

Vitamin D



Welcome to this Choices booklet about vitamin D

MS-UK listens to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position – people who can truly understand and empathise with your current thoughts and feelings.

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Vitamin D

What is vitamin D?

Vitamin D is sometimes called the 'sunshine vitamin' because it is the only vitamin that the human body can manufacture itself by absorbing sunlight. As with any vitamin, vitamin D is required for optimum health.

Vitamin D is important for a healthy immune system, brain development and function, and the cardiovascular system (heart and blood vessels). Vitamin D helps regulate the amount of calcium and phosphorus in the body – the building blocks for strong bones, teeth and muscles (1).

How do we get vitamin D?

Our body creates vitamin D when our skin receives direct sunlight when we are outdoors. Exposure to the sun can produce up to 90 per cent of the body's daily vitamin D. Vitamin D is fat soluble, which means the body can store it for months until it is needed.

Many health professionals advise that people should expose as much

skin as they can to the sun, as is possible and practical, with more in winter and less in summer. If you live in the northern hemisphere, the sun is only strong enough to deliver the amount you need between late March or early April to the end of September, between the hours of 11.00am and 3.00pm (2).

For people with MS, it is important to be mindful that heat intolerance can exacerbate MS symptoms, such as cognitive ability, fatigue, mobility, and others. Some people who experience heat intolerance more easily may find they need to rely on supplementation instead.

It is not fully known how long a person needs to spend in the sun to produce the amount of vitamin D required. This can vary as several factors can affect how vitamin D is made.

For example, some people do not make sufficient vitamin D, even with the right amount of skin exposure.

- Elderly people have thinner skin than younger people and are unable to produce as much vitamin D
- People with dark skin, such as those of African, African-Caribbean or South Asian ethnicity, are not able to make as much vitamin D, therefore, require longer in the sun to produce the same amount as someone with lighter skin
- Some medical conditions can affect the way the body metabolises vitamin D which can lead to a deficiency. For example people with coeliac disease, Crohn's Disease, and some types of liver and kidney disease
- Concerns about skin cancer means many people are covering their skin up before going in the sun, either with clothing or creams containing a sun protection factor (SPF). This prevents the

absorption of the sun's UVB rays. Exposing the skin for up to 20 minutes is important to start building up sufficient vitamin D levels without damaging the skin. However, if the skin starts to turn red or burn sooner than 20 minutes, take care to cover up and protect your skin from damage (2).

- Vitamin D is also found in a small number of foods, including oily fish such as salmon, mackerel, herring, and sardines. It is also found in red meat and egg yolks. Vitamin D is also added to some breakfast cereals, fat spreads and non-dairy milk alternatives.
- As our bodies do not make enough vitamin D from sunlight alone), and it is almost impossible to obtain enough just from food, supplementation can be considered (2).

Vitamin D and general health

A statement from Public Health England (PHE) and the National Institute for Health and Care Excellence (NICE) says that everyone in the UK is advised to take a supplement of vitamin D during the winter months (3).

It is known that a deficiency in vitamin D can lead to bone problems such as rickets in children. Adults can also experience bone pain and muscle weakness which could increase the risks of falls in older people.

For many who are not able to go outdoors often, or those who live in care homes, PHE advises taking a vitamin D supplement all year round.

Low levels of vitamin D can also lead to a higher risk of osteoporosis. This is a condition whereby the bones become thin and brittle due to lower bone density. The bones are more likely to break as a result.

People with MS have a higher risk of developing osteoporosis if

- they have low levels of vitamin D

- have reduced mobility and therefore may be unable to weight bear
- take medications that can cause bone density loss, such as steroids

To help prevent bone density loss, it is important to

- ensure adequate calcium levels for good bone health
- to monitor vitamin D levels as a low level can lead to reduced absorption of calcium
- avoid excessive alcohol consumption and to either reduce, or stop smoking
- exercise regularly, paying attention to weight-bearing exercise where possible (4)

Vitamin D and the link to MS

Countries with the highest prevalence of MS are those furthest away from the equator. For example, the parts of Asia, Africa and America that lie on the equator have very low levels of MS compared to Canada and Scotland that have much higher rates. This has led to further research into the potential role vitamin D could have in MS.

It is widely believed that there are environmental and genetic factors associated with an overall higher risk of developing MS, although these are not absolutely understood.

Studies have shown a link between genetically lowered levels of vitamin D and MS. This means people who had naturally lower



levels of vitamin D were more strongly associated with increased susceptibility to MS. However, it is not yet known if increasing vitamin D levels can either delay or prevent the possibility of the onset of MS (5).

Additional studies have investigated maternal vitamin D levels during pregnancy. The month of birth has been described as a risk factor for developing MS and it is thought that this is due to the amount of ultraviolet B (UVB) light exposure received from the sun throughout pregnancy. Studies have shown that those born in April have an increased risk of developing MS, compared to those born in October and November (6).

This research suggests that there are some environmental risk factors in the development of MS that are present before birth. More research is required to understand this risk (7).

It is also thought that higher levels of vitamin D are associated with lower rates of relapse in relapsing remitting MS. Therefore, if a lower level of relapse was seen in studies this suggests vitamin D has a beneficial effect on disease course. More studies are also required, to look into this further (8).

Low vitamin D levels could potentially cause MS to be more active. Higher levels of MS activity could then lead to lower levels of vitamin D as you are more likely to spend less time outdoors.

According to NICE, in the clinical guidelines for MS, vitamin D is not to be offered solely for the purpose of treating MS (9).

However, many neurologists test vitamin D levels at point of diagnosis and prescribe dependent on the level. According to a blog post by The MS Blog, fifteen MS neurologists from around the world were asked a series of questions about vitamin D. Nearly all test at diagnosis, supplement accordingly and then monitor annually (10).

Vitamin D levels are mostly measured in nanomoles per litre (nmol/L) and supplements are usually prescribed in international units (IU).

According to the National Institutes of Health (NIH) and the Office of Dietary Supplements, a vitamin D level of 30nmol/L to less than 50 is generally considered inadequate for bone and overall health in healthy people. A level of 50 or higher is generally considered adequate for bone and overall health in healthy people. And anything over 125 could cause potential adverse effects, particularly if over 150 (11).

What are the recommended doses for vitamin D supplementation?

Dietary supplements of vitamin D can be found in two different forms – vitamin D2 and vitamin D3. Many studies show that vitamin D3 is more effective than vitamin D2 at raising the blood level to the required amount (12).

PHE and NICE advise that the general population in England should take a supplement of vitamin D, especially during the winter months. During the spring and summer months, it is felt that most people make enough vitamin D from sunlight on the skin (13).

For the general population, PHE recommends a daily dose of 10 micrograms, which is the same as 400 IU. They also state that products providing up to 25 micrograms or 1000 IU are suitable for everyone (13). This amount is in relation to bone health and not MS specifically. A higher level may be required for people with MS to receive the same effect on blood levels.

You can ask your GP, MS nurse, or neurologist for a blood test to see if your vitamin D levels are within the normal range. If your levels are low, you will be prescribed a dosage that will bring your level back up to an adequate amount. This will need to be monitored to make sure the blood level stays within the correct range.

Most neurologists advise a daily dosage of anything between 2,000 IU to 5,000 IU and like their patients to have a vitamin D level of above 75 nmol/L (10).

Dr George Jelenik's Overcoming Multiple Sclerosis (OMS) programme recommends a daily dosage of 5,000 IU in summer and 10,000 IU in winter. Their programme states the most you can take without risk of serious side effects is 10,000 IU per day (14).

MS Research Australia have been looking into a trial of different dosage levels in people with Clinically Isolated Syndrome (CIS) who have experienced a single isolated neurological attack. The idea behind the trial is to investigate whether vitamin D supplements can delay or even prevent a second attack from occurring. A second attack for a person diagnosed with CIS would lead to a diagnosis of MS. The trial is testing three different dosages, 1,000, 5,000 and 10,000 IU, against a placebo (15). Results are yet to be published but will be interesting to see if vitamin D may have an impact on the development of MS.

Vitamin D dosage for families of those with MS

Often, people diagnosed with MS wish to investigate whether they should encourage their family members to supplement with vitamin D by way of prevention.

A comprehensive review published in 2018 says that since vitamin D was proposed as an important risk factor in the development of MS in the 1970s, many studies have since looked into whether it can help to prevent MS.

The review states, 'observational study data does suggest that adequate vitamin D levels may reduce the risk of MS

and affect the course of the disease'. However, more research is needed to establish the recommended levels of vitamin D supplementation necessary to reduce the risk for MS and MS clinical activity (16).

Overcoming MS (OMS) suggests ways to prevent MS in family members. One suggestion is that close adult relatives of people with MS should take 5,000 IU of vitamin D each day in winter and if sun exposure is limited in summer. They also suggest a suitably reduced dose for children (17).

The Department of Health and Social Care recommends everyone, including pregnant and breastfeeding women, should consider supplementing with the recommended daily amount of 400 IU. Children aged one to ten years should not take more than 2,000 IU per day. Infants under 12 months should not have more than 1,000 IU per day (18).

Some people with MS wish to give their children higher doses than that. A conversation with your general practitioner (GP) is advisable if you intend to give a much higher dose than the amount the NHS suggests is adequate.

Great Ormond Street hospital has guidance for children with a diagnosis of MS. They test levels upon diagnosis but also advise all their patients to take 1,000 IU per day (19).

Side effects of high dose vitamin D supplementation are rare and very low at these levels. However, taking too much can lead to a build-up of high levels of calcium in the blood (hypercalcemia). High levels of calcium can cause nausea, vomiting, abnormal heart rhythm and kidney stones (19).

Depending on the amount given, it may be that your GP would wish to monitor levels and ask for regular blood tests.

Further information

NHS

www.nhs.uk/conditions/vitamins-and-minerals/vitamin-d/

The MS Blog

<https://multiple-sclerosis-research.org/>

Overcoming Multiple Sclerosis

www.overcomingms.org

MS-UK news and research

www.ms-uk.org/MSnews

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About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

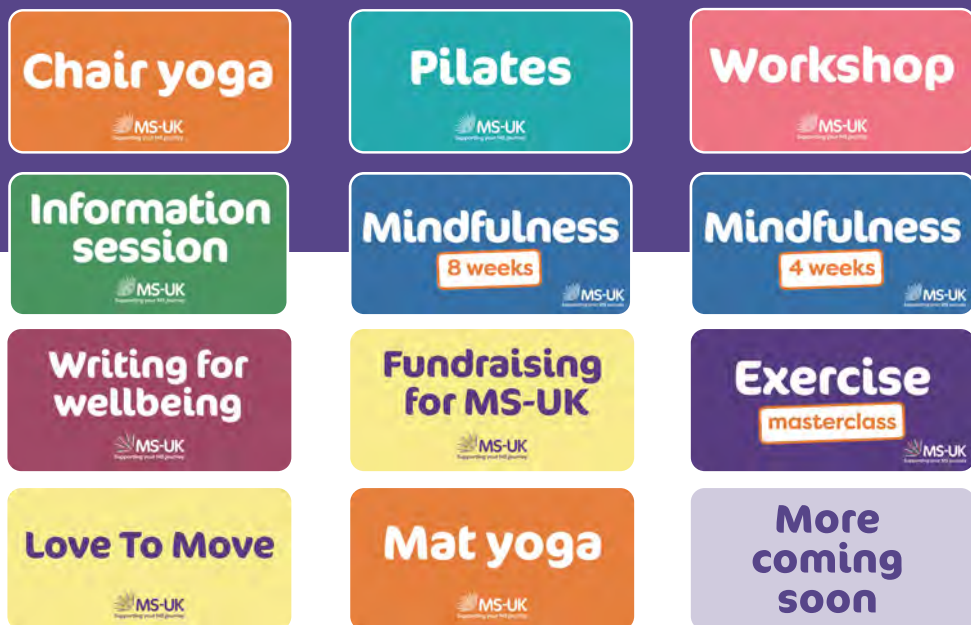
Available in print, audio version, large print and digitally.

About MS-UK

Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





Online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

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Check out MS-UK's online activities

Live a happier and healthier life with MS



- ✓ Accessible online exercise classes
- ✓ Chair yoga classes
- ✓ Mindfulness courses

- ✓ Interactive workshops
- ✓ Information sessions
- ✓ Peer Support Service

Don't miss out – sign up for our new online activities today!

Visit www.ms-uk.org or contact us at register@ms-uk.org

 **MS-UK**
Supporting your MS journey

Registered charity number 1033731

Stay in touch

MS-UK
D3 Knowledge Gateway,
Nesfield Road,
Colchester,
Essex, CO4 3ZL

www.ms-uk.org

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MS-UK Helpline
0800 783 0518
info@ms-uk.org



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VAT Number 632 2812 64

Registered Office D3 Knowledge Gateway,
Nesfield Road, Colchester, Essex, CO4 3ZL



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