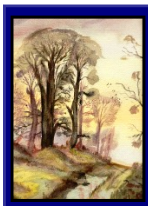


Pathways

Price £ 3.75 (Free to members)

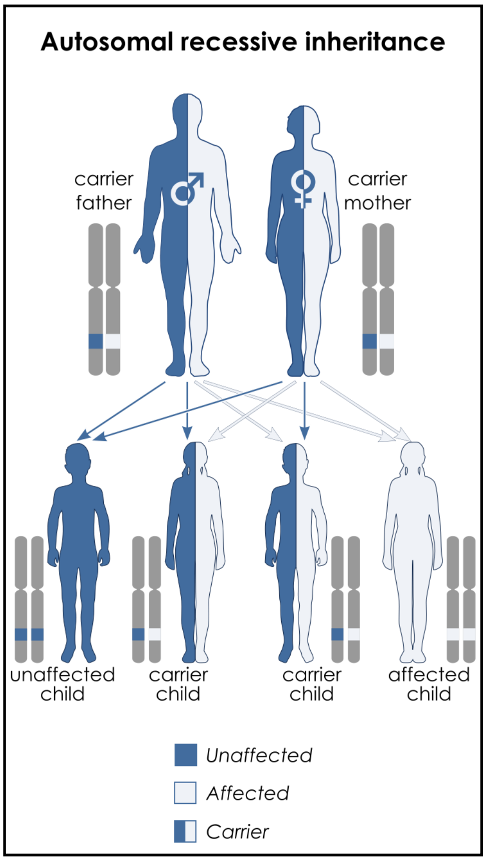
The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Welcome to Pathways No. 53. (Autumn 2017)

Rowan (Sorbus aucuparia) Berries
It is also known as Mountain Ash.
Picture taken in the of Autumn 2017
Scawsby area of Doncaster.

Your Write In

June writes: I've been following the Charlie Guard case. If you remember, Charlie was a baby born with mitochondrial DNA damage. This is a rare genetic condition that causes progressive brain damage and muscle failure, including the muscles needed to breathe. There is no treatment, and it causes death in infancy. The parents brought him to a London hospital for treatment, but eventually they decided that all they could do was give him palliative treatment (to relieve symptoms) and allow nature to take its own course. We them heard reports about experimental treatment in the USA and a court battle for access ensued. We all knew about the outcome. I see many features in Pathways about mitochondrial involvement with ME/CFS, patients don't die from it. Have you any thoughts about this?



Firstly, in the case of Charlie, there was no chance of a normal life because the he was born with defective Mitochondrial DNA. In the past these children would have died from cot death or 'failure to thrive'. The situation was made clear to the parents but desperation they tried every strategy they knew to disprove the hospital, a process known as denial. I once spoke to an experienced nurse about a similar case, and she thought that the parents were being selfish and not thinking about the best interest of the child. Professionally, I've seen this happening in some case with terminal cancer. I think that the parent should have had better counselling—and it didn't help when the American preacher got involved. Then of course the Pope and President Donald Trump put their offers in. The parents look the right sort of age to try again for a baby, but ideally, they should receive genetic counselling first. They may have to resort to test tube strategies to select a disease-free embryo. The recently licenced three parent technique is designed to overcome these types of inherited diseases. Regarding mitochondrial disease and ME/CFS. There is increasing evidence that mitochondria are damaged. But in these cases, people are born with normal Mitochondrial DNA, it is damaged by some disease process which is at present still speculated about. The medical term for is 'acquired disease'.

Gwengie Writes: Regarding Janes letter about Metformin in Pathways No. 52. I had the same problem with metformin and tummy problems. I managed to work around the problem by drinking peppermint tea. I did discuss it with my doctor, and he prescribed me peppermint oil capsules on the NHS. I think it has had a positive effect on my IBS as well.

Does anyone else out there have any similar experiences?

Bill writes: I'm a member of our local village gardening club, and we all pride ourselves on growing and eating our own food produce. This year I had a bumper cherry crop from one of his trees. This coincided with my wife buying him one of these bullet style smoothie makers. Having plenty of cherries to hand he tried macerating them into a smoothie. I found it tasted of almonds with a cherry type flavour. Within 25 minutes I felt extremely tired and had a headache. I was rushed into the local accident and emergency hospital department, where was treated with the stomach pump, and given a cyanide antidote. I recall what came out of his stomach container being blue. I was ill for a few days—but will not eat any more cherries. I was also was too traumatized to talk about it at first. Any idea about what had happened?

Well, Agatha Cristae fans will have already guessed with the almond flavour and blue staining. Cherry stones (seeds) contain a cyanide precursor, a substance call amygdalin. This reacts with an enzyme present in separate cells within the seed. When the seed cells are damaged e.g. by maceration a chemical reaction takes place releasing the cyanide. The blue stain would be caused by the cyanide antidote converting the cyanide to an inactive form Prussian blue, the same dye used in classic paints. Macerated food usually takes longer to pass through the stomach—and that may have bought time for the cyanide took hold. It is though that this mechanism for producing cyanide is a natural defence to deter the seeds from being eaten.

Historically, wild cherry bark was an ingredient of children's cough medicines— seemed to be effective. Something similar happens which is well known to farmers. Flax seed (linseeds) can be used as an animal feed. If, however it is left mixed with water too long cyanide appears by a similar chemical process. It is a well know hazard when manufacturing linen. Other food do contain cyanide, but in very small harmless quantities and the Foods Standard Agency has all the relevant information. Incidentally, we have had a good cherry crop this year, but not seen a single red cherry. The blackbirds in our garden have a liking to green cherries, and must instinctively know about the hazards of cyanide because they leave us the cleaned stones in the bird bath!

Julie Writes: Could you do a feature in pathways for a ME Facebook support group for Doncaster please? As most towns have one apart from ours.

We are quite happy to support Facebook group or Twitter Group. All it needs is someone to volunteer to act as moderator and be responsible for maintaining the service. Would anyone out there like to volunteer.?

Rene Writes: I bank with HSBC. As many members will know, they have closed the local branches around Doncaster. If you are disabled it is difficult to access the Doncaster branch because it is in the town centre, even though I have a blue badge. While I can draw out money at many local cash machines, I have problems paying in. I contacted HSBC and they told me the I can pay in via any post office branch using special enveloped for the purpose. So, I called in at the nearest post office. This is a post office run by a chain of *first call* type shops. I had to wait my turn because there was only one assistant at the counter, who normally works the post office side. After waiting five minutes I finally managed I asked about the HSBC paying in envelopes. They denied all knowledge of such an arrangement. I was very frustrated, and feeling quite sore and tremor as you do if you have ME/CFS. So, I thought I would try the local post office across the Great North Road. There were specific parking places so that I could just get out of the car and walk a few years into the shop. As soon as I walked in I was approaches by an assistant who ask how she could help me. I was directed to the post office counter as the back of the shop. I had to pass a display counter of greeting and cards and stationary which is traditionally typical of more well-run post offices. Although there were a couple of people queueing they were quickly dealt with an it became my turn. I asked about HSBC paying in envelopes. The assistant disappeared and shortly returned with a handful of envelopes. She gave me them saying ‘’Take these and fill in your paying in forms before you come next time. It will save you queueing”. In noted that cheques I had paid in took a day long to appear in my account. I know which post office I will be visiting in future.

John writes: I had an Amazon return. I took it to one of the *first call* type post offices. There was only one assistant on duty and she was busy at the general counter. There was a lady waiting to do some post office business. I had queued about ten minutes when I was told to stand back because the lady this lady had confidential business. There was no sitting or waiting area. So, I complained. Instantly the manager appeared out of a back room welding a cup of tea. I told her about me being disabled and it being painful for me to stand. She was deferent. So, I explained, and she was more deferent, so I just thrust the parcel—told her all that was needed was to scan the barcode. A few hours later, I checked and I was reported as having been received on the Amazon website. I have worked in retail for many years and been a manager for almost as many. One thing that I would not have done is leave on assistant female assistant alone on the shop floor and vanish into the back room. It’s just bad management.

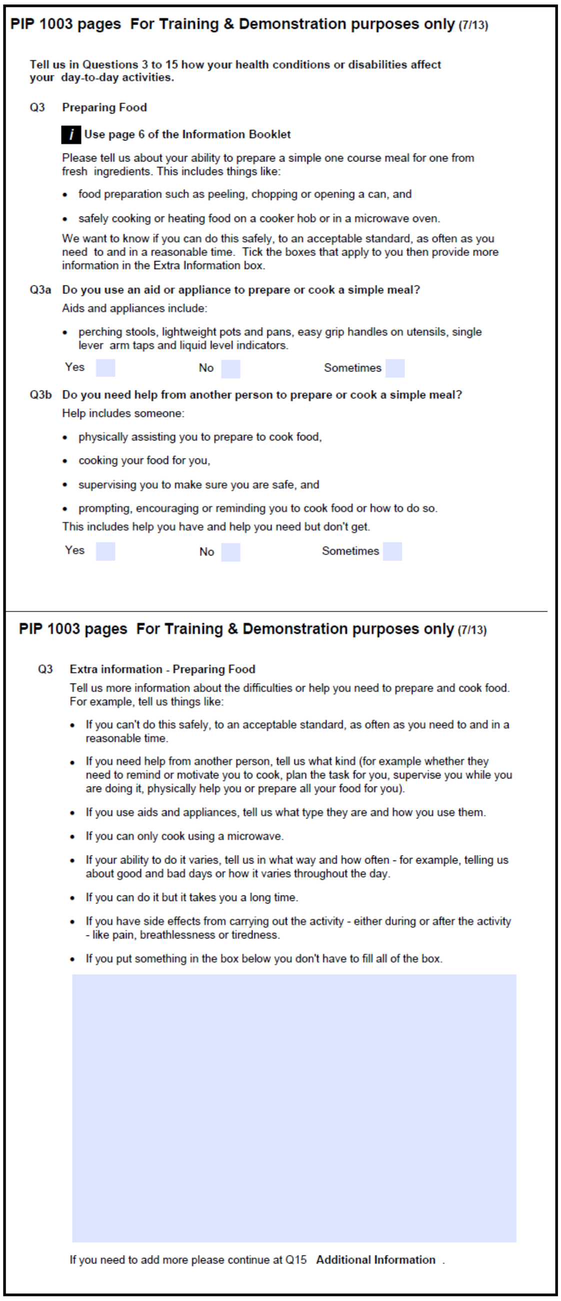
There is a vast different between the experience of the two local post offices. I know which I would use. On a separate note, Leger ME uses an HSBC bank account, and when a cheque is received it must be posted via by the post office to the HSBC cheque clearing centre. We normally wait until we have a number to cheques because of the cost of postage. On the membership forms we include the bank account details for all members who want to make a BACS or direct payment. The vast majority of subscriptions are paid into the bank account directly. We are considering changing banks for this reason. If you prefer to pay cash at the group meeting, there are ways to send cash to HSBC not involving the post office.

Welfare rights: The New Personal Independence Payment (PIP) Review form.

With thanks to Aileen for bringing this to our attention.

Over the last twenty years or so to get any welfare rights payment, members have been bombarded with many forms. Most of the forms have been for claims which have resulted usually in a fixed term award. PIP is the most recently introduced a review form, and we are beginning to see long awards over many years. However, the DWP have always made it clear that any changes that may affect your level of entitlement whether should be reported. While in the past this has been a voluntary arrangement this looks like the future DWP strategy. Such a form has been received by one of our members in Scotland. The form is different to anything we've seen before asking about changes since the last form was submitted. We've included an example of the original PIP claim forms alongside of the PIP review forms.

PIP Claim form



PIP 1003 pages For Training & Demonstration purposes only (7/13)

Tell us in Questions 3 to 15 how your health conditions or disabilities affect your day-to-day activities.

Q3 **Preparing Food**

i **Use page 6 of the Information Booklet**

Please tell us about your ability to prepare a simple one course meal for one from fresh ingredients. This includes things like:

- food preparation such as peeling, chopping or opening a can, and
- safely cooking or heating food on a cooker hob or in a microwave oven.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time. Tick the boxes that apply to you then provide more information in the Extra Information box.

Q3a **Do you use an aid or appliance to prepare or cook a simple meal?**

Aids and appliances include:

- perching stools, lightweight pots and pans, easy grip handles on utensils, single lever arm taps and liquid level indicators.

Yes ☐   No ☐   Sometimes ☐

Q3b **Do you need help from another person to prepare or cook a simple meal?**

Help includes someone:

- physically assisting you to prepare to cook food,
- cooking your food for you,
- supervising you to make sure you are safe, and
- prompting, encouraging or reminding you to cook food or how to do so.

This includes help you have and help you need but don't get.

Yes ☐   No ☐   Sometimes ☐

PIP 1003 pages For Training & Demonstration purposes only (7/13)

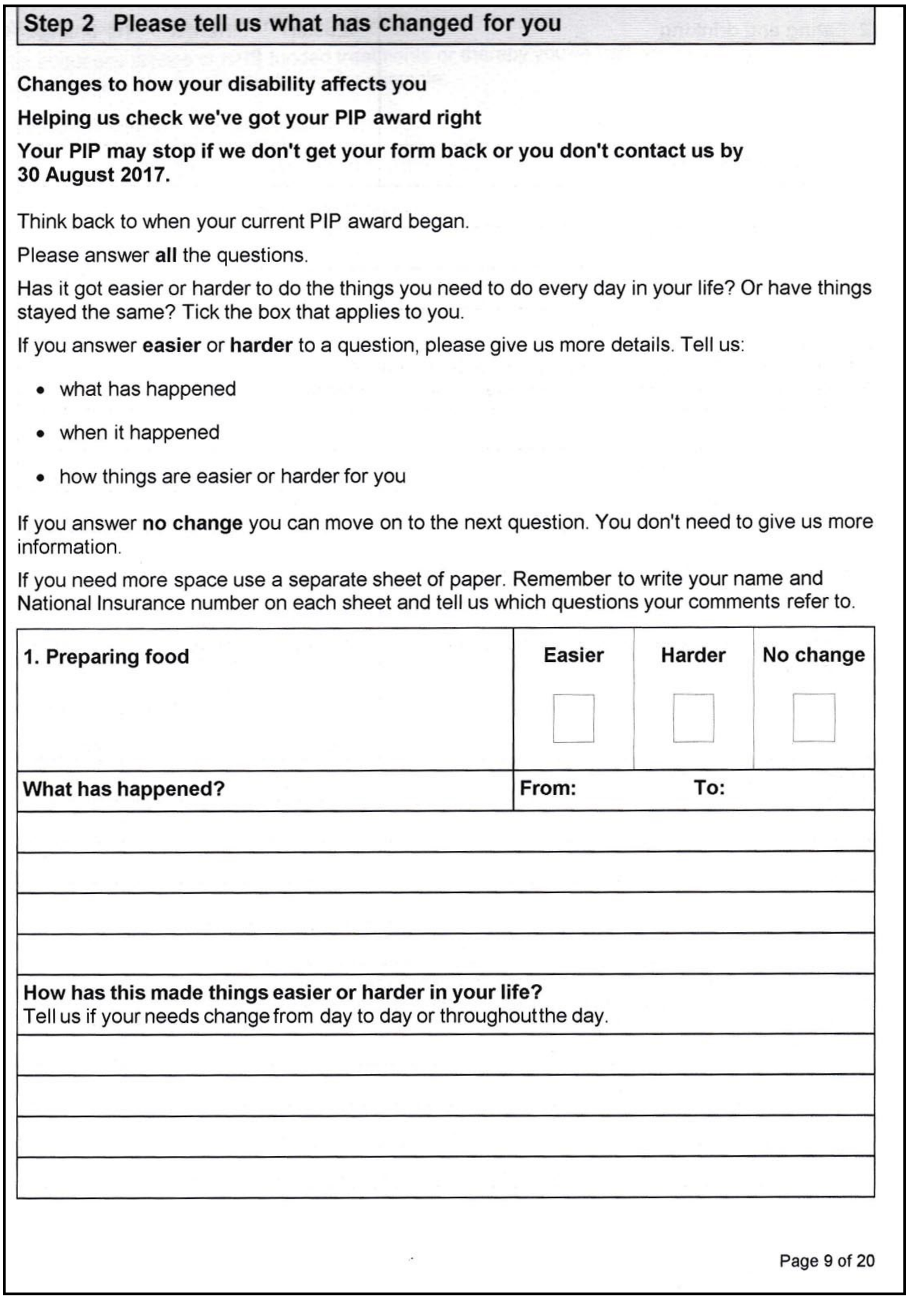
Q3 **Extra information - Preparing Food**

Tell us more information about the difficulties or help you need to prepare and cook food. For example, tell us things like:

- If you can't do this safely, to an acceptable standard, as often as you need to and in a reasonable time.
- If you need help from another person, tell us what kind (for example whether they need to remind or motivate you to cook, plan the task for you, supervise you while you are doing it, physically help you or prepare all your food for you).
- If you use aids and appliances, tell us what type they are and how you use them.
- If you can only cook using a microwave.
- If your ability to do it varies, tell us in what way and how often - for example, telling us about good and bad days or how it varies throughout the day.
- If you can do it but it takes you a long time.
- If you have side effects from carrying out the activity - either during or after the activity - like pain, breathlessness or tiredness.
- If you put something in the box below you don't have to fill all of the box.

If you need to add more please continue at Q15 **Additional Information** .

PIP Review form



Step 2 Please tell us what has changed for you

Changes to how your disability affects you

Helping us check we've got your PIP award right

Your PIP may stop if we don't get your form back or you don't contact us by 30 August 2017.

Think back to when your current PIP award began.

Please answer **all** the questions.

Has it got easier or harder to do the things you need to do every day in your life? Or have things stayed the same? Tick the box that applies to you.

If you answer **easier** or **harder** to a question, please give us more details. Tell us:

- what has happened
- when it happened
- how things are easier or harder for you

If you answer **no change** you can move on to the next question. You don't need to give us more information.

If you need more space use a separate sheet of paper. Remember to write your name and National Insurance number on each sheet and tell us which questions your comments refer to.

1. Preparing food	**Easier**	**Harder**	**No change**
	☐	☐	☐
What has happened?	**From:**	**To:**	
How has this made things easier or harder in your life? Tell us if your needs change from day to day or throughout the day.			

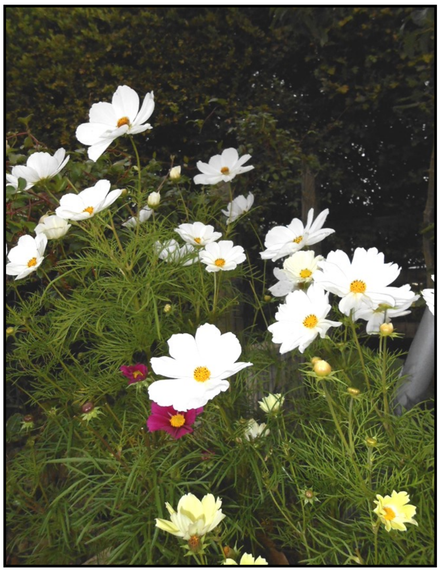
Page 9 of 20

Although some may think that the form is a public relations exercise, it is quite clear that from the information requested, that is effectively ending the original award, and claiming afresh. It also means that medical evidence has be submitted. Do-it-yourself DWP forms are the biggest cause of benefit refusals. As with all DWP forms our advice is not do fill them out yourself without the help of a welfare rights advisor. Drafting forms and Work and Benefit guides are available from the Leger ME office for fully paid up Leger ME members upon request to the Leger ME office.

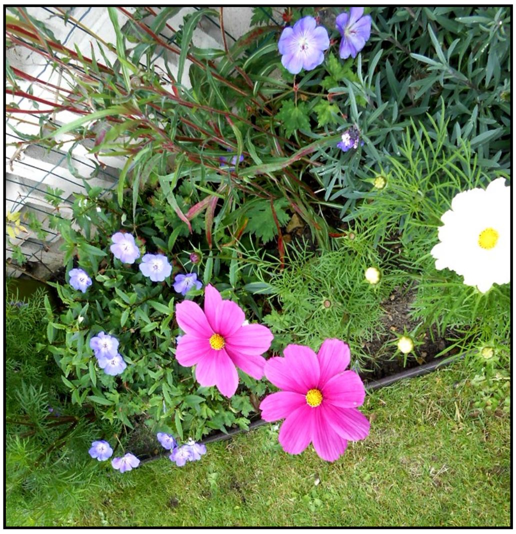
Garden Watch: Summer *by Carolyn*

Summer, did I hear `what Summer`! I do have a now rather distant memory of us enjoying a few evening meals on the patio back in June. Surprisingly though, even with the poor weather we have a back garden full of flowers at the moment, it feels like the garden held its breath through July and then all of a sudden everything bloomed at once. The young orchard area has been full of fruits for the first time with delicious Comice Pears, Cox`s Apples and the Greengages and yes, they turned out to be greengages and not plums - tasted so good. Even the blackberries did us proud although they kept disappearing off the bush in the beak of our resident Blackbird who we found out is also partial to a nice juicy pear!

Colour showtime



I needed colour for the garden this year and chose to plant Cosmos, a plant I knew nothing about really and what a success that has been. I have dead headed them regularly and they are still in full flower though we are now well into September. I am going to collect seed from certain ones in order to grow them again next year. I know now which height and colours I like best so I will be able to place them in the border for the best display next year. The Cosmos in pots and containers have done just as well as those planted directly into the ground but I will remove them soon so that the spring bulbs which are also in those pots and containers can start to push through again.



Talking of bulbs, I have ordered 60 fragrant Poeticus Narcissi (the Poet`s Daffodil) to add in with the existing daffodils the idea being to extend the season as they flower after the snowdrops and daffodils, mid-April to May. Have also just planted out some native primroses into the orchard area for May flowering along with the bluebells, and am having fun and games with the slugs and snails that would like to eat them! Luckily the hedgehog family is still around most nights so they help with clearing the slugs from the garden.

I now have a dilemma though as having ordered the spring flowering bulbs I wanted, I now find that the company are sending me some `freebies` -50 trumpet daffodils and 30 tulip bulbs! That`s my kind of nightmare as I really don`t like trumpet daffs and I hate tulips!! However, I have a plan for the free daffs bulbs as a member of the family has just moved to a house with a very large garden; they will be getting a present! As for the tulips, well I must admit that the picture of the `Ronaldo tulips` in a deep velvety red, almost black colour looks interesting, so I`ll be planting them down one side of the front garden; don’t need to look at them from any windows but can observe how they do.

Unexpected addition to big pond

I wonder if any of you remember the tiny little fish that arrived with some frogspawn a group member gave to us last year and who lived through winter in the wildlife pond, we thought it was a minnow?

When I came to clean out the pond in springtime I got a shock to find a rapidly growing fish that definitely was not a Minnow at all! The fish which we now know is a Goldfish, remains dark brown in colour. `Minnow` as she will always be known, has now joined the other three goldfish in the deep fish pond and is settled and doing fine. It is a happy outcome because the young frogs have also kept returning to the wildlife pond through Spring and Summer and it was getting a bit crowded with a fish in there as well!!

The star indoors this year has been the White Orchid I was given as a Christmas present last year. It has bloomed again with very little help from me apart from watering it and keeping it on a nice light windowsill. When the flowers die off I plan to repot it and hope it flowers yet again this Christmas.

Garden visitors

In addition of the birds and squirrels, we get frequent night visitors. Usually at around 10.00pm we hear definite chomping and something disturbing the bird feeder trays in the garden. Roo our dog knows that there is something around, but usually just can`t find it. When we go for a look, whatever it is make a rapid discreet exit. If we are quick and quiet and turn on the lights, we see we have hedgehog visitors. So far, we’ve seen two small ones and one big one. I put on a couple of thick leather gardening gloves and brought the big one into the house. We took his photograph and put him back to where we had picked him up.

The `one-night wonder plant` is our lemon evening primrose as that is exactly what the flowers do, they open overnight and last for the following day and then die. So long as they are regularly deadheaded, they flower for months and are always a joy to see.

There is plenty to do in the garden, as well as planting all the new bulbs, it must be tidied up for the winter months and the nicest job of all for me will be to buy a new bird feeding station so we can enjoy watching the wild birds that visit the garden through Winter time.

ME/CFS Politics: Medical Abuse of ME Sufferers Campaign (MAIMES)

With Thanks to Dr. Myhill. Presented as received unedited. Please see editors' comments over page.

Dr. Myhill has formed the MAIMES campaign - Medical Abuse in ME Sufferers - and the preliminary but very important stage in this campaign is detailed below. Dr. Myhill is in contact with very many support groups and is sending out the same message to them.

For decades PWME ('People With ME') have been subject to medical abuse by doctors who have repeatedly refused to accept that this illness has a physical basis. The evidence for this is:

- Patient testimony. PWME suffer clear physical symptoms but are told by their doctors that these are "all in the mind". They are made to feel like hypochondriacs. As a result, PWME have been denied proper treatments, compensation, disability and pension rights.
- Such abused patients have organised themselves into support groups. These groups have lobbied valiantly but have failed to achieve proper recognition for their disease. These groups include: Gulf War Veterans, carbon mon-oxide poisoned PWME, Sheep Dip flu PWME, Aero toxic pilots, 9/11 fireman, survivors of silicone PWME, sick building syndrome, mercury amalgam poisoned PWME, Lyme disease and co-infections and many others at home and abroad.
- PWME are at best referred to a team in which a psychiatric and symptom suppressing approach is applied. The psychiatrists employ two "therapeutic" tools namely Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET). These tools were subject to a Government funded trial (called 'PACE') which purported to show evidence of their effectiveness. This study has now been shown to be scientifically flawed. The PACE trial is at best incompetent and at worst a fraud and yet its conclusions are still believed and applied to PWME. In consequence, the above abuses were and continue to be perpetrated. Patients have been given wrong advice, their condition has worsened and state welfare and other benefits have been denied based on this incompetent and potentially fraudulent study.
- Doctors who recognise the seriousness and physiological basis of ME and treat them accordingly are targeted and prosecuted by the General Medical Council. Complaints against these doctors have arisen because their recommendations do not conform with conventional medical treatments and NICE guidelines.
- NICE Guidelines contain no logical, evidence based treatment for PWME. By contrast practitioners working outside conventional NICE Guidelines have established many effective treatments which are safe and efficacious and which get people back to work and off benefits. The British Society for Ecological Medicine, a group of likeminded medical doctors, spearheads many such techniques.

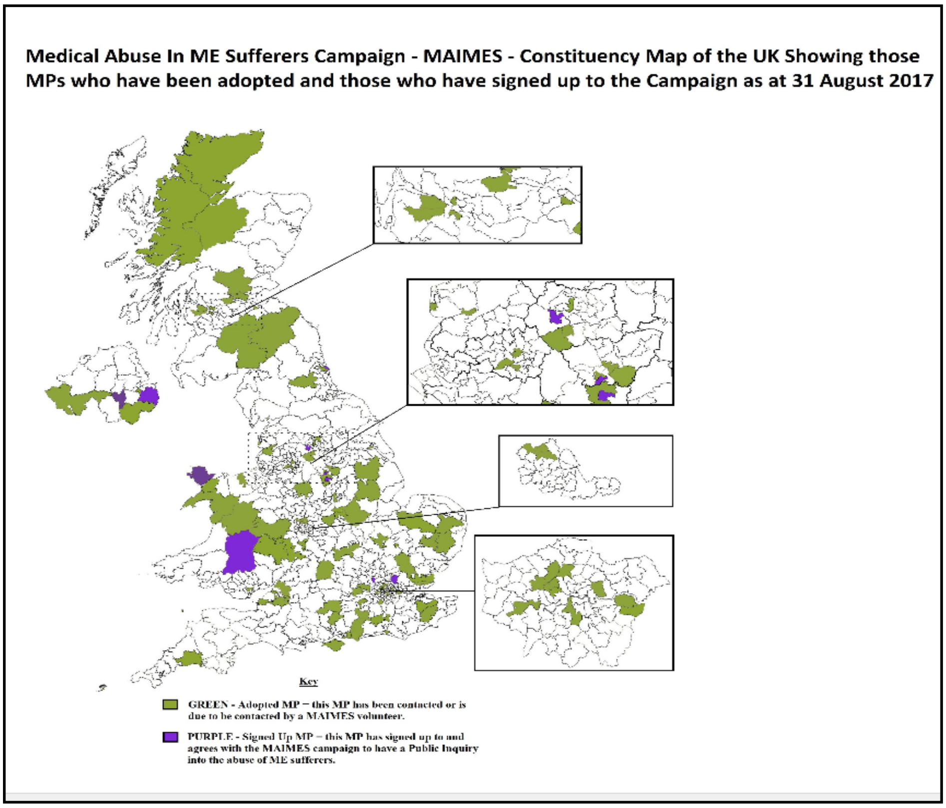
The above abuses have many parallels with the mental and physical abuse of children. Both groups are unable to properly defend themselves and are at the mercy of a misled, incompetent and ill-informed Establishment which employs many techniques to keep hold of its power-base, including cover-ups. Like the case of mentally and physically abused children it is time for a proper investigation into the abuse of ME sufferers.

Campaign MAIMEs is a drive for a Government Public Inquiry aimed at:

- Achieving proper recognition that this is a physical illness so that patients can properly access benefits and appropriate treatments. The abuses of PWME must be reversed.
- Rewriting NICE Guidelines using evidence based medicine that is logical, biologically plausible and with a proper scientific evidence base.
- Establishing that PWME should be treated by practitioners with specialised training in the physical causes of ME. These practitioners should include doctors, nutritional therapists and experienced patients.

Jargon buster

- An Adopted MP is an MP who has been contacted or is due to be contacted by a MAIMES volunteer. An adopted MP has not yet signed up to the campaign. MAIMES volunteers can still arrange to meet these MPs and try to convince them. See below for more details!
- A Signed-Up MP is one who has signed up to the MAIMES campaign to have a Public Inquiry into the abuse of ME sufferers



Medical Abuse In ME Sufferers Campaign - MAIMES - Constituency Map of the UK Showing those MPs who have been adopted and those who have signed up to the Campaign as at 31 August 2017

Key

🟩 GREEN - Adopted MP – this MP has been contacted or is due to be contacted by a MAIMES volunteer.

🟪 PURPLE - Signed Up MP – this MP has signed up to and agrees with the MAIMES campaign to have a Public Inquiry into the abuse of ME sufferers.

Overview

- This is a campaign to get MPs to sign slips that will be used to demand a Public Inquiry into the abuse of ME sufferers over the last few decades. This campaign is called MAIMES.
- The first goal is to sign up as many MPs as possible to the aims of MAIMEs. Once we have sufficient MPs on side we will approach the Secretary of Health to demand a Public Inquiry.
- We first need “adopters” who are physically able to attend their MPs’ surgery and who feel that they can explain the issues as detailed below in as convincing a manner as possible! Please - we don't want anyone to feel pressurised in any way to do this. Our goal is to make people better, not worsen their condition by attempting something they are not capable of. Therefore, we also suggest family, friends or Carers getting involved where this may be possible.
- If you can be such an “adopter” please email your details and your MP’s name and constituency details to Gail (gail@doctormyhill.co.uk)
- Gail will then send the adopter a free copy of Dr. Myhill’s new book second edition: “CFS/ME – it’s mitochondria not hypochondria”. Your chosen MP becomes 'Adopted' at this stage
- Attend your local MPs surgery, give him/her the copy of the book, show them Chapter 1 and try to convince to them to sign the slip!
- If you are successful, please scan the slip and return it to Gail (gail@doctormyhill.co.uk). At this point your chosen MP becomes 'Signed Up'
- If you cannot convince your MP to sign the slip, please leave them with the more detailed ‘MAIMES letter’ - see below for link to detailed MAIMES letter. Please also continue to contact your adopted MP and try to convince them via sheer persistence!
- If your constituency MP has already been adopted by someone else, then you can still try and convince them - use the information below and either visit your MP or email them. The more people who contact their constituency MPs in this way, the better!
- Also, if you want to go in groups to visit your constituency MPs then please do - this will also improve things as it will mean that there is less chance of brain fog getting in the way of persuasion - two heads are better than one!
- Or if you feel that friends and family or your carer or anyone could act on your behalf then that would be great too!

Editors Comment

- *This campaign seems to be mainly lead by Dr. Myhill. Unless I’m wrong, I don’t think the ME Association or Action for ME, the two main National ME/CFS Charities are involved. I’m not really content about this.*
- *The second issue is that she seems to be giving away the latest edition of her book. Is this a genuine philanthropic act or just a promotion gimmick?*
- *While I totally agree with the campaign objectives, I have reservations about approach. I’ve dealt with MP’s and campaigns before. It needs things clearly explained with definite and simple objectives by people with the necessary experience to put the case forward.*
- *I see plenty of inappropriate treatment with the NHS and certainly even more systemic abuse with the DWP and Benefits system during daily group business.*

Welfare Rights Matters *With thanks to Steve Donnison and Benefit and Works Newsletter*

Even by our standards this is a pretty gloomy newsletter. We have the disappointing news that the success rate for disability living allowance (DLA) to personal independence payment (PIP) transfers is almost at the lowest level has ever been. Then there is the unsurprising news that a survey has found that PIP assessments are harmful to your health. There is the revelation that repeat testing of ESA claimants is back with a vengeance. There are now more repeat assessments than fresh claims, in spite of a DWP promise to stop unnecessary testing. And the number of warnings that speeding up the universal credit rollout from next month will lead to a catastrophe for claimants is growing. There is, though, the slightly more positive news that whilst the backlog of social security appeals has almost doubled in the last year, claimants continue to win in the majority of cases except in connection with one benefit. Finally, we would like your feedback on whether you have used our PIP GP Notes, before we decide whether to create a similar resource for ESA.

DLA to PIP award rates fall to almost record low

The latest figures from the DWP show that award rates for DLA to PIP have fallen to their lowest level almost since the transfer of DLA claimants began. In January 2017, 72% of DLA to PIP claimants received an award, rising to a high of 75% in March 2017. However, the award rates have now been falling for the last four months for which figures are available. In July 2017, the award rate for DLA to PIP reassessments had fallen to 68%. Only in January and February 2014, when reassessments first began on very small numbers of claimants, were success rates lower.

Work Capability (ESA) repeat assessments at highest ever level

Back in 2014, Benefits and Work broke the news that all repeat WCA medical referrals to Atos were to be stopped until further notice, due to a massive backlog of cases. We can now reveal that the number of repeat assessments has risen to a record high since they were reintroduced in December 2015. In the quarter to March 2017, the most recent for which figures exist, there were 154,200 repeat WCAs. This is more than double the number carried out in the same period last year, which stood at 72,000. It means that, in the most recent quarter, 54% of all WCAs were repeat assessments as opposed to 42% which were initial claims. Yet in October 2016 the secretary of state for work and pensions, Damian Green, told MPs We will stop reassessing people with the most severe health conditions and disabilities. *(That’s why we recommend sending in medical evidence).* Green went on to say that the IT changes needed for the new system would be completed by the end of 2017, but in the meantime, we will be working to ensure these people are not reassessed unnecessarily. The latest figures suggest that the exact opposite is happening.

PIP assessments harmful to health and income

It will come as no surprise that a survey by the Disability Benefits Consortium has found that 79% of claimants reported that the stress and anxiety of the PIP assessment process had made their health worse. In some cases, people said that the experience of claiming PIP was so distressing that it had caused new conditions to emerge. The survey also found that almost three quarters (71%) of respondents found the PIP application form had or very hard and 11% of respondents were unable to complete it at all. Over half (58%) of people said that assessors did not understand their condition. Half (50%) they were receiving less money under PIP than they were previously entitled to under DLA, or they had lost their award completely.

Universal Credit: Disaster and catastrophe

Citizens Advice has warned the government that its plans to massively speed up the rollout of UC from next month will cause a disaster. The chair of the work and pensions select committee, Frank Field, meanwhile has warned that it will be a catastrophe. Both are particularly concerned about the massive hardship caused by the 6 week wait for a first payment, which is often made even longer by processing problems. Citizens Advice say that the expansion of UC is 'a disaster waiting to happen', as new findings show it is pushing people further into debt. Frank Field was even more outspoken, warning of a human and political catastrophe€. He said that his committee was: Hearing evidence of people being plunged into all sorts of vulnerability as a result of the debt, risk of hunger and homelessness, and resulting stress of being migrated onto Universal Credit, with its in-built 6 week delay in receiving a first payment and much longer waits for many people. "People already on low incomes simply cannot cope without any income for such a long period of time.” An announcement from the secretary of state about whether the rollout will be delayed is expected next month.

Claimants win majority of growing appeals backlog

The number of social security claimants waiting to have their appeal heard has increased by 88% in a year, according to the latest tribunals service statistics. The vast majority of these cases are PIP at 46% and ESA at 38%. And, whilst around 80% of claimants continue to lose at mandatory reconsideration stage, those who go on to appeal have a very good chance of success. 68% of ESA claimants won their appeals, as did 65% of PIP claimants. The success rate was lower for the small number of DLA appeals, at 55%. But only for JSA, where the success rate was 49%, is the DWP able to say they won in the majority of cases. The message remains clear: you won’t get a fair result from a mandatory reconsideration, but you might well do from an appeal tribunal.

BDA The Association of UK Dietitians

Food Fact Sheet

Eating without wheat

This fact sheet is intended as a basic guide to eating wheat free.

How careful do I need to be?

If you have been diagnosed with a wheat allergy, you will have to be very careful with what you eat and avoid any food containing even the smallest amount of wheat. If you are intolerant to wheat you may not react to trace amounts and may not need to be so careful. You need to check with your doctor or dietitian to see how sensitive you are. Your doctor or dietitian will advise whether you also need to avoid rye, barley and oats as well as wheat.

It is also important to check with your doctor that you do not have coeliac disease (a sensitivity to gluten in wheat and other cereals) before excluding wheat. This is because the blood test that is used to diagnose coeliac disease needs enough gluten to be present in your diet for it to be accurate.

Some gluten free foods may contain wheat starch where the gluten has been removed. These are therefore not suitable if you have wheat allergy.

Also, wheat free foods may not be gluten free if they contain rye, barley or standard oats. It is important to always check labels.

Where is wheat found?

Wheat is a grain. Wheat is a main ingredient of many foods such as: breads, chapattis and naan breads, breakfast cereals, biscuits, crackers, crumpets, scones, pancakes, wafers, cakes, pizza, pasta, pastries and Yorkshire puddings. It is also found in many convenience foods such as soups, sauces, spices, malted drinks, processed meats and ready made meals.

Always check the label

Under current EU law, wheat along with other common allergens, must be clearly labelled on packaged foods and drinks. These allergens have to be clearly emphasised e.g. in bold or highlighted. For foods sold without packaging e.g. in restaurants, cafes or delicatessens, allergen information must be provided in writing or verbally.

Ingredients or foods to avoid

The following are all types of wheat or ingredients which contain wheat:

breadcrumbs	hydrolysed wheat protein	wheat bran
bulgar wheat	kamut	wheat germ
couscous	rusk	wheat gluten
durum wheat	semolina	wheat malt
einkorn, emmer, farola, freekah	spelt	wheat starch
flour/unbleached flour	triticale	whole wheat

Are there any alternatives?

There are many foods that can be used as a substitute to wheat that will provide variety to your meals and help you get all the nutrients you require from your diet.

These include:

There are now many wheat free products available to buy from supermarkets, health food shops and online.

Grains	barley, corn, maize, millet, quinoa, rice, rye buckwheat and sorghum
Flours	barley, bean, buckwheat, corn, gram, lentil, millet, pea, potato, rice, soya, oat, teff, coconut and tapioca
Flakes	barley, buckwheat, millet, rice and soya
Others	amaranth, ground nuts e.g. almonds, oats, polenta, sago, soya, tapioca and quinoa

Remember that ‘wheat free’ does not mean a product is gluten free as other grains contain gluten. ‘Gluten free’ does not mean a product is wheat free as gluten can be removed from wheat making it gluten free but all the other parts of the wheat are still there.

Useful tips

Breads: There are a wide range of brands available in supermarkets, health food shops and online. Crackers, crispbreads, rye crackers, oatcakes, corn cakes and rice cakes can be used in place of bread for meals and snacks.

Batter and breadcrumbs: are made from wheat flour. Try wheat free alternatives or finely crush cornflakes to make a good substitute for breadcrumbs.

Sausages: often contain rusk and so contain wheat but wheat free alternatives are available in supermarkets, butchers shops and meat producers at farmers markets.

Chinese and Thai dishes: containing soy sauce will contain wheat as soya sauce contains wheat. At home try a Japanese variety of soy sauce made without wheat.

Gravy: try vegetable stock or wheat free stock cubes and thicken with corn flour. If a little colouring is needed add gravy browning. Look for wheat-free instant gravy products too.

Pasta: There are many wheat free pastas available made from other grains such as corn, rice, buckwheat, bean flours or quinoa. Try not to overcook them as they may break up.

Sauces: To make sauces use a wheat free flour such as corn, rice or potato to thicken the sauce. To prevent lumps forming, first mix the flour with a little cold water. Heat the milk (or milk alternative if using) in a pan. Add a small amount of the liquid to the cold mix and stir whilst continuing to add all the liquid. Then add any flavouring e.g. cheese, parsley.

Beers and Lagers: are mostly made from barley. However some beers are made from a mix of barley and wheat and some European beers are made from wheat. Check the can or bottle to see which grains are used or contact the relevant brewery to check. There are also now many gluten free and wheat free beers available to buy but do check ingredients labels carefully.

Baking: wheat free flours have different baking properties to wheat flour but can make tasty biscuits, cakes and pastries. Be extremely accurate with weights and measures – always use scales and measuring spoons. Use a wheat free baking powder, available from most large supermarkets and health food shops.

Ready blended self-raising and plain wheat free flours are readily available. Xanthan gum is a useful ingredient that can be added to improve the texture and help to bind the mixture. When making your own pastry, chill for 20 minutes before rolling it out between two sheets of cling film to stop it from sticking. Good flour combinations are rice and soya flour or potato and polenta flour. You could also try a ready-to-roll wheat free pastry.

Summary

Wheat is found in many foods so a wheat free diet can be restrictive. Try to replace with suitable alternatives to ensure that your diet remains balanced. For further advice, ask your doctor to refer you to a dietitian.

Further information:

Food Fact Sheets on other topics including Food Allergy and Intolerance and Food Allergy and Intolerance Testing are available at **www.bda.uk.com/foodfacts**

Useful links:

www.coeliac.org.uk
www.anaphylaxis.org.uk
www.allergyuk.org

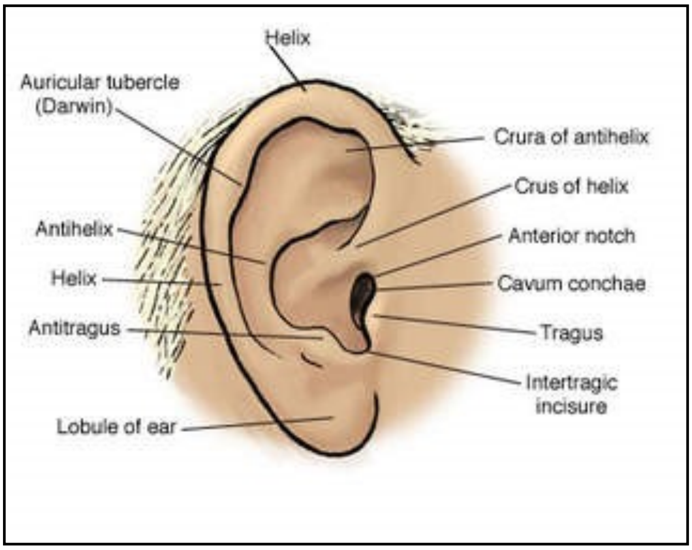
Written by Jane Calder & Liane Reeves, Dietitians on behalf of the BDA Food Allergy Specialist Group.

The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts

The Ear, and ME/CFS.

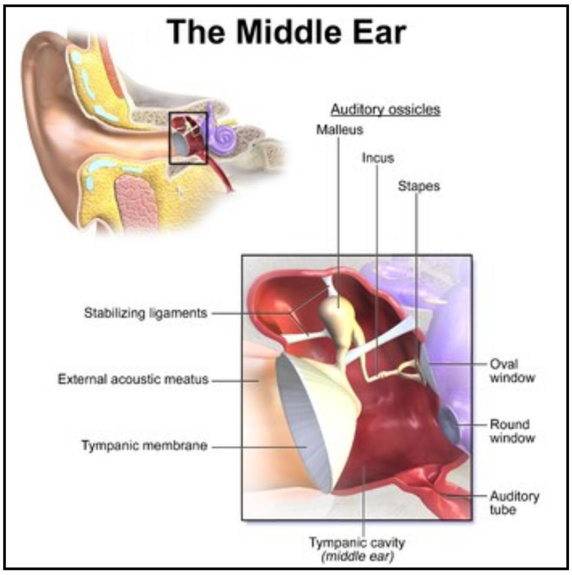
The ear is a dual-purpose organ concerned with hearing and balance. There are three main parts : The External Ear, Middle ear and the Internal ear.

The External Ear. Can be thought of as a structure to collect sound, a sort of antenna. This selectively to boost the sound pressure 30- to 100-fold for frequencies around 1 kHz. This amplification makes humans most sensitive to frequencies in this range—and explains why they are particularly prone to acoustical injury and hearing loss near this frequency. Most human speech sounds are also distributed in the bandwidth around 1 kHz. The sounds are then funneled down the auditory canal to the ear Drum



The Ear Drum (tympanic membrane) can be thought of as a microphone to convert sound into mechanical vibrations. It is a thin normally transparent structure tensioned so that it vibrated when sound is received. The image to the right is what the doctor sees when he looks through an otoscope as someone's ear. It forms the border of middle ear.

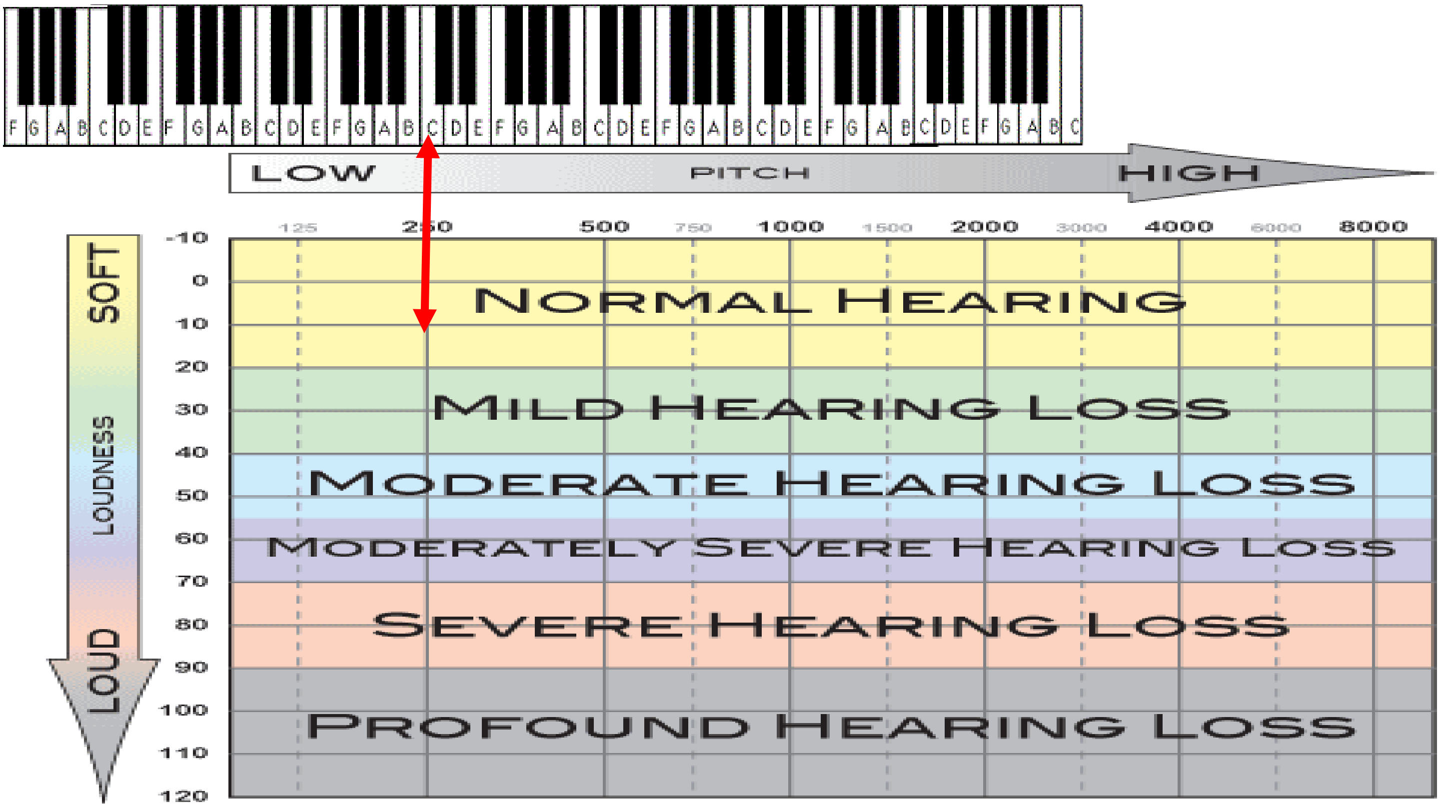
The Middle Ear is where three of the smallest bones in the body are to be found, hammer (malleus), anvil (Incus) and stirrup (stapes). The hammer tensions and transmits sound to the anvil, which in turns transmits sound to the stirrup. The stirrup in turn transmits sound to the oval window as the border of the middle ear. These bones are held in place by ligaments with tiny muscles to control the tension of the ear drum, and thus its sensitivity to sound. To equalise the pressure inside the middle ear to atmospheric behind the ear drum is the auditory tube (Eustachian tube) which connects to the back of the throat.

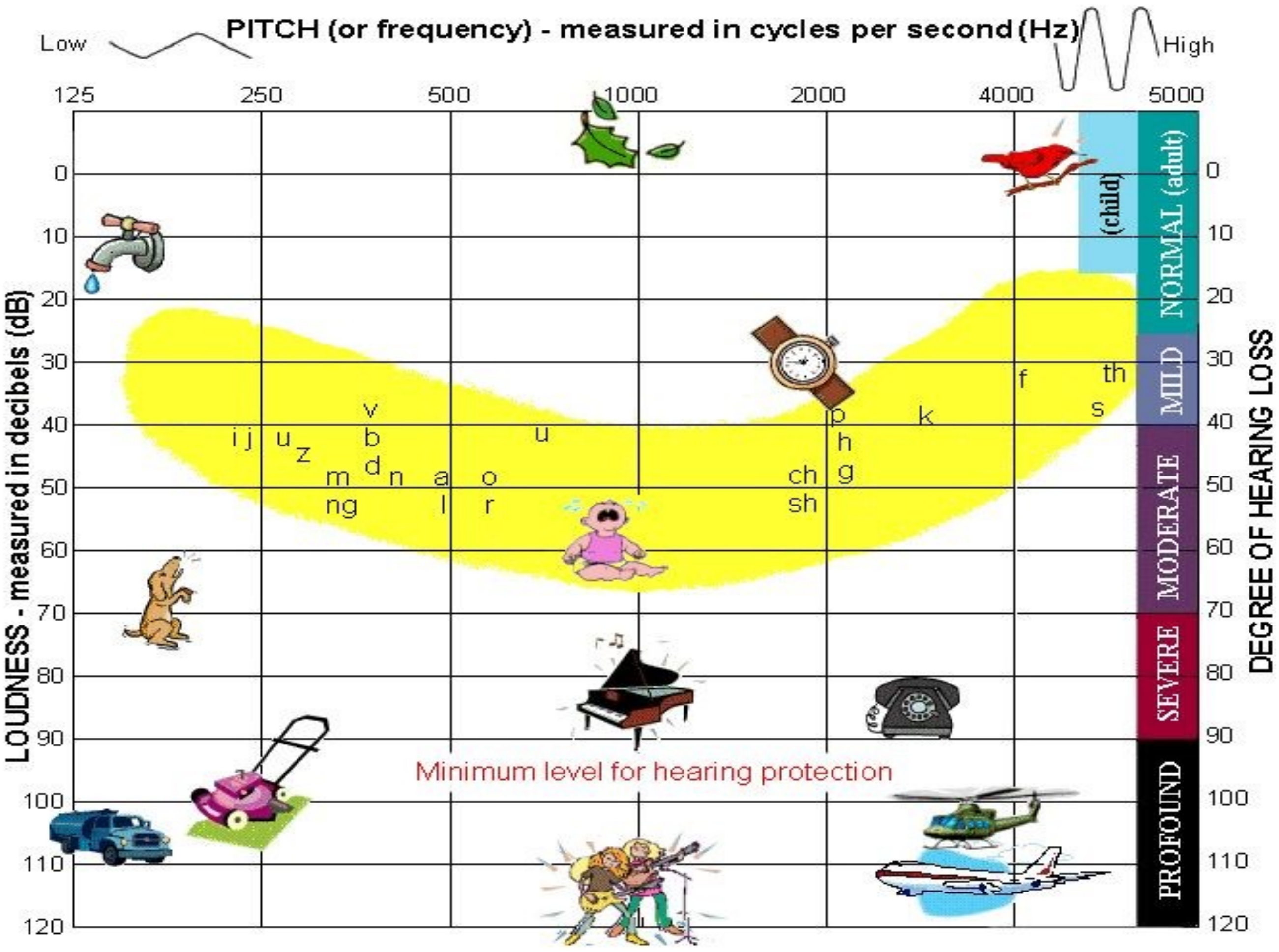


The Internal Ear is an organ that has a dual function. Firstly, there are three semi-circular ducts at right angles to ear other to detect motion. There are tubes filled with fluid which reacts to movement. Changes in the flow and pressure of the fluid are detected by tiny hairs on the inside of the tube attached to nerve cells, and converted to an electrical signal. This is then sent via the vestibular nerve to the brain for processing in the balance centre. The brain the interprets these signals and converts them to a sense of motion and balance.

Secondly, there is a snail shell like structure, fluid filled, with tiny hairs on the inside surface like the semi-circular canals. The vibration from the stirrup acts on the oval window set up a disturbance within the fluid, which the hairs detect, and convert to and electrical signal which is transmitted by the vestibular nerve to the hearing centre in the brain. It is thought that the hairs in the cochlea are pitch selective (a bit like the keys on a piano.)

For hearing assessments pitch and loudness are taken into account on an audiogram. Pitch is the frequency of the note and it measured in hertz or cycles per second. Middle C on the piano is the C nearest the keyboard over lock. It has a pitch of about 250Hz depending on the tuning (red arrow).



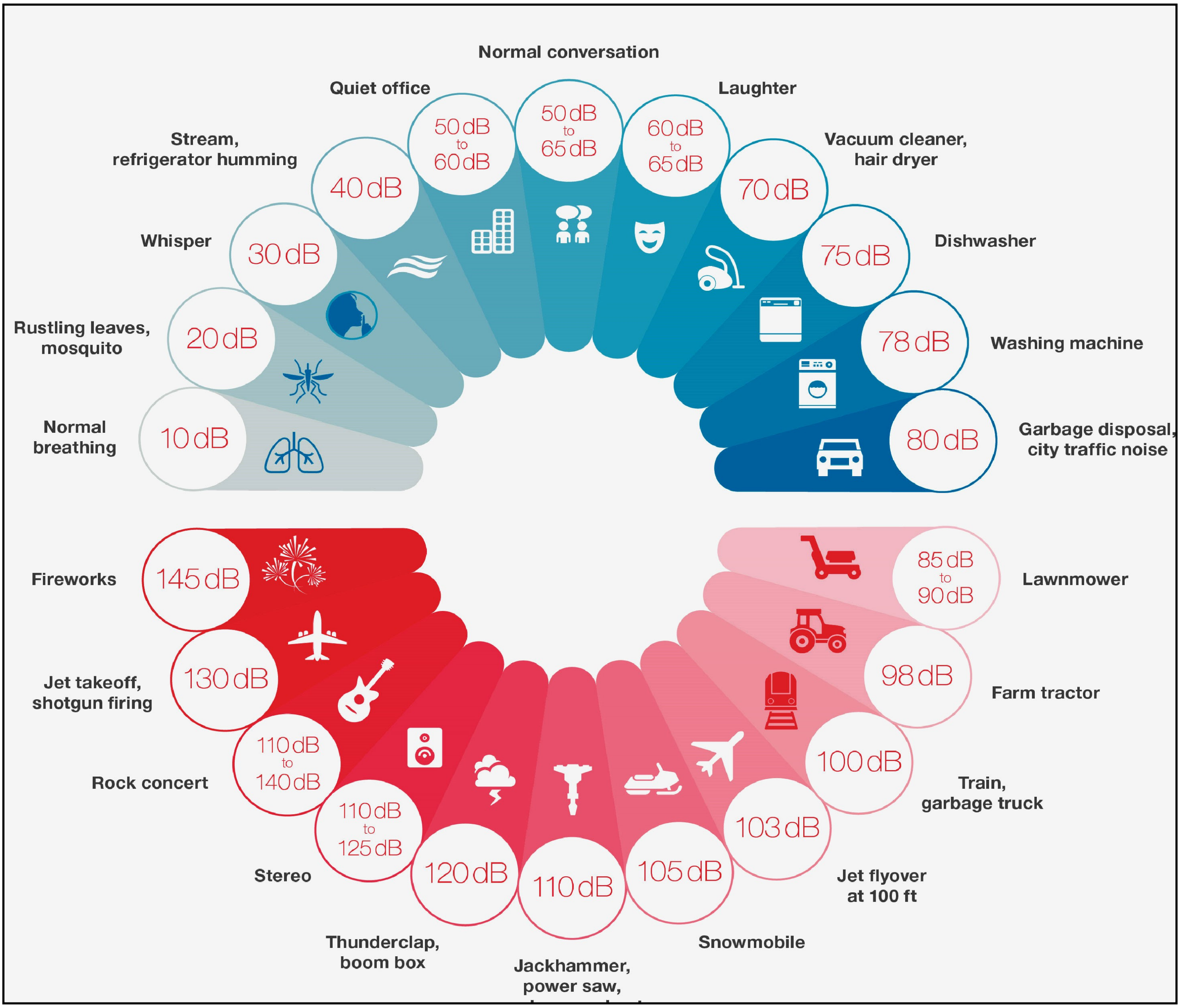


The yellow banana shape is the pitch and intensity of various sounds of the alphabet in normal speech. It is no coincidence that the sounds of a crying baby is bang in the middle of the of the audiogram.

Sound intensity and Avoiding Hearing Damage

Sounds is measured in decibels, usually abbreviated to dB. You will see this quoted on vacuum cleaners, kitchen equipment and other noisy appliances. It is often quoted in advertisements—but really means nothing unless you under understand. I came across this following diagram on the internet. The blue sounds are generally considered safe. The redder the sound, the more likely it is to cause hearing damage.

How Load is too Loud?



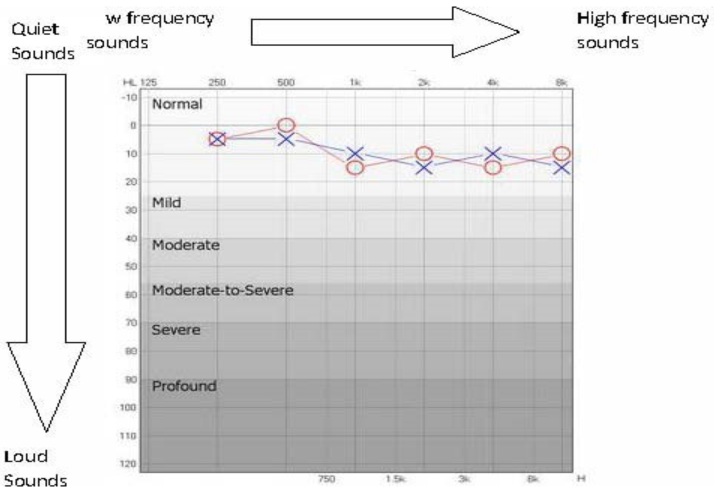
***Quick Thinking** from Roadsmart Autumn 2017*

Are you in a car being followed by a lorry or coach? Remember cars can stop more quickly than the distances quoted in the Highway Code, but heavy vehicles can't so the figures remain unchanged,

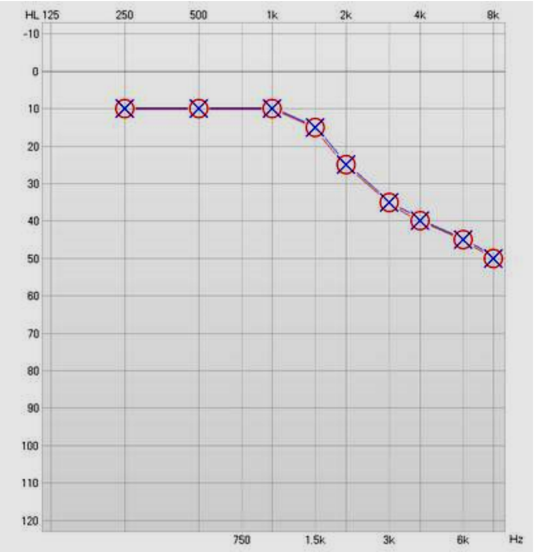
Richard Gladman of IAM RoadSmart head of driving and riding standards, says: "The driver's thinking distance is the same in a car or lorry, but the latter takes twice as long to stop from 30mph. The reaction time is quoted as 0.7 secs; 9 meters to think. and 14meters to stop, giving 23meters.A car can stop in just over 7 meters, but a laden 12-tonne truck needs at least 14meters.

Got a lorry close behind? Ensure you can brake to a stop gently; if you do an emergency stop, his will likely be an emergency slow with you assisting his stop!"

Audiometry and Hearing Loss Examples

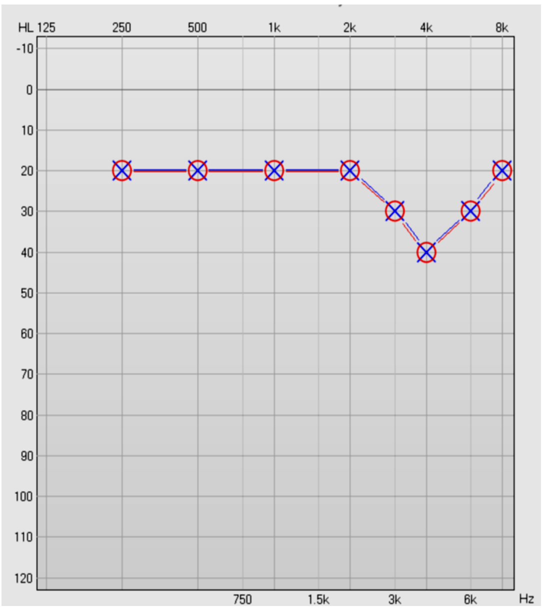


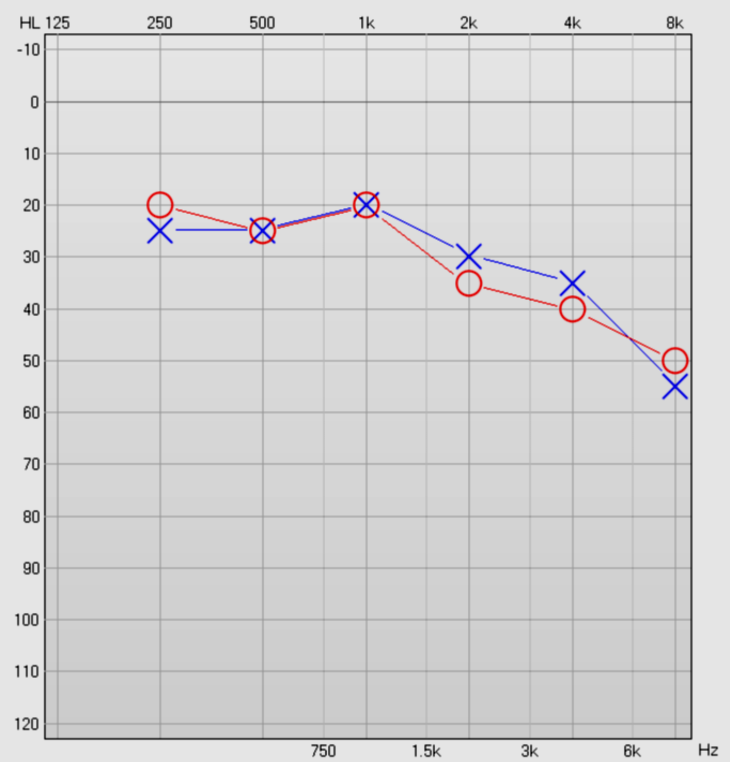
An audiogram shows the quietest sounds you can just hear. The red circles represent the right ear and the blue crosses represent the left ear. Across the top, there is a measure of frequency (pitch) from the lower pitched sounds on the left going to higher pitched sounds on the right. Each red circle and blue cross represents the individual frequencies of sound that have been presented. These sounds are measured in Hertz (or cycles per second). Down the side of the audiogram, there is a measure of loudness. At the top of the graph are the very quiet sounds, going down to moderate, and then very loud sounds. The points (red circles and blue crosses) marked on the graph represent the quietest sound which can be just heard. This loudness is measured in a scale called decibels (dB). Any points that are heard at 20dB or quieter are considered to be within the normal range. The lower down the graph the points are plotted, the worse the hearing. The different shaded areas indicate the different classifications of hearing loss. For example, if an individual's thresholds were all between 40 and 60 dB we would say they have a moderate hearing loss. The most common way of helping someone with a hearing loss is to fit hearing aids. However, the worse a hearing loss is, the more difficult it is to fit hearing aids. When thresholds are above 100dB, the hearing loss may be difficult to aid as the sound quality the patient gets from the aid is likely to be poor. This is because the louder the hearing aid must make the sound the more distortion it creates.

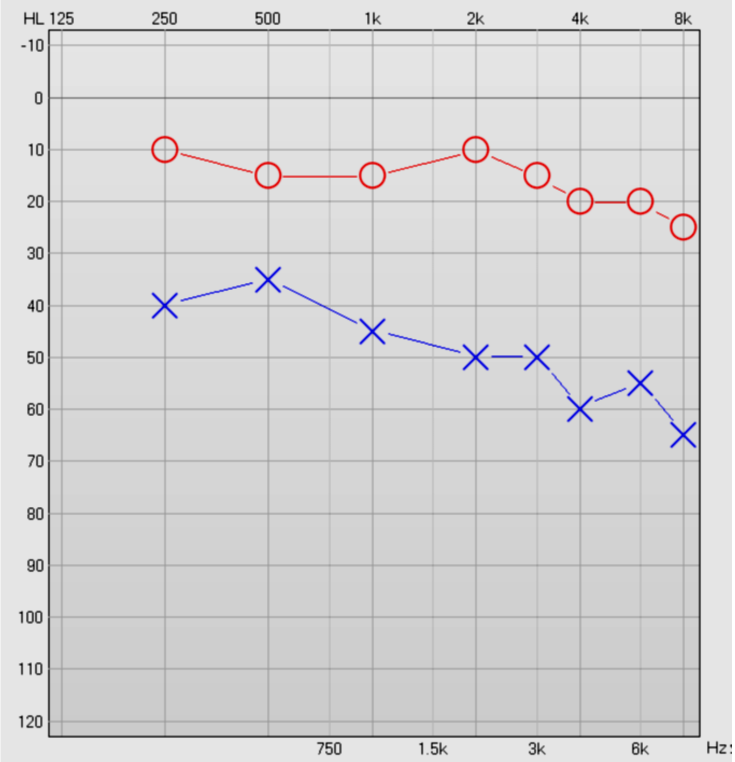


Presbyacusis is an age-related hearing loss. It usually affects the high frequencies more than the low frequencies. The audiogram below shows the sounds must be made louder before they are heard in the high frequencies (the right side of the audiogram), leading to a slope on the audiogram as seen below. This audiogram shows normal hearing up to 1KHz (mid frequency) and a mild hearing loss in the mid to high frequencies. Depending on the degree of the hearing loss, the sounds may have to be made louder before they were heard than shown below, but the general pattern is likely to be similar for all presbyacusis hearing losses. A right-hand sloping hearing loss with the left and right ear usually deteriorating at equal rates. Noise induced hearing loss is where loud noise has caused damage to the hearing organ, the cochlea. This most commonly occurs at 4KHz. Therefore, if a hearing loss is noise induced you would expect that the sounds must be made louder before they are heard at 4KHz than at any other frequency. This leads to a dip in the graph as seen below. The frequencies around 4KHz will also be affected. Symmetrical hearing loss is one where the hearing loss is roughly the same in both ears. We consider a hearing loss to be symmetrical if the points for each ear occur within 10dB of each other. The red circles show the thresholds for the right ear, whilst the blue crosses show the thresholds for the left ear. When there is a decline in hearing it commonly occurs at equal rates.

Noise induced hearing loss is where loud noise has caused damage to the hearing organ, the cochlea. This most commonly occurs at 4KHz. Therefore, if a hearing loss is noise induced you would expect that the sounds must be made louder before they are heard at 4KHz than at any other frequency. This leads to a dip in the graph on the right. The frequencies around 4KHz will also be affected.

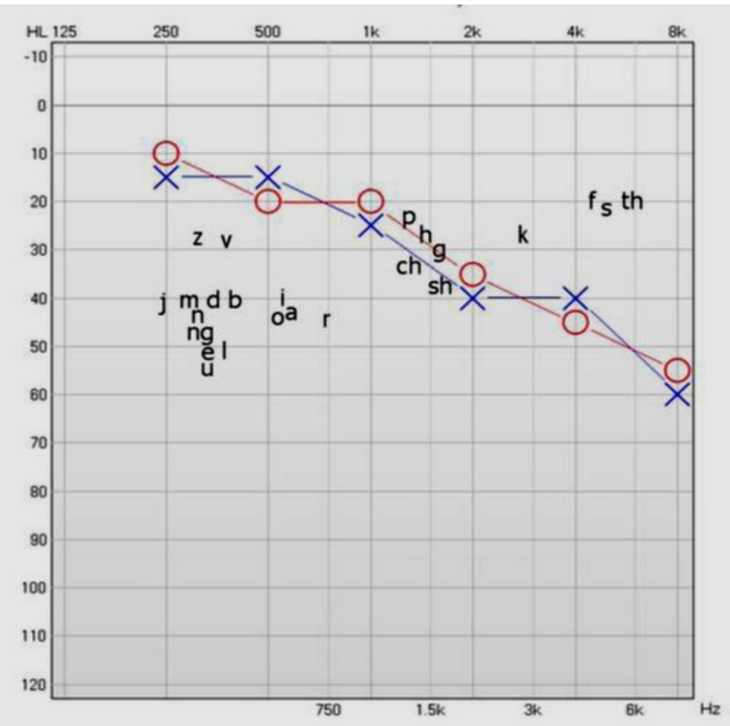


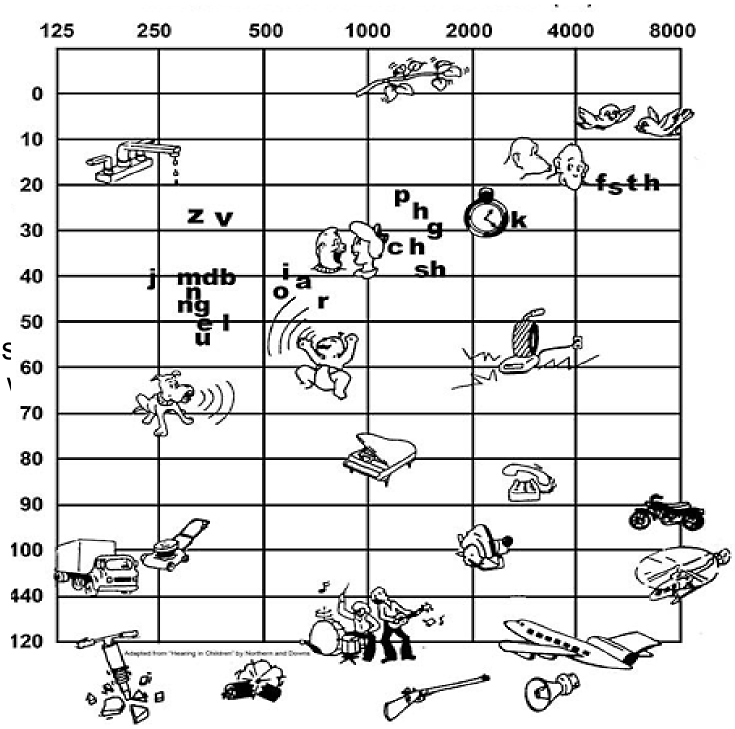




Symmetrical hearing loss is one where the hearing loss is roughly the same in both ears. We consider a hearing loss to be symmetrical if the points for each ear occur within 10dB of each other. The red circles show the thresholds for the right ear, whilst the blue crosses show the thresholds for the left ear. Then there is a decline in hearing which commonly occurs at equally.

Asymmetrical hearing loss. This means that the hearing is different in each ear. On the audiogram below the right ear is mostly within normal limits, whilst the left ear has a mild to moderate hearing loss across the frequencies. This implies something must be affecting the left ear only.





In the audiogram above, some of the hearing thresholds are below the levels at which speech sounds are made. This means the individual will be unable to hear the speech sounds above their thresholds, and as a result may feel speech sounds muffled or complain that others are mumbling. By aiding these frequencies, we aim to make these speech sounds audible, and therefore make it easier for the patient to hear and understand speech. Women's and children's voices tend to be of a higher frequency compared to men and thus harder to hear with a high frequency hearing loss.

Common Hearing problems with ME/CFS.

Auditory (Sound) disturbances
In ME/CFS these all come a go from and are usually symptoms of bad management and pacing. These may also be caused by other health problems with needs careful management.
Hyperacusis - This is a dislike of sounds or sounds acceptable for healthy individuals which are painful and irritating to someone with ME/CFS. The only real management strategy is avoidance or ear plug/defenders. It is not clear if the problem is within the ear or brain or both.
Deafness - is measurable hearing loss and may mask or occlude other causes of deafness. This is unusually treated with hearing aids or similar devices. In ME/CFS deafness is usually variable and it becomes difficult for an audiologist to prescribe suitable hearing aids. Most hearing aids are supplied with a fixed sound magnification which causes problems with ME/CFS patients. Ideally the old obsolete type with a volume control would allow the user to adjust the sound to comfortable levels. Again, it is not clear if the problems are within the ear or brain or both.
Tinnitus is hearing a sound that is not there. The sounds can sound like whistle, winds noise cracks and bangs. It is important that these are investigated because there are other causes of these problems than ME/CFS. Most people with ME/CFS find tinnitus disabling and irritating and usually relate to the intensity of fatigue. Yet again, it is not clear if the problem is within the ear, brain or both. Tinnitus can be treated with certain medicine. Also, sometimes a hearing aid type device that produces counterpoising or neutralising sounds that can help.

Balance disturbances
Disequilibrium, dizziness and vertigo are all symptoms on ME/CFS and like many other symptoms of ME/CFS come and go. Quite of lot of people with ME/CFS reports that these problems are associated with the intensity and poor overall ME/CFS management. For some people, medicines are effective, for other the problems are relieved by rest. Balances disturbances can be related to problems with the semi-circular canals, nerves or the brain. This cluster of symptoms can be related to other health problems, and it is important that these are fully investigated first.

Implications for DWP Benefits.
Sensory hearing problems are a disability and should always be disclosed on DWP questionnaire forms. If possible an audiogram, evidence of appliance use e.g. hearing aid or specialists report should be included as additional evidence. The * in the table below indicated the sections which hearing and balance problems should be declared and explained.

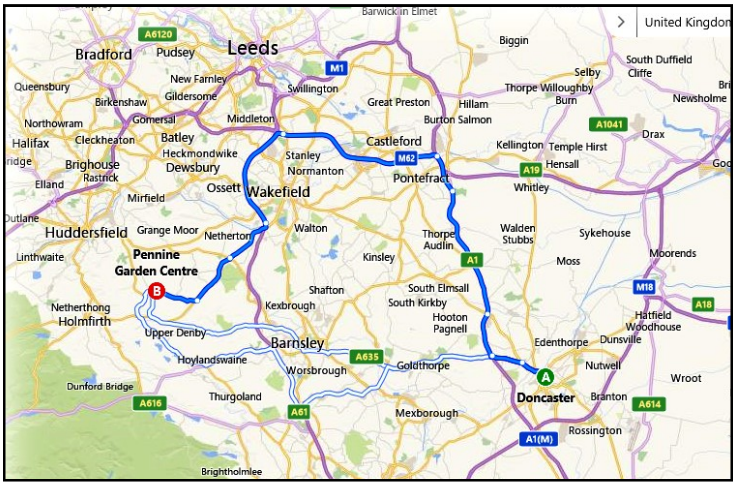
Question	ESA 50 (Hearing)	ESA 50 Balance	Question	PIP Balance	PIP Hearing
Quesiton1 Moving around and using steps		*	Question 3 Preparing3Food	*	
Question 2 Standing & Sitting		*	Question 5 Mangling treatment	*	*
Question 6 Communicating speaking	*		Question 6 Washing and Bathing	*	
Question 7 Hearing	*		Question 8 Dressing and Undressing	*	*
Question 8 Getting around safety	*	*	Question 9 Communications		*
Question 12 Awareness of Hazards or Danger	*	*	Question 11 Mixing with other people	*	*
Question 15 Going out	*	*	10 Question13 Going Out hearing	*	*
Question 16 Coping with Social situations	*	*	Question14 Moving around	*	*
Question 17 Behaving appropriately	*	*			

Out and About: The Dearne Lea Tea Rooms and Pennine Garden Centre

By Jean Burton

I find it interesting to read about the Kirklees Light Railway in Pathways 52 (Summer edition). Myself and my husband regularly visit the Dearne Lea Tea Rooms which are just alone from the Pennie Garden Centre and both of which are suitable for people with mobility problems. Also, the parking and toilets have disabled facilities.
I and my husband both love it up there and both places are very popular with stunning views.

To reach the venues from Kirklees Light Railway, travel along the road for about half a mile turn right at the Shelly sign. Keep travelling until you reach the Pennine Garden Centre.



Pennine Garden Centre Huddersfield Road
Shelley, Huddersfield West HD8 8LF

Opening Hours:

Garden Centre:
Monday to Saturday - 9am to 6pm.
Sunday - 10.30am to 4.30pm.

Restaurant:
Monday to Saturday - 9am to 5pm.
Sunday - 10am to 4pm.

Local Strategies for dealing with Chronic Pain at the Mexborough Pain Clinic.

With thanks to my colleague Lee.

I recently attended a professional meeting lead by two staff from the Mexborough Pain Clinic. Many Leger ME member pass through this clinic at some time. Chronic pain is a prominent feature of Fibromyalgia, and Myalgic Encephalomyelitis, and in most cases Chronic Fatigue Syndrome stem, but not necessary always. Chronic pain is also a feature of many chronic and long-term conditions like MS and Arthritis. Fibromyalgia did get a mention,

The problems with chronic pain

In a feature by the Royal College of General Practitioners UK Pain Messages, 2015, the following is stated:
It is estimated that 14 million people live with chronic pain (pain which lasts for more than six months) in England alone. 16% of sufferers feel their chronic pain is so bad that they sometimes want to die. Low back pain is ranked highest out of 291 conditions studied, by the Global Burden of Disease study, ranking number one for years lost to disability worldwide. In fact, four of the top 12 disabling conditions globally are persistent pain conditions (low back and neck pain, migraine, arthritis, other musculoskeletal conditions). Most people living with chronic pain are managed by their GP and primary care services.

At the pain control units, there are four problems area which are Distress, Disability, Dependency and Drug Escalation (gradually Increasing doses of medicines) which are addressed.

What is Pain Management?

Any pain management approach, whether as part of a specialist service or based in primary care, should look at addressing disability or quality of life issues as well as any possible reduction of pain symptoms. Overall it is agreed that any pain reduction methods are likely to have limited benefit in isolation and so these are usually considered as adjunct treatments with the focus being self-management. Chronic pain conditions need to be addressed in much the same way as other long-term conditions (i.e. through behavioral change). A pain management teams includes.

- Cognitive Behavioral Therapists (CBT)
- Consultant Pain Physicians
- Physiotherapy Practitioners
- Specialist Pain Nurses (SPN)
- Support staff

Patients may see one or these clinicians depending on their presentation. A ll new patients will have a biopsychosocial assessment by a consultant or physiotherapy pain practitioner.

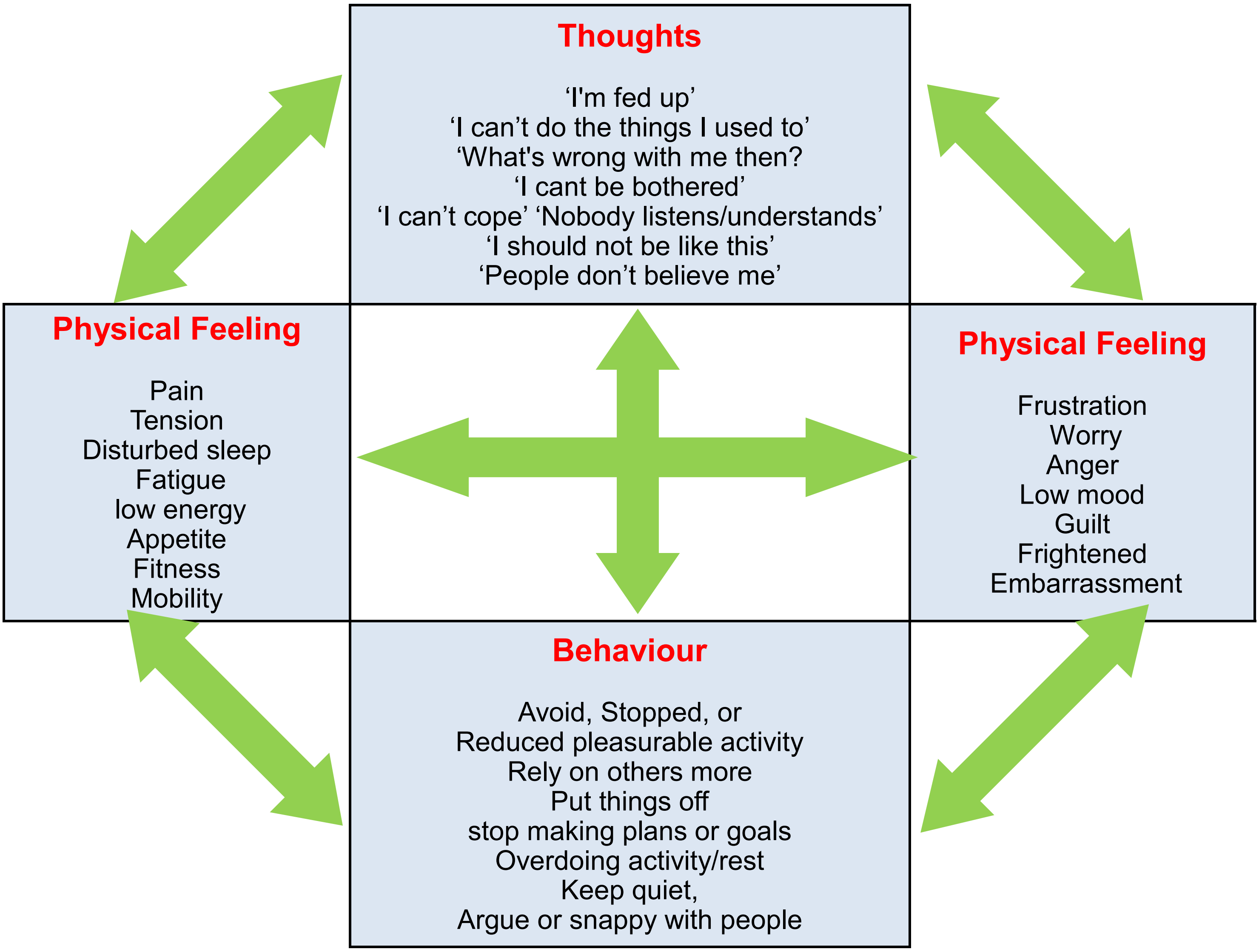
Common goals

Detailed biopsychosocial assessment is key including assessment of patients thoughts and beliefs associated with their pain. Questions asked include obtaining information about Work, Benefits, Home life and function Leisure/Social pursuits, Mood (including questioning on any suicidality if appropriate) The assessment is designed to identify any patient goals. Patient expectations should be discussed at initial point of access and any unrealistic expectations should be addressed.

Roles and responsibilities

- Consultants and SPN – provide treatments including injection therapy and acupuncture. Their role also includes prescribing and providing patient education regarding medication use.
- Physiotherapy practitioners – Work towards functional goals and exercise based goals with patients by addressing beliefs and barriers that may impact on behavioral change.
- CBT – provide psychological assessment. Use psychological therapy to address pain related distress, anxiety, depression, unhelpful beliefs and behaviour.

The Cognitive Behaviour Therapy Model of Pain Control



Thoughts

'I'm fed up'
'I can't do the things I used to'
'What's wrong with me then?
'I cant be bothered'
'I can't cope' 'Nobody listens/understands'
'I should not be like this'
'People don't believe me'

Physical Feeling

Pain
Tension
Disturbed sleep
Fatigue
low energy
Appetite
Fitness
Mobility

Physical Feeling

Frustration
Worry
Anger
Low mood
Guilt
Frightened
Embarrassment

Behaviour

Avoid, Stopped, or
Reduced pleasurable activity
Rely on others more
Put things off
stop making plans or goals
Overdoing activity/rest
Keep quiet,
Argue or snappy with people

Pain Management Programmes (PMPs) are aimed at promoting participation and enhancing quality of life for persons presenting with persistent pain and disability. The aim of the group is to bring about behavioural change through use of the CBT model. Each session involves discussion, exercise and relaxation with an aim of challenging beliefs and promoting participation and self management throughout.

- Acceptance of chronic pain,
- Improved communication with others ,
- Asking for help more frequently
- Being more assertive with others
- Increased awareness of important aspects of life (values)
- Making goals for the future
- Not overdoing physical activity
- Changes to work/life balance
- Increased participation in exercise
- Increased use of mindfulness
- Making time for enjoyable activities
- Use of relaxation techniques
- Reduced analgesia

Context of CBT and ME/CFS

Many Leger ME members will be a little concerned about CBT and its reputation among ME/CFS patients. In the pain control clinic CBT is a recognised strategy for pain chronic management with not expectation of 'cure'. I've received many positive reports from Leger ME members. I have encouraged many Leger ME member to ask their doctor for a referral to the Mexborough clinic.

CBT as a treatment for ME/CFS is totally out place and certainly in my view the NICHE misleads many health professionals, including many at the regional ME/CFS clinicals. *See Medical Abuse of ME Sufferers Campaign* in this newsletter. CBT was one of first strategies tried for AIDs, and we all know how wrong that turned out to be.

Aspects of Pain Medicines and the Pain management Programme (PMP)

As part of the pain management programme one of the specialist pain nurses spends a session with the group discussing medication. The aim of this session is to ensure that the patients are well informed about what they are taking, why, realistic expectations and potential side effects. For a number of patients this leads to decreases in their medication use or changes in how they manage these medications as part of their overall self-management strategy.

Signposting

At times people managing long term pain conditions may have periods where their mood/mental health is impacted. The Talking Shop is available to contact or drop in at the following locations:

- Doncaster – 63 Hall Gate, Phone:01302 565650
- Scunthorpe – 19 Market Hill, Phone:01724 867297
- Rotherham -23a Clifton Lane, . Phone: 01709 447755

Adjunct (additional Methods) at Pain Management Unit

TENS machines currently not recommended for back pain and sciatica according to NICE guidance, but does still recommend this as an adjunct therapy to consider for osteoarthritis. Most Leger ME members prefer to buy their own for use at home. The most expensive items are the sticky pads which must be frequently changed.

Acupuncture is currently not recommended for back pain and sciatica and for osteoarthritis according to NIHCE guidance. Some of my Leger ME members will strongly dispute this.

Analgesic Medicine Use in Persistent (Chronic) Pain

Most Leger ME members suffer from neuropathic pain. The general principles for this strategy are to assess for neuropathic component and treat as appropriate. For any analgesic prescribed, there is a need to assess for efficacy in terms of pain reduction and functional gain. It is important to avoid escalation of opioid analgesics (increasing doses) by slow upward titration (where appropriate) with regular assessment. The use of PRN (as required) opioids avoiding particularly if injected, increasing beyond 120 mg morphine equivalents). Reasons to avoid overprescribing opioids due to lack of proven efficacy and potential harms. For the treatment of chronic pain, the sufferer will live for many years so there is a great potential for long terms side effects to show. For shorter term pain control e.g. after injury or sugary or in palliative care pain control is one required for a limited time. Half of all drug related deaths in 2015 involved an opioid (risk increases with increasing dose). In addition to acute and well know short term sides effects of constipation (chronic), drowsiness & nausea and vomiting, the long-term opioid consumption is associated with a range of adverse immunological and endocrine. This including hypogonadism via HPA axis (which is impaired in ME/CFS anyway) and potential cancer risks.

What are Opiates?

Traditionally opiates are medicines originally obtained from the Opium Poppy e.g. Morphine and Codeine. Heron is a morphine derivative (modified chemically).

In more recent years synthetic (chemical) opiates have appeared example are: Pethidine, fentanyl, dihydrocodeine, tramadol

With analgesic patch prescribing there is a need to beware of potency especially fentanyl patch potency. A 25mcg/hr patch equivalent to 90mg of morphine. It is important to ensure safe patch disposal. The recommended method is to fold in half (sticky side inwards) and replace in original packet before disposing in the bin (or ideally in a sharps bin or suitable container from the local council. Buprenorphine may have a role, but is relatively expensive, but is available as a weekly patch.

Neuropathic Adjuvants Medicines

Like the NIHCE for ME/CFS the NIHCE guidance for chronic pain control. However, these are non-specific. All the is says is just tell us to “Use one of the drugs in the British National Formulary aka NHS medicines bible” (i.e. amitriptyline, duloxetine, gabapentin or pregabalin). However, there are needs for local guidance. There is some good advice around concerns and expectations, and considerations for adjuvant choice. For example, for carbamazepine (Tegretol) the only specific recommendation is for trigeminal neuralgia. There is advice against use of opioids aside from specialist practice.

Strategies for Neuropathic Adjuvants prescribing

Step 1 Consider amitriptyline (where no cautions or contraindications like anticholinergic side effects)
Step 2 Consider gabapentin (be cautious about weight gain)
Step 3 Consider pregabalin and/or Pain Management Unit referral

So, what can be used?

Paracetamol – but a poor evidence base highlighted. Many doctor’s surgeries will now not prescribe.
NSAIDs – e.g. ibuprofen, voltarol. A risk benefit analysis required is required based on cardiac, renal and GI side effect profile. There medicines have caused stomach bleeding and kidney failure
Weak opioids – for example co-codamol co-dydramol. There are generally converted to low doses of morphine; process may not be consistent. There are problems with consistency for poor or hyper-metabolisers may lead variable results/to inconsistent effect
Lidocaine patches – Needs to be prescribed under specialist supervision for localised neuropathies.
Nefopam – this as a poor very poor evidence base and should be only prescribed by those highly specialised in analgesia.

Take home messages

- Opioids are very good analgesics for acute pain and for pain at the end of life but there is little evidence that they are helpful for long term pain.
- A small proportion of people may obtain good pain relief with opioids in the long-term if the dose can be kept low and especially if their use is intermittent (however it is difficult to identify these people at the point of opioid initiation).
- The risk of harm increases substantially at doses above an oral morphine equivalent of 120mg/day, but there is no increased benefit.
- If a patient is using opioids but is still in pain. the opioids are not effective and should be discontinued, even if no other treatment is available.
- Chronic pain is very complex and if patients have refractory and disabling symptoms, particularly if they are on high opioid doses, a very detailed assessment of the many emotional influences on their pain experience is essential.

Recipe Corner *by Carolyn*

Is anyone else getting their fruit ready for making Christmas cakes? If you want a guaranteed recipe... Here's one...

Ingredients:

1 or 2 quarts. of Brandy
1 cup butter
1/8 tsp. sugar
2 large eggs
1 cup dried fruit
baking powder
1 tsp. baking soda
lemon juice
brown sugar
nuts

Method

Before you start, sample the Brandy to check for quality.
Select a large mixing bowl, measuring cup, etc. Check the Brandy again. It must be just right! To be sure the Brandy is of the highest quality, pour 1 level cup of Brandy into a glass and drink it as fast as you can. Repeat.
With an electric mixer, beat butter in large fluffy bowl.
Add 1 seaspoon of thugar and beat again.
Meanshile, it’s important to make sure the Brandy is of the finest quality—try another cup.
Open the second quart of Brandy if necessary. Add 1 arge leggs, 2 cups of fried druits and beat till high.
If the druits get stuck in the beats, just pru it loose with a drewscriver.
Sample the Brandy again for cinscistincy.
Next, sift 3 cups of salt and feffer (it really doesn’t matter). Sample the Bandy again.
Sift 1 pint of lemon goose, add 1 bablespoon of brown thugar, of whatever color tou can find. Mix well.
Grease oven, turn cake pan to 350 greeds.
Noe, pour the whole mess sinto the boven and ake.
Check the Bindy again and go to bed. *Hic! Hic!*

***North of Doncaster Personal** comment by Trevor Wainwright*

A travel diary to the Holy Land Part 4:

The River Jordan Baptismal site. It is also the border, between Israel and Jordan marked by floats in the middle of the river.

We arrived at the Baptismal site, it was and sunny getting hotter as we walked to the river, both Israel and military flags were flying leaving no doubt whose territory it was. Initially it had only opened once a year but was now open all year round. There were minefields to either side of the path but warning signs too. We looked down at the river, near to a marker depicting the height of the river in January 2013, when it came above the steps that led to the baptismal site. It was much lower as we walked to the platforms. A small line of floats in the middle of the river denoted the border. Beyond was a Russian Orthodox Church, how I would have loved to go visit it. On the platform at the other side a bored looking Jordanian border guard sat looking and playing on his cell phone.

We renewed our baptismal vows with water from the river, and a short service. On the other side a couple came down. She went in the water her partner took pictures, the guard left them to it, and walked slowly up the steps away from the river. Our vows renewed we made our way back up the steps where a young female Israeli soldier was sat at the top, she smiled as I wished her “good morning” in her own language. As we drove away inspiration was again forming I had already written one poem., looking out of the bus window I saw that mine clearance had already begun, it would make a great area for a plantation to feed the people and the ruined church I saw in a compound would again come to life as a place of worship for many.

The Mount of Temptation

Monastery of Qarantal.

Back on the main road we drove through a barren landscape which Joseph described as `the wilderness`, then it was to the oasis city of Jericho, “the Biblical City of Palm Trees”, in the centre, was a water feature encircled by palm trees as if depicting an oasis, it was said to be the scene of the miracle of Jesus making blind Bartimaeus see, after which we stopped near a Sycamore tree like the one Zacchaeus is said to have climbed to see Jesus. Joseph repeated the story. We carried on past a walled area which was aiding to be the old Jericho, scene of the famous battle. It was now just a walled off area consisting of a road with palm trees and hedges at the side, and just beyond was what looked like a housing estate. We carried on through the town to an area where we stopped briefly to view the Mount of Temptation and the Monastery of Qarantal which clings precariously to the face of the mountain, we could only see it from a distance but stood in wonder at the thought of its construction and how the materials would have been got there.

As usual we were besieged by vendors one of which not only charged for a camel ride but for taking pictures of it, 10 out of 10 for enterprise, but the Yorkshire man was cleverer. I took a picture from the coach as we passed. We drove back the way we came stopping at a Christian run souvenir shop where we were given light refreshments and invited to have a look round, no pressure. Many of the goods on offer were hand carved olive wood, ranging from full nativity scenes to smaller items’ they were indeed beautiful. I decide on a basic chalice, much as I thought Jesus would have used at the last supper, I didn’t trust myself with anything bigger, and I’m not a great souvenir hunter at the best of times.

Excavations at Qumran, the Dead Sea is in the background

Then it was to Qumran our next stop. On the way I saw two young figures walking across a barren landscape towards what look like a collection of sheds, it was in fact a Bedouin Camp. Thereywere children coming home from school, at least they would be getting an education. How I would have liked to stop and visited for a while. We arrived at Qumran formerly an early settlement of the Essenes who documented stories told by travellers. These stories, many concerned with the bible would eventually become The Dead Sea Scrolls, which on discovery but for the keen eye of a sandal maker would have become sandals. At the visitor centre we were told the story of the community how they wrote down what they heard from passing travellers and how it was a thriving community said to have existed between roughly 100 B.C. and A.D. 68, when it was captured by the Roman army and destroyed in a fire, prior to which the Essenes had hidden the scrolls, and left hoping to return, but never did.

The cave in which most of them were found

The scrolls were first found in 1946 or 1947 when a young shepherd by was looking for a stray goat. At one point “he was amusing himself by throwing stones”. One of these fell into a small hole in the rock and was followed by the sound of breaking pottery; he climbed in and found several ancient manuscripts in a jar. Altogether seven scrolls were subsequently removed from the cave, thinking they were leather he took them to a sandal maker to be made into sandals. Fortunately, the sandal maker had an interest in archaeology and knew what he was given was special, he got further advice, and so excavations began more and more scrolls were uncovered and their stories told, stories thought at one time only to be fables. The visitor centre gave us an idea what life would have been like, what the jars holding the scrolls would have looked like, replicas of the scrolls, a reconstruction of a ritual bath and other artefacts including pottery.

We got an even better idea when we were looking at the excavations, where and how the Essenes had lived from where we had a view of the Dead Sea which we would soon be visiting. It was obvious that they were well organised, and how they managed the water situation ensuring there was plenty as ritual bathing seemed to be carried out on a regular basis. Looking down into the valley where the caves were there was something familiar about one of them, then I realised it featured in the video of Greg Lakes “I believe in Father Christmas”. All that was left of the settlement were the bases but they were remarkably well preserved and kept so by walkways to prevent damage and ensure visitor safety, adequate notices informed the visitor the purpose of each building.

A copy of the Dead Sea Scrolls

Then it was back on the bus to the dead sea, a quick change and we were in, the water had an oily texture to it, it was easy to float but getting back up was a problem, as was getting the salt water in your eyes it was a devil to wash out due to its oily texture. It was great floating but what else we enjoyed was covering ourselves, in the mineral rich mud, playing at swamp monsters. The time was short but enjoyable, after which we showered and changed and boarded the bus for our destination of the day, Jerusalem.

We drove up through the hills of Judea to Jerusalem, passing more Bedouin encampments on the way and it began to rain. Joseph explained that it is always ‘up’ to Jerusalem due to its height above sea level, and on the way, he related the story of the Good Samaritan. It was still raining as we arrived in Jerusalem. We stopped briefly on the summit of Mount Scopus for a view of the old city of Jerusalem it was still breath-taking, although we were unable to the beautiful surrounding medieval walls. We drove to our hotel which was within the old city walls; this meant we had to park outside and walk through the Jaffa Gate to it, only cars were allowed in, it wasn’t far and the rain had held off, as we passed through the Jaffa Gate. The shops blended nicely into the old buildings, our hotel `The Gloria` was a large stone building with a small courtyard, with ample disabled parking spaces on the street. The building itself was four floors, had recently been modernised but still retained its character inside. The top floor was the dining room which offered wonderful views of Jerusalem outside the city wall, and provided us with a wonderful evening meal then our rooms were on suite and comfortable. I had been making notes and tried to catch up on my poetry journal. Eventually I turned in, but not before a last look out of the window at the skyline on which there was an illuminated clock tower.,

And so to the Dead Sea

I wondered what it was and would find out later that it was Terra Santa High School built between1924 and 1927 bought by the Franciscan Order in 1928 for the promotion of sports activities soon after becoming a school for all faiths. It took the name Terra Santa in WW2 to hide its Italian connections. In 1999 it was refurbished to serve as a hostel for pilgrims. It is under the supervision of the Franciscan fraternity, and serves as the seat for the Cultural Centre of the Holy Land Custody.

I was woken early by the sound of a bell, looking out of my room window. I saw a nun disappear into a building in the back yard where there were two flags, one the Cross of St George the other the flag of Greece. The building turned out to be the Greek Orthodox Patriarchate Museum which had apparently been a Coptic Orthodox Monastery in 325 AD, the word ‘Copt’ being the Greek word 'Aigyptos', *meaning.*
I took some photos and went for breakfast; again, we were spoiled for choice. After breakfast we got ready, with my notebook in my back pack, I made for the coach; I would catch up with my writing as we travelled. It was raining as we set off as if the sky was weeping, it would have some significance as we made our way to where Jesus began his final date with destiny. *To be continued...*

Fun and frolics in the dead sea