

VITAMIN D AND ME/CFS

WHY IT'S IMPORTANT FOR PEOPLE
WITH ME/CFS AND LONG COVID



What is Vitamin D?

Where Vitamin D comes from

Causes of Vitamin D deficiency

Symptoms of Vitamin D deficiency

Vitamin D deficiency in ME/CFS

Vitamin D deficiency treatments

Vitamin D safety





Vitamin D and ME/CFS was written by **Dr Charles Shepherd**, Trustee and Hon. Medical Adviser to The ME Association.

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.

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INTRODUCTION

There is growing interest in the role of vitamin D – the ‘sunshine vitamin’ – in both ME/CFS and Long Covid. Firstly, because there are reasons why people with ME/CFS and Long Covid are at increased risk of developing vitamin D deficiency. Secondly, because vitamin D deficiency can cause muscle symptoms and fatigue that add to the ill health and disability experienced by people with ME/CFS and Long Covid.

Key points

- Vitamin D helps to regulate the amount of calcium and phosphate in the body and keeps bones, teeth and muscles healthy.
- A lack of vitamin D can lead to potentially serious bone diseases called osteomalacia (softening of the bones) and osteoporosis (loss of bone density).
- The body creates vitamin D from direct sunlight on the skin when people are outdoors.
- The 2021 NICE guideline (at section 1.12.23) states that people with ME/CFS, especially those who are largely or totally housebound, are at increased risk of developing vitamin D deficiency.
- Research evidence has confirmed that some people with ME/CFS, especially those with severe or very severe ME/CFS, have a significant deficiency of vitamin D.
- Vitamin D status should therefore form part of the clinical assessment of people with ME/CFS along with appropriate treatment of any deficiency.
- The Department of Health and Social Care recommends that people who are not often outdoors should take a supplement containing 10 micrograms (400 international units) of vitamin D throughout the year.
- Overdosing on vitamin D supplements can cause serious side-effects. Doses above the recommended daily dose should therefore be prescribed by your doctor.



Vitamin D has a range of important functions - particularly involving bone, muscle, brain and immune-system function.

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.

In relation to ME/CFS there is evidence that vitamin D helps to:

- Increase muscle strength
- Increase resistance to infections
- Improve energy levels
- Reduce the risk of falls

Vitamin D may also reduce the risk of depression and low mood.

So there are plenty of reasons why it's important for people with ME/CFS (and Long Covid) to try and make sure they are not deficient in this important vitamin.

Also of interest is evidence (but not always consistent) to indicate that vitamin D deficiency is a risk factor for multiple sclerosis. A recent treatment trial reported that treatment with vitamin D reduced disease activity in early relapsing and remitting MS:

<https://tinyurl.com/3v7pmny2>

Vitamin D deficiency has also been proposed as a risk factor for the development of Long Covid:

<https://tinyurl.com/45as62jj>

WHERE DOES VITAMIN D COME FROM?

The main and best source of vitamin D is the skin - from exposure to the sun's ultraviolet rays, which triggers vitamin D production. So people who are able to regularly go outdoors are normally able to make all the vitamin D they need from early April to the end of September. From October to March we don't make enough vitamin D from sunlight.



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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. People with dark skin - from having an African, Caribbean or South Asian background - may also have a reduced ability to make vitamin D from sunlight.

Dietary sources of vitamin D include:

- Fortified foods such as margarine and some breakfast cereals
- Egg yolks and some dairy products, if fortified, e.g. yogurt/yogurt drinks. Cow's milk isn't a good source because it's not fortified
- Fortified foods - such as some fat spreads and breakfast cereals
- Oily fish such as herring, mackerel, salmon, sardines and trout
- Red meat
- Liver - but you should avoid liver if you're pregnant. Find out about foods to avoid in pregnancy on the NHS website here:

<https://tinyurl.com/bdexvhpd>

However, it's difficult to get enough vitamin D from dietary sources alone and this can be further reduced if you are on any sort of restrictive diet.

Lack of, or reduced exposure to the sun and/or restrictive diets, can lead to progressive vitamin D deficiency.



WHAT CAUSES VITAMIN D DEFICIENCY?

Lack of, or reduced 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/or cut out foods that contain vitamin D.

Less common causes of vitamin D deficiency include:

- Kidney disease
- Liver disease
- Drugs such as phenytoin (for epilepsy) and warfarin (for blood clot prevention)
- Malabsorption due to coeliac disease or Crohn's disease

WHAT HAPPENS TO VITAMIN D INSIDE THE BODY?

Vitamin D is converted by the kidney into what is known as its active metabolite: 1,25 dihydroxyvitamin D. This metabolite plays a key role in maintaining the right balance of calcium and phosphate in the body. Vitamin D helps to produce and maintain healthy bones and teeth, as well as normal activity in organs such as the brain, pancreas and stomach.

Vitamin D also acts on the immune 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 can cause 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 symptoms 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.

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HOW COMMON IS VITAMIN D DEFICIENCY IN ME/CFS?

Firstly, it's worth noting that a significant proportion of the normal population have vitamin D deficiency - most of whom are not aware that they do.

In relation to ME/CFS, the simple answer is we just don't know because very little research into vitamin D status in ME/CFS has been carried out. Anecdotal reports indicate that it can often be an 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.



Concentrations between 25 nmol/L and about 50 nmol/L are generally regarded as being insufficient for good bone health and may be associated with adverse effects. However, the level required to maintain optimal bone health remains uncertain.

HOW IS VITAMIN D DEFICIENCY DIAGNOSED?

This can be done by measuring the level of 25-hydroxyvitamin D (25-OHD) in the blood.

- A serum 25-OHD level below 25 to 30 nmol/L is generally regarded as an indication of significant or severe vitamin D deficiency
- Concentrations between 25 nmol/L and about 50 nmol/L are generally regarded as being insufficient for good bone health and may be associated with adverse effects. However, the level required to maintain optimal bone health remains uncertain
- A level above 50 nmol/L is generally considered to be adequate for most people – but this will depend on individual circumstances
- Above 75 nmol/L is an optimum level

Please note that there are a range of views on where the cut off points for the different blood levels of 25-OHD should be.

The blood level of phosphate and calcium may be reduced and alkaline phosphatase increased. These are investigations that should form part of routine diagnostic assessment 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 sometimes upset the parathyroid gland, a control centre in the body for calcium. So parathyroid function may need to be investigated as well.

HOW CAN VITAMIN D DEFICIENCY BE PREVENTED WITH SUPPLEMENTS?

The Department of Health now recommends that everyone should consider taking a vitamin D supplement that contains 10 micrograms of vitamin D during the autumn and winter months. People with ME/CFS who are at increased risk of developing a deficiency should take a 10 microgram supplement, possibly higher (i.e. 25 micrograms) under medical guidance, all the year round.

Sometimes the amount of vitamin D in a supplement is expressed as international units (IU). 1 microgram of vitamin D is equivalent to 40 IU. So 10 micrograms equals 400 international units.



HOW CAN VITAMIN D DEFICIENCY BE PREVENTED WITH SUPPLEMENTS?

You can purchase vitamin D supplements - which come in various forms - from pharmacies and health shops. Boots, for example, produce a relatively low cost 10 microgram tablet of vitamin D3 (the most bioavailable form). This should be taken daily with plenty of water:

<https://tinyurl.com/5a967acz>



Some supplement manufacturers recommend taking vitamin D3 and vitamin K2 together on the basis that vitamin D3 helps the body absorb calcium, while vitamin K2 helps direct that calcium into bones and away from blood vessels. This synergy may support bone strength and help prevent calcium build-up in arteries, though more research is needed. However, the jury is still out as to whether this is really necessary in relation to vitamin D supplementation in people who are not vitamin D deficient.

There are various types of treatments available for vitamin D deficiency. These treatments are sometimes combined with calcium. They can be taken by mouth or by injection (for long-lasting effect).

TREATING A DEFINITE VITAMIN D DEFICIENCY

There are various types of treatments available for vitamin D deficiency. These treatments are sometimes combined with calcium. They can be taken by mouth or by injection (for long-lasting effect).

Choosing the right product, the right dose, and the best method of delivery will depend on how severe the deficiency is and what it is being caused by. Selecting the most appropriate product may not be a simple decision - so this is something that requires a guidance from your doctor rather than 'doing it yourself'.

If further help is required, referral to either an endocrinologist (hormone specialist) or a bone and calcium clinic should be discussed with the GP.

The South West London Integrated Care Board (ICB) has produced some helpful detailed guidance for health professionals on the treatment of vitamin D deficiency:

<https://tinyurl.com/2k2phhry>



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 must be used with care.



Symptoms of overdosing on vitamin D include loss of appetite, lassitude, nausea and vomiting, diarrhoea, weight loss, sweating, headache and thirst.

So there is a real danger of vitamin D toxicity occurring if people who do not have a vitamin D deficiency start taking unnecessarily high doses of vitamin D as a preventative measure.

This is because high doses of vitamin D increase the amount of calcium being absorbed and high levels of calcium in the blood (hypercalcaemia) can cause serious health problems.

Symptoms of overdosing on vitamin D include loss of appetite, 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.

More information on vitamin D toxicity can be found here:

<https://tinyurl.com/mp92p287>

Breast milk from women taking higher doses of vitamin D may cause hypercalcaemia (a raised blood calcium) if given to an infant.

Vitamin D can interact with some types of prescription-only medication - including digoxin and thiazide diuretics. So care is required if you are taking some types of drugs.



RESEARCH INTO VITAMIN D STATUS IN ME/CFS

Several research studies have now reported on vitamin D deficiency in ME/CFS

Berkovitz *et al* assessed vitamin D levels in 221 ME/CFS patients. They reported that: 25-OH vitamin D levels are moderately to severely suboptimal in ME/CFS patients, with a mean of 44.4 nmol/L (optimal levels >75 nmol/L). These levels are lower and the difference is statistically significant ($p < 0.0004$) than those of the general British population from a recent national survey, but similar to those in patients with other chronic conditions.

Earl *et al* compared vitamin D levels in 94 people with ME/CFS compared to 94 age matched healthy controls. They reported that there was: No evidence of a deficiency in serum total 25(OH) vitamin D (25(OH)D2 and 25(OH)D3 metabolites) in individuals with ME/CFS and Low serum concentrations of total 25(OH)D do not appear to be a contributing factor to the level of fatigue of ME/CFS.

Kodoma *et al* measured serum 25-hydroxyvitamin D levels in 28 patients who developed ME/CFS after COVID-19 vaccination between August 2022 and February 2024. They reported that: for patients developing ME/CFS after COVID-19 vaccination with insufficient or deficient vitamin D levels, appropriate vitamin D replacement therapy under medical guidance may lead to symptomatic relief. This group is now preparing a randomised controlled trial to evaluate the efficacy of vitamin D replacement therapy in individuals with ME/CFS who have developed vitamin D deficiency following COVID-19 infection or vaccination.

Jawale *et al* measured vitamin D status in 100 people with ME/CFS. They reported that: Among the 100 participants, 68% were found to have Vitamin D deficiency, 22% had insufficiency (20–30 ng/mL), and only 10% had sufficient levels (>30 ng/mL). A significant association was found between Vitamin D deficiency and higher fatigue severity scores ($p < 0.01$)



NICE Guideline on ME/CFS: An ME Association Summary

This booklet is recommended reading. It lets you know what to expect from the NHS and social care services with regard to symptom recognition, diagnosis, management, referral, and ongoing care and support. It can be downloaded free from our website:

**NICE Guideline
on ME/CFS: An
ME Association
Summary**



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FURTHER INFORMATION

■ NICE guideline recommendations on vitamin D supplementation:

<https://tinyurl.com/2y9a3k44>

■ General information on vitamin D deficiency:

<https://tinyurl.com/45chdxh7>



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THE ME ASSOCIATION

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■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today.**

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. All our staff and volunteers have knowledge and understanding of these medical conditions. We provide a personalised service and we're here when you need us most. You can contact us via our telephone support line (this is a FREEPHONE number) or by email. Please see back page for more details. You can also join ME Connected (Discord online community). To view the ME Connect telephone support line opening hours, please visit: <https://www.meassociation.org.uk/me-connect>

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £2m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations of the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

“The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research.”



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THE ME ASSOCIATION

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■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guideline reproduced in full in an easy-to-use **database**.

MEDICAL MATTERS

Medical Matters is an easy-to-use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic, then we can help. We have listed all secondary care referral services in an easy-to-use **database**.





ME CONNECT

The Support and
Information Service for
people affected
by ME/CFS/PVFS
and Long Covid



Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/mec

Contact ME Connect
HOW TO GET IN TOUCH:
by phone or email



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We are here to
listen, validate and
empathise with any
issues you might be
facing.



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