Talking Pump

June 2001 Official Journal of the M.E./C.F.S. Society (SA) Inc.

Your Society

forget-ME-not

Office Ph: (08) 84108929 Fax: (08) 8410 8931

Support & Information Line City Callers: 84108930 Country Callers: 1800136 626

www.sacfs.asn.au

ME/CFS Society (SA) Inc.

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

- Promote recognition and understanding of the disease among the medical profession and the wider community;
- Provide information and support for sufferers; and
- Promote and foster research towards a more effective treatment and cure.

Membership

Patron:

Lady Neal

Advisory Panel:

Judy Lovett: Past President of the ME/CFS Society (SA) Inc., Chairperson of the ME/CFS Association of Australia Ltd.

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

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

New Members:

Single membership…….	$32
Single Concession ……..	$22
Professional…….	$40
Family ……...…….	$38
Family Concession …….	$28
Overseas – as above plus…...…….	$10

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

Talking Point Subscriptions:

Professionals:……..	$30
PWME/CFS:……..	$22
Overseas (Asia-Pacific):……..	$32
Overseas (Rest of World): ……..	$38

Management Committee 2001

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

President: Boris Dontscheff
Vice-President: Paul Leverenz
Secretary: Steph Retallick
Treasurer: Margaret Wing
Management Committee Members:
Margaret Whyatt, Beulah Carter, Marion Hansen, Luke Pullen, Peter Evans.

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.

Deadline for Next Issue
August 31st

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.

Disclaimer

The ME/CFS Society (SA) Inc. aims to keep members informed of the various 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 products, treatments or services (including paid advertisers). Always consult your medical practitioners before commencing any new treatments.

Notice to Vendors

The ME/CFS Society (SA) Inc. does not permit direct marketing of products to our members. This includes distributing promotional literature, providing demonstrations of products or approaching members at any of our events.

If you have information about products which you wish to bring to the attention of the Society, you should direct it to the Society 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 our membership list for direct marketing will be investigated and dealt with appropriately.

Donations

Donations are an important source of income for the Society and are welcome at all times.
All donations of $2.00 or over are tax deductible and a receipt will be issued.

Office

The Society has an office: Room 510, 5th floor, Epworth Building, 33 Pirie St, Adelaide. Currently office hours are Tuesday & Thursday 11am-2pm.

CHARITY DIRECT
A SIGN OF ETHICAL FUNDRAISING

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

EDITORIAL

Well – what a response to our first new-look edition! We have been overwhelmed with people's enthusiasm for Talking Point – especially the letters we have had in. This has led to this edition being a huge one! Hmmm….We don't think we can keep this size up….it depends on your responses and what you send in.

The feedback has been that many have been encouraged by the 'coping strategy' articles that appeared last time. We've continued on with those this time round.

We had a last minute dilemma, with the revised National Draft Guidelines on Chronic Fatigue Syndrome coming out just as the final touches were being put to the journal. Members will receive a more detailed critique of them in the mail. The article about the Guidelines was written prior to their release, but is still relevant.

We are working hard to bring the Talking Point publication dates back into line, and so we do ask that all contributors heed the deadline. We will be very strict about the deadline, and will not guarantee publication of anything later than that date.

It is worth remembering that Talking Point is your journal; and the more you, the membership, contribute the richer it will be. We welcome your submissions whether it is your life story, your methods of coping with ME/CFS, your recipes, your wisdom or your humour.

For all the GPs who come by Talking Point, we welcome your contributions too. We hope to improve the quality of the medical section with more input from health professionals. Specifically we are looking for clinicians willing to review and write about research being done around the world, and on the pros and cons of various treatments.

That's enough from us, enjoy the read and keep that feedback coming in!

Warm wishes,

Paul Leverenz
Farrah Tate
Editors

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VICE-PRESIDENT'S REPORT

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Hi,

Due to illness in the family of our President, and his own poor health, I have continued to act as President since the last Talking Point.

A lot has happened during the last 3 months – the pace has been frenetic!

GP Seminar 11th May

Our GP seminar was great with 32 attending – best of all was that 50 or so GPs who couldn't make it faxed us wanting to know what was presented at the meeting!

We are now working hard to ensure we follow up these GPs and develop better links.

May 12th Public Seminar.

The public seminar featuring Hugh Dunstan from the Newcastle University Collaborative Pain Research Unit was a success with 200 or so in attendance; a number of new people came along and signed up. Special thanks go to Hilary McKay who put an ad in the Hills Courier Mail and was successful in getting a few new people along.

Since that meeting memberships have been coming in regularly.

The office

The big news is that our society has gone up in the world – by one floor to be exact! We are now located in Room 510 (5th Floor) of the Epworth Building, 33 Pirie St, Adelaide.

The room is just a little bit bigger and has an excellent storage area which should enable us to keep the place presentable. With new carpet and a fresh paint-job, I think you will be impressed with how it looks.

We will be having an open day on WED August 1st for members to come in and have a look. You're welcome to come have a look at anytime of course during the office hours.

Office Hours

With the current hands on deck, the office hours will remain at 11 am-2 pm TUES and THURS. This doesn't mean it's the only time we are in the office – the answering machine and email is checked often. (Thus far we have been able to achieve a quick turn around for almost all phone calls and emails.) As our team expands we will seek to increase our number of official office hours. Special thanks to Karen Zweck who has been a big help around the office.

Education Support Programme

The society now has an Education Support Programme which is being co-ordinated by our Secretary, Stephany Retallick. She has been dialoguing with SSABSA and has made some breakthroughs concerning the rights of persons with ME/CFS undertaking secondary education. A group of SAYME parents will now work toward improving the consideration these people receive, and will document information for other parents of secondary students.

If you come by anyone doing Secondary Education who is having difficulty dealing with their school, or just struggling in their situation then please get them to ring the office to speak with someone from the School Support Programme.

Strategic Planning

The Management Committee has commenced strategic planning; our preliminary discussions have helped us to map out the sorts of services that we need to develop. A full report on that will follow later in the year.

In order to gain a rough idea of the services our member's would like, we surveyed attendees of the May 12th Seminar. We understand this was not a representative sample of you all, but it was clear that many people would appreciate self-management courses. Several things have reiterated the importance of developing such courses since that day. We are convinced it is a priority consideration.

Membership Fees

Members should have received their membership renewal form by the time this edition is published. You will see that we have reduced some of the fees, and have introduced a split system where new members pay a little more than renewing members – to try to encourage renewal on time.

We have included a new membership category – the *Family Concession* rate for families where the breadwinners are concession holders.

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We have a couple of interesting meetings coming up:

Get-to-Know-Each-Other Meeting

Sat July 21st 12:15 for 12:30 at DIRC, 195 Gilles St. Speaker: Judy Lovett. Bring a plate of food to share.

The Management Committee believe it is really important to continue to build a strong community within the society. To that end we want to a relaxed get-together, incorporating a meal. Over a shared lunch we can all get to know each other a little better.

Following lunch I have asked Judy Lovett to speak to us briefly about the National ME/CFS Association of Australia. I think it's important we are kept informed with what they are doing, and its important we take an active interest.

There will be time to ask Judy questions, and the Management Committee. (STOP PRESS: This meeting will also be a good chance to explain the significance of the National Guidelines for CFS and the implications for persons with ME/CFS.)

Medical Seminar

August 11th 1:10 for 1:30pm Uni of South Australia, Frome Road (Full details on page …)

You may have heard about (or even taken part) in some new research being conducted in Adelaide – a partnership between the RAH and the QEH. These researchers are doing SPECT scans to study brain blood flow.

It must be stressed that this work is in its infant stages. Initial results are very promising with quite conclusive results for FM and ME/CFS sufferers. It seems there may

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LETTERS TO THE EDITOR

Thankyou to those of you who have written in. We cannot thank people enough for the encouragement they have given us over the last Talking Point. It was a lot of work, but the gratefulness gives us more energy to keep on – but special thanks go to those who have written in when it has cost a lot of precious energy to do so.

Whilst we cannot always publish every sentence people write – these efforts are not to be shortened, edited, truncated, lopped, chopped or condensed. We think they are helpful windows into so many of our people's struggle.

Eds

LETTERS...

To the Editors:

I have lived with ME/CFS for many years and have been through all of the ups and downs including seeming to be in remission and living a so-called normal life, (although still feeling ghastly at times), to being house-bound for a period of about 5 years.

This is not a Pollyanna story. I have experienced the humiliation of not being able to work, sliding down the financial ladder, losing most of my old friends, my husband, my house, my ability to drive a car, to travel and move around freely. And having been my own carer throughout the illness, I have felt very deeply the isolation that having ME/CFS can bring. I know about touch deprivation of which people only talk in terms of the elderly, but you don't have to be elderly to experience it.

I have been through all the emotional ups and downs, the "Why did this happen to me?"; thought seriously about suicide; felt resentful that my friends were continuing with their lives, but over a period of years, my life, which I know is far from normal, is now the only life I know. This is it – and I wring every drop of enjoyment out of it that I can.

During my period of being house-bound, when life hardly seemed worth living, and I was looking at little patches of the world through my windows, I constantly thought about how I could become a part of the community again, and how I could make myself important in at least one other person's life. After many telephone calls, I discovered the Home Tutor Scheme. Because of my varied work background and travel experiences I was accepted as a Home Tutor (this is voluntary work) and due to my inability to move around in the community or to drive a car, instead of me going to the home of my students which is the usual arrangement, my students were perfectly happy to come to me.

I began with one student a week, a young woman from China, an artist, who was studying English with professional teachers, but needed tutoring, extra individual support and a place where she could make mistakes and not feel uncomfortable. I had never done anything like this before, so it was a huge learning curve for me. Over a period of time, I realised that I had become very important to Mei-Mei because her mother and sisters still lived in China, so I became like an aunt. She would often bring me gifts; flowers, a beautifully hand carved bracelet from China, embroidered handkerchiefs, things which were obviously some of her personal possessions, but she wanted to let me know how much she appreciated me. So I achieved my aim of needing to be useful.

There were times when I had to cancel lessons with Mei-Mei, because I was too ill to get out of bed, but she didn't seem to mind. And as the years went by, her English improved, she and her husband bought a car, she learnt to drive and she would collect me and take me to their house to have afternoon tea. She knew I had a serious health problem, and although she understood little of the complicated ramifications, that didn't make me any less of a person in her eyes. I recovered my self-worth.

What was most important about becoming a Home Tutor was that not only did it take me in a completely new direction, it gave me the opportunity to meet people from different countries and to learn about their way of life. It was also a way of becoming involved with people who I realised were also on the margins of the society, because most of my students were political refugees. I could relate immediately to these fellow human beings due to my experience with ME/CFS. I too had lost my peer group support network, I had lost my ability to work, I'd been cast out of the mainstream, ejected from my tribe and I'd experienced ridicule, not because of my inability to speak the language, but because people didn't believe what I was telling them.

Then something really wonderful happened, I was lucky enough to have several political refugees from one particular Latin American country. They were struggling so hard to learn English, so I decided I was going to study Spanish seriously, thus making my communication with them a little easier, and also they'd have the benefit of laughing with me at my attempts to speak their language, instead of being constantly ridiculed by people here at their attempts to speak English. I began studying Spanish as an external student through TAFE Adelaide. Another door had swung open.

Prior to my Spanish studies, I'd already completed a 3-year part-time Freelance Writing Certificate course as an external student with TAFE Adelaide, and from that experience wrote 2 film scripts. That was something else I didn't know I was capable of!

At some stage, I became aware of the danger of actually becoming the illness rather than remaining a person with the illness. The thought of becoming a helpless victim to the illness kept me searching for ways to reinvent myself. I learnt to let go of the things I could no longer manage to do and realised I could not simply sit (or lie) around and wait until scientists worked out how to change my state of constant sickness. It was up to me to work within the boundaries of my available energy and to make my life as interesting as possible. And I continued to be political

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regarding the appalling treatment of people with ME/CFS and wrote letters to various politicians and loud-mouthed radio broadcasters whom I considered knew very little about anything much at all.

Wanting to go further with my Spanish studies I discovered that TAFE in Perth offered a 4 year certificate course for external students. I completed 3 years of that course, then took a year off and began studying French. The marvellous thing about studying languages is that it allows me to travel without all the drama of actually leaving home and watching the news on SBS television daily direct from Paris and Madrid, gives me an enormous insight into the world at large, thereby enriching my life.

Another powerful insight into the world was joining Amnesty International about 11 years ago. I've been a member of the Urgent Action Letterwriting Network for years now. Reading constantly about the appalling treatment of people in many countries of the world, has helped put my life and ME/CFS into perspective, and I know that when thousands of Amnesty members around the world target certain government leaders on behalf of another human being, it can make a difference to someone's life.

This year I decided to really go for broke and study for a Bachelor of Arts degree. Having left school many, many years ago, with no formal qualifications, I had to write an essay about myself convincing enough to get me a place. I consider it one of my great achievements that I am now an undergraduate external student at the University of New England, Armidale, N.S.W.

I chose subjects which did not have mandatory attendance at residentials, (when I'm well enough to actually get on a plane and travel to Armidale, I can assure you I'll be getting on a Singapore Airlines flight and heading straight to Madrid) and although one of the subjects had a compulsory attendance, I was able, with the help of a letter from my G.P. and using forms provided by the Disability Contact office at the university to put my case for an exemption which was granted. I've also requested special arrangements be made for sitting exams at home with a suitably qualified person as my supervisor, but at least for the first semester I don't have to worry about that.

You're probably wondering how I manage to do any studying, the answer is that I pay scrupulous attention to what I put in my mouth and my physical energy output. I've found that the only way to keep my energy levels from zooming to feeling as though I can take on the world, to ending up in a comalike sleep for 2 hours after eating a meal, is to stay away from complex carbohydrates. I do very well on a high protein diet and this also helps my brain function well. I know the foods which will bring me undone within about 15 minutes of eating them, and as far as I'm concerned I'm not interested in doing that to myself. Also, I've been one of the lucky ones and have responded to antibiotic treatment. This does not mean that I have recovered from ME/CFS, nothing could be further from the truth, but what I have learned to do is manage the illness to the best of my ability.

The fact that I live alone I believe makes the management easier, I don't have anyone calling on my already low energy level, I can focus on myself, and am able to decide what is important and has to be done, and what isn't important.

Living with ME/CFS is not easy, I would rather be well however I'm not, so I'm doing the best I can under extraordinarily difficult circumstances and try only to do things which enrich my life.

Jennifer Tosolini

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To the Editors,

Re: Article from "Helpful Hints: A guide to understanding, supporting and encouraging people with Chronic 'Debilitating Illness".

I found this article so immensely helpful to myself and my eternal struggle with frustration and anger at my own inabilities (still, after just over 8 years!) and so very descriptive of C.F.S. that I am going to photocopy both this article and the following one about "Repairing Self Esteem" by Val Rubie, to give to my various family members and the few friends I have left. Everyone thinks they understand and they do try, but the odd comments of –

(1) If perhaps you tried a little harder, a little more each day.
(2) You hardly eat a thing, how come you're so fat or how come you've gained 6 stone over what you always weighed when you don't eat hardly a thing?
(3) Perhaps you need to make yourself exercise more each day and ignore the pain.
(4) Make yourself get up early and don't let yourself sleep later in the day.
(5) You need to change your doctors, they're not helping you. Do they know what they are talking about? (
(6) Sure you aren't a closet cream bun eater? (The very thought makes my stomach turn!) It's gone on so long, I think there are those in my life who perhaps are starting to believe that this exceedingly energetic person of "before" is really just letting laziness creep in until it becomes a way of life for me. The "real" me is still there screaming to get out and do a dozen things at once at what now seems an impossible speed to me, impossible life. But I fight every day, I will never accept the "now" me, and perhaps that does make me my own worst enemy. When I dare to actually 'look' at myself in the mirror, I see a fat-faced, fat-bodied stranger I don't know and don't want to be. I feel self-conscious, frumpish and being in a position now of hardship, my finances do not stretch to what may be flattering garb for an overweight person. My once confident self is no longer there. What's self-esteem?! I feel like an idiot when someone tries to teach me an new craft or tells me something. From a quick mind, I am now left with sludge! It's like being deaf and not seeing someone's lips move, or the ears hear but don't pass on the sound to the brain. I doubt anyone, except my husband (and carer) to a degree, really could possibly understand the fibromyalgic pain. I had osteo-arthritis from a young age, but learnt how to do things

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and help my bones in the work I did even if I still had bad days. But there can be no let-up in this pain. My family was used to me coping with pain and I don't think they realize this is just not manageable in any way. Although we learn! And so on to the next query of "Your experiences on paper".

Having been involved in arts and crafts prior, I now find these interests are what keep me going. While I could still afford it I took classes in Folk Art which I found difficult because I had done painting throughout school and after where realism was required. There were so many differences, but I finally got there, developed my own style between the two types and through Folk Art learnt to paint landscape which I couldn't do before. I'm terribly slow now, but sometimes I believe painting and other crafts are all I live for. In my isolation it's all encompassing, but I can no longer take an order on consignment to make a little extra as I am too slow.

I can sew, but I am so frustratingly slow and I have to really be in the mood these days as cutting-out hurts and I often get confused and make mistakes. I tend not to do too much because of the frustration and discomfort. The enjoyment has gone out of it. Craft work and painting are always a joy and give me a great sense of achievement when completed. I cannot achieve much in summer as my body cannot take any heat these days and I don't feel the cold very much after being such a 'cold frog' in my former life.

A man told my husband his wife has a back injury and one day while sanding the wall for painting he ran the sander over his wife's back as she hobbled past. They discovered a wondrous thing to pass on to us. My husband uses the electric sander (minus sandpaper!) over my back, legs, arms, etc. while I have a blanket over my body. Oh, the relief! We'd tried a borrowed massager, but that hurt me more. However, the sander run lightly over my body for 15 minutes or so is so wonderful for me. One draw-back however is that my body or muscles relax so thoroughly I can't force myself to get up after, I'm too weak and it makes me so sleepy. But it's a QUALITY sleep after. This may not work for all, but it's truly wonderful for me. One man's joke has turned into lovely therapy. We started at 5 minutes or less, the body tells you when it's had enough. I would love it every day, but if I want some hours in the day to do at least something, then I can't allow myself that luxury. Besides my husband's arm can only take so much and the sander has other jobs in the shed. A light blanket is essential to cover myself with as it is too strong over a sheet. For me, anyway.

When I go out in public I find it easier not to deal with people who don't understand my illness. When I am asked how I am, I just say, "No change", and change the subject to their lives. After they tell me how healthy I look! Fat, shiny and healthy! I put on a happy, easy-going, laughing façade, (which wasn't a façade in my past life) and hobble home to die! Just putting on a façade drains me of energy, let alone the pain in walking around! I have to travel everywhere by public transport, so and appointment day is a big day for me. I've been using a walking stick for some years because my balance is not very good and it helps to lean on. The pain in my feet and back and elsewhere is too bad not to have it with wobbling and falling.

I believe that all things that happen to us in life are for a reason, a lesson if you will. Well, I know what it's like to be old, slow, in pain and crotchety and forgetting everything, before I'm old. But if it's patience I've to learn as well then my lesson isn't going to be over for a long time! And even if I did have the where-with-all, I wouldn't know how to dress as a big person anyway (in a flattering way). I like my clothes a little on the unconventional side, but have no knowledge of "slimming"-look clothes, having never had to in my past life. I like a tailored look for conventional, but a bit way-out and unusual for my usual taste. I've lost that and I want it back, I hate being slow of body, but most of all I hate being slow of mind! I hate the pain, the size I am, the isolation, the final having to admit a lot of things are really beyond me, mentally and physically. (I do read at night, every night, though). So I'm left with my worst aspect – impatience and unacceptance. I just cannot "go with the flow".

Thank you for reading this – it has been a mammoth effort.

G

[G – that was a mammoth effort, thankyou for sharing your struggles with all of us. We expect a roaring increase statewide in hardware sales after your massage revelation – Eds]

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Dear Editors,

Firstly, many congratulations to the new Editors and format of your 'Talking Point' magazine. It's a most informative and interesting magazine with a whole new fresh outlook. Your article 'Helpful Hints' is a real benefit to pass on to non-believers etc of C.F.S.

Love your new cover.

Could you please do a report on chemicals & foods in relation to C.F.S. as I feel sure it would be a great benefit too many of your readers?

SP

[Eds – hope we have obliged in part. We really would like to have some people send in their discoveries on chemicals and CFS.]

****

Dear Eds

I am currently on Ampligen treatment consisting of two infusions per week. (Luckily my veins are good) My reading for the R-Nase L protein determination test was extremely high being 52:3 (the normal range is less than 2.0.) Since being on Ampligen my reading has dropped to 3.8. Not everybody is a suitable candidate for Ampligen. The blood test gives a definate reading as to their suitability. Also one must qualify on the Karnafsky score. My reading on the latter scraped in at a mere 20 out of the score of 100 for normal functioning ability. I have slowly progressed to approx 4.5.

In 1993 I got a virus after which I became increasingly more physically debilitated. The last 4 years I have spent in my bedroom racked with horrific pain and numerous

PESTICIDE BLUES

by Peter Evans

Anyone living in Adelaide in recent years probably knows about the Mediterranean fruit fly eradication program. This is the small army of blue overall-clad men, with backpacks of poison and truckloads of toxics, ready to spray at high pressure into your back yard and onto your fruit trees and vegetables. This blanket spraying with organophosphate pesticides is done so that South Australia can sell fruit and vegetables to Europe, while claiming it to be free from Mediterranean fruit fly. If you're lucky, you might see the blue army coming. You certainly won't know where they have left their poison, because they leave no notification.

Unfortunately exposure to these kinds of pesticides can result in acute poisoning, as well as prolonged periods of poor health. In fact, organophosphate exposure is implicated by medical research as a triggering event which may later result in multiple chemical sensitivity. Common symptoms of organophosphate exposure, particularly in the chemically sensitive, are sore throat, asthma or difficulty breathing, skin rash, bloating or gastrointestinal disturbance, concentration and memory difficulties and persistent fatigue - to name a few.

The Department of Primary Industries and Resources insist that its fruit fly program is conducted safely. A recent series of public meetings to discuss the issue took a different view. The tone of the meeting was, at times, quite angry. Many people spoke of the damage that pesticide exposure had caused to their health, some had been hospitalised. There were distressing stories of dying dogs, cats and birds, as well as lost insect populations in organic gardens.

After considerable discussion, the meeting approved a motion to call on the Premier of South Australia to adopt a moratorium on the use of organophosphates and other poisons in the Mediterranean fruit fly program, until they are proven to be safe. In response to this the Government has ceased cover spraying with one of the pesticides, fenthion - for the time being - but will continue baiting flies using malathion, a hormone disrupting pesticide under increasing international scrutiny for its toxic health effects.

South Australia's fruit fly eradication program places people with chemical sensitivities at serious risk of organophosphate pesticide exposure, either from direct contact in treated areas or by spray drift. The program gives little or no recognition that chemical sensitivity even exists. If you have concerns about the way the fruit fly eradication program is being conducted, write to:

The Honorable Rob Kerin MP
Minister for Primary Industries and Resources
GPO Box 668
Adelaide SA 5001

Consumers to get refunds for alleged CFS treatments

aap

A federal court has decided that consumers misled by claims of a cure for ***chronic*** **fatigue syndrome** will be reimbursed.

The Australian Competition and Consumer Commission took PAUL and LINDA STORER to court over their claims about their medical qualifications, and the benefits of using their
health products in isolation.

The federal court in Perth has now found the STORERS made misleading and deceptive claims about their products, OMX probiotics and USANA supplements.

The court has found Mr STORER'S claim to be a doctor with a PhD in microbiology was false.

It also found Mr STORER misled the public with claims that 1,000 published articles supported the use of his probiotics product, and that it had a success rate of 60 to 70 per cent.

The court has ordered Mr STORER to offer refunds to consumers, and to issue prominent corrective advertisements in newspapers.

BE AWARE

The story above should serve as ample warning to all ME/CFS Sufferers to be very careful about people pushing products they have a financial interest in.
See article on page 40 by Professor John Dwyer

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other symptoms including emotional and neurological. I became more sensitive and intolerant of different medications. I have been accused of 'putting it all on.' (as if that is even feasible.) Alternatively it was assumed I had a psychiatric disorder. I now have proof I have an organic physical illness and Ampligen is helping me slowly to get back to being me.

It was a hard road getting Ampligen "Out of the Blue" but believe it or not that is exactly how I got it. I have now been on it for 48 weeks and hope by staying on it longer that I will continue to improve until I can cope.

I still get disheartened when I can't do things or if I've had a bit of an 'up' and then go 'down.' I have yet to find out how this will end up. I hope that I will eventually have more 'ups' than 'downs', and level out eventually.

This ws my only option as no other treatment helped and I have been limited in what my body took and 'rejected.' Not just my health has been destroyed by this, but we have been financially drained, I have been robbed of years of love and joy with my family – unable to function normally as other families do. I hate this illness and my one aim is to find something to stop its devastating effect on its victims and their families. I am testing this Ampligen not just for me, but for all of us – for all of us.

I feel very alone in this and sometimes just want to give up.

M

Disclaimer: Please take note of our full disclaimer on page 2. Mention of particular treatments in Talking Point does not imply a recommendations of them by the ME/ CFS Society (SA) Inc.

ME Plague hits 2500 young Scots

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Scotlands's schools are being gripped by an explosion of crippling M.E.

Charities say a hidden plague of devastating myalgic encenphalomyetis is responsible for more than half of all long-term school absences.

And they say youngsters will continue to suffer because doctors are not doing enough to diagnose the exhausting condition. They have commissioned fresh research which they hope will thrust the issue back into the public health spotlight.

Research by M.E. charity the Tymes Trust found that an estimated 2500 children in Scotland suffer from the illness. The study found 51 per cent of long-term absentees had the debilitating disease.

Victims feel fatigued and get severe headaches and muscle pains. In the worst cases, the sufferer is often laid up in bed for months, too weak to lift their head. But charity organisers are so concerned their findings were not acted on, they are to mount a nationwide study to discover the full extent of the problem.

Former head teacher Jane Colby is chief adviser and children's officer with the Tymes Trust. She said yesterday: "We are fund-raising so we can do fresh research, which will include a study across Scotland. It will be the first major M. E. research done specifically on children. We fear more children are suffering from M.E. and that there is a hidden groundswell of sufferers who have not been diagnosed. Research found it is the biggest cause of long-term absences in school. Nothing compares to it."

Her view is supported by other M.E. charities. Action for ME - a charity founded in Scotland - is campaigning for better awareness of the syndrome. Chief executive Chris Clark said: "It's possible children are suffering from this, but haven't yet been diagnosed. The medical profession isn't very good at tackling illnesses that it can't easily manage and there is no magic pill for M.E. The symptoms of M.E. are worse in children than adults, but, thankfully, children have a better chance of recovering."

Yesterday, Kirsty Strain, 20, described how she descended into a suicidal depression after being struck down as a child. She said: "I lost my youth to M.E. and it made me angry that the condition was not diagnosed sooner. It was also very difficult for my mother. She didn't know what was wrong and no-one could tell her."

Dr Michael Sharp, consultant in psychological medicines at Edinburgh University, admitted there is little research because of the priority given to Scotland's big killers - cancer and heart disease. He said: "There is much more going on in the United States. Over there, Congress has mandated money to be spent on this."

Action for ME have a helpline open Monday-Friday: 01749 670799. The Tymes Trust can be contacted on 01245 263482.

Case Study

Student Kirsty Strain, 20, from Robroyston, Glasgow, began suffering symptoms of M.E. when she was nine. But it took eight years for doctors to diagnose the condition. Her condition improved after consulting a herbalist.

She said: "My mum, Maureen, took me to the doctors, but by the age of 12, I was seeing a child psychologist for depression. I dropped out of school at 16.

Eventually a reflexologist suggested I might have M.E. and I was diagnosed. But I was 17 and my childhood was gone. I was angry at the doctors. Now I'm determined to make the most of my life and I'm studying to become an actress."

ME/CFS Guidelines – Write to your MPs

Facts you and your local member of parliament need to know.

- After much lobbying some 5 years ago the Federal Government funded the Royal College of Physicians to produce some evidence based guidelines to assist GP's with the diagnosis and treatment of people with ME/ CFS.
- We understand that at least $200,000 was provided.
- A number of Drs were co-opted to work on the Guidelines. Ironically very few of them had significant contact with patients with ME/CFS.
- Important researches working in the field were also not included in this group inspite of requests for inclusion. (The Newcastle University group was one such group).
- Various groups went away and prepared their papers including consumers who wrote from across Australia and whose paper was under the management and support of the Consumers Health Forum.
- The Committee was under the control of Dr Robert Loblay and Dr Graham Stewart.
- After a significant period of time the Guidelines were released in Draft form for further comment.
- They were also placed on the MJA website where they still sit years later.
- The content of the document was seriously questioned and the two main areas of concern CBT (cognitive Behavior Therapy) and exercise were contested strongly. Also the lack of weighting given to the consumer perspective.
- It was agreed that a review of the document should take place.
- In the meantime the guidelines sat on the MJA website and were being used by DRS as a basis for treatment and in court cases for the purposes of detrimental outcomes for ME/CFS sufferers.
- ***These Guidelines have no standing; they have never been subject to rigorous peer review.***
- All Drs who formed part of this working group have been contacted by consumer groups and some have expressed concern about both the content and process to which they are party.
- In the later part of last year all parties were advised that A review would take place under the direction of Dr Robert Loblay and that we would have a certain timeframe in which to respond.
- Dates came and went and the matter was not progressed to any visible degree.
- In the meantime patients were suffering at a result of these guidelines being in use.
- The GP community was not being helped with sound information from those charged to do so.
- The RACP and MJA were asked by consumers and others in the research sector to remove the guidelines from the website. This did not happen.
- The National Association lobbied very heavily to have the situation reviewed by the current Minister of Health. He did not even reply or acknowledge receipt of letter. This year, in sheer desperation the National Chairperson contacted Ms Trish Worth MP and eventually a response was received from the Minister.
- ***The Minister has refused to meet with The National Association to discuss this serious matter. The registered office is in his electorate.***

In April our consumer representative [On the guidelines committee] received and email from the RACP which included the following statement :

"Dr Rob Loblay has almost finished revising the Guidelines, and we would like to forewarn you that you will soon be sent the 2nd Draft for your comment.
The College is very keen to complete this project as soon as possible, and therefore we have to work to very short timelines. When you receive the 2nd Draft, you will have one week to provide comments to Rob."

(Who in their right mind would seriously ask any Doctor or professional of any worth to respond to such an important document within one week!!! Especially as it has been years since the last contact.)

- The Consumer representative advised the RACP that a one-month time frame would be manageable.
- In May this request was acceded to however there is still no draft document released for comment.
- Consumer representatives have raised this situation with Government Ministers including the Office of the Prime Minister. There appears to be general dismay about the situation.
- Government employees have used terms such as disappointment, slippage and concern when discussing the matter.

[At the time of publication the ME/CFS societies have just received electronic copies of the guidelines to review – ED]

Armed with the above information, you might like to write to your local and federal members of parliament.

- Take the opportunity to point out the reality of ME/CFS and how it affects you
- Make them aware the ME/CFS Community is appalled at the way the Clinical Guidelines for ME/CFS have been/are being developed – list a few of the concerns outlined such as the lack of peer review, the suspected small number of people actually working on them providing a bias toward the psychological/psychiatric focus of the few key players, and the attempt by the RACP to rush through the guidelines without sufficient time to comment
- Ask for their support to call for an review of these guidelines and how they were developed. Insist that public monies should not be spent on second-rate enterprises, and the RCGP should be called to account for jeopardizing the health of persons with ME/CFS by commissioning such second-rate scientific endeavors.
- Remind them that the ME/CFS community of Australia provides the finances to:
  1. ***1.*** Support sufferers
  2. ***2.*** Educate GP's
  3. ***3.*** Fund research
  4. ***4.*** Provide information
  5. Run medical conferences bringing in world-renowned experts and researchers.

Thanks to Judy Lovett and the National ME/CFS Association of Australia for the information provided for this piece.

Tired for Life

Chronic fatigue syndrome makes life a battle for the people it strikes, writes Matthew Hart

TIRED of being dismissed as little more than lazy or weak, people battling chronic fatigue syndrome believe it is time to put some of their demons to rest.

Despite the condition affecting scores of high profile Australians, such as Brisbane Lions AFL player Alastair Lynch and Queensland ironwoman Linda Halfweeg, public scepticism remains strong, with many dubbing it ``yuppie flu".

But as more than 200,000 Australians can attest, the mysterious condition is much more than the name implies.

There are the joint pains, the headaches, the nausea, the short-term memory loss, and the unrefreshing sleep which make it impossible for sufferers to lead a normal life. And the more active they are, the worse their condition becomes.

``Unfortunately, much of the negative public perception all comes back to the name," says 34-year-old Brisbane lawyer Peter Evans, chairman of the CFS Association of Queensland.

``It's actually a very flu-like illness with headaches, joint pains, sore throats. But unfortunately chronic fatigue syndrome just sounds as though you feel tired, that you're not tough enough, that you're just being lazy and trying to get out of work. The name damns people."

Amid the theories and debate surrounding CFS, there is near unanimous agreement about one thing -- it is an awful name for an illness.

This has prompted advocacy groups around the world, led by those in America, to begin pushing for an official name change which better reflects the true nature of the illness.

They say that not only is the name imprecise but it also carries a negative stigma which affects patients' access to medical care and social services.

Chronic fatigue syndrome is a condition with a diverse range of symptoms but particularly characterised by persistent tiredness which disrupts the ability to carry out normal activities.

Today, there is an internationally recognised list of diagnostic criteria.

Four or more from the following symptoms must be present for at least six months: short-term memory loss or severe concentration problems, mild fever, nausea or irritable bowel syndrome, sore throat, swollen glands, muscle pain, pain in a number of joints, headaches, unrefreshing sleep and severe tiredness lasting more than 24 hours after exertion.

A number of other symptoms are commonly found, such as sensitivity to light, dizziness, irritability, panic attacks, irritable bowel symptoms, menstrual problems, rashes, unexplained weight loss or gain and fever.

Exacerbating the problem is the fact that researchers have yet

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to pinpoint what causes the condition.

There is no known means of transmission for CFS but it appears that acute viral infections can trigger it.

Many people report having a bout of flu which prompted development of the symptoms.

It may often start with a headache and muscle aches and fatigue that don't go away after a week or two like normal flu-like symptoms.

All that has been determined so far is that people with CFS have a higher rate of biological abnormalities compared with their healthy counterparts.

But latest findings by Australian researchers are helping to not only unlock the mysteries behind CFS but also slowly turn the tide of public misunderstanding.

'Unfortunately, much of the negative public perception all comes back to the name'

University of Newcastle researcher Dr Neil McGregor and his colleagues are about to publish a series of papers detailing the effects of a group of enzymes on the immune system's ability to fight viruses.

From data collected from more than 2000 patients, McGregor says about 80 per cent of CFS patients appeared to have anomalies in the enzyme system which inhibits the body's ability to fight off viruses.

He said this anomaly leads to the general symptoms of CFS, such as fatigue and swollen lymph glands.

Other muscular and neurocognitive symptoms reported by sufferers, such as inability to think clearly, muscle pain, mood change, appeared to be the body's response to the first group of symptoms, McGregor says.

``In some ways it is similar to HIV in that the body's immune system is compromised, paving the way for infectious agents, such as bacteria or viruses, to take advantage of the situation."

Dr McGregor says the latest research should end any debate over the authenticity of the disease.

``Once you start looking at evidence you've got that should be a thing of the past," he says.

``We know enough about the problem to document what is going on and once you can do that you know you are dealing with a real condition.

``But it is only once you understand the mechanism that you can make a therapeutic intervention."

Meanwhile, doctors at Brisbane's Greenslopes Private Hospital have discovered a genetic link to CFS after identification of a rare genetic mutation. It is seen as a major breakthrough towards understanding why CFS strikes members of the same family.

In one family at least 32 members who later developed CFS were found to be affected by the gene mutation.

This genetic anomaly affects the body's ability to produce a protein known as cortisol binding globulin (CBG). The protein's main function is to transport the hormone cortisol around to various tissues of the body via the blood stream.

University of Queensland endocrinologist Dr David Torpy says people who inherit one copy of the mutated gene produce only half the normal amount of CBG, and those with two copies of the mutation did not produce any.

``We have found that people with one or two mutations in this family have a marked tendency to develop chronic fatigue and also relatively low blood pressure," he says.

WHILE Torpy believes it is unlikely that the mutation is the only cause of the complex disease, research is now trying to determine the proportion of people with CFS who have the mutation.

``If the CBG mutation turns out to account for even 1 per cent of CFS, then this would be a big advance -- particularly if it is treatable," he says.

After first falling ill in 1994, Evans was forced to stop work completely for 3 1/2 years after finding it impossible to perform physical or mental work.

``It was quite frightening at the time. You are unable to do your work properly and doctors initially can't diagnose you," he says.

At the peak of his CFS, Evans was sleeping 14 hours a day, but over the past seven years he has managed to cut that back to nine hours and can now do some part-time work.

``People think it is trivial and will go away, but it is long-lasting and most people have a long-term problem with it," he says.

``The range of disability does vary across the board, but most people, if they are working or at school, are likely to be weeks off work and well over half will face years off work," he says.

``About 20 per cent of people really have serious problems from physical restriction. They may not be bed bound, but certainly house bound."

Perhaps the most frustrating and frightening aspect of the condition is the way in which it can leave people's lives in limbo, making public understanding of the condition even more important.

``You can't tell anyone they're going to get better," Evans says.

``If you have had the condition for under two years, there is a good chance of coming out of it. But beyond five years, the rate of recovery is much lower.

``But you never give up hope."

The CFS Association of Queensland can be contacted on (07) 3832 9744.

(appeared Thursdaty 31 MAY 2001, Page 13.)

Was it something you ate?

By Sabine Spiesser BS, Grad Dip Dietetics.

Reactions to food

Many people with CFS believe that they react adversely to some foods. Although there are no good statistics about this, the experience of dietitians in the field, and information from the ME/CFS Society of SA, suggests that possibly 20 to 30% of people with CFS are so affected.

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There are many ways that food can cause reactions, including true food allergy, and more commonly, a drug-like intolerance to natural or added food chemicals. Some people with CFS may also experience problems with maldigestion or malabsorption of food.

A true food allergy can be life-threatening in some cases. Most reactions however, are less severe. Neither food allergies nor food intolerances are trivial, as they can cause tremendous discomfort for sufferers.

Types of reactions to foods:

- Food allergy
- Food intolerance or pharmacological reactions
- Histamine intolerance
- Food indigestibility
- Food poisoning
- Enzyme deficiencies
- Coeliac disease
- Food aversion

Food Allergy

A true food allergy (delete is any adverse reaction to a food or food component) involves the body's immune system. Is there a way of simplifying this section? Eg This occurs when a food allergen, which is usually a protein or sequence of amino acids, enters the body and stimulates food-specific antibodies, known as IgE antibodies. These antibodies are located on the outside of Mast cells or basophils, which are part of the immune system, and when stimulated, trigger these cells to release histamine, thereby causing the symptoms. Some allergic reactions can occur when substances attach to proteins and form an allergen, e.g. nickel allergy.

Not all reactions are due to contact with allergens. Mast cells can also respond to other stimuli, such as heat, cold, exercise etc..

Allergens and antibodies are food specific, just as lock and key are specific for each other. The severity and location of a reaction depends on the amount of food eaten, the form of the food, food processing, exercise, and the quantity of histamine and other chemicals released. Sometimes minute traces of food left on equipment or contaminating other foods can cause very severe reactions. Everybody with a food allergy should have a written **INDIVIDUAL ACTION PLAN** developed by their doctor. Do not assume that all doctors are familiar with food allergies, anaphylaxis or other food reactions.

While most allergic reactions to food are relatively mild, a small percentage of food-allergic individuals have severe life-threatening reactions. Anaphylaxis is a rare but potentially fatal condition in which several different parts of the body experience food-allergic reactions simultaneously, causing hives, swelling of the throat and difficulty in breathing. Affected people need to carry syringes loaded with epinephrine (adrenaline) for immediate self-injection (Epi-Pen) as well as medic alert bracelets.

Reaction time varies from a few minutes (early) to a few hours (delayed) to a few days (late response). In anaphylaxis an immediate type of reaction is often followed by a delayed one, making a visit to an emergency centre vital.

Anaphylactic shock is the most severe allergic reaction, involving many organs of the body, including the:

Nose - sneezing, blocking, watering and runny nose
Upper airways - swelling of the throat and vocal cords leading to obstruction of breathing, blue lips indicating oxygen deficiency
Lungs - wheezing and asthma
Skin - itching hives (urticaria)
Circulatory system - a fall in blood pressure and collapse

Food allergies and intolerances can cause range of symptoms in different parts of the body, including :

- Gastrointestinal system: Abdominal bloating, flatulence, cramps, pain, colic, nausea, vomiting, diarrhoea, anorexia (loss of appetite), early satiety, rectal burning, IBS. Food allergy may be a cause in about 10% - 15% of colicky infants.
- Skin: Itchy rash, redness, eczema, hives, welts, local swelling
- Respiratory system: Coughing, wheezing, asthma , nasal congestion, itchy and runny nose, sore throat, hay-fever, difficulty speaking
- Face: Itching eyes, swelling of lips, throat and tongue
- Cardiovascular system: Rapid thumping heartbeat, dizziness, fainting, collapse, low blood pressure, pale & floppy infant
- General: Anaphylaxis, fatigue, fever, flushing, sweating, muscle aches,
- Neurological: Headache, irritability, dizziness, faintness, drowsiness, loss of consciousness, hypoglycaemia type symptoms.

Symptoms of a food allergy are highly personal and usually begin within minutes to a few hours after having eaten the offending food. Immediate reactions are usually obvious, but any other reaction needs further investigation. Usually, people are truly allergic to only one or two foods. Food allergy is more common in children, and many children grow out of their allergies over time.

The most common food allergens are milk, soy, wheat, egg, fish, shellfish, , peanuts, and tree nuts such as walnuts. However, all foods contain proteins, which can potentially act as antigens. Sometimes patients allergic to latex also react to certain foods such as avocados, bananas, kiwis or chestnuts. Reactions are also possible between botanically related or unrelated foods. This is termed Cross-Reactivity.

In Oral Allergy Syndrome, individuals react to uncooked foods with mouth and throat itching or swelling. Fresh fruits, nuts and vegetables are often the culprits. These reactions are brief and believed to be due to pollen protein cross-reacting with proteins found in fruits and vegetables. Often reactions are to other members of the same botanical family. The responsible proteins [profilins] are inactivated by cooking. For example, persons sensitive to birch tree pollen may react to fresh apples. The same people, however, might tolerate cooked apples, as in apple sauce. More serious allergic

reactions can occur, if exercise is undertaken soon after eating a lot of this type of food. Occasionally individuals are allergic to many different fruits and vegetables.

Examples of cross-reactivity:
Exercise Induced Anaphylaxis.
In this condition, individuals develop itching, rashes, angioedema and upper airway obstruction with bronchospasm

Allergen	Foods
Ragweed Pollen	Melons, banana, chamomile
Birch pollen	Apple, carrot, hazelnut, potato, almond
Mugwort pollen	Celery, apple, kiwi
Latex	Banana, kiwi, avocado, chestnut

during or shortly after strenuous exercise taking place within a few hours of eating certain foods. This allergic condition may occur up to 12 hours after eating wheat, celery and shellfish, especially prawn. These patients have no reaction to the foods if at rest.

Food Intolerance

Food intolerance is an adverse reaction to food which does ***not*** involve the body's immune system. These reactions are called "pharmacologic reactions" because the culprit substances behave like drugs, possibly acting on the nervous system. In adults, this sort of reaction is far more common than true food allergy, and seems to be increasing.

The symptoms of pharmacological food intolerance can be the same as symptoms of food allergy eg hives, swelling, eczema, headaches, asthma and other respiratory tract symptoms, bowel symptoms, and cognitive disturbance.

The severity of the reactions depends on the dose eaten, as well as other chemicals consumed at the same time, and other factors such as stress , hormone levels (eg women often are more reactive before menstruation), and use of other medications (especially NSAIDs). Food intolerance reactions can be caused by both added and natural substances in foods. Most people have no problems consuming these natural food substances and additives - reactions occur in individuals who happen to be more sensitive. Reactions are becoming more common to the increased ingestion of these substances in processed foods. Common offenders are:

- **Amines:** histamine, tyramine, tryptamine, serotonin, dopamine, phenylethylamine Present naturally in foods and produced during fermentation, aging and storage in other foods.
- **Salicylates** are aspirin- like compounds present in a wide variety of herbs, spices as well as fruit and vegetables. Reactions to these may be even more common than reactions to artificial colours and preservatives. Salicylates are concentrated in the surface areas of fruits and vegetables and levels decrease as the fruit ripens. Tea contains very high salicylate levels.
- **Glutamates:** (E 620-623) MSG stimulates nerve endings, perhaps accounting for its function as a "flavour enhancer", amongst other properties.. MSG is the sodium salt of glutamic acid, an amino acid found naturally in the human body and in all protein-containing foods such as cheese, meat and milk as well as some vegetables, without causing reactions.
- **Sulphites:** (E 220 – 228) These chemicals are commonly found processed fruits, vegetables, meats/ fish/poultry products, alcoholic and fruit drinks. They are sprayed onto foods to keep them fresh and prevent discoloration or browning. Their use is widespread and cannot be listed here.. Sodium metabisulphite (223) is commonly used as a flour treatment agent.
- **Benzoic acid and Parabens**..(E 210 – 219). Benzoates are both a preservative, and also occur naturally in many plant foods (e.g .berries, concentrated tomato products, spices)
- **Sorbates** (E 200-203) – a preservative used in a wide variety of foods.
- **Food Colourings** (E 100 – 180). This includes all the artificial colours, as well as the natural colour, annatto (code 160b).
- **Antioxidants**: (E 319 - 321) Butylated hydroxyanisole (BHA) and Butylated hydroxytoluene (BHT) are found in high fat foods to prevent rancidity as well as some cereals.
- **Nitrates and nitrites:** (E 249 – 252). Used as a preservative in processed meats and some cheeses.

It can be very difficult for people to identify food intolerances, because reactions can be inconsistent (depending on the dose eaten), can be delayed and build up over many days, individuals can react to several different food chemicals, and each food chemical can be found in many different foods, all contributing to the total dose.

Food ingredients possible of causing allergy or gut irritation

- **Meat tenderiser**, Papain can cause allergy and food intolerance (Processed meat products)
- **Irritant substances** in foods such as p aprika and chilli (capsaicin) or stimulant effects of naturally occurring substances in food such as caffeine in coffee and tea
- **Gums** (E 400 – 418) (agar, guar gum, tragacanth, carragenan, xanthan gum) can cause abdominal distension and bloating when consumed in large quantities

Anaphylactoid reactions to food chemicals are anaphylaxis-like reactions, but don't involve antibodies. Metabisulphite or sulphur dioxide induced asthma is an example of such a reaction

Histamine Intolerance
Histamine, and histamine-like substances called amines, occur naturally in foods, and can trigger symptoms that mimic allergy. This is particularly true of fermented foods that contain high quantities of the vasoactive amines such as Histamine, Phenylethylamine, Serotonin, Tyramine, and Dopamine. Vasoactive substances affect the diameter of blood vessels (vasodilating = widening, vasoconstricting = narrowing) Amines can act directly on small blood vessels to expand their capacity, perhaps accounting for their effects such as flushing, migraines and nasal congestion in some patients. Common symptoms of vasoactive amine ingestion are abdominal cramping, flushing, headache, palpitations and hypotension. The symptoms are usually dose related, and occur when the enzyme that metabolises amines, diamine oxidase, does not work well enough to metabolise the amines ingested, or to handle high levels of amines when eaten in large amounts. Symptoms are worse in sensitive people with low levels of enzymes or if alcohol is consumed at the same

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time. Certain food chemicals such as benzoates, HBA, HBT, the food colour tartrazine, salicylates, nitrates and sulphites can inhibit these enzymes.

Certain non-histamine containing foods, and food chemicals, can trigger direct histamine release from Mast Cells. IgE is not involved in the reaction and specific IgE antibodies to these foods are not elevated. Foods that have been implicated in this type of reaction include: raw egg white, shellfish, strawberries, chocolate, citrus fruit, pineapple, tomatoes, alcohol, fish and pork meat, as well as salicylates and metabisulphites. The histamine liberated in this reaction will cause symptoms that may mimic true food allergy.

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Food indigestibility

Certain food components, when ingested in large amounts, cannot be digested properly and end up in the large intestine where bacteria feed on them. This can lead to bloating, flatulence and diarrhoea. The most common culprits are fructose and the sugar alcohols, sorbitol, xylitol and mannitol.

Food poisoning

Food poisoning is caused by plant toxins such as aflotoxins in mouldy peanuts or soya beans, and bacterial micro-organisms in food, such as salmonella in chicken and bacterial toxins in uncooked meats and certain fish. In some instances, food poisoning can mimic an allergic reaction. For example, in scombroid fish poisoning, spoiled tuna or other fish contain large amounts of histamine produced by contaminating bacteria. When the spoiled fish is consumed, symptoms develop that closely resemble an allergic reaction to food.

Enzyme deficiencies Enzyme deficiencies may sometimes be mistaken for food allergies or intolerances. However, it is important that they are distinguished from food allergies, to enable appropriate treatment.

- Lactase deficiency causes an inability to digest the milk sugar, lactose, causing diarrhoea if too much milk is consumed.
- Sucrase-isomaltase deficiency causes an inability to digest sugars, causing diarrhoea if sugar is eaten.
- G6PD deficiency causes a serious reaction to Fava beans

Coeliac disease

Coeliac disease is an inherited immune disease, which does not involve IgE. In coeliac disease, the intestinal mucosa is damaged (flattened villi) by exposure to gluten, a protein found in wheat, rye, barley, oats, triticale and all their

Foods containing vaso-active amines:

Histamine	Tyramine	Dopamine	Serotonin	Phenylethylamine
Banana Beef Beer Cheese-yellow ripened Chicken liver Egg Plant, Aubergine Fish, all, fresh, frozen, canned Meat, all processed Salami Sauerkraut Soya and Soy products (fermented) Spinach Strawberry Tamari Tomato Tomato sauce, puree Wines , all Yeast	Beans- fermented Beer Bovril, Bonox, Camembert Yeast extracts: Vegemite, Marmite, Cheese-Ripened Chicken Liver Cured, processed meat Dried Milk Egg Plant Fava Bean, Broad Beans Orange, Citrus fruit Pickled Herring Sauerkraut Soy sauce, Miso, Tempeh Wine Yoghurt	Avocado Banana Broad, Fava Bean	Avocado Banana Kiwi Octopus/squid Pawpaw Pecan Pineapple Plantain Plum Tomato Walnut	Cheesecake Cheese-yellow Cherry Mushroom Raspberry Pie filling, Chocolate Cocoa Red wine Redcurrant Pie filling Strawberry, canned
Tryptamine: Cheese, Tomato				
Octopamine: citrus fruit				
Histamine releasing foods: Raw egg white, shellfish, strawberries, chocolate, citrus fruit, pineapple, tomatoes, alcohol, fish and pork meat				
Enzyme inhibitors: benzoates, HBA, HBT, the food colour tartrazine, salicylates, nitrates and sulphites				

REGULAR CHECKUPS

Please remember to have regular medical checkups with your doctor.

ME/CFS does not confer immunity to other illnesses. New Symptoms may not be due to ME/CFS and should be discussed with your doctor.

products. Diagnosis is by endoscopy and biopsy, after screening tests (Antigliadin IgG, IgA and antiendomysial antibody tests). The only treatment is life-long complete avoidance of all gluten containing foods. This is vital in the prevention of gastrointestinal malignancy. Coeliac disease symptoms include diarrhoea, abdominal distension, failure to thrive, weight loss and occasionally nausea and vomiting. Coeliac disease is usually diagnosed in early childhood but may be first diagnosed in adults. Adults can present without the usual symptoms, fatigue being at times the only sign.

A negative small intestinal biopsy rules out coeliac disease if it was done while consuming a high gluten diet. It is still possible to be allergic or intolerant to wheat, and not have coeliac disease, as wheat contains a large number of proteins, every one of them potential allergens.

Food aversion

Food aversion is a psychological condition where a person has a reaction, caused by emotions associated with food. This reaction does not occur if the food is given in a disguised form.

How are food allergies diagnosed?

Food Allergy Testing

The most commonly used diagnostic test in Food Allergy is Skin Prick and RAST (blood test) with Food Allergens. The negative predictive value of food allergy testing is good - if a test is negative, then there is a 95% chance of there being no allergy to that food, but the positive predictive value is less specific - a positive test requires a challenge with the food for diagnosis.

Skin prick tests have no place in the diagnosis of food intolerances.

Food intolerances are diagnosed by an elimination diet, followed by food challenges and gradual re-introduction of foods and food chemicals. Make sure to seek help from a dietitian familiar with this process, and who hopefully is familiar with CFS. The type of elimination diet depends on your symptoms and the severity of your reactions.

Before you make an appointment, be sure to keep a food and symptom diary, preferably in table format. Record every bite and sip crossing your lips. This is most important in tracking possible patterns. It also helps to rate the symptoms, as you can easily forget how severe the symptoms were when you feel better. If you are accurate in portion size and food description, you could have your food intake analysed for nutritional adequacy. It is vital to keep a diary while challenging and re-introducing foods. Always make sure the dietitian is accessible (phone or e-mail) in case you need assistance.

Follow the diet strictly without interruption. If your symptoms do not start to improve within 14 – 21 days, re-introduce foods. You can then eliminate the foods eaten during the diet to make sure they were not the culprits. If symptoms persist, other causes need to be looked into. Some people experience 'withdrawal reactions" in the first week on an elimination diet, but improve after that, so don't give up too soon!. Sensitivity to fumes and other environmental chemicals may also increase during this time.

It is important to emphasize that "elimination diets" are prescribed like we do a medication: short term, under supervision, and only for very good reasons. Long term restricted diets are dangerous and can lead to malnutrition, particularly in children.

(see Sample food diary below)

Treatment

Treatment in food allergies requires the complete elimination of culprit foods, and the use of antihistamines and other medications as prescribed by the doctor. In food intolerance, the reactions are dose dependent, and the tolerance level needs to be established. Fortunately, the tolerance level can gradually be increased over time. It is vital that you seek help from a dietitian in developing an eating plan as well as making food choices to prevent Hidden Food Allergens. Foods labels can contain a variety of names for a specific food. Foods can be contaminated by unknown foods. Never be satisfied with the statement: "you need to just eliminate xyz." Detailed instructions of which foods to include/avoid as well as possible hidden allergen sources are vital. If major foods are eliminated, a dietitian will need to offer advice on how to obtain the missing nutrients.

Websites to browse (see box above)

Books to read:

1. J. Brostoff and Linda Gamlin, Bloomsbury, ***The Complete Guide to Food Allergy and Intolerance***,

(Continued on page 18)

Sample food diary

Time	Food eaten	Amount	Brand names	Medications	Symptoms	Rate				
						1	2	3	4	5

An example: Reaction to green capsicum.

Capsicum contains several possible reactive chemicals: histamine, salicylates, capsaicin, chavicine. There are several questions waiting to be answered:

- Is the reaction due to the chemicals or a true allergy?
- Are there possible cross-reactions with other foods from the same plant family.
- Does the capsicum contain profilins and hence cause cross-reactions to un-related plant foods, pollens or latex?
- Which other foods contain the same chemicals?
- Capsicum in its dried form is called paprika. This spice is added to many spice mixes and processed foods. Which foods could contain paprika ?
- Capsanthin is a paprika extract used in the food industry. What is the most likely use?
- Are there alternative names used in the food industry for capsicum or paprika ?
- How large a dose is tolerated?

Avoidance of "capsicum" is, in practice, not as easy as it sounds.

Websites to browse:

www.allergyfacts.org.au/	FACTS: Food Anaphylaxis Children Training and Support Association
www.allergy.org. au	Australian Society of Clinical Immunology and allergy
www.allergysa.org/	Great website to search for any info related to allergies
www.foodallergy.org/	American organization for patient support
www.celiac.com/index.html	Information and support for coeliacs
www.quackwatch.com/	Dr. Stephen Bennett's website on health quackery
www.docguide.com	Up to date medical information.
http://allergies.about.com/health/allergies/mbody.htm	Lots of links to allergy websites
www.adelaide.net.au/~ndk/no_milk.htm	Information on milk allergy and lactose intolerance

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(Continued from page 17)

London, Bloomsbury, 2000,
2. John Emsley, Peter Fell,. ***Was it something you ate****? Food intolerance, what causes it and how to avoid it.* Oxford University Press, 1999
3. Ardys Zoellner> ***The SNAK*** *(Sensitive New Age Kitchen), 80 recipes FREE of dairy, wheat, eggs & sugar)*- available through FACTS
4. Maurice Hanssen. ***The new additive code breaker***, Lothian books, 1999
5. AR Swain, VL Soutter, RH Loblay. Royal Prince Alfred Hospital Allergy Unit ***Friendly foods***, Murdoch Books, 1998
6. Joan Breakey ***Are you food sensitive?***

The individual action plan should include detailed instructions on….

1. Removing the trigger
2. Giving antihistamines
3. Watching for danger signs
4. When and how to seek medical assistance
5. Injecting adrenalin if needed
6. Resuscitation – first aid course
7. Observation for relapse under medical supervision
8. Written information to inform medical staff.
9. Wearing a medic alert bracelet.

Disclaimer:
This article has been written for people wanting to obtain some general information of food induced reactions. Readers are cautioned against self-diagnosis and self-treatment based on the limited information provided. This article is not a substitute for professional assessment by allergists/immunologists or dietitians. If you suspect that you might be reacting to food, please consult a specialist. No responsibility is taken by the author for the consequences of treatment initiated by patients who have not been seen by me in consultation. The knowledge in this document reflects general current knowledge and may become outdated as new research information surfaces. Many of the symptoms mentioned in the paper are not specific to food reactions, but general symptoms experienced in a variety of organic diseases. I strongly advise individuals to consult their doctor for a thorough medical check-up prior to any further investigation.

Sabine Spiesser is a dietitian with a private practice in Melbourne. Her special fields of interest are food intolerance/allergies, gastrointestinal problems and eating disorders. She has had CFS/FMS for many years.
For appointments please call: Glen Waverley Dietetic Consultancy , Tel (03) 9561 5342
Sabine has just started up her own website:
http://users.bigpond.net.au/allergydietitian/

"Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitating Illness."

written by The Invisible Disabilities Advocate, Sherri L. Connell.

EDITOR'S NOTE

We have been kindly been given permission to print parts 2, 3 and 4 of this booklet. In this issue we'll look at the first half of part 3.

Part 3: "I Never Know What to Say"

It Seems Like I Can Never Get It Right!

Have you ever wanted to encourage someone with a chronic illness, but it seems like you never know what to say? And, when you finally think of something you know will make them smile, they just snap back at you with frustration?

Actually, you are not alone. Most "well" people have great intentions and just want to help; yet, they are left feeling like they can never say anything right. This chapter will give you a sample of what comments are discouraging and what comments are encouraging and why people suffering from these illnesses feel that way.

I Really Don't Understand Where They Are Coming From!

When someone has a chronic illness, the devastation is indescribable. They need others to have an understanding of what they have lost, so it is hurtful for them when others do not. Obviously, no-one can truly understand the depths of the mourning and incredible battles, unless they have experienced them first hand. However, showing compassion for their situation, new limitations and unwanted life changes is not only possible, but it is crucial and absolutely vital!

The intent of this chapter is to list some "do's" and "don'ts" and to explain how some well-meaning comments can be heart-wrenchingly painful to someone suffering from a chronic illness; you may not understand it completely, because you are not the one suffering from a debilitating disease. Yet, if you desire to encourage your loved one, rather than to discourage them... read on

Couldn't I Just Try To "Cheer Them Up?"

Remember, a person who is locked inside a broken body, can sense if you have the, "buck up and live with it" attitude; and, if you tend to blurt out these types of comments, you are only proving your lack of compassion and sensitivity. Most likely, they do have a positive attitude, but don't expect them to always be "happy" about their circumstances! They will smile when you tell them you are sorry for what they are going through, not when you tell them it is "not that bad!" And, they will find strength when they can stop using their energy in attempt to gain your support, because they no longer have to fight your disbelief.

But, I Really Do Think My Suggestions Are Helpful!

I realize that you may honestly mean well and want to "fix" the problem, because you cannot stand to watch your loved one suffer. Therefore, I really do understand your desire to "make it all better" with your advice and well meaning comments. However, the purpose of this booklet is to explain to you why some of the "answers" you have may be hurtful, destructive and actually make you seem as if you really do not care at all.

However, if after reading this booklet, you still feel unable to refrain from the "be happy, because it could be worse" attitude and refuse to acknowledge the tragedy of their losses, please learn to stick with conversation that does not address the illness at all; it is much easier to be around people who do not ask about the illness at all, than people who give pat answers, advice and make hurtful comments.

After all, battling a chronic illness and all of its limitations is difficult enough in and of itself! Your loved one does not need to feel as if they are fighting for your belief, respect and compassion in addition to fighting for their lives!

So, Why Do I React That Way?

There are four basic, natural emotions which occur in response to seeing a loved one become ill. All of these emotions stem from the first stage of tragedy, called denial. Although these reactions are normal, they are often followed by comments which make it apparent to the sufferer that you are not only in denial, but you are refusing to step along side to support them in what they have lost and what they are facing.

Therefore, the problem lies in the fact that, for some reason, loved ones tend to get stuck in the stage of denial and refuse to move on to acceptance. And, this can be quite difficult, frustrating and hurtful, because action, love and practical problem solving cannot take place when a person is still in denial.

1. You truly do care and do not want them to have to go through this, so, you want to fix it, by constantly giving them advice; yet, your suggestions are often impractical or inapplicable and leave your friend or family member feeling like they have to be "fixed," before they are loved.

2. You cannot bear to see them suffer so deeply, so, you try to minimize the severity of the situation, by continually telling them "it is not so bad," "it could be worse," etc; yet, those comments show you are unwilling to really delve into reality, be compassionate and be empathetic.

3. You fear accepting the reality of a disease means "giving in" to the disease, so, you combat your loved one's statements of fact about their illness; yet, by constantly refusing to listen to the information and arguing with their diagnosis, you are refusing to stand by them to help them deal with the illness at hand; and you can't begin to address the illness until you know and accept the facts you are up against!

4. You need desperately to believe you are in complete control of your own health, so, you try to find fault in what they are doing or have done, so you can continue to believe that illness is under your control; yet, this is destructive to

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(Continued from page 19)
treat your loved one this way; they did not ask for the illness and they certainly do not want to have to live their lives with losses, limitations and shattering of dreams!

In all, your reactions have been perfectly "normal," because everyone faces denial when they are presented with a tragic situation, even when it is not directly happening to them. Yet, when you continue to tell them they have to be "fixed," act like their losses are "no big deal" treat them like they are "at fault" and refuse to "accept" the facts, they will be left feeling alone and isolated in their battles.

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Therefore, it is time to move on to acknowledgement and acceptance of the facts, so that you can be supportive, deal with the illness at hand and be a source of strength to your loved one. Again, do not worry that accepting the situation means "giving into" the illness or "giving up!" Instead, what it really means is that you are willing to stand by their side, love them and help them overcome the obstacles.

This will not make your loved one want to quit, it will make them want to fight even harder! And, it only means that you are showing your loved one that you, too, mourn their losses and limitations; by doing this, it becomes apparent that you truly care, respect their feelings, believe their word and are standing beside them in support!

What "Discourages" A Chronically Ill Person?

1. Do Not Treat Them Like They Have Chosen To Have The Disease: "Why didn't you..." "If you would have..." "If you really wanted to work, you would." "If you really wanted to be well, you would be." Tragically, most often when a person suffers from a chronic, debilitating illness, they are treated as if their situation is of their own choosing. And, they are told if they would just try harder, have a better attitude and use "mind over matter," they would not be suffering. This is incredibly insensitive, because if you look a little harder, you will see that they are fighting this illness every step of the way with courage you may never experience! Therefore, treating them as if they have "chosen" to have this illness and have "chosen" to quit taking part in activities, is both destructive and outrageous!

You could not imagine saying to a person who is confined to a wheelchair, "you just don't want to walk," or, to a person having an epileptic seizure, "stop it, you can control it if you want to, " or to a child dying from Leukemia, "you just don't want to be like other kids, playing, having fun and living a full life." So, why would you say to someone stricken with a debilitating disease, " you just don't want to work," or "you just don't want to go to the church function," or "you just don't want to play outside with your children?"

2. Do Not Expect Them To Be Happy They Are Ill!

"Cheer up!" "Be positive!" "Look at the bright side!" "You are doing great!"

Give them a break! They are imprisoned in bodies that won't allow them to live their lives the way they grew up dreaming they would live them. They were forced to give up careers, friends, hobbies and often raising children! They have even had to forgo life's simple pleasures like dusting furniture, making meals, going shopping and showering every day!

Yes, they should be able to laugh and get some enjoyment out of life and that is what they strive to do, every single day! In fact, your visits, playing games and watching movies often affords them that joy; but, please don't expect them to speak of their illness, and all of the loss it has caused, as if it were a blessing. You don't need to point out "the bright side," they will find it on their own, when you stand by them with compassion!

3. Do Not Assume Or Put Words Into Their Mouths:

"You look like you are feeling well!" "You must be doing better!" "You must be having a good day!" "You're doing better, aren't you!" This shows you don't really want to ask how they are doing, because you don't really want to know how they are doing; instead, you want to tell them how they are doing; and, you want to tell them they are doing fine! Prove to them you honestly care, by asking them how they are doing and being prepared to accept the answer, even if it is difficult for you to hear.

4. Do Not Disagree With Them, Because You Can't See It:

"But, you don't look sick!" "But, you look like you feel good!" "But, you look good!" "But, you are here, so you must be doing well!" "But, you look fine to me!"

Often someone will take the time to ask with all sincerity what it is really like to have a chronic illness and what the person is going through. This makes them feel loved and truly cared about until after they explain their situation, you oppose what they are telling you.

When you say things like, "but, you don't look sick," you are really saying, "but, I don't care what you are telling me, because I can't see it, so I don't believe it." They are being honest with you, try to believe in them and be strong for them! After all, when you treat someone like you do not believe what they are saying, aren't you calling them a liar? You do not really want to call your loved one a liar, do you?

5. Do Not Disregard Their New Limitations.

"Come on... you can do it." "It's not that hard." "You always say, 'no'!" "Aren't you better off when you push yourself?"

If you broke your leg, would you be better off hopping on it or using crutches? If you had major surgery, would you recover better if you went hiking or if you rested in bed?

Your loved one is naturally going to push themselves too hard, because they want to live their lives and accomplish goals. Yet, after being very ill for a while, they will begin to learn how to "juggle" their efforts and they will discover what and how much causes them to collapse. So, if they have to say, "no" to you, it is not because they want to; it is because they need to!

6. Do Not Point Out What They Least Have:

"At least you have..." "At least you can..." "At least you're not..."

Believe me, they are well aware of what they "least have." In fact, because of their situation, they often count blessings you never even thought of! For instance, when was the last time you were elated that you made it to the bathroom in time? And, have you ever thanked God that you had the energy to clean off your nightstand? And, when did you ever lie in bed counting your blessings, because you took a

shower AND made dinner all in one day, even though you are lying there in horrific pain, feeling like you are going to die?

So, please don't treat your loved one like they have not been thankful for everything they "least have;" I can guarantee they have been grateful for things that you don't even blink an eye at and take for granted every day!

7. Do Not Minimize Their Situation:

"It is not that bad!" "It could be worse!" "You're lucky you don't have to work!"

Trying to act like having lifelong hopes, dreams and desires stolen away by a disease is "no big deal," is not only extremely hurtful, but ridiculous! Unless you are in their shoes, you have no right to tell someone "it is not that bad," when you are sitting there knowing you can get up the next day and reach for your goals.

And, it can always "be worse" for anyone in any situation, you can always find someone who is worse off, no matter what; but, really now, how does that make their losses go away? In fact, you are asking them to discount their own losses and battles to give someone worse off all of the compassion, when you yourself are not doing that for your loved one who is worse off than you!

In addition, most people mourn the loss of being able to go to work, because it provides an environment for personal accomplishment, social interaction and goal structure. So, telling them they are "lucky they do not have to work," does not make any sense; they did not give up their career, because they "do not have to work," they were forced to stop working, due to a debilitating illness!

8) Do Not Act Like You Can Relate:

"I know what you mean, I'm always tired, too." "Join the club." "Ya, I can't get anything done, either." "Hey, I would like to have a maid, too."

If you do not have a chronic illness, you do not know what it means to be sick all of the time! For some reason, people tend to think that if they do not show they can empathize, then they cannot show compassion. Yet, in this situation, it backfires, because you cannot empathize!

Many sufferers resent comments like, "join the club," because the well person does not have the right for one minute to think they are in the same boat. If a friend is exhausted at the end of the day, I will give them all of the compassion they need; but, when they try to tell me they feel the same as I do, I have to draw the line.

You see, a well person may be extremely tired, but why? Because they got up, took a shower, got dressed, fed their kids, went to work, accomplished goals, ran some errands, car-pooled their kids, made dinner, went to a social event, etc. A person with a debilitating illness spends their day feeling achy, nauseas, exhausted and pushes themselves around to accomplish big things like going to a doctor's appointment.

No, we are not part of your "club." Because in your club, you are able to chase your dreams, raise your children, participate in social functions, enjoy a career, go to the grocery store without a thought and make meals for your family. You may be tired from running around and living your life, but we are sick, from nothing worth while at all!

9. Do Not Act Like Fixing The Problem Is Simple:

"Why don't you just..." "Why can't you just..." "Why can't they just..."

At the very moment a person becomes ill, they start searching out ways to get better... they see a doctor, they take vitamins or medications and they try to rest... then, when the illness does not seem to go away, they see the doctor again... then they see another doctor... then they have tests done... then they lose more time from work... then they spend more money on medical bills... then they get a diagnosis or are told the doc doesn't know what is wrong... then they start researching their illness... then they search out doctors who want to help... then they believe the medicines will work... then they become distraught when the symptoms don't go away... then they go back to the doctor... then they have more tests... then they get more medications that don't work... then the doctor says there is nothing more to do... then they go home and do more research... then they find people who are suffering with the same things... then they try everything else other people are trying... then they keep trying, keep researching, keep looking, keep hoping, because they do not want to live this way!

So, there is no "why don't you just..." "why can't you just...," because they have already just... over and over and over again for months or even years. And, guess what? As long as they are conscious, they will keep trying, searching and hoping, because no one wants to live a life of broken dreams!

The second half of Part 3 will appear in the next issue.

"I Never Know what to say" was written by The Invisible Disabilities Advocate, Sherri L. Connell. It is Part 3 of Sherri's 40 page booklet, "Helpful Hints: A Guide to Understanding, Supporting and Encouraging People With Chronic, Debilitating Illness." To order this booklet, please send US$5 each (includes postage from the US, discounts available for 15 or more). Make the check payable to W. Connell and send to: IDA 41553 Madrid Drive, Parker, CO 80138.
Visit IDA's website at www.InvisibleDisabilities.com!

EDITORS:

Tell us what you think of this part of "Helpful Hints". Did you relate to it? Has it helped you explain things better to friends/ relatives? Are there additional points you can think of? If so, please send them in to us.

DEAR CFIDS/FM FRIENDS

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06-15-2001

Dealing with our diseases on a day to day basis, how many of us have times when we feel worthless? I know I sure have those days. Just yesterday, I had to call my doctor about something, and I was napping when he returned my call. When he commented that I sounded kind of sleepy, instead of saying I was napping, I said I was being lazy. My self-talk told me that I was worthless, because I was not doing something the world would see as worthwhile. I said it even though I'm sure my doctor would have supported the idea that napping is something I need to do.

Recently I got an email message from a friend that made me think about my value. Perhaps it will give all of you something to think about too.

"PRICELESS: A well-known speaker started off his seminar by holding up a $20 bill. In the room of 200, he asked, "who would like this $20 bill?" Hands started going up. He said, "I am going to give this to one of you, but first, let me do this" he proceeded to crumple the bill up. He then asked, "who still wants it?" Still the hands were up in the air. Well, he replied, "what if I do this?" he dropped it on the ground, and started to grind it into the floor with his shoe. He picked it up, now crumpled and dirty. "Now, who still wants it?" Still hands went into the air,

"My friends, you all have learned a very valuable lesson. No matter what I did to the money, you still wanted it, because, it did not decrease in value. It was still worth 20 dollars. Many times in our lives, we are dropped, crumpled, and ground into the dirt by the decisions we make and the circumstances that come our way. We feel that we are worthless. But, no matter what has happened or what will happen, you will never lose your value, dirty or clean, crumpled or finely creased, you are still priceless to those who love you. The worth of our lives comes not in what we do or who we know, but by who we are. You are special. Don't ever forget it! Pass this feeling on to those you care about. You will never know the lives it touches, the hurting heart it speaks to or the hope that it can bring. Always count your blessings, not your problems."

I don't know who this speaker was, as there was no identification included by the friend who sent it to me. In fact, I got a couple of versions, and I suspect it is just one of those stories that wander the Internet. But it makes an important point. Each of us is priceless, to our selves, to our loved ones, and to those individuals we may touch as we make our way, however carefully, and painfully, through our lives.

Remembering that I am a valuable person has been much more difficult since I had to leave my job as a nurse. Certainly, losing the financial support has been an issue, but not the biggest one. I always said that if I ever became a nurse who no longer had feelings, for, and with her patients, I would leave nursing. Fortunately, that never happened for me. I had all the same love for my patients, whether easy to love, or difficult, that I had when I began as an idealistic student nurse over 35 years ago. The job situation could be frustrating, but I always got a lot back from what I was able to give my patients, in physical care, and emotionally. It took a toll on me, yet it was worth every tear I shed over the years.

I am trying to learn that my value is in how I share myself, rather than how much I am able to accomplish. I can stay in touch with friends and family, and support them in their celebrations, and their times of difficulty. I have the privilege of writing this column and answering your letters, hopefully providing some support for those of you reading. I know I enjoy hearing from you, in your accomplishments and defeats.

My ways of finding value in my life have changed, yet most days I am able to find that value. I have to remind myself that negative self-talk, i.e. "I'm being lazy" is damaging to me. I need to remind myself frequently that although I am not able to contribute to society in the way I used to, that does not make me of less value as a human being. I have to remember that things of value are taken care of. That means taking care of myself in the best way possible. Napping is taking care of myself, not being lazy.

Each and every one of you, no matter how crumpled and creased, no matter how much fatigue or pain you endure, are of value. You deserve to be taken care of, most importantly, by yourself, and by your loved ones. Try to remember that each of you is priceless, and treat yourself appropriately. Take care and be well.

Yours in health,

Eunice Beck

Reprinted with permission of ImmuneSupport.com, the largest Web site dedicated to Chronic Fatigue Syndrome and Fibromyalgia. Eunice writes regularly for them.

ME/CFS AWARENESS

Imagine a pain so severe that nothing is of comfort. Un-able to sleep; as bones dive through your skin, with every toss & turn.

Imagine waking up, not being able to walk. So tired; you¹re un-able to speak, nor comprehend. Everything hurts.

Imagine no one believes! Relying on your own ability from one moment to the next, is no longer your option.

Imagine having the flu for twenty years. Enjoying life's pleasures only once or twice a year; when you are able to fake it!

Imagine a life robbed; each day gets dimmer. Days turn to night. And, the fog like the Bay sets in - never clearing the way..

Imagine a world where there is no one around, but you.. in your bed with only your thoughts & memories; of who you once were.

Imagine your only joy in life is an occasional phone call, or the UPS man stopping by for a signature.

Imagine taking a shower, and feeling as though you accomplished a new worlds record. Then, calling it a day.

Imagine a life filled with so much pain; tears just roll down your face. A life without comfort. A life filled with fear.

Imagine living in your head, because it's the only place you can walk to... besides; you'll never get lost on your way back.

Imagine watching the world pass by, without so much as a glance... Youth turns it¹s back; while life passes in the night.

Imagine having to ignore all of this, so you don't concern the only ones that are still left to care. God Bless you!

Imagine being 35, and still 'looking good' so you are told, but that doesn't change a thing.. imagine being me!

or close to the million others who suffer daily with CHRONIC FATIGUE SYNDROME

How long must we suffer?

Retired in 1996, at the age of 33, as a Graphic Designer & co-owner of a Publishing company. Still suffers from Chronic Fatigue Syndrome, since 1984. And, remain fully disabled at this time.

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Row-a-thon Fundraiser support

The University of Newcastle Boat Club (NUBC) organised a marathon row on Sunday the 10th of June, to raise money for scientific research in the fields of chronic pain and fatigue, as well as for the development of the rowing club. The course was an estimated 40 Km along the Hunter River, starting at the Newcastle Rowing Club based in Newcastle Harbour, and finishing at the Endeavour Rowing Club at Berry Park. This stretch of river is remarkable for it's length and relatively few tight corners. Several crews took part in the event, including a mixed eight, two quads, two doubles and a single scull.

Dr Hugh Dunstan, a member of the Collaborative Pain Research Unit (CPRU) at the University, took part as a member of the "eight" crew. The course took the rowers along striking contrasts in scenery varying from the heavy industry around the harbour to beautiful natural vegetation and rural settings along the river. The row took just under 5 hours to complete and included rest stops for hydration and energy intake. We calculated that it required more than 5,500 strokes to complete the gruelling event! The event was extremely successful in raising awareness of chronic fatigue and pain illnesses with articles appearing in the Newcastle Herald, The Sunday Magazine, local newspapers, and interviews on ABC Radio and NBN Television News. We have raised approximately $3,000 dollars so far and we are still receiving sponsorships and donations.

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The event was so successful that the NUBC would now like to consider promoting this marathon next year as a formal time-trial competition based on the famous Boston Marathon held annually in the UK. They have called for expressions of interest, and the opportunity now exists to develop an annual major fund raising event for chronic pain and fatigue research.

If anyone would like to contribute to the fundraising effort, please send sponsorships by the end of July, 2001, to Sandra Dimmock, School of Biological and Chemical Sciences, The University of Newcastle, Callaghan, NSW 2308.

ME/CFS Conference: Funding Required

The Alison Hunter Memorial Foundation, with the support of the ME/Chronic Fatigue Syndrome Association of Australia and all state ME/CFS societies, announces:

The Third International Clinical and Scientific Meeting for ME/CFS - Collaborative Research Symposium 30 November 2001 - Conference for Medical Practitioners 12 December 2001

Professor Anthony Komaroff, Harvard, will be the key note speaker. He has a long-standing commitment to ME.CFS research, particularly chronic 'post-infectious' fatigue syndrome, with a wealth of publications in esteemed journals. Professor Komaroff has had a significant role in the reinvigorated US Centers for Disease Control and Prevention (CDC) CFS Program. Eminent international researchers also participating will include Professor Peter and Dr Wilhemena Behan, University of Glasgow and Professor Kenny De Meirleir, Vrije University, Brussels.

These meetings aim to improve equity of access and quality of care for people with ME.CFS by - providing the latest scientific information and identifying opportunities for researchers and clinicians to work collaboratively; and - targeting areas for the provision of care and services, responsive to the needs of people with ME/CFS and their carers.

This meeting depends on receiving adequate funding and all donations, large or small, will be greatly appreciated.

Cheques to be sent to (your local society) and, for tax deductibility, made payable to 'M.E./Chronic Fatigue Syndrome Society of Victoria Incorporated' who will direct all monies to the Alison Hunter Memorial Foundation Conference Fund.

Donations will be acknowledged in conference abstracts and proceedings published after the conference. "

Exciting Work being done in Adelaide on cerebral blood flow

SPECT SCANS?

S.P.E.C.T. stands for single photon emission computerised tomography. It is an imaging technique that measures the emission of photons of a given energy from radioactive tracers introduced into the body.

Work being conducted in Adelaide using this technique is able to determine the blood flow to different areas of the brain. This sort of research had been/is being done all round the world – but now with more accuracy than ever. We are very lucky in Adelaide that the QEH has (one of only three in Australia) a state of the art scanning machine. These new machines provide a new level of accuracy in measurement to the point where significant results can be obtained where previous tolerances failed to produce clear results.

Pilot tests on FM and ME/CFS patients show a specific area (different for each illness) of the brain which appears not to receive the same blood flow as in 'healthy' people. It is still very early days but if monies can be raised to do big enough studies, and the results prove conclusive, we may have found a piece in the elusive puzzle of a diagnostic test. It is worth our attention.

Following is a commentary on the FM study which started this all off in Adelaide.

Eds

South Australian Fibromyalgia research: New discoveries about cerebral blood flow

In the largest project of its kind yet published, a team of Adelaide scientists used improved statistical brain scanning techniques to measure blood flow to the brains of women with Fibromyalgia. The researchers not only confirmed previous findings of reduced cerebral blood flow in FM, but with more accurate methods they were also able to pinpoint decreased activity in a previously unsuspected area of the brain.

JENNY FAULKNER of Fibromyalgia SA interviewed Dr Richard Kwiatek, head of the research team, in order to write this article explaining the significance of the results.

Congratulations to South Australia on the long awaited publication in December 2000 in the premier international rheumatology journal Arthritis & Rheumatism of world class seminal research into basic brain processes underlying fibromyalgia, conducted by the Departments of Rheumatology and Nuclear Medicine at the Queen Elizabeth Hospital (QEH), Adelaide.

This was the culmination of four years' dogged work in a study without any official funding. By performing a SPECT scan (which measures regional blood flow) and MRI scan (which measures structure) of the brain of each participant, the QEH team discovered that blood flow in the brain stem -- the primitive "reptilian" part of the nervous system that connects the brain to the spinal cord -- in 17 women with fibromyalgia (FM) was reduced by an average of 12% when compared with that of 22 age- and education-matched healthy women.

REGIONAL CEREBRAL BLOOD FLOW IN FIBROMYALGIA:

Single-Photon-Emission Computed Tomography Evidence of Reduction in the Pontine Tegmentum and Thalami

[Clinical Science] (ABSTRACT OVER PAGE)

Originally the study was done to see if the findings of a study of the University of Alabama at Birmingham, published in 1995, could be replicated.

Improved methods

The QEH study used the state-of-the-art technique of Statistical Parametric Mapping on the SPECT scans to screen the whole of the brain for difference in blood flow between FM subjects and healthy controls. In fact the QEH team improved the technique for the purposes of this study by using the average of the SPECT scans of all the healthy controls.

The previous finding of blood flow reduction in the thalami, important relay-stations deep within the brain, were confirmed, but reduction in a region of the brain stem known as the pontine tegmentum was also demonstrated, the brain stem being an area never before investigated.

Moreover, the QEH research team confirmed their own findings by re-analysing the suspicious regions within the SPECT scans by discovering a way of aligning each participant's SPECT and MRI scans in cyberspace more accurately than ever done before, again from the average of all the SPECT scans of the healthy participants. The borders of structures of interest were then drawn on the MRI scan and thereby automatically drawn on the aligned SPECT scan, yielding an accurate measure of blood flow for the area of concern.

A surprise result

Reduction in regional blood flow presumably means the nerve cell activity in the region of interest is reduced, ie nerve cells are under-active. As explained by Dr Richard Kwiatek, head of the research team, other evidence suggests that the reduction in blood flow in the vicinity of the thalami in FM is probably a non-specific response of the body to chronic pain of any sort. The reduction within the pontine tegmentum was a surprise, said Dr Kwiatek. Circumstantial evidence suggests that the reduction here is a true reflection of reduced nerve cell activity, but the problem is that FM is classically regarded as not having any associated "objective" abnormalities on both neurological examination and standard neurological investigations.

Therefore the question is: what does this blood flow reduction mean? - not least because, as Dr Kwiatek explains, the precise location of the deficit is not currently recognised to be part of the well-known system within the brain stem which modulates pain messages as they travel up from the spinal cord through the brain stem on their way to higher brain centres.

(Continued on page 26)

A clue, says Dr Kwiatek, might come from recent brain imaging studies investigating the chronic fatigue syndrome, which have also shown reduction in brain stem nerve cell activity in a similar, but to date less precisely defined, area.

Physiological abnormalities

However, the point is that all studies so far published are unable to tell if the blood flow and/or nerve cell activity reduction is the cause and/or effect of the FM or CFS syndromes. More work is definitely needed, but Dr Kwiatek says the demonstrated defects within the brain stem offer tantalising suggestions as to where future research into these syndromes should be directed. He explains that the brain stem controls basic vital functions of the whole body, which could be critical in the development of the devastating syndromes of FM and CFS with their protean and multi-system symptoms.

Moreover, he suggests that the work of the QEH team can be regarded as contributing important additional evidence that physiological abnormalities do occur in FM; although confirmation that the blood flow deficits are unique to the FM state and not a non-specific response to chronic pain, chronic sleep deprivation or any other of the non-specific symptoms of FM is still needed.

Community support and co-operation

Fibromyalgia SA was intimately involved in the QEH research team's efforts both through direct support and through most of the FM participants being associated with the organisation's predecessor, the Fibromyalgia Interest Group.

Several of the healthy controls were individually recruited by FM subjects, but due acknowledgment is needed of the many otherwise unrelated healthy women who selflessly and courageously answered a local press advertisement to be involved (from as far afield as Mt. Barker and beyond!). All of these women can be proud to know that their involvement has led to significant advances in SPECT brain scanning methods, and that they have potentially contributed to a major advance in understanding the basic disease processes behind FM.

In fact Dr Kwiatek states that publication of the QEH research team's work satisfyingly demonstrates how much can be achieved, despite few financial resources,through careful strategic planning, intelligent insights and generous cooperation between multiple disparate groups, both professional and community-based.

He claims that the achievements of the South Australian group are even more significant as the QEH's study represents the largest published functional brain imaging study in chronic unrelenting pain, involving probably the largest homogeneous healthy control group. The SPECT scans of the healthy control subjects are already being anonymously used by several international centres as controls for other studies, in addition to having led to several significant advances in the analysis of SPECT brain scans.

South Australia can therefore be proud of what it has achieved. As has already been commented, it has elegantly applied and developed techniques of the United Nations' Decade of the Brain (1990-1999) to a problem which will hopefully become an increasing initiative of the United Nations' Decade of the Bone and Joint (2000-2010).

- January 2001

Reprinted with permission from "FM Tender-Points" the official newsletter of Fibromyalgia SA . To contact Fibromyalgia SA write c/o the Arthritis Foundation of SA Inc., 1/202-208 Glen Osmond Road, Fullarton SA 5063. Phone (08) 8379 5711, Freecall 1800 011 041.

ABSTRACT: Regional cerebral blood flow in fibromyalgia: single-photon-emission computed tomography evidence of reduction in the pontine tegmentum and thalami.

Kwiatek R, Barnden L, Tedman R, Jarrett R, Chew J, Rowe C, Pile K.

The Queen Elizabeth Hospital, Adelaide, Australia.

OBJECTIVE: To determine whether regional cerebral blood flow (rCBF) is abnormal in any cerebral structure of women with fibromyalgia (FM), following a report that rCBF is reduced in the thalami and heads of caudate nuclei in FM. METHODS: Seventeen women with FM and 22 healthy women had a resting single-photon-emission computed tomography (SPECT) brain scan to assess rCBF and a T1-weighted magnetic resonance imaging (MRI) scan to enable precise anatomic localization. Additionally, all participants underwent 2 manual tender point examinations and completed a set of questionnaires evaluating clinical features. SPECT scans were analyzed for differences in rCBF between groups using statistical parametric mapping (SPM) and regions of interest (ROIs) manually drawn on coregistered

MRI. RESULTS: Compared with control subjects, the rCBF in FM patients was significantly reduced in the right thalamus (P = 0.006), but not in the left thalamus or head of either caudate nucleus. SPM analysis indicated a statistically significant reduction in rCBF in the inferior pontine tegmentum (corrected P = 0.006 at the cluster level and corrected P = 0.023 for voxel of maximal significance), with consistent findings from ROI analysis (P = 0.003). SPM also detected a reduction in rCBF on the perimeter of the right lentiform nucleus. No correlations were found with clinical features or indices of pain threshold.

CONCLUSION: Our finding of a reduction in thalamic rCBF is consistent with findings of functional brain imaging studies of other chronic clinical pain syndromes, while our finding of reduced pontine tegmental rCBF is new. The pathophysiologic significance of these changes in FM remains to be elucidated.

Source: Journal of Arthritis & Rheumatism, Volume 43(12) December 2000 pp 2823-2833

Dealing with chronic severe pain (From a Sufferers Perspective)

by Kit

Kit first shared her pain story with fellow members of the OzME mailing list. Later the story appeared in Chameleon *magazine, and she also kindly gave me permission to post it here. Kit warns: "I have no medical qualifications, and what I write is based on my own experience and what I have read on the topic."*

The effects of chronic severe pain

As a support group leader I have come to appreciate that I can't help others in my support group unless I honestly acknowledge the devastation and debilitation of living with constant, 24-hour-a-day pain. Sometimes I find it helpful to relate some of my experience, as this often encourages people to share their own experience and, sometimes, their desperation for help. Silent desperation is deadly. From my experience as a Lifeline telephone counsellor (some years back now), silent suffering frequently contributes to suicidal ideation.

And don't forget the carers either! Think about it. The person you love so dearly is suffering constant severe pain - and you often feel that there's absolutely nothing you can do about it. You may feel helpless, frightened, agitated etc. So remember that pain reaches well beyond the boundaries of an individual.

CFS and FMS patients all experience pain in one form or another. It may not be global myalgia (muscle pain) or arthralgia (joint pain) as in FMS, but headaches, migraines, lymph node pain, sore throats ... these are all pain (and all sub-criteria of the research diagnostic criteria for CFS). Then there is also temporomandibular joint pain (TMJ), myofascial pain, muscle fasciculations, and the severe pain that can be associated with irritable bowel syndrome (IBS). The list goes on.

In the recent Quantum program about chronic pain research, I found the following comment particularly interesting, as it rings true with my personal experience as well:

> "There's growing evidence that prolonged severe pain can diminish or kill pain inhibitors - the body's volume control on pain. If inhibitors are out of action, there's no way the nervous system can regulate pain reaction levels." (see note)

There have been times, like this week, when the pain (tonight it's in my legs) feels like a constant, low-level electric shock running through every nerve. It's similar to the feeling I got once when I once touched a tap that was "live" (after I flooded the bathroom!). Naturally I removed my hand fairly smartly. But what do you do about it when it's a pain that lasts for days or weeks, months or years ... and you have no way of physically removing yourself from it?

Convincing your GP to take your pain seriously

In my experience, some GPs (even some who are otherwise "simpatico" to ME/CFS/FMS sufferers) are too quick to tell their patients, "Oh, the muscle and joint pain? That's just a part of the condition." To me, pain is never "JUST" anything. However, doctors can be extremely cautious/circumspect about prescribing pain medication. Doctors must comply with government regulations (especially concerning S8 prescriptions) and must be vigilant in maintaining good clinical practice in the use of pain medication (for clinical reasons, as well as legal ones).

So we, as patients, have to be insistent. If you have 50 symptoms, but pain is the number one worst thing you experience ... don't go and tell your GP about the pain in the middle of a list of the 49 other symptoms, or your GP is likely (understandably) to assign pain the same level of importance (in treatment priorities) as all the other 49 symptoms.

When I talk with CFS/FMS sufferers who are suffering severe, intractable pain, I suggest that they go to their GP and ONLY tell them about the pain ... and give examples of how it directly impacts what they can and can't do in daily life. Your GP is not **able** to observe the effect it has on you **on a daily basis**, so you have to draw them a picture. They can't "see" your pain. But they will understand it better if they realise how it is affecting your quality of life.

If you feel it will help, get a calm, objective family member to accompany you, so that they can tell the doctor what they have observed about the impact that pain has on your life and your well-being (emotionally as well as practically). This can be especially helpful if they knew you before you became ill, and can tell the doctor how you are now in contrast to how you were when you were well.

I was fortunate enough to have a GP who had known me for many years before I got CFS/FMS, so he could see the difference for himself. I remember, about 6 months into my (effective) pain management, he looked at me thoughtfully and said, "You know what, Kit? You're back! You're really back! This is the Kit that I know and love. It's SO good to see that sparkle and fun in your eyes again". (An emotional moment for both of us. As you can probably tell, my GP and I are very good mates, and I love him dearly!)

So, with your GP, if pain is the number 1 symptom for you, give it the centre stage ... and this will help your GP to understand that it REALLY is a significant problem and requires treatment. Also, bear in mind that treatment options that you try out with your GP will probably follow a fairly systematic progression starting with non-medication options. You will probably have to try out a number of pain management options until you find one that works for you. You should also realise that finding a solution for your pain management is going to take some time. (Believe me, you don't want to start with the "big guns" if you don't have to ... too many side effects.)

Finally, pain "relief" is not the same as pain "absence". You shouldn't expect that any treatment will completely eradicate ALL the pain that you experience. It doesn't work that way. I still have a certain level of pain ... but now I also have a life (and a satisfying, fulfilling one at that)!

Developing a pain management strategy

I now have a whole strategy for pain management, and medication only forms part of it. This strategy includes:

- distraction / other activity
- meditation & relaxation techniques
- massage and osteopathy
- heat packs, warm bath *or* cool packs (whichever is appropriate)
- gentle stretching

(Continued on page 28)

(Continued from page 27)

- NSAID topical ointments (as required)
- pain medication (some daily and some as required for severe pain "spikes")

You'd be surprised how effective the first item, distraction, can be! If I can become "absorbed" in a good book, or talking to a friend on the phone, or doing some email correspondence, or even playing a mindless computer game ... then my mind doesn't have as much ability to "concentrate" on the pain. (I no longer have the same capacity for concentrating on more than one thing that I had before I got CFS/FMS!)

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Regarding sudden, very severe, acute pain: I steer clear of medication if I have this kind of pain (though I'll try all the other strategies). This kind of blinding pain, especially if it's not something that I've experienced before, is my body's way of telling me that something is not right. It stands to reason that, if I "smother" it with medication I will have no way of telling if it's getting worse, or if the pain is significant enough for me to consider getting it checked out at Emergency. In the past I've had some events that have required urgent medical attention ... and the only way I knew something was wrong was from the sensation signals I was getting from my body.

The social stigma of some pain medications is certainly a contributory factor to untreated pain and should not be ignored. However, don't let your decision (in consultation with your GP of course) be determined by social "judgements" ("What will people think!?"). Discuss any proposed medication treatment with your doctor and ask as many questions as you need to until you understand what the pros and cons are for this treatment. What are the possible side effects? How can you differentiate between these side effects (if they occur) and the symptoms associated with your CFS/FMS (not always an easy call)? And remind your doctor about ALL the other prescription and over-the-counter medications you're taking, in case there could be interactions.

Another big problem is the subjectivity of pain. You can't measure it, you can't test for it, you can't easily quantify or qualify it. (This is why I suggest that people talk, instead, about the impact that the pain is having on their life.) Doctors may dismiss the "perceived" pain of their patients ... particularly if they have little experience in detecting the difference between "pain relief seeking behaviour" and "drug seeking behaviour". To compound the problem, little is understood (or published) about the safe and effective use of narcotics in the treatment of severe chronic (non-cancer) pain.

Because of all these aspects, it often falls to the patient (or their carer) to "convince" the GP that they are in true need of an effective pain treatment. This is where a knowledgeable support worker can help. If you are a support worker, talk it through with the PWC on the phone; let them "practice" describing their experience of pain and how it affects them. Offer suggestions about how to explain the situation more clearly. An unfortunate but significant factor is that women who are more articulate, and less emotional, than average are more likely to be taken seriously (by some doctors).

Using opiates

Medicine often defines "acceptable" uses of opiates to include only terminal diseases, cancer, etc. And many doctors that I have spoken to about this refer to narcotic pain treatment as the "last resort" mostly only applicable if the patient is approaching death.

I can understand a certain amount of hesitancy. Many of these medicines have the potential of resulting in addiction - though this rarely occurs in true cases of severe chronic pain, according to the recent research. The reason for this became very clear from my own experience: If you take morphine for severe chronic pain, the medication has so much "work" to do in lessening the pain that you don't get a "buzz", or "euphoria", or "bliss", or anything like that. All you get is somewhere back toward "normal"! This is why dosage is so important. Work with your doctor to determine the lowest effective dose of pain medication and review this dosage regularly. In my experience, once the pain is under control, the required dose decreases over time.

My doctor commented that, if I started on the pain management strategy that we were considering, it was quite probable that I would become *physiologically dependent* on the pain medication. This is quite different from addiction, and is something that I was prepared for. To make both my doctor and myself comfortable with my pain control treatment trial, we made a deal: if I developed a tolerance to the medication (i.e. I kept asking for higher and higher doses), he promised to assist me in getting off the medication using a controlled withdrawal strategy. This was *my* condition for embarking on the trial.

Use of many of these medications will result in physiological dependence (the body comes to rely on the medications to function normally). And, in my experience, withdrawal from the medication (which I have recently done voluntarily, having found a more effective, non narcotic medication combination) can be very unpleasant - even without addiction. You may want to discuss this process in detail with your doctor before you decide which options you are willing to explore.

> In line with current research, my required dosage actually decreased continually. The theory is that constant pain is self-perpetuating. Nerve cells (pain receptor cells) are dealing with a continual flow of pain information. They, in turn, recruit nearby nerve cells to adapt their function to become pain receptors, and so more pain messages are sent through. Once my pain was treated effectively, many of these nerve cells got out of the habit of pain reception, and so my need for medication decreased.

This is one of the reasons why constant, low level sustained release medication is a better solution than only taking something when the pain reaches an intolerable level. If you do that, the body seems to begin to generate messages for this high "intolerable" level of pain quicker and more often - since that is the "trigger" (cause) for pain relief (i.e. you finally take a codeine). So, in the long run (and in my experience) this kind of sporadic treatment is more likely to perpetuate severe pain, than relieve it.

It wasn't until after I experienced (for the first time in years) my first pain free day, that I truly comprehended the severity of the pain that I had been struggling to co-exist with. I can now acknowledge (without any self-congratulation) that I'm a very, very brave and stoic woman. But this trait was also a problem, because I didn't really give my doctor enough information/description at the outset for him to realise the severity of the pain I was suffering.

My hope for those of you who are suffering chronic, severe

(Continued from page 28)

pain is that you will also be able to find a caring and compassionate doctor who will work with you until you find an effective pain management strategy. I know that this is an achievable goal and I hope that, in sharing my experience with you, that you can find the courage to persevere until you succeed.

Note: Kit is referring to a report on chronic pain by the ABC's science program *Quantum* in October 2000 which featured research being done at the Sydney's Royal North Shore Hospital. The researchers were looking at nerve injury, and the mechanisms by which pain can become chronic. The report warned, "if severe pain is not treated effectively, the result can be lasting damage to the nervous system."

Reprinted from Moira Smith's website
http://www.masmith.inspired.net.au/

[Our medical advisor thought that it might be useful to mention that an effective strategy re pain control not mentioned is the use of low dose tricyclics.

-Eds]

Thirteen-Year Follow-Up of Children and Adolescents With Chronic Fatigue Syndrome.

Pediatrics, May 2001, 107(5): 994
David S. Bell; Karen Jordan; Mary Robinson.

Objective

To describe the educational, social, and symptomatic outcome of children and adolescents with chronic fatigue syndrome 13 years after illness onset.

Methods

Between January 1984 and December 1987, 46 children and adolescents developed an illness suggestive of chronic fatigue syndrome. Follow-up questionnaires were obtained from 35 participants an average of 13 years after illness onset. Data were obtained concerning subsequent medical diagnoses, amount of school missed, presence and severity of current symptoms, and subjective assessment of degree of illness resolution.

Results

Of the 35 participants, 24 were female (68.6%) and 11 were male (31.4%). Average age at illness onset was 12.1 years. Eight participants (22.9%) had an acute onset of symptoms, 27 (77.1%) had a gradual onset. No participant received an alternative medical diagnosis that could have explained the symptom complex between illness onset and follow-up. Thirteen participants (37.1%) considered themselves resolved of illness at follow-up; 15 participants (42.9%) considered themselves well but not resolved; 4 (11.4%) considered themselves chronically ill; and 3 (8.6%) considered themselves more ill than during the early years of illness. Correlation with the Medical Outcomes Study Short Form Health Survey was good for current level of symptoms and degree of recovery. Eight participants (22.9%) missed [is greater than] 2 years of school, and 5 of these were still ill at follow-up. Amount of school missed correlated with both illness severity at follow-up and perceived social impact of the illness.

Conclusions

These data demonstrate the presence of an illness consistent with the current definition of chronic fatigue syndrome. Eighty percent of children and adolescents affected had a satisfactory outcome from their fatiguing illness, although the majority of these participants had mild to moderate persisting symptoms. Twenty percent of participants remain ill with significant symptoms and activity limitation 13 years after illness onset. Chronic fatigue syndrome in children and adolescents may result in persistent somatic symptoms and disability in a minority of those affected. Pediatrics 2001;107:994-998; chronic fatigue syndrome, pediatric chronic fatigue syndrome.

In search of quality in general practice

by Mark Harris

There is increasing attention to the issue of quality in health care prompted by consumer demand as well as the need to ensure value for money in spending finite health dollars and by evidence of adverse events in hospitals and other health care institutions (Wilson 1995).
This article focuses on the measures being taken to maintain and improve the quality of care in general practice.

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What is quality in general practice?
Quality in general practice encompasses a myriad of aspects. It includes issues such as:

- the availability and access to general practice care especially after hours and in rural and remote areas, despite Medicare;
- the facilities and organisation of practices including reception, waiting areas, records and sterilisation systems;
- quality of care provided by General Practitioners (GPs) including the extent to which GPs are able to assess and manage health problems in a patient-centred way, while still being in accord with the latest and best evidence. A key component of this is the quality of communication with patients and involving the patient and their carer in decision making. However, this is difficult given the frequent communication misunderstandings between GPs and their patients(Britten et al 2000).
- access to and quality of the services to which GPs refer and the way the GP communicates with other providers (as many adverse events are due to poor communication).

How is quality in general practice achieved and maintained?
A variety of measures have been established to assure and improve the quality of general practice. These include:

- undergraduate and vocational training in general practice with a specific qualification-the FRACGP (Fellowship of the Royal Australian College of General Practitioners);
- quality assurance and continuing education which all GPs must do after finishing training. These require GPs to attend educational activities and conduct at least one audit of an aspect of their practice every three years. Clinical audits are especially important because they provide GPs with feedback on how their care differs from accepted standards, to encourage them to improve their care where necessary;
- efforts to improve access to general practice care by patients in rural areas and after hours service and improve the access which GP patients have to other services especially allied health services;
- accreditation of practices, based on agreed standards. This involves self-assessment as well as a site visit by external reviewers including GPs, practice managers or health consumers.

While these provide an important basis for ensuring quality, there has been a re-appraisal of their effectiveness in preventing human error in health care delivery. In particular, there has been growing emphasis on the need for systems to support GPs in their clinical decisions by the use of information technology. Such tools include those designed to help detect health problems early, electronic guidelines and databases, reminders which pop up in computer patient records or which are sent to the patient from a register. These are particularly useful for patients who have multiple problems, or who have complex conditions requiring monitoring of different aspects of care (such as diabetes).
Feedback from patients can also help especially if it is truly anonymous and patients are prompted to identify aspects of care that they feel might be less than optimal. To be effective, this should be conducted externally to the practice with patients feeling secure that they can make critical comments without their identity being known. Another mechanism is to seek input from outside groups such as self-help groups.
Bringing a student or trainee into the practice can also help ensure that the GP stays up-to-date with recent advances and reflects on how he or she manages their practice. Similarly involvement in research can be useful in helping GPs to reflect on their own care. Many Universities are working with Divisions to help GPs to become more involved in education and research within their practice.

So how can the consumer tell?
The consumer can look for some more obvious markers of quality in practice such as in the following questions:

- Is the GP vocationally registered or does he or she hold the FRACGP?
- Is the practice accredited and/or a training or academic practice?
- How available is the GP (this should ideally be outlined in an information sheet about practice services)?
- What sort of system is there for records? (records in folders or computer records are often better than small cards)
- How does the GP manage time? Are waiting times long and unpredictable?
- Does the GP spend extra time when it is necessary or do you always feel rushed to leave?
- Does the GP use adequate systems to support decisions in the consultation-for example, relevant guidelines in books or computer systems?
- Does the GP spend time explaining things in an open and clear way and is this supplemented by written material when appropriate?
- Does the GP encourage the patient and carers to share in decisions about management?
- How does the GP communicate and work with other services? Is there information available about different specialists and a range of allied and community services?
- Does the practice have information about and refer to self-help groups?
- Does the practice send prompts for care that may be necessary between visits, e.g. reminders for preventive health care?

These provide some indication that the GP is making an effort to improve quality.

How can we improve quality across general practice as a whole?
So far I have discussed a number of aspects of the quality of individual GPs or practices which may be of interest to the consumer. However, there is a need to ensure quality across general practice for the community as a whole. This means ensuring that the system is fair and equitable. Medicare ensures that, with some exceptions, most people in most communities can access general practice services. However many low-income patients face increasing 'downstream costs' of drug therapy, specialist and other referral services or poor access to services such as allied health. GPs

individually and collectively have a important role in advocating for improved access to these services possibly in collaboration with local community and self-help groups.
Furthermore there has been a decline in continuity of care with an increasing number of patients using a number of different GPs or practices. This may be a result of incomplete service provision, for example, with consumers having to use alternate practices to get after-hours care. Whatever the cause, it is associated with an increased risk of adverse events, decreased quality of patient education and increased costs. This in turn can compound inequitable access to other services which the consumer may need, such as allied health.
At a structural level there is need to improve linkages between community and consumer organisations and general practice organisations. Divisions of general practice have, with some success, attempted to involve and consult with consumers in the implementation of their programs. It is important that this is developed with greater focus on improving the quality of care as defined by consumers as well as the health system itself.

Professor Mark Harris is Professor of General Practice and Health of the School of Community Medicine at the University of New South Wales.

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GPs: Considerations for seeing ME/CFS patients

Individuals with chronic fatigue syndrome (CFS) have special needs practitioners should consider during office visits. Here are some suggestions to help you provide optimum care:

- Provide a place to lie down. CFS patients may not be able to sit up for long periods of time in the waiting room, your office, or the exam room. They may also be too self-conscious to ask for a place to rest.
- Expect body temperature abnormalities. CFS patients often have low body temperatures and get chilled quickly; they may need a sheet or blanket to be comfortable.
- Draw patients out verbally. The cognitive problems in CFS patients may make it difficult for them to express themselves during the verbal part of the examination. Make questions very specific so that a long response is not required. They may also underreport the type, duration, and severity of symptoms, especially in regard to chronic pain.
- Acknowledge the illness. Saying "you look great" or "you seem much better" can be very discouraging given the fluctuations in symptom severity most patients experience. These types of remarks can be interpreted by patients that the physician does not accept or understand the daily reality of living with CFS.
- Address sensitive issues. It will be difficult for some patients to discuss loss of libido, changes in appetite and weight, and the need for home services, such as help with house cleaning, errands, and bathing. You may need to initiate the conversation.
- Account for medication sensitivity. CFS patients are hypersensitive to medicines, foods, and vaccines. Many also experience unusual side effects. Try prescribing a quarter to a third of the normal initial dosage to start and then increasing slowly as necessary to achieve symptom relief.

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website: www.cfids.org

WANTED: YOUR EXPERIENCES ON PAPER

HAS ANY PARTICULAR TREATMENT HELPED YOU?
HAVE YOU DEVELOPED ANY INTERESTING WAYS TO COPE WITH THIS ILLNESS?
HAVE YOU DEVELOPED WAYS TO DEAL WITH PEOPLE WHO DON'T UNDERSTAND THIS ILLNESS?
WHAT HOBBIES / ACTIVITIES DO YOU FIND THERAPEUTIC?
Please send in details of your experiences so we can share them with others. Talking Point GPO Box 383 Adelaide SA 5001

[AACFS] Conference Expands CFS Findings

By Charles Shepherd, M.D.
ME Association, United Kingdon

The American Association for Chronic Fatigue Syndrome (AACFS), an organization of research and health care professionals dedicated to chronic fatigue syndrome (CFS), held its fifth international research, clinical, and patient conference in Seattle, Jan. 27-29, 2001. The conference attracted researchers and clinicians from more than 10 countries and included more than 200 presentations and posters.

The conference covered many areas under investigation and clinical treatment tips. Following are highlights from the research and clinical portions of the meeting.

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Epidemiology/natural history

Past research often lumped CFS patients into one homogenous group. An encouraging trend noted by researchers at this AACFS meeting was the number of studies presented that used subtyping to shed light on the pathophysiology of the illness as well as provide targeted treatment strategies.

Leonard Jason, Ph.D., of DePaul University presented data that may assist in subgrouping CFS patients.[1] Factors considered relevant included a stressful life event at the onset of illness and a current or lifetime diagnosis of psychiatric illness.

Leonard's study also confirmed that more severe symptoms were found in women, minorities, and non-working individuals.

Rosane Nisenbaum, Ph.D., of the U.S. Centers for Disease Control and Prevent-ion examined the natural history of a group of CFS patients one year after diagnosis.[2] Treatments reported to reduce their fatigue included traditional medical therapies (77%), vitamins (68%), and changes in diet (73%). No association was found between illness improvement and type of onset.

A study conducted by Lea Steele, Ph.D., of the Kansas Commission on Veterans Affairs found a higher prevalence of CFS in veterans with Gulf War illness (GWI) than in the community at large, but also found veterans more often experience headache, diarrhea, and night sweats than CFS patients.[3] She also discovered that the mean age of onset of CFS in GWI was a decade earlier than in civilians.

Physiology

Several studies examined the role that dysfunction of the autonomic nervous system (ANS) may play in CFS.

A researcher from the University Hospital in the Netherlands, Patricia Soetekouw, M.D., presented data showing increased heart rate and blood levels of epinephrine in CFS patients in response to active standing and head-up tilt, which would indicate increased activity in the sympathetic arm of the ANS.[4]

Arnold Peckerman, Ph.D., University of Medicine and Dentistry of New Jersey, discussed how ANS dysfunction in CFS may involve the baroreceptors that help control and maintain blood pressure and output of blood from the heart during long periods of standing.[5] His data suggests that CFS patients experience a decline in baroreflex sensitivity during orthostatic challenges.

James Baraniuk, M.D., of Georgetown University described how acoustic rhinomanometry, a technique that is used to measure the volume of air inside the nose and reflects the degree of blood vessel constriction, can be used to assess sympathetic activity in CFS patients.[6] His study may also explain why some people with CFS develop nasal irritation, watering, and blockage.

Microbiology

Christopher Snell, Ph.D., of the University of the Pacific described a study that indicates elevated levels of RNase L, an enzyme in the antiviral pathway, are associated with decreased oxygen consumption during exercise, which could explain exercise intolerance in some CFS patients.[7]

Dharam Ablashi, M.D., of Advanced Biotechnologies in Columbia, Md., presented data to support the hypothesis that active, ongoing infection with human herpesvirus 6 (HHV-6) is involved in the pathogenesis of CFS.[8]

Using cell culture and polymerase chain reaction analysis, he found cell-free HHV-6 in the blood and spinal fluid samples of CFS patients and concluded that the virus could be involved in the development of neurological symptoms.

Seven of the patients showing active HHV-6 infection were treated with three different antiviral drugs - foscarnet, ganciclovir, and valciclovir - but most only showed slight improvement.

Immunology

Kevin Maher, Ph.D., of the University of Miami focused on the possible role of perforin, a natural killer (NK) cell lytic protein, in CFS.[9] If perforin is removed in mice, immune abnormalities similar to CFS result.

Maher found that intracellular perforin was reduced in NK cells and in cytotoxic T cells in CFS patients and that intracellular content of perforin correlates with the cytolytic potential of the cell.

The research supports the claim that an NK-associated defect is present in CFS and suggests a molecular basis for reduced cytotoxicity.

A study of autoimmunity in CFS was presented by Eng Tan, M.D., of the Scripps Research Institute.[10] Low titers of auto-nuclear antibodies have been found in CFS patients; this study showed the presence of autoantibodies to a particular cellular protein, MAP2, which is expressed primarily in neuronal cells. Autoantibodies directed at brain tissue could help explain some of the neurological and cognitive symptoms found in CFS.

Genetics

Niloo Afari, Ph.D., of the University of Washington studied twin pairs where one twin has CFS and found that the offspring of the twins with CFS were at substantial risk of developing chronic fatigue.[11] Children of healthy fraternal twins seem to be at even greater risk than children of identical twins, which may suggest familial clustering of fatiguing illness in extended families with a member who has CFS.

Leslie Aaron, Ph.D., of Harborview Medical Center, Seattle, did a co-twin study that revealed a high rate of co-morbidity with irritable bowel syndrome, fibromyalgia (FM), chronic pelvic pain, multiple chemical sensitivity, and temporomandibular joint disorder in wins who had CFS.[12]

Neurology

A study examining brain activity in CFS patients and healthy controls was described by Roderick Mahurin, Ph.D., of the University of Washington.[13] All subjects had a SPECT scan of the brain while performing mental arithmetic; the CFS group showed decreased brain activity in certain areas and

increased activation in other regions of the brain, particularly the anterior cingulate gyrus. The study provides evidence of brain inefficiency in CFS, particularly in the area of complex mental processing.

Greta Moorkens, M.D., Ph.D., of the University Hospital, Antwerp, Belgium, presented data on hormonal abnormalities in CFS that affect the brain and endocrine systems.[14] Her research involved giving CFS and FM patients neuroendocrine challenge tests using stimulation by growth hormone-releasing hormone and Hexarelin, a growth hormone secretagogue. The tests showed clear differences between CFS and FM patients, suggesting different pathological mechanisms for the illnesses.

Treatment

Kottil Rammohan, M.D., of Ohio State University described a clinical trial with modafinil (Provigil) to manage fatigue in multiple sclerosis (MS) patients.[15] The drug improved energy and decreased daytime sleepiness in the MS group. Studies with CFS patients are needed to determine if modafinil could alleviate fatigue in CFS.

A pilot study of another drug, etanercept, was presented by Kristin Lambrecht, PA-C, of the University of Minnesota. Etanercept, which blocks the action of tumor necrosis factor, may play a role in the immunological dysfunction in some CFS patients. The drug significantly decreased the level of fatigue, muscle pain, headaches, and painful lymph nodes in CFS patients, leading researchers to suggest further studies.

Katherine Rowe, M.D., of the Royal Children's Hosp-ital, Australia, presented a follow-up study of CFS patients receiving intravenous immunoglobulin.[16] Results indicate that patients experienced significant improvement following treatment, with 75% able to work or study full time. However, it is unclear whether this was due to the immunoglobulin or the natural history of the illness.

Nancy Klimas, M.D., of the University of Miami Medical School discussed results of an immune therapy for CFS that resulted in favorable immunological and clinical results in a small number of patients, indicating further clinical trials are warranted.[17]

Researchers surgically removed CFS patients' lymph nodes and cultured them with anti-CD3 and interleukin-2 to shift the cells from a predominant TH2 to a TH1 immune response. The cells were then infused back into the patients.

The clinician-to-clinician session at the conference provided physicians with the opportunity to brainstorm together on how to best treat CFS and FM. Practitioners discussed treating pain, headaches, and orthostatic intolerance, covering non-pharmacologic approaches and proven therapies.

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The following references refer to abstracts presented at the conference. Program books with abstracts are $20 for AACFS members, $25 for nonmembers. Write to AACFS, c/o Harborview Medical Center, 325 9th Ave., Box 359780, Seattle, WA 98104. Make checks payable to the AACFS.

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Dr. Charles Shepherd is in private practice in the United Kingdom (U.K.) and is a member of the Chief Medical Officer's Working Group on CFS/ME at the U.K. Department of Health.

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Is CFS Linked to Vaccinations?

By Charles Shepherd, MD,
ME Association, United Kingdom

There is widespread agreement that a variety of infections are capable of precipitating chronic fatigue syndrome (CFS) in susceptible individuals. In l988, Lloyd et al reported that several of their patients had linked the onset of CFS to receiving a vaccination in the absence of any coincidental infection.[1] Since then, other anecdotal reports have also linked vaccinations to the onset of CFS.[2,3]

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The explanation for vaccine-induced CFS may be because the primary purpose of any vaccine is to mimic the effects of infection on the immune system. If an antigenic challenge by infection can precipitate CFS, then it is conceivable that vaccines could act in a very similar manner.

This reasoning is further strengthened by the fact that immunologically based illnesses, such as arthritis, can occur when a susceptible host and an environmental trigger, such as an infection or vaccination, interact.4 It is also interesting to note that vaccinations have been suggested as a possible precipitating factor in the development of Gulf War illness.

Causal vaccines

My research interest in this aspect of developing CFS is largely based on clinical evidence from patients seen in my practice over the past 10 years. As a result, I have gathered details on more than 200 patients with a history of either developing CFS or experiencing a significant relapse/ exacerbation of CFS symptoms following a vaccination.

In addition, I have more than 150 reports referring to such a link from members of myalgic enceph-alomyelitis (ME) or CFS self-help support groups and/or their physicians throughout the world.

This data (although unpublished) suggests that tetanus, typhoid, influenza, and hepatitis B are the most commonly implicated vaccines in cases of CFS. I have reports of very few cases involving hepatitis A (using immunoglobulin), polio, or rubella vaccine, or those predominantly given during childhood—-with the possible exception of Bacillus Calmette--Guerin vaccine (three cases).

Almost all of my cases involve adults, and in a significant minority the vaccine was administered when the person had not yet fully recovered from an infective illness such as infectious mononucleosis (known as glandular fever in the U.K.) or had already experienced an adverse reaction to a previous dose of the same vaccine (as is sometimes the case with hepatitis B accine).

About one third of my cases involve vaccine-induced/ exacerbated CFS following receiving the hepatitis B vaccine (HBV). Most of these patients are health care workers, particularly nurses. Most of the other patients received HBV for occupational health purposes, often as a condition of employment and without any information on side effects, such as severe neurological reactions.

The prognosis in this group has been poor, with less than 10% of the patients I have personally followed reporting any significant relief of CFS symptoms.

Although chronic debilitating fatigue is the most frequently reported symp-tom of CFS after vaccine administration in this group, around 20% also complained of significant joint pain/arthralgia, a finding consistent with several reports linking HBV to arthritis and other autoimmune disorders.[5]

Less than 5% of the patients also reported neurological complications/side effects such as tremors or one-sided weakness, which appear to be separate from their CFS symptoms.

For instance, one female patient developed an acute disseminated inflammation of the brain and spinal cord (encephalo-myelitis) shortly after the second dose of vaccine. This was followed by the gradual onset of CFS.

Hepatitis vaccines are highly immunogenic compounds, and a number of possible explanations exist as to why they may be more likely to trigger CFS.

One explanation involves a preexisting genetic susceptibility, which after antigenic stimulation with HBV, results in a pathological process (possibly involving immune complex formation) leading to a clinical disease.

Another explanation is that a hypersensitivity reaction occurs to a component of HBV, such as the preservative thimerosal.[6]

Researchers in Canada, who made similar observations of a link between HBV and CFS, hypothesized that this may involve an autoimmune reaction with a microscopic form of demyelination not visible on magnetic resonance imaging.[7]

Despite growing anecdotal evidence from other experienced physicians who also believe that HBV can precipitate CFS,[2] vaccine manufacturers do not acknowledge any causal link. In fact, a report by an independent working group in Canada that dismissed any such causal link is frequently quoted as a reason for dismissing these claims, even though it contained some very questionable assumptions to support the conclusions.[8]

For example, the report inaccurately states that chronic carriers of hepatitis B infection without signs of ongoing liver damage do not complain of tiredness. The report also uses results from a one-week follow-up study of 700 health care students, which found excessive short-term tiredness in about 14% after vaccination with HBV to refute any link

IS YOUR HEALTH PRACTITIONER KNOWLEDGEABLE ABOUT ME / CHRONIC FATIGUE SYNDROME?

If your doctor understands ME/CFS and you find he/she helpful in dealing with your condition, then please tell us (8410 8929). Ask he/she if they would like to be on our mailing list.

with chronic fatigue.

Practical advice

Health care providers caring for CFS patients who require vaccinations clearly must weigh the pros (i.e., how effective? how necessary?) and cons (i.e., risks of adverse effects and exacerbation of CFS symptoms) for each individual vaccine. I would advise against having routine nonessential vaccinations if a patient is:

- In the very early stages of CFS, particularly when it obviously follows an infective episode;
- Continuing to experience flulike symptoms, including sore throat, enlarged glands, fevers, and joint pains; or
- Has previously experienced an adverse reaction to that particular vaccine.

If the vaccination is potentially lifesaving, then considerations relating to CFS must take a lower priority. As for some of the more commonly required vaccines, my advice on their use is as follows:

Hepatitis A. Short-lived protection using immuno-globulin does not seem to cause any problems in CFS patients. I have not received any adverse feedback from CFS patients who have used hepatitis A vaccine.

Hepatitis B. If a patient requires HBV for occupational health purposes, clinicians should weigh the pros and cons as previously discussed and then discuss with the patient.

Influenza. If a patient has any medical condition that could be severely affected by an attack of the flu, such as heart disease, asthma, or bronchitis, influenza vaccine should certainly be considered.

My own data indicates approximately 60% of CFS patients experience some form of exacerbation in their fatigue and flulike symptoms (sometimes quite marked) following an influenza vaccine.

Meningitis C. My feedback from approximately 30 children and adolescents with CFS who have been given the meningitis C vaccine in the U.K. is that there were no serious side effects or exacerbations of CFS symptoms. The only adverse effects reported have been minor exacerbations of fatigue and headache.

Polio and diphtheria. One research study showed evidence that people with CFS do not experience adverse reactions to polio vaccination.[9] This is also my own impression from feedback received from patients I have advised receive polio boosters in relation to foreign travel.

Polio vaccinations or boosters should clearly be given to patients traveling to countries where polio still occurs. The same advice applies to diphtheria, which is becoming increasingly common in parts of Eastern Europe.

Tetanus. Maintaining up-to-date protection is vital for individuals whose employment (e.g., working on a farm) or leisure activity (e.g., gardening) places them at risk of contracting tetanus.

However, tetanus vaccine can produce side effects in healthy people and may well cause CFS patients to relapse. The pros and cons need to be carefully considered as tetanus vaccine has been reported to precipitate CFS.[1,2]

Typhoid. The typhoid vaccine can cause side effects in healthy people. The feedback I received from my CFS patients, however, indicates that the oral form of typhoid vaccine was generally well tolerated.

Whenever vaccinations are considered necessary, they should be given when CFS patients are feeling reasonably well and not under any undue stress. It is also wise to make sure that all travel vaccinations are completed at least two weeks before departure in the event a patient experiences exacerbated symptoms or a relapse.

Not surprisingly, patients with possible vaccine-induced CFS often face considerable difficulty in obtaining disability benefits on the grounds of permanent ill health. However, some of my patients in the U.K. have successfully argued their cases and been awarded injury payments on the grounds that HBV given for occupational health reasons caused their CFS. I am also involved in a number of cases where the debate is likely to be settled in court.

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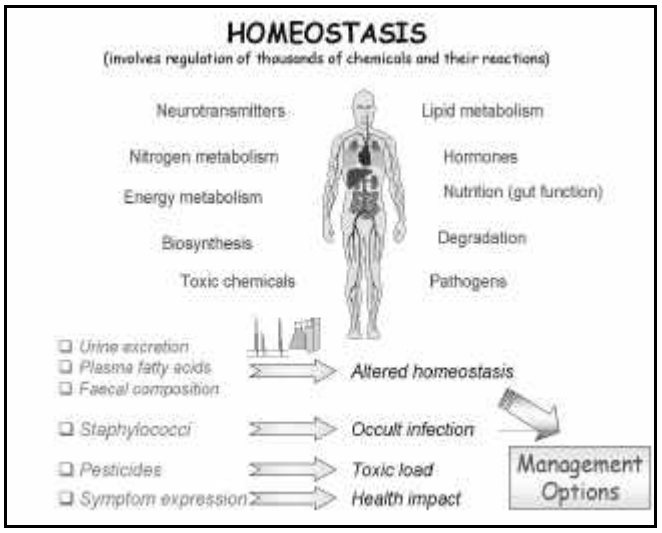
Summary of lecture delivered May 12th: An update on ME/CFS research at the University of Newcastle

Dr. Hugh Dunstan spoke at a public meeting on May 12th 2001, at Urrbrae Education Centre.

What I would like to talk about today are new advances in CFS research in symptom presentation, homeostasis and the host response in the body, and a new way of thinking about the disease entity in terms of common aspects that occur in the majority of patients. This leads to concepts of nutrient support and effective patient management. I would like to finish by presenting some concepts of evolution and infection.



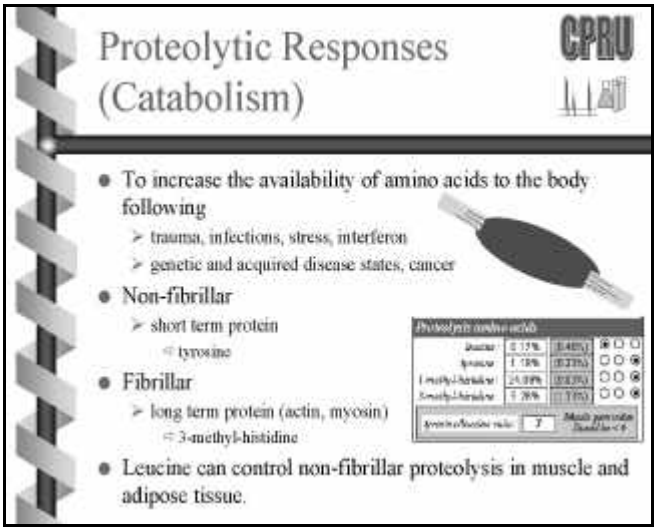
Many of the core symptoms of CFS, like fatigue and muscle pain, are non-specific in nature, indicating a generalised host response to pathogenic challenge. While these symptoms are associated with an infection, none are useful in characterising a disorder. The definition of CFS is one of exclusion, but there are many general features of this host response system that are relevant to CFS patients.

In our work with multivariate statistics, we look at the whole range of symptoms and try to group people in terms of complex symptom profiles. A graphic analysis of this data shows the controls all clustered together. The CFS patients with fatigue only can be separated, but specifically those patients with fatigue and pain can be very well separated. Different symptoms can be grouped to reduce the amount of information to help construct a clinical management program for the patient.

The big question In CFS has always been is it psychological or organic? The body's homeostasis regulates many thousands of compounds and reactions. In disease, homeostasis is thrown into disarray. Our work picks up these imbalances by looking at urinary excretion, or fatty acid components in the blood. In our faecal analyses we have found remarkable alterations in gut performance indicating a significantly altered homeostasis, so that clinicians can now begin to look at appropriate management options. This is really at the heart of where we are trying to head, to produce options that are useful, effective and lead to an improvement in health status. We have been looking at the presence of staphylococci and at how the microflora can affect homeostasis, particularly in conditions with pain and fatigue. We have also looked at the significant effects of pesticides in relation to toxic load.

Many of the symptoms of CFS are consistent with a host response to pathogenic challenge. The issue we are focussing on is the proteolytic response, or catabolism, which involves muscles, acting as a protein reservoir, which release amino acids to fight infections and to build new materials when needed. This well documented response is seen in trauma, infection, stress, certain genetic anomalies, acquired disease states and cancers. There are two types of storage reservoirs, the fibrillar reservoir of muscle fibres used for contraction and strength, and the non-fibrillar reservoir of non-structural proteins from inside the cytoplasm in the cell.

A key amino acid indicating non-fibrillar catabolism is tyrosine. Increased levels of urinary tyrosine are a very well documented indicator of a proteolytic response. Urinary tyrosine levels in most patients with CFS indicate a non-fibrillar response. What this means is that there is an underlying organic process in most of the patients with chronic fatigue or chronic pain conditions. When the non-fibrillar response is insufficient to meet demands, the fibrillar response is switched on like a back up system. In many patients we see

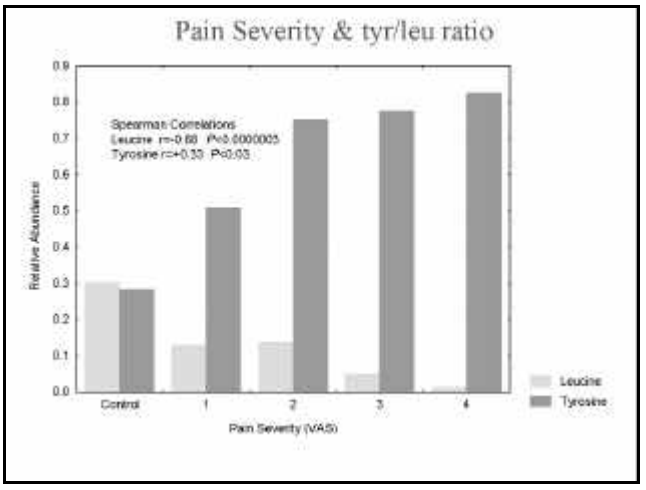


the amino acid 3-methyl-histidine, which is the marker of this fibrillar response. So, using well documented markers of metabolism, we have found that the body is responding to some kind of prolonged, traumatic, perhaps infectious, challenge.

As the protein reservoirs release nutrients, rising levels of the branch chain amino acid leucine switch this proteolytic process off. We find in most patients that the leucine level is very low, sometimes undetectable, meaning catabolism will be sustained. The tyrosine/leucine ratio then gives us an indication of the extent of the proteolytic response.

We are heading towards designing urine testing to identify anomalies and deficits in amino acid homeostasis. Importantly, we have a marker of the body's muscle catabolism and can also possibly identify other markers associated with certain staphylococci strains as pathogenic agents.

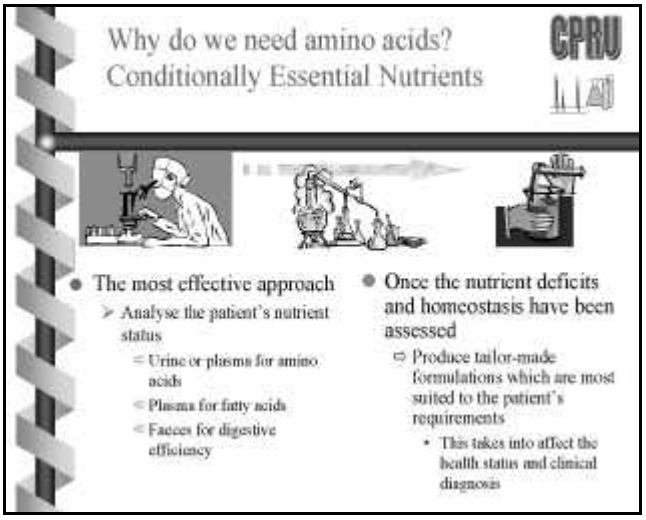
Most patients report gut function problems and our faecal analysis studies indicate digestive problems. The gut secretes hydrochloric acid, which breaks down proteins into amino acids. Some of these protein fragments are immediately absorbed and act as hormones to stimulate pancreatic secretion of digestive enzymes. Without adequate acid secretion, protein breakdown is insufficient to activate the digestive process. We believe this is extremely relevant and some additional gastric acidity can be very effective in producing a



substantial increase in health status.

Certain protein digest products also stimulate bile production so that essential fatty acids can be absorbed. Bile is produced by the liver and is responsible for the absorption of cholesterol and dietary fats. Without bile secretion, you do not have fat absorption. So this process is central to a lot of potential problems in essential fatty acid metabolism and effective acquisition of nutrients, including B group vitamins. If you don't have acid production, you don't get the absorption of B group vitamins and we have heard about the efficacy of using B group supplementation. The gastric acid also acts as a protective barrier against pathogenic organisms in food.

Reduced gastric acid secretion can occur following stress, trauma, strenuous exercise or as a result of bacterial or viral infection. So we have some mechanisms that can begin to explain some of the digestive problems that we observe and how some aspects of nutrient deficit can be achieved in long term patients. Our research group proposed that acid secretion was a very important entity for future investigation of food absorption. Some clinicians use Betaine HCl as a potential method of management and this fits well with our emerging hypothesis. It appears that these kinds of management strategies might be appropriate to assist in the improved efficiency of absorption of nutrients



I am often asked "why you can't get sufficient amino acids from eating a healthy diet, a good, thick, red-meat steak" One of the many reasons why amino acids might not be available in the diet, or in red meat, is because patients have insufficient acid secretion for digestion. Foods also contain free amino acids, organic acids, sugars and essential nutrients within the cytoplasm of the cells. The availability of these compounds for absorption in the food that we eat is very important. Different people may have different needs for particular nutrients and this may form the basis for why products like glyconutrients are useful in certain types of patients.

> During prolonged illness or injury the host response may result in unusual metabolic demands. If patients are maintaining a sustained metabolic response over a period of years then it may have a very substantial impact on homeostasis - draining the system. Amino acids that may normally not be essential can then become essential. It is possible that certain foods or materials may provide sufficient supplements. Our strategy is to exactly identify the patient's nutrient status, by assessing the urine, the plasma essential fatty acids and the faeces results. From this we want to produce tailor made formulations matching the specific nutrient requirements governed by the patient's illness demands.

A recent publication looked at our data set on just under 4000 patients. We wanted to see if there were groups of people who have certain types of nutrient requirements. Remarkably, a multivariate analysis of the 36 compounds in each urinary excretion profile produces a scatter plot with six very tightly packed groups of amino acid requirement profiles, possibly reflecting different amino acid homeostasis in population genotypes. Each amino acid grouping had a characteristic set of amino acid deficiencies, organic acid anomalies, and symptom presentation.

So we are beginning to see why there might be reasons for diversity in the CFS chronic or pain population. With different underlying nutritional requirements and types of biochemistry, there can be an underlying basis for different responses to environmental and pathogenic challenges. We see this as a reflection of an individual's requirement for essential, semi-essential and conditionally essential amino acids. What is "non-essential" can become "essential" if the nutrients cannot be manufactured by the body at a rate required to support demand.

Looking at two well defined patient groups of fibromyalgia and rheumatoid arthritis, again the six different patient groupings appear and may provide a rationale for treatment. This approach can produce a separation in patients with CFS with generalised pain, localised pain or pain with gut dysfunction. Extending this principle to some new work from our colleagues, you can get very good urine excretion profile differentiation with autism patients, and you can also separate attention deficit hyperactivity disorder from autism.

We are doing a great deal of work in studies of faecal analysis and can detect dysfunction in both aerobic and anaerobic gut bacteria. We see *Candida* in 20 - 30% of patients. Of those, the actual numbers of *Candida* organisms cultured are never high but, when they are present, they seem to be associated with specific pain symptoms.

In lipid biochemistry, we find fat malabsorption and this ties back in with the potential problems of insufficient acid production in the stomach: low secretion of bile and poor absorption of fatty acids from the diet. The faecal results seem to support this new proposal of insufficient acid production as having a role. It is well documented that some of the fats we measure are an indication of colonocyte integrity.

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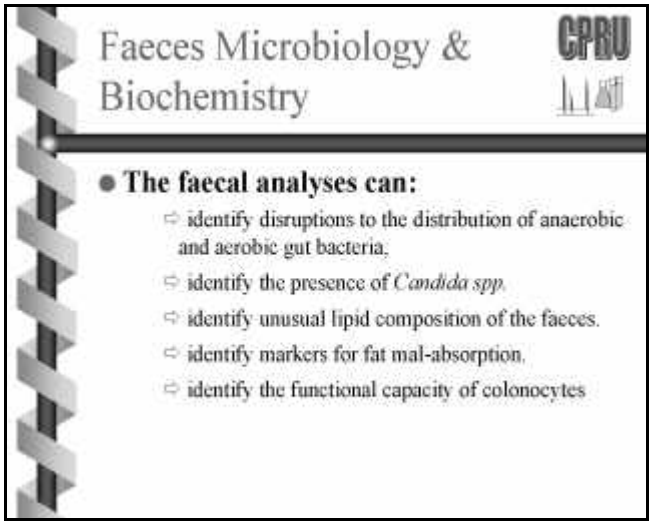
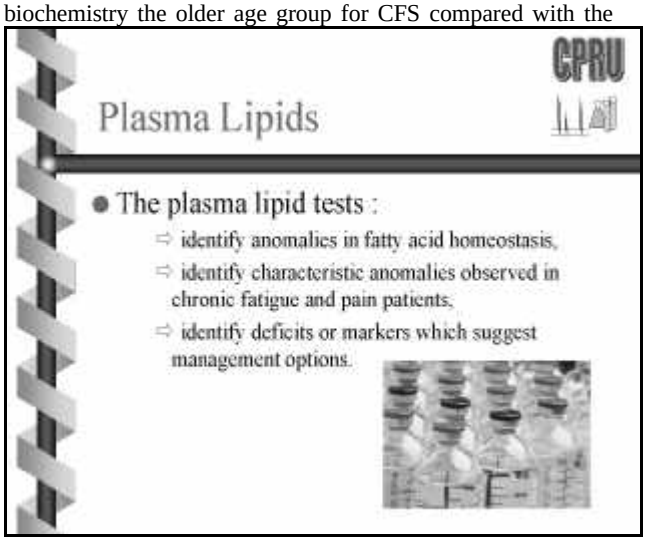
Fatty acids are poorly understood and represent a very complex area of biochemistry. They are important components of the cell membrane, which must remain flexible to function correctly. This fluidity is governed by essential fatty acid and cholesterol content. The major membrane components are



phosphatidyl-choline and phosphatidyl-serine. Serine is an amino acid repeatedly found to be reduced in many CFS patients and this may be linked with cell membrane integrity. With a serine deficit it is unlikely that sufficient phosphatidyl-serine can be made.

Our very extensive studies on fatty acids show that patients have lower cholesterol levels - two thirds were very low, one third were closer to normal. A very low cholesterol will impact on membrane function and integrity. Low cholesterol results in reduced bile production and problems absorbing essential fatty acids. As cholesterol is a precursor to steroid hormones, it is likely there is an impact on steroid hormone production, with substantial follow on effects.

With multivariate analysis we can differentiate by fatty acid biochemistry the older age group for CFS compared with the

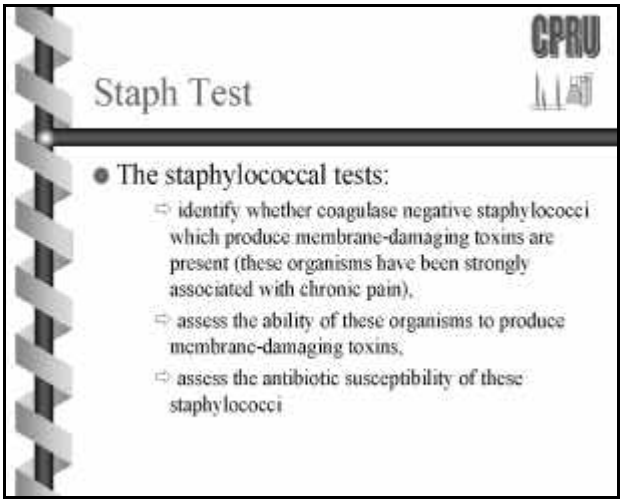


under 25 age group. We also looked at the difference between sudden onset and gradual onset patients. One group of sudden onset patients had no evidence of active viral infections but did report a history of a possible viral infection as a mechanism for their onset. A particular viral attack strategy is to impair essential fatty acid metabolism, which immune cells use to fight off potential infection. When looking at this in the literature, viruses can have a significant impact. A viral infection is likely to cause disruption to essential fatty acid homeostasis and the capacity to reconstitute a normal homeostasis is limited. Looking at the sudden and gradual onset groups we found they were differentiable by their fatty acid profiles, consistent with the reported effects of viral infection on the fatty acid homeostasis.

In autism, we can show that the controls are vastly different from autism and there are now a number of publications showing essential fatty acid deficits in autistic children. We also looked at a smaller number of attention deficit hyperactivity disorder patients. Because of these results we are now looking at stomach function in autistic children where anomalies exist in faecal analysis, indicative in some perturbation in stomach function and perhaps acid secretion.

Analysis of plasma lipids can identify specific anomalies. There is at least one very good study by David Horrobin which shows great efficacy in relieving pain using essential fatty acids in post Epstein-Barr virus patients. Using the right essential fatty acid supplements is very important. For example, fish oil is very high in arachidonic acid, a precursor to the pro-inflammatory prostoglandins. Whereas flax seed oil has no arachidonic acid and is high in α-linolenic acid, an omega 3 series essential fatty acid and precursor to the anti-inflammatory prostaglandins. These types of concepts are important in deciding optimal management programs for individual patients.

The final entity to focus on is the toxin-producing staphylococci strains we have consistently investigated in three primary studies. Pain severity was associated with the number of toxin-producing strains isolated. No toxin-producing strains



were isolated in the controls. The carriage of toxin-producing staphylococcus strains seems to be associated with the reported pain intensity. As the carriage of the toxin-producing strains increases, so does the magnitude of the catabolic response. These toxin-producing species may possibly be agents in instigating the catabolic host response and causing or contributing to the presentation of pain. In the same toxin profile, we found that cognitive symptoms followed a similar transgression.

Although we do not have clear evidence of a causal effect, there are very strong indicators that need to be followed through, looking a the toxin production by these organisms. We have produced a staphylococcus test to identify the toxic strains and we are working to develop specific polymerase chain reaction technology to really characterise the strains.

In concluding, I was asked by one of my colleagues to put this to you. If you look at the evolutionary history of

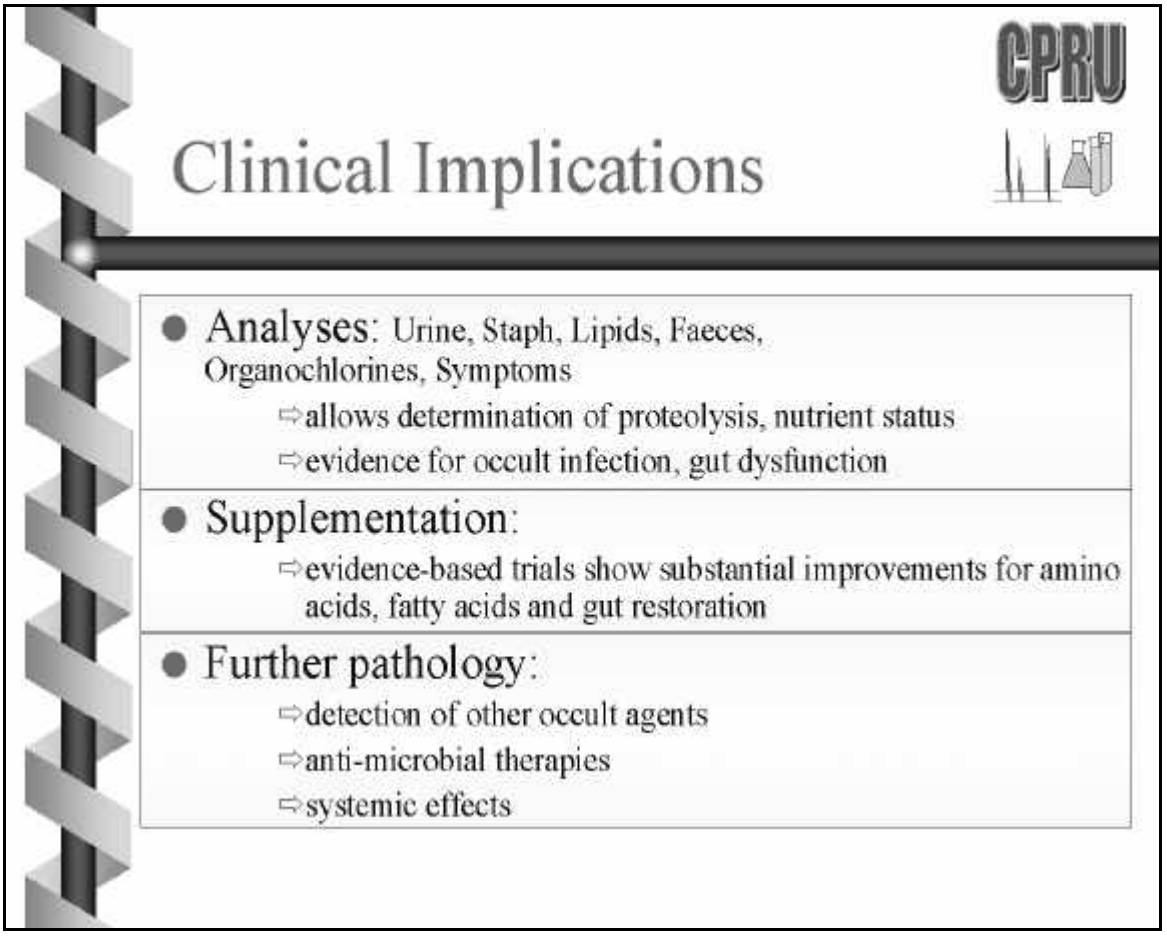
staphylococcus over the last three decades, the organism has evolved immensely to be resistant to antibiotic treatments. This is basically an example of evolution in progress. As we look at many of the non-infectious illnesses, it may well turn out to be that we a talking about pathogenic entities.

Recently discovered examples of infectious illnesses are helicobacter pylori in gastric ulceration and chlamydia with heart and vascular disease. We have heard about nano-bacteria, the size of viral particles and unknown until just a few years ago, which are now being found in kidney stones. The rickettsia and chlamydia, are also brilliant intra- cellular infectious agents.

In another example it was recently reported that a new bacterium had been found in crystal clear sea water. Modern analysis methods identified the most abundant biomass organism on the planet, unknown just one year ago! So we must keep our minds open, there might be organisms at bay that we just don't know about. Certainly our work suggests that at least some of the factors are suggestive of a host response.

To give a biochemistry example, not very long ago we had never heard of anadamides. These molecules represent a whole new set in biochemistry, acting in concert with the prostoglandins. Incredibly important in controlling emotional states, if you inject anandamides it gives a feeling of bliss and euphoria and this has cropped up in cannabis research and its effects on receptors. This could be very important in chronic fatigue and pain research, and I mention it because we are all learning about a whole new class of molecules which control vascular tone, intestinal motility and immune responses, and so are very important.

Trying to summarise all this work is difficult . One of the processes that underlie many patients with chronic illnesses such as in CFS or FM conditions, is proteolysis. There has been a net drain of amino acids and other organic acids and probably a lot of futile or vicious cycles in gastrointestinal performance and efficiency, with subsequent anomalies in gut and organ function. This process obviously involves the host response system, and I don't think that we can deny that that has occurred in a great proportion of the patients. If that can be developed or integrated into a management program, then it might bring some relief to the patient. The challenges are multifactorial as we do not yet have a single disease causing entity that can be handled by a process of epidemiological investigation.



EVALUATING MEDICAL BREAKTHROUGHS

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

By Professor John Dwyer

How does an intelligent, interested but non expert lay person evaluate claims of "breakthroughs" in the area of medical science? Doing so without some guidance is becoming more rather than less difficult. Take the Internet, for example. An abundance (? over abundance) of information is available, but certainly cyber space has just as much nonsense as new science. I thought we should discuss this topic when another example of the difficulties to which I am referring popped up in our media last week. The news concerned the currently incurable condition known as Chronic Fatigue Syndrome or CFS. The name does a gross injustice to those suffering from the condition for it sounds relatively benign yet is anything but. Until we know more about the actual cause of the condition, however, it will be hard to come up with a more accurate title.

Breakthrough stories are always more poignant when they deal with incurable diseases as sufferers will naturally find their hearts leaping into their throats as their hope of relief is renewed by this story or that. Since the 1850's numerous reports of a highly recognisable illness, now known as CFS, have peppered the medical literature. By international agreement, "establishment" scientists accept a diagnosis of CFS in a patient who for more than six months has suffered a complex of symptoms that feature grossly abnormal fatigue after minimal physical activity, muscle aches and pains of a particular type most commonly affecting the shoulders and neck, difficulties with concentration and short term memory and quite often a feeling that one is constantly suffering from a flu-like infection. Headaches and sleep pattern disturbance are also common. Whilst some patients gradually slide into this condition it is common for the illness to be precipitated by a virus infection or something that has the features of such an encounter. Certainly in our community we see many cases following infection with the herpes family of viruses (particularly the Glandular Fever Virus) and Ross River Virus. Only one doctor is capable of actually curing the problem. I am referring here to "mother nature" who fortunately rescues most patients from this dismal condition. The rest of us continue our research and try and supply encouragement and relief of symptoms.

Now, good research in the last two decades has taught us a lot about this very real illness but the exact cause remains unknown. We know, for example, that the disease is not fatal (unless depression leads to suicide; it is a miserable condition) and indeed for researchers one of the great puzzles remains the excellent general health of patients with the disease. How can all one's vital bodily functions be working so normally when one is feeling so terrible? Two tantalizing clues that might help us answer that question came our way about 15 years ago. It was discovered that the symptoms we all experience when we get, for example, the flu, are not directly caused by the virus itself but rather by the chemicals our immune system releases to deal with the invader. When some of the chemicals in question were purified and found to help patients with, for example, chronic hepatitis caused by viral infections it was observed that the injection of the immunological chemicals produce all the symptoms of CFS. Suffice it to say for our purpose this week, that modern research has demonstrated that a very high percentage of patients with a convincing story for CFS have chronically activated immune systems as if they are always at war with the world. While this could result from abnormalities in the way the immune system is controlled the truth is we have yet to discover the reason for such phenomenology. We know genetics plays a part as the problem can run in families.

Let me tell you about last week's story wherein health professionals and the public, especially those suffering from CFS, were invited to hear lectures from a husband and wife team who swept into town from Western Australia. They claimed that CFS was a bacterial disease and that the title really encompasses a whole range of other conditions such as Gulf War Syndrome, Multiple Chemical Sensitivity, etc etc, all linked to the same problem. The couple claim that an organism that commonly causes pneumonia in our community suppresses the immune system and reactivates viruses lying dormant in our bodies. They suggest that the addition of some good bacteria to the bad ones that inhabit the intestinal tract of patients with this disease can produce significant improvements.

Well this is not the place to debate in detail each point described above but you should know that there is absolutely no convincing scientific data documented in any of our respectable medical journals that would move these concepts from the hypothesis stage to established fact. Indeed there is much published evidence to make these assumptions unlikely to be true.

So how can the lay person evaluate such claims? You certainly won't get a great deal of help from our media. Investigative journalism to help put such claims (widely broadcast last week) in perspective is a rarity in Australia where our media is addicted to sensationalism and has no respect for a concept that claims such as those we are discussing, should always be balanced by a comment from those who deserve to be regarded as experts in the field. No, the average lay person needs to look elsewhere.

It is always a good idea to start by checking the credentials of the individuals involved in putting forward claims for breakthroughs particularly looking at their record for publishing the data they are describing in peer reviewed journals of good repute. Good science is always published before it is publicised as good journals always demand that of their authors. Be suspicious of the lecture you are invited to that involves a fee and discusses unpublished results. Never accept the excuse that "as we are not part of the establishment we don't have sufficient money to publish all our observations". Be particularly wary of "scientists" who are selling you something directly or indirectly especially if they are linked to a company which in fact sells something they recommend to you. When it comes to diagnostic tests, if such tests are claimed to be part of a research program, you should not have to pay for that test.

The world of science moves forward because of the development of hypotheses. The best ones are usually generated from an understanding of research done to date in an area. Sometimes a truly lateral thinker comes up with an important and really novel hypothesis. Such items are welcome if there is a knowledge background that allows the innovative thought to be recognised as just that rather than nonsense. Problems arise when good or bad hypotheses are presented to an uninformed audience as if they were factual. Certainly suggestions that any one simple approach (for example, the addition to the diet of "good" bacteria) can cure a myriad of essentially different ills should engender skepticism. For those involved in a struggle with serious and/or incurable diseases and where understandably emotion may overrule

intellectual analysis, I can give you no better advice than to discuss any claims you come across with your own doctor who knows you well and who is trained to evaluate scientifically these "breakthrough" stories.

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How Significant are Primary Sleep Disorders and Sleepiness in the Chronic Fatigue Syndrome?

Sleep Res Online 2000;3(2):43-8

Le Bon O, Hoffmann G, Murphy J, De Meirleir K, Cluydts R, Pelc I.
Brugmann University Hospital, Brussels 1020, Belgium.

In order to study both the prevalence of Primary Sleep Disorders (PSD) and sleepiness, and their association to the Chronic Fatigue Syndrome (CFS), 46 unselected outpatients (34 women, mean age 36.5) were examined clinically and underwent two nights of all-night polysomnography and multiple sleep latency tests (MSLT). Forty-six percent presented with a Sleep Apnea/ Hypopnea Syndrome Index (AHI>=5), 5% with a Periodic Limb Movements syndrome. No subject received a diagnosis of Narcolepsy or Idiopathic Hypersomnia. Thirty percent showed the presence of objective sleepiness as measured by MSLT<10 minutes. Objective and subjective measures of sleepiness were not associated with CFS, nor with the double diagnosis of CFS and a PSD. The presence of PSD or sleepiness was not associated with any of the clinical scales that were used to measure anxiety, depression, somatisation, physical or mental fatigue, or functional status impairment. Fifty-four percent of CFS patients had no PSD, and 69% no sleepiness. These patients could not be distinguished clinically from patients having a PSD or from those with sleepiness. Therefore, it is unlikely that CFS is simply a somatic expression of any PSD observed in our sample or of sleepiness per se.

Relationship of brain mri abnormalities and physical functional status in chronic fatigue syndrome

Int J Neurosci 2001 Mar;107(1-2):1-6

Cook DB, Lange G, DeLuca J, Natelson BH.
Department of Neurosciences; UMDNJ-New Jersey Medical School, Newark, NJ 07103, USA.

Chronic Fatigue Syndrome (CFS) is an unexplained illness that is characterized by severe fatigue. Some have suggested that CFS is a "functional somatic syndrome" in which symptoms of fatigue are inappropriately attributed to a serious illness. However, brain magnetic resonance imaging (MRI) data suggest that there may be an organic abnormality associated with CFS. To understand further the significance of brain MRI abnormalities, we examined the relationship between MRI identified brain abnormalities and self-reported physical functional status in 48 subjects with CFS who underwent brain MR imaging and completed the Medical Outcomes Study SF-36. Brain MR images were examined for the presence of abnormalities based on 5 general categories previously shown to be sensitive to differentiating CFS patients from healthy controls. There were significant negative relationships between the presence of brain abnormalities and both the physical functioning (PF) (rho=-.31, p=.03), and physical component summary PCS (rho=-.32, p=.03) subscales of the SF-36. CFS patients with MRI identified brain abnormalities scored significantly lower on both PF (t (1,46) =2.3, p=.026) and the PCS (t(1,41) =2.4, p=.02) than CFS subjects without an identified brain abnormality. When adjusted for age differences only the PF analysis remained significant. However, the effect sizes for both analyses were large indicating meaningful differences in perceived functional status between the groups. These results demonstrate that the presence of brain abnormalities in CFS are significantly related to subjective reports of physical function and that CFS subjects with MRI brain abnormalities report being more physically impaired than those patients without brain abnormalities. PMID: 11328679

PLEASE HELP YOUR SOCIETY BY RENEWING YOUR MEMBERSHIP AS SOON AS POSSIBLE

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

The ME/CFS Society (SA) Inc.

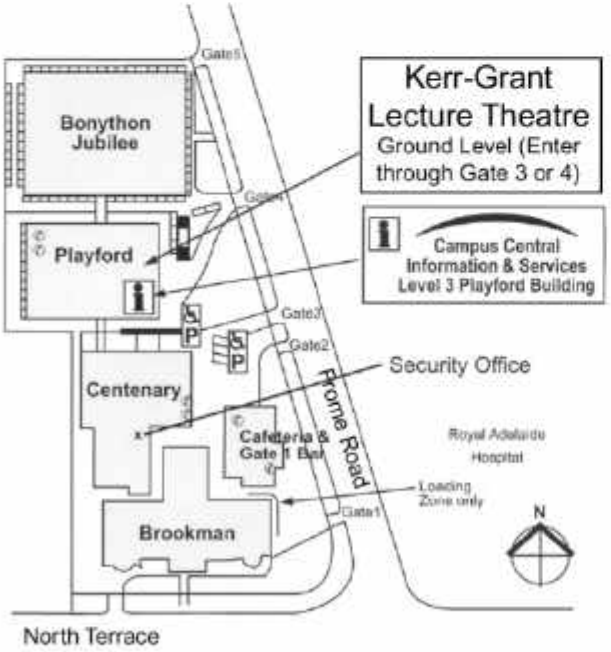
invites you to a:

PUBLIC MEDICAL SEMINAR

A REPORT ON EXCITING NEW SPECT SCAN (BLOOD FLOW TO THE BRAIN) RESEARCH BEING CONDUCTED INTO ME/CFS - A COLLABORATIVE EFFORT BETWEEN THE Q.E.H. AND R.A.H. - PLUS NEW RESEARCH BEING CONDUCTED BY DR. BURNETT / PROFESSOR SCROOP

Speakers: Dr. Rey Casse (RAH), Dr Peter Del Fante & Dr Richard Burnett

SAT. AUG 11th 2001, 1:10 pm for 1:30pm



Location

Kerr-Grant Lecture Theatre, University of South Australia
Entrance at ground level off Frome Road (Enter through gate 3 or 4)

Arrival

Registration starts 1:10pm for a 1:30pm start. Please allow time for parking.

Costs

Members: $4 (GST inc.)
Non-members: $7 (GST inc.)
Members will need to show either their 2000-2001 or 2001-2002 membership card to obtain discount.
There will be facilities to join the society on the day.

IMPORTANT NOTE: Please refrain from wearing hair spray, aftershave, and other perfumed products, to ensure this is a safe environment for those with chemical sensitivities.

Members: Please support your society by inviting interested friends and health practitioners along to this event!

Upcoming Events

Get-Together: July 21st 12:30 pm start
DIRC 195 Gilles St Adelaide
Bring a plate of food to share

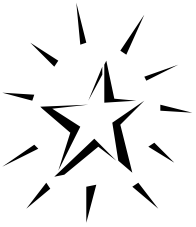
It would be great for as many of you as possible to come along and take some time to get to know each other a little better.

Speaker: Judy Lovett on the National ME/CFS Association of Australia. (Stop Press: We will also spend some time disucssion the Guidelines for Chronic Fatigue Syndrome whose second draft has just come out. We will provide a short, sharp and shiny overview of them and will explain the effect they will have on us.

ME/CFS Society Office Open Day
WED August 1st, 10 am – 4 pm
Room 510, 5th Floor Epworth Building, 33 Pirie St, Adelaide

Come along and see our new office. Drop in for a cup of coffee and meet the various members of the management committee.

Public Medical Seminar
August 11th 1:10 pm registration for 1:30 pm start



Full details on adjacent page. Please allow time for parking and registration before we begin at 1:30 pm.

Speakers: Dr Rey Casse, Dr Peter Del Fante and Dr Richard Burnett

PLEASE SUPPORT YOUR SOCIETY BY INVITING OTHERS ALONG!

SOCIETY MATTERS

Know anyone who has ME/CFS but isn't a member of the society?

Invite them along to the May 12th event and let them see what the society can do for them.

The larger our membership, the greater our clout! Clout means funding, and funding means services.

We would like a minimum of 500 members to have a significant voice. Help us raise this membership by telling family and friends – convince them to stand with us in our cause and have them become members too.

Thankyou

to all those who have recently made donations to the Society. Your generosity is appreciated.

The

Allergy and Chemical Sensitivity Association.

For people with

- **Food allergies / intolerances**
- **ME/CFS**
- **Chemical Sensitivites**
- **Hyperactivity – ADD**

Answering Service
(08) 8214 1548
PO BOX 104
North Adelaide
5006

Services: 4 Magazines / year, answering service and access to a library of reference materials

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Tidying up the year 2000

The year 2000 had its ups and downs. Rightly or wrongly it was decided not to publish the President's report in the December Talking Point.

On Feb 10th, at a special General Meeting of the Society, the caretaker Management Committee promised to investigate the concerns raised by the outgoing president in his report, and publish our findings in TP.

Following is a report by Bill Daniels who was president for roughly the first 9 months of the previous Management Committee's term. Between this report and the outgoing President's report we get an overview of the whole year.

You will find a copy of the outgoing president's report following, and the Management Committee's report on the state of the society.

The Management Committee

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

President's Report November 1999 – September 2000

I am grateful to the new Committee for giving me the opportunity to say good bye from my time as President.

The Society has gone through many personnel changes in the past few years. In an attempt to reduce the re-invention of the wheel, a major focus of the new management committee was an attempt to improve record keeping and to find a sense of accountability, which should give a boost to self esteem and a strengthening of the Society.

As already documented, the year had its fair share of turmoil, built on a lack of managerial experience, illness, conflict of interests and personality clashes and a failure to stick to/develop clear goals that all Committee members respected and understood.

Earlier in 1999 I had written "An Orientation Program to the Society", and Cathie and I delivered it to eight eager members. It was to set the standard for all servants of the Society from Committee people, through our service arms and to include all new volunteers. Unfortunately lip service was paid to subsequent induction, as the need for the day to day running of the Society was seen as more important. Without a corporate training program, our organisation may continue to struggle, as well-meaning servants may not have the understanding of the aims and objectives of the Society, the structures already in place and an awareness of the methods of using them.

Despite some negativity, there were some real growths for the Society:

- the new Treasurer set about developing an accurate recording system;
- the Secretary overhauled the filing system, with the help of volunteers;
- the Volunteer Project was defined, with the attempt to evaluate the availability of resource people and so offer those services;
- the position of Membership Officer was create to manage these records;
- more Country Support Groups and Contact People were established;
- more structure and support for the Telephone Support Line;
- the development of an advisory panel for the Committee, made up of a past President and an understanding Medical Practitioner;
- the seeds were sown for the Information Project;
- Development of the SAYME website

I have not named people involved, as they have been mentioned in my earlier reports, but their collective effort gave your Society purpose.

On a personal note, it was good to be approached WEA to develop and present a course on Managing Chronic Fatigue Syndrome – which I've been able to do 3 times - and use that opportunity to raise awareness about the society to non-members.

A range of interesting speakers enlightened those members who were able to go to the Quarterly Meetings from Disability Action, Centrelink and SAYME. The Committee and friends went to great lengths to provide a trading table, raffle and afternoon tea, to give us all a chance to socialize briefly after meetings.

Awareness Week culminated in a brave gathering of over 100 people (torrential rain, with local flooding!) participating in a meeting to hear Dr Ian Buttfield, Tania Emms and Dr Henry Butt talk of their research as members of the Collaborative Pain Unit at the University of Newcastle. The Newcastle group has offered a lot of hope to our members in recent years and it was good to hear of future developments.

A monumental change, which was beyond our control, was the shift to new premises. We are very grateful to DIRC for allowing us the extended tenure at DIRC, but the independence, with economic rent presented a real challenge. Teams from the Committee viewed and evaluated over a dozen possible locations ever aware of the constraints of travel, parking, chemical sensitivities, and physical access for our members. I actively encourage members to visit the new facilities in Pirie Street, to experience the support our Society can give.

I know people have felt "threatened" by requests for help, but every little bit helps, and reduces the load for fellow sufferers, who have put up their hand. It is one of the major ways Our Society can grow.

I am humbled by the time people are willing to give to our Society. I wish the new Committee well, and hope the Society can continue to grow. I have appreciated the support and best wishes members have given me.

I believe we can all play a positive public role in increasing the awareness of ME/CFS, through openly challenging people to accept and understand our illness.

Warm regards,

Bill Daniels
20th June 2000

President's Report: 9th September – 25th November 2000

Presented by Harry Hup

Thank you all for making yourselves available for this AGM meeting 25th November 2000

As President of the Society since 9th September 2000 I have observed in brief the following:

THE SOCIETY

1. The Constitution in its present form is outdated and should be re-looked at.
2. Membership is down to 276 paid members to date and declining since 1998 when it was reported 124 previous members did not renew and now this figure has reached 201.
3. Working in an unstable style management and structure.
4. There is no manual/handbook that every new committee can refer to on how to access the requirements necessary to perform any duties, tasks and adherence to law requirements.

THE COMMITTEE

1. Inappropriate behaviour at meetings not befitting the Society, position and responsibilities.
2. The committee overextending itself in its services it wants to provide while the basic running of the organisation has extreme flaws, ineffective in many areas in particular its daily operations.
   e.g. 1) The income and expenditure statement for the year ending 30th June 2000, of which you have a copy, showing the year 1999 surplus of $59898 & the year 2000 a surplus of $30878 a fall of $29,020.00 – this means the amount was spent by July 99 committee and up to the June 2000 Committee. This is serious money and a large expenditure.
   2) In the September Talking Point on page 3 it has been reported to you "We are getting there" and on page 4 it is reported under membership 'coming along nicely' suggesting we might get up to 500 members but membership is down and our financial status does not look healthy and the bulk of the money is earmarked for Research which leaves an amount of some $12,000 for the Society to function on, at this rate I predict the Society becoming insolvent within a period of twelve months if no assistance is sought.

POLICIES

1. Lapsed members playing an effective, influencing and advising roles within the Society eg The Support Line Team is made up of 6 people which only has two (2) paid up members, but all Six (6) have been given the members database list which gives out all our personal information?
2. At the November committee meeting the whole committee voted that to have access to this type of information you must be a paid up members and reimbursed reasonable out of pocket expenses.
3. The Committee members must abide by the rules as per the Constitution and yet a sub-section of the Society can as it were please themselves and all providing very convincing arguments which is not extended to the committee members. Why rules for on and rules for others?

MEMBERS

1. members must also take neutral stance where possible to rumours and the like and not react to them instantly without going to the source or request for more information to gain proper outcome.
2. It is also the member/s responsibility to assist the Society in getting it right e.g. dare to ask questions, understanding the difficulties running a Society, become involved and not sit in judgement will all help towards the cause or whatever you think is necessary because your investing, by way of a yearly fee, in your own illness and health, which stands today at a maximum of $0.67 cents per week which is not even a pasty a week but some members wants service and/or consideration for a pasty with sauce and if at all possible a small carton of iced coffee, but one thing do not leave it up to the Committee members only to get it right because we are all in it together.

This ends my report for this period of 9th September till today 25th November 2000. Thank you.

M. E. / C.F.S. SOCIETY (S.A.) INCORPORATED

INCOME & EXPENDITURE STATEMENT FOR THE YEAR ENDED 30TH JUNE 2000

	2000	1999
INCOME		
Advertising	1365	1378
Concert ' Any Dream Will Do '		8022
Concert Donations		425
Donations (note 3)	8804	18261
Fundraising (note 4)	6010	9662
Interest Received (note 5)	2380	2153
Membership Subscriptions	8963	11093
Adelaide Bank Charitable Foundation	2606	2394
SBSA Staff Charitable Fund	750	
Community Benefit SA		4860
Alison Hunter Memorial Foundation (refund of expenses)		1650
Total Income	**$30878**	**$59898**
Less: EXPENDITURE		
Bank Charges	98	4
Books & Videos	1231	1217
Concert		6500
Conference (Alison Hunter Memorial Foundation)		1939
Consultancy (Fundraising)	1696	1200
Depreciation	2365	2128
Donation		100
Efamol	972	2034
Fundraising (Restathon)	2111	933
General Expenses	530	544
Gift Cards, Bookmarks	33	98
Insurance	2407	1907
Meetings	1635	1949
Newsletters & Printing	4317	5133
Photocopying	1081	333
Postage	3378	2296
Stationery Supplies & Advertising	3395	2418
Rent of Office	1128	572
Repairs & Maintenance	96	166
Research Donations (note 6)	6753	3530
S.A.Y.M.E. Expenses	1832	763
Subscriptions	580	225
Telephone	3999	3164
Training Fee	25	520
Travel	424	
Total Expenses	**40086**	**39673**
SURPLUS / (DEFICIT) FOR THE YEAR	**(9208)**	**20225**
	$30878	**$59898**

Report from the Management Committee

As a Management Committee we undertook on the 10th Feb at a Special general meeting to investigate and report back on the state of the Society, with reference to the outgoing president's (Harry Hup) report. (Because it has been referred to in the report on page 45, and in this report, a copy of the financial statement for the year 1999/2000 has been included on the previous page.)

Constitution: Advice on our constitution indeed suggests that the most basic template was used to construct our constitution. Whilst there is nothing 'wrong' with it, it is indeed need of a review to bring it up to date and more in line with where we are currently at. However the job of fixing it up is no small one – and will require a significant amount of attention to do the job properly, and in one hit. The Management Committee is yet to decide when it will undertake a review of it. We are agreed that any review should be comprehensive not piecemeal, and should involve consultation with members.

Membership: we are pleased to announce that since the last Talking Point (TP), things have picked up and we are up to 360 members. Low membership has been the product of leadership turnovers, run down services and few services for the long-term sick. We have addressed these issues beginning with TP which we have beefed up. Next we will focus on producing a range of information brochures. We have commenced analysis other group's information brochures, and programs for coping with long term illness.

Management Committee handbook/manual: This Management Committee has begun compiling a reference manual for Committee Members. At this stage we have included useful information regarding the role/ responsibilities of Management Committees. Before the year is out we intend to draw up a list of Standing Orders that the Committee is currently using, and we will document the various responsibilities/relationships we have with other organisations. This will help with continuity from this one to the next.

Expenditure: We are puzzled at the references to income/ expenditure. The figure $59, 898 is not the surplus for the year ending June 30th 1999 – it is the income. And similarly the figure $30, 878 is not the surplus for the year ending June 30th 2000 – it is the income. There was a fall in income of $29, 020 in the last financial year, as compared with the one before. The higher income was due to a successful grant applications, more donations, a concert & higher membership.

The financial statements therefore show that expenditure was virtually the same in these financial years (around $40,000). Thus the difference in surplus is coincidently equivalent to the difference in income over these two years. The difference in the profit of $20, 225 to the end of Jun 99 and the loss of $9,208 to the end of Jun 2000 is $29, 433 to be exact.

The question is 'why this turnaround' and it is largely due to a smaller income. Administration/office costs seemed to be a little up and we have tried to this point to minimise them, whilst maintaining services for members.

Policies: The new management committee doesn't believe that volunteers have to be members of the society to help with it. In fact we want to encourage 'outsiders' to get involved. The Society benefits enormously from the assistance of those who are not members; parents, friends, recovered former members to good-hearted members of the community. In fact, it would be difficult to maintain our services without their support and we thank them for it.

Is this legal? YES. The constitution requires only that management committee members be members of the society. We can sign on volunteers to work with us without them becoming members. With regard to confidentiality there is no problem. Like most organisations we have strict policies on maintaining confidentiality. Our volunteer manual has a section on this, and all volunteers are referred to that during orientation. Volunteers are required to sign a form agreeing to abide by the Rules and Constitution of the society. We see no problem in volunteers being exposed to members' information, as they are working under the same conditions and privacy protection requirements that would apply if they were paid staff.

We think it unfair that the Support Line workers were singled out in this document as they do a great job and provide a service to members – and we are especially thankful to those who do not have our condition and give of their time for us. We know from member-feedback that many have appreciated the 'friendly ear in a time of need' which these volunteers provide. So in this the International Year of the Volunteer we celebrate all volunteers – members and non-members alike!

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We do not believe that our society can run on membership monies alone – we require serious funding. The new Management Committee has formed a Grants Working Party, which has met several times and is in the process of gathering and writing up the materials necessary to write grant applications. We expect to apply for many grants over the next 12 months.

We are working flat out and to lay the foundations for a strong organisation. Expansion of services will require an expansion of our volunteer team.

Therefore the Society and it's Services currently reflect the combined effort of all of us. The Management Committee is currently working on 'overload' to bring us into line with the funding achievements of other states – through both government and private sources.

Until we can rely on outside funding, we are dependent on the finance and voluntary support of all members. This no-where more apparent than in office and management roles that are carried by paid staff in many similar organisations and sister societies. When this changes it would be a great pleasure for us to drop membership prices, but until this occurs we are left with little choice.

We look forward to a hugely productive and enjoyable year ahead. We thank members for their existing support and welcome your participation in our society's regeneration. At both a national and state level there are now tremendous opportunities for this society to represent members on the provision of services and education of health care providers.

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

Photo Gallery

Leader's Dinner, early May: (Across Back L-R) Peter Scott (our webmaster), Paul Leverenz, Margaret Whyatt & Margaret Wing. (in foreground) Stephany Retallick

May 12th Public Seminar: Paul Leverenz & Bill Daniels

ME/CFS Society Management Committee Meeting (L-R): Paul Leverenz, Beulah Carter & Peter Evans

Leader's Dinner, early May (Clockwise around): Vicki Foote, Luke Pullen, Peter Scott, Paul Leverenz, Margaret Whyatt, Margaret Wing, Bob Everitt, Peter Evans, Elaine Balfort, Beulah Carter, Stephany Retallick & Jon Foote.

Leader's Dinner, early May (Clockwise around): Margaret Wing, Peter Evans, Elaine Balfort, Beulah Carter, Stephany Retallick, Jon & Vicki Foot, Luke Pullen, Peter Scott & Paul Leverenz

ME/CFS Society Management Committee Meeting (L-R): Paul Leverenz, Beulah Carter & Peter Evans

VOLUNTEER POSITIONS AVAILABLE/HELP NEEDED

JOB DESCRIPTION FOR SUPPORT LINE WORKERS

- Take calls between 10am and 4 pm and give support/non-specific within the guidelines of the society.
- Document all calls made and received.
- Maintain confidentiality at all times.
- Keep up to date on the latest issues relating to ME/CFS.
- Notify the Support line co-coordinator or office of any issues relating to difficult calls etc.
- Ensure adequate supplies of materials for client information.
- Be aware of other agencies which clients can be referred to.
- Be able to attend at least one meeting per quarter (support line workers meet monthly usually on Wednesday).
- Is not required to possess counselling experience or knowledge of ME/CFS but is expected to be willing to learn (training provided if necessary).
- Is expected to undergo a police check and sign confidentiality and code of conduct agreement.

Assistance needed for Dr Rey Casse

Dr Casse is urgently looking for someone to gather and compile questionnaire data from the participants in his SPECT SCAN work (the pilot work they are doing is not funded and the researchers could use our help). If you are interested in helping leave you details with the office or the Support and Information Line, and we will get you in touch with him.

Assistance needed for Dr Richard Burnett

Dr Burnett urgently needs a volunteer to 'secretary' his latest studies which have limited funding. The job is not demanding but requires someone who is organised and who can co-ordinate bookings for subjects to the various components of the study.
This is a good opportunity to be involved in research, and get a feel for how the research world works. Once again, if you or someone you know is interested please let the Office or Support Line know.

Expand/develop your skills!!

Financial Assistant
(total 1-2 hours per week)

We require someone to assist the Treasurer with the bookeeping/reporting. We would prefer applicants to be computer literate as we explore ways of computerising our accounts. An applicant must obviously be good with figures, and be able to do budgeting and forward planning. Please be aware that the job is not that arduous as our small society doesn't have a huge volume of transactions per month.

Media Liaison
(average only 1-2 hour per week)

The society needs someone with skills / or willing to develop skills in writing media releases. Anyone interested in this job must be able to write well. Lack of experience is not an obstacle – we are prepared to arrange training for anyone willing take on this job for 18 months – 2 years, and train others at the end of this time. A great opportunity to expand your CV!

Membership Officer
(2-3 hours per week)

We require a volunteer with enthusiasm and ideas for this position. As well as keeping a record of new memberships each membership year, this job requires someone willing to explore ways to increase our membership, and who is prepared to follow up people who do not renew to find out why they haven't done so.

Advertising Consultant
(2 hours week)

We require someone to sell advertising space in Talking Point, and on our websites. Such a job requires someone who is positive, who has a good phone manner and who is willing to cold-call businesses. The role could expand as much as the person wanted it to. No experience necessary.

IF YOU WOULD LIKE TO HELP THE SOCIETY IN SOME WAY WE CAN MATCH YOU TO A TASK THAT YOU ARE SUITED TO BOTH IN TERMS OF SKILLS AND TIME COMMITMENT.

'Understanding and managing ME/CFS/CFIDS' Project

June 2001 Talking Point: The Official Journal of the M.E./C.F.S. Society (SA) Inc

A request to all ME/CFS/CFIDS associations and PWCs around the world to submit/nominate articles that help and encourage others with this debilitating condition

Aims:

1) To encourage and help persons with ME/CFS/CFIDS
2) To encourage global partnerships and goodwill between ME/CFS/CFIDS groups around the world.
3) To recognise those individuals / groups who have produced good work
4) To publicise online works of excellence
5) To provide a helpful resource to ME/CFS/CFIDS groups around the world

NOTE: The intention is to produce a down-to-earth, heart warming resource – literary excellence will not be put above a hearty and passionate communication.

The Project: To gather together articles that do at least one of the following:

1) explain the illness in simple terms
2) explain what it is like to have this illness eg symptoms, lifestyle changes, expectation changes etc…
3) offer 'management strategies' for persons with ME/CFS/CFIDS (either directly or simply by a personal account of how the author copes)
4) promote understanding of the illness to non-sufferers
5) offer encouragement and lifts the spirits of PWCs
6) identify and discuss flow-on issues such as mental and emotional wellbeing.

There is no set time-frame on when works were published, nor wether they have been published previously – pieces just have to be relevant to today. Pieces must be no more than 1000 words.

Publication:

Selected articles will be compiled in booklet form. The sort of copyright we are looking for could be called *'Society-ware'*.

Our intention is to make the masters of this booklet available to ME/CFS/CFIDS societies around the world to reprint in whatever format they require. Whilst the content cannot be altered, other societies may change the layout and form of the publication, and include their own preface/forward if they desire.

Our recommendation is for groups to sell the booklet for a small profit with all profits to go to the local society. Thereby all authors can have satisfaction in knowing their work is helping the cause of ME/CFS/CFIDS around the world.

Editorial Process

All submissions will be rated by a focus group of PWCs. This will form the basis for inclusion/exclusion, but we will retain the right to decide the final mix and balance of the publication.

Nominating another author's work

leverenz@picknowl.com.au

If you would like to nominate an article you found then please email me on the address above. Guidelines:

1) Please include a copy of the text OR the URL of the piece if it is online
2) If you are nominating someone else's work then please include the name and contact details of the author (if you are able)

Submitting your own work:

leverenz@picknowl.com.au
If you have written a piece and would like to offer it up to this project, then please email me on the address above. Guidelines:

1) Please make clear you are the author and give your permission for your work to be included in this project
2) Please include/attach a copy of the text in Test, Word or rtf document.
3) Please include the URL of the piece if it is online
4) Please make clear whether the work is unpublished.

Award

We will judge the best unpublished work submitted for this project, and recognise it by placing it on our website and publishing it in our journal.

Publicity

Acknowledgments at the end of each piece should include the author, their origin, and the ME/CFS/CFIDS group they are affiliated with.
For those authors whose work is online – whether on their personal website, or on a third party's site - full acknowledgment and a URL to the piece will be placed at the end of the article if requested.

Deadline

Nominations close August 31, 2001

Proposed Completion Date:

A list of the names of successful nominees will be posted on our website www.sacfs.asn.au by October 31st, 2001. As soon as possible afterwards the master-layout of the completed booklet will be emailed to ME/CFS/CFIDS groups around the world in an Word rtf document.

Vice-President
ME/CFS Society (SA) Inc.
Paul Leverenz

Full details can be found on our website at:
www.sacfs.asn.au

SOCIETY MATTERS: VICE-PRESIDENT'S REPORT Ctd...

(Continued from page 4)

be a distinct part of our brains, which isn't receiving the blood flow it should – and FM and ME/CFS patients can be differentiated between each other.

Dr Rey Casse (RAH) will give us an overview of their research.

Dr Burnett is also working with Professor Scroop at Adelaide Uni gut function, blood volume and bond density (once again, some of you may have been participants in it). Dr Burnett will briefly update us on that too.

Please mark this one in your diary.

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The Management Committee has undergone several changes since the last Talking Point. Farrah Tate has resigned due to her study commitments; she will be concentrating on Talking Point which in itself is enough work!

Peter Evans and Luke Pullen have joined the Management Committee and have been able already to make valuable contributions.

In our seemingly never-ending quest for a permanent Treasurer we have finally found one in Margaret Wing. We are so glad she has offered her services; thanks go to Marion Hansen who did a great job as an interim Treasurer until we found someone who could take the job on fully. Marion continues on the Management Committee.

We have been very lucky to receive assistance from SACOSS, who have provided funding for an auditor. Since this Committee was inducted, we have had to do a catch-up job Treasury-wise. Thanks go Fiona Thompson, Marion Hansen and Stephany Retallick who have got them under control.

It is a priority, once an audit is completed to the end of the financial year, that the Management Committee set out budgets for the next 12 months. This will ensure any new management committee coming into office will know where they stand from the beginning of their term.

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The Management Committee is pleased to announce that Lyn Rossiter has been made a Life-member of the Society for her many years of service as Talking Point Editor.

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We have many jobs ahead of us before we finish out our term as a management committee. Over the next few months we will be:

1) Updating our Information Brochures/Packs. We have already started work on this but it has been delayed and taking longer than first anticipated.
2) Updating our Doctor's list – in fact we are going to overhaul our list and set up criteria for GPs to be on our referral's list, and to work toward increasing the number of GPs on it. We also hope to list the treatments different clinicians use, so members interested in a particular type can be referred to a clinician using that treatment.
3) Embarking on a promotion campaign to encourage as many GPs as possible to take out a Talking Point subscription and work more closely with us.
4) Develop an OHS, Conflict Resolution and Harassment Policies
5) Increase support for Support Group Leaders
6) Apply for funding

The latter is so crucial if we wish to expand our services. Unfortunately, as with many other things, I had hoped to be further advanced in grant writing. The good news is we have done the bulk of the hard work to gather all the information we need to write good, solid grant applications. We just need to bring that stuff together and we are on our way.

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STOP PRESS: Just as this issue was about to go to print we have just received the Revised Draft of the Chronic Fatigue Syndrome Guidelines. A quick review of it shows there is little substantive change to their psychiatric/ psychological emphasis. This is disturbing.

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In conclusion, I hope we can all work together to build a strong society; no individual can make that happen – a team effort is required.

I wish you all the best with your illness-management, and hope that – despite obstacles – you can be an 'over-comer' and continue to discover new things in life worth living for!

Paul Leverenz
Vice-President

MEDICAL RECORDS?

How many of us could document the medical appointments and tests we have had over the last 5 years?

Not many I 'd suggest. And certainly not I.

However, if you are applying for the certain benefits you may be asked to provide records over such a period of time!

It would pay to keep a medical diary just in case you get asked for such detailed information.

This certainly applies if you move interstate and wish to apply for benefits – you need to show your history.

Chances are you may never have all that info at your fingertips, but I think it a case where its far better to be safe than sorry – especially with our memories!!

Paul Leverenz

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Duke of Edinburough Scheme

The Duke of Edinburgh Award Scheme
And now for something completely different....
The Society has recently become an Operator of the Duke of Edinburgh's Award. This means that young people aged 14-25 years in South Australia will be able to enrol in this Award under the management of the ME/CFS Society (SA) Inc. At both the Bronze and Silver levels of the Award, all supervision is co-ordinated through the Society.

So what does this mean?

Many eligible members will be surprised to find that they already participate in many of the activities which qualify for the Award. It's not all bungy jumping! We were thinking of calling it the ME/CFS Extreme Sports Club – after all, going to the shop is an extreme sport for many ill young people and the Award is most of all about achievement to an individual 'personal best'. However, it can be as active or inactive as is individually possible. The separate components which make up the Award offer us the opportunity to provide worthwhile activities which might ordinarily be organised by us but put all together make up an Award Certificate. So members can do as little or as much of the available stuff as they like. And if it turns out to be the Award – great. If not, still great. This is what the Award literature has to say about it's own philosophy

The Duke's Award began in Britain in 1956 and is now international. It has spread to nearly sixty countries and is known by some interesting names – The Prince Makhosini Award (Swasiland), The Crown Prince Award (Jordan), The Head of State Award (Ghana) and The Source of the Nile Award (Uganda). Many people in Australia give of their time to support the Award - our outgoing South Australian Governor, Sir Eric Neal, was formerly the National Chairman in Australia.

So why do we want to do this?

To re-confirm to young members the worthwhile contribution they are already making to our community and themselves. To group a structure of activities to promote safe 'pushing of personal boundaries' for each individual. To enable young members to see themselves as adventurous, risk-taking and 'normal' – whatever that means for them.
Yes, it might mean a trip to the shop if you've been bed-bound for a year – that's a major achievement! It might mean abseiling, knitting, cooking, pet care, reading, sailing, internet browsing or horse-riding. The program can be structured around many limitations.

Over the page is a table outlining some of the Duke's Award suggested possibilities (some I've obviously included for fun).

The final expedition or exploration component is a little different. It involves spending (for Bronze) at least one night away on the trip. We're planning an end of year (schoolies week) camp in mid-December in which all the components of this area will be catered for. For instance, with the expedition choice there's a requirement to know how to put up a tent – but no requirement to sleep in it. There's a requirement to plan the food, but others can cook it. Alternatively, an exploration can be undertaken which can be exploring any unfamiliar environment, for example, lying on blankets and cushions and watching wildlife. It can be a visit to a facility or attraction which has never been seen before. Both of these options will be available at the camp. We're planning comfortable, heated accommodation in the Grampians and hope that there will be something on offer for many types of needs. There are nearby services which will

A few facts about the Duke of Ed Scheme

Non-competitive

The Award is a personal challenge, not a competition against others. The only set standards are those necessary to ensure the safety of participants. The Award Program is based upon personal choice and should reflect the abilities and interests of the individuals.

available to all

There is one Award which is available to all, with no discrimination on the grounds of gender, cultural background, religion or political affiliation. An Award is gained through individual improvements and achievements.
voluntary
The Award is run by volunteers for volunteers. Every young person makes a free choice to enter the Award and must commit leisure time to complete the activities.

flexible

The Award program can be adopted to fit local facilities and should be designed for the individuals taking part.
balanced
Whatever the level, there are four sections (five at Gold). The challenge is to extend and develop existing abilities and to try something new.

progressive

Through it's levels the Award demands more time and an increased degree of commitment, improvement and responsibility.

achievement focussed

The Record Book notes positive achievement across a broad range of activities.

marathon not a sprint

The Award demands a persistence and commitment and cannot be completed in short bursts of enthusiasm
(help – Ed.).

Process not a prize

The Award is a process of personal and social development and the program and activities are a means to that end. It should introduce participants to a range of new opportunities, allow them to learn from their experiences and enable them to discover hidden capabilities and talents.

enjoyable

Above all, it is important that both young people and their adult helpers find participation in the Award enjoyable, exciting and satisfying.

come to the camp such as the Aboriginal Cultural Centre. This camp will be also available for other young persons in Australia with ME/CFS. An Australian first I think.

So what about the cost?

We're planning for little or no cost to participants (who will need more than the usual amount of paid or special support for activities). This means donations from members, grants and service clubs. More on this next issue – but please get in touch if you've got any ideas.

Most importantly, each Award can be completed over many years. We've all lived with that before. With this however, the Society can award official certificates for the completion of each of the 3 areas outlined below and the expedition – and provide ongoing support with programmed activities regardless of whether the member chooses to eventually complete the Award.

I'll keep you posted. We (at least some of 'we') go wall-climbing soon as part of the Society organised Activity Program! Perhaps on the day we'll just do that one as an exploration....or not. We're not tied to any expectation when the 'personal best' marker is continually changing.

Steph Retallick
Society's Duke of Ed Co-Ordinator

For more information please contact Steph Retallick, Duke of Edinburgh Award Co-ordinator
C/- ME/CFS Office.

In the Skills Section	In the Physical Activity Section	In the Service Section
Arts and crafts Meteorology Chess Computer programming Guitar playing Toy making Religion Aeroplane modeling Cinematography Confectionery Dog handling Interior decorating Knitting Puppetry Film-appreciation Plant study Bird observation Or something completely different	Karate Abseiling Archery Horse-riding Bowling Table tennis Bird watching Tai Chi Qong Walk in the park Rock climbing Sailing Dancing Go to the shop! Go outside! Participate in the Society run Activity Program	Publish the SAYME mag Organise a SAYME event Help run SAYME! Sunday School teaching St John's Ambulance Help in the Society Office Write articles for us Mentor another member Do artwork for our publications Take photos of our events or find something away from us!

A FEW TIPS ABOUT NEW TREATMENTS

1. Beware of miraculous new treatment stories which appear in the media from time to time. Always look for treatments which have some scientific evidence of effectiveness, such as those backed by clinical research trials.
2. Always consult your medical practitioner before starting a new treatment.
3. Do a bit of research before try a new treatment: ask around about it at the very least.
4. Be wary of those claiming good results from a particular product that they are selling. Their commission might be colouring their story.
5. It is best to try only one new treatment at a time, so you can be certain of what is actually helping/aggravating your condition.
6. Very few treatments are without side-effects. Sometimes you must weigh the good against the bad.
7. Don't be discouraged should a particular treatments fail to work for you. ME/CFS is a confounding illness. Some treatments can have dramatic effects on only a small percentage of sufferers, and not benefit the rest.
8. Pace yourself – don't tire yourself out by trying too many treatments in a rush.

JOIN THE TALKING POINT TEAM

We are looking to expand our Talking Point team. We need the following: 1. health professionals to act as advisors and/or write articles for Talking Point. 2. Someone who is able to track down journal articles for us. 3. someone with some medical background who can do background research on specific topics, and prepare materials for our planned medical advisory team. 4. people to scour the internet for interesting articles and to look out for developments in the ME/CFS world.

IF YOU ARE INTERESTED THEN PLEASE CALL THE OFFICE: 8410 8929.

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SUPPORT GROUPS: METRO

CONTACTS

Adelaide Support Group

4th Wed of the month
Venue: (Trial Venue) ME/CFS Society Office, Room 510, 5th Floor Epworth Building, 33 Pirie St Adelaide
Time: 1:15 pm – 3:15 pm Date: 25th June
For locations on 22nd Aug. and 26th Sept ring the Support Line a few days before.

Glenelg Support Group

3rd Wed of the month
Usual Venue: Cinema Centre Coffee Lounge, Jetty Road, Glenelg
Dates: 18th July, 15th Aug, 19th June
Time: 1 pm
Please ring the Support and Information Line to confirm details: **8410 8930**.

North Eastern Social & Support Group: 'Better Together'

2nd Wednesday of each month
Location: 3 Irene Ave, Hope Valley
Date: 11th July, 15th Aug., 10th Sept.
Time: 1:30 pm – 3:00 pm
Phone: Julie on **8264 0607**

Southern Suburbs Support Group

4th Monday each month
Venue: Happy Valley Church of Christ (Cnr Windebanks Rd and Hub Drive, Aberfoyle Park)
Date: 23rd July, 27 Aug, 24 Sept.
Time: 1 pm-2:30 pm
Phone: Daryl **8322 0329** for more details.

Western Support Group

Apologies to any members who have turned up for this group and found the meeting was not on. We have suspended the commencement of this group.

SUPPORT GROUPS: COUNTRY

Northern Yourke Peninsula CFS Support Group

Venue: Community Health Centre Wallaroo
Phone: Jane 8826 2097

Murray Bridge Support Group

Venue: Murray Mallee Community Health Centre
Date: 1st Wednesday of the month 10:30am.
Phone: Fran McFaull (Dietician) **8535 6800**

Southern Fleurieu Support Group

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

MEMBERS MAY PLACE SMALL ADS IN TALKING POINT AT NO CHARGE

(subject to advertising policy on page 3)

SA Support Groups

Adelaide City	Support and Info Line	8410 8930
Aberfoyle Park	Darryl	8322 0329
Glenelg	Marion	8234 2342
Murray Bridge	Fran	8535 6800
North Eastern	Julie	8264 0607
Northern Yorke Peninsula	Jane	8826 2097
Southern Fleurieu	Melanie	8552 0600

Misc. Support Contacts

Highbury	Pat	8264 9328
SAYME	Paul	0500 523 500
SAYME Parents	Marg	8276 5353

Country Support Contacts

Barossa Valley	Dennis	8563 2976
Murray Bridge	Fran	8535 6800
Port Lincoln	Jade and Pauline	8683 1090
Port Pirie	Marj	8633 0867
Riverland	Ros	8588 2583
Northern Yorke Peninsula	Jane	8826 2097
Victor Harbor	Melanie	8552 0600
Whyalla	Peter	8644 1897
Yorke Penisula	Glenys	8837 6375
Yunta	Gloria	8650 5938

YOUTH SUPPORT GROUP: SAYME

Parents Welcome

SAYME meetings are actually 2 meetings in one – one for youth, one for parents. Two separate rooms are provide at each venue – one for each of these groups to chat away independently of the other.
Last Friday of the Month 7:30 pm
PH: **0500 523 500** for more details

TOASTER OVEN NEEDED

Do you have a bar fridge you could give or sell cheaply to the society? We desperately need one in the office.

STORAGE NEEDED FOR WHEEL CHAIR

The society has a wheel chair that can be hired for a nominal fee. it is taking up valuable space in the office – could you house it for us until it is needed?

INFORMATION ABOUT ME/CFS

WHAT IS ME/CFS?

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

HOW IS ME/CFS DIAGNOSED?

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

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

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

2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

HOW IS ME/CFS TREATED?

Treatment for ME/CFS is intended primarily to relieve specific symptoms. It must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies and depression are some of the symptoms which can be relieved through the use of prescription drugs, over-the-counter medications and other interventions such as physical therapy. Persons with this illness **may have** unusual responses to medications, so extremely low dosages should be tried first and gradually **increased as appropriate.**

Lifestyle changes, including increased rest, reduced stress, dietary restrictions, nutritional supplementation and minimal exercise are recommended frequently. Supportive therapy, such as counselling, can help to identify and develop effective coping strategies.

ME/CFS strikes people of all age, ethnic and socio-economic groups.

Carefully designed studies have yielded estimates that more than 800,000 adults in the U.S. have ME/CFS. In women, ME/CFS is more common than multiple sclerosis, **lupus, HIV infection, lung cancer and many** other well-known illnesses.

DO PWCs [persons with CFS] GET BETTER?

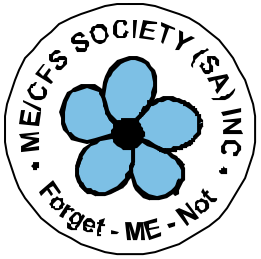
The course of this illness varies greatly. Some people recover, some cycle between periods of relatively good health and illness, and some gradually worsen over time. Others neither get worse nor better, while some improve gradually but never fully recover.

The CDC [USA Center for Disease Control] is conducting a long-term study of PWCs to learn more about the course of illness. CDC investigators have reported that the greatest chance of recovery appears to be within the first five years of illness, although individuals may recover at any stage of illness. Investigators have also found an apparent difference in recovery rate based upon type of onset. PWCs with sudden onset reported recovery nearly twice as often as those with gradual onset. This study is ongoing and observations about the course of illness are likely to change as more data is collected.

This document is based on another appearing in the CFIDS Chronicle – itself an *abridged and* up-to-date version *of* "Understanding CFIDS," a comprehensive, 16-page *booklet about ME/CFS published by The* CFIDS Association *of* America. Minor changes have been made to replace 'CFIDS' with 'ME/CFS' in several places.

We are working towards producing our own document, relevant to Australia. As more studies are conducted in Australia we will be able to provide numbers of sufferers, average length of illness and demographic breakdowns specific to our country.

ME & You, ME/CFS Society of NSW Inc., Royal South Sydney Community Health Complex Joynton Ave., Zetland. NSW 2017.
Emerge, ME/CFS Society of Victoria Inc., 23 Livingstone Close, Burwood Vic 3125.
Queensland ME Quarterly, Queensland ME/CFS Syndrome Society, PO Box 938, Fortitude Valley Qld, 4006.
ChaMEleon, ACT ME/CFS Society, Shout Office, Collett Place, Pearce ACT 2607.
ME/CFS News, ME/CFS Society W.A. Inc., c/- WISH, PO Box 8140, Perth, WA 6000.
The CFIDS Chronicle, CFIDS Association, PO BOX 220398, Charlotte, NC28222-0398, USA.
Perspectives, Myalgic Encephalomyelitis Association, Stanhope House, Hight Street, Stanford le Hope, Essex SS17 OHA, UK.
Country Network, Journal of the Northern Rivers ME/CFS/FM Support Assoc. Inc. PO Box 6024 Lismore NSW 2480.
MESA News, ME Association of South Africa, PO Box 1802, Umhlanga Rocks 4320, South Africa.



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