Pathways

Price £ 5.00 (Free to members)

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

Welcome to Pathways No 76.

Summer 2023 Edition

Featuring Blue Badge Applications and Hay Fever

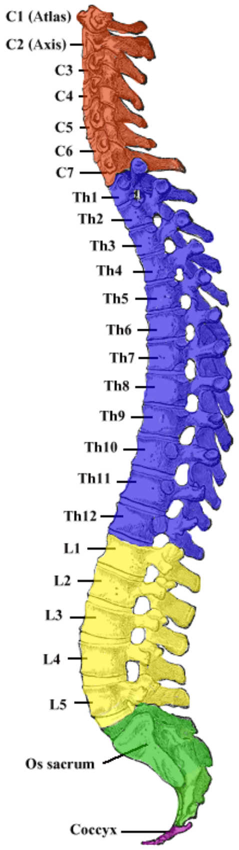
A laburnum tree produces a massive floral display in late spring/ early summer

You write in: *Questions answered for Pathways readers.*

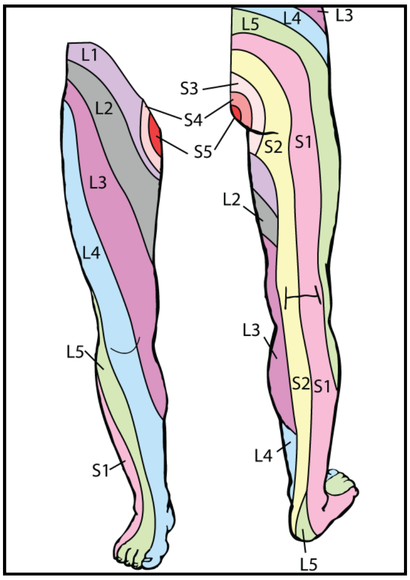
Sally Writes: Do you know when the next date for the next £150 Disability Cost of Living Payment is due to be paid?

The DWP has announced that the next £150 disability cost of living payment will be made automatically over a two week period between 20th June and 4th July 2023. To be entitled to a payment, you need to have been eligible for one of the following benefits on 1st April 2023. Disability Living Allowance, Personal Independence Payment, Attendance Allowance, Scottish Disability Benefits (Adult Disability Payment and Child Disability Payment), Armed Forces Independence Payment, Constant Attendance Allowance, War Pension Mobility Supplement. Some people will have already received their payment by the time this edition of Pathways is received.

William Writes: I have a dead patch on the side of my knee. I cannot feel anything if I touch it. My knee joint is perfectly mobile. The skin is the normal colour and there are no cuts or other injuries. Can you explain what it could be, and should I see my doctor about it?



I quite often hear reports of dead patches or areas around the body, as though a dentist had injected a local aneasthetic by mistake. Sometimes patches of skin can also become abnormally sensitive or painful. There are a number of neurological diseases that can cause this. ME/CFS is one, but it can also be caused by diabetic neuropathy and other diseases such as multiple sclerosis. This can also be caused by vitamin B12 deficiency.



The root of the problem are the sensory nerves which branch out of the spinal cord to the skin. They emerge in pairs and are labelled as the image on the right. The areas of skin that each nerve serves can be mapped out in the surface of the skin know as a dermatome. The area of skin affected is usually in one area. So, a doctor will be able to say for example that your problem is due to the nerves from for example L2-3. Damage or injury along that nerve would cause the same result. It is his job to work out what has been causing the problem. It could be an injury or slipped disk or something else abnormal. When a nerve ending is inflamed, as for example in shingles, the rash and painful areas always follow the dermatome map. My advice is that you report it to your doctor at the next routine appointment. If, however, the area changes colour, becomes painful or something else changes, then this should be reported urgently. Most of the time no action is needed, but occasionally an intervention is needed.

John Writes: Ofgem has announced that energy rates will be going down this summer. The good news is that from July I will be paying less for my energy. However, they tell me that I might not see a change in the amount I pay straight away. They tell me that when they next review my Direct Debit, they will consider the overall costs of your energy, including any credit or debit balance you may have, before working out my new Direct Debit amount. Here is what they estimated my usage would be our estimated annual costs at a glance:-.

£4,127.15 at the old tariff price, £3,355.33 at the new tariff price, the saving being £771.82

Just remember that these figures are an estimate or forecast. If you owe money in your energy account, I would take a good look at the figures. If possible, increase your direct debit to clear any amount owing or make a one off payment. You have to be careful that your energy suppliers are not overcharging because of the estimate. It is possible that energy charges will drop further, and no doubt many suppliers will keep the high rate direct debits. It's all a matter of the checking your meters, and energy accounts. Most energy suppliers have a facility for people to submit meter reading outside the normal billing periods. It is important you use this facility to ensure your bill and estimates are accurate.

Sandy writes: Hi everyone, I am a Pathways reader and I live in Cincinnati in the USA. No doubt you will have heard about the forest fires in Canada. Today, shouldn't have been outside because after a few days break from five days of poor air quality alerts arriving from the Canadian forest fires, another started last night at midnight and is in effect, so far, until Sunday night…..however, my dog, Ashley likes what I call her 12 o'clock when we go outside for another little walkabout and maybe some gardening. So I stayed on the porch with her and read my book for a while so she could lay at my feet for a while and watch for any critter (animals) or people activity.

While we were there, I became aware that the doe was back alone, walking across Maple Avenue to the yard on the street behind us and on the other side. I stood up and greeted her, she looked for a second, while I was wondering if I should put a bowl of water out, but then she walked behind their garage, apparently going to weave her way through the backyards of the opposite end of Hegner Avenue to forage. will have left the fawns somewhere safe (maybe she knows when the air quality is poor and they should rest, eh?).

We do see deer around Doncaster, but they are all very timid and melt away into the woods.

Crafters Corner

Firstly we have three pictures from Ann Fisher, who has been doing what she described as 'a bit of pottery.'

We think they are lovely !!

Hedgehogs

Large Planter

Honey Pot

Meanwhile multitalented Claire Poultney has sent us the followings images of her craftwork.

Homemade Afternoon Tea

Coronation dog wear

Bronte text flowers

Butterfly card

Origami card

Heart card

Welfare Rights Matters

By Steve Donnison.

Benefits and Work
Guides you can trust
SUPPORTING CLAIMANTS SINCE 2002

Proposed WCA Abolition Update: No Legal Safeguards.

MPs have begun to quiz DWP ministers about the proposed abolition of the WCA. (*WCA = Work Capability Assessment aka IB50 UC50 form).*

So far, the results are not encouraging. Labour MP Karen Buck asked whether there would be a substantial risk test in the new system, comparable to the one in the WCA. This rule states that you will not have to undertake work-related activity if, because of your condition or disability, there is a substantial risk to the mental or physical health of any person. DWP minister Tom Pursglove's answer was clearly a No without actually saying No.

As part of the new approach to support, work coaches will have personalised conversations with claimants to figure out their individual circumstances and how their health condition affects them. This will mean that people will have their requirements tailored to their needs, which can include having no work-related requirements at all while the claimant seeks mental health support.

Buck also asked whether claimants would have a right to appeal a work coach decision that they were capable of work-related activities. Pursglove would not be drawn, saying only that the DWP will take time to carefully consider how best to implement these changes and ensure it provides the taxpayer with value for money and is accessible and effective in delivering for our service users. Again, this sounds very much like a No.

In fact, under the proposed changes, there are no legal tests to decide who is or is not capable of work, only the opinions of a work coach. It is hard to see how any such decision could be challenged via an appeal tribunal, which can only look at the law.

Finally, Buck asked whether a benefit sanction that reduced UC Standard Allowance to zero would remove a claimant's entitlement to the Health Element of UC.

Pursglove's response was an unhelpful stalling statement:

As we develop our reform proposals, we will consider how some interactions with the UC system will be reflected in the reformed system.

As the charity Z2K tweeted:

It is unbelievable that the Minister for Disabled People cannot confirm that, under his proposals, disabled people will not be hit harder by sanctions than non-disabled people must urgently confirm that a sanction will not put your Health Element at risk.

Needless to say, they have not. So far, it looks like every opportunity to build legal safeguards into the system and reassure disabled claimants is being deliberately avoided by the DWP.

Over Half a Million UC Claimants Sanctioned in A Year for Not Attending Interview

The latest statistics released by the DWP this month show that 541,000 UC claimants were sanctioned in the year to January 2023.

The overwhelming majority of these - 530,000 - were sanctioned for not attending or not taking part in a mandatory interview. The figures stand for an exceedingly small fall from the peak sanction rate, but the number of claimants sanctioned is still more than double what it was pre-pandemic.

In January 2020 18,462 claimants were sanctioned. In January 2023, the figure was 44,888. With the DWP planning to give work coaches the power to decide who is capable of work, these figures are a reminder of the vast power such unqualified staff will wield.

First, they will rule on whether a claimant is able to take part in work-related activities. Then they will be able to recommend a sanction if the claimant does not attend a meeting or does not take part as fully as the work coach wishes. Claimants can try to show good cause for not attending a meeting or not being able to take part in it properly, including issues with their health. But if the work coach is skeptical

Dates for the next £150 Disability Cost of Living Payment Announced.

The DWP has announced that the next £150 disability cost of living payment will be made automatically over a two week period between 20th June and 4th July 2023. To be entitled to a payment, you need to have been eligible for one of the following benefits on 1st April 2023: Disability Living Allowance, Personal Independence Payment, Attendance Allowance, Scottish Disability Benefits (Adult Disability Payment and Child Disability Payment), Armed Forces Independence Payment, Constant Attendance Allowance, War Pension Mobility Supplement

UC Calls Answered 24 Times Faster Than Pip Calls

Figures released by the DWP show that calls about universal credit (UC) were answered 24 times faster than calls about PIP in March of this year, even though there were almost twice as many UC calls. In answer to a question from Labour MP Beth Winter, Tom Pursglove revealed that in March 2023 there were 1,345,024 calls to the UC helpline compared to 684,306 calls to the PIP helpline. Yet, in response to a separate question from Winter employment minister Guy Opperman explained that that the average speed of answer or the UC helpline was 1 minute and 28 seconds in March of this year. For PIP it was 37 minutes. So, UC calls were answered 24 times faster than PIP ones in March, even though there were twice as many. The reality may be much worse, as the DWP have almost certainly deliberately cut off many calls to the PIP helpline before they could be answered. So, clearly the problem with the PIP helpline is not due to an overwhelming volume of calls. It is much more about where the DWP chooses to invest its resources. And, at the moment, disabled claimants are at the very back of the queue.

Almost Half a Million Pip Helpline Calls Deliberately Disconnected in April

Almost half a million callers to the PIP helpline in the month of April were deliberately disconnected by the DWP before they could even wait in a queue, a freedom of information request by Benefits and Work has revealed.
In May, we asked the DWP to tell us the number of calls made to the PIP Enquiry Line which were cut off. And bear in mind that just because you get into the queue, that does€™t mean you will ever get to speak to anyone, as so many members have found to their dismay.

Month	Calls put in queue	Calls blocked
February	415,552	34,860
March	488,965	306,865
April	388,265	494,044

The worry is that the DWP is now in a downward spiral of increasingly awful customer service and that increased claimants will lose out as a result.

Average Waiting Time on Pip Helpline Rises to Over 40 Minutes

The average waiting time for callers to the PIP helpline has risen from 25 minutes in January to over 40 minutes from March onwards, according to official statistics.
The average speed of answer for the PIP helpline in minutes and seconds since the beginning of the year was: *(see table to right)*

Put these increased waiting times together with the fact that hundreds of thousands of callers never even get put into the queue and it just adds to the impression of a service in meltdown.

Month	Wait
Jan	25:14
Feb.	34:50
March	40:22
April	43:59
May	40:43

The Truth Is Finally Out About WCA Outcomes for ESA And UC

After years of refusing to do so, the DWP have finally bowed to pressure and published statistics showing the outcome of work capability assessments (WCAs) for universal credit (UC).

65% have limited capability for work and work-related activity (LCWRA) the UC equivalent of the support group.
19% have limited capability for work (LCW).
16% were found fit for work.

By comparison, in the quarter to December 2022, the figures for ESA were:

65% placed in the Support Group
12% placed in the Work Related Activity Group
22% were found Fit for Work

So, the proportion going into the support group was virtually the same for ESA and UC. The proportion found fit for work was actually higher for ESA.

These figures leave us wondering why the DWP have tried to keep them secret for so long? There was nothing to hide, as far as we can tell. Is it simply that the DWP fight to keep everything they possibly can hidden, because it is easier for them to work in the shadows with as little public scrutiny as possible?

That way, we never know whether they are keeping secrets because their actions have caused real harm or simply because they always keep secrets, even when they do not need to fall in appeal success rates for PIP, DLA, UC, and ESA There have been falls in the success rates for almost all of the benefits covered by Benefits and Work site in the most recent quarterly figures released by HMCTS. The statistics cover the period from January to March 2023. The success rates for different benefits were:

PIP 68%, down 4% on last year
DLA%, down 4% on last year
ESA%, down 12% on last year
UC 53%, down 2% on last year

No explanation for this across the board fall has been offered. However, it is worth noting that the number of disposals cases dealt with increased by 60% compared to last year and it is possible that the speed with which cases are being dealt with has increased, to the detriment of claimants.

Referral to the Sheffield ME/CFS clinic

The CFS/ME Service is a specialist, regional therapy service for people affected by CFS/ME across South Yorkshire and North Derbyshire. The service is available to individuals who have a provision diagnosis of CFS/ME, are registered with a GP within the region and who have been unable to self-manage their condition with the advice and management provided from primary care. ADDRESS: Michael Carlisle Centre, 75 Osborne Road, Sheffield S11 9BF

1) Eligibility: For individuals aged over 16 years.

Primary complaint of unexplained and debilitating, persistent or relapsing, fatigue (not caused by conditions such as inflammation or chronic disease): -

* Of definite or new onset but a minimum of 4 months duration.
* Not due to ongoing exertion and not substantially relieved by rest.
* Severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities.

Symptoms are worsened by increased physical or mental exertion often with a delayed impact (i.e., it is felt later the same day or next day) and lasting for more than 24 hours. Recovery from such relapses may take days, weeks or even months.

Plus at least 4 of the following symptoms in addition to the fatigue:- * Frequent sore throats; * Memory, concentration, or word-finding problems; * Unrefreshing or disturbed sleep; *Tender lymph nodes; * Nausea; * Dizziness; o Flu-like symptoms; * multi-joint pain without swelling or redness;* Headaches of a new type, pattern or severity; *Muscle pain or twitching.

2) The Referral Process: Adults over 18 years of age can be referred directly to the CFS/ME Service by their GP once recommended screening tests have been completed and provisional diagnosis of CFS/ME has been made following a minimum four month period of persistent symptoms. Sheffield Health and Social Care, NHS Foundation Trust

3) Geographical Population Covered : Individuals registered with a GP practice within the South Yorkshire and North Derbyshire region (Including Sheffield, Doncaster, Rotherham, Barnsley, North Derbyshire County, and Hardwick Clinical Commissioning Groups).

Medicines Matters: What happened to Zantac.

Two variants of Zantac now withdrawn.

Ranitidine, sold under the brand name Zantac among others, is a medication used to decrease stomach acid production. It is commonly used in treatment of peptic ulcer disease, gastroesophageal reflux disease, and Zollinger–Ellison syndrome. It can be given by mouth, injection into a muscle, or injection into a vein. Common side effects include headaches and pain or burning if given by injection. Serious side effects may include cancer, liver problems, a slow heart rate, pneumonia, and the potential of masking stomach cancer. It is also linked to an increased risk of Clostridium difficile colitis. Ranitidine is an H2 histamine receptor antagonist that works by blocking histamine, thus decreasing the amount of acid released by cells of the stomach.

In September 2019, the probable carcinogen N-nitroso dimethylamine (NDMA) was discovered in ranitidine products from a number of manufacturers, resulting in recalls. In April 2020, ranitidine was withdrawn from the United States market and suspended in the European Union and Australia due to these concerns. In 2022, these concerns were confirmed in a nationwide population study "ranitidine increased the risk of liver", lung, gastric and pancreatic cancer by 22%,17%, 26% and 35%, respectively. It increased overall cancer risk 10%.

Ranitidine was discovered in England in 1976 and came into commercial use in 1981. It is on the World Health Organization's List of Essential Medicines. It is still available as a generic medication via the internet. It has been withdrawn at regulator request from most markets, including the United States; it has been discontinued globally, according to the NHS. By 2020, it was the 177th most commonly prescribed medication in the United States, with more than 3 million prescriptions, vs nearly 19 million in two years.

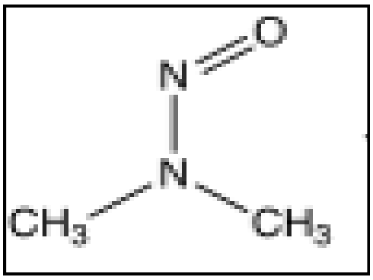
What is the recall about?

NDMA is classified as a probable human carcinogen (a substance that could cause cancer) on the basis of animal studies. It is present in some foods and in water supplies but is not expected to cause harm when ingested in very low levels. In the UK, The MHRA has asked manufacturers to quarantine all products which may contain the active pharmaceutical ingredient (API) that is potentially affected by this issue. The four in the recall are made by GlaxoSmithKline (GSK).

Over-the-counter products (Zantac 75 Relief (PL 02855/0081 [GSL]) and Zantac 75 Tablets (PL 02855/0082 [P]), which people can buy in pharmacies without a prescription, are produced by a different company and are not affected by the recall. The MHRA is investigating other ranitidine medicines which may also be affected and will provide updates soon.

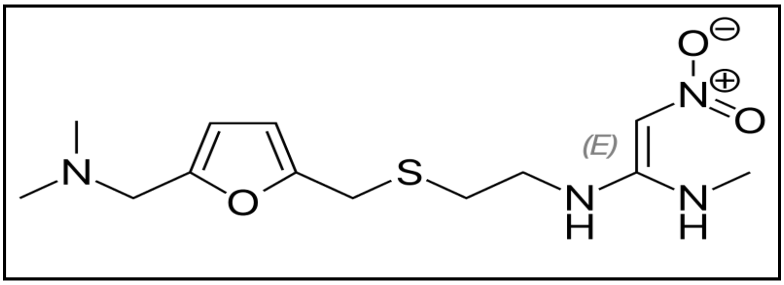
Currently, there is no evidence that medicines containing this type of impurity have caused any harm to patients, say experts. Dr Andrew Gray, from the MHRA, said:

"Whilst this action is precautionary, the MHRA takes patient safety very seriously. "We have asked companies to quarantine batches of potentially affected medicines whilst we investigate and we will take action as necessary, including product recalls where appropriate. We have also requested risk assessments from the relevant companies which will include the testing of potentially affected batches."



Left: Structural Formula of NDMA

Right: Structural formula of ranitidine, also known as Zantac



About Leger ME: This feature appeared in Interaction
With thanks to Action for ME printed is received.

"We are regaining lost ground"

Leger ME Group was set up in 2004 to provide support for people with M.E./CFS in the City of Doncaster (pictured) and adjacent areas in South, West and North Yorkshire.

A self-funded community group, Leger ME Group uses the term "fatigue syndromes" to mean M.E./CFS, post-viral fatigue syndrome, Fibromyalgia and Long Covid. Anyone living with these long-term conditions, often occurring with many other major chronic conditions, is welcome to join.

Currently the group has around 75 members, with more visiting their website for information and updates. They have in-person meetings on the third Thursday of each month from 1pm and 3.30pm at The Linney Centre, Weston Road (behind the shops), Balby, Doncaster DN4 8NF.

Person-centred support

Mike, the contact for the group, says: "We provide local person-centred support by interaction with likeminded people, through shared experience, recognition and acceptance. This can either be by peer support at our events and meetings, or by our one to one mentoring service for more complex personal problems.

"Mentoring is all about a veteran member, guiding a less experienced member, with the benefit of their experience, and opportunities to share skills and expertise. It focuses on providing them with the resources to cope with the burden of M.E./CFS through regular communication and on-going coaching, feedback and signposting, including dealing with DWP forms, and related health and welfare matters."

The group also has a members Facebook page, an email Newsround circulated with up-to-date information about what is happening locally, and a quarterly 24-page newsletter called *Pathways*.

Openly available on the Leger ME website as well as posted to members, Pathways features M.E./CFS and related health information, age-related health issues, welfare benefits information, and articles of general interest. December's issue included updates on the Autumn Budget and increases in disability benefits rates; articles on cholesterol, statins, Long Covid, Vitamin D3; and members' craft projects, recipes and top tips.

Valued resource

The group is a valued resource for members, says Mike. "We have helped the vast majority of our members receiving PIP and other welfare payments. A number of members have formed a craft group and sell their creations. There have even been several romances.

"With the onset of Covid and lockdowns our regular activities were curtailed due to the loss of the old meeting venue. We tried online meetings, but these were not very successful. However, Doncaster Council offered us the Linney Centre which is ideal for use although some distance from the old venue.

"The main issue we have is that our members are sensitive to bad weather and extreme weather. Additionally, like many other community groups, we have lost continuity due to Covid and financial problems. But we are slowly regaining lost ground. For the summer we are looking at a canal boat trip around the Doncaster Canal network and some social outings."

The group is named after the St Leger Festival horse race associated with the city.

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Food Fact Sheet: Glycaemic Index (GI)

With thanks to the British Dietetic Association

Carbohydrates (carbs) are digested at different rates, and this has an effect on your blood glucose (blood sugar) levels. The Glycaemic Index (GI) is a ranking from 1-100 and relates to how quickly these foods make your blood glucose levels rise after eating them.

What is GI?

Each time you eat or drink something sugary or starchy, the blood glucose level in your body rises. Some of these are quickly digested and cause quick and sharp rises in your blood glucose levels - they are called high GI foods and drinks. Low GI foods and drinks are more slowly digested and will make your blood glucose rise more slowly.

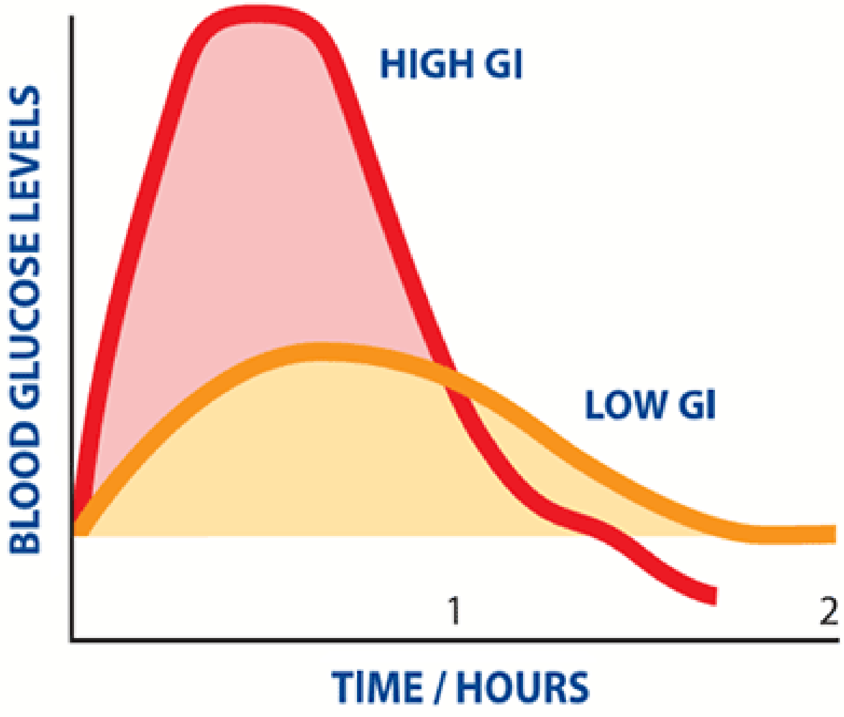
These are sometimes called 'slow release' carbs. Starchy and sugary food and drinks contain carbohydrates:-

- Starchy foods such as bread, pasta, chapattis, potatoes, yam, noodles, rice, and cereals.
- Fruit and fruit juice.
- Some dairy products such as milk and yogurts.
- Sugar and other sweet foods.
- Non-diet soft drinks

Foods with a high GI are not necessarily bad foods. For example, potato crisps have a medium GI, but a baked potato has a high GI. Despite this, a baked potato is better for your health than potato crisps, which are higher in fat and salt. And all lower GI foods are not necessarily healthy – chocolate and ice cream have a low to medium GI rating. I f you focus only on the GI of foods, you could end up eating a diet that is high in fat and calories, making you more prone to weight gain and heart disease. So, the key is to use GI in the context of balanced eating.

Why is GI important to me?

Most recommendations on eating a diet that includes a range of low GI foods are directed at people with diabetes, since this can help to control blood glucose levels. Research suggests that it is the amount of carbohydrate you eat rather than its GI rating that has the greatest influence on your blood glucose level after a meal. Diabetes UK advises that people with diabetes eat sensible portion sizes of carbs and include low GI foods into everyday meals. The GI value of a food is evaluated on the food when eaten on its own, and there are published lists of high, medium, and low GI foods. However, it is not helpful to use the GI values in isolation, as we generally eat food in combination with other foods. GI needs to be taken in the context of varied balanced eating for it to be successfully incorporated into a healthy diet.



GI and balanced eating

- Here are some everyday examples of lower GI carb choices.:_
- Multigrain, granary, rye, seeded bread, sourdough bread.
- New potatoes in their skins, sweet potato, yam, cold boiled potatoes
- All pasta cooked until al dente, instant noodles.
- Basmati rice, long grain, or brown rice
- Bulgur wheat, barley, couscous, quinoa
- Porridge, muesli, some low-sugar oat, and bran-based cereals

Many low GI foods are a good source of fibre or wholegrains. A healthy way to use the GI principles is to incorporate a range of lower GI carbs that are also rich in fibre and low in saturated fat. For weight management, you also need to think about reducing your overall calorie intake by incorporating lower calorie foods into your meals and snacks. Consider the overall balance of your meals by looking at labels and choosing foods that are lower in saturated fat, salt, and sugar, and keep an eye on your portion sizes.

GI and diabetes: There is good scientific evidence to suggest that basing your diet on low GI foods and keeping an eye on the total amount of carbs you eat may help to control blood glucose levels for people with type 2 diabetes. Choosing low GI foods as part of a balanced diet can help to minimise fluctuations in blood glucose levels. In the long term this can help reduce the risk of complications of diabetes such as heart and kidney problems.

GI and weight management:
There is some research to suggest that slow, steady rises and falls in glucose may help control appetite. Although many low GI foods are filling, there is not enough evidence to suggest that all low GI foods can help you to feel full.

10 Top Tips

1. Carbohydrates come in different forms, and some are healthier than others.

2. ‘Slow release’ or low GI carbs have been shown to help stabilise blood glucose levels.

3. GI can be helpful in diabetes because lower GI meals and snacks can help to keep blood glucose levels steady (which helps to reduce the risk of long-term complications of diabetes).

4. The amount of carbohydrate you eat is more important than GI in diabetes.

5. If you have diabetes and want to know more about how to use GI to help regulate your blood glucose, ask your GP to refer you to a dietitian.

6. Lower GI foods can only help you to manage your weight if they are eaten as part of a calorie-controlled diet combined with regular physical activity.

7. Lower GI foods like wholegrains, fruit, beans, lentils, and vegetables are generally lower in calories too.

8. GI is about the physical make-up of a food, and it is important to consider the mix of foods you eat, not just the GI value of the carbs.

9. Some lower GI foods (such as chocolate cake) may be high in fat or calories and so they are not a healthy choice.

10. In general, high fibre lower GI foods such as beans, peas, lentils, porridge, muesli, fruit, and vegetables are good choices and can help you keep to an overall healthy eating plan.

Applying for a Blue Badge with ME/CFS

If you are disabled or have a health condition that affects your mobility, you can apply for a Blue Badge.

- Councils can charge for a blue badge. The most you can be charged is £10.
- If you get certain benefits, you will automatically be able to get a Blue Badge. The application will be straightforward.
- You do not need to be able to drive to apply for a Blue Badge, unless you are applying because of problems with your arms.
- You can only get a Blue Badge from your local council or at GOV.UK. No one else can provide a genuine Blue Badge - if you think you have been defrauded, you should report it.

Who can get a Blue Badge ?

You are automatically eligible for a Blue Badge if you:-

- get the higher rate of the mobility component of Disability Living Allowance (DLA) - (check your decision letter if you are not sure)
- get War Pensioners' Mobility Supplement
- received a lump sum payment as part of the Armed Forces Compensation scheme (tariffs 1 to 8) and have been certified as having a permanent and substantial disability.
- If you get Personal Independence Payments (PIP) you area automatically eligible for a Blue Badge if you either:
  a) scored 8 points or more in the 'moving around' area of your PIP assessment
  b) scored 10 points in the 'planning and following journeys' area of your PIP assessment and were put in category 'E' - this means your stress, anxiety or other mental health issue stops you leaving the house . Check your PIP decision letter if you are not sure.

If you are not automatically eligible

You can still get a badge if you have long term problems walking or going to places - including problems caused by stress, anxiety, or other mental health issues. OR you have severe problems using both your arms OR you are applying on behalf of a child aged over 2 who has problems walking or going to places, or a child under 3 who needs to be close to a vehicle because of a health condition.

Applying for a Blue Badge

You can apply for or renew your Blue Badge online on GOV.UK. Some councils also let you apply on a paper form - contact your local council to check. You have to apply through your local council - your doctor cannot help you get a Blue Badge. Your local council might also arrange an appointment to visit you - they will let you know if you need this.

Blue Badge Form Fillout

Filling in the application is usually straight forward unless you are not automatically eligible If not you' will need to fill in an extra part of the application form to explain why you think you need a Blue Badge. If you have a terminal illness your council will usually fast-track your application. You will need to send a copy of the medical form that shows you have a terminal illness – this is called form DS1500 from your doctor or consultant.

Documents you will need.

Before you apply, make sure you have: your National Insurance number, the number, expiry date and local council on your current blue badge, if you have one . You will also need.:-

- your original decision letter from the Department of Work and Pensions - if you are automatically eligible for a badge.
- details of your medical condition - if you are not automatically eligible for a badge.
- proof of identification - for example, a birth or marriage certificate, passport or driving license
- proof of your address from the last 12 months - for example, a council tax bill, driving license or letter from a government department.
- A recent digital photograph of the person the badge is for - this can be from your own device or from a photo booth or shop. You need to get the copy of your proof of identification checked by a professional person, like a solicitor - this is called ‘certifying a document. Some professional people might charge to certify a document. *(Contact us in the office for help with this.)*

What happens after you have applied It could take a long time for your application to be processed. You should contact your council if you have not heard back within 6-8 weeks. You might be asked to do a mobility assessment. A health professional will look at your ability to conduct a range of mobility activities. They will tell your council whether they think your health condition or disability limits your ability to move around enough for you to need a badge. You also might be asked to send in extra information or speak to a member of the council.

If you are refused a Blue Badge, you can ask your council to reconsider their decision. The decision letter from the council will tell you how to ask for a review and what the time limit is.

Example of the wording of a Refusal Letter.

Thank you for your recent application for a Blue Badge.

In support of your application we require some medical evidence to provide further insight into the difficulties you face during the course of the journey. Your medical evidence should provide additional information about your medical history which would be relevant to your application. This can include topics such as the range of movement within the joints and how this may affect your mobility, the distance you are able to walk without significant difficulty, your walking speed, your manner of walking, the level of pain or breathlessness you experience, or any use of walking aids or coping strategies, such as the presence of another person. If applicable, your evidence should also clearly outline what professional support you receive in relation to any hidden disabilities you may have, including any psychological distress or the serious risk of harm you may experience while undertaking a journey.

Please see below some examples of medical evidence you can send to us:
diagnosis letters patient summaries, Education, Health and Care plan (EHCP), details of any disability benefits received, documents for any treatment or medication you receive to help you manage your condition, All medical evidence should be provided and verified by suitably qualified health or social care professionals.

Please note that a letter from your GP will not be deemed sufficient to establish your eligibility if no other evidence is provided based on the guidance from Department for Transport. It is applicant's responsibility to provide medical proof to support their application. We will not be able to contact medical professionals on your behalf to obtain relevant information.
Please forward your medical evidence to the above address or email it to us at (our office). Please do not send any originals.

Once we have received your documentation, we will review your application again and notify you of the decision that has been made. There still may be a requirement for you to provide further information from a clinical professional involved in your care or to attend an Independent Mobility Assessment, if the information provided is not sufficient to establish your eligibility for a Blue Badge.

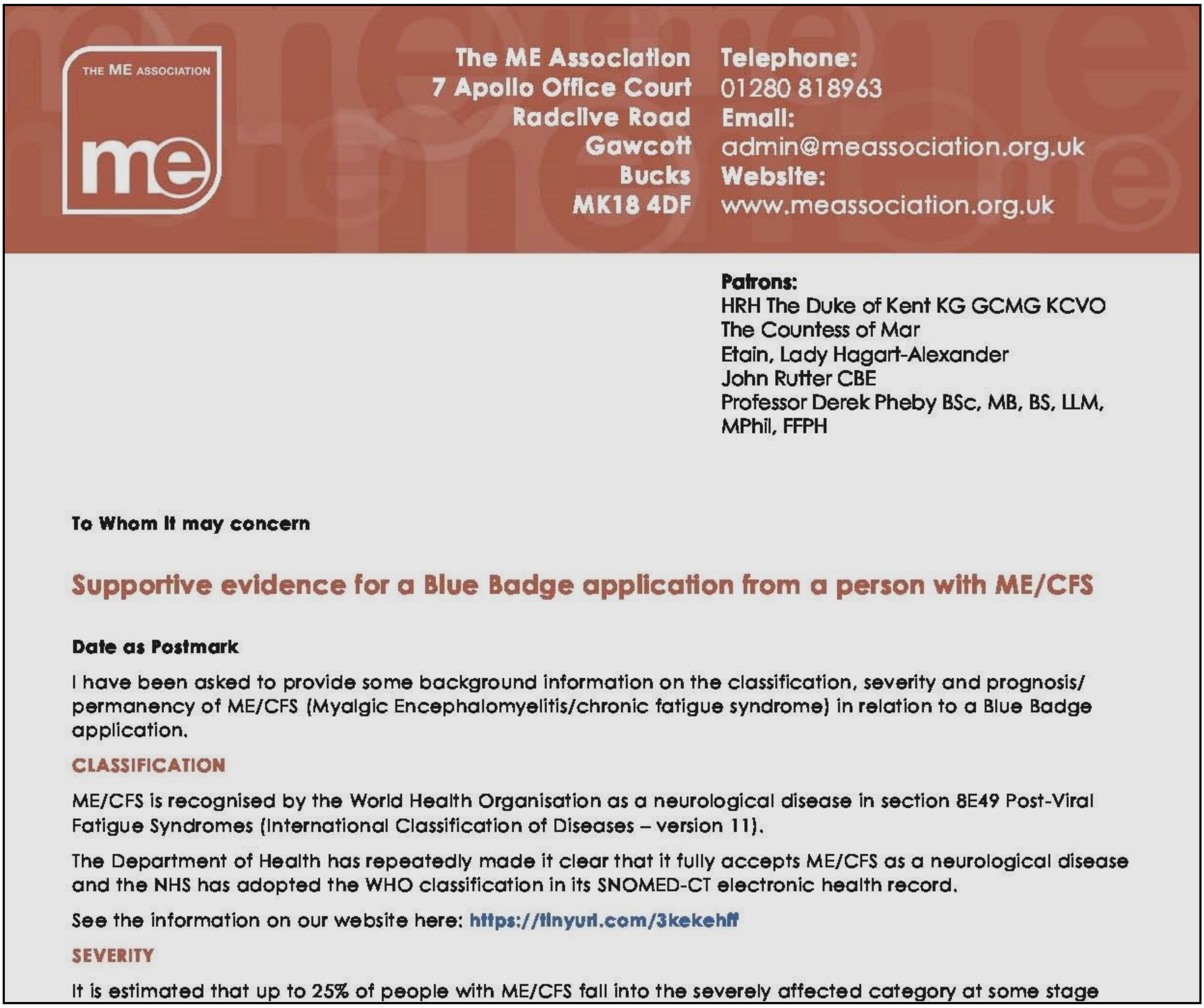
Getting Supporting Evidence for a discretionary Blue Badge ME/CFS

If you do not have the requisite award level (e.g. PIP or DLA) it may be worthwhile applying for them. You may not qualify on age grounds for PIP or DLA if you are over 65. There is no automatic entitlement for an Attendance Allowance holder. In this case a discretionary paths needs to be applied for.

With ME/CFS not all assessors will be familiar with the condition so you we suggest you include the following information to support your claim

- Documentation to prove your diagnosis. The standard letter from a local ME/CFS clinic will help.
- The first few pages of your summary care record from your G.P.
- Information and evidence of any mobility aids you use or have.
- Specific information about your limitations e.g. How far you can walk
- Information regarding rebounds or payback
- Information regarding any falls, hospital admissions or services you use.
- A needs assessment e.g. from Social Services
- A Case Review report .

Another useful document is the following document which is available from the ME Association website. Contact the office for further details.



The ME Association
7 Apollo Office Court
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The Countess of Mar
Etain, Lady Hagart-Alexander
John Rutter CBE
Professor Derek Pheby BSc, MB, BS, LLM, MPhil, FFPH

To Whom it may concern

Supportive evidence for a Blue Badge application from a person with ME/CFS

Date as Postmark

I have been asked to provide some background information on the classification, severity and prognosis/permanency of ME/CFS (Myalgic Encephalomyelitis/chronic fatigue syndrome) in relation to a Blue Badge application.

CLASSIFICATION

ME/CFS is recognised by the World Health Organisation as a neurological disease in section 8E49 Post-Viral Fatigue Syndromes (International Classification of Diseases – version 11).

The Department of Health has repeatedly made it clear that it fully accepts ME/CFS as a neurological disease and the NHS has adopted the WHO classification in its SNOMED-CT electronic health record.

See the information on our website here: **https://tinyurl.com/3kekehff**

SEVERITY

It is estimated that up to 25% of people with ME/CFS fall into the severely affected category at some stage

The HPA Axis in ME/CFS

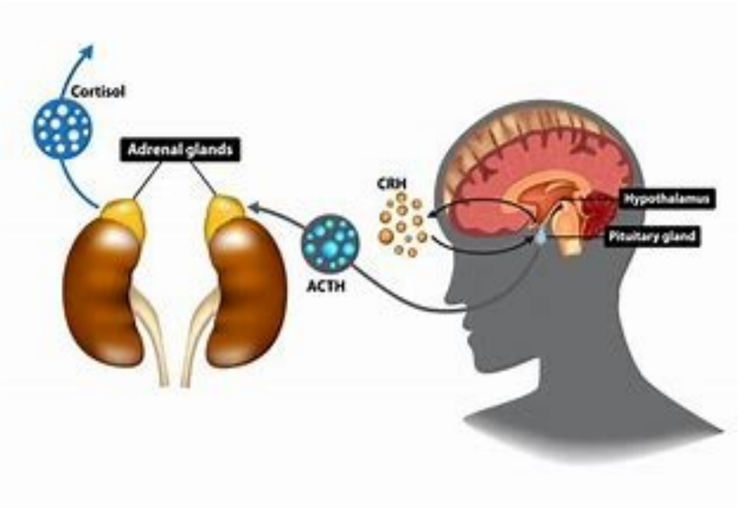
With thanks to input from (Dr) Sarah Myhill

One of the earliest findings that proved ME/CFS was in not a mental health problem was a piece of pivotal research done in the early 1990s. The research reference is

J Clin Endocrinol Metab.;:-1234 Demitrack M,Dale J,Straus S, et al.
"Evidence for impaired activation of the hypothalamic-pituitary-adrenal axis in patients with chronic fatigue syndrome."

What it showed was that people with ME/CFS had impaired activation of the HPA axis. So, what is it all about?

The hypothalamic-pituitary-adrenal (HPA) axis involves the central nervous system and the endocrine system adjusting the balance of hormones in response to stress. Stress results in the hypothalamus stimulating the pituitary gland to release hormones that further cause the adrenal glands to release cortisol. Cortisol prepares the body for "fight or flight." High levels of cortisol signal the hypothalamus that it no longer needs to stimulate the pituitary gland to raise levels further. Long periods of stress leading to chronically high cortisol may suppress the immune system and increase the risk for several conditions.



The hypothalamic-pituitary-adrenal (HPA) axis is a vital body system. The parts of the HPA axis include the hypothalamus, the pituitary gland, and the adrenal glands. The HPA axis is connected to the central nervous system and the endocrine system. Together they work to adjust the balance of hormones in the body and affect the stress response. The stress response is how the body reacts to a stressful event, which can include raising the heart rate or sweating.

The HPA axis is made up of the hypothalamus, the pituitary gland, and the adrenal glands. Hormones play an important role in the HPA axis. Hormones are chemicals in the body that act like messengers. They give various body systems orders to start or stop different functions. The hypothalamus is a small structure in the brain. It is located at the centre of the base of the brain, near the pituitary gland, and is about the size of a walnut. The hypothalamus is important in regulating hormone levels in the body. It also plays a role in regulating many body systems including the sleep/wake cycle, body temperature, and weight. The pituitary gland is about the size of a pea and is located at the base of the brain. Its role is to create and release hormones in the body. Hormones are vital in many body functions, including those that affect growth and maturation. The hormones that the pituitary produces which are important in the HPA axis include:

Adrenocorticotropic hormone: A hormone that causes the adrenal glands to release cortisol, which is involved in the stress response.
Corticotropin-releasing factor: A messenger hormone that tells the pituitary gland to release adrenocorticotropic hormone.

The adrenal glands are found in the abdomen, on either side of the body, above the kidneys. They are responsible for producing several types of hormones, including cortisol, aldosterone, adrenaline, and noradrenaline.

When the body experiences some kind of stress, the HPA axis may get activated. It sets off a series of events in the body in response. Stress can mean not only emotional stress but also being scared or nervous. The HPA axis gets the message and goes to work in seconds. The hypothalamus then releases corticotropin-releasing hormone. That activates a part of the nervous system (called the sympathetic nervous system), which reacts by increasing heart rate and sweating, for example.
In addition to those physical changes, corticotropin-releasing hormones also affect the pituitary gland.

It tells the pituitary gland to start releasing adrenocorticotropic hormone. The adrenocorticotropic hormone is released into the bloodstream. Through the blood, it makes its way to the adrenal glands in the abdomen. It binds to a spot on the adrenal glands. The adrenal glands then get the message that they should start producing cortisol and other substances.

Normal Function

The result of the activation of the HPA axis is the release of cortisol. Cortisol is a steroidal hormone. It has many effects and is sometimes called the “stress hormone.” Cortisol must be balanced in the body: too much or too little can have wide-ranging health effects. Cortisol has many properties that help the body respond to a stressful event. It sends more blood to muscles, increases the amount of glucose in the blood, and increases blood pressure.

These are all helpful responses during a stressful event that might be a “fight or flight” situation. That is how we define a situation where there may be a need to defend oneself or run away from a harmful event. Cortisol also turns off or dials down those body functions that won’t help in a stressful situation. There is another part to the HPA axis, called the negative feedback loop. Cortisol isn't supposed to be produced for long periods of time. Its production should end when the stressful event is over.

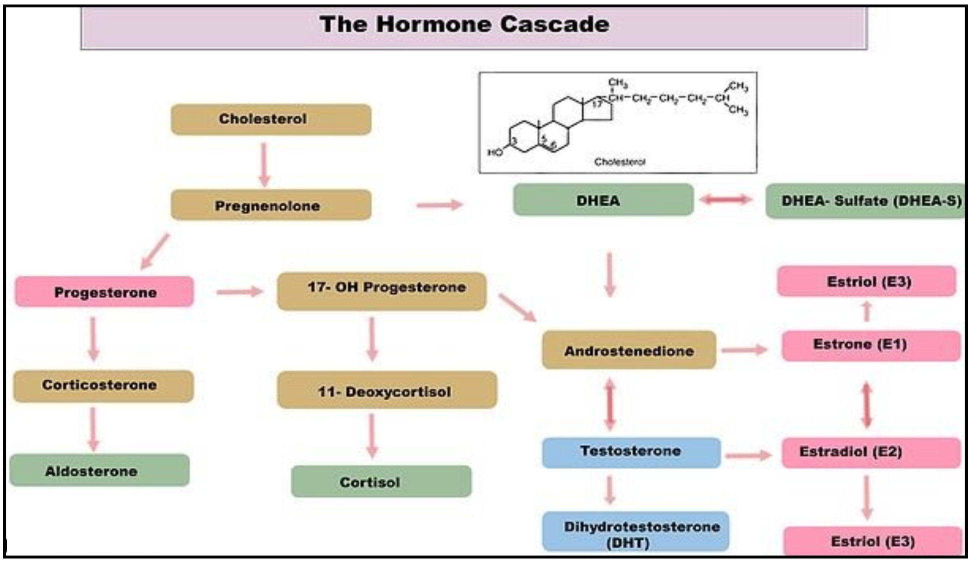
Common Hormonal Problems in ME/CFS – Adrenal Underactive adrenal gland (DHEA and cortisol)

The adrenal gland is an essential part of energy delivery mechanisms. It allows us to match energy expenditure to energy demand, so none is wasted. This is an essential evolutionary survival mechanism. In response to any stress (physical, psychological, mental or whatever) the gear box will pour out the required hormones to cope. For short term stress (seconds to minutes) the hormone is adrenalin, for medium term stress (minutes to hours) we need cortisol and for long term stress (hours to days) - DHEA. As mentioned earlier, in CFS/ME there is a general suppression of the hypothalamic/pituitary/adrenal (HPA) axis, often associated with adrenal fatigue. Indeed, as we age, we all experience declining function in these departments! If the pituitary gland is under-functioning then the adrenal gland will also under-function. However, the gland itself may fail as a result of chronic stress.

The Hungarian physiologist Hans Selye showed that if you stressed rats, their adrenal glands enlarged to produce more stress hormones (cortisol and DHEA) to allow them to cope with that stress. If the rat had a break and a rest, then the adrenal gland would return to its normal size and recover. However, if the rat was stressed without a break or a rest, he would be apparently all right for some time, but then suddenly collapsed and died. When Selye looked at the adrenal glands, they shriveled up. The glands had become exhausted.

The same thing happens in CFS. The Western way of life is for people to push themselves more and more. Many can cope with a great deal of stress, but everybody has their breaking point. The adrenal gland is responsible for the body's hormonal response to stress. It produces adrenaline, which stimulates the instant stress hormone response (fight or flight reaction). It also produces cortisol and DHEA, which create the short and long term stress hormone responses. When the gland becomes exhausted, CFS develops and tests classically show low levels of cortisol and DHEA.

The mother of adrenal hormones is cholesterol. That is converted to pregnenolone. This is the starting point for synthesis of progesterone, cortisol, DHEA, testosterone and oestrogen. All are essential in men and women.



Research Corner: Hydrocortisone Treatment Trial

Abstract Evidence for impaired activation of the hypothalamic-pituitary-adrenal axis in patients with chronic fatigue syndrome.
J Clin Endocrinol Metab.;:-1234 Abstract Demitrack M, Dale J, Straus S, et al.

Background: Reports of mild hypocortisolism (low cortisol) in chronic fatigue syndrome led us to postulate that low-dose hydrocortisone therapy may be an effective treatment.

Methods: In a randomised crossover trial, we screened 218 patients with chronic fatigue. 32 patients met our strict criteria for chronic fatigue syndrome without co-morbid psychiatric disorder. The eligible patients received consecutive treatment with low-dose hydrocortisone (5 mg or 10 mg daily) for 1 month and placebo for 1 month; the order of treatment was randomly assigned. Analysis was by intention to treat.

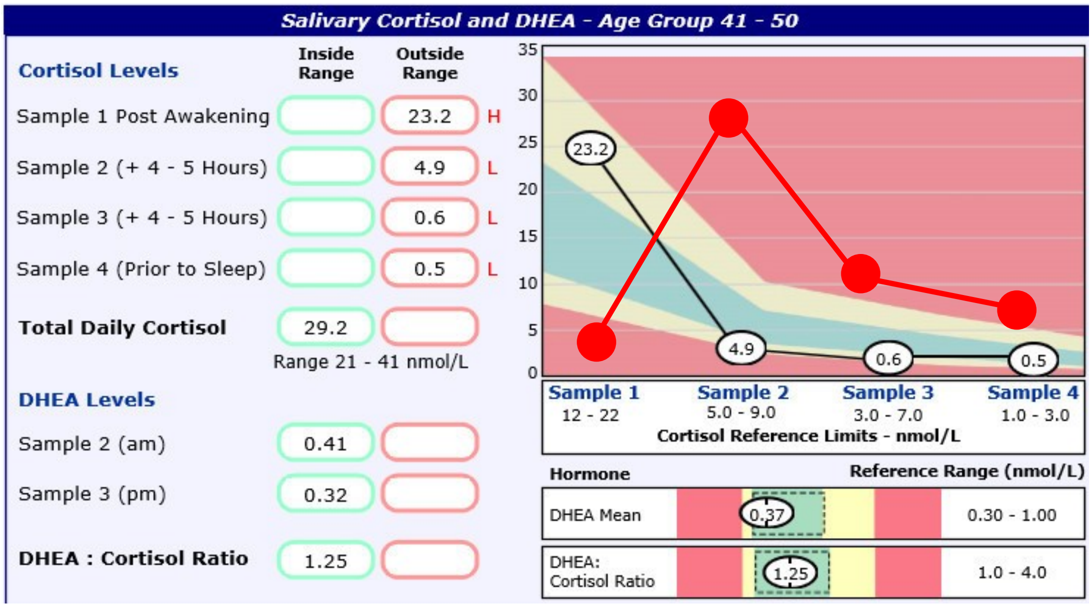
Results: None of the patients dropped out. Compared with the baseline self-reported fatigue scores (mean 25·1 points), the score fell by 7·2 points for patients on hydrocortisone and by 3·3 points for those on placebo (paired difference in mean scores 4·5 points [95% CI 1·2–7·7], p=0·009). In nine (28%) of the 32 patients on hydrocortisone, fatigue scores reached a predefined cut-off value similar to the normal population score, compared with three (9%) of the 32 on placebo (Fisher's exact test p=0·05). The degree of disability was reduced with hydrocortisone treatment, but not with placebo. Insulin stress tests showed that endogenous adrenal function was not suppressed by hydrocortisone. Minor side-effects were reported by three patients after hydrocortisone treatment and by one patient after placebo.

Interpretation. In some patients with chronic fatigue syndrome, low-dose hydrocortisone reduces fatigue levels in the short term. Treatment for a longer time and follow-up studies are needed to find out whether this effect could be clinically useful.

Comment: Around that time there have been several follow up papers. Although some people reported positive results, they were not positive enough to justify any further follow up. Furthermore a number of private doctors treating ME/CFS tied it with their private patients. Again results were mixed, and furthermore the practice was discouraged by the professional bodies. The net result weas the doctors concerned ceasing to practice medicine as was the case with (Dr) Sarah Myhill as featured in Pathways 75.

Hydrocortisone and related medicines are Prescription Only Medicines - so they must be prescribed by a doctor, by law. The is no current NHS guidelines, even in the laiesst set of NICE guidelines, so it is very unlikely that a doctor would prescribe hydrocortisone. So is there any alternative treatment available? Well sort of. If you check out Dr. Myhills website, there is a Salivary Adrenalin Stress Index test. Based on the results from that test it may possibly be appropriate to use food supplements DHEA and pregnenolone. While cholesterol is the great grandmother of many naturally occurring hormones, Pregnenolone is the grandmother. Taking a pregnenolone supplement may up levels further down the chain,

On the right is a typical result within normal limits from an adrenal stress index test. I have added in red they typical results from someone with ME/CFS.



Salivary Cortisol and DHEA - Age Group 41 - 50

Cortisol Levels	Inside Range	Outside Range	
Sample 1 Post Awakening		23.2	H
Sample 2 (+ 4 - 5 Hours)		4.9	L
Sample 3 (+ 4 - 5 Hours)		0.6	L
Sample 4 (Prior to Sleep)		0.5	L
Total Daily Cortisol	29.2		

Range 21 - 41 nmol/L

DHEA Levels		
Sample 2 (am)	0.41	
Sample 3 (pm)	0.32	
DHEA : Cortisol Ratio	1.25	

Sample 1	Sample 2	Sample 3	Sample 4
12 - 22	5.0 - 9.0	3.0 - 7.0	1.0 - 3.0

Cortisol Reference Limits - nmol/L

Hormone		Reference Range (nmol/L)
DHEA Mean	0.37	0.30 - 1.00
DHEA: Cortisol Ratio	1.25	1.0 - 4.0

Causes of Morning Stiffness and ME/CFS.

Morning stiffness is a common complaint for people with various forms of arthritis. For some, it can be so severe that they may feel like they can hardly walk when they get up in the morning. The stiffness that occurs upon waking can affect those with osteoarthritis, rheumatoid arthritis, and psoriatic arthritis, and is due to a variety of factors. What is not that well know is that people With Fatigue syndromes can also suffer from morning stiffness.

Causes of Morning Stiffness: Morning stiffness is a persistent problem for many people with arthritis, even those on a regular treatment regimen. This symptoms can vary with the type of arthritis you have. For example, if you have rheumatoid arthritis (RA) or another type of inflammatory arthritis, your morning stiffness will likely last more than an hour—or even several hours. Morning stiffness that goes away after half an hour or less is more likely to be Osteoarthritis (OA) or another non-inflammatory musculoskeletal condition. People with fibromyalgia and ME/CFS also suffer from morning stiffness, although it is not that well known to the medical establishment.

The Gel Phenomenon: A possible cause of morning stiffness is called the "gel phenomenon." Inside your joints, there is a liquid called synovial fluid. When your joints are not in motion, this fluid may get thick or "gel-like," causing stiffness. Once you start moving, the fluid returns to its normal liquid state. Just think about brown sauce - it will not easily come out of the bottle unless it is really shaken up them it flows more freely.

Low Cortisol: Some researchers think morning stiffness involves hormone fluctuations over a 24-hour cycle. It is suspected that some conditions involve low nighttime levels of the hormone cortisol. Low cortisol overnight leaves your body unable to tamp down cells called pro-inflammatory, such as interleukin-6 (IL-6). That means you wake up with extra inflammation. Cortisol levels tend to peak in the morning, so the hormone can gradually decrease cytokine levels and relieve you as the morning goes on. Low cortisol in the morning is a well know problem with ME/CFS. Psoriatic arthritis (PsA) is a chronic, autoimmune form of arthritis that causes joint inflammation. It occurs with psoriasis, an autoimmune skin condition. Around one-third pf people with psoriasis develop PsA. As with other forms of arthritis, joint stiffness and pain are often worse in the morning. In PsA, morning symptoms can last for 30 minutes or more.

Role of Obesity: Carrying extra weight puts extra stress on your hips and knees. According to the Centres for Disease Control and Prevention, 1 in 3 Americans with obesity have been diagnosed with arthritis versus 1 in 5 among the general population. It is worse in the UK. Anyone overweight or obese may feel especially stiff in their legs and knees in general and upon awakening.

The Role of Vitamin D Deficiency
Most people with Fatigue syndromes have vitamin B12 deficiency. Some research has shown an association between low vitamin D levels and joint pain, particularly in the knee and hip. One 2017 study found that increasing vitamin D intake may be beneficial for patients who have pain and a vitamin D deficiency. However, this does not seem to be the case for people who have adequate vitamin D levels. More studies are needed in

Strategies that may help include

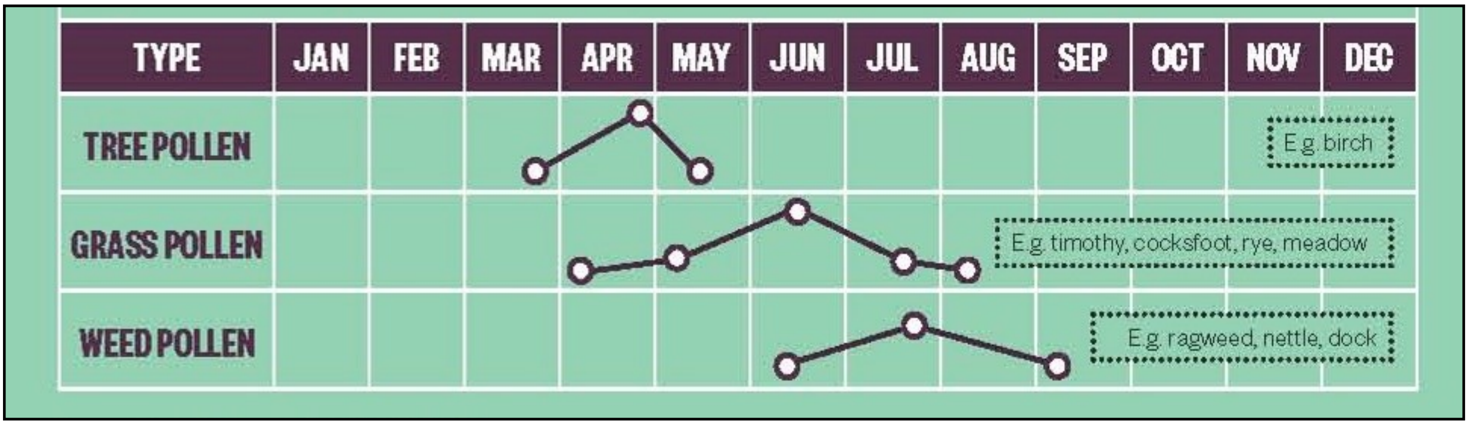
- Supporting your joints while you sleep, possibly with pillows or braces
- Staying warm by using electric blankets or heating pads or turning up the thermostat
- Doing simple stretching exercises before you get out of bed
- Taking a hot shower first thing in the morning to relax your joints and muscles
- Doing light exercise once you begin to loosen up
- Trying to let go of stress before going to bed
- If possible, delay activity until later in the day, such as requesting a later start time at work or not making early appointments.

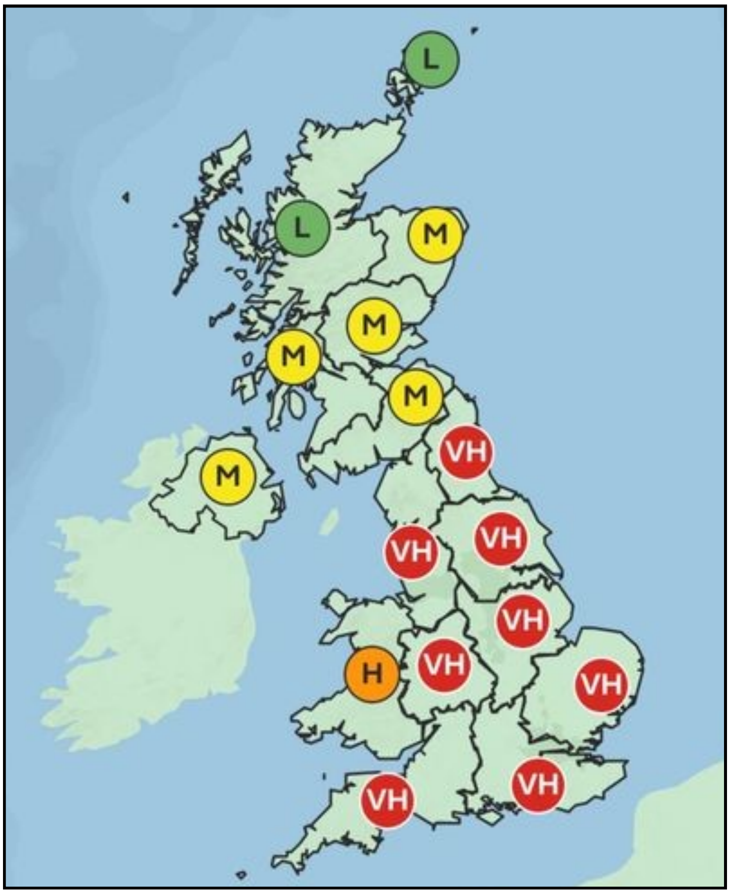
Some methods may work better for you than others. Experiment with different changes and see what helps.

Hay Fever and ME/CFS

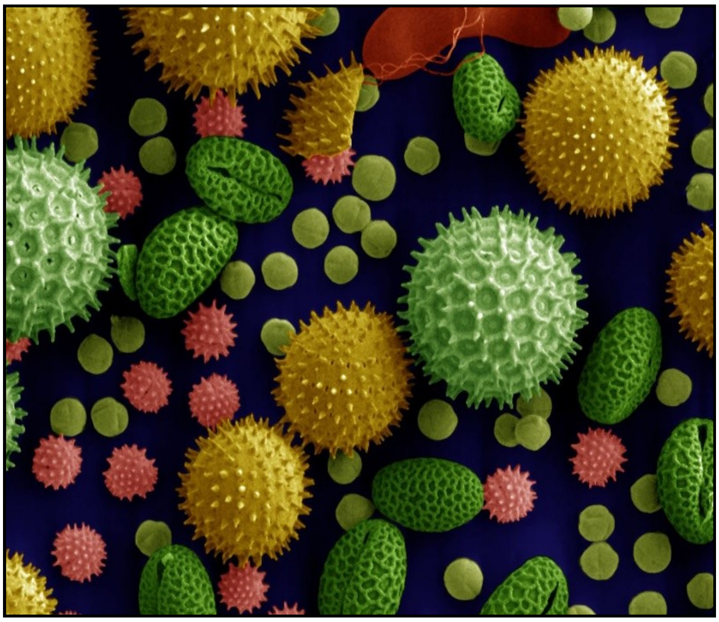
Seasonal Allergic Rhinitis or Hay Fever is an allergic condition caused mainly by pollen in the Air. Hay fever is usually worse between late March and September, especially when it's warm, humid and windy. Inline with current NHS policy, NHS England has advised doctors not to routinely prescribe products that are available over the counter for this condition. So unless you have an additional serious health condition like Asthma or COPD, you will be expected to manage the condition yourself and purchase treatment from Pharmacies and Supermarkets.

Many people with ME/CFS have an atopic tendency to be allergic or sensitive to substances. Hay fever is a common allergic reaction to pollen, with the main triggers being tree, grass and weed pollens, which are produced between March and September.





The Met Office produces a daily or hourly forecast of pollen levels as part of the weather forecast service.



The culprits. Many plants are wind pollenated. They release pollen grains into the air which causes the irritation. The pollen grains are of a mixed type as shown above.

Miscellaneous Pollen facts

With thanks to the Met Office

1. Link with anxiety.
n some people there is a correlation between pollen levels and anxiety. According to the International Journal of Child Health and Human Development, high pollen levels can affect anxiety levels in people with recurrent mood disorders, such as bipolar.

2. Your pets can get hay fever.
Yes, like us cats and dogs can get hay fever. Contact your local vet for further information - don't try to treat yours as antihistamine can cause fits in dogs. The usual treatment are animal versions of steroid inhalers.

3. The pollen season lasts longer than you may think.
The pollen season can start as early as January and end as late as November. Our pollen forecast is now live, click to find the latest Pollen forecast.

4**. Hay fever affects 1 in 5 people.**
The irritation can be completely disabling and stop people living or working normally.

5. Spiderlings eat pollen.
Although usually carnivorous, spiders feed pollen to their young. It's not known how they manage to eat it though, since their mouths are not large enough.

6. It can fight crime.
Well not quite; pollen is used in forensics to determine where a person or object has been. It has even been proposed that pollen is added to bullets to enable them to be tracked.

7. Alcohol worsens the effects of pollen.
Beer, wine and other spirits contain histamine - the chemical that sets off allergy symptoms in the body.

8. Pollen was first observed in rocks over 120 million years old.
It's a critical component of natural selection in plants.

9. Rain can be bad news for hay fever sufferers.
It helps the grass grow well and if it's followed by dry weather there will be higher levels of pollen.

10. Air quality and pollen.
Urban areas tend to have lower pollen counts than the countryside, but pollen can combine with air pollution in the city centre and bring on hay fever symptoms. It's not just in the summer months either; it can peak as early as April and May.

Use of face masks for hay fever.

During the recent Covid pandemic some people reported that using a surgical face mask that was used to avoid the coronavirus worked for hay fever as well.

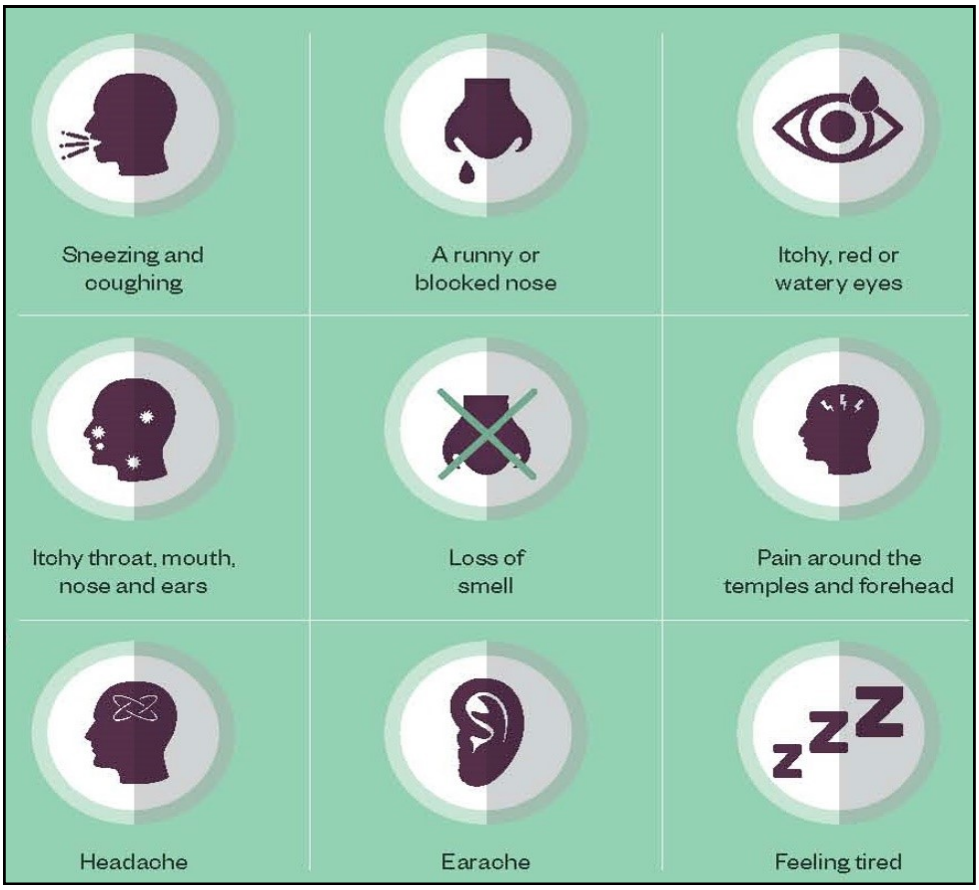
There is good reason for this. Pollen grains are around the same size of viruses or maybe bigger. These will be effectively filtered out by the material. With there being plenty of face masks around it is worth having a go.

Just remember though your eyes will still be exposed!

Hay Fever Self Management of Symptoms

Apart from avoidance of pollen, treatment is symptomatic, in other words suffering and only managing the symptoms. There is no one treatment that helps everyone. It's a case of try it and see. The first steps in the management of hay fever should be allergy avoidance, and saline (salt and water) irrigation may reduce peoples reported disease severity. Sea water or saline nasal sprays have become increasingly popular.

Patients with mild hay fever symptoms (those that do not impact daily life) are typically started on an oral antihistamine, whereas patients with moderate or severe symptoms are initiated on nasal corticosteroid. If one treatment fails (e.g. oral antihistamine), the patient can try another (e.g. nasal corticosteroid .



Allergen Avoidance Checklist.

- Check the pollen count. Symptoms may be worse on days with a high pollen count.
- Stay indoors Keep windows and doors closed. Avoid being outside in the early evening and mid-morning when the pollen count tends to be the highest. Try to stay at home and avoid contact with other people if you have a high temperature or you do not feel well enough to do your normal activities. Keep windows and doors shut as much as possible.
- Wear glasses instead of contact lenses Wear sunglasses when outside.
- Wear wraparound sunglasses to stop pollen getting into your eyes.
- Shower and change clothes regularly Pollen may be attached to clothes, skin and hair.
- Bathe eyes in cold water.
- Apply petroleum jelly to the nostrils to trap pollen.

Things to Avoid

- Do not cut grass or walk on grass.
- Do not dry clothes outside.
- Buy a pollen filter for the air vents in your car and a vacuum cleaner with a HEPA filter.
- Do not spend too much time outside.
- Do not keep fresh flowers in the house.
- Do not smoke or be around smoke – it makes your symptoms worse.
- Do not dry clothes outside – they can catch pollen.
- Do not let pets into the house if possible – they can carry pollen indoors

Management of Hay Fever with Medicines

The first steps in the management of hay fever should be allergy avoidance, and saline irrigation may reduce patient reported disease severity. People with mild hay fever symptoms (those that do not impact daily life) are typically started on an oral antihistamine, whereas people with moderate or severe symptoms are initiated on nasal corticosteroid. If one treatment fails (e.g. oral antihistamine), the patient can try another (e.g. nasal corticosteroid).

Oral antihistamines

This family of medicines will reduce Sneezing; Rhinorrhoea, Itching nose, palate and eyes. The new generation of antihistamines (e.g. cetirizine and loratadine) should be recommended as the older generation (e.g. chlorphenamine) can cause unwanted effects, including sedation and psychomotor impairment. The most common ones contain Cetirizine, or ,Loratadine ,and Acrivastine. These are available over the counter and may be sold in a branded or proprietary presentation. Doctors are very reluctant to prescribe these, and expect people with buy them.

Nasal Corticosteroids

There are nasal sprays which reduces Sneezing; Congestion; Rhinorrhoea; Itching nose, palate and eye symptoms. Intranasal steroids take several days to reach full effectiveness and maximal effect may not be apparent for two weeks. They commonly used contain Beclomethasone dipropionate, Triamcinolone, Fluticasone or Budesonide and as with oral antihistamines may be sold under a brand or trade name. Some can be purchased over the counter and some are prescription medicines. Some of these ingredients are to be found as asthma preventer inhalers which are designed to treat the lower respiratory tract (windpipe and lungs) rather than the ear, nose and throat.

Additional medicines

If the above does not work, it might be worth trying :-

- Eye drops to manage ocular symptoms (e.g. sodium cromoglicate). These block the local allergic response.
- Nasal decongestant as a short-term adjunct for up to seven days if nasal congestion is severe (e.g. xylometazoline hydrochloride). If you choose this option be careful not to overdose because you could make things worse.

There is no evidence that an oral antihistamine confers additional benefit to a nasal corticosteroid alone.

Problems and interactions with Hay Fever medicines

You need to see your doctor if your over-the-counter treatment has failed to manage your symptoms.

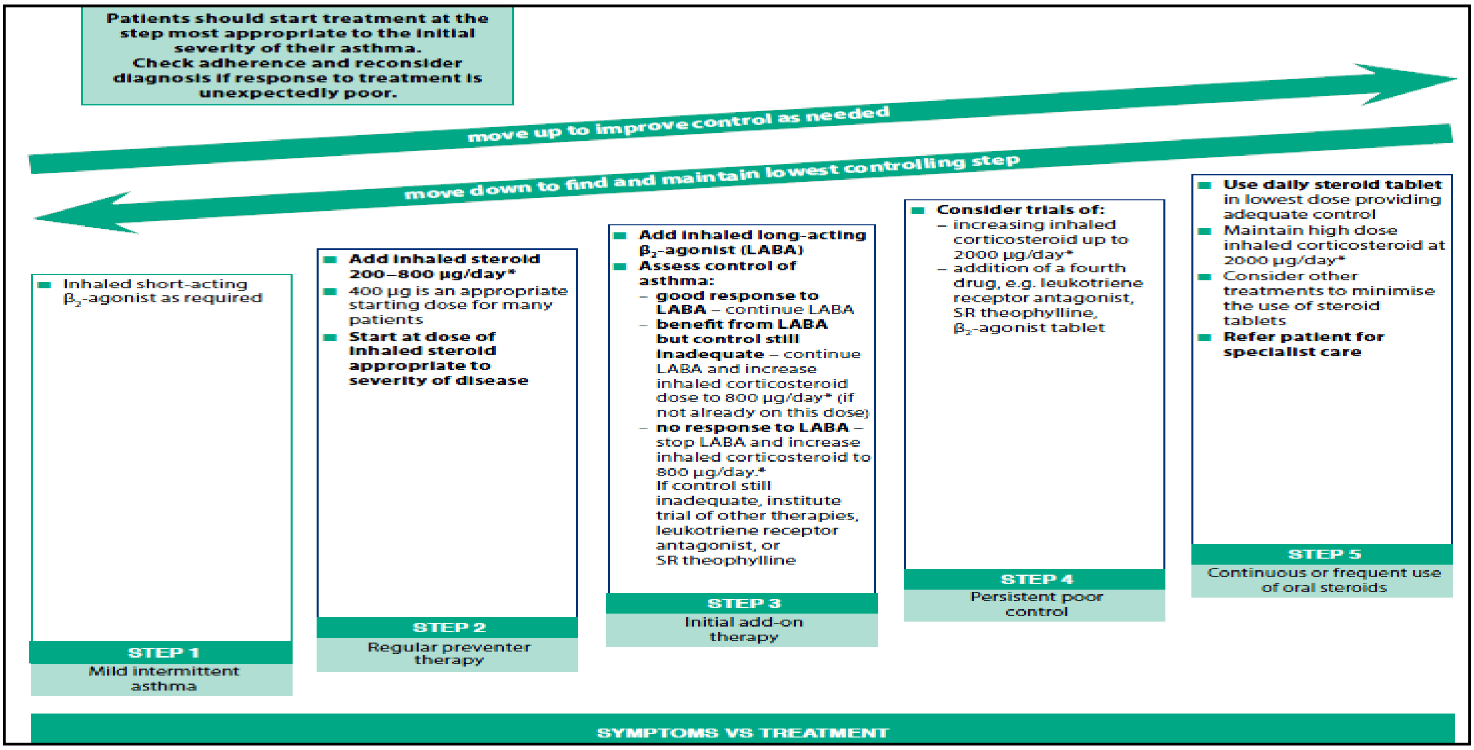
Initial management by the GP may be to prescribe a nasal corticosteroid in combination with a nasal antihistamine (e.g. azelastine plus fluticasone). If treatment fails, the patient may be referred to a specialist or offered an alternative treatment, for example:- Intranasal ipratropium, Leukotriene receptor antagonists (Montelukast), Immunotherapy, Oral corticosteroids;, or surgery.

Avoid the use of Salbutamol inhalers for Hay Fever

Many people with ME/CFS use salbutamol inhalers (Ventolin) acquired from a family member or the black market. While many claim they help breathing they are stimulants and can have adverse effects on the heart, lungs and harm the lower airways. The ongoing use of this type of inhaler is associated with many deaths in asthma patients. The local NHS now has a policy of using a combined inhaler containing a longer acting salbutamol substitute and steroid to reduce inflammation.

New Strategies for Asthma Treatment in Doncaster

The way Asthma is treated has changed. The single use of a short acting beta agonist (SABA) without a supporting steroid inhaler is associated with a bad outcome and many unexpected deaths. The table below sums up the old strategy.



Patients should start treatment at the step most appropriate to the initial severity of their asthma.
Check adherence and reconsider diagnosis if response to treatment is unexpectedly poor.

move up to improve control as needed

move down to find and maintain lowest controlling step

STEP 1 Mild intermittent asthma
- Inhaled short-acting β_2-agonist as required

STEP 2 Regular preventer therapy
- **Add inhaled steroid 200–800 μg/day***
- 400 μg is an appropriate starting dose for many patients
- **Start at dose of inhaled steroid appropriate to severity of disease**

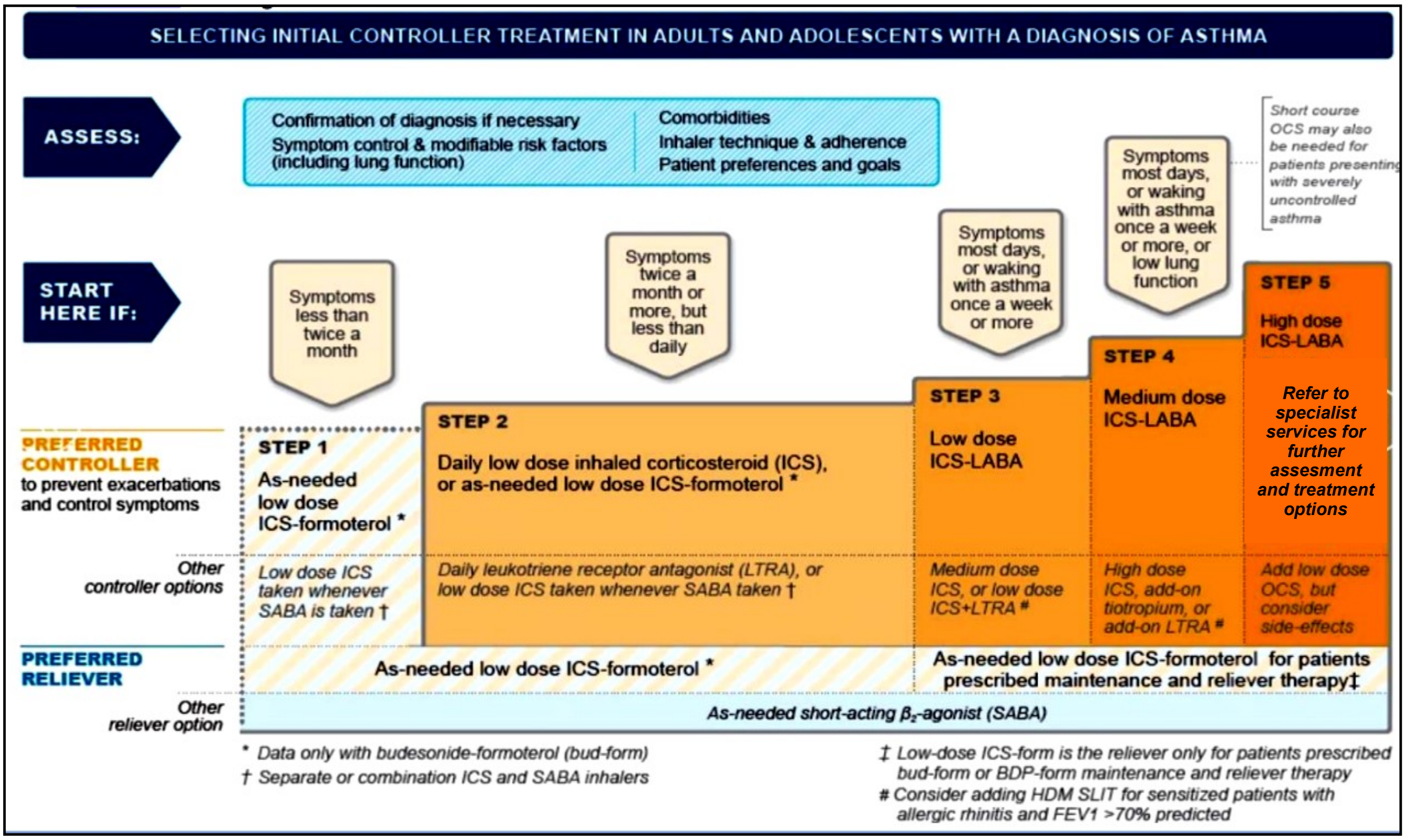
STEP 3 Initial add-on therapy
- **Add inhaled long-acting β_2-agonist (LABA)**
- **Assess control of asthma:**
  - **good response to LABA** – continue LABA
  - **benefit from LABA but control still inadequate** – continue LABA and increase inhaled corticosteroid dose to 800 μg/day* (if not already on this dose)
  - **no response to LABA** – stop LABA and increase inhaled corticosteroid to 800 μg/day.* If control still inadequate, institute trial of other therapies, leukotriene receptor antagonist, or SR theophylline

STEP 4 Persistent poor control
- **Consider trials of:**
  - increasing inhaled corticosteroid up to 2000 μg/day*
  - addition of a fourth drug, e.g. leukotriene receptor antagonist, SR theophylline, β_2-agonist tablet

STEP 5 Continuous or frequent use of oral steroids
- **Use daily steroid tablet** in lowest dose providing adequate control
- Maintain high dose inhaled corticosteroid at 2000 μg/day*
- Consider other treatments to minimise the use of steroid tablets
- **Refer patient for specialist care**

SYMPTOMS VS TREATMENT

The new strategy involves a inhaled corticosteroid (ICS) along with a Long Acting Beta Agonist (LABA). A LABA works exactly in the same way as a SABA (aka Salbutamol or Ventolin but lasts longer). This may include a leukotriene receptor antagonist LTRA like Montelukast taken as a tablet. So, you may be moved over to a combined inhaler - but beware the NHS will want to use a dry powder type that is harder to use correctly for people with ME/CFS than the traditional metered dose type.



SELECTING INITIAL CONTROLLER TREATMENT IN ADULTS AND ADOLESCENTS WITH A DIAGNOSIS OF ASTHMA

ASSESS:
Confirmation of diagnosis if necessary
Symptom control & modifiable risk factors (including lung function)
Comorbidities
Inhaler technique & adherence
Patient preferences and goals

START HERE IF:
Symptoms less than twice a month
Symptoms twice a month or more, but less than daily
Symptoms most days, or waking with asthma once a week or more
Symptoms most days, or waking with asthma once a week or more, or low lung function

Short course OCS may also be needed for patients presenting with severely uncontrolled asthma

	STEP 1	STEP 2	STEP 3	STEP 4	STEP 5
PREFERRED CONTROLLER to prevent exacerbations and control symptoms	As-needed low dose ICS-formoterol *	Daily low dose inhaled corticosteroid (ICS), or as-needed low dose ICS-formoterol *	Low dose ICS-LABA	Medium dose ICS-LABA	High dose ICS-LABA *Refer to specialist services for further assesment and treatment options*
Other controller options	*Low dose ICS taken whenever SABA is taken †*	*Daily leukotriene receptor antagonist (LTRA), or low dose ICS taken whenever SABA taken †*	*Medium dose ICS, or low dose ICS+LTRA #*	*High dose ICS, add-on tiotropium, or add-on LTRA #*	*Add low dose OCS, but consider side-effects*
PREFERRED RELIEVER	As-needed low dose ICS-formoterol *		As-needed low dose ICS-formoterol for patients prescribed maintenance and reliever therapy‡		
Other reliever option	*As-needed short-acting β_2-agonist (SABA)*				

* *Data only with budesonide-formoterol (bud-form)*
† *Separate or combination ICS and SABA inhalers*
‡ *Low-dose ICS-form is the reliever only for patients prescribed bud-form or BDP-form maintenance and reliever therapy*
\# *Consider adding HDM SLIT for sensitized patients with allergic rhinitis and FEV1 >70% predicted*

The Ethel Trust

The Ethel Trust is a unique charity which helps local people enjoy the forgotten pleasure of exploring the South Yorkshire waterways on their community barge. Run entirely by volunteers, the trust works with people of all ages and runs a flagship project for disadvantaged young people.

A spokesman told us: “We do want to expand the groups we work with. At the moment we work a lot with older people social groups and young people too but we want to expand our services to more groups across South Yorkshire. We would like to get back involved with probation services so we can support young people at risk of falling into crime. That is how the project originally started back in 1988.”

At the time of writing, the Ethel Trust is currently in the middle of its season and is in the process of running over 60 day trips and 10 residential trips booked already. The charity is based in Sheffield at Victoria Quays but run their trips from Thorne in Doncaster during the summer boating season.

The South Yorkshire’s Community Foundation (SYCF) a local grant making charity supported the trust with a grant to help cover staffing costs for their young people project.

Ruth Willis, CEO of SYCF said: “The Ethel Trust is a fantastic project and gives so many people the opportunity to do something fun and quite unique. We have been funding the Ethel Trust for a long time and watched it grow over the years. Now we are celebrating our 30th Anniversary giving to charities and community groups like them, it makes us very proud to look at the difference they are making to so many lives, knowing that we have been able to help.” “As a grant making charity we fund South Yorkshire community groups working for community good and I encourage groups big or small to see if they can benefit from our grant funding programmes. Our latest impact report revealed that our grants supported 1 in 10 people in South Yorkshire last year. I want us to beat that number this year!”

The new boat Pearl moored in Thorne

Keith continued: “We got another bit of feedback from someone who came on a trip with Bridlington Therapy Centre. They said ‘I had such a wonderful day. It means so much to me having a broken past’. We know that there are young people and old people whose lives are touched by what we do and the feedback we get is very important to us.” “We are so busy at the moment, I was talking to another volunteer the other day and he said that he had been on Ethel 7 out of 9 days, doing back to back residentials. He was going home to sleep straight after talking to me! So more volunteers would be fantastic. They all love what they do and want everyone who comes on board to have a good time. We always fully train our crew members and skippers and we always say that before anyone commits that they should come and do a trip on the boat to make sure that they are happy to continue first.

For the first time since Covid we will be running a canal boat trip again mi July . If you are interested, please contact the Leger ME office.

North of Doncaster – Goes West

Personal thoughts from Trevor Wainwright

Well, I thought it was time for a change of tack with my column, since 2011 with the exception of 2020 and 2021 due to the pandemic, America mostly Texas has been an annual event. Some may ask what made me want to go to America, in 2008 I had been invited to go to join some Pakistani work colleagues on a trip to Pakistan, sadly my wife fell ill and I wasn't able to go, in 2009 we tried again this time it was me, a month before going I had a detached retina, further problems with it meant another cancellation this time I had managed to get a visa and flight booked, and so the eye problems persisted a retinal tear and cataracts, in all five operations. During the wait for the cataract operations my friend form Austin, Thom "World Poet" Woodruff came over for a tour during which I asked, "Can I come and see you when my eyes are well?" His reply, "Come over for the Austin International Poetry Festival," so an idea was born. If I could not go East, I would go West.

The initial plan was to fly into New York pay my respects to the victims of 9/11 visit the UN Headquarters Meditation Room then travel down central America through Memphis and on to Austin, After Austin it would be a drive up the Eastern Seaboard back to New York. It did not go down well with my wife, it being my first time driving in America, she was against it from the start. However, things did not go as planned as my final cataract operation kept getting cancelled, so a compromise was reached. I would, to give my eyes longer to recover, fly into Austin, pick my hire car up from there, but come hell or high-water I was coming home via New York. Both my wife and Thom thought it a great idea, so that was it, sorted. Eventually the op went ahead successfully and on the first Friday in February I was given all clear. Texas / America was on, by Sunday I had booked hire car, insurance, flight, ESTA (Electronic System for Travel Authorisation) and arrival and departure accommodation, I would sort the rest of the accommodation out as I went along. It would be in two parts Austin then to Lamesa for their Poetry Festival after which it would be as Thom called it, My Great American Adventure Part 2.

It was a wonderful sense of anticipation as I looked at the google maps often. Then it begun on 5th April 2011 with me nervously waiting at Leeds Bradford Airport hoping the slip of paper I has was all I needed, it was I would fly via Amsterdam and Memphis. Getting off the plane at Amsterdam it was raining, my thoughts were "I wonder if it's raining in Memphis". Memphis was sunny, it was great sitting there waiting for my final flight, it arrived, I was on and away, Austin at last and to a friend sent by Thom to lead me to my motel. It was driving along Interstate 35 when it suddenly hit me "Hey I'm driving in America", yes, I was there after a long day. Austin the State Capital of Texas, a city that would become my spiritual home, and I would find out about its history and what it had to offer a travelling poet, I was not disappointed.

After declaring its independence from Mexico in March 1836, Austin had numerous locations as its seat of government. This being seen as a problem attempts were made to select a permanent site for the capital. Eventually in 1838, after at least five temporary capitals including Houston. A bill previously passed by Congress in May 1838, specified that any site selected as the new capital would be named, Austin after the late Stephen F. Austin; not the Six Million Dollar Man but an American-born empresario. Known as the "Father of Texas" so the site named Waterloo upon selection as the capital was renamed Austin, and the city began to develop. But not without problems as Sam Houston in December 1842, wanting Houston to be the capitol of Texas, ordered the secret removal of the archives of the Republic to safekeeping in Washington-on-the-Brazos, known as "the birthplace of Texas," because, on March 1st, 1836, Texas delegates met in the town to formally announce Texas' intention to separate from Mexico and to draft a constitution for the new Republic of Texas.

Local tavern owner Angelina Eberly, realizing that the symbols of national government were being removed from the city, fired a six-pound cannon into the General Land Office Building, which aroused the town to what it considered to be theft. The ensuing conflict became known as the Archive War, which was won by the Austinites and preserved Austin as capital of Texas, becoming official in 1846, and keeper of the archives. A statue commemorating this is on Congress Avenue where the incident is said to have taken place.


Angelina Eberley saving the day

Congress Avenue is a major thoroughfare in Austin, Texas. The street is a six-lane, tree lined avenue that cuts through the middle of the city from far south Austin and goes over Lady Bird Lake leading to the Texas State Capitol in the heart of Downtown, starting at The Capitol Grounds and ending at the very Southernmost part of Austin, where it becomes South Congress.

Free rent ? Austin humour

People's piano on Congress Avenue in 2011, the young man is playing John Lennon's Imagine

A typical shop front on Congress Avenue

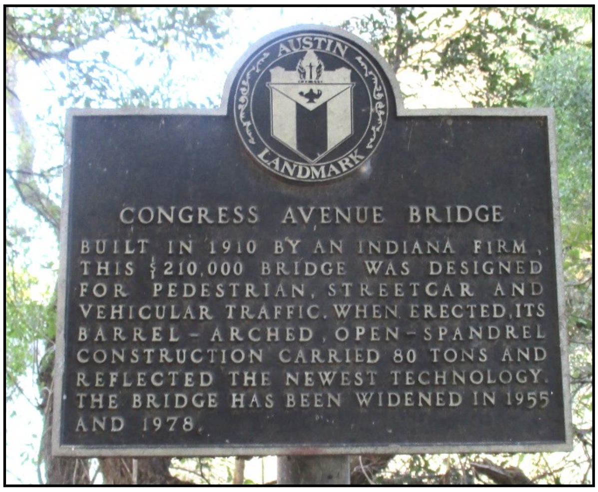
Congress Avenue looking North at evening

Keeping Austin weird

Congress Avenue Bridge of the Colorado River

Where it crosses the Colorado River and where there is a very important conservation project.

Congress Bridge hosts the largest urban bat colony in the world, estimated at 1.5 million bats.
It is a maternity colony, and female Mexican free-tailed bats raise an estimated 750,000 pups each year at the bridge. Large numbers of bats began roosting in the Bridge in the early 1980s, shortly after it was renovated. Few people understood how valuable the bats were, and many feared them. It took a lot of effort by Bat Conservation International and other bat-friendly folks to help turn the tide of public opinion. Today, Austin loves its bats, and this international tourist attraction brings 140,000 people and as much as $10 million to Austin every year!



CONGRESS AVENUE BRIDGE

BUILT IN 1910 BY AN INDIANA FIRM, THIS $210,000 BRIDGE WAS DESIGNED FOR PEDESTRIAN, STREETCAR AND VEHICULAR TRAFFIC. WHEN ERECTED, ITS BARREL-ARCHED, OPEN-SPANDREL CONSTRUCTION CARRIED 80 TONS AND REFLECTED THE NEWEST TECHNOLOGY. THE BRIDGE HAS BEEN WIDENED IN 1955 AND 1978.

The Bat Party waits for action

Mexican free-tailed bat

The Bats set off out hunting

The bat night flight takes part every sunset when they are in residence and is a great way to end the day after spending it exploring what Congress Avenue has to offer. With its wide sidewalks various shops and eateries, every food taste catered for, some displaying Austin humour, and watch out for the colourful characters that give rise to the local slogan “Keep Austin Weird.”
Nobody (excuse the pun) bats an eyelid.