



Talking *Point*

2005 Issue 2

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

*Your
Society*



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ME/CFS Society (SA) Inc.

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

- promote recognition and understanding of the disease among the medical profession and the wider community
- provide information and support for 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 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:
August 1, 2005

Talking Point

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

Talking Point Subscriptions:

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

Management Committee 2004/2005

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

President: Peter Cahalan

Vice-President: (vacant)

Honorary Secretary: Peter Mitchell

Treasurer: Geoff Wilson

Management Committee Members:

Donna Brieze, 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.

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



Disclaimer

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

Contents

Society matters

From the President, <i>by Peter Cahalan</i>	4
Management Committee meeting photos.....	6
Northern Yorke Peninsula Support Group news.....	7
Arthritis SA.....	7

Articles

"Moving Towards Wellness 2005" course.....	8
WEA course guide	9
Letter to the editor.....	10
Federal Budget announcement for people with disabilities	11
Disability Support Pensions – bias against people with CFS, <i>by Rosemary Smith</i>	12
Connect to the Internet cheaply, <i>by Michael Ritter</i>	14
IT learning/support opportunities for CFS members in South Australia, <i>by I and D Chessell</i>	15
Educating a child with ME/CFS in South Australia, <i>by Jenni Gay</i>	16
Kirsty Prior and her research	18
Review of <i>Osler's Web</i> , <i>by Peter Mitchell</i>	20
Internet resource on the case against graded exercise therapy and CBT, <i>by Jodi Bassett</i>	21
Fatigue schmatigue, <i>by Jodi Bassett</i>	22

Medical pages

Dietary guidelines in CFS, <i>by Dr Rosamund Vallings</i>	26
Coeliac Disease – the great mimic, <i>by Dr Ian Brighthope</i>	28
Exercise and allergens possible biomarkers	29

Miscellaneous

Information about ME/CFS	30
Support groups and contact numbers.....	31

Advertising

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From the President

By **Peter Cahalan**

Page 4

June 2005

Well, this is the letter you get when the president and committee are flat out. A short one!

As I write, we're preparing for two linked events which have been occupying much of my time over the past month or so. By the time you read this, however, they'll be over and done.

The first is the significant public meeting to be addressed by internationally important CFS researcher Prof Kenny De Meirleir. That's on the evening of June 2 and replaces the originally scheduled annual awareness night on May 11.

(You might recall that we celebrate May 12 as International CFS Day because it's Florence Nightingale's birthday and she's generally held to have suffered from CFS. I was interested to read recently that another eminent Victorian, Charles Darwin, is now thought to have been hit by it also.)

On the two days after the meeting Prof Kenny De Meirleir and a group of Australian researchers will have locked themselves away at the University of Adelaide to work on sharpening the definition of CFS.

This event has been brought to Adelaide courtesy of the indefatigable Christine Hunter of the Alison Hunter Memorial Foundation in Sydney. She unavailingly sought Federal funding for it. We contributed \$2000 towards the estimated overall costs of around \$7 000 and other societies and the Foundation have contributed others.

As I write we still face a shortfall. But we're not daunted. Our committee had no hesitation in committing the funds – the biggest amount of any State society – because we believe that this sort of meeting is a potentially powerful way of improving the political position of our cause here and elsewhere. Certainly the attention it

will bring to South Australia will be gratifying.

Meanwhile, life goes on. It's great to record again that the Society's focus on improving communications with members is drawing a very positive response from you. The tempo of correspondence to us has gone up. And we have noted a small but gratifying increase in the number of new members. It's not a flood, but the trend is in the right direction.

If you have access to the Internet, can I as usual direct your attention to our excellent website, managed by Peter Scott? We have been adding new items to the site at the rate of two or more a week since February and recently the pace has been more like three a week. We posted an item about the Federal Budget and the Disability Support Pension within a day and a half of the Budget.

We've added a number of new medical articles drawn to our attention by our medical experts. You can find them either on the main page or under the In the News and Medical sections of the site. So please keep an eye on it.

Badge Day is also looming on May 27. For the first time in

four years, our finances at this time of the year have not shot from the red to the black by a late donation from an anonymous donor. She has given us \$12 000 each year and this has cemented our financial position and given us the capacity to contribute to the De Meirleir workshop and so on.

This year, however, the situation is that our basic costs are about \$20 000 for the year. Memberships contribute about a third of that. The rest has to be found via Badge Day, donations and any other source we can find the time to pursue. We're grateful to the good-sized team of volunteers who have offered to rattle the tin on the 27th.

(Continued on page 5)



(Continued from page 4)

In that regard, I was delighted today to learn that my own workplace, the SA Tourism Commission, has decided to make the Society its first charity of choice in a new program of Friday casual clothes day fundraisers. We get six Fridays and I'm hoping that it raises a few hundred dollars for us. We got the front position because I stood up at our staff meeting when it was announced and put the hard word on the organisers! If you can get your own workplace to do something like that for the Society, that would be great. Even just a few hundred dollars from each venture will start adding up and we'll start getting into the thousands.

And while I think of it – our thanks to Carole Carroll and the great bunch of volunteers who hit the Adelaide Railway Station with badges on the Friday morning of Pope Paul II's memorial mass at Adelaide Oval. They took \$600 – about three times what I'd expected. I assumed it must be all those kind Roman Catholics heading off to the oval. But I'm told the givers were just your normal grizzled, grumpy commuters. Well done to them and our gang.

And now I must go. I hope that by the time you get this I might have had a chance to see you at the De Meirleir public meeting.

I wish you the best health that it is sensible to wish you. And I hope as always that if you are not physically well then you are strong in mind and spirit.

Peter Cahalan
President



Page 5

Talking Point – 2005 Issue 2

OSLER'S WEB

Inside the Labyrinth of the
Chronic Fatigue Syndrome
Epidemic

HILLARY JOHNSON

Peter Mitchell, Honorary Secretary of the ME/CFS Society (SA) Inc, has reviewed *Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic*, by Hillary Johnson. Read Peter's review on page 20.

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

Management Committee meeting photos

March 2005.

Page 6

Talking Point – 2005 Issue 2



From left:
Peter Cahalan (President); **Geoff Wilson** (Treasurer).



From left:
Emma Wing (Committee member); **Marg Wing** (Committee member); **Adrian Hill**. (Committee member).



From left:
Donna Briese (Committee member); **Emma Wing** (Committee member); **Marg Wing** (Committee member); **Adrian Hill** (Committee member).



From left:
Geoff Wilson (Treasurer); **Donna Briese** (Committee member).



From left:
Adrian Hill (Committee member); **Peter Mitchell** (Honorary Secretary)

Northern Yorke Peninsula Support Group news

Jane Gill has stepped down as convenor of the Northern Yorke Peninsula support group. The Society thanks her for her fabulous work over the past few years.

We also wish her and the Gill family well as they deal with the news that one or more of their children might have a rare disorder known as Fanconi Anaemia.

The Society welcomes David Shepherd as the new convenor for the Support Group.

David lives in Balaklava and his contact details are:

Phone: (08) 8862 1665

Email: shepherd@rbe.net.au

Page 7

Talking Point – 2005 Issue 2

Arthritis SA



Representatives from Arthritis SA and ME/CFS SA met at Arthritis SA headquarters in March to discuss areas of common interest and possible future combined meetings.

From left:

Cathie Powell (Chair of Fibromyalgia SA committee);

Peter Mitchell (Honorary Secretary, ME/CFS SA);

Peter Cahalan (President, ME/CFS SA); and

Pauline Kelly (Education Services Manager, Arthritis SA).

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

"Moving Towards Wellness 2005" course

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

Page 8

Talking Point – 2005 Issue 2

ARTHRITIS FOUNDATION

Unit 1, 202 Glen Osmond Road, Fullarton

Day Courses

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

October 25 to November 29 (Tuesdays) – 7:00 to 9:30pm

ELIZABETH – RESTHAVEN NORTHERN THERAPY SERVICES

Gillingham Road, Elizabeth

Phone Rosalind at Resthaven on 8252 6811

May 25 to June 29 (Wednesdays) – 10:00am to 12:30pm

MARION – MARION R.S.L.

31-39 Norfolk Road, Marion

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.

May 24 to June 28 (Tuesdays) – 1:00 to 3:30pm

August 9 to September 14 (Tuesdays) – 1:00 to 3:30pm

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

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

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.

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



WEA course guide

Introduction

The WEA (www.wea-sa.com.au) offers a discount fee on most of its courses to full-time students and people who have or are eligible for a Seniors Card. The discount fee (disc.) is different to the concession fee (conc.). The concession fee is available only to those who have been means-tested by the federal government.

To obtain the discount fee, evidence is required. Please send or fax a photocopy of your Student Card or Seniors Card with your enrolment, or enrol in person, with your card, at the WEA Centre, 223 Angas Street, Adelaide, during office hours 9am to 5pm weekdays.

Recipients of Social Security or Austudy/Abstudy – up to 35% off

A concession fee of up to 35% is available on most WEA courses for pensioners, unemployed people, supporting parents and any other adult who possesses a Health Benefits or Health Care Card or receives Austudy or Abstudy. Concession fees are not available on some courses.

We need evidence that you are eligible – please send or fax a photocopy of your card or letter, or enrol in person with your card at the WEA Centre, 223 Angas Street, Adelaide, during office hours 9am to 5pm weekdays.

People with a disability – up to 75% off

The WEA's Integration and Access Project offers up to 75% reduction on most course fees to any adult who has a disability and who wishes to enrol in a WEA course.



Integration and Access Project

The WEA's Integration and Access Project (IAP) offers a range of services to any adult who has a disability and who wishes to join in mainstream education and enrol in a WEA course.

To encourage and support the involvement of people with a disability, IAP offers:

- Physical access: ramps and the front and rear of the WEA Centre and accessible car parking.
- Fee concession: up to 75% reduction on most course fees (subsidised by the South Australian government's Disability Services Office)
- Assistance from volunteer companions.
- Free place for a personal supporter.
- Adaptive equipment for use with computers and sign language aides.
- Free transport via Access cabs (conditions apply).

For further information please contact Carolyn on:
Phone: 8223 1272 or TTY 8224 0189
Fax: 8232 3690
Email: iap@wea-sa.com.au



Letter to the editor

Naturopaths and Agent Orange

Page 10

Talking Point – 2005 Issue 2

“And ye shall know the truth,
and the truth shall make you free”
– John 8:32

Dear Editor,

I am the sister of Lyn Rossitor, the original editor of this magazine. Anyone related to a Vietnam veteran, or anyone who has worked, lived in or near a market garden, fruit orchard, vineyard, motor vehicle repair industry or in the processing plants (of the oils and margarine made from vegetable plants (canola etc) – even the farmers/farm hands on these farms – or anyone with mercury dental fillings would find my family's experiences of interest.

My eldest daughter came down with ME/CFS at the age of 18 in 1991 – at the same time her aunt (and my sister) Lyn was still suffering from CFS (she was bedridden the first two years then up and down for the next 10, suffering digestive problems, aches and pains in muscles and joints, anxiety attacks, allergies etc, along with the chronic fatigue). In 1999 I also came down with Chronic Fatigue.

In 2003, a friend who had suffered chronic fatigue for 12 months plus went to a naturopath and had a live blood test. The naturopath found it was because the mercury in his fillings was leaking and seeping into his body (via his bloodstream) so our daughter decided to go and have a live blood test, too. The naturopath found her blood cells all joined and stacked up like coins one on top of the other and that she had a toxin in her. The naturopath then tested her for all the common toxins in Australia but she had none of these. The naturopath was puzzled because our daughter at that time had not been out of Australia. Our daughter asked if it would have anything to do with her dad, Jeff, being in Vietnam. The naturopath had found 'Agent Orange' (245T) in Vietnam veterans before, but never in a child of a Vietnam veteran.

Our daughter had 'Agent Orange' and I had 'Agent Orange' as well. My husband and our other five children who were born (9 years to 17 years after their sister) not only had 'Agent Orange' but heavy metal poisoning as well (it coincides with Jeff working with petrol/turps

(other motor trade chemicals).

Since being detoxified, none of our family has suffered from Chronic Fatigue, and our allergies (food, respiratory) have all but disappeared. My husband, myself and our eldest daughter who had 'Agent Orange' poisoning for 30 plus years still suffer depression, anxiety attacks (shaking) and other nervous system and brain dysfunctions but are taking a medicine which contains serotonin to replace that which the 'Agent Orange' had robbed us, but as I stated before we have no Chronic Fatigue!

Only people who have had true Chronic Fatigue could understand what a blessing it is not to have it anymore.

A friend of mine, who for years had had Chronic Fatigue went and had a live blood test at the same clinic as us. She had had no contact with Vietnam, but a toxin in her blood was found to be one that had been used in the orchards where she had lived for many years earlier in her married life.

My niece works for a winery in the Barossa Valley and she was telling her mother just recently that some of the people who had worked in the vineyards for many years were sick with Chronic Fatigue and other symptoms just like Uncle Jeff and his family.

I was speaking to a new friend I made a few weeks ago and she was telling me about her family. Her brother had had Chronic Fatigue for three years (he is now in his early 40s) and for many years, he has grown (sprayed) strawberries and lived near orchards in the Adelaide Hills.

I hope my letter helps at least some of your members. The naturopath who has a test for 'Agent Orange' is, as far as I know, the only one in South Australia but many naturopaths give live blood tests and have detoxifying procedures for mercury. You have my permission to use all of this information in this letter, and if you wish to know more (e.g. the naturopath who tested my family) you can write to me and or ring me on (08) 8389 5260 and I will be only too willing to help in anyway that I can.

Yours sincerely,
Mrs R Hill (now free from Chronic Fatigue)
Lobethal

Federal Budget announcement for people with disabilities

The Federal Government, in its 2005-06 Budget, has announced changes to the Disability Support Pension. Of interest to ME/CFS Society (SA) Inc members will be the following section which appears in the Federal Government's booklet, Welfare to Work, released on May 10, 2005, and on its Web page: www.finance.gov.au/budget/2005-06/overview2/html/welfare_05.htm.

Page 11

Welfare to Work: What does it mean for people with disabilities?

Current Disability Support Pension (DSP) recipients will not be required to seek work, but will be encouraged to do so and will remain on DSP. After 1 July 2006, people with disabilities seeking to go on DSP who can work 15-29 hours per week will have an obligation and payment that reflects their capacity to work.

Current Disability Support Pensioners

People in receipt of Disability Support Pension (DSP) prior to 1 July 2006 will remain on DSP with no part-time work obligation. They will be subject to the normal review process for DSP which will apply the existing eligibility criteria based on being able to work 30 hours per week.

Payment applicants after 1 July 2006

People seeking to go on DSP after 1 July 2006 will receive DSP if they are assessed as being incapable of 15 hours work a week at award wages. If they are capable of working 15-29 hours per week, they will receive enhanced Newstart and be subject to an obligation to seek part-time work.

Payment applicants after Budget night

People applying for DSP between 11 May 2005 and 30 June 2006 will be assessed for DSP under the existing 30 hours test. However, they will be reassessed in periodic reviews (usually every two or five years) against the 15-29 hour test after 1 July 2006. Those able to work 15-29 hours per week will have an obligation to seek part-time work and will receive enhanced Newstart.

Other benefits for people with disabilities

People with disabilities with a part-time obligation will receive the Pensioner Concession Card and Pharmaceutical Allowance. They may also be eligible for a higher rate of Mobility Allowance of \$100 per fortnight.

New obligation and payment arrangements for people with disabilities

Income support recipient

Obligation Payment

Disability Support Pensions – bias against people with CFS

Page 12 Here's a letter sent by **Rosemary Smith**, a Victorian woman with CFS to her local Federal MP. She has circulated it to State associations.

Last Thursday I talked with your assistant regarding some disturbing statistics that I found on a DEWR web-site regarding DSP grants for people with Chronic Fatigue/Post-Viral Fatigue Syndrome. The statistics, taken from the FACS database, detailed a 44.94% decrease in the proportion of people with CF/PVFS claiming DSP between June 2002 and June 2004. By comparison, the total number of people on DSP rose by 8.89% during this time. Given that no new treatments for PVFS have been made available to the public in the last few years I find the fall in the number of DSP grants for this condition very disturbing.

The statistics quoted appear to refer to Disability Table 20, which is also used to assess conditions such as morbid obesity and organ transplant recipients with chronic rejection syndrome. Cancer is also mentioned but given a separate classification in these statistics. ME/CFS would most likely be the most common use for table 20, CF/PVFS. Most other conditions listed with ME/CFS with chronic fatigue as a symptom are easily validated and would not account for the decrease in CF/PVFS numbers.

Don't be fooled by the trivial sounding name, CFS is a condition which according to the RACP guidelines (2002), is comparable in terms of disability with conditions like Multiple Sclerosis and Rheumatoid Arthritis. William Reeves, when talking about a recent CDC study into CFS in Wichita Kansas, compared the severity of CFS to conditions like COPD and heart disease. In a study conducted in Richmond Valley NSW, 43% of sufferers were unable to work or attend school. (Lloyd 1992)

Although somewhat of a taboo topic, the recovery rate for people with CFS who are sick enough to qualify for the DSP is very small, and I have been unable to find reliable statistics, simply because a large scale study has not been done. The closest I can offer you are again from the RACP guidelines:

"In people who have been severely disabled and unable to work for more than

five years, the probability of substantial improvement within 10 years is less than 10% – 20%. This may be regarded as 'permanent disability' for medico legal purposes." (RACP guidelines pg. S47)

Charles Shepherd, a prominent English doctor and CFS advocate believes that anyone who has been unwell for more than four years and no significant degree of recovery has taken place, the possibility of permanent disablement must be taken very seriously. My own view is that it would be very unfair not to grant a pension at this stage. (Shepherd 1998)

Regarding recovery, Reyes states that "recovery" rates for CFIDS are unclear. According to one of the few published studies, the probability of significant improvement was about 30% during the first five years of illness and 48% during the first 10 years. However, even "recovered" patients stated that they still had some CFIDS symptoms, and one-third had relapsed six months later. (Reyes M. 1999)

The epidemiology statistics I have seen estimate a prevalence of between 0.2% and 0.7% of the general population. (RACP 2002, CDC 2004) By June 2004 the proportion of people on the DSP for CFS as a primary diagnosis was 0.5%.

Seen in this context, something is very wrong with the way Centrelink is dealing with CFS patients. Here again I can only offer suggestions; maybe the doctors and social workers making the decisions to grant DSP have become more ill-informed in recent years but most likely there's increased pressure from administrative sources to reduce the numbers of people on welfare.

Not only is it difficult to prove using standard medical testing that a person has CFS, sufferers tend to react very adversely to stress and would be much less likely to initiate an appeal. My doctor, Donald Lewis, whose practice treats CFS and Fibromyalgia patients almost

(Continued on page 13)

(Continued from page 12)

exclusively, has said not to apply for DSP because it is not worth the impact stress will have on my health. In addition to this, the CFS lobby is weak, under-funded and cannot adequately support people in their attempts to claim their entitlements. I suspect that many people are not receiving DSP simply because they are too sick to endure the process of appealing an inaccurate assessment. Consequently, Centrelink is choosing those that can deal with the bureaucracy above those that most need its help.

Below are a summary of the statistics I found at www.jobable.gov.au/DSPreport/default.asp.

2004

New Claims Granted: 6

Total Customers: 3435

Total as %: 0.5%

2003

New Claims Granted: 216

Total Customers: 4870

Total as %: 0.7%

2002

New Claims Granted: 1007

Total Customers: 6239

Total as %: 0.95%

2001

New Claims Granted: 955

Total Customers: 5490

Total as %: 0.88%

From 2002-2004 the number of people on DSP increased by 8.89%. All other medical conditions had an

increase in the number of people on DSP. But the number of people with "Chronic Fatigue/Post Viral Syndrome" has decreased by 44.94%. This is the only medical condition that decreased.

From 2002 to 2004 there was an increase of:

[Condition]	[No of people]	[%]
Acquired brain impairment	671	4.03%
Amputation	35	2.08%
Cancer/tumor	527	4.11%
CFS/Post Viral Syndrome	-2,804	-44.94%
Chronic Pain	986	20.77%
Circulatory system	1,022	2.88%
Congenital abnormality	693	6.47%
Endocrine and immune system	2,488	16.54%
Intellectual/learning	7,363	10.97%
Muscular-skeletal and connective tissue	17,363	7.90%
Nervous system	2,145	10.46%
Psychological/psychiatric	21,050	13.49%
Respiratory system	69	0.35%
Skin disorders and burns	162	9.66%
Visceral disorder	102	1.08%

I would appreciate it greatly if you would be able to verify these statistics and find some more specific information regarding DSP grants for CFS; namely the numbers of rejected claims, the numbers of appeals and their outcomes and, if possible, the numbers of people whose primary diagnoses were changed from CF/PVFS to other conditions.

Thank you for your time and consideration.

Yours sincerely,

Rosemary Smith



Problems with Fibromyalgia? The FM Association can help.

Fibromyalgia SA c/o The Arthritis Foundation of SA Inc.,
Unit 1/202-208 Glen Osmond Road, Fullarton SA 5063.
Phone (08) 8379 5711,
Freecall 1800 011 041.



Connect to the Internet cheaply

By **Michael Ritter**, Information Technology Infrastructure Coordinator for the ME/CFS Society (SA) Inc.

Page 14

Talking Point – 2005 Issue 2

Did you know there are cheap ways of getting people that are on a disability benefit on a cheap computer and have access to the Internet for free? It's simple – this guide will show you how.

Acquiring a cheap computer

Recently, one of our members went about getting a cheap computer to connect to the Internet. She contacted IT share on 8339 3116 (www.itshare.org.au) and talked to one of their people. When you apply you'll be placed on a waiting list. The computer is free but the modem and a monitor will cost you about \$75 (or less).

You will need a space in your home for the computer – somewhere close to the power and phone outlet for connecting to the Internet.

Running the Linux operating system – why?

Because Linux is cheap. In fact, it's free. Linux is a copy of a 30-year-old operating system, UNIX. Linux is much older and therefore more stable than Windows XP as it has had many years of refinement by computer professionals before it even got to the PC.

There are a number of 'flavours' around but IT share will put the Ubuntu version of Linux on your machine. It has all the software components you will need: email; Web browsers; Open Office (word processing); and Xwindows – all free.

Connecting to the Internet – what's available?

You can get an email account from Enablenet, run by the Disability and Information Resource Centre (195 Gillies Street), and it will cost you nothing. Phone Phil on 8236 0555 to apply for a free account.

You have access only to Web sites that have relevance to disabilities, but there are hundreds.

What to do while on the Internet

Email

If you are a member, you can send us an email (sacfs@sacfs.asn.au) and request to be included in our (nearly) weekly bulk email. It will cost you nothing, and so far we at the office have sent over 4,200 email messages to our members. Send us an email before a Wednesday or Thursday and you'll receive a reply by one of our office staff.

Whilst on it why not email your local parliamentary member and ask them for a permanent cure for CFS, or do the next best thing. A permanent research project at the local University. You could also ask for the ME/CFS organization to be permanently funded like that of interstate organizations. Then email the opposition to tell them the present government is not doing enough for you.

You can find the best doctors in the world on CFS and email them. You can contact doctors not just in Adelaide but ones from overseas in America, Canada and the United Kingdom. The more experts you contact, the more ideas you can get on managing your particular symptoms.

The World Wide Web

Once you have become competent with email, then you can move on to the World Wide Web part of the Internet.

The Web is like walking into the biggest library on the Earth, with millions of computers all hooked into each other.

To find all sorts of information, you can use Google (www.google.com.au). Google is an Internet search engine (equivalent to a library's card catalogue), and using it is straightforward. If, for example, you wish to find out more about CFS and fibromyalgia, just type in those two words. Google will give you a list of links to the relevant Web sites. Clicking on any of the links will take you to those Web sites.

IT learning/support opportunities for CFS members in South Australia

By I and D Chessell.

Page 15

It seems that 'IT is the new literacy' to overcome the physical limitations and isolation of CFS members.

Initially we thought these needs would be met by a form of the 'Home Tutor Scheme'. This old scheme, now superseded by other programs, matched literate volunteers with usually teenage school students and young adults needing help with English expression, communication and general approaches to study. So I explored whether there is a 'IT is the new Literacy' home tutor or equivalent program, what is available, what 'could be' available etc.

Focus of search

I focussed on home-based or near-home, low-cost, slow-paced and friendly environments, with some opportunities for ongoing 'buddy schemes' or other ongoing support and contact.

Details of IT learning/support opportunities

Most available **home tutor programs** are focussed on special needs people attending/enrolled in formal study programs. Mostly IT learning/support for CFS members doesn't fit the criteria, being informal Adult Education. The present formal programs include: the State-run English Language Services providing English programs to migrants with Home Tutoring available; Country Women's Association Cancer Scholarship and Home Tutor program (and similar other programs) for children with cancer and other children in their family; and the University of South Australia home tutor program for enrolled Aboriginal students.

Primary and high schools (public and private) tend to use volunteers at school for extra English and IT tuition. However, quite a proportion of Schools have weekend IT classes and access for parents and friends etc, and offer evening access variably. We suggest people ring and ask a local school or ask a neighbour with children.

Community Centres offer cheap IT courses with much support.



A resource worth visiting online is the Community Houses / South Australian Community Education website. It includes a list of addresses (Community Houses SA) including about 55 Community and Neighbourhood Centres in metropolitan Adelaide where a range of Adult Education classes are run, many in IT. These are mostly in a separate quiet room of each centre with additional hours use of computers available at other times. People are tutored/taught in small informal groups or individually. Teaching can be in a variety of languages, there are generally some day and some evening group/individual tuition, all for little cost, most with concessions, and most well staffed by experienced people who are not in such a 'hurry' so they can provide support and encouragement at a good pace. Mostly, once CFS people have attended a group session or two, informal arrangements can be made to provide a 'lift home'. Apparently group members then assist one another online or group tutors are available, or the centre has a continuing system for computer usage with other users and some tutors variously available for questions.

Also available is the Community Houses & SA Learn-Scope (flexiblelearning.net.au/learnscope) IT project with Adelaide TAFE (www.tafe.sa.gov.au). (Adult Ed. IT) Worth watching as this develops.

Educating a child with ME/CFS in South Australia

This article was prepared from notes taken by **Jenni Gay** at the ME/CFS Society (SA) Inc's seminar in March. Thanks to Jenni, to Open Access College counsellors Julie Harwood and Kaye Naughton, and to parents Sue Frazer and Cassie Barrett.

During 2005, we are preparing a kit for schools and parents, and this information will be summarised in that kit.

Open Access College

If your child or teenager is unable to attend school personally, a useful option is the Open Access College (OAC) whose administration is based at Marden*. It is part of the Education Dept and follows the SA Curriculum as would any SA school. The OAC's programmes are available to students who are unable to attend their own school for a range of reasons including medical conditions such as ME/CFS. In 2005, there were approximately 20 to 25 students with ME/CFS enrolled in the OAC.

Adults with CFS can also do subjects at home by distance education.

OAC consists of 3 separate schools:

- R-10 School
- Senior Secondary School
- School of the Air which is for the Primary years only and is based at Pt Augusta

R-10 School

In order to be able to part of the R-10 school:

1. Parents need to talk to the student counsellor at their child's school to see if that school can be flexible and offer a suitable curriculum;
2. If not, then parents need to obtain a doctor's certificate and health care plan;
3. Parents then contact the R-10 counsellor (who has plenty of experience dealing with children with disabilities) at OAC and negotiate the placement of their child with the school; and
4. The OAC always tries to maintain links with the student's old school (which could be just going back for visits or doing one favourite subject with their friends).

The Student's Programme

- While workbooks, CD-ROMs and videos are provided by the OAC, the student's programme is tailored by their teachers to match the needs of individual students.
- Each student has a half hour phone lesson once a week for each subject they are taking. The college is moving to using online chat sessions with 5 or 6 students at a time which is something young people are very comfortable with.
- A support teacher is allocated to each student.
 - The teachers organise some activities and excursions during the year in order to connect the students so they have some personal contact with other as they can become very isolated.



Senior Secondary School

If the student is under 16 years of age, they must be enrolled in their own school as well as OAC.

If they are over 16 years, they can enrol directly with the

OAC.

The lessons are of longer duration than for the R-10 school but still based on phone and Internet contact.

The OAC will organise test supervisors so that the students can sit for their Year 11 and 12 exams (South Australian Certificate of Education).

(Continued on page 17)

(Continued from page 16)

Problems students may encounter

- Isolation
- Work deadlines – but these can be negotiated with teachers
- Students can apply for special consideration at Year 11 and 12 eg spreading a semester's study over 1 year
- SSABSA (the examining body for Yr 11 and 12) cannot be flexible over exams
- The subject load is set for each student individually depending on their ability to study
- Not a lot of visiting teachers in the metro area but there are itinerant teachers for outback students.

* Open Access College: 1-37 Marden Road, Marden.
Phone: 8309 3500.

From the parents' perspective

- Take it one day at a time
- Can take family members some time to accept that child/sibling has ME/CFS.
- Social contact is immensely important and for some very ill students; email, text messages, internet chat, portable and mobile phones (including headsets for those too exhausted to hold the phone) and VOIP (new technology of voice over internet protocol) is vital. This also allows them to share their successes with fellow sufferers who can relate to these triumphs.
- Parents have to be an advocate for child both in education and medical matters.
- Student may be ostracised by friends who can't understand or accept the limitations this condition imposes on their formerly active friend.
- Important to help student to set realistic short term goals.
- Celebrate every success no matter how small!
- OAC staff are marvellously supportive and will often go the extra mile to help a student.
- Other siblings can miss out on parental attention which is focussed on sick sibling and this can cause jealousy and resentment.
- Have a child/teenager can leave parents without time for themselves, their own interests and activities or their wider family and makes travelling difficult or impossible.

- Some of these children/teenagers become very insightful as a result of their illness and are often very tuned into other people's feelings. Their isolation from friends can make them introspective and more attuned to nuances.
- Sometimes it is difficult to navigate the system as you don't always know the right questions to ask (Hint: talk to other parents).
- Parents need to be advocates for their children when faced with unsympathetic comments from the people they come into contact with.
- Stay positive as often as possible.
- Important for child/teenager to see the sun each day for a good sleep at night.
- Encourage gentle exercise if they are well enough but don't force it.
- Important to have some social contact with people who understand. A number of young people finding joining SAYME a valuable and fun support.
- Have to balance priorities and energy levels.
- Encourage your child to focus on what they can do, not what they can't do.



Kirsty Prior and her research

Kirsty Prior is a PhD student who has prepared an Illness Impact Survey that many of our members have completed. In doing so, a number of members have raised concerns about the research and its purpose. Our President, Peter Cahalan, made Kirsty aware of those concerns. Kirsty has addressed our concerns in the response following her background information about the survey. We thank her for her care in outlining the nature and purpose of her research. She is very clear that each of the illnesses to be examined is considered to be an established medical condition with underlying disease activity at a physiological and/or structural level. There is no suggestion that psychological factors played any role in people developing any of the four medical conditions she is studying.

In corresponding with Kirsty, I have also raised with her the separate concerns of some members about interpretations of a few of the questions themselves, and how some of us struggled with parts of the questionnaire. She has responded thoughtfully to the issues raised. We do encourage those members who are thinking about helping Kirsty's research, to do so. We always like to encourage research into CFS: we all know how little is being done in the field. If you find difficulty with any of the questions, our advice is to complete them as best you can, and let us know if you found any of it confusing. We can pass that information on to Kirsty.

Peter Mitchell
Honorary Secretary

Some background information about the Illness Impact Study

Kirsty Prior
PhD Student
School of Medicine
Flinders University

My research study involves people with one of four chronic medical conditions: asthma, diabetes, chronic (benign) pain or chronic fatigue syndrome (CFS). An additional group comprises people who are relatively healthy and have not been diagnosed with any of these four conditions. With the exception of those who comprise the 'healthy' sample, every other person is selected on the basis that he or she already has a particular disease/medical condition (i.e., asthma, diabetes, CFS or chronic pain). My research focuses on the variety of ways in which people *deal with* the *effects* of any illness situation. Specifically, my study aims to learn more about the variety of ways in which people think, feel and behave when they experience illness. There is no inference that such factors contribute to the *development* of illness. Each of the illnesses to be examined is considered to be an established medical condition with underlying disease activity at a physiological and/or structural level.

My study proposes that thoughts, feelings and behaviours influence the ongoing management of illness at a variety of levels (e.g., physical health, psychological well-being, social and occupational functioning, etc.). While

the degree of underlying biomedical/physiological activity certainly accounts for some of the variation in illness experiences among individuals, it is well-documented that the ways in which people think about, feel towards and behave in response to illness also account for some of the differences observed in physical, psychological, social and occupational functioning. My aim is to identify those particular ways of thinking, feeling and behaving that are associated with better physical health, irrespective of the type of underlying illness experienced. It is possible that there are general ways of responding to illness that are common to each of the chronic medical conditions being examined. Alternatively, there may be particular ways of responding that are specific to a particular illness. An understanding of such findings is of importance not only to psychologists but also medical practitioners who are centrally involved in the management of chronic illness.

A series of scales has been included in the questionnaire distributed to participants. With the exception of the health section that seeks information specific to the particular illness group, each scale is given to all participants, irrespective of their illness. None of these standard scales has been altered in any way prior to completion by a particular illness group. One of the main aims of my research is to determine the degree to which these scales are relevant to the situation of all people, irrespective of the type of illness experienced. It may well be the case that some of the scales, or certain items contained

(Continued on page 19)

(Continued from page 18)

within a scale, do not provide a useful or informative insight into the ways in which some people might manage a particular illness. Consequently, it is hoped that by obtaining responses from all participants to this standard set of scales, it will be possible to gain a clearer and more accurate insight into the variety of ways in which people deal with illness. Only then will it be possible to decide whether certain scales are relevant to the situation of particular illness groups or whether the scales presently used to understand illness-related beliefs and behaviours need to be modified so that they more appropriately reflect the unique situation associated with a particular medical condition.

Health psychology research is typically underpinned by a biopsychosocial framework. This model acknowledges contributions from all of biological or disease factors, psychological factors and social factors to the experience of health and illness. Moreover, health and illness are influenced by an *interplay* (or interaction) among these three factors; each factor can affect and be affected by any of the other factors. While we are **not** suggesting that the model explains the development of a particular medical condition (i.e., by identifying causes, etc.), it does facilitate a better understanding of how these three factors may influence the *management* of illness. For example, it is well-documented that there is considerable variation among individuals in the degree to which people experience a symptom such as pain. There is much evidence from both the medical and psychological literatures to suggest that the degree of perceived pain is a reflection of the extent to which there is an underlying biomedical abnormality (i.e., biological factor), the person's *interpretation* of the pain sensations and perceived ability to manage the pain (i.e., psychological contribution) and the manner in which other people such as family members and friends respond to any expressions/displays of pain (i.e., social factor).

Hopefully this research will provide a clearer insight into the range of strategies (both general and specific) used to deal with chronic medical conditions such as asthma, diabetes, chronic fatigue syndrome and chronic pain. It may even be possible to identify certain ways of managing these conditions that are associated with better health outcomes (e.g., fewer and less severe CFS symptoms and improved overall health). Of course, information about the nature of the underlying condition also needs to be taken into account (e.g., the severity of current symptoms, functional ability, etc.). While my research is not designed to offer any kind of 'quick-fix' or

wonderful 'cure' for any of the illnesses examined, it is hoped that the findings will at least make some small contribution to knowledge about the ongoing management of chronic illness. Perhaps the study's findings will allow health professionals to better understand the circumstances of people with chronic medical conditions such as CFS.

Response to the Society's concerns

While we generally thought the questionnaire straightforward, we did raise some specific issues with Kirsty about parts of it, particularly where they might appear to be ambiguous to a person with ME/CFS.

As mentioned above, Kirsty responded to our specific concerns, but we have agreed not to print the details of her responses at this stage, because they might influence surveys from those members yet to complete the questionnaire.

Kirsty did make this point about the questionnaire itself in her second letter to us:

"Let me emphasise that one of my aims is to re-evaluate the reliability and validity of the scales in my questionnaire booklet. Some of them have never been subjected to rigorous testing, while others were developed some time ago and are in need of updating. Indeed some of the scales have never been properly evaluated using people with CFS (nor those with diabetes, asthma and chronic pain). Many researchers and clinicians continue to use these scales in their present format without conducting a proper evaluation of them prior to their use. My present research strives to undertake a comprehensive and systematic assessment of such scales."

In the light of that commitment, which we commend, we reiterate to members taking part in the research that, if they have comments about any questions in the questionnaire, they bring those to either Kirsty's attention or to ours.

Peter Mitchell

Review of Osler's Web

By **Peter Mitchell**, Honorary Secretary, ME/CFS Society (SA) Inc. *Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic*, Hillary Johnson, Crown Publishers 1996.

Page 20

Talking Point – 2005 Issue 2

You may ask why I would bother to review a book published in 1996, and not updated since. The answer is, because it has much to say about what is still happening; why the illness was labelled "yuppie flu"; why "chronic fatigue syndrome" was used as a label by government scientists in the USA (in the face of protest from those who knew much more about the illness than they did); and why they insisted on retaining the title in the face of continued protests. You can often understand much about a current situation by studying its origins, and this book does that.

I will use the blurb to summarise the book, because it says most of what I would anyway:

"A relentless, meticulous, and highly persuasive expose by a journalist who spent nine years investigating the medical research establishment's failure to take seriously chronic fatigue syndrome (CFS).

"...Johnson interviewed hundreds of people: CFS patients, physicians treating them, and researchers throughout the country. ... Her enormous cast of characters features Dan Peterson and Paul Cheney, physicians at Incline Village, Nevada, whose concern about the outbreak in their community eventually led to a hasty CDC investigation; Jon Kaplan and Gary Holmes, CDC epidemiologists cynical about the reality of an illness that did not fit any disease model they were familiar with; Elaine DeFreitas of the Wistar Institute in Philadelphia, whose finding of a new retrovirus in CFS patients could not be replicated by CDC virologists; and Stephen Straus, chief investigator for CFS at the National Institute of Allergy and Infectious Diseases, who has dismissed CFS as a psychiatric disorder for which patients are partly to blame. In a chronology that runs from 1984 to 1994, Johnson crams in fact after telling fact, building up a dismaying picture of a rigid and haughty biomedical research establishment unwill-

ing or unable to respond to the challenge of a multifaceted disease..." (*Kirkus Reviews*)

The book has villains and heroes. The prime villain is undoubtedly Stephen Straus, who bobs up again and again, like a villain in a melodrama. Straus was a scientist used throughout the whole period covered by the book as chief advisor on CFS to the US government and the community. He had enormous influence on the lack of acceptance of CFS as other than a psychiatric illness in the US. If the author is to be believed, he maintained a skeptical and scoffing attitude to sufferers throughout that time, and she clearly expects he will be reviled by medical history.

An institutional villain is the group of US government scientists at the Centres for Disease Control and the National Institutes of Health, many of whom were actively and derisively mocking of the people they were supposed to be studying. Their administrators are taken to task by Johnson for openly defying Congress. It seems that members of Congress even in these early days were supportive of research into CFS, but the medical bureaucracy spent moneys targeted at CFS on everything but that disease, then falsely reported to Congress that they were actively pursuing their CFS research.

On the side of the heroes, we have first of all Dan Peterson and Paul Cheney, who were GPs at a small but prosperous ski town called Incline Village on Lake Tahoe in Nevada, when dozens of cases of a mysterious illness started appearing. Peterson and Cheney first identified the illness, and doggedly tried to get the government to recognise it and begin studies on it. They sacrificed much of their lives, energies and careers to the pursuit of this disease and the support of their patients.

The second half of the book focuses partly on Elaine De Freitas, researcher, who was convinced she had found a new retrovirus which was causing the illness. She was eventually attacked by the government scientists and abandoned by the US patients' CFIDS association.

(Continued on page 21)

(Continued from page 20)

There is lots of bad news in here, but to understand why we are stalled in our current situation, it will help you to read this book. If you have ever wondered why it seems that we can't shift from this mindset that CFS is "all in the mind", your answer probably lies in these pages. If you wonder why the US has not led the field more strongly in the field of CFS research, you may find an answer here. And you may also learn why "chronic fatigue syndrome" as a name has been a millstone around the neck of sufferers and their advocates for twenty years. It's all in there, and a persistent reader may be rewarded.

A couple of warnings first. One, Johnson is a very thorough researcher, and this is a very long and detailed book (700 pages). Two, it is very technical at times. Three, she has a journalistic style, where she swings back and forth from place to place and situation to situation continually. You may like that style, you may not. You could probably dip in and out of it, but I didn't. It is not for the faint-hearted, nor for those of us in the midst of the dreaded "brain fog".

Why the title *Osler's Web*? Sir William Osler was a British Canadian physician and teacher who lived from 1849 to 1919. He was renowned for his descriptive and diagnostic skills. It is Paul Cheney who first describes Osler's web in the book when he puts the challenge in the context of "what Sir William Osler was famous for being able to do – defining an illness well enough clinically so that you could study it long enough to eventually ferret out those objective features. The bench researchers are going to take us out of Osler's web." What Osler was also famous for, and what he taught his students, was the importance of listening to the patient, and keeping what he called an "open minded watchfulness", for "it is not... that some people do not know what to do with truth when it is offered them. but the tragic fate is to reach, after years of patient search, a condition of mind-blindness, in which the truth is not recognized, though it stares you in the face."

Lastly, those who have been around the CFS scene for a while may enjoy pages 324-7, where NSW Prof. John Dwyer heroically takes on the cause of people with CFS and their doctors in the face of an ignorant and mocking medical "establishment".

Internet resource on the case against graded exercise therapy and cognitive behaviour therapy

By **Jodi Bassett**.

I am compiling what I hope to be a fairly comprehensive resource on graded exercise therapy (GET) and cognitive behavioural therapy (CBT), how they are either useless or at worst very harmful in 'treating' the illness. My website is *A Hummingbirds Guide to ME/CFS*: www.ahummingbirdsguide.com.

I am trying to include all sorts of medical articles and studies, political essays, and also quotes from sufferers who have been harmed or at least not 'cured' by these treatments. I would really love to get some short comments from some of you about your experiences with GET or CBT, if at all possible. It would be fantastic to have a really large amount of testimonies from individual sufferers.

Anything from a sentence, to a paragraph to a few paragraphs about what treatment they had, what effect it had on them and their level of illness, would they recommend the treatment to others? or anything at all relating to their experiences with GET or CBT. People can either be credited with their quote by their first name or may just as easily opt to be anonymous – just let me know.

Whether you can help or not, I wish you all the best.



Fatigue schmatigue

By **Jodi Bassett** (March 2005).

Page 22

Talking Point – 2005 Issue 2

It's a well-known fact that pretty much everyone who has it absolutely loathes the name 'Chronic Fatigue Syndrome,' particularly for its use of the 'f' word – and for good reason. Yet when the same group of people describes the effects of the illness in their own words, almost every one of them goes on and on about how 'fatigued' they are! It's bizarre when you think about it.

So what does the word fatigue really mean?

Fatigue: Physical or mental weariness resulting from exertion (American Heritage Dictionary, 2000). A feeling of excessive tiredness or lethargy, with a desire to rest, perhaps to sleep. Often it causes yawning (Wikipedia, 2001[Online]).

Compare that definition to descriptions of CFS (otherwise known as ME/CFS) given by some of the worlds leading experts (and/or authors) in the field. Dr. Anne Macintyre (in her book on the illness), describes ME/CFS as:

Feeling horribly ill, collapsed, as though poisoned, with visible muscle twitchings, intense pains in the muscles and maybe joints; nausea, sweating, insomnia and nightmares; maybe elevated temperature and recurrence of sore throat and tender, enlarged glands. (1998, p.146)

Dr Paul Cheney and Dr Dan Peterson, two doctors who have specialised in treating ME/CFS patients for many years, describe the illness as:

'A global disablement, nearly comparable to paralysis.' (Johnson 1996, p.34)

Lynn Michell summarises what the ME/CFS patients she interviewed for her recent book, said about the illness:

It is as if someone has frayed the ends of every nerve in the body and left them raw and exposed. It brings an overwhelming need to close down sensory input and, for

many, to retreat from everyday ordinary stressors – conversation, noise, light, movement, TV – since they are agonising to deal with. Everyone said that they were not fatigued. (2003, p.24)

Dr Elizabeth Dowsett (an award-winning microbiologist with 30 years' experience in ME/CFS research) comments that:

"'Fatigue' is the wrong word. Fatigue is a silly word." (Colby 1996, p. 167)

Dr David Bell M.D., who specialises in treating ME/CFS patients (and has also written several books on the subject), shuns the use of the word fatigue, describing it as:

A very inappropriate term for what patients experience. It's not really fatigue at all, which is defined as a normal recovery state from exertion and that is precisely what does NOT happen in this illness... They may say they're fatigued, but what's really restricting their activity may be pain, tremulousness or weakness – a sense that they are on the verge of collapse. That is not fatigue as we commonly think of it. (1995)

It's not only that ME/CFS is 'more than just fatigue' as you hear so often, the real issue that we all seem to have missed entirely – is that it's not fatigue at all. I had the flu recently and with it I experienced quite a bit of genuine fatigue. I felt extremely relaxed and drowsy and had lots of little naps throughout the day, I just couldn't seem to stay awake. It really brought home to me the reason why there is such utter public apathy about ME/CFS: fatigue really isn't that unpleasant! It is also not in any way, shape or form an actual symptom of ME/CFS at all, least of all the worst one.

Comparing fatigue with the symptomatology of ME/CFS is like comparing a flea to a nuclear missile or... a

(Continued on page 23)

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hedgehog to a three-storey house with an indoor pool – there is no comparison. Tiredness is a normal part of everyday life. ME/CFS is a serious acquired illness that can severely disable or even kill you; it's absolutely nonsensical that ME/CFS, and the sensation of tiredness felt after exertion by healthy people, could both be described using the exact same word.

So why do we use the 'f' word so often if it's so inaccurate?

Perhaps we assume that if we have an illness called 'CFS' that our main problem must then be fatigue; a completely logical assumption to make, provided that the name was chosen in good faith (and for sound medical reasons) in the first place. Except that it wasn't, unfortunately. In fact the manner in which this name was bestowed upon ME/CFS patients was undeniably one of the darkest moments in medical history to date. Hillary Johnson, author of a book which documented the mid-eighties ME/CFS outbreak in the US (*Osler's Web*), explains that the name was selected:

[By] a small group of politically motivated and/or poorly informed scientists and doctors who were vastly more concerned about cost to insurance companies and the Social Security Administration than about public health. Their deliberate intention – based on the correspondence they exchanged over a period of months – was to obfuscate the nature of the disease by placing it in the realm of the psychiatric rather than the organic. The harm they have caused is surely one of the greatest tragedies in the history of medicine. ... The Government's choice of names was so inept, in fact, that many observers came to view it as a deliberate effort to defuse the potentially panic-inducing issue of the eruption of a life-altering infectious disease. "CFS" after all, hardly sounded "catching". (1996, p.219)

The word fatigue was used to make sufferers of the illness appear tired instead of ill, unable to cope psychologically with the normal pressures of modern life certainly, but not really any sicker than anyone else. Indeed the terms 'fatigue' and 'chronic fatigue' were not associated with this illness at all until the name was changed to

CFS in 1988 (Hyde [online]). The ultimate goal of such word choices was undoubtedly to save the Government (and other organisations such as insurance companies), billions of dollars; money saved from all the services that these groups would have been obliged to provide (and pay for) if this were to be seen as a 'real' illness. (Hooper *et al.* 2001 [online]) Because of the political motivations behind the naming of this illness, the common and seemingly logical assumption that CFS symptoms – no matter how far they deviate from or even completely contradict all known definitions of the word – must still be 'fatigue' because of the name, is in fact completely illogical. **The 'f' word was selected entirely for what it could achieve politically: it was never intended to be a genuine medical description of the symptomatology of this illness.**



Maybe our readiness to use the 'f' word is also due to the fact that we (the ME/CFS community) have given it our own special meaning? Because of course we all know that it's not just normal fatigue or tiredness that we're experiencing, the word fatigue is seldom used all by itself when describing the illness to others; instead it's very quickly followed by an explanation of what we actually mean by the word. We use a word that means 'A', and then follow that by saying, 'but by A, what I really mean is B.' Of course people are always going to be left thinking that although we said B afterward, that what we must really mean is A, as after all, that was the terminol-

(Continued on page 24)

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ogy that we used.

Perhaps the biggest issue surrounding our use of the 'f' word though, is that there is no perfect alternative word just waiting for us. ME/CFS is an extremely severe and complex multi-system illness and there just aren't words created yet that even come close to describing its full horrors – but we can still do better than the pathetically inadequate and politically damaging 'f' word. It is undeniable that the word fatigue is easier to use, in comparison to listing all of one's individual symptoms and sensations, but surely its mere ease of use can not make up for its utter inaccuracy and myriad other disadvantages?

But surely one little word hasn't caused all of the credibility problems that ME/CFS has?

No, of course it didn't, the way the illness was re-named CFS was just a brilliant starting point. It meant that the illness was disassociated from its previously established name (Myalgic Encephalomyelitis), from all its previous research and case studies (dating back to 1934) as well as its World Health Organisation classification (as an organic neurological illness) (Quintero 2002 [online]). This then left the path clear for the Government (and the other financial stakeholders) to basically re-write history to suit themselves, to create new definitions of the illness which excluded all of the cardinal symptoms of M.E. and instead focused almost entirely on 'fatigue.' It was also made a condition of the diagnosis that there be no observable physical signs of illness – this despite the fact that such signs are always present in M.E. patients. (Hooper et al. 2001 [online])

The effect of such diagnostic criteria was that the name CFS soon came to denote both a behavioural (psychiatric) disorder involving 'chronic fatigue' with no physical signs which is perpetuated by aberrant 'illness beliefs' and 'personality,' as well as a severe and debilitating organic illness which is synonymous with Myalgic Encephalomyelitis. (Hooper et al. 2001 [online]) With these new 'definitions' of the illness in place, the crea-

tion of a substantial body of research to back up this manufactured psychiatric paradigm of CFS was only too simple. This pseudoscientific research – conducted primarily by the US Government as it was – was seen by a trusting public as being completely and unquestionably credible, this despite the absolutely enormous holes and inconsistencies in it both scientifically (and even just plain logically) when you looked at it close up. The problem, as we all know, is that almost nobody ever did.

The way the illness was re-named CFS and branded as a psychological 'fatiguing illness' was clearly just the first stage (for the stakeholders involved), in concealing the truth about ME/CFS from the public; the foundation as it were.

But who says that WE can't use words as weapons too?

It's a commonly held belief (in the ME/CFS community) that as soon as we have enough good solid evidence, that the medical recognition so long overdue will somehow be forced to instantly materialise. That all those doctors who deny the reality of ME/CFS will have no choice in the face of such rock-solid research but to concede that they were

wrong. The reality is that there is already an abundance of credible research that has unequivocally demonstrated an organic pathology for ME/CFS; and very little has actually changed. But is this really so surprising? As long as the main feature of ME/CFS is seen to be fatigue, legitimate research into ME/CFS and the sham science that is sponsored by financial stakeholders, will be seen as interchangeable. Then it is all too simple for all of the genuine, reputable and complex ME/CFS research to be ignored in favour of the easy (and inexpensive) answers that are associated with studying the symptom of fatigue. Good science alone will never be enough; we also need to disassociate the 'f' word from this illness so that the legitimate ME/CFS research can finally stop being so easily buried under the suffocating weight of the inaccurate typecasts of mere 'fatigue' as is happening so often now

(Continued on page 25)



(Continued from page 24)

Many ME/CFS patients and advocates are also (understandably) anxious to get the name of the illness changed away from CFS before anything else. But even if a name change (for example, in favour of Myalgic Encephalomyelitis) is achieved, will it really make any difference if those with the illness continue to use the 'f' word to describe the illness, and continue to be accepting of it's use by others? How can a name change possibly achieve anything if this also remains a 'fatiguing' illness, with everything that that entails?

But what if just by refusing to use or accept one word we could finally start to change things for ourselves? We may be stuck with the jargon of the name officially but we can at least stop ourselves (and those around us) from describing its absolutely horrific effects in such an utterly ridiculous way.

It's as simple as talking about how ill you are, instead of how fatigued you are

If we only stopped the use of the 'f' word within the ME/CFS community and amongst our friends and family, that would be a fantastic start, and who knows where it might lead? At the very least, by disassociating ourselves with fatigue, perhaps it will stop every second person we meet from saying 'Oh yeah, I think I might have that, I get really tired sometimes too.' The possibilities are endless and we risk nothing by trying. It's true that before fully escaping the stigma of fatigue attached to ME/CFS that we desperately need more research funding and education campaigns, as well as decent standardised criteria to diagnose and define the illness, as well as a name change. But no matter how you look at it, eradicating the 'f' word *has to be* an integral part of obtaining all of these other objectives too.

Every journey must begin with one step, and this first step is so simple and for once, totally within our control AND our very limited abilities! So just stop using and accepting the 'f' word. **Let's see where this first step might take us.**



See www.ahummingbirdsguide.com for further information.

**Note: ME/CFS = Myalgic Encephalomyelitis and (ME equivalent) Chronic Fatigue Syndrome as classified by the World Health Organisation's International Classification of Diseases since 1969.*

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Recommended reading

Of course this article contains only a very brief and condensed version of events – for the complete story on the history, politics and medical facts about ME/CFS read:

- *Osler's Web* by Hillary Johnson, Stricken edited by Peggy Munson
- *CFS: A Treatment Guide* by Verillo & Gellman
- *Skewed: Psychiatric Hegemony and the Manufacture of Mental Illness in MCS, GWS, ME and CFS* by Martin J Walker.

Dietary guidelines in CFS/ME

Many people with CFS/ME are very sensitive to their diet and getting it right can be critical in feeling well and helping to get on track to recovery. **Dr Rosamund Vallings** gives us some guidelines based on the latest medical research into CFS/ME.

Page 26

(This article reprinted from Meeting Place, the quarterly journal of ANZMES Inc, March 2005 issue.)

Over the past 20 years many diets have been suggested for the management and even 'cure' of CFS/ME, but the truth is that there is no 'magical' diet out there to fix this illness.

There is nothing better than 'good nutrition' and this should be the aim of anyone with CFS/ME. There is a wealth of information describing what should or should not be eaten and most people now will have had a good nutrition education in school. The importance of trying to incorporate a good range of foods with a balance of proteins, fats and carbohydrates cannot be emphasised enough. It has been shown in research that minerals and vitamins are better absorbed if they are obtained through food rather than pills and potions. It stands to reason that the sight or smell of a delicious platter of food will immediately stimulate salivary and gastric juices, so important for efficient breakdown and absorption, and it is very unlikely that one would salivate in response to a handful of pills.

Many with CFS/ME will have a tendency to food intolerances but this usually develops because of too much of a particular food over a short period of time. The approach therefore should be to have as much variety in the diet as possible, never having any one food in excess and rotating the range of foods regularly. Everyone has a certain level of tolerance for each individual food and, when this is exceeded, a reaction may occur such as headache or skin rash. In CFS/ME the tolerance level may be lowered. If a reaction does occur, avoiding that food for a short period of time and then re-introducing it in small quantities usually works well, so that the diet never needs to become too restrictive. Un-

doubtedly there will always be some people with true food allergies, but these are not as common as many imagine – and usually a person will be already aware of food allergy, which is very different to intolerance. Allergies are histamine mediated reactions to foreign protein (eg shellfish, pork, peanuts etc) and are usually characterised by itchy rash, swelling, breathing difficulties and severe gastrointestinal reactions. Some foods and drugs can increase the risk or severity of allergic reaction (eg strawberries, aspirin).



Some with CFS/ME feel extremely bloated and unwell after a meal and in the past issues such as food reactions or candida infections have been blamed. There is, however, now clear evidence that, for some people, it is the large quantity of food which may be too much for the stomach to handle. Overload is a bit like sending the stomach on a marathon run and can be likened to the effects on the leg muscles if one did try to run a long way. Exhaustion and abdominal pain may therefore result. It is also likely that frequently the metabolism is very slow and the stomach contents move on very slowly so that drinking a large quantity during the meal

may cause the stomach contents to swell up and give a feeling of bloating and move forward even more slowly. It is very important to drink plentifully, but it may be useful to try drinking mainly between meals rather than with the meal.

There is no evidence that candida in the gut is implicated in CFS/ME. In fact it is very unlikely because the

(Continued on page 27)

(Continued from page 26)

gastrointestinal tract is a very acidic environment and candida does not survive well in acidity. However, for those with problems of reflux and indigestion, it is possible another bug may be residing in the stomach creating problems. This is called *Helicobacter pylori* and is the bug now implicated in the development of stomach ulcers. So if a person has these symptoms, it is worth investigating for *H.pylori*, as this is very treatable and, while it is unlikely to be the cause of CFS/ME, it may be aggravating the illness. Similarly, symptoms suggestive of irritable bowel may be due to a residual infection, such as campylobacter or giardia rather than food aggravation. Further investigations may therefore be appropriate.

There are probably some foods which can aggravate CFS/ME. Caffeine and alcohol are both hard work for the system to deal with. Both also can interfere with an already poor sleep pattern. It is not necessary to avoid these altogether but intake should be minimised and they are best avoided towards evening. A high fat intake is also hard on the liver, which is sometimes implicated in the initial illness (eg glandular fever, hepatitis) and often remains vulnerable. A certain amount of fat is needed in the diet but vegetable and fish oils are the most appropriate. There is good evidence that the omega 3 fish oils are helpful in improving brain function and incorporating a regular intake of oily fish (salmon, tuna, sardines, etc) seems worthwhile. It has been suggested that, in some CFS/ME patients, cholesterol is too low and for these people increasing the dietary cholesterol may be helpful, as all cells need a certain amount of cholesterol to function efficiently.

There are also those whose blood pressure is very low with accompanying symptoms of light-headedness, pallor and palpitations. For these people increasing salt intake can be helpful and this should be done regularly through the day, not just with the evening meal, as the body turns over salt quite rapidly or loses salt, particularly in hot weather or during exercise. If salt intake is increased, and this may be by as much as three teaspoons daily (though blood pressure should be regularly checked), extra potassium should be incorporated in the diet by eating more bananas or kiwifruit.

Some with CFS/ME cut right back on sugar intake, but this may deplete the energy even further. A regular intake of carbohydrate is important and as long as sudden excesses are avoided and sugars are in as simple form as possible (such as fruit) they can help with energy. It is

General guidelines for nutrition in CFS/ME

- Eat as much variety as possible.
- Choose foods which are as fresh and natural as possible.
- Do not overcook, as this may destroy important nutrients.
- Rotate foods to avoid excesses.
- Eat little and often to avoid stomach overload (graze like a sheep).
- Drink minimally with the meals, drinking mainly in between meals.
- Have medical checks for gastro-intestinal symptoms, particularly if onset is recent.
- Minimise caffeine and alcohol intake.
- Increase salt regularly if blood pressure is low, but remember to increase the fruit intake.
- Use vegetable or fish oils in cooking, but increase cholesterol intake if blood level is low.
- Supplements are usually only necessary if there is a proven deficiency on blood testing, or if the diet is restrictive in certain components (eg vegetarians may need extra iron).
- Allergic individuals should avoid known foods which may cause serious allergic reaction.
- Avoid diets which are very restrictive, as nutritional deficiencies can easily occur.
- Avoid diets and supplements which are very expensive or promise a 'cure'.

unlikely that sugar restriction will be beneficial. There is however no firm evidence that glyconutrients, currently being aggressively marketed, are helpful in this illness.

Dairy products are a very important part of good nutrition and low-fat milk or yoghurt will provide good calcium intake. This is particularly important for those unable to exercise fully, adolescents or women who are over 45 or pregnant. Checks can be done for lactose intolerance and there are blood tests to check for wheat intolerance.

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Coeliac Disease – the great mimic

A report by the ME/CFS Society of NSW on a talk given by **Dr Ian Brighthope**, director of Nutrition Care.

Page 28

Talking Point – 2005 Issue 2

We would like to report on a meeting that we attended on the April 5, 2005. Dr Ian Brighthope, who is well known to many of you, and has been a pioneer in the area of nutritional medicine in Australia and is a director of Nutrition Care, gave a talk on Chronic Fatigue Syndrome, Coeliac Disease, and “wheat poisoning”.

Dr Brighthope said that CFS/ME was a “disease of every cell and tissue in the body”, and I certainly echo this opinion. He started off speaking about misleading synonyms, for example the Royal Free Disease, neurasthenia, and post viral syndrome. He also spoke about the difficulties of using the term myalgic encephalomyelitis, when myalgia is not always present and there has not really been a lot of evidence for encephalomyelitis.

When speaking about the myriad of symptoms, I did like his use of dysomnia instead of insomnia, as this certainly does say more about the total dysregulation of the sleep cycle in all its forms rather than insomnia. With respect to the symptoms, he did believe that the cognitive dysfunction, in particular the concentration and memory problems, could be alleviated with intramuscular high potency B vitamins.

He mentioned social aspects to the disease including the term malingering, the fact that it has been unresponsive to treatment, the high alcoholism, divorce, and suicide rates, the psychiatric and social stigma, the poor employment records, the repeated inappropriate medical referrals, and the general high costs.

Looking at the general causes of fatigue, he mentioned the importance of looking for other causes including medical conditions and drugs, psychological, nutritional, lifestyle and environmental. With respect to the medical, he stressed the importance of chronic inflammation, for example, a dental abscess, a low grade sinus, prostatitis, or even tinea, can be culprits in the cause of chronic fatigue states. I certainly concur that there is often some degree of chronic inflammation which is missed or untreated in this condition. Dr Brighthope did state that he was not in favour of long term antibiotic treatment as he

said that this did not deal with the problem.

He mentioned the predisposing factors to chronic fatigue syndrome. These include genetics, heavy metal overload, chemical pollutants, nutritional imbalance, viral or bacterial infection, antibiotics, chronic bowel toxemia, and chronic emotional stress.

He also spoke about hypohydration, that is the fact that most people have inadequate water intake. He mentioned that as people age they have less ability to detect thirst, and often feel chronically tired due to dehydration. He also mentioned that due to our high sodium diet that there is often a high sodium and low potassium and this electrolyte imbalance impedes the bioelectrical cellular energy current.



Dr Brighthope spent a lot of time discussing Coeliac Disease, “the great mimic”. He also called this gluten sensitive enteropathy, also referred to wheat/grain poisoning. He spoke about how toxic glutenin and gliadin are (from wheat, barley, rye, and oats), and stated that the elimination of wheat from the diet can lead to a dramatic relief in symptoms in people who are chronically unwell. He spoke about how we are addicted to the peptides in our foods, and we become addicted very early in our lives. He said that as little as three grams or one teaspoon of gliadin can cause a

relapse in Coeliac patients and a hundred grams of gluten will cause sickness in normal people. Coeliac Disease can present with weight loss and fatigue and in some cases with diarrhoea and floating bad smelling stools. He spoke about the concept of “pre celiac”, that is many of us have damaged the villi in our small bowel from overdosing on wheat products, but that we don’t actually go on to have full-blown Coeliac Disease.

Coeliac Disease is associated with multiple clinical disorders. These include the following: irritable bowel syndrome, aphthous mouth ulcers, hepatitis, cirrhosis, reflux oesophagitis, adenoma of the small bowel, neurological

(Continued on page 29)

(Continued from page 28)

conditions such as peripheral neuropathy, epilepsy, ataxia, myelopathy, psychiatric conditions including depression and schizophrenia, endocrine conditions including type 1 diabetes, infertility, recurrent abortion (which he states the incidence of which can be decreased by fifty percent by giving two grams of vitamin C daily), thyroid disease, Addisons Disease, renal conditions such as IgA nephropathy, haemopoietic diseases including the anaemias (he stated that in refractory anaemias copper deficiency should always be looked for), coagulation disorders, IgA deficiency, hyposplenism, T-cell lymphoma. He also mentioned locomotor problems, dermatologic, dental, cardiomyopathy, alopecia areata, Sjogrens Syndrome, finger clubbing, and pharyngeal and oesophageal cancer.

He stressed the importance in Coeliac Disease and also in Chronic Fatigue Syndrome, of going on a gluten-free diet (he did state that wheatgrass was fine). He spoke about cutting out wheat totally, also initially cutting out dairy and sugar. He spoke about the importance of adding in digestive enzymes, drinking lots of water, and eating fats of a high quality. He spoke also about the importance of saturating the gut with lactobacillus and bifidobacillus to try and improve the health of the gut alongside these other measures.

If any of you reading this article wish to try a wheat-free diet for a period of time, we would be most interested to hear whether you felt if this has been helpful or not.

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Page 29

Talking Point – 2005 Issue 2

Exercise and allergens possible biomarkers

Sorensen B, Strieb JE, Strand M, Make B, Giclas PC, Fleshner M, Jones JF. Complement activation in a model of chronic fatigue syndrome. *Journal Allergy Clin Immunol*, August 2003; 112(2):397-403.

A National Institutes of Health grant assisted researchers in Denver and Boulder, Colorado, in exploring their theory that either exercise or nasally administered allergen challenges would aggravate the defining symptoms of CFS/ME, causing the production of biological markers that correlate with an increase in these symptoms.

Participating in the study were 32 CFS/ME patients and 29 controlled matches. The submaximal, steady-state exercise challenge, consisting of 20 minutes on a stationary bicycle ergometre at 70 percent of the subject's predicted maximum workload, was completed by 22 CFS/ME patients and 23 controls. Fifteen CFS/ME patients and 10 controls with positive skin prick test results performed the nasal allergen challenge. A histamine challenge was performed with 22 patients and 20 controls as a negative control for systemic responses expected to occur only in the allergen challenge and also to test the effect of inducing symptoms in nonallergic persons.

Researchers hypothesised that cell-associated cytokines, complement split products and/or eosinophilic cationic protein in the CFS/ME group would immediately increase after the exercise and allergen challenge and that the levels would continue to rise for 24 hours.

The exercise challenge significantly aggravated CFS/ME symptoms and reliably increased the complement C4a. The detection of this single protein after exercise, along with increased symptoms, makes the creation of a diagnostic test with an exercise challenge a possibility. Even though it was accompanied by increased fatigue and reduced motivation, the allergen challenge experienced a lack of measurable changes in the biological parameters, raising questions regarding the uniformity of mechanisms of fatigue production. Researchers suggest that symptoms in the CFS/ME group after the allergen challenge were related to untested allergy-related processes.

Researchers conclude that they are regarding exercise-induced C4a as a potential marker of CFS/ME. Further study on the biology of the protein is necessary before researchers make an assumption about its possible role in the pathophysiology of CFS/ME. In view of the frequency of atopy in CFS/ME, evaluation of its role in conjunction with factors such as exercise remains an important and complex task.

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

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.

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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 0HA, UK.

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

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.

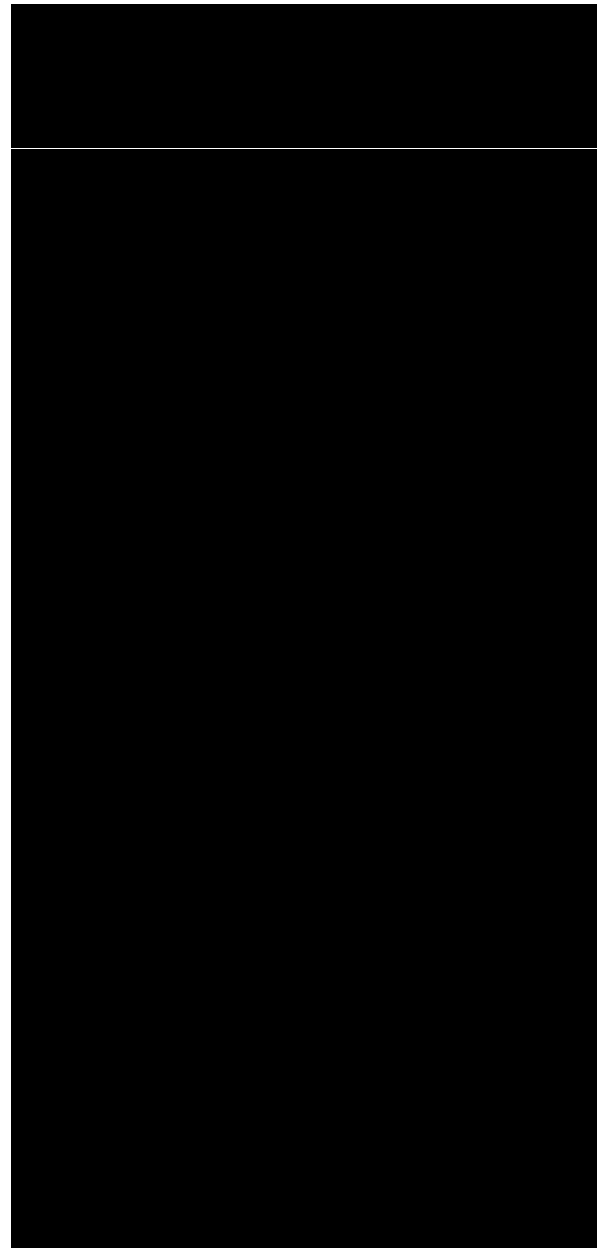
Phone: Fran McFaul (Dietician) 8535 6800.

Please note that meeting times are subject to change.

**If you are attending a meeting for the first time please call
the contact or the Information and Support Line for
confirmation of meeting days and times:**

8410 8930 or 1800 136 626

Support Contacts



Youth Support: SAYME

South Australian Youth with ME/CFS

The idea behind having a Youth group is to get young people with Chronic 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.



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