

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 69. Autumn 2021 Edition.

All about Vitamin D3 and Preparing for the Winter Months



*Water Lobelia with
thanks to Carolyn.*

Planning for Dealing with Covid 19 pandemic over the Winter months.

In a recent press conference Boris Johnson, PM warned that the Covid 19 still remains a "significant risk". He detailed two strategies depending how the case count goes:

"Plan A" is designed to prevent the NHS being overwhelmed and promotes vaccines and testing. This includes the booster jabs for millions - but hold in reserve measures like vaccine passports for certain settings.

"Plan B", to be used if the NHS is coming under "unsustainable pressure", includes measures such as face masks.

Plan 'A' further details

Under Plan A of the autumn and winter plan, ministers will:-

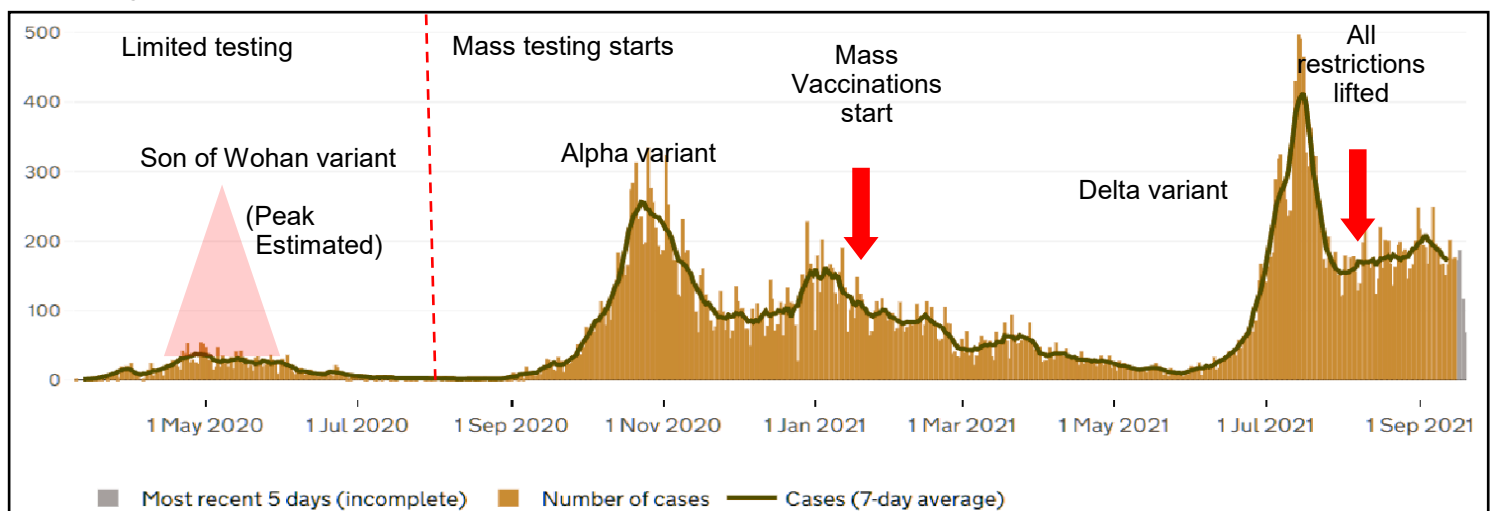
- encourage the unvaccinated to be vaccinated
- offer vaccines to 12 to 15-year-olds
- begin a booster jab programme for millions
- The plan will also include continuing testing, tracing of cases and self-isolation for those who catch the virus.

Plan 'B' further details

Under Plan B - which ministers say would only be enacted if further measures are needed to protect the NHS:-

- the public would be urged to act more cautiously
- mandatory vaccine passports could be used for mass events and other settings
- face coverings could be legally mandated in some places
- Guidance on working from home may also be issued under this plan.

History of Covid 19 Cases Count in Doncaster.



The above graph is taken from the Government Covid website on the 20th of September. The most recent figures are following the national trend. When all the restrictions started to be lifted from June there was a massive surge and the numbers have settled to around 400 cases per 100,000. This corresponds to around 1200 cases a week. At the time of writing, the most recent trend was a slight reduction in cases. In order to control the pandemic instead of lockdown and limitations for freedom, the Government is hoping that vaccinations will do the same job. However, vaccinations are only at 82% of people locally who have had the first dose and 75% the second. So, there is still a long way to go. Our advice is still to limit where you go and wear faces masks if you are away from your home, especially indoors. The concern now is that there may be a surge in influenza, or other respiratory tract infections. There is a possibility that a new variant may arise and put the spanner in the works.

You Write In

Berni Writes: I have received an update below about the decode ME Research study. I thought the update might be of interest to you for the group.

Decode ME is a project to try and identify if there is a generic relationship in the DNA between people with ME/CFS. There are some well known health problems related to DNA. For example, it is well known that a mutation of the Delta F508 gene is responsible for cystic fibrosis, and in a number of cases it has been shown to be a change in one base pair. While cystic fibrosis is an inherited condition ME/CFS is not.

With type 2 diabetes for example, there is an inherited trait from both parents. We also know there is a 1 in 4 chance of someone getting Type 2 diabetes in later life, if one parent has the problem. We know that ME/CFS is acquired through some life incident or event, and it is not inherited. However, there is a tendency for ME/CFS to run in families, so there may be a genetic predisposition to ME/CFS under certain circumstances.

The Decode ME Study is to try and find out if there are any common factors in the DNA of ME/CFS sufferers. If a definite pattern is identified and confirmed, then a long overdue diagnostic DNA ME/CFS test could be produced, and also maybe a gene therapy produced to control the condition.

If you wish to take part, further information can be obtained from the Decode ME webpage:

<https://www.decodeme.org.uk/>

Gary Writes: I have just be trying to renew my blue badge online. Although I have a PIP award, it looks like I cannot get a new one from the information on the website. Is there anything else I can do to get a blue badge?

Yes. A few years ago, it was possible to get high rate mobility for Disability Living Allowance for ME/CFS. This automatically carried a blue badge entitlement. Then along came Personal Independence Payment and things got more complicated and difficult.



PIP Points Mobility Score	Motability Car Entitlement	Blue Badge Entitlement
12 or more	Yes	Automatic
8 or more	No	Automatic
Less than 8 points	No	Discretionary, depending on case. Supporting evidence needed
Nil points or too young or old to claim PIP	No	Discretionary, depending on case. Supporting evidence needed.

Taking the point score for the PIP Mobility for ME/CFS section into account the situation is as follows:- In your case as you have less than 8 points, but with some points you could use part of your PIP scoring sheet as evidence for a discretionary blue badge. You will need additional evidence and may have to attend a medical assessment by a Physiotherapist. You also may have to go through an appeal process.

Sonya writes: My name is Sonya Chowdhury, and I am of Chief Executive of Action for M.E. As you may be aware, we have been exploring a merger with the M.E. Trust, as announced in August.

Yesterday our respective boards agreed to proceed with the merger. We now anticipate merging both charities and launching our combined service offer in late November/early December. We will continue to keep our website updated with further information about the merger including timescales.

As charities, we remain frustrated by the considerable lack of provision for people with M.E. with a postcode lottery and access to specialist services and huge variability between them. There is simply not enough support for children and adults with M.E. now, let alone with an increase in diagnoses following Covid-19.

In response to this public health crisis and gaps in existing service provision for people with post-viral syndromes like M.E., we will be merging with the M.E. Trust. This merger would allow us to combine the power of our organisations and strengthen the services we offer to people with M.E. The M.E. Trust is a UK charity that offers individually tailored whole person care to people with M.E., including access to doctors, nurses, physios, nurses, counsellors, and chaplains. As well as listening and caring for the needs of the whole person, the charity offers encouragement and support to families and immediate community of carers. We will scale up the current clinician-led, holistic health and wellbeing support currently delivered by the M.E. Trust to fill the gaps more quickly.

The merged organisation will continue to be known as Action for M.E. and I, Sonya Chowdhury, will remain as CEO. Helen Winning (CEO of The ME Trust) will join the organisation in a new role as Director of Healthcare Services.

We wish them well and hope the merger will make a difference to people with ME/CFS.

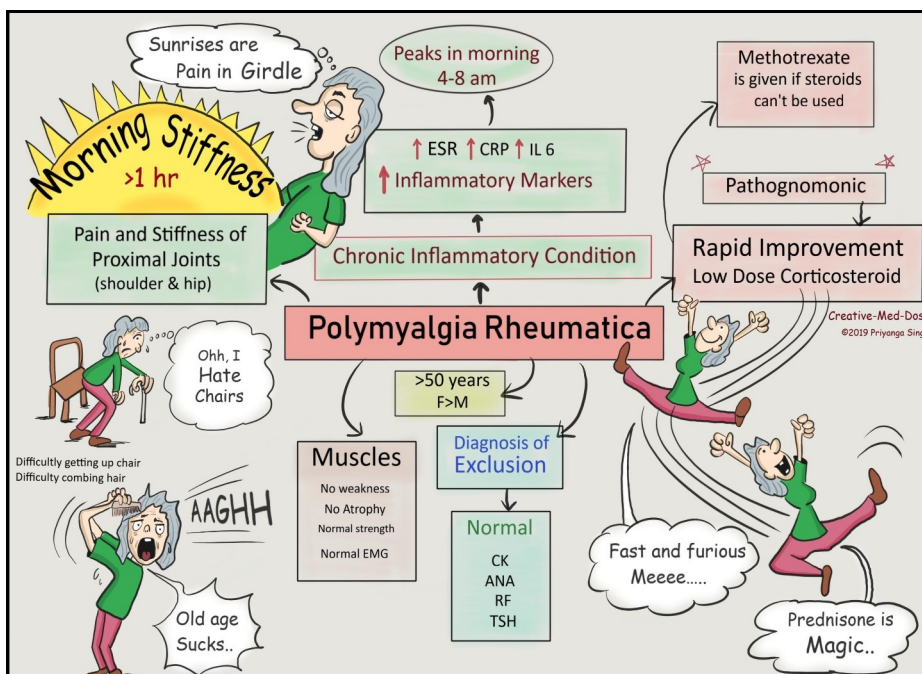
Janet Writes: I thought I had ME/CFS, but I've just been diagnosed by my doctor with Polymyalgia Rheumatica (PMR). What's the difference?

PMR is an inflammatory disease which results in muscle ache and stiffness in different parts of the body. It commonly affects shoulders, arms, neck, and hips. It has many similar symptoms to ME/CFS but is treatable with steroids or antimetabolite medicines. Unlike with ME/CFS there are abnormalities in the blood tests.



About 20% off people develop temporal arteritis (also known as giant cell arteritis), where the arteries in the head and neck become inflamed. If a severe headache that develops suddenly (your scalp may also feel sore or tender) pain in the jaw muscles when eating problems with sight, such as double

vision or loss of vision you need to contact a GP immediately, go to 111.nhs.uk, call NHS 111 or go to your nearest urgent care service.



If you are treated with steroids, you should always carry a 'Steroid card' with you. Steroids can cause thinning of bones and osteoporosis, so you'll need to a DXA scan at some point. They also have a diabetic causing effect, so if you are glucose intolerant or already diabetic, you will need to have your diabetic medicines adjusted. If you are asthmatic, you may notice that you may not need to use your inhaler(s) as much.

Carolyn Writes: I didn't intend to take photos this summer, but here are a few. I hope you enjoy them.



Most gardens have a resident Robin. I got this action packed picture of ours landing on our bird feeder tray.



This is a clematis known as Prince Charles. They are climbing plants. This one has grown over the top of our 6 foot fence.



During the recent lockdowns, we replaced the pond with the one on the left. The water Lobelia flowers came as a pleasant surprise



This is a pot of Begonia 'Glowing Embers' which gave an intense vibrant display of orange colour during early summer.



Pink and Blue. To the back are the blue geraniums, in the foreground are small pinks, part of the carnation family.

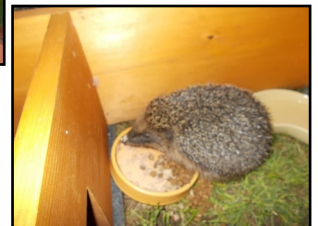


Budhia is well known for attracting butterflies and insects. This year we did not see as many butterflies as last year. They are also notorious for spreading and getting out of hand. Ours are pot grown for this reason. The white one to the right is known as Buzz



This is a wild foxglove which provided a 6 foot tall flower spike during the summer.

Below is a welcome garden visitor. During the dry months we have been visited by several Hedgehogs. We think the one pictured here in our special feeding station is one of this year's young.



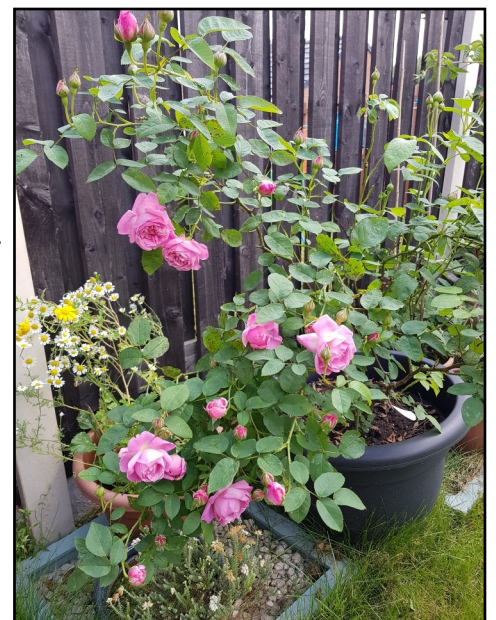
Thanks for the photos. I hope Pathways readers enjoy them.



Susan writes: I've recently moved house, and I am just starting to get my garden into some sort of order. Here are a couple of my photos.

Looks like you are going to get a good crop of blackberries. I think this is a variety called Apache, which is thornless. Usually only one berry will ripen in a cluster. Don't leave the ripe ones on because they will acquire a nasty taste if left too long.

The roses look great, and as long as you cut off the dead heads, you will get a great ongoing display through the autumn until the first frost.



Whole Gas prices are rising, and small Suppliers are Ceasing trading.

Wholesale prices for gas are up 250% since January - with a 70% rise since August. Business Secretary Kwasi Kwarteng is talking to suppliers and operators to hear how wide-reaching the impact of surging prices could be on companies and households. High global demand, maintenance issues at some gas sites and lower solar and wind output are blamed for the rise. Mr. Kwarteng has been having individual calls with some of the top suppliers and will convene a meeting which will include officials from infrastructure operator National Grid and Ofgem.

This has led to a number of small energy suppliers going bust and ceasing trading. However, if your energy supplier goes bust, you will still be able to receive gas or electricity. Ofgem will move your account to a new supplier, but it may take a few weeks. Your new supplier should then contact you to explain what is happening with your account. You will still receive gas, but it will be more expensive.

Why is this happening?

This is happening because many smaller companies have not insured - or hedged - their exposure to rapidly rising prices and some of the ones that have are cashing in that insurance now to survive - leaving them vulnerable to further shocks. The end of summer is the time of year when credit balances are at their highest as customers have been paying their usual monthly amount but not using much energy for heating their homes. Ofgem may have to allow the cost of those balances to be spread across the industry - adding hundreds of millions of pounds to energy bills through industry-wide levies. Under normal circumstances there is a competitive auction process with the company offering the lowest energy price being rewarded with the additional customers. That is not the case in current market conditions.

Some suppliers have already stopped producing carbon dioxide because of gas cost. This has a knock on effect because it leads to a shortage of CO₂. It is used heavily in the food chain as a preservative and refrigerant and the limited supply is leading to processed food shortages.

Gas prices have soared in the last year

Price per therm, Pence



Gas prices have risen massively this year. Gas is bought on the international market as we do not have enough for our own use from our own UK resources.

The Case of Robin Hood energy

Robin Hood Energy was a small supplier which serviced many Doncaster customers. It offered gas and electricity at far cheaper prices than the big suppliers. However something went wrong, and they were bought out by British Gas, with special arrangements for RH customers. Most customers kept the Robin Hood tariffs until it was due for renewal. On renewal, most people found that their gas prices had rose by about 20%.

With British Gas there were issues around incorrect estimates for direct debits and getting credits which took a couple of months to sort.

What to do if your supplier ceases trading .

The Citizens Advice Bureau advises that while to hear from your new supplier: check your current balance and - if possible - download any bills and take a photo of your meter readings.

If you pay by direct debit, there is no need to cancel it straight away. Wait until your new account is set up before you cancel it. If you are in credit on your account, your money is protected, and you'll be paid back. If you were in debt to the old supplier, you'll still have to pay the money back. The new supplier should contact you to arrange a payment plan.

Once you have been informed of your new supplier, make sure you're on the best tariff for you. You can switch if you're not happy with your new supplier or tariff without any penalties, but don't do this until the account has been moved over.

Welfare Rights Matters

*with thanks to Steve Donnison,
Benefits and Work Publishing Ltd*

**1) Guide To Online Pip Claims**

Benefits and Work have now published a guide to the online PIP2 “*How your disability affects you*” claim form. The online claims system was originally supposed to go national in July 2021. but there have been repeated delays and it appears that it is still only at the pilot stage. The pilot version of the online form that we have seen is not, in reality, an online form at all.

Instead, claimants who have both a mobile phone number and an email address are sent a link to their email address which allows them to download a pdf and/or a Word version of the PIP2 form. You can complete the form bit-by-bit, saving it to a laptop or desktop as you go. When you have completed the form, you return it via a link you received in the original email.

However, it also seems that some claimants are now receiving a paper version of the PIP2 form that matches the online claim form. The paper version is likely to be dated January 2021 or later on the bottom left of each page.

2) Major Change to Pip and Work Capability Assessments (WCA)

The DWP are to introduce a major change to the assessment system for PIP and the work capability assessment for ESA and UC with just one company carrying out both assessments for any given claimant from August 2023. This means that the same company will have to have expertise in both PIP assessments and the WCA and will be able to use some of the evidence from one type of assessment when carrying out the other for the same claimant. At present, all WCA ‘s is carried out by Maximus. PIP assessments are carried out by IAS (formerly Atos) and Capita.

Many readers will remember that Atos abandoned its WCA contract in 2014 after suffering years of increasingly negative publicity. The contract went to Maximus instead.

Atos may well be unhappy at the thought of returning to carrying out WCAs, but it seems to have little choice if it is to have any hope of holding on to its lucrative PIP contracts. But the main concern is likely to be that insufficient and misleading evidence for, say, PIP assessment will then be used as part of the evidence for a WCA, even if the PIP decision is subsequently overturned on appeal. In addition, whilst the DWP say that there are no plans for a single assessment for both PIP and the WCA, a real fear is that evidence about say mobility from one assessment will be considered for the other, even though the criteria are quite different.

The attraction of doing this for assessment providers is that assessments would be shorter and greater profits could be made. The changes will not apply to Scotland, where PIP assessments will be carried out in-house by Social Security Scotland. Discussions are ongoing about changes to the system in Northern Ireland.

3) PIP Long-Covid Claims High Success Rate

Claimants with long-Covid as their main disabling conditions have now begun to appear in the PIP statistics. Although the numbers are still tiny, initial indications are that the success rate is significantly higher than the overall rate for new PIP claims. So far, according to the DWP’s Stat-Xplore statistical tool, there have been just 34 assessments in March and April for PIP where Covid-19 was the main disabling condition. of these assessments resulted in an award.

This includes 14 claimants who got the enhanced mobility component, although only 5 received enhanced daily living. Nonetheless, the indications from this very small sample are that claims for Long-Covid have a high success rate at 74%, compared to just 42% for new PIP claims in general. Clearly these statistics may change as more claims are assessed. But the vital thing to understand is that if you have been affected by Long-Covid, then you may be entitled to an award or a higher award.

The New NIHCE Guideline ME/CFS Due August 2021 Delayed.

"It heralded a new beginning and was a guideline we could support, but NICE has paused publication at the last minute,"
The ME Association.

The National Institute for Health and Care Excellence (NICE) has been working on a long-awaited and much-needed new clinical guideline for ME/CFS. The clinical guideline is important as it provides a framework of recommendations to health and social care services in England, Wales, and Northern Ireland – and is recognised in Scotland

The review began in 2018 after many years of advocacy because the previous guideline was not fit for purpose. The guideline committee – comprising experts, clinicians, and patients – has worked very hard and provided evidence-based recommendations to NICE following extensive stakeholder consultations which began last November. NICE then produced a final draft of the guideline which was sent to stakeholders in the first week of August 2021

The final guideline was expected on 18th August, but at the last minute, and in an unprecedented move, NICE decided to halt the process. We don't yet know the full reasons behind this decision, or who in particular might have influenced this move, but it would appear to relate to the management recommendations.

However, there are a great many improvements to the new guideline that have been overlooked by those who are complaining and in the many reports from the news-media. We have been waiting 14 years for a clinical guideline that provides safe and practical recommendations and gives due consideration to the most vulnerable in the patient community.

This further delay, after 4 years of evidence-based review is of real concern and as we have no idea when the guideline might finally emerge – or what it will look like – it could have a detrimental effect on people who are waiting for a diagnosis and practical help from health and social care services.

The ME Association is a steering group member at Forward-ME, and we helped to produce a press release and statement that endorsed the new guideline. We then had to issue a rapid response when it was announced by NICE that the process had been suspended hours before publication. Journalists had already received the press release and since then the news-media has been reporting what it can discern about the reasons for this delay.

It is our hope that the roundtable meeting (announced 27th August) will enable stakeholders to reach agreement and for the guideline to be published soon. The recommendations go beyond issues relating to graded exercise and cognitive behavioural therapy. They better explain symptoms and diagnostic criteria, provide better guidance for people severely affected, for children and young people, and they would help to reduce the stigma that still surrounds the condition, while restoring relations with the NHS.

It was a good and improved guideline that promised real and much-needed support. NHS primary and secondary care would have continued to play key roles in making an accurate diagnosis, providing ongoing accessible care, and helping people manage ME/CFS safely and effectively.

**Dr Charles Shepherd, Hon.
Medical Adviser, ME Association
commented:**

"We should have been welcoming the arrival of a completely new NICE guideline on ME/CFS today. A guideline that acknowledged ME/CFS as a serious and complex medical condition..."

"It was a guideline that contained sensible advice on activity, energy, and symptom management – along with a revised timeline and advice for early and accurate diagnosis, and it placed special emphasis on the care and management of children and young people and those who have severe or very severe ME/CFS."

"Instead, we are discussing the huge disappointment felt by the patient community to yesterday's announcement from NICE to cancel publication today and to pause proceedings while discussions take place around objections to the new recommendations regarding CBT and GET – objections that were discussed and resolved as part of the long review process."

"On a personal basis, having spent a considerable amount of my time over the last four years working with colleagues on the preparation of this new guideline, I feel frustrated and angry..."

of PIP. And you do not need to have had a positive test result or a formal diagnosis of Long-Covid in order to claim.

4) Misleading Pip Letters Re Audio Recording

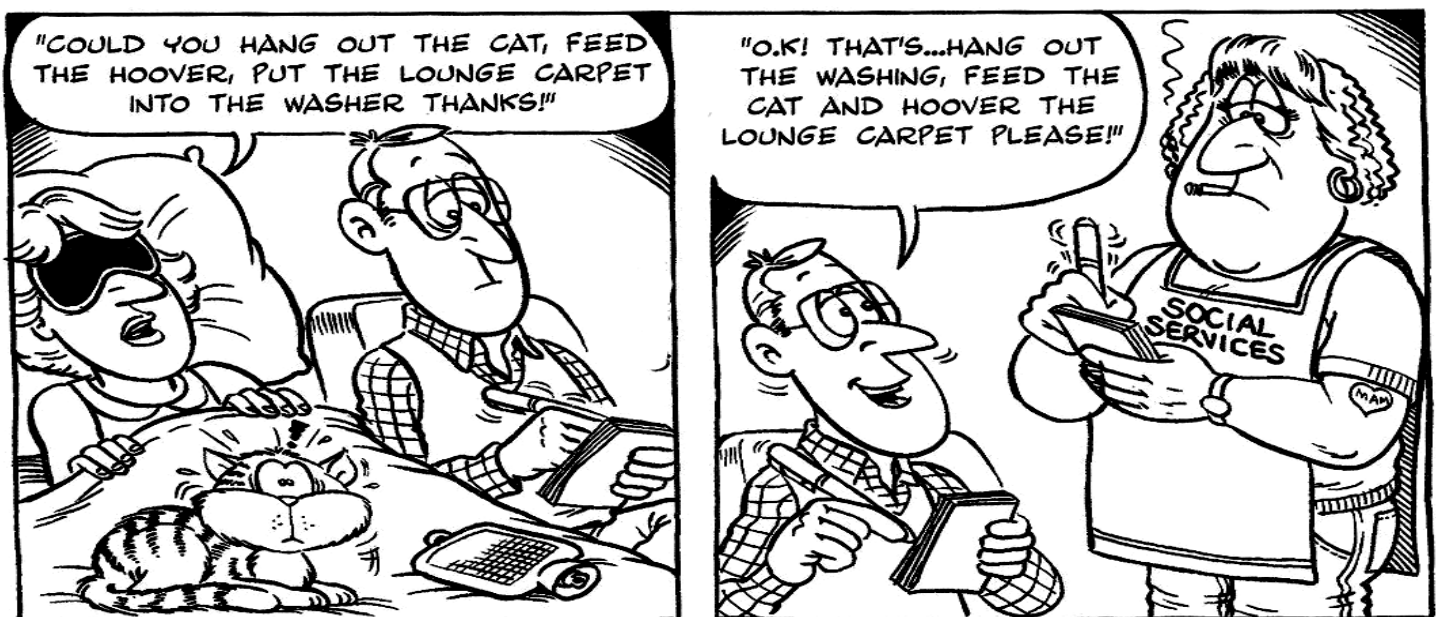
A member has warned us about a misleading letter they received from an assessment provider which led to them missing out on having an official recording of their PIP assessment. According to our member the letter stated that "at the start of the call if I wish to have it recorded to ask". Our member did so but was told that if they wished to have the assessment recorded, they had to inform the provider in advance. Asking on the day was not an option. Rather than try to rearrange the appointment, our member went ahead with the assessment and covertly recorded it on their phone. So, this is just a reminder to readers that regardless of what letters are sent out, the current position is that if you want to have your PIP assessment recorded you need to arrange this in advance by contacting the assessment provider as soon as you get a letter from them. And, as we stress in our guide, it is always worth considering making a covert recording of the call yourself in case anything goes wrong with the official recording.

5) Final Attempt to Challenge Leap Review

In spite of hundreds of responses from readers, Benefits and Work have yet to find a suitable claimant to take forward a case against the DWP for the way that the LEAP review has been carried out. We have been working with a leading firm of solicitors in an attempt to find a suitable claimant who would be willing to be litigant in a judicial review.

However, many of those who have taken the time to contact us have not had a LEAP letter or received their letter more than three months ago are not eligible for legal aid or don't meet one of the other necessary criteria. We are having one last try to find a suitable candidate. If you have received a LEAP letter in the last three months, please consider supporting this action. It will be an enormous injustice if the DWP get away with the blatant scam that the LEAP review appears to represent, depriving huge numbers of eligible PIP claimants of thousands of pounds. So, if you have received a LEAP letter in the last three months, please check to see if you could be the one to make a difference.

Leger ME has an organisational subscription to Benefit and Guides as part of the membership benefits. Please contact the office should you require one. The guides are provided as a PDF file, but can be printed at cost. This is usually £8-£10. If you are sent a WCA or PIP form, please contact the office for guidance as soon as possible. Don't just send in a form without it being checked by a welfare rights advisor. It is always better to submit supporting evidence.



Sometimes an Interpreter is needed:

This is a humorous example of mixing of words quite often affects ME/CFS patients.

Recipe Corner.

Cauliflower Cheese Soup

This recipe has a preparation time of around 30 minutes and takes an hour to cook and serve 4.

Cooking Method

- 1) Put the onion, celery, garlic, butter and olive oil into a large saucepan set over a low-medium heat. Gently cook the vegetables for 7–8 minutes until tender but not coloured.
- 2) Add a pinch of cayenne to the pan, stir well and cook for a further 30 seconds. Add the cauliflower, potato, bay leaf, milk and vegetable stock. Season with salt and freshly ground black pepper, stir well, half cover the pan with a lid and slowly bring to a gentle simmer. Continue to cook for about 30 minutes, or until the vegetables are tender.
- 3) Remove the bay leaf and using a bar mixer or blender, whizz the soup until silky smooth. Add the grated cheese, mustard, and Worcestershire sauce, if using, and blend again to thoroughly combine. Taste and add more seasoning as required.
- 4) For the cheesy croutons, preheat the oven to 180C/160C Fan/Gas 4.
- 5) Cut or tear the bread into rough pieces, tip onto a small baking tray, sprinkle with the garlic granules and season with salt and freshly ground black pepper.
- 6) Drizzle over the olive oil and mix well to coat. Slide the tray into the oven and cook the croutons for about 7 minutes, or until golden-brown and crisp, turning the croutons over halfway through.
- 7) Scatter the cheese over the top of the croutons and return the tray to the oven for 2 minutes to melt the cheese. Ladle the soup into bowls and scatter with the hot cheesy croutons and snipped chives and serve immediately.



Ingredients

1 large onion, finely chopped
 1 stick celery, finely chopped
 1 garlic clove, crushed
 25g/1oz unsalted butter
 1 tbsp olive oil
 500g/1lb 2oz trimmed cauliflower florets, cut in 3cm/1¼in chunks
 1 medium-sized floury potato, such as Maris Piper, peeled and roughly chopped
 pinch cayenne pepper
 1 bay leaf
 400ml/14fl oz full-fat milk
 400ml/14fl oz vegetable stock (from bouillon powder)
 100g/3½oz mature cheddar, grated
 1 tsp Dijon mustard
 1 tsp Worcestershire sauce (optional)
 salt and freshly ground black pepper
For the cheesy croutons
 3 x 1cm/½in thick slices sourdough bread
 ¼ tsp garlic granules
 2 tbsp olive oil
 50g/1¾oz mature cheddar, grated
 1 tbsp finely snipped chives

Asparagus Frittata

This recipe serves 2. The preparation time is about 4 minutes and takes about 7 minutes to cook. This is ideal for people with ME/CFS because it is a light recipe, and takes a short time to cook.

Cooking Method



- 1) Spray a small frying pan with the light and fry the spring onion and asparagus for a few minutes, over a medium heat, until softened

- 2) Add the spinach and cook until it has wilted.
- 3) Pour the eggs into the pan, spread the asparagus through the mixture and cook until the edges are starting to brown.
- 4) Remove from the hob and place under a hot grill until browned.

Ingredients

Light cooking oil spray
 250g bunch fresh asparagus, cut into chunks and ends removed
 half bunch (60g) spring onion, finely chopped
 3 medium eggs, beaten and seasoned with black pepper
 half medium bag (150g) fresh spinach leaves

Flu vaccinations for season 2021 -2022

Last year saw the roll out of the biggest NHS influenza vaccination programme ever. with the aim of offering protection to as many eligible people as possible during the coronavirus (COVID-19) pandemic . During very these challenging times this resulted in the best influenza vaccine uptake rates ever achieved.



As a result of non-pharmaceutical interventions in place for COVID-19 (such as mask-wearing, physical and social distancing and restricted international travel) influenza activity levels were extremely low globally in 2020 to 2021. As a result, a lower level of population immunity against influenza is expected in 2021 to 2022. In the situation where social mixing and social contact return towards pre-pandemic norms. it is expected that winter 2021 to 2022 will be the first winter in the UK when seasonal influenza virus (and other respiratory viruses) will co-circulate alongside COVID-19.

Seasonal influenza and COVID-19 viruses have the potential to add substantially to the winter pressures usually faced by the NHS, particularly if infection waves from both viruses coincide . The timing and magnitude of potential influenza and COVID-19 infection waves for winter 2021 to 2022 are currently unknown, but mathematical modelling indicates the 2021 to 2022 influenza season in the UK could be up to 50% larger than typically seen . It is also possible that the 2021 to 2022 influenza season will begin earlier than usual . Influenza vaccination is therefore an important priority this coming autumn to reduce morbidity and mortality associated with influenza, and to reduce hospitalisations during a time when the NHS and social care may also be managing winter outbreaks of COVID-19 .

The national influenza immunisation programme aims to provide direct protection to those who are at higher risk of influenza associated morbidity and mortality . Groups eligible for influenza vaccination are based on the advice of the Joint Committee on Vaccination and Immunisation (JCVI) and include older people. pregnant women. and those with certain underlying medical conditions.

Groups eligible for NHS influenza vaccination in 2021 to 2022 are:

- All children aged 2 to 15 (but not 16 years or older) on 31st August 2021
- those aged 6 months to under 50 years in clinical risk groups
- pregnant women
- those aged 50 years and over
- those in long-stay residential care homes
- carers
- close contacts of immunocompromised individuals
- frontline health and social care staff employed by a registered residential care or nursing home
- registered domiciliary care provider
- a voluntary managed hospice provider
- Direct Payment (personal budgets) and/or Personal Health Budgets, such as Personal Assistants.
- All frontline health and social care workers are expected to have influenza vaccination to protect those they care for

Since 2013, influenza vaccination has been offered to children in a phased roll-out to provide both individual protection to the children themselves and reduce transmission across all age groups to protect vulnerable members of the population. The expanded influenza vaccination programme that we had last year will continue in 2021 to 2022 as part of our wider winter planning when we are likely to see both influenza and COVID-19 in circulation. This means that as a temporary measure the offer for 50 to 64 year olds will continue this year to protect this age group, as hospitalisation from COVID-19 also increases from the age of 50 years onwards. As a temporary measure, the programme will also be extended this year to 4 additional cohorts (groups) in secondary school so that all those from years 7 to year 11 will be offered vaccination . Vaccinating children reduces transmission of influenza and the JCVI recommended expanding into secondary schools would be cost-effective, particularly if COVID-19 is still circulating .

Advice from Dr . C . Shepherd. MEA Hon Medical Adviser

At the moment it looks as though the same criteria for having a free NHS flu vaccine as last year will apply . In addition, everyone over the age of 50 and anyone classified as being in a clinical risk group will also be able have a free NHS flu jab this year. As we constantly point out, people with ME/CFS should be able to have a free NHS flu jab – if they choose to do so . This is because the WHO classification of ME/CFS as a neurological disease is accepted by NHS England and catching flu (or COVID-19) is very likely to cause a significant exacerbation or relapse of ME/CFS symptoms. The NHS flu vaccine website also makes it very clear that anyone with a long term neurological condition should be able to have a free flu jab.

As far as possible, people with ME/CFS and their Carers should have a flu vaccination. I do appreciate that some people will be reluctant to have a flu vaccination. In my case because of a flu vaccination, I became allergic to eggs. It used to be the case that all flu vaccines were grown on egg as part of the manufacturing process. However, this year there are two egg free vaccines, and if you are going to have a flu jab, it would be prudent to have one of these egg free vaccines. Personally, compared to the Covid 19 vaccinations. the egg free flu jab for me was symptomless.



A significant number of flu vaccines are still grown on eggs.as part of the manufacturing process.

Vaccine	Egg based ?	Type	Route of administration	Age range	Typical Price	Manufacturer
Fluad Tetra	Yes	Quadrivalent Inactivated Adjuvanted (aQIV)	Intramuscular injection	From 65 years	£11.80	Seqirus UK
Flucelvax Tetra	No	Quadrivalent Cell-grown Inactivated (QIVc)	Intramuscular injection	From 2 years	£9.94	Seqirus UK
Fluenz Tetra	Yes	Quadrivalent Egg-grown (LAIV)	Intranasal spray	From 24 months to less than 18 years of age	£18.00	AstraZeneca
Influvac sub-unit Tetra	Yes	Quadrivalent Inactivated (QIVe)	Intramuscular or subcutaneous injection	From 6 months	£9.94	Mylan
Quadrivalent Influenza vaccine	Yes	Quadrivalent Inactivated (QIVe)	Intramuscular or subcutaneous injection	From 6 months	£8.00	Sanofi Pasteur
Supemtek	No	Quadrivalent Cell-grown Recombinant (QIVr)	Intramuscular injection	From 18 years	£22.00	Sanofi Pasteur

Comparison of this seasons main Influenza vaccines

Quadrivalent means the vaccine is targeted at for variants or strains of the flu virus . Flu viruses mutate every year a bit like the Covid 19 virus, and a great deal of research goes into which strains should be included in a season's vaccines . Normally included are strains from the far East.

Cell grown mean the vaccine is grown on a stable cell line in a test tube and has never seen an egg .

QIVe (standard egg-grown quadrivalent influenza vaccine). split virion. inactivated .

QIVr (quadrivalent Influenza vaccine (recombinant. prepared in cell culture) .

aQIV (egg-grown quadrivalent Influenzae antigen. inactivated . **LAIV** (live attenuated influenza vaccine).

Introduction of E10 Petrol with thanks to the government website

For many years there has been a quiet revolution in petrol engine fuel. This year, the last country using lead tetraethyl ceased production. Lead was introduced into petrol because it stopped a process called *knocking* which caused damage in higher compression engines. This was revolutionary allowing better performance and economy because petrol engines could be manufactured with higher compression ratios. It was not long before it was realised that car exhaust was causing lead poisoning, and in this country leaded petrol has been banned. Currently there is a substitute additive to replace lead in petrol which is far less toxic. The introduction of catalytic converters in cars also made cleaner exhaust emissions.

In some countries like Brazil for quite a while Ethanol (ethyl alcohol) has been used as a motor fuel. Engines designed to run off ethanol need specific design changes. Ethanol is the major component of many alcoholic drinks of course, made by a process of fermenting sugars. Ethanol for use as a fuel is made by a similar process, in the UK from fermenting wheat starch or in the case of Brazil, from sugar cane. Fuel ethanol is a blend of ethanol plus other substances to protect the engine and is not suitable for drinking. Ethanol is not a fossil fuel, because it is produced from biomass it is a bit greener than oil derived and fossil fuels. Locally, Drax power station burns biomass, mainly waste wood, but did you know that some of Doncaster black bin waste is also used to produce biomass fuel?

Introducing E10 Petrol. Current blends of the standard (95 octane) petrol contain about 5% Ethanol. This is known as E5 petrol. During summer 2021, the standard petrol grade in Great Britain will become E10. The change in fuel applies to petrol only, not diesel. Almost all (95%) petrol-powered vehicles currently on the road can use E10 petrol and all cars built since 2011 are compatible. However, if your petrol vehicle or equipment is not compatible with E10 fuel, you will still be able to use E5 by purchasing the 'super' grade (97) petrol. E10 petrol contains up to 10% renewable ethanol, which will help to reduce carbon dioxide (CO₂) emissions associated with petrol vehicles and tackle climate change. E10 petrol is already widely used around the world, including across Europe, the US and Australia. It has also been the reference fuel against which new cars are tested for emissions and performance since 2016.

CO₂, one of the greenhouse gases that contribute to climate change and the main benefit of E10 petrol is that it reduces overall levels of CO₂-based vehicle emissions. By blending petrol with up to 10% renewable (biomass) ethanol, less fossil fuel is needed, helping us reduce carbon emissions and meet climate change targets. It is estimated that the introduction of E10 petrol at UK forecourts could cut transport CO₂ by 750,000 tonnes a year – the equivalent of taking 350,000 cars off the road, or all the cars in North Yorkshire. Renewable fuel blends, such as E10 petrol, are generally introduced to reduce overall CO₂ emissions. However, they have little impact on emissions associated with air quality and public health. The production of renewable ethanol for blending with fossil petrol also results in valuable by-products, including animal feed and stored CO₂. There is however a downside. Using E10 petrol can slightly reduce fuel economy (the number of miles you are able to drive on a gallon of fuel). You may see a reduction of around 1%, but it is unlikely to be noticeable in everyday driving. Other factors – such as your driving style or driving with under-inflated tyres or a roof rack – have a much more significant impact on fuel economy than using E10 petrol.

About 95% of petrol-powered vehicles on the road are compatible with E10 petrol. All new cars manufactured since 2011 are compatible with E10 petrol, and most cars and motorcycles manufactured since the late 1990s are also approved by manufacturers to use E10. However, some vehicles may not be compatible with E10 petrol. These include classic, cherished, and older vehicles and some specific models, particularly those from the early 2000s, some mopeds, particularly those with an engine size of 50cc or under. There is a government website where you can check whether your vehicle is approved to use E10 petrol using the government's E10 vehicle checker, which covers cars, motorcycles, and mopeds. To access this, follow this link:

<https://www.gov.uk/guidance/e10-petrol-explained>



Vitamin D

Sunshine, not food, is where most of your vitamin D comes from. So even a healthy, well balanced diet, that provides all the other vitamins and goodness you need, is unlikely to provide enough vitamin D. Read on to find out the best ways to get enough vitamin D safely.

What is vitamin D?

You make vitamin D under your skin when you are outside in daylight, which is the reason vitamin D is sometimes called the 'sunshine vitamin'. A vitamin is something that helps our body function – a 'nutrient' – that we cannot make in our body.

Vitamin D is different because even though we call it a vitamin, it is actually a hormone and we can make it in our body.

What does vitamin D do to the body?

Vitamin D works with calcium and phosphorus for healthy bones, muscles and teeth. Vitamin D is also important in protecting muscle strength and preventing rickets, osteomalacia and falls.

Even if you have a calcium-rich diet (for example from eating plenty of low-fat dairy foods and green leafy vegetables), without enough vitamin D you cannot absorb the calcium into your bones and cells where it is needed. Vitamin D may have other important roles in the body, but there isn't enough evidence at the moment to make any conclusions.

What happens if i don't get enough vitamin D?

Some babies are born with low levels of vitamin D and some do not get enough in breast milk; this can result in fits or rickets.

Older children who do not get enough vitamin D can also develop rickets. Rickets can cause



permanent deformities to the bone, weaken muscles and reduced growth.

Adults who don't get enough vitamin D can develop osteomalacia. This makes the bones softer as the minerals needed to keep them strong cannot get into the bone. People with osteomalacia experience bone pain and muscle weakness.

When is vitamin D made in skin?

The amount of vitamin D you make depends on how strong the sunlight is. You will make more in the middle of the day, when the sun is strongest. You will also make more when you are in direct sunlight than in the shade or on a cloudy day.

Sun safety

It is the sun's ultraviolet rays that allow vitamin D to be made in the body. You do not have to sunbathe to make vitamin D. In the UK, ultraviolet light is only strong enough to make vitamin D on exposed skin (on the hands, face and arms or legs) during April to September. However strong sun also burns skin so we need to balance making vitamin D with being safe in the sun - take care to cover up or protect your skin with sunscreen before you turn red or get burnt. Find out more about sun safety on the NHS Choices website.

During the autumn and winter, we get vitamin D from our body's stores and from food sources but these are insufficient to keep up vitamin D levels. The only way to ensure a healthy vitamin D status at this time of year is to take a supplement.

Groups at risk of low vitamin D

- babies and young children, and children and adolescents who spend little time playing outside
- pregnant and breastfeeding people

- people over 65 years old because their skin is not as good at making vitamin D
- people with darker skin tones –people of Asian, African, Afro-Caribbean and Middle Eastern descent – living in the UK or other northern climates
- if you always cover most of your skin when you are outside
- the further north you live, the less sufficiently strong sunlight there is for you to make vitamin D
- anyone who spends very little time outside during the summer – the housebound, shop or office workers, night shift workers
- if the air is quite polluted

Which foods contain vitamin D?

Help your body get more vitamin D by eating plenty of vitamin D rich foods, including:

- oily fish such as salmon, sardines, pilchards, trout, herring, kippers and eel contain reasonable amounts of vitamin D
- cod liver oil contains a lot of vitamin D, but don't take this if you are pregnant
- egg yolk, meat, offal and milk contain small amounts but this varies during the seasons
- margarine, some breakfast cereals, infant formula milk and some yoghurts have added vitamin D

Where are vitamin D supplements available?

Vitamin D supplements and multivitamins are now widely available to buy from chemists/pharmacies, supermarkets and health food shops. Some people who are pregnant or breastfeeding and children aged six months to four years may qualify for Healthy Start vitamins which contain vitamin D. Ask your health visitor about this.

A supplement only needs to contain 10 micrograms to meet the recommendation – those with a higher content of vitamin D are unnecessary and could be harmful in the long run.

Who needs a vitamin D supplement?

- All adults and children over the age of one should consider taking a daily supplement containing 10 micrograms of Vitamin D especially during autumn and winter.
- Those in the at risk groups, as above, should consider taking a supplement containing 10 micrograms of Vitamin D all year round.
- All babies under one year should be given a daily supplement of 8.5-10 micrograms unless they have more than 500mls of fortified formula milk.

Taking a vitamin D supplement as well as eating foods rich in vitamin D and spending a lot of time outside in sunshine is not a problem.

However do not take more than one supplement containing vitamin D (count cod-liver oil as a supplement) as you could exceed the 10 micrograms recommendation. Always choose a supplement tailored to the age group or condition, as fish liver oils and high dose multivitamin supplements often contain vitamin A, too much of which can cause liver and bone problems, especially in very young children, and the elderly.

Summary

Vitamin D works with calcium and phosphorus for healthy bones, muscles and teeth. You make the most vitamin D under your skin when you are outside in the middle of the day in the summer months.

You can get vitamin D from some foods including fortified foods and everyone is recommended to take a supplement, especially during autumn and winter.

There are some at risk groups who are recommended to take daily vitamin D supplements all year round. If you are concerned you are not getting enough vitamin D, speak to your doctor, health visitor, or ask to be seen by a dietitian.

Vitamin D Depletion and ME/CFS

The ME association have produced a leaflet which covers this topic, and can be download from their website. We have used this leaflet as a basis for the following feature.

Vitamin D Deficiency and ME/CFS

There is growing interest in the role of vitamin D – the ‘sunshine vitamin’ – in ME/CFS. Firstly, because there are a number of reasons why people with ME/CFS could be at increased risk of developing vitamin D deficiency. Secondly, because there are several theories why vitamin D could have a part to play in the treatment of ME/ CFS.

What Is Vitamin D?

Vitamin D is a fat-soluble vitamin – meaning that it is stored in the body and can start to accumulate if taken in excess. Besides being a vitamin, it also acts as a hormone. Vitamin D has a range of important functions – particularly involving bone, muscle, brain, and immune system function.

Where Does Vitamin D Come From?

As green plants photosynthesize food from sunlight, we make Vitamin D3. The main and best source of vitamin D is the skin – from exposure to the sun’s ultraviolet rays, which trigger vitamin D production. So, levels are at their lowest in spring and highest in the autumn. For people with fair skin, 10 minutes exposure to the arms and face each day produces plenty of vitamin D. But sunscreens with a protection factor of 8 or more will block out these ultraviolet rays and significantly reduce the production. Good dietary sources of vitamin D include: Fortified foods such as margarine and breakfast cereals, Eggs and some dairy products, Oily fish such as sardines and salmon, and fresh meal.

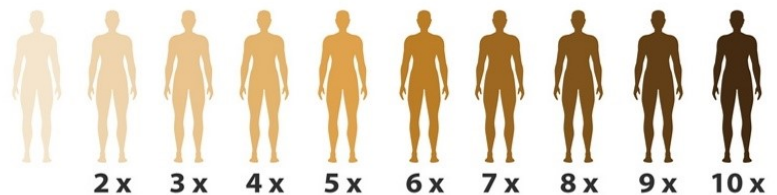
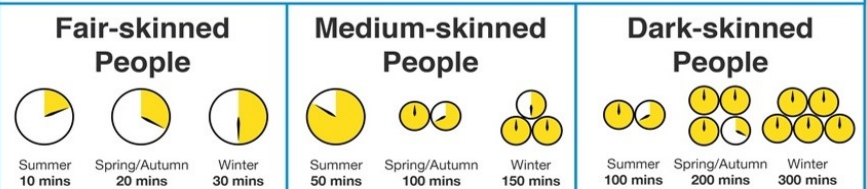
However, it is difficult to get enough vitamin D from dietary sources alone.

What Causes Vitamin D Deficiency?

Lack of exposure to the sun and/or restrictive diets can lead to progressive vitamin D deficiency. Not surprisingly deficiency is far more common in people who are inactive and housebound and cut out foods that contain vitamin D. The recent Covid 19 pandemic with its lock downs and self-isolation is the most common factor. However, less common causes of vitamin D deficiency include: Kidney disease, Liver disease, Medicines such as phenytoin (for epilepsy) and warfarin (for blood clot prevention) and malabsorption syndromes like due to coeliac disease or Crohn’s disease.

Vitamin D Sun Exposure Guide

Recommended Amount of Sun Exposure



The darkest-skinned people need up to 10X more sun exposure than the fairest-skinned since darker skin absorbs fewer UV rays.

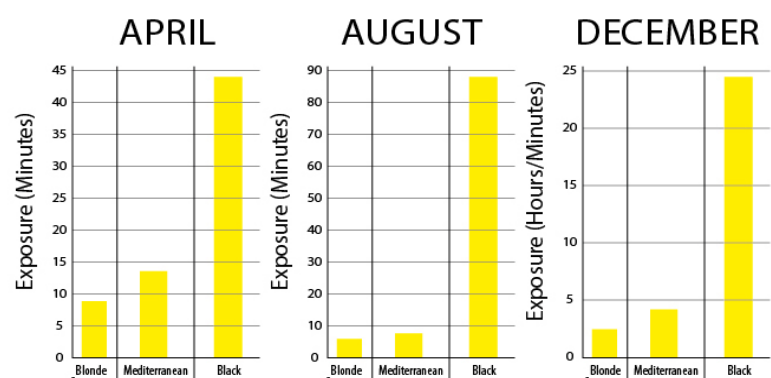
Based on exposing face, arms, legs, and back.

No sunscreen.

Must be outside. UVB does not penetrate glass.

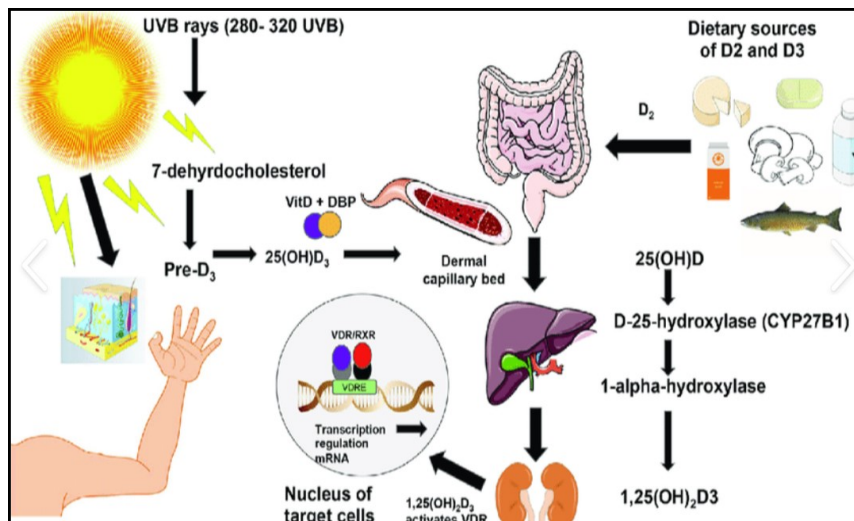
HOW MUCH SUN DO YOU NEED TO GET YOUR VITAMIN D LEVELS.

Based on an example from London



What Happens to Vitamin D Inside the Body?

Vitamin D is converted by the kidney into what is known as its active metabolite (or form): 1,25 dihydroxy vitamin D. This metabolite plays a key role in maintaining the right balance of calcium and phosphate in the body. So, it helps to produce and maintain healthy bones and teeth, as well as normal activity in organs such as the brain, pancreas, and stomach. The right balance of Calcium and phosphate is also important in bone diseases. Vitamin D also acts on the immune (body defence) system where it has an immunosuppressive role – meaning that it can ‘dampen down’ an over-active immune response and possibly prevent the occurrence of autoimmune diseases such as diabetes.



What Are the Symptoms of Vitamin D Deficiency?

In children, vitamin D deficiency leads to the bone disease known as rickets – which is more common in Asian children where the skin is covered up. In adults, deficiency causes a similar bone condition called osteomalacia leading to bone pain and fractures. Vitamin D deficiency can also play a role in the development of osteoporosis and bone fractures in later life. The type of bone and/or muscle problem described by people with vitamin D deficiency is often weakness or tenderness, especially in the thighs – causing difficulty getting out of a chair or climbing stairs. Vitamin D deficiency can also produce a range of vague symptoms including fatigue.



Rickets (bow legs) is caused by lack of vitamin D in early childhood. Breast milk does not contain enough vitamin D, so a lot of food products are fortified with vitamin D to avoid this problem. It is also more common where children are fully clothed and not exposed to sunlight.

How Common Is Vitamin D Deficiency in ME/CFS?

The simple answer is we just don't know because no proper research has ever been carried out. However, anecdotal reports indicate that it could be an often unrecognised problem for people with moderate to severe ME/CFS – especially in those who are largely or constantly housebound and not receiving enough regular exposure to natural sunlight.

The Doncaster Angle

Several years ago, I was attending a meeting of the Sheffield clinic LPIG Group which is a patient representation group. Several people at that meeting told us of their surprise when their GP had carried out a Vitamin D3 level test and found that they were depleted. More interesting news came when they were prescribed vitamin D3 by their doctor, their levels increased. Surprisingly they reported their pain and overall fatigue reducing significantly. As a result of this finding, I advise all the people I see to have their vitamin D3 levels checked, and almost without exception the levels come back depleted -so they were prescribed D3 by their G.P.

However, there are some G.P. s who will not prescribe Vit D3. You can have Vitamin D levels checked privately and more importantly there are versions that are not prescriptions medicines which can be bought from a local Pharmacy chain for around £1.50 for a month's supply. Generally, vitamin D3 has to be present for many bodily functions. It is when it is not present in sufficient amounts that problems occur. Mega dosing is not recommended.

Generally, a lot of people are deficient in Vitamin D3 depletion, and there has been a lot of interest in recent years. It is though thought that people in residential homes and most of the population will be suffering from vitamin D3 depletion due to lack of exposure to direct sunlight. A lot of the Leger ME members report levels of 20-30 nm/l on D3. Generally, it is considered that a level of 80nm/l is the ideal level. This corresponds to taking around 800 units daily. Some private doctors specialising in ME/CFS recommend higher levels. - Mike.

How Is Vitamin D Deficiency Diagnosed?

This is best done by measuring the level of 25-hydroxyvitamin D (25- OHD) in the blood. A serum 25-OHD level below 20 nmol/l is generally regarded as an indication of significant vitamin D deficiency. Concentrations up to about 40 nmol/l may be associated with adverse effects. The level required to maintain optimal bone health remains uncertain. The blood level of phosphate and calcium may be reduced, and alkaline phosphatase increased. These are investigations that form part of routine screening for people with ME/ CFS. Other blood tests may also be necessary to rule out the possibility of deficiency being caused by kidney or liver disease. Vitamin D deficiency can also upset the parathyroid gland, another control centre in the body for calcium, and so parathyroid function may need to be investigated as well.

How Is Vitamin D Deficiency Treated?

There are various types of vitamin D supplements available – both on prescription and over-the-counter. Vitamin D is sometimes combined with calcium. Supplements can be taken by mouth or by injection (for long lasting effect) – products include ergocalciferol, alfacalcidol, calcitriol, colecalciferol and dihydrotachysterol. Choosing the right one, the right dose, and the best method of delivery will depend of how severe the deficiency is and what it is being caused by. Selecting the most appropriate product may not be a simple decision – so it's best to discuss vitamin D supplementation with your doctor rather than doing introducing preventative measures yourself', especially for those at increased risk.

If further help is required, referral to increasing dietary intake is unlikely to either an endocrinologist (hormone be successful, as is the use of artificial specialist) or a bone and calcium clinic exposure to sunlight, which runs the risk should be discussed with the GP. of skin cancer.

Are Vitamin D Supplements Safe?

As vitamin D can accumulate in the body, and there is only a narrow margin between safe and toxic levels of vitamin D, supplements have to be used with care. Symptoms of overdosing on vitamin D include anorexia, lassitude, nausea and vomiting, diarrhoea, weight loss, sweating, headache and thirst. Anyone taking a larger (i.e. pharmacological) dose of vitamin D should have their plasma calcium levels checked regularly (weekly to start with) and whenever nausea or vomiting occurs. Breast milk from women taking higher doses of vitamin D may cause hypercalcaemia (a raised blood calcium) if given to an infant.

Can Vitamin Deficiency Be Prevented?

Many experts feel that the current official recommendations for dietary intake of vitamin D intake are inadequate. In the UK, 400iu (10 micrograms daily) is recommended for those aged 65 and over, but there is a strong case for introducing preventative measures – especially for those at increased risk. Increasing dietary intake is unlikely to be successful, as is the use of artificial exposure to sunlight, which runs the risk of skin cancer. However, there is growing evidence to show that a daily supplement (e.g., calcium and ergocalciferol tablets) containing 800 iu (20 micrograms) of vitamin D is safe and free from side-effects.

Research Into Vitamin D

We need to know how common vitamin D deficiency is in ME/CFS – especially in those with moderate to severe disease; to what extent we should be trying to prevent vitamin D deficiency occurring through the use of supplements; and whether vitamin D might also have a role to play in the treatment of ME/ CFS – due to its immunosuppressive action in the body.

<p>■ Allergies. Vitamin D deficiency is associated with a greater risk of allergies, such as to pollens.</p> <p>■ Back pain. In a report of six patients with chronic lower-back pain, vitamin D supplements led to either a partial or complete elimination of back pain.</p> <p>■ Fibromyalgia. Low vitamin D levels are typical in this disease, and boosting vitamin D reduces symptoms.</p> <p>■ Heart disease. Low vitamin D levels are associated with up to a 50 percent higher risk of heart attack.</p>	<p>■ Mental health. Low wintertime vitamin D levels may be a factor in Seasonal Affective Disorder (that is, seasonal depression), as well as in schizophrenia.</p> <p>■ Multiple sclerosis. The risk of multiple sclerosis increases progressively in populations living at latitudes farther from the equator. A growing body of research suggests that adequate vitamin D might slow its progression, at least in the early stages of MS.</p> <p>■ Skin cancer. Some research suggests that for certain populations, vitamin</p>	<p>D, in combination with sun exposure or calcium supplementation, might offer some protection against skin cancer.</p> <p>■ Type 2 diabetes. Considerable research indicates that vitamin D, often in combination with calcium, helps regulate blood sugar and may reduce the risk of type 2 diabetes.</p> <p>■ Vaginal infections. Bacterial vaginosis affects nearly one of every three women. Maintaining normal vitamin D levels might reduce the risk of this type of infection.</p>
---	--	--

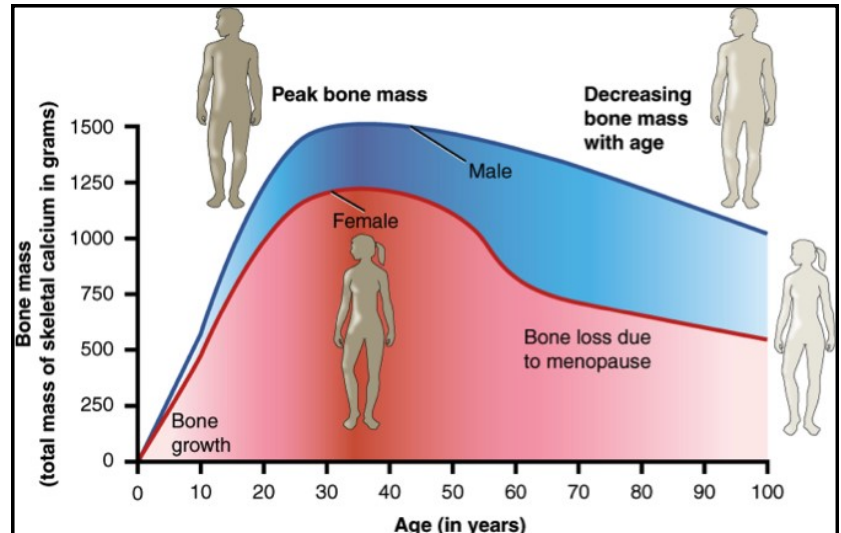
Vitamin D deficiency features heavily in health magazines.

Osteoporosis

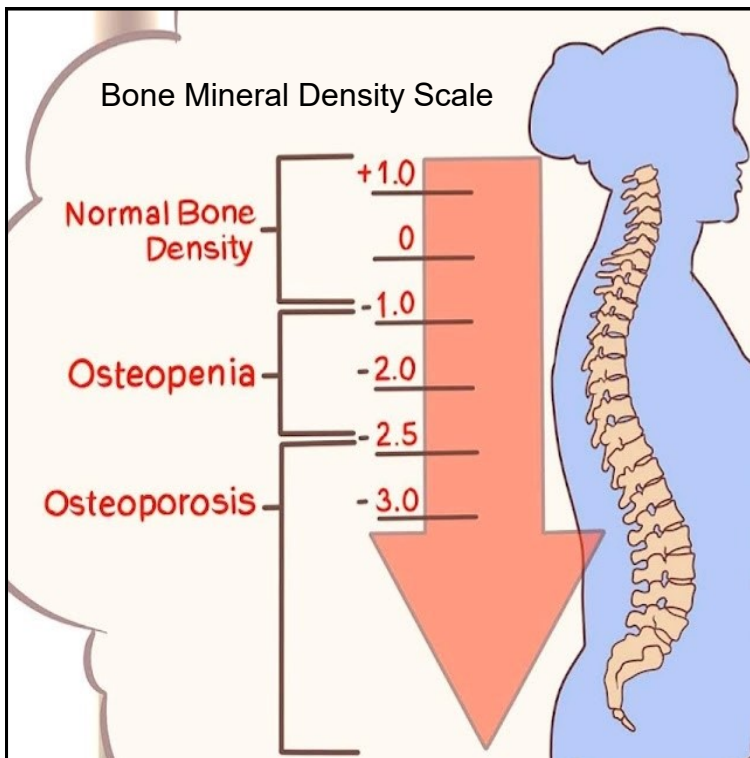
What is Osteoporosis?

Osteoporosis is a progressive disease which is characterised by low bone mass, or bone mineral density (BMD), and structural deterioration of bone tissue, and therefore increased bone fragility and risk of fracture. Osteoporosis is asymptomatic and is often diagnosed as a result of a fracture. Vertebral fractures, most of which are osteoporotic, may go unrecognized.

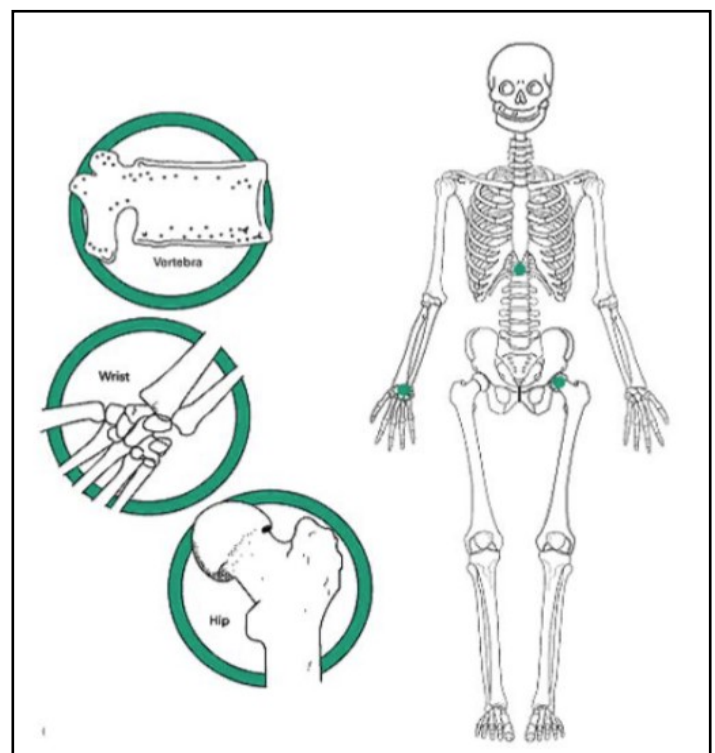
In the UK, approximately 536,000 new fragility fractures occur each year, and more than one in three women and one in five men will sustain one or more osteoporotic fractures in their lifetime. Osteoporosis occurs more frequently in women as not only do they suffer from age-related bone loss (which occurs in both men and women), but they experience a decrease in oestrogen production at the menopause which accelerates bone loss. Additionally, women generally have a longer life expectancy than men, therefore, bone tissue continues to be lost over a longer period of time.



Osteoporotic fractures, which occur as a result of osteoporosis, are classified as fragility fractures. Fragility fractures occur following a low-level trauma; WHO have quantified this as a force equivalent to a fall from standing height or less. The most commonly affected bones are wrist, spine, and hip but fragility fractures may also occur in the arm, pelvis, ribs and vertebrae. Vertebral fractures may occur spontaneously, or as a result of routine activities such as bending or lifting.



Osteoporosis severity is expressed as a T-score, i.e., a T-score less than -2.5 would indicate osteoporosis. A lower T-score means a lower Bone Mineral Density (BMD). It should be noted

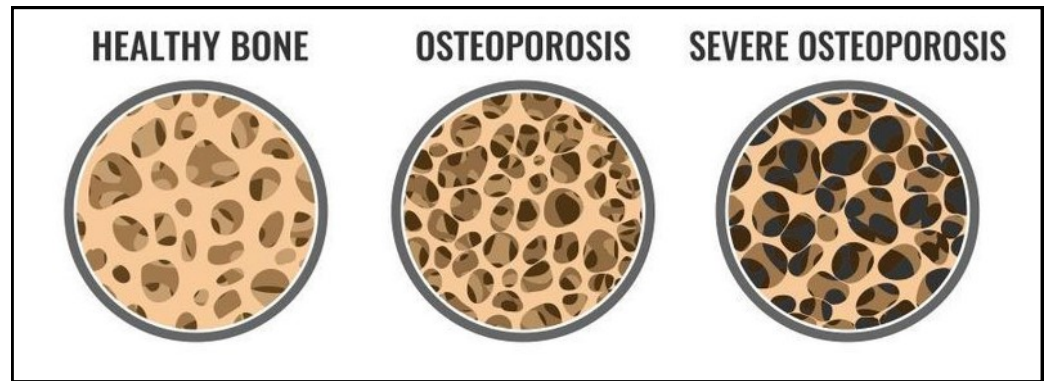


that BMD measurement does not provide information relating to the structural deterioration, and that most osteoporotic fractures occur in women who do not have osteoporosis as defined by a T-score equal to or less than -2.5. Osteopenia is an intermediate condition which if diagnosed should sound alarm bells that some sort of intervention is needed.

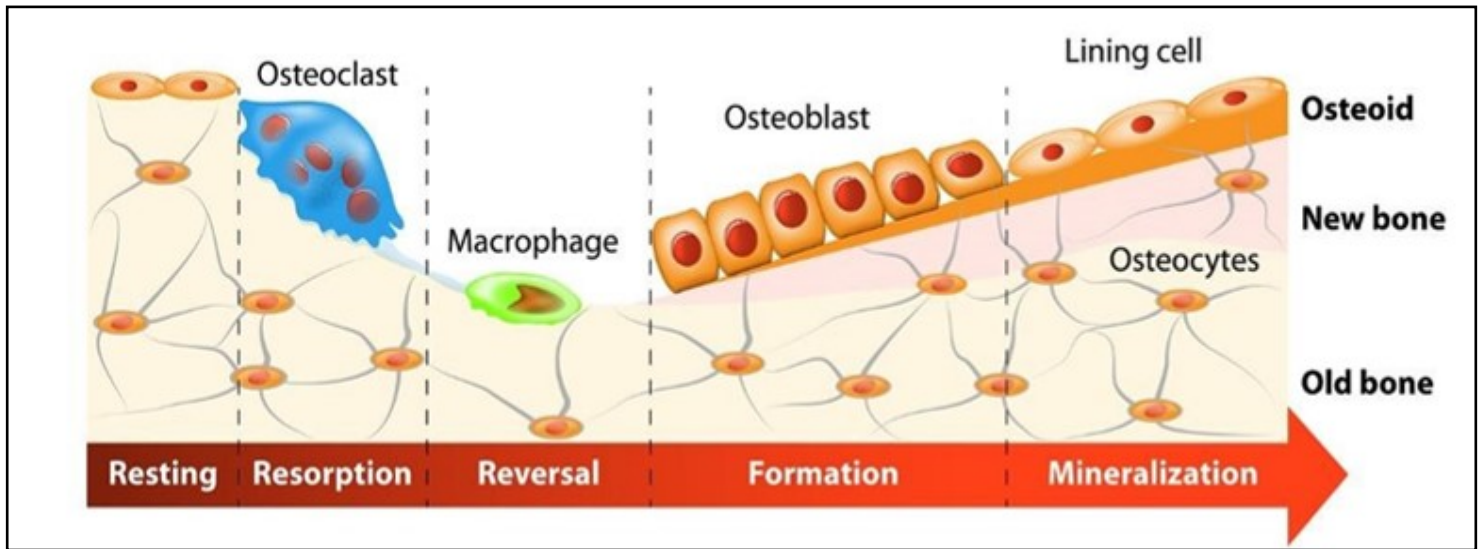
Common sites for Osteoporotic fractures

What goes wrong ?

As a person grows up, they put one bone mass up to adolescence, where it reaches a peak, and then is maintained throughout adulthood. There is a continuous cycle of bone being resorted and regrown throughout life. This is known as bone remodeling.



Healthy bone has a sponge like appearance. As osteoporosis progresses, the amount of bone reduces as the holes get bigger



The bone remodelling process. A continuous process of demolition and rebuilding.

The combination of the process of bone acquisition and the process of bone maintenance results in a person's current BMD. If the amount of bone mass that is acquired up to adolescence is lower than normal, this can reduce BMD, additionally BMD is reduced by disruption to the process of bone remodeling. If the process of bone remodeling works well, then this maintains bone mass.

Osteoporosis is a result of abnormal bone remodeling (and can be worse if normal peak bone mass is not achieved). The diagram below shows the bone remodeling cycle. If this ordered process is functioning well, then it will keep bone tissue healthy.

Cells called osteoblasts are activated by endocrine signals (hormones and interleukins). They work to form new bone in a carefully ordered matrix while releasing signals that cause osteoclast cells to co-ordinate bone resorption (digestion of bone tissue). This process is complex and delicately balanced. In osteoporosis the balance is shifted, osteoblast activity is reduced which results in loss of bone tissue. During mineralisation phosphate and calcium are added to the bone matrix to strengthen it, and during the process of resorption calcium and phosphate are released from the bone tissue into circulation. This complicated process is partly a way of ensuring that circulating calcium and phosphate levels are maintained.

There are three hormones which regulate calcium levels and play an important role in bone health:

- **Parathyroid hormone (PTH)**, maintains the level of calcium in the blood and stimulates both resorption and formation of bone tissue.
- **Calcitriol**, a hormone derived from vitamin D, which stimulates the intestines to absorb enough calcium and phosphorus. It also acts on the bone directly.
- **Calcitonin**, which inhibits bone breakdown and is important for maintaining bone development and normal blood calcium levels in early life.

Causes and Risk Factors. (BMD = Bone mineral density)

Low BMD is one of the key risk factors for osteoporotic fractures but is poor at predicting fracture risk when used without considering other risk factors.

- **Low body weight:** a body mass index of less than 18.5 kg/m² is linked to low BMD. Additionally, older people with low body weight have less fat padding around the hips to cushion the impact of a fall, increasing fracture risk
- **Smoking:** there is evidence to suggest that postmenopausal bone loss is greater in smokers, but the risk of osteoporotic fracture is largely independent of BMD. Smoking is associated with earlier menopause and a lower body weight.
- **Alcohol:** high intake of alcohol is linked to a significant risk of osteoporotic fracture which is largely independent of BMD. Consumption of three or more units of alcohol daily is listed as a risk factor by NIHCE.
- **Age:** risk increases with age; some of this risk relates to bone loss and increasing fragility, but the effects of age are at least partially independent of BMD. In addition, risk of osteoporotic fracture increases with age due to increased falls risk. This can be due to certain medicines, poor vision, balance problems, muscle weakness or other medical conditions including ME/CFS.
- **Gender:** risk is higher in women due to increased life expectancy, menopause, and bone size.
- **Other factors affecting BMD include:-** endocrine disease, gastrointestinal conditions that cause malabsorption (for example inflammatory bowel disease), chronic kidney disease, chronic liver disease, chronic obstructive pulmonary disease and immobility.

Other factors independent of BMD include:

- **Oral corticosteroids:** effect depends on the dose and duration. Corticosteroids can reduce bone formation by inhibiting the gene transcription of osteoblasts and can also reduce osteocyte viability. This may be an issue with people given corticosteroids for Asthma. The risk of a fracture is highest during the first few months after starting treatment with a corticosteroid.
- **Previous fragility fracture:** after one osteoporotic fracture, risk increases by two to three times. Risk also increases with increasing number of previous fractures.^{1,6,7}
- **Rheumatological** conditions such as rheumatoid arthritis, and other inflammatory bone diseases.
- **Parental history** of hip fracture.
- **Certain medicines.** Risk factors affecting bone strength that have unestablished mechanisms include the use of selective serotonin reuptake inhibitors, proton pump inhibitors and anticonvulsant drugs, in particular enzyme inducing drugs, such as carbamazepine.

Prognosis and complications

One of the most serious complications associated with osteoporosis is hip fracture, which nearly always leads to hospitalisation. It is fatal in 20 percent of cases and permanently disables half of those affected. Treatment of hip fracture usually involves surgery and potentially a hip replacement.

Diagnosis/detection

As previously stated, osteoporosis is often undiagnosed until a fracture occurs. However, WHO and the International Osteoporosis Foundation recommend that dual-energy X-ray absorptiometry (DXA) scanning of the femoral neck to measure BMD (T-score) may be used to aid diagnosis. DXA scans may be used before a fracture occurs in those with risk factors, or after a fracture to determine if it is osteoporotic and to help determine risk of further fractures. The results are then used to aid risk assessment and diagnosis, along with assessment of other factors. Women with a prior fragility fracture should be considered for treatment without the need for further assessment, although BMD measurement is sometimes appropriate, particularly in younger postmenopausal women. Fragility fracture risk is usually calculated before offering a DXA scan. NICE recommends that the predicted risk of major osteoporotic or hip fracture over ten years, expressed as a percentage, is calculated using either the QFracture® risk calculator or the FRAX® tool.

Fracture risk should be considered in women aged 65 years and over, and in men aged 75 years and over, or in patients below these ages who have risk factors for fractures. Fracture risk should not routinely be considered in patients aged below 50 unless they have a major risk factor.³ To learn more about risk assessment with these tools access the following NICE guidance Osteoporosis: assessing the risk of fragility fracture [CG146].

Treatment with medicines

After clinical assessment, interpretation of the results of the risk assessment tools and BMD (if measured), a clinician may recommend pharmacological treatment to reduce the risk of fracture. Pharmacological treatments include bisphosphonates, non-bisphosphonates, calcitriol and hormone replacement therapy (HRT).

Bisphosphonates increase bone mineral density by altering the activity of osteoclasts¹ and are recommended if a person has no other contraindications. They are derived from alendronic acid and risedronic acid. Bisphosphonates have a major side effect of osteonecrosis (death of bone) of the jaw and external auditory canal. This risk is dependent on bisphosphonate potency, route of administration, dose, treatment duration, smoking and other medical conditions. One of the ways that the risk of this can be reduced is by maintaining good oral hygiene. Additionally, it is recommended that patients visit their dentist before initiating bisphosphonates and any necessary dental treatment should be carried out before starting or at the start of treatment with bisphosphonates.

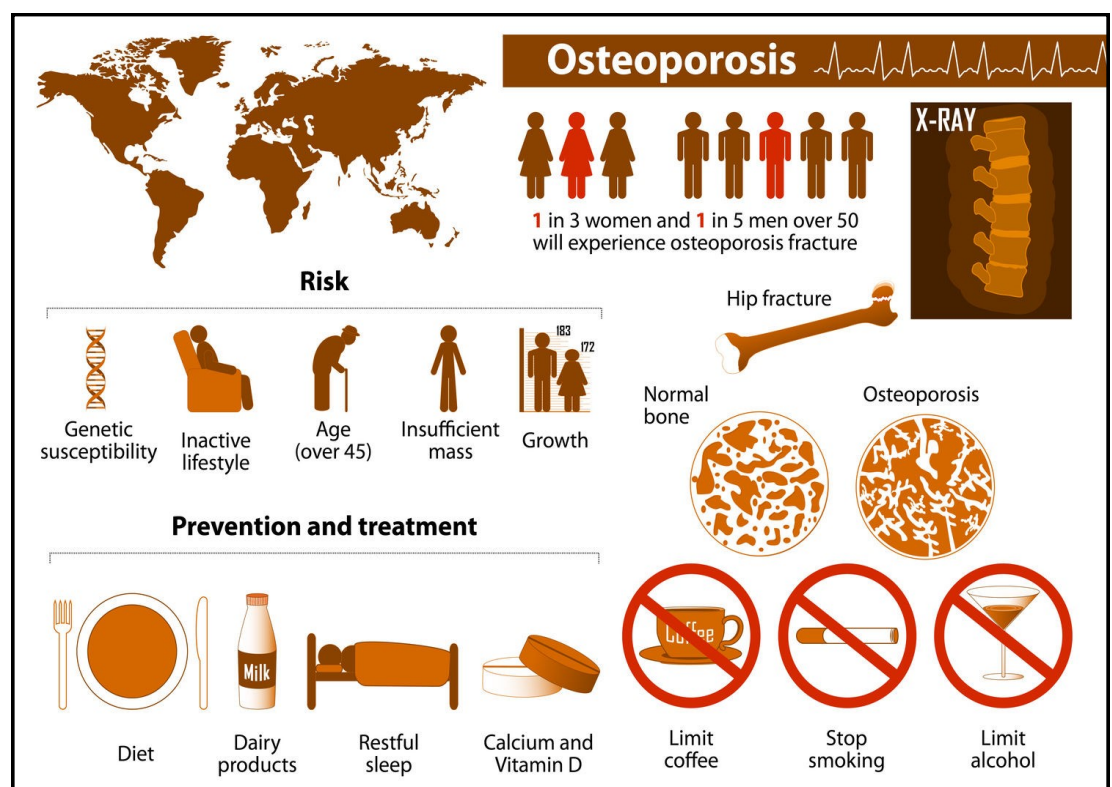
If a person cannot tolerate oral bisphosphonates, or they are contraindicated, then a specialist may initiate treatment with zoledronic acid (a bisphosphonate administered annually by intravenous infusion), or non-bisphosphonate: raloxifene (selective oestrogen receptor modulator), denosumab (monoclonal antibody), or teriparatide (synthetic parathyroid hormone). Note that strontium ranelate is no longer recommended, following a decision by its manufacturers to stop marketing and supply of this treatment. strontium ranelate (Protelos) no longer available.

Dietary calcium intake should be between 700 mg and 1200 mg per day. If a person is not receiving enough calcium in their diet, they should be offered a supplement containing vitamin D and at least 1000 mg of calcium daily. Vitamin D can be offered if a person's calcium intake is low. Calcium and 10 micrograms colecalciferol (400 international units) per day is recommended as standard, or 20 micrograms (800 international units), for postmenopausal women and men over 50 years at increased risk of fracture, and elderly people who are housebound or living in a care home.^{10,19} If dietary intake of calcium is adequate but a person is not exposed to much sunlight, 10 micrograms (400 international units) of vitamin D can be offered without calcium. It should be appreciated that Vitamin D supplementation should also be considered for all during the winter months, as well as in people taking antiepileptic drugs.

HRT may be offered to women who experience a premature menopause before 40 years of age. This treatment has been shown to reduce the risk of frailty fractures in addition to relieving menopausal symptoms.

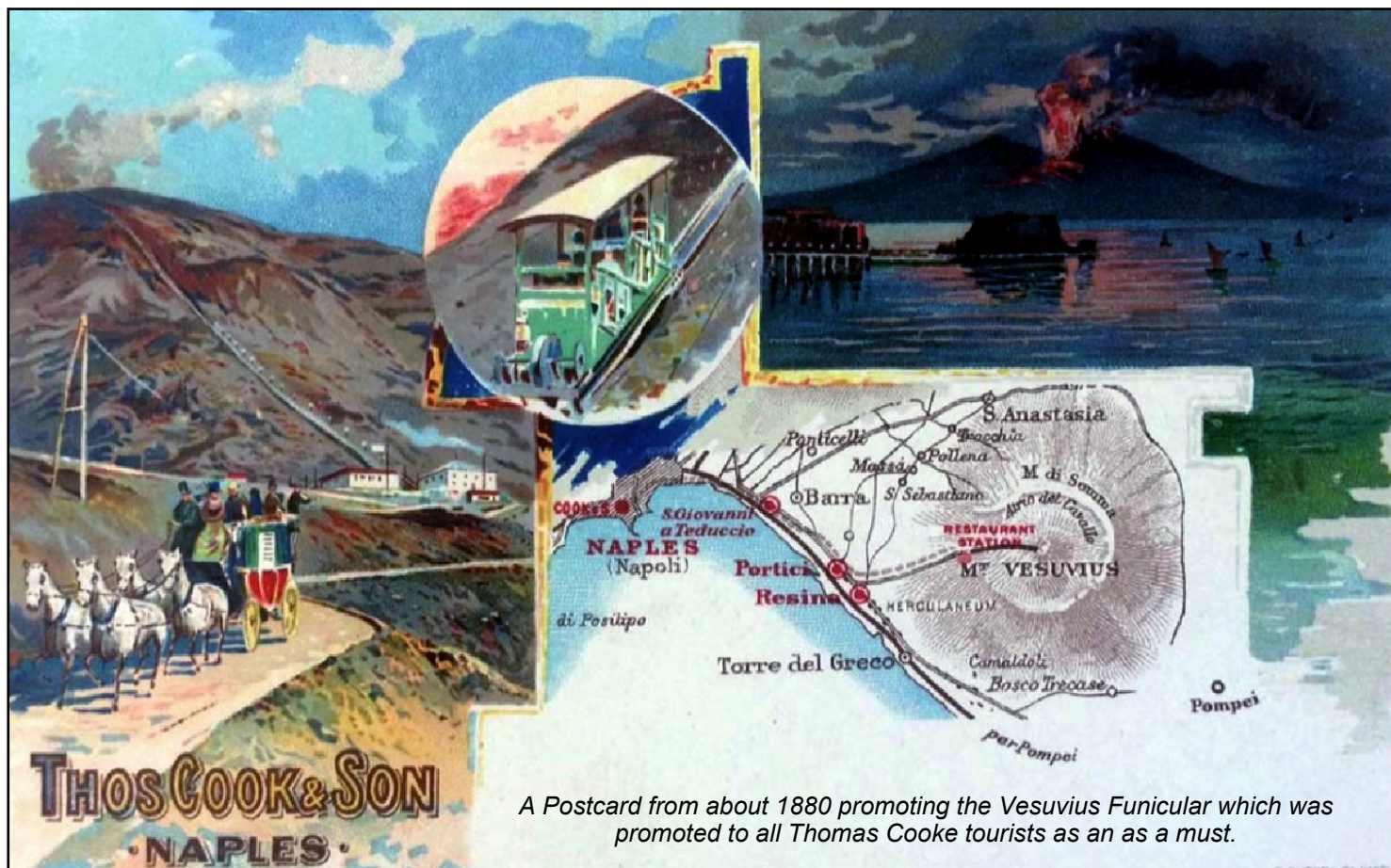
HRT may be offered to women who experience a premature menopause before 40 years of age. This treatment has been shown to reduce the risk of frailty fractures in addition to relieving menopausal symptoms.

Right: A graphic which simply summarizes osteoporosis.

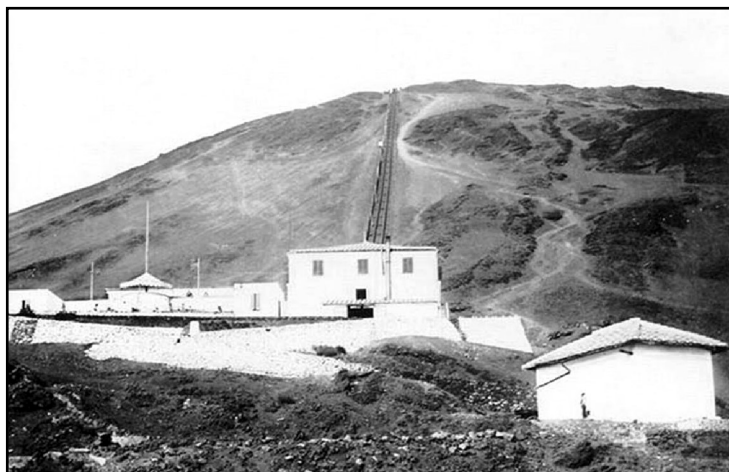


North of Doncaster: Personal thoughts from Trevor Wainwright

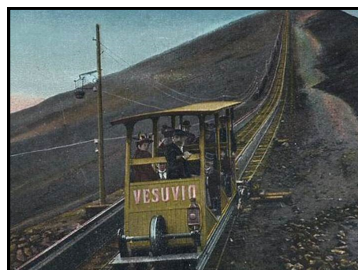
The Vesuvius Funicular Railway



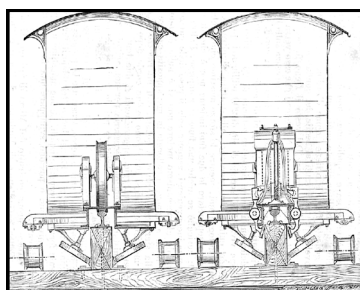
As said in last quarters issue, a funicular is a form of cable railway which connects points along a railway laid on a steep slope. The term derives from the Latin word funiculus, which translates to "rope". That's what they used to be made from! There were rope cables in the system powered by water, humans, or animals.



Looking up from the Lower Station c. 1880-1890



One of the two original 1880 cars named Etna and Vesuvio which seated 8 people. These cars were replaced in 1889 by new cars with 10 seats, also named Etna and Vesuvio, as part of renovations by John Mason Cook, son of Thomas Cook founder of the travel agents.



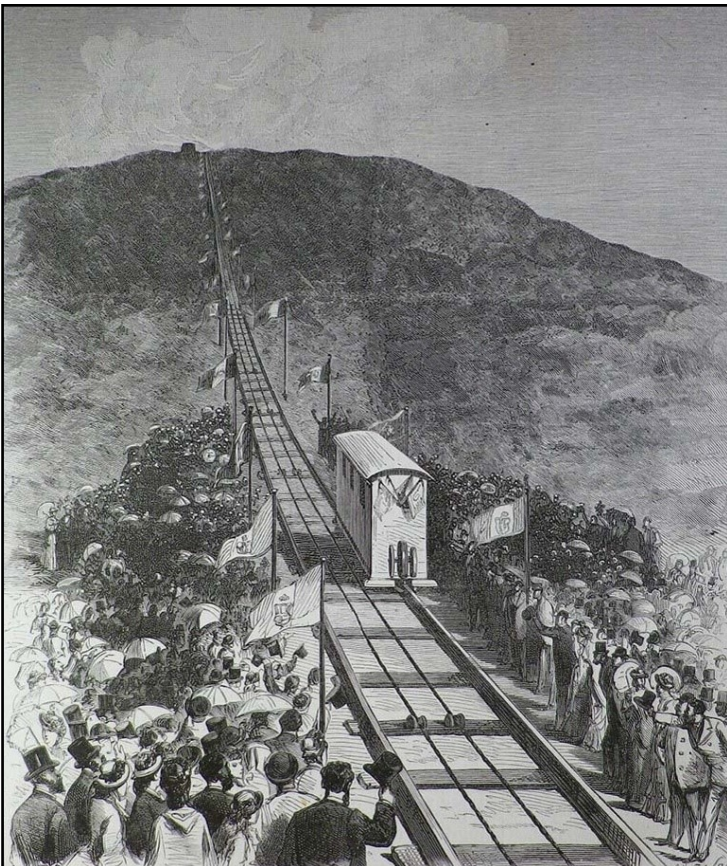
The Vesuvius funicular had a strange monorail type arrangement. There was a longitudinal wooden sleeper on the top of which was carried a single rail. The cars had a double flanged wheel at each end which ran on this rail. In addition, there were two angled rails, one fixed to each side of the sleeper at its base. The cars had wheels mounted from their floors which engaged on these side rails and kept the cars upright. Each track had two continuous cables carried on pulleys which were fixed to each side of the car. As the cars were always on a slope, the were constructed in a skew fashion.



For the musically minded of you the term may sound familiar in Classical Music and the song often associated with the late Lucciano Pavarotti 'Funiculi Funicula' by the Italian composer Luigi Denza to lyrics in a Neapolitan dialect by Peppino Turco a renown Italian songwriter, journalist and poet marking the birth of the modern Neapolitan song (Canzone napoletana) ordinarily for the male voice singing solo, although well represented by female soloists also and expressed in familiar genres such as the love song and serenade.

It was written to mark the opening of the first funicular railway on Mount Vesuvius on the 6th of April 1880, four years and nine months after Scarborough's South Cliff Funicular. After the inauguration, the cable car did not have great success, the tourists continued to climb Vesuvius using mules or porters, a more romantic tradition. There were various other incidents from which it bounced back until it was destroyed by the 1944 eruption of Vesuvius.

The song served, therefore, also to make a new means of transport popular, and soon became a success known all over the world. The song depicts a young man taking his sweetheart on a trip up the mountain on opening day 'Funiculi Funicula' refers to the direction of travel, funicular up, funicular down. In addition to its classical fame, it has been used in adverts for Italian food, notably pasta. So, what of the song itself, In Turco's original lyrics, a young man compares his sweetheart to a volcano, and invites her to join him in a romantic trip to the summit.



Left : Vesuvius Funicular. Inauguration day on the 6th June 1880. This is from a sketch by M Lazzaro from front cover of 'Illustration: Journal Universal'.

English translation

I climbed up high this evening, oh, Nanetta,
Do you know where? Do you know where?
Where this ungrateful heart
No longer pains me! No longer pains me!
Where fire burns, but if you run away,
It lets you be, it lets you be!
It doesn't follow after or torment you
Just with a look, just with a look.

(
Chorus

*Let's go, let's go! To the top we'll go!
Let's go, let's go! To the top we'll go!
Funiculi, funicula, funiculi, funicula!
To the top we'll go, funiculi, funicula!*

Let's go from here below up to the mountain,
A step away! A step away!
You can see France, Procida, and Spain,
And I see you! And I see you!
You rise, pulled by a cable, quick as a wink,
Into the sky! Into the sky!
We'll rise up like a whirlwind all of a sudden
Knows how to do! Knows how to do!
(Chorus) ...

The car has climbed up high, see, climbed up high now,
Right to the top! Right to the top!
It went, and turned around, and came back down,
And now it's stopped! And now it's stopped!
The top is turning round, and round, and round,
Around yourself! Around yourself!
My heart is singing the same refrain:
We should be wed! We should be wed!
(Chorus) ...

A Newspaper clipping translated.....

The famed Thomas Cook funicular railway that once took passengers to the summit of Mount Vesuvius is to be restored 60 years after it was closed in the last eruption. Officials in Naples said yesterday that an agreement on restoring the 19th-century railway had been signed by the Campania region, the Vesuvius National Park and the Vesuvius Observatory, which monitors the volcano for seismic tremors.

Despite the risk of eruptions, Amilcare Troiano, director of the Vesuvius National Park, said that feasibility studies had already been conducted as part of a scheme to "improve the environmental and tourist facilities of the Vesuvius area".

At the time of writing there was no sign of any action being taken,