

Talking Point

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

2007 Issue 4

*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.

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:
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At the time of printing the office hours are:
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Our email address is: sacfs@sacfs.asn.au.
Our Web site address is: www.sacfs.asn.au.
Our youth Web site address: www.sayme.org.au.

Membership

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

New Members (cheaper rates apply for renewal):

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

(Family membership is designed for families with more than one person who will directly benefit from the membership at the same place of residence. Family Concession applies when the main breadwinners are concession card holders.)

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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 Secretary, 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.

See notice regarding Advertising on page 2.

Management Committee – 2007/2008

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

- **President:** Peter Cahalan.
- **Vice-President:** (vacant)
- **Honorary Secretary:** Peter Mitchell.
- **Treasurer:** Richard Cocker.
- **Management Committee Members:** Lynda Brett; Melanie Cocker; James Hackett; Adrian Hill; Spen Langman; Emma Wing.

Patron

The role of patron to the ME/CFS Society (SA) Inc is currently unfilled.

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.
Editor: Peter Scott (pmrscott@tpg.com.au).
Assistant Editor: Jenni Gay (jrgay@iprimus.com.au).

Talking Point subscriptions

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

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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.

The ME/CFS Society (SA) Inc is a member of *Charity Direct*.



Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed about research projects, diets, medications, therapies etc.

All communication both verbal and written is merely to disseminate information and not to make recommendations or directives.

Unless otherwise stated, the views expressed in *Talking Point* are not necessarily the official views of the Society or its Management Committee and do not imply endorsement of any products or services (including those appearing in paid advertisements) or treatments.

Always consult your medical practitioners before commencing any new treatments.

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President's report for 2006/2007

By **Peter Cahalan**, President ME/CFS Society (SA) Inc.

I want to begin by acknowledging the spirit of all those people who fight valiantly against the challenges of ME/CFS. The Society itself is the expression of that spirit.

The last year saw some terrific achievements for the Society as well as the usual vagaries of fortune. It is my pleasure to report to you on the year that has passed.

1. The 2007 Experts Forum

For the second time in three years Adelaide was fortunate to be the host city for an important gathering of international and Australian experts on ME/CFS. The forum was organised by the wonderful Alison Hunter Memorial Foundation as part of its long campaign to improve the state of research into the condition in Australia.

Professor Kenny De Meirleir (Belgium) returned to Adelaide after being the keynote expert in 2005. Professor Abijhit Chaudhuri (UK) came to speak about his work in trying to improve pathology protocols in cases where people have died from ME/CFS – an important issue for researching and validating the condition. Dr Dan Petersen (USA) is an eminent figure in the American scene and emeritus Professor Malcolm Hooper has campaigned for people with ME/CFS and MCS (multiple chemical sensitivity).

The four spoke at a packed meeting at Norwood Town Hall on 25 March. They then spent two days in an intensive series of presentations and discussions with Australian researchers and clinicians. I sat in on the meeting and came away struck by how many biological markers of the condition are emerging from research around the world. Such an event with many hundreds of people attending requires lots of work

from many people. I want to thank Lynda Brett again for her outstanding coordination of the event, ably supported not only by the whole committee but also by about a dozen other hard-working volunteers. Without their enthusiastic support, it would not have been the huge success it was. I particularly give thanks to Di Fleet for her huge effort in helping to promote the event.

2. Seminars

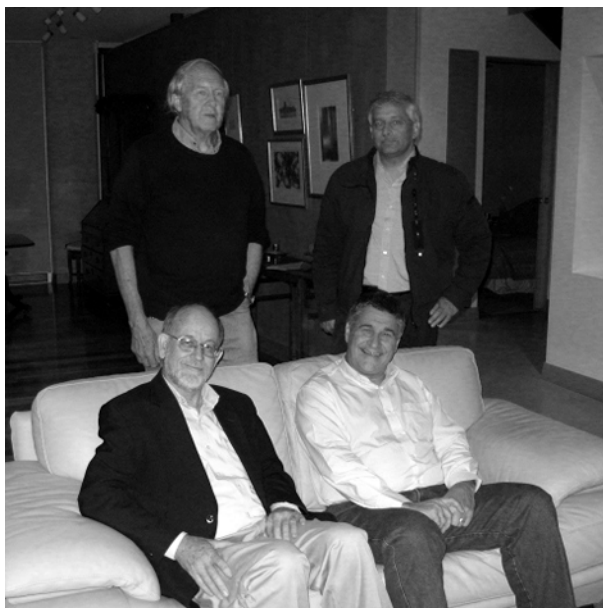
We have struggled in previous years to organise a structured annual seminar program. This year saw a major breakthrough. One of our members, Lorenzo Pizza, stepped forward to organise the program and take pressure off our small and hard-pressed committee. As a result, we had our best year of seminars in recent memory. Our thanks to Lorenzo for marshalling speakers and managing the series. His work took a big burden off the committee, and allowed them to focus on other matters.

The seminars were as follows:

- In April, we planned a feedback session on the Experts Forum. As none of the Adelaide experts at the forum were able in the event to make this session, we improvised. I reported on the forum to a small group of people who enjoyed what one called an

excellent support group encounter with much interaction between everyone.

- In May, we had an impressive performance from Emeritus Professor Barrie Marmion AO, one of those people better known internationally than in his own city. Prof Marmion is a world authority on Q Fever and national moves are in train to attempt to maintain the momentum of his research into a virus which can trigger ME/CFS.
- In July, we heard about two alternative therapies



A group of leading medical practitioners met with Peter Cahalan in October to discuss future directions for medical support for people with ME/CFS in South Australia.

Rear: Dr Ian Butfield; Dr Peter Del Fante.
Front: Dr Peter Cahalan; Dr David Mitchell.
(Photographer: Dr Richard Burnet)

used by a number of our members. Tim White spoke on kinesiology and Dr Andrew Barrie discussed bioresonance therapy.

- In August, psychologist Liz Vaskin stepped forward after our scheduled speaker fell ill. Liz, herself a member of the Society, spoke on the value of using psychology in coping with ME/CFS.
- In September, dietitian Melanie Reid spoke to a large gathering on the role of diet in helping to deal with the condition. Diet had been noted at the Experts Forum as a key factor in treatment in these times when more fundamental 'silver bullet' cures are not available.

Several of these presentations and associated material are available on our website. We thank all the speakers for giving us such a great series.

To have delivered a planned and coherent series of seminars was a real fillip after the previous years of drought. Most hearteningly, Lorenzo had by August already prepared the 2008 seminar series. In fact, we now face a potential surfeit of riches and might delay several sessions until 2009. It's a nice place to be in and undoubtedly it's been one of our best achievements for 2007.

3. Political campaigning

Dr Dan Peterson made a very interesting comment during the Experts Forum. He remarked that ME/CFS societies around the world had made the mistake of focusing overwhelmingly on providing support to people with the condition and ignored politics. If we are to get more funding for research and improved health, education, welfare and employment conditions for people with ME/CFS, then we have to get out and lobby. The trick of course is to work out how to both support members and also do this political work.

We took heed of Dan Peterson's comment. We spent much effort this year encouraging members to take on the task of lobbying candidates in the Federal election. We decided that in the long run it is better to mobilise collective effort than to rely on the Society's hard-pressed official representatives to do all the political work. We have also found that the political lobbying process allows many of our members to make a contribution to the society, even while house-bound. A single letter or email from a member can help enormously, especially if it is repeated ten- or twenty-fold across the membership.

We used our website as our key campaigning tool. Member James Hackett pulled together data on all eleven electorates in South Australia. We encouraged members to tackle local candidates and furnished

them with material from the ME/CFS Association of Australia and the Western Australian Society. A number of members responded and in fact we had enquiries from people in other States seeking advice on how to approach their candidates. The overall number of members who took up the challenge was small, but nevertheless a good start. But we believe that we have learned a lot from the exercise and have helped to encourage a number of people to learn how to play the political game more effectively. Hopefully we can keep building momentum in this crucial area of collective advocacy. Our ultimate target will be a really strong showing in the next State elections, to be held in two years' time. Thanks to all who put the effort in this time.

4. Communications

We have continued to build our reputation for excellence in communicating with members and other people with ME/CFS.

- **Talking Point.** At the end of last year member Jenni Gay volunteered to assist our Editor, Peter Scott, with the magazine as well as with sourcing items for the website. Peter heroically combines both tasks. The move has been a great success. *Talking Point* has come out regularly and at a high level of quality – helped by Emma Wing's good work in sourcing a new printing house and hard work from Peter on improving the layout. Despite the IT revolution, members still hang out for the printed word and so being able to strengthen our magazine has been a real plus for the year. Thanks again to both Peter and Jenni.
- **The website.** We have fed a constant stream of items to the website and as a result its audience has continued to build. I first looked at the statistics for the site in September 2004 and was impressed that 30 000 visitors used it a year. The statistics now stand at 160 000 visitors and over 1.5 million hits. This puts us in the international A-League for ME/CFS sites, as far as we can tell. We made a start towards the site becoming the basis for a national site when the Victorian Society closed its site for maintenance and directed anyone accessing it to our site. We now have a Victorian segment and the flow of Victorian news to it has increased steadily.
- **E-bulletins.** These have continued for most weeks of the year except for a break over the main summer holiday period. Keeping them going has

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at times been demanding and our Honorary Secretary Peter Mitchell now shares the task with me. I thank him and also Michael Ritter, our IT Coordinator, who manages all the backroom side of this and other communications work for us.

We also keep in touch with members via SMS text messages and phone calls. The latter work has rather dropped off this year and we hope that if we can recruit some additional volunteers we can once again renew stronger contacts with members – especially those not accessible by email.

As a result of the continuing efforts to keep in touch and also as an outcome of our increased seminar activity, we gained a whole swag of new members this year. There has not been a great net increase in membership – as a few people always drop by the wayside – but we have stabilised at the 300 mark.

5. National Association

The ME/CFS Association of Australia Ltd is our national peak body. I'm the SA Society's nominated director and Peter Mitchell is my alternate director and sits in on our teleconferences. The Association ended last year strongly with an excellent two-day meeting of Directors in Melbourne. We decided on a series of achievable projects to get on with and left each other in positive spirits. This year unfortunately saw the energy sag. I'll comment on why.

We had intended to concentrate on doing the few simple tasks we had agreed on. We have no real funding and the directors are mostly people already flat chat running State societies and other groups. So keeping it simple and steady made sense. Instead, we found ourselves embroiled in what the SA delegates from the beginning saw as an unproductive debate over what name to use for the condition. Several members decided that we ought to revisit the name ME/CFS and wanted to get rid of the 'CFS' tag altogether. A flurry of long emails followed and in the end we were left still without a consensus on that matter and feeling less cohesive than when we had left Melbourne.

So we hit a rather low spot for a while. It coincided with the decision of our eminent president, Simon Molesworth QC AM, to resign because of the pressure of work and other business. Our able company secretary Nola Miles also resigned to deal with an increased flow of work for the Victorian society, which has been very successful in securing a range of grants for projects. Another director also resigned leaving us at present without a Western Australian representa-

tive. But we have pulled through and our former SA president Paul Leverenz has been voted in as our new National president and we believe we have found an able new company secretary.

The moral of this is that working as we do with so few resources and so many challenges, those of us in the ME/CFS movement need to be pragmatic and mutually tolerant. This Society has copped occasional flak from people who think we ought to get rid of the words 'chronic fatigue syndrome' from our title, for instance. Frankly, your committee is not going to spend its scarce time struggling with medical terminology or looking at changing our name. Developing an international consensus on nomenclature and definitions is a job which we will leave to international forums and better-resourced movements.

Meanwhile we have recommitted to a high level of support for the National Association. We will get nowhere without one and have agreed that we will boost our funding support to it and continue to help in every way we can.

6. The Multiple Chemical Sensitivity campaign

The campaign to extract the maximum benefit from the 2005 parliamentary report on MCS entered a new phase this year. Last year we had been frustrated at government inaction and highlighted this by running an MCS Clock on our website. Partly in response to our pressure, the Department of Health finally in December 2006 convened a Reference Group and in 2007 that committee slowly cranked into action. The committee includes representatives of the Department of Primary Industry and Resources SA, the Environment Protection Authority, Safework SA, the Department of Families and Community and the Department of Health. There are also two representatives of the Local Government Association. "Consumers" are represented by Peter Evans, the indefatigable convenor of the SA Task Force on MCS (and a member of the Society), Cathie Powell of the Bridges and Pathways Institute and myself representing the Society. In addition Drs Bruce Wauchope and Ian Buttfield are members and both are good allies.

After a slow start as we got to know one another, the committee gathered momentum over the last few months. PIRSA has drafted a set of guidelines on the use of pesticides and herbicides for use by local government authorities especially. The Department of Health has committed itself to shaping protocols for hospitals regarding the treatment of people with MCS. The Department of Families and Communi-

ties has also committed itself to improving its policies and procedures on MCS and to disseminating them throughout the public sector. There is still much water to flow under the bridge before these various policies are fully shaped, endorsed and implemented. But for the veteran lonely campaigners, they represent a decided increase in the momentum of the campaign.

We have also renewed late in the year our discussions with the Catholic Education Office about MCS policies for Catholic schools. The CEO hopes to have a policy endorsed by March 2008 and has already moved to improve its approach to building and refurbishing facilities.

It has been nice to move beyond huffing and puffing noisily – and perhaps thereby stirring some members to ask whether we were too focused on MCS issues – to a quieter and more focused phase of the campaign.

7. SAYME

SAYME again had a quiet year. Coordinator Emma Wing has been heavily burdened with her general work on the Society's committee and in the office and yet has managed to hold one gathering at her home, along with telephone and email contact with members of the group. The Committee has tried to give some time to working out how to give more support to SAYME as we regard it as fulfilling a crucial role in a number of areas. We have not been able to find a solution yet but will keep looking.

One long-term project relating to the needs of young people with ME/CFS almost came to fruition this year. Peter Mitchell took on the role of reviving a long-dormant project – for which we had a grant – and we are ready to go to print with two brochures for schools and students about how schools can assist young people to gain the best possible education despite the challenges which ME/CFS poses. The brochures will make some impact once disseminated widely for the 2008 school year.

8. Support groups and the support line

It was a year of some growth in this area, although our Adelaide Support Group folded early in the year. But that loss was offset by the establishment of a new Riverland Support Group. I attended an excellent meeting in Berri in October and we thank Simon and Raelene Jackson for their work. We also thank David and Glenda Shepherd for attending on behalf of the excellent Northern Yorke Peninsula Support Group.

That group has had a good year. It held its usual meetings and also staffed a booth at the Paskeville Field Days. David Shepherd is also helping to launch a Clare Valley support group within a few weeks. The three country groups together cover the middle belt of regional SA from Renmark to Wallaroo. They are joined by the one continuing city group based at Glenelg and capably led by Marion Hansen.

It would be great if we could see one or two more regional support groups established in the next year. In all cases we rely on the leadership of committed members such as those mentioned above. That country members – especially if not on the Internet – can feel particularly isolated is a matter of continuing concern to the Society.

Meanwhile our wonderful trio of support line workers continue to answer telephone enquiries from all parts of the State. Elaine Balfort, Vicki Foote and Alex Harris have stayed at this task for years now. The committee gets regular reports from them and is always struck by the range of issues about which they are called up on to provide advice. We gather that the internet revolution has changed their work in two ways. At one level there is somewhat less demand than some years ago as more people use the web to find answers and information. At another level the high profile of our own website has meant more enquiries from interstate.

9. Thanks

Once again the effort to support people with ME/CFS and get a better deal for them has fallen largely upon a few people. Almost all have ME/CFS or are close family and supporters of people with the condition. Once again it is my pleasure to thank them.

- **The committee.** Lynda Brett, Spencer Langman, Emma Wing, Adrian Hill, Mel Cocker, Richard Cocker and Peter Mitchell, have continued to work in close harmony and with good humour. Those are qualities never to be taken for granted in a committee! It makes volunteering for the Society a pleasure to have such nice people to work with. The achievements of 2007 are in no small measure due to their commitment and wise stewardship.
- **The office team.** Lynda Brett took on the role of office coordinator this year and has handled this absolutely pivotal role with great competence. Our thanks go too to Emma Wing, Mike Ritter, Jacquie Smith and Spen Langman for their regular attendance to handle the basic administration of

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the Society. They were augmented on occasions by a number of other volunteers who assisted with particular events or projects and to all of those people we send our grateful thanks. Mind you, we are always in need of more help and we really struggled to keep up with membership related work especially – processing applications, sending out renewals, packing and sending every member a free copy of the South Australian and Canadian guidelines. We really do need more help to take the pressure off the few hard workers.

- **Fundraising.** Thanks to Carole Carroll for organising this year's Badge Day. We're delighted that she's willing to do it again in 2008. We rely on it as we have few sources of fundraising otherwise. Once again, though, we can express our delighted thanks to the anonymous donor who has for five years now sent us an annual cheque for \$12 000. We also gained our first bequest in years – for \$1560. And we received continuing sponsorship from the Adelaide Bank and the Bank SA Staff and Charitable Fund as well as sponsorship from Eco Pest Control for our public meeting with the international experts.

10. Reflections and future directions

There are some key trends and issues for us. They include:

- Improving our capacity to advise people with ME/CFS about expert and empathetic health practitioners. This has been a vexed problem for us with out of date and partial lists to work from. We have made a start by asking all members to provide us with their own recommendations and hope to systematise the results.
- Doing what we can to improve the supply of health practitioners with a knowledge of and commitment to treating ME/CFS. There is a real concern that not enough new medical practitioners are entering the profession as older members with expertise and accrued wisdom leave the scene. This was the focus of a meeting of four interested doctors and myself as the Society's representative in October. This is a complex issue which will not be easy to address but we hope to do more in 2008.
- Supporting the National Association in its efforts to create a more concerted and mutually supportive national movement of people with ME/CFS.
- Reviewing our efforts to encourage members to become self-confident and well-armed political

lobbyists on the many issues of concern to people with ME/CFS.

- Keeping up the pressure on the State and Federal governments to do more for people with chemical sensitivities. I believe that one of the most important of these is getting a better deal for them with regard to safe housing. It's an issue which comes before us several times a year and the needs of the most seriously ill and chemically sensitive people are dire.
- Finding ways to enable more members to contribute from home rather than having to come into the office – whilst rebuilding our office team from its present too-fragile size.
- Continuing to stay open to possibilities for working more closely with other disability groups and in time coming to share accommodation and resources with them.

I want to conclude this annual report with greetings and respectful best wishes to all the courageous and talented people who share in the work of our Society – which, incidentally, celebrated its twentieth birthday this year.

Peter Cabalan

17 November 2007



2008 Meeting

Saturday 2 February 2008

1 pm

St Peters Holy Name Church
80 Payneham Road, Stepney

Speaker: Julie Peacock

(Marion Physiotherapy)

Julie will discuss pain management, pacing, stretching, and task modification to maximise quality of life for people with ME/CFS.



Talking Point: old issues

Jenni Gay is calling on anyone who may have old issues of Talking Point.

We are keen to preserve our Society's history before it is too late and would appreciate hearing from people who were around in the late 80's when the Society started.

Our first president and founder was Lyn Drysdale of West Lakes Shore. The first committee consisted of:

President	Lyn Drysdale
Secretary	Simon Fisher
Treasurer	Kay Botroff
Committee	Brian Caire
	Colleen Harris
	Chris Hughes
	Phil Kirk
	Jeff Gregory

We need to compile 3 complete collections of *Talking Point* as they are an important record of our Society's activities. We have some early issues but need the following issues to complete this project.

Please contact me:

- by email jrgay@iprimus.com.au
- write to me c/- of the Office
- phone the Office on Wednesdays: 8410 8929 ☞

Volume	Issue	No. needed
Volume 1	Issue 1	3
Volume 1	Issue 2	2
Volume 2	Issue 1	3
Volume 2	Issue 2	3
Volume 2	Issue 3	3
Volume 2	Issue 4	2
Volume 3	Issue 1	2
Volume 3	Issue 2	2
Volume 3	Issue 3	2
Volume 3	Issue 4	2
Volume 4	Issue 1	2
Volume 4	Issue 2	2
Volume 4	Issue 3	2
Volume 4	Issue 4	2
Volume 5	Issue 1	2
Volume 5	Issue 2	2
Volume 5	Issue 3	2
Volume 5	Issue 4	2
1992	Only have Dec	3 of any issues
1993	Only have Jun	3 of any issues
1994 - 2000		3 of all issues
2000 - present		3 of all issues

Social Support and Fibromyalgia Research

A new research study focusing on Fibromyalgia is underway at Victoria University. The study is being conducted by **Jane C Mulcahy** in the University's School of Biomedical and Clinical Sciences as part of a Masters Degree in Health Science. Jane has provided some general information about the study:

If you have been diagnosed with Fibromyalgia, we are inviting you to participate in this research study.

All men and women who reside in Australia who are aged between 20-80 years are eligible for this study.

If you agree to participate in this study, you will be provided with a participant information sheet and two questionnaires to complete. It will only take a total of 15 minutes to complete. The two completed questionnaires and participant information sheet are required to be mailed back to the researchers via pre-paid envelope. No physical examinations or interviews will be required. The return of the questionnaires automatically implies consent.

There will be no further contact from the researchers. Participants' involvement in the study is entirely voluntary and you have the right to discontinue at any time.

Your participation will provide the researchers with important information that may assist health professionals who treat patients with Fibromyalgia.

To obtain the research material or obtain further information about the study please contacts Jane Mulcahy by telephone on (03) 9919 1140 or email jane.mulcahy@vu.edu.au.

Jane C Mulcahy
Victoria University, PO Box 14428, Melbourne 8001 ☞

Riverland CFS Support Group meeting report

Here are some comments from Society member **Simon Jackson** about the Riverland CFS Support Group's very first meeting, held on 26 October 2007 at the Berri Library Multi Media Room in Berri:

It's Friday the 26th of October 2007 and the Riverland ME/CFS Support Group has its very first meeting at The Berri Public Library's Multi Media Room.

Fifteen very enthusiastic people met for an informative and thought provoking meeting.

Society President Peter Cahalan made the long journey up from Adelaide to be the first of two guest speakers. Peter gave a descriptive of the workings of the S.A. ME/CFS Society's role in the ME/CFS world.

And world it is. Peter explained how so many people are now viewing the Society's webpage and it seems that the S.A. site is extremely popular with overseas guests and Australian viewers from every state commending the Society's hard working committee and volunteers with the content of the site.

A slightly jerky start with a live feed of Internet content of the Society's webpage was viewed by attendees, Peter ran through the various links that people with Internet access could go to, to obtain information on a wide range of topics related to the illness on the site.

The content is continually being updated and there is no shortage of stories, advice, world news and even poems and jokes, yes there is a lighter side of everyone as even the sick need to laugh.

Peter told us that a popular form of communication between the Society and members was the e-bulletin which is emailed to members every week.

Our second speaker, David Shepherd, runs a support group in Balaklava (Northern Yorke Peninsula).

David told us how he took over the group a couple of years ago. I must add that his wife Glenda helps with the group as well.

David gave a brief history of his farming life with CFS. He said that he contracted glandular fever and then to top it off got Q fever which he says contributed to CFS.

David spent several months in bed very ill, something I'm sure we can all relate to. The enthusiasm shown by David and Glenda has to be commended. David has had to cut back his workload on the farm quite considerably.

He is also starting up another group in Clare in the latter part of November.

The discussions after the meeting was over had people busy networking and exchanging ideas and thoughts. It was good to see strangers come together with a common goal; it seemed everyone got on well, and with this in mind it promises to be a successful nucleus for a support group.

Coordinators Raelene and Simon Jackson were thrilled at the roll up of people wishing to know more about ME/CFS and associated illnesses. They would like to thank Peter Cahalan, David and Glenda Shepherd for making the journey to Berri for the first meeting of the support group.

And to all who attended we hope you got something out of the day and that you will come along to further meetings.

- Email riverlandcfsupport@gmail.com
- Phone (mobile) 0449 120 715



David Shepherd and Simon Jackson



Members of the audience

Riverland CFS Support Group meeting photos

Here are some comments from Society president **Peter Cahalan** about the Riverland CFS Support Group meeting, as well as a few photos from the event:

David and Glenda Shepherd drove from Balaklava and I headed to Berri from Adelaide on Friday 26 October 2007 for the launch of the new Riverland Support Group.

Simon and Raelene Jackson had done a fantastic job of publicising the event and their efforts were rewarded with a respectable rollup of 10 persons with CFS plus partners and several apologies from people too ill to get there on the day.

Louise, a volunteer from 93.9 Riverland Life FM, was there and the station will be joining other local media in discussing ME/CFS.

The spirit of the occasion was terrific. People shared openly and respectfully with each other and all the signs are that it will be a great group. We all owe thanks to the Jacksons for their determination to fill a need.

Two of the 10 attendees joined the Society there and then, joining the three members also present. Glenda took pics of the occasion. ☘



(l to r) David Shepherd, Glenda Shepherd, Peter Cahalan, Raelene Jackson, Simon Jackson



The audience



All of the group who came to the first meeting



David Shepherd addressing the group



Peter Cahalan addressing the group

ME/CFS Gets the Nod

From ProHealth's **ImmuneSupport.com**, 30 October 2007.

The CFS Name Change Advisory Board (NCAB) has amended its initial proposal and now recommends that the name for 'chronic fatigue syndrome' be changed to the acronym ME/CFS. (Note: Many illnesses are known by their acronym – e.g., HIV.) The resolution modifies their earlier recommendation that the 'ME' in ME/CFS should stand for Myalgic Encephalopathy.

The NCAB recommends the transitional use of 'CFS' in the new name for logistical reasons – primarily to prevent harming patients involved in disability and medical insurance issues, and to provide continuity in the research area. Ultimately, over time, the 'CFS' will be eliminated.

The Board encourages the change because the trivializing nature of the name 'chronic fatigue syndrome' negatively affects diagnosis, patient care, and research funding. Although estimates suggest that more than a million Americans have ME/CFS, less than 20 percent have been diagnosed. Even though doctors equate the experience of CFS with that of a cancer patient undergoing chemotherapy, few patients receive adequate medical care. The severity of CFS is as significant as that experienced with other serious diseases, such as multiple sclerosis, COPD, end stage

AIDS, and kidney failure; yet CFS consistently ranks among the poorest federally funded diseases.

The Board's resolution to propose the acronym ME/CFS demonstrates their sensitivity to disagreements within the patient community. Many patients insist that ME stands for Myalgic Encephalomyelitis, the name that has been commonly used to describe the illness in most countries for over 50 years. Others maintain that ME stands for Myalgic Encephalopathy, stating that encephalopathy is more diagnostically correct. The acronym ME removes the 'which is best' barrier. Many illnesses have several names. By supporting the acronym ME/CFS, we build unity within the patient community against the terrible harm that has been caused by the term chronic fatigue syndrome.

The NCAB includes eight of the most distinguished experts in the field, who collectively bring to bear more than 150 years of ME/CFS research and clinical experience. Members include Drs. Lucinda Bateman, Paul Cheney, David Bell, Leonard Jason, Nancy Klimas, Anthony Komaroff, Charles Lapp, and Daniel Peterson. ❀

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The CFS Name Change Advisory Board (left to right): Drs. Anthony Komaroff, David Bell, Nancy Klimas, Leonard Jason, Charles Lapp, Lucinda Bateman, and Paul Cheney (Dr Daniel Peterson not present).

Tips for surviving Christmas

Jenni Gay has a few timely hints on making the best of a potentially stressful time of year, Christmas.

CHRISTMAS CARD OPTIONS

If you have too much pain or too little energy to write cards:

1. Don't send them.
2. Get other family and friends to write them for or with you.
3. Type up address labels in Word. I use the L7163 Address label which is 2 across and 7 down on an A4 sheet (available at any big office stationers). I have refined this over the years and organised my list into 3 sections. The first page contains the overseas addresses which I do first, the second contains the interstate addresses and the rest of the pages are South Australian. It is a lot of work to set up in the first year but is a breeze from then on. I just alter the file during the year as people move or sadly die. Come November, I make any other necessary alterations and then all I have to do is to print them off and stick them on the envelopes. This takes no time at all and for me, beats writing 63 envelopes.
4. Some years ago, when I accepted I couldn't manage writing the cards even if I only did 3 a day because of the resultant shoulder pain, I started typing individual notes on address labels. Often I needed to use a smaller size for cards and the L7159, which is 3 across and 8 down, was ideal. I included Christmas clip art, used different fonts and colours to individualise the label before sticking it on the card. Over the last few years, I have also done this for the cards I sent out to my colleagues at work.
5. Two years ago I discovered that Australia Post sold a Christmas card that goes through the printer (probably most do but I haven't tried). It takes a bit of trial and error to get the text in Word into the right spot but once you have that right, you just type the individual message you would have written by hand and then run the card through the printer. Job done in no time!!
6. If you are creative and have the interest and the energy, you might enjoy designing your own cards on the computer and printing them on coloured or Christmas paper.

CHRISTMAS LETTER

A number of us send an annual letter to friends we only write to at Christmas time summarizing the family's activities for the year and I must say that every year I look forward to opening these letters from our friends. I started using a computer to do this 20 years ago when I realised that I couldn't write them any more because of the pain in my shoulder. It wasn't very pretty as it was done on a Commodore 64 (our first computer) and printed on a dot matrix printer. The letters look a lot more attractive now printed on Christmas A4 letter head which is available at a wide range of shops.



CHRISTMAS PRESENTS

Reduce the number you buy to the ones you really have to. If you are able to shop, carry a list with you in the months beforehand of the names (and ages of children) of the recipients so if you see a bargain, you can check your list and see if it would be suitable for anyone. This saves that horrendous last-minute rush which you probably don't need in the lead up to Christmas.

For those of us unable to shop, you have at least three options:

1. Ask family and friends – I use the store catalogues to choose and make up my shopping list for my family.
2. Buy online and have your selection delivered to your door without having to leave your computer.
3. Order by phone or online from some of the Adelaide stores; but be aware some of them are slow to deliver – I have waited over 2 weeks for a delivery from a store only 5 kms from my house.

Whatever you do, start planning now so that you may be able to enjoy the Christmas period and not end up having a relapse.



Healthy eating made easy

*"I'm living on Lucozade because I have no energy to cook!" was one of many comments from InterAction readers which inspired **Jane Harries** to compile the M.E.-friendly recipe book, Eat to Beat Fatigue. In this article from Action for ME's InterAction magazine, Jane shares some tips for energy-saving ways to shop, cook and eat healthily.*

(Editor's note: While some of these recommendations may be UK-specific, most have global relevance e.g., you can purchase seat-sticks [here](#), of the type referred to in the article, and there is now at least one online supermarket service available in the Adelaide metro area.)

Supermarket sweep

Here are your tips for surviving supermarkets:

Relax and take your time, asking where items are, rather than using up energy in the search. Wrap up warm as it gets chilly in the frozen food sections and make sure you take a list so you don't forget anything.

Consider investing in a 'walking stick seat' if you want something to lean on and the chance to sit down at any point; trolleys are also helpful to lean on! Pat has found a walking aid provided by her occupational therapist useful for shopping, not only because it saves her legs but also because it lets others know she has a disability, making it easier to seek assistance.

Most stores will now take your stuff through checkout if you ask for help, and all will help you load your car.

Abigail finds it less tiring to do a mammoth shop once a month, stocking up on frozen food and essential items, rather than having to shop too often.

Finally, shopping trolleys (or 'wheelie-bags') are a good investment so you're not carrying heavy bags.

Shop from home

The whole process of getting food from a retail outlet and then preparing it can seem like climbing Mount Everest when you're weak and tired. I save a lot of energy by having my groceries delivered. If you're able to use the Internet, or have someone who can do so on your behalf, there are supermarkets that let you shop online; just check which chains offer delivery in your area.

Big supermarkets have refined their websites to make online shopping as easy as possible, for instance letting you keep a list of favourite grocery items to save time when you next order. Most people I spoke to found these home-delivery services a godsend and that complaints were handled well. But there are some drawbacks: not all delivery people are willing for in-

surance reasons to carry bags to the kitchen for you (do ask your supermarket's policy on this), and on brain-fogged days shopping online can still be confusing, especially if it's your first time.

For these reasons, you may prefer to use smaller stores that offer a more personal service, albeit sometimes at higher prices; for example I ring the village shop, email my local health food store and have organic veg delivered regularly. There are also a number of online stores where you can purchase organic food.

Consider getting meals home delivered

Home meal delivery services (meals on wheels) exist across the country for people who are regarded as being at risk of poor nutritional status. These provide a hot meal (usually cooked at a local hospital) delivered five days a week and can be obtained via a referral from your GP or other health professional. This service may be worth considering for those with severe ME.

Stock up and get organised

Ensure you keep a good stock of staple, healthy foods with a decent shelf-life to snack on, so you don't end up eating the wrong things; nuts and seeds are popular. Having ingredients that last in the house also means that you don't have to shop so often.

Some of you recommend paying the extra for prepared salads, and buying cold food like cooked meats and fish and healthy dips like hummus, to avoid having to cook too often.

Organising your kitchen so that items you use regularly like cutlery and pans are easily accessible will also help save energy. Here are some of your other recommendations:

- Have jars of things on the counter so you don't

have to lift them.

- Hang favourite pans and utensils near the stove.
- Keep a strainer near the sink.
- Put things where you need them – one member keeps hot drinks and mugs near the kettle, and glasses near the fridge.

Use labour-saving equipment

Your recommendations for energy-saving kitchen essentials include:

- Perching stool with adjustable seat, e.g. from an occupational therapist, so you don't have to stand up to chop or wash up. Or sit at a kitchen table to chop.
- Dishwasher, if you can afford it, saves time and effort.
- Jar opener.
- Easy electric can-opener.
- Paper plates and plastic cutlery to avoid the need for washing up on bad days.
- Microplane graters – expensive but make cheese-grating easier.
- Pressure cooker – enables you to cook large amounts very quickly. Although they're heavy to lift and wash up, small one-person cookers are available now. Good for cooking pre-soaked beans..
- Slow cooker – very energy-efficient and recommended by many readers. You put in your ingredients in the morning, and the meal is ready by dinnertime, using as little electricity as a light bulb. Ideal for stews and soups – makes meat very tender. Also ideal if you can't eat a lot in one go, as it keeps warm for ages and you can help yourself periodically.
- Health grill – halves cooking time by cooking both sides and contents simultaneously, and drains away fat.
- Food processor to help prepare vegetables and mix baking ingredients.
- Hand blender saves lifting pans and again, reduces washing up compared to a normal blender.
- Plastic fridge/freezer boxes e.g. from takeaway food, or any retailer.

- Use lids on pans to cook more quickly, and be able to do things like risotto without constantly stirring.
- Keep your knives sharpened to save energy.

There are many other useful tools from light-weight peelers, bendable cutlery and kettle tippers, to easy-grip knives, bottle/jar openers, and trolleys that can be used to transport heavy items. An occupational therapist may be able to supply this sort of equipment.

Find ways to save time and energy

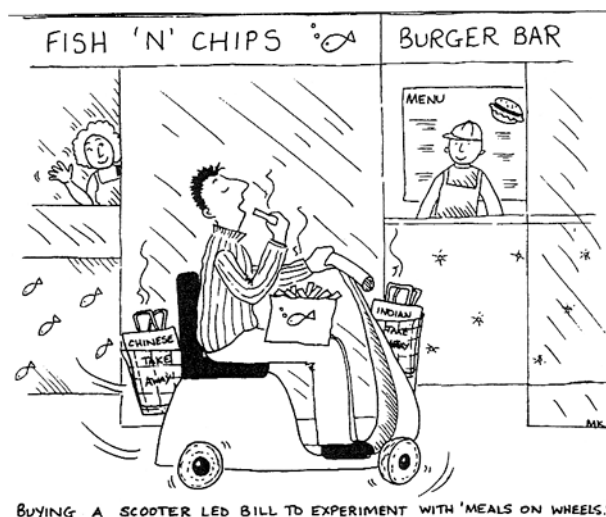
The key seems to be to set up a system that works for you. Kate says, "My partner makes up loads [of each recipe]... then puts the leftovers in Chinese takeaway boxes... which fit perfectly in the mini-fridge and microwave I keep near me, though you need to stir

to make sure the contents are thoroughly reheated. When my partner's away I get veggie gluten-free pasties from zedz foods which can be frozen and then microwaved."

Here are some more of your tips:

- Cook plenty. Leftovers can go into soups, spreads and stir-fries, or be frozen.
- Freeze some meals and snacks.
- Stock up on emergency rations such as tinned soup and ready meals, for bad days. Also have quick items and treats tucked away for when you need a boost.
- Prepare meals at a time of day when you feel strongest, or do a mass cook on good days. Three dishes can be made out of the same base, e.g. chick pea soup, hummus and curry.
- If you're feeling hungry, eat a small snack before cooking a main meal, so your blood sugar doesn't drop too low.

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BUYING A SCOOTER LED BILL TO EXPERIMENT WITH 'MEALS ON WHEELS.'

Mum's the word – or is it?

*Deciding whether and when to have children is a huge decision, and harder to make if you're battling ill-health. In the first of a three part series on becoming a parent, Action for ME's **Yvette Keitley** looks at issues members have addressed in making their decision. This article is from Action for ME's InterAction magazine.*

Parenting, even with health on your side, can be exhausting, not least because your sleep gets so disrupted. As an 'M.E. mum' I can relate to many of the concerns potential parents with the illness have when thinking about having a child.

For me, making the decision wasn't the hard part – I knew I wanted a baby regardless of my illness – it was more the unanswered questions surrounding our decision. As a friend said, when I told her I was expecting, "How on earth will you cope?"

Practical Issues

Money matters

A major concern which affects all couples is finance. Whether or not you can manage on one wage is often a key factor in making the decision.

In some cases, couples with M.E. are already used to surviving on one income, so there wouldn't be a great deal of change. However, nappies and formula milk don't come cheap, making a decent hole in the only pay packet.

Many new mothers struggle to cope with giving up work, being at home all day and financially dependent on their partner. However, for the majority of women with M.E. this is nothing new as the illness may have meant you've been unable to work or get out much for some time.

Family support

Most parents with M.E. say that having support from family members and friends is vital. If I didn't have my parents and partner's parents close by I doubt I would have survived. People doing chores like ironing or cleaning leaves you with some energy to look after the baby. Practical and emotional support from family becomes even more important if you are faced with being a single parent at any point.

Wanted: Hands-on partner

To cope with the pressures of illness and parenthood, your relationship with your partner has to be super-strong.

Robert cares for his wife Marie and their son Ryan is 17 months. He agrees that the relationship between him and his wife has to be tough to withstand the pressures of being parents.

"Sometimes it's hard when I get in from work and Marie is exhausted, Ryan's been running round all day, and I have to start work again by cooking tea. Marie doesn't take me for granted, but I do a lot of things for them both. From my point of view, it's like doing two lots of work in one day. It does put pressure on our relationship, but I wouldn't change it for the world."

Positives to having a baby

Personally, not one day has gone by since my son Alex was born when he's not made me laugh. He's 22 months old now, and if I think that each day he's been around I've laughed, I know it must be doing me some good. A lot of parents with M.E. say their child brings a meaning and importance to their life which they didn't have before. especially if they'd been too ill to maintain a career.

Shannon, whose daughter Bethany is six months old, couldn't agree more: "Some days I do feel awful, especially if Bethany has been awake all night, but I know that even though I feel rough, there's one little person who loves me regardless. It makes me feel needed, a feeling I lost through being ill."

Concerns & fears

Can M.E. be passed on?

One of the major concerns many people with M.E. have is whether the illness can be passed on to their baby. The simple answer is 'no', according to Dr Charles Shepherd, author of *Living with M.E.*, and father of three healthy children conceived since he's been ill.

However, he does recommend postponing conception until your condition has stabilised if you're in the early stages of the illness and if time is on your side. This is especially relevant if you're continuing to experience ongoing 'infective' type symptoms such as sore throats, swollen glands and a temperature.

While there is little research into this area, some doctors do make the point that the condition is slightly more common in families. This may be because there's a genetic influence in how we respond to most infections, though findings are far from clear-cut.

Will pregnancy make me worse?

It's encouraging to note that many women with M.E. find that their illness improves during pregnancy, possibly due to the immune system suppression that occurs to prevent the foetus being rejected.

However this isn't always the case and I'll be taking a closer look at managing pregnancy in the next issue.

Relapsing is another fear expressed by many people. Back-up strategies would need to be in place if the worst happened and you couldn't take care of the baby. Cleaners, nannies or childminders could all be considered, but again, as long as family and friends are available to help you, then most problems can be overcome with good advance planning.

Problems conceiving

Depending on how badly you want a baby, one point to consider is the prospect of IVF. If you couldn't conceive, would you be able to cope with the drugs and procedures?

Ondine successfully had IVF and now has Tatyana, aged 15 months. She says, "The drugs did affect my M.E., which flared up after each of the five IVF cycles I had to undergo. The clinics emphasise that you'll feel dreadful on the drugs, but each person has to work out what will minimise the effects for them. IVF is a huge strain so you need to do everything you can to make your life easy in other respects if trying it."

Childlessness

The physical limitations M.E. imposes mean that some couples decide they wouldn't be able to cope with bringing up a child, while others live away from

family, so no support would be available. This can be devastating if having a baby was important to you, and it's important to talk through any feelings of grief and anger so they don't consume you.

By choosing not to have a child, couples naturally have more freedom, money and quality time together. However, becoming an auntie, uncle or godparent can be wonderful as the enjoyment of the child can be on your terms – but they can be given back too!

Margaret and her husband Alan decided that as both of them suffer from M.E., bringing a child into the world would be unfair. "Neither of us is at full strength to look after a baby," Margaret explains. "We wouldn't be able to give him or her all the care we'd like, as both of us are housebound."

"Taking care of our two cats, while no substitute of course, brings us both pleasure and is something we can enjoy together."

Making the decision

Ultimately, no couple can be told whether to have a child or not. You need to decide together what is best for you and your family – and to be sure that you definitely 100% want to be a parent, because it's going to be pretty hard work. In my experience and from talking to other mums with M.E., the key to success is support from family and friends.

Having M.E. is awful, but having a child is wonderful. and often the good outweighs the bad. I can't pretend that life is easy with Alex, but not once have I regretted having him, and without him, I would be missing out on a completely amazing, albeit exhausting, world.

Further information

- Visit www.mecfparents.org.uk for a range of features on pregnancy and parenting with M.E. ☘

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Yvette Keitley with partner Russ

Baby in waiting: your guide to a healthy pregnancy

Feeling broody, but worried about how you'd cope with pregnancy, labour and motherhood? In the second in her series on having children, Action for ME's **Yvette Keitley** addresses some common concerns raised by mums-to-be with ME. This article is from Action for ME's InterAction magazine.

After making the decision to start a family, the next big step is actually conceiving and then coping with pregnancy and birth.

Many people with M.E. find even the mere thought of pregnancy exhausting – after all, your body is doing the very strenuous job of creating a new life!

My personal experience of pregnancy and birth in relation to M.E. is a very positive one. Thankfully, I felt better during the pregnancy, but not all women are as fortunate.

Let's do it

Any way of making intercourse less strenuous, but still pleasurable, needs to be considered. Probably the best way is the 'spoons' position where the woman lies on her side and her partner lies behind her, enabling easy and comfortable penetration. It sounds complicated, but practice makes perfect!

If your M.E. is severe, then it might be worth buying an ovulation kit. Simple to use, they measure the hormone levels in your urine to detect when you are ovulating. If you know when the best time to conceive is, this will allow you to use energy for lovemaking when it's most likely to help you fall pregnant.

It's a good idea to have a chat with your GP before you try to conceive to check on any contraindications of drugs you may be taking. Plus, you will need to organise folic acid supplements to cut down your chances of having a spina bifida baby.

One thing that puts some people with M.E. off starting a family is the concern that their illness might be a risk to the baby. But as Dr Charles Shepherd, author of *Living with M.E.* writes, "There is no evi-

dence that women with M.E. are more likely to have a miscarriage. Neither are there any reliable reports of such women producing anything other than perfectly normal healthy babies. There is, however, a small but theoretical risk of passing a persisting viral infection across the placenta. Consequently it may be better to err on the side of caution if you are continuing to experience infective-type symptoms."



Countdown

Just because you're pregnant and have M.E doesn't mean you are facing a disaster. You will just need more help, love and understanding than the average mother-to-be. It's important to inform your GP, midwife and consultant about the way your M.E. affects you as early as possible, so that extra care can be arranged if possible.

The best piece of advice anyone gave me while I was pregnant was: let your body get as much rest as possible now, because once the baby is born, there won't be much chance to take a kip when you want it.

Eating a well-balanced diet is also important to give body the extra energy and nutrients it needs to create a new life.

Be prepared

Jessica, who had her daughter Holly 13 months ago says, "A few weeks before Holly was born I had a massive cooking session. My partner and mum helped me make up loads of shepherd's pies, soups and lasagne which I froze. Once Holly was born we had lots of meals ready. That way I could rest and devote my time

and energy to Holly.”

Some women find their M.E. goes into remission while pregnant, probably because high levels of hormones suppress the immune system to prevent rejection of the foetus. I know I felt my best while I was expecting Alex. I was tired, but without that horrible M.E.-type exhaustion. I could definitely differentiate between the two types of tiredness.

A recent survey of 72 women with M.E. and fibromyalgia found that during first pregnancies, one third of women felt better. Unfortunately, a small amount of women find that pregnancy and M.E. don't mix and experience a deterioration in their health.

This was the case for Joanne, who says, “During most of my pregnancy, I was very exhausted and slept through many afternoons. I was so unwell that I couldn't go to the parent-craft classes, and I have to say that my midwife was fairly uninterested in M.E. so I took to reading as much as I could. I dreaded all the hospital appointments as I felt too ill to attend, but in fact they went quickly and smoothly and I found the staff to be kind and reassuring.”

Midwives and hospital care

Another option, if you can afford it, is to pay for extra care. One member, who has severe M.E., paid a total of £2000 to use a midwife who was able to spend more time with her, addressing individual concerns and problems while acting as her advocate. Too ill to attend regular hospital appointments, this member was lucky enough to have a consultant who agreed to talk with her on the phone instead – 10/10 for him! However she says it's vital that you do make it to scans to check the baby's progress.

Deciding on a home or hospital birth is also important. Jenny wanted to feel in control of her environment and for it to be quiet, but she feared a home-birth in case of complications. Her midwife contacted the head of midwifery at the local hospital to get her ‘on side’, and due to Jenny's illness, managed to get her a private side room in the hospital.

Dietary problems also make going into hospital extra stressful for some with M.E., so as well as ear-

plugs and an eyemask, do have foods you can tolerate to hand.

Many people with M.E. who are drug intolerant have found that alternative remedies can be used to treat a wide range of common conditions during pregnancy. Acupuncture, herbalism, aromatherapy, hypnotherapy, homeopathy, and some forms of massage have been used beneficially by expectant women to alleviate their symptoms.

Even though holistic therapies can take their time to work, they aim to address the cause and heal the whole body, rather than suppressing symptoms. These alternative practices can often be included as pain relief during labour. Or if you wish to use a birthing pool for this purpose, notify your midwife early on in your pregnancy to see if this can be arranged.

Pain relief

As I didn't know what effect pain relief drugs would have on my illness, I decided to steer clear of anything I hadn't had before. In the end I used just one paracetamol and a TENS machine, which works with your body's natural electrical impulses to block the pain. Towards the end of my 16-hour labour I had two puffs of gas and air, but didn't like the floaty sensation it gave me, and threw the mouthpiece across the room!

Visualisation, breathing techniques and relaxation are good skills to learn if you can manage it. They can help you

turn the negativity of pain into a positive feeling, getting you closer to delivering your baby. Plus, the more relaxed you are, the easier it is for your body to dilate the cervix.

A popular option among women with M.E. is an epidural, where an anaesthetic is injected into the spinal canal, allowing your body to labour without the exhaustion of pain. This way you can save your energy for the pushing and delivery. However, it does mean that you can't move around, as it blocks all sensation from the waist downwards.



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Labour Day

If you can manage it, any position during labour that allows gravity to help is ideal to help reduce labour time. Some people use a birthing ball (a big bouncy gym ball) to sit on while making gentle rocking movements. This eases pain and also helps the baby's head to descend. If you need to lie down, be sure to lie on your left side in the recovery position, surrounding yourself with pillows or beanbags to get comfortable.

For women with severe M.E., or those who feel that they couldn't cope with labour at all, a caesarean section is worth considering. An epidural is preferable over general anaesthesia as this provides a quicker recovery time. However, you need to weigh up the benefits of avoiding a lengthy labour against the recovery time of abdominal surgery.

Michelle felt she was too weak to go through a natural labour so opted for an epidural and caesarean. She explains: "I was worried about the effects of the epidural, but it couldn't have been better. I was awake the whole time and felt no pain. I'm glad I chose to have a caesarean, as I think my M.E. would have been a lot worse after a natural birth."

Ultimately, writing a 'birth plan' for your midwife long before you go into labour is the best option. Keep it straightforward so it can be read quickly. As well as including which drugs you prefer, mention about having M.E. and the ways it might affect your labour, birth and recovery period. This might include drug sensitivity, muscle fatigue and possibly the need for an assisted delivery (forceps or suction cap) if you get too tired. A birth plan helps others know what you would prefer to happen if things did go slightly off track.

Ask for help

Once the baby has arrived, you will not only be on cloud nine, but also very exhausted! To limit the risk of relapse, ask your midwife if you can have a single room on the ward away from the noise of other babies. Explain that you may need extra nursing support during your stay.

If a single room isn't available, make sure there will be support available at home, so you can have a full night's sleep and plenty of rest periods on your return.

Anna, who gave birth to her son Jacob two years ago, felt guilty for taking offers of help. "I wanted to be a super- mum: breast-feeding, nappy changing, washing, ironing and cooking, but in reality my M.E. was wiping me out. All I could manage to do for the first three weeks was lie in bed with Jacob and feed him every two hours. I felt awful that everyone else was running around after us. I'm glad I did give in though – I think I would have had a major relapse if not."

No-one, especially your newborn, will hold it against you if the ironing is piling up and the pots are left in the sink!

As you and your new baby adjust to life together you will be able to do more things, but during the first few weeks, take time to get to know one another. Everyone agrees that your health is less likely to suffer if there is help on hand from your partner or family.

Worth it in the end

Pregnancy and childbirth, although painful and exhausting, are amazing experiences. Some women with M.E. find that they are in complete awe of their body creating a new life – doing something right and good for a change!

Others say that it makes them feel 'normal' – after all, nearly every pregnant woman suffers from morning sickness, piles and varicose veins; having M.E. doesn't make you any different in that sense, though you might be surprised at the increased level of support and compassion people show you while you're pregnant.

Further Information

- www.mecfsparents.org.uk – Contains features on pregnancy and parenting with M.E.
- www.survey2002.org.uk – results of the CFS/ M.E. pregnancy survey mentioned above, including hundreds of quotes vividly describing CFS women's experiences of pregnancy, childbirth and looking after their children
- www.wellbeing.org.uk – reputable charity offering a 'virtual pamphlet rack' with detailed leaflets on subjects including infertility, pregnancy nutrition, coping with loss through miscarriage and post-natal depression. ☘

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Bringing up baby

*Parenting with ME: Definitely not easy, but rewardingly achievable – if you have enough support. Young mum and Action for ME member, **Yvette Keitley**, offers advice on caring for a baby without breaking the energy bank. This article is from Action for ME's InterAction magazine.*

Since my son Alex was born nearly three years ago, my M.E. has been through many different phases. While I was pregnant I felt relatively well, in contrast to the first six weeks after the birth, when I was extremely ill and exhausted; but now, happily, life is becoming easier again. In the final part in my series on pregnancy and motherhood, I will highlight the problems many mothers with M.E. encounter during those precious early years and share ideas for tackling them.

Life after birth

Obviously, the amount of energy expended by giving birth is vast, and plenty of time to recover is vital. For at least the first ten days try to ensure that your partner, mum, sister or a reliable friend is both available and comfortable with all aspects of caring for a newborn – including changing nappies and cleaning up baby sick! After those ten days, if you feel less exhausted, don't let your 'baby-helper' disappear immediately; instead allow yourself time to gradually get used to your new family and routine.

If your partner can't take too much parental leave from work and finances permit, it may be worth hiring a full-time carer to help you adjust in the first few weeks.

Once you've got past the initial post-natal period and your baby helper has gone, ask your husband, partner or carer if they'll make up your lunch either the night before or in the morning. This avoids you wasting valuable energy on making food when you need to be feeding, changing and caring for the baby. This also applies for making up the baby's bottles if you decide to use formula milk. The more energy-consuming tasks you can delegate to someone else, the better.

Plan ahead

35-year-old Alice has had M.E. for five years and is mum to Jack (one) and Molly (seven). She advises all new parents to plan their feeding and changing routine long before the baby arrives. "Keep a pack of nappies and wipes in each room, or upstairs and downstairs, then you don't have to move if you feel awful. Consider investing in a small portable fridge to

keep in your main room where you will be with the baby for formula/expressed milk, and high-energy snacks for you. Again this saves you leaving the one room if need be."

Another energy-saving tip I found when Alex was starting on solid food was to keep a highchair (or low chair with tray attached) in each room that we ate in. We had a highchair for use in the dining room when I had enough energy to sit at the table, and a low chair in the living room for when I needed to rest on the sofa so Alex could sit by me and eat. I kept a light hand-held vacuum cleaner nearby to pick up crumbs afterwards.

It might seem a strange idea, but explaining to your baby when you need to rest may help you in the long term. Angela, who is mum to 18-month-old Erin, always told her when she was feeling too tired: "At first it seemed pointless as she didn't understand, but I persevered and eventually at around eight months she seemed to pick up on the tone of my voice when I was ill and for short periods understood that I needed her to be quieter."

Lower your standards

Exhausting tasks such as bathing should be left for days when you feel stronger and there is someone to help. Daily baths are not needed even though it may seem odd not to be doing as other mothers do. Personally, I often found it was easier to get in the bath with Alex. I wasn't leaning over, straining my back and leg muscles, and my son was easier to hold and control when I was on the same level. The wearing jobs of lifting, drying and dressing the baby can hopefully then be taken on by your partner or carer while you have a well-deserved soak.

If you need to rest and want your toddler with you then a safety gate can keep them secure with you in one room. A travel cot is also useful as this again keeps your baby in one place and allows them to fall asleep without you having to carry them upstairs to bed.

Make use of your child's willingness to help from the start. 40-year-old Maggie, who's had M.E. for

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CFS symposium report

The following is a report by Emerge Medical Editor **Dr Nicole Phillips** on a presentation she gave to the Congress of Royal Australian and New Zealand College of Psychiatrists in May 2007.

A lot of society members are aware that I gave a symposium at the annual Royal Australian and New Zealand College of Psychiatry Congress on the Gold Coast at the beginning of May 2007.

It was entitled *Chronic Fatigue Syndrome: from Scepticism to Science*. There have been a number of requests to provide that talk for Emerge, so I hope you enjoy it as much as the hundred or so psychiatrists who heard it in May did!

Members might be interested that the symposium was given during a concurrent session and so there were a number of other presentations on at the same time.

Interestingly, I found myself in the smallest room in the convention centre. Most of the other rooms had seating for 120 people or so and mine had seating for 60. I can only make the assumption that the conference organisers thought there would not be much interest in the topic. How wrong they were! The seats were quickly taken and people kept pouring in, sitting on the ground and standing for the 1¼ hours at the back of the lecture theatre.

There were a number of people who couldn't even get in because of the crowds at the back, telling me after that they would have loved to come in and listen to the talk.

One of the audience members was Natasha Richardson, presenter of Mind Matters on ABC radio. She requested an interview with me at the end of the day, which she used in conjunction with several other interviews with ME/CFS experts to put together a really excellent program in the middle of this year. I hope some of you were able to catch this.

Chronic Fatigue Syndrome: from Scepticism to Science

SUMMARY

- 1. The Name
- 2. Definitions
- 3. Symptoms
- 4. Epidemiology
- 5. Research
- 6. The Biology
 - a) The Immune System; b) Infection;
 - c) Central Nervous System

- d) Autonomic Nervous System and Cardiovascular System
- e) Neuroendocrine System; f) Genetics
- 7. Paediatrics
- 8. Psychiatry
- 9. Treatment

1. The Name

“What’s in a name? That which we call a rose by any other name would smell just as sweet” (Juliet). At this point I discussed how wrong Juliet was and how important the name of a condition like Chronic Fatigue Syndrome was.

I went on to discuss the history of a number of names that this condition has had, including Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME), CFS/ME, ME/CFS, Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), Post Viral Fatigue Syndrome, Post infectious Fatigue Syndrome (PIFS), Yuppie Flu, Chronic Fatigue, Neurasthenia, Neuropsychiatric Syndrome.

I mentioned that the term Chronic Fatigue Syndrome came to be in the mid 1980s with Holmes, at that stage giving us the first case definition. The history of Myalgic Encephalomyelitis started in 1956 with a leading article about a series of outbreaks around the world. The Royal Free Hospital outbreak of 1955 was discussed and was described by Ramsay, the consultant in charge, who described unusual motor and sensory symptoms, myalgia and emotional lability.

I discussed that many years later two psychiatrists by the name of McEverdy and Beard re-defined this outbreak as mass hysteria.

I discussed the term neurasthenia that initially was defined as a disease of excessive fatigability / nervous exhaustion and it affected physical and mental function. The term was introduced by a New York Neurologist in 1869 but was also discussed around the same time by a psychiatrist in the American Journal of Insanity. This was mirroring the wider confrontation between neurology and psychiatry at that time and eventually the neurologist triumphed. By the turn of the century neurasthenia was considered quite a fashionable disease. I discussed how important it was not to call the condition chronic fatigue and why and also how the term Neuropsychiatric syndrome came

into the Australian literature because of a powerful psychiatrist and his colleagues based in Sydney. This term has not been used anywhere else in the world and should not be used.

I quoted Dr Klimas; “Even the name belittles the extent to which CFS debilitates patients’ lives. If it were called Chronic Neuroinflammatory disease, people would understand it”.

I also gave the example of calling the flu Acute Fatigue Syndrome.

2. Definitions

“ME/CFS is an acquired organic pathophysiological multi-system illness that occurs in both sporadic and epidemic forms” (Carruthers, B. 2005).

Section G 93.3 of ICD 10 – WHO classifies ME and now CFS as a neurological condition.

Case definitions were then discussed. In 1981 and 1988 Ramsay defined Myalgic Encephalomyelitis as:

- Fatigue after minimal exertion (not daily fatigue) and delay of recovery of muscle power following exertion.
- One or more symptoms implying circulatory impairment.
- One or more symptoms implying central nervous system impairment.
- Fluctuating symptoms.

After his interest the attention then went more from epidemic to sporadic cases.

In 1998 Holmes et al gave us the first real case definition of Chronic Fatigue Syndrome and coined the name CFS. There had to be new onset fatigue lasting a minimum of 6 months, accompanied by at least 8 out of 11 specified symptoms. The problem with Holmes’ definition was that it did not differentiate from psychiatric problems or chronic fatigue particularly well, and symptoms had to be either present or absent, and that there was no regard to severity or frequency. Post-exertional malaise and cognitive problems were optional.

In 1994 the US Centres for Disease Control and Prevention were involved in the Fukuda criteria, which are as follows:

a) Clinically evaluated, unexplained, persistent or relapsing fatigue

And;

Persistent for 6 months or more; new or definitive onset; not the result of on-going exertion; not substantially alleviated by rest; causes substantial reduction in previous levels of occupational, educational, social or personal activities.

And;

b) 4 or more of the following symptoms are concurrent, persistent for more than 6 months and must not have pre-dated the fatigue; impaired short term memory or concentration, sore throat, tender cervical or axillary lymph nodes, muscle pain, multi joint pain without arthritis, headaches of a new type, pattern or severity, unrefreshing sleep, post exertional malaise lasting more than 24hrs.

There were conditions to be excluded including other medical disorders causing fatigue, major depressive disorders, medications, alcohol or substance abuse.

The Canadian Clinical Case Definition was then discussed which in summary is “A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction and pain, have 2 or more neurological/cognitive manifestations, and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations”.

I discussed that I felt the Canadian definition was the best one that we have at the moment and that it was a positive factor that the definition required the condition to worsen following exercise and that certain other symptoms must be present.

A study by Dr Leonard Jason, DePaul University of Chicago 2005 was discussed. Dr Jason studied the difference between the Canadian criteria and Fukuda criteria and fatigue from psychiatric conditions and found that the Canadian criteria selected patients with more physical functional impairment, more fatigue / weakness, neurocognitive and neurological symptoms and had more variables that significantly differentiated them from the psychiatric group. This suggests the utility of designating post exertional malaise and fatigue, sleep dysfunction, pain, clinical neurocognitive and autonomic/neuroendocrine symptoms as major criteria.

3. Symptoms

The symptom Triad:

- Energy
- Brain
- Pain (not seen in 5%)

Each of these 3 symptoms was discussed in more detail, in particular the concept of energy and the importance of post-exertional malaise. A study by Staci Stevens, Pacific Fatigue Lab and Fatigue Consultation Clinic, which was presented at the International Association of CFS conference in January 2007, showed

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with a group of ME/CFS patients (20) and a group of sedentary controls (20), after a maximum cardio pulmonary exercise test, that it took the ME/CFS group on average 4.1 days to recover and the control group 1.1 days. Within 24 hours 85% of the controls indicated full recovery versus 0% of the ME/CFS patients. The remaining 15% of the controls recovered within 24hours, only 1 ME/CFS patient recovered within 24hours. 50% of the ME/CFS patients required more than 5 days to recover and this provides an explanation for activity avoidance.

The push – crash phenomenon was discussed which then leads to patients having limited boundaries and therefore the concept of pacing.

ME/CFS's crisis of credibility was discussed. "Multiple sclerosis was once called hysterical paralysis and doctors treated patients like hypochondriacs or assumed that they were depressed and couldn't cope with life. Then with the advent of new technology, in this case MRI, scientists and clinicians were able to see brain lesions in MS patients, and scepticism vanished". (Nancy Klimas. MD University of Miami, School of Medicine).

4. Epidemiology

Quality of life: Quality of life tests indicate people with ME/CFS feel similar to patients with AIDS, months before their death in their ability to do things (Munson 1995). Australian researchers found more dysfunction than MS, the degree of impairment more extreme than end-stage renal disease and heart disease and that only in terminally ill cancer patients and stroke patients was the sickness impact greater than in ME/CFS. (Marshall et al, 2001).

International prevalence:

USA: 4 to 420 per 100,000, approximately 900,000 Americans, only 16% diagnosed.

Australia: 37 (1990) to 1,500 (1999) per 100,000 estimated number of Australians with ME/CFS 100,000 to 120,000.

New Zealand: 127 per 100,000.

UK: 6 to 500 per 100,000 (excluding comorbid disorder) 6 to 2,600 per 100,000 (including comorbid disorder).

Netherlands: 112 per 100,000. Age – most common 40-49, Gender – female to male 3.5 to 1. Onset – 60%-80% following viral illness.

The reason for the high rates in the UK was discussed and it is most likely due to their definitions, the large input of psychiatry into the condition in the UK

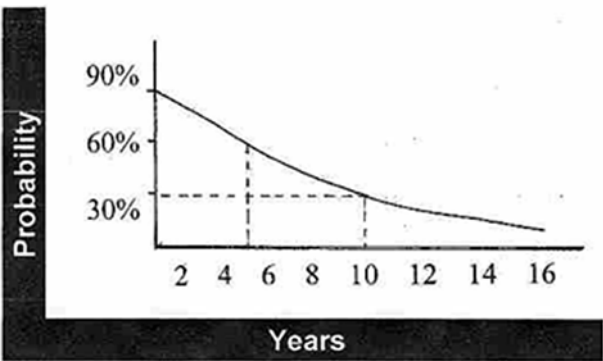
and the inclusion of psychiatric disorders because of this.

Prognosis, relapses, and remissions over a long time: Median duration – 7.3 years. Full remission – 5%-10%, improvement 40%. "The good thing about CFS is that although you may wish you were dead, it rarely kills you" (Paul Cheney, North Carolina).

History of atopy/allergic illness – 50%-80%.

EPIDEMIOLOGY

Probability of Functional Recovery
(A. Komaroff, Harvard)



5. Research

1. Troublesome case definitions

There are a lot of difficulties in research because there are many different case definitions. The case definitions themselves cause heterogeneity. It is a low prevalence disorder and you need a screening instrument with a high sensitivity, specificity and predictive value.

2. "Crisis of credibility" (Simon Molesworth)

Because there is no diagnostic test or biologic marker, and there has been difficulty in attracting funding and a lot of funding has gone to psychiatry, this has all added to the crisis.

3. Identifying sub-groups

There is variability in presentation in the patient population. Variables include: age of onset; present age; mode of onset (gradual or abrupt); comorbid conditions; duration of illness; hormonal status (including pregnancy and menopause); body weight; medications; deconditioning; and diurnal rhythms.

4. Measuring Outcomes

There is no standard assessment of illness severity. The difference between self-report questionnaires and evaluating such things as sleep, pain, fatigue, memory, self care and leisure activities

were discussed. It was also discussed that perhaps improvements are due to better coping, because of lowered expectations versus actual recovery.

5. Selecting control groups

Recruitment methods and selection criteria.

6. Problems in attracting researchers

There is the lack of status, lack of funding and lack of units.

7. Bias

Bias is seen in researchers' work and in journals. An article by Goudsmit in 2004 was discussed. She did a literature search on CFS and ME in the British Medical Journal between 1995 and 2000 and found a significant bias. None used accepted diagnostic criteria, they used the older UK Oxford criteria. There was a bias with psychological and psychiatric aspects, there were no papers on immunology or virology and one editor wrote, "Supporters of the illness have manipulated the WHO". There was only one study on non-psychological issues.

6. The Biology

"We know that Chronic Fatigue Syndrome has identifiable biologic underpinnings, because we now have documented a number of underlying pathophysiologic processes involving the brain, the immune system, the neuroendocrine system and the autonomic nervous system". (Nancy Klimas, MD).

"A growing literature reports a number of objective laboratory findings that clearly distinguish patients with ME/CFS from healthy control subjects (and, in some cases, from comparison group patients with various fatiguing in psychiatric and organic diseases). I conclude that the controversy as to whether CFS is real should be over" (Anthony Komaroff, MD 2001).

a) The Immune System

1. Impaired function of natural killer cells:

- Reactivation of Epstein Barr and herpes viruses may be secondary to reduced NK cell cytotoxicity.
- NK cell function used as an outcome measure in treatment studies of Immunovir, Ampligen and interferon alpha.
- Perforin is a protein found in intracellular granules of NK and cytotoxic T cells important in lytic processes, immune surveillance and homeostasis of the immune system Perforin is decreased in both.

2. Increased numbers of destructive T cells and increased percentage of T cells expressing activation markers:

- More in those with acute onset.
- Other evidence of immune activation:
- Increased expression of cell surface markers CD38, CD28, CD26 and HLADR.
- Degree of cellular immune activation is associated with severity of symptoms and perceived illness burden.

3. Activation of several pro-inflammatory cytokines:

- -TNF - alpha, TNF - beta, IL-1 alpha, IL-1 beta, IL-2, IL-4, IL-5, IL-6, IL-10

4. Disregulation of the 2' 5' A RNase L antiviral pathway (immune activation)

- Interferon activates 2' 5' a synthetase which converts ATP to 2' 5' A which activates RNase L which degrades RNA destroying the ability of viruses to replicate. It also destroys human RNA and causes fatigue states especially in mononucleosis. This increased RNase L activity does imply that there is a viral origin; a low molecular weight form of RNase L protein is found which is not seen in healthy controls, fibromyalgia or depression. The higher the level of the smaller forms of RNase L the more severe the illness (The most ill have almost none of the normal form of RNase L).

5. Predominance of Th-2 cellular immunity:

- There is a Th-2 shift and reactivation of latent viruses suggesting deficient humoral immunity.

6. Differential expression of gene markers whose products cause T cell activation.

b) Infection

"Ultimately I think micro-organisms will be shown to play a role in causing many (but not all) cases of CFS. I would be surprised if just one novel organism is involved. Rather, my guess is that the problem can be triggered by multiple organisms, all of which have the capacity to escape complete eradication by the immune system, and are therefore the target of an on-going low grade response on the part of the immune system". (A. Komaroff, MD. Harvard Medical School).

Post infectious fatigue syndromes are more likely after certain infections, in particular, EBV, Q Fever, Toxoplasmosis and CMV. The Dubbo infection study was discussed, in which cohorts of EB viruses were followed up longitudinally. The finding:

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The severity of the acute illness was the major predictor of the development of ME/CFS and was independent of psychiatric disorder and about 10% of people developed ME/CFS after this condition.

The questions put forward were: is the infection still persistent in the body (“stealth” viruses)?; has there been reactivation of latent infection?; and the question of persistent production or lack of inhibition of production of mediators responsible for symptoms despite the resolution of infection?

There are a lot of reasons to suspect viruses:

- ME/CFS starts with flu-like episode
- Symptoms wax and wane
- Anti viral pathways are activated
- ME/CFS symptoms are similar to many viral conditions
- Geographic outbreaks are reported
- Gene expression profiling has found genetic variants that implicate anti viral pathways
- Anti viral treatments are effective in small studies

The infection candidates were discussed:

1. EBV: we know with this virus there is an acute fatigue in 47% (infectious mononucleosis) and lasting a mean of 8 weeks. We know that ME/CFS may follow infectious mononucleosis in about 10% of cases. Infectious mononucleosis may have a prolonged course with exacerbations. As a member of the herpes virus family, EBV becomes latent in all infected people and may become re-activated. There is no increased incidence of psychiatric disorder preceding the infection in those who go on to develop ME/CFS.

2. HHV-6: This is a life long infection and is widely trophic - which means it has an ability to hang around in cells, in particular T and B cells, monocytes, macrophages, salivary cell glands, glial cells in the brain etc. There is an association with benign and malignant lymphoproliferative disease. It is known to persist in the central nervous system after roseola (HHV6) and it is thought to be associated with seizures, multiple sclerosis and cerebral palsy. Dr Ablashi from Columbia USA has done most of the work on herpes viruses and has found that more than 65% of ME/CFS patients have HHV6 infection.

3. Persistent enterovirus infection: Group B Cocksackievirus has been implicated. Dr Chia in California has done most of the work on this and has identified by PCR in muscle of ME/CFS patients that about 20% of ME/CFS sufferers have the virus versus 0% healthy controls.

4. Mycoplasma: Dr Garth Nicholson of the Institute for Molecular Medicine in California has

found that 52% of his group of ME/CFS patients have mycoplasma with m.pneumoniae being the most common. In Europe, 68% of patients have been found positive, with m.hominis being the most common. Multiple infections are common.

It is important to remember that symptoms of infections are very similar to those with ME/CFS, in particular the general malaise, tender lymphadenopathy, recurrent sore throat, new sensitivities and crimson crescents on the tonsils, which are seen with ME/CFS.

c) Central Nervous System

Dr Byron Hyde of Canada states, “The evidence suggests that ME/CFS is caused primarily by a diverse group of viral infections that have neurotrophic characteristics and appear to exert the influence on the CNS”.

1. Cognitive Deficits

These are seen in 99% of patients.

Impairments are seen in:

- Acquiring new information
- Processing Information
- Concentration
- Attention
- Verbal memory
- Visual memory
- Reaction time
- Word searching
- Multi tasking
- Spatial organization
- Sensory and information overload

Overall, there is a slower reaction time and slowness in acquiring new information as opposed to more mistakes being made. To process challenging information, ME/CFS patients utilise more extensive cellular networks and have more diffuse brain activation, particularly if there is no psychiatric disorder.

2. Neuroimaging study results

a) *MRI* – small hyper-intensities in the white matter (more likely if no psychiatric disorder)

b) *Cerebral atrophy*

- Reduction in grey matter seen in 8% (F. de Lange, Netherlands 2005)
- Reduction in grey matter in bilateral prefrontal areas in 11.8% (Okado. Japan 2004).

c) *Reduced cerebral blood flow* (more so, if no psychiatric disorder)

d) *Abnormal brain metabolism* – abnormal glucose metabolism, increased ventricular lactate (levels correlate with fatigue levels), decreased acetyl carnitine uptake.

A study was presented that looked at proton magnetic resonance spectroscopic imaging by Nestadt et al, Department of Psychiatry, Mount Sinai School of Medicine. They looked at 16 ME/CFS patients, 16 healthy controls, and 16 patients with generalised anxiety disorder. They looked at ventricular lactate and found that the ME/CFS patients had a 297% higher level than those with GAD and a 348% higher level than healthy controls.

Lactate levels correlated with the level of fatigue and they introduced the term “brain cramp” and discussed the issue of anaerobic energy conversion in the brain and/or mitochondrial dysfunction.

Also seen are higher protein levels and/or white blood cell count in cerebral spinal fluid in 30% of ME/CFS patients (more so if there is no psychiatric disorder). Sleep disturbance is seen with disrupted fragmented sleep, a feeling of “tired but wired”, and hypersomnia especially at the onset of the illness, poor delta sleep (intrusion of fast delta waves). You do not see the shortened REM latency characteristic of depression and sleep disruption is associated with increased proinflammatory cytokines and decreased natural killer cell response.

You also see desynchronization of temperature and melatonin circadian rhythm.

There are symptoms suggestive of central nervous system dysfunction including brain fog, overload phenomena, motor and perceptual disturbances, muscle weakness, fasciculations, poor coordination, loss of balance, visual accommodation and focusing difficulties causing double and blurred vision.

e) Autonomic Nervous System/Cardiovascular System

Orthostatic intolerance, which is Neurally-mediated hypotension (NMH) and Postural Tachycardia Syndrome (POTS), is seen. The use of the tilt table to diagnose this was discussed.

Chronic orthostatic intolerance is the inability to sustain upright activity with symptoms of exhaustion and urge to lie down, confusion and worsening of other symptoms. What is seen is low circulating erythrocyte volume but not plasma volume. The blood pools and there is a decreased stroke volume and cardiac output with the circulatory problems correlating with symptom severity. Neurally-mediated hypotension is a precipitous drop of more than 20-25mm of mercury of the systolic blood pressure on standing. The symptoms include light-headedness, dizziness, chest pain, visual changes, pallor, fainting, and an urge to lie down.

In POTS when one is standing, one sees a rapid increase in heart rate plus or minus the decrease in blood pressure with the same symptoms as NMH. You also see delayed postural hypotension with palpitations and chest pain and other autonomic system symptoms such as breathing dysregulations, symptoms to do with the gut and bladder, sweating and shivering.

You also see abnormal T waves on a 24-hour ECG, T wave flattening and/or T wave inversions. You see tachycardia (an increased heart rate) at rest, abnormal cardiac motion and cardiomyopathy at biopsy.

Dr Lerner from the Department of Medicine at William Beaumont Hospital and Wayne State University has done the work here and has found improvements with anti-viral therapy.

Anaemia has also been seen which is undetectable with standard blood tests. This is due to a decreased red blood cell mass, mainly seen in females and has led to some treatment studies with erythropoietin (EPO)

An abnormal stress test has also been seen.

f) Neuroendocrine System

There is impaired function of the HPA axis:

- Cortisol lower in blood and urine
- Lower salivary cortisol response on wakening – probably due to CRH deficiency (Cortisol Releasing Hormone)
- Role of cortisol in suppressing the immune response
- Concept of “adrenal exhaustion”
- Shrunken adrenal glands
- This had led to discussions regarding various treatments using corticosteroids

The symptoms that fit in with this include loss of thermostatic stability, heat and cold intolerance, weight changes, hypoglycaemia and the fact that stress worsens symptoms. It is also important to note that in Addison's disease, which is a glucocorticoid deficiency, you get fatigue and somatic physical symptoms.

g) Genetics

There are differences in gene expression in white blood cells. Kerr of St Georges University in London has found differences in 35 out of 9522 genes analysed using DNA chip technology, 15 genes are up to 4 times as active. W. Reeves from CDC in Atlanta 2006 was involved in the study that found patterns of expression of about 24 genes involved in immune

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function, cell signalling and other roles were different.

7. Paediatrics

It was discussed that ME/CFS is seen in children and adolescents and there is often more medical misunderstanding in this group. These kids are often labelled as having school avoidance, anxiety and depression. Children predominantly have an acute onset and a better prognosis although 20% don't recover. They seem to have greater symptom variability. It was noted that the condition is not usually seen in children under 10, and this is possibly related to hormonal changes that occur at puberty. Comorbid psychiatric conditions are uncommon. Neurally-mediated hypotension and POTS are very common. There is also increased joint hypermobility seen and, in some, movement restrictions such as with the ankle or leg. There is a group currently working on a new case definition for children, which will be a good breakthrough. Also it was noted children tend to adapt to their symptoms and so it is often harder to detect and treat.

8) Psychiatry

The "turf war" between psychiatry and neurology going right back to the 1800s was discussed with respect to the history of neurasthenia. It was interesting to note Freud and his colleague Bernheim believed in the organic hypothesis and believed the condition was not amenable to psychotherapy.

The Royal Free Hospital outbreak of 1955 was discussed in further detail.

Because ME/CFS has been described in psychiatric literature as a somatization disorder, somatization was first defined.

"A process by which patients experience physical symptoms, most probably the result of psychological distress, but are attributed by the patient to a physical cause". "Somatiform disorders are characterised by physical symptoms that resemble medical disease but they exhibit no organic pathology or known pathophysiological mechanism". Dissecting these definitions, one can easily see that a ME/CFS patient could in fact fit into these definitions.

The importance of knowing how to differentiate ME/CFS from depression was discussed. It was noted that rates of psychiatric disorders seem to be the same as in other chronic medical conditions (30%-40%), rates of personality disorder are not elevated, the ge-

netics of ME/CFS are independent, illness severity and not psychological symptoms predict outcome. A scale called the Hospital Anxiety and Depression Scale (HADS) has been shown to be a validated screening instrument for ME/CFS.

"Mistakenly attributing the symptoms of CFS to depression wastes valuable treatment time, leads to unnecessary medications and potentially drives the patient – who is certain that it's an organic problem and not a psychiatric one – to distrust the medical profession and seek alternative care" (Charles Lapp, MD).

When patients have concurrent depression the reasons were discussed. Obviously there are all the issues of having a chronic illness in general including grief and loss of identity. Then there are specifics of ME/CFS including social stigma, lack of credibility, misunderstanding, patients may look "well", variability of symptoms, uncertain prognosis and the "push/crash phenomenon". The biology of the illness leads to an association between inflammation and depression, the role of cytokines was discussed, and we also know that when cytokines are given therapeutically they can cause depression.

The role of a psychiatrist in ME/CFS patients' lives was discussed. There are a lot of psychological issues to deal with including fear, despair, isolation, the impact of scepticism and doubt, stigma and shame, self-blame, grief and loss, dealing with work, family, friends and dismissive or hostile doctors. The psychiatrist should be involved in liaison and advocacy, use antidepressants when required and obviously be up to date with the medical literature on the condition.

CFS/ME and PSYCHIATRY

	CFS	Depression
Onset	Abrupt, flu-like	Insidious
Symptoms	Infective/inflammatory	-
Fatigue	Severe Exercise intolerance(post-exertional malaise)	Improvement with exercise over time
Mood	Parallels symptom, severity Less guilt, SI, Preservation of S.E. Proactive re recovery	Withdrawn Hopelessness Guilt
Sleep	Fast alpha wave intrusion into delta. Comorbid primary sleep disorders 18-63% am stiffness & fogginess	Decreased REM latency
Neuroendocrine	H-P-A AXIS ↓ (↓ cortisol, ↓ DHEA, ↓ adrenal size)	↑ cortisol (↑ CRH, ↑ ACTH)
Autonomic Dysfunction	+	-
Electrodermal	↓ skin electrical conductance levels - ↑ skin temp in arms and legs	
Epidemic	+	-

9) Treatment

The group of psychiatrists were told that there was no magic pill, although a number of things have been tried including antivirals, antibiotics and corticosteroids. I explained that I believe that an integrative approach was important. Symptom management was also important – for example, pain and sleep, helping people with coping strategies, talking about pacing and switching and treating concurrent depression.

The use of complementary/alternative therapies

was discussed and the cognitive-behaviour therapy and graded exercise debate was also discussed with me clearly stating that cognitive behaviour therapy is not a “cure” but can aid people with their coping skills and that graded exercise therapy, although it has been helpful in some cases, can be potentially harmful if put in the wrong hands.

Dr Nicole Phillips.



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seven years, is especially proud of her three-year-old: “Patrick was always a helpful and placid child. When I felt well enough to do some washing he would try to join in, so now he is a bit older I ask him to empty the washing machine and load the wet clothes into the tumble-drier for me. I sit and supervise, but it saves my arm muscles and gives him a sense of responsibility as well as learning how to do the laundry!”

Ask for help

If you suffer from M.E. severely and you can afford it, consider sending your child to a private nursery. Even half a day there can give you enough of a break to catch up on some rest, while enabling your child to be independent and learn about sharing and playing with others. If you can't afford a private nursery, ask if grandparents can have the child for one night each week.

Should you find yourself in the position of being a single parent with M.E. then support from other people is even more vital. Priscilla found herself alone with Isabella, now two, unexpectedly. “I find parenthood with M.E. hard of course, but such a joy as well,” she says. “My advice to others would be to get as much practical help as possible, accept any offers of help and don't be afraid to ask for what you need.”

Find ways to cut corners

Another way of saving energy is to order your weekly shopping over the Internet. Most of the large supermarkets now have an online or telephone ordering facility. Basically, any way you can find to save energy is a bonus for you and your growing child. Many parents with M.E. have a sense of guilt that they don't do

enough things with their child like running about or that because of their illness the child doesn't spend as much time with them.

The best thing to remember in this situation is that we can make up for our energy shortage in many other ways. I read a lot to Alex and know for certain that he's more confident, helpful and sympathetic because of my situation, as well as being a real bookworm. Even though he may have to spend more time being cared for by other people, when Alex hurts himself, the first person he cries for is “Mummy!” so I guess I must be doing something right!

Useful information

- Parent centres are great for information and support for all things related to being a parent. Visit the Parenting and Child Health section of the Children, Youth and Women's Health Service website: <http://www.cyh.com/SubDefault.aspx?p=98>.
- Disability, Pregnancy and Parenthood International provides a personal and confidential enquiry service and produces a number of information sheets. Visit www.dppi.org.uk or write to Disability, Pregnancy & Parenthood International, National Centre for Disabled Parents, Unit F9, 89-93 Fonthill Road, London, N4 3JH, UK.
- www.mecfsparents.org.uk is a website dedicated to parents with M.E. offering a message board and helpful articles
- *New Toddler Taming* is a parents' guide to the first four years by Dr Christopher Green. Advising on issues such as tantrums, sleep problems and general behaviour concerns. It's published by Vermilion.



Reprinted with permission (and minor modification) from InterAction, quarterly magazine of UK charity Action for ME.

Information about ME/CFS

What is ME/CFS?

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is characterised by severe, disabling fatigue and post-exertional malaise. Fatigue is just one symptom – there are a multitude of others. ME/CFS is a not uncommon medical disorder that causes significant ill health and disability in sufferers.

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is also known by other names such as Post Viral Fatigue Syndrome, Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and Myalgic Encephalomyelitis.

It is now officially recognised by the World Health Organization International Classification of Diseases and by recent international and Australian guidelines on ME/CFS.

Prevalence

ME/CFS affects all social and ethnic groups. There is a predominance of females (2 to 1) and a bimodal distribution with peaks between 15-20 year olds and 33-45 year olds. The prevalence of ME/CFS varies between 0.2% and 0.5% of the total population. In South Australia this translates to between 3,000 and 7,000 cases at any one time.

Main characteristics of ME/CFS

Disabling fatigue for at least 6 months, along with cardinal symptoms such as:

- muscle aches and pain;
- unrefreshing sleep or altered sleep patterns;
- neuro-cognitive dysfunction (e.g. poor concentration and memory);
- gastro-intestinal symptoms (e.g. irritable bowel);
- orthostatic intolerance (e.g. low blood pressure);
- and unusual headaches.

A hallmark of the condition is that symptoms are usually worsened with minimal physical and mental exertion.

Definition

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to earlier sets of criteria, this new definition made it compulsory that to be diagnosed with ME/CFS, a patient must become symptomatically ill after minimal exertion. It also clarified other neurological, neurocognitive, neuroendocrine, autonomic, and immune manifestations of the condition. The Canadian Consensus criteria are wholly supported by ME/CFS SA and by the National Board of ME/CFS Australia. Copies are available from the ME/CFS SA website.

Diagnosing ME/CFS

Note that there are many other conditions which may need exclusion by your doctor before a diagnosis of ME/CFS may be made. These include: Hypothyroidism; Hyperthyroidism; Diabetes Mellitus; Addison's Disease; and Multiple Sclerosis, just to name a few.

ME/CFS may also co-exist with or mimic symptoms associated with: fibromyalgia; multiple chemical sensitivity; Irritable Bowel Syndrome; depression; anxiety disorders; and somatoform disorders.

This can make the diagnosis of ME/CFS and any coexisting conditions difficult.

How is ME/CFS treated?

All treatment should be patient-centred and involve supportive counselling, lifestyle management and the setting of realistic goals. There is no known cure for ME/CFS. Management is geared at improving functionality and symptom control through an effective therapeutic alliance between the patient and their GP.

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 may be relieved through the use of medications and other interventions.

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

There is still a great deal of controversy surrounding the issue of whether people with ME/CFS should undertake intentional exercise. Most ME/CFS patient groups recommend that sufferers pace themselves by starting with gentle exercises and slowly increasing levels of exercise without causing a significant relapse of symptoms. 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.

Prognosis

The prognosis for ME/CFS patients is variable. Most will generally improve in functionality to some degree over time, usually 3 to 5 years. However, symptoms may fluctuate or relapses may occur from time to time. Early intervention and positive diagnosis often result in a better prognosis. However, a significant proportion of patients will remain quite debilitated for longer periods of time.



Contact numbers

Miscellaneous Support Contacts

North Eastern	Julie	8264 0607
North Eastern	Pat	8264 9328
SAYME	Emma	8381 4417
SAYME Parents	Marg	8381 4417

Country Support Contacts

Auburn	Kay Hoskin	8849 2143
Barossa Valley	Dennis	8563 2976
Mt. Gambier	Di Lock	8725 8398 or 0438 358 398 (mobile)
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yorke Peninsula (central)	Caroline	8837 4335
Yorke Peninsula (northern)	David	8862 1668
Yunta	Gloria	8650 5938

YOUTH SUPPORT: SAYME

South Australian Youth with ME/CFS

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

The Youth group is open to young people up until the age of 30.

Please contact Emma Wing in the office on Wednesdays on 8410 8929 for a program of events or if you would like to receive our quarterly magazine. We would love to meet you.

Support groups

Glenelg Support Group

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

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

Time: 1:00 pm.

Phone: Marion Hansen on (08) 8234 2342.

Riverland CFS Support Group

Venue: Riverland Community Health Resource Centre, 9-11 Seekamp Street, Berri.

Phone: Raelene or Simon on 0449 120 715.

Email: riverlandcfssupport@gmail.com.

Northern Yorke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo.

Phone: David on 8862 1665.

Disclaimer

Please note that meeting times are subject to change.

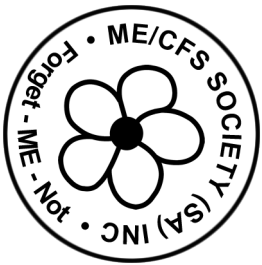
If you are attending a meeting for the first time please call the contact or the Information and Support Line for confirmation of meeting days and times: 8410 8930 or 1800 136 626.

Changes

In order to keep us up to date, please send any alterations, additions or deletions to the Editor:

- Mail: GPO Box 383, Adelaide 5001.
- Email: pmrscott@tpg.com.au.





If undeliverable return to:
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GPO Box 383
ADELAIDE SA 5001

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PP 532154 / 00023

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