



Talking *Point*

December 2003

Official Journal of the ME/CFS Society (SA) Inc

*Your
Society*

forget-ME-not

Office Ph: (08) 8410 8929 Fax: (08) 8410 8931

Support & Information Line City Callers: 8410 8930 Country Callers: 1800 136 626

www.sacfs.asn.au

ME/CFS Society (SA) Inc.

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

- promote recognition and understanding of the disease among the medical profession and the wider community
- provide information and support for 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 1 to June 30, and includes subscription to the magazine Talking Point. Membership rates for first-time members are as follows (GST included):

New Members (cheaper rates apply for renewal):

Single membership.....	\$35
Single Concession	\$25
Professional	\$50
Family.....	\$40
Family Concession.....	\$35
Overseas – as above plus	\$10

(Family membership is designed for families with more than 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.)

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.

Deadline for next issue:

March 1, 2004

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.

Talking Point Subscriptions:

Professionals:.....	\$35
Persons with ME/CFS:.....	\$22
Overseas (Asia-Pacific):.....	\$32
Overseas (Rest of World):	\$38

Management Committee 2003/2004

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

President: Peter Cahalan

Vice-President: vacant

Honorary Secretary: Denise Stephens

Treasurer: Geoff Wilson

Management Committee Members: Margaret Wing
Peter Evans
Adrian Hill

Contact Details

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

Note: It is our policy to ignore anonymous correspondence.

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

At the time of printing the office hours are:

Tuesday and Thursday 10am to 3pm (subject to volunteer availability).

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

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.

Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed about 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 any products or services (including those appearing in paid advertisements) or treatments – always consult your medical practitioners before commencing any new treatments.

Contents

Society Matters

President's report: AGM November 8, 2003	4
Raising awareness at the Paskeville Field Days.....	6
Southern Communities Transport Scheme.....	7

Multiple Chemical Sensitivity

Multiple Chemical Sensitivity – ideas needed	8
Inquiry into Multiple Chemical Sensitivity.....	9

Interview

Alastair Lynch.....	10
---------------------	----

Coping with ME/CFS

A sideways look at pacing, by Julia Derbyshire	14
Where are my meaning-laden bits?, by Danielle Gamble.....	16
Hope... after ten years, by Goldie Freedman.....	18
Phone pals.....	19
As good as it gets, by Christine Low.....	20
Why I volunteer, by Sonya	21

Medical Pages

Sleep and ME/CFS, by Dr Nicole Phillips	22
CFS and decreased red cell volume – a new treatment trial	26
Publication of new vascular research	27
Exercise, by Dr Charles Shepherd.....	28

CFS/ME Severe Symptoms Questionnaire	29
--	----

Support groups and contact numbers.....	30
---	----

Information about ME/CFS.....	31
-------------------------------	----

Thanks to *Emerge* for articles that appear in this issue of *Talking Point*.

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

AGM November 8, 2003

Page 4

Talking Point - December 2003

The Society has had a fairly active year throughout 2003. A number of projects have been brought to completion and a cadre of committed members and volunteers have put considerable effort into maintaining a steady stream of activities. The response of members to various initiatives has been quite varied. We enjoyed excellent attendances at several events. And yet other projects, several funded by sponsors, met with only a small level of interest. As always the Society will do its best to read the signs of the times and try to work out where its always limited resources can best be directed.

Management Committee

The Committee met monthly throughout the year. Our outgoing president and driving force, Paul Leverenz, chaired all meetings except the last. Paul left to take up work interstate in October. Several other members retired through the year for a range of reasons. I thank Peter Evans, Peter Worsley, and Rebecca Cordingley for their contributions. Continuing members included Kirsty Cordingley, Glen Domeika, Adrian Hill, Geoff Wilson, and Margaret Wing. We were pleased to welcome a new member late in the year when Denise Stephens was coopted as Honorary Secretary.

Achievements

Our key achievements included:

- 450 people attended a public awareness seminar on 10 May which we organised with Fibromyalgia SA and the assistance of the Asthma Foundation.
- Over 120 people attended a film evening at the Mercury Cinema on 16 May. We showed the powerful *I Remember Me*, a personal journey exploring the story of ME/CFS in the United States. The evening was an outstanding achievement for a team of dedicated volunteers in the office, especially coming as it did less than a week after the awareness seminar.
- Our annual badge day was a smaller affair than the year before but still raised a healthy amount for our treasury and as usual led to a range of people coming to our badge-sellers to discuss the impacts of CFS on themselves or others. I believe that these days are an important form of outreach for the Society.
- We developed closer contacts with a range of other disability societies and with the Department of Human Services. I attended a long series of meetings convened by DHS to investigate whether one-stop-shop disabili-

ties helpline could be established. The original goal proved elusive. Nonetheless the Department provided some headphones and computers to support our helpline and information services. Perhaps more importantly, we forged close contacts with several other societies. I will speak more of that later.

- We continued to improve our office systems. Good office systems liberate the energies of the Society's volunteers to do more and to do it without undue burden on their own health and sanity. The committee has been very thankful that the Society's administrative systems have been in increasingly good order this year.
- We went to our first ever Agricultural Field Day [see page 6]. This was the brainchild of office manager Patricia Smith working with Jane Gill of the North Yorke Peninsula Support group. Our well-sited and well-stocked stall attracted thousands of passers-by over the three days of the Field Day and country CFS sufferers who came by told us they were pleased that the Society had had a presence at the event.
- The SAYME group had an active year with a 20-30 group meeting on several occasions in addition to the normal run of Rice Cracker and Spring Water Evenings. These themselves developed a new focus with games and other resources provided by a Community Benefit SA grant. The grant also enabled SAYME to hold a camp at Mylor in October which was attended by 11 people and to produce four issues of its magazine in 2002-03. A grant from the Foundation for Young Australians also funded the development of an upgraded and quite snazzy website for SAYME. I think it quite remarkable that the small South Australian society is the only one in Australia to sustain both a magazine and a website for its younger members.

Grants

I have acknowledged above two grants which have assisted our youth wing to undertake several useful initiatives. We also secured in 2002 a grant from the Sunshine Foundation to enable us to explore ways of better targeting self-management courses to meet the needs of people with ME/CFS. Trying to acquit this in fact turned into something of an epic. Several volunteers for a leaders' training course dropped out at the last minute on more than one occasion. After stretching the goodwill of the Foundation with several extensions we amended our approach and a

(continued next page)

(continued from previous page)

number of members are now undertaking the basic self-management course run by the Arthritis Foundation. We will hold a review meeting in December and pass on any recommendations to the course managers.

Finances

The Society's financial resources remain limited. We have been fortunate that for the second year in a row we have been sent an anonymous donation of \$12,000. Roughly speaking this has meant that instead of facing a deficit of around \$6,000 we have finished the year in the black by around the same amount. We cannot of course count on this good fortune in the future.

Key directions and issues

I believe that we need to find ways to sustain services to members and to lobby on their behalf without burning out the few members and volunteers who come forward to work for the common good. To this end we will look at ways of working with other disability societies.

This year we investigated collocating with Cystic Fibrosis SA. The aim was to reduce our rental costs, share resources, maintain extended reception desk hours and go for grants together. In the end the idea fell through but we hope to maintain our links with CFSA and shared accommodation remains on the table. We also this year took another step in this direction. To rationalise the effort which goes into *Talking Point*, especially with the departure of Paul Leverenz, we have negotiated with the Victorian ME/CFS Society. Henceforth we will use key material from its journal whilst maintaining South Australian content.

My personal view is that we must continue to look for ways to share resources. We must value our identity as a supporter of and a voice for people suffering from one of society's less high profile illnesses. But we remain only a means to an end and if we can find better ways to work for our members by sharing resources then we should be happy to go that way.

I am certainly mulling as I write this as to whether our membership alone is adequate to sustain some of the programs for which we work hard. The low response to the SAYME camp and the self-management course lead me to think that we would do better to keep broadening the catchment of our users by sharing projects with other societies in this State. This is an issue on which I would appreciate members' feedback.

Thanks

This is a moment to thank one person above all. We are much the poorer for losing the passion, talent, skills and determination of Paul Leverenz, our president for the last

several years. Paul has been simply outstanding and is respected nationally for his leadership here. He has worked hard to maintain contact with the medical and research communities here and I hope that we can fill his shoes in that and other areas. It is wonderful that he now has full-time paid employment and we all wish him well.

I want also to thank especially Patricia Smith for her work not only in managing the office so well but for being there to either assist or to drive all our major events this year. With her in the office has been a group of volunteers who are not only efficient but who create a calm and pleasant atmosphere: Donna Brieese; Donna Smedley; Marg Wing; Trisha Moores; Joseph; Di Fleet; and Christine Hickman.

I thank also the coordinators of our various support groups throughout the State. Not least the Society is grateful to the people who coordinate and run our crucially important Support and Information Line: Jon and Vicki Foote; Alex Harris; Elaine Balfort; David Andrews; and Marilyn Pen-nack.

SAYME's varied programs this year would not have taken place without the work of a number of its members. Elizabeth Cahalan above all has not only edited the magazine but assisted with both the support groups and in general has been the de factor coordinator of the SAYME program. Other key members have been Kristin Mulvihill, Skye Yuill, Emma Wing, and Sarah White, whilst Bec Cordingley was designer and webmaster of the website.

As usual, in thanking some people by name one is conscious that other members and volunteers have done great service but have been left in the shadows. I hope that they accept my apologies for passing them over.

Conclusion

There are many people in this State who are affected directly or indirectly by ME/CFS. Their needs are paramount and the Society exists only so that their lives might be made more pleasant and productive. They deserve more support than the Society, alone and unaided, can give them. It makes all those of us who work for them more than a little angry that the Society has to operate without any level of State or Federal government support whilst societies serving similar or even smaller numbers of clients receive recurrent funding support. We won't see that change in the near future. But we will persist in working towards it. In this and other ways the Society remains the best hope of a better deal for South Australians coping with the challenge of ME/CFS.

Peter Cahalan

November 8, 2003

Raising awareness at the Paskeville Field Days

Page 6

Talking Point – December 2003



Some 55,000 people, over three days, attended the recent Paskeville Field days, and I'm sure most of them filed past the Society's stall in the middle of the Bowley Pavilion during that time.

Our presence was to raise awareness about Chronic Fatigue Syndrome and the support offered by the Society. Volunteers from the Wallaroo and Auburn support groups, along with some of the office staff from Adelaide, were overwhelmed by the reception and number of inquiries we received!

The sale of home made biscuits and Heat Wheat bags helped to cover the costs involved, with the excess raised has been earmarked for the Wallaroo group.

Our thanks to volunteers Jane and Brett Gill (Wallaroo group), David Shepherd (Auburn), Margaret and Emma Wing, Peter Cahalan, and Rob Smith (all from Adelaide), who manned the stall.

Special thanks to Jane and Margaret who helped make biscuits and wheat bags, and David who kindly donated the wheat.

Patricia Smith
Office Co-ordinator

PS from the President

I took my turn on the stall on the last day of the Field Days. The local organisers and the head office team had turned the experiment – this was the Society's first go at a Field Day – into a spectacular success. For a start we had an excellent spot – secured after some careful negotiating by Jane. And the stall was better stocked than some with saleables. These defrayed our costs. But, more importantly, they gave us a stronger presence and lured more people into stopping by.

The Society is headquartered in Adelaide and its committee members are all drawn from there. Yet many members and CFS sufferers live in country SA. I think that the Adelaideans and the local support group members each enjoyed working and meeting together.

Based on the success of Paskeville 2003 we will certainly be looking at attending other Field Days in future. The project was the brainchild of Patricia Smith, the driving force behind our office team over the last two years. I'm glad we listened to her.

Peter Cahalan



Southern Communities Transport Scheme

Anyone living in the Victor Harbour, Goolwa, or Middleton areas may wish to avail themselves of The Southern Communities Transport Scheme.

The scheme involves the coordination of local transport and volunteers as a cost-effective means of improving access to services and opportunities for people living in the local area. The scheme assists those who are transport disadvantaged in all age groups. There are two main services, **Medi Ride** and **Dial a Ride**. Commercial operators are utilised for local transport where possible.

The scheme is also a transport information resource for the region. Any member of the community is invited to contact the office to discuss what transport services are available.



Medi Ride

Medi Ride is a door-to-door community car service available for transport to medical or essential appointments both locally and in Adelaide. Transport is also provided for visiting nursing homes or hospitals etc.

Donations are most gratefully accepted from clients to contribute towards the cost of the service provision.

Please note: If you are a patient of the Flinders Medical Centre, Royal Adelaide Hospital, Queen Elizabeth Hospital, or a card holder for Veterans Affairs, you may be eligible for travel reimbursement from that organisation. If you have limited mobility you may be eligible for the SATSS taxi voucher scheme.

Dial a Ride

Dial a Ride is a scheduled bus run which provides a door-to-door service to and from central Victor Harbor. This is available on Tuesdays and Thursdays for Port Elliot, Victor Harbor, and Encounter Bay, and Fridays for Goolwa and Middleton. Please phone the office to book your seat.

Cost is a donation.

For people with ME/CFS

Explain that you have ME/CFS and the drivers will oblige by omitting to wear deodorants, perfumes etc for the chemically sensitive.

Details

Coordinator: Amanda Cowan
Address: 2/91 Victoria Street,
VICTOR HARBOR 5211
Phone: (08) 8552 5709
Fax: (08) 8552 5304
Email: scots@granite.net.au

Thanks to Sue Prider for her contribution to this article.

Multiple Chemical Sensitivity – ideas needed

Page 8

Talking Point – December 2003

Efforts by the SA Task Force on Multiple Chemical Sensitivity (MCS) and support by the Democrats has led to the Social Development Committee inquiring into and reporting on Multiple Chemical Sensitivity. The Social Development Committee is a standing Parliamentary Committee of six elected representatives who regularly investigate issues of public concern.

The Committee will investigate the issue with particular reference to:

1. which chemicals are most responsible for MCS symptoms and how exposure can be minimised;
2. the effect of chemical exposure on human fertility;
3. status in other countries of MCS as a diagnosed medical condition;
4. best practice guidelines for handling chemicals to reduce chemical exposure;
5. current chemical usage by government departments and changes that could be made to reduce chemical exposure; and
6. ways that South Australians with MCS might better access support from government agencies.

The Social Development Committee is accepting submissions now on MCS and will consider these after February 2004. The CFS Society is planning to provide a submission from a CFS perspective, particularly as it relates to points 5 and 6 above.

If you have any ideas, examples, case studies or human interest stories on MCS, please contact Lorenzo Pizzini by February 28, 2004 on 8161 7721, 0405 122 988, or e-mail themoz3@hotmail.com.

Please feel free to give personal stories of the difficulties which you've faced in confronting chemical exposures.

See also: "Inquiry on Multiple Chemical Sensitivity" on page 28.



Chemical Sensitivity Information

For people with:

- Food intolerances
- ME/CFS
- Chemical sensitivities
- Hyperactivity – ADD

(08) 8381 9286

Inquiry into Multiple Chemical Sensitivity

On July 9, 2003 South Australia's Upper House, the Legislative Council, voted unanimously to support an Australian Democrat's motion requesting the Social Development Committee to inquire into and report on multiple chemical sensitivity. The Social Development Committee is a standing Parliamentary Committee of six elected representatives, three from the Upper House and three from the Lower House, who regularly investigate issues of public concern.

A copy of the motion and its terms of reference is below. Statements in support of the motion can be found on the website of South Australia's Parliament in the Hansard records of July 9, 2003 for the Legislative Council (see www.parliament.sa.gov.au/dbsearch/lc-hansard.asp and search for "chemical").

A parliamentary inquiry into MCS is a big step forward and a great opportunity for people with MCS and their supporters to tell their story and present their case to legislators. The inquiry will help to inform the basis for future public health policy and guide reforms in chemical regulation.

Submissions to the inquiry are now open but will not be formally considered until after February 2004.

Both national and international submissions from people with MCS and their supporters are welcome.

Submissions can be presented by post to:

Ms Robyn Schutte, Secretary
Social Development Committee
Parliament House
North Terrace
Adelaide SA 5000

or by email to sdcc@parliament.sa.gov.au.

There will also be an opportunity to present verbal submissions to the Social Development Committee both in person or by telephone after February 2004.

For more information contact Parliament House in South Australia at the above contact details or telephone national (08) 8237 9100, international +61-8-8237-9100.

*Peter Evans, Grad Dip Health Counselling
Convenor
SA Task Force on MCS*



SANDRA KANCK

Australian Democrats Deputy Parliamentary Leader
Member of the Legislative Council
July 9, 2003

MOTION:- MULTIPLE CHEMICAL SENSITIVITY

The Hon. SANDRA KANCK: I move:

That the Legislative Council requests the Social Development Committee to inquire into and report on Multiple Chemical Sensitivity, with particular reference to:-

I. Which chemicals or chemical compounds are responsible for the majority of symptoms of Multiple Chemical Sensitivity and how exposure to them can be minimised;

II. The effect of chemical exposure on human fertility;

III. The comparative status in other countries of Multiple Chemical Sensitivity as a diagnosed medical condition;

IV. Best practice guidelines in Australia and overseas for the handling of chemicals to reduce chemical exposure;

V. Current chemical usage practices by Local Government and State Government Departments and changes that could be made to reduce chemical exposure to both workers and the public; and

VI. The ways in which South Australians with Multiple Chemical Sensitivity might more effectively access sources of support through government agencies.

(Passed unanimously, July 9, 2003)



Interview: Alastair Lynch

The following is a transcript of part of **Warwick Hadfield's** interview with Alastair Lynch which was broadcast on 26 September 2003 on The Sports Factor on ABC Radio National. On the following day, Alastair Lynch played for the Brisbane Lions in the AFL Grand Final. He kicked four goals which helped the Lions win the Premiership flag for the third year running.

Warwick Hadfield:

To be still playing the game at his age (35) is an achievement in itself. To be doing so despite suffering from Chronic Fatigue Syndrome lifts the Alastair Lynch story from the sports pages and into that special space where he becomes an inspiration to a much larger world.

In his early days in Queensland he had the usual ups and downs of all footballers – good years and bad injuries – but in 1994 he was struck down with the illness that changed his life forever.

Alastair Lynch:

It was mid-September '94 and I knew straight away there was something pretty wrong. We'd had a week-end away, an end-of-season footy trip, as they're probably known. The team went up to Cairns and I certainly wasn't a big drinker but we had a few drinks and a bit of a relaxing weekend and came back quite rightly on the Monday a little bit dusty – and that was to be expected. I even woke up on the Tuesday and still didn't feel that flash, but on the Wednesday morning I remember waking up and I just could not lift myself out of bed. I had pains in the stomach, headaches and was just totally drained. It was probably like your worst hangover, but it just didn't go. So straight away I knew something was wrong and when I finally did get up and get to the bathroom I was passing blood, so there was a fair chance of something not right with my body. And it was a big chase to try to find a solution from that time on.

Warwick Hadfield:

So you actually can be physically ill as well?

Alastair Lynch:

Yes, very much so in my situation. I think different people have different things, but I was passing blood and it felt like there was a lead weight across my chest, and that was keeping me down in bed, and this went on for quite a while. And, basically, doctors were giving me feedback that they could detect there was a virus in my system and with a virus there was nothing

they could do about it and it would go in a few weeks. I'd go back three weeks later and say, "Look, I still can't do much and it certainly hasn't gone." So that was when it was starting to be difficult when I just couldn't find an answer.

Warwick Hadfield:

And how did you ultimately get the answer that you had Chronic Fatigue Syndrome?

Alastair Lynch:

After about six months of going nowhere I went to Melbourne and we involved the best people to try to find out, or through a process of elimination tried to find out, what was wrong. So we went through that over a couple of days and after numerous tests I was told that I had a post viral syndrome called Chronic Fatigue Syndrome. I'd probably heard the term used before but did not know much about it. The instruction from the doctor I was seeing in Melbourne was that I had to rest for about six months and make sure that I didn't do much and really look after myself, otherwise I would have trouble for a long time.

Warwick Hadfield:

How hard was it to take that decision to sit out pretty well the whole of the 1995 season, given that you were this player on the fabled ten-year contract, supposedly the first million-dollar AFL footballer? You would have known that people would have been talking about you in corners if you're missing a whole season for this rather nebulous disease?

Alastair Lynch:

Yes, it was hard I suppose. As a footballer I was expecting that my best years were going to be from the age of 26 to 29, maybe 30 years old, and to be struck down by something that no-one really understood was difficult, and certainly that was hard, and to be told that I was definitely going to miss the whole season was very frustrating. But at the time I had no chance of playing. I just felt like I couldn't recover from efforts. On my best days I felt like I had the 'flu

(continued next page)

(continued from previous page)

and I could do things, but the days after I was just destroyed.

Warwick Hadfield:

Chronic Fatigue Syndrome doesn't just affect the sufferers. It also has a huge impact on those around them: family, friends and, in Lynch's case, team mates. Richard Champion played alongside Alastair Lynch and his admiration for the 'big fella' grew as he watched him battle with this little-understood illness.

Richard Champion:

He tried everything in the book. He went to health farms, he went everywhere, he tried everything. He had to have a maintenance programme in place and just do enough so it didn't trigger it off again, but, of course, playing professional sport – that is very hard to do when you're training seven days a week, twice a day. He had to make sure, with his maintenance programme, that he didn't overdo it and he had to have a very understanding coach and club to allow him to do that. So he's been pretty lucky in his situation to get through that, but it must have been very frustrating at times and you could see that on his face. I can remember one training session in Brisbane we were doing sprint work and he overdid it a bit and he was spewing up afterwards. It was just really sad to see that this great player was being troubled by this disease that no-one really knew how to fix – and that was the frustrating point about it.

Warwick Hadfield:

According to the experts, Chronic Fatigue Syndrome is a persistent or relapsing fatigue that lasts at least six months. Doctors and patients have also argued whether the term "syndrome" trivialises what is a very serious illness.

There is by now a wide range of treatments for Chronic Fatigue Syndrome and on top of that list is physical activity, but sufferers have to balance that against worsening their condition. Drugs can also treat some symptoms but, for Alastair Lynch, just gaining an understanding of the illness was as important as any medication.

Alastair Lynch:

I think one of the difficult things was not having a protocol to follow, to know that as a Chronic Fatigue sufferer in twelve months time you were going to be fine but you had to do this, this and this, or take whatever medication – there wasn't anything like that. So I think it was difficult for people to believe they

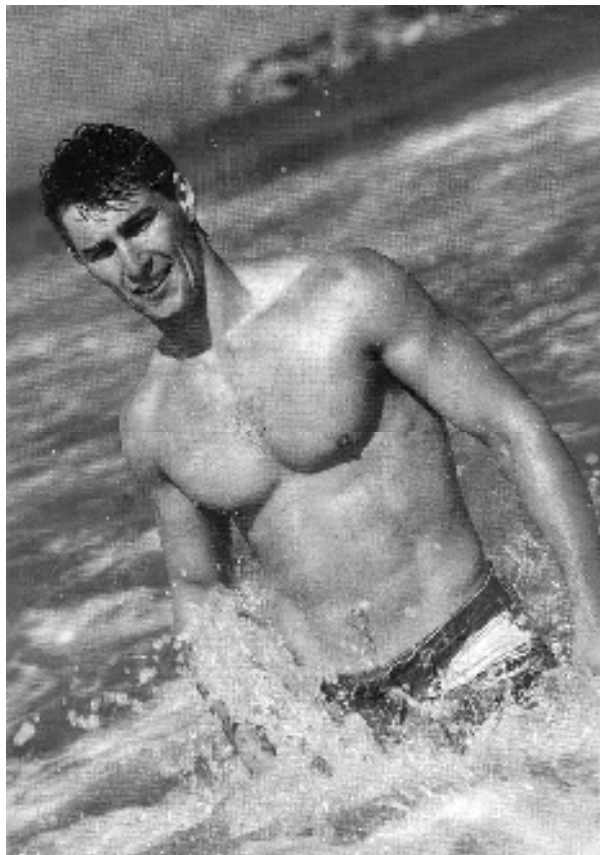
were going to be well again when there wasn't a lot of assistance around. I spoke to a number of people who had similar problems to me and who were athletes and had returned to full training. So that helped me cope with the problem and realise that, at some stage, I was going to get better. Certainly on the dark days I felt that I was never going to get back on to the footy field, which wasn't the major concern – I just wanted to get back into a general life. I wasn't able to socialise; I wasn't about to do anything active really. So it wasn't as if I had had a knee reconstruction and I couldn't play footy, it was an energy

-health issue where I couldn't do anything. So that was very difficult.

Warwick Hadfield:

Layne Beachley, the world champion surfer on an earlier edition of The Sports Factor, said that, when she was going through this period where she couldn't do anything, by four o'clock in the afternoon she was starting to dream up painless ways to end her life; did you ever go through depression like that?

(continued next page)



(continued from previous page)

Alastair Lynch:

Yes, I did. I remember distinctly one day I got to training and I was very down and was at the stage where we didn't really have any answers to what was going on and doctors were still telling me that. "Yes, you've got a virus, but you will get over it." I just wasn't getting any better. So I was at a very low point. Certainly there were a few concerns but, thankfully, with the support of people close by, it certainly didn't get down to the too bad of lows.

Warwick Hadfield:

How hard was it for your family?

Alastair Lynch:

Extremely difficult for my family. My wife, who was my girlfriend at the time, had made the move with me to Brisbane, which she wanted to do, obviously, but it's always difficult to move away from family and everything like that, so it was a big move. And to have the problems as we did, and for her to be my only real family support here at the time, put a lot of pressure on her and, I think, for the ones you are close to, it's often more difficult. I have the problem and I was coping the best way I could, but for those close to you to see you struggle and not be able to do or be the person you used to be is very hard.

Warwick Hadfield:

By 1998 Alastair Lynch had begun to rebuild his life and his football career. Then along came another monumental setback. A herbal remedy he had been prescribed contained DHEA, a substance subsequently banned by the Australian Sports Drug Agency. Even though he had not tested positive, he notified both ASDA and the AFL that he had been taking the substance.

Surprisingly, he was charged by the AFL and had to endure twenty gruelling hours of hearings spread over three weeks. I used to see him leave those hearings, an ashen-faced and crumpled figure, and, of course, that begs the question now: did he ever regret coming clean?

Alastair Lynch:

Yes, many times I have. I've thought: "why did I say anything?" I'd been treated by a doctor who prescribed me this medication and, after conversations with ASDA, there were no dramas. Once I was told that it had been listed, I instantly contacted ASDA again to confirm this and they advised me to let the AFL know, apply for an application to use it and I should be fine. Which I did. And then I was charged under the Doping Code under some clause other than a positive test and that was very disappointing. It was a very tough time and I lost a fair bit of confidence at that moment. Thankfully, the AFL Tribunal found that I had no case to answer whatsoever and had done nothing wrong.

Warwick Hadfield:

Alastair, you still suffer from Chronic Fatigue Syndrome, but you limit your training to make sure you never become exhausted and in matches these days if a young bloke runs you around a bit too much your team-mates cover for you. But you never travel with the Lions when they play in Perth these days. Why is that?

Alastair Lynch:

The oxygen quality in planes when you fly is not the same sort of quality and seems to have an effect. I think if people fly from Melbourne to London, then get off the plane and try to go for a run, they feel somewhat fatigued and I suppose for some reason I seem to have the same sort of effect but on a lesser journey like the five or six hour flight to Perth from Brisbane. So I don't understand it, but from what I'm

(continued next page)



(continued from previous page)

told it's the pressurised cabin and just the effects of the flight seem to have some sort of adverse effect on me.

Warwick Hadfield:

In many ways it could almost have been a benefit, because you're 35 and still play, so because you didn't play for a lot of time when you were 25, 26 and so on, you have got an extended career. But from a personal point of view, were there also benefits as well? Because you've had to look so deeply into yourself have you found an inner strength, an inner well of power?

Alastair Lynch:

Yes, without doubt. I think I'm different from the person that became ill in 1994. I think I appreciate a lot of things. I appreciate the people around me and I understand my health and my body much better. I

never used to think of my health as anything. I mean if you're ill, I used to always find you'd wake up the next day or the day after and feel fine again. It wasn't until I kept waking up feeling terrible and having no energy that I really appreciated what I supposed life and health was all about. So I certainly look after myself much better and I hope I'm a better person to be with and, certainly with loved ones, hopefully I'm a better father and a better husband for it.


Editor's Note: Some editing of this transcript has taken place in the interest of clarity, but nothing of substance has been changed.

Reprinted from Emerge Summer 2003.


from the earth.
NATURAL FOOD SUPERMARKET
 195 Magill Road, Magill 5069
Ph: 8363 1911 Fax: 8363 0007

- Adelaide's specialists in macrobiotic products
- Large selection of local and interstate special dietary breads
- Organic fruit and vegetables, eggs, meat and chickens
- Dried fruit and nuts (organic and naturally dried where possible)
- Organic and biodynamic flours and grains
- Cold pressed oils, natural honeys, milks (organic where possible)
- Nutritional supplements
- Natural hair and skin care products

10% discount for ME/CFS members
 on production of current membership card for cash purchases of \$10.00 and over (excluding bread and specials).



⇒ **Your Health**
 ⇒ **Your Home**
 ⇒ **BIO Paints**



Indoor pollution is a growing concern. A main contributor are conventional paint products.


But here is the good news for You. Bio's natural and non toxic paints will create a healthier home.

Do You want to use these environmental responsible products? They are easy to use, of high quality and have no bad smell.

Phone us on our Freecall Number
1800 809 448

and we'll send you **FREE Toxic Information** and a **coloured Brochure**, which tells you the different applications for each product and surfaces. This is invaluable for anyone looking at painting.

Bio Products Australia Pty. Ltd.
 25 Aldgate Tce., Bridgewater S.A. 5155




A sideways look at pacing

By Julia Derbyshire

Julia Derbyshire takes a sideways look at pacing. A great idea in theory, if only life didn't keep getting in the way.

Page 14

Talking Point – December 2003

A favourite cartoon of mine from *InterAction* is one in which poor old Jim sets to with a piece of wallpaper, a bucket of paste and a confused look. 'No Jim,' the caption reads, 'The doctor said you've got to PACE yourself!' It's guaranteed to raise a wry smile because 'pasting' is something I'm naturally good at: as in giving myself a good 'pasting' or thrashing for not being able to achieve all I want to.

In reality, 'pasting' of this nature is how many attempt to conquer the illness at first, perhaps in the absence of appropriate medical advice, or in the face of misunderstanding and scepticism, vowing, 'I will beat this somehow'. Time has demonstrated that it's not unusual to be plunged into a worse mess as a result of trying to tackle things this way.

Kidney beans and kids' concerts

Take for example those familiar twins, shopping and cooking. My pattern often goes something like this: helpful family members join in with meal preparation until suddenly they can't and it's my turn. The reason they can't soon becomes apparent – I'm either going to need loads of ingenuity with a few kidney beans or a major trip to the supermarket. I'm too exhausted for either but kidney beans don't appeal, so I drag myself martyr-like round the store, feeling grim but shopping for Britain. Afterwards I can collapse for a few days while others use up the easy meal options until – guess what – it's kidney beans and my turn again.

Then there's the inevitable school concert: "Mum you are coming to listen to me play my trumpet aren't you?" asks my teenage son. "When's that then?" I ask, trying not to look too alarmed. "Tomorrow evening" he answers, with characteristic short notice. I make feeble grunts in reply, ask casually how long it's likely to last and wonder secretly if anyone will notice if I wear earplugs.

What's my choice then – beat myself up emotionally for not supporting my child, or whip myself into going and take the consequences?

I do need to unlock the secrets of pacing as an important aspect of the recovery journey. But 'pasters' go carefully: even the gentle art of pacing can be subtly turned into a stick to beat oneself with rather than to lean on; something else to 'fail' at, or become a slave to.

Yes, well it's all very good in theory

My first and only encounter with verbal medical advice on pacing came eighteen months into the illness from a caring consultant with a special interest in CFS/ME. He told me that it was important never to overdo it (better late than never!) and to pace myself carefully. Then he described a daily routine of "Get up, sit down and rest; have breakfast, sit down and rest..." etc, pointing out that I would probably get very bored. Too right! So began my first attempt at pacing. The fatal flaw in the scheme related to the fact that for me there is a significant degree of thyroid involvement and often the hardest thing I have to do in a day is wake up at all!

I don't have to 'do it right';
I have to get it right for me...

So, having propped open the eyelids, how does one begin to pace apparently non-existent energy? My first attempt went something like this: Wake up (well sort of), clean teeth, sit down, fall asleep; wake up an hour later feeling groggy, have breakfast, sit down, fall asleep; wake up mid-morning feeling worse, clear away breakfast things, sit down, fall asleep; give up on pacing, consider reverting to 'pasting' which at least gets the breakfast dishes washed!

(continued next page)

(continued from previous page)

Getting with the beat

Evidently, knowing the sound principles is only the start. Despite a core of common features, each person's overall experience is unique. Therefore pacing has to involve not only careful budgeting of the day's energy, but also the rhythm that works best for each of us.

I don't have to 'do it right'; I have to get it right for me with my balance of physical and cognitive symptoms. What is very demanding for me may be easy for someone else. Like a heart pacemaker supporting the beating heart, I need a mental 'pacemaker' which keeps me in tune with what my body's telling me.

Two pictures involving rhythm help me with this. The first illustrates something of the 'how not to'. Imagine a musical metronome – that wooden pyramid-shaped box with a ticking pendulum inside. The pendulum is adjusted to specified speeds to set the correct tempo for a piece of music. So far so good. But anyone who has ever attempted to play in time to the relentless ticking pendulum for a whole piece will know how frustrating this is. Similarly, a realistic underlying pace for my daily life 'music' is a good starting point, but it can't then be allowed to control my day to the extent that there's no room for spontaneity or occasional changes of tempo.

Remember 'Chariots of Fire'?

My second picture jumps out of the music room and into the mud! During years of watching family members endure the struggles of cross-country running, I observed the need for each runner to develop a personal rhythm and vary their pace tactically as a race progresses. This may involve getting off to a flying start, easing off to a steady pace later and conserving enough energy to put on a final spurt without making themselves sick at the finish (ring any bells?).

While my own pacing journey is limited by low levels of strength and stamina (the equivalent of a muddy terrain rather than nice firm ground underfoot), I can still work out a rhythmic pattern of energy-use which will help me move forward without making me sick later.

In practical terms this translates as follows: on waking I potter slowly, attempting small household tasks until sufficiently awake to sit down without falling asleep. After lunch a short jaunt in the fresh air – without overdoing it – helps to rouse the reluctant brain. On return I can rest physically but use my newly awakened brain to attempt a mentally taxing enjoyable activity before resting properly to prepare for later demands.

Extras, like a child's school concert, will mean changes to the basic pattern. Similarly, a change of routine, such as being on holiday, requires a reassessment of activity within my acceptable levels. 'Switching' between physical and mental activities (e.g. washing up followed by reading a bit) is a useful way of budgeting energy.

On the pacing journey we don't travel alone, but we do move at different speeds. We rest and advance in ways which suit us best, making use of varying rates of progress. So in the words of Sydney Carter's modern hymn, "One More Step," I'll be humming along the way:

'As I travel through the
bad and good
Keep me travelling
the way I should
And it's from the old
I travel to the new
Keep me travelling
along with you.'

Source for this article: InterAction, quarterly members' magazine of UK charity Action for M.E., August 2003. www.afme.org.uk, email: info@afme.org.uk.

Reprinted with permission from Emerge Summer 2003.

Wanted To Buy HOUSE

For chemically-, geopathically-, and
EMR-sensitive person
Phone: Mary on 8554 3843

Where are my meaning-laden bits?

By Danielle Gamble

Page 16

Talking Point – December 2003

I do not claim to have ever been especially eloquent. However, since acquiring CFS/ME I have noticed, at times with a barely contained distress, the progressive deterioration in my ability to communicate as well as I used to. This phenomenon is often attributed to 'brainfog' in the list of symptoms suffered by people with this illness. I don't like this term, though, because I think it denotes a somewhat benign experience of vagueness or haziness. The reality, in my experience, is more malignant.

On a bad day my vocabulary seems to have shrunk by fifty or sixty percent. It feels like I'm trying to convey all my needs and thoughts with the language capacity of a toddler: Danielle sick, Danielle sore; Danielle go sleep. My tools of communication – my words, those meaning-laden bits which help me craft my interpretation of the world and express to you *how trucking bad I feel today* – have receded to parts of my brain I don't know how to access any more. Sometimes the rate with which I can retrieve these labels is so delayed that the word may not be there at all. These days, like Moses did in the Bible, I too complain of faltering lips and a stiff tongue.

Complex concepts now have a habit of tying up my brain and tongue in such a way that, when I open my mouth, nothing but random bits will splutter out: "Did...I...was...oh – it doesn't matter..." And what I wanted to tell you is left unsaid. The effort of unravelling the cluster of words that express how I feel is just too immense and I detest how defective I sound if I persist with my spluttering. Sometimes I choose to take the path of least resistance and save face by just staying silent.

The more complex the idea I want to convey, the more difficulty I have. I'm not talking about academic complexity here so much as relating an idea with several components. My ability to narrate a story, for instance, an idea with a beginning, middle and end is a pretty screwed-up enterprise. When I try to tell a joke or describe to someone how I went about completing a task, I find myself flailing. No longer being able to

contribute to a conversation with the effortlessness I am used to is humiliating and frustrating. It perplexes me too that if I do persist with 'telling my story' – splutters and all – my listeners have to exercise such patience. It is a pride thing, I know, but I want people to enjoy listening to me, not to find it a chore that requires an excessive expenditure of their energy.

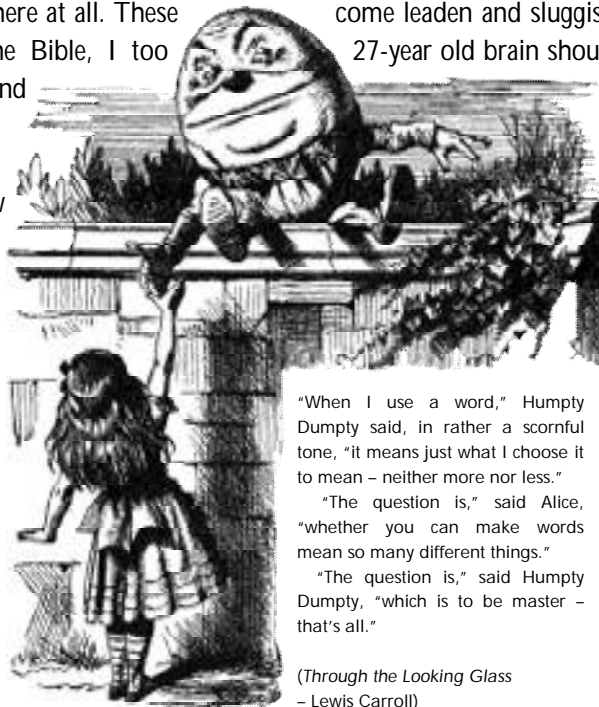
It is not only the act of talking which I find difficult. Since acquiring CFS/ME my thinking has also become leaden and sluggish. My brain is not agile like a 27-year old brain should be. I do not have the same

command of its potential that I used to. It's like my thinking organ has been cauterised. Practically this means I can no longer perform tasks like adding up or subtracting numbers in my head and I frequently lose my train of thought before I've hardly even set out upon it. What's more, I forget the names of people I know very well. In fact, if I told them I'd forgotten their name I don't think they'd even believe me!

I am often bemused by the tendency of others (even family!) to forget that I do not have the same levels of endurance as they. My brother recently asked if I wanted to play tennis with him! But then I forget that this illness clothes the wearer in a cloak of involuntary camouflage.

However, I have a theory that the cognitive symptoms of CFS/ME, somewhat ironically perhaps, are not quite so invisible as some of the more 'physical' ones. I wonder if, when people like my family hear

(continued next page)



"When I use a word," Humpty Dumpty said, in rather a scornful tone, "it means just what I choose it to mean – neither more nor less."

"The question is," said Alice, "whether you can make words mean so many different things."

"The question is," said Humpty Dumpty, "which is to be master – that's all."

*(Through the Looking Glass
– Lewis Carroll)*

(continued from previous page)

me struggling to tell them something, or hear me give up on telling them something (which I would never have done in the past), this might be some kind of more tangible evidence that, indeed, all is not right with me.

In March 2003 I had the privilege of seeing a speech pathologist. She gave me some tests to see if my memory, narration and retrieval difficulties were significantly different from normal. To my relief my scores were significantly worse than average. To have this fact objectively confirmed was like magic! There were, moreover, strategies I could use to help compensate for the various impairments I was experiencing.

One of the strategies the speech pathologist advocated was writing out what I needed to say before making telephone calls or conveying a 'complex' idea to someone. So, if I need to make a phone call to the bank or to Centrelink or someone who I don't know I just read out what I have written in front of me. I've had too many instances of picking up the phone and completely forgetting what I wanted to say or not being able to convey my query in an intelligible form to go back to winging it. I find this strategy rather self-reflexive (particularly when I write down things to read out to my parents!) and almost feel like I'm cheating in some strange way. However, there are plenty of situations where this 'unease' is far preferable to not succeeding in the transfer of some critical information.

The speech pathologist's suggestions inspired me to start thinking of my own 'compensation' strategies in order to locate some footholds in a world in which my altered ability to communicate can often make me feel oh-so-powerless. In the last few months I have taken to writing words and notes on index cards and sticking them up on my bedroom wall. For me, this is like projecting a small portion of my vocabulary, my 'meaning-laden bits', onto a place where I don't have to hunt endlessly for them. I relish being able to see the words. I also keep a notebook in most rooms of the house so that if one of my stray words does come to mind I'm ready to catch it and tie it down on paper.

Although this illness continues to ravage my mind and body in various ways, I don't feel quite so powerless to its wiles as I used to. What was a barely contained distress is now a more manageable one. I still have faltering lips and stiff tongue but I have discovered some new ways of coping with the fiercest out-workings of this 'brainfog' phenomenon. My hope is that when people, particularly those I know well, hear me struggling for my words, for my 'meaning-laden bits', this struggle will remind them that my battle with this illness is an ongoing one. Not that it will make them feel guilty or inadequate, just that they won't forget that, whilst I might look damned fine, mostly I'm a hundred miles from that particular destination.

Reprinted with permission from Emerge Summer 2003.



Problems with Fibromyalgia?



The FM Association can help.

Contact details:

FM Association C/O Arthritis Foundation of SA Inc.,
1/202-208 Glen Osmond Road, Fullarton SA 5063.

Phone (08) 8379 5711,
Freecall 1800 011 041.

Hope... after ten years

By Goldie Freedman

I have had CFS/ME for ten years and I am writing to share some good news with Emerge readers about my progress.

For six years I had a fulfilling career as a barrister working in Melbourne. I left work in order to have a baby. However, in 1993, when my daughter was two, I was diagnosed with CFS/ME. My physician recommended total rest, which was just as well as I could not get out of bed anyhow.

In the initial phase of the illness, I spent months in bed and lacked the strength to do anything. Sometimes my husband even had to feed me as I was too weak to do it myself. I mainly experienced debilitating fatigue and very bad muscle pain and I had to rely on my husband and others to care for my daughter.

Slowly I did improve and was eventually able to resume some normal daily tasks, but for years certain things, like doing the supermarket shopping, were just too exhausting. Even as I improved, I still felt that every day was a struggle and I was functioning well below my pre-illness level. Each day I awoke feeling so physically dreadful that I often wondered how I would get through the day.

Significantly, whenever I felt I was getting on top of my CFS/ME, I suffered a relapse and went back to square one. This was really disappointing for me as I felt like I was on a roller coaster over which I had no control. One relapse was so severe that I was placed on medication for the pain – this helped me but there were side effects.

I also experienced a bewildering array of new symptoms that my doctors could not understand and felt like I was becoming increasingly intolerant to nearly everything – many foods, chemicals and smells amongst other things.

I tried various treatments such as naturopathy, cognitive behaviour therapy, psychology, Qigong and others; however, I experienced my main relief from two things over the years – acupuncture and rest.

I was not well enough to go back to work, even part-time, so my days were spent in this limbo of trying as hard as I could to lead a normal life, looking after my family, but feeling as though my illness was preventing me from achieving my goals. I have always been a pretty determined person but no amount of willpower seemed to change anything substantially.

I vividly remember the week before my 40th birthday, which was six years after first becoming ill, when my husband pushed me round Chadstone Shopping Centre in a wheelchair so that I could buy a new outfit for my party.

I kept praying for something that would help me – so many years of living like this was wearing me out and hope seemed a hard thing to hang on to.

Late last year my husband, who is a pharmacist, was told by another pharmacist about a range of nutritional supplements which she had researched and thought could help me. I was sceptical as I had tried many vitamins and they did not seem to do much. I was also concerned about experiencing a negative reaction, as had happened with other treatments. But I was encouraged by speaking to another CFS/ME sufferer who had been taking the products and had experienced great results.

So I started the products very slowly and I gradually built up so as to minimise any chance of a reaction. I am now taking the full programme and am thrilled to say that the last few months have been absolutely the best I have felt in ten years.

(continued next page)



Goldie Freedman

Phone pals

My name is Debbie. I am 42 years old and a member of the NSW ME/CFS Society. I have had ME/CFS severely since 1989. I have had some improvement but am still severely debilitated and feel isolated at times. I would like to talk to other ladies for mutual support. As I am a Jehovah's Witness, I would especially enjoy talking to others of the same faith.

You can contact me by phone on (02) 6624 6602 or email: debontheweb@dodo.com.au.

Best wishes,

Debbie Skinner.



(continued from previous page)

During these months I have managed much more than I ever could before with more stamina, less fatigue and minimal pain. I have even stopped taking the medication that I was on for eight years.

I don't believe I am cured of my CFS/ME and realise that I still need to be cautious, but I feel that I am improving all the time. I actually feel that the nutritionals are regenerating my body from the inside and are creating well cells to replace my old sick cells.

I am thrilled to say that I have started working again, something that I was unable to do for ten years – in fact if someone had suggested to me a year ago that all this was possible I would not have believed it. I am making new friends, doing new hobbies and regaining my sense of self-confidence. I am enjoying my life so much more and, as you can imagine, my husband and daughter are so excited for me. Friends say they can again see the "old Goldie" they used to know.

So my final message to other people with CFS/ME is simple: please don't give up hope even if you have been sick for a long time, as you never know where the answer may come from.

If I can be of help, I am happy to speak with other CFS/ME sufferers. My details are: (email) goldief@bigpond.com; (phone) 0412 952 227.

Editor's Note:

This forum is simply for the dissemination of information. CFS/ME Victoria does not recommend treatments. Opinions expressed are those of individual members only. Some treatments which are beneficial to one person can cause another to have a major increase in severity of symptoms.

Before embarking on any form of treatment please discuss it with your medical adviser.

CFS/ME Victoria is committed to the principles of privacy as set out in the Privacy Amendment (Private Sector) Act 2001. The Society recognises that people are very protective of their personal details and places strict limits on how such information is collected and handled. The Society has developed a set of Privacy Guidelines which will be made available on request to all persons who interact with CFS/ME Victoria. The Society is committed to ensuring that details of its supporters (being members both financial and non-financial and volunteer helpers) are not released to other parties (except where required to do so by law) without their prior permission.

Reprinted with permission from Emerge Summer 2003.

As good as it gets

By Christine Low

Page 20

Talking Point – December 2003

Sometimes the prospect of recovery seems so far away that the good fortune of others is hard to bear. Nonetheless I still think it's inspiring to know that some people do genuinely get better. For this reason I made a promise to myself that when (on good days) or if (on bad days) I recovered I would tell my story.

I have had CFS/ME for just over ten years. After my doctor's prognosis that I'd be better within one to two years proved false, and two years stretched to five, I gradually gave up thinking of a future without CFS/ME.

Good, better, best

So am I fully recovered now? The short answer is no, but I am better – much better. My improved state of health is reflected by the fact that I am able to make arrangements and keep them, overdo things and recover relatively quickly, enjoy the cinema and theatre and actually contemplate working again.

Rest continues to feature in my daily routine and I still experience times of exhaustion. However, my quality of life has improved so much that this may be 'as good as it gets' for me. Reassurance that people can improve substantially after being ill for several years is helpful but the inevitable question is: 'How?'

Much as there were a variety of factors which contributed to my becoming ill, I think there have been many reasons for my continuing improvement.

Time is a healer

Like many people with CFS/ME, I've tried various alternative therapies. If nothing else, they helped keep me sane by giving me the feeling that I was doing something to help myself and also by providing an impartial professional with time to listen. Time, no doubt, was also involved – the illness had run its course perhaps.

In addition I've grown expert at pacing over the past few years. I've practised remedial yoga and, more recently, have attended meditation classes.

For a couple of years I was on an antidepressant to

help with anxiety (which seemed to get worse the longer I had CFS/ME) but it also had the effect of easing the 'brain fog' which had been one of my most prominent symptoms. I was lucky enough to come off it without major problems and now find my anxiety lessened by meditation alone. I also started setting goals; small ones at first, then more ambitious, but always realistic.

Turning point

Several years of plateau were followed by two during which I noticed some improvement, but the turning point came last year with a remarkable increase in how much I could do. The plateau state for me involved an acceptance of the limitations imposed and a constant attempt to avoid pushing the boundaries too far so I wouldn't relapse again. This period was marked by see-saw feelings of hope and disappointment.

Different kinds of skills are needed now, not the least the ability to recognise the thin line between positive and unrealistic thinking and the continued need to pace myself.

Mostly I'm delighted when I do something I haven't been able to do for years, but occasionally it emphasises how incapacitated I once was and I feel a sense of bitterness for the lost time. I should be grateful that I can walk easily, but I still want to run.

The fact that I've had CFS/ME for so long definitely contributed to a growing sense of failure as the illness progressed. Why couldn't I recover if others had managed to?

I don't know the answer to this, but I got there in the end. So the message of this article is: don't give up hope – however long you've been ill.

Source for this article: InterAction, quarterly members' magazine of UK charity Action for M.E., August 2003. www.afme.org.uk, email: info@afme.org.uk.

Reprinted with permission from Emerge Summer 2003.

Why I volunteer

By Sonya

I have suffered from CFS/ME for nearly six years. When I first became sick I had no idea what was wrong with me and neither did the doctors I consulted.

In suffering all my debilitating symptoms, I quickly realised that whatever was happening to me was pretty serious. I had to leave work and stop driving a car and I very soon became dependent upon others to get things done during the day. Ever since I became sick I have never stopped looking at treatments to help me beat this illness but, like many other people with CFS/ME, it's not an easy illness to arrest or cure – the more I try to cure it, the more baffling it becomes to me.

Needless to say, my sense of self took a huge battering. I felt so hopeless and sick and I'm sure the people closest to me thought it was all made up. 'Attention-seeking' is apparently what I was doing. Half of my problems with CFS/ME were that no-one understood me – no-one could understand why I couldn't just get into a car and drive and when I did try to explain how my symptoms were affecting me I wasn't believed and was told that most of it was in my head. That had huge effects upon my self-worth because I felt so misunderstood and no-one could understand just how 'out of whack' I felt. I reckon only CFS/ME sufferers would truly understand. I didn't know the body was capable of so much dysfunction. CFS/ME can sound so unbelievable because the symptoms can be so bizarre and there are so many of them.

As the months went by I started to feel isolated and totally frustrated. Although I was not as house-bound as I was at the onset of the illness, I was still not capable of committing to any type of paid work because of the unpredictable nature of my symptoms. The thought of volunteering at CFS/ME Victoria came to me and, let me tell you, it was the best thing I could have done.

I walked into the premises of CFS/ME Victoria and I immediately felt accepted and understood. I'm volun-

teering among people who understand CFS/ME because many of the other volunteers suffer from it themselves.

Sometimes all I could do was just sit. I felt that was all I could cope with at the time and I wasn't judged. I was given small tasks to do such as stamping envelopes, photocopying, putting library books away, etc. Just doing those small jobs made me feel I was doing something worthwhile.

Volunteering gives me a sense of purpose and a feeling that I am part of the world again.

I have met a lot of people with CFS/ME and spoken to many others over the phone and it has become

apparent to me that so many people out there are just looking for understanding and somebody to talk to about their illness. I know what it's like to feel alone, frustrated and all the other emotions that come with CFS/ME and it's so fulfilling to be able to be there for others.

Volunteering gives me a sense of purpose and a feeling that I am part of the world again.

Reprinted with permission from Emerge Summer 2003.

VITAMINS

Are you paying too much?

Buy direct and save!

10% discount to all ME/CFS Society Members

Direct Nutritional Supplies Pty Ltd offers a direct mail service for all your vitamin, mineral, herbal and Aloe Vera products. Savings are passed directly to you as there are no middle men to mark up prices.
Remember No Obligation - Just Savings.

For a FREE 48 page Colour Catalogue

Ph: 1800 633 106

(Free Call)

Direct Nutritional Supplies Pty Ltd

Sleep and ME/CFS

By Dr Nicole Phillips

Page 22

Talking Point – December 2003

Basic facts on sleep

Sleep stages

There are two kinds of sleep: non-rapid-eye-movement (NREM) also called orthodox, quiet, slow-wave, or "S-state" sleep; and rapid-eye-movement (REM), also called paradoxical, active, fast sleep or "D-state". Within NREM, there are three stages:

- Stage 1 is a transitional phase between full wakefulness and sleep. Reactivity to outside stimuli is diminished, thoughts drift and short dreams often occur. In this phase, many people subjectively feel that they are awake.
- Stage 2 is the first "real" sleep.
- This is followed by delta sleep (used to be called stages 3 and 4).

REM sleep alternates with NREM sleep at about 90-minute intervals in adults and at about 60-minute intervals in infants. In about 80% of awakenings from REM sleep, people recall dreams Vs 5% of NREM awakenings resulting in full-fledged dream reports (in 60-80% of cases sleepers can recall thought-like fragments).

Sleep cycles

After going to bed most young adults pass through stages of relaxed wakefulness (alpha waves on EEG), into stages 1, and then 2 and into delta sleep within 30-45 minutes. It persists for anything from minutes to an hour then returns to stage 2. About 70-90 minutes after sleep onset, the first REM period occurs. It usually lasts about 5 minutes and is the last intense REM,

physiologically and dream-wise.

In the second cycle, there is usually less delta sleep. The second REM period occurs about 3 hours after falling asleep and lasts about 10 minutes.

For the rest of the night, stage 2 and REM sleeps alternate in 90-minute cycles. Delta sleep lessens and REMs become more intense.



Depth of sleep

Of the NREM stages, delta sleep is deepest and stage 1 is lightest. REM seems to be about as deep as stage 2.

Circadian rhythms

The sleep-wake cycle, body temperature, endocrine secretions and metabolism are all examples of circadian rhythms.

Humans in an underground cave with artificial light but no clock still maintain a circadian rhythm, however, the rhythms usually increase from 24 hours to 24-28 hours.

There are a number of things that synchronise the circadian rhythm e.g. clocks, meal times, work periods, positions of the sun. The most important of these in people with circadian difficulties is a regular wake-up time.

Sleep physiology

Sleep may affect some physiologic variables. Airway reflexes are altered, e.g. noxious stimuli usually do not produce coughing. The more sleep-deprived or sedated people are, the more stimulation required for

(continued next page)

(continued from previous page)

arousal – a risk for some people. Cardiac output falls, some dysrhythmias diminish. Stomach acid secretion diminishes. NREM sleep, especially delta, is characterised by a low steady metabolic rate, with heart rate and blood pressure at their 24 hour minima. Respiratory rate is decreased as is brain temperature and cerebral blood flow.

REM sleep can be divided into tonic and phasic components. Tonic REM is characterised by near paralysis in many muscles. Increases in brain temperature and cerebral blood flow suggest increased brain metabolism. Sweating and shivering stop as thermoregulation is absent. Phasic REM is characterised by instability of regular cardiac systems.

Deprivation of specific sleep stages

REM

When humans are awakened each time they start a REM period, pressure to restore the lost REM builds up. After falling asleep again, the time to REM is reduced and REM becomes more intensive (increased eye movements and more intense dreams). This is called REM rebound. Interestingly, REM deprivation is a very effective antidepressant in people with severe depression.

Delta

There is also a delta rebound in delta deprived people. Compared to REM deprivation where people become more agitated and aggressive, delta deprivation causes people to be physically uncomfortable and withdrawn. The delta depressed may also have symptoms of musculoskeletal tenderness and increased sensitivity to pain – perhaps delta sleep is related to musculoskeletal recovery (highly relevant to CFS/ME patients) and REM sleep is related to psychologic recovery.

Sleep disruption in ME/CFS

Chronic fatigue syndrome patients report more difficulty falling asleep, more interrupted sleep and more daytime napping than healthy or chronically ill comparison subjects; however, polysomnography has yielded variable results. Some studies of chronic fatigue syndrome have revealed a characteristic “alpha intrusion” during non-REM sleep and decrease in stage 4 sleep while other studies have not. Thus, in contrast to findings with major depression, the results of polysomnography in chronic fatigue syndrome have not shown a consistent or diagnostic sleep disturbance. It is interesting to note that sleep disruption

does not appear to correlate with fatigue severity or degree of functional status impairment. Finally, some individuals with the symptoms of chronic fatigue syndrome, who are assessed with polysomnography are discovered to have a sleep disorder such as sleep apnoea. Such conditions are readily treatable and, if they are severe, exclude a diagnosis of chronic fatigue syndrome. Some investigators believe sleep disorders are the

most commonly overlooked medical diagnoses among chronic fatigue syndrome patients, underscoring the importance of distinguishing fatigue from sleepiness.

Other causes of insomnia

Psychiatric disorders

Anxiety disorders can cause early insomnia (difficulty in getting to sleep) associated with rumination over particular worries or concerns. With depression, it is typical to have middle insomnia (waking in the early hours of the morning) and late insomnia (waking earlier in the morning than is usual and being unable to go back to sleep). The depressive pattern may also have an associated anxiety disorder so sleep is disturbed throughout the night. Alcohol abuse often causes wakefulness in the middle of the night.

(continued next page)



(continued from previous page)

Environmental factors

Such things as a bedroom being too hot, too cold, too noisy, a cramped or uncomfortable bed, restless sleeping partner, crying baby are all factors that can cause disrupted sleep.

Physical factors

Other than CFS/ME, many illnesses and pain syndromes may contribute to insomnia. Jet lag and shift work similarly disrupt sleep patterns.

Behavioural factors

Trying too hard to sleep

Trying too hard to sleep can become a bad habit. Stress causes arousal and as a result poor sleep. As stress-induced sleep deprivation increases, the need for sleep becomes a strong preoccupation. A vicious circle then develops – the more one needs and tries to sleep, the more one increases arousal and the less one sleeps. People like this often fall asleep when not trying, e.g. whilst watching television.

Conditioned wakefulness

After a period of stress-insomnia, the bedroom may become associated with frustration and trigger arousal. These people often sleep better away from home.

Disruption of the sleep-wake rhythm

People who sleep poorly because of stress often fall asleep toward morning then oversleep. They also often take daytime naps “to catch up”. This may then cause desynchronisation of the circadian rhythm.

Fear of insomnia

In people who have labelled themselves “insomniacs”, the fear of insomnia becomes a self-fulfilling prophecy.

It is important to note that behavioural factors can be caused by any of the other factors and, in CFS/ME patients, must be considered as maintaining factors in insomnia.

Treatment of sleep problems

Evaluation

It is important if you have a sleep disorder to fill out a “sleep log” in order for your sleep to be evaluated by your doctor. Your log should be a diary over 24 hours and should include:

- habits and patterns of getting ready for bed
- time of going to bed
- time of going to sleep
- time(s) of waking(s)
- time(s) to get back to sleep
- what you do while awake
- features that help settling
- features that add to disturbances
- daytime sleeping, times, duration



A night in a sleep laboratory may be valuable. This monitors physiological factors such as sleep EEG, numbers of arousals, body temperature, breathing and can exclude primary sleep disorders.

Exclude treatable causes

Often in CFS/ME patients, other causes must be excluded. As mentioned alcohol or caffeine excess, pain, other medical conditions, primary sleep disorders and medications are all important factors.

(continued next page)

(continued from previous page)

Sleep hygiene

This includes a number of social and behavioural interventions to improve sleep. Cognitive behaviour therapy is an excellent treatment for the behavioural insomniacs.

1. Develop a regular pattern of going to bed at about the same time each night and getting up at about the same time each morning. The latter is the most important for regulating the circadian rhythm. On waking, let natural light fall onto your eyes. Get natural light throughout the day. Lying in a darkened bedroom all day is a disaster for regulating sleep.
2. The bedroom should be comfortable and quiet, not the focus of arguments, anger or disasters. Use earplugs if necessary. Put in black-out curtains or a shutter. Do not get overheated. Never use anything heavier than two light blankets or a summer doona.
3. Turn your bedside clock away from you. Clock watching causes anxiety.
4. Do not watch television or do other brain-arousing activities just before sleep.
5. Caffeine and alcohol should be avoided several hours before bed.
6. If not sleepy, either relax in bed and not think about sleep or get up and stay in a dimly lit room doing something boring.
7. Avoid long daytime sleeps. If a nap is necessary, restrict to 20 minutes or less. Many CFS/ME patients find this very difficult.
8. Never stay in bed if awake and feeling frustrated. Leave the bed for a while.
9. Biofeedback and relaxation techniques are helpful.
10. CFS/ME patients who are well enough should do some exercise, as tolerated, daily. This should preferably be done prior to late afternoon.



Natural and complementary treatments

Valerian, skullcap, and camomile are herbal preparations that are calming and sedative. Melatonin may be helpful, particularly in phase shifts. Acupuncture may also be helpful.

Medications

Antidepressants

SSRIs and venlafaxine, in many, reduce actual sleep time and efficiency and may increase awakenings.

Nefazadone, mirtazapine and the tricyclic group of antidepressants can increase the depth of sleep and may be helpful in insomnia, particularly when depression is a problem.

Benzodiazepines

These drugs all have similar actions including sedative, hypnotic, anxiolytic, anticonvulsant, muscle relaxing and amnesiac effects. They include diazepam (valium), lorazepam (ativan), oxazepam (serepax), alprazolam (xanax), temazepam (normison, euhypnos), nitrazepam (mogadon), flunitrazepam (hypnodorm).

These drugs are useful in the short-term only or for occasional use as they have a number of problems associated with them, including habituation (needing more for the same effect). When ceased suddenly after prolonged use they have a withdrawal syndrome including insomnia. I recommend ½ - 1 clonazepam (rivotril) to use from time to time as a "catch-up" – this tends to be effective with minimal hangover.

Newer agents

These include zaleplon, zopiclone, and zolpidem. These are not necessarily safer than benzodiazepines.

Reprinted with permission from Emerge, Summer 2003, and prepared by its medical editor, Dr Nicole Phillips.

CFS and decreased red cell volume – a new treatment trial

Excerpt from an interview with Dr Barry Hurwitz, Professor of Psychology and Biomedical Engineering, University of Miami, Miami, Florida

Page 26

Talking Point – December 2003

Give an overview of your study in laymen's terms.

Dr Hurwitz: We discovered that people who have chronic fatigue syndrome have a decreased volume of red blood cells. As a consequence, we are attempting to examine whether the drug Procrit will increase the number of red blood cells that these individuals have and improve their fatigue symptoms.

So, we are enrolling about 150 men and women who have chronic fatigue, who have been diagnosed with this persistent fatigue that is severe and relapsing and is greater than six months of duration. Then, when they are enrolled in the study, they are assigned to the treatment conditions in which they receive the Procrit drug or they are assigned to the control condition where they receive a substance that is not the drug but is called the placebo.

Explain how you think Procrit should work.

Dr Hurwitz: Procrit is a drug that was created to emulate a normal hormone that is released from the kidney. This hormone acts on the bone marrow and affects the bone marrow to produce red blood cells. People who have chemotherapy due to their cancer or individuals who are on hemodialysis because of their kidney failure have tendencies to have decreased volumes of red blood cells. So this drug was created to treat these individuals. Now, what we have found is that individuals who have chronic fatigue syndrome typically have an inability to sustain an upright posture. They feel faint under physical challenge or even mental challenge, and of course, their fatigue, as a

consequence of this energetic expenditure, lasts for days and days.

But, oftentimes they find that they become faint during these activities and it was thought that perhaps there was a blood regulation problem – an inability to provide enough blood flow to the brain. So in investigating this, we looked at their red blood cell volume and discovered that about 80 percent of the women who have chronic fatigue syndrome and about 60 percent of the men have decreased volumes of red

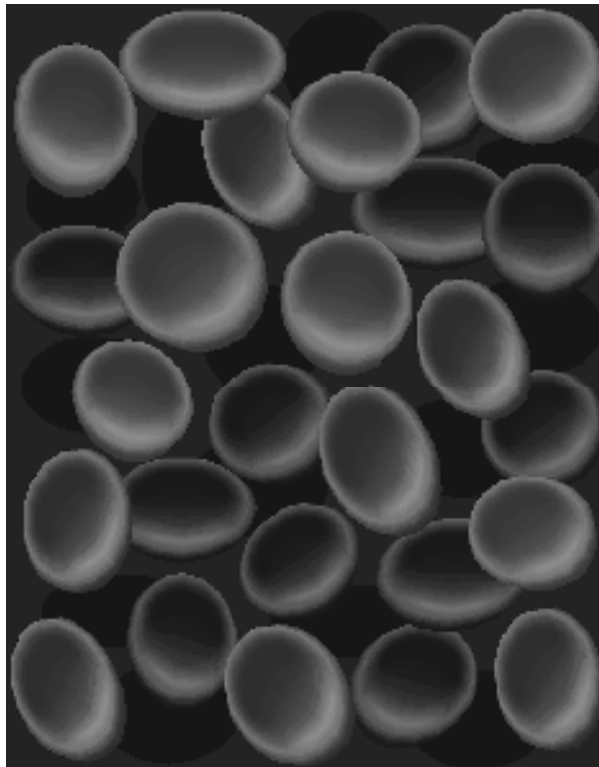
blood cells. And, so consequently, we thought this drug, Procrit, would help these individuals. Because the red blood cell transports oxygen and glucose to the cells, it is vitally important in providing the nutrients. Without it, we feel fatigued, and so consequently, and very simply, we felt that if we treated this condition, perhaps we could decrease the fatigue and remedy the problem, and least in part.

Is Procrit working? What have you found?

Dr Hurwitz: It's too early to tell right now. We are

still in the middle of the study. Some people have shown remarkable improvement and have gone back to work and in others it's been less effective. But, in all cases, we have been able to increase the red blood cell volume so the drug is effective. What it is enabling us to do by understanding whom it works for and whom it doesn't work for, we are able to understand more about the underlying causes of the disease. We are not only doing this treatment, but we are giving a comprehensive cardiovascular work-up so we

(continued next page)



Publication of important new vascular research

From Dr Vance Spence et al

Following on from research which has already identified abnormalities in the cerebral circulation (= blood flow to the brain) and low blood pressure in the peripheral circulation which can manifest itself as orthostatic intolerance (= symptoms worse on standing), Dr Vance Spence and colleagues at the University of Dundee have been examining whether these findings could be caused by changes involving a chemical transmitter called acetylcholine (ACh) that controls the size of blood vessels – a process known as cholinergic transmission.

Vance and his colleagues have already published findings, which demonstrate an enhanced level of blood vessel dilation in the skin when ACh is applied to the skin in people with ME/CFS. They have now taken this one step further by studying the time course of ACh induced vasodilatation in 30 patients with CFS and 30 matched controls. No differences in peak blood flow were found between the patient and the controls but the time taken for the ACh response to return to normal was significantly longer in the CFS group.

This prolongation of the ACh induced response suggests that there may be a problem within the endothelium (part of the lining membrane in the blood vessel



wall) in CFS. And it may also help to explain some of the vascular symptoms – such as low blood pressure, feeling faint, orthostatic intolerance – which are seen in many people with ME/CFS.

The patients were recruited from a local ME/CFS support group and all met Fukuda *et al* research criteria for CFS.

Source: "Prolonged acetylcholine-induced vasodilatation in the peripheral microcirculation of patients with CFS". Clinical Physiological Functional Imaging, 2003, 23:282-285.

Reprinted with permission from Emerge, Summer 2003, and prepared by its medical editor, Dr Nicole Phillips.

(continued from previous page)

can assess the functioning of the heart in relation to its ability to perform under different circumstances, as well as looking at whether the immune system is involved because, for many people, the immune system appears to be abnormal. It appears to be activated and as if the individuals were fighting some infection, but no infection has been found to be the cause of chronic fatigue syndrome. So, it turns out there is an immune system hormone or substance that is released that actually causes the red blood cell volume to be depressed. That is, it stops the bone marrow from producing red blood cells. So, we are looking at this link.

Are there any negative side effects from Procrit?

Dr Hurwitz: No. There have been no adverse events related to the Procrit administration, and this is a drug that has to be very carefully administered and monitored by the physician.

This article was reported by Ivanhoe.com.

If you would like more information, please contact:
Alex Gonzalez
University of Miami
Behavioural Medicine Research Centre
1201 NW 16th Street
Miami, FL 33125
(305) 575-7154.

Reprinted with permission from Emerge, Summer 2003, and prepared by its medical editor, Dr Nicole Phillips.

Exercise

Excerpt from Living with M.E. by Dr Charles Shepherd

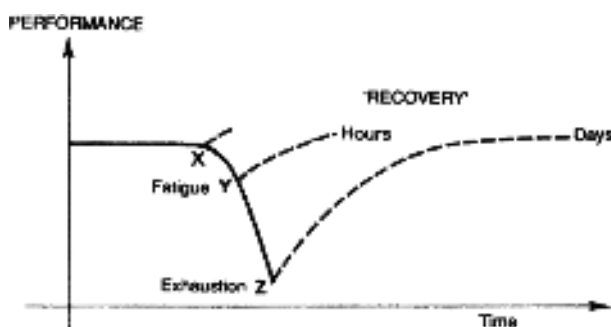
One of the most difficult aspects of coming to terms with a new lifestyle is striking the right balance between taking an adequate amount of rest on the one hand, and what might be described as 'beneficial exercise' on the other.

All too often one hears about M.E. patients – and here I include myself – who, in the earliest stages of the illness, before any diagnosis has been made, have tried to get better by overdoing exercise and not taking sufficient rest.

First, how much exercise should you be taking and in what form? Like everything else, exercise tolerance in M.E. varies considerably from patient to patient, but each individual soon learns to recognise his or her own limitations – be it walking, gardening or any other physical activity. The cardinal rule when taking part in any sort of activity is to avoid pushing yourself to the point of fatigue and never to the point of exhaustion. In practice this is probably best explained by using a diagram (above).

You know already from your own experiences that after starting to go for a walk you can carry on at a fairly steady pace till you reach X – when the muscles start to tire. For some people this may only be 100 yards, but for others it may be half a mile or so. If you then decide to push beyond point X the fatigue becomes steadily worse, till you reach a point Y, where it's becoming difficult to go much further. If you still

decide to carry on beyond Y there is a rapid deterioration, and you're very quickly exhausted and weak at the knees, forcing complete cessation of activity – Z.



The aim in all physical activity must therefore be to learn how much you can usefully achieve before reaching the point of fatigue and exhaustion, and keep within those limits at all times. If you stop your physical activity at or before the point of fatigue

your recovery period back to normal strength should be fairly short – minutes or hours. Going to the point of exhaustion may mean that it takes days before you feel relatively normal again, and the muscle strength has returned.

Reprinted with permission from Emerge Summer 2003.

REST

Essential for recovery but if prolonged can be harmful.

ACTIVITY

Beneficial, provided you keep within your own limitations – excess will produce a relapse.



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.



Talking Point – December 2003

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

Please go along to tertius.net.au/foothold/questionnaire whenever you next can. Any questions please send to rb@tertius.net.au and I will answer as soon as possible. Oh, and you don't have to have a doctor's diagnosis to participate! You just have to fit the criteria for CFS, which are available at the website for you to check.



Ricky Buchanan

To find out what is different about people with very severe CFS, I need to study ALL of the CFS/ME community though. So even if your CFS is mild, please help us by completing this questionnaire anyway!

Another thing that's special about this questionnaire is I plan to publish the raw data (with no names, of course – your data will be completely anonymous) in a form that other researchers can easily import into a databases or spreadsheet and use.

I know that these questionnaires take precious energy to complete, so this one is divided into six small sections. You can complete them on different days, just whenever you have a little energy. And please, if you are not well enough to fill out the questionnaire yourself, get somebody close to you to help you. Also, the questionnaire will be available to complete until February 28, 2004.

Please be a part of this important research! Wander along to tertius.net.au/foothold/questionnaire and fill in the sections as slowly or fast as you are able to.

Ricky Buchanan



Support Groups: Metro

Adelaide Support Group

Venue: ME/CFS Society Office, Room 510, 5th Floor, Epworth Building, 33 Pirie Street, Adelaide.

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

Contact: Bill Daniels or Darryl Turner.

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

Dates: 2003: December 23.

2004: January 27; February 24; March 23;
April 27; May 25; June 22; July 27;
August 24; September 28; October 26;
November 23; December 28.

Glenelg Support Group

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

Time: 1:00 pm.

Contact: Marion Hansen.

Phone: Ring Marion on (08) 8234 2342.

Dates: 2003: December 17

2004: January 21; February 18; March 17;
April 21; May 19; June 16; July 21;
August 18; September 15; October 20;
November 17; December 15.

Support Groups: Country

Auburn Support Group

First Thursday of each month.

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

Time: 1 pm.

Phone: Kay on 8849 2143.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: Jane on 8826 2097.

Southern Fleurieu Support Group

Second Thursday alternate months.

April, June, August, December.

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

Murray Bridge Group

The Murray Bridge group is not meeting at present.

Please ring to register your interest.

Phone: Fran McFaul (Dietician) 8535 6800.

**Please note that meeting times are subject to change.
If you are attending a meeting for the first time
please call the contact or the Information and Support
Line for confirmation of meeting days and times:
8410 8930 or 1800 136 626**

Support Contacts

SA Support Groups

Adelaide City	Office	8410 8929
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
Nthn. Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

SAYME	Liz	8278 2093
SAYME Parents	Marg	8276 5353

Country Support Contacts

Barossa Valley	Dennis	8563 2976
Murray Bridge	Fran	8535 6800
Central Yorke Peninsula	Caroline	88374335
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Nthn. Yorke Peninsula	Jane	8826 2097
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yunta	Gloria	8650 5938

Youth Support: SAYME

South Australian Youth with ME/CFS

General enquiries:

- Skye on 8339 1614; or
- Liz on 8278 2093.

SAYME has two support groups. **The Rice Cracker and Spring Water Extravaganzas** (RCSWE) are aimed at school-aged sufferers as a fun way of meeting new people in a friendly environment. Parents are invited too. These meetings are held in members' houses on the last Friday of each month. These meetings are actually two 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. Contact: Sarah on 8296 9051.

The **20s-30s meeting** is for CFS sufferers over school age. These meetings are less structured than the RCSWEs and involve various activities such as meeting for a meal, drink, movie or gentle walk. Group contacts: Kristen on 8297 1274; Emma on 8381 1417.

Information about ME/CFS

What is ME/CFS?

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

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

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

How is ME/CFS diagnosed?

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

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

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

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

How is ME/CFS treated?

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

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

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

Do persons with ME/CFS get better?

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

Prevalence

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

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

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

RACP, Chronic Fatigue Syndrome Clinical Practise Guidelines 2002. Published in the Medical Journal of Australia May 6, 2002, page S28. See online: www.mja.com.au/public/guides/cfs/cfs2.html.

Copyright © 2003 ME/CFS SOCIETY (SA) Inc. Copies of articles copyrighted to the ME/CFS Society (SA) Inc. may be used by similar non-profit organizations if accompanied by clear acknowledgment of each item and the inclusion of the ME/CFS Society (SA) Inc.'s postal address PO Box 383, Adelaide South Australia 5001 and website address www.sads.asn.au.

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

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

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

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

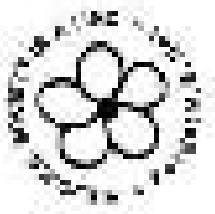
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.

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

Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanhope le Hope, Essex SS17 OHA, UK.

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

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



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

Print Post Approved:
PP 532154/00023

**SURFACE
MAIL**

**POSTAGE
PAID
AUSTRALIA**