Price £ 4.00 (Free to members)

Pathways

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. 61. (Autumn 2019)

You Write In:

Julie writes: I suffer from fibromyalgia. However during my period, my pain is worse, and is of a different sort. My doctor has given me different medicines which help to a point. I am curious as to why this happens, and is there anything I can do about it?

I came across this graphic on the internet. The white model is a replica a normal uterus. The red model is about twice as big and represents the swelling of the uterus during a period. If something quickly grows twice as big in your tummy, it is bound to be painful and cause other problems to adjacent organs. You body is also stressed with bleeding and hormone level changes. One common way to stop periods is to take a type of oral contraceptive. However, if the medicines are not working well you should really be discussing this with your doctor and looking at your options.

Carolyn writes: I've posted the following picture on the LME Facebook page. It gorgeous! This was taken at Dalegarth Station, on the Ravenglass and Eskdale Railway.

Cover picture: The South side of Bassenthwaite Lake taken from the Whinlatter pass.

For the benefit of Pathways readers this railway runs 15 inch gauge scaled down models of steam engines to pull its trains. This is the most recent addition to the fleet, Whillan Beck was officially launched into service this May. Originally built to run at the Ibero-American Exposition in Seville and following nearly 90 years out of action, the engine, originally named Pinta, was restored in Barcelona but hadn't been steamed. Following another two years of work by the Ravenglass & Eskdale Railway Preservation Society the engine is now in full working order and can be spotted at the front of our trains very regularly. The name Whillan Beck follows the tradition of the railway in naming its engines after local streams and rivers.

Whillan Beck

Tony Writes: Thank you for the Feature about Personal Independent Payment and demistifying the inner working for the assessment system in Pathways 60. Is it possible to produce a similar feature for Employment and support Allowance.?

Yes, and it's in the later pages of this edition of Pathways.

Gwen Writes: Have you any thoughts about what might happen with Brexit, and how it may affect us.

At the time of writing Parliament had been prorogued. Boris Johnson had lost his majority and been painted into a corner regarding No Deal Brexit. Parliament is on a five-week holiday for the Party Conferences. It's difficult to say what will happen, but I'll bet once thing and that is the Brexit Deal will be in the hands of the EU. Once thing is certain, and that is there will be a General Election soon.

Natalie writes: I run a Volkswagen Lupo which is about six years old, and I have problems at the moment! I took it in for its service and MOT and before I went, I had noticed there was some doggy sand in the rear seat buckle and thought I should vacuum it before taking the car in. I forgot and the mechanics, thinking it was a stone fiddled about with it and totally broke the mechanism. To replace the buckle so that the car passes the MOT is going to cost £ 160! I also need a new cam belt, their recommended time to change it is 120,000 miles or 5 years. My car is now 6 years old and has done 16,000miles. New fan belt £ 439 + vat. Then the tyres, although the tread is 5.3 mm there are small cracks showing deep in the tread....so they have told me to get four new tyres costing £ 90 each ASAP!

Firstly, the cam belt change. Generally, it is not just the cam belt, but it involves a kit of parts for the job including the cam belt, a selection of replacement hardware including pulleys, and tensioner and maybe a water pump (right image). It is false economy not to use new parts for the job because it could lead to premature failure. Once a Cam belt snaps, it usually causes massive damage to an engine mangling pistons and valves. This will usually mean engine beyond economic repair and result in the car being scrapped. The cost of parts is around £120, and a good mechanic should be able to fit these in a couple of hours. Mechanics time is usually charged at £120 per hour. VW parts are expensive so I would say the price is about right.

Regarding the tyres. When the rubber on a tyre starts to crack it usually means that the tyre is old or the rubber has perished. It also means that a tyre in this condition is likely to burst, particularly when under stress like in high speed driving. In other words, it is dangerous, and tyre in this condition should be replaced ASAP. Generally good quality tyres cost between £ 65 to £ 85. A new tyre may need a new valve and balancing which would bring the price up to what you were quoted. If you bought four new tyres, most garages would offer a discount of about 10%. I would recommend that you shop around for tyres to get the best deal. With winter coming, also think about the sort of tyres you need.

Regarding the seat belt buckle. You'll possibly find that that price is the cost of a replacement seat belt kit. Because it is VW, you'll have no choice but to buy their replacement. Price sounds about right.

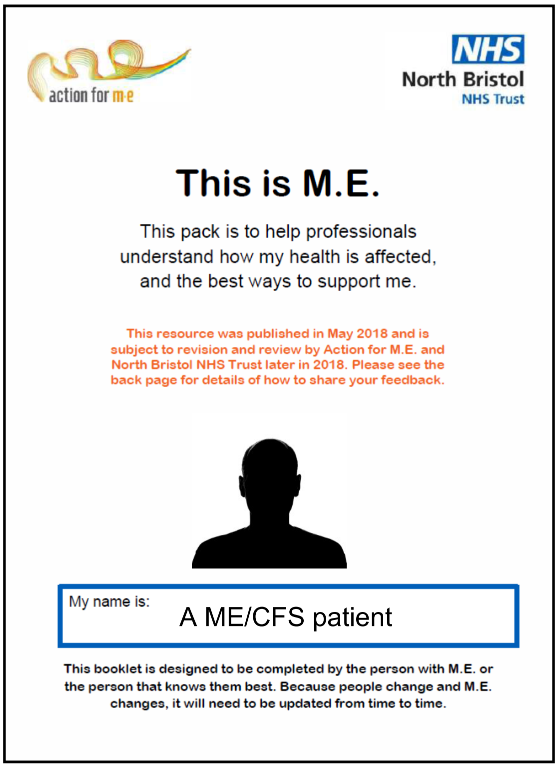
I always reckon that where a car is concerned you need to have about £1000 in your bank account to cover wear and tear repairs and servicing. every year.

Sandra writes: I was using my computer on Facebook when clicked on a download link. The computer screamed a full volume, locked up, and displayed some message to ring a telephone number on the screen to fix it. This looks like blackmail. Fortunately, my husband is a computer engineer and he just pulled out the plug, waited five minute and the restarted my computer. I had lost a letter what I had been typing on my computer. The following day he bought me to an antivirus programme.

I've heard this one before. Usually there is no way to stop this Howler malware once it starts except by a power down or system reset. In some case this can corrupt system files and stops a computer from working properly. You husband has acted correctly in buying the antivirus programme and installing it. You need to ask him to setup a backup scheme for all your files. Also please be aware that internet security software needs to be regularly updated. The popular brands also include protection for any other household computers and mobile phones for the same price.

Strategy Document Review: This is M.E.

I came across this document on the AfME website. One thing that I hear time after time is that GP and other health professional have difficulty understanding ME/CFS, and the experience of their patients. Additionally, the organisation that the DWP uses for medical examination are totally oblivious to ME/CFS, unless it is spelled out to them. This has the potential to help ME ME/CFS patients. I've reproduced the header page on the right.



action for me

NHS
North Bristol
NHS Trust

This is M.E.

This pack is to help professionals understand how my health is affected, and the best ways to support me.

This resource was published in May 2018 and is subject to revision and review by Action for M.E. and North Bristol NHS Trust later in 2018. Please see the back page for details of how to share your feedback.

My name is: A ME/CFS patient

This booklet is designed to be completed by the person with M.E. or the person that knows them best. Because people change and M.E. changes, it will need to be updated from time to time.

The second page carries the following narrative.

What is M.E.?

I live with a condition called myalgic encephalomyelitis (M.E.), also diagnosed by the NHS as Chronic Fatigue Syndrome or CFS/M.E. Both of these names are used around the world, but this guide will call it M.E.

The main symptom of M.E. is fatigue, both mental and physical, which feels different from normal tiredness. This fatigue can be made worse by small amounts of physical and/or, mental activity and the symptoms may worsen over a 2-3 day period after the activity. This is known as post-exertional malaise and it is a key feature of M.E. Along with this are a range of other symptoms. I have indicated the symptoms that affect me in the table on the next page.

Different people experience some symptoms more than others. For example, pain can be a big problem for some, and not for others. The condition affects people in different ways: some people are mildly affected, others moderately or severely affected. Some have frequent setbacks or relapses, whilst other people's symptoms are more stable. It helps if carers and other professionals understand that just because an individual can manage an activity (e.g. a conversation) one day doesn't necessary mean they can another: please don't be offended or surprised by this.

What causes M.E.?

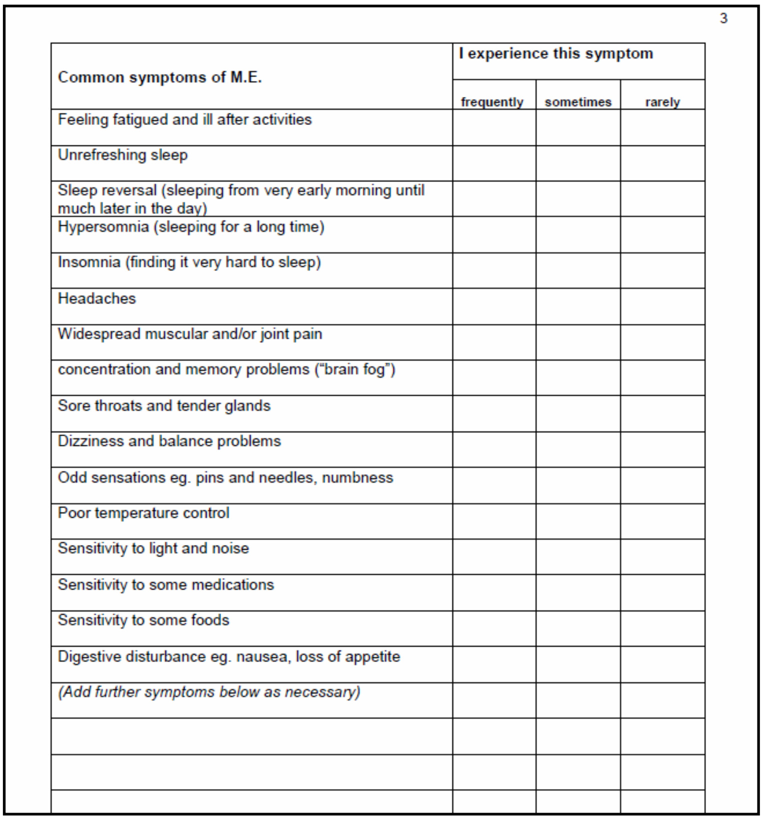
Sometimes people develop M.E. following an infection, such as glandular fever. For other people, their illness may have been triggered by a significant amount of stress. A combination of an infection and stress is commonly reported. Occasionally, it seems to come "out of the blue".

The exact mechanisms underlying M.E. are still unknown. Our current understanding is that the nervous system and possibly the immune and endocrine systems of the body are likely to be involved in M.E. These systems are complex and operate at a deep level inside us. For this reason, someone with M.E. may look well on the outside, even if they are having a really bad day.

With M.E., the body's systems are thought to have become poorly regulated and hypersensitive. The body is in a constant state of "high alert" almost as if a switch has been thrown and the whole system is in a state of emergency. This is thought to be why the smallest of stressors such as noise, light, or physical activity can have a big impact on the symptoms of M.E. Often too much stimulation from things such as noise or light can result in someone with M.E. feeling worse the next day.

Activity and M.E.

People with M.E. often have varying symptoms from one day to another, or even within the same day. This can make it difficult to decide whether or not to attempt an activity. It can be tempting to try and do more on a better day. However, if someone with M.E. does too much in one day, they are likely to feel worse afterwards and have several days recovering. This can lead to big swings in activity over time, known as "boom and bust". This boom and bust pattern is unsustainable and over time and leads to a reduction in the level of activity a person can manage.



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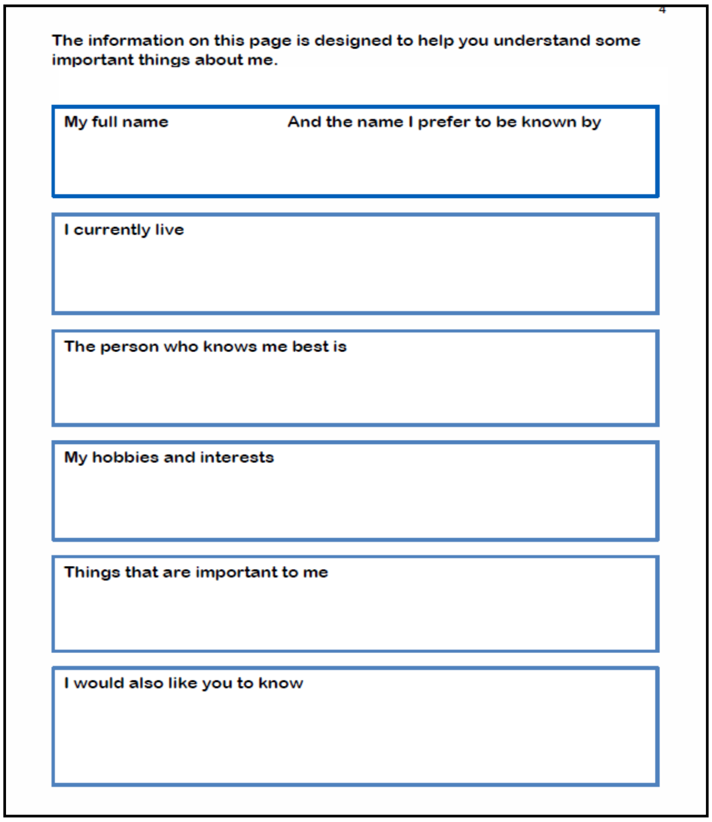
Common symptoms of M.E.	**I experience this symptom** **frequently**	 **sometimes**	 **rarely**
Feeling fatigued and ill after activities			
Unrefreshing sleep			
Sleep reversal (sleeping from very early morning until much later in the day)			
Hypersomnia (sleeping for a long time)			
Insomnia (finding it very hard to sleep)			
Headaches			
Widespread muscular and/or joint pain			
concentration and memory problems ("brain fog")			
Sore throats and tender glands			
Dizziness and balance problems			
Odd sensations eg. pins and needles, numbness			
Poor temperature control			
Sensitivity to light and noise			
Sensitivity to some medications			
Sensitivity to some foods			
Digestive disturbance eg. nausea, loss of appetite			
(Add further symptoms below as necessary)			



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The information on this page is designed to help you understand some important things about me.

My full name **And the name I prefer to be known by**

I currently live

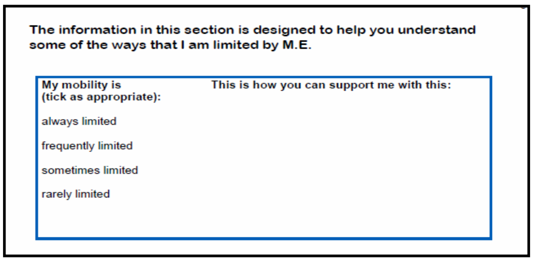
The person who knows me best is

My hobbies and interests

Things that are important to me

I would also like you to know

Page three (see top left) contains table with the main symptoms for ME/CFS for the patient to fill out. Page four (see to right left), contain information designed to help the health professional understand some important things about the patient. The next page starts with the following box to the right, and there are similar boxes for Concentration, Communicating, Light Sensitivity, Sound, Sleep, Personal Care, Medication and Diet.



The information in this section is designed to help you understand some of the ways that I am limited by M.E.

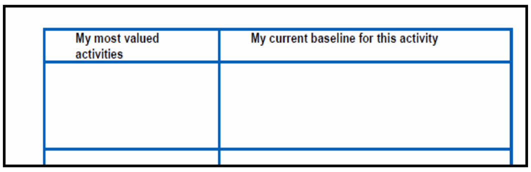
My mobility is (tick as appropriate):	**This is how you can support me with this:**
always limited frequently limited sometimes limited rarely limited	

The next page states There *are a number of things around the house that I would like regular help with. These are?*

Moving on there is a table with the following narrative:-

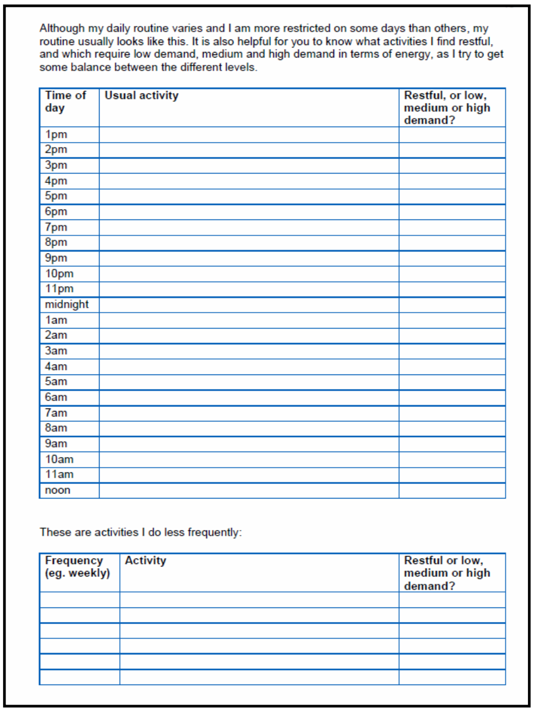
Managing my activity and baselines

One way of avoiding the boom and bust pattern of activity is to stick to a baseline. A baseline is the level of a particular activity that someone can manage consistently, without triggering off a bad day. It's essential to recognise that baselines are unique to each individual: even lifting an arm or sitting up in bed can be above the baseline for some people. Baselines can be measured using the amount that someone does of a certain activity (e.g. reading four pages), the length of time they do a certain activity for (e.g. reading for five minutes), and sometimes the distance travelled doing a certain activity (e.g. Walking 10 meters). Baselines change over time and for some people – but not everyone – they can be slowly increased by consistently undertaking an activity.



My most valued activities	My current baseline for this activity

You are the invited to state your most valued activities and state your current baseline. The following page is as the right-hand side frame.



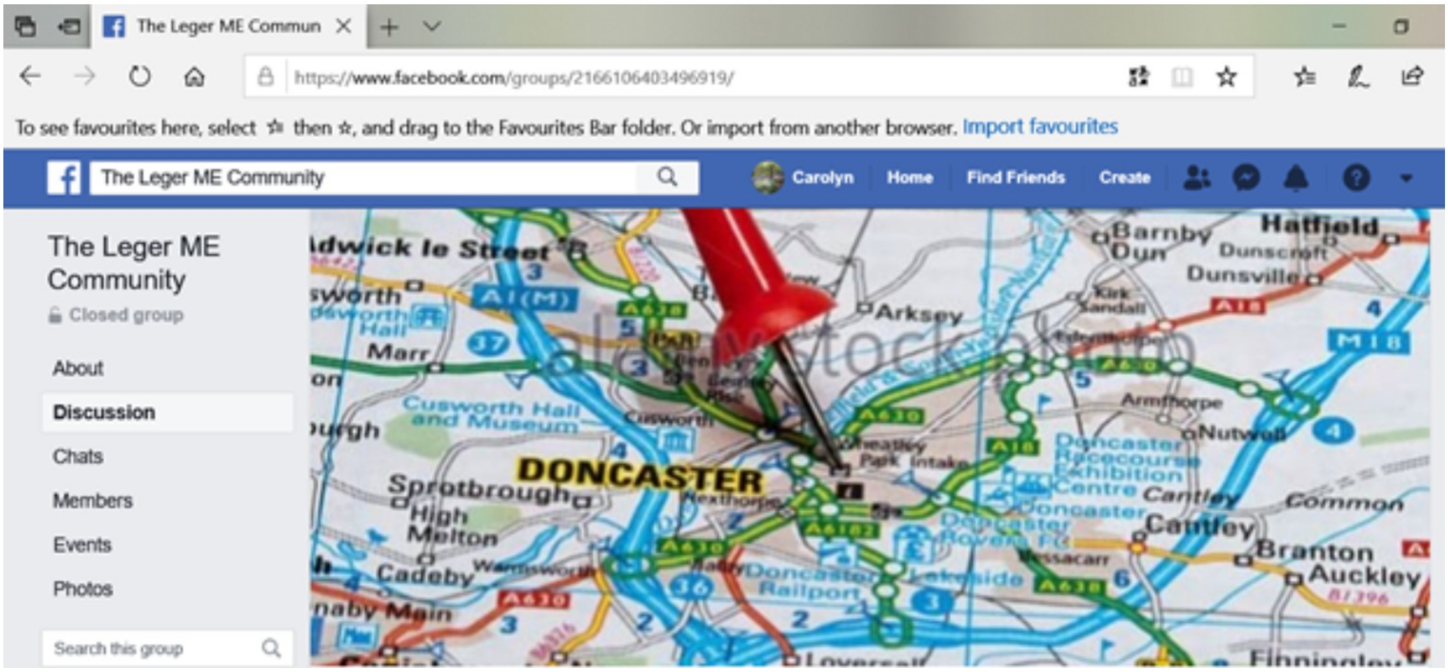
Although my daily routine varies and I am more restricted on some days than others, my routine usually looks like this. It is also helpful for you to know what activities I find restful, and which require low demand, medium and high demand in terms of energy, as I try to get some balance between the different levels.

Time of day	**Usual activity**	**Restful, or low, medium or high demand?**
1pm		
2pm		
3pm		
4pm		
5pm		
6pm		
7pm		
8pm		
9pm		
10pm		
11pm		
midnight		
1am		
2am		
3am		
4am		
5am		
6am		
7am		
8am		
9am		
10am		
11am		
noon		

These are activities I do less frequently:

Frequency (eg. weekly)	**Activity**	**Restful or low, medium or high demand?**

Leger ME Community Facebook Group



To see favourites here, select ☆ then ☆, and drag to the Favourites Bar folder. Or import from another browser. Import favourites

The Leger ME Community Facebook page.

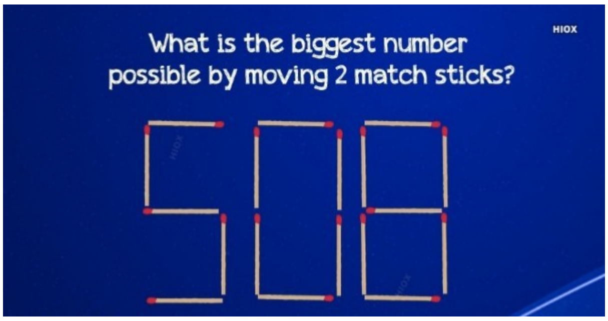
Come and join us in the newly launched Facebook group that is exclusively for our members. Those that have already joined are chatty and friendly and it is proving a great place to get to know new people and enjoy their humour, gossip and company. To enrol, all you need to do is search on Facebook for **The Leger ME Community**

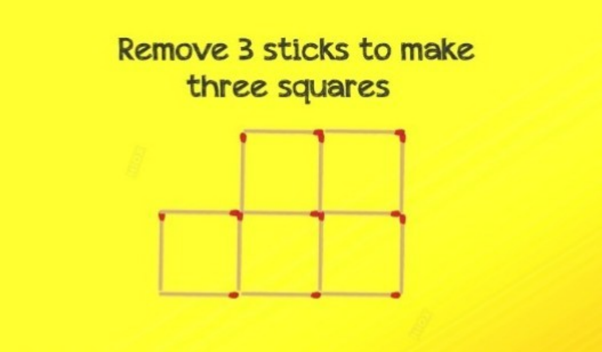
You will be asked three very short questions just to check that you are a fully paid up member. If you have any problems with Facebook then please do not hesitate to contact me, Nichola, at **njstockton@talktalk.net** . Looking forward to seeing you there!

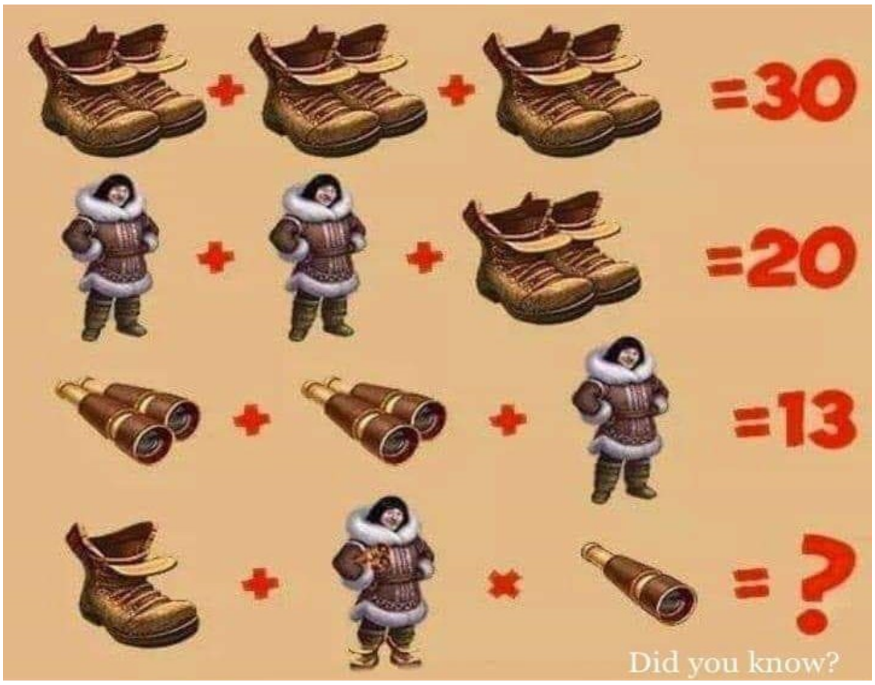
Puzzle Corner

By Nichola Stockton

Over the past few months I've posted puzzles on the Leger ME Facebook Pages. I though it would be something different. Please send your answer to me via the Facebook pages, and I'll publish the solution in the next Pathways.







ME/CFS, the ESA 50 and UC 50 Forms

For many people who get ME/CFS there are work difficulties. This usually involves time off work, reduced hours and ultimately termination of employment. At some point people are put on statutory sick pay. When this runs out you have to claim Employment and Support Allowance (ESA) or Universal Credit (UC).

First, there is an assessment phase in which your eligibility for the benefit which is three months. After that, the DWP will carry out a Capability of Work assessment. There are three possible outcomes: -

1) You are not entitled to a sickness benefit and will be expected to claim Jobseekers Allowance.

2) You could qualify for the Limited capability for work assessment. You would join the work-related activity group (WRAG). Here you will receive extra money above the assessment rate. You will also have to attend compulsory work-focused interviews and you may be required to attend a Work Programme.

3) You would qualify for the Limited capability for work-related activity assessment LCWRA and the Support Group. Here you will receive extra money above the assessment rate. You will receive a basic allowance plus a support component which is paid at a slightly higher rate than the work-related activity component. You won't have to have any compulsory work-focused interviews, although you may be contacted by the DWP to see if there is any help, they can offer you. Most Leger ME members are awarded the Support Group.

The actual way the awards are made is complex. Some people can be assessed from doctor or hospital reports for example. However, for most cases we come across an ESA50 or UC50 questionnaire is sent for fillout. The questions on these forms are identical, the only difference being the benefit claimed. The way these questionnaires are set as required by law and are not ME/CFS friendly. Furthermore, if you tick the wrong box you could be effectively denying yourself the benefit to which you would be entitled. If you get one of these forms, contact us for further guidance. Paid up Leger ME members have access to Work and Benefit Guides and can be assisted via the 121 service.
There are other organisations around the country who provide similar services.

Most times, but not always, you the be asked to attend a medical examination. The is usually carried out locally by a 'health professional'. This could be a nurse, occupational therapist, paramedic or rarely a doctor. There are ruses and pitfalls the assessors use to test if you are telling the truth. For example, you could receive a personal walking and bus route to get to the examination office. If you claim you have difficulty in walking 50 meters on the form, and walk the route they suggest, that will blow the assessment. Always go by car or taxi. What is quite clear is that not all these health professionals are knowledgeable about ME/CFS. So, it is necessary to include further evidence with your ESA50/UC50. See the list I published in Pathways 60 on page 19. There are two mandatory documents, these being a copy of your Patient Summary Record from your GP and the Support letter from the Sheffield ME/CFS clinic. If you are not happy with the decision you can ask the DWP to look again at its decision (this is called asking for a mandatory reconsideration) or the next stage a tribunal.

The majority of people who get into the support group do so by scoring 15 points, but there are other ways of passing this test and not all involve points. ESA and UC approaches to this are similar, but not identical.

ESA

There are three ways of passing the test:
1. You can be treated as satisfying the assessment and therefore not need to show that you score enough points. This is also called being 'exempt' from the assessment.
2. You can score 15 or more points in the assessment.
3. Yu can fail to score enough points but be covered by the exceptional circumstances' regulations.

UC

There are two ways of passing the test:

1. You can be treated as satisfying the assessment without having to show that you score enough points.
2. You can score 15 or more points in the assessment.

There are however other ways to get into the work-related activity group without scoring any points

There are a number of grounds on which claimants can be treated as satisfying the limited capability for work assessment; this is sometimes called 'being exempt from the test'.

1) You are terminally ill, i.e. you are suffering from a progressive disease and your death in consequence of that disease can reasonably be expected within 6 months.

2) You are receiving one or more of the following types of therapy:
Chemotherapy or radiotherapy, Hemodialysis, plasmapheresis, or total parenteral nutrition. This only applies for those weeks when you receive this treatment. There is a tick box in the form relating to cancer treatment and a form for your health professional to complete in relation to cancer treatment.
3) In some circumstances, if you are pregnant
4) You have, or have been in contact with, a notifiable disease Infectious Diseases such as typhoid, salmonella and hepatitis may be covered.'
5) You are an in-patient in hospital or recovering from in-patient treatment
6) You are suffering from a severe life threatening disease
For your condition to qualify, the regulations require that:
(i) there is medical evidence that the disease is uncontrollable, or uncontrolled, by a recognised therapeutic procedure, and
(ii) in the case of a disease that is uncontrolled, there is a reasonable cause for it not to be controlled by a recognised therapeutic procedure.
So, for example, you may have severe inflammatory bowel disease, such as Crohn's disease, which is not currently being controlled by medication or you may have stopped taking medication because of very severe side effects.
7) There is a substantial risk to you, or others, if you are found not to have a limited capability for work. The regulation enables you to pass this test without having to score enough points if:
8) 'you suffer from some specific disease or bodily or mental disablement and, by reasons of such disease or disablement, there would be a substantial risk to the mental or physical health of any person if you were found not to have limited capability for work.'

The different routes into the support group – descriptors or other grounds

For both ESA and UC there are two ways of passing the second assessment:
1. You can be treated as having limited capability for work related activity. The grounds here are the same, or very similar, to the 'treated as' rules from the first test. Again, this is sometimes referred to as being 'exempt' from the test .
2. You can be covered by one of the descriptors. These are mostly the highest scoring descriptors from the activities in the first test, but there are some differences and the descriptor numbers are therefore different in places.

We deal with both methods of passing the limited capability for work-related activity test in detail in this guide. One of the grounds for being 'treated as' having limited capability for work-related activity – the substantial risk – rule needs to be looked it in particular detail, so we devote a special section just for this.

There are four ways to get into the support group without using the descriptors
If you pass the limited capability for work assessment you will go on to be assessed under the limited capability for work-related activity assessment. Once again, the first question is whether you are exempt from assessment. The following claimants are treated as having limited capability for work-related activity and will be assigned to the support group:

1) You are terminally ill, i.e. you are suffering from a progressive disease and your death in consequence of that disease can reasonably be expected within 6 months
2) You are receiving treatment for cancer by way of chemotherapy or radiotherapy
For this to apply you must either be actually receiving it, or:
you are likely to receive such treatment within 6 months; or
you are recovering from such treatment;
and the decision maker is satisfied that you should be treated as having limited capability for work-related activity.
3) You are pregnant
4) There is a substantial risk to you, or others, if you are found not to have a limited capability for work-related activity. This ground is so important that there is we need to devote a special section to it.
www.benefitsandwork.co.uk 'Guides you can trust' - 23 -

More on the very important 'substantial risk' rules.

The substantial risk rules are very important – they are one of the most common ways that claimants are placed in the support group. You will be treated as having limited capability for work-related activities if: 'you suffer from some specific disease or bodily or mental disablement and, by reasons of such disease or disablement; there would be a substantial risk to the mental or physical health of any person if you were found not to have limited capability for work-related activity.' This is almost identical to one of the exceptional circumstances for the work-related activity group except that now you need to show that you would have to refrain from 'work related activity' rather than actual work. This could include things such as attending a Jobcentre.

ME/CFS and the ESA 50 and UC 50 Forms: The Basic Rules and Tariff

The descriptors: what the law says you score points for

1. Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid is normally, or could reasonably be, worn or used.

(a) Cannot either
(i) mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion
or
(ii) repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion. 15 points
(b) Cannot mount or descend two steps unaided by another person even with the support of a handrail. 9 points
(c) Cannot either
(i) mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion
or
(ii) repeatedly mobilise 100 metres within a reasonable timescale because of significant discomfort or exhaustion. 9 points
(d) Cannot either
(i) mobilise more than 200 metres on level ground without stopping in order to avoid significant discomfort or exhaustion
or
(ii) repeatedly mobilise 200 metres within a reasonable timescale because of significant discomfort or exhaustion. 6 points
(e) None of the above apply. 0 points

2. Standing and sitting.

(a) Cannot move between one seated position and another seated position located next to one another without receiving physical assistance from another person. 15 points
(b) Cannot, for the majority of the time, remain at a work station, either:
(i) standing unassisted by another person (even if free to move around) or;
(ii) sitting (even in an adjustable chair); or
(iii) a combination of (i) and (ii),
for more than 30 minutes, before needing to move away in order to avoid significant discomfort or exhaustion. 9 points
(c) Cannot, for the majority of the time, remain at a work station, either:
(i) standing unassisted by another person (even if free to move around) or;
(ii) sitting (even in an adjustable chair); or
(iii) a combination of (i) and (ii),
for more than an hour before needing to move away in order to avoid significant discomfort or exhaustion. 6 points
(d) None of the above apply. 0 points

3. Reaching.

(a) Cannot raise either arm as if to put something in the top pocket of a coat or jacket. 15 points
(b) Cannot raise either arm to top of head as if to put on a hat. 9 points
(c) Cannot raise either arm above head height as if to reach for something. 6
(d) None of the above apply. 0 points
4. Picking up and moving or transferring by the use of the upper body and arms.
(a) Cannot pick up and move a 0.5 litre carton full of liquid. 15 points
(b) Cannot pick up and move a one litre carton full of liquid. 9 points
(c) Cannot transfer a light but bulky object such as an empty cardboard box. 6 points
(d) None of the above apply. 0 points

5. Manual dexterity.

(a) Cannot either:
(i) press a button, such as a telephone keypad or;
(ii) turn the pages of a book with either hand. 15 points
(b) Cannot pick up a £1 coin or equivalent with either hand. 15 points
(c) Cannot use a pen or pencil to make a meaningful mark.9 points
(d) Cannot single-handedly use a suitable keyboard or mouse. 9 points
(e) None of the above apply. 0 points

6. Making self understood through speaking, writing, typing, or other means which are normally, or could reasonably be, used, unaided by another person.

(a) Cannot convey a simple message, such as the presence of a hazard. 15 points
(b) Has significant difficulty conveying a simple message to strangers. 15 points
(c) Has some difficulty conveying a simple message to strangers. 6 points
(d) None of the above apply. 0 points

7. Understanding communication by—

(a) verbal means (such as hearing or lip reading) alone,
(b) non-verbal means (such as reading 16 point print or Braille) alone, or
(c) a combination of (a) and (b),
using any aid that is normally, or could reasonably be, used, unaided by another person.
(a) Cannot understand a simple message due to sensory impairment, such as the location of a fire escape. 15 points
(b) Has significant difficulty understanding a simple message from a stranger due to sensory impairment. 15 points
(c) Has some difficulty understanding a simple message from a stranger due to sensory impairment. 6 points
(d) None of the above apply. 0 points

8. Navigation and maintaining safety, using a guide dog or other aid if either or both are normally, or could reasonably be, used.

(a) Unable to navigate around familiar surroundings, without being accompanied by another person, due to sensory impairment. 15 points
(b) Cannot safely complete a potentially hazardous task such as crossing the road, without being accompanied by another person, due to sensory impairment. 15 points
(c) Unable to navigate around unfamiliar surroundings, without being accompanied by another person, due to sensory impairment. 9 points
(d) None of the above apply. 0 points

9. Absence or loss of control whilst conscious leading to extensive evacuation of the bowel and/or bladder, other than enuresis (bed-wetting), despite the wearing or use of any aids or adaptations which are normally, or could reasonably be, worn or used.

(a) At least once a month experiences
(i) loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder; or
(ii) substantial leakage of the contents of a collecting device, sufficient to require cleaning and a change in clothing. 15 points
(b) The majority of the time is at risk of loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, sufficient to require cleaning and a change in clothing, if not able to reach a toilet quickly. 6 points
(c) None of the above apply. 0 points

10. Consciousness during waking moments.

(a) At least once a week, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration. 15 points
(b) At least once a month, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration. 6 points
(c) None of the above apply. 0 points

11. Learning tasks.

11 (a) Cannot learn how to complete a simple task, such as setting an alarm clock. 15 points
11 (b) Cannot learn anything beyond a simple task, such as setting an alarm clock. 9 points
11 (c) Cannot learn anything beyond a moderately complex task, such as the steps involved in operating a washing machine to clean clothes. 6 points
(d) None of the above apply. 0 points

12. Awareness of everyday hazards (such as boiling water or sharp objects).

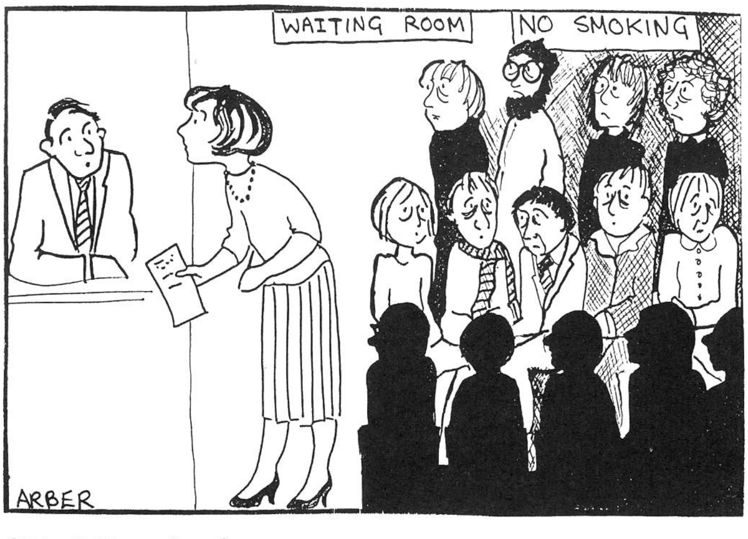
12 (a) Reduced awareness of everyday hazards leads to a significant risk of:
(i) injury to self or others; or
(ii) damage to property or possessions,
such that they require supervision for the majority of the time to maintain safety. 15 points
12 (b) Reduced awareness of everyday hazards leads to a significant risk of
(i) injury to self or others; or
(ii) damage to property or possessions,
such that they frequently require supervision to maintain safety. 9 points
12 (c) Reduced awareness of everyday hazards leads to a significant risk of:
(i) injury to self or others; or
(ii) damage to property or possessions,
such that they occasionally require supervision to maintain safety. 6 points
12 (d) None of the above apply. 0 points

13. Starting and finishing tasks

13 (a) Cannot, due to impaired mental function, reliably initiate or complete at least 2 sequential personal actions. 15 points
13 (b) Cannot, due to impaired mental function, reliably initiate or complete at least 2 personal actions for the majority of the time. 9 points
13 (c) Frequently cannot, due to impaired mental function, reliably initiate or complete at least 2 personal actions. 6 points
13 (d) None of the above apply. 0 points

14. Coping with changes

14 (a) Cannot cope with any change to the extent that day to day life cannot be managed. 15 points
14 (b) Cannot cope with minor planned change (such as a pre-arranged change to the routine time scheduled for a lunch break); to the extent that overall day to day life is made significantly more difficult. 9 points
14 (c) Cannot cope with minor unplanned change (such as the timing of an appointment on the day it is due to occur), to the extent that overall, day to day life is made significantly more difficult. 6 points
4 (d) None of the above apply. 0 points



THERE'S A RUMOUR GOING ROUND THAT YOU WERE KIND TO SOMEONE WITH M.E .

15. Going out

15 (a) Cannot get to any place outside the claimant's home with which the claimant is familiar. 15 points
15 (b) Is unable to get to a specified place with which the claimant is familiar, without being accompanied by another person 9 points
15 (c) Is unable to get to a specified place with which the claimant is unfamiliar without being accompanied by another person. 6 points
15 (d) None of the above apply. 0 points

16. Coping with social situations

16. Coping with social engagement due to cognitive impairment or mental disorder
16 (a) Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the individual. 15 points
16 (b) Engagement in social contact with someone unfamiliar to the claimant is always precluded due to difficulty relating to others or significant distress experienced by the individual. 9 points
16 (c) Engagement in social contact with someone unfamiliar to the claimant is not possible for the majority of the time due to difficulty relating to others or significant distress experienced by the individual. 6 points
16 (d) None of the above apply. 0 points

17. Behaving appropriately

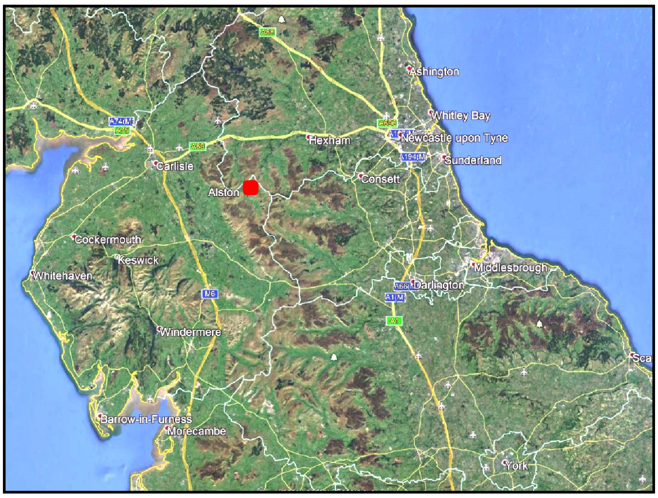
17. Appropriateness of behaviour with other people, due to cognitive impairment or mental disorder
17 (a) Has, on a daily basis, uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace. 15 points
17 (b) Frequently has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace. 15 points
17 (c) Occasionally has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any workplace. 9 points
17 (d) None of the above apply. 0 points

18. Conveying food or drink to the mouth.

(a) Cannot convey food or drink to the claimant's own mouth without receiving physical assistance from someone else;
(b) Cannot convey food or drink to the claimant's own mouth without repeatedly stopping, experiencing breathlessness or severe discomfort;
(c) Cannot convey food or drink to the claimant's own mouth without receiving regular prompting given by someone else in the claimant's physical presence; or
(d) Owing to a severe disorder of mood or behaviour, fails to
convey food or drink to the claimant's own mouth without receiving —
(i) physical assistance from someone else; or
(ii) regular prompting given by someone else in the claimant's presence.
16. Chewing or swallowing food or drink
(a) Cannot chew or swallow food or drink;
(b) Cannot chew or swallow food or drink without repeatedly stopping, experiencing breathlessness or severe discomfort;
(c) Cannot chew or swallow food or drink without repeatedly receiving regular prompting given by someone else in the claimant's presence; or
(d) Owing to a severe disorder of mood or behaviour, fails to—
(i) chew or swallow food or drink; or
(ii) chew or swallow food or drink without regular prompting given by another person in the physical presence of the claimant.

These pages are from the latest Work and Benefits Guide as the time of writing and are subject to change. For the latest information place contact he Leger ME office.

Out and About: The South Tyndale Railway



At the top of England, in the middle in the North Pennines is to be found the village of Alston with is located in the South Tyne river. It is the sort of place you wouldn't visit unless you had a reason to go there. The river valley flows to the northward toward Haltwhistle, about midway between Carlisle and Hexham. There was a branch railway line that connected Alston to Haltwhistle which was closed in the late 1970's. The South Tyndale Railway has been relayed as a narrow-gauge line going north from Alston. We have been visiting Alston over a number of years, and each time the railway has extended a little further north. At the time of writing, a new station had been built on the old site of the former Slaggyford station which is the northern limit of the railway.

This time on arriving at Alston station, we noticed while driving over the level crossing to the car park, a new station canopy had appeared covering both platforms, which were previously open to all the elements. There was also a strange looking locomotive at the head of the train. On our previous visits we had seen steam engine. It soon became quite clear that the railway had had a revamp and gone green! What was at the front of the train was a battery locomotive. They were surplus to requirements from contractors building tunnels in the London area. They were used to transport men and materials to the work while the tunnels were under construction on temporary railways. The locomotive has been modified to run on the two-foot gauge railway. Furthermore, the batteries were charged from solar cells fitted to the engine shed roof. We also noticed that the old station building had been extended to include a larger café area.

We bought our tickets and prepared to board the train. There were three coaches. Two were closed and one open. I noted that the open coach had blankets on the seats. It was made quite clear by the staff that people in summer cloths needed to wrap up well because of the cold wind on the exposed parts of the railway. South Tyndale railway claims to be the highest narrow-gauge railway in England. The train movements are controlled from the Alston signal box using the old mechanical lever system. There is a many semaphore type signals the station area.

Soon were seated, our tickets checked, up went the signal and we were off. One strange thing I notice and that was there was no sound from the engine. It was completely silent. The only noise was from the rails and droning of the coach panels. It was difficult to know the speed, but a good guess would be 20 mph. Most heritage lines have a limit of 25 mph. The railway runs high up the west side of the South Tyndale valley. On one side you can see the farmland and hills of the pennies. At times on the other side you can see over a scenic steep drop to the river and the east side of the valley. The track itself is single, except for passing points. Throughout the route there is a footpath by the side of the railway, which in BR days was occupied by a second track. This is something common to heritage railways.

Parts of the railway are in Northumberland, and other parts and in Cumberland. The picture on the left can easily be missed when you are looking at the scenery.

There are unstaffed halts at Gilderdale, and Lintley. These are like bus stops, allowing the train to pick up walkers, who prefer to walk part of the route

Soon we passed the yellow distance warning signal. This means that we were entering the Saggyford station section and the present end of the line.

The train stops at the platform. The engine was uncoupled, and it moved further up the track to change over the passing loop track, were it again disappeared and then reversed to the train to be coupled up for the return journey.

Slaggyford Station is a small country station which serves as a break point in the journey. There is a signal box and level crossing. There is a waiting room and toilets including disabled ones. There is an old carriage parked in a siding set up as a buffet car with the old seating and tablet still intact. The return journey gives you a chance to view what you have missed.

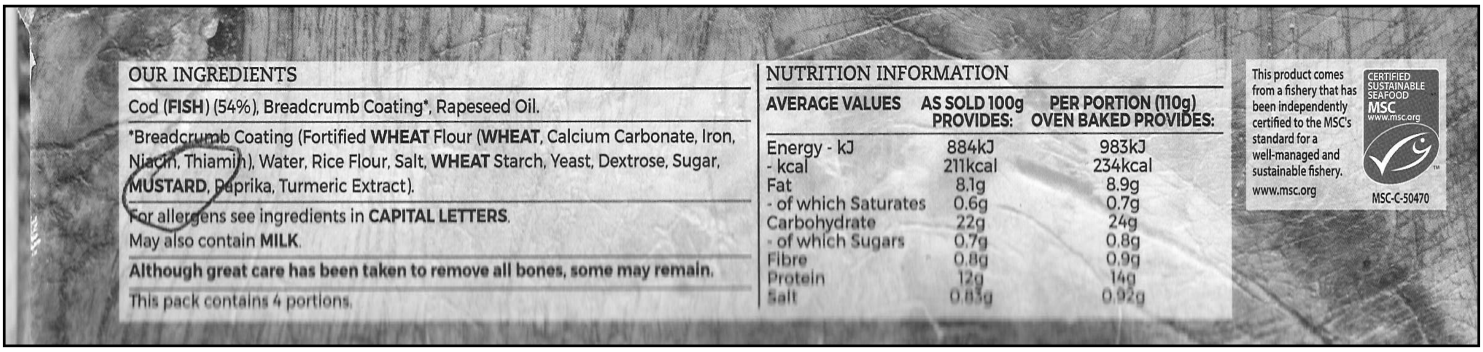
South Tyndale Railway is generally accessible to all visitors regardless of ability. There are large car parks at Slaggyford and Alston and all station buildings with the exception of the signal boxes are level access. There are ramps to platforms and to the ticket office and shop at Alston station. The buffet car at Slaggyford Station is very narrow but they have wheelchair suitable tables in the ticket office where you can enjoy your refreshments. On every train journey a carriage with access for wheelchair users and all areas of our sites are dog friendly so assistance dogs are welcome everywhere. We had no problem with Roo our dog now blind. Every visit to South Tyndale railway has brought us something new and different. I am looking forward to the day when the line reaches the old terminus at Haltwhiste.

MECFS and Food Sensitivities: New Product Variants *by Mike Valentine*

Quite a lot of people with ME/CFS like me have irritable bowel syndrome and food sensitivities. They react abnormally to 'normal' foods. These reactions can vary from just an unpleasant exacerbation of IBS type symptomology to life threatening reactions like anaphylaxis. We will all have seen the news about the death of a young lady from angioedema due to contamination of flour to make bread from a sandwich shop to the Chinese takeaway proprietor who lied about the content of Soya in takeaway products which resulted in a death and was subsequently prosecuted

For people with this problem manufactured food products are a nightmare. Many people stick to well-known brands known to be 'safe'. However, from time to time manufactures for commercial reasons will change the formation to improve the products. For quite a long time my partner has purchased Birdseye breaded Cod. I have eaten it with no problems many times until just recently. There was no problem with the flavour or appearance, but several hours after I began to feel ill, and overnight ended up with a total bowel evacuation. From past experience, I know this can happen with something that irritated my bowel. The reaction is similar to taking an irritant laxative (purgative) like Senna or Cascara. When this happens, you get fluid loss and any medicines you have taken will be ejected down the toilet. If you have other health problems like me, these can be very dangerous, and the diahorrea could leave me dehydrated or needing hospital treatment.

Once an episode like this occurs, I always try to identify to offending food, to avoid further exposure. In this case it was "Birdseye beaded cod with new crispy golden crumbs". The 'new' (red ring) is the clue, because it means that the product has been reformulated and that is always a **red flag** for people with food sensitivities because the ingredients will have changed. On checking the side panel, of concern to me are the Mustard, Paprika and Turmeric extract.



OUR INGREDIENTS

Cod (**FISH**) (54%), Breadcrumb Coating*, Rapeseed Oil.

*Breadcrumb Coating (Fortified **WHEAT** Flour (**WHEAT**, Calcium Carbonate, Iron, Niacin, Thiamin), Water, Rice Flour, Salt, **WHEAT** Starch, Yeast, Dextrose, Sugar, **MUSTARD**, Paprika, Turmeric Extract).

For allergens see ingredients in **CAPITAL LETTERS**.
May also contain **MILK**.

Although great care has been taken to remove all bones, some may remain.

This pack contains 4 portions.

NUTRITION INFORMATION

AVERAGE VALUES	AS SOLD 100g PROVIDES:	PER PORTION (110g) OVEN BAKED PROVIDES:
Energy - kJ	884kJ	983kJ
- kcal	211kcal	234kcal
Fat	8.1g	8.9g
- of which Saturates	0.6g	0.7g
Carbohydrate	22g	24g
- of which Sugars	0.7g	0.8g
Fibre	0.8g	0.9g
Protein	12g	14g
Salt	0.83g	0.92g

This product comes from a fishery that has been independently certified to the MSC's standard for a well-managed and sustainable fishery. www.msc.org

CERTIFIED SUSTAINABLE SEAFOOD MSC www.msc.org MSC-C-50470

As with most problems of this nature it is very difficult to pin down the exact cause of the problem. It is not food poisoning because my partner is not affected, and my body temperature was abnormally low. The most probable the culprit is mustard. Mustard contains allyl isothiocyanates and 4-hydroxybenzyl isothiocyanate which is responsible for the sharp, hot, pungent sensation in mustards. Thiocyanates are produced when the mustard is ground. The problem is that allyl thiocyanates can sensitize the immune system to substances normally considered safe. People with ME/CFS are prone to adverse effects. There are two health warnings where mustard in concerned:

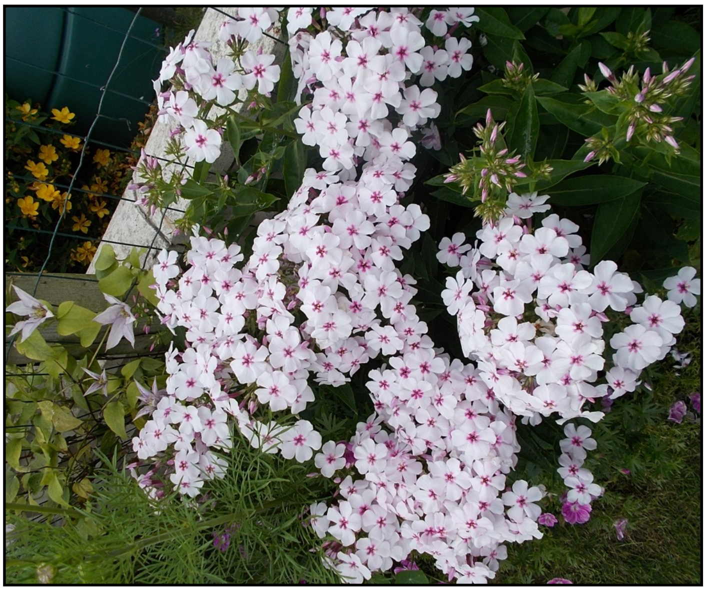
a) Diabetics who take sugar-control drugs (hypoglycemic agents) must take care when they take mustard as the level of blood sugar might become too low.
b) Pregnant women must not take large amounts of mustard as this might result in a miscarriage.

I also have how issues with the packaging. Firstly, there is no obvious warning of the potentially allergic contact without getting a magnifying glass to read the side panel. In the package I recorded there is no batch or sell by date.

Please be aware unless you have the sort of heath condition from which I suffer,
this product and others similar should not cause you any problems.

Garden Watch – Summer

By Carolyn



The truth is there have been some really good results with the Pots and Container gardening and one utter disaster in the garden! The plants have been baked in extreme heat, blown by the winds and nearly drowned in the torrential rain of this year`s Summer. The back border that I worked on so enthusiastically this time is a real disappointment but the better news is that the few perennials added to the border have survived and are becoming stronger and will hopefully cope with the winter and give me a basis for trying to do better next year. The `Phlox Paniculata` has flowered off and on since June, is a complete joy and still has flowers growing.

The Pots and Containers thankfully are a different story, have done very well and are still going strong into September.

The picture on the right is the `Hawkshead White` Fuchsia have grown from tiny plug plants into graceful displays around the garden both in pots and also in the ground.

A really good plant in a container has been the Begonia `Glowing Embers` (below)- a striking plant that seems to withstand all the weather can throw at it and now in September is still in full flower. But the real Begonia `star` in the garden is a trailing one named `Pendula White` (bottom right) is still flowering and which most visitors to the bungalow and also my online gardening club pals have commented on very favourably. Easy to grow it really is one I would recommend. When both begonias finish flowering, I will lift the corms and over winter them in a dry cool place ready to replant them after the frosts are finished next May in the hope, they will both do a good repeat performance.

I planted Nasturtium seeds in the ground in a shady area of the garden and they have simply gone mad, growing huge leaves and providing plenty of colour but I have had a much better effect from those I put in containers and any seeds taken from them will be confined to being grown in containers next year. The `Whirlybird Lemon` (left) is long flowering and a pretty nasturtium, also excellent value with the added bonus that the flowers and leaves can be used in salads.

A plant I really recommend for the small garden or large patio container, is `Parahebe Avalanche` (right) which grows into a small shrub and looks lovely, either growing under taller plants or on its own in a large container. It flowers all summer long, is hardy and a really good plant with pretty flowers which is happy in sunshine or dappled shade and also very easy to take cuttings from.

I have been really pleased with the dwarf Buddleia `Buzz Ivory` (left). I planted last year. It has stayed at 2-3ft and produced pretty `Ivory` flowers which the bees and butterflies love and so do I. It has the added bonus of having lovely scent to it. Another name for buddleia is ‘buffer bush’. In most summers these plants attract numerous butterflies and small insects. However, this year there have not been many butterflies around. Normally, if grown in the garden buddleias grown quite quickly and can easily reach the size of a house. Growing in pots massively reduces this problem.

And finally, to end with here is a picture taken by Leger M.E. member `Sandy` of her `hostas` growing in the front garden of her home in Ohio, USA. (right)

I remember these being planted and how well they have grown! I love the grasses behind them too. Sandy definitely has `green fingers` and we thank her for sharing this photo with Pathways.

Already the fruit trees are beginning to drop their leaves so autumn is just around the corner. Happy gardening!

Recipe Corner *by Carolyn*

Italian chicken with ham, basil and beans

Preparation time: – 10 mins. Cooking time – 1hr 15 mins Serves 4. Nutrition per serving: - 455kcal, 16g fat, saturates 4g, carbs 22g, sugar 10g, salt 1.7g

Cooking Method: -
Season the chicken thighs all over with salt and freshly ground black pepper. Pinch off 8 sprigs from the basil (about 3 leaves each per sprig) and lay one on top of each chicken thigh. Wrap each thigh in a piece of ham, with the ends tucked underneath. Heat the oven to 160C/fan 140C/gas 3. Heat the oil in a large roasting tin over two of the burners on the hob. Add the chicken and fry for about 4 mins or until the ham is just crisped and the chicken is lightly golden. Turn and repeat.

Meanwhile, cut the garlic bulbs in half around the middle and halve the tomatoes if small, quarter them if they are big. Pick the leaves from the rest of the basil. Once the chicken has browned on both sides, add all of the tomatoes, half of the basil and the wine. Season, then cover with foil and leave to cook slowly in the oven for 40 mins. Take out of the oven and turn the heat up to 220C/fan 200C/gas 7. Remove the foil from the pan and stir the beans into the tomatoey juices. Return to the oven, uncovered, for 30 mins until the tomatoes chicken and garlic are starting to crisp around the edges and the chicken is very tender. Just before serving, tear the remaining basil roughly then stir it through or scatter over the pan.

Ingredients:

8 skinless chicken thighs, with the bone in
8 slices prosciutto or other dry-cured ham
2tbsp olive oil
2 whole heads of garlic
800g tomatoes (a mix of smaller yellow and red tomatoes look good)
175ml dry white wine
(the quality of the wine makes a difference in this recipe so make sure you only use one you would be happy to drink)
400g tin cannellini beans or other white beans, rinsed and drained
Good bunch of basil

Vegan Korma Curry

Kcals per serving 506: Makes 4 servings. Preparation Time 30 minutes: Cooking Time 1hr 15mins

Cooking Method: -
Cover the cashew nuts with cold water and leave to soak while you cook the butternut squash.
Bring a pan of salted water to the boil and cook the squash for 15min, or until tender. Drain well and leave to steam dry for a couple of minutes. Whizz in a blender with the drained cashews and plenty of seasoning until smooth.

Heat the oil in a large pan over medium heat and cook the onion for 10 minutes until softened. Add the garlic, ginger, spices and onion seeds and cook for a further 2 minutes. Add the cauliflower and 100ml water, cover with a lid and cook for 5 min.

Stir in the squash sauce, 1 litre water and ½ tbsp fine salt. Bring to the boil and simmer for 25 min, adding the beans and Quorn for the final 10 minutes. Stir in the oat cream and mango chutney and check the seasoning. Sprinkle with extra cashews and serve with brown rice, if you like.

Ingredients:-

150g Cashew nuts, plus extra to serve
700g peeled and diced Butternut Squash
1 tbsp, Vegetable oil
1 Onion, finely chopped
2 Garlic cloves, crushed
5tbsp of a piece of fresh Root Ginger, peeled and finely chopped
1tsp Mild chilli powder
2tsp ground Coriander
4tsp Garam Masala
1tsp Black onion seeds
1Medium Cauliflower, cut into small florets
200g Fine Green Beans, trimmed
280g Quorn vegan pieces
2tbsp. Mango chutney

Chronic Conditions: Endometriosis

Endometriosis is a condition where tissue similar to the lining of the womb starts to grow in other places, such as the ovaries and fallopian tubes. Endometriosis can affect women of any age, but it's most common in women in their 30s and 40s. It's a long-term condition that can have a significant impact on your life, but there are treatments that can help.

Symptoms of endometriosis

The symptoms of endometriosis can vary. Some women are badly affected, while others might not have any noticeable symptoms. The main symptoms of endometriosis are:

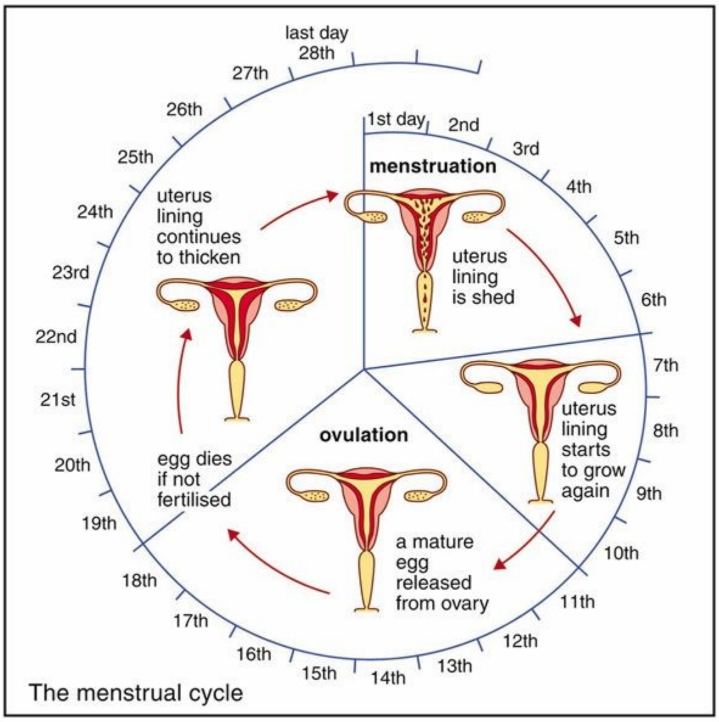
- pain in your lower tummy or back (pelvic pain) – usually worse during your period
- period pain that stops you doing your normal activities
- pain during or after sex
- pain when peeing or pooing during your period
- feeling sick, constipation, diarrhoea, or blood in your pee during your period
- difficulty getting pregnant
- You may also have heavy periods. You might use lots of pads or tampons, or you may bleed through your clothes.

Patients with Endometriosis and ME/CFS or fibromyalgia have trouble in attributing their aches and pains because they are vague and nonspecific. The clue however is elaboration at the time of a period.

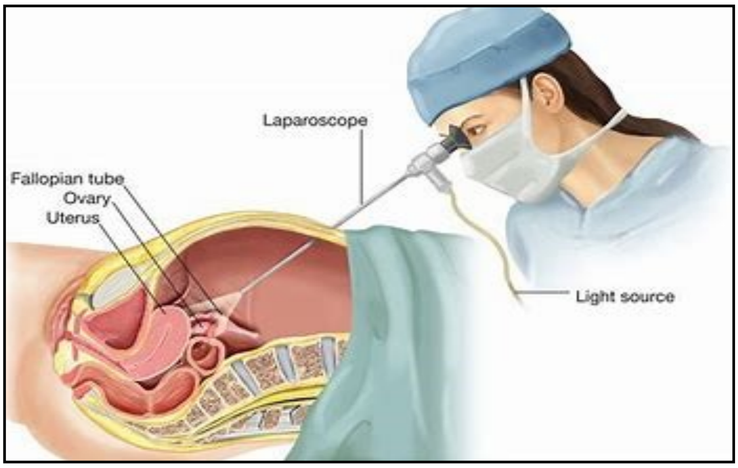
Diagnosis

It can be difficult to diagnose endometriosis because the symptoms can vary considerably, and many other conditions can cause similar symptoms. A GP will ask about your symptoms and may ask to examine your tummy and vagina.

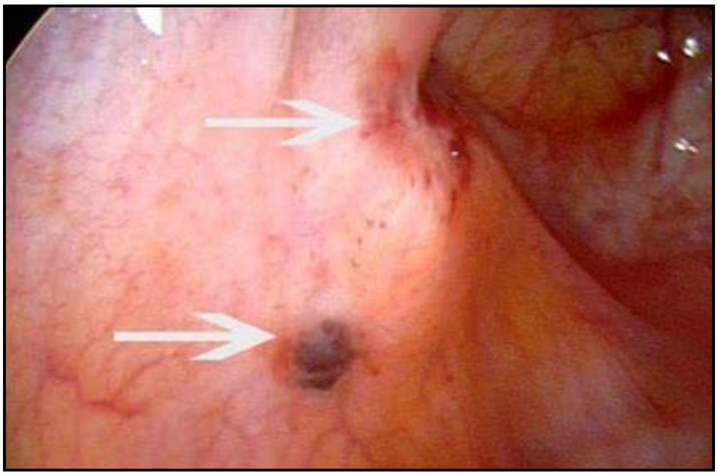
They may recommend treatments if they think you have endometriosis. If these do not help, they might refer you to a specialist called a gynaecologist for some further tests, such as an ultrasound scan or laparoscopy. A laparoscopy is where a surgeon passes a thin tube through a small cut in your tummy so they can see any patches of endometriosis tissue. This is the only way to be certain you have endometriosis.



During the normal menstrual cycle, if the egg is not fertilised the whole uterine lining is shed normally via the vagina. Due to the action of hormones, any extrametrical tissue (uterine lining) that is elsewhere in the body also tries to shed and break down. However is has nowhere to drain and they form large painful cysts.



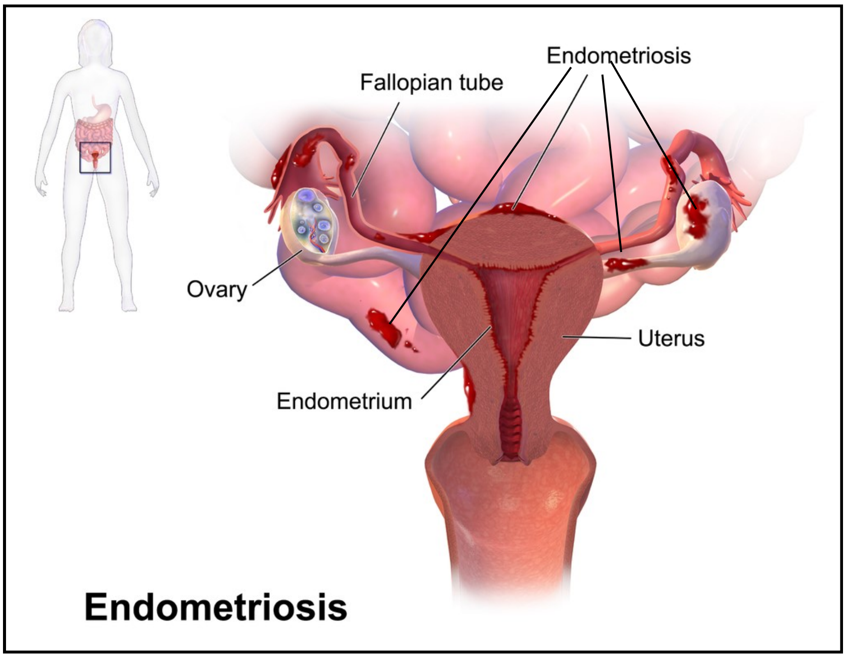
When a doctor carries out a laparoscopic examination, he blows up the pelvic floor area like a balloon. This means that he can inspect the pelvic floor area the for abnormalities. He may see something like the image below. Endometrial lesions are show with the while arrows.



Treatments

There's currently no cure for endometriosis, but there are treatments that can help ease the symptoms. Treatments include:

- painkillers – such as ibuprofen and paracetamol
- hormone medicines and contraceptives – including the combined pill, the contraceptive patch, an intrauterine system (IUS), and medicines called gonadotrophin-releasing hormone (GnRH) analogues
- surgery to cut away patches of endometriosis tissue
- an operation to remove part or all of the organs affected by endometriosis – such as surgery to remove the womb (hysterectomy).



Endometriosis usually affects local pelvic floor organs including the bowel and bladder. However, in rare cases it can affect anywhere in the body. In the more severe cases an affected organ may stick to its neighbour by forming an adhesion.

Your doctor will discuss the options with you. Sometimes they may suggest not starting treatment immediately to see if your symptoms improve on their own.

Complications

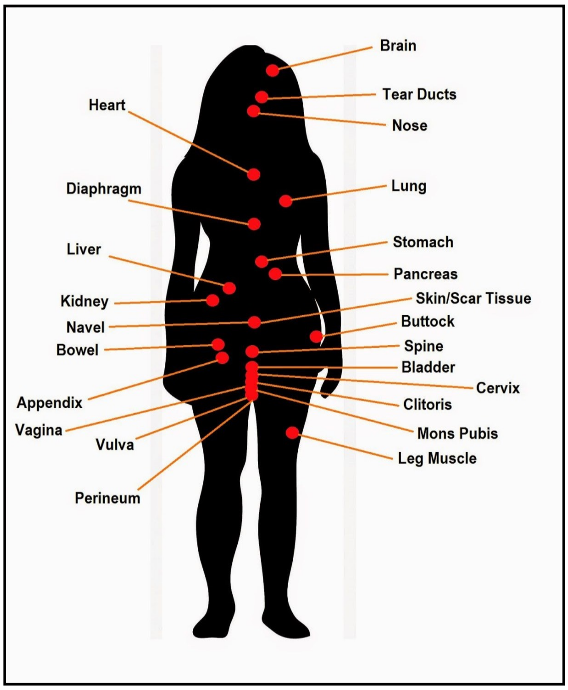
One of the main complications of endometriosis is difficulty getting pregnant or not being able to get pregnant at all (infertility). Surgery to remove endometriosis tissue can help improve your chances of getting pregnant, although there's no guarantee that you'll be able to get pregnant after treatment. Surgery for endometriosis can also sometimes cause further problems, such as infections, bleeding or damage to affected organs.

Causes of endometriosis

The cause of endometriosis is not known. Several theories have been suggested, including:

- genetics – the condition tends to run in families, and affects people of certain ethnic groups more than others
- retrograde menstruation – when some of the womb lining flows up through the fallopian tubes and embeds itself on the organs of the pelvis, rather than leaving the body as a period
- a problem with the immune system, the body's natural defence against illness and infection
- endometrium cells spreading through the body in the bloodstream or lymphatic system, a series of tubes and glands that form part of the immune system

But none of these theories fully explain why endometriosis happens. It's likely the condition is caused by a combination of different factor



Living with endometriosis

Endometriosis can be a difficult condition to deal with, both physically and emotionally. As well as support from your doctor, you may find it helpful to contact a support group, such as Endometriosis UK, for information and advice.

In addition to detailed information about endometriosis, Endometriosis UK has a directory of local support groups, a helpline on 0808 808 2227, and an online community for women affected by the condition.

Brain Fog and ME/CFS

Adapted from Dr Myhills website

What is brain fog?

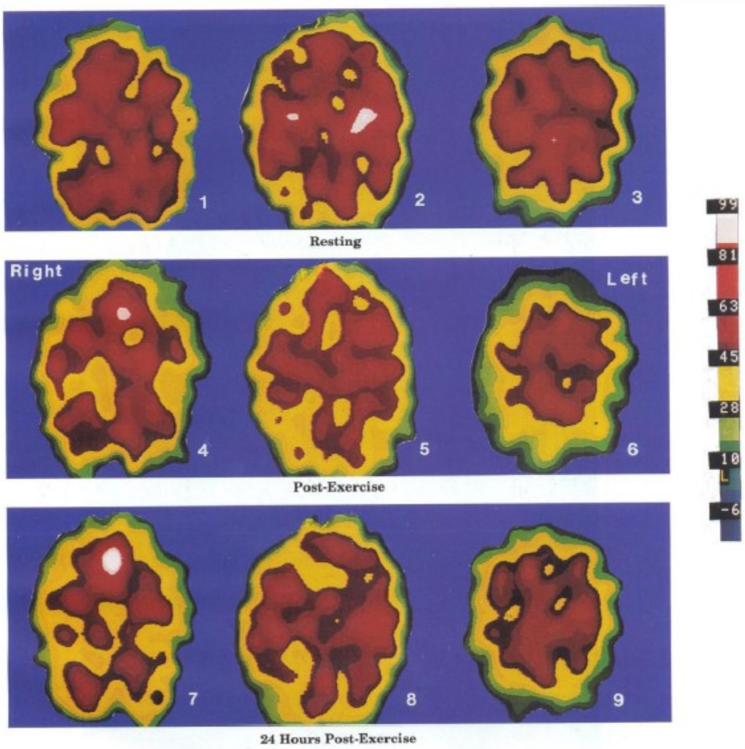
- Poor short-term memory
- Difficulty learning new things
- Poor mental stamina and concentration – there may be difficulty reading a book or following a film story or following a line of argument
- Difficulty finding the right word
- Thinking one word, but saying another

All these are symptoms of ME/CFS and other fatigue syndrome but also include dementia and multiple sclerosis. If you have a diagnosis from an ME/CFS clinic then it's just part of the ME/CFS deal, **BUT** if you suffer from brain fog without a diagnosis you need to be checked out by your doctor.

Good Energy Supply to the Brain

A normal nerve will pass a nerve impulse in 75 microseconds. The slower the time, the more we "lose it". Reaction times are slowed with alcohol. If this interval extends to 140 microseconds, one has dementia; longer than that and we go unconscious - as exemplified by the effects of a general anaesthetic. What allows good energy supply to the brain is a good fuel and oxygen supply good blood supply. So, this means that for normal operation you need: -

- adequate amount of blood
- sufficient blood pressure
- sufficient oxygen
- sufficient fuel (Glucose or blood sugar)
- Good mitochondrial function



So is there any hard evidence of an abnormality. The answer is yes. The image on the right shows SPECT scans, page vii of Dr. Byron Hyde's book 'The Clinical and Scientific Basis of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome.'

These are Xenon SPECT scans of a 37-year-old female M.E./CFS patient and their concept were provided by Dr. Jay Goldstein of Anaheim, California. The technical expertise is that of Dr. Ismael Mena, UCLA Harbor, California.

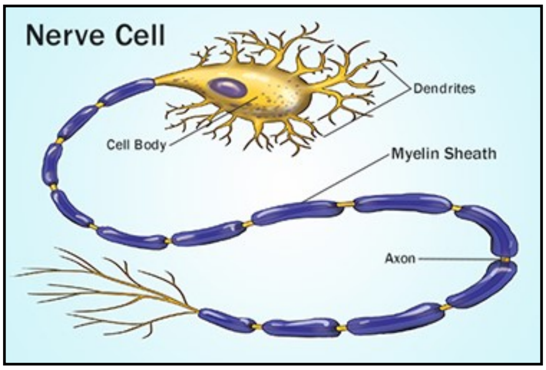
The colours are interpreted as corresponding to glucose metabolism.

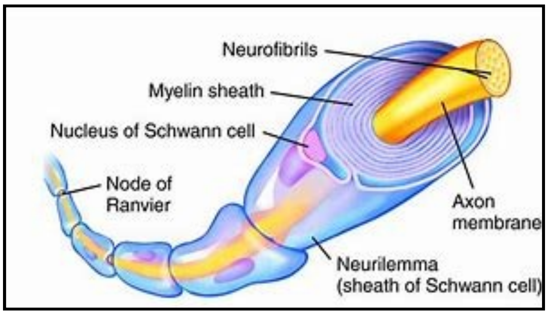
- Images 1, 2 and 3 represent the abnormal resting state of an M.E./CFS brain, with perfusion defect (poor blood flow).
- Images 4, 5 and 6 represent a further decrease in perfusion immediately after exercise.
- Images 7, 8 and 9 illustrate the severely decreased brain perfusion of the same patient 24 hours after physical exercise.

Similar brain perfusion could be produced in an M.E./CFS patient as a result of sleep deprivation, a secondary infectious state, cognitive, sensory or emotional factors. A normal healthy patient will probably exhibit increased brain perfusion after similar modest exercise. Similar results were found in the 1990 in the UK by Dr. Costa.

Myelin sheath function

There is a further interesting peculiarity with respect to the energy supply to the brain which is different from that used by the rest of the body. Although the brain weighs just 2% of total body weight, in use it absorbs 20% of the body's energy requirement. This cannot be explained by the number of mitochondria in the brain (there are not enough), which means there must be another energy-generating source. Brain cells are also very different from normal cells. They have a cell body, and very long tails - or dendrites - which communicate with other cells. Indeed, if a nerve-cell body from the spinal cord that supplied one's toes was sitting on my desk and was the size of a football, the tail would be in New York. These tails (dendrites) are too small to contain mitochondria, but it has been suggested that the energy supply comes directly from the myelin sheaths themselves. They too can produce ATP and it is this that supplies the energy for neurotransmission. Myelin sheaths are made up almost entirely of fats, so we need to look to oils and fats for improved energy supply to brain cells.





Brain fats and oils

Humans evolved on the East Coast of Africa eating a diet rich in sea food. It is suggested that the high levels of oils, particularly DHA (Docosahexaenoic acid), allowed the brain to develop fast, thus allowing humans to outstrip other mammals. So, Homo Sapiens came to have bigger brains allowing intelligence to develop. Here is lots of research showing that essential fatty acids are indeed "essential" for normal brain function; so oils that would be helpful in addition to coconut oil would be omega 3 (fish), omega 6 (evening primrose) and omega 9 (olive), together with lecithin (which is phosphatidylcholine – i.e. the main component of all cell membranes. Throughout life, the brain creates a million new connections every second. This means there is huge potential for healing and repair; it is simply a case of moving things in the right direction. But the brain has to have the optimum energy supply to allow this process to happen.

Research done by Professor Caroline Pond at Oxford has shown that the immune system, like the brain, is also fat loving. Wild animals, if they have a food glut, will first deposit fat around lymph nodes where energy is needed for immune activity. This may explain why people who are apple-shaped are more prone to heart disease compared with those who are pear-shaped. Fat deposited around the gut indicates inflammation there (possibly allergy or fermenting gut) and inflammation results in arterial damage.

CFS, alcohol and foggy brains

Alcohol intolerance is almost universal in CFS. This has always puzzled me. It could be partly explained by poor detox, but clinically there seems to be some direct effect on the brain, like a hypersensitivity. The above explains all. Alcohol readily dissolves fats and would be excellent at changing the consistency of the myelin sheath cell membranes. It works just like a general anaesthetic – and, indeed, many CFSs are intolerant of anaesthetics. My guess is that the more fat-dissolving a chemical, the greater its ability to produce foggy brain in CFS. This could also apply to a range of prescription medication. This knowledge is very useful clinically. Those people who are intolerant of alcohol need brain fats and oils as above. Indeed, as we age, intolerance increases - indicating our greater need for the correct fats and oils as we become metabolically less efficient with the passage of time.

Treatment of the foggy brain

The general approach to maintaining and restoring good health. It would be worth checking out products like VegEPA, and omega 3,6,9, supplements as they have a reputation for helping with brain. Vitamin B12 sometimes helps but is not available on the NHS. Dr. Myhill has her own way of dealing with brain fog, and I would recommend checking her website out

https://drmyhill.co.uk/wiki/Brain_fog_-_poor_memory,_difficulty_thinking_clearly_etc

North of Doncaster *Personal comment by Trevor Wainwright*

It was 2017, I was at an open microphone in Leeds and decided to read “Along the Texas Coastline”, as it depicted being somewhere over a period of time, I described it as a Walkin’ in Memphis type poem but not Walkin’ in Barnsley. I read the poem to great applause and a few days later was doing some ironing when I thought, ‘why shouldn’t there be and so things took shape. After all, since hearing Walkin’ in Memphis I had wanted to write something similar and now was my chance. The opening and chorus soon took shape but who would take the place of WC Handy?, Dickie Bird was ideal. Initially the ghost of Elvis was to be that of Brian Glover with the words:

He being the bloke, That wrote the documentary. That living in Barnsley was no joke!

I heard about a mining disaster in 1866, and did some research. Straight away I had my ghosts, black pudding and pork pies would take the place of catfish, Muriel would be replaced by Barnsley FC “The Tykes”, it was all taking shape a chair would replace a prayer.

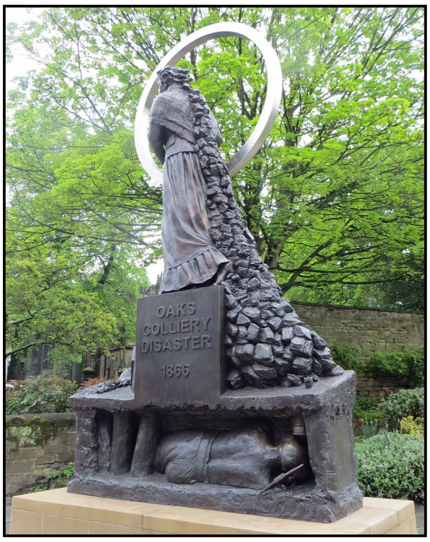
In a short while it was done, the next thing was to go to Barnsley and do the walk, taking pictures to go with it. My wife took the one of me in my flat cap. I took the rest myself, going to all the places that would feature.

The first ever reading in my Yorkshire accent went down well, to rapturous applause, particularly when I put my flat cap on before reciting, later I would change the 4th line of the chorus from “Do I really feel the way I feel” to “Lookin’ for summat for my next meal”.

In 2018 I would decide to add an introductory verse incorporating how I first heard Marc Cohn talking about and singing ‘Walkin’ in Memphis’ but would not mention it, leaving it apparent when I began the main body of the poem. It worked! The reaction from the audience; the realisation from where it had come dawned. It would go down well at many open mics and at a performance for the Ilkley Literature Festival Open Mic 2018 which got meHighly Commended, an improvement from finishing nowhere the previous time I entered.

The Oaks Colliery Explosions

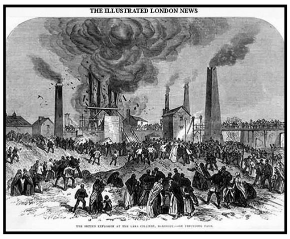
A series of explosions occurred at the Oaks Colliery, near Hoyle Mill Barnsley on the 12th December 1866. Altogether 361 miners and rescuers were killed. The disaster happened when a series of explosions caused by firedamp (methane) ripped through the workings. It is the worst mining accident in England and the second worst mining disaster in England.



Walkin I’ Barnsley

It was 1994 I was stuck in a traffic jam on the A64
Radio playin’ an’ a guy talkin’ about the time he was walkin’
Wearin’ blue suede shoes through a town in the land of the Delta Blues
Its lyrics such a wonderful rhyme, it became my favourite song of all time
Little did I know what the future would bring

23 years later I would write similar about walkin’
Through a town in a land where coal was once King
When I put on me owd flat cap an’ boarded the train
Got off on Barnsley Station in the shadow of Barnsley Main
Dickie Birds statue lifted my gloom
With a smile and his up raised finger, thinking of him sending



Another Lancashire batsman back to the changing room
Then I’m walkin’ i’ Barnsley. Lookin’ to buy some tripe an’ cow heel
Walkin’ i’ Barnsley Lookin’ for summat for me next meal
Saw the ghosts of 384 miners walking through the town
Followed them up to the site of Oaks Colliery
An’ I watched them all go down

As I remembered what happened a disaster so long ago
They blamed it on firedamp, but will we ever really know
Then I was Walkin’ i’ Barnsley lookin’ to buy some tripe an’ cow heel
Walkin’ i’ Barnsley. lookin’ for summat for me next meal
They got black pudding on the table pork pies all golden brown

An’ folk’ll say “come in lad sit thi down
don’t worry about a chair cos’ they’ll get thi a chair i’ Barnsley”
Now the Tykes play at Oakwell on a Saturday afternoon
An’ dads took their kids to see ‘em to cheer ‘em on
An’ cos’ at the time they were doin’ alreet

I was asked “would you like to be a fan?” so I said, maybe I will one neet
An I’m Walkin’ i’ Barnsley lookin’ to buy some tripe an’ cow heel
Walkin’ i’ Barnsley lookin’ for summat for me next meal
Put on me owd flat cap an’ boarded the train
Got off on Barnsley Station in the shadow of Barnsley Main

Got off on Barnsley Station in the shadow of Barnsley......Main

There is a copy of the poem and more photos depicting each part of it on my Facebook page, in the album section Walkin’ i’ Barnsley.

One thing more I saw Dickie Bird in a restaurant in Wakefield quickly scribbled the poem on a serviette, gave it to him, he read it and said: “It’s good is that lad”, “thanks” I said “You’re welcome and came away. Later I realised I could have said “Show it to Geoff Boycott and say, ey up Boyks
I bet thy hasn’t got one o’ these written about thi”.
He may have said “Aye lad I will”.

Right—Barnsley town hall is a prominent local landmark which can be seen from many miles away.