Talking Point

2003 Issue 2 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

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

Membership

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

New Members (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 sufferer, or more than one person who will directly benefit from the membership at the same place of residence. Family Concession applies when the main breadwinners are concession card holders.)

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.

Deadline for Next Issue
Aug 15th 2003

Talking Point Subscriptions:

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

Management Committee 2001/2002

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

President: Paul Leverenz
Vice-President: Peter Cahalan
Secretary: Peter Worsley
Treasurer: Geoff Wilson
Management Committee Members:
Margaret Wing, Peter Evans, Kirsty Cordingley, Glenn Domeika, Adrian Hill & Rebecca Cordingley.

Contact Details

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

Note: It is our policy to ignore anonymous correspondence.

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

Talking Point

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

Donations

CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

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.

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.

EDITORIAL

Welcome to another edition of Taking Point.

The Society has just completed one of its most successful awareness campaigns ever. See the *Society Matters* section for all the details and summaries.

The Awareness Events held were only made possible by the kind support of Paul Newman's Own, HomeStart Finance and the Department of Human Services.

As far as news goes there has been a breakthrough in the UK, with many millions of pounds allocated towards the needs of ME sufferers (see article on page 8).

Dr Charles Lapp has provided an excellent summary of the material presented at the American Association of CFS earlier this year. For other summaries visit: www.aacfs.org

Hope you can keep warm over the winter months—something easier said than done for many of us who suffer from cold extremities. Get those heat packs out and rug up!

Remember to be kind to yourself and treat yourself occasionally—even if its just something small. Its important to keep your spirits up.

Wishing you all the best.

Paul Leverenz
Editor

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From the President

Welcome to another issue of Talking Point.

We have just gone through one of our best awareness periods, and can be very proud of what we have achieved. Many people helped make this possible – I won't try to list everybody because I'm likely to leave someone out. Special thanks go to our office team of Patricia, Dianna and Christine who organized the Film Night, and Adrian Hill who organized the Badge Day.

Awareness Events

In brief, our *Leading the Way* seminar was well attended despite inclement day and limited car parking. Approx 450 heard a number of speakers with the main focus being on local research into Fibromyalgia and Chronic Fatigue Syndrome. For many the information presented on the day validated their condition. Many family members and health professional learned that CFS was a legitimate condition. Hopefully many more of us will now be treated with the appropriate level of respect and compassion. If you would like to purchase a copy of the video of the *Leading the Way* seminar for $25 (incl. postage and GST), please our Support Line, the Arthritis Foundation on 8379 5711 or download an order form from the front page of our website. (Thankyou to the Arthritis Foundation for handling the sales for us.)

Our small raffle was an excellent success – with very little lead-in time we were able to sell over 500 tickets. This is something we will be looking at doing on a much larger scale in the future.

The raffle was drawn at our Film Night which was attended by 120 people. Our feature film, 'I remember ME' by Kim Snyder, is a powerful, thought-provoking work, and it produced a lot of excellent conversation and questions afterward.

Finally, on 31 May we held our Badge Day in the city, and this was also successful. Thanks to everyone who helped – you all did a great job. We didn't have as many people as last year, and consequently we were only able to raise $1300. But that's the way these things go. (If we had 60 people we could easily raise $5000.)

Office Accommodation

The Management Committee is looking at alternative accommodation for our office. This is for two main reasons. We are having difficulty reducing our expenditure, and it seems rent is one area we can possibly make savings. Also, given the change of ownership of the Epworth Building, which we are currently in, now is the time to make a long-term decision. The Epworth Building changes hands in September, and if we want our rent frozen we must commit for a number of years. Given, as I said, we are looking at reducing expenditure, this is not an attractive option. But to stay and not commit to a long-term lease will mean our rent will rise.

With this background, we are looking for alternate accommodation, and are looking at co-location with another group. There is every possibility the could end up being a win -win situation for us, with cheaper rent and improved facilities including a meeting room, kitchen and car parking. We already are looking at some workable options.

Money Matters

I have previously drawn members' attention to budget struggles. It is not my intention to weigh you down, or bore you with too many details, but it is important that you are kept abreast of the situation.

Unfortunately we had budgeted for approximately $4000 for Badge Day (which was perhaps an optimistic figure). Modest profits from the Film Night, *Leading the Way* Seminar and raffle will cover the shortfall. We are still looking at a minimum of $5000 loss for this year. (In rough terms, we seem to be able to raise about $10K per year, but $15K-$18K is out of our reach at present.)

It is the feeling of the Management Committee that our next budget should balance and we are going to have to be pretty tough to achieve that. We have reduced the size of Talking Point and this has brought some savings. Reduced rent and other cuts will go a way to making this possible. We will continue to economize in the office and minimize our administration costs. However, as such a large proportion of our budget (over 50%) is made up of donations and fundraising, we, like every other charity, can never guarantee our income or our cash-flow.

Membership and Renewal Fees

Membership fees have remained fixed for a number of years. In fact, when the GST was introduced we absorbed that money. The Society actually has to outlay much more per member than it receives in fees, making up the difference through fundraising and grants. Our long-term plan, with government funding, is to reduce membership fees.

However, I do not believe that we have any short-term alternative but to make modest increases in fees – of the order of $2 per membership. I fully appreciate that many of you do it 'pretty tough' and that this is not welcome news. I also appreciate that our Society is only able to 'scratch the surface' of addressing your real and often desperate needs. I would ask all of our members to 'hang in there' with us, because I believe our lot in South Australia is about to improve. Please read on….

Long-term strategy

As I have stated previously, my focus is to use the minimal time and resources we have to initiate projects of long-term significance and benefit. The other side of this is that we may not necessarily be doing as much right now that will directly meet your needs.

What are we doing? Firstly, we are working with researchers and specialists to set up a research network. This is already fostering interest from many people from a range of specialties. Getting these people talking is very strategic in raising awareness of ME/CFS in the medical community. And there will be flow on benefits such as added pressure on

the government to support the Society and ME/CFS research. Realistically we will need 2-5 years before we see substantial benefit.

Second, we are working with the SA Dept. of Human Services to produce guidelines for all GPs. These will hopefully be ready and distributed to every GP and specialist by the end of the year. Our simple goal is to have a uniform basic treatment approach by GPs to everyone in this State who develops ME/CFS. The aim is to increase the speed and accuracy of diagnosis.

These are only a start. But given our lack of resources, its not too bad, and we will be leading the country in this regard.

Modifying my Role

Having worked hard for the Society these last couple of years – which I have thoroughly enjoyed – it is time for me to pull back a little. I will continue to work as President for as long as I am able (and as long as I'm wanted), but I have been effectively been doing 3 jobs on top of that: Office Manager, Talking Point Editor and assisting with the Support and Information Line team. I also handle most of the email requests that come into the office. I think you'll understand that I cannot continue to do all of that, and it would good for the organization for some others to step up and take on some of those roles. If in the short term people can't be found we will have to get by in whatever ways we can. This situation will be helped considerably if we are able to obtain some funding from the government.

* * * * * * * *

I value and appreciate your continued support of this organization, and encourage you to hang in there if you have this illness, and to continue to support your loved ones if you are a friend/relative/carer of someone afflicted.

Believe me, every ME/CFS Society in this country is struggling for survival. Every single one is under-resourced and under-funded. I am not prepared to give up and 'let the apathetic medical profession and bureaucrats win'. Your committee is working to redress the funding situation and in the meantime ask for your continued support for the Society.

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Paul Newman's Own

Without the help of Paul Newman's Own our *Leading the Way* Seminar and the May 16th Film night would have not been possible. As our major sponsor their contribution was significant, and we cannot fully express how grateful we are for their support.

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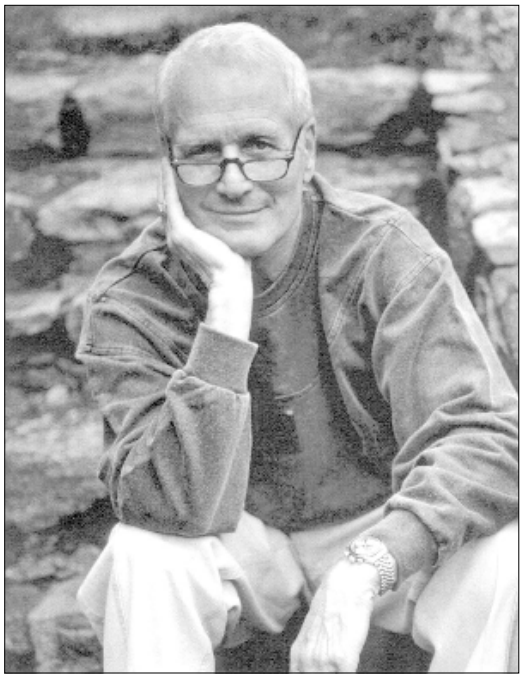
PAUL NEWMAN'S OWN

ALL WORLDWIDE PROFITS TO CHARITY

Shameless Exploitation
In Pursuit of the Common Good



Australians can feel good about buying Paul Newman's Own salad dressings and pasta sauces because all after-tax profits are distributed amongst needy Australian charities.

Department of Human Services

At the 11th hour the Department of Human services were able to contribute to the running of our *Leading the Way* seminar—enabling us to make the event bigger and better than we could have imagined.

human services

SOUTH AUSTRALIA
Government of South Australia

Leading the Way – with some help from HomeStart Finance

HomeStart Finance was proud to be a sponsor of the "Leading the Way" conference - held at the Norwood Concert Hall on May 10.

Providing home ownership opportunities for low to moderate income earners in South Australia – HomeStart is a State Government initiative with a strong track record in assisting special needs groups in the community.

HomeStart is all about giving people the chance to realise their dreams and achieve their objectives – often, when it may have seemed out of their reach.

The association with the CFS conference was a great fit.

With over 450 people attending, HomeStart not only helped to promote an awareness of CFS in the community, but also supplied information about its unique HomeStart Carers Loan product.

HomeStart Finance Chief Executive Officer Gary Storkey was pleased with the conference outcome and is positive about the Carers Loan.

"The basic message is that the HomeStart Carers Loan can make the difference between a family member staying at home or having to move house.

"We recognise the important role that carers play in the community and that those who care for others often have special financial circumstances that prevent them from borrowing money from a traditional lender," Mr Storkey said.

"Developed in conjunction with the Carers Association, the loan is designed to improve the quality of life of both carers and people being cared for.

"It's tailored for people who own, or nearly own their own home, but who have a reduced income.

"The loan can be used for a home extension, home repairs or modifications or to buy a new car – basically anything that will improve quality of life."

A recent Carers Loan customer said, the loan enabled her to modify her home so that her father could move in with her.

"I needed my Dad to move in with me so I could take better care of him," she said.

"My place needed some fixing up and we needed a bigger car that he can get in and out of easily.

"The Carers Loan enabled us to do this and, because the repayments are in line with my Carers Allowance, it isn't difficult to manage."

Mr Storkey said the flexible repayment terms of the Carers Loan were a major benefit for many Carers Loan customers.

"Repayments on the Carers Loan are tailored to the applicant's income and generally don't exceed 25 per cent of their income," he said.

"Adjusted annually in line with inflation, the amount you pay is stable regardless of interest rate rises – an important consideration for those on fixed incomes."

Other benefits include fortnightly or monthly repayment options, limited account keeping fees, the ability to make extra payments without penalty and a convenient redraw facility.

Customers may be able to borrow up to 2.1 times their income, up to a maximum of $35,000.

To be eligible for a Carers Loan, applications must:

- Receive a regular income, which can include Centerlink benefits.
- Receive a Carers Pension and/or Carers Allowance,
- Be over 18 years of age.
- Be a permanent resident in Australian and have Australian citizenship.
- Your home must be in SA.

For more information on the HomeStart Carers Loan, call (08) 8210 0500 or country callers 1800 144 744.

Government of South Australia

8210 0570

www.homestart.com.au

HomeStart FINANCE

Eligibility criteria, terms and conditions apply.

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UK Government Announces ME/ CFS funding of £8.5 million pounds over three years

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Monday 12th May 2003

Health Minister Jacqui Smith, announced today a cash injection of £8.5 million for services specifically designed for people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). This money will develop clinical services where none currently exist.

The investment will pump prime service development by:

- Establishing centres of expertise across the country to champion the development of services and improve clinical care;
- Setting up satellite multidisciplinary community teams to develop services within primary care to support GP's and other health professionals;
- Facilitating access to specialist assessment diagnosis and advice on clinical management to patients, families and health professionals;
- Supporting clinical research; and
- Providing education and training of health care professionals.

Speaking at a Chronic Fatigue Unit in Essex, Jacqui Smith, said:

"In January 2002, we responded to the report of the independent working group on CFS/ME. We endorsed the view of the working group that CFS/ME is a debilitating and distressing condition, which affects people of all ages. This is an important step in the development of NHS services and means that we can start making improvements in the care and treatment of people with CFS/ME. The causes are still not fully understood and this investment will enable the NHS to set up centres of expertise to develop clinical care, support clinical research and expand education and training programmes for health care professionals.

"We are setting up an implementation group to oversee the service development work. We are very pleased to announce that Professor Anthony Pinching, (Associate Dean for Cornwall, Peninsula Medical School and former Deputy Chair of CFS/ME Working Group) will chair this group. This is very good news for people with CFS/ME and their families.

"As a first step, in July, health organisations will be invited to bid for development funds to set up specialist centres. These new centres will initially support local community teams to provide a broad spectrum of expertise and integrated care packages to people with CFS/ME.

Professor Anthony Pinching said:

"I am delighted to be able to help with implementing this essential new investment in services for people with CFS/ME. I am very keenly aware of the very large gaps in service provision for CFS/ME across the country, which leaves many patients, carers and frontline professionals without support or guidance.

"We will ensure that appropriate new local services are established, supported effectively by larger centres with expertise and experience. As well as providing diagnosis and treatment, the new services would assist with professional training and could also create a valuable clinical research network.

"I know that there are many areas where such services are already being planned, but where current commissioning funds are already fully committed. This very welcome additional funding will give local teams and patients the break that they desperately need."

Notes

1. The £8.5 million will be released to the NHS from April 2004 and is for 2004 to 2006.
2. The Medical Research Council (MRC) published a research strategy for CFS/ME on the 1st May. This strategy will enable researchers and funders to develop research proposals on all aspects of this illness. The strategy was developed by an independent Research Advisory Group in response to a request from the chief medical officer for England. It was informed by contributions from patients, carers, charities, patient groups, researchers and clinicians via a consultation exercise in summer 2002. The MRC has also announced two initiatives in response to the strategy. One is a highlight notice to the research community welcoming high quality proposals across the entire spectrum of CFS/ME research. The other is a scientific meeting to discuss the potential for epidemiological studies in the UK.
3. The Independent Working Group's report into CFS/ME was published on the 11th January 2002.
4. Action for ME have been awarded a Department of Health grant, of £177,300 over the next three years, to support the development of clinical networks.

Life with Multiple Chemical and Environmental Sensitivities

Late last year one of our members, Elizabeth Steele-Collins, was interviewed by Today Tonight in Adelaide. What follows are some of the questions and answers she was prepared ahead of that interview. She has kindly allowed us to print them in Talking Point, hoping to raise awareness about a situation which many suffer with in silence.

How old were you when you first started to develop symptoms of MCS?

I was about 20 when I became ill while working in Offset Printing and using industrial solvents, but *it was during the following 10 years I became progressively more sensitive* to both foods and chemicals.

How difficult was it to be diagnosed by doctors?

When I first became ill in the 70s, there were not many doctors who understood much about environmental medicine. In that sense, it was difficult to get a diagnosis. By the mid 80s there was more awareness of the links between chemicals and the symptoms I was experiencing and we began trying to minimise exposure to various chemicals. However, it wasn't until the late 80s (when I was in my early 30s) that my problems with chemicals became more severe and I was diagnosed with MCS. This was later confirmed when I spent a number of weeks having tests in the Environmental Control Unit in Melbourne under an Allergist who specialises in Environmental Medicine. These tests showed that I was very sensitive to minute concentrations of a large number of everyday chemicals. I consider myself fortunate that I had access to the expertise necessary to diagnose my condition. Many doctors still are not trained in environmental medicine and are therefore unaware of the possible chemical connection to the symptoms their patients present.

Is there any forms of treatment?

No, not really. Avoidance is the principal *strategy; that means trying to avoid the chemicals that trigger symptoms.* There are some treatments that help to alleviate some of the symptoms but, as far as I know, there is no known treatment for making one less chemically sensitive. Some therapies are recommended to try to strengthen the body's immune system. (or defence mechanisms)

This emphasises the necessity for research - to be able to find out the cause and to understand the biology and mechanisms involved might eventually lead to treatment.

How does someone know if they are affected by MCS?

There are many people who have low grade effects with sensitivities to chemicals. Some people can pick what chemicals are causing symptoms eg perfumes, photocopying machines, paint fumes etc.

For others it is more subtle and they are unaware of the chemical connection to their symptoms. eg: I know of people who have gone to an allergist with sinus problems that have developed and it's been established that they were reacting to the polyester in their pillow. Symptoms improved after removing the source of the chemical irritant.

What sort of things provoke the disorder?

A lot of things can provoke the disorder. In most cases there is an initial exposure to chemicals, usually pesticides, solvents, or indoor air contaminants etc., which leads to a profound breakdown in the natural tolerance of these substances. These are termed *initiators* as they seem to initiate the condition. After that, any number of things can, even at concentrations considered insignificant, *trigger* a toxicological response. These can be just about anything which the affected person's defence system interprets as 'harmful'. Triggers vary from individual to individual just as symptoms can. One could describe the condition as an abnormally heightened response to chemicals in one's environment. Since there seems to be no way one can regulate the body's response, the only effective action to avoid the unpleasant symptoms and disability experienced, is to avoid the triggers that activate them.

Generally, how has MCS affected your life?

MCS has effected every area of my life. Probably the most devastating impact was being unable to continue caring for my disabled child. Having to give her up to permanent foster care was an extremely difficult and painful decision. The condition impacts on just about everything I do. It also affects my family and friends. The extra effort that family members (& friends) have to go to so as to minimise chemical exposures to me is significant. Even chemical residues on their clothes can cause problems. I am very sensitive and react to even *minute concentrations* of chemicals. Most of the time I am at home because the very few occasions I need to go out, almost always result in my becoming very ill. Ironically, even going to medical appointments often results in a deterioration of my condition because of the everyday chemicals I encounter along the way. Depending on the chemicals involved and the length of exposures, I can have brief reactions or ones that last many days. Some symptoms can come on immediately, others may delay for many hours. Sometimes I haven't recovered from the effects of an exposure before having another one which causes more problems and recovery time is prolonged. *Some* of the symptoms I experience after exposures are:

headache, dizziness, muscle/joint pain, inability to concentrate, muscle spasms, severe gut pain and spasms, diarrhoea, nausea, mouth ulcers, fatigue, irritability, sleep disturbances, anxiety, depression, numbness, nose bleeds, sore throat, cough, orthostatic intolerance and increased food hypersensitivity.

I used to have an oxygen supply that allowed me to go to some venues where we knew I was going to be exposed. This helped a lot and also helped clear my symptoms quicker after exposures but is very expensive and we couldn't continue its use.

Have you encountered any resistance to this illness?

Yes, I have. I've been accused of 'putting it on'. I've even been compared to Christopher Skase when seen using oxygen in a public place. If only I was 'putting it on'… then it

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wouldn't be affecting so many systems of my body and every aspect of my life. But then again I too was once sceptical. I used to love wearing a nice perfume and for a long time I didn't believe that those who suffered from exposure to perfume were quite 'genuine'. I understand now, of course, after my own suffering. I suppose it is part of human nature to be sceptical of whatever we don't understand or have experience of.

Why have you chosen to live at Waitpinga Cliffs?

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Because of the severity of my symptoms and to prevent further deterioration in my health, I was advised by a number of doctors to relocate to as clean an air environment as possible, preferably in a coastal location. I was also advised to consider building a chemical free house.

Eight years ago in 1994 we started taking a serious look at property around the Fleurieu Peninsula and even considered Kangaroo Island.

The allotment at Waitpinga Cliffs was chosen because it was far enough away from the usual obvious chemical sources, but only 10 kms from a main hub like Victor Harbor which means, for the most part, we are able to avoid chemical influences without being too isolated.

Looking into building a chemical free house was very challenging and involved a great deal of research. We had to get an MSDS (Material Safety Data Sheet) on every building material and it took a lot of work to establish which materials were most appropriate for our needs. Many building materials have chemicals as part of their make up or added to them as a preservative. These chemicals continue to offgass out into the air inside the house for years afterwards. We tried to identify most of these and avoid them in the construction.

My case with MCS is severe and that is why I have gone to extreme measures like building a chemical free house in a clean air environment. I am trying to reduce my exposure to chemicals so as to enable me to have the best quality of life possible.

Does this help you deal with MCS?

Living here on the South Coast has helped me a lot. Even though I am still very unwell, I am far worse when I go anywhere else. Even a short trip into Victor Harbor can exacerbate my symptoms and a trip to Adelaide can bring about severe reactions that can last for days afterwards.

Although I find it very hard living with this condition, I have tried to adjust and have worked hard to be accepting of a chronic health problem. I have gone on with life the best I could, bringing up a lovely daughter (who is now 20) and trying to live a quality of life within the limitations that my health permits me. Two years ago I remarried and my husband helps a great deal with my everyday care. This enables me to get the rest that the condition requires. Before that time, when I was on my own I had to struggle on with the supports that were available, whether I was well enough to cope or not.

How do you handle visitors?

Unfortunately yes. It sounds terrible but visitors can make me sick. They don't mean to of course, but the chemicals that they inadvertently bring with them are often triggers to my condition. It is hard for the average person to understand how insidious chemical use has become in our society. They are conditioned to it; unaware of it to a large extent. They are used to daily 'automatically' putting on their:

- perfume and 'hygiene' products
- aftershaves
- sunscreens
- hairspray and hair products
- scented deodorants etc.
  I've even been told by some that they feel 'naked' without them.

Then there are the products in which their clothes are washed:

- strong smelling washing detergents
- fabric softeners
- freshly dry-cleaned clothing
  and the list goes on. A lot of these products are very tenacious. It can often take several attempts to get rid of their traces on hair, skin or clothing.

Even after all of this, one can 'pick up' chemical residues from things like:

- air fresheners in rooms or cars
- chemicals from materials in newer car interiors
- tobacco smoke
- petrol products
- solvents
- pesticides
- and dozens of other chemicals from hundreds of sources on the way to visit.

I guess the bottom line is that most people are not prepared to go to that much trouble to minimise the amount of chemicals they 'carry', so we don't get a lot of visitors. Even the best intentioned sometimes arrive with something 'smelly' on them and we are forced to sit outside or open all windows and doors to let the breezes keep the chemicals as dilute as possible. Close friends and family will sometimes shower on arrival if there is a need, but it makes it awkward and I feel a nuisance not being able to be free and spontaneous with them.

What do you think your future as a MCS patient is?

We have gone to a lot of trouble and expense to try to create an environment in which I can live without continual insidious exposure to the chemical triggers that were causing my health to deteriorate. While there is no guarantee that isolation from these chemicals will eventually see me completely well again, I hope to at least achieve better functioning levels and that my systems will be strengthened.

What's next for you?

I'd also like to continue to be an encouragement and support to others who are also struggling with the debilitating effects of MCS. I would like to make a difference for not only those suffering now but for future generations whose welfare may very well be determined by a significant reduction of the use and misuse of chemicals of all kinds.

Unless there is some radical medical breakthrough in the foreseeable future, I don't see much chance for change in my condition. I will continue to do the best I know how and be as positive as I can, taking one day at a time.

Future research?

The key to finding any kind of effective therapy or cure lies in research. Science does not know what causes the body's defence mechanisms to respond as inappropriately as they do in those of us with MCS. The only chance for an effective cure

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Both sides now

This is an extract from a talk that Dr Ken Jolly gave to the Association of New Zealand ME Societies (ANZMES) last year. Dr Jolly is a New Zealand GP and his topic was "My perspective of ME as patient and doctor." In this extract he discusses the difficulties we face when we are sick, and reminds us that - as with all experience - there is also an upside.

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Stigma and other problems

For many years my wife and I didn't talk openly about my illness because of the stigma surrounding ME. You are wary when people say "you are wrong, you have made it up," or that "you believe in something incorrectly." Words like this can be very hurtful when it is your very own life that they are talking about. So it feels risky speaking about events that affect you personally, but I hope others may do the same in the future. The more people that stand up and speak about their experiences with ME the less others can deny the illness or tag it 'psychogenic.'

A recent study studied "hassles" that occur in ME people's lives compared to those with other chronic illnesses. Although other chronically ill people certainly do experience major hassles the ME group tended to report different ones. They were more varied, they tended to be greater in number and more often occurred in the psychosocial sphere. The researchers felt that these type of hassles occurred because of the 'hidden' nature of ME and because it often labelled as psychogenic or non-existent. Thus, although ME patients suffered all the normal problems associated with other physical disabilities, there were additional ones too because of the stigma of the condition. When feeling awful patients have to often keep this to themselves. They experience societal and media disbelief, rudeness, insensitivity, doctor disbelief, psychiatric aspersions and the list goes on.

A friend recently pointed out that social events often become nightmares. We can't concentrate, can't remember people or their names, feel awful, distant, disorientated and sleepy. We can't hear because of tinnitus, feel like we might faint or create some terrible social indiscretion, such as vomiting. On top of this we are then often asked questions that we can't give sensible answers to, like "what job do you do?" or "how are you?"

We lose friends, spouses and medical professionals faster than the eye can blink. But we do usually try very hard and to give credence so, in general, do those people. It is hard for people to understand this illness and in my more objective times I can understand how difficult it is for them. How can they understand when they see you out shopping one day, apparently well, and then hearing from you the next day, saying that you can't attend the funeral of their best friend or pet rooster or whatever it may be.

ME should be in the Guinness book of records for being the illness with the most symptoms of any disease in the world. Because ME has so many symptoms it makes it difficult to explain the illness to people, adding to people's general disbelief. Who has the time to listen to a list of 50, or 100, or however many symptoms there are? And of those that do, most would have you labelled as a hypochondriac well before you had got past even the first ones.

So instead, when asked about the illness, many often gloss over a proper answer and end up mumbling something about fatigue or headache or something and in so doing cleverly add to the general public's misconceptions about the illness. But how can you tell someone briefly or concisely about something that is so complicated, so variable and so personal?

The main problem is that you know that most people's experience of illness is of acute, short-lived problems that get better. So you are on the backfoot before you start. The complexity of this illness makes explanations about it more difficult. Most of you probably recognise that experience of seeing people's eyes glaze over, or that look of disbelief that begins to creep across their faces as you attempt to describe it. Such experiences tend to make us wary about getting into complicated descriptions of the illness. On the other hand, many sufferers have memories of times when they had the chance to educate a genuinely interested person, but then blew it. There are other times when you have to explain to people that you can't tell them about it because you haven't the energy to explain to them. A Catch-22. "I can't tell you about the illness because having this illness means that I can't tell you about it." A weird sort of circular argument that we get trapped in. In this situation we worry that the enquirer thinks we are being purposely obtuse or aren't interested in explaining anything to them. And the more we try to concentrate on these explanations often the worse it makes us feel.

On the positive side

I met someone with ME once who said, after she had introduced herself, "welcome to the club." I remember making some facetious comment at the time about it being "not a very good club to belong to" but when I thought about

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is to have a clear understanding of the biological mechanisms involved. Even that is not a guarantee of a cure, but it would be a big step towards finding one. It would also go a long way toward understanding to what degree our current dependence on chemicals is putting our collective health at risk. It might then become easier to decide what we can and cannot live with.

It is easier and cheaper to prevent this condition than it is to cure it. Those in authority must recognise the need for a coordinated, multi-disciplined, collaborative, team-oriented approach to research. Now is the time, while the issue is still in its infancy, at least when expressed as a percentage of the population. The potential for it to grow is all too real.

There's a great need for more intensive research into the causes and biological mechanisms of MCS. Funding is needed and it is better spent now as part of a *preventative* strategy than later in the search for cures.

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it later I realised what she had meant. The ME Club is a select one. Fortunately only a few people (as a percentage) get to belong to it. I wonder though, if this percentage may be increasing. It is a club in the sense that to gain membership to it you have to suffer from ME. That is you have to 'know' what the symptoms feel like. Some of these symptoms can be pretty weird and it is difficult for people not in the club to understand all of them. Being a member of course brings mostly very bad things into your life. However there are a few, a very few, things which when you are in a very positive frame of mind (and this usually requires that you are also in a 'well' phase) that could barely be described as being beneficial. They are of small comfort and everyone with ME wishes every day that they were not in this club. However I always try to look at things positively although this can be very hard at times. I thought I would mention some of these small 'good things' that I have discovered. I won't go over the terrible things that this illness does do to us as most of you are reminded of them personally, every day. I am only able to think of these 'good things' when feeling well and think more negatively when feeling like hell on earth.

One of these 'good things' is that I think I am more 'complete' as a person than I was before having the illness. This might sound ironic as so often we physically feel like only a fragment of a person. What I mean is that I feel I have a greater understanding of humankind and the woes that the human race can be forced to face. Consequently we learn how people react to chronically ill people. Although we are ill well people surround us and each reacts in individual ways. This may not seem important but I think it is. I think how people react to the chronically ill reflects in some way upon the deepest aspects of humanity. And I think you have to be ill, to really see this. People seem to fall into two basic groups in this regard. There are those who innately seem to be able to accept chronic illness and it's associated trappings and those who cannot. This division occurs amongst the general public as well as with health professionals. Thus how a health professional reacts is, I think, a reflection of their innate humanity and not due to their educational influence. It is important to be able to make this distinction so that you can eliminate those people from your life that are unable to accept chronic illness. Younger sufferers might describe this as ridding their lives of negative energies, although I am way too old to understand this concept. In my experience those people who cannot accept chronic illness seem incapable of change and for this reason it is a waste of vital energy to try to get them to.

Another small 'benefit' is the incredibly 'good' people that you meet in ME circles. Many of these people have ME themselves and you thus end up sharing a special bond because you empathise over how this ME-monster has devastated both of your lives. I guess once again that this is the 'club' aspect that the person I mentioned was referring to. It is comforting and relaxing to be in the company of other MEers because we struggle so hard at times, whilst in the company of healthy people. It is my experience that people who have ME in general, become kinder, more caring and more insightful through having this illness. Because of this many close bonds and friendships are made between people with ME. We all try to support each other, even if this is in a limited fashion due to our energy allowances. As well, **people with ME learn to appreciate things in life which healthy people never become aware of.** These are usually the simpler pleasures of life because we have had to give up on more energetic activities. We take notice of the things in the world around us. This is because we are forced to 'just sit' so often that we tend to end up gazing at the things around us. We might not be able to do a lot of things but because of this we have at least learned to 'smell the roses.' In this way it appears that people with ME become more attuned to nature. Statues of Buddha and 'The Thinker' both remind me of people with ME. We do a lot of sitting and thinking at times. People with ME learn to gain enjoyment from looking at the sky or at gardens, as examples. 'Normal'people are often too busy rushing about in their daily lives to notice such things. In a similar way ME people often take up hobbies of some sort, as these are much gentler on the body than sports or other such activities. These open up new avenues of interest for many sufferers.

ME has also taught me not to worry about the little things in life. We see people being stressed by small issues all the time. When you haven't got your health you realise these things are not important and not worth 'stressing over.' ME has taught me also to relax. If I overly worried about things I would tense my muscles, this would expend energy and I would soon feel worse. It didn't take long – through Pavlovian Conditioning – for me to realise that to avoid these awful symptoms I had to relax. That is, negative reinforcement quickly extinguished this behaviour. Unfortunately not all my symptoms went away of course – only those that I induced in this way. As well, this 'calmness' also had a negative effect. In this way I learnt to not get excited about things, as this also used energy and made me feel worse. Subsequently I didn't look forward to family trips etc. If I thought about them and got normally excited I would feel worse and then I would be not well for the all-important initial travelling part, for which my body would need to be in reasonable shape. It has been theorised that adrenaline can exacerbate symptoms and this may explain some of this experience. So I missed this enjoyable – and free part – of travelling. I am not well enough now, in general, to travel at all.

I discovered that deep relaxation helped overcome the symptoms of sleepiness and weariness etc. Yoga and meditation are probably effective in a similar way. I don't mean to give a picture of ME people as being 'all calm and placid and floaty' and drifting about the world in some sort of self-induced, semi-comatose, drug-like state. This illness has also generated, I am sure, some of mankind's more explosive moments.

Having a chronic illness teaches you how precious life is. This is a practical lesson that most people probably go throughout life never learning. It shows you how 'good' life is. Well that is it would be, if you were well. I remember in medical school being taught about a survey that asked people to list, in order, what the most important things in life were. Inevitably 'health' always came at the top of the list because all the other things were always dependent on having good health to begin with.

This article is an extract from a talk Dr Jolly gave at the 2002 Annual General Meeting of. the Association of New Zealand ME Societies (ANZMES.—www.anzmes.org*) Reprinted with permission.*

Medical Matters

CFIDS and Overlapping Disorders: Variations on a Theme?

By Katrina Berne, PhD

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Many chronic disorders share common features, including symptoms and abnormalities. Studies of illnesses such as chronic fatigue and immune dysfunction syndrome (CFIDS), fibromyalgia (FM) and irritable bowel syndrome (IBS) show that several chronic disorders often occur in the same patient. Since these illnesses are compartmentalized and labeled, each is studied as a discrete disorder. But as common factors become more apparent, the boundaries between illnesses tend to blur.

Because of the number of overlapping symptoms and characteristics, there is speculation that many chronic conditions are either related or are different manifestations of the same illness, perhaps caused by similar factors. Muhammad Yunus, MD, considers CFIDS, FM, Gulf war illness, multiple chemical sensitivity disorder and others to be part of a greater grouping that he calls "central sensitivity syndrome," or CSS.

A group of overlapping disorders is presented below. Numerous others have been excluded due to space constraints. The illnesses profiled here overlap in terms of symptoms; complexity; poorly understood pathophysiology; variability among cases; increased prevalence in women; possible involvement of infectious agents; dysfunction of the immune and central nervous systems; known or suspected autoimmune component; and dismissal or lack of "real" illness status unless a marker or test has been identified.

Their relationships to one another remain unclear. Similarities of symptoms and multiple dysregulations suggest a common mechanism in several conditions, possibly hypothalamic-pituitary-adrenal (HPA) axis dysfunction. The HPA axis controls the release of hormones in response to stressors; in CFIDS, the axis may be disrupted because of abnormalities in the central nervous and immune systems. The mechanisms of the HPA axis are complex and delicate, and minor variations in dysfunction might account for similarities among these disorders.

Fibromyalgia

About 75 percent of people diagnosed with CFIDS meet the criteria for FM. Fifty-eight percent of females with FM, and 80 percent of males with FM, meet CFIDS criteria. Symptoms of both illnesses include pain, gastrointestinal problems, cognitive difficulties, sleep disturbance and neurological problems such as lightheadedness, fainting and dizziness.

People with both conditions typically show normal results on routine lab tests. Both illnesses are most common in women in their middle years. Strenuous activity can trigger relapses, the illnesses wax and wane and secondary psychological problems such as depression, anxiety and mood swings are common for people with both diseases.

There are also a number of physiological similarities. For instance, abnormalities in the central nervous system, such as low levels of brain transmitters serotonin and norepinephrine, are common to both illnesses. Immune system abnormalities are often similar, and include decreased function of natural killer cells, increased antibody (cytokine) levels and disturbances in hormone secretion and function.

Differences between two conditions have been noted. Fatigue is more common in CFIDS, while people with FM have tender points and "trigger" points that cause pain. Substance P, a brain chemical associated with pain signal transmission, is elevated in FM but more often normal in CFIDS. And abnormal versions of the blood-based protein RNaseL are common in CFIDS but much less prevalent in FM cases.

The scientific community cannot yet give us a definitive answer to the question of the relationship between CFS and FM for many reasons. Diagnostic criteria vary among studies, making it difficult to compare results. No objective tests exist to measure such symptoms as fatigue. And large-scale comparative studies have not been funded.

Whether it is the same illness, subtypes of one illness, or different illnesses, the bottom line is the same: More funding and larger, better-designed studies are needed.

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Inflammatory Bowel Disease (IBD) and IBS

Gastrointestinal symptoms are common in people with CFIDS and FM. IBD is a serious, chronic condition, often accompanied by arthritis-like pain and occurring in a waxing-and-waning pattern that significantly impacts one's lifestyle. Two serious types of IBD are Crohn's disease, a severe inflammation of a part of the gastrointestinal (GI) tract, and ulcerative colitis, an inflammatory process of the large intestine. Crohn's is characterized by abdominal pain, diarrhea, fever and weight loss, sometimes with serious complications. Symptoms of ulcerative colitis include abdominal cramps, blood and mucus in the stool and increased urgency to defecate. Attacks may be severe and sudden, with the possibility of severe complications.

IBS is more common than IBD in people with CFIDS. It is a function of bowel function rather than structure, and is estimated to affect 20 percent of adults in the Western world. A distressing disorder that greatly affects one's quality of life, IBS was once dismissed as a mild, psychogenic disorder of gut motility. It is now regarded as the result of brain-gut dysfunction with dysregulation of the autonomic nervous system. This autonomic dysfunction may account for the presence of IBS in both CFIDS and FM.

Gulf war illness

The U.S. government has alternately acknowledged and denied the existence of a group of symptoms experienced by at least 100,000 of the 700,000 U.S. troops deployed to the Persian Gulf in 1990. Although no case definition for Gulf war illness (GWI) exists, its symptoms strongly resemble those of CFIDS, FM and rheumatoid arthritis. More than half of GWI patients meet criteria for CFIDS.

Symptoms occurring in Gulf war veterans include debilitating fatigue, post-exertional fatigue, widespread muscle and joint pain, sleep disorders, temperature dysregulation, night sweats, headaches, numbness, swelling in joints and extremities, irritability, depression, malaise and a number of neurological symptoms, including cognitive impairment, blurred vision and balance problems. Many Gulf war veterans have suffered long-term health problems, and their significant others have become ill as well.

GWI patients often show immune abnormalities similar to those in people with CFIDS. These include overreaction of cytokines and T-cells; diminished numbers of, and unusual changes in, natural killer cells; abnormal ratios of immune cells called CD4 and CD8; and reactivation of Epstein-Barr virus and human herpesvirus 6 (HHV-6).

Multiple Chemical Sensitivity Disorder

Multiple chemical sensitivity disorder (MCS), also known as environmental illness, is characterized by immediate or delayed reactions to various environmental chemicals. Toxins are everywhere in our environment. Offending chemicals are found in food additives, drugs, perfumes and other scented products, pesticides, herbicides and room deodorizers, natural gas, tobacco smoke, solvents, carpets and household furnishings. When these chemicals are inhaled, eaten or drunk, they are able to cross the blood-brain barrier, causing neurological damage.

Various studies suggest that MCS is present in 40-80 percent of people with CFIDS, and the majority of people with a primary diagnosis of MCS have concurrent CFIDS, FM, GWI and allergies. Although there is no specific test for MCS, abnormalities have been detected on immune and brain imaging tests.

Symptoms of MCS can span multiple organ systems. These symptoms include dizziness, headache or migraine, nausea and other neurological sensations, breathing difficulty, impaired concentration and memory, balance difficulties, musculoskeletal and abdominal pain, irritability, depression and anxiety.

Lyme disease

Lyme disease is a multisystem inflammatory disorder that may affect the skin, joints, heart, eyes and nervous system. It is caused by the bite of a tick infected with the spirochete Borrelia burgdorferi or related species. Lyme disease often begins with a telltale bull's-eye-shaped rash and joint and muscle pain, although many patients are unaware of receiving a tick bite.

Antibiotic treatment is most successful in the early stages. Some patients respond well to treatment, others recover over a long period of time, and some fail to recover fully, with a lingering post-infectious syndrome or development of other serious illnesses such as Lyme arthritis.

Months to years after the initial infection, later symptoms include arthritis pain and swelling, sleep disorder, generalized achiness, stiffness, weakness, heart palpitations, headache, fever, shortness of breath and many other physical and cognitive problems. The possibility that Lyme disease is related to CFIDS has been explored, with no clear consensus. Some physicians find that patients diagnosed with CFIDS and FM actually have undiagnosed Lyme disease.

Endometriosis

Endometriosis, or overgrowth of cells from the uterine lining into the abdominal cavity, is characterized by menstrual pain, fatigue, bloating, heavy and/or irregular bleeding and bowel disturbances. Some studies indicate a statistically significant overlap with CFIDS/FM, while others do not. The two conditions may exist simultaneously but there is no known causal relationship at this point.

Depression

Depression does not cause CFIDS and is not present in all cases; however, many patients are given a psychiatric diagnosis such as depression when a physiological diagnosis is not apparent. Overlapping symptoms, presence of depressed mood in some patients, lack of a known cause or marker and simple ignorance causes confusion between CFIDS and depression.

Depressive symptoms in physically ill patients may be a result of immune activation and cytokine secretion, in addition to a psychological reaction to illness-related distress and incapacitation. Complex interactions among the immune system, the HPA axis and other neurological factors affect stress levels, emotions and vulnerability to

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illness. Illness, in turn, affects these body symptoms. Studies show that immune activation may precede the development of depression, with increased levels of certain cytokines.

This article was adapted from "Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses: The Comprehensive Guide" (Hunter House, 2002).

Postpolio syndrome

Many survivors of paralytic and nonparalytic polio have developed symptoms years after the initial infection, possibly caused by damage to neurons. Symptoms of postpolio syndrome include new-onset chronic fatigue triggered or worsened by physical exertion and emotional stress; joint and muscle pain; cold intolerance; sleep disorder; cognitive impairment; headache; neck pain; muscle pain (myalgia); low-grade fever and increased sleep.

Outbreaks of "abortive" or "atypical" polio cases occurred in numerous locations. In the 1940s, an illness dubbed the "summer grippe" was characterized by abrupt onset, duration of less than a week and flu-like symptoms. These cases were typical of nonparalytic polio, caused by a mild polio virus. None of the people with summer grippe developed full-blown polio; apparently the mild polio virus conferred immunity against it.

However, even mild viruses may have damaged the central nervous system. "Potentially half of those diagnosed today with [CFIDS] may have in fact had summer grippe or undiagnosed nonparalytic polio as children in the years before the vaccine became available," reports Richard Bruno, MD.

Katrina Berne, PhD, is a clinical psychologist and author of Chronic Fatigue Syndrome, Fibromyalgia, and Other Invisible Disorders, and CFIDS Lite: CFS (M.E.) with 1/3 the Seriousness.
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US Center for Disease Control Shifting to Clinical Studies

By Richard Podell, MD, MPH

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Chronicle Q & A: CDC shifting to clinical studies
The U.S. Centers for Disease Control and Prevention (CDC) runs the world's largest CFIDS research program. Last year, the CDC spent nearly $9 million on programs to study the illness and educate health care providers about diagnosis and treatment. Yet the CDC remains highly controversial in the CFIDS community. From 1995–98, officials diverted $12.9 million earmarked for CFIDS research to other programs. The funds are being paid back to the CFIDS program over the course of several years.

In this interview, Dr. William Reeves, head of the CFIDS program at CDC, talks about current research underway at CDC — and discusses the future of the CFIDS program in light of current terrorist threats facing the nation.

Q. What are the CDC's main goals for CFIDS research?

A. We have several objectives. The first is to estimate the magnitude of the public health problem that CFS (another term for CFIDS) poses in the United States . We accomplish this by surveillance. Information from surveillance is important for health care providers and is critical to determine allocation of health resources.

Our second objective is to try to determine if CFS represents a single disease or is a common response to more than one insult. The analogy I like to use is arthritis. By definition, arthritis is hot, tender, swollen joints. This can be caused by autoimmune diseases, like rheumatoid arthritis or lupus; by repetitive stress or other injuries; or by infection. They all present the same way as far as the patient is concerned, but their causes, treatment and prevention are completely different. I don't believe it is clear whether CFS is a "thing," or if it's more like arthritis, a common final response to quite different causes.

Our third objective is to determine the pathophysiology of the disease; in other words, how does CFS affect normal body processes? The fourth is to identify causal agents, risk factors and diagnostic markers for CFS, and the fifth is education. We're doing some of that now with The CFIDS Association.

Our entire program reflects CDC's mission to prevent and control disease. But until we figure out risk factors, diagnostic markers, and what causes CFS, we really can't develop effective prevention and control.

Until recently, the CFS program has emphasized surveillance. However, I think it's pretty clear from our studies, and from other population-based studies (such as those of Dr. Leonard Jason), that we have a pretty good idea of the magnitude of the problem. It's somewhere between half a million and a million adult Americans with the disease. Although CFS affects adolescents, it is much less common than among adults.

Q. You have cancelled a nationwide study on the prevalence of CFIDS. Why?

A. The main reason the study was put on hold was Sept. 11. We had started a pilot study about three months before and we ended about three months after. We encountered some problems following the tragedy. People weren't so willing to answer personal questions — and we had some real worries that 9-11 might have changed the occurrence of CFS. We're doing some analysis to see whether that has happened. We did screen more than 7,000 people in eight areas around the country, which should yield some interesting data.

Cost and staff resources were also a big consideration. It didn't look from the pilot study as if our estimates of occurrence would change substantially. So it didn't appear to justify the $3 million or $4 million to complete it. We felt the funds and scientific effort would be better applied to other priorities. As an aside, The CFIDS Association collaborated in coordinating the pilot survey and was responsible for the clinical evaluation component.

Q. So your emphasis is starting to change?

A. We're moving much more into pathophysiology and clinical studies now. We have some incredible opportunities to study groups of people with CFS in ways no research group has been able to do before.

Much of this has been possible because of our surveillance program in Wichita , Kan. Wichita is like a poster city for mainstream America . We screened 20 percent of the entire city's population for CFS and followed 4,000 subjects annually over four years.

We have identified a representative sample of people with CFS, of people with not-quite CFS, and with CFS with various co-morbidities, like major depressive disorder. They represent the general population— we are not limited to patients with CFS who are seeing health care providers. If you only look at those folks, you don't get an accurate picture of the scope of everyone suffering from CFS.

We now have the opportunity to study these people clinically. And that's what we're doing. We have invited all subjects we identified in Wichita who have ever had CFS; those who would have had CFS except that they have exclusionary depressive disorders; people with severe chronic fatigue who didn't quite meet the case definition for CFS; and a group selected from the general population, who are matched by age, race, sex and body mass index. It's about 400 people, including seventy-some with CFS. They are representative of the Wichita population.

We are inviting them for a two-day hospital stay, during which they'll have a complete battery of neuroendocrine and immune function studies. Response has been excellent so far and most are volunteering to participate. Since most people with CFS report sleep problems our subjects also have formal sleep studies. These include two overnight sessions

and multiple sleep-latency tests. Evaluating sleep at night, one can tell a lot about sleep problems. But you also have to look at people during the day, too. That's called sleep latency. You look at how quickly you can nap during the day, how easily you can stay awake in a darkened room — things that are influenced by different sleep disorders.

Most people with CFS also report problems with concentration and memory. People in the Wichita clinical study are also undergoing formal mental function (cognitive) studies, using a group of tests called the CANTAB. In order to separate interactions between CFS and depression, we are assessing subjects' psychiatric status.

It's increasingly clear that neuroendocrine and immune function reflect physiologic adaptation to accumulated events over one's life. So, we're doing a rather complete measurement of the subjects' lifetime stress history and their reactions to stress.

Finally, all of those with CFS, and the controls, will have tilt-table testing done. The study is about as comprehensive as we could possibly make it.

Q. What other clinical studies are underway?

A. The big ones are modeling studies. In modeling studies, you enroll subjects who have been exposed to something that you know will cause symptoms of CFS and measure how the body reacts. We're doing two studies with Emory University , and another one in Australia (see box).

All of our studies include cutting-edge laboratory tests using gene expression and proteomics. Gene expression measures activity of messenger RNA. We are able to describe the activity of 10,000 to 30,000 genes at a pop — which ones are "on," which ones are switched "off," which ones are turned up a little and which ones are turned down. Differences in gene expression profiles can help to distinguish between people who have CFS and those who don't.

In contrast, proteomics measures all the proteins that exist in a sample of someone's blood. Genes code for the creation of proteins, so proteins can only be there if the genes call for them. But there is not a one-to-one relationship. Proteins have their own cycles, and regulate each other, to some extent independently of gene expression.

Q. Why are these tests important?

A. There are several benefits. First, if we can identify a pattern of gene expression that distinguishes people with CFS from controls, we will have a diagnostic test for CFS.

In addition to diagnosis, gene expression analysis provides a window into the pathophysiology of CFS. What protein or cell pathways are these over- or under-expressed genes part of? How might these relate to CFS? While it doesn't really matter what the particular gene or protein is for a diagnostic test, it makes a big difference when you're looking at what may be causing CFS or searching for targets amenable to therapy.

The two sets of data together can be powerful. We've done some preliminary work that shows we can separate people with CFS from non-fatigued controls.

Q. What new studies are in the pipeline?

A. We are already thinking about the next clinical study. We have done everything we can imagine in the Wichita clinical study — but we haven't done any of it in great detail.

For instance, for the neuroendocrine measurements, we're only collecting blood once. This will be less disruptive to cognitive and sleep studies. Detailed measurements of neuroendocrine function would have an IV in the subjects over one or two days and they would be sampled constantly in conjunction with application of various stimuli, perhaps done in conjunction with brain imaging.

The comprehensive set of measurements we're collecting in Wichita will tell us what we might need to examine in more detail. It's a starting point. We will do a much more detailed study based on what we find.

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Q. Are you cutting back on anything?

A. Surveillance, as I said before. And we've suspended our efforts to identify infectious agents as causes of CFS. It is clear from studies that we and other people have done that none of the infectious agents we know of are the direct cause of most cases of CFS. We've recently completed a comprehensive set of studies to identify novel or previously unknown infectious agents in CFS — there are ways to do that — and no infectious agent is significantly associated with CFS. Clearly, some people develop CFS following an acute infectious illness such as mononucleosis (Epstein-Barr virus) but this is not the case for most people with the CFS. We believe it will be more productive to focus on clinical studies and searching for markers. This may lead us back toward an infectious agent, at which point we'll look again.

Q. Has the funding scandal and payback helped raise CFIDS awareness at CDC?

A. I honestly think that CDC has been very supportive and enthusiastic about the CFS program and about the findings.

Did it raise the profile of CFS? It certainly did that, and the breadth of our current program reflects the "jump-start" restoration of the funds provided. However, and more importantly, it catalyzed the implementation of improved management and accounting procedures throughout CDC.

Q. What about the new emphasis on bioterrorism in the Bush administration? Will it erode the budget for CFIDS?

A. As world events have shown, the emphasis on bioterrorism is critical to national security and CDC must be a pivotal player in these efforts. I don't really think it will cut into our budget. CDC support, interest, and involvement in CFS hasn't gone away.

Although I truly don't think the budget will be cut, I do worry about possible loss of focus on the overall CDC mission. Many issues of homeland security such as smallpox, anthrax, and chemical agents are related to programs at CDC. I'm concerned that issues of terrorism could dilute attention from CDC's core mission. Things like influenza immunizations, childhood diarrhea, eradicating polio, cancer control — and CFS.

For more information on the CDC's research program for CFIDS , check the CDC Web site at http://www.cdc.gov/ncidod/diseases/cfs/index.htm.

ME: All in the Brain?

Glasgow neurologist Dr Abhijit Chandhuri draws parallels between MS and ME. Interview by Theresa Coe of Action for ME www.afme.org.uk

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Tell us about your clinical experience - how did you come to be interested in ME?

Professor Peter Behan introduced me to the problem of chronic fatiguing disorders in neurology while I was working with him as a clinical lecturer. Fatigue symptoms in MS, Parkinson's disease and stroke are also remarkably similar to the fatigue experienced in M.E./CFS. Like pain, fatigue is a complex neurological symptom. MS and M.E. patients both experience symptoms of focal and generalised fatigue that fluctuate and are influenced by physical or psychological stress and temperature extremes. The clinical similarities of fatigue and also the fact that both MS and M.E. may follow a viral infection stimulated me to take a special interest in M.E./CFS.

You're probably aware that some neurologists view M.E. as psychological rather than neurological…

I am aware of this view and think it is rather unfortunate. I say this because M.E. is classified as a neurological disease by the World Health Organisation and the disabilities in M.E. patients are comparable to those experienced by patients with chronic neurological diseases like MS.

I think the example of pain may be useful here because human response to pain has a behavioural component. Depending on how bad your migraine headache is, you may choose to work at a slower pace or go to a dark room and sleep it off. This is also true for fatigue.

But to dismiss fatigue as a largely psychological problem would be very similar to the rejection of the sensation of pain itself and to suggest that your migraine headache did not exist in the first place. This is a rather simplistic argument but I think the overemphasis on psychology and behaviour therapy in M.E. in the past has not really helped our understanding of chronic fatigue.

Their argument would seem to be that while with MS, you can see clear evidence of damage from brain lesions that gives rise to symptoms, there aren't any such clear markers indicating a neurological basis for M.E.

There is little evidence that the changes you get in MRI brain scans of MS patients are the markers of *fatigue.* There are papers to suggest that some M.E./CFS patients with more severe cognitive symptoms may have MRI brain scan changes showing small areas of increased signals. But the fatigue they experience is very similar to that of other patients who do not show these abnormalities. Conventional MRI brain scans in MS or M.E. therefore seldom identify the specific brain changes that may contribute to the genesis of fatigue.

I agree that there aren't at present any clear neurological markers for M.E. just as we do not have a 'painometer' to measure pain or any laboratory tests for migraine. However, neuroscience is advancing at an amazing speed and we are experimenting with newer types of brain scanning that were previously considered impossible in a living brain. We've only made progress in MS research by way of new brain scanning in the last twenty years. Before that, many MS patients were also considered to have a psychological cause for their symptoms. I think M.E. is a very young problem to neuroscientists – we're only just beginning to understand it.

Given the apparent similarities, can the field of M.E. benefit from research done on fatigue in MS?

Yes, I certainly believe so. Take the anti-influenza virus drug amantadine, for instance. This was noted as effective in Parkinson's disease and was then researched in MS patients to see if it could alleviate their fatigue. A good response was noted in about half these patients and amantadine still remains the best available treatment for MS fatigue.

My clinical experience suggests that it also helps a minority of M.E. patients at smaller doses. We have used a combination of low dose amitriptyline (an antidepressant) and amantadine with a degree of success in some M.E. patients but I don't think a randomised controlled trial has been done yet, which is a shame.

All these drugs are about symptom control rather than treating any underlying problem though aren't they?

That's right. Unfortunately, this is also true of most chronic neurological disorders. We all know there is still no cure for M.E./CFS, MS or Parkinson's disease. As physicians, all we can do is try to treat the symptoms and improve quality of life with advice on lifestyle changes. In my experience, antidepressants are being used far more liberally in M.E./CFS than in other neurological conditions, with a false hope that they will work for fatigue even if the patient is not depressed or anxious.

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But there isn't there a difference with other chronic illnesses, in that some people with M.E can improve or even recover?

I don't think there is ever 100% improvement in most adult patients if they have been symptomatic for over a year. What does happen is that some will get substantially better to a point where they may be able to continue with their normal daily activities. Most who will recover fully tend to be younger and do so spontaneously in the first one to two years after symptom onset.

Are there any neurological tests which may be useful in diagnosing M.E?

Not yet. What you can do with neurological tests and other assessments is firstly exclude other conditions and then perhaps use them as a tool to aid understanding of the problem. It's very often a case of looking at the broad symptom complex. If you see someone with joint swelling and pain in addition to fatigue, for instance, you might check the blood for possible rheumatological problems. On the other hand, if your patient has fatigue and neurological symptoms such as balance problems, you might wonder if it could be MS. Quite a few MS patients talked about having 'M.E.-type fatigue' until an MRI scan showed the true cause of their particular set of symptoms.

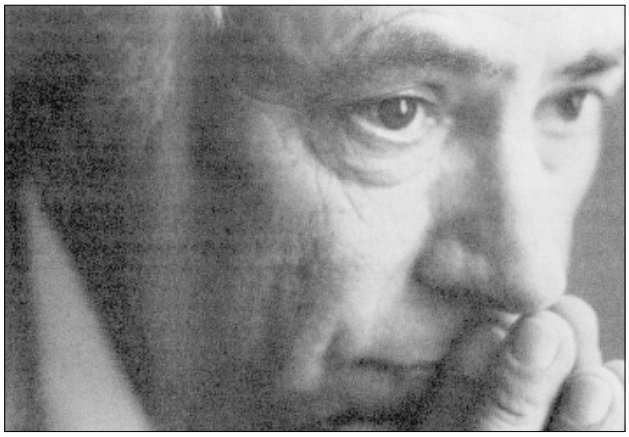
Many M.E. patients can't understand why blood test results come back as normal when they feel so desperately ill. Why is this?

It's because what we test is based on what we already know and clearly we don't have sufficiently sensitive tests for M.E. There are some subtle abnormalities in M.E. patients, but nothing that is really unique to this illness. Put simply, fatigue in M.E. (or MS) is not due to an abnormality in immunity, liver, kidney or thyroid functions so these tests may all come back as normal. It's more likely to do with alteration in the level of brain activity. However, M.E. isn't the only condition where diagnosis needs to be clinical. Blood tests won't show a change in migraine patients, for example, yet we know they are genuinely ill. You can't dismiss the pain they are experiencing.

What problems do you think are caused in both research and treatment by 'lumping together' all CFS and M.E. patients?

We have to define what we're dealing with. If we use the broad term CFS which does not exclude all patients with psychological fatigue then there will be a subset of patients who would benefit from an entirely different kind of approach. A good comparison again is chronic headache. If you don't distinguish migraine sufferers from those that have simple anxiety or tension headaches, you cannot treat them effectively. That's where clinicians are important and scans or reports will not help.

We sit down and try to work out what is more likely to be the



cause of a patient's symptoms, accepting that sometimes we might get it wrong – and that in some cases there will be overlaps. For some conditions there are tests that may confirm your clinical diagnosis, and in other cases there aren't – you just have to make an informed judgement, listening carefully to the patient.

When I have a patient with chronic fatigue, I always try to make out whether they're suffering primary depression and associated fatigue or a post-viral M.E.-type fatigue. For the latter I use term 'M.E./CFS'. I had a letter published in the *Lancet* some time back regarding the need to separate out neurological versus psychogenic chronic fatigue, in the same way as we clinically distinguish between different types of headaches or Parkinsonian disorders.

There has already been some work done using SPECT brain scans which have shown a lack of oxygen to the brain stem in many M.E. patients studied

Yes, Costa's studies have shown changes in blood flow through the brain stem and we have shown here that blood flow changes are present in the cerebral cortex. However, patterns of blood flow changes in M.E./CFS are not specific. Cerebral blood flow is influenced by a number of factors including the rate of brain activity (metabolism). I think SPECT scans in this illness only provide indirect evidence that there are changes in brain function as compared to a normal brain. By themselves, altered SPECT blood flow patterns do not generally identify a specific disease.

What particular research would you like to see investigated further?

Currently, my main interest is in new forms of brain scanning in chronically fatiguing neurological disorders and I would like to apply this tool to both M.E. and MS. We're also trying to experiment with some form of laboratory markers that may indicate proneness (susceptibility) to M.E./CFS.

We have been able to identify fairly robust abnormalities showing up in the specialist brain scans of a small number of M.E. patients whom we have studied so far. However, we also need to look at these changes over time. Equally at a more

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basic level we need to understand why some patients develop M.E. after infections and some not. I think part of the answer lies in genetics. If you can identify pathways between genetic predisposition to viruses and subsequent neurological disorders and fatigue that would be a major advance in science.

How would you treat a patient that may have some degree of mood disorder but who primarily has what you consider to be neurological M.E?

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It would be important to identify whether the mood disorder is primary or reactive to the illness. For M.E., we'd offer basic symptomatic management of fatigue and advice on lifestyle changes to minimise relapses, just as we would to a patient with MS. Our advice would also include treatments to alleviate pain, sleep problems, physiotherapy to address any joint problems and where indicated, antidepressants for depression or mood disorders.

Why do you think the role of depression in M.E. is given so much emphasis in this country?

The role of depression in M.E. is perhaps no more important than that in any other chronic medical illness where it may exist as a co-morbid factor. If you match MS or heart disease patients with healthy controls, they will have substantially higher risks for depression and suicide than healthy people. I don't think M.E. is any exception. However, because depression can be more easily treated than the underlying neurological problem in M.E., it has received more attention.

Sadly, few neurologists have shown any special interest in the neurology of chronic fatigue, despite it being a very common problem in clinical practice. Instead it has been with the psychiatrists and psychologists for a while who have used their own methods to try and find an answer to this problem. Naturally, every speciality approaches a clinical problem from its own area of expertise and the psychiatrists have developed a theory that they believe may apply to chronic fatigue as a medically unexplained symptom.

Some physicians may confuse reactive or secondary psychiatric complications in a medical disease with primary depression and so feel compelled to use psychological interventions without fully assessing their appropriateness. There is also an increasing trend to use a psychological paradigm to explain symptoms that are hard to quantify, like fibromyalgia or irritable bowel. In my view, that's probably more convenient than scientific.

Is the field changing now?

I think so. I have been referred M.E./CFS patients seen by psychiatrists who confirm that they did not have a primary depressive or psychiatric illness. I'm sure many have come to realise that the conventional psychiatric model for this illness as a depressive, somatising disorder is perhaps too naive and no longer valid.

Perhaps a tendency to focus on the mind in these patients has been influenced by the fact that their tests and scan reports are normal. Maybe we have to ask ourselves if we should pay more attention to patients rather than reports. We need a return to traditional practice of medicine that makes use of the technology to understand, rather than to reject, what the patient is telling us.

Do you have concerns around the NHS mainstay of treatment for M.E./CFS which seems to revolve around graded exercise therapy and cognitive behaviour therapy (CBT)?

CBT and graded exercise therapy are two of the possible options in the management of M.E./CFS - but these interventions do not cure M.E. and are not suitable for every patient.

Let's take the issue of graded exercise. In any form of neurological disorder if physical inactivity is present for some time, that will lead to muscle wasting and deconditioning which of course will compound the problem. To overcome that, within their limitations, patients need some degree of exercise. But you can't 'beat' M.E. by pushing yourself to your limit because one of the core problems is post-exertional malaise. On the other hand, if you use physical activities as part of a rehabilitative strategy to maintain muscle condition, this can be very helpful so long as you pace yourself and don't overdo it.

And what's your view of CBT?

Well, research certainly demonstrates that it does help a proportion of patients, but we aren't sure why. It's very interesting that psychiatrists believe CBT is effective because it challenges 'unhelpful' illness beliefs, but this is entirely hypothetical - I don't think that the effectiveness of CBT in a patient implies that his or her M.E./CFS was due to abnormal illness behaviour. In depression, interpersonal therapy seems to be effective in changing brain metabolism and blood flow where antidepressants have failed. You obviously have an explanation for CBT that is nothing to do with simply 'challenging beliefs'. That's where my reservations about the psychologisation of M.E. come in. I think more research is required in this area.

Any final advice for patients?

Trust yourself rather than anyone who says you do not have a disease or who advises you to push yourself harder even if that makes you feel worse. Make sure your lifestyle is regulated and try to keep to a flexible programme of physical and mental activities on a regular basis. Always remain positive and take measures that can improve the quality of your life, but don't be entirely dependent on the advice of doctors – it's you who has to live with your condition.

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AACFS 6th International Research and Clinical Conference

Chantilly Virginia January 31- February 2, 2003
Summary of Presentations by Charles W. Lapp, MD

The biannual scientific conference of the AACFS was attended by over 190 physicians and professionals from more than 14 countries. This year's format was new. The first day was an introductory course on the diagnosis and basic management of CFS taught by Drs. Charles Lapp and Leonard Jason. This was attended by over 170 professionals, and was highly acclaimed by the attendees. (This entire program is available to professionals in text, video, or web-based formats at www.cfids.org or on the CDC website. Professionals may earn 2-3 hours of CME credit, and earn a certificate of competency on successful completion of the course.) The next two days were devoted to summaries by the faculty and to new research reports.

At the Saturday night award ceremony, Dr. Ben Natelson was applauded as the outgoing president; Dr. Dan Peterson (Incline Village , NV) was given the prestigious Perpich Award for his outstanding devotion and contributions; and Dane Cook, PhD (Research Physiologist at the University of Medicine and Dentistry of NJ) was given the Junior Investigator Award. On Sunday, February 2, Dr. Dharam Ablashi assumed the presidency of the organization. For more information on the AACFS, log on to www.aacfs.org.

The following is my overview of the papers presented at this meeting. Summaries are short, and only the most relevant papers are reviewed. They represent my personal understanding of the material, of course:

Leonard Jason, PhD (Chicago, clinical psychologist and renowned CFS researcher) headed the epidemiology section. His introductory remarks compared the 1988, 1994, and Canadian case definition criteria for CFS. Jason's studies reveal that the 1988 research criteria select higher rates of sore throat and lymph node tenderness, and patient's with poorer health (based on the MOS SF-36 survey). On the other hand, the new Canadian clinical criteria are less likely to select for psychiatric co-morbidity and more likely to select for functional impairment, fatigue, weakness, neuropsychiatric problems and neurological symptoms. Jason also points out that when CFS patients have psychiatric disorders, their primary physicians correctly identify the condition only 64% of the time. Lastly, Jason reviewed the results of his well-known community prevalence study. CFS was most prevalent at ages 40-49 years, mostly in women. Surprisingly, Latinos and Afro-Americans were much more likely to have CFS than Caucasians (at least in the Chicago metro area), and skilled workers were much more likely than professionals to fall ill. This is contrary to previous common opinion, of course. Jason found the prevalence of CFS to be 522 / 100,000 persons for women, and 291 / 100,000 for men. These prevalences are much higher than HIV (125/100K), lung cancer (43/100K), and even breast cancer (26/100K), in women. Lastly, his study of over 3000 nurses showed the greatest prevalence – over 1000 per 100,000. This may be attributed to on-job stress, rotating shifts, occupational exposures, or other factors, he surmised.

Dr. William Reeves of the CDC then reported on the 1994 case definition for CFS. A committee has met annually since 1992 to revise and improve the definition, and minutes of these meetings are available on the CFS section of the CDC home page. They specifically address ambiguities in the exclusionary and co-morbid conditions; and evaluate instruments to measure intensity, disability, and case-defining symptoms.

Sleep assessment in CFS was the topic addressed by Dr. Elizabeth Unger of the CDC. Her studies, performed at Moldofsky's sleep lab in Toronto, confirmed that PWCs are indeed fatigued, not just sleepy, and that non-restorative sleep and nighttime restlessness were closely associated with CFS.

Trudie Chalder, PhD, a nurse and behavioral psychologist from England, addressed the epidemiology of CFS/ ME in 5 - 15 year olds. 1354 children were identified by their parents as being fatigued. 24 (0.6%) were determined to have "chronic fatigue" while 8 were shown to have true Chronic Fatigue Syndrome (0.2%). The parents were only able to identify CFS correctly in 4 of these patients. Chalder concluded that the prevalence of CFS in children is lower than expected; anxiety and depression are highly correlated to fatigue (but not CFS, necessarily); and parents have difficulty identifying CFS in their own children.

Kim Buschio, MA (NJ Medical School) studied physical impairments in CFS and FM. She concluded that pain is a better predictor of impairment than fatigue in both CFS and CFS with FM.

Dr. Bob Suhadolnik of Temple University (Philadelphia) headed up the session on biochemistry and genes. He began with an excellent overview of biochemistry -- nitric oxide formation, peroxynitrate, oxidative stress, elevated levels of RNaseL and PKR, decreased acyl carnitine, and increased glutamate in persons with CFS.

Drs. Suzanne Vernon (research microbiologist at the CDC) and Wilhemina Behan (Glasgow University, Scotland) introduced us to the exciting new concept of gene expression profiling. It is now possible to take blood (or other tissue) and apply it to a small glass slide containing over 20,000 gene identifiers. When processed and scanned, scientists can determine which of those 20,000 genes is turned on, off, or somewhere in between. This vast array of information is

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specific for various states of health and disease in each individual. Thus, gene profiling can now distinguish between several types of lymphoma in a patient, thereby allowing more specific treatment for the patient. Using 25 cases of CFS supplied by the CDC, Vernon could accurately distinguish CFS from healthy controls, and seven specific genes were identified as "turned on" in the disorder. Behan studied muscle biopsies of three patients with CFS and found 3 genes upregulated and 33 genes downregulated. 24 genes were positive in controls but absent in CFS. Patrick Gaffney, MD (Minneapolis) also studied gene profiling and found 166 genes "different" in CFS when compared to normal controls. Thus, gene profiling might some day provide us a diagnostic test, as well as a means to distinguish infectious, immunological, or other causes.

Toxicology was broached by Gwen Kennedy (Ninewells Medical School, Scotland), whose studies indicated that oxidized LDL cholesterol and isoprotanes (oxidation radicals) were increased in PWCs, and blood glutathione levels were decreased. She compared CFS patients to those with organophosphate toxicity and Gulf War Syndrome, both of which have symptoms similar to CFS.

Infection and Immunology was headed by Dr. Jon Hay, SUNY/Buffalo. Dr. Kevin Maher (University of Miami Medical School) described the molecular basis of immunological defects found in CFS, including activated T cells, elevated cytokines and immunoglobulins, reduced NK cell activity, and poor delayed skin hypersensitivity. His studies concluded that perforin and granzymes (used by T-cells for killing other sick or infected cells), was depressed in the T cells of persons with CFS. Also, activation of T cells is correlated with increased IL4 and decreased IL6, as typically seen in CFS.

Dr. Suhadolnik (see above) described the 2'-5' OAS / RNaseL antiviral system and how the enzyme RNaseL is markedly and persistently increased and in CFS but not in control or depressed persons.

Dr. Ben Natelson (director of the CFS Research Center at UMDNJ-New Jersey Medical School) headed up the treatment section. He reviewed the recent multi-center randomized placebo controlled study of the stimulant drug modafinil (Provigil™), concluding that the drug did not seem effective in CFS although it has been shown quite effective in treating fatigue in FM and multiple sclerosis. Dr. Natelson, however, felt that the study was flawed. He suggested that a different study plan using different instruments and end points would probably show that modafinil was useful in CFS. (At Hunter-Hopkins Center we have found modafinil extremely helpful in improving alertness and mental clarity particularly in CFS patients who report daytime drowsiness.)

Olof Zachrisson, MD, PhD, of Sweden hypothesized that immunity in CFS may be disturbed by repeated or persistent bacterial infection. He treated 51 PWCs with a staphyloccal (bacterial) vaccine for 12 weeks, and obtained a positive response in 16. There were modest decreases in pain and fatigue that correlated with antibody production in the individuals. However, the response was not maintained unless the vaccine was continued monthly. The vaccine is produced privately in Switzerland, but is neither publicly nor commercially available.

Dr. Dan Clauw (director of the fatigue research center at the University of Michigan) studied 1092 veterans with Gulf War Syndrome who were randomized to Cognitive Behavioral Therapy (CBT) alone, CBT plus an exercise program, exercise alone, or "usual medical care." After 3 months, there were very modest improvements in those vets treated with CBT or CBT + exercise, especially for cognitive symptoms and mental health. When followed up 6 and 12 months later, these modest gains were lost.

Low intensity aerobic interval training was discussed by Dr. Claudia Lennartson (Huddinge Hospital, Stockholm, Sweden). She exercised 20 PWCs by walking them 15-30 minutes at their own pace, then taking a 15 minute break. This was done once weekly at the hospital, and twice weekly at home. Participants completed an average of 25 sessions, but 5 dropped out of the study. Fatigue was no worsened in any subject, and there were modest gains in physical function and exercise duration. (NB: At Hunter-Hopkins Center, we recommend that PWCs start with 3-5 minutes of activity alternating with 5 minutes of rest. This level of aerobic interval activity is low enough to be tolerated well by virtually all patients, and rarely triggers significant flares of fatigue or symptoms).

Dr. Dan Peterson, Incline Village, NV, introduced the first morning session on February 2nd by describing his experience with Human Herpesvirus 6 (HHV6). Peterson reminded us that HHV6 subtype "b" is common in infants (roseola) and has been associated with MS, while subtype "a" is highly associated with CFS. He studied 135 patients who had encephalopathic features (such as vertigo, headache, and significant neurocognitive symptoms) and abnormalities on both MRI and SPECT scanning. 29 of these subjects had viruses identified in their cerebrospinal fluid: EBV (1), CMV (1) and HHV6a (27), but none had HHV 6b, 7, or 8. Treatment with the antivirals valcyclovir and gangcyclovir were unsuccessful. However, on intravenous foscarnet 8 subjects improved and 4 were able to return to gainful employment.

Dr. Ben Natelson (UMDNJ-New Jersey Medical School) enumerated the encephalopathic features seen in CFS, namely cognitive dysfunction (tested by the PASAT and tests of complex attention), subcortical high intensity areas in the frontal cortex on MRI, and modestly increased ventricular (brain) volumes. Lumbar punctures in 39 CFS subjects revealed elevated protein or > 5 white cells per hpf in 15 cases. Interestingly, none of the subjects with abnormal CSF were depressed or carried an Axis I psychiatric diagnosis, while all CFS patients with normal CSF had concurrent depression.

Dr. Rich Gracely (University of Michigan) then present two papers on functional MRI (fMRI), which rapidly measures cranial blood flow in response to physical challenges such as pain. His group applied thumb pain either intermittently or constantly, and obtained fMRI scans of the Fibromyalgia subjects every 5 seconds. This demonstrated that with intermittent pain the FM patients had decreased blood flow in the cingulated, secondary somatosensory cortex, cerebellum, and insula; only patients with FM showed activation

(increased flow) in the thalamus and putamen.

With constant thumb pain, FM subjects showed increased cranial blood flow in the mid frontal gyrus and inferior frontal gyrus (Broca's speech area); only FM subjects showed activation in the caudate and lentiform areas. Only control subjects, on the other hand, had activation when the pain stimulus was released. These studies confirm once again that persons with FM (PFMs) respond differently to painful stimuli than do normal controls.

We were shocked to learn from Dr. Akemi Tomoda (Kumamoto University School of Medicine, Japan), that 2% of Junior High School students and 5% of High School students in Japan are disabled by CFS symptoms, especially fatigue and cognitive dysfunction. In a study of 319 students with CFS, Tomoda demonstrated that many (116) had abnormal responses to the Visual Evoked Potentials test, most had shortened R-R intervals on the electrocardiogram (a sign of autonomic dysfunction) and all had low scores on the KANA Pick Up Test, which measures attention and comprehension.

The Technology Session was ably headed by Yoshi Yamamoto, PhD, from the Educational Physiology Lab at the University of Tokyo. He first demonstrated that autonomic symptoms can be improved modestly by distraction with extraneous noise or electrical stimulation. That is, abnormal autonomic responses were blunted when the subject was distracted. This fits clinically because many patients report that their symptoms are not as noticeable when they are distracted by noise, bright lights, activity, commotion, or discomfort; however, it was not previously clear if such stimuli simply distracted the subject or actually improved the dysautonomia.

Next, Dr. Yamamoto introduced the ECOLOG Monitor Watch. This device looks like a watch and normally displays the time and date; but periodically it beeps to remind the wearer to record symptoms and to take a brief cognitive function test. Also, the device is an Actimeter that constantly monitors the activity of the wearer. After several days this data can be downloaded to a personal computer and the data utilized in standard Microsoft based programs such as Excel.

Dr. Yamamoto's associate, K. Yoshiuichi, MD PhD, demonstrated the utility of this ED (electronic diary). In a preliminary study of PWCs versus controls, Yoshiuchi has demonstrated that PWCs are more active than controls, more fatigued, sleep less well, and have more performance difficulties on the neurocognitive test. Remarkably, PWCs performed more work over the course of the day than normal counterparts, but it was accomplished in short bursts of intense activity during the day and separated by periods of rest. This may have represented PWCs who tend to "push and crash," and may not be a healthy trend at all.

Angela Lyden, MS, of the University of Michigan introduced another actimeter, the Actiwatch™, which measured general levels of activity over a 2 day period. Her 25 subjects also demonstrated considerable variability (i.e., "push and crash") over the course of the day.

The Chief of Clinical Neuroendocrinology at the National Institutes of Health, Dr. Phillip Gold, gave a wonderful talk on the neuroendocrine differences between CFS and depressed patients. Profoundly depressed subjects were

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described as hopeless, anhedonistic, and anxious. Biologically they demonstrate increased plasma cortisol, decreased growth and reproductive function, immunosuppression, elevated blood pressure and heart rate. In CFS, on the other hand, plasma cortisol and ACTH are reduced and BP is frequently decreased. Dr. Gold then described "atypical depression," whereby patients are severely depressed but manifest increased sleepiness, overeating, lethargy, and profound fatigue. Unlike typical depression, these subjects have increased immunity and their stress hormones (cortisol, epinephrine, norepinephrine) are turned off. These patients clinically tend to be very anhedonistic, withdrawn, and socially isolated; they respond best to Wellbutrin but not at all to tricyclic antidepressants.

Dr. Gold also described the biochemical response to maximal exercise in PWCs: decreased levels of plasma cortisol, ACTH, an catecholamines in response to this physical stress. This highly suggests that such individuals would respond poorly to any stress.

A New York cardiologist, Dr. Julian Stewart declared that Postural Orthostatic Tachycardia Syndrome, a common autonomic abnormality in CFS / FM, was related to decreased arterial vasoconstriction in the lower extremities. He performed Whitney strain gauge plethysmography in adolescents with CFS to demonstrate that most have "low flow POTS." This means that blood flow to the lower extremities is slow, peripheral venous resistance is high, and such patients frequently have acrocyanosis (skin turns bluish in color) on prolonged standing. He studied 14 subjects aged 13-19 years.

In the UK a number of farmers and shepherds have been reported with CFS-like symptoms, presumably due to chemicals they use in "dipping sheep." These chemicals are typically organophosphates, which are well-known to cause CFS-like symptoms. Similar chemicals have been available in the US as diazinon and malathion, for example. In an effort to test the effect of such cholinergic drugs, V. Spence, PhD applied acetyl choline to the skin of PWCs and controls. Remarkably, only patients demonstrated an increase in skin blood flow and prolonged vasodilation after application.

Dr. Yoshiuchi returned to the dais to present a study of the R-R interval (on electrocardiogaphy) in 18 PWCs who did not have POTS, and an equivalent number of controls. Invariably the R-R interval was slightly decreased in patients compared to controls or – in other words – patients tended to have faster heart rate than controls.

Lastly, Dr. Dan Clauw (see above) described his extensive evaluation of autonomic function in "Chronic Multisystem Illness," or CMI. CMI includes person with CFS, FM, and Gulf War Syndrome, all of whom typically demonstrate increased sympathetic tone and reduced catecholamine excretion. His subjects had either CFS, FM, or CFS + FM, and were admitted to a clinical research center where they submitted to 4 stresses: pain, a cognitive challenge, isometric handgrip exercise, and a submaximal exercise test. To make a long story short, only the exercise test was able to demonstrate a slight increase in epinephrine and norepinephrine in response to "stress," and the effect was most noticeable in those with FM alone. Dr. Clauw has concluded that PWCs and PFMs likely have slightly different responses of the Hypothalamic Pituitary Adrenal Axis.

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Dr. Lapp is a member of the board of the AACFS. He is director and founder of Hunter-Hopkins Center, PA in Charlotte NC. His full biography (and this same summary) may be found on his website: www.drlapp.net.

Your Society Matters….

Leading the Way Seminar

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450 people attended an informative seminar on both Chronic Fatigue Syndrome and Fibromyalgia. The meeting featured Dr David Torpy and showcased the excellent South Australian research being done on these conditions. It also highlighted the need for increased funding and services for research and for people with these conditions.

Dr Torpy (pictured above with the MC Pauline Brooks, OAM) discussed the role of stress on our bodies. In this context stress broadly defined as anything that puts pressure on us and includes chemical exposure, traumatic events, and illness.

He discussed the role of the adrenal or stress system, and particularly his research which has shown lower cortisol levels in some people with Fibromyalgia (and other research has also indicated this in CFS patients) – and indication of stress-system dysfunction. The fact that lower than average levels occur in some patients indicates that stress is a factor but certainly not a sole cause. It does indicate the need to reduce stress as part of a broad commonsense management strategy.

A brief summary of other speakers follows.

Dr David Gilles

Dr Gilles explained that Chronic Fatigue Syndrome and Fibromyalgia were two syndromes in the mix of several that had overlapping symptoms. His belief is that only abnormalities in brain function can explain the wide range of symptoms experienced by sufferers. In these patients hormones (cortisol) are affected, as well as blood vessels, the immune system and the gut.

Dr Gilles was at pains to point out that there are currently no cures for either condition, and people should be wary about those who try to claim they have such. He emphasized that a whole of life approach was the only effective treatment strategy. Many had to address 4 or 5 areas of their lives, before an overall improvement was experienced.

Dr Peter Del Fante

Dr Del Fante outlined current problems there are in defining Chronic Fatigue Syndrome and explained some of the strengths and weakness of the current internationally accepted definitions—both for research and diagnosis. He went on to summarise some of the research that has been conducted in Adelaide into CFS.

He reported that a Clinical and Research Group has been established in Adelaide. Its mission is to:
"To improve the collaboration between Researchers, Clinicians & other healthcare providers, Patients and their support groups, and Public policy makers; and to advance our understanding and management of this debilitating condition."

Dr Richard Kwiatek

Dr Kwiatek has completed significant work in brain imaging of Fibromyalgia Syndrome patients (Kwiatek et al, Arthritis and Rheumatism, 43, 2823, 2000).

SPECT scans of fibromyalgia patients confirm reduced reduced blood flow in the thalami and neighbouring structures of the brain.

Also MRI imaging suggests reduced signal in midbrain, and also suggests widespread (subtle) reduction in signal in predominantly white matter. Biological changes do exist in the brains of people with fibromyalgia.

He concluded that MRI results suggest that structural changes exist in the brains of people with fibromyalgia; these changes may not all be permanent, but appear to be widespread. He suggested confirmation and determination of their significance is required.

Dr Rey Casse

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Dr Casse spoke on his SPECT scan work on CFS patients. As previously stated in Talking Point, he explained that areas of the brain had reduced blood flow in CFS patients. Specifically, areas of the brain which control recall of numbers and words are effected, which is consistent with symptoms experienced by CFS sufferers.

The latest data shows that whilst these results are significant, they are unlikely to be able to be used as part of a diagnostic test. We do not as yet know why the reduced blood flow is occurring.

Keith Evans

Keith Evans, *Acting Director of the Primary and Community Care Branch* of the Department of Human Services, discussed the government's Generational Health Review which is about to be released. The purpose of this review has been to re-evaluate the state's health service with a view to it becoming more pro-active in illness prevention—as opposed to the hospital focus of the current system. If people are able to be cared for in the community, less people will get to the acute stage where they require hospital care.

Mr Evans went on record as saying that if services did not approve for people with Fibromyalgia and Chronic Fatigue Syndrome, then the buck stopped with him.

Jenny Bennett

Jenny Bennett, coordinator of Self-Management programs at the Arthritis Foundation of SA, briefly spoke of her personal experiences with self-management courses, which had helped her greatly in her own life. She emphasized the whole-of-life management approach that was important for chronic illness sufferers, and explained the helpful role of self-management courses within that. (Jenny can be contacted at the Arthritis Foundation on 8379 5711.)

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Thankyou to all our members who volunteered on the day to make the day possible. Special thanks go to the Arthritis Foundation, and Fibromyalgia SA, who co-organised the event with us. It was a real tea effort.

Paul Leverenz

Misc photos *Top Left*: Foyer during refreshment break *Top Right*: Expert Panel of Speakers during question time *Bottom left*: Disability Action Stall (one of 18 stalls that operated on the day) *Bottom Right*: The ME/CFS Society (SA) Inc. Stall

I Remember ME Film Night Photo Gallery

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I Remember ME Film Night

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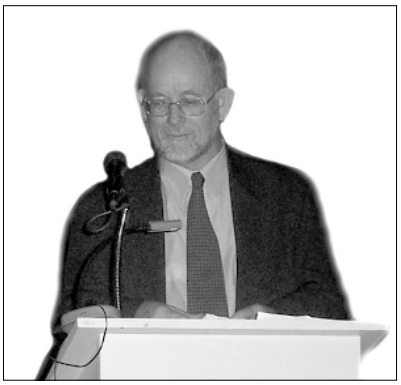


A busy annual Awareness Week came to a triumphant conclusion at the Mercury Cinema on the evening of Friday 16 May. Over 120 paying members and their guests filled the cinema for a showing of the powerful "I Remember Me".

Kym Snyder is a talented American filmmaker whose career went on hold when she came crashing down with ME/CFS a decade ago. An obviously enormously determined person, she began tracking her encounter with the illness – her visits to doctors and specialists, the tests she underwent, the attempts at cures and her evolving moods. It's a very dark and sombre beginning and I think after the first 15 minutes you could be forgiven for not wanting to see much more. All of us who deal with the blight of CFS know its dark impacts on our lives already!

But then the film moves us on. Snyder goes on a journey into the past. She looks at various outbreaks in the USA at places such as Lake Tahoe in the 1970s. She uncovers committed people who struggled with community incomprehension and insensitivity and some medicos who were variously deeply committed to supporting the sufferers and others who themselves look back now and can see that they were less than empathetic.

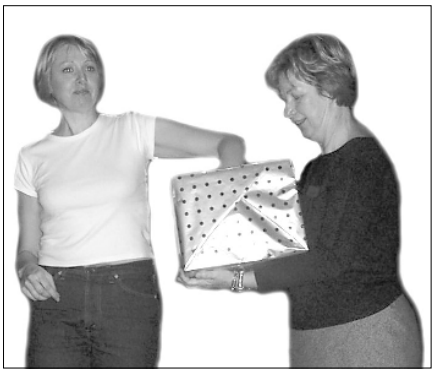
The film's peak moment - and certainly the one which you'll find most reviewers refer to if you check reviews on the internet – comes when a teenage boy who has been totally bedridden and helpless for two years is taken in an ambulance to his high school for his graduation ceremony. He's treated as a hero by his classmates – none of whom have kept in touch with him and supported him during his sickness. It's a scene full of emotion and irony.

"I Remember Me" is in the end a positive and political film. It helps us to see that our own stories are connected to a general history. It tells us that we aren't isolated in our condition and in that sense it makes us feel less lonely and helpless. And it makes the viewer downright angry. And those two elements - anger and a connectedness to other likeminded people – are the building blocks of all movements for change. There's lots to fight for in a place such as South Australia. For a start, your own society, even though it represents thousands of people, doesn't get a cent in ongoing support from the State government. Contrast that with the funds provided to other community health and disability societies and you'll see that we've work to do collectively. I felt terrifically energised by watching this movie.

The evening itself was unusually elegant for the Society. There was champagne and nibbles beforehand; Wendy's ice creams to eat; and a splendid supper afterwards. The evening, and an associated raffle, was organised by several amazing people to whom we all owe our thanks. Patricia Smith, our volunteer office co-ordinator, along with Di Fleet and Christine Hickman - both parents of CFS sufferers and volunteers in our office - took on the challenge. I confess here that I told them that they were mad to try to run the evening less than a week after our major Awareness Day public meeting since that involved them also. They said they could do it and they proved that they could. They got sponsors for the wine – BRL Hardy. That plus a grant from the Paul Newman Foundation – make sure you buy Paul Newman products – meant that the evening was a financial success as well as an important social and political occasion. So to Patricia and her team - thanks a bunch.

Peter Cahalan
Vice-President

Raffle



Congratulations to the Following Prize Winners

1st Prize a night for two plus breakfast at the Rendezvous Allegra Hotel Adelaide, 55 Waymouth St, valued at $340.
Winner: Belinda Phillips

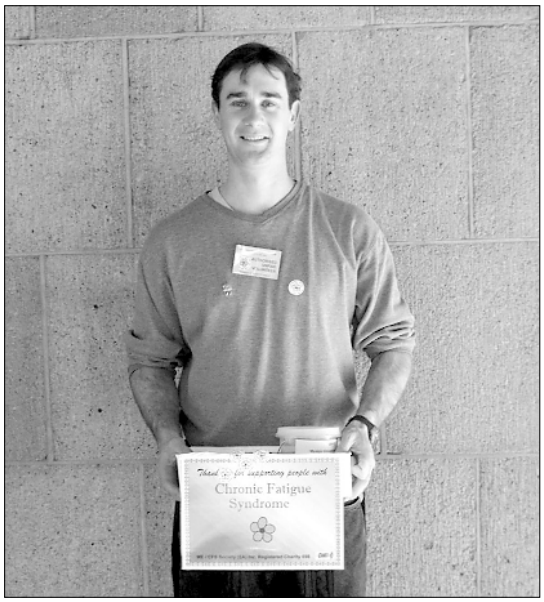
2nd Prize a night for two plus breakfast at the Embassy Hotel, 96 North Terrace, valued at $280.
Winner: Jenni Gay

3rd Prize gift basket valued at $120.00
Winner: Robert Mignoni

4th Prize wine pack valued at $40
Winner: Debra Black

Badge Day Friday May 30th 2003

Thanks to the many people who helped with Badge Day!



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ME/CFS Book

Calling all artists, photographers & writers with ME/CFS

Contributions required for a brand new book, describing what ME/CFS actually 'feels' like, through the words and pictures of sufferers. All prose, poetry, photos & artwork considered. Do you have a story to tell, an image to show the world? International publication planned.

For guidelines and submission form see: www.geocities.com/mecfsbook or send self-addressed envelope (+ international reply coupons) to: 'ME/CFS Contributions', 18
Bishops Way, Buckden, Huntingdon, Cambs,
PE19 5TZ, United Kingdom

Best wishes
Sarah Scott
UK

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SUPPORT GROUPS: METRO

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

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

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

SUPPORT GROUPS: COUNTRY

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

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

Central Yorke Peninsula Support group
Carer Support Yorke Peninsula, 48 Elizabeth Street Maitland SA
Phone: Caroline 88374335

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

SUPPORT CONTACTS

SA Support Groups

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

Misc. Support Contacts

SAYME	Peter	0500523500
SAYME Parents	Marg	8276 5353

Country Support Contacts

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

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

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

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

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

WHAT IS ME/CFS?

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

HOW IS ME/CFS DIAGNOSED?

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

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

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

2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; 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 & 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[1] figure for the prevalence of ME/CFS is 0.2—0.7% of the population. From these figures we expect that 3000—10 500 people in South Australia have ME/CFS.

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

ME & You, ME/CFS Society of NSW Inc., Suite 204, 10 Help Street Chatswood NSW 2067
Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.
Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.
ChaMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.
The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.
Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, High Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.

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