Talking Pump

2005 Issue 1 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

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www.sacfs.asn.au

ME/CFS Society (SA) Inc.

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

- promote recognition and understanding of the disease among the medical profession and the wider community
- provide information and support for people with ME/CFS and their families

Patron

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

Medical Advisor

Dr Peter 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:
April 1, 2005

Talking Point

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Talking Point Subscriptions:

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

Management Committee 2004/2005

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

President: Peter Cahalan
Vice-President: (vacant)
Secretary: Peter Mitchell
Treasurer: Geoff Wilson
Management Committee Members:
Donna Briese, Adrian Hill, Emma Wing, Margaret Wing

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:
Wednesdays and Thursdays 10am to 3pm (subject to volunteer availability).
Our email address is: sacfs@sacfs.asn.au
Our Web site address is: www.sacfs.asn.au

Donations

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

CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

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.

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*By **Peter Cahalan***

Welcome to the new year of activities for our Society. Let's hope it's a good one for us all – as a group and as individuals working to create full and rich lives for ourselves despite (and because of) CFS.

Our efforts to improve communications with you

There's no need for me to repeat at length what I've said before. We're doing all we can to keep in touch with each member. There are five main ways:

The Internet. Over 100 of our members get our regular e-bulletins. What's great – and a bit scarey! – is that increasingly some of them are getting back to us with comments, ideas or questions which they'd like us to find the answer to. We're trying.

- **The telephone**. Lynda Brett has been on the phone each of the last few Wednesdays contacting members who don't have email connections. She reports that it's immensely satisfying and enjoyable work.

- **SMS messages**. Yep. We're about to learn something from those youngies with the thumbs that move like lightning across their tiny mobile keyboards. Michael Ritter of our office team has now set us up to start SMSing members with mobile phones. As I write he's developed a list of 64 and Lynda has a few more for us. We need 100 on the list to gain the best value for it but are more than happy with our starting point. By the time you get this those of you on the list should have had one message – about our March 12 meeting. If you didn't get one, phone the office on 8410 8929 and leave your mobile number.

- **The website**. I've been mildly astonished at how the international network of CFS societies has discovered our site over the past few months. We're now given star rating on a number of sites. It's great. It also means a bit more work as emails come in from around the world about projects which people think our members might be interested in. Success generates work! But it's satisfying and a credit to Peter Scott and all concerned for lifting it to the heights.

- ***Talking Point***. I think you'll see an increasing amount of South Australian content in TP over the next year. One outcome of our improved communications is that members are coming out of the woodwork with offers of articles.

PS: Should I add snail-mail to the list? From time to time we'll send you a notice of something. But we seem to be following the global trend to using ordinary mail less.

Anyway, I hope that we can sustain the flow of contacts and that you gain something from it.

Projects for the year

As I write your committee – Peter, Marg, Adrian, Geoff, Donna, Emma, and I – are trying to work out how best to advance a number of projects on the books. I'll list them briefly here. More about them as the year progresses.

- **The research database project**. I'm delighted to announce that the Alison Hunter Memorial Foundation has just sent a cheque for almost $33,000 to the University of Adelaide School of General Practice. This will fund the pilot stage of a database recording the experience of people coping with CFS in this State. I've told you about this before and it's a bit early to explain it again as it will undoubtedly evolve.

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- **Schools resource kit**. Peter Mitchell has been joined by Sue Heard to work on developing a resource manual for schools regarding appropriate support for students with CFS. He will also be using other members and his education contacts including the Open Access College to make this "manual" a good resource for young people with CFS and their parents.

- **Allied Health Initiative**. The committee has to find a way of getting this project – aimed at getting CFS sufferers more ready access to Care Plans put together by GPs – up to speed. Lorenzo Pizza prepared a report for us late in 2004 and we are spending time at several meetings trying to sort it out. Our good friend and advocate Dr Peter Del Fante – keeps prodding us about it. He regards it as having real potential to improve the delivery of physio and other services to CFS people. But it's not one of those simple little projects.

- **Running more seminars**. Several years ago we got to a point of running only two meetings a year. We improved that slightly last year and this year we aim to do better again. We want to get one or more members to take this one on by drawing up a list of speakers and topics for us. We'll certainly have a meeting around September with one or two of the politicians who sat on the inquiry into Multiple Chemical Sensitivity speaking to us about their report. (It's expected to go before State Parliament in August.) And there'll be at least one seminar with some of the State's best medical experts updating us on where research and treatment trends are heading.

- **Forging closer links with the medicos**. Let's see if we can get a few people onto the task of getting our excellent network of medical experts and researchers together to discuss their common agendas.

SAYME

SAYME, our young persons' group, is simply one of our most important enterprises. SAYME leaders and representatives of your committee had an excellent meeting in January to plan the year and to look at how the Society can better support SAYME's activities. Sarah White and Emma Wing are sharing the leadership of the group and have already got out one copy of the newsletter and held a very successful gathering with the biggest rollup in several years to a SAYME meeting.

International Awareness Day

Seminar on May 11

Keep free the evening of Wednesday May 11 for our annual seminar. This year the keynote speaker will, we anticipate, be Christine Hunter. Christine runs the Alison Hunter Memorial Foundation. She has done an outstanding job fighting for more resources for research into CFS in Australia. She's a passionate advocate and I'm looking forward to hearing her speak, having only ever chatted to her over the phone and internet. We'll put out a flyer about this nearer to the event. The venue will be the Burnside Civic Centre at the corner of Portrush and Greenhill Roads.

Memberships

We're running at just under 300 members. We'd like it to be more. Do encourage anyone you know who's not yet supporting our work to join up.

As you can see, we have a reasonably busy agenda mapped out already. As the year progresses, it's a dead cert that more things will come our way. They'll certainly include one or two advocacy issues. When they emerge, we'll let you know and will encourage you to make sure that the decision-makers hear our voices.

Peace, good health and a rich inner life are my wishes to you all. I send them on behalf of the committee and the other volunteers who maintain the collective presence of people with CFS within our State.

Peter Cahalan
President

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Notes from the Annual General Meeting

The Society's AGM was held at DIRC in Adelaide on November 13, 2004. There was a pleasing attendance of 40 people. Notes from the meeting are printed below.

Treasurer's Report

Geoff Wilson presented the Treasurer's report, and presentation of audited Financial Statements. In summary, the Society had had a reasonable year financially, bolstered by an anonymous donation of $12,000 (the 3rd year in a row that this donor had made such a donation). There had been an increase in funds of just over $2000 for the year.

Election of Management Committee

The ongoing members of the Committee are Peter Cahalan, Geoff Wilson, Margaret Wing, and Adrian Hill. Those newly elected were: Emma Wing, Donna Briese, and Peter Mitchell.

Election of Office Bearers

The following were elected unopposed:

- Peter Cahalan as President
- Geoff Wilson as Treasurer
- Peter Mitchell as Secretary

Volunteers

The President called for volunteers to put their names down on a list with task preferences. A pleasing number of those present did so. A question was asked from the floor regarding the possibility of volunteers telephoning members from home. This was taken on board for the Management Committee to discuss.

News

The Disability Information Resource Centre (DIRC)

We'd like to draw your attention to the fact that DIRC houses the Society's reference collection of material on ME/CFS. Carolyn Gerhardy, DIRC's Library and Information Officer have written to us as below: saying that DIRC would be delighted to see more people using this part of its library. DIRC is at 195 Gilles St and you can find details of opening hours etc at www.dircsa.org.au.

Badge Day – call for volunteers

To generate funds for the society Badge Day draws close. This is a call for volunteers. An extensive program this year requires people that either can collect, be the collector at their school or are able to pass a can around the office. If you can help, or know someone who can, then call Badge Day organizer, Adrian Hill, on (08) 8376 7991.

A new online survey on CFS

We have been asked to encourage members to contribute to the survey. It's collecting data on the perceived effectiveness of each of a wide variety of treatments for CFS/ME/FM and is located at the non-profit website www.scientific-consultants.com/cfs-q2te.html. We encourage you to participate.

The Guidelines go Canuck

Our Guidelines for GPs continue to draw international attention. FM-CFS Canada, one of Canada's two national associations for the condition, has not only put it up near the top of its "Best 100 Educational Resources" segment, but also written to the South Australia co-authors asking us if we'd mind that it has re-edited it as a set of guidelines on Fibromyalgia. The Canadians thought that our format as well as our content was fantastic. Will Port Power supporters allow us to say at this point: "Go the Crows!"?

"Moving Towards Wellness 2005" course

For each course you attend 2½ hours one day a week for six weeks.

ARTHRITIS FOUNDATION
Unit 1, 202 Glen Osmond Road, Fullarton
Day Courses
March 10 to April 14 (Thursdays) – 1:00 to 3:30pm
May 25 to June 29 (Wednesdays) – 1:00 to 3:30pm
August 16 to September 20 (Tuesdays) – 1:00 to 3:30pm
October 27 to December 1 (Thursdays) – 1:00 to 3:30pm
Evening Courses
March 8 to April 19 (Tuesdays) – 7:00 to 9:30pm
October 25 to November 29 (Tuesdays) – 7:00 to 9:30pm

CAMPBELLTOWN – NORTH-EASTERN COMMUNITY HOSPITAL
Lower North East Road, Campbelltown (in the Board Room near the Kiosk)
March 7 to April 16 (Mondays) – 1:00 to 3:30pm
(There will be no session on Easter Monday – March 28)

ELIZABETH – RESTHAVEN NORTHERN THERAPY SERVICES
Gillingham Road, Elizabeth
Phone Rosalind at Resthaven on 8252 6811
March 23 to April 27 (Wednesdays) – 10:00am to 12:30pm
May 25 to June 29 (Wednesdays) – 10:00am to 12:30pm

GAWLER HEALTH SERVICE/COMMUNITY SERVICES DAY CENTRE
February 22 to March 20 (Tuesdays) – 10:00am to 12:30pm

GLANDORE COMMUNITY CENTRE
25 Naldera Street, Glandore
March 3 to April 7 (Thursdays) – 10:00am to 12:30pm

MARION – MARION R.S.L.
31-39 Norfolk Road, Marion
March 2 to April 6 (Wednesdays) – 10:00am to 12:30pm
August 2 to September 6 (Tuesdays) – 1:00 to 3:30pm

MODBURY – ADELAIDE NORTH-EASTERN DIVISION OF GP's
Education Centre, Modbury Public Hospital, Smart Road.
March 8 to April 12 (Tuesdays) – 1:00 to 3:30pm
May 24 to June 28 (Tuesdays) – 1:00 to 3:30pm
August 9 to September 14 (Tuesdays) – 1:00 to 3:30pm

PROSPECT UNITING CHURCH LIFE CENTRE
5 Clifton Street, Blair Athol
March 2 to April 6 (Wednesdays) – 10:00am to 12:30pm

WALLAROO
Northern Y.P. Community Health Service (Old Hospital Building)
March 8 to April 12 (Tuesdays) – 10:00am to 12:30pm
For this course you can ring our toll-free number 1800 011 041 and ask to speak to either Vivienne or Jenny, or ring Francis on 8825 2246

Dates for the locations listed below and others still need to be confirmed

ASTHMA SA
300 South Road, Hilton

ADELAIDE CITY
Mutual Community Building – Gawler Place Level 2

WOODVILLE – QUEEN ELIZABETH HOSPITAL

ONKAPARINGA/MITCHAM
Ring Cathie Powell on 8358 6086

GOOLWA
Alexandrina Centre for Positive Ageing, Goolwa
Ring Heather on 8555 2134

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Other areas where courses are offered

WHYALLA AND PORT LINCOLN
Ring the Resource Centre on 8649 2983

MT. GAMBIER
Ring Jenny Cox on 8721 1460

NOARLUNGA HEALTH SERVICES
Ring 8384 9233

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Course fees

Member Participant:	$31.00
Non-member Participant:	$38.50
Member Pensioner:	$22.00
Non-member Pensioner:	$27.50
Accompanying person:	$5.00

Mutual Community members phone Bennett on 8423 0902 or Vivienne on 8423 0916. You may be eligible to have your costs covered, but only in any of the above courses.

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More information

For more information on the courses listed above you can:

- Phone Vivienne Tomlinson on 8423 0916 or Jenny Bennett on 8423 0902
- Phone 1800 011 041
- Visit www.arthritis.org.au

The invisible burden

*By **Jackie Mulrooney**.*

I came down with CFIDS (CFS/ME) in September 1984, but I wasn't diagnosed until eight years later. My history and symptoms read like a textbook case. In one day I went from a healthy, tennis-playing 25-year-old to a handicapped person with the energy of an 84-year-old.

The first six weeks were the hardest. I was unable to climb even one flight of stairs to go up to the kitchen to eat. I was in bed and completely unable to run the computer software consulting firm I had just started.

CFIDS destroyed my ability to function properly and work a full-time job. At the time I became ill my big client was a Department of Defence contractor. The paranoia of the Cold War was running rampant. With my cognitive abilities severely impaired, I made an innocent mistake at work. To make a long story short they thought I was some kind of a spy. Even though I was one of the best consultants they had they fired me just before Christmas. I don't know which was worse: being incurably sick, losing the job or being suspected of not being a loyal American.

The years rolled by, punctuated with frustrated hopes and abandoned dreams. This unknown disease was like a quicksand that pulled me down whenever I struggled against it. I was the kind of person who got a sense of self-worth from what I accomplished. In my mind, the lack of accomplishments equalled a lack of self-worth.

Unable to work full time, I searched for meaningful ways to use what little energy I had. I decided to go to school one day a week. I hoped that, if I had two days to recover for every day I spent out of the house, I could maintain an even energy level instead of losing ground. I managed two days a week out of the house, one day for school and another day for getting groceries and prescriptions and doing other errands.

It was then that "my life on the balance beam" started in dead earnest. I learned a very important principle: only do what is most important. I tried to protect my energy level and my time. Not being able to sleep at night and falling prey to bronchitis, colds and other infections was a recurring fight. The fevers, swollen glands, sore throats, joint pain and other CFIDS problems were constant companions.

It took four years to finish the school program, but it was time well spent. Then in 1987 I got married. For our honeymoon we went to Epcot Centre and I remember lying exhausted on a park bench and being completely miserable. My husband, who knew I was sick, couldn't understand why I couldn't just get up after thirty minutes of rest. The park required way too much walking and I wasn't pacing myself or planning my activities around my energy level.

Boredom became my biggest enemy and I was constantly tempted to do more than I should to keep it at bay. If I did too much I ended up in bed for three days in a row. My limitations seemed to change from week to week, making it very difficult to know what I could manage. I had to learn patience. I simply couldn't do what I wanted to do, even after reducing my expectations again and again. I went backwards much faster than I could make progress by resting. I realised I had a certain amount of gas in my tank. I could use it up quickly or slowly. The burning questions were: "How much gas is left?" and "How can I get more gas in the tank?"

I then started studying my energy levels. I discovered that on the days I needed a two-hour afternoon nap, I was quite sick and could only be out of bed and functioning normally for about two hours. When I required a one-hour nap it was an indication that I had an average energy level day, so I could manage three or four hours of normal functioning. On days when I needed only a 45-minute nap, I discovered I could handle a glorious four to five hours out of bed.

Eventually I found I could gauge when to quit and rest. This led to being able to slowly gain ground. So principle number two was forged: stop everything and rest before you lose ground.

After seven years of fighting a mysterious illness, I finally accepted the fact that I was sick. I stopped looking for a quick cure. Acceptance brought some relief, psychologically at least. I learned not to take every up and down so seriously. I was out of the worst of the mental quicksand of angst and guilt so many of us experience.

But CFIDS is always presenting new challenges mentally

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and physically. Although the mental quicksand diminished, the mental fog did not. Words didn't come easily any more. That was a shock because I had always been a brilliant student with an unusual ability in languages. I was no longer just fighting infections, but a mental fog as well.

The first sign of the speech problems came when I asked my husband to hand me a utensil in the kitchen. I said, "Hand me the hole with the spoons in it", instead of "Hand me the spoon with the holes in it."

Sometimes I use similar sounding words incorrectly. The one I substitute always has the same first letter as the one I was trying to say. I think my brain's speech generation ability and word search memory pathways are damaged. The words are wrong in my brain before they are ever spoken.

I finally had the courage to take a full-time job in 1990 because I was feeling stronger. Two months later I was exhausted and had contracted pneumonia from the added pressure of working full-time and commuting. Luckily they let me stay on part-time. I took Wednesdays off and worked twenty hours a week.

After working part-time for about a year, I went steadily downhill. I had to quit even part-time work so I could get my stamina back. A sabbatical was a must.

I was not diagnosed with CFIDS until 1992. One day I heard an ad on the radio for a seminar on chronic fatigue and its various causes. I went to see the doctor conducting the seminar and finally had my answer: fibromyalgia and CFIDS. He gave me something to correct my sleeping problem. Suddenly, I was sleeping at night! I finally had a handicapped parking pass! I knew what was wrong with me. Hooray! My life had turned a corner.

The next eight years were full of hard-fought rehabilitation. The hardest thing to do was to make myself exercise. In 1993 I adopted an adult dog named Darien who, like me, was handicapped. Slowly he and I rehabilitated together. The first goal was to walk to my mailbox. It was only fifty yards away, but looked like a mile. But we did it and I started to believe I could do more. By doing a tiny bit of exercise twice a day we were able to walk around our small block. Months later we walked around the large block.

I wondered what goal I should set next. I wanted to be able to run. I had even stopped running in my dreams because my subconscious had finally accepted the fact that I could no longer run. I set a goal to jog around the big block. This goal was a lot harder than the rest. Progress was anything but slow and steady. Some days I couldn't even walk around the block, much less run part of the distance. I almost gave up believing I could do it.

At this point Darien had put on muscle and was getting stronger, so my 95 pound German shepherd did most of the work by pulling me around the block. The neighbours laughed and said he was taking me for a walk and not the other way around. Still, I kept it up, sometimes twice a day, for fifteen minutes. He kept pulling me along until I could do it for myself.

Finally the day came when he and I jogged the whole way around the large block. I felt like I was crossing the finish line at the Olympics when I got home. But there was no cheering crowd. No-one understood what I had accomplished. I hugged Darien and cried. I finally had more gas in my tank, but it had come very slowly. And so principle three was proven: you can improve!

We people with CFIDS live in a twilight world where joy is a hard-won commodity. We not only suffer from this unrelenting quicksand of a disease but from the ignorance of the people around us. Even our friends, families and co-workers and churches don't understand us. That is perhaps the biggest hurt of all. A doctor who specialises in CFIDS told me this disease is more stressful than cancer. Cancer patients get attention and sympathy. Instead, I get stared at or chewed out for parking in a handicapped space, even though I had a permit. It took me twenty years to reply calmly to these busybodies.

Despite everything, progress is possible. Do you want to be one hundred percent better? My advice, gained through personal experience, is to learn how to do a hundred things one percent better. Eat one percent better. Take vitamins one percent more consistently. Sleep one percent better. Assess your energy levels one percent better. Believe you can improve just one percent more. Stop feeling sorry for yourself one percent less. There is no miracle cure for CFIDS yet. So for now we must rely on one percent improvements. In time they add up.

(This article reprinted from CFIDS Chronicle, Fall 2004.)

Reprinted with permission from Emerge *Autumn 2005.*

Venturing out

*By **Michelle Grant***

When my husband Ashley came home from work just after the New Year and said "We're off to Vanuatu for your 30th birthday," I literally froze for a split second.

Not for the fact I was entering the flirty thirty years but for the sheer thought of lugging my body to an unknown environment.

Of course the trip sounded like paradise – six nights at Le Lagon Resort in Port Vila, with beautiful views and not to mention the warm water. Ash had always wanted to go back to Vanuatu and I was excited as this would have been my first time. However, as often was the case, that annoying thought flashed across my mind like a radar warning… "but how will your body cope?"

Travelling to the unknown terrified me because, over the last two and a half years of having CFS/ME, I have lived a safe life, only venturing out to my comfortable social limits (which were quite limited). Living in a remote part of the state didn't give me much confidence - it only made the task at hand feel more out of reach.

I only ever gave myself small challenges when planning trips, as when accomplished they became big personal victories. The town I live in is small with a population of only 900 people and it is almost five hours drive to Melbourne. This alone had always been my biggest challenge when travelling. A CFS/ME body cooped up in a car for this length of time was a walking time bomb for a relapse. However, over the years I had learnt to read my body and compromise on how to get the best out of it. Mind you I have had some failures along the way!

I started to analyse where I was with my health. I had gone from extreme to moderate to mild and back again with CFS/ME over the years. But at the moment I felt mild (able to do about five hours of light activity per day with rest in between). For some reason my health was so much better in warm weather. I hated winter as my body ached and I felt crippled and I hardly left the house (extreme to moderate).

I don't know why this was the case but I have often thought about moving to a warmer climate.

The key to this whole trip was to pace myself. We gave ourselves four nights in Melbourne with friends before the flight and were lucky to stay near the airport for that extra sleep in. Early morning starts often ruined me for days, so the fact that we had to check in at the airport at 7:30am was another obstacle to overcome.

I requested a seat with more leg room on the flight and the airline was fantastic at attending to my needs. Every now and then I would do some light stretches and some relaxing breathing. I couldn't help but think of how CFS/ME people don't travel well. My doctor always told me that's the reason why Alastair Lynch didn't often play in Perth.

The first thing I noticed when arriving in Port Vila was the humidity. It hits you like a slap in the face. This was another obstacle… weather change! Ash carried my bags for the whole trip which was a huge help. I saved my energy where possible and during the trip continued with light stretches and small walks and paddles at the beach.

After a false sense of feeling humanly well I treated myself to a cocktail. I haven't had any spirits during my CFS/ME years but somehow I felt more powerful inside and I could take it on. Big mistake – not that it flared up a relapse, but it made me unwell with an upset stomach and diarrhoea. So Wednesday and Thursday were spent relaxing in the room. Thinking back it may have been a good thing for me to rest after breaking so many of my rules.

Friday I had improved and we hired a bus to tour the island. This was very interesting and we met some of the locals. Saturday was a favourite. I snorkelled for the first time amongst some of the world's most colourful and amazing fish. This was yet another obstacle! I hung onto

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Ashley's neck while he swam me out to the pontoon. I rested for ten minutes, snorkelled for about five minutes, then rested again. This went on for about an hour.

For every activity that required some movement – snorkelling, shopping, walking and paddling – I rested for a couple of hours after or in between. We used buses and taxis all the time to get around and ate the freshest of fresh food.

By the end of the week I was feeling fantastic and gave myself a little pat on the back for accomplishing something I wouldn't have dared thought was possible. I secretly think Ash thought it was time to go that extra step by going on this trip, although I kept telling him he was mad for thinking I could cope. I think those around us see our strengths differently to how we view them. The focus of CFS/ME in our relationship had been huge so it was a reward also for Ash for all of his hard work and loyalty in helping make my life as health wise as possible.

Every CFS/ME body manages differently. It is always important to weigh up your own health situation before attempting to do something different. It had taken me two and a half years of trial and error to reach today's level. I think that having to travel to Melbourne for specialist appointments every six weeks has made my travel time threshold so much longer. If I lived in the city I don't think that travel would be easier for me because those five hours in a car would not have been practised.

Perhaps, when the time is right for you, ask someone to take you for a drive into the country. The change of scenery would be most welcomed.

Some travel tips:

(I am not a doctor – these tips are purely from a CFS/ME patient sharing what works for me that may benefit others.)

- Do not travel if you feel you can't cope. Listen to your body. I never travel if I'm extreme. Don't feel guilty if you have to cancel plans. We don't need the extra stress.
- If it is your first trip since CFS/ME go on a small Sunday drive instead.
- Do your packing the night before or ask someone to do it for you.
- Have a good sleep and keep to your diet (eat well). If you're not an early bird, sleep in and leave when you are ready.
- Do not lift heavy bags. Pack lightly or ask for help.
- Ask someone else to drive or, if driving yourself, undertake only short distances.
- Rub your feet (acupuncture points) – good for circulation and energy.
- Continually sip water throughout the trip.
- Have some stops along the way for that much needed stretch – perhaps every hour or two. Stop for a break for lunch.
- If going for a few days don't plan any activity for the first day or two after you arrive.
- Try and enjoy your trip and put your everyday stress behind you. Give yourself small but manageable goals. I always take the Panadol just in case!

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Hummingbirds

*By **Jodi Bassett***

A few months ago I was flicking through a book when I came upon a stage-by-stage illustration of hummingbirds hovering and it struck a real chord in me. After a few moments it hit me why. In the same way a hummingbird comes crashing to the ground with a big fat SPLAT! if it falters or even pauses in the complex series of movements that keep it in the air, in a different sort of a way so do I.

I contracted CFS/ME ten years ago and since then I've been forced to keep on 'flapping my wings' endlessly lest I fall into a pain-filled soggy heap – rest is never an option. My version goes something like this:

- **FLAP!** Making sure I don't spend too much time flat in bed or my vertigo becomes much more severe than usual and the room just spins and spins horribly.
- **FLAP!** Trying not to stand or sit up for too long or my heart can't cope and struggles to beat properly and I feel really faint-headed and vague for hours afterward

Then I forget for just a few moments about having to be careful about how much light I expose my eyes to and instantly…

- **CRASH!!!** (Burning pain that lasts for hours leaving me unable to open my eyes.)

But still I can't rest and have to get myself back in the air straight away…

- **FLAP!** I manage to make my bath neither too cold, which leaves me shaking and unable to get warm for hours, nor too hot, which makes me light-headed and my heart rhythms go irregular for the next six hours.

But then I forget to avoid one of the foods I am intolerant/allergic to (that I tolerated completely well the day before) and a few minutes later…

- **THUD!!!** (Abdominal pain, bloating, itching and nausea for hours afterwards.)

Then I forget to put my blanket over myself properly and within a short while…

- **SPLAT!!!** (I get so cold I can't get myself warm again and it turns into a horrible shivering fever, which leads to delirium and eventually loss of consciousness for hours afterwards.)

Because so many normal everyday things cause me to 'crash' I have to constantly monitor everything I do and every aspect of my environment to try to keep me 'in the air' as much as possible. It's a never-ending task and a thankless one too, as my base level of functioning is pretty low anyway. I'm 100% housebound and 99.5% bed-bound no matter what I do. I always wake up paralysed for a few hours every morning and all the rest of it. But if I were to stop I'd be even more sick, so I am forced to keep going with my efforts, even though they take so much out of me themselves. It's a lose/lose situation.

With a bit more research, however, I soon found a much better reason to identify with hummingbirds – you see, although at first glance they are tiny, seemingly defenseless and extremely vulnerable to attack from anyone or anything, they are actually really tough little critters when you really look at them. They never back down from a fight, even if the odds are overwhelmingly against them, taking on other birds much larger than they are when they need to. What their bodies lack in strength and power is made up for by their bravery, strength of mind and… spirit I suppose you'd call it.

I've met so many people with CFS/ME who share that same spirit, particularly those who suffer with severe CFS/ME People who remain kind, giving and hopeful and determined to make the best of what they have, de-

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spite dealing with unbelievably severe illness, often without the support of family, friends or the health and welfare systems. Indeed they often face a lot of direct opposition, criticism and sometimes even abuse from these people and organisations.

I consider these people no less beautiful inside than a hummingbird is to the eye. The human spirit is capable of amazing resilience and endurance and I can see no greater example of this than people suffering from severe CFS/ME. I think they are all truly inspiring. When every hour of every day is so difficult and painful and there's no foreseeable end in sight, the fact that, along with the obvious sadness and frustration that such a life inevitably entails, there can also be some hope and humour is just amazing in my opinion.

The world is full of supposed-to-be inspiring stories about people triumphing over (compared to severe CFS/ME) fairly small problems, always with the complete support of everyone around them and much back patting and praise when they've finished their short 'ordeal'. Nothing wrong with that except that, on the other hand, desperately ill people with severe CFS/ME who have no support at all yet are able to somehow keep going through one horrendous ordeal of one day after another are not only never congratulated on their hard work and amazing strength, but are sometimes actually labelled as malingerers, or seen as mentally weak or defective in some way. It really does boggle the mind that there can be so huge a gap between perception and reality.

I've since featured hummingbirds in many of my paintings and drawings and this is why. I see the same sort of strength and beauty, combined with such heartbreaking vulnerability in my CFS/ME friends everyday. Nothing I've seen on this earth is more inspiring to me, more beautiful, or more tragic, heartbreaking and utterly disgusting too.

So I think of people with CFS/ME as hummingbirds now – vulnerable, strong and eye-hurtingly beautiful all at once, and more than overdue for some consideration and care in this world.

(This article is dedicated to my friend Ingeborg, the most unappreciated but nonetheless beautiful hummingbird there is, if only those around her could see it. And if you'd like to see more of my CFS/ME writings or paintings go to: www.ahummingbirdsguide.com)

Editor's note: Jodi is a member of the Society from WA. The following is a review of her art exhibition held in Perth from the West Australian*, 22 January 2005 from a review of art exhibitions by Ric Spencer:*

> "There is a cherub of a show at the Free Range Gallery in Hay Street, Subiaco. *Hummingbird Lives* is the first solo effort for Jodi Bassett. The exhibition is a cascade of small works, overlaid variously by hammering, drilling and weaving. Each depicts a hummingbird, caught in different stages of flight.
>
> Bassett could not be at the opening because she is bed-bound with myalgic encephalomyelitis or chronic fatigue syndrome, a debilitating illness that manifests symptoms based on neurological, cardiac, immunological and endocrinological dysfunction. She can't sit up for too long so the fact that she has managed to put this show together lying down is astounding. She has chosen the hummingbirds as her proxy and also as a metaphor for her relationship with her illness.
>
> It's easy to overdo a metaphor, or even simply miss with it, but in this case it works well. These hummingbirds are meticulously painted, treated with love. They are controlled, but they break out, venting their frustration at every opportune time. They are both the artist and the illness.
>
> I couldn't help but think of Matisse's bed-bound later works while viewing *Hummingbird Lives*. Matisse's cut-outs give me that feeling of insight into the personal nature of the artist as an organic entity, dealing with both fragility and strength.
>
> I left *Hummingbird Lives* in adoration of Bassett and the relationship she has with her illness. This exhibition speaks of respect, awe, containment and hatred. This is a critical and intensely personal show and I felt very humble viewing it."

Congratulations, Jodi..

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Talking Point – 2005 Issue 1

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

Evidence for graded exercise

By ***Susanna Agardy***

A key chapter in Mary Jahne's moving autobiographical work, The Bitter and the Sweet, *describes her battle to come to terms with the transition between life as an 'ordinary' person and that of a housebound, bedridden CFS/ME sufferer.*

This section deals with Mary's experience of exercise.

Recently, in the Medical Journal of Australia, Professor Andrew Lloyd announced that "one can safely conclude ... that graded physical exercise should become a cornerstone of the management for patients with CFS."[1] Only the severely ill are exempted.[9] Several media articles have echoed the advice. This treatment has not worked for me and others and some sufferers have become much worse following exercise. The uncritical acceptance of the statement in some quarters has prompted me to explore some features of the evidence provided by the studies relied upon by Prof. Lloyd.

All of the studies reflect the Cognitive Behavioural Therapy (CBT) approach to CFS which states, briefly, that our illness is perpetuated by our beliefs that our illness has physical causes and that exercise exacerbates our symptoms because it has done so in the past. This thinking results in our avoiding exercise and causes physical deconditioning. Therefore, it needs to be corrected by CBT which may include motivational interviewing so that graded exercise can occur which can improve our functioning[2] and reverse deconditioning. Two of the authors indicate that they do not believe there is any serious physiological basis for CFS.[2 3]

The three studies, two British[2 3] and one Australian[4], all found significant improvements in fatigue and functioning of CFS participants who completed a graded exercise program compared with controls who did stretching or relaxation or received medical care. Patients' beliefs about the physical cause of their illness changed with their improvements in fatigue.[2] To what extent can the results of these studies be generalised to all people with CFS?

Professor Lloyd states that "…the cardinal phenomenon of fatigue in CFS is characterised by a marked and prolonged exacerbation of symptoms following minor physical activity…"[1] However, two of the studies upon which Professor Lloyd relies show no evidence of directly addressing what we know as post exertional malaise and do not even mention it.[2 3] In the third study, Wallman, whose design allows for working around the possibility of it, found there was "no relapse" during the course of treatment.[4]

The authors are much occupied with 'fatigue', an amorphous and confusing term, and aim to find a way to mitigate it. But 'fatigue' does not cover post-exertional malaise which is often delayed, severe and long-lasting and has additional symptoms. This should be enough to indicate that there is something extraordinary, rather than just exacerbated fatigue happening here. It can be serious enough to stop sufferers from entering exercise experiments or to cause dropping out of them.

Two of the studies[2 3] used the Oxford Criteria of 1991 for CFS formulated by the Oxford Consensus Meeting.[5] The main difference between the Oxford Criteria and the later Fukuda (1994)[6] and Canadian Criteria (2003)[7] is that the Oxford Criteria do not include some physical symptoms for example, sore throat, but include mental fatigue and may include depression and anxiety. Unlike the other criteria, the Oxford criteria do not include post-exertional malaise. Only the Canadian criteria actually require it in order to be diagnosed with CFS.

According to the guidelines for research under the Oxford Criteria "…it should be stated whether the fatigue is greatly increased by minor exertion…"[5] but it does not require the inclusion of people having this problem. None of the authors shows any evidence of having explored whether their subjects experienced increased fatigue after minor exertion prior to the treatment. Wallman[4] required doctors' certificates to state that patients met the Fukuda Criteria[6]. Although these criteria include post-exertional malaise it is not essential to have it in order to be certified as having CFS. We do not know whether the certifying doctors specified it for the participants. Therefore, these studies leave themselves open to the interpretation that many of the subjects in the studies may not have suffered from post-exertional malaise.

In addition, Fulcher[3] excluded people with sleep disorders because these were thought to have an independent effect

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on fatigue. Sleep disorders are included in all the criteria mentioned above. This could have further excluded CFS sufferers.

Why did Fulcher[3] and Powell[2] use these outdated criteria when the more updated Fukuda criteria were already in existence and specified more of the symptoms rather than just focusing on fatigue?

The CBT approach is concerned with overcoming the experience of post exertional malaise, so it is even more amazing that none of the authors shows evidence of asking the participants if in fact they suffered from it prior to the treatments.

Secondly, the studies by Fulcher[3] and Wallman[4] began with a pre-treatment assessment involving aerobic capacity and target heart rates. For example, Fulcher used a treadmill at 5km/h with the slope increasing every two minutes. Perhaps these tests do not appear to be overly demanding to healthy individuals, but they can have serious consequences for people with severe post exertional malaise, for many of whom aerobic exercise is having a shower, or even less activity. All the authors seem oblivious to the contradiction of giving CFS sufferers sustained aerobic exercise before they underwent the carefully designed graded exercise program. Yet, no complaint or problem is reported.

The studies are also subject to volunteer bias, that is, people who feel they are able to do exercise or feel they can perform in such a study will participate and those who are more severely affected will be excluded. This may be unavoidable, but the conclusions able to be drawn from such studies will be limited.

These studies do not justify claims which imply that graded exercise assists in overcoming the effects of post exertional malaise. Until this limitation is resolved CFS sufferers are rightly sceptical of generalisations of the results of the studies to themselves.

The CBT view of the illness proposes only one type of explanation for our situation . It assumes that we perpetuate the illness by avoidance of exercise due to inappropriate thinking. The proponents of this theory do not seem to stop to ask why we stopped our normal activities in the first place. They do not seem to consider the fact that we were ambushed by an illness and that perhaps the continuation of the same illness, rather than irrational thoughts, prevents us from exercising.

Our beliefs are also interpreted unequivocally as irrational. No consideration is given to the possibility that perhaps they represent a reasonable self-protective mechanism and that perhaps many of us are already doing as much as we can. Many of us are already motivated and do not need therapists to motivate us to do exercise. Nor do we want therapists to tell us to ignore important signals from our bodies while they ignore evidence of our physical abnormalities. The CBT-exercise theory inspires no confidence while activity has not made us better and our concerns and experience are swept aside.

Perhaps graded exercise programs help some people with some varieties or a milder degree of CFS (or people who have only 'chronic fatigue'). Although CFS is accepted as being heterogenous,[8] the research has not attempted to identify subgroups who could benefit from exercise or CBT.

In view of the absence of direct evidence from the studies that graded exercise alleviates the effect of post-exertional malaise, the diversity of the illness, the lack of predictors as to who might benefit from exercise and whom it might harm, the lack of a diagnostic test and lack of knowledge of the stage of the illness in various sufferers, it seems risky to prescribe a 'one size fits all' treatment.

I am not arguing against exercise and move about as much as I can. However, we should not be forced into programs which mislead busy doctors and allow policy-makers to file away the problem as fixed, thus depriving the illness of the attention and funds which are so badly needed.

(Note: Throughout, I have used the term 'CFS' in keeping with the term used in the studies.)

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Talking Point – 2005 Issue 1

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

The exercise problem

*By **Mary Jahne***

A key chapter in Mary Jahne's moving autobiographical work The Bitter and the Sweet *describes her battle to come to terms with the transition between life as an 'ordinary' person and that of a housebound, bedridden CFS/ME sufferer.*

This section deals with Mary's experience of exercise.

One of the realities of many months of enforced bed rest was that my muscle tone was non-existent. My muscles had wasted away. This was only to be expected, I suppose, under the circumstances.

When I had reached a stage whereby I was able to move around the house with ease I decided that it was time to do something about it. I began by just tensing then relaxing all of my muscles as I lay in bed. I only managed to do this two or three times a day in the beginning but after a few weeks I was gradually able to build this into a routine of three or four times an hour.

Light exercise was recommended in a couple of the books I read. It was, however, stressed in the strongest of terms that the sufferer keep any physical activity within their own limits and avoid reaching the point of fatigue and total exhaustion, as this would only result in rapid deterioration or a possible relapse.

Walking was recommended for those who could manage it. Commencing with short distances and gradually increasing, all the while keeping in tune with your energy levels.

This advice made sense but walking was out of the question for me as I could not support my body for any length of time in the first two years of my illness. I could barely make it out to the mail box and back without feeling exhausted. I realised that I needed to undertake some form of exercise in which my body was supported so that the energy I used was being utilised for the benefit of my muscles.

In the study there sat an exercise bike which had once belonged to Roland's Dad. It had been gathering dust for almost two years. Despite good intentions neither of us had put it to use. This instrument of torture provided me with an answer to my diminished leg muscles. Its days of idleness were over.

My first attempts were fairly paltry. With no tension whatsoever on the wheel, I could just manage to pedal for a minute before I began to show the signs of exertion. My heart rate would increase. I'd be gasping for breath and beginning to perspire if I went on any longer.

Not to be daunted, however, my poor performance only served to spur me on. Each day I exercised. Progress was exceedingly slow but my determination kept me at it. I spent my minute on the bike and as time went by I was gradually able to increase this time slightly. Within six weeks I was able to last for five minutes a day. I began to feel stronger in my legs. They no longer looked or felt like jelly.

As I increased my time and durability I found that, in order to sit and pedal for any length of time, I needed a distraction from the continual pumping movement of my legs and the agonising protest my muscles were issuing. Once again Michael Bolton came to the rescue, this time in the form of music videos. Now instead of watching the hands of the clock dawdle round the dial, I watched my favourite singer as he performed and sang across the screen. I began timing myself to songs instead of minutes.

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Some days for some inexplicable reason my legs would not co-operate with my will. I would reach my limitation in a shorter period of time. When this happened I stopped. There was no pattern or reason that I could determine. I had to play it to the dictates of my body.

Despite the fact that this aerobic exercise was paying dividends as far as my muscle strength was concerned, it made no discernible difference at all to my energy levels. This was disappointing, as I had optimistically held the hope that it might have helped me regain some of my former vigour or, at the very least, increase it a little, but this was not to be. On the other hand, it did not appear to be impeding that minimal progress I made in the beginning.

So I continued with the routine which I was eventually able to extend to include a few mild floor exercises.

After several months, which included some setbacks, I was finally able to exercise for twenty minutes a day. I considered this sufficient for my needs but unfortunately I was able to sustain this for a period of only about six weeks when, without warning, I suffered another relapse and was unable to do any exercise for some time.

I decided after that to do what I could, when I could, making moderation the key. I persevered with it on the days that it was possible because I didn't want to relinquish what little progress I had made. I found it extremely frustrating and discouraging when on some days my level of energy was at such a low ebb that I could barely manage half of what was possible prior to my relapse. There appeared to be no rhyme or reason.

Eventually I was unable to do any at all and so I was forced to admit that it was no longer a feasible proposition. It was another choice that I was forced to rethink.

Once more the exercise bike went into retirement.

(Editor's note: Mary tells us she is now very well and at around the 90% level – unfortunately, however, her daughter is still very sick.)

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Address by Dr Peter Del Fante

Dr Peter Del Fante, Medical Director of SA's Western Division of General Practitioners, spoke to an audience of about 40 people at the Society's Annual General Meeting on November 13, 2004. Dr Del Fante spoke entertainingly and comprehensively of his recent trip to the USA to attend the conference of the American Association of CFS, in Madison, Wisconsin. The AACFS are the researchers and clinicians in the field. There are now plans to expand this group into an international association. Fifteen countries were represented at the Wisconsin conference, including Dr Del Fante and Christine Hunter from Australia.

Dr Del Fante reported on a number of theoretical advances, and debates surrounding key issues. He wanted to highlight these issues and show some ways forward. On his trip, he also visited the UK, and was able to report on developments there.

Definition debate

Dr Del Fante was able to report that CFS is now a recognised medical condition – there is consensus on this. The World Health Organisation classifies CFS as a neurological disorder. However, there is still significant tension between on the one hand the *psychological* model and on the other the *biological* model of ME/CFS. Those committed to the psychological paradigm see a continuum of fatigue, where the chronically fatigued are at one end of that continuum. In that sense, the words "chronic fatigue" complicate the issue.

The most widely used research case definition for ME/CFS is the one developed by Fukuda (1994) at the US Centers for Disease Control (CDC). At the Wisconsin conference it was almost unanimously agreed that the Fukuda definition is now out of date. It is vague and over-inclusive (for example, a follow-up of people who initially met the Fukuda criteria showed that up to 1 in 4 ended up having some other diagnosis than ME/CFS). A new Canadian set of criteria appears to identify the ME/CFS group more accurately, but has not got wider acceptance as yet. The CDC in Atlanta is now looking at redefining a new set of criteria for CFS. Dr Del Fante believes it is important that we get involved in that and get it right.

On the other hand, in the UK there is an acceptance of the Oxford and London criteria, put together by psychiatrists. Dr Del Fante talked about the overlap of symptoms between ME/CFS and depression/anxiety disorders, but emphasised the differences between ME/CFS and depression states. For instance, ME/CFS patients have intact self-esteem, are motivated, and suffer no loss of pleasure in daily activities. Further, ME/CFS sufferers are unlike those suffering from depression in that they have post-exertional fatigue with minimal effort, orthostatic intolerance, and specific cognitive impairments not seen in depression, as well as unusual neurological symptoms. Patients having CFS for long periods will become depressed, but that is *reactive* depression, because they have been so ill for so long.

Epidemiology

It appears that ME/CFS affects all social and ethnic groups, with a predominance of females (2 to 1). The onset can be acute (60%) or gradual. Its prevalence in the community is 0.2 to 0.5%, which would lead to a figure of between 3000 and 7000 cases in SA at any one time.

Impact

Dr Del Fante summarised the impacts of ME/CFS as severe disruption to the ability to socialise, work and study; social and economic hardship, along with high cost to the community and economy; significant impact on partners, family and children; poor quality of life (in fact the quality of life for ME/CFS sufferers can be worse than for those with depression, and equivalent to patients with chronic heart failure). Measures in the USA of productivity losses due to ME/CFS have estimated the cost to that nation of $US9bn per year.

Causes/Aetiology

In this area, the Wisconsin conference did not highlight anything really new. The causes of the illness are not well understood. There appears to be multi-system involvement, with multiple symptoms of varying intensity, and mostly neuropsychological. Genetic pre-disposition is important. Clear genetic markers may be able to be sued to identify people at risk of developing the illness. Triggers appear to include virus or infections, chemical exposure (eg Gulf War Syndrome), or significant life events. The psychological model pursues attribution theory and a concept known as *increased interoception* (*British Medical Journal,* October 2004). The latter basically means introspec-

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tive hypochondriasis. The paper in the BMJ suggests sufferers had previous poor health or psychiatric problems (a theory debunked by the recent Dubbo study in Australia, which found no such links). The advocates of the psychological model advocate treatment that reprograms the "interoception" and increases the patient's activity. The article has drawn 30 responses so far, some very interesting. Dr Del Fante noted that treatment centres based on this psychological paradigm have been well funded throughout the UK.

Pathophysiology

Dr Del Fante reported that there is a lot of evidence that brain function in CFS patients is not normal, eg there is reduced blood flow and activity in deep brain structures, and other central nervous system disturbances. There is also a lot of physical evidence re abnormalities, including reduced oxygen uptake during exercise, and other biological markers.

Treatment

There was not much new presented to the Wisconsin conference in terms of treatment. One paper addressed Ampligen treatment for CFS, which has been around for 10-15 years. Not only is this expensive, but any improvements on this drug are very moderate.

ME/CFS management

The main interest in the topic of ME/CFS management at Wisconsin was around the San Diego group which has developed an exercise regime, building patient fitness gradually, with frequent rests stops. Patients had not relapsed. There was also a paper on omega 3 benefits, and one on low-GI diets.

Prognosis

Functional improvement can take years (average 3-5 years). Only 10% of sufferers achieve full remission. Research suggests that the earlier the diagnosis, and the younger the patient, the more likely an intervention will lead to functional improvement.

ME/CFS developments in the UK

After the Wisconsin conference, Dr Del Fante visited the UK to observe developments there. There are an estimated 240,000 sufferers in the UK. The cost is estimated at $AU9bn per year. Treatment centres for ME/CFS have been set up in 12 locations around the UK at a cost of $AU21m. The centres aim to integrate local services and GPs. They are predominantly based on the psychological/psychiatric model, using cognitive behaviour therapy and graded exercise programs. Dr Del Fante reported that, because those supporting this model define fatigue as a continuum, they have had some success with some patients, who are not really suffering from CFS, but are merely fatigued.

Directions

Dr Del Fante is part of a group of medical experts from across the world who have agreed to collaborate, following on from the Wisconsin conference. Our Society will support his involvement. Some directions he suggested for the future were:

1. The creation of an ME/CFS patient register for: a longitudinal study of ME/CFS outcomes/progress; cohorts for clinical and basic research; linking of research and clinical findings within the database.
2. An SA referral centre for multi-disciplinary assessment, management and support for more severe patients (based on a different treatment model to those in the UK).
3. Chronic care plans, to follow the planned changes in Medicare arrangements. This could support patients in accessing allied health care via Medicare.
4. Promoting community awareness and professional recognition of CFS.
5. Focus our research on "real" ME/CFS patients.
6. Funding must be provided for both research and treatment of all aspects of this condition within the context of a balanced bio-psychological-social model.

Summary

In summary, Dr Del Fante quoted William Cullen (1710-90):

> "A physician who does not admit to the reality of a disease cannot be supposed to cure it."

There followed half an hour of stimulating questions and discussion.

Members may note that a DVD was made of proceedings. It has been distributed to our regional support group leaders, and a few copies are available through the ME/CFS office..

AACFS 7th International Research Conference

This article will focus on the proceedings of the American Association for Chronic Fatigue Syndrome 7th International Conference, held in Madison, Wisconsin October 8-9, 2004. A day of research presentations was followed by two clinical days with a patient conference running in parallel. The following summary has been taken from summaries made available by two conference participants – Dr Rosamund Vallings and Paul Carnes.

Talking Point – 2005 Issue 1

Research overview

By A.Komaroff (Harvard School of Medicine, Boston)

In Chronic Fatigue Syndrome, functional status is much reduced in all areas and $9 billion is lost annually in productivity in the USA. Over time 10% of sufferers can expect complete remission and 23% will receive an alternative diagnosis eventually. The illness follows a relapsing and remitting course, and research has shown abnormalities in many systems:

Brain:
Abnormalities seen on MRI and SPECT scans.
Cognition – IQ within normal range, but marked difficulties in mental processing etc.
Sleep – polysomnographic abnormalities, with up to 28% increase in non-refreshing sleep.
Neuro-endocrine dysfunction.
Autonomic dysfunction – basal and postural hypotension, reduced peak O2 consumption and haemodynamic instability.

Immune activation:
Activated lymphocytes cross the blood-brain barrier leading to microglial activation and perivascular activation. These effects can last decades, and lead to the secretion of pro-inflammatory cytokines and nitric oxide, with resulting injury to the peripheral nervous system and chronic low level immune activation in the brain. There is also neutrophil apoptosis.

Microbiological studies:
Many different post-viral fatigue states have been described. Examples include:

- Enteroviruses (Coxsackie, polio, echo) – abnormal lactate response to sub-anaerobic exercise demonstrated.
- Enteroviral RNA in muscle without γP-1 protein suggests defective viral replication.
- Q Fever (rickettsial) – nucleic acid persists for up to 10 years in circulation mononuclear cells.
- Parvovirus: ongoing elevation of IFNγ with associated fatigue.
- Mycoplasma: found in up to 68% of European CFS patients (5.6% in controls)

Energy metabolism:
Disturbances seen in urinary metabolites: such as depletion of amino-hydroxy-N-methyl pyrrolidine, slight elevation of β alanine and depletion of UM2 (serine).

Gene expression:
The genes involved in immune activation and energy metabolism are turned on more often in CFS.

Vitamin D connection:
Low levels lead to musculo-skeletal pain. Patients who have fibromyalgia tend to have lower plasma levels of Vit D as do people living in areas with long periods of darkness in the winter, with resultant tendency to osteoporosis.

Treatment:
Placebo controlled trials of treatment with omega-3 fatty acids have shown benefit in CFS. There is decreased production of inflammatory mediators and direct antiviral activity. Endogenous levels may be reduced by chronic viral infection.

Epidemiology overview

By W C Reeves (CDC, Atlanta)

Fatigue is a very common symptom in medical practice, involved in up to 50% of consultations of which 75% are psychiatric. The prevalence of CFS (existing cases) in the US is 4-75 per 100,000. Onset is usually sudden and average duration is 5 years (range 2-7 years). In the US it is more common in rural areas, with a predominance in females and lower socio-economic groups. Minority races area at greatest risk. Annual loss in productivity in the US is $US9 billion and the average annual loss in family income due to CFS is $20,000. IN the UK, $US4 billion is spent on direct costs such as medication. Patients are often as severely or more disabled than those with heart failure or chronic lung disease.

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Fibromyalgia overview

By D Clauw (Michigan)

There has been a paradigm shift in diagnosis of fibromyalgia (FM) considering tenderness as part of a continuum rather than relying on definite numbers of specific tender points. The tenderness is usually diffuse, and using tender points for diagnostic purposes is affected by anxiety, expectation and distress. Random measures of tenderness are more relevant and accurate.

Causes of FM include a strong genetic tendency, and abnormality in pain-processing. This correlates with abnormalities in other sensory areas such as light and sound. There is generalised hyperalgesia and allodynia. Pain processing is either psychological (expectancy, hypervigilance) or neurobiological (peripheral or central). Dimensions of pain may be sensory, cognitive or affective.

Functional MRI (fMRI) shows areas of FM patients' brains activate at levels far lower than normals indicating they are indeed feeling more pain. Cognitive factors such as catastrophizing and loss of locus of control may cause changes in pain processing and correlate with poor prognosis. Other regional pain syndromes show similar changes in fMRI to that seen in FM.

Cerebrospinal fluid of FM patients shows high levels of corticotrophic releasing hormone even after controlling for depression. Increasing serotonin and noradrenalin reduces pain signalling, suggesting antidepressants may help.

Treatment: SSRIs, tricyclics and norepinephrine reuptake inhibitors all have some benefits in FM. Amitriptyline and imipramine are more analgesic than nortriptyline. Milnacipran is a new drug showing promise.

Microbiology and immunology

This part of the conference was introduced by Dharan Abalashi who listed the many viruses and other microbial agents studied in relation to CFS. HHV6, enteroviruses, Mycoplasma, Chlamydia and parasitic infections are all creating interest.

R. Suhadolnik (Philadelphia) discussed the current immunological situation 20 years after the Lake Tahoe epidemic and reported on a recent study of 66 CFS patients, 62 controls and 51 depressed patients. CFS patients showed marked impairment compared to the other 2 groups. The study supports the cytokine/immune activation model, showing direct correlation between the abnormalities in the RNasL pathway and NK cell function. The 37/80 kDa ratio strongly correlated with the changes seen in CFS and symptom severity. The RNasL activity leads to an ion channelopathy with patients experiencing many symptoms.

C. Raison (Atlanta GA) had experience with the use of IFNα in the treatment of Hepatitis C. IFN (interferon) is a cytokine released early in viral infection and causes a variety of symptoms including fatigue. 109 patients receiving IFNα for treatment of hepatitis C were studied. During treatment 70% of patients reported marked fatigue and 30% developed symptoms sufficient to fit the criteria for CFS. (p=.0001) This study supports the role of antiviral immune response in the pathophysiology of fatiguing illnesses.

J. Jones (Atlanta GA) reviewed the Dubbo Infections Outcome Study on behalf of Sydney colleagues. Patients who had had infectious mono, Q Fever and Ross River virus were followed up. He concluded that post-infective fatigue states (PIFS) following documented infection represent a valid and informative model for CFS. CFS oc-

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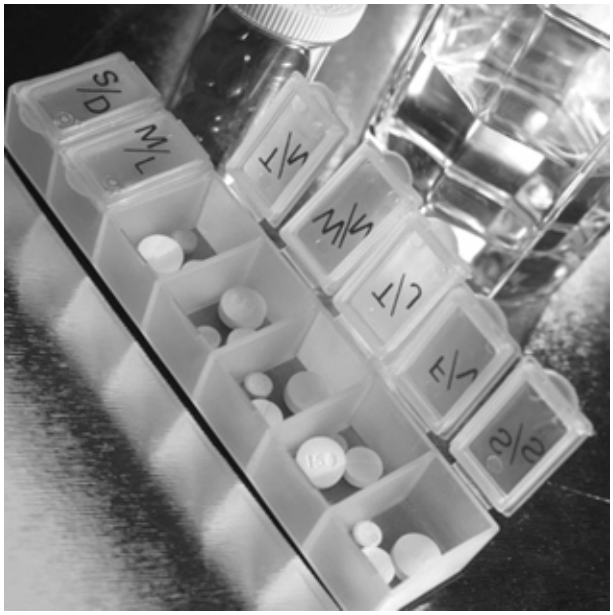
curred in 10% after these illnesses. Severity of the primary illness was the strongest predictor of development of PIFS and was not associated with premorbid psychiatric characteristics.

K. Knox (Milwaukee WI) discussed signal transducers and activators of transcription (STAT) which are a family of proteins playing a central role in the responses of cells to cytokines. She suggested that a study of a sub group of CFS patients who had an abnormally low STAT1 response to interferons, may explain the increased susceptibility to infections sometimes seen in this illness.

K.J. Maher (Miami FL) discussed the decreased NK cells cytotoxicity frequently reported in CFS patients. The abnormalities in cytotoxic T cells and NK cells including reduced perforin and reduced concentrations of Granzyme A and B may provide biomarkers in the future.

D. Raciatti (Chieti, Italy) reported on a study of 130 patients looking at the potential role of STDs in the pathogenesis of rheumatoligical syndromes characterised by prolonged fatigue. Significantly high percentages of infections with Chlamydia, Ureaplasma and Mycoplasma were found serologically and when treated there was recovery from fatigue and other symptoms.

M. Fremont (Brussels, Belgium) reported patients show a genetic susceptibility to immune dysfunction. Some have a reduced capacity to mount a normal immune and inflammatory response, whilst others have an increased PKR expression and activation leading to induction of nitric oxide which furthers the inflammatory response.



Epidemiology

D. Wagner (Atlanta GA) compared 2 scales measuring fatigue and health; the MFI and the SF36. These 2 scales as anticipated were found to be negatively correlated i.e higher fatigue associated with lower mental functioning, and this supports the construct validity of the MFI.

A. Morris (Chicago), a professor in computer science, has devised a computer list of 26 survey questions to accurately diagnose CFS.

H. Harrison (Phoenix AZ) produced support for the hypothesis that there are genetic contributions to coagulation protein abnormalities seen in some CFS/FM patients. Distinguishing these factors may help to guide therapy.

R. Underhill (New Jersey) in a pilot study of 219 CFS patients revealed that 20.5% of the patients had family members with CFS. Secondary cases of CFS occurring in unrelated household members may indicate that a low level infectious agent causing CFS may persist and be shed into the environment. Increased prevalence in genetic relatives indicates that genetic factors may be involved in a subgroup of CFS patients.

Neurophysiology

J. Stewart (New York NY) overviewed the varieties of orthostatic intolerance in CFS. He described 3 types of peripheral blood flow in these patients: low flow, normal flow and high flow. During orthostasis it was shown that there is enhanced thoracic hypovolemia related to inadequate cardiac venous return.

H. Kuratsune (Osaka, Japan) showed results of PET scans showing cerebral hypoperfusion in CFS suggesting that CNS dysfunction maybe related to the neuropsychiatric symptoms found in CFS. Density of 5HTT in the anterior cingulate cortex was significantly reduced in a study of CFS patients and this was negatively correlated with pain scores. This alteration in seratoninergic neurons is thought to play a key role in the pathophysiology of CFS. These results may help explain why SSRIs are sometimes helpful in CFS patients.

J. Nils (Brussels, Belgium) studied elastase activity in relation to impaired exercise capacity in CFS. The data provides evidence for an association between intracellular immune dysregulation and impairments in cardiorespira-

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tory fitness. Results showed correlation between increased elastase activity and exercise functionability and maybe related to impairments of lung diffusion and oxygen delivery to the tissues. NB Antibiotics decrease elastase activity in humans.

K. Yoshiuchi (Newark NJ) confirmed reduced cerebral blood flow (CBF) in CFS. He also found that psychiatric status and severity of illness do not play a role in the reduced cerebral blood flow.

Physiology

S. Levine (Columbia) analysed the metabolic features of CFS. An elevated lactate production was found in 20% suggesting the possibility of a mitochondrial metabolism dysfunction. Elevation of thalamic choline was also demonstrated in some patients, suggesting the presence of neuronal damage.

U. Hannestad (Stockholm, Sweden) showed in a small study that the more severe the symptoms of CFS the greater the excretion of β-alanine. There are structural similarities between β-alanine and GABA, and high concentrations in the CNS may account for some of the typical CFS symptoms. Symptoms similar to CFS are often seen as side effects in those with epilepsy being treated with drugs which increase GABA.

M. Fremont (Brussels, Belgium) presented a further study showing that cells expressing ankyrin fragments of RNasL have been demonstrated, and this can contribute to increased sensitivity of patients to chemicals including heavy metals. Involvement in the maintenance of Th1/Th2 balance by interaction of the multidrug-resistance protein (MRP-1) and the ankyrin fragments is also relevant in CFS.

M. Pall (Washington State) described a number of mechanisms operational in CFS and related illnesses and produced evidence of increased nitric oxide and peroxynitirite levels in CFS, which lead to oxidative damage and further increase in cytokine levels. He described Vitamin B12 as a nitric oxide scavenger, which may explain why some people do well on B12 despite having normal blood levels.

Clinical conference

A. Lyden (Michigan MI) presented a study on 27 FM patients. Their response to pain, thumbnail pressure and thermal pain was 11x greater than in controls. They also had an increased sense of "work" on exercise bikes.

C. Javierre (Barcelona, Spain) showed CFS patients have lowered oxygen uptake when exercising.

J. Alegre (Barcelona, Spain) evaluated 511 outpatients at a fatigue clinic and found that 350 fulfilled the CDC criteria for CFS. These patients had substantial reduction in physical and work activities: 85% were women, mean age = 40. 50% experienced gradual onset and there was significant elevation of RNasL. 10% patients improved over time and 53% worsened. Only 33% were able to work.

F. Friedberg (Stony Brook) had done a cross sectional study of support group attendees looking at the benefits and problems encountered. In general subjects had found the group experiences helpful, but somewhat surprisingly active support group members reported greater symptom severity and less illness improvement than inactive members.

D. Strayer (Philadelphia PA) discussed the Phase III clinical trial of Ampligen v placebo in CFS. The trial involved 234 severely affected patients. 400mg ampligen or placebo equivalent in saline infusion was given IV twice weekly for 40 weeks. Exercise treadmill duration was improved twofold over placebo. There were no significant differences in laboratory parameters. Ampligen has provided the most

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promising results compared with other drugs tried such as galantamine, antidepressants and corticosteroids.

L. Jason (Chicago) compared and contrasted the various case definitions for CFS/ME. The London ME criteria select a more symptomatic group of individuals than the Fukuda criteria. Using the Canadian criteria, there is less psychological morbidity included and more physical and functional impairment. There are more symptoms relating to fatigue and weakness coupled with neuropsychological and neurological symptoms.

J. Jones (CDC, Atlanta) defined fatigue as a regulatory or protective process in illness – a component of illness behaviour. It is controlled by antagonistic activity of inhibitory/activating systems in the brainstem. Mediation of immune responses occurs in illness and prolonged illness maybe due to exuberant or inadequate host responses. Damage is a trigger for immune response. He described also the effects of unconscious self regulation which included psychological and philosophical components. Acute sickness causes a response to primary altered self, and repeated episodes can lead to conditioning and produce effects such as chronic fatigue. Targeting the prevention of the circle of CFS seems appropriate for further research and treatment.

K. de Meirleir (Brussels, Belgium) described CFS as an immuno-vigilance disorder, with host/environmental problems. The initiating factors are heterogenous. There is an abnormal level of apoptosis, and the nuclei cannot ingest all the resulting fragments. RNasL fragments then accumulate. Some thyroid suppression may occur without abnormalities in TFTs. PKR activity is increased along a continuum. A number of patients are IgM positive to intestinal pathogens, and when treated antibiotics (eg ciproxfloxacin) these patients show a 74% decrease in elastase and 58% clinical improvement over 3 months. Therapeutic strategies should include: restoration of immune competence, elimination of micro-organisms, restoration of hormones, restoration of normal intestinal flora and decrease of PKR activity.

The next clinical segment was devoted to issues around autonomic dysfunction. C. Lapp (Charlotte NC) gave an overview. He described the autonomic nervous system as controlling all the automatic functions in the body. He gave background to the original research by P Rowe et al and described the various types of orthostatic intolerance: Orthostasis, Postural Orthostatic Tachycardia Syndrome (POTS), Symptomatic Orthostatic Tachycardia (SOTS) and Neurally Mediated Hypotension (NMH). These conditions can be distinguished using tilt table testing. He stated a tilt test should be done with no medication. Anaemia, diabetes, and dehydration can invalidate the results. The room should be warm, dark and quiet with no talking. Heart rate and blood pressure should be continuously monitored. Most patients will faint within 30 minutes if they have autonomic dysfunction. Various causes were outlined including: low blood volume, low total body water, CNS disorder, venous pooling. Possibilities for managing orthostatic intolerance include: volume expansion (salt and water), fludrocortisone, midodrine, beta-blockers, SSRIs, amphetamines, IV fluids and erythropoietin.

D. Bell (Lyndonville NY) discussed his findings relating to volume depletion and ADH in CFS. He described how polyuria and thirst maybe early symptoms in CFS. He reviewed his original study where red blood cell (RBC) mass, plasma volume and circulating volume were found to be significantly depleted in CFS patients studied. RBC mass is probably the most important issue. 73% of patients studied had low RBC mass. If blood volume is low, ADH should rise but if levels are low there is increased osmability leading to low BP, nausea and hypoxia. Some patients in the past have responded to various IV infusions (eg γ-globulin, Vit C, antibiotics) and it is probable that this has been a "placebo" type response just due to

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increasing blood volume. Bell has used daily one litre IV saline infusions with some encouraging results in 17 patients. 2 stopped treatment, 5 had slight improvement and 10 had good to excellent results. However serious risks such as line infections maybe encountered.

B. Hurwitz addressed therapy using erythropoietin. He described patients who suffered from episodic hypotension with a tendency to syncope fainting when upright. These patients had a lowered cardiac ejection fraction and decreased cardiac tone. Lowered blood volume was associated with mildly elevated ESR, suggesting the presence of a heightened inflammatory process. Earlier studies using volume expansion had produced some good results, but adding erythropoietin has the potential to improvement in non-responders. Erythropoietin is produced in the kidneys and stimulates the production of erythroid cells. A deficiency leads to normocytic anaemia. Production is modulated by the sympathetic nervous system. His hypothesis focussed on treating with erythropoietin to improve cardiovascular and autonomic symptoms and thus improve quality of life. Ongoing research with 94 patients to test this hypothesis was outlined, and involved three subcutaneous injections weekly. Supplemental iron and salt were included. There is one year left in this promising study.

S. Schwarz (Tulsa OK) discussed whether CFS and chronic Lyme disease are the same. An excellent overview of the research into diagnosis and management of Lyme disease was presented. It seems still unclear as to whether fatigue after Lyme disease is a form of CFS or is due to unresolved infection with persisting immune dysfunction. Antibiotic treatment has not conclusively been shown to be effective in randomised trials, but this maybe due to the choice of antibiotics used. There may also be different varieties of Lyme in different parts of the world.

N. Klimas (Miami FL) and L. Jason (Chicago) discussed the subgrouping of CFS by various means taking care to avoid the tendency to generalise. CFS represents a heterogenous syndrome. Subgroups can be based on biological markers; duration, severity and symptom complex (predominantly cognitive or associated with pain), and acute versus slow onset. There are a number of overlapping subpopulations with symptomatology relating to the immune system, the autonomic system, HPA etc. all within the chronic fatigue complex. Subgrouping could also be done looking at gene expression. Finding distinct sub-populations has clear clinical implications by defining groups for targeted intervention. Objective measures are

needed for this approach and can include issues such as: neuroendocrine (hypocortisolism), autonomic (orthostatic intolerance), immune (cytokines, cell function), cognitive (PASAT), psychological co-morbidity (SCID), physical exam findings (+ve Romberg, hypermobility), documented infection at onset etc. Subgrouping is the key to understanding how CFS begins, how it is maintained, how medical and psychological variables influence its course and how it can be prevented, treated and cured.

A lawyer, T. Bush (Madison WI), provided some good useful advice for doctors who have to produce reports determining disability impairment. An objective opinion of the level of function is needed. Patients may be turned down for disability benefits if there is no medically determinable impairment. There is considerable difficulty in proving one cannot do a sedentary job. Doctors must record detail in the medical records such as distance patient can walk, time able to stand etc. Including lab results can help in explanation. It is not often possible to perform a work simulation. If there is a past history of annual physical examination, previous capacity etc this should be included and there needs to be stress on the issue of "changed health".

N. Klimas (Miami FL) lead a panel discussion/advocacy workshop. Various points were noted. There is risk of defining the illness behaviourally if research is not supported. Physicians' voices carry more weight than those of patients. The WHO has reclassified CFS as a neurological illness rather than psychological. The word "fatigue" however is still very unpopular and unhelpful and many felt, outdated, but it was unlikely to be changed in the immediate future. Continuing action for recognition and support was strongly supported.

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Workshops

Exercise workshop

Because studies have shown that exercise can be beneficial in CFS a full session was devoted to an exercise workshop, and the first presentation was by exercise scientists S. Stevens and C. Snell who discussed strength and conditioning in CFS. Emphasis was on forgetting the "Athlete Model". Aim should be to focus on improving quality of life and developing coping tools to manage the illness and restore function. They described two types of patients: the roller coaster and the activity avoider, the latter compounded by the fear factor. When planning a strategy, questions need to be asked such as issues of post-exertional malaise (immediate and delayed), recovery responses including length take to recover etc. The aim should be to pay back oxygen debt with rest. Fatigue after exercise is due to oxygen deficiency. A programme of "analeptic exercise" should be initiated which trains the short term system, restores functional movement and improves range of motion and strength. Appropriate exercise should be included in the daily routine and payback involves focussed breathing (3 seconds in/3 seconds out). The programme needs to be justified and the therapist needs to understand the physical limitations of the illness.

The progressions should include:

1. Stretching/strengthening
2. Stretch with resistance training
3. Dose controlled interval training, and
4. Maintenance

C. Lapp (Charlotte NC) discussed interval exercise in CFS/FM. He pointed out the fact that even minimal exercise can trigger a flare of symptoms, while there is a fantasy that exercise is the cure. People often get sick when the patient aims for the anaerobic threshold (AT). This threshold occurs much sooner in those with CFS than healthy people. The relationship of energy expended to impairment is used to measure the impairment, the AT can be worked out and that should be the maximum time and level that the patient exerts. Interval exercise can slowly improve fitness. A study example was given showing how using repeated bursts of 3 minutes of exercise followed by 3 minutes of rest over 1 hour lead to benefit. These patients were quite severely affected and none relapsed.

J. Hoffman has developed an exercise and conditioning programme for those with FM. Aerobic fitness, flexibility and strength are all decreased due to lack of activity rather than the disease. Four steps were outlined to improve muscle fitness:

1. Alignment of body, breathing and relaxation
2. Flexibility by stretching with rest and relaxation between moves
3. Resistance training to build core strength (maximum of twice weekly, and avoidance during relapse)
4. Endurance training for 20 minutes 2-3 times weekly of low to moderate intensity

Repetition and holding poses should be avoided. During relapses there should be emphasis on reducing level of exercise, decreasing endurance, hydrating well and using warmth and medication. The patient should be encouraged not to stop altogether. Patient needs to constantly "hold back" to avoid the roller coaster crash and burn effect. Exercise needs to be fun with extrinsic rewards and group adhesion.

Cognitive Behaviour Therapy workshop

F. Friedberg (Stonybrook) explained the importance of understanding and utilising CBT in the management of CFS. He gave a detailed overview of his approach point-

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ing out that many CFS patients often had poor coping styles leading to greater illness severity. For improvement to occur there needs to be sustained lifestyle change, with efforts equal to that seen in investments in alternative treatments. If a full programme is undertaken for 6 months, there is likely to be at least 20% improvement and 50% is possible. Relaxation, sleep, anger management, pacing with graded activity, easing into pleasurable feelings and enlisting support networks are included in Friedberg's protocol.

E. Van Hoof (Brussels, Belgium) continued with this workshop presentation and stressed that there should be an aim to change cognition and behaviour to improve quality of life and allow life within the constraints of the illness. She utilises a phase approach, which includes: explanation and understanding, illness awareness and shift of locus of control, stabilisation based on behavioural therapy, restructuring and re-integration. Patients often improve by not focussing on bodily symptoms and by setting realistic goals.

12 weeks of CBT group therapy is utilised by M. Segota (Miami FL) taking a stress management and relaxation (SMART) approach aiming to interrupt the CFS-stress-illness continuum. In each 2 hour session, 90 minutes is spent on CBT and 30 minutes using relaxation and imagery. The primary goal is to provide cognitive skills, optimise activity, relieve anxiety etc. The sessions cover stress management, cognitive restructuring, resolving interpersonal difficulties, self esteem enhancement and personal fulfilment. Working in groups has been shown to be cost effective.

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Awareness Night 2005

May 11, 2005
Burnside Civic Centre
7:30pm

Key note speaker:
Christine Hunter of the
Alison Hunter Memorial Foundation

The Alison Hunter Memorial Foundation is a Sydney-based foundation that raises money for CFS research, and has been an important advocacy group within the medical system raising awareness of the need for more research and for more positive attitudes to CFS within the Australian health and research systems.

There will be a panel of other speakers. We'll let you know more later.

Meanwhile, put this important event in your diary.

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.

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, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.

Support Groups: Metro

Adelaide Support Group

The Adelaide Support Group meets on the fourth Tuesday of each month.

Venue: Uniting Pilgrim Church, 14 Flinders Street, Adelaide (behind Adelaide City Council).
Time: 12:00 pm to 2:00 pm.
Contact: Darryl Turner.
Phone: The office on (08) 8410 8929 to confirm attendance.
Dates
(2005): January 25 (cancelled); February 22; March 22; April 26; May 24; June 28; July 26; August 23; September 27; October 25; November 22; December 27.

Glenelg Support Group

The Glenelg Support Group meets on the third Wednesday of each month.

Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg.
Time: 1:00 pm.
Contact: Marion Hansen.
Phone: Marion on (08) 8234 2342.
Dates
(2005): January 19; February 16; March 16; April 20; May 18; June 15; July 20; August 17; September 21; October 19; November 16; December 21.

Northern Metropolitan Support Group

Contact: Merindah Whitby.
Phone: Merindah on (08) 8287 3195.

Support Groups: Country

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 McFaull (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

[redacted]

Youth Support: SAYME

South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronica Fatigue Syndrome together at the same place at the same time to relax, chill out, and to have a bit of fun within the limits of their condition and to develop a network of friends with Chronic Fatigue Syndrome that understand the issues we face. Together we can help each other through the tough times.

The Youth group is open to young people up until the age of 30. Please contact Donna Briese in the office on Wednesdays on **8410 8929** for a program of events or if you would like to receive our quarterly magazine. We would love to meet you.

Notes

Notes

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