



# Talking *Point*

2004 Issue 3

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

*Your  
Society*



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## ME/CFS Society (SA) Inc.

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

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

## Patron

Her Excellency Marjorie Jackson-Nelson  
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## Medical Advisor

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

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

**President:** Peter Cahalan

**Vice-President:** vacant

**Honorary Secretary:** Denise Stephens

**Treasurer:** Geoff Wilson

**Management Committee Members:** Margaret Wing

Peter Evans

Adrian Hill

## Contact Details

Any correspondence should be directed to:

ME/CFS Society (SA) Inc. PO Box 383,  
Adelaide, SA 5001.

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

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

At the time of printing the office hours are:

Wednesdays and Thursdays 10am to 3pm (subject to volunteer availability).

Our email address is: [sacfs@sacfs.asn.au](mailto:sacfs@sacfs.asn.au)

Our Web site address is: [www.sacfs.asn.au](http://www.sacfs.asn.au)

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## Contents

### Society Matters

From the president, <i>by Peter Cahalan</i> .....	4
MCS Workshop report, <i>by Peter Evans</i> .....	8

### Articles

An age-old issue, <i>by Val Rubie</i> .....	14
Insurance company accepts CFS as a real condition, <i>by Toula Mantis</i> .....	16
Media Watch .....	17, 23
The road less travelled, <i>by Zoe Williams</i> .....	18
Ambulance transfers – another option, <i>by Ricky Buchanan</i> .....	20
Self-hypnosis for CFS pain, <i>by Ricky Buchanan</i> .....	22
Personal story: How I contracted CFS, <i>by Wendy Dorey</i> .....	24
Personal story: Susan McGregor .....	25

### Medical pages

Paced exercise helps CFS/ME.....	26
Exercise, explanation key to the CFS puzzle.....	27
Depression not cause of cognitive symptoms.....	28
Pre-CFS/ME patients visit doctors more often .....	28
A comparison of pregnancies that occur before and after the onset of CFS .....	29
Essential fatty acids associated with symptom remission in CFS .....	30
NIAID collaboration yields new test for Lyme disease.....	31

### Miscellaneous

Awareness Night photos.....	32
Multiple Chemical Sensitivity Workshop photos .....	33
Support groups and contact numbers.....	34
Information about ME/CFS.....	35

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## From the president

By **Peter Cahalan**

*September 2004*

Page 4

Talking Point – 2004 Issue 3

I am very pleased to be able to report on a productive time for the Society over the past few months.

### Guidelines for general practitioners

Well, the Guidelines are well and truly out and about. Every GP in the State now has one. Whether they've all read them is of course not very likely. But the stories are coming in. One tells of a doctor lending their copy to a patient. Others indicate that people with CFS would love to have a copy themselves. This, by the way, is a bit of a problem for us. The Society was given a box of the Guidelines. But these copies have to go a long way and will have to be husbanded for giving out to people who are, for example, working on projects for the Society.

We've had a terrific reaction from other State societies. The Victorians have grabbed copies to show to the health authorities there. And the NSW Society has inquired about the price of getting 7,000 additional copies printed so that it can distribute them to every GP in that State. That won't be a cheap exercise and we haven't heard back from our friends there since sending them on an estimate of costs provided by the Department of Health (formerly the Department of Human Services). But if we were in a position to print a large second run of the Guidelines, then we'd be able to sell copies pretty cheaply to our members. If you're on the internet, of course, you can download them easily from our website at [www.sacfs.asn.au](http://www.sacfs.asn.au). I'm just sorry that it's not as easy as that for people without direct access to the net.

I can vouch for the usefulness of the Guidelines from personal experience. Through another route it was suggested to our family that we have our daughter Elizabeth tested for hemochromatosis. In my lay understanding that is a condition involving excess iron in the blood. When I mentioned that to Dr Peter Del Fante, he remarked that testing women with CFS for it should be automatic and pointed out that it's in the Guidelines. I looked and, sure enough, there it is. It's listed as



one of a series of linked conditions. I'd seen it but paid no attention – it was just some obscure condition in amongst better-known ones such as fibromyalgia. Dr Del Fante also pointed to another part of the document. It notes various tests which a doctor should consider ordering carried out on a person suspected of having CFS. One is "Fe test (for women)". The "Fe" stands for iron.

What that showed me was that the document looks deceptively simple and is certainly quite short. But it's packed with clues which you might want to check for. And, having done so, you can then go into your next visit with your doctor better armed to negotiate with them. In our case, Elizabeth has just been tested for hemochromatosis. There seems to be no problem there, though we're not certain. But the point is that the Guidelines helped us to ask our very good and compassionate family doctor to order a test which more specialised medicos have long known should be mandatory for female CFS sufferers. So it's already proved itself as an instrument of change and awareness-raising within the broader medical profession.

### Research database project

The Guidelines in a sense behind us, those who put them together are now moving on to the next project. This means that the Society is collaborating with the Department of General Practice at the University of

*(Continued on page 5)*

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Adelaide and with the network of doctors and researchers of whom Dr Del Fante is a key representative. Dr Del Fante and I met recently with Prof Justin Beilby, head of the Department (which trains many of our State's GPs). We shaped up a proposal for the first stage of a long-term project to study a cohort of CFS sufferers.

Most CFS studies tend to be framed to test a particular theory about the illness. This one will instead aim to track people over a number of years and to accumulate a database about their experience of the condition. From that a range of studies could then be undertaken.

The first phase will be a pilot study involving 120 patients for initially a year. They'll probably be selected from the patient lists of a small number of the doctors who specialise in treating the condition. However, if the pilot works we can use it to generate large grants for the project. And in that case we will be encouraging you to join up and to encourage everyone you know to join up. Ultimately it would be great to have 1,200 people or more involved.

The first phase is going to cost around \$30,000. This will enable the Department of General Practice, which is an accredited research institute, to employ a project officer to develop the questionnaire and coordinate data collection and entry.

The funding will, if the application succeeds, come from the Alison Hunter Memorial Foundation. This excellent body funds research into CFS. (Have a look at its website at [www.ahmf.org](http://www.ahmf.org).) Raising funds for CFS is not easy. But in this case the Foundation was given a



mighty boost by a team of people in Melbourne. They held an art auction with the assistance of Sothebys and raised, I believe, around \$27,000. And they did it specifically for the "South Australian research project", as it's been called nationally for some time.

The point is that our network of committed doctors and medical researchers are highly regarded within the national network of CFS societies. And South Australia is also a nicely compact society. It has good networks of communication. Our Society's relations with the medical community are good. And the medical professionals themselves communicate well with each other. So we have a better organisational and social basis for carrying out research into CFS than larger communities.

So let's hope that the funding comes through for the pilot project. Carrying out the really big project – a study conducted over five or more years – will cost a quite considerable sum. It could be as much as a million dollars. But carrying out the pilot project will enable our South Australian researchers to pitch for that kind of money.

Watch this space. We will perhaps put the final version of the proposal on our website to give you a fuller understanding of it.

### **The multiple chemical sensitivity campaign**

I write this a few hours after attending the annual rally on Chemical Injury Action Day. As usual the crowd was small. That's not surprising. It's pretty hard for someone with chemical sensitivities to stand around in the toxic soup of central Adelaide for an hour or more. I spoke on the behalf of the Society and was pleased to see that several members attended as a result of being reminded about it via our efforts.

The rally was attended by various political candidates. I explained to each of them that the Society is willing to provide access to its website for any party or candidate with policies which meet the needs of people with CFS and MCS.

Anyway, the rally was just the latest episode in a busy

*(Continued on page 6)*

## Annual General Meeting

**Date: Saturday November 13, 2004**

**Place: 195 Gilles Street, Adelaide**

**Time: 1:00pm to 3:00pm**

*(Continued from page 5)*

time for the Society on the campaign trail for a better deal for people with MCS. We finalised and sent in our submission to the State parliament's inquiry into MCS. A draft version of it is available on our website. I urge you to read it. And the I hope that you have the chance to ask questions of any Federal candidates who come your way about what they intend to do to develop national strategies to improve life for people with MCS (and indeed for everyone).

The Society also convened a workshop on MCS in conjunction with the Task Force on MCS. A report on that is included elsewhere in this issue of Talking Point. I was pleased that members of the Society comprised a high proportion of those attending it. We've been trying hard to get the news out to you about what's going on and it does seem to be working. I was particularly struck by the strong pleas made by participants for better access to health care and hospitals. Our large hospitals are far from the safe places which they should be for people suffering from chemical sensitivities. This was brought home to me quite starkly that very day. I got home from the meeting only to race off to the Flinders Medical Centre an hour later with a sick son. Over the next few days I was acutely aware of how stale the air is in such places and of just how many chemicals and volatile organics compounds swirl around within them. I can see the day when our society will start winding the clock back and rediscovering old wisdoms – such as the virtues of openable windows!

Anyway, the next step in the campaign will involve me appearing before the parliamentary committee of inquiry at some time in October. Peter Evans of the Task Force remarked at the rally that he had been impressed by the seriousness with which the members of the

committee were approaching their task.

Once again, I urge you to read our submission and, if you have the energy, try to do something to lobby State politicians or Federal candidates about the urgent need to improve the situation of people with MCS.

I might take this opportunity to send best wishes to one of our key volunteers, Donna Smedley. Donna was our regular office staffer on Thursdays. That is until the new landlord in Epworth Building, where our office is, began repainting the building. Donna has had to lay off work with us for the present. She's been a great worker for us and I hope that she can return to work with us again soon. In the meantime, if you're chemically sensitive and need to drop by the office for some reason – check with us first. The best day to do so is Wednesday, when our regular office coordinator Donna Briese and volunteers Michael Ritter and Jenny Turner are in there.

### The committee

Not long ago I was becoming somewhat anxious about the state of the committee. Our numbers had dropped to four for a brief moment: Marg Wing, Geoff Wilson, Adrian Hill and myself. However, we've bounced up again with great speed. Within a week or so no less than four new people volunteered for service and were coopted. They are:

- **Emma Wing:** Emma has been a mainstay of SAYME, our youth group, for some time and I'm delighted that we have someone on the committee

*(Continued on page 7)*

(Continued from page 6)

to represent the interests of our younger members.

- **Donna Briese:** Donna, as stated, is our stalwart Wednesday volunteer and someone who has diligently backed up the committee by ensuring that information flows to it as it comes into the office.
- **Donna Smedley:** Nothing daunted by her enforced absence from the office, Donna has also come aboard. Donna S and Donna B between them join Marg Wing in bringing to the committee an excellent working knowledge of the Society's operations, as they have all been regular office volunteers over the last several years.
- **Peter Mitchell:** Peter is a longstanding member who has just retired from the Education Department after many years as a high school principal. His last school was Brighton High. He was active for many years in the affairs of the high school principals' association and was in fact its honorary secretary for a long time. We saw Peter coming, as they say, and in short order he assumed the vacant position of honorary secretary of our Society. We have also asked Peter to take on another task. He will join Penny Cahalan in convening a working group to finish off a project which has been in abeyance for some time. That is to produce a resource kit for schools on how to deal appropriately with and support students with CFS. Watch this space for more on that.



CFS. So it should be a highly informative talk.

We were contemplating inviting another person to speak to us on the day. But in the end we felt that it would be better to have her kick off the 2005 lecture season for us rather than have to share a crowded agenda at the AGM. Christine Hunter runs the Alison Hunter Foundation which raises funds for projects such as our research database mentioned above. She has also fought many battles in the fight to have CFS treated as a serious condition and to prevent it from being treated as some kind of psychologically induced (or 'neurasthenic') condition. She is attending the American convention and is being financially supported to do so by the national association of State CFS societies.

Why are we sending Christine? Well, there is the possibility that the medicos there will accept amendments to the formal criteria for assessing people as having CFS which could lead to a more 'psychological' approach being taken to it... Sadly, that campaign is based on an Australian program called Sphere developed by Professor Ian Hickie of Sydney. I urge those of you who can dig into the background to this on the web to do so.

I hope that you can attend our AGM. I'm a bit apprehensive that, if a lot of people decide to roll up on the day, the place could become a little crowded. Could I suggest that you leave a message with the office to say if you're coming? And can I urge those of you who can't make it to follow the usual practice and nominate me, as president, as holder of your proxy vote?

That's it for now. Your Society seems at the moment to be in good shape and I thank once again everyone who works so hard for it. They know who they are. And I wish you that which I am in the habit of wishing our wonderful webmaster Peter Scott every time I send him something for our website or Talking Point. I hope that you are as well as can be and that, whatever the state of your health, your spirit is strong.

*Peter Cahalan*  
President

## The Annual General Meeting

Our AGM will be held on 13 November at 1 pm. The venue will be the Disability Information Resource Centre. Details are provided elsewhere. I am really pleased that this year, after several years where we've gone for a speakerless meeting, we will augment the usual business with an excellent speaker. Dr Peter Del Fante – yes, his name keeps cropping up – will report on an overseas trip which is taking him to a very important annual convention of the American association for ME/CFS. He then travels to Britain to look at a series of specialist health-care facilities for the treatment of people with

# MCS Workshop report

By **Peter Evans**, SA Task Force on MCS

Page 8

## Background

On Saturday 4 September 2004 a public meeting and workshop was held to offer people with Multiple Chemical Sensitivity an opportunity to provide input into the parliamentary inquiry into MCS by the Social Development Committee. The workshop was a joint event that was co-sponsored by the SA Task Force on MCS and the ME/Chronic Fatigue Syndrome Society and was advertised through the membership of both groups.

The main objective of the workshop was to identify the most important issues affecting people with MCS to be presented to the parliament, with the goal of incorporating disability access and other strategies to enable a better quality of life for people with MCS.

Twenty people attended the meeting. Around three-quarters of the group reported that they had been diag-

nosed with chronic fatigue syndrome, with some reporting a simultaneous diagnosis of both CFS and fibromyalgia. Everyone with a CFS diagnosis reported experiencing multiple chemical sensitivity. Two participants had symptoms of MCS but without profound fatigue and no diagnosis of CFS. The remainder of the group consisted of parents and carers of people with MCS who were unable to attend the meeting due to severe illness.

## Workshop process

### *Individual discussion*

The group was initially asked to talk to the person next to them about how their lives had been impacted by MCS. Participants were asked to write down a list of at least six important issues that they would like to see addressed by the parliamentary inquiry.

### *Identification of major issues*

Participants were then asked to call out the issues they had identified, which were listed on a black board. This was accompanied by some group discussion of the issues.

Most of the time assigned to this activity was taken up by problems experienced with medical services.

### **Medical Issues**

There was clearly deep dissatisfaction amongst the group with the medical profession, the medical misunderstanding of MCS, the misdiagnosis of MCS by GPs, and the lack of accepted diagnostic criteria and any diagnostic laboratory tests for MCS. People expressed great frustration that doctors generally did not acknowledge the views of people with MCS regarding their own illness. It was felt that GPs discriminated against people with MCS, particularly against women with MCS who were often dismissed as hysterical. The group felt that men with MCS were more likely to be taken seriously by their doctor and less likely to be la-

*(Continued on page 9)*





*(Continued from page 8)*

belled with a psychiatric diagnosis. It was very clear that the group felt that a psychiatric diagnosis for MCS was highly inappropriate and that people with MCS who were labelled with a psychiatric diagnosis were disadvantaged when attempting to access medical and social services. There was concern that Centrelink was discriminating against people with MCS.

The group felt that there was a general lack of access to informed medical services and GP services and suggested the formation of a list of empathetic doctors. However, only one participant in the group could recommend a GP who was particularly informed on MCS but this doctor had closed his books and was not taking on any more new patients. The absence of a network of supportive professional medical practitioners was clearly a major issue. It was suggested that an MCS patient care plan be developed for distribution to GPs.

The lack of home care, nursing care home placements and respite care was identified as a major issue for people with severe MCS/CFS. These people are confined to their homes, are often unable to get out of bed and cannot access services. It is almost impossible to get informed medical care for such people. Services that normally provide home care do not cater to people with MCS due to ignorance and lack of MCS protocols. People with severe MCS often do not fit general criteria such as age or medical diagnosis that allow them access to services.

Participants reported that they had found practitioners of natural medicine, naturopaths, homoeopaths, etc, helpful but that the cost of accessing alternative health care was prohibitive. Although naturopaths recognised MCS and could offer helpful treatments they were not able to provide sickness certificates in relation to work or access to social services.

### **Toxic Hospitals**

Hospitals were identified as toxic environments where people with MCS were discriminated against by the lack of hospital protocols to manage MCS. Nurses often refused to accommodate chemical sensitivity in the hospital situation. MCS nursing protocols are needed.



### **Workplace Issues**

The group found that there was no recognition of MCS in the workplace and that occupational health and safety policies should include MCS.

People with MCS need to educate their workplace about their needs, either by writing to their employer or by other channels.

The use of fragrances and smoking in the workplace was identified as a particular problem, with the suggestion for fragrance free / smoke free signage in workplaces.

### **Causes of Chemical Sensitivity**

People reported increased chemical sensitivity following exposure to pesticides and herbicides, with subsequent loss of tolerance to low grade smells from cleaning products, household chemicals, perfumes, hair shampoos and conditioners, after shave, and detergents, which would normally have been tolerated before the pesticide/herbicide exposure. Photographic chemicals were reported as a cause of MCS in one case.

### **Symptom Triggers**

Products commonly reported to trigger symptoms of MCS were perfumes, cigarette smoke, wood smoke, vinyl flooring, carpeting, vehicle exhaust, synthetic fabrics, solvents, cleaning products, personal care products, shampoos, paints, pesticides, herbicides.

*(Continued on page 10)*

(Continued from page 9)

### Other issues

There is a general impact on people's social life and the ability to participate due to chemical barriers.

The group felt that local councils were not acting to make the community a safe place for people with MCS because of herbicides. Councils did not provide warning signage so that people with MCS could avoid areas that had been sprayed.

The use of toxic paints in road line marking caused problems when travelling and warning signage was needed.

Pesticides such as termite treatments caused difficulties. Grape growing near residential areas was identified as a particular problem due to pesticides.

Chlorinated pools cause symptom triggering.

Car exhaust is a problem. Improved vehicle exhaust standards and better policing of existing standards is required. There were limitations on the amount of time people with MCS could spend driving, particularly during peak hour traffic.

Personal fragrances and air fresheners cause symptom triggering. Fragrance free policies are required in public services and public transport.

Smoking in public areas is a disability access issue, such as outside cinemas, shopping centres, hospitals, bus stops, etc.

Urban wood smoke from neighbours' home heating is particularly a problem in winter.



Indoor air quality (IAQ) is poor in most buildings. Better IAQ standards are required but the existing building code standards for IAQ are not being met or monitored at present.

Disability access for people with MCS is very poor. People with MCS are denied civil participation due to chemical barriers. Some strategies that would assist this problem are fragrance free codes, low allergy paints, ceramic tiling instead of carpets, no smoking at entrances to buildings, and fragrance free, non-toxic cleaning products. Some people are sensitive to noise and light as well as chemicals.

Public housing for people with MCS is inadequate. The South Australian Housing Trust does not respect the health needs of people with MCS. The Trust uses toxic products for renovation and maintenance and will not remove or replace toxic products that are causing health problems - for example vinyl tiling.

Public education on MCS is lacking. There needs to be better public education on health problems caused by pollution.

### Small Group Brainstorming

The issues identified by individual discussion were divided into six main headings.

1. Doctors / Medical
2. Workplace
3. Public Education
4. Local Councils
5. Housing
6. Disability Access / Civil Participation

Participants were then asked to break into six individual groups to brainstorm these topics and offer suggestions on how to rectify the problems. The groups were asked to identify what would need to change and how the parliament and the community could support people with MCS.

The six groups were asked to record their discussion on paper and present the information to the meeting on completion.

(Continued on page 11)

(Continued from page 10)

## Reporting of Brainstorming

### 1. Doctors / Medical

Particular problems identified by this group were the lack of communication between doctors and allied health professionals such as naturopaths, the lack of any kind of case management for people with MCS, and the excessive cost of medicines, both natural or medical.

Proposed solutions for these problems were to develop a list of doctors and allied health professionals who have experience in the field of CFS/MCS. The GST on all treatments for CFS/MCS should be removed. Private health funds should cover all treatments for CFS/MCS.

The group found that people with MCS needed access to general health care and medical services and recommended that all hospitals, doctor's surgeries and dental surgeries develop MCS protocols.

The group recommended the development of a specialist health care centre that could provide diagnosis and treatment for MCS. The centre would also educate other medical professionals in the practice of clinical ecology and the medical management of MCS.

The Department of Health needs to conduct education workshops on MCS for GPs and other medical professionals.

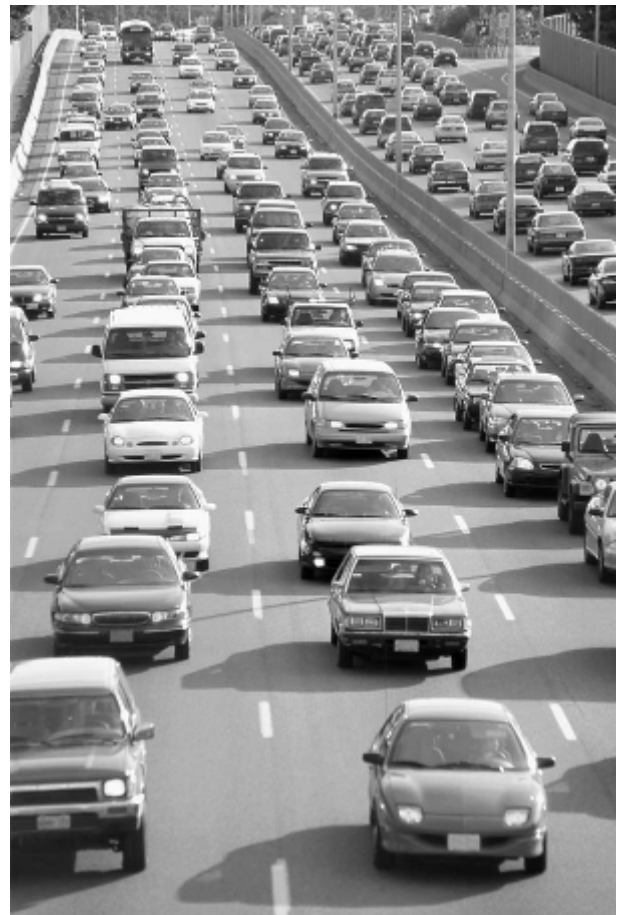
### 2. Workplace

This group found that poor indoor air quality in workplaces caused problems for people with MCS and that access to work opportunities was limited.

The group recommended that occupational health and safety policies should recognise MCS.

Some solutions included a fragrance control policy in the workplace.

The use of protective equipment, including facemask



and gloves, when handling chemicals in the workplace was recommended.

For those who were sound and light sensitive, dimmer switches could be installed on lighting or sunglasses and earplugs could be worn.

### 3. Public Education

This group found that there was a general lack of accurate information on MCS. Individuals suffering from MCS need to be empowered to speak up about the problems they experience.

Smokers need to be educated about the problems they cause for people with MCS. The placement of ashtrays in public places and general wind direction are factors.

One of the first steps to address chemical pollution and MCS is public education about fragrances and the need for fragrance-free products.

(Continued on page 12)

*(Continued from page 11)*

There needs to be a "whole of life" education process about MCS with a broad population focus beginning at kindergarten and primary school levels.

It would be useful to get the SA Film Corporation to fund a documentary on MCS as a public education strategy.

More research onto MCS is required, including a cross comparison of MCS patient data to inform medical education.

MCS should be recognised as a physical illness not a psychiatric illness.

Education programs are needed for carers of people with MCS, families, friends, nurses and other health care professionals.

Public programs are needed to promote environmentally clean air and soil.



There needs to be public education and awareness of MCS in relation to healthy, accessible housing and buildings.

## **4. Local Councils**

Councils need to adopt an environmentally friendly attitude with more natural solutions to pest management to protect us against poisoning by herbicides and pesticides. Political parties such as the Greens or organisations like the Environmental Defenders Office may have a role to play in this.

It is unclear whether local governments support the community's wishes for less toxic methods of pest control. Do conflicts of interest exist in Councils' spraying campaigns?

Councils need to be educated about MCS and lobbied about the disability needs of people with MCS.

Councils need to know about the legal rights of people with MCS and the possibility of civil action against them by people who have been damaged by sensitivity reactions and health problems from exposure to poison sprays.

What is the role of the Environmental Protection Agency in protecting the public against the use of pesticides by local Councils?

There needs to be a publicly accessible register of spraying activities so that the public health consequences of spraying can be identified and help provided to sufferers of pesticide sensitivity.

## **5. Housing**

Public housing cannot cater for people with MCS because of the current guidelines.

There needs to be education and monitoring of contractors in public housing to ensure that the needs of people with MCS do not get ignored.

Both indoor air quality and outdoor air quality are disability access issues when housing people with MCS.

*(Continued on page 13)*

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People with MCS require a specialist, low-chemical, low-allergy community housing project in a clean air environment.

There needs to be guidelines developed for affordable, low allergy housing construction.

Public housing needs to look at low chemical / low-allergy housing generally. Changes in products used in public housing would benefit wider groups such as asthmatics and people with allergies. There needs to be education and understanding that low chemical / low allergy housing is much healthier for everyone, is not much more expensive than standard housing and is able to accommodate everyone.

There needs to be recognition of disability access for MCS and the availability of priority public housing for the special needs of people with MCS.

People with MCS need advocates who really understand MCS.

## **6. Disability Access / Civil Participation**

There is a need for improved indoor air quality codes and standards and more testing of indoor air to ensure good indoor air quality.

The definition of disability needs to be expanded to include MCS in all public policies, disability access strategies, codes and legislation. The Local Government Association needs to strengthen its policies and education programs to include MCS.

There needs to be improved warning signage for public sites during renovations and construction.

The Human Rights and Equal Opportunity Commission needs to be more involved in recognising MCS as a disability.

National standards need to be improved, including building code standards.

Remove fragrances from buildings.



Educate disability access coordinators to include MCS disability access issues.

The state government to establish a working group of key agencies to create a continuous improvement process in MCS disability access.

The government to review the safety of current chemical exposure standards, do surveys on the health impact of workers exposed to chemicals and provide research funding for a longitudinal study of MCS.

## **Summary**

This workshop provided some insight into MCS and some suggestions for practical solutions to the problem from the perspective of people living with MCS. It is clear that more public debate and attention to MCS is required. Both government and the medical profession need to take the growing problem of MCS much more seriously in order to address the complex issues involved.

Thanks to all of those people involved in organising and conducting the meeting, with special thanks to Kerry Reid for facilitating the workshop and Jenny Turner for promoting the meeting by telephone to ME/CFS Society members.

*Peter Evans*

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## An age-old issue

*One of the many misconceptions surrounding ME (CFS/ME) is that it only affects younger people. Unlike society, however, the illness does not discriminate and can hit anyone: male or female; black or white; young or old. In this article, psychotherapist **Val Rubie** considers the particular problems of ME for the older person.*

Page 14

Talking Point – 2004 Issue 3

Most of us expect to remain active throughout our sixties, seventies and even eighties. We see pension advertisements involving cruises and sunsets while vitamin and food supplement catalogues show pensioners paragliding over the Mediterranean.

This is the age which I suspect is very neglected in terms of diagnosis, as illustrated by [Action for ME UK member] Beryl Modan's letter: "My doctor recognised the symptoms of ME in me but thought it was unlikely to be the right diagnosis because of my age. Instead he sent me to a geriatrician, which I found quite humiliating."

Letters from members reflect the same picture, although, to be fair, a few mention really understanding and accepting GPs for whom age is not a factor when considering a diagnosis of ME.



### What do you expect at your age?

I was very shocked when I met my first retired person with ME many years ago. Unthinkingly I'd assumed it to be an illness associated with younger age groups; as if viruses have some predilection for young bodies. I quickly learned how cheated ME makes you feel when older.

You may have worked hard for many years supporting a family, building a career and finding a life with suits you. You also may have looked forward to easing up and doing what you never had time for, only to find that you don't have the energy to enjoy it. Life may become very flat and meaningless.

The most unfair thing of all is that refrain: "What do you expect at your age – of course you can't do what you used to ... you will just have to be realistic and slow down."

Moreover you may be told to feel glad that you haven't got a life-threatening illness like some of your peers. It is possible that the harder an older person tries to get any contacts to understand ME, the more he or she is accused of failing to accept the ageing process. Our society is guilty of turning a deaf ear to the voice of our older generation.

### Making light of a sad situation

A letter we received from Florence in Kent put it well: "The hospital physician gently and courteously told me that after an active life I was finding it difficult to adapt to the slowing down caused by old age." But as she said to her GP: "I had already experienced the slowing down caused by age and could testify that it is very different from the exhaustion which still hits me every day." However, this same lady feels there are certain

*(Continued on page 15)*

*(Continued from page 14)*

advantages to being an older sufferer as “..no-one expects much of an octogenarian” but I feel this is making rather light of a sad situation. At the onset of her ME she was half way to her fourth Open University credit and clearly wanted to continue.

Perversely perhaps there is even more of a blame culture against people of this generation with ME. We have been encouraged to believe that a healthy old age is possible if you avoid saturated fat and go to the gym. Ergo those who are not healthy must have been lazy and eaten junk food so how dare they complain if they are exhausted and in pain. The comment “ it’s your own fault for not looking after yourself” may hang unspoken in the air. This totally denies and overlooks the fear associated with symptoms which people with ME of any age experience. But how dreadful to wonder, like Florence, if your forgetfulness is just ME or the early signs of Alzheimer’s.

### Who cares?

Bereavement in some form is usually a significant part of old age. It is also a significant part of ME in a subtler way, whatever one’s age. We lose people – lovers, friends, colleagues – for a variety of reasons: they don’t understand, they disapprove, or they get plain fed up with the restrictions of our illness.

However, true bereavement can be a double whammy for an older person who may lose their principal carer as well as their lifetime companion. Is one’s disability likely to be taken seriously by those who have the power to provide alternative care? After becoming widowed Megan moved into sheltered accommodation where she is fortunately well enough to join in some social activity. But what about those who are severely affected – is it easier for an elderly person with ME to gain access to care?

### Celebrating small triumphs

Each age group affected by ME comes with its own set of medical justifications and stereotypical explanations. The spectre of a purely psychological diagnosis hovers over all of us – it is just phrased in slightly different ways depending on our age-related and personal cir-



cumstances. Each phase of life, even without illness, has its problems and its triumphs. For people affected by chronic illness those same problems may on bad days seem insurmountable. Perhaps on our better days we can concede that there will be smaller, different triumphs – like getting out for the first time in months.

Beryl writes: “It has not been easy for me to restrict my activities but I am blessed with an understanding family and am looking forward to my first great-grandchild.”

I’ll end with some advice that has helped Mr GL. It was given to him by his late wife, an MS sufferer: “If you pity yourself, no-one will sympathise with you.”

But the final word goes to Florence. She believes that the emphasis must be on younger people whose whole life is still before them but pleads:

“Don’t marginalise old people. Our time ahead may be limited but our quality of life remains important.”

*This article reprinted from InterAction, July 2002.*

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# Insurance success

*The story of **Toula Mantis**'s successful insurance claim after a four-year legal battle.*

Page 16

Talking Point – 2004 Issue 3

Insurance company ACE Insurance Limited has confirmed that Chronic Fatigue Syndrome (CFS/ME) is a neurological condition comparable to Multiple Sclerosis following its acceptance of a claim made for \$100,000 under its American Express Recovery Assist Plan.

The successful outcome came in April this year when the insurance company changed its original ruling from CFS/ME not falling "within the criteria of the benefit" to CFS/ME was a "neurological condition to its full satisfaction".

It follows a four-year battle and the threat by the legal firm Maurice Blackburn Cashman Pty Limited to make a formal complaint against the insurance company because it had not followed the proper procedure in this matter on behalf of its policy holder, Toula Mantis, who was a CFS/ME sufferer.

The final determinant was the finding of clinical neuropsychologist, Mr Martin Jackson, acting on behalf of the insurance company. He conducted an intense neuropsychological assessment on Toula covering seven key areas including general intelligence, attention and concentration, new learning and memory, language function, executive functions, behaviour and emotion, and test taking behaviour.

The assessment proved that Toula did indeed show at least moderate persisting neurological abnormalities with the impairment of function but not necessarily confining her to a wheelchair or bed; hence satisfying the policy definition of "Multiple Sclerosis – Other Neurological Conditions" as set out in the insurance policy.

Toula, a technology journalist with a biological science background, was convinced that CFS/ME was a neurological condition after having discovered that the Neurological Council of Western Australia had included CFS/ME in its list of neurological disorders during its Neurological Expo 2000.

Armed with this information, the legal firm Maurice Blackburn Cashman was appointed to manage the claim process in an effort to maximise the chance of a

successful outcome. The legal advice received was to produce evidence from a medical practitioner that CFS/ME could be described as a "neurological condition". The evidence was provided by Dr Michael Oldmeadow in 2001.

In his evidence Dr Oldmeadow wrote that "the exact pathogenesis of this disorder is yet to be confirmed but strongest evidence would suggest that it reflects a disorder of the neuroendocrine axis, most specifically at the level of the hypothalamic-pituitary-adrenal axis. The primary disorder is thought to be that of central nervous system dysfunction." This medical description of CFS/ME provided the ammunition the legal firm required to pursue the case.

Despite there being a strong case, the insurance company in 2002 declined the claim that CFS/ME was a neurological condition. It stated that CFS/ME did not fall within the criteria of the benefit headed "Multiple Sclerosis – Other Neurological Conditions."

However, the insurance company had failed its own policy procedure by not having requested that Toula undergo a neurological examination to confirm whether or not any impairment could be shown prior to making a decision on the claim.

Under its insurance policy, the sufferer is required to be diagnosed by a neurologist as having a "neurological condition" resulting in "moderate persisting neurological abnormalities with impairment to function".

Insurance and income protection policies pay benefits for specific disabilities, although some exclude CFS/ME-related disabilities.

Maurice Blackburn Cashman advise that if you have any type of insurance policy you check which illnesses it covers.

Contact CFS/ME Victoria and you will be referred to Maurice Blackburn Cashman for free legal advice.

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## Media Watch

Susanna of *Slanderwatch*, along with many other CFS/ME sufferers, wrote to *Woman's Day* about the advice given to the mother of a sufferer by a psychic. She received a reply from Joanna Martin, Assistant Editor of *Woman's Day* as follows:

*"Thank-you so much for your comments. You are not alone in your concern about our psychic writer's response to the letter concerning CFS. She is not a health specialist and, unfortunately, the answer to this letter was published without being checked."*

*"We have since apologised to the mother and I can assure you that great care will be taken in the future not to let such a comment go unchecked or unchanged."*

*"I also extend an apology to you and to the many sufferers who wrote in to tell us how justifiably upset and angered they were by this misinformed response."*

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Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) have received top billing in the media over the last few months. The results of a study by Dr Karen Wallman of the Exercise Physiology Department of Edith Cowan University in Western Australia were published in the *Medical Journal of Australia* in the first week of May. This report was taken up by Norman Swan, who interviewed Karen Wallman on ABC Radio's *Health Report* on 10 May 2004, and by *The Age* in the same week. The study involved sixty people with CFS/ME who were given a twelve-week course of light graded exercise and all showed improvement at the end of the trial. They were able to pace themselves and were not pushed beyond their abilities. On a bad day they could reduce or cancel the exercise. The abandonment of "avoidance behaviour" was also mentioned. Norman Swan asked when he interviewed Dr Karen Wallman, "It's all very well doing a twelve-week study, but what happens a year later?"

Susanna of *Slanderwatch* wrote to Dr Karen Wallman and received a very lengthy reply in which she said, "Nonetheless it was not a cure! What did happen is that people were able to do a little more, such as their shopping, attend a movie or barbecue. I think that this is important."

CFS/ME gets a mention in some unlikely outlets such as *Big Brother* on Channel 10 (23 July 2004) and on *The Footy Show* on Channel 9 (15 July 2004).

According to the discussion on *Big Brother* CF and CFS/ME are the same thing, 'syndrome' merely meaning 'for a long time'. I hope not many people took too much notice of all this because their knowledge on health matters obviously was seriously lacking. They also discussed the 'fact' that AIDS was spread by people having sex with monkeys.

*The Footy Show* featured an item on Alastair Lynch. He was interviewed by Eddie McGuire because he was due to play his three-hundredth game the following weekend. Mention was made of his CFS/ME. Extra information supplied by the person who sent us the details of the Channel 9 interview stated that Alastair Lynch's training is different from other footballers and when he comes off the footy field he often has a fast heart rate and feels like he has a hangover and has the dregs of CFS/ME.

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One of our regular contributors, Ricky Buchanan, featured in an article in the *Weekend Australian* of 3 July 2004. She featured at the beginning of the long article, but the main thrust was a general coverage of CFS/ME and the use of CBT and GET and contained quotes from Professor Andrew Lloyd and Dr Rob Loblay. In a highlighted piece at the end of the article under a photo of Ricky was a piece entitled *Pros and cons of exercise in fighting CFS*. It quoted Professor Lloyd's statement in the editorial in the *Medical Journal of Australia*: "Graded physical exercise should become a cornerstone of the management approach for patients with CFS" as it often enabled them to "achieve a substantially better quality of life while awaiting recovery."

However, Dr Loblay urged caution about generalising from the exercise studies, which never include people with severe CFS/ME. "All these studies involve people willing and able to participate," he says. "The people who find it makes them feel lousy drop out."

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## The road less travelled

Severe ME (CFS/ME) makes for a mean travelling companion, but **Zoe Williams**, having heard from many others with ME, is full of ideas to tackle problems encountered on the road.

Page 18

Talking Point – 2004 Issue 3



Profound difficulties with travelling are common among people severely affected by ME. I have left my village seven times in a decade; others have not moved from their homes at all and those who are able to go out need to pace themselves with care.

### Why travelling is so difficult

Simon McGrath echoes many when he says, "The straighter and smoother the road the better. It's bends, roundabouts, bumpy roads and stopping and starting that are most tiring for me." Dr Michael Midgley explains, "Travelling uses lots of energy partly because the muscles try to compensate for the movement and vibration; you can't relax completely when you are being jolted around and in ME the muscles don't function normally."

I received both positive and negative reports of motorways: positive because they are smooth and straight; negative because they are noisy and full of fumes. Dr Anne MacIntyre in her book *ME: A Practical Guide* says a reaction to chemicals when travelling can be helped by taking extra Vitamin C (1-3g) before and during the journey and by drinking plenty of water.

Your hard-learned lessons are many and varied: Linda, for instance, makes sure the driver has put enough petrol in the tank before transporting her because petrol stations make her feel worse, while Tilly finds sucking peppermints helps her travel sickness.

### Comfort is paramount

Try to get as comfortable and well supported as possible before setting off. You may benefit from having padding under your legs and arms, a neck pillow and perhaps a hand towel around your waste as a lumbar support. Reduce vibration by sitting on a pillow and putting another under your feet.

Some of you mentioned that relaxation techniques such as breathing exercises can help to reduce the impact of the movement. Playing a relaxation tape or gentle music on a Walkman if you are well enough can aid relaxation and mask external sound.

If you have trouble getting in and out of a vehicle, a transfer board may be useful if the seat of your wheelchair and those in the car are of compatible height. One end of the board goes on the wheelchair seat and the other on the car seat creating a continuous surface along which to manoeuvre. No longer being able to transfer into most vehicles, Thian has now had a caravanette specially adapted with a rotating passenger seat, ramps and a permanent bed installed for rest stops.

Vonne, on the other hand, has discovered how to make a bed chair in her car by winding the front seat down flat. She sits on the back seat with legs raised on a pillow on the lowered front seat. "It's like sitting up in bed," she says. "Being further back in the car also means the scenery does not rush past so quickly."

Difficulty with sitting upright is common in severe ME. The most widely used method is to recline the seat, although if you are able to travel sitting up it will give you the protection of a safety belt, also a legal requirement.

Probably the safest method of travelling in a horizontal position is by stretcher ambulance. [Editor's note: See next article, *Ambulance transfers – another option.*]

(Continued on page 19)

*(Continued from page 18)*

My own favourite method has been travelling in a friend's people carrier. With the back seats laid flat the boot space is big enough to create a large bed using travel mattresses, doonahs, blankets and a beanbag. Having lots of padding considerably reduces the vibration. Von, on the other hand, lies along the back seat of a car well supported by cushions and pillows.

### Travel survival kit

It's a good idea to have a 'travel pack' of things you might need on your journey. Rachel's bag contains an eye mask, ear defenders, plastic bags for travel sickness, a damp face washer, tissues, lots of water to drink and snacks. She also recommends using a vehicle with good suspension. Earplugs and ear defenders can be invaluable for the noise sensitive, while wrap-around sunglasses and/or a sun hat will make light easier to bear. A mobile phone is also useful in case of emergencies.

Another common problem can be needing the toilet frequently. If there is no public loo nearby, or if none are wheelchair accessible, Linda sensibly suggests planning routes around toilet stops or, if necessary, take a urine bottle or ladies' slipper urinal.

Finally, keeping your eyes closed when travelling reduces stimulation, frustrating though this is when you want to look at the scenery.

### Is it worth it?

The impact of travelling can be significant and, as with other activities, pushing beyond your own limits could trigger deterioration. Bear in mind that you may feel worse than usual after the journey and so be less able to tackle stairs, walking and general activity. It's an idea to try to organise for a room to be ready before you arrive so you can rest without delay. Packing and other preparation should be done well in advance (ideally by another person) to enable you to get plenty of rest before the journey.

If possible explain a bit about your needs to the person driving; for example asking them to drive as smoothly as they can and perhaps not to chat or have the radio on. If you are able to rest in the vehicle, it can help to

stop regularly – although some people find it easier to do the whole lot in one go and then collapse into bed afterwards.

There are, of course, different levels of travel – a long journey, five minutes round the block, a trip downstairs or into the garden. If the aim of an outing is to improve quality of life and yet you suffer so much that it has the opposite effect, you may find you benefit more from staying at home and finding other things to enjoy. Linda says, "The most important thing I have learned about trying to go anywhere is to say 'no' if I'm too ill. It's not worth pushing yourself if you really can't make it."

But for those of you who can make it out I'll end with Graham's advice, "The key to a successful journey, whether long or short, is meticulous planning – seeing problems before they actually happen and being prepared for them if they do."

Good luck on the road less travelled.

*Article reprinted from InterAction, Issue 42, October 2002. Some paragraphs in the article that are UK-specific have been omitted.*



## Ambulance transfers – another option

By **Ricky Buchanan** (formerly known as Bek Oberin).

Page 20

Talking Point – 2004 Issue 3

I am on pain medication which requires that I visit my pain specialist every two months come rain, hail or CFS/ME crashes. Since I am also at the 'very severe' end of the CFS/ME scale, it was getting to the point that it took me over a month to recover from the trip to the specialist.

One day on an Internet mailing list for people with CFS/ME I was grumbling that spending half my life recovering from visiting this specialist wasn't my idea of 'a life', CFS/ME or not. Somebody suggested that I use the non-urgent ambulance transfers to get there – I wouldn't have to sit up, or drive my power wheelchair at all, so it shouldn't be such a shock to my system.

In February this year I finally bit the bullet and used the ambulance transfer to visit my specialist. The ambulance transfer was brilliant, compared with the usual wheelchair-taxi trip. The doctor let me queue-jump when I arrived, he saw me straight away and the ambulance men waited and took me home again as soon as the doctor was finished. This meant that my total time out of bed was one and a quarter hours – without the ambulance it would have taken one to three hours longer at least. Plus I would have had the stress of being semi-upright the whole time in my reclining power-wheelchair, having to drive it around the hospital to the specialist's rooms and bouncing around uncomfortably in the back of a wheelchair-taxi.

I thought about the transfer a lot before it happened and figured out how I thought it would be the least stressful on my system. I arranged with the ambulance people to take my own pillows and cushions and quilt from my bed so I felt comfortable with appropriate and well-known things to hold up my head and knees and something that was soft and light over my legs instead of using standard ambulance pillows and blankets

which are, in my opinion, scratchy and rock hard. And, since I was essentially still 'in bed' with a quilt over me, I stayed in my pyjamas. That helped me even more with the exhaustion because I didn't have to extend my out-of-bed time by getting dressed before I went and undressed when I returned, which is very hard even with a carer to help me and there isn't always a carer around.

I think that using my own pillows and covers was a very good move because I didn't have anything next to my skin that I wasn't used to and I wasn't breathing in strange chemicals from unknown detergents and cleaners used to wash or sterilise the bedding or pillows. Sure, there were still some weird chemical smells

around the ambulance. I wouldn't recommend it for anyone with severe MCS who can't deal with a regular car trip, but for somebody like me with few inhalant allergies it was better than I could have hoped for. Oh, and I saved the \$15 that a half-price taxi would have cost me too!

I would say that the difference, healthwise, is that recovering from the ambulance trip takes me a bit less than a week, whereas recovering from the wheelchair-taxi version of the same trip usually takes nearly a month.

Ambulance transfers like this – on a stretcher but in a non-urgent "transfer" ambulance – have to be organised by your doctor or his receptionist. If you have a health card or pension card or if you are an ambulance member, then it's totally free of charge. If the doctor can see you right away, then you will stay on the ambulance stretcher all the time and the same crew will usually take you back; but if the crew can't wait they'll move you on to a bed in the doctor's surgery and then

(Continued on page 21)



*(Continued from page 20)*

another ambulance team puts you on to another stretcher for the return journey.

In conclusion, I very highly recommend this method of travel to anybody in the 'very severe' category of CFS/ME – for example people who usually would not travel outside the house, but have to go to see a doctor.

### **An important note from Ricky**

Hello – it's Ricky Buchanan here. I need to let you know that I used to be known as Bek Oberin – same person, new name. I thought I'd better write a little bit down here just so I didn't confuse you all too badly.

I changed my name from Bek Oberin to Ricky Buchanan over two years ago but decided then to use Bek Oberin for my writing so that I didn't confuse people. It worked for a while but I don't feel that "Bek" fits me now and I want everybody to know that my name is Ricky.

Why did I choose Ricky Buchanan for a name? Ricky because I liked it a lot and I feel that it fits me very well; Buchanan because it was my maternal grandfather's surname and he was the most important person in the world to me.

If anybody wants to ask questions feel free to e-mail me on [rb@tertius.net.au](mailto:rb@tertius.net.au). Thank you for understanding.

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### **THE RUDE PARROT**

David received a parrot for his birthday. The parrot was fully grown with a bad attitude and worse vocabulary. Every other word was an expletive. Those that weren't expletives were, to say the least, rude.

David tried hard to change the bird's attitude and was constantly saying polite words, playing soft music, anything he could think of to try and set a good example... nothing worked. He yelled at the bird and the bird yelled back. He shook the bird and the bird just got more angry and more rude.

Finally, in a moment of desperation, David put the parrot in the freezer. For a few moments he heard the bird squawk and kick and scream – then suddenly, there was quiet. Not a sound for half a minute. David was frightened that he might have hurt the bird and quickly opened the freezer door.

The parrot calmly stepped out onto David's extended arm and said, "I believe I may have offended you with my rude language and actions. I will endeavour at once to correct my behaviour. I really am truly sorry and beg your forgiveness." David was astonished at the bird's change in attitude and was about to ask what had made such a dramatic change when the parrot continued, "May I ask what the chicken did?"

*This was sent to us by Vivienne, EMERGE's proofreader. Her husband, Harvey, found it in the programme for the 28th Historic Winton motor sports race meeting.*

## Self-hypnosis for CFS/ME pain

By **Ricky Buchanan** (formerly known as Bek Oberin).

Page 22

Talking Point – 2004 Issue 3

Having been on serious prescription-level painkillers for years and still being in pain which spiked at 9.8 on the usual 0-10 scale (0 = no pain, 10 = worst pain imaginable), I have been fairly desperate for some pain control which actually works.

I joined a chronic pain mailing list to get some ideas about what alternative methods people were using to control pain and one that jumped out at me was self-hypnosis. It seemed, from what I could read on the web about it, to be a little similar to the EMDR (Eye Movement Desensitisation and Reprogramming) which had very successfully cured a phobia which I had several years ago. And I already know that I'm a highly hypnotisable person from past events.

Another huge advantage was that I could learn it myself at home by buying a pre-made self-hypnosis-for-pain recording. By using it every day I would automatically learn as I had more practice at it. Being both broke and bedridden, there is no way I could attend a psychologist's office each week for several months, like a method such as CBT would require. So, all in all it seemed like a good thing to try. Thus began my self-hypnosis quest.

The first thing I needed was a recording and after a lot

of searching I found a site which had a recording for pain control available for download. The site (one by somebody called Kenneth Grossman in case others want to look) was fairly tacky looking but I really wanted to start with something and at least it wasn't as expensive as most of the others. The recording I purchased cost about \$US40 at the time.

That night at about the time I usually started, and failed, to go to sleep, I put on the self-hypnosis recording. At first it took a lot of wriggling around before I was as comfortable as I could be and I ended up stopping the recording and starting again before I could settle down. Later I set up the computer to play a slow, calm song which I like to play immediately before the recording. This gives me time for wriggling around and getting comfortable before the self-hypnosis recording commences.

That first night, after having spent up to twelve hours getting to sleep each night for the last several months, the recording magically sent me right to sleep before it had even ended! The second day I was still awake when the recording ended, but was asleep five minutes later. When I analysed how I felt

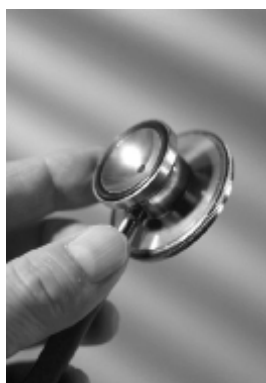
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## Regular checkups

Please remember to have regular medical checkups with your doctor.

ME/CFS does not confer immunity to other illnesses. New symptoms may not be due to ME/CFS and should be discussed with your doctor.



(Continued from page 22)

after the recording, it wasn't exactly the pain itself was less, it was that somehow it wasn't being labelled 'important' by my brain and was easy to ignore.

After a lot of experimenting with these tapes and recording the results along with my pain level before and after the recording, I have found interesting things I have never known before. These are the things I have found:

When my pain is at or less than around 4 - 5 when I start, then the recordings do indeed help with the pain and help me to relax a lot as well. When the pain is at this level I find it very easy to go to sleep during or soon after the recording.

However, if the pain is above 5, then the pain is so strong that it seems to prevent me from concentrating on the recording properly. If I try to relax physically when the tape says to, then the pain appears to increase even more and I can't stand it. When the pain level is about 5 the recordings don't relax me emotionally or physically and do not help to reduce the level of pain either.

So, if the pain is really out of control, then the self-hypnosis is utterly useless!

The claims of the recording that they will permanently lower or even eliminate the pain have, from my experience, nothing to do with reality, but that's not so surprising when we are talking about advertising. Even when the pain level is low to begin with and the recording helps me, the help is only temporary.

I have found the best way for me to use the self-hypnosis recordings is to play them soon after I take my pain medication and immediately before going to bed. Then, instead of my usual several hours of pain-caused insomnia, I am able to drop off to sleep quite easily during or very soon after the recording plays.

**In conclusion: Well worth the price because of the effect on my insomnia, but the recordings do not come even close to living up to their claims of 'permanently lowered pain'.**

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## Media Watch

Media coverage in brief...

- The Bass Coast Fibromyalgia Support Group featured in an article in the *Bass Coast Sentinel* on 1 July 2004 under the heading *Spotlight on a crippling condition*. A good article, except for one mention of 'chronic fatigue'.
- Queensland's *Sunday Mail* on 13 June 2004 contained an article on Linda Halfweeg's return to sport after four years recovering from CFS/ME. Halfweeg's return is with Channel 7 news in Brisbane.
- Launceston's *Sunday Examiner* on 16 May 2004 published an article with the heading *Fighting the fatigue* and the sub-heading *I went from a superwoman to a super-nothing in eight years and I can't cope with that*. The article is centred on the members of the Launceston Support Group. A well balanced article.

- *Mildura Midweek* of 11 May 2004 under the heading *Focus on debilitating illness* gave a very good description of our illness and a suggestion that more information could be obtained from our Society.
- *The Maryborough Advertiser* on 11 May 2004 featured Jenny, a CFS/ME sufferer for the last thirty years. There was also a good description of the illness by the newspaper's health advisor.
- In a publication called *Your Doctor*, May 2004 there was a small but good article about CFS/ME, spoiled by the heading which was *Chronic fatigue is a real problem*.
- In Talbot's *Today and Tomorrow* of May 2004 an advertisement from the Community Information Centre stated that pamphlets giving information on CFS/ME were available from the Centre.

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## Personal story: How I contracted ME/CFS

By **Wendy Dorey**

Page 24 Wendy had been a flight attendant for 22 years when she contracted CFS/ME in 1999.

On 19th October 1998 I was in London at a medieval banquet with many overseas tourists. There was a big piece of damper that everyone at my table touched as they broke off their bread. The next day I was very ill with stomach problems and dizziness. I flew out of London the next night and landed in Melbourne on 2nd November.

I was not due back at work until mid November but I was ill with an upper respiratory tract infection so I did not return to work until 1st December. From 1st to 6th December I worked six consecutive ten hour days. On 6th December I was struck by an unusual and severe headache at work. My doctor gave me two weeks off and I returned to work for the last week of December and somehow worked through January 1999. I took leave in February but did not feel my normal self, so I did very little.



On 1st March 1999 I was back at work but was experiencing grabbing pain in my kidney and pains in my lymph nodes in my groin and under my arms. A kidney ultrasound revealed nothing. I was feeling worse and was doubled up in pain with an irritable bowel and I took sick leave for the rest of March. X-rays revealed gastrointestinal problems and a slightly swollen spleen.

Still unwell I returned to work on 1st April 1999. I flew to Cairns overnight and was in intense pain, had a bad headache and was shivering. At this stage I was becoming worried and felt I should be in the Cairns hospital. Somehow I got back to Melbourne the next day and was helped to my car by fellow employees. Little did I know that was to be my last day of work after 22 years as a flight attendant.

I was put on antibiotics for Irritable Bowel Syndrome but I continued to worsen with ringing in my ears 24

hours a day, sensitivity to light and noise and feeling very weak and dizzy.

Early in May 1999 a blood test revealed I had had Cytomegalovirus (CMV), most probably caught six months earlier in London at the medieval banquet or on the flight back to Australia.

My doctor informed me that CMV was similar to Glandular Fever and that I obviously had a post viral disease called Chronic Fatigue Syndrome. I was told I would not be able to work for a year or more. This disease was also confirmed by a physician in July 1999, September 2001 and more recently in November 2003.

I was bedridden for the first 18 months to two years and I still suffer severe relapses lasting for months at a time caused by any mild exertion or secondary infection. I have now had CFS/ME for five

years and I am on a disability pension.

*In an attachment to her story, Wendy wrote the following:*

### **Examples of exhausting movements:**

- Showering, raising arms to wash hair (I have not been able to blow dry or towel dry my hair for five years).
- Dusting and hanging out washing are "no-nos."
- I recently planted ten seedlings and I was unable to stand for 16 days.
- Socialising is out as talking and concentrating are very exhausting.
- Any physical or mental exertion lowers the blood flow to the brain for one to three days.
- The more I do, the less I sleep, the worse I get.

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## Personal story: Susan McGregor

*Susan McGregor shares her experience of CFS/ME with us.*

**Knock! Knock!**

**Who's there?**

**ME!**

**Me who?**

**Myalgic Encephalomyelitis**

Sick joke, huh? Yes, that's what I thought when I first heard those words – Myalgic Encephalomyelitis. Truthfully, my first word was "What?" I didn't know what it was. It hadn't crossed my mind but I soon learnt, although it was only putting a diagnosis to the symptoms I had been suffering for the previous eighteen months.

Okay, I thought, now I know I can deal with it – get better and get back into life again. I know I can hear you laughing – naive little soul I was. I didn't realise that I was going to get worse. I didn't realise that two years later I would hit rock bottom – relapse. The dreaded relapse that sneaks up on you just when you think that all is starting to get well again.

During this stage I dug out some old meditation tapes. I found it hard to meditate at first, most of the time my brain was somewhere else.

The visualising meditations were too difficult to get my head around but the Yoga Nidra style relaxation tapes in which you relax and heal each part of the body were invaluable. A fifteen-minute session was enough, but little by little there was an improvement. I must mention that, instead of sleeping for seventeen hours a day, I stopped sleeping – one to two hours a day for two years – so any relaxation was going to be beneficial. If you or a friend are able to go to the library and borrow some tapes I recommend doing so.

Six months later a friend encouraged me to join her yoga class – a very gentle Hatha Yoga class. I talked

with the instructor. We worried that I may not be able to walk up all the stairs to the classroom but I managed. If I struggled with anything I stopped and sat it out. My friend drove me to and from the class. I persevered little by little. At the beginning of that year I could barely walk to the front gate; by the end of the year I could work through a whole class and my balance had improved. During the following year the Neighbourhood Centre began another yoga class – Iyengar – which is much more difficult. I gave it a go and am still attending both. Yes I take pain killers before each class. It hurts. But for every step back (the next day I feel terrible) ultimately I take two forward. The trick is finding the balance between progress and relapse. Have I found it? I don't know. But I refuse to give in and let this beat me.



I have come to terms with the fact that my old life has gone for ever. I don't even miss it any more. If I focused on the things I have lost I would sink into a depression, so I don't! I am looking to a new future trying to find the positives. Maybe having CFS/ME will turn out to be a good thing. I am writing now, something I always

wanted to do but wouldn't have had the courage. I am a lot more outspoken and, considering that before I was never outspoken, this is a good thing. I look to what I can do, not what I can't do. I can knit and crochet for charity (Wrap With Love Inc. or the Guardian Pharmacies projects) and make a difference.

Over the last seven years my life changed dramatically, as it does for anyone who contracts this disease. I only hope that, ultimately, it will have changed for the better.

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## Paced exercise helps CFS/ME

*Physical exercise should become a cornerstone of the management for patients with chronic fatigue syndrome (CFS/ME), new Australian research suggests.*

Page 26

While exercise was not a panacea for CFS/ME, it was undoubtedly beneficial, said Professor Andrew Lloyd of the University of NSW Inflammation Research Unit.

Commenting on new research from WA, Professor Lloyd said it was realistic to expect patients with CFS/ME to feel and function better after a program of graded exercise.

"In combination with appropriate interventions to improve sleep hygiene and to treat any comorbid mood disturbance, patients with CFS/ME managed in this way to often achieve a substantially better quality of life while awaiting recovery", he wrote in an editorial (*Med J Aust* 2004; 180:444-48).

The study of 61 patients with CFS found that exercise improved their capacity to work, and reduced mental fatigue and depression.

When compared with a program of relaxation and stretching over 12 weeks, aerobic exercise such as walking, cycling and swimming boosted the mood of participants and achieved a range of physiological improvements, including lowered blood pressure and optimum heart rates.

It was important that the exercise program was paced individually, so that if a participant found a session was too much, the next one was shortened or cancelled, the researchers said.

CFS/ME patients commonly believed that exercise resulted in exacerbation of symptoms, which then led them to avoid exercise. But no relapses were recorded in the exercise group, suggesting that pacing had broken this cycle.



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### BRASS MONKEYS

In the heyday of sailing ships, all war ships and many freighters carried iron cannons. Those cannons fired round iron cannon balls. It was necessary to keep a good supply near the cannon, but how to prevent them from rolling about the deck? The best storage method devised was a square-based pyramid with one ball on top resting on four, resting on nine, which rested on sixteen. Thus, a supply of 30 cannon balls could be stacked in a small area right next to the cannon.

There was only one problem...how to prevent the bottom layer from sliding or rolling from under the others. The solution was a metal plate called a 'monkey' with 16 round indentations. But, if this

plate was made of iron, the balls would quickly rust to it. The solution to the rusting problem was to make 'brass monkeys'. Few landlubbers realise that brass contracts much more and much faster than iron when chilled. Consequently, when the temperature dropped too far, the brass indentations would shrink so much that the iron cannonballs would come right off the monkey. Thus, it was quite literally, "Cold enough to freeze the balls off a brass monkey."

And all this time, you thought that was an improper expression, didn't you?

Sent in by a member who assures us it is all true.

## Exercise, explanation key to the CFS puzzle

*Exercise and explanation may be the key to unlocking the chronic fatigue syndrome (CFS/ME) mystery, long-term follow-up has shown.*

Page 27

More than 50% of CFS/ME patients were free from the syndrome two years after starting a graded exercise program, UK researchers found.

The results came from a program in which 114 patients were both given an evidence-based explanation of their symptoms and enrolled in an individual home-based exercise plan for gradually increasing their activity.

Patients were also given guidance on how to regulate their sleeping patterns.

After one year, 69% of the intervention group had improved, compared with only 6% of the control group.

Some members of the control group then switched to the intervention group.

By two years, 55% of the treated patients had maintained the improvement and were no longer classified as having CFS.

However, it appeared that delay in treatment reduced its efficacy, as patients who switched from the control group fared less well and needed more intensive therapy after starting active treatment following a one-year delay.

Nevertheless, approximately 47% of patients who switched from the control group also achieved a good outcome.

The key to success was to empower patients by giving them a physiological explanation that focused on physical deconditioning and sleep abnormalities, the study authors said (British Journal of Psychiatry 204;184:142-6).

"In the absence of an appropriate explanation ... symptoms can be misinterpreted as signs of an underlying pathological condition leading to reduced activity and chaotic sleep patterns which perpetuate the syndrome", they said.

*Medical Editor's Note:* I have included the above 2 article summaries regarding paced exercise as discussion about exercise always gets a heated response!

I have published previously why exercise may benefit (a healthy effect on the HPA axis and the immune system). It may also harm.

I believe that in the acute phase of the illness or in acute relapses, where there are "toxic" symptoms, such as enlarged glands, fever and night sweats, aerobic exercise is counter-productive.

In the "chronic" phase, where these symptoms have settled, and fatigue and sleep disturbance predominate, paced exercise may help. This includes walking and swimming, not jogging or vigorous gym-workouts!

As vigour improves, very light weights can be used to improve muscle tone.

In my own case, I found swimming helpful and combined this with "cold water therapy" by swimming in a cold pool or the sea.

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## Depression not cause of cognitive symptoms

**Daly E et al.** Neuropsychological function in patients with chronic fatigue syndrome, multiple sclerosis and depression. *Applied Neuropsychology*. 2001;8(1):12-22

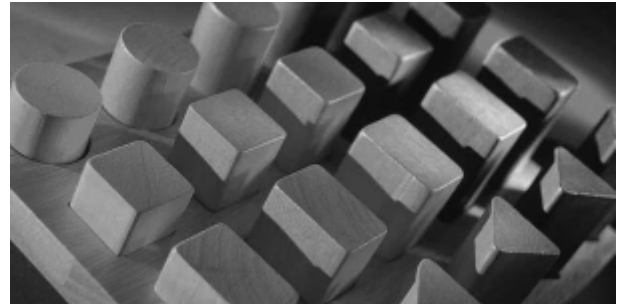
Page 28

Cognitive deficits in patients with chronic fatigue syndrome (CFS/ME) cannot be fully explained by accompanying depressive symptoms, according to a new study in the journal *Applied Neuropsychology*.

Researchers looked at 101 patients, 29 of whom met the modified 1994 international research case definition for CFS/ME. The depression group included 23 non-CFS/ME patients with a history of major depressive disorders. A third group of 24 patients had been diagnosed with clinically definite multiple sclerosis (MS). There were 25 healthy controls.

The subjects were given a battery of neuropsychological tests. The scores were grouped into five cognitive domains: attention, memory, language, executive function and spatial ability.

In general, the depression group showed the highest levels of cognitive impairment compared to controls,



followed by MS patients, then CFS/ME patients. While CFS/ME scores were generally worse than controls, the difference did not reach statistical significance.

After adjusting scores for CFS/ME patients based on self-reported depressive symptoms, the authors write that the presence of depression in CFS/ME patients "cannot solely account for the cognitive differences among the patient groups."

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## Pre-CFS/ME patients visit doctors more often

**Hamilton WT et al.** Frequency of attendance in general practice and symptoms before development of chronic fatigue syndrome: a case-control study. *Brit J of Gen Practice*. 2001; 51:553-558

People who develop CFS/ME consult their physicians more frequently than other patients in the year prior to their illness, according to new British research.

The study looked at records from 14 general medical practices in Devon, England. Researchers tracked the

histories of 49 CFS/ME patients and 49 matched controls. The researchers found that CFS/ME patients visited their doctors nearly twice as often in the controls during the 15-year period prior to diagnosis.

CFS/ME patients were 8.5 times more likely to visit a doctor with complaints of upper respiratory tract infections than were controls. They also were seven times more likely to complain of vertigo.

The authors offer several explanations for the increased office visits – including the possibility that the patients already had CFS/ME and were undiagnosed.

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## A comparison of pregnancies that occur before and after the onset of CFS

**Schacterle Richard S and Komaroff Anthony L**

*Arch Intern Med. 2004; 164:401-404*

Page 29

**Affiliation:** From the Division of General Medicine and Primary Care Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, Mass. The authors have no relevant financial interest in this article.

**Background:** Many women with chronic fatigue syndrome (CFS/ME) fear that pregnancy will worsen their condition, increase the risks of maternal complications of pregnancy, or threaten the health of their offspring. Little empirical evidence, however, has been published on this matter.

**Methods:** A detailed questionnaire was administered to 86 women regarding 252 pregnancies that occurred before or after the onset of CFS/ME and the outcomes of these pregnancies were observed.

**Results:** During pregnancy, there was no change in CFS/ME symptoms in 29 (41%), an improvement of symptoms in 21 (30%) and a worsening of symptoms in 20 (29%) of 70 subjects. After pregnancy, there was no change in CFS/ME symptoms in 21 (30%), an improvement of symptoms in 14 (20%) and a worsening of symptoms in 35 (20%) of the subjects. The rates of many complications were similar in pregnancies occurring before the onset and in those occurring after the onset of CFS/ME. There was a higher frequency of spontaneous abortions in the pregnancies occurring after, vs. before, the onset of CFS/ME (22 [30%] of 73 pregnancies vs. 13 [8%] of 171 before;  $P < .001$ ), but no differences in the rates of other complications.

Developmental delays or learning disabilities were reported more often in the offspring of women who became pregnant after, vs. before, the onset of CFS/ME (9 [21%] of 43 children vs. 11 [8%] of 139 children;  $P = .01$ ).

**Conclusions:** Pregnancy did not consistently worsen the symptoms of CFS/ME. Most maternal and infant outcomes were not systematically worse in pregnancies occurring after the onset of CFS/ME. The higher rates

of spontaneous abortions and of developmental delays in offspring that we observed could be explained by maternal age or parity differences, and should be investigated by larger, prospective studies with control populations.

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### NUTSHELLS...

... My philosophy is that, while patiently waiting for our scientists and researchers to work out what is going on in our bodies and what we can do about it, let us concentrate on improving our quality of life and at least feel human again.

– Joy Stevenson, *Emerge*, Summer 2001

## Essential fatty acids associated with symptom remission in CFS

Page 30

**Puri BK, Holmes J, Hamilton G**

Eicosapentaenoic acid-rich essential fatty acid supplementation in chronic fatigue syndrome associated with symptom remission and structural brain changes – a case study

*MRI Unit, Imaging Sciences Department, MRC Clinical Sciences Centre, Imperial College School of Medicine, Hammersmith Hospital, London UK*

**Summary:** Lateral ventricular enlargement has been reported in chronic fatigue syndrome, while cerebral neurospectroscopy has recently indicated that essential fatty acid treatment may be of value in this condition. An essential fatty acid supplement rich in eicosapentaenoic acid (EPA) \* was therefore given daily to a female patient with a 6-year history of unremitting symptoms of chronic fatigue syndrome. Cerebral magnetic resonance scanning was carried out at baseline and 16 weeks later. The EPA-rich essential fatty acid supplementation led to a marked clinical improvement in her symptoms of chronic fatigue syndrome, starting within 6-8 weeks. Accurate quantification of the lateral ventricular volumes in the baseline and 16-week follow-up registered images of high-resolution magnetic resonance imaging structural scans showed that the treatment was accompanied by a marked reduction in the lateral ventricular volume during this period, from 28940-23660 mm<sup>3</sup>.

**Discussion:** Supplementation with a high EPA-containing essential fatty acid preparation was associated with the first remission for the patient of symp-

toms and signs of chronic fatigue syndrome in over 6 years. The patient has chosen to continue with this supplementation and, to date, no adverse side effects have been observed.

The relatively large reduction in lateral ventricular size is likely to be causally linked to the essential fatty acid supplementation, because phospholipids are important in the formation and remodelling of dendrites and synapses.

Although a spontaneous remission or a placebo response cannot be ruled out, in view of these findings and the protracted nature of the patient's illness, and the fact that her illness had not previously gone into remission, it seems likely that the dramatic improvement was associated with the essential fatty acid supplementation. Moreover, these findings are consistent with the cerebral proton neurospectroscopy findings mentioned earlier and with the fact that essential fatty acids have direct antiviral actions. A randomised double blind, placebo-controlled trial of essential fatty acid supplementation that incorporates magnetic resonance scanning is indicated.

\*Following the baseline investigations, the patient was asked to take the high eicosapentaenoic acid (EPA) essential fatty acid supplement eye q TM (Equazen Ltd, London, UK) at a total dose of 10 capsules daily, taken as five capsules twice daily. This provided the following daily essential fatty acid doses: 930 mg of EPA; 290 mg of docosahexaenoic acid; and 100 mg of gamma-linolenic acid. In addition, the preparation also supplied 16 mg vitamin E daily.

*Medical Editor's Note:* This is a single case history, and although the results certainly seem dramatic; obviously no scientific conclusion can be reached.

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## NIAID collaboration yields new test for Lyme disease

**Schacterle Richard S and Komaroff Anthony L**

*Arch Intern Med. 2004; 164:401-404*

Page 31



A new test developed with funding from the National Institute of Allergy and Infectious Diseases (NIAID) in the USA has been shown to be highly accurate and sensitive for detecting antibodies to Lyme disease. Produced by Immunetics, Inc. of Cambridge, Massachusetts, the new assay recently won approval from the Food and Drug Administration (FDA) for use as a diagnostic test for Lyme disease.

It is the first diagnostic tool to use a synthetic product called C6, a hybrid chemical marker based on components derived from the surface of *Borrelia burgdorferi*, the tick-borne bacterium that causes Lyme disease.

It is the first diagnostic tool to use a synthetic product called C6, a hybrid chemical marker based on components derived from the surface of *Borrelia burgdorferi*, the tick-borne bacterium that causes Lyme disease.

The C6 test is sensitive only to antibodies generated during an active infection.

Lyme disease can be difficult to diagnose, especially in later stages of infection when an individual's antibodies can fall to very low levels. Laboratory testing showed

the C6 approach resulted in a high rate of sensitivity to antibodies from both the early and late stages of Lyme disease. The kit also resulted in fewer false positive readings when compared with current screening methods. Significantly, no false positive readings were obtained when the kit was used to test people who had previously received LYMERix (TM), the Lyme disease vaccine. Another advantage is the test's liability to detect antibodies specific to both U.S. and European strains of *Borrelia*.

"The C6 test is the result of years of collaboration in an ongoing effort to improve our ability to diagnose Lyme disease," explains microbiologist Phillip Baker, PhD, NIAID's Lyme disease program officer. "This new approach is an important first step in that direction".

NIAID is a component of the National Institutes of Health (NIH). NIAID supports basic and applied research to prevent, diagnose and treat infectious and immune-mediated illnesses, including HIV/AIDS and other sexually transmitted diseases, tuberculosis, malaria, autoimmune disorders, asthma and allergies.

Press releases, fact sheets and other NIAID-related materials are available on the NIAID Web site at: [www.niaid.nih.gov](http://www.niaid.nih.gov).

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## Awareness Night photos

May 12, 2004

Page 32

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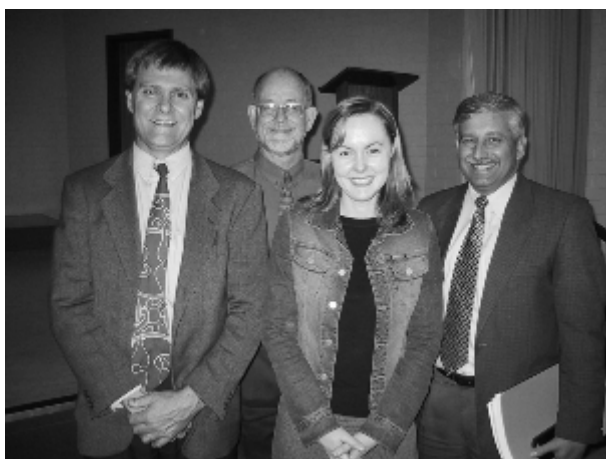
Talking Point – 2004 Issue 3



The audience



Professor Beilby speaks as the rest of the panel listens.



The four speakers at the seminar (l to r): Prof Justin Beilby, Dr Peter Cahalan, Kristin Clark, and Dr Peter Del Fante.



## Multiple Chemical Sensitivity Workshop photos

September 4, 2004

Page 33

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Talking Point – 2004 Issue 3



The workshop group gathers. Note the open door.

It was a cool day but we kept it open to keep the air fresh for the most sensitive members of the group. The Ellengowan Centre at the St Peter's Catholic Church was chosen because it is well-kept but hasn't been renovated for some time. So problems of toxic air quality from net carpets etc were not too bad.



Lorenzo Pizza (centre), who drafted the Society's submission to State Parliament. With him are Peter Evans (convenor of the Task Force on MCS) and Peter Cahalan (President) who also contributed to the submission.



Keynote speaker, John Steele (left), addresses the Workshop.



Peter Evans (Convenor of the Task Force on MCS) addresses the crowd with typical forcefulness. Peter's determination has been a key factor in pushing the campaign in this State as far as it has progressed.

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

# Information about ME/CFS

## What is ME/CFS?

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

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

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

## How is ME/CFS diagnosed?

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

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

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

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

## How is ME/CFS treated?

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

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

There is a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake exercise. Most ME/CFS patient groups recommend that sufferers exercise as much as they are able – to pace themselves. It is important to maintain physical fitness if possible, but we recognise that exercise is not always the best possible use of sufferer's limited energy reserves.

## Do persons with ME/CFS get better?

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

## Prevalence

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

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

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

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

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

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

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

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

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

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

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

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

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

## Support Groups: Metro

### Adelaide Support Group

Venue: Uniting Pilgrim Centre, 14 Flinders Street, Adelaide  
(behind Adelaide City Council).

Time: 12:00 pm to 2:00 pm.

Contact: Bill Daniels or Darryl Turner.

Phone: Ring the office on (08) 8410 8929 to confirm attendance.

Dates: 2004

January 27; February 24; March 23; April 27; May 25;

June 22; July 27; August 24; September 28; October 26;

November 23; December 28.

### Glenelg Support Group

Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg.

Time: 1:00 pm.

Contact: Marion Hansen.

Phone: Ring Marion on (08) 8234 2342.

Dates: 2004

January 21; February 18; March 17; April 21; May 19;

June 16; July 21; August 18; September 15; October 20;

November 17; December 15.

## Support Groups: Country

### Auburn Support Group

First Thursday of each month.

Venue: Dennis Tea Rooms, Main North Road, Auburn.

Time: 1 pm.

Phone: Kay on 8849 2143.

### Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: Jane on 8826 2097.

### Southern Fleurieu Support Group

Second Thursday alternate months: April, June, August, December.

Phone: Melanie Stratil (Dietician) 8552 0600 for venue details.

### Murray Bridge Group

The Murray Bridge group is not meeting at present.

Please ring to register your interest.

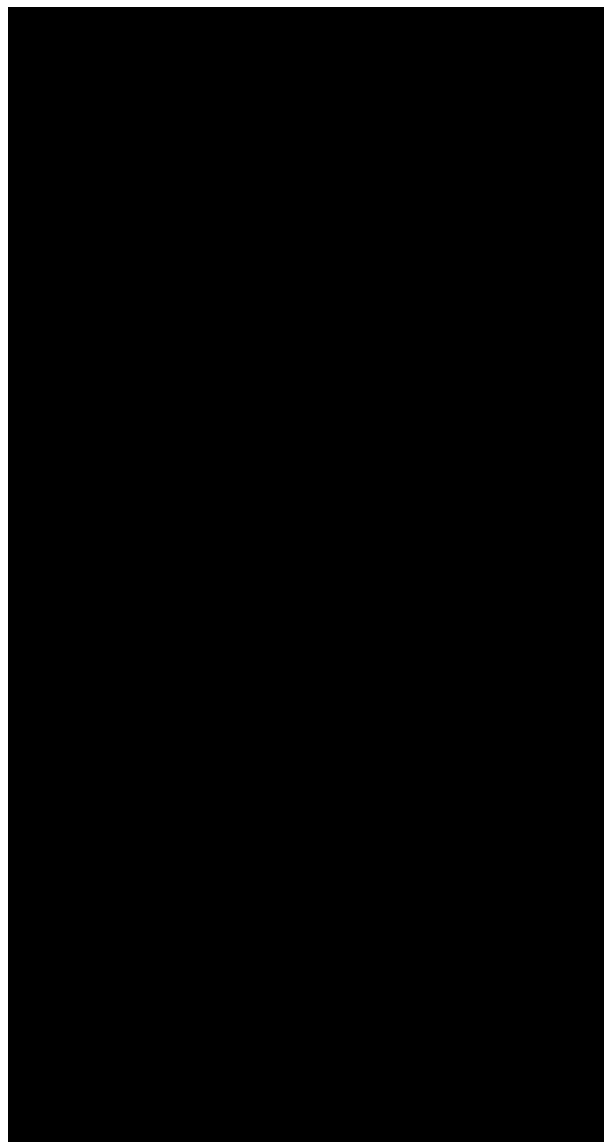
Phone: Fran McFaul (Dietician) 8535 6800.

**Please note that meeting times are subject to change.**

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

**8410 8930 or 1800 136 626**

## Support Contacts



## Youth Support: SAYME

### South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronic Fatigue Syndrome together at the same place at the same time to relax, chill out, and to have a bit of fun within the limits of their condition and to develop a network of friends with Chronic Fatigue Syndrome that understand the issues we face. Together we can help each other through the tough times.

The Youth group is open to young people up until the age of 30. Please contact Donna Briese in the office on Wednesdays on **8410 8929** for a program of events or if you would like to receive our quarterly magazine. We would love to meet you.



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

**Print Post Approved:**  
**PP 532154/00023**

