Talking Pump

September 2001 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

Office Ph: (08) 84108929 Fax: (08) 8410 8931

Support & Information Line City Callers: 84108930 Country Callers: 1800136 626

www.sacfs.asn.au

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; and
- Promote and foster research towards a more effective treatment and cure.

Membership

Patron:

Lady Neal

Advisory Panel:

Judy Lovett: Past President of the ME/CFS Society (SA) Inc., Chairperson of the ME/CFS Association of Australia Ltd.

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

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
Single Concession …….. $22
Professional……. $40
Family ……...……. $38
Family Concession ……. $28
Overseas – as above plus…...……. $10

(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.
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PWME/CFS:…….. $22
Overseas (Asia-Pacific):…….. $32
Overseas (Rest of World): …….. $38

Management Committee 2001

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

President: Paul Leverenz
Vice-President:
Secretary: Steph Retallick
Treasurer: Margaret Wing
Management Committee Members:
Peter Cahalan, Marion Hansen, Luke Pullen, Peter Evans.

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.

Deadline for Next Issue
November 16th

Talking Point

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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.

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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 Society 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 our membership list for direct marketing will be investigated and dealt with appropriately.

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.

CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

Office

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide. Currently office hours are Tuesday & Thursday 11am-2pm.

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

EDITORIAL

Hi there, another issue of Talking Point has been completed. Unfortunately we had to leave a couple of items out because we ran out of room and time. Specifically for those of you who were keen to see a report on the SPECT scan research presentation in August will have to wait for the December edition (due to Christmas it will come out in the first few weeks of Janruary.)

It would be awesome if some of the essayists amongst you were able to produce some materials for the magazine - based on personal experience. We have plenty of topics you could write on; just ask us and we'll give you some tips. Failing that, tell us what products/ services/treatments have worked for you - or not worked for you for that matter. Also, if you have questions we'll try to have them answered for you.

You may be interested why the topic of CBT (Cognitive Behaviour Therapy) keeps coming up when it really hasn't hit SA in a big way yet. Worldwide CBT is currently riding high on a wave of hype. Paper after paper is coming out on the subject. Press releases and so-called comprehensive treatment reviews are hailing it as the only effective CFS treatment - along with Graded Exercise. It's an issue of concern.

CBT may heap some people but it will not significantly help most ME/CFS sufferers because our condition is physical. CBT therefore must be kept in perspective. The battle is persuade governments to allocate research funds to groups attempting to study the physical nature and cause of ME/CFS.

On the local scene, once elections are out of the way, it will be important for us to introduce ourselves to our newly elected members. It is a good opportunity to educate them about ME/CFS. More about that in the next issues.

Paul Leverenz & Farrah Tate
Editors

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President's Report

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Greetings. I have to start with a sad announcement – an era has ended. Judy Lovett has retired as our representative to the National ME/CFS Association – of which she was Chairperson. This ends a long run of tireless and productive involvement in both the National ME/CFS Association and our Society. Many thanks go to her for the years of hard work and service that she has rendered our cause.

The last 3 months have continued to be busy and tiring for the Management Committee! You may notice a new voice in our office if you ring. We have set aside some funds to pay for *Norma* to help us out. Whilst we have each been languishing to different extents we have needed someone fit and healthy in the office to keep our heads above water. It has also freed us up a bit to a bit of strategic planning and grant writing.

A brief summary of what has been happening…

Guidelines

The draft guidelines came upon us all of a suddenly at the end of June, necessitating a change of plans and priorities. (For those who don't understand what we mean by 'the guidelines' please refer to the explanatory articles in the June 2001 Talking Point.)

It was very encouraging to have so many along to the July Meeting where we discussed, amongst other issues, the subject of the guidelines.

A response to the guidelines was written on behalf of the society (for those with internet access see www.ahmf.org for a collection of responses made by people all over Australia).

Office

We had hoped to break the back of setting up the new office, a number of issues have delayed our progress. Some of those things have been planned, others not.

For example, we had a setback in the office – the combined smells from new carpet and paint played a little havoc with some of us. We have done what we can to improve the situation but for the really sensitive only time will alleviate the problem.

Our most urgent long-term need is to find healthy, altruistic people who can do shifts in the office for sustained periods of time ie 12 months. We don't expect sufferers to take this on (unless in recovery) because too many people in the past have burnt themselves out. And the constant turnover of people is damaging. We need healthy people who can be regularly committed to specific jobs, who are willing to get to know the organisation and its operations, who have good people skills, and who are semi-computer literate. OK, so these people are not that easy to find, but It's an important first step to know what we are looking for.

Personnel

For health and personal reasons we have had a few Management Committee members resign. Many thanks to Boris Dontscheff, Beulah Carter and to Margaret Whyatt who each contributed to our efforts this year. I also give thanks to Peter Cahalan and Sue Heard (both parents of sufferers) who have come on board to help. I would also like to give mention Karen Zweck and Penny Cahalan who have been helping in the office too.

The Management Committee has been doing the best job it can with the resources it has – we are constantly having to reassess our priorities, and adjust what we take on.

Public Meeting

We were privileged to hold a public medical seminar on August 25th. This featured input from Dr Del Fante, Dr Rey Casse and Dr Richard Burnett. The materials presented were fantastic and everyone who turned up got their money's worth.

The only disappointment was that it could not possibly have been a worse day weather-wise. It was miserable and no-doubt kept a lot of people away. And, of course, this was disappointing from a financial point of view.

For those of you who didn't attend this meeting, and the one back in May, you haven't missed out: consider purchasing a video. Our videos have been professionally cut and edited and cost $16.50 (GST included) + $3.50 delivery. We have tried to keep the price down (we only make a small margin on the tapes.) Copies of both are available for loan from the Disability Information and Resource Centre. See page 40 - (Aug. Meeting Not Listed)

We hope that these videos prove to be a great resource for you - something you can lend to your doctor or to a friend.

GP Seminar

I'm pleased to report we had another successful GP seminar on September 22nd ; it was attended by 30 Clinicians. The event was run in partnership with Fibromyalgia SA - with one half the seminar dedicated to Fibromyalgia, the other to ME/CFS.

It was great to forge bonds between our group and Fibromyalgia SA – hopefully we will be able to do a lot more together in the future. Their group has a lot to offer, and I certainly encourage those of you who suffer from Fibromyalgia to look them up. I recommend their 2 hour seminar: 'The Laypersons Guide to Making Sense of Fibromyalgia' (next one in March I think).

International Scientific and Clinical Meeting Sydney 2001

With a great rush the International ME/CFS conference is coming upon us. (This conference is for health practitioners only). Along with the Alison Hunter Foundation each of the State Societies are helping to make this event a success.

I am pleased to announce our Society has donated $4000 to the Conference; this has paid for all of the South Australian ME/CFS Medical Research groups to attend the conference.

The Conference is no small undertaking (over $50, 000 budget.) Monies are tight has necessitated a letter-writing campaign to Politicians and Corporations to seek funding – and this has taken a lot of time and energy.]

National ME/CFS Organisation

(Continued on page 43)

Letters to the Editor

Dear Editors – Paul & Farrah,

It's with pleasure I look forward to reading your informative magazine. I thought you might wish to include the following helpful hints.

For anyone very sensitive to washing powders, even perfume free as the packets absorb smells from the supermarket aisles, try the following. It is very economical, very biodegradable, and safe on the environment and contains no chemicals. It will remove muddy animal paws from a bath towel but can't be sure of removing very soiled items.

RECIPE: WASHING CLOTHES

2 cups Borax
2 cups Washing Soda
2 cups Carb Soda

Dissolve in 12 litres of very hot water. Bottle up when cool. Add 1 cup to each machine tub of water. Very good. Can be halved in quantity.

DAMP AID

To help absorb moisture, dampness, mould, etc. **Damp Rid** is available from hardware stores, Big W. Cost is approx. $8 - $9. It takes 3 weeks to become effective. It is completely safe, **no** chemicals or odour at all. Natural mineral in crystal form. The crystals can be replaced.

COUNCIL WEED SPRAY

Ask council to inform you when they intend spraying (this time of year usually). They usually are very co-operative re C.F. S. The spray can drift 1½ kms or further on windy days.

AIR CLEANERS – HONEYWELL

To overcome pollution entering your home, etc., or when visitors arrive with their perfumes, etc.
Envirecaire Air Cleaner: Almost all metal, no plastic components in motor, etc., to heat and cause health problems. Available in 3 sizes. Filters need replacing every 3-4 months. Large cost $9.00 approx. Filters are 2 for $72.00. Very efficient. Phone 8274 3214 (UMCOS).

EZIBUY CLOTHES & HOME & GIFTS

Catalogue – Phone 1800 148 148.
Men's, women's, teenagers' clothes, good quality, mostly 100% cotton and pure wool. Good range and modern colours. Can be returned if unsatisfactory. No odours as the garments come direct from the factory.

Phone Sue re further inquiries on 08 8555 2861.

Thank you
Sue Prider

Name Change for ME Association

Posted 20th July 2001

ME Charity leads the way with change of name

There has been long and far-reaching debate about the name of this illness, and there still has not been a satisfactory outcome. However, in the year of our 25th birthday, The ME Association, at an EGM held on 14 July, has voted for The ME Association to change its name from The Myalgic Encephalomyelitis Association, to The Myalgic Encephalopathy Association. This is a reflection of the increased understanding over the last 25 years into the nature of the illness. It will also coincide with the introduction of a new corporate identity over the next month or two.

Having accepted the inaccuracy of the term encephalomyelitis, The ME Association has substituted the word 'encephalomyelitis' with 'encephalopathy', meaning an abnormality of brain function. We believe that encephalopathy is now the most appropriate description for the various central nervous system abnormalities (i.e. hypothalamic, autonomic and cognitive dysfunction; cerebral hypoperfusion) that have been reported in the research literature.

The debate about nomenclature is ongoing and The ME Association will also continue to use the term ME/CFS in its literature in accordance with its restated charitable object that is 'to offer relief to persons of all ages with ME/CFS through the provision of information and to further education in all aspects of the illness and to support research and to publish the useful results of such research'.

Severely Neglected ME in the UK

Action for M.E. Membership Survey March 2001

Introduction

It is widely estimated that at least 150,000 people in the UK have ME.

Despite its prevalence, there continue to be reports of severely ill people being unable to access the most basic services; services that people who have other chronic illnesses more widely recognised than ME can access as a matter of course.

It is in this climate that Action for ME conducted a major study of its members, in order to establish what their experiences were in the fields of health and social services and to assess what the ramifications were for the wider ME community throughout the UK.

Surveys were distributed to AfME's 7,529 members in August 2000 of whom 2338 responded (31%), making it the biggest survey ever done of ME in the UK.

As the report shows, the findings were profoundly disturbing. They reveal a catalogue of failure and discrimination. Perhaps the most disturbing fact that emerges from the report is that those who are most severely ill get the least support and care.

In summary, the conclusions are:

- 77% experienced severe pain because of the illness
- Over 50% had felt suicidal as a result of the illness
- 33% received a diagnosis only after 18 months and 52% reported that this had made "a huge difference" to the severity of their illness
- Nearly 2 out of 3 had received no advice from their GP on managing the illness
- 70% are either never able, or are sometimes too unwell to attend a doctor's clinic
- 80% of those who are currently bedridden by ME report that a request for a home visit by a doctor has been refused
- Many people do not receive state benefits to which they are clearly entitled and desperately in need of to survive

Action for ME believes that this report should act as a wake-up call to the statutory agencies which are presently failing a great many people with ME. We have made a number of recommendations which are at the end of the report.

Severity and Impact

ME is described by the World Health Organisation as a disease of the nervous system. For some the illness is relatively mild, allowing the continuation of a fairly normal life. However, many are so severely affected that they are bed-ridden for months, even years, on end.

Participants were asked about their level of severity:

- 2,076 (89%) of the respondents (28% of those mailed) replied that they are or have been severely affected (i.e. either bed-ridden or house-bound)
- Of the 2,338 respondents, 710 (30.4%) are currently severely affected
- 110 (4.7%) are very severely affected i.e. "bedridden - totally reliant on others for care" 957 (41%) reported having been bedridden now or in the past
- 1211 (58%) experienced this level of disability for over 1 year and 495 (24%) were at this level for over 4 years
- 1,176 (50.3%) replied "yes" to the question "Have you ever felt suicidal as a result of your illness" Those who have had the illness worse with the most severe pain and who have had late diagnosis and management, are the most likely to have considered suicide.
- 35% of respondents use a wheelchair 14% described themselves as deteriorating while 25% were improving

Note: Fluctuations in each of these groups are common

- 4 out of 5 suffered severe pain as a result of their illness. 29% reported experiencing severe pain much of the time

Diagnosis

There is no definitive test to diagnose ME so the illness is identified by a process of elimination. Action for ME believes that early diagnosis, coupled with sound advice on management can help prevent the illness becoming severe.

Participants were asked about the diagnosis of their illness:

- Whilst 30% were diagnosed within 6 months, 33% waited more than 18 months and 6% were diagnosed only after 10 years
- 42% were diagnosed by their GP, 39% by a

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consultant and 19% by an M.E. specialist

- Participants were asked what difference an earlier diagnosis would have made to the severity and/or chronicity:

Management and Advice

The effect that an earlier diagnosis would have made	
No difference	26%
A little difference	22%
A huge difference	52%

Sensible advice on managing ME early in the course of the illness can, in many cases, encourage recovery. It is important that doctor and patient work in partnership to establish the best method of recovery.

Participants were asked about their experiences of management and advice:

- The question was posed "Did you receive advice from your GP on managing your illness - within 6 months of onset / after 6 months of onset / Not at all"

Did you receive GP advice on managing your illness?	
Before 6 months	19%
After 6 months	17%
Not at all	65%

- 41% felt that this lack of advice contributed to their illness becoming more severe or chronic.

Accessibility to Healthcare services

Action for ME believes that it is a basic right that those who are ill are given access to healthcare. The survey revealed that, in fact, the most severely affected ME patients receive the worst level of support

Participants were asked about their access to healthcare since developing ME:

- Participants were asked whether their condition was regularly monitored, and if so, by whom. Only 47% reported that their condition was monitored. In only 16% of cases was a specialist involved
- Of the 110 currently bedridden, only 50 report that they are monitored
- 53% of those who have considered suicide at some point are not monitored by their doctors
- 8% reported that they were never well enough, and 62% were sometimes too unwell to attend a doctor's clinic
- 935 had requested a home visit by a doctor, 17% reporting that their request had been refused
- Of the 110 who are currently bedridden, 88 (80%) have been refused a request for a home visit by a doctor
- 240 had requested a home visit by a nurse, 13% reporting that their request had been refused
- 334 are visited by members of community teams
- Of the 110 currently bedridden, only 60 report that they are visited by members of their community NHS teams

Management and Treatment

Pacing and rest were reported to have been most beneficial and graded exercise was reported to be the treatment that had made most people worse.

Private Practitioners

There was evidence of extensive use of non-NHS practitioners, with only homeopaths and herbalists receiving a less than 50% response of having proved beneficial.

* e.g. acupuncture, aromatherapy, massage, reflexology, yoga

In-patient care

There is an enormous gap between the number of people severely affected by M.E. and specialist in-patient provision for the illness in the UK.

The most severely affected ME patients frequently have painful sensitivities to light, noise and chemicals. The survey revealed that, where patients have been admitted to general wards, many report being made worse because of the environment or treatment they received for their illness.

Participants were asked about their experience of in-patient care:

- Of those who had been admitted to hospital (22%), more reported having been made worse than better

Note: Some also reported mixed results

Benefits

Like all seriously ill people, ME patients are entitled to state benefits.

However, there has been repeated evidence that many ME sufferers have been refused benefits to which their level of disability would seem to entitle them:

Participants were asked about their experiences of accessing benefits:

- 64% of respondents (1,490) received state benefits
- 44% of respondents (1,039) had applied for Disability Living Allowance (DLA)
- 44% of those who applied for DLA had to go to appeal
- Of those who applied for DLA, 25% were rejected (with or without appeal)

Notes to the survey

- 2,338 replies to the survey were received - a response rate of 31%
- 10% were aged under 18
- 81% of respondents were female
- 39% were aged between 26 and 40 at the time of onset of M.E. 38% were aged between 41 and 65 at time of onset
- 15% had more than one family member who had had ME and 4% had two or more affected

Conclusion

It would be disingenuous to claim that this report details the experiences of every single ME patient in the UK. On the other hand it would be absurd to suggest that it is only Action for M. E. members who will have experienced an NHS which fails them and a social services system which seems to discriminate against them.

Rather, it would be reasonable to assert that this report typifies the terrible struggle that many ME sufferers have to endure just to get the most basic level of care and support. It also indicates that the thousands of people who are most severely affected by M.E., who are bed-ridden and cut-off from society, receive the worst level of treatment from the NHS and Benefits Agency.

Action for ME makes the following recommendations to address the issues raised in this report:

- Establishment of community services, including monitoring of severely ill patients
- Establishment of specialist services including appropriate in-patient care and specialist out-reach services aimed at those who are bed-ridden by ME
- Guidelines on early diagnosis and prompt information issued to all doctors
- Government sponsored research into the cause and management of ME
- Education and training for all health professionals on ME
- Education and training for Benefits Agency staff on the impact of ME

It is clearly a misconception to think of ME as a "mild" illness. It is neither mild for the people who have it, nor is the impact on the wider community mild. The loss to the economy is substantial, in terms of both lost revenue and social costs. A large portion of the ME community is, at one level invisible, but we should be under no illusions that the impact of this illness affects far more than the 150,000 people who actually have it.

This report clearly demonstrates the level of isolation and exclusion suffered by thousands of ME patients.

It is time that those who have ME are given the type of treatment and services that the illness so clearly deserves.

Management and Treatment	Helpful	No Change	Made Worse
Drug medication for pain	856	385	153
Drug medication for sleep	870	223	207
Pacing your activities	1949	201	30
Graded exercise	417	187	610
Diet changes	1216	590	58
Nutritional supplements	1190	699	64
Rest, including bed rest	1962	169	31
Cognitive Behavioural Therapy	21	191	73
Other	663	96	119

Private Practitioners	Helpful	No Change	Made Worse
Doctor	529	407	112
Counsellor/psychotherapist	354	244	80
Osteopath/chiropractor	459	232	100
Homeopath	436	456	112
Herbalist	227	251	71
Nutritional therapist	400	217	48
Healer	403	349	45
Complementary therapist (other)	690	334	111

Response to the RACP Draft Guidelines

In the previous edition of Talking Point, we discussed the issue of the draft ME/CFS guidelines for. On June 28th our Society received the long awaited for second draft of the guidelines. All consumer groups had one month to respond. Responses from all around Australia can be viewed on the Alison Hunter Memorial Foundation Website at: http://www.ahmf.org/advocacy.html#racp

The following letter was composed by Paul Leverenz on behalf of the Society.

ATT: RACP Working Party – Chronic Fatigue Syndrome Project

The ME/CFS Society (SA) Inc. thanks the RACP for copies of the Chronic Fatigue Syndrome Guidelines Revised Draft 2001. It is unfortunate, however, that we have been only given 1 month to comment on them – as a result this response has been rushed and is no where as thorough as it could have been. It is disappointing that such an unprofessional, un-collaborative approach should appear to be taken with regard to such an important document.

Persons with this debilitating condition and clinicians treating them deserve something much better. It is indeed a shame that this project, at a considerable cost to the taxpayer, has bumbled along only to produce this. In this document we shall argue that this whole project be re-evaluated for ethical, legal, scientific and professional reasons.

What do we believe about Chronic Fatigue Syndrome?

To understand our reaction to this document and for us to communicate clearly it is helpful you know where we are coming from.

We believe that Myalgic Encepathomyelitis (ME) / Chronic Fatigue Syndrome (CFS) is an debilitating condition. There is no diagnostic test, no curative treatments and the aetiology is unknown. Often ME/CFS is brought on following a viral infection, or chemical exposure. In no way does it have a psychogenic causation. Symptoms can cause varying degrees of impairment, some are mildly affected, others are virtually bedridden – some have died from the disease. Although some symptomatic relief may be found, recovery from the condition is indeed spontaneous – but it seems that many do not fully recover, and carry a measure of disability for life. Personal motivation and determination plays no part in the speed of recovery. The duration of the condition can vary from a year to a lifetime. In research we would tend to support the use of the Fukuda (1994) definition – but would actually prefer something a little stronger to ensure only genuine ME/CFS patients are selected.

What do the guidelines state about CFS?

A careful reading of these guidelines will show an inconsistent, double-mined portrayal of the condition.

At first glance these guidelines appear supportive of our understanding. The guidelines correctly state that the current internationally accepted research definition is the Fukuda et al. (1994) definition. They clearly indicate the illness is not psychosomatic – that external pathogens (p19) are involved in it's onset. They state the need for a positive diagnosis, and for GPs to be understanding of their patients. The guidelines clearly stress that CFS can be quite disabling. This document categorically states that the condition is distinct from depression, although reactive depression may be present. It stresses that treatments focus on symptomatic relief and that recovery is spontaneous. We commend the following statement on page 16:

> "Our goal as physicians is not only to identify and treat disease, but also to help relieve suffering and disability, whatever the cause."

It may seem like there is considerable common ground, however, throughout the draft guidelines there is an undercurrent that undermines these concepts. The 'underlying message' is that although an external pathogen initiated the condition, the disease can be psychologically propagated. Whilst you may argue we are reading that into the document, we believe that this conclusion will be drawn by many, because of the lack of non-psychotherapy management options, and the number of conflicting statements.

Such an emphasis is placed on exercise that we are concerned about readers losing perspective. The fact is that any chronic illness, which reduces functionality, will inevitably lead to some degree of physical de-conditioning. We forget which is the causal factor, and which is the product. The level of debilitation caused by the illness is qualitatively different from the debilitation caused by the de-conditioning; de-conditioning per se is not the end of the world.

The patient's responsibility to under-goe exercise, sleep therapies and CBT are emphasised so much that one could easily come away from these guidelines with the idea that the ME/CFS patient must exercise and have good sleep hygiene in order to get over their CFS. The implication then becomes that the person who doesn't appear to be doing these things isn't trying to get better. This is not the case. As people with ME/CFS recover, they find they can do more and so their activity levels increase.

We are concerned with the down-playing of the chronic-nature of the condition. If a condition is chronic, sufferers need to be empowered by being told so. It enables them to set appropriate goals and pace themselves. This document suggests people can resume acceptable levels of functioning in 3-6 months (p36), but also quotes a study that the illness lasts for 2-4 years (p50) and effects them for 1-9 years. Where is the consistency here?

Theoretical problem: Fatigue and the Nature of CFS

You will note our insistence on referring to CFS as ME/CFS. You will no doubt know that there has been a raging debate amongst the ME/CFS community over the name of our condition. Suggested names have been: Neuroendocrine Immune Disorder, ME, Polyalgic Asthenia, Nightingale Syndrome, and Ramsay's disorder.

CFS is not liked because undue emphasis is placed on fatigue to the exclusion of the other major symptoms. The confusion we wish to avoid regards fatigue – although it is the common symptom between sufferers, it is not helpful to define the condition by it. Although fatigue is the common symptom in people with CFS, it is not always the most severe or disabling – it is certainly not the sole disabling factor in this condition – chemical sensitivities, muscle pain, neurocognitive impairment, bowel dysfunction can be equally disabling.

ME/CFS is a multi-system and multifactorial illness. Stigmitizing it by the common symptom of fatigue began in (1988)- before which it was just called 'ME'. This had the apparent advantage of making it more accessible/understandable to people, but it labelled the condition with the main symptom. This has reduced awareness of the other symptoms, and removed the focus from a symptom-set to and individual one.

We reject, therefore, the model used by the authors of CFS lying along a continuum of fatigue states with different severities p16. We reject the assertion that ME/CFS is merely a fatigue state. We acknowledge the symptoms of ME/CFS on their own are extremely generic, and hence there is overlap with many conditions, but together they form a package – one which admittedly may have several sub-groups. It is completely arbitrary to link conditions on the basis of a common symptom. To invent the construct of 'fatiguing' conditions is therefore but one methodology – but it is not a logical necessity that we do so. For example, apart from fatigue what is similar about depression and anaemia? Once the diagnosis is made, we realise we are dealing with two completely different diseases.

The 'fatigue states' perspective dove-tails with Cognitive Behaviour modelling.

> "Cognitive behavioural models suggest that a combination of physiological, behavioural, cognitive, affective and social factors contribute to chronic fatigue syndrome. Cognitive behaviour therapy is used to modify behaviour and beliefs that may maintain disability and symptoms" (Deal 1997, Am J Psychiatry 1997; 154;408-414)

Cognitive behaviour modelling whishes to incorporate all the products and results of ME/CFS back into the condition itself. Both these models thrive on reducing ME/CFS to fatigue and equating the two.

Please consider the possibility that ME/CFS might just be a specific disease with pretty run-of-the-mill symptoms – making it initially hard for sufferers to be picked out of a crowd. All round the world research is showing physiological problems in persons with ME/CFS indicating real damage/disruption to many of the systems in our bodies. Recent neuroimaging studies are showing up significant brain dysfunction in ME/CFS patients – evidence on ongoing physical impairment. As we improve our understanding of the condition, we can improve our research definitions to better select ME/CFS sufferers, you will be able to see a clearer demarcation between persons with ME/CFS and persons with generalized 'fatigue.' All our jobs will be a lot easier then.

In this document, the construct of 'fatigue states' is a smoke-screen to try to equate CFS with chronic fatigue and make it non-specific. These guidelines play upon that blurring of definition – the implication is that treatments which reduce fatigue are actually fixing the ME/CFS. This, of course, not true. We are not dealing with just fatigue by itself. In fact, some of the proposed treatments may exacerbate ME/CFS.

Consider this argument. Chronic Hepatitis causes fatigue. De-conditioning increases fatigue. Graded exercise prevents de-conditioning; therefore it is vital for Chronic Hepatitis sufferers to undertake graded exercise to manage their Chronic Hepatitis. Pretty ridiculous reasoning? With this example there is no confusion between hepatitis and fatigue – one is a product of the other. Is it equally clear that fatigue is a product of ME/CFS but not ME/CFS itself?

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What does the RACP believe about the nature of CFS?

Does this document truly portray ME/CFS, or is the landscape blurred? Does the document portray the condition one way, then contradict/undermine this view in other places? Are the models helpful, or do they actually cause the confusion? You need to decide whether this document has selectively chosen management options, and ignored many others.

This document cannot have it both ways. Either we have a genuine condition – with pathogenic causation, spontaneous recovery and which is chronic – or we don't. If we do, then it needs to be stated clearly, and not undermined by innuendo of it being psychologically propagated. If our condition is chronic then we deserve compassion and understanding, not to be bullied into removing so-called impediments to recovery. Are people with other chronic conditions subjected to such levels of suspicion and mistrust?

Discussion relating to behaviours which may generate similar symptoms to ME/CFS belong in an appendix. In doing so there is no confusion between recovery from a disease, and re-establishing a healthy lifestyle once you have recovered.

Who is this document aimed to help?

At the beginning we are told: "These guidelines are primarily aimed at assisting general practitioners" page 4

Our contention is that these guidelines do not help GPs and other practitioners who would not otherwise know anything about the condition. This document grossly under-informs GPs about the medical nature of the illness, and is biased towards psychotherapies in its assessments of what can be done to help patients. It is therefore unhelpful.

Selective Information

The guidelines state: "there are no abormal physical findings in people with CFS". This ignores symptoms such as irritable bowels, poor concentration, & orthostatic intolerance to name just a few.

These guidelines fail miserably at a point most critical – they do not outline the international research currently being conducted into ME/CFS. This is surprising for a condition whose aetiology is unknown. Why would the RACP not want GPs and other clinicians to have an overview of the different findings and theories on this condition? Are the authors trying to down-play physiological abnormalities in people with ME/CFS?

Please note that the following authors are recognised ME/CFS researchers and they have been either not quoted or selectively under-quoted:- Rowe P.C., Bell D., Komaroff A.L., Lapp C., Moldofsky H., Dowsett E.G., Simpson L.O., Costa D.C., Suhadolnik R.J., Mena I., Demitrack M.A., Natelson B.M., Bombardier C.H., Snow. P, Woodward R.V., Goldstein J, Klimas N, Boda. W.L, DeLuca J., Lerner M., Dunstan H., Haier G., Barrows D.M., McGregor N., Baker E.L., de Meierleier K., Bianchedi M., Miller C. S., Ziem G., Bell I., Winder C., Little C., Walden R.J., Martin J., Richards R.S., Jason L., Burnet R., Pearn. J., Scroop. G., Chaudhuri A., Behan P.O & W.M H., Jadin C. L., Hyde B., Roberts T.K., Marcel B., Piirmohamed J., Butt H.L., Tirelli. U., Goudsmit. E., Chester A.C., Spurgin M., Schwartz R.B., Nixon P.G., Sandman C.A., Corrigan F.M. et al

What of the large and growing literature on ME-specific neurological, immunological, endocrinological, cardiac, heaemotological and other abnormalities in ME/CFS. What of MRI, PET and SPECT Scan peculiarities, aberrant urinary markers, ion channel abnormalities and the high incidence of orthostatic hypotension (OH) and of related circulatory and haemotological problems? Are they trivial?

When it comes to work done here in Australia, why has only work being done in Sydney on sleep therapy been added? Wouldn't it be good for practitioners to know that there is research being done in Newcastle, Brisbane, Adelaide and Perth into ME/CFS? Wouldn't it be good if some of this work was also referred to? And what about the two International ME/CFS conferences – Brussels (2000) and Seatle (2001) – or the 1998 and 1999 Manly ME/CFS Conferences? No mentions of or references to these for GPs to follow up.

Why are these findings deemed un-important? Clearly the authors are so enamoured with their own theories, are so confident that they are the answer, that everyone else's work isn't worth mentioning. But we were led to believe the guidelines:

> "… are based on information available at the date of publication, and are intended to provided a general guide to best practice." p4

It is an absolute disgrace that this document and 'best practice' appear in the same sentence. This document disempowers GPs through under-and-mis-information.

Management of ME/CFS

The following statement sets the emphasis of the document toward management:

> "To date, no pharmacological agent has been reliable shown to be effective treatment for CFS. Management strategies are therefore primarily directed at minimising impediments to recovery:

REGULAR CHECKUPS

Please remember to have regular medical checkups with your doctor.

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

> loss of aerobic fitness, disruption of the sleep-wake cycle, intercurrent depression and social isolation" p8

Firstly, whilst no pharmacological agent has been shown to directly treat CFS, there are a number of options that work for some people. Given we are still in the early stages of understanding this condition, it seems unwise to adopt a 'wait until things are proven' attitude. GPs need to be informed about a whole range of options – with, of course, the appropriate warnings. Whilst on one hand we agree that there is no point embarking on a phrenetic pursuit of one treatment after another, we can't agree that it is wise to abandon attempts to find relief. There is a certain let-down if a practitioner says 'well, there is nothing we can do' as opposed to 'let's give this a try, I can't promise anything, but it can't hurt.' This tack doesn't give the patient false hope, yet gives them a focus.

To take the stand you have of focussing on 'minimizing impediments to recovery' is flawed and unduly negative. Management strategies should be directed at improving quality of life by treating symptoms – and encouraging lifestyles that help people 'get the most out of themselves' and achieve a 'maximum sense of well-being' under the circumstances. A holistic approach must be taken to this. The unduly defeatist manner in which this is approached, wrongly implies that nothing can be done symptomatically.

This approach also takes the patients focus off the here and now, and has them working towards an event that may not occur for several years. This is an unnecessary burden / pressure. Let the patient come to terms with resuming a normal lifestyle once the underlying disease has gone. There is no rush. Why insist on things such as having 8 hours sleep a night?

In the mean time, the person with ME/CFS, along with their GP, must find their own level of physical and mental activity, sleep patterns and durations, and time spent socializing that is best for them. The balance of these things will be found at a point which enables them to achieve the best quality of life, without exacerbation of their ME/CFS.

These guidelines make many references to the need to avoid – excessive rest (which we endorse) – but why do they not spend equal time warning people against overdoing it and making their condition worse? We are not just talking about exacerbation of symptoms, we are talking about relapsing – a qualitative increase in severity of the underlying condition. Is it too much to ask for a balance in this regard?

Impediments to Recovery

Further to the previous point, we wish question whether "loss of aerobic fitness, disruption of the sleep-wake cycle, intercurrent depression and social isolation" are actually impediments to recovery. Where is the support for this statement? There is no proof of this. It is a long bow to draw and can only be done if we confuse fatigue with ME/CFS. Remember that recovery from ME/CFS is spontaneous over time. Cause and effect are once again confused.

We ask for all statements implying that these factors are impediments to recovery be removed if they cannot be substantiated by double-blind placebo-controlled trials (as you suggest should be the benchmark).

Exercise

We maintain that this document is dangerously imprecise about exercise therapy. If the following is true:

> "In people with CFS, fatigue is typically exacerbated by relatively minor physical or mental activity" p6

Don't the following statements seem a little confusing?

> "As exercise tolerance improves, duration and intensity of activity can be gradually increased. Graded exercise programs have been shown to be safe for people with CFS, and can improve both aerobic capacity and functional status." p9 [NOT REFERRENCED]
>
> "It is important to discuss with the person with CFS the vicious circle whereby initial avoidance of physical activity may lead to longer-term avoidance of all activity." p9

The authors of this document are sending mixed-messages. If a person can be so sick their symptoms can be exacerbated by relatively minor activities, then how can such unqualified, emphatic statements about the efficacy of exercise be allowed to follow? There is no sense of the chronic-nature or the severity of the illness. Taken out of context, this document could be used to make any person with ME/CFS undergoe graded exercise to the detriment of their health.

We ask that the RACP remove the following comment "Graded exercise programs have been shown to be safe for people with CFS" p9. This statement is out of place and unsupported. If a ME/CFS sufferer is made to undertake graded exercise as a result of this statement, and their symptoms are worsened or they relapse, then the RACP could be held accountable. It only takes one case to refute such a categorical suggestion.

There is no justification for the over-emphasis on exercise in this document. It is commonsense that sufferers should remain as active as possible, but any understanding of what is possible should not be abstracted from the chronic, debilitating nature of the illness. Nor should any confusion be allowed in which one might be led to believe that exercise will improve the ME/CFS, or hasten its natural improvement.

When managing this condition it is a patients right to spend their energy as they see fit – putting it into the sort of exercise that will increase fitness may not achieve the best quality of life for that person. Eg. Students may choose to do minimal exercise because it exacerbates their cognitive dysfunction and prevents them from undertaking their vocation.

If a condition is chronic and debilitating, physical de-conditioning is inevitable. Several studies show that the deconditioning of ME/CFS sufferers is not different to sedentary healthy people (sorry – not enough time to provide references). So why pick on us? Since when did lack of fitness become a crime? As we recovery from ME/CFS we'll have more energy to do things, and our lifestyles and fitness will reflect that.

CBT

The issue of CBT is moot. Simple CBT – illness education, encouragement to be as physically/mentally active as possible and encouragement not to socially withdraw are commonsensical, and surely can be carried out by GPs. Also patient support groups such as ours make these emphases. There is little need for formalised CBT in most CFS patients. We strongly dispute the unsupported assertion that studies have shown CBT to be helpful for ME/CFS patients. Very few CBT studies actually use the Fukuda 1994 research definition that the guidelines themselves acknowledge to be the international standard. Patient groups worldwide have condemned most CBT research for that reason. These studies have mostly been conducted with a much weaker research definition such as the 1992 Oxford definition. The problem with weaker definitions is they mix in plain fatigued patients

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with ME/CFS patients. They also tend in these studies to only look at mildly affected people – they are not representative of the ME/CFS population – and this is often not made clear.

CBT study outcome evaluations are problematic even in the eyes of some researchers (Deal 1997). They involve the patient to self-evaluate their mood and physical capabilities. Such self-assessments are extremely subjective. We contend those suffering fatigue may derive benefit from CBT, but genuine ME/CFS patients will generally not because there is an organic basis to their fatigue that neither activity nor positive thinking will reverse.

We would like to see CBT studies based on the Fukuda et al. (1994) definition before we evaluate CBT.

We would argue that more funding needs to be given to patient support groups such as ours, to enable us to provide more meetings, information sessions, and encouragement to persons with ME/CFS. These services will help people with ME/CFS get the most out of themselves in the here and now. There is a cathartic need to share with others who have a similar disability – we provide the context for this need to be fulfilled.

Groups such as ours do not encourage malingering, wallowing in depression, or excessive rest; and our focus is on persons with ME/CFS getting the most out of themselves through careful self-management. The guidelines should pay more attention to recommending people get involved in support groups.

Issue of Biases

This document, because of the models used, is biased towards behavioural/psychotherapies to the exclusion of a great deal of research findings, medical knowledge and medical treatment options.

It is overly biased towards the symptoms of sleep disturbance and fatigue. Yet CFS involves a broad range of symptoms such as irritable bowels, impaired cognitive function and muscle pain. Why are these treated differently? Why are these not classified as impediments to recovery?

The authors fail to mention dietary modifications and many other treatments which have positive effects on many patients. Whilst some of these may not yet be proven, we are in the early days and thus they are not yet 'proven to be wrong.'

Overlapping Conditions

This document fails to list Multiple Chemical Sensitivity and Gulf War Syndrome as related illnesses. (The Fukuda et al. 1994 CFS research definition mentions Multiple Chemical Sensitivity Syndrome.) Are the authors trying to suppress knowledge about related conditions which don't fit their models and illness-understandings that well? We were led to believe that this document incorporated all available information at the time of writing.

Chemicals

Sensitivity to organophosphates, pesticides, herbicides, solvents or other chemicals are not listed as initiators or potential exacerbators of ME/CFS. In fact no references are made to chemical sensitivities at all. This is strange as a significant proportion of ME/CFS sufferers report sensitivity to certain chemicals and food intolerances.

A study done at the University of Newcastle has shown persons with ME/CFS have higher levels of pesticides than healthy people.

We cannot help thinking that this document wants to suppress all references to possible pathogens and physical explanations of the illness, so that cognitive/behavioural factors get all the attention.

Confusing Comment

We would ask that the following comment be removed:

> "Factors associated with a poorer [recovery] outcome include older aged, concurrent psychiatric disorder, and the person's belief that the illness is purely physical in origin." [Emphasis ours]

We feel that this comment is insulting and undermining. If this condition is not psychogenic as the draft suggests, then what is the underlined statement in there for? It is another example of the document sending mixed messages. Does this mean you do not believe ME/CFS is purely physical in origin?

Sleep

Since when was this document a forum for the authors' personal theories to the exclusion of hundreds of others?

> "Clinical experience suggests that sleep interventions in people with CFS may reduce symptoms and improve functional capacity, although direct evidence for this is currently lacking." p11

Just because some symptoms can be recreated by disturbing healthy people's sleep patterns (see quote) – how can one reverse the argument to suggest that fixing persons with ME/CFS's sleep patterns will remove the symptoms? How can a professional document be published with such poor

reasoning?

> "It is known that chronic disruption of the normal sleep pattern can induce symptoms in healthy volunteers, including fatigue, musculoskeletal pains, irritability and concentration impairment." p10

The authors have confused cause and effect. Our sleep patterns are abnormal because of the ME/CFS.

The following suggestions are far too prescriptive:

> "restrict the night-time sleep period to about eight hours, avoid going to bed too early in the evening, reduce (to less than 30 minutes) or abolish daytime naps" pp 43,44

They fail to take into account the range of severity of ME/CFS, and pose a two-fold legal problem. Persons with ME/CFS may be denied claims because they are sleeping more than 8 hours a night; they may be forced into sleeping less and their health could be jeopardised. If people are put in this position, based on these guidelines and are made worse by it, then the RACP could be open to litigation.

Scholastic quality of document

No references are given to the following assertions.

> "Graded exercise programs have been shown to be safe for people with CFS and can improve both aerobic capacity and functional status."
> "There is a growing view that sleep disturbance in patients with CFS may be part of a wider abnormality of sleep-wake cycle function, and that restoration of the normal sleep-wake cycle…should be an important goal of therapy."

How can a professional document make sweeping statements such as these without backup? These comment are not asides, but form part of the argument for the main two suggested management strategies to this condition. They appear to add considerable weight to the argument, but they are not fact. We argue that these are both unsubstantiated theories – no more or less plausible than a hundred others.

Throughout the document there appear several (*) missing references. We requested we be given them and we were told they were not yet available. How can a document be put up for review when there is not a complete list of references?

Previous comments have highlighted the biased nature of the referencing, and the bias of the management suggestions to the psychological and the suppression of the physical.

Who controls this illness?

There is clear bias towards the psychiatric/psychological fields of study in these guidelines. In fact, there is a bias towards research being conducted in and around Sydney – with the sudden inclusion of a series of sleep studies – to the exclusion of important international research, and research being done in Newcastle, Brisbane, Perth and Adelaide into the physical disruptions in ME/CFS.

The models used, the fatigue-orientated illness-understanding, the insistence that the condition is an illness not a disease, the bias towards CBT and sleep / behaviour therapies and the suppression of much medical/research information all serve to keep this condition in the hands of psychiatrists/psychologists AND validate the need for that sort of research over and above research exploring the physical basis of the disease.

We can't conclude without specific reference to the inclusion of 'Neurasthenia' as a related illness to the exclusion of Multiple Chemical Sensitivity and Gulf War Syndrome. How is Neurasthenia possibly related to a condition with a pathogenic causation?

Just why are a group of Sydney researchers calling for the re-acceptance of the name: Neurasthenia – a psychiatric term? It does not escape us that it is an obvious ploy to keep ME/CFS associated with the psychiatric fields.

We deserve better

We deserve better than to be the object of a power game for jurisdiction over our condition.

People with ME/CFS need government funding going into researching the organic basis of this condition, and into the assessment of different treatment options. Our support groups need funding. We need GPs to be informed about the real state of our understanding of this condition – not a selective serving with minimal medical content.

We deserve an expansive international view on this condition; not a harbour-view.

Economic rationalism never wins in the end. In the short term you may screw a few of us, but in the long term you screw yourself.

Repercussions

Should these guidelines be accepted they will be disastrous for people with ME/CFS – people who have suffered greatly over the last 20 years because of non-recognition of the illness.

One concern is that, in legal cases all round the country, person's with ME/CFS will be refused benefits and rights they deserve on the basis that they aren't undergoing formal CBT or sleep therapy, or they are sleeping more that 8 hours a night. The document will do more harm than good to our members.

The lack of clarity and consistency in the document means anyone could take anything away from it.

Our major concern is that GPs who know nothing of the illness will not be medically wiser by reading this document – where are book, website, & research references?

In conclusion

Along the way we have listed ways in which this document fails to do ME/CFS justice. We have highlighted flaws in it from scientific, legal and professional / scholastic viewpoints. This document sells practitioners and persons with ME/CFS short – it doesn't befit an illness with unknown aetiology. It fails to give GPs the right tools to understand the illness, lacks self-consistency, confuses cause and effect, is overtly biased towards 2 of the many symptoms, and is out of step with international thinking on this condition. Above all it unfairly targets sufferers of ME/CFS, placing them under undue pressure to be involved in sleep and exercise therapies – and opens the door for a wrong interpretation that these will improve patient's ME/CFS. The document sends mixed-messages about the nature of ME/CFS, and we reject the authors' fatigue-states model of the illness.

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Superannuation & Insurance

by John Berrill

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

INTRODUCTION - WHAT THIS ARTICLE IS ABOUT

One of the biggest legal issues facing people living with CFS/ME is access to superannuation and insurance benefits. Whether claiming their preserved superannuation contributions, total and permanent disablement lump sums, or insurance income protection payments, people with CFS/ME often have problems with superannuation funds and insurance companies.

This pamphlet gives you general information about superannuation and insurance policies, superannuation contributions, how to make claims, particularly for disability benefits, the effect on Centrelink payments and what happens if you return to work.

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The lack of peer-review processes undermines our confidence that this project is free from hidden agendas separate to the interest of sufferers of ME/CFS and clinicians of people with ME/CFS. We do not enjoy our health being jeopardised by petty power struggles.

We would ask the RACP to re-asses this project. After all that has transpired over the last 5 years, it would be best if this attempt was scrapped and we started again. We would suggest an impartial person be appointed to chair a brand new attempt at it. We would prefer it if the working party consisted of people with clinical experience in treating ME/CFS patients. We would ask that sufficient resources be given to the project, so that there is time and funding to undertake an extensive peer review process at the end of draft stages. These measures would ensure best practice.

Yours Sincerely,

Paul Leverenz, B.Sc.
On behalf of the ME/CFS Society (SA) Inc.

The pamphlet also includes details of your rights of appeal and the CFS/Disability Advice Service.

SUPERANNUATION BENEFITS

(1) Introduction

Since 1992, work superannuation has been compulsory. Employers must pay contributions increasing to 9% of salary by 2002/3 into a superannuation fund for their employees if they earn at least $450.00 per month.

Most Superannuation Funds also include disability lump sums if you can't keep working because of injuries or illnesses. They "top up" the contributions in your Fund.

Some Superannuation Funds also have disability pensions paid for two years or more and death insurance benefits.

Many people living with CFS/ME may be able to claim a lump sum or pension if they have any superannuation policies.

But many people don't know that they can claim disability benefits from their superannuation or when they can get a payout of their contributions.

Benefit statements are sent out by Superannuation Funds every year, although some statements are hard to understand.

If you are not sure whether you have disability benefits or if you can't find any statements, ask for help.

(2) When Must Superannuation Contributions Be Made?

Under the superannuation laws, your employer must usually pay superannuation contributions into a Fund for you at least every year.

However, many employers have agreements with Superannuation Funds to pay contributions more often e.g. monthly.

Some industrial awards also say that employers must pay superannuation contributions more often.

(3) What if Superannuation Contributions Aren't Paid?

If your employer doesn't pay superannuation contributions into a Fund for you, you should contact the Australian Taxation Office and tell them.

They might ask you to fill in a form and they should try to collect the contributions from your employer and pay the money into a Superannuation Fund for you.

However, it can take a long time for the ATO to collect the money and if your employer has gone out of business, the contributions might never be collected. You might also lose valuable

disability and death cover.

If you are covered by award superannuation or if your work agreement includes superannuation you may be able to sue your employer to collect the contributions and any insurance benefits you have lost.

It is very important to make sure your employer keeps paying the contributions by regularly checking with the Superannuation Fund and checking your benefit statements. If the contributions aren't being paid, get help straight away.

(4) Superannuation Contributions Payouts

Your contributions paid up to 1 July 1999 can be paid when you leave a Superannuation Fund.

However, employer contributions must usually stay in a fund until age 55 or 60.

The exceptions are if:-

(i) You have been on Centrelink payments for at least 6 months and can't pay your living expenses (or 9 months if over 55 years and 9 months of age up to July 2001).

(ii) Your house is about to be repossessed by a lender.

(iii) You need money for palliative care, funeral expenses, modifications to your house or car or medical and transport expenses for treatment outside the public health system for yourself or dependants.

(iv) You are permanently incapacitated.

(v) You have an account balance of less than $200.00.

SUPERANNUATION DISABILITY CLAIMS

(1) Permanent Disability Benefits (TPD)

To get a disability lump sum you usually have to show you can't ever go back to your old job or other suitable work that fits your education, training or experience (called TPD benefits).

However, you don't have to be unfit for any work at all.

For example if you have only worked as a labourer or process worker you will only have to show that you can't do manual work again to get a disability lump sum. If you don't have the skills to do office work, it won't matter if your doctors say you can do that work.

It doesn't matter how your CFS/ME occurred and all disabilities and illnesses can be used for a superannuation disability claim.

You don't have to show you will definitely never work again. It is enough if, on the balance of probabilities, your CFS/ME is not likely to improve in the foreseeable future to the point where you could return to work.

Many people on Centrelink Benefits will be able to claim.

Many people with CFS/ME may be able to claim disability benefits - although proving permanency can be a problem.

Relevant factors include the period of incapacity for work, the severity and fluctuation of symptoms and your age, work and education background.

(2) Temporary Disability Benefits

Some superannuation funds have weekly or monthly payments if you can't do your usual job.

With some policies you have to be unfit for your usual duties although with others, it's enough if you can't do one of the duties necessary for your job.

The payments can be up to 75% of your wage and may be paid for up to two years or perhaps even to age 65.

Under some policies, to get payments after two years, you must be unfit for your usual job or any other suitable work that fits your education, training or experience.

Temporary payments might stop if your job finishes and some payments are offset against workers' compensation or Centrelink payments.

(3) Making a Disability Claim

You can usually make a claim at any time, although it's better to make a claim as soon as possible.

It doesn't matter if you have been paid out your superannuation contributions even if that happened a long time ago.

Disability claims can also be made by the estate of a person after they die.

There will be claim forms to fill in and medical reports and other papers to send in.

It is important to give the right information and reports to help a disability claim. In particular, it's important for medical reports to support the definition of disability in the policy.

It may take many months before a decision is made and you may be asked to go to some medical examinations.

If a claim is rejected, you can lodge a Complaint with the Fund.

If the claim is still not successful, you can appeal to a Court or the Superannuation Compaints Tribunal, although time limits might apply. Many appeals win or are settled.

Get help with a claim or appeal.

STATEWIDE SUPERANNUATION TRUST

(1) South Australia

Many South Australian employees are members of the Statewide Superannuation Trust.

The scheme is an accumulated contributions fund which pays lump sums on resignation or retirement.

The scheme also pays insurance lump sums on TPD or death and temporary disability insurance payments for up to two years.

The claims process for disability benefits is the same as for other superannuation schemes.

(2) Commonwealth Government Superannuation Funds

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Most Commonwealth public servants are members of generous defined benefit schemes - C.S.S., P.S.S. or the Military Superannuation and Benefits Scheme.

These schemes include invalidity benefits usually paid as lifetime pensions if you are permanently unfit for your usual job or any other suitable work.

Under the Military Superannuation and Benefits Scheme the rate of the invalidity pension depends on the severity of your disability.

Some Commonwealth government employees are members of an accumulated contributions scheme, AGEST, which includes a TPD lump sum.

The claims process for invalidity benefits is the same as for other superannuation schemes. Appeals are heard by the Superannuation Complaints Tribunal but time limits apply.

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PERSONAL INSURANCE BENEFITS

(1) Introduction

Some people with CFS/ME may be able to claim disability benefits from other insurance or superannuation policies they have.

(2) Types of Insurance Policies

Some people have their own superannuation or life insurance policies which may include disability lump sums or premium waiver benefits.

Most self-employed people and other people in the work force have income protection insurance to cover them if they can't work.

Banks and finance companies ask their customers to take out insurance to cover mortgage or loan repayments if they can't keep up the payments because of a disability.

Some credit cards include disability lump sums and some banks, employers, unions, credit unions and sporting and social clubs have disability insurance policies for their members.

(3) Making Claims and Appeals

Insurance disability claims can usually be made at any time although it's better to make a claim as soon as possible.

There will be insurance claim forms to fill in and medical reports and other papers to send in to the insurance company.

It is important to give the right information/reports to help a claim - particularly medical reports supporting the definition of disability in the policy.

It may take many months before a decision is made and you may be asked to go to some medical examinations.

If an insurance claim is rejected you can lodge a Complaint with the insurer.

If the claim is still not successful, you can appeal to a Court or to an industry complaints scheme (FICS or the IEC), although time limits might apply. Many appeals win or are settled.

It is important to get help with a claim or appeal.

(4) Getting New Insurance or Superannuation Policies

If you already have CFS/ME, it may be difficult to take out a policy with disability or death benefits.

If you try to take out your own insurance or superannuation policy, you will usually have to fill in a medical questionnaire to work out the health risks.

If you know you have CFS/ME, you may have to tell the insurer and they may then refuse to cover you for disability payments.

If you knew you had CFS/ME when you joined but didn't tell the insurer, they may refuse to give you a payment - although not always.

However, it may be possible to get disability and death cover by joining a "group" superannuation or insurance scheme - e.g. with your employer, union or credit union.

In such schemes, you may be offered automatic cover without any health tests or questions.

If you want to take out a private insurance policy, it's usually best to approach an insurance broker, rather than apply direct to insurer companies.

SUPERANNUATION/INSURANCE AND CENTRELINK

(1) Superannuation Lump Sums

A superannuation lump sum payout will usually be taken into account in the Assets Test to work out your Centrelink payments.

However, if you are under 55 years and 9 months of age and keep the money in a Superannuation Fund it won't count as an asset until the money is taken out or at least until you reach 55 years and 9 months of age.

As from the 1st of July 2001, this age limit is lifted to the normal retirement age ie sixty-five for males and sixty-one and a half for females.

(2) Superannuation Pensions

Superannuation pensions are usually treated as income and may reduce your Centrelink payments.

(3) Insurance Lump Sums

An insurance lump sum pay-out will be taken into account in the Assets Test to work out your Centrelink payments.

(4) Insurance Income/Pension Payments

Insurance income replacement payments are usually treated as income and may reduce your Centrelink payments.

SUPERANNUATION/INSURANCE AND RETURNING TO WORK

If you have stopped work because of CFS/ME but your health improves and you feel you can go back to work, there is nothing to stop you from doing so.

If you do go back to work and you have already been paid a superannuation or insurance disability lump sum, you will not have to repay the lump sum.

If you are receiving a superannuation or insurance pension, you would have to tell the Fund or insurer that you are returning to work.

If you return to work and you are earning more than $450.00 per month, your employer will have to pay superannuation contributions again.

Your new Superannuation Fund may also include death and disability benefits even though you already have CFS/ME or even if you have previously been paid a disability benefit.

CFS/DISABILITY ADVICE SERVICE

(1) Need to Get Advice?

Many people don't know that they can claim disability benefits from their superannuation or insurance.

If your work is cut short because of CFS/ME you won't have enough superannuation to live off. Any extra disability benefits will help a lot.

If you have any disability insurance policies, it will be important to maximise the benefits you can claim

(2) Where Can I Get Help?

A free superannuation and insurance advice service has been set up to provide legal advice to people with CFS/ME and others.

The CFS/Disability Advice Service offers free legal advice to people living with CFS/ME, their family and friends and health providers.

You can call from anywhere in South Australia on (03) 9605 2742.

We will look at your papers and give you free advice and assistance with any claims/appeals on a "no-win, no-charge" basis.*

Written by John Berrill
Maurice Blackburn Cashman, Solicitors (03) 9605 2742 and member of Chronic Illness Alliance Superannuation Planning Group

The information in this pamphlet is current as at June, 2001

*** Some conditions apply**
Prepared by:
Maurice Blackburn Cashman, Lawyers

WANTED: YOUR EXPERIENCES ON PAPER

- HAS ANY PARTICULAR TREATMENT HELPED YOU?
- HAVE YOU DEVELOPED ANY INTERESTING WAYS TO COPE WITH THIS ILLNESS?
- HAVE YOU DEVELOPED WAYS TO DEAL WITH PEOPLE WHO DON'T UNDERSTAND THIS ILLNESS?
- WHAT HOBBIES / ACTIVITIES DO YOU FIND THERAPEUTIC?
- GOT ANY GOOD RECIPES FOR US?
- CAN YOU TELL US ABOUT PRODUCTS YOU HAVE FOUND TO BE GOOD FOR THOSE WITH CHEMICAL SENSITIVITIES?

ALSO WANTED: YOUR QUESTIONS

We will try to get someone to answer them for you?

Please write to the Editors: Talking Point GPO Box 383 Adelaide SA 5001

Between a rock and a hard place – the costs of chronic illness and poverty

by Fiona Tito

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Imagine you were a young person with cystic fibrosis (CF). Thirty years ago only 2 out of 10 people with CF lived to 18 years. Today, 9 out of 10 people with CF expect to live to 20 years-but this requires strict adherence to medication and other treatments.

The medication costs more than $65 a week, just to keep you alive. You are working in a low-skill casual job that pays about $10 an hour and you struggle to work a 40 hour week. Because of your earnings you cannot get a Health Care concession card, which would reduce the costs of your medication by more than 80 per cent (from $21.90 per prescription to $3.50) until you reach the threshold (around 3 months). Thereafter the saving is less, but still substantial over a year.

> Your reward for working is to pay more than 16 per cent of your earnings for medications that are literally the difference between life and death.

The Report by the Chronic Illness Alliance, entitled **A concession card for people with chronic illness**, documents 14 case studies like this. Cases where people with chronic illnesses that involve high medication costs, such as CF, severe asthma, HIV/AIDS, some cancers and a range of other often multiple conditions are caught in a real poverty trap when it comes to participation in work.

Anyone who has been financially dependent on social security income support payments knows that the level of payment maintains you in poverty. For people with chronic illnesses, the upside of being a social security recipient is access to concessional pharmaceuticals and care costs through the accompanying concession card. Depending on the place you live and the nature of the payment you receive, this card can also provide you with access to other discounts, which can offset the non- optional costs associated with your chronic illness. For example, discounts can apply to energy bills and you can access subsidised dental care.

You can also get a Health Care Card if your income falls below $315 per week. That is annual income of less than $16,400. To allow a bit of leeway, the cut-off point is a little higher. You don't lose it until your income exceeds $395 per week. The earnings are assessed over an eight week period, so if you are able to earn good money for only a short period in the year, you need to make sure you apply at the right time in your earning cycle!

If you do not have access to a card, you have to pay the first $21.90 of all prescriptions up to the safety net of $669.70 in anyone calendar year. This is a large amount for low income families with chronic illness. Compare this to a concession card cost of $3.50 per prescription with free access after meeting a threshold of $182.00!

This makes the transition off social security payments and into employment doubly problematic. Most people making such a transition are going into relatively low-paid jobs. For people with chronic ill health, they can face attitudinal barriers and structural inflexibilities that may make it hard for them to keep their jobs.

If you are not sure how long you will be in work and how long you are going to be well, any decision which results in the loss of a significant financial help like a Health Care Card can be thought by many to be a big risk indeed! Potential loss of health care card assistance makes it very difficult for people whose illness precludes them from working consistently full-time in well-paid work. As one of the case study people said :

> 'I find that the prospect of losing my Health Care Card entitlements, particularly the pharmaceutical concessions is a significant deterrent to my seeking gainful employment. It is an unwelcome burden on my finances at a time when I am supposed to be making use of every available opportunity to contribute to society, a burden that very, very few other people are forced to ensure.' (page 15, case study #3)

The report also documents strategies that people use in order to live day-to-day without a Health Care Card. These include being non-compliant with medications and taking a little less every day to save money; going without food, clothing and entertainment; and budgeting on utilities and other health needs to afford essential medication. Other stories show people 'choosing' which of their family will do without medication in order for other family members to receive theirs! They also tell of people stockpiling once they reach thresholds or when they fear they may lose their Card. There are also stories of people who use medication rather than allied health services, which may be more appropriate for their health needs, because they cannot afford the co-payments associated with such services. It is a pretty dark picture really!

The figures on costs in the Report relate to the date of survey (1997) and other changes to the Pharmaceutical Benefits Scheme mean that the problems faced by people with chronic illness and without access to a health care card are much worse. There are stories of people spending more than 25 per cent of their earnings on expenses related to their chronic illness.

The Report argues strongly for access to a non-income tested Health Care Card on the basis of chronic illness. They use the precedent of the Disability Support Pension paid to blind people. It also argues that such access may be justified on a cost-benefit basis, not only because people would be better able to afford the care and medications they need, but because they would not then be discouraged from participating to whatever extent they could in the labour force and, more generally, in the economic and social life of the community.

This Report provides examples from the lives of real people- this is the raw face of the 'socio-economic determinants of health'. Looking at these case studies, the cyclical relationship between poverty and illness becomes very stark indeed: People have a chronic illness. Often this limits or removes their access to paid work and so they are affected by poverty. But then their poverty compounds their disadvantage because

(Continued on page 21)

"Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitating Illness."

"I Never Know What to Say!" Part 3B

What "Encourages "A Chronically Ill Person?

1. Acknowledge Their Situation

"What you have been through is horrible!" "I can't believe what you must go through every day!" Oftentimes when a person is ill, the people around them refuse to move out of denial about the situation. Instead of listening, believing and showing compassion for what they have been through and what they are facing on a daily basis, they refuse the facts and minimize the severity of the disease. Unfortunately, by doing this they are treating the person like they are choosing to be ill and are giving in to the illness, by simply communicating their struggles.

Acknowledging your loved one's situation, lets them know that you are there to accept the facts and move on to practical help. They will know that you are truly there for them, to help them deal with their limitations and adjustments. But most of all, they will know that you love them, even in their broken state and respect them for their perseverance!

2. Acknowledge Their Losses

"I am so sorry you can't work anymore!" "It must be horrible, because you can no longer..." "I can't imagine what you have been through!" Losing the ability to participate in activities, work and enjoy hobbies is incredibly devastating! Thus, when a person is stricken with a debilitating disease, they fight, research and spend thousands of dollars, trying to find a cure, treatment or something that will give them their lives back!

Acknowledging their losses will show them you have compassion for what they can no longer do or enjoy. Most of all, it shows that you believe that losing their ability to do something they once had, is something that is unimaginably heart-wrenching for them and not in any way something they have willfully chosen for themselves!

3. Show Them You Are Listening

"Honestly, how are you doing?" "How can I pray for you?" "So, what is really going on?"

(Continued on page 22)

(Continued from page 20)

they are unable to afford or to access what they need to optimise their health. So the cycle continues.

The report argues for a framework of support through continuing access to a Health Care Card. This would enable and encourage people with chronic illnesses to work as they are able, without fear of losing their crucial assistance with the non-optional health care costs associated with their illness.

The Final Report of the McClure Committee on Welfare Reform called **'Participation Support for a More Equitable Society'** supported the need for fundamental reform in relation to social security arrangements. It identified the concentration of disadvantage within various groups of people in our society, one of which is clearly people with chronic illness.

The Chronic Illness Alliance Report show us that these are the very people who face 'structural or systemic barriers to participation, including discrimination and problems with access to appropriate services and support'. McClure suggests that developing and implementing active strategies to meet the needs of people in these difficult situations is the 'other side' of mutual obligation It is the Government's turn to 'do something positive' in a mutual obligation debate which has often been very one-sided and imposed only greater duties on people affected by poverty. A Health Care Card for people with chronic illnesses might be just the place to start this new 'helping-hand' approach.

Fiona Tito launched the Chronic Illness Alliance Report on behalf of the Australian Council Social Service (ACOSS) on 15 February 2001. She is the ACOSS Principal Policy Resource Coordinator in Health. The views in this paper are her own and not necessarily those of ACOSS. This 'case study' was adapted from the case studies in the Report, but uses updated figures, as the Report related to 1997 figures.

The Consumers' Health Forum has consulted extensively with its members over the past decade about the cost of chronic conditions. The report on these consultations is: 'Easing the Burden-the Pharmaceutical Benefits Scheme and People with Chronic Conditions' 1999, in which the work of the Chronic Illness Alliance was acknowledged.

Reprinted from 'The Australian Health Consumer' – journal of the Consumer's Health Forum of Australia Inc.- No 3, Winter 2001; with permission.

(Continued from page 21)

Certainly, if you meet up with someone with a chronic illness just in passing or in a social setting, they would not expect you to stand there and listen to all of their problems; yet, when the time is right, you may want to take a moment to do so. You do not have to worry about doing this every time you talk to them or see them; in fact, they will appreciate it if you don't, because just spending time with you is often enough, when you have shown that you care.

Also, if your loved one tells you they do not have "good" days and are instead very ill every single day, stop asking them how they are feeling, if all you want to hear is that they are feeling good! There is nothing good about feeling horrible to deathly ill all of the time, so why do you expect them to say it is good? Doing this only makes them realize you are not listening, have absolutely no idea what they are going through and will not love them until they get better or lie.

Instead, why not try, "how are you doing?" This will spark an answer that addresses how they are dealing with their challenges, struggles and emotional state, which unlike how they are "feeling" can fluctuate.

4. Show Them You Are Aware Of Their Circumstances

"I am so glad you are here, I know it is a huge sacrifice for you!" "Wow! Thank you for coming! I know it is very difficult for you!"

When a chronically ill person shows up to a gathering, you can bet they had to sacrifice a lot to get there! Unfortunately, they are often met with comments such as, "wow, you must be feeling better" or "you must be having a good day," when nothing could be farther from the truth; and, these types of comments just make them realize people do not have a clue what they had to go through to get there.

In fact, pushing to make it to a gathering, then sitting, smiling and talking is like having major surgery, climbing Mt. Everest, then being crushed by King Kong. And, it is not because they are feeling well that they are there, it is because they desire fellowship and friendship and are willing to pay a high price to get it.

Thus, by showing them you acknowledge how much effort went into getting there, you are making it apparent that you are aware of the mountains they had to climb and the horrible price they will have to pay later. By doing this, they will realize that you appreciate their endeavor, respect their challenges and feel like you are honored by their sacrifice.

5. Show Them You Are Willing To Help:

"I'm going to the store, can I pick something up for you?" "Can I bring you lunch tomorrow? And, maybe you will let me fold some towels or something while I am there!"

There are basically 2 reasons why people are unwilling to assist a person debilitated by chronic illness: Either they seem to think they do not require assistance, because they think they "look fine," therefore they must be "getting along fine" or they tend to fear that helping another person will require a big commitment and be too time consuming.

First of all, by reading this booklet you have already learned not to correlate how someone looks to how they feel. Second, you have learned to listen and realize your loved ones situation. Third, it only takes a little bit of your effort to make a very big difference!

Because what used to be a simple task to them has become insurmountable, they are faced with constantly struggling to get things done! They can spend an entire day trying to do things that you can do in an hour and then at the end of the day, they still were unable to accomplish what you take for granted, like getting in the shower or making a meal!

Do not make the mistake of thinking you have to come clean their house, do all of their laundry and cook all of their meals in order to help! If they are bedridden and in need of that much help, get several friends, family or church members and neighbors to pitch in and help or pool together their money to hire someone.

What they really need is for you to help without it being a burden on you. Try, "I am going to the store today, what can I pick up for you?" This keeps you from investing a lot of time, keeps them from feeling guilty about you going out of your way and saves them days of energy and sacrifice! For more ideas on how to help, read on to the next chapter!

6. Let Them Know You Enjoy Their Company

"Oh, good! I was hoping you would make it!" "I am so glad to see you!" "It is great to have you here!" "I enjoyed visiting with y ou yesterday!"

The biggest reward for all of the effort that goes into making it to a social gathering, meeting for lunch or just having a visit, is being appreciated! Show your loved one you are happy to see them and respect their sacrifice! And, drop them a note that confirms your enjoyment of their company, so when they are at home paying the price, they are reminded of how much it was worth it!

7. Show Them Your Admiration

"I can't believe how strong you are!" "I can't believe how hard you keep fighting!" "You are so courageous!" "You amaze me!"

Disturbingly, it is common for a person suffering from a chronic illness to be treated as if they are not positive enough, do not try hard enough, do not have anything to complain about and they just do not want to get better.

You cannot imagine how horribly devastating it is to be imprisoned inside a body that will no longer cooperate with your desires! Every morsel of your will yearns to do the things you used to do, but no matter how hard you try, you collapse with incapacitating, crippling, bone-crushing fatigue that grips you in its hands and pulverizes your very being!

If others would just take a moment to realize how much the person has been through, what they go through daily, how many tests they have had, how many doctors they have seen, how many medications they have tried, how much research they have done and how much money they have spent to battle the illness, they would recognize their loved one's amazing courage and perseverance!

After all, don't you become a bumbling, sobbing, whining blob of Jell-O when you get sick, even when you know you will be better in a few days? Think of how amazing your loved one is for their persistence to find a way to remove or at least alleviate their symptoms and to find meaning for their new lives. So, isn't it time to voice your admiration for their incredible strength and determination? ..... I THINK SO!

8. Let Them Know You Appreciate Your Health

"You have made me realize how much I take for granted."

"You really make me appreciate being able to do things I never even thought about before."

Nothing is worse than a healthy person complaining to an ill person about all of the things they had to do. These are things they were able to do and things that chronic illness sufferers could only wish they could do. It is sort of like complaining to a person confined to a wheelchair that they had to walk a couple of blocks or they had to play in the park or go rollerblading.

A person stricken with debilitating illness knows that if they ever got their lives back, they would dance through the streets, feeling free and thankful for every step they take! They know, without a doubt, that they would live their lives differently than they did before; they would appreciate what they once took for granted and look at every morning like it
was a gift! So, it is refreshing and consoling when a loved one takes a moment to realize what they have; and it is a relief to know that they did not have to lose their lives, in order to learn this.

9. Give Them A Compliment

"You look very nice today." "I like your hair that way." "That is a nice outfit." "You have good ideas." "Wow, you know a lot about..."

Have you ever given your loved one a compliment, only to be glared at as if you said something awful? As addressed previously in this chapter, it was probably because you connected how they are looking with how they are feeling. This is hurtful, because you are showing that you are unwilling to listen or believe what they go through, since you cannot see their illness on the outside. So, if you really do think they look nice, just say, "wow, you look nice!"

Also, contrary to popular belief, the brain is often severely effected by chronic illness! Many times people will say, "at least you have your brain" or "at least your brain is not effected." However, this is quite untrue!

Most sufferers have lost large degrees of their cognitive abilities as they struggle greatly with memory, function and word recall; this is commonly referred to as "brain fog" and feels as if cement has solidified in the brain, keeping it from operating! Therefore, they often feel self conscious about their inability to express their intelligence; so, you might want to try letting them know how smart you think they are once in a while and believe them when they share with you their struggles with cognitive functions.

Being A Comfort In The Face Of A Tragedy.

In all, you honestly mean well and truly want to be an encouragement and comfort to others. Therefore, because you genuinely care, you desire to come up with the "answers" to "fix" the problem; and, because you cannot bear to see your loved one suffer, you desperately want to believe "it is not so bad."

Yet, if you were at a funeral, you would not tell the widow, "oh come on, he'll be fine tomorrow." Instead, you acknowledge his death and show her compassion for her loss. Or, if your friend broke their leg, you would not say, "hey, you just need to get a positive attitude, your leg is not really broken!"

Hopefully by reading this chapter, you have learned that your "natural" instincts of denial, in order to protect both you and your loved one, must be developed into loving acknowledgement. After all, no one can battle an enemy when they refuse to believe they exist!

Therefore, remember, it is absolutely impossible for you to be
compassionate, until you have acknowledged there is a situation to be compassionate about! In other words, how can you say, "I am sorry you are so ill," if you are always saying, "I do not believe you are so ill?"

Yes, accepting what is happening to your loved one means having to deal with all of its pain, mourning and changes, but do not sell yourself short! After all, if they are forced to live with it, you can certainly choose to live next to it!

In addition, please remember that your loved one would never choose to willingly give up activities they used to enjoy! In fact, people stricken with debilitating illness would do just about anything to get their lives back! Therefore, you can rest assured, knowing they will keep fighting, researching and pursuing ways to regain their lives or at least prevent further progression of the disease.

Once you express your acknowledgment of their losses, belief in their word and desire to understand, you will see a huge change in their attitude toward both you and the illness! They will gratefully receive your declaration of concern, embrace your compassion and gain strength from your faith in them. Assuredly, with you standing by their side and not confrontingly before them, they will rise like a flower in the sun, reaching for the sky!

"Truly Love Me,
By First Believing In Me!"

Part 4, and our last instalment, will appear in the next issue.

"I Never Know what to say" was written by The Invisible Disabilities Advocate, Sherri L. Connell. It is Part 3 of Sherri's 40 page booklet, "Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitating Illness." To order this booklet, please send US$5 each (includes postage from the US, discounts available for 15 or more). Make the check payable to W. Connell and send to: IDA 41553 Madrid Drive, Parker, CO 80138.

Visit IDA's website at www.InvisibleDisabilities.com!

EDITORS:

Tell us what you think of this part of "Helpful Hints". Did you relate to it? Has it helped you explain things better to friends/ relatives? Are there additional points you can think of? If so, please send them in to us.

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Dr Charles Shepherd Responds on Behalf of Patient Groups to a CFS Treatment

Director of the UK ME Association:
DR CHARLES SHEPHERD
MEDICAL DIRECTOR
M E ASSOCIATION

TO: THE EDITOR, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION RE: 'CHRONIC FATIGUE SYNDROME - TRIALS AND TRIBULATIONS' INTENDED FOR PUBLICATION

Dear Editor

In his editorial (1) on two systematic reviews of treatment interventions for chronic fatigue syndrome (CFS), Simon Wessely rightly concludes that many patient advocates will criticise the way the results are likely to be interpreted and demonstrate no desire to lobby for increased provision of cognitive behaviour therapy (CBT) and graded exercise therapy (GET) programmes for these patients. He is, however, being disingenuous to infer that this is due to misguided passions over the possible causes of CFS.

Like most patient support groups, the ME Association provides information on all treatment options currently under review. But rather than just base our conclusions on results from a very limited number of randomised controlled trials, we also take account of evidence that includes feedback from both patients and their clinicians.

In the case of GET, the results of three large treatment surveys involving (UK) patients indicate that there is more dissatisfaction here than with any other form of management intervention. The largest survey (2), involving 2,338 respondents, found that out of 1,214 who had tried GET, 34% believed it was helpful, 16% reported no change, but a disturbing 50% (ie 610) believed GET had made their condition worse. The reason for this may well relate to the view that many CFS patients are already functioning at
or near their level of maximal physical performance and that inappropriate extra activity can easily produce a relapse (3). In addition, there is growing evidence that the explanation behind GET - ie that CFS patients are physically unfit and deconditioned - is not consistent with objective measures of physiological functioning (4).

With CBT, patient support groups have no problem in acknowledging that formal programmes aimed at improving the way in which patients cope with practical aspects of their illness, such as sleep disturbance and activity management, can sometimes be helpful.

Unfortunately, most CBT is administered in a psychiatric setting where there is a strong emphasis on the controversial hypothesis that CFS is largely perpetuated by abnormal illness beliefs and behaviour - an approach which many patients find unhelpful and unacceptable. Again, the results of all three treatment surveys - the largest of which (repondents = 285) found that 67% reported no change; 7% found CBT helpful, and 26% were made worse - are very different to those obtained in randomised controlled trials.

So long as research evidence and patient experience remain so far apart in the areas of CBT and GET, the ME Association feels fully justified in maintaining its current position.

Dr Charles Shepherd

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NOTE TO EDITOR RE POTENTIAL CONFLICTS OF INTEREST:

Simon Wessely quite rightly declares his involvement with Prisma Health - a commercial organisation that acts for insurance companies by arranging rehabilitation programmes for people with CFS that involve CBT and GE. He does not however refer to the fact that he is a member of the Advisory Panel to the York Systematic Review - surely this should have been noted. And was a doctor so closely involved with the review the correct person to write an editorial that makes a number of very serious criticisms aimed at those of us who act as patient advocates in what is a very difficult area of medicine?

Sydney 2001 Conference

PRELIMINARY NOTICE

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Chronic Fatigue Syndrome
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Explore the Science and Advance Clinical Care in 2001
Saturday 1 and Sunday 2 December, 2001
Manly Pacific Parkroyal, Sydney, Australia

KEYNOTE SPEAKERS

Anthony Komaroff
Professor of Medicine Harvard Medical School, Boston USA

- as Director of the Division of General Medicine and Primary Care established one of USAÕs premier academic units
- has an active research program in CFS in particular chronic "post-infectious" fatigue syndromes
- has significant role in reinvigorated CDC CFS Program.

Wilhelmena Behan
Professor of Pathology University of Glasgow, Glasgow UK

- directs a leading neuroscience research program to elucidate the pathogenesis of CFS, in collaboration with eminent scientists in neurology, nuclear medicine, exercise science and medicine, molecular genetics
- first to describe mitochondrial dysfunction in CFS.

Supported by NSW Health Department

Direct inquiries to:

Christine Hunter

Conference Secretariat
Alison Hunter Memorial Foundation
PO Box 2093
BOWRAL NSW 2576
AUSTRALIA

Telephone: +61 2 4861 3244
Facsimile: +61 2 4861 3255
Email: chunter@ahmf.inspired.net.au

or

Ellie Stein MD FRCP (C)
Chair Scientific Programme Committee
Suite G100 Holy Cross Centre
2210 – 2nd St. SW Calgary, Alberta
T2S 3C3 CANADA
www.cdnpsych@telusplanet.net
Telephone: (403) 685-4861

Problems with Fibromyalgia?

The FM Association can help. Contact Details:

FM Association C/O Arthritis Foundation of SA Inc., 1/202-208 Glen Osmond Road, Fullarton SA 5063. Phone (08) 8379 5711, Freecall 1800 011 041.

The Biology of Chronic Fatigue Syndrome

Anthony L. Komaroff, MD

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Chronic fatigue syndrome is an illness defined exclusively by a group of symptoms, according to a case definition developed under the leadership of the US Centers for Disease Control and Prevention (CDC) [1]. Moreover, all of the symptoms are nonspecific, occurring in many illnesses, and some of the symptoms—disrupted sleep, difficulty with memory and concentration, myalgias, and fatigue itself—are common in depression. It is therefore fair to ask whether there are any objective biological markers in patients with chronic fatigue syndrome, and whether those markers can distinguish them from patients with other fatiguing illnesses, including depression.

In my view, that question has been answered for quite some time. Many controlled studies have compared patients with chronic fatigue syndrome with age-matched and gender-matched healthy control subjects, and with matched groups of patients with various fatiguing illnesses. As argued in more detail elsewhere [2], several objective biological abnormalities have been found significantly more often in patients with the syndrome than in the comparison groups. The evidence indicates pathology of the central nervous system and immune system.

However, two things must be said. First, not all patients who meet the case definition of chronic fatigue syndrome have these objective biological markers. Although many abnormalities have been found more frequently in groups of patients with the syndrome, none have been found in every patient. Perhaps the abnormal findings wax and wane and were not present on the day the patient was sampled, or perhaps heterogenous results, each producing different biologic footprints, can lead to the final common pathway (presumably in the brain) that produces the symptom complex we call chronic fatigue syndrome. Moreover, some patients who meet the case definition are likely suffering from some other illness.

Second, the various biological abnormalities do not yet explain the pathogenesis of the illness. Some of the symptoms of chronic fatigue syndrome (eg, impaired memory or concentration, unrefreshing sleep, and fatigue) directly suggest involvement of the central nervous system. Other symptoms (eg, myalgias, athralgias, headaches, sore throat, and postexertional malaise) could reflect a lowered central threshhold for perceiving pain or pathology outside the central nervous system. As argued below, a state of chronic immune activation could affect the central nervous system, producing these symptoms. Although there are bits and pieces of evidence in support of this very general hypothesis, however, much more evidence is required.

What is the evidence of central nervous system pathology? As summarized elsewhere [2], magnetic resonance imaging has revealed punctate areas of high signal in the white matter. Single photon emission computed tomography (SPECT) signal abnormalities also are found more often in patients with chronic fatigue syndrome, abnormalities like those seen in patients with encephalopathy due to the acquired immunodeficiency syndrome (AIDS) and unlike the findings in patients with depression [3]. Autonomic nervous system testing has revealed abnormalities of the sympathetic and parasympathetic systems that are not explained by depression or physical deconditioning [4]. Studies of hypothalamic and pituitary function have revealed neuroendocrine abnormalities not seen in healthy control subjects, and generally opposite to those found in major depression. There is often a central down-regulation of the hypothalamic-pituitary-adrenal axis, resulting in a mild hypocortism [5], as well as disruption of both serotonergic and noradrenergic pathways [6,7].

There is considerable evidence from different investigators, using different technologies and studying different groups of patients, of a state of chronic immune activation in many patients with chronic fatigue syndrome. Most investigators have found increased numbers of CD8+ cytotoxic T cells with antigenic markers of activation [8] and depressed function of natural killer cells [9]. The relation of these immunological findings to the symptoms reported by patients is unclear [10]. One hypothesis is that a state of chronic immune activation could lead to the production of cytokines that disrupt neurotransmitter function and result in the symptoms of the syndrome.

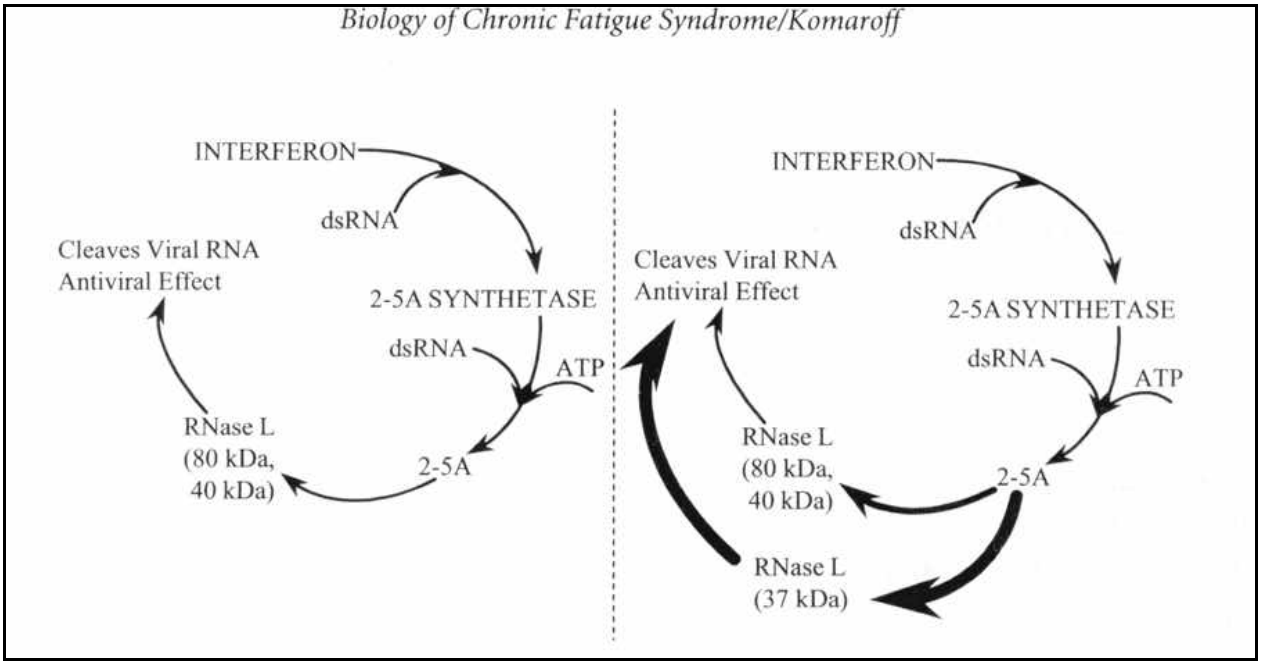
In this issue of *The American Journal of Medicine*, De Meirleir, Bisbal and their colleagues [11] from Belgium and France report finding another immunological abnormality in these patients. Their work was prompted by a previous report from Suhadolnik and colleagues [12] in the United States. Both the European and US teams studied an enzymatic pathway in lymphocytes called the 2-5A synthetase/ribonuclease L pathway (hereafter called the 2-5A pathway). As shown in the **Figure** [above], viral infection and interferon induced by viral infection turn on this enzymatic cascade, leading to increased levels of two polypeptides, 2-5A synthetase and 2-5A-dependant ribonuclease L (hereafter RNase L). The RNase L then selectively degrades viral RNA. Thus, viral infection elicits a compensatory antiviral effect through the 2-5A pathway.

In a study involving patients with chronic fatigue syndrome and healthy control subjects from four different parts of the United States, Suhadolnik and colleagues [12] showed that the 2-5A pathway was turned on much more often in patients with chronic fatigue syndrome. Measured activity levels of the normal form of RNase L (an 80 kDa polypeptide) were elevated. Subsequently, Suhadolnik et al [13] showed that patients with chronic fatigue syndrome also often had a novel low molecular weight (37 kDa) form of RNase L.

Using a somwhat different technique, De MeirLeir, Bisbal and their colleagues studied an entirely different and considerably larger group of patients, including not only healthy control subjects but also comparison patients with major depression and fibromyalgia. Like Suhadolnik et al, the European team found increased levels of the normal 80 kDa and 40 kDa forms of RNase L in patients with chronic fatigue syndrome, as well a novel low molecular weight form (weighing 37 kDa). The ratio of the novel 37 kDa protein to the normal 80 kDa protein was high in 72% of the patients with chronic fatigue syndrome compared with 1% of healthy control subjects and none of the depression and fibromyalgia control patients, a striking and highly significant difference.

What is this research telling us? It is another piece of evidence that the immune system is affected in chronic fatigue syndrome, and it reproduces and extends the work of another investigator, lending credibility to the result.

Has the research uncovered, at long last, a diagnostic test for the syndrome? Not yet. At best, the novel proteins are present in only about 70% of patients: The false negative rate is about 30%. The false positive rate, however, is a remarkably low 0% to 1%. It remains to be determined if the false positive rate will remain this low when larger numbers



of comparison subjects and patients with additional fatiguing illnesses, such as multiple sclerosis and systemic lupus erythematosus, are studied.

Does this research bring us nearer to understanding the pathogenesis of chronic fatigue syndrome? Some of us who study the syndrome suspect that it can be triggered, in susceptible patients, by chronic infection with any of several agents that are difficult or impossible to eradicate. Indeed, several latent viruses may be reactivated in some patients [2]. The hypothesis is that the chronic infection leads to a chronic low-level "war", with the immune system attempting in vain to rid the body of infection. The ongoing war leads to the production of various cytokines that cause the symptoms of the syndrome. This is an attractive but unproven hypothesis. Finding aberrations in an "antiviral" pathway, as Suhadolnik, De Meirleir, Bisbal, and their colleagues have done, is consistent with the hypothesis that there is an underlying chronic viral infection. However, the 2-5A synthetase pathway may have other roles besides its antiviral activity, and aberrations in the pathway may not reflect the presence of an infectious agent.

In summary, there is now considerable evidence of an underlying biological process in most patients who meet the CDC case definition of chronic fatigue syndrome. The report by De Meirleir, Bisbal, and their colleagues is another strong piece of evidence that is consistent with the hypotheses that the immune system is activated and that the object of the immune system's attack could be a chronic infection. Furthermore, the report is inconsistent with the hypothesis that chronic fatigue syndrome involves symptoms that are only imagined or amplified because of underlying psychiatric distress—symptoms that have no biological basis. It is time to put that hypothesis to rest and to pursue biological clues, such as the observations reported in this issue of *The American Journal of Medicine*, in our quest to find answers for patients suffering from this syndrome.

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September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

CFIDS and Anasthesia: What are the risks?

By Elisabeth A. Crean

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Anecdotes have piled up over the years about the especially difficult time persons with CFIDS (PWCs) have recovering from anesthesia. PWCs are hypersensitive to many medications, including anesthetics, often tolerating just a fraction of the standard dosage levels. The reactions some patients experience may be a sign that their immune and endocrine systems don't respond normally to pharmaceutical challenges and stimuli. Unfortunately, no rigorous scientific studies have been published on any of these issues. Meanwhile, every day PWCs are facing the imminent possibility of surgery, and need to educate their doctors now.

What the doctors say

When a question about anesthesia and PWCs was posted on the Internet, most responses quoted two doctors, Dr. Patrick. L. Class of Nevada and Dr. Paul R. Cheney of North Carolina. Here is what Dr. Class recommends for CFIDS patients who must undergo surgery: "I prepare long before the surgery takes place by performing skin tests for all the agents I am considering using, to see if the patient is allergic to any of them. With CFIDS patients, I recommend Diprivan as the induction agent; Versed, fentanyl (a short-acting narcotic) and droperidol (an anti-nausea agent) during anesthesia; and a combination of nitrous oxide, oxygen and Forane as the maintenance agent."

In contrast, Dr. Class notes, "There is a commonly used group of anesthetics, known as histamine-releasers, which are probably best avoided by CFIDS patients." This group includes the thiobarbituates, such as sodium pentathol, probably the most common induction agent and a known histamine-releaser. "In addition, there is a broad group of muscle relaxants in the Curare family, namely Curare, Tracrium, and Mevacurium, which are also potent histamine-releasers and should be avoided by CFIDS patients." Because many histamine-releasing agents are commonly used during emergency surgery, Dr. Class advises PWCs: "Wear a medical alert bracelet in the event you are unconscious. I would mention on the bracelet that you cannot receive any histamine-releasing drugs." Other options for communicating this information include carrying instructions in your wallet, educating your family and insisting that it be included in your medical chart.

CFIDS can be an indication that certain organs, like the liver, may already be overtaxed, and processes like cell metabolism disturbed. An anesthesia plan must take this into account. Dr. Cheney advises against using anesthetic gases like Halothane that can potentially be toxic to the liver. "Patients with CFIDS are known to have reactivated herpes group viruses, which can produce mild and usually subclinical hepatitis. Hepatotoxic anesthetic gases may provoke fulminate (sudden, severe onset) of hepatitis."

Dr. Cheney also notes that electron beam x-ray spectroscopy techniques have shown that PWCs do not have enough magnesium and potassium in their cells, which can be problematic. The mag-nesium and potassium depletion can result in cardiac arrhythmias during anesthesia. "For this reason, I would recommend the patient be given Micro-K using 10mEq tablets, 1 tablet BID and magnesium sulfate 50% solution, 2cc IM 24 hours to surgery."

As technological advances like laproscopy make surgery less invasive, surgeons can perform more procedures where they combine a local anesthetic with a sedative instead of using general anesthesia. But even local anesthetics used outside of surgery should be approached with caution when being administered to PWCs. "Lidocaine should be used sparingly and without epinephrine," Dr. Cheney says.

In an article for the February CFIDS Support Network update, Dr. Charles Lapp of North Carolina also emphasizes checking serum magnesium and potassium before surgery and replenishing these minerals if the levels are borderline or low. Seriously ill patients, or those frequently on steroid therapy, might need pre-operative cortisol testing and supplementation as well. According to Dr. Lapp, doctors may also have to modify pre- and post-operative sedation. "Most CFIDS patients are also extremely sensitive to sedative medications--including benzodiazepines, antihistamines and psychotropics--which should be used sparingly and in small doses until the patient's response can be assessed."

The consequences of neurally mediated hypotension (NMH)--frequently seen in CFIDS patients--concern Lapp as well. These include low plasma volume, low red blood cell mass, venous pooling and vasovagal syncope (fainting). "Syncope may be precipitated by catecholamines (epinephrine), sympathomimetics (isoproterenol) and vasodilators (nitric oxide, nitroglycerin, beta-blockers and hypotensive agents)," Dr. Lapp says. "Care should be taken to hydrate patients prior to surgery and to avoid drugs that stimulate neurogenic syncope or lower blood pressure." The need for extra hydration might mean checking into the hospital the day before surgery--as was customary in pre-managed care times--instead of just a few hours before.

Almost everyone feels weak and tired after an operation. But people with CFIDS should prepare to experience increased fatigue and problems with memory and concentration for a much longer period than normal, says Dr. Charles Shepherd of Gloucestershire, England, in his book Living with ME. He speculates that reduced blood flow to the brain during surgery and the immediate post-operative recovery period may partially explain this. Other possible culprits may be specific anesthesias, particularly those used to correct a low heart rate or reverse muscle paralysis, which can further disturb brain chemistry already altered by CFIDS.

Dr. Shepherd suggests referring surgeons and anesthesiologists to a research paper about acetylcholine levels in PWCs (such as Chadhuri, A., et al, Chronic fatigue syndrome: a disorder of central cholinergic transmission, *Journal of Chronic Fatigue Syndrome*, 1997; 3: 3-16). This may be a good way to alert them to possible complications with your recovery.

How you can prepare

These steps should help you get ready in the event that you need anesthesia. Remember that the following applies to dental procedures requiring anesthesia as well, so don't forget to inform your dentist or oral surgeon.

1 Avoid unnecessary surgery, since the risks of anesthesia for PWCs are still not well-defined.
2 Ask that the specific information about the use of anesthesia in PWCs mentioned in the "What the doctors

say," section of this article be placed in your medical chart in case you need emergency surgery.

3 Always seek a second opinion--and a third or fourth, if necessary--when a doctor recommends you have surgery. This applies even in emergency situations. Let your family know your wishes.

4 If non-surgical treatment options exist, explore these first. For instance, there are new, non-surgical techniques to remove kidney and gallstones.

5 If you have to have surgery, choose the least invasive surgical technique. There are new "keyhole" procedures available that involve less anesthesia, less trauma to the body and a quicker recovery time. This may mean traveling to a big city hospital where the higher tech equipment is more prevalent and surgeons have more experience using it. Be careful to investigate all options carefully first, so you can avoid being a guinea pig for an inexperienced doctor trying equipment for the first time.

6 Insist on meeting with the anesthesiologist and surgeon as far ahead of the surgery as possible, so you can discuss CFIDS-specific issues and he can have time to do additional research on what will work best for you. Ask him or her to explain exactly what will happen during the procedure.

7 Make sure your surgeon and anesthesiologist know the dosage and frequency of every medi-cation you are taking, including herbs, supplements and vitamins. Don't forget to mention any drugs you have recently stopped taking, as some substances take weeks to clear from your system. There may be contraindications to or interactions with the medicines they plan to use.

8 Make sure your doctors know all allergies and hypersensitivities you have to medications, foods and chemicals.A latex allergy is an obvious example, but did you know that a shellfish allergy might mean you will react badly to certain x-ray dyes?No allergy information is too insignificant to mention.

9 Ask if you can leave information on CFIDS for the nurses who will be caring for you after the surgery. They may not read it, but it is worth the attempt to educate them about possible complications.

10 After the surgery, try not to overdo and give your body appropriate time to heal. Keep in mind that your healing may be slower than is normal, and make sure your health care providers and caregivers are aware and pre-pared for that possibility beforehand, so that a longer hospital stay or special care can be arranged.

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website: www.cfids.org

CDC Payback Funds Put to Use

The chronic fatigue syndrome (CFS) research program at the Centers for Disease Control and Prevention (CDC) continues to benefit from the restoration of $12.9 million in funds that were wrongly diverted from 1995-98.

In the fiscal year that ended Sept. 30, 2000, the program received an extra $1.9 million on top of its $5.8 million baseline budget. Spending figures for the current fiscal year will be released in the fall.

The funds are being restored to the program after the Inspector General found that CDC had used the money for other programs and then misled Congress about it. The bulk of the money will be repaid during Fiscal Years 2002 and 2003. The funds are not earmarked for specific CFS projects.

Under the leadership of Dr. William Reeves, the CDC will expand its in-house CFS surveillance studies--including a new national population-based survey slated to begin late this summer. Molecular epidemiology studies using cutting-edge technologies to identify unique gene patterns in CFS patients are another primary component of in-house studies.

The CFS program is also supporting activities to educate primary care providers about the disease. Dr. Reeves and his group also continue to lead efforts to refine the CFS case definition. The group held a workshop in May 2001 to review classification models and assessment tools that might be useful in revising the CFS case definition.

The CFS program has expanded collaborations with academic researchers as well. Dr. Nancy Klimas plans to take a sabbatical from her duties at the University of Miami to work with CDC on case definition and other research issues.

The program also has provided financial support to Dr. Sidney Grossberg in his studies of a novel virus that may be associated with CFS.

In addition, Dr. Andrew Lloyd s Australian research group will follow cases of acute infection. They will assess risk factors for cases that do not resolve and lead to a CFS-like illness.

The CFS program s most significant collaboration is with a multi-disciplinary group at Emory University. The group is using alpha-interferon treatment as a model for CFS, and studying a number of neuroendocrine aspects of CFS.

The CDC also has agreed to co-sponsor the Association's third research symposium, to be held in October on the immunologic aspects of CFS.

A more complete report on CDC's use of restored research funds is anticipated at the next meeting of the DHHS CFS Coordinating Committee, expected to be held this fall.

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The CDC's CFS website is at:
http://www.cdc.gov/ncidod/diseases/cfs/

CBT: Good or bad?

By Theresa Coe, Editor of *InterAction*

CBT=Cognitive Behaviour Therapy

InterAction is a quarterly magazine produced by *Action for ME (AfME)*

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

The debate rages on…

We have been asked by some to explain our position on CBT (cognitive behavioural therapy), and whether by failing to campaign against it we are 'giving in' to the psychiatrists.

Issue 31 of *InterAction* carried an article on CBT by practitioner Stephanie Jones, explaining how this particular approach works. Cognitive-behavioural therapy (CBT) attempts to tackle and change inaccurate views and irrational, unhelpful behaviours which may cause or exacerbate an existing condition. It is recommended by some clinicians as a treatment helpful for people with a wide range of chronic conditions, including AIDS, MS and ME. It should not be a substitute for physical treatment, but certainly helps some people to better manage the *consequences* of their illness. However, problems may arise when it is poorly applied, or given by a therapist who does not understand or accept the physical constraints that ME can impose.

This is illustrated by the experience of Amanda Cornu, who writes:

'Initially, I found keeping daily charts of my rest/sleep and activity useful, and it made me more aware of where my patterns, perhaps, impede my progress towards better health. It was suggested that I cut my periods of activity back which gave me more energy and enthusiasm although I was still pretty ill…'

However, Amanda's health deteriorated after a trip abroad, and she was surprised when her therapist advised her to continue exactly the same programme she'd followed prior to her setback. She adds: 'I was unhappy with this advice and was placed in quite a dilemma. CBT had had helped me in the past – yet I knew that I now needed a lot more rest…I felt on several occasions that I was going towards a severe relapse. My therapist told me that I had not done so far so this would not happen! I believe that the idea behind this approach was 'mind over matter'. Unfortunately, and quite obviously, this approach is not going to help someone with an organic illness. It denies the person's experience.' For this reason, Amanda feels that CBT is potentially detrimental to the health of people who have ME severely and are faced with constant relapses.

'Good' versus 'bad' CBT

Tony Willis is in the unique position of being a CBT practitioner who also has ME. He is adamant that in cases such as Amanda's it is not the therapy but the practitioner who is at fault.

'CBT should be about sorting out thoughts that you don't want to face or have avoided' he explains, 'Changing perceptions and thinking differently to maximize your quality of life is risky, in as much as you're going to make changes and they may not work.'

Tony speaks from personal experience, having feared that he'd see himself as crippled or 'weak' if he used a wheelchair, 'leaving my brain behind along with the use of my legs'. But in fact with the wheelchair he could go places not possible without it. He is concerned, however, that CBT is often confused with graded activity programmes, perhaps because the two may be offered simultaneously.

'The best way to exercise is to perform tasks to improve your quality of life, such as eating fresh food instead of "ready meals"; you shouldn't use up energy in pointless exercise' he points out.

'One man I treated was doing graded exercise but couldn't cook for himself as he had no energy left to do so! CBT should be about helping people to make informed choices, knowing all the consequences.'

What does research show? AfME Medical Advisor Dr Andy Wright comments:

'The first UK trial of CBT for CFS (Butler et al) showed some positive results but this was heavily criticised for its high drop out rate, the lack of any control group and no independent assessment of outcome. Then a large Australian trial (Lloyd et al) concluded that a CBT rehabilitation programme conducted in an outpatient setting provided no more benefit in global wellbeing, physical capacity or functional status than attendance at an ordinary medical clinic.

A further UK trial carried out in Oxford (Sharp et al) divided a group of 60 patients into 30 receiving CBT and 30 who were given no further explanation or advice about their illness. Although the people treated with CBT *did* statistically improve compared to the placebo group, of particular interest was the fact that a significant number of patients in both groups were also suffering from a depressive, anxiety or somatisation disorder. This study was also criticised for not controlling the effects of therapists' time and attention.

In a further study (Deale et al) with strict control for therapists' time and attention, 60 patients were randomly assigned to receive either thirteen sessions of CBT and graded activity *or* relaxation therapy. This study did show that 63% of those in the treatment group improved, that is, reported a good outcome compared to only 17% in the control group. However, this study was flawed in that 21 patients had a current psychiatric diagnosis and 12 patients were receiving additional anti-depressant therapy.

Dr Wright concludes, 'the problems arising from ME studies for CBT are in the case definition for the illness which is used. Researchers tended to use the Oxford Criteria, which does allow psychiatric illness as part of the case definition.'

Not everyone needs CBT

The therapy may then be less beneficial to patients who don't suffer from anxiety and who can still see a light at the end of the tunnel. This is illustrated by former nurse Gill Allen's experience. Gill's course of CBT was arranged by her haematologist against her GP's wishes, as she felt Gill was coping and pacing herself well already. The therapist she saw was not keen on her being in a self-help group and also suggested that she was too insular and needed to get out more. Gill says 'actually, since I have stopped working I probably see *more* people!'

He suggested Gill needed to take more exercise and that maybe she was frightened to push herself because of the risk of worsening the myalgia (muscle pain). 'My husband thought this was laughable as I am always being reprimanded for doing too much by friends and family.' she continues. 'I attempted graded exercise as suggested…which certainly made my muscle pain and cognitive function much worse. One aspect I did find difficult was that at times I felt I was being asked to change my personality.' She did have one positive thing to say about her experience though: 'I do feel it was useful to talk through the CFS scenario with the CBT practitioner. He is the only person in the last six years who has had the time to listen - a very rare phenomenon in the NHS these days.'

Help rebuilding confidence

Not everyone has had a bad experience with CBT. It probably helped Fiona Agombar more than any other therapy. 'Although my therapist believed my ME was physical, she still used CBT to help me to see things more positively, pace myself more appropriately and look at what I had - not at what I had lost'. However, she is worried that some CFS clinics appear to view ME as a 'learned behaviour disorder'. 'I think the bad ones use CBT to encourage the patients to 'rethink' their illness as something they can push themeslves out of. That would be very dodgy'.

Moira Boughtwood's experience has also been incredibly positive. After a bad relapse, she was offered CBT along with a graded activity program. Moira remembers that 'with every remaining ounce of strength I fought this, but in my desperation, I gave in…' First, her carer had to keep a diary of activity and rest periods so that the Occupational Therapist could ascertain her energy levels. She was then given three tiny activities to do daily, which were gradually built up. 'Being made aware of thought processes, I managed to recognise how I could think differently, which has slowly helped rebuild my confidence in myself. My progress over the last year has been amazing. I would urge anyone to give CBT a chance.'

She makes a point which perhaps sums up the difference between 'good' and 'bad' CBT: 'The key seems to be to work in partnership with the professional and not have anyone dictate the speed of the progress.'

Not a cure, but a coping mechanism

Colin Cretton also had a bad relapse earlier this year, which left him depressed and full of anxiety at the 'apparently dwindling prospect of returning to anything like a normal life'. He was referred to a community psychiatric nurse specializing in counseling patients suffering from disability-related anxiety and found this helped him to turn a corner. 'During six months of consultations, involving the use of CBT, I gradually became able to cope more effectively with my situation and to reduce dramatically my anxiety levels. There was no attempt to force me to attempt activity which my physical energy would not sustain.' This is another example of sensitively applied CBT. His therapist was adamant that the therapy is not a 'cure' for ME, but it did help Colin to see the future more positively. He concludes: 'It was of immense value in restoring my self- confidence. As it happens, the physical symptoms have also been ameliorating over the last few months. This improvement has undoubtedly been reinforced by the reduction in energy previously expended in worrying.'

Some clinicians, patients or carers assume wrongly that because CBT can help, ME must have been a psychological problem in the first place. Clearly, this could have harmful effects if the practitioner is insensitive to the concept of pacing and the potentially dangerous consequences of ignoring pain or exhaustion. Nonetheless, there is sufficient evidence of its usefulness that it would be irresponsible for AfME to campaign against its use, where appropriately applied.

In summary, Action for ME supports CBT that involves:

- working in partnership with the patient, to explore ways towards a better quality of life, in whatever form that takes
- applying the therapy in the same way that one would for any other chronic illness such as MS or Parkinsons' disease

We recommend that people with ME avoid CBT practitioners who:

- don't respect the physical limitations imposed by the illness, e.g. by attempting to 'push' the patient beyond their physical limits
- believe that CBT can cure ME i.e. that it is a psychological illness
- are inflexible or dogmatic in their approach

CFS, Bias and the British Medical Journal

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Introduction

Chronic fatigue syndrome (CFS) is a common, potentially disabling illness which carries a substantial socio-economic burden (1). The true prevalence of this disorder may have been underestimated in the past(2).Without doubt, the condition deserves serious consideration both from the research scientists and physicians in clinical practice.

The British Medical Journal (BMJ) is the official organ of the British Medical Association, the largest professional body of physicians in the UK. Readers expect the journal to publish original research on CFS and to keep them up-to-date with developments documented elsewhere. The publication of a broad range of views allows practitioners to make informed decisions and is an essential part of the scientific process. For clinical and epidemiological purposes, patients with CFS are currently defined by the CDC criteria which were developed by the International study group and introduced in 1994 (3) .

We reviewed the content of the publications on CFS which have appeared in the BMJ since 1995 to see if the nature of the papers reflected the global research, clinical opinion and changes in the diagnostic approach in relation to this condition.

Methods and Results

A search of Medline for publications in the BMJ between January 1995 and August 2000 on chronic fatigue syndrome and myalgic encephalomyelitis (ME) identified 41 articles and letters. They included 6 original papers, three editorials, one review, a case history, a book review and a number of letters. A similar search using the BMJ's own search engine plus an independent database identified three additional items, all written by the BMJ editorial staff. To analyse the content of the published papers and the diagnostic criteria used by the authors in case selection, we targeted original research papers (including short papers), editorials and review articles identified by this search. There were six papers featuring original research (4-9).

Not a single paper used the latest CDC-criteria for case selection. Where reported, the definitions used for case selection in these papers were the Oxford criteria (10) though one paper did not make it clear except to note that the patients fulfilled criteria for "neurasthenia" (6). Only one report of original research included findings inconsistent with a psychiatric explanation (4). One challenged the adequacy of a measure to assess abnormal illness behaviour (5) while two supported the management of CFS using cognitive behavioural therapy (CBT) and/or graded exercise (7,8). In a paper which confirmed previous observations of altered neuroendocrine control in CFS, the authors concluded, without any direct experimental evidence, that the abnormal responses might be the result of prolonged
inactivity or a disturbance of the sleep-wake cycle (6). Moreover, a short report misrepresented the illness ME (9), thought to be a subgroup of CFS.

The only review during this period was an extract taken from Clinical Evidence. All the authors were mental health professionals (11). There were also three editorials on the illness (12-14). One was written by two psychiatrists (12). Another dealt with childhood CFS and was written by a paediatrician (13). The third, a commentary on the Royal Colleges Report, was written by a virologist (14). All three editorials expressed views consistent with a psychiatric explanation of CFS. The book review covered a text co-authored by two of the aforementioned psychiatrists and was highly complimentary (15). However, given that it was written by a former colleague of one of the authors (not declared), this is perhaps not surprising.

Comments

Between 1995-2000, none of the published papers on CFS used the currently accepted international diagnostic criteria (CDC) to define their patient population. Since the Oxford criteria are less specific than all the other published guidelines, the conclusions of these papers cannot be applied to all those suffering from CFS. We found that the paper by Trigwell et al was an appropriately designed study since it compared CFS patients with people suffering from multiple sclerosis (MS) (5). However, the paper by Lane et al was the only report focusing on the possible role of non-psychiatric influences on fatigue in CFS (4). It was the only research of its kind published in the BMJ during the past five years.

Most editors of medical journals respect the need for balance in the content of papers, particularly on controversial topics such as CFS. However, in relation to CFS, the editors and reviewers have clearly leaned towards the psychological and psychiatric aspects during the period in question. The fact is that most of the papers in the journal have emphasized the role of inactivity, mood disorders and/or maladaptive beliefs. There were no papers on the immunological or virological aspects nor any item referring to new research on these topics published elsewhere. We believe that the result has been to give readers the impression that the majority of patients with CFS are suffering from phobic avoidance and following unhelpful advice.

Responding to earlier suggestions of bias, the editor had claimed that: "We don't consider ourselves to be pushing any theory: we are simply sorting among the 5000 papers submitted to us to find the best" (16). However, this is hard to believe, given the inadequacies in the various papers supporting the psychiatric view. For example, Sharpe et al (7) indicated in their report that the patients who were going to receive CBT spent more than twice the amount of time in bed compared to the comparison group, despite having the same level of disability and fatigue. This and one other finding suggests that the researchers had inadvertently included more people with psychological problems in the treatment group, which could explain their favourable response to CBT. The paper on the graded exercise was similarly flawed in terms of patient selection and did not provide any long term follow up (8).

The claim to publish 'best evidence' is also difficult to reconcile with the uncritical review of treatments (11). Firstly, this overlooked a number of relevant trials in order to support their contention that CBT was "effective" and that graded exercise produced "substantial improvements". Secondly, it disregarded notable flaws in the 'successful' trials, such as the fact that the only symptoms assessed were fatigue and

emotional distress and that all had included patients with psychiatric disorders; a subset likely to respond to CBT and exercise (7 8). Thirdly, the review failed to note that the follow-up of Sharpe et al had not confirmed the initially reported differences between the groups. In our view, this paper was partial, biased and clearly misleading.

Another example is the editorial which suggested that many doctors still advocate the "rest cure" and implied that most patients take that advice (12). The fact is that the strategy described has not been recommended in relation to the clinical management of CFS in any medical journal in the past two decades, nor has it been advocated by the two national patient groups during this time. The most commonly used coping strategy is in fact pacing, but this was not mentioned here, or in the review. Sadly, errors are not always corrected, nor flaws discussed. Although multiple criticisms and shortcomings of the review of treatments were reported in the electronic form of the journal (eBMJ), none were published in the paper version despite the promise made by the BMJ to Dr X personally. Moreover, in a personal communication to one of us (Dr Y), the editor of Clinical Evidence accepted that there were shortcomings in the review but this was not made known to the readers of the BMJ.

We are not the first to have documented a far from balanced editorial policy in the BMJ. An independent report published more than seven years ago, noted that the mainstream British medical journals tended to limit their coverage of CFS to papers favouring a psychological explanation (17). In the past, one of the BMJ editors actually offered his support to the psychiatric explanation and reinforced the negative stereotype of the CFS patients by writing a factually incorrect commentary (18). For example, he implied that the patients with CFS had manipulated the World Health Organization (WHO) and persuaded them to "include myalgic encephalomyelitis under the diseases of the nervous system in ICD-10." This is simply untrue, as a call to the WHO would have confirmed. He was also incorrect when he claimed that "supporters of myalgic encephalomyelitis.... landed a Myalgic Encephalomyelitis Act on the British statute books, requiring an annual report to be made to parliament on its causes, effects and treatment". There is no ME Act in the existing British statute books.

Taken in conjunction with this background, our knowledge of papers which have been rejected and the fact that between 1995-2000, only one paper was published in the BMJ linking CFS with a non-psychological aetiology, there remains little doubt that the current editorial policy of the BMJ is uncritically supportive of the psychiatric view of CFS. This, we feel, has seriously compromised the quality of information provided on CFS to the readers of the BMJ. Our analysis supports the view that the journal's editorial policy has consistently ignored the non-psychiatric professional views on CFS. Based on our knowledge of this illness, we were unable to find sufficient scientific reason to justify this bias.

Flawed scientific research is probably even more harmful than fraudulent research since the principle of self-correction by science cannot be applied. In addition, the editor's decision on the selection of scientific communications and nomination of authors for review articles and editorials on CFS should not only be fair, but must be seen to be fair. We were unable to see this transparency or balance of opinion on CFS in our search of papers published during the past five years in the BMJ.

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Epilogue

The request for a more evidence-based, as opposed to theory-led, editorial policy was rejected by the editor and BMA Ethics Committee. Arguments included 1. that the 'preference' was no different to that in similar journals, and 2. that it reflected editorial freedom.

Here is our response:

With regard to editorial freedom, should a mainstream medical journal have a policy which promotes one theory at the expense of others? Should a scientific publication censor all the research supporting alternative theories? Should the editor overlook major flaws and disinformation as part of the policy? Does all this not undermine the scientific process? If the editor is to have this 'freedom', should the journal not admit to having a 'preference' so readers are aware of it and realise that they need to seek information on the immunological and virological aspects elsewhere? And should that journal claim to support evidence-based medicine when it selects articles on one illness largely on the basis of the editor's personal preferences?

Details of analysis of other journals (same time period)

Analysis of papers in JAMA

The Medline search identified 14 items. Of these, two were original papers, 2 were case histories (same case over one year) and 10 were letters. The subjects of the research papers were treatment (hydrocortisone) and the
relationship between CFS and neurally mediated hypotension. With only two studies, it is not possible to discern a clear bias

(Continued on page 36)

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

'Live' Blood Analysis for CFS patients – exciting breakthrough or

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Action for ME Medical Advisor Dr Andy Wright takes a look at new technology enabling 'live' blood analysis and asks 'Could this help ME patients?

Various workers have developed high magnification video microscopy over the past twenty years, notably Robert Bradford at his research institute in California. There are hundreds of these systems throughout the world, mainly used by practitioners of integrated medical therapies. It is not just a microscope for CFS/ME patients but is used for a multitude of chronic disorders to help in planning treatment protocols. It's important to note that it is not a diagnostic tool for ME and is not marketed as such.

The unique features of this system are
1) Extremely high magnification- X10 000-18 000,dependent on which model is used (about 10-20 times higher than specimens are usually viewed at in hospital labs)
2) Ease of switching between various means of specimen illumination i.e. from direct viewing to phase contrast and dark field illumination, enabling particular cells and organisms to be easily identified
3) The ability to keep photographic and video records of patients' blood samples as well as storing them on computer

What can you expect to see?

The difference to other microscope techniques is that instead of heating specimens to fix them on the slide and then staining them to pick out certain features, we look at two different types of blood sample (blood is always taken from the same place to standardize the procedure). The first is a live drop of blood under high magnification. This is not a standard medical technique and not routinely done in hospital settings. At X 8 000 and above magnification you are able to see various features such as abnormalities in the movement of white cells. You are able to see any damaged cell walls in both red and white cells and various microbes you would not normally expect 'if present', such as yeast-like forms.

Also evident is microclotting of blood with small clots evident about the size of one to three red cells and larger microplaques. Microclotting is common in many chronic illnesses and occurs because the blood becomes 'sticky'. This seems to be a combination of inborn genetic predisposition, a response to microbes (bugs in the system) and through oxidative stress. Dr Berg has published independent studies, showing that the blood of CFS (ME) patients is indeed 'sticky'. He was able to tell with 95% accuracy whether or not blood tested by him was from a CFS / Fibromyalgia patient or a healthy person in a study of 54 patients and 23 controls. He has also found encouraging results using standard blood thinning therapies.

In a study published this year, Professor Roberts has also shown that high free radical activity is present in CFS/ME and the higher the amount the more symptoms people have.

Just what is oxidative stress?

Dr Hyams explains: "Oxidative stress is commonly seen in chronic debilitating illnesses as the result of too much free radical activity in the body, leading to cellular damage (both to the membrane and the nucleus) in any organ. This may initially be caused by the triggering infection but is sustained due to secondary infections or an inability to detoxify as the illness progresses (due to a 'burnout' of the body's enzyme resources which neutralise free radicals).

A free radical is a molecule with an imbalanced number of electrons and the level of damage to the red blood cells is visible on a high powered microscopy. This in itself can explain the functional disorder seen at cellular level in CFS patients on the video microscope. Conventional blood tests of ME patients may appear normal as they are not sensitive enough to measure oxidative cell damage – just tissue damage.

There is a wealth of research to show the role of free radicals causing normal ageing. If you have any chronic illness where the reserve of scavengers which fight free radicals in the body is reduced (as in CFS/ME) and the production of free radicals increases, then cells can age prematurely, leading to the symptoms of fatigue seen in ME."

In a blood sample showing a sequence of drops of clotted blood, you are looking mainly for high levels of oxidative stress caused by excessive free radical activity. One can see large amounts of soluble fibrin deposited in the clot, appearing as white clots within the larger red clot.

There are other ways of testing for oxidative stress such as getting your doctor to check a blood test called methaemoglobin. If it is high you would benefit from improvements in your nutrition and supplementation with broad spectrum balanced anti-oxidants (see AfME factsheet).

Dr Majid Ali's theory of CFS

The main expert in interpreting and researching the high magnification findings has been Majid Ali in the USA, Professor of Pathology and also of Integrated Medicine. He is therefore well qualified to comment on which abnormalities seen with any Medical microscope.

The appearances I see do support his theory that excessive free radical activity, coupled with poor oxygen utilization and acidosis could explain at a cellular level the clinical symptoms sufferers describe. He explains that microclots can block up the blood supply to your muscles, brain and internal organs and also block your lymphatic vessels, which drain toxins and

IS YOUR HEALTH PRACTITIONER KNOWLEDGEABLE ABOUT ME / CHRONIC FATIGUE SYNDROME?

If your doctor understands ME/CFS and you find he/she helpful in dealing with your condition, then please tell us (8410 8929). Ask he/she if they would like to be on our mailing list.

waste products away from your tissues. This results in a build up of acids and toxins in tissues and a failure of your waste disposal or detoxification system.

Sickest patients have most abnormal findings

This abnormal chemistry of the blood (the low amount of oxygen present, coupled with high levels of oxidative stress), then allows proliferation of what Professor Ali calls 'Primordial Life Forms' such as yeast, which clump with the microclots and worsen the problems outlined above.

In my experience, there is a correlation between the amounts of these anaerobic bugs seen and the severity of the illness.

Certainly my sickest patients have the most abnormal blood appearances on the video microscope. However these appearances are not only seen in CFS (ME) and Fibromyalgia (FM), but in many chronic illnesses. This is because at a cellular level the oxygen problems also exist in these illnesses. What I feel is important though is that the clots and yeast are a very important co-factor.

Is there any evidence that the microbes seen are indeed yeasts/ candida type organisms? Majid Ali has done work correlating the severity of appearance under the microscope with increased urinary excretion of organic acids produced by yeasts, providing some evidence that these are a real phenomena. One of these, Tartic acid has also been shown to show decreasing levels when patients are treated with anti-fungals.

Professor Ali has published his findings in the Journal of Integrative Medicine. He has also done studies showing that treatment with anti-fungals decreases the amount of yeast-like forms and improves symptoms:

Dr Charles Shepherd, Medical Director of the ME Association, has serious reservations about the video microscope. He comments:

'I don't think you'll find any reputable NHS (National Health Service – UK health system) haematologist (blood specialist) who believes that this type of technology can provide reliable diagnostic information on the presence of vitamin deficiencies, heavy metal intoxication, opportunist bacterial and fungal infections, undigested food particles or oxidative cellular damage as the manufacturers claim. I therefore think it is wrong to aim expensive and unproven diagnostic techniques such as this at very vulnerable patients.

A proposal

'The only way that sceptics like myself are going to change our minds about the value of video microscopy is to subject the technique to an independently assessed clinical trial.'

Dr Shepherd suggests that a useful study would involve taking several blood samples at approximately six times throughout one week from a number of people: perhaps one with AIDS and secondary candida infection, one with a bacterial infection, one with ME and some healthy controls. If the blood samples could then be 'matched' with any accuracy to the illness of the person whose blood was being analysed, 'then it would definitely be worthy of further assessment.'

Professor Anthony Pinching, CFS Specialist at St Barts' Hospital, adds:

'I'm not aware of anything in the peer-reviewed scientific literature that shows the validity of the video microscope for the detection of disease. …but I have to say that some of the suggestions seem inherently implausible to me.' He supports Dr Shepherd's wish to see a 'clear demonstration in an objective fashion that the claims being made can be demonstrated and justified.'

Dr Michael Jenkins, CFS specialist at the Royal London Homeopathic Hospital comments: 'I saw a fascinating demonstration of the video microscope after the Fatigue 2000 conference. Of course, there's going to be a lot of junk going about in the blood anyway so what wasn't clear to me was how you interpret what you see. In any case, I can't see the NHS funding it – it would mean not only buying the expensive technology but training doctors to use it and interpret the results. No chance.'

Dr Julian Kenyon, integrated medicine practitioner, has the final word:
'I became involved in Dark Field Microscopy over 20 years ago in America. I found the pictures produced fascinating but was unsure of their meaning. Claims were made by the Dark Field Microscopists that fungi and bacteria could be seen in the bloodstream, which my bacterial colleagues all said was nonsense. However, some years later I was looking at Dark Field Microscopy on a range of cancer patients whose blood showed large amorphous bodies, which were claimed to be plemorphic bacteria (ie with no cell wall). I remained sceptical until I came across many cancer patients who had been significantly helped with a vaccine made from this bacterium. This gave me some more reality for the strange forms often seen on Dark Field Microscopy.

'I remain fascinated at how conventional haematology looks at things when they are dead. It strikes me that when they are in a living state they are potentially more informative. Dark Field Microscopy looks at the qualities of the various bloods cells seen and the way they interact. In my clinical experience this has been very useful and helpful to patients with chronic illnesses.

However, even looking at healthy people who have a proper diet and take reasonable exercise, only a small percentage of them have entirely 'clean' blood with no bacteria, plaque or candida (yeast spores) or evidence of free radical damage – so this is certainly not a diagnostic tool for any one condition.'

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Response to CFS Article in Australian

To: Editor, Gut Feelings, Australian Doctor
Date: 11th August 2001
Re: **Depression with fatigue not CFS**

I refer to the recent article on Chronic Fatigue Syndrome (CFS) by Dr Jeremy Couper (How to Treat, 3 August).

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

The author refers to the RACP CFS Guidelines (1997) which are not only at least 5 years out of date and incomplete, but biased to a psychological model of CFS. Also the CFS criteria (Fukuda 1994) used for research case definitions is "vague, over-inclusive and has poor diagnostic reliability" (J of CFS 2000 Vol7(3) p17-22). The recent US - State of the Science Conference on CFS (Oct 2000, Arlington Virginia) also acknowledges the need for CFS patient populations to be sub-grouped/stratified when it comes to research (and management).

All of the CBT studies to date ignore the above facts, and even modify the criteria used. CBT (and supportive therapy) is a useful tool, but it does not treat the underlying (as yet unidentified) disease processes in CFS.

The "Jenny" case in the article says it all. I showed it to my GP colleagues who quickly diagnosed her as suffering from Depression. The alcohol abuse alone gives it away. Even one of my CFS patients (with no psychiatric disorder after assessed by two psychiatrists) recognised the depression in "Jenny". My patient reminded me that the majority of CFS patients actually become intolerant to alcohol.

New research in neuro-imaging (SPECT and PET) shows significant, localised, reductions in blood flow to areas of the limbic system and brain stem regions. The areas affected are different from those seen in patients with depression. Research also indicates that CFS patients are no more de-conditioned than sedentary controls. Most can undertake a rigorous exercise test in a lab, but the next day (usually 24 hours later) many are bed-ridden, and we don't know why.

There is clearly a core group of "classic" CFS patients who have: Chronic fatigue easily exacerbated with minimal physical or mental effort, neuro-cognitive dysfunction, sleep dysfunction, myalgia (especially in the initial stages), plus or minus orthostatic intolerance symptoms. In those who develop depressive symptoms, they invariably have reactive depression.

Fortunately, most GPs have access to good management guidelines from the ME/CFS support groups, which include patient information on self-care.

Yours Sincerely

Dr Peter Del Fante GP Adelaide
Medical Director
Adelaide Western Division of General Practice

(Continued from page 33)

towards any one theory.There was certainly no policy favouring the CBT model.

Analysis of papers in the American Journal of Medicine

The Medline search identified 42 items consisting of 21 articles in a supplement (conference proceedings), 10 original reports and 11 letters.

The supplement covered a broad range of subjects and views. Of the original papers not in the supplement, one was on treatment, three covered biochemistry and physiology, one focused on the validity of the diagnostic criteria, and two assessed risk factors. De Meirleir et al's study concerned immunological aspects of the illness, with one editorial discussing its findings and another (by Manu) directing readers' attention to the evidence linking CFS with cognitive-behavioural factors.

Readers of the American journal of Medicine were well informed about the latest research. No study focused solely on one psychiatric theory, but there was an editorial and a number of letters which discussed CBT. There was no evidence of any bias or preference.

Analysis of papers from the Annals of Internal Medicine

The Medline search identified 12 items, with one original paper (on prevalence), one review (on functional somatic syndromes), and ten letters.

There are two few papers to assess bias, but the review on somatisation was balanced by the publication of six critical letters. We therefore cannot conclude that there was evidence of a preference towards one school of thought.

Analysis of papers from the Archives of Internal Medicine

The Medline search identified 14 items, consisting of 6 original papers
and 8 letters.

The subject matter of the studies included treatment (fludrocortisone), prevalence, overlap with other conditions, a ten year follow-up with recovery rates and a similar paper on outcome, and the results of laboratory tests. There was no study focusing exclusively on a psychiatric aspect of the illness, though one of the letters discussed psycho-social factors.

There was no study on the virology or immunology.

Again, we found a wide range of articles and there was no evidence of a preference towards one aspect as opposed to another.

By Ellen Goudsmit, C.Psychol, et al

ME/CFS Society AGM

Sat November 24th
1pm – 3pm
DIRC: 195 Gilles St, Adelaide
Please Arrive at 12:45 for Registration

Bring plate of afternoon tea to share.
Further details will be sent out at least 14 days prior to the event

Please Note: The AGM is one of the few times in the year the Management Committee get to meet up with the members. It is a great opportunity to raise concerns and discover what the society

Parking Permits

The Motor Vehicles Act states: - 'A person - (a) who is, by virtue of a permanent physical impairment unable to use public transport; and (b) whose speed of movement is, by virtue of that impairment, severely restricted, may apply to the Registrar for a Disabled Person's Parking Permit.

Application

To have access to any handicap parking space you need a permit. You apply for a permit at Transport SA. The cost of application is $17 for five years.

The process requires you to pick up a form from a Transport SA office. A component must filled out by your GP or CFS doctor. Your return the form to Transport SA and await notice of the result in the mail. If successful, the permit will be sent to you.

Using your Permit in the city

(I) One the road, simply place permit on left hand side dash. It doubles the time displayed on the time limit sign or adds 90 minutes, which ever is greater!
(ii) U-Park: Apply to Adelaide City council (Pirie St Entrance, 1st Floor, for a book of vouchers. Each voucher gives you your first two hours park free. (Approximately 50 vouchers per year - you send in the re-

Notice

Many of our members have used the Bioscreen testing services. The Society often receives complaints from members that they cannot get their tests interpreted by their GP. In response to these complaints I have contacted Bioscreen to see what we can do about this.

It is important to stress that once you have decided to have a test done, you should make sure your GP is willing to follow up on testing after you get the results. If you have to badger your GP to get the test done in the first place, don't be surprised if they are slow to do the follow up work you would like.

Bioscreen have informed me they are doing all they can to improve the followup service people receive. Over the last few months key improvements to the service have been introduced:

- Retesting prices have been reduced to $137 per test
- Tania Emms can be booked for patient consultations - covered by private health insurance.
- Dr Henry Butt is now employed full time and available to speak with medical practitioners about test results and possible treatments

The last point is crucial. Make sure your GP is aware he/she can gain assistance subsequent to testing.

If you are going to spend a lot of money on this sort of thing, make sure you have done your homework and discussed it thoroughly with your GP beforehand. If your GP is not familiar with the testing service, and not likely to take an interest, then find a clinician who is willing and able to help.

Paul Leverenz

DISCLAIMER: This notice is a response to member concerns. It is not an endorsement for the Bioscreen testing services, but a provision of information for our many members who have already used them. Patients and their clinicians must make their own minds as to the benefits of these services.

SUPPORT LINE CHRISTMAS BREAK

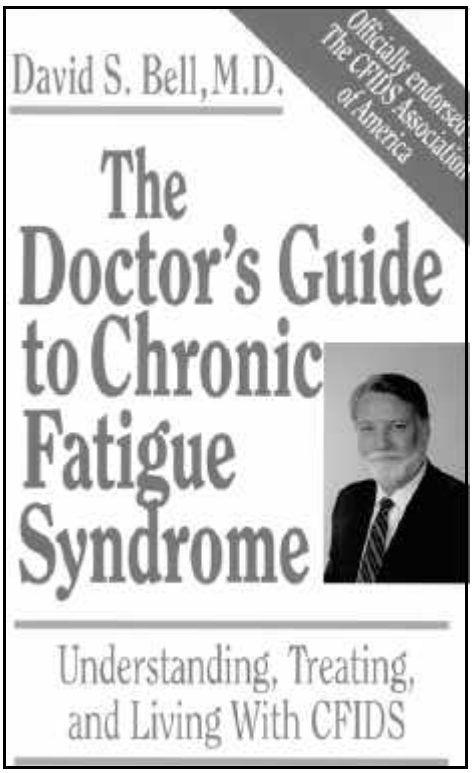
The Support Line will be closed over Christmas from:
Friday 14th December to
Monday 4th February.
The Message Bank will remain in operation and will be checked weekly over this period. For urgent support needs please contact

The Doctor's Guide to Chronic Fatigue

$24.00 (inc. GST) + $3.00 Postage and

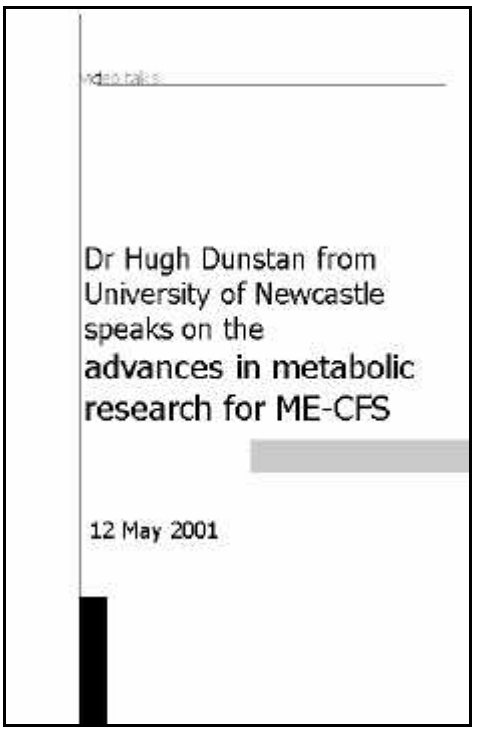
September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Many of you would know this book by the first edition name: "A Disease of A Thousand Names"

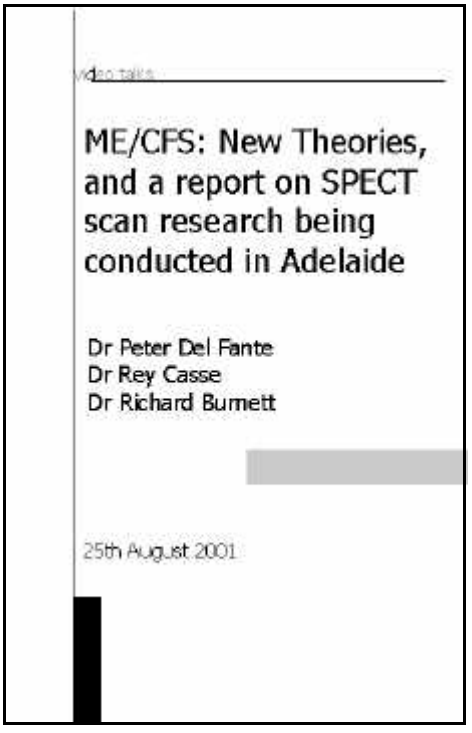


Videos

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

RED by Stephanie

"To all those courageous people struggling to win the fight against CFS, we wish you the very best. From Stepahanie and Red" is the inscription Stephanie worte in the copy of her book 'Red' which she presented to the ME/CFS Society recently.

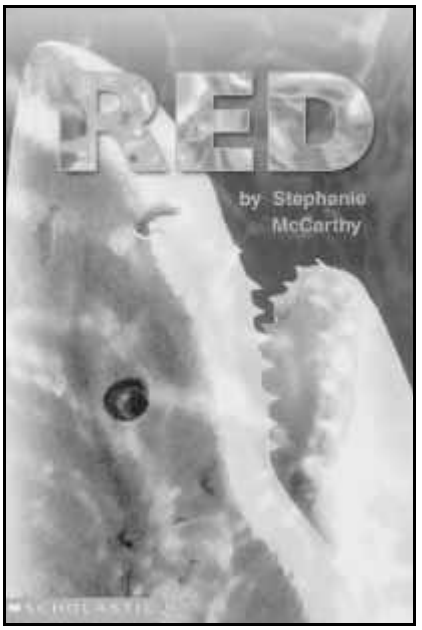
Her passion to get the message across to young people, especially in the mid teenage bracket, that Chronic Fatigue Syndrome is an authentic illness, led her to write this sequal to her book 'Diary Z'.

Fifteen year old Red lives on the West Coast of South Australia. Because of his involvement in some extraordinary events during the year he decides to write a book. Encouraged by his English teacher, who "couldn't wait to read it", he tells of his adventures and the situations in which he finds himself.

Red's mate Shep has this CFS thing. Red doesn't understand why Shep's too sick to go to school or footy but volunteers for the Country Fire Service! His girlfriend explains to him that CFS stands for Chronic Fatigue Syndrome. "Of course", Red says, "everyone knows that Chronic Fatigue Syndrome is a toally wanky lazy faky bludgy nothing disease." And he is quite disgusted. Anyway, Shep's parents, who are both vets, plan to go away for a week to a conference and ask Red if he would stay with Shep to care for him. Red thinks the money might just come in handy - he has his eye on a new wet suit - and so he agrees to the offer, thinking it would be a breeze.....

'Red' is action packed, full of adventure, suspense and surpises. From a too close for comfort encounter with a great white shark, to.... well, that's for you to discover! 'Red', although written in the language of a teenager, is a gripping book for readers of all ages.

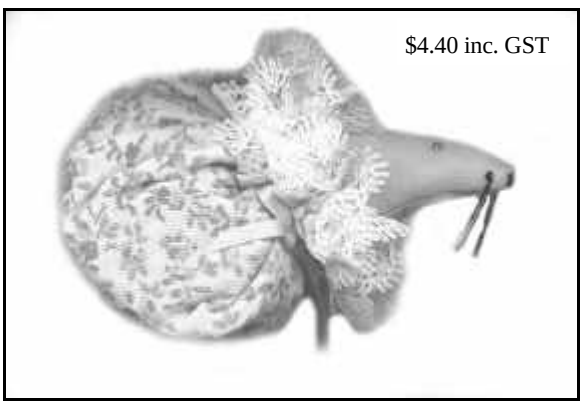
"To all those courageous people struggling to win the fight against CFS, we wish you the very best." From Stepahanie and Red



Special Price:
$12 (GST included) + $2 P&H

Mouse Pomanders

Thanks to Marie Mogg who has made us some lovely mouse pomanders to sell for SAYME. Look out for them at the AGM!



Hand-made Cards - Ideal for Christmas

Cost: $3.30 (GST Inc.)

Thanks to Marilyn Pennick who has kindly made us 100 wonderful Christmas Cards.

These cards feature a bright blue frame and depicts a bunch of Forget-Me-Not flowers.

The picture here does them no justice! You can see or appreciate the layers on the front cover.

BOOKS

The following are available for loan through the Disability Information and Resource Centre Library
195 Gilles St Adelaide, Ph: (08) 8223 7522 http://www.dircsa.org.au/
(NOTE: If your local library doesn't have some of these titles, then you can arrange inter-library loans through your local library)

	230.7 BELL	**The disease of a thousand names : Chronic fatigue/Immune Dysfunction Syndrome** / By David S Bell. NY: Pollard Publications, 1991 --198p
*	**230.7 BELL**	**The doctor's guide to Chronic Fatigue Syndrome : Understanding, treating and living with CFIDS** / by David S Bell Revised edition-- Sydney : Addison-Wesley Publishing, 1993 -- Includes bibliographical references and index --ISBN:0 201 62616 0 --275p
	230.7 BERN	**Running on Empty : Living with Chronic Fatigue Immune Dysfunction Syndrome** / by Katrine Berne USA : Hunter House, 1992 -- Includes bibliographical references and index --ISBN:0 89793 100 9 --321p
	230.7 BRIG	**Fighting fatigue and the chronic fatigue syndrome / Dr Ian Brighthope** Vic : Allen and Unwin, --ISBN:1863731571 --236p
	230.761 COLB	**M E : The new plague** / by Jane Colby Ipswich : Ipswich Book Company, 1996 -- Includes bibliographical references and index --ISBN:1 8608 3215 6 --196p
	230.793 FINC	**Energy in the red : Living with Chronic Fatigue Syndrome / by Jacqueline Finch** NSW : Jacqueline Finch, 1995 --ISBN:0 646 24730 1 --289p
	GOLD 230.7	**Chronic Fatigue Syndrome : The lymbic hypothesis / by Jay A Goldstein** NY : Haworth Medical Press, 1992 -- Includes bibliographical references and index --ISBN:1 56024 9048 --259p
	230.7 JOUR	**Journal of Chronic Fatigue Syndrome** Haworth Medical Press, -- Vol 1 Nos 1 (4 copies) ,V1- 2 (2 copies), V1-3/4 (2 copies). Vol 2 Nos 1 (2 copies), V2-2/3 (2 copies) V2-4(2 copies). Vol 3 no 1, V3- No 2.
	230.72 KLIM	**Journal of Chronic Fatigue Syndrome / edited by Nancy G.Klimas and Roberto Patarca 1995** --ISBN:1057 3321 --125 plus supplement
	230.761 MACI	**M.E. Post-Viral Fatigue Syndrome : How to live with it / by Anne Macintyre** London : Unwin Hyman, 1989 --ISBN:0 04 4403186 --342p London : Thorsons, 1992 --ISBN:0 72252624 5 --331p London, UK : Thorsons, 1998 --ISBN:0 7225 3539 2 --408p
	230.761 RAMS	**Myalgic Encephalomyelitis and Post Viral Fatigue States : The saga of Royal Free Disease / by A Melvin Ramsay** 2nd-- London : Gower Medical Publishing, 1988 -- Includes bibliographical references --ISBN:0 906923 99 9 --68p
	230.7 SHEP	**Living with ME : The chronic post-viral fatigue syndrome / by Charles Shepherd** London : Cedar, 1992 --ISBN:0749312645 --381p

VIDEOS

	230.791 CHRO	**Chronic fatigue syndrome : Victor Harbor Seminar. 27th November 1998. Part 2 / by Southern** Fleurieu Community Services 1998 -- VHS Video
*	**230.79 DRHU**	**Dr Hugh Dunstan from University of Newcastle speaks on the advances in metobolic research for ME/CFS / by ME-CFS Society (SA) Inc** SA : Sandbark Pty Ltd Video Production, 2001 -- VHS Video : Duration 104 mins
	230.79 DRHU	**The lived experience of ME-Chronic Fatigue Syndrome : Human rights and equity issues facing tertiary students with ME-CFS** SA : Sandbark Pty Ltd Video Production, 2001 -- VHS Video : Duration 72 mins. A video featuring Dorothy Morris PhD student speaking on her research
	230.791 HORI	**Horizon : Believe M E / Author not stated** -- VHS Video Duration Unknown
	230.7 TWEE	**Tweed 96 Conference. Part 1 / by Northern Rivers ME/CFS/FM Support Association** 1996 -- VHS Video : Duration 2hrs 35 mins
	230.7 TWEE	**Tweed 96 Conference. Part 2 / by Northern Rivers ME/CFS/FM Support Association** 1996 -- VHS Video : Duration 1 hr 35 mins
	230.7 LIVI	**Living Hell : CFS A "real" disease** / -- VHS Video

* Available to Purchase from our Office

Volunteer Positions Available / Help

MANAGEMENT COMMITTEE MEMBERS

What does Management Committee Entail?

Management Committee members are expected to be:

- prepared to partake in orientation training and familiarise themselves with the Society and its operations
- prepared to work in a team situation
- physically capable of attending Management Committee Meetings 2 – 3 hours in length (with a break in the middle) – at least one per month.
- prepared to serve on at least one Sub-Committee
- capable of preparing clear, written reports
- willing to pre-read documents distributed before meetings for discussion
- prepared to represent the society, as the need might arise

Should you be interested, please ring the office, leave your details and a Management Committee Member will return your call.

Sub-Committees

If Management Committee is too much of a commitment, then please consider joining a sub-committee or taking one of the many small tasks required to keep the society functioning.

Usually at least one Management Committee member will be on each Sub-Committee. Sub-Committees generally will meet once a month, but it may be more or less often depending on the tasks at hand.

At present we have several Sub-Committees – most have been formed this year, and are still in their developmental stages. Most require additional active, enthusiastic members for them to be more productive.

Existing Sub-Committees:

- Information, Research and Publications (vacancies)
- Office Administration, Facilities and Occupational Health and Safety Sub-Committee
- Grant Applications and Fundraising (vacancies)
- Education Support Programme (vacancies)
- SAYME

Meeting Teams

(15-20 hours per event)

3 people are needed (1 to co-ordinate) are needed to organise public meetings. This involves organising speakers, publicity, room hire, equipment hire, and on the day setup such as registration tables and stalls to sell Society merchandise.

JOB DESCRIPTION FOR SUPPORT LINE WORKERS

- Take calls between 10am and 4 pm and give support/ non-specific within the guidelines of the society.
- Document all calls made and received.
- Maintain confidentiality at all times.
- Keep up to date on the latest issues relating to ME/ CFS.
- Notify the Support line co-coordinator or office of any issues relating to difficult calls etc.
- Ensure adequate supplies of materials for client information.
- Be aware of other agencies which clients can be referred to.
- Be able to attend at least one meeting per quarter (support line workers meet monthly usually on Wednesday).
- Is not required to possess counselling experience or knowledge of ME/CFS but is expected to be willing to learn (training provided if necessary).
- Is expected to undergo a police check and sign confidentiality and code of conduct agreement.

New Member Team

3 People (total 1-3 hours per week)

We require a team of people to work on welcoming new members, and possibly arrange new member meetings. This job would require applicants who are confident phoning strangers, and willing to get to understand the workings of the society and to keep up to date with the latest ME/CFS issues.

Video / Tape Assistant

(average only 1-2 hour per week)

The society needs someone who is prepared to familiarise themselves with our stock of videos/tapes and maintain our library. This job involves making copies as they are needed to fill orders.

Office Cleaner

(2 hours fortnight)

Perhaps someone is looking to help out in a small way and has a little energy? We would love to have someone who could come in on the weekend, or on an evening, and clean our office. This entails vacuuming, cleaning, dusting, washing dishes and emptying the bins.

IF YOU WOULD LIKE TO HELP THE SOCIETY IN SOME WAY WE CAN MATCH YOU TO A TASK THAT YOU ARE SUITED TO BOTH IN TERMS OF SKILLS AND TIME COMMITMENT.

'Understanding and managing ME/CFS/CFIDS' Project

A request to all ME/CFS/CFIDS associations and PWCs around the world to submit/nominate articles that help and encourage others with this debilitating condition.

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Aims:

1) To encourage and help persons with ME/CFS/CFIDS
2) To encourage global partnerships and goodwill between ME/CFS/CFIDS groups around the world.
3) To recognise those individuals / groups who have produced good work
4) To publicise online works of excellence
5) To provide a helpful resource to ME/CFS/CFIDS groups around the world

NOTE: The intention is to produce a down-to-earth, heart warming resource – literary excellence will not be put above a hearty and passionate communication.

The Project: To gather together articles that do at least one of the following:

1) explain the illness in simple terms
2) explain what it is like to have this illness eg symptoms, lifestyle changes, expectation changes etc…
3) offer 'management strategies' for persons with ME/CFS/ CFIDS (either directly or simply by a personal account of how the author copes)
4) promote understanding of the illness to non-sufferers
5) offer encouragement and lifts the spirits of PWCs
6) identify and discuss flow-on issues such as mental and emotional wellbeing.

There is no set time-frame on when works were published, nor wether they have been published previously – pieces just have to be relevant to today. Pieces must be no more than 1000 words.

Publication:

Selected articles will be compiled in booklet form. The sort of copyright we are looking for could be called *'Society-ware'*.

Our intention is to make the masters of this booklet available to ME/CFS/CFIDS societies around the world to reprint in whatever format they require. Whilst the content cannot be altered, other societies may change the layout and form of the publication, and include their own preface/forward if they desire.

Our recommendation is for groups to sell the booklet for a small profit with all profits to go to the local society. Thereby all authors can have satisfaction in knowing their work is helping the cause of ME/CFS/CFIDS around the world.

Editorial Process

All submissions will be rated by a focus group of PWCs. This will form the basis for inclusion/exclusion, but we will retain the right to decide the final mix and balance of the publication.

Nominating another author's work

leverenz@picknowl.com.au

If you would like to nominate an article you found then please email me on the address above. Guidelines:

1) Please include a copy of the text OR the URL of the piece if it is online
2) If you are nominating someone else's work then please include the name and contact details of the author (if you are able)

Submitting your own work:

leverenz@picknowl.com.au
If you have written a piece and would like to offer it up to this project, then please email me on the address above. Guidelines:

1) Please make clear you are the author and give your permission for your work to be included in this project
2) Please include/attach a copy of the text in Test, Word or rtf document.
3) Please include the URL of the piece if it is online
4) Please make clear whether the work is unpublished.

Award

We will judge the best unpublished work submitted for this project, and recognise it by placing it on our website and publishing it in our journal.

Publicity

Acknowledgments at the end of each piece should include the author, their origin, and the ME/CFS/CFIDS group they are affiliated with.
For those authors whose work is online – whether on their personal website, or on a third party's site - full acknowledgment and a URL to the piece will be placed at the end of the article if requested.

Deadline

Extended to December 31st, 2001

Proposed Completion Date:

A list of the names of successful nominees will be posted on our website www.sacfs.asn.au by Feb 2002. As soon as possible afterwards the master-layout of the completed booklet will be emailed to ME/CFS/CFIDS groups around the world in an Word rtf document.

ME/CFS Society (SA) Inc.

Full details can be found on our website at:
www.sacfs.asn.au

MEMBER FEEDBACK – From July Meeting To Discuss How the RACP Guidelines Might Affect Members in

At the above meeting members of the society had a lively discussion, about some of the areas of the community with which they currently have contact. People highlighted parts of their life that might be affected by the process of diagnosing an illness, the amount of time, which this might take, the suggestions for treatment, and the outcome in terms of accessing resources, and eventual quality of life for sufferers. Thank you to all those present for contributing to the meeting.

As members have requested us to make these available, the following was a summary of people's concerns about the need to think carefully of ramifications of medical policy in particular the RACP guidelines.

For instance, the issue of **pharmacological treatments** was raised (which medications were available and limitations on amounts), the amount of blood tests which may be available to assist diagnosis, and the cost of tests – both under the PBS and private sector.

The knowledge base of **medical practitioners** in regard to diagnosis, belief systems of causality and cure, treatment options and management and how the guidelines would impact on access to hospital care etc was raised.

Members also thought there might be issues for carers and respite as well as access to community services such as council programmes HACC funding and Domicillary Care.

Another large concern was the effect of policy/guidelines on the legal aspects of obtaining housing, family court decisions, obtaining income protection insurance and other insurance. Workcover and workplace issues could be effected by a medical policy, as well as long-term entitlements through Centrelink - in particular assessment for eligibility of benefits.

Educational issues were also seen as being relevant - in so far as implications for school attendance, opportunities for equity in all levels of secondary and tertiary institutions - curriculum, face-to-face schooling, exams - assessment procedures, and course structures.

In summary, it was clear that many people who have a chronic illness, have to put a lot of energy into obtaining fairly basic resources, often in several areas of their lives and this can create a great deal of stress and anxiety.

SUE HEARD, (Scribe)

Know anyone who has ME/CFS but isn't a member of the society?

Invite them along to the May 12th event and let them see what the society can do for them.

The larger our membership, the greater our clout! Clout means funding, and funding means services.

We would like a minimum of 500 members to have a significant voice. Help us raise this membership by telling family and friends – convince them to stand with us in our cause and have them become members too.

(Continued from page 4)

On the 14th October I took part in the AGM of the National ME/CFS Association as the South Australian representative.

Simon Molesworth QC, president of the Victorian ME/CFS Society (SA) Inc., has agreed to be the National ME/CFS Association President. We are very lucky to have such a skilled and knowledgable person heading up our cause.

The main topics of discussion were, as you would imagine, the guidelines and the upcoming Conference.

Concluding Comments

Well it's that AGM time of year. It would be great to meet as many of you as possible at the AGM. Not only will we review the year just gone, but we'll be discussing plans for the next year – this is important because we are going to face one of our most challenging years. And there will be plenty of time to meet others in the society over our shared afternoon tea together.

Finally, I would like to be firm about an issue. I ask for everyone to pull together and support one another and the management committee.

Please bear in mind that our Society is run by volunteers who are either sufferers of ME/CFS or carers of someone with ME/CFS. Understandably we have a turnover of people who help – people do their bit whilst they have a 'window of wellness.' Given these limitations we cannot possibly promise to you five-star service and professionalism.

It is emotionally draining and deflating at times when people expect our Society to be run like a Swiss watch. There are times when we run well, and times when the ride is a little bumpy. Just beware of 'cutting off the hand that feeds you' – it might not seem like a great hand at times, but I can assure you we are doing our best.

I would therefore ask for all your 'positive energy' and encouragement; we will need it to continue on.

God Bless

Paul Leverenz
President

Captain ME

September 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA)

Next SAYME Mag: Coming Out Soon! Captain ME Returns!

Adelaide Support Group Report

The Adelaide Support Group, at its last meeting spent a considerable amount of time discussing the direction they group wanted to go. Two years ago we had a yearly planner, and although it was successful, there was no support for preparing another one for the year 2001. The average numbers have dropped from around twenty to eight. Most attendees over the past two years have been contacted, and whilst positive about the need for Support groups, can't attend for various reasons.

We decided that the Support should continue to run on a monthly basis, at the Society's office. [Plenty of off-street parking or good public transport access.]

We decided to change the day and time of meeting - FOURTH TUESDAY IN THE MONTH, 12 NOON TO 2PM. The next meeting will therefore be Tuesday 23rd October. [Time to catch transport at off-peak rates, eat and chat, go to the market, or do a little business/shopping if necessary.]

From January 2002, we will alternate the meeting between social and informative. A schedule will be in the next issue of Talking Point BUT IF IN DOUBT, RING THE SOCIETY OR CHECK THE WEBPAGE.

The Informative meetings may have the following as themes - no order inferred:

- quick and easy recipes
- medications especially pain killers
- places to go for help
- Centrelink …
- Latest research
- Major things I have achieved despite having CFS
- Dealing with friends who have forgotten you exist.
- A major plus that has come out of lifestyle changes as a result of having CFS.

The Social meetings

- Tram to Glenelg
- Art Gallery/Museum
- Picnic ? (only three turned up last time!)
- Visit Hahndorf or Victor Harbor
- Visit a Coffee Shop
- shared lunch

BILL DANIELS

ACCOMMODATION NEEDED

One of our members needs some help finding accommodation in Tasmania. This is his (30 yr old male) situation:

"I am a member of the ME/CFS society of SA & was wondering if anyone can help me find temporary accommodation for about 3-4 months between Jan-Apr next year anywhere in Tasmania. My symptoms worsen 100 times than usual during summer.... I would prefer to live on my own, ie a single flat etc, but would consider sharing (I am a vegetarian)… I am on a DS Pension, therefore I would like cheap accommodation..."

Please call the office if you can help.

INTERNATIONAL NO PESTICIDES DAY

MONDAY DECEMBER 3, 12 MIDDAY
PARLIAMENT HOUSE NORTH TCE ADELAIDE

Peter Evans would like to encourage people to get along and protest the use of pesticides.

SOME OF THE GLOBAL COSTS OF PESTICIDES

- 25 MILLION PEOPLE POISONED EVERY YEAR - MORE THAN 200,000 DIE
- MANY MILLIONS OF CHILDREN WITH SERIOUS PHYSICAL AND MENTAL BIRTH DEFECTS
- MANY MILLIONS OF PEOPLE PERMANENTLY DISABLED WITH PESTICIDE DISEASE
- DISEASE CAUSING PESTICIDES IN THE FOOD CHAIN AND IN YOUR BODY FAT
- DESTRUCTION OF THE ENVIRONMENT AND LOSS OF SPECIES

AUSTRALIA IS ONE OF THE FASTEST GROWING MARKETS IN PESTICIDE

STOP THE PESTICIDE PLAGUE

PESTICIDES ACTION NETWORK:
www.pan-international.org
Contact Peter On: peterev@senet.com.au for more info

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.

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
Dates: 18th July, 15th Aug, 19th June
Time: 1 pm
Please ring the Support and Information Line to confirm details: **8410 8930**.

North Eastern Social & Support Group: 'Better Together'

2nd Wednesday of each month
Location: Hope Valley
Time: 1:30 pm – 3:00 pm
Phone: Julie on **8264 0607**

Southern Suburbs Support Group

ON HOLD AT THE MOMENT

SUPPORT GROUPS: COUNTRY

Northern Yourke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo
Phone: Jane 8826 2097

Murray Bridge Support Group

Venue: Murray Mallee Community Health Centre
Date: 1st Wednesday of the month 10:30am.
Phone: Fran McFaull (Dietician) **8535 6800**

Southern Fleurieu Support Group

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

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	0500 523 500
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
Yorke Penisula	Glenys	8837 6375
Yunta	Gloria	8650 5938

YOUTH SUPPORT GROUP: SAYME

Parents Welcome

SAYME meetings are actually 2 meetings in one – one for youth, one for parents. Two separate rooms are provide at each venue – one for each of these groups to chat away independently of the other.
Last Friday of the Month 7:30 pm
PH: **0500 523 500** for more details

INFORMATION ABOUT ME/CFS

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 mononucleosis, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and auto-immune diseases such as lupus. [The illness is also 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?

Treatment 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 the use of prescription drugs, over-the-counter medications and other interventions such as physical therapy. Persons with this illness **may have** unusual responses to medications, so extremely low dosages should be tried first and gradually **increased as appropriate.**

Lifestyle changes, including increased rest, reduced stress, dietary restrictions, nutritional supplementation and minimal exercise are recommended frequently. Supportive therapy, such as counselling, can help to identify and develop effective coping strategies.

ME/CFS strikes people of all age, ethnic and socio-economic groups.

Carefully designed studies have yielded estimates that more than 800,000 adults in the U.S. have ME/CFS. In women, ME/CFS is more common than multiple sclerosis, **lupus, HIV infection, lung cancer and many** other well-known illnesses.

DO PWCs [persons with CFS] GET BETTER?

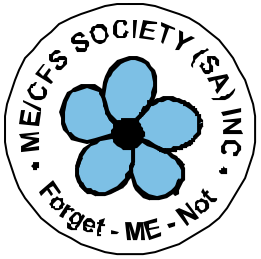
The course of this illness varies greatly. Some people recover, some cycle between periods of relatively good health and illness, and some gradually worsen over time. Others neither get worse nor better, while some improve gradually but never fully recover.

The CDC [USA Center for Disease Control] is conducting a long-term study of PWCs to learn more about the course of illness. CDC investigators have reported that the greatest chance of recovery appears to be within the first five years of illness, although individuals may recover at any stage of illness. Investigators have also found an apparent difference in recovery rate based upon type of onset. PWCs with sudden onset reported recovery nearly twice as often as those with gradual onset. This study is ongoing and observations about the course of illness are likely to change as more data is collected.

This document is based on another appearing in the CFIDS Chronicle – itself an *abridged and* up-to-date version *of* "Understanding CFIDS," a comprehensive, 16-page *booklet about ME/CFS published by The* CFIDS Association *of* America. Minor changes have been made to replace 'CFIDS' with 'ME/CFS' in several places.

We are working towards producing our own document, relevant to Australia. As more studies are conducted in Australia we will be able to provide numbers of sufferers, average length of illness and demographic breakdowns specific to our country.

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.



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GPO Box 383
ADELAIDE SA 5001

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