Price £ 4.00 (Free to members)

Pathways

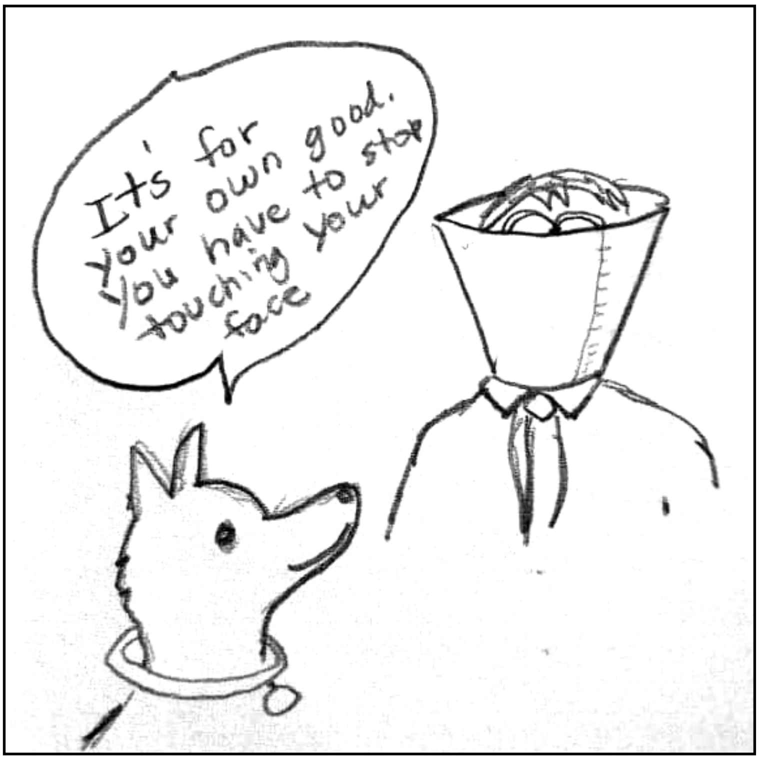
The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Welcome to Pathways No. 63. (Spring 2020)

Special Coronavirus Feature See page 19

Thurnscoe Park, Rotherham
Photograph taken mid March 2020

You write in



As the Covid 19 pandemic developed I sent bulletins around via Email and Facebook. I've e made them into feature later in this issue.

Michelle writes: Thank you for the update Mike - very helpful.

Trevor writes: Thanks for this Mike, informative and straight to the point how info should be

Dave Writes: Thank you for the advice regarding COVID 19. I agree with you entirely.

Just a funny thing I wanted to run past you in case anyone else has said something similar. My Partner lives in Sheffield and works in Barnsley although predominantly lives with me in effect. She caught a virus in late December that was a dry cough and a fever it only affected her for a few days.

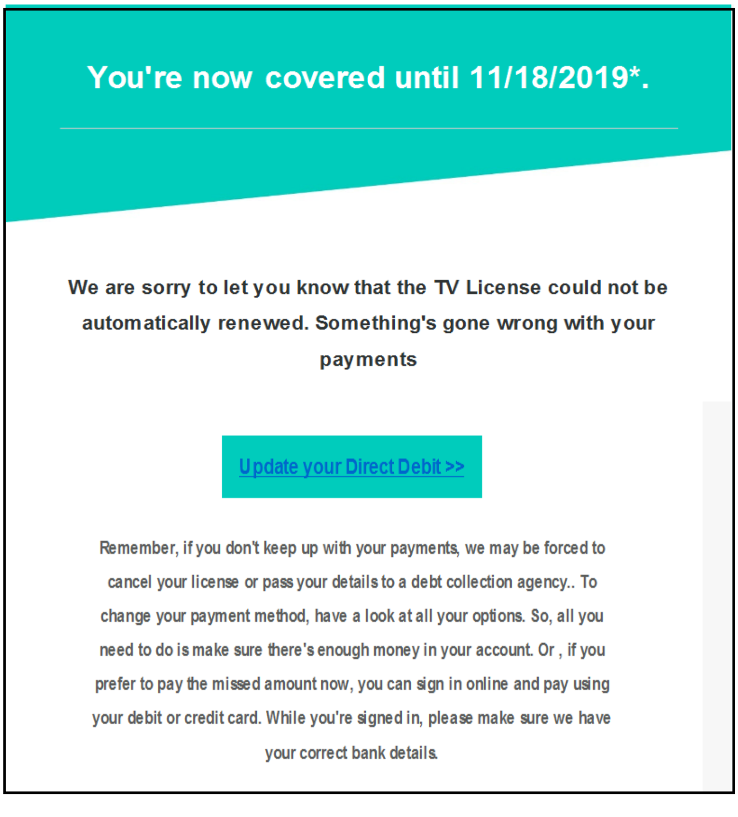
Around 7 days later I developed a fever and the worst nonproductive cough I have ever had. After a few days it went to my chest and I was coughing up some phlegm. I called the Duty Doctor who appeared in a car a very short time later. He heard my cough and prescribed Antibiotics. He said if it didn't improve to see my GP. After 7 days I saw my GP in Mid-January I was prescribed a further course of Antibiotics. By now I was struggling to breathe especially at night and my test was tight and they thought I had Pneumonia. This second course of Antibiotics failed to work as well. So, in the third week of January I was prescribed a different Antibiotic and sent to DRI for an Xray. I struggled on and the virus cleared although my sinuses still feel blocked. I cannot stop myself thinking the virus I had was strikingly similar to COVID19. My partner was only mildly affected yet me with ME was severely affected by it. I just wondered if you had heard of anyone else who had a bad viral infection in January.

I've not come across anything like it this year. It's either antibiotic resistance or a viral infection. It's impossible to say and can't be proved one way or the other. You may have a chronic problem with your sinuses being infected. If antibiotics don't work, you can have them surgically cleaned out at hospital. You really need to discuss this with your doctor.

Have you had your Vit D levels checked by your Doctor? Low levels of D3 are associated with onset of neurological disease, increased fatigue and pain in people like us.

John Writes: I've received a strange email about my TV license. I have renewed it at the post office several months ago. It doesn't look right, so I've ignored it. Is it something I've received in mistake or is there another problem. ?

This is definately a phishing email. The date is in the American format. If you clicked on the Direct Debit button it would take you to another website to try and get your bank account details. With the information gained they would empty your bank account. Best place for this is the recycle bin.


You're now covered until 11/18/2019*.

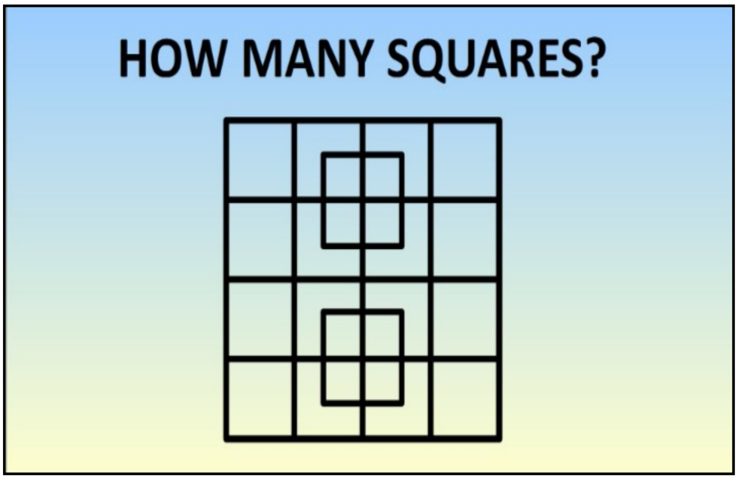
We are sorry to let you know that the TV License could not be automatically renewed. Something's gone wrong with your payments

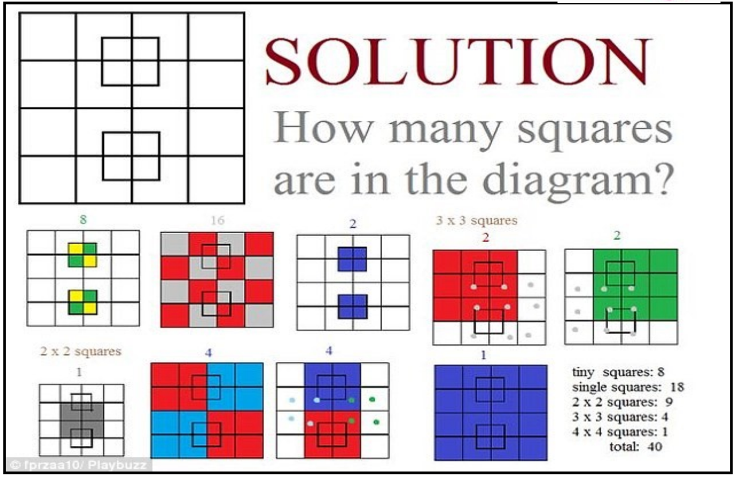
Update your Direct Debit >>

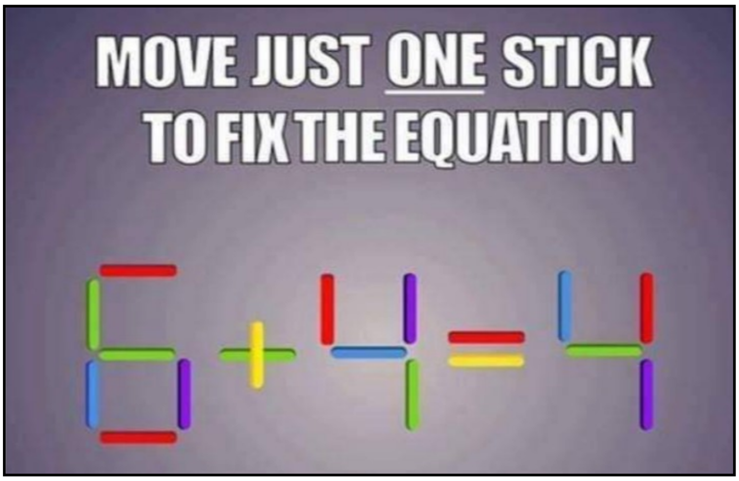
Remember, if you don't keep up with your payments, we may be forced to cancel your license or pass your details to a debt collection agency.. To change your payment method, have a look at all your options. So, all you need to do is make sure there's enough money in your account. Or , if you prefer to pay the missed amount now, you can sign in online and pay using your debit or credit card. While you're signed in, please make sure we have your correct bank details.

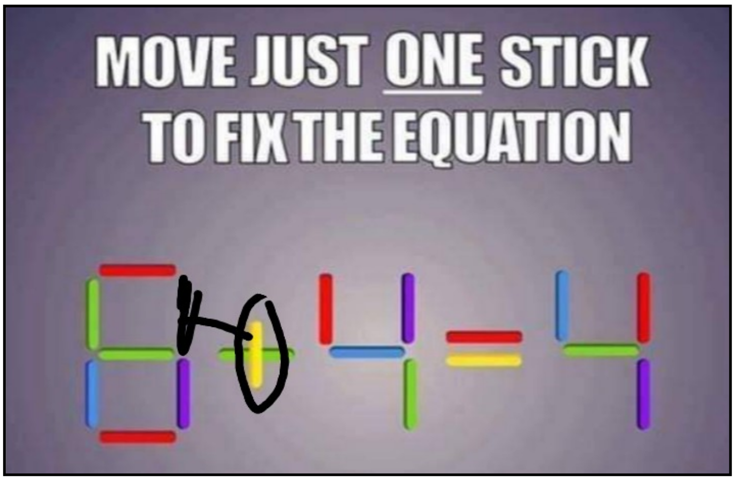
Puzzle Corner *By Nichola Stockton*

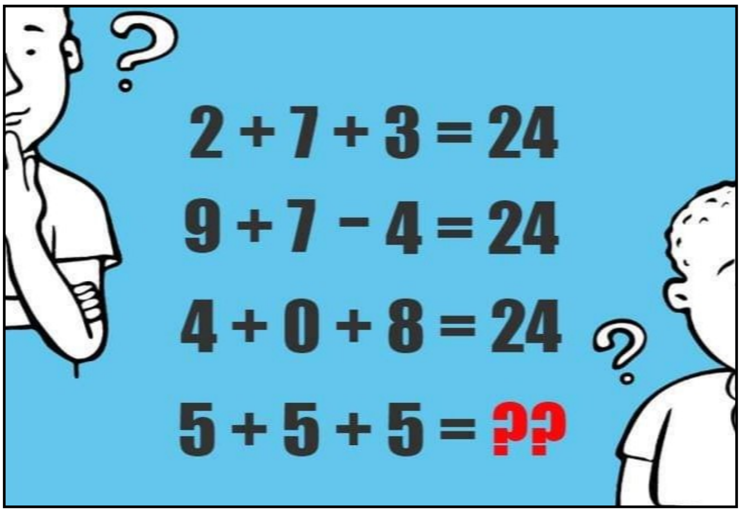
I hope you enjoyed the puzzles in the last issue. Here are the solutions











Here's the explanation for the last puzzle.

2 + 7 + 3 =12.   Double it gives 24
9 + 7 - 4 = 12.   Double it gives 24
4 + 0 + 8 = 12. Double it gives 24

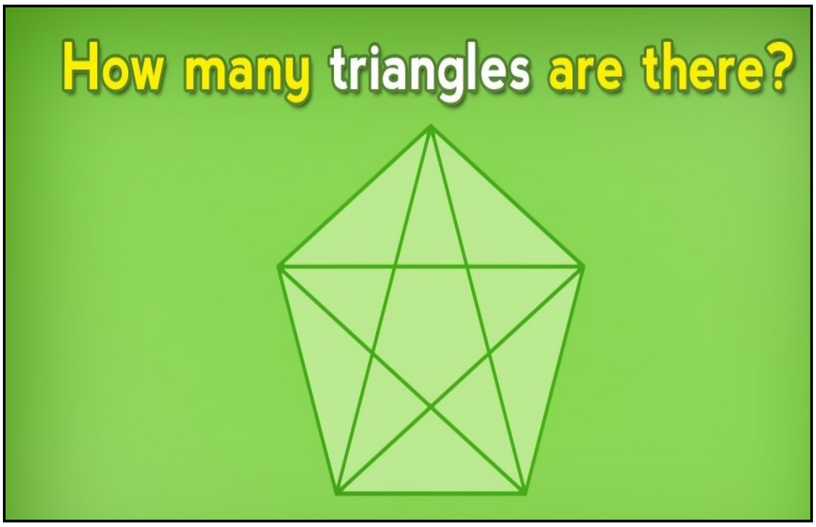
So 5 + 5 + 5 = 15.
Double it gives <u>30</u>!

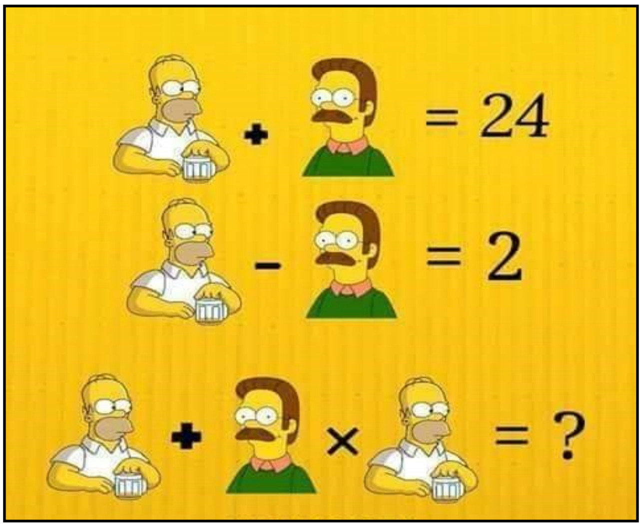
Nature Bits

by Paul Goodman.

This is what my bedraggled resident robin has been up to for the past few days.

Raising a family certainly does require at lot of hard work..





Word Search

D T E X E V A G S H R R H X I Y U Q G U B X X A G S E Q O P
W B S U P J Y K C R S F G E H V Z V E A Z E O J L O V C X L
E X R I O A F B K C S Z M W O S L G R D Y Q A J A K F Q H Y
A W J C D B Q J R Q T S U X H I K O D U Z W F G T P V T K H
T N M Z R U Z K Z H I X C E G E O P O L L I W O G H R D P J
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E S H V C A Z S U G B B V Y S B O F L O W E R S B X H G L S
R T P C X B O Q S M K W I H C B R C M D C A R A B B I T Y C
D Z Y L H Y Q C P S B B A N J T M M W E U P F Z Q T H Y E R
A V I O A A Z W R Y S R M C H G N I U A B U T T E R F L Y O
D I S C S N M R S B E B E U A W R D F F X T H X S A I J G C
F F P K Z I H Q Z C S E D L P E A S T E R R W H L B I Y J U
X T R S S M Y R W E V P O X L Y H N H F Y M W G J R E M N S
F H O C K A O L R S N G R R G A H Y X P R R Z N N E G H O Z
D A U H R L N K F Y A X X I Y V Y Q A Q M K R W S Z G U X M
H W T A O S P C M H A V E C N Z L R Y C S G U G B W S B A A
B Y M N C H W U S C M A R C H G B G V E I V X F G U P X I A
V K A G N H U R Q X M Q R V T S C K B U N N Y G B R L R N Z
R J F E A G I J B B J J A M X H M L S X T O T D H Y O B I E
T T E S L R H C B E Y G I N W O Z Y E R X C K H G A F Q S Z
O L Q R B O G V K V O S N L P W F T L A J X T O U F T B D Y
X E R A N W B G Z K Z Q B H T E X P D Y N Q D U V K O Y W I
S G P B D V D M O S F U O E G R P L D P Q I I W Q Y Y R O T
F E C Y R F G F Y U T I W T M S V R P I G V N T X S H B B Z
Q Y L K C X V O L N T L E V I U I D O R P X A G Z K X J E J
W Z I G K V D S D S F Q K I L E U P U D D L E S S C O N G F
S J M W Z S X C V H X D A F F O D I L F T L A G R F D R M A
Z H B I I X V O T I N B L O S S O M U T J Y G I M F R N I H
D Y D Q X B W X S N T D U D U N S T U L I P O C X M A Q O B
H A F L R U C N P E N R P S D C F O N N H A S N O W D R O P

Spring Cleaning
Hyacinth
Daffodil
Puddles
Rabbit
Sprout
Bulbs
Eggs

Clocks Change
Umbrella
Polliwog
Blossom
Easter
Chick
Tulip
Thaw

Baby animals
Sunshine
Showers
Flowers
March
Hatch
April

Butterfly
Snowdrop
Rainbow
Weather
Crocus
Bunny
Grow

Out and About around Doncaster: Roche Abbey

Roche Abbey is a now-ruined abbey in the civil parish of Maltby, South Yorkshire, England. It is in the valley of Maltby Dyke (known locally as Maltby Beck) and is administered by English Heritage. It is a scheduled monument and Grade II* listed in the National Register of Historic Parks and Gardens.

Early history

The abbey was founded in 1147 when the stone buildings were raised on the north side of the beck. The co-founders of Roche were Richard de Busli, likely the great-nephew of the first Roger de Busli, the Norman magnate builder of Tickhill Castle, and Richard FitzTurgis. When the monks first arrived in South Yorkshire from Newminster Abbey in Northumberland, they chose the most suitable side of the stream that runs through the valley to build their new Cistercian monastery. Twenty-five years later, at the end of the century, the Norman Gothic great church, dedicated to the Virgin Mary, had been finished, as well as most of the other buildings. The control of the abbey was vested in the de Vesci family, lords of Rotherham, who in turn sub feuded the land to Richard FitzTurgis, Lord of Wickersley (and who took Wickersley as his surname).

From the start, the Abbey of Roche, built for the so-called White Monks, as the Cistercians were known, had an almost otherworldly air. It was, after all, built at the northern end of an area once covered by Sherwood Forest, and it was said that Robin Hood went to Mass here. (A diocesan pilgrimage is still made today on Trinity Sunday.). At its height it supported a community of around 175 men, of whom about 60 were choir monks, the remainder being lay brothers, a Cistercian innovation.

Eventually, on the death of co-founder FitzTurgis, control of the abbey passed to his son Roger, now 'de Wickersley', and then eventually to a granddaughter Constantia, who married William de Livet (Levett), a family of Norman origin who were lords of the nearby village of Hooton Levitt. The abbey continued in the Levett family until 1377, when John Levett sold his rights in the abbey to the London merchant Richard Barry. By the time of the dissolution full control of Roche Abbey was held by Henry Clifford, 2nd Earl of Cumberland, who came in for numerous grants at the Dissolution as he was married to the niece of King Henry VIII.

An ariel view of the site thanks to English Heritage.

The Roche Abbey records have been either lost or destroyed, so there are no accounts of the abbey's activities, other than that there were 14 monks and an unknown number of novices at the time of the dissolution by Henry VIII on 23rd June,1538. It was this that lead to the abbey being reduced to ruins, although the surviving parts of the walls of the north and south transepts are still impressive. The local community at time of the dissolution decided they had first right of claim on Roche Abbey and its possessions. A very detailed account exists citing the terrible destruction of the abbey and its valuable artefacts. Timber, lead and stone were also removed in vast quantities.

Above and below The main transept ruins. Photographed by Carolyn on a recent visit

The chronicle of the despoliation was written by Michael Sherbrook, a priest and rector of nearby Wickersley who watched the pillaging. "For the church was the first thing that was spoiled; then the abbot's lodging, the dormitory and refectory, with the cloister and all the buildings around, within the abbey walls," wrote Sherbrook in his eyewitness account. "For nothing was spared except the ox-houses and swinecoates and other such houses or offices that stood outside the walls – these had greater favour shown to them than the church itself."

"This was done on the instruction of [Thomas] Cromwell, as Fox reports in his Book of Acts and Monuments", wrote Sherbrook in his remarkable account. "It would have pitied any heart to see the tearing up of the lead, the plucking up of boards and throwing down of the rafters. And when the lead was torn off and cast down into the church and the tombs in the church were all broken (for in most abbeys various noblemen and women were buried, and in some kings, but their tombs were no more regarded than those of lesser persons, for to what end should they stand when the church over them was not spared for their cause) and all things of value were spoiled, plucked away or utterly defaced, those who cast the lead into fodders plucked up all the seats in the choir where the monks sat when they said service."

"These seats were like the seats in minsters; they were burned, and the lead melted, although there was plenty of wood nearby, for the abbey stood among the woods and the rocks of stone," continued Sherbrook. "Pewter vessels were stolen away and hidden in the rocks, and it seemed that every person was intent upon filching and spoiling what he could. Even those who had been content to permit the monks' worship and do great reverence at their matins, masses and services two days previously were no less happy to pilfer, which is strange, that they could one day think it to be the house of God and the next the house of the Devil – or else they would not have been so ready to have spoiled it.

Left in ruin, the land passed through many private hands until the 4th Earl of Scarborough decided it needed revitalising to enhance his adjoining family seat at Sandbeck Park. Lord Scarborough enlisted the talents of Capability Brown. With an astonishing disregard for history, Brown demolished buildings, built large earth mounds and turfed the whole site. Until the end of the 19th century Roche Abbey remained buried beneath Brown's work and wooded parkland. But subsequent excavation in the 1920s returned Roche to its former splendour.

The abbey today

The site is now in the care of English Heritage. The cliff path walk provides access to a view across the abbey grounds where its layout can be appreciated. Many of the buildings are low-standing but the walls of the church still stand to full height and the gothic French idealism thrust into its design and architecture is visible. Later additions to the buildings included a kitchen area and abbot's quarters, built on the other side of the beck and accessed by a bridge which still stands. The monks' latrines were over Maltby Beck, so the running water took away the waste. The stream was dammed higher up to ensure fast-flowing water: quite a modern facility for the 13th century. There are several local legends concerning ghosts, tunnels to other buildings, and even a lost wishing well.

The ruins of the gate house

We have visited Roche Abbey on several occasion recently. Access is 1½ miles south of Maltby off the A634 via a narrow farm track. There is parking for about 10 cars and is about 250 yards from the admissions path on a rough path. Alternative parking available for disabled visitors beside admission point. For the purpose of satnav, the postcode is S66 8NW. There is no easy access for pedestrians.

There is a shop selling a selection of English Heritage gifts and themed souvenirs. It also sells drinks and snacks. There is a vending machine selling hot drinks. The shop sells a selection of snacks including crisps, cold drinks and confectionery. There are information boards describing the site and abbey in the shop. There are also male, female and disabled toilets. There is no picnic area, but you are welcome to bring a picnic to eat in the grounds, which have lovely views over the abbey ruins. There several benches are around the site - although not picnic benches. Wheelchairs access is possible if you have a robust wheelchair.

Overall conclusion—Well worth a visit.

A Word of Caution

A beck runs trough the site. This is unfenced and is in a deep gully six to ten feet deep. So any disabled persons, small children or dogs could easily fall into the fast flowing was. Roo, our dog fell in on our last visit and was rescued by one of the security guards. We later found he had become blind.

Sheffield ME/CFS Clinic News: Conference Update

There is a plan for changes within the CFS/ME Service for South Yorkshire and North Derbyshire following the ‘Shaping the way forward together’ event on 9th October 2019

Additional support

In response to the concerns related to individuals feeling unsupported at various points in the CFS/ME pathway the service is introducing:

- An extended open appointment following active treatment from 6 months to 12 months during which time individuals can contact the service for further support.
- Access to bookable, 15-minute, telephone support calls during the waiting time for therapy the 12 months open appointment.
- an additional 12 months beyond the open appointment.
- Three drop-in sessions per year facilitated by the clinical team and held at the CFS/ME clinic.
- A ‘discharge pack’ including links to relevant services and helpful information leaflets.

Communications

In response to feedback that the service needs to improve the clarity of all communications to minimise misinterpretation of key information, we plan to:

- Offer the option of contact with the service by email and / or hard copy for all communications.
- Adapt the flow chart we reviewed at the event to show a clear overview of the pathway through the service and any likely timescales / waits.
- Review and simplify the information that is currently sent out by the service

Review Panel

The Service has already had interest shown from individuals wanting to be involved in setting up a review panel of service users, support group representatives and clinicians to be involved with:

- Developing and / or reviewing the information highlighted in bold overleaf and below.
- Meeting twice a year to keep abreast of local, regional and national developments.
- This will include reviewing the outcome measures from the Service and sharing data to create a clearer overview of the range of experiences for people with CFS/ME.
- This can then be used to provide more detailed information for service users, providers and commissioners across the region.

Attitude of others

There are also valid concerns from service users regarding dismissive attitudes to CFS/ME across primary and secondary services, and about the recommendation of particular interventions without understanding or awareness of the potential impact on CFS/ME symptoms.

Suggestions from the attendees at the event included:

- Educating medical students and GPs about CFS/ME (the service already does this but only to an extent due to limited capacity).
- Ensure there is accessible information about CFS/ME in GP surgeries
- Review the communication between the CFS/ME Service and GPs and explore how this can be made more helpful to service users.
- Create a flow chart to show what people should expect before accessing the service which could be helpful for GPs as well as service users.

Welfare right s Matters *by Steve Donnison with thanks to benefit and work*

Last month's statistics from the DWP and the Tribunals Service are full of percentages that matter enormously if you are a claimant. It desperately matters, for example, whether you are one of the almost 50% of DLA to PIP claimants who have so far had their benefits stopped or reduced.
Or one of the 70% of new PIP claimants who did not get any award at all.
Or, if you did get a PIP award, you were one of the 71% whose award lasts two years or less
More happily, you could be one of the nearly 60% of new ESA claimants who are put in the support group.
And, even more happily, you may be one of the over 75% of PIP and ESA claimants who are now winning their appeals. Ending the flood of statistics, we also have news of small changes to the appeals process which are part of a much larger plan to get almost everything online.
And finally, we reveal that the fight for justice for Jodey Whiting isn't over yet.

A***LMOST HALF OF DLA TO PIP CLAIMANTS HAVE BENEFIT STOPPED OR REDUCED***

Up to October 2019, a lucky 39% of claimants have had their benefit increased when they moved from DLA to PIP. But set against that is the fact that 25% have lost their entire award on being moved.
And a further 22% have had their benefit reduced but not stopped altogether.

In total, up to October 2019, those percentages mean that 657,000 individual claimants have had to cope with the misery and distress of a sudden, and often dramatic, drop in income.
Claimants most likely to have their awarded stopped are those with mental health conditions such as anxiety and depression, where 40% have had their award stopped and 13% have had it decreased.
But claimants with any condition can find themselves losing out. 16% of claimants with arthritis, for example, lost their award altogether and 35% have had it reduced. The DWP would like you to believe that the massive changes in who gets an award, and at what rate, is based on a more accurate assessment system. The reality is that it is founded on a randomly altered set of criteria whose only aim is to reduce the benefits bill, regardless of the effect on individual claimants' lives.

FEWER THAN ONE IN THREE PIP CLAIMS SUCCEED

Meanwhile, the success rate for new pip claims continues to plummet.
Only 30% of new claimants got an award in October 2019, down from an average of 42% since PIP was introduced. In the last three months for which figures are available, the award rates for all new claims, excluding terminal illness, has fallen dramatically:

August 2019 37%
September 2019 32%
October 2019 30%

There has been no explanation from the DWP as to why this is happening.

MOST NEW PIP AWARDS LAST LESS THAN TWO YEARS

Another aspect of PIP that is causing concern is the brief nature of many awards.
71% of new PIP claimants were given an award lasting only up to two years in October 2019.
Again, it is claimants with mental health conditions who are most likely to get the worst deal.
The government has said it intends to double the length of the minimum PIP award, from 9 to 18 months, but this may not reduce the number of awards that last two years or less.

ALMOST 6 OUT OF 10 NEW ESA CLAIMANTS PUT IN SUPPORT GROUP

On a happier note, the latest DWP statistics show that, for the quarter to June 2019, 58% of new ESA claimants were placed in the support group, This is an increase of 5% on the previous quarter.

17% were placed in the work-related activity group (WRAG), down 4% on the previous quarter.
26% were found fit for work, unchanged from the previous quarter.
For repeat ESA assessments:
80% were placed in the Support group
13% were place in the WRAG
6% were found fit for work.

ESA AND PIP APPEAL SUCCESS RATES RISE YET AGAIN

There's another piece of positive news for claimants and deeply shaming news for the DWP.
The success rates for PIP and ESA appeals are continuing to rise.
The success rate for claimants who appeal against a PIP decision now stands at a colossal 76%. The rate has risen by 1% every quarter since the beginning of 2018/19.

For ESA, the figure is even higher. The success rate has jumped 2% since the last quarter and now stands at 77%.
For DLA the success rate is 69%.
For UC the figure is 61%.

However, the DWP will take great comfort in the effectiveness of their campaign to cut the number of claimants who actually make it to an appeal.

Overall, the number of social security appeals has dropped by 22%, compared to the same quarter a year ago.

The most dramatic fall has been in ESA appeals, which have plunged by 54%. In part, this can be explained by the replacement of some ESA awards with UC.

But PIP appeal numbers have also fallen by 15%.

One thing we can be sure of: the fall is not due to an improvement in DWP decision making.

CHANGES IN APPEAL PROCESS

Staying with appeals, we have news of impending changes to the process as the Tribunals Service continues its race to digitise everything it can.
The current changes are small, but they are part of a programme that will lead to a very different appeal system over time.

Later this month a new paper appeals form, the SSCS1PE, will replace the current SSCS1 form for people who do not make use of the 'Appeal a decision online' service.

The layout of the new paper form will mirror the sequence of screens used in the online form. This will allow appeal forms to be bulk scanned and digitised by the Tribunals Service.

Current forms will still be accepted but will take longer to process. So, agencies with stocks of the old form might want to replace them as soon as the new form appears.

A new 'Manage Your Appeal' service is also due to go live soon. It will allow appellants not only to submit and track their appeal online, but also to carry out other actions that are currently only possible on paper. This will include submitting further evidence and withdrawing an appeal.

Please remember that if you have any DWP forms to fill out, you should be using the services of a welfare rights advisor.

The Benefits and Works guides are available to Leger ME members as part of the membership deal. They are in electronic format as they are frequently undated. Paper editions are available at printing cost. Please contact the office for further deals.

Benefits and Work
Guides you can trust

Chronic Fatigue Syndrome and Diet. Food Fact Sheet

With thanks to the British Dietetic Association

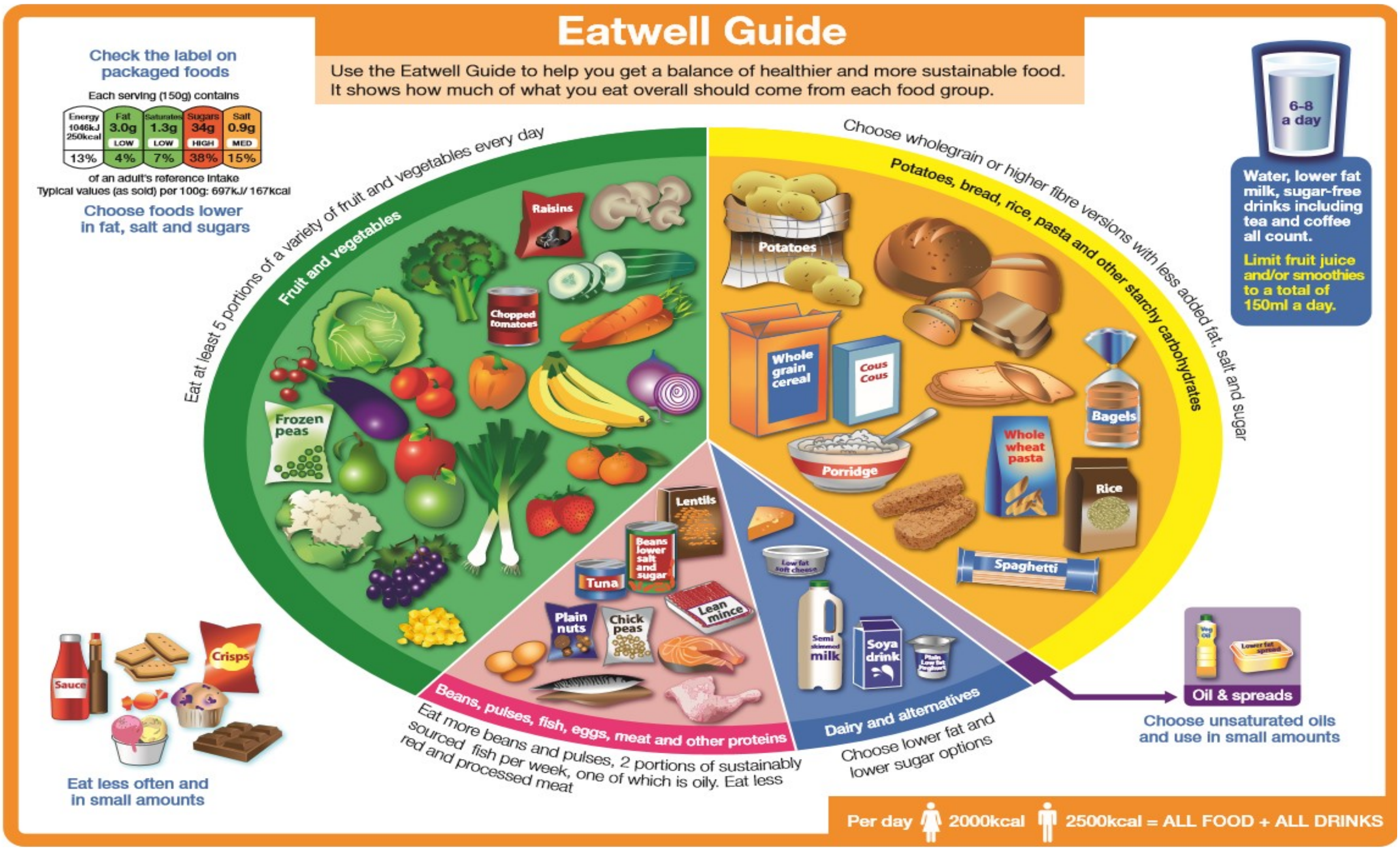
Chronic fatigue syndrome (CFS) is also called ME, which stands for myalgic encephalomyelitis, (or encephalopathy). CFS/ME affects both adults and children, and can be serious, causing long-term illness and disability.

What are the symptoms?

Symptoms include some, or all, of the following:

- constant, overwhelming mental and physical tiredness (exhaustion)
- sleep disturbance, un-refreshing sleep
- post-exertion malaise (feeling worse after exercise)
- muscle pain and/or weakness or joint pain
- headaches, poor concentration or poor memory recurring sore throats or 'flu-like' symptoms
- feeling sick, (nausea)
- symptoms of IBS (Irritable Bowel Syndrome), such as wind/bloating, stomach pain, diarrhoea and constipation
- intolerance, or sensitivity, to alcohol, caffeine, some foods or medications

CFS/ME is poorly understood, with no specific diagnostic test. Diagnosis is made by excluding other causes of the symptoms.



Eatwell Guide

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.

Check the label on packaged foods

Each serving (150g) contains

Energy	Fat	Saturates	Sugars	Salt
1046kJ 250kcal	3.0g LOW	1.3g LOW	34g HIGH	0.9g MED
13%	4%	7%	38%	15%

of an adult's reference intake
Typical values (as sold) per 100g: 697kJ/ 167kcal

Choose foods lower in fat, salt and sugars

Eat at least 5 portions of a variety of fruit and vegetables every day

Choose wholegrain or higher fibre versions with less added fat, salt and sugar

Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat

Choose lower fat and lower sugar options

Water, lower fat milk, sugar-free drinks including tea and coffee all count.

Limit fruit juice and/or smoothies to a total of 150ml a day.

Choose unsaturated oils and use in small amounts

Eat less often and in small amounts

Per day 2000kcal 2500kcal = ALL FOOD + ALL DRINKS

Can what I eat help CFS/ME?

Eating a variety of healthy foods is very important for your health and wellbeing. Although diet alone isn't the cause, or cure, of CFS/ME, a poorly balanced diet can compromise your health. Use the Eatwell guide to ensure your diet contains the best balance of foods from each group.

- **Potatoes, bread, rice, pasta and other cereals**, especially wholegrain provide fibre and energy. Try to include low GI (Glycaemic Index) foods, such as oats and wholegrains, which slowly release energy, helping to keep your energy levels stable. Eat a portion at every meal. If you are less active, because of your ME/CFS symptoms, you will use fewer calories, so choose healthier types over those high in added sugars and fats.
- **Fruit and vegetables.** Aim to eat more- 5+ portions a day.
- **Beans, pulses, fish, meat, and eggs.** These provide protein. Eat two portions a day. Eat more pulses and beans, and fish, and less processed meat, such as ham, sausages and burgers. Nuts also provide a nutritious snack, or addition to a salad or cereal.
- **Dairy and alternatives.** An important source of calcium for good bone health. This includes milk, cheese, yoghurts and calcium-enriched milk alternatives, such as soya-based products. Note: not all milk alternatives, particularly organic ones, are calcium enriched.
- **Fluid.** It is important to have a good fluid intake, 6-8 mugs / glasses per day is a good goal. Having too little fluid can lead to headaches, constipation and reduced alertness. Any type of fluid such as squash, juice, water, tea and coffee all count towards this

Eating a little and often may help your symptoms. For example, have three smaller meals daily, with the addition of three snacks in between.

Unwanted weight changes?

People with CFS/ME may put on weight because they are less physically active. They may also eat more, because of low mood, boredom, comfort eating, or wanting to boost energy levels. Some report feeling more hungry than usual, (polyphagia). To combat weight gain, keep higher calorie, fat and sugar foods, such as biscuits, chocolate, cake, crisps and sugary drinks to a minimum. Instead try vegetables and fruit or other healthy snacks.

Weight loss can occur because you are eating less. This may be because of a poor appetite, feeling sick, having altered taste and smell, or if exhaustion makes it difficult to buy, prepare or chew food. It will help to eat regularly, having small, softer texture, meals, quick and easy to prepare, and nourishing snacks and drinks.

If you are feeling sick, try snacking on dry, starchy foods, (such as toast/plain biscuits), eat little and often, and sip drinks throughout the day. Having something at breakfast may help.

Gut symptoms

IBS-type symptoms, such as wind/bloating, abdominal pain, diarrhoea and constipation are common in CFS/ME. For managing IBS-type symptoms refer to the BDA Food facts on IBS.

If you need further help, ask your doctor to refer you to a dietitian. They may suggest you trial a complex and challenging diet, which reduces short-chain fermentable carbohydrates, (also known as a low FODMAP diet). It is strongly recommended that this is done with the support of a dietitian.

What about gut bacteria (microbiome) and CFS?

There is a lot of research into the role of the gut microbiome and the gut lining, or membrane “leaky gut” in CFS. So far, the results are inconclusive, and it is too early to recommend a specific diet such as gluten-free. There is evidence that some probiotics can be useful for IBS.

Myths about CFS/ME and food

There is a lot of conflicting advice and information on the internet. Many people with CFS do report an improvement in symptoms after changing what they eat. Yet there is no scientific evidence to support the claims that such as the Anti-Candida (low sugar/yeast) diet, or other restrictive diets, like the Paleo/Stone-Age or Blood Type diets or eating chocolate help CFS. These are not recommended and can create much more work and effort for sufferers and their Carers. Although it is often thought to be better to avoid certain food types it can limit your choices, cost more and be less healthy. Many gluten-free foods, for example, are higher in fat and sugar. Many non-dairy milks are also lower in protein.

Food allergies and intolerances

CFS may affect or be affected by the immune system, but exactly how is unknown. However, CFS food related problems are more likely to be food intolerances, (not involving the immune system), than food allergies (immune system reaction). A detailed history by an experienced healthcare professional is required to diagnose and manage these. There are many commercially available tests claiming to diagnose food intolerance and allergy. These should be avoided as they have no scientific basis.

Are supplements helpful?

There are many claims that nutritional supplements help CFS, including multi vitamins, B vitamins, magnesium, essential fatty acids (omega-3s), carnitine, and co-enzyme Q10. Any benefit of supplements in CFS is unproven and there is need for further research in this area. Some are very expensive and contain huge doses of the active ingredient.

Large doses, for instance of Vitamin A and B6, can be harmful. If you are concerned about your nutritional intake, a multivitamin and mineral supplement, that provides no more than 100% of the recommended daily amount, (RDA - see the ingredients label), may be recommended. If you are housebound, or don’t go outside much, your doctor should check your vitamin D levels, as you are at risk of low Vitamin D status. *(Almost all Leger ME members find they have low vitamin D3 levels which when corrected reduces pain and fatigue –ED)*. A Vitamin D supplement of 10 Micrograms daily is recommended all year round for those at risk.

Summary

CFS is a medically unexplained illness, with many unproven claims of diet and supplement treatments. If making changes yourself to your diet, care needs to be taken that your diet remains healthy, nutritionally adequate, and that there is no unwanted weight loss/gain. If you need further help with your diet ask your doctor to refer to a registered dietitian.

References & Source(s) of Information

Although many other sources were consulted, and CFS/ME research was read, there is little research that actually provided good evidence for diet intervention or nutrition supplementation in CFS/ME. That is not to say that there is no role for diet, just that as yet there is no evidence to support or even define an appropriate evidence-based intervention.

Currently the best evidence-based advice is that of achieving a healthy diet and managing symptoms.

1. Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC, USA: National Academies Press; 2015.
2. NICE. Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (or encephalopathy): Diagnosis and Management of CFS/ME in Adults and Children (NICE guidelines CG53) London: 2007. p. CG53.
3. Carruthers BM, van de Sande MI, De Meirleir KL, et al. Myalgic encephalomyelitis: International Consensus Criteria. Journal of Internal Medicine. 2011;270(4):327-338. doi:10.1111/j.1365-2796.2011.02428.x.
4. BDA, Manual of Dietetic Practice 5th ed, 2014, Wiley and Sons, West Sussex
5. PHE 2016 Eatwell guide. Accessible atwww.gov.uk/government/publications/the-eatwell-guide
6. SACN. Carbohydrates and Health. 2015. London TSO. Accessed at:://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/445503/SACN_Carbohydrates_and_Health.pdf
7. National Institute for Health and Clinical Excellence (2008) CG61 Irritable bowel syndrome in adults: Diagnosis and management of irritable bowel syndrome in primary care. Updated Feb 2015 Available at://www.nice.org.uk/guidance/cg61
8. Lomer, M, McKenzie,Y et al (2010) The Dietetic Management of Irritable Bowel Syndrome in Adults, BDA Gastroenterology Group Clinical Guideline Birmingham: BDA
9. Campagnolo N, Johnston S, Collatz A, Staines D, Marshall-Gradisnik S. Dietary and nutrition interventions for the therapeutic treatment of chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review. Journal of Human Nutrition and Dietetics. 2017;30(3):247-259. doi:10.1111/jhn.12435.

Recipe Corner *by Ann Fisher (aka The Cake Lady)*

By popular request the secret is revealed. Here are the recipes for Ann's favourite cakes which she brings to group meetings from time to time.

Victoria Sponge Cake

Ingredients

All in one method:

3 eggs
6oz self raising flour
6oz margarine
6oz sugar
Level teaspoon baking powder
Half teaspoon either lemon or vanilla essence

Lemon curd for filling and icing sugar for top

Cooking Method.

Beat everything together and divide into two 7 inch lined tins. Bake for 25 to 35 mins at 180 C
The cake was a basic Victoria sponge filled with lemon curd and dusted with icing sugar.

Lemon Drizzle Cake

Ingredients

4oz margarine
1 cup sugar
2 eggs beaten
1 1/2 cups plain flour
1/2 cup milk
1 teaspoon baking powder
1/2 teaspoon salt
Grated lemon rind

Topping:
Juice of lemon
1/4 cup sugar

Cooking Method.

Cream together margarine sugar and eggs, add milk, flour, baking powder, lemon rind and salt, bake in a loaf tin180 C for one hour.

Remove loaf from oven and leave in the tin, mix lemon juice and sugar and pour over loaf, allow to stand 30 mins before turning out.

Enjoy!

Ann

CFS Checklist. *Abridged from Dr Myhill's Website*

Chronic fatigue syndrome is not a diagnosis - merely a group of symptoms which may have many causes. By the time someone has been ill for several years there are often several causes. The best results are obtained by identifying as many different causes as possible and tackling them all at once. Known disease processes must first be considered. By the time people come to see me they have already had a series of blood tests. If you have not had tests done recently, then I recommend doing the disease screening group of tests. I used to do things one at a time in order to see what does and does not work. I now do things the other way around - treat everything I think to be important, get the patient better, then relax the regime to end up with a balance between the patient's wellness and the toughness of the regime. Indeed, there is now good evidence that mitochondrial failure is not just a part of chronic fatigue syndrome – it is also part of the normal ageing process. What this means in practice is that as we get older we can stay just as fit and just as well but we have to work harder at it and become more disciplined with respect to diet, sleep, micronutrient supplements, the right balance between work and rest, detox regimes and so on..

The following is the programme of treatment I go through with every patient. If I try to cut corners, I often end up missing important problems. The patient who thinks about their illness and works out things for themselves has the best chance of getting better. I can point you in the right direction, but you have to do the donkey work! I suggest you print this checklist out and use it to find your way round the website! It lists the things I need to think of in the management of CFS. Don't go on to the next stage until the earlier ones have been fully explored.

Stage 1: Make sure it's CFS

1) **Is the diagnosis right** - has known pathology been excluded? e.g. Cancer, MS, autoimmune disorders.
2) The two symptoms which are common to every case of chronic fatigue syndrome/ME are **poor stamina and delayed fatigue.** These are explained by mitochondrial failure . Indeed, it is the delayed fatigue which should determine how much or little you can do in a day. If you get fatigue the next day, then you have overdone things and must pace more carefully. Actually, this is true for everybody – athletes who do not observe this rule develop overtraining syndrome and worsen their performance.
3) Have a careful think about what caused your CFS as this will give a guide to treatment. Think about the time building up to the start of the illness, what **the trigger was, which illnesses run in the family?**
4) **CFS is a diagnosis of exclusion.** Tests to exclude serious disease may be helpful, but even if they are all normal, you could still have other serious disease. The opinion of a good physician should always be taken to make the diagnosis. Recent onset of symptoms which may be worsening would suggest serious underlying disease.

Stage 2 - Observe six fundamental rules: This applies to all CFS sufferers:

1) **Pacing:** adopt the 80% rule (which means: know what you are capable of in a day and do just 80% of that. 20% is "getting better" energy), get enough mental and physical rest. Get organised. Accept help. Arrange for deliveries to house. Delegate work. Prioritise: list the 10 most important things in your life, then ignore the last five. You can't do everything.
2) **Sleep:** quality sleep is essential to life. Don't be afraid to use tablets to restore the normal day/night diurnal rhythm. Sleep disorders. Avoid caffeine after 4pm as it will interfere with sleep.
3) **Supplements:** it takes at least 6 months for body stores to replete. Supplements are for life. Everybody, regardless of whether they have chronic fatigue syndrome or not, should take a basic package of nutritional supplements. This is because Western agriculture has resulted in food which is deficient in essential micronutrients. We then have what I call the "bolt-on extras" for specific problems. For people with fatigue syndromes there is a package of supplements to support mitochondria which one can either take empirically or, ideally, do the mitochondrial function test first to define this further.
4) **Diet:** the two dietary problems most often linked to fatigue are a tendency to hypoglycaemia and allergy. The starting point is always the Ketogenic diet - the practical details which is of low glycaemic index and avoids the major allergens. A (not if pregnant), vitamin C, zinc, selenium and propolis
5) Do a **chemical clean** up: throw out all the smellies in your house, keep the house well ventilated, avoid sprays, polishes, aerosols, new paints, new carpets, gas cookers and heaters etc.

Stage 3: fighting and nurturing

The interventions below need to be done over and above all the interventions listed in Stage 2 above. At this stage you should consider having the Mitochondrial Function Profile and bring into your recovery plan the nutritional regime specifically designed to support your mitochondria. Some interventions work for a high proportion of sufferers (B12 injections, magnesium injections, D-ribose, Coenzyme Q 10 etc.). Do as many of these things at the same time as you can. By the time you have been ill for several years, more than one thing will be wrong - you need to tackle them all at the same time to see improvement. The priority is to get well. Once you are better, these things can be knocked off one at a time to find out which is important. The maneuvers to try, in order of importance, are:

1) Feed your **mitochondria**
2) Get **magnesium** levels checked
3) **Pain:** this too is just a symptom - try to work out the cause.
4) **B12 injections**: should be tried at some stage. Don't waste money measuring B12 levels, they are irrelevant. It is the response to injections which is important
5) **Correct hormonal disturbances**: adrenal gland dysfunction, hypothyroidism
6) Gut symptoms: getting gut symptoms right is central to getting the CFS right.
7) Care with female **sex hormones**. The Pill and HRT worsen CFS in the long term and certainly predispose you to getting CFS because they suppress the immune system and induce nutritional deficiencies.
8) **Low dose antidepressants**: many CFSs do well on tiny doses of tricyclic antidepressants such as amitriptyline 10mgs, dothiepin 10mgs, trimipramine 10mgs at night. In these doses I would not expect much effect on depression.
9) **Chronic low-grade undiagnosed infection**
10) **Hyperventilation** can cause fatigue. Often driven by food intolerance and low magnesium levels. Helped by relaxation techniques
11) **Chemical poisoning:** exposure at work to organophosphates (farmers), dog and cat flea treatments, human head lice treatments, Vapona fly blocks/sprays, woodworm treatments. Contaminated water. Any silicone implants - silicosis? Gulf War Syndrome? Chemical poisoning often leads on to MCS
12) MCS (**Multiple chemical sensitivity**) Suspect if symptoms are better out of doors, better in the summer, better away on holiday. Do chemical clean up. Eat organic where possible .

Stage 4: allergy

If you are still struggling despite having tried all the above, then it is likely your problems are caused by multiple allergy to foods, to chemicals or to moulds.
1) **Get moulds and allergy tested**: either by skin tests or by going abroad to a warm dry climate, ideally for one month, but two weeks may give you an idea. Make sure that the holiday house is chemically clean. I know it is not easy, but it is important It is also possible to have a mould sensitivity test done through Acumen Laboratories.
2) **Consider Desensitisation** such as neutralisation or my preferred technique (EPD) for foods and possibly chemicals. EPD does not work so well for moulds allergy.
3) **Consider Reprogramming the Immune System** – where conventional and complementary medicine can come together
4) **Consider Oral immunotherapy**: switching off food allergies using food.

Stage 5: New ideas.

One of the problems with CFS is that it is a quack's charter! It is important to look at new ideas and treatments, but not before all the known, and tried and tested, treatments have not succeeded. Especially the psychological treatments should not be considered until the physical issues have been sorted. here are some people who have benefited from the following:

1) **Imunovir** - again some patients have reported improvement, but it is too early to say if this is going to be useful.
2) **Gammaglobulin injections** - I am uncertain about these - they do help some patients, but they are derived from blood products and could theoretically transmit viruses and prions (BSE).
3) Consider **Hyperbaric oxygen** therapy (HBOT)

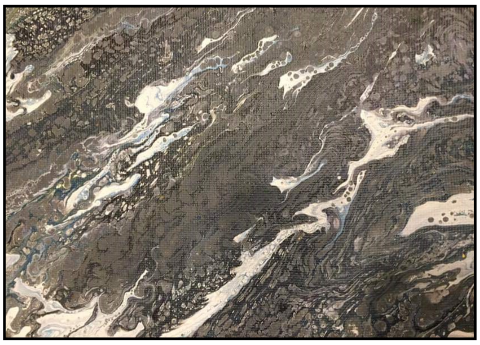
Crafty Corner
by Nicola Stockton

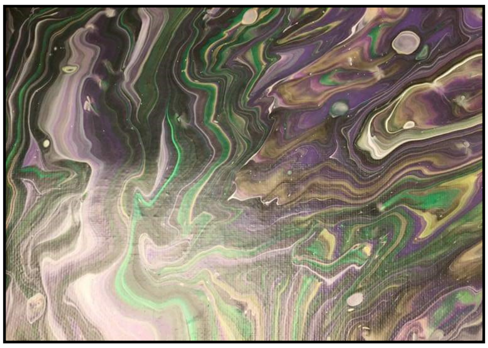
Here on the Leger ME Facebook pages we have launched 'Crafty Corner' where members can share what they've been making. There are several crafters in the group, all very different. Here's a selection for your perusal. It would help if you could imagine the music from Take Hart's Gallery as you look through them! :

Let's start with Vicky's flower arranging.

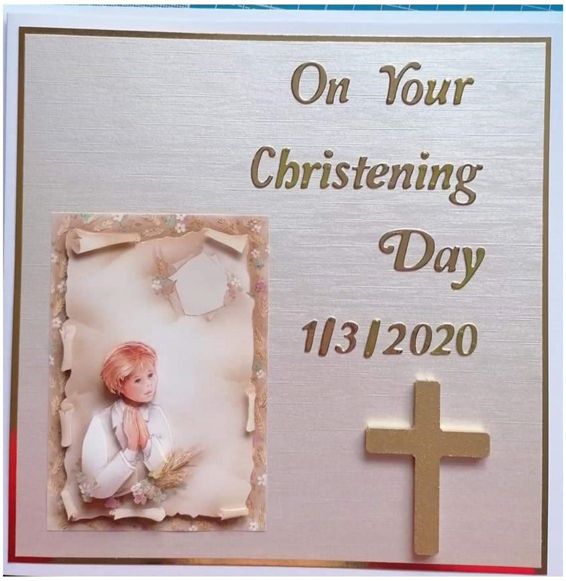
Then there's Claire and fabrics.

There is Ann’s oil film water art. This technique was formally used to provide security book edge page marking many years ago for account books and Legers





And finally, my papercraft.



If you have a hobby that you'd love to share then please join us on Facebook at Leger ME Community. *-Nicola*

Research Corner *With Thanks to Breakthrough and ME research UK*

Clinical trial results confirm rituximab has no clinical benefit in ME
Last year the disappointing news that preliminary results from the Norwegian randomised trial of rituximab were not showing any clinical benefit of the drug in people with ME/CFS. The final results of the trial have now been published in the Annals of Internal Medicine, and unfortunately confirm these initial indications. Rituximab is an antibody that attacks B-cells and has been used to treat some cancers and autoimmune disorders. Following promising results in patients with Me/CFS, a randomised, placebo-controlled trial of rituximab was started in 2014 at five centers in Norway. One hundred and fifty-one adult patients with ME/CFS (defined according to the Canadian consensus criteria) were treated with either rituximab or placebo over the course of a year and followed up for a further year.

A total of 26.0% of patients who received rituximab achieved a treatment response (defined as a slight, moderate or major improvement in symptoms), compared with 35.1% of those on placebo, and the difference between the treatment groups was not statistically significant There were also no group differences between the treatment groups in other outcomes such as self-reported function and physical activity. Rituximab has been one of the greatest hopes in recent years for an effective treatment for ME/CFS. But it remains to be seen exactly what this means for the drug as far as ME/CFS is concerned, and for our understanding of the pathophysiology of the illness.

The lead investigator, Dr Øystein Fluge, and his colleagues conclude that: “The lack of clinical effect of B-cell depletion in this trial weakens the case for an important role of B lymphocytes in ME/CFS but does not exclude an immunologic basis. “If this is the end of the road for rituximab, let us hope that it stimulates further research into other aspects of immunity in Me/CFS, like the studies we are currently funding in Vermont,Alabama, Newcastle, and Berlin.

Mitochondrial complex activity *Tomas et al., PeerJ, 2019*
The mitochondria are the power plants of the body, generating the energy needed to support life. Substantial evidence suggests that mitochondrial function is abnormal in people with ME/CFS, but what part of the energy production pathway is faulty? In a study from Newcastle University, Cara Tomas and colleagues looked at the activity of protein complexes within the mitochondria. These complexes are involved in the generation of a molecule called ATP, which is used to transport energy within the cell. Using a technique called extracellular flux analysis, the team found no differences in mitochondrial complex activity or respiratory activity between cells from patients and those from controls, and this was true in both white blood cells and skeletal muscle cells. These results suggest that the abnormality in energy production in ME/CFS lies upstream of this respiratory chain, and this agrees with previous findings from other groups

NO problem? New study looking at nitric oxide production in ME/CFS
The immune system is a hot topic in ME research, with many studies published or currently ongoing.
And we have recently awarded funding to Dr Francisco Westermeier and colleagues at the Institute of Biomedical Science, FH Joanneum University of Applied Sciences in Graz, Austria to explore immune abnormalities in ME/CFS.

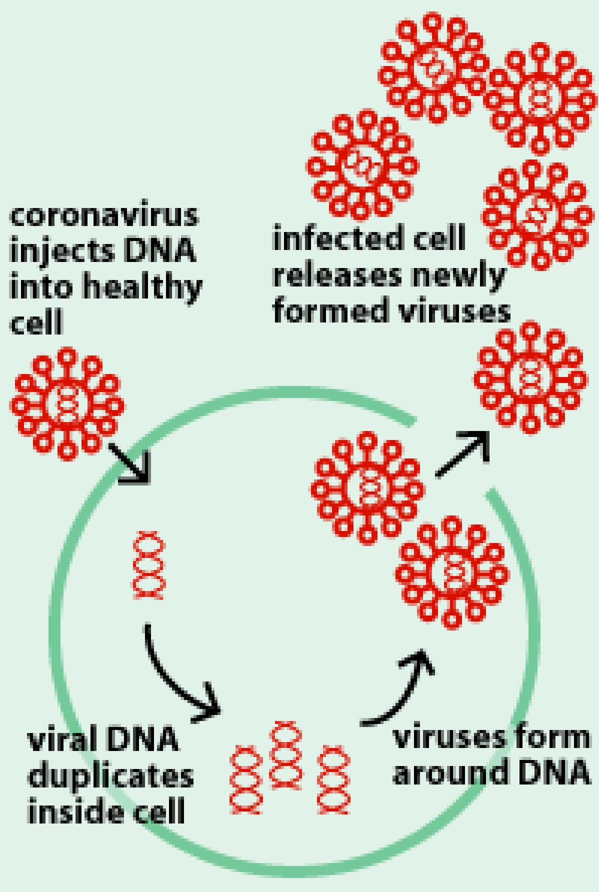
One consequence of an activated immune system is inflammation. This is part of the body’s defence mechanism – increased blood flow to an injured area, and an influx of immune cells into the tissue to repair damage. But sometimes inflammation can persist for longer than required, or be triggered unnecessarily, itself causing damage. Inflammation has been implicated in a number of cardiovascular conditions, specifically its impact on the function of the endothelium. This is a layer of cells lining every blood vessel involved in controlling their opening and closing, and hence the amount of blood flowing.

Some of the first research funded by us was conducted 20 years ago by a team at the University of Dundee looking at endothelial function in ME/CFS. One of the ways the endothelium controls blood flow is through the release of a chemical called nitric oxide (NO). But NO is a double-edged sword – while it is essential in normal endothelial function, too much can be damaging and lead to prolonged inflammation. Dr Westermeier is exploring this complicated relationship in more detail by looking at whether the cellular mechanisms that control NO production are altered in ME/CFS.

Using blood samples obtained from the UK ME/CFS Biobank, he will assess levels of NO and the proteins involved in its production. He will also investigate whether this is altered in endothelial cells exposed to ME/CFS blood samples. The researchers hope their findings will throw new light onto the role of these complex mechanisms in ME/CFS, and possibly identify new biomarkers. Dr Westermeier says that ME/CFS is “still poorly recognised in Austria, in part due to the lack of funding and research”. He hopes this project will also help raise awareness of the condition in his country.

The Coronavirus COVID-19 Pandemic

COVID-19 is a new illness that can affect your lungs and airways. It's caused by a virus called coronavirus. This particular virus is believed to have jumped species from wild animal, possibly a bat. The first cases were found China in late 2019. Since then many cases have been found worldwide, and it is quite clear at the time of writing that its impact will be worldwide. A virus is a homeless gene manifested as a capsules containing DNA. A virus particle enters a host cell, and hijacks it to produce more viruses. In theory, it only takes one successful virus to give someone the disease. As this is new virus to medical science, the is no vaccination as in the case of influenza. What seems to be quite clear is that it very infectious, the main method of transmission being droplets of water expelled by victims in coughing and sneezing. To infect someone the virus has need to contact a mucus membrane e.g. mouth, nose, eye or genitals.



The life-cycle of a coronavirus. The virus uses a healthy cell as a factory in which to replicate and form additional viruses, which in turn attack other cells. In the case of SARS, the virus tends to attack lung cells.

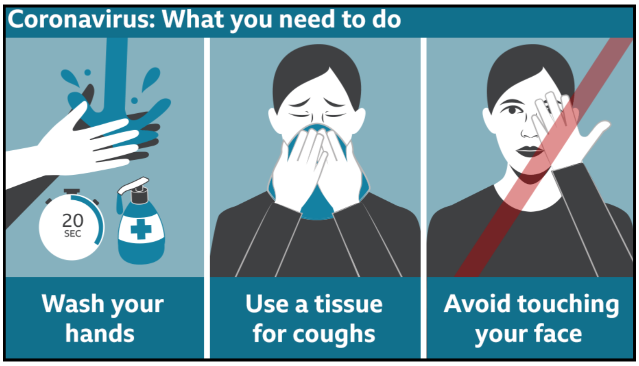
What are the symptoms of coronavirus infection?

- a cough
- a high temperature
- shortness of breath

These symptoms do not necessarily mean you have the illness. The symptoms are similar to other illnesses that are much more common, such as cold and flu.

How coronavirus is spread?

Because it's a new illness, it is not known exactly how coronavirus spreads from person to person. Similar viruses are spread in cough droplets. What seems to be quite clear is that it very infectious, the main method of transmission being droplets of water expelled by victims in coughing and sneezing. To infect someone the virus has need to contact a mucus membrane e.g. mouth, nose, eye or genitals. It's very unlikely it can be spread through things like packages or food.



Do I need to avoid public places?

Most people can continue to go to work, school and other public places. You only need to stay away from public places (self-isolate) if advised to by the 111 online coronavirus service or a medical professional.

How to avoid catching or spreading coronavirus?

Do

- wash your hands with soap and water often – do this for at least 20 seconds
- always wash your hands when you get home or into work
- use hand an alcohol sanitiser gel if soap and water are not available
- cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze
- put used tissues in the bin straight away and wash your hands afterwards
- try to avoid close contact with people who are unwell

Don't

- do not touch your eyes, nose or mouth if your hands are not clean

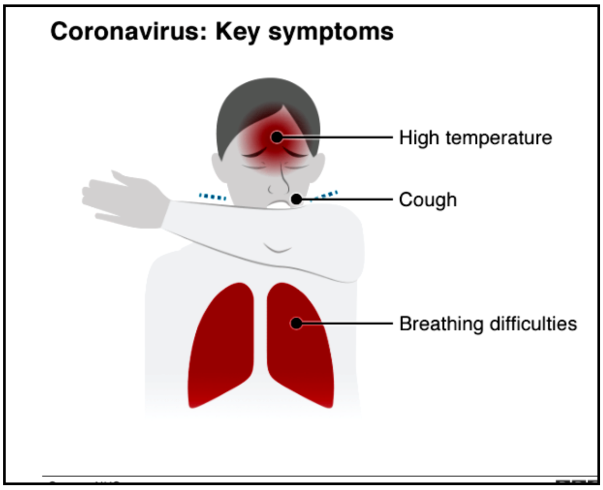
Coronavirus: What it does to the body *with thanks to the BBC & NHS*

Incubation period.

This is when the virus is establishing itself. Viruses work by getting inside the cells your body is made of and then hijacking them. The coronavirus, officially called Sars-CoV-2, can invade your body when you breathe it in (after someone coughs nearby) or you touch a contaminated surface and then your face. It first infects the cells lining your throat, airways and lungs and turns them into "coronavirus factories" that spew out huge numbers of new viruses that go on to infect yet more cells. At this early stage, you will not be sick and some people may never develop symptoms. The incubation period, the time between infection and first symptoms appearing, varies widely, but is five days on average.

Mild disease

This is all most people will experience. Covid-19 is a mild infection for eight out of 10 people who get it and the core symptoms are a fever and a cough. Body aches, sore throat and a headache are all possible, but not guaranteed. The fever, and generally feeling grotty, is a result of your immune system responding to the infection. It has recognised the virus as a hostile invader and signals to the rest of the body something is wrong by releasing chemicals called cytokines. These rally the immune system, but also cause the body aches, pain and fever. The coronavirus cough is initially a dry one (you're not bringing stuff up) and this is probably down to irritation of cells as they become infected by the virus. Some people will eventually start coughing up sputum - a thick mucus containing dead lung cells killed by the virus. These symptoms are treated with bed rest, plenty of fluids and paracetamol. You won't need specialist hospital care. This stage lasts about a week - at which point most recover because their immune system has fought off the virus. However, some will develop a more serious form of Covid-19. This is the best we understand at the moment about this stage, however, there are studies emerging that suggest the disease can cause more cold-like symptoms such as a runny nose too.



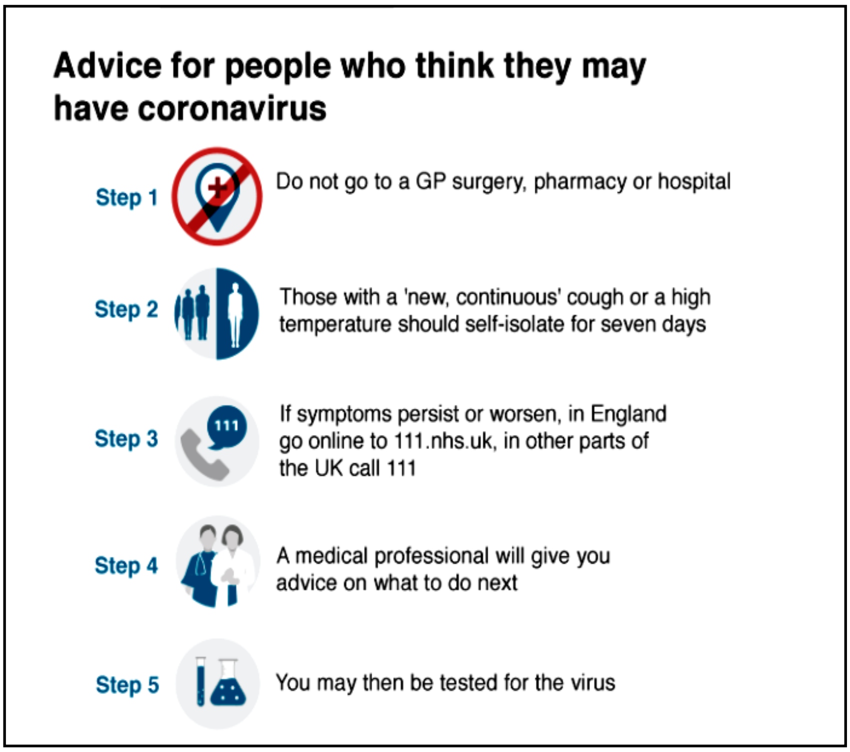
Coronavirus: Key symptoms

Severe disease

If the disease progresses it will be due to the immune system overreacting to the virus. Those chemical signals to the rest of the body cause inflammation, but this needs to be delicately balanced. Too much inflammation can cause collateral damage throughout the body. The virus is triggering an imbalance in the immune response, there's too much inflammation. How and why it is doing this is not known.

The first deaths

Doctors have described how some patients died despite their best efforts. The first two patients to die at Jinyintan Hospital in Wuhan, China, detailed in the Lancet Medical journal, were seemingly healthy, although they were long-term smokers and that would have weakened their lungs. The first, a 61-year-old man, had severe pneumonia by the time he arrived at hospital. He was in acute respiratory distress, and despite being put on a ventilator, his lungs failed and his heart stopped beating. He died 11 days after he was admitted. The second patient, a 69-year-old man, also had acute respiratory distress syndrome. He was attached to an ECMO machine but this wasn't enough. He died of severe pneumonia and septic shock when his blood pressure collapsed.



Advice for people who think they may have coronavirus

Step 1 Do not go to a GP surgery, pharmacy or hospital

Step 2 Those with a 'new, continuous' cough or a high temperature should self-isolate for seven days

Step 3 If symptoms persist or worsen, in England go online to 111.nhs.uk, in other parts of the UK call 111

Step 4 A medical professional will give you advice on what to do next

Step 5 You may then be tested for the virus

Dealing with the Coronavirus

What are the treatments for coronavirus?
There is currently no specific treatment for coronavirus. Antibiotics do not help, as they do not work against viruses. Treatment aims to relieve the symptoms while your body fights the illness. You'll need to stay in isolation away from other people until you've recovered. See the latest Government response and action plan.

What about people with pre existing health problems.
What seems to be happening is that with people in good health Covid 19 seems to cause a mild infection. However, in people with preexisting medical conditions like chest or cardiovascular disease, a weakened immune systems, or someone elderly things are more serious.

ME/CFS: For people with ME/CFS these are type groups. For those with a weakened immune system who seems to be prone to picking up infections, these people will be at a higher risk than those with an overactive immune system.
Asthma: For those with asthma and COPD , Asthma UK advises to Keep taking your preventer inhaler (usually brown) daily as prescribed. This will help cut your risk of an asthma attack being triggered by any respiratory virus, including coronavirus. Carry your blue reliever inhaler with you every day, in case you feel your asthma symptoms flaring up. If your asthma is getting worse and there is a risk you might have coronavirus, contact NHS 111. If you have been prescribed oral steroids like prednisolone for flair ups, please seek medical advice as soon as possible because steroids are immunosuppressive. Remember to keep a record of your peak flow meter readings as advised by your asthma nurse as these may give advanced warning of a potential problem.
Diabetes: For those with diabetes. either type 1 or type 2 diabetes you could be at greater risk of more severe symptoms. Dan Howarth, head of care at Diabetes UK, said: "Coronavirus or Covid-19 can cause complications in people with diabetes. "If you have diabetes and you have symptoms such as cough, high temperature and feeling short of breath, you need to monitor your blood sugar closely and call the NHS 111 phone service." If your BMs (blood sugar readings) are stable, and they suddenly rise without an explanation, this could be an early warning of an infection before symptoms show.

Use of face masks

Many news reports show people wearing face masks. The British Lung Foundation says: "We do not recommend using a face mask to protect yourself as there isn't enough evidence to show how effective they are. Also, for people living with a lung condition wearing a face mask can make breathing more difficult." However, a face mask will protect the lips and nose from being accidently touched by the hands and reduce cough and sneeze droplets.

Smokers.
Deborah Arnott, chief executive of public health charity, Ash, advises that those who smoke heavily should either cut back or try to quit entirely to lower their risk. "Smokers are more likely to get respiratory infections and twice as likely to develop pneumonia as non-smokers," she said. "Quitting smoking is good for your health in so many ways and smokers should see coronavirus as further motivation to give quitting a go to build up their body's defences now before coronavirus becomes widespread in the UK."

It is quite clear that the situation in the UK is developing, and further advice or restrictions may follow. It is important to watch the latest news bulletins or the NHS website to be up to date.

https://www.nhs.uk/conditions/coronavirus-covid-19/

How to self-isolate if you're asked to

If there's a chance you could have coronavirus, you may be asked to stay away from other people (self-isolate).

This means you should:
- stay at home
- not go to work, school or public places
- not use public transport or taxis
- ask friends, family members or delivery services to do errands for you
- try to avoid visitors to your home – it's OK for friends, family or delivery drivers to drop off food
- You may need to do this for up to 14 days to help reduce the possible spread of infection.

More on COVID 19

Tipping the balance in your favour.

In the last group meeting I covered the nutritional support of ME/CFS and allied conditions. Here are things you can do to optimise your health in such a way that if you got a coronavirus infection you would stand a better chance of dealing with it.

- **Magnesium.** According to Dr Myhill you lose magnesium if your body is stressed. It is important that you keep up your nutritional content of magnesium. All green plants contain magnesium. You can also insure against depletion with food supplements.
- **Zinc and Vitamin C.** There is research evidence that both along with other substances have a theoretical action which enhances the body's reaction against certain coronavirus. They are often sold together as cold treatment. If your diet is ideal, then you should not need these but again you can insure against depletion with food supplements.
- **Vitamin D3.** Almost every person I come across within Leger ME has vitamin D3 depletion. If you have not had is checked by your GP do so ASAP. It is a common finding among people with ME. You can buy supplements for vitamin insurance purposes. Vitamin D3 is found in fish oils and animal produce
- **Prioritise sleep and relaxation.** Sleep is the opportunity for our body to 'rest and repair' and is just as important as nutrition when looking to strengthen our immune system. Strikingly, research has shown that those with less than 7 hours sleep per night were up to 3x more likely to develop the common cold after experimental exposure to rhinovirus than those with more than or equal to 8 hours sleep per night. Therefore, aim for 8 hours or more uninterrupted sleep per night by any means you can. Given the anxiety that we are prone to feel when it comes to the current coronavirus outbreak, this recommendation could not be more important!
- **Sugar and Alcohol.** Watch your sugar and alcohol intake. Try to choose healthier alternatives, such as dark chocolate, nuts, and non-alcoholic drinks, since both can have a draining impact on our immunity.
- **Smoking** of any kind damages the body including the immune system. Why not make an effort to stop smoking? There is plenty of help and information around.
- **Get the pacing right.** Listen to your Body and react accordingly. With ME/CFS you'll know your limits and stick to them.

Useful Home Medical Instruments.

Clinical thermometers. The electronic versions are cheap and robust enough to enable anyone to get a reliable reading. The radiation type does not need to touch to get a reliable reading. People with ME often get a low temperature reading. With one of these instruments you can detect fever (reading > 37.8C) and at least be reassured and take the guesswork out of necessary actions.

Pulse oximeter. This is an oversize thimble that clips onto your figure end. It gives a heart rate reading and oxygen saturation reading. If the oxygen saturation falls being 90% for example, it is an indicator that something serious is wrong. There again it can provide reassurance or signal that action needs to be taken.

Blood Glucose meter. These are used by diabetics to monitor their diabetic treatment. An infection will cause the bloods sugar readings to rise abnormally hours before symptoms occur. So, any high reading needs to the investigated along with other indications.

Peak flow Meter. People with breathing problems such as COPD or Asthma use this sort of device to monitor their treatment. An unexpected low reading less than 300 could indicate a potential problem. Most people will have been given instructions by the special nurse about what action to take.

General hygiene. This is the key strategy to control the spread of the virus. It was believed that water droplets from coughs and sneezes was the main vector. There are now reports that indicate that virus is excreted via the front and back passages. When a toilet is flushed there is evidence that it produces an aerosol which is as contagious as coughing. So, an additional precaution is to keep the toilet lid down when flushing.

Dealing with the Pandemic.:

The Government Strategy Response

Although accurate at the time of writing, please check for current information before taking any action.

Containment phase

Aim - Prevent disease taking hold as long as possible

Trace and isolate first cases and close contacts

Establish expert team and ensure supply of key medicines

Delay phase

Aim - Slow spread of virus, with the following options:

Ask those with minor symptoms to self-isolate

Limit large gatherings

Encourage home working

Close schools

Mitigation phase

Aim - Ensure treatment for worst cases and minimise impact on society, with the following options:

Delay non-urgent care and employ retired medical staff

Instruct emergency services to cover critical functions only

Research - ongoing

Research to better understand the virus

Pool international knowledge

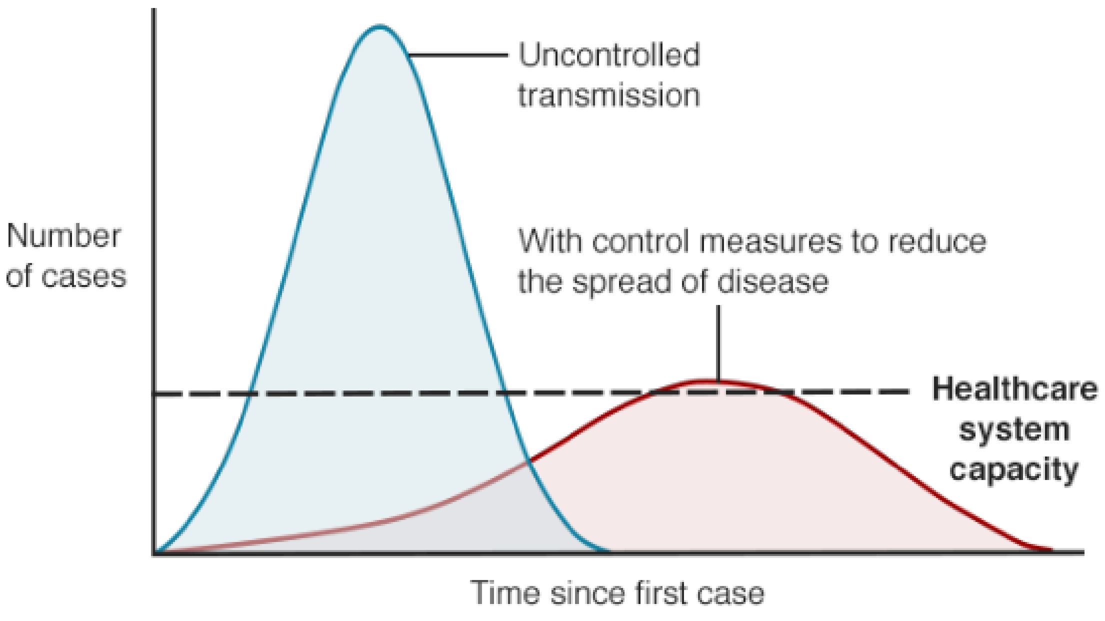
The Prime Ministers Statement.

One the 12th March 2020 at 5.00 pm after the COBRA meeting the Prime Minister stated,
“Many Families will lose loved ones.”

This a bleak and frank assessment and may have caused unnecessary anxiety with some people. However, this statement is out of context. Compare that to how many road deaths there are. Just think about the 1700 plus people killed every year, around five per day – yet no one blinks an eyelid, and people don’t stop going out or driving because of this.

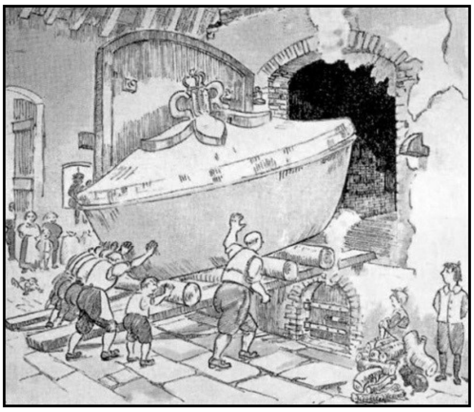
The government tactics are now to delay cases to such a level that the NHS could cope. If you like it’s a sort of rationing. However, many people who I’ve spoken to have reservations including myself in the way the matter is being handled. It doesn’t really give any guidance to individuals except ‘go forth and be ill’.
To ME’s, its sounds very familiar.

How an epidemic peak might be delayed and numbers reduced



North of Doncaster *by Trevor Wainwright:*

Yorkshire Pie



Well before Walkin' i' Barnsley was Yorkshire Pie, but not the one that is set in Leeds, the original was a musical mock of Madonna's version done for charity, chosen because of its length. It came about as a result of a chat during preparation for a joint ME/FMS joint fundraiser. One of the pubs I used to collect at had been taken over by a singing duo, their daughter who was taking singing lessons said she would sing if they paid her, I quipped they'd pay me to stop. So was hatched the plan, she would sing and the punters would put money on a tray, when she stopped it was counted but not disclosed as I was to sing and the total would have to be beaten to get me to stop. So I began singing in a Yorkshire accent as tone deaf as possible, (quite easy). It went down a storm people collapsing in their seats, acknowledged as one of my finest stunts. I'd just done the chorus when the shout went up "stop we've beaten it" between us we raised over £50 and something I'd never forget.

Following the success of Walkin' i' Barnsley, the memory of it came to the fore, there were some bits I could keep but it would have to be Yorkshireised. But where would I set it and I needed a background. I decided to change newspaper to Yorkshire Post, cried to roared then thought Leeds would be perfect, the structure of the King James Bible led to verse 2 and then as well as Yorkshire being a mining county, cricket seemed ideal for the final verse, and so eventually it became the poem it is today and goes down well. Certain parts can be adapted to certain people, which is part of its attraction. There are two ways of introducing it:

To say it was a poem I wrote in the 1970's stolen and Americanised by Don McLean: Or: I ask the audience to imagine he was born in Leeds, had a paper round, worked as a miner and liked cricket, before emigrating to America and setting it there. Either way it goes down a storm

Miss Yorkshire Pie

A long long time ago I can still remember how t'music used to make me smile
An' I thought go on gimme a chance an' mebbe I could make those people dance
An' mebbe they'd be happy for a while
But February made me shiver wi' every Yorkshire Post I'd deliver
Bad news on the doorstep I couldn't take another step
I can't remember if I roared* When I read about our troops being killed abroad
Something touched me deep inside The day the music died
Bye, bye Miss Yorkshire Pie Drove my Mazda to t'Asda but t'Asda were dry
And them good ole boys bought a chicken stir fry Singin' this'll be the day that I die,

Di tha write t'book of love An' does tha believe in God above
An wi' all the thee's thy's an' thou's it had, were t' Bible written by a Yorkshire lad
Well I was a minin' lad an' somewhat skinny Drivin round in a beat up old mini
But it were great hearin' the latest hit, drivin home after a shift down t'pit
An' it really was a surprise, the day of the music's demise
Bye, bye Miss Yorkshire Pie Drove my Mazda to t'Asda but t'Asda were dry
And them good owd boys bought a chicken stir fry Singin' this'll be t'day that I die,
This'll be the day that I die

I met a lass who sang t'blues, an' I asked has tha got some happy news
But she just smiled and turned away
So I went down to the sacred store where I'd heard the music years before
But the man there said the music wouldn't play
So we couldn't dance and swing our hips we thought we've had our chips
No new songs would be released, the day of the music was deceased
Bye, bye Miss Yorkshire Pie Drove my Mazda to t'Asda but t'Asda were dry
And them good owd boys bought a chicken stir fry Singin' this'll be t'day that I die
This'll be the day that I die

At Headingley in a summer swelter, the birds flew off with t'fallout shelter
What happened next weren't cricket, they dropped it reyt on t'wicket
An' Lancashire couldn't get in to bat, so the Yorkshire fans laughed an' sung Ilkla Moor Baht 'at
An' the three men I admired moast Father, Son an' Holy Ghoast
Went an' caught a train to t'East Coast
An' we all thought things have gone to t'dogs the day t'music popped it clogs
Bye, bye Miss Yorkshire Pie Drove my Mazda to t' Asda but t'Asda were dry
And them good owd boys bought a chicken stir fry singin' this'll be t'day that I die
This'll be the day that I die

Trev "The Road Poet" Wainwright

Roared* Yorkshire spake (speak) for cried: This is usually mentioned as an aside in the poem straight after "roared", and gets a chuckle.