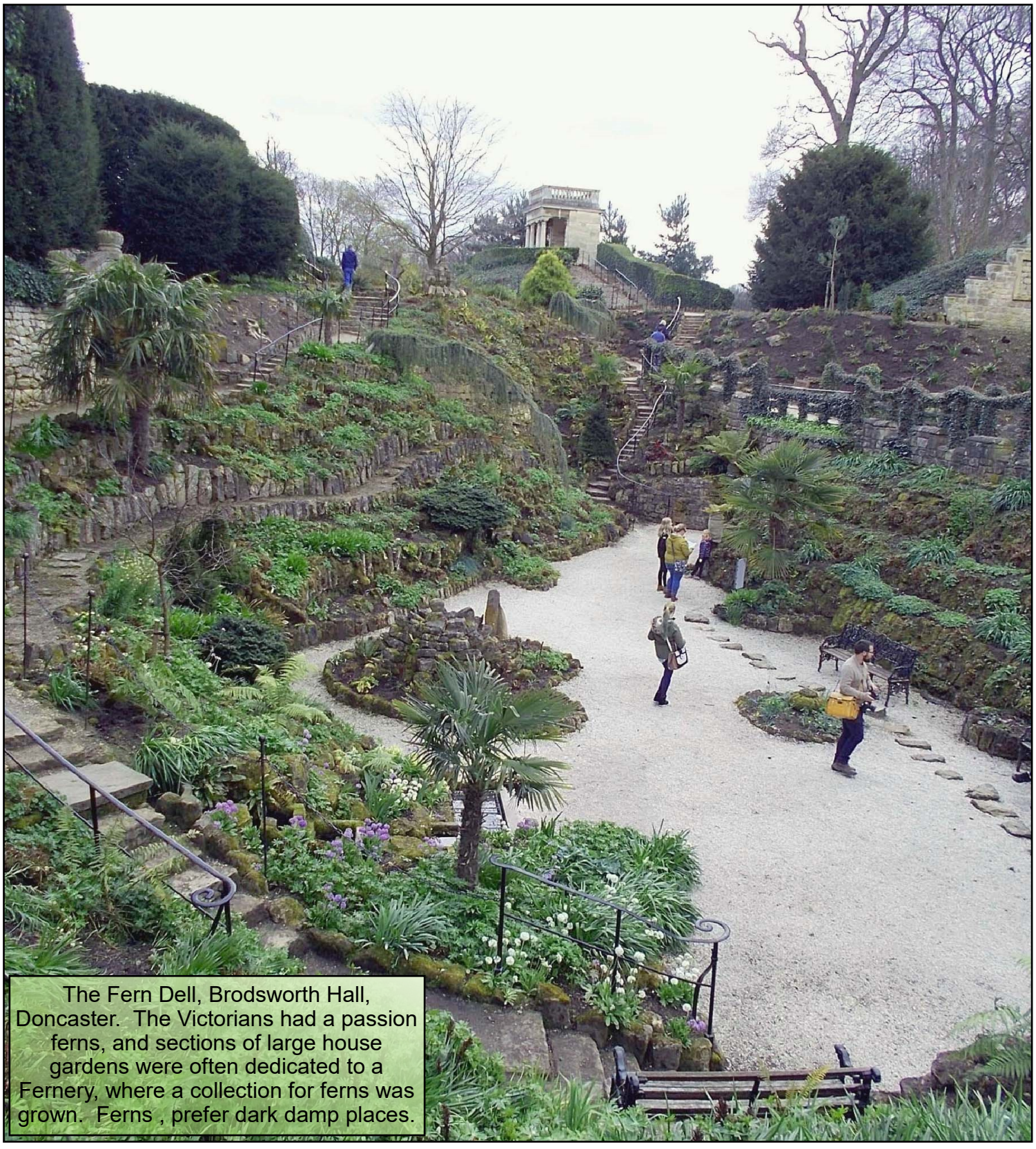
Price £ 4.00 (Free to members)

Pathways

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

Welcome to Pathways No 71. Spring 2022 Edition.

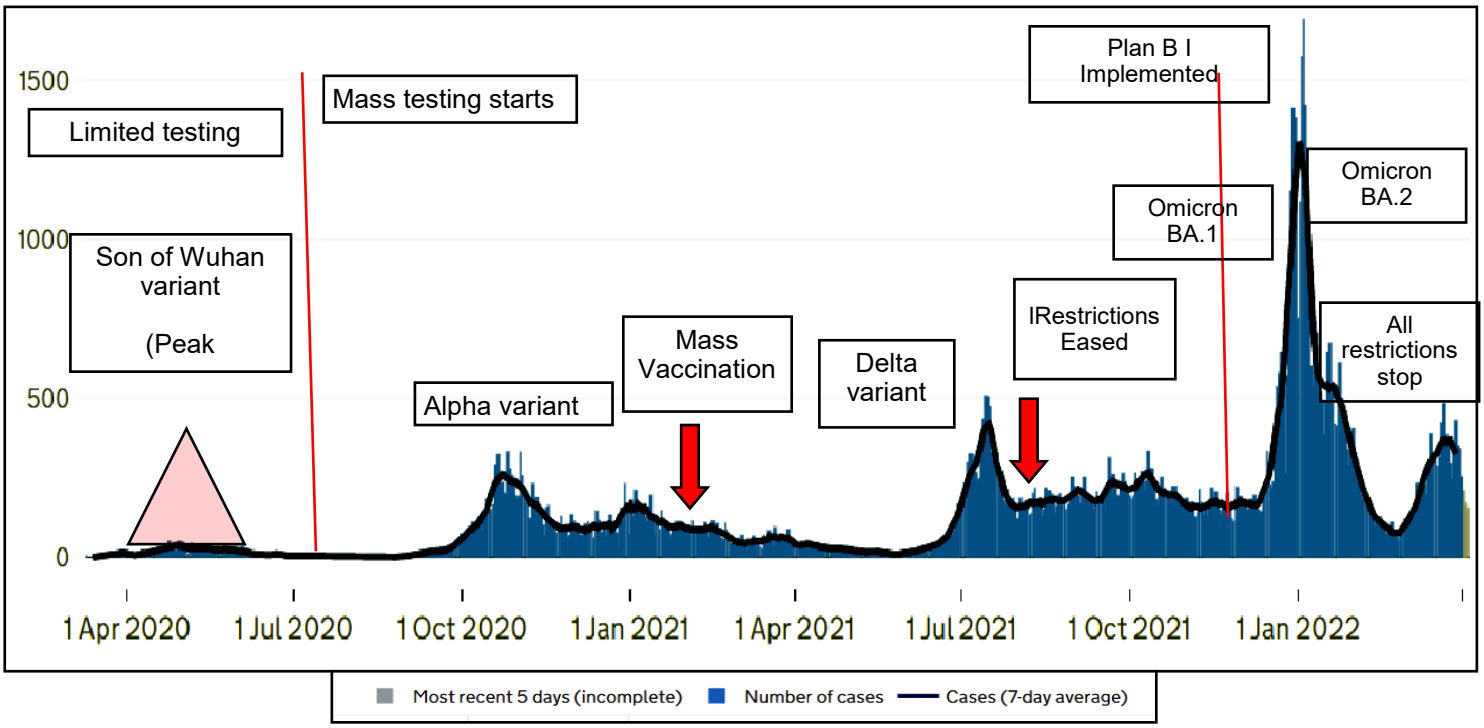
The Yorkshire Fatigue Clinic Dysregulation Model of ME/CFS



The Fern Dell, Brodsworth Hall, Doncaster. The Victorians had a passion ferns, and sections of large house gardens were often dedicated to a Fernery, where a collection for ferns was grown. Ferns , prefer dark damp places.

Local Covid Matters

Here is the history of cases in Doncaster from the Government Website



The above graph represents the number Covid cases in Doncaster. In January there was a massive peak of the BA.1 Variant. Currently we are just getting over the peak of the BA.2 variant. At the time of writing (early April 2022), the mandatory wearing of face masks has stopped except in health establishments.

The bad news: -

- The BA.2 variant is endemic and is very contagious. In other words it is going around communities, especially schools. Many people who have had a past Covid infection are catching it a second or third time..
- The BA.2 variant is far more like a common cold than the earlier variants. It also appears to be less severe than early variants for causing hospitalisation and death.
- Most of the cases are mainly those with weakened immune systems and the elderly.
- People double jabbed can catch the Omicron variant – it is thought, but not proven, that they may have some protection from severe disease.
- People who have received a booster jab are estimated to have a 76% of protection. So, 24 % of triple jabbed can be expected to suffer some form of mild disease.
- If you have had Covid before, is does not give any significant protection against Omicron.
- There are a significant number of people who have not come forward for vaccination.
- Free Covid testing has ended for the general public.

The good news: -

- Face masks, hand washing, distancing, as a well-ventilated environment will reduce the risk of infection of Omicron just as with the early previous variants as well as colds and flu.
- For the most vulnerable a fourth Covid vaccination programme has started.
- It is expected that top-up vaccinations will be given later this year also with annual flu vaccinations. A n Omicron specific vaccine is under trial.

As an ME/CFS community, I think we need to be cautious. Your best defence is to get your vaccine status as up to date as possible.

Remember: Covid 19 BA.2 has not gone away. We have to learn to live with it

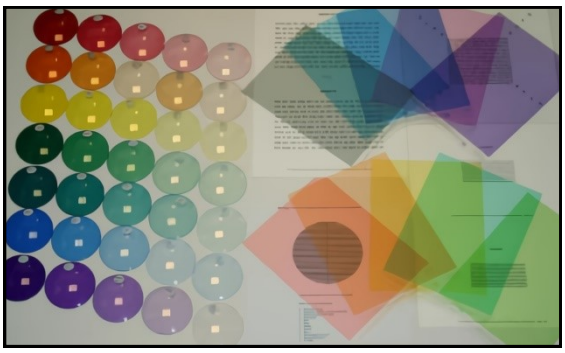
You Write In

Adam Writes: I have problem with light sensitivity. It has happened in the past, but I had forgotten to report it. I have just had a reminder. I have recently been in a meeting at school for my son's support plan and during that meeting my vision felt unusual. I have forgotten about it until now. Under the white artificial classroom light, I was feeling really dizzy, drowsy and strange. This also happened months back at my previous job whilst I went to say see to my former work mates and had to leave the room feeling depressed and distressed.

What you are reporting is Photophobia which is common in ME/CFS– but with slight twist. Meares-Irlen Syndrome. It is a common problem in autistic children and with certain neurological conditions. With you it's likely to be due to the third cranial nerve injury due to ME/CFS.

What you are describing is the colour or quality of the light affecting you. It is not unusual for this to happen. The usual fix is to use a light source where you can vary the colour or vary the intensity. Fluorescent lights used in workplaces emit a lot of ultraviolet light (which you can't see), and have an overall green balance, and the light comes in a series of very fast flashes. It is something like this that is affecting you.

Two simple aids for Meares-Irlen Syndrome



There are no instant fixes. There are some fixes. Firstly you can install a light dimmer. In our house, all the main lights have dimmers fitted. A dimmer can be substituted for a light switch, and they cost between £12-20. We use table lamps which are shaded and have a daylight balance bulb most of the time. If you used a multi colour bulb you would find that a warm reddish yellow is less stressful than a blue colour.

The other way is to filter the light entering your eyes. One lady I know uses yellow acetate filters to cover her book or computer screen. One lady I know has several tinted glasses red and blue for different circumstances. You can buy the set of filters on A4 size from Amazon for about £10. The other option is to have tinted glasses from an optician, but they have to be qualified to supply Irlen Syndrome spectacles.

This is the sort of thing your workplace should have been aware of. If you can get it recognised by a doctor or optician, we can use it to get a couple of points for PIP.

Maria Writes: I have been treated privately at the Yorkshire Fatigue Clinic by Dr. Sue Pemberton. I have been advised that she is retiring in April 2023, and after this date will no longer be able to provide and privately (self) funded service. Have you any idea where I could go next ?

Sue and several others originally worked for the Seacroft Leeds ME/CFS clinic, which was set up around 1990, being one of the first ME/CFS clinics in this area. Due to reorganisation within the Leeds Seacroft clinic, they decided to set up independently as the Yorkshire Fatigue Clinic. In due course they became a contracted provider for NHS assessment and rehabilitation for patients with ME/CFS in North Yorkshire, excluding adults in the Harrogate and rural area. However, they retained their private patients.

Coincidently, when Sue retires, there will be a change in the business model, and they will then only be dealing with NHS referrals from within their designated service area. Nationally the NHS ME/CFS clinics have territories. Where Doncaster is concerned, all NHS referrals are sent to the Sheffield and North Derbyshire ME/CFS in the Michael Carlisle Centre in Sheffield.

If you or anyone else for that matter feel that you need a private service such as like what Sue provided, the best thing to do is arrange a case review with me, and then we can have a look at the options available.

Current Welfare Rights Matters

With thanks to Steve Donnison from Benefits and Work

Benefits and Work
Guides you can trust
SUPPORTING CLAIMANTS SINCE 2002

Leger ME is subscribed to Benefits and Work publishing. Their guides are available to members as part of the membership deal. Contact the office for further details

DWP hide falling pip assessment success rates

In yet another lurch towards secrecy, the DWP have suddenly stopped publishing PIP assessment success rates in their quarterly statistical reports. However, using the DWP's Stat-Xplore tool Benefits and Work has created them for you and they show a further drop in claimants getting an award.

The percentage of new PIP claimants who got an award following a Capita or Atos (IAS) assessment are:

November 47% December 46% January 46%

The average assessment success rate for the whole period since PIP was introduced stands at 55%. A drop of 9%, the difference between the January average and the overall average, means around 4,500 fewer claimants are getting an award of PIP every month. That is an awful lot of disabled people missing out on financial support that could change their lives. And the decision by the DWP to stop publishing these figures suggests that they expect this figure to continue to fall - and they would rather claimants did not know about it. But we will make sure you do.

PIP, DLA, ESA and UC appeals success rates all fall. The success rate for appeals has fallen across all the major benefits, the latest quarterly figures released by HM Courts & Tribunals Service this month reveal. The figures relate to the period October to December 2021.

The PIP success rate was 68%, down 6% on a year ago.
The DLA success rate was 65%, down 1% on a year ago.
The ESA success rate was 60%, down 9% on a year ago.
The UC success rate was 46%, down 11% on a year ago.

B&W do not have an explanation for the fall in success rates, though the switch to telephone hearings may play a part.

DWP Increasing pressure ESA and UC claimants The Disability News Service (DNS) has been told by a DWP whistleblower that claimants with significant mental distress are being forced to attend weekly meetings with work coaches whilst waiting for a work capability assessment. The whistleblower is now very concerned that DWP's new, even stricter, approach might lead to more people taking their own lives. Separately, Benefits and Work has heard from a whistleblower who says they are a former DWP employee. told us that work coaches are being named and shamed for not pushing claimants off ESA and onto UC and also being bullied into sanctioning claimants. B&W have not been able to independently verify these claims.

DWP confirms PIP awards will continue. The DWP has confirmed in its latest personal independence payment (PIP) statistical release that many planned award reviews are on hold, but that claimants will continue to receive their current level of benefit until a review takes place. This will come as a great relief to many thousands of claimants who have been left in a state of anxiety and uncertainty by a lack of news from the DWP about their award review. The delay is caused by the DWP prioritising new claims over reviews. But as there are now over a third of a million (340,000) new claims in progress mostly waiting for an assessment - the delays could be very long indeed.

PIP for Long Covid on benefits and work YouTube channel. We are dipping our toes into YouTube videos. The first of these is a video asking could you claim PIP for Long Covid. It is primarily aimed at people with no prior knowledge of PIP whose life has been affected by Long Covid. It just goes to show if you keep pestering them and point it out in black and white the rules they do actually listen. So, I would say to anyone who thinks they meet the criteria do not give up.

An example of Problems with Personal Independent Payment (PIP) and Assessments by 'Health Professionals'.

With thanks to 'Ruti'

When someone applies for PIP, there is a form, a PIP2 fill out. The most recent forms have minimal guidance and questions and are a blank piece of paper. If someone fills these out without the proper experience or guidance, they generally do not say the right things, this results in outright benefit refusal.

If you get the form right, then it goes to the next stage. You will contacted by a so called Healthcare Professional whose job it is to decide the claim and make recommendations in a report to a DWP Decision Maker. The HP will go through the case very thoroughly line by line. They produce a PIP 1077 or RV4 form which is about twenty pages long. The HPs these days are not doctors. They tend to be Nurses, Physiotherapists, Occupational therapists or even Paramedics. To a large extend due to the recent Covid pandemic nurses have been excluded, and the remaining HP have little knowledge of issues around chronic conditions.

This has led to some outrageous assessments. The most outrageous example involved one of our members in Northeast Lincolnshire who had a hip replacement. The assessment was over the phone. Because that person had been discharged from hospital, it was assumed our member was cured and could live a normal life. Replacement joints are far from problem free and need frequent medical intervention. This case involved a very heated phone call with the so called Health Professional. Once the DWP make a decision, be it right or wrong they will stick with it. In our members case, the matter was taken to a Tribunal Service which is a branch of the Family Court division of the Judiciary. We eventually won, but it took well over a year, and our member received a large back payment.

At Leger ME, from experience we have found ways of minimising the problems with case mishandling, and more importantly this has to be dealt with from the first fillout of the PIP2 form. Most of the time we get it right but sometimes it goes wrong, and this involve me writing exceptionally long and complex support letters. What follows is an extract from such a letter. In this case the HP was a nurse

Here is an extract from a support Letter regarding HP inaccuracies and disputed.

The HP appears to have made a number of major errors in the PIP 1077. The decision maker has just followed the report verbatim. Here are my views.

* You are prescribed a moderate dose pain killer for the majority of days, low dose night medication, and your other medications are only over the counter only, which you do not take to the maximum dosage.

Taken out of context: People with ME CFS are overly sensitive to medicines side effects, so multiple medicines at a low dose are often needed. NICE Guidelines NG 206 10 .1.1131

* You have been discharged from many of your previous specialists, and informal observations by your assessor noted there were no signs of tiredness or lethargy during the consultation, and you were very talkative throughout.

The talkativeness observed is part of the fatigue syndrome because of fear and anxiety. This is a snapshot taken out of context. (Our member) rested up for several days before the interview, preparing like she would for an exam. On the following days she suffered bouts of Post Exertional Malaise which lasted a week. It is normal for ME/CFS patients to be discharged into the care of the GP as no effective ME/CFS treatment is available other than palliation.

* Your worse days are on the majority of days, and you work 4 days a week for five and a half hours as a Health Professional.

This is true but inappropriate, (our member) works from home, and when she is able. Avoidance of travelling reduces her daily energy requirements. (Covid 19 helped (our member) from the home

working context). The current situation is that her current level of working is unsustainable.

* You have no diagnosed cognitive conditions, no prescribed mental health medication and you demonstrated good cognition during your assessment, you have not prescribed medications or input for your heart or your reported dizziness.

This is a total misunderstanding. Cognitive and mental health problems are part of the ME/CFS spectrum

*(Our member) member reports taking a long time to chew your food is not considered within the scope for the taking nutrition activity. You report eating three meals a day and you have no dietetic input.

Disputed. (Our member) has been advised by a private dietician along the guidelines of the British Dietetic Association. Chewing is consuming energy, which has to be taken as part of the overall pacing strategy. (Our member) eats lots of vegetables as advised be her specialist. So, most of her food needs chewing well as they are plant based.

* You have no input or prescribed medication for your reported incontinence.

(Our member), like almost all the ME/CFS patients has urge incontinence. He/She uses adsorbent pads changed many time on a daily basis which are classed as an appliance.

* Overall, there is no evidence to state you have a physical, functional, cognitive, mental, sensory, or behavioural impairment that could prevent you from completing these activities unaided safely, reliably, and repeatedly on the majority of days.

Disputed. All of the conditions stated are part of the ME/CFS spectrum.

* You said you have difficulty planning and following journeys. Although you report anxiety. You have no prescribed mental health medication and limited input.

Disputed. Nortriptyline, Amitriptyline and Lorazepam are all medicines used to treat mental health problems. The Tricyclics have a long-term action which lasts for days.

* Your reported anxiety symptoms do not meet the high threshold of overwhelming psychological distress.

Disputed. During recent mentoring sessions with (our member) has reported symptoms of post-traumatic stress disorder. There are two reasons for this: Firstly, an unfair PIP decision and secondly pressure from her employer due to her health issues.

* You have no prescribed medications or input for your heart or your reported dizziness I decided you can stand and then move more than two hundred metres.

Out of context. Dizziness is part of the symptom spectrum of ME/CFS. Moving more than twenty meters causes post exertional malaise with (our member). (Our member) has to limit his/her movement as part of the pacing strategy. To date this has substantially reduced the disease progression and is critical for her future welfare.

What is quite clear from the descriptor is that The HP has not considered Fatigue and Post Exertional Malaise. This is a major error on her part.

The above points in a support letter, and with a heavy load of addition with additional medical evidence from other healthcare professionals resulted in an award of PIP Standard Care.

The take home message is if you are going to apply for ESA/UC/PIP get help from someone who knows what they are doing. Contact the office for further information. Mike.

The Yorkshire Rhubarb Triangle

The Rhubarb Triangle is a 9-square-mile area of West Yorkshire, England between Wakefield, Morley and Rothwell famous for producing early forced rhubarb. It includes Kirkham gate, East Ardsley, Stanley, Lofthouse and Carlton. The Rhubarb Triangle was originally much bigger, covering an area between Leeds, Bradford and Wakefield. From the 1900s to 1930s, the rhubarb industry expanded and at its peak covered an area of about 30 square miles .

What is rhubarb? Rhubarb the fleshy, edible stalks (petioles) of species and hybrids (culinary rhubarb) of Rheum in the family, which are cooked and used for food. The whole plant which is an herbaceous perennial growing from short, thick rhizomes is also called rhubarb. Historically, different plants have been called "rhubarb" in English. The large, triangular leaves contain high levels of oxalic acid which is poisonous. However the Victorians found it useful for removing iron stains from clothing. The leaves and roots contain Anthraquinone glycosides, which give extracts of rhubarb a pink colour. These have a laxative effect. There are also cautions about rhubarb based medicines being given in pregnancy and while breast feeding. The small flowers are grouped into a large inflorescence and are leafy greenish-white to rose-red.

The precise origin of culinary rhubarb is unknown. The species Rheum rhabarbarum (syn. R. undulatum) and R. rhaponticum were grown in Europe before the 18th century and used for medicinal purposes. By the early 18th century, these two species and a possible hybrid of unknown origin, R. × hybridum, were grown as vegetable crops in England and Scandinavia. They readily hybridize, and culinary rhubarb was developed by selecting open-pollinated seed, so that its precise origin is almost impossible to determine. In appearance, samples of culinary rhubarb vary on a continuum between R. rhaponticum and R. rhabarbarum. However, modern rhubarb cultivars are tetraploids in contrast to the diploid the wild species.

Although rhubarb is a vegetable, it is often put to the same culinary uses as fruits. The leaf stalks can be used raw, when they have a crisp texture (similar to celery, although it is in a different family, but are most commonly cooked with sugar and used in pies, crumbles and other desserts. They have a strong, tart taste. Many cultivars have been developed for human consumption, most of which are recognised as Rheum × hybridum by the Royal Horticultural Society.

History

Growing and forcing rhubarb was originally done by many hundreds of small farmers, smallholders and market gardeners. In later years some growers expanded and owned many thousands of roots and extensive forcing sheds. In the late 19th century early forced rhubarb was sent to Spitalfields and Covent Garden markets in London in time for Christmas and was sent to Paris for the French market. A special express train carrying rhubarb was run by the Great Northern Railway Company from Ardsley station every weekday night during the forced rhubarb season from Christmas until Easter. Up to 200 tons of rhubarb sent by up to 200 growers was carried daily at the peak of production before 1939. In 1962, a rail strike caused the growers to look for alternative transport and the service ended shortly after. Wakefield Museum has a permanent exhibition about forced rhubarb. Rhubarb became less popular

after the Second World War when more exotic fruits became more available. The Oxford English Dictionary dates the name "rhubarb triangle" to a 1965 textbook mentioning pre-war trains called rhubarb specials that ran from the West Riding rhubarb triangle to London and it was mentioned in the Guardian newspaper in 1986.

In the Victorian kitchen garden, forcing pots were use to keep light off Rhubarb in the soil in its second or third year.

Forced Rhubarb Cultivation

Rhubarb being a native to Siberia and thrives in the wet cold winters in Yorkshire. West Yorkshire once produced 90% of the world's winter forced rhubarb from the forcing sheds that were common across the fields there. The cultivation method for forced rhubarb was developed in the early 1800s. The fields were fertilised with large quantities of horse manure and 'nitrogen rich from the nearby urban areas and woollen waste from "mungo and shoddy" mill

Rhubarb plants growing in the field.

The rhubarb plants spend two years out in the fields without being harvested. While in the fields the plants store energy from the sun in their roots as carbohydrates. The roots are subjected to frost before being moved into sheds in November where they are kept in complete darkness. In the sheds the plants begin to grow in the warmth and the stored carbohydrate in the roots is transformed into glucose resulting in forced rhubarb's sour-sweet flavour. The sheds are long low buildings which are heated; originally with coal, which was plentiful and relatively cheap in the area, but this has been replaced by diesel.

A typical rhubarb forcing shed

Forced Rhubarb by candlelight

Forced rhubarb grown in the sheds is more tender than that grown outdoors in summer. Without daylight the rhubarb leaves are a green-yellow colour, and the stalks, measuring around two feet, are crimson in colour with a smooth texture.

Hand harvesting forced Rhubarb by candlelight

Traditionally, the pickers pull the stalks in candlelight as any exposure to strong light will stop the growth. By the end of March the harvest is over and the root stock is totally exhausted and used for compost.

EU recognition of Yorkshire forced rhubarb

A group of twelve farmers who farm within the Rhubarb Triangle applied to have the name "Yorkshire forced rhubarb" added to the list of foods and drinks that have their names legally protected by the European Commission's Protected Food Name scheme. The application was successful and the farmers in the Rhubarb Triangle were awarded Protected Designation of Origin status (PDO) in February 2010. Food protected status accesses European funding to promote the product and legal backing against other products made outside the area using the name. Other protected names include Stilton Cheese, Champagne, Parma Ham and Melton Modbray pies.

Forced Rhubarb.

Culture

Today, there are twelve rhubarb growers still established within West Yorkshire`s Rhubarb Triangle, and in 2010 they joined forces to ensure `Yorkshire Forced Rhubarb` secured protected status by the European Commission. So the great agricultural tradition is still thriving, and West Yorkshire remains the spiritual home and traditional centre of the world`s rhubarb industry, where an annual festival in Wakefield celebrates it and where the vital ingredient for crumbles, pies, fools and even gin can be sourced.

Wakefield Council holds an annual Rhubarb Festival in February, celebrating the area's links and promoting the surviving rhubarb industry. A Farmers' Market, cookery demonstrations, walks and tours of the forcing sheds are among the attractions. In 2005 Wakefield council erected a sculpture depicting a rhubarb plant in Holmfield Park Wakefield. Rhubarb growing and the 'Rhubarb Express' are featured in Wakefield Museum.

A Rhubarb sculpture in Wakefield

Recipe Corner: Rhubarb crumble

This recipe serves four, has a preparation time of less than 30 mins, and a cooking time of 30 mins to one hour. The fructose can be substituted with ordinary table sugar.

Cooking Method

1) Preheat the oven to 180C/160C Fan/Gas 4.
2) Cut the rhubarb into 7½cm/3in long sticks and place on an oven tray. Sprinkle with 4 tablespoons of water and the sugar. Roast for 10 minutes. Sprinkle over the ginger and mix well.
3) Fill an ovenproof dish about 4cm/1½ in deep with the rhubarb.
4) Rub the butter into the flour then mix in the demerara sugar to make the crumble topping. Sprinkle over the rhubarb and bake for 35–45 minutes, or until the crumble topping is crisp and golden-brown and the rhubarb filling has softened and is bubbling.
5) Allow to cool slightly before serving with double cream.

Nutrition: Each serving provides 630 kcal, 6g protein, 97g carbohydrates (of which 59g sugars), 23g fat (of which 14.5g saturates), 4g fibre and 0.5g salt.

Ingredients

10 sticks of rhubarb
8 tbsp sugar
1 tsp ground ginger
110g/4oz butter, softened
110g/4oz demerara sugar
200g/7oz plain flour

To serve
double cream or custard

Crafts Corner

Here is a quarterly round up of members' craftwork

Claire is always a busy crafter and is making Sunflower Brooches to raise funds for Ukraine; she and craft her group have already made £800.

Claire has also made a banner from collage work done her daughter`s Year1 class to enable them to display their work at school.

John and his partner **Kathryn** went to The Old Iron Forge in Herefordshire where they made a knife BLADE from a piece of flat bar together.

Beth finds Diamond Art simple and cheap to do and is enjoying it but will be glad when she can get back to her usual painting.

Kerry`s craft work takes a lot of time and patience.

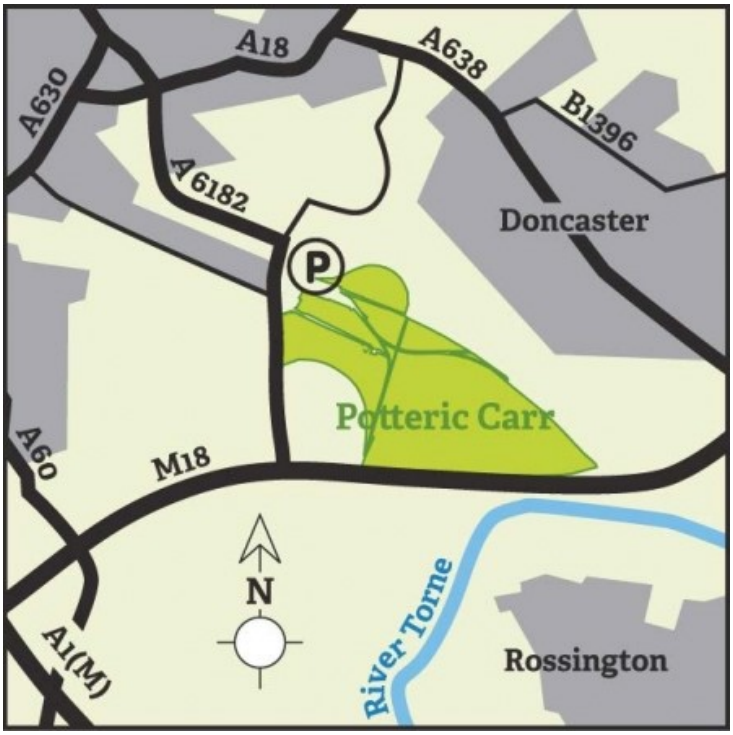
The detailed cuts on the paper are made by a dedicated machine which looks like a small table top printer.

Out and About in Doncaster: Potteric Carr Nature Reserve

Potteric Carr is a nature reserve under the care of the Yorkshire wildlife trust. It is in the green heart, south of Doncaster

Potteric Carr is a wild oasis just waiting to be explored. Now nestling between motorway and railway, it's a remnant of the vast fenland that once stretched all the way the Humber basin to the coast. Around each corner you'll discover a true mosaic of habitats, from reedbeds swaying gently under big open skies to woodland trails and networks of ponds teeming with life.

During summer, the meadows are full of butterflies and abuzz with insects, while winter brings the magic of thousands of starlings creating incredible aerial displays. Listen carefully and you might even hear the booming of the elusive bittern.



Potteric Carr Nature Reserve Visitor Centre, Mallard Way, Doncaster, DN4 8DB

Potteric Carr's brand new visitor centre is now open. The centre further enhances the experience of all those that come to the site Famed for its wetland birds including bitterns and marsh harriers, Potteric Carr has a network of paths enabling visitors to explore the mosaic of habitats and enjoy the stunning vistas found at this large nature reserve. The paths and facilities are wheelchair accessible, but you would need a rugged model with plenty of cushioning. The only negative aspect of the site is that dogs are not allow. The stated reason for this is for the protection of the wild animals

We recommend that prior to vising you contact the visitor centre for further information.

Opening Times & Prices Contact: Telephone 01302 325736

Email: potteric.carr@ywt.org. Website: https://www.ywt.org.uk/potteric-carr

The Yorkshire Fatigue Clinic Dysregulation Model of ME/CFS

For further information see http://www.yorkshirefatigueclinic.co.uk/

Understanding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and the theories behind our therapy approach.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a multi-system illness that affects many different aspects of the body's physiology. Current research indicates dysregulation of several systems in the body and this may explain the wide range of symptoms that people experience.

the key pathology which underpins CFS is potentially best understood in computational terms as resulting from altered messages passing amongst homeostatic networks

(Clark et al 2019)

To understand this dysregulation, it is useful to firstly understand how healthy systems work and what symptoms can occur if each of these systems are not regulated. Then the interaction of the systems and how they impact upon each other, before considering how dysregulation can be applied to ME/CFS.

What are demands on the body and how does the body respond to demands?

Our body needs to respond immediately to the demands of life combining information from internal systems within the body and information from the external environment. The body responds dependant on the needs at the time - either active or restorative, that will help to maintain or return the body to a stable state. This state is referred to as homeostasis (Selye 1956). Homeostasis could be summarised as the body maintaining balance to provide ideal internal conditions for long term health and survival.

Demands are many and varied. There are internal demands that are part of everyday life such as hunger, thirst, physical activity, cognitive activity, processing emotions and sleep. There can be additional internal demands that occur including infection, inflammation, injury, and disease. The body also needs to respond to external demands including gravity, temperature change and pollution. Demands on the body can be increased by disruptions to daily patterns which affect circadian rhythms or our body clock, for example shift working, sleep disruption, lack of daylight exposure or changes in eating patterns.

The circadian clocks are present at both cellular and system control levels and are essential time-tracking systems in our bodies that anticipate regular environmental changes and adapt appropriately to the time of day. For example, coordinating the hormones we need to wake up in the morning and go to sleep at night. Disruption of these rhythms greatly influences health (Koch 2017).

Ultimately the body's response to demand, change or need is achieved by regulating various *dynamic* systems at a body-wide and cellular level. At a body-wide level three of the systems involved are the **Autonomic Nervous System** (neurological), the **Hypothalamic Pituitary Adrenal Axis** (neuroendocrine), and the **Immune System** which all work together to coordinate a response to change or demands. At a cellular level, the processes of **Metabolism** are involved.

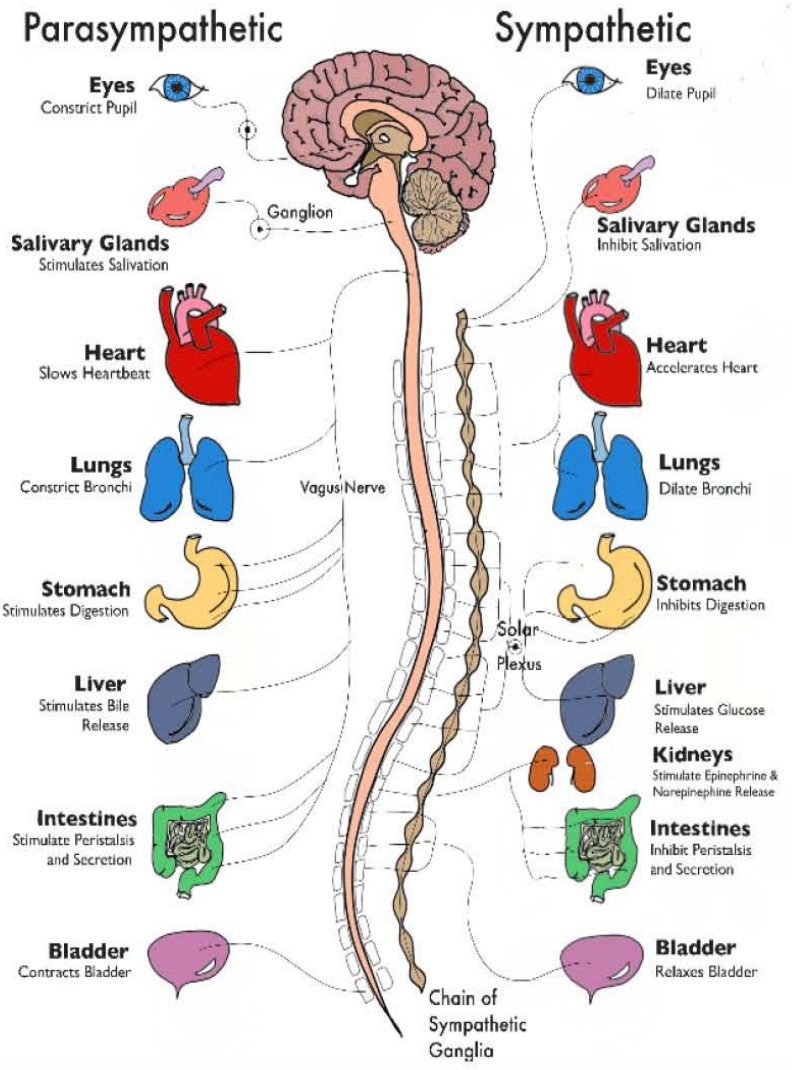
How do these systems work?

Autonomic Nervous System

The **Autonomic Nervous System** (ANS) is key in automatically and rapidly responding to demand, regulating many body processes including:

- Blood pressure
- Circulation
- Heart rate
- Breathing rate
- Body temperature
- Sweating
- Digestion including saliva and digestive enzyme production, and gut motility
- Metabolism including regulation of blood sugar
- Balance of water and electrolytes, including urination
- Sexual response
- Pupil response

The ANS has two main divisions, **sympathetic** and **parasympathetic** which have an opposite effect on different organs in the body. For example, increased sympathetic activity would increase heart rate and increased parasympathetic activity would decrease heart rate. Therefore, the ANS responds by changing body processes through the stimulating actions of the sympathetic division (turning up) or inhibiting processes through the parasympathetic division (turning down). Consequently, the sympathetic division is sometimes referred to as the 'fight and flight' response and the parasympathetic division is sometimes called the 'rest and digest' response. Both systems are active, but one will be more dominant depending on the situation and the needs of the body.



Autonomic Nervous System

Postural hypotension – some people can experience feeling faint or have vasovagal blackouts

Fatigue - different and more debilitating than the typical tiredness that everyone can experience

Muscle Pain – dysregulation in the circulatory changes during physical activity can contribute to the accumulation of lactic acid in muscles which can cause muscle achiness often likened to the feeling of having done a lot of exercise

Headaches – generalised headaches sometimes provoked by activity or upright position. Potentially some association with migraine type headaches

Palpitations – some people will experience a postural pattern whereby they feel their heart rate speed up in response to standing but there can also be random and unexplained episodes of palpitations

Breathing symptoms – altered breathing patterns while awake and during sleep can occur. Breathlessness provoked by minimal activity or occurring for no reason.

Gastrointestinal symptoms – problems related to gut motility such as nausea, reflux, feeling full with reduced appetite, diarrhoea and constipation. There can also be patterns related to the timing of eating with significant escalation in fatigue 20-30minutes after eating sometimes accompanied by sweating or a need to lie down or sleep.

Sensory changes – increased sensitivity to sensory input including light and sound, often provoking feelings of distress or anxiety. Problems regulating pupil size can contribute to light sensitivity along with difficulty focusing vision.

Temperature regulation – instability in regulating body temperature often swinging rapidly from too hot to too cold

Sweating – can be increased or decreased

Anxiety – a physiological sensation of anxiety in the body that wasn't provoked by having anxious thoughts or worries

Cognitive symptoms – changes in cerebral perfusion may contribute to the cognitive symptoms experienced including word finding difficulties, poor concentration and short-term memory problems

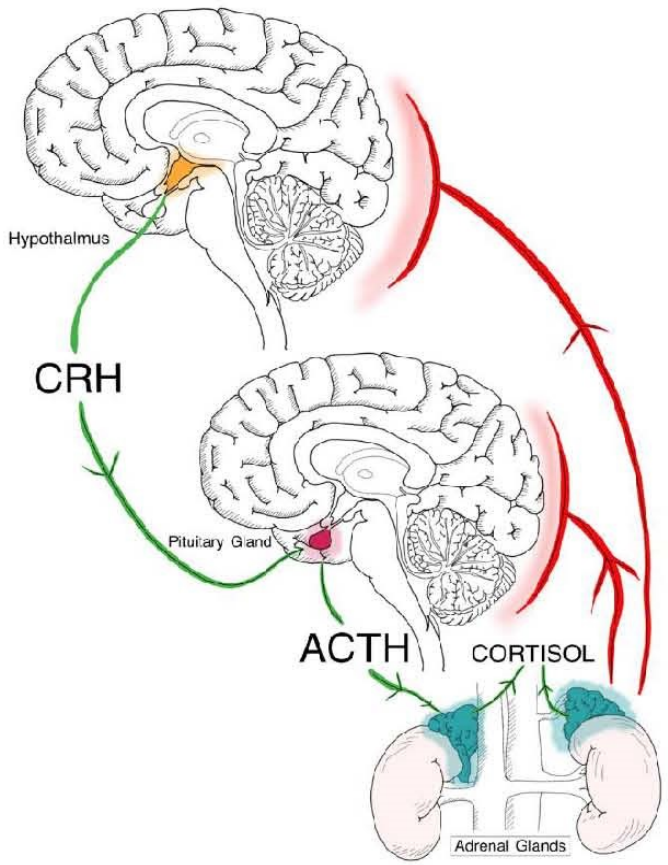
Hypersomnia – some types of autonomic dysregulation can lead to increased daytime sleepiness. Often occurs at the point of stopping physical activity or after eating a large meal

Sleep disturbance – inappropriate sympathetic activation during dreams can result in night time wakening

Hypothalamic-Pituitary-Adrenal Axis

The endocrine system is made up of many different glands throughout the body which release hormones that travel through the blood stream. They cause changes in many different body processes and help to regulate the activity of cells and organs.

The **Hypothalamic-Pituitary-Adrenal Axis** (HPA Axis), is one part of the Neuroendocrine system where parts of the nervous system and parts of the endocrine system operate together to regulate physiological processes in the body. It is another system which contributes to the body's response to demand and aims to maintain **homeostasis**. It tends to work more slowly and has a longer impact than the ANS response.



The Hypothalamus is a part of the brain which is responsible for regulating metabolic processes and the autonomic nervous system and it also has an important role in regulating circadian rhythms or 'the body clock'. It releases corticotropic releasing hormone (CRH) which acts on the pituitary gland.

The pituitary gland is a very small structure which sits at the base of the brain and releases several different hormones. The CRH from the hypothalamus stimulates the pituitary gland to make and release adrenocorticotropic hormone (ACTH) which then acts on the adrenal glands.

The adrenal glands are located above the kidneys and produce several different hormones including adrenaline, cortisol, and aldosterone. In response to ACTH from the pituitary gland, the adrenal glands release cortisol.

There is a feedback loop in this system which means the glands can detect the levels of circulating hormones and alter production levels in order to achieve or maintain homeostasis.

Factors which influence hypothalamic function include:

- Physical activity
- Illness
- Sleep/wake cycle
- Stress
- Levels of cortisol (from the adrenal glands)

The HPA axis is responsible for regulating many systems including:

- The metabolic system
- Cardiovascular system
- Immune system
- Reproductive system
- Central nervous system

Through its action on these systems, the HPA axis integrates physical and psychosocial factors which allow the body to adapt to its environment and the resources available in a way that optimises survival.

Symptoms that can occur due to HPA axis Dysregulation

Disrupted sleep cycle – changes in sleep patterns including insomnia and difficulty waking

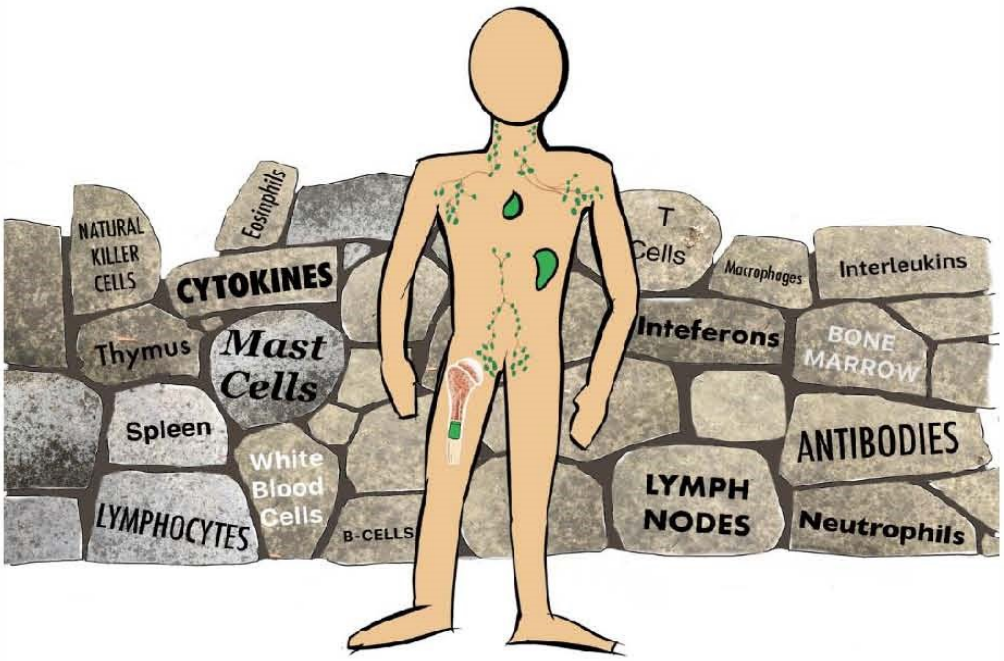
Body temperature changes – feeling cold all the time or experiencing hot flushes

Appetite – reduced appetite, nausea and weight changes

Mood – low mood/depression can be associated with altered cortisol patterns

Fatigue - often described as exhaustion

Immune System



The immune system is a network of structures, cells and processes whose primary role is to protect the body against attack. Parts of the immune system include the spleen, bone marrow, lymph nodes and thymus, white blood cells and antibodies and the complement system and lymphatic system.

The immune system also has roles to play in many other body processes including healing, growth, cancer prevention and reproduction.

The immune response is how the body recognises and defends itself against bacteria, viruses, and substances that appear foreign and harmful (antigens). There is an innate

system which responds immediately in a non-specific way and an adaptive system which can learn from previous antigen exposures and improve future immune responses.

The immune system is also involved in the normal responses to physical activity and exercise. The immune system creates small amounts of inflammation to improve muscle strength and improve metabolic processes. Therefore, it is normal to ache after exercise. Inflammation is also required for healing and repair.

The immune system influences many body processes by producing a wide variety of chemical messengers called Cytokines. Cytokines can trigger and promote inflammatory processes in the body and other cytokines can act to reduce inflammation. In a healthy person the immune system's reaction to infection includes the release of pro-inflammatory cytokines which then influence the cells around them and attract blood cells that attack the foreign substances. Many of the symptoms of infection such as fever, sore throat and tender lymph nodes are caused by the body's own immune responses. Once the infecting organism has been killed, it is important that the body is able to stop the inflammatory response otherwise damage will be caused to the tissues of the body.

Cytokines can travel throughout the body including into the brain where they can have direct effects on neurological processes. Immune system changes can influence mood, behaviour, and pain responses.

The immune system must, therefore, be able to respond rapidly, activating many complex systems, upregulating and downregulating activity as required and then stopping in order to allow recovery and restoration of homeostasis.

Symptoms that can occur due to Immune System Dysregulation

Malaise - a general whole-body fatigue and feeling of being unwell as if dealing with an infection

Tender Glands/sore throat– typically lymph nodes in the neck are affected but can be at other sites

Pain – some cytokines are released from pain neurons so increased pain sensitivity and allodynia can occur

Headaches – generalised headache associated with malaise

Cognitive fatigue – difficulty concentrating, reduced short term memory capacity

New sensitivities to medications, foods etc. – repeatable escalation in symptoms in response to specific triggers which resolves when the trigger is removed e.g. gluten/wheat sensitivity in the absence of coeliac disease

Mood – some cytokines can cross the blood-brain barrier and exert direct neurological effects which can result in symptoms of low mood

Metabolism

The chemical processes of metabolism in the body serve 3 main functions:

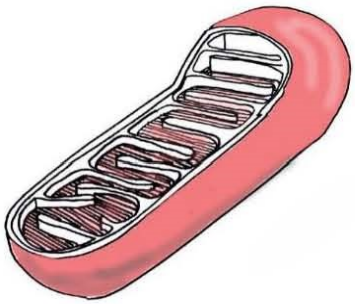
- The conversion of fuel into energy
- To make building blocks such as proteins, fats, and carbohydrates
- Elimination of waste

Metabolic reactions can be either anabolic i.e. 'building up' reactions or catabolic i.e. 'breaking down' processes. There are thousands of metabolic pathways in the body which occur at a cellular level and affect the body on a global level. These reactions must constantly adapt and regulate to maintain homeostasis.

When considering energy metabolism at a cellular level, one of the key metabolic pathways is the production of adenosine triphosphate (ATP). ATP is the chemical that the body makes in order to fuel many of the processes required to sustain life including muscle function, nerve function and chemical synthesis. ATP can be thought of as the chemical currency of energy. Most ATP production takes place within the mitochondria which are present in varying amounts in virtually all cells in the body.

Mitochondria

Aerobic Metabolism
Fuel + Oxygen = ATP



ATP can be made via 2 different metabolic routes- aerobic (with oxygen) and anaerobic (without oxygen).

Aerobic metabolism is where ATP is made using oxygen and fuel (e.g. glucose or fat). This is the most efficient way for mitochondria to make ATP. When the demand for energy is greater than the ATP available from aerobic metabolism, more ATP is made through anaerobic metabolism (i.e. without oxygen). Anaerobic metabolism is a less efficient process and creates lactic acid as a waste product which can accumulate in muscles and cause pain. The process of breaking down lactic acid requires more energy from ATP.

The anaerobic threshold refers to the point where ATP production has switched from aerobic to anaerobic and lactic acid is being produced at a higher rate than it is being used up resulting in an accumulation in cells.

Mitochondria constantly adapt and communicate with other structures to produce the appropriate amounts of ATP for the demands of the body. If the capacity of the aerobic process is reduced there will be an increase in anaerobic metabolism.

Symptoms that can occur due to Metabolic Dysregulation

Exercise intolerance – decreased ability to do physical activity due to fatigue with slow recovery after activity

Post-exertional malaise – worsening exercise intolerance 1-2days after increased activity due to changes in the anaerobic threshold

Muscle pain – increased utilisation of anaerobic pathways can result in lactic acid accumulation in muscles

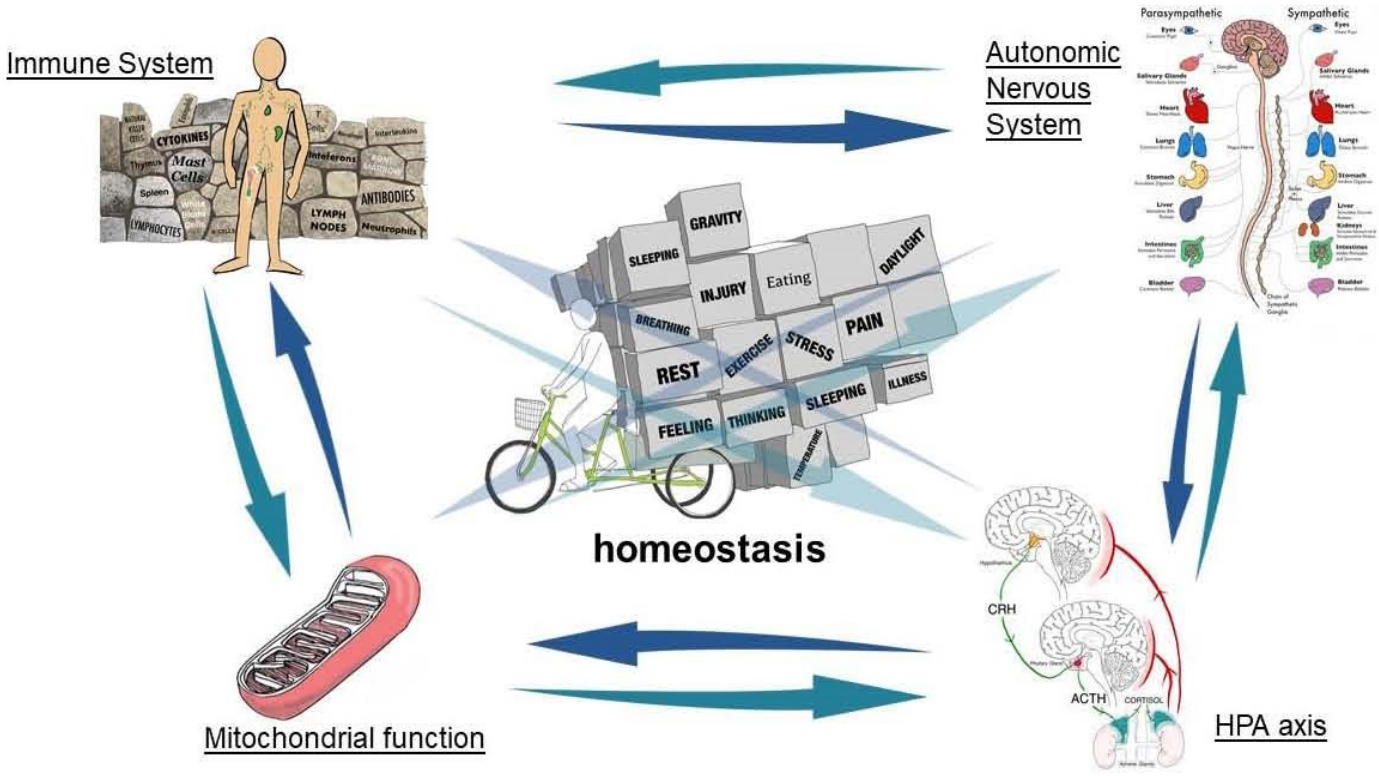
Medication sensitivities - possibility of disrupted enzyme pathways affecting drug metabolism

How do these systems interact with each other?

The autonomic nervous system innervates immune system structures such as the spleen, thymus, and lymph nodes. It can contribute to the up or down regulation of inflammatory responses in the immune system. Immune system cytokines can have a direct influence on the activity of sympathetic and parasympathetic nerves. The HPA axis is involved in regulating immune responses and cytokines involved in immune responses can influence HPA axis function. The Hypothalamus acts as the central control for the Autonomic Nervous System. Mitochondria have a key role to play in regulating immune system activity and during infections mitochondrial function alters. Changes in circulation responses directed by the autonomic nervous system can influence metabolic processes. So, all the dynamic systems are interconnected.

The nervous, endocrine, and immune systems continue to interact as part of the response to infection and this includes hypofunction (suppression) of the HPA axis, sometimes referred to as the sickness response or sickness behaviour. This triggers appropriate physiological and behavioural changes to infection or injury such as fatigue, pain, fever, reduced appetite, and increased anxiety, and activates the body's stress response, to allow it to prioritise fighting infection and recovery. This is also a protective action, limiting activity and exposure to potential threats when we are more vulnerable (Viamontes 2009).

What might go wrong in ME/CFS?



Although our understanding is still developing around the biological pathways for this illness, current information suggests multisystem involvement.

It has been described as the following:

Although no single dysfunction turned out to be a hallmark of the illness, our understanding of CFS has increased substantially. The onset of CFS is often sudden and precipitated by an infectious episode, but in some patients, onset is more insidious and can be preceded by negative, stressful life events. The latter may explain the malfunctioning of the short-term (autonomic nervous system) and long-term (hypothalamus–pituitary–adrenal axis) stress response systems. Indeed, patients with CFS have many autonomic manifestations, and the hypothalamus–pituitary–adrenal axis is characterised by mild hypocortisolism (Nijs et al, 2012).

Research evidence suggests a range of systems and responses that may be dysregulated or not responding in the expected way, such as:

- Repeated exposure to excessive demand can result in alteration of Autonomic System function and can lead to lasting adaptations in the body, for example in energy metabolism and immune response (Danese and McEwan, 2012).
- Sensitisation of the sympathetic nervous system or kindling (Jason et al 2009) – the SNS is more sensitive and reactive to triggers, the body can become stuck in a state of high sympathetic arousal, responding as if survival is threatened, even when resting or sleeping.
- Orthostatic Intolerance or difficulty regulating the body's response to gravity is seen as a key feature associated with ME/CFS (Garner and Baraniuk, 2019)
- Cerebral blood flow in ME/CFS patients is reduced during tilt testing even when BP and pulse readings are normal and correlates with symptoms of orthostatic intolerance (van Campen et al 2020)
- Different patterns of ANS dysregulation generate different patterns of symptoms and may account for some of the variation in severity of the illness (Slomko et al, 2020)
- HPA axis changes are evident in many people with ME/CFS however there is a lot of interindividual variation which suggests multifactorial causes and could indicate it is causal in some cases and a secondary consequence in others (Tomas 2013)
- For some people there may be ongoing hypofunction of the HPA axis with prolonged sickness response – the body continues to respond as if a virus/infection is present wanting to shut the body down (Van Houdenhove et al 2009)
- There may be variance in the expected level of cortisol which is associated with increased levels of fatigue (Torres-Harding et al, 2008)
- Disorganised circadian rhythms which can be linked to metabolic changes including how energy is used in cells (Lacourt 2018)
- Increased activation of the immune system such as elevation in the level of pro-inflammatory cytokines (Montoya et al 2017)
- Prolonged inflammatory response to exertion and slower recovery to baseline – for example in muscles (Van Oosterwijck, 2017)
- Alterations in anaerobic and aerobic threshold in muscles (Van Ness, 2003) – the type of energy production changes at a lower level of demand moving away from using oxygen.
- Abnormal recovery processes after physical activity leading to compromised oxygen delivery following the induction of post-exertional malaise (Keller 2014).

These biological changes may alter over time as it is thought there may be differences in new onset ME/CFS compared to someone who has had it longer term (Horning et al 2015).

The symptoms that occur in people with ME/CFS can be complex and involve multiple different systems and organs of the body. Exploring the patterns of symptoms can often give clues as to which systems may be dysregulated, however it is also important to recognise that similar symptoms can be generated from different systems and the symptom patterns can change through the course of the illness. Equally some people will have additional medical conditions or other body systems which become dysregulated which can also contribute to the symptom burden.

So, although there is no clearly understood pathway regarding the disorder, based on the evidence we have so far, a simple way to think about the illness may be:

Risk factors:

- In some people there may be a pre-existing vulnerability, such as possible genetic factors or increased activation of the immune system during its development (Morris 2019). Developmental changes occurring through childhood could be another vulnerability factor. Many patients were highly active before becoming unwell, often describing an inability to rest or relax prior to the illness and this may indicate a pre-existing highly responsive sympathetic nervous system (on mode) and poor responses in the parasympathetic nervous system (off mode). Some conditions including Hypermobility and Autism may also constitute an underlying vulnerability as they are now being recognised to have associations with Autonomic System Dysfunction.

Onset:

- In some cases, there is a clear trigger for the onset of symptoms, for example a viral infection or a major emotional event such as a bereavement.
- In other cases, chronic demands over time act as the trigger possibly by causing the body to enter an immune reaction or sickness response, with changes in the HPA Axis and Autonomic Nervous System.

Dysregulation:

- The illness may impact on the regulation of the autonomic nervous system, causing dysautonomia including orthostatic problems (our body's response to being upright against gravity)
- The body remains in a protective state and is highly reactive to any changes in internal and external demands, for example having an increased immune response to exertion (Post Exertional Malaise).
- In some people the nervous system remains in high sympathetic arousal and the parasympathetic responses are inhibited restricting the body's restorative functions, such as sleep, and making it hard to achieve and maintain homeostasis (HPA regulation).
- Mitochondrial function can be altered with disordered recovery after activity meaning there is a reduction in the anaerobic threshold following physical activity.

So, the dynamic systems in the body that are supposed to work together and regulate each other to keep us well or in homeostasis are now dysregulated and may work in opposition to each other. Many patients describe that their brain wants to go but the body wants to stop.

The sympathetic division is needed for every-day activity, such as physical movement, and is also a basic survival response preparing the body for stressful or emergency situations. Therefore, its actions have been termed the fight and flight response due to its role as part of the evolutionary development of human beings. Bodily changes include

- Increasing heart rate and force of heart contraction
- Widening blood vessels (vasodilation)
- Widening airways
- Releasing stored energy
- Increasing blood flow to peripheral areas of the body
- Increased sweating
- Increasing conscious processing of sensory information
- Altering focus of thoughts onto more immediate survival needs
- Slowing body processes that are less important for immediate survival such as digestion and reproduction.
- Working with the somatic nervous system to stimulate skeletal muscle and send energy to fuel muscle contraction.

The parasympathetic division, or the rest and digest response, conserves and restores, and reverses the processes above to allow recovery with the following bodily changes:

- Slowing the heart rate
- Decreasing blood pressure
- Stimulating digestive and reproductive systems
- Using energy from digested food to restore and rebuild tissues
- Filtering out unnecessary sensory input and focussing on what is necessary
- Enabling logical cognitive processing.
- Focus of thoughts onto more long term and strategic needs.
- Supporting sleep.
- Working with the somatic nervous system to relax muscles and conserve energy.

This is a simplified explanation of the ANS as there can be complex changes occurring where both the sympathetic and parasympathetic divisions are active and exerting different effects on different organs at the same time.

There are differences in how the ANS responds to acute demand or stress on the body and how it responds to long-term excess demand. In repeated exposure to excessive demand there can be lasting adaptations in the body, for example in energy metabolism and immune response (Danese and McEwan, 2012).

Symptoms that can occur due to Autonomic System Dysregulation

There are many different conditions that can give rise to Autonomic System problems and there are different types of Autonomic System dysfunction which can generate different patterns of symptoms. These are some of the common symptom patterns seen:

Orthostatic intolerance – escalation in symptoms (often fatigue and pain) in response to being upright/standing still. Often described as a feeling of energy draining out. May be accompanied by a feeling of needing to fidget or move around, lean on something or sit or lie down. Can also impact when showering or bathing and result in significant escalation in fatigue in response to these activities.

What can be done about dysregulation?

As these are complex systems that need to regularly adjust and change in response to demands and our world, it is difficult to find one factor that will correct dysregulation. However, we know factors that can aggravate dysregulation along with strategies that can improve stability and support homeostasis.

The approaches that can be helpful to therapy include:

- Regulation of the body clock and circadian rhythms, including sleep, light and eating patterns.
- Desensitisation of the sympathetic nervous system and increasing the parasympathetic response.
- Supporting orthostatic tolerance through fluid levels and management techniques.
- Matching energy availability and energy expenditure, understanding that there are different currencies for different types of activity, such as physical, cognitive, social and emotional. Working within the energy envelope, not pushing outside of it.
- Working aerobically within tolerance levels and reducing heart rate at rest and on exertion.
- Minimising immune activation and triggers for increased inflammation
- Balancing and managing overall demands and activity to remain within limits and allow recovery, reducing the impact of a boom and bust pattern on the HPA.
- Recovery time for restorative rest following exertion to allow return to baseline
- Ensuring diet is providing appropriate nutrients and supporting regulation of blood sugar levels.

Initially the focus is on consistency and regulating, to support stability before increasing the level of demand. This should be done gradually allowing development of tolerance and adaption prior to any further increases in demand, to enable the body to rebalance. This is the reason why the therapy approach we use works on different phases of stabilisation and then building tolerance. It is important that any strategies are implemented after a careful assessment of the individual's condition, and which aspects of dysregulation are most prominent and need to be addressed to support greater stability. Understanding how the body's physiology can be affected by this illness is an important starting point to any therapy programme.

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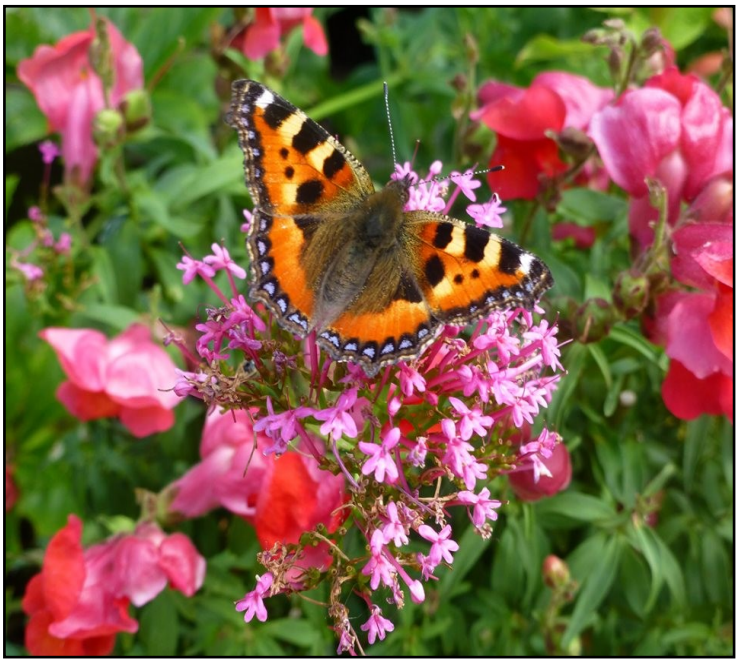
The Leger ME Facebook Group



Come and join us in our growing Facebook Group which is exclusively for our members.

Those who have joined are welcoming, friendly and very supportive and it is a good place to get to know others and enjoy their humour, gossip and company.

To enrol just type Leger ME Members Group into your Facebook search, then click on Member request and Admin will do the rest and bring you in.

We look forward to seeing you!

Sandra and Carolyn

Medicine Money Matters

There is no hike in prescription charge for first time in 12 years.

This is the first time in 12 years that the DH has frozen prescription charges. The last time prescription charges in England were frozen was in 2010, when they stayed at £7.20 per item.

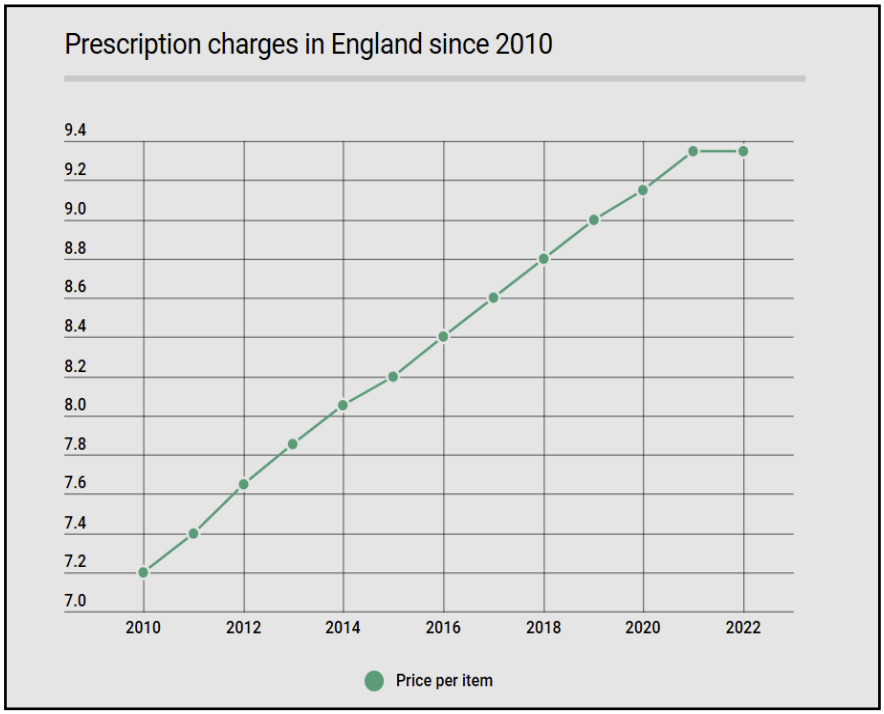
The Health minister Edward Argar said that there are no "planned" announcements for "any future increase". "Decisions on increases take account of a range of evidence, including the Gross Domestic Product deflator".

What is the Gross Domestic Product deflator?:

This is an indicator that measures the changes in prices for a country's products and services. It shows the extent of price level changes.

Last year, charges rose to £9.35 per prescription item. This meant that the price of a three-month prescription pre-payment certificate (PPC) increased to £30.25 and a 12-month PPC went up to £108.10.

If you are in need of two or more prescriptions a month and need to pay for prescriptions it is well worth while obtaining a prepayment certificate.



The increase served as a "reminder" that community pharmacy teams are "also tax collectors", the Pharmaceutical Services Negotiating Committee pointedly remarked at the time. The government proposal, launched a last year proposed raising the upper age exemption for prescription charges – currently set at 60 years of age – to 66 to align with the state pension age. In its consultation document, the DH wrote that 1.1 billion items had been dispensed in 2018, with almost 90% of these being handed to patients free of charge.

"Almost 63% of all items were dispensed free of charge because the patient was aged 60 or over.

Recipe Corner

With Thanks to Jane from the Linney Centre.

Cheesey Sweet Potato & Cauliflower

Ingredients (Serves 2)

1 Sweet potato, peeled and cut into wedges.
¼ Cauliflower, cut into florets.
¼ Broccoli, cut into florets.
100ml Semi Skimmed milk 25g Mature Cheese, Grated.
15ml (1 Tablespoon) Cornflour.
2 Spring onions, chopped.

Cooking Method

1. Pre heat oven to 180oC, 375oF or Gas mark 5.
2. Boil or steam the sweet potato, cauliflower and broccoli florets in a large pan of water until tender. Drain and transfer to ovenproof dish.
3. Meanwhile, mix 15mls (1 tablespoon) of cornflour with a little milk to make a paste. Heat the remaining milk in a pan and gently bring to the boil. Add the cornflower paste and stir continually until the sauce thickens stir in the grated cheese.
4. Pour the sauce over the vegetables and bake in the oven for 10-15 minutes or until golden brown.

Mince and Pasta Bake

Ingredients (Serves 2)

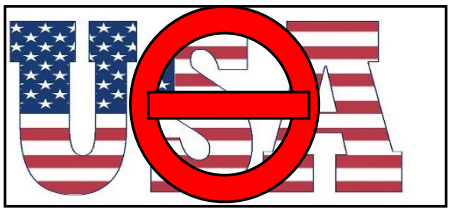
225g (1/2lb) Lean mince
225g (5oz) Pasta shapes
100g (4oz) Low-fat cream cheese
26g (1oz) Mature cheddar, grated
1 Onion, peeled and finely sliced
1 Courgette, sliced
75g (3oz) Mushrooms, sliced
200g (1 small) Tin of chopped tomatoes
15ml (1 Tablespoons) Tomato puree
2ml (1/2 teaspoon) Mixed herbs

Cooking Method

1. Pre-heat the oven to 200oC, 400oF, Gas mark 6.
2. Cook the pasta in a large pan of boiling water according to the manufacturer's instructions (don't add any salt), drain. Stir in the cream cheese and half of the grated cheese.
3. Meanwhile, using a non-stick pan gently fry the mince in 20-35ml (1-2 Tablespoons) of water until browned. Drain off any excess fat. Add the onions, courgettes and mushrooms. Cook for 2-3 minutes then stir in the chopped tomatoes, tomato puree and mixed herbs. Continue to cook gently for 10-15 minutes then transfer the mixture to an oven proof dish.
4. Place the pasta on top of the mince and sprinkle with the remaining grated cheese. Bake in the oven for 15-20 minutes or until golden brown and cooked through.
5. Serve with salad or seasonal vegetables.

North of Doncaster : *Personal comment from Trevor Wainwright*
The Castleford Airedale Local Covid Food Bank

Well, this issues article could have been about Texas post lockdown had things gone to plan with the lifting of the travel ban to America and could have included my first ever visit to Texas for Thanksgiving. Things looked really great; some of my work had been read out at an event in Midland College West Texas in September where it had hoped the ban would have been lifted and the event billed as "The UK's Trev the Road Poet and The Permian Basin Poets present Summer Rhymers." Not wanting me to feel left out I was asked if someone could read my poetry, normally I would say '**no'** due to previous bad experiences, but there was something in the request that said, let it be done so I let them be read, and the people were impressed. So much so that they offered me an open invitation, meaning I just had to give them notice and they would arrange something for when I got there, there would be other regular open mic's plus I would again be able to volunteer at Austin Wildlife Rescue.



Then came the news that the (Covid) ban was to be lifted on the 8th of November, so plans were made to get my Covid test on the 8th, clearance on the 9th and fly out on the 10th, arriving back on Dec 12th. But first things first, I needed my ESTA, a 2 year travel permit that allows visits of up to 90 days at a time. On Monday October 25th and before setting out on my food bank deliveries I decided to apply for it so off my application went and then so did I on my round.

Trevor reciting at the Event in Bradford where his fee went to the Food Bank

Loaded and away, at my second delivery I noticed a slight twinge to the left of my lower back, thinking I could work it off I carried on, what a mistake that was a few more deliveries and that was it, total agony, so I called it a day. I ended up taking 2 weeks off hoping it would heal and I could maybe go out later, the symptoms persisted though, I did get back to the food bank and tried various therapies and treatment all to no avail. A Physiotherapist said I had tight hamstrings which could have contributed to the problem, she gave me some exercises to try, so the next plan was to go out in February come back for March and go out again in April. Sadly, the exercises did not make it any better. When it looked like plan B was not going to come off, the doctor was consulted, various medications were tried none of which seemed to work fully so it was decided to send me for a scan, which at the time of authoring this article I am still waiting to be called for. Although I was still able to work at the food bank in a limited capacity, various other events such as open mics online or live were put on hold as I have been unable to drive or sit for extended periods. This has meant no travelling for a while, even missing out on visiting parts of my beloved Yorkshire

What about the food bank, and what is involved?

The food bank itself started on 17th September, my co-worker Kath and I met when working for Castleford Isolation Support since March 2020. My first parcel for them was on March 27th, the day I should have been flying out to Texas for my 2020 tour. When it closed, Kath saw the need for the food bank in Airedale, Castleford, and asked if I would like to join her, initially working out of a community centre, often taking parcels home on a weekend in case they were needed in an emergency, eventually the council provided us with a unit at a local business park along with another unit for the baby and children's bank section. Things really took off, we developed a reputation for good service as the number of parcels delivered daily rose to double figures at times. Sadly many thought we would be a soft touch and tried to rip us off, they were soon caught out and put on our blacklist, leaving more for the needy not the greedy. On the plus side it did bring us in more support, we were one of the few food banks that stayed independent not paying into any franchise, preferring to spend the money on much needed food for the vulnerable, rather than have the pockets of some CEO on a 5 or 6 figure salary, while none of us get paid, not even petrol money.

So, what does a food parcel consist of, a basic one for 1 - 2 people. Usually it is two carrier bags one containing UHT milk, tea, tinned beans, tomatoes, spaghetti, peas, sweet corn, soup, meat, fish, also tinned carrots and potatoes when there is no fresh available. The second contains cereal, dried pasta, passata, tinned rice, jam, biscuits, cheese butter and anything we may have a surplus of. More of each item can be added for bigger families.

Entering the food bank, there are more shelves to the left and right, the two boxes under the table are for large families

How does the Food Bank Work

The client contacts a referral agency, who then ascertain how many will it be for, name address and contact number, forward us the details, we pack contact and deliver. Sadly, though some try to contact more than one agency, but we are ready for them, and onto the blacklist they go. Since starting we have delivered over 6,500 parcels plus baby parcels, often at times working 7 days a week, maybe not as many as the city food banks who get all the publicity, but equally as important and all thanks to both corporate and public support. But the abiding question seems to be “how long will we be needed,” and when will my back heal so I can get back on my travels, and do more, get back to full capability?

Packing area no.1, items for bag

Packing area 2 items for bag 2, this is an early photo, due to finance available sugar and toilet paper is now given out only on request

Our dedication was rewarded in 2021 when we were given two Mayoral Awards, one as individuals and one under the umbrella group Airedale Neighbourhood Management Board, both from different Mayors one of whom was an old school chum and in November came further recognition when we were voted Community Group of The Year in the annual Wakefield District Housing Love Where You Live Awards, which along with the trophy brought in prize money of £200, also I had been invited to read at a poetry event in Bradford, with a fee of £100, yes I accepted and the fee went to the food bank. Both events I attended with my back still bad, but I was determined to get to them.

Group Award Mayor Saya Thanks July 2021
Mayor Tracy Austin 2021 - 2022

Bags packed and loaded ready to go out, there will also be fresh vegetables added to them

In a small room other items we could supply if needed