Talking Pond

Issue 1 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.

Medical Advisor

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

Membership

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):

New Members:

Single membership……	$32
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Professional……..	$40
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(Family membership is designed for families with more than one sufferer, or more than one person who will directly benefit from the membership at the same place of residence. Family Concession applies when the main breadwinners are concession card holders.)

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Deadline for Next Issue
June 10th 2002

Management Committee 2001/2002

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

President: Paul Leverenz
Secretary: Penny Cahalan
Treasurer: Geoff Wilson
Management Committee Members:
Margaret Wing, Peter Evans, Peter Cahalan, Kirsty Cordingley, Glenn Domeika and Adrian Hill.

Contact Details

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

Note: It is our policy to ignore anonymous correspondence.

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.

Office

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

At the time of printing the office hours are:
Monday, Tuesday & Thursday 10 am 3 pm.
(Subject to Volunteer Availability)

Our email address is: sacfs@sacfs.asn.au

EDITORIAL

Hi,

We hope this edition of Talking Point finds you in good spirits. This year promises a lot and we are looking forward to what it will bring.

A lot has been happening in the CFS-world as you will soon discover.

The release of a Report into CFS/ME in the UK dominates the first section of this edition.

Please take note of the upcoming events in May—you'll want to put them in your diary now.

We are pleased that the amount of material being sent in to us is increasing. Your contributions are welcome and go to make Talking Point—'our journal'.

Thanks to Brian Caire and Margaret Jackson who have made significant contributions to this edition.

Enjoy reading!

Regards,

Paul Leverenz
Farrah Tate
Editors

For those of you who don't know the Editors:
Farrah Tate is completing her Masters in Nutrition and Dietetics at Flinders Uni this year.

Paul Leverenz spends most of his energy on his work with the Society.

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Introduction

This year is shaping up to be big and exciting. The Management Committee is quite optimistic about our upcoming Awareness Week and Badge Day we expect to improve our membership numbers and financial position.

For those of you relatively new to the organisation, have a look in the Society Section where the significance of May 12th is explained; you will find full details of our Awareness Evening and Expo (May 13th) and Badge Day (May 31st).

You will also find enclosed a flyer for the Awareness Evening. Please pass it along to anyone who isn't a member or put it in your local supermarket window!

Patron

We are pleased to announce that Her Excellency the Governor of South Australia, Marjorie Jackson-Nelson, AC, CVO, MBE, has accepted our invitation to be our Patron. We look forward to her assistance her first duty will be to open the May 13th *Awareness Evening and Expo*.

Commonwealth Bank

We cannot thank the Commonwealth Bank enough for a donation of $3000 to assist us with our Awareness projects this May. Without this sort of support we would be unable to put on events of this scale.

Sunshine Foundation

It was a pleasant surprise to receive a cheque for $2, 870 from the Sunshine Foundation. This was in response to a grant application submitted back in December.

The money has been given to evaluate the effectiveness of the Stanford Chronic Illness Self-Management Course on people with CFS.

Royal & Sunalliance Foundation

One of our members, Peter Heading, applied to his employer to make a donation to the Society. We thank the Royal & Sunalliance Foundation for their kind gift of $1000.

Office

Going into the 'Awareness Week Period' we are extending our office hours. For a trial period we will be opening on Mondays. Our hours are now: Monday, Tuesday & Thursday from 10 am 3 pm.

I will stress that opening hours are dependent on volunteer availability, and there are the odd unfortunate occasions when we cannot meet these commitments. I suggest it wise to ring before coming in just to make sure.

Badge Day

Our Badge Day fundraiser is going to be great - Our target is $6000. The thing I'd like to stress is that little amounts add up. If you can help out in any of the ways we have suggested, then let us know.

Tracey Ash

Last but not least…. It was very sad to hear of the death of Tracey Ash. She was a wonderfully bright and bubbly person. It is a tragedy that CFS prevented her from fulfilling her dreams. It reminds us all of the absolute pain and isolation this condition can bring to us at different times yet others endure it 24 hrs a day. It is time we lobbied hard for better care for the really sick who are so often forgotten. See page 37 for more about Tracey and the Fund that is being set up in her name.

Conclusion

The Management Committee is excited about this year. We hope you can share in our enthusiasm and are encouraged by some of the progress we have made.

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.

Letters to the Editor

Dear Talking Point Editors,

In response to your request for experiences of activities that members find therapeutic and beneficial I would like to convey the positive effect Tai Chi has had on my condition and life in general.

Firstly, let me state clearly: IT IS NOT A CURE for CFS. I still have CFS but to a much lesser extent than when I began Tai Chi six years ago.

Tai Chi is a low impact exercise combining slow, controlled movements with deep breathing, which results in a relaxed, meditative state. Apart from being great for combating stress (and most CFS sufferers are aware of the negative impact stress has on their condition), in the longer term Tai Chi improves muscle tone, balance, coordination and posture.

However, I am the first to concede that not everyone with CFS would be up to attending a Tai Chi class of 1 hour or more. A set of simpler breathing exercises based on Tai Chi principles called Chi Kung (also Qigong) may be a more realistic goal fur some. These take about 20 minutes, and are performed standing up but can be modified to be done sitting down.

An instructor who understands and is sympathetic to your condition is a must. It was necessary for me to sit down halfway through class many times in the beginning, and of course some weeks I could not attend class at all. Thus, if possible negotiate with the instructor to pay on a class by class basis instead of a whole term fee upfront.

As I'm sure most sufferers can relate to, it was a 2 steps forward, 1 step back process to learn Tai Chi but I didn't give up and the long term benefits have validated my persistence. I was fortunate to have two very understanding instructors in Victor Harbor and gained some wonderful new friends as a bonus. The whole experience has also impacted positively on my self-esteem, which had taken a dive after coming down with CFS and having to give up work, sport etc.

Any members with any general questions about Tai Chi may contact me on (08) 8552 5152 (Victor Harbor). Best wishes to all members and thankyou to the Talking Point team for this marvellous journal.

Heather Gormlie.

News Release
CFIDS Association: Immunological symposium consensus statement

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Media Alert: 14/12/2001

Below is the text of a news release about The CFIDS Association's research symposium on the immunological aspects of CFS. An expert panel of researchers convened for two days of intense discussions aimed at exploring the evidence, outlining the limits of current knowledge and seeking to improve and accelerate future research. The result was a statement that addresses key questions about the immunology of CFS.

The statement will be submitted to a peer-reviewed scientific publication to communicate the findings and opportunities in CFS research and encourage researchers to bring their knowledge and interests to bear in this area. To preserve the ability to publish the statement in the medical literature, it is not yet available for distribution.

The symposium has already been covered by several news outlets, including Reuter's Health. The CFIDS Association continues to pitch the results of the symposium to the media, and will inform you of additional coverage.

Renee Brehio
Director of Communications
The CFIDS Association of America

Immune System Dysfunction May Play a Key Role In Chronic Fatigue Syndrome

Scientific panel evaluates research findings, calls for more collaboration

Bethesda, Md.--Research on the immune system could shed light on the cause of chronic fatigue syndrome (CFS), including whether a pathogenic agent such as a virus or bacteria is involved. This was one conclusion reached by a panel of experts that convened in October for the third in a series of scientific symposia on CFS. The symposium was sponsored by The Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) Association of America, the U.S. Centers for Disease Control and Prevention (CDC) and the National Institutes of Health Office of Research on Women's Health (ORWH).

A number of studies have suggested involvement of the immune system in CFS. New findings include the discovery of autoantibodies in CFS patients, which has led to increased speculation that the illness may be an autoimmune disorder. Because many cases of CFS begin with a flu or mono-like illness, viruses, bacteria and toxins have also been studied as possible causes. "The immune system may provide important clues to CFS, but it cannot be studied in isolation," said Kimberly Kenney, President & CEO of The CFIDS Association of America. "A new emphasis on multidisciplinary research to explore links between the immune, neuroendocrine and cardiovascular systems in CFS is crucial to developing a better understanding of this complex illness."

Following a day of presentations by experts from around the world, an independent panel composed of researchers and practitioners in many fields, including biostatistics, endocrinology, immunology, infectious disease, internal medicine, microbiology, psychiatry and rheumatology, developed a statement on the key issues surrounding the role of the immune system in CFS.

The panel agreed that:

- The immune system is involved in CFS. There has been substantial published evidence that a large proportion of CFS patients have immunological abnormalities, including increased natural killer cell activity, increased number or activated T cells, decreased lymphocyte stimulation and increased production of some pro-inflammatory cytokines, which act as chemical messengers between cells. The panel noted that the ability to understand the exact role these changes play in the development of CFS is constrained by major limitations in the studies conducted to date.

- Infections may also play a role. The panel concluded that direct and indirect evidence points to the involvement of active viral or bacterial infections in the development of some cases of CFS, although no single agent has been found in all patients. For example, studies have found persistent activity of Epstein-Barr virus and/or human herpesvirus 6 in up to 30% of CFS patients.

- CFS is a multisystem disorder. In addition to the immune system, the endocrine and autonomic nervous systems may be implicated in CFS. There is some evidence that CFS is associated with underactivity of the hypothalamic-pituitary-adrenal axis, which could explain findings of upregulation of the immune system and an

increase in circulating cytokines. Reproductive hormones may also influence cytokine production and help account for clear differences in gender prevalence in CFS. The panel acknowledged that little is known about the influence of the immune or endocrine systems on autonomic function in individuals with the illness.

- Experimental models for CFS exist. The panel noted that some viral infections appear to trigger CFS-like symptoms and could be used as models for the study of immune dysfunction in CFS. Epstein-Barr virus (EBV) has been the best-studied experimental model to date. Other infectious agents that may serve as models include cytomegalovirus, Ross River virus, Q Fever and the newly described JHK virus. Abnormal levels of several cytokines have been associated with CFS, and the panel suggested changes in response to therapeutic administration of cytokines might provide another useful research model.

- More research is needed to define the immunological aspects of CFS. The panel outlined future research needs, including multiple site, longitudinal studies to: explore the possible association of infectious agents with the immunological profile seen in CFS; link immunological findings to symptoms and functional disability; and explore the use of anti-inflammatory cytokines, antivirals, antibiotics and immunomodulatory agents in the treatment of CFS. Panelists also suggested ways to overcome research barriers, such as establishing standardized methodology to differentiate between latent infections normally present in most individuals and those that are more frequently activated and associated with CFS symptoms.

The CFS assessment symposia series is designed to examine the role of the neurological, endocrine, circulatory and immune systems in CFS. The symposia gather experts to evaluate research findings, identify the most promising next steps for research, define research and funding priorities and create research collaborative teams.

The CFIDS Association of America, which developed the symposia series, is the nation's leading organization working to conquer this illness. Since 1987, the Association has invested nearly $12 million in education, public policy and research programs in its efforts to bring an end to the suffering caused by CFS.

The CDC protects people's health and safety by preventing and controlling diseases and injuries, provides credible information on critical health issues and promotes healthy living through strong partnerships with local, national and international organizations. The agency conducts a CFS research program under the auspices of the National Center for Infectious Diseases.

The ORWH promotes, stimulates and supports efforts to improve the health of women through biomedical and behavioral research. ORWH works in partnership with the NIH institutes and centers to ensure that women's health research is part of the scientific framework at NIH and throughout the scientific community.

CFS, also called chronic fatigue and immune dysfunction syndrome (CFIDS), is a debilitating and complex disorder characterized by profound fatigue, pain and cognitive problems that are not improved by bed rest and may be worsened by physical or mental activity. For more information, call 1-800-442-3437 or visit www.cfids.org.

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Special Feature

Guidelines Released by UK Chief Medical Officer

January 2002

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Items on UK Report

- Commentary / Summary by Moira Smith
- Statement by *Action for ME*
- Statement by *ME Association*
- Chronic fatigue syndrome: a step towards agreement (Several Authors)
- BMJ: Editorial Simon Strauss
- BMJ: letter by Lynn Eaton
- Response to BMJ by *25% Severe ME Group*
- Newspaper Article: Trevor Wainwright

It is our desire to present a series of commentaries, overviews and opinions on the recently released UK Guidelines. These guidelines are important - they represent a major step forward. This is not to say they are ideal they are far from it. But given the say Psychiatrists have had on UK CFS, it should be seen as the first step forward in a long journey to come.

The full report can be found at:
http://www.doh.gov.uk/cmo/cfsmereport/index.htm

We begin with a summary by Moira Smith, and move on to responses by consumer groups and researchers giving a range of perspectives.

Paul has also written an editorial which can be found on our website at: http://www.sacfs.asn.au/about/issues/uk_guidelines.htm

Editors.

The UK CFS/ME Report, 2002

Introduction

The *Report of the Working Party on CFS/ME to the Chief Medical Officer for England and Wales* was released on 11 January 2002. In the Foreword, the chair of the Working Party states that CFS/ME "can, and should, be approached and managed clinically like any other chronic illness". He talks of "improving care" for patients, and says "There is much to do".

Headlines in the British and Irish press encapsulate a key message of the "CMO's Report":

"Doctors told they must take ME seriously" - *Daily Telegraph*
"ME recognised as chronic condition " - *Guardian*
"Yuppie flu' is recognised as a real illness" - *Times*
"ME is not all in mind, say experts" - *Irish Independent*

However the report not only states that CFS/ME is "a genuine illness" (as indeed the Australian Guidelines do) but also acknowledges the recent research evidence of physiological abnormalities. It recognises two groups of sufferers whose needs have been neglected - children and the severely affected. The needs of carers and people of ethnic background are also acknowledged. The report expresses concerns about lack of understanding amongst professionals and the public, not enough good quality research, too few services, and the length of time taken to get a diagnosis. Its recommendations are aimed at improving health and support services through professional education and better planning. There are also specific recommendations about research.

Unlike the Australian guidelines, the "CMO's Report" has been generally well received by consumers (though there were dissenters: see below). The larger patient groups in particular welcomed its key findings. The ME Association said, "This is really a wake-up call for the medical profession." Action for ME (AFME) described its publication as "potentially the most significant event to date in the field." The Association for Young People with ME (AYME) called it "a huge step forward" and said: "We believe that the report is open, honest and fair and that its recommendations will provide a sound basis of care for all sufferers".

Consumer involvement

There was considerable community consultation in the preparation of this report, with all the main consumer organisations in the UK taking part. Patient representatives on the Key Group were from AFME, BRAME, the ME Association, and the 25% Group; there were also two independent patient reps, and a carer. A separate Children's Group also included reps from AYME and The TYMES Trust, and there were more patients and carers on the Reference Group.

Two large "Sounding Board" discussions - one for

affected children and their parents, the other for adult sufferers - were held to gather community views, and the Working Party also examined surveys and other material submitted by the consumer organisations. The report devotes a whole chapter to evidence from patients and their carers.

"Having worked within the NHS and voluntary health sector for 30 years this has been the most inclusive process that I have seen," commented Chris Clark, Chief Executive of Action for M.E. and Key Group member in the British Medical Journal (2002;324 -19 January)

Dissenters

Predictably, the process was not without controversy. Six Key Group members withdrew shortly before the report was to be released, refusing to sign off on its findings. "Two psychiatrists, a public health doctor, and a nurse therapist have resigned, saying that the report plays down the psychological and social aspects of the condition and concentrates on a medical model," said a news item in the British Medical Journal. These four, proponents of the "Wessely school" (two were colleagues of Professor Simon Wessely at King's College Hospital) felt the report was too subjective and not evidence-based enough. They objected to the inclusion of "pacing" among possible treatments due to lack of supporting research (BMJ 2002;324:7 - 5 January). By implication, they also disapproved of patients' and doctors' experience being cited as evidence in addition to, or instead of, research data.

Two of the patient members of the Key Group - Tanya Harrison who started the BRAME (Blue Ribbon for the Awareness of ME) movement, and Simon Lawrence of the 25% ME Group, representing people with severe illness - also refused to endorse the report. Lawrence said he couldn't agree to its inclusion of cognitive behaviour therapy and graded exercise. "Many of our patients are severely affected because they have tried these types of treatments," he said (BMJ 2002;324:131 - 19 January)

These were just the latest events in a history of controversy and disagreement. In May 2001, Malcolm Hooper of the University of Sunderland circulated a document by "Sally Montague" (a pseudonym for a group of consumer advocates) voicing concerns that due to the influence of the "Wessely school" the report would focus too much on the biopsychosocial - or "psychiatric"- model of the illness and overlook physical research findings.

Indeed there was widespread pessimism among consumer advocates about the outcome, based on what had gone before (for example, the 1996 Royal Colleges Report, which Dr Charles Shepherd had described as "far too biased towards the

(Continued on page 10)

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psychological aspects of the illness"). There was concern about the number of known proponents of "psychiatric" theories on the Working Party, and also about the funding the project was receiving from the Linbury Trust, noted for its generous financial support of Wessely and his colleagues.

Whether these fears were realised is a matter of opinion; however the fact that Wessely and his colleagues are far from satisfied with the result indicates that they were unable to influence the proceedings as much as they would have liked.

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The treatment controversy

Ideas about treatment reflect underlying theories about the cause of CFS/ME. Psychiatrists and others who embrace the biopsychosocial model favour graded exercise therapy (GET) and cognitive behavioural therapy (CBT), claiming research findings support their effectiveness. Most patients and consumer groups, however, strongly reject GET and CBT, maintaining they don't take account of the realities of the illness, and that the research evidence is flawed and incomplete.

The CMO's Report steers clear of recommending any particular treatment outright. The recommendations relating to treatment are fairly general, concerning appropriate care and support. They stress that management should be in partnership with the patient and tailored to their needs and circumstances (6.2 Treatment and Care).

In the chapter on management, GET and CBT are listed among possible treatments but pacing (preferred by consumer groups) is also included. The report canvasses the pros and cons of GET and CBT, acknowledging consumer concerns, and pointing out problems with the research. It concludes that "appropriately supervised, graded exercise therapy . . . can benefit many, though not all, ambulant patients" but also draws attention to the high proportion of negative reports on GET from patients (4.4.2.1). Cognitive behavioural therapy is described as "helpful in improving quality of life and day to day functioning" (4.4.2.2), in contrast to the way it is portrayed by some writers, as a cure-all corrective therapy for the wrong thinking that has caused the illness. The report also points out that most approaches have not been sufficiently studied in the severely affected (4.4.1.1).

The Name

The Working Party noted that there is work going on in the USA on a name change, and decided on CFS/ ME as an "umbrella term" rather than choose between CFS and ME. This is a sore point with some patient advocates, who believe that the definition of Myalgic Encephalitis as a separate disease has already been established, and object to the various case definitions of 'Chronic Fatigue Syndrome' as being too inclusive and tainted by association with psychiatric theories of causation. Meanwhile comments by doctors of the "Wessely School," which does not believe in ME, portray the use of the double name ME/CFS as evidence of the capitulation of the Working Party to the delusions of the patient lobby.

Contrast with the RACP Guidelines

The impression I get from reading the "CMO's Report" is that it was a very genuine effort to cover all the ground. It is - in my opinion - far superior to the Australian Guidelines not only in its contents but also in several other respects:

- It is well written and organised, and appears to have been thoroughly researched. The project was well resourced with an editorial team of five people and a secretariat of eight. The Australian Guidelines had a secretariat of one or two, and was as far as we know written or compiled by one person, Dr Rob Loblay.

- There were several different groups involved including a large Reference Group with wide representation - not just doctors and patients but also carers, health workers, and people from support services. The Australian working group had just one consumer representative, and the attention paid to his contribution left much to be desired.

- The report bases much of its discussion about treatment on patient reports and doctors' clinical experience, citing lack of suitable research evidence as justification (1.3.3). This is in contrast to the Australian Guidelines, which take an evidence-based approach relying heavily on the results of a limited number of controlled research studies.

Brian Dow of the patient organisation Action for ME (AFME) said: "This report is not perfect - there would be certain things here and there that we would have put differently. However, in terms of a platform to build on, I can honestly say that the status and official recognition given to M.E. in the UK is on a totally different plane to the one it occupied last week and for that reason we ought to be celebrating" (letter to Co-Cure mailing list, 15 Jan 2002).

Moira Smith
January 2002

This article can be found online at:
http://www.masmith.inspired.net.au/aus_info/gdlines/ukreport2002.htm
Used with Permission.

Action for ME Response

So at long last the UK Government's Chief Medical Officer has published his report on the treatment and management of M.E.

As one of the leading patient groups involved in the Working Group, Action for M.E. like most other interested parties is relieved that the speculation (and in many instances deep concern) over its content can be replaced by a cool-headed analysis of its merits and consideration of where the field goes from here. I'd like to offer a quick overview on our role on putting the report together as well as giving a sense of where we stand on the main issues arising.

We have been unable to say a great deal about the report to date because we have sought to abide by the confidentiality clause imposed on parties regarding content. This, in truth, has not always been easy to observe given the huge interest in the report but we felt it was right and politically astute to do so.

In terms of the evidence we gave to the Working Group we sought to steer a "middle-ground" position, mindful of the "them and us" culture which has done so much damage in terms of our mutual search for answers. That said, our own evidence pointed up a terrible lack of support from the statutory agencies, particularly for those people who are more severely affected and we were robust in outlining our position that M.E. is a serious, chronic illness - we gave as evidence Severely Neglected, which is the largest study ever done in the UK of the more severely affected patients. This report showed that a third of people with M.E. had waited over 18 months for a diagnosis and 2 out of 3 had received no advice from their GP on managing the illness. Like others we consistently rammed home the case for better high quality research and improved services.

We regard it, therefore, as a major breakthrough but it needs to be the first of many.

We are hugely encouraged that the Chief Medical Officer Prof Liam Donaldson himself is quoted as having said at the launch:
"Until now on the whole this has been a disease in the wilderness. Sufferers have been ignored, not always taken seriously, sometimes labelled hypochondriacs, urged to pull themselves together and get better on their own. From today that changes."

In terms of its main successes, early diagnosis, recognition of severity, call for more research, clear instructions on developing more and better services, and sensible advice on managing the illness (including recognition of pacing) are the most obvious. People will see that it also notes that graded activity and CBT have proved helpful for "some, though not all ambulant out-patients" and also expressly says that some people have been harmed by inappropriate treatment. It also stresses that these approaches are not curative and that any treatment should be done on an "individualised" basis, in full cooperation with the patient. Throughout the report the terrible impact of the illness and the clear statements on the damage that imposed, rigid treatments can do are extremely encouraging.

We all know that such rehabilitation strategies do not help all (by any means) and we are massively encouraged, therefore, that there is a clear call for research into all aspects of the illness. Obviously we are disappointed that no money has yet been earmarked but believe that the Chief Medical Officer has created the environment for serious work on immunology, virology and enocrinology (amongst others) to be carried out. We will, however, be campaigning vigorously to ensure that this does happen and that all the recommendations (which are very good) actually are put into practice. This report will be totally pointless if the words are not translated into action. We intend making sure this is the case!

AfME has published its own guide to the report which is available on our website at http://www.afme.org.uk/
I would finally like to pay tribute to the other parties who have worked tirelessly to get this report out - I can only outline our own position but I know they also played an extremely important role.

This report is not perfect - there would be certain things here and there that we would have put differently. However, in terms of a platform to build on, I can honestly say that the status and official recognition given to M.E. in the UK is on a totally different plane to the one it occupied last week and for that reason we ought to be celebrating.

Regards,

Brian Dow Press and Campaigns Manager

Action for ME (AfME)
www.afme.org.uk

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ME Association Responses

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Posted 11th January 2002

The ME Association welcomes the key findings contained in the Chief Medical Officer's Working Group report into CFS/ME. The report clearly identifies that this is a very genuine illness with a potential to cause long-term severe disability. In particular, we are very encouraged to see recognition that a great deal more needs to be done in education of the medical profession regarding both diagnosis and the various approaches to management that may be helpful.

The MEA Chief Executive, Val Hockey, commented, "This really is a wake-up call for the entire medical profession. It is no longer acceptable for doctors to claim that 'CFS/ME is an illness that does not exist' or that 'nothing can be done' to help these people. We are particularly pleased to see so much emphasis being placed on the severely affected and children with CFS/ME - two groups whose needs are often ignored or dealt with very badly. The MEA is taking the view that the report marks the beginning of a process, it is not an end in itself'.

MEA Medical Adviser Dr Charles Shepherd, commented: 'Obviously there are going to be some people who are disappointed with certain aspects of the report. It does not, for example, solve controversies such as what is the cause of CFS/ME - but this was not the remit from the CMO. Regardless of any deficiencies, we welcome the very clear message about the need for early diagnosis and a flexible management plan that is tailored to suit each individual patient. There are some very specific recommendations regarding research, diagnosis and management of this illness - powerful words which now need to be converted into action.'

Posted 17th February 2002

The report is a major step forward in persuading the public and medical profession that ME/CFS is a genuine and disabling illness that is not well managed and urgently requires more research.

There was excellent coverage of the patient experience along with a clear message that doctors and patients have to work together in partnership when it comes to the management of ME/CFS.

The report highlighted the diverse range of problems faced by the severely affected, and gave detailed information for doctors on the clinical assessment of patients.

There was sound advice on issues affecting children - a major improvement on the advice contained in the Royal Colleges' report.

The ME Association was delighted to read of the unambiguous and genuine support for the report from the CMO.

Despite major differences of opinion at times, the process demonstrated that doctors and patients can work together to achieve a high degree of consensus. By leaving all the really contentious issues - pathogenesis, CBT, graded exercise - to the final stages, and not having an adequate discussion, the failure to achieve consensus here was, in part, a self-inflicted wound.

What will change?

Public perception of ME/CFS should become much more positive.

The report will have some positive effects on medical opinion, but not as much as many people with ME/CFS are expecting - especially in general practice (very few doctors will actually read the report unless they are already interested in ME/CFS - their 'information' on the content will come from the BMJ and other professional journals).

There will be more research activity - possibly as a result of MRC funding.

Chronic fatigue syndrome:
a step towards agreement

The Lancet, Volume 359, Number 9301 12 January 2002

The 1996 report by the Royal Colleges of Physicians, Psychiatrists, and General Practitioners, *Chronic Fatigue Syndrome*,[1] received a mixed reception--approved by some,[2] but severely criticised by others, including *The Lancet*.[3] The patients' organisations were among the harshest critics, and the report was seen by some as a cogent criticism that patients' views had not been included within the report.

Now a new report has been published, and we hope that it will mark a turning point in the history of the illness. A working group on Chronic Fatigue Syndrome and Myalgic Encephalomyelitis or Encephalopathy, the name preferred by patient advocate groups in the UK, was set up in 1998 to report to the Chief Medical Officer of England and Wales.[4] The fact that both names for the illness were used symbolises respect for different viewpoints whilst acknowledging the continuing lack of consensus on a universally acceptable name.

The brief of this 16-member working party was to review management and practice with the aim of providing guidance for professionals, patients, and carers, and to make recommendations, including those for research. It attempted to achieve a consensus between patients' representatives and health professionals. How did it work out?

The good news is that a substantial amount of centre ground was established between medical researchers, practitioners, and patient advocates. However, not surprisingly there were serious and principled disagreements on several issues, which led to six members (all clinicians) deciding that they could not endorse the final report. Not surprisingly there were serious and principled disagreements on several issues. Four clinicians were unable to endorse the final report, arguing that it was insufficiently evidence based and paid too little attention to the biopsychosocial approach. Two patients also declined to endorse the final version, believing that it paid too little attention to pathological models and portrayed rehabilitation approaches in too favourable a light. Nevertheless, whilst of concern, the disagreements should not detract from what was achieved by all the members.

So where is the centre ground? First, there is agreement with the report's conclusion that the illness "is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a very substantial impact on the individual and family". It is also agreed that it can affect both sexes, and a wide range of ages, including children. The report makes plain that it will no longer be acceptable for clinicians to state that they do not "believe" in CFS/ME. The report is explicit: it states "inaction . . . due to ignorance or denial of the condition is not excusable".

The report notes that a significant minority of patients who are very severely affected often receive the least support. Particularly welcome is the conclusion that patients need positive early diagnosis and appropriate management and advice, and that patients' organisations have an important role to play in this. All parties will also welcome the conclusion that this often disabling and chronic disorder has not been addressed by sufficient research activity and public funding.

What treatments do the report recommend? One of the main polarities has been about rehabilitative treatments such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET). These have been reported as beneficial in trials but have been criticised by the patients' organisations because

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It has to be demonstrated that there will be any significant improvement in hospital-based services. There also is a danger that where a new service is set up that this will be dominated by an approach involving CBT and graded exercise.
The positive aspects far outweighed the negative.

But, as yet, there is no designated money for research, education or service provision.

The report was not GP-friendly - as shown by the way it was either ignored or received negative coverage in the BMJ and GP media.

The failure to promote the very critical paper on benefits, presented as an annexe, especially considering that the CMO Report was produced by an 'independent' working group, was disappointing. The ME Association is considering ways in which the issues raised in the benefits annexe might be taken forward.

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of negative reports from some of their members and the still limited evidence base. Furthermore, some have drawn the understandable, but erroneous conclusion that the success of either CBT or GET implies a psychogenic cause of the disorder.

The report now signals acceptance of what is an unpalatable fact to some--symptom management and rehabilitative treatments, such as GET and CBT, are for now the best available in terms of evidence-based strategies.[5] But there are key messages that both practitioners and patients need to understand in applying these therapies.

None of the rehabilitation approaches is intended to be curative, no approach has been found to be beneficial for everyone, and all can be tainted by poor practice by therapists lacking proper understanding of the disorder. Furthermore, the systematic review underpinning the report noted that those with the severest disabilities, and the young, have not been included in the randomised controlled trials to date, limiting the conclusions that can be drawn concerning either of these crucial groups.

The report is also correct to draw attention to the myths held by some patients and practitioners surrounding treatments such as CBT or GET that need to be overcome. For example, neither GET nor CBT insists on blind adherence to strict exercise regimens. CBT, for instance, is instead based on the principle that activity, physical or mental, must first be made consistent and predictable, even if this concept means initially reducing excessive activity.

Moving beyond the evidence from controlled trials, the report does endorse an additional approach to activity management known as "pacing", which has been advocated by patients' organisations and is consistently reported by their members as being helpful. Pacing proposes a balance, both of activity and rest, with the aim of maximising recovery and promoting self-empowerment. However, it has not yet been well defined or evaluated[5] and should also be the subject of research.

Some of the recommendations will be continue to be controversial. Much of this controversy stems from the false view that those therapies pioneered by psychiatrists imply that the illness is, in that awful phrase "all in the mind", or that failure to respond is the patients' own fault. There are still too many reports from the field of patients being treated with disrespect or disbelief, and not being true collaborators in treatment. It is vital for the future that practitioners agree that there is no place for "boot camp" ideologies, as in overaggressive attempts at crude exercise regimens. Equally, there is no longer any place for a fatalistic acceptance of the disorder. Finally, those who, despite every effort, still remain severely affected, require service provision and further research.

This has clearly been a difficult and challenging experience for many of the participants in the working group. There is likely to be continuing discussion and even argument about many of its conclusions. Some of those not involved in the report and holding entrenched positions will continue to fire broadsides at its conclusions. However, nothing must detract from perhaps the most important area of progress--namely, that in a complex and controversial field, it is possible to develop dialogue and find centre ground.

We can now endorse the recommendation that better service provision for patients is urgently needed. We agree that not all the answers to this illness are in hand and that there is a need for high-quality research. We agree that ideologies both within and without the health professions have not served patients well in the past, and that both doctors and the patients' charities need continued humility in this uncertain area. In particular, we believe that the time has come to move on and for patient advocates, practitioners, and researchers to work together to both press for better services and fair benefits for sufferers, as well as for further research into the causes of this complex condition. The ball is now in the government's court.

C C and A M (a retired medical practitioner and person with M E) were members of the core group of the Working Party and S W was a member of the external reference group. S W is honorary member of the supervisory group of PrismaHealth care, which provides rehabilitation for patients on permanent health insurance.

**Christopher Clark, Dedra Buchwald, Anne MacIntyre, Michael Sharpe, Simon Wessely*

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Caring for patients with chronic fatigue syndrome:

Conclusions in CMO's report are shaped by anecdote not evidence

By Stephen E Straus

In 1998, the chief medical officer of England and Wales commissioned a working group to advise on best practice guidelines to improve the quality of care and treatment for people with chronic fatigue syndrome / myalgic encephalomyelitis. Now issued, the group's report reflects the good efforts of the scholars, practitioners, patients, and advocates who joined to address this complex matter.[1]

Given the controversies surrounding chronic fatigue syndrome, it is not surprising that the report admits to broad domains of disagreement among its members. If anything, it is remarkable that most of the original group weathered the undertaking, as there were resignations both among patients who deemed the evolving product insufficiently sympathetic and among academic practitioners who chafed at recommendations untempered by data.

The report identifies the sentinel issues that concern patients and practitioners alike: how one makes the diagnosis of chronic fatigue syndrome; the treatments to consider; and research that remains to be done. Unfortunately, despite more than 2000 relevant papers indexed on PubMed since chronic fatigue syndrome was first named in 1987, the group's conclusions appear more shaped by anecdote than by evidence. In particular, major systematic reviews, including the recent one by Whiting et al, are not cited and do not seem to have significantly informed the guidelines.[2]

Case definition, and hence estimates of prevalence, are pivotal issues. While there is no universal definition of chronic fatigue syndrome, the widely used ones all require significant fatigue and a set of attendant symptoms for at least six months. [3] [4]

The least restrictive of these definitions leads to estimates of as many as 200 to 400 cases per 100 000 people, with relatively higher rates among women than men, and among adults than children or adolescents. [5] [6]

The report argues that these are underestimates and suggests considering individuals in whom fatigue has persisted for only six weeks as incipient cases of chronic fatigue syndrome. Even more remarkable is the proposal to accommodate within the rubric of chronic fatigue syndrome children in whom "fatigue may not be a presenting problem." [1]

Three types of treatment modalities are highlighted, with each given equal weight on which to build the

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therapeutic approach to chronic fatigue syndrome: graded exercise, cognitive behavioural therapy, and pacing. How these disparate methods emerged from the menu of options is symptomatic of irreconcilable perspectives within the group. The seminal studies that established the utility of graded exercise and cognitive behavioural therapy were proofs of concept, confirming that one can apply standard metrics of illness and document clinically meaningful improvement in chronic fatigue syndrome.[7 9] Yet they are specialised modalities and too limited now in their availability for the typical patient. Pacing, based on the sensible notion that a patient with limited physical and cognitive resources should expend them cautiously, however, emerges as a key recommendation without any formal proof, perhaps because anyone can advise it and undertake it. While pacing may prove beneficial, one must be concerned that encouraging patients to avoid incremental increases in activity for fear that their symptoms will be aggravated may condemn them to stay ill longer.

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As to the capacity of medical institutions to afford full service needs for people with chronic fatigue syndrome, the limitations are predictably the same as for those with other chronic diseases. Resource use needs to be based on competing public health needs, and above all on evidence as to what is most effective. In the United Kingdom, the National Institute of Clinical Excellence is one body to which this and related reports could be referred for further opinion.

The report does not articulate a detailed research plan. Emphases are placed on epidemiological studies and more clinical trials. There is certainly a need to understand better the range of chronic fatigue syndrome in children and adolescents and to determine whether severe neurological problems can be documented, as claimed, to represent features of chronic fatigue syndrome.

What the report expresses well is that core issues for chronic fatigue syndrome are those of belief and trust, in that patients are not believed and that medical institutions are not trusted to serve them adequately. One senses the need to testify repeatedly in the report that chronic fatigue syndrome "is a genuine illness." While there will always be those who doubt the evidence, as there are those who doubt HIV is the cause of AIDS, the time has come to move on. Whatever one presumes chronic fatigue syndrome to be, people suffer with it and because of it. A report of a joint working group of the royal colleges made that point abundantly clear in 1996.[10]

Too often we fail to appreciate that despite our inclinations or abilities to comfort patients, they will seek other solutions in the healthcare marketplace. This underlies the enormous popularity of complementary and alternative medicine. While there is little evidence that these approaches benefit people with chronic fatigue syndrome[2], they are accessible and are best addressed, like the patients who seek them, through serious investigation. [11]

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Recognising chronic fatigue is key to improving outcomes

By Lynn Eaton

The government has finally issued its long awaited report on the management of chronic fatigue syndrome (also known as myalgic encephalomyelitis, or "ME"), after delaying publication earlier this month because several committee members resigned (5 January, p 7).

The report says that health professionals should recognise the condition as a chronic illness and that early recognition is key to improving outcomes.

Speaking at the launch, chief medical officer Professor Liam Donaldson acknowledged that the three years spent drawing up the report had been "enormously difficult, complex, and at sometimes controversial."

"I've received a large amount of correspondence about this," he said, admitting, "I'm a little surprised we have been able to get such a comprehensive and valuable report."

As the *BMJ* reported last week, four clinicians and two patients resigned over the final version of the report. The clinicians argued that the psychosocial side of the condition should have had greater emphasis and were concerned that "pacing" where patients limit their activities depending on the day to day severity of the condition was included as a form of treatment. Research into the effectiveness of pacing is limited, although the treatment is recommended by many of the patient groups and some doctors.

The patients who resigned objected to the inclusion of graded exercise as a treatment option. Simon Lawrence, coordinator of the 25% ME Group, representing people with severe chronic fatigue syndrome, said he couldn't sign up to its recommendation of cognitive behaviour therapy and graded exercise.

"Many of our patients are severely affected because they have tried these types of treatments and have come out [worse]" he said.

Even the name has been controversial, said Professor Donaldson, who said that the condition would now be known as CFS/ME. He said a referral to the National Institute for Clinical Excellence to provide guidance on management and treatment would be considered "in due course."

Despite the controversy, the report was welcomed by Action for ME, one of six groups representing people with the condition.

"It's not the end of the road, but as far as we are concerned it is a breakthrough that the government is recognising the severity of the condition," said the group's chief executive, Chris Clark.

Professor Anthony Pinching, head of pathology at Barts and The London NHS Trust and deputy chairman of the working group, said many GPs were reluctant to diagnose the condition.

"If they think it might be CFS/ME, they don't know what to do. It wasn't taught at medical school, and what they have heard about it doesn't encourage them to get involved."

He accepted that some patients had been pushed to do too much when they were not physically able. Treatments had to be adapted to individual patients' needs, he said.

Michael Sharpe, senior lecturer in psychological medicine at Edinburgh University and a pioneer of cognitive behaviour therapy for the syndrome, said the report represented an "uneasy compromise" between the consumer's view and the scientific view.

But he added that doctors would not accept pacing as a treatment just because it was recommended in the report.
The report of the CFS/ME Working Group is available at: www.doh.gov.uk/cmo/publications.htm

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25% ME Group Response to BMJ

Reply to BMJ regarding Working Party Report
by Simon Lawrence: Co-ordinator of 25% M.E. Group

Key issues of CMO's Report are unacceptable

It has been reported that the CMO's report on CFS/ME may not be published. This is not surprising, given the extreme difficulties that have been met throughout the Working Party process. These difficulties were primarily due to the remit:

'To review management and practice in the field of CFS/ ME with the aim of providing best practice guidance for professionals, patients and carers to improve the quality of care and treatment for people with CFS/ME' .

Apart from being extremely narrow, this remit also had to encompass a wide range of 'fatigue' states (many of which have no relationship to ME), under the same umbrella term CFS/ME.

It is reported that "four key members resigned from the working group", and that "two patients are understood to have also resigned recently". This is not strictly true.

The two people (who were mentioned in the BMJ paper), each represent a patient group, one of which is the 25% ME Group for severe ME sufferers, stayed to the end. They then indicated that they could not sign up to the report. This decision was taken because they disagreed with the central treatment and management methods that were being put forward as the 'most promising' i.e. CBT and GE.

Both representatives are well aware that CBT/GE, although potentially appropriate for other patients with 'fatigue' conditions, have been shown to be harmful in ME. The recommendation of such treatment for ME sufferers is irresponsible and completely misguided.

One of the main failures of the Report is that there will not be any significant advancement in care for the patient with this condition/conditions. Material presented in the report leans heavily towards a psychiatric model; many members of the medical profession seem to hold the view that this illness is 'just all in the mind' and this material will not shift them from that perception.

My deep concern, as a patient, and someone who represents many who are severely affected by ME, is that at best this report will only strengthen the 'status-quo' of such treatment methods of CBT and GE Therapy.

In conclusion, if we just accept the myth that ME is a 'biopsychosocial' illness that can be treated with 'psychosocial' methods then we will be abandoning the truth and the need for rigorous biological research into this serious neurological illness. That will be a tragedy for patients with ME.

Simon Lawrence 25% ME Group

Campaigner Welcomes Government U-Turn

A LONG-serving campaigner and fundraiser for a disease dismissed as being "all in the mind" has welcomed a Government report, which finally accepts it as a condition that demands serious consideration.

Trevor Wainwright is one of an army of people worldwide who have fought to see ME sometimes known as Chronic Fatigue Syndrome and often dismissed as "Yuppie Flu" recognised as a real complaint that needs early diagnosis and proper research.

Mr Wainwright and his wife Margaret have fought the disease at home too daughter Paula, now 19 has suffered from the debilitating illness since she was ten years old.

The Castleford-based firefighter, who likens the incurable condition to a prison sentence with no parole for both sufferers and families, said: "It s certainly good news that ME has been accepted as a reality but it's long overdue.

"Families have to go through enough hardship and heartache when someone is suffering, without the added insult of having medical experts not believe that your child is really ill."

He said Paula was struck down suddenly, suffering severe stomach pains and becoming more and more lethargic soon after having a polio jab.

She deteriorated so quickly that she was confined to a wheelchair within nine months of becoming ill. Medical opinion, however, suggested the family encourage her to do as much, physically, as she could.

Mr Wainwright added: "Paula's GP at the time said we should get her out of the wheelchair and doing more exercise which was all wrong."

In fact, in tandem with homeopathic remedies, including liberal doses of vitamin C, what helped Paula as much as anything was a balanced programme of physical action, which allows the patient to set achievable mobility goals.

Mr Wainwright stressed patients and families of patients suffered an emotional and mental strain on top of the physical aspects due to the attitude of the medical profession.

But he is optimistic that attitudes will change following the Government Chief Medical Officer's promise of more funding into research and better services.

Meanwhile he is happy to wear the "prisoners uniform" he dons when fundraising for ME research charities as an illustration of the life sentence sufferers endure.

Getting Rid of Mould

By Catherine McIver

Allergies and sensitivities to mould are very common. Unfortunately so is mould.

Outdoor moulds

The various moulds found outside peak at different times of the year and vary according to weather conditions. Your allergist can give you more information. Of course moulds in outdoor air will get into indoor air as well, but you can do something about that. A HEPA air filter does a good job with mould spores, so using one in the bedroom at night and taking it into the room you are in during the day should greatly reduce your symptoms. If you have severe symptoms from going outside try to limit your time there until the mould count drops. If soil moulds are a problem wear a mask when doing gardening tasks that stir up the soil, or get someone else to do it.

Is your home mouldy?

If you can see mould or your home smells musty to you or others you need to find out why. The most common causes of mould problems are:

- No exhaust fan in the bathroom &/or kitchen
- Exhaust fans vented into the wall or roof space instead of to the outside of the house
- Failing to turn on exhaust fans
- Clothes dryer not vented to the outside
- Rainwater pooling beside or under the house
- A leaking pipe, window or roof
- Damaged or obstructed gutters
- Windows left open when it is raining or damp outside
- Lack of ventilation
- Lack of light because of large trees or neighbouring houses
- Incomplete dampcourse leading to rising damp
- Any of these problems will have to be fixed to deal with mould effectively. If you have a serious mould allergy/ sensitivity and your house has a mould problem you can't fix, consider moving

Cleaning

Don't use formaldehyde or chlorine products (bleach). They can cause severe reactions in people with chemical sensitivities and initiate chemical sensitivity in people who were previously ok. You can get rid of mould with non-toxic products.

Visible mould can be cleaned off with either sodium bicarbonate or vinegar.

Wallpaper may have mould growing behind it. If so, it should be removed.

Walls and ceilings in a musty room can be wiped down with either sodium bicarbonate in hot water or vinegar in hot water.

Hard floors can be cleaned the same way. Ceramic tiles can be cleaned with a steam mop.

Carpets cannot be thoroughly cleaned and it is best to remove them. They invariably get mould when liquid or food is spilt on them. If you cannot remove the carpet, use a powerful vacuum with a HEPA filter.

Fridges can be cleaned with sodium bicarbonate in water. Check the tray under the fridge and put sodium bicarbonate in it.

Towels, washers, tea towels and any clothing that smells because it has been left damp too long can be soaked overnight with sodium bicarbonate (about half a cup to half a bucket of water) before washing. Towels etc can be hung outside to dry when it's sunny.

Bathrooms should dry out completely when not in use. Use a heater if necessity. Leave windows open in good weather, as long as it won't result in damp air being blown into the rest of the house.

Dishcloths can he soaked with sodium bicarbonate overnight.

Clothes that have been worn or are slightly damp should not be put away in wardrobes or drawers.

Wardrobes need ventilation. Consider using open hanging racks and wiredrawers.

House plants have mould in the surrounding soil so it's best to find them a new home.

Musty mattresses / upholstered furniture may be impossible to clean, but you can try sprinkling sodium bicarbonate, leaving for a day or two, then vacuuming thoroughly.

Annie Berthold-Bond reported in Our Toxic Times August 2000 success cleaning a mouldy ceiling from a leaking roof, a musty bureau, a musty rug and a mouldy shower curtain with tea tree oil. She recommends 1 teaspoon of tea tree oil in 2 cups of water in a spray bottle. Shake to blend and spray on problem area. Don't rinse off (the smell goes in a few days). Obviously this isn't a suitable method for people who are sensitive to tea tree oil.

She also suggests equal parts 3% hydrogen peroxide and water. Spray on mould Don't rinse. Or scrub area with borax and water paste, leave until borax is dry,

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Reflections on recovery

by Val Rubie

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RECOVERY - Bring or come back to life, consciousness, health or normal position (Concise Oxford Dictionary)

How many of us have said a silent prayer 'Please, please make this pain/sickness/headache go away and I'll never ever complain about anything again'? At that point it seems that if only we weren't in pain or being sick life would seem just perfect. Then there we are, the pains are bearable, the headaches less frequent and for a while we feel very grateful. But soon we find ourselves wanting something else. Life doesn't seem as perfect as we thought it would. This is one of the dilemmas of recovery. It is all we hope for, long for, and pray for. However those lucky enough to experience it often discover there are a multitude of inexplicable feelings, frustrations and unexpected difficulties. Moreover some people find it very hard to admit that things are not so hunky-dory as they'd hoped. Confiding that to anyone is difficult, but most of all to another person with M.E. who may still be very ill.

Frustration is a good sign

I believe that feeling frustrated is a sign that recovery is happening. Being really ill and 'out of it' means that one is surviving moment to moment. There is no spare energy to consider anything else. The next stage is beset by a different confusion of feelings. There may be euphoria at feeling better and pleasure in being able to do things abandoned for so long. This can be followed quickly by fear that the recovery may not last, a belief that you could never survive feeling so ill again, guilt about others you know who haven't been so lucky. There is confusion about what to do next, anxiety about the mountain of practical things you haven't been able to sort out for so long. There can be fear about keeping up in a world of fit, fast-moving people. What seems most ungrateful of all is a wish to be even better. Yes, you may be able to walk outside your house or room again but what you really want is to be able to run the marathon or throw a party. It is like surfacing into 'real' life again as taken for granted by the rest of the world. You look around for the first time in years, months or weeks. The view is suddenly overwhelming. Where to start? You are out of practice.

Of course recovery after years of being ill is quite different to recovering after a few months. In the lost years life has moved on completely. Children have grown up, friends have married, and sometimes people have even died. There has been a whole generation of books unread, films unwatched, music unheard.

Let yourself off the hook

So don't beat yourself up if, in spite of your recovery, you can't be as happy as you hoped. Recovery is a transition. Human beings tend not to like transitions. It means finding new 'rules' and ways of coping. If you've been ill for a long time then you've probably acquired all kinds of strategies for surviving that bit. You might have learned, for instance, that you need to spend the next day sleeping/resting after a day requiring some energy expenditure. Now you don't need to and you're at a loose end. You can remember the times in bed thinking of myriad things to do. Now you can do them and suddenly you can't remember what they were or you can't decide which to do first. It's easy to get angry with yourself. Further along the line you might be more engaged with the world. You'll find lots of little things you still can't do which you couldn't anticipate. Pam found she couldn't operate a push button to flush the loo (not enough strength in her fingers). She had the brilliant idea of pressing it with a key the key chain got caught and there she was stuck!

Joking aside, recovery can be difficult. For one thing with M.E. the process can last for years with many setbacks. Part of it is glorious: the joy at seeing the world again open skies, the smell of grass after rain, the feel of sun or a pleasant breeze on your face. For other parts you may be as much in need of emotional support as you were when ill.

Express yourself

One of the major tasks during recovery is to come to terms with and understand the full implications of the illness, to mourn all that you have lost because you were ill. This may include loss of a partner, career or even the opportunity to start work at all; friends who have drifted away and activities given up. If you were ill from a young age then whole phases of your life

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then dust off.

Maintaining a mould-free house

The secret is to keep every surface and object clean and dry, but this is easier said than done. House dust contains mould spores so clean thoroughly and regularly. Use a HEPA filter. Dr Sherry Rogers recommends wiping down walls and ceilings with sodium bicarbonate once a month. There are paints that deter mould and natural paints with citrus oils are also reported to have this effect, but be sure to test any paint for sensitivity before you use it.

If you are building a new house or renovating, plan good cross-ventilation and lots of natural light. Consider whether an ensuite is worth the increased risk of mould in the bedroom. Also consider double-glazing as this prevents condensation - a source of moisture and so mould.

'Getting Rid of Mould' first appeared in Sensitivity Matters No. 28, June 2001, published by the Allergy and Environmental Sensitivity Support and Research Association Inc. (AESSRA), PO Box 298 Richmond Vic 3134, www.vicnet.net.au/~aessra
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have passed you by. For instance leaving home and becoming independent, exploring your sexuality or building up a network of friends and acquaintances. It may mean that you have had little chance to discover who you are other than just a person with serious M.E. This can lead to a tremendous loss of confidence in yourself and a belief that you will never be able to cope with anything approaching a normal life again.

Grief brings with it anger, which can feel threatening and overwhelming. It is a rage that consumes and is best dealt with. Try not to feel it is counter-productive as it will only come out somewhere. Although it seems unlikely, talking it out, naming all the things you are angry about and why, can be very helpful. Try using a creative method. For instance, even if you believe that you are not artistic, get some children's crayons or felt tips and give your anger colour and form. If music is your thing, find something that sounds just like you feel whether it's The 1812 Overture or loud rock music. Perhaps something dark and brooding. If you can make your own music even better. Write a poem or a story don't mince your words. What would you like to say to all those people who ignored your M.E., the professionals who patronised you, the work colleagues who forgot you? Expressing these feelings is important, so don't feel you need to censor yourself. Imagine giant billboard posters where your own thoughts are written in letters 20 feet high. If your anger feels too great for any of this then perhaps you do need professional help in the form of counselling or therapy.

Rehash your life

Another task during recovery is that of rehabilitation. Interestingly my dictionary (admittedly an old one) gives the definition as 'rehash'. Perhaps an apt word, for it does require you to rehash your life. Your old life probably won't suit you any more. What was fun to do at 19 may not be what you want to do at 35. Unlike most people you may not have had the experience of growing out of your teenage or younger years gradually. As a person with M.E. once said to me, 'I went to bed aged 25 and woke up feeling 96'. Most people find it difficult to say what being their particular age feels like but at least when you've 'grown into it' you have more of an idea. Knowing how to be 45 years old without the in-between years is a puzzle. Sarah went from being a young adult to middle age during the course of her M.E. One of the more minor things she had to come to terms with was that 70s disco dancing definitely wasn't the thing anymore. Completely rebuilding a life or constructing it from scratch is a daunting prospect. (Those who have not been so lucky as to recover will probably now be thinking, 'I'd love to find out'. I wish anyone in that position the good fortune to recover to that extent).

Live in the moment

Rebuilding takes time and energy and you may fear you will run out of both before you get there. Enjoy what you can of the journey rather than just focusing on the end result. Think of the other meaning of recovery to salvage. You can decide what you want to salvage from your old life and what you want to throw away. You may be in a position to get rid of things you did to please other people. Who knows, one day you may find that there you are in this new life and it's not so bad after all. On a good day you may even have a sneaking suspicion that it is rather better than anything you had before. In saying that I am not suggesting that having M.E. is worth it. To those who say to me 'You must have learned so much' I say 'Yes but I could have learned to sub aqua dive, ride a horse, or ski and that would have been much more fun than just learning to live with an illness.' Who would choose that?

Val Rubie, who had M.E. for over 15 years, has recovered enough to qualify as a psychotherapist and has set up a counselling and psychotherapy practice specialising in problems the illness can create.

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'Well-Being' and Being Well

by JOY Stevenson

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

One of the difficult things about CFS/ME is that, because there is no scientific measure for how sick we are, there is no scientific measure of how well we are. If we are so sick that we can't get out of bed, it is perfectly clear we are dreadfully ill (to ourselves at least). But if we are well enough to push ourselves to do something (whether it is having a shower, or keeping our full-time job) it is easy to decide we are well enough to do that thing. If we are sick in an up and down way (as most of us are) we find it hard to have any concept of our state of health. Most of us are optimists and most of the time (in spite of all signs to the contrary) we are sure that we are really getting better now.. .

We don't usually make a distinction between 'Being Well', as in having good health and 'Well-Being', as in having a good quality of life - they generally go together. However, it is a useful distinction with CFS/ ME. Often with CFS/ME there are clear times when you can improve your well-being (by getting a good night's sleep, by leaving your job, by stopping your aerobics class.. whatever). This does not mean your health has improved.

It is one of those things that is perfectly obvious but that can take years to see. If we saw someone walking around on their broken leg and complaining about how much pain they were in we would look at them in disbelief. Similarly, if they were lying in bed with their leg in traction and with suitable medication and said, "The pain is just about gone, so I must be better" everyone around them would be telling them exactly how untrue that is.

If only we had that sort of support with CFS/ME. The nebulous, up and down, vague and shifting symptoms that are often part of CFS/ME make it a difficult illness to monitor.

I was ill for several years before being diagnosed and I remember in that time thinking that I could count on the fingers of one hand the times in the previous years I had felt positively well. I am not talking about more than a momentary feeling of well-being, maybe for a few minutes one morning, or surprising me at another time. I was (am) so programmed to what I should be doing and capable of, that my own sense of health or well-being came a long way behind in what I expected for myself. Like most people who plough through their work day with a hangover or the flu, or who keep looking after their children with no sleep or break, I accepted that you just got on and did things, no matter how you felt. So, for me, it was a revolutionary step to put my well-being first.

But a large step forward came when I let go of trying to race back to good health (being well) and concentrated instead on improving my quality of life (well-being). The first and most precious outcome was that I got my concentration back. Precious, precious, precious. Once again I could read, I could be continually more confident of holding a conversation and holding an idea. This, although I hadn't realised it, was more important to me than being able to walk, garden or stand up for more than 30 seconds. Precious, precious mental faculties!

With them I felt like a human again. How exciting to play a computer game on the computer, and do it! How exciting to answer the phone easily, without dread. What a pleasure to take on a job of facilitating Telephone Link-Up for the Society and to be able to do it.

Such immediate success served to consolidate my programme. I had to keep within my parameters and so had to get serious about supports like home help, disability sticker, never pushing myself to go up steps or walk further than I was able. It took such a lot of effort (and overdoing things) to get those supports in place, that I am still working on the fine-tuning..but there is no doubt about it, my quality of life has improved 400%, 500%, much more than that.

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

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Medical Matters

The Onset of CFS

by Dr David S. Bell

The onset of CFS, like nearly every other aspect of this illness, has been a subject of debate over the years. There appear to be several ways CFS may begin. Do the differences in onset imply separate illnesses? Do the differences imply different prognoses? What would chemical exposure, viral infection and emotional stress have in common that could result in similar symptom patterns? In this piece I would like to explore the differing types of illness onset.

The onset pattern most studied is the acute onset following a viral type of infection such as the flu or mononucleosis. In this scenario, a person has been in excellent health with no activity limitations, sometimes even being exceptionally healthy. There occurs a flu-like illness, usually unremarkable, with which the individual reluctantly acquiesces, but without concerns that it is anything more than a typical virus. Three or four days later there begins a slow improvement, followed by a return of symptoms with exhaustion being prominent. These symptoms then persist for months and years.

While this pattern is by no means universal, it occurs with enough frequency that I would consider it the “classic” presentation. What is most interesting to me is that this viral illness seems to begin resolving, just as it should in a few days. Then for some reason, there is a turn for the worst, and CFS begins. Of course it is many months, sometimes years, before the diagnosis is made, but it can be traced back to a specific illness. Many people remember the specific day it began, a few remember the hour it began.

Is there anything unusual about this initiating illness? It has been my belief that the degree of exhaustion in the first few days is greater than usual. However, this observation may be an artifact as the persistence of fatigue make people remember it more prominently, a phenomenon called recall bias. Some persons may have a typical flu, some an intestinal bug with nausea and vomiting. Some are said to have mononucleosis, and some really have mono. CFS has been seen after unusual infections, such as Psitticosis.

It is possible that prolonged fatigue and neurologic symptoms following Lyme disease is not due to persistence of the Lyme organism, but is the CFS reaction after an initiating infection. Of interest, I have seen many persons who have come down with CFS following a flu-like illness shared by other family members where the family members recovered.

One interesting series of studies has taken place in Australia where prolonged fatigue has followed Q fever, an infection rarely seen in the US.

In these cases there was no doubt about the diagnosis of the initial illness, and appropriate therapy was begun. Yet instead of the normal, expected recovery, a prolonged debility persisted. In another Australian study, four different viral agents were identified by blood specimens that appeared to result in CFS .A variant of poliovirus has long been suspected as the cause of CFS.

Thus it may be that there is no single agent that causes CFS, **but** instead multiple agents that initiate a process which results in CFS. If this is true, then identification of the abnormal process would result in a treatment. If this turns out to be true, who cares about what set it off?

A variation of acute onset occurs. In this variation, persons develop numerous infections over weeks or months and seem to recover between episodes. Several sore throats, sinus infections, a walking pneumonia or two.

At first it seems coincidental, bad luck, and courses of antibiotics are given, younger persons sometimes losing their tonsils to the hope of returning to an infection-free state. But the episodes continue and begin to coalesce; full recovery does not occur between episodes. Finally the symptoms become constant and CFS is established.

This type of onset is interesting because it raises two questions. First, it may be that an individual’s immune response is not normal, and that person is now more susceptible to sore throats and sinus infections. This has been assumed for many years in the study of CFS, and people frequently talk of their decreased immunity.

Grocery stores now sell immune enhancers, whatever they are. I do not like this theory for the simple reason that serious or identifiable infections rarely occur. If someone’s immune system was damaged to the degree that it caused recurrent viral infections, they should also develop big time (ie. real) infections such as abscesses, meningitis, and pneumonia.

A second possibility: suppose for a moment that these episodes are not separate viral infections, but some

(Continued on page 24)

Follow-Up Survey of Lyndonville Children

Most report At Least Partial Recovery From CFS Symptoms

By Mark Giuliucci

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Eighty percent of children stricken with chronic fatigue syndrome (CFS) during a cluster outbreak in the 1980s report making at least a partial subsequent recovery, according to a follow-up study published in the journal Pediatrics.

The findings were based on questionnaires returned by 35 of the 46 children and adolescents who developed CFS-like symptoms in Lyndonville, N.Y. from 1984-87. Of the 35 respondents (24 female, 11 male), 13 (37.1%) report they "recovered completely and feel entirely well." Fifteen (42.9%) said they "have never recovered completely but feel pretty well." Four participants (11.4%) said they "recovered somewhat but remain ill," and three (8.6 %) say they are "more ill" than they were 10 years ago.

All 35 respondents retrospectively met the 1994 international research case definition for CFS at the onset of their illnesses. Each respondent developed unexplained, activity-limiting fatigue for at least six months and at least four of the eight case criteria symptoms (see sidebar). None reported a subsequent diagnosis that would explain their symptoms.

The children were part of a group of 214 Lyndonville residents who developed CFS-like symptoms in the 1980s. No cause has been found for the cluster of CFS cases.

The survey questionnaire included the following items:

- Medical Outcomes Study Short Form Health Survey (SF-36);
- Subsequent medical and emotional diagnoses;
- Visual analog scores (VAS) indicating present severity of 12 CFS-related symptoms;
- Subjective effect of the illness on social and educational life.

Of the 13 respondents who reported complete recovery, none said that their symptoms disappeared within one year of onset. Two "recovered" within one or two years; one "recovered" within two or three years; three "recovered" between three and four years after onset; and three "recovered" after four years. The final

(Continued from page 23)

other process that is beginning to become established. After all, what we diagnose as a sinus infection is not always due to a viral illness. It may be allergic, inappropriate production of cytokines, or some other process.

Could it be possible that what we assume is .a viral infection may not be related to a virus at all? In clinical medicine, physicians rarely delve into this point. After all, if someone comes into the office with a runny nose and fever, patients are unhappy if I say I have no idea what is causing the symptoms. Instead, I smile, say the magic word !infection! and write for an antibiotic, which sometimes actually helps. But suppose the mechanism that makes an Echovirus cause a cold is actually shared with something else. Is there a common denominator that underlies the symptoms we assume is due to a virus?

The third onset type is the gradual onset. Here it is impossible for an individual to date the beginning of the illness. Instead, over months or years there has been a gradual increase in fatigue and other symptoms, at first assumed to be stress, overwork, or depression. But when the degree becomes extreme or when there is no recovery with rest, the diagnosis of CFS is entertained.

This type of CFS is discriminated against even more than the other types of CFS .It is one thing for a marathon runneo wake up one day and be unable to get out of bed, in comparison to a person that slowly, without apparent reason gets more and more run down. Persons with the gradual onset also adjust over the months. Their illness is coming on gradually and they take steps, cutting down on certain activities or taking more rests. They do not experience the sudden shock of the acute onset where there is no doubt that some illness has occurred.

A fourth type of CFS onset includes the stragglers with onset descriptions that are diverse, yet still result in the symptom pattern characteristic for CFS. Some persons develop CFS after a head injury , some after exposure to paint or other chemical fumes. CFS has been described as a consequence of organophosphate poisoning and ciguatera poisoning, but I find I rarely ask my patients if they may have eaten Carcharhinus in Madagascar before they became ill. One patient I saw had CFS following a clear-cut case of lead poisoning.

respondent reported that symptoms disappeared after 9.5 years.

Bell says that the 80 percent recovery figure is somewhat misleading. More than half of those who reported improvement still suffer from lingering CFS symptoms. Many of them have been forced to adopt coping mechanisms that include restricted activity, flexible daily schedules and a lack of sustained activities.

VAS results generally correlated with self-reported recovery rates. The scores used for analysis were the sums of 12 symptom-specific categories that were self-graded between 0 (no symptom) to 10 (severe symptom). Those who reported complete recovery average a VAS of 15.4, while those who said they had grown more ill reported an average VAS of 74.7.

The SF-36 results showed similar correlation. Subjects who reported better recovery scored higher than others in all eight test domains.

The respondents' perceived recovery also matched their reports of how the illness affected their social lives. Twelve of the 35 (34.3%) said the illness did not have an overall effect on them socially; 10 of those 12 had reported complete recovery. Sixteen respondents (45.7%) said the disease had a mild impact on their social lives, three (8.6%) claimed a moderate effect and four (11.4%) said that CFS severely impacted them socially.

Notes for clinicians

Guidelines for diagnosing CFS do not differentiate between pediatric and adult cases, but Bell says his experience indicates that two symptoms are often more prominent among children. The first is activity limitation. Children with CFS are more likely to report being forced to curtail daily activities than their adult counterparts. Children also appear more likely to suffer from the effects of orthostatic intolerance (OI). Bell says it's not clear whether children with CFS develop OI more frequently than adult patients. They may simply be more sensitive to the symptoms of OI than adults.

Bell also believes that physicians should not shy away from diagnosing CFS for fear of encouraging illness behavior. Bell and his co-authors write that this would create "severe difficulties in clinical management." Diagnosing CFS can actually help reduce patient and parental anxiety, can reduce the number of unnecessary laboratory tests and evaluations and can help with attempts at symptom control.

The study also addresses similar concerns about "sympathetic" physicians encouraging children to continue to complain about symptoms. Bell was the primary physician for all 35 respondents during the early years of their illnesses, but continued to care for only 10 of them after the initial treatment period. The other 25 either saw another doctor or "recovered" and did not need additional care. Responses from the questionnaire show no differences between group of 10 and the group of 25. Bell says this indicates the attitude of the treating physician about CFS has little to do with the eventual outcome of the disease.

David S. Bell, MD, FAAP; Karen Jordan, PhD; and Mary Robinson, MS. "Thirteen-Year Follow-Up of Children and Adolescents With Chronic Fatigue Syndrome." Pediatrics. 2001; 107(5): 994-998.

Research Review
Summer 2001
The CFIDS Association of America
P.O. Box 220398,
Charlotte NC 28222-0398
www.cfids.org.

A FEW TIPS ABOUT NEW TREATMENTS

1. Beware of miraculous new treatment stories which appear in the media from time to time. Always look for treatments which have some scientific evidence of effectiveness, such as those backed by clinical research trials.
2. Always consult your medical practitioner before starting a new treatment.
3. Do a bit of research before try a new treatment: ask around about it at the very least.
4. Be wary of those claiming good results from a particular product that they are selling. Their commission might be colouring their story.
5. It is best to try only one new treatment at a time, so you can be certain of what is actually helping/aggravating your condition.
6. Very few treatments are without side-effects. Sometimes you must weigh the good against the bad.
7. Don't be discouraged should a particular treatments fail to work for you. ME/CFS is a confounding illness. Some treatments can have dramatic effects on only a small percentage of sufferers, and not benefit the rest.
8. Pace yourself – don't tire yourself out by trying too many treatments in a rush.

ME/CFS/PVFS

What should we call this illness & how should it be defined?

A personal view by Dr Charles Shepherd, 2001.

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

In July this year The ME Association decided to change the E in ME from encephalomyelitis (meaning inflammation of the brain and spinal cord) to encephalopathy (meaning a serious disturbance in various aspects of normal brain function). The decision was largely made as a result of growing opposition from all shades of medical opinion to the use of the term encephalomyelitis when there is no sound scientific evidence to demonstrate that this type of brain damage is present. On the other hand, there is now growing evidence of the type of brain abnormalities, which could be consistent with an encephalopathy.

In practice, the continued use of the term encephalomyelitis not only meant that many GPs and Consultants were unwilling to make a diagnosis of ME. We also had to face the fact that all of the leading medical journals were abandoning any constructive use of the term ME and simply referring to CFS (chronic fatigue syndrome).

The Association also acknowledged that while we will still be using the term ME, the majority of the medical profession will probably continue to prefer the term CFS in both routine clinical practice and research activity. So whilst we share the views of many people with this illness, as well as a significant number of doctors, that CFS is a derisory and completely inappropriate name, there is no point in ignoring the fact that CFS is the only name that many doctors are currently willing to use. And this is why The Association has decided to refer to ME/CFS in all our literature in a spirit of compromise, but not one of agreement that CFS is an acceptable way of either naming or defining the illness.

What an illness is called and how it is defined are obviously crucial when it comes to research into both cause and management, and ME/CFS is no exception. The problem here is that if patients continue to talk about ME, their doctors stick to CFS, and The Association refers to ME/CFS are we all talking about the same illness when it comes to symptoms, cause and treatment?

As far as symptoms are concerned, the answer is only a partial yes because although most people with ME as described by Melvin Ramsay would also meet the research criteria for CFS, there are others who do not. And because the definition of CFS encompasses a much wider group of people with an illness where fatigue is a prominent feature --including some whose problem is mainly psychiatric -- some of this group would not fit into the Ramsay description of ME. This is obviously a messy and unsatisfactory situation.

The answer is even more complicated when it comes to the question of whether there is a different pathology (= disease process) going on in ME and CFS, and consequently a different response to treatment. Sadly, there has been very little high quality research carried out in people with Ramsay--described ME. In fact, most of the research that has demonstrated physical abnormalities in muscle, brain and immune system function has all been carried out in people with CFS. And the same reasoning applies to studies on various forms of treatment, almost all of which have been carried out on people with CFS, with no clear indication that those with ME respond any differently to any treatments currently in use. So anyone who argues that ME and CFS are completely different illnesses from the point of view of pathology and response to management does not have a case that would stand up in a court of law.

So is there a way forward? My own view is that we first have to accept that there is no ideal name for this illness (or group of illnesses) at present. In the short term, the compromise of ME/CFS - covering as it does a range of people with conditions in which mental and physical fatigue are the prominent features - is one way of trying to bring doctors and patients together. At the same time, there is an urgent need for more research into both the clinical and pathological processes which may help to separate out what are undoubtedly a range of different sub-groups of patients under the ME/CFS umbrella. These sub-groups might be based on clinical symptoms (eg presence or absence of psychiatric

problems, muscle pain etc) or pathological findings (different types of brain, hormonal or immunological abnormalities). It may eventually turn out that the illness described as ME has a distinct pathology but we cannot make that conclusion at present. When the sub-grouping finally does become clearer, we may even end up with an illness like arthritis which includes a number of distinct conditions -- rheumatoid, osteo-, psoriatic, infective etc -- which all have important similarities and differences when it comes to cause, disease process, and management. In the meantime, it is just not possible to maintain that ME and CFS are two completely separate conditions. Anyone who does has not done their homework!

The Three Main Definitions

1. Melvin Ramsay's description on ME

(Source: Ramsay M, Myalgic enchepalomyelitis and fatigue states, Cower Medical and postviral fatigue states, Cower Medical Publishing for the ME Association, 1988)

Acute onset often following an infection.

- Muscle fatigue (which is brought on by relatively minor degrees of physical exertion), spasms and twitchings (fasciculations), and pain or tenderness.
- Circulatory impairment, including cold hands and feet, increased sensitivity to temperature change (particularly night sweats), and pallor of the face.
- Cerebral dysfunction affecting memory, concentration and word finding abilities.
- Other symptoms include headaches, giddiness, paraesthesiae (sensory disturbances felt in the skin), blurred vision, tinnitus (noises in the ear), palpitations, and a general sense of 'feeling awful'.
- A tendency to become chronic with a considerable variation and fluctuation in symptoms.

2. USA (CDC/FUKUDA) Definition of CFS -1994

(Source: Fukada et al, Annals of *Internal Medicine, 1994, 121, 953-959)*

- A new onset of severe disabling fatigue that is not relieved by rest and results in a substantial reduction in normal everyday activities.
- Symptoms have to be present for six months at least.
- Four other symptoms from a list of: cognitive dysfunction (memory and concentration problems), sore throat, tender enlarged glands, muscle pain, headaches, unrefreshing sleep, joint pain, post-exertional malaise.
- Cognitive dysfunction may be present but this is not an essential part of the diagnosis.

All known physical causes and some psychiatric causes of chronic fatigue have to be excluded.

3. UK (Oxford) Definition of CFS - 1991

(Source: Sharpe et al, Journal of the Royal Society of Medicine, 1991, 84, ***118 - 121)***

- New onset of severe disabling fatigue affecting both physical and mental functioning.
- Symptoms have to be present for six months at least.
- Other symptoms not specified but mental fatigue is required.
- All known physical causes and some psychiatric causes of chronic fatigue have to be excluded.

Conclusion

I still believe that Melvin Ramsay's clinical description of this illness is by far the best. The other two international definitions have become so broad in their inclusion of all kinds of people with undiagnosed chronic fatigue that they have become almost meaningless. They are also of little value for routine clinical assessment because of the way in which symptoms have to be present for six months or more before the diagnosis can be confirmed.

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Recently published study briefs

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Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Long-term outcome of cognitive behaviour therapy versus relaxation therapy for chronic fatigue syndrome: a 5-year follow-up study.

Deale A, Husain K, Chalder T, Wessely S.
Am J Psychiatry 2001 Dec;158(12):2038-42

This study evaluated the long-term outcome of cognitive behaviour therapy versus relaxation therapy for patients with chronic fatigue syndrome. Sixty patients who participated in a randomized controlled trial of cognitive behaviour therapy versus relaxation therapy for chronic fatigue syndrome were invited to complete self-rated measures and participate in a 5-year follow-up interview with an assessor who was blind to treatment type. Fifty-three patients (88%) participated in the follow-up study: 25 received cognitive behaviour therapy and 28 received relaxation therapy.

A total of 68% of the patients who received cognitive behaviour therapy and 36% who received relaxation therapy rated themselves as "much improved" or "very much improved" at the 5-year follow-up. Significantly more patients receiving cognitive behaviour therapy, in relation to those in relaxation therapy, met criteria for complete recovery, were free of relapse, and experienced symptoms that had steadily improved or were consistently mild or absent since treatment ended. Similar proportions were employed, but patients in the cognitive behaviour therapy group worked significantly more mean hours per week. Few patients crossed the threshold for "normal" fatigue, despite achieving a good outcome on other measures. Cognitive behaviour therapy was positively evaluated and was still used by over 80% of the patients.

Cognitive behaviour therapy for chronic fatigue syndrome can produce some lasting benefits but is not a cure. Once therapy ends, some patients have difficulty making further improvements. In the future, attention should be directed toward ensuring that gains are maintained and extended after regular treatment ends.

The neuroendocrinology of chronic fatigue syndrome and fibromyalgia.

Parker AJ, Wessely S, Cleare AJ.
Psychol Med 2001 Nov;31(8):1331-45

The hypothalmic-pituitary-adrenal axis (HPA) is the primary endocrine stress axis in the human body. The HPA is involved in the complex secretory regulation of cortisol, a stress hormone with multi-organ/tissue effects. Control of the HPA is partly regulated through reciprocal interactions with the 5-HT (serotonin) system. Such interactions are complex and are not yet fully understood.

Disturbance of the HPA may be important in the pathophysiology of chronic fatigue syndrome (CFS) and fibromyalgia. Symptoms may be due to: (1) low circulating cortisol; (2) disturbance of central neurotransmitters; or (3) disturbance of the relationship between cortisol and central neurotransmitter function. Accumulating evidence of the complex relationship between cortisol and 5-HT function, make some form of hypothesis (3) most likely.

Parker et al reviewed the methodology and results of studies of the HPA and other neuroendocrine axes in CFS. Medline, Embase and Psychlit were searched using the Cochrane Collaboration strategy. A search was also performed on the King's College CFS database, which includes over 3000 relevant references, and a citation analysis was run on the key paper (Demitrack et al. 1991[1]).

One-third of the studies reporting baseline cortisol found it to be significantly low, usually in one-third of patients. Methodological differences may account for some of the varying results. More consistent is the finding of reduced HPA function, and enhanced 5-HT function on neuroendocrine challenge tests. The opioid system, and arginine vasopressin (AVP) may also be abnormal, though the growth hormone (GH) axis appears to be intact, in CFS.

The significance of these changes, remains unclear. There is currently little understanding of how neuroendocrine changes relate to the experience of symptoms. It particularly unclear whether these changes are primary, or secondary to behavioural changes in sleep or exercise. Longitudinal studies, following populations at risk for CFS, will help to resolve these issues.

[1] Demintrack M, Dale J, Straus S et al, 1991. Evidence for impaired activation of the hypothalamic-pituitary-adrenal axis in patients with CFS. Journal of Clinical Endocrinology and Metabolism, 73: 1224-34.

See also the article by M. Werbach in this issue.

Symptom occurrence in persons with chronic fatigue syndrome.

Jason LA, Torres-Harding SR, Carrico AW, Taylor RR. Biol Psychol 2002 Feb;59(1):15-27

This investigation compared differences in the occurrence of symptoms in participants with CFS, melancholic depression, and no fatigue (controls). The following Fukuda et al. [Ann. Intern. Med. 121 (1994) 953] criteria symptoms differentiated the CFS group from controls, but did not differentiate the melancholic depression group from controls: headaches, lymph node pain, sore throat, joint pain, and muscle pain. In addition, participants with CFS uniquely differed from controls in the occurrence of muscle weakness at

multiple sites as well as in the occurrence of various cardiopulmonary, neurological, and other symptoms not currently included in the current case definition.

Converse to previous investigations (Komaroff et al, 1996) muscle weakness and arthralgias uniquely differentiated the CFS group from controls, while anorexia and nausea did not differentiate the CFS group from controls. Findings consistent with previous studies (Komaroff et al, 1996; Hartz et al, 1998) were that the symptom of sleep disturbance did not differentiate the CFS group from controls, whereas muscle weakness (at multiple sites) and sensitivity to alcohol did differentiate the CFS group from controls.

Differences between this current investigation and prior investigations could be the result of the sampling methods employed, with prior research relying predominantly on clinic-based samples, which may represent a more severely ill population, or at least a population which reports greater frequency and extent of symptom occurrence and severity. Most studies, including the current study, have had limited statistical power, imposed by small sample sizes of comparison groups. This may have precluded the detection of significant differences between groups, and therefore further research with larger samples is necessary to replicate these results. Another limitation of the current study is the lack of a comparison group, other than the melancholic depression group, who also report similar fatigue-based subjective symptoms. A suitable comparison group could consist of Multiple Sclerosis patients, as investigated by Komaroff et al (1996).

Maximal oxygen uptake and lactate metabolism are normal in chronic fatigue syndrome.

Sargent C, Scroop GC, Nemeth PM, Burnet RB, Buckley JD.
Med Sci Sports Exerc 2002 Jan;34(1):51-6

Previous studies in chronic fatigue syndrome (CFS) have reported reductions in maximal oxygen uptake (VO_{2max}), yet often the testing procedures have not followed accepted guidelines, and gender data have been pooled. The present study was undertaken to re-evaluate exercise capacity in CFS patients by using "gold standard" maximal exercise testing methodology and stratifying results on a gender basis.

Sixteen male and seventeen female CFS patients and their gender-, age-, and mass-matched sedentary controls performed incremental exercise to volitional exhaustion on a stationary cycle ergometer while selected cardiorespiratory and metabolic variables were measured.

VO_{2max} in male CFS patients was not different from control values (CFS: 40.5 +/- 6.7; controls: 43.3 +/- 8.6; mL x kg^{-1} x min^{-1}) and was 96.3 +/- 17.9% of the age-predicted value, indicating no functional aerobic impairment (3.7 +/- 17.9%). In female CFS patients, VO_{2max} was lower than control values (CFS: 30.0 +/- 4.7; controls: 34.2 +/- 5.6; mL x kg^{-1} x min^{-1}, $^{\dagger}P$ = 0.002), but controls were higher than the age-predicted value (112.6 +/- 15.4%, P = 0.008) whereas the CFS patients were 101.2 +/- 20.4%, indicating no functional aerobic impairment (-1.2 +/- 20.4%).

Maximal heart rate (HR_{max}) in male CFS patients was lower than their matched controls (CFS: 184 +/- 10; controls: 192 +/- 12; beats x min^{-1}; P = 0.016) but was 99.1 +/- 5.5% of their age-predicted value. In female CFS patients, HR_{max} was not different from controls (CFS: 183 +/- 11; controls: 186 +/- 10; beats x min^{-1}) and was 98.9 +/- 5.1% of the age-predicted value. The VO_2 at the lactate threshold (LT) in each gender group, whether expressed in mL x kg^{-1} x min^{-1} or as a percentage of VO_{2max} , was not different between CFS patients and controls.

Therefore, in contrast to most previous reports, the present study found that VO_{2max} , HR_{max} , and the LT in CFS patients of both genders were not different from the values expected in healthy sedentary individuals of a similar age.

($^{\dagger}P$ = Probability; < 0.05 is usually designated as a significant finding, as the result may occur by chance only 5/100ths (or 1/20th) of the time.)

Blood volume and its relation to peak O_2 consumption and physical activity in patients with chronic fatigue.

Farquhar WB, Hunt BE, Taylor JA, Darling SE, Freeman R. Am J Physiol Heart Circ Physiol 2002 Jan;282(1):H66-71

Individuals with chronic fatigue syndrome (CFS) experience a number of somatic complaints including severe, disabling fatigue, and exercise intolerance. We hypothesised that hypovolaemia, through its interaction with central haemodynamics, would contribute to the exercise intolerance associated with this disorder. We examined blood volume, peak aerobic power, habitual physical activity, fatigue level, and their interrelations to understand the physiological basis of this disorder.

Seventeen patients who met the Centers for Disease Control criteria for CFS and 17 age-matched controls participated in the study. Blood volume was assessed using a single bolus injection of Evans blue dye. Peak oxygen consumption was measured during exercise on an upright cycle ergometer. Supine cardiac output and stroke volumes were measured using CO_2 rebreathing. Questionnaires were used to assess habitual physical activity and fatigue.

Patients displayed a trend for a 9% lower blood volume (58.3 +/- 2.1 vs. 64.2 +/- 2.5 ml.kg^{-1}, P = 0.084) and had a 35% lower peak oxygen consumption (22.0 +/- 1.2 vs. 33.6 +/- 1.9 ml/kg, P < 0.001). These two variables were highly related within the patients ($^{\dagger}r$ = 0.835, P < 0.001) and the controls (r = 0.850, P < 0.001). Peak ventilation and habitual physical activity were significantly lower in the patients. Fatigue level was not related to any of the

(Continued on page 30)

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measured physiological parameters within the CFS group.

In conclusion, individuals with CFS have a significantly lower peak oxygen consumption and an insignificant trend toward lower blood volume compared with controls. These variables were highly related in both subject groups, indicating that blood volume is a strong physiological correlate of peak oxygen consumption in patients with CFS.

(‡r = Regression coefficient; gives the strength of linear relation between the variables (the amount by which one variable changes as a result of a unit change on the other variable. A perfect positive linear relation is represented r=1.0; the closer to this value, the greater the relation between variables, with 0.70 usually designated as strong, 0.4, as moderate, and 0.2, as weak.)

Family cognitive behaviour therapy for chronic fatigue syndrome: an *uncontrolled* study.

Chalder T, Tong J, Deary V.
Arch Dis Child 2002 Feb;86(2):95-7

This study examined the efficacy of family focused cognitive behaviour therapy for 11-18 year olds with chronic fatigue syndrome.

Twenty-three patients were offered family focused cognitive behaviour therapy. The main outcome was a fatigue score of less than 4 and attendance at school 75% of the time. Twenty patients completed treatment. Eighteen had completed all measures at six months follow up.

15 of the 18 patients (83%) improved according to predetermined criterion. Substantial improvements in social adjustment, depression, and fear were noted.

Family focused cognitive behaviour therapy was effective in improving functioning and reducing fatigue in 11-18 year olds. Gains were maintained at six months follow up.

Enablenet

www.enable.net.au

Frustrated at not being able to find the disability information that you need? Fed-up with hours of fruitless surfing of the Internet? Sick of cluttered sites with things all over the place? Don't give up GO TO www.enable.net.au - EnableNet is a Disability Portal created and maintained by the Disability Information and Resource Centre (DIRC). It is the one-stop-site on the Internet for information on all aspects of disability.

DIRC has structured EnableNet in a clear, reasonable and consistent way to ensure that you can find the information you want with a minimum of fuss.

This is not just another website with a page of links. It is an access point to more than 2,700 websites. To make life easier the contents of all websites are summarised so that you can decide at a glance if they are relevant for you. And the sites are all indexed using the *EnableNet Thesaurus* so that you can browse for the specific subject area that interests you.

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Aboriginal Australians & Indigenous Issues; Access; Accommodation Options & Living Skills; Advocacy/ Social Justice; Aids & Equipment; Community Services; Disabilities, Diseases & Disorders; Education; Employment; Finance & Management; Human Relations/Psychology; Information & Library Services; Politics & Legislation; Recreation, Sport & the Arts; Statistics & Surveys; Transport/Travel.

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Another great feature of EnableNet is that you can set it up to accommodate your particular needs. We provide you with options to change colours, size of font and turn off graphics so that EnableNet appears on your screen in the way you want it. (As Joe Clark said "Accessibility is about accommodating characteristics a person cannot change by providing options")

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Serotonin in Chronic Fatigue Syndrome & Fibromyalgia

By Melvyn R. Werbach

While the picture is far from clear, serotonin metabolism appears to play a role in both chronic fatigue syndrome (CFS) and fibromyalgia although the nature of that role appears to differ. Tryptophan is the dietary precursor to serotonin and, for fibromyalgia, there is some evidence that tryptophan levels are depressed. For example, in a study of fibromyalgia patients suffering from severe pain, plasma free tryptophan levels were inversely related to the severity of their pain. [1] Moreover, when fibromyalgia patients were compared to normals, plasma tryptophan levels tended to be lower in the patient group, and their transport ratio of tryptophan to the other competing amino acids was significantly decreased, suggesting that brain serotonin levels may also be depressed. [2] Does the administration of a serotonin precursor help patients with fibromyalgia? In the general population, tryptophan supplementation usually provides a mild degree of analgesia. Moreover, it may be especially effective for the subset of chronic pain patients with a disorder of serotonergic transmission. [3] As to fibromyalgia, a group of 50 patients received 100 mg 3 times daily of 5-hydroxytryptophan, the metabolite of tryptophan and immediate precursor of serotonin, in an open trial. After 3 months, nearly half of the group had a fair to good degree of overall improvement. There were highly significant improvements in fatigue, the number of tender points, pain intensity, anxiety and sleep quality. [4] These results were similar to those of an earlier double-blind study by the same group of investigators, [5] and suggest that fibromyalgia patients may respond to L-tryptophan supplementation similarly to other patients suffering from anxiety, depression, insomnia and pain.

Turning to CFS, at least 3 studies have found L-tryptophan to be depressed in the plasma of CFS patients [6-8] -- a finding already noted in fibromyalgia patients. However, in contrast to fibromyalgia, there is evidence that OFS is marked by serotonergic hyperactivity. One study found not only that CFS patients had higher baseline plasma tryptophan levels, but also that these levels failed to rise and fall normally during exercise, causing the researchers to speculate that an abnormally high level of brain serotonin may cause the persistent central fatigue. [9] (In healthy subjects, L-tryptophan administration can cause central fatigue. [10]) Moreover, several other studies have also found evidence of increased serotonergic activity in CFS patients." [11-14]

If CFS is marked by serotonergic hyperactivity, then medications that block serotonin receptors may be beneficial. Indeed, a small pilot study found that the use of serotonin (5-HT3) receptor antagonists was followed by at least a 35% improvement in about one-third of patients. [15] Would nutritional supplements be equally effective while having less danger of adverse side effects? The efficacy of nicotinamide adenine dinucleotide (NADH), the reduced coenzyme form of niacin, has been investigated in a double-blind crossover study. At baseline, CFS patients were found to have elevated urinary concentrations of 5-hydroxyindoleacetic acid, the major metabolite of the neurotransmitter serotonin. They received 10-mg daily of NADH or placebo. Not only was NADH significantly more effective in reducing CFS symptoms than placebo, but the elevated 5-HIAA levels dropped to normal suggesting that the efficacy of NADH could well be due to an ability to normalize serotonergic hyperactivity. [16]

Perhaps other nutritional approaches that reduce brain serotonin levels would also be effective. For example, CFS patients could be placed on a low-tryptophan diet, or they could be supplemented with the essential amino acids that compete with tryptophan for brain uptake (phenylalanine, tyrosine, leucine, isoleucine, and valine). Hopefully, researchers will eventually pursue these lines of investigation.

Doctor Werbach cautions that the nutritional treatment of illness should be supervised by physicians or practitioners whose training prepares them to recognise serious illness and to integrate nutritional interventions safely into the treatment plan.

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FACT SHEET: Laboratory and Clinical Differences between CFS and Depression

By Eleanor Stein MD FRCP(C)

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Laboratory / Research Findings	
CFS	**Depression**
Decreased urinary 24 hour cortisol (Cleare *et al*, 2001)	Normal or increased urinary 24 hour cortisol
Dexamethasone over-suppression	Dexamethasone non supression
Decreased urinary cortisol (Scott & Dinan, 1998)	Increased urinary cortisol (Scott & Dinan, 1998)
QEEG abnormalities different from depression (Flor Henry *et al*, 2001)	QEEG abnormalities different from CFS
Low prestimulus electrodermal level	Normal prestimulus electrodermal level
High prestimulus digital skin temperature	Normal prestimulus skin temperature
Cerebral blood flow decreased in brain stem (Costa *et al*, 1995)	Cerebral blood flow decreased in prefrontal cortex (MacHale *et al*, 2000)

Clinical Presentation	
CFS	**Depression**
Fatigue is the primary symptom	Mood change is the primary symptom
Both physical and mental fatigue	Physical fatigue rare
Fatigue both physical and mental worsened by physical or mental exertion (Blackwood *et al*, 1998)	Fatigue and mood improve with exercise
Decreased positive affect (energy, enthusiasm, happiness)	Increased negative affect (apathy, hopelessness, suicidal ideation, self reproach)
Attributional bias only for somatic complaints	Generalized negative attributional bias
Externalizing attributional style (Powell *et al*, 1990)	Internalizing attributional style (Powell *et al*, 1990)
Personality dysorder no more common than control samples (Pepper *et al*, 1993)	Increased prevalence of personality disorder than controls (Pepper *et al*, 1993)
Infectious onset in > 80% of cases	Rarely follows infectious illness
Physical (somatic) symptoms: requires at least 4 eg. swollen lymph nodes, sore throat, muscle and/or joint pain and headache	Not usually associated with physical symptoms
Cognitive dysfunction most problematic symptom present in absence of depression (slow reaction time and slow effortful processing) (Crowe & Casey, 1999) (Michiels & Cluydts, 2001)	Similar to CFS but able to be differentiated on neuropsychological testing (Daly *et al*, 2001)
Orthostatic intolerance/autonomic dysfunction common (Rowe & Calkins, 1998)	No association with autonomic symptoms
Sleep disorder common	Sleep disorder common
Diurnal variation with pm the worst time of day	Diurnal variation with am the worst time of day
	Symptom variability not marked

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See www.ahmf.org for meeting abstracts.

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Nutritional treatments for 87 different illnesses are covered in Doctor Werbach's internationally acclaimed book, Nutritional Influences on Illness. Further information, or a free brochure describing all of his books, is available from Third Line Press Inc., 4751 Viviana Drive, Tarzana, CA 91356, USA. (Tel: 818-996-0076; FAX: 818-774-1575; E-mail: tlp@third-line.com; Internet: http://www.third-line.com).

Source: Townsend Letter for Doctors and Patients, Nov 2001 p140.

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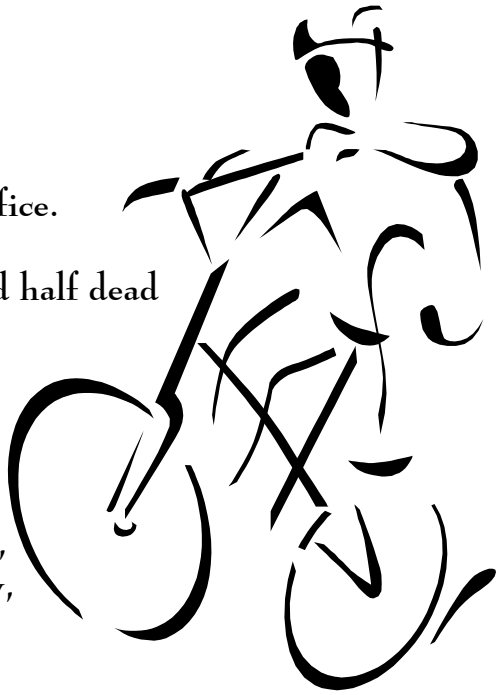
'TWO DAYS IN A ROW'
-- A C.F.S. Dream



I'd like to feel well two days in a row,
Two days in a row feel energy flow
Three would be better,
Four would be nice
If I can't manage that, then two would suffice.

I would not stay in bed feeling stressed and half dead
or half comatosed -- I'd be active instead
I'd throw caution away
And venture outside
I'd borrow a bike and go for a ride.

I'd walk and I'd swim and be active all day,
Careful not to indulge in a strenuous way,
I would water my garden
I'd pick some nice flowers
Or find a good book and sit reading for hours.

I'd eat what I like and my mind would be clear,
With no little bells ringing loud in my ear
And as for the pain
It would all dissipate
What wouldn't I give for this euphoric state.

I'd love to feel well two days in a row,
Two days in a row feel energy flow
In a time yet unknown
I'll be active and well
When that time comes the whole world I will tell.

For now, I'll just dream about normality,
And stick to the things I do comfortably
To push myself harder
Is fruitless -- I know
But, what wouldn't I give for two days in a row.

Written by Brian M. Caire, a ME/CFS Society of SA member.

Your Society Matters....

MAY 12th: International ME/ CFS/FM Awareness Day

May 12th has been International ME/CFS/FM Awareness Day for over a decade.

May 12th was chosen as it marks the birthday of Florence Nightingale who, despite suffering a CFS-like illness, dedicated her life to helping others. She is known as the pioneer of modern nursing and reformer of hospital sanitization methods.

Each year the Society holds an Awareness Week around the date of May 12th. This year we are concentrating on two major events. May 12th is Mother's Day this year so we have chosen to hold our main event, "*The Awareness Evening and Expo*", on a different day. It will be in the evening of Monday May 13th.

Our major fundraiser for the year is a Badge Day which we try to have in Awareness Week. This is not always possible as we have to work in with other charities and the Adelaide City Council who allocate different Fridays to different groups. This year we have been given May 31st for Badge Day.

Badge Day

31st May

For those new to the Society: Badge Day is our main fundraiser for the year. It involves us having collectors stand on street corners 'rattling tins'. This year we are not just focussing on the CBD, but will also be collecting at some suburban shopping precincts.

We encourage members (or more probably their family / friends) to give us a hand if they can. Due to the fact that the health our membership is not generally conducive to this sort of thing, we tend to recruit a lot of outsiders to help get the job done.

This year we hope to raise $6000.

Help is needed for the following:

- collecting for 2-3 hrs (city and metro locations)
- driving collectors around
- overseeing collectors at suburban locations

We also encourage a little lateral thinking. If you would like to take a tin and some stickers to your work to take up a collection for the Society we'll be happy to supply you with the materials.

Please let us know if you have any sporting / social / service club contacts that might be useful to us.

Please register your interest by phoning the office: Ph: 08 8410 8929

Thankyou.

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ME / Chronic Fatigue Syndrome Awareness Evening and EXPO

Overcoming and Managing ME/CFS

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ME / CFS represents a serious health concern in our Community.

People need information and encouragement on how to overcome and manage the condition in order to achieve the best possible lifestyle that they can.

We are very privileged on several fronts. Simon Molesworth, AM QC, is our keynote speaker. Simon is the President of the National Association of ME/CFS and also President of the Victorian Society for ME/Chronic Fatigue Syndrome. His is a powerful speaker, and knowledgeable on the main issues confronting people with ME/CFS.

Simon's became involved in ME/CFS issues in the course of caring for his son who has had ME/CFS.

We are excited that our new Patron Her Excellency Marjorie Jackson-Nelson, AC, CVO, MBE, Governor of South Australia, will open the event for us.

The Event will have an interactive feel, with several groups providing trade stalls on the night. Come at 6:45 pm for the Trade stalls or 7:30 pm for the start of official proceedings.

Everyone is welcome cost is simply a gold coin donation.

If you can't attend then please support the Society by purchasing a Video Tape of the Event for $25 including postage and handling. (Audio tapes $8) - phone the office 08 8410 8929 and an order form will be sent out to you or download one from the website.

Looking forward to seeing as many of you there as possible,

Regards,

Paul Leverenz

Trade Stalls

Representatives from the following organisations (plus many more) will be present to help answer your questions:

- Centrelink
- Independent Living Centre
- Disability Action
- Fibromyalgia SA
- Carers Association of SA Inc

Stalls open from 6:45 pm.

Date / Time / Venue

May 13th at the Burnside Community Centre Corner of Portrush and Greenhill Roads. The official meeting starts at 7:30 pm, but the Trade Stalls will be open from 6: 45 pm.

Please refrain from wearing perfumes, aftershaves and other scented products.

Videos: $25 including postage and handling

video talks

Managing and Overcoming ME/CFS
13 May 2002

Featuring Mr Simon Molesworth, AM QC

Presented by the ME/CFS Society of South Australia

VALE ~ TRACEY ASH
(02/12/1975 – 07/03/2002)

At age 20, Tracey Ash was doing exactly what she desired, living in an apartment in down town Rundle Street, Adelaide amongst intelligent, artistic friends; studying at University; working in cafes and restaurants to sustain her way of life; making web-sites for major functions; and achieving top marks and recognition for her academic endeavours.

Tracey loved to party with friends and family, was sporty, artistic and keenly interested in people from all walks of life and their culture.
She was a person who was prepared to challenge herself emotionally, spiritually and intellectually, not to mention those around her. Her tenacity and resourceful nature stood her well for she did achieve; she was always courageous and had a wonderful ethical basis for her life.

The onset of Tracey's illness is disputable. True, there was a day when struck down with a virus, she said, "I felt extreme pain in my neck and spine and the fog descended." But in hindsight there had been a violent trauma in her life 2 years earlier and she had been "sicker than most of my friends".

From then onwards her life gradually changed as her condition worsened. During the following years Tracey constantly searched for new possibilities of getting well for her greatest desire was to recover from her illness and to heal herself permanently.

Tracey suffered from ME/CFS, Fibromyalgia, Multiple Chemical Sensitivity, Rickettsia, and an unbearable, undiagnosed source of pain. This caused difficulty in speaking and an inability to do even the most simple of routine tasks to care for herself.

She also suffered the frustrating normality of many standard medical tests and the indignity and tendency of orthodox medicine to attach a psychiatric label to her collection of illnesses. Added to this was the inability of being able to travel, tolerate hospital environments or see medical specialists.
All she had was a local doctor, striving to understand and find answers to support her and her family.

The words of one of Tracey's friends describe Tracey in a beautiful way. She wrote:

> "Tracey will live on in my heart forever as a great teacher and friend and is a major contributor to who I am today. She was a great support for me in my experience of CFS; she was a spark igniting my growth. Tracey was a great artist, communicator, dancer, writer, motivator, philosopher, interior designer, teacher and friend. One of the greatest lessons I learned and hold dear to my heart is that love is all that matters. Tracey told me this last year and I try to apply it wholly in my life."

In the end Tracey's mountain became too high and too steep with too many obstacles in her path. Wellness became a faded and unreachable distant light. And so it was that Tracey, with dignity, thoughtfulness and great courage gently and peacefully commended her soul to God.

It is a tragedy that Tracey, a person with such zest for life had to spend such a lot of it in excruciating and relentless pain. She so much wanted to live. This and other desires that Tracey had will now remain as dreams unfulfilled. We are thankful for all the great memories we have of her.

Our wish is that people who knew Tracey will find strength comfort and joy in her memory. That her unique and beautiful character will live on forever and her spirit will continue to influence our lives. Remember her compassion, wit, intellect and the brilliance of her smile.

It is hoped that Tracey's untimely death will light the way for health professionals to improve their knowledge of ME/CFS and inspire them to view this collection of illnesses in a new light. To this end the Tracey Ash Fund was born.

Glenn & Sandra Ash

TRACEY ASH FUND

The Alison Hunter Memorial Foundation will administer the Tracey Ash Fund.
Donations will be directed towards improving medical care for people suffering from Chronic Fatigue Syndrome group of illnesses.

A particular area of emphasis of the Fund will be:

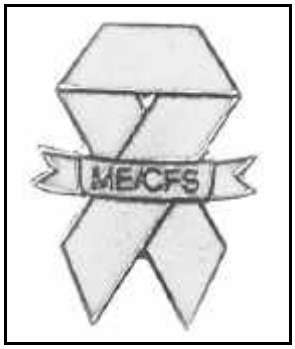
- to work to bridge the gap between research and the local doctor level
- to promote the spirit of generosity and openness in information sharing, educational activities and literature
- to support partnerships between General Practitioners, carers and sufferers particularly at the severe end of the illness
- to work to improve access to a range of appropriate and timely services for severely ill people.

Donations in Tracey's memory may be made to
The Tracey Ash Fund
C/- Alison Hunter Memorial Foundation
P.O. box 2093
BOWRAL, NSW 2576

Items Available from the Society

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

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



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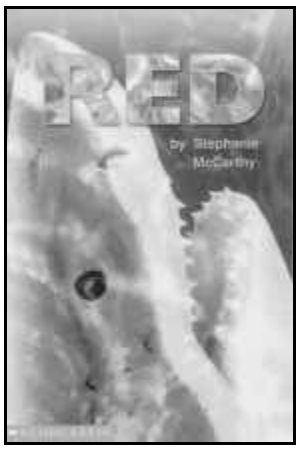
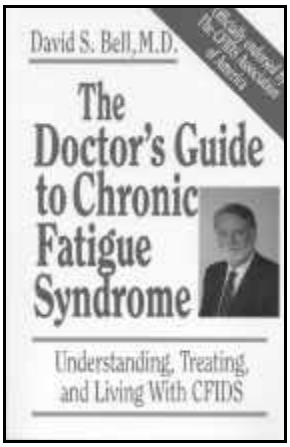


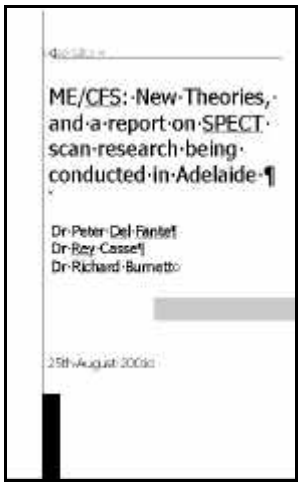
The Doctor's Guide to Chronic Fatigue Syndrome $24.00 (inc. GST) + $3.00 Postage and Handling



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

Cheque Presentation

The Society was blessed to receive a donation of $5,300 from the Adelaide Bank Charitable Foundation. Since 1981 the Foundation has donated a total of $3.8 million dollars to over 309 South Australian Based Charities.

Ms Karen Tham from the foundation kindly joined our office staff for a light lunch and afterwards presented the Society with the cheque. Ms Tham is featured in the photo below, along with our President Paul Leverenz. Also pictured is the computer equipment we have been able to purchase with the funds: a computer, 17 inch monitor, digital camera, scanner and laser printer.

The value of this computer equipment cannot be understated. Already the office has been able to achieve a lot more since we acquired it!

Healthy Research Subjects Needed for SPECT Scan Pilot Study

Dr Rey Casse is looking for healthy people matching the age/sex requirements outlined in the adjoining table.

The Pilot study has been hampered by difficulties in finding matching controls. Funded studies could afford to pay controls, but in this study the researchers are reliant on peoples' generosity.

This particular study requires participants to have a SPECT scan at the QEH the whole procedure takes 3 hours, including time to fill out a couple of questionnaires.

Please register your interest by calling the office, on 08 8410 8929.

Age Range	Males	Females
18-21	-	5
22-26	-	4
27-31	-	2
32-35	1	2
36-41	3	1
52-56	1	-

Recipe Corner

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

BIRCHER MUESLI

Serves 4

A delicious breakfast, which can be partly made the night before.

Ingredients

1 cup rolled oats or rice
1 cup soya milk (calcium enriched)
1 cup low-fat natural yoghurt
4 grated apples
2 pears, cored and chopped
1 mango, peeled and diced (optional)
1 banana, sliced
½ cup raw cashew nuts, chopped

Method

- Place rolled oats (or rice) in a bowl and stir in soya milk and yoghurt.
- Cover and leave overnight in refrigerator.
- In the morning add the grated apples and pears, adding more soya milk if the mixture is too dry it should be creamy.
- Lightly stir the mango and banana through.
- Serve in individual bowls sprinkled with cashew nuts.

Note: add a few sultanas for extra colour, or some chopped dried Turkish apricots.

LENTIL AND BEAN VEGETABLE SOUP

SERVES 6 - 8

Lentil and bean vegetable soup keeps well, and gives you easy lunch options each day.

This soup can have less liquid added and be allowed to cool, when it thickens like an Indian dhal. It can then be used cold as a vegetarian protein dish to have with salads and/or yoghurt. It can also be warmed and served over steamed rice.

Ingredients

1 clove garlic, chopped
2 small or 1 large leek, sliced and washed
2 sticks celery, sliced
1 dessertspoon canola oil
2 carrots, peeled and diced
10 green beans, cut into 1cm pieces
1 cup red lentils (1 ½ cups if you prefer a thicker soup)
1 ½ litres chicken or vegetable stock (use only 1 litre for dhal)
1 can cannellini beans, drained and mashed.

Method

- Fry garlic, leek and celery in oil.
- Add carrots, sweet potato, green beans, lentils and stock.
- Bring to boil and simmer for 20 30 minutes.
- Add cannellini
- beans and stir through well
- Serve with rice crackers or rice cakes.

INDONESIAN STIR-FRY

Serves 4

Ingredients

1 clove garlic, chopped
2 small leeks (or 1 large), white parts only, sliced
2 stalks celery, sliced
1 tablespoon canola oil
500g lean mince (chicken, turkey or veal)
2 carrots, cut into small cubes
2 cups cabbage, shredded
1 cup frozen peas
2 dessertspoons arrowroot
2 cups chicken stock
1 teaspoon soya sauce (optional)

Method

- Cook garlic, leek and celery in canola oil in a wok or large frying pan until just transparent.
- Add chicken (turkey or veal) mince and brown slightly.
- Cook carrots and cabbage in a little water in microwave for 3 minutes.
- Add to mince mixture with frozen peas and cook, stirring, for a few minutes until peas are cooked.
- Mix arrowroot with chicken stock and soya sauce.
- Add to mince mixture and bring to boiling point.

Serve over brown rice or rice noodles.

RICE WITH YOGHURT

An easy snack

Cooked rice and yoghurt are two items that can always be kept in the refrigerator for emergencies! They are good for quick snacks or as a dessert or a light meal.

Ingredients

Equal quantities of:
Cooked brown or white rice (or both)
Yoghurt.

Method

- Mix well together.

Different flavouring ideas:

Savoury:

- Natural yoghurt and rice with chopped celery and a little salt and pepper.
- Natural yoghurt and rice with a little chopped cucumber, served with bean dishes
- Natural yoghurt and rice with salad vegetables of your choice.

Sweet:

- Fruit yoghurt and rice served with stewed apples.
- Natural yoghurt and rice with a chopped banana stirred through.
- Vanilla yoghurt and rice with diced pear stirred through.
- Vanilla yoghurt and rice with chopped fresh apple and chopped cashew nuts.

Talking Point 2002 Issue 1: The Official Journal of the M.E./C.F.S. Society (SA) Inc

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: 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.

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**

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
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

Highbury	Pat	8264 9328
SAYME	Paul	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

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

MEMBERS MAY PLACE SMALL ADS IN TALKING POINT AT NO CHARGE
(subject to advertising policy on page 3)

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

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.
GPO Box 383
ADELAIDE SA 5001

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