2016 Issue 1

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AND MORE
**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**

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Note: It is our policy to ignore anonymous correspondence.

**Disclaimer**

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

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

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

Always consult your medical practitioner before commencing any new treatments.

**Notice to Vendors**

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

If you have information about products which you wish to bring to the attention of the Society, you should direct it to the Secretary:

- PO Box 28, Hindmarsh 5007

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

**Management Committee 2016**

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

- Acting President: Emma Wing
- Secretary: Peter Mitchell
- Treasurer: Sheree Ellis
- Membership/Seminar officer: Anne Fleuren
- Committee members: Penelope Del Fante
  Penelope MacMillan

**Membership (by donation)**

We offer membership on an individual basis, i.e., people pay what they can afford.

Membership is by donation – whatever you can afford.

The nominal membership fee is $5. Anything above $5 will be receipted as a tax-deductible donation.

It costs the society about $80 per year, per member, to operate. If you can donate more to help subsidise those less well-off, we would all really appreciate it.

Membership is renewed on July 1st every year. If you are unsure about your current or past membership status, please contact membership officer Anne Fleuren:
afleuren@internode.on.net

**Online Payments**

We are able to receive payments over the Internet, via www.givenow.com.au/sacfs. New members will still need to send us their membership form details, but can do that electronically (via email). Existing members just need to advise us of changes. Alternatively, you can still post your information and payment to us.

**Donations**

Donations are an important source of income for the Society and are welcome at all times. All donations of $2.00 or over are tax-deductible and a receipt will be issued.

**Talking Point**

Talking Point is the official journal of ME/CFS Australia (SA) Inc. It is financed primarily by members’ fees and donations.

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

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Society Seminars For 2016

Saturday 20 February 2016
1:30 pm
**Topic:** Dr Katia Ferrar and Ms Minh Pham from the University of South Australia discuss the research study “Physical activity and time use patterns of adults with chronic fatigue syndrome”.

Saturday 9 April 2016
1:30 pm
**Topic:** A screening of the ME/CFS documentary, *Forgotten Plague*.

Saturday 25 June 2016
1:30 pm
- **Dr Ian Buttfield** discusses the Australian National Register Of Environmental Sensitivities website.
- **Mr Max Nelson** discusses his PhD and two-day bike test study.
- **Dr Katia Ferrar** presents her information document on her research ([see above](#)).

Saturday 27 August 2016
1:30 pm
**Annual General Meeting** (see page 7)

Saturday 19 November 2016
1:30 pm

**Location**
All seminars are held at Sophia House, Cabra Dominican College, 225 Cross Road, Cumberland Park. [See map below left](#)

**How to get there**
Sophia House is at the western end of Cabra Dominican College (i.e. the seaside end, not the hills end). It’s ten minutes from the city centre by car or bus. Turn west (towards the sea, not the hills) from Goodwood Road. The carpark entrance is off Cross Road at the small Sophia House sign on a brick gate post. There’s a walk from the carpark to Sophia House of about 50 metres but you can also be dropped off at the door as some people are. Sophia House is a particularly comfortable venue with chairs, a couple of sofas and a decent carpet if you are better lying on the floor. Bring whatever you need to be comfortable.

**Reminders**
Many people with ME/CFS are extremely chemically sensitive, so we ask attendees to refrain from wearing aftershaves, perfumes etc, and please refrain from smoking at our meetings. We will make every effort to clear the venue of fragrances and chemicals. There have been MCS issues there in the past and we have been in contact with Sofia’s management to find ways to minimise or remove any potential issues for future meetings. We will continue to make every effort we can to minimise these problems at our meetings.
Society Matters: New Volunteers / Office Closure And Relocation

New Volunteers

There’s been a surge in volunteers that we are pleased to find. We have had a few vacancies in the society recently, with people moving on, so we are very pleased to confirm the new people coming to help us, or returning after a break in Lorenzo Pizza’s case.

Management Committee: Penny Del Fante, Anne Fleuren, and Penelope McMillan have all nominated for the committee. You may recognise them from previous seminar audiences, or from Facebook. We met with them and we were very pleased to have them nominate. They bring a wealth of experience from different fields, knowledge of the illness, and some very positive energy. This is exactly what we needed. It will help us to free up energy for us all: will be able to strengthen our core services, get back up to speed with our additional elements (like bulletins, fundraising, grants, etc.) and hopefully broaden to some of the projects we have had on the back-burner.

Treasurer: Sheree Ellis is another new member to our team, who has been volunteering with John in the office this year, and will be taking over from Lyn Bird. Sheree has experience with bookkeeping and it’s a huge relief to have someone able to fill that vacancy. Thanks go to Lyn for all her help over the recent years, as treasurer and generally on the committee. We appreciate her help setting up our online meeting system. This has allowed us to operate successfully with committee members located all around the city and with our president in Quorn.

Seminar Officer: Lorenzo Pizza is returning for a second tour of duty, having been the Membership Officer and Seminar Officer in the past. We’re sure many people will remember him for his cheerful management of the seminars in the past. Thanks to Jenni Gay who has volunteered for a number of years also in both of those roles, on the committee with us, and on the national board in the past. We have had some enormously successful seminars over the time Jenni has coordinated them. She has done a great job putting together a varied program of speakers each year.

Many thanks to everyone: continuing, incoming and outgoing. Your efforts are greatly appreciated. We wish Jenni and Lyn all the best for their futures. Together we have been making a significant difference to ME/CFS sufferers, and our future is looking strong.

Best regards,

James, Emma, Peter, and Spencer
(Members of the Management Committee), Feb 2016

Office Closure And Relocation

We have moved out of our office on Port Rd, Hindmarsh. Thank you to all the volunteers who helped with the move, and to committee member Anne Fleuren’s parents who are now storing the bulk of our furniture. And thanks to the others who are holding our files and other resources.

We are in the process of looking for new premises, and in the meantime, all of our usual services are still active. We are using the appeal for new premises as an opportunity to help educate politicians and the public about the plight of ME/CFS sufferers by explaining our difficulties in the appeal letter.

Again, if any of you know of charitable landlords of commercial or retail real estate who might be able to help us, we would be pleased to hear from you. Ideally we’d like a central location with easy disability access, approximately 100 m². We don’t require a prominent position. There seems to be a lot of vacant premises at the moment, so we’re hoping someone would see this as a good opportunity to help us while we receipt the value of the donated rent in return and cover some of the outgoing costs for them.

• 1300 Line will remain functional
• Talking Point continues unchanged
• Website continues unchanged
• PO Box continues unchanged
• Email contact is still available

Please contact us via one of those ways if you require any assistance.
Society Matters: Resignation Notice

Dear members and friends,

It is with some disappointment that health and personal reasons are causing me to need to resign my position as president.

I have had ME for ten years. I have been volunteering for the society for nine of those, and president for nearly seven.

When the president’s position became vacant, the committee encouraged me to take it. I cautiously accepted, as a kind of caretaker president, on the basis that my health was not good, and that I would do the best I could under that constraint, while hoping that a non-sufferer living in Adelaide could be found to take over.

As we all know too well, the ME/CFS environment is complex and often difficult. A lot of the work has been challenging and often not good for my health or wellbeing; the same goes for many volunteering ME/CFS sufferers. A lot goes on behind the scenes. However, I have also had a lot of satisfaction from the work we have done, and I’ve enjoyed a lot of it. Over the last seven years, we have introduced a number of successful initiatives, some of which have been adopted by other ME/CFS organisations. I’ve made a lot of great friends and I’ve enjoyed being a part of a team working to help people who generally don’t get a lot of support, despite their desperate need.

When I started, we had just lost the regular $12,000 donations (from Mrs Miller) that had been previously keeping us afloat. We needed to adapt to avoid running out of funds – we had 5 years left, at the rate we were going. The Membership by Donation system, with the generosity of our membership, meant that we are now in a better financial position than we were, while relieving the burden on those who need our help but can’t afford to pay more. Ideally, we’d prefer not to charge for membership at all, but we need to find corporate or government funding to support that.

There is still a long way to go and I’m sorry I can’t stay any longer to help further, but I intend to continue volunteering in another capacity, if and when circumstances permit. Most of the work has been prepared for a political and public campaign to promote the illness and the society’s need for support, and I think that has potential to make a significant difference.

I’ve always enjoyed volunteering and I recommend it, if your health permits. There are a number of small jobs that can be done from home at a time that suits you. If you can volunteer or know someone else who can help, please let the society know. We have a good group of long-serving volunteers, but could do with more and new committee members, and in particular of course a new president. My own feeling is that an ideal president would be a relative of a sufferer with a professional background, someone who has the energy we lack, to follow through with some of the great ideas and initiatives already in the pipeline. If you know of someone who may fit the bill, please ask them to talk to us.

Finally, I’d like to thank everyone who has shown their appreciation and support for our efforts, and my friends in the society for all of their help and support over the years. I wish you all the best and I hope the society can continue to provide the services it does while adapting to the difficulties, and continuing to grow. I will remain in contact and attend the seminars when able, so look forward to maintaining the many friendships I’ve made during my time with the society.

There are so many people I’m grateful to. I can’t thank them all here but I’m particularly thankful to the stalwart regulars. Aside from my gratitude for them, I’m sure the Nordic Noir discussions and musical detours will continue with the Peters and Mel. There’s no stopping John and his perpetual, pun machine’s comic relief. The Langmans’ (?Langmen) Polish delicacies and hospitality, and Emma’s constant, selfless support has also been greatly appreciated. Thank you, to you all.

Best wishes,

James Hackett

Sunday, 8th May 2016
Dear Members,

I am writing to inform you of a number of things.

1. President Changes — For those who receive our E-bulletins you will already know that James Hackett has resigned after seven years of service as ME/CFS Australia (SA) President. [See previous page] His health has had to become his main focus, and after much consideration he decided to resign immediately. This has meant, as Vice President I had to take on the role as President. This was a job I did not want nor ask for as I too was planning on resigning at the next AGM after 10+ years on the committee, and more volunteering. Nevertheless, I have taken on the President’s role and will do the best job possible.

So what this means is, we are calling an Annual General Meeting to take place on August the 27th. I will serve the next few months as President and do the best job I can but come August the position of President will become vacant along with Vice President.

Secretary, Peter Mitchell, has also decided to resign come the AGM, so his position too will be vacant at the AGM. All three of us resigning this year was not planned, and we all came to the decision on our own. It just happens to be unfortunate that it all be this year. Spencer Langman has also decided to retire as a committee member.

The committee will still have four ongoing committee members. However, we need more members to join. So I’m asking you to please, please consider becoming a committee member. If you have ever thought about it, now is your chance. We’d like to add at least four more members to the committee and we invite you to meet with us if you are interested in joining.

Please also consider asking close friends or family to see if they can spare a few hours a month.

2. Membership Renewal Notice — It is that time of year where your membership has come up for renewal. We have made two small changes. We have replaced it with age brackets instead. We have also removed the box for SMS seminar reminders, this will no longer be happening as a result of cost-saving measures. Other than that our form remains the same. Please fill in your form and return it as soon as you are able or bring along to any seminar.

3. Constitution Changes — We are making some changes in order to bring it in line with current standards in 2016. You will have a chance at the AGM to voice your opinion about the changes.

4. Important Diary Dates —
   25th June: Dr Ian Buttfield will be discussing the ANRES (Australian National Register of Environmental Sensitivities) website.
   Max Nelson will be discussing his PhD and two-day bike test study.
   Dr Katia Ferrar will be presenting her information document on her research, “Active Video Gaming To Increase Physical Activity In Adults With ME/CFS”.
   27th August is our Annual General Meeting. Speaker to be confirmed.
   I urge everyone who is well enough to please attend. If you are too ill to attend, perhaps a family member or friend can come in your place.
   19th November: Speaker to be confirmed.

I hope you are all coping as well as possible in this extremely wintery weather, that life is treating you as well as possible, and that you especially are treating yourself well.

Emma Wing
Acting President
Friday, 17 June 2016
Study Finds Medical Marijuana Safe And Effective For Chronic Pain Relief

By Charles Moore in Fibromyalgia News Today.

In a national multicenter study investigating the safety of medical cannabis use by patients suffering from chronic pain, a research team led by Dr. Mark Ware from the McGill University Health Centre (MUHC) in Montréal, Canada has found that chronic pain patients who used cannabis daily for one year, when carefully monitored, had no increase in serious adverse events compared to pain patients who did not use cannabis. The study results, which have been published online in The Journal of Pain, will serve as a benchmark study on cannabis side effects of when used for pain management.

The Journal of Pain Open Access paper, entitled “Cannabis for the Management of Pain: Assessment of Safety Study (COMPASS)” (The Journal of Pain, 2015; DOI: http://dx.doi.org/10.1016/j.jpain.2015.07.014), is coauthored by Mark A. Ware, MBBS MRCP MS, Tongtong Wang, BMed PhD, Stan Shapiro, PhD, Jean-Paul Collet, MD PhD, Aline Boulanger, MD, John M. Esdaile, MD, Allan Gordon, MD, Mary Lynch, MD, Dwight E. Moulin, MD, and Colleen O’Connell, MD.

The coauthors note that Cannabis is widely used as a self-management strategy by patients with a wide range of symptoms and diseases including chronic noncancer pain, but the safety of cannabis use for medical purposes has not been systematically evaluated.

They conducted a prospective cohort study to describe safety issues among subjects with chronic noncancer pain, with a standardized herbal cannabis product containing a consistent 12.5% Tetrahydrocannabinol (THC) was dispensed to eligible subjects for a one-year period. Controls were subjects with chronic pain from the same clinics who were not cannabis users. The study’s primary outcome consisted of serious adverse events (SAEs) and non-serious adverse events (AEs). Secondary safety outcomes included pulmonary and neurocognitive function and standard hematology, biochemistry, renal, liver and endocrine function. Secondary efficacy parameters included pain and other symptoms, mood, and quality of life.

Beginning in 2004, 215 individuals with chronic pain were recruited to the cannabis group (141 current users and 58 ex-users) and 216 controls (persons with chronic pain but no current cannabis users) from seven clinics across Canada, located in Fredericton, New Brunswick; Halifax, Nova Scotia; London and Toronto, Ontario; Vancouver, British Columbia; and Montréal, Quebec (two sites). The median daily cannabis dose was 2.5g herbal cannabis per day from a licensed cannabis producer and dispensed through the hospital pharmacy at each site. Patient participants collected their supply every month after completing the necessary visits and tests, with medication delivered via smoking, vaporization, or as edibles. There was no difference in risk of SAEs between groups. Medical cannabis users were at increased risk of non-serious AEs (adjusted most of which were mild to moderate such as headache, nausea, dizziness, somnolence, and respiratory problems associated with smoking), and there were no differences in secondary safety assessments.

Based on the study findings, the researchers conclude that quality-controlled herbal cannabis, when used by cannabis-experienced patients as part of a monitored treatment program over one year, appears to have a reasonable safety profile, and that longer term monitoring for functional outcomes is needed. The study was registered with http://www.controlled-trials.com (ISRCTN19449752).

“This is the first and largest study of the long term safety of medical cannabis use by patients suffering from chronic pain ever conducted,” says lead author, Dr. Ware, pain specialist at the Montreal General Hospital of the MUHC and associate professor in Family Medicine and Anesthesia at McGill University, in a McGill release “We found that medical cannabis, when used by patients who are experienced users, and as part of a monitored treatment program for chronic pain over one year, appears to have a reasonable safety profile.”

Along with information on adverse effects,
subjects underwent lung function and cognitive testing, and were asked about their pain, mood and quality of life over the one year of follow up. Several of the subjects underwent complete panels of blood tests for routine biochemistry, liver and kidney function, and selected hormone levels.

“Our data show that daily cannabis users had no greater risk than non-users (control group) to experience serious adverse events,” says Dr. Ware, who is also a researcher for the Brain Repair and Integrative Neuroscience Program at the RI-MUHC. “We found no evidence of harmful effects on cognitive function, or blood tests among cannabis consumers and we observed a significant improvement in their levels of pain, symptom distress, mood and quality of life compared to controls.”

However, the researchers did report an increased risk of non-serious adverse events in medical cannabis consumers such as headache, nausea, dizziness, somnolence, and respiratory problems associated with smoking.

“It is important to note the limitations of the study,” adds Dr. Ware. “Patients were self-selected, not randomized, and most were experienced users. So what we are seeing is that it appears to be a relatively safe drug when used by people who have already determined that it helps them. We cannot draw conclusions about safety issues of new cannabis users.”

A previous study led by Dr. Ware published in 2010 in the journal CMAJ (Canadian Medical Association Journal), found that patients with chronic pain have reported using smoked cannabis to relieve pain, improve sleep and improve mood.

The study, entitled “Smoked cannabis for chronic neuropathic pain: a randomized controlled trial” (CMAJ October 5, 2010 vol. 182 no. 14 First published August 30, 2010, doi: 10.1503/cmaj.091414) is coauthored by Dr. Ware with Tongtong Wang, PhD, Stan Shapiro, PhD, Ann Robinson, RN, Thierry Ducruet, MSc, Thao Huynh, MD, Ann Gamsa, PhD, Gary J. Bennett, PhD, Jean-Paul Collet, MD PhD, variously of McGill University, Boreal Primum of Montral, Quebec; and the University of British Columbia Centre for Applied Health Research and Evaluation in Vancouver, British Columbia.

The coauthors note that chronic neuropathic pain affects 1% to 2% of the adult population and is often resistant to standard pharmacologic treatment. Many patients with chronic pain have anecdotally reported better results using cannabis to relieve pain, improve sleep and improve mood.

Participants in the crossover trial (International Standard Randomised Controlled Trial Register no. ISRCTN68314063) with post-traumatic or postsurgical neuropathic pain were randomly assigned to receive cannabis at four potencies (0%, 2.5%, 6% and 9.4% tetrahydrocannabinol) over four 14-day periods, and inhaled a single 25-mg dose through a pipe three times daily for the first five days in each cycle, followed by a nine-day washout period. Daily average pain intensity was measured using an 11-point numeric rating scale. The investigators recorded effects on mood, sleep and quality of life, as well as adverse events.

Twenty-three participants were recruited (mean age 45.4), of whom 21 completed the trial. The average daily pain intensity, measured on the 11-point numeric rating scale, was lower on the prespecified primary contrast of 9.4% v. 0% tetrahydrocannabinol (THC) (5.4 v. 6.1, respectively) Preparations with intermediate THC potency yielded intermediate but nonsignificant degrees of relief. Participants receiving 9.4% tetrahydrocannabinol reported improved ability to fall asleep faster, more drowsiness, and improved quality of sleep relative to controls receiving 0% tetrahydrocannabinol. THe investigators found no differences in mood or quality of life, and the most common drug-related adverse events during the period when participants received 9.4% tetrahydrocannabinol were headache, dry eyes, burning sensation in areas of neuropathic pain, dizziness, numbness and cough.

The researchers conclude that a single inhalation of 25 mg of 9.4% tetrahydrocannabinol herbal cannabis three times daily for five days reduced the intensity of pain, improved sleep and was well tolerated.

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“I was completely revitalised,” says Karen. “Suddenly, I could be sociable again. I would go to work, go home, eat dinner and feel restless.”

Karen (not her real name) experienced this relief from chronic fatigue syndrome while taking a drug that is usually used to treat the blood cancer lymphoma and rheumatoid arthritis (see “Karen’s experience”, below).

She was one of 18 people with CFS who reported improvements after taking rituximab as part of a small trial in Bergen, Norway. The results could lead to new treatments for the condition, which can leave people exhausted and housebound.

Finding a cause for CFS has been difficult. Four years ago, claims that a mouse virus was to blame proved to be unfounded, and some have suggested the disease is psychosomatic.

The latest study implicates the immune system, at least in some cases. Rituximab wipes out most of the body’s B-cells, which are the white blood cells that make antibodies.

Øystein Fluge and Olav Mella of the Haukeland University Hospital in Bergen noticed its effect on CFS symptoms in 2004, when they used the drug to treat lymphoma in a person who happened to also have CFS.

Several months later, the person’s CFS symptoms had disappeared. A small, one-year trial in 2011 found that two-thirds of those who received rituximab experienced relief, compared with none of the control group.

The latest study, involving 29 people with CFS, shows that repeated rituximab infusions can keep symptoms at bay for years.

“Eleven of the 18 responders were still in remission three years after beginning the treatment, and some have now had no symptoms for five years,” says Fluge. “Suddenly, their limbs started to work again and their hands were no longer cold or sweaty.”

“I am very intrigued by the rituximab story,” says Nancy Klimas, an authority on CFS at Nova Southeastern University in Fort Lauderdale, Florida. “It’s particularly exciting when people seem to have experienced very long periods of remission, and
even speak of recovery,” she says.

The researchers think the body’s own antibodies are to blame in at least a proportion of people with CFS. Relief started four to six months after the first dose of rituximab, approximately the time it would take for existing antibodies to be cleared from the body. Participants relapsed after about a year – roughly how long B-cells take to regrow and start making new antibodies.

“We think the pattern of responses and relapses involves some mechanism with these antibodies,” says Fluge.

An infection may trigger the body to produce antibodies that then turn against a person’s own tissues, he says. His team suspect that these antibodies may stop blood from circulating properly, preventing people from getting enough oxygen, explaining their extreme fatigue.

The researchers caution that their theory is just speculation for now, but they do have some very preliminary evidence. “We think the antibodies target the blood vessel system, because patients have very low anaerobic pressure, and produce waste lactate earlier, which stops muscles working,” says Mella.

If this theory turns out to be true, it would explain why people with CFS suffer muscle fatigue but show no signs of muscular abnormalities.

Clinicians who have focused on treating the disease psychiatrically have also welcomed the findings. “This uncontrolled treatment study of rituximab shows promising indications of effectiveness,” says Fred Friedberg of Stony Brook University in New York.

“There is now a strong case to be made for a larger trial,” says Simon Wessely of King’s College London, who has treated people using cognitive behavioural therapy. “The belief that [CFS] is all in the mind has been around since the beginning,” he says. “It’s tragic that it might take a study like this to take sufferers seriously.”

A 150-person study is now under way, and includes a control group. While the 2011 study included a placebo, the most recent trial did not, leaving it vulnerable to the placebo effect.

But Karen, for one, is convinced that the benefits of rituximab were genuine. “They were absolutely 100-per-cent real,” she says. “There are some things you just can’t fake.”

Karen’s Experience

How were you before you tried rituximab?

I was really bad. I was unable to work as a teacher, I couldn’t manage it any more. I just didn’t have any energy. I couldn’t focus, and it was painful in the joints and muscles. When I went to post a letter, it felt like I’d run a marathon.

You were unknowingly in the placebo group for the earlier trial in 2011. What was that like?

I waited, and was hoping, but nothing happened. Of course I was disappointed it didn’t show any effect. I thought okay, probably I got the placebo. I wanted to finish my university degree and have a social life and job, and I couldn’t.

What was it like receiving the drug in this latest study?

This time, I knew I was going to get the medicine. I was very excited, but also terrified – what if it didn’t work? There’s no other treatment so it was my only chance. I got an effect quite early on. I was suddenly getting bursts of energy for maybe a half-hour or so. Then gradually I felt better. Suddenly, it was okay to keep my body upright. I restarted my master’s degree and did it in half a year – I got an A. Then I started working full time. I was completely revitalised.


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The mechanism that causes high-performance athletes to “feel the burn” turns out to be the culprit in what makes people with chronic fatigue syndrome feel exhausted by the most common daily activities, new University of Florida Health research shows.

Published in the February issue of the journal Pain, the study shows that the neural pathways that transmit feelings of fatigue to the brain might be to blame. In those with chronic fatigue syndrome, the pathways do their job too well.

The findings also provide evidence for the first time that peripheral tissues such as muscles contribute to feelings of fatigue. Determining the origins of fatigue could help researchers develop therapies or identify targets for those therapies.

Researchers focused on the role of muscle metabolites, including lactic acid and adenosine triphosphate, or ATP, in the disease. The study has demonstrated for the first time that these substances, released when a person exercises his or her muscles, seem to activate these neural pathways. Also, UF Health researchers have shown that these pathways seem to be much more sensitive in patients with chronic fatigue syndrome than in patients without the disease, something that hasn’t been studied before.

Chronic fatigue syndrome, which the Institute of Medicine recently renamed systemic exertion intolerance disease, or SEID, is characterized by extreme chronic fatigue. Because its chief symptom -- fatigue -- is often associated with many other diseases, it can be difficult to diagnose SEID for the more than 1 million people who actually have the disease, according to the Centers for Disease Control and Prevention. The disease has no root medical cause, and researchers don’t know what triggers it. But they are studying aspects of the disease to figure out ways to treat it.

“What we have shown now, that has never been shown before in humans, is that muscle metabolites can induce fatigue in healthy people as well as patients who already have fatigue,” said Dr. Roland Staud, a professor of rheumatology and clinical immunology in the UF College of Medicine and the paper’s lead author.

During exercise, muscles produce metabolites, which are sensed by metaboreceptors that transmit information via fatigue pathways to the brain, according to the researchers. But in patients with SEID, these fatigue pathways have become highly sensitive to metabolites and can trigger excessive feelings of fatigue.

“For most of us, at the end of strenuous exertion we feel exhausted and need to stop — but we will recover rapidly,” Staud said. “However, these individuals tire much more rapidly and sometimes just after moving across a room, they are fully exhausted. This takes a toll on their lives.”

Staud and co-author Michael E. Robinson, a professor in the department of clinical and health psychology in the UF College of Public Health and Health Professions, recruited a group of 39 patients with SEID and 29 participants without the disease. The researchers asked the participants to don a blood pressure cuff just above their elbows on their dominant side, pick up a spring-loaded device and squeeze it to 100 percent of their maximum capacity, which was measured by a dial.

With research assistants encouraging them, the study participants then squeezed the device so that the dial showed they were gripping at 50 percent of their maximum capacity for as long as they could.

At the end of the hand-grip exercise, the blood pressure cuff on the participant’s arm was inflated, almost instantly trapping the metabolites generated by the exercise within the forearm muscles. This allowed the metabolites to collect in the forearm tissue without being cleared by the circulatory system. There, the metabolites continued to activate fatigue pathways, sending messages of fatigue to the brain and allowing researchers to measure how much fatigue and pain may occur because of the trapped metabolites.

With the blood pressure cuff still inflated, the
participants rated fatigue and then pain in their forearms every 30 seconds. Both patients with SEID and patients without the disease reported increasing fatigue, but patients with the disease recorded much higher levels of fatigue and pain.

“We found that the fatigued individuals reported more fatigue than the non-fatigued individuals during the exercise, and also found that they had more pain compared to the non-fatigued individuals,” Staud said.

On the Fatigue Visual Analog Scale used to measure participants’ fatigue, patients with SEID rated their fatigue at approximately 5.5 on a scale of 0 to 10 after the hand-grip exercise while wearing the inflated blood pressure cuff, whereas participants without the disease rated their fatigue at approximately 1.5.

After 30 minutes, the participants repeated the exercise, but with the opposite arm and without the cinching blood pressure cuff so the metabolites could be cleared from the arm. Both sets of participants experienced fatigue, but the feeling of fatigue in those with the disease was much lower than when the metabolites were trapped with the blood pressure cuff.

“This suggests that hypersensitive fatigue pathways play an important role for the often pronounced exercise-related fatigue of patients with the disease,” Staud said.

Next, Staud plans to explore treatment interventions and to conduct brain-imaging studies of patients with SEID.

“The take-home message here is, like many of the pain studies we have conducted, there are both peripheral and central nervous system factors at play in these complex syndromes,” said Robinson, who is also the director of the UF Center for Pain Research and Behavioral Health. “Our study seems to highlight the important role of these peripheral tissues.”

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Hyperbaric Hope For Fibromyalgia Sufferers

From the US’s Rice University.

Women who suffer from fibromyalgia benefit from a treatment regimen in a hyperbaric oxygen chamber, according to researchers at Rice University and institutes in Israel.

A clinical trial involving women diagnosed with fibromyalgia showed the painful condition improved in every one of the 48 who completed two months of hyperbaric oxygen therapy. Brain scans of the women before and after treatment gave credence to the theory that abnormal conditions in pain-related areas of the brain may be responsible for the syndrome.

Results of the study appear in the open-access journal *PLOS ONE*.

Fibromyalgia is a chronic pain syndrome that can be accompanied by – and perhaps related to – other physical and mental conditions that include fatigue, cognitive impairment, irritable bowel syndrome and sleep disturbance.

More than 90 percent of those diagnosed with the syndrome are women, said Eshel Ben-Jacob, a lead author of the proof-of-concept study who developed the analytical method used to show the association between patients’ improvement and changes in their brains. He is an adjunct professor of biosciences at Rice University, a senior investigator at Rice’s Center for Theoretical Biological Physics and a professor of physics and member of the Sagol School of Neuroscience at Tel Aviv University.

“Symptoms in about 70 percent of the women who took part have to do with the interpretation of pain in their brains,” Ben-Jacob said. “They’re the ones who showed the most improvement with hyperbaric oxygen treatment. We found significant changes in their brain activity.”

Scientists have not pinned down the syndrome’s cause, although another recent *PLOS ONE* study identified a possible RNA-based biomarker for its diagnosis. A variety of treatments from drugs to lifestyle changes have been tried to relieve patients’ suffering, with limited success, Ben-Jacob said.

“Most people have never heard of fibromyalgia,” he said. “And many who have, including some medical doctors, don’t admit that this is a real disorder. I learned from my M.D. friends that this is not the only case in which disorders that target mainly women raise skepticism in the medical community as to whether they’re real or not. However, these days there are increasing efforts to understand the effect of gender on body disorders.”

Researchers at the Sagol Center for Hyperbaric Medicine and Research at the Assaf Harofeh Medical Center and Tel Aviv University were studying post-traumatic brain injury patients when they realized hyperbaric oxygen treatment (HBOT) could help patients with fibromyalgia.

“Patients who had fibromyalgia in addition to their post-concussion symptoms had complete resolution of the symptoms,” said Dr. Shai Efrati, who noted his own mother suffers from the syndrome. Efrati is lead author of the study, head of the research and development unit at the Assaf Harofeh Medical Center and a member of the Sagol School of Neuroscience at Tel Aviv University.

Hyperbaric oxygen chambers that expose patients to pure oxygen at higher-than-atmospheric pressures are commonly used to treat patients with embolisms, burns, carbon monoxide poisoning and decompression sickness (known to divers as “the bends”), among many other conditions.

One effect of exposure is to push more oxygen into a patient’s bloodstream, which delivers it to the brain. Efrati’s earlier trials found HBOT induces neuroplasticity that leads to repair of chronically impaired brain functions and improved quality of life for post-stroke and mild traumatic brain injury patients, even years after the initial injury.

Ben-Jacob said two patients spearheaded the push for the study. One was an Oxford graduate student who developed fibromyalgia after suffering a traumatic brain injury in a train crash. “By chance, the secretary of the department where she worked is the mother of the nurse in charge of the HBOT. She said you have to go and try to do it,” he recalled.

The other, he said, is a professor of sociology who specializes in post-traumatic stress disorders.

(Continued next page)
due to child abuse. The professor had suffered from fibromyalgia for many years. Her symptoms got worse through the initial treatments – a common experience for other patients in the study who she said had suppressed memories due to child abuse – before they got better. But by the end of treatment both women showed remarkable improvement, Ben-Jacob said.

Efrati said some patients will likely require follow-up sessions. “The abnormalities in brain regions responsible for the chronic pain sensation in fibromyalgia patients can be triggered by different events,” he said. “Accordingly, the long-term response may be different.

“We have learned, for example, that when fibromyalgia is triggered by traumatic brain injury, we can expect complete resolution without any need for further treatment. However, when the trigger is attributed to other causes, such as fever-related diseases, patients will probably need periodic maintenance therapy.”

The clinical trial involved 60 women who had been diagnosed with fibromyalgia at least two years earlier. A dozen left the trial for various reasons, but half of the 48 patients who completed it received 40 HBOT treatments five days a week over two months. Half of the 48 patients who completed the trial received 40 HBOT treatments five days a week over two months. The 90-minute treatments exposed patients to pure oxygen at two times the atmospheric pressure.

The other half were part of what Ben-Jacob called a crossover-control group. They were evaluated before the trial and after a control period that saw no improvement in their conditions. After the two-month control, they were given the same HBOT treatment as the first group and experienced the same relief, according to the researchers.

The researchers noted the successful treatment enabled patients to drastically reduce or even eliminate their use of pain medications. “The intake of the drugs eased the pain but did not reverse the condition, while HBOT did reverse the condition,” the researchers wrote.

Efrati said the findings warrant further study. “The results are of significant importance since, unlike the current treatments offered for fibromyalgia patients, HBOT is not aiming for just symptomatic improvement,” he said. “HBOT is aiming for the actual cause – the brain pathology responsible for the syndrome. It means that brain repair, including even neuronal regeneration, is possible even for chronic, long-lasting pain syndromes, and we can and should aim for that in any future treatment development.”

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Hi everyone, this is Niki Gratrix and welcome to another episode of the Abundant Energy Summit. I have the pleasure today of introducing Dr. Sarah Myhill.

Dr. Myhill worked with the NHS for 20 years before entering into private practice. She was the Honorary Secretary for the British Society for Allergy and Nutritional Medicine for 17 years, and has worked with over 5,000 patients with fatigue.

She believes the central mechanism is mitochondrial dysfunction. She is the author, with colleagues, of three scientific studies in the International Journal of Clinical and Experimental Medicine showing that the level of mitochondrial dysfunction correlates with the degree of fatigue. She is also the author of the book, It's Mitochondria Not Hypochondria.

Q: You have a car analogy in your book. Please explain that.

Myhill: Let's start from the beginning. The first and most important thing to grasp about Chronic Fatigue Syndrome is that it is not a diagnosis, it is a clinical picture that may have many causes. It is my job as a physician to find the causes. The second important thing to grasp is that we have symptoms for a very good reason. Symptoms protect us from ourselves. If we didn't experience fatigue we'd work all day and all night. And we'd be dead in eleven days, because nobody has survived eleven days without sleep.

The symptom of fatigue can arise for many reasons that have to do with delivery systems and energy expenditure – how we spend and create our energy. We always have to keep ourselves where our energy demands don't exceed our energy delivery. We need to pay attention to both sides of the equation: energy demands vs energy delivery.

The body is just another machine, like a car. Like any machine it needs the right fuel in the tank. That fuel has everything to do with diet and gut function.

How do we burn our fuel to create energy?

Mitochondria are essential for creating energy from fuel. They are the little engines that exist in every cell in the body, and in every cell in every living organism. Without mitochondria we wouldn't have life as we know it.

What mitochondria do is they take fuel from the bloodstream derived from carbohydrates, fats, and proteins (in the form of acetate groups) and burn them in the presence of oxygen to produce ATP. Think of ATP as a molecule with which you can do any function in the body.

The thyroid gland is also terribly important. It determines how fast those mitochondria go, like an accelerator pedal in a car. We have to be careful about how we spend our energy. Spend it too fast and we wouldn't have survived a harsh winter.

What allows us to gear up energy spending is the adrenal gland, which I think of as the gear box in a car. Adrenaline is the short-term immediate hormone for energy delivery; cortisol is the intermediary and DHEA is for long-term energy delivery. Those hormones allow us to adjust energy demand to energy delivery very closely.

Of course, all cars have to be serviced regularly. We service our bodies during sleep. Every single living thing, even bacteria, need a time in which metabolic processes shut down to allow healing and repair to take place.

Those are the central, important aspects.

Q: You talk about how the immune system takes up a huge amount of energy.

Myhill: That's on the other side of the equation, where we look at how energy is spent in the body. An astonishing amount of energy – two-thirds of all energy we generate – just goes into staying alive: basic metabolic rate, heart function, lung function, gut function, liver function, brain function. All those things demand energy. The rest we should spend...
physically, or mentally, in terms of mental exercise.

I think of the immune system as a brain that isn’t contained within the skull, but is spread throughout the body. It’s intelligent, it’s decision-making. It’s highly active, and it’s highly demanding of energy. It likes to run on fat, and so on. But when the immune system is activated it uses up a massive amount of energy.

How do I know that? If a normal person gets flu, they get instant ME. They’re bed-bound for a week or two until their immune system switches off and they get well again. When their immune system is activated because of infection, that’s normal, desirable, and essential to dealing with an infectious threat.

But if the immune system is activated because of allergy, that’s what I call useless inflammation. The body is spending immunological energy on something that is not a threat. That kicks an immunological hole in our energy bucket.

Q: Let’s focus a little more on the mitochondria. Would you please expand on the production of ATP?

Myhill: When ATP is being efficiently recycled, ATP forms ADP. Then it goes back into the mitochondria where it again forms ATP. That is an extraordinary efficient cycle. In fact, when we are functioning at our maximum potential, a molecule of ATP can be recycled back through our mitochondria every ten seconds. If there was no such recycling, then we would burn more than our body’s weight of ATP every day.

We run into problems when energy demand exceeds energy delivery. The body has some emergency mechanisms. Let’s say I have to run for my life, all these energy systems would be employed.

One of them is to switch into anaerobic metabolism that produces lactic acid. We all know about that. It’s the lactic acid burn that slows athletes down and stops them, and stops ME patients as well.

Another mechanism is when two molecules of ADP combine to form one molecule of ATP and one of AMP. The ATP can be quickly recycled, but the AMP is recycled very slowly. So suddenly, you’re pulling the plug on your supply of ATP. It’s all draining out of your system. That is what I suspect causes the delayed fatigue in ME.

Interestingly, another paper has come out recently, where they tried to reproduce that idea in a computer using low rates of metabolism and putting in all the variables. And they came up with the same conclusion.

Q: What are some of the causes of mitochondrial underfunction?

Myhill: Broadly speaking, there are two important causes. The mitochondria can be deficient in raw materials – magnesium, CoQ10, acetyl-l-carnitine, vitamin B3, and D-ribose. Those are the 5 things we see that mean the mitochondria are deficient. We measure these things when we do mitochondrial tests.

Or, mitochondria can be going slow because they are blocked by something. Blocking factors can include environmental toxins, energy delivery blockers, heavy metals, and fermenting gut products.

You can block mitochondria by stacking things on top of the mitochondrial membrane. It’s no good making ATP if you can’t get the ATP out of the mitochondria and into the cell where it’s needed. Mitochondrial membranes are made up of proteins that act like a little shuttle that takes ATP out of the mitochondria and then brings ADP back into the mitochondria where it is turned into ATP. There are lots of things that can block that shuttle. We can do tests to determine what those blocking factors are.

As an aside, I got interested in ME when I started seeing farmers with sheep dip flu. They had been poisoned by organophosphates. Organophosphates inhibit oxidative phosphorylation. That is how they block the mitochondria’s ability to make ATP.

Broadly speaking those blockers fall into two (Continued on page 18)
groups: they can be toxins from the outside world, such as pesticides and heavy metals, or they can be products from within the body. I suspect a major source of these is products from the fermenting gut.

Q: And inflammatory processes lead back to the gut.

Myhill: Mitochondria are important, but I spend as much time with my patients talking about diet, and talking about gut function. So many problems start with the gut.

Q: Mitochondrial malfunction explains the illness brilliantly, but it’s not the cause, it’s the effect.

Myhill: The whole thing is circular. We all come into this area with different theories, but we all end up offering similar patterns of treatment – diet, detoxing regime, nutritional supplements, correcting hormones, and so on. But mitochondria are central players.

Q: Diet, pacing, micronutrients and sleep are your four foundational things. Do you want to expand a little on that, especially pacing?

Myhill: It’s back to square one. Fatigue is a mechanism that protects us from ourselves. If someone is experiencing fatigue because they are overdoing it, they are constantly stressing their mitochondria and their energy supply and they are constantly going into anaerobic metabolism and producing lactic acid.

Let’s talk about anaerobic metabolism. Normally, mitochondria function on oxygen. When you burn a molecule of sugar in the presence of oxygen, you’ll produce about 26 molecules of ATP. But when you stress your mitochondria and switch to anaerobic metabolism, burning a molecule of sugar only produces two molecules of ATP. If you do this on a regular basis you get a buildup of lactic acid.

To convert that lactic acid back to pyruvic acetate takes six molecules of ATP. What that means is if you overdo things it takes an awfully long time to get back to square one. The point of pacing is to avoid getting into anaerobic metabolism. So, pacing is crucially important. People will get better if they pace. If they don’t pace, eventually there is tissue damage and inflammation sets in, which kicks another hole in the energy bucket.

Q: You have a basic protocol for micronutrients, what is that?

Myhill: Although I began by seeing patients with ME, I have come to the conclusion that no matter what a patient comes to me for, there is a basic package of treatment that we should all be doing. In terms of diet, this consists of a “stone age diet”: meat, fish and eggs, nuts and seeds, lots of veggies, and low-fructose fruits, such as berries.

Number two is sleep. Most people are sleep deprived. If you need an alarm clock to wake up in the morning you are sleep deprived.

The third thing I talk about is micronutrients. Because modern farming depletes the soil of minerals, we should all be taking a basic package of micronutrients – vitamins, minerals, and amino acids.

Q: Talking further about the Stone Age Diet, are you recommending a grain-free diet?

Myhill: Grains are too toxic for humans to consume. So, remove all gluten completely. The fermenting gut is a very big problem.

The upper gut should be a near-sterile carnivorous digesting gut to deal with meat and fat. The lower gut, which is teeming with bacteria, digests vegetable fiber. So, the lower gut is a fermenting gut. If we overwhelm our liver with sugar, for example, we switch into the fermenting gut and have all the problems of metabolic syndrome.

What I am saying is that a modest amount of carbohydrate is fine if you’ve got perfect digestion. But my ME patients don’t have perfect digestion. So, carbohydrates are a major risk factor for chronic fatigue syndrome.

I consider being vegetarian a major risk factor for chronic fatigue syndrome for two reasons. Vegetarian foods tend to be high GI, that is, grains and fruits. They are also high in the major antigens: dairy, gluten, and yeast.

Q: Would you talk a little about B12 and magnesium?

Myhill: Magnesium is centrally important for mitochondrial function. In fact, 40% of all the energy that comes out of mitochondria simply
maintains the ion pumps that kick calcium out of cells and drag magnesium in. If the mitochondria are going slow, they can’t kick the calcium out, which is toxic within cells, and they can’t drag the magnesium in. So they don’t have the magnesium they need to make the mitochondria even work. There is a vicious cycle here. If you can’t get the magnesium in, the mitochondria won’t work, and if the mitochondria can’t work, you don’t get the magnesium in.

The reason magnesium injections are so helpful is that you are spiking the level of magnesium in the blood for a short period of time. All of a sudden it’s much easier to drag the magnesium into the cells. The mitochondria then start working again properly. Magnesium injections kick start the mitochondrial engine.

With B12 I think there may be a similar mechanism going. The thing about B12 is that it is very poorly absorbed. Even people with the best gut function will only absorb 1% of the B12 that they are taking. Only about another 1% actually gets into the brain, where it is very important for cognitive function.

The point about B12 is that if you inject it, you spike the levels in the blood, and you get the B12 into the brain. I’m only hypothesizing, because so many of my ME patients find their brain function and their mood is so greatly improved with B12 injections. B12 is performance enhancing in athletes, and even in horses. Trainers give horses B12 injections, and they go faster. That means their mitochondria are working better. And, B12 injections are an incredibly safe thing to do.

Q: Are you having much luck with transdermal forms?

Myhill: Transdermal forms of B12 are better than oral forms. They get about 6% absorption. But again, it’s not as good as the injection because you don’t spike blood levels.

Q: You mentioned the mitochondrial cocktail?

Myhill: When we do tests, we tailor treatments to individuals because we measure CoQ10, carnitine, B12, magnesium, and ATP. But if you can’t access those tests, you can do no harm by taking those supplements.

I have yet to find an ME patient with normal levels of CoQ10. These days I tend to use ubiquinol, which gets much better blood levels. 200 mg of ubiquinol will correct all my patients.

Q: Diet and environment need to be under control for any of this to work.

Myhill: That’s very important. We are living in an age in which we are being overwhelmed with toxins. A supplement I routinely prescribe for my ME patients is glutathione, which is essential for getting rid of heavy metals and is a potent antioxidant. With 250 mg a day of glutathione you can do no harm.

Another interesting facet of mitochondria is that they determine aging. We age at the rate that our mitochondria age.

Q: There have to be different approaches for different people. Some may need thyroid support, some adrenal support.

Myhill: I always say that getting people well from chronic fatigue syndrome or ME is like a jigsaw puzzle. You’ve got to have all the pieces in place at the same time. You can’t try one thing, and when it doesn’t work, you try another. You’ve got to start with the foundation stones of pacing, diet, supplements, sleep. Then you build on that with the mitochondrial stuff, thyroid stuff, adrenal stuff, gut fermentation stuff. You can do a lot of this yourself with simple nutritional therapy. It’s very doable.

Q: What about tests?

Myhill: The tests we use are all documented research tests. We apply them clinically. The problem with new, innovative tests is that they are hideously expensive. But don’t wait for the tests to come out to start to get better. Put the basic package in place as well as you possibly can. It’s all about tipping points.

I say to my patients, all we have to do is get you 51% better and your body will do the rest.

You can find out more about Dr. Myhill at DrMyhill.co.uk.

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**South Australian Health And Medical Research Institute (SAHMRI) Calling For Research Participants**

**What is Chronic Fatigue Syndrome?**
- Chronic Fatigue Syndrome (CFS) is characterised by a constellation of symptoms in previously healthy and active individuals.
- Because of these symptoms, quality of life of people with CFS can be extremely compromised. While the search for a clear-cut cause remains elusive, we believe that we can make a major contribution to a person’s quality of life by elucidating the biological basis of their clinical symptoms.
- If the biology underlying the disabling symptoms of CFS is elucidated, we will be able to target treatments aimed at symptomatic improvement.

**What is the purpose of this study?**
- To evaluate the relationship of the hormones (cytokines) Leptin and Interleukin-6 on the symptoms of Chronic Fatigue Syndrome. We can test these by using a blood sample. We are also embarking on the development of a genetic database for CFS.

**Who are we looking for?**
- Adults 18-65 years-old. Participants must be fluent in English. People able to answer simple questionnaires without any help from others. You must also be non-pregnant and not breastfeeding.
- Those without serious active medical or mental illness that may affect the results for Chronic Fatigue Syndrome. We will exclude Obesity Class II (World Health Organisation) Body Mass Index greater than 34.99. Those not taking medications such as sleeping pills. Those not using illicit drugs or abusing alcohol in the last 3 months.

**Healthy Participants?**
- We also want healthy people to participate. You will undergo the same procedures as those with CFS. This will enable us to compare healthy people and those who have CFS.

**What are we going to do?**
- Ask you questions regarding your medical history (past and present), including mental health, your mood, food intake, smoking and alcohol consumption.
- Assessment part 1: An initial interview and questionnaires, then collect 19mls of your blood for a health assessment (Approximately 3 hrs.).
- Assessment part 2 (9.5 hrs. – 8am to 5:30pm): Complete a DEXA scan (dual-energy X-ray absorptiometry) and take bloods across a normal day (9am to 5pm), taking blood samples every 7 minutes. A cannula will remain in your arm throughout the day allowing us to take the samples easily. You will complete some visual scales to indicate how you are feeling each hour. A genetic sample will be taken from this phase of the assessment (phase two). Please note that the genetic sample is for use in later research into CFS, and will help us develop a genetic database for this disease. We will provide you with food, drinks and entertaining material (iPad / magazines / TV).
- Your samples and research data will be de-identified which makes them anonymous.
- Participants who complete the study (must include assessment part 2 described above) will be given a $100 voucher for participation in this study.

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007) – incorporating all updates.

If you want to participate please contact:

Dr Michael Musker, Research Fellow,
SAHMRI Mind and Brain Theme:
http://mb.sahmri.com/
Or Tel: (08) 8128 4714
Or Email: michael.musker@sahmri.com
Jodi Bassett, Creator Of The Hummingbird’s Foundation For ME, Is Dead At The Age Of 39

By Cort Johnson in Health Rising.

Jodi Bassett, longtime Australian Myalgic Encephalomyelitis (ME) patient, author and advocate died on 11 June 2016. She was either 39 or 40 years old. She had been ill with a severe case of ME for over 20 years. Her cause of death was not stated.

Jodi Bassett came down with ME in 1995 at the age of 19.

After being prescribed exercise therapy her disease rapidly progressed until she was severely ill. For the past 15 years or so she had to spend most of her time in bed.

Jodi felt that her attempts at exercise turned what was a mild to moderate case of ME into a severe one that she never recovered from.

That never-ending relapse marked her; from then on in she would constantly warn about the dangers of too much exercise particularly early in the disease. She rejected the idea that deconditioning was causing or contributing strongly to ME and research has borne that out.

She was able to work on ME issues for about an hour a day from her bed, but nevertheless built the huge Hummingbird’s website in 2004 which came to encompass hundreds of pages. Her review of CBT/GET (“Smoke and Mirrors”) ran to dozens of pages. In 2009 she founded the Hummingbird’s Foundation. In 2011 she wrote an 160 page book called Caring for the ME Patient.

A important theme for her always was the establishment of ME as a disease separate from CFS. She defined ME strictly as a disease characterized by damage to the brain stem caused by an enterovirus infection.

Bassett was not swayed by evidence that a chronic fatiguing illnesses could be triggered by a number of pathogens. Epstein-Barr Virus played no role in ME for her, and neither did other infectious agents such as other herpesviruses, hepatitis, Q fever, Ross river virus, giardia, Borrelia, etc. that many now associate with the disease. She believed that ME was purely a enterovirus driven disorder which had strong similarities to polio.

She believed that if your brain scan was normal you had something other than ME

Chronic Fatigue Syndrome A Wastebasket Diagnosis

Jodi also believed that chronic fatigue syndrome was always a waste-basket disease; that there was essentially no such disease as “CFS”. If you were diagnosed with CFS, she felt you automatically had something else. (Ironically, almost all of the tests she listed as being determinative for ME were validated using patients who met the definition for CFS.)

She believed that chronic fatigue syndrome was created “for the benefit of various political and financial vested interest groups.”

Dedicated Painter

Jodi was also a dedicated painter and regretted that her illness kept from pursuing painting more. In 2005, however, she had an exhibition and in 2012 participated in group show.

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16 Things People In Chronic Pain Want You To Know

By Tea Lynn Moore.

1. We try really hard to look good
   We often hear “you don’t look sick” but the truth is that most of us try very hard to pass as normal. We rest before going out and take our pain meds at the optimal time. At times we hurt so much and are tired from trying to play healthy that we feel like laying down right then and there, but we (usually) hold it in until we get home to our beds.

2. It’s not all in our heads
   Just because you can’t see it, it doesn’t mean it isn’t there. Our pursuit of healthcare is not driven by hypochondria or need for attention, it’s driven by physical discomfort. What we are doing is looking for something to improve our quality of life, and sometimes the cause of our pain if it is not known.

3. We are not making a mountain out of molehill
   We are actually in more pain than you think we are in. Studies have shown that, generally speaking, people tend underestimate other people’s pain. This may be because chronic pain itself is difficult to imagine, especially if you have never experienced it firsthand. Even those who have experienced similar types of pain in the past have a difficult time remembering it until they experience it again.

4. No matter how long we’ve been suffering for, it still hurts
   Having pain for an extended period of time does not give us superpowers to feel it less. However, most people with chronic pain have learned overtime to exhibit less pain related behaviours. So you can never really tell how much pain a person is in just by looking at them.

5. Sometimes we just don’t have the spoons
   Spoon Theory is an analogy to explain what it’s like to live with a chronic illness such as chronic pain. Christine Miserandino, a woman who lives with lupus, originally coined the term on her website ButYouDontLookSick.com.

   The basic premise is that when you have a chronic condition you wake up each day with a certain number of spoons. Every time you exert effort – by getting out of bed, cleaning, getting dressed – you lose a spoon. When you run out of spoons, that’s it, the day’s activities are done.

   Chronic pain can be an exhausting condition and this analogy demonstrates the need to budget and loss of control some people experience. So if we cancel our plans with you, it may be because we ran out of spoons.

6. We’re not lazy
   In fact, we often have to work twice as hard to accomplish the tasks that most people do easily.

7. If we don’t have a job it’s for a reason
   Some of us just don’t have the spoons to work on top of our activities of daily living. It can turn our pain from bearable to unbearable. Also, most employers are not eager to hire someone that can only work a few hours a week, is completely unreliable, may or may not show up, and may end up leaving at any point during the shift due to pain flares that make being productive impossible.

8. It’s really hard to get out of bed in the morning… and always!
   But that doesn’t mean we still can’t have fun from bed.

   So if we can’t make it out you can always bring the party to us!
9. Every minute feels like an eternity when waiting

Whether it's an hour in a waiting room or 5 minutes in line, every minute drags out when you have to hold an uncomfortable position. It's not that we are impatient, we would just prefer to use our spoons on more important things.

10. We are not ignoring you

Pain can be very distracting and mentally draining. We try our best to stay sharp and attentive but if we seem not to fully be there please don't take it personally.

11. We get REALLY excited when we have a good day

Physically feeling good is just about the most exciting feeling in the world cause it means we can finally get stuff done! It's like going on a mini vacation. (Instead of doing nothing, we try to do everything!)

12. And get really bummed when we have a bad day and can’t do the things we love

13. It can be hard to find a good doctor

Unfortunately, most health care professionals have little knowledge in pain management because it is rarely part of their training. We often go through many doctors before receiving a proper diagnosis and wait months to years (literally!) to see a pain specialist for treatment. Also, doctors too fall victim to the cognitive error of underestimating other's pain, and vary few doctors are willing to take the legal risks involved in prescribing pain pills. So if we happen to find a good doctor who listens and is willing to treat us, we feel like we’ve died and gone to heaven!

14. We are not drug seekers

We are pain relief seekers. Sometimes our medical treatment does require the use of opioids or medical marijuana to keep the pain under control and help us resume to as close to a normal life as we can. We take it just like any other medication. We dislike the side effects just like any other medication. And if we find pain relief from another means, we simply stop taking it, despite months or even years of use.

As the Cleveland Clinic explains: addiction appears to be distinctly uncommon in patients without a prior history of addiction. It's important to keep in mind that addiction is different than physical dependence/tolerance. Physical dependence can occur with many different types of medications (e.g. beta-blockers), whereas addiction is a psychological phenomenon that is not caused by “chemical hooks” and usually requires a setting very different than that of a chronic pain patient. Unlike street-users, the medical patient is under the supervision of a doctor, is taking the medication in a slow-acting form, and is going home to a life where he or she is surrounded by the people they love.

15. You don’t need to give us suggestions or medical advice

We appreciate the thought, but it can be exhausting hearing advice all the time and frustrating when it doesn’t work. Unless we ask or you have chronic pain yourself, it's best to leave this to the experts.

16. All we really need is your love and support

Sometimes all you can do is just be there, and that’s saving someone’s life!

About the Author

Tea Lynn Moore is a University of Toronto psychology student and researcher who lives with chronic pain from Craniocervical Instability and Trigeminal Neuralgia due to Ehlers-Danlos Syndrome.

You can follow Tea Lynn’s work on…

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Is Chronic Fatigue Syndrome an organic disease that should be addressed by biomedical research, or is it only a psychological condition best treated by some form of psychotherapy? Until recently, the answer to that question was in dispute, with immunologists and microbiologists tending to take one side, and a group of psychiatrists on the other. The latest research, however, has come down decisively in favor of the physiological explanation, to the embarrassment of the doubters and the relief of many long suffering patients.

Chronic Fatigue Syndrome (also known as Myalgic Encephalomyelitis, or ME/CFS) is an incurable disease with devastating symptoms that include blinding headaches, profound exhaustion, muscle weakness verging on immobility, exertion intolerance, extreme sensitivity to light and sound, and the inability to stand or sit upright. Most patients will tell you, however, that by far the worst part has been the scorn they once had to endure from physicians, employers, and even friends and family, who frequently refused to believe that they were truly sick.

Fortunately, the situation has improved significantly in the United States, where there is now widespread recognition that Chronic Fatigue Syndrome is a biomedical illness with physiological causes. Regrettably, other countries have not all gotten the news – most notably the United Kingdom, where prominent psychiatrists have successfully argued that it should be treated primarily as a cognitive and behavioral disorder. That may also be about to change, however, because a new investigation – just published on the website of a Columbia University virology expert – has thoroughly debunked the underpinnings of the British psychiatrists’ approach.

There has seldom been good news for ME/CFS patients, many of whom have been housebound or bedridden for years. Fortunately, 2015 turned out to be a very encouraging year for ME/CFS sufferers in the United States. In early February, the Institute of Medicine released a long-awaited report titled “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” stating that “ME/CFS is a serious, chronic, complex, systemic disease that often can profoundly affect the lives” of as many as 2.5 million Americans. In addition to criticizing the many physicians who “mistake it for a mental health condition,” the IOM committee proposed new diagnostic criteria and called for greatly increased research funding for ME/CFS. In the words of the committee chair, Dr. Ellen Clayton, a professor of both medicine and law at Vanderbilt University, “It’s time to stop saying that this is a just figment of people’s imagination. This is a real disease, with real physical manifestations that need to be identified and cared for.” The IOM report broke the barrier of indifference, but of course it could not do anything to solve the intractable nature of the disease.

Even better news arrived later the same month when Drs. Ian Lipkin and Mady Hornig, of Columbia University’s Center for Infection and Immunity, announced the results of their multi-center cohort studies of ME/CFS patients. The study revealed altered plasma immune signatures among ME/CFS patients, thus providing a possible first step toward identifying a biomarker, which in turn could be a crucial step toward effective clinical diagnosis and treatment. The Columbia results left no doubt that ME/CFS “is a physical disorder that may be kick-started by an infection.” In the words of Dr. Hornig, “We now have evidence confirming what millions of people with this disease already know, that ME/CFS isn’t psychological.”

The era of enlightenment has not yet dawned in the United Kingdom, however, where medical research has been sidelined while psychiatrists continue to insist that ME/CFS is best addressed by Cognitive Behavior Therapy and an increase in activity known as Graded Exercise Therapy. The founder of the group is Dr. Simon Wessely, whose theory is that ME/CFS is “perpetuated predominantly by dysfunctional illness beliefs and coping behaviours [that] interact with the patient’s emotional and physiological state and interpersonal situation to form self-perpetuating vicious circles of fatigue and disability.”
Patients, and many U.S. researchers, have for years rejected the idea that ME/CFS is caused by nothing more than a “dysfunctional illness belief,” but Wessely and his followers have been adamant. Writing in the journal of the American Psychosomatic Society, for example, that ME/CFS “represents one of a cluster of functional somatic syndromes, which all share similar psychosocial etiological and maintaining factors,” including childhood abuse.

A multi-year study called the PACE trial, financed by the British government at a cost of nearly $8 million (at current exchange rates), was designed to definitively establish the validity of the Wessely theory. The results – first published in 2011 in *The Lancet*, with later updates in other papers – seemed to confirm that ME/CFS patients showed significant improvement and even “recovery” after treatment with Cognitive Behavior Therapy (CBT) and graded exercise therapy (GET). If valid, the PACE trial would indicate that the persistence of ME/CFS indeed has a powerful psychological component.

Dr. Peter White, one of the leaders of the PACE trial, makes just that claim, arguing that the apparent success of CBT and GET demonstrated a “reduction in fear avoidance” among subjects, meaning that the disabling symptoms of ME/CFS had previously been due not to some organic cause, but rather to patients’ ungrounded fear of exercise.

The soundness of the PACE study, however, has been questioned from its inception, not least because it required participants to make regular trips to medical offices for therapy. That excluded all bedridden or housebound patients, the extreme severity of whose symptoms could least be attributed to “physical deconditioning” from exercise avoidance. Thus, the PACE study has gotten mixed reviews in the U.S. The CDC has obliquely referenced it on several occasions, and once recommended CBT and GET in its “CFS Toolkit.” On the other hand, the PACE results were not even mentioned in either the IOM report or the Lipkin/Hornig study. Even so, the PACE trial has remained the gold standard for ME/CFS research in Britain with Dr. Wessley calling it “a thing of beauty.” That characterization, however, has now been firmly discredited by the medical journalist David Tuller.

Writing on *Virology Blog* – an internet site hosted by Dr. Vincent Racaniello, a microbiologist at Columbia University – Tuller has exposed such deep flaws in the PACE trial as to make it highly unreliable at best. Most significantly, it turns out that some of the PACE results were essentially predetermined to support the effectiveness of CBT and GET. As Tuller learned, the baseline criteria for inclusion in the study actually indicated better health – in terms of fatigue and physical function – than the benchmark for “recovery” at the end. In other words, a patient could be simultaneously sick enough to be included in the PACE study, and healthy enough to be counted among the positive outcomes. In fact, 13% of the study participants were actually “recovered” on at least one of the two key measures before the trial even began.

Tuller, who runs the journalism and public health program at the University of California, Berkeley, also discovered that the PACE team had potentially skewed the outcome by publishing a “participants newsletter” in the middle of the study that touted the effectiveness of CBT and GET – the very therapies for which they were supposed to be gathering unbiased results. The newsletter included testimonials from earlier participants about how much better they felt after the treatment and therapy they received during the trial, which could well have primed later subjects to report similar improvement.

Tuller’s findings have been commended by many American experts on medical research. For example, Dr. Ronald Davis of Stanford University expressed surprise that the PACE study had ever survived peer review at *The Lancet*, and Columbia’s Dr. Bruce Levin called it “the height of clinical trial amateurism.”

Meanwhile, there is still no cure for ME/CFS, and patients would be facing a grim outlook if their future were solely in the hands of benighted British psychiatrists. Fortunately, promising biomedical research is proceeding at an unprecedented pace in the U.S., so there is finally cause for hope. “I think the microbiome is going to be where the action is in ME/CFS,” said Columbia’s Dr. Lipkin. “I am really eager to pursue that work.”

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I've done my share of denying that I'm chronically ill. It's tempting to pretend that I'm as healthy as can be, but when I ignore my limitations by staying out too long or by insisting on engaging in activities that are beyond my energetic abilities, invariably, I land in bed for days. And so, I'm working on giving up pretending. It's not good for me physically or emotionally.

My husband and I had an experience many years ago that illustrates the sad consequences that can follow when a person who is chronically ill (or his or her caregiver) are in denial about how their life actually is. We had a childhood friend who lived about two day's drive from us. Her husband was in his late 40s and had early onset Alzheimer's. We'd been told by our friend's brother that her husband was getting progressively impaired and was “absent” mentally most of the time. He didn't understand what was being said and, when he did try to talk to others, he rarely made sense.

You can imagine how tragic this was for our friend. She could no longer do something as simple as sharing her daily experiences with her partner. Even though I'm mostly housebound, my husband and I are still able to share our lives and do some things together. We can watch a movie and share our reactions to it. We can talk about friends and family. We can toss around ideas for my writing.

One day, we got a call from our friend. She said that she and her husband were taking a road trip and would like to stop and visit us. We were surprised because we thought he was particularly uncomfortable in unfamiliar surroundings and, as a result, they no longer travelled far from home. Of course, we said it would be wonderful to see them. After the phone call, my husband and I decided that perhaps we'd misunderstood the state of his illness.

When they arrived at our house, we immediately sensed that he was disoriented. Nevertheless, we took our cue from our friend, that cue being: “treat him normally.” And so we sat in the living room and tried to visit. As the afternoon progressed, we watched him become increasingly confused and agitated. We also watched our friend become increasingly exhausted as she worked harder and harder to make everything appear normal. For example, if my husband or I asked him a simple question, he would start to say something unrelated to what we'd asked, so our friend would anxiously jump in and “fix” his response.

We'd bought some deli food for the occasion, but when my husband got up to bring it in from the kitchen, our friend signaled to him that he should not bring out either food or beverages, so he didn't. And that's how the afternoon went.

After they left, I burst into tears over this tragic situation. Then I called our friend's brother. He hadn't known about the trip and was surprised to learn that his sister had attempted it. But he wasn't surprised to hear how difficult and stressful the afternoon had been for both his sister and his brother-in-law. He said his brother-in-law was barely functional when

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You Aren’t Entitled To An Opinion On My Chronic Illness

By Rosie Fletcher in The Huffington Post.

I thought my media outrage was done for the week when Buzzfeed published an article that casually suggested people with disabilities are unattractive. Little did I know the front page of the Telegraph would scale new heights in Totally Overwhelming Nonsense.

The article in question reports on a study led by Professor Michael Sharpe of Oxford University into the role of Graded Exercise (GET) and Cognitive Behavioural Therapy (CBT) in patients with M.E./Chronic Fatigue Syndrome. It’s proved controversial enough amongst sufferers who feel it undermines the physiological symptoms they face without the dumbed-down misinterpretation of these findings in both the Telegraph and the Daily Mail.

Both report that M.E. can be overcome by “positive thinking and exercise”. The Telegraph even goes so far as to open with the words “Chronic Fatigue Syndrome is not a chronic illness.”

I have been suffering with M.E. for nearly two years. If this is not chronic, I do not understand what is. M.E. is a long-term debilitating illness and misreporting of studies like this only fuels public misunderstanding of a complex and difficult disease.

No other illness is treated the way M.E. is. The public is given a stake not only in how it should be treated, but its very status as a recognised illness. No newspaper would put ‘Hepatitis: Consider Milk Baths’ on its front page, but debates about spurious treatments for M.E. continue to rage in print.

It’s this attitude that leads well-meaning but misguided friends and family to routinely suggest new treatments. “Ooh M.E.! Someone I know knows someone with that. Have you tried not eating wheat? What about yoga? Or painting runes across your chest and running backwards around the garden in the mist?” These suggestions are hard to handle because you know they come from a place of love. It’s like being surprised by a distant relative with a birthday present that turns out to be a dead frog. It’s lovely to be thought of, but you’ve still given me a dead frog.

It’s over two years since I first sought professional medical help for my symptoms. I’ve also spent the best part of those two years housebound with a high speed internet connection. There isn’t a single thing...

(Continued next page)
that hasn’t been tested for or that I haven’t heard of and investigated. It may surprise you, but if you have read one article, you do not know more about M.E. than me or, more importantly, my doctors.

These articles woefully misunderstand what is meant by GET and CBT. They are not “positive thinking and exercise” as has been reported. M.E. is a broad diagnosis and there will be some people who will, over time, benefit from these two therapies. I’ve just begun a course of Graded Exercise Therapy; it aims to slowly but surely build up my strength and, as a comparatively active sufferer, I have high hopes. But given that the most severe sufferers can’t open their eyes in bed, illustrating articles with happy joggers is as relevant as illustrating them with a panda in a hat. I will keep saying this until people stop suggesting that you can exercise yourself better: you cannot walk M.E. off. It is not a big dinner.

As for positivity, the people with chronic illnesses I know are some of the most positive people you could hope to meet. Every time they go to work and volunteer, every time they cook a meal or change a bed, every time they face another doubting doctor or inaccurate article, they are telling a disease that could so easily get the better of them: “Not today.” We are positive, resilient people with a deep desire to be rid of the weight of this disease.

To cap it all, YouGov ran an online poll asking whether people think M.E. is a real illness or not. Cheerily capped with a hashtag, they seem to have no idea how outrageous and offensive and slightly bizarre this is. You don’t get to vote on facts: WHO recognises M.E. as a real disease and, strangely enough, I trust their estimation over Joe Public and his online polls. M.E.’s classification is not up for debate. It’s a real illness whether Telegraph sub-headings or ill-informed pollsters say otherwise.

M.E. is hard enough to live with, but it is the bright sun around which revolves a planetary system of misunderstanding and misinformation. Media misreporting of this makes our already tough situations tougher – that’s something it’s difficult to remain positive through.

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he was away from familiar surroundings. He told me that this was probably why his sister hadn’t told him about the trip; she knew he’d try to talk her out of it.

In the end, her brother and I concluded that, out of the anguish of having lost her partner in the world, she had irrationally decided to pretend – just for a few days – that everything was okay. So she put her husband in the car and took this road trip. It was the last trip they took together.

It still makes me sad to recall that day, especially because it was so difficult for our friend. Years later, after becoming chronically ill myself, I truly came to understand why, out of denial, she took that trip. I understand…because I’ve done similar things.

I’m still learning from that painful day that it’s better to live within the limits of what I can reasonably do than to pretend things are as I wish they would be.

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Information About ME/CFS

What is ME/CFS?
Myalgic Encephalomyelitis/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.

ME/CFS is also known by other names such as Post-Viral Fatigue Syndrome (PVFS) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).

It is now officially recognised by the World Health Organization International Classification of Diseases (ICD-10-CM Diagnosis Code G93.3) and by recent 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 who have ME/CFS, or who have suffered from ME/CFS in the past and have substantially recovered.

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);
- 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, and immune manifestations of the condition. The Canadian Consensus criteria are wholly supported by ME/CFS Australia (SA) Inc and by the National Board of ME/CFS Australia. Copies are available from ME/CFS Australia (SA) Inc’s website (sacfs.asn.au).

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; Addison’s Disease; and Multiple Sclerosis, 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, so it is recommended that you are diagnosed by a doctor with experience of the condition.

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 toward 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 and/or 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 studies have shown that exercise is not always the best possible use of sufferers’ 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.
Australian ME/CFS Societies

**Australian Capital Territory**

ACT ME/CFS Society, Inc
Address: PO Box 717, Mawson ACT 2607
Phone: (02) 6290 1984
Fax: (02) 6290 4475
Web: www.mecfscanberra.org.au
Email: mecfscanberra@shout.org.au

**South Australia**

ME/CFS Australia (SA) Inc
Address: PO Box 28, Hindmarsh SA 5007
Phone: 1300 128 339
Web: www.sacfs.asn.au
Email: sacfs@sacfs.asn.au

**New South Wales**

ME/CFS & FM Association of NSW
Address: PO Box 5403, West Chatswood NSW 1515
Web: www.mecfsnsw.org.au

**Victoria**

Emerge Australia
Web: emerge.org.au

**Tasmania**

Northern Territory

**Western Australia**

The ME/CFS Society of WA (Inc)
Address: The Centre for Neurological Support, The Niche, 11 Aberlare Road, Nedlands, Perth WA 6009
Phone: (08) 9346 7477
Fax: (08) 9346 7534
Web: www.mecfswa.org.au
Email: info@mecfswa.org.au

**Queensland**

ME/CFS/FM Support Association Qld Inc
Address: c/o Mission Department, St. Vincent’s Hospital, Scott Street, Toowoomba 4350
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Northern Yorke Peninsula ME/CFS Support Group
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Email: shepherd@rbc.net.au

Jamestown
Contact: Gloria Tiver
Phone: 8664 0540

Port Pirie
Contact: Marj Turner
Phone: 8633 0867

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

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- Phone: 1300 128 339
- Email: sacfs@sacfs.asn.au
- Office Manager: John Leverenz

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:

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