Talking Pawa

2002 Issue 3 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

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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 people with ME/CFS and their families

Patron

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

Medical Advisor

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

Membership

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

New Members:

Single membership…….	$32
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. Family Concession applies when the main breadwinners are concession card holders.)

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Professionals:……..	$30
PWME/CFS:……..……..	$22
Overseas (Asia-Pacific):……..	$32
Overseas (Rest of World): ……..	$38

Management Committee 2001/2002

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

President: Paul Leverenz
Secretary: Penny Cahalan
Treasurer: Geoff Wilson
Management Committee Members:
Margaret Wing, Peter Evans, Peter Cahalan, Kirsty Cordingley, Glenn Domeika, Adrian Hill & Peter Worsley with assistance from Rebecca Cordingley as minute secretary

Deadline for Next Issue
Dec. 10th 2002

Contact Details

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

Note: It is our policy to ignore anonymous correspondence.

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide.
At the time of printing the office hours are:
Monday, Tuesday & Thursday 10 am – 3 pm.
(Subject to Volunteer Availability)
Our email address is: sacfs@sacfs.asn.au

Talking Point

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

Disclaimer

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

Donations

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

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

CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

EDITORIAL

Greetings to all our members and readers out there.

It is amazing how this condition is known world-wide, and presents itself identically, yet it is frustrating how little is done about it. We have to stick together and remain strong – the tide is in the process of turning for us.

We hope you find this edition of Talking Point interesting and informative; it has been a quiet quarter as far as our Society goes, but we have managed to find some interesting articles from other places. Thanks to Zoe Beveridge, and to Cherry and Katya Adams who have done some marvellous cartoon-work and allowed us to publish it.

It is our desire to continue to improve Talking Point.

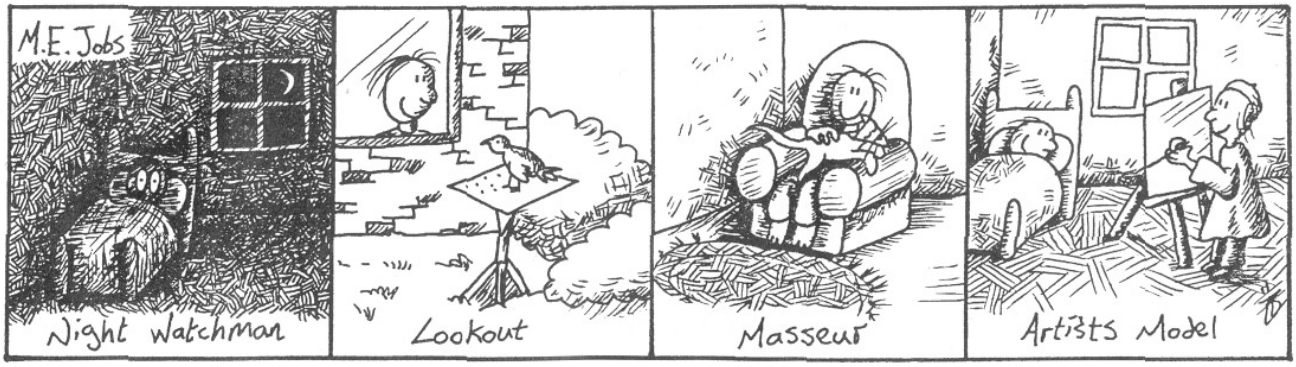
We really would love to have more original & local content so please send in you poems, recipes and letters. Its great how people have already been supporting us.

We would like to take it further. Let us know which treatments are helping you – whether they be conventional or alternative. Talking Point is about the members of our Society helping each other.

Paul Leverenz Farrah Tate
Editors

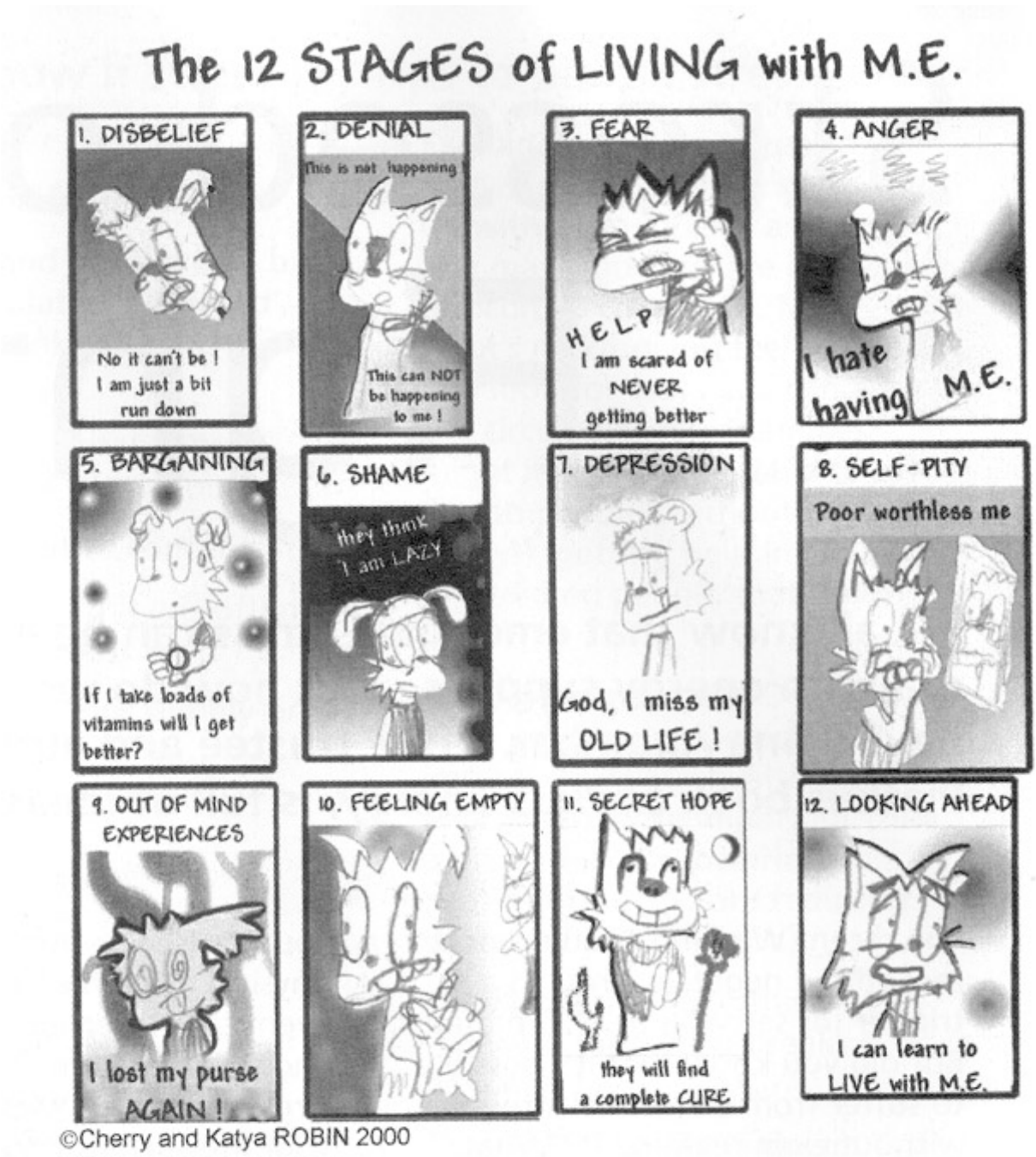
Contents

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc



Zoe Beveridge, Used with permission. See her website: www.bluechickeninaflowerpot.com

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc



Notice to Vendors

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

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

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

Advertising

To advertise your products or services in Talking Point, please call the Society office on (08) 8410 8929. Small ads submitted by our members are free subject to the following conditions. Talking Point reserves the right to reject any advertisement it considers unsuitable for publication or decline to publish for any reason at its absolute discretion. Advertisements lodged with Talking Point must comply with the Advertising Codes of the Media Council of Australia and with the interpretations of the Advertising Standards Council.

President's Report September 2002

Greetings to all.

The last few months have been productive. A lot of work has been going on behind the scenes. Administration-wise we have been tied up processing membership renewals and the questionnaires so many of you kindly filled in.

The Management Committee has been working on obtaining funding from the Department of Human Services. Our initial request has been for $18, 000 p.a. to employ an office administrator to work 3 days a week, plus an additional $15, 000 funding to support our services. We have met with the Department and unfortunately this first approach has been rejected which is perhaps not surprising given we are not a well known organisation. We need time to establish contacts and build relationships in the relevant government depts.

I can assure the members (and the government) that we will not give up until we receive the recognition by way of funding that we ought. (NOTE that the ME/CFS Society of NSW receives approx $70 000 p.a., VIC $30 000 p.a. and QLD approx $8000 in rental subsidies). We will keep at the department of Human Service, seeking out different angles and avenues for support. This battle is not peculiar to ourselves, - there are many small-ish organisations servicing people with chronic illnesses that do not receive help. I do not believe this is acceptable as we perform a valuable public service that assists our government.

Allergy and Chemical Sensitivity Association (ACSA)

On September 1st, at their AGM, ACSA voted to close down its organisation. This decision was made with mixed emotions. It was certainly sad to see the organisation fold; why did it have to close? It was just not viable from both a financial and from a human resource perspective. The internet and other factors has seen it difficult for organisations such as ACSA (and ours) to retain official membership numbers. It was explained to us that from 500 in its early years, its membership was now down to under 200. A significant drop—yet not a reflection of the needs in the community. And, like ourselves, ACSA is heavily reliant on membership monies to stay afloat.

And of course there is also the perennial problem of finding enough people to do the work. For the last few years ACSA has been run by the outgoing President. Unfortunately there was no one able to take that person's place.

it was, however, encouraging that members, by joining the Victorian equivalent will not be disadvantaged in any way. The Victorian Allergy and Environmental Sensitivity Support and Research Association Inc. (AESSRA) have agreed to take on South Australia and service it. Specifically they will fund, on a trial basis, a phone support line in South Australia for their SA members and the general public. Naturally, those who join up will receive the AESSRA's quarterly newsletter by which they can keep abreast of important issues relating to environmental allergy and intolerance.

What is my reaction? As was pointed out at the ACSA AGM, organisations have a lifetime. They must be viable. They can never exist just for the sake of it. There is no shame in closing down. And who knows? it might stir up people in a few years time to really get serious about having a South Australian organisation dedicated to helping people with allergies and chemical sensitivities.

Whilst I would hope we never find ourselves in this position, we too must remember that our existence cannot be taken for granted.

Meeting on October 20th, 2002

The Management Committee believe it is a good idea to provide an opportunity for members to share ideas and learn from each other. On October 20th some of our members (see page 35) have been asked to speak about a range of issues they have faced in their lives with ME/CFS. There will be opportunities to ask questions and interact with each other.

Commotion on the Murray

Keep a eye out on the news for a man called Ash Thomas. He and a support crew intend to drive a ski boat down the length of the Mighty Murray River—the purpose being to raise awareness about ME/CFS! They depart on the 19th of October and should end up at Goolwa on approx Nov 4th. Well done! (See page 36 for full details.)

Final Thoughts

I'm pleased that most of the this year's Management Committee are re-nominating for next year's committee. This continuity is badly needed. However, we must add to our team in the next 12 months or I and others will burn out. I want to 'lay down the gauntlet.' If you have skills/time/energy then please make yourself known to us. Even doing a small job will be a big help. For example, we need a couple of people who can help organise our 2 or 3 public meetings next year. Give me a call if you are interested.

All the best.

Paul Leverenz

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Letters to the Editor

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Dear Editor,

Thank you for your most informative and helpful magazine.

I have recently purchased an 'air vital' air cleaner (HEPA / Carbon cloth) and found it very helpful. Its attached to the ceiling, easily installed, approx measures 45 cm X 36 cm. Re-circulates the air every 5 mins and find it extremely efficient. All steel, no plastic.

You can find out more from:
Cleaner Air Solutions
Peter Worden Ph/Fax (08) 8322 3860
Mob: 0418 862 624

Sue Prider

[Ed: The recent advances in air filters is welcome to those with chemical sensitivities. This new 'all metal' unit is another step forward. The only possible negative with the unit is the noise when placed on full – equivalent to evaporative ducted air conditioning which can be quite noisy. Those sensitive to noise may not be able to get full value from the product. Its worth looking into. But like everything, I cannot promise it will help you – you will have to do some research and try it for yourself. If you would like to speak with Sue, she has been kind enough to agree to let us pass on her number. Call the office – refer to this note – and we'll pass on the number.]

Androderm Testosterone Patches

One of our members purchased a box of these patches, costing $150, but found he was allergic to them. If your Dr. has recommended you try these patches then this member is willing to sell you the box at a very good price. Call the office, refer to this note and your number will be passed on to this member.

Dear Editor,

For some three years now, I have been involved as a volunteer with your Society's Information and Support Line. I came onto the line via a training course the Society conducted back in 1999.

My experience interacting with the phone callers to the line has been richly rewarding.

Thankyou for the great privalege I enjoy of working alongside Alex Harris and Jonathon Foote and Elaine Balfort, still very much the new boy on the support line. Forty or so years ago, when I thought I was planning my career, I don't think I could even have dreamt of stumbling across, quite by accident, a more fulfilling vocation,

With every good wish,

David Andrews

CFS Sufferer

Ann B, a CFS sufferer from South Australia, has successfully claimed a superannuation total and permanent disability benefit after reading an article in the CFS/ME Society magazine.

Ann had been working full time as a Bursar with the Department of Education in South Australia when she became unwell in 1995. She suffered a range of symptoms, including fatigue, dizziness, nausea and anxiety and depression.

Ann managed to continue working until February 1998 when, because of her illness, she was forced to stop work altogether and has not been able to return to work since.

Like most workers, Ann's employer contributed to a superannuation fund on her behalf. Ann also had a personal life insurance policy.

Both policies included insurance lump sums paid if she was totally and permanently disabled. However, like many people, Ann did not realise that she might be eligible for either lump sum.

After reading an article in the September 2001 issue of the CFS/ME Society magazine, Ann sent her superannuation and insurance papers to Maurice Blackburn Cashman for free legal advice about the possibility of making disability claims. After checking her papers, Ann was advised that she had reasonable chances of success with both claims.

Ann instructed Maurice Blackburn Cashman to make the total and permanent disability claims on her behalf. The claim forms and medical reports were lodged, and written submissions made as to why Ann was totally and permanently disabled.

The work superannuation disability claim has been successful, and Ann has been paid a disability lump sum. The claim for the disability benefit under her life insurance policy is continuing.

Like Ann, many people with CFS are forced to leave work or reduce their hours of work because of their illness. Many don't realise they may be covered for disability benefits under their superannuation or insurance policies, and many think that they won't be able to prove they are totally and permanently disabled.

Although there is still some suspicion amongst insurers about whether CFS exists, the main hurdle for disability claims is whether a person is permanently unfit for work.

However, as Ann's case shows, total and permanent disability claims **can** be won, particularly if you put forward the right medical evidence and make the right submissions.

If you have been forced to stop work because of your CFS or if you are thinking of stopping work, it is very important that you check what rights you might have to claim disability lump sums or pensions perhaps.

If you would like free legal advice about your rights and to have your papers checked, please contact the CFS/ME Society of South Australia, or telephone Maurice Blackburn Cashman directly on (03) 9605 2742 for free advice and help.

CFS Diagnosis and Management

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

[This was written subsequent to the publishing of CFS guidelines on May 6 as a supplement to the Medical Journal of Australia. It appeared in the magazine of the QLD ME/CFS Society.]

[The guidelines]...were surprisingly better than anticipated. However, this is an improvement from "atrocious and a health hazard to patients" to "not good". I am not sure what caused the guideline authors to back off from their original position. However, pressure from patients undoubtedly played some part, and those of you who helped with letters to the various authorities can be pleased that your actions made some difference.

A considerable amount of "psychobabble" was dropped. The reference to patients who strongly believed that their illness was physical doing worse than those who believed it was psychological was dropped in light of recent findings. A study, which found levels of psychiatric morbidity in CFS patients was the same as other chronic illnesses such as multiple sclerosis, was quoted. The psychiatric notions of "abnormal illness behaviour" and "secondary gain" were specifically disapproved. References to "school phobia" in CFS children were toned down though unfortunately not eliminated.

2 pages were devoted to a fairly comprehensive listing of the studies of physical abnormalities in CFS. However, there remained an irritating, slight bias to downplay the significance of these findings. For example, despite the fact that there are now 10 studies reporting orthostatic hypotension (low blood pressure)/ orthostatic tachycardia (rapid heartbeat) problems in a proportion of CFS patients, the evidence in this area was awarded only the 4th highest level of evidence rather than its rightful highest placing.

The graded exercise/cognitive behaviour therapy (CBT) recommendations are much more boxed in and less of a threat to patients. The limitations of studies which recommend such approaches was acknowledged, but unfortunately in a rather small paragraph towards the end of the particular section. It was conceded that the studies only dealt with people well enough to attend clinics for treatment and it was difficult to extrapolate findings to more severely affected patients. The original "Graded exercise is safe and effective for CFS" and "CBT is safe and effective for CFS" have been changed to "Graded exercise may be effective for some people with CFS" and "Cognitive-behaviour therapy may be effective for some people with CFS. It was further conceded that:

(1) Many studies had significant drop out or refusal rates,
(2) Patient selection differed between studies as well as the nature of treatment, and
(3) Improvement was not observed in certain studies or was only very modest in others.

There is some recognition of the relapsing nature of CFS, and that patients can overdo it and subsequently be subjected to days of very bad health. The guidelines state that any rehabilitation plan must be individualised according to the patient and their personal preferences and adjusted according to response.

However, the whole approach in this area remains completely unacceptable. Doctors are given the very strong impression that upon seeing a CFS patient, they should make them do more. They are told they should warn about the dangers of prolonged rest, discourage social withdrawal, and make an individual plan to increase activity.

Needless to add this is completely the wrong emphasis. CFS patients need to reduce their activity initially to a level with which they are very comfortable. Then, if they are getting an improvement, they can cautiously increase the level of what their doing. This approach can be described as "pacing" or the "energy envelope theory". There is some reference to "pacing" in the guidelines, but it appears to be a tokenistic coating to mollify patients around a CBT approach.

Doctors are also told that "many" patients can achieve "acceptable levels of functioning" over 3 to 6 months. This raises unrealistic expectations on the part of doctors as to how quickly many patients can recover.

I can forsee unfortunate attempts by various doctors to "encourage" (bully, goad, push might be better adjectives) patients into too much activity, and with the consequence of sicker patients who are in a constant state of battle with their own doctor. Another unfortunate consequence may be attempts by insurance companies to throw people off benefits if they are not doing exercise/ activity programs to the expectation of the company.

The irritating aspect of this area is that the authors of the guidelines are being intellectually dishonest about the medical evidence levels of their approach. The guidelines award the highest level of evidence to CBT and the second highest level to graded exercise. They don't mention which medical studies support the awarding of such levels. The reason appears to me to be that what is described in the "limitations" paragraph is actually fatal to the validity of the supporting studies. The major problem is that these studies rarely use properly diagnosed CFS patients.

A further problem is that the levels of evidence have been changed (ie the goalposts have been moved) to ensure that exercise/CBT approaches are promoted. A problem the guideline authors had in the draft process was that 2 studies found that CBT didn't work better than the placebo arm of the trial. One of these studies was fairly rigorous. According to the levels of evidence, where there is a good, conflicting study, the second lowest level of evidence must be awarded. Faced with this, the guideline authors changed the goalposts, stating that where one study was in conflict, but the overwhelming mass of studies pointed in the other direction, you could still award higher levels of evidence.

A further problem for the authors developed one year before the final version of the guidelines. A third study reported that CBT was no better than counselling. This shot a hole in the already fiddled levels of evidence. The final report simply ignores this study.

The annoying rubbish about sleep hygiene remains (restricting daytime sleep to less than 30 minutes, going to bed and getting up at preset times), though the suggestion that one should keep night time sleep to 8-9 hours has been dropped. The authors also were honest enough to admit that there was no direct medical evidence for their sleep hygiene suggestions, which begs the question as to why they were included.

In light of the problems listed above with the guidelines, it was decided unanimously by the Joint Australian CFS Associations at a National Association board meeting to reject the guidelines.

Peter Evans
President, QLD ME/CFS Society

New Car Drivers Exposed to Toxic Emissions

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Press Release 19 Dec 2001; Ref: 2001/290

New car headaches may involve more than minor warranty problems. Research by CSIRO has found high levels of air toxic emissions in new motor vehicles for up to six months and longer after they leave the showroom.

Dr Steve Brown, head of CSIRO's Air Quality Control research says, "Just as air inside our homes and workplaces is often much more polluted than the air outside, so sitting in a new car can expose you to levels of toxic emissions many times beyond goals established by Australia's National Health & Medical Research Council (NHMRC)". During its two-year study using three new motor vehicles from three weeks of their delivery to purchasers, CSIRO became aware of anecdotal reports, such as:

- A solicitor who was ill for several days (headache, lung irritation, swelling) after collecting a new locally built car and driving it for only 10 minutes (the solicitor eventually swapped it for an 18-month-old car, which did not affect her health).
- A government worker who felt ill when driving new government cars during the first 6 months after their delivery.
- A chemically sensitized person who felt 'spaced out' when in any new car.
- A salesman who regularly updated his locally built car and found he became lethargic on long trips (e.g. from Melbourne to Geelong) when the car was new.

Dr Brown says, "Measurements made during the CSIRO study found that total volatile organic compound (TVOC) concentrations were initially very high (up to 64,000 micrograms per cubic metre) in two Australian-made cars which reached the market 3–10 weeks after manufacture". Controlled exposures of human subjects by other researchers to a 22-compound mixture at concentrations of less than half this have produced effects within minutes, such as subjective reactions (odour, discomfort, drowsiness, fatigue/confusion), eye/ nose/throat irritation, headache and (in symptomatic subjects) neuro-behavioural impairment. Brown says, "These levels decreased by approximately 60% in the first month, but still much exceeded the NHMRC indoor air goal of 500 micrograms per cubic metre". The third car was imported, reaching the market four months after manufacture when the concentration of TVOCs was 2000 micrograms per cubic metre. "This is still four times more than the recommended goal and remains a concern", says Dr Brown.

Air toxics being emitted inside new cars during the CSIRO study and the effects they may cause include:

- Benzene – a known human carcinogen for which an annual exposure goal of
- 16 micrograms per cubic metre has been recommended in the UK.
- Cyclohexanone – a possible human carcinogen.
- Ethylbenzene – a systemic toxic agent.
- MIBK – a systemic toxic agent.
- n-Hexane – a neurotoxic agent.
- Styrene – a probable human carcinogen.
- Toluene – a central nervous system dysfunction.
- Xylene isomers – foetal development toxic agent.

Dr Brown says, "To avoid some exposure to this toxic cocktail, people who buy new cars should make sure there is plenty of outside air entering the vehicle while they drive, for at least six months after the vehicle has been purchased, although this may not be possible in heavy traffic due to air toxics from car exhausts. Ultimately, what we need are cars with interior materials that produce low emissions".

CSIRO is also keen to develop a Green Air Label to assist consumers to choose healthy indoor air environments and environmentally friendly products. David Lang, Director Technical Services of the Australian Automobile Association says, "CSIRO's work shows the need for further study on motorists to identify any effects that may impair driving". RACV's Environmental Programs Officer, Kathryn Hannan says, "The RACV would like to see further investigations conducted into the potential health effects of VOC emissions from new car interiors".

Petar Johnson, President of the Australian Environmental Labelling Association, says, "This study has conclusively shown that designers of car interiors must give greater consideration to the materials that are used in furnishings. In order to continue to deliver cars responsive to consumer health and choice for the 21st century with innovations such as dual-fuel and recyclable parts, the subject of VOC and human toxicity exposure while driving must be high on the priority list for car redesign for environment programs".

The exposure of Australians to air toxics is part of an ongoing study by CSIRO Thermal & Fluids Engineering which has so far studied new homes, paints, wood-based panels and furniture, unflued gas heaters, workplaces and offices. CSIRO estimates that indoor air pollution costs the Australian community in excess of $10 billion a year in illness and lost productivity. The results of our air toxics program are being passed on to Government regulators and agencies as they come to hand for further action.

CSIRO says there's now an urgent need to move from this assessment phase to implementing control strategies, such as the Green Air Label, across all indoor air environments.
http://www.csiro.au

A Sideways Look at Positive

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Have your rose-tinted glasses misted up? Fed up with looking on the bright side of life? AfME member Julia Derbyshire offers a different perspective on positive thinking.

'Live your life not your illness'

> Wouldn't it be nice, I find myself wondering, if someone were to turn round one of these times, and tell me to think negatively? 'Go on', I imagine the friendly voice saying; 'I would if I were you! After all, your life's a mess isn't it?' Then, with this cheerful encouragement, I could sit in a corner, impressed by my own misfortune. I could wallow indulgently with increasing self pity on my lack of social life, money, sleep and energy …and so it could go dolefully on.

Empty encouragement

The problem is that being regularly encouraged to think positively can get a bit wearisome when it's dished out by well meaning people in robust health, whether health care professionals or the local hairdresser. Too often it seems to carry the hidden implication that maybe you're not really trying.

'I'll do what I can and that will be a worthwhile achievement'

A recent example springs to mind, involving a chiropractor's secretary. After several sessions of small talk while making appointments, I made the mistake of mentioning I had M.E. The change in her manner was subtle but noticeable, as she said condescendingly, 'I always believe that positive thinking is so important, especially in *that* kind of illness.' What kind of illness would that be then? One caused by being a depressive negative thinker or a malingerer? Her words had the effect of making me crawl out vowing to keep my big mouth shut in future.

Now if the same advice had been trotted out by someone like Job in the Old Testament story - a man smothered in awful skin problems, very ill, and facing overwhelming tragedy in his family life - I dare say I'd have reacted differently and been well impressed! Encouragement from a fellow sufferer (maybe after a good moan) can be very helpful in maintaining a positive outlook – and it's good to know that others too sometimes feel like sitting in a corner and indulging in a bout of self pity.

A healing state

In the short term it often seems to take more energy to be positive, while complaining comes naturally to all but the saints among us. But the fact remains that seeing the best of a situation is important. Attitude can affect the immune system for good or ill: who hasn't heard of stress related ill health these days? Positive thought can have an impact on serious illness, not necessarily altering the ultimate outcome but by influencing our ability to cope with it and develop a better quality of life. A positive outlook simply makes for a happier and

(Continued on page 12)

(Continued from page 11)
more peaceful frame of mind, a healing state in itself.

'Easier said than done', is a typical 'bad day' response from me to these conclusions, - and I suspect I'm not alone! However, for me, the key to developing this desirable but elusive state of mind lies in realising what positive thinking is *not*.

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Common Misbeliefs

First and foremost, positive thinking is *not* lying to myself. It's not about trying to con myself into false beliefs such as 'I'm fine', when I really feel awful. Saying 'I'll be alright tomorrow…or next week…' when this is in doubt, will probably make me feel even more downcast as the subconscious mind refuses to accept it. Nor does it mean that I have to bully myself with statements like, 'I *can* do this' or even worse, 'I *must* do this'. The complete opposite however is a totally negative approach which follows the reasoning, 'I can't do this so I can't do anything and I'm useless'. Better to move away from both extremes and opt for: 'I can do a little of this, so I'll do what I can and that will be a worthwhile achievement' or as philosopher Edmund Burke put it 'Nobody made a greater mistake than he who did nothing, because he could only do a little.'

Another mistake is believing that positive thinking is about putting on a brave face for the sake of others. Realistically, this can be an all too necessary part of everyday life for many, trying to protect our families from how ill or lonely we feel. But if we must be sparing with the truth for others, we owe ourselves honesty in our positive approach.

True positive thinking is accurate and realistic, while still choosing to see the glass as half full rather than half empty: focusing on the 'can do'. There are choices to be made all the time about how things are perceived. Positive thinking learns to choose realism, praise, and encouragement, keeping things in perspective. At the same time it rejects global sweeping statements like 'everything is bad', 'there is nothing I can do', or 'nobody cares'.

Illogical thoughts multiply effortlessly and need to be knocked on the head rapidly. For me as a mother this may involve thoughts like: 'I'm a useless mother because I can't ferry my children about, or have their friends round for tea like other mums do.' Such sentiments can be challenged with a response along the lines of: 'I love my teenagers, I do the best job I can as a mother and we have a special quality about our relationship.'

Hope is obviously another important factor and it can be helpful to cultivate attitudes like, 'it's never too late to make progress', or 'give in, but don't give up'. At the same time, self worth needs feeding liberally. I try and accept myself as a valuable person for 'who I am' not 'what I do' (so very contrary to the expectations of today's demanding society); never blaming myself for lack of what may be considered measurable achievement.

During this pilgrimage into positive thinking, a key catch phrase for me recently came in the form of advice from a lupus sufferer: 'Live your life not your illness'. At first glance this seems a little harsh, even impossible with an illness which can so dominate every aspect of life, as lupus also can. But it does make for a subtle and worthwhile change. Personally I sometimes feel that I live my illness, with tiny bits of life slotted in-between. If this is turned on its head, the circumstances may not alter at all, but the perspective does. The illness is relegated to second place and thus the outlook is better.

Added to this I'm working on my final antidote to a good moan: learning how to enjoy. Most of us had the hang of it as children, but the seemingly frenzied world of modern adulthood soon makes it all too difficult, even without a chronic illness. So, I'm determined to enjoy any little thing: stroking the dog, hearing a skylark, my favourite music or food…even a cup of tea. Hence my new motto when the light at the end of the tunnel seems rather faint: Carpe Diem … seize the moment. Live it, enjoy it: tomorrow is another day!

Stamp out negativity

My Life With ME/CFS

by Aoife Ryan, Dublin, Ireland.

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Introduction

I slowly open my eyes, awaking from a night's sleep that was filled with vivid dreams/nightmares and punctuated by periods of wakefulness when I couldn't keep still or get comfortable. My head feels "stuffed" full of candyfloss, and its throbbing with such a severe pain it feels as though my brain is going to burst through my skull. I cant think straight - what day is it ? what do I have to do today ? I'm finding it hard to focus and concentrate properly. Every muscle in my body is aching, they are objecting vigorously and sending pain coursing through my body. I cannot make my arms and legs move, they just will not obey. They are too tired. My throat is raw and tender, as if someone scraped it with the nib of a fountain pen during the night.

Yet, I am not waking up after completing a staggering physical feat, I did not run a marathon yesterday, I wasn't out last night with the girls dancing and consuming large amounts of alcohol, and I do not have a bad case of influenza. This is just another day in my life - my life living with M.E./C.F.S.

In the following pages I am going to discuss my illness and my ways of coping with M.E./C.F.S. I am speaking from experience not as an expert.

Life goes on.....with M.E./C.F.S.

When I first began to have problems such as fatigue, pain, headaches, "fuzzy brain", I thought I was doing too much so I began to cut back on socialising, going to the gym etc. As time went on my symptoms continued to get worse. I was diagnosed fairly quickly with M.E./C.F. S. but this did not help me. My initial reaction was " I can beat this illness, I'm a survivor and a fighter". So I began to push myself to do more and more, of course, this did not work at all, and I ended up with a walking stick, and eventually totally bed bound. My life came to a complete standstill.

Over 4 years later, I realise that I am a survivor and a fighter, but I cannot beat M.E. I have to live with it. For me, this illness called M.E./C.F.S. is not life threatening, it is life changing.

Its "OK" to feel glum

Having M.E./C.F.S. is no party! Apart from the physical symptoms (which are difficult enough to tolerate) having to change your lifestyle can be extremely difficult. Some days I feel very isolated, as if I'm not fully participating in life. Living with M.E./C.F.S. can make you feel very vulnerable. Many days you have an all over general feeling of not being well. You cannot make plans to do anything because you just do not know how you will feel. Having to give up a career that I loved was devastating for me. I also had to give up sport and other of physical activities I was involved in. My social life changed dramatically. Gone (for the moment) are the days of polishing off a bottle of wine over dinner and then dancing until 4am (of course this is not altogether a bad thing !!).

Be good to yourself !

On the other hand however, I have learned to slow down and appreciate the smaller pleasures of life. I love to listen to the waves crashing onto the seashore, I love to watch my niece and nephew laugh and play together. I derive great pleasure from looking at a beautiful sun-rise, I adore the smell of freshly brewing coffee or the taste of fresh strawberries dipped in rich melted milk chocolate. I love to be sitting beside a roaring fire, cosy and warm, when outside the wind and rain beat against the windowpane. These are all things that I did not have time for prior to M.E./C.F.S. Instead of dinner, wine and dancing at night, I have herbal tea, croissant and quiet conversation at lunchtime. Instead of mountain walking, I enjoy gentle beach strolling. Instead of talking non-stop, I listen. I have been forced to slow down and change my lifestyle, and I can honestly say, life without deadlines is wonderful. I do still have ambitions of course, and I set goals for myself, but the goalposts have widened.

It is important to remain positive. Allow yourself time to feel sad or frustrated - even have a good old cry, but then pick yourself up and dust yourself down, and get on with your life.

Talk about your illness. Many people find it very hard to understand M.E./C.F.S. but they only way they will learn about the illness is if you talk about it.

Take time to pamper yourself - light candles, burn

(Continued from page 13)

aromatherapy oils, have your hair done, get a manicure, have a cup of cocoa, fill a hot water bottle, have a massage, indulge in some fine cuisine, wrap yourself up in a fluffy dressing gown, put some bright flowers around your house - do whatever you are able to so that you feel special.

Laugh - a deep belly laugh at least once a day.

Above all remember, this is your life, you have M.E. but that does not mean that you should not have fun. Stay positive.

Other peoples attitudes

When a person is healthy they can do whatever they want whenever they want. They can plan dinner out, a holiday, a trip into town to shop. When you have M.E./ C.F.S. you cannot even plan a couple of hours in advance. It is extremely hard for a healthy person to understand this. I think that if I did not have M.E. I would find it hard to understand the many facets of the illness and the implications on the life of the PWME. There will always be people who do not understand our illness, and may look at you with disbelief. But there will be many more who will offer their support and help. You know that you have a real illness, it does not matter what others think. Real friends - those you want around when you have recovered - will surprise you with their kindness and support. Do not waste time and, more importantly, precious energy, worrying about the others.

Conclusion

It is not easy to accept that you have M.E./C.F.S. Having to change the way I live my life has been the hardest thing I have ever had to do. I've always been an "action person". M.E. has helped me become more of a "thinker". I've become more understanding of others and more compassionate. Life has become precious to me. Living my dreams and encouraging others to do so is essential. Being sick has made me appreciate what being healthy really is !

M.E./C.F.S. is life changing - it is up to you to make it a life change for the better.

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Medical Matters

Infections in CFIDS (ME/CFS)

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By Joseph F. John, Jr., MD and Kenneth Friedman, PhD

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Many people with chronic fatigue and immune dysfunction syndrome (CFIDS) suffer from fever, sore throat and lymph node swelling and tenderness. These symptoms often accompany diseases caused by microorganisms such as viruses and bacteria. It seems logical, therefore, that microbial infections could be linked to the development or perpetuation of CFIDS.

Yet the role of infections in CFIDS remains unclear and, in many cases, controversial. Good data suggest that one, or possibly many, microorganisms can trigger the onset of CFIDS or worsen its symptoms. But much work remains to identify these microbes and discover how they may function in CFIDS.

It is clear that at least 50 percent of people with CFIDS (PWCs) have an infectious episode prior to the development of CFIDS.[1] In some cases the inciting event is a mononucleosis-like illness, occasionally a standard Epstein-Barr virus (EBV)-associated mononucleosis. More often, it is a non-specific upper respiratory infection, a sinusitis or bronchitis or occasionally an influenza-like illness, the latter characterized by severe muscle pain, high fever and extreme malaise.

Some PWCs may actually describe vividly an event at a specific date and time of day when they became ill, relating that after that event they never felt healthy again. Paradoxically, the initial symptoms may blur over time for many patients with CFIDS, making them difficult to recapture in the medical history obtained years later.

Looking for a link

Many infectious agents seem capable of inciting CFIDS, but few good studies have linked the illness to specific agents. One early study depicted an outbreak of disease probably associated with human herpes virus 6 (HHV-6) at Incline Village, Nevada. In this outbreak there was evidence of depletion of B-cell lymphocytes, a specific type of immune cell that makes antibodies, and development of symptoms consistent with CFIDS.[1,2]

Older observations from Europe suggested that an illness called myalgic encephalomyelitis had occurred in clusters that suggested an infectious/contagious basis for the outbreak.[3] Although it is tempting to attribute CFIDS to an unresolved infection secondary to viral infection like mononucleosis or influenza, it is difficult to attribute the constellation of symptoms and signs that currently define CFIDS as due to a single infectious agent.

There is some evidence, however, that CFIDS may be associated with unresolved or persistent infectious agents. For example, most patients with CFIDS have persistently and, at times, markedly elevated antibodies to portions of the EBV, suggesting that their latent infection with EBV has in some way been re-activated. This indicates that they have been exposed to EBV at least once and possibly on an ongoing basis. The same can be said, albeit less assuredly, for HHV-6. Belgian and French co-workers also have reported recently that certain types of bacteria known as Mycoplasma are associated with precipitating or perpetuating the illness.[1] One species of special interest is *Mycoplasma fermentans*.

Other evidence for an infectious basis for CFIDS hinges on the recent observations that one of the major antiviral pathways in the immune systems of PWCs is dysfunctional. Over the last decade it has become clear that PWCs generate abnormal concentrations of an intracellular enzyme called RNase L.[1,4,5] Activated RNase L serves as one final arm in a more general antiviral pathway, triggered initially outside the cell by a group of compounds called interferons. Interferons are produced in response to foreign double-stranded DNA (usually a virus), and, in turn, stimulate the activation of a substance called 2-5 adenylate inside the cell. This substance activates RNase L, an enzyme capable of degrading single-stranded viral RNA or perhaps other messenger RNA and halting the virus from producing further damage.[4,5]

(Continued on page 16)

(Continued from page 15)

In a sense, this system works as a nonspecific defense mechanism before specific humoral (antibody) and other specific cellular responses take over. Patients with CFIDS tend to fragment the functional, large molecular weight RNase L (80 Kda) and produce instead a dysfunctional, low molecular weight RNase L (37 Kda). So the symptoms suggestive of recurrent viral infections in PWCs may be due to such an alteration in this antiviral pathway.

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Weighing the evidence

Very few infectious diseases cause the number and diversity of symptoms seen in patients with CFIDS. The disease that most resembles CFIDS is acute and subacute EBV infection. But patients with mononucleosis tend to be younger and do not suffer from the other primary symptoms of CFIDS such as cognitive dysfunction, sleeping disorders and allodynia.

Nevertheless, EBV was initially thought to be the cause of CFIDS. When blood was tested for antibodies against two EBV replicating enzymes, abnormal titers of antibodies were found twice as often in PWCs than in controls (34.1% vs. 17.1%). While this may indicate a more frequent occurrence of EBV in patients with CFIDS (or perhaps that EBV may precipitate CFIDS in a subset of PWCs), EBV is not the universal cause or precipitant of CFIDS.[6]

Buchwald et al tested 548 chronically fatigued patients, including patients with CFIDS, for prevalence of antibodies to 13 viruses. No consistent differences were found in PWCs compared to control subjects. An earlier study by Mawle et al at the U.S. Centers for Disease Control and Prevention (CDC) could not find elevated antibody titers to any herpes virus, including EBV.[7] Recently, workers at CDC examined 26 patients and 52 controls for the presence of HHV-6 and HHV-7 and found no differences between patients and controls.[8]

The recent report of an "outbreak" of CFIDS in Japan[9] which may be affecting as much as one-third of the Japanese workforce may rekindle efforts to identify an infectious agent as the cause of CFIDS. A preliminary report suggests that this is a post-hepatitis B vaccination outbreak and may be due to a contaminating organism.

The failure to find a single virus in all patients with CFIDS has led to the assertion by some that CFIDS is not caused by a viral agent. However, the failure to identify a causative viral agent does not preclude the possibility that CFIDS is caused by a yet-to-be-identified virus or co-infection with two or more viral agents or an unknown infective agent.

An intriguing, unifying hypothesis put forward by Lerner et al is that CFIDS symptoms are caused by a viral infection of the heart.[10] These investigators have described electrocardiographic changes that can be explained by changes in membranes of some heart cells.[11] They believe that such changes may be caused by the presence of a virus and claim success with long-term therapy with antiviral medication.

Other non-CFIDS literature documents the ability of viral infection to alter the way that a cell moves substances across its membrane through specific "channels." Human immunodeficiency virus type 1 (HIV-1) has been shown to inhibit a potassium channel in some brain and human spinal cord cells,[12] while herpes simplex virus has been shown to inhibit sodium channel activity in some nerve cells of adult guinea pigs.[13] Virus-induced alteration of cell membrane function, therefore, is a possible, but unproven, mechanism of CFIDS pathophysiology.

There is other indirect immunologic evidence for persistent viral infection. Patients with CFIDS often have lower numbers of immune system cells called lymphocytes, in particular CD4+ and CD8+ lymphocytes. This type of depletion should not be confused with the CD4+ depletion seen with HIV infection. In HIV disease the CD4+ to CD8+ ratio is usually reversed.

Other diagnoses

Bacteria, viruses and parasites have been linked to fatiguing syndromes including brucella, bartonella and cyclospora.[14] Not widely known, it has been reported that the cat scratch disease due to *Bartonella henselae* may be present as chronically fatiguing illness.[11] In considering bartonella infection as a cause of fatigue, a good history of cat exposure including being licked by or sleeping with the cat and cat scratch disease serology, coupled with newer techniques to amplify bartonella DNA in blood, should help eliminate that diagnosis.

Some patients complain of recurrent oral or vaginal candidiasis. Some may insist that they are chronically infected with yeast, a holdover from the pseudoepidemic promul-gated by some health care providers claiming that many patients with undefined disease had deep-seated, unresolved mycotic infection due to *Candida albicans* , thus the term "the yeast connection."[15] Nevertheless, in some patients *C. albicans* can be cultured at times from the oral cavities and genital tracts. Some patients in fact report improvement of fatigue when oral azoles are used to treat the mucosal infections.

In patients with Lyme disease, exhausting fatigue, deep bone and body pain and cognitive dysfunction are unusual. Nevertheless, in areas of the country where Lyme disease caused by *Borrelia borgdorferi* is endemic, patients with CFIDS and physicians will fixate on Lyme disease as a cause. To confound the clinical picture, Lyme disease does have a chronic form, and blood serology showing increased antibodies to *Borrelia borgdorferi* that was positive early in the disease may persist for years. Ehrlichiosis

caused by agents related to the rickettsia is an emerging disease endemic in the same geographic regions as Lyme disease. The capacity for *E. canis* to produce a chronic disease like CFIDS has not been investigated.

As mentioned, workers in Belgium have reported in abstract form an association of circulating peripheral blood cell-associated *Mycoplasma fermentans* with CFIDS. This bacterium awaits more definitive studies to define its role in CFIDS.

In this age of emerging infectious agents, including those of bioterrorism, other new microbial agents will surely arise as causes of chronic fatigue.

Diagnostic tests

To initiate the workup of PWCs after a thorough history and physical examination, primary care physicians can obtain blood tests for EBV, HHV-6, cytomegalovirus (CMV), toxoplasmosis and HIV. The next level of testing could include other serologies, tests for HHV-6 viremia, RNase L determinations, Mycoplasma, ricksettial or chlamydia DNA amplification by PCR. These advanced tests may be difficult to obtain because of lack of insurance coverage. PWCs often have to secure and pay for this testing themselves by finding the most appropriate laboratory to perform the testing and arranging third-party payment – a very frustrating process indeed.
Regional specialty labs may be helpful to patients arranging specialized diagnostic testing. An infectious diseases physician specializing in CFIDS can assist the primary care physician in choosing tests that may support the diagnosis of CFIDS or other infectious diseases. The chart above outlines the diagnostic tests involving some infectious agents that may be considered for the patients with CFIDS.

Therapy

There are no studies that support the routine use of anti-infective medications in the therapy of CFIDS.[16] Nevertheless, since CFIDS is devastating to individuals and their families, and since there is evidence that CFIDS may be associated with persistent infectious agents, it is reasonable to expect careful trials of antivirals, antibacterials and, in certain instances, antifungal agents.

PWCs with early CFIDS and high titers of antibody to DNA viruses may benefit from a one-to-two month trial of antivirals, usually starting with an agent like valcyclovir at doses of 500 mg two or three times a day. If there is no response at two months, therapy should be stopped.
Ampligen is a 50-base-pair compound consisting of double-stranded RNA that several studies have shown improve the Karnofsky score, a measure of well-being.[17] Ampligen is a proprietary compound manufactured by Hemispherx Biopharma. Preliminary evidence has also been presented to show that Ampligen can decrease the level of low molecular

(Continued on page 18)

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

weight RNase L. A current clinical trial now underway with Ampligen compared to placebo will determine if the product will be approved by the federal Food and Drug Administration*.

Some PWCs will give a history of a profound response to an incidental antibacterial they had taken in the past. While there are no studies to substantiate empiric use of agents like the macrolides or quinolones, when patients are debilitated it seems reasonable to attempt one- or two-month trials in selected patients who have had such beneficial responses historically. New studies are underway to determine the efficacy of antimicrobials in those patients with evidence of active Mycoplasma infection. Since cytokine regulation may play a role in CFIDS, agents to modulate cytokine pathways like isoprinosine, infliximab or thalidomide will serve as yet another potentially exciting area for clinical trials.[18-20]

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A sociological perspective on CFS: a modern malady in need of humane

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Introduction

Chronic fatigue syndrome calls out for explanation using all the diagnostic powers of modern medicine and its medical scientific technology. Yet it remains baffling to medical science, despite thousands of medical papers explaining probes and procedures ranging across every human bodily system. It is a syndrome that also requires full understanding or 'Verstehen' as to its emergence with renewed vigour in modern man. This paper argues that medicine, while it has maximised its quest for scientific solutions to the disease has, in so doing, neglected the essential communication processes essential for a fuller understanding of the psychic lives of the sufferers of chronic fatigue syndrome.

In common with the hermeneutic tradition of Dilthey, (Makkreel 1992) and building on his requirements to explore the deep meanings people attach to their lives and their communications with others, medical sociologists have sought to understand the 'illness experience' of sick people through their illness narratives, both spoken and unspoken (Hughes 2000:16). To recognise these narratives as a guide to better human science of understanding , the doctor-patient relationship is seen as the critical locus of analysis, for it is here that there is a transfer of more than language , there is a transfer of hope, trust, and above all identity with its full bodily integrity and meaning(Hunter 1991;Toombs 1992 in Little 1995).

For sociologists, bodies speak as well as their incumbents, and modern medicine has to a large extent spurned illness narratives and consigned them to the realm of 'quackery'; unworthy of detailed analysis. Doctors in dealing with ' anomalous' medical conditions have lost patience with bodies and their incumbents and turned away from the illness narratives. This is the case with Chronic fatigue Syndrome and its multitude of sufferers world- wide. What we find in place of co-operation between doctors and patients for explanation and understanding of this syndrome is extreme tension, evolved from socially acquired mutual mistrust and hostility .From the side of medicine, ME/CFS has now cost modern societies dearly, medical budgets groan yet the syndrome is still a thorn in the side of medical success and there is a shifting of the emphasis gradually from somatic to psychiatric solutions, making sufferers get on with coping with the disease by employing clinical regimes to develop positive attitudinal change. From the side of ME/CFS sufferers there is increased disappointment and anxiety that their unique illness experience has been down-graded and they fight for continue medical and societal attention to their disease with the hope of full legitimation of their illness experiences.

ME/CFS: The anomalous nature of the syndrome

Chronic fatigue syndrome is a Chimera-like medical anomaly, a variant illness entity that like the mythical creature, the Chimera, is made up of a mysterious combination of parts which defy not only a clear description, but more exacting calculations as to how the complex illness is created. A review of the breadth of the medical and clinical literature over the past decade alone reveals a staggering quest for explanation of the strange creature that is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) (Jason et al 1999; Jason et al 2000. Komaroff 2000). Currently the two major medical explanations of the etiology of ME/CFS are pathologies of the central nervous system and immune system dysregulation (McCully et al 1996; Komaroff 2000).

Three psychiatric models of the causes of ME/CFS have been advanced aggressively over the past decade - the depression model, the somatization model and the stress model (Farrar et al 1995). Research suggests that CFS results from somatization of psychological symptoms (Lipowski 1988; Wessely et al 1998). The shift towards favour of psychiatric models for ME/CFS is an indication that biomedicine has lost confidence in finding a purely biological agent of disease causation for ME/CFS and has given over the 'troublesome' medical anomaly to the psychiatrists to pursue.

Sociologists of health and illness and sociology of

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the body (Foucault 1978; Shilling 1993;Turner 1995,1996) go a step further and argue in essence that the medical and lay experts have become embattled for control of the definitions, practices and meanings associated with medicine (read ME/CFS) .This tense political discourse over who controls the symbolic 'ill body' and the 'well' body is the great battle for future authority over medical practice between the medical practitioners or non-medical and lay experts (including illness sufferers).

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The medical profession is a powerful one supported by the modern state, which underpins its clam to be the key agent of scientific reason in the diagnosis and treatment of diseased bodies. The lay public is ideally expected to conform to the judgements of rational biomedical thought, expressed through the work of medical practitioners (Kleinman 1973; Kirmayer 1988). The history of medical practice is that it is the servant of positivism and commonsense and it in the main medicine ignores contradictory truths. The philosopher of science Thomas Kuhn (1970: 52- 63) stated that particular models of action in historical periods dominate scientific enterprises such as medicine. Changes in method and ways of understanding and interpreting problems only come about when anomalous information that challenges dominant models becomes widely accepted. According to Jacobs (1991: 24-25) medicine is a good example of a so-called ideal 'normal' science for it seeks to maintain the bases for legitimising disease categories, often in the face of changing facts, complaints and contrary laudations for accepting new truths from opponents within the scientific community and from informed lay communities in the wider society

Patient power and the quest for legitimacy of ME/CFS

The medical scientific community remains fragmented in its approach to ME/CFS. This has a direct impact on consumers. ME/CFS sufferers across many continents express illness narratives that express frustration with medical science and practice that is on the whole unsympathetic to their anomalous medical condition. Most tell stories of long periods of undefined, but serious 'unwellness', compounded by a loss of employment, of adverse social consequences accompanying the search for a diagnosis. Many of them speak of their fears that they had cancer or were going insane. Most describe the overall experience as one that has profoundly affected their lives.

Consumer experience takes place on several levels: there is the consumer/medical practitioner interface; the social experience of CFS; political activism. In some cases, though by no means all, the experience of the first two levels, leads CFS sufferers to move on to the level of political activity. At the consumer/ medical practitioner interface after prolonged exclusionary testing the 'legitimacy' of their initial illness quest drains out of the relationship and given that the medical practitioner is the mediator of many social benefits, his/her support in prolonged and disabling illness is essential. It for the ME/CFS patient the difference between paid and unpaid sick leave, access to diagnostic tests, and treatments. Many CFS sufferers experience the relationship with their doctor as negative one rather than therapeutic. When this happens consumers commonly cite that a poor relationship with medical practitioners has adversely affected their recovery. The experience of illness as illegitimate within this relationship leads to the experience of themselves as "illegitimate" in the broader social context.

Sociologists recognise that most people who contract any serious long-term illness undergo a changed identity (Goffman 1963;Figlio 1982; Bury 1990; Frank 1991, 1995) With ME/ CFS there is an additional impact which is felt in relating to other institutions. The person with ME/CFS assumes an 'ambiguous' identity. They are no longer a "worker" or "income –earner"; neither do they have the legitimacy of the identity of the "cancer sufferer". Without the legitimacy of an identity that has the full consensus of the medical profession, relations with other institutions, such social security systems or employees become very difficult to negotiate. Hence this ambiguity manifests itself in difficulties in receiving social security benefits, insurance claims and sick pay. It may also lead people to undertake legal proceedings for work related compensation since there is no aetiological precedent to suggest a lack of relationship. Within the wider health system, the ambiguous identity of CFS sufferer is experienced as lack of representation in health policies and lack of access to allied health programs (Millen and Peterson 1996; Peterson et al 1999)

However, for some people a completely new identity will emerge, built around the political project of having the illness recognised. Such an identity as political activist usually comes about when the CFS sufferer becomes aware that his/her experience is not unique and that much of the negative experience is due to the poor standing of ME/CFS in the medical community.

Political activism of ME/CFS sufferers

I have commented elsewhere (Millen et al 1999) that self-help and activist consumer groups have begun to give a voice to people with chronic illnesses and disability in a variety of settings.Groups become politically active when they publicly voice their dissatisfaction with medical and other health and community services. Although the primary focus of such groups may be support for one another, many have moved into trying to influence the community and professional understanding of their problems. In Australia, New Zealand, the United Kingdom and the United States, CFS self help group, under a variety of names have adopted this approach.

In the US and the UK, CFS groups have successfully used governmental processes, the media and research funding to attempt to legitimate the illness. In the UK,

a Parliamentary Bill to bring awareness of the illness and its effects was presented in 1989, and an All Party Parliamentary Committee on ME (myalgic encephalomyelitis, the name most commonly used for this illness in the UK) was formed to develop policy initiatives in relation to this illness (Annual Report of the ME Association (UK) 1990). In the US, a policy resolution on CFS was passed at the Governor's Association meeting in February 1990. This is only the second policy resolution on a health issue ever passed by this group (Heart of America News, Spring/ Summer 1990). Twenty-three US states have declared CFS Awareness Days or Weeks. An international CFS day has also been declared following collaborative efforts by self-help groups in different countries.

In the most recent five years concerns by ME/CFS patient support and political pressure groups have centred on three key issues, namely,

- the name change and reclassification of ME/ CFS (UK) and CFIDS(USA) to CFS and the possible change back internationally to a new generic name (CNDS- Chronic Neuroendocrineimmune Dysfunction Syndrome)(Donna Dean, leader of the cfs name change working group- final version, 24 Oct 2001) and all this entails in the effects on clinical diagnosis and treatment;
- (ii) the shifting of the classification of ME/ CFS on the WHO International Classification of Diseases (ICD-10)(1992), from present inclusion under the somatic diseases of the nervous system (G93.3) to mental and behavioural disorders (F48.0)(selections from ME- leaders website). The view is sustained that this shift has been provoked by several prominent psychiatric scholars allied to a dominant school of thought in the UK (Wessely 1995, Wessely et al 1998) and followed in Australia (Hickie et al 1996) ;
- the growing influence of an alliance between psychiatric views on CFS as a somatoform disorder and the need for graded exercise through a regime of Cognitive Behaviour Therapy (CBT) (Sharpe et al 1997; Sharpe 1998) These are the main contests for legitimation of ME/CFS facing the patient/ suffer groups at present in their quest for better recognition across the domain of western biomedicine.

Conclusion

Political activism by CFS sufferers has the designated ability to "steer" the current name-change in their direction of classification and further campaigns are aimed towards legitimisation of the diagnosis through:

- Strategic funding of diagnostic and clinical research projects
- The advancement of individual practitioner's and researcher's careers
- Political lobbying for public health initiatives to fully understand the impact of the ME/CFS illness experience on the lives of sufferers.
- Participating in the broader social health agendas to educate the medical profession more broadly about ME/CFS, in particular to take notice of patient's illness narratives
- Educate the lay public about the impact of stigma through the lack of illness legitimation by the medical profession on ME/CFS sufferers and their families

In adopting this activist role, ME/CFS sufferers have seized on the anomalous position of CFS in current bio-medical science and have exercised the ability to influence the current debate so that their total illness experience, including personal illness narratives, can be viewed by more holistic medical models applied by a humane, inquiring medical profession and with ME/ CFS legitimated in a wider and more meaningful context.

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REGULAR CHECKUPS

Please remember to have regular medical checkups with your doctor.

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

The Neuroanatomy of Post-Polio

Fatigue is the most commonly reported, most debilitating and least studied Post-Polio Sequelae (PPS) affecting the more than 1.63 million American polio survivors. In the 1985 National Survey of 676 polio survivors, 91 percent reported new or increased fatigue, 41 percent reported fatigue significantly interfering with performing or completing work and 25 percent reported fatigue interfering with self-care activities. Fatigue was reported to be triggered or exacerbated by physical overexertion in 92 percent and by emotional stress in 61 percent. In the 1990 National Survey of 373 polio survivors, between 70 percent and 96 percent of respondents reported that fatigue was accompanied by problems with concentration, memory, attention, word-finding, maintaining wakefulness and thinking clearly, with 77 percent reporting moderate to severe difficulty with these functions.

These problems with attention and cognition suggest that the symptoms of post-polio fatigue cannot be explained merely by the poliovirus damaging the spinal cord motor neurons and causing muscle paralysis. And autopsies performed 50 years ago on people who died after having had polio did show that poliovirus not only damaged the spinal cord but almost always damaged specific areas of the brain. Those brain areas include the reticular formation (also called the reticular activating system or RAS), hypothalamus and putamen-all parts of the brain's "activating system" that turns on the cortex (the brain's super computer), keeps you awake and allows you to focus attention. Poliovirus also damaged the neurons that produce the neurotransmitters dopamine and ACTH, which themselves activate the brain and stimulate the cortex to focus attention and process information.

Since poliovirus damages the brain's activating system, one would expect that a poliovirus infection should cause brain activating problems, such as trouble with concentrating and staying awake. Articles written about polio 430 years ago describe problems with brain activation. Drowsiness, lethargy, prolonged sleepiness and even coma were described during the acute poliovirus infection. Holmgren reported that 34 percent of patients with paralytic and non-paralytic polio demonstrated "mental changes" such as "disorientation, apathy, pronounced sleep disorder (and) irritability." These changes were related to abnormal slowing of brain wave activity on the electroencephalogram (EEG) in those with paralytic and non-paralytic polio. Further, Meyer reported that a "high percentage of children clinically recovered from poliomyelitis, insofar as motor disability is concerned, reveal qualitative difficulties in mental functioning (such as) fatigability and fleeting attention" for months after the acute episode.

These reports of persistent drowsiness, fatigue and fleeting attention following the acute poliovirus infection are similar to polio survivors' recent complaints of late-onset fatigue and impaired attention. These symptoms are also reminiscent of nearly two dozen outbreaks during this century of a seemingly viral illness that was termed myalgic encephalomyelitis (M.E.) in the 1950's and has been called chronic fatigue syndrome (CFS) in the United States since a Nevada outbreak in 1984. Like post-polio fatigue, both M.E. and CFS are characterized by chronic fatigue and impaired attention that are triggered or made worse by physical exertion and emotional stress. There are a number of other clinical, historical, anatomical and physiological parallels between polio and these post-viral fatigue syndromes (PFS) that may help us to understand the cause of and identify treatments for chronic fatigue.

HISTORICAL AND CLINICAL PARALLELS

Myalgic Encephalomyelitis

Beginning in Los Angeles in 1934 and continuing for more than 20 years, there were over a dozen outbreaks of a disease that was at first diagnoses as poliomyelitis, then as "abortive" or "atypical" poliomyelitis and finally named M.E. Like poliomyelitis, initial symptoms of M.E. included headache, neck pain, low-grade fever and muscle pain that were often followed by muscle weakness. Patients were chronically sleepy and had "conspicuous changes in their levels of concentration" that persisted for months after the acute illness. Slowing of the EEG similar to that seen in polio survivors was also noted.

Unlike poliomyelitis, there were frequent complaints of numbness or tingling, usually no respiratory involvement, infrequent muscle paralysis and, almost invariably, no fatalities. Also unlike poliomyelitis, recovery from the acute symptoms of M.E. sometimes required months and most patients were left with a marked "exhaustion and fatigability" that were "always made worse by exercise (and) emotional stress." Patients continued to demonstrate fatigue, chronic sleepiness and impaired concentration and reported "an inordinate desire to sleep," difficulty finding words

(Continued on page 24)

(Continued from page 23)

and that they were "not as quick or incisive in thought as before, (had) a decreased ability to learn and a decline in their short-term memory" for years after the acute episode.

Despite the differences between poliomyelitis and M. E., some association with the poliovirus was suggested by the fact that, of the more than one dozen M.E. outbreaks before the introduction of the Salk polio vaccine in 1954, nine occurred during or immediately after outbreaks of polio and several involved hospital staff who cared for polio patients.

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Iceland Disease

The most intriguing M.E. epidemic occurred in Akureyri, Iceland in 1948 and was described by Sigurdsson. following the diagnosis of two clear cases of poliomyelitis, dozens of patients began presenting with fever, muscle pain and weakness and were at first diagnosed as having poliomyelitis. After about a month, this diagnosis was discarded as patients reported additional symptoms not typical of polio, including tingling, numbness, "nervousness" and "general tiredness." Importantly, poliovirus was never isolated from any of these patients.

Sigurdsson returned to Akureyri in 1955 to follow up on the epidemic. Six years after the original infection, 87 percent of patients re-examined still had symptoms, the majority of which were again atypical of polio. The most frequent symptoms were "nervousness and general tiredness" in 72 percent, "muscle pains" in 62 percent and "loss of memory" in 21 percent.

Sigurdsson suggested two alternatives for the cause of these varied symptoms that he called Akureyri Disease, but was more commonly referred to as Iceland Disease (ID): "Either a strain of poliomyelitis virus with unusual pathologic properties and of low virulence was responsible for this epidemic or...some unknown... virus has been present." Support for an "unusual" poliovirus as the cause of ID came from Sigurdsson himself. There was an "extensive epidemic "in Iceland during 1955 of poliomyelitis caused by Type I poliovirus that coincided with and was followed by outbreaks of ID. Remarkably, two cities in which ID outbreaks were reported in 1955, as well as the area affected by the 1948 "Akureyri Disease" epidemics, were untouched by poliomyelitis. None of the children tested in the ID-affected cities showed any antibodies to Type I poliovirus. Following poliovirus immunization, children in one of the ID-affected cities showed antibody titers to Type II and Type III poliovirus that were 4 and 25 times higher, respectively, than titers in a city where ID had not been reported. Sigurdsson concluded that Type I poliovirus did not cause ID but that inhabitants of the ID-affected areas had at some earlier time been exposed to an agent immunologically similar to Type III poliovirus.

An interesting coda to these findings is the report that when an American airman who had contracted polio in the 1955 Iceland epidemic returned to Massachusetts, a small outbreak of ID and polio occurred. More recent support for a relationship between poliovirus and M.E. came 1989 when a "dangerously rising titer" to Type III poliovirus was documented in a patient who did not have polio but had been diagnosed with M.E. Taken together, these reports suggest that there may be an association between an agent immunologically similar to Type III poliovirus and the symptoms if ID and M.E.

Chronic Fatigue Syndrome

A constellation of symptoms resembling M.E. was termed chronic fatigue syndrome (CFS) following a Nevada outbreak in 1984. Like M.E. and post-polio fatigue, CFS is characterized by complaints of chronic fatigue and impaired concentration that are triggered or made worse by physical exertion and emotional stress. Unlike M.E. or post-polio fatigue, CFS patients report recurring sore throat, swollen glands and fever. These symptoms have prompted the suggestion that CFS may by caused by an as-yet unidentified persistent viral infection that is not one of the three types of poliovirus. Importantly, it should be noted that there is no support for the hypothesis that post-polio fatigue (or any PPS) is caused by a persistent infection by any virus, including poliovirus.

Another similarity between polio, M.E. and CFS is the report that all three groups have shown slowing of the EEG. Further, both CFS patients and polio survivors report subjective impairment of memory and difficulty with word finding. And, although polio survivors are, on average, at least 10 years older and significantly less disabled by fatigue than are patients with CFS, the level of education, sex distribution, incidence of difficulty with concentration and psychological symptoms are nearly identical in the two groups.

The recent emergence of CFS has allowed it to be studied using techniques that were unavailable during the polio, M.E. and ID epidemics and that now allow other parallels between this most recent PFS and post-polio fatigue to be explored.

NEUROPSYCHOLOGIC PARALLELS

Some of the subjective difficulties with attention and thinking in CFS patients and polio survivors have been confirmed by documenting clinical abnormalities on neuropsychological testing. CFS patients and polio survivors with severe fatigue have been shown to have clinical impairments of attention and information processing speed. Polio survivors reporting severe fatigue required 23 to 67 percent more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no or mild fatigue. In spite of these marked impairments of attention, CFS patients and polio survivors have been shown to be within the high normal or superior range on measures of higher-level cognitive processes and IQ and have higher than average levels of educational and professional achievement. Further, despite the high frequency of subjective complaints of memory impairment in CFS patients and in 87 percent of polio survivors reporting fatigue, verbal memory has been

shown to be intact on neuropsychological testing in both groups.

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

NEUROANATOMIC PARALLELS

To test this hypothesis, magnetic resonance imaging (MRI) of the brain was performed in hope of documenting evidence of poliovirus lesions in the brain's activating system. Small area of hyperintense signal (which look like white spots) on MRI were seen in the brain's activating system (reticular formation and putamen) and in the myelinated (insulated) neurons that connect the brain stem to the cortex in 55 percent of subjects with post-polio fatigue but none of the subjects without fatigue. These findings are interesting since hyperintense signal on MRI is associated with damage to brain neurons and their supporting tissues. The presence of hyperintense signal was significantly correlated with fatigue severity but not with depressive symptoms or difficulty sleeping. The presence of hyperintense signal was also significantly correlated with the frequency or severity of subjective problems with recent memory, clear thinking, mind wandering, attention and concentration.

These findings support the hypothesis that areas of hyperintense signal in the brain activating system are associated with late-onset fatigue and subjective problems with attention in polio survivors. This notion is supported by a number of other studies that have documented a relationship between hyperintense signal on MRI, impaired attention and fatigue. Notably, hyperintense signal in myelinated neurons had been seen in 40 to 100 percent of CFS patients and has also been associated with impairment of attention and information processing speed in elderly adults similar to those documented in polio survivors and CFS patients.

NEUROENDOCRINE PARALLELS

The association of hyperintense signal in the brain activating system with the symptoms of post-polio fatigue suggested that the effects of poliovirus on other brain areas might also be evident in polio survivors. For example, poliovirus lesions were often seen on autopsy in the hypothalamus, which automatically controls the body's internal environment and response to stress. To test the functioning of the hypothalamus, polio survivors' blood concentrations of ACTH (one of the body's stress hormones whose release is triggered by the hypothalamus) were measured following an overnight fast (a mild stressor known to cause ACTH release).

Not surprisingly, ACTH was increased outside of the normal range following the fasting stress in the mild fatigue subjects. In contrast, there was no ACTH increase in subjects reporting severe daily fatigue. Further, the higher the level of ACTH, the lower the severity or frequency of problems with recent memory, work finding and staying awake during the day.

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

A MODEL FOR POST-VIRAL FATIGUE SYNDROMES

Taken together, the findings presented above suggest a model for the mechanism of PFS:

*Some viruses damage the brain activating system and are associated with acute and chronic fatigue and with impairment of cortical activation and attention;

*MRI and neuroendocrine findings indicate damage to the brain activating system and neuropsychological testing shows impaired attention in patients with chronic fatigue;

*Therefore, viral damage to the brain's activating system may be responsible for decreasing cortical activation, impairing attention and generating the symptoms of chronic fatigue.

Poliovirus may be the prototype for a fatigue-producing agent since it routinely and often preferentially damaged the brain activating system. But, poliovirus is not the only virus that attacks the brain activating system. Lesions in the brain activating system are caused by a variety of viral infection (e.g., equine encephalitis, Central European Encephalomyelitis, Coxsackie, echo and herpes viruses) whose symptoms include markedly impaired cortical activation and symptoms of chronic fatigue.

While a virus-damaged brain activating system could cause an acute impairment of cortical activation, inattention and fatigue, it is the chronic nature and recurrence of these symptoms, or their appearance decades after the acute infection, that are more difficult to explain. The persistence of impaired attention in M.E. and ID long after the acute illness may simply reflect the persistence of damage to brain areas responsible for cortical activation. The absence

(Continued on page 26)

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

(Continued from page 25)

and then recurrence of these symptoms during physical or emotional stress in M.E. and PPS may reflect the ability of these stressors to uncover otherwise unseen damage to the brain activating system. However, the recurrence of fatigue and impaired attention coupled with sore throat, swollen lymph glands and fever in CFS have suggested the as-yet unproven hypothesis that a persistent or recurrent infection may be responsible for this most recent PFS. Finally, the emergence of late-onset fatigue in polio survivors decades after the acute illness may result from normal age-related changes in and the loss of brains activating system neurons that had survived the acute viral infection--combining with and already decreased number of these neurons as a result of the original poliovirus infection, impairing the brain's activating system sufficiently to decrease cortical activation and produce impaired attention and fatigue as polio survivors reach mid-life.

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IS FATIGUE "HARD WIRED" INTO THE BRAIN?

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

Motor Behavior, Attention and the Basal Ganglia

Groups of neurons near the bottom of the brain called the basal ganglia are uniquely situated to monitor the level of cortical activation and stop an organism from moving when its attention is inadequate to allow efficient and safe motor behavior. All parts of the cortex connect to one of the basal ganglia, called the putamen, which is said to "listen" to the cortex and "accumulate samples" of cortical activity. Cortical activity stimulates the putamen and turns off the normal inhibition of cortical areas where learned motor behaviors are stored. A decrease in cortical activation could decrease stimulation of the putamen and thereby prevent the release of learned motor behavior. Damage to the putamen in animals has been shown to decrease motor behavior. Damage to another of the basal ganglia, the substantia nigra (which produces the neurotransmitter dopamine), decreases or even stops movement in both animals and man. Damage to the putamen and the substantia nigra also impairs cortical activation and attention in both animals and humans.

The importance of the basal ganglia and especially dopamine in releasing motor behavior and focusing attention is evident in patients with Parkinson's disease (PD). PD patients, who have damaged substantia nigra neurons that produce too little dopamine, show both decreased motor behavior and an impaired ability to focus their attention. Importantly, fatigue is also a prominent symptom of PD. "Excessive fatigue" was reported by 48 percent of PD patients while nearly one-third reported that fatigue was their "most disabling symptom." It is noteworthy that one of the first descriptions of PD could serve as a definition of post-viral fatigue, i.e., a syndrome "characterized by a diminution of voluntary attention, spontaneous interest, initiative and the capacity for effort and work, with significant and objective fatigability and a slight diminution of memory.

Basal Ganglia as the Brain Fatigue Generator

Taken together, these data suggest that the basal ganglia are in a position to generate the mental and physical symptoms of fatigue in both normal and pathological states. "Normal fatigue" would result from a long, hard day at work tiring (that is, slowing the firing of) the neurons of the brain activating system, especially in the reticular formation. This decrease in the firing of activating neurons would decrease cortical activation and impair attention and information processing speed. The decrease in cortical activation would also slow the firing of putamen neurons and thereby inhibit the release of motor behavior. Under these conditions, animals would decrease or even stop their activity. Humans would notice problems with focusing attention, feel an aversion to physical activity and be able to move only with significant conscious effort. In both man and animals, rest or sleep would increase the firing of brain activating system neurons, restore cortical activation, increase the firing of putamen neurons and once again allow motor behavior.

Pathological states, such as chronic fatigue, could be produced by damage to the brain activating system, especially to the reticular formation, putamen and dopamine-producing neurons. This damage would chronically reduce the firing of reticular formation and putamen neurons, decrease cortical activation and produce the symptoms of fatigue.

CLINICAL IMPLICATIONS

This description of the basal ganglia as the brain fatigue generator suggests that increasing brain levels

(Continued on page 27)

CFS Research:
The Need for Better

By Nancy Klimas, MD, University of Miami
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The scientific literature on chronic fatigue syndrome as an entity begins in 1988 with the first case definition that coined the controversial term "CFS" and established a set of criteria for researchers to use in selecting study subjects. Over the past 14 years, the field has grown in both the number of researchers and disciplines represented. Yet for all that's been learned since 1988, much remains unknown about this enigmatic illness. Each research finding seems to raise more questions than it answers.

The bulk of the blame, of course, lies with the vagaries of CFS itself. But the research effort also is hampered by poorly conceived, constantly changing — even non-existent — standards. Tighter research methodology could improve individual studies and enable greater comparability of research findings across studies. What follows is an overview of the areas most in need of clarification and consensus, and a summary of the efforts to achieve overarching agreement among CFS researchers.

Case definition

Authors of the 1988 case definition set out to identify a group of patients sharing similar symptoms and clinical signs, but problems using the definition quickly became apparent. A revision in 1994 by an international consensus group (see back cover) attempted to address some of the difficulties, but the resulting guidelines are rife with ambiguity and vagueness. Symptoms are counted either as present or absent, without regard to severity or frequency. Terms such as "substantial reduction" and "not lifelong" are subject to varied interpretation. The use by some groups of outdated case criteria developed in England and Australia obscures comparability as well.

Thus, the case definition itself contributes to the heterogeneity of the patient population, creating a shaky foundation for CFS research. The U.S. Centers

(Continued on page 28)

(Continued from page 26)

of dopamine (the neurotransmitter that stimulates the basal ganglia) might "turn on" the brain activating system, increase cortical activation, increase attention, release motor behavior and reduce the symptoms of chronic fatigue. We are currently studying the use of a drug that stimulated dopamine receptors i the basal ganglia to treat post-polio patients whose fatigue has not responded to the current treatments of choice (adequate rest, energy conservation, the pacing of activities and reducing physical and emotional stress). Preliminary results show that fatigue and difficulty staying awake during the day decrease as the dose of the drug increases. If dopamine receptor stimulating drugs are found to be effective in polio survivors, they may also be of use in the treatment of CFS.

It is also possible that damage to the basal ganglia may be related to other symptoms reported by polio survivors and patients with CFS. Word finding difficulties are reported by 82 percent of polio survivors with fatigue and appear similar both to word finding problems reported by CFS patients and the "tip-of-the-tongue" phenomena seen in Parkinson's patients. We continue to study the basal ganglia to help identify the cause and treatment of post-polio fatigue and other post-viral chronic fatigue syndromes and to understand the physiology of fatigue itself.

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for Disease Control and Prevention (CDC) has convened an international group of CFS investigators to develop a new case definition. The group has a paper in press that outlines ways in which the case definition could be strengthened.

Subgrouping

Another weakness in CFS research stems from the lack of information about illness course and long-term effects. Patients are often enrolled in studies solely on the basis of currently meeting CFS criteria, without regard to the length of their illness, which could account for differences in biological markers (e.g., cell subsets, viral titers) and functional status. Researchers have discussed the need for "staging criteria" as a means of grouping patients by length and severity of illness, but none have been established. Variations among study participants in age at onset, present age, co-morbid conditions, menstrual cycle, body weight, medication use, deconditioning, diurnal rhythms and other factors may also limit study conclusions.

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Control groups

The selection of controls is a particularly tricky element of study design. If the study hypothesis calls for "healthy" or "normal" controls, recruitment techniques can present unintended biases. For instance, healthy controls recruited from a health club near the investigator's site would probably differ from control subjects obtained from an urban hospital clinic or patients' families. Unrecognized medical issues in "healthy controls" may taint study results. In some studies, the researcher may seek to compare CFS subjects with people with other illnesses – if so, defining appropriate disease groups can be problematic, in part because the symptoms of CFS overlap with so many conditions. Selecting disease control subjects who have fibromyalgia, multiple sclerosis, migraine, orthostatic intolerance or depression may make scientific sense, but investigators must consider the potential for overlap, as individual CFS study subjects may meet criteria for one or more of the comparison conditions. Although the study hypothesis may dictate the type of control subjects to use, it is important that recruitment methods and selection criteria be thoroughly described, so that reviewers fully understand group definition, and investigators hoping to duplicate the study conditions are capable of performing confirmatory studies.

Lab methods

Laboratory studies of cell subsets, cytokines, immune activation, hormones, etc. often suffer from the lack of agreed-upon protocols for sample collection, handling and storage. At a recent CFS research conference, one reviewer noted that clinical samples are often "treated more carelessly than last night's leftovers." Variability in lab processing standards can also contribute to differences in test results. Academic research laboratories are typically held to a high standard in establishing methodologies and quality control measures not necessarily seen in lower cost send-out laboratories. Yet published papers in CFS that have been peer reviewed often neglect to disclose the site of the laboratory or quality control measures used in determining the results of the study. Similarly, differing procedures and conditions for tilt table tests, sleep studies and exercise tolerance may account for discrepancies in the literature. Standardization of procedures is a lofty goal that has evaded most disciplines, but better documentation of protocols in research reports is an important first step.

Outcome measures

In 1992, the federal Food and Drug Administration convened an advisory meeting on outcome measures used in CFS research. Participants tried to agree on standard measures of improvement in treatment studies. No consensus was reached, and the field still lacks a widely endorsed instrument by which to judge clinical improvement. This leaves the decision to individual investigators, some of who rely on simplistic self-report questionnaires (e.g., "Do you feel better than you did before the study began?"), while others conduct exhaustive batteries that evaluate progress across numerous domains (e.g., sleep, pain, fatigue, memory, self-care, leisure activity). As part of its effort to revise the case definition, CDC is evaluating numerous instruments and piloting use of a panel developed for CFS studies.

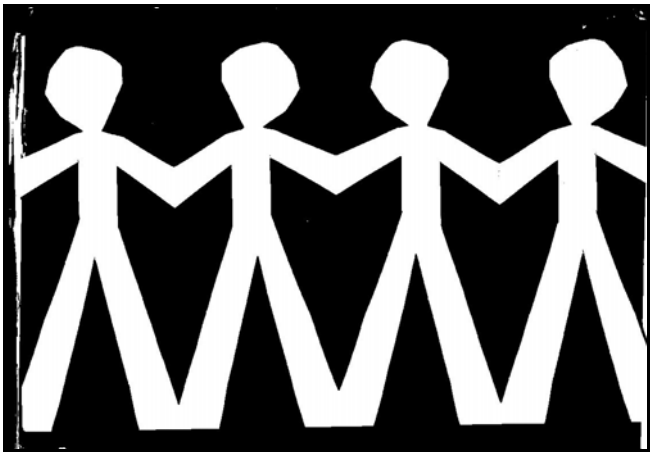
Funding considerations

Investigators are attracted to new areas of investigation by two draws: scientific curiosity and availability of research funding. Funding levels drive the rigor of scientific studies; pilot efforts squeezed from funds for ongoing research activities generally suffer from small subject numbers, few formal measures and cursory data analysis. Well-funded projects more often ascribe to standards for study design and evaluation. Multiple well-characterized patient and control groups, stratification on several different symptomatic and demographic measures, careful assessment of domains pre- and post-study, optimized handling of clinical samples and thorough statistical analysis of data all add strength to research findings and conclusions. Ironically, it's often the presence of these design standards that attracts funding in the first place. Developing greater funding for pilot projects and more multidisciplinary studies is essential to building a critical mass of research on CFS.

Federal health officials are increasingly working with CFS researchers in academic centers to attract more senior investigators from related fields and to spur novel, yet testable, hypotheses. A stronger research effort will enhance credibility for the illness, and will propel advocacy efforts to increase CFS research funding at the National Institutes of Health (NIH) and the CDC. Overcoming the methodological challenges of studying CFIDS is essential to making progress in

(Continued on page 34)

ME in Families



M.E. in families
I have M.E. and so does my daughter. Is there any research to indicate why some families have more than one member affected? Could there be a genetic predisposition to getting this illness?

Professor Tony Pinching comments: 'There is anecdotal and some limited formal evidence that the condition is more common in families. This is not surprising since CFS/M.E. is often triggered by infection, and there is a genetic influence in how we respond to and are affected by most infections. So people may be genetically predisposed to getting a fatigue state after certain infections.

'Another possibility is that several members of the same family or household have been exposed to some common environmental factor (infection, or other trigger) that can provoke fatigue, or that can make it more likely to occur after some trigger. The most common triggers are common-or-garden infections that most people handle normally as short acute illnesses.

'It is likely that more than one factor applies for the observation that CFS/M.E. is a bit commoner in families. The fact that there seem to be cluster outbreaks of this illness seems to argue against genetics as being the sole factor.

'Recent research done in the USA indicates that identical twins are more likely to be concordant (ie both have the illness), which provides some formal support for the role of genetic factors. However, CFS/M.E. is not a genetically inherited disease, in the sense that muscular dystrophy or haemophilia are. But, just like heart or autoimmune disease, genetic tendencies can make an individual more susceptible to the effects of other factors. '

Tony Pinching stresses that the risk for M.E. is still low among those whose close relatives are affected. He sensibly advises that a family member of a sufferer should perhaps be especially careful to avoid 'working through' or pushing themselves back to work prematurely after any infections; a period of convalescence to allow recovery might lower the risk of developing a fatigue syndrome.

Dr Sarah Myhill adds that she often sees two or more members of one family similarly affected with M.E. 'This is hardly surprising. All diseases are caused by a combination of genetic and environmental factors, while linked conditions like thyroid disease, micro-nutrient deficiencies and allergies often run in families. Furthermore, families live together in the same environment, eating a similar diet and exposed to similar toxins and infectious agents.'
She tends to find that what works for one family member also works for others: 'I have had several cases where one member is used as a guinea pig to do the elimination dieting, for instance, and the others latch on to whatever worked. A knock on benefit for other family members is that they tend to adopt the healthier lifestyle and the sleep and supplement regime of the M. E. patient, thus improving their health too.'

Dr Kelly Morris explains that there is little research on M.E. running in families, as opposed to milder fatigue states. However, she notes that in addition to the factors outlined above, family attitudes and coping strategies are suggested to play a part in some cases – for example, some children may adopt a 'don't let illness stop you working' attitude from their parents.

However, given than fibromyalgia and chronic pain can also be familial, Dr Morris notes that some researchers have raised the question of possible genetic defects in pain pathways. 'Rarely a family will have a specific genetic defect, as in the case of one family with many members affected by CFS who shared a defect in the activity of their natural killer immune cells.'

Taken from the 'Dear Doctor' column in Issue 39 2002 of InterAction, produced by Action for ME, www.afme.org.uk
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Relative increase in choline in the occipital cortex in chronic fatigue

Acta Psychiatr Scand 2002 Sep;106 (3):224-226

Puri BK, Counsell SJ, Zaman R, Main J, Collins AG, Hajnal JV, Davey NJ.

MRI Unit, MRC Clinical Sciences Centre, Imperial College School of Medicine, Hammersmith Hospital, London, UK, John Howard Centre, London, UK, St Mary's Hospital, London, UK,
Division of Neuroscience and Psychological Medicine, Imperial College School of Medicine, Charing Cross Hospital, London, UK.

Relative increase in choline in the occipital cortex in chronic fatigue syndrome.

Objective: To test the hypothesis that chronic fatigue syndrome (CFS) is associated with altered cerebral metabolites in the frontal and occipital cortices.

Method: Cerebral proton magnetic resonance spectroscopy (1H MRS) was carried out in eight CFS patients and eight age- and sex-matched healthy control subjects. Spectra were obtained from 20 x 20 x 20 mm3 voxels in the dominant motor and occipital cortices using a point-resolved spectroscopy pulse sequence.

Results: The mean ratio of choline (Cho) to creatine (Cr) in the occipital cortex in CFS (0.97) was significantly higher than in the controls (0.76; P=0.008). No other metabolite ratios were significantly different between the two groups in either the frontal or occipital cortex. In addition, there was a loss of the normal spatial variation of Cho in CFS.

Conclusion: Our results suggest that there may be an abnormality of phospholipid metabolism in the brain in CFS.

Illness experience, depression, and anxiety in chronic fatigue syndrome.

Journal of Psychosomatic Research 2002 Jun;52(6):461-5

Lehman AM, Lehman DR, Hemphill KJ, Mandel DR, Cooper LM.

Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada

OBJECTIVE: Given the high rate of psychiatric comorbidity with chronic fatigue syndrome (CFS), we considered two possible correlates of anxiety and depression: lack of illness legitimisation and beliefs about limiting physical activity.

METHOD: A total of 105 people diagnosed with CFS reported on their experiences with medical professionals and their beliefs about recovery and completed the depression and anxiety subscales of the Brief Symptom Inventory.

RESULTS: Those who said that their physician did not legitimize their illness (36%) had higher
depression and anxiety scores (P's<.05) than their counterparts. Those who believed that limiting their physical exertion was the path to recovery (55%) had lower depression and anxiety scores (P's<.01) than their counterparts.

CONCLUSION: Lack of illness legitimisation ranked high as a source of dissatisfaction for CFS patients, and it may aggravate psychiatric morbidity. Many CFS patients believed that staying within what they felt to be their physical limits would improve their condition. This belief, and possibly an accompanying sense of control over their symptoms, may alleviate psychiatric morbidity.

* * *

Eds
We wish to challenge the statement "Given the high rate of psychiatric comorbidity with chronic fatigue syndrome." If by this the authors mean that co-morbidity is higher than in most chronic illness then we disagree. It is debatable whether the psychiatric co-morbidity is higher in CFS than in equally debilitating chronic illnesses. The literature is divided on this.

Peripheral blood mononuclear cell beta-endorphin concentration is decreased in chronic fatigue syndrome and fibromyalgia but not in depression: preliminary

Clinical Journal of Pain 2002 Jul-Aug;18 (4):270-3

Panerai AE, Vecchiet J, Panzeri P, Meroni P, Scarone S, Pizzigallo E, Giamberardino MA, Sacerdote P.

Department of Pharmacology, Istituto di Ricerca e Cura a Carattere Scientifico, University of Milan, Italy.

OBJECTIVE: The aim of this study was to examine the possible role of the immune system in the pathophysiology of chronic fatigue syndrome and fibromyalgia syndrome and in the differential diagnosis of depression by investigating changes in peripheral blood mononuclear cell levels of beta-endorphin, an endogenous opioid known to be involved in regulation of the immune system function.

DESIGN: Beta-endorphin concentrations were measured by radioimmunoassay in peripheral blood mononuclear cells from healthy controls (n = 8) and patients with chronic fatigue syndrome (n = 17), fibromyalgia syndrome (n = 5), or depression (n = 10).

RESULTS: Beta-endorphin concentrations were significantly lower in patients with chronic fatigue syndrome or fibromyalgia syndrome than in normal subjects and depressed patients ($p < 0.001$ and $p < 0.01$, respectively). They were significantly higher in depressed patients than in controls ($p < 0.01$).

CONCLUSIONS: Evaluation of peripheral blood mononuclear cell beta-endorphin concentrations could represent a diagnostic tool for chronic fatigue syndrome and fibromyalgia and help with differential diagnosis of these syndromes versus depression. The results obtained are also consistent with the hypothesis that the immune system is activated in both chronic fatigue syndrome and fibromyalgia syndrome.

Chronic fatigue and chronic fatigue syndrome: a co-twin control study of functional status

Qual Life Research 2002 Aug; 11(5): 463-71

Chronic fatigue and chronic fatigue syndrome: a co-twin control study of functional status.

Herrell R, Goldberg J, Hartman S, Belcourt M, Schmaling K, Buchwald D. Division of Epidemiology-Biostatistics, University of Illinois at Chicago, USA.

Chronic fatigue syndrome (CFS) and the symptom of chronic fatigue may be accompanied by substantial functional disability. A volunteer sample of twins discordant for fatigue was identified from throughout the US. Fatigued twins were classified using three increasingly stringent definitions: (1) > or = 6 months of fatigue (119 pairs); (2) CFS-like illness based on self-report of the Centers for Disease Control and Prevention CFS research definition criteria (74 pairs); and (3) CFS assessed by clinical examination (22 pairs). Twins with chronic fatigue were compared with their unaffected co-twins on the eight standard scales and two physical and mental component summary scales from the medical outcomes study short-form health survey (SF-36). Substantial impairment was observed for fatigued twins across all levels of fatigue, while scores in the healthy twins were similar to US population values. Mean scores among fatigued twins on the physical and mental component summary scales were below 97 and 77%, respectively, of the US population scores. Diminished functional status was found across increasingly stringent classifications of fatigue and was associated with a dramatic decrement in physical functioning. The symptom of fatigue has a pronounced impact on functional status, especially in the domain of physical functioning.

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Pharmacists offer home

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By Sarah Fogg

Consumers can now take advantage of a new medication review service where the pharmacist comes to you.

The new service, called Home Medicines Review, started in late 2001. A medication review is a review of all the prescribed, over-the-counter and complementary medicines being taken by a consumer at a particular point in time. They involve a more in-depth process than the decision-making that should be undertaken each time a doctor prescribes or a pharmacist dispenses a new medicine for a consumer. The purpose is to identify and address any medicine-related problems, improve quality use of medicines and maximise the health and wellbeing to be achieved from medicine use.

The pharmacist that actually undertakes the Review must have done additional training and be accredited. Pharmacies are paid for undertaking (or organising) Home Medicine Reviews in collaboration with doctors who have a new MBS item to cover their part in Reviews.

Home Medicines Reviews are open to anyone, as long as their GP agrees that their circumstances, health conditions or the medicines they take would make a Review worthwhile–and with the agreement of the person involved. People who may find a Review useful include (but not is not limited to) people who:

- are taking 5 or more regular medicines or taking more than a total of 12 doses of medicine per day,
- are having difficulty coping with their medicines or in taking them correctly,
- have had or may have had an adverse drug reaction,
- are attending a number of different doctors, both GPs and specialists,
- have just come out of hospital.

Pharmacies are paid for undertaking (or organising) Home Medicines Reviews in collaboration with doctors who have a new MBS item to cover their part in Reviews. The pharmacist that actually undertakes the Review must have done additional training and be accredited.

Home Medicines Reviews are fairly new. By the end of April 2002 approximately:

- 2 000 pharmacies had signed up to offer Reviews (about 40% of the total),
- 1 000 pharmacists had become accredited to undertake Reviews, and another 1500 were in the pipeline,
- 2 800 Reviews had been conducted (from October to end March).

Making consumers the focus

The Framework envisages that the consumer will be the focus of a Review and that his or her needs and interests will be paramount. Poor quality use of medicines can take many forms, many of which are caused, at least in part, by failure to involve consumers in decisions about their medicines and failure to communicate key information to consumers.

Relatively common problems include:

- Poor compliance by consumers caused by prescribers failing to find out consumer preferences and beliefs about medicines, or failing to explain why a medicine is being prescribed and how it is supposed to work.
- Medicines taken inappropriately by consumers because of failure to convey essential information to them about how and when to take them.
- Consumers ill-prepared on how to cope with common side effects or to recognise and deal with unexpected problems because of failure to discuss them.
- Interactions occurring because prescribers are unaware of OTC or complementary medicines also being taken, and failure to discuss this possibility.

Too often consumers are treated as if they simply need to be told what to do and to be reassured, rather than treated as responsible adults capable of taking in information about their medicines and making informed choices. Such paternalism saps consumers' confidence and undermines their ability to cope.

A recurrent theme from consumers is that they would

like to know more about the medications they take or are recommended. Consumers, particularly older consumers, often struggle to cope with complex regimens of multiple medicines and/or frequent changes to their medicines. In practice, the environment of the doctor-patient consultation or a community pharmacy is not always conducive to good communication about medicine issues, and other sources of information are often not easily available to consumers.

So while the development of better working relationships between GPs and pharmacists is undoubtedly important, a possibly even more important feature of Home Medicine Reviews is that they take place in consumers' homes (their territory) and offer a rare opportunity for detailed discussion and information exchange on medication matters of importance to consumers.

Reviews will give consumers an opportunity to ask questions about their medicines that their GP or pharmacist may not always have the time to answer. Such as:

- any difficulties in understanding dosage instructions;
- how their medicines may interact with other medicines or health care products;
- side effects;
- how to manage their medicines with the least possible disruption to lifestyle;
- explanations of brand and generic names, whether one medicine is the same as another or not ; and
- the use of devices such as spacers and nebulisers.

Home Medicines Reviews therefore offer the potential to make substantial gains towards improving the quality of medicines, minimising the problems associated with multiple medication use and improving quality of life. However, if this potential is to be fully realised, it is essential that consumers' needs, concerns and preferences are truly the central focus of Reviews and, secondly, that the perspective of consumers is incorporated into the on-going development and evaluation of the Home Medicines Review service.

Strategies for eliciting consumer feedback in the development and evaluation medication reviews

While the broad national Framework for Home Medicines Reviews has been agreed, many implementation issues are yet to be fully explored and consumer input into the developing service will be necessary. For example, on the provision of Reviews in rural and remote areas where accredited pharmacists may be thin on the ground, in indigenous communities and for older people of non-English speaking backgrounds.

Consumers should be involved in the development of local promotional strategies to assist in identifying how best to reach and interest those consumers who may benefit from the service. Careful strategies will be needed to ensure that low income consumers, those of non-English speaking background, with low literacy, cognitive deficits and those who are transport disadvantaged obtain information about Home Medicines Reviews and are able to access them.

Involving consumers in the design of the evaluation of the Home Medicines Review service will increase the chance that the evaluation will ask salient questions and address significant issues, complementing other measures of performance such as changes in medications, clinical outcomes and feedback from the other stakeholders.

Going beyond 'satisfaction'

It is expected that older people will be the main recipients of Home Medicines Reviews. Many older consumers, especially those in upper age ranges, are reluctant to act as 'active consumers' and are more used to leaving decisions about health care in the hands of their doctors and other health professionals.

One of the striking features of many surveys of consumers of home-based care services is the consistently high level of 'satisfaction' recorded. This has also been noted in patient satisfaction surveys conducted by health services, and in research with older people about their relationships with health professionals. It is not uncommon for older people in focus groups, for example, to speak very positively about their doctors but then make some critical comments about their practice at the very end or even after the focus groups have concluded.

There is no doubt that strong forces may artificially inflate older and dependant consumers' expressed satisfaction with a service. These include :

- social desirability – giving answers consistent with perceived social norms, for example, about following doctors' and pharmacists' instructions
- acquiescence – a tendency to agree with statements regardless of the content, especially if the question is not fully understood
- fear of reprisal or adverse consequences – for example, fear of becoming labelled as a troublesome patient, being placed in a nursing home, or loss of access to the only local doctor who speaks their language
- gratitude – such that significant deficiencies are overlooked and not mentioned
- low expectations – such that any review, even if cursorily conducted, exceeds expectations
- loyalty – for example, not wanting to make any comments that they think might reflect badly on their doctor or pharmacist or that may result inconvenience or extra work for their already busy doctor.

People may also not want to admit dissatisfaction if doing so is tantamount to admitting that they have been are meekly putting up with a poor quality service without protest.

(Continued on page 34)

(Continued from page 33)

These factors means that *any* intimations of negative views that older consumers do make need to be carefully followed up and explored, in order to uncover sources of dissatisfaction that many otherwise remain uncovered and to give service providers the information they need to improve their services. Seeking feedback only from carers may also be a source of bias, although carers' views are relevant and important in their own right and are critical in the case of Home Medicines Reviews if they are playing a role in a consumers' management of their medications.

Asking consumers for feedback on *particular* features of a service is generally a better way of gaining an accurate picture of the strengths and weaknesses of a service and how it might be improved, rather than asking for feedback on the *overall* quality of a service.

In summary

Home Medicine Reviews offer an opportunity to enhance the quality use of medicines in Australia and to do so through a true partnership between doctors, pharmacists, nurses and consumers. This paper has highlighted the importance of ensuring that consumers are involved in Reviews of their medicines and in the development, monitoring and evaluation of the service.

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i. Coulter, A., After Bristol; putting patients at the centre, *British Medical Journal* 2002; 432; 648-651
ii. Coulter, A. ibid.
iii. See for example various publications from the Consumers' Health Forum (CHF) and the Pharmaceutical Health and Rational use of Medicines Committee (PHARM).
iv Australian Institute of Health and Welfare (AIHW), *Obtaining consumer feedback from clients of home based care services: A review of the literature*, Welfare Division Working Paper No. 21, 1998

This paper is derived from a project undertaken for the **Consumers' Health Forum.** A fuller paper on the project, *Consumer evaluation of domiciliary medication management reviews*, June 2001, is available from CHF and on www.chf.org.au.
For more information about Home Medicines Reviews ask your doctor, pharmacist or call 1800 020 613.

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(Continued from page 28)

understanding this complex illness and to uncovering more direct means of diagnosis and effective treatments.

Nancy Klimas, MD, is the director of an NIH-sponsored Center for CFS Research and Professor of Medicine at the University of Miami School of Medicine. She has chaired three methodology workshops held in conjunction with The CFIDS Association of America's research symposia series (see below).

Initiatives to Strengthen CFS Research

The CFIDS Association of America Symposia Series (2000–2002): Three research meetings on specialized topics have brought together multi-disciplinary groups of scientists studying chronic fatigue syndrome and conditions that share important features. Each of the three symposia featured a day-long methodology session.

Pilot Studies Funding Program: Since its inception in 1987, the Association has funded $3.4 million in CFIDS research, and now solicits annually for pilot project applications, supporting those most likely to compete well for larger grants from the National Institutes of Health (NIH) and other major funding sources.

National Institutes of Health Program Announcement: On Dec. 11, 2001, NIH published its first CFS research solicitation since 1996. Eleven divisions of NIH made this joint announcement of research priorities and opportunities. On-Campus Collaboration: A working group of NIH staff from various institutes meets regularly to discuss CFS research and mechanisms to stir interest and recruit talent to the field.

Centers for Disease Control & Prevention (CDC) Case Definition Revision: The CFS program has led a group of international CFS researchers working to refine the CFS case definition. Much of this effort has been devoted to improving the comparability of studies through standardized methodology.

Expanded Research Partnerships: CDC has greatly increased the number of, and funding for, collaborative research efforts with top-notch research groups in the U.S. and abroad.

Your Society Matters....

"Meet the real experts"

Sunday October 20th 2:00 pm — 4:00 pm

(Cnr Greenhill and Portrush Roads)

Speakers Include: Kristen Mulvihill, Bill Daniels, Liana Taylor & Penny Cahalan

This meeting is chance for our members to learn from each other's experiences. Several people have been asked to speak for a few minutes about their experiences with ME/CFS. There will be time for people to ask questions.

Cost $2

AGM

9th November 2 pm
Disability Information Resource Centre, 195 Gilles St, Adelaide

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Commotion on the Murray

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raising awareness

Ash Thomas and Nathan Fenton

We aim to drive a ski boat the length of the Mighty Murray River, departing on the 19th of October 2002. The aim is to raise awareness for Chronic Fatigue Syndrome through print, television, radio and word of mouth. This entire trip will span 3 states, starting at Walwa (200km upstream of Albury) and ending in Goolwa, at the sea in South Australia. The river itself is the border between Victoria and NSW, until it crosses into South Australia. We will travel around 2300km by boat, removing the boat twice to navigate dam walls at Yarrawonga and Hume Dam (That's roughly from Melbourne to Brisbane). It will take around 15 days to complete. We will pass through 13 locks. We will use around 1000 litres of fuel, at around 40 litres per hundred kilometres. We should average around 35km per hour over the trip, traveling about 7 hours per day. Nights will be camped on the river bank We intend to set a new World Record (possibly unofficial) for a ski tube, with Nathan taking up the challenge for some 400km or two days worth.

Commotion II is a V8 308 Holden engine powered, 16ft Ski craft 'Clinker Deluxe' ski boat from the late 70's, in original condition with only minor modifications for the expedition such as 12v electrical outlets and solar backup.
In its travel configuration, we will be carrying 6 jerry cans of fuel, have room for 3 people and be self sufficient (excluding weekly resupply) Fuel will be a daily resupply from Advance Petroleum, as we simply cannot carry enough. A stereo has also been fitted to ensure sanity prevails.
The support team will use a Pajero (with thanks to Chris Mannering) and Magna for moving the boat and other vehicles to assist the boat with fuel and supply requirements.
By using a regular ski boat, we hope it allows many people to associate with us, and not place us on a pedestal. By being approachable, we hope to use that to gain more interest and thus more awareness of CFS/ME.

Ash Thomas

Collectors Needed

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

Please let Adrian Hill (via our office) know if you can help in any way.

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City Badge Day Locations (Suggested Dates Only)	
1. Norwood parade a) North mall area b) South mall area	9th October 2002
2. Glenelg a) Jetty road b) Plaza (brighten road) c) Holdfast bay region	13hth October
3. Arndale shopping centre	16th October 2002
4. Tea tree plaza	23rd October 2002
5. Marion shopping centre	31st October 2002
6. West lakes shopping mall	7th November 2002
7. Central market a) Central area b) West wing	24th January 2003
8. Railway station a) Central station b) Arcade	31st January 2003
9. King William road	19th February 2003
10. Unley shopping centre	26th February 2003
11. Belair road shopping centre	7th March 2003

Country Badge Day Locations (Suggested Dates Only)	
1. Handorf (main road)	13th November 2002
2. Victor harbour	13th November 2002
3. Murray bridge	13th November 2002
4. Mount Gambier	13th November 2002
5. Pt Lincoln	28th February 2003
6. Belair road shopping centre	7th March 2003
7. Whyalla	7th March 2002
8. Port Pirie	7th March 2003
9. Loxton	7th March 2003

Items Available from the Society

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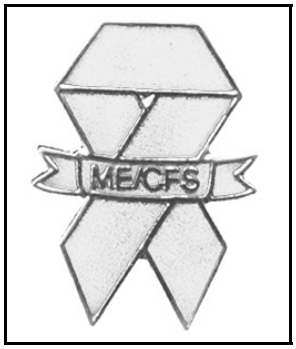
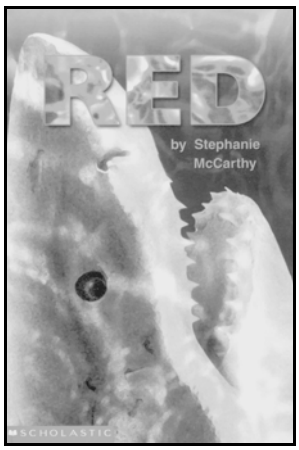
Stock Clearance:
We have Efamol Marine Oil $22 per bottle—or 3 for $60 (GST Included)
Pickup from Office

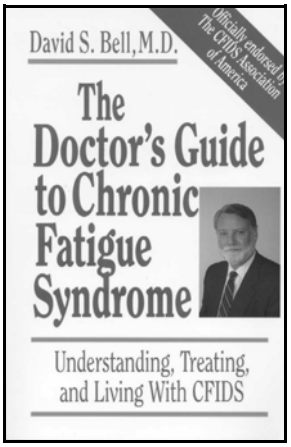
Lapel Pins $2 each (pins are blue with yellow edging)



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

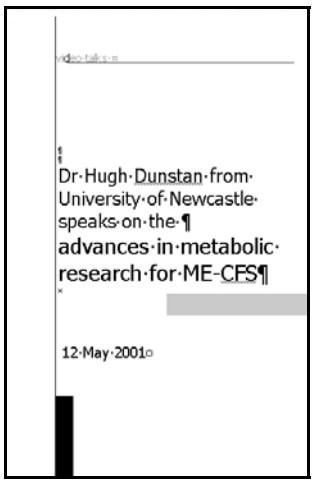


The Doctor's Guide to Chronic Fatigue Syndrome $24.00 (inc. GST) + $3.00 Postage and Handling



Video & Audio Tapes

Video Duration 104 mins



Video Duration 96 mins

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

TROUBLE WITH COUNCIL WEED SPRAYING?

Council weed spraying affects many of our members. If you are one of them, then there is something you can do about it. Councils are becoming more aware of this problem – some are fully sympathetic, other are a little more difficult to deal with.

In order to protect yourself, you must write to your local council. Phoning will not be as effective. All government organisations must respond to letters and they are kept on file. Phone conversation have no weight – anything said can be denied later on.

Any correspondence is best done with an accompanying letter from your doctor explaining that you can be made ill by fumes from the spraying (if your doctors will do that for you).

What should you ask for? I suggest you ask for 48 hours notification of spraying in your area, and ask that spraying not be conducted on your footpath – you may even have to ask for more than this if you are severely affected. Some have asked for spraying not to be done 50m either side of their property. I know of one council that doesn't spray in the entire street of a person who is sensitive to spraying.

Council have alternate means to weed control (in most cases.) For example hot water can be used; an another alternative is just to mow. Some areas of Adelaide have more grassed areas than others, and I suppose this may play a part in which councils are more receptive to others.

If your council is completely unresponsive, then please let us know and we will send them some information.

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A FEW TIPS REGARDING 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.

Recipe

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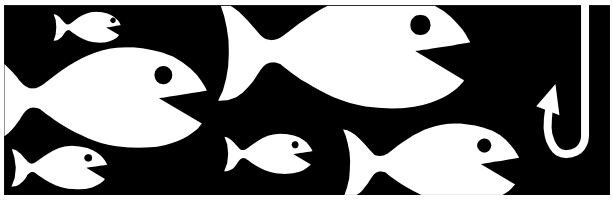

Baked Paprika Fish

A very simple dish to prepare!

Ingredients

1 fillet of fish per person (not too thick)
black pepper
paprika (just a little for colouring)
small amount of grated lemon rind
canola oil

Method

- Place fish fillets in an ovenproof dish and sprinkle with pepper and paprika.
- Place a sprinkle of lemon rind and a little canola oil on each fillet.
- Cover dish with foil and bake in a moderate oven (200C) for 12 minutes.
- Serve with a tossed salad and baby potatoes.

FRUIT SALAD SOUP

Serves 6 - 8

This is a really easy, delicious and versatile recipe. It stores well in the refrigerator, and can be used to top your breakfast cereal, as a dessert, or as a snack. Any combination of fruits can be used, and in winter when peaches and apricots are not available you can just add a small can of these fruits instead.
The banana gives it a slightly tropical flavour.

Ingredients

2 peaches
2 apricots
1 banana
1 punnet strawberries
1 ½ cups water
squeeze of lemon juice
1400g can unsweetened pears

Method

- Wash fruit. Peel, core and stone as required, chopping fruit into pieces.
- Place fruit in a saucepan with water and lemon juice.
- Add canned pears and juice.
- Cover and simmer for 10 minutes until tender.
- Allow to cool and place in a blender and puree.
- Chill thoroughly before serving.
- Garnish with finely sliced strawberries.

Delicious served with natural yoghurt or vanilla icecream (dairy or soy) or Vitari.

Corner

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Basic Coleslaw

Serves 4

To this basic recipe may be added snow peas, sugar snap peas, bean sprouts, chopped raw cashew nuts, a small amount of red capsicum, grated carrot or whatever you like.

Ingredients

2 cups shredded cabbage
2 carrots, peeled and grated
1 red apple, quartered, cored and cubed
1 tablespoon chopped parsley

Method

- Mix all ingredients together
- Stir dressing through

Dressing ingredients

½ cup natural yoghurt
1 tablespoon canola oil
1 tablespoon malt vinegar or apple or pear juice

Shake all ingredients together in a screwtop jar.

LATKES (RAW POTATO PANCAKES)

Serves 2 for a light meal, 4 as a snack.

Ingredients

2 large potatoes, grated
1 onion, grated
2 eggs, beaten
2 tablespoons rice flour
pepper
small amount of canola oil for frying

Method

- Place potatoes and onions in a sieve and squeeze out all excess moisture.
- Place in a bowl.
- Stir in eggs, flour and pepper and mix with a fork.
- Heat oil over medium heat in a frying pan.
- Drop tablespoon lots of mixture in hot oil and flatten with a spoon.
- Fry for approximately 5 minutes or until golden brown.
- Flip over and fry for a further 5 minutes.
- Drain on paper towels.

Serve with applesauce and natural yoghurt. You can buy applesauce at the supermarket, or simply peel and cook 1 apple per person with a little water in the microwave, mash and serve.

Thanks to Margaret Jackson for supplying these recipes.

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

SUPPORT GROUPS: METRO

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

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

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

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

SUPPORT GROUPS: COUNTRY

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

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

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

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

SUPPORT CONTACTS

SA Support Groups

Adelaide City	Support and Info Line	8410 8930
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

SAYME	Peter	0500523500
SAYME Parents	Marg	8276 5353

Country Support Contacts

Barossa Valley	Dennis	8563 2976
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Ros	8588 2583
Northern Yorke Peninsula	Jane	8826 2097
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yunta	Gloria	8650 5938

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

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

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

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

WHAT IS ME/CFS?

(M.E.) myalgic encephalomyelitis / (CFS) chronic fatigue syndrome is a serious and complex illness that affects many different body systems. The cause has not yet been identified. It is characterised by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. ME/CFS can be severely debilitating and can last for many years. ME/CFS is often misdiagnosed because it is frequently unrecognised and can resemble other disorders including chronic viral infections, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and auto-immune diseases such as lupus. [In the USA it is known as CFIDS or Chronic Fatigue and Immune Dysfunction Syndrome.]

HOW IS ME/CFS DIAGNOSED?

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

According to the CFS case definition published in the Dec. 15, 1994, issue of the Annals of Internal Medicine, diagnosing ME/CFS requires a thorough medical history, physical and mental status examinations and laboratory tests to identify underlying or contributing conditions that require treatment. Clinically evaluated, unexplained chronic fatigue can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i. e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.

2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

HOW IS ME/CFS TREATED?

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

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

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

DO PERSONS WITH ME/CFS GET BETTER?

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

PREVALENCE

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

In Australia, very few studies have been undertaken to determine the prevalence of ME/CFS in the community; estimates range from 0.3 to 2.5% or even higher. These studies use different criteria for defining ME/CFS and consequently arrive at widely differing results.

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

Talking Point 2002 Issue 3: The Official Journal of the M.E./C.F.S. Society (SA) Inc

ME & You, ME/CFS Society of NSW Inc., Royal South Sydney Community Health Complex Joynton Ave., Zetland. NSW 2017.
Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.
Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.
ChaMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.
The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.
Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, Hight Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.

If undeliverable return to:
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