

Shropshire ME Group

239 For those affected by **MYALGIC ENCEPHALOMYELITIS**
CHRONIC FATIGUE SYNDROME or POST-VIRAL FATIGUE SYNDROME
(Registered Charity Number 1072171)
www.shropshiremegroup.org.uk



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Editors: Any of this material may be used as long as the original source is acknowledged

Greetings from Your Editor.

At last those awful explosions will be finished for another year. I hope you were all able to avoid the noise of the fireworks which seem to get louder, more indiscriminate and blast us over a longer period each year. Soon my long-suffering dogs will dare to leave the house after dark and stop crowding me whenever I move! There'll be just the usual dins to contend with... like building work, the TV, power tools, motorbikes, wheelie-bins being trundled and my cries when I drop something heavy on my foot through clumsiness!

Much of this issue is taken up by the MEA Question Time meeting. I've tried to do a complete report on it so that no-one will feel they've missed anything and because it was important: Shrewsbury was chosen for its venue and it coincided with our 25th Anniversary. You can borrow the DVD from our library as well as the "Voices from the Shadows" video.

The rest of the news had to be squeezed but I have tried to choose mainly items that are the most encouraging and helpful. We won't know the outcome of Georgina's efforts for some time but the links are included so that you can find out more about the EU directives and the pressure on our government to abide by them. Research seems to have been given a boost by the Obama interest and the implications of the epigenetic studies, though the benefits of these will take a long time to reach any of us. There is also interesting information emerging from the formerly closed MRC files at Kew that few believed would ever be made available to us. It does tend to vindicate those accused of being conspiracy theorists about biological research into ME being deliberately undermined! Wouldn't it be good if the MRC felt so guilty that we *know* now what went on that they lean over backwards to be super-generous to real research now? What also emerges is how hard Doris Jones worked and fought on the behalf of all PWME.

While there is nothing startlingly new to us older PWME in the report on the Swedish lecture on exercise testing in ME/CFS (page 22), it gives a good overall picture of what PWME – and GPs – need to know. I hope it will be useful and enlightening to our more recent recruits.

A Telford member provided the recipes that are in accordance with the Stone Age Diet, except for the little bit of honey, and I hope they will inspire you to share your favourite recipes with us, too. A special note to carers who are not often remembered: on page 32 you'll find out about sessions for handicrafts days that you are invited to in Telford. If you are able to escape for a few hours, they promise to be interesting and to provide a complete change!

Every Good Wish to you all for Better Health from

Daphne

Shropshire ME Group Mugs by Maralyn



As part of our 25th Anniversary celebrations we have commissioned a special Shropshire ME Group mug for your favourite tippie. Cheerfully displaying our charity logo on one side of the mug, it has a fuzzy-headed fellow sufferer shown on the other. It is carefully designed to bring about humour, empathy and awareness to the debate wherever it is seen. Buy them for home, friends, workplaces, doctors, fellow sufferers and carers. An original and splendid present at just £5 - with all of the profits ploughed back into supporting the work of the Shropshire M.E. Group.

To order your mug(s) please phone Maralyn (07516401097) who will try and arrange delivery. Whilst our committee members live in various parts of the county, it may be difficult to get them to outlying areas and at present we don't have the facility to post them. Please also see the comment below about getting mugs if you live in Telford.

Telford Meetings

We enjoyed chatting and swapping tips. It's such a relief to talk to others in the same position and who understand how we feel! There were only four of us but we hope to see more of you next time. This will be at my house – address on front cover – on Wednesday, 21st November. Please note the change of time by popular vote to the afternoon: 1.30 to 3.30 pm.

All are very welcome but if you are allergic to dogs, I need to warn you that I have two of the beasts who will be newly bathed and kept away from the actual meeting!

Please bring some money with you as I shall have SMEG mugs available for you to buy!

Dr Sarah Myhill

Taken from Mid and West Wales Newsletter.

Dr Myhill was called by the GMC (General Medical Council) to appear in front of an Investigation Committee on 2-4 October 2012 in Manchester. The GMC accused her of holding opinions which are contrary to National Guidelines with respect to the prescribing of the Pill and with respect to mammography.

Her view is that prescribing the Pill is dangerous medicine and that mammography causes more harm than good. She contested the opinions of the GMC Expert Witnesses Dr Savla (the Pill) and Dr Ann Hubbard (mammography.)

At the hearing the GMC placed a Formal Warning on her practice of medicine. She had already removed two pages of her website relating to those subjects in May, 2010.

On a positive note, the GMC in the determination said: “The Committee accepts that you are a committed, well respected and caring practitioner and notes the significant number of patients who use your website and hold you in high regard” and “It accepts that despite a number of previous investigations, you have a previous good history and no action has been taken on your registration. A Formal Warning does not impact on her practice in any way – she still has the full rights of a fully licensed doctor. She says: I shall continue to strive to provide a high quality service to my patients as well as to disseminate information which I believe to be helpful to the general reader.

[Dr Myhill had taken the pages off her website nearly two and a half years ago! I wonder whether Dr Ann Hubbard has seen the BBC item dated 30th October at <http://www.bbc.co.uk/news/health-20121043>? It includes the sentence: “The review, published in the Lancet medical journal, showed that screening saved 1,307 lives every year in the UK, but led to 3,971 women having unnecessary treatment.” Ed.]

Dr Gordon Skinner.

Although he was completely exonerated of all charges last year, the GMC has called Dr Skinner again to the Interim Operations Panel on 9th November. If you have been his patient and would like to support him, please send letters very quickly to IOP PANEL c/o Elisa Summerfield, General Medical Council, 3 Hardman Street, Manchester M3 3AW quoting the date of this IOP as a reference. E-mails in support of Dr Skinner, can be sent to esummerfield@gmc-uk.org.

ME Association Question Time

We had a good and well attended event on Saturday, 6th October. The panellists were charming and approachable, and ensured that they answered us clearly and fully. Dr Speight's outspoken and humorous comments were received particularly enthusiastically! The panellists took turns to answer on different aspects of the questions in their individual specialities and were obviously at ease with each other. It was such a successful meeting that it ran on until nearly five o'clock instead of finishing at its appointed time of four o'clock!

We were very pleased that so many people had managed to come: there were visitors from all the surrounding counties as well as from parts of Birmingham, Oxford, Bristol, Dorset, Bucks and even Yorkshire! The whole event was recorded and the DVD is available for loan from our library.

Peter Ruberry gave an introductory address to welcome everyone and introduce the panellists. He announced his imminent departure from the SMEG committee and thanked the MEA for helping to celebrate our 25th Anniversary. He spoke about his own experiences with ME and later presented the co-founders, Reg and Jo Watson, to us from the audience.

When the microphone was handed over to Dr Shepherd, he outlined the course of events. First he went over the items on the sheet previously distributed about the recent preoccupations in the ME world, giving the latest news and developments as appropriate:

ME Question Time in Shrewsbury

HOT TOPICS - which may form the basis for some questions...

BENEFITS

- Harrington Review of WCA descriptors
- DLA switch to PIP in 2013

MANAGEMENT and EDUCATION

- NICE guideline on ME/CFS review in 2013
- Rituximab - need to replicate the trial
- CS presentation to GP conference in mid Wales last week - included Shropshire GPs

PARLIAMENTARY

- APPG on ME and Forward ME Group

RESEARCH

- MRC initiatives: Expert Group on ME/CFS; grants X5; highlight notice includes 'neuroinflammation'
- UK ME/CFS Research Collaborative - first steps
- ME biobank and post-mortem tissue bank + patient database

- XMRV - time to draw a red line and move on

SERVICES

- ME/CFS clinics under financial pressure

- Health and Social Care Bill: GP commissioning in 2013.

On the first item, Dr Shepherd told us that the amended descriptors were to be tried by the DWP to see if they were fair and effective for PWME. The other up-date was that there is soon to be a meeting with the Telegraph and the Times to discuss their coverage of ME news in their newspapers.

He introduced the panellists who spoke briefly about themselves and their involvement with PWME.

Dr Speight (**NS**) joked that he has not been allowed to retire! He is still the consultant paediatrician for the Tymes Trust and AYME. He made his position clear in stating that misuse of the Mental Capacity Act allows for bullying of adults as well as children and mentioned a recent case where a PWME had been imprisoned for five years.

Dr Myhill (**SM**) is a GP who treats many PWME. She wants the answer to the question "Why?" people have ME and outlined her approach to treating ME with her analogy of the human body's function with that of a car as explained more fully in her CFS book on her website. The essence is that if you get the diet and gut function right this should lead to recovery. She thinks she has the right questions but does not yet have all the answers.

Simon Toghill (**ST**) gave information on his role of Occupational Therapist in SET. The rehabilitation service they offer is in five disciplines: psychological, neurotherapy, physical, speech and language and diet. He stressed that there is no medical support now.

Jane Colby's (**JC**) focus is on education and she runs the Tymes Trust. She explained that she is an ex-headteacher who had a severe case of ME. She deals with many child protection cases and mentioned that 70 families who were helped recently were found innocent. She showed us the poster that was available at the back. They are working on new guidelines on education for children with physical needs.

Question 1

The effectiveness of spot tests for Epstein-Barr Virus (one strain of glandular fever) was queried. The questioner's 18-year-old daughter, ill for nine years, had had negative tests at five and 14 but has now been diagnosed as having ME as a result of EBV.

NS wanted to know what the latest test actually was but it was not known. He suspected that the GP was fastening on a recognised disease from the history

that avoided using the dreaded term “ME.”

CS said that EBV is known as a common trigger for ME but that the history of the illness, which can be difficult to interpret, is secondary to effective management and treatment now.

SM said that viruses in general are well known for switching on fatigue as they are for switching on auto-immune diseases and agreed that the actual history may be not be very helpful in dealing with its results. The actual mechanism – perhaps on mitochondria - is not known but could be by means of allergies affecting mitochondrial function. She mentioned that Dr Lerner (USA) is looking into similar effects of post-EBV infection which might produce useful information.

JC said that Dr Dowsett knew more than anyone else about ME and described a complicated association between EBV and ME. EBV can be mimicked by enteroviruses which are good at producing long-term symptoms whereas EBV is usually of a shorter duration.

Question 2

The lady had been told that malaria is “the biggest” trigger for ME and asked whether a special thyroid test might be helpful.

CS talked about the three stages of ME: predispose; precipitate and perpetuate. He said that any immune stressor could precipitate it, not just viruses but vaccines, his particular area of interest, especially Hepatitis B vaccines, but also salmonella, dengue fever, etc. His personal view was that the thyroid is not necessarily involved. He wouldn't treat PWME with thyroxine as he has seen no evidence of it being needed.

SM said it is part of the “story.” Doctors tend to treat blood test results and not patients. She gave the example of T4 where anywhere between 12 and 22 is “normal.” Most healthy people have been found on repeated tests to have a range within a couple of points inside the normal range which is *normal for them*. A result of 12 or so may not be normal for the PWME being tested so a slightly higher level could help. In addition, there is the consideration that conversion from T4 to T3 might be the problem or other parts of the system may have poor converters and be blocked. She cited the case of Diabetes Type 2 where there is plenty of insulin being produced but because of hormone resistance against the receptors, it is not getting to where it is needed. Random testing has shown that hormone receptor resistance has led to Diabetes Type 2. Also, in those with high loads of pollutants, e.g heavy metals, PCBs, etc. there were 38 times the number of people with diabetes.

There has been no good study into the effects of endocrine function in ME so the only way forward is *very careful* trial and error to find the dose that will

overcome the resistance.

CS agreed that more research on thyroid function in ME/CFS is needed and stressed the dangers of treating people with thyroxine if their cortisol levels were low.

Dr Skinner's abandoned research on this was mentioned from the floor. [Dr Skinner risked being suspended by the GMC more than once for using his clinical judgment in prescribing thyroxine to patients who were very glad of his expertise and were greatly helped by it. He has been called again to appear at an IOP hearing on 9th November, 2012. Ed.]

CS said he would welcome detailed study in this area in a large cohort by endocrinologists.

NS endorsed **SM**'s comments and said that as we have so little to offer PWME, he advocated listening to patients and being brave enough to try treatments. He told the story of a Scottish doctor who wanted to treat a man for Lyme disease. The man had been told he didn't have Lyme disease so the GP gave him the antibiotics but claimed he was treating the patient for acne!

CS said that clinical judgment was being eroded. Doctors need to focus on treating their patients but if it means straying from NICE guidelines, they faced serious consequences.

NS said that doctors should be brave enough to put their patients first.

JC told the story of a PWME who was denied thyroid treatment despite her condition steadily worsening over a number of years. When it was finally looked into, her thyroid gland was dying so it is important to keep watching.

CS advocated proper thyroid tests every one to two years for PWME, particularly if over 50, as ME affects the thyroid.

NS suggested that any new or worsening symptom should be checked and not just assumed to be part of ME.

Question 3

Is there a higher incidence of thyroid cancer amongst PWME as Byron Hyde has suggested?

CS thinks not. There have been cases of other cancers, e.g. breast cancer, reported but no thyroid cancer in all the patients he has treated or through the MEA.

SM agreed: she had only come across one incidence of thyroid cancer among her thousands of patients.

Question 4

Advice was sought on the options in the ESA application form for proving

relapse on repeated activity.

CS explained that this is a key part of the WCA negotiations as the tick-box system doesn't allow for fluctuating conditions. He referred to the report on the WCA descriptors submitted to DWP minister, Lord Freud, that activities *have* to be capable of repetition.

The recommendations for reform are on the MEA website in full and are now in testable form but will not be used by Atos until the results are in for discussion by parliament so will not be implemented before the middle of 2013 at the earliest. You need to be able to do the activity "reliably, safely and in a timely manner and you should be able to repeat it." If you can't, then the recommendation is that you be classified as unable to do it.

In the meantime he advises challenging their decision on appeal using the information from the MEA about this classification of not really being able to tick those boxes and supplying supporting medical evidence. There is a high rate of success on appeal.

NS said that if a doctor is unsupportive by serving their paymaster before the good of their patients then they are guilty of unprofessional conduct and you should refer the documents to the GMC.

CS further commented that 8-10 Atos workers had already been referred to the GMC and went on to mention the APPG meeting with Atos scheduled for the following week.

JC remarked that Atos interviews should be recorded as people are more likely to be careful in their behaviour if they know they are accountable. She also pointed out that they have a welfare rights officer at Tymes Trust who can help and that the SMEG website has very good advice.

CS commented further that Atos doesn't bother about considering medical backing which is even more difficult where there is no consultant or you have an unhelpful GP.

SC confirmed that Shropshire has no medical consultant for ME who could supply supporting statements and that SET doesn't often get asked for medical evidence.

CS talked about an Occupational Therapist in Leeds who has given support in certifying what patients are not able to do.

SM said that she is heavily involved in providing documentary support for her patients. She praised the expertise of the laboratory she uses and briefly described her recent research papers on mitochondrial function. As these test results give an objective measure of mito dysfunction which correlates with the patients' experience, they are very useful for this purpose.

A member of the audience said that her daughter had been put into the work

group although bed-bound. How can you be put into the support group by Atos when you're not of retirement age or have only six months to live?

CS pointed out that Atos assessments depend on the tick-box responses and that they don't look at the medical reports unless made to. He repeated the advice given above and that you must go in person to present your case.

SC recommended seeking advice and help from A4U and the CAB in filling in the form and putting your case across.

Before the second half **NS** presented the DVD "Voices from the Shadows," calling it "a horror story." [I reported on this briefly on page 8 of the October issue and gave the website where you can buy copies.] It is a powerful film about severe ME and is very moving.

Question 5

Before posing the question the speaker gave a vote of thanks for the SET course which she recommended to others. The question was for information about the work of the charities on biomedical research.

CS explained that there are many charities involved with ME which are funding research. He outlined the focus of the British charities. Examples are the liME initiative for an ME centre in East Anglia and the MEA involvement with the Biobank and post mortem tissue bank and the research being undertaken by The CFS Foundation into genetics and gene expression.

CS talked about the Rituximab research to be funded by charities including the MEA working together in the new ME/CFS Research Collaborative [see page 21 of October issue.] The cost of £300,000 is too high for just one charity! The drug itself is also very expensive.

JC made the point that even when results of ME charity-funded research are published there is prejudice against the findings precisely because of that. She gave the example of the research on the blood of children with ME at Newcastle University by Dr Newton, which had no input from the Tymes Trust apart from the funding, being treated with suspicion.

CS said research is very expensive. Examples given were that the typical cost of a research project is £300,000 and the Biolab has cost £160,000 so far with another payment of £160,000 needed for the second stage. This level of outlay is not sustainable indefinitely. Another problem is that there just aren't enough researchers in this field.

NS pointed out that it isn't really the job of charities to fund such research particularly in view of what has been lost by PWME through Atos's agency. He talked about Rituximab being a very interesting drug used in rheumatology, etc.

CS gave the history of the discovery by the two cancer specialists, Drs Fluge and Mella, in Norway that Rituximab seemed to cure ME after three months of treatment with Rituximab for cancer of the lymph gland. It's not known why and there is speculation that it might work by attacking B cells. These are responsible for autoantibodies that may be reactivating ME symptoms or may be a reservoir for the infection leading to its perpetuation but much more research is needed because the potentially severe side effects - including death!

JC questioned the delay in its effects and **CS** and **NS** concurred that that could be an argument against Rituximab working as speculated. We'll have to wait for the results of the research.

Question 6

A mother asked how she could increase the six hours only home tuition that her 13-year-old daughter was allowed.

JC quoted from Dr Dowsett that there are five strands to treating a child with ME:

- 1) They should rest until they are over the worst
- 2) All stressors should be removed
- 3) They should be allowed to keep in touch with their peers
- 4) Their best time of day should be selected for education
- 5) The number of hours of tuition should be dictated by the child's need

Here she referred to the guidelines being negotiated for the special needs of sick children that allow for individual cases. She explained that the rules on sick children are separate from those for children with special educational needs. If necessary, legal aid should be sought where there was a conflict and the Tymes Trust can offer help and advice on all this.

She said that you shouldn't believe a "no" answer unless it's according to the law and gave the example that it is often claimed that home tuition can only be allowed on a consultant's recommendation. This is not true and in any case, children are unlikely to be seen by a consultant in the stipulated 15 days of illness.

She advised contacting the Tymes Trust.

NS asked to "have another word" with her and her daughter before they left.

JC showed a relevant booklet with Dr Dowsett's views under a different name.

Comment rather than Question

A mother of a child with ME aired the educational myth that children can't catch up if they miss school. They can. She added that she had found that Shropshire teachers have been flexible and supportive.

Question 7

The questioner's doctor refused to use the term ME and she wanted to know about the difference between ME and CFS as ME is so much more than just fatigue.

CS gave his view that CFS is as inappropriate for ME as calling Alzheimer's disease "Chronic Forgetfulness Syndrome."

CS gave the history of the change in the 1980s to include ME along with disparate other illnesses in the umbrella term of CFS. There was conflict over the "Encephalomyelitis" part as it was argued that not everyone deemed to have ME actually had inflammation of the brain and spine with some psychiatrists even trying to persuade us that the illness was psychological. Doctors tend to prefer CFS and patients ME.

NS recommended quoting the CMO's report in 2002 to doctors where he said that it was reasonable to use the two terms together as ME/CFS.

JC said that you have a practical term and sometimes you have to quote documents where CFS is used. She then read out from the 2011 International Consensus Criteria, which she pointed out was formulated by professors, virologists and medical professionals in other countries:

The label "chronic fatigue syndrome" (CFS) has persisted for many years because of lack of knowledge of the etiological agents and of the disease process. In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term "myalgic encephalomyelitis"(ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization's International Classification of Diseases (ICD G93.3.)

She went to say that the term "ME" is still being used and should be preserved and that there is discussion of sub-groups in CFS... However, she further quoted from the 2011 International Consensus Criteria:

No other fatiguing disease has 'chronic fatigue' attached to its name – e.g. cancer/chronic fatigue, multiple sclerosis/chronic fatigue – except ME/CFS. Fatigue in other conditions is usually proportional to effort or duration with a quick recovery and will recur to the same extent with the same effort or duration that same or next day. The pathological low threshold of fatigability of ME described in the following criteria often occurs with minimal physical or mental exertion and with reduced ability to undertake the same activity within the same time for several days.

This neurological fatigue is the classic, post exertional fatigue felt in ME which is particular to this disease only.

CS said that looking into neuropathology is one reason for the post mortem tissue bank. Four or five post mortems have been done and only one case of dorsal root ganglionitis (inflammation in a bundle of nerves outside the spine and the peripheral nerve system) had been found but no evidence of encephalomyelitis (brain and spine inflammation.) This could explain the sensory symptoms of tingling and pain. These are also symptoms of Sjögren's syndrome which involves peripheral neuropathy.

SM felt that too much energy has been expended on looking for an appropriate name when the real matter is "Why?" What are the underlying pathological reasons for this disease? Byron Hyde has done functional brain scans on PWME which have shown holes in the brain like those caused by stroke: energy was just not being supplied there for those parts to function. However, structural scans fail to show up any problem. Again she used the analogy of a car: with defective spark-plugs it wouldn't work but would look fine. Therefore, she doubted that PM studies could be very helpful because the problem is at cellular level. Heart failure, for example, is the result of mitochondrial disorder even where the blood supply is inadequate. If the mitochondria are not supplied with adequate energy or can't convert it to O₂, ATP, etc. then the heart muscles cannot contract properly. PMWE have low cardiac output: this explains their low blood pressure, feeling better when lying down and having POTS.

At rest the brain weighs just 2% of the total body weight but uses 20% of the body's energy; if it is not delivered then the brain can't work properly so cognitive dysfunction results. The eye works 10 times as fast as the brain so severely affected PWME don't have the energy for the conversion of photons to images to the brain so intolerance results. She thinks that energy delivery is behind these fundamental lesions in the brain.

CS Agreed that mitochondrial function is important and mentioned the muscle biopsy done on his leg but that we still need to look at PM tissue for more information on the pathology as well.

JC picked up on the mention of Byron Hyde who considers the name ME as important. She quoted that 30 years ago a set of tests were performed on patients presenting with suspected ME but after use of the term CFS these are no longer done. The conclusion is that doctors thought ME an important disease but not CFS.

CS agreed that there is hostility to ME by doctors but this can only be reversed by pathological evidence to support it.

JC joked that we must educate them.

CS, also jocularly, commented that we need the evidence in order to do this.

NS said we wouldn't need this evidence if we could find a cure. You wouldn't see the psychiatrists for dust! This caused hilarity and applause in the audience.

Question 8

There was a long preamble apparently from someone from Oxford who was not easy to hear talking about the IACFS/ME Treatment Primer "Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Primer for Clinical Practitioners" [see page 10 of the August, 2012, SMEG newsletter.] It is freely available on the internet, as are the International Consensus Criteria but how can we get GPs to read them?

JC said that GPs are vital as ignorance can cause more harm than help.

CS said that there is slow progress in educating GPs. He spoke about his recent meeting with about 150 GPs in Wales on chronic pain and CFS. They showed interest and no hostility to ME, wanting to know how to manage this illness.

Barbara Stafford interjected that if anyone had a GP who needed or wanted to know more about treating ME, we should let Tony Britton have their name and address. She went on to mention the MEA funding campaign at Christmas to send the educating booklet on ME to GPs.

NS remarked that if we have a good GP we should reward them by giving them presents e.g. champagne at Christmas!

Question 9

Does the panel think there is anything useful to us in the so-called "secret files" on ME at Kew?

CS explained that the files were closed rather than secret. The DWP ones are now open but not the MRC ones, which he thinks are unlikely to be opened in the near future. From those already seen he suspects there are just embarrassing comments in the correspondence (very often with him!) that they contain rather than an attempt to hide actual secrets or to suppress information on a cure.

A further question was whether organophosphates were mentioned in the files to which the answer was that there was no mention.

JC started to talk about a statement she has from the Royal College of Psychiatrists but had to be interrupted because Dr Speight had to leave at 4.30 to catch his train. He was given rousing applause by way of appreciation for his support for PWME.

CS picked up the theme again to explain that the files from the 90s show his battle to get ME accepted as a neurological illness by the DWP. It had been so

defined by the WHO in 1969. This was so that benefits could be paid and for influencing guidelines. His protagonists were psychiatrists but the WHO classification was accepted in the end.

Question 10

Advice on PWME having flu vaccinations has been that some react adversely and some benefit so it's probably better to avoid them. Following Dr Mercola's report that having flu jabs can lead to added risk of new flu strains like Swine flu, etc. is there any reason to change this advice?

CS gave MEA's general advice as outlined in their leaflet on the website which in turn resulted from a website poll. On balance, it's better not to have a flu jab unless there are risks from heart disease, etc. in which case PWME should weigh up the pros and cons.

SM said that vaccinations can trigger ME or make it much worse so she is chary of jabs – even advising PWME who need vaccinations for holiday destinations to choose somewhere else to go so that they can avoid them! A better course is to increase your protection through nutrition. Of particular benefit is vitamin D3. We need the equivalent of half an hour's Mediterranean sun each day. As this is not possible here, we need to take supplements. You can now get a D3 test on the NHS and her acceptable level is between 75-200. She recommends taking at least 2000, but better, 5000 µm a day and recommended the Vitamin D Council website where they give information on the health benefits of Vitamin D3 for guarding against heart disease, cancer and so on.

At this point there was an interjection from the floor asking whether there is a link between ME and SAD (Seasonal Affective Disorder)?

SM replied to this one as well. She said that both are affected by broad spectrum light deficiency. It is known that the further from the Equator you live, the greater is the risk of autoimmune disorders.

CS pointed out that a D3 test forms part of the tests recommended in the Purple booklet and that D3 is particularly important for those who are deprived of exposure to sunlight because of being bed- or house-bound.

JC concurred with the advice against vaccinations, particularly when it was easy to avoid exposure to the infections being involved and when there was already an infection present. An example is of a polio vaccination that contributed to a case of polio and made it very much worse.

ST said that he wasn't a great one for vaccinations as he didn't like needles anyway!

A further comment from the floor was that a request for a D3 test produced

a rude response and the statement that: “We don’t measure that.”

CS explained that as it’s not proscribed in the NICE Guidelines, doctors aren’t obliged to offer them so it’s a case of persuading your GP to do one.

Question 11

This concerned sleep reversal in a child; the cause and any suggestions for coping with it were requested.

CS asked whether any expert advice had been given and was told that it had but it hadn’t worked. CS said that this was a common symptom and that research was being done on a new drug for children with severe sleep problems. Had melatonin been tried?

It had but made no difference.

CS advised seeking a referral to a sleep laboratory and explained how this worked by hooking up the patient to monitors which could measure what was going on.

The mother had asked for this but been turned down.

SM said there was no easy cure for sleep difficulties which could produce feelings of permanent jet-lag. She mentioned the adrenal stress test where hormone levels are measured to determine sleep details and gave examples of timings and levels of T3 that control when we feel sleepy and when we feel wakeful. These endocrine secretions need to be in tune for the body to function normally.

JC said that this problem is typical of a child with ME but if possible, we should try to live with the child’s rhythm to ensure that they can sleep when they need to. It resolves itself in time and it’s cruel to wake the child up unnecessarily when they desperately need sleep. It’s just a practical problem and shouldn’t be thought of as anybody’s fault.

The meeting ended at 4.45. CS thanked everybody for their interesting questions and thanked the panel for taking part. SMEG Chairman, Jonathan Kidson, thanked the panellists for their answers to difficult questions and the MEA for holding the meeting in Shropshire. There was loud applause for the panellists and Jonathan thanked SMEG members for coming and the Shropshire Disability Network for their presence and added support.

Silly Moggy Jokes

What happened when the cat ate a ball of wool ?

She had mittens !

What did the cat do when he swallowed some cheese ?

He waited by the mouse hole with baited breath !

Why happened when the cat swallowed a coin ?

There was some money in the kitty !

News in Brief

1. The Scottish Cross Party Group on ME seemed to start well but has now disappointingly been disbanded. There were high hopes that the SMPs would be concentrating on ME rather than the hotch-potch of fatiguing illnesses under the CFS banner and that real progress would be made in providing educational support for child sufferers. All the hard work done by Scottish ME groups has come to nothing and they must start all over again.
2. The makers of Ampligen, Hemispherx Biopharma, announced a meeting with the Arthritis Advisory Committee in December to discuss applying for FDA approval to use it for CFS. You can see the PDF of the previous meeting on this at <http://tinyurl.com/8r7n3nz> and there was to be a public meeting on 25th October.
3. You'll remember the couple who involved Barack Obama in the push for ME research, Courtney and Bob Miller, of Reno, Nevada. They have now launched an initiative to increase funding to Simmaron Research Foundation through an Australian scheme that offers to contribute five times the amount raised. Simmaron Research needs support to fund a groundbreaking study in collaboration with researchers in Australia and Wisconsin to answer why Natural Killer Cells don't work correctly in ME/CFS patients [see page 20.] They are appealing for donations to complete the Australian pilot study and unlock \$1 million in sophisticated research for ME/CFS: <http://bit.ly/Reinhe>
4. The MEA has posted a link to a helpful, official video on ESA appeals at <http://www.meassociation.org.uk/?p=13201>
5. The Greenmedinfo website claims to have 30 research articles on the benefits of eating small amounts of chocolate. Amongst those mentioned at <http://tinyurl.com/8qz56yd> are as a safe alternative for statins and to improve hypertension, endothelial dysfunction, insulin resistance, low HDL, stroke, heart disease, etc. They claim that chocolate can **reduce your risk of dying from all causes by 50%** and as it is a food, it has fewer side effects. See website for the list of conditions it is said to help.
6. Benefits and Work www.benefitsandwork.co.uk report that the DWP could stop ESA payments to those who appeal. Instead, claimants will have to try to sign on for JSA and harsh new rules are to be applied potentially incurring benefit sanctions of up to three years.
They also claim that Disability Rights UK is to be one of the subcontractors helping Capita to carry out the PIP assessments that will end the working age DLA and a severe loss of income for around half a million disabled claimants.

Personal Independence Payments

Following the report on the information given at the SDN meeting in last month's issue, you can now see and download PDF files from the DWP website at: <http://tinyurl.com/ctxpag5>. They are on frequently-asked-questions, up-dated on 22nd October, and "myth busters."

Important points are that they are only for working-age claimants and that they are not automatic for those already receiving DLA. In his recent newsletter, Mike of Leger ME writes:

... As expected, it has become quite clear that (PWME) members receiving the DLA high rate mobility component are unlikely to receive the equivalent PIP award. People receiving DLA low rate personal care will not qualify for PIP as there is no equivalent PIP award. ..The changeover date is 2013 and everyone will be reassessed, even if a lifetime award has been given.

For some time now I have been advising members with a mobility car NOT to take out a new lease agreement without careful consideration. If you check the Mobility website, you will see that if someone has a Mobility car and they don't qualify for PIP when it come in the new year, then the contract will be cancelled and the car will be reclaimed by Motability.

Looking at the mobility deals of offer, and comparing them to what is available through the usual dealers channels, most of our members would be far better off owning their own vehicles outright and using the DLA towards their upkeep. There are exceptions for this guidance, and that is: if you have other conditions to qualify for a mobility award or you need substantial modifications a car to be able to drive.

Provision of Care for PWME in Norway from an article by Ragnhild Lund at: <http://bit.ly/Spg1KA>

The publication of new Guidelines for the treatment of ME/CFS in Norway has sparked this strongly-worded article which is almost identical to our criticisms of NICE Guidelines: ME lumped in with other fatigue states; psychological bias; severest sufferers ignored and carers' experience dismissed; abuse of power in refusal to acknowledge this increases the isolation and neglect of ME patients; no interest by doctors in seeking the truth in preference to apparently preserving their self-esteem and important roles.

She accuses the Health directorate of dereliction of duty on not having the courage to insist on imposing the International Consensus Criteria to differentiate genuine ME sufferers and thereby sentencing PWME to further serious illness and accusations of merely having "motivation(al) failure and negative thoughts."

Pesticides Campaign

Georgina Downes has been working on the EU Pesticides Forum submission that was closed on 22nd October. You can read about her activities at: <http://tinyurl.com/m255bk> and more about the EU Forum at: <http://tinyurl.com/cgjkf9z>. The DEFRA Consultation letter and Consultation document can be seen at:- <http://tinyurl.com/d64mbky>

Files on Refused Research Linking CFS and Vaccinations From post by Dr Mark-Alexander Fluks. Source: VacTruth, 6th October, 2012, by Christina England. <http://tinyurl.com/d2k3xf0>

Ref: Files:

<http://tinyurl.com/cfrvrch>; <http://tinyurl.com/c62338b>;
<http://tinyurl.com/ch4q4sz>; <http://tinyurl.com/d4nfhmf>;
<http://tinyurl.com/d7vmcrt>; <http://tinyurl.com/bpuuwgt>;
<http://tinyurl.com/cgc59qt>; <http://tinyurl.com/cc3q8lr>;
<http://tinyurl.com/cb26lwp>; <http://tinyurl.com/c6sjwjp>;
<http://tinyurl.com/crwldqa>; <http://tinyurl.com/cys4318>;
<http://tinyurl.com/czkgwwb>; <http://tinyurl.com/bl93thj>.

In the article by Ms England, she reports on the bias of the MRC against Doris Jones's application for funding to research links between ME with vaccinations and antibiotics. Using the FOI laws it has been possible to have some of these MRC files of the early 1990s opened with redactions to preserve confidential information, possibly about specific patients. She states:

(...) Papers hidden in archives for years clearly show that when medical researchers applied for funding to study the link between vaccinations and the debilitating condition known as ME/CFS in more detail, their applications were turned down in favour of psychiatric research, which was said to be preferable.

After detailing Doris Jones's attempts to reverse the MRC's decision to reject her application she concludes:

By cherry picking their research preferences, the MRC has potentially condemned many to suffer a life blighted by this tragic condition.

Instead of funding studies researching a variety of possible causes, it appears the MRC only chose to fund the 'it's-all-in-the-head' theories drummed up by psychiatrists only interested in lining their own pockets. It is a pity they have such a closed view when handing out financial support. How can we ever learn more about this debilitating disorder when research is being suppressed in this appalling manner?

[For a profile on Mrs Doris Jones go to: <http://tinyurl.com/caf73ff> and for her Paper on ME and Vaccinations go to: <http://tinyurl.com/d7omn2z>. Ed.]

Cytotoxic Lymphocyte MicroRNAs as Prospective Biomarkers For

CFS/ME Epub 8th May, 2012; [J Affect Disord.](#)

(<http://tinyurl.com/8pmfjso>) 10th December, 2012.

[Brenu EW](#), [Ashton KJ](#), [van Driel M](#), [Staines DR](#), [Peterson D](#), [Atkinson GM](#), [Marshall-Gradisnik SM](#).

Source: Faculty of Health Science and Medicine, Population Health and Neuroimmunology Unit, Bond University, Robina, Queensland, Australia; Faculty of Health Science and Medicine, Bond University, Robina, Queensland, Australia. Electronic address: ekbrenu@bond.edu.au.

Abstract

BACKGROUND:

Immune dysfunction associated with a disease often has a molecular basis. A novel group of molecules known as microRNAs (miRNAs) have been associated with suppression of translational processes involved in cellular development and proliferation, protein secretion, apoptosis, immune function and inflammatory processes. MicroRNAs may be implicated in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), where immune function is impaired. The objective of this study was to determine the association between miRNAs in cytotoxic cells and CFS/ME.

METHODS:

Natural Killer (NK) and CD8(+)T cells were preferentially isolated from peripheral blood mononuclear cells from all participants (CFS/ME, n=28; mean age=41.8±9.6 years and controls, n=28; mean age=45.3±11.7 years), via negative cell enrichment. Following total RNA extraction and subsequent synthesis of cDNA, reverse transcriptase-quantitative polymerase chain reaction (RT-qPCR) was used to determine the expression levels of nineteen miRNAs.

RESULTS:

There was a significant reduction in the expression levels of miR-21, in both the NK and CD8(+)T cells in the CFS/ME sufferers. Additionally, the expression of miR-17-5p, miR-10a, miR-103, miR-152, miR-146a, miR-106, miR-223 and miR-191 was significantly decreased in NK cells of CFS/ME patients in comparison to the non-fatigued controls.

LIMITATIONS:

The results from these investigations are not yet transferable into the clinical setting, further validity studies are now required.

CONCLUSIONS:

Collectively these miRNAs have been associated with apoptosis, cell cycle,

development and immune function. Changes in miRNAs in cytotoxic cells may reduce the functional capacity of these cells and disrupt effective cytotoxic activity along with other immune functions in CFS/ME patients. Copyright © 2012 Elsevier B.V. All rights reserved.

Relevance of “Junk” DNA to PWME

<http://www.prohealth.com/library/print.cfm?libid=17650>>

On page 16 of last month’s issue the announcement was reported of discoveries about the role and function of previously called “junk” DNA, the content outside the mere 2% protein-coding genes, which was all that scientists had so far unravelled.

Rich Carson, ME patient and ProHealth Founder, posted an article on 24th October called: “Founder’s Corner: Breakthrough Offers Promise for ME, Fibromyalgia.” He lists some of the many triggers for ME and FM and observes that most people are exposed to these but don’t develop ME or FM and he questions why that is and why researchers still know so little about what these diseases are, what causes them and why they generally last for life. He writes:

I believe we are on the eve of learning that ME and FM are caused by damaged DNA and, more specifically, the DNA in our cells that controls the genes - the epigenetic regions of the chromosomes, which is the DNA directly above and below each of our 21,000 genes. Until only recently, science has lacked the tools to understand these 'epigenes', and how they - and not the genes - may be responsible for countless diseases including FM and ME. While those 21,000 genes take up space on our DNA chromosomes, the fact is that 98% of our genetic material is not composed of genes ... (but)... epigenetic DNA ..., the 'brains' of the chromosome ... that controls whether the genes are turned on or off....

The study of this 'junk' DNA is called epigenetics and it is the hottest thing in the science of genetics since the discovery of genes themselves because if the mechanism that controls the genes isn't functioning correctly, an organism can not live the way it was designed to live.

This epigenetic 'software' that controls our genes, the 'hardware,' which in turn controls everything about us (what we look like, who we are, and how our body responds to the environment), can tell us a great deal about the many remaining mysteries of the human body. As we now know, having our genes turn on and off at exactly the right times is (important) when it comes to how our bodies handle everything, from pathogens to stresses and the environment in general. If an organism doesn't have an appropriate immune response to a pathogen or some other stressor because of faulty gene expression, the

organism could die, malfunction, and/or suffer from a chronic disease.

Leading ME researchers are turning their attention to epigenetics and I believe it is here that we will find the answers to the mysteries of ME, Fibromyalgia, and other neuro-immune diseases. Research in this area has already started and numerous gene function abnormalities have already been discovered in ME.

If I may offer an optimistic perspective on the miserable way the biomedical world has perceived and scientifically pursued ME and FM, consider this:

It is possible that medical science has not had the necessary knowledge or tools even to begin to understand how and why these diseases exist, because the answer could only be found in something they'd never imagined - our damaged genetic software; our junk DNA. If this is the case, the answers could not have been found until now because the tools researchers had in their arsenal were too crude, too primitive to delve into the complexities of ME and Fibromyalgia. It may be that only now, with the powerful new technology driving the science called epigenetics (and its sister science, proteomics, which measures the activity of genes), that we can finally begin to understand what ME and Fibromyalgia are, why they exist and how they can be treated and cured. I believe this new science will lead to a cure for ME, Fibromyalgia, and many other diseases including cancers.

To start learning more about epigenetics and its potential for understanding ME, FM, Lyme disease, Autism, and many others, see the articles and videos:

- Time Magazine article: <http://tinyurl.com/cptzdss>
- New York Times article: <http://tinyurl.com/8dsyq9o>
- Informative video: <http://www.youtube.com/watch?v=kp1bZEUgqVI>
- Dr. David Crews: <http://tinyurl.com/d3noua6>

FM and DNA

The FM Association UK at <http://tinyurl.com/czku2n4> is advertising for volunteers to take part in research into the DNA of FM sufferers. [More details at the above web address.] If you can take part, either phone 0207 188 1928 or go to <http://tinyurl.com/cbcts98> to register.

It involves filling a questionnaire and having a blood sample taken at your local surgery for which the researchers will send a blood-taking kit.

From a Summary of Clinical Exercise Testing in CFS/ME Research and Treatment

Posted on 4th October, 2012, by Lydia from the lecture at the CFIDS conference in Sweden. There is a link to the original lecture at this website: <http://bit.ly/R5iTLt>.

On an exercise test where a person has to exercise until they are exhausted, a healthy person will recover usually within a day, definitely within 48 hours at the very most. When they did this test with CFS patients, only one person recovered within 48 hours – the average recovery was four days. CFS patients also had symptom flares as a result of this test.’

Problems with the PACE trial were raised. The results were very selectively reported; they only took high-functioning CFS patients; they used the 6-minute walking test (see below); at the end of the trial patients were still walking at a severely disabled speed, even when they had improved the distance they could walk. If a patient who needed a heart transplant could only walk at this speed due to a lung problem, they would not be allowed onto the transplant list because they would not be deemed well enough actually to survive. There is no mention of any improved functioning in any other area for any of the trial participants.

There are problems with the 6-minute walking test (as used in the PACE trial as a measure of functioning) and other similar tests. They assume that the patient does not exercise to exhaustion, or anywhere near exhaustion. All the understanding of the results are based on the assumption that it was just a casual exercise experience that they could easily repeat. It does not work for specific groups of unhealthy people, it is designed only for a healthy population, so results from an unhealthy group can't be interpreted validly.

This is because they rely on the heart rate as a measure of energy production but the way the heart rate and energy production are linked in a healthy person is not necessarily the same in a sick person. Many studies, in fact, show that the link between them in certain diseases is very different, meaning you cannot rely on these tests in sick individuals, without first carrying out studies to determine what the connection is.

The American Heart Association advises against the use of tests with heart-rate measures, as many people take heart-rate controlling medication (eg: for POTS, migraines.) The best way to assess physical function is to use “cardio-pulmonary exercise testing”, which is measures oxygen consumption (as oxygen is used directly to produce energy, this will always be a correct measure and is effected by lungs, heart and muscles); the “anaerobic threshold,” which is the point at which the carbon dioxide you breathe out is greater than the oxygen you take in. In a healthy person this is 50-60% of maximum oxygen consumption; in an athlete it may be as high as 90%. In CFS patients it is very low, and going above it makes you worse and this is very easy to do.

You can prove beyond doubt that someone is not faking these results because you are measuring the amounts of oxygen and carbon dioxide in the air they breathe in and out. You can establish beyond doubt that the person's capabilities in the test have nothing to do with motivation or effort because the "effort" of the person is shown in the oxygen intake/carbon dioxide given out. These are a good measure of function as they are very reliable and accurate and there are already established measures of this for many other healthy people and disease states, meaning you can compare ME patients to others easily.

Exercise will not cure ME/CFS but people who do not exercise will suffer the effects of a sedentary lifestyle, so if you can do some exercise without making symptoms worse, it is probably beneficial to do so. Post exertional malaise occurs across all the spectrum of ME/CFS patients – regardless of how severe they are.

It does not show up in a single exercise test – you need to test again. (They do it 24 hours later.) This allows them to measure the post-exertional effect. (Many ME/CFS patients could be assessed as normal on a single test, for example because of having rested beforehand. It is the second test which shows they are ill.) It is hard to separate the effects of deconditioning from the effects of CFS with a single test but with multiple tests you can see what CFS has done. At 37 minutes into the lecture there is a table of results for ME patients. The second test shows that ME/CFS patients do worse on the second test: they are significantly worse (in terms both of workload they accomplish, and the oxygen/anaerobic measures.) Non-ME/CFS patient will improve on the second test (graph at 42mins.) ME/CFS patients have a drop in the oxygen consumption, but a much worse drop in the amount of work actually achieved. This shows that the exercise on the second test is less efficient. The drop in peak-oxygen consumption is actually less for severe patients than for milder patients but severe patients start out with a much lower oxygen consumption than milder patients. The drop in workload done is greater in severe patients than in milder patients.

The theory is that there is a basic level of oxygen consumption that you need in order to survive and the more severely affected you are, the closer you are to this base level. Severe patients cannot drop any lower or they would die, so they reduce workload instead.

This is a reproducible, reliable test which shows the extent of the post-exertional malaise; other research groups have replicated these results. Their tests show objectively for CFS patients: an atypical recovery; an abnormal stress-test; post exertional malaise. There are many theories as to why post-exertional malaise occurs. Their research shows ME/CFS patients:

have a reduced physical working capability; the aerobic energy generation (the production of energy in the presence of oxygen) is impaired; activity exacerbates symptoms (every ME/CFS patient has post exertional malaise.)

Their research can be used as an objective proof of disability (for example, for disability assessments and clinical trials.) It is quantifiable: that is it can measure accurately to a degree how ill the patient is. It reveals abnormality across many systems.

Cognitive behavioural therapy is not a cure for ME/CFS but it can be useful to help patients manage and/or adjust to their illness. ME patients can go a very long way into the anaerobic threshold (longer than most people manage) because they have adjusted to being ill; but this results in huge PEM. So short-term, patients can often manage a lot more than they can manage long-term.

Avoiding activities above the anaerobic threshold will help patients avoid PEM. Heart rate monitors can help: they are set to go off just before you hit the anaerobic threshold and so get you to rest instead of using too much energy. Activity logs can help as you can identify the activities which make you worse by identifying what activities make you ill; how do you feel the next day; whether you get PEM and whether you can carry out other normal activities as well as these activities. “Rates of perceived exertion” can help. This is a fancy way of saying, if it feels like a lot of effort, it *is* a lot of effort so stop!

Resting will help recovery from going into the anaerobic threshold. If you go above the anaerobic threshold, you will have to pay back far more energy. Physiotherapy can help – but physios often need to be re-trained to understand ME/CFS.

Reconditioning will not work with ME/CFS patients. They have a therapy called “energy conservation therapy.” I think this is basically working out how to manage your life now with less energy. It involves pacing, body positioning (ie: sit instead of stand to use less energy), protecting joints, using assistive devices, planning activities (to make sure you don’t over-exert), using any energy-saving thing you can, etc.

They also have a “therapeutic exercise program” (nothing like GET!) This can be aided by trained physios. Examples are learning to breathe properly; training the anaerobic system, not the aerobic system; exercise must be recovered from within 24 hours (if you take longer than that to recover, it is harming you, not helping); stretching; only doing a little at a time, only ever increasing the level if you aren’t experiencing symptom increase (decrease the level if you experience symptoms.)

He closed with the comment: “It doesn’t really matter what you call it, there are hundreds and thousands of people who are really, really sick. If the medical profession is not helping them, their government representatives are not helping them. They need help urgently.”

Parliamentary Question

<http://tinyurl.com/cddgq6n>

The Countess of Mar tabled the following question for a Short Parliamentary Debate on 8th October, 2012:

“ . . . to ask Her Majesty's Government what assessment they have made of the effects of the PACE trial (Pacing, graded Activity and Cognitive Behaviour Therapy: a Randomised Evaluation) on provision of health and social care and welfare benefits for people with chronic fatigue syndrome, or myalgic encephalomyelitis.”

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Coping with Christmas from MEChat by Von, Katya, Kitty, Serena and Bernard <http://www.mechat.co.uk/db/tips.htm#Coping>

[Items 1-6 are in the October issue. Ed.]

7. Stick pre-printed address labels with your own address from eg [Able labels](#) on Christmas card envelopes.
8. Wrap (and label!) parcels as they arrive to avoid last minute rush. You (or someone else!) could make re-usable cloth bags for family gifts or use pretty paper bags.
9. Order online and get them sent straight to recipient e.g. wine, or get companies to wrap for you - cost varies but can be cheaper than postage.
10. Order online and get them sent to recipient's family and send paper and card separately so they can wrap up for you .
11. Be environmentally friendly and leave in original bag :-) - you could stick a bow on it!
12. Put parcels in different boxes/bags for different destinations e.g. different members of the family, to avoid a tiring last minute sort out .
13. You can agree not to send presents and cards at all or to send a donation to charity instead.
14. Make sure as much of the food as possible is prepared well in advance to save last minute rush.
15. Beware of standing too long e.g. when decorating Christmas tree or hanging cards.
16. Try to space out visitors or other activities so you have time to rest in

15. Beware of standing too long e.g. when decorating Christmas tree or hanging cards.
16. Try to space out visitors or other activities so you have time to rest in between.
17. Have Christmas dinner on Christmas Eve if you have kids, so more energy can be spent with them on Christmas Day.
- [18. Sign up to an online card firm such as www.jacquelawson.com to send your animated cards and greetings. Ed.]
-

Two Gluten- and Dairy-free Recipes for you to try

1. Coconut Bread

Ingredients:

¾ cup of coconut flour (6 oz/ 170g)	6 eggs
½ cup of melted butter (4oz/ 113g)	1 tbsp honey
½ tsp salt	1 tsp baking powder

Method:

Blend eggs, butter, honey and salt. Combine flour and baking powder and whisk. Cook in a greased loaf tin for 40 minutes at 175°C.

2. Almond and Pumpkin Seed Cake

Ingredients:

100g (3½ oz) almond butter	4 medium egg whites
Handful of pumpkin seeds	1 tsp lemon juice
1½ tbsp water	Pinch of salt

Method:

Pre-heat oven to 180°C/160°F – mark 4.) Line a 450g loaf tin with greaseproof paper. Put almond butter, one egg white, pumpkin seeds, lemon juice, salt and water in bowl and stir to combine. In a separate bowl whisk remaining three egg whites until they form stiff peaks, fold into mixture. Put in loaf tin and bake for 30 minutes.

Thoughts

I don't want to become immortal through my work. I want to become immortal through not dying.

Believing in fortune cookies leads to a crummy life.

I intend to live forever. So far, so good.

The best way to destroy your enemy, is to make him your friend.

We can't solve problems by using the same kind of thinking we used when we created them.

Never argue at the dinner table for the one who is not hungry always gets the best of the argument.

Minds are like parachutes: they work best when open.

Hints for Completing the DLA Form – Part 9

49. Do you usually have difficulty or need help during the night?

Difficulty turning over or changing position in bed.

Do you need help changing position or rearranging the bedding and pillows to help with breathing difficulties?

Difficulty sleeping comfortably.

Do you need a hot water bottle making for you during the night or painful areas of your body massaged? Do you become distressed and need comfort and reassurance to help you go back to sleep?

Difficulty with my toilet needs.

See the information at question 36 in this guide. In addition, you may need someone with you when you go to the toilet at night because you have to walk past the stairs and there is a danger that you could fall. Alternatively, you may use a commode during the night – in which case do you need help with this?

Difficulty with my incontinence needs.

See the information at question 36 in this guide. In addition, do you sometimes have an episode of incontinence and need someone to strip the bed, help you wash and change, put on fresh bedding and put the soiled bedding in to soak or wash?

How often and how long – toilet and incontinence

To work out how often you have difficulties you need to make an estimate of how many times at night you use the toilet.

When working out how long each time, include time getting to and from the lavatory, time needed to wash yourself and to clean the toilet if necessary. If you use a bottle or commode but need someone else to empty and clean it immediately afterwards, include the time taken to do that here.

50. Difficulty taking medication.

Do you need someone to bring you medication, drinks or anything else during the night?

Is there anything else you want to tell us . . .

Example

I have problems when I am in bed because of ME. I have to sleep propped up on pillows so that I can am not in pain. But in the night I slip down on the pillows and then I wake up in pain. I can't sit upright again or rearrange my pillows without help. I also need reassuring and calming down in order to get back to sleep because I get very distressed. . I need my partner to help me sit up, rearrange the pillows and reassure me.

If you say that you need someone to bring you medication, drinks or anything else during the night the decision maker will suggest that these things can just be left within reach in case you need them. If there is a reason why this would not be practical you should explain why in this box. For example, you may not be able to take the medication or the drink without physical help or you may be too confused or distressed to do it for yourself.

Reminder

Do you use any aids or appliances in connection with help at night? For example, a bed raiser, special pillows If so, make sure you have given details at question 22.

51. Watching over you at night

Do you need someone to watch over you?

This is a very important page because you may be entitled to the middle rate of the care component if you need someone to watch over you to avoid substantial danger to you or someone else, even for short periods at night. Only tick No if you have read the examples on the form and read the information below and decided you don't have any such problems.

To prevent danger to myself or others.

For example, do you need someone to be awake when you go to the lavatory because you are unsteady on your feet due to medication, weakness or fatigue? How many times a night does another person need to be awake to watch over you?

At night the supervision needs to be at least twice, and probably three times, a night or for at least twenty minutes to count.

How long, on average, does another person need to be awake to watch over you at night?

At night the supervision needs to be for at least twenty minutes or at least twice, and probably three times, a night to count.

Is there anything else you want to tell us . . .

It's important that you give as much information as possible if you're hoping to get an award on watching over grounds. See the information about question 46, supervision from another person, for more about the kind of evidence you need to provide.

53. Please tell us anything else you think we should know about the difficulty you have or the help you need.

Use this space for additional information about difficulties you have.

54. When your care needs started

This may be many months or years before you were actually diagnosed. DLA

is only payable when your problems have lasted for at least 3 months.

58. About other benefits you are getting or waiting to hear about.

This section asks whether you, or someone else in your household, is getting any of a range of other benefits or tax credits (DLA will be paid in addition to all of them, with the possible exception of Constant Attendance Allowance, where there may be some overlap). It also asks whether you have been turned down for, or stopped receiving, DLA or attendance allowance in the last three years.

60. Statement from someone who knows you

You don't have to get anyone to complete this page but good supporting evidence always helps a claim.

Photocopy this sheet and give the copy to the person you want to complete it or, if you prefer, take several copies and give them to a number of different people to complete. If you are happy with what they write staple the sheets to this page. If you are unhappy with what someone has written, give them another blank copy and ask them if it would be possible for them to change what they have written. If this is not possible get someone else to fill in the statement instead.

If possible one of the people who completes this statement should be a professional involved in your care, such as your GP, specialist or a nurse. Make an appointment to see that person so you can answer any questions they might have and take the Health Professionals Sheet at the back of this guide with you. Ask the person to complete the statement there and then if possible.

If they can't, or wish to write a longer report, ask them to send it to you and tell them when you need to have it by. Don't delay returning the form if you don't receive a statement in time, send any additional evidence afterwards if necessary.

You may also want your partner or main carer to complete one of these sheets.

61. Please tell us anything else you think we should know about your claim.

If there is information about your condition, or the way it affects you, that you think is relevant but you haven't been able to include elsewhere, put it on this page. Or if you have had hospital admissions or surgery that demonstrates the seriousness of your condition, you can give more details here. Below are some other suggestions about what you might put on this page.

Looking after young children

If you care for a young child but your condition means that you need help or supervision to do so then you may be able to claim DLA on this basis.

You can give details of the extra help or supervision you need on this page

Middle rate care

Although the claim pack asks lots of questions about how often you need help and how long for, it doesn't ask you about when in the day you need help. However, this information can be very important. If you need help for at least an hour a day, but only in one chunk, or only at the beginning and end of the day – perhaps help with washing, dressing and undressing – you are likely to qualify only for the lower rate of the care component. But if you need help 'frequently throughout the day', even for less than an hour, you may receive the middle rate of the care component instead.

'Frequently' has been defined for benefits purposes as meaning 'several times – not once or twice', but there is no clear definition of what 'frequently throughout the day' means. The decision maker has to decide each case on the facts: it may be helpful if you make those facts as clear as possible. So, if you wish, you can use this page to list when you need help on an average day.

For example:

Help I need throughout an average day

7.30 am help with getting out of bed washing and dressing.

8.30 am help with cutting up food for breakfast

12.30 pm help with cutting up food for lunch

2.30 pm (or thereabouts) help with putting on shoes and coat and help to get either to the library, to visit friends or relatives, or to visit the park or the shops for leisure and just to get out of the house.

4.00 pm help removing outdoor clothing

6.00 pm help with cutting up food for evening meal

10.30 pm help with washing, undressing and getting into bed

Help with shopping, cleaning and cooking

The law on help with shopping, cleaning and cooking is confused. On the one hand, social security commissioners have decided that shopping, cleaning and cooking are not sufficiently personal services that they can be counted towards your DLA entitlement. (Although you may get lower rate care if you pass the cooking test, see 'Preparing a cooked main meal for yourself'.

If you go to the shops as a leisure activity, rather than to shop for necessities, that may also count: see Help you need when you go out during the day or in the evening.). Generally, though, if you need someone to do your shopping, cooking or cleaning for you, this isn't relevant to your claim.

On the other hand, courts have also decided that if it's reasonable for you to do shopping, cleaning and cooking yourself, then if you need help actually to carry out those tasks, the help you need can be counted. So if you have ME,

for example, but wish to cook and clean your home yourself ^{because that is} part of living an ordinary life, then you may be able to include any help you need towards your DLA entitlement.

Because there is nowhere else on the form to give information about the help you need with shopping, cleaning and cooking you may want to do so here.

Support for Carers

Telford area. Support group meets every third Wednesday of the month at 10.30 am in Room 8 in Leegomery Community Centre. For more information call Lara 01952 240209 of the Telford and Wrekin Council for Voluntary Service (the umbrella body for the voluntary and community sector.)

Community Council of Shropshire Carers' Support Service.

Phone -01743 341995 or email carersupport@shropshire-rcc.org.uk for full information on help available and free newsletter.

Carers' Days Out in Telford.

www.wyldwoods.co.uk

Wyldwoods, based at Dean Corner Farmhouse, Broseley, TF12 5JH, off the B4376 Broseley to Much Wenlock road, is a registered charitable organisation. They offer free educational courses in practical skills for local people.

They are offering free, artist-led workshops every week from 11 am to 3 pm for carers on the dates below:

Weds, 7.11.12 – Christmas decorative textiles: learn how to make rag rug decorative Christmas wreaths.

Tuesday, 13.11.12 – Ceramics (this session is already fully booked.)

Tues, 20.11.12 – Gift wraps, boxes and paper gifts: ideas for packaging gifts.

Tues, 27.11.12 – Lino printing: create original prints which could be used as Christmas cards or gifts.

Tues, 4.12.12 – Christmas “smellies:” soaps, bath bombs and pot pourri together with ideas for containers.

Weds, 12.12.12 – Christmas eats: goodies and treats, gift ideas or for yourself.

Tues, 18.12.12 December – Christmas wreaths: fabulous wreaths to adorn your home, made with an emphasis on mainly seasonal, natural materials.

Contact Wyldwoods to get registered as a Telford and Wrekin PCT/Council carer, other free activities in Shropshire and if transport is needed. Telephone 01952 884224 or email artyaml@hotmail.co.uk or steph@wyldwoods.co.uk.

DISCLAIMER

Please note that any information contained in this newsletter, in any other circular, or given verbally does not imply endorsement of any product or service nor necessarily represents the views of the Editor, Trustees or Group Committee.

Any treatment, tests or remedies mentioned may be tried at your **own risk, but preferably after consultation with your GP**. While every effort is made to ensure accuracy of information, this cannot be guaranteed.

INFORMAL MEETINGS

All are welcome to drop in for a chat.

Bridgnorth (01902 758822)

Meetings are held on the first **Tuesday** of each month from around 12–2 p.m. at the Parlour's Hall Hotel. Please note change of day.

Oswestry Area (01691 657730)

At The Wynnstay Hotel, Church Street, Oswestry 11.00-1.00, on the third Thursday each month. Please phone Meg Campbell to confirm venue before the meeting.

Shrewsbury Area (01743 361689)

Held in the front foyer lounge of The Lord Hill Hotel, Abbey Foregate on the first Thursday each month between 11 am and 1 pm.

Telford (01952 272613)

Telford members are invited to come to 64, Withywood Drive, Malinslee, TF3 2HU at 1.30 - 3.30 pm on Wednesday, 21st November.. Please note the change of time and see the article on page 3.

North Shropshire (01948 770471)

Meetings are no longer viable because of low numbers. If you are interested in reviving them, please contact Amelia at 01948 770471

Montgomery/South Shropshire (01686 669685)

Karen and Mike hold meetings in Montgomery about every two months, usually on a Wednesday. If you would like to know more about where and when, phone or email Karen at karen@kandm46.plus.com

Please ring your local phone contact or a committee member if you wish meetings to be held in YOUR area.

Happy Birthday to all who celebrate in November:

*Rachel Cullup-Smith Claire Dempsey Jennie Edwards
Janet Gale Jenny Halliwell Rosemary Hanna
Caitlin Rugg Karlynnne Sellstrome Vivienne Swensen*

Welcome to New Member:

Claire Dempsey

ME Connect

The ME Association's ME Connect helpline is available every day of the week on 0844 576 5326.

Please phone between these times: 10am-12 noon, 2-4pm and 7-9pm.

You can also email ME Connect meconnect@meassociation.org.uk

ME CHAT (www.mechat.co.uk)

This is a website for PWME run by PWME. MEchat is primarily an email support list for ME sufferers and their families in the UK and it can act as a lifeline for isolated people to access folk who understand.

It has been written by mechatters for mechatters but also includes information and tips useful to anyone in the UK who is ill with ME.

It offers a wealth of useful information on and tips for coping with ME but much, much more. There are recipes, including ones for those with difficulty swallowing, and pages of helpful advice.

Clever signs

On a plumber's lorry: "We repair what your husband fixed."

On the lorries of a local plumbing company: "Don't sleep with a drip. Call your plumber."

Pizza place slogan: "Seven days without pizza makes one weak."

At a towing company: "We don't charge an arm and a leg. We want tows."

On an electrician's lorry: "Let us remove your shorts."

On a taxidermist's window: "We really know our stuff."

In a podiatrist's office: "Time wounds all heels."

On a fence: "Salesmen welcome! Dog food is expensive."

Abbreviations used

AfME = Action for ME
APPG = All Party Parliamentary Group (on ME)
CMO report = Chief Medical Officer's Report on CFS/ME
published January, 2002
CCRNC = CFS/ME Clinical Research Network Collaboration - now
BACME = British Association for CFS/ME
CDC = US Centers for Disease Control and Prevention
CFS = Chronic Fatigue Syndrome
CNCC = Clinical Network Coordinating Centre, Education and Support
(based in University of Dundee)
DDT = **d**ichloro**d**iphenyl**t**richloroethane, is an organochlorine
insecticide, banned in UK in 1984; 1973 in USA.
DEFRA Department for Environment, Food and Rural Affairs
FM = Fibromyalgia similar to ME/CFS but pain is main symptom
FOI = Freedom of Information - regulation granting access to (some)
government and other official papers
GMC = General Medical Council (oversees conduct, etc. of GPs)
GPSI = GP with Special Interest (in ME/CFS)
HDL = high-density lipoprotein, the "good" cholesterol
HSE = Health and Safety Executive
IOP = Interim Operations Panel, GMC, 1st step in disciplining GPs
LMDT = Local Multi Disciplinary Team
ME = Myalgic Encephalomyelitis
MEA = ME Association (National ME Support organisation)
ME Research UK - formerly MERGE = ME Research Group for
Education and Support (based in University of Dundee)
MS = Multiple Sclerosis, a neurological disease less prevalent than ME
NIAID = US National Institute for Allergy and Infectious Disease
NIHR = National Institute for Health Research
OPs = organophosphates, toxic chemicals used in pesticides
PCT = Primary Care Trust - your local health service provider
PHI = Permanent Health Insurance (to provide some income during
long-term illness/disability)
PRH = Princess Royal Hospital, Telford
PWME = Person/people with ME
RSH = Royal Shrewsbury Hospital
SET = Shropshire Enablement Team
S&WMES = Shropshire & Wrekin ME Support - changed to
SMEG = Shropshire ME Group

COMMITTEE MEMBERS & POSITIONS:

Chairman:	Jonathan Kidson	01952 691269
Secretary	Vacant - volunteer wanted	
Meetings Administrator	Maralyn Hepworth	01743874254
NHS liaison rep.	(Peter Ruberry*	01743 356018)
Changing after October to	Jonathan Kidson	01952 691269
Membership Secretary	Keith Williams*	01743 369015
Treasurer	John Dalby*	01743 235638
Membership Tel. Contact	Maralyn Hepworth	07516401097
Website Manager	Margaret Jolly	01743 873925
Newsletter Editor	Daphne Caton	01952 272613
N/L Researcher	Richard Seabury	07981930093
N/L Mailing & Database	Keith Williams	01743 369015
Librarian	Maralyn Hepworth	01743874254
Fundraising Co-ordinator	Jonathan Kidson	01952 691269
Young Members' Rep.	Vacant - volunteer wanted	
Member	Liz Grant	01743 874359
Member	Pat Hirst*	01746 763947
Member	Monica Dalby	01743 235638

* denotes Trustee member

Local Telephone Contacts:

Bridgnorth Area	Elisabeth Gilson	01902 758822
North Shropshire	Amelia Saywell	01948 770471
Oswestry Area	Meg Campbell	01691 657730
Shrewsbury Area	Yvonne Street	01743 361689
South Shropshire	Rosemary England	01584 861642
	Sally Harris	01584 823313
Telford & Wrekin Area	Daphne Caton	01952 272613

National Organisations:

ME Association	01280 818968	www.meassociation.org.uk
25% ME Group	01292 318611	www.25megroup.org
TYMES (Young PWME)	0845 0039002	www.tymestrust.org
liME	02380 251719	www.investinme.org
MERUK	01738 451234	www.meruk.org