

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. 49 (Autumn 2016)



The Ethel entering Kirk Bramwith Lock taken on the 2016 Leger ME Summer Canal Boat Trip in mid July. Photograph with thanks to Peter.

You write in

Garry writes: *Many thanks for sorting out my DLA to PIP changeover form. After the medical examination in Doncaster I only had to wait for several days before I got the results of my application. It's good news and bad news. I've got the standard rate of care for PIP which is worth £55.10 a week. Previously I was getting the low rate of care DLA which was worth £21.80 per week. So I've got an increase of £33.3 a week. However, things are not so good for mobility. I used to get high rate mobility £57.45, but now I'm only getting the Standard rate of £21.80. So from £79.25 my total weekly payments have dropped to £76.90 so in fact I've lost £2.35 a week. Considering the difficulties, I've had with the DWP before in the past. I prefer not to challenge the decision and to stick with this because the loss is so small.*

However, there is a sting in the tail. I have a Motability car, and I'm now told that I can't keep it. I think that the car is great—do I have any options?

OK, let's do the easy bit first. Because of the difference with the way PIP is assessed it is unrealistic to expect that you would be awarded the equivalent levels as with DLA. Most Leger ME members should get the standard rate of care PIP, so I wouldn't query that award. However, the mobility side is different. PIP was deliberately set up so that most of the people who got Motability cars through DLA would lose them. It's politics which I don't want to go into at this point in time. For the past few years I've been advising Leger ME members NOT to take out Motability contract hire agreements. This was for two reasons— firstly because of the stress of unexpected loss of the car and secondly because it is cheaper to run and own your own car using your mobility money. The only justification for the average Leger ME member to get a Motability car would be because of insurance difficulties through disability and adaptations being needed.

According to the information I have the DWP will write to Motability who will then in turn write to you asking for the car back. As the Motability contract has to terminate, and it is not your fault, there will be an option for you to purchase the car should you so wish. As far as I know you are the first person that this has happened to so I don't have any cases I can refer back to. When your contract terminates through PIP changeover, there are special golden exit arrangements. There is a statement on the Motability website from the chair about this situation. It will be well worth reading.

From the Motability website

... As soon as the DWP confirms that you are no longer eligible for the Scheme, we will write to you giving you more information specific to your situation. This will include a personalised letter which outlines the transitional support package that may be available to you, as well as the purchase price of your vehicle...

The problem for Motability is that they have a car they have to do something with it because it can't be hired out again. Usually such cars are auctioned through the motor trade. This usually means that it costs them money to transport, and pay auctioneers commission. However, they could sell you the car, and if you had the money upfront you could buy it if the deal was viable. I've no idea what your car would be worth or at what they would offer it to you. But look at it this way. Motability buy cars from manufacturers at a massive discount, and there is some way they can recover back the VAT and other taxes. The usual result is the cars are offered at "fair market price". There is also a special exit 'golden handshake' plus a rebate and any deposit would be returned. Just remember as well you have your mobility money from the PIP and extra money from care component – so if you bought the car, you should be able to run it on what you are receiving. You would obviously have to buy your own insurance, but the Motability insurers have a deal on offer for this situation. Obviously you would have to tax it and pay for maintenance and repairs. Overall if you play your cards right you could save money in the long term. You would own the car, and you can sell or use it as a deposit for your next car.

What I would do is wait until you hear from Motability and then look at your options. I would suggest that you check the value of your car through Glasses guide or the motoring magazines or the prices of similar models advertised by the motor trade. If the offer on the table seems a good one, then by all means go and buy the car. Please remember that there is no scheme for finance through Motability, so you'll have to find the money yourself either from a bank or from your own savings or resources. The other thing to remember is that if you have standard rate mobility PIP you are still entitled to a blue parking badge and there is a scheme for reduced car tax.

A Case of Employment and Support Allowance Refusal

When someone claims ESA, eventually they are sent an ESA 50 form to fill out. It contains 18 sections, asking you for detailed information about your illness and health. In past editions of *Pathways*, we have covered the various issues around this form-fill. Most people need help to fill it out and generally this aspect of an ESA claim presents no problems.

Once the form is submitted to the DWP, they contact your doctor and ask for further information. This is where the problems could start. Unless your doctor has first-hand knowledge of your case, it is unlikely that he or she will be able to give the DWP the information they need. In this case the member was newly diagnosed, and was waiting for an appointment with the Sheffield ME/CFS clinic. The member also had anxiety and asthma (omitted by the doctor from the first page). The second page briefly requests more detailed information about the member's condition. The relevant tick boxes have been left blank as has the narrative. While the member had taken considerable care to detail all her problems very concisely, the GP has really done nothing to help. This form was submitted to the DWP and the GP was paid a substantial fee (around £80) for his/her signature at the bottom of the form.

So what happens when the decision maker reviews this form and assesses the claim—it just goes on to the reject pile. What happens next is the member receives a summons to the local DWP medical examination centre. In all cases like this they will examine the person just to confirm that they are not making a mistake. In this specific case, the person who examined the member possibly didn't know about ME/CFS and so tagged along with the GP's lead. As a result, a refusal letter was received. This is usually the time we become involved in a case, usually from a distressed member on the helpline.

The problem is that you can appeal against the decision, but you are appealing blind because you can't get access to these forms. You only get to see the 'evidence' when the case is going to tribunal—and usually that is after a 12-month wait.

In this particular case, the GP didn't do his job and probably was negligent. The DWP medical examiners aren't really much help—just don't trust them. When I see the case paper many of the reports contain many errors and inaccuracies which are easily disputed. But it is only at tribunal you get a chance to state your case. Fortunately, many cases are won and the pay is backdated. Like many things in life, prevention is better than cure. The golden rules are: -

**DO NOT FILL OUT A DWP FORM BY YOURSELF.
SEEK HELP FROM A WELFARE RIGHTS ADVISOR.**

The is no one way to avoid things like this happening, but the following points are helpful.

- Keep in regular contact with your GP, it doesn't matter what for, and at least once a year.
- Submit additional evidence with your ESA 50. Contact us for guidance of what to submit.
- If you are a Leger ME member, ask us for a copy of Work and Benefit guides.

Many months later this case was eventually won. This was only after a lot of letters, further evidence being submitted and a tribunal being held.

Welfare rights: DWP Benefit Disputes from *Benefit and Works* by Steve Donnison

It's been a thorn in the side of the DWP for many years. Whenever they try to argue that disability and incapacity benefit assessments are fair, someone will always ask why, in that case, are so many decisions overturned at appeal? The introduction of the mandatory reconsideration before appeal system was intended to bring tribunal success rates for claimants crashing down. It didn't. In fact, only this month the Scottish government pointed out that:

"It is absolutely staggering that 65% of people who dispute their PIP award are successful in their appeal of that decision."

But now, the government have a plan that may well succeed. A new online system for appeals is to be introduced, along with more decisions being made on the papers and the ditching of medical and disability members from most panels. The result is likely to be a significant and sustained fall in both the volume of appeals and the success rate for claimants.

Case officer says 'No'. Under the new system, some matters that are currently decided by judges will be dealt with by 'case officers' instead. This could mean clerks deciding whether your appeal is in time, for example, or whether your appeal will be held online, in person or on the papers.

More decisions 'on the papers' The government's intention is that:

Where a case is relatively straightforward or routine, representations will be made online in writing for a judge to consider outside of a traditional court room, without the need for a physical hearing, meaning a more convenient experience for everyone involved.

What is really *convenient* for the DWP about this is that the success rates for paper hearings are drastically lower than for appeals where you appear in person. At the moment claimants get to choose whether they want to appear before a panel or just submit written evidence. In the future it will be a clerk or a judge who makes that choice for you.

More virtual hearings. Even if you manage to avoid a paper hearing, the chances of having your appeal in the same room as the tribunal judge are very slim indeed.

Where a judge needs to listen to the parties make their arguments, it will be possible in many cases to hold the hearings over telephone or video conference, without the need for the parties to travel to a court building. There will still be an important place for physical court hearings for criminal trials and other serious or complex cases, but where they are appropriate, virtual hearings offer an easy and convenient alternative for everybody.

For some claimants, removing the stress and pain involved in travelling to a hearing will be an enormous advantage. But for others, the sheer strangeness of an online exchange and all the technical problems it may involve will make it very hard for them to give detailed and persuasive evidence.

More haggling. Many claimants may not even get as far as a hearing, whether online or on the papers, even after lodging an appeal. The government says:

"In appropriate cases, we will encourage parties to settle their disputes themselves, without the intervention of the courts."

The real fear here is that the DWP will effectively be able to bully claimants into accepting a lower award than they believe they are entitled to, in order to avoid the risk and emotional trauma of an appeal.

Fewer panel members. The government also plans to streamline the appeals system by making much less use of additional panel members.

In the First-tier Tribunal (Social Security and Child Support), for example, many cases must be heard by a judge, a medical member and a member with experience of providing or receiving care for disability, regardless of the circumstances of the case in question.

Influenza Vaccination and ME/CFS

Now is the time to consider flu vaccination. Many Leger ME members and their Carers are eligible—but it may not be appropriate in some cases. Some people have been made worse by flu vaccination—particularly with new allergies as a result of the vaccination or just making the ME/CFS worse. My Pharmacist colleague Emily who is a volunteer for Action for ME has written the following dialogue.

It's the start of the 2016/17 flu season and people with ME/CFS and Carers are entitled to free vaccination at pharmacies and GP surgeries. Here is updated information

About flu.

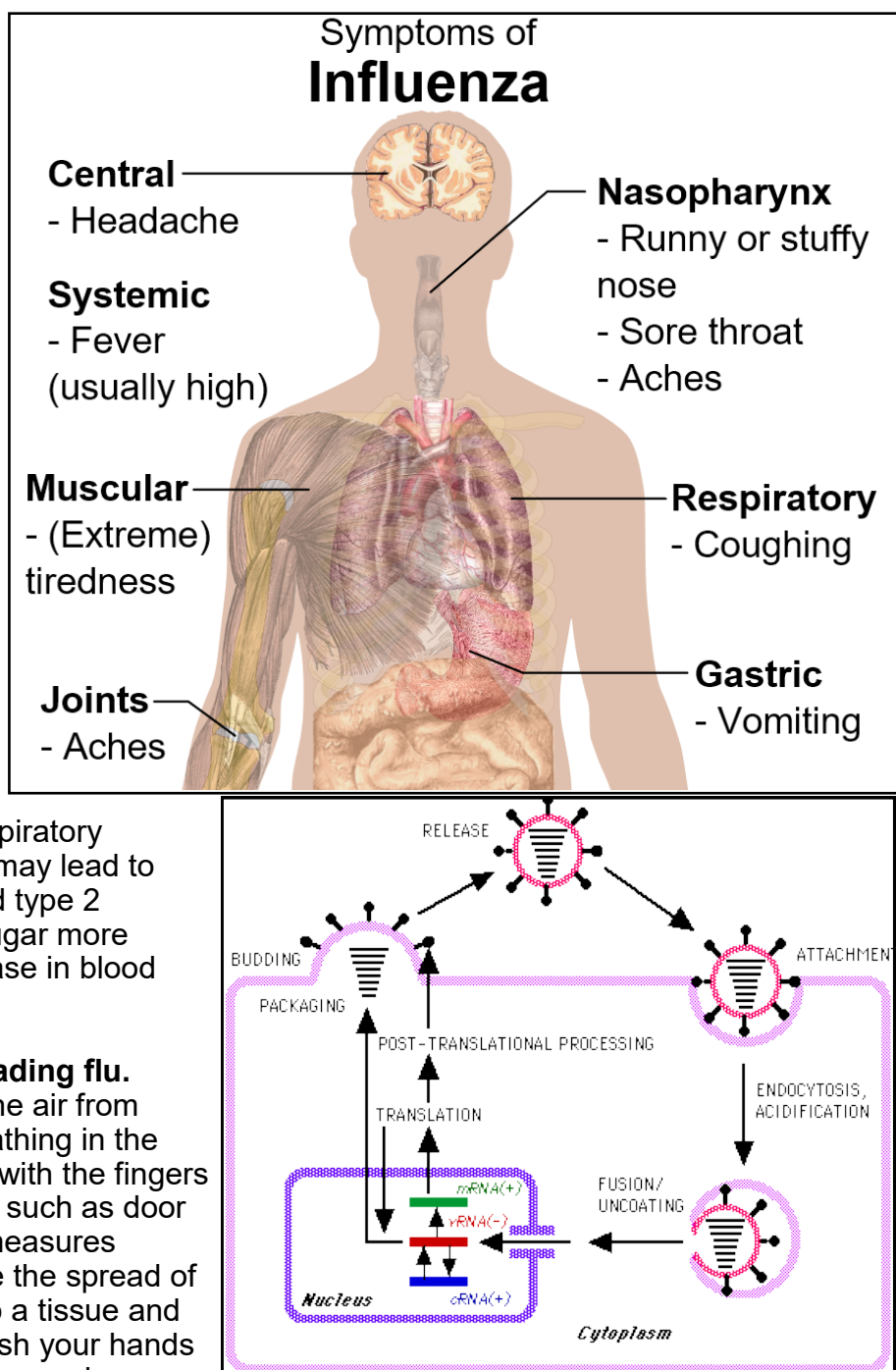
Seasonal influenza, or flu, is a highly contagious viral winter illness. The symptoms of flu come on suddenly and include fever, sweating, aching muscles, sore throat, cough and feeling exhausted. For most healthy people, flu is what we call self-limiting, meaning that the body's immune system fights the virus and they get better after about a week, usually without treatment. Antibiotics don't help fight flu because they only work to treat bacterial infections rather than viral ones.

Complications of flu.

Even otherwise healthy people can become seriously ill because of the complications of flu but some people are at a much higher risk of needing to be hospitalised or even being fatally ill. People at higher risk of complications include young children, pregnant women, the elderly and people with some long term health conditions. Complications include bacterial infections which can become serious and develop into life-threatening pneumonia. Other possible complications of flu include tonsillitis, ear infections, and sinusitis. It's rare but flu can also cause febrile convulsions (fits during a fever or high temperature), meningitis and encephalitis. Flu can cause a worsening, or exacerbation, of the respiratory conditions asthma and COPD, which may lead to hospitalisation. People with type 1 and type 2 diabetes should monitor their blood sugar more closely as flu usually causes an increase in blood sugar levels.

Ways to prevent catching and spreading flu.

Flu is spread by droplets of saliva in the air from sneezing, and is caught by either breathing in the droplets or touching the eyes or nose with the fingers after touching a contaminated surface such as door handles and surfaces. Some simple measures should be used by everyone to reduce the spread of the flu virus: e.g. cough or sneeze into a tissue and throw it away as soon as possible, wash your hands as soon as possible after coughing or sneezing and have a flu vaccination if appropriate.



Influenza is caused by a virus which infects body cells, and turns them into virus factories.

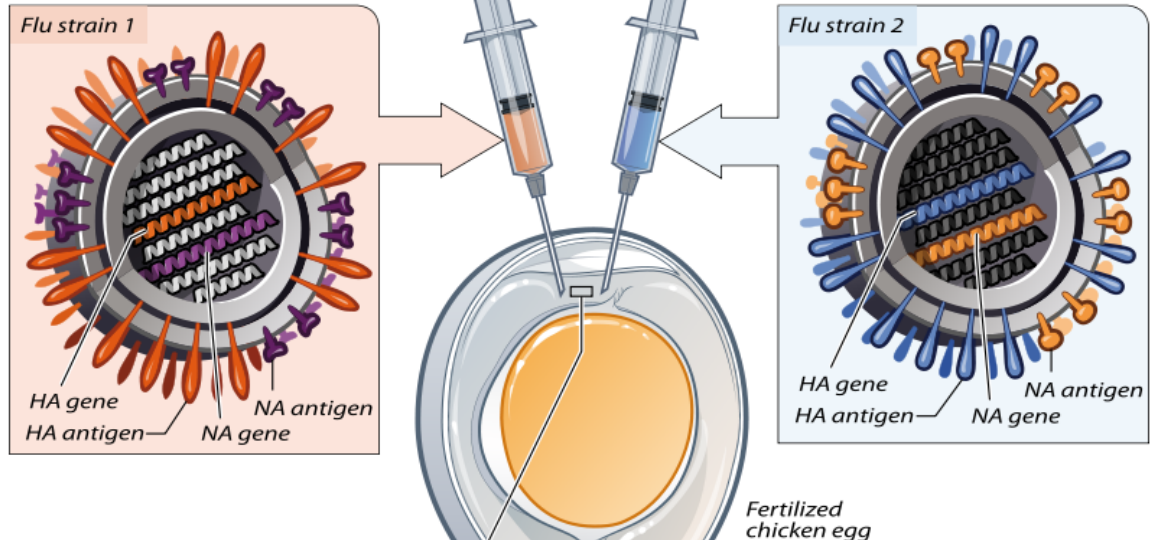
The flu vaccine.

The annual flu vaccine is an injection for adults and a nasal spray for children. The reason people need to have the vaccination each year is because the strains, or variations, of flu are constantly changing. The World Health Organisation predicts which strains are going to be the most common in the coming winter and the vaccine is made specifically against those strains. This winter, the vaccine protects against 3 strains, including swine flu. If you opt to have the vaccination, it's best to have it as early on in the flu season as possible, to get the best protection. People who have had a serious life-threatening anaphylactic reaction to the flu jab in the past, for example if you are allergic to eggs used to make the vaccine, are advised to tell their GP so that an alternative vaccine can be given. If you currently have a fever from a cold or other infection, it is advised that you wait until you no longer have a fever before having the vaccine, but in my

Egg based Flu Vaccine

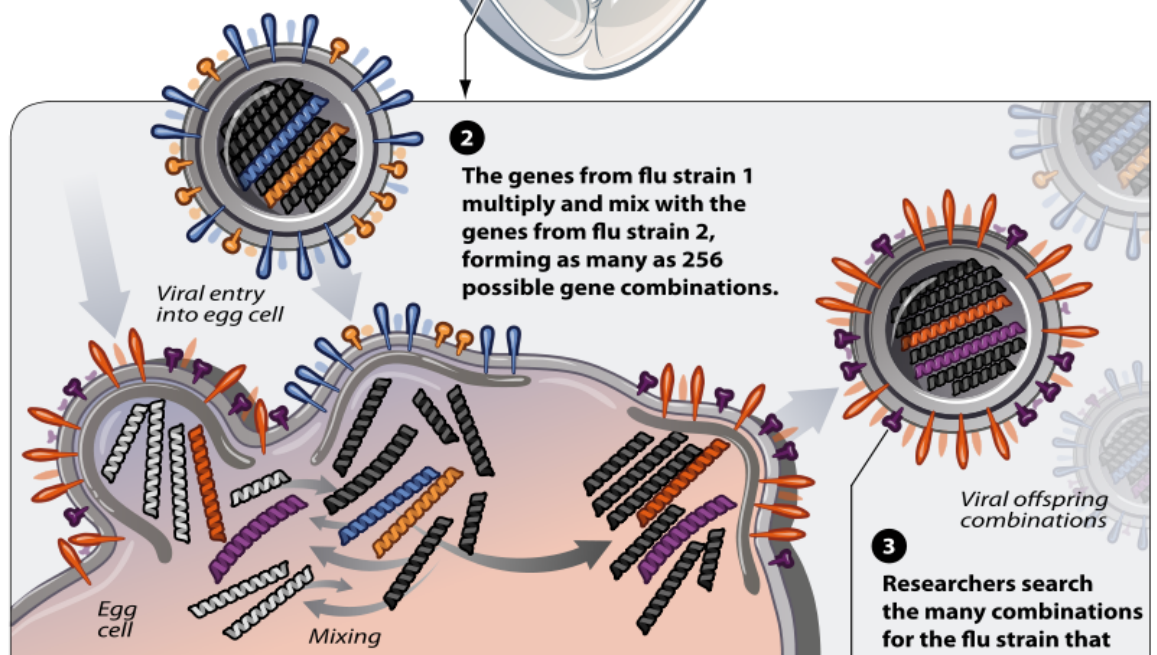
A flu virus contains eight gene segments. The goal is to combine the desired HA and NA genes from flu strain 1 with genes from flu strain 2, which grows well in eggs and is harmless in humans.

1 Flu strains 1 and 2 are injected into a fertilized chicken egg.



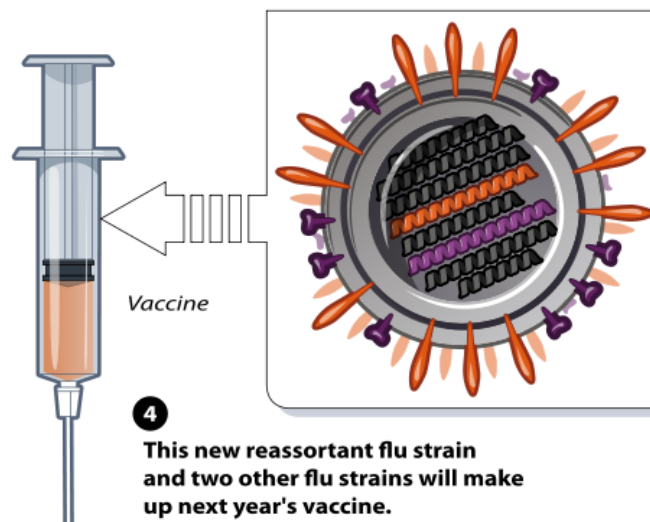
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The genes from flu strain 1 multiply and mix with the genes from flu strain 2, forming as many as 256 possible gene combinations.



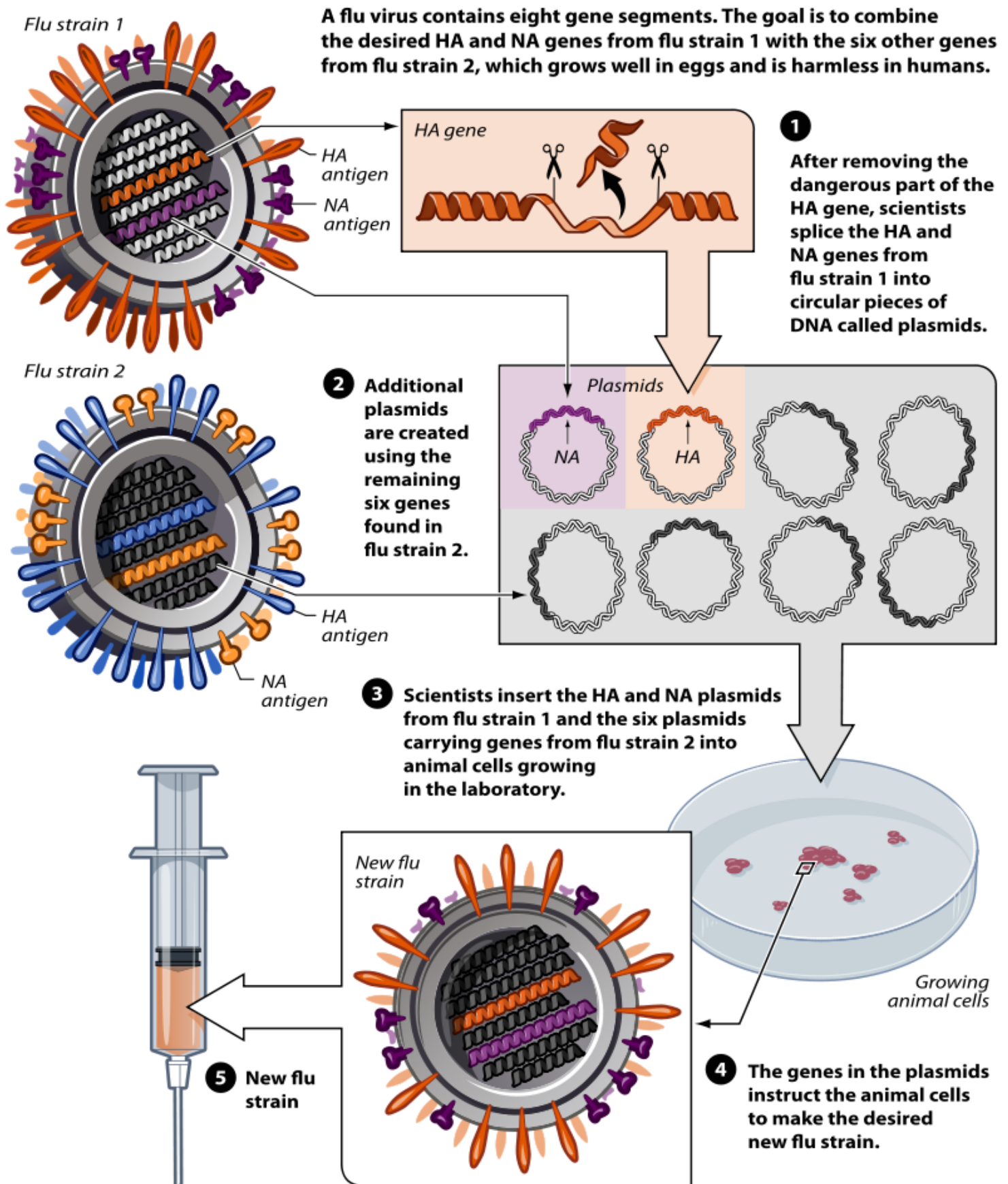
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Researchers search the many combinations for the flu strain that contains the HA and NA genes from flu strain 1 and genes from flu strain 2 that ensure that it is able to grow efficiently in eggs.



With thanks for these images to Wikipaedia and Mouagip

None Egg based Flu Vaccine made by recombinant technology.



experience many people report a temporary worsening of ME/CFS. It seems that after having the vaccination it's normal to have a slight fever, aching muscles or a sore arm but this lasts only a day or two. It's not possible to catch flu from the jab because it doesn't contain the live virus and the nasal spray for children only contains a weakened form.

Eligibility for free vaccination.

The following groups are entitled to the free flu vaccination in England. If you live elsewhere in the world, try looking on your health service's website or ask your doctor's surgery if you are eligible. This list isn't definitive and the conditions listed are just examples. We have contacted Public Health England to check the eligibility of people with ME/CFS, and you may be eligible because of your ME/CFS or another condition on the list, but as with all other conditions, it's always an issue of clinical judgement. If there are any doubts, discuss it with your GP or ME/CFS specialist.

- All people aged 65 years and over (including those becoming age 65 years by 31 March 2017).
- This also applies to people aged from 18 and less than 65 years of age with one or more of the following medical conditions: chronic respiratory disease, such as severe asthma (about 40% of Leger ME members have asthma), chronic obstructive pulmonary disease (COPD) or bronchitis
- chronic heart disease, such as heart failure;
- chronic kidney disease at stage three, four or five;
- chronic liver disease;
- chronic neurological disease, such as Parkinson's disease or motor neurone disease, or learning disability;
- diabetes;
- a weakened immune system due to disease (such as HIV/AIDS) or treatment (such as cancer treatment); or splenic dysfunction
- pregnant women aged 18 or over (including those women who become pregnant during the flu season);
- people aged 18 or over living in long-stay residential care homes or other long-stay care facilities;
- Carers aged 18 or over; or
- household contacts of immunocompromised individuals who are aged 18 or over.
- Children aged two, three and four plus children in school years one, two and three, and children with a long-term health condition may have the vaccination. These may be offered at school or at your GP's surgery but the pharmacy service doesn't include children.
- Carers may be eligible for the free vaccination, whether the person with ME/CFS they care for has the vaccine or not, if the person with ME/CFS's care will be affected if the carer becomes ill. The criteria define a Carer as "someone who is in receipt of a carer's allowance, or those who are the main carer of an older or disabled person whose welfare may be at risk if the carer falls ill". You can read more information about the flu jab for Carers on the Carers UK Website.

Where to have vaccination

You can have your vaccination at GP surgeries and registered pharmacies. Flu vaccination pharmacy service was launched last season in England for everyone eligible for a free flu vaccine, with the exception of children, who can receive the nasal spray at a GP's surgery. Some pharmacies also offer private flu vaccinations costing around £15. You or your carer could have the jab at your pharmacy when picking up medication, or just go along without an appointment. Your GP will be informed for you, so that this can be added to your medical records. Many GP surgeries have special flu vaccination days when you can go along and have your vaccination. If you are housebound, the surgery may provide vaccinations at home but pharmacists can't. Contact your surgery to find out what arrangements they have in place.

Is flu vaccine safe and effective for people with ME/CFS?

Last year I heard from people who didn't want to have the vaccine because they were worried it might make them relapse. I heard from others who said flu itself made them relapse and that they were having the jab to prevent this happening again. This is somewhat paradoxical so I looked at the evidence about having the flu vaccination with ME/CFS. It's worth noting that in surveys of ME/CFS, more patients who had never been vaccinated against flu reported fears of a relapse than those who had been vaccinated. If you've had the vaccine before and had nothing more than the common mild side effects yourself, you are highly unlikely to have a bad reaction to this year's vaccine.

Several studies have tested the immune response of CFS patients (CDC criteria) compared with controls, following flu vaccination. The blood tests of the CFS patients showed a slightly heightened immune response to the vaccine compared with the healthy controls. This did not translate into self-reported worsened side effects or a relapse. The vaccine successfully achieved the desired antibody response in the CFS patients, so it would be as effective against flu as in the healthy controls. The results of an ME Association poll from 2009, showed that roughly half said they felt the same, or slightly better following vaccination, and around half said they felt slightly worse or much worse. It's worth bearing in mind that this wasn't a scientific, controlled study and was open to bias. We all have different circumstances and react to things like vaccines differently. This is worth bearing in mind if others with ME/CFS tell you their experience too.

Though there isn't much research and the studies are small, all of the scientific research papers conclude that the advantages of having the flu vaccination in protecting against the complications and a flu-related relapse, still outweighed the risk in people who have ME/CFS. This blog post looks at the evidence for safety of the flu vaccine in people who already have ME/CFS but there is also a study comparing flu itself and the vaccine for causing the onset of ME/CFS. The study used data from the entire population of Norway after a flu vaccine campaign. It concludes that catching flu increased the risk of onset of ME/CFS and that the vaccine had no effect on risk of ME/CFS.

Whether you have the flu vaccination is entirely your decision. If you're unsure, it's about weighing up risk of flu complications compared with the effects, if any, that you get. This might be different for everyone, depending on your circumstances, your own experiences, and if you have other health conditions which make you at risk of complications.

The following is from the NHS website

Treating flu

Usually, you can manage flu symptoms yourself at home and there's no need to see a GP. Most people feel better within a week. You should consider seeing your GP if you're at a higher risk of becoming more seriously ill. This includes who are 65 or over, pregnant, have a lung, heart, kidney, liver or neurological disease or have a weakened immune system. In these cases, your GP may advise taking antiviral medication.

Managing your symptoms at home

If you're otherwise healthy, you can look after yourself at home by resting, keeping warm and drinking plenty of water to avoid dehydration. If you feel unwell and have a fever, you can take paracetamol or anti-inflammatory medicines such as ibuprofen to lower temperature and relieve aches. Children under 16 shouldn't be given aspirin because of the risk of Reyes syndrome. Stay off work or school until you are feeling better. For most people, this will take about a week. See your GP if your symptoms get worse or last longer than a week.

Antivirals

In 2009, the Institute for Health and Care Excellence (NICE) recommended that doctors should consider treating people in the at-risk groups mentioned above with the antiviral medications oseltamivir (Tamiflu) or zanamivir (Relenza) to reduce the risk of complications of flu. Antivirals work by stopping the flu virus from multiplying in the body. They won't cure flu, but they may help slightly reduce the length of illness and relieve some of the symptoms. Recent research has suggested that Tamiflu and Relenza may not be effective at reducing the risk of flu complications and could cause side effects, so not all doctors agree they should be used. But there is evidence that antivirals can reduce the risk of death in patients hospitalised with flu. In the light of this evidence, Public Health England says it is important that doctors treating severely unwell patients continue to prescribe these drugs where appropriate.

Please be cautious if you are someone who has multiple allergies or you have desensitising treatment like neutralisation or EPD. This certainly needs to be discussed with your allergist because a flu jab is given with the wrong timing it could make matters worse. An antiviral medicine can be prescribed as an alternative to a flu vaccination.



The 2016 Leger ME Canal Barge trip on the 'Ethel'.

Narrative by Marianne Sonksen, Photographs by Peter.

"Unlocking confidence" is the motto of the canal barge crew from the Ethel Trust. Skipper Terry, who steers the romantic barge through tight South Yorkshire waterways past oncoming boats that forget to sound their horn at a blind bend or youngsters jumping off a 20-foot gantry across the aqueduct entry, sets a fine example of quiet confidence. It is infectious. His two 'first mates', Rodger and Rob, work hand in hand, banter aside, as if they had just arrived on the QE2.

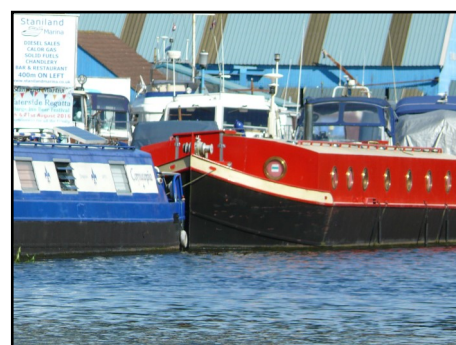
This example of serene mindfulness was medicine for a tortured soul like Tim. He can suffer from incredible bouts of anxiety that make him unable to leave the house or even his bed. Pangs of agoraphobia can make the trip to the paper shop an insurmountable task that requires superhuman strength. Agoraphobia is an irrational fear that a bodily symptom might happen to you when you are out and about. Tim's late father was a master mariner, so boats are a great part of his childhood memories. Dad would come home to York every three years to see his family.



Special dispensation had been obtained from the Ethel Trust for Tim to take his therapy dog Chica.



The barge made her way from Thorne Marina along the tranquil Keadby Canal with lush greenery and yellow water lilies, the latter a bio marker for unpolluted water.



Above and below Thorne Marina

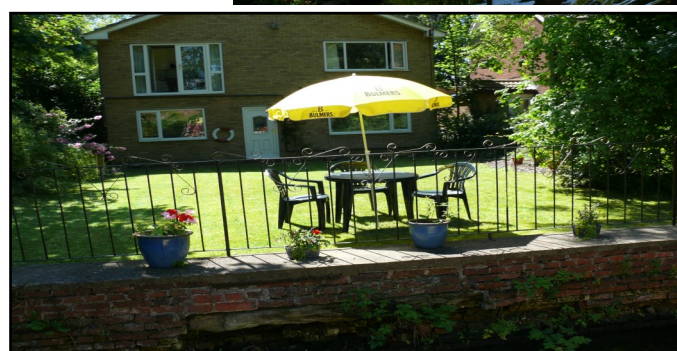


Above. On the canal we passed many narrowboats and saw swans.

Below. The New Inn Stainforth, a well known venue visited by the canal community.



*Right
The are some
people lucky
enough to
have back
gardens which
directly back
onto the canal*



As soon as Tim heard that the skipper needed 'a helping hand' all the anxiety, tiredness and apprehension he normally feels went out of the window and overboard. Only five hours sleep, the trouble of getting up early and leaving the house did not seem to matter then. Help was needed to pass through a lock! The boat's 8 cylinder Perkins bus engine gurgled away in its sonorous bass that was only disturbed by quacking ducks and swans practicing noisy waterborne take-offs, their black webbed feet batting the water surface. Soon there appeared Bramwith lock and the skipper slowed down the engine.

Tim was full of enthusiasm as Rodger explained what was to be done:
"Ideally you need 4 people, 2 for each lock gate. You will also need 2 windlass (turning handles)."

On reaching the lock, mooring and making sure the boat was safe the shore party disembarked and made their way on foot to the lock. "First we work out if the lock is 'in our favour'. How do we know? If the level of the water in the lock is at the same level as our water then we will have priority."

Well, everything was in our favour that day—priority it was. Rodger and Rob supervised so efficiently that everybody thought the 'newbies' had done it all before.

Two people were needed to open the bottom lock gates and Tim was one of them! Rodger gave a nod. The best way to do it is to lean against the wooden beam with your bum.

All was done at a quiet, steady pace. Tim looked on with pride when the barge gently rose a metre and then another one. It was clear that the crew was experienced in working with people who needed a confidence boost.

The reward for all this work was for everyone to see—before us lay a wider waterway, the 'New Junction Canal', a sparkling beauty on that hot summer day. One leaving Bramwith lock we moored to the bank and had Sunday dinner on the bank under



a shady tree. The way was free for the passage across the 1905 engineering masterpiece: the impressive Don Aqueduct which carries the canal over the River Don.

If you have ever suffered from a mental health problem and its debilitating effects, when confidence sinks to its lowest ebb, imagine how it must feel when you have caused a broad-beamed barge to rise two metres or more.
If you can lift a boat you can lift anything.

On that day you feel like Atlas who carried the world on his shoulders.

The Young ME Sufferers Trust

With thanks to Jane Colby and the Tymes Trust.

The Trust is a national ME charity specialising in children and young people. In 2010 we received the Queen's Award for Voluntary Service - the MBE for volunteer groups - for pursuing the educational rights and advancing the care of young ME sufferers.

Our Ethos

We are the longest-running national organisation supporting children with ME, inaugurated in 1989 by two young people with ME. We realise that much distress is experienced when a young person is diagnosed with a serious and disabling illness. Members tell us that our friendly, personal approach, coupled with the provision of reputable information supplied by a professional and experienced team, makes us a 'lifeline' and a 'port in the storm' of controversy surrounding ME. We hope that we shall be able to help you too.

The Trustcard

Carry the Young ME Sufferer's Trustcard at school or college to make sure you get the help you need. It is endorsed by the Association of School and College Leaders and was launched at the House of Lords by the Parliamentary Under-Secretary of State for Schools.

Support the Trust

Let us together support this excellent charity that is providing so much practical help to children with ME. As you consider whether to donate, I urge you to remember that everyone at the Trust works free of charge. This is a cause they believe in.

*Lady Elizabeth Anson, Cousin to the Queen
ME sufferer, Patron of the Trust*

Go to www.tymestrust.org/donations.htm to make your contribution, or just write in with your cheque. We will not contact you again unless requested. Thank you.

Incidence of ME

An estimated 25,000 of the 300,000 UK sufferers are children. ME is the biggest cause of long-term sickness absence in schools; a study of 333,000 pupils revealed that 51% of those on long-term sick leave had ME. This is the biggest category of pupils with medical needs requiring home tuition or distance learning on a long-term basis. Clusters of ME occur in schools, families and communities.

Management

- There is no known cure.
- The body needs energy to heal, so personal energy management is a safe way to live with ME without provoking side-effects.
- Pacing life carefully, using physical aids and finding alternatives to energy-sapping activities are often effective in promoting recovery.
- Studies claiming the effectiveness of 'graded exercise' have generally been restricted to the less sick or the partially recovered, and to those without classic ME symptoms. Some treatments may be harmful, such as overzealous physiotherapy. The condition naturally fluctuates, and may improve despite, rather than because of, treatments.
- GPs may be able to assist with symptomatic relief but medication can cause side effects and may not always be of benefit e.g. for inducing sleep or relieving pain.
- The illness tends to resolve over an extended period but relapses can occur.
- If treated inappropriately, the patient can become much worse. In extreme cases, children can suffer fits or collapse. Some go through periods of partial paralysis and may have to be tube-fed.
- Good old-fashioned convalescence is a good start, followed by careful management of the young person's life and education to avoid the downturns associated with trying to force recovery

The Young ME Sufferers Trust



Quick Tour of ME Symptoms, Management and Trust Services

Registered Charity 1080985

www.tymestrust.org

0845 003 9002

PO Box 4347
Stock
Ingatestone
CM4 9TE

Myalgic Encephalomyelitis

ME (Myalgic Encephalomyelitis) is a potentially chronic (long-lasting) and severe neurological condition. It was formerly known as Atypical Polio. The term Chronic Fatigue Syndrome (CFS) is also used but may include other fatigue states. Viral infections are known triggers of ME.

Symptoms of ME

Brain and central nervous system

- Loss of memory, concentration, balance, coordination and fine motor skills
- Difficulty sequencing words and numbers, speaking, thinking and absorbing information
- Abnormalities of sensation (e.g. pins and needles, numbness), vision, hearing, sleep rhythm, appetite, temperature control, digestion, blood pressure, circulation, hormone production, response to stress
- Development of sensitivities (e.g. to light, sound, touch, certain foods, chemical substances such as perfume, paint, medication and anaesthesia)
- Bouts of racing pulse (tachycardia) and breathlessness
- Mood swings, panic, anxiety or depression may result from brain dysfunction and the distress of misunderstood illness

Generalized pain and weakness

- Pain in muscles, joints, head, back, limbs, chest and stomach
- Muscular weakness and twitching is common

Exhaustion, up to 72 hours after effort

- Even minimal exertion (cognitive or physical) can trigger exhaustion and worsen symptoms. The delayed effect is a classic sign of ME, differentiating it from other types of fatigue.
- Temporary hyperactivity may be experienced due to brain dysfunction, resulting in exhaustion.

Education in Young People

Inappropriate educational demands impede recovery and are a key cause of relapse in children. Energy Efficient Education (home education, home tuition, distance or virtual learning) can maximise achievement whilst protecting health. Social contact can be preserved through visits from school and friends and through making new friends who understand the limitations imposed by the illness. Children with ME are legally entitled to education suited to their needs.

Advice Line

The Trust provides an Advice Line manned by our own Advice Line Team. All have personal experience of ME. Many are parents and some have also had ME themselves. They have full information. Leave your message at 0845 003 9002. One of our team will call you back with information to assist with your query - please speak clearly when leaving your number, and let us know the best times to call.

Publications

Members receive our publications, with medical and educational articles, activities for and contributions from children and young people. We send little prizes and gifts to brighten their day. Professionals Referral Service We can refer doctors, teachers, social workers and other professionals to an appropriate ME expert from our panel. Your doctor could talk with an ME specialist doctor, your teacher could talk with an ME specialist teacher and so on. We can also advise them directly if you arrange it.

Parents and supporters

To hear from us regularly, and be invited to our events, register to join our 26+ group.

www.tymestrust.org

Much more information (including this leaflet) is available free from the Trust's website, from a single sheet to give friends to show them how to help, to detailed guides for your doctor or your school. You can find out about the Young Hearts book of poetry, watch the ITV Central News interview with Jane Colby which was aired when the book was launched by Terry Waite at Warwick Castle, and register for free email Alerts.

To Register

To register for our services and receive your Welcome Pack, fill in the form online at www.tymestrust.org. Do you want to discuss whether to register? Call and speak to one of our Advice Line Team. You do not have to be a member to obtain a Trustcard. With love to all of you from all of us. Registration Form We ask for a contribution of £10 when you register. From then on, services are free to young people with ME under 26 and their families (if you are over 26, we ask you to contribute each year). Send to The Young ME Sufferers Trust, PO Box 4347, Stock, Ingatstone, CM4 9T.

The Young ME Sufferers Trust: The T Rex in The Room

From a speech given at the Tymes Trust Awards, House of Lords, 30th June 2016 presented by Jane Colby Executive Director, The Young ME Sufferers Trust

An introduction to our 2016 leaflet Paediatric ME, CFS, SEID for Families and their GPs

Because I was a GP's wife, I know that GPs need practical ways to help patients where there is no curative treatment. And they also need knowledge of what treatments, or types of management, might be actively unhelpful. Because I was a head teacher, I know how education can be modified for sick children so they can achieve whilst protecting their health and recovery. And because I got ME (diagnosed by that name) from a coxsackie B virus, I have personal experience. But of course I have also learned a huge amount through working with medical professionals who understand ME. And when I say ME, I do mean, ME. More of that later.

The late Dr. Alan Franklin was one of the foremost experts in paediatric ME, and it was a real privilege to work with him on the Chief Medical Officer's Working Group on CFS/ME. This leaflet I'm holding, which we're launching today, has been produced in commemoration of him and his wonderful, compassionate work for children. Everyone respected Alan and he still is sorely missed. Now some of that personal information is in the leaflet. There's a reason for that. OK, so here was the challenge. One sheet of paper. Why? And what's it all about? First, the Why. Over my years dealing with—and suffering from—ME, I've worked with some pretty eminent doctors.

Dr Elizabeth Dowsett was my first. She was a renowned microbiologist who probably knew more about ME than anyone in the medical establishment at that time. She diagnosed me, she demonstrated the cause, through tests - a virus related to polio. She told me that mine was almost the severest case she had ever seen. And she asked me to help her, long before I was really well enough (and she got told off for it by my mum, who was my main carer!) She asked me to help spread knowledge of ME in children, and that was how our schools research began. We discovered that no other illness causes such long term sickness absence from school. It really is that disabling and Lord Clement Jones has explained to you one of the reasons for that. Among the doctors I've worked with, including our guest Dr Charles Shepherd, there was a GP with whom I wrote articles. He called me in to advise the local education authority in a very severe paediatric case of his. He said to me: "Hmm. GPs. Keep it to one sheet!" We've taken his advice.

What's it all about? Well, we thought it was high time to tackle the Tyrannosaurus Rex in the room - the thorny issue of how ME and CFS are actually not the same thing, and why the present emphasis on fatigue is potentially unsafe for people who would once have been diagnosed with ME—Myalgic Encephalomyelitis—as originally described by Ramsay—but who now either go undiagnosed be a bit of a dinosaur when it comes to this type of revolution. There are those who seem to believe that there is some kind of moral virtue in just getting to the school building.

I don't need to tell you how oppressive it is to have your children forced to school when they are not yet well enough...never mind the educational results. And then I suppose there is the fear: we surely can't buy in a virtual education course for this child—suppose they all want one! But the bottom line is a child's needs must be catered for. That's the law.

Tymes Trust, whenever it can, sticks to talking about ME. But this is an occasion when it is important to give you one sheet that your GP can see is fully medically referenced, explains how ME, CFS and SEID (Systemic Exertion Intolerance Disease - a name suggested by the American Institute of Medicine) relate to each other, and carries medical authority for the information within it. Of course, doctors, patients, me—author of the leaflet—we're all human. Connecting personally with other people is what it's all about. In the final analysis, GPs want solutions for their patients. We hope this will help.



Recipe Corner by Carolyn

Autumn is definitely here judging by the chilly mornings so thoughts turn to comfort foods and, being a Lancashire Lass, my first thought was Lancashire Hot Pot of course, then I remembered all you Yorkshire Lasses and Lads might run me out of town if I gave you that recipe. Here instead is something very comforting and suitably Yorkshire for you to try.

Sausage and stuffing toad-in-the-hole with onion

To prepare takes 25 mins

Cooking is 1hr 10 mins but see the note in 4.

Serves 4 people

Nutrition per serving:

690kcal. Fat 39g. Saturates 11g. Carbs 54g.
Sugars 12g. Fibre 4g. Protein 31g.

Ingredients

140g plain flour

1 tsp English mustard powder

3 large eggs

300ml milk

4tbsp sunflower oil

2 large onions, sliced

85g pack breadcrumb stuffing mix

Small handful sage leaves, chopped

8 sausages

For the Gravy:

2 tbsp plain flour

2 tbsp caramelised onion chutney

2 tsp Marmite

500ml beef stock.



Method

Whisk together the flour, mustard powder, eggs and milk with a good pinch of salt until smooth. Leave to rest for at least 30 minutes.

Heat 1tbsp of the oil in a small pan. Add the onions with a pinch of salt and cook for 10-15mins until really soft. Meanwhile, make up the stuffing following the pack instructions, adding the sage. Scoop out a quarter of the onions and add these to the stuffing mixture too –leave the rest in the pan for the gravy.

Heat oven to 230C/210 fan/gas 8.

Shape the stuffing into 8 walnut-size balls. Pour the remaining oil into a large roasting tin or dish and brush it all over the bottom and sides. Add the sausages and stuffing balls, and cook for 15 mins.

Remove the tin from the oven, loosen the sausages and stuffing from the bottom of the tin if they are sticking, then pour over the rested batter. Return the tin to the oven on a middle-high shelf, but give it space to rise. Bake for 35-40 mins until puffed and golden. (Watch it carefully from 25 minutes onwards as ovens vary BUT, don't be tempted to open the oven door until you are sure it is done or the batter might sink.)

While the toad-in-the-hole is cooking, make the gravy. Add the flour, onion chutney and Marmite to the onion pan and mix to a paste. Cook for 2 mins until bubbling, then pour in the stock, bit by bit, stirring continuously so it does not go lumpy. Bubble for 5 mins and season if needed. Keep warm until ready to serve.

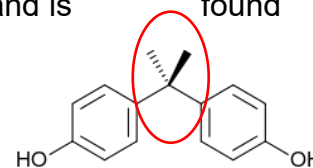


Why we should be wary about plastic food containers.

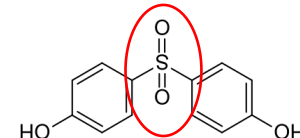
Over the past couple of years, premature human births have risen as has the number of people experiencing the early onset of puberty. It has been suggested that one contributing factor is the use of endocrine-disrupting chemicals, such as bisphenol A (BPA), which mimics the effects of estradiol, a female hormone. BPA has been used to harden plastics for more than 40 years and is found in a wide range of products including polycarbonate baby bottles, food storage boxes and the can-linings of canned foods and drinks. BPA can leach into food and beverages, particularly when containers are heated. As a result, almost all of us have BPA in our bodies. One study found it in 95% of urine samples tested.

In recent years BPA has been linked to a variety of health problems. Evidence from animal studies has led to particular concern about its potential effects on foetuses, infants and young children. Some experts believe it could disrupt normal hormone levels and affect children's brains and behaviour. In both children and adults, it may also increase the risk of cancer and heart problems. It has also been connected with many other conditions, including obesity, diabetes and attention deficit hyperactivity disorder. Because BPA's toxicity has resulted in public concern and some government-imposed restrictions, many manufacturers have replaced it with bisphenol S (BPS). Yet the new products, often boldly "BPA-free", may be no safer, because BPA and BPS are similar.

BPA



BPS



The BPS molecule simply replaces BPA's central dimethylmethylen group with a sulfone group, but it still has the two phenol rings that allow BPA to mimic estradiol.

The researchers also found that low-level exposure to the chemical led to an overstimulation of the endocrine neurons that regulate reproduction. This could lead to premature puberty and of the reproductive system. Furthermore, the research showed that BPA and BPS both affect the thyroid hormone system. Since these hormones have a significant influence on brain development during gestation, the research could have important implications for understanding general embryonic and foetal development.

All in all, it seems that we may face a health hazard from any plastics that come into contact with our food and drinks. But how do we avoid the risk? Here are some suggestions:

- Use food containers made of glass, porcelain or stainless steel rather than plastic.
- Buy more fresh, frozen or glass-bottled foods.
- Don't heat plastic containers in the microwave or pour boiling water into them, and don't put plastic items in the dishwasher.
- Throw out chipped or cracked plastic products, which are more likely to leach chemicals.
- Replace liquid baby formulae with powdered products, which are less likely to absorb chemicals from container linings.



The largest exposure humans have to BPA is by mouth from such sources as food packaging, the epoxy lining of metal food and beverage cans, and plastic bottles.

The main action needs to be taken by national and international health bodies. They should investigate all chemicals used in food and drink containers and force manufacturers to use only those that have been proven to be safe.

***Garden Watch to Autumn* by Carolyn.**

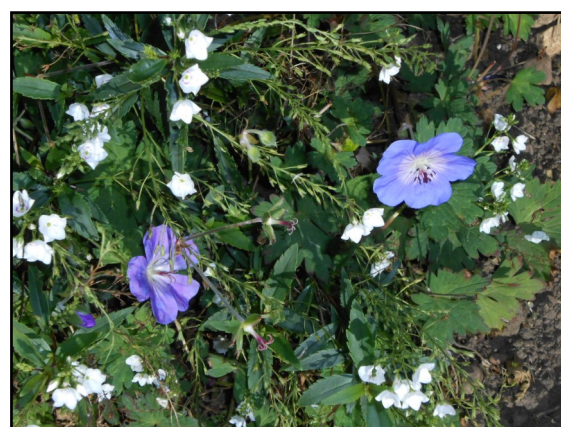
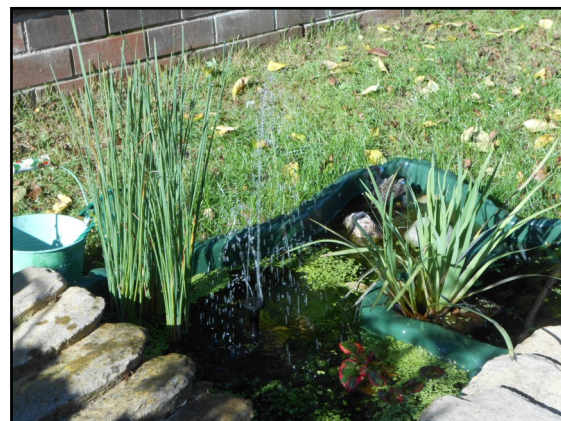
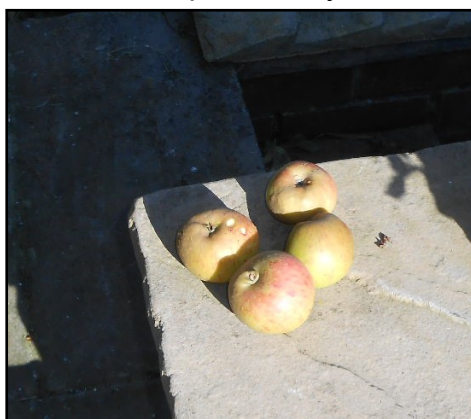
I am pleased to report that all the little frogs all escaped the jaws of the lawn mower and this last week it has been clear 'something' has been visiting the wildlife pond at night knocking over the bulrush pot on the way in and I am not sure if it is a frog or my old friend Toady who lives behind some old bricks in a corner of the garden. It is said that frogs always return to the pond where they were born, so we may be in luck.

Let's get the bad news over first. The pot of summer bulbs which should have been such a joy was a complete disaster, mostly due to all of that rain back in June. The leaves of the 'Acidanthera' became huge and they did eventually flower in August but they were a big disappointment. The 'babiana' that were also in the pot simply didn't flower at all. All very sad but the good news on this is that nothing will be wasted. I let all the green leaves die back to put the goodness back into all of the bulbs and will take them out before the first frosts, overwinter them in brown paper bags in a dark corner of the garage then plant them out into the garden next year and hope better things happen! We will see.

Lots of things have grown well and in the border I hit accidentally on a combination that has flowered happily through summer and is still looking good even though we are into October. I planted Parahebe 'Snowcap' and then Geranium 'Rozanne' a bit too close together and the Rozanne has climbed through the Snowcap to make such a pretty show. Two wonderful plants, both are hardy and such good value. I will be making more use of both next year.

In the front garden the Maples have continued to grow well and now have their autumn tones of deep green and gold amongst the red. I suspect their good progress is down to taking notice and using the right compost for them, also they like rain! I wanted to find some small bulbs to add into the pots to give some spring colour so have now planted Winter Aconite Eranthis Cilicica bulbs around the outer edges of each pot, which are a small ground covering plant with bright yellow flowers not unlike a buttercup.

The best surprise this year has been how well the small orchard strip has done. We have had full size pears from the four year old tree for the first time and plenty of them to keep the man of the house happy, and also the family of Blackbirds who ate most of the cherries earlier in the year! We've even got a few olives this year which is a first! And the very young Apple tree managed to produce some fruit as well, have just picked the last of the Coxes.



So now it is bulb planting time and seed gathering time; I am busy adding some spring-flowering bulbs to hopefully give added colour when the daffodils appear. I also have been collecting wildflower seeds but more of that in the next edition. Off out to feed the birds. Carolyn

The Doncaster Assisted Waste and Recycling Collection Service

Doncaster Council provides various kerbside waste and recycling collection services to Doncaster residents. There are a number of reasons why a resident may not be physically able to present their waste and recycling bins/containers to the kerbside for emptying, however, there is no single criteria that can be used to grant automatic approval for the Assisted Waste and Recycling Collection Service. The Assisted Waste and Recycling Collection Service is only available to residents that are unable to present their waste and recycling bins/containers to the kerbside due to disability or incapacity. The service can be provided to meet both short and long term needs. An assisted collection will only be granted if no other member of the household can move the waste & recycling bins/containers to the kerbside for collection. To apply for this scheme an application form may be obtained:-

- in person from the One-Stop-Shop at the Civic Centre, Waterdale, DN1 3BU.
- by writing to Doncaster MBC, Civic Centre, Waterdale, DN1 3BU).
- by visiting the Council's website www.doncaster.gov.uk/recycling
- by telephoning 01302 736000 with the following:-full name, address and details of any medical conditions which will support the application.

Application forms should be returned to the Council along with documentary evidence of any disability or incapacity that impacts on the resident's ability to present their waste and recycling bins/containers to the kerbside for the standard kerbside collection service.

4. Eligibility

The majority of residents are physically able to present their waste and recycling bins/containers to the kerbside for collection, although it is appreciated that the elderly or infirm and those with disabilities may require assistance.

To be eligible to apply for this service:

- the applicant must be a resident of Doncaster;
- the applicant must permanently reside at the property for which the application is made;
- the applicant must be paying the appropriate level of domestic council tax at the property for which the application is made;
- the applicant must have a genuine reason for not being able to place their waste and recycling containers to the kerbside for collection (the Council reserves the right to request evidence of any infirmity or disability);
- there must not be another able bodied person aged 16 or over residing at the household who could reasonably be expected to place the property's waste and recycling bins/containers to the kerbside for collection;
- the distance from the property's waste and recycling bin container storage location to the normal collection point must be no more than 20 metres and you must be able to provide evidence they meet one of the following criteria:-
- aged 80 or over;
- has a registered disability (Blue Badge holder);
- in receipt of Disability Living Allowance (mobility or care at the high rate) or in receipt of Attendance Allowance;
- in receipt of Personal Independence Payment (PIP); in receipt of free personal care;
- not in receipt of any disability benefits, but can provide suitable documentary evidence of a disability;
- elderly or frail with a written reference from a Carer or Healthcare Professional; suffering from short or long term illness with a medical certificate or letter from a Hospital/Doctor confirming incapacity;
- pregnant and living alone with no one able to offer support;
- blind or visually impaired and living alone with no one able to offer support.

On receipt of a completed application form a Council Officer will visit the resident to discuss their application, to ensure that the eligibility criteria for the service are met, and that there are no obstacles in performing the service. The purpose of the visit will be to assess the viability of providing the standard service, or an adjusted service, suitable to the circumstances. Consideration will be given to:

- How disability or incapacity affects a resident's ability to use the standard service;
- The layout of the property and how this affects the resident's ability to use the standard service;
- The placement of bins/containers on the property and possible alternate solutions that will satisfy both the resident and the waste collection contractor.

There is an expectation that any able bodied person aged 16 or over that is living at the property will be required to present the waste and recycling bins/containers for collection:

- Properties where some occupiers are physically able but others are not will not be eligible for the Assisted Waste and Recycling Collection Service;
- Properties where a resident is absent from home due to work commitments etc. will not be eligible for the Assisted Waste and Recycling Collection Service;
- Properties where it is simply inconvenient (long driveways etc.) to present waste and recycling bins/containers for collection will not be eligible for the Assisted Waste and Recycling Collection Service;
- Properties where regular home help can reasonably assist with presenting waste and recycling bins/containers at the kerbside for collection (which may include caretakers, neighbours, friends and family) will not be eligible for the Assisted Waste and Recycling Collection Service.

The number of properties receiving the Assisted Waste and Recycling Collection Service impacts on the efficiency and costs of providing collection services, it is therefore crucial that only those households that have a demonstrable need for the service are accepted onto the scheme.

Doncaster Council will cross reference information provided with other council departments and checks will be undertaken periodically. The decision made by the Council may result in an Assisted Waste and Recycling Collection Service being granted, or it may result in adjustments to the standard collection service.

Research Corner with thanks to ME research UK

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

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

Different EEG patterns Wu et al., Neuropsychiatric Disease and Treatment, 2016.

An objective biomarker for ME/CFS is the diagnostic holy grail, so all avenues need to be explored. Researchers at the Chinese Medical Hospital in Shandong compared waking brain EEG patterns in 24 patients and 23 healthy people using novel technology to unravel the 'deterministic chaos' of brain activity. They found that brain electrical activities were significantly reduced in the patients, particularly in the right frontal and left occipital regions which are associated with memory, vision and judgment. We don't know why this should be – levels or uptake of chemical messengers in the brain may be reduced – but this is the second study to show EEG anomalies in ME/CFS patients, and the technique is worth investigating further.

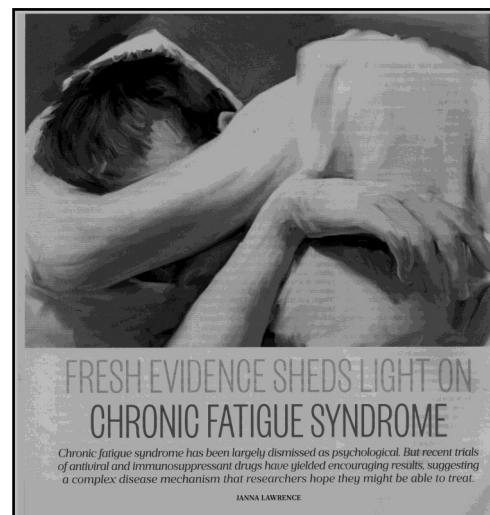
The trouble is that there is plenty of research but, where is the treatment?

Feature Review: **Fresh evidence points to a cause and possible treatments for chronic fatigue syndrome**

A review of an original feature published in the *The Pharmaceutical Journal* 15th July 2016.

The feature starts by stating that in recent years trials of antiviral and immunosuppressant drugs have produced 'encouraging' results implying a complex disease process. They suggest that there is a mechanism at play that researchers are hopeful they might be able to treat. Within our group 40% have asthma, many have food allergies and sensitivities, many have suffered migraines. This is a reasonable conclusion. Any stressor in the immune system like an infection or insect bite or sting very often will reduce a remission. So there must be an immune component, but exactly what is unclear. The authors then proceed to quote a patient who was given rituximab, a monoclonal antibody used to treat lymphoma (a type of cancer) and rheumatoid arthritis. Rituximab kills B lymphocytes, the white blood cells which produce antibodies against invading organisms (and sometimes the body's own tissues). They then talk about ME/CFS and the Chief Medical Officer's report of 2000 and the historical aspects which we have covered many times in past issues of *Pathways*.

They then cover a case where a doctor in the USA conducted a trial of antiviral drug valganciclovir to treat ME/CFS in fatigue syndrome/myalgic encephalomyelitis which improved the fatigue marginally but not enough to justify further research or investigation. There has been a common finding over the last 20 years or so, where over the years there have been multiple clinic trials with many drugs to treat ME/CFS but all the results have been similar. In 2015, research found ME/CFS patients had increased levels of interferon gamma, usually produced as a cytokine released in response to viral infections and which the researchers say is consistent with the theory of a reaction to a viral trigger. There have been reported changes in the gut microbiome (candida?) and inflammatory microbial markers in blood samples. There is a case quoted when an ME/CFS patient was treated for Hodgkin's lymphoma (a type of cancer) whose ME/CFS improved greatly after chemotherapy intended to treat the cancer. There is a theory that ME/CFS is caused by 'rogue antibodies' produced by lymphocyte B cells. They also discussed the cases of several CFS/ME patients with breast cancer being treated using cyclophosphamide (an anti-cancer drug) who experienced a remission of their CFS/ME. The results of the trial are expected in 2017. I await the results with interest. Using anticancer drugs to treat ME/CFS in a way is like using a sledgehammer to smash an egg the treatment is more likely to cause more health problems than it cures. Locally within our group many people with ME/CFS-related allergies and sensitivities by EPD often experience several months' remission which is thought to be related to white blood cells.



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

The next section then discussed Cognitive Behavior Therapy (CBT) and Graded exercise GET it says are the proven therapies, and then discusses Adaptive Pacing Therapy. Locally this approach has been used by the Sheffield ME/CFS clinic. For me the approach of CBT and GET is really offensive. The parallel I often quote is like trying to convince Long John Silver that his crutch is as good as his

missing leg. I have pointed this out in a previous Pathways feature comparing treatment of fatigue in multiple sclerosis (MS) and ME/CFS. CBT and GET are not even mentioned in MS. The British Association of CFS/ME (BACME) guide for therapy and symptoms management in CFS/ME has a strategy using readily available medicines.

There is no medicine based therapy for the following symptoms:

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

The feature then goes on to quote a physiotherapist, and explains that the strategy with both CBT and GET aim to stabilise a patient at a baseline of activity so they can gradually trying to improve. The remainder of the feature is speculative and talks of future research and funding etc.

The researcher seems to have ignored the ME Association and Action for ME who are the main patient support organisations who produce quite a wide range of information which is more relevant to practice. Overall I'm unimpressed by the feature, simply because it is not of any practice value.

Conclusion: Satisfactory but could have been much better if more practical information was included.

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

from ME Research UK

Abnormal connections among brain regions and reductions in white matter that continue as the illness progresses are reported. Most research studies are cross-sectional, a snap-shot at a particular time. These studies have their uses, but they don't tell us about long-term changes, which can be considerable if there is continuing disease.

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

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

The IFOF is a bundle of nerve fibres that passes backwards from the frontal lobe of the brain, its fibres radiating out in a fan-like pattern. It represents one of the many 'long association fibres' that unite different parts of the same hemisphere of the brain. It's thought that the IFOF connects attention, language processing and working memory networks, so its shrinkage over time may be associated with the memory, concentration or attention problems and visual deficits known to occur in ME/CFS.

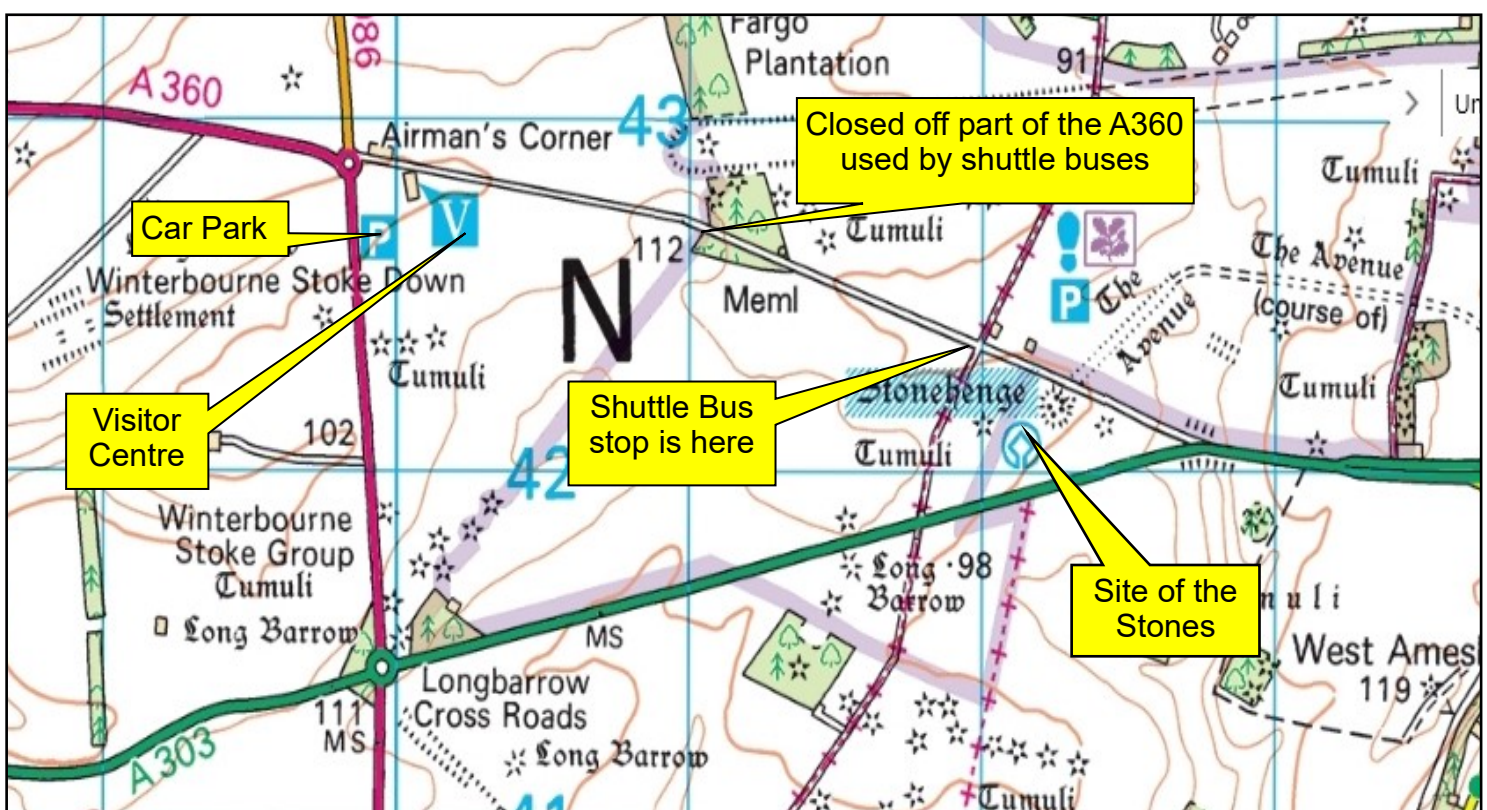
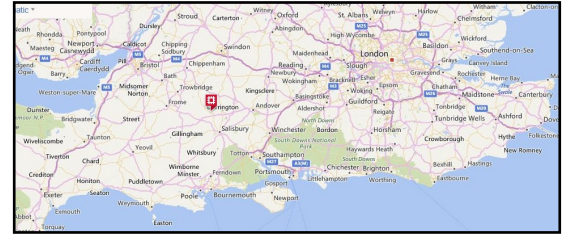
Out and About: Stonehenge

We've all heard about it sometime in our lives, so while we were on holiday in Wiltshire, we decided to spend an afternoon there. On our way to where we were staying, we had passed the site which we could just see located on the horizon on a hilltop on the north side of the A303. Normally on holiday we take an Ordnance Survey map of the locality. Having checked, we found discrepancies with the tourist information we were given. It turns out that a section of the A360 has been closed off and a visitor centre built just off Airman's Corner Roundabout. We were guided by signposts into the car park. Although the blue badge places are nearest the visitor centre, there is still a 300-400-yard walk to the new visitor centre itself. This itself is bad planning by English Heritage who seem to have taken no account of people with limited walking abilities.

Stonehenge has been a legally protected Scheduled Ancient Monument since 1882 when legislation to protect historic monuments was first successfully introduced in Britain. The site and its surroundings were added to UNESCO's list of World Heritage Sites in 1986. Stonehenge is owned by the Crown and managed by English Heritage; the surrounding land is owned by the National Trust. As we are English Heritage members we get in free, but we still had to book our visit several days before on the English heritage website. The normal adult ticket cost is £15.50. It soon became apparent why. The visitor centre is about 1½ miles from the Stones. There used to be access to the stones from the old visitor centre just across the road. Now visitors are directed to the new visitor centre, and you walk the 1½ miles to the Stones or take the shuttle bus, the fare being included with your admission ticket. We were packed into the shuttle bus, with many people standing. The shuttle journey itself is on the closed part to the A360, which terminated at a stop about 500 yards from the Stones.

Right: A view of the Stonehenge Site from the main A303 trunk road.

Below : A map of the Stonehenge site.



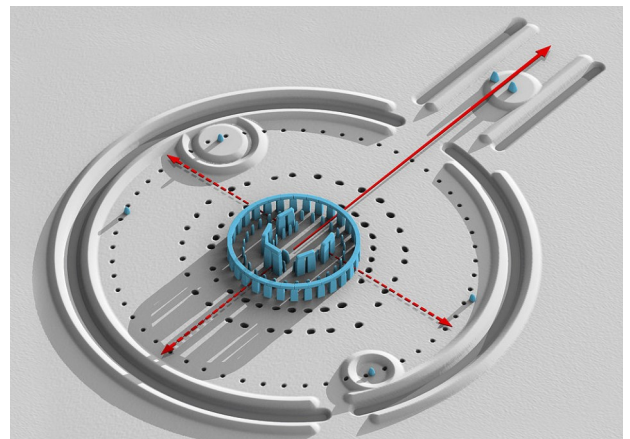
On entering the main site, you are confined to a walkway around the monument—about 25 yards away from the Stones. There are plenty of English heritage staff around to ensure you stick to the Pathway. Surprisingly the site was crowded, with many of the visitors from foreign lands, many were oriental. Many were taking pictures of themselves with the Stones in the background with their mobile phones on selfie sticks.



Once we got to the front of the crowd we could see the Stones. Stonehenge evolved in several construction phases spanning at least 1500 years. There is evidence of large-scale construction on and around the monument that perhaps extends the landscape's time frame to 6500 years. How the people of the time managed to move such massive objects with primitive equipment is not recorded. What are known as the blue Stones came from Pembrokeshire in Wales. The site has been changed and used in at about half a dozen phases, and its use has been mainly religious, ceremonial or as a calendar—as some of the key Stones are placed to record astronomical events. e.g. mid summers and winterers sunrise.

Having seen the Stones, we walked the distance to the bus stop, and boarded the shuttle back to the visitor centre. In true English Heritage style, the bus put us down next to the Visitor Centre shop and its adjacent café. Also on the visitor centre site was the museum, which plenty of ancient artefacts. There was a circular room with projectors in the ceiling which over 5-10 minutes provide a historical show as if you were in the centre of the Stones over the various phases in history. Also outside there was a big sledge with a copy of a massive stone on it. The children who were climbing all over hadn't bothered to read that this exhibit was an illustration of how it was though the Stones were transported many miles in antiquity. There were also reconstructions of stone age roundhouses complete with their contents.

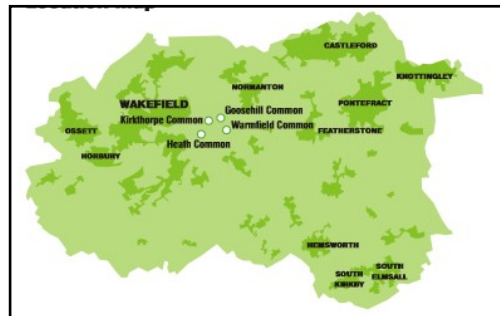
Over all it's a reasonable site to visit if you are able bodied, but if you have limited mobility there are problems but not insurmountable. One thing is certain though, Stonehenge is the jewel in the crown of English Heritage, and their biggest earner drawing many thousands of visitors from abroad.



A computer generated image of the site at its pinnacle of use.

North of Doncaster Personal *comment by Trevor Wainwright***Heath Common – A Country Spoof**

The word spoof has many meanings and in different languages, among which are joke, hoax, send up, and no doubt the English Countryside will be full of such in the form of tall tales made up by the locals. Two miles from the centre of Wakefield lies Heath Common running northwards from the A638 to what was once a rural community, a village a scattering of stone houses for both gentry and workers, with its own Smithy, Village Pub, Bowling Green, Carpenters Shop, Farms, Golf Course and School. Among its past attractions was the Heath Common Fair which still runs today every Easter, what isn't known though is the fact that it once had a race course, a point to point race course.



So where was it? A good giveaway is the name of the buildings at the end of it 'Horse Race End', which is also the official address for the pub there, The Horse and Groom. So how do we get there?

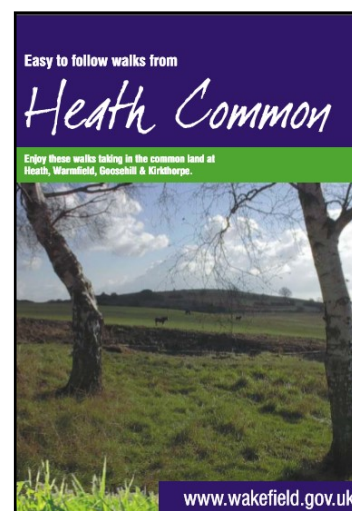
Heading East out of Wakefield on the A638 (Doncaster Road) we go under a railway bridge, and we are at the bottom of the Common, we take a left turn at the traffic lights and follow the road to Normanton, called Black Road, just over half a mile on the left we come to two semi-detached houses called Horse Race End, then The Horse and Groom, then another block of Houses also called Horse Race End. Just after this a road runs to the left, Hell Lane, along which is Heath Farm, with its old stables and accommodation block. The race course ran in a straight line from Black Hill (after which the road behind the houses was probably named). It apparently stopped just before the pub.

The spoof came in one day when I remembered someone saying, in fun, that the Grand National was once run there. I was driving past with a colleague during my time in the Fire Service, Community Safety, and decided to embellish it. Pointing out Horse Race End I mentioned there was a real racecourse behind the buildings a point to point one on which the first ever Grand National was run. The background to this was the early 1800's and the fact that Heath Common was on what was then in the days of horse and cart, the trade route from Wakefield to Doncaster, eventually to the port of Grimsby. Heath Easter Fair was initially a travellers' horse fair due to its location and layout. Horses would be bought and sold some being taken to Europe through the port of Grimsby.

I added, so what better way to attract buyers and sellers than by holding horse races to give an idea of what the horses were like, how fit they were—a good way of increasing their value. Because many were sold in Europe and traders came from all over England it was proposed to call the meeting Heath Easter Fair Races run over the period of the fair with the main event being called The Grand Easter International. It would eventually become The Grand National and being a point to point depended more on the speed of the horse than the skill of the jockey, who had only one thing to do—stay on the horse. This proved to be the race's undoing.

I then came up with the story that there needed to be a better way of testing the jockeys' riding skills, and so a better location needed to be found and after much searching it was decided build a race course fit for the purpose. This was at the time fast clipper ships were opening up transatlantic travel so with its proximity to Liverpool docks Aintree was chosen and the Grand National moved there. Horse racing at Heath Common gradually diminished, as more and better racecourses were built and point to point race courses became redundant. Well, the guy believed me, even more so when I told him that a hill we could see opposite was called Mount Tarry. Because of its name, it was officially the smallest mountain in England and was so called because of its location on a public footpath from Wakefield to Normanton. It gained its name when the path was well used and people used to stop and enjoy the views, thus tarrying by it. All of this could be backed up by showing the location of the two sites on an old Ordnance Survey map which hung on the wall in the foyer of Wakefield Fire Station. The map showed the fire station's area in the days of Wakefield City Fire Brigade before reorganisation in 1974, when, along with other city brigades WCFB was incorporated into West Yorkshire Fire Service. The last bit is true by the way

A great follow up was when I was telling the story to a female colleague. She asked in amazement if it was all true about Heath Common. I fell about laughing telling her it was all made up by me. She said it sounded so convincing...



Spoof? Pathways investigators found this downloadable leaflet on Wakefield Council's website. Draw your own conclusions