Talking Forget-ME-Not

Issue 2 2002 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

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ME/CFS Society (SA) Inc.

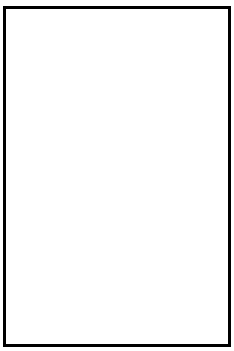
The ME/CFS Society (SA) Inc. is a non-profit organisation (Registered Charity 698) which aims to:

Promote recognition and understanding of the disease among the medical profession and the wider community

Provide information and support for sufferers

Patron

Her Excellency Marjorie Jackson-Nelson, AC, CVO, MBE, Governor of South Australia.



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

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

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

Deadline for Next Issue
September 10th 2002

President: Paul Leverenz
Secretary: Penny Cahalan
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Note: It is our policy to ignore anonymous correspondence.

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

Talking Point is the official journal of the ME/CFS Society (SA) Inc. It is published quarterly, and is financed primarily by member subscriptions.

Disclaimer

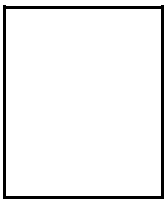
The ME/CFS Society (SA) Inc. aims to keep members informed of the various research projects, diets, medications, therapies etc. All communication both verbal and written is merely to disseminate information and not to make recommendations or directives. Unless otherwise stated, the views expressed in Talking Point are not necessarily the official views of the Society or its Management Committee and do not imply endorsement of products, treatments or services (including paid advertisers). Always consult your medical practitioners before commencing any new treatments.

Donations

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

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

EDITORIAL



Greetings to all our members and readers out there.

Best wishes to Farrah, my usual co-collaborator, who has been unable to assist with this edition of Talking Point.

This edition is somewhat simple with coverage of various recent events dominating the content.

The medical section is dominated by three substantial articles. Each are important in their own right and deserve publication—they are worth making their way through.

A bit about each.

Nicole Phillips, Psychiatrist, presented a paper at the recent International CFS Conference in Sydney. We have been fortunate to gain that paper for publication.

There are similarities between Post-Polio syndrome and CFS. Post-Polio research is years ahead of CFS research so perhaps we have bit to learn from them. This Post-Polio paper provides a good overview of the condition.

Jerome Burne has done a fantastic job as an investigative journalist to probe the ME/CFS debate in the UK in 'Battle Fatigue'. I believe he has wonderfully outlined the subtleties (confusing vagueness ?) of those we would consider on the 'other side of the debate.' It is important to be properly informed. The 'other side of the debate' do not maintain that CFS is 'all in the head.' No-one seriously believes that CFS is purely Psychiatric. The debate is in how much the illness is maintained by our psychology and learned behaviours.

As I outline on page 8, if you come across a medical practitioner who suggests that CFS is 'all in the head' please let us know. It is 'not-on.'

Enjoy reading!

Paul Leverenz

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Introduction

I hope this edition of Talking Point reaches you in good spirits. It is so important not to let this dreadful condition get on top of you. I'm not suggesting you won't get down, or have any depression from time to time; somehow paradoxically one can still have those but remain proactive and positive in ones thinking.

This last quarter has been exceptionally busy time for the Society with one important issue after another rising: National Guidelines, Awareness Week, Badge Day and dealings with the Government.

Donations

Our spirits have been buoyed by several generous donations of late. We have had donations of $12 000, $3000, $500, $400, as well as other substantial sums of late. These gifts have been timely, and have boosted our bank balance enough that we know we can operate for another year at the same level as this year.

As the Society grows and is able to effect change in government and social policies and attitudes toward ME/CFS, I hope that we continue to attract such gifts. They are needed.

Guidelines

In late April the office sent out letters to state politicians warning them about the RACP CFS guidelines which were published on May 6th. This was part of the wider campaign to make sure that people knew about the guidelines before they were released.

CFS societies around Australia uniformly were critical of the Guidelines and this generated a range of media opportunities. Matt Abraham and David Bevan on ABC morning radio interviewed Simon Molesworth (president of the national ME/CFS Association), Penny Cahalan (from our Society) and Dr Peter Del Fante (Medical Director of the Western Division of General Practice) on the morning of Tuesday 7th May. The number of talkback callers that rang in showed just how common CFS is in the community – and how similar our experiences are when it comes to the medical profession!

Simon Molesworth was questioned on many media forums. In Adelaide he spoke on 5UV for 10 minutes on Wednesday May 1st. He was also interviewed by Norman Swan on the ABC Health Report (in what was arguably the only less than fully sympathetic treatment by a journalist anywhere in the country of the concerns of CFS groups about the Guidelines). There was also an extensive interview on Tony Delroy's Nightlife program broadcast on 5AN.

In all I think we achieved a lot through this campaign, and everyone with ME/CFS in Australia owes a lot to Simon Molesworth our National President for all the media work he did. Whilst we did not avert the guidelines being published, we did create a significant noise and got the key issues out there.

May 13th Awareness Evening and Expo

It was pleasing to have 400 people attend a weeknight meeting. Special thanks must go to the Governor for attending, as well as to the speakers and all the organizations that provided Trade Stalls on the night. All of these contributed to quite a positive and encouraging evening. A report appears later in this edition of Talking Point.

This years Awareness Week public meeting was the biggest we had put on for several years. Nothing was held back and we must thank the Commonwealth Bank whose $3000 donation was timely to cover our expenses. We needed every bit of it.

You may be interested to know that all State politicians were invited to this meeting, but none were able to attend. However we have had positive approaches from Joe Scalzi and Robin Geheraty since the meeting. [Full Report on page 32]

Meeting with the Department of Human Services, May 14th

Penny Cahalan, Peter Del Fante, Simon Molesworth and I met with an advisor to the Minister for Health for 1 hour. These meeting are really important because they not only provide an opportunity to ask for assistance, but they are invaluable opportunities to explain the realities of CFS. At every turn we find ourselves needing to break down the basic stereotypes

Notice to Vendors

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

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

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

about CFS – that it is just 'chronic fatigue' and that 'nothing is known about its physical basis.' Fortunately I have found that most people (non-medical) respond well once the basics are explained. (Our difficulties are with health professionals who are set in their beliefs.)

We put our case forward for funding for the Society for $33 000 p.a. outlining our need to stabalise the administration of the Society with a paid office worker, and our need to fund our existing programs. In addition we discussed issues such as the following which have been put to the minister:

- Problems with the RACP National Guidelines on CFS
- Working with the DHS to promote ME/CFS awareness
- The ME/CFS research that is being done in South Australia
- Hospital Accommodations for those with Chemical Sensitivities including reactivity to cigarette smoke

We left the meeting happy that we were heard. It was a positive meeting.

National Meeting Sunday May 26th

I was encouraged by an excellent National ME/CFS Association meeting conducted by telephone linkup. It was one of the most positive CFS meetings I have ever been involved with. We are making some good progress. Here is a summary of the key points.

Key points:

- The number of politicians Australia-wide who are showing an active interest in CFS is growing
- Simon Molesworth has had productive talks with advisors to the Federal Health Minister
- Simon has also had productive talks with the ex-head of the RACP, Prof Richard Larkins. There are in

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the process of drafting a joint position paper on CFS – outlining the common ground. Hopefully this letter will be published in the MJA, and possibly sent to every doctor.

- A Tasmania Politician is prepared to get up and speak about CFS in parliament
- Senator Allison has brought up CFS several times in the senate
- Simon has been having good meetings with health ministers in every state
- NT government very supportive of CFS, and we assume will support the Support Group which is being started up there
- TAS well into process of incorporation of there Society – President to be Liz Wood.

The importance or the National ME/CFS Association cannot be underestimated. A national body is needed to lobby on a National level. It would be fair to say that the National Association, which has existed for 3 years, has struggled in the past, but it is now just beginning to gel and we are seeing some of the fruits of our labours. But, as with everything, it is limited by lack of funds. If you are not aware, our Society gives $1 from each membership to the National Association, and we were pleased recently to donate an additional $350 to it.

Badge Day, May 31st

After several years where we have not had the personnel to organize Badge Day – and it takes a bit of organizing. Adrian Hill did a great job for us this year and I would like to take this opportunity to thank him and everyone who assisted with the collection on the day. It is hard work for we people with CFS. Special thanks to Patricia and Ling (who help in the office and put in an extra day to assist with counting money) and the school children from Seymour College and Glenunga High who assisted.

We were able to raise approximately $2500 in the city, $500 at Burnside and close to $1000 from members doing collections in their workplaces and amongst their friends. This is very pleasing given we had to completely 're-invent the wheel' to run the badge day, and given that the weather was quite miserable on the day.

In the second semester of this year we will conduct other Badge Days – in country locations and suburban shopping centres.

Our Current Financial Situation

Most of you will know we are at a cross-roads in our development. We need to garner some sort of assistance from the government if we are to survive with any comfort, let alone expand our services. Without this support we battle just to survive and have to do the best we can with what we have got.

It is important that the Management Committee keep the financial situation of the Society in the fore-front of their minds. I have very great hope and faith that things will work out well for us—but with some hard work thrown in for good measure. The full picture will be made clear when a budget for next financial year is produced. Roughly we need to pull in between $10 000 - $15 000 p.a. in donations / fundraising.

Until we obtain government assistance to help our budget deficit, AND until we can get our membership up much higher, we will be forced to work extra-hard to find ways to increase revenue. The Management Committee must focus its fundraising efforts on the Society's survival - not so much on research as has been the case in the past. For that reason we will not be running a 'Restathon' this year (aimed at raising research funds).

Conclusion

The tide is definitely turning for CFS. I am confident that we have some exciting years ahead of us.

Letters to the Editor

Dear Editor,

You may wish to include the following hint in your magazine, for any hospital operation, etc.
If you intend visiting hospital and need an operation ask as many questions you can think of regarding operation procedure, chemicals in use, etc. (if you're chemically sensitive).
Ask your anaesthetist if you can have 'gas' in lieu of chemicals as it's a lot less invasive towards the body.
Wear a mask at all times and ask nursing staff to keep it in your tin (provided by you) at all times (or as much as possible).
If a bandage or dressing is required, or a sling:

1. Ask if they'd be so good as to not apply any chemicals to the bandage or similar; paraffin is used to prevent any blood etc from a wound adhering to the bandage.
2. Dressings are a different situation as the dressings are impregnated with vaseline, so ask to leave it off as soon as it's safe to do so.
3. Make your own cotton sling as the hospitals' ones absorb hospital odours even when kept in a plastic or paper bag.

Yours truly,

Sue Prider.

[NOTE: Sue also suggested that those members who have a problem with chemical weed sprays could contact the Environmental Protection Agency as they have been referring chemically sensitive individuals on to a toxicologist working in this area. Sue enclosed several clauses of Section 17 of the Public and Environmental Health Act (1987), a potentially useful resource to cite when challenging chemical spraying detrimental to health.]

* * * * *

Dear [Editor],

I am writing to you to add my input to "Talking Point" which I enjoy reading when it comes out but unfortunately there haven't been any answers so far but still we hope. I have had the disappointment of spending $300 on a urine test with Bioscreen, Newcastle University which at the time seemed very interesting and promising. However I have not been able to obtain any follow-through with interpretation of the test or treatment. SA doctors seem pretty sceptical. Would love to hear from others who have success in working this out.

I refer to Dr. Bell's article on the "Onset of CFS" and other in the 2002 Issue 1 volume of talking point. He notes and I agree that there are different viral agents for CFS. But is CFS a separate illness or is fatigue a symptom'? Do doctors go far enough to find the true cause'?

An interesting website dated 6/8/2002 which I would like to share with you all lists 77 causes for chronic fatigue, unfortunately the author is not listed.

(http://www.semaphorecorp.com/misc/cfs.html).

For those who do not know the cause I would suggest that finding it would be a good start before initiating treatment. The cause determines the treatment which is most effective. To everyone I wish them success with this. An excellent book which goes into some of the hormonal causes for chronic fatigue and which advocates a liver cleansing diet for chronic fatigue is "Boost your energy, fine-tune your body and mind with natural ant-aging hormones" by Dr. Sandra Cabot. I've tried some of her supplements with some improvement but again would love to hear from others and how they have succeeded with this. Most people who try her recipes need to keep their allergies in mind and steer clear of those ingredients. However Dr. Cabot addresses some of the causes of fatigue such as adrenal gland exhaustion, fibromyalgia, an overloaded immune system, hormone imbalances and menopause.

Some of the supplements such as DHEA and pregnenolone which are controversial are mentioned (Cabot, 1997, P. 38-9). If any has had success with trying these and the designer yeast powders she mentions would love to hear from you in "Talking Point", also would love to know which doctors believe in this form of therapy. So far the hormone clinic run (*by a doctor) in Nth. Adelaide is the only one I know of and the Green pharmacies which are the only ones who dispense natural products.

Yes lots of us know that our illness started with a viral infection but what do we do now about the effects on our body and how can we help our bodies to repair?

Happy hunting for solutions,

Cheryl King RN.

RE: Bioscreen (and other) Testing The Society discourages members from having testing (such as the Bioscreen testing done without a doctor's support.) Biocreen and other services such as (Analytical Reference Laboratories http://www.arlaus.com.au/) offer many tests that aren't standard—so not every GP will immediately understand them. Bioscreen does provide doctors with notes along with your test results. There is also improved phone support for doctors to interpret them. Tests are often based on the latest research and theories. It is important to have realistic expectations about what they can deliver— they are often, by nature of the case, a resort for those who have found regular testing turns up nothing. Even when these tests do find things 'wrong' with us its another matter to find appropriate treatments. The answers are not always immediately obvious—and certainly there is not always a simple 3-step action plan for each abnormality. If your GP is not willing to read the notes, dig a little, and think about some of these tests then unfortunately you may feel you are left with a very expensive piece of paper outlining a few things 'wrong' with you. (I would demand a look at the Doctor's notes if you have paid for a test already.) Unfortunately most of the doctor's who use the Bioscreen testing are ones who are booked up for months. There is some value in being persistent and encouraging your doctor to understand them.

-ED

DEBRIEFING ON THE RACP CFS GUIDELINES

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The RACP guidelines are disappointing for many reasons—too many to go into now. One of the major concerns is that the guidelines do not properly reflect the condition we all have. One reads the guidelines and wonders if we are talking about the same condition. Specialists somehow refuse to see our distinctive condition with its varied symptoms and which to concentrate on a more generic ailment 'chronic fatigue.' This is despite a research definition for CFS that doesn't solely focus on fatigue.

Another significant concern is the lack of clarity with which the guidelines describe the condition—despite statements that say CFS is real - after reading the guidelines one is not confident as to the legitimacy of the condition. This is as due to poor writing and lack of consistency in the document as to anything else. This is desperately unfortunate. Given the bad press CFS has had over the years, we needed a document which unequivocally confirmed the reality of the condition—this could be done whilst still acknowledging we do not understand much about it.

No longer can medical practitioners dismiss CFS. If your doctor dismisses it as being something 'made up' or 'all in the mind' then please let the Society know.

Another issue where the guidelines lack leadership—or simple editorial integrity—concerns the treatment options. It is fine to suggest that the only treatment options shown to be successful are Cognitive Behaviour Therapy and Graded Exercise, but there is not enough qualification of this. For example, the guidelines do not point out that the literature is flooded with this sort of research. And they do not offer the simple qualification that more physical research is needed before possibilities might open up. This would help to prevent readers from jumping to conclusions about the real nature of the condition. The bias of the guidelines is reflected in the recommendation of rigid sleep therapies despite openly stating they are not proven. In fact whilst the authors hide and claim they are merely reflecting the literature in this process, they show their bias and hand at this point.

The only redeeming feature of the final version of the guidelines is the admission that much of the Cognitive Behaviour Therapy research done on CFS to date has not been representative of the general CFS population—it has excluded youth and largely focussed on the mildly affected. These are important admissions and rightly cast doubt on our ability at this point to draw strong conclusions from the research findings before us.

Until we have conclusive proof of a physical cause of CFS, no guidelines will assist us sway the sceptical medical practitioner into 'believing in CFS.' These guidelines might help us with some of the more openminded people. The very fact that guidelines have been written means that CFS is a serious concern—and not something made up. No longer can medical practitioners dismiss CFS. If your doctor dismisses it as being something 'made up' or 'all in the mind' then please let the Society know. We will send them an information pack. In fact, please write directly to the Minister for Health—or we we will write to her on your behalf if you give us permission.

Given that the guidelines have been published there is now little use in 'crying over spilt milk.' We can use some of the positive aspects of the guidelines, to further our case.

Having unsuccessfully lobbied the Medical Journal of Australia to defer publication of the guidelines— a process which got a little heated—we tried to adopt a positive approach. See our website for the

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Letter to MJA Editor from Mr Simon Molesworth and Professor Richard Larkins

Mr Simon Molesworth AM, QC
Chairman
ME/Chronic Fatigue Syndrome Association of Australia
19 Linacre Rd
Hampton, Victoria 3188

Professor Richard Larkins
Immediate Past-President
Royal Australasian College of Physicians
145 Macquarie St
Sydney, NSW 2000

Dear Sir,

The ME/Chronic Fatigue Syndrome Society of Australia Ltd. has expressed its concern over the content of the Royal Australasian College of Physicians' Chronic Fatigue Syndrome Clinical Practice Guidelines published in the Medical Journal of Australia. Recognising a shared objective to overcome the challenges of CFS, neither the ME/Chronic Fatigue Syndrome Society of Australia Ltd nor the Royal Australasian College of Physicians believe that conflict will provide a useful path to future answers. Accordingly, as the Chairman of the ME/Chronic Fatigue Syndrome Association of Australia and the President (at the time of the publication of the Guidelines) of the Royal Australasian College of Physicians we would like to document the common ground that has been identified.

- We acknowledge, as do the Guidelines, that CFS is a serious, disabling illness.
- There is no evidence that the illness is primarily psychological in origin.
- There is significant evidence of a range of biological abnormalities occurring in people with CFS. It remains unclear whether these are primary or secondary.
- Treatment should be personalised according to the symptoms and circumstances of the individual patient. Treatment plans should be worked out by the patient together with a health care professional and designed to be within the capabilities of the patient.
- Scientific evidence concerning aetiology, pathophysiology and treatment is, at this stage, grossly deficient. More research is required to understand the biological mechanisms involved and to clarify the role that genetic, environmental and infectious agents might have in the aetiology and pathophysiology of this complex and debilitating illness.
- The medical community, other health professionals and patients and their families should work together to encourage increased funding and research into the epidemiology, aetiology and pathophysiology of CFS so that we may find more effective treatments for this condition (or these conditions).

All clinical guidelines should be viewed as documents that will, in time, require refinement, rewriting and replacement. Medical practitioners must be cognisant of the limitations of all such guidelines and be aware that the investigation and management of a patient's condition must be determined with the assistance of the best and latest information as it emerges and in all instances be tailored to the needs of the individual patient.

Yours sincerely,

Professor Richard Larkins FRACP
President
RACP (demitted May 6th, 2002)

Simon R. Molesworth AM, QC
Chairman
ME/CFS Association of Australia

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interchange between Simon Molesworth and the Editor of the MJA:

http://www.sacfs.asn.au/news/2002/guidelines.htm

Subsequent to the RACP CFS Guideline's publication we have wanted to establish common ground with the RACP. Above we have a joint letter outlining some important points about CFS, and qualifying the role of the guidelines—that they are a work in progress, and further research may provide a clearer picture of the condition.

Our next task is to convince government that we need to commence revising the guidelines.

Paul Leverenz

The guidelines can be viewed or downloaded from the web at:

http://www.racp.edu.au/hpu/policy/chronic_fatigue.htm

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Report on chronic fatigue fuels row

By Julie Robotham
April 29 2002, The Age

A bitter row has erupted between doctors and patients over the diagnosis and treatment of chronic fatigue syndrome (CFS).

The stand-off concerns new CFS guidelines for doctors, which patient groups say trivialise the condition, blame sufferers for their illness and promote harmful therapies. They have unanimously rejected the long-awaited document and demand it be withdrawn.

And they have warned that the Royal Australian College of Physicians, which developed the guidelines, and the Medical Journal of Australia, which plans to publish them on Sunday, could be legally liable if patients became more sick as a result of doctors following them.

Simon Molesworth, the president of the ME/Chronic Fatigue Syndrome Association of Australia, said the recommendations presented CFS, which is estimated to affect up to 150,000 Australians, as primarily a psychological illness and characterised patients as malingerers. They under-emphasised research pointing to biological causes and included therapies that could be dangerous.

So-called "graded exercise", in which patients perform an increasing volume of activity over time, could have serious consequences for very ill people, said Mr Molesworth, whose organisation represents patient support groups in all states and territories, which together include 15,000 members.

He also said there was no evidence that a regime of strict control of sleep was effective, and there was insufficient scientific basis to recommend antidepressants. Both therapies are included in the document.

But the chief author of the guidelines, Robert Loblay, an immunologist at the University of Sydney and Royal Prince Alfred Hospital, said the six-year preparation of the document had involved extensive consultation with patient groups.

"Our job has been to evaluate the evidence as best we can and tread a middle path," he said.

The president of the College of Physicians, Dr Richard Larkins, said the college supported the "helpful" guidelines, but they should be viewed as "a living document" because knowledge about CFS was incomplete.

Used with Permission

Riddle of the quiet killer

By Julie Robotham

May 4 2002, Sydney Morning Herald

Alison Hunter used to say she had lemonade in her legs and "shimlers" in her face. Still in primary school when she first became ill, those were the words she chose to describe the bizarre and frightening sensations that afflicted her.

Vocabulary was still an issue when Alison died. Despite a decade of crippling physical symptoms and abnormal pathology and neurology tests, medical science never came up with anything more tangible than chronic fatigue syndrome (CFS) to describe her illness.

Her mother Christine nursed her daughter round the clock until she died in her arms, at home, six years ago at the age of 19.

With its mysteriousness and suggestion of psychological upset and malingering, she believes the CFS tag gave many doctors licence to ignore Alison's decline and trivialise her distress.

Such attitudes are about to be institutionalised in Australian medical practice, says Simon Molesworth, the president of the ME/Chronic Fatigue Syndrome Association of Australia, courtesy of new treatment guidelines that will be sent to just about every doctor in the country, starting tomorrow.

Molesworth says the guidelines - intended primarily for GPs with no specialist knowledge of CFS - present an overtly psychological construction of the illness and skip too lightly over emerging evidence that metabolic disorders, infections and immunological problems can cause CFS.

According to Molesworth, the document fails to distinguish adequately between patients with less debilitating transient illnesses and those like Alison Hunter who are very severely ill and at risk of death.

Particularly contentious is the reference to cognitive behaviour therapy (CBT) - a psychological technique aimed at giving people additional insight into a negative behaviour so they can change it.

The guidelines say examples in CFS include, "a fear that any increased physical activity will cause harm or prolong illness; a belief that all treatment is futile and that only complete rest will help; a belief that complete withdrawal from work, school and social activities is necessary."

Alison did not want to withdraw from school. "She was so desperate to participate," says Christine Hunter, who at her daughter's insistence bought her school uniform gym kit even though she could not use it. After a remission in the first bout of illness, at age 10, Alison went back to school swimming lessons but taking it easy was against her nature; she swam laps until she collapsed.

According to the guidelines, the use of psychological therapy in the treatment of CFS does not mean its cause is psychological: "Some patients find psychological terminology alienating, believing it to imply that their symptoms and disability are imaginary, contrived or 'psychosomatic'. Such beliefs are unfounded."

Alison learned, to the contrary, that some doctors were determined her illness must be psychological, despite any amount of evidence otherwise. She learned to wear her school uniform for doctor visits to short-circuit the suggestion that her "real" problem was her attitude to school. She was also suspected of having anorexia nervosa, despite repeated complaints from her parents over many months that her inability to digest food - the real cause of her weight loss - had never been investigated. Doctors later formally discounted the possibility of anorexia. Nurses walked past her bed, ignoring her in favour of those with readily defined diseases.

Six weeks before her death, a new specialist suspected Alison might have the complex immune syndrome Behcet's disease. With a legitimate label, the establishment became accepting of Alison, and even kind. "It was almost too cruel," says her mother, "to see her treated as she should have been all along."

But Behcet's was never confirmed and by then Alison was so very ill. In the end, heart damage, massive ulceration to her throat, failure of her gut and bowel and horrendous neurological symptoms, conspired todefeat her.

James Isbister, the head of hematology at Royal North Shore Hospital, treated Alison when she was a child and again when her illness returned in her teens (though on other occasions she was under the care of a different Sydney hospital). And he had a personal connection; his own daughter was a schoolfriend of Alison, whom he describes as, "a brilliant girl, intellectually very vibrant".

"To be honest I felt helpless towards the end," Isbister says. "On many occasions I was extremely embarrassed about the way she was treated by the system. A lot of the terrible things Alison went through were doctors projecting their own fears and inadequacies. How anyone could not think she had a major medical illness was beyond me." Alison, he said, was, "like someone going through a concentration camp" - suffering terrible physical distress compounded by insults and inhumanity.

Isbister laments the edifice of medicine that cannot acknowledge things it does not understand. A teacher, he tries to impress on medical students the value of broad-mindedness, and the need to concentrate on people more than on symptoms. He tells them: "If you don't believe in a disease you'll never diagnose it."

While inclusion of the word fatigue may make CFS sound indistinct, the criteria for diagnosing it are actually very strict. At least six months of unexplained fatigue must be confirmed, but so must other signs including memory or concentration difficulty, sore throat and tender neck glands, muscle and joint pain,

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headaches, and long-lasting malaise after exercise.

It may range from relatively moderate to severe, and while severe forms may be rarer, they afflict significant numbers of Australians.

When he discusses his son with other people, Jim Chambers tells them: "If you're going to get sick in this society, for God's sake make sure it's a mainstream illness." Jeremy, 28, whose condition is still deteriorating, lives in a darkened room. Formerly an avid writer and reader and a postgraduate student, Jeremy can no longer look at a book because he cannot stand the glare of light on the page.

Chemical smells are agonising. "Can you tell me someone who can spot after-shave at 50 paces - and it can set him off and give him migraines - has a psychological illness?" demands his furious father. "These kids are being hung out to dry. It's a complex disease and the so-called experts are only looking at one set of information."

Jeremy's girlfriend, who is now recovering, has also suffered with CFS, which began after both came down with glandular fever five years ago. But those facts have sparked not a sniff of interest from local researchers, Jim Chambers said. The family is now seeking experimental therapies from overseas.

Jenny Hill, a Cowra woman, developed CFS as a teenager, but was not taken seriously until she lost control over her legs, her feet flopping loosely from her ankles. "I was just as sick for three years before I couldn't walk," she says. She realised she had been considered a psychological case when her Sydney doctor abruptly referred her elsewhere, saying, "It's a medical problem now."

Jenny, 22, is now improving, which she believes is thanks to regular sessions of plasma pheresis - a transfusion technique in which plasma is stripped from her own blood and replaced with donor plasma. But doctors have told her the resource should be reserved for sicker people.

"It shouldn't be this hard to get help for an illness," she says.

Chronic Fatigue Syndrome

· First defined in 1988 by the US Centres for Disease Control, CFS is also sometimes called myalgic encephelomyelitis or ME (in Britain) and chronic fatigue and immune dysfunction syndrome (CFIDS) in the US.

· CFS may affect between one in 500 and one in 200 people, according to US and British estimates. A hundred thousand Australians may be affected.

· The most common age at onset is between 20 and 40. Women are thought to be affected more often than men.

· In contrast to the "yuppie flu" tag it attracted a decade ago, some research has found CFS is more common in lower socio-economic groups.

· Some people with CFS also have depression but many do not.

· Few patients who have CFS long-term ever fully recover, though half or more may improve.

· The cause is unknown but may include infection, immune reaction, hormone disturbance or a brain processing disorder.

· Immunologist Dr Robert Loblay developed the new treatment guidelines for the Royal Australasian College of Physicians. They do not say that CFS is a psychological illness, but patient groups' concern is that, nevertheless, the psychological language in the document will subtly influence doctors. The guidelines are flavoured by the fact that some of the limited research studies that exist are work by psychologists and psychiatrists. "We can't get away from those words," Loblay said, "because they're in the scientific literature." The guidelines picked up on helpful aspects of cognitive behavioural treatment, leaving aside the accompanying baggage of "Freudian theory", he said. It was a valid complaint that the research papers his group considered were distorted by the characteristics of study participants. "People who are too ill drop out," he said. "People who don't like psychological language drop out." Those who were house-bound could not take part, and had never been formally studied.

This story was found at: http://www.smh.com.au/articles/2002/05/03/1019441432740.html

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Neurotic [sic] or Misunderstood?

Sufferers of chronic fatigue syndrome insist their illness is real. But doctors can't find a physical cause
By Daniel Williams

When he was 10, Lachlan was a very sick boy. Or so it seemed to his parents. Their ordeal began with a phone call from the school. The boy was off color. Best come and get him. Lachlan, of Melbourne, got steadily worse as the months passed. Confined to bed, unable to bear strong light, he was vomiting and sweating profusely; his weight almost halved and he had to be fed through a tube. But doctors could find nothing wrong with him. One day, during the boy's fourth week in hospital, an eminent doctor leaned over him and declared, "By God, Lachlan, you're going to be one hell of an actor one day."

The anger that welled in Lachlan's father at that moment hasn't diminished. Indeed, it's just been recharged by the release in Australia of new clinical practice guidelines for chronic fatigue syndrome, the mysterious ailment with which Lachlan was eventually diagnosed. Patient groups had been eagerly awaiting the document, which they hoped would legitimize CFS in the minds of doctors and the community 14 years after the illness was named. But their hope has turned to frustration.

A close reading of the guidelines suggests patients aren't being over-sensitive. Though doctors are urged to acknowledge CFS patients' suffering, they're advised to "discourage excessive rest" to break the "vicious cycle" of inactivity, and urged to make a psychological evaluation of the patient and note any family history of "depressive disorder, self-destructive behavior or substance misuse," before reaching a diagnosis.

For Simon Molesworth, president of the ME/Chronic Fatigue Syndrome Association of Australia, the guidelines contain echoes of the skepticism and insensitivity directed at his son Lachlan seven years ago. They're a "backward step," he says, that traps sufferers in a "double horror." While enduring a debilitating condition, "they're faced with doubt among family, friends, employers, schools-wherever they go-as to whether they're just malingerers or neurotics."

Lachlan, who recovered slowly and resumed fulltime school this year, wasn't a typical CFS patient. More commonly, sufferers are women between the ages of 20 and 50 with less severe symptoms (see box). The diversity of symptoms has stumped doctors, who despite intensive research in many countries haven't nailed any biological cause for the illness, though the trigger often seems to be a viral infection or emotional trauma. There's no test nor cure for CFS, which is diagnosed only after an exhaustive process of elimination, and sufferers rarely look as terrible as they feel. CFS remains fertile ground for psychiatrists-to the dismay of patients, who are anxious for the discovery of a physical cause. Afflicted by something that disables their bodies, they resent the idea that the problem is in their minds.

The document was bound to disappoint them because it was co-authored by a leading villain in the eyes of CFS lobbyists-Ian Hickie, professor of community psychiatry at the University of New South Wales. Hickie is unusual in the medical profession, for he speaks with something like certainty about the origins of CFS. While doctors investigate the possible role of immune breakdown, hormone imbalances, allergy, poor nutrition and defective muscle tissue-and speculate about interaction between some or all of these-Hickie doesn't hesitate when asked what bodily system CFS should be sheeted home to. "The brain," he says. The symptoms of CFS "are all brain mediated, and we should see the bleeding obvious: CFS must involve brain dysfunction."

To illustrate, Hickie compares normal joint pain, which is accompanied by swelling, and CFS joint pain, which isn't. "But that's not to say that CFS sufferers aren't experiencing joint pain ... it's simply that that sensation may be arising in the central nervous system." CFS sufferers, he says, tend to "lose the plot" at the mention of a psychological disorder, but it's all a misunderstanding: "This notion that there are physical disorders which are real and lie in real body organs, and psychological disorders that are unreal and lie outside of body organs is a myth and very unhelpful," Hickie says. "It's a false dichotomy arising from the stigma that surrounds psychiatric illness."

Hickie believes CFS is partly a disturbance of the wake-sleep cycle. Many sufferers, he says, view their energy as like fuel in a car: push too hard for too long and you conk out. If this were true, he says, a long rest would make them feel better. But his experience is that it makes them worse. Better to regard the body as a

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rechargeable battery: patients shouldn't submit to tiredness but should gradually become more active during the day so they sleep better at night. He also argues that depression is often a precursor to CFS, or a consequence of it.

Hickie's views offend not only many patients but some psychiatrists. "There were months and months over a period of years when I could literally not get out of bed. Talking about a graded exercise program when you're that sick is just a joke," says Melbourne-based psychiatrist and former CFS sufferer Nicole Phillips, who developed the illness in 1989, at the age of 30, after a bout of viral pneumonia. GPs, she says, shouldn't automatically refer suspected sufferers to psychiatrists, many of whom regard CFS as a psychosomatic disorder. Phillips, who is medical advisor to the ME/CFS Association of Australia, took seven years to shake CFS-about the average duration of the illness. Her theory is that CFS involves not just the brain but also the immune system, which for some reason goes on permanent "heightened alert." For treatment, she recommends a "holistic" approach of sunshine, laughter, meditation, dietary supplements-and time.

Another former sufferer, Diana, 36, of Sydney, says she became exasperated with doctors who trivialized her symptoms. Relief came after consultations with a naturopath, who attributed Diana's condition to undetected food allergies and chemical poisoning, and prescribed a regime of vitamins, herbal tonics and food supplements. Guidelines co-author Hickie doesn't dispute that certain therapies may work for certain patients, but that doesn't justify their inclusion in the guidelines. "The best evidence at the moment is in favor of the behavioral approaches combined with ... anti-depressant drugs."

For lobbyist Molesworth, this amounts to a suggestion that CFS sufferers really just can't cope with the complexities of their lives and want out. "But I haven't met a single CFS patient-and I've met thousands-who doesn't desperately want to get well," he says. "I could line them up on the street and they will look drawn and weak and some will be leaning on sticks, but by God they want to retrieve their lives."

A Sydney GP whose mother has CFS recommends that the illness's name be changed to avoid the slightly feeble connotations of "fatigue." He suggests "Nightingale Syndrome"-in honor of the legendary British nurse who's thought to have been a sufferer. But only a breakthrough on cause, diagnosis or treatment is likely to change the perceptions of skeptical doctors. "Doctors like to fix people," says psychiatrist Phillips, "and with CFS they can't. Their subsequent feelings of frustration and impotence are often directed toward the patient." The bitter irony for CFS sufferers is that they must somehow muster the energy to continue the fight.

Personal Story: Jo Tonkin

My name is Jo Tonkin. I'm a long-term CFS sufferer with severe chemical intolerances. Many people tell me I live an extra-ordinary life but to me ,my restricted life-style has become the norm. Thirteen years ago I could not have imagined the course my life was going to take. I was your average teenager, heavily involved with school, Uni, sport, music, friends and life. In late'87 all of this changed –and changed dramatically.

After having numerous `viruses' that never seemed to go away, I was diagnosed with CFS in late '87.It was not until mid '88 , after a large exposure to gas as workmen fixed a leak out the front of our home, my health took a dramatic turn for the worst. To add insult to injury, the workmen told us that the leak may have been present for 6 months prior to the repairs. The gas exposure affected me quite severely. I began to have breathing difficulties, seizure-like symptoms, muscle cramps, disorientation, heart palpitations and I lost my ability to walk. As a result, I was taken by ambulance to hospital.

The local public hospital dealt with my case like most. I saw a specialist physician, followed by the obligatory psychiatrist. Strangely enough, she took my illness seriously, believing that there was something seriously wrong with me physically. She showed much concern and wanted to help me with pain management. I have tried to forget most of my hospital experiences. To many CFS/MCS patients it is enemy territory. All the tests come back negative and this means that there is nothing wrong. You are now on trial and you and your family must become witnesses for the defense. It's very frightening to be disregarded when you need medical care.

Our hospital experience taught us that we were going to have to manage this mystery illness at home, with the help of a good G.P. My doctor had experience with CFS and encouraged us to try to find out if anything was aggravating my CFS. Mum had read about a chemical connection, so we began reducing the chemical usage in our home. Since the gas had caused me so many problems, we decided firstly to remove all gas appliances from our home, replacing them with electric ones. After a `near- death' experience with a new microwave, we had to make sure that the new electric appliances were actually pre-loved. The out-gassing process for appliances can take some time. We stopped using household chemical cleaners, detergents, hair products, including shampoos, conditioners and perms. Hairspray became a dirty word and dry-cleaning was banned. New clothes were washed thoroughly in organic washing detergent before wearing and new shoes were aired before they were brought inside. Printed material was put under plastic slip covers and large smelly newspapers and glossy magazines were relegated to outside only. I had Technical Aids For The Disabled make me a reading/ writing box so that I could finally write and read inside. I purchased an ionizer/air filter to help reduce the pollution and chimney smoke. I must mention here that it doesn't get rid of all chemicals, just the ones that respond to the negative ions. We asked visitors to not wear or wash their clothes in chemicals as I still reacted quite severely to many. Basically, everyone needed to `detoxify' before coming near me.

As you can imagine, investigating just what was giving me reactions was a long, difficult learning process, and yes, we learnt the hard way on many occasions. There were ongoing traumas about going without many of the conveniences we all took for granted, especially in the area of vanity. `Bad hair days' increased BUT something amazing happened! I began to walk more easily, the amount of bad reactions reduced, I felt as if my brain was waking up after a long fuzzy nightmare and I was able to reduce my continual pain medication. Reducing my pain medication also had a positive effect on my energy levels.

Despite much welcome improvement in my condition, I was still occasionally experiencing some symptoms that were causing me a lot of grief. I was sure that there was something we must have been overlooking. After reading about diet and its possible impact on CFS, I began to look more carefully at what I was putting through my face. My doctor had observed that many CFS patients seemed to have trouble with alcohol, chemical additives, cheese, possibly milk and sugar. However ,the problem seemed more complex in my case. I was still getting anxiety attacks, severe headaches, occasional seizures, heart palpitations depression and breathing difficulties when I ate certain foods-even foods that were considered healthy, like fruits, vegetables and grains. I began to read about food chemistry salicylates, amines, gluten, etc..A process of elimination and observation revealed I was reacting to many` healthy' foods. The biochemistry of food is a widely overlooked area in CFS management. Speaking from personal experience, it was a major factor for me. I hated the fact that after eating certain foods I was no longer able to be myself. I would go from being as 'happy as Larry' to wanting to jump off the jetty!. I also consumed only biodynamic fruit and vegetables, drank chemical-free spring water from Mt. Lofty Springs (as this is the highest spring in SA, free from pesticide run- off) and we installed a water filter to reduce chlorine and other chemicals from entering my system. Going `back to basics', being mindful of what I ate, drank, inhaled and absorbed into my skin made such a positive impact on my health.

Unfortunately, living in the twenty-first century means that you are still very vulnerable to what is out there in the external environment. We live on the edge of suburbia, in the foothills and the air is fairly pollution-free compared to many inner city suburbs. .Travelling has always been very difficult for me. The moment we hit a lot of traffic I begin to have trouble breathing, I get really disoriented, my muscles can seize up and I can black out. As a result, we try to restrict my trips in the car to emergencies, such as dentists visits and the inevitable bushfires, that are part and parcel of living in the foothills.

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We have found it essential to inform our neighbours about my condition so that they can give us prior warning if they are going to use chemicals We informed our council, gas co. electricity co. and other relevant bodies .(A supporting letter from the doctor has helped)When the council laid new bitumen in our street, it was necessary to escape to a friend's flat for a month. You can shut up the house whilst a chemical is in use but subsequent fumes can take months to out-gas This is still the bane of my existence. When neighbours paint, especially outside, I get really crook for months. My severe symptoms all return and I lose weight again.

In recent years ,the greatest improvement to my illness has come from getting tests done with The University of Newcastle. Their scientists have worked with my doctor and me. It has been a true revelation to finally have tangible proof that my illness has measurable, physical causes. For so long CFS patients have been largely treated on mass. We have all at some stage taken something that we read was good for CFS, only to discover that it made us worse ! I overdosed on primrose oil, that `CFS treatment' that we were all encouraged to take a few years back. The Uni found sky high levels in my blood and this, along with many other biochemical anomalies that could be addressed. My diet was again changed and at this stage, I was given the best piece of advice by the researchers. Not to take anything unless a test result implied I required it! No more pill archive. Finally those barely used, over the date bottles, would be replaced with tailor-made treatments. They also found significant levels of DDE in my blood, (a by-product of DDT), and this provided clues as to why I was so chemically affected.

Today, I still live a very restricted life. I have to get up extremely early to air our house before people start using washing detergents, lawn mowers and household chemicals etc. Instead of being bedridden, I now have a few hours in the morning that I am able to spend doing tasks that were previously impossible. I can read, write, play with my new puppy, learn new skills like trying to work out my new lap-top and become computer literate. Although there are some definite chemicals I have to avoid like the plague, I now can sit outside for a while when there is light traffic. It's also wonderful to feel the sunshine again on my skin. I have the usual cognitive difficulties, aches and limited energy levels like most CFS. sufferers, I am by no means `cured' BUT compared to the early years, I have come a long way.

To achieve such improvement, it has truly taken a massive collaborative effort on behalf of my family, doctors, neighbours and friends. I have met my dearest friends through SAYME and the support and information sharing has been invaluable. Sure, like any tough situation, there has been some fall-out. The restrictions my MCS. places on others has occasionally brought on some rather adverse responses. People can be very selfish and cruel when asked to go to extra trouble for you. I have lost friends and family members over my illness. From many years of communication with other MCS sufferers, I must say that a simple lack of consideration and acceptance of the severity of chemical intolerances, has brought about immeasurable and sadly, preventable pain and suffering to many. However, due to the understanding and acceptance of many great people, I have part of my life back.

From day one I have always adopted a policy of leaving no stone unturned. I believed that every one of my CFS symptoms had a cause and I enlisted as many informed people as I could to help me maximise my health potential. It has been, and I know, will continue to be a long struggle but we have come too far to give up now. I keep going because I am a Christian and God gives me strength I know that God has put me here for a reason and in whatsoever capacity I am able to function, I will.

I sincerely ask those of you who aren't so chemically affected to help represent MCS in an informed manner. We are a hidden and misunderstood minority, too often portrayed by the media as `freaks.' We really require help because we often can't get out into the 20th century to ask for assistance for ourselves. Many are isolated, living without the support of others. We really require chemical-free housing, as this is our best treatment. Doctors and other healthcare workers need to be educated about our condition also. There is much work to be done.

Those who study MCS see the chemically ill as warnings to the world. They tell us that the human race wasn't created to withstand the ever-increasing chemical soup we are pumping out. By using more natural and sustainable alternatives we can contribute to preventing illness People have to live more simply, so that others may simply live.

Medical Matters

The Place of Psychiatry in the CFS debate – Prejudice, Power and Pitfalls

(This paper was presented at The Third International Clinical and Scientific meeting for Chronic Fatigue Syndrome, Sydney Australia Dec. 2001)

Introduction

As a psychiatrist and medical editor of Emerge, the quarterly journal of the Victorian ME/CFS Society, I am continually confronted by psychiatric literature and conference presentations by psychiatrists "interested in" CFS.

My profession has had a shameful presence in the CFS debate, right back from its involvement in reclassifying the obvious physical illness seen in the Royal Free Disease as "hysteria" up until the current time.

Over the last few years in Australia, there have been some powerful voices in psychiatry propped up by a huge amount of research funds and grants. These people are regularly publishing in reputable medical journals, research which implies CFS is "neurasthenia" or "somatisation."

My presentation will focus on some of this work and discuss its flaws.

How psychiatry can become more involved in a positive way will also be discussed.

Summary

This paper will discuss the concepts of neurasthenia and somatisation and how these and other psychiatric terms have infiltrated the psychiatric literature on CFS. A selection of publications from the Australian psychiatric literature will be presented to show these trends, followed by a brief discussion on cognitive-behaviour therapy and graded exercise therapy. The paper will conclude with the author's ideas as to the reasons for psychiatry taking this path and with an idealistic view of how psychiatry could be involved.

Neurasthenia

The New York neurologist, George Beard, is widely credited with introducing the term neurasthenia in 1869. However, the psychiatrist Van Deusen has an equal claim to the authorship of neurasthenia, as he introduced the term in The American Journal of Insanity in the same year. The confrontation between neurology and psychiatry at that time continues to this very day, but at that time it was Beard, the neurologist, who became most credited with the "discovery" of neurasthenia [1,2].

Neurasthenia has been defined as "a disease of the nervous system, without organic lesion, which may attack any or all parts of the system, and characterised by enfeeblement of the nervous force, which may have all degrees of severity, from slight loosening of these forces down to profound and general prostration" [3]. Over all, at that time, it was considered a disease of excessive fatigability and it was considered that the fatigability could affect physical and mental function equally. Even at that time it was noted that there was a significant discrepancy between physical disability and physical examination, with sufferers typically looking quite normal. By the turn of the century, neurasthenia was considered a "fashionable disease".

It is interesting to witness the changing ideas over time regarding the aetiology of neurasthenia. Initially the prevailing neurological paradigm was the "reflex hypothesis", in which excessive irritation of the nervous system was considered to cause exhaustion of peripheral nerves. The next step was that neurasthenia was considered to have a central origin in which there was exhaustion of supply of energy in the central nervous system and this was a consequence of "cortical weakness" or "cortical irritability". This was thought to be caused by problems with blood supply to the brain, overwork, or from toxic, metabolic or infective causes. As time moved on, social theories overtook neurological ones and it was thought to be a condition of modern civilisation, primarily from overwork. This also incorporated the changing status of women at that time and it was thought that the female nervous system, inherently weaker than the male, may give way as a result of excessive occupational demands. Due to the failure or the organic paradigm and other social class issues, such as the illness now being documented also in lower classes (previously considered a disease of upper classes), the psychogenic paradigm became the dominant one by the early 1900's. Neurasthenia had become a psychological illness with a stigma attached. By the 1920's the concept of neurasthenia started to dissolve, as it was replaced by psychiatric diagnoses, such as depression. This move towards the psychological then had a number of underlying reasons, including the neuropathological basis of the condition being discredited, the "rest cure", which often involved many months of hibernation in a spa, being seen as either unsuccessful or efficacious due to psychological

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reasons, changes in social class distribution and the emergence of the new profession of psychiatry.

Looking at the concept of modern neurasthenia, in the United States and United Kingdom, formal interest had disappeared by 1960 and it was dropped from the DSM-111. The term has remained in the International Classification of Diseases (ICD-10). The diagnosis is commonly made in some parts of Europe and also made in Asia, being seen as a physical illness without stigma. In Japan it tends to be used instead of a psychiatric diagnosis, as Japanese society has a particular abhorrence of serious mental illness.

It is quite clear that the historical debates about organic versus psychogenic paradigms, quite clearly parallel the current debate in the chronic fatigue syndrome literature.

In the last few years the term neurasthenia has made its way into the chronic fatigue syndrome literature, particularly in the psychiatric press[4]. In such papers, quotes such as the following have been seen: "Whether or not it is worthwhile to distinguish between neurasthenia and dysthymic disorders, must depend on the demonstration that such syndromes have different social covariates or pursue a different course or have particular responses to treatment. Until such studies are forthcoming the distinction seems especially insubstantial".

The author strongly believes that reviving the term neurasthenia and using it in the chronic fatigue syndrome literature is counterproductive, due to the historical connotations of this term, particularly as it did finish up as a psychological diagnosis, despite the fact that the organic versus psychological debate was never really resolved.

Somatisation

An even more concerning trend has been to use the term somatisation in the chronic fatigue syndrome literature. Somatisation can be defined as "a process by which patients experience physical symptoms, most probably the result of psychological distress, but are attributed by the patient to a physical cause". Somatisation is considered the commonest way for a psychiatric disorder to present and somatoform disorders are characterised by physical symptoms that resemble medical disease, but that exhibit no organic pathology or known pathophysiological mechanism[5]. It can be seen that these definitions can easily brought into the area of chronic fatigue syndrome. Firstly, if the doctor's ideas about the illness differ from the patient's, they already fulfill the first definition of somatisation, because if the patient with chronic fatigue syndrome is attributing his or her symptoms to a physical cause and the doctor is attributing them to a psychological one, the first definition if fulfilled. Looking at the second definition in which there are physical symptoms resembling medical disease, but no organic pathology or known pathophysiological mechanism, chronic fatigue syndrome can again be readily fitted in to this definition, as can many other illnesses which still defy our current level of medical knowledge.

The author strongly concludes that somatisation is a term that must not be used under any circumstances in discussing chronic fatigue syndrome.

A Selection of Papers

CFS and Dieting Disorders: Diagnosis and Management Problems,

Griffiths A, Beaumont P, Moore G, Touyz S. Australian and New Zealand Journal of Psychiatry; 30:834-838, 1996.

This article describes three cases of young people with an obvious diagnosis of chronic fatigue syndrome, who the authors "successfully" re-diagnose with eating disorders. For example – Case 1 Linda is a 13-year-old girl with glandular fever diagnosed with a positive EBV virus IgM and typical symptoms of chronic fatigue syndrome. She is described as having "12-months of extreme tiredness, exhaustion, myalgia, poor concentration, short-term memory, intermittent feelings of depression, nausea when eating, loss of appetite". "Unsuccessful treatment for chronic fatigue syndrome" is described. The authors give a "diagnosis of anorexia nervosa, but neither she nor her parents would accept it". They "did not believe she had anorexia nervosa, preferring to have a physical disease diagnosis". The authors state "Denial is a well-known psychological concomitant of anorexia nervosa and if the patient believes she may have a disease diagnosis, such as chronic fatigue syndrome, denial in inadvertently re-enforced". They discuss "secondary gains with her CFS" and conclude stating "CFS and dieting disorders have several features in common. They mostly affect young perfectionistic females, who are high achievers with vulnerable personalities". This author expresses extreme concern about this paper and other papers which re-diagnose very ill chronic fatigue syndrome sufferers as suffering with eating disorders.

2. Chronic fatigue syndrome and Australian psychiatry: lessons from the UK experience. Couper J. Australian and New Zealand Journal of Psychiatry; 34:762-769, 2000.

Jeremy Couper is a Melbourne psychiatrist with "an interest" in chronic fatigue syndrome. He talks about the UK experience and discusses the fact that membership of a chronic fatigue syndrome society correlates with a poorer outcome. He discusses, under the title of the Australian experience, the first international conference of chronic fatigue syndrome in 1998, in which there was "a program which focused almost exclusively on research into organic aetiologies". He talks about a pioneering study of "cognitive-behavioural therapy", produced by the Sydney researchers Lloyd, Hickie et al, and goes on to say "CFS can be seen as a potential Trojan horse for psychiatry, enabling psychiatry to perform a broader role in medical research and a more truly integrated role in the health system". The implications of psychiatry needing to re-medicalise itself will be discussed later.

3. Chronic fatigue syndrome in adults. Couper J. Australian Doctor, August 2001.

The following are some quotations from this paper –

"Patients are often encouraged to be suspicious of the medical profession's attitude to CFS by self-help group literature."

"the ideas CFS patients have about the cause of their

symptoms can be seen as the patient's attempt to understand their illness in terms of whatever is at the cutting edge of the scientific research of the day."

"the more somatic symptoms a patient has, the greater the likelihood of a psychiatric disorder."

"the very distinction between CFS, neurasthenia and depression has been questioned."

"hyperventilation, anxiety and panic disorder produce feelings of fatigue and increased subjective effort."

"somatoform disorders ... Whether CFS belongs in this category largely depends on the doctor's perspective."

"robust research data support the use of antidepressants."

4. The School of Psychiatry, University of NSW, led by Ian Hickie, has published a lot of contradictory papers in psychiatric literature over the last few years. In the late 1990's they talk about the "Immunological bases for post-infective fatigue states" "role of cytokines" and the fact that "resolution of fatigue is associated with improvement in cell-mediated immunity"[6],but by 2001 they had published a study which stated that 32% of people diagnosed with chronic fatigue syndrome had features of a somatoform illness[7].

5. Sphere – A National Depression Project, Medical Journal of Australia; 175 Supplement, 2001. This has been a major concern, with the New South Wales researchers being largely behind the project. Using a 12-item questionnaire that they devised and called Sphere (Somatic and Psychological Health Report) they found that 49% of patients attending general practitioners have "mental disorders".

The Sphere has 6 items relating to psychiatric symptoms

- Feeling nervous/tense
- Feeling unhappy/depressed
- Feeling constantly under strain
- Everything getting on top of you
- Losing confidence
- Being unable to overcome difficulties (Psych-6 items)

and has 6 items relating to somatic symptoms

- Muscle pain after activity
- Needing to sleep longer
- Prolonged tiredness after activity
- Poor sleep
- Poor concentration
- Tired muscles after activity (Soma-6 items)

If a person has a score of 2 or more on the Psych-6 and/or 3 or more on the Soma-6, he or she is defined as having a mental disorder. It is quite clear to see that a patient with chronic fatigue syndrome, or glandular fever or a number of other medical illnesses for that matter, can very easily be defined as being a "mental case". This project has large implications for anti-depressant prescribing in general practice as the project concludes with statements relating to the under-prescribing of anti-depressants for mental disorders.

6. The Second Draft Guidelines

Royal Australasian College of Physicians 2001

The draft guidelines initially published in 1998 have been an attempt to summarise the current working knowledge on chronic fatigue syndrome. Unfortunately throughout this paper the influence of psychiatrists is quite clear.

(a) "What other terms are commonly used for chronic fatigue syndrome"

Neurasthenia is mentioned and "its specific relationship with CFS and common psychological disorders are not resolved."

(b) Does chronic fatigue overlap with other illnesses?

"Perhaps the most difficult diagnostic uncertainty between CFS and psychological illness is in relation to somatoform disorders."

"As the causes of CFS are "unexplained", there is obvious overlap between the diagnostic criteria for the somatoform disorders and chronic fatigue syndrome".

(c) What is known about the pathophysiology of Chronic Fatigue Syndrome

There are 5 leading hypotheses mentioned, 2 of which involve psychiatric aetiological theories.

A neuropsychiatric disorder with clinical and neurobiological aspects suggesting a link to depressive disorder.

A psychologically determined response to infection or other stimuli occurring in "vulnerable" individuals.

Cognitive-Behaviour Therapy and Graded Exercise Therapy

There have been a number of studies in the medical literature about these 2 "treatments" for chronic fatigue syndrome[8]. A number of papers have discussed the "promising results" seen with these 2 "treatments". The author makes the comment that a number of these studies are methodologically flawed, and it is quite ludicrous to extrapolate that these 2 therapies can be considered a treatment for chronic fatigue syndrome. The author comments that they should be seen as adjuncts only. She has considerable concern that the number of papers being published about these 2 "treatments" implies that the underlying aetiology must be psychological.

Psychiatry's Stance – The Reasons

The author believes that there are a number of reasons why psychiatry has tried to "capture" CFS for itself.

The name - chronic fatigue syndrome. Because of its non-specificity and because it relies on fatigue as the core feature in the title, "poaching" by any area in medicine is easy. Fatigue is extremely non-specific and is seen in many conditions in psychiatry, in particular depression, anxiety and somatisation. Insidiously, in many papers the word "syndrome" has been dropped and the term chronic fatigue, even more non-specific, used and sequestered by psychiatry. In the author's opinion chronic fatigue syndrome nowhere

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near adequately describes this illness and a new name needs to be found, for example, Nightingale's illness (after Florence Nightingale who supposedly suffered with CFS). In this way it clearly places it outside the reach of psychiatry.

There is a strong need for psychiatry to "re-medicalise" itself. "Both scientifically and economically there are questions about the survival of psychiatry, hence the need to cling to its status as a "medical science"" [9]. "Born of an alliance between the research of biological psychiatry and the funding of multi-national drug companies, pharmacological interventions (the psychopharmacotherapies) are currently being heavily promoted as primary modalities of treatment"[9]. Because psychiatry is a low-status specialty and because research funds are given to those who work in the biological field, it is quite clear that some sections of psychiatry would want to claim fatigue for psychiatry.

Continuing on from the points made in 2. Money, power and politics play a large role. The funding comes to those researchers working in the biological area. The power comes to those who "discover" new syndromes or treatments and the behind-the-scenes politics in all this means that those researchers who get the money, who get the publications, get more money and more power. Economically also, there has been an erosion financially within psychiatry with changes to certain Medicare items, making it much more difficult to see people for extensive psychotherapy.

Poorly-designed research abounds in all areas of medicine, but certainly a number of papers published in the last few years, as described earlier in this paper, have been poorly-designed with results that are subsequently flawed.

There has also been a bias in research publishing, with certain journals only choosing to publish papers in chronic fatigue syndrome that deal with psychological issues, for example, cognitive-behaviour therapy.

There of course is the problem of co-existing depression, grief and other psychological complications of chronic illness, which can for many people unfamiliar with this condition over-shadow the biological component.

"Stupid medicine" – this is the term this author uses to describe medical specialists only seeing what they are trained to see, for example a psychiatrist only being able to see depression or a surgeon only seeing something to cut out.

Reading narrowly in one's own specialty is a real problem, because the average clinical psychiatrist will only be reading 1 or 2, if that, journals in his or her own area and is very unlikely to be reading up-to-date research in other medical journals about chronic fatigue syndrome, therefore getting an extremely biased view.

Many clinical psychiatrists will admit to the fact that they have never seen someone with chronic fatigue syndrome, which means their experience in the condition when they do have someone in their practice with it, is extremely limited. In many cases, they have in fact "seen" chronic fatigue syndrome in their practice and have mis-diagnosed it as a psychiatric condition.

Psychiatry and CFS – An Optimistic View of the Future

Many researchers, clinicians and patients have a clear view that psychiatry has no place in chronic fatigue syndrome. This author does not hold that view and believes that psychiatry and psychiatrists can contribute significantly to research and to clinical practice. For psychiatry to have a future in chronic fatigue syndrome, psychiatrists need to take the time and trouble to educate themselves widely and not just believe what they are reading in peer-reviewed journals. Psychiatrists can provide a supportive, educational and validating environment for patients with CFS as well as advocacy such as at school or in the work place. A psychiatrist can provide relationship and family support, help maintain hope and optimism, use adjunct therapy such as relaxation, meditation and hypnosis, obviously treat co-existing psychiatric illness and use appropriate psychotherapies, for example grief counselling and cognitive-behaviour therapy.

In summary, a significant amount of ill-will towards psychiatry by those in the chronic fatigue syndrome area, has been warranted. The author hopes that in the future, psychiatrists will take the time to educate themselves more widely about chronic fatigue syndrome and is optimistic that over the next few years, as general medical research moves towards a unifying aetiological hypothesis and hopefully appropriate treatments, that the debate about whether chronic fatigue syndrome is biological or psychological will fade into oblivion.

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Battle Fatigue by Jerome Burne

Introduction

For ME sufferers, the bitter feud between the scientists as to whether it is a genuine physical complaint, or more a disease of the mind, has only added to the dispiriting nature of their ailment. After all, if even the experts don't know what's wrong with them, what hope is there? Jerome Burne meets the warring parties - and finds that, at last, they're discovering some common ground

Jerome Burne
Guardian

Saturday March 30, 2002

One of the last surviving catch-phrases of the 1980s was consigned to the verbal scrapheap in January. "Yuppie flu", still occasionally used as a macho way of dismissing the crippling symptoms of chronic fatigue syndrome (CFS), was officially declared unacceptable. A working party set up by the chief medical officer (CMO) had laboured for three years to produce a report, which concluded that, far from being a malingerer's charter, CFS should be recognised as a chronic and treatable condition.

Sir Liam Donaldson, the CMO, acknowledged that, in the past, sufferers of CFS, or myalgic encephalomyelitis (ME), had all too readily been "dismissed as hypochondriacs and urged to get better on their own". No longer, the report declared, will it be acceptable for clinicians to state that they "don't believe" in CFS/ME. While the media coverage generally represented this as some sort of resolution of an odd medical anomaly - most of the patients clearly aren't faking it - a more accurate description would be a temporary ceasefire in a long-running battle.

A glimpse of the infighting behind the scenes was provided by the resignation of six of the working group just before publication, together with a few bland comments by the CMO about a larger than usual postbag on the issue. But none of this conveys the depth of feeling involved. There was no mention, say, of a vendetta by a group of patients against one of the leading consultants in the field. And no acknowledgment of a professor emeritus so infuriated by a leaked early draft of the report that, in defiance of protocol, he posted a devastating critique on the internet.

Breaking the embargo was regarded as heroic by the radical wing of the CFS community, and outrageous by at least one of the patient groups. Calls for legal and disciplinary action filled the internet news groups for weeks. It is worth remembering that these are not political activists, but many are desperately ill people - the debilitating effects of CFS have been described as worse than having a heart condition. It was the vendetta against a leading consultant, however, that provided my own introduction to the CFS battlefield.

One morning, two bulky packages thudded on to my doormat. Their combined 400 pages were a cry of rage, channelled into the impersonal format of an academic critique. Rather quaintly, they were entitled Denigration By Design: Review With References Of The Role Of Dr Simon Wessely In The Perception Of Myalgic Encephalomyelitis (ME).

Once past an initial disclaimer about there being "no personal animosity whatsoever directed at Dr Wessely", the authors of the densely typed and impressively referenced pages launch into their real business: a sustained attack on Wessely's professional competence, his ability as a scientist and his truthfulness.

Professor Wessely, as he now is, is one of the country's leading experts in CFS/ME. I had been sent the documents as evidence that here was a tale of perfidy that needed exposing. Later, more documents came with a letter that read: "If you are able to expose just how biased, unscientific and indeed evil Wessely is, you would be regarded as a saviour of mankind."

Both Denigration... and the breaking of the embargo on the web were aimed at a single target: to gain recognition of the fact that CFS is a physical disorder, as real as tuberculosis or Aids, rather than some nebulous psychiatric disorder. But wasn't this precisely the sort of misunderstanding that the CMO's report was designed to address? And didn't the fact that it declared CFS to be a chronic and treatable condition show that the reality of the disease had been acknowledged? Well, yes, but this is where the ground starts to become rather swampy, and why the CMO's report is unlikely to result in more than a temporary ceasefire.

Joint statements by old adversaries in all walks of life are often more revealing in what they don't say, and what the CMO's report signally did not say was anything about the physical basis of CFS. It was this absence that prodded Malcolm Hooper, a professor emeritus from Sunderland university, into action. Already known for his support for Gulf war veterans, he analysed a leaked draft copy and published a blistering critique on the web. The resulting calls for lawyers and disciplinary actions can still be heard.

"Once these official reports come out they get set in stone," Hooper said in his steady and deliberate northern tones. "Afterwards, if you have a complaint, or you want to change anything, you just get referred back to the report. The assumption is that all the experts have looked at it and this is what they came up with. I couldn't let that happen. A growing body of scientific literature clearly shows that there are profound disturbances of, and damage to, the neuro-endocrine-immune systems of these patients. All that evidence was just being ignored."

For the past three years, Hooper has been involved with Gulf war illness (GWI), another condition where

the patients say they are physically ill while many mainstream medics continue to maintain that their problem is essentially psychiatric. He has found himself sitting on the opposite side of the fence to Wessely, who also researches in this area. "Gulf war patients are clearly ill," says Hooper. "Fit young men walking on sticks. They have obviously been poisoned, but will anyone do proper tests for the toxins we know they have been exposed to? They will not."

Hooper has attracted a following - and it is not hard to see why. A professor of medicinal chemistry, he can talk toxins, disordered sulphur metabolism, enzyme pathways and up-rated immune responses all day long. It is the sort of language that patients in both the CFS and GWI camps yearn to hear. He is supported by a dauntingly technical website, run by the autism research unit at Sunderland University, which explains the physiological links between what have been dubbed "The Overlapping Syndromes", which include CFS, multiple chemical sensitivities and GWI. He describes them as "sharing many common symptoms, together with an emerging pattern of biochemical dysfunction... that requires non- routine tests for its identification".

He outlined for me just a few of the physiological changes in the bodies of CFS patients. For instance, some CFS patients - it is always "some", which is a large part of the problem - have been found to have lowered levels of sulphate. This makes sense of a problem that many CFS sufferers share: being unable to tolerate normal levels of certain drugs or foods. The link is that drugs and foods have to be broken down in the body, and sulphate plays a vital part in this process, especially for handling a class of chemicals called phenolics. Three substances that "some" CFS patients become abnormally sensitive to are: paracetamol, citrus fruits and the adrenalin that comes with an anaesthetic injection at the dentists - all three are phenolics.

The second link concerns blood cells. Sulphation and unsaturated fatty acids are involved with keeping the walls of cells, including blood cells, strong and flexible. Research teams in Australia and New Zealand found that not only are blood cells deformed and irregular in some CFS patients, but they also identified five different subgroups of patients with different fatty acid deficits. The teams are now trying to find links between the types of distortion and the patients' symptoms.

Is this definitive? No, it is not. Does it provide a marker for CFS? No, it doesn't. However, it may link into a research project at Dundee university, reported last year. This found that "all" - very unusually - the CFS patients examined with a very sophisticated non-invasive laser had problems with the bloodflow in the tiny capillaries just below the skin after receiving a dose of acetylcholine, one of the key chemicals of the nervous system. Could it be related to irregularly shaped blood cells? Maybe.

The sulphation story was just one of many that Hooper told me. Others related to the problems some patients have with certain lipids (fats) that also build cell walls, and with their guts, which can create toxic molecules that set off the immune system. They were all evidence for Hooper's central point - if we are ever going to find a cure, or even a treatment, we need to know more about how these pathways get messed up. And to do that we should be regularly running tests on patients' blood, their sulphate levels, the functioning of their guts, and so on.

Historically, the establishment view has been that "only limited testing is necessary". Psychiatrists have regularly warned against the dangers of "over investigation", which could make patients worse by encouraging the belief that they had a physical illness. The joint 1996 Royal Colleges Report On CFS concluded that "immunological abnormalities should not... focus attention towards a search for an 'organic' cause".

From what Hooper had seen of the leaked CMO's report, it seemed to him that history was going to repeat itself and the need for extensive testing would again be underplayed. And so he fired off his salvo.

Meanwhile, the daily reality for CFS sufferers in the UK is pretty grim. A sympathetic GP may provide some support for your symptoms, but more than 60% of patients don't feel happy with the way the medical profession has treated them. That's not too surprising, given the attitude that it's apparently acceptable to adopt in magazines aimed at GPs. Here's Dr Mary Church, writing a bright column in Pulse last October on how to deal with ME: "Never let the patients know you think ME doesn't exist and is a disease of malingerers... At the end of the consultation, I say goodbye, not au revoir. Always refer ME patients to a local expert. It's a wonderful way of passing the buck."

The only officially approved treatment in the UK, cognitive behaviour therapy (CBT), is not readily available, and its benefits are disputed. The number of psychiatrists specialising in it is tiny, and their waiting lists run at about two years. The percentage of patients who make a full recovery from CFS is estimated at about 4%. If you want your CFS treated as an illness, you will generally have to go private and/or travel outside the UK.

Dr Kenny Meirlier, at the Fatigue Clinic in Brussels, for instance, focuses on the immune system; specifically, a sequence of chemical changes that take place in our white blood cells when they are fighting off a viral infection, known as the "RNaseL" pathway. He's found evidence that in CFS patients, the key enzyme involved in breaking down the invading virus and destroying the infected cell is only half its normal molecular weight. This chemical spanner in the works has all sorts of effects at a microscopic level, which could well lead to many of symptoms CFS patients complain about.

One satisfied patient, who spent a fortune and 18 months being treated by Meirlier, is "Judy". After running an exhaustive gamut of tests on her blood, immune function and the rest, he prescribed a drug that targeted her immune system and later added antibiotics. Now she is no longer confined to bed and is starting to work part-time. "I first developed

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glandular fever in 1993. It made me feel very tired for months, and I never really got better," she says. "There were periods when I was okay and I got a good law degree, but I kept relapsing. I had all the standard tests for viruses and bacteria, and a rheumatologist checked me out for autoimmune problems, but everything came back negative.

"I was offered CBT, but I knew I didn't have any psychological problems, I wasn't making myself ill, I had everything to live for. I tried various alternative therapies, but nothing made much difference. By the time I heard about the clinic in Belgium, in 1999, I was in a wheelchair, I actually slept for only two hours a night and I couldn't do anything except wash and eat."

Meirlier takes a combined approach, targeting both the damaged immune system and the pathogen he believes is causing it. One drug he used until very recently is called Ampligen and is aimed at the immune system. Although it is expensive and has pretty debilitating side-effects, there has been at least one small but controlled trial to show that Ampligen is beneficial. However, it has not been licensed in the US or in the UK, so its use is still experimental. Meirlier claims that an eight-year follow-up of patients treated successfully with Ampligen found that 92% had not relapsed.

The other arm of the treatment, which has really come on stream only in the past year, targets what might be called the "missing link". It is now well established that a fair proportion of CFS cases begin, like Judy's, in the wake of some sort of viral infection. The mystery is what keeps it going? Why don't the patients recover when there is no longer any sign of the virus? "We have found that 68% of patients with CFS are also infected with mycoplasma," says Meirlier. This is a tiny bacteria-like creature damaging to the immune system. Hence the treatment with antibiotics.

Again, his claims are dramatic. "You have to take a long course, about a year, and we find that the younger ones who have had the condition for a shorter time do the best. Patients who have been ill for a long time start to develop damage at the cellular level that can't be reversed. However, about 80% of patients who take the antibiotics show a great improvement." There haven't, alas, been any properly controlled trials.

Meirlier's findings, comparing the working of the RNaseL pathway in CFS patients with that in healthy controls, were published last year in the prestigious American Journal Of Medicine. In a commentary on the paper, Anthony Komaroff, professor of medicine at Harvard, remarked that the finding was "another strong piece of evidence that is consistent with the hypothesis that the immune system is activated [in CFS patients] and that the object of the immune system's attack could be a chronic infection". As for the psychiatric approach, he went on to say, "It is time to put that hypothesis to rest."

Inevitably, the value of RNaseL as a marker for CFS hasn't gone unchallenged. Last October, the results of a UK trial looking at RNaseL levels in CFS patients were published. They concluded that it was "unlikely to form a rational basis for a diagnostic test for CFS". Meirlier's response was that the researchers had done the test wrongly. "They don't have the correct probe, because it has been patented," he retorted. "It is difficult to do, but other labs have replicated it and there is a standard procedure, which has been approved by the Food And Drug Administration."

UK experts don't take the mycoplasma connection seriously, either, referring to trials showing that it wasn't a factor. However, it is a different story in the US. The Centre for Disease Control (CDC), in Atlanta, despite initial scepticism, recently set up a large-scale programme that involves detailed testing of CFS patients for such classic signs of disease as faulty gene activity, poorly functioning hormones and damage to the immune system. One project, for example, is looking for "novel pathogens", while another is screening patients' blood samples for the DNA of mycoplasma and certain bacteria.

So, there's no shortage of research going on into the possibility that CFS patients have genuine underlying physical problems. What would Wessely have to say about it all? The man who, the radicals say, had almost single-handedly caused all this hopeful research to be consigned to scientific obscurity.

I began by quoting to Komaroff's comment that the psychiatric hypothesis was dead. Wessely's response surprised me. "Oh, it's years since anyone has denied there is a biological basis to CFS," he declared. "That's just tilting at windmills. We have been most active in looking at the biological basis of CFS." What? Was the war over? Has the psychiatric camp folded up its tents and melted away? I felt like an old Tory war-horse challenging the early Tony Blair over Clause Four and increased taxation. "We were one of the first to show there was a neuroendocrine difference between CFS and depressed patients," he said, rather proudly. "When I started out, I had been struck by the similarities between CFS and depression, but this was evidence that they were different. I was surprised, I would have thought they would be the same, but you have to follow where the results lead, and I admit I changed my mind."

Later, he assiduously emailed me a list of 23 studies involving physical markers done by his unit at King's College School of Medicine in London. "I have several grants to look at immune factors in CFS," he added. "So I'm afraid another myth goes up in smoke."

But it turned out that what Wessely meant by a biological basis wasn't quite the same as what researchers such as Hooper and Meirlier understood by the phrase. "We aren't confident about the physiological basis of ME," Wessely said a little later. "It's an ambiguous illness that you can't make black and white. It's possible that, in the future, we will have a biological basis for the disease but, until something does stand up to proper testing, we are right to be sceptical."

It was also hard to get him to speculate on what this basis might be, although he was clear about what lines of research he rejected. Problems with the energy units in cells - mitochondria - had been tested and found wanting. So had mycoplasma, retroviruses,

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RNaseL and a urine test. "Over the past 10 years, I have lost count of the number of objective tests that have been proposed as diagnostic markers, which have gone down the plughole. If I had £1 for every dramatic breakthrough, every miracle cure since I have been dealing with the issue, I wouldn't need to worry where my merit award is coming from."

That just leaves supporters of what the report terms the "psychosocial approach" championing CBT, which doesn't seem enough. This inadequacy was illustrated by a piece of research published last December. It was based on the well-known fact that many patients, such as Judy, develop CFS after an infection that brought on CFS-like symptoms. For example, Lyme disease, caused by the bacteria Borrelia burghdorferi , has symptoms that include fatigue, headache, muscle aches, joint aches, cognitive disorders and sleep disturbance. But instead of clearing up once the infection had gone, they persist. Why? It was the same question that had interested Meirlier. Factors identified by this new study, which involved glandular fever patients, tended to be external: being less fit, having swelling in the lymph nodes and having initial bed-rest. Graded physical activity was recommended as a way of reducing the chances of CFS developing.

Now contrast that with a study currently underway at the University of New South Wales, under a contract from the CDC, looking at exactly the same thing: patients who develop post-infectious fatigue after catching Q fever, Ross River virus or Epstein-Barr virus. The factors the Australian researchers are testing for are physiological: immune system changes, pathogens persisting in the body for an unusually long time, genetic factors and psychological factors.

It must make more sense to look at these other possibilities, rather than just the social and psychological. Of course, psychological factors may play a part - they do in every disease - but to look for them exclusively seems wilfully limited, not least because one of the abiding puzzles of the psychiatric view is why these patients, some of whom are bright, successful people, should want so drastically to limit their lives by maintaining this illusion of illness? Suggestions in the literature include "learned helplessness" and "culturally sanctioned expressions of distress". Maybe some are driven by these, but all of them?

It is undeniable that some of the Freudian explanations for conditions classed as psychiatric only a few decades ago have since been discredited. One example, understandably popular with CFS patients, is the one for Parkinson's disease. Now Parkinson's is accepted as a neurological disorder, caused by a decline in dopamine production in a certain area of the brain. But in the 1940s, a psychiatric explanation was that it was the result of "conflict between an aggressive drive to action and an equally strong internal pressure to inhibit action". The specific conflict was the result of "the wish to masturbate in the ambitious moralistic man". A century ago, hysteria was the common diagnosis for symptoms with no physical cause. (In fact, one modern writer - the professor of English, Elaine Showalter - has infamously classified CFS sufferers as hysterics, along with self-proclaimed victims of alien abduction.) All this vividly illustrates the huge fault-line that runs through modern medicine, otherwise known as the mind-body split. Traditional medical systems don't make this distinction; often, they combine the psychological and the physical in a single treatment - herbs and meditation, for example. We demand a physical cause - genetic, infectious, lifestyle - with a psychological component added. So we accept that cancer patients who have had chemo-therapy, do a lot better if they go to a support group. Heart attacks are about as physical as you can get, but a recent study found that a major predictor is whether or not you have an optimistic outlook.

Psychiatrists take stick from groups on both sides of our self-imposed divide. Patients with depression, say, often complain that their treatment is far too biologically based, and call for less drugs and for more attention to be paid to the meaning of their disorder. It doesn't seem a very big stretch to include both sides, physiological and psychological, in the way CFS is researched and treated. It might even be imminent.

As I shuttled between Hooper and Wessely in the weeks before publication of the report, it began to seem that they shared a lot of common ground. "I'm interested in running specialised tests on patients, if they can be done as part of controlled studies," said Wessely. Earlier, he'd stated that there was not "a cigarette paper's thickness" between his approach and that of the CDC and its programme into physical causes. And Hooper was happy to admit that CBT, the psychiatrists' cure-all, might be useful in some cases.

One of the radical's many charges is that the psychiatrists use this particular therapy to challenge patients' belief that they have an illness. And yet, here again, Wessely proffered an olive branch, admitting that, in the past, he had, perhaps, put things in rather an abrupt way. Rather extraordinarily for a psychiatrist, he added, "Then, I was not so sensitive to the power of language. I've changed a bit." Now he says he would never challenge anyone's belief as to what the underlying illness was, except if they thought it was Aids.

It's certain that neither side has the stomach for a style of conflict more often seen in the political arena. All the combatants have said how hurt and upset they've been by enemy action. Wessely himself recently issued a call for some sort of peace. So what are they all waiting for?

Guardian Unlimited

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THE CAUSE AND TREATMENT OF POST-POLIO FATIGUE

By Richard L. Bruno, Nancy M. Frick, Susan J. Creange, Todd Lewis, and Terry Molzen.

Fatigue is the most commonly reported, most debilitating and least studied Post-Polio Sequelae (PPS) affecting the nearly 2 million North American polio survivors. Among polio survivors, 91% reported new or increased fatigue, 41% reported fatigue significantly interfering with performing or completing work and 25% reported fatigue interfering with self-care activities (1,2). Fatigue was reported to be triggered or increased by physical overexertion in 92% and by emotional stress in 61%. Importantly, polio survivors distinguish between the physical tiredness and decreased endurance they associate with new muscles weakness, and a "brain fatigue" that is characterized by problems with attention and thinking. Between 70% and 96% of polio survivors reporting fatigue complained of problems with concentration, memory, attention, word-finding, maintaining wakefulness and thinking clearly, with 77% percent reporting moderate to severe difficulty with these functions (3).

Problems with attention, memory and thinking suggest that the symptoms of post-polio fatigue cannot be explained merely by the poliovirus damaging anterior horn motor neurons (4). Autopsies performed fifty years ago on people who died after having had polio, whether they had paralysis or not, showed that the poliovirus almost always damaged specific areas in the brain (Figure 1). These damaged areas include the brain's activating system that keeps you awake and allows you to focus your attention. The poliovirus also damaged neurons that produce neurotransmitters, including the enkephalins and endorphins (called the "body's own morphine") as well as dopamine and ACTH which activate the brain.

With poliovirus damaging the brain's activating system, you would expect that the original polio infection should cause brain activating problems. And, reports written during the polio epidemics did describe "drowsiness," lethargy, prolonged sleeping and even coma during the acute polio infection (7,12,21,22). One-third of patients with acute spinal, spinal and bulbar and even non-paralytic polio showed "disorientation, apathy, pronounced sleep disorder (and) irritability" (4). These mental changes were associated with the abnormal slowing of brain wave activity on the electroencephalogram (EEG). Further, a high percentage of children clinically recovered from poliomyelitis insofar as motor disability is concerned, had qualitative difficulties in mental functioning such as "fatiguability and fleeting attention" for months after the acute polio (5).

These reports of persistent drowsiness, fatigue and fleeting attention following the acute poliovirus infection are similar to polio survivors' recent complaints of late-onset fatigue and impaired attention (25). And, both acute and late-onset post-polio fatigue are reminiscent of nearly two dozen outbreaks during this century of post-viral fatigue syndromes (PFS) that are related clinically, historically or anatomically to poliovirus infections (26-28). These relationships and recent studies comparing post-polio fatigue and chronic fatigue syndrome will be described in an attempt to understand the cause and treatment of post-polio fatigue.

Can the Poliovirus Cause Fatigue?

Type II Poliovirus and Decreased Brain Activation. During the polio epidemics of the 1950's, there were several small outbreaks of patients having drowsiness, prolonged sleeping, slowing of brain waves, as well as some of the symptoms of both bulbar polio and Parkinson's disease (e.g., tremor and rigidity) (29-30). In 1952, Type II poliovirus was isolated from one group of patients having these symptoms and it was found that the neurons in their brain activating system had been damaged.

The association of decreased brain activation and Parkinson's disease symptoms remind Dr. Oliver Sacks of the "sleeping sickness" patients with Parkinson's disease he described in his book Awakenings. The relationship between "sleeping sickness," Parkinson's disease and polio may be important for understanding post-polio fatigue, since all of these have conditions are associated with damage to a part of the brain activating system called the basal ganglia. For example, Parkinson's disease (PD) patients have severe damage to one of the basal ganglia, the substantia nigra (sub-STAN-sha NYE-gra), which produces the neurotransmitter dopamine (doe-PAH-mean). PD patients often describe fatigue. "Excessive fatigue" was reported by 48% of PD patients in one study (40) while nearly one-third of PD patients reported that fatigue was their "most disabling symptom" (39). As a matter of fact, one of the first descriptions of Parkinson's disease (41) could serve as a definition of post-polio fatigue, i.e., a syndrome "characterized by a diminution of voluntary attention, spontaneous interest, initiative and the capacity for effort and work, with significant and objective fatiguability, and a slight diminution of memory" (38).

Figure 1. Brain areas lesioned by the polio virus as seen in 158 human autopsies. Severe lesions: Reticular formation (RF); vestibular nuclei (V); cerebellar roof nuclei (R); periaquiductal gray (PG). Moderate lesions: Paraventricular hypothalamic nucleus (PV); posterior hypothalamic nuclei (P); substantia nigra (SN). Mild lesions: Globus pallidus and putamen (GP); locus ceruleus (LC); median raphe nuclei (MR); preoptic hypothalamic nuclei (PO); thalamic nuclei (T).

"Atypical Poliomyelitis" and Chronic Fatigue. Beginning in Los Angeles in 1934 and continuing for more than

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twenty years, there were over a dozen outbreaks of a disease that was at first thought to be poliomyelitis, was then called "abortive" or "atypical" poliomyelitis and finally named "Myalgic Encephalomyelitis" (ME) (6). Like poliomyelitis, initial symptoms of ME included headache, neck pain, low-grade fever and muscle pain that were often followed by muscle weakness. Patients were excessively sleepy and had "conspicuous changes in their levels of concentration" that lasted for months after the initial illness. Slowing of the EEG similar to that seen in acute polio was also noted.

Unlike poliomyelitis, there were frequent complaints of numbness or tingling, usually no breathing problems, paralysis or muscle wasting and almost invariably no deaths. Also unlike poliomyelitis, recovery from the initial symptoms of ME sometimes required months with most patients being left with a marked "exhaustion and fatiguability" that were "always made worse by exercise (and) emotional stress." Patients continued to have fatigue, excessive sleepiness, trouble concentrating, difficulty with word finding, memory and thinking for years after the acute episode.

Despite the differences between poliomyelitis and ME, an association with the poliovirus was suggested by the fact that, of the more than one dozen ME outbreaks before the introduction of the Salk vaccine, nine occurred during or immediately after outbreaks of polio and several involved hospital staff who cared for polio patients (7).

Type III Poliovirus and Chronic Fatigue in Iceland. A more direct association between the poliovirus and ME was seen in 1948 in Akureyri, Iceland. Patients there presented with fever, muscle pain and weakness and were at first diagnosed as having poliomyelitis. After about a month, this diagnosis was discarded as patients reported additional symptoms not typical of polio, including tingling, numbness, "nervousness" and "general tiredness." Also unlike poliomyelitis, no deaths were reported and poliovirus was never isolated from any of these patients. When patients were reexamined six years after their original illness, 72% still had chronic "nervousness and general tiredness" and 21% reported a of "loss of memory."

It was suggested that either an "unusual" and mild poliovirus or some unknown virus caused these symptoms that were called "Akureyri Disease" but are more commonly referred to as "Iceland Disease" (ID). Support for an "unusual" poliovirus as the cause came in 1955 (10). There was an extensive epidemic of poliomyelitis in Iceland caused by Type I poliovirus that coincided with and was followed by outbreaks of ID. Remarkably, two cities in which ID outbreaks were reported in 1955, as well as the area affected by the 1948 "Akureyri Disease" epidemic, were untouched by poliomyelitis. None of the children tested in the two ID-affected cities and only 13% of the children in Akureyri had antibodies to Type I poliovirus as opposed to 86% of the children tested in the polio epidemic areas. Further, following poliovirus immunization, children in one of the ID-affected cities demonstrated antibody titres to Type II and Type III poliovirus that were four and twenty-five times higher than titres in a city where ID had not been reported. It was concluded that Type I poliovirus was not the cause of ID, but the citizens of the ID-affected areas had previously been exposed to something that was immunologically similar to Type III poliovirus.

An interesting coda to these findings is the report that when an American airman who had contracted polio in the 1955 Iceland epidemic returned to Massachusetts, a small outbreak of ID and polio occurred (11). More recent support for a relationship between poliovirus and ME came in 1989 when a "dangerously rising titre" to Type III poliovirus was documented in a patient who did not have polio but had been diagnosed with ME (12).

Post-Polio Fatigue and Chronic Fatigue Syndrome. A group of symptoms resembling ME was termed "Chronic Fatigue Syndrome" (CFS) following a Nevada outbreak in 1984 (13). Like ME and post-polio fatigue, CFS is characterized by complaints of chronic fatigue and trouble with concentration, memory and word finding that are triggered or exacerbated by physical exertion and emotional stress. And, although polio survivors are on average at least ten years older than patients with CFS, the years of education, sex distribution, frequency of difficulty with concentration and psychological symptoms are nearly identical in the two groups (Table 1)(17,18,19). However, unlike ME and PPS, CFS patients report recurring sore throat, swollen glands and fever, suggesting to some that CFS is caused by a recurring or chronic viral infection. It is important to keep in mind that there is no evidence that PPS is caused by a persistent infection by any virus, including poliovirus (14,15).

The recent occurrence of CFS has allowed it to be studied using techniques that were not available during the polio, ME and ID epidemics and now allow neuropsychologic, neuroanatomic and neuroendocrine comparisons between this newest PFS and post-polio fatigue.

Comparisons of Post-Polio Fatigue and CFS

Neuropsychologic Studies. Some of the subjective difficulties with attention and cognition in CFS patients and polio survivors have been confirmed with neuropsychologic testing. CFS patients and polio survivors with severe fatigue have been shown to have clinical impairments of attention and information processing speed (Table 1)(16,19). Polio survivors reporting severe fatigue required 23% to 67% more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no or mild fatigue. In spite of these marked impairments of attention, CFS patients and polio survivors have been shown to have I.Q.s within the high normal or superior range and have higher than average levels of educational and professional achievement (Table 1) (17). Further, despite the high frequency of subjective complaints of memory impairment in CFS patients and in 87% of polio survivors reporting fatigue, verbal memory has been shown to be intact on testing in both groups (16,19,20). However, polio survivors

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have twice been shown to have trouble recalling visual information whether or not they report fatigue (7,16).

These findings indicate that fatigue in CFS patients and polio survivors is associated with impairment of attention and information processing speed but not of memory or thinking ability. Given the findings of frequent and severe poliovirus lesions in the brain's activating system, it was hypothesized that damage to the brain's activating system is responsible for both fatigue and impaired attention in polio survivors.

Brain Scan Studies. To test this hypothesis, magnetic resonance imaging (MRI) of the brain was performed to look for evidence of poliovirus lesions in the brain's activating system. In a first study, small areas of hyperintense signal (which look like white spots) on MRI were seen in the brain's activating system and in the myelinated (insulated) neurons that connect the brain stem (at the bottom of the brain) to the cortex (the "supercomputer" at the very top of the brain) in eleven of twelve polio survivors (1). In a second study, white spots were seen in 55% of polio survivors with fatigue but were not seen in any of the subjects without fatigue (Figure 2)(21). The presence of the white spots were not only related to increased fatigue severity, but also to problems with memory, thinking clearly, mind wandering, attention and concentration.

Finding white spots on MRI supports the theory that fatigue and problems with attention in polio survivors may be related to damage the poliovirus did to the brain activating system. This conclusions is supported by a number of other studies that have shown a relationship between white spots on MRI, fatigue and problems with attention. Notably, white spots have been seen in between 40% and 100% of CFS patients (13) and even in healthy elderly adults who have problems with attention similar to those seen in CFS patients and polio survivors (22).

Figure 2. A 24 mm2 focus of hyperintense signal (arrow) in the centrum semiovale in a 50 year old female polio survivor reporting moderate daily fatigue and frequent problems with concentration, thinking clearly, short term memory and staying awake (putamen lesion not seen in this view).

Hormonal Studies. The association of white spots in the brain activating system with the symptoms of post-polio fatigue suggested that the effects of poliovirus on other brain areas might also be evident in polio survivors. For example, poliovirus lesions were often seen on autopsy in the hypothalamus (hypo-THAL-ah-mus), the brain area that automatically controls the body's internal environment and its response to stress.

To test the functioning of the hypothalamus, we measured polio survivors' blood concentrations of ACTH (a-DRE-no cor-ti-co-TRO-pick hormone), one of the body's stress hormones whose release is triggered by the hypothalamus. ACTH was measured following an an overnight fast, which is a mild stress known to cause the release of ACTH (7). ACTH was increased outside of the normal range (as it should be following stress) in polio survivors who reported mild fatigue. However, there was no ACTH increase in subjects reporting severe daily fatigue. Further, the higher the ACTH level, the lower the subjects' reported fatigue and the less the difficulty with memory, word finding, muscle weakness and staying awake during the day.

These findings indicate that the hypothalamus had not been activated in the subjects with post-polio fatigue and that ACTH production is reduced in these individuals. This conclusion is interesting for two reasons. First, ACTH has been found in humans to promote alertness, increase attention and decrease fatigue by directly stimulating the brain activating system. Thus, a decrease in ACTH production may prevent brain activation and contribute to the symptoms of post-polio fatigue. Decreased activation of the hypothalamus has already been found in patients with CFS and a decrease in ACTH stimulation of the brain has been suggested as a cause of CFS (23).

Second, a decrease in ACTH production may be caused by a decrease in production of its parent molecule, POMC. POMC also produces beta-endorphin (BAY-ta en-DOOR-fin) which along with the enkephalins (en-KEF-ah-lins) are "the body's own morphine." Since poliovirus also damaged the brain area that produces enkephalins, both beta-endorphin and enkephalin production may be reduced in polio survivors. A reduction in the body's own morphine would help to explain why polio survivors have a nearly doubled sensitivity to pain (1).

A Model for Post-Polio and Chronic Fatigue

Taken together, these findings suggest a model for the cause of post-polio fatigue:

* Poliovirus damaged the brain activating system;

* MRI and hormonal findings suggest that damage to the brain activating system is present today in polio survivors;

* Neuropsychological testing shows impaired attention in patients with post- polio fatigue;

* Therefore, poliovirus damage to the brain's activating system may cause decreased brain activation, impair attention and generate the symptoms of post-polio fatigue.

While poliovirus damage to the brain activating system would be expected to cause the sleepiness, inattention and fatigue reported during the original polio infection, it is the recurrence of these symptoms, or their appearance decades after the acute infection, that are more difficult to explain. The emergence of fatigue decades after the acute polio may result from normal age-related changes in and loss of brain activating system neurons that had survived the acute polio infection, combined with an already decreased number of neurons as a result of the original poliovirus infection. Eventually, the loss of brain activating system neurons would decrease cortical activation, reduce attention and produce the symptoms of fatigue as polio survivors reach mid-life (1). The occurrence of these symptoms during physical or emotional stress in polio survivors may

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reflect the ability of stressors to uncover otherwise unseen damage in the brain activating system.

Is Fatigue "Hard Wired" into the Brain?

The findings presented above describe an intimate relationship between impaired attention and fatigue. However, difficulty with attention is not fatigue's only symptom. Even more disabling is the physical experience of fatigue: feelings of exhaustion, "passivity and an aversion to continued effort" that generate an aversion to both mental and physical activity. However unpleasant these feelings are in man, passivity and aversion to activity have clear survival value, especially in organisms without conscious awareness that their attention and thinking speed are impaired. For example, an animal that continues to explore its environment even though its attention is impaired would be less able to direct attention on the goal of its exploration (e.g., searching for food) and would thereby waste already diminishing energy stores. More importantly, impaired attention could also render the animal unaware of dangers in its environment (e.g., a predator stalking the animal in search of its food). Thus, there would be survival value in a brain mechanism that monitors cortical activation, biases an animal toward stopping motor behavior and promotes rest when attention and thinking speed are impaired.

The Brain "Listens" to Itself. Groups of neurons near the bottom of brain called the basal ganglia are in an ideal location to monitor the level of brain activation and stop an animal when it has too little attention to allow efficient and safe activity in its environment. All parts of the cortex connect to one of the basal ganglia, called the putamen (pew-TAY-men), which "listens" to the activity level of the brain (24). If the brain is awake enough, the putamen allows us to focus attention, to move and to act. When the brain activating system turns down, the putamen stops the cortex from allowing us to move. Damage to the putamen in animals has been shown to slow movement, while damage to another of the basal ganglia, the substantia nigra, decreases or even stops movement and prevents us from focusing attention (7).

The importance of the basal ganglia - and especially the neurotransmitter dopamine - in focusing attention and allowing us to move is most evident in patients with Parkinson's disease (PD). PD patients, whose damaged substantia nigra neurons produce too little dopamine, show not only slowed movement and an inability to focus attention but also excessive and disabling fatigue (7, 38-41). And, remember Oliver Sacks' Awakenings patients whose damaged basal ganglia caused both Parkinson's disease and "sleeping sickness."

The Brain Fatigue Generator. It appears that the basal ganglia could produce the mental and physical symptoms of both normal and pathological fatigue. In normal fatigue, a long and hard day of work would slow the firing of brain activating system neurons. This decreased activity would impair attention and information processing ability (recognized by humans as symptoms of fatigue) and produce a decrease in cortical activation that would slow the firing of putamen neurons, prevent the release learned motor behaviors and slow or stop activity (Figure 3). Humans would notice problems with focusing attention, feel an aversion to activity and would be able to move only with significant conscious effort. Animals would slow or even stop their activity. In both man and animals, rest or sleep would increase the firing of brain activating system neurons, restore cortical activation, increase the firing of putamen neurons and once again allow the release of motor behavior.

Figure 3. A model for the brain fatigue generator. Fatigue would be produced by a reduction in reticular activating system (RAS) activity that would directly decrease cortical activation, impair attention and cognition and prevent the firing of putamen neurons (dark lines). The reduction in putamen activity would then inhibit the release of motor behavior, further decrease attention and produce the visceral feelings of "exhaustion" and aversion to effort that accompany fatigue (stippled lines).

Pathological states such as chronic fatigue syndromes could be produced by viral damage to the brain activating system, putamen and/or dopamine-producing neurons. This damage would chronically reduce the firing of brain activating system and putamen neurons, decrease cortical activation and produce the symptoms of fatigue. Poliovirus would be expected to cause fatigue, impaired cortical activation and decreased attention since it damages all of these brain areas.

Clinical Implications

This description of the basal ganglia as the brain fatigue generator suggests that increasing brain levels of dopamine (the neurotransmitter that stimulates the basal ganglia) might "turn on" the brain activating system, increase cortical activation and attention, release motor behaviors and reduce the symptoms of chronic fatigue. We are currently studying the use of a drug that stimulates dopamine receptors on brain neurons to treat post-polio patients whose fatigue has not responded to the current treatments of choice, i.e., adequate rest, energy conservation, the pacing of activities and reducing physical and emotional stress (2,17,27,28). Preliminary results show that fatigue, impaired attention and difficulty staying awake during the day decrease as the dose of the drug increases.

However, there is the very real danger that taking a drug that reduces fatigue will allow polio survivors to resume their hyperactive, Type A lifestyles (as they do now when they feel better following physical, occupational and psychological therapy for PPS) and further stress poliovirus-damaged, "metabolically vulnerable" neurons in the brain and spinal cord. Decreasing "overuse abuse" will always be necessary to treat PPS, regardless of whether a drug is found that decreases the symptoms of fatigue.

It is also possible that damage to the basal ganglia and a lack of dopamine may be related to other PPS symptoms. Word finding difficulties, reported by 82% of polio survivors with fatigue, appear similar both to word finding problems reported by CFS patients and the "tip-of-the-tongue" phenomena seen in PD patients (Table 1)(1,7). And, in a study we have just completed, polio survivors with severe fatigue had low scores on a test of word finding ability - scores that

were identical to those in Parkinson' patients.

In addition, 63% of polio survivors report Generalized Random Myoclonus (GRM), the slow contraction or rapid twitching of hand, arm, trunk and leg muscles at night that disturb sleep in 33% of polio survivors (2). GRM may provide more evidence that polio survivors have a brain dopamine shortage, since GRM are similar to "periodic movements in sleep" seen in PD patients.

We continue to examine the possible role of the basal ganglia and dopamine in PPS to help identify the cause and treatment of not only post-polio fatigue, but also other PPS, CFS and to understand the neurophysiology of fatigue itself.

Acknowledgements

The authors gratefully acknowledge the participation of the subjects, the support of the Joel Leff Charitable Trust and Deluxe Corporation, the continued support of the George Ohl, Jr. Foundation, and the efforts and expertise of Mary Ann Solimine, R.N., M.L.S., without whom this work would not have been possible. We also thank Drs. Leonard Kurland and Oliver Sacks for their criticisms of the manuscript and Esther Carlton of Nichols Institute who provided the 11:00 AM norms for cortisol and ACTH.

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For more information on Post-Polio see:

http://members.aol.com/harvestctr/pps/polio.html
http://www.postpolioinfo.com/

Polio (Post) Support Group of SA Inc
Regency Park Centre Days Rd Regency Park
5010
Ph: (08) 8243 8388

New Directions for Researchers of Chronic Pain Disorders

Talking Point 2002 Issue 2: The Official Journal of the M.E./C.F.S. Society (SA) Inc

July 1, 2002

Dear Supporter

The Collaborative Pain Research Unit CPRU has been active in research into chronic fatigue and pain conditions for over 8 years. It has produced a large number of publications and instigated some major research collaborations.

The founding members included A/Professor Tim Roberts, A/Prof Hugh Dunstan, Dr Henry Butt, Dr Neil McGregor and Professor Iven Klineberg. The team has worked well together over these years, but demands and commitments have become too large to enable the pre-existing team structure to continue working effectively.

At the beginning of the year 2002, the CPRU ceased to continue operating as an active collaborative group and will no longer act as a single unit for propagating new research initiatives. The CPRU will, however, continue to publish findings from its pre-existing research projects during 2002-03.

Hugh and Tim have already initiated new research programs at the University of Newcastle into the basic science of pain and fatigue whilst Neil, Iven and Henry will continue their clinical research and pursue the commercialisation of pathology testing in Melbourne. All will continue to foster and develop links with national and international institutions.

Several exciting new projects are under way at the University of Newcastle laboratories in the field of chronic fatigue and pain research and include:

- Methods for detection of pathogens which cannot be readily cultured in the laboratory.
- The role of intracellular bacterial infections in chronic fatigue and pain conditions.
- The identification of urine markers for pain, fatigue and autism.
- The role of chlorinated products in mains water supply on gut function and integrity.
- The development of biofilm models for investigating the function of the gut micro-flora

These represent novel initiatives for pain and fatigue research at the University of Newcastle. Tim and Hugh have forged a new working group gathering more analytical expertise, known as the Molecular Structure and Detection Group and now have access to a very impressive array of analytical techniques. This has been achieved largely through some recent successes with ARC grant applications. We look forward to your continued support to help us with sustaining the research students and the development of new research initiatives.

Hugh and Tim have formed the Gideon Lang Research Foundation (GLRF) to raise funds for supporting research into chronic fatigue and pain conditions. Dianne Wisniewski has been appointed the operations manager and although in its infancy, we hope that in 2 years time the GLRF will be in a position to fund major programs in multi-disciplinary pain & fatigue research. An information brochure is attached [ED– see website www.gideonlang.com], and we would encourage you to support this initiative.

The University research team now seeks support for upgrading our PCR facility, which is the major apparatus used for identifying the intracellular pathogens in human samples and potential contaminant sources. The new equipment will greatly enhance our analytical capacity and efficiency. Our Target is $30,000 – we have so far raised $10,000 and we will be applying for equipment grants throughout the year. Any support would be very much appreciated.

Yours Sincerely

Hugh Dunstan & Tim Roberts

Associate Professor Associate professor

NOTE: The above letter was sent to the Society, as it has been a supporter of the CFS research at Newcastle University. Whilst the composition and location of teams, as well as the group titles may change, CFS research is continuing on. We wish each of these CFS researchers the very best in their future endeavors and partnerships. ED

Your Society Matters….

Meeting with Fibromyalgia SA….

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A delegation from our Management Committee recently met with their counterparts from Fibromyalgia SA. It was a good chance to for both groups to get to know each other better—to understand our goals, emphasis and business situations.

It is important that we continue to develop ties with groups that have similar focuses. We may never achieve the things we want if we work alone.

We have agreed to hold a joint meeting later in the year (see below).

Peter, Joy, Jenny, Paul, Ben, Kaye & Penny (left to right)

PUBLIC MEETING

Saturday September 14th
1:00 pm —3:00 pm
Trades Hall 11 South Tce
(Close to the West Terrace end of South Terrace)

Speakers: Liana Taylor (Psychologist)
& Kaye Kenefick (Movement Specialist)
More details to follow closer to the event

Cost $2

May 13 Awareness Evening and Expo

Peter Cahalan Introduces Expert Panel

Talking Point 2002 Issue 2: The Official Journal of the M.E./C.F.S. Society (SA) Inc

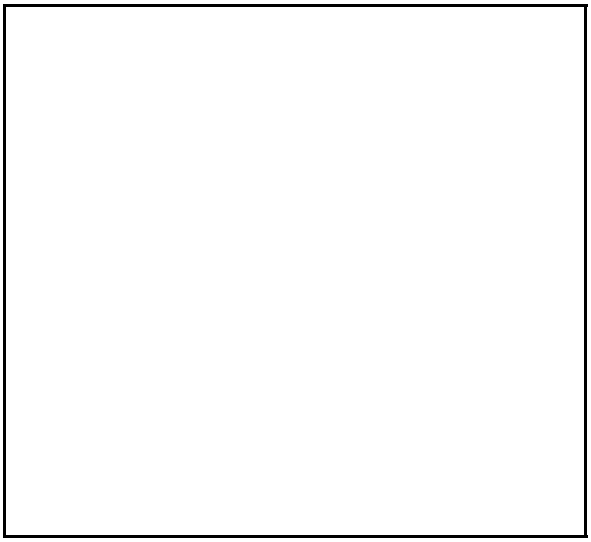
An excellent crowd of 400 jammed the Burnside Civic Centre on 13 May for the 2002 main gathering for ME/ CFS Awareness Week.

A lot of work had gone into ensuring that there'd be a good crowd on the evening. Publicity was sent to every politician in the state, as well as libraries, health centers, GPs on our mailing list and of course past and present members. We also enjoyed excellent support from Fibromyalgia SA who advertised the event through their extensive networks. Paul Leverenz spoke on radio 5RPH and Adrian Hill also appeared on the morning television show AM Adelaide. Adrian also secured community awareness spots on several radio stations. We gained excellent publicity because only a week before the Royal Australian College of Physicians had released the first-ever official guidelines for medical practitioners on treating people with CFS. Simon Molesworth spoke on several radio stations about this issue, which got our name in the spotlight. Overall this was the greatest amount of publicity which we've had for some years and it helped to draw a crowd on the night of 13 May.

ABOVE: (left to right) Her Excellency the Governor, Lieutenant Currie, Simon Molesworth, Glenn Domeika

The evening was opened by the Society's patron, Her Excellency Marjorie Jackson-Nelson, AC CVO MBE, the Governor of South Australia. The Governor joined the committee for a few minutes before the start of the meeting and told us of a friend of hers who had had chronic fatigue syndrome for some years. It was a reminder that this is an illness that has been steadily coming out from the shadows as more and more people know someone who has it. The Governor also expressed surprise at the large number of people at the meeting. After opening proceedings she then stayed for the entire meeting, which was just terrific. Since what followed was extremely informative, we can assume that we now have a patron who is not just naturally supportive of the Society but also knows a lot about the illness.

Paul Leverenz, the Society's president, followed with a brief overview of CFS. Paul is an extremely hardworking president, pushing himself hard even though he suffers from CFS himself, and is also very well briefed on the many issues – political as well as medical – surrounding the condition. So it was a typically thorough and lucid presentation complete with powerpoint slides. It was Paul, incidentally, who organised it so that the evening was filmed and projected live on to a large screen - so that no one had



Simon Molesworth, President of the National ME/CFS Association

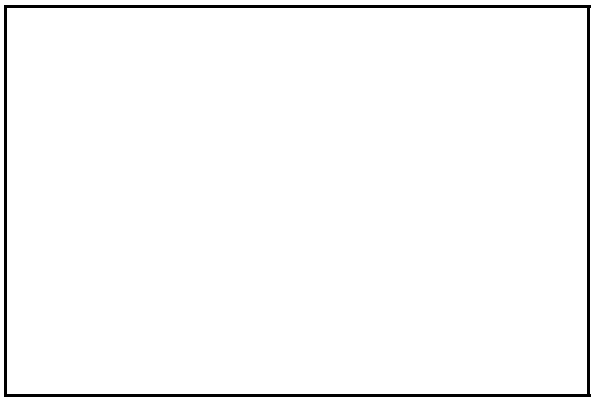
to peer at the speakers.

The keynote speaker was Simon Molesworth QC AM. Simon is an extraordinary person. He is national president of the ME/CFS Association, the umbrella body bringing together all the State and regional societies. In addition, he happens to be president of the Australian Council of National Trusts -the umbrella body for the National Trust in all states and is a nationally prominent environmental lawyer. He is also not least the father of three children, the oldest of whom has been severely affected by CFS although he is now valiantly working his way through Year 12. Simon's pretty fired up about the injustices meted out to people with CFS and has done a magnificent job of lobbying on the issue of the defective National Guidelines on CFS put out on 6 May –a bare week before the meeting –by the Royal Australian College of Physicians.

Simon's theme was that the battle to achieve breakthroughs in the diagnosis and treatment of CFS was on the way to being won. He contrasted today's situation favourably with that which he described at a national conference on CFS three years ago. He expressed optimism that medical research –including some excellent research in Adelaide –was making great strides in finding out what causes CFS. And at the political level he felt that there had been a seachange in public attitudes to the illness. The new Guidelines have serious flaws. They unduly emphasise cognitive behaviour therapy and graded exercise as treatments, thereby potentially encouraging busy GPs to think that depression and a refusal to push oneself physically are key factors in CFS as a longterm condition. But, he went on, while the Guidelines are imperfect they nonetheless represent a definitive change in the situation facing people with CFS in Australia. For the first time the condition has been accepted in a public policy document as a "real" illness. And so the fight for a better deal for CFS sufferers goes on but on a firmer basis than in the past.

The first half of the evening concluded with a four-minute video in which a range of young people with CFS spoke about how they dealt with the challenges of their lives. It was incredibly moving. Sandbark Productions, which put it together, intend to use it as a pilot for a larger documentary production which could be used as a discussion starter for support groups and other gatherings. I hope they pull it off and I'd like to thank them not only for it but also for their hard work on the evening on the sound and video systems.

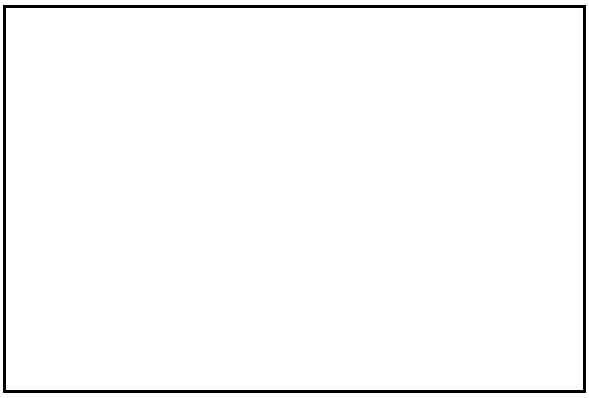
The interval was well used. People spread out in all directions to talk over coffee and visit the trade stalls. We were really pleased with the number of service providers who decided to staff stalls at the meeting. The Disability Liaison Officers from the three universities attended after gathering for a meal



Centrelink Trade Stall

beforehand. Given that the three universities have all been difficult environments for students with CFS, it was just great to have the DLOs all there learning about the condition. The Independent Living Centre stall was well attended and the staff member on duty said that she had gained an enormous amount from being there. Other groups with stalls included Disability Action, Centrelink, the ME/CFS Society and its arm for young people, SAYME.

The second half of the evening comprised a panel of speakers followed by questions from the floor. Trevor Shepherd from Disability Action detailed how DA acts as an advocate for people with disabilities. CFS sufferers have not used the service much but he outlined one case of a person who sought to be treated with DHEA. The request was met with stonewalling from the authorities -a reaction which Trevor suggested had much to do with the politics of the Olympic Games and fears about anabolic steroids.



University Support Trade Table

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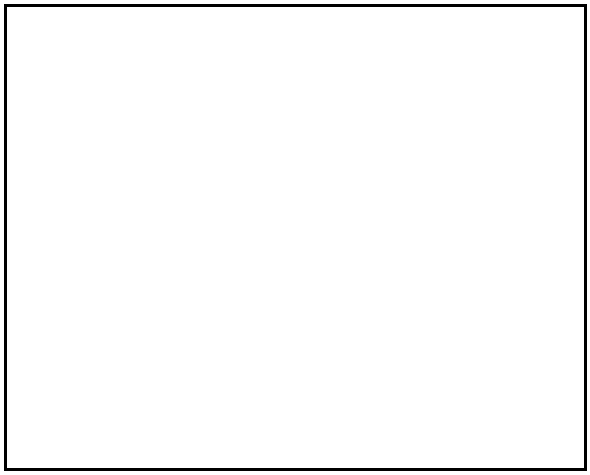
That DHEA is not an anabolic steroid didn't seem to matter! Once the Olympics were over, the request was authorised. Apparently DHEA can now be purchased over the counter –if you have a

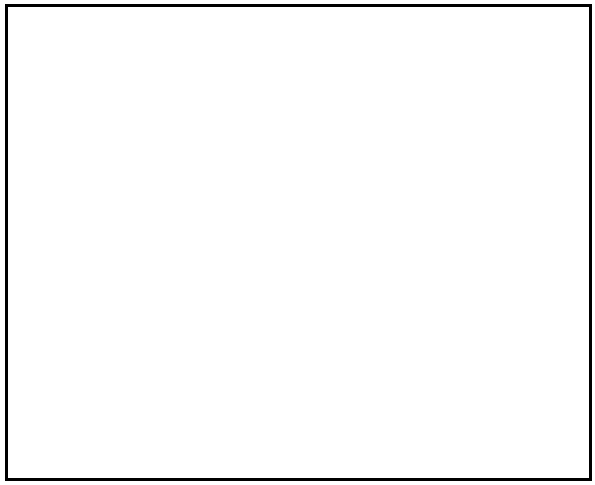


Trevor Shepherd, Disability Action

prescription –from pharmacies in Adelaide. This was one of those moments in the meeting where I found myself brought up to date. I'd last heard of DHEA several years ago when Brisbane Lions star player Alistair Lynch had been in the press for his efforts to be able to use DHEA to treat his CFS symptoms. I had no idea that DHEA could be found in Adelaide.

Psychologist Liana Taylor made an impact as someone who was both counsellor of , amongst others, people with CFS and also as someone coping with CFS and caring for a child with it. She spoke of the strategies required to deal with a longterm illness and impressed with her comment that people with CFS need – and often have-superior psychological skills to cope with the illness itself and the indifference and misunderstanding of others. She explained the value of cognitive behaviour therapy (CBT) - which in essence seeks to focus the mind on dealing realistically and without denial with whatever confronts the person. As she pointed out, everyone could use a little cognitive behaviour therapy !

[The Society is opposed to the suggestion that people with CFS psychologically maintain their illness and that CBT is needed to directly treat CFS. CBT, in the form

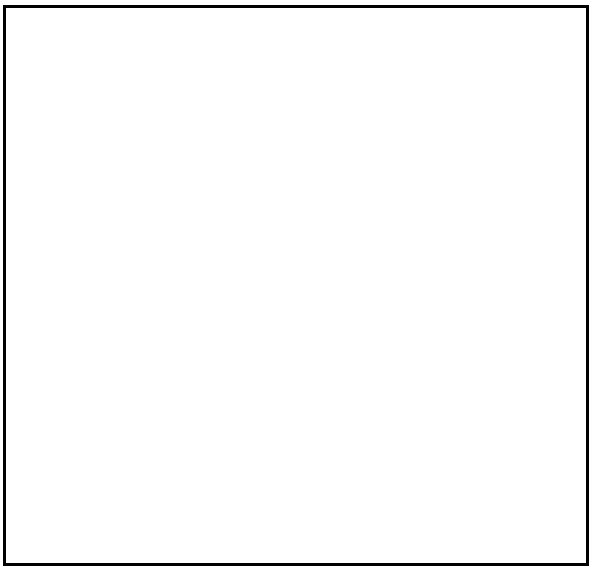


Liana Taylor, Psychologist

described above, is a broad use of the term – closer to 'supportive counseling'. It could be used to assist anyone cope better with their life situation. This is different from the CBT being advocated by various published research studies. – ED]

Dietician Melanie Reid outlined how diet can assist in coping with CFS. I found particularly helpful her list of good cookbooks to use if you need to cook healthy and low-allergy meals as part of managing food intolerances. (Listed at end)

Dr Bruce Wauchope, a general practitioner who has a number of patients with CFS, arranged widely over how GPs and sufferers can work together to deal with the condition. He encouraged patients to study up on the condition and take information to their GPs. He also stressed that GPs have to be conservative with their treatments due to legal reasons. In the case of more experimental treatments, many doctors may not feel comfortable suggesting them – but if the patient is determined and initiates the suggestion the doctor may be more receptive. [In all cases doctor's must 'do no harm' when instigating treatments, and they must

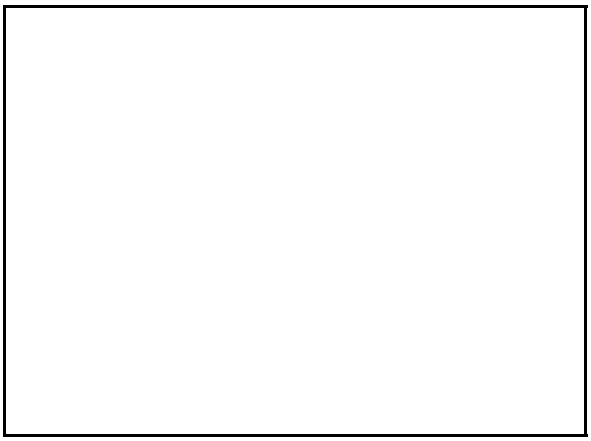


Melanie Reid, Dietician

have a basis for trying what they do.] Amongst other things On a practical note, Bruce mentioned some of his patients have found pineapple helpful with brain fog.

The evening ended on the dot of 9.45 pm, as promised. As the audience stood whilst the Governor departed, the consensus was that this had been a morale-boosting occasion for those who attended. People commented that it was good just to be with so many other people who are concerned about CFS either because they have it or are caring for people with it as loved ones, friends or professionals.

Were there any down sides to the evening? When the State Committee reviewed it two weeks later, there had been at that point only a small number of new membership applications flowing from it. When the last Awareness Evening was held three years ago, there had been a higher number –perhaps because then we did not hand out membership forms but instead asked people to sign up there and then. Next



Dr Bruce Wauchope, GP

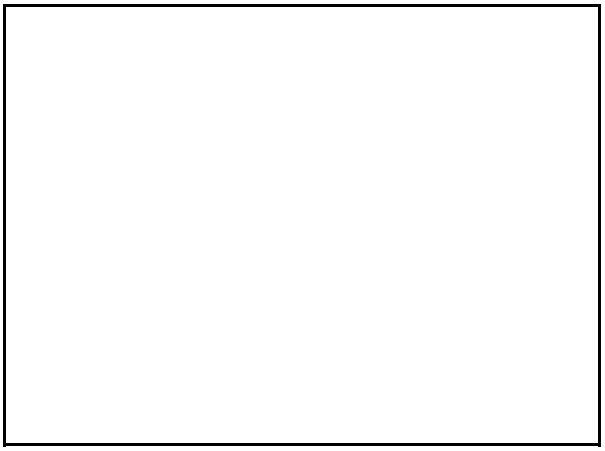
time we'll know what to do. (It should be noted that memberships have risen steadily over the last 6 months from around 250 to over 360.)

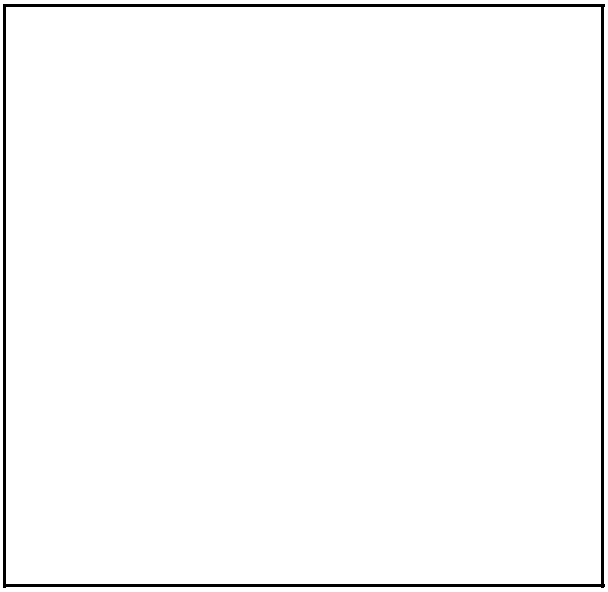
We were also disappointed at the financial contributions on the evening. There were many expenses associated with promoting the event, paying the venue costs, setting up the sound system and providing tea and coffee. So it was disappointing to hear of people walking through without paying a gold coin donation as requested. In one case, a person put a 20 cent coin in the tin and the person behind them went through without paying saying, "I'm with them". Lousy, is all one can say. Fortunately, a timely and generous donation from the Commonwealth Bank allowed us to underwrite our expenses. The Committee reluctantly has decided that in future there will be a stricter enforcement of entry fees – we will have to move from the polite request for a 'gold coin donation' to a set entry fee. The financial position of the Society demands that we recover our basic costs from these meetings. But these were small things against the many pluses from the event.

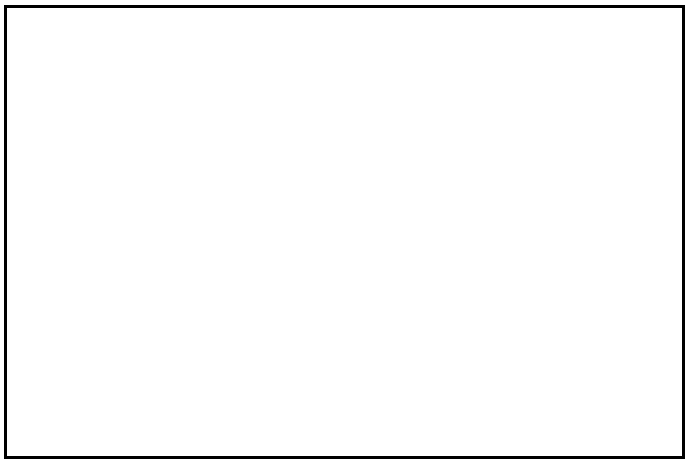
The Society has not held a meeting like this for several years and the attendance suggested that there's a real demand for such meetings. It's true that several people there commented that they had heard much of it before. But many of those in the audience were not members of the Society and had never been to such a meeting before and it was for them especially that the night was designed. Even so, for plenty of others with more than enough experience of attending meetings and seminars about CFS, there were nuggets of information and new insights. For example, I found myself thinking, as I listened to the panelists, that one goes through cycles of determinedly seeking answers and then settling down with a mix of solutions – medications, naturopathic remedies, a particular medico – and perhaps then missing out on some good ideas from elsewhere.

So it was a valuable experience for most people. And it was a powerful political moment for the Society and for everyone coping with CFS in South Australia. Our thanks to Simon Molesworth for making time in a very crowded schedule to be in Adelaide for the meeting and to all the speakers. Thanks also to Paul Leverenz, Adrian Hill and all those who helped them to make it an outstanding success.

Peter Cahalan







ABOVE LEFT: Her Excellency the Governor and Paul Leverenz
LEFT: Post Polio Association Trade Stall
ABOVE: ME/CFS Society (SA) Inc. Trading Table

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Video: May 13th Awareness Evening and Expo

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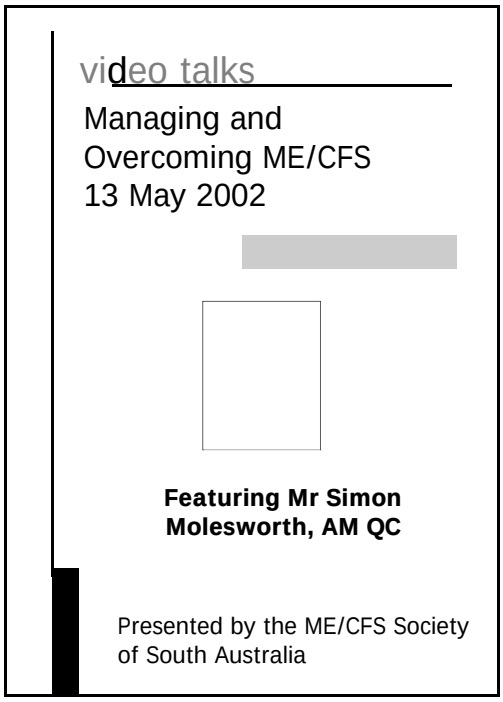

Couldn't make it to the Awareness Evening and Expo?

Purchase a Video

Videos: $25 including postage and handling

Suggested Reading

The Royal Prince Alfred Hospital
Professional advice- allery@immu.rpa.cs.nsw.gov.au
Or phone 02 9515 8244
Fax 02 9515 8420

Books
Simplified Elimination Diet—Ring the hospital for avaialability

Friendly Food - Avoiding Allergies, Additives and Problem Chemicals By Dr A R Swain, Dr V L Soutter, Dr R H Loblay (Royal Prince Alfred Hospital). 112pp Full colour. ISBN 1740451791

- **Dr Joan Breakey (dietitian)**
  Book –Are you food sensitive? " How to investigate your own diet"
  ISBN 0-646-35440
  Buy direct from author $22.00
  Fax 07 5496 8194
  Phone 07 5490 8207

- **Allergy/food intolerance website-**
  http:// users.bigpond.net.au/allergydietitian

- **Sue Dengate** (mother, teacher and activist extraordinaire)
  Books- Different Kids, Fed Up, The Failsafe Cookbook
  Failsafe email support group – failsafe-subscribe@yahoogroups.com
  Failsafe newsletter – www.ozemail.com.au/-sdengate

- **Figleaf, National Newsletter for the Food Intolerance Group**
  Susan Bridgeman, editor,
  ph (02) 6968 1212
  figleaf@dragnet.com.au

Badge Day, May 31st, CBD

Peter Cahalan and I arrived in town at 7.00am to set up for our badge day. We had to share with another worthy charity, the Cranial Facial Unit. Our collectors arrived at 7.30am and began collecting on the west side of town in the morning, then the east side of town in the afternoon. The day was successful considering that we had to share with another group and the weather was not the most accommodating for our collectors.

Last year, the badge day collections amassed $300. This year we have collected almost $4000. The improvement is largely due to our great collectors and more of them. They worked very hard and volunteered their time for a great cause. The society want to thank the amazing efforts that all of our collectors and money counters put into this day. This is only the beginning of our fund raising efforts. We will be targeting shopping centres and then country towns in the next few months and we hope to raise another $10,000. This money is very important for the life of the society that helps support sufferers of CFS.

Adrian Hill

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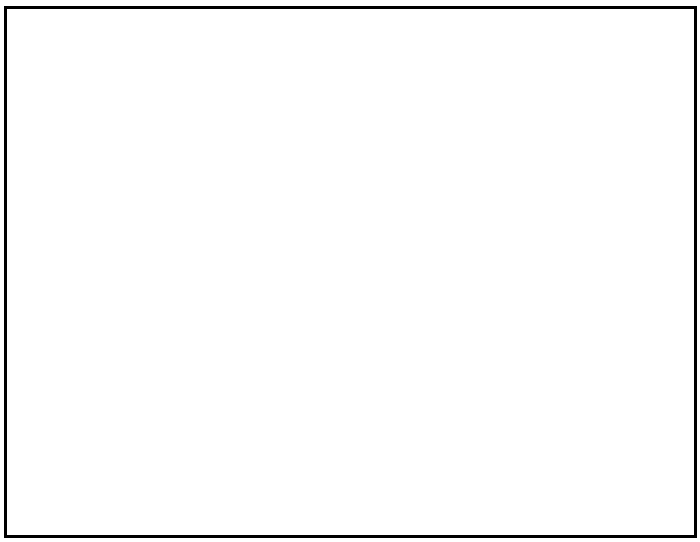
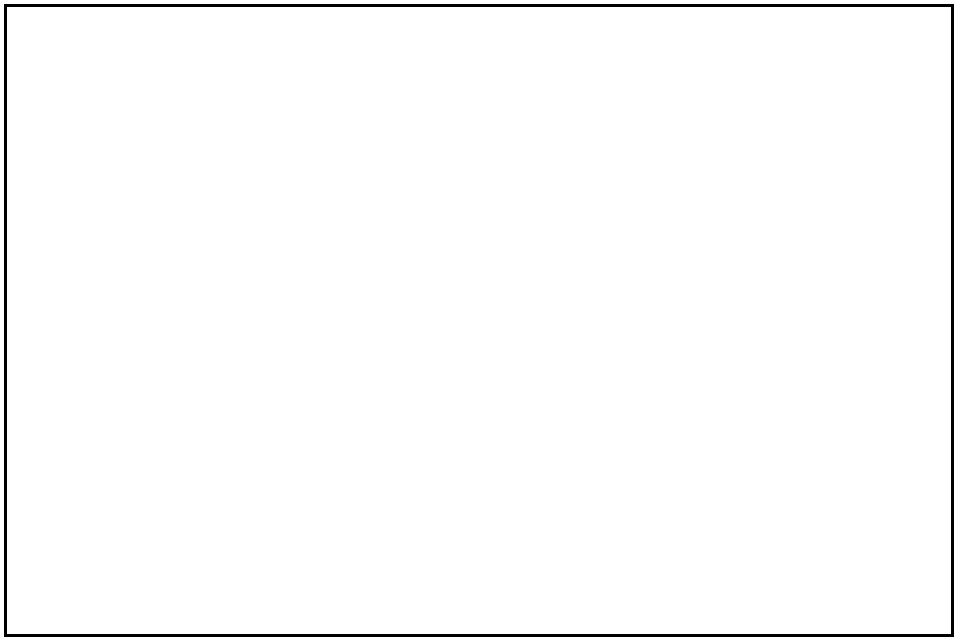
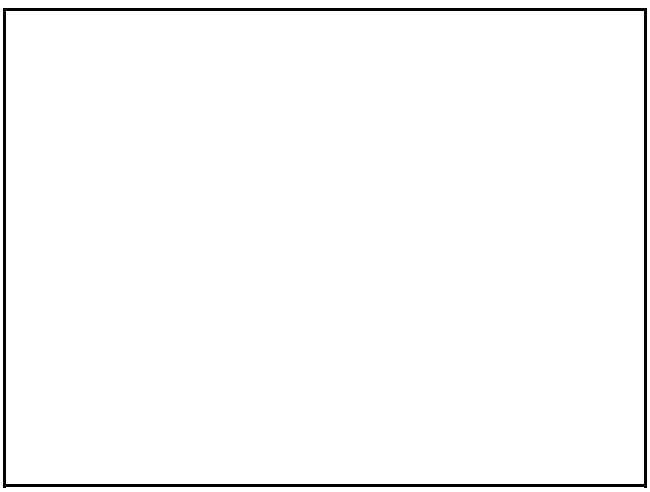
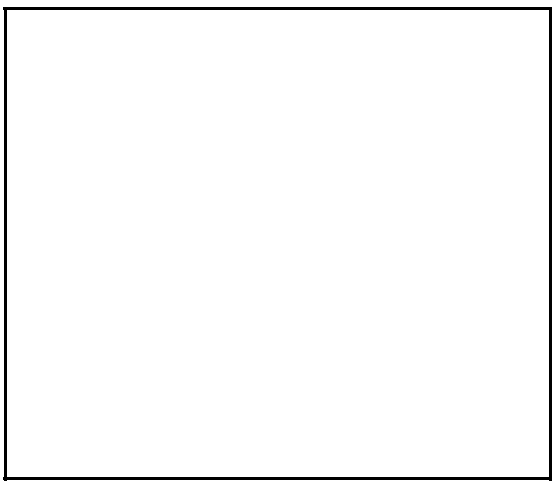
Badge Day, May 31st

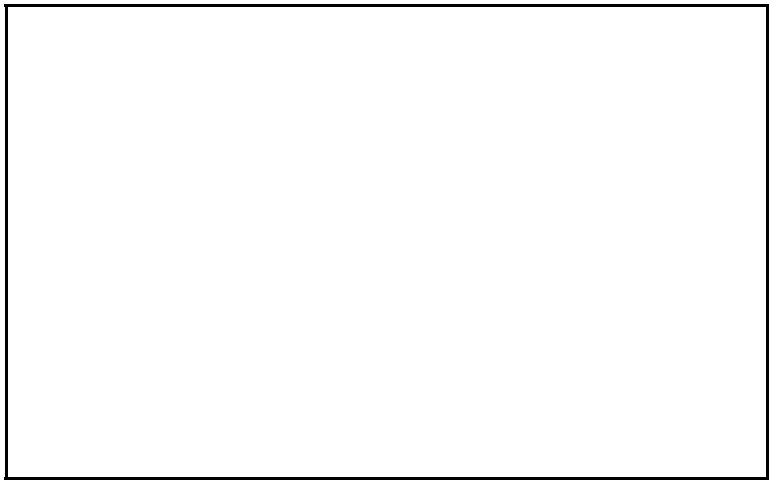


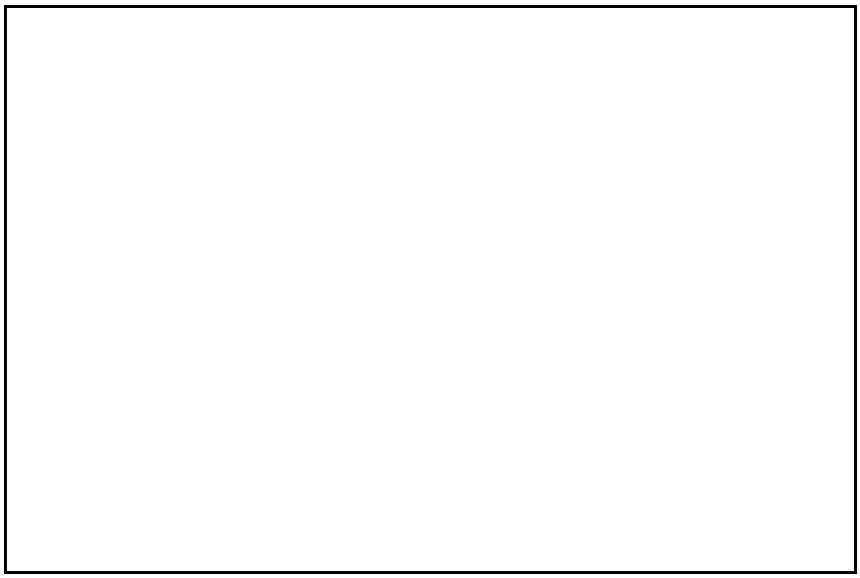


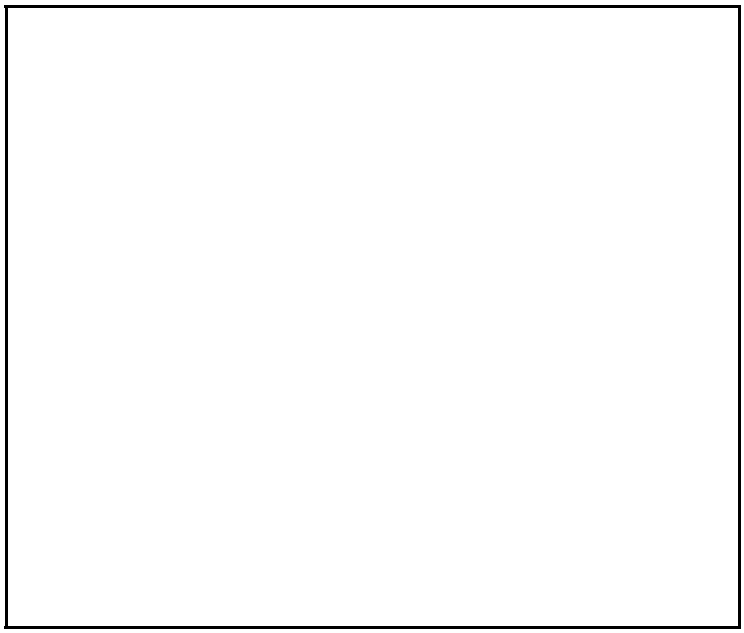




Badge Day, May 31st







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Badge Day, May 31st
Burnside Village Shopping Centre

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Collectors Needed

We are off to a great start with our fund raising following our badge day in town. Now we are focussing our efforts in shopping centres and the country regions.

Please let Adrian know if you can help in any way.

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People Profile: Peter Worsley

Allow me to introduce myself. My name is Peter Worsley, and I would like tell you a little about myself, as I am becoming more and more involved with the Chronic Fatigue Society. I am 23 years old and I have battled with CFS since I contracted glandular fever when I was 11. I have been a financial member of the society for two or three years, but I have only recently started devoting some of my time to supporting this organisation which has supported me since I joined. At present, I divide my time between helping the CFS Society and studying part-time at the Adelaide Hospitality and Tourism School in the city.

For the last few months, I have been helping in the office and I recently helped out with the awareness evening and badge day, however my main interest lies in developing the youth group (SAYME) with Elizabeth Cahalan and Rebecca Cordingley. Liz and Bec have been doing a wonderful job producing a quarterly magazine and keeping the support group going. The youth group is my main interest because I understand how important it is to provide support and understanding to young people who suffer from any illness, whether it be CFS or anything else. With the initial onset of symptoms it is very difficult not to begin a negative and destructive thought process. I had a difficult time accepting what was happening to me and found myself feeling alone and scared most of the time. I really do not want others to experience similar feelings when there is no need to go through this alone.

Personally, I have benefited greatly from participating in the monthly get-togethers. It is an enormous relief to meet people who understand what I am going through. We are also developing an older group, (20 years and over) that can meet occasionally for similar reasons. If you are interested in meeting some wonderful people and engaging in some 'scintillating' conversation, please let me know.

I am now on the Management Committee, and am able to provide a voice for SAYME and any ideas or concerns can be directed to me via the office or by email: elpedro78_@hotmail.com. If anyone feels that they can help support our youth in any way or if you need someone to talk to for any reason, please don't hesitate to call me via the office: 8410 8929.

Member Request

Can someone provide discount or free guitar lessons to a ME/CFS Society of SA member, who is living in South Plympton? Due to health difficulties and financial constraints associated with the illness this member has had to give up her previous guitar tuition. If you think you may be able to help out, please call the Society office. 8410 8929

Items Available from the Society

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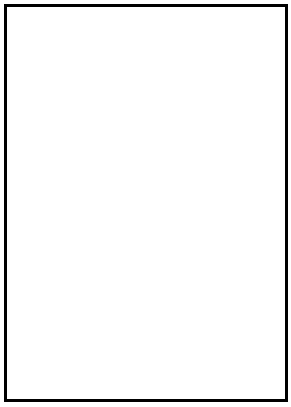
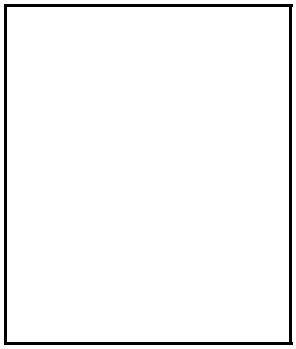
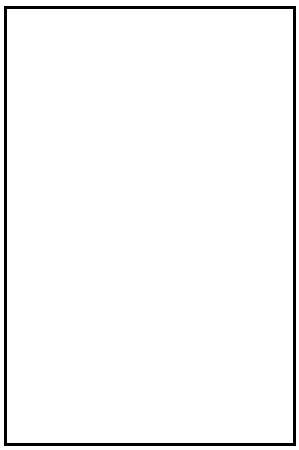
Stock Clearance:
We have Efamol Marine Oil $22 per bottle—or 3 for $60 (GST Included)
Pickup from Office



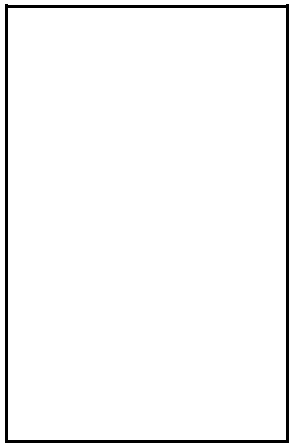
Lapel Pins $2 each (pins are blue with yellow edging)



RED by Stephanie McCarthy
Special Price: $12 (GST included) + $2 P&H

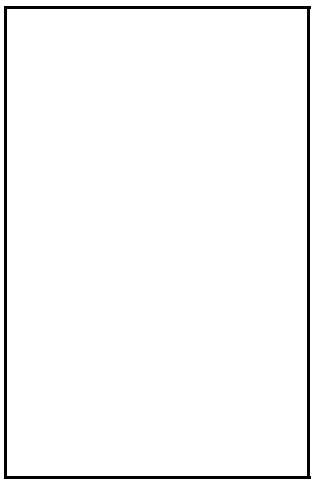


The Doctor's Guide to Chronic Fatigue Syndrome $24.00 (inc. GST) + $3.00 Postage and Handling

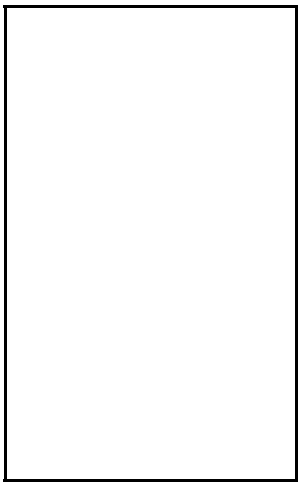


Video & Audio Tapes

Video Duration 104 mins



Video Duration 96 mins



Special Price: $16.50 (GST included) + $3.50 P&H
Audio Tapes: $4.40 (GST included) + $2.60 P&H

Out and About

Not an original heading I know...but worthy of a thought...
I know that for many of us who are carers and or who have CFS, there are often restrictions on places where we can safely venture for shopping and outings.

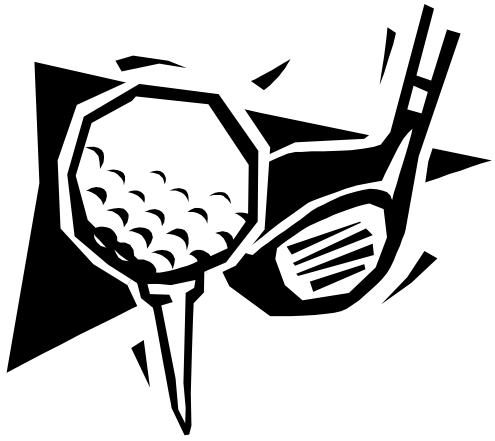
Often, we tend to think of all of the things we can't do (and heaps of others seem to be able to do), and the list is admittedly rather long. However, I thought it might be a good idea for us to share some ideas on places we are able to enjoy, and which have a combination of essential factors.

Some of these essential factors might include

- **Locality** - Nearness to traffic, amount of area pollution, seasonal plants which create allergies etc
- **Accessibility** – parking, public transport
- **Interior** – carpets, air conditioning, fresh air, non-smoking policy, seating space-distance between tables in restaurants etc.
- **Activities** – Flexibility, transferable (to another day), range of foods (for allergies to dairy, wheat etc).
- **Cost**

The experience that has motivated me to start the ball rolling, with the out and about idea, is when I recently visited a putt-putt golf range with my family.

Over the years we have tried most of the ranges in Adelaide and been pretty disappointed with their presentation, up-keep and cleanliness, accessibility and skill level. The value of putt-putt golf is that it is low intensity, flexible – you can go when you are up to it and the cost is not exorbitant. It is a good family activity and the **kids can easily beat the adults** – (eleven shots per hole is **not** a record to be envied).



West Beach Mini Golf PH: (08) 8353 0335

- Locality – situated off Military Road West Beach, between the sand hills and the golf course. . No nearby industries. Can have sea breezes – so pick your day. Situated near the West Beach Caravan Park and Woolshed.
- Accessibility - Parking is easy, and there is a bus along military road nearby
- Interior- Very clean, outdoors seating area where drafts boards etc on tables, and seating are on the north facing sheltered side. Course is immaculate and well maintained.
- Activities – different size putt-putt golf sticks. 18 holes, with interesting formats. It took 3 of us about an hour to go around – bear in mind the range from 1 – eleven shots per hole. Special kids menus and party deals, and adult's special meal and game prices.
- Cost: Children under 11 years ($5) per game Children 12-17 years ($6) per game and adults ($7) per game- includes stick hire and gst.

Note: - doesn't have a no-smoking policy, but managers said they rarely ever get smokers and don't smoke themselves. The only place people can smoke is under the pergola and they would be prepared in the instance of people who can't tolerate smoke to set up an area the other side of the building for would-be smokers. In a group situation it would probably be possible to negotiate for all smokers to be off the premises – near the car park

PLEASE LET MANAGERS KNOW IN ADVANCE IF YOUR REQUIRE SPECIAL CONSIDERATIONS.

If you do decide to trial this can you let us know, so that we may be able to use that information to negotiate future discounts etc?

If you have a special outing venue suitable for families and kids could you let us know so that we may do a preview. We are also looking at lower-allergy accessible shopping centers, as well as restaurants and coffee places.

CONTACT SUE HEARD: petersue@senet.com.au

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Recipe Corner

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PUMPKIN AND PARSNIP SOUP

Serves 4-6

This is a delicious soup and easy to make. It can be served with a bowl of natural yoghurt for people to add for themselves.

Ingredients

1 dessertspoon canola oil
1 white onion, chopped
2 cloves garlic, peeled and chopped
¼ of a Kent or Jap pumpkin, peeled and diced
6 parsnips, peeled and sliced
2 litres chicken stock
Coriander, parsley or chives to sprinkle.

Method

- Heat oil in a 4-litre saucepan.
- Add onion and garlic and cook until transparent.
- Add pumpkin, parsnips and chicken stock.
- Cook (boiling gently) for 20 minutes or until vegetables are soft.
- Blend.
- Sprinkle with chopped coriander, parsley or chives.

Serve with yoghurt if liked.

CHEESY VEGETABLES

You can use any vegetables you have available. Topped with cottage or ricotta cheese, cashew butter or hoummous this makes a delicious and easy meal.

Ingredients

Potatoes
Carrots
Sweet potato
Parsnip
Beans
Pumpkin
Peas
Cabbage
Parsley
Ricotta cheese, cottage cheese, hoummous or cashew butter.

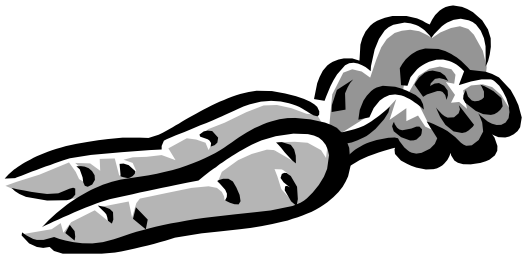
Method

- Cut peeled carrots, sweet potato, parsnip and potatoes into 2cm cubes or chunks. (leave potatoes unpeeled if you prefer)
- Peel and cube pumpkin.
- Cut beans into 2cm lengths, and cabbage into approx. 2cm squares.
- Cook vegetables in a little water in the microwave – carrots, sweet potato, parsnips, potatoes and beans first, then pumpkin and last of all cabbage and peas together.
- Pile into a serving dish and sprinkle with parsley.
- Serve with a bowl of cottage or ricotta cheese for topping.

Note: you can mix hoummous with the cheese for extra flavour and protein. If you don't eat dairy products you can just top the vegetables with hoummous or cashew butter.

Cashew butter:

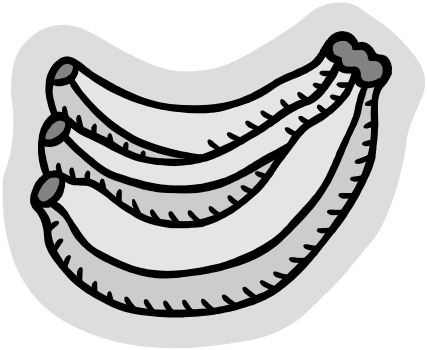
Blend raw cashew nuts with enough canola oil to make a smooth paste. Mix 1 heaped tablespoon of the per person with enough water to make a pouring consistency to serve with vegetables.



FRUIT SMOOTHIES

Serves 1

Smoothies are a delicious snack or easy breakfast and could have milk, soya milk, buttermilk, rice milk, apple or pear juice, water or mineral water as a base.



Ingredients

250ml low fat milk, soya milk, or liquid of your choice
1 small banana, cut into pieces
1 teaspoon vanilla essence

Method

Place all ingredients in a blender and blend until smooth.

Optional flavours to add:

A small nectarine, peach, apricot or mango
Yoghurt
Stewed pears
Stewed apples
A tablespoon rice bran
Canned fruit – peaches, pears, apricots, apples.

FRUIT CRUMBLE

Serves 4

This is an easy, wheat-free version of an old favourite.

Ingredients

Stewed apricots, apples, pears, nectarines or a combination of fruits – eg.
apples and a few strawberries, pears and apples.

Topping ingredients

2 tablespoons rice flour
2 tablespoons rolled oats
2 tablespoons chopped raw cashew nuts
½ teaspoon cinnamon
2 tablespoons canola oil
1 dessertspoon apple or pear concentrate to sweeten (optional)
or 2 dessertspoons sugar

Method

- Mix flour, rolled oats, cashew nuts and cinnamon together.
- Add canola oil and fruit concentrate or sugar and stir through.
- Place fruit in pie dish and sprinkle with crumble mixture.
- Bake in a moderate oven (200C) for 20 minutes or until topping is lightly browned.

Serve with yoghurt, custard or ice cream.

Thanks to Margaret Jackson for supplying these recipes.

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SUPPORT GROUPS: METRO

Adelaide Support Group
4th Tuesday of the month
Venue: ME/CFS Society Office, Room 510, 5th Floor Epworth Building, 33 Pirie St Adelaide
Time: 12:00 pm – 2:00 pm
Best policy is to ring Support Line a few days before to confirm details.

Glenelg Support Group
3rd Wed of the month
Usual Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg
Time: 1 pm
Please ring the Support and Information Line to confirm details: **8410 8930**.

North Eastern Social Group: 'Better Together'
2nd Wednesday of each month
Location: Hope Valley
Time: 1:30 pm – 3:00 pm
Phone: Pat on 8264 9328 or Julie on 8264 0607

It is good practice to call the information and Support Line for Confirmation: 8410 8930 OR 1800 136 626

SUPPORT GROUPS: COUNTRY

Northern Yorke Peninsula CFS Support Group
Venue: Community Health Centre Wallaroo
Phone: Jane 8826 2097

Southern Fleurieu Support Group
2nd Thursday alternate months
April, June, Aug, Dec
Phone: Melanie Stratil (Dietician) **8552 0600** for venue details.

NEW:
Central Yorke Peninsula Support group
First meeting is to be held on the Tuesday 9th July 2002 from 1.30pm - 3.30pm
Carer Support Yorke Peninsula, 48 Elizabeth Street Maitland SA
Phone: Caroline 88374335

It is wise for newcomers to phone and confirm meeting times as the regularity of events does change according to demand.

SUPPORT CONTACTS

SA Support Groups		
Adelaide City	Support and Info Line	8410 8930
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600
Misc. Support Contacts		
SAYME	Peter	0500523500
SAYME Parents	Marg	8276 5353
Country Support Contacts		
Barossa Valley	Dennis	8563 2976
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Ros	8588 2583
Northern Yorke Peninsula	Jane	8826 2097
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yunta	Gloria	8650 5938

Murray Bridge Group
The Murray Bridge group has been scaled back— there will now just be the occasional special meeting.
Please ring for event times—or to register your interest.
(Next event time not available at time of publication)
Phone: Fran McFaull (Dietician) **8535 6800**

YOUTH SUPPORT GROUP: South Australian Youth with ME/ CFS (SAYME)

SAYME meetings are actually 2 meetings in one – one for youth, one for parents. Two separate rooms are provided at each venue – one for each of these groups to chat away independently of the other.

Meetings Each Month. Please call the Information and Support Line for more details or 0500 523 500

WHAT IS ME/CFS?

(M.E.) 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 Dec. 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; unrefreshing 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 & 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 0.3 to 2.5% or even higher. These studies use different criteria for defining ME/CFS and consequently arrive at widely differing results.

A reasonable[1] figure for the prevalence of ME/CFS is 0.3—0.7% of the population. From these figures we expect that 3000—10 500 people in South Australia have ME/CFS.

1. RACP, 2nd Draft Guidelines for ME/CFS

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ME & You, ME/CFS Society of NSW Inc., Royal South Sydney Community Health Complex Joynton Ave., Zetland. NSW 2017.
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, Hight Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.

If undeliverable return to:
ME/CFS Society (S.A.) Inc.
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