

Pathways

Price £ 6.25 (Free to members)

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

Welcome to Pathways No 81. Autumn Edition 2024



Turton Towers Park in Early Autumn
With thanks to Carolyn

You write in

Bill Writes: I am aware that the new government have intention of reducing the benefits that I'm on. I'm worried that the DWP might be watching me. Yesterday I saw a big Range Rover between my neighbour's house and mine with 3 women inside and they stayed there for about an hour and a half. Do you think they were watching me?

I went for a walk with my stick, then later cut my grass. They were still there couldn't see any cameras etc., but the fact they were there a long time couldn't see anyone visiting/getting in or out. Am I losing it or what? I hope it's not a silly question but with everything on the news my severe anxiety is through the roof as it is?

If you see a suspicious vehicle, the first thing to do is get the registration number and check it on the DVLC website. This will tell you it's age, MOT status and some other information. You'll have to work out what that means for yourself. You could also ask your neighbours if they know anything about it and if you are still worried contact the police.

In our street a strange car turned up with two women in it. It turned out that it was a domestic cleaning service working for one of our neighbours. Sometimes as well strange cars on our street are those visiting nurses attending someone at home. A few weeks ago, a white Fiesta appeared at the end of our street. It was there for a couple of days. One of the neighbours reported it, and it was no long before the police turned up as it was a stolen car. It could have easily been a burglar checking if someone is at home. Also bear in mind that if you were being watched, a direct approach would spook any clandestine observer to move elsewhere.

In the benefit cases that I am aware of, where the DWP have intervened, it has usually been an obvious problem. One case was a jealous neighbour whistle blowing. In another case the person concerned was running an illegal business. There are many fraud cases were discovered by the DWP monitoring Social Media such as Facebook.

Just bear in mind that ME/CFS under certain circumstances can make you think and act illogically. So, if you do have a concern certainly do something about it, or talk to someone.

At the time of writing the new government have only moved the winter fuel payment to means tested benefits. Whatever happens to benefits in the future, Pathways will keep you posted.

Janet writes: That you for the help with my PIP form now I have come back from abroad after being away for four years. However, the application has been rejected because I do not meet the Past Presence test. Can you explain what this means and how can I rectify the situation?

PIP and some other benefits can only be paid if you are present in the UK at the time of the application. But also, you must have been present in Great Britain for 104 weeks out of the last 156. In other words, you must have been resident in the UK for two years out of the last three. There are some exceptions, but knowing your circumstances there are no grounds for appeal. The only advice I can give is to reapply two years on the anniversary of your return to the UK. Depending on your circumstances you can use the case review information to support a blue badge application claim or a working age sick pay application like employment and Support Allowance or universal Credit.

Jane writes: I am worried about the winter fuel payment because as well as being on a state pension I have a private pension which just puts me over the limit to qualify. Will the new government be cutting any other benefits.

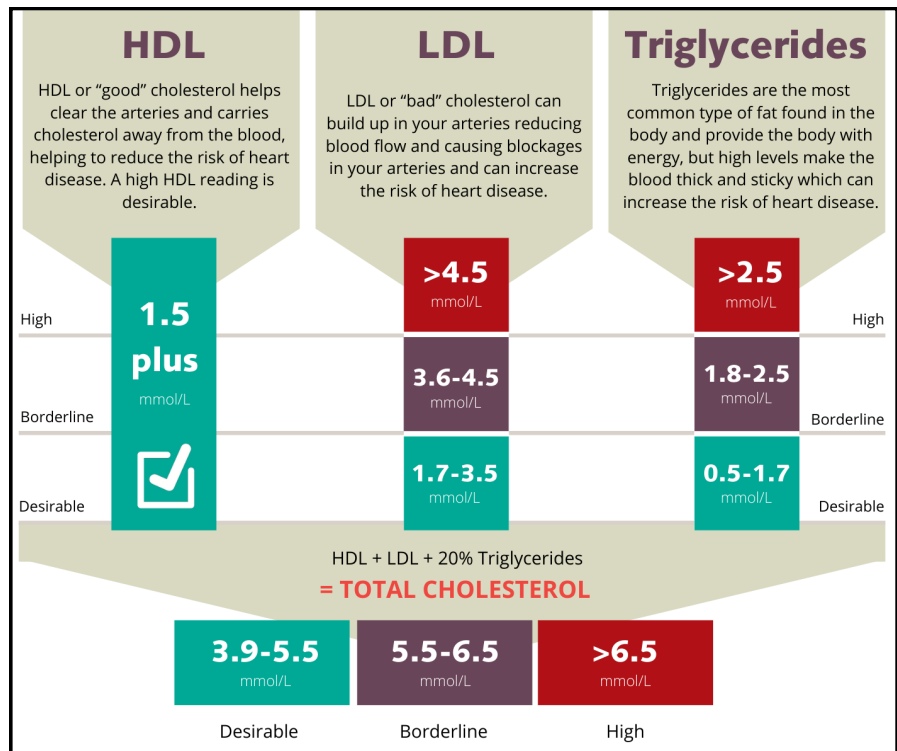
At the time of writing, only the winter fuel payment had been made means tested. A national newspaper has hinted that the Prime Minister may be looking at quashing the 25% council tax single person's discount. There is a budget due in October, it is most likely that any changes will be announced then. These will need a law change, so we will get plenty of notice of any proposed changes. Don't forget that your state pension is also due to increase in next April which will exceed the £300 loss of winter fuel payment.

Queenie Writes: Thank you for your help with my PIP application. However, I am a little puzzled about being at an unacceptable risk of a catastrophic cardiovascular event (i.e. Heart attack or stroke) due to my very high cholesterol levels which at the last check were 8.2mmol/l. My doctor has said nothing about it.

You have a big potential problem.

I have also put your data into a QRISK3 assessment programme which is used by many doctors to assess cardiovascular risk.

Your 10 years cardiovascular risk factor comes out at 9.2%. However, it does not take into account your high cholesterol levels.



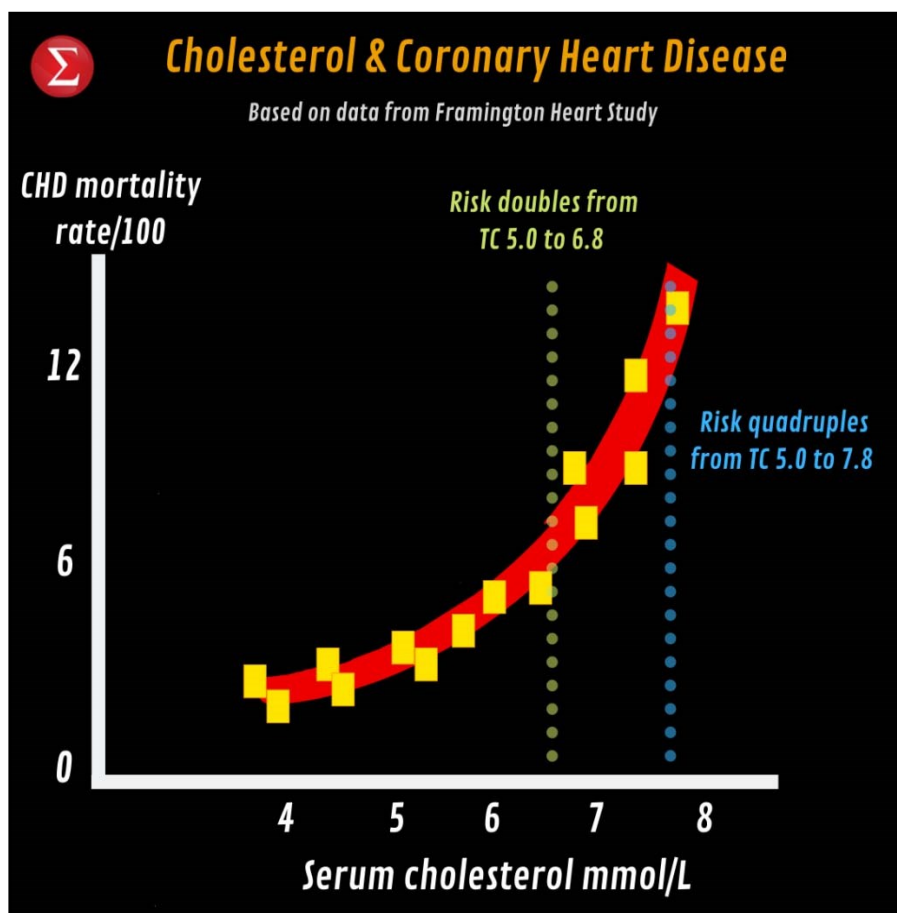
I've pasted an infographic (right) which explains why I am concerned. My best estimate for the Cholesterol Cardiovascular risk is about 15%. So, the total 10 years risk is about 9 + 15 = 24%. With problems like heart attacks and strokes, they are sudden and very often people are shocked when they happen. Most are preventable by simply getting the numbers into the desirable zone.

A total cholesterol as high as 8mmol/l cannot be controlled by dietary means alone. You will need a combination of 2-3 medicines to get the numbers into the safe zone. I've covered this topic in Pathways 74 starting at page 8 which you can download from the www.danum.me website.

What you need to do is make an appointment with your GP or their practice nurse, and discuss ways to get your cholesterol numbers down. You need to get your numbers to well below 5mmol/l to get your risk to acceptable levels.

You need to be cautious of any statin class medicines as usually these cause side effect for people with ME/CFS to tolerate. A good starting point would be ezetimibe and/or bempadoic acid which recent research suggests are as potent as statins without the side effects. Definite ME/CFS friendly treatments are EPA and high dose Niacinamide. The exact choice of medicines vary from area to area.

One long standing group member had a cholesterol score as high as yourself. It took three sorts of medicines to control her cholesterol. With recent weight loss she feels better than she has done for many years. Getting her numbers right has given her a bonus relief of many of her ME/CFS problems.



Cholesterol levels and cardiovascular risk with thanks to Sigma Nutrition

Welfare Rights Matters*with thanks to Benefits and work***New PIP and WCA Assessment Companies**

A new system for work capability assessments

(WCA) and personal independence payment (PIP) assessments started on Monday 9th September. The Health Assessment Advisory Service (HAAS) has taken over providing WCA and PIP assessments. HAAS is part of the DWP. It provides training, guidance and software for assessors. But the assessors themselves still work for private sector companies. There are four of these now involved in carrying out benefits assessments: Maximus, Capita, Serco and Ingeus. These companies now carry out all benefits assessments in their geographical area, including both PIP assessments and WCAs. The assessments remain entirely separate, however. There is no joint assessment that combines both PIP and the WCA at a single meeting, contrary to claims in the national media. In reality, it is likely to be exactly the same health professionals carrying out the assessments as before, having in some cases been moved en-masse to new employers.

However, with the DWP now having complete control over training, software and guidance it will be more straightforward for changes to be rolled-out in the future.

But for the moment, although the companies making the profits may have changed, there will be virtually no difference for claimants being assessed for PIP, ESA or UC. We've updated our main PIP and UC/ESA claims guides to reflect the new system and will be updating other guides and web pages over the coming weeks.

ESA to UC Migration – No Sign Of Postponement

There are no signs yet that the DWP intend to postpone the forced migration of income-related ESA (IR-ESA) claimants to universal credit (UC), due to start this month. There had been hopes that an incoming Labour government might delay the move, given demands by organisations such as Citizens Advice that better safeguards should be put in place before migration begins.

Yet all the signs are that Labour is not listening, possibly more interested in the potential £5 billion to be saved by moving claimants sooner rather than later. Firstly, the DWP updated its "Move to Universal Credit if you get a Migration Notice letter" web page on 30 August. It now includes confirmation that claimants migrating to UC from ESA without a break do not generally need to provide fit notes. Then the September edition of Touchbase, the DWP's newsletter, revealed that the department considers that the "correct level of support is in place to safely move customers over to UC". And finally, in a response to the Public Accounts Committee dated 5th September, the government stated that it needed "to be ready for migration of the Employment and Support Allowance cohort in 2024-25 as opposed to 2028".

So, at this stage, everything points to the DWP sticking to its schedule for moving ESA claimants onto UC. However, we have not yet heard from any readers in receipt of ESA who have received a migration notice, unless they were also in receipt of child tax credit.

One Third Of UC Migration Claimants Fail To Make A Successful Claim. Statistics released in August by the DWP show that 32% of all claimants sent a UC migration notice failed to make a successful claim and had their legacy benefits terminated. In total, a shocking 284,660 individuals did not make a valid claim and had their benefits stopped up to the end of February 2024.

The DWP are quick to point out that "households who have been sent a migration notice to date may not be representative of the complete population who will be sent a migration notice" because the majority are tax credit households. The reality is, however, that the DWP have no idea whether the number of people who will disappear from the system when it is income-related ESA claimants who are being transferred, will be smaller or even greater.

Labour Adopts Hated Tory Bank Surveillance Plan

Labour is to revive hated Tory plans to force banks to carry out surveillance on claimants' accounts and give the DWP police type power to search premises and seize possessions. The Fraud, Error and

Debt Bill will give the DWP:

- power to force banks and financial institutions to share data that may show indications of potential benefit overpayments,
- new powers of search and seizure, so the DWP can take greater control investigations into criminal gangs defrauding the taxpayer,
- power to recover debts from individuals who can pay money back but have avoided doing so.

The outline of the new bill was published today by the DWP to coincide with Kier Starmer's first speech as prime minister to a Labour party conference. In his speech, Starmer said, "If we want to maintain support for the welfare state, then we will legislate to stop benefit fraud and do everything we can to tackle worklessness."

Back in April of this year the then prime minister, Rishi Sunak, outlined his plan to give the DWP police powers. He did this whilst setting out his five-point plan for welfare reform in a speech at the right-wing think tank, the Centre for Social Justice, founded by Iain Duncan-Smith. Just five months later, Keir Starmer has announced similar measures, this time in a speech to the Labour party conference. The other four Sunak points were:

- The WCA to be made harder to pass
- GPs no longer to issue fit notes
- Legacy benefits claimants to move to UC sooner and work requirements to be increased
- PIP no longer always a cash benefit and fewer people to be eligible

We will now have to wait for Labour's welfare reform white paper to see how many of the four remaining points will also be adopted as Labour policy.

More Pip Reviews But Fewer Assessments

The DWP have recruited additional PIP case managers and are now aiming to increase the number of PIP review decisions made without the need for the claimant to attend an assessment.

This is welcome news, but detailed "evidence/information", though not necessarily medical evidence, will be vital for claimants who wish to be spared an assessment. The move to catch up on the massive backlog of PIP reviews was revealed by the minister for disabled people, Stephen Timms, in a parliamentary written answer last week.

Timms said that additional resources would now be devoted to PIP award reviews and they hoped to complete cases more quickly, because "Where sufficient evidence/information is available, Case Managers can make decisions on reviews, avoiding the need for a functional assessment, which means many customers receive a decision faster." Benefits and Work can also reveal that the DWP carried out pilots in February and June of this year in which DWP case managers made decisions on fresh claims, rather than reviews, without the claimant having to attend an assessment. Further testing is almost certainly now taking place. The news underlines the importance of giving detailed information when making a fresh claim or a review claim, especially if you hope to avoid having an assessment.

Record 3.5 Million People Now Getting Pip

The latest PIP statistics show that at the end of July there were 3.5 million claimants entitled to PIP in England and Wales, a rise of 3% over the last quarter.

37% received the highest level of award, up from 36% in April.

The success rate for new claims was:

46% for all new claims, this is identical to the same period last year

53% for claims that got as far as assessment, an increase from 52% in July 2023

Most awards were very short, however:

79% were short term (0 to 2 years)

13% were longer term (over 2 years)

7% were ongoing

And clearances times continue to be a problem.

Whilst the DWP did manage to clear slightly more new claims than were registered in the last quarter, they fell further behind with planned reviews, changes of circumstances, mandatory reconsiderations and DLA to PIP transfers. In fact, the number of planned review decisions was 9% lower than in the same quarter last year.

Audio Record Your WCA On Your Phone

Claimants now have the right to audio record their work capability assessment for UC or ESA using their phone or other device, the latest DWP official guidance makes clear. The right to record has been available for PIP claimants for some time and we have suggested for years that claimants consider covertly recording assessments and other interactions with the DWP.

Until very recently, however, the only official way for a claimant to record their WCA themselves was to come equipped with very expensive dual recording equipment. However, the most recent edition of the DWP's guidance for healthcare professionals carrying out WCAs, the "WCA Handbook", makes it clear that claimants have the right to audio record their assessment using any device they choose, including their phone. The only stipulation is that you should inform the assessment provider in advance that you intend to audio record your assessment.

Your Experience Of Capita, Ingeus, Maximus and Serco Assessments

Now that there are four different companies - Capita, Ingeus, Maximus and Serco - providing WCAs and PIP assessments, we'd like to hear about your experiences of dealing with them, so that other claimants can know what to expect. Everything including:

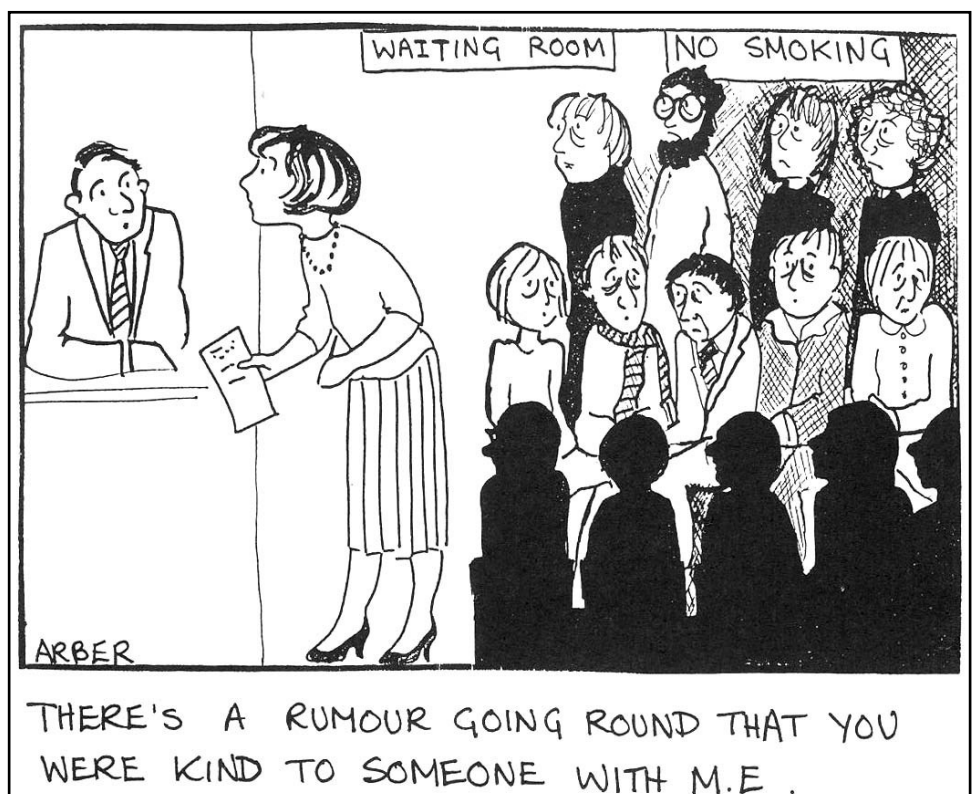
- are letters from them clear and detailed;
- can you get through on the phone,
- do they offer face-to-face assessments at a nearby and accessible location,
- can you easily change the date or assessment type,
- are assessors courteous,
- are assessments accurate.

Claiming Attendance Allowance (AA) Online

The option to claim AA online has been quietly introduced by the DWP on their main AA page on gov.uk. A limited number of online applications now become available every Monday but, once they have all been used, no more are forthcoming until the following week. As well as scarcity, the new service seems to have a number of drawbacks, including:

- no obvious way to save a partly completed form;
- no way of submitting additional evidence online;
- no additional information boxes, just tick box responses for difficulties with a given activity.

Readers applying for AA may want to stick to paper applications for now, unless the current online service is improved.



Possible UC/ESA and PIP Descriptor Overlaps.

With Thanks to Benefit and Work.

Many of our members claim both PIP and UC/ESA. We have known for many years that there is some relationship between the descriptors for both benefits, but up to date we have not seen anything published. While the two benefits are separate entities and have different criteria, it is possible that for example medical examination, a single medical will be used for both benefits. The table below summarises the possible link between to two benefits descriptors.

PIP Descriptor		UC or ESA descriptor											
		1	2	3	4	5	6	7	8	9	10	11	12
		Preparing Food	Eating & Drinking	Managing Treatments	Washing & Bathing	Managing Toilet Needs	Dressing & Undressing	Communicating	Reading	Mixing With People	Making Money Decisions	Planning & Following Journeys	Moving Around
1	Moving Around & Using Steps	3				3							2
2	Standing & Sitting	3			3	2							2
3	Reaching				3		3						
4	Picking Up & Moving Things	3											
5	Manual Dexterity (using your hands)	3			3	3	3						
6	Communicating - speaking, writing, typing							2					
7	Communicating - hearing & reading								2				
8	Getting Around Safely											1	
9	Controlling bowels, bladder - collection device					2							
10	Staying Conscious when awake	3	3	3	3		3			3	3	3	
11	Learning how to do tasks	3		3							3	3	
12	Awareness of hazards & danger	3	3	3	3	3						3	
13	Starting & finishing tasks	3	3	3	3	3	3		3	3	3	3	
14	Coping with change											3	
15	Going Out											2	
16	Coping with social situations									1			
17	Behaving appropriately									2			
18	Eating & Drinking		1										

Key to numbers:

- 1) There is a strong similarity between the PIP and UC/ESA criteria, but there may still be differences. For example, Coping with Social Situations (UC/ESA) and Mixing with People (PIP)
- 2) Here there is a good similarity but there are still major differences. For example, Moving Around (UC/ESA & PIP). The UC/ESA test includes the use of a wheelchair whereas the PIP test does not.
- 3) Here the criteria are criteria not similar but relevance could be argued. For example, Dexterity (UC/ESA) and Preparing Food (PIP). Dexterity problems could mean a claimant is unable to hold a knife safely in regard to preparing food.

Further Notes:

- 1). The UC/ESA activities Staying Conscious When Awake and Awareness of Hazards & Danger would be applicable to PIP activities where Supervision is included.
- 2). The UC/ESA activity Starting & Finishing Tasks would be relevant to PIP activities where prompting is included.
- 3). UC/ESA: For the medical tests Universal credit and Employment and Supports Allowance and are identical. Only the title of the questionnaire is different.
- 4) PIP and AA Overlap. There is strong overlap between Personal Independence Payment and Attendance Allowance. However, AA only has a care component and no mobility component.

Eating, drinking and ageing well

Having a nutrient-rich diet over the age of 65 is important for everyone, which means choosing foods with slightly more protein, calcium, folate (folic acid) and vitamin B12. The amount of carbohydrates, sugar, fibre, fat, and salt you need are likely to remain the same as for younger adults.

Enjoyment of eating and drinking



Taking pleasure in food and drink can help you eat well and maintain your health. Enjoyment can be increased by getting involved in choosing food and drinks that you like and preparing, cooking and serving meals. For some, sharing a meal with friends or family helps or for others eating alone is more beneficial. Cultural and religious identity is often linked with food and drink too and is there to be celebrated.

Weight



As you get older maintaining your weight is usually best for good health, giving you enough energy to stay well, socialise and be active. If you have a low body weight you may need some support. If you are very overweight, losing weight may be good for your health but it is important to still eat a nutrient-rich diet, take regular activity and maintain muscle. If you are slightly overweight, losing weight might not actually improve your health.

Activity



Moving more and keeping active, together with eating a nutrient-rich diet keeps your muscles, bones and joints strong.

Be active

at least **150** minutes moderate intensity per week (increased breathing able to talk)

at least **75** minutes vigorous intensity per week (breathing fast difficulty talking)

OR

or a combination of both

Build strength on at least 2 days a week

Minimise sedentary time Break up periods of inactivity

Improve balance For older adults, to reduce the chance of frailty and falls

Examples of activities: Brisk walk, Cycle, Swim, Gym, Yoga, Tai Chi, Bowls, Dance, Carry heavy bags, Stairs, Run, Sport.

Additional tips: Some is good, more is better; Make a start today: it's never too late; Every minute counts.

Vitamin D



Vitamin D supports bones, muscles and teeth. It helps preserve muscle strength, preventing falls, the softening of bones and the risk of fractures.

Vitamin D supplements purchased from a supermarket or pharmacy should provide 10micrograms (400 IU) each day and are the most effective way to meet your needs.



They should be taken in winter but you may benefit from them all year round. Vitamin D3 is your best choice, however, people following a vegan diet may find vitamin D2 more useful.

Supported by: Friends of the Elderly

BGS British Geriatrics Society Improving Healthcare For Older People

BDA The Association of UK Dietitians
Older People Specialist Group
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Eating, drinking and ageing well. A nutrient-rich diet is....



Fruit and vegetables

Fruit and vegetables provide a wide range of vitamins and minerals. Have at least five varied portions every day. Pick leafy greens like kale, spinach, and lettuce which are good sources of folate.

1 portion =	fresh, frozen or canned
	80g
	30g dried

1 portion =	cooked meat or poultry
	90g
	fish or shellfish
	140g
	2 : eggs
	100g : meat alternative
	150g : cooked beans or lentils
	30g : nuts

Protein
Protein is good for muscle strength, so have at least one portion with each meal. Consider having two or more portions of fish per week, one of which is oily, such as salmon or mackerel. Limit processed meats.

Carbohydrate (Starchy)

Carbohydrates provide energy, especially for the brain. Have one portion of something starchy at each meal.

1 portion =	cooked pasta, rice or grains
	190g
	bread or chapati/roti
	80g
	breakfast cereal or flour
	30g
	potato, sweet potato, yam, cassava, plantain
	150g

Milk and milk-based foods

Milk and milk-based products are a key source of calcium. Have three portions of milk and milk-based products per day such as milk, yoghurt, or cheese. If you don't like, or can't have milk and milk-based foods, choose calcium-fortified milk-free alternatives.

1 portion =	milk
	200ml
	30g cheese
	125g yoghurt

Fibre

Fibre gets your gut working normally, supporting good gut bacteria and it can also help mental health. To help maintain a healthy gut choose wholegrain carbohydrate options and eat fruit, vegetables, beans and lentils.

Fat

Fats are high in energy and should be eaten sparingly but they can help you absorb vitamins like A, D, E and K. Limit high-fat foods like processed meats and pastries. Swap butter/ ghee for unsaturated vegetable, rapeseed, olive and sunflower oils and spread. Nuts and seeds are also good choices.

Vitamin B12

Intake can be low in older adults but vitamin B12 can help maintain energy levels and health. Regularly have foods fortified with it, for example breakfast cereals or yeast extract, or have animal products including lean meat, fish, poultry, eggs, milk and milk-based foods as outlined above.

Drinking enough?

Fluid is also important as you age. As you get older, you might not recognise the feeling of thirst as you used to, but you still need to drink. All fluids count, not just water. Other fluids include tea, coffee, milk, squash, fruit juice, fizzy drinks, hot chocolate and weak alcoholic drinks (up to 4% strength (ABV). Water, tea, coffee (without added sugar) and milk are the best choices for your teeth. Men and women have slightly different fluid needs:

WOMEN
at least
1600 ML
per day
= 3 PINTS

MEN
at least
2000 ML
per day
= 3½ PINTS



Cups & glasses can be lots of different sizes so it's important to know how much fluid they hold.
Drinking often during the day can be the key to getting all the fluid you need.



Alcohol
Alcohol isn't an essential nutrient and intake should not exceed national recommendations of 14 units per week. Spread your intake across the week, rather than drinking in large quantities in one go – and have some alcohol-free days.



Sugar
Sugar doesn't provide the body with anything it needs to keep well. Limit your intake of sweet snacks, sugary drinks and confectionery.



Salt
Salt can make food tastier but too much can increase your risk of high blood pressure. Limit it and try replacing with herbs, spices, garlic, vinegar and lemon juice. Reduce your intake of processed meats and salty snacks, as well as the amount of salt you add when cooking or at the table.

Book Review: *The diagnosis and Treatment of Chronic Fatigue syndrome, Myalgic Encephalitis and Long Covid.*

by (Dr) Sarah Myhill and expert patient Craig Robinson.

(Dr) Sarah Myhill's features activities in the ME/CFS field have been featured many times in past Pathways issues

Since the publication of its first edition in April 2014, according to reviewers, (Dr) Myhill's guide to understanding and overcoming CFS/ME has become a must-read for sufferers from this poorly understood condition.

Comments like *'Extremely useful, well written, concepts well explained, absolutely great investment of money and time in reading it.'*

In the seven years since the second edition was published (January 2017) both new research and new clinical findings have thrown further light onto a condition that for sufferers is life-stopping but for many doctors is *'all in the mind'*.

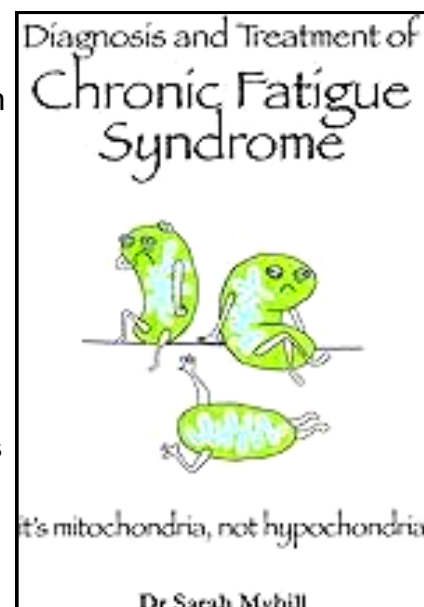
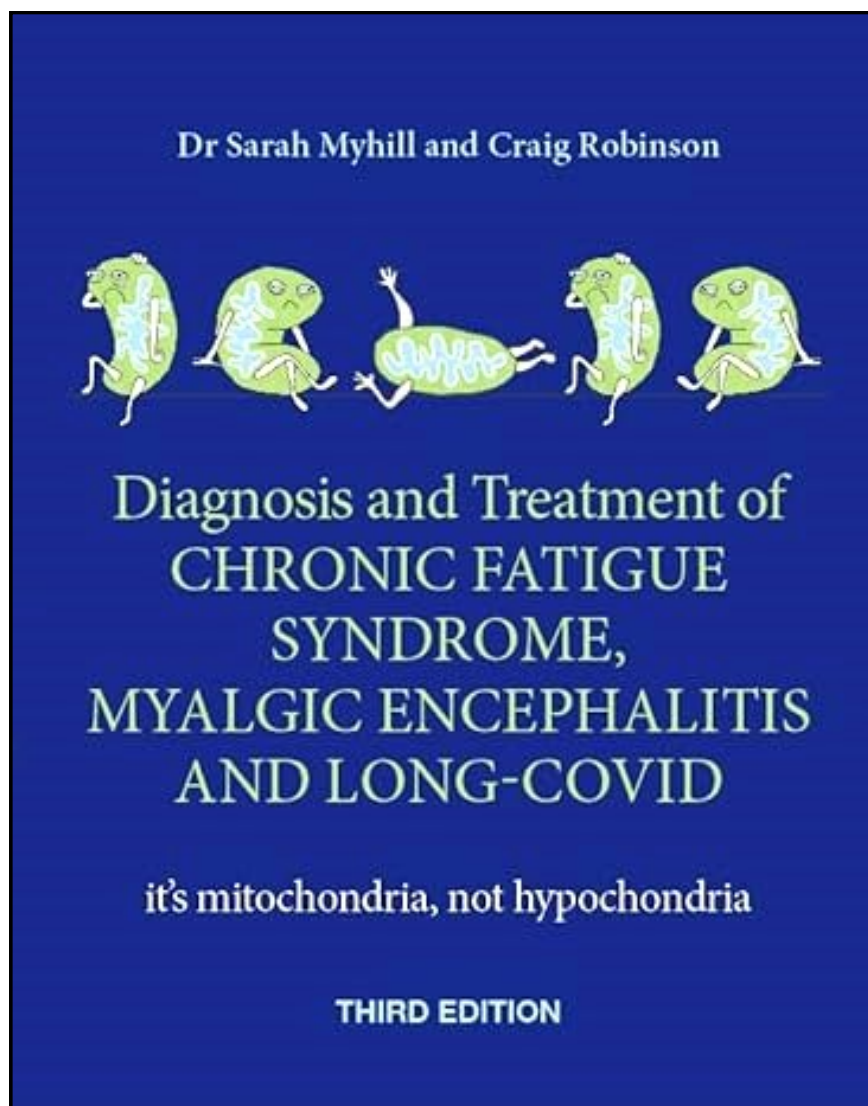
Most recently, the UK's NICE guidelines have been updated and Long Covid has changed mainstream perceptions of post-viral fatigue, while (Dr) Myhill has looked further beyond mainstream medicine into often-ignored more traditional treatments including methylene blue and DMSO (Dimethylsulphoxide).

Dr Myhill, supported by expert patient Craig Robinson, has fully rewritten and updated her book to include new insights throughout and new chapters on the PK diet, photodynamic therapy, micro-immunotherapy, ME and Long Covid, and the politics of CFS and ME.

Sarah Myhill's treatment methods and ideas have all too frequently clashed with the UK medical establishment. However, from our own experience, what we do know is that her patients seem to fair better with her treatment methods of fatigue syndromes. The first edition of the book was well received. It included details of private research level ME/CFS specific tests that were available from Biolab, Acumen and other service providers. However, when Biolab started Covid 19 testing, they ran into problems with the Care Quality Commission with tests during the Covid Pandemic as such ceased trading.

However, Sarah has organised more conventional tests, which are available on her website. One of the inclusions in this edition is a table of commonly misinterpreted conventional medical tests. Another inclusion is guidance of how to fill out a PIP form and specific advice of how to present your case in the DWP questionnaires.

If you wish to purchase this book you can through your usual bookseller, or loan the book from our group library.



The first edition.

The 2024 UK law on using a mobile phone when driving.

With thanks to Parkers Graham King, and Police UK.

Most of us like to stay entertained while driving, whether by making a quick call or changing music on our smartphones. Using a phone while driving has been illegal in the UK for years, but changes in 2022 closed some loopholes. The changes were clearly needed — Home Office data that hand-held phone use behind the wheel has surged by over 90% in the past two years. Prosecutions reached a seven-year high, with 13,332 drivers convicted in 2023, compared to 6,990 in 2022. This figure only reflects those who were caught by the police.

It's worth mentioning that the majority of new cars come equipped with features like Apple CarPlay and Android Auto, or at the very least, Bluetooth connectivity. These systems enable hands-free phone use and make it completely unnecessary to physically pick up your phone whilst driving.

What new rules on using a mobile phone while driving were introduced in 2022?

The big change introduced in 2022 was a tightening of the rules to make it illegal to touch your phone at all while driving, or even when stopped in traffic.

Previously, the law had only banned hand-held calls and messaging – so-called 'interactive communication'. Using your phone for anything else such as scrolling through playlists, taking photos and videos, or setting navigation was, in effect, entirely legal. Though prosecutions were brought for using a phone in these ways, they were successfully challenged and the charges dropped.

The rule changes introduced in 2022 closed those loopholes. Any hand-held use of a mobile phone while driving is now punishable with a fine and points on your driving licence. You may face even harsher punishment if caught making a video call while driving. These rules also apply if you're supervising a learner driver. Get caught twice and you face an instant ban from driving. In a genuine emergency, when it's necessary to call 999 and there's no safe place to stop, some flexibility will be shown if you have to get your phone out. If your car has an SOS call button, you should use that instead.

You can't touch your phone while driving, even if it's in a cradle.

Can I use my phone in a cradle while driving?

If your phone is attached to your car's windscreen, dashboard or air vent, using a phone cradle, you're not contravening any rules. Indeed, you're doing the sensible thing, especially if you need to use your phone for navigation.

However, you are not allowed to touch your phone for any reason. If you really need to handle your phone, stop in a safe place and turn the car's engine off. In an ideal world, your phone will be connected to the car's Bluetooth, or you'll use its voice controls. That way you can make and receive calls without even taking your hands off the steering wheel. If your car doesn't have Bluetooth, you can get a device which plugs into your car's stereo.

Note that making video calls, even with your phone in a cradle, is an absolute no-no that can attract severe punishment.

The rules don't prohibit touching your car's system display driving, however if the system has voice control you should use it in preference to the touchscreen or click wheel. The offence of driving without due care and attention still exists and if the police stop you because they believe you were dangerously distracted by something in the car, whatever it is, you could face prosecution.



Is it legal to use a phone as Sat Nav?

Yes, it is. However, you can't touch your phone for any reason while driving. If you need to touch your phone to accept a route change or set a new destination, stop in a safe place and turn the car's engine off to do so. Or use your phone's voice controls.

To use sat nav, you should have your phone in a cradle somewhere close to your line of sight. If it's down by the gear lever, it could be considered a distraction. If it's on the windscreen, within the area that's cleared by the wipers, it's considered an obstruction.

Am I likely to get caught if I keep my mobile out of view?

It's an old trick, this, holding your phone down by your side so no-one can see that it's in your hand. But that won't cut it anymore, especially on the motorway. Ten police forces across the country are currently rolling out new AI technology, designed to detect drivers not wearing a seatbelt or using a mobile phone while driving.

The new type of technology captures footage of passing motorists, which is then processed using artificial intelligence to determine whether the driver is using a handheld phone. The police are subsequently provided with the images to assess if any action needs to be taken.

What's more, many cars have a driver attention monitor that sounds a warning or gives some other form of prompt to focus you back on the road if you have become distracted. Such systems are able to detect mobile phone usage and are now compulsory in new cars.

Can you use your phone while parked with the engine running?

In a word, no. Even if you've pulled up in a roadside lay-by, or stopped in a car park, you're still considered to be driving when you're sat in the driver's seat and the engine is running. You should at least turn the engine off and, if it's safe to do so, get out of the car before handling your phone. You're also not allowed to touch your phone when sat in stationary traffic, regardless of whether or not the engine is running. There is, however, one very specific exception to the rules.

Messaging while driving is an absolute no-no.

What's the exception to the law about using your mobile when driving?

You may well be one of the fast-growing number of people who use their phone to pay for things. You may even have stopped carrying your bank and credit cards entirely. If this is your preferred payment method, you can handle your phone if you need to pay for something while sat in your car's driver's seat. For instance, if you're using a drive through or paying a road toll.

Frequently Asked Questions

What are the penalties if I get caught holding a phone while driving?

You'll be issued with a wallet-denting £200 fine and given six penalty points on your driving licence. Get caught again and you'll be up to the maximum 12 points and therefore be automatically disqualified from driving for six months, possibly more if other motoring offences are on your record.

Depending on how long you're banned for, you may have to retake both a theory and practical driving test get your licence back. All at your own cost.

Can I use my Apple watch whilst driving?

No, you can't. Similar rules governing phone use apply to Apple and smartwatches. While they offer convenient features like checking time, making payments, and answering calls, using them while driving can lead to fines up to £1000 and points on your licence if caught.

Are these rules really necessary?

Distracted driving has been proven to be more dangerous than drink- or drug-driving and there's a national campaign to make it as stigmatised as drink-driving. There are some circumstances in which becoming distracted is unavoidable, for instance if you have crying children in the car. However, by handling a phone you're essentially choosing to become distracted, hence the clampdown on that behaviour.



Road safety manager of England for the Royal Society for the Prevention of Accidents, Rebecca Needham, said: *The change in the law and updates to the Highway Code further underscore the importance of clear and enforceable penalties for distracted drivers and this will help change the belief that holding a phone is consequence-free. Using a mobile phone behind the wheel has been shown to reflect a deep-seated and irresponsible attitude rather than an in-the-moment reaction.*

A Summary of Driving and using mobile devices

It's illegal to use a handheld mobile phone while driving a motor vehicle on the roads in the UK.

Even using a hands-free option can incur penalties if your driving is deemed to be dangerous.

The police have the right to stop you if they think you're distracted and not in control of your vehicle, and you can be prosecuted.

It's still illegal to use your hand-held mobile device if you're:

- stopped at traffic lights
- queuing in traffic
- supervising a learner driver
- driving a car that turns off the engine when you stop moving
- holding and using a device that's offline or in-flight mode when driving your car

You can use a hand-held phone when:

- you're safely parked and engine off
- you need to call 999 or 112 in an emergency and it's unsafe or impractical to stop
- you're making a contactless payment in a vehicle that is not moving, for example at a drive-through restaurant
- you're using the device to park your vehicle remotely
- Using your mobile device hands-free

You can use hands-free mobile devices while driving your car as long as you do not hold them at any time during usage. The device must not block your view of the road and traffic ahead.

Penalties

You can get six penalty points on your licence and a £200 fine if you use a hand-held phone when driving. If you get six points within two years of passing your test you will lose your licence. You can get three penalty points if you don't have a full view of the road and traffic ahead or proper control of the vehicle. You can also be taken to court where you can be banned from driving or riding, get a maximum fine of £1,000 (£2,500 if you're driving a lorry or bus)

Having points on your licence will result in higher insurance costs.

High Dose Niacinamide

With Thanks to Dr. Myhill

Niacinamide is Vitamin B3, strictly speaking, is not a vitamin because the body can make it from the amino acid tryptophan. However, if people are eating low protein diets, then niacin does become an essential B vitamin. It is present in three forms, namely nicotinic acid, niacin and niacinamide - the first two cause dreadful flushing and so please make sure that you use niacinamide, if you are buying it as a supplement.

The active form of niacinamide in the body is NAD (Nicotinamide adenine dinucleotide) and this is a vital intermediary in energy production. Essentially, it links the two major biochemical pathways of Kreb's citric acid cycle with oxidative phosphorylation in order that the body can make our essential energy molecule, namely adenosine triphosphate (ATP). Without sufficient NAD, energy production is slowed and every single cell in the body will go slow. Therefore, it is not surprising that a deficiency of NAD has widespread effects and, by implication, NAD has many therapeutic uses. For this reason, I recommend Niacinamide to my CFS/ME patients.



For the reasons given above, low B3 will result in fatigue. Any condition associated with poor mitochondrial function, such as chronic fatigue syndrome, any organ failure, and any neurological disease such as Parkinson's disease, may well benefit from high doses of NAD.

Arthritis: Work done by Dr William Kaufman in the 1940s and written up in his book "The Common Form of Joint Dysfunction" demonstrated that many forms of arthritis can benefit from high dose B3. Kaufman was insistent that the full daily dose of as much as 3000 - 5000 mg be given in many small divided doses throughout the day. He got excellent results. I believe that this is an intervention well worth trying.

Schizophrenia and Psychosis: Dr Abram Hoffer routinely uses high dose niacinamide, up to 3 grams daily, with excellent results for patients suffering from psychosis. It may take some months, or even years, to get the full benefit, but normal mental health can be restored. This is taken in conjunction with other nutritional supplements. A study comparing the benefits of high dose niacinamide compared to diazepam came up with the interesting result that niacinamide was more effective. The reference for the study can be found at Nicotinamide is a brain constituent with benzodiazepine-like actions, although, sadly, this paper is not open source.

Control of blood sugar levels: I find myself talking more about the control of blood sugar levels so much. I only talk about diet more! It is not just a case of maintaining a low glycaemic index diet. Taking Nutritional Supplements, reducing allergies, correcting hormonal imbalances and managing stress efficiently are all essential in maintaining normal blood sugar levels. Neurotransmitter levels.

Niacinamide may be converted by the body back to tryptophan and this is the raw material for the pathway that includes 5-HTP, serotonin and melatonin. This pathway will have profound effects on mood and sleep. So, for example, tryptophan and 5-HTP are very effective in the treatment of depression. Melatonin - the sleep hormone obviously essential for quality sleep.

High dose Niacinamide

To get these therapeutic effects, one has to use niacinamide in much higher doses than the recommended daily allowances. Because it is so short acting, the best effects are achieved through small doses taken regularly throughout the day. With Niacinamide 1500 mg slow release, this problem is overcome by taking a morning dose. In doses above this, there will be a few people who will develop abnormal liver enzymes and this is almost invariably accompanied by a feeling of nausea. In this event, therefore, check liver function tests. Having said that, I have recommended niacinamide to hundreds of patients and have yet to see any abnormal liver function tests. I think this is because side effects and problems with drugs and nutritional supplements almost invariably arise as a result of nutritional deficiencies.

More on Niacinamide with thanks to Healthline

Niacinamide is one of the two forms of vitamin B3 — the other being nicotinic acid . Vitamin B3 is also known as niacin. Niacinamide and nicotinic acid both provide vitamin B3 activity, but they differ in chemical structure and how they affect your health. Niacinamide is a form of vitamin B3 (niacin) — one of the eight vitamins the body needs for good health. Vitamin B3 plays a vital role in converting the you eat to usable energy and helps your body's cells carry out important chemical reactions. Since it's water-soluble, your body doesn't store this vitamin, which is why you need to eat nicotinic acid or niacinamide daily.

Vitamin B3 is generally found as niacinamide in animal-based products, such as meat and poultry, and as nicotinic acid in plant-based foods like nuts, seeds and green vegetables. Many refined grain products, including cereals, are also fortified with niacinamide. Your body can also make vitamin B3 from, an amino acid present in most protein foods. However, the conversion of tryptophan to vitamin B3 is inefficient, as it takes 60 mg of tryptophan to make just 1 mg of vitamin B3. Historically, vitamin B3 was called vitamin PP, an acronym for pellagra-preventive. That's because a deficiency of vitamin B3 or tryptophan leads to a disease called pellagra, which is characterized by the four D's — diarrhoea, dermatitis, dementia and, if left untreated, death. Pellagra is rare in developed countries like North America and Europe, but the disease is still frequent in some developing countries. Nicotinic acid and niacinamide can both treat pellagra, but niacinamide is preferred since it's associated with fewer side effects, such as blushing of the skin.

Helpful for Certain Skin Conditions:

Niacinamide plays an important role in keeping your skin healthy. For this reason, it's a popular additive in the cosmetic and skincare industry. When applied topically (directly) or taken orally as a supplement, niacinamide has been shown to have anti-inflammatory effects on the skin. It has been used to treat skin conditions like rosacea, a facial skin disorder characterized by redness. This makes niacinamide a popular alternative to oral or topical antibiotics for treating acne or rosacea

Melanoma is a serious type of skin cancer that develops in the cells that produce melanin, the pigment that gives your skin its colour. Exposure to ultraviolet (UV) radiation, either from the sun or tanning beds, damages the DNA of your cells over time and is strongly correlated with melanoma. Owing to its role in keeping your cells healthy, oral supplements of niacinamide have been shown to enhance DNA repair in UV damaged skin in humans. As such, niacinamide is a promising supplement that may protect against melanoma, especially in high-risk populations, such as those who have had previous nonmelanoma skin cancers.

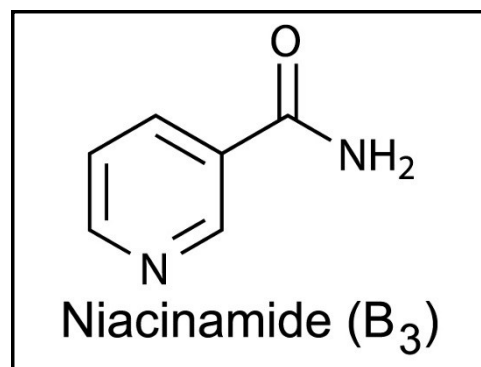
Niacinamide is useful for Chronic Kidney Disease:

Chronic kidney disease is the progressive loss of kidney function that affects your body's ability to clean and filter blood and control blood pressure. This can cause a harmful buildup of chemicals, such as phosphate, in your blood. Research suggests that niacinamide may help decrease phosphate levels in people with kidney dysfunction by blocking its absorption. Phosphate levels are otherwise typically managed through diet, medications or dialysis, depending on the severity of the buildup.

May Slow the Progression of Type 1 Diabetes:

Type 1 diabetes is a condition in which your body attacks and destroys the insulin-producing beta cells of the pancreas. It's been suggested that niacinamide protects and preserves the beta cells, thereby preventing or delaying the onset of type 1 diabetes in at-risk individuals. However, research doesn't support the notion that niacinamide can prevent the onset of type 1 diabetes, although it may help delay its progression by preserving beta cell function. While promising, more research is needed before niacinamide supplements can be recommended as an intervention for type 1 diabetes.

Helps reduce cholesterol. Niacinamide, can help lower cholesterol levels. It boosts levels of good HDL cholesterol and modestly lowers bad LDL cholesterol. It can be used alongside other cholesterol lowering medicines to treat high cholesterol.



British Psychological Society: Guidelines for ME/CFS

From Action for ME, September 3rd, 2024.

The British Psychological Society is working with people with ME/CFS, Action for M.E. and the ME Association to produce good practice guidelines for psychologists working with people with ME/CFS, based on the 2021 NICE guideline. These will support clinicians to provide a good quality service with the aim of improving the lives of people with ME/CFS. The professionals and patients leading this work, and Action for M.E., are very clear that ME/CFS is NOT a psychological illness. As Joan Crawford, a member of the ME/CFS Working Group leading this project has said:

“There are several psychologists with ME involved in leading this project. It is not about promoting treating people with ME with psychotherapy. That has zero evidence base. It is about ensuring psychologists know this and have information about ME to support them appropriately.”

Alongside Joan, bringing experience from clinical, counselling, occupational health and educational psychology backgrounds are Sara Meddings, Louise Kenward and Nita Baker, plus two experts by experience: Katherine Langford, Action for ME; and Russell Fleming, ME Association.

Earlier this year, our volunteer Katherine shared her experience in an article for the British Psychological Society, urging professionals to use appropriate, evidence-based resources when working with people with ME/CFS. She wrote:

“Sadly, it is common for people to have received bad medical advice or a lack of support from the medical profession. I came down with ME when I was 13 and was sent to see a paediatrician.

Unfortunately, he (incorrectly) thought my ME was psychological. He told me to push through my symptoms and get back to school as quickly as possible but this caused my health to crash completely. I remember being so exhausted that I did not even have the energy to roll over in bed.”

Action for M.E. is supporting this project because we want to reduce harm caused to hundreds of thousands of people with ME/CFS, like Katherine.

They said:

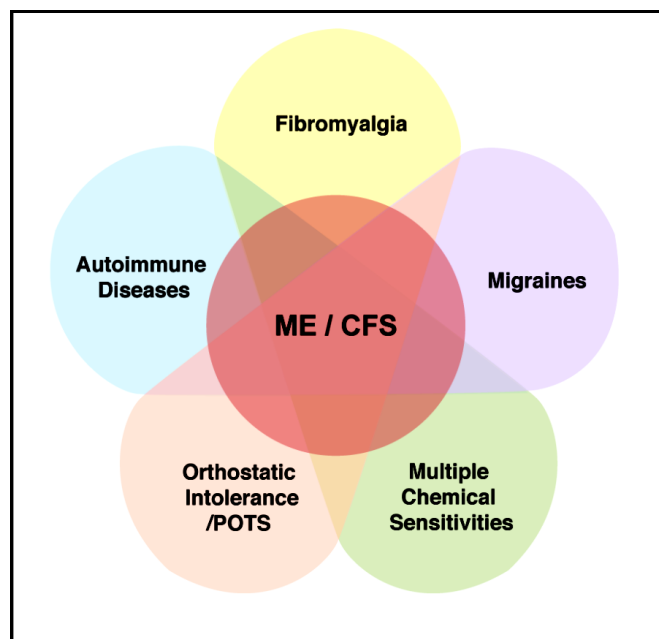
“We believe it is essential that psychologists have accurate information and examples – along with what NOT to do - on how to provide the best care and support they can, firmly underpinned by the 2021 NICE guideline for ME/CFS.”

In a thread on X.com (formally Twitter), ME/CFS Working Group member Louise Kenward explains that the British Psychological Society have been involved to contribute to the DHSC implementation process for the NICE guideline, and that developing good practice guidance is the next step in this work:

“I think the good practice guidance will be a great step towards improving care & treatment of people w ME and may also help people with ME to understand the role psychologists have (& what we can help with) too.”

To develop their guidelines, the British Psychological Society is seeking the views and experiences of people with, or caring for someone with, ME/CFS, whether or not you/they have seen a psychologist. They will collate anonymised information from this initial survey and use the insights and experiences you share to inform the guidelines.

The closing date to complete this survey is 9th October 2024. Preliminary findings from responses received by 15th September will be shared at the first co-production meeting for the guidelines.



Energy Saving Tips from Doncaster MBC



Food and cooking

- Consider alternative ways to cook such as using a microwave or a slow cooker as this uses less energy and can save you money
- Batch cook meals and freeze leftovers to save money and energy
- Try to plan your meals for the week ahead. This will help to reduce food waste, save money on your shopping bill and save energy when cooking
- Keep lids on saucepans and pots to reduce condensation and use the extractor fan where possible

Appliances

- Wait until you have a full load before putting on a wash
- Avoid using a tumble dryer as these use a lot of energy
- If possible, have a shower instead of a bath, this uses less water and less energy to heat the water. Also, try to have shorter showers as this will use less energy and save you money.
- Avoid overfilling your kettle, only boiling the water that you need
- Turn off non-essential appliances when not in use and switch lights off when you leave a room

Heating system

- You could save money by putting radiator foils behind your radiators, which would reflect heat back into the room.
- Spend some time getting to know your heating system – using it effectively will save you time, energy and money
- Where you can, make sure you have a yearly service of your heating system by a professional
- Turn your boiler flow temperature down to 60 degrees visit www.moneysavingboilerchallenge.com for more information on how to do this

Around the house

- If it's sunny, try and let light and heat into the room by opening curtains and blinds. Close curtains and blinds when it's not sunny, to trap in heat and save energy.
- Using draught-proofing strips around the window frame can stop heat escaping and prevent the cold getting in.
- Move your furniture away from radiators and avoid drying clothes on radiators to let heat circulate
- If you're not very mobile, 65+, or have a health condition, such as heart or lung disease, try to heat living areas to at least 18 degrees – 21 degrees, and your bedroom to 18 degrees. If you need support in heating your home to these temperatures, please speak the Sustainability Unit for information about support



Cost of Living Key Contacts

Advance

Tailored employment support.
 Call: 01302 735554. Option 2: Advance Team
 Email: advance@doncaster.gov.uk
 Website: advancedoncaster.co.uk

Disabled Facilities Grant

Grants for helpful housing adaptations.
 Request financial assessment for an adult:
 01302 737391.
 Request financial assessment for a child:
 01302 737391.
 Website:
doncaster.gov.uk/services/housing/home-improvements-and-grants

Doncaster Wellbeing Service

Advise and support on a range of issues including finance and home.
 Call: 01302 735553
 Email: wellbeing@doncaster.gov.uk
 Website: doncaster.gov.uk/services/get-involved/wellbeing

Household Support Fund

Support with essentials such as food, energy and school meals.
 Call: 01302 735336 - select option 1
 Email:
householdsupportfund@doncaster.gov.uk
 Website: doncaster.gov.uk/services/council-tax-benefits/household-support-fund

Private Rental Tenants

For landlord & tenant advice.
 Website:
www.doncaster.gov.uk/services/housing/private-sector-housing

Doncaster Sustainability Unit

Information on local support and grants, including Boiler on Prescription.
 Call: 01302 737053
 Email: energy.team@doncaster.gov.uk
 Website:
doncaster.gov.uk/services/housing/energy-saving-tips

Housing Adaptions

Providing adaptions to stay mobile in and around your home.
 Call: 01302 737391 - select option 3
 Website:
doncaster.gov.uk/services/housing/adaptations

St Leger Homes

Support and advice for Council tenants.
 Call: 01302 862 862
 Email: info@stlegerhomes.co.uk
 Website: www.stlegerhomes.co.uk

Your Place Hubs

Call, email or drop in, 8:30 am - 4:30 pm, Monday to Friday. Find your local hub on Your Life Doncaster.
 Website: www.yourlifedoncaster.co.uk/your-place-your-family-team
 South- Call: 01302 736644
 Email: LocalSolutionSouth@doncaster.gov.uk
 Central- Call: 01302 736409
 Email: LocalSolutionCentral@doncaster.gov.uk
 North- Call: 01302 736787
 Email: LocalSolutionNorth@doncaster.gov.uk
 East- Call: 01302 736336
 Email: LocalSolutionEast@doncaster.gov.uk



Cost of Living Key Contacts

Winter Fuel Payment Centre

Support with the winter fuel payment.

Call: 0800 7310160

Online enquiry form:

secure.dwp.gov.uk/contact-winter-fuel-payments-centre/contact-form

Website: gov.uk/winter-fuel-payment/report-change-circumstances

Local Assistance Scheme

Supporting residents to meet immediate short-term needs and independence.

Email:

LocalAssistanceScheme@doncaster.gov.uk

Website:

doncaster.gov.uk/services/council-tax-benefits/local-assistance-scheme

Live Inclusive

Help with daily living expenses and/or furniture items and white goods.

Call: 01302 592400

Email: admin@liveinclusive.org.uk

Website: <http://www.liveinclusive.co.uk/>

Ofgem

Information on discounted energy bills.

Website: www.ofgem.gov.uk/information-consumers/energy-advice-households

Citizens Advice Doncaster Borough

Advice and support with debt, housing, employment, energy, finances and more.

Call: 01302 243057

Email: Web Chat: bit.ly/ca-webchat

Website: www.cadoncasterborough.org

Foodbanks

Details of foodbanks in each locality.

Website: www.yourlifedoncaster.co.uk/food-bank-information

Stronger Families Programme

Support for families.

Email:

StrongerFamiliesProgramme@doncaster.gov.uk

Website:

doncaster.gov.uk/services/schools/what-is-stronger-families

Changing Lives

Drug, alcohol and housing services.

Call: 0191 273 8891

Email: central.office@changing-lives.org.uk

Website: www.changing-lives.org.uk

Occupational Therapy Team

Assisting people to be safe, well and independent.

Call: 01302 736000 between 8.30 am – 5 pm

Monday - Friday

Website: doncaster.gov.uk/services/adult-social-care/occupational-therapy

Your Life Doncaster

Information and support for adults, young people, children, local information and the cost of living .

Website: www.yourlifedoncaster.co.uk

Homelessness Outreach Service

Concerned about someone sleeping rough?

Call: 01302 558014

Email: nsno.doncaster@riverside.gov.uk

Website: Report via Streetlink:

www.streetlink.org.uk

If the person is in immediate danger or requires urgent care, call 999.

Housing Options Team

If you are homeless or think you are going to become homeless.

Call: 01302 736000 (Mon - Fri, 08:30 - 17:00)

(Outside office hours - 01302 323444)

Email:

housingoptionsteam@doncaster.gov.uk



Autumn Recipe Corner.

Turkey meatballs with roasted veg brown rice

Prep: <30 mins Cook: ½ - 1 hour: Serves:

Cooking Method

- 1) Preheat the oven to 210C/190C Fan/Gas 6½. Line two large baking trays with greaseproof paper and place into the oven to preheat.
- 2) Tip the rice into a sieve and rinse under cold water until the water runs clear. Place a medium saucepan over a medium-high heat and add the rice along with 400ml/14fl oz water. Season with salt and add a drizzle of oil. Give the rice a stir, then cover with a lid and bring to the boil.
- 3) Reduce the heat to low and cook for 30 minutes until the rice is tender and the water has been absorbed. Turn off the heat and leave covered for 10–15 minutes.
- 4) Meanwhile, combine the peppers, chopped courgette, red onion, za'atar and 2 tablespoons oil in a large bowl. Season with salt and pepper and spread evenly on one of the preheated baking trays. Cook for 15–25 minutes until soft and slightly charred.
- 5) Drizzle the remaining baking tray with 2 tablespoons oil and put back into the oven.
- 6) Meanwhile, in the same bowl that had the veg in, combine the turkey mince, grated courgette, lemon zest, spring onions, parsley and 1 tablespoon of the mint. Season with salt and pepper and mix well.
- 7) Divide the mixture in half and then into quarters, and shape. You're looking to get roughly six small meatballs from each quarter (24 meatballs in total).
- 8) Transfer the meatballs to the preheated baking tray and cook for 20 minutes, turning halfway through.
- 9) Meanwhile, make the yoghurt dressing by combining the yoghurt, remaining mint, 1–2 tablespoons lemon juice and a little salt and pepper.
- 10) Once the rice is cooked, fluff-up with a fork and mix through the roasted vegetables.
- 11) Serve the meatballs with the vegetable rice, a handful of rocket and a good drizzle of the yoghurt dressing.

Gluten free Squash Beanotto

Serves 4 Prep: 15 mins Cook: 30 mins

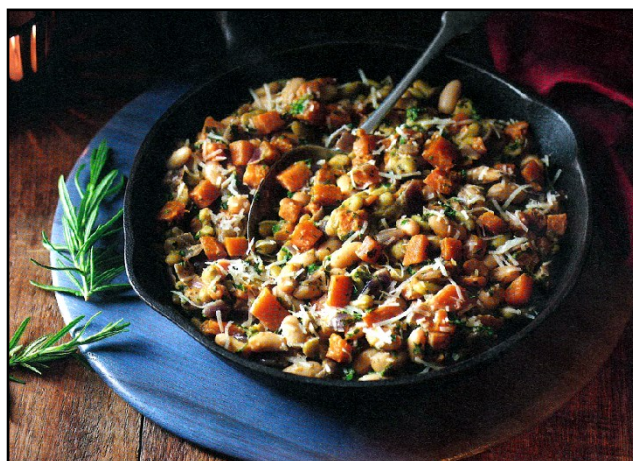
Cooking Method

- 1) Heat the oil in a large frying pan.
- 2) Add the butternut squash and red onion, cover and fry over a low heat, stirring frequently for 20 mins until softened and beginning to brown.
- 3) Stir in the garlic, chilli flakes, smoked paprika and rosemary and fry for a further 2 mins until fragrant.
- 4) Pour over the stock, stir in the kale, and simmer for 4 mins. Add the beans and cook for 2-3 mins, stirring occasionally until warmed through.
- 5) Stir in the creme fraiche. Season to taste with freshly ground black pepper and serve scattered with Parmesan cheese.



Ingredients

200g/7oz brown rice
 4 tbsp olive oil, plus extra for drizzling
 2 peppers, chopped into 1–2cm/½–¾in pieces
 2 medium courgettes, 1 coarsely grated and 1 chopped into 1–2cm/½–¾in pieces
 1 red onion, chopped into 1–2cm/½–¾in pieces
 1 tbsp za'atar
 500g/1lb 2oz turkey mince (ideally around 5–10% fat)
 1 lemon, zest and juice
 2–4 spring onions, thinly sliced
 1 tbsp finely chopped fresh parsley
 2 tbsp finely chopped fresh mint
 150g/5½oz natural yoghurt
 100g/3½oz rocket salt and freshly ground black pepper.



Ingredients

2tsp olive oil
 Small butternut squash, about 700g, peeled, deseeded and finely chopped
 1 large red onion, peeled and, finely chopped
 2 garlic cloves, crushed
 pinch dried chilli flakes
 1tsp smoked paprika large sprigs rosemary, leaves only, finely chopped
 200ml low-salt vegetable stock, made using % stock cube
 75g kale, woody stalks discarded, and finely chopped
 400g can flageolet beans, rinsed, and drained
 400g can cannellini beans, rinsed, and drained
 2tbsp half-fat creme fraiche
 freshly ground black pepper
 2tbsp finely grated Parmesan cheese

Medicine Matters

Here is a resume of the medicine headlines since the last Pathways.

Lecanemab h

This medicine has been shown to slow down progression of Alzheimer's disease. However, the benefits are too small to justify the costs, says NICE in draft guidance

Eladynos (abaloparatide)

This is a new option for the treatment of osteoporosis in postmenopausal women. This new osteoporosis treatment launches following NICE approval.

Vibegron

This medicine is provisionally approved by NICE for overactive bladder problems. It is a new non-anticholinergic treatment for overactive bladder (OAB) has been recommended in draft NICE guidance

Shingles vaccine

It has been found that this vaccine could reduce dementia risk, studies suggest. The shingles vaccine Shingrix has been linked to a significant reduction in the risk of dementia in a large observational study.

Wegovy (semaglutide)

This medicine has been approved for cardiovascular disease prevention in adults with obesity in overweight adults. This is in addition to its use for the treatment of type 2 diabetes and weight loss. The GLP-1 agonist Wegovy becomes the first weight-loss drug approved in the UK as a preventative option for those at risk of cardiovascular events.

There is no evidence that GLP-1 agonists cause suicidal behaviour, suicidal ideation, self-injury or depression, an MHRA review has found.

Mpox (aka Money pox) vaccine.

The U.K. government has ordered 150,00 doses of Mpox vaccine. At the time of writing there were no Mpox cases in the UK. The vaccine is intended for certain health workers, close contacts of known Mpox cases and gay and bisexual men. Mpox is related to smallpox, and the vaccine technology has been moved over from smallpox vaccine in a similar way that SARS vaccine technology has been has been moved over to Covid Vaccines.

Ryeqo

This medicine becomes the first in a new class of treatment for women with endometriosis. It is an oral medicine

Epilim (Valproate)

This medicine is a medicine used to treat epilepsy and some pain problems. It is also teratogenic in that it causes Thalidomide like problems in women who are pregnant. E.g. missing or deformed limbs in the developing baby. The standard advice is in a women is being treated with this medicines to take appropriate contraceptive precautions from becoming pregnant.

It has now emerged that valproate medicines can cause sperm damage in men, and the contraceptive advise has been extended to men being treated with valproate

Triptans

A recent study has found that some triptans are more effective than newer, more expensive migraine drugs.



Flu vaccines available for the 2024 to 2025 season:

The eligible groups to receive the vaccine free are

- aged 2 and 3 years on 31 August 2024
- eligible school aged children (Reception to Year 11)
- those aged 6 months to under 65 years in clinical risk groups
- pregnant women
- all those aged 65 years and over
- those in long-stay residential care homes
- carers, those in receipt of carer's allowance or main carer of an older or disabled person
- household contacts of immunocompromised individuals
- frontline health and social care staff.

Vaccine	Manufacturer	Licensed from age
Cell-based Quadrivalent Influenza Vaccine (QIVc) Egg-free	CSL Seqirus	licensed from 6 months of age
Fluenz, live attenuated influenza vaccine (LAIV)	AstraZeneca	licensed from 2 years to under 18 years of age
Quadrivalent Influenza Vaccine, egg-grown (QIVe)	Sanofi	licensed from 6 months of age
Influenza Tetra MYL, Quadrivalent Influenza Vaccine, egg-grown (QIVe)	Viartis	licensed from 6 months of age
Quadrivalent Influenza Vaccine – High Dose egg grown (QIV-HD)	Sanofi	licensed from 60 years of age
Adjuvanted Quadrivalent Influenza Vaccine <input type="checkbox"/> (aQIV)	CSL Seqirus	licensed from 65 years of age

If you are not eligible for a free vaccination and require one you can pay for one through or GP or Pharmacies. If you have a problem with egg-based vaccine or you are vegan or vegetarian usually you have to ask. Availability depends on the local supply arrangements.

Covid Update

With thanks to the BBC News 16/9/24

No, it's not gone away. It's still around. A BBC news feature dates 16th September 2024 reports that people have started catching a new Covid variant that could soon take off and become the dominant type, according to scientists. The new strain was Identified in Germany, in June, cases of the XEC variant have since emerged in the UK, US, Denmark and several other countries. It has some new mutations that might help it spread this autumn, although vaccines should still help prevent severe cases, experts say. For those more likely to become seriously ill from Covid, the NHS offers a free booster shot. The vaccines have been updated to better match recent variants, although not XEC, which has emerged from earlier Omicron subvariants. Prof Francois Balloux, Director of the Genetics Institute at University College London, told BBC News that although XEC has a "slight transmission advantage" over other recent Covid variants, vaccines should still offer good protection. He says it is possible XEC will become the dominant subvariant over the winter though.

Covid vaccines are also available, if required is an similar way to Flu vaccines.

Crafters Corner

Although many of our members have ME/CFS this though not stop them from making things, here are examples of what our members have been doing over the past few months.

What we have from Anne is a lovely, varied collection of her work this year as follows :-

Sandra has made two Thermal Lunch Bags with removable linings for washing. This is very difficult to achieve without the use of an industrial machine capable of sewing thicker layers! A few months ago, we saw photos of what Sandra referred to as prototypes; all I can say is that they are looking pretty smart and ready for use in this latest photo!



Thermal Lunch Bags with removable linings for washing

Claire has been busy with different projects and has shared her Diamond Art boat picture and a pretty crochet cushion cover for us all to see.



Diamond Art boat



crochet cushion cover

Ann has been very busy with a variety of projects.



Wet and needle felted coaster and soap.



Needle felted Felted animals



Peter Rabbit Style garden.



Wildlife pond.

Five things to know about Long COVID and ME/CFS.

With thanks to Gavi.org based in the USA.

In the USA scientists are looking into the similarities between Long Covid and ME/CFS.

Here are their conclusions:-.

1). Half of Long COVID patients have chronic fatigue syndrome

While fatigue has been linked to Long COVID right from the first few cases, Long COVID also presents with a constellation of symptoms including gastrointestinal issues, shortness of breath and loss of smell or taste. In people who have had chronic fatigue syndrome (ME/CFS), infection with SARS-CoV-2 could trigger viruses that have been dormant, leading to a resurgence of ME/CFS symptoms. To understand the prevalence of chronic fatigue in Long COVID patients, researchers in Iran, a meta-analysis covering 52 studies with 127,117 participants. They found that 42.5% of people who develop Long COVID have chronic fatigue that often persists for months. despite medical care.

2). Antivirals could help prevent Long COVID and treat ME/CFS . Maybe.

People who took the antiviral drug nirmatrelvir shortly after becoming sick with COVID-19 were 26% less likely to develop Long COVID, according to a study published in November 2022a pre-print website. The study looked at people older than 60 years, and it's not clear yet whether the antiviral could be protective against Long COVID in younger people. There has been anecdotal evidence the use of this antiviral to treat Long COVID symptoms, and researchers suggest antivirals could give people with ME/ME/CFS enough of an immune boost to get relief from their symptoms, yet there have been no conclusive clinical trials yet.

3. COVID-19 could reactivate chronic fatigue symptoms

In people who have had chronic fatigue syndrome (ME/CFS), infection with SARS-CoV-2 could trigger viruses that have been dormant, leading to a resurgence of ME/CFS symptoms, according to a study published in December 2022. Herpes viruses such as Epstein-Barr virus (EBV) have been linked to triggering ME/CFS. The researchers found that antibody levels against several herpes viruses including EBV were raised in people who had ME/CFS compared with in people who had never had ME/CFS. This suggests that COVID-19 reactivated viruses linked to chronic fatigue symptoms.

4. Long COVID has reignited research into the causes of ME/CFS

Long COVID has caused a resurgence of interest and study into ME/CFS: a still mysterious condition that has had little attention from the research community for decades. Beth Pollack, chronic disease researcher at MIT, describes ME/CFS as a "neuroimmune, neuroinflammatory illness that affects numerous organ systems throughout the body, involving dysfunction of the vascular, autonomic, neurological, mitochondrial, metabolic, connective tissue, endocrine, and immune systems ". An estimated 90% of people with ME/CFS are never properly diagnosed, and many cases have been dismissed as a condition existing purely "in the mind " that can be treated with exercise therapy. In the US about 15 doctors specialise in ME/CFS.

5. There is controversy in treating Long COVID just as with ME/CFS

There are no established treatments for Long COVID, just as there aren't for ME/CFS. For decades, graded exercise therapy was advised for ME/CFS, an approach that operated on the principle that steadily increasing the amount that people exercised would eventually return them to full health. Others argued that this was a challenging treatment programme for people to follow when they often struggled to walk to the end of their road. However, it is still now widely recommended treatment. Long COVID has seen a division of opinions on the best approach to treatment, with some doctors to emphasise the role of exercise in rehabilitation and others opposed to it. A better understanding of the underlying causes behind both ME/CFS and Long COVID, as well as investment into clinical trials for treatment should help our understanding of both these conditions.

See : [Five things to know about Long Covid and Chronic Fatigue Syndrome \(gavi.org\)](https://www.gavi.org/press-releases/five-things-to-know-about-long-covid-and-chronic-fatigue-syndrome)

At Leger ME we view that Long Covid as a Post Viral Fatigue Syndrome, and as such for practical purposed we see no significant difference between the two conditions.

An Interview with a Doctor who got ME/CFS or Long Covid?

With thanks to, Jamie Coulson, Health Correspondent, BBC Yorkshire

Dr. Becky Williams said she had lost her "job, friends and independence" due to long Covid. Becky Williams, 34, first caught Covid in March 2020 and has been left house-bound ever since, with her symptoms including extreme fatigue, brain fog and pain.

A doctor from Leeds who developed long Covid and the debilitating effects of ME has said NHS patients like her have been "left to rot".

Dr Williams, who said she had "lost my job, lost friends, lost my independence", has joined about 200 other healthcare workers who have signed a letter calling on the government to provide better support for patients with these conditions.

The Department of Health and Social Care said the government would "ensure patients receive the care they deserve". Dr Williams initially developed long Covid, but for the past two years has also met the criteria for ME (Myalgic encephalomyelitis), also known as chronic fatigue syndrome (CFS).

Often developing after an acute viral or bacterial infection from which people are unable to fully recover, ME has many overlapping features with long Covid.

It is estimated at least 250,000 people in the UK have ME, which affects multiple systems within the body and which can lead to symptoms like fatigue and a flu-like malaise, though the ME Association believe that figure is likely to be "significantly" higher.

Dr Williams said: "I've lost my job, I've lost friends, I've lost my independence, my ability to drive and to look after myself. I can't even wash my own hair."

'Safety concerns'

Dr Williams said she had signed a letter organised by campaign group #ThereforME calling on Health Secretary Wes Streeting to improve care.

The letter asked Mr Streeting and the government to acknowledge that gaps in NHS care for ME patients were leading to "serious patient safety concerns".

According to the letter, "patients at the severe end of the disease spectrum are bedridden, sometimes tube-fed and confined to quiet, darkened rooms due to extreme light and sound sensitivity".

"In the most extreme cases, patients languish behind closed doors with little or no support," it added.

Dr Williams said: "I feel we've all been left to rot - which I know sounds dramatic - neglected and not being listened to."

She said the campaign would "give us all a voice", including those who are who are so severely affected they are "generally left unheard".

Dr Williams, said she and others in a similar position had been "left to rot"

A Department of Health and Social Care spokesperson said: "This government will ensure patients receive the care they deserve.

"We are committed to improving the care and support for people with long Covid, Myalgic encephalomyelitis and chronic fatigue syndrome. "We recognise how devastating the symptoms can be, and the significant impact they can have on patients and their families."

The spokesperson said the government "welcomes applications for high-quality research to understand the causes, consequences and treatment of ME/CFS and long Covid".

"We are actively exploring next steps for research in this area," they said.

Inquest calls for Treatment after ME patient's death

With Thanks to BBC South West health correspondent

Maeve Boothby-O'Neill, 27, suffered from severe chronic fatigue syndrome for a decade before she died at home in October 2021. Maeve Boothby-O'Neill had been admitted to hospital three times. An inquest in Exeter heard she had been admitted to the Royal Devon and Exeter Hospital three times that year for treatment for malnutrition. The coroner said: *"The reality of this case is it is not possible for me to say if any treatment could've halted her decline - I hope lessons will be learned in the hope future deaths can be prevented."* Maeve's mother Sarah called for institutional change in ME care.

Dr Lucy Shenton, who cared for Miss Boothby-O'Neill, told the inquest doctors needed more help to treat patients with ME. "Regarding severe ME, there needs to be more funding and research into ME to provide the evidence and guidelines for clinicians to work from," she said. "There needs to be somewhere within the NHS providing specialist care for patients with severe ME and an easy mechanism to access that provision."

Miss Boothby-O'Neill's mother, Sarah Boothby, told the inquest her daughter's death was "premature and wholly preventable" as malnutrition in cases of severe ME was "common". "I believe the evidence shows Maeve is likely to have died from malnutrition and dehydration because she had severe ME," she said. "I therefore believe her death was both premature and wholly preventable."

After the inquest, Ms Boothby called for "institutional change" in the care of ME patients. She said "Unless NHS England takes responsibility for the many other deaths from ME that have gone unrecorded and therefore unreported there will be more," she said.

Maeve Boothby-O'Neill died from malnutrition and dehydration said her mother. Other families told the BBC they lived in fear and were terrified of what could happen to their loved ones with ME.

Rosie Barrett's sister Alice has been living with ME for nearly four years. Last year, the Royal Devon and Exeter Hospital changed its care plan for Alice after her family campaigned for her to be fed lying down, a deviation from the hospital's usual policy. It was the same hospital that treated Miss Boothby-O'Neill two years before. Ms Barrett said: "Because there is no known treatment for ME the unknown of how long she will be this ill or whether she'll make it to recovery is hard. "I think Maeve's case has increased awareness within the public." She also said there had been changes in the hospital's operating procedures, "however there is still a very long way to go".

The inquest heard from medical experts who said there was no specialist unit for ME patients anywhere in the country. It has highlighted the need for properly funded research and better understanding around the condition. It also noted some doctors expressed doubt ME has a biological basis, a stigma that some groups are campaigning to change.

Sonya Chowdhury, of Action for ME, said: "We need a tangible pathway of care for people with ME and for people with severe ME, having direct access to experts. "And we also need to see education and an acceleration of research because one day there will be treatments and that has to happen sooner rather than later."

Prof David Strain, from the University of Exeter, said the disease had been "tremendously stigmatised" because there was no diagnostic test. "The difficulty we still face with ME is because it is unlikely to be a single disease, there is no one diagnostic test," he said. "That is still a barrier we face today."

A Department of Health and Social Care spokesperson said: "Our deepest sympathies are with Maeve's family and friends in this tragic case. "This government will ensure that patients receive the care they deserve. "We are committed to improving the care and support for people with chronic fatigue syndrome (CFS). We recognise how devastating the symptoms of CFS can be, and the significant impact they can have on patients and their families."

Andrew Gwynne, Minister for Public Health and Prevention, said Miss Boothby-O'Neill's case was a "heart-wrenching example of a patient falling through the cracks". "Maeve and her family were forced to battle the disease alongside the healthcare system which repeatedly misunderstood and dismissed her," he said. "I am committed to improving the care and support for all those affected, and we intend to publish a final delivery plan this winter which will focus on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease."

Adrian Harris, chief medical officer at the Royal Devon University Healthcare NHS Foundation Trust, said "everybody involved in caring for Maeve has been profoundly impacted". "We have learned from Maeve's case and strengthened the information available to staff caring for patients with severe ME," he said. "The trust will take time to consider in full the coroner's detailed findings from today and will take forward learning identified once the coroner has heard evidence on the progress made since Maeve's tragic death."

The evidence in relation to the prevention of future deaths is being heard separately and a hearing date is set for 27th September.

North of Doncaster Goes West.

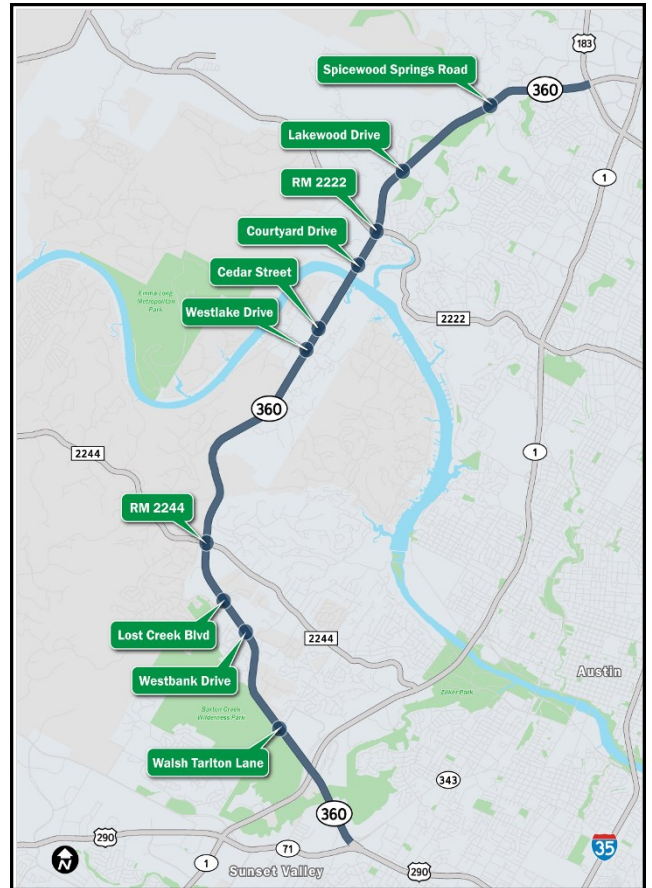
A Personal Travel diary by Trevor Wainwright

Following on from my Pathways 80 feature.

I follow the Colorado River of Texas as it runs South into Austin and you come to what looks like a simple metal arched bridge. It is called Pennybacker Bridge aka 360 Bridge, called as such as the 360-loop road aka The Capital of Texas Highway, passes over it, the second bridge in the world to be built with a cable support system.



The Pennybacker Bridge



Map of the '360'

In 1984, the Federal Highway Administration's Excellence was the bridges first place for highway design. It was designed by Civil Engineer Percy V. Pennyback who wanted to create a cable support system to keep the water below clear for activities like boating and paddling. The bridge has four lanes, two in each direction, separated by a middle barrier wall. The bridge also has a 6-foot-wide (1.8 meters) bike and pedestrian lane. The bike access on the bridge is one reason for Loop 360's popularity with cyclists. The south approach provides a turnaround under the bridge along with lake access for public boating. The weathered rust finish allows the bridge to blend in with the surrounding hills and lake. From the North a rocky outcrop has been split in two for the road to run over the river. Next to this outcrop, there is parking located on the west side of the road, north of the bridge. Overlook Trail is a must-see. is only a short, 10-minute hike, but it is a little rocky, and sturdy shoes are recommended for a safe climb as you hike up to this memorable view. At the top the views are rewarding.



Looking down from viewpoint



Looking up river from viewpoint



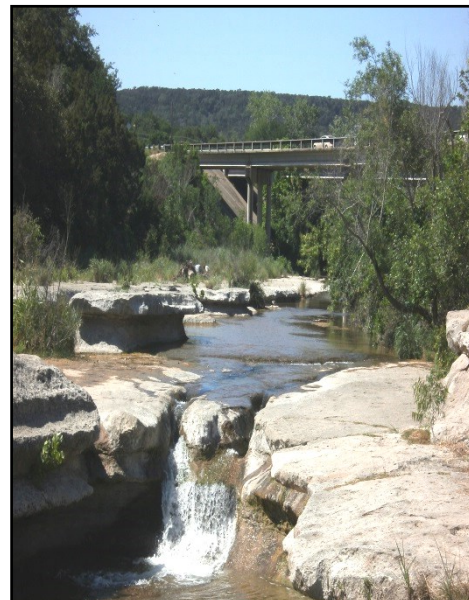
Looking downriver from viewpoint

To the North of the bridge also on the 360 is Bull Creek, a tributary of the Colorado River originating in the Texas Hill Country. The creek passes through some of the more scenic areas in the Austin region and forms a greenbelt that is the habitat for many indigenous species of flora and fauna. It runs beneath steep slopes and benches surfaced with shallow clay loams (soils) that support Ashe, juniper, escarpment live oak, mesquite, and grasses.

Among the early Anglo settlers to the Bull Creek area were Will Preece brought his family to Texas about 1838 and settled in the Bull Creek area. The name "Bull Creek" is attributed to the killing of a male buffalo on Bull Creek, either by Will Preece, or by his son Dick. The Preece family owned about "three thousand acres that stretched from Lake Travis to Cedar Park.

Archaeological investigations of the Bull Creek area show a long history of utilization by humans. One study sponsored by the Bull Creek Foundation found prehistoric utilization dating from "Early Archaic to Late Prehistoric (Toyah phase)", a period which began about 10,000 years ago and lasted until 3,000 years ago.

It is divided into three sub-periods: Early (10,000 to 8,000 years ago), Middle (8,000 to 5,000 years ago), and Late Archaic (5,000 to 3,000 years ago). Today It is possible to walk from where it starts at Bull Creek Greenbelt Upper across the 360 and back over till it reaches Bull Creek District Park and if you don't feel like walking it's a great place to just go and relax. Bull Creek itself is a great place to enjoy fauna and flora away from the bustle of Austin. I hope you enjoy viewing the natural history as I did.



Bull creek, with the 360 in the background.



In the overhang



Blue Bonnets, the Texas state flower.



Flowers more known locally as Indian blankets



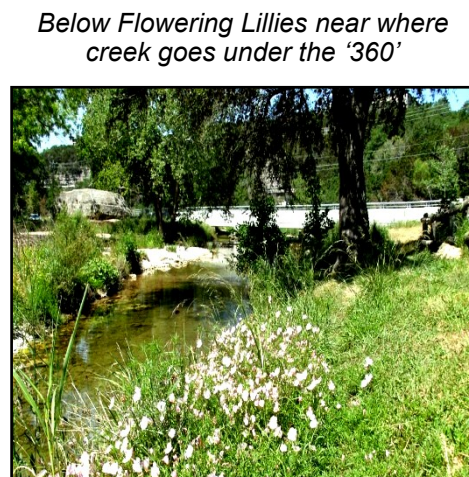
A Butterfly taking a break



There are even poppies in Texas



A Monarch butterfly.



Below Flowering Lillies near where creek goes under the '360'