



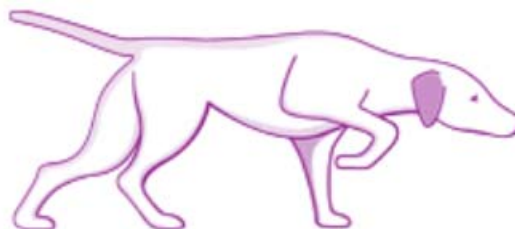
Pathways

Price £ 2.50 (Free to members)

The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Benefits and Work Guides you can trust

Benefits and Work

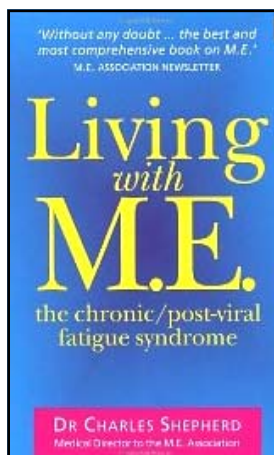


The Benefits & Work Guides

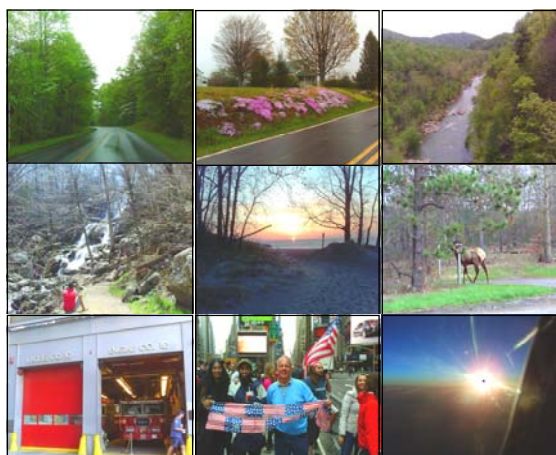
Leger ME members have had access to Benefits & Work Guides since Easter, which was about the same time as ESA 2 started. The feedback we are receiving is very positive, but it is too early to be complacent. There are still some unsatisfactory outcomes and really we can't win 'em all. We have listed the most common guides and given an example of the help that they gave a member to complete her ESA 50. See from page 6 onwards.



How Sarah's babies led to a diagnosis for advanced senile dementia See page 12.



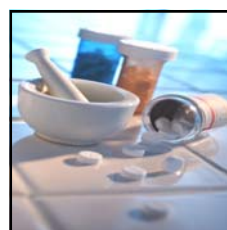
The Leger ME Group Library See page 5



Trevor's Personal American Travel Diary - Part 2 See page 20



Late September Butterflies See page 20



The NHS' New Medicine Service. See page 11



Helen Writes: My DLA and IB will be due in November 2012, have you any idea when I am likely to be contacted? Also, regarding my DLA, I ordered a car through the mobility scheme in July which will probably be ready in November; if it is later than this then I will be unable to take delivery as I will have less than one year's DLA available to me, are there any options open to me?

DLA renewal forms are usually sent six months before the current award expires. In your case, expect a renewal form around May 2012. Unless you are having major modifications like special adaptations or controls I would think twice before going for a mobility car. Some dealers hike the price of cars for the mobility scheme and I've found that in some cases it is possible to get the model you want for cash at a considerable discount.

I'm looking at a new car, and I'm not prepared to take the risk of being marooned without a mobility car that I could lose if I ran into DLA problems. There is no right to buy out the car if you lose DLA, although it is possible to keep it while an appeal is in progress. Really the best time to get a mobility car is when the new award is given. There is a further issue, DLA is likely to stop in 2014 and be replaced by Personal Independence Payments (PIP). We don't know, although there are indications that the award will be similar to high rate mobility. We don't know what any transition arrangements will be, and I would not like to speculate. One of our members has volunteered to be a 'guinea pig', and be assessed on a trial basis for PIP. The DWP have given her a £30 shopping voucher for volunteering.

Lorna writes: I've had worse fatigue and new symptoms for the last couple of months. I found out a few weeks ago that I have an iron deficiency as my ferritin is below the normal range. My haemoglobin is normal and my specialist told me you can have an iron deficiency and normal haemoglobin. Ferritin is stored iron. My level was 10. I was not anaemic. Levels of below 50 have been linked to fatigue. I have probably had low ferritin levels for months if not years contributing to fatigue. I would really recommend everyone with ME having their ferritin levels checked. If your GP won't do it then show him one of the two articles below. This is the biggest discovery I've made to potential improvement since having ME. Women of menstruating age are the group most likely to have ferritin deficiency or levels below 50.

<http://www.drbriffa.com/2007/08/31/the-link-between-low-iron-levels-and-fatigue-and-why-this-diagnosis-is-often-missed/>

<http://www.mydr.com.au/womens-health/iron-may-help-fatigue-in-women-even-when-haemoglobin-ok>

Ferritin is an iron-protein complex found in most tissues, but particularly in the bone marrow and reticuloendothelial system. It is a primary iron-storage protein and often measured to assess a patient's iron status. Various diseases can cause changes in the amount of ferritin present, and I don't think ME/CFS is an exception. It is an 'acute phase' protein and may be increased in inflammation, neoplastic and liver disease. As ME/CFS is a chronic condition we recommend that you have a yearly check up with your doctor. In some of the test results I've seen, ferritin has been checked, and it is also checked as part of the ME/CFS diagnostic exclusion criteria.

Carol Writes: I have a PHI (Permanent Health Insurance), and I need to make a claim as I cannot work due to ME/CFS. Have any of the Leger ME members made a claim?

We've had some members with PHI problems, and won. A couple of cases are still on-going. We've found that if the policy is a 12 months policy then usually the insurers will pay out without difficulty. However if it is some sort of permanent health policy, if you get ME at 40, then they have to pay out for 25 years until retirement age. It's going to cost the insurance company a lot of money, and they need a lot of convincing. If you have difficulty with the claim, we found that, as with State benefits, there is no single magic letter from a consultant or ME/CFS specialist that is going to work.

We think the first option is to get ESA and then claim DLA. You also need the support of a ME/CFS clinic or hospital consultant. Once these are in place then you are in a good position if they are arguing.

The most recent case took 14 months. One of the things that the insurance company picked up on was the member concerned was on the company directors register. This was because he was a trustee of a local non-profit organisation. The only option was for him to resign and get a doctor's letter to say he had been given stern advice. So it is quite clear that PHI companies will check public records. They also check social networking sites in the same way as the DWP. One case that we have at present is a NHS nurse claiming through the nurses' pension fund, and there are problems. The strategy we are using is to get all the state benefits we can and then have another go. One thing that you need to be aware of is that the PHI insurance companies often seek advice from organisations about ME/CFS in a similar way to how the DWP obtain advice from Atos. We are all aware of the issues that causes. So, the state benefits first approach is really the key, unless of course you have plenty on money and a good solicitor.

Rowena writes: I sent in a request that 'they' look at my DLA as my condition had worsened. They refused to increase my DLA to start with, but I appealed over the phone and asked they look at it again. They had totally ignored the additions I had included on my form. They then wrote to my specialist and then requested I have a medical professional to come to my house. The first time the doctor came I had asked her to let herself in using a key safe, which she did, but then she couldn't wake me up. I called and she rebooked my appointment. She said she thought it was just formality, but came for second appointment. I heard just over a week later that they were increasing DLA to high care and high mobility. They are backdating to May and have extended the term until April 2014. I thought that I would call DLA to get the visiting doctor's report as my ESA medical form has just gone in and I thought it might be worth sending in a medical report—what do you think?

Well done in getting the DLA upgrade – there are always arguments for the high rate care. It makes a refreshing change that a DIY upgrade has been successful (although of course you had a good tutor). I've only seen high care for one other person recently. I think you should tell the ESA people that you have high mobility and high care, because you are likely to get a summons to the local DWP medical centre. They may get quite stroppy because no one will have told them about it and you will be expected to attend the examination, and they will send you a personalised map showing bus time tables and walking route instructions. They will not accept your request to be seen at home for ESA. A home visit must be requested directly from your doctor, and normally it is usually faxed to Atos.

Sandy Writes: I'm not sure of how to write to you directly, but just wanted to make sure that you were aware of the document that was issued July 15, 2011 (maybe I missed it in the recent *Pathways*. sometimes, no, often, my brain lets me down) entitled 'ME: International Consensus Criteria'. If not, please let me know. If you were, I know you share the "pleasure" in learning that the consensus is that it is more appropriate and correct to use the term "Myalgic encephalomyelitis." I have always wondered what a different road my own life might have taken if the atrocious, irresponsible and disrespectful term "CFS" had NEVER been created here in the U.S.

It's possibly better if you can send me a copy of the document or reference to it. CFS: sentiments same here, although it is for us ME/CFS or CFS/ME and this has gained acceptance within the NHS.

Ian Writes: Can you tell me the difference between Leger ME & Danum ME?

Leger ME is a 'Community Group' set up for people with ME/CFS by its members. It a member of the Redmond Centre Community Group, which is the Doncaster MBC-supported user group of the Redmond Centre, Carcroft, Doncaster. There are two sorts of members. Local members are well enough to attend the Redmond Centre, and Distance members cannot, some living outside Doncaster. Ever since Leger ME was first formed, the bulk of activity has been internet based. We now run a monthly meeting the third Thursday in the month plus other services like welfare rights, counselling and mentoring. 'Pathways', our quarterly newsletter, is mailed to members, and posted on the internet. When Leger ME was first conceived, we wanted to call the group Doncaster ME. We wanted to use that email address.

However Doncaster.ME had been acquired by a speculative company, and, like many internet names starting with a town or city name, was only available at an extortionate price. We went for the next best available which was Leger.ME.uk The name Leger is derived from the well known local horse race 'The St. Leger', and is used by many local businesses and local organisations in Doncaster. 'Danum' is also used by many organisations in Doncaster, and is derived from the old Roman name for Doncaster. Danum.ME is my own personal internet identity, and used by me as a separate identity to keep ME/CFS issues separate from my personal affairs.

Market Research Opinion Surveys

Wendy writes: I recently received an email from Pinecone research asking me to recruit people to take part in their surveys. You get a £3 luncheon voucher for filling in a survey (usually taking around 15-20 minutes) and get sent around one or two surveys a month. I assume this does not count as working or earning income as it's a luncheon voucher. Please let me know if you think anything different as I want to do them myself. And I am thinking of doing occasional ones (not well enough to do more) with other companies which give gift vouchers (as opposed to cash) - likewise I am assuming this would not be counted as work. I have heard the tax office does not count things like vouchers and prizes from on-line surveys as taxable. However, they may possibly do so if actual cash is involved - not sure here. Pinecone is one of the better on-line survey companies and pays better and is quite difficult to get into if you don't know anyone who can send you an invite. Sometimes you get sent free samples to comment on too.

As a member in good standing, you've already seen the benefits of being part of PineCone Research. So please, share the benefits of membership with a friend. Remember, please don't tell them about any of the products that you have seen in our questionnaires or tried in your home. It's important that your PineCone Research survey and product testing experiences remain confidential. While this is not a paid referral program, we genuinely appreciate your help in spreading the word that PINECONE IS GROWING!

Some Leger ME members have received similar emails, the typical text of the email (above right). There are three issues. Firstly, passing on to a third party some else's email address without their explicit consent goes against the principles of the data protection act. You are exporting data, and, strictly speaking, if you are going to pursue this, you must register with the Data protection registrar. Secondly vouchers are taxable as 'cash in kind', and, need be declared on income tax and ESA income forms. Thirdly, the DWP, would be within its rights to review ESA, with all the anxiety & hassle that involves. Your activities would be direct proof of your communication abilities and dexterity.

Rose Writes: I am one member of the group who has been doing surveys for 'Pinecone' for a good few years now. They are one of the very best internet market research companies. Luncheon vouchers are accepted at supermarket checkouts for grocery payments. Here are a few good online UK market research companies:

'Valued Opinions' - pay vouchers e.g. Tesco or Boots ones from them which I find very useful.

'Shop and Scan' - this company is different as they send you a 'clicker'. What you do is to scan your shopping barcodes with the clicker and take a copy of the receipt and then upload to their website at the end of each week. They issue Debenham vouchers.

'Yougov' give you points and pay money once you reach £50 (and also have prizes). It takes me over a year to do enough surveys to earn the £50 payout from them.....very nice when it arrives but not exactly a quick moneymaking game...

Just one thing to bear in mind. Some of the questions can be very searching; I have known people who signed up for companies and then backed out feeling they are too intrusive. All I can say is that I have found it absolutely fine because all of these Good and Genuine UK companies are bound by the data protection laws and are very safe to be with, I have never had a problem with any of them in over five years now. I am with a few other companies.

Harriet Writes I have been with Pinecone for a while now - I have found them very good. I have registered with a few more. Am registered with My Survey, Global Test Market, NewVista, Panelbase, Toluna, YouGov and Just the Answer.

While surveys do provide a small income, the money you get for the time it takes is slave labour. Market Research is a hobby, and does not cover the cost of the computer and internet bandwidth as a business.

The Leger ME Group Library

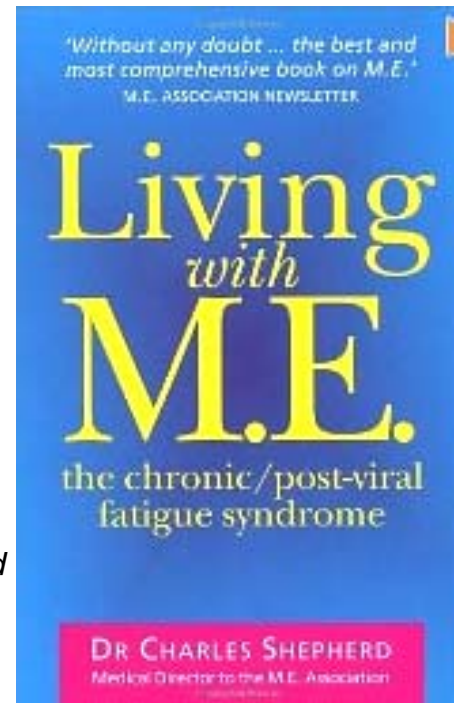
I'm very pleased to announce that Sheffield ME Group have kindly agreed to lend us a number of books for a period of 12 months. This has enabled us to get our library up and running. We have a member Susan who has volunteered to run the library service and books can be requested via a dedicated e-mail address on a first come first served basis. A waiting list will also be operated. Due to the fact we have 72 members and only 27 books we would ask that members request only one book at a time.

This is how the system works. You send a request for the book of your choice to lib@leger.me.uk. If the book is available it can be collected from a group meeting or it will be posted to your home via first class mail (or you will be informed that you will be put on the waiting list for it). The lending period will be one month from the date of posting and the return date will be written on a slip of paper enclosed with your book. You will need to ensure you return the book to the Redmond Centre or post the book via first class mail to The Redmond Centre, using the sticky label supplied, so that it gets back into the system by the end of your month's loan period. The system will rely on members returning the books within the given timeline. We still have some money to purchase a few books of our own and ideas are welcome.— Susan

Book Review: *Living with ME* by Dr Charles Shepherd

The first I knew about ME/CFS was when I was travelling up from a professional meeting in 1990, having purchased an expensive medical textbook. It read something like this:

Postviral fatigue syndrome (Myalgic encephalomyelitis) is an ill-defined condition that occurs predominantly following a viral infection. It affects mainly adults, with a greater proportion of women reporting symptoms. Although a wide range of causes and aetiological factors have been postulated, the chronic presence of enteroviruses in muscle and gut is the most likely cause, but has not been conclusively demonstrated. Symptoms often appear after an upper respiratory-tract infection and may last for months or years. The dominant features of the syndrome are muscular fatigue and emotional disturbances. Fatigue is aggravated by exercise, even to the extent that it may last for weeks following a single session of activity. Emotional disturbances may be apparent in the presence of disturbed sleep patterns, inability to concentrate, anxiety and depressive disorders. A wide range of other symptoms have also been associated with the syndrome (e.g. headache, neck pain, paraesthesia, cold extremities, muscle weakness and blurred vision). There is no proven treatment for the condition other than complete rest. Symptomatic treatment may be beneficial and includes analgesics. In cases of underlying emotional disturbances and with appropriate professional support, anxiolytics and antidepressant drugs may be used.



Twelve months later with severe ME/CFS, I found myself desperately searching for further information. There were neither NICE nor CMO guidelines in those days—and ME/CFS was a Cinderella condition, many doctors not even recognising it. At that time DRI was willing to give a diagnosis and then you were told to 'go home and be ill'. I desperately searched the literature and libraries for information, eventually finding an insignificant number referred to the M.E. Association. After a long 'phone call to their helpline, I realised what all the issues were, and started to look for further information.

What really saved my sanity was Dr Charles Shepherd's book 'Living with ME' which I bought a few months after diagnosis and read from front to back. Although a little dated, being first published in 1989 (this edition is some 22 years old) there have been various revisions. It is still the textbook on ME. I look forward to reading the updated version. For me, this book is essential reading, and a copy is available through the group library. —Mike.

The Benefits & Work Guides

Leger ME has membership of Benefits & Work (www.benefitsandwork.co.uk), allowing members access to their Guides to a range of benefits and disability-related issues. The Guides are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge, plus use of the Freedom of Information Act.

The Guides are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal. These Guides are available to all Leger ME members through the Redmond Centre. They are supplied as PDF files via email, or via a memory stick through our library service. You can have your own personal subscription of course which will cost £19.45 a year, but if you joined Leger ME you get access as part of the membership deal for around half that price. We reckon it's better for you to print what you need yourself. Printing can be done in our office but is expensive at 6p per page. I recently printed out all the ESA documents for a member and it cost just short of £18.

Are they any good? If you are filling out a form or appealing yourself without a welfare rights advisor then I think that they are a reliable source of information. The main problem is that they are general disability and not ME/CFS-specific. As an experiment, we supplied a couple of members with ESA 50 forms with the relevant ESA guides. I then reviewed their forms against what we would use in the welfare rights service. The DIY forms that the members came back with were 98% there, only needing a few minor modifications prior to submission. Because we specialise in ME/CFS, we will always have differences. If we do a form fill-out at the Redmond Centre, members are given a copy of the appropriate guide to crosscheck against the information they have given us before they sign it and send it in. All in all, these B&W Guides have saved many hours of counselling. From my point of view they are worthwhile. For example it normally takes about six hours to fill out at DLA form. If the member is given one of the B&W guides beforehand, their information becomes more focused and the time needed is reduced to less than two hours.

Employment & Support Allowance *(figure in brackets is the number of pages)*

Understanding Employment and Support Allowance (43)

ESA claims for mental health and learning difficulties (88)

ESA claims on physical health grounds (65)

ESA appeals (35)

Permitted Work (6)

Knowing Your Rights at Pathways to Work Interviews (12)

Work Capability Assessment Score Sheet (12)

Disability Living allowance & Attendance allowance

The best possible Attendance Allowance claims on physical health grounds (44)

The best possible Disability Living Allowance claims for adults on physical health grounds (61)

The best possible Disability Living Allowance claims for adults on mental health grounds (53)

The best possible Disability Living Allowance claims for children on physical health grounds (65)

The best possible Disability Living Allowance claims for children on mental health grounds (58)

70 questions you are likely to be asked at your DLA medical (5)

The best possible way to challenge a DLA or AA medical report (28)

The best possible support for clients with DLA and AA appeals (41)

Appealing against a DLA decision (16)

Giving persuasive information about how far you can walk (13)

Challenging the claim a bottle or commode will replace the need for help (8)

DLA renewal claims (6)

Changes of circumstances for people claiming DLA (8)

Letter claimant to decision maker requesting reconsideration because of additional evidence (3)

Other

If I do any work can I continue to claim my ...? (4)

Caution, it may not count as voluntary work (5)

Am I covered by the Disability Discrimination Act? (9)

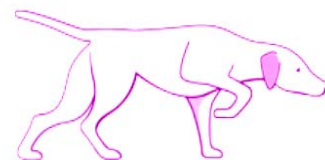
Which benefits can I claim? (9)

Reasonable adjustments: Employers and Jobseekers (8)

Work and benefits for people with long term health conditions (7)

Benefits and Work
Guides you can trust

[Benefits and Work]

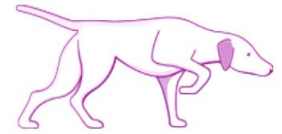


The screenshot shows the homepage of the 'Benefits and Work' website. At the top, there is a search bar and the site's logo. The main content area is divided into several sections:

- Get the benefits you're entitled to:** A central section with a call to action to register for free guides and tips.
- Disability Living Allowance >:** A section with a link to learn how to complete a DLA claim and a link to register for free DLA hints and tips.
- Employment and Support Allowance >:** A section with a link to take a free ESA test and learn how to register for free ESA hints and tips.
- Incapacity Benefit >:** A section with a link to find out about moving from IB to EIS.
- DW Training >:** A section with a link to find out about moving from IB to EIS.
- Free stuff >:** A section with a link to free DLA tests, ESA tests, caselaw and newsletters.
- News:** A section with a link to Professor Harrington's blog.
- Latest Forum Posts:** A section with a link to the latest forum posts.

Testing the Benefit & Works Guides for ESA

Benefits and Work
Guides you can trust
[Benefits and Work]



Kathy is a Leger ME member who was helped with her ESA 50 form at a recent master class. While it is possible to fill out a quite a lot, in the short time available at the Redmond Centre meetings, is usually only the bare bones. Part of the process we have adopted is to get people to check what we come up with against the Benefit & Work guides. Kathy is grade 3, and got the Support Rate. Here is something that Kathy sent me by Email which I think made all the difference. What she says applies to her case, and is listed here as an example which may or may not apply to other people.

Hi Mike,

I have taken a look at the guide against this ESA form we did and there are just a few bits that I think I may have committed and have gone back and added them in on my ESA form and these are as follows:

Details of medication I have added my medication can leave me very disorientated, fatigued, confused and occasionally means I have no understanding of my environment around me. However all my medication is needed because of the symptoms of my condition such as the extreme pain I have to deal with every minute of every day, poor sleep, migraines and mild depression.

Moving around and using steps The benefits and work advice recommended that you mention you wouldn't be able to push yourself in a wheelchair (even if you do not actually have a wheelchair), and also to advise them how you move around the house and as they use this as a gauge of how far you can walk i.e. if you have no problem walking around house and garden they will believe you can walk quite a way even though you have ticked the box that says you can't. So I have added the following to this section: "I am physically not capable of pushing myself in a wheelchair due to fatigue, pain, weakness etc, however my partner/carer does push me in a wheelchair as walking causes me extreme pain, rebound, fatigue and exhaustion. I have to use crutches or furniture or a carer to help me move around my house and I have to sit down to rest from room to room, (even though I have a very small house)."

Going up and down steps, I have just added that I do not go downstairs on worse days as the bathroom is upstairs (apparently the ESA people see where the bathroom is as an indicator on how you manage stairs). I have also added that it is dangerous for me to attempt stairs and that trying to do stairs causes unbearable pain (I think it is the danger aspect that they may be looking for).

Standing and sitting There was a recommendation that you put in whether you could repeat any of these things as if you can't repeat them then you should be classed as unable to do them at all. Therefore I have added I would never be able to repeat any of the tasks described in the question more than once. The majority of the time I would either be totally physically unable to repeat the tasks and the rest of the time trying to repeat these activities would cause rebound worsening fatigue and all my other symptoms to worsen. They also recommended that you advise them of how you get on and off the toilet, in and out of car, how you watch TV or use a computer as all of this would indicate how long you could sit for and how you sit and stand. Therefore I have added the following: "I have a toilet frame which helps me getting on and off the toilet and I get assistance to get in and out of the car and the bed. I cannot sit and watch TV or use my computer seated as it causes my symptoms to worsen and the pain is unbearable I have to do both these things lying in bed."

Reaching They recommend that you add examples of what you find hard so I have added the following: "I cannot wash or dry my hair and my carers do this for me and even cleaning my teeth causes me a substantial amount of pain and I struggle to hold the brush."

Picking up and moving things Again it is recommended that you use examples of basic things you can't do so I have added: "I cannot do even very basic household tasks such as: I have to use a straw to drink a lot of the time as I cannot hold the weight of the glass, I cannot do laundry because I cannot lift or carry it, I cannot put something in or take it out of the oven etc"

Manual dexterity It seems to be recommended that if your abilities get worse during day you should mention it and also mention examples of daily activities you struggle with so I have added the following: "Because of the symptoms already mentioned the majority of times I cannot even pay for an item with a card as I cannot use the chip and pin machine." I also feel I need to say that the later in the day it is the less I can do I struggle to clean my teeth in the morning as I cannot hold the toothbrush easily and often drop it but I cannot even do this by the evening.

Communicating with people They say that if it is considered you could type or write it doesn't matter if you can't talk so it is worth mentioning difficulties you have with writing and typing as well as talking so I have added the following after my first paragraph in this section: "Because of my symptoms I also struggle to write or type as I cannot think of the words and put a coherent sentence together and I struggle to use a pen or type because of the problems I have illustrated in the dexterity and reaching questions. I have also mentioned that talking on the phone is also a non starter the majority of the time.

Other people communicating with you They say that you should also use examples of newspapers and computers as examples of others communicating with you so I have added: "I also really struggle with reading anything at all a lot of the time as my vision blurs so making newspapers and e-mail beyond my ability."

Learning how to do tasks It is recommended that you mention confusion and making mistakes if you try to do tasks again as this means that you should be classed as you cannot learn tasks, also to mention that you may be able to repeat a task straight away but not an hour later and how medication affects your abilities so I have added this: "I also get very confused and make mistakes because of the symptoms I have just mentioned. Sometimes I may be able to remember instructions immediately after but would not be able to remember them or repeat them later. The medication that I have to take also means I get confused disorientated etc. which can prevent me from learning and even understanding what someone is saying."

Awareness of hazards or danger They say that you should mention how your medication affects this, why you need supervision and also to mention about how fatigue can cause problems so I have put this bit in: "I also have limited grasp on reality a lot of the time, and get confused because of the medication I take (gabapentin, tramadol, sumatriptan) and this can cause me to have limited awareness of hazards and danger. The severe fatigue I have also means I have very little awareness of any hazards and dangers."

In the below paragraph I have added the underlined bits as they are looking for damage to yourself or property and to look for ways that you do daily tasks and if you can do these it means that you have a good idea of hazards or danger:

"Some of the reasons I no longer try to do anything without supervision are below:

I have left gas rings on causing burnt saucepans but luckily not a house fire, the oven on with food in causing burnt dinner and again luckily no fire burnt. Leaving lights on all night, leaving candles lit again fortunately no fires. I have left water running causing floods which could cause electrical fires and damaged property; I have fallen up and downstairs causing serious bruising and a worsening of all my symptoms. I do not go out anywhere or attempt anything in the house without supervision because of all the near misses I have had and because of all the physical problems I have stated earlier. I never leave the house without a carer."

Initiating actions I have added the words below in because in the benefit and work advice it flags up that if you stop an action before you have finished it then forget to go back to it then this is classed as you being unable to initiate actions: "When I stop an action before it has been finished I then forget that I was doing this task and when I feel well enough to start a task again I start something different as I don't remember what I was previously doing."

Coping with change I have just added to my existing answer that I find any changes very distressing.



'Torrent of abuse' hindering ME research

From the BBC website Science correspondent, Today programme 29 July 2011

An estimated 250,000 people in the UK suffer from Chronic Fatigue Syndrome. Scientists working on Chronic Fatigue Syndrome (CFS or ME) say they are being subjected to a campaign of vicious abuse and intimidation that is hampering research into the causes of the condition. The harassment has included death threats, vilification on internet websites, and a series of official complaints alleging both personal and professional misconduct to universities, ethical oversight committees and the General Medical Council (GMC).

"It's direct intimidation in the sense of letters, emails, occasional phone calls and threats," says Professor Simon Wessely, of King's College London, who has received a series of death threats and threatening phone calls, and now has his mail routinely scanned for suspect devices. "But more often indirect intimidation through my employer or the GMC. All of it is intended to denigrate and try and make you into a leper." Behind the vitriolic nature of the attacks, the core objection, by some activists, is the association of Chronic Fatigue Syndrome with mental illness. They claim the real cause is biological and want research to focus exclusively on identifying the - as yet undiscovered - virus responsible.

"Sadly some of the motivation seems to come from people who believe that any connection with psychiatry is tantamount to saying there is nothing wrong with you, go away, you're not really ill," says Dr Wessely. "That's profoundly misguided. They fall victim to the label, and believe that the mere involvement of psychiatry denigrates them and denigrates the condition." Chronic Fatigue Syndrome is a debilitating condition involving severe fatigue, painful muscles and joints, gastric complaints and poor memory and concentration. It is estimated there may be as many as a quarter of a million sufferers across the UK, but exactly what causes it is still a mystery. That has been incredibly frustrating for patients who have often received short-shrift from doctors, and been branded as malingerers - the victims of "yuppie flu" - in the media. Even the existence of the condition has only recently received widespread acknowledgement by the medical establishment.

Speaking on the programme on Friday, ME Association's Dr Charles Shepherd condemned the abuse of researchers, but said sufferers had a justifiable complaint that almost no government-funded research was looking at the bio-medical aspects of the illness.

"The anger, the frustration, is the fact that all this effort, all this government-funding, has just been going to the psychological side," he said.

Hostility towards a psychiatric explanation for Chronic Fatigue Syndrome reached a peak in 2009 when research published in the journal *Science* appeared to show a link to the XMRV retrovirus.

But a series of follow-up studies failed to replicate the finding, unleashing another torrent of abuse - this time aimed at virologists, including Professor Myra McClure, of Imperial College, London. "It really was quite staggeringly shocking, and this was all from patients who seemed to think that I had some vested interest in not finding this virus," she said. "I couldn't understand, and still can't to this day, what the logic of that was. Any virologist wants to find a new virus."

Professor McClure says she will not be doing any further research in this area, and that may be the single most important consequence of this campaign of abuse and intimidation. According to the Wellcome Trust's Dr Mark Walport it would be a tragedy if serious researchers are put off working on Chronic Fatigue Syndrome. "We clearly don't yet understand exactly what's going on, and if we're going to find out it needs good scientists to work on it," he says. "But why would any scientist work on it if they know that all they're going to receive is a torrent of abuse?"

At Leger ME we are interested in the person and not the politics.

Chronic Fatigue Syndrome or ME (Myalgic Encephalopathy) is a debilitating condition involving severe fatigue, painful muscles and joints, gastric complaints and poor memory and concentration. It can leave patients bed-ridden in severe cases. Up to a quarter of a million people suffer from the disorder in the UK.

News from Fairlawns.

(The South Yorkshire & North Derbyshire Chronic Fatigue Syndrome/ME Service)



I represent the Leger ME group, along with Michèle Young, from Derbyshire ME Support Group and Ute Elliott from Sheffield ME Support Group. For this edition of *Pathways* we are including a digest of issues of interest to members which were brought up at the LPIG meeting on 16.09.2011. Various ways to extend the clinic's services were discussed.

One of the group members is already a volunteer at the clinic. In the reshuffle of NHS services new requirements for volunteers have been implemented. A volunteer is someone who gives their time free of charge to a service like the clinic. However you can't just go and offer your services. You have to apply, be interviewed, have a Criminal Records Bureau check, have basic health and safety training before you can even take part in training. At present there are three places available. Of particular value are patients who have been through the clinic process and feel they want to give something back to the clinic. The catch is that you have to have the DWP's and your doctor's agreement. There may be issues with ESA especially if you are in the Limited Capability of Work Group. Being a volunteer can be a halfway house to getting you back to work or you may just have time in your hands. If you are thinking about being a volunteer please contact the clinic lead Anne Nichol. If you are a Leger ME member please ask us for the information on volunteering (ref: wk_caution).

About a third of people do not attend pacing session appointments, mainly because of 'bad days'. The clinic is considering a DVD 'Introduction to Pacing' which could be sent to patients unable to attend or who miss sessions, and enable them to at least have the information, albeit second best. There is no product available within the NHS or via the ME organisations that would meet the clinic's requirements, so they considering a 'Sheffield Special' DVD and booklet which will be geared to teaching by example rather than being didactic (school teacher style). We will be asked to review the content at some point, and if the DVD is used elsewhere in the NHS it may eventually bring in income to offset the expenses of running the clinic.

August is normally a quiet month for new referrals to the clinic, but for some reason this year there has not been a lull in referrals to the clinic. Consequently, waiting times will be increased as there are not further resources available in terms of manpower or appointment times. One of the biggest causes of delays in being seen by the clinic is insufficient or the right sort of information not being sent by doctors referring into the service. If your doctor suspects that you have ME/CFS he should carry out a number of blood tests and other investigations first. If these confirm ME/CFS he should refer you to the clinic. Part of the referral procedure involved your doctor sending the result on paper to the clinic. Before agreeing to accept you for treatment, the clinic will look at the results. If they get what they need, an appointment is arranged. Otherwise further telephone calls or letters are sent requesting the appropriate information. The clinic itself has not the facility to do the diagnostic tests. There is no point in their duplicating these tests if they are already been carried out at a local hospital or doctor's surgery. The sort of information that is required has been published in past issues of *Pathways* and is downloadable from the Sheffield clinic tab. System one is a NHS patient record database used by some hospitals and G.P. surgeries, but not all. The clinic is considering access. In the case of referrals for example, it would eliminate the need for letters or faxes, and the clinic could directly check the test results, resulting in a quicker response. However there are issues about confidentiality and who has access to what information. This is a major NHS issue, and requires loads of paperwork and permissions to be clarified (e.g. who can see what data) even before they can think of ordering or installing the necessary information technology equipment.

One issue I brought up was that we are getting very positive feedback from the Benefit & Work guides regarding welfare rights forms. The Doncaster group members are given copies of these to fill out DLA and ESA forms. I'm seeing the completed forms before submission which are 99% there. Outcome is that most are getting Limited Capability of Work, with 9 points 'mobilising' and 6 points from either 'sitting and standing' or 'reaching'. The later sections on mental health are not being considered because 'passes' are coming from the physical side. My recommendation is the Clinic supplies or recommends these guides to its patients if appropriate. It gets around the local cuts in welfare rights services. The situation in Barnsley and Sheffield is very similar.

The NHS' New Medicine Service (NMS).

From the 1st of October, NHS pharmacies will be offering a 'New Medicine Service' NMS. The NMS is intended to provide support to patients who have been newly prescribed medicines to maximise the benefits of the medication they have been prescribed for specified conditions. (See right)

The service is split into three stages:

1). **Patient engagement** – following the prescribing of a new medicine covered by the service, patients may be recruited to the service by prescriber referral or opportunistically by the community pharmacy. The patient will be asked to consent for information to be shared with their GP as necessary. The pharmacy will dispense the prescription and provide initial advice as it normally would.

2). **Intervention** – the intervention will take place between seven and 14 days after patient engagement at an agreed time and through a method agreed with the patient (this could be face to face or by telephone). The pharmacist will use an interview schedule to assess the patient's adherence, identify problems and the patient's need for further information and support that the pharmacist will provide.

3). **Follow up** – the pharmacist will follow up with the patient 14 to 21 days after the intervention (again face to face or by telephone) to discuss how the patient is getting on with their medicine. They will also provide advice if required.

At both the intervention and follow up stages, the pharmacist may identify a problem which requires the prescriber to review the prescription. Where this is required, the pharmacist will complete an NMS feedback form to provide the GP with the details they require. The new medicine service (NMS) focuses on patients with long term conditions who have been prescribed new medicines. It is hoped that NMS will also lead to the following outcomes:

- improve medicines compliance
- increase patient engagement with their condition and medicines, which will support them in making decisions about their treatment and self management
- reduce medicines wastage
- reduce hospital admissions due to adverse events associated with medicines
- increase reporting of medicine adverse reactions by pharmacists and patients
- positive patient assessments
- provide evidence base on the effectiveness of the service

*It would be nice if this level of service could be applied to ME/CFS.
Maybe one dayMaybe ...*

Conditions to which the NMS service applies and the context for Leger ME members.

Asthma is episodic temporary reversible airways obstruction which causes breathing difficulties, and if not properly managed it can be fatal. The treatment is mainly by two sorts of inhalers, 'preventers', and 'treaters'. There are various designs and unless the patients learns and understand when & how to use these properly and is given the inhaler that suits them they are ineffective. About 40% of LME group members are asthmatic to a minor degree, mainly due to allergy and substance sensitivity.



COPD (Chronic Obstructive Pulmonary Disease) is where there is permanent airways damage. Historically within the Doncaster area, the main cause was coal dust inhalation, but is being overtaken as a consequence of smoking. Apart from medicines, the mainstay is inhalers of a different type—but these need to be used properly.

Type 2 diabetes (DM2) is usually older onset diabetes, where there some insulin produced, but not enough. The first corner-stone of treatment is diet, then tablets are used to magnify or enhance the patients own depleted insulin. These are not without side effects, and the purpose of the NMS is to check these out. Sometimes blood sugar monitoring is carried out by the patients and a patient needs to learn how to use the blood glucose meter. About 10% of Leger ME members are DM2.

Hypertension is abnormally high blood pressure, and very often doesn't show symptoms until a heart attach or stroke, unless checked for at a medical examination. Treatment usually requires several lots of tablets for life. These tablets can have side effects and it may be trial and error to find the right one. It is not common with LME members unless they have type 2 diabetes.

Antiplatelet/anticoagulant is given to people who have suffered blood clots possibly from deep vein thrombosis, or heart attack or stroke. The main one used is warfarin (rat poison). It is effective, but the does has to be adjusted very finely by regular weekly hospital clinic visits. Warfarin interacts with almost every known medicine, and people have to carry a yellow warning card. There some new anticoagulant drugs not as hazardous, but careful supervision is sill required.



Myhill v. GMC Latest

As received from Dr. Myhill's office. Sarah Myhill Limited Registered in England and Wales Registration No: 4545198 Registered office: Upper Weston, Llangunllo, Knighton, Powys, Wales LD7 1SL 15 August 2011

**PRESS RELEASE****DOCTOR DIAGNOSES THE GENERAL MEDICAL COUNCIL WITH DEMENTIA**

In an astonishing U-turn, the General Medical Council has reinstated Dr. Sarah Myhill to the Medical Register. In the previous twenty one months Dr Myhill was either suspended from the Medical Register or forced to practise medicine under severe restrictions. The GMC has conducted a series of prosecutions against Dr. Myhill since 2001, during which time she has faced the prospect of seven Fitness to Practise Hearings, the most recent having been booked for a full 25 days. All Hearings have been cancelled with no case to answer.

Dr. Myhill has observed *"The GMC has been incompetently prosecuting me since 2001. In doing so it has broken its own procedures and the laws of the land. Allegations against me have been vexatious, inconsequential and often untrue. The GMC is a dysfunctional organisation, not fit for purpose"*.

Sources close to the GMC say that this has been an orchestrated witch hunt against Dr. Myhill and that the GMC will be deeply embarrassed by their most recent incompetent handling of her case. Indeed, embarrassment might not be the GMC's only problem because, after a recent Freedom of Information request, it has transpired that, even only considering the most recent action against Dr Myhill alone, the GMC has spent £62,751.60 on solicitors' fees and other external costs. In addition the GMC's own internal legal team has clocked up 147 fruitless hours on this most recent case, with the investigation team being unable to disclose its hours!

Dr. Myhill is a private GP with a special interest in treating ME. Indeed, she has over 20 years' experience in this field and has treated many thousands of patients. She believes she has been targeted by the GMC because she treats ME as a physical, rather than a psychological disorder. The most recent investigation of her was triggered in June 2009, shortly after Dr. Myhill published a scientific paper showing that ME was associated with mitochondrial failure (Ref: Int J Clin Exp Med (2009) 2, 1-16; www.ijcem.com/files/IJCEM812001.pdf). Mitochondria are responsible for energy production in the body.

In its prosecution, the GMC has contravened the 1983 Medical Act by failing to inform Dr. Myhill what charges she faced until after her fourth IOP Hearing. In addition, the GMC has contravened the 1998 Data Protection Act by taking patients' private and confidential NHS medical records without patient knowledge or consent and without informing the patient. This appears to be routine procedure for the GMC – it has no respect for patient confidentiality. At one of Dr Myhill's public hearings the GMC released so much patient information into the public arena that a seriously ill patient at the centre of one of the complaints could easily be identified.

Neither this patient nor the patient's family had complained about Dr Myhill and throughout the investigation process, their wishes regarding anonymity were flagrantly disregarded by the GMC. This loss of anonymity caused much distress to the patient and family, distress that was only made worse when malicious and obscene comments were made about the patient on the public forums of the Bad Science website.

By contrast, Dr. Myhill has consistently refused to use the patient's notes in her defence because permission to use those notes had not been granted by the patient and family in an attempt to protect anonymity. As a result of this disparity in available evidence, Dr. Myhill was denied a fair trial.

In its prosecution the GMC also broke Human Rights legislation. There was no proper separation of prosecution and adjudication teams, Dr. Myhill did not know what charges she faced, the GMC refused to consider the facts given to them by Dr. Myhill and they unquestionably accepted vexatious and untrue allegations from unqualified members of the public and doctors. Indeed, at her third Interim Orders Panel Hearing in October 2010, Dr. Myhill told the General Medical Council it was acting like a kangaroo court. She was immediately suspended from the practice of medicine because, she was told, “she lacked respect for her disciplinary body”, i.e. the GMC. At her December 2010 hearing the GMC presented Dr Myhill with yet another anonymous complaint from a member of the public reporting that Dr Myhill had acted outside her area of expertise by delivering babies at home. The GMC had not realised this was a spoof featuring Dr Myhill’s pet pig Rosemary who had indeed delivered 10 healthy piglets that week. It was clear that the GMC had not taken even the most basic investigatory steps, involving merely clicking on a web link which would have revealed all, before presenting this information before a full session of the Interim Orders Panel. In such circumstances is it any wonder that respect begins to ebb away?

Dr. Myhill has written to the GMC President Professor Peter Rubin to inform him that he was overseeing the activities of a dysfunctional organisation, but he never replied to her letter. The Trustees of the GMC were similarly informed of all the above issues on two occasions, but again there was no response.

Dr. Myhill formally complained to the GMC about the incompetence and dishonesty of six of its officers, but none of her concerns were addressed. One of these officers briefed an expert witness describing Dr. Myhill as “a male consultant anaesthetic”. One would think it would be difficult to construct a sentence with four untruths in three words, but in this the GMC has at least succeeded.

No patient has ever complained to the General Medical Council about Dr. Myhill. All complaints have emanated either from other doctors who do not agree with her nutritional approach to medicine and her approach to treating ME, or from anonymous members of the public who do not concur with Dr Myhill’s opinions which, along with an online book, have been made freely available on her website.

As Stephen Fry wrote in his latest autobiography, such bloggers “grow up to become trawlers on the internet site and specialise in posting barbarous mean, abusive, look at me anonymous comments..... Such swine specialise in second guessing the motives of those who are brave enough to commit to the risk of making fools of themselves in public and they are blight on the face of the earth”.

Dr. Myhill said *“it is not for the GMC to judge whether one doctor’s opinion is better than another’s. My opinions, which are evidence based from the scientific literature, have been central to the recovery of thousands of ME patients. In its summing up of my case, the GMC states that I have substantially improved the health of 70% of ME sufferers. This is considerably better than the results of the now discredited regimes of graded exercise therapy and cognitive behaviour therapy. Clearly ME is a physical disorder requiring physical treatment”*.

Despite prosecuting Dr. Myhill for ten years, a necessarily stressful and time consuming business for her, the GMC remain unrepentant. It appears that the GMC has no inclination to correct its ways, or to try to restore Dr. Myhill’s professional reputation. The GMC was similarly heavily criticised by Dame Janet Smith in her report on the Shipman enquiry. Some years later she commented that the GMC was *“like a leopard – it never changes its spots”*.

Dr. Myhill is calling for a full enquiry into GMC incompetence, law breaking and misfeasance in public office. The GMC is the oldest regulatory body in the world and is showing all the symptoms of an advanced senile dementia.



Rosemary and her ‘babies’

Recipe Corner by Carolyn

Sunday lunch idea, Roast Stuffed Lamb Fillet with Honeyed Shallots *A Perfect change for Autumn Sunday lunch this lamb roast has a delicious stuffing made with fresh mint, dried apricots and pine nuts. Serve with boiled and buttered small potatoes, steamed seasonal veggies, and a spoonful of tangy redcurrant sauce. Serves 4, takes 1hr 30minutes.*

25 g (1oz) butter	2 tbsp fresh chopped mint
1 small onion, finely chopped	Salt and freshly ground black pepper
1 garlic clove, crushed	2 large lamb fillets
75g (3oz) fresh white breadcrumbs	2 tbsp light olive oil
25g (1oz) pine nuts	8 shallots, halved
8 no-need-to-soak, dried apricots, chopped	1½ tbsp honey, warmed
2 tsp beaten egg	



Preheat the oven to 190C/375F/Gas Mark 5. Heat the butter in a frying pan and gently fry the onion for 10 minutes until very soft, adding the garlic after 5 minutes. Remove from the heat and stir in the breadcrumbs, pine nuts and apricots. Leave to cool. Stir the egg and mint into the cooled mixture and season with salt and freshly ground black pepper. Place the lamb fillets on a chopping board and, using a sharp knife, make a deep cut along the length of each fillet (taking care not to cut all the way through). Open each fillet out and flatten slightly with a meat mallet or rolling pin. Spoon the stuffing down the centre of one fillet and then place the second fillet on top to enclose the stuffing. Tie together at intervals with fine string. Heat half the oil in a large frying pan and quickly fry the stuffed lamb over a high heat until just browned all over (this to seal the flavour into the meat). Now place the stuffed lamb in a shallow roasting tin. Cook the shallots for 1 minute in a pan of lightly salted boiling water. Drain well then place in the roasting tin around the lamb. Pour the remaining oil over the shallots. Roast the lamb and shallots for 25 minutes. Remove from the oven and drizzle the warmed honey over the shallots. Roast for a further 10-15 minutes until the lamb is cooked to your liking. Cover the lamb and leave to rest in a warm place for 15 minutes before carving.

Christmas Cake *This is a recipe often baked by the author (Carolyn) and shared for the first time with the group for Pathways and is best made end of October and stored. This recipe, though it looks a bit old-fashioned with all the greaseproof paper and brown paper etc., has been baked many times by the group member writer, and it makes a lovely, not too expensive, traditional Christmas cake.*

225 g (8 oz) currants	½ level teaspoon ground mace
225 g (8 oz) sultanas	½ level teaspoon ground cinnamon
225 g (8 oz) stoned raisins, chopped	225 g (8 oz) butter
100 g (4 oz) mixed, chopped peel	225 g (8 oz soft brown sugar
100 g (4 oz) glacé cherries, halved	Grated rind of 1 lemon
50 g (2 oz) nibbed almonds	4 large eggs, beaten
225 g (8 oz) plain flour	30ml (2tbsps) brandy
Pinch of salt	



Line an 8in cake tin, using two thicknesses of greaseproof paper. Tie a double band of brown paper round the outside. Clean the fruit if necessary. In a bowl, mix the prepared currants, sultanas, raisins, peel, cherries and nuts. In a bowl, sift the flour, salt and spices. In a bowl, cream the butter, sugar and lemon rind until pale and fluffy. Add the eggs a little at a time, beating well after each addition. Fold in half the flour, salt and spices, using a metal spoon, then fold in the rest of the flour, salt and spices, and add the brandy. Lastly, fold in the fruit. Put the mixture into the tin and spread the mixture out evenly, making sure there are no air pockets, and make a dip in the centre. Stand the tin on a layer of newspaper or brown paper in the oven to bake at 150 deg C, 300 deg F, mark 1-2 for about 3> hours. To avoid over-browning the top, cover it with several thicknesses of greaseproof paper after 1 hour. When the cake is cooked, leave it to cool in the tin and then turn it out on to a wire rack. To store, wrap it in several layers of greaseproof paper and put it in an airtight tin. If a large enough tin is not available, cover the wrapped cake entirely with tin foil and store in a dry cupboard.



'The Way Forward for ME - A Case for Clinical Trials'.

From the 6th 'Invest in ME' International ME/CFS Conference 2011

Report by Dr. Megan Arroll m.a.arroll@uel.ac.uk originally published in 'Outreach' the newsletter of the West London ME Self Help Group, Autumn 2011,

There were 11 speakers giving scientific presentations at this one day conference, in addition to introductions by 'Invest in ME' and Professor Malcolm Hooper.

Annette Whittemore was the first speaker, from the Whittemore-Peterson Institute in Nevada, USA. Mrs. Whittemore began by stating that the Institute is an organization that studies the aetiology of neuro-immune diseases such as ME, fibromyalgia and Gulf War syndrome, using a 'systems biology approach to disease'. The Institute's physical building holds an administration department, research centre and, later this year, a fully functioning clinic will be opened. This set-up will allow a clear route of communication between researchers and clinicians. Mrs. Whittemore went on to describe some of the challenges in researching ME, most notably the lack of funding. She quoted that in the USA \$135 million is spent in multiple sclerosis (MS) research whereas only \$6 million is devoted to ME research. However, she spoke with a great deal of hope in identifying a clear physiological pathway and subsequent treatments for neuro-immune disorders.

Dr. David Bell, also from the USA, followed with a very interesting talk on a longitudinal study of a cluster of 210 individuals with ME/CFS in the town Lyndonville, New York. Dr. Bell stated that at 13 years after the initial study in 1985, 80% of children sampled (60 of the 210 individuals) were 'doing well', with 20% reporting continuing symptoms. Of this 80% of children that said they were 'doing well', at closer inspection half had ongoing symptoms whereas half could exercise and did not present with ME/CFS symptomatology. This led Dr. Bell to question whether the participants' 'recovery' was an adaptation to symptoms rather than the complete absence of ill health. In attempt to explore this idea, Dr. Bell carried out an additional study on the original sample and used a number of questionnaires and also an upright activity- measure (i.e. counting the number of hours of upright activity and movement) and found that only 8% could be defined as 'well'. The remaining participants fell into a 'remitting' group (72%) and a 'persistent' group 20%). The key finding in this study was that although the 'remitting' group define themselves as 'well', on inspection of the questionnaires and activity measure they would still defined as having mild to moderate ME/CFS, in other words they had adapted their lives to the restrictions of the condition and did not identify themselves as still having an illness even though they did experience symptoms.

Annette Whittemore from California and the founder of the Open Medicine Institute presented a model of collaborative, translational research which integrated biotechnology, informatics, social networking and bio sampling. The key to this model was proposed as personalised rather than generalised medicine and appeared suited to such a complex illness as ME/CFS.

Dr. Kogelnik outlined a number of technological advances that may help shed light on this condition including integrated activity monitors that are connected directly into a research database.

Dr. John Chia, an infectious disease specialist (again from California) outlined the role of enteroviruses in the aetiology of ME/CFS. Dr. Chia stated that there are more than 70 different types of enteroviruses that can affect the nervous system, heart and muscles and the symptoms reported by those with ME/CFS are consistent with these findings. In his paper 'Chronic Fatigue Syndrome Associated with Chronic Adenovirus Infection of the Stomach' Dr. Chia and his colleagues found a high number participants (82%) had enteroviral RNA in their digestive systems and additionally there was a correlation between disability and antiretroviral RNA in the samples. Dr. Chia's work points to the possibility that antiviral drugs may be used as an effective treatment for ME/CFS and he has found that around half of patients tested respond to antiviral treatments.

Prof. Geoffrey Burnstock presented a talk on purinergic signalling and central nervous system disorders. The role of ATP as a co-transmitter with established neurotransmitters in both the peripheral and central nervous system was outlined and the importance of purinergic signalling in a range of disorders including stroke, and neurodegenerative diseases, epilepsy, cognitive, mood and neuropsychological disorders was described in relation to the potential development of novel pharmacological therapies based on this mechanism.

Dr. James Baraniuk of Georgetown University, Washington DC, discussed his team's work on proteomics (proteins). Dr. Baraniuk and colleagues investigated differences between genetics, pain sensitivity, muscular and autonomic nervous system function between individuals with Gulf War Illness (GWI) and healthy veterans. This research has unearthed an association between a certain genotype for the enzyme carnosine dipeptidase-I, which degrades two of the body's important antioxidants, and GWI. Currently the Georgetown University team is conducting a similar study into ME/CFS whereby a lumbar puncture will be carried out to measure the spinal fluid pressure in those with ME/CFS and an evaluation made of the proteins in spinal fluid. It is these proteins Dr. Baraniuk believes will differentiate those with GWI and ME/CFS from healthy controls, and therefore help to understand the aetiology of illness.

Prof. Simon Carding from the University of East Anglia and the Institute of Food Research presented 'A Gut-Brain Link for ME/CFS'. Prof. Carding studies the gastro-intestinal tract in an effort to understand the relationship between our immune response and gut function and, in particular, how the microbes that reside in the gut and environmental microbes cause disease. Prof. Carding discussed a very interesting theory regarding the breakdown in tolerance of commensal gut bacteria and illnesses such as in inflammatory bowel disease, where the body's immune system is activated because it can no longer ignore or tolerate these microbes. This work highlights the possibility of probiotic treatment for those with ME/CFS who are found to have this intolerance.

Dr. Oystein Fluge and Prof. Olav Mella from the Institute of Medicine, University of Bergen in Norway outlined work on B-cell depletion in ME/CFS. All conference attendees were asked not to pass on details of the pilot study as the researchers are in the process of publishing the results.

Prof. Kenny De Meirleir from the Virje Universitet in Brussels outlined a staggering number of tests that he has found to show abnormalities in those with ME/CFS. Prof. De Meirleir suggested that individuals could be treated on a case-by-case basis in line with their physiological test findings.

Dr. Judy Mikovits who made the final presentation was one of the research team in the recent XMRV study. Dr. Mikovits strongly argued against the theory that the association between XMRV and ME/CFS in the original Lombardi et al. 2009 paper was due to contamination. Dr. Mikovits' research group has carried out subsequent studies and she believes there is a role for antiviral drugs, non-steroidal anti-inflammatory drugs and metabolic/mitochondrial support in the treatment of ME/CFS. This view of antiviral treatment for ME/CFS was supported by Dr. Wilfried Bieger who describes data from a German study where the Epstein-Barr virus was seen in a sample of ME/CFS patients.

Conclusion

Overall, my personal feeling is that, at present, there is a great deal of high-quality, biomedical research being conducted around the world an attempt to understand the aetiology of ME/CFS; all with the goal of funding effective treatment. Research is a slow process that takes time and, perhaps, more importantly money, so I would refer back to Mrs. Whittemore's illustration of the gap between funding for ME/CFS and MS. I sincerely hope that some of the studies presented at this conference will instigate more grants and financial support for research in this area and thank 'Invest in ME' for organising such an informative event.

Carers' Information: 25% ME Group Adult Care Services Survey Family Carers Analysis Report

Adapted from The QUARTERLY, (newsletter of the 25% Group) Issue 31

100 people with severe M.E. participated in the 25% ME Group's adult care services survey. Respondents ranged in age from young adults to pensioners, and resident in locations throughout the UK. Most had been ill for many years. Not surprisingly, family and voluntary carers emerged as a vital source of care support. Seven out of ten respondents (70 people) were receiving voluntary care assistance, normally from family, and for just over a third (n=38) family were the sole care providers.

Overview of Carers' Responses: Just over half of the questionnaires received [51] included a completed carers' section. These illustrated a wide range of family circumstances and care scenarios, from young adults who had had severe M.E. since childhood receiving intensive care from parents, to elderly people coping with their own deteriorating health while struggling to provide adequate care to meet the care needs of a spouse or son/daughter with severe M.E. There were also instances of young people looking after sick relatives. 15 had received a carer's assessment, of whom 13 had been provided with assistance following assessment, while 2 had received no respite support from social services; however one of these carers now receives help from a voluntary organisation. This meant that 14 carers were receiving some form of support. However, only 4 felt that they were receiving all the help that was needed. The remaining 37 were shouldering responsibility for care without any form of carers' support. This group encompassed a range of expressed needs, from ten carers who indicated that they did not feel that they required any support, to a similar number who indicated dissatisfaction that there was no service - or no suitable service - available to meet their needs.

Carers' Experience of Support Services

How Long Did You Have To Wait For Respite Help From The Carers' Assessment Stage?

1-4 weeks: 7

4 - 8 weeks: 3

More than 2 months: 2

(13 'successful' assessments; 1 non response: n=12)

What Type Of Services Do You Receive?

(Some carers received more than one type of service)

Short break services (respite):

In the home 9

Where the person with ME stays in a care home 2 other services:

Carers' flexible break grant; member of Carers' link

Short break vouchers, used for domestic help 1

Can phone carers' resource - that's all 1

Meals given to patient 1

2hrs cleaning & ironing 1

Feedback about these services

Remarkably few had access to respite care where the person with severe M.E. stayed in a care home. Some highlighted the lack of any suitable option in this regard, for example:-

"There is a real lack of understanding of the needs and limitations of severely affected ME sufferers on the part of social services ... The only respite care offered is not suitable for severely affected ME sufferers e.g. Nursing homes (over 65), learning disabilities etc." [Sussex]

"Don't receive all the help needed due to lack of funds and also wife's condition - she can't tolerate noise. I am allowed to ask when I need it, or talk to a carer's social worker. (Care package) ... enables me to have some independence - seeing friends, attending own medical appointments. I am 75 years old. My own health problems are receiving ongoing help - memory problems can cause severe difficulties but using more 'notes' to help this. Carer's outreach have been sent to me + I have talked to

my own social worker re problems. Have received respite services in the home, and used to get respite where person with ME stays in care home, but difficulties taking up these services. Quiet room in care home is no longer available locally for wife due to change of use of home." [Conwy, Wales]

Another person with severe M.E. reported "Have been in respite. Didn't like it. Care was poor." [North Wales]

One carer noted how uncertainty around provision of short breaks service at home was difficult for her: "Short breaks service gives me 4 hours per week. This has been under review for about 15 months as the council want to halve the service because of cost involved. No decision has been made ... Stress of not knowing the outcome is extremely wearing." [West Dunbartonshire, Scotland]

She was caring for a woman aged 35-45, who had been severely ill with M.E. for over 20 years and clearly required a high level of care. Although social services were providing some care support, she had requested a cut in hours: "... as I couldn't cope with someone in my home for long. My mum knew my condition and I preferred having her tend my needs. "Against this background, short breaks service had been introduced to help meet carers' needs. Her carer also observes: "There is a huge difference in support from social services for learning difficulties adults and physically disabled adults. Only one scheme caters for 2nd group and it's very limited by funding shortage/ staff shortage. "

For How Many Years Have You Been Receiving This Service?

0-4 Years (8), 5-9 Years (4), 10-20 Years (1)

(14 receiving service, one non response; n=13)

Are You Satisfied With The Quality Of The Service That You Receive?

Yes 10, No 3

(14 receiving service; one non response here: n=13)

All carers were asked: Do You Think That You Have Had Enough Information about Care Services That Are Available to Help You?

Yes 9, No 21, Don't know 9 (51 carers; 12 non response: n=39)

Just over half of those who responded felt that they hadn't had enough information (54%). An equal number of the others replied 'yes', and 'don't know'.

Carers' Role In Community Care Assessment: Carers might play an important role in supporting a person with severe M.E. in the process of Community! Care Assessment. For example, eleven Community Care Assessments had been instigated/arranged by family or friends. Informal carers could also help by being present during the Community Care Assessment. Several respondents had been too ill to be involved in the assessment any way, and had been represented in the course of their assessment by family or an advocate. Around half of those who had been involved in their assessment had had someone with them while being assessed. In about half of these cases, that person had felt that they were listened to by the assessor.

Refusal To Provide Care if Family Carer 'Available': Unfortunately, the presence of a family carer in the home could mitigate against the provision of any care from social services to the person with severe M.E. Several respondents described such situations. For example:-

"Was only given help because my husband and carer broke his leg - care package ended when he could walk without 2 crutches. Would never have got any help otherwise!" [Northern Ireland]

"I did ask for help from social services but was assessed as only needing help with housework and shopping - my husband was helping me with other things. I think as my husband was my carer they didn't consider I needed other care help although he was working full time. They stopped providing this type of help about 10-12 years ago so I now get housework etc. done privately." [Greater Manchester]

"Care was stopped because my youngest child had just turned 4 (school age) therefore I no longer needed help! Plus lack of funds. The M.E. did not stop simply because our son reached school age. We asked again several times, but were refused as there were 'no children involved'. So who did they think would do the school runs, shopping, washing, cleaning? - A 4-year-old should walk home alone and prepare his own meals because his mother was ill in bed! We paid for a private child minder, and still pay for private domestic help. The carer has to hold down a full time job." This woman has had no care service for 17 years. [West Midlands]

Other Carers' Issues: Elderly Carers: Lack of awareness of services & no longer eligible for Carers' Allowance. Several elderly carers highlighted an inequity in that people of pensionable age don't qualify for Carers' Allowance. Also, lack of awareness of the existence of care services and disability benefits and carers' support services was notable among elderly people. For example, one elderly carer, living in Herefordshire, commented:

"I receive a state pension, so don't qualify for help. "The person being cared for is also aged 65+, and had been severely ill with M.E. for over 20 years. They report: "The only service I get is from my partner. I'm not aware of any other help being available. An NHS doctor came in response to my claim for DLA & Mobility Allowance"

This DLA assessment had resulted in receipt of care component at the low level, despite the person being bed bound. Other than this, this elderly couple appear to have had no assistance to meet care needs at any time.

Similarly, one elderly mother reported: "I care for my daughter (aged 56), who needs full time monitoring. I am aged 82, so I don't receive carer's allowance. "[Sussex]. Her daughter had initially been assessed to receive care services. However, service had subsequently been withdrawn on review, citing lack of funds, with the result that they were now paying privately for assistance.

Another elderly carer spoke highly of her experience with statutory services and appeared to have been granted the care assistance required, and supported by health service staff. However, the stopping of carer's allowance had produced an understandable sense of grievance:

"Excellent, understanding care manager & OT But unhappy carer's allowance has ended now that I receive a state pension." [Devon]

Experience of Care Services Operating As a Barrier to Carers' Seeking Support

Some feedback illustrated how struggles to achieve care service for a person with severe M.E. could deter their family carer from seeking support, for example: "Haven't asked for carer's help because doubt anything would be forthcoming. Hard enough to get what we did."

[Kent & Lincolnshire]

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And Finally...

Some feedback shed a harrowing light on the experiences of carers' and the people they cared for. For example:-

Person describes their condition as: "Very severe ME 100% 'bed locked'." They had lost the support of their partner and were now entirely reliant on care from social services. This loss of partner and carer was directly attributed to lack of carers' support:-

"MY FORMER PARTNER 2000-2005 - NO HELP OFFERED OR GIVEN EVER DESPITE YEARS OF SUPPORT TO ME. HENCE 'FORMER' PARTNER."

[Surrey]

"I am 18 years old. I've looked after my auntie every night for 5 years. My auntie asked social services for respite for me to have a break but they said there was no funding for this purpose. I dare not leave my auntie (who is very severely affected) in case she falls over. She can't do things for herself. I feel my auntie is treated badly and is invisible to most people." [Yorkshire]

Doncaster's Local Carers Organisation

Doncaster Partnership for Carers (DPFC), St Wilfred's, 74 Church Lane, Bessacarr, Doncaster, DN4 6QD 01302 531333

North of Doncaster: Personal American Travel Diary by Trevor Wainwright Part 2

In the morning in Asheville I awoke to the sound of gentle rain and saw mist on the top of the hills near the motel, it looked good, just the right temperature for driving too. The trees looked a really wonderful green and the whiter blossom on the smaller trees stood out. After breakfast I set off but not before calling at the visitor centre for further details then off past the sign "Blue Ridge Parkway. An All American Road". It was still raining, then I saw a sign 'Fog Warning', hopefully I would be above it, and at first it seemed it was so as the road climbed above it all providing some spectacular views and fantastic opportunities for photos. The rain stopped briefly then came back again bringing the fog with it, this was to be the set up for the rest of the day, in and out of fog patches but even that did not stop my enjoyment in fact it added an eerie beauty to the trip. I took it steady and stopped at a family run motel for the night, it was still raining but the fog had cleared. Most of the tourist attractions were closed but I was able to have a look round at what life had been like in those pioneering days.

The following day the early mist lifted and the sun came out, it would remain fine for the rest of the trip which would take me also along the Skyline Drive into Maryland. Along the drive over the next few days I would see waterfall, lakes, deer, squirrels, wild turkeys, bobcats and my first eagle in the wild, breathtaking scenery and enjoy eating local produce in an area proud of its civil war history.

From Maryland I moved into Pennsylvania. At a tourist centre I was told of the Flight 93 memorial and so decided to pay it a visit. I was glad, it was an emotional time, I had two Fire Service badges in my back pack and decided to leave one there; the curator was pleased. I thought about going to Pittsburgh but it rained again so I decided on Lake Erie, a long but pleasant drive with plenty of stopping places. I watched the sun go down and spent well over an hour there just looking out over the lake and feeling the wind on my bare arms. It was fantastic, at times it was hard to believe I was there.

The following day I went through the Allegheny National Forest. It was great driving off the beaten track, rivers swollen by the rain, the scenery again fantastic and almost like stepping back in time. Some of the small towns looked as though they had not changed since the day they were built, other than horse and buggy replaced by pick up truck and trailer. Near a place called Ridgefield is the Elk Run, reclaimed land made fit for habitation by elk which can be photographed in the wild and they were. Leaving the Elk Run it clouded over again and I got a photo of an angry looking grey cloud after which the heavens really opened. Apparently it was another tornado and the cloud was breaking up as it went out to sea.

I realised that somehow I was a day in front and so headed south again to Gettysburg and a tour of the battle field, really interesting despite its bloody past. *(continued page 22)*

Sheffield M.E. Group

Annual Conference

29th October 2011

1.00 p.m. to 4.00 p.m.

The Circle

33 Rockingham Lane

Sheffield S1 4FW

Speaker: Ashok Gupta

'THE GUPTA PROGRAMME for HOPE and HEALING'

Light refreshments available Bring your family/friends/carers

A donation of £3 suggested

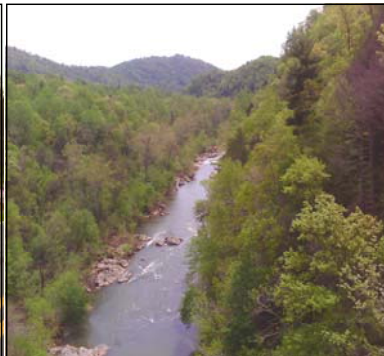
The 'Gupta Programme' can be purchased at a discount

For further information call the office on 0114 2536 700

Pathways Photo Gallery

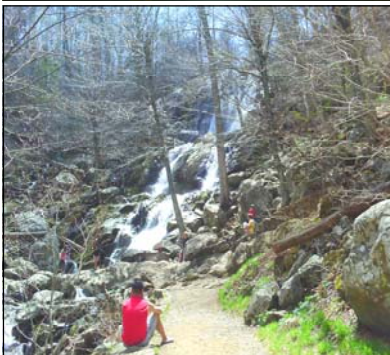


During the last week in September I was well enough to visit the local park. The weather was very hot, almost like summer. In the walled garden there were many butterflies just in one part of the gardens. I had my camera with me, and here is a photograph of some of the different ones I saw. The left is a comma butterfly, centre upper is in a speckled wood butterfly, the lower centre is a Peacock butterfly, and the right is a red admiral butterfly *Carolyn*



My American Trip

- 22.4.11 Setting off along the Blue Ridge Parkway
- 22.4.11 Roadside Spring flowers just off the Parkway
- 23.4.11 The Roanoke River and Gorge as viewed from the Parkway



- 23.4.11 Vesuvius, North Virginia, were it not for the cars very little has changed
- 26.4.11 Sunset over Lake Erie tranquil and really mind blowing
- 27.4.11 Wild Elk in Pennsylvania, the area is nicknamed Elk County



- 1.5.11 Engine House 10 just across from Ground Zero
- 2.5.11 Times Square New York celebrating the end of Bin Laden
- 5.5.11 Sunrise over the Atlantic

-Trevor

From there it was to Baltimore and an evening walk along the waterfront where I would have breakfast the following morning while the royal wedding was going on. Then it was north through Amish Country back into Pennsylvania again off the beaten track and again some fantastic views and more local produce to eat and enjoy. By the time I reached Lancaster I decided enough was enough and drove to Allentown my last stop before New York. It was there where my mobile phone gave up the ghost I having lost the charger for it.

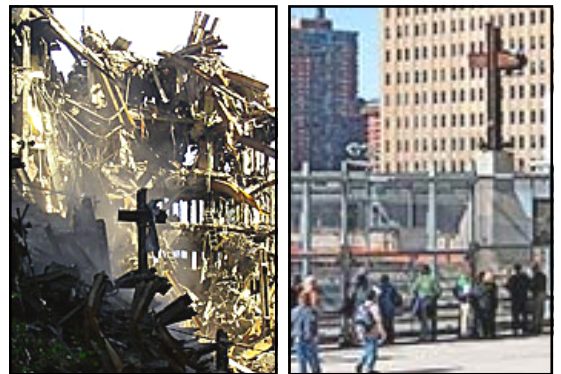
It was a steady drive to New York and although the satnav did send me the wrong way once I dropped the car off without further trouble. It was like saying good bye to an old friend. I took a taxi to the hostel and that's where the fun began, it had been closed as a hostel, the city council make these rules without consideration for any outstanding booking. So, I had to find another. The staff helped and there was one not far away which would be more expensive and no breakfast, but it was only for four nights.

Once booked in and my stuff stored I went to Central Park. That was mission 1. Had a hot dog and soda, nice they were too, then to Union Square to find a poetry venue, Bar 13. Realising I had almost a full afternoon I went to the UN headquarters and the Quiet Room (mission 2). I had read about it and long wanted to visit and it was wonderful. The following day it was Ground Zero, calling first at Firehouse 10 with the mementoes then a look at the rebuilding on the site a hive of activity with the American flag flying proudly near the site office.

The centre piece will be what was the Freedom Tower would when it was finished be called One World Trade Centre and will have a total height 1776 feet in reference to the year of American independence. There was what looked like a cross but was in fact a t-beam found among the rubble after the attack, it became a symbol of hope, faith and healing for the many rescue and recovery workers who were searching for the remains of the thousands who perished in the attack. At the foot of the cross is a wreath, just above the wreath a rectangular sheet of metal on which had been written in electric welding rod:

THE CROSS AT GROUND ZERO, FOUNDED SEPT 13,
2001 BLESSED OCT 4, 2001 TEMPORARILY LOCATED
OCT 5, 2006 WILL RETURN TO THE WTC MUSEUM A SIGN
OF COMFORT FOR ALL.

Leaving Ground Zero I texted home "Missions accomplished". I spent the afternoon Central Park where I was able to relax and chill. The following day Bin Laden's death was being celebrated in Times Square; I was able to be part of it and also took two open-top bus tours and a trip on the Hudson River. I recited at Bar 13 a poem I had written there and then in honour of the occasion and as a warning to terrorists, ending with "God bless America". It brought the house down. The remainder of my time in New York was spent seeing it from an open-top bus and more chilling out in Central Park which is beautiful in spring, even on the last morning when it rained.



To the astonishment of recovery workers at Ground Zero, the Cross appeared miraculously from the wreckage on the site of the former World Trade Centre.

Flying home in the afternoon I watched the sun go down, then a few hours later watched it come up again, fantastic, then the final flight to Leeds / Bradford and the taxi home. So many memories, drives of over 4,700 miles, over 80 poems written, some of which I recited over there, done what I wanted to do, gone where I wanted to go and met some great people.

Will I go again? Yes I'm already planning a pre-festival tour of Texas for next year in which I hope to once again discover America in Poetry.

Oh and lastly: What was that little number that Marc and Muriel did?

'Amazing Grace' in 1986, and it was this encounter that inspired him to write 'Walkin' in Memphis'.

Trev.