Pathways

Price £ 3.75 (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.

Welcome to Pathways No. 50 (Winter 2016)

Light Maypole at Cusworth Hall Enchanted Christmas Garden take by Carolyn on 18/12/16

You write:

Sarah writes: Many thanks for your email hope your meeting goes well. I am currently worrying as I haven't got many of the magnesium sulphate injections left and I am wondering where I can obtain another prescription from as my NHS GP will no longer issue me with one. The Private Dr. who very kindly does my injections for me is reluctant to provide a prescription as she isn't my GP, also she isn't an M.E. specialist. It is causing me a great deal of anxiety as I know how ill I was when I went without the injections for 10 months until June. I have contacted Dr. Mayhill's secretary but the cost of a skype consultation or medical health questionnaire is very, very expensive and as my husband and I are both medically retired we would struggle to pay it as we have had a huge cut in our income due to the very low interest rates. I am wondering if you know of anyone that provides the prescriptions for fellow ME/ CFS. sufferers please?

You may have to go to that expense with Sarah Myhill, as I don't know anyone else you could turn to locally. I've not been impressed from the results of magnesium injections. But on the other hand, it is a major player in mitochondrial biochemistry. The issue could be related to dietary magnesium depletion in which case I can't see why supplements by mouth could be tried. Sarah has a transdermal version of magnesium which costs about £10 from her online shop or you could try Milk of Magnesia is magnesium hydroxide. Medical Epsom grade salt is magnesium sulphate, and chemically is the same stuff that magnesium injections are made from. Magnesium salts taken by mouth tend to have a mild laxative effect. So, if you do go down that route be prepared.

Anne Nichol (Head of Sheffield ME/CFS clinic) writes: We are trying to develop a resource of online links and apps that could be useful to the people referred to our service. It would be helpful to have any feedback (pros and cons) from people from all support groups who have tried out any of the apps relevant to CFS/ME and fibromyalgia. We have identified some apps but there may well be many more:

http://www.mecfsdiary.com/
https://www.me-cfs.org/
http://fibromapp.com/
http://myhealthapps.net/app/details/191/activeme
http://chronicpainapp.com/

We will pass on any feedback on these websites from Pathways readers, and maybe someone could write us a review for Pathways? Is there anyone out there who can help?

Bill writes: At the last group meeting you said you had declined to help two people this year I don't understanding your reasoning behind this. Could you please explain?

Before I do let me explain. Leger ME is not a charity, and no one has a right to access any of our facilities. We are a community Group Co-operative where we all voluntarily contribute in some way or other. There is no charge to members for anything we do at the Redmond Centre provided it is carried out at routine group meeting. This along with access to Work and Benefits guides is included in the annual membership fee. There may be small charges for materials and postage, and many members make an annual donation on top of their membership fee or when they feel they want to. I also operate a private scale of charges outside the group —for example an ESA form fill out is £120 and an appeal is £240. I encourage members as far as possible to do as much as they can themselves—under our guidance. Leger ME pays around £400 a year for indemnity and public liability related to welfare rights services to be able to offer the service to members.

Case 1 was a lady I helped get her occupational pension released and DWP benefits. She was highly offended when we sent her a membership renewal form this year and she wrote a nasty letter. In total, she donated £5 to Leger ME. We can do without this kind of person within the group.

Case 2 was a lady who I helped in a similar way to case 1. We received a small donation from her in 2011. She then disappeared off the books, only to contact me a few weeks ago, because she had lost her Mobility Car through doing a PIP form fill out without advice form a welfare rights specialist. In all fairness to group members I declined her request, firstly because she should have known better than to do a self-fill out, and secondly, she was not a current member and had not contributed to the group

for five years. I offered to deal with the benefit refusal as a private case for the £240 scale rate. I made it clear that things would have been different had she had retained contact with ourselves. She was extremely angry and nothing has been heard by me since then. I do know a bit about her financial circumstances, and there are two occupational pensions going into the household and they are running two very expensive cars.

If you remember at the meeting I outlined case 2 and everyone unanimously agreed that my action was appropriate. It takes an average of four hour to do a DWP from start, and I've got an epidemic of DLA to PIP changeovers among paid up members. We can do without people who are timewasters wanting freebies from ourselves. Almost all people who we have helped are grateful for the help and make a substantial donation to the group, usually equivalent to a week's benefit payments, which is which is the normal practice with other similar service providers locally.

Monica Writes: I am an ex-GP who is now in the final year of an MRes at Manchester University. I wonder if you can help. I am researching the possibility of setting up of a clinical trial of low dose naltrexone (LDN) in patients with ME/CFS. This will involve me doing a systematic review of naltrexone (probably adverse events in clinical trials) for my dissertation. My reason for doing the MRes was to learn the skills necessary for designing and conducting clinical trials of LDN (and other drugs) in people with ME/CFS.

The major problem with any clinical trial is trying to keep it simple so it is affordable, while also taking in all the advances of research (which now are coming out thick and fast). I decided that as this was a feasibility study rather than a definitive study likely to lead to licensing of LDN on the NHS, it was more important to simply show some people responded rather than categorize responders which would need a very much bigger study. If we show it works in a proportion of patients, we then go on to a classic RCT, where subtyping would be very important.

The beauty of N-to-1 trials is that it doesn't matter if we have exactly the right diagnosis in every case. Each trial is complete and if someone responds, that is a valid outcome for that patient. As there isn't yet a diagnostic test for ME/CFS, we don't yet know what the important features of the illness are except from epidemiological studies. You may be right about fibromyalgia and atypical MS, but again, aiming to include them increases sample size and costs enormously.

I have already separately sent you is already expected to cost about £160,000 for 20 patients in a General Practice setting, as we can only conduct the trial with a full Clinical Trials Unit involvement because LDN is classified as an industry manufactured product that matches our purposes. It's all very frustrating, as GPs used to write out prescriptions for exactly this type of medication without being called into question. If that had happened, we would now already know if LDN worked or not! (I know that also lead to unsafe practices, so shouldn't really moan).

We'll this is good news!

For Pathways readers benefit Naltrexone is an opiate receptor antagonist. It is used within the NHS as an antidote of opiate poisoning e.g. after an overdose of morphine or heroin, and counteracts the respiratory depression. While the normal dose for this purpose would be around 50mg, and according to the internet sources, dose of 3.5 to 4.5mg are used, and reputed to be effective. That is about 10% of the usual clinical dose. It is unlikely that in these low doses have a different mechanism of action to the opiate receptors activity. Who would have expected 30 years ago, that aspirin supplied many as a painkiller and anti-inflammatory would be superseded by other medicines and its main use now would be for heart attack prevention?

I know that Sarah Myhill has used this with her patients in the past. The main issue with her practice is that it is private, outside the NHS and the information is shared with group of around twenty like-minded doctors but is not academically shared. Is there anyone out there who has tried low lose naltrexone? I'll certainly pass on any contacts or information I receive to Monica. I'll also look at Low dose naltrexone as a future Pathways feature for readers.

At least Naltrexone doesn't have the nasty side effects that more vicious drugs do—see later in this issue. My bet is of this having a high chance of being successful.

Benefit and Work Newsletter 07/12/16

Paid up Leger ME members have access to these guides as part of the membership deal.

In this edition, we learn that the minister for disabled people is claiming that the Motability scheme will be opened to claimants who don't get the enhanced rate of PIP mobility. We also breathe a sigh of relief that David Cameron's plan for enforced medical treatment for some claimants is being dropped. The revelation that the DWP now have a legal right to access people/s browsing history is not such good news, however.

PIP mobility improvements:

It's very good news if true. But few claimants will be holding their breath whilst they wait for further news of major improvements to the PIP mobility component and the Motability scheme. Penny Mordaunt, minister for disabled people, told MPs last week that she was planning to: -

- Allow claimants to keep their Motability vehicle whilst appealing a decision that they do not qualify for the enhanced rate of the mobility component of PIP.
- Allow claimants to continue receiving the mobility component of PIP if they are abroad for more than 13 weeks, even where the reason for absence is not connected with medical treatment.
- Allow claimants to access the Motability scheme even if they are not in receipt of the enhanced rate of the mobility component of PIP.

Too good to be true???

That the DWP is considering letting claimants keep their Motability vehicle whilst appealing where they will have around a 60% chance of success is surprising, but it is the last of these suggestions that is the most remarkable. The standard rate for PIP mobility is £21.80 a week. The enhanced rate is £57.45. If Mordaunt is suggesting that claimants getting the standard rate should also have access to Motability then the obvious question is: how will the shortfall be made up? If the proposal is that simply that standard rate mobility recipients can get a Motability vehicle provided they make up the shortfall of £35.65 a week themselves, then this is not much of a gesture. On the other hand, it is very hard to see how the cost of a Motability vehicle could be reduced to just £21.80 a week. Worryingly, Mordaunt referred in her announcement to people in receipt of the higher Motability component by that, the minister appeared to mean the enhanced rate of the mobility component. A minister who has yet to master even the most basic terminology relating to her portfolio is not one who inspires confidence . . . let alone hope. We'll keep you posted, all the same.

Enforced medical treatment threat dropped:

It's undoubtedly positive news that Dame Carol Black has decided that forcing claimants to either accept treatment for drug and alcohol dependency or obesity or lose benefits is a bad idea. In fact, it was almost certainly an utterly illegal measure from the outset. However, the suggestion that Job Centre staff should be placed in treatment centre is less welcome. And the plan to link treatment centre payments to their success in getting people in recovery into work could have a dramatic effect on relapse rates. But perhaps most worrying of all in Blacks report is the call for more research to be done into *the extent to which obesity plays a role in health-related benefit claims, long-term ones.* Although only 1,600 ESA claimants have obesity as their main disabling condition, Black hopes to link obesity to up to 800,000 more claimants with conditions such as diabetes. This, Black says, would help build a case for *further societal, employer and government action.* How long before the DWP press office kick-starts this societal action with a full-scale media hate campaign against claimants who are obese?

DWP web history access:

The Investigatory Powers Act 2016 is now law. Amongst other things, it requires internet service providers to keep details of your web browsing history for 12 months and provide these to a range of agencies on request. One of these agencies is the DWP. At the moment, only Senior Executive Officers in Fraud and Error Services at the DWP can request your web browsing history under the new Act. But experience has taught that once such powers are granted for one purpose, they are quickly used much more widely. The Regulation of Investigatory Powers Act 2000 was intended to be only used for the most serious of crimes, such as terrorism. But very quickly, large numbers of local authorities were using it to carry out surveillance for much more minor issues, such as littering and putting out the bins too early. How many claimants will trust the DWP to use their latest powers only to investigate fraud?

Research Corner: A selection of research features from ME Research UK's magazine 'Breakthough'.

As time goes by— Changes in brain white matter over 6 years.

Most research studies are cross-sectional, a snap-shot at a particular time. These studies have their uses, but they don't tell us about long-term changes, which can be considerable if there is continuing disease.

One of the very few longitudinal studies in ME/CFS was recently reported by researchers at Griffith University, Australia. The patients had originally taken part in a study in 2011 which found a reduction in white matter in the midbrain. After approximately 6 years, 15 of the original ME/CFS patients and 10 healthy controls agreed to participate in a repeat evaluation, using the same MRI scanner to measure any brain changes.

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Overall, there were no significant differences between the patients and the controls in the total volume of brain grey matter (which contains the bodies of nerve cells that help process information) or white matter (mainly nerve fibers). It was when the researchers looked at two specific areas that they noticed pronounced changes over time. In ME/CFS patients, but not in the controls, there was a decrease in the volume of white matter in the left inferior fronto-occipital fasciculus (IFOF) and/or the arcuate fasciculus. There were also correspond-ing changes in grey and white matter volumes in neighbouring brain regions, and the brain volume changes correlated with patients' symptom scores.

The IFOF is a bundle of nerve fibers that passes backwards from the frontal lobe of the brain, its fibers radiating out in a fan like pattern. It represents one of the many 'long association fibers' that unite different parts of the same hemisphere of the brain. It's thought that the IFOF connects attention, language processing and working memory networks, so its shrinkage over time may be associated with the memory, concentration or attention problems and visual deficits known to occur in ME/CFS. Similarly, the arcuate fasciculus connects two areas that are important for language, and abnormalities in this structure were reported recently in ME/CFS patients by US researchers at Stanford University.

The Australian researchers concluded that ME/CFS is a chronic illness with abnormal connections among brain regions and reductions in white matter that continue as the illness progresses. This is in line with the findings of a recent review suggesting that structural changes in the brain and alterations in connectivity are a feature of the disease.

What remains unknown is why the abnormalities in brain white matter are occurring. It may be, as the authors suggest, that a gradual and chronic reduction of blood flow (hypoperfusion) to the brain contributes to continuing shrinkage of white matter, with a corresponding increase in regional grey matter as the brain tries to compensate for the loss. However, white matter is thought to be highly susceptible to inflammation, and its loss could well be the result of chronic oxidative stress or an ongoing infectious process.

One step at a time: Walking and coordination problems in ME/CFS

Lots of ME/CFS patients have difficulties standing, but they can also have problems walking. In fact, one of our previously funded investigations at Glasgow Caledonian University found that the energy demands of walking were greater than normal for people with the illness. For some years, researchers at Antwerp University Hospital have been taking an in-depth look at the physical capabilities of people with ME/CFS. Two of their most recent findings are that patients' upper limb muscles recover more slowly from exercise, and that they have weaker muscles in the trunk and arms.

Continuing their programme of work, the Belgian researchers have now examined 'automaticity' in women with ME/CFS. Automaticity involves being able do things automatically, without the mind being occupied with more basic tasks. A good example is the ability to walk and speak at the same time; famously, Julius Caesar was able to ride a horse, hold a conversation and read a book at the same time. Automaticity while walking (gait automaticity) is particularly important, though it is no easy task. A variety of factors can interfere with it, including central nervous system damage and vision problems, and that's why gait automaticity is used to indicate frailty and is a good predictor of falls among the frail elderly.

The Belgian researchers' findings were very revealing. When starting to walk, only 3% of non-disabled controls looked down at the ground first, com-pared with 24% of patients. After closing their eyes and being asked a question, 56% of the patients stopped walking compared with only 5% of controls. The researchers also observed deterioration in walking during the test, whether slow-ing down or extending the arms to keep balance, losing direction or changing pace dramatically. While walking with closed eyes, 38% of patients had either a severe deterioration in their gait or had stopped walking. The fact that ME/CFS patients find it a challenge to multi-task when walking chimes with findings in patients with other chronic illnesses such as stroke or Parkinson's disease.

Many people with ME/CFS will not be surprised by these results - after all, they have lived for many years with the cognitive impairment and neurological dysfunction that underlie problems with automaticity. And, in fact, expert clinicians have long recognised these symptoms in their patients; as the Canadian Consensus Document said in I n 2003: "Ataxia, muscle weakness and fasciculations [twitches J, loss of balance and clumsiness commonly occur" . Yet, these impairments in basic day-to -day functioning in people with ME/CFS remain unknown to scientists, GPs and other healthcare professionals. They may, however, have clinical or diagnostic value, and should not be ignored.

Mitochondrial DNA mutations
Billing-Ross et al., Journal of Translational Medicine, 2016

Mitochondria produce energy, and mutations in their DNA (mtDNA) can have very serious consequences. As some symp-toms of ME/CFS could be due to mitochondrial abnormalities, investigators at Cornell University examined mtDNA from 193 ME/CFS patients and 196 control subjects stored in the CFI Biobank. Fascinatingly, disease causing mtDNA mutations were found in none of the ME/CFS patients, though one mutation was found in the controls. Also, the incidence of heteroplasmy (more than one type of mtDNA), which can also have detrimental effects, was low. While these findings will be welcome news to many patients, mitochondrial genes may still play a part in affecting particular symptoms and their severity.

Intestinal bacteria and exercise
Shukla et al., PLoS ONE, 2016

The microbiome is the hidden world of microbes living mainly in the gut, and it can dramatically influence health. Researchers in Wisconsin wondered whether the movement of bacteria or their products from the intestine into the bloodstream during exercise could be causing some of the symptoms of ME/ CFS.

To test this, they collected blood and stool samples from ME/CFS patients and controls before and up to 72 hours after an exercise challenge. Overall, there were increases in specific bacterial clusters (Firmicutes/Bacilli) and a delay in the clearance of bacteria from the blood in patients compared with the controls. If the microbiome really is involved in post-exercise symptoms, increased intestinal permeability could be a key factor.

ME Association Quick Surveys

When we meet as the Sheffield ME/CFS clinic, many things are discussed. Michelle from the North Derbyshire usually bring a list of MEA Quick Survey results. This is very important as it given us another window into what other people and doing and thinking. Anne who is the clinic head is always interested best for her it give her a window into what is happening outside the world of the NHS clinic.

Have you had a blood test (25-hydroxyvitamin D) to check your vitamin D level? And if yes, what was the result before any treatment?

- Raised (2%, 8 Votes)
- Normal (10%, 34 Votes)
- Low (22%, 77 Votes)
- Very Low (30%, 105 Votes)
- Awaiting result (0%, 0 Votes)
- No - never tested (36%, 131 Votes)

Number taking part = 355

100% of Leger ME members I've dealt with had low vitamin D levels when check by their doctor

It's really one of the musts that all ME/CFS patients should have checked by their doctor.

Where found low and treated a with daily dose of vitamin D,, often leads to reduced pain and fatigue.

How disabled are you at present on the MEA Disability Rating Scale?

- 100% (3%, 9 Votes)
- 90% (4%, 13 Votes)
- 80% (14%, 42 Votes)
- 70% (20%, 59 Votes)
- 60% (21%,62Votes)
- 50% (12%, 35 Votes)
- 40% (12%, 35 Votes)
- 30% (8%, 25 Votes)
- 20% (3%, 8 Votes)
- 10% (2%, 7 Votes)
- 0% (1%, 3 Votes)

Number taking part = 298

The ME Association disability scale is the inverse of the Bell scale — so a 80% disability on this scale only leads to 20% of remaining function.

The NIHCE scaling of Mild, Moderate and Severe is more appropriate and follows the convention of many other conditions.

Leger ME believed that there should be a very severe category for patients with other serious co-existing conditions e.g. diabetes.

What happened if you recently applied for, or tried to renew, a Blue Badge for disabled parking)?

- Approved (25%, 52 Votes)
- Approved following appeal or reconsideration (3%, 6 Votes)
- Refused on first application (4%, 9 Votes)
- Refused on renewal (3%, 6 Votes)
- Awaiting decision (4%, 9 Votes)
- Never applied for one (39%, 80 Votes)
- Automatic acceptance following DLA or PIP mobility award (22%, 43 Votes)

Number taking part = 205

Where possible Leger ME members are encouraged to apply for DLA or PIP which carries entitlement to automatic acceptance of a blue parking badge. There are a few members who have a discretionary blue badge.

We think that there is a right of passage where members with no DLA or PIP Motability entitlement are automatically refused and are expected to appeal.

From these figure it is clear the many who would be entitled to a blue badge don't bother to apply.

Should or should not the anonymised data from the PACE trial be released for independent analysis?

- Should be released (99%, 1,459 Votes)
- Should not be released (1 %, 8 Votes)
- Not sure (1 %, 11 Votes)
- No opinion (0%, 2 Votes)

Leger ME like the ME Association totally agree with this because we feel that the PACE trial is flawed and biased, and detrimental to the wellbeing of many ME patients but not CFS patients.

Number taking part = 1,480

Following the re-analysis of the PACE trial data, should NICE remove its recommendations on CBT and GET?

- Yes - definitely (92%, 669 Votes)
- Yes - to some extent (6%, 44 Votes)
- Neutral(l%,4Votes)
- Probably not (0%, 3 Votes)
- Definitely not (1%, 5 Votes)

This depends on the outcome.

At Leger ME we consider the evidence, and form our own balanced opinion.

Number taking part = 725

Have you applied for a Personal Independence Payment (PIP) from the DWP? If so, what was the initial decision on your claim?

- Refused at initial application (24%, 53 Votes)
- Refused on appeal (5%, 10 Votes)
- Awarded care and mobility at either rate (26%, 57 Votes)
- Care only at enhanced rate (0%, 1 Votes)
- Care only at standard rate (7%, 16 Votes)
- Mobility only at enhanced rate (1 %, 2 Votes)
- Mobility only at standard rate (5%, 12 Votes)
- Application in progress (8%, 18 Votes)
- I'm not applying for PIP (24%, 53 Votes)

At Leger ME almost all members PIP applications result in something, but it's too early to draw conclusions.

The main reason for refusals is self filled out forms without the advice of a welfare rights advisor.

All fully paid up Leger ME members are entitled to access to Work and Benefit Guides as part of their membership service.

Number taking part = 222

Which supplement, if any, have you found to be the most helpful for managing your ME/CFS?

- Carnitine (2%, 6 Votes)
- Co-enzyme Q10 (9%, 28 Votes)
- EPA/eicosapentaenoi acid (2%, 7 Votes)
- magnesium (12%, 39 Votes)
- multivitamin preparation (2%, 8 Votes)
- NADH/Enada (2%, 6 Votes)
- vitamin B12 (11%, 35 Votes)
- vitamin D (13%, 42 Votes)
- none of them (30%, 98 Votes)
- Never taken supplements (17%, 54 Votes)

Supplements either work or they don't For those where they work, they work well. The most common are VitD3 and VegEPA with Leger ME members.

All people with ME/CFS should try a EPA/GLA combination like VegEPA, a products that is research evidence based.

Vitamin D levels should be checked by peoples GP's regularly and levels corrected if necessary with prescriptions medicines.

Number taking part = 323

CBT & ME/S: Professor Malcolm Hoopers response to Professor Fred Friedberg's recent Editorial about CBT. (Dated 15th October 2016)

Professor Fred Friedberg asks why cognitive behavioural therapy (CBT) is so vilified in the chronic fatigue syndrome community. He opens his Editorial by stating: *"Cognitive behaviour therapy (CBT) is a well-established psychosocial intervention for psychiatric disorders, pain management and stress related to medical conditions"* (Editorial: Cognitive-behavior therapy: why is it so vilified in the chronic fatigue syndrome community?0 Fatigue, Biomedicine, Health & Behavior 2016:vol 4: no:3:127-131) but ME/CFS is not, and never has been, a psychiatric disorder and CBT has no more role in its management than in the management of Multiple Sclerosis, MND, Parkinson's Disease, malignancies or other autoimmune disorders such as Lupus or RA. CBT is not mandated as the primary management approach in those other disorders, so why in ME/CFS?

Patients with ME/CFS do not summarily reject any intervention that would help them: what they reject is a psychosocial intervention that is used with the intention of changing their correct perception that they are very sick with an organic disease, not with a behavioural disorder that is curable by "cognitive re-structuring" if they would only co-operate.

Friedberg appears to assume that, where there is stress related to a medical disorder, CBT supports patients to help them cope better with their disease.

However, a key consideration which he fails to mention is the significant difference between supportive CBT and directive CBT.

In relation to ME/CFS, in the UK PACE trial CBT was not supportive but directive: Professor Sir Simon Wessely, currently President of the Royal College of Psychiatrists, has publicly stated: "CBT is directive - it is not enough to be kind or supportive" (New Statesman, 111 May 2008).
No amount of directive "cognitive re-structuring" can result in "recovery" from such a multi-system inflammatory disease process as has been demonstrated in ME/CFS. The Centres for Disease Control (CDC) has archived its toolkit that recommended CBT and GET as interventions for ME/CFS (*http://www.cdc/gov/cfs/toolkit/archived/html*) and the National Institutes for Health (NIH) has produced a report which acknowledges the harm done to patients; *(http://annals,orgJarticle,aspx?articleid=2322804);* their conclusions were based on comprehensive reviews of over 9000 peer-reviewed research papers and testimony from expert researchers and clinicians.

Does this not provide the answer to Friedberg's question as to why CBT is so vilified in the ME/CFS community?

Diverting scarce resources from biomedical research by funding psychosocial interventions that have been conclusively proven to be ineffective can only harm patients further.

Money must now urgently be made available by institutions such as the MRC for research that is relevant to the disorder; for example, Professor Faisal Khan (recently appointed to the Chair of Cardiovascular Sciences, Division of Molecular and Clinical Medicine at the University of Dundee) is working on NRF2 (nuclear receptor factor 2) in ME/CFS patients and his work ties in with the study by Japanese researchers who looked at index markers in ME/CFS patients with dysfunction of TCA (the tricarboxylic acid cycle, also known as the Krebs cycle, which is the biochemical pathway used to generate energy) and urea cycles (http://www.nature.com/articles/srep34990).

Behavioural researchers who for over 30 years have shown disregard for the scientific process should have no influence on future research. Patients with ME/CFS do not need "behavioural" guidance from a profession which has visited such harm upon them.

To spell it out: directive CBT does not work for patients with true ME/CFS, and it is time that those psychologists and psychiatrists who insist that it does returned to reality.

Welfare Rights: The PIP Form Question 14, a case study.

Question 14 of the current PIP form is about moving around. In previous Pathways I've warned members about it being interpreted in a different way to the standard DLA form. On our PIP questionnaire drafting forms this is what one of our members wrote.

Q14 Moving around

i Use page 11 of the Information Booklet

Please tell us about your ability to physically move around.
We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
Tick the boxes that apply to you then provide more information in the Extra Information box.

Q14a How far can you walk taking into account any aids you use?

- to give you an idea of distance, 50 metres is approximately 5 buses parked end to end.

Less than 20 metres ✔ Between 20 and 50 metres Between 50 and 200 metres

200 metres or more It varies

Q14b Do you use an aid or appliance to walk?

Walking aids include:

- walking sticks,
- walking frames,
- crutches, and
- prostheses.

Yes ✔ No Sometimes

Q14c Do you use a wheelchair or similar device to move around safely, reliably and repeatedly and in a reasonable time period?

Yes No Sometimes ✔

In some period for 2-3 weeks at time some I cannot walk at all and I am bedbound this is the case for most of the time. I have to use a wheelchair. At other times I can hobble walk with crutches up to 20 meters at a time at best, but I am still in pain, suffering from dizziness & muscle weakness and the round effects of ME/CFS and osteoarthritis of my knee.

Pain and chronic fatigue are my main problems, which have not got better after I stopped cancer chemo therapy. I fall nearly every day due to dizziness fatigue & muscle weakness. On my worst days, I cannot take any steps due to being bed bound and suffering with severe pain and dizziness. I need someone to push me in a wheelchair. Pushing myself to walk on a given day has major repercussions on the following day and for the next several days or even weeks I get a rebound.

I need help from a carer or use aids like a grab rail. I cannot safely use steps if there is no means of support.
Pain and chronic fatigue are my main problems, which is there all the time and does not ever lift. I fall nearly every day due to dizziness fatigue & muscle weakness.

Our member was subsequently called to a medical examination and this is as page from the examiner report RV4. This is a copy of the actual page.

Activity	Descriptor	
12. Moving around	a. Can stand and then move more than 200 metres, either aided or unaided.	○
	b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.	○
	c. Can stand and then move unaided more than 20 metres but no more than 50 metres.	○
	d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres.	◉
	e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided.	○
	f. Cannot, either aided or unaided – (i) stand; or (ii) move more than 1 metre.	○

Justification for descriptor choice

The claimant did not report significant functional problems with this activity in their questionnaire or at consultation, and there was no evidence to suggest otherwise. ☐

If not ticked, reason given below:

The reported difficulties are consistent with
- her history of chronic fatigue and arthritis.
- the MSO shows she has significantly reduced power in her right leg.
- she is on a moderate dose of pain relief.
- the functional history states she can walk for 1 minute before stopping for a few seconds.

Therefore it is reasonable to say she can stand and move 20 metres but no more than 50 metres with aids reliably.

The nett result was

Moving around (scored out of 12)

You can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. **10**

This is what the law says :

What this activity is about ?

This activity looks at your physical ability to stand and then move around outdoors.
The descriptors: what the law says you score points for

a. Can stand and then move more than 200 metres, either aided or unaided. 0 points.

b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. 4 points.

c. Can stand and then move unaided more than 20 metres but no more than 50 metres. 8 points.

d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres . 10 points.

e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. 12 points.

f. Cannot, either aided or unaided,

(i) stand; or
(ii) move more than 1 metre. 12 points.

Legal definitions

Remember, words like ‘unaided’, ‘prompting’, ‘supervision’ and ‘assistance’ appear in many activities and have strict legal definitions:

Enhanced rate mobility

It came as an enormous shock when, in December 2012, the DWP produced their final version of the PIP points system and revealed that the maximum distance you need to be able to walk to qualify for enhanced rate mobility had been slashed from 50 metres to 20 metres. There had been no reference to this in previous - obscurely worded - drafts of the descriptors.

Bear in mind though that if you score points for ‘Planning and following journeys’ you can add these to any points you score for the ‘Moving around’ activity. Nonetheless, there’s no doubt that hundreds of thousands of people who qualify, or would in the future have qualified, for higher rate mobility DLA will now either get only the standard rate of PIP or will not get an award at all.

Th is is what the decision maker said:

You said you have difficulty moving around. The musculoskeletal examination showed you have significantly reduced power in your right leg, and you take a moderate dose of pain relief, you said at the assessment that you can walk for one minute before stopping for a few seconds, it was observed that you walk slowly. Therefore I have decided you can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. This is consistent with your medical history, your

So what is the implication?

This award only gave our member the standard rate of mobility, which if our member had a Motability car and was transferring over from DLA would mean they would no longer qualify under the Motability scheme and the car would have to be returned. On the form submitted our member quoted less than 20 meters, not 20-50 meters which the Decision Maker Awarded. If the Decision Maker had awarded less than 20 meters, this would have been worth 12 points and would carry on Motability entitlement.

What I can say is that the member has ME/CFS, but if you notice the text, Fatigue is not even mentioned or taken into account. The award is based mainly on a physical joint problem. In the early day of DLA, fatigue was not taken into account in a similar way. An appeal was appeal to the House of Lords, and the subsequent ruling from Commissioner Jacobs broadly stated that fatigue had to be taken into account for DLA.

However PIP was a clean sweep of disability benefits intended to cut costs. It swept away all that went before it, and with it went all the commissioners decisions that were made in favour of ME/CFS. Where DLA was concerns the most common award for Leger ME members was high rate mobility, and low rate care. With PIP so far, the most common awards are expected to be standard rate card and standard rate mobility. In terms of cash value of the benefit it is the same, but there is no Motability car entitlement. However there is still an automatic right entitlement to a Blue Parking Badge.

To be entitled to a Motability car you need PIP Enhanced Mobility rate. That was clear some five years ago when the first PIP drafts were circulated that many people with ME/CFS would no longer be entitled to a Motability car, and this why over the recent years I've warn against taking out new Motability Contract Hire contracts. I advised the member in question that if they to go to an appeal or tribunal, there was a good reason to appeal against the decision. However a decision was made by the member to accept the aware as is and avoid the stress and worry of the appeal process. Maybe one day someone will take the issue about Fatigue to the House of Lords and sense may prevail.

Two new British Dietetic Association Fact Sheets.

The BDA Food Fact Sheets are written by dietitians to help you learn the best ways to eat and drink to keep your body fit and healthy. These resources are for you to download and print for your own reference. The Fact Sheets are for information only: they are not a substitute for proper medical diagnosis or dietary advice given by a dietitian. The Fact Sheets are intended for adults unless they sit under the 'babies and children section' or make a specific reference to babies and/or children. The information is correct at the time of publishing, and undergoes periodic reviews to comply with the Information Standard and ensure up-to-date evidence. Over the next pages are Fibre and Christmas

BDA The Association of UK Dietitians

Food Fact Sheet

Fibre

Fibre is an essential nutrient for the normal functioning of the gut. It is related to a reduced risk of chronic diseases such as diabetes, cardiovascular disease, type 2 diabetes and bowel cancer.

Most of us need to eat more fibre and having a very good intake from a wide variety of foods is linked to a better overall nutritional intake.

What is fibre?

Dietary fibre is the edible parts of plants resistant to digestion and absorption in the small intestine. It is completely or partially broken down by bacteria in the large intestine. Fibre includes carbohydrates called polysaccharides and oligosaccharides, plus lignin.

The many health benefits of fibre are shown in Table 1.

Table 1:

Health benefits of fibre

Why increase your fibre intake	High fibre foods to eat
To lower your risk of heart disease, diabetes and colorectal cancer.	All foods high in fibre, in particular cereals and wholegrains
To treat or prevent constipation, make stools softer and easier to pass.	All foods high in fibre, in particular wheat and other cereals
To help lower a high blood cholesterol level or high blood pressure.	Oat bran

Some of the best food choices for fibre are:

- starchy foods: porridge, oat bran, high fibre breakfast cereals, sweet potato, potato with skin, wholemeal or wholegrain bread and pasta (see our Food Fact sheet on Wholegrains)
- beans and pulses such as baked beans, hummus and dahl
- vegetables: peas, parsnip, mixed veg (from frozen), green beans, carrot, canned sweetcorn and broccoli
- fruits: pear, apple, raspberries and blackberries, plums and prunes, banana and orange
- seeds such as linseeds and chia seeds
- nuts such as almonds, hazelnuts and peanut butter.

When you read food labels check for the grams of fibre per serving or 100 g. A food product is: 'high fibre' if it contains at least 6g of fibre per 100g a 'source of fibre' if it contains at least 3g of fibre per 100g.

How much fibre do you eat?

In the UK, the average fibre intake for adults is 60% (18g) of what it should be (30g). Overall for children, those at primary school age should try to eat 5g more a day, whilst those secondary school aged should try to eat 9g more. For adults, dietary fibre intake should increase to 30g a day, as part of a healthy balanced diet.

Table 2:

Age Group	Amount of recommended fibre (grams per day)
Children (2-5 years)	**15g**
Children (5-11 years)	**20g**
Children (11-16 years)	**25g**
Adolescents (16-18 years)	**30g**
Adults	**30g**

How much fibre should I have?

Table 3: Fibre containing foods

Type of food	Total fibre per 100g
Cereals and Carbohydrates	
Fibre flake/Bran cereals	13-24.5g
Wholemeal bread (2 slices)	5.0g
Brown rice (boiled)	0.8g
Wholemeal spaghetti (boiled)	3.5g
Fruit and Vegetables	
Apple	1.8g
Banana	1.1g
Broccoli (boiled)	2.3g
Carrots (boiled)	2.5g
Nuts and seeds	
Almonds	7.4g
Peanuts	6.4g
Sunflower seeds	6.0g
Peas and beans	
Peas (boiled)	4.5g
Baked Beans (in tomato sauce)	3.7g
Chick peas (boiled)	4.3g

Tips on how to increase your fibre

- Have a high-fibre cereal at breakfast.
- Add fruit to breakfast cereal.
- Have an oat-based cereal bar as a snack (*be aware of sugar content - check the label)
- Mix linseeds into yogurt.
- Have a wholemeal sandwich at lunch with carrot sticks and hummus.
- Try a homemade vegetable soup with rye bread?
- Have wholemeal pasta with vegetables at dinner time.
- Add pulses such as baked beans and lentils to dishes.
- Add extra vegetables to sauces such as bolognaise, curry and chilli.
- Keep a supply of frozen vegetables so you are never without!
- Leave the skin on vegetables and fruit and aim to have 5 portions of fruit and vegetables a day. Have fresh fruit as a snack.
- Blend together some fruit and milk/yogurt for a refreshing smoothie.
- Other snack ideas include an oat-based cereal bar, trail mix, popcorn or a slice of wholemeal toast.

An example of foods to choose to provide you with the recommended 'at least 30g of fibre' in a day (for an adult)

Breakfast		
	Portion size	**Fibre per portion (g)**
Porridge	**50g**	**5g**
with rasberries	**80g**	**2.5g**
Snack		
1 banana or apple	**1 medium sized**	**2g**
Lunch		
Baked Potato	**180g - medium cooked**	**5g**
Baked Beans	**80g**	**3g**
Sweetcorn (tinned)	**80g**	**2g**
Dinner		
Wholemeal Spaghetti	**150g**	**5g**
Suggestion: add a tomato based sauce and vegetables		
Snack		
Wholmeal Bread	**2 slices**	**6g**
Peanut Butter	**1 Tablespoon**	**1g**
TOTAL		**31.5g**

If you need further help, ask your doctor to refer you to a dietitian.

Summary

Remember to increase your fibre intake gradually to avoid gastrointestinal symptoms such as bloating and gas and allow your gut to adjust to the higher intake.

Remember to drink plenty of fluid, to allow the fibre to do its job properly, aiming for 8-10 cups of fluid per day at regular intervals.

BDA The Association of UK Dietitians

Food Fact Sheet

Christmas

At Christmas we're often surrounded by masses of delicious food and drink. While there is no reason to feel guilty about enjoying yourself, it's worth remembering that, on average, people gain from 1-5lbs (1-2.5kg) over this holiday period. But don't despair, you can enjoy yourself and make healthier choices too.

Did you know that many people eat their way through about 6,000 calories on Christmas Day? That's about three times as much as we need. So, think about your portion sizes and follow these simple tips to help you eat, drink and be healthy.

Start the day with a healthy breakfast

Try breakfast cereals, porridge, wholegrain bread/ rolls, English muffins, scones, malt loaf, fruit bread and bagels which are all good sources of energy to help get you through a busy morning and they're all low in fat too. Choose wholegrain varieties whenever possible to ensure a good fibre intake to keep you feeling full, so you are less likely to snack throughout the morning.

Adding fruit will boost your 5-a-day target, why not try seasonal citrus fruit like satsumas and clementines, or stewed or baked apples with fresh/dried dates, figs or cranberries. You could add a small 150ml glass of fruit juice or a fresh fruit smoothie. Vegetables such as mushrooms or grilled tomatoes are tasty on toast or in an omelette and baked beans also count as one of your 5-a-day! Fruit and veg are a great source of both vitamins and fibre.

Low-fat yoghurt or milk (or non-dairy alternatives fortified with calcium e.g. soya or coconut milk) on cereal, to make porridge or added to a smoothie will give you calcium for strong teeth and bones.

Christmas meal

Starters Try smoked salmon, which is a good source of omega-3 fatty acids, needed to keep your heart healthy; melon or vegetable soup a further boost to your 5-a-day target.

Main course

Turkey is low in fat and high in protein (to help your body grow and repair) so enjoy it. Most of the fat that is present in a cooked turkey will be found just under/ in the skin. Why not take the skin off before you tuck in? A side of salmon is also a great alternative to meat. If you are a vegetarian try a roasted vegetable medley with added nuts, seeds, beans or pulses for protein.

All the trimmings:

Roast potatoes Use unsaturated vegetable oil like rapeseed or sunflower oil rather than goose fat or lard; try using a spray or brush which spreads less fat further and roast on a non-stick tray/foil. Cut the potatoes into large chunks, as these absorb less fat than smaller ones.

Fill up on vegetables Aim to cover at least a third of your dinner plate with a variety of vegetables, such as unbuttered Brussels sprouts, peas and carrots which are all rich sources of vitamins, minerals and fibre to help protect against heart disease and cancer. Cook for the shortest length of time possible in the smallest amount of water necessary, steam or microwave to keep all the nutrients in. As long as they are not covered in butter or any other fatty spreads, all vegetables are low in calories and fat and contribute to your 5-a-day.

Gravy, stuffing and sauces Use a chestnut and/or fruit-based stuffing and make bread sauce with low-fat milk. When making gravy why not use the water from your cooked vegetables? If using meat juices, let the fat rise to the surface, then skim it off and use what's left behind.

Pigs in blankets If you can't resist these, grill or roast alongside your meat instead of frying so you can throw away the extra fat.

Dessert

Christmas pudding is packed with fruit and quite low in fat, so to keep it this way, serve with low-fat custard or crème fraiche. You could also prepare a fresh fruit salad and serve with natural yoghurt. Homemade mince-tarts with filo pastry are just as tasty as mince pies with less pastry, so less fat!

Cheese and crackers

Cheese is creamy so you won't need butter and a stronger cheese means you can go for a smaller portion. Lower-fat options include Edam, goats cheese, camembert or Danish blue. Choose wholegrain crackers or oatcakes.

Leftovers

Turkey or salmon sandwiches on wholemeal bread with a low-fat spread or spicy chutney and plenty of salad are a delicious, filling and healthy lunch or supper. Leftover vegetables can be made into soup or mixed together and turned into a traditional bubble and squeak – mash or chop the veg, adding onion, garlic and herbs if you like, with a spray of olive or sunflower oil in a non-stick pan, press down and then flip over once crispy and brown to cook the other side. Serve alone or with leftover cold meat or salmon.

It's usually all the little extras that pile on the calories...

Alcohol

Remember, drinks have calories too. Why not alternate your alcoholic drinks with non-alcoholic ones (remember if you are having fizzy drinks choose sugar free or diet varieties), or even better, offer to drive and don't drink alcohol. Try sparkling water with a few slices of seasonal fruit, or warm through some unsweetened apple juice with spices for a non-alcoholic warm drink. Always have a jug of water on the table at mealtimes.

Snacks

With all the tasty snacks around at Christmas it's easy to over-indulge. So if you can, keep tempting treats out of sight and make sure you have healthy options to hand:

- satsumas are a great source of vitamin C and look festive, so keep a large bowl of these and other fruit handy
- chestnuts are the only low fat nuts around, so roast a few and leave the salted peanuts to one side
- choose a handful of unsalted nuts, plain popcorn or pretzels or raw veg and low fat dips
- dried fruit makes a tasty snack – dates, figs and apricots are all good choices.

Above all enjoy yourself!

Don't forget that being active will help you work off those extra calories. Why not dance the night away at all those office parties and on Christmas day, wrap up warm and go for a walk after lunch.

Summary

Christmas is a wonderful time to eat, drink and be merry - following the tips in this Food Fact Sheet will help you have a good time without overindulging. After your main meal, go for a brisk walk to burn off the extra treats you couldn't resist.

Further information: Food Fact Sheets on other topics including Healthy Eating, Sport and Fruit and Veg - how to get five a day, are available at **www.bda.uk.com/foodfacts**

Recipe corner: Winter Warmth Vegetable soup Vegetable Soup

Serves 4

2 medium sized potatoes
2 leeks
2 carrots
1 onion
50g frozen peas
1 454g tin chopped tomatoes
1 454g tin mixed beans (drained)
Vegetable stock cube
Pepper to taste
750 ml (1¾ pints) water

To serve 4 you need:-

2 medium sized potatoes
2 leeks
2 carrots
1 onion
50g frozen peas
1 x 454g tin chopped tomatoes
1 x 454g tin mixed beans (drained)
Vegetable stock cube
Pepper to taste
750 ml (1¾ pints) water

Preparation method

1) Peel the potato and chop into small chunks.
2) Wash the leeks, carrots and then slice thinly.
3) Peel the onion and finely chop.
4) Place all the above vegetables in a pan add 750mls of water and crumble in the vegetable stock cube.
5) Gently heat the stock and vegetables until they start to boil.
6) Turn the heat down, put a lid on the pan and simmer for 20 minutes or until the vegetables are tender. If the water starts to simmer dry add a little more.
7) When the vegetables are tender remove from the heat.
8) Take out about ⅓ of the vegetables add half of the tinned tomatoes and blend (puree) them to a smooth paste. You can use a blender or push the vegetables through a sieve with a spoon to do this.
9) Put the puree back in the pan with the rest of the stock and vegetables. Add the frozen peas, tin of mixed beans and the rest of the tinned tomatoes.
10) Put the pan back on the heat and cook until boiling hot.
11) Season with a little pepper.

Recipe Corner *by Carolyn*

Cranberry and Cream Cheese Muffins

Preparation time 10 minutes, Cooking time, 30 minutes
Easy to do, Makes 12

Per Muffin: 220kcal, 9g fat, 2g saturates, 36g carbs, 23g sugars, 1g fibre, 3g protein, 0.33g salt

These sweet muffins have a lovely creamy middle and go down a treat with a cup of tea.

Method

Heat oven to 190C/170C fan/gas 5.
Line a 12hole muffin tin with muffin cases.
Beat the soft cheese with 25g of the sugar and chill until needed.
Heat the cranberries together with another 25g of sugar until they start to pop. Mash lightly and cool.

Sift the flour into a large bowl and add the remaining sugar, baking powder and a pinch of salt. Add the eggs, oil, vanilla and cranberry mixture and stir together. Don`t worry if the mix looks a bit lumpy. Divide it between the cases so they each look about two-thirds full. Make a small dip in the centre of each and put a blob of soft cheese in. Bake for 25 minutes or until risen and golden. Cool on a wire rack.

Ingredients:

100g soft cheese
250g caster sugar
175g cranberries
200g plain flour
2tsp baking powder
2 eggs
75ml flavourless oil, such as sunflower
1tsp vanilla extract

Polar Bear Peppermint Creams

Preparation 30 minutes, Easy to do, Makes 15-20

These little minty treats are lovely for any youngsters around at Christmas time. If you want a more classic cream, then coat the bears in melted dark chocolate.

Ingredients:

250 grams icing sugar
1 egg white, beaten
A few drops of peppermint essence
15 chocolate sweets, smarties or similar

Ingredients:

250 grams icing sugar
1 egg white, beaten
A few drops of peppermint essence
15 chocolate sweets, smarties or similar

Method

Sieve the icing sugar into a large bowl. Mix in the egg white, a little at a time – stop adding it when you have a soft dough that feels like plasticine.
Add 3 drops of the peppermint essence, mix well and taste. Add another drop if it isn`t minty enough.
Roll half the mixture into 15 balls about the size of cherry tomatoes, then flatten them with your hand to make the bear heads..
Place on sheets of baking parchment on a large board or tray. Using half the remaining mixture, make blueberry-sized balls and flatten them out onto the heads to make snouts. Add chocolate sweets for the noses. Use the rest of the mixture to make the ears. Shape them into tiny balls and press them gently into the top of the heads with your fingertips. Use a cocktail stick to shape the eyes.
Leave the polar bears to dry for 3-4 hours, or overnight. Eat within one month.

Feature Review:

Fresh evidence points to a cause and possible treatments for chronic fatigue syndrome.

A review of a feature from The Pharmaceutical Journal of 15th July 2016. There feature is by The Pharmaceutical Journal reporter Janna who joined the Pharmaceutical Journal in 2012 and works as a news reporter. She has a background in biochemistry and scientific research.

Abstract: Chronic fatigue syndrome, or myalgic encephalomyelitis, has been largely dismissed as psychological. But recent trials of antiviral and immunosuppressant drugs have yielded encouraging results, suggesting a complex disease mechanism at play that researchers are hopeful they might be able to treat.

The main text of the feature and starts off with a general clinical picture of ME/CFS. it CFS, which we all know about. It then quotes the case of Anna (whose name has been changed) who was enrolled in a phase II double-blind placebo-controlled trial testing a radical new treatment for CFS/ME. The research group, from Norway's Helse Bergen University, who after taking part in the clinical trial in the placebo section we given the treatment for real. The feature then moved on to review Disease recognition and then the real or imaginary issues which we all know about. The lack of funding for research into CFS/ME is something that has been hampering treatment for years,

The role of GET AND CBT is discussed, from point of view of Leger ME as that of the ME Association, is that neither therapy is appropriate as a main treatment for ME/CFS except in rehabilitation and management.

Some further research is then discussed. A finding of "a band of fibers that is thicker" in patients with ME/CFS brains, then they discuss increased levels of interferon gamma, related to viral infections. Abnormal findings in the gut microbiome (flora or candida) and inflammatory microbial markers in blood samples. The possible inflammatory nature is discussed, but this is not something we see locally. I had been noticed that a ME/CFS patient treated for Hodgkin's Lymphoma (a type of blood cancer) had dramatically improved. The medicine concerns was Rituximab, a monoclonal antibody. The theory of s of inflammation, this also means it might be reversible and rogue antibodies produced by immune system B cells, which Rituximab targets. Rituximab is *a viciously toxic drug*, which has the typical side effects of chemotherapy drugs. At the time of writing, a 40-person open-label clinical trial was underway, with the expectation that they would be available in January 2017. This will be of interest to anyone with ME/CFA, because it may point the way to a disease modifying treatment, rather than just palliative or supporting treatment which seems to be the mainstay of the NHS. But even if that is successful further clinical trains will be necessary and it could be a number of years before as routine treatment is available.

This finding is consistent with recent published research which there are links to the immune system and gut biome in schizophrenia and Parkinson's disease. It is believe that Motor neurone disease and multiple sclerosis may be as a result of rogue antibodies or other Immune system complements, so why not ME/CFS ?

Over the years, there have been a significant number of Leger ME members with cancer treated with chemotherapeutical agents. I have noticed that some, but for some, but not all, have partially recovered from ME/CFS. These drugs knock the immune system, and I would place a bet a large bet that the future of ME/CFS disease modifying treatment will be based on medicines which target the immune system.

But what did others think of the feature?

Scot wrote: This is a good overview of history and the key points of current focus for ME/CFS but Janna Lawrence failed to mention several independent analyses (David Tuller and several others) that refute the findings of the PACE trial and show in fact that neither CBT nor GET results in any significant improvement in symptoms. In fact, there is evidence that GET can be harmful. Considering this significant omission, a revision of this article, including the perspectives of the omitted material, should be reposted immediately.

Lori wrote: It is difficult for me to contrast what appears to be science in the main subject of the article with the suspect results of the PACE study. They appear to be given equal weight, and that makes me concerned with whether I can trust the scholarship.

Joanna the feature author responded:

I try my best to speak to as many relevant people as possible, but it's not possible to speak to all relevant people. Please comment further if you think this deserves more discussion.

Michael Valentine: As someone who deals with patients ME/CFS in South Yorkshire daily I find this feature totally related to reality as I see it. I certainly think I could produce a more practice relevant feature which is more relevant to pharmacists in practice. I would be happy to co-author a follow up feature if anyone is interested?

There were also two tablet quotes from the National ME/CFS Collaborative

Symptoms for which there is no pharmacological therapy.

Source: British Association of CFS/ME (BACME) guide for therapy and symptoms management in CFS/ME

- Fatigue: the hallmark of CFS/ME, which is chronic and disabling. It is not somnolence (sleepiness) and if somnolence is present, an alternative diagnosis, such as sleep apnoea, should be considered.
- "Payback": post exertional malaise defined as worsening of symptoms after excess exertion.
- "Brain fog": cognitive impairment, including low grade confusion and memory loss.
- Lymphadenopathy: a common complaint from patients, if not attributable to any other source, cannot be treated pharmacologically.
- Frequent upper respiratory tract infections: there is no role for prophylactic or frequent therapeutic antibiotics, unless there is convincing evidence of an acute bacterial infection.

Symptoms for which there are pharmacological medicines therapy is available.

- Pain: Low-dose tricyclic antidepressants (e.g. amitriptyline), anticonvulsants (e.g. gapapentin or pregabalin), non-steroidal anti-inflammatory drugs
- Nausea: Functional non-ulcer dyspepsia or gastro-oesophageal reflux disease
- Irritable bowel syndrome. Antihistamines if associated with migraine
- Antacids: Proton pump inhibitors
- Antispasmodics, loperamide, antimotility, macrogol laxative, linaclotide, low-dose tricyclic antidepressants
- Autonomic symptoms, commonly including postural hypotension or postural tachycardia syndrome: Increase fluid intake to 2.5 liters
- Sleep disturbance: Amitriptyline, short-term zolpidem or zopiclone, antihistamines
- Co-morbid mental health issues, such as PTSD, depression and anxiety disorders: Citalopram, fluoxetine, sertraline, mirtazapine, duloxetine.

I have put my copy pf the Pharmaceutical Journal in the Leger ME group library at the Redmond centre which members can loan.

Notable Historical Christmas Cards

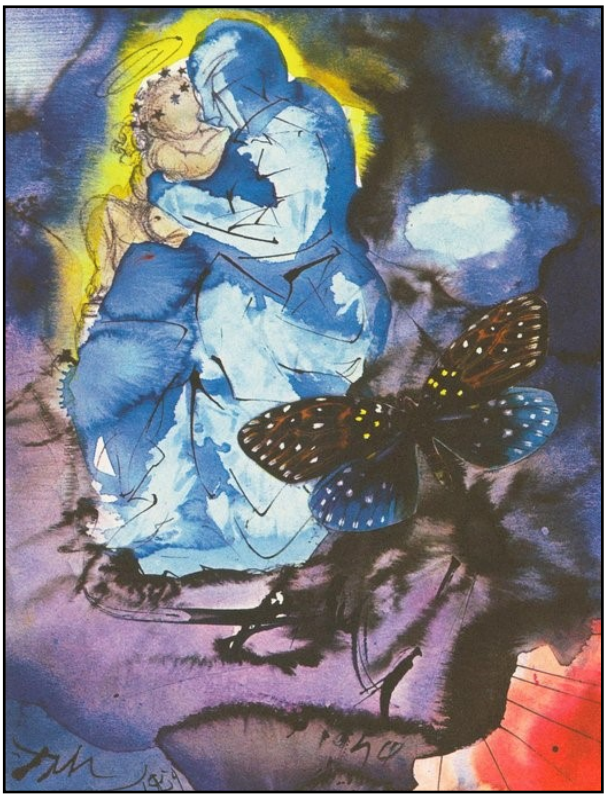
With thanks to Wikipedia

The first commercially produced Christmas card.

The first Christmas cards were commissioned by Sir Henry Cole and illustrated by John Callcott Horsley in London on 1st May 1843. The central picture showed three generations of a family raising a toast to the card's recipient: on either side were scenes of charity, with food and clothing being given to the poor. Allegedly the image of the family drinking wine together proved controversial, but the idea was shrewd. Conveniently Cole had helped introduce the Penny Post three years earlier. Early English cards rarely showed winter or religious themes, instead favouring flowers, fairies and other fanciful designs, possibly sentiment for the approach spring.

Soldiers in the first world first world war often sent topic Christmas cards. To the left an example of soldiers crossing no man's land, illuminated by a flare often used to exposed night movements. This example was sent by the 46th North Midland division in 1917.

The production of Christmas cards was, throughout the 20th century, a profitable business for many stationery manufacturers, with the design of cards continually evolving with changing tastes and printing techniques. The now widely recognized brand Hallmark Cards was established in 1913. The Hall brothers capitalized on a growing desire for more personalized greeting cards, and reached critical success when the outbreak of World War I increased demand for cards to send to soldiers.



There are some Christmas cards which bucked the tread as the design on the right by artist Salvador Dali, a Spanish painter of the early 20th Century. The card to the right is full of symbolism, and was at one time offered by Hallmark, However, the design proved too controversial and was quickly withdrawn from sale.

Nostalgic, sentimental, and religious images have continued in popularity, and, in the 21st century, reproductions of Victorian and Edwardian cards are easy to obtain. Modern Christmas cards can be bought individually but are also sold in packs of the same or varied designs. In recent decades changes in technology may be responsible for the decline of the Christmas card.

North of Doncaster *Personal reflections from Trevor Wainwright.*

A travel diary to the Holy Land and Jezreel Valley. Part 1

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For a long I have time yearned to visit Bethlehem and the Holy Land at the appropriate time. Due to the political disturbances in that region. It was looking like it was never going to happen. Earlier on this in our local church. I saw a brochure advertising a pilgrimage to the Holy Land following in the footsteps of Jesus through Israel and Palestine

I paid my money and on November 28th flew out of Manchester. We arrived at Ben Gurion Airport Tel Aviv then by tour bus to our hotel at the side of the Sea of Galilee, each room overlooking it. Arriving at night I wouldn't see it fully until the following morning but did, before turning in look across it at the lights on the other side, and listen to it gently lapping on the beach at our side.

The following morning I looked out on the sea Israel's largest even though it is a freshwater lake, and still fished. Situated 680 feet below sea level, 200 feet at its greatest depth, bounded by hills, especially on the east side where they reach 2000 feet high. The hills to the North gradually faded into the mist on the Eastern horizon, no worries I would see more later. *To be continued*

If I'd been there

I saw where the baby Jesus was born it was said
And the manger where he lay his head
What would I have done if I'd been there?
What gift would I bring, would it be gold to crown him a king?
Or a toy to give him childhood joy
What would I have given if I'd been there?
What would I have said to mum and dad parenthood just begun?
Congratulations on the birth of your son
What would I have said if I'd been there?
Would I have sat a while tried to make him smile
Held his little hand or gently stoked his hair
Yes, what would I have done if I'd been there?

From Shepherds Field

I looked at Bethlehem from Shepherds Field
Thinking of a special night when a star shone bright
The heavens ringing with angel voices singing
The Angels telling the Shepherds to find
A Holy Child, the hope for mankind
I looked at Bethlehem from Shepherds Field
From the hill the shepherds went down to find the baby in that little town
Shouldn't have been any trouble at all, in their day it was probably small
Now it's grow spreading far and wide,
I'm looking at it from the opposite hillside
And running through my mind, how long would it take me to find
How long would it take my search to yield?
His birthplace if I was sent to Bethlehem from Shepherds Field