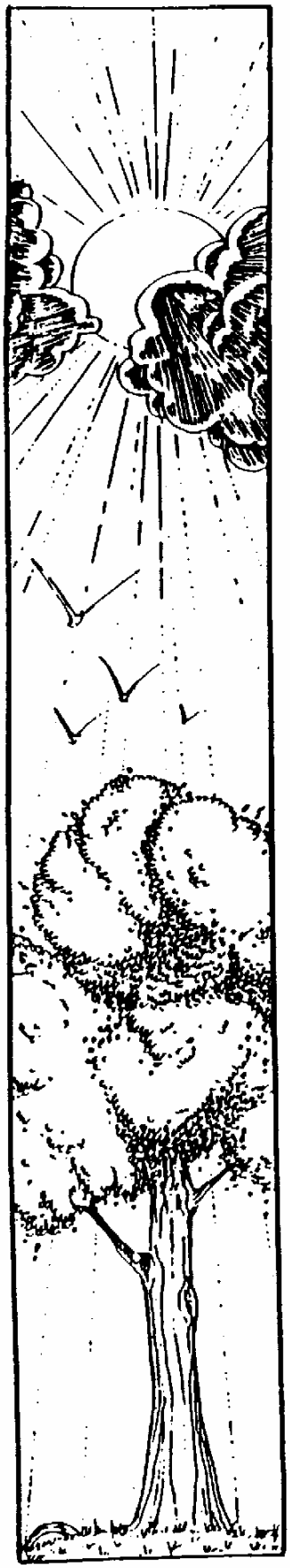

ME

POST-VIRAL / CHRONIC FATIGUE SYNDROME

BURY/BOLTON ME/CFS SUPPORT GROUP

'Breaking the Isolation'

Newsletter 37

Summer 2008

Supported by

HEALTH FOR BOLTON

The Bury/Bolton ME/CFS Support Group was founded in September 1990

CONTENTS

GOOD NEWS

At our meeting with the ME/CFS clinic team in May we were informed that the budget for the team has been significantly increased on a recurrent basis.

This will mean that there can be an increase in the staffing levels so that we will have an extra 0.5% Occupational Therapy, 0.5% extra Physiotherapy and an extra 10 hours extra for counselling.

All this will ensure that more people can have one to one service with special emphasis on pain relief and pain management. It is also hoped that more help can be offered to the severely affected in their own home.

It is vital that we obtain as much good quality information as possible about the number of severely affected patients and their needs. Please let Pam know if you are severely affected and if confined to your home and whether or not you receive any care at present from the Health Services or your GP.

DATE FOR YOUR DIARY — FRIDAY 10TH OCTOBER 2008

Dr Vance Spence of ME Research UK, a leading National charity, funding biomedical research into ME/CFS and energising ME research globally.
This promises to be a fascinating update on ME research in the UK and around the world.
Starting at 11 am at the Toby Carvery, Heaton Chapel, Stockport this will be an open meeting for ME Groups across the North West

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A big thank you to everyone who has rejoined the group for another year, funds are especially tight due to lack of grants. If you would like to renew your subscription to continue to receive the flyers and the newsletters, send your details with a donation of at least £6 please to: Kim Finney, Treasurer, Bury/Bolton ME/CFS Support Group, Wits-End, 19 Hillstone Close, Bury, BL8 4EZ. If you have forgotten whether you paid or not, you would have received a membership card if you did. Cheques payable to Bury/Bolton ME/CFS Support Group please, all donations are greatly appreciated!

Don't forget the group gets 5% commission on all your purchases from Amazon.co.uk if you follow the links from our website, **www.mesupportgroup.co.uk**. Click on any Amazon images or the amazon.co.uk link in the left-hand-side navigation bar, and then make a purchase within 24 hours and we get money for referring you. Thanks to people making some large purchases we have made quite a lot from this. You can do all your gift shopping on Amazon.co.uk - they sell CD's, DVD's, shoes, books, electronics, games, home & garden items, kitchen gadgets, jewellery, exercise equipment and more. There is free shipping when you spend over £15 on most items. This is an easy way to support the group. Thank you!

Would anyone like to receive the flyers and newsletter by email instead of post? Postage is our biggest expense so please let me know on 01204 525 955 or email caroline@mesupportgroup.co.uk if you would like email instead of postal contact.

Support Group Information Sheet

A reminder of who is what during 2007/8 with Telephone numbers for contact if required

Support Group Leadership

The 'Bury/Bolton ME/CFS Support Group' is managed by a Committee of 8 Members: -
Pam Turner, Margaret Benn, Ann Richards, Caroline Higson, Maria Sale,
Sheila Myerscough, Stephen Walker, and Kim Finney,

Support Group Posts

Group Contact / Welfare & Benefits Advice:	Pam Turner	01204 793846
Treasurer:	Kim Finney	01204 882826
Minutes Secretary:	Margaret Benn	0161 761 2723
Web Master, Membership Secretary, and Newsletter Distribution:	Caroline Higson	01204 525955 **caroline@mesupportgroup.co.uk**
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Meetings Secretary:	Maria Sale	01204 575613
Parent's Contact:	Kim Finney	01204 882826
Link Up Co-ordinator:	Stephen Walker	01204 842395 **stewalker@postmaster.co.uk**
Librarian:	Vacant	
Door at Meetings:	Sue Forshaw	01204 883506

OUR MEETING DATES FOR WINTER 2008

Meetings are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, usually on the third Thursday of each month from 7.30pm until 9pm, except in April, August and December when there is no meeting but our newsletter goes out. We started to meet here formally as a support group in September 1990 after several years when we met in each others homes. Simple refreshments are provided.

18th September: Derek Vernon on Lightning Therapy.
Derek used to be the Chairman of the Stockport support group, and is now the campaigns manager, so many of you will have met him. He has had ME for 21 years, and went through the process in April of last year. He is now fell walking!
Several members of the Stockport group have been through the process with good or excellent results: one member is now a qualified practitioner. Derek will tell us of his personal experience.

16th October: Karen Martin, occupational therapist, on Aids for Living.
Karen is based at Disabled Living, Cheetham Hill, Manchester, which is a registered charity. She will bring some mobility and other aids for demonstration, and discuss the other services they offer.

20th November: The Pre Christmas Social and Bring and Share Buffet Supper.

SOCIAL GROUP
Our Social Group have been meeting informally on the first Monday of each month at the Sweet Green Tavern in Bolton. (127 Crook St. – go past the station on Trinity Street, through the lights and it's on your left.)

Remember that you can ring Pam if you wish to borrow our wheelchair or our light box

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS. Many thanks.

BURY & BOLTON ME/CFS GROUP MAY 15TH 2008 MEETING
Ross Percival Customer Services Officer DWP

Ross came to our meeting to tell us about how to claim DLA Benefit; he was an excellent speaker and it was so nice to have both seen and heard someone so knowledgeable and so enthusiastic that deserving claimants should receive benefits

From 1st April the department he works for at the DWP is called the Pensions, Disability and Carers Service as the DLA department and the Pensions Department have now joined together. Ross works at the Manchester Office which is situated just behind Kendals in Manchester. He reassured us that they are one of the best offices in the country and they do their utmost to ensure people obtain the benefits to which they are entitled. First time claims for benefit by people living in the area between Clitheroe, Nelson, Colne in the North, to Buxton and Macclesfield in the South, and from Royton to Oldham are dealt with by his office.

Every brand new claim from people living in the area will be seen by their officers, who see whether you have enough needs and whether your needs are there most of the time to qualify for benefit, either DLA or Attendance Allowance.

Ross then went through the benefits they deal with, what they look for, how to fill the form in, what happens when the form comes into the office, where they would go for further evidence and how it would be interpreted.

The benefits dealt with at his office are DLA if you are under 65 and Attendance Allowance if you are over 65. There is a separate form for children to claim, but Ross said he hasn't seen too many claims for DLA for children with ME.

If you are under 65 when you make your first application for benefit, it is Disability Living Allowance, if you go past pension age during your award you will continue to receive DLA, which is advantageous as the Attendance Allowance which is paid to applicants over the age of 65 does not have the mobility component. Ross said that the people who are entitled to DLA are significantly disabled and have usually had to give up work completely. The benefits are designed to help with extra needs such as help with personal care, not for help with housework, and for help needed within the home or for supervision outside the home. Although they are hard to get, the benefits make a real difference and are very helpful. The cash is available for you to spend in any way you want, to get the help you need to make your lifestyle a little better.

Ross gave us an example of his mother who was over 65 when she claimed Attendance Allowance. Prior to claiming she received her pension and a small amount of pension credit, this totalled £70 per week but she was awarded £30 Attendance Allowance and because she lived alone and no one was claiming carers allowance for her, she was also given a severe disability premium of a further £30. This transformed her income from £70 per week to almost double at £130 per week. That made a very big difference to her and she had a much better quality of life.

Last year the Manchester office dealt with 62,000 claims. If you are not happy with the answer you get on your claim you can be asked for it to be looked at again and a new decision maker can look at it again to see if your claim can be supported. If you are still unhappy with the decision it can be appealed and looked at again. **Ross stressed that if you are turned down or if you are unhappy with the decision you should always ask for it to be looked at again.** It will be reconsidered to see if your claim can be supported.

The vital importance is giving enough information for the decision makers to understand the difficulty that you have when doing every day things. What often happens is that people receive the form which is 50 or 60 pages long and fill it in themselves and don't put in enough information. The best thing to do is to ask the Department of Work and Pensions for help to fill in the form; you can either have help via a telephone call or by a person coming to your home to help you. Ross said the people who help fill in the forms are experts at getting the right information in the best way to show your needs and even though they are expert at filling in the forms it can take one hour and a half to complete. The helpers will ask you how bad things are and ensure that all the difficulties are put down clearly for the decision makers. Ross says that they recognise that it is difficult admitting the things you can't do but it is important to face up to it and write it clearly so it is better for them to fill it in so that they put all the information on the form. The more you tell them the better chance of getting the claim accepted. The benefit is paid not on diagnosis but on how it

affects you personally. It is a difficult benefit to get so it is much better if you ask their staff for help. Ross reminded us that many of us adopt coping strategies and gave the example of a person living alone answering the question "do you need help getting up and down stairs"? because they live alone and have to get up and down, they may answer no help needed, when in fact they go up one stair at a time and come down on their bottom; so the answer should be yes, help needed; even though they don't get help, the effort they have to make is unreasonable.

Again Ross stressed that the more information you provide at the start, the lees they need to seek clarification to consider the claim.

Under 65's claims can be for Mobility or for help and supervision outside, also for help or care and supervision inside.

Ross told us that when assessing whether a person is entitled to mobility allowance they consider how far you can walk, and also how long it is before you suffer discomfort, how fast or how slowly you walk and the manner in which you walk. To be entitled to the high rate of mobility you need to be virtually unable to walk, i.e. cannot walk at all or only a very few yards without discomfort or assistance. To grant this allowance they usually seek a medical opinion, possibly from your consultant or doctor, especially for the high rate of mobility allowance. If you are given the high rate for a period of at least 3 years you can use it to have a motability vehicle which is either a car or a powered wheelchair/scooter. If you opt for the car you get free road tax, insurance and servicing and up to 4 replacement tyres during the lease period (3 years). You would also be entitled to a blue badge; the vehicle is to be used for the benefit of the disabled person but another person can also be the named driver.

The lower rate of mobility allowance is paid if you need supervision and guidance outside, e.g. if you have fits or seizures or falls or if you would get lost if you were alone; it is not for reassurance if you are afraid to be out alone it is for a supervision if there is a risk.

The mobility allowance is not available to new claimants over the age of 65 who will get Attendance Allowance, but if you already claim it before you reach 65 it continues.

Disability Living Allowance is paid if for most of the time you need extra care and supervision either regularly through the day or for the high rate for both day and night. If, for example, you only need help to get out of bed in the morning or back into bed at night you probably won't get the award; you have to need help regularly or constantly throughout the day. The award is for help with personal care such as getting up, dressing, bathing, going to the toilet, climbing stairs, taking medication, preparing or eating food; it is not for help with cleaning, ironing or shopping.

Ross said that although with ME you may be able on some occasions to do some of the things, if for most days of the week you need help you may expect an award. He assured us that they try very hard on each claim to get the decision right. He told us that the Manchester Office is a good one and although they do occasionally get things wrong generally they give the right decision. Because this award has lots of grey areas it is vital to give lots of good information and describe the problems properly.

Even if you live alone and don't get help they pay for the needs you have, not whether or not you get the help.

Ross explained as well the need for supervision inside the house if for instance you are at significant risk of falls.

There are three levels of award:-
Lower Rate which is payable if you have difficulty planning and preparing a simple meal for one person. You may have problems holding a knife or chopping food or lifting a pan, or just not enough energy to stand and prepare it or even sit and prepare it, and then can't face eating it.
The Middle Rate is for needs during the day
The Higher Rate is for needs both day and night for significant periods e.g. 2 or 3 times a night for 20 minutes.

The advantage of DLA is that it is not a contributory benefit, i.e. you don't have to have paid a national insurance stamp to be entitled to claim it and it is not taxable nor is it means tested so anyone can claim it.

Ross said that if you claim DLA and go back to work it does not automatically mean that the DLA will be stopped. If you still have the same needs your benefits should continue. Again Ross stressed always ask for us to look at it again if you feel that the decision is wrong. He said that medical evidence is useful and sometimes they may need clarification so they usually contact the consultant or doctor who sees you most. There is a panel of doctors that the

decision makers can ask if they have a question regarding the claim
.

ALWAYS

i) **Apply and ask the DWP to help you fill in the form**. When you request a form from the DWP they stamp it with the date of the request and if your claim is awarded it is dated back to this request date.

ii) **Keep a copy of your claim form for your records**.

Ross encouraged people who have received the award for a period of time to request that the award be made a life award. If your condition has not changed over a long period of time and is not likely to change it saves having to fill forms in every 2 or 3 years.

Be aware that very few children with ME have applied for DLA and it is available for children.

DLA helpline 08457 12 3456 7.30am to 6.30pm Monday to Friday

If you have hearing problems Textphone 08457 33 4433

Benefit Enquiry Line 0800 88 22 00
Textphone 0800 24 3355

Customer Service Problems 0161 831 2048

LAUGHTER TIME

FOUR GOOD REASONS

The local news station was interviewing an 80-year-old lady because she had just married - for the fourth time. The interviewer asked her questions about her life, about what it felt like to be marrying again at 80, and about her new husband's occupation.

"He's a funeral director," she answered. "Interesting," the newsman thought, then asked her if she wouldn't mind telling him a little about her first three husbands and what they had done for a living.

She paused for a few moments, needing time to reflect on all those years. After a short time, a smile came to her face and she answered that she'd first married a banker when she was in her early 20s, then a circus ringmaster when in her 40s, later on a preacher when in her 60s, and now in her 80s, a funeral director.

The interviewer, quite astonished, asked why she had married men with such diverse careers. She smiled and explained.

"I married one for the money, two for the show, three to get ready, and four to go."

*****

The quickest way for a parent to get a child's attention is to sit down and look comfortable.

*****

EMBARRASSING ANSWERS

RTE Radio 2fm Ireland

Presenter: What is the name of the long running TV comedy show about pensioners. Last of the..... ?

Caller: Mohicans

University Challenge(BBC2)

Bamber Gascoigne: What was Gandhi's, first name?

Contestant: Goosey

Richard and Judy (C4)

Q: Which American actor is married to Nicola Kidman A: Forrest Gump

Thanks to Phoenix – Central Lancashire ME/CFS Support Group

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EXERCISES FOR THE OVER 50'S

Just came across this exercise suggested for older adults, to build muscle strength in the arms and shoulders. It seems so easy so I thought I'd pass it on to some of my friends. The article suggested doing it three days a week.

Begin by standing on a comfortable surface, where you have plenty of room each side. With a 5 1b potato sack in each hand, extend your arms straight out from your sides and hold them there as long as you can. Try to reach a full minute and then relax. Each day, you'll find that you can hold this position for just a bit longer. After a couple of weeks, move up to 10 1b potato sacks.

Then try 50 1b potato sacks and then eventually try to get to where you can lift a 100 1b potato sack in each hand and hold your arms straight for more than a full minute. (I'm at this level). After you feel confident at that level, put a potato in each of the sacks!

With thanks to Clwyd Support Group

BURY/BOLTON ME/CFS GROUP MEETING 17TH JULY 2008
Steffie El Hassan - Homoeopathy And Flower Remedies

For those of you who missed our July meeting, you missed a real treat: Steffie is such a lovely, genuine person and a really interesting speaker. She did not do the usual formal presentation about the background to homeopathy and a lot of facts and figures; she gave us an insight to her philosophy on how the body works as a whole and is so very clever that it knows how to heal itself. She managed to get us all to join in and gave us the hope that with support we can regain the balance in our bodies that we appear to have lost.

Steffie started by explaining her understanding of what health and ill health are really about and why she believes that things like homeopathy and flower essences work and can help.

She said that she has come to see, over the years, that our bodies are incredibly wise, they have an amazing wisdom and they choose to develop the symptoms that they do because they are trying to talk to us and give us clues, give us some understanding of what they need, so that we can make ourselves better again. Our bodies have a wonderful ability to get themselves better and to get back in balance. When we get symptoms it is because we have become out of balance and our illness is the body's way of saying "excuse me, excuse me, something is not ok in here!" so it is demanding some sort of attention.

We have choices, for example, we may be under some kind of stress and we may feel under the weather for a few days, but we don't give it a lot of notice and we hope that it will go away, generally it does at first. But if the stress repeats itself and we still don't take notice, it goes up a notch. Next time it sort of says "Excuse me! You just haven't got it have you?" and then we may start with migraine or a stomach ulcer, and now we have to take a day or two off work. If we still don't get it, the stress, whatever it is such as an environmental stress, work stress, dietary stress, relationship problem, any of the very many physical, environmental or emotional stresses at all, if we don't understand that our body is out of balance, it will keep trying to tell us.

The symptoms it creates are always very meaningful. Steffie said that she is always fascinated by why a particular person's body creates symptoms such as migraine or irritable bowel syndrome. Whatever it is, there is a reason why these symptoms have happened, it is not accidental and the body speaks a very clear language but if we don't understand it, it gives us clues to help. For instance, if someone repeatedly gets throat problems, it may be that person needs to say something: or if the person gets irritable bowel or stomach problems it may be that they have something in life that they can't digest. It is very individual and so even if two people have throat problems the reason for it will be different; it is so individual that only that person can really make sense of it. The homeopath will try to help the person to really understand the message that the body is trying to give them. The homeopath will try to be along side trying to help us understand, how we can help the body to get back in balance. Any illness or disease is about something being out of balance at some level. Steffie really believes that it is possible to get back that balance. People may have many, many symptoms but what they are reflecting is one imbalance. It's almost as if the body is saying "you didn't get it when I expressed it this way so maybe you will get it if I express it differently". There will be a theme or a pattern which connects all the symptoms that we might have. Once we can see the pattern that connects all the symptoms it can be a very important step.

Steffie gave us an example of a patient who suffers migraine which is always worse when they are out in the sun. They suffer from very dry cracked lips, dry mouth, they have severe hay fever which really streams. They may say that they are very emotional but they really bottle it up, they can't cry or even say they won't cry, they won't give in to it because it makes them feel very vulnerable. They may also be very constipated. She then asked if we could see what connected all these things and it was at first thought dehydration may cause it, but then came a suggestion that because they don't cry and release their emotions the body is showing them that they are too dry. Steffie said this was exactly the case, the dryness is lack of flow, and the hay fever shows an excess of flow.

Another example was of a patient with hot flushes and fever and Steffie said that somewhere there will be a problem to do with chilliness, there will be an opposite somewhere.

There is always a combination of the physical, the emotional and the spiritual aspects. Steffie sees her role as a little like that of being a detective, trying to find out what is out of balance. Why is the body doing this? What is the story? What is it trying to tell us? When we start to understand this we can start to

shift things. There is the possibility to understand anything and to cure anything if we can only understand what our body is trying to tell us, this is our individual story.

What attracted Steffie to homeopathy was the fact that it treats the whole person, how everything connects up and everything is meaningful, what we need to do is understand it. She feels it is a real privilege to be able to help people to help themselves. Steffie said that homeopathy comes from a different perspective to Allopathy i.e. conventional medicine; she has a lot of respect for the GPs and Doctors and feels that there is a place for both; they just each come from a different understanding and perspective. She said that the homeopath is fortunate enough to be able to give people time, to be alongside and to help the person to understand what is going on.

Then Steffie went on to explain how flower essences and homeopathic remedies fit into the process.

Homeopathic remedies can be made from anything and there are 1000's of them available, but of course flower essences are made from flowers. She then explained very simply how they work by telling us a very simplified version of quantum physics. We are made of matter, which is composed of minute particles which vibrate in space, in time with one another. The essences work on the same principle and the homeopath tries to find one that fits the same vibration e.g. if you play a note on a C string on a violin the vibration you create would cause another C string nearby to vibrate. In the same way the essences and remedies give their vibration which helps the body particles to vibrate. The principle with homeopathy is that like will help like, illness is where we have become stuck and need help getting back.

Steffie then got us all joining in when she asked about spiders and said "what do you think are the properties of spiders?" They make webs to catch flies, are strong, climb, dangle, run very fast. She then asked who might benefit from a remedy made from spiders and the answer was correctly guessed as being hyperactive children. Another example was chocolate, it is comforting, gives energy, feels good, given as a reward or present, can be given to children as a substitute for an emotional need, when upset it makes us feel better. The remedy made from chocolate can help people who have an unresolved emotional need - they are often chocoholics.

The example of the patient who was dry may get help from a remedy made from salt. The last example she gave us was a remedy made from gold – it is expensive and the ultimate in wealth so this remedy may help someone who has worked hard for the best or to be the best but has been unable to achieve their ambition.

The flower essences have been used by ancient cultures, for example the Aborigine people used the dew from flowers to help people regain balance. Flowers have a huge symbolic meaning, they can lift your spirits and they are very gentle and work alongside us.

Again Steffie reminded us that Allopathy uses opposites e.g. if we can't sleep we are given a medicine which induces an artificial sleep where as homeopathic treatment may be made from coffee in that hope that it will remind the body what it needs to do to balance itself. Onions burn and sting the eyes so a treatment made from onions can help hay fever, colds or allergies.

It is interesting to learn that much of the available information about homeopathy comes from poisoning records because they show what happens to the body when a strong dose of a substance is taken. Of course all homeopathic remedies are extremely dilute, some are taken as drops and some are tablets.

Steffie had with her a pack of beautiful picture cards which were pictures of the flowers used in Australian Bush Flower Remedies and she laid some out on the tables and asked us to look at them. She said that we are usually drawn to the one that can help us and it was fascinating to pick out a flower and then read the few words which were written on the card, many people felt the words were relevant although they only read them after they had chosen the flower picture.

Steffie said that we all know what we need but we need the opportunity to tune into it. We all have a very deep wisdom and knowing but need to get in touch with it. The good thing is that there is a way to get in touch and we have the tools to help.

This was a truly fascinating insight given by a truly lovely lady.

Steffie works in South Manchester and kindly stepped in at the last minute when our planned speaker could not come. Anyone wishing to contact Steffie for an initial free chat, more information or an appointment can contact her at **steffie.elhassan@hotmail.co.uk** or tel: 07930918364. There are of course homeopaths registered in the Bolton and Bury areas

NEWS IN BRIEF

Following the talk by Judith Smith about the expert patient programme, I have had several people let me know that the course is excellent and they have enjoyed it very much and found it useful.

As you are aware, we are trying to get good quality hospital services for ME sufferers who need it. However if you have had a bad experience in hospital and want to make a complaint but do not know where to start or cannot manage to write a letter; just follow in the footsteps of one of our intrepid members.

Firstly she contacted the PALs (Patient's Advocate and Liaison) at the hospital; they do their best to put things right immediately but if that is not possible they put you in contact with ICAS (Independent Complaints Advocacy Service). The people there are fantastic and will make notes about your problem and will write any letters for you. This is a free service and has been very helpful. Tel. 0161 475 1730

On Thursday 4th July Maria and Pam attended a Long Term Neurological Conditions planning meeting. The Speakers were Dr. John Dean, Medical Director of Planning, and Lynda Helsky of Bolton Primary Care Trust.

Maria and Pam had opportunity to speak to Dr. Dean and he assured us that ME is taken very seriously by the PCT and has a legitimate place within the neurological services. Our own ME clinic is highly esteemed by Dr. Dean, he also discussed our concerns about the lack of in patient services and the need for all health service staff to be educated about the problems facing ME sufferers and carers.

And a thank you to all those who completed our questionnaire about hospital treatment.

At our July meeting we held an Extraordinary General Meeting to vote Kim Finney on as Treasurer. Unfortunately, Chris Tyson our elected Treasurer has been unable to take on the role.

Thanks to Greg at the Bolton branch of Staples for kindly waiving the servicing and stapling fees for this newsletter.

UK doctors have received a letter from the manufacturer (Cephalon) of modafinil/Provigil warning about the need to be aware of two serious side-effects that have recently been identified.

SERIOUS SKIN RASHES requiring hospitalisation and discontinuation of treatment have been reported in adults and children in association with use of modafinil within one to five weeks of initiation of treatment. Modafinil should be discontinued at the first sign of a rash and not restarted.
PSYCHIATRIC ADVERSE EVENTS including psychosis, mania, delusions, hallucinations, suicidal ideas and aggression have also been reported. If psychiatric symptoms occur, modafinil should be discontinued and not restarted. Caution should be exercised in administering modafinil to patients with a history of psychosis, depression or mania. Modafinil is not approved for use in children for any indication.

MODAFINIL IN RELATION TO ME/CFS:
Modafinil is a drug that is currently being used in the symptomatic relief of excessive sleepiness associated with narcolepsy, obstructive sleep apnoea/hypoapnoea syndrome and moderate to severe shift work sleep disorder in adult patients.
Modafinil has also been assessed as a possible form of treatment for ME/CFS and two papers have been published in relation to this (Turkington et al 2004; Randall et al 2005). Given this new information it would not be sensible for people with ME/CFS to take part in clinical trials if they have a history of drug induced skin rashes or psychiatric illness.
For further information on the use of modafinil in ME/CFS see section 7:3 of 'ME/CFS/PVFS - An Exploration of the Key Clinical Issues' (MEA publication: 2007)

Thanks to the CFS/ME Rotherham group for this article on Modafinil.

Reminder. Don't forget that you may be entitled to have a reduction – down one band – in your council tax if you have had alterations to your property to accommodate your disability
e.g. if you have another bathroom or shower room,
or if you use your wheelchair in the house,
or if you have to make your bedroom downstairs because you can't get up the stairs.
The notice is on your council tax bill along with the number to ring.

Print your own stamps!
To save you time queuing up for stamps in shops and post offices, you can buy and print stamps off from your home PC which is great if you run out of 1st or 2nd class stamps or you have an odd-sized envelope to send, and you're not well enough to go further than a post box.
The website to visit is: **www.royalmail.com** and click "Print postage online"

KI HEALTH – MY EXPERIENCE

I am a long-term member of the Stockport ME group, 41 years old and have had ME for over 12 years, following a virus. I have been badly affected and spent a lot of time housebound, though fortunately, not bed bound. I had to give up my career as a professional musician due to the illness. Over the years I have tried numerous therapies and treatments including osteopathy, nutritional therapy, reiki, acupuncture, reflexology, aromatherapy... the list goes on. Most of them were beneficial but only took me so far.

I first met Ki Health at the Mind Body Spirit show at G-Mex in autumn 2006. I was immediately attracted to the stand by the sound the practitioners, called Ki Masters, were making - a loud 'shhh' sound. The information said that their treatment, which uses sound and acupressure, was effective for all sorts of conditions including ME. One of the people on the stand had suffered from ME herself and looked very healthy so I decided to have a treatment.

It was like nothing else I had ever experienced. I found it very relaxing although there was some discomfort especially round my tummy. Master Chun, who gave me the treatment, said that I had some tight energy blockages and that I needed more treatments. She suggested coming back the next day. It was when I got home and later in the day that I really noticed a difference. I remember feeling sleepy but knots in my shoulders that had been there for years felt much better. My back felt much freer and I felt more settled. I was amazed and delighted. Needless to say I went back the next day and again was impressed with the results.

After Christmas I decided that I would go down to London and have 5 treatments over 3 days, which is what was suggested. I had no idea how I would manage. By the end of the weekend I had not only managed to go in for the treatments but they had given me enough energy to do some sightseeing and eat a very enjoyable meal. Since then my progress has continued. I stayed with relatives not too far from the London training centre and joined Ki Training classes. This is energy training, to help you gather energy for yourself, so that you don't have to rely on treatments. I also did some family healing, which addresses deep rooted inherited blockages. There were lots of people at the centre with ME and two of the Masters have recovered from it themselves.

The complete Ki package includes movement, meditation, chanting, and a spiritual path, which doesn't conflict with religious beliefs. The philosophy behind it is mainly Taoist and comes from South Korea. It is a wonderful way to health and happiness and they have a real reverence and gratitude for life, which is inspiring. It is now possible to do the Ki Training via the Internet, which I am currently doing from home. Finally I am getting my life back and what a wonderful life! My hope now is to share this with other people and to get a group together for the Internet training.

Ki Masters now visit Manchester on a regular basis. Treatments take 15 minutes and prices start from £25. You remain fully clothed.

If you want to know more you can talk to me – e-mail **suehutchins@ntlworld.com** Tel: 0161 718 0659 or 07929 574263. Sue Hutchins

Thanks to Hermes for this article.

Since Sue wrote the article she has started volunteering for 2 afternoons at a local charity shop as well as helping organise Ki Health visits to Manchester. There is also now a group meeting once a week for internet training

LOOKING FOR A BREAKTHROUGH
By Suzanne Vernon, PhD, Scientific Director CFIDS

Over the last two decades, more than 3,500 peer-reviewed articles have been published about CFS. Investigators from all over the world have made contributions, with the majority of work coming from groups in Australia, Europe, Great Britain, Japan and the United States. Judging by attendance at the last conference of the International Association of CFS/ME (IACFS/ME) and other indicators, it appears that more scientists are studying CFS than ever before, however, the field still needs to grow in terms of numbers and types of expertise to decipher the complexities of CFS.

Defining CFS was an important first step in 1987, even though there have been several case definitions since then, and the subject continues to generate debate. With a definition, researchers were able to begin studying the distribution and determinants of illness in specific populations. The first studies focused on clusters of ill people (like those in the Incline Village, Nevada, and Lyndonville, New York, "outbreaks") or clinic populations. Later, other studies looked at broader populations like Chicago, Wichita and Georgia.

From these efforts we've made significant progress describing the epidemiology (how often diseases occur in different groups of people and why) of CFS, and we can now confidently state that CFS is a common and severely debilitating condition that affects more than one million Americans. Women are more likely to get CFS than men. Adults are at higher risk for CFS than teens, and teens get it more often than young children. Less than 20 percent of people with CFS have been diagnosed. The illness imposes great economic burdens on the individual, the family and the nation as a whole.

But what do we know about what CFS does to the body? Investigators, using the traditional tools of science to poke around numerous body systems, have discovered evidence of often subtle abnormalities in the immune system, the brain, the hypothalamic-pituitary-adrenal (HPA) axis, the cardiovascular system, the autonomic nervous system and the endocrine system.

Over the past five years, completion of the Human Genome Project has given us new technologies such as genomics, proteomics and gene microarrays to understand what's going on at a molecular level in CFS patients. Now, rather than running one blood test to get one result, a single blood sample yields millions of pieces of information about possible genetic variations and the state of thousands of gene expression patterns and proteins. Additionally, bioinformatics (computational study) has allowed us to examine large complex data sets and to identify patterns linking findings that would have been nearly impossible to see using only traditional data analysis techniques.

In investigative terms, we've narrowed the suspect list and implicated some key participants in this illness but we're still searching to find the primary culprit behind all the damage being done.

After 20 years we still don't have definitive telltale physical signs, accessible anatomical lesions or readily measured biological markers for CFS, but the two paths of investigation, traditional and molecular, have converged on some important and promising discoveries. For instance, some of the early studies of CFS pointed to atypical levels and responses associated with several chemical messengers called neurotransmitters that help regulate sleep, body temperature, heart rate, appetite, mood and immune function. These early and astute observations underscore the findings of recent genetic studies. There is now evidence that genes involved in the function of serotonergic, dopaminergic and catecholaminergic systems display unusual sequences in people with CFS. These unusual sequences, known as polymorphisms, are not likely to cause CFS, but they might make people more vulnerable to the illness. This both helps support the earlier findings of abnormal levels of some neurotransmitters and helps focus future investigations to understand what they might mean.

Linking molecular data to clinical information about characteristics CFS patients display in sleep studies, stress tests and functional imaging studies will accelerate what we know about CFS in general and under various conditions. It may also help us "sort" CFS into different subtypes, as four teams of researchers did during the C3 challenge I led while at the CDC; and as Jonathan Kerr, MD, PhD, and a team of United Kingdom researchers recently reported in their own study. These approaches can also help refine our understanding about sets of individuals

with similar CFS profiles rather than trying to understand a very diverse patient group all at once.

The convergence of these research paths is also helping us understand the key contributions of both genes and the environment in CFS. We're taught in high school biology that our genes determine some aspects of who we are and how we look—our sex, eye colour, height, etc. But our genes face an ongoing barrage of challenges from our environment that ultimately determine who we become. Nature and nurture combine to influence events as basic as how we digest various foods to processes as complex as how we weather personal crises. CFS is probably influenced by the interaction of our genes with our environment as well.

One of the most fascinating areas of research where this dynamic can be observed is in infection. From the very beginning, clues pointed to at least a subset of CFS that follows infection. In fact, CFS was initially thought to be a chronic form of mononucleosis and was associated with Epstein-Barr virus (EBV). That trail went dead for a while when not every case of CFS could be linked to EBV (or other viruses that were studied), but new tools are focusing on gaining a better understanding of what happens when people don't recover from certain viral and bacterial infections, and symptoms consistent with CFS persist well beyond the usual period of acute illness. One study by Andrew Lloyd, MD, and his colleagues found that 10 percent of people who became infected with one of three very different agents—EBV, Ross River virus and Q fever—remained ill for months after the other 90 percent had recovered. The severity of the initial infection was a key predictor for who stayed sick and who got better, and studies continue in search of genetic or gene expression factors that may also separate the two groups.

We also know from studies performed at the CDC and by Kerr and other groups that CFS patients demonstrate disturbed gene expression patterns in several different "compartments" of the immune system. These differences might play a role in how individuals respond to infection.

Also one form of CFS may arise from certain genetic vulnerabilities challenged by particularly severe infections under conditions that prevent the body from returning to homeostasis (stability). Science is beginning to reveal the biologic underpinnings of this illness.

With as much as we've learned about CFS over the past 20 years, we now have an opportunity to integrate data and harness this knowledge in new and powerful ways. By focusing on abnormalities that show up using both traditional methods and newer ones—and for which the evidence is supported by lab and clinical studies—we can greatly accelerate the pace of progress in identifying biologic indicators of CFS. This will aid early detection, objective diagnosis and effective treatment.

Taken from the CFIDS Chronicle Winter 2008
www.cfids.org – modified by Selina L Wilkinson, also thanks to Phoenix

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GREAT TRUTHS LITTLE CHILDREN HAVE LEARNT
When your Mum is mad at your Dad, don't let her brush your hair.
If your sister hits you, don't hit her back. They always catch the second person.
You can't trust dogs to watch your food. Don't sneeze when someone is cutting your hair.
You can't hide a piece of broccoli in a glass of milk. The best place to be when you're sad is Grandpa's lap.
GREAT TRUTHS ADULTS HAVE LEARNED:
Raising teenagers is like nailing jelly to a tree.
Wrinkles don't hurt.
Families are like fudge... mostly sweet, with a few nuts.
Laughing is good exercise. It's like jogging on the inside.
GREAT TRUTHS ABOUT GROWING OLD:
Growing old is mandatory; growing up is optional.
Forget the health food. I need all the preservatives I can get.
When you fall down, you wonder what else you can do while you're down there.
You're getting old when you get the same sensation from a rocking chair that you once got from a roller coaster.
It's frustrating when you know all the answers but nobody bothers to ask you the questions.
Time may be a great healer but it's a lousy beautician.
Wisdom comes with age, but sometimes age comes alone.

Thanks to Central Lancashire ME/CFS Support Group

UP-DATING RESEARCH FUNDED BY THE FOUNDATION

For those who have become our supporters recently it may be necessary to give a brief outline of this current project studying the genes of people with CFS/ME. Until 2001 researchers funded by the Foundation had studied different aspects of the disease and we had acquired a good deal of useful information. The research committee then decided that with this information, the mapping of the human genome and the explosion of sophisticated scientific techniques, it was possible to study the basis of the illness. An ambitious project was designed to compare the genes of people with CFS/ME with those of normal healthy people. Scientists from 3 laboratories in medical schools in the UK and 1 laboratory in the USA were involved and continue to be part of the project.

There is now exciting news to report from the CFS Research Foundation. Dr Jonathan Kerr, the principal investigator, and his team, who are comparing the genes of people with CFS/ME with those of normal healthy people, have made discoveries which take CFS/ME research into a new dimension. They first found that 88 genes behaved in an abnormal manner, but remain normal in the control group of healthy people.

At the outset the researchers faced a problem. Gene expression (that is the behaviour of genes) was being used to study many diseases, but always a sample was taken from a lesion. But there are no lesions in CFS/ME so it was decided to see if results could be obtained by using blood. This proved to be successful and a pilot study was carried out examining 9,522 in the white blood cells of 25 CFS/ME patients and 50 age and sex matched normal blood donors. They found that 15 genes in the CFS/ME group became more active and 1 under active while they remained normal in the control group. It was found that these genes showed problems in various systems including the immune system, neurological function and mitochondria metabolism (the mitochondrium is the powerhouse of the cell).

Dr Kerr and his team then set out to determine the total number of genes and pathways which were normal in the blood of CFS/ME patients. DNA microarray analysis of CFS/ME patients and normal controls found a pattern of 88 genes that were abnormal in CFS/ME patients. They then analysed the gene data further and found evidence of 7 subtypes of CFS/ME. What they found to be of special interest was that these subtypes had distinct differences in clinical symptoms and severity. Each CFS/ME subtype had a different list of genes which were abnormal.

Of the 7 subtypes; Subtype 7 had the most pain and the most severe individual symptoms including swollen glands, sore throat and headaches. Subtype 1 had the worst cognitive and mental health score and poor sleep despite having the least pain. Subtype 4 had moderate neurocognitive function and cognitive defects combined with moderate levels of bodily pain and sleep problems. Subtype 5 had the best mental health, but poor neurocognitive function, gastrointestinal complaints and the most marked muscle weakness and postexertional malaise. Subtype 2 had marked postexertional malaise, muscle pain and joint pain but with poor mental health.

It is particularly interesting that in these gene subtypes there were distinct clinical syndromes.

Another point of interest is the geographical locations. Subtypes 4 and 6 were predominant in Dorset, Subtype 4 was predominant in London and New York and Subtype 5 was predominant in Bristol.

The news, which we all long for, is that drugs to help or cure the condition have been identified. The discovery of these 7 subtypes means that it will be much easier to identify appropriate drugs for each subtype. Two papers covering this work have been accepted for publication and should be appearing almost immediately. The first "Seven genomic subtypes of Chronic Fatigue Syndrome" was accepted by the Journal of Clinical Pathology. The second, "Differentially expressed genes in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis patients reveal seven subtypes with distinct clinical phenotypes".

But there is a bonus. CFS/ME has been dismissed by scientists for decades as not being a biological illness, but when Dr Kerr submitted one of these papers to the Journal of Infectious Diseases, a most distinguished American Journal, it was reviewed by two scientists as is normal. Usually reviewers are very critical whatever the subject and the Journal of Infectious Diseases, being such an important publication, was expected to be highly critical but the comments of the two reviewer's were:-

Reviewer One: "Exceptional cutting edge study into pathogenetic biomarkers of CFS/ME...."

Reviewer Two: "This is an important study that addresses the single greatest problem in CFS research: to stratify patients according to clinical phenotype and molecular characteristics. The study is very well done and provides important insights into mechanisms of pathogenesis of CFS Viruses have long been suspected as triggers in CFS and this study links, for the first time, specific clinical subtypes to viral gene expression."
These comments raised the spirits of the researchers, members of the research committee, trustees and office staff. We are sure that our readers will share these feelings.

THE FUTURE — AND DRUGS

We have every right to feel elated when we read of the progress being made by scientists funded by the Foundation. Our donors can feel a sense of achievement that they have contributed to this success. But we must still look towards the future and ask ourselves if we can confidently expect these scientists to find drugs which will firstly be of help in relieving the symptoms and then bring about a cure. Some months ago this team gave consideration to a drug which it was felt would be likely to help some people. Dr Kerr approached 5 firms who manufacture the drug, but all 5 refused to supply it. No reasons were given, but it may have been because the manufacturers, knowing that CFS/ME patients react so badly to almost all drugs, did not wish to supply a drug which might cause problems. It may have been that they wished for more evidence of its likely efficacy. This naturally caused disappointment, but the team continued to study the behaviour of the genes and they discovered the 7 subtypes. This transformed the work of finding appropriate drugs. It will be seen that each subtype is likely to need different drugs, in other words, the drug will be tailored to the patient.

The significance of these findings is enormous and they will be essential to understanding CFS/ME patients and developing and testing specific treatments.

The Research Committee has now to use all this new information to guide researchers in seeking the appropriate drugs which will transform the lives of so many people. We shall also be seeking researchers to carry out this work. As soon as our plans are clear we shall be mounting our biggest fund-raising campaign yet. We all feel the desperate urgency in this work. We have to rescue young, middle aged and elderly people from the effects of this devastating disease. We now know we can do it.

Taken with our thanks from the CFS Research Foundation Newsletter No 12

ACUPUNCTURE

According to the Oxford Concise Medical Dictionary acupuncture is "a complementary therapy in which fine sterile needles are inserted into the skin at specific points on the body," writes InterAction volunteer Louise Hawkes. Developed by Eastern physicians, this traditional Chinese system of healing aims to release the body's own natural painkillers (endorphins) by recognising "pathways and flows of energy within the body called 'chi'."

The British Medical Acupuncture Society (BMAS) says, "The practitioner will assess each person's case and treatment will be tailored to the individual. Typically, fine needles are inserted through the skin and left in position briefly, sometimes with manual or electrical stimulation. The number of needles varies but may be only two or three.

"Treatment might be once a week to begin with, then at longer intervals as the condition responds. A typical course of treatment lasts five to eight sessions."

The British Acupuncture Council describes the type of needles used as bearing "little resemblance to the needles used in injections and blood tests. They are much finer and solid, not hollow.

"When a needle is inserted, the sensation is often described as a tingling or dull ache. Needles may be inserted and immediately removed, or may be left in place, depending on the effect required. During treatment, patients commonly experience heaviness in the limbs or a pleasant feeling of relaxation."

WHAT IS IT USED FOR?

BMAS make clear that there are no guarantees that acupuncture will be of benefit to everyone: "Some people react very well to acupuncture while other people notice little change." They do however list some areas in which it may be effective:

- pain relief e.g. back, shoulder, neck and leg pain
- migraines, trapped nerves, chronic muscle strains, sports injuries and various kinds of arthritic and rheumatic pain

- functional bowel or bladder problems such as irritable bowel syndrome or even mild forms of incontinence
- menstrual and menopausal symptoms, e.g. period pains and hot flushes
- allergies such as hay fever, perennial allergic rhinitis and some types of allergic rashes such as urticaria (itchy rash) and prickly heat
- some other skin problems such as rashes and ulcers, itching, and some forms of dermatitis
- sinus problems and chronic catarrh
- dry mouth and eyes
- stopping smoking.

WHAT ABOUT M.E.?

Action for M.E.'s principal medical adviser Professor Pinching says: "I am no expert on acupuncture, but I hear quite a lot about it from my patients. As so often with other therapies, some people find it helpful and some don't. The most consistent story is that it can often help reduce nerve pain, and also some headaches. This fits with work in other illnesses, and with our knowledge of pain pathways, which acupuncture can affect.

"Some therapists suggest that they can have a wider effect on illness, or on other symptoms. I have heard a few impressive individual stories, but there is no clear pattern on which I could offer advice beyond treatment of pain.
"If you want to give it a try, make sure you see a therapist who has treated quite a few other people with M.E. and who can tell you how that went.

"There are different approaches to acupuncture and the therapist may have a big effect, for reasons we don't fully understand. One patient told me that, having had benefit for pain from one therapist, she had no such benefit from another one, to whom the first had introduced her (when he left) as doing the same sort of acupuncture!

"Finally, you need to remember (as with other complementary or alternative therapies) that the terms and concepts used may not mean the same thing as they do in conventional medicine (e.g. 'energy' 'boosting the immune system')."

BMAS report that: "There is no compelling clinical evidence that acupuncture is helpful in treating M.E./CFS. However, acupuncture often improves sleep, promotes relaxation, and results in a feeling of improved wellbeing. Many people find that they feel better after acupuncture treatment, even if there is no real improvement in their medical condition."

Alison Lindsay is a registered acupuncture practitioner and has treated many people with M.E. Alison says: "I have found it to be a positive and beneficial therapy. The philosophy behind acupuncture is that poor health is a result of an imbalance in our energy – acupuncture treatment aims to restore this natural balance and promote good health.

"People I have treated for M.E. have come with a range of symptoms and they are looking for a therapy that works on a number of different levels. Acupuncture treatment can be successful in alleviating many of the physical symptoms associated with M.E. – feelings of exhaustion, muscle fatigue, heaviness and aching.

"On a different level acupuncture can be effective in the treatment of psychological symptoms – poor memory and concentration, and feelings of depression.

"Acupuncture is an individual therapy and people make progress in their own time – my experience has been that acupuncture supports people with M.E. in attaining and maintaining good health."

IS IT SAFE?

In 2004 the Foundation for Research into Traditional Chinese Medicine published a research paper: *Patient reports of adverse events associated with acupuncture: a large scale prospective survey*.

Over a period of three months, 6,348 patients completed questionnaires about their treatment. Of these, 682 reported adverse events caused directly by the process, the most common being severe tiredness and exhaustion.

From these findings the Foundation concluded: "Our published results show that acupuncture is a relatively safe intervention when practiced by qualified and regulated practitioners."

The full report and other research studies can be viewed on their website: **www.ftcm.org.uk** or tel.: 01904 709688. The Acupuncture Research Resource Centre also conducts research into the potential benefits of the therapy: www.acupunctureresearch.org.uk, tel.: 020 8209 4277.

"In the hands of properly trained practitioners, acupuncture appears to be a very safe form of treatment", claim the BMAS. "However, any

procedure that involves inserting needles into the body has some potential problems. In addition, there are a few 'side effects' produced by acupuncture treatment that can be troublesome in certain people."

WHAT DO READERS THINK?

Kate Chambers first began using acupuncture combined with Chinese herbal medicine to treat severe menstrual pains and allergic asthma: "I was amazed that in six months my periods were no longer heavy and full of clots. This physical evidence was extremely important to me – I needed both to see and feel proof! I was also encouraged that although I still experienced allergic asthma, the use of my inhalers were (and continue to be) significantly reduced."

When she was diagnosed five years later with suspected chronic fatigue, she returned to her practitioner with a focus on alleviating the symptoms of M.E., "I have over the years seen an observable improvement in each condition focused on. I no longer take daily asthma drugs, my periods are much more manageable and generally 'normal' and slowly but surely my M.E. symptoms are also getting more and more manageable and less and less frequent.

"I really believe that when my body is flagging, the acupuncture assists me in giving energy. It is particularly effective in relieving joint pain in my neck, shoulders and arm – targeting the meridian band that runs from my left shoulder.

"I find receiving acupuncture quite empowering as I feel I have a part in overcoming the problems in my body. I am initiating my body to repair itself and boosting my immune system."

Danny Sherwood decided to try acupuncture when it was first suggested by his doctor. "I was cynical. I don't believe that my M.E. is caused by problems with the flow of my Chi, so using needles to improve this flow seemed an odd way to deal with the problem. On the other hand, having had the illness for a year and having been unable to find any effective treatments, I was happy to give it a go.

"After the initial session, I felt exactly the same as I had before, except the areas where the needles had been were a little sore. I explained this when I went in the next week and the practitioner tried putting needles in different places. Still no change. She suggested that different practitioners work better with different patients, so I got a new practitioner. Again, no change.

"Over the course of ten weeks of treatment, I had five different practitioners. None of the sessions made the slightest bit of difference. Each practitioner was genuinely surprised that the treatment didn't work and it wasn't until the last session or two that they accepted that acupuncture wasn't going to help."

HOW DO I FIND A PRACTITIONER IN MY AREA?

It is worth asking your doctor as although acupuncture isn't routinely available in the NHS, some GPs do offer it, and it is also available in some pain clinics. The following organisations also provide details of registered practitioners:
British Medical Acupuncture Society **www.medical-acupuncture.co.uk**. Tel.: 020 7713 9437
British Acupuncture Council
www.acupuncture.org.uk Tel.: 020 8735 0400

Alison Lindsay, who is quoted in this feature, may be contacted at:
Bristol Natural Health Service, 407 Gloucester Road, Horfield, Bristol BS7 8TS.
www.alisonlindsay-acupuncture.co.uk Tel.: 0117 944 4448
Our thanks to InterAction

RECIPE SECTION

MACKEREL PASTA

Serves one
4oz / 100g pasta 200g tin mackerel Juice of half a lemon Half a red pepper
Half a tin of chopped tomatoes Half tsp fennel seeds (optional) Grated Parmesan or Parmezano*
1 clove garlic to garnish
Cook pasta according to instructions on packet.
Gently fry diced pepper and fennel seeds and add crushed garlic.
Combine chopped mackerel with chopped tomatoes and lemon juice and add to the pan.
Heat through and add sauce to pasta. Serve with Parmesan or Parmezano (*a non-dairy substitute) sprinkled on the top.
From Eat to Beat Fatigue, complied by Jane Harries

LAMB TAGINE

Serves 4-6

2 tbsp olive oil 750g - 1 kg / 1 lb 10oz - 21b 4oz lamb cut into 2½cm / 1 inch cubes e.g. neck of lamb
450g / 1 lb onions, chopped 1 clove of garlic, chopped 55g / 2oz red or yellow lentils
1 tsp ginger 1 tsp coriander ½ tsp cinnamon A pinch of salt
115gm / 4oz dried apricots 2 tbsp browned slivered almonds

Heat the oil in a large flameproof casserole and brown the lamb. Add the onions, garlic and lentils and stir. Add the spices and salt and cook for one minute before adding enough water to just cover the lamb pieces. Add the apricots, cover the pan and cook for one hour on a low heat. The lentils and apricots will absorb the water and thicken the stew.

Serve with spinach on a bed of pilau rice or cous cous and sprinkle with the almonds just before serving.

From Michael Barry's book Michael Barry's Waitrose recipes, reproduced in Eat to Beat Fatigue, complied Jane Harries

MOIRA'S PRUNE OR APPLE CAKE

10 oz rice flour 8 oz pure sunflower margarine 4 tsp mixed spice
2 eggs or 2 egg yolks plus 20g egg substitute to bind if you cannot eat egg white
8 prunes, chopped or 2 eating apples, grated Handful of chopped seeds and/or nuts
Rice milk to mix

Put rice flour in a bowl and add eggs or yolk/egg substitute, margarine and spice, then mix with rice milk to achieve a sponge cake mix consistency (almost dropping consistency). Add seeds/nuts and chopped fruit. Divide mixture between two sponge tins and bake for 25 mins at 150°C (fan oven), 170°C (ordinary oven). Cut into slices when cold and freeze. It is rather crumbly. Moira says, "Eat warm with rice milk and melted carob in a dish with a spoon."

SOPHIE'S HAZELNUT CAKE

Sophie says: "Mum was a great savoury cook, but couldn't bake cakes to save her life. Except for this one, which was her pièce de résistance. This cake has little saturated fat and no flour, so is great for a gluten free diet and anyone looking after themselves. It is also my favourite cake. It tastes great and is so easy to make!"

Ingredients:

285g ground hazelnuts – source of protein and essential fats 300g of caster sugar 8 egg whites

Method:

Preheat oven 160C. Blitz nuts and sugar together in an electric blender. Then whip the egg whites and gently fold in the nut and sugar mix. Pour into a cake tin and bake for 40-50 minutes. Serve with raspberries and low fat crème fraiche.

With our thanks to InterAction for the above recipes

DAIRY FREE AND GLUTEN FREE RECIPES

Carrot and sweet potato soup serves 2

1 tablespoon of olive oil 2 large carrots, peeled and chopped
½ onion chopped 1 medium sweet potato, peeled and chopped
1 pint of vegetable stock 2 fluid ounces of Soya cream (optional)
Salt & pepper coriander leaves

1. Heat oil in saucepan over medium heat. Stir in carrot, onion and sweet potato and cook for about 4 minutes
2. Add the vegetable stock, bring to the boil and simmer for 25 minutes until carrots and sweet potato are soft. Remove from heat and allow to cool slightly.
3. Puree in blender until smooth and creamy. Return to pan, stir in soya cream and reheat. Season to taste, add coriander and serve hot.

Why not make double quantity and freeze half.

Easy Chicken curry

8 oz of cooked chicken 1 clove of garlic 1 large onion 1 baking apple
¼ green pepper ¼ red pepper 1 stick of celery 1 pint of stock
1 teaspoon madras curry powder (hot) 2 tbsp sultanas 1 tbsp desiccated coconut
1 teaspoon cornflower black pepper

1. Dice onion, celery, peppers and chicken, grate apple, press garlic
2. Place all except cornflower in pan, boil then simmer for 50 minutes
3. Mix cornflower in a little water and stir in to thicken, cook for two more minutes.

Serve with Basmati rice

"ONE DAY I FELT FINE THEN BANG!"

In the first of a two-part feature about the potential triggers that can lead to M.E., Leigh Fenton looks at what some researchers have said might cause the illness and speaks with readers who have come to their own conclusions.

I have heard a vast and wide-ranging array of accounts from people concerning what they understand to have been the trigger(s) for their condition. It is clear that difficulty in diagnosing M.E. contributes to this broad spectrum of ideas, emphasising once again the need for research into this area.

I was told, vaguely, that "some sort of viral infection" was the trigger for my M.E. back in 1992 and it frustrates me that there is still this lack of clarity in defining the causes of our condition.

Often it is not scientifically possible to identify the specific trigger that leads someone to develop M.E. In the Christmas issue of InterAction, Professor Nancy Klimas referred to studies which have looked at the following model of M.E. causation:
Genetic predisposition --Triggering event/infection --Mediators (immune, endocrine, neuroendocrine, psychosocial)--Health outcome/persistence

The Chief Medical Officer's (CMO) Report on CFS/M.E. in 2002 stated that: "Good-quality evidence indicates that certain infections are more common triggers for CFS/M.E. than others. Glandular fever, viral meningitis, and viral hepatitis are followed by CFS/M.E. in about 10% of cases of the primary infection.

"CFS/M.E. can follow infections with herpes viruses, enteroviruses, hepatitis viruses, and some other viruses, and also non-viral infections such as Q fever. CFS/M.E. has been reported after salmonellosis, toxoplasmosis, and brucellosis.

"Influenza and 'flu-like' infections can trigger CFS/M.E., but common upper respiratory tract infections do not seem to. Available evidence suggests that abnormal persistence of infectious agents does not occur in CFS/M.E., although certain chronic infections can cause similar symptoms."

CURRENT RESEARCH

ME Research UK has an impressive database of over 3,000 research publications on M.E. and CFS, derived from sources such as MEDLINE and the *Journal of Chronic Fatigue Syndrome*, which includes a number of papers on possible triggers. See: **www.meresearch.org.uk/information/researchdbase/index.html**

For example, one describes research into viral infections in M.E. conducted in June 2007 at Tottori University, Japan, which stated that although "no single underlying cause has been established for all CFS patients, epidemiological studies reveal that a flu-like sickness precedes the onset in the majority of cases." It continues: "The major hypothesis of the pathogenesis of CFS is that infectious agents such as viruses may trigger and lead to chronic activation of the immune system with abnormal regulation of cytokine production."

Harvard Medical School in Boston, USA, conducted research in December 2006 questioning whether the human herpresvirus-6 could be a trigger for M.E.: "Most studies have found that active infection with human herpesvirus-6 (HHV-6) – a neurotropic, gliotropic and immunotropic virus – is present more often in patients with CFS than in healthy control and disease comparison subjects."

OTHER TRIGGERS

Other triggers suggested by people with M.E. and health professionals, tend to fall into the categories of immunisations, life events, toxins or physical injuries. In all of these cases, research is still weak, something that the CMO report made clear six years ago in its discussion of immunisations: "It is biologically plausible that some processes seen after infections could also occur after immunisations but this has yet to be confirmed by a good quality cohort study."

Major life events, such as bereavement, abuse and stress seem unlikely to be the single trigger for developing M.E., although they are often recognised as potential triggers for relapses.

Exposure to toxins in the environment has been suggested as a plausible trigger for M.E. and we have certainly been contacted by members who feel that such exposure is the definite cause of their condition. Once again, evidence other than anecdotal is sparse and reports suggest that this is not a common or widespread trigger. The same can be said for physical injury, be it a trauma from an accident or operation.

WHAT HIT YOU?

Looking back, the onset of my M.E. happened quite quickly. One day I just started to feel unwell and was sick several times. I wasn't sick again after this but

was left with severe fatigue, nausea and sharp pains in my body.

These symptoms were thought to be a viral infection of some sort and the assumption was that it would clear up in a week or so. Six months later all the symptoms of the virus were still with me and after what felt like every test under the sun, I was diagnosed with M.E.

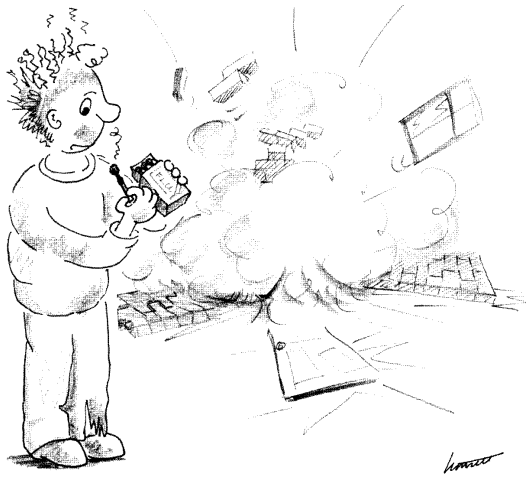
Amy finds it more difficult to pinpoint a single probable cause of her M.E. because there were so many possibilities during the period when she first became ill.

"I was living in a rural farming area where organophosphate crop spraying regularly took place within close proximity of our home.

"I also had a mercury-based dental filling and in the same year suffered a spinal fracture after falling on some ice. Throughout that year I had been receiving ineffective treatments for suspected sinusitis and laryngitis, some of which I had severe allergic reactions to.

"However, blood tests later showed I had the Epstein Barr virus – glandular fever – and this is thought to have been the primary trigger, possibly compounded by the other factors."

Andrew found that: "Having a tonsillectomy lowered my immunity in early 1985. Then came along what is believed to be an enteroviral respiratory infection, against which my immune response was weak. The pathogen then entered my central nervous system where it remains in an active state."



For Gillian, the Pill seems to have been the problem. "The trigger for my M.E. was an allergic reaction to medication – to be specific, the contraceptive pill, which I had been prescribed for acne.

"I tried three different types of pill and each time got the same reaction – constricted chest and breathing difficulties and after three days I was really struggling for breath. As the breathing problems stopped after I stopped taking the pills, I didn't realise they were affecting my long-term health as well, or I'd have given up after the first lot.

"My M.E. was very mild when it started, and it was some time before I realised I was ill, but looking back now it is easy to trace the start of the symptoms to this trigger."

GLANDULAR FEVER

Karen first had glandular fever when she was 15 years old in 1977 and was off school for six months. "I recovered but always knew that if I got excessively tired I would probably come down with something.

"I then became ill in 1984 with glandular fever-type symptoms but no positive test. I went back to work as a social worker after two months. In 1986 1 was admitted to hospital for tests and glandular fever was diagnosed again. This was the start of the more prolonged M.E. symptoms.

PROLONGED SYMPTOMS

"I struggled on, trying to go back to work until August 1987. I medically retired after a year on the sick. I have not made any significant improvement since, just better and worse times."

Rose recalls a childhood plagued by illness: "Following the mumps I developed bladder dysfunction (of unknown cause), poor vision and focusing, sensitivity to toothpaste as well as muscle and joint pains which strangely rotated around my body.

"A few years later I became ill with pancreatitis, which was to go on to trigger lethargy, irritable bowel syndrome, poor concentration and cognitive function. Within months I had glandular fever which simply seemed to compound everything, without the glandular symptoms ever going away and new ones, such as nausea and increased pain cropping up.

"The next two years were filled with infection upon infection – once again, making everything worse. A flu vaccine when I was 14 was the last straw before I was diagnosed as I was simply unable to get over those initial flu-like feelings."

Another member, who prefers to remain anonymous, said: "My husband fell ill with meningitis-type symptoms; this was the on-set of his M.E." For her, "Emotional trauma triggered a number of subsequent exponential downers in the M.E."

Sheila simply "had a virus, with swollen glands, flu-like symptoms, and the fatigue that goes with that illness. The first two symptoms disappeared and the fatigue stayed." Many people will identify with that, I'm sure.

Taken from InterAction with our thanks.
In our next issue we will be looking at triggers from a medical perspective, with comments from our medical adviser Professor Anthony Pinching and other health professionals.

'INVISIBLE DISEASE' IS NOW EASIER TO READ.

A simple blood test may revolutionise the way we treat patients with ME, reports Bob Ward

British researchers are close to developing, for the first time, a blood test and potential drug treatments for myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), following groundbreaking work on its genetic origins. ME/CFS affects about one in 200 people, and women sufferers outnumber men by six to one. It causes a constant feeling of extreme exhaustion and malaise for more than six months, along with sleep abnormalities, memory and concentration difficulties and a great deal of pain. In its most extreme form, the disease leaves sufferers bed-ridden and can even be fatal.

But patients now have new hope, thanks to research published in the *Journal of Clinical Pathology* by Dr Jonathan Kerr of St George's University of London and his colleagues. They have identified 88 genes that produce different levels of proteins and other molecules in ME/CFS sufferers compared with the rest of the population.

Dr Kerr's team carried out a complex analysis of the records of 55 patients and found that they could be divided into seven sub-types according to the specific gene combinations found in their white blood cells, and the severity of their symptoms. The most acutely affected patients had 71 of the 88 gene abnormalities.

The results of this work should allow better understanding of the causes and development of the disease. Many of the genes are known to be affected when a person contracts a virus, a factor which is believed to trigger many cases of ME/CFS.

Importantly, the researchers also recognised that five of the 88 genes are targeted by drugs which are already used to treat other diseases. The team is now investigating whether the faulty genes produce abnormal levels of proteins that can be detected as minute quantities of "biomarkers" in the blood of patients.

"If proven to be sensitive and specific indicators of the illness, the discovery of protein biomarkers could lead to the development of a diagnostic test for ME/CFS, which would revolutionise our approach to this disease," explains Dr Kerr. He will present his results at a conference on ME/CFS biomedical research in Cambridge in May.

The research may even lead to a change in attitudes to the disease, often trivialised as "yuppie flu".

Sarah, 31, who was diagnosed with ME/CFS two years ago, says: "The stigma associated with the disease can sometimes be as much of a problem as the symptoms. Some think that it is 'all in the mind' and can be cured by a good night's sleep. It can be difficult to get friends and work colleagues to understand just how difficult it is to live with a disease that is so debilitating but virtually invisible."

Attitudes among funders of medical research also need to change, says Dr Neil Abbot, operations director at the charity ME Research UK. "Studies on the psychological aspects of ME/CFS seem to have vacuumed up attention and funding at the expense of hard-core biomedical studies," he says. "Most of the £3 million spent by the Medical Research Council on the illness in the last six years has gone towards projects on the psychological management of the disease, while there is evidence that around 30 applications, some from established biomedical research groups, have not been funded."

The work carried out by Dr Kerr and his colleagues is funded by a small charity, the CFS Research Foundation, which was set up in 1993 by a group of doctors and scientists who were concerned about the direction and quality of work on the disease. Its director, Anne Faulkner, is optimistic about the search for a cure: "We believe that this disease can and will be conquered, but it will need the dedicated work of distinguished research scientists and the determination of people in the community to bring this about."

Bob Ward has donated the fee for this article to the CFS Research Foundation and ME Research UK. He is former winner of the Bayer/Telegraph science writer award, judged by a panel that includes Sir David Attenborough and Adam Hart-Davis.
Reprinted from the Daily Telegraph with kind permission of the CFS Research foundation.

YOU AND YOURS

In November, BBC Radio 4 broadcast an important series of programmes which looked at different aspects of M.E., from why it is such a controversial illness to what treatments are available and the current state of research. This is the concluding part of the article.

DIFFERENCES

PW: "You see these differences are part of the reason, it seems to me, why there is so much disagreement between patients and doctors, doctors and doctors, patients and patients.

"I mean, a listener's already suggested to us that Action for M.E. doesn't represent people with M.E. because as a charity you're too sympathetic to the CFS definition. I quote that just to illustrate the kind of things that have come in to us before we've even started this series."

WE NEED TO LISTEN

Ondine: "We certainly aim to represent everyone with M.E. That is our goal. We're run by people with M.E. for people with M.E. But we've got to work with the doctors (who use the term CFS) to find the solution while also listening to the people who have M.E. because they know what it's like everyday.

"It's quite possible that a lot of useful research in the future will come from patient surveys, from finding that certain treatments have actually helped some people and then doing research into (those results), rather than starting with the doctors."

PW: "So Professor White, is that part of the problem? You've already acknowledged that this is putting a lot of things in the same basket. Is that why people accuse you, for example, of being wedded to the fact that M.E. is in the mind as opposed to in the body? Are you just all trying to deal with too many things under one umbrella?"

Prof White: "I think it has been a problem in understanding the cause of this illness. I think what happens with the heterogeneity is that one group of scientists finds one answer, say the immune abnormality in the illness, and another group independently comes along and perhaps they are actually studying a different group of patients and therefore don't find the same thing.

"In terms of the issue about being all in the mind – I am a psychiatrist and I do not believe that M.E.'s all in the mind, I think it's both physical and psychological. We have to remember that our current understanding of neuroscience has advanced beyond the dualistic understanding that this illness is either physical or psychological. Like many, many illnesses.

"If I have something going on in my brain, such as thinking, that is a physical process happening in my brain and therefore if I have a feeling or a thought it is physical, it's not entirely psychological."

PW: "Doesn't this make the whole business of diagnosis difficult?"

Dr Weir: "First of all, to follow on what Professor White said, Cartesian dualism has bedevilled this situation for many years and the medical profession in the past has been the subject of legitimate criticism because we have tended to concentrate on one organ system or another to the exclusion of the rest of the patient.

"I think that psychiatrists also can be legitimately criticised because they tend to concentrate on the mind, although I'm glad to hear Professor Peter White say that this illness has physical components.

"Basically the mind and the body, if one continues to use those philosophical entities, are very closely interactive and when the body goes wrong the body feels ill and the mind feels ill as well. But fundamentally the cause of this is an organic disturbance of bodily function and I think that the likeliest common denominator is a disturbance of the immune system.

"There is recent work which suggests that the immune system is up-regulated and causes symptoms which are the fundamental problem with this illness."

CANADIAN GUIDELINES

Presenter John Waite: "If I could just interject – one of the posts on the BBC message board says we should be using the Canadian guidelines criteria for M.E., which is more stringent and encompasses more of the wide-ranging and truly debilitating symptoms of M.E."

PW: "So what are these guidelines and why aren't they used? Peter White, perhaps I can put that to you."

Prof White: "Well they're clinical guidelines and they're designed for use in clinical practice. The problem is – and the reason why I don't use them – is

they're very complicated to use. They will require me to do tests on my patients that I don't think ethically I should be doing on my patients – and I don't find them useful. If guidelines aren't useful then we don't use them.

"The problem is, what we need is more research to understand what the illness is. That research is starting to take place now, I'm glad to say and that's how we'll get our advances.

"The other thing I'd like to make a point on, in terms of this controversy, (is that) there are some reasons for hope, which I think it is important that we share."

PW: "You mentioned tests you don't think it's right for you to do – such as?"

Prof White: "Such as the tilt-table test where in the Canadian guidelines the idea is that I would have to exclude the condition called postural hypotension. That is the fall of blood pressure when you stand up. It is quite a complicated test and I don't think that's justified. I do a clinical test, as I'm sure probably Dr Weir does as well, where I measure the blood pressure when they're lying down and when they're standing, if they get dizzy when they stand up, that is sufficient. And that is why the guidelines aren't useful."

PW: "So you think they're unethical because they're too demanding?" Prof White: "Yes. It's an unpleasant test. Why should I put my patients through an unpleasant test that is unnecessary?"

PW: "You mentioned research. I'll put this to William Weir first of all. The suggestion is coming to us that a disproportionate amount of money has gone to research on the psychiatric side, not enough on the bio-physical side which you've both agreed is an element in this."

Dr Weir: "Yes I agree entirely. I think that a very large amount of money is currently being applied to research into disturbances of the mind in relation to this disorder and the biomedical causes of this condition have been neglected by the people who hold the purse strings."

PW: "Why?"

Dr Weir: "I think because the overall culture hitherto has been very much in favour of the psychiatric definition of this disease, the psychiatric understanding of this disease. The current PACE study (see below) has really been funded to an extent which I think should be equalled by appropriate biomedical study and it's not the case."

TOO MUCH EMPHASIS ON PSYCHIATRY?

PW: "Let me put that to Peter White. This is your field – psychiatry. Has too much money been spent on the psychiatric side?"

Prof White: "No, I don't think so at all because I don't classify my research as being purely psychiatric in the way that is meant in the conversation so far. "The PACE trial has been mentioned by Dr Weir and I'm glad to say that Action for M.E. backs our research and they back it for a very good reason. It's research that is not just purely psychiatric research. We're going to compare four treatments for this ghastly illness – and we've heard how severely it affects people. We're going to compare pacing, which the patient charities think is the most helpful treatment."

PW: "Pacing – it's literally what it sounds like."

Prof White: "Exactly, balancing activity versus rest and making sure you live within your limits.

"We're going to compare that directly with the two treatments that NICE thoroughly support for a very good reason, because the research evidence is there – namely CBT, cognitive behavioural therapy, and graded exercise therapy.

"On the aetiological or the causative side, the two studies that we're about to start at Bart's look at cytokines – an immune hormone – to see if that is elevated in people who undertake exercise and activity and at the same time, not only looking at the immune system, but reaction with the brain because we know that the immune system affects the brain.

"We're going to look at whether the brain perceives fatigue abnormally in this illness because we suspect it does, so it's both brain and immune system, it's mind and body, it's a way forward for this illness."

PW: "Ondine Upton, what do you think we ought to be doing? Is the money being spent in the right place and where do you want it spent?"

TOO LITTLE RESEARCH

Ondine: "I think the main issue is that actually far too little money is being spent on research for such an incredibly serious illness. And absolutely I would echo we need more biomedical research – but I think we need more research full stop.

"The cause is not understood, there are no treatments that have been fully investigated. We have a huge jigsaw of which most of the pieces are missing."

PW: "And why do you think this creates such passion amongst people and is that creating more heat than light sometimes."

Ondine: "I think the passion has been created by the fact that people with M.E. haven't really been understood. It's taken a long time for people to be confident they could go to their GP and get a diagnosis.

"When I first got M.E. 18 years ago, I was very lucky that the first doctor I saw was Dr William Weir. But I've spoken to a lot of people who got M.E. at that time who had horrific experiences. That is changing.

"One of the keys to this illness is early diagnosis. Those who are diagnosed earlier – I mean in three or four or five months after they start the illness – are far more likely to recover much faster.

"We hear horror stories of people who take a couple of years to get diagnosed and they're the ones who are likely to be ill long term."

ALTERNATIVE TREATMENTS

On 8 November, You and yours looked at some of the alternative treatments on offer for M.E. with Action for M.E.'s principal medical adviser, Professor Anthony Pinching, academic researcher and homeopath, Dr Elaine Weatherley-Jones, neurologist, Professor Leslie Findley, former GP David Mickel and GP and homeopath Dr Susie Rockwell.

Early in the programme, reporter Anna McNamee (AM) spoke to the founder of Mickel Therapy:

MICKEL THERAPY

David Mickel (DM)-. "I'm formerly a general practitioner. I gave it up to develop Mickel Therapy, a talking treatment for M.E. which involves no medication or dietary change or supplements.

"It works on the basis that the cause of the condition is rooted in the hypothalamus gland, which is a very important central gland in our brain. The hypothalamus has gone into an overdrive state and Mickel Therapy is a process that's designed to correct that.

AM: "How does Mickel Therapy work?"

DM: "Because we haven't actually studied the answer to that question, we don't actually know. Often this is the hardest selling point we have because it is just a talking therapy. Basically Mickel Therapy is a series of tools that we teach people with M.E. to apply to their symptoms that allows these symptoms to start to reduce until they finally stop."

AM: "How many times would an M.E. patient expect to have to see you and what would that cost?"

DM: "The number of times varies from individual to individual but the average number of sessions tends to be around eight. Currently in the UK it's about £80 a session."

AM: "So we're probably looking at something in the region of £640-£800 over the course of the treatment?"

DM: "Yeah that's right."

AM: "Have there been any studies that actually show that Mickel Therapy works?"

DM: "All we have at the moment is a caseload of 850 successfully treated people which represents 92% of our caseload over the years. But nobody seems to want to believe it. I've written to the MRC and ministries of health to ask for our work to be studied because it's all very well us saying it but unless an external body examines it, there's no credence really."

CA: "Professor Anthony Pinching, what do you make of Mickel Therapy?"

Prof Pinching: "I don't think I can comment on it other than to say that some people find it has been helpful and others find that it has not. This is just like any other intervention, whether it's a medication or a supplement or a diet or a talking therapy – any of them can be studied and should be studied. Until (then), all we can say is we're dealing with anecdote."

CA: "Professor Leslie Findley, are you getting patients coming to you saying, 'I've tried Mickel Therapy and it does work for me'?"

Prof Findley: "I have some that say it works and some say it doesn't but the important question is: intuitively could something that influences the function in the hypothalamus help chronic fatigue syndrome?

"Well we know the single factor that worsens fatigue syndrome is stress and if this therapy through the hypothalamus or any other organ actually reduces

stress and the effects of stress then that will benefit chronic fatigue syndrome.

"That's the talking bit. Really it's not that different in theory from reverse therapy – influencing the function of the hypothalamus which is said to be in conflict between the mind body and the brain body."

CA: "Many people would argue this is actually about seeing a therapist rather than the therapy. We all feel better if we talk things through, don't we?"

Prof Pinching: "Whether it's a talking therapy or another intervention the therapist effect may be there and needs to be understood.

"We also need to understand that some of the talking therapies, conventional or otherwise, involve a common substrate of lifestyle management, adjustment and coping, ways of thinking about what the symptoms mean, reinterpreting the experience of illness in a way that empowers the person to live better and to reduce the secondary impact of illness.

"I think those are things which we need to separate out from a specific intervention which may be the headline label of the therapy."

HOMEOPATHY

CA: "Dr Susie Rockwell is an NHS GP and she also runs a private practice offering homeopathic treatment."

Dr Rockwell: "Homeopathy is a natural system of medicine where we're aiming to stimulate the body to heal itself. It works on a principle of similars – treating like with like. For example, if you chop an onion you normally get streaming eyes and nose, so if someone's experiencing those same symptoms, for instance, with hay fever or a cold, if one gives them the remedy, Allium cepa, which is made from the red onion then the chances are that will improve their symptoms.

"M.E. is like any other condition that I'd treat homeopathically. I think, what is it that's special for this person about why they're ill. What makes them tick, what upsets them, stresses them – that sort of thing. By pulling together all those factors I can hopefully find a remedy which will help that person and improve their condition.

"Most remedies don't kick in instantly and give a sudden dramatic improvement. With M.E., usually it's much more subtle onset. After two or three weeks people start to say, 'I don't feel so ill' or 'I feel better in myself."'

AM: "How much would this all cost?"

Dr Rockwell: "I charge £110 for my first appointment and £45 for follow up appointments. Obviously people who are not doctors do charge rather less than medical homeopaths."

AM: "Is there any proof that homeopathy works when it comes to treating M.E.?"

Dr Rockwell: "Certainly at Bristol Homeopathic Hospital M.E. or chronic fatigue is the second most commonly treated condition. I've got a graph of their results. 22% of people felt much better, 34% better, 38% slightly better, 3% had no change and 3% felt slightly worse.

"Unfortunately these days most people are hung up on double blind placebo controlled trials which are regarded as the gold standard in medicine. The difficulty is, with both homeopathy and M.E., they're complex conditions and complex approaches. While live studies have been attempted there's a problem with getting enough people recruited."

CA: "Dr Elaine Weatherley-Jones, you're an honorary researcher in homeopathy and you have treated people with M.E. Do you think it works and if so why?"

Dr W-J: "It's very difficult to answer the question, why does it work. What we aim to do, as clinicians, is to treat the totality, the entire symptom picture that a patient presents with – and to choose an individual remedy for that person. "

CA: "So how would you decide who to give what to?"

Dr W-J: "For example, somebody with M.E./CFS may have had symptoms ever since they had a particularly bad respiratory infection, such as pneumonia or a very bad bronchitis. Another person may have had CFS symptoms since they had a particularly bad emotional trauma."

CA: "Let's talk about the example of bronchitis or pneumonia. How would you treat somebody like that who had M.E.?"

Dr W-J: "(With) any one of 3,000 homeopathic medicines. But it needs to be prescribed by a professional homeopath and also it's very important to say that in the treatment of M.E., patients should –

before they come to any complementary practitioner – have had enough tests to make sure that the diagnosis has been confirmed and they haven't got any other underlying causes for their fatigue."

CA: "You have done some research, when you were at Sheffield University. What did you find?"

RANDOMISED CONTROLLED TRIAL

Dr W-J: "I did what's called a gold standard – a randomised controlled trial – with a group of patients who had some dummy pills and a group of patients who had some real homeopathic medicine. Over 100 people took part. They were recruited from two hospitals in Yorkshire, infectious disease departments treating CFS/M.E. Each patient saw a professionally-qualified homeopath for a period of six months, about once a month.

"We were trying to tease out: is this the therapist or is this the therapy? Is there something in the consultation – is there something in the homeopathic medicine?

"And what my results showed was that nearly half of the people who had the real medicine showed an improvement on a scale of general fatigue, whereas just under a third of those people who had a dummy pill also improved on that general fatigue.

"This difference, when tested statistically, is likely to be due more to the homeopathic medicine itself than to the therapist effect. However, if we looked at the results overall, a quarter of people improved on all of the measures of fatigue that we were looking at – so there is also likely to be a therapist effect as well."

NUTRITION

CA: "Many people with M.E. are given advice on nutrition. Anna McNamee went along to see Niki Gratrix at the Optimum Health Clinic on London's Harley Street."

Niki Gratrix (NG): "I'm a qualified nutritional therapist and I work with M.E. patients using diet and mainly supplementation to help treat their illness."

AM: "Somebody who suffers from M.E. could see a dietician on the NHS, why wouldn't they just do that, why would they come and see a nutritional therapist instead?"

NG: "I'm looking at the latest research and I'm applying that, whereas a dietician tends to follow much more the orthodox line.

"(M.E.) is a complex illness. There are sub-groups with different underlying causes and problems, so it's very difficult to get studies done that are replicated that prove that there's one particular treatment. The dieticians have to follow the party line and until something like double-blind placebo-controlled experiments are done and the NHS agrees with them, then they're not going to be doing much else. So we're the ones looking at the latest research and applying it straightaway.

"When I see patients we spend a lot of time talking about mitochondria function. One of the things that we look at is how we can help improve the function of mitochondria because these are responsible for producing energy at a cellular level. The sort of things that we'd use to help treat this are things like D-ribose, vitamin B3, co-enzyme Q10, co-enzyme A. Magnesium is also very important in quite high dosage. And we'd also look at things which would help to clear out any toxins that are blocking mitochondrial function."

AM: "How much does it cost?"

NG: "For an initial consultation it's £135 – that's an hour and a half. The nutritional therapists are £90 an hour and the follow-ups are usually 45 minutes by phone."

AM: "Once somebody does sign up we're talking hundreds, possibly thousands of pounds?"

NG: "Yeah, unfortunately. We think we should get government funding."

AM: "For those that it doesn't help, it's a lot of money. It's a big gamble for somebody who's already ill."

NG: "There's probably about 10-20% of patients that are really tricky to treat with this illness. For anybody who thinks that we're just in this to make money: if I was motivated by money I would have stayed in my last job. I'm a qualified chartered accountant. In the job that I'm doing now I don't even earn half of what I was earning, working in the City. If I was financially motivated I'd have stayed in that."

CA: "Professor Findley, does nutrition have a role in controlling the symptoms of M.E.?"

Prof Findley: "It does because food intolerances, irritable bowel and so on are very common in people with fatigue syndrome."

CA: "Do you think there's evidence that giving supplements, paying out money for magnesium or capsules or whatever it is, is worth doing?"

Prof Findley: "No I don't think going to that extreme is worth doing but conventional nutritional input is of value and this is available through the health service in most places."

Prof Pinching: "At my previous unit, the dietician and other colleagues analysed a widely recommended diet for people with M.E., the so-called anti-candida low sugar, low yeast diet. They compared it with a healthy eating diet in a randomised format and also divided people into those with irritable bowel syndrome and those without. Although it was a relatively small study it was pretty clear that first of all, the healthy eating diet was easier to stick with and not so costly – but secondly that there was no clear benefit that the anti-candida diet gave, beyond what you get with a healthy eating diet."

WHAT WORKS?

CA: "So Professor Pinching, if you had to pick out things that your patients are telling you work, what would those things be – even if there's no evidence?"

Prof Pinching: "Lifestyle management, pacing, graded rehabilitation, whatever you want to call it. How to reorder their lives in the context of illness.

"The bottom line is that it works for everybody. It's very hard to do. It's very boring. It needs guidance and support because it's a major change in a person's life. But with an appropriate level of support, information and guidance and the individualisation of therapy, it does work for the vast majority of people, either to manage better within the level they're at or to improve the level they're at."

InterAction hopes to bring you extracts from other programmes in the series, in the next issue. To listen to recordings or read the full unedited transcripts of the You and yours M.E. series, go to: **www.bbc.co.uk/radio4/Youandyours/me–series.shtml**

**The BBC transcripts on which this feature is based were typed from recordings and not copied from a script. Because of the risk of mishearing and the difficulty in some cases of identifying individual speakers, the BBC cannot vouch for their complete accuracy. With permission from the BBC, Action for M.E. has adapted these transcripts for InterAction purposes, editing in the interests of space and readability*

COPING WITH STRESS

Here are some great ways of dealing with the burdens of life.
Accept that some days you're the pigeon and some days you're the statue.
Always keep your words soft and sweet, just in case you have to eat them.
If you lend someone £20 and never see that person again, it was probably worth it.
Since it's the early worm that gets eaten by the bird, sleep late.
The second mouse gets the cheese.
When everything's coming your way, you're in the wrong lane.
Birthdays are good for you. The more you have, the longer you live.
Some mistakes are too much fun to make only once.
A truly happy person is one who can enjoy the scenery on a detour.
You may be only one person in the world, but you may also be the world to one person.
Thanks to Central Lancs. Support groups -Phoenix

GIVE US A LAUGH...

How many people does it take to change a person with M.E.'s light bulb?
Doctor: "The light bulb is not broken. You just think it is."
Consultant: "The light bulb is broken, but I can't help."
OT "We need to get you to the point where you can change it yourself."
Alternative therapist "You must learn to love your broken light bulb as it is."
Benefits officer: "Fill in form LB06 if you think you are entitled to a replacement light bulb, or form LB08 if your carer is less than 5 feet tall."
Government minister: "Bogus light bulb claimants will be named and shamed."
Spouse/parent/carer.- "There you are. That's done now."
Person with M.E.: "Ow! Turn it off! You know I'm sensitive to light!"

Sent in by Paul Lack thanks to InterAction

STONE AGE DIET
BY DR. SARAH MYHILL www.drmyhill.co.uk

There are five aspects of diet and gut function which commonly cause symptoms from irritable bowel syndrome to fatigue. These are:
High carbohydrate intake - this is probably the largest single cause of modern diseases such as hypertension, obesity, syndrome X, heart disease and cancer
Food allergy
Toxins in the diet (lectins naturally present in foods; artificial additives, colourings, flavourings; artificial sweeteners; pesticide residues, plasticiser residues, etc) social chemicals (alcohol, caffeine, tobacco etc)
Gut dysbiosis (wrong bugs in the gut)
Poor digestion of food due to low stomach acid (Hypochlorhydria - Lack of stomach acid - can cause lots of problems) and poor pancreatic enzyme production.

This diet tries to address the top three problems at the same time, since they often co-exist in the same patient. This is the diet I like all my patients (including me) to eat long term. This is because it is the evolutionary correct diet and by eating this we can avoid long term health problems and postpone degenerative conditions. I would settle for getting my Parkinson's disease when I am 120!

As a general principle it is important to remember that **carbohydrates** tend to cause fatigue, even in "normal" people. We should be eating protein and fat in the day and saving carbohydrate (CHO) until the evening, when it helps sleep. At present Western diets are completely upside down because we eat cereals and toast at breakfast, sandwiches at lunch and meat in the evening - it makes you feel tired in the day and wakes you up at night!

Food allergy is a common cause of many symptoms such as irritable bowel, asthma, mood swings, headache, arthritis, allergic muscles and of course fatigue. The commonest offenders are grains, dairy, yeast and toxins in the diet.

Chemicals in the diet inhibit enzyme systems and slow up metabolism - this applies to drugs as well as food additives and pesticide residues. Avoid additives, colourings, flavourings etc, avoid plastic wrappings (especially if heated!) on food and try to switch to organic foods wherever possible.

Gut dysbiosis and **poor digestion** of foods, whereby foods are fermented instead of being digested, can also cause these symptoms.

This diet, therefore, has foods of low glycaemic index (GI) in the day and moderate GI index in the evening, it avoids the common allergens, avoids mouldy foods and foods of high fermentable substrate and is as free from chemicals as possible. Actually, in the long term I see this as a diet for life. My view is that we should be mimicking Stone Age principles - the following is the evolutionary correct diet. Once the diet is established, one does not have to follow it slavishly, but it should make up our staple diet and ultimately the forbidden foods should become treat foods and not staple foods.

ALLOWED FOODS

The following foods are allowed both in the day and the evening
Any meats: choose from chicken, beef, lamb, pork, turkey, duck, 'game' meats such as venison, pheasant, goose etc., bacon and ham, salami. Liver, kidney and offal are fine too.
Eggs - an excellent source of lecithin (eat soft yolks), which reduces blood cholesterol levels.
Any fish: salmon, mackerel, cod, haddock (care with smoked fish which often contains dyes). Tinned fish in brine or olive oil is fine. Tinned shrimps, prawns, mussels, cockles etc.
Any green vegetables
All salads: lettuce, tomato, cucumber, celery, peppers, onion, cress, bamboo shoots etc.
French dressing: make your own from olive oil, lemon juice, garlic, mustard.
Any low CHO fruit: apple, pear, orange, grapefruit (no sugar!). Berries are excellent.
Seeds: sunflower, poppy, sesame.
Nuts: peanut, brazil, hazel, cashew, pistachio, walnut etc.; nut butter spreads, tahini (sesame seed spread).
Use cold pressed nut and seed oils liberally such as sunflower, olive, sesame, grapeseed, hemp, linseed, rape and so on.
Soya products
Spices and herbs: chilli, cumin, ginger, coriander, pepper, cloves etc
Herbs, salt (ideally Solo - a sodium reduced sea salt), olives, pork scratchings
Allowed drinks in the day Bottled or filtered water
Herbal teas: redbush ("rooibosch", "11 0'clock tea"), rosehip tea.
In the evening you can eat all of the above, plus modest amounts of higher GI foods
Rice and potato e.g. rice cakes or puffed rice from health food shops.
Root vegetables - carrots, parsnip, turnip, celeriac
Specific grains: millet, buckwheat, sago, quinoa.

Some high carbohydrate fruit: banana, avocado, grapes, melon
Dried fruit: sultana, apricot, prune, raisin, fig, date etc
Pulses: lentil, butter beans, chick peas, flageolets etc
Mixture of nuts, seeds, dried fruits
Arrowroot flour: for thickening gravies
Diluted fruit juice: Grape juice, pineapple juice, apple juice, tomato juice - best drunk diluted.
Most foods from packets and tins will have **hidden additives**, so avoid these. Be careful with sausage which contains rusk. **ALL OTHER FOODS ARE FORBIDDEN!!!** - this means no tap water, tea, coffee, chocolate, alcohol, wheat (bread, biscuit, cake, pasta, pastry), rye (Ryvita), oats, corn, dairy products (milk, butter, cheese, yoghurt, dried milk), vinegar and sugar. Try to avoid drugs and medicines, many of which contain fillers of corn, lactose, colourings etc.

GETTING WORSE ON THE DIET

This is almost to be expected. The reasons for worsening are as follows:
Hypoglycaemia - this is the commonest reason for worsening and may take weeks to settle. There are some nutritional interventions which help greatly (see HYPOGLYCAEMIA - Not just about diet!)
Caffeine withdrawal - again common. Usually results in headache which clears in four days.
Food allergy withdrawal may cause many different symptoms. Some people report feeling 'flu like. Typically this lasts four days, but with symptoms like eczema, arthritis, allergic muscles and fatigue it can take weeks to clear. One patient with prostatism took 4 months to clear!

MEAL SUGGESTIONS

Breakfast
Bacon, eggs, fried tomato.
Smoked fish (kippers, mackerel with lemon juice).
Nuts and seeds with soya yoghurt (see Probiotics - we should all be taking these all the time and double the dose following antibiotics and gastroenteritis)
Lunch
Cold meat, fish (tinned fish in olive oil is fine), prawns, salami, smoked fish, rusk free sausage (i.e. 100% meat)
Salad (lettuce, cucumber, tomato, celery, peppers etc), French dressing.
Green vegetables with nut/seed oils
Home-made soup (made from meat stock, not cubes, only with allowed vegetables).
Nuts and seeds with soya yoghurt
Supper
Meat, fish or eggs, potato or rice, any vegetable.
Fruit, soya yoghurt.
Muesli made from rice flakes, millet flakes, nuts, seeds, dried fruit, fresh fruit etc (some health food shops do "gluten free" muesli with the above ingredients). Use soya milk or fruit juice to wet the dry cereal. Puffed rice or rice cakes with soya margarine, nut butter. Buckwheat flakes.

Always remember: Breakfast like an Emperor, lunch like a King and supper like a pauper!

What to do if you are no better on the diet
Stick with it! This is the evolutionary correct diet and greatly reduces your risk of heart disease, cancer and degenerative conditions! The three common reasons for not improving are:
Because of multiple allergies to foods (so that there is something on the diet that you continue to react to). In this case consider a rotation diet, or start on desensitisation.
Because of a gut dysbiosis - i.e. the wrong bugs in the gut. Consider a gut fermentation test or Comprehensive Digestive Stool analysis to look for parasites, bacterial overgrowth or yeast overgrowth.
Poor digestion of foods.

RECOMMENDED READING

"The Complete Guide to Food Allergy and Intolerance" Brostoff and Gamlin, £9.99.
"Not All In The Mind" - Richard Mackarness
"The Food Intolerance Diet Book" Workman, Hunter and Alun Jones. Dr Atkins Diet Revolution: Dr Robert C Atkins.
The Detox Diet Dr Paula Baillie-Hamilton 0-718-14545-3 from **www.penguin.com**

IF YOU WISH ALSO TO LOSE WEIGHT.

As a general principle I don't like my CFS patients dieting because cutting calories makes you tired, cold and depressed and you can do without those things! However, if you are extremely strict with CHO, the body switches into a state of ketosis. To burn fats in the body is a two stage process - the first stage is conversion of fats to ketones, the next is ketones to carbon dioxide and water. Both stages release energy for the body to use. However, the second stage requires some CHO - if there is none then ketones are excreted in the breath and in the urine - one literally pees out calories. This is very good for morale when every time you pee you lose calories and weight! To do this diet properly you really need to get the book Dr Atkins Diet Revolution which goes into detail of exactly which foods you need. Also I can supply ketostix which measure ketones in the urine and tell you if you are doing the diet correctly. Atkins permits dairy products but I recommend avoiding these. He also permits various artificial sweeteners which should be avoided
Our thanks to Danum ME Newsletter

POETRY CORNER

It's never easy to be glad when all around is gloom,
It's never easy to prevent what pessimists may groom.
It's never easy to put right what's wrong as time goes by,
Although it's never easy at least it's worth a try.

J. M.Robertson

Lord grant me I pray.

Courage when the best things fail me,
Calm and poise when storms assail me,
Common sense when things perplex me,
A sense of humour when they vex me,
Hope when disappointments damp me,
Wider vision when life cramps me,
Kindness when folk need it badly,
Readiness to help them gladly,
And when effort seems in vain –
Wisdom to begin again.

Anon.

When the road is steep and rocky
And the way is hard to find,
When your problems all oppress you
And the world seems so unkind,
Just reach out a hand in silence,
Take a moment you can spare,
Soon you'll feel your special angels
All around you everywhere.

When the night is dark and stormy
And the stars forget to shine,
When you feel that sleep eludes you
They will bring a peace divine.
When you see the sun awaken
And you sense a bright new start
You will know your special angels
Took your hand and touched your heart.

Iris Hesselden.

Thoughts for the day.

Our days are happier when we give a bit of our heart rather than a piece of our mind.
It may be the early bird who gets the worm but it is the second mouse who gets the cheese.

BOOK REVIEW.

David S.Bell, Cellular Hypoxia And Neuro-Immune Fatigue.

David S.Bell MD author of *The disease of a thousand names* and *The doctor's guide to Chronic Fatigue Syndrome* has just written another book called *Cellular Hypoxia and Neuro-Immune Fatigue*. In it he describes ME/CFS, Fibromyalgia, orthostatic intolerance, Dysautonomia, Multiple chemical sensitivities and chronic Lyme disease as being due to cellular hypoxia.

Hypoxia is a technical term meaning the inability to transform oxygen into energy. Most frequently it refers to not getting enough oxygen into the lungs, or not getting enough oxygen into the blood stream once it reaches the lungs. A person becomes hypoxic while drowning or with lung damage in emphysema. Hypoxia also occurs if there is a problem delivering the blood to the tissues, even though there is plenty of oxygen in the air and lungs. When blood vessels are blocked with a blood clot, the downstream tissues become 'hypoxic.'

However, there is a fourth type of hypoxia where there is plenty of oxygen in the air, plenty of oxygen in the blood, and the blood gets into the tissues. This fourth type is called 'cellular hypoxia' and it is due to a problem at cellular level converting oxygen into energy.

The term 'cellular hypoxia' was first coined by Dr. Mitchel Fink referring to septic shock; he reviewed the series of events occurring in septic shock. First, a serious infection. Next the infection stimulates the production of cytokines. These cytokines, while trying to fight the infection, increase the amounts of nitric oxide within the cell. This nitric oxide then interferes with the production of energy, to the degree that a person can die of septic shock even though oxygen is given and blood is flowing into the organs. In severe septic shock the impairment of energy production by nitric oxide is similar in effect to the effect of cyanide.

ME/CFS/Fibromyalgia is different to septic shock. But, is it possible that a similar mechanism, albeit slower and chronic, may be taking place? Neuro-immune fatigue may just be a minor and chronic form of septic shock.

This book goes on to explore this concept in detail and presents evidence that there is a series of events which end up disrupting the energy production cycle, and thus produce the symptoms which exist within this spectrum of illnesses. He doesn't list treatment but states there are supplements, vitamins and drugs which will be able to inhibit nitric oxide synthetase or improve the function of the enzyme systems to eliminate the reactive oxygen species.

The only substance he mentions by name that can reduce the amount of nitric oxide within a system is vitamin B12 (which has long been known and is safe). Which reminds me I have not done my daily B12 injection today- Irene. Thanks to CFS/ME Rotherham Group

DEAR DOCTOR - TEMPERATURE CONTROL

I would like some advice about coping in hot and humid conditions and how those affected can prevent a relapse, especially as now we are experiencing hotter summers. My last relapse due to temperature problems lasted up to a year and now I have to keep out of the sun, even if it is only 18°C.

Professor Anthony Pinching replies:
Thank you for this. As well as responding to your specific question, I will broaden my reply to wider issues about temperature control in M.E./CFS. Many people with M.E. have problems with external temperature. This can be through effects on symptoms and functioning in different weather conditions, as in your situation. Or it may be a sense of not being able to control body temperature – sometimes feeling hot when it is cold, at others feeling cold when it is hot, and often varying from one to the other for no obvious reason.

Most people with M.E. also find it very hard to adjust to extremes in external temperature, whether it is very hot or very cold. This may reflect a general difficulty in adjusting to change in this illness.
(87% of the 2,000+ respondents to our 2006 'M. E. – More Than You Know' survey reported problems with body temperature control; 66% reported these as severe; 85% reported wildly fluctuating body temperature – Ed).

However, apart from such extremes, people with M.E. frequently seem to have their own preferred external temperature for optimal function and comfort with their illness. In fact, most often, people seem to prefer warmer (and preferably drier) climatic conditions. But for others, like you, cooler conditions are better. Some seem more affected by humidity than by heat. Patients with other chronic neurological disorders (e.g. multiple sclerosis) also show variation in symptoms or function at different external temperatures – the usual preference being for warmer conditions. We are not sure of the biological basis for this, but it is perhaps not surprising that the complexity of the nervous system will be sensitive to ambient conditions.

The regulation of our body temperature depends mainly on the fine control of the autonomic (inner) nervous system. We know that this part of the nervous system may be affected by M.E., for example with the control of blood pressure leading to a tendency to faintness on standing up quickly. It is probably because the fine control of this system is disrupted in M.E. that so many people find it hard to get to a comfortable temperature. Obviously, this can lead to a lot of extra energy consumption, quite apart from the discomfort.
Most patients with M.E. do not however seem to have an actual increase in body temperature from their illness. But a few do have persistent slight low-grade fever, for no apparent other cause. This may be because of the increased levels of pro-inflammatory cytokines (immune chemicals involved in inflammation) that have been found in research studies.

You ask how to prevent a relapse due to such changes. A lot of this depends on your exact circumstances, but I can outline some general ideas. By the way, the Department of Health does offer useful public health advice during hot spells, and this should be checked for ideas that may help you.

In a hot summer, it is a good idea to shut south-facing curtains in the daytime, to reduce the effect on room temperature of sunlight coming through windows. If you are able to stay in north-facing rooms, or in areas that are more shaded externally, there will be less extra warming of the walls. Keep windows shut when the outside temperature rises, and open them in the cool evenings and at night time. Reduce to a minimum the use of all indoor power-emitting sources, especially in the rooms you usually use (don't forget that freezers emit a lot of heat). If you can afford even simple air-conditioning, it could help if you are very much affected.

It is obviously advisable to keep out of the sun, but also to avoid going out in the heat of the day. Take plenty of water to replace what you lose. If you put some water on the skin and leave it to evaporate, that can cool you down a bit. Cool showers during the day can also help, if you can manage them. Wear light and loose clothing. Fans can help too.

If your own housing limits your options, you may want to approach social services to assess whether there are any modifications that could be made which could assist in your specific circumstances.

Overall, there are no easy solutions, but knowing why there is an issue can help quite a lot. Common sense solutions are worth remembering, adapting them to your own needs.

Heatwave, a guide to looking after yourself and others during hot weather, is available from the Department of Health. Quote 40313/Heatwave and contact the DH publications orderline (8am-6pm, Mon to Fri) on: 08701 555 455. E-mail: dh@prolog.uk.com.
www.dh.gov.uk/publications

MEDIA ON MOOD

There was a great deal of media discussion earlier this year about talking therapies and, in a separate story, about the effectiveness or otherwise of Selective Serotonin Re-uptake Inhibitors or SSR1s, also known as 'new generation' anti-depressants. Professor Anthony Pinching comments.

For people who have disorders of mood, such as anxiety and depression, recent announcements, publications and the media reports that followed them, must have been puzzling and even worrying.

Although M.E. is not, in my view, primarily a psychological disorder, we know that 60% of patients have significant levels of anxiety or depression, alongside or as a result of the illness (see InterAction 62, p 34). So these issues are relevant.

Furthermore, we know that some patients can be helped in adjusting to the impact of the illness and in adopting different ways of functioning despite illness, with the help of therapists who work psychologically.

The government has announced a plan to increase the number and availability of psychological therapists (by 2010/11, 3,600 new therapists will be trained and employed at an annual cost of £170 million per year). For anyone who has tried to access such therapies, this must be good news. Many patients benefit from 'talking therapies' and accessibility is usually a problem because need exceeds capacity.

I recall a young man with M.E. whom I saw soon after starting the Cornwall service. He had wanted and needed help with adjusting to his illness and its impact on his life. He had been referred to three services with psychologists but each time, after a long wait, he was told by the therapists that he fell outside their criteria, even though they agreed he could have benefited from their skills.

By the time he arrived to our service, he had come to terms with his illness himself! But he could have got there more readily and less painfully if therapists had been available to provide for his needs.

The second news item was about a study on SSRI anti-depressants, conducted by the University of Hull. In essence, it questioned whether the data that had led to drugs such as Prozac (fluoxetine) being licensed in the USA were sufficient to justify doing so. They looked at some unpublished studies, although their approach excluded studies published after licensure. Inevitably the media rather simplified the story, and may have worried people who are currently taking such treatments.

The report (Initial severity and antidepressant benefits: a meta-analysis of data submitted to the FDA, published in PLoS Medicine) did not say that they didn't work. It said that the studies had not shown them to be as likely to be as effective as had been supposed, especially in mild depression.

They certainly work for some people and have transformed lives. Other people have side effects that outweigh any advantages. And they just don't seem to help some people at all.

We know that talking therapies can be effective in treating mood disorders, but the simultaneous publicity implied that there was a sudden lurch from pills to psychotherapy. In reality, clinicians and patients will assess the role of such treatments on the basis of all the evidence and its relevance to the individual, considering either, neither or both.

If medication is helping you, then statistical analysis of some previous research is interesting, but not very relevant. If medication didn't suit you, or you decided that it wasn't your thing, the news doesn't change that; but maybe you feel more confident in saying that you don't want to try them (again). If you haven't needed to consider anti-depressants before, but develop mood problems, you and your doctors can weigh up the pros and cons together. I don't think this study will make a big change in that process, but it may shape it at the edges.

Of course, these studies and announcements were on the treatment of depression and anxiety in general, not specifically on people with M.E. But they have relevance because they are amongst the tools that are needed some of the time by some people with M.E. We use these anti-depressant medications not only for depression and anxiety but also for some sleep problems and some cognitive problems. If people with M.E. need a therapist trained in psychological methods to help with adjusting to their illness or its effect on them and their interactions with others, then increased availability of such therapists is encouraging. For those people with M.E. who don't want or need them, nothing changes.

(NB. I have neither funding from, nor consultancy role with, any pharmaceutical company, and have not for over five years. I have no financial interests or other conflicts of interest regarding psychological therapies. I am a clinician who offers available and appropriate treatments to patients on the basis of my knowledge and experience, but only if they wish to try them – AP)

Thanks to InterAction for these two articles

SOME CONTACT NUMBERS AND ADDRESSES YOU MAY FIND USEFUL

Benefits Agency Information Officer (Bolton). 01204 367000 (Bury) : 0161 762 2000
Bolton Primary Care Trust : 01204 907724
Bury Primary Care Trust : 0161 762 3100
Citizen's Advice Bureau Bury : 0161 761 5355 Bolton 01204 900200(/213 Housebound)
Disabled Living : 0161 832 3678
DIAL Disability Information and Advice Line: equipment and gadgets and where to get them 0161 703 8887
Bolton Community Voluntary Services: 01204 546010 Carers Support (Bolton) : 01204 363056
Bury Council for Voluntary Services :0161 764 2161
Bury Carer Services : 0161 253 6008 and **Bury Carer Assessment** ; 0161 253 7190.
Bolton Market Place - Wheelchair Service : 01204 361100
Shopmobility, Trafford Centre : 0161 749 1728
Basic Neurocare Centre, 554 Eccles New Road, Salford, M5 2AL. 0161 707 6441
Ring & Ride Bolton : 01204 388500 Bury : 0161 764 1999
Welfare Rights Advice Line : 01204 380460
Benefits Helpline : 0800 882200. **Completing Forms** : 0800 44 11 44
The Disability Rights Commission www.drc-gb.org
Job Centre Plus http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled/
Access to Work http://www.jobcentreplus.gov.uk/JCP/Customers/HelpForDisabledPeople/AccesstoWork/
General government guidance on entitlements http://www.direct.gov.uk/DisabledPeople

ACTION FOR ME, 3rd floor, Canningford House, 38 Victoria Street, Bristol. BS1 6BY.
Tel 0845 123 2380 (or 0117 9279551). e-mail admin@afme.org.uk for general enquiries
Welfare Rights Helpline 01749 330136 9am to 1pm Mon Tues Thurs 9am to 12.30 Fri
e-mail **pauline@afme.org.uk** Telephone support - advice and information for anyone affected by ME (including non-members) 0845 1232314 11am to 1pm Mon to Fri
Web site www.afme.org.uk Young people with ME **www.a4me.org.uk**

ME ASSOCIATION, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks. MK18 4DF 01280 818968.
Information Line: 0870 444 1836 (10am to 12noon, 2pm-4pm and 7pm to 9pm – every day)
www.meassociation.org.uk/

M.E.R.G.E. MERGE is the Myalgic Encephalomyelitis Research Group for Education and Support
http://www.meresearch.org.uk/

BRAME (Blue Ribbon for the Awareness of ME) 30, Winner Avenue, Winterton on Sea, Great Yarmouth, Norfolk. NR29 4BA. Tel/Fax 01493 393717. The BRAME campaign was launched to create a greater awareness and understanding that ME is a very real and debilitating illness. **www.brame.org**

CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION, 2, The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. This charity (formerly the Persistent Virus Disease Research Foundation) was established to concentrate entirely on research into ME and on informing the medical profession of any new findings.

NATIONAL ME SUPPORT CENTRE, Disabled Services Centre, Harold Wood Hospital, Romford, Essex, RM3 9AR. 01708 378050

The 25% ME GROUP, Simon Lawrence, 4, Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ ME Group for the Severely Affected ME sufferer. e-mail **enquiries@25megroup.org**

CHROME (Case History Research on ME), 3 Britannia Road, London SW6 2HJ. This charity was set up to identify as many severely affected ME sufferers as possible in the UK and monitor the course of their illness over 10 years. The study will supplement medical research into the condition.

TYMES TRUST-(The Young ME Sufferers Trust) P.O. Box 4347, Stock, Ingatestone, CM4 9TE,
www.tymestrust.org Advice line 0845 003 9002 (Mon-Fri 11-1 or 5pm-7pm).

ME PUBLICITY CAMPAIGN, Russ Bassett. 7, Ridgefield, Watford, Herts. WD1 3TU. 01923 226253
A Campaigning Organisation dedicated to enhancing the rights and profile of the ME/CFS sufferer.

AYME (Association for Young People with ME) Box 605, Milton Keynes MK2 2XD. 08451 23 23 89.

RIME Research Into Myalgic Encephalomyelitis 10 Carters Hill Close Mottingham London SE9 4RS
THE NATIONAL ME CENTRE www.nmec.org.uk/ lists many contacts