Talking Point

Official Journal of ME/CFS Australia (SA) Inc

2008 Issue 4

Your Society forget-ME-not

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ME/CFS Australia (SA) Inc.

ME/CFS Australia (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 Australia (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.

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Family..... $45
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- **President:** Peter Cahalan.
- **Vice-President:** (vacant)
- **Honorary Secretary:** Peter Mitchell.
- **Treasurer:** Richard Cocker.
- **Management Committee Members:**
  Lynda Brett; 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).

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Always consult your medical practitioners before commencing any new treatments.

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President's report

*By **Peter Cahalan**, President ME/CFS Australia (SA) Inc. This report was presented to the Society at its Annual General Meeting held on Saturday 9 November 2008.*

I begin by acknowledging the powerful spirit of all those who endure ME/CFS and live life to its depths despite it.

A glass half full report

This is my sixth report as Society president. In all the others I have been able to report in generally optimistic tones about how we've done over the past year. This time I feel obligated to report more soberly. This has not been a great year for us. It's not been bad, but it could have been better. The committee and key volunteers merely happen to be the elected or coopted willing workers from amongst a membership of 250 or so people. So it does neither them nor the general membership much good to gloss over things and hope that it'll all turn out right in the end (as it has so often in the past).

There were some terrific highlights during the year, and I will come to good news later, but I want to start with the issues.

First, the bad news...

- **Staffing the office.** We had real problems this year keeping the office open each Wednesday. Key volunteers were taken off line by health, family and work pressures. One outcome was that occasional volunteers came by from time to time only to find no one there to let them in. We need a core or people in the office to deal with phone calls and basic administration. We just don't have enough of a team at present. And without a reliable team of experienced people we actually can't build further when other people volunteer.
- **Budget.** We logged our biggest deficit in years – around $18 000. We had anticipated a tough outcome given the loss of our long-term donor Ms Miller and her generous annual gift of $12 000. We anticipate getting a cheque for $5 000 from her estate some time soon, helping us to a better result in 2008/09, but the deficit was more than expected. Simply put, memberships cover only a quarter of our costs. We have to raise the rest through sponsorships and donations. We have the reserves to cover us for a while. But we can't keep on going with the red ink so red for too many years more.
- **Finances.** We have struggled in recent years to manage our book-keeping – everything from processing cheques and paying bills to the general paperwork required by the authorities. We have to get a handle on this and that will be something the committee will look at carefully in the next month or so.
- **Tired leaders.** This was a year when a number of veteran workers for the Society have not been able to put in anywhere near their former level of effort. I include myself in that. You wear out after a while. It's not true of all our committee or other key volunteers, I hasten to add. But the truth is, as some old hands have reminded me from time to time, the Society comes to rely on a few people for too long. We need a few more fresh faces and need to gear up for this time next year when several of the committee will, they have told us, step down.

The truth is that one's energy runs down over time anyway. But it runs down more quickly when there's a constant background noise of little administrative issues going awry. So if we can expand that cadre of volunteers who run the administrative basics of the Society, that would re-energise those of us charged with the more strategic end of the business.

There. I feel better now for sharing that with you. And…

It does get better

There were some really positive aspects to the year. One was the development of a new support group in the Riverland – about which more follows.

Another was the effort put in by Jayne Warwick to greatly improve our database of health practitioners. Our big FAQ is: where can I find a good doctor or other health professional? Our old list had become outdated and Jayne has worked on a project basically akin to painting the Sydney Harbour Bridge. We now have a much better list from which to offer advice to enquirers. Thanks Jayne.

And another highlight was having a highly competent and reliable person step forward to take on the role of Membership Officer. We were being driven

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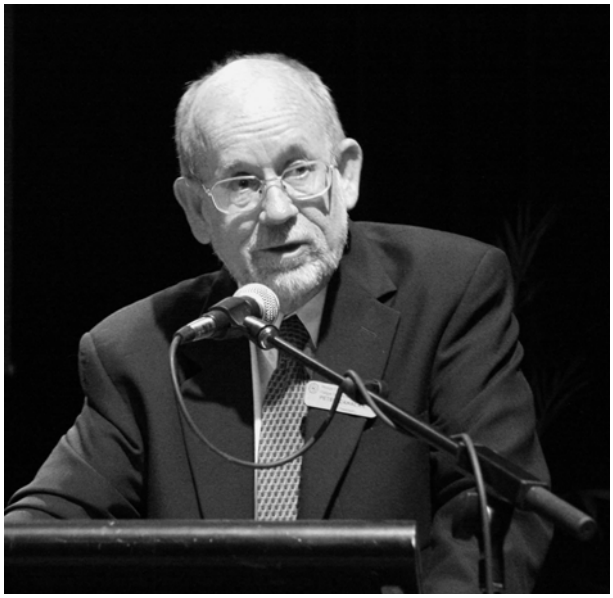
mad by constant problems with our membership database and with complaints from people who had not received Talking Point and so on. It was very dispiriting and of course it's not pleasant to think that formerly faithful members are getting cross enough to threaten not renewing their membership.

Well, a few months ago Lorenzo Pizza took on the job. And he's done it splendidly. We now have our databases sorted and Lorenzo is taking seriously his brief to be our members' advocate – ensuring that we offer the right range of benefits to members and so on. Thanks Lorenzo.

Seminar program

Lorenzo again organised a very good seminar program for the year.

The year kicked off in February with a very practical lecture by physiotherapist Julie Peacock. Julie had us all up and about doing exercises. As luck would have it we didn't have a videorecorder there on the day. This was one of those lectures which can't be easily taped or noted down – you had to see it! Psychologist Liana Taylor addressed us in April. Liana had been booked for a gig in 2007 but fell sick. We were glad to book her in again. Our focus on allied health professions continued with occupational therapist Edwina Shannon in June. Dr Anne-Marie Southcott, president of the Sleep Disorders Association of SA, spoke on sleep disorders in August. And we had naturopath Katie Behlau in October. The year is to be capped off by a lecture at this AGM by our great supporter endocrinologist Dr Richard Burnet speaking on his latest research.



Peter Cahalan

Thanks to all our speakers, to Lorenzo and to Colin Northey who has taken on the task of filming the lectures. We are not producing DVDs generally but have the recording on hold for copying when people ask – although again this is one of those areas where we run into labour shortages from time to time.

The website and our communications program

I always spark up when I come to this item. Peter Scott for yet another year has diligently and cheerfully kept the website running smoothly. In fact I did a quick count of news items from 8 November 2007 till today and came up with 280 or so. That is, we posted a new item almost daily over the past year. It's an amazing achievement. Peter was helped by a small band of suppliers of content. Jenni Gay assisted him with this and Talking Point content for much of the year till pressure of other work compelled her to take a step back. Judy Rhodes from Yorke Peninsula has since taken on those roles capably. And Michael Ritter ably supplies photographic content.

For much of the year we hosted content for the Victorian Society while it was re-jigging its site. This seems to have boosted our readership and at peak in May 641 people a day were visiting the site. The annual totals are over 170 000 visitors and over 2 million hits. So we continue to serve a big market and meet the needs of many people hungry for information on ME/CFS. We also targeted the specific interests of people with MCS and Fibromyalgia by creating special sections on those topics.

We continued our weekly e-bulletins. I am particularly grateful to Peter Mitchell who has shared that task with me this year. His jokes section has gone down well. I'm a terrible jokester myself but appreciate the importance of maintaining good humour in the face of adversity. Thanks Peter.

Talking Point

We produced four issues of *Talking Point* this year. As noted above, Peter Scott, Jenni Gay and Judy Rhodes made that possible. So also did Emma Wing who has covered backroom logistics such as getting it to printers and from there to the mailroom.

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The Schools Brochure

At last I am able to report that the glossy brochure for young people with CFS and one for their school staff have been completed. During the year, we got copies into schools in all three systems: Government; Catholic; and Independent. They are there available to parents who come to the school with a child diagnosed, or to staff who work with students with ME/CFS. All three systems were supportive of our aim to get the information where it was needed. We would particularly like to thank the Catholic Education office for couriering copies into every Catholic school at their own cost. Tiffany Linke designed the brochure, and she gave us enormous value for our money in the task. We now have lots of copies available to respond to requests from parents/caregivers and schools. We even had a request from Dublin for some copies recently. Thanks also to the parents, young people and Open Access College staff who assisted greatly along the way.

ME/CFS Australia Ltd

ME/CFS Australia is our national peak body. I'm the Society's nominated director with Peter Mitchell as my alternate director. The company secretary this year was member Jenni Gay. We've had a busy year in those capacities as the Society has moved into higher gear under the driving leadership of President Paul Leverenz – our previous State president. So South Australian input to the board's activities was considerable – especially when Peter Scott's input to a working party on a national website is added to the list. At times indeed we were spending more time on national business than on the Society's own affairs – which made for an interesting balancing act.

The board met by teleconference monthly. Key issues included working on a policy for the national website and on developing the agenda for a two-day meeting in Canberra in late November. This will be only the second such meeting ever held, the first having been held in Melbourne in late 2006. Trying to forge a stronger national body for ME/CFS is a slow and difficult process given distance and the utter lack of resources available to the board. But it has to be done and it is being done and I pay tribute to Paul Leverenz for his energetic leadership.

The Multiple Chemical Sensitivity Campaign

It's been slow, but hopefully steady enough going in the struggle to get a better deal for people with chemical sensitivities this last year. It was the second full year of activity for the Minister of Health's Interagency Reference Group on MCS. Peter Evans and I are both consumer advocates on it and are joined by Cathie Powell and by Drs Ian Buttfield and Bruce Wauchope. The other members represent a range of agencies.

The meetings have been irregular, and at times little seems to be happening, but overall there has been a pleasing outcome in terms of a draft hospital protocols document and a policy for Government agencies booking venues. They have to take chemical sensitivities into account; a draft policy on controlling spraying for local government; and several other items.

Peter Evans and I also attended a summit for MCS lobby groups in Canberra convened by the Office of Chemical Safety. The purpose was to consider a draft report on MCS issues before the Office released it for public comment. It was a most interesting day for me, introducing me to a number of highly-talented and dedicated persons from all over Australia who are fighting for a better deal.

I do have to say that too much falls on the shoulders of too few in this regard. Peter Evans has been remarkable, but he, even with me helping a bit, can only do so much. We both feel that too many opportunities have passed us by this year to push harder – even on the Reference Group itself – because we've been too stretched. One example is the work we, along with Deb Paior, did with the Catholic Education Office. After meeting with the CEO over several years we have not secured a concrete outcome in terms of a policy on chemical safety and health for Catholic schools. The key CEO officer retired and we lacked the time and energy to keep pushing. I take this chance to urge our members who have a direct interest in the MCS campaign to come forward and take on bite-sized parts of the struggle.

Support groups, the Support Line and Facebook

Our one metro support group based at Glenelg folded its tents during the year. Our thanks to Marion Hansen who did so much to keep it going. On the other side of the ledger the newly-formed Riverland

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Support Group has had a great year under the enthusiastic leadership of Simon and Raelene Jackson. The new Clare Valley group has likewise met quarterly and so has the older-established Northern Yorke Peninsula group. David Shepherd convenes both with assistance from his wife Glenda. These are vital links in our chain of support to people with ME/CFS and we thank these leaders for their great contribution.

One of our greatest other assets is our long-running support line. It once fielded a team of volunteers but the group has shrunk over the years. This year our veteran fount of knowledge at the end of a phone, Elaine Balfort, retired from the work. This left only Alex Harris and Vicki Foote in the team and they have adopted a lower profile for the moment. We thank them all sincerely for their work and can only hope that we can continue to provide a support line service.

Meanwhile, new opportunities arise for helping people to get information about the condition. Committee member James Hackett has set up a Facebook group, ME/CFS Australia, which as I write has 64 members. It's not highly active at present but is building a presence and has several discussion threads going on topics such as helpful medications and good doctors. James' project is a great addition to our overall campaign to make the fullest use of new technologies to create a stronger community of ME/CFS persons in South Australia and beyond.

Thanks

Once again I want to thank the small band of people who do the work that aims to benefit South Australia's 7 000 or so ME/CFS sufferers and their families. Some I have mentioned already. The others include:

- **The committee.** Lynda Brett, Spen Langman, Emma Wing, Adrian Hill, Richard Cocker and Peter Mitchell continued serving the Society this year. Mel Cocker resigned during the year but the gap was filled by James Hackett who, as a Quorn resident, is our only country-based member. The committee has continued its tradition of meeting at the Wing family home which provides a relaxed setting and contributes to the pleasant way in which our business is conducted.
- **The office team.** Lynda Brett, Emma Wing and Mike Ritter have been mainstays of the office this year. Jacquie Smith has been the other most regular volunteer. Together they have struggled to keep up with the paperwork and phone calls and we thank them for their work. Without them we would be, to use the vernacular, stuffed.
- **Fundraising.** Once again we have cause to thank Carole Carroll for organising a successful badge day. It goes without saying that without other forms of income generating we are in the mire and it's great that she takes on this task each year. We had one particularly nice surprise this year when the Daimler Interest Group of SA wrote to us out of the blue with two cheques of $1 250 each for us and the Alison Hunter Memorial Foundation. The money came our way through the efforts of members Harold and Rosalie Parslow who pointed the Group in our direction and we thank them for that. Finally, we continued to gain support from the Bank SA Staff and Charitable Fund.

Future directions

We have one over-riding task in 2009. That is to build our base of reliable volunteers to staff the office and handle our administrative and financial affairs steadily. Without a firm base there we cannot direct our energies easily to the higher affairs and larger issues which you need your Society addressing: promoting research, encouraging medical education, lobbying on disability and other issues, continuing the MCS campaign and so on.

Until we do that it's a case of hanging in there. Please join with me in wishing us all luck on the journey.

Peter Cahalan ❀

Riverland Support Group's 1st birthday

The Riverland ME/CFS Support Group celebrated its first birthday on Friday 24 October 2008 at the Berri. Here is a report of the celebrations from members Raelene & Simon Jackson.

10 people arrived on a pleasant Friday morning to celebrate the Riverland ME/CFS Support Group's 1st birthday.

They were "Snapper" (Lindsay), Lyndon, Sandra, Corrado, Sue, Cheryl, Delly, Liz, Raelene & Simon. Unfortunately several people were unable to attend due to illness or prior arrangements.

A welcome is extended to our new members Sue & Lindsay.

It's hard to believe that a year has passed since the group had its 1st meeting at the Berri Library in 2007.

It was a much laid back gathering and people moved around the tables and mingled and of course the odd conversation was heard to include ME/CFS (funny about that) it was nice to be able to talk about any & everything not just ME/CFS and of course change the world.

Raelene spent Thursday evening whipping up a large sponge cake for everyone to savour.

Friday morning fresh cream was added just to make it more mouth watering, & I can tell you there weren't any complaints.

We hope that the group will still be here in another 12 months with all the enthusiasm & caring that everyone has, they are all a great bunch of people.

Thanks must go to the Society & members for all their support and to our great group who make it so successful.

Raelene & Simon Jackson
Riverland ME/CFS Support Group ❀

"A Group For Riverlanders With ME/CFS"

RIVERLAND ME/CFS
Support Group
Raelene and Simon Jackson

Phone: 0449120715

E-mail: riverlandcfssupport@gmail.com

Orthostatic intolerance

*By **David S. Bell**, MD, FAAP. The Lyndonville Journal. Lyndonville News May 2000 Volume 2 Issue 3. (With thanks to Susanna for submitting the article.)*

Orthostatic intolerance (OI) is a term used for illnesses, which are characterised by inability to maintain the upright posture. It is a group of illnesses that overlaps with CFS (Chronic Fatigue Syndrome) just as fibromyalgia does, and it may give up leads as to the underlying pathology of the illness. The most exciting new leads are happening in the world of orthostatic intolerance.

Because much of the literature on OI may be unfamiliar to the reader, I will try to summarise it. For those interested in more in-depth reading, I would start with the February 1999 issue of the *American Journal of the Medical Sciences*, (Am J Med Sci 1993; 317(2). This issue is devoted to a review of OI, and much of what I will say here is taken from that issue. The parallels with CFS are tremendous, starting with the title of the first article by David Robertson, "The epidemic of orthostatic tachycardia and orthostatic intolerance."

Defined simply, OI is the presence of symptoms due to inadequate cerebral perfusion on assuming the upright posture. The usual symptoms include fatigue, nausea, light headedness, heart palpitations, sweating, and sometimes passing out. Many persons with medically proven OI have been assumed to have emotional problems when they don't. Like CFS, there have been many terms in the past to describe this group of disorders, including "asthenia". Sound familiar? It is not known what is the exact relationship between OI and CFS, and up until recently studies in the two areas have followed separate tracts. The one very nice advantage OI has over CFS is that it can be proven and there are well defined subgroups.

Over the past year in our office we have been testing patients with CFS for OI by two methods. One has been a circulating blood volume study, and the second is a test for orthostatic intolerance. This test is easily done in the office and requires only a blood pressure cuff and a good nurse to catch the patient before passing out.

The test is relatively simple. The patient lies comfortably for ten minutes and BP (Blood pressure) and pulse are taken several times. Then the patient stands quietly (no moving around) with the blood pressure cuff on, and BP and pulse are taken every few minutes. This is a poor man's tilt test, and I would argue that it is more accurate because it reproduces exactly what happens to a patient waiting in the check out line at a supermarket.

A person with CFS nearly always has orthostatic intolerance. They describe the symptom of fatigue (which is not fatigue at all) which is characterised by being relatively OK while walking down the aisle of the supermarket, but being unable to stand in the checkout line. The orthostatic testing describes physiologically why this occurs.

There are five separate abnormalities that can occur during quiet standing:

a) Orthostatic systolic hypotension where the upper number (systolic) blood pressure drops.

The normal person will not drop BP more than 20 mmHg on standing up. One patient I follow with CFS had normal BP lying down (100/60) but it fell to 60/0 on standing. No wonder she was unable to stand up – a blood pressure that low is really unable to circulate blood to the brain. In any ICU (intensive care unit) they would panic seeing a BP like that. And she was turned down for disability because she probably was a hypochondriac.

b) POTS stands for postural orthostatic tachycardia syndrome.

A healthy person will not change their heart rate standing up for an hour. In a person with POTS, the heart rate increase 28 beats per minute (bpm). Some experts say the heart rate should exceed 120 bpm to have POTS. But either way, this increase occurs frequently in CFS. I think the increase in heart rate is linked to the decrease in blood volume. (Orthostatic intolerance has been called Idiopathic hypovolemia in the past.)

c) Orthostatic narrowing of the pulse pressure.

The pulse pressure is the difference between the lower number of the BP from the higher number. For example, a normal person with a BP of 100/60 would have a pulse pressure of 40. It is actually the difference between the upper and lower number of the BP that circulates blood. If the pulse pressure drops below 18, it is abnormal and blood would not circulate in the brain well. We routinely see in our patients with CFS blood pressures of 90-80, thus a pulse pressure of 10. The current record holder is a young woman

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Immunomodulation by vitamin B12

Immunomodulation by vitamin B12: augmentation of CD8+ T lymphocytes and natural killer (NK) cell activity in vitamin B12-deficient patients by methyl-B12 treatment.

J. TAMURA, K. KUBOTA, H. MURAKAMI+, M. SAWAMURA, T. MATSUSHIMA, T. TAMURA, T. SAITOH, H. KURABAYSHI* & T. NARUSE Third Department of Internal Medicine, Gunma University School of Medicine, Maebashi, *Department of International Medicine, Kusatsu Branch Hospital, Gunma University Hospital, Kusatsu, and +School of Health Sciences, gunma University, Maebashi, Japan.* Clin Exp Immunol *1999;116:28-32.*

SUMMARY

It has been suggested that vitamin B12 (vit.B12) plays an important role in immune system regulation, but the details are still obscure. In order to examine the action of vit.B12 on cells of the immune system, lymphocyte subpopulations and NK cell activity were evaluated in 11 patients with vit.B12 deficiency anemia and in 13 control subjects. Decreases in the number of lymphocytes and CD8+ cells and in the proportion of CD4+ cells, an abnormally high CD4/CD8 ratio, and suppressed NK cell activity were noted in patients compared with control subjects. In all 11 patients and eight control subjects, these immune parameters were evaluated before and after methyl-B12 injections. The lymphocyte counts and number of CD8+ cells increased both in patients and in control subjects. The high CD4/CD8 ratio and suppressed NK cell activity were improved by methyl B-12 treatment. Augmentation of CD3-CD16+ cells occurred in patients after methyl-B12 treatment. In contrast, antibody-dependent cell-mediated cytotoxicity (ADCC) activity, lectin-stimulated lymphocyte blast formation, and serum levels of immunoglobulins were not changed by methyl-B12 treatment. These results indicate that vit.B12 might play an important role in cellular immunity, especially relating to CD8+ cells and the NK cell system, which suggests effects on cytotoxic cells. We conclude that vit.B12 acts as an immunomodulator for cellular immunity. ❀

Comment from the ME/CFS Society of NSW Inc's Medical Editor, Nicole Phillips: *This is a small study and the subjects were B12 deficient. We know that cellular immunity is abnormal in CFS and there is some recent work looking at Vitamin B12 therapy. I would be interested to see this study in CFS patients without B12 deficiency to see whether the same immune effects occur.*

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with CFS whose pulse pressure fell to 6 mmHg before she passed out.

d) Orthostatic diastolic hypertension.

The lower number of the BP often reflects the systemic resistance, and while standing many persons with OI and CFS will raise their lower BP number (diastolic) in an attempt to push blood up to the brain. Sometimes this is dramatic.

One patient being followed with CFS had a low blood volume, about 60% of normal. While lying down, his BP was 140/80. After standing, his BP rose to 210/140 before we made him lie down. His pulse went up to 140 bpm. He felt rotten but refused to sit down by himself.

As an aside, everyone thought he was a fruitcake – a healthy looking man who said he felt poorly and couldn't work. He was denied disability as usual. Yet when we did the test, he was so determined to stand up I was afraid he was going to stroke out and croak. But he was standing with a BP of 210/140 and a pulse of 140 bpm. He is definitely not a wimp.

After the test, we gave him a litre of saline in the office because he didn't look too good and his blood pressure fell to 90/60 after an hour or so. It is important to note that we had measured his volume the day before so we knew he was hypovolemic. Normally you would never give saline to someone with high blood pressure, it just makes it go higher. In the future, orthostatic testing will require being done in an intensive care unit because these numbers are so scary. Now it is ignored and patients with CFS are called fruitcakes!

e) Orthostatic diastolic hypotension.

This represents a fall in the lower number of the BP, and seems to be the least frequent abnormality in patients with CFS I have tested. ❀

Interview with Dr John Chia

Dr. John Chia, MD, stunned the ME/CFS research world with his findings that 80% of patients had evidence of enteroviral infections in their gastrointestinal system. In this two-part interview, conducted in August 2008, Dr. Chia talks to ***Cort Johnson*** *about his personal history with this disease, how his ideas evolved, and the treatment options available.*

Introduction

Dr. Chia jolted the small chronic fatigue syndrome (ME/CFS) research world when he published a paper indicating that 80% of his patients had a previously undiagnosed enteroviral infection. This in combination with the results of a small but quite successful antiviral trial by Dr. Jose Montoya of Stanford thrust infections back into the spotlight.

Given this, it seemed appropriate to give a brief overview of the 'Pathogen Question' in chronic fatigue syndrome (ME/CFS) before Dr. Chia's interview. Because the interview with Dr. Chia is rather technical at spots, a brief summary of Dr. Chia's work is given below the 'Pathogen Question' overview.

The Pathogen Question – A Short Overview

The Pathogen Question: There may be no issue in chronic fatigue syndrome (ME/CFS) more complex or confusing than the role pathogens play in this disease. The disease often starts with some sort of infection but standard follow up pathogen tests are usually negative. Pathogen and immune research dominated the research agenda in the 1990s but dropped off greatly as research efforts brought sometimes intriguing but hardly jaw-dropping results; certainly there was little that appeared to be substantial enough to explain a disease as severe as this one. The underwhelming results resulted in a shift in federal funding priorities from the immune system to identifying the multi-systemic abnormalities found in the disease.

Immune Research: If pathogens can't be found directly, they can often be inferred by tests indicating that an on-going immune response is present. Researchers particularly look for high levels of powerful immune messengers called cytokines which travel through the blood activating the different components of the immune system. Chronic fatigue syndrome (ME/CFS) patients do show signs of immune activation and/or immune abnormalities (unusual RNase L activity, NK cell dysfunction etc.) but the significance of these abnormalities has been unclear to the traditional medical community.

Several of the abnormalities involve segments of the immune system which are relatively 'new' to science (RNase L) or which previously have not been deemed particularly important (NK cells). What researchers really wanted to see were blatant problems with T-cells or cytokines. Chronic fatigue syndrome (ME/CFS) cytokine studies have had mixed results, however; except for early in the disease, when many CFS patients are in the throes of infection, ME/CFS patients do not show the startling cytokine up-regulation seen in many infectious diseases.

Still, chronic fatigue syndrome (ME/CFS) patients' symptoms (fatigue, muscle and joint pain, sore throat, swollen lymph nodes) and the immune studies suggest immune activation is occurring. Dr. Chia believes ME/CFS patients' symptoms are caused by an inflammatory response but that the specific agents of that response – whether they are cytokines, chemokines or others – have not been elucidated.

Hidden From View: If pathogens are at the heart of this disease they will be unusual in either their type, or where they are found, or the kind of activity they engage in. Indeed each current theory focusing on pathogens in this disease assumes that they must be hidden in some way. HHV-6A, for instance, is not only difficult to detect but is found in a part of the body – the central nervous system – that is almost impossible to directly access. Dr. Chia suggests that enteroviruses in chronic fatigue syndrome (ME/CFS) could have an unusual structure and/or are located in a part of the body (gastrointestinal system) that pathologists rarely examine.

The question of whether a hidden chronic infection is present in ME/CFS has gained more currency as pathogen detection techniques have improved. Some researchers are looking for and finding more evidence of pathogen activity in ME/CFS and the Whittemore Peterson Neuro-Immune Institute is using highly sophisticated tests in an attempt to document the immune abnormalities present in at least a subset of ME/CFS patients.

Still, how important a role pathogens play in this disease is very much up in the air. Different research groups tend to find abundant evidence of 'their path-

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ogen' but not others – an unsettling situation for patients. Studies and anecdotal reports do indicate that antiviral therapies can work very well – at least for a time – in some patients, but there is little talk at present of a cure.

The researchers studying pathogens in ME/CFS are basically on their own; mostly without federal funding, they've had to raise the money on their own (Dr. Chia), rely on state and private funding (Dr. Peterson) or get help from drug companies (Dr. Lerner, Dr. Montoya) and other foundations (Dr. Montoya, Dr. Peterson). Will this small group of researchers unlock the key to this disease? Only time will tell.

Dr. John Chia, MD: Enteroviruses and Chronic Fatigue Syndrome (ME/CFS)

Dr Chia is one of the most articulate proponents of an infectious cause of this disease. He came to chronic fatigue syndrome (ME/CFS) the way many, if not most professionals have, via a personal connection. His son Andrew was 14 when he came down with a mysterious illness. It took a year in the lab for this infectious disease specialist to track down the bug (a Coxsackie virus) and several years before his son fully recovered.

"There's no doubt in my mind that this is a treatable disease."

By the time his son recovered, Dr. Chia had taken on chronic fatigue syndrome (ME/CFS) as a cause of his own and he had a new partner – his son. Andrew Chia graduated with honors from UC Irvine in 2005 and is now applying for medical school intending to focus on chronic fatigue syndrome (ME/CFS). Indeed, with Dr. Chia's wife offering support, studying chronic fatigue syndrome (ME/CFS) has become something of a family affair. At the London conference he laughed, saying "Other families go out to candlelight dinner; we head out to the lab" as he thanked his wife for her help.

The interview with Dr. Chia provides hope tinged with a dose of reality; this is a very complex disease and many questions remain unanswered, but Dr. Chia has created a window into it that has paid dividends and, given sufficient funding, will hopefully pay more in the future. That future, however, still appears to be quite distant.

A Personal Search: Dr. Chia is one of a very small handful of researchers who have displayed an interest in enteroviruses in chronic fatigue syndrome (ME/CFS) and he is the only researcher able to maintain a consistent focus on it over time. Although he's only recently become well known to the public, he's been studying the disease for over 15 years.

His first efforts: looking for traces of enteroviral infection (RNA) in the blood – were hardly promising, with early tests being positive in only about 5-10% of patients on the first pass. Many researchers might have left it there but, wary about closing the door on pathogens too quickly after his son's experience, Dr. Chia took another look.

Multiple tests suggested that up to 30% of the patients carried the pathogen. Importantly, while the percentage of positives in chronic fatigue syndrome (ME/CFS) patients increased as Dr. Chia repeated his tests, the percentage of positive controls remained low. As he's refined the testing process, the percentage of positive test results has increased; he now picks up the infection in about 30% of patients on the first pass.

A New Focus: Still, he felt the reliance on blood as a testing medium was questionable. Enteroviruses generally enter the body through the nose and move to the lungs, or enter through the mouth and move to the gut. Could the low blood levels be misrepresenting a more extensive infection in the gut? The high rate of gastrointestinal symptoms in his patients prompted him to take a look and what he found was somewhat shocking; multiple tests indicated that fully 80% of his patients (but only 20% of controls) had evidence of enteroviral infection in the gut. He now believes the stomach is the primary source of enteroviral infection with the viruses disseminating into the other organs from there.

There were more surprises; instead of killing the cells, the viruses appeared to be living inside them. (These kinds of smoldering infections are particularly difficult to detect in blood tests because they don't produce lots of 'loose' viruses (virions) that travel through the blood.) The inflammation he found was also 'mild'. This suggested that a localized inflammatory process centered on the infected cell was not likely the source of his patients' symptoms. Indeed, it is unclear exactly how the enteroviruses cause the symptoms of ME/CFS.

Extensive research suggested that enteroviral infections were the major problem in his patients. At the London Conference he reported that of 200 pa-

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tients about 9% had chlamydiae pneumoniae, 3% had Epstein-Barr virus, 1% had other viruses (cytomegalovirus, HHV-6, varicella-zoster, parvovirus), 22% didn't have any known pathogens, and a whopping 55% had a chronic enterovirus infection. Many of these infections (chlamydiae pneumoniae, Epstein-Barr virus, parvovirus, etc.) are treatable, but enteroviruses present special problems.

Treatment: Dr. Chia gathered a good deal of evidence indicating that rates of enteroviral infection were significantly increased in his patients. But were they significant? Were they causing his patients symptoms? Enteroviruses are, after all, amongst the most ubiquitous of pathogens with virtually everyone having been infected by one at one time or the other. Were they causing ME/CFS or were they simply another opportunistic infection that happened to set up shop in his patients?

It was his success in the treatment arena that convinced Dr. Chia he had found a major cause of this disease. As with his diagnostic work, Dr. Chia's learning curve in the treatment arena was steep. His son Andrew's case provides a case in point. Andrew had a Coxsackie (enterovirus) infection. Early attempts to use ribavarin resulted in reduced titers and improved health, but were followed by a quick relapse. Ribavarin plus interferon seemed to result in a complete return to health, but after Andrew pushed too hard on a vacation he relapsed badly and his antibody titers shot up (320) and stayed that way for 3-4 years.

Now Dr Chia often combines interferon-y (IFN-y) and interferon-delta (IFN-d), two very strong and very expensive ($5,000/month) drugs, to treat many patients with enteroviral infections (Dr. Chia gives the patient the option of going on a full dose for a month or ½ dose for 2-3 months). Because insurance companies consider the protocol experimental, patients are on the hook for the full bill. Side effects can be intense with some patients becoming bedridden in the early stages of the treatment but success rates have been high; according to his talk at the London conference about 50% of his patients with documented enteroviral infections are 'significantly improved' by the treatment.

Relapse rates, however, are also quite high, with most patients enjoying 9-12 months of greatly improved health followed by a relapse. Interestingly many of the worst off patients have received the greatest benefits. Dr. Chia reported that the best responders tend to have really severe muscle pain and that this pain often clears up completely in the first two weeks of IFN-y/IFN-b treatment.

Effectiveness: How effective is Dr. Chia in treating this disease? According to a lecture given at the 2008 London Conference about 15% of his patients appear to have non-enteroviral infections that are treatable. Fifty-five percent have enteroviruses and about a quarter of his patients are simply mysteries – they have no known pathogen. About half of the enteroviral patients respond well to the interferon treatments. This suggests that Dr. Chia is able to 'significantly improve' the health of about 40-45% of the patients he sees.

The Future: Dr. Chia has continued to expand his findings. Through EV Med Research, a privately funded R&D laboratory dedicated to defining the pathogens responsible in ME/CFS and developing treatment strategies, Dr. Chia is focused on determining how the enteroviruses maintain themselves in the stomachs of CFS patients and has been able to use special techniques to grow them in the lab – an important step that will allow him to test treatment options. Unfortunately, thus far the drug companies have shown little interest.

"There are many great researcher/physicians in the academic centers but few are interested in this illness, partly due to the lack of funding and approach. There is certainly not a lack of patients."

Recognizing that many patients can't afford the double IFN treatment protocol Dr. Chia is examining Chinese herbs to see if they can help to bolster the immune response and reports that some of them work in some patients and not in others. There are no quick answers to the enteroviral problem; Dr. Chia estimates it will take 7-10 years to develop an effective drug to combat them. With no drug companies hammering on his door, one wonders if even that is an optimistic projection.

Interview With Dr. John Chia, M.D. Part I.

Like so many researchers and physicians, your interest in this area is personal – your son has chronic fatigue syndrome (ME/

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CFS). Can you tell us what happened to him and what his level of health is now?

He is much better and can go the gym to work out every day. He can run 3 miles easily and swim one mile, 3 times a week. He can stay up 16+ hours every day. Rarely, he does look tired but it was not like what he had in the past. When he first got sick, he was not as sick as some of the patients I have seen over the last 10 years, but his energy level was probably no better than 4-5/10, and was much worse after minor exertion.

Before he became ill with the respiratory infection that was followed by CFS and GI symptoms, he was able to run 5-10 miles day and playing on the high school tennis team. His grades dropped due to severe brain fog but he eventually graduated from UC Irvine with honors in 3/2005. He spent most of his spare time in the past 7 years working in the laboratory to help me define this illness. He is applying for medical school at this time and he truly feels that this illness will make him a better physician in dealing with patients who are afflicted with this illness.

"I talked to enterovirus experts in the US, including the ones at CDC, but was told that chronic enterovirus infection does not occur in the immunocompetent hosts and this is not the cause of CFS."

There are many great researcher/physicians in the academic centers but few are interested in this illness, partly due to the lack of funding and approach. There is certainly not a lack of patients.

You're a rare breed of researcher/physician. Do you have a background in research?

Thank you for your kind comment. There are many great researcher/physicians in the academic centers but few are interested in this illness, partly due to the lack of funding and approach. There is certainly not a lack of patients.

I was in academic medicine for a few years (1985-1990), where I had great teachers who taught me scientific approaches to difficult problems. I worked in immuno-pathogenesis of infection (the immune response to infections that lead to disease state), immune responses to HIV. I have always been interested in undefined medical problems. I continued to publish papers, mostly case reports, after I left the bench and teaching position at Cedars-Sinai Medical Center in 1990.

After my son became ill, I critically looked at the published papers on viral infections in CFS and eventually decided to work on this area since enterovirus infection fit(s) the illness the best in most of our patients. I talked to enterovirus experts in the US, including the ones at CDC, but was told that chronic enterovirus infection does not occur in the immunocompetent hosts and this is not the cause of CFS.

(The issue of 'immunocompetence' is a central one in chronic fatigue syndrome (ME/CFS). People with impaired immune systems ('immuno-incompetent' people) such as untreated HIV/AIDS patients, people with organ transplants, etc. can get severe infections from common viruses the rest of us are able to hold in check. Since chronic fatigue syndrome (ME/CFS) patients don't display the gross immune abnormalities found in HIV/AIDS patients – and aren't dying from common pathogens – the assumption was apparently that researchers didn't need to look deeper for pathogens. But did the more subtle immune abnormalities found still leave patients at peril from hidden infections?)

Enteroviruses

Enteroviruses have been a kind of shadowy pathogen in chronic fatigue syndrome (ME/CFS). Some researchers have speculated for years that they play a central role but study findings have been inconsistent. They've never received the kind of attention that other viruses like HHV-6 and Epstein-Barr Virus (EBV) have. Now you've found evidence of unusually high levels of enteroviral infection in the stomachs of ME/CFS patients. How did you decide to focus on this particular type of virus and in this location?

The reason that "finding of enterovirus in the blood of CFS patients is inconsistent" is that viremia (virus in the blood) ceases after the body mounts an antibody response that would neutralize any virus that come(s) out of the dying or damaged cells. The yield for enterovirus RNA in the blood was low even by the best (researchers) from the UK, but our researchers could not reproduce the same findings.

(Dr. Chia appears to be stating that the enteroviruses are active inside the cells but are being destroyed as they leave them. Because of this, attempts to find them in the blood have been difficult; the few enteroviruses able to successfully get out of the cells and into the blood stream are hard to pick up by our current tests. A similar situation may occur with regard to HHV-6)

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The people who studied poliovirus, one of the enteroviruses, realized that the initial symptoms of the acute infection that led to CFS in many patients were consistent with enteroviruses. As science advanced, physicians often forgot the most important part of diagnosing a disease is the history and the relevant information. Later, but unfortunately, I think most people made the assumption that virus should be detected in the blood, as in the blood of HIV-infected or hepatitis B-infected patients, to have a chronic infection.

This assumption is obvious incorrect in some cases since reactivation of HSV or shingles is not usually accompanied by viremia. Furthermore, patients with HIV and hepatitis B do not usually have CFS symptoms even though they have more than millions of circulating viruses in the blood.

The first pathogen I worked on was Chlamydia pneumoniae (reported in CID 1999) since persistence in the coronary artery and in the respiratory tract have already been demonstrated. Ever since I found this intracellular organism as one of the treatable causes of CFS, I realized that most of the CFS cases are probably due to persistent infections of intracellular organisms. The largest groups are the viruses but organisms such as Chlamydia, Coxiella, Brucella can also do this. I also determined at this time, a proposed pathogen needs to have a favorable response to a specific antimicrobial drug in order to validate its role in this illness.

"As science advanced, physicians often forgot the most important part of diagnosing a disease is the history and the relevant information. Later... I think most people made the assumption that virus should be detected in the blood."

I went on to define the various pathogens in this illness since it is unlikely that one organism is responsible for all of the cases. It turned out that the initial symptoms and signs of infection in patients are the most helpful clues to the diagnosis of the acute infection and then the chronic persistent infection (diverse etiology of the CFS, CID, 2003). Dr. Stephen Strauss, the leader of CFS research at the NIH, who was one of my teachers, showed that EBV and other herpesviruses are not the major causes of this illness.

I have tried antiviral medications on more than several hundred CFS patients but only a few responded to therapy. We also saw a number of patients who had frequent recurrence of shingles in spite of daily antiviral therapy. We realized that there must a derangement of the immune response, which is not explained by the T-lymphocyte numbers. Interestingly, most of these patients gave a history of traveling and GI illness that preceded the onset of shingles. HHV6 and EBV, if reactivated, are difficult to see, but visible shingles, caused by Varicella-zoster virus (VZV), is a classic representation of reactivation of endogenous herpesviruses.

Even the GI doctors in academia do not think about chronic virus infection in the GI tract.

We also tried to find enterovirus RNA in the blood of CFS patients. We did more than 2500 blood draws from more than 600+ patients and did more than 200 blood draws with paxgene tubes, which preserved the RNA). The yield for a single draw in a regular blood tube is probably about 5% but increased to about 30% when multiple samples were obtained from each patient. The sensitivity of the paxgene is about 30% for one draw but it still does have not enough sensitivity as a routine test to capture the virus.

Many of the CFS patients complained of GI symptoms but the evaluation of these problems are usually done by the GI doctors. Even the GI doctors in academia do not think about chronic virus infection in the GI tract. In my recent paper, I talked about how infected respiratory secretions or ingested contaminated water or food would get (to) the stomach, and not (be) killed by the acid. Since many patients have upper GI symptoms, this provided the clue to look for the virus in the stomach.

We've seen more and more evidence of gastrointestinal abnormalities in chronic fatigue syndrome (ME/CFS) including leaky gut problems and increased rates of the 'bad' bacteria. These enteroviruses could clearly be contributing to the gut problems in ME/CFS but what about the fatigue, cognitive problems, widespread pain, etc.? Could these be caused by a gut infection?

Other investigators clearly demonstrated the presence of viral RNA in the brain and muscles of CFS patients but these findings were largely ignored. The cause of the symptoms you mentioned are not the direct effect of the gut infection but more likely viruses that disseminated to these areas, which are well-known sites of secondary infection. The brain thinks, the muscles contract on command, the cognitive dysfunction and myalgia are probably the ongoing re-

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sponse to the viruses in these organs, respectively.

You found that the stomach biopsies from most chronic fatigue syndrome (ME/CFS) (95%) patients had evidence of 'mild inflammation'. As a patient it's difficult to see how anything 'mild' could translate into something like ME/CFS. Is this mild inflammation enough to cause chronic fatigue syndrome (ME/CFS) or is something else going on?

Good question, but another common assumption. The inflammatory response may not be directly responsible for the dysfunction and only means something is there to attract a few inflammatory cells. We have not yet seen the true power of the viruses in our experimental approaches.

If I'm reading this correctly you've suggested in a past paper that enteroviral activity in chronic fatigue syndrome (ME/CFS) is a function of metabolic activity; i.e. the more patients exercise the more active enteroviruses are. Is there a way to measure this? Could you do something as simple as have patients exercise and then test for evidence of enteroviral activity?

This is a difficult test to do since the increase in viral replication is in the muscle cells but the infection is not cytopathic (does not kill the cells they live in), so one cannot easily measure the viral load in the blood after exercise. We have done these types of experiments but the results are not any more positive than the pre-exercise blood results. This just means that we cannot easily measure the virus's effect in the blood, which has made the search for these viruses difficult for the past 27 years. This does not mean we cannot measure the activity in muscles but this is not the area we work on.

"The brain thinks, the muscles contract on command, the cognitive dysfunction and myalgia are probably the ongoing response to the viruses in these organs, respectively."

What about the post-exertional fatigue in ME/CFS? In my case I can often get through an initial exercise period OK but it's the aftereffects in the hours and even days later that really get to me. Can you account for post-exertional malaise using enteroviruses?

I think the muscle fatigue, soreness and weakness are easier to explain based on the local effect of viruses in the muscle cells. What causes the post-exertional malaise is still a difficult phenomenon for me to explain. This may be due to increase in cytokine production in response to increase in tissue viral load, but it is also difficult to measure. The patients who felt so fatigued to start with, actually felt worse during interferon treatment. After the treatment finished, the patient felt much better as the tissue viral load decreased. This may be a partial answer to your question.

(Interferon is a cytokine. As an antiviral treatment it works to boost the immune response thus hopefully clearing out the pathogens present. Interferon is notorious for producing symptoms similar to those seen in chronic fatigue syndrome [ME/CFS]. Dr Chia appears to be suggesting that exercise may increase the viral load thus causing the immune system to respond with cytokines – thus making the patients feel worse, just as they did when he gave them interferon.)

You've suggested that the production of double-stranded enteroviral RNA produces an inflammatory reaction in CFS and this causes the symptoms of the disease. An inflammatory reaction seems to be a necessary component of most 'pathogenic paradigms' in ME/CFS. But while we do see increased oxidative stress, the results of the cytokine studies have been mixed. Shouldn't we be seeing really high levels of pro-inflammatory cytokines, particularly in exercise studies?

The studies on cytokines are all measured in the blood, an easy compartment to do studies, but the actions of these viruses are in the deeper tissues. The study on cytokine profiles should be in the tissue compartment rather than the blood. The results may still turn out to be the same but no one has done this, just like no one has looked into the stomach for the viruses!

The effects of these viruses on our cells/tissues are more complex than most of us think. Inflammatory responses to viruses are not the same as the responses to bacteria. Furthermore, the dysfunction seen in the tissues may not be related to inflammatory responses but to other properties of these viruses, as demonstrated in a transgenic mouse model of viral myocarditis.

Enteroviruses can be found all over the body; the gut, the muscles, the heart, the brain. Some studies have found evidence of enteroviral infection in the muscles of chronic fatigue syndrome (ME/CFS) patients but others have not. If you find enteroviruses in the stomach are they likely to be elsewhere? Do you plan to look elsewhere?

We do not plan to look elsewhere since there is a dilution effect with hematogenous dissemination (viruses spread from the initial site of replication through the blood to the secondary sites). If the virus is in the secondary sites of infection, it must have the capability to persist in the primary sites of infection (i.e. the stomach). The other sites, like the blood, are too dif-

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ficult to find the viral RNA consistently to be useful for long-term investigations. The nice data from other investigators are consistent with the pathogenesis of this infection, and provide a reasonable explanation for this disease when taken together.

An Interview With Dr. John Chia M.D. Part II: Persistence, Treatment and the Future

You're an infectious disease specialist and thus the types of patients you see, I presume, have an acute onset of ME/CFS that was associated with an infectious event. Do you have any idea if your findings will relate to gradual onset patients?

I do not pick the patients who came to see me. About 20% or more of the patients have so called gradual onset of CFS without a clear-cut flu-like illness. It is important to look for prior episodes of fatigue following a flu-like illness. Several patients became debilitated without an obvious preceding flu, but already had a prior episode of fatigue that lasted a few weeks to a few months years earlier. Many of them had frequent respiratory infection in the previous year, or "IBS" or functional dyspepsia for years before developing more fatigue.

"The study on cytokine profiles should be in the tissue compartment rather than the blood... no one has done this, just like no one has looked into the stomach for the viruses!"

The case I presented at the symposium illustrated this principle. The patient developed a respiratory infection in November but did not have abdominal pain and onset of fatigue until May of the next year. After the colonoscopy performed in August, the patient developed a severe flare of the viral infection, including fevers, myalgia, profound fatigue, abdominal pain, vomiting, and leukopenia, requiring hospitalization. She had 100,000 copies of viral RNA in the 40 micron section of the terminal ileum biopsy obtained one week earlier. It is not an accident that the flare happened after the colonoscopy and biopsy. The infection has been active but at different sites. One would swallow the infected respiratory secretions into the GI tract, but the initial GI symptoms will not manifest since the patient is still fighting the viruses in the respiratory tract.

Later on, which can be months down the line, after the immune response subsided, the viruses in the GI tract will start to grow. These are not necessarily two different infections. One patient had clearly documented viral myocarditis following severe bronchitis in December, but did not develop CFS until June the next year without another infection. We have seen a number of patients who could have respiratory symptoms for one week, to follow by severe GI symptoms; the latter often were attributed to the side-effects of antibiotics. However, the same cycles would occur even without taking the antibiotics. Months later, the patient would develop ME/CFS.

Furthermore, a number of patients would tell me the CFS started in March or April but could not even remember that they had recurrent bronchitis in the previous October through December. The GI symptoms could only be 1-2 days when the patients were traveling, which they thought were self-limited food poisoning. The interval between the initial infection and the onset of ME/CFS can be variable, so the absence of a flu-like illness has to be scrutinized by very thorough questioning.

You related several instances of a patient getting ill with one infection, seeming to recover and then being unable to recover from the next one. They seem to have recovered but apparently they really didn't. Do you have any ideas concerning what's happening between that first and second infection?

We have noticed that patients often would have two symptomatic infections before developing ME/CFS; the two episodes could be occurring within one year or years apart. In animal models, one can demonstrate that a prior viral infection can predispose to more severe, subsequent enterovirus infection. I believe, although this is difficult to prove in humans, that pre-existing antibody against a prior strain of virus can bind to, and yet not be able to neutralize, the new viruses, and eventually result in uptake by the monocytes. These infected monocytes become the "Trojan horses" that would home into the tissues such as brain, heart and muscles (tropism) and become macrophages. This process could be associated with variable inflammatory symptoms. One could not even start to suspect the "Trojan horses", if the process is clinically silent !

(Dr. Chia appears to be elucidating the following process; an enteroviral attack results in the production of antibodies against that one strain of enterovirus. Upon a subsequent second attack by a slightly different strain, the immune system misfires and – instead of creating

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new, different antibodies – raises the same antibodies, which bind to but are not able to completely neutralize the new virus. Immune cells called monocytes pick up these incompletely neutralized viruses and themselves get infected. As they travel around the body they infect other tissues.)

A closely spaced infection may predispose to a more severe, second infection when the immune response has not shifted back to normal. A shift to the Th2-dominant response occurred when patients received steroids at the onset of the respiratory illness associated with asthma, or when they developed "allergic rashes" after eating shellfish, or severe neck or back pain. Many of the patients who developed recurrent respiratory infections, often with asthma or allergic rhinitis, during childhood are Th2 -polarized in response to the next infection. If the infective pathogens do not persist in the body, then nothing more will happen. If the next infection is capable of persisting in the body, such as EBV, enterovirus, adenovirus, parvovirus and others, then chronic infection will occur.

"There is no doubt that an inappropriate immune response to persisting pathogens is an integral part of this illness."

An appropriate immune response, manifested as fevers, nausea, vomiting along with flu-like symptoms in acute hepatitis B, would usually eradicate the viral infection. But minimal inflammatory symptoms at the onset of this type of infection is often followed by chronic persistence of hepatitis B infection. An appropriate immune response is paramount in controlling and eradicating the initial infection.

(Again this suggests that an inappropriate immune response in ME/CFS patients does not eradicate the virus. This theory contrasts with findings of the Dubbo project which suggest that ME/CFS patients tend to have more severe symptoms during the triggering infection and a heightened cytokine response compared to people with the same infections who did not come down with the disease.)

If I understood this correctly, when you put biopsy tissues into culture the viruses didn't grow out unless you blocked the immune response. Does this mean that viral infections in chronic fatigue syndrome (ME/CFS) patients persist at least in part because of a problem with the immune response?

This was the only way we could grow viruses from human stomach tissues in monkey kidney cells. The *in vitro* finding does not necessarily correlate with the *in vivo* situation, but "this thinking" led to the experimental conditions that allowed us to grow the non-cytopathic virus. There is no doubt that an inappropriate immmune response to persisting pathogens is an integral part of this illness, as in tuberculosis or any other disseminated infections.

Do you accept gut biopsies from patients for testing for enteroviruses? If so, how do they arrange to have them sent to your office? What is the cost? Should they send more than one if possible?

The best area to biopsy is the antrum of the stomach, which is also the best place to look for H. pylori. We will need 5 unstained slides, on charged slides for immunochemical staining. The charge is $250 for the staining. This test is far more sensitive and specific as compared to serum antibody and serum viral RNA testing. The results of the comparison will be presented at the next IACFS meeting.

Treatment

Is there an effective treatment for these viruses? Are strong anti-virals needed? Will immune supportive therapies help? How about therapies designed to aid the gut such as probiotics?

What is the ultimate drug useful for the chronic viral infection remains unclear. I believe that antivirals directed against RNA replication (interferons) will be useful for this illness. Immune support or modulation may help but these viruses are capable of controlling our immune responses to allow their own persistence. Probiotics may help to change the microbial flora but will not change the viral infection in the lining of the gut.

It's been reported that some antivirals temporarily worked quite well but that your patients tended to relapse after the therapy has been stopped. This is an atypical response to anti-virals is it not? What's going on here?

It is not an atypical response if one assumes the infection is chronic and persistent. Do any antivirals for HIV actually cure the disease? One would be totally surprised if HIV does not rebound (relapse) when one stops HAART (highly active anti-retroviral therapy) in these patients, and the same often apply to hepatitis B and C. Do antiviral drugs cure herpes virus (HSV1 or 2)? Recurrence of disease is common after treatment for cold sores or genital herpes but this does not make the antiviral an ineffective treatment

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for the disease. The good news about what we have shown in our patients is that CFS is a treatable disease even if they relapsed after treatment. With better and more tolerable treatment, we should be able to control the symptoms and even put the patient into remission, but a cure may be difficult to achieve.

As someone who's treated over a thousand chronic fatigue syndrome patients could you outline what you've found to be more effective in treating the following symptoms:

My approach is not different from anybody else when treating the symptoms.

- Poor sleep: any medications for sleep but the usual hypnotics do not work well. Most of the patients need more powerful drugs.
- Fatigue: stimulants such as Ritalin or Provigil. The effect is quite variable.
- Pain: Ultram or Ultracet. Fetanyl patch seems to work better than the higher potency narcotics.
- Problems with concentration: stimulants as above.
- Depression/anxiety: SSRIs and anxiolytics.
- Orthostatic intolerance: Midodrine

Several of your patients have mentioned that you're trying oxymatrine. Is it an important part of your protocol? Are there any other over the counter immune enhancers you recommend or are exploring?

We have tried a number of Chinese herbs alone or in combination. The response is variable. Oxymatrine could boost the immune response, and we will present data at the next IACFS meeting. We'd like to get more funding to study Chinese herbs, since "Western medicine" is not going to come through for many years, especially when people are studying different viruses after 28 years of investigations. Some of the OTC (over the counter) immune enhancers have not been too helpful when tested in a carefully controlled study conducted by the National Institute of Complementary and Alternative Medicine. Thymosins from other species are not effective in the human since these proteins are species-specific.

The Future

Your attempts to identify the specific viruses (varicella-zoster, parainfluenza viruses, adenovirus and respiratory syncytial virus) present probably failed, as you noted, because of some technical problems. Is it necessary to identify the specific enteroviral agent present in order to come up with the right therapy? Where do you go now in your attempts to identify the pathogens?

The failure to identify these agents by staining did not mean the testing failed but rather meant these viruses were not found in the stomach by our testing. We have used multiple antiviral antibodies to see if other agents are in the stomach. The absence of other viral agents made the enterovirus even more important in our paper.

The NIH turned its back on pathogen research in chronic fatigue syndrome (ME/CFS) a couple of years ago. You, Dr. Montoya and Dr. Lerner, however, have recently come out with studies suggesting pathogens can play an important role for at least some chronic fatigue syndrome (ME/CFS) patients. You attended the Grantsmanship Workshop held by the Office of Research for Women's Health (ORWH) last September that was designed to provide CFS researchers opportunities outside of the NIH's CFS research program. How did that go for you? Did you find any funding opportunities?

I appreciated the opportunity to go to the Grantsmanship Workshop and met the delightful directors/leaders of ORWH who are genuinely interested in helping with this elusive illness. There are funding opportunities for CFS but there is not yet a clearly designated source of funding where one can easily get money. The funding will probably take 24 months from the start of the grant writing process, approval process and then final allocation of money. I hope that some of the great investigators can get funding quickly for their projects.

Do you have funding for more studies? What's the next step for you?

I have funding for our studies at this time. EV Med Research is a privately-funded R&D laboratory whose mission is to define the most common pathogens responsible for CFS and to develop effective treatment strategies for this illness. We will try to define the mechanism of viral persistence and immune response in the stomach tissues, a place we can consistently find the viral protein. We have reproducibly grown the enteroviruses from some of the stomach biopsies with special techniques. We'd eventually like to look at chemicals that can stop viral replication. We'd like to define the "viral form" that persists in the tissue. ❀

Dr. Chia's Research Foundation, the Enviromed Foundation, accepts donations. The Enviromed Foundation is focusing on developing diagnostic tests and treatment for chronic fatigue syndrome (ME/CFS).

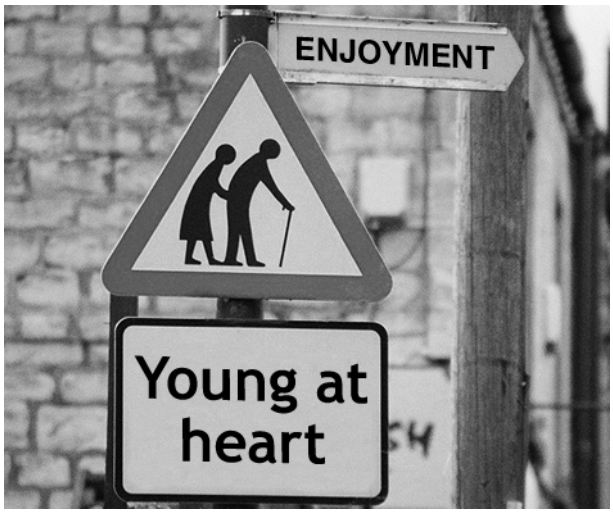
Cort Johnson's website is CFS Rising: http://phoenix-cfs.org. Cort can be contacted via email: phoenix-cfs@gmail.com.

Being elderly with ME/CFS (believe it or not – there are advantages)

*By **Maureen Jepson**.*

When the human body reaches or exceeds its allotted three score years and ten (70), it is automatically assumed that it starts falling to bits. Things are supposed to happen like short-term memory loss, balance problems, the need for assistance with walking, the need for plenty of rest, confusion, jumbled words etc. Does this sound familiar? Even the doctor said that at my age I should be putting my feet up. I told him if it wasn't for ME/CFS I'd be out on the golf course regularly and going for a brisk walk each morning.

The advantage of this overall perception by 'youngsters' is that I no longer need to explain these symptoms – apparently, it's all caused because I'm getting old. The resultant disadvantage is that it is difficult to assist in the awareness of ME/CFS when so much is put down to old age. My contemporaries also have a long list of ailments so it is difficult to get a word in edgeways about ME/CFS anyway.



How did all this time elapse? I can pinpoint the exact times when I first of all became middle-aged and then elderly.

At the age of 42 I was working at a local large company in charge of the secretarial centre (posh name for typing pool). My juniors were very junior – around 19 or 20. I quoted something from The Goon Show to a sea of blank faces. I became middle-aged then because I realised there was a whole generation that had not grown up with The Goon Show as I had.

Becoming elderly was even easier. My husband asked our then Home Help lady what attracted her into such work. "I have always wanted to work with the elderly," she said. So, at that moment we became elderly.

As a result of all these perceptions, I no longer have to explain, if asked, why I turn up for medical/dental/optical appointments with sometimes a walking stick (on a 'good' day) and other times with my walker or a wheelchair. I'm elderly – no questions asked. I no longer have to explain why I can't walk that far, or stand for very long. Because of my 'great age' (ha!) I get loads of assistance and consideration on these trips.

I can now avoid the stress of constant explanations and watching expressions of disbelief on the faces of younger people. I'm elderly – of course I am housebound, tottering and have a bad memory.

I have also found the enormous advantages of using a walking aid. If you have access to a walker with a seat or a wheelchair – use them. If you are not elderly, you may have to do a bit of explaining, but I can assure you that you receive better service wherever you go. People are alerted to the fact that there is something wrong with you (other than, in my case, old age). Just a good old-fashioned walking stick to help with your balance does alert people to the fact that staying upright is a problem.

Another very important advantage is that you will find the trip out will not be quite so exhausting because you have not had to do a lot of walking or standing.

Until you become elderly like me, use whatever walking aids are available to you to get better service and to save energy, bone up on your explanations and patiently wait for old age when you won't have to explain anything at all. ❀

Reprinted with permission from the Summer 2008 issue of Emerge*, official journal of the ME/CFS Society of NSW Inc.*

Explaining the inexplicable

Explaining ME (ME/CFS) can be a bewildering task, especially if you yourself are coming to terms with the illness. ***Johanna Tesson*** *bites the bullet.*

It is not easy explaining an illness about which there is so little scientific evidence. The task itself can take up a huge amount of energy, causing frustration and stress. There is a danger of becoming isolated when the people around you do not understand and without their support life can become very difficult indeed.

Unfortunately, a delayed diagnosis is not uncommon for ME, so a person with ME may not know what is happening to them for some time. Not surprisingly they will not know what to tell other people. Sue says:

"When I first had ME I really didn't understand what was happening to me. Friends who I played squash with could see I had problems, but it was difficult to explain.

When I found out that the pain was caused by inflamed tendons – that made sense to them, but it was impossible to explain the fatigue which was so intense compared with anything I had ever experienced before."

In the past ME was not well represented in the press and it has taken a long time to shed the 'yuppie flu' image. It is one of those illnesses, like diabetes, that is mostly invisible to others. A person with ME may look perfectly 'normal' on the outside while feeling terrible. Tory says:

"I still find myself now not making an effort so how I look is a bit more reflective of how I feel – to remind people that I'm ill.

It's terrible, I know, but even my husband sometimes says not to bother with make-up as looking pale helps encourage people's empathy (though it doesn't help me feel good about myself!)."

Also the amount of activity you do can be misleading to others because they are judging you by their own ability. Rachel told us:

"People ask why I feel so tired. They say I'm resting all the time because I'm just at home watching telly."

Her kids found it hard having a mum who was always exhausted. Small children in particular can struggle to come to terms with a parent's inability to join in or be around much. Rachel involved the children in helping her around the house.

Making things a team effort and saying 'thank-you' is a small but effective way of creating mutual understanding in the home.

So, how do you go about explaining your condition to people? Sometimes the most effective way is the simplest. Dorothy thinks:

"The best way to explain ME to friends and family is to give them some ME literature from a magazine or an ME newsletter or from an ME website."

You might want to come up with a couple of pat answers to take the anxiety away from common situations. Practise your response. It's important that you have confidence in what you are saying and it makes sense to you. Have a short explanation and a longer version for closer friends/relatives. You can talk longer to people if they are interested. Once you have said it, it's up to them.

Tory has fond an analogy which she finds useful:

"I tell people that living with ME is like living on the breadline when Everyone else is a millionaire.

I am so poor I have to 'spend' my energy very carefully. They cannot expect to do the normal things they do when they are with me as I can't afford them. It's the whole thing of trying not to overspend energy and going into overdraft.

They need to adjust themselves and their expectations in order to spend time with me."

Try to be understanding yourself – what might seem like common sense to you now may sound strange to others who don't have ME.

Sue feels that her partner seems to understand:

"But then sometimes he gets it so wrong and assumes I can do something – when it's clear to me that I couldn't do it even on a better day. My response is now a slightly exasperated 'I've got ME!'"

Try putting yourself in the other person's shoes.

Hazel explains her ME by describing feelings people can understand., e.g.

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"It's like being hung over and jetlagged on the day after the worst stomach upset you have ever had. Couple that with how you feel when you get up in the middle of the night when you go to the loo, as far as how your brain works!"

She finds this gets a good response and helps people to empathise.

Often people struggle with normal life when they first become ill. Co-workers, employers, family and friends may make unreasonable demands which you used to be able to handle. It can be hard to let go of what you used to be able to do. Do not be tempted to push yourself over your physical limit in order to fit in. It can cause a relapse and delay recovery. Sue found:

"It was awkward at work trying to explain that I never felt well and that some days the fatigue and brain fog made work impossible. As the frequency of my sick leave increased, before I got a year's sick leave, some colleagues did not really believe I was too ill to work."

As symptoms tend to vary from day to day and between individuals, ME can be difficult for people to pigeonhole. Where a label can be a difficult thing to live with, the upside is that at least people remember you are ill when it matters! Don't be afraid of seeming different.

"I was at a singing event on Saturday evening and most people were standing to sing," says Araya. "I stuck to sitting. It's frustrating – on the other hand, not half as frustrating as not being able to go at all!"

Socialising at home can take up more energy than you might think. Yvie plans in advance:

"My visitors are told I can handle an hour. Before they arrive I rest and when they leave I do the same. This sounds as though I socialise a lot – in fact I live a very quiet life."

For bigger events, advance planning is even more important. Yvie finds it easier to tell family or friends what her restrictions are beforehand so that she can relax at the event:

"I really wanted to attend my aunt's 80th birthday at her son's home. I arranged to have access to a bedroom in which to rest in peace and quiet.

During the afternoon I disappeared twice and relaxed listening to calming CDs. Nobody noticed I had gone! More importantly, I enjoyed myself because I felt in control."

Simply live within your limits and show by example, and people may be more understanding than you think. ❀

This article reprinted from InterAction*, the magazine for Action for M.E. (www.afme.org.uk).*

CFS/ME DEFINITION – 2002 OXFORD CONCISE MEDICAL DICTIONARY

When one looks up the new sixth edition 2002 Oxford medical dictionary under Chronic Fatigue Syndrome, ME, Myalgic Encephalomyelitis or Myalgic Encephalopathy you are referred to CFS/ME. It reads as follows:

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

Coming to terms with ME

ME (ME/CFS) is a long-term illness with a broad range of symptoms and, as we all know, their pattern and severity can vary from day to day.

In the May 2008 edition of Interaction, ***Cathy Stillman-Lowe*** *looked at how some people have come to terms with the ups and downs. This extract from the article highlights Emily's ideas of coping with the illness.*

This illness can last a frustratingly long time. The physiological causes are not yet clear, nor is there a magic 'cure'. ME is therefore a difficult condition to manage and there is no one way through the maze that is guaranteed to work for everyone.

Emily from London describes how she coped: "After the initial acceptance of a chronic illness – what comes next, I think, is adaptation which in itself brings further acceptance."

"I was certainly ready to change my life – ready to leave behind the misery of trying to keep up with my peers (an impossible task) and start something new and ME-friendly."

"Some of the decisions I made came immediately and others developed over time. All have stood me in good stead for surviving ME and have brought greater acceptance."

Emily's advice is to be realistic and enjoy life's simple pleasures. "Do what comes naturally to you. Focusing on your natural talents depletes less vital energy than trying to do something that you struggle with. It also leaves you far more fulfilled.

"For me this meant that home tuition was out but five years volunteering (from home) for the Association of Young People with ME (AYME) was in. It was an education and a career in one. It gave me back the confidence that ME had eroded over the years."

Be realistic

Emily advises: "No cure-seeking. I felt if I looked for a cure the disappointment of not finding one in every treatment I tried would leave me stuck in an unbearable cycle of disappointment. Instead I opted for symptom management and living my life to the best of my ability.

"As far as I could I felt that I should not look back nor forward to compare my abilities with other times. Instead, I must enjoy what I was capable of at the present time."

"I am convinced this has made a huge difference to my happiness over the years, but anyone with a chronic illness will know that it is not always possible and I have certainly cried many tears over ME, particularly regarding deterioration in health or lack of recovery."

"After experimentation with a boom/bust lifestyle that ended in a nasty relapse, I decided that the best course for me was (more or less) not to do something one day that I then wouldn't manage on each of the following days. In other words my daily activities must be consistent. It's a theory that seems to have worked for me."

Consistency and structure

Emily continues: "Following on from keeping things regular, I realised that my days needed a pattern that my body could get used to and rely on. This meant waking up at the same time every day (ideally in the morning even when further sleep would be needed during the day) and organising all daily activities – such as washing, dressing, eating, working and so on – to take place at regular times."

"It was so helpful that, with the advice of friends, when I became very severely affected, I turned the structure into a strict timetable. I divided up high and low energy activities as well as mental and physical activities with rest."

"It really put me in control of my life and has been

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easy to alter in response to fluctuations in my health. With the variety it naturally brings, I find myself able to do more than I could without it."

Practical stuff

Emily continues: "When we fall ill our lives are not usually set up for dealing with the disability that we become stuck with. The first thing I had to do was to get a wheelchair and then I had to get over my embarrassment at looking like an invalid rather than Emily. (Using the chair regularly soon banished that irrational idea.)"

"Next I claimed benefits; by this point I had worked out that ME could last a long, long time and I knew I needed to save as much money as I could for an uncertain future."

"Finally, I plucked up the courage to admit that I couldn't cope in the house without adaptations and disability equipment. I obtained a referral to occupational therapists. What they provided, and have promised to provide in the future, has been and will be invaluable."

Dealing with emotions

Dealing with emotions can be hard. Emily's last decision – to face her emotions – was indeed the most difficult for her to make and therefore took some time to come.

"Who wants to face all the losses, rejections, prejudices and changes that are forced upon us because we are chronically ill? Who wants to face their fears about the future?"

"For some time I thought that a diagnosis was sufficient for me to accept the illness. But it was not. So much pain comes with ME and you cannot bury it for ever."

"Eventually I came to terms with the fact that I needed medication (anti-depressants and anti-anxiety) as well as professional guidance. Sadly, the latter is hard to find unless you are willing, unlike me, to let a therapist (of the emotional variety) have a bash at curing you!"

"No, for me, other than the pills, the decision was to use exercises, the best of which, I think, is to divide all your negative emotions into simple statements under different headings. By doing this you can face them all one by one without being overwhelmed. The tactic I personally take is to give myself the advice I would tell someone else dealing with each emotion – it works a treat!"

"Acceptance of ME is not something that happens all in one go, but instead is a series of steps that we take throughout our illness. Some steps will take us further away from acceptance whilst others – such as meeting people with ME and thus gaining greater perspective – will bring us closer."

"We will probably never attain full acceptance of this horrendous illness, however, for we are human and our instinct is to fight, but we can gain something close to acceptance and that makes a tremendous difference to our lives." ❀

This article reprinted from InterAction*, the magazine for Action for M.E. (www.afme.org.uk).*

Going to hospital when you have ME/CFS and FMS

*By **Mary Campbell**.*

When going to hospital for reasons not related to Myalgic Encephalomyelitis (ME)/ Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FMS), I found my body does not react in the same way as other people because I have ME/CFS and FMS. This what I learnt from my experience, everyone is different and if you are considering surgery, some or all of these points may or may not be applicable to your situation.

Take information

Take copies of the Canadian Guidelines with you so that you have information should a medical professional question the validity of your illness. Discuss with your surgeon the impact ME/CFS may have on your recovery time, pain levels and recovery regime prior to surgery. If applicable ask them to put a note on your chart if they expect your recovery process to be different to normal.

Recovery time may be longer

I received keyhole surgery and this usually takes 6-8 weeks to recover. The surgeon looked at my chart, saw that I had ME/CFS and said I might take 6 months to recover. Luckily I was able to return to part time work within 2 months however it took me 2 years to fully return to my health level prior to surgery.

Pain may be extended

Typically, after a certain period of time the pain after surgery should be reduced. After my surgery my pain took a lot longer to subside and as such I needed strong pain medication for longer than most people.

Balance advice with your limitations

These days to minimise recovery time there is a focus on activity and quickly reducing pain medication. While I suggest we should all aim for that, it may need to occur at a slower rate for someone with ME/CFS and FMS than a normal person. For me in and out of hospital it was a matter of listening to my body and working within my limits.

Pain medication should be reduced according to your pain levels, not a pre-determined rate. If your pain is under control your body can focus on healing. This has to be balanced against not taking medications (including morphine and codeine) long term as that might damage your health.

Activity levels need to be the maximum in order to heal without causing a ME/CFS and/or FMS relapse. For example, if your health is such that normally you can't walk all day, then clearly walking up and down the hospital corridor all day is not appropriate. To work out what you can manage, look at your pre-surgery activity level, then take into account the surgery and rest accordingly. Lying in bed however can cause deconditioning, so do as much activity as recommended by medical professionals as you can manage.

Ask to see a doctor

If you are not receiving appropriate treatment, ask to see a doctor and/or ask for a second opinion. My experience in one country town hospital was that the nurses did not believe that I wasn't recovering like a 'normal' person. The only way I could receive proper treatment that took into account my health level at the time, rather than their predetermined opinion of my health level, was to ask to speak to a doctor. When I was told I couldn't see a doctor until the next day although I was crying with pain, I kept on asking to see a doctor and eventually one came and addressed the issue.

Complaints

If you were not treated appropriately there are methods to lodge a complaint. The first port of call is to contact the hospital and enquire about the complaints procedure. The next step is to write a letter including details of what happened and the objective of your complaint. Your objective may be to receive acknowledgement or apology and to know actions are being taken to stop anyone else being treated the same way again. Options to take the complaint further include complaints tribunals, legal proceedings and possibly discrimination/human rights complaints. ❀

A Marshall Protocol experience

South Australian author and ME/CFS sufferer, ***Andrea Rowland****, writes about her experiences with the Marshall Protocol.*

I began to get more tired than usual in 1998 and by the time my son was born in the year 2000, I was utterly exhausted. Of course all medical tests came back normal, and I was left frustrated and told to carry on. My health continued to deteriorate and more and more symptoms appeared. In 2003 I was finally diagnosed with Chronic Fatigue Syndrome and also Rickettsia. Antibiotics were prescribed for the next year but my health worsened and I finally realised that I wasn't getting any better.

By August 2006 I no longer could walk and was confined to a wheelchair. My right arm seized up and I now faced the world as a cripple. Most of the time bedridden, my GP and Physician were at a loss and could offer nothing.

In October a friend of a friend told us about a treatment called the Marshall Protocol and lent us some DVD's to watch. My GP visited at home and we asked him about this treatment. He said we were clutching at straws and that it was too risky. My physician also said he didn't totally agree with the research and advised against it. So the medical profession left me there. In that bed, to die. Feeling toxic all day and only tolerating to sit in a chair for no more than 10 minutes, I felt completely abandoned. My faith in Jesus stopped me from ending it all.

With no doctor backup, I commenced the Marshall Protocol in November. Not the Australian version that many doctors here are saying doesn't work. The proper American treatment uses a drug called olmesartan together with different antiobiotics. Staying out of daylight is also imperative and following a strict diet.

It was an absolute miracle as in only 2 weeks I was walking again and after 4 weeks the toxic feeling finally disappeared.

Improvements came every month and I slowly completed phase 1 of the three-phase treatment. I was able to run – yes, run – with my son! However during phase 2, I had trouble with my allergies and couldn't continue the program. NO doctor here would work with Dr. Marshall in America via the internet to help me stay on the program. Shockingly, this is the truth.

As for now, I am staying positive as I have maintained walking and am still driving every week. My homeopath has helped me a great deal and my new book, *JUST FOR A SEASON*, is a wonderful achievement. It is a detailed account of how I became ill and includes my poetry written over the past 8 years.

As for what will happen to me now? Only God knows that answer. ❀

For further information visit www.marshallprotocol.com. JUST FOR A SEASON is available from www.trafford.com. Andrea Rowland's email address is rowlandm@adelaide.on.net.

Disclaimer: *Before beginning any new treatment,* Talking Point *recommends consultation with trusted medical practitioners to ensure it is appropriate for your particular condition and circumstances.*

On my way

Having lived with ME for four years, ***Jonathan Raimondi*** *talks about the factors that have helped him accept his ME and move forward..*

I knew something was wrong. I was 23 years old, fit and strong. I played a lot of football, was writing a novel and my work as a shop manager was very physical. But in 2004 I started losing weight and became pale and gaunt. I felt absolutely shattered all the time and would fall asleep when I tried to write. I made mistakes at work and suffered from dizziness and fainting spells.

Above all, I had no spark. There was no life in my eyes. Friends suggested I should go to the doctor but, although it sounds stupid, my symptoms crept up so gradually and I couldn't put a finger on there being anything wrong. I thought I was just run down and that it would all just go away… until one morning I woke up and couldn't move.

I spent a couple of months very poorly in bed and had numerous tests. I continued to get worse. I had headaches, nausea and stomach cramps. I felt sore and bruised all over my body, my joints gave way and I had visible popping spasms and cramps throughout my muscles. I had to crawl up and down stairs, as walking a few steps would have me panting for breath and pouring with sweat like I'd run a marathon.

My brain didn't work, I had terrible memory problems and confusion – nothing made sense. I would sometimes wake up not knowing who or where I was, or put the phone down and not know who I had just spoken to. I couldn't concentrate on what people were saying and my own speech would slur.

When I was diagnosed with ME it was a relief. I suppose I thought I could just grit my teeth and see it off. I spent the next couple of months becoming mobile again, learning bit by bit to walk and dragging my legs along behind me, always to the point of complete exhaustion.

I even managed to return to work for eight hours a week, but I was a walking zombie and couldn't manage to do anything more than stack toilet rolls and cereals as they were all I could lift. This would leave me bedbound for the rest of the week. Giving up work was probably my first step in getting better.

After around a year I was at a point where I felt like I'd tried everything – exercise, work (and giving up work) more rest, less rest. It felt like the harder I tried the more I struggled. I finally realised that I couldn't just wish my ME away.

I felt so frustrated at nothing changing, I decided to change everything else. I needed to remind myself who I still was and, by getting rid of the things that didn't mean anything any more, I could see the things that did.

I sold hundreds of CDs and gave away lots of books and other belongings. I changed my room around, switched furniture, changed posters – anything I could to surround myself with my favourite things and feel as comfortable as possible.

And I did the same with people. I learnt to see the people who really cared about me and kept them around. Without a doubt, something changed. Even if it was just a psychological boost, I was taking control and getting unstuck.

I also began to get to grips with pacing. I used to feel that my ME was beating me if I stayed in bed – as though I was cheating or failing in some way and should have been doing more to get better. But I actually found that better rest helped my sleep settle at night and that after rest I felt a bit more normal and was able to do a little more.

I then had a really difficult six months or so. I seemed to catch every bug going. I didn't really know where the viruses ended and the ME began. I didn't know what I was doing wrong, whether I was overdoing it or just unlucky. I had no idea what to do and anything I tried seemed to make no difference.

So I hid away in my bad times – I never wanted anyone to see me at my worst. My friend's girlfriend had experienced ME with her mum. She was a great help and became a good friend. I never wanted anybody's sympathy, but she had empathy and that's a lot more useful. Having someone understand how hard I was trying and help me to realise how well I was doing gave me courage, hope and belief when mine had run out.

She and my friend moved to Spain for a year and wanted me to join them for a holiday. It didn't feel possible, but for the next six months I tried harder than I ever have at anything in my life. I really took control of my pacing. I kept a structured amount of rest and stuck to my routine. The times when I could be active seemed to grow and grow and I set myself targets, gradually doing more to try to match the hours I would need for the journey day.

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I was excited and scared about the holiday. My friends had only ever seen me at my best when I was doing something. They hadn't seen the preparations I had to go through before or the state I was in after.

I rested for days before I left for Spain and for a couple of days after the journey. The majority of the time there was spent in bed as I knew it would be, but the whole experience felt like a turning point for me.

It changed everything and I felt so proud. I could sit and stare at the sun shining on the sea, listen to the waves rolling in and feel myself stop. I cleared my head. I know a bit of sun does everybody good, but it gave me energy and soothed sore muscles and aching joints. I felt it wash over and relax me like a massage.

At the top of the hill where my friends lived was a small shopping plaza with a balcony that looked over a valley of miniature houses, cut across the sea to one side with mountains to the other. The first time I saw that view it was sunny and beautiful and the mountain tops were covered in the first snowfall of the year. I just stayed there for about an hour – I couldn't make myself look away. That feeling, after two and a half years staring at the same four walls, was something I'll never forget. It was like my brain gave a huge sigh of relief.

We sat looking at that view, watching the sun set over the mountains and put the world to rights. I spoke about all the things I had never spoken about before. Instead of tying it all up inside me and trying to do everything myself, I realised that I'd done as much as I could on my own.

I hadn't returned to the doctor since I was diagnosed. It was stupid but I didn't want the condition on my record for the sake of my future. I didn't want to be labelled and, though it sounds awful, I didn't want to think of myself as 'disabled' or admit how poorly I was. I'd also worried about not being taken seriously or being made to feel stupid and I resented the thought of anyone dismissing my illness.

When I finally decided to get some help my GP referred me to a consultant who was understanding about why I hadn't been before and was sympathetic and knowledgeable about the illness. He was encouraging and supportive about how well I had already done. It was a huge relief and gave me a real boost. He made me feel very proud of myself and I felt he genuinely wanted me to succeed. I went though all the tests until I had the official diagnosis.

My flat is small but it's easy to look after and I've managed fine. I've also got better at asking my friends for help. My aches, pains and spasms are easing. My recovery and stamina are improving and I'm getting and looking stronger all the time. Best of all, my brain works again. I'm feeling more confident and more myself every day.

My best days used to stick out like a sore thumb. They were something to catch up with, to aspire to, but now the improvements are almost week to week and it's all just sort of happening without thinking too much about it. I don't have to try so desperately hard to force improvements and prove to myself and others that I'll be okay. I can tell from my friends that I'm a bit better each time they see me. They're excited and I don't feel like I'm doing a bad impression of myself any more, like I'm trying to think what I would normally have said or done. I'm making people laugh again.

I'm not all the way there yet. I still have to spend an awful lot of time resting and have to be very strict with that or I'm soon laid up again. But it doesn't feel like I'm just making improvements any more – it feels like I'm getting better. ❀

Reprinted from InterAction*, August 2008*. InterAction *is the quarterly journal of Action for ME, UK*.

ME/CFS Australia (SA) Inc wishes you and your loved ones a very merry Christmas and a happy new year!

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, neuro-cognitive, 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	Andrea and Mark	8552 9857
Whyalla	Peter	8644 1897
Yorke Peninsula		
(central)	Caroline	8837 4335
Yorke Peninsula		
(northern)	David	8862 1668
Yunta	Gloria	8650 5938

If undeliverable return to:
ME/CFS Australia (SA) Inc
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