

# 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. 42.

As this issue is due just before Christmas, we've included some special Christmas features. Firstly we have some simple recipes from Carolyn followed by the seasonal issues about Christmas fairy lights. For our young-at-heart members we've included a feature reviewing the NORAD website. Last Christmas I watched a picture of Santa on his annual worldwide trip delivering presents. As a Pathways exclusive, we've included some secret pictures which our younger members should find of extreme interest. We then have a feature of historical interest about Christmas trees and on the final pages we include some Christmas humour.

For 'Out and About' in this issue have an article about the Elsecar Heritage Centre, which includes the Elsecar Heritage Railway. There are many time out venues locally, but because they are 'just down the road' we end not using them. This Elsecar Heritage Centre is open all the year round, and if you have a spare afternoon it's well worth a visit. I've visited this venue many times over the years, and I find something different every time!

There is some long overdue news from the ME Association and the Medical Research Council: The ME Association is funding Professor Anne Mc Ardle from the University of Liverpool to conduct research into assessment of mitochondrial dysfunction in ME/CFS in muscle. There has been plenty of fragmented research on this topic over the years. Currently a test is available within the private sector, which relates a mitochondrial function score to observed fatigue in a subset of white blood cells. It will be interesting to see what the outcome of this new research is, but this will take some time. There is usually a ten-year lead time before research findings find their way to something useable. I think that mitochondrial disease will feature more prominently in the future.

We've got a feature on the usual issues of welfare and working-age benefits based on information from Work and Benefits. Most worrying of all is David Cameron's remark. Health-wise we've included a feature updating irritable bowel syndrome, a problem experienced by many members. There are some newer medicines available for IBS, so it may be well worth a review. It is well known that vitamin D levels drop in winter—due to reduced exposure to sunlight. Many members report that their aches and pains get worse in winter. Some group members who have had their vitamin D levels checked by their doctors and been prescribed a vitamin D supplement report that, once they start to take the supplement, their pain level drops significantly. Maybe there is something in that; so we've also included factsheet from the British Dietetic Association about Vitamin D.

2015 is a general election year. Whoever ends up in power will have to re-balance the country's books. That implies more public service cuts and higher taxes irrespective of whatever the politicians say or would like us to think. One major issue next year is that the transfer of DLA to PIP will begin. I foresee many of our members being affected and possibly losing out financially. With our current experience of PIP, we think that it is possible for many members to be transferred from DLA without financial loss. However as the nature of the assessment process has changed it is more important than ever that the right sort of information is given to the DWP. If your DLA is due for renewal next year or you have had an indefinite award for more than five years, you need to be taking action now, as you are most likely to be targeted. Starting in January, we will be contacting members who we anticipate will have problems, and inviting them for an early case review to check everything is in place. Because of extra costs incurred this year, we have no choice but to limit this service to members only; so please remember this when your membership is due in the New Year.



## You Write

**Sandy writes:** I want to wean myself off the Neurontin which I take for trigeminal neuralgia. It grogs me out too much so that I cannot always get up to take care of Aly and get very much done during the day. I am on 300 mg x 6 per day. How should I do this? In other words how do reduce the dosage over how many days.

*The medicine belongs to a group of drugs known as neuroleptics. Other variations are Gabapentin, Pregabalin and Lyrica, and are in the same class a carbamazepine and sodium valproate. Basically they work by depressing nerve function. While this is desirable for neuropathic pain and neurological conditions like certain types of epilepsy, they are unselective and cause depression of other neurological functions—hence this explains the sedation you are experiencing which is additive to the fatigue from which you suffer and many other side effects. The biggest complaint I see with this type of medicine is weight-gain. These types of medicine are so strong that one member reported that he could not feel himself being pricked by a pin. Strangely enough, your letter coincided with a feature in 'Perspectives'. This feature reports that in an ME Association survey 29% of people were made worse; in 23% the drug was ineffective while the remainder reported a variable outcome. This medicine is also reported as being the best of it class with respect to ME/CFS by MEA members*

*Neurontin is not a disease-cure or disease-modification medicine. It is used in your case for symptom control. So, it is not going to make a lot of difference if you don't take it—apart from the pain associated will come back because there is nothing to mask it. In fact, for a while it could come back with a vengeance if abruptly stopped. This medicine is made in in the following strengths 100mg, 300mg, 400mg, 600mg and 800mg as well a liquid formulation. It may be possible that a small dosage reduction could reduce side effects to a tolerable level. The dose you take is about halfway through the usual dose range—so there is plenty of scope for you and your doctor to adjust the dosage to find the best level. Effectively you take 600mg three times a day. You could step down to 400mg and see how things go. The process of dosage adjustments and seeing what happens is known as titration—and is the usual way to determine the most appropriate dose for other similar medicines.*

**Gwegnie writes:** When I last contacted you my doctor had started me on a medicine called Metformin for my diabetes. I had tummy problems with taking the tablets and you suggested looking at taking it with food or asking my doctor for it as a powder in sachet form that dissolves in water. Unfortunately the sachets are no longer available. However, I've managed to get the dose up to one tablet in a morning. However I had to start with cutting the tablets up into an eighth or a quarter, getting used to that and then working the dose up to one every morning. Also the other thing—can I get (from my doctor) any testing gadget to check my blood sugar to give me an idea what's happening?

*Well, last first. The test strips are very expensive. You could purchase them form the pharmacy if they were important to you. If you are taking only metformin, they are not considered essential. If you were on insulin or taking a medicine like glicazide there would be problem as both these medicines can cause hypoglycaemia which is dangerous and life threatening if blood sugars are not kept under tight control. Although test strips were considered essential with insulin treatment, it is only just recently that it has been found out that glicazide like medicines can cause similar problems to insulin. In fact, according to new EEC regulations, you should test your blood sugar levels before driving—that's possibly been the driving force behind agreeing test strips. It is widely assumed that metformin alone does not produce hypos. I completely disagree with this, because many people with ME/CFS get hypos without being diabetics. In any case with diabetes how can you balance your foods, activity and medicines to keep your blood sugar within tight limits without being able to measure it? Without doing you own tests how can you be sure you are getting it right or wrong. It's like driving a car around Doncaster without a speedometer. I gather that the NHS are unaspiringly on an economy drive and are going to limit the types of test strip available to the most economic brand. By the way, well done for persisting with the metformin. I thing think it always needs to be taken with food. The stale fish taste can be disguised with milk. This may be important because over time that medicine will need to be increased. Having any sort of diabetes is bad enough, be when you have ME it just makes life more complicated,*

## ***Welfare Rights Matters: ESA & PIP are now linked.***

*As many Leger ME members have been told on many on many occasions ESA & PIP are linked. Now it's confirmed. I've received the following email, from Steve Donnison at Benefits & Work.*

Employment and Support Allowance (ESA) medicals and Work Capability Assessments (WCAs) are being used to make decisions about eligibility for Personal Independence Payment (PIP) a Government Minister has confirmed. Benefits and Work also has evidence that the reverse is true: existing ESA awards are being looked at again and changed on the basis of a PIP medical report. What's more, in an effort to reduce the PIP backlog, many thousands of decisions are being made by temporarily promoted DWP staff who aren't really decision makers at all.

So, it's probably never been more important to ensure that you give the most detailed and accurate information you can, backed up with supporting evidence if possible, when you are applying for either ESA or PIP. Indeed, what you include on your claim forms can not only influence whether you get an award, it can also decide whether you have to endure a face-to-face medical assessment.

Mark Harper, Minister for Disabled People, told MPs

*"... we take the ESA85—the report from the work capability assessment—and put it with their PIP form and any other evidence they have provided. That is enabling us to make more decisions based on the paperwork without needing to call people in for assessments."*

And it's not just for PIP that detailed evidence can help avoid a medical assessment.

The recent independent review of the WCA has confirmed not only that regulation 35 (2)(b) is now the most common reason for claimants getting into the support group, but also that two thirds do so without having a face-to-face medical. Regulation 35 (2)(b) is a 'safety net' regulation. It allows entry to the support group for people who aren't covered by the relevant descriptors, but where there would be a substantial risk to their health or someone else's if they were not put in the support group. There are no questions on this regulation in the ESA50 claim form, but there's more information about it, and how to give evidence, in our guides.

Still with the WCA, you won't see it trumpeted in the pages of the tabloids, but recent figures show that in 2013 only 7% of Incapacity benefit (IB) to Employment and Support Allowance claimants were found capable of work. A staggering 59% were placed in the support group. The figures raise a huge question mark over what the transfer process has achieved, other than causing enormous hardship, distress and, in some cases, the death of claimants. Actually, one thing the IB to ESA transfer process did achieve was to cause a massive backlog in the whole ESA assessment process. A Minister has confirmed that there are now more than half a million ESA claimants trapped in the assessment phase, many of whom should be in the support group.

And whilst the DWP are now placing their hopes of getting back on top of assessments with Maximus, the American company due to take over from ATOS next year, there is no prospect whatsoever of improvements being made to the WCA itself. The fifth and final review of the WCA has cast doubts on its suitability, but recommended that it should have a period of stability before being completely replaced sometime around 2020. And finally, there's the grim news that, according to the very reputable and entirely non-radical charity Contact A Family, more and more families with a disabled child are being forced to choose between heating and eating because of cuts in their benefits.

So, although David Cameron recently told Ed Miliband in an exchange in the Commons:

*"I don't need lectures from anyone about looking after disabled people. I don't want to hear any more of that."*

The truth is that, regardless of his own personal tragedy, Cameron needs to hear an awful lot 'more of that' from as many people as possible.

**Karen Writes:** I've just started receiving some strange telephone calls again. A couple of weeks ago I have a telephone call out of the blue asking if someone has had an accident recently. The answer was 'no' – and then the line went dead. Since then I have had a number of telephone calls where no one answers when the phone is picked up. On the number calling display all that shows up is 'Withheld', 'Unregistered', 'International' or 'Unavailable'. I'm registered with the telephone preference service yet these calls are still happening, I've tried ringing the callers back and all I get is an 'unobtainable' sound. Any ideas as to what I can do to stop it?

*As you are registered with the telephone preference service, these types of offensive calls are against the law. However since they originate out of the country, it is difficult for the UK authorities to stop them. We often get calls which are unwanted on the group helpline. Anyone who doesn't release their number and display is left to the answering machine. If we do answer the phone the first thing is to give out your number and ask who they are calling and what is it about. If they don't do that I always put the phone down. Until is clear who is calling you don't give out your address or any other personal details. The telephone preference service only works on about half of the unwanted calls.*

*A few months ago I was talking to a NHS security consultant. They reckon that the source of many of these calls is Nigeria or some other West African country. There is a black market in phone numbers that are sold and traded illegally amongst fraudsters. The quickest way to deal with such calls is via an answering machine or answering service. The scammer's just flag up that number 'a dead number -avoid it' and let their friends know it's a 'dead' number. On our phone system we have caller display on our phones, which when a known number rings us .e.g. a group know member we get a difference ringtone. At that point we are aware who is calling, and if we choose to answer the phone at least we are prepared for the sort of call to expect.*

*There is a specialised answering machine called 'Truecall' for dealing with landlines called which automatically asks the caller to state their name. It then puts the caller on hold and rings the telephone and gives you a choice of accepting, declining or sending the calls to the answering machine. We have one of these in the office—but at present it remains packed up in its box. The same applies to a device that could record conversations. Telephone service providers can provide extra services like premium number (09), barring and anonymous caller barring. The problems are that the police, hospitals and some doctors' surgeries don't usually release their number; it may bar some genuine or urgent calls. Overall I think that an answering machine is the best option.*

*Just a word of warning, **never ever give a bank account or PIN number out over the phone.** Don't use a debit card over the phone as it gives direct access to your bank account. Using credit a card is safer as the credit card company has certain legal guarantees and obligations to fulfil.*

**Ross Writes:** Here are a couple of poems one from twitter another from George Orwell—all connected to DWP PIP sites. This refers to power companies trying to rip people off (presumably like ATOS).

"Power is not a means, it is an end;  
the object of persecution is persecution.  
The object of torture is torture.  
The object of power is power."

~ George Orwell - 1984.



*I find the ATOS Silent Night disturbing. It reminds me of the sort of horror of World War I, which we have been reminded about quite heavily this year. This form of poetry must give the author some form of satisfaction and I often think it is a safety valve. Our concern is that Leger ME's members' experience tends to support this point and what has been reported in the national press fully reflects the experience of many Leger ME members. See the following pages.*



## Other DWP Benefits News

Although the Chancellor of the Exchequer has not made any comment in his Autumn Statement about welfare rights forms, there is doubt that the economic deficit is behind target and further cuts and savings will be sought, possibly after the election, irrespective of whichever party gets into power. However it is quite clear that in the back room somewhere there are stealth strategies to save money. At the time of writing there are a couple of worrying topics that have turned up

Firstly over half a million people are trapped in the assessment phase of employment and support allowance (ESA) whilst waiting for a work capability assessment (WCA) and hundreds of thousands more are dealing with the uncertainty of not knowing when their next assessment will be, a Minister has confirmed and secondly untrained staff are being drafted in for PIP decision making. The quality of decision making for personal independence payment (PIP), is being called into question following the revelation that hundreds of staff without the proper experience and training are being temporarily promoted to the rank of PIP decision maker.

The situation is outrageous. We are hearing reports that benefit changes are killing the vulnerable, say campaigners. For example one case hit the national news. Recently the sister of a mentally ill man who starved to death in David Cameron's constituency after his benefits were wrongly cut has accused the Government of "killing the very vulnerable", as official figures emerged suggesting dozens of people could have died in similar circumstances. Heat or eat is becoming a choice for families with disabled children, Soaring numbers of such families are being forced to go without food or heating because they can no longer afford the basics, a major study shows.

We are also hearing rumours of a proposal to reduce the Limited Capability of Work component to the same as Jobseekers Allowance which, if carried through, would mean a cut of £25 a week for those receiving this benefit.

### More positive news.

**Regulation 35 (2)(b) is now the main route into ESA support group.** Although there are no questions about it in the ESA50 questionnaire, a recent report has revealed that regulation 35 (2)(b) is now the most common reason for claimants getting into the support group of employment and support allowance (ESA). There is no direct question relating to this:

*A claimant who does not have limited capability for work-related activity as determined in accordance with regulation 34(1) is to be treated as having limited capability for work-related activity if—*  
*(a) the claimant suffers from some specific disease or bodily or mental disablement; and*  
*(b) by reasons of such disease or disablement, there would be a substantial risk to the mental or physical health ..etc.*

**Only 7% of IB to ESA transfers were found fit for work.** Statistics released today by the DWP show that only 7% of incapacity benefit to employment and support allowance (ESA) claimants were found capable of work in 2013, with almost 60% being placed in the support group.

**Please member that all paid up leger ME members are entitled as part of their membership to receive the Benefit & Work Guide. Please ring 01302 787353 or email [mike@danum.leger.me.uk](mailto:mike@danum.leger.me.uk). Please remember if you are filling in a DWP or other form that the biggest cause of benefit refusal are do it yourself from fill outs. Use welfare rights advisors or an organisation like us.**

**Benefits and Work**  
 Guides you can trust



**Christmas Recipe Corner** by Carolyn**Mini Mince Pies with Lemon Icing**

**Method:** For the pastry:- Place the flour, butter, ground almonds, icing sugar and egg in a food processor and whizz until the mixture forms a ball. Turn out onto a lightly floured surface and knead very gently. Wrap in cling film and chill in the fridge for 30 minutes.

**Ingredients:-**

200g plain white flour, sifted  
100g cold butter, cubed  
25g ground almonds  
1 egg, beaten  
410g jar mincemeat  
50g icing sugar

For the icing:-  
8 tbsp icing sugar  
1 lemon, zest and juice

Preheat the oven to 200C, gas mark 6. Roll out the pastry on a lightly floured surface to the thickness of a £1 coin.

Using a 6cm pastry cutter, cut out 36 rounds and line 3 x 12-hole mini bun or muffin tins. Fill each case with mincemeat. Bake the pies for 10-12 minutes, or until the pastry is just beginning to brown around the edges. Cool for 5 minutes, then transfer to a wire rack and allow to cool completely.

Mix the icing sugar with just enough lemon juice to make a smooth but thick paste. Cover each mince pie with icing and top with a little lemon zest. (If packing into boxes, allow to set first. The pies will keep for up to a week in an airtight container)

**Left-over Christmas Pudding Trifle**

Use leftover Christmas pudding to rustle up this speedy and sumptuously creamy trifle with Grand Marnier-steeped oranges. The preparation time is 15 minutes, no cooking is required, and it serves six. To serve add a handful of grated laked almonds or toasted dark chocolate.

**Method:** Peel the oranges using a sharp knife, ensuring all the pith is removed. Slice as thinly as possible and arrange over a dinner plate. Sprinkle with the demerara sugar followed by the Grand Marnier and set aside.

Crumble the Christmas pudding into large pieces and scatter over the bottom of a trifle bowl. Lift the oranges onto the pudding in a layer and pour over any juices.

Beat the mascarpone until smooth, and then stir in the custard. Spoon the mixture over the top of the oranges.

Lightly whip the cream and spoon over the custard. Sprinkle with the flaked almonds and grated chocolate. You can make this a day in advance if you like, chill until ready to serve.  
Note: - You could use clementines instead of oranges





## Being Safe with Christmas Tree Lights

Going back to schooldays, there are two way of connecting up light bulbs. The first is known as a series circuit which is a bit like daisy chaining. The mains voltage is shared

between all the lights in the circuit. In this sort of arrangement all the bulbs are low voltage. For example in a chain of 24 bulbs each one would be rated at 10 volts. The catch with this type of circuit is that if one bulb fails all the lights go out. These sets are usually supplied with a spare bulb, and

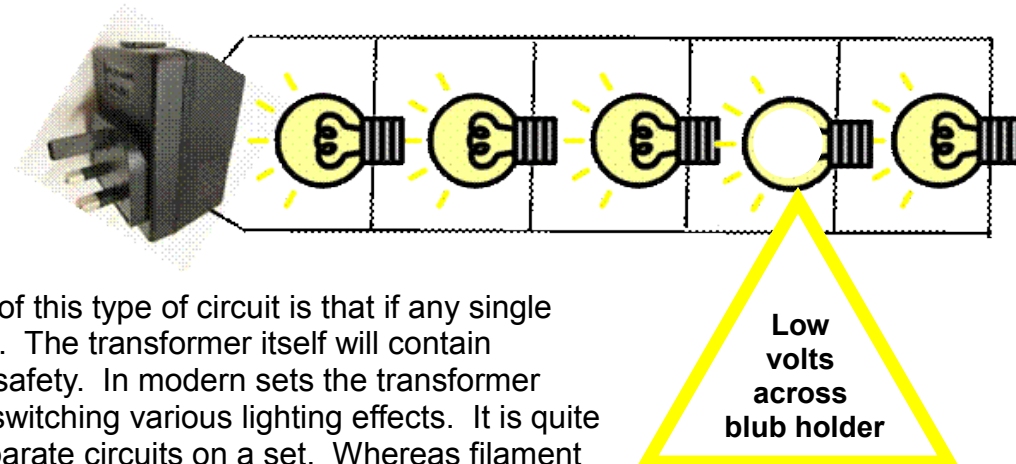
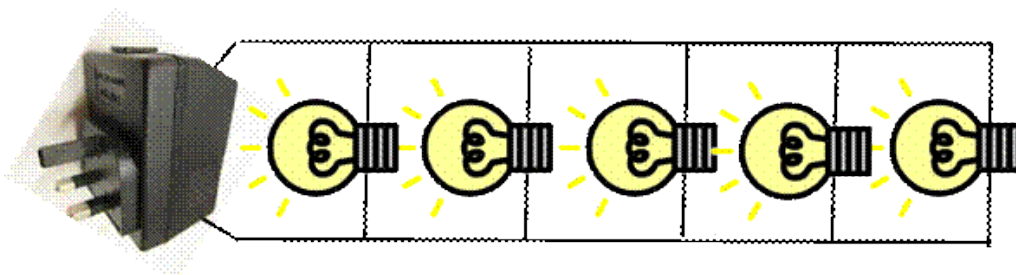
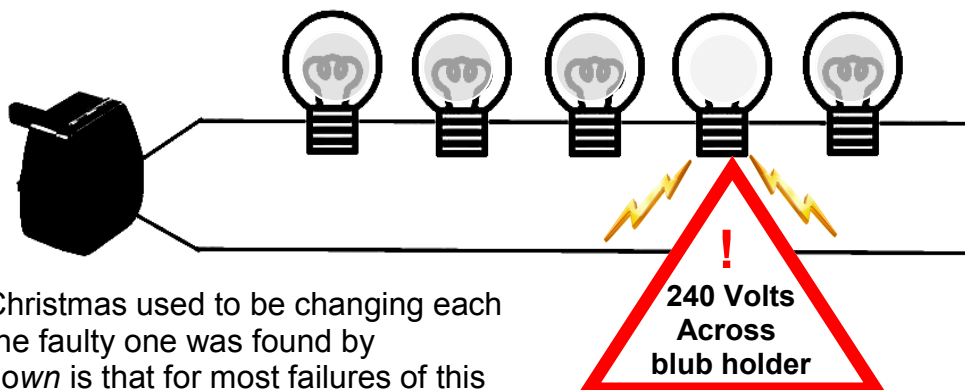
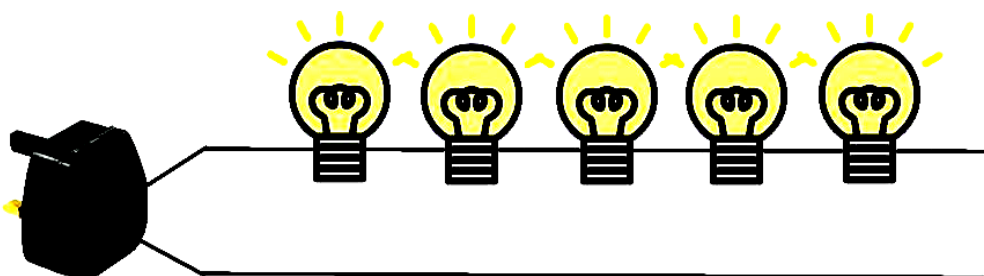
one of the most laborious jobs at Christmas used to be changing each individual bulb one at a time until the faulty one was found by elimination. What is not so well known is that for most failures of this sort of circuit, the full mains voltage can appear across the socket

connections. This type of circuit is used mainly on old sets although this year I've seen sets like this on sale in the shops. There is usually a fuse bulb included for safety -it's always best to switch off first.

There are gadgets available in the shops for checking things like light bulbs and other electrical items. These are usually worth their weight in gold in terms of time saved.

The second method of connecting lights is known as a parallel connection. Here the bulbs are wired on what could be thought of as runs on a ladder. For domestic lights these are usually connected the mains via a step transformer to anything between 3 and 12 volts which

is far far safer. The advantage of this type of circuit is that if any single bulb fails, the rest will remain lit. The transformer itself will contain several internal fuses for extra safety. In modern sets the transformer also contains a control unit for switching various lighting effects. It is quite common for there to be 2-4 separate circuits on a set. Whereas filament bulbs are mandatory for series sets, parallel sets can use filament lamps for the more modern semiconductor LEDs (light emitting diodes) which are more reliable and cheaper to run but slightly more expensive to buy.



*An example of LED lamps. available in many colours shapes and sizes, the light emitting from a silicon chip which is far more efficient and wastes less electricity as heat..*



*A filament lamp available in many colours shapes and sides. The light emitting part is the filament at the top of the bulb which often breaks causing failure.*

## More on Christmas Lights Safety

Around early December is when Christmas decorations and lights are retrieved from storage areas that can be dusty and damp. Damaged fairy lights can cause fires and electric shock but there are some simple precautions you can take to check they are safe to use.

- Check if lights are damaged or broken before using and look out for loose wires.
- Only use replacement lamps of the same type and rating as those originally supplied and replace them immediately, to prevent overheating.
- Don't use lights outdoors unless they are specifically designed for such use and don't connect different lighting sets together.
- Use an RCD-protected socket for outdoor lights (an RCD or residual current device cuts off the electric current as soon as a fault is detected).
- Try LED lights instead of traditional ones - they're more energy efficient and reduce the risk of electric shock. Try to get Christmas lights with an extra-low voltage transformer.

Please remember to switch off the lights when you're not around to enjoy them. Visits from family and friends tend to multiply around Christmas - along with the cooking! But while the kitchen may be the heart of the home, half of all house fires start there. Fires can be caused by the build-up of fat on electric cookers, air vents being blocked by objects left on top of microwaves, or by dirt, dust and crumbs blocking ventilation and causing products to overheat. For extra safety use a smoke alarm.

One of the nicest things about the festive season is in the giving and receiving of gifts. Increasingly, these are likely to be various electric gadgets. But with a proliferation of these items comes the need to charge them - and finding an available socket or extension lead. Many people don't realise that overloading sockets can lead to fire and that different types of electrical products use different amounts of power. The marking on an extension lead will tell you:

- Its 'rating' - usually 13A but sometimes it's only 10A.
- Never plug so many items into the lead that you overload its rating and never 'daisy chain' extension leads together.

Use multi-way bar extension leads rather than block adaptors and *Electrical Safety First* have developed an online tool to help you avoid socket overload. It's easy to forget trailing leads can be dangerous, particularly for older people. Make sure that leads are out of the way, so they can't cause accidents. Remembering these things - and treating electricity with respect - will help ensure you can have a very merry Christmas, safely, in your home.

## Where to get further help

*Electrical Safety First* has created an app for smart phones, which helps you undertake a basic electrical check of your home. If you would like to download the app, use the online socket calculator, or obtain printed guides for using Christmas lights and for further information on electrical safety, visit:

### Pearls Corner: Christmas Greetings'

Bring out the tinsel and the bedraggled Christmas tree,  
Tis the season to be merry; Tra la la, he he he,  
Set a feast for who's eyes?  
My friends have gone like the year's mince pies.

If you can't be life and soul,  
You may as well dig a hole,  
They don't understand why she can't she  
Just be like she used to be?

Always up for it, last to go; Full of fire, put on a spread,  
She's always tired or in bed.  
Best forget her they moan,  
So they are gone, I am alone,

But there's one who doesn't go,  
Here forever full of evil glee,  
My best wishes to all I express  
You in my heart; all who have CFS.





## **Research News from the ME Association and Medical Research Council:**

*Professor Anne McArdle, University of Liverpool – assessment of mitochondrial dysfunction in ME/CFS University of Liverpool press release:*

Scientists at the University of Liverpool are the first to use a new laboratory technique that could reveal the causes of Chronic Fatigue Syndrome (CFS).

CFS is a severely debilitating illness, characterised by prolonged fatigue that can be triggered by minimal activity. Fatigue is accompanied by symptoms that may include painful muscles and joints, disordered sleep patterns, gastric problems and cognitive impairment.

The causes of the condition are unknown, but some studies have suggested that a defect in the energy producing components of muscle cells, called mitochondria, could be responsible. Other studies, however, have not been able to demonstrate this defect. It is thought that limitations in the methods used to determine mitochondrial function in human muscle fibres could be the reason why the causes of CFS have been difficult to explore.

Scientists at Liverpool are the first to implement a newly developed technique that is more sensitive to identifying mitochondrial function within the muscle's fibres. Researchers anticipate that these new methods will demonstrate whether skeletal muscle mitochondria in patients with CFS are dysfunctional, which would result in muscle fatigue and further complications lead to chronic inflammation and pain.

Professor Anne McArdle, from the University's Institute of Ageing and Chronic Disease, said: "The mechanisms that lead to debilitating muscle fatigue and pain in CFS patients are unknown. The time required for diagnosis further complicates the identification of the factors responsible for triggering the illness. Reversal of the severe fatigue that follows remains the most promising form of treatment.

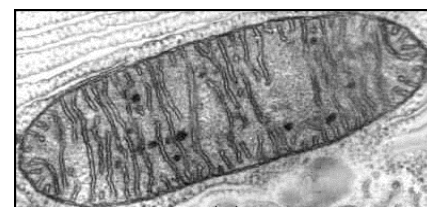
"Scientists have hypothesised that mitochondria malfunction, significantly reducing the energy supply to the muscle cells that allow the body to carry out its daily activities.

The pain and inflammation that follows can cause further mitochondrial abnormalities and so the vicious cycle of events continues.

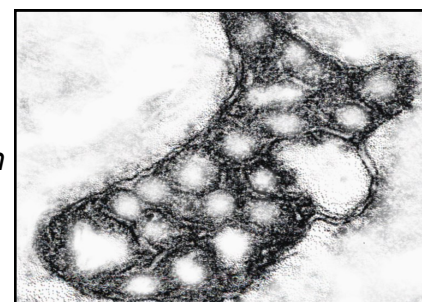
"At Liverpool we have established newly developed techniques in the laboratory that can identify dysfunction as it occurs in the muscle cells. It is at this point we can look at interventions to reverse or halt further damage."

The ME Association is funding: £30,000 towards this project.

*Comment: NOT BEFORE TIME! Dr Sarah Myhill and her colleagues have been working in this area for many years. They have published several papers the first of which related the observed fatigue to a mitochondrial function test in 2009 and a second which related a number of mitochondrial abnormalities to observed mitochondrial function test in 2012. This test is available, and a significant number have had this test carried out. It has not been accepted in NHS circles simply because the research was funded privately. So far no one I know of has been able to confirm or refute this research. Maybe there will be answers soon. Mitochondrial abnormalities in ME are nothing new and have been known for many years with plenty of research evidence to support this. Abnormal mitochondria have been found in ME patients. The known mitochondrial diseases also respond in a similar to ME/CFS. I also know that some cases of diabetes are related to abnormal mitochondria. See previous issue of Pathways for further information.*



*A normal mitochondrion*



*An abnormal mitochondrion from a ME/CFS patient.*

**NORAD Website Review: Why we track Santa.**

See <http://www.noradsanta.org/>

For more than 50 years, NORAD and its predecessor, the Continental Air Defence Command (CONAD) has tracked Santa's flight. The tradition began in 1955 after a Colorado Springs-based Sears Roebuck & Co. advertisement misprinted the telephone number for children to call Santa. Instead of reaching Santa, the phone number put kids through to the CONAD Commander-in-Chief's operations "hotline." The Director of Operations at the time, Colonel Harry Shoup, had his staff check the radar for indications of Santa making his way south from the North Pole. Children who called were given updates on his location, and a tradition was born. In 1958, the governments of Canada and the United States created a bi-national air defence command for North America called the North American Aerospace Defences Command, also known as NORAD, which then took on the tradition of tracking Santa. Since that time, NORAD men, women, family and friends have selflessly volunteered their time to personally respond to phone calls and emails from children all around the world. In addition, we now track Santa using the internet. Millions of people who want to know Santa's whereabouts now visit the NORAD Tracks Santa® website. Finally, media from all over the world rely on NORAD as a trusted source to provide updates on Santa's journey.

**How do NORAD track Santa?**

As many children find on Christmas day, Santa visits everyone. If you stay up waiting for him on Christmas Eve he never seems come, but once your attention drops he been and gone in a flash.

It is only in the last 50 years or so that his trip around the world on Christmas has been seen using the most modern recent technology.

**Radar:** It all starts with the NORAD radar system called the North Warning System. This powerful radar system has 47 installations strung across Canada's North and Alaska. NORAD makes a point of checking the radar closely for indications of Santa Claus leaving the North Pole every holiday season. The moment our radar tells us that Santa has lifted off, we begin to use the same satellites that we use in providing warning of possible missile launches aimed at North America.

**Satellites:** These satellites are located in a geo-synchronous orbit (that's a cool phrase meaning that the satellite is always fixed over the same spot on the Earth) at 22,300 miles above the Earth. The satellites have infrared sensors, meaning they can see heat. When a rocket or missile is launched, a tremendous amount of heat is produced - enough for the satellites to see them. Rudolph's nose gives off an infrared signature similar to a missile launch. The satellites detect Rudolph's bright red nose with no problem.

**SantaCams:** The third system we use is the SantaCam. We began using it in 1998 - the year we put our Santa Tracking program on the Internet. NORAD SantaCams are ultra-cool, high-tech, high-speed digital cameras that are pre-positioned at many places around the world. NORAD only uses these cameras once a year - on 24 December. We turn the cameras on about one hour before Santa enters a country then switch them off after we capture images of him and the Reindeer. We immediately download the images onto our web site for people around the world to see. SantaCams produce both video and still images.

**Jet Fighters:** The last system we use is the NORAD jet fighter. Canadian NORAD fighter pilots, flying the CF-18, take off from Newfoundland and welcome Santa to North America. Then at numerous locations in Canada other CF-18 fighter pilots escort Santa. While in the United States, American NORAD fighter pilots in either the F-15s, F16s or F-22s get the thrill of flying with Santa and the famous Reindeer - Dasher, Dancer, Prancer, Vixen, Comet, Cupid, Donner, Blitzen and Rudolph. Even though Santa flies faster than any jet fighter (Santa actually slows down for us to escort him), all of these systems together provide NORAD with a very good continuous picture of his whereabouts.

Frequently Asked Questions (FAQs)

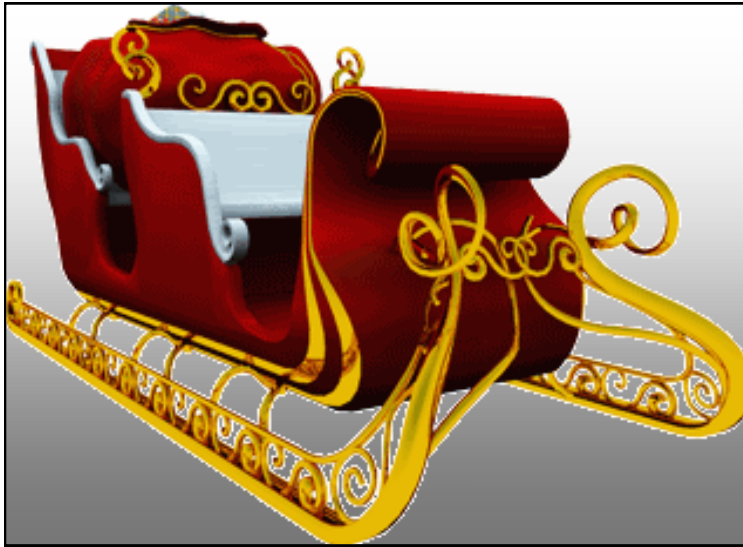
**How long has NORAD been tracking Santa?** NORAD's predecessor, the Continental Air Defence Command (CONAD), began tracking Santa in 1955. NORAD replaced CONAD in 1958 and took over the mission of tracking Santa's flight around the world, and they have been tracking Santa every year since!



*Secret Blue-prints of Santa's sleigh*

In Late November, NORAD arranged for a Pathways reporter to visit Santa's secret grotto somewhere near the North Pole. We are sworn to secrecy, but we can show you a couple of declassified pictures.

*Santa's Sleigh parked at the North Pole, as seen by a Pathways reporter*



*Designer & Builder K: Kringle & Elves, Inc.*

*Probable First Flight: Dec. 24, 343 A.D.*

*Home Base: North Pole*

*Length: 75 cc (candy canes) / 150 lp (lollipops)*

*Width: 40 cc / 80 lp*

*Height: 55 cc / 110 lp*

*Note: Length, width and height are without reindeer*

*Weight at take off: 75,000 gd (gumdrops)*

*Passenger weight at take off: Santa Claus 260 pounds*

*Weight of gifts at take off :60,000 tons*

*Weight at landing: 80,000 gd (ice & snow accumulation)*

*Passenger weight at landing: 1,260 pounds*

*Propulsion: Nine (9) rp (reindeer power)*

*Armament: Antlers (purely defensive)*

*Fuel: Hay, oats and carrots (for reindeer)*

*Emissions: Classified*

*Climbing speed: One "T" (Twinkle of an eye)*

*Max speed: Faster than starlight*

*Right: Long Distance view from space of Santa's headquarters at the North Pole.*



*Lower: Overview of of Santa's Village as seen by our Pathways Reporter—  
photograph taken from an aeroplane*





**Why does NORAD track Santa?**

Twenty four hours a day, 365 days a year, NORAD tracks airplanes, missiles, space launches and anything else that flies in or around the North American continent, while also completing some other very important missions. While the tradition of tracking Santa began purely by accident, NORAD continues to track Santa. We're the only organization that has the technology, the qualifications, and the people to do it. And, we love it! NORAD is honoured to be Santa's official tracker!

**When will Santa arrive at my house?** NORAD Tracks Santa, but only Santa knows his route, which means we cannot predict where and when he will arrive at your house. We do, however, know from history that it appears he arrives only when children are asleep! In most countries, it seems Santa arrives between 9:00 p.m. and midnight on December 24th. If children are still awake when Santa arrives, he moves on to other houses. He returns later...but only when the children are asleep!

**What route does Santa travel?** Santa usually starts at the International Date Line in the Pacific Ocean and travels west. So, historically, Santa visits the South Pacific first, then New Zealand and Australia. After that, he shoots up to Japan, over to Asia, across to Africa, then onto Western Europe, Canada, the United States, Mexico and Central and South America. Keep in mind, Santa's route can be affected by weather, so it's really unpredictable. NORAD coordinates with Santa's Elf Launch Staff to confirm his launch time, but from that point on, Santa calls the shots. We just track him!

**Does Santa visit everyone?** Indeed! Santa visits all homes where children believe in him.

**How can Santa travel the world within 24 hours?** NORAD intelligence reports indicate that Santa does not experience time the way we do. His trip seems to take 24 hours to us, but to Santa it might last days, weeks or even months. Santa would not want to rush the important job of delivering presents to children and spreading joy to everyone, so the only logical conclusion is that Santa somehow functions within his own time-space continuum.

**How old is Santa?** It's hard to know for sure, but NORAD intelligence indicates Santa is AT LEAST 16 centuries old.

**What does Santa look like?** Based on flight profile data gathered from over 50 years of NORAD's radar and satellite tracking, NORAD concludes that Santa probably stands about 5 feet 7 inches tall and weighs approximately 260 pounds (before cookies). Based on fighter-aircraft photos, we know he has generous girth (belly), rosy cheeks from sleigh riding in cold weather, and a flowing white beard.

**How does Santa get down chimneys?** Although NORAD has different hypotheses and theories as to how Santa actually gets down the chimneys, we don't have definitive information to explain the magical phenomenon.

**Do your planes ever intercept Santa?** Over the past 50 years, our fighter jets (F-16s, F-15s, F-22s and CF-18s) have intercepted Santa many, many times. When the jets intercept Santa, they tip their wings to say, "Hello Santa! – NORAD is tracking you again this year!" Santa always waves. He loves to see the pilots!

**Does NORAD have any pictures of Santa taken from your planes?**

Our fighter pilots love to take photos of Santa. We also have NORAD Santa Cams in space which take video of Santa as he flies round the world. See [www.noradsanta.org](http://www.noradsanta.org) on December 24th.

**Does NORAD have any statistics on Santa's sleigh?** NORAD can confirm that Santa's sleigh is a versatile, all weather, multi-purpose, vertical short-take-off and landing vehicle. It is capable of traveling vast distances without refuelling and is deployed, as far as we know, only on December 24th (and sometimes briefly for a test flight about a month before Christmas).

## ***The Christmas Tree Tradition***

The custom of the Christmas tree can be traced to the 16th century or earlier. There are records Christmas trees were hung in St. George's Church, Sélestat since 1521. The Christmas tree has also been known as the "Yule-tree". The tree was traditionally decorated with edibles such as apples, nuts, or other foods. In the 18th century, it began to be illuminated by candles which were ultimately replaced by Christmas lights after the advent of electrification. Today, there are a wide variety of traditional ornaments, such as garland, tinsel, and chocolate. An angel or star might be placed at the top of the tree to represent the Angel Gabriel or the Star of Bethlehem from the Nativity. Historically although the tradition of decorating the home with evergreens was common, the custom of decorating an entire small tree was unknown in Britain until some two centuries ago. It was George III's German-born wife that first introduced a Christmas tree at a party she gave for children in 1800.



*'Chichilaki' A Georgian Christmas Tree Variant*

The custom did not at first spread much beyond the royal family. Queen Victoria as a child was familiar with it and a tree was placed in her room every Christmas. The custom became even more widespread after her marriage to her German cousin Prince Albert and by 1841 many wealthier middle-class families followed the fashion. In 1842 a newspaper advert for Christmas trees makes clear their smart cachet, German origins and association with children and gift-giving. A boost to the trend was given in 1848 when the Illustrated London News, in a report picked up by other papers, described the trees in Windsor Castle in detail and showed the main tree, surrounded by the royal family, on its cover. In fewer than ten years the trees' use in better-off homes was widespread. By 1856 a northern provincial newspaper contained an advert alluding casually to them, as well as reporting the accidental death of a woman whose dress caught fire as she lit the tapers on a Christmas tree. They had not yet spread down the social scale though, as a report from Berlin in 1858 contrasts the situation there where "Every family has its own" with that of Britain, where Christmas trees were still the preserve of the wealthy or the "romantic".



*Queen Victoria's Christmas tree at Windsor Castle 1848*

Their use at public entertainments, charity bazaars and in hospitals made Christmas trees increasingly familiar. However, in 1906 a charity was set up specifically to ensure even poor children in London slums 'who had never seen a Christmas tree' would enjoy one that year. Anti-German sentiment after World War I briefly reduced their popularity but the effect was short-lived and by the



mid-1920s the use of Christmas trees had spread to all classes. In 1933 a restriction on the importation of foreign trees led to the 'rapid growth of a new industry' as the growing of Christmas trees within Britain became commercially viable due to the size of demand. By 2013 the number of trees grown in Britain for the Christmas market was approximately 8 million and their display in homes, shops and public spaces a normal part of the Christmas season.

*Since 1947 the pine tree in central London has been a gift from the people of Norway in recognition of Britain's support during World War II.*

## ***Irritable Bowel Syndrome (IBS) Revisited and Updated.***

Although part of ME symptomology, many NHS ME/CFS clinics regard IBS as a separate condition. For doctors, IBS carries many parallels with ME in that diagnosis can be challenging, there are few specific symptoms, and many conditions have the same symptomology so “ME/CFS” is usually a diagnosis of exclusion. ME is a Cinderella condition. There is general lack of in-depth knowledge and treatment options are not always effective, which can be frustrating to both patients and doctors. I’ve sometimes come across IBS without ME/CFS before this, in the case review scenario. Here is an example of a case. We’ll call her June. June is in her late 30’s. She is a busy Mum working full time; she could be the mother of a Leger ME member.

**June:** “Over the past year or so 12 months, I’ve seen my own doctor and four others in the same practice. I get uptight about things and anxious about things—but I’m worried because I get constipation, gripes and headache. This has been going on and off for 10 years or so. Although doctors have sent me for many tests; I’ve never had a definite diagnosis”.

**Mike:** “What your doctors will have done is eliminate any serious or nasty diseases and waited for a while. After all this time they will assume it is IBS as a diagnosis of exclusion, and what has taken place is similar to what happens in ME/CFS cases. If you had reported what’s called an **Alarm Symptom** that would have triggered immediate in-depth investigations. As you told me none of these are present so currently it would imply an IBS type diagnosis.

### **IBS related Alarm Symptom's**

**June:** But what would happen there were any further changes in my symptoms,

**Mike:** Obviously if there were other health issues like you were of pension age, had dietary problems or didn’t get any exercise, were overweight, smoked, had high alcohol intake, or there was a strong family history of other serious conditions which might produce the same symptoms then you would be sent to see a specialist. The same thing would happen if your doctor had a genuine uncertainty about the diagnosis or you or your doctor just needed reassurance after the many tests and consultations. So at present to move forward we have assumed you have a diagnosis of IBS, Irritable Bowel Syndrome.

Age 50+	Anaemia
Short symptom History	Back Passage Bleeding
Unplanned weight loss	Recent antibiotic use
night time symptoms	Abnormal tummy lumps
Being a Man	Family History of Bowel / Ovarian cancer.

**June:** I’ve been on Dr. Myhills website, and she takes the view that it is a ‘dustbin’ diagnosis.

**Mike:** Yes that used to be the case, but you have to regard Dr Myhill as someone specialising in ME/CFS and related conditions. If you check her website you’ll see that she links it to some other conditions – which is are for the sorts of patients she sees. You have to remember also that her network is private medicine, and in private medicine things are different. Anyway, things have moved on for non-ME’s. Previously IBS was considered a diagnosis of exclusion a bit like ME/CFS with your son. However, a positive diagnosis can be made using symptoms, alarm features, and minimal tests. You fall within the most common group of patients with your history. Kate has features typical of IBS patients. You are a lady, thirty something and have been a frequent customer at your doctors. You may not have had the newer tests done.

**June:** - Yes but what are they?

**Mike:** Well now there are two tests for markers calprotectin and lactoferrin. Well, they could help may distinguish IBS from IBS (C). Faecal calprotectin is an inflammatory marker. Doctors reckon that this test will be useful to determine which patients require endoscopy for IBS(D). Faecal lactoferrin2 is similarly useful for discriminating inflammatory bowel disease patients from IBS patients and healthy people. IBS is NOT an early indicator of Inflammatory Bowel Diseases e.g. Crohn’s Disease.



**June:** So exactly what goes wrong in IBS?

**Mike:** You get altered gastric motility (peristalsis) occurring, particularly in IBS (C). It is decreased in IBS (C) and increased in IBS (D). Whatever the type, the colonic response is enhanced by feeding or emotion. You also get a similar change when toileting. (C=constipation, D=diarrhoea)

**June:** You mean a bit like 'butterflies' just before an exam.

**Mike:** Exactly. Stress can make symptoms worse.

**June:** Surely that means then it's a mental health condition?

**Mike:** "No. No. No. IBS is NOT a purely psychological condition. That's just an old wives tale. There are also some other myths - regard IBS. IBS is NOT due to food allergy and it does not cause cancer.

**June:** Well my IBS is mainly due to constipation. How would you suggest I go about treating it?

**Mike:** I think firstly you have to understand that constipation does not cause 'auto-intoxication' and long-term laxative use definitely does not lead to addiction. You could try increasing your fibre intake.

**June:** But I've heard that there are two kinds of fibre.

**Mike:** Yes, There are two kinds of fibre. Soluble fibre attracts water and turns to gel during digestion, and Insoluble fibre that does not dissolve in water adds bulk to stools. However there is no consensus about which sort to take, but the powers that be favour increasing soluble fibre intake. However I don't think it is as simple as that. I also recommend that people do a dietary clean-up. It is important that you have regular meals drink plenty of fluids and take time to eat. It is important to reduce intake of caffeine/fizzy drinks/alcohol, and reduce intake of resistant starch in

#### The low FODMAP diet

There is a growing body of evidence that the low FODMAP diet is effective in improving symptoms of IBS. FODMAP stands for:

- Fermentable
- Oligosaccharides
- Disaccharides
- Monosaccharides
- And
- Polyols

These are a group of short-chain carbohydrates that are not very well absorbed in the gut (small intestine). These carbohydrates are easily fermented and cause more fluid to enter the large bowel, leading to gas, bloating and diarrhoea. Reducing the total amount of these fermentable sugars may improve IBS symptoms. The low FODMAP diet should be done with the assistance of a dietician.

#### Dietary Fibre

**Insoluble fibre** This type of fibre is not dissolved in water. It is not readily broken down, so it passes through the digestive system mostly intact. It absorbs water, adds bulk to stools, and allows waste to be passed through bowels more quickly. Reducing this type of fibre may help to improve symptoms of diarrhoea. Foods to reduce or avoid:

- Skin, pith and pips of fruit and vegetables
- Wheat and bran
- Corn (maize)
- Whole grains

**Soluble fibre** This type of fibre does dissolve in water and can be broken down by the natural bacteria in the bowels. It softens stools (faeces) and makes them larger. Increasing this type of fibre may help to improve symptoms of constipation. Foods to include are:

- Oats
- Barley
- Psyllium and ispaghula
- Seeds
- Fruit and vegetables
- Beans and pulses

Whole grains (eg, wholemeal bread, brown rice and whole-wheat pasta) may also help with constipation. Although increasing fibre may help to improve symptoms, it may also generate gas and cause pain and bloating. Monitoring is important to help identify this and to adjust your fibre intake according to your symptoms.

If fibre intake is suddenly increased, this can cause symptoms of wind and bloating. Introduce high-fibre foods gradually to allow the gut to become used to the extra fibre. Introduce one new food over a 2- to 3-day period and monitor any symptoms.

processed food.

**June:** "I read about the FODMAP diet in a 'Woman's World'. They reckon that is the best diet to try for IBS. Is that true?"

**Mike:** Well not quite. No. Some patients benefit from a low FODMAP diet if food intolerance is a problem, but this is best sorted out by a dietician. Some people with IBS may have a food intolerance. Testing and diagnosing a food intolerance involves a hydrogen breath test which can be arranged by your doctor. However, this is not always available or appropriate. Diets that exclude suspected foods can help to identify a food intolerance. If it is thought that particular foods are causing symptoms, a dietician

may advise you to exclude these foods for a certain time period. This is to monitor whether symptoms improve when these foods are taken out of the diet. After this time period (usually 2-4 weeks) the foods are gradually re-introduced to see if symptoms come back. Common intolerances include lactose (found in milk and dairy products), wheat (found in bread, cereals and pasta) and caffeine (found in tea, coffee or cola). Some people consider these as junk foods.

**June:** Well that is the sort of things I've had to do for my son with his ME.

**Mike:** Yes, this is reminiscent of Dr. Myhill's method for rotational diets and gut fermentation. I've yet to work out what really the difference is.

**June:** What about probiotics. I've heard they can help.

**Mike:** I've no direct experience with them but some people I know who are in 'in the know' reckon that probiotics are finicky. How well they work varies with the strain of bacteria used, and is dose-specific to that strain. They are thought to increase beneficial aerobic bacteria and decrease pathogenic anaerobic bacteria.

**June:** I've heard that some medicines have side-effects which can have an effect on IBS.

**Mike:** Well yes, but you are not taking anything which I would suspect. Common medicines that cause constipation are opiate pain killers (Codeine family), calcium channel blockers (often used to treat heart & circulation problems), iron supplements and tri-cyclic anti-depressants (TCADs) e.g. amitriptyline. On the other hand there are drugs which cause diarrhoea like some antibiotics and ACE inhibitors which are used to treat high blood pressure.

**June:** Thanks for that information. So what are my treatment options now and what about the medicines and how can my doctor help me?

**Mike:** How IBS is treated depends on the sort of symptoms you get. It is being increasingly recognised in medical circles that IBS comes in several types: The first type IBS (D) is where the predominant symptom is excess bowel activity e.g. diarrhoea. The second type is IBS (C) when the predominant activity is recognised reduced bowel activity e.g. constipation. The third type is IBS (M). The M stands for 'Mixed' where both IBS(C) and IBS (D) symptoms occur.

**June:** But I have tried loads of different medicines over the years both from the Pharmacy and from the doctors and nothing has really made any lasting difference.

**Mike:** Well, medicines are not the complete answer. Most of them are just for symptom relief, and don't really get to the root of IBS. As well as ME/CFS, IBS patients often have medically unexplained conditions e.g. fibromyalgia, chronic pelvic pain, temporomandibular joint disorder psychological conditions and backache.

**June:** So we come back full circle?

**Mike:** I think perhaps you need to go and have a word with your doctor. Just to give you an idea what to expect. The strategy with medicines for IBS is to treat the symptoms, give relief to the most troublesome symptoms, rather than cure. Different subtypes require different management for example some antispasmodic medicines are effective for pain. They are generally anticholinergics, for example, dicycloverine, propantheline, hyoscine (Buscopan). These antispasmodics work best if you are not constipated and should be taken before meals. There is a group of medicines which calm the bowel down known as smooth muscle relaxants e.g. mebeverine, alverine and peppermint oil. TCA medicines provide significant benefit in improving lower tummy pain and general symptoms. Only about one in four people will benefit whereas SSRI antidepressants are marginally better in this context.

**June:** What about threatening diarrhoea

**Mike:** Well then anti motility agents are effective. They work by reducing bowel movement , slowing transit down and increasing anal sphincter tone. Loperamide commonly sold for holiday diarrhoea is the preferred choice. But there are few side effects with no dependency or addictions. When all else fails, rifaximin, a non-absorbed antibiotic may help but that would have to come from a hospital consultant. One report claims that it gives overall relief of IBS symptoms and bloating. A new medicine has just been introduced but you will have to ask your doctor about that one.

**June:** So you are saying that there are plenty of medicines and other treatments out there that I have not tried yet?

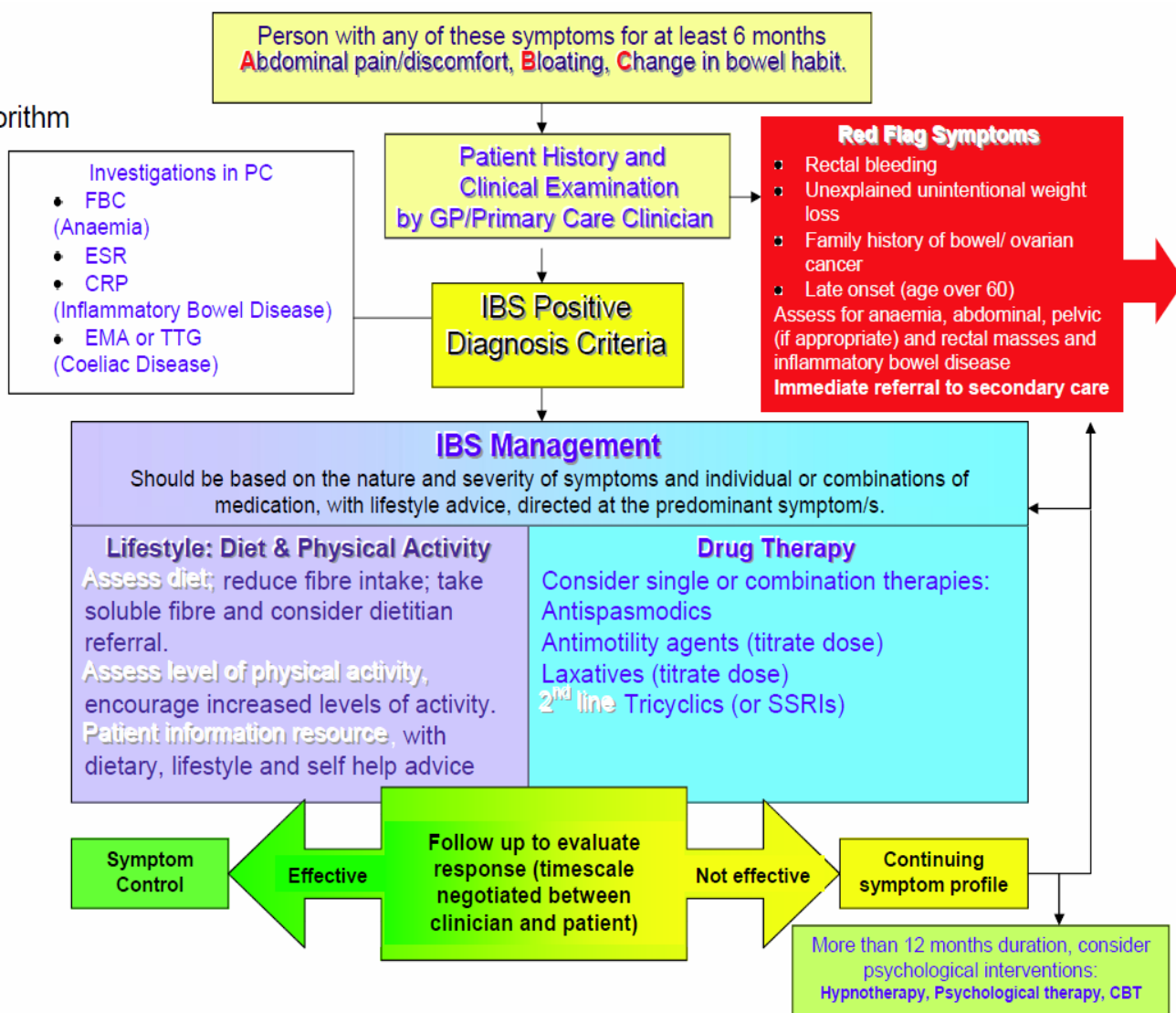
**Mike:** Yes. I think perhaps the next stage is for you to keep a diary of all your symptoms for a week and then go and have a word with your doctor. I recommend that people buy a little A6 pocket book and keep a diary of how your symptoms vary with what you eat and drink. It should be worthwhile if you could record your bowel motions as on the Bristol stool map, with what you have taken, eaten and anything else you feel necessary. In that way you will soon know what works and what doesn't.



**June:** I'll do that: thank you very much.

*Here is a summary of the current NICE Guideline for dealing with Irritable Bowel Syndrome.*

#### IBS Algorithm





## Vitamin D

Sunshine, not food, is where most of your vitamin D comes from. So even a healthy, well balanced diet, that provides all the other vitamins and goodness you need, is unlikely to provide enough vitamin D. Read on to find out the best ways to get enough vitamin D safely.

### What is vitamin D?

You make vitamin D under your skin when you are outside in daylight, which is the reason vitamin D is sometimes called the 'sunshine vitamin'. A vitamin is something that helps our body function – a 'nutrient' – that we cannot make in our body. Vitamin D is different because even though we call it a vitamin, it is actually a hormone and we can make it in our body.

### What does vitamin D do in my body?

Vitamin D helps your body absorb calcium for healthy bones and teeth. Even if you have a calcium-rich diet (for example from eating plenty of low fat dairy foods and green leafy vegetables), without enough vitamin D you cannot absorb the calcium into your bones and cells where it is needed. Vitamin D may have other important roles in the body, but there isn't enough evidence at the moment to make any recommendations.

### When is vitamin D made in skin?

The amount of vitamin D you make depends on how strong the sunlight is. You will make more in the middle of the day, when the sun is strongest. You will also make more when you are in direct sunlight than in the shade or on a cloudy day.

### Sun safety

It is the sun's ultraviolet rays that allow vitamin D to be made in the body. You do not have to sunbathe to make vitamin D.

In the UK ultraviolet light is only strong enough to make vitamin D on exposed skin (on the hands, face and arms or legs) in the middle of the day (around 11am - 3pm) during April to September.

If you go out in the sun two or three times a week for at least 15 minutes (before applying sunscreen) in this period, your body will make enough vitamin D. During the winter, we get vitamin D from our body's stores and from food sources. People over 65 or with darker skin would need more exposure. You can also make a smaller amount of vitamin D when the skin is covered by fine material.

If you are concerned about the risk of skin cancer, and always use a high factor sunscreen or cover your skin when outside, the only way to ensure a healthy vitamin D status is to take a supplement.

### At risk groups for low vitamin D

- Babies and young children, and children and adolescents who spend little time playing outside
- Pregnant women and breastfeeding mothers
- People over 65 years old because their skin is not as good at making vitamin D
- People with darker skin tones - that is people of Asian, African, Afro-Caribbean and Middle Eastern descent – living in the UK or other northern climates
- If you always cover most of your skin when you are outside and the further north you live
- Anyone who spends very little time outside during the summer – the housebound, shop or office workers, night shift workers
- If the air is quite polluted

## Which foods contain vitamin D?

Help your body get more vitamin D by eating plenty of vitamin D rich foods, including:

- Oily fish such as salmon, sardines, pilchards, trout, kippers and eel contain reasonable amounts of vitamin D
- Cod liver oil contains a lot of vitamin D (don't take this if you are pregnant)
- Eggs, meat and milk contain small amounts but this varies during the seasons
- Margarine, some breakfast cereals, infant formula milk and some yoghurts have added or are 'fortified' with vitamin D

## What happens if I don't get enough vitamin D?

Some babies are born with low levels of vitamin D and some do not get enough in breast milk; this can result in fits or rickets. Older children who do not get enough vitamin D can also develop rickets. Rickets can cause permanent deformities to the bone, weaken muscles and reduced growth.

Adults who don't get enough vitamin D can develop osteomalacia. This makes the bones softer as the minerals needed to keep them strong cannot get into the bone. People with osteomalacia experience bone pain and muscle weakness

Low levels of vitamin D may put men at increased risk of colorectal cancer and women at increased risk of developing breast cancer.

## Where are vitamin D supplements available?

Vitamin D supplements and multivitamins are now widely available to buy from chemists/pharmacies, supermarkets and health food shops.

Some women who are pregnant or breastfeeding and children aged six months to four years may qualify for Healthy Start vitamins which contain vitamin D. Ask your health visitor about this.

## Who needs a vitamin D supplement?

- People aged 65 years or older and people who are not exposed to much sun should take a supplement of 10 micrograms a day
- Pregnant and breastfeeding women should also take 10 micrograms of vitamin D a day.
- All babies and children aged six months to five years should be given a daily supplement of 7-8.5 micrograms unless they have more than 500mls of fortified formula milk
- Breastfeeding babies may need to be given a vitamin drop from one month of age if their mother had not taken a supplement during pregnancy

## Can I have too much vitamin D?

Taking a vitamin D supplement as well as spending a lot of time outside in sunshine is not a problem as your body only makes as much vitamin D as it needs. However do not take more than one supplement containing vitamin D (count cod-liver oil as a supplement).

Always choose a supplement tailored to the age group or condition, as fish liver oils and high dose multivitamin supplements often contain vitamin A, too much of which can cause liver and bone problems, especially in very young children, and the elderly.

## Summary

Vitamin D helps your body absorb calcium for healthy bones and teeth. You make vitamin D under your skin when you are outside in the middle of the day in the summer months. You can get vitamin D from some foods including fortified foods or by taking a supplement. There are some at risk groups who are recommended to take daily vitamin D supplements. If you are concerned you are not getting enough vitamin D, speak to your doctor, health visitor, or ask to be seen by a dietitian.

This Food Factsheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian. If you need to see a dietitian, visit your GP for a referral or: [www.freehousedietitians.org](http://www.freehousedietitians.org) for a private dietitian. To check your dietitian is registered check [www.hpc-uk.org](http://www.hpc-uk.org)

This Food Factsheet and others are available to download free of charge at [www.bda-uk.com/foodfacts](http://www.bda-uk.com/foodfacts)

Written by Judy More, Dietitian. Updated by Sylvia Turner, Dietitian.

The information sources used to develop this fact sheet are available at [www.bda-uk.com/foodfacts](http://www.bda-uk.com/foodfacts)

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## ***A Frustrating Hospital Admission***

*Sarah suffers from a rare hereditary disorder which causes neurological degeneration. She is forty something and a single Mum. She has encountered many emergency admissions and is a heavy user of the local town hospital neurological ward and intensive care wards. Over the past few years Sarah has suffered swallowing problems, and lost weight heavily. In-depth investigations have revealed that she frequently loses her swallowing reflex. In desperation the hospital has fitted a nasogastric tube to feed her directly into her stomach. With everyday visits by the nurses and supervised feeding she has gained weight. However a nasogastric tube is unsuitable for long term use. After much pondering the hospital reluctantly decided that she needs a PEG tube to be fitted so she can be fed directly via a fistula in her tummy wall. Normally the operation is a day case done under local anaesthetic and no worse than a tooth extraction — but due to her medical history it has to be done with a general anaesthetic.*

Email from Sarah just before going into hospital: Not been great, just want this over and done with, it seems to have gone on for ever! Had to see the anaesthetist several times as they were concerned about a few things. I have to be at the hospital at 07.15 a.m. tomorrow morning but not sure when I will go to theatre. I would imagine I will be one of the first with me having the complaint.

Email from Sarah to mum 36 hours later: Came home last night. I was meant to have a general anaesthetic; I didn't get to theatre, they gownned me and got a line in, and then I didn't get any further, they couldn't operate as my blood pressure dropped, temp dropped and blood sugar dropped. They then kept me in to try and find out why, but no answers. I'm really fed up. I've been re-listed for the week before Christmas. I was supposed to be going to Portugal for 3 days for my friends 40th. It's all paid for. It's not raining, it's pouring at the moment!! Oh, thank you for the flowers they were lovely, I feel guilty as you sent them and I didn't have it done!  
Sarah x

Mum's response Email later that day: - Do you feel angry now about what's happened?

I think the cutbacks are now so severe that the NHS is no longer functioning properly. Just read on.....

I've had 3 operations with general anaesthetic in my life and on each occasion I was taken into hospital the afternoon before, settled in and the anaesthetist came and sat by the bed to talk through everything, then you'd be taken down to theatre the following morning after a night's sleep. That's how it used to be, not back in the dark ages but up around 2006. You were actually looked after!

What has happened now is that all the 'NICE Guidelines' came in and from the GP's right through, the person/human being/patient/ is forgotten. It is assumed that all people are the same and the same and not individuals. Guidelines are followed for every patient having your operation, taking no account of what the individual needs of the patient are.

SO.....they haven't looked at your history; no one has seen that this op has been put back and put back all through the months whilst you get more and more stressed, and more ill and worst of all, they have taken no account of your health problems. What they did was to forget all about you as an individual; they rushed you in at a ridiculously early hour for someone with morning problems; they shove a gown at you and line into you and then "wonder why everything went haywire". It doesn't take a great brain to work out what has happened; there has been no caring, no compassion, and no common-sense at all, just a thorough wound up stressed young lady, having a nightmare with them!

You must be very disappointed to say the least in the NHS at the moment and it makes me wonder if you want to go on with the Royal Bolton or, would a fresh start with a second opinion....maybe the city is the way to go now?

*This could be repeated with ME/CFS. We have the appropriate information for doctors to avoid this situation occurring when going into hospital. Contact the helpline for a copy.*



## ***Out and About: The Elsecar Heritage Centre & nearby places of interest...***

Frequently we visit the Elsecar Heritage Centre. It's one of those places within half an hour of Doncaster that is not so well known. It is owned by Barnsley MBC. You can spend half a day there and not see everything. The site itself is composed of the building of the former National Coal Board Area Workshops which have been converted into a museum and heritage centre set in the attractive conservation village of Elsecar. In earlier days these were ironworks and colliery workshops of the Earl Fitzwilliam. Restored historical buildings now house an antique centre, individual craft workshops, and exhibitions of Elsecar's past.

The Elsecar Heritage Centre, Wath Road, Elsecar, Barnsley, S74 8HJ is open 7 days a week, 10am to 5pm, although individual shops and businesses within Elsecar Heritage Centre have varying opening times. Parking and entry to the site is free (admission fee applicable to some special events and attractions). A regular public transport service is available to Elsecar via train, (Leeds, Sheffield, Barnsley, Wakefield), or bus route 66 from Barnsley Station. Cycle racks are available on-site. Responsible dog owners are welcome. Disability-wise, we always find all the disabled places are full so have to park in an outer car park.



Around Elsecar Heritage Centre is Elsecar village, an early industrial village with its stone cottages built for the miners and foundry workers now being an attractive feature. Just across the road from Elsecar Heritage Centre you will find one of the prettiest small parks with an adjoining reservoir, popular with anglers and bird watchers. Nearby is the village of Wentworth with the grand stately home Wentworth Woodhouse and Wentworth Garden Centre. Adjacent to the main site are the Elsecar Steam Railway and Newcomen's Beam Engine (*see next page*). Elsecar Village is an excellent example of an early industrial village with its stone cottages built for the miners and foundry workers now being an attractive feature. Just across the road from Elsecar Heritage Centre you will find one of the prettiest small parks with an adjoining reservoir, popular with anglers and bird watchers. Nearby is the village of Wentworth with the grand Wentworth Woodhouse stately home and Wentworth Garden Centre. Activities include concerts, dog shows, health fairs and so on.

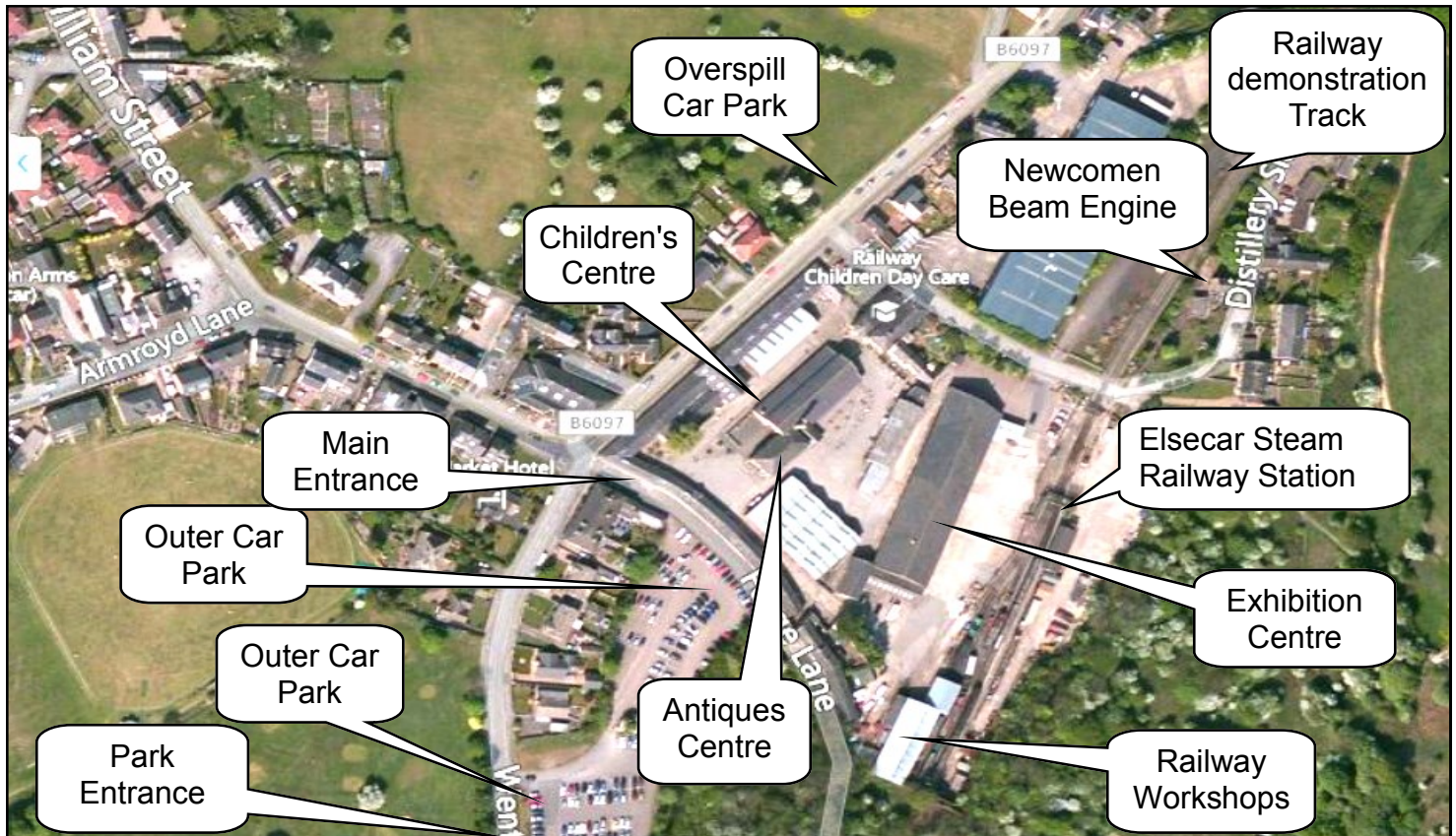
### ***History of Elsecar.***

The 4th Earl of Fitzwilliam inherited the Wentworth Estate from his uncle in 1782 and by the end of 1795 the Elsecar New Colliery has been sunk. By this time the Elsecar Ironworks has also been built by John and William Darwin & Co., and were originally situated near outcrops of ironstone towards the back of the Centre – you can still see the ruins of the buildings today. The ironstone was mined close to Elsecar, although the best ironstone came from Tankersley and was brought to the ironworks by horse and cart. Darwin & Co. sold pig iron and made domestic ranges, spouting rails for colliery tramways, window frames and arches which can still be seen on various buildings around the site. The Elsecar workshops were built in 1850 to facilitate a more effective management of the various industrial enterprises around the Fitzwilliam estate. The coal board took over the workshops in 1947 following the nationalisation of the pits. As the collieries began to close the demand for the workshop facilities began to decline, eventually leading to their closure. In 1986 the Department of the Environment listed most of the buildings to be of special architectural or historic interest. Barnsley Council purchased the workshops along with the Newcomen Beam Engine in 1988 and started a programme of conservation and restoration.



**Verdict:** Well worth a visit, and it needn't cost you a penny.



**The Elsecar Site** *(Thinks to Bing)***The Coalfield Memorial Line**

The Elsecar Heritage Railway is made up of a group of volunteers committed to the preservation, restoration and expansion of a preserved railway in South Yorkshire. EHR Volunteers carry out all duties on the railway, from driving the engines to maintaining the track. On the 1st of March 2006, the Elsecar Railway Preservation Group signed a lease for the railway from Barnsley Council. The gaining of a lease for the railway has been achieved after many years of hard negotiations. The group have signed a 50 year lease of the railway which was previously managed and funded Barnsley Council. This is a major milestone in the history of the Elsecar Railway as the group is now able to apply for much needed funding for locomotive overhauls and the extension of the line to Cortonwood.

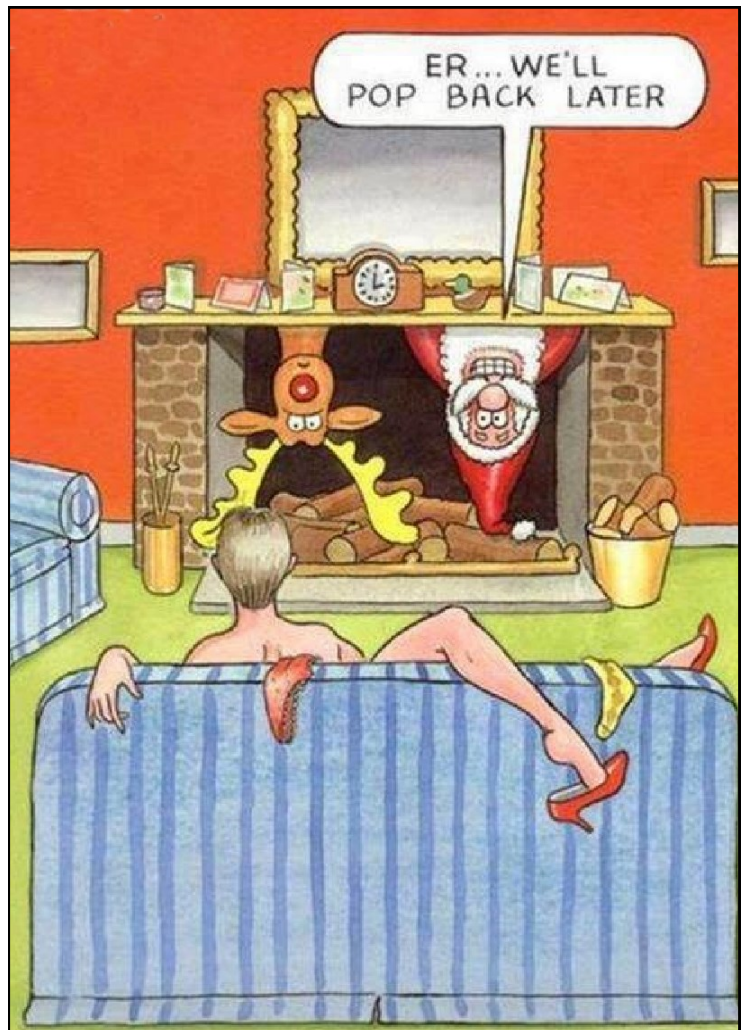
**The Newcomen Beam Engine**

This is one of South Yorkshire's finest surviving legacies of the Industrial Revolution. It is the only Newcomen-type atmospheric pressure beam engine in the world to have remained in its original location. It was built to extract water from Elsecar New Colliery in 1795. The Beam Engine ran from 1795 until 1923 when it was replaced by electric pumps. It also ran briefly in 1928 when the electric pumps were overwhelmed by flooding.





YOU PLAYED WITH IT BEFORE YOU GAVE IT TO ME, DIDN'T YOU?



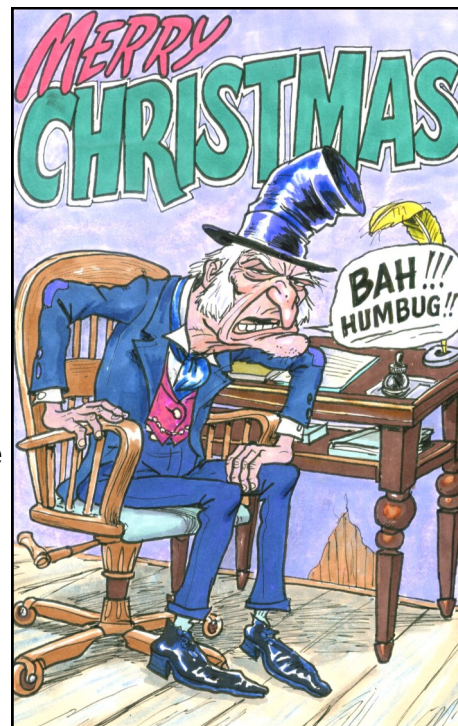


**North of Doncaster.** *Personal thoughts from Trevor Wainwright*

Every year Christmas seems to start earlier, hardly have we brought in the harvest and the adverts are there. I do like Christmas and prefer to let it come in its own good time, enjoy the run up listening to Christmas music and as it gets nearer the anticipation of the children, enjoy the moment and let it go. I have an interest in Christmas carols having, during my time as hospital radio presenter, played and talked about the story behind them. And, like most, I have sung the alternative versions. Recently I had a look at how a 19th century Cornish Christmas carol Sans Day Carol became a protest carol. The original has only 4 verses, but I just kept finding more colours to rhyme but it is still sung to the same gentle lilt, with a Christmas message at the end. Christmas Commercialisation: Bah Humbug

In reality a humbug is a person or object that behaves in a deceptive or dishonest way, often as a hoax or in jest. The word was first described in 1751 as student slang, and recorded in 1840 as a "nautical phrase. It is now also often used as an exclamation to mean nonsense or gibberish. When referring to a person, a humbug means a fraud or impostor, implying an element of unjustified publicity and spectacle. In modern usage, the word is most associated with Ebenezer Scrooge, a character created by Charles Dickens. His famous reference to Christmas, "Bah! Humbug!", declaring Christmas to be a fraud, is commonly used in stage and television versions of A Christmas Carol.

Here is the original

**Christmas Commercialisation: Bah Humbug**

*Now the holly bears a berry as white as any milk; And all the fuss over Christmas it sure does ilk  
With all this commercialisation I think have we lost the plot, Should I say "Bah Humbug" and not give a jot*

*Now the holly bears a berry as pink as any rose; And we all love Christmas the media suppose  
With all this commercialisation I think have we lost the plot; Should I say "Bah Humbug" and not give a jot*

*Now the holly bears a berry as yellow as the sand; And repeated TV programmes are getting out of hand  
With all this commercialisation I think have we lost the plot; Should I say "Bah Humbug" and not give a jot*

*Now the holly bears a berry as brown as the earth; And some Christmas presents cost more than they're worth  
With all this commercialisation I think have we lost the plot. ;Should I say "Bah Humbug" and not give a jot*

I just kept finding more colours to rhyme but it is still sung to the same gentle lilt, with a Christmas message at the end. Well I'm not a total grump! Merry Christmas!

Trev

