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. 67. (Spring 2021)

The New Draft NIHCE Guidelines for ME/CFS

Blue Violas, one of the many early spring flowers. During the recent lockdown many people have revived their interest in gardening

You Write In

This time we have a selection of correspondence received at the Leger ME Office and on the Facebook Pages. The big topic in this quarter is Covid Vaccination.

Trevor writes: No effects from the first jab just waiting for the second.

Pauline writes: I had the vaccine back in January. I did not feel a thing. The only reaction was a bit of an achy arm. I was fine, although I am a bit worried about the second shot as I have heard people are really getting quite severe reactions.

Michele writes: I was lucky with my Covid-19 Oxford AstraZenica vaccine not to have any serious side effects as I reported to you. My sister and several friends were unwell for 2-3 days after having the Oxford jab including headache, shivering, fever, sore arm and one friend also vomited. This temporary feeling of unwellness as you have said far outweighs having Covid-19 illness.

Christine writes: I was pleased to hear about vaccine experiences from people who know what ME is like and I will pass the info and advice onto my daughter. Thanks for offering to speak with her and I very much hope she will take up your offer.

Irene Writes: I had my first Oxford jab last week at home, I took an extra antihistamine before and after, had no side effects at all except a sore burning twitching area where the needle went in.

Marie Writes: I had Oxford/AstraZeneca vaccine a week ago. Side effects developed as follows: immediately after jab, dizziness. A few hours later, neurological symptoms - numbness and tingling, especially in extremities. A few hours after that: violent shivering, could not get warm. Also, the site of the vaccination became quite painful. All symptoms disappeared by the end of the 2nd day, except sore arm, which persisted all week (albeit getting better).

Stewart Writes: I had my jab with the Pfizer vaccine the other day at Thorne everything went very well side effects for me where headache, aching arm, slight wheezing { asthma symptoms slightly worse } only lasted a day.

Bernie Writes: Just as a personal update, I have had my vaccination and experienced side effects including shivers, severe muscle aches, fever, and a lengthy headache. Thankfully all but the headache subsided, and it is just about building back up again. I have recently been asked to do graded exercise by physio at DRI but am unable currently to do this anyway. I find my brain does not let me access all the information I hold about why I should not do it, reminds me of dementia patients.

Graded exercise is not appropriate for ME/CFS. My advice is to decline it unless it is under the guidance of one of the ME/CFS clinics. It is in the new NIHCE guidelines and they should be complying with these.

Terry writes: I sent the template letter from the MEA to my G.P. regarding being moved up the list for the vaccination, it was a complete waste of time and energy made no difference, the doctors just ignore the word ME/CFS. I would love to hear how other people got on with it ?

In our experience, it is a mixed bag getting an earlier Covid Vaccination. It worked with some surgeries and not others.

Then on the day I was having my first vaccination, I called the ME/CFS clinic in Sheffield for advice as to which vaccination is more suitable for a person suffering with moderate to severe ME. Again, a complete waste of time no advice whatsoever, but since having the vaccination it has made me ill. I feel weaker, no energy, not eaten as I constantly feel nauseous, keep having hot and cold sweats and my arm feels like a lead weight. I called the ME clinic in Sheffield on Thursday as I needed to cancel an appointment and again, I asked if there was anybody to speak with for advice. So, I have concluded nobody is bothered about giving any advice regarding the effects with the condition. So, this has made my mind up not to have and further vaccines, I've never had the flu jab and certainly won't be now, I don't know if anybody else feels let down by disinterested groups and clinics and GPs I would love to hear.

Firstly, it is no surprise that you did not get anywhere with the Sheffield clinic. Why didn't you call the Leger ME office? We could have given you the necessary guidance. The fact that you had a reaction to the vaccination tells me that if you had Covid for real you would have been in very deep trouble.

Most vaccines work by showing the immune system some part of the real bug in the hope that it will remember for the future how to deal with an infection. In effect it is a 'paper tiger'. The fact that you reacted proves that it is working. Those who have had Covid 19 for real before getting the vaccine tell me that reaction to the vaccine is nothing compared to the real thing. You will not be doing yourself any favours by declining the second dose.

Regarding the flu vaccination. Many are egg based and contain traces of raw egg. That is more than enough to cause a reaction. There is an egg free flu vaccinee available, and I know for next year one surgerys in Doncaster will be using this in preference. The main side effects reported with Covid vaccine are anaphylaxis, a type of allergy. It is believed that it is due to PEG. This is a polyethylene glycol like substance used in the food industry and some medicines. It is used in the Pfizer Covid 19 Vaccine.

A Message from Doncaster MBC .

What to do for Covid Vaccinations and ME/CFS.

Now the vaccination campaign is in full swing, here is a summary of what we know so far:-

1) When you are offered a vaccination accept the offer. Declining it will leave you wide open to infection, and that would be detrimental to your wellbeing.
2) Plan you vaccination day like a special day. Rest up the day beforehand. The vaccination will work better if you are calm and not stressed. If possible get someone to drive you to the vaccination centre and don’t forget your face mask.
3) This type of vaccination is designed to challenge your immune system by showing it a lookalike of the Covid surface spike. If it works, it will trigger some sort of reaction which can be akin to having flu-like symptoms. That is good news. The time to worry is if you don’t get a reaction of some sort.
4) If you have the atopic or allergic form of ME/CFS e.g. VOC’s or food sensitivities or you are sensitive to various things, it will help if you take an antihistamine tablet a couple of hours before the vaccination, for example Cetirizine.
5) If you are susceptible to pain, e.g. with fibromyalgia you could take a paracetamol tablets before going to the vaccination centre..
6) On the following few days after the vaccination, rest up and take things easy. Give yourself time and energy to let things work. Some people report getting a day of ME/CFS remission on the third or fourth day. Carry on with your pacing as usual and don’t over do it.
7) For future reference you will be given a handout about the vaccine which lists the possible side effects. Keep your vaccination card for future reference. It records the vaccine type, date and batch number. If a known side effect and lasts more than a week or you think you have a previous unknown side effect, then send in a yellow card report. Contact the office for help.
8) Don’t let any side effects from the first dose put you off having the second dose. The second dose is essential to complete the immune response and get the best protection. Most people are reporting different, but mild side effects to the first dose. Most commonly reported is a sore injection site.
9) Please remember that a fully blown Covid infection could be very detrimental to your health and leave you with Long Covid Syndrome. Experience so far has shown that Long Covid Syndrome is dangerous, and long lasting. It is quite clear from members feedback that the effects of Covid 19 are additive to ME/CFS problems and would leave you with more serious ME/CFS problems should you become infected.
10) If you have any concerns, discuss this with your doctor. One of the issues is that the Pfizer vaccine contains something like polyethylene glycol (PEG), which is a food additive which is used in the vaccination manufacturing process. It is absent from the Oxford AstraZeneca vaccine. Both version of the Covid vaccine are egg free, and do not contain substances of animal origin so are suitable for vegetarians and vegans.

Poets Corner - Here are two topical Poems from Trevor Wainwright

08.02.21

The media did tell the vaccinations were going well
Once more time to bless our second to none NHS
Could a private company have done better, I thought “come off it”
We needed those who put people before profit.
Not the disgrace that we had when
private companies ran track and trace
By the media they were pasted, millions of pounds wasted
Media kept telling us the score
The numbers of vaccinations got more and more
As the numbers grew, I knew my turn would not be far away
I was right when I read a text on my phone today
I was delighted to be invited to look for a space
at a vaccination place
On the internet link I looked found a space and booked
Confirmation text came through, nothing more to do
But wait for the time and date and not be late
I wondered shall I broadcast it then thought with a smile
"Nah, others are doing so an’ it gets boring after a while".

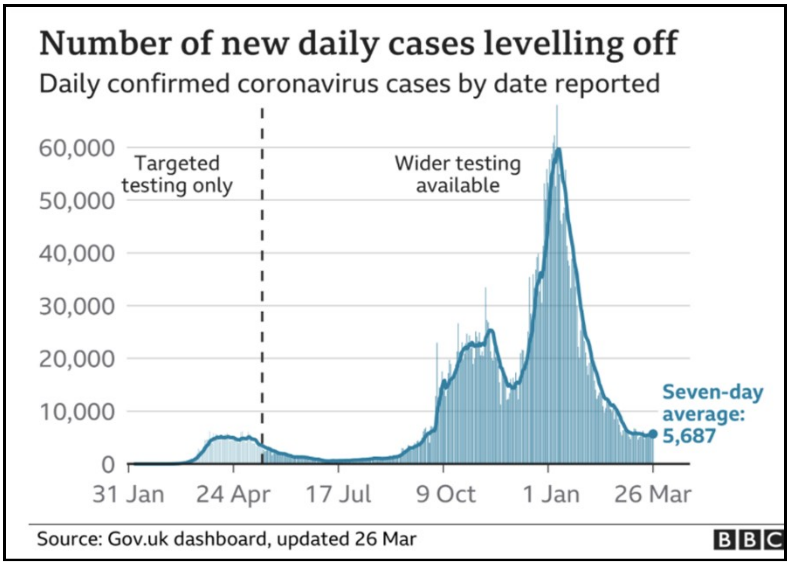
10.02.21

Vaccination day today but first I have to be away
Doing the deed food parcels to those in need
And say goodbye to a friend
who has come to life’s end
Then no hesitation, get to the vaccination station
Given a number take a seat no time for slumber
Number called I’m awaiting my name I have to say
Sit and wait but things
are going like a song I’m not waiting long
Jacket off jersey adjusted then I’m knowing
I’m called again time to be going
No hesitation for the first inoculation
Everything's ready, relax and steady
Didn’t wince, say ouch or grouch
Just thought “that’s it I’m done,
now roll on the second one”.

Covid 19 -What next ?

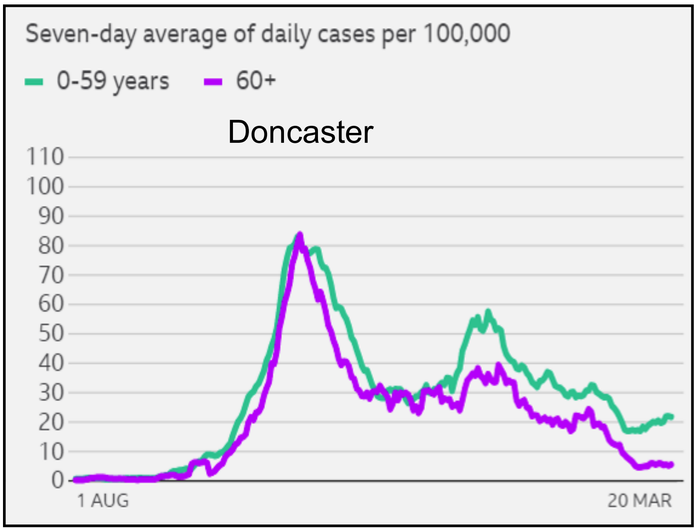
Its just over a year since the start of the first lockdown, and what a year it has been. The graph on the right shows the Uk wide national daily confirmed cases While the lockdown and vaccinations have reduced the case numbers.

However with the return of children to school and college, cases have stopped dropping.


Number of new daily cases levelling off

Daily confirmed coronavirus cases by date reported

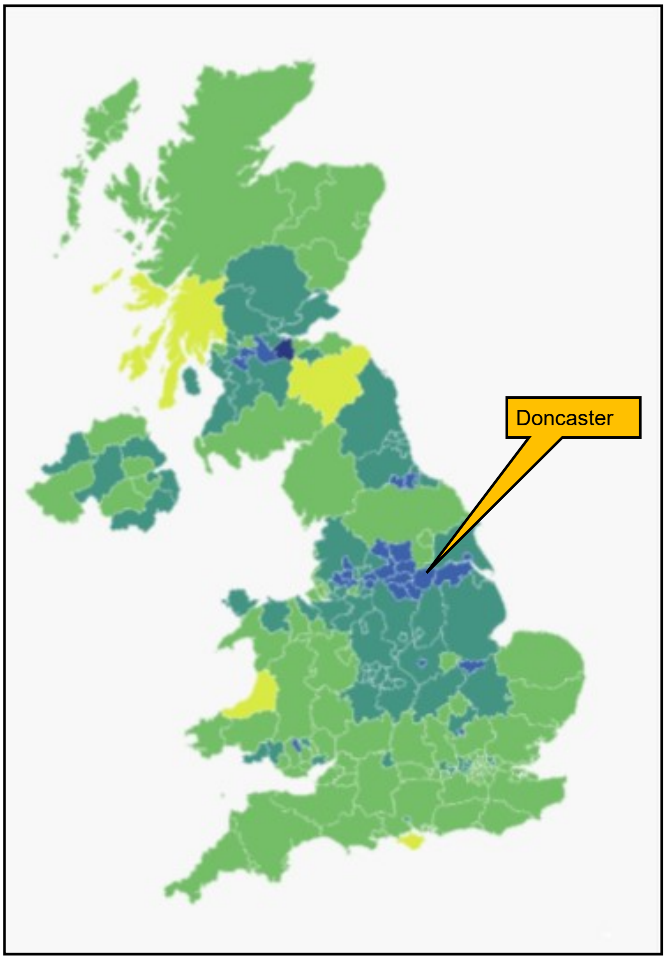
Source: Gov.uk dashboard, updated 26 Mar


Seven-day average of daily cases per 100,000

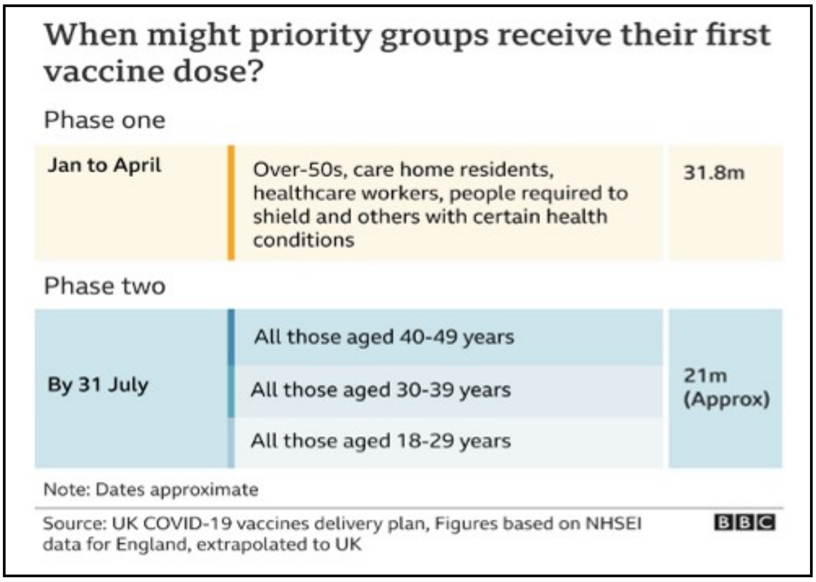
Looking a the local situation, the over 60 group numbers are flat. While the under 60 group is rising. According to Dr Rupert Suckling the Director of Public Health in Doncaster,:

“Whilst our rise in numbers is primarily being driven by school age children and young people, we're also seeing more cases in 20-29 year olds. We believe this is most likely due to the virus spreading in the workplace, so if you are still going into work, please stick to all the guidance in place””

Nationally, Doncaster's case numbers is in the higher group shown by blue in the map. It is though that this is due to us being part of the old heavy industrial areas where multigenerational occupancy of housing is high enabling transmission through close contact.



While lockdowns, distancing and face maskes have their place, the only real way to beat the Covid virus is through vaccination. While more than half the adult population is vaccinated, the government expect all the adult population have the first vaccination by July 2021


When might priority groups receive their first vaccine dose?

Phase one

Jan to April	Over-50s, care home residents, healthcare workers, people required to shield and others with certain health conditions	31.8m

Phase two

By 31 July	All those aged 40-49 years	21m (Approx)
	All those aged 30-39 years	
	All those aged 18-29 years	

Note: Dates approximate

Source: UK COVID-19 vaccines delivery plan, Figures based on NHSEI data for England, extrapolated to UK

However, things are not that simple. With the emergence of new variants, the vaccine manufacturers are busily formulating new vaccines to cope with the new variants from Kent, Brazil and south Africa. Under development are children vaccinations, and I cant see that we will minimalize the pandemic until all the children are vaccinated. Expect a yearly vaccination top up booster in the Autumn.

Welfare Rights Matters

With thanks to Benefits and Work

Benefits and Work
Guides you can trust

Benefit and Work guide downloads are available to members for Leger ME as part of the membership deal.

Claimant successfully sues ATOS and sends in the bailiffs.

A claimant has successfully sued Atos for negligence and failure of duty of care and then sent in the bailiffs when they failed to pay up. Rebecca has epilepsy, a heart condition, anxiety, depression, and memory problems. Despite this, and the fact that she was receiving the enhanced daily living component, she received zero points for daily living following her PIP assessment. Fortunately, Rebecca had recorded her assessment. The recording was listened to by an appeal panel, who compared it to the assessor's account of what had been said. The panel then found in Rebecca's favour, restoring her entitlement to the enhanced rate of the PIP daily living component until 2023.

Rebecca was so angry at the treatment she had received from Atos that she sued them through the County Court for 'mental distress, anxiety and hardship'. Atos made no attempt to defend the claim. The County Court found in Rebecca's favour and awarded her compensation of £2,500. When Atos failed to pay up, Rebecca arranged for enforcement officers to visit their offices in London, resulting in an extra £2,000 in costs to the company, which finally had to pay up. We (B&W) know we will be speaking for many claimants when we say that we have nothing but admiration for Rebecca's courage and her refusal to be bullied or ignored, even when coping with so many health conditions.

Video PIP and ESA Assessments Now Enshrined in Law

The government has passed legislation allowing the DWP to require a PIP or ESA claimant to take part in an assessment by telephone or by video, as alternatives to a face-to-face assessment.
The new regulations came into force on 25th March and enshrine all three options in law. In the case of PIP, the regulations already stipulated that an assessment could be in person or by telephone, but the words 'or by video' have now been added. In the case of ESA and Universal Credit (UC), the regulations only stipulated that a claimant may be called to 'attend for a medical examination'. The words 'in person, by telephone or by video' have been added. So far, video assessments are still at the trial stage, but they are already a source of concern for many claimants who worry about the data protection and privacy issues. Benefit and Work would be extremely interested to hear from anyone who has been invited to have one.

Integrated PIP/ESA/UC assessment trials to resume.

The DWP is to resume trials of an integrated assessment for PIP/ESA/UC in April. The idea is not to have a single test for both benefits, but a single assessment at which the evidence needed both for PIP and a WCA will be collected. The DWP originally announced plans for an integrated assessment system back in March 2019. Two years later, it seems that virtually no progress has been made. The DWP say they had "started to test a single digital platform in a small number of assessment centres but this was paused due to the impact of COVID-19".

The work will now go ahead within the Departmental Transformational Area (DTA). This is an area where new processes can be tested on claimants before being rolled-out across the country. The first DTA is at an undisclosed site in London and work will begin in April of this year. While the idea of reducing the number of assessments claimants have to attend is a welcome one, the possibility of losing both benefits at once because of a rushed or incompetent assessment is a very alarming one.

DWP has paid out £32 million to claimants so far for pip errors

The DWP has paid out £32 million so far to PIP claimants who lost out because of legal errors by the department, according to an update released last week. Yet the DWP originally claimed the cost would be £3.7 billion The DWP is still trawling through millions of claims looking for people owed money after it lost two landmark legal cases. In a decision known as MH, it was found that the DWP had been misapplying the law in relation to psychological distress and following the route of a journey. In RJ, the DWP was found to have got the law wrong in relation to safety and supervision. The latest figures show that, since June 2018, around 890,000 cases have been looked at in relation to the MH decision and around 990,000 in relation to the RJ decision. Approximately 6,600 payments have been made so far, amounting to £32 million. Of this, £18 million has been paid in relation to MH and £14 million relating to RJ. It is worth noting that when the government tried to change the law in 2017, in order to get round the MH ruling, the DWP issued a press release claiming that failure to change the law back would lead to an extra £3.7 billion being spent on PIP by 2022. The attempt to change the law failed, and yet they have paid out just £18 million in relation to MH. So, were they lying in 2017? Or are many thousands of claimants not getting the back payments they are entitled to?

The Errol Graham case fails

The High Court has rejected the claim by relatives of Errol Graham, who starved to death after his benefits were stopped, that the DWP's safeguarding policies are unlawful. Errol Graham was 57 when he starved to death in June 2018. His ESA and housing benefit were stopped after he failed to attend a work capability assessment. This was done without checking on his mental or physical wellbeing, even though he was known to have serious mental health issues. In the High Court, Errol Graham's family argued that even though the DWP had very recently introduced new safeguarding policies, they were still unlawful. This is because the burden of proof for showing good cause for failing to attend an assessment is still placed on the claimant, even though their mental health may prevent them from meeting such a requirement.

However, the judge held that with 1.9 million ESA claimants, the system would be unworkable if the burden of proof were placed on the DWP. Errol's family say they are shocked by the ruling and may now appeal further. His son's fiancée said:

"The fight's not over. If the law can put people like Errol in this position, then I need to ask - should I challenge the law? We need a change that will protect people like Errol and this judgement is not good enough."

My Experience of a Telephone Employment and Support Work Capability Assessment (WCS)

By Maria Prucyk

My first appointment was cancelled on the day due to covid. The second date was one and half hours late on 28th January 2021. I had requested a recording. The assessor said that her machine was not working (I personally do not believe it!).

Here are the questions which they asked me about:-

1) All my health problems and all symptoms.
2) My medications
3) How often I have chats with my M.E. specialist.
4) How do I move around my home?
5) About the aids I use e.g., pill tray
6) The diary I did covering 7 days.
7) How have you found the Covid lockdown?
8) Any new conditions since filling WCA forms.
9) About the dietitian, the reports what to eat or avoid with my Irritable Bowel Syndrome.
10) The Pain clinic and what medication was recommended.

I think question 7 was a trick question as with ME/CFS and Fibromyalgia. It feels like lockdown all the time as most of the time is spent at home. The points I highlighted to the assessor are that every activity I do causes PEM (Post exertional Malaise). This causes me to feel fatigued which can bring on flare up. I cannot do any activity for more 10 mins e.g. reading. I cannot do this repeatly.

During the medical, I said I am getting fatigued and have foggy brain. I found my assessor who was a nurse, professional, had knowledge about my health conditions and had empathy. She had read through all my paperwork before the medical. She apologised for the stress the assessment had caused me and understands stress can cause relapse. My medical was 40 minutes long. Take what you like from this report. I hope it helps.

Covid 19. The Road Map to Lock Down Easing.

Here is how the lockdown rules are changing in England. Scotland, Wales and Northern Ireland have their own arrangements.

Conditions for easing restrictions?

1) The coronavirus vaccine programme continues to go to plan.
2) Vaccines are sufficiently reducing the number of people dying or needing hospital treatment.
3) Infection rates do not risk a surge in hospital admissions.
4) New coronavirus variants do not fundamentally change the risk of lifting restrictions.

Stage 1

What's already changed?

- Schools and colleges have reopened, and university students can return for practical courses
- Two people from different households can meet outside for recreation, which can include "a coffee on a bench"
- Care home residents can have one nominated visitor, with testing and social distance precautions

From 29th March?

- People will be allowed to meet outside, either with one other household or within the "rule of six", including in private gardens
- The stay at home rule will end, but the government will urge people to stay local as much as possible
- Outdoor sport facilities will reopen, including golf courses and tennis and basketball courts, and formally organised outdoor sports can restart
- Weddings can take place, attended by up to six people

Stage two (no earlier than 12th April):

- All shops allowed to open, along with close-contact services, including hairdressers and beauty salons (including in people's homes)
- Restaurants and pubs allowed to serve food and alcohol to customers sitting outdoors
- Gyms and spas can reopen, as can zoos, theme parks, libraries and community centres
- Members of the same household can take a holiday in the UK in self-contained accommodation
- Weddings attended by up to 15 people can take place
- A waitress serving food in a pub garden

Stage three (no earlier than 17th May):

- People can meet in groups of up to 30 outdoors
- Six people or two households can meet indoors
- Pubs, restaurants and other hospitality venues can seat customers indoors
- Up to 30 people can attend weddings or other life events, like christenings
- Remaining outdoor entertainment, such as outdoor theatres and cinemas can open
- Indoor entertainment such as museums, theatres, cinemas and children's play areas can open
- Performances and large events can restart, but with limits on audience numbers
- Hotels, hostels and B&Bs can reopen
- International leisure travel may resume, subject to restrictions that may be imposed by other countries.
- Adult indoor group sports and exercise classes can restart

Stage four (no earlier than 21st June):

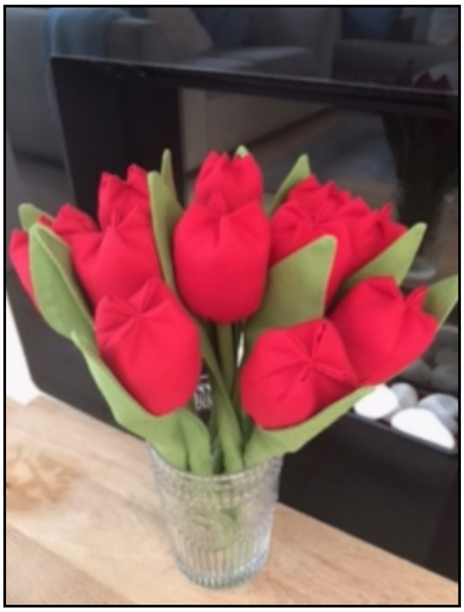
- All legal limits on social contact will be removed
- No legal limits on the number of people who can attend weddings, funerals and other life events
- Nightclubs will be allowed to reopen.

Craft Corner

It's always great to see what members are doing despite their ME/CFS problems. There are two contributors this edition

Firstly to the right, from Ann, we have a of piece of acrylic flow art which she did a few weeks ago. It measures 30cm x42cm. and is A3 size. I think I've got it the right way up !

Secondly, we have two submissions from Claier, who tells us that she has been making Mothers Day tulips. They are quite cheery!



Well done ladies! Anne and Clair can be contacted via our Facebook group.

If you have made something, please send us something for out next edition which is due in June.

Photographers Corner

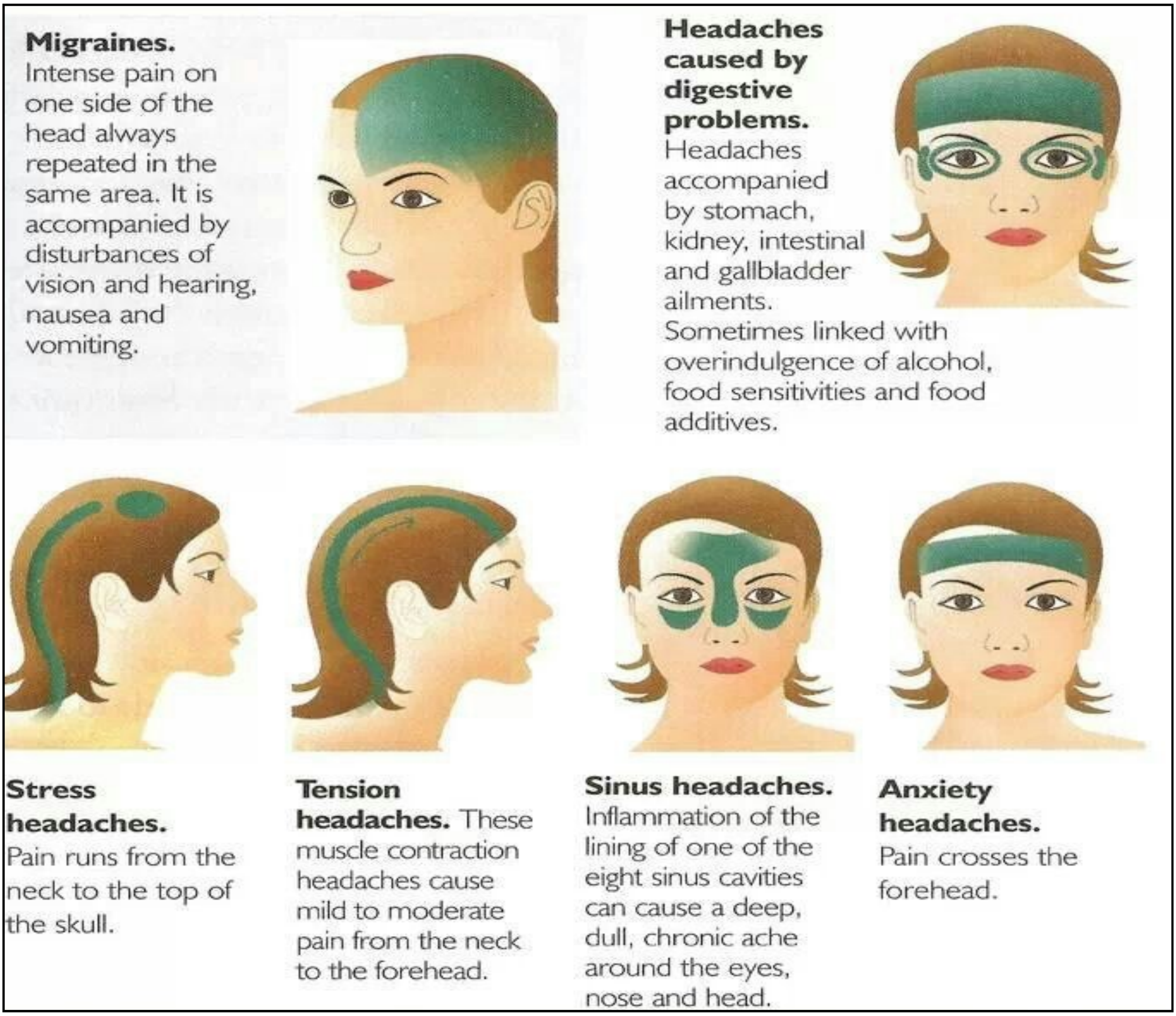
Here are a couple of interesting natural history photographs I have received from David. The right photo is of a Grey Heron who has just picked up a frog out of his wildlife garden pond. Grey Herons are a problem for people with fish in ponds and water gardens because they have found ornamental fish an easy meal. Most gardeners resort to using netting over their ponds to deter their fish from being easy meal. The other option is of course to have a deep pond, too deep for the herons to wade.

"It does not matter, there are plenty more in the pond." writes David. The lower left picture is frogs mating and spawning. The male frogs sit on top of the females, poking their heads above the water. The males had a special pad on their wrists to hold the female while she lays the eggs and he fertilises them. Once laid the frogs go their separate ways, leaving the eggs to swell into the familiar form of frog spawn.

For the technically minded the Camera he used was a Cannon EOS 2000D set to F/5 with a 160 mm lens. Exposure time was 1/320 second.

Common Types of Headache

Headache is among the most common symptoms people get with ME/CFS. However, there are headaches and headaches. Here is a list of the most common types:-



Migraines. Intense pain on one side of the head always repeated in the same area. It is accompanied by disturbances of vision and hearing, nausea and vomiting.

Headaches caused by digestive problems. Headaches accompanied by stomach, kidney, intestinal and gallbladder ailments. Sometimes linked with overindulgence of alcohol, food sensitivities and food additives.

Stress headaches. Pain runs from the neck to the top of the skull.

Tension headaches. These muscle contraction headaches cause mild to moderate pain from the neck to the forehead.

Sinus headaches. Inflammation of the lining of one of the eight sinus cavities can cause a deep, dull, chronic ache around the eyes, nose and head.

Anxiety headaches. Pain crosses the forehead.

Headaches: Red Flag Symptoms

If you get any Red Flag symptoms if you suffer a headache, this means that you need to contact your GP for further investigation as soon as possible

1) Thunderclap headache: rapid time to peak headache intensity (seconds to five minutes) - same-day specialist assessment needed.
2) New onset headache associated with new systemic or neurological features;
3) Headache if regularly using analgesics (painkillers) on more than 4-5 days per month (to discuss preventive treatment so as to avoid medication overuse headache);
4) Headache that becomes worse on immediate upright posture. This could be possible spinal fluid.
5) New onset of, or change in, headache if you are aged over 50 years.
6) Headache in patients who are aged under five years;
7) Headache started by coughing, laughing or straining;
8) Headache after head injury, or within 90 days of a head injury.;
9) New-onset headache in a patient with a history of cancer that can metastasize to the brain, or aged under 20 years with a history of malignancy.

Type of headache	Prevalence	Male to Female ratio	Life Impact	Duration/ Frequency	Triggers	Associated symptoms	Recommended treatments	Prevention
MIGRAINE HEADACHES	14%	Affects twice as many women as men	Severe reduction of function	·4-72 hours, 1-2 attacks per month • Classed as chronic if headache is present more than15 days per month for more than3 months, of which more than8 days have features of migraine	Sleep disruption, skipped meals, hormone fluctuations, stress and relaxation from stress, thundery weather.	Sensitivity to light and sound, nausea and vomiting, visual disturbances (flashing lights, shimmering lights, zigzag lines, stars, blind spots), tingling on one side of the face or one arm.	Acute: simple analgesics (aspirin, diclofenac, ibuprofen, naproxen, paracetamol), which may be combined with a triptan (almotriptan, eletriptan, frovatriptan, naratriptan, rizatriptan, sumatriptan, zolmitriptan) and/or an antiemetic (domperidone, prochlorperazine, metoclopramide).	For patients with four or more migraine days per month, amitriptyline, candesartan, propranolol, topiramate, onabotulinumtoxin A chronic migraine only). If at least three preventive drugs have failed, try erenumab, galcanezumab (chronic or episodic migraine), fremanezumab (chronic migraine only)
Medication Overuse headaches	up to 20-50% of the chronic headache population.	Affects 1½ times as many women as men	Moderate to severe reduction of function	Present more than15 days a month for 3minths	Taking ergotamine, triptans or opioids more than10 days per month, simple analgesics 2'.15 days, for more than3 months; however, medication overuse headache reported with all for use more than 8 days per month.	None but features of migraine or tension type headaches can be seen	Acute: completely withdraw acute headache treatment for at least 8 weeks.	preventive treatment may be started. If experiencing more than4 headaches days per month. Overused medicines may be reintroduced after 2 months but restricted to 8 days per month.
TENSION HEADACHES	26%	Affect 15 times as many women as men	Mild-to-moderate reduction in function.	30 minutes to several days. Classed as chronic if present on more than 15 days per month for more and more than3 months.	Stress physical exhaustion	Tight neck and shoulder muscles.	Acute: paracetamol. Aspirin or ibuprofen.	if symptoms are causing significant disability, .amitriptyline.
CLUSTER HEADACHES	Less than 1%	Affects 3 times more men than women	Unable to function. Rooking or pacing.	15 minutes to three hours, repeated 1-8 times a day. Every day for 4-12 weeks. followed by a period of remission.	Alcohol and some chemicals	Restlessness, agitation, nasal congestion, eye tearing. Swelling or redness, sweaty face. smaller, pupils. nausea and vomiting. sensitivity to light and sound.	Acute: sumatriptan injection. sumatriptan or zolmitriptan nasal spray or oxygen therapy (oral therapies are not effective in acute treatment).	verapamil. lithium. Corticosteroids.

Long Covid Syndrome. Another variation of ME/CFS? Or PVFS

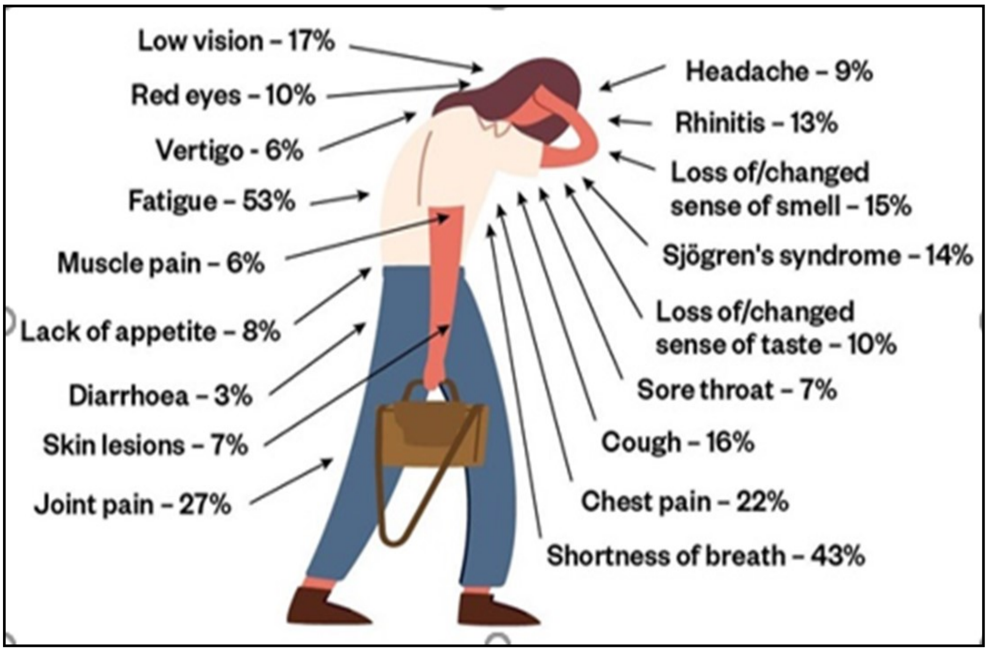
Long Covid affects approximately 60,000 in the UK and is characterised by persistent and fluctuating fatigue, breathlessness, cognitive blunting ("brain fog") and pain. The cause of Long Covid is unknown, but it is thought to be due to an inflammatory reaction. Most patients get better slowly over time, but perhaps 10% are left with significant organ damage and their long-term outlook is unknown.

Body system	**Impact**
Mental health	Anxiety, depression, post-traumatic stress disorder and sleep disturbance.
Musculoskeletal & other	Pain in joints and muscles, body aches and fatigue.
Brain & Nervous system	Loss of sense of smell (anosmia) which can result from thrombo-embolic events such as pulmonary embolism, heart attack, stroke. Cognitive impairment (e.g. memory and concentration). Confusion.
Heart	Damage to heart muscle or heart failure.
Lung	Damage to lung tissue and restrictive lung failure.

The National Institute for Health Research (NIHR) Centre suggested long COVID may actually be four different syndromes :

-

- post-intensive care syndrome.
- post-viral fatigue syndrome (ME/CFS);
- long-term COVID syndrome.
- And permanent organ damage,



Most of the reported symptoms of Long Covid Syndrome are the same as for ME/CFS.

as well as the possibility that some patients may experience more than one condition simultaneously. What is clear is that, as COVID-19 infections continue to rise steeply in the UK, cases of long COVID are likely to become increasingly common term outlook is unknown. So wide is the range of symptoms experienced, in fact, that it has created ongoing diagnostic uncertainty. In the first dynamic themed review of scientific evidence on the condition. What is clear is that, as COVID-19 infections continue to rise steeply in the UK, cases of long COVID are likely to become increasingly common.

Somewhere within the cluster of symptoms is ME/CFS. We do know that people with ME/CFS who have had Covid 19 tell us that the symptoms are identical to ME/CFS. Furthermore, the net fatigue is additive - suggesting a common problem. The agencies are busy trying to make sense of the problem. A national network of clinics has been set up to manage Long Covid syndrome. Reports from some of our members indicate that the clinics are without direction. One thing that is quite clear- they are not aware of the issue with ME/CFS around post exertional a malaise. Maybe the Post Covid new research will shed light on ME/CFS. Who knows?

Recipe Corner *by Carolyn.*

Lentil and Chicken Curry

Here is a recipe which serves 4 people. Preparation time us 20 minutes and cooking time is 35 minutes
Tip: If you are cooking for one or two only then this meal can be portioned and frozen.

How to Cook

1) Add the cumin and coriander seeds to a dry saucepan and toast for 1-2 minutes. Add the oil and the onions. Cook for 5 minutes stirring regularly until browned.
2) Add the garlic, ginger, green chillies and chicken pieces and cook for another 2-3 minutes, stirring regularly.
3) Add the chilli powder, garam masala and turmeric with the lemon juice, tomatoes *and* 500ml water.
4) Bring to the boil, mix well, reduce the heat and simmer for 15 minutes, stirring regularly.
5) Add the lentils and simmer for another 15 minutes, stirring regularly until cooked.

Nutrition: Carbohydrate: 32g per serving, Calories 332 per serving, Sugars: 9.3g, Fat: 5.3g,Saturated Fats 0.5g, Salt 0.3g.

Ingredients:-

1 tsp ground cumin seeds
1tsp coriander seeds
1tbsp rapeseed oil
4 onions, thinly sliced
4 cloves garlic, thinly sliced
3cm fresh ginger, finely chopped
1-3 green chillies, split open
400g chicken breast,
cut into small pieces
½ tsp chilli powder
1tsp garam masala
1tsp turmeric powder
Juice of 1 lemon
400g tin chopped tomatoes
150g red lentils

Cauliflower Pizza

This recipe serves two. The preparation time is 30 minutes and cooking time is 30 minutes

How to Cook

1) Preheat the oven to 180C/Gas4
2) Remove the stalks from the cauliflower, break into large pieces and hand grate or blitz in a food processor.
3) Add the cauliflower to a bowl, cover with clingfilm and pierce the film a couple of times.
4) Cook in the microwave on high for 4-5 minutes. Allow to cool.
5) Once completely cooled, place the cauliflower onto a clean tea towel and squeeze over the sink to remove the excess water.
6) Meanwhile, make the pizza topping. Heat the oil in a frying pan and fry the onion, red pepper and courgette for 4-5minutes until starting to brown. Add the tomatoes, garlic and oregano and cook for another 2 minutes. Mix well and set aside.
7) Add the cauliflower to the bowl with the egg and parmesan. Mix well.
8) Line a round baking tray or pizza sheet approximately 25cm in diameter with non -stick baking paper. Spread the cauliflower, to a thickness of ¾ cm, onto it. Bake for 15 minutes, remove from the oven and top with the vegetables and mozzarella slices. Bake for a further 10 minutes. Serve sprinkled with the basil leaves and chilli flakes, if using.

Nutrition: Per Serving:- Carbohydrates: 23.3g, Calories: 326 , Sugars 17.2g, Fat 13.4g, Sat Fat 5.7g,Salt 0.7g.

Ingredients:-

1 cauliflower
1 tsp rapeseed oil
75g red onion, thinly sliced
150g red pepper, thinly sliced
150g courgette, diced
2 fresh tomatoes, chopped
2 cloves garlic, crushed
1 tsp dried oregano
1 egg, beaten
15g Parmesan, finely grated
50g reduced-fat mozzarella, sliced
6-8 fresh basil leaves, torn
½ tsp chilli flakes (optional)

The New draft NIHCE Guidelines for ME/CFS

Adapted from an original feature by Russel Fleming, of the ME Association. The original feature can be downloaded from the MEA website.

The National Institute for Health and Care Excellence (NICE) has published the draft of the new clinical guideline for ME/CFS. The new guideline will provide an essential framework to NHS and social care services that explains how people with ME/CFS should be treated when they need support from healthcare services. Indications are that the new guideline has the potential to be a significant improvement on the current situation. We are listing selected extracts which we think will be of interest to Pathways readers.

Recommendations.

There are recommendations of the following topics

- Information and support (including social care).
- Safeguarding.
- Access to care.
- Supporting people with ME/CFS in work, education, and training.
- Multidisciplinary care.
- Managing ME/CFS.
- Managing coexisting conditions.
- Managing flares and relapse.
- Review (annual review recommendations).
- Training for health and social care professionals.

PRINCIPLES OF CARE FOR PEOPLE WITH ME/CFS RECOMMENDATIONS

1.1.1 Be aware that ME/CFS is:

- is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is unclear
- can have a significant impact on people's (and their families and corers') quality of life, including their activities of daily living, family life, social life, emotional wellbeing, work, and education
- affects each person differently and varies widely in severity -in its most severe form it can lead to substantial incapacity (see recommendations 1.1.8 and 1.1.9)
- is a fluctuating condition in which symptoms can change unpredictably in nature and severity over days, weeks or longer -ranging from being able to carry out most daily activities to severe debilitation.

1.1.2 Recognise that people with ME/CFS may have experienced prejudice and disbelief and feel stigmatised by people who do not understand their illness. Take into account:

- how this could affect the person with ME/CFS
- that they may have lost trust in health and social services and be hesitant about involving them.

1.1.3 Health and social care professionals should:

- acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them take time to build supportive, trusting, and empathetic relationships
- use a person-centred approach to assess people's needs involve family members and carers (as appropriate) in discussions and care planning if the person with ME/CFS chooses to include them.

1.1.4 Recognise that people with ME/CFS need:

- early and accurate diagnosis so they get appropriate care for their symptoms
- regular monitoring and review, particularly when their symptoms are worsening or changing (see the section on managing flares and relapse).

1.1.5 Explain to people with ME/CFS and their family or carers that they have the right to decline or withdraw from any part of their management plan and it will not affect other aspects of their care. They can begin or return to an intervention if they feel able to resume.

1.1.8 Be aware that people with severe or very severe ME/CFS may experience some of the following symptoms that significantly affect their emotional wellbeing, communication, mobility, and ability to interact with others and care for themselves:

- severe and constant pain, which can have muscular, arthralgic or neuropathic features
- hypersensitivity to light, noise, touch, movement, temperature extremes and smells
- extreme weakness, with severely reduced movement
- reduced ability or inability to speak or swallow
- cognitive difficulties, causing a limited ability to communicate and take in written or verbal communication
- sleep disturbance such as
- unrefreshing sleep, hypersomnia, altered sleep pattern
- gastrointestinal difficulties such as nausea, incontinence, constipation, and bloating
- neurological symptoms such as double vision and other visual disorders, dizziness
- postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

1.1.9 Recognise that symptoms of severe or very severe ME/CFS may mean that people:

- need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)
- are housebound or bed-bound and may need support with all activities of daily living
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- need aids such as wheelchairs
- cannot communicate without support and may need someone else they have chosen to be their advocate and communicate for them
- are unable to eat and digest food easily and may need support with hydration and nutrition (see the section on dietary management and strategies)
- have problems accessing information, for example because of difficulty with screens, noise and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

1.1.10 Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are:

- known to the person and their family members or carers wherever possible
- aware of the person's needs.

SUSPECTING ME/CFS

1.2.1 Explain to people presenting with possible symptoms of ME/CFS that there currently is no diagnostic test for ME/CFS, and it is recognised on clinical grounds alone.

1.2.2 If ME/CFS is suspected carry out an assessment, which should include:

- a comprehensive clinical history
- a physical examination
- psychological wellbeing assessment
- baseline investigations to exclude other diagnoses.

1.2.3 Suspect ME/CFS if:

- the person has had all of the persistent symptoms for a minimum of 6 weeks in adults and 4 weeks in children and young people
- the person's ability to engage in occupational, educational, social, or personal activities is significantly reduced from pre-illness levels
- symptoms are new and had a specific onset.

1.2.4 Be aware that the following symptoms may also be associated with, but are not exclusive to: ME/ CFS:

- orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position
- temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold
- neuromuscular symptoms, including twitching and myoclonic jerks
- flu-like symptoms, including sore throat, tender glands, nausea, chills, or muscle aches
- intolerance to alcohol, or to certain foods, and chemicals
- heightened sensory sensitivities, including to light, noise, touch, and smell
- pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain, or joint pain without acute redness, swelling or effusion.

1.2.5 Do not delay making a provisional diagnosis of ME/ CFS. As soon as ME/CFS is suspected, based on the criteria in recommendation 1.2.3, give the person advice about symptom management (see the section on managing ME/CFS).

1.2.6 When ME/CFS is suspected, continue with any tests needed to exclude other conditions and explain to people that this does not affect their provisional diagnosis of ME/CFS.

1.2.7 Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed.

REFERRING CHILDREN AND YOUNG PEOPLE WITH SUSPECTED ME/ CFS

1.2.8 When ME/CFS is suspected in a child or young person based on the criteria in recommendation 1.2.3:

- refer them to a paediatrician for further assessment and investigation for ME/CFS and other conditions
- write to the child or young person's place of education or training to advise about flexible adjustments or adaptations.

ADVICE FOR PEOPLE WITH SUSPECTED ME/ CFS

See section 1.11 for recommendations on managing specific symptoms. This guideline does not cover all the symptoms that can occur in ME/CFS and refers to other NICE guidance in section 1.12.

SYMPTOMS FOR SUSPECTING ME/ CFS

Debilitating fatigability that is not caused by excessive cognitive, physical, emotional, or social exertion and is not significantly relieved by rest and

Post-exertional symptom exacerbation after activity that:

- is delayed in onset by hours or days
- is disproportionate to the activity
- has a prolonged recovery time lasting hours, days, weeks or longer and

3. Unrefreshing sleep, which may include:

- feeling exhausted, flu-like, and stiff on waking
- broken or shallow sleep, altered sleep pattern or hypersomnia and

4. Cognitive difficulties (sometimes described as 'brain fog'), including problems finding words, temporary dyslexia or dyscalculia, slurred speech, slowed responsiveness, short-term memory problems, confusion, disorientation, and difficulty concentrating or multitasking.

1.3.1 When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:

- not to use more energy than they perceive they have -they should plan their daily activity to stay within their energy envelope and not push through activity
- to rest as they need to
- to maintain a healthy balanced diet, with adequate fluid intake.

1.3.2 Explain to people with suspected ME/CFS that their diagnosis can only be confirmed after 3 months of persistent symptoms. Reassure them that they can return for a review if they develop new or worsened symptoms, and ensure they know who to contact for advice.

DIAGNOSIS

1.4.1 Diagnose ME/CFS in a child, young person or adult who has the symptoms in recommendation, 3 that have persisted for 3 months.

1.4.2 After a diagnosis, refer adults directly to a specialist team experienced in managing ME/CFS to develop a management plan.

1.4.3 If ME/CFS is diagnosed in a child or young person after assessment by a paediatrician (based on the criteria in recommendation in 1.2.3), refer them directly to a paediatric specialist team experienced in ME/CFS to develop a management plan.

ASSESSMENT AND CARE PLANNING BY A SPECIALIST ME/ CFS TEAM

1.5.1 After confirming a diagnosis of ME/CFS, carry out and record a holistic assessment. This should include:

- a full history (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is
- known to exacerbate or alleviate symptoms, sleep quality and other causes of physical or emotional stress)
- physical functioning
- the impact of symptoms on psychosocial wellbeing
- current and past experiences of medicines (including tolerance and sensitivities), vitamins and mineral supplements
- dietary assessment (including weight history before and after their diagnosis of ME/CFS, use of restrictive and alternative diets, and access to shopping and cooking).

1.5.2 Develop a personalised management plan with the person with ME/CFS (and their family members or carers, as appropriate) informed by the holistic assessment. Based on the person's needs, include in the plan:

- information and support needs (see section 1.6 on information and support)
- support for activities of daily living (see recommendation 1.8.7 on maintaining independence)
- mobility aids and adaptations to increase or maintain independence (see recommendations 1.8.9 to 1.8. 11 on aids and adaptations)
- education, training, or employment support needs (see section 1.9 on supporting people with ME/CFS in work, education and training)
- self-management strategies, including energy management (see recommendations 1.11.2 to 1.11.10 on energy management)
- physical maintenance (see recommendations 1.11.11 to 1.11.14 on physical maintenance)
- symptom management (see recommendations 1.11.27 to 1.11 .50 on managing symptoms)
- guidance on managing flares and relapse (see section 1.13 on managing flares and relapses)
- details of the health and social care professionals involved in the person's care, and how to contact them.

1.5.3 Recognise that the person with ME/CFS is in charge of the aims of their management plan. The plan should be mutually agreed and based on the person's:

- preferences and needs
- skills and abilities in managing their condition
- hopes, plans and priorities
- symptom severity
- physical and cognitive functioning.

1.5.4 Give the person (and their family members or carers, as appropriate) a copy of their management plan and share a copy with their GP.

PEOPLE WITH SEVERE OR VERY SEVERE ME/ CFS

1.5.5 Offer home visits to people with severe or very severe ME/ CFS to carry out their holistic assessment and develop their management plan.

MANAGING ME/ CFS

1.11.1 Be aware there is no current treatment or cure (non-pharmacological or 4 pharmacological) for ME/CFS.

Refer to relevant NICE guidance for managing symptoms associated with ME/CFS that are not covered in this section.

MANAGING ME/ CFS ENERGY MANAGEMENT

1.11.2 Discuss with people with ME/CFS the principles of energy management, its role in supporting them to live with their symptoms, the potential benefits and risks and what they should expect. Explain that it:

- is not curative
- is a self-management strategy led by the person themselves but with support from a healthcare professional
- can be applied to any type of activity
- helps people understand their energy envelope so they can reduce the risk of overexertion worsening their symptoms
- recognises that each person has a different and fluctuating energy limit, and they are the best judge of their own limits
- can include help from a healthcare professional to recognise when they are approaching their limit (children and young people in particular
- may find it harder to judge their limits and can overreach them)
- uses a flexible, tailored approach so that activity is never automatically increased but is
- progressed during periods w hen symptoms are improved and allows for the need to pull back when symptoms are worse
- is a long-term approach -it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity
- does not assume that deconditioning is the cause of ME/ CFS .

1.11 .4 Based on the person's assessment, establish an individual activity pattern within their current energy envelope that minimises their symptoms. For example:

- reduce activity as the first step
- plan periods of rest and activity, and incorporate the need for pre¬emptive rest
- alternate and vary between different types of activity and break activities into small chunks.

1.11.5 Agree how often to review the person's energy management plan with them and revise it if needed.

1.11.6 Advise people with ME/ CFS to reduce their activity if increasing it triggers symptoms, or if they have fluctuations in their daily energy levels.
1.11.7 Make self-monitoring of activity as easy as possible by taking advantage of any tools the person already uses, such as an activity tracker, phone heart-rate monitor or diary.

1.11.8 Refer people with ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service if they:

- have had reduced physical activity or mobility levels for a long time
- are ready to progress their physical activity beyond their current activities of daily living
- would like to incorporate a physical activity programme into the management of their ME/CFS.

PEOPLE WITH SEVERE OR VERY SEVERE ME/ CFS

1.11.9 Refer people with severe or very severe ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service for support on developing energy management plans.

1.11.10 Be aware when agreeing energy management plans with people with severe or very severe ME/ CFS (and their families and carers as appropriate) that changes in activity should be smaller and any increases (if possible) much slower.

PHYSICAL ACTIVITY

1.11.15 Do not advise people with ME/CFS to undertake unstructured exercise that is not part of a supervised programme, such as telling them to go to the gym or exercise more, because this may worsen their symptoms.

1.11.16 Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a treatment or cure for ME/CFS generalised physical activity or exercise programmes. This includes programmes developed for healthy people or people with other illnesses any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy
- structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS therapies derived from osteopathy, life coaching and neurolinguistic programming (for example the Lightning Process).

Medicines and ME/CFS

6 1.11.29 Do not offer any medicines or supplements to treat or cure ME/CFS. Medicines are for symptom management

8 1.11.30 Offer people with ME/CFS a medication review in line with the NICE guidelines on medicines adherence and medicines optimisation.

10 1.11.31 Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment and have more severe adverse effects.

Consider:

- starting drug treatments at a lower dose than in usual clinical practice
- gradually increasing the dose if the drug is tolerated.

15 1.11.32 Drug treatment for the symptoms associated with ME/CFS for children under 16 and young people should only be started under guidance or supervision from a paediatrician.

Comment

The problem I find with the NIHCE guidelines had always been the level of certainty or proof that is needed to be adopted. Within the health community NIHCE sarcastically know as the *National Institute for Health and Clinical Economics* rather than *Care Excellence.*

It is more about spending public money wisely than treating people with ME/CFS. The problem with ME/ CFS is that there are at least seven subtypes, and until recognised, there is will be no real progress regarding treatments.

NICE National Institute for
Health and Care Excellence

Improving health and social care
through evidence-based
guidance

Curiosity Corner

From Ian .

Here is a an interesting picture.

The question is how was this picture created? .

Bear in mind that these days software packages like Photoshop can manipulate, pictures, distort them and generally manipulate pictures about to such point that it is difficult to tell what the original looked like.

We will not publish the answer, if you look at is long enough and in the right way the answer will be obvious!

From Carolyn

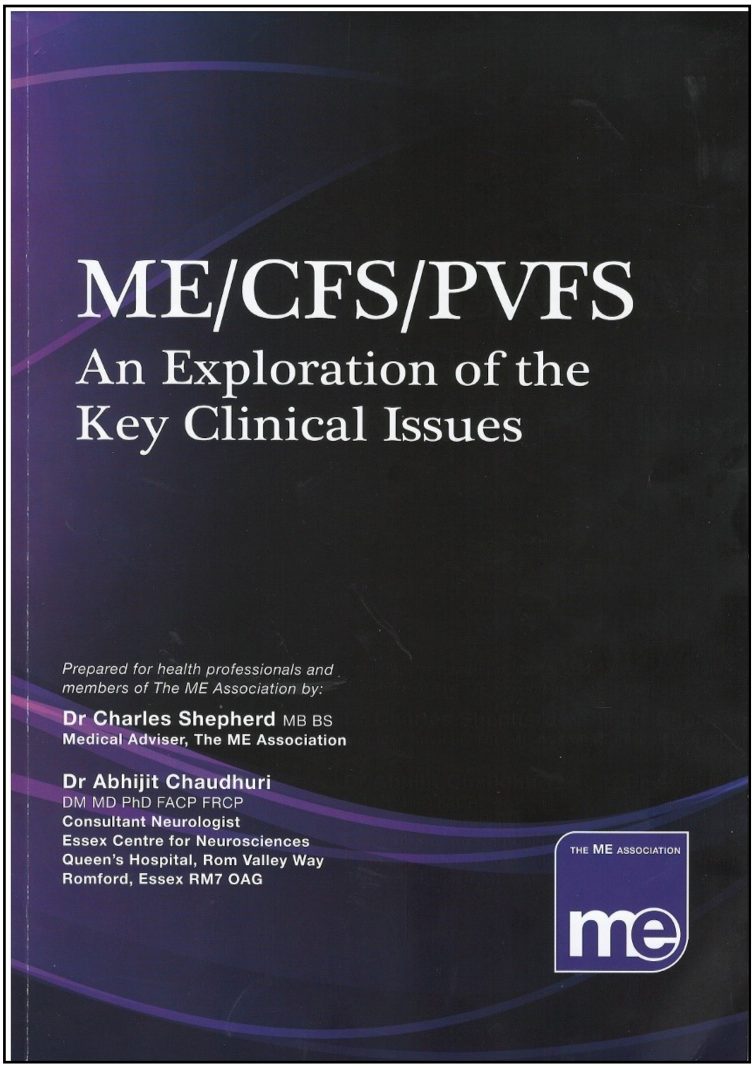
Here is a strange one.

During recent months we have been dog walking in Thurnscoe park. I have recently passed this sculpture many times - and we just know it as ‘The Frog’.

After the local mine closed there was much revamping of the park. Many of the old features remove and the whole layout changed so that it has required minimum maintenance. Many years ago the was a full time park keeper employed, but now it is maintained by volunteers. It appears that ‘The Frog’ was sculptured from a dead tree in situ. One of the locals told us that when it was first carved is was painted with bright colours.

Does anyone know any more about it, especially who the sculptor was ?

Book Review: ‘The Purple Book’



ME/CFS/PVFS
An Exploration of the
Key Clinical Issues

Prepared for health professionals and members of The ME Association by:

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THE ME ASSOCIATION
me

The latest edition of ‘ME/CFS/PVFS – An Exploration of the Clinical Issues’, (also known as the ‘Purple Book’), is a comprehensive 150-page guide to research, diagnosis, symptoms, and all aspects of management. It has an improved layout and updated sections – including the new genetics investigation: Decode ME – and over 600 of the most important published studies, Covid-19, and the importance of a correct management approach for people with M.E.

It is an authoritative publication representing the most comprehensive, evidence-based summary currently available and contains everything that health professionals and patients need to know about this devastating neurological disease.

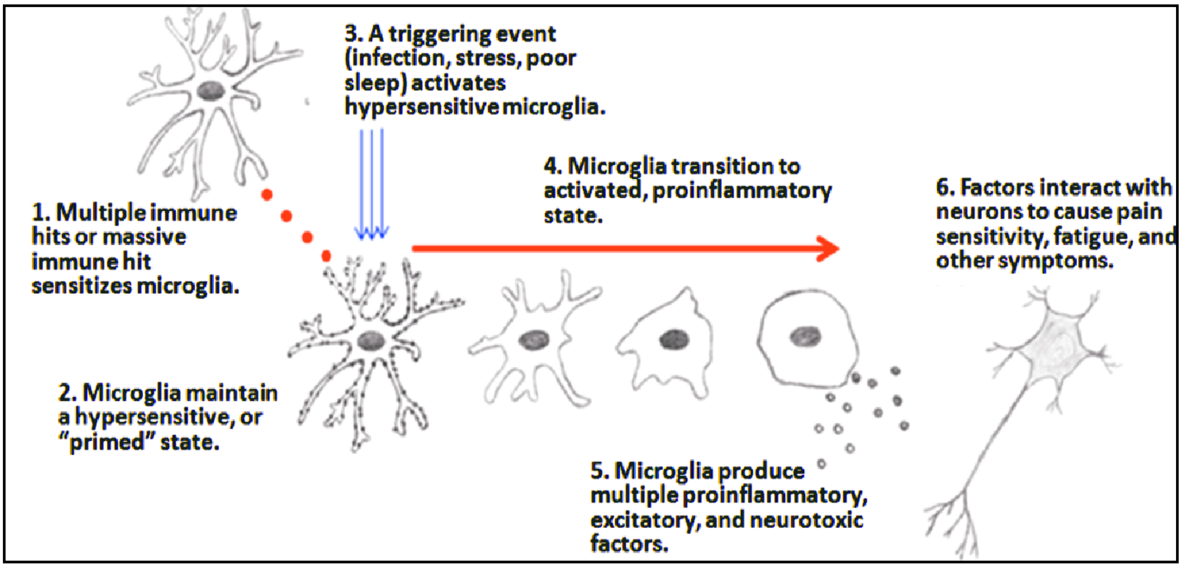
There are also chapters on epidemiology, prognosis, the NICE clinical guideline review, children, and adolescents, as well as severe M.E. and many more topics relevant to this condition.

ME/CFS is characterised by post-exertional malaise and exertion-induced muscle fatigue with a significant impact on a person’s normal ability to function. The most usual onset appears to be following a viral infection and for many sufferers it feels like having a constant flu-like illness with muscular aches and pains, cognitive problems, and poor sleep, often accompanied by dizziness or vertigo and bouts of nausea and stomach upsets.

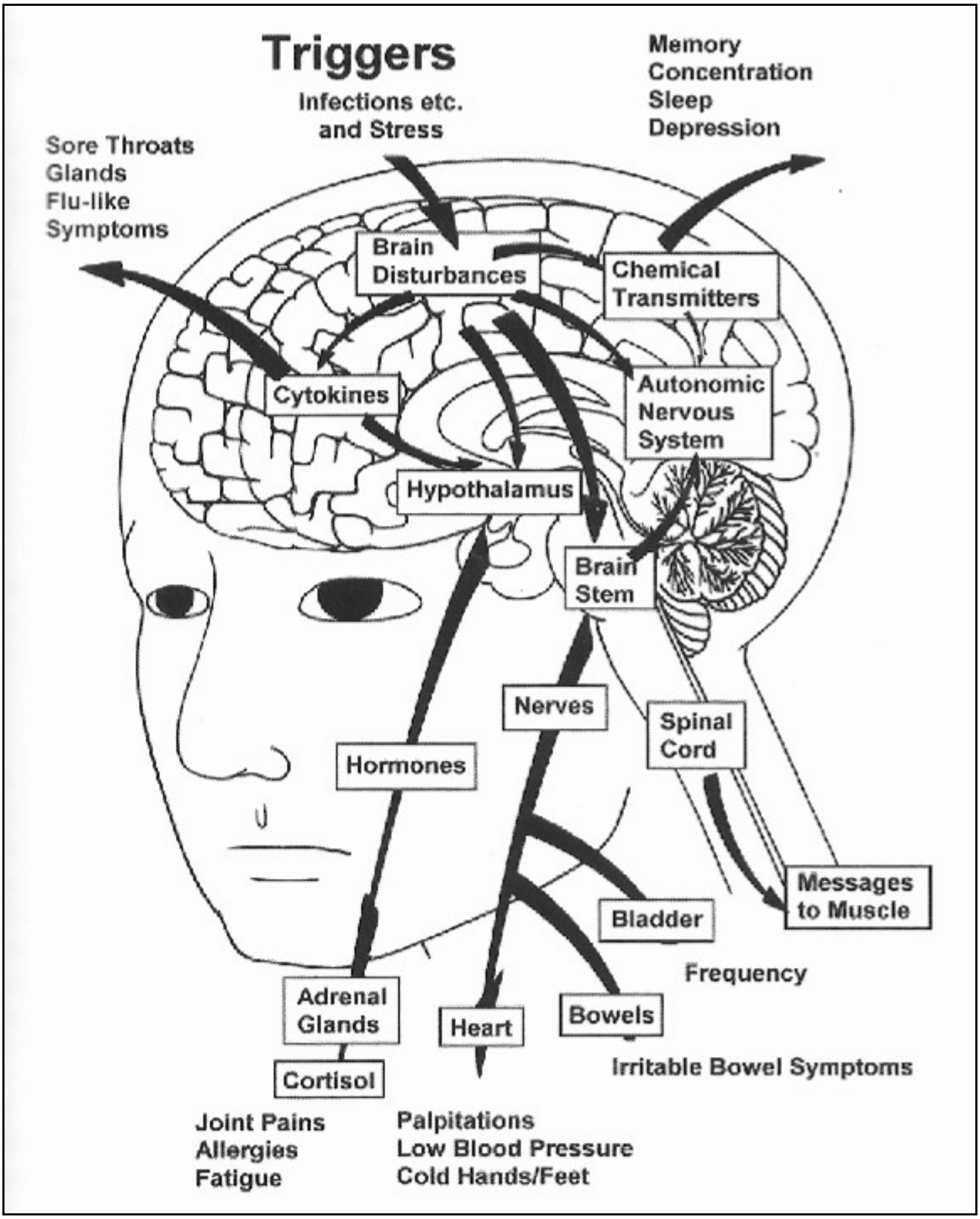
It is a relatively common disease affecting an estimated 265,000 children and adults in the UK (and several millions world-wide) and has been estimated to cost the UK economy £3.3bn each year. It is recognised by both the World Health Organisation and the UK Government as a neurological disease but remains badly neglected in terms of money spent on biomedical research and healthcare support.

ME/CFS can affect all ages, genders and ethnicities and there is evidence that it is more debilitating than multiple sclerosis. Among children, it is the most common cause of long-term sickness absence from school.

ME/CFS can affect people differently and at different times. It is regarded as a fluctuating condition but some either seem to get progressively worse, are stuck for many years and unable to improve for the better or seem to be more affected by a cycle of relapse and remission.



Included in the book is the Microglia Hypothesis of ME/CFS



Include in the book is the above illustration of how ME may be affecting the nervous system. This image is originally from Charles Shepheard's ‘Book Living with ME’

There is no cure or effective treatment, and recovery is not possible for everyone. It can be a slow and tortuous process of careful activity and symptom management with patients enduring daily fluctuations in symptom severity and functional ability.

People who are severely affected will require help to move about, to attend to personal needs, and will need a great deal of rest. Those most affected will need 24-hour care and be bed-bound for all of the time. They will experience an often extreme intolerance to light, touch and noise and are often unable to speak. They can require tube-feeding and be subjected to atypical seizures and have swallowing difficulties.

Healthcare staff are often at a loss as to what to do for the best, because they have received no structured training in ME/CFS as part of their medical education. Misdiagnosis is common, healthcare plans and regular patient reviews are often non-existent. Patients can feel that their doctors do not understand or empathise, and they are reluctant to make appointments or ask for help despite an urgent and deserving need.

No other guide to ME/CFS is updated so regularly. It is a fount of knowledge for every medical and healthcare practice. You can also purchase the guide in from the ME Association Website or in Kindle format from Amazon for around £10 plus postage and shipping.

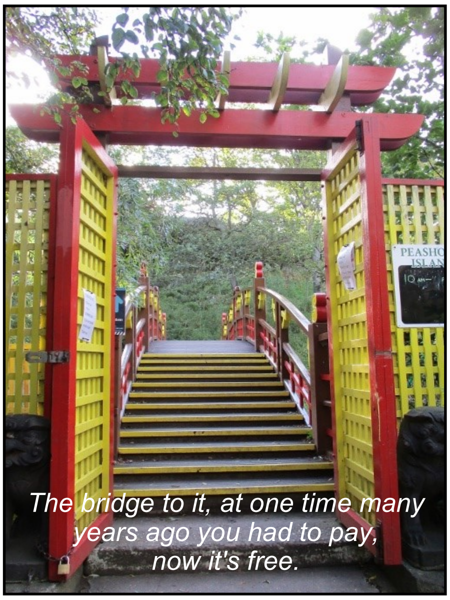
North of Doncaster:

Personal thoughts from Trevor Wainwright

In this issue we really are North of Doncaster eventually, but we begin in Castleford where on March 27th the day I should have flown out to Texas having enjoyed the new experience of train travel to the airport as opposed to a taxi, but instead I did my first delivery for Castleford Isolation Support, a voluntary organisation set up during the first lock down to do what it says, deliver food parcels, shopping, collecting prescriptions and so on. It also proved inspirational for Poetry for the annual National Poetry Writing Month a creative writing project held in April in which participants attempt to write a poem each day for one month. Usually, it would form part of my Texas Tour, but this year due to it being cancelled, I did it as a standalone project, using my time and experiences as a community volunteer and looking at what could have been poems about a missed journey.


Entering the park and looking at Peasholm Island

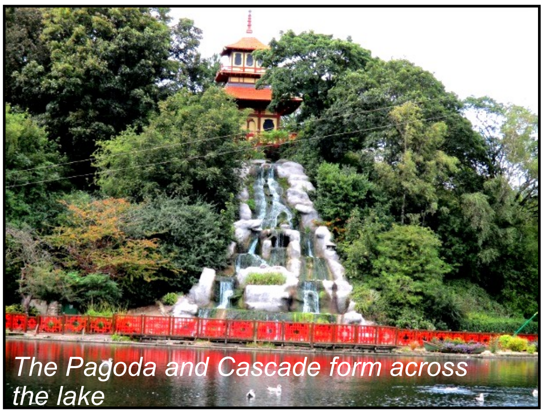
We were busy from the start, later on things started calming down and as lockdown began to be eased, I thought about some time off. So, deciding to have a few days in Scarborough, as I had no photos for my Facebook album, “My Beloved Yorkshire” this would be a chance to add some. I booked online a room for two nights at The Grand, which was anything but, on top of the price of the room, wi-fi, parking and breakfast were extra adding £22 a night to the bill. The free cancellation option was used, and I headed to the North Bay where I found a passable room including wi-fi and parking much cheaper but no breakfast. However, this was no problem there was a cafe nearby.


The bridge to it, at one time many years ago you had to pay, now it's free.

So having unpacked camera, off I went starting at Peasholm Park on what would be a journey of childhood memories. Built in 1912 to an oriental theme, the lake fed by Peasholm beck which with its glens and waterfalls would become Peasholm Glen and which became part of the park in 1924. The Naval battles for which the Park is famous began in 1927 and the crowning glory. The Pagoda on the island based on Thomas Minton’s willow pattern plate of 1720.


View of the Japanese garden from the Pagoda

So, my walk round triggered memories of what it was like in the 1950’s and early 60’s when I used to come for a holiday or day trip. Instead of the Dragon Boats style pedalos they have now, there was a choice of Indian canoe or rowing boat, and for families with young children a motor launch. Crossing the bridge to the island I remembered how once you had to pay extra and there were other exhibits, old toys, and animated working toy exhibitions, then these were removed, and the island restored to its oriental theme. Along the edge of the island some of the old rowing boats had been filled with soil making good flower exhibitions. In what looked like a small boathouse was one of the old launches and an old Indian canoe. Making my way to the top of the island to the pagoda and gardens I stopped and looked at the view from the top of the cascade. Looking down at the bandstand I was reminded of the time I watched a waterskiing show as a child. The gardens were well set out and tranquil with the addition of chicken wire and steel rod sculptures of a crocodile and a lizard.

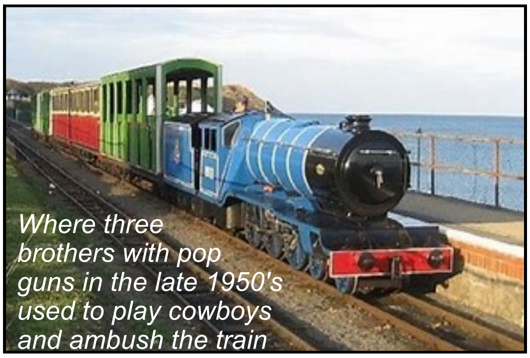

The Pagoda and Cascade form across the lake


Part of The Glen Trail, this was where kids used to sail clockwork boats in the1950's

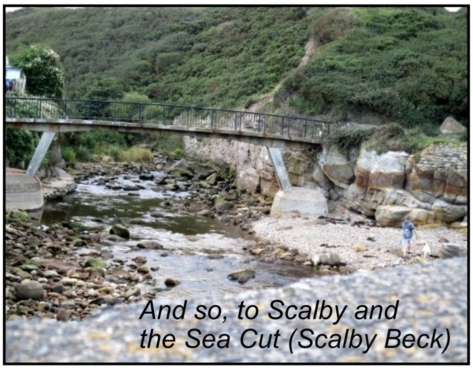
Leaving the island, I carried on by the lake, and came to Peasholm Gap from where I could see the North Beach, and to where the Corner Cafe once stood. Memories again came flooding back of the time there was once a water park and swimming pool, along the side of the road with booths selling beach novelties, ice cream, sweets and fruit, it was where I tried my first ever slice of melon. On a nearby roundabout the Naval Battles were depicted by an old battleship. “Nice touch” I thought. “Keep it out of landfill and it is part of the town’s heritage”. I carried on by the lake thinking of the time I had once referred to the area as “Timeless Scarborough”. There was a slight change, what had been the aviary was now a public seating area. There was a special place I wanted to visit following the Glen Tree Trail which really is unchanged. This is where a series of three ponds feed into the next one down fed by Peasholm Beck, and where at certain times of the year squirrels are prevalent and will come to you for food. The middle pond was what I was looking for, the only one with a concreted area of the main path. It was where in the 1950’s on an evening it would be alive with kids sailing their clockwork boats.


Manor Park's Water chute

Smiling at the memory I made my way back and out of Peasholm Park, crossed the road and into Manor Park home to The North Bay Railway and Scarborough’s open-air theatre. The railway was shut but I remembered in the 1950's when the carriages were open, and the guard use to let kids wave his flag. I would return another time when it was open. The water chute was still there, along with a new attraction, a rope and timber based climbing frame called “The Sky Trail”. Everything had closed giving the park a rundown look. The lake was being used though, by model boat enthusiasts, with quite a variety of craft. Sadly, the Open Air Theatre looked in a state of disrepair nothing like in its heyday, only a white hut remained on the stage. The water area in front which tiered seating was still there and in good condition but the atmosphere that once was there had gone.


Where three brothers with pop guns in the late 1950's used to play cowboys and ambush the train

I followed the railway track towards Scalby where I came across another memory from the 1950’s, in the shape of a hill behind which me and my two brothers would lie on with popguns primed ready to ambush the train. Moving on past the pylon’s relics of a bygone age, which once carried the chairlift from Manor Park to Scalby. But for the addition of a crazy golf course near Sea Life nothing much had changed. Just off the beach in the pond created by Scalby Beck before it ran into the sea, I watched a couple interacting with a dog. During conversation they told me their dog was on palliative care having an inoperable brain tumour, and on the coming Thursday they would have to make a heartbreaking decision, I knew how they felt having had to do similar in 2015. The following week I would return and drop two roses into the pond.


And so, to Scalby and the Sea Cut (Scalby Beck)

I walked back along the beach looking at Scarborough Castle in the distance, the chorus of Out Along the East Coast running through my mind “The sea rushes in, castles crumble and die, I walk along the ocean and talk to the sky”. Reaching the end of the beach I looked at what was now a luxury holiday complex with shops below and again remembered the Corner Cafe and the meals there, always good and just down from it were more beach booths selling everything you needed for the beach, it was where I had my first ever waffle. Turning round I looked at where the North Cliff Lift or Funicular as they were often called, had been, it used to cost two pence (2p) in old money, in the 1950’s you could get a few sweets with than. More often than not I would take the two pence off my dad, then run up the steps when he wasn't looking, I think he guessed though but didn’t mind. It was the last of 5 to be built in Scarborough, but what of the other four? But that is for the next issue...