Pathways

Price £ 4.00 (Free to members)

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

Welcome to Pathways No. 65. (Autumn 2020)

Coronavirus 19: The Rule of Six

Coronavirus (COVID-19): Meeting with others safely (social distancing) Published 9 September 2020 (Aka the rule of Six)

There is no doubt we are now in a second wave situation. The government needed to introduce these are the new rules which apply from today. They are the law.

This is guidance that applies to England only. If you live in an area where local restrictions are in place you should also consult the local restrictions guidance, for information about what you can and can't do to manage the outbreak. It is critical that everybody observes the following key behaviours:

- **HANDS** - Wash your hands regularly and for 20 seconds.
- **FACE** - Wear a face covering in indoor settings where social distancing may be difficult, and where you will come into contact with people you do not normally meet.
- **SPACE** - Stay 2 metres apart from people you do not live with where possible, or 1 metre with extra precautions in place (such as wearing face coverings or increasing ventilation indoors).

1) Distancing

- To reduce the risk of catching or spreading coronavirus, try to keep at least 2 metres away from people you do not live with. Social distancing is essential to stop the spread of the virus, as it is more likely to spread when people are close together. An infected person can pass on the virus even if they do not have any symptoms, through talking, breathing, coughing or sneezing.
- When with people you do not live with, you should also avoid: physical contact; being close and face-to-face; and shouting or singing close to them. You should also avoid crowded areas with lots of people; and touching things that other people have touched.
- Where you cannot stay 2 metres apart you should stay more than 1 metre apart, as well as taking extra steps to stay safe. For example:
- wear a face covering: on public transport and in many indoor spaces, you must wear a face covering by law, unless you are exempt
- move outdoors, where it is safer and there is more space
- if indoors, make sure rooms are well ventilated by keeping windows and doors open
- You do not need to socially distance from anyone in your household, meaning the people you live with.
- You also do not need to socially distance from someone you're in an established relationship with, or anyone in your legally-permitted support bubble you are in one.
- It may not always be possible or practicable to maintain social distancing when providing care to a young child, or person with a disability or health condition.
- You should still limit close contact as much as possible when providing these types of care, and take other precautions such as washing hands and opening windows for ventilation.

2) Seeing friends and family

When seeing friends and family you do not live with you should follow social distancing rules limit how many different people you see socially over a short period of time meet people outdoors where practical: meeting people outdoors is safer than meeting people indoors because fresh air provides better ventilation.

Front page photo with thanks to Carolyn. Doyenne Du Comice pears ripening in late August. Besides ourselves the local blackbirds help themselves. Many people through the CV19 lockdown have tried to grow vegetables with mixed success. Fruit trees need truly little attention and crop heavily most years.

Limits on the number of people you can see socially are changing.

- From Monday 14 September, when meeting friends and family you do not live with you must not meet in a group of more than 6, indoors or outdoors.
- From 14 September - when the new rules apply - it will be against the law to meet people you do not live with in a group larger than 6 (unless you are meeting as a household or support bubble)
- The police will have the powers to enforce these legal limits, including to issue fines (fixed penalty notice) of £100, doubling for further breaches up to a maximum of £3,200.

There will be exceptions where groups can be larger than 6 people, including:

- where everyone lives together or is in the same support bubble, or to continue existing arrangements where children do not live in the same household as both their parents
- for work, and voluntary or charitable services
- for education, training, registered childcare, or providers offering before or after-school clubs children
- fulfilling legal obligations such as attending court or jury service
- providing emergency assistance, or providing support to a vulnerable person
- for you or someone else to avoid illness, injury or harm
- participate in children's playgroups
- wedding and civil partnership ceremonies and receptions, or for other religious life-cycle ceremonies - where up to 30 people will be able to attend
- funerals - where up to 30 people will be able to attend
- organised indoor and outdoor sports, physical activity and exercise classes (see the list of recreational team sports, sportexercise allowed under theand leisure centre guidance
- youth groups or activities
- elite sporting competition or training
- protests and political activities organised in compliance with COVID-19 secure guidance and subject to strict risk assessments

3. In other venues and activities

Venues following COVID-19 secure guidelines will be able to continue to host more people in total - such as religious services in places of worship - but no one should visit in a group of greater than 6.

When you visit one of these places, such as a pub, shop, leisure venue, restaurant or place of worship you should:

- follow the limits on the number of other people you should meet with as a group - no more than six people unless you all live together (or are in the same support bubble)
- avoid social interaction with anyone outside the group you are with, even if you see other people you know
- provide your contact details to the organiser so that you can be contacted if needed by the Test and Trace programme

Please remember that there are people about who are symptomless carriers who can infect others.
So the safest assumption is to assume that everyone is a potential risk.

Remember HANDS FACE SPACE

Poets corner

Many people with ME/CFS get great comfort by write poetry. Many also enjoy reading it. Here is Bill Layton contribution to Pathways.

Stick With It

1.

In life we like to fit right in
To mix in with the crowd
Not to shout, not stand out
Not to be too loud
.

2.

But sometimes things just come along
That force us into change
I'm talking Chronic Illness
Making life so strange
.

3.

When M.E. hits, it hits you hard
Some want to spread the word
Some keep it to themselves
For most our thoughts are blurred

4.

It's tough to feel you're not the same
Sometimes think that you're to blame
But legs don't work, you feel a jerk
Many even struck with shame

5.
With me, my legs have caused me pain
It takes so little for strength to drain
My balance is shot, and that's not all
I need some help to stop a fall

6

It took some months to finally admit
I needed some help to get around
A stick to help me balance
To stop me meeting with the ground

7.

But a walking stick isn't really me
It's not who I'm supposed to be
Never been in this position before
So kept it behind the kitchen door

8.

Months went by, I struggled on
Stupidly it took a while to dawn
That I needed help, forget my pride
If I wanted to venture back outside

9.

I was feeling so self conscious
I was wary of the stares
But I soon found, looking around
That no one really cares

10.

Their minds are busy, stuff to do
Not really bothered about me and you
I strangely felt it was a bit of a win
We really just tend to blend right in

11.

My magic wand, of which I'm now fond
Would find me a seat on a bus
It opened a door like never before
With hardly any fuss

12.

So after all my worries
About who I have become
I'm still me, but with a stick
No reason to be glum

13.

We all have other issues
I'm sure you have a list
But don't add to them by being scared
Don't add to what you've missed

14.

I know that many bound to home
Would crave to have such a gift
So I count my blessings every day
To have something that gives such a lift

15.

I learned my lesson, use the stick
Even if not the life we'd pick
Regenerate like Doctor Who
Try to embrace the newer you.

You Write In

Dawn Writes: Despite PIP telling me I would hear something about my renewal which is due to end at the end of the month, I haven't heard anything. So must presume it will continue?
Also have you ever known anyone move to another EU/EEA country i.e. France and be allowed to keep their PIP?. I have researched it a bit and I'm gathering in some instances your allowed to keep both elements but generally after 3 months you cannot keep the mobility component?

Firstly, with the current Covid 19 situation, the DWP have quite a lot on their hands dealing with new universal credit claims. I would wait until you are asked to submit another claim by the DWP, and not rock the boat until they take action.
Secondly, because we are coming out of the EEC next year (we are currently in an exit transition) I don't think it can be carried forward. You may not get a straight answer because the Brexit terms are not yet agreed. I know that state pensions can be paid abroad and in the Irish republic but at a reduced rate. Private pensions and occupational pensions are usually able to be paid abroad, but they will be taxed both in the UK and in the country of residence. In any case you should talk this out with your pension provider.

If you are thinking of moving abroad, just bear in mind that the health services of other countries are different and involves health payments in excess of the NI contributions. If you do move house or move abroad it will always trigger a PIP review in any case. We have one member whose family own a holiday a villa. She goes in Autumn and returns to the UK in spring. She doesn't say anything to DWP. This is three month residency rule for most DWP benefits after which they are reviewed automatically, and reduced. This for example could be a long stay in hospital or time spend abroad.
If you are emigrating abroad don't do this until the Covid situation has resolved, because there is more trouble to come.

DWP Habitual Residence and Presence

To make a claim for PIP you need to be present in Great Britain, and habitually resident in the Common Travel Area which is the United Kingdom, the Channel Islands, the Isle of Man and the Republic of Ireland. Members of the armed forces and their families are treated as habitually resident in Great Britain whilst serving abroad.

In addition, a 'past presence' test means you need to have spent at least two out of the last three years, 104 out of the last 156 weeks in Great Britain.

The 2 year rule may not apply in some cases, including where you currently live, or have lived, in the European Economic Area or Switzerland. In some circumstances you may need to demonstrate 'a genuine and sufficient link to the UK social security system' which may include issues like having spent years living in the UK, worked here, or you or someone you depend upon is getting a benefit that can only be received through having paid UK national insurance contributions.

For more information, in the first instance you can contact:
Exportability Team Coordinator
exportability.team@dwp.gov.uk Exportability Team Room B215 Pension, Disability and Carers Service Warbreck House Warbreck Hill Road Blackpool FY2 0YE

Gary Writes: Have you thought about contacting the team at Sheffield University researching the long term effects of Viruses in relation to Covid-19 and offering our support and input?

That is a good question. I do get approached about research from time to time, but this is usually psychology students doing a project and is unlikely to benefit anyone with ME/CFS. In any case if I though there would be a beneficial outcome, I would go through the Sheffield ME/CFS clinic.

ME/CFS is a long term chronic condition like Asthma, Diabetes or MS for example. It is heterogeneous simply because of getting ME/CFS from different things. There are at least six subtypes, and as with other conditions and treatment will depend on the subtype. Current ME research ignores the existence a subtypes. Looking a, this come in two main types 3-4 rarer types, which require quite different management strategies. So I would expect that different ME/CFS subtypes would need different strategies.

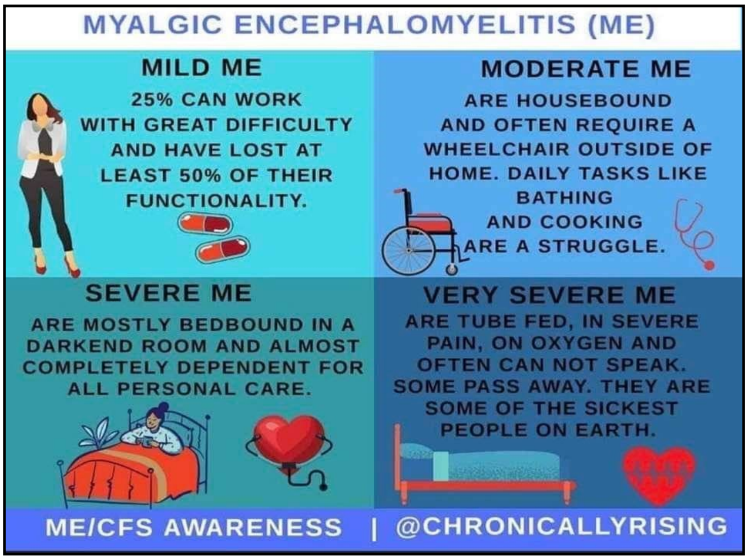
Most of the research effort for CV19 is being put into vaccination development and management *particularly of the hospitalised cases. What is quite clear is that have severe problems with Covid 19 are likely to suffer from Post Covid Syndrome which is effectively post viral syndrome. If that persists more than 6 months them it will ne ME/CFS.*

If you are thinking about research there has to be a clear objective. then you have to compete for funding, and have whatever you are researching scrutinised before it starts. Then there is the question of obtaining ethical consent from the GMC. and then you have to compete for funding along with other projects. The Sheffield ME/CFS clinic did look into this a project, but nothing came out if it.

What I do know from the cases locally is that the severe course of CV19 in not a pure disease. There are often infections both viral and bacterial along with. I also know that severe CV19 forces people into diabetes, and these people have to be treated with insulin while in hospital. and on discharge. There is still a lot to learn.

The CV 19 cases only started in March in this country. I'm waiting with interest just to see at the six month stage how many people are suffering from Post Covid Syndrome.am watching for developments with interest. I do hope there is a beneficial spin off for us with ME/CFS. I've attached the leaflet from the ME Association. Which may partly answer some questions. I've already distributed around 30 copes.

Karen writes. This image (right) was posted on the Facebook group as few days ago. What do you make of it?



MYALGIC ENCEPHALOMYELITIS (ME)

MILD ME

25% CAN WORK WITH GREAT DIFFICULTY AND HAVE LOST AT LEAST 50% OF THEIR FUNCTIONALITY.

MODERATE ME

ARE HOUSEBOUND AND OFTEN REQUIRE A WHEELCHAIR OUTSIDE OF HOME. DAILY TASKS LIKE BATHING AND COOKING ARE A STRUGGLE.

SEVERE ME

ARE MOSTLY BEDBOUND IN A DARKEND ROOM AND ALMOST COMPLETELY DEPENDENT FOR ALL PERSONAL CARE.

VERY SEVERE ME

ARE TUBE FED, IN SEVERE PAIN, ON OXYGEN AND OFTEN CAN NOT SPEAK. SOME PASS AWAY. THEY ARE SOME OF THE SICKEST PEOPLE ON EARTH.

ME/CFS AWARENESS | @CHRONICALLYRISING

Extract from NICE Guidelines GC57.

Mild: People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.

Moderate: People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe: People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

This posting of concern because it relates to the grading in ME/CFS which is does not relate to the UK. It is a copy of others I've seen on American or South African websites. These countries have their own way of defining ME/CFS, which considerably differs from the UK view. One the right I have included he NIHCE guidelines (GC 57) which are in current use by the UK NHS clinics below this image for comparison. The posting is a corruption of the Finley Grading system which I detailed in Pathways No 1 from page 5. Certain aspects are misleading and could be harmful in certain circumstances particularly to mental health. Leger ME adopted these GC 57 guidelines. However, we also add a further grade of Very Severe ME/CFS where other major illness or complications are present. Very few Leger ME members have pure ME. - Very often they have additional major physical or mental illness. The is a flaw in the NIHCE guidelines, is that Fibromyalgia is not included nor are associated things the commonly occur at the same time like Irritable Bowel Syndrome (IBS), Postural Orthostatic Tachycardia Syndrome (POTS) and Immune Abnormalities. About 40% of our members are Asthmatic, and 10% are Diabetic.

Regarding tube feeding, in the past 30 years or so I know of only one case locally. Regarding deaths of ME/CFS patients locally there have been due to cancer, especially breast cancer, heart problems and suicide. The people who need oxygen usually have Chronic Obstructive Pulmonary Disease (COPD), usually as a result of smoking. There is only one death nationally associated to ME/CFS that I know of and that is the Sophia Mirza case which occurred outside our area.

The Department of Work and Pensions do not recognise the NIHCE grading system for welfare rights and benefits purposes.

Welfare Rights Matters *from Benefits and Work*

Benefits and Work
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Claims and Challenges Plummet

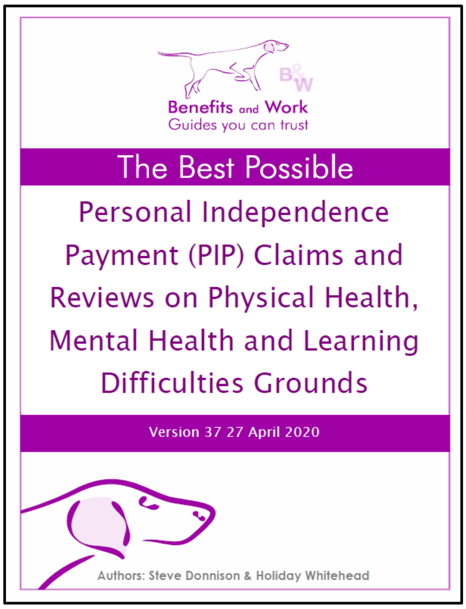
Figures for Northern Ireland released last week show that claims for PIP have plummeted and so too have mandatory reconsideration requests, since the pandemic hit. The figures show that fresh claims for PIP in April and May are down by almost 60% compared to the same period last year. Mandatory reconsideration requests have also imploded.

There has been a fall of 90% compared to April and May of last year. The figures for Northern Ireland are following the same route as the PIP figures released by the DWP in June of this year. As we reported then, new claims for PIP had fallen by 40% in April 2020, compared to a year ago. In addition, mandatory reconsiderations were at their lowest since January 2016. The fall in new claims and in mandatory reconsiderations has yet to be explained. But it seems likely that the difficulty of accessing support during the pandemic, especially from advice agencies, means fewer people have been told that they may be eligible for PIP. Also, fewer who have claimed and been refused get the support they need to challenge a refusal.

This is something that I have noticed with Leger ME members Ed.

DWP Spends Tens of Millions to Lose More Appeals

The DWP has dramatically increased its spending on fighting PIP and ESA appeals, whilst losing an ever-higher proportion of cases. Figures obtained by the Independent, show the DWP spent £121m between 2017-19, with £58m spent on mandatory reconsiderations and £63m spent on tribunal appeals. When broken down annually over three years, it shows that the amount spent on mandatory reconsiderations increased by 19% between 2016-17 and 2018-19, and the cost of tribunals surged by an extraordinary 64%. Yet the DWP is actually losing more and more appeals, with the success rate for PIP claimants now at 76%. The willingness of tribunals to trust claimants, rather than private sector health professionals, seems to be one problem that the DWP cannot solve just by throwing money at it.



Benefits and Work
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The Best Possible

Personal Independence Payment (PIP) Claims and Reviews on Physical Health, Mental Health and Learning Difficulties Grounds

Version 37 27 April 2020

Authors: Steve Donnison & Holiday Whitehead

Online PIP Claims by The End of The Year

The DWP says it should be possible to claim PIP online by the end of the year. Responding to an MP’s question about whether PIP forms could be completed online during the pandemic, Justin Tomlinson, minister for disabled people, said:

“We are committed to providing a digital channel - “PIP Apply” - to widen claimants’ choices on how to make a new claim for PIP. Using the digital channel is optional and we will ensure we provide effective alternatives for those who are unable or prefer not to use our online services. We are aiming to provide this service by the end of the year.”

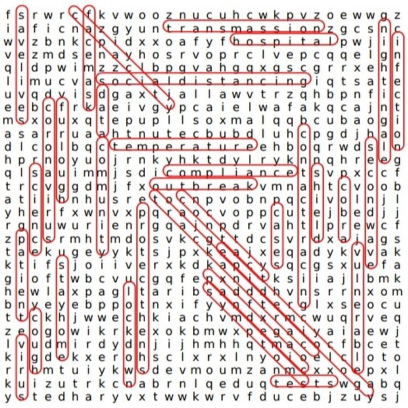
With many housing, health, and advice workers still unable to meet clients face-to-face, an online claims system could be an enormous help if it allows different people to view and add to the same form. But only if the online system is reliable and allows claimants to give all the evidence they want. Benefit and Work will be testing it out for our readers as soon as it appears.

Comment. *An electronic version Employment and Support Allowance form EAS 50 has been available for many years. To date it has seemed odd that the was not an equivalent form for PIP. We have our own e version of the PIP form, but only for use as drafting aid. Our advice is to avoid using these electronic forms and stick to a paper versions. Until the bugs are cleared out of what seems to be endemic in new DPW forms. Please remember we can send the appropriate Benefit and Works guide by email as part of the membership deal. Printed versions cost about £ 8-10.*

Puzzle Corner *By Nichola Stockton*

I hope you enjoyed the puzzles in the last issue Pathways 64. Here are the solutions.

Coronavirus Word Search

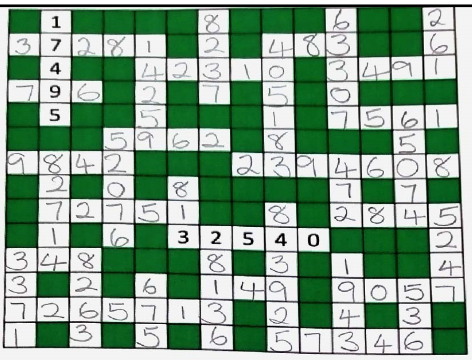


Social distancing
Transmission
Coronavirus
Infection
Stay home
Hospital
Contact
Virus
Furlough

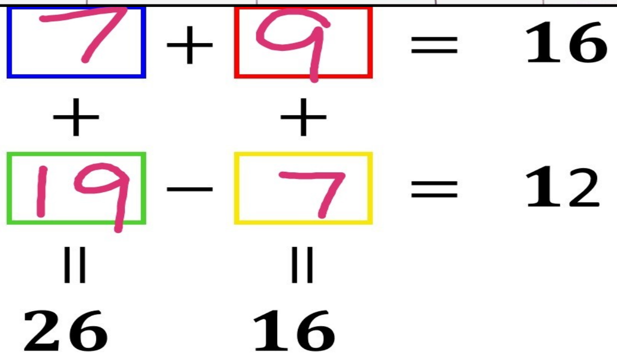
Contact tracing
Temperature
Compliance
Vulnerable
Community
Lockdown
Science
Tests
Data

Protect the nhs
Epidemiology
Nightingale
Face mask
Outbreak
Patient
Cases
Cough

Track and trace
Second wave
Save lives
Pandemic
Capacity
Symptoms
Cobra
Shield



3 DIGITS		4 DIGITS		5 DIGITS		6 DIGITS	7 DIGITS
149✓	536✓	1943✓	7561✓	14259✓	52076✓	405183✓	2394608✓
261✓	675✓	2845✓	8237✓	~~17495~~	57346✓	843925✓	7265713✓
348✓	796✓	3371✓	8263✓	28136✓	63307✓		
472✓	813✓	3491✓	9057✓	~~32540~~	65074✓		
483✓		5247✓	9842✓	37281✓	72751✓		
		5962✓		42310✓	82714✓		



7 + 9 = 16

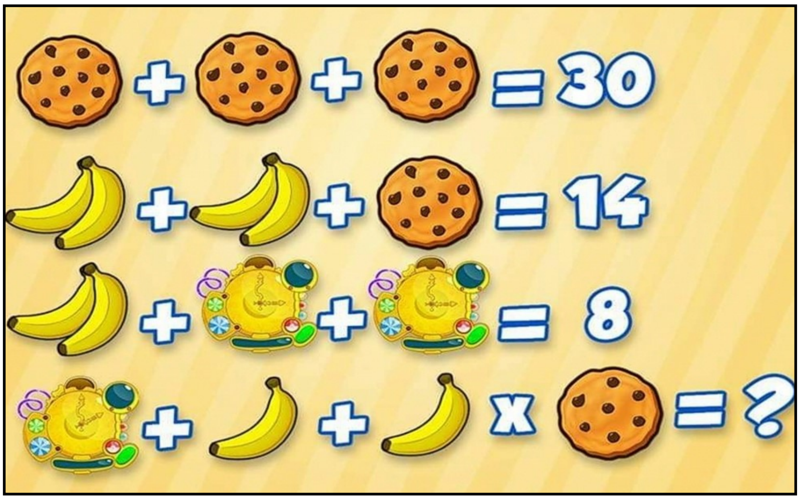
+ +

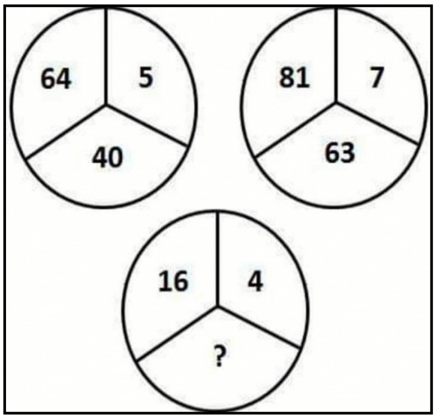
19 − 7 = 12

= =

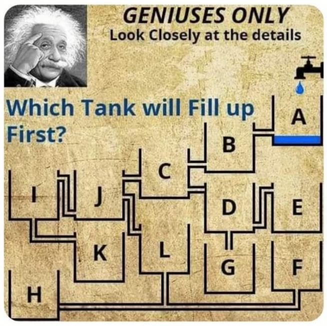
26 16

Here are this issues puzzles.





TIP : IT'S NOT G



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

air conditioner
backpacking
sweltering
lightning
vacation
fresh fruit
seashore
camping
ice cream
flowers

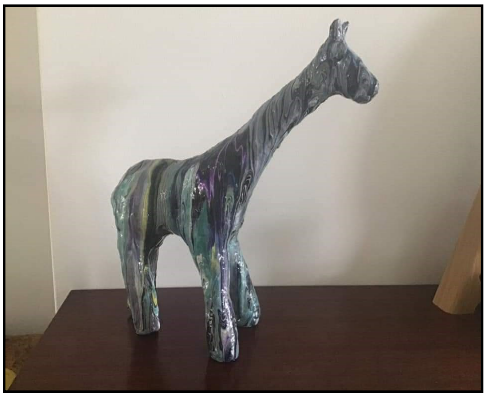
blistering heat
bathingsuit
sandcastle
waterpark
waterski
stifling
canoeing
showers
thunder
outings

fourth of July
warm weather
sightseeing
sunscreen
swimming
sundress
frisbee
humidity
outside
trunks

thunderstorm
watermelon
recreation
gardening
sunflower
road trip
boating
holiday
sailing
hiking

Crafty corner. A selection of craft from our members.

Ann has made some fabulous creatures from aluminium foil covered paper mâché and then painted them using her distinctive poured acrylics technique.


Sandra has taken to the sewing machine to produce these brilliant iPad / tablet/ phone cushions. T hey are multi angle and have zipped liners filled with polystyrene beads.

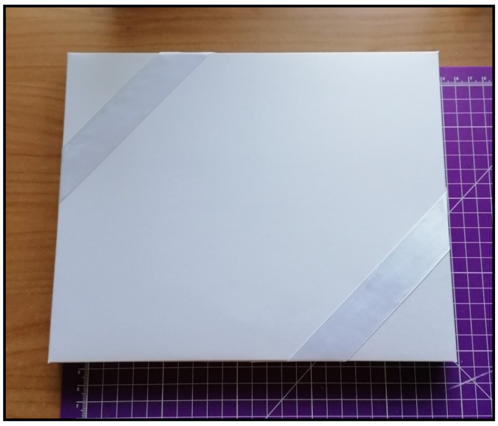


John has made this fantastic scarecrow, with help from Dave (in the first picture) for his local scarecrow competition.



Nicola ’s latest project was a wedding horseshoe for one of my partner's nephews. It's made out of fimo clay. She Made the box too!





Official Guidance Changes to Medicines in Commons Use:

New NIHCE guidance advises doctors not to prescribe analgesics for chronic pain.

A draft NIHCE guideline is open for public consultation until 14th September that offers to doctors guidance on chronic pain warns that prescribing opioids and other commonly used drugs has little benefit and can lead to addiction. Paracetamol, NSAIDs (e.g. Ibuprofen), benzodiazepines and opioids should not be offered to people with chronic primary pain because there is little evidence that they make any difference to people's quality of life, pain, or psychological distress, according to NICE.

The draft guidance, which is NICE's first ever guideline on the assessment and management of chronic pain, also says that antiepileptic drugs (including gabapentinoids), local anaesthetics, ketamine, corticosteroids and antipsychotics should not be offered to people to manage chronic primary pain. Instead, patients should be offered supervised group exercise programmes, certain types of psychological therapy (e.g., cognitive behavioural therapy [CBT]), or acupuncture. Some antidepressants (duloxetine, fluoxetine, paroxetine, citalopram, sertraline, or amitriptyline) can also be considered, NIHCE says, although their use in this context is off label (unlicensed).

The guideline committee highlighted evidence that CBT improved quality of life for people with chronic pain, while exercise reduced pain and improved quality of life compared with usual care. The committee also concluded that acupuncture reduced pain and improved quality of life in the short-term; however, to ensure cost-effectiveness of this intervention, NIHCE said it should only be provided in a community setting, by a band 7 or lower health professional, and involve no more than 5 hours of that person's time.

For patients already taking antidepressants, opioids, gabapentinoids or benzodiazepines, GPs should explain the risks of continuing to take the drugs. If a shared decision is made to stop treatment, prescribers should be aware of the problems associated with withdrawal. The guideline emphasises the importance of 'putting the patient at the centre of their care', and of fostering a 'collaborative, supportive relationship' between the patient and healthcare professional. It also highlights the role of good communication and its impact on the experience of care for people with chronic pain. 'This guideline, by fostering a clearer understanding of the evidence for the effectiveness of chronic pain treatments, will help to improve the confidence of healthcare professionals in their conversations with patients. In doing so it will help them better manage both their own and their patient's expectations.'

This is certainly going to be unpopular with people suffering from ME/CFS and Fibromyalgia -Ed.

New restrictions introduced on sales of stimulant laxatives to counter risks from overuse

People who take stimulant laxatives for constipation are being advised that these will now be sold in smaller packs, with additional on-pack warnings. The Medicines and Healthcare products Regulatory Agency (MHRA) has taken action to reduce abuse and overuse of these products, and new packs will begin to appear in stores over the summer. Additional label warnings make clear that stimulant laxatives do not help with weight loss.

Anyone with regular bouts of constipation is advised against the long overuse of stimulant laxatives (including products containing bisacodyl, senna or sodium picosulfate) which can result in damage to the digestive system, including chronic constipation and damage to the nerves and muscles of the colon. Instead, they should talk to a healthcare professional, who will provide advice, first on trying alternatives, such as diet and lifestyle changes, but also on switching to other products such as bulk laxatives, which work in the same way as fibre to increase the bulk of stools.

Parents and carers can talk to a pharmacist about treatment of short-term constipation in children over 12. However, they should seek advice from a prescriber such as their GP if the child is younger than 12 years or they are worried about their child's health.

Stimulant laxatives can provide short-term relief to some people with occasional constipation, and most people use these medicines safely. However, there is evidence of misuse by people with eating disorders, and of long-term use by the elderly, as well as inappropriate use in children. Misusing laxatives can have a serious impact on the health of patients and the new risk minimisation measures will improve patient safety.

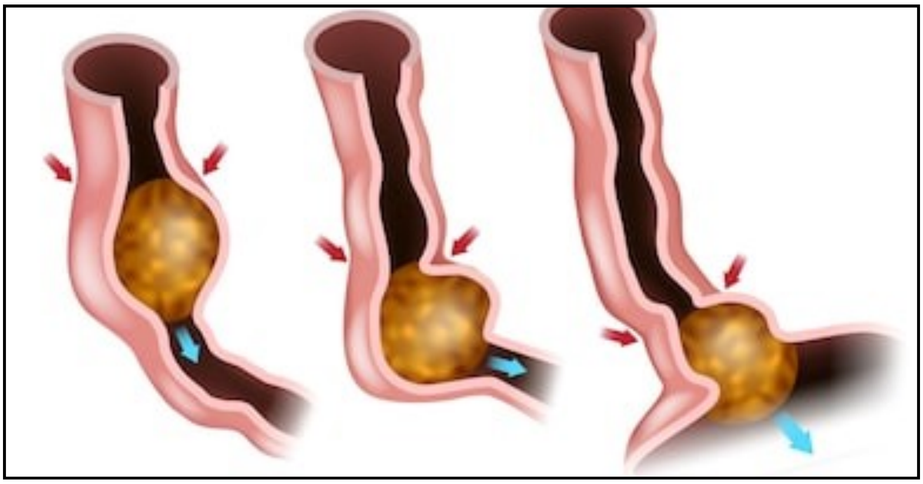
This you need to know when taking a Stimulant Laxative?

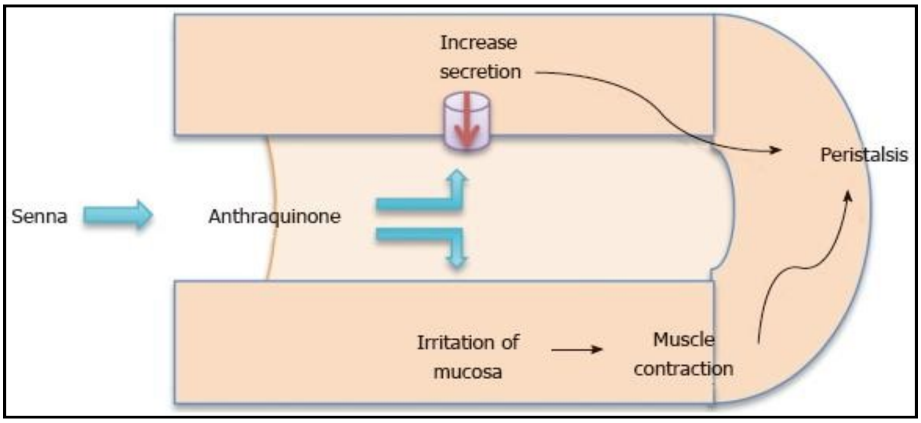
- Overuse may lead to fluid or mineral depletion. Magnesium may be lost increasing fatigue.
- Tell all of your health care providers that you take Stimulant Laxative (docusate and senna). This includes your doctors, nurses, pharmacists, and dentists.
- Do not use Stimulant Laxative (docusate and senna) for more than 1 week unless told to do so by your doctor.
- Do not use other stool softeners unless told to do so by the doctor.
- If you have rectal bleeding or you do not have a bowel movement after using Stimulant Laxative (docusate and senna), talk with your doctor.
- Tell your doctor if you are pregnant, plan on getting pregnant, or are breast-feeding. You will need to talk about the benefits and risks to you and the baby.

Laxatives can prove attractive for people affected by eating disorders, but also have the potential to cause serious health problems. A 2014 survey on sufferers who abused laxatives found that nearly all had bought laxatives over the counter, and 66.7% said they had developed a dependency on them. The new guidelines have been introduced following a review into the safety of these medicines. The review, by the Commission on Human Medicines (CHM), was prompted by concerns regarding the overuse and misuse of stimulant laxatives by patients with eating disorders, overuse in the elderly and use in children without medical supervision. Additional warnings regarding the risk of overuse and making clear that these products do not help in weight loss are being added to packs.

Stimulant laxatives work by stimulating the muscles that line your gut, helping them to move stools along the back passage.13.9 million packs were sold in the UK in 2016 and approximately 1 million of these were prescribed. Stimulant laxative medicines available in the UK over the counter are bisacodyl (such as Dulcolax), senna and sennosides (such as Senokot), and sodium picosulfate (such as Dulcolax Pico).

Right -With ME/CFS the local autonomic neural network maybe compromised which contracts the gut smooth muscle and does not work properly. Also, certain medicines e.g. opiates codeine or anticholinergics (e.g. amitriptyline) inhibits peristalsis. (the normal movement of the bowel). Stimulant laxities work by forcing the contractions. There are plenty of other laxative classes which are safer to use.





Garden Watch: A House in the Garden

by Carolyn

Over the past four years we have had hedgehogs visiting the garden on a regular basis during the summer months and have fed them and enjoyed watching them.

In late Autumn as the weather became colder they would disappear off to hibernate, perhaps in the hedgerows of the field beyond the garden, but I would sometimes still see a smaller hedgehog looking for food long after the bigger ones had stopped visiting, often coming to the garden in daylight hours which isn`t a good sign as Hedgehogs are nocturnal. I wondered whenever I saw a little one like this if it would actually make it through winter if it wasn`t feeding well and up to the right weight for hibernation. I decided it was time to do something about it, to learn how to really care for them.

`Could we build a Hedgehog House`? I asked the other half. After doing some research on all the materials that would be required to build this new home in the garden it was decided that it would be cheaper to buy a good sturdy one readymade! The Hedgehog House duly arrived and was set up with food and meadow hay bedding.

After a couple of weeks, the food began to disappear and a very neat hedgehog shaped hole appeared in the bedding most mornings, it was clear someone had been late at night, eaten up and left early! One cold morning in late Spring I went to collect the food bowl and there tucked up fast asleep in the hay was a medium sized Hedgehog who we named `Harley` because of the speedy way in which he moves purposefully around the garden. (Hedgehogs have quite long legs and can move as quickly as we walk. They can also climb and swim well).

I had been learning more about Hedgehog life and realized that something was wrong with the set up. If we had a hedgehog use the house for giving birth to hoglets then we wouldn`t be able to keep going in and out with the food as an adult may take fright and abandon the nest or, worse, eat the tiny hoglets! What we needed was a separate feeding station, so in went the order. The feeding station was soon in place a short distance away from the house and within a couple of days the hedgehogs were happily going in for their food.

So now all we have to do is to keep on supplying the food and this, along with what they forage naturally, should help in making sure they are strong enough to hibernate successfully this coming winter. (Hedgehogs only eat the food we put out for them as *an extra* to the slugs and snails etc., they find for themselves, they never eat it instead of their natural foods).

I have learned quite a lot more about caring for them this past few months and know that it is possible that a group of hedgehogs, possibly as many as six, could all hibernate together in the Hedgehog House, now that would be a big responsibility through winter !!

Ten Key Aspects of ME/CFS Management: The Local Aspects

Adapted from a feature on the ME Association website by Dr Charles Shepherd, Medical Director of the Association, from where the original can be downloaded.

1) Make Sure the Diagnosis Is Correct and Don't Automatically Attribute New or Worsening Symptoms To ME/CFS

Where ME/CFS-like symptoms follow an acute infection, it is quite likely that a diagnosis of a post-viral/ infectious fatigue syndrome (PVFS), or post-viral debility, will be used during the first few weeks. But if symptoms persist, a diagnosis of ME/CFS might then be made or should certainly be given serious consideration. The 2002 Chief Medical Officer's Working Group Report and the 2007 NICE guideline on ME/CFS, and the MEA guidelines all state that doctors should be aiming to confirm a diagnosis in straightforward cases after three months of symptoms in children and adolescents and four months in adults.

One of the reasons why some doctors find it difficult to make a diagnosis of ME/CFS is that this must be based on medical history alone -as there is no diagnostic blood test for this illness. However, a number of specific blood and urine tests should always be checked before a doctor confirms a diagnosis of ME/CFS. This is because there are a considerable number of other illnesses - endocrine/hormonal, infectious, immunological, neurological, rheumatological -that can produce symptoms which are remarkably similar to ME/ CFS.

Routine blood tests that should be arranged to exclude other possible causes of an ME/ CFS like illness:

- ESR and C-reactive protein (markers for inflammation and infection)
- Hemoglobin, red blood cell indices and serum ferritin (for anaemia and iron status)
- White cell count and differential (markers of infection)
- Biochemical panel including calcium, urea, and electrolytes (sodium and potassium), total protein, blood sugar and Hb1acc (for diabetes)
- Liver function tests
- Serum creatinine (kidney function test)
- Thyroid function tests
- Creatine kinase (muscle function test)
- Immunological screening test for coeliac disease

It is also important to check with your doctor when a new symptom appears, especially what are known as 'red flag' symptoms by doctors (e.g. weight loss, joint swelling, persisting fever or raised temperature) , or an existing symptom (such as joint pain) becomes significantly worse, or changes in character. Do not automatically assume that this is just another aspect of your ME/CFS. The same advice applies when you have a significant relapse or exacerbation of ME/ CFS symptoms and there is no obvious explanation -such as an infection or a significantly stressful event such as a surgical operation or physical trauma. Vaccinations can also occasionally trigger ME/CFS and/or cause an exacerbation of ME/CFS symptoms.

2) What Can Health Professionals Do to Help?

Most people with ME/CFS can, and should, be managed by their general practitioner but in the first case they should be referred to the Sheffield NHS ME/CFS clinic the Michael Carlisle Centre Sheffield for management guidance. Decisions about any aspect of management should be properly discussed with the health professional involved and mutually agreed -following the principles of informed consent that are produced by the General Medical Council and those set out in the NICE guidelines. If there is a query over diagnosis, or help is required in relation to any aspect of management, or you have a GP who just isn't interested in ME/CFS, you can ask for a referral to a hospital-based specialist or ME/CFS service.

If you are severely affected -i.e. wheelchair-bound, house-bound or bed-bound -you should be assessed by a doctor with expertise in ME/CFS at least once and preferably be under the joint care of a hospital-based team who can carry out domiciliary (home visiting) care and your GP. For children and adolescents who are sufficiently unwell to be continually away from school, ongoing care should also involve a paediatrician.

3) Medicines Can Help to Relieve Symptoms BUT We Don't Yet Have A Cure With ME/CFS.

At present, there are no drug treatments that can successfully treat or cure the underlying disease process. Until we know a more a successful drug treatment is some time away. A number of medicines that are designed to modify the disease process rather than symptoms are now being, or have been, a regularly assessed in clinical trials. Examples include updated versions of hydrocortisone, modafinil, low dose now be appearing naltrexone, rituximab, and valganciclovir as a free download (an antiviral drug).

There are, however, a number of drugs that can help to provide relief from some of the key symptoms found in ME/ CFS -in particular, pain, sleep disturbance, irritable bowel, and depression (when this occurs). Examples include the use of a low dose of a sedating antidepressant drug called amitriptyline for pain and sleep disturbance, and gabapentin or pregabalin for more severe pain.

4) Pacing: Striking the Right Balance Between Activity and Rest

Energy management -in other words achieving the correct balance between activity and rest -remains the most important part of ME/CFS management. This is because the key biological defect in ME/CFS is the inability to produce energy to carry out and sustain mental and physical activities. Energy management has to involve physical, mental, and emotional activity -all of which require some form of energy production and can worsen ME/CFS symptoms when carried out beyond a person's limitations.

In practice, this should involve an individual activity management programme that takes account of three factors: stage of your illness, severity of your illness, and to what extent your symptoms fluctuate. In considerably basic terms this involves finding a baseline of activity that you feel comfortable with and then carrying out physical and mental activities in small flexible amounts. Gradual increases in physical and mental activity levels should only be introduced when you feel comfortable to do so and are not resulting in any form of symptom exacerbation.

Locally adaptive pacing -which is a flexible approach to activity management -is the best and safest method of managing your ME/CFS. This is the standard method the Sheffield clinic uses for management. They have their own strategy which is a rite of passage for most patients.
Leger ME like the MEA does not believe that graded exercise therapy (GET) , which is based on the flawed theory that decreased mobility is mainly due to deconditioning and fear of exercise, and which involves progressive and inflexible increases in activity regardless of how a person is coping or feeling, is appropriate for people with ME/ CFS . We, like most ME/CFS organisations charities we believe that Pacing is far more helpful to people with this condition.

5) Dealing with Emotional and Mental Health Issues

As with any other chronic medical illness, people with ME/CFS sometimes develop emotional and mental health problems. The reasons for this are complex but probably involve both internal factors (i.e. the effects of the illness on brain function and brain chemical transmitters) and external factors (i.e. losses and problems relating to benefits, doctors, family, finances, friendships, work).
ME/CFS brings with it a lot of "losses" but it may also produce some "gains" -such as being able to spend more time with a family. So, it may be helpful to prepare a list of your losses and gains, and then work through how you are going to try and deal with these issues.

To do so you may find it helpful to talk to a professional counsellor, especially if you are having difficulty in coming to terms with sudden and dramatic losses in so many important aspects of normal life. Alternatively, an approach known as cognitive behaviour therapy (CBT) can be helpful for people who are finding it difficult to cope with all the lifestyle adjustments and losses that come with having ME/CFS. NB**: CBT is not a treatment for ME/CFS.**

If you are feeling anxious or depressed, as opposed to just being "fed up", you must talk to your GP and make use of whatever help is appropriate and available. Any form of significant clinical depression -which includes symptoms such as poor appetite, loss of interest, loss of self-esteem, worthlessness,

being tearful at times and even suicidal thoughts or intentions -would normally require treatment with CBT and/or antidepressant medication.
If antidepressant drugs are prescribed, it should be noted that people with ME/CFS tend to be sensitive to drugs that act on the central nervous system. So, antidepressants need to be used with care and probably started at the lowest possible dose, with gradual increases until an optimum dose is achieved

6) Dealing with Work, Education and Family Responsibilities

Many people with ME/CFS, especially during the early stages, find they are no longer able to continue with their normal work, education, domestic or family responsibilities. In the case of work, it is important to stay in touch with key people at work (i.e. a personnel/ human resources manager and/or occupational health department) to keep them regularly informed about how you are progressing.
The same applies to a child or young person at school or university -because input from a paediatrician can be especially helpful if there are problems about attendance or obtaining home tuition. As time goes on you may find yourself in a position where some form of limited return to work or education becomes possible. For others, the outcome is much less certain, and retirement on the grounds of permanent ill health may need to be considered.

ME/CFS is an illness that is covered by the Disability Discrimination Act and section 6 of the 2010 Equalities Act. This legislation provides important provisions in relation to modifications to hours, duties, travel, etc. that an employer would be expected to make to enable a sick or disabled employee stay in work or return to work. You might also be able to make use of this legislation if you are being threatened with dismissal on the grounds of continuing ill health.
People with ME/CFS who are employed may experience all kinds of difficulties with their employers. So, it is normally sensible to remain a member of your trade union or professional body whilst off sick. These organisations will normally provide free legal and employment advice to their members. The MEA also has a link to an employment solicitor who may be able to provide some initial free legal advice om It May Concern letter covering modifications relating to exams.

7) Obtaining State and Private Sector Benefits

The Department of Work and Pensions (DWP) has made it clear that people with ME/CFS are entitled to claim a full range of state sickness and disability benefits -provided you meet the eligibility criteria. Unfortunately, the way in which eligibility for these benefits is assessed is problematic when it comes to people with fluctuating medical conditions like ME/CFS.

It is worth noting that decisions on benefit entitlement should primarily be made on the degree of disability and ill health and not the diagnostic label. The CMO Report also pointed out in section 4.4.2 that It is not appropriate hat participation in a particular treatment regimen is made an absolute condition for continuation of sickness/disability payments. However, the process of claiming state benefits may sometimes seem like jumping over a never-ending series of hurdles, with far too many people still only being successful after going to reconsideration or an appeal.

For those who are unable to work, the way in which this is assessed for Employment and Support Allowance (ESA) through the Work Capability Assessment (WCA) continues to cause major problems when it comes to conditions like ME/CFS where people are unable to perform both mental and physical tasks in a regular, reliable and sustained manner.

So do make use of the fact that the DWP now accepts that you must be able to carry out the WCA descriptor tasks reliably, repeatedly, safely and in a timely manner. Anyone who is more severely affected from the point of view of mobility or care needs should consider applying for a Personal Independence Payment -which has replaced Disability Living Allowance. Leger ME members have access to Work and Benefit Guides as part of their membership. We strongly advise the involvement of a welfare rights advisor in dealing with DWP paperwork as ‘homebrew for fillout are the main cause of benefit refusals.

Claiming on an income protection policy (also known as permanent health insurance) can be just as difficult. If an internal appeal fails to resolve a dispute, you should take legal advice or refer your case to the Financial Ombudsman: www.financial-ombudsman.org.uk.

8) How to Obtain Social Support, Practical Assistance, Disability Aids and Help for Carers

If you are more severely affected, you may be entitled to various forms of practical assistance such as a wheelchair, adaptations to the home, or a home help. If you have very limited mobility you may be entitled to a Blue (car parking) Badge -but do note that the eligibility criteria relating to restrictions on mobility are quite strict and some people with ME/ CFS find it very difficult to obtain a Blue Badge. Loss of friendships with social contacts, neighbours and work colleagues is not unusual if you have an illness like ME/CFS. Consequently, you are likely to find yourself becoming increasingly dependent on a partner, or even a child, for both emotional and practical support.

For a career, having to make all kinds of social, emotional, and financial adjustments is often a very stressful experience. So, it is important to think about the needs of those who care for you -because they may not have anyone else who is thinking about their own health needs as well as their mental and emotional wellbeing. Your carer may be able to claim a DWP Carer's Allowance if he/she cares for you at least 35 hours per week and you receive the daily living component of PIP.

9) Vitamins, Minerals, Supplements and Nutrition

People with ME/CFS have more than enough restrictions on their lifestyle without adding a highly restrictive diet to the list. There are, however, a number of sensible dietary changes that can be made. Besides eating a healthy balanced diet, “it’s a good idea to include complex carbohydrates -things like pasta -which help to ensure that blood sugar levels remain steady throughout the day. Keeping the body well hydrated with water, especially if you have orthostatic intolerance (i.e. problems with remaining in an upright position) or low blood pressure symptoms, is also important.
If you have irritable bowel-type symptoms, exclusion of certain groups of foods may be helpful. These can be identified through trying an exclusion diet, where different foods, or food groups, are removed in rotation -preferably under the guidance of a qualified dietitian. Trying what is called a FODMAP diet may also be helpful here.

Some aspects of ME/CFS -i.e. lack of sunlight, inactivity, dietary restrictions -may increase the risk of vitamin D deficiency as well as osteoporosis. If this is so, you need to discuss calcium and vitamin D supplementation with your doctor or dietician. It is our experience that most Leger ME members have depleted vitamin D levels when tested. We recommend asking your doctor to check these and prescribe if necessary. You can buy vitamin D3 over the counter.

We do know that certain food supplements can make a significant difference in some people. So, supplements need to be used with care, especially those that contain high doses of certain ingredients. We recommend a A-Z general supplement that contains the recommended daily amounts. One type of supplement that is well be worth trying is an essential fatty acids supplement with eicosapentaenoic acid (EPA) and Gamolenic acid (GLA). VegEPA or Omega 3-6 supplements are examples. We recommend the guidance leaflet of the British Dietetic Association

10) Alternative and Complementary Approaches

If you have faith in an approach such as acupuncture (perhaps for pain relief), meditation, osteopathy or homeopathy, this may be worth a try -even though there is no sound scientific evidence that any of these approaches work in ME/CFS. But do try and find a reputable practitioner who is not making exaggerated claims and you can afford the fees. The Health Professions Council website has details of qualified and properly registered dieticians and other practitioners in some of these areas (www.hpc-uk.org).

The downside to alternative and complementary medicine is that all kinds of bogus and extremely dubious claims for approaches such as anti-candida programmes, immune system-boosting supplements, and even talking therapies have been aimed at a vulnerable groups of patients -including those with ME/CFS.

Some people with ME/CFS have lost a great deal of money chasing the latest "Miracle Cures" or “Processes”.

Pets in my Home: Lop Eared Rabbits.

by Sherri

I keep long eared rabbits as pets. I am not a breeder but take in rescue bunnies where their owner can no longer cope with them. I find that my rabbits give me companionship, comfort, and emotional support.

Marley

About Long Ears

Unlike the erect ears of the majority of rabbits, lop breeds have ears loosely drooping, with the opening of the ear facing the skull. This is due to the slightly raised cartilaginous ear base, the head of many lop rabbits (with the exception of English Lops) has a small bulge, referred to as the crown. A rabbit's ear, with its blood vessels close to the surface, is an essential thermoregulator, for keeping cool, since rabbits cannot sweat. Longer ears are associated with warmer climates, and possibly even with a late-spring birth in cooler climates when such rabbits are thought to develop summer ears. The additional weight of a longer or thicker ear is not always fully supported by the rest of the ear structure, resulting in ears that droop. The ears of some young lop rabbits may not achieve their full adult droop until the ear growth is finished.

Health Matters

Well-kept rabbits will normally live for 5-7 years, but I had one who lived until he was 12 years old. Rabbits do get problems, and very often like with most pets, a vets intervention is often. Common ailments include, ear infection in lop ear rabbits, pasteurellosis, rabbit sniffles and upper respiratory issues. Commonly rabbits develop teething problems, due to either poor diet or breed of rabbit. Rabbits develop spurs on their teeth that need to be filed down under general anaesthetic. The best way to avoid this is a diet of hay and forage for chewing e.g. branches.

Layla. What a lot of people are unaware of is that rabbits can be house trained to use a litter tray in the way a cat can be trained. Like a dog they can be trained to come on command. They normally sleep inside the house in adapted kennels or dog cages.

Above :
Like most animals which are herbivores (plant eaters), a rabbits teeth grow through its lifetime.
It is important that they have plenty of roughage to wear them down,
If the teeth are misaligned or they do not have a opposite tooth in the other jaw to wear against, they get spurs which can be quite painful and stop the rabbit eating.
A vets intervention is always needed.

Vaccinations

Like most pets, rabbits have to be vaccinated. The key vaccinations are Rabbit Viral Hemorrhagic Disease (RHD1/RHD2) and Myxomatosis. These are essential as they can be unpleasant and fatal.

Neutering

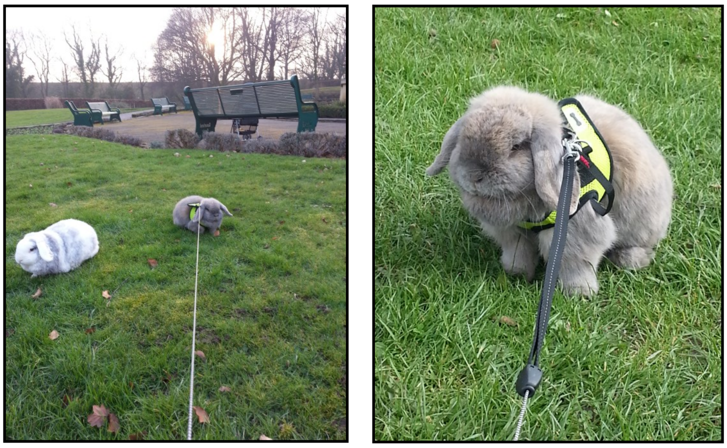
Any conscientious owner will have their pets neutered of spayed and neutered. Intact male rabbits full of testosterone can get very dominant and fight other rabbits. Where females are concerned it is important that they are neutered to prevent unwanted litters, and prevent cancer of womb.

Nutrition

Rabbits are herbivores, eating plants. Their digestion only extracts a small amount of nutrition. Some cloven footed animals regurgitate food for a second chewing. (chewing cud) to get further nutrition at a second pass. Rabbits, have a second pass system to extract further nutrients. Rabbit stools are normally a hard pellet during the day, daytime poo. which is mixture of the high fibre they eat. Then they have night-time stools which looks like tiny bunch of grapes shiny soft texture bit like our own stools which they recycle at night. .

Eddy

Eddy is the white shared bunny was mistreated and was kept in a 3ft hutch outside with very little human interaction. He was very poorly when I got him. He had been left to breath in his own excrement for years and as a result he suffers really badly from upper respiratory issues. When I got him, he was very under weight and had never been given hay. As a result he will more than likely need dental work in the future.



Eddie: Rabbits can bet taken for a walk in the part with a suitable harness. BUT, Sherri advises that you would need to be very careful with regards to walking rabbits.

In public places there is always the danger of picking up a virus from wild rabbits. Also out of control dogs can be a problem Layla was an exception,

I would instead say that some experienced rabbit handlers and certain rabbits have found a way to safely exercise there rabbit using a harness i.e. in there garden or safe spaces

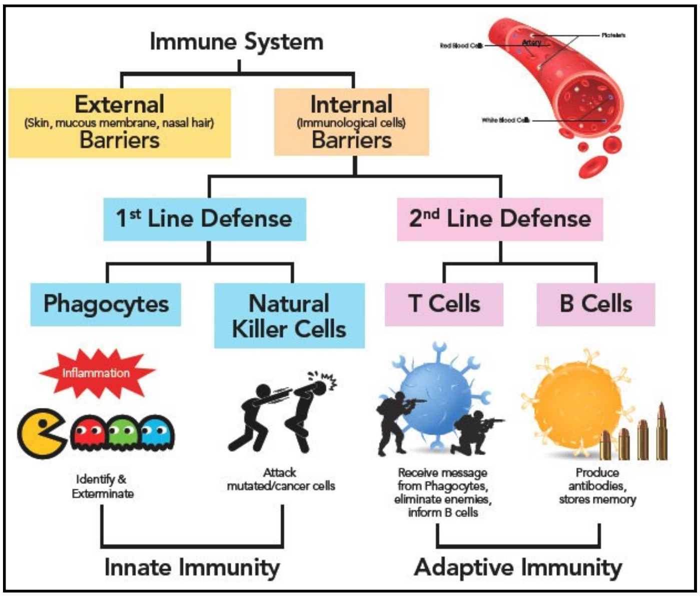
Looking after a pet and ME/CFS

When my ME/CFS flares up and is bad, he goes to boarding were he has another family who care for him. He goes about every 2-3 weeks for anything between 1 week and 2 weeks . So its like 50% ownership.

This does mean that I don't need to worry about he wellbeing and know he well looked after.

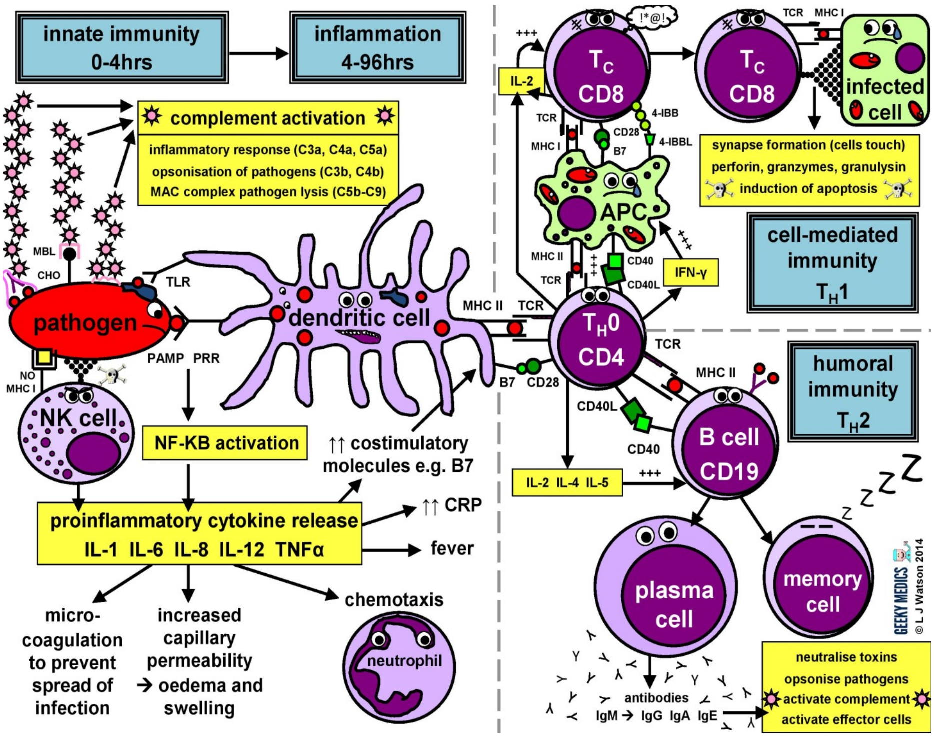
The Immune System

The immune system is a host defence system comprising many biological structures and processes within an organism that protects against disease. To function properly, an immune system must detect a wide variety of agents, known as pathogens, from viruses to parasitic worms, and distinguish them from the organism's own healthy tissue. In many species, there are two major subsystems of the immune system: the innate immune system and the adaptive immune system. Both subsystems use humoral immunity and cell-mediated immunity to perform their functions. In humans, the blood–brain barrier, blood–cerebrospinal fluid barrier, and similar fluid–brain barriers separate the peripheral immune system from the neuroimmune system, which protects the brain. Pathogens can rapidly evolve and adapt, and thereby avoid detection and neutralization by the immune system; however, multiple defence mechanisms have also evolved to recognize and neutralize pathogens.



An overview of the immune system.

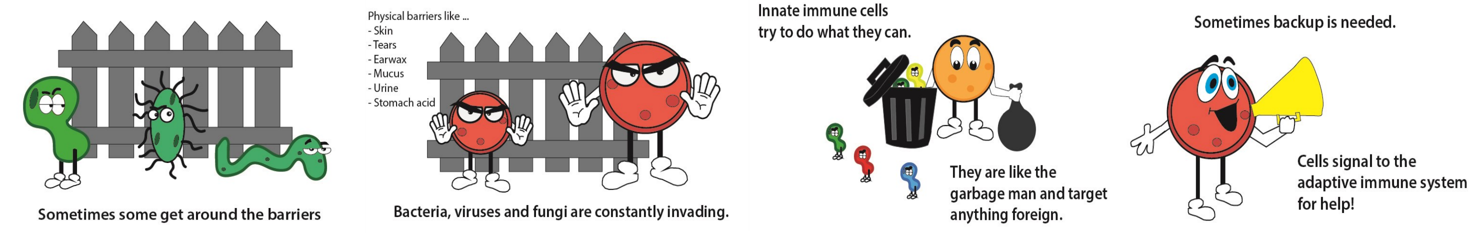
These mechanisms include phagocytosis, antimicrobial peptides called defensins, and the complement system. Jawed vertebrates, including humans, have even more sophisticated defence mechanisms,[1] including the ability to adapt over time to recognize specific pathogens more efficiently. Adaptive (or acquired) immunity creates immunological memory after an initial response to a specific pathogen, leading to an enhanced response to subsequent encounters with that same pathogen. This process of acquired immunity is the basis of vaccination.



Above: The immune system like is a well oiled machine, each component has a part to play

Below: The Innate side of the immune system is the first line of defence

Disorders of the immune system can result in autoimmune diseases, inflammatory diseases and cancer.[2] Immunodeficiency occurs when the immune system is less active than normal, resulting in recurring and life-threatening infections. In humans, immunodeficiency can either be the result of a genetic disease such as severe combined immunodeficiency, acquired conditions such as HIV/ AIDS, or the use of immuno-suppressive medication. In contrast, autoimmunity results from a hyperactive immune system attacking normal tissues as if they were foreign organisms. Common autoimmune diseases include Hashimoto's thyroiditis, rheumatoid arthritis, diabetes mellitus type 1, and systemic lupus erythematosus. There is a very strong suspicion that ME/CFS is an auto immune disorder. Immunology covers the study of all aspects of the immune system.



Anaphylaxis: A potential life threating clinical emergency

Anaphylaxis normally develops suddenly and can be fatal if not correctly identified and managed. Anaphylaxis is a life-threatening, generalised or systemic hypersensitivity reaction, involving the release of mediators from mast cells, basophils and recruited inflammatory cells, and is characterised by rapidly developing life-threatening airway and/or circulation problems with associated and mucosal changes. It is often the result of an allergic response that can be immunologically mediated, or non-immunologically mediated or idiopathic. It is estimated that around 1 in 1,350 people in England has experienced anaphylaxis at some point in their lives. There are around 20 anaphylaxis deaths reported each year in the UK, but this this may be an under-estimate.

The IgE (Immunoglobulin E)-mediated response.

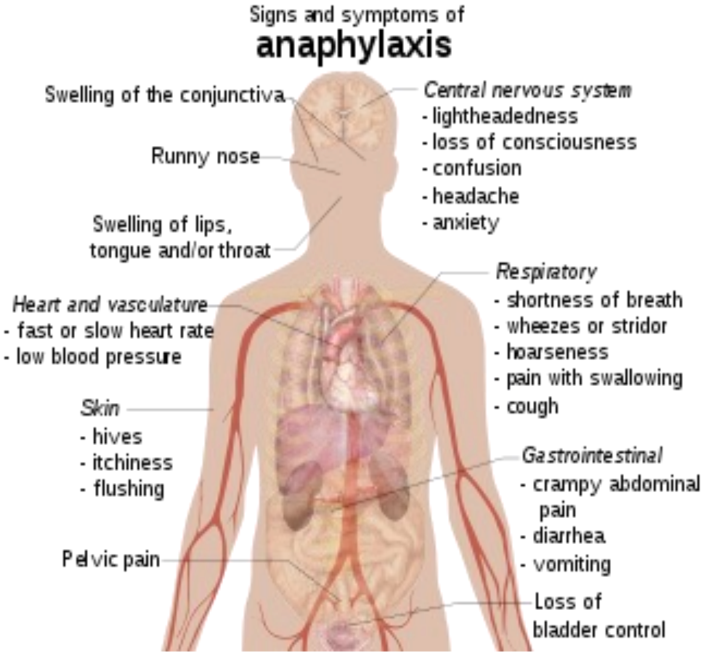
Usually anaphylaxis arises as an acute (sudden onset), generalised IgE -mediated immune reaction. The reaction requires priming.(i.e. an initial exposure and sensitisation) by an allergen (something that the body is sensitive to), followed by re-exposure. (e.g. introduction into the body via ingestion, inhalation, injected or through the skin. On first exposure, a susceptible person forms IgE antibodies specific to the antigen presented that attach to high-affinity Fc receptors on basophils and mast cells. On subsequent exposure, binding of the antigen to the IgE antibodies leads to the cross-linking of two IgE molecules. This triggers a process which causes degranulation of mast cells and the release of chemical mediators like histamine and tryptase. These so called mediators subsequently lead to the clinical manifestation of anaphylaxis.

Broadly there are sorts of response.

1) **The IgE response.** IgE-mediated episodes of anaphylaxis tend to be more severe and have a more rapid onset than other non-IgE-mediated mechanisms. In children this is nearly always the case.
2) **Non-IgE- response.** This response is poorly defined, both clinically and scientifically, and is thought to occur through mechanisms such as complement activation, kinin production or potentiation, and direct mediator release. It may occur on first exposure to an agent and does not require a period of sensitisation.

Signs and symptoms

The clinical presentations of both sorts are the same. Symptoms can develop within minutes (e.g. through injected antigen exposure) or gradually over a few hours in the case of through the mouth or skin exposure. Anaphylaxis is characterised by rapidly developing life-threatening airway and/or circulation problems, usually associated with skin and mucosal changes, but a number of other symptoms may be experienced.



Skin

Around 80–90% of patients with anaphylaxis will have skin features, such as urticaria, a rash , pruritis or itching, flushing and/or angioedema. Any area of the skin can be affected. Skin changes do not always indicate anaphylaxis, they can suggest other problems.

Respiratory system

Around 70% of allergic reactions affect the respiratory tract. Patients may experience swelling of the mouth, throat or tongue, which can cause breathing and swallowing difficulties. Patients may also have a hoarse voice and stridor (a loud, harsh, high-pitched sound produced by turbulent airflow through a partially obstructed airway), or wheeze. Hypoxia with an oxygen saturation of less than 92% and central cyanosis (blue skin or lips; indicates severe anaphylaxis and requires urgent treatment.

Cardiovascular system

Increased vascular permeability (fluid leaking out of veins), vasodilation (opening up for veins) and myocardial dysfunction can result in hypotension (low blood pressure) and cardiovascular collapse. Adults are more likely to have cardiovascular symptoms than children. In the worst case scenario, blood my not return to the heart and it will stop.

Other manifestations

Light-headedness, confusion, anxiety, sweating, syncope (loss of consciousness) or coma may also occur. effects, such as nausea, vomiting, abdominal cramps and diarrhoea with soiling, may also be associated with anaphylaxis; however, these are usually overshadowed by more immediately life-threatening symptoms (e.g. breathing difficulties)

Causes

There are a range of causes of anaphylaxis, which can be grouped together. If a cause or trigger cannot be identified, it is described as idiopathic anaphylaxis. The following sections discuss some of the common causes in more detail.

Foods: Between one-third and half of anaphylaxis cases that present to emergency departments are caused by food s, with the highest incidence of these cases occurring in young children. Food triggers include fruits, nuts, eggs and fish, with peanuts being the most common cause. Ingestion of the allergen is the most common route of exposure; however, aerosolised food proteins may also induce reactions,cow's milkfish. For some patients, even just handling the food can trigger a severe reaction.

Medicines: Some medicines can cause anaphylaxis in a small number of people, with penicillin being the most common cause. Serious reactions to penicillin occur around twice as frequently following intramuscular or intravenous administration compared with oral administration. However, it is necessary to correctly determine if a patient has a true allergy, as those who are falsely labelled as having a penicillin allergy risk being treated with alternative antibiotics (e.g. broad-spectrum, non-penicillin antibiotics) that have higher incidence of antibiotic resistance and poorer health outcomes[13]. Aspirin and nonsteroidal anti-inflammatory drugs (NSAIDs) can also cause drug-induced anaphylaxis, as well as anesthesia. The incidence of anesthesia-related anaphylaxis ranges from 1:10,000 to 1:20,000 cases, with 4–10% of reported reactions being fatal.

Insect bites and stings: Reactions to insect stings i.e. wasps, bees and ants) occur in up to 3% of the UK population.

Latex (Rubber): Reactions follow direct contact, parenteral contamination (e.g. in operating theatres) or aerosol transmission. Healthcare, hair, beauty, catering and motor industry workers are more likely to have a latex allergy.

Exercise: Anaphylaxis can occur with physical activity; however, up to 50% of cases are associated with prior ingestion of food or either aspirin or an NSAID. Food-associated, exercise-induced anaphylaxis when a patient exercises within 2 to 4 hours of ingesting a specific food (e.g. wheat, celery, shellfish); however, it may occur after ingestion of any food. In these cases, it is thought that both cofactors exercise and food may be required for a reaction.

Risk factors

Patients who have previously experienced an episode of anaphylaxis are at increased risk of further occurrences .

Generally, parenteral antigens are more likely to trigger anaphylaxis than oral antigens.

Above: Three clinical presentations of Urticaria

Swelling of hand due to contact allergy.

Cyanosis due to circulatory failure. Clinical emergency:

Swelling around eyes due to environmental sensitivity

Other risk factors include:

- Age– children are more likely to experience food-related anaphylaxis, whereas adults are more likely to experience anaphylaxis owing to antibiotics, radiocontrast media, anesthesia and insect stings. Children and older people are at an increased risk of severe anaphylaxis;
- Gender– women have a higher risk of anaphylaxis owing to latex, aspirin, radiocontrast media and muscle relaxants, whereas men have a higher risk of anaphylaxis owing to insect venom;
- Atopic history– an atopic background could be a risk factor for exercise-induced and latex-induced anaphylaxis, but not drug-induced anaphylaxis;
- Comorbidities– people with asthma, cardiovascular disease, mastocytosis (abnormal accumulations of mast cells in the skin, bone marrow and internal organs) and substance misuse are at an increased risk of anaphylaxis. So do some people with ME/CFS/

Diagnosis

Presentation of anaphylaxis is varied, and the signs and symptoms are not specific. The diagnosis of anaphylaxis is clinical because management cannot wait for laboratory confirmation of allergy[20]. Anaphylaxis is likely when all three of the following criteria are met:

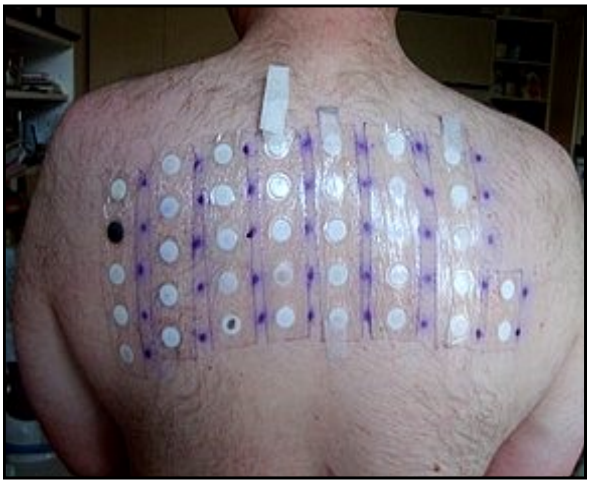
- There is sudden onset and rapid progression of symptoms;
- There are life-threatening airway and/or breathing and/or circulation problems;
- There are skin and/or mucosal changes (flushing, urticaria, angioedema).

Patients with known risks should carry two EpiPen's for emergency injection of Adrenalin.. These are very expensive and have short expiry dates- so should be checked regularly.

People should try to establish exposure to a known trigger; however, lack of obvious exposure does not exclude diagnosis. Some conditions have overlapping symptoms with those of anaphylaxis and may lead to differential diagnosis — for example, severe asthma may also present with wheezing, coughing, and shortness of breath. However, associated itching, urticaria, angioedema, abdominal pain, are more suggestive of anaphylaxis. Like anaphylaxis, sepsis manifests with low diastolic blood pressure; however, associated skin changes are more likely to be petechiae (tiny purple, red, or brown spots on the skin) or purpuric (purple) in sepsis, compared with the erythema (patchy, or generalised, red rash) or urticaria (also called hives, nettle rash, wheals, or welts) associated with anaphylaxis.

Emergency First Aid

If the patient is experiencing anaphylaxis, this is an emergency and an immediate intramuscular injection of adrenaline (epinephrine) into the middle of the outer thigh is required. Anaphylaxis is life-threatening; therefore, if suspected, call 999 and stop the suspected causative agent immediately. In cases where a patient experiences an acute allergic reaction, healthcare professionals should refer them to an allergy clinic. Here, testing for the precipitating allergen can be undertaken and the necessary steps taken, following the results, to ensure allergen avoidance and reduce the risk of recurrence.



Skin prick test. These are sometimes sometime carried out on the arm

Allergy Testing

Skin prick test. A drop of liquid containing the suspected allergen is dropped onto the forearm. The skin under the drop is then pricked. A positive result is when a wheal (a raised, red bump) greater than 3mm in diameter and larger than the negative control (using saline) appears within 15 to 20 minutes .

In vitro This type of test measures allergen-specific-IgE. It is less sensitive than skin testing and depends on clinical correlation, and the availability of specific assays. The evolving Basophil Activation Test can potentially reproduce the immediate-type allergic reaction in the test tube without any risk to the patient.

Challenge test. Positive skin and invitrotests do not confirm the clinical relevance of the sensitisation; clinical history and challenge tests are usually required to make a formal diagnosis. A challenge test involves 'challenging' the patient with increasing amounts of the allergen, usually via the oral route. B Although this is the best method of confirming diagnosis of allergy, it is not without risk and requires access to experienced staff in a safe medical environment.

Blood test. Tryptase, an enzyme realised from mast cells during an immune response, can be measured to differentiate IgE- from non-IgE drug-induced reactions. Serum tryptase levels are normally undetectable (<1nanogram/mL) in healthy individuals who have not had anaphylaxis in the preceding hours. Acute elevation of serum tryptase indicates degranulation of mast cells that can occur owing to an IgE-mediated mechanism (e.g. penicillin allergy) or may result from direct degranulation of mast cells through non-IgE-mediated means (e.g. NSAIDs or opiate allergy). Serum or plasma for tryptase should be obtained as soon as possible after emergency treatment has begun and a second sample ideally taken within 1 to 2 hours (but no later than 4 hours) from the onset of symptoms[4]. To determine the baseline level of tryptase, an additional sample should be collected at least 24 hours after all symptoms have resolved.

Commercial allergy tests: Complementary commercial allergy testing kits, such as hair analysis, kinesiology and Vega tests, are not recommended. There is little scientific evidence to support their use and there are concerns that patients may be misled by results that could be false[

A well known case& new law.

Natasha, 15, suffered a severe allergic reaction after eating sesame in an artichoke, olive and tapenade baguette bought in Heathrow Airport. The teenager died after an allergic reaction to a Pret A Manger baguette.

Under "Natasha's law", food businesses will have to include full ingredients labelling on pre-packaged food.

The law, which will apply to England, Wales and Northern Ireland, is set to come into force by the summer of 2021. Businesses will be given a two-year implementation period to adapt to the changes.

Treatments: Apart from emergency treatment, antihistamines offer some degree of protection. Avoidance is sone strategy. There are desensitising treatments like low dose antigen and neutralisation. However these treatments need to be carried out by specialist. Enzyme Potentiated Desensitisation is a well know method, and has been proven safe over many years. This treatment is not available on the NHS, but there is a private clinic in Sheffield..

Mechanism of allergic reaction*	Group	Examples
IgE-Mediated	Drugs, chemicals and biological agents	Antivenoms, cephalosporins, chlorhexidine, ethylene oxide, formaldehyde, gamma globulin, insulin, muscle relaxants, penicillins, protamine, semen, sulphonamides, thiamine, vaccines
IgE-Mediated	Foods	Eggs, fish, flour, fruits, milk, peanuts, shellfish, tree nuts, vegetables
IgE-Mediated	Venoms and insect saliva	Ants, bees, hornets, jellyfish, scorpions, snakes, ticks, wasps
IgE-Mediated	Other	Angiotensin-converting enzyme inhibitors, aspirin, N-acetylcysteine, nonsteroidal anti-inflammatory drugs, opiates, radiocontrast media, vancomycin
Non-IgE-mediated	Food additives	Metabisulphite in jams and preserves, tartrazine
Non-IgE-mediated	Physical factors	Cold, exercise, heat
Unknown	Unclassified	If a cause or trigger cannot be found, it is described as idiopathic anaphylaxis

North of Doncaster *Personal thoughts from Trevor Wainwright*

Well as many of you know April is my poetry tour month in Texas, the poems I write form a collection each one, America Tour and the year. Sadly, this was not to be we all know why and it became America 2020 Tour (Not). Although the poems started out full of optimism at the run up unfolded, it is a few of those I would like to share with you this issue.

As usual the collection starts with when I book my flight, so this was the first poem written in June when bargains are at their best	I thought I'd save a heap, my usual travel on the cheap Always a delight to get a cheap flight Normally wait till August but thought I'd give June a try Thought it may be cheaper to book earlier but it seemed in vain Prices the same or more, so try again The time I wanted seemed so dear compared to last year Other flights cheaper but stopovers far too short Cheaper flights the main agencies did regale it all seemed to no avail Then one day a surprise it said clear, cheaper than last year Not the time I wanted to fly but decided to give it a try
Then I noticed something not quite right I checked and found there was a mix up on the dates, so this poem followed:	I decided to have a look at the details of my flight Logged on and got a bit of a fright Slight feeling if dread, I'd booked to fly out on Friday instead All not lost made a phone call to see if there would be a cost They said they would get back, they did I nearly dropped through the floor I felt a bit sore when they asked for £347 more I thought it would be cheaper to take the flight And book a motel for the extra night The rates were checked it proved to be so So no change in flight I extended my stay for the extra night And I get to touchdown, a day earlier in Austin, my spiritual hometown
It's normal to have writers block this was my first one for 2020 written late January having nothing since early December:	So far I've written nothing this year, But there's no need to fear May be some event will get me writing with intent And as my April Texas tour draws near, no doubt I'll write more Score after score as inspiration strikes and the creative bells start ringing When someone starts singing Or what someone may say will get me writing away Yes one thing's for sure I'm gonna write some more Then there'll be my Texas tour which'll again yield many a score As again I'll more'n likely be scribblin' away from break of day. Till the sun going' down be it on the road or in town. Often without rest the Road Poet at his best
This was the penultimate one written at the back end of February before the poetry turned to be about Covid.	We've had storms Ciara & Dennis Causing flooding and despair, everywhere Social media lets us know, some places have had snow Now they've gone and life carries on Drying out, cleaning and rebuilding to be done Community sprit coming to the fore as it has so often done before We've still got cold wind and, rain once more beating on my window pane Then it stops a brief respite, blue sky and then it's back again And I'm thinking "If music hath charms to soothe the savage breast". Then let me pick out and play some of my best Get it going, soon I can feel inspiration flowing Poems to be done, no sign of the sun but I finish one Then the music inspires me to write another score Then sit back relax and let it flow once more

Well it was not to be, I have been doing some volunteering which I captured in rhyme in Write a Poem a Day for April part of a what I should have been doing and what I was actually doing project. And as I was stuck in Yorkshire I have as things have eased been able to get out and about and would like to share some photos with you of Sowerby Bridge and the canal from my, "My Beloved Yorkshire" Facebook photo album. In the next issue a trip to Sowerby Bridge along with photos of it from my Facebook album, My Beloved Yorkshire. It can run as a stand-alone article. -Trev