society, just not participating in sport is viewed with scorn. Thankfully most schools and teachers are delighted to receive accurate information about this illness and put their newly found knowledge into practice.

Forming and maintaining relationships is hard for anyone who is sick. Relationships can be hard work and energy is limited. Again many just do not understand the illness, although those close to a person with CFS/ME usually have good understanding of how this person has changed and they do see the side which outsiders rarely see. Some people cannot cope with illness and back off, while others become the true and caring friends. An illness such as this can make or break a relationship and many marriages have foundered, while others have become stronger and long lasting.

Many of my patients just wish this illness had a better name. They are so often told by non-sufferers "Oh I feel tired too", but of course this is a normal tiredness as opposed to the very abnormal and far reaching fatigue in CFS/ME. Changing the name repeatedly leads to more scepticism. It is as if we do not really know what we are talking about. Internationally the term CFS/ME now seems acceptable to the medical profession, and any future changes should only occur when we more fully understand the complexities of the illness. So we need to accept it – adding the ME component certainly seems more scientific and helps us move away from "chronic fatigue" which is very different from the syndrome CFS/ME as chronic fatigue will occur in almost every chronic illness, and is probably the symptom most often seen in any medical practice. In the past it has been confused with CFS and some of the older research has even confused the 2 conditions – one a disease (CFS) and one a symptom (chronic fatigue).

I can only say that from the point of view of a doctor seeing many people with this illness, things have improved enormously over the past 30 years. The key has been the exciting research developments, coupled with good education for everyone involved in this illness, be they health professionals, employers, social welfare agencies, friends and family. We are fortunate in New Zealand that our government acknowledges this illness and is supportive towards those who have it. With our small population, dissemination of information to health professionals and others is possible and ongoing, and ANZMES has been instrumental in this endeavour. ❀

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Misuse of a Disabled Person's Parking Permit

A person must not display or allow a permit to be displayed other than to transport the holder of the permit, or if the permit is issued to an organisation, for the transport of a disabled person to whom the organisation provides services.

Cancellation of a Disabled Person's Parking Permit

A disabled parking permit may be cancelled if the holder of the permit is no longer eligible for the permit or if the holder of the permit is convicted of misusing a permit. ❀

Reprinted with permission from www.transport.sa.gov.au/permits/parking/disabled.asp.

Reflections on a diary: growing up with M.E.

***Leigh Fenton**, publications and communications assistant for UK publication* InterAction*, tells about her journey towards recovery.*

Writing my story was far more difficult than I imagined it would be. I now realise that I have tended to clump seven years of my life into one blurred memory of feeling ill. Trying to recall dates, experiences and times proved very tricky. Then I remembered my diaries.

I finally found them in a cluttered box under my bed and began, for the very first time, to read about my life as a young girl with M.E. Distinct memories and emotions came flooding back to me; specific feelings of disappointment, frustration – and hope for recovery.

The beginning

My life with M.E. began in 1992. The first diary entry relating to this was at age 11:

> *1 Oct 1992: On Monday I was sick. I was sick five times! I have got these chest pains and so I am off school. I keep getting pains in my neck and my ankle and I keep getting very tired. I went to the doctors on Tuesday and he said I have got a virus that makes my bones ache. He said that if I don't get any better to come back on Thursday for some tests and an x-ray! And if it gets worse then he will take me to hospital. I am a bit worried but I think it'll be gone by Thursday.*

Evidently I wasn't any better by Thursday and although I was never sick again, that week I began my battle with constant nausea, fatigue, aching joints and muscle pain. There were hospitals and tests. It felt so sudden to me. I needed to be carried to the toilet, to be washed and dressed. I had no idea what was happening. My mum became my full-time carer and I was extremely dependent on her, both physically and emotionally. She was (and still is) a constant source of support.

After a few months, I began to go through cycles of feeling a bit better and then relapsing. Every single time I felt better I was sure – and I mean absolutely positive – that I was recovering:

> *28 Jan 1993: I went to school today. That means I have done two days this week! I did that last week as well! I'm really getting better now.*

Of course, the downfall when I would relapse was always devastating and something I never seemed to get used to:

> *03 Feb 1993: I felt awful today I just don't think I'm ever going to get better. I've been quite annoyed with everyone as well. I know it is not their fault. I don't know Maybe I'm just too tired for anything.*

After numerous tests, I was diagnosed with M.E. in February 1993. "M.E." meant nothing to me. I had never heard of it and at the time I was certain my symptoms would be gone shortly. I remember asking the doctor that when my symptoms did go, was there any chance they'd come back? "No," he said, emphatically.

My primary school was very unsupportive. My mum had to fight to get homework for me and I was never once visited, called or had my progress checked. I remember making it in one day and staying on to watch my friends in a school play. During the interval I started to feel very fatigued and pains were developing in my hands. My teacher, however, refused to let me call my mum and go home. I think she thought I was pretending. I remember her commenting that it didn't kill me to stay on after all. Of course, she did not see me the next day, when I could barely move from my bed. This inconsistency with the condition

has always been a massive frustration for me; it always felt so impossible to explain.

I realised quickly how isolating and lonely M.E. can be. I couldn't go out like my sister Nicky. My friends became used to me saying no to invitations. They stopped asking. I felt like I was being forgotten. Missing school camp and coming in the next week to hear everyone talking about how great it was, that was really hard.

When I was not with my mum, I spent a lot of time with my grandad. I didn't miss out at all that way. I was lucky to have my family.

Starting secondary school

In September 1993 I started secondary school. I was absolutely petrified. I could not imagine I had anything to offer any new friends and I felt so alone and distanced from my old ones. They were still classmates but I had been off school for so long, their lives were very different from mine.

As secondary school was much more demanding mentally, my brain fog kicked in big-time. I was constantly lost for words, I couldn't concentrate, I felt sick and achy all the time and I was extremely self-conscious. I had lost weight due to my nausea and was very thin. I was in a constant state of confusion.

My mum would drop me in for lessons as and when I was able. Although this was the best solution, it was really disorientating and I often forgot where I was going. Some teachers understood, others clearly didn't believe me. My confidence was non-existent.

23 Oct 1993: I went to school today but I couldn't remember what lesson I had. I got really worried so I went to reception and the first alder came to see me. I tried to say I was confused because I was tired but she was horrible to me. So I lied and said I had a headache so she would be nice.

Missing so much school, I felt I didn't know anything.

14 Jan 1994: I'm so stupid. I'm behind in everything and no one wants to help me. I'm still doing last term's work.

25 Nov 1994: I don't think I'll ever get better. Its just not fair.

I made it my new year's resolution to get better for 1995. The year did start off well...

13 Jan 1995: I made it to school again! That means I've done a whole week! I'm so pleased!

Then again, two months later:

10 Mar 1995: Guess what? I did the whole day! That means I've done 10 lessons this week. I'm so happy. That must mean I'm getting better now

Slow but evident progress

I was fortunate to have a supportive head of year at secondary school, Mr Hibbs. In 1996 we produced a revised timetable where I would study for six GCSEs instead of the standard 10. This allowed me to go home and rest so that I could focus more during lessons. I found studying for GCSEs more structured. I could work. I revised. Through some miracle, I managed to pass them all!

I remember reading my results and being absolutely stunned. I thought there must have been a mix up. For the first time in four years I didn't feel stupid and I realised that I must actually be better than I thought. I was so used to M.E. being a part of me and controlling my life, I never really stopped to look back and acknowledge my very slow but evident progress.

This was also around the time I stopped keeping a diary. Whether I felt strong enough to be without it, or it was more a case of being busier, I don't know.

I didn't find a specific treatment that worked well for me, except pacing. I tried all sorts of homeopathic treatments but for me, they did not help. We discussed trying an exclusion diet but I was already so thin that we decided against it. I cannot say exactly what started my recovery from this illness. All I can say is that I am proof that, in time, people can and do recover from M.E.

When I was about 16, my mum, dad, sister Nicky

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A Weird Business

*By **Susanna Agardy**.*

A friend once said to me, "I have never seen so many weird arrangements in anyone's house as I have seen in yours." The funny thing is, I couldn't even tell you what some of these are now.

The combination of my worsening ME/CFS and multiple chemical sensitivities (MCS) has resulted in many adjustments and apparently strange requests to people over the years. Most of these are incomprehensible to even sympathetic normal people and often too tiresome to explain.

Could my friend have been referring to the box of expensive, minimally perfumed washing powder and the dubious soaps stored outside my kitchen door so that the fumes can evaporate in my absence? Thinking that they are some kind of neglected rubbish, people have offered to dispose of them for me. I just say, "Oh never mind, I'll take care of it."

Or could it be the new chairs which were on my front verandah covered with a sheet for months with the purpose of airing them off? Who knows what chemicals there are in new furniture which is not good news for chemically sensitive people. Some chemicals in a new office triggered my ME/CFS so I am wary for good reason. Plus, I was told that the chairs had been fumigated upon importation. One by one, the chairs are now making their way into the house to their eventual destination. So far, so good. My cleaning lady, who is looking forward to having chairs around the table in a conventional fashion, will be very happy when this has been achieved. So will I – but she is doing the carrying.

My cleaning lady has also noted that I have no less than nine pillows or other propping arrangements on my bed. I am not in the habit of counting them but they are all unique and are useful at specific times.

As for needed repairs to my exhausted house – well, they don't get far. I have called for umpteen quotes – one was for tile repairs. Luckily, I asked to have a sniff of the tile glue before agreeing to its use – sentence: instant headache. The tiles remain off the wall. Painting? All I did was to show the painter the jobs and asked to sniff-test the supposedly non-toxic paint – sentence: two days of heavy-duty debilitation. As far as my body is concerned the jobs are done, it's just that the house looks the same.

One day I was standing on the front verandah surveying my newspaper at the bottom of five steps and contemplating my mail in the letterbox. These days I don't lightly walk up and down five steps. Easy enough at the time and therefore tempting, but the operation produces crippling consequences. I was asking myself, "Are just two reasons enough for me to do this?" I normally only do this for a big reason like going to the doctor. Is there some other activity in the next few days that I'm endangering if I do this now? In the middle of my calculations a young man in the street came into view: 'Excuse me!' At first he seemed a bit bewildered as I explained myself while he gathered up my things. What's a bit of a dent in self-image and appearing strange while relying on the kindness of strangers compared with days of debility? I have not seen him since but if he decided to pass by on the other side of the street he is just as likely to be ambushed by my neighbour who is disabled for other reasons.

All the possible consequences of an action or treatment must be considered and then, when you are affected with ME/CFS and MCS, anything can have unintended consequences. I found this out when I tried Reiki, which is supposedly healing or relaxing, some years ago. Instead of any promised benefit, all I got out of it was sore muscles for several days from lying on a firm surface for an hour. In addition, on the cold winter's day I had to ask the treaters to open a

Continued on next page

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window to dilute the smell of the incense which was getting overpowering! With MCS any spiritual or romantic association with scents goes out the window. Perfume, paint, incense, essential oils, car exhaust – they're all the same: just chemicals your body has to deal with and therefore to be avoided.

Being acutely aware of how everything takes energy, I try to economise by achieving as much as possible with minimum effort. So, for example, I try to carry as much as possible in one trip – a trip being a walk from one room to another. Of course, invariably something gets dropped, water is spilt or something is mislaid which then has to be searched for later. But I still try to recommend the same human-energy-saving principles to people not affected by ME/CFS. When I ask someone to do something for me they get plentiful advice on how to do the job while using as little energy as possible, They take no notice!

With this disease we need to make adjustments, think up our own unique solutions and be ready to handle unforeseen consequences. It is not our reactions and arrangements that are strange. They are a perfectly natural and necessary survival response to the extraordinary symptoms and challenges put in our way. At the least, we deserve acknowledgement for our ongoing problem-solving achievements. ❀

Reprinted with permission from Emerge*, Autumn 2008*.

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and I were able to go abroad on holiday for the first time. We went to an apartment in Majorca. It was beautiful

Well enough at 70%

I sat my A-levels and after taking a year out to rest and decide what to do, I started a course in English Literature at Exeter University. It was one of the best experiences of my life. Having independence was amazing; just not feeling totally dependent on another person meant so much to me. I began to feel I had options in my life and could go after what I wanted.

My energy levels were still low and I caught every cold that came along, but in comparison to a few years before, I was considerably better. Being 70% OK felt good enough for me.

After years of being at secondary school together, I also started seeing Phil, who's now my boyfriend. He hadn't intended to go to university but one year later, there he was, studying in Exeter too.

Here and now

Am I recovered? Well, I don't think of myself as suffering from M.E. anymore, but I am very aware that my energy levels are low and I do still struggle with concentration and stamina sometimes.

Although my body and brain have improved dramatically, my emotional side took a lot longer to catch up. Being confident in myself, believing in my abilities, feeling worthwhile and of interest to other people are not easy. It is something I notice in other people I talk to with M.E. too.

Growing up with a condition that robs you of your self-esteem and identity gets built into your psyche as your personality and ideas of yourself develop. I am aware that a lot of my insecurities and anxieties stem from this and sometimes feel angry that M.E. still has this hold over me. I automatically pace myself and I still find it hard to know when I should stop or when I should keep going.

On the plus side, I feel overwhelmingly lucky and privileged to have recovered from M.E. I do not take anything for granted and I treasure my family and friends who support me – feeling secure in their love is an amazing feeling, especially when I felt for so long that I didn't deserve any.

Working for Action for M.E. is a rollercoaster ride. I feel so very connected with our members. When you have gone through something devastating in your life and come out the other side, you really empathise with others who are going through it now. Of course, the memories, coupled with other peoples' tragic and devastating stories, can prove very emotionally demanding. That's why I'm training to be a counsellor. I feel extremely passionate about dedicating my time so that other people with this distressing illness can feel support, validation and experience their own path towards recovery. ❀

Reprinted with permission from Meeting Place (*Issue 91 April 2008*)*, quarterly magazine of Associated New Zealand Myalgic Encephalopathy Society.*

A Short Story about a Long Story

***Katy Wimhurst**'s moving account of life with severe M.E. (ME/CFS) won her a runner-up position in* Action for ME*'s short story competition in 2004. This is what she has to say.*

On most days it feels to me as if some psychopathic scientist has injected something cold and dead like lead into my veins; he has removed my lungs and replaced them with solid domes of ice and he has secreted vampish leaches into my adrenals which suck steadily at my vitality.

I also suspect that, not to be outdone, a sadistic geneticist, who maybe once worked for some secret intelligence service, has crossed an octopus with a vice to create 'octovice' – an inexplicably invisible torture device that has been placed around my head and is tightened slowly every day.

However, do not think that it is the purgatorial physical sensations that vex me the most. No, what really pains me is that I seem to be trapped in a story I have little power to change.

This story – the long, relentless story of severe M.E. – has for the past six years largely written the outlines of my life's script; it has set the bedrock reality of what I can achieve or do or be. And, between me and you, the script is not particularly attractive. Even Ingmar Bergman, the Swedish film director famous for his bleak meditations on the human condition, would probably reject it as unpalatable. "Sorry, but the severe M.E. story is just too damn gloomy for me," Bergman might say. "I only deal with death, failed relationships or existential despair."

Some people, of course, do not believe that the story of M.E. exists at all. In my time I have visited men in bullet-proof white coats with stethoscopes hanging around their necks like power medallions who have said, "Your story is not real – see, it does not appear in my textbooks which, as you know, are terribly clever and exhaustively true." And I have replied, "Do you really think your books are so omnipotent that they contain all the stories in the world? Where would we be today if no-one had ever questioned the official textbooks of their age? And, anyway, don't you know that what is taken for cleverness in our society is often nothing but brilliant stupidity?"

Actually, I didn't say that at the time. I wanted to but the words were choked by my rage and grief at the disbelief which made me mute. So I am writing them here instead.

I have made endless attempts to change my story with poetic words like 'milk thistle', 'cat's claw' and 'passion flower', with abbreviations like CBT and NADH and with technical terms like osteopathy and homeopathy. Sometimes these attempts have made minor changes to the script, but the story has continued on its same inexorable path.

The ancient Aztecs of Mexico believed that the experienced world was in fact a written (and painted) book, endlessly penned into being by the Giver of Life. Butterflies, hummingbirds and even gastroenteritis were thus all 'glyphs' of the gods and each individual life was a tiny chapter in the Great Tome of Written Existence.

If, say, the Aztecs were right, I can only hope that the sadistic celestial sod who is writing the chapter of my life will at some time delete the recurring words like 'pain', 'patience', 'pacing' and 'pissed off' and replace them with more pleasurable phrases of plenitude.

Actually, I would like to steal the great cosmic typewriter myself and make some major plot amendments throwing in phrases like, "Went for a long walk on the tropical beach in the soft dusk," "Danced until dawn to the rhythmic tom-tom of the Djembe drums," or even, "Went shopping for sexy undies at Next." Just for the sheer surreal hell of it I might also write, "Woke up one morning with a kangaroo's tail." OK the tail would make wearing knickers difficult but it would make jumping about in healthy glee more fun.

Despite the fact that I bitterly dislike the story

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Physically handicapped, ME

Marlene Pooley *has always admired physically handicapped people who have a positive outlook on life. But having ME isn't so different from being physically handicapped, and in this article she explores what we can learn from this.*

Since I was young I have admired physically handicapped people, who through their handicaps laugh and smile and seem to enjoy life often more than their able-bodied counterparts. They laugh with the people around them and seem to enjoy what they do. You see, at some stage their world crashed, their active lifestyles were cut short and they embarked on the long slow road to recovery. Through heartache and tears they came to grips with the changes in their lives and battled to salvage something of their once active lifestyles.

How not so different is this to us with ME/CFS? Whether catapulted into it suddenly or conveyed there over time ME/CFS has life changing consequences and a long slow road to recovery, at least presently. We all wait eagerly for the detailed diagnostic tests and targeted treatment regimes specific to each person. But until then we do our best each day with what we have and who we are, and hopefully too with the support of some people in our lives, as well as the supplements and medication we may be taking.

But what can we learn from this? First off, in our pursuit to understand what has happened to us, we learn a lot about ME/CFS and what supplement or medication can help with what. (And what a difficult learning curve that is while battling brain fog, a lack of concentration, no energy and coping [or not] with what has happened.) But as we journey on there are also lessons we can learn as we live life a little differently: Life lessons that can give US a greater enjoyment of life day to day than we experienced as an able-bodied person.

For instance, you have to weed out everything that isn't necessary in a day; you can't worry about what you don't manage; you have to slow - down and re-prioritise what's important to you; you take pleasure in small, but significant achievements; your perspective on life changes; family and friends become more important, and supremely, patience is no longer an unused word from the dictionary.

And, let's remember that your value is not in what you do, but in the fact that you have intrinsic value as a person, simply being who you are. Remember, you are SIGNIFICANT, you are IMPORTANT to those around you, you will GRADUALLY IMPROVE as you do the right things and you can still CONTRIBUTE to the wellbeing of those around you in small, but significant ways. SO, today is looking better! Isn't it? Tell yourself these things, keep your thoughts positive, relax in this knowledge and some of your inward struggles may dissolve releasing even more energy to heal and allowing you to enjoy everyday life.

If you wish to comment I can be contacted at b.m.pooley@xtra.co.nz. ❀

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in which I am trapped, I have certainly learnt things from it. I have learnt a lot about suffering and a little about understanding. I have learnt to appreciate aspects of life I previously overlooked like the arias of blackbirds and skylarks, the yellow grins of Spring primroses and the ever-mutable sculptural forms of passing clouds.

And I have also come to comprehend that, even if I cannot change the outline of my story, I can at times change my attitude to it – there are smiles and stars even in the darkest night.

Ultimately mine is not a pretty story. It is not a fairy story with a happy ending. I am not a princess who goes to bed and sleeps for seven years and is then awoken by a handsome prince who sweeps me of to an enchanted castle for ever, or even to the Maldives for a fortnight. As yet, there is no ending to my long story. Or, rather, there have been far too many endings when what I really want is a new beginning. ❀

Reprinted with premission from Interaction*, the quarterly magazine of UK charity Action for M.E. (afme.org.uk), Issue 54 (Nov 2005).*

You know you're having a fibro fog day when...

This is an edited list that was compiled from various people who contributed to "Simple Pleasure with Fibromyalgia", an online discussion forum: http://www.flickr.com/groups/simple_pleasures_with_fibromyalgia/discuss/72157606160743404/. We thank them all!

- You leave the house to go somewhere, get in the car, and buckle your seatbelt. Then you realize: I'm going by myself. And I'm in the passenger seat.
- Your husband reminds you to take your meds, you go to the medicine cupboard and wonder what you're there for.
- You put the kettle on for yourself, put the tea bag in the mug, and when the water is boiled you ask whose tea that is.
- You spend 30 minutes hunting through the parking lot, sweating and crying because your car has been stolen. You call your husband who's been waiting at the movie store for *you* to call when you were done so he can come get you – after all, he dropped you off.
- Make a chocolate cake from scratch, decorate it, serve it to your daughter's new boyfriend – only to realize that you forgot to put sugar in the cake batter.
- Drive the 20+ miles to the supermarket, fill up the cart, and realize that your wallet is on your desk at home.
- Put the teapot in the fridge and the milk container on the stove.
- When you make a phone call and don't remember who you called, even after they answer and you have to ask who you are talking to.
- When you finally remember to take your medicine, then you are afraid to take your medicine, because you think that you have already taken your medicine and don't want to overdose on it.
- When working on a word search puzzle, SEARCHING for a particular word, you keep searching and searching and searching, only to realize that you have already found it, have circled it, and forgot to cross it off the list.
- It's when you forget to change from your animal slippers to a pair of shoes, you walk out front door trying to "push" yourself with positive energy to be able to manage to the cafe were your friend is waiting. Half way to the cafe you notice that you're still in your slippers and people are laughing at you, but the best part is that your not wearing your handbag but the garbage bag still. I sat down on the street and cried... Life is wonderful, isn't it? :)
- Getting outside the door to go to work – in my pyjamas.
- Drive past the gas station on your way home only to discover once you are home that you might not have enough gas to get back there.
- I have so many yellow notes/post-its with millions of chores written on them, only to forget them... and then I write on other post-its so I end up with 10 little post-its notes and have to rewrite them all in a new concentrated one – and of course I come to work and forget to bring the big one... So I start over again...
- I've forgotten that I've put on my ROC retinol cream and put it on twice, and end up with a rash for three days. Unfortunately that was last week and I had to go to my gramma's funeral with a rash on my face. At least it gave them a reason to not be depressed.
- When you find your purse in the trash can – or you don't notice when you wear two different shoes, and wonder why one leg feels longer than the other one.
- I have a friend with fibro who lost her wallet. After three days of desperation she found it in the freezer when she went there to get something else out. The same person couldn't remember her daughter's name. She told her husband that "Jerry's daughter" called (her husband's name. I changed it cause they don't want their names mentioned). He said, "But I'm Jerry." She said, "I know. Jerry's daughter called...". Ever since then her daughter has started introducing herself as "Jerry's daughter" and it makes everyone laugh.
- You try to call your mother with the remote control. ("Alex, why isn't the phone working!?")
- You go into PT and he says "Your appointment was yesterday." ❀

Jokes

The Society occasionally includes jokes in its e-bulletins. Here is a selection...

How to get ahead in business

A young businessman had just started his own business. He's rented a beautiful office and had it superbly decorated. Sitting there, he sees a man come into the outer office.

He wants to appear busy in order to make a good first impression, so the young businessman picks up the phone and starts to pretend he's working on a big deal. He excitedly yells huge figures and makes giant commitments.

Finally, he hangs up and asks the visitor, "Can I help you?"

The man says, "Sure. I'm here to install the phone!"

It's hunting season

A couple of hunters are out in the woods when one of them falls to the ground. He doesn't seem to be breathing, his eyes are rolled back in his head. The other chap whips out his mobile phone and calls the emergency services. He gasps to the operator: "My friend is dead! What can I do?"

The operator, in a calm soothing voice says: "Just take it easy. I can help. First, let's make sure he's dead."

There is a silence, then a shot is heard.

The chap's voice comes back on the line. He says: "OK, now what?"

To infinity and beyond

When NASA first started sending up astronauts, they quickly discovered that ballpoint pens would not work in zero gravity.

To combat the problem, NASA scientists spent a decade and $12 billion to develop a pen that writes in zero gravity, upside down, underwater, on almost any surface including glass and at temperatures ranging from below freezing to 300°C.

The Russians used a pencil.

Turtle trouble

A turtle was walking down an alley in New York when he was mugged by a gang of snails. A police detective came to investigate and asked the turtle if he could explain what happened.

The turtle looked at the detective with a confused look on his face and replied "I don't know, it all happened so fast."

Chainsaw

An old farmer walks into a hardware store and asks for a chainsaw that will cut 6 trees in one hour. The salesman recommends the top of the line model. The old farmer is suitably impressed, and buys it.

The next day he brings it back and says, "This chainsaw is defective. It would only cut down ONE tree and it took ALL B----- DAY!"

The salesman takes the chainsaw, starts it up to see what's wrong, and the old guy asks, "What's that noise?"

A monk's life

A man joins a monastery and takes a vow of silence: he's allowed to say two words every seven years. After the first seven years, the elders bring him in and ask for his two words. "Cold floors," he says.

They nod and send him away. Seven more years pass. They bring him back in and ask for his two words. He clears his throat and says, "Bad food."

They nod and send him away. Seven more years pass. They bring him in for his two words. "I quit," he says.

"That's not surprising," the elders say. "You've done nothing but complain since you got here."

Grand Final

It's the AFL football Grand Final and a man makes his way to his seat right on the wing. He sits down, noticing that the seat next to him is empty.

He leans over and asks his neighbour if someone will be sitting there.

"No," says the neighbour. "The seat is empty." "This is incredible", said the man. "Who in their right mind would have a seat like this for AFL Grand Final and not use it?"

The neighbour says "Well, actually, the seat belongs to me. I was supposed to come with my wife, but she passed away. This is the first AFL Grand Final we haven't been to together since we got married in 1967."

"Oh ... I'm sorry to hear that. That's terrible. But couldn't you find someone else, a friend or relative, or even a neighbour to take the seat?"

The man shakes his head "No, they're all at the funeral." ❀

Information about ME/CFS

What is ME/CFS?

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

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

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

Prevalence

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

Main characteristics of ME/CFS

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

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

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

Definition

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

Diagnosing ME/CFS

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

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

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

How is ME/CFS treated?

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

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

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

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

Prognosis

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

Support groups

Clare Valley ME/CFS Support Group

Venue: 20 Beare St, Clare.
Contact: David Shepherd.
Phone: 8862 1665.
Email: dcshepherd@dodo.com.au.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.
Phone: David on 8862 1665.

Riverland CFS Support Group

Venue: Riverland Community Health Resource Centre
9-11 Seekamp Street, Berri.
Phone: Raelene or Simon on 0449 120 715.
Email: riverlandcfssupport@gmail.com.

SAYME Support Group

Time: 7:30 pm
Date: First Friday of each month.
Phone: 0500 523 500 for more details.
Website: www.sayme.org.au.

Changes

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

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

Disclaimer

Please note that meeting times are subject to change.

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

- 8410 8930; or
- 1800 136 626.

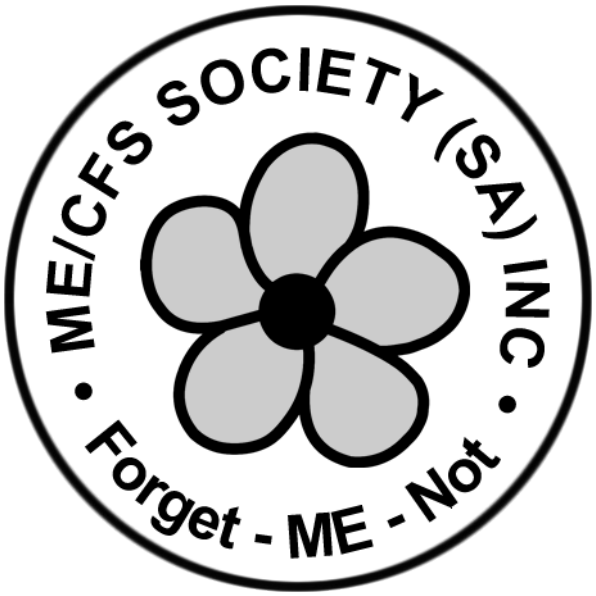
Contact numbers

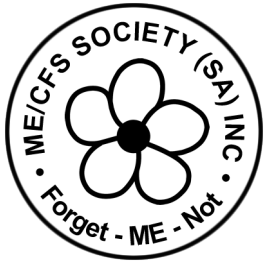
Miscellaneous Support Contacts

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

Country Support Contacts

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





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