Choices

MS-UK
Supporting your MS journey

Vitamin D

Multiple sclerosis information

www.ms-uk.org

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.

Contents

What is vitamin D?

Vitamin D is a fat-soluble hormone that provides essential support for many of our bodily functions.

It is important for a healthy immune system, brain development and function, and cardiovascular health. Vitamin D helps to regulate the amount of calcium and phosphorus in the body, these are the building blocks for strong bones, teeth and muscles (1).

The influence of vitamin D in the health of human immune systems has been proven over time, with scientific studies showing that avoiding deficiency helps to underpin good immune health and reduces susceptibility to autoimmune conditions (2).

The human body relies on an assortment of environmental, dietary and supplement interventions to help it get the amount of vitamin D that it needs. We will take a look at these in more detail later in this booklet.

Vitamin D deficiency

Given the essential role that vitamin D plays in many different bodily functions, it follows that problems can occur for those whose levels are compromised.

It can be the case that people who are deficient in vitamin D may not experience any noticeable symptoms. However, there are various symptoms that may indicate deficiency, these include muscle and bone pain, muscle weakness, tingles or pins and needles sensations in the feet and hands, muscle spasms, twitches and tremor. It is worth noting the similarities between these and MS symptoms.

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 and are more likely to break as a result. Some people with MS are at 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. This can also occur in those who take medications that can cause bone density loss, such as steroids, which are occasionally used to manage MS relapses.

To help prevent bone density loss, it is important to monitor vitamin D levels as deficiencies can lead to reduced absorption of calcium, avoid excessive alcohol consumption, stop smoking and exercise regularly, paying attention to weight-bearing exercise where possible (3).

It is also known that childhood deficiency in vitamin D can lead to bone problems such as rickets. This is a condition that affects the development of bones, can impair growth and create musculoskeletal deformities which may lead to disability if left untreated.

More information

Our 'Exercise and MS' Choices booklet provides more information about accessible exercise and how it can be used to help manage the impact of MS.

www.ms-uk.org/multiple-sclerosis-exercise-choices-booklet

Vitamin D and the link to MS

The link between vitamin D and MS is thought to be both environmental and genetic in nature. It is widely believed that these

factors are associated with an overall higher risk of developing MS, although more evidence is required for a better understanding.

Geography is just one environmental factor. For instance, countries with the highest prevalence of MS are those that lie furthest away from the equator, ones which do not enjoy as much sunlight in terms of both sunshine hours and intensity, when compared to their equatorial counterparts (4). As we will explore later in this booklet, access to natural sunlight is an essential part of vitamin D consumption.

Studies have shown a link between genetically reduced 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. More research is required to underpin the active role that vitamin D plays in the delay or prevention of developing the condition (5). That said, the evidence currently available holds some promise.

Research to date has found that variants of the gene known as HLA-DRB1 may be associated with an elevated risk of developing MS (6). This gene plays a significant role in the functions of the human immune system and variants of it are linked to shaping our body's autoimmune and inflammatory responses. One variant particularly associated with the onset of MS is called HLA-DRB1*15 and so far, research has found that vitamin D could potentially inhibit its influence on the immune system (7). Further evidence to underpin this link is needed but it could well provide us with more answers not only about the potential causes of MS, but also the part which vitamin D may play in this.

A possible link between vitamin D levels during pregnancy and MS risk has also been found. 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 the mother's pregnancy. One particular study showed that those born in the months April and May have an increased risk of developing MS, compared to those born in October and November (8). This is applicable to countries in northern latitudes, meaning those situated north of the equator, which experience less exposure to sunlight during the winter months. It follows that the same logic can be applied to people residing in countries further south of the equator, but in reverse.

There is conflicting evidence regarding the role vitamin D plays in the progression of MS for those who have received a diagnosis. For example, MS Brain Health has reported that two reviews published in 2018 found vitamin D levels had no significant effect on relapse occurrence, annual relapse rates and disability progression. Other studies have returned converse results. For example, a meta-analysis of 14 items of research concluded that there was a relationship between levels of vitamin D concentration and disability in MS – the lower the concentration of vitamin D in an individual, the higher the degree of disability (9).

To add further weight to the potential positive impact vitamin D may have in managing MS, a systematic review published in 2021 concluded that, when weighing up all of the available scientific evidence, moderate doses of vitamin D supplementation seem integral to the prevention and management of multiple sclerosis (10).

According to the National Institute for Health and Care Excellence (NICE) clinical guidelines for the management of MS in adults, vitamin D is not to be offered solely for the purpose of treating MS. Interestingly they do recommend that further research should be undertaken to ascertain whether or not vitamin D can slow down the progression of disability in MS (11).

Regardless, some neurologists will request that their patients have their levels of vitamin D tested at the point of MS diagnosis. They may also suggest supplementation depending on individual need. In a post published on The MS Blog, fifteen MS neurologists from around the world were asked a series of questions about vitamin D. Nearly all of them stated that they test their patient's vitamin D levels at diagnosis, supplement accordingly and then monitor periodically (12).

How do we get vitamin D?

Sunlight

Our body creates vitamin D naturally when our skin receives direct sunlight whilst outdoors, hence it is sometimes referred to as the 'sunshine vitamin'. The NHS suggest that people living in the UK should make enough vitamin D from exposure to the sun during the spring and summer months (1). This logic would apply to those who reside in other countries within the northern and southern hemispheres that experience similar seasonal patterns.

It is not fully known how long each individual person needs to spend in the sun to produce the amount of vitamin D that they need. This can vary as several factors can affect how vitamin D is made. Indeed, some people do not make enough vitamin D, no matter how long they are exposed to the sun's UVB rays, with the following being common examples

- Elderly people, who 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 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 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 up before going in the sun. This could be with clothing or creams containing a sun protection factor (SPF) which prevent the absorption of the sun's UVB rays. Short periods of UVB exposure are important to start building up sufficient vitamin D levels and for many, if cautiously managed, will not lead to skin damage. However, if the skin starts to turn red or burn, take care to cover up immediately to protect it from further damage.

For people with MS, it is important to be mindful that heat intolerance can exacerbate MS symptoms, such as cognitive ability, fatigue, mobility, and more. Some people who experience this problem more easily may find that they need to be more reliant on supplementing with vitamin D rather than spending time in the heat of the sun.

During months where the sunlight hours are reduced, and the sun's UVB rays are weaker, or if your body struggles to produce vitamin D even with sun exposure, additional support is required to prevent deficiency. Again, supplementation is the most effective solution.

Diet

Ensuring regular intake of foods containing Vitamin D provides a good way of bolstering levels of this nutrient. It can be found in a small number of foods, including oily fish such as salmon, mackerel, herring, and sardines, red meat, liver and egg yolks. Fortified foods such as breakfast cereals, fat spreads and non-dairy milk alternatives may also contain varying levels of vitamin D (1).

Supplements

The NHS suggest that everyone should consider using vitamin D supplements, particularly during the darker months (1). Dietary supplements of vitamin D are readily available and can be found in two different forms, these being vitamin D2 and vitamin D3. A recent systematic review and meta-analysis of twenty previous comparative studies found that that vitamin D3 is more effective than vitamin D2 at raising serum 25-hydroxyvitamin D levels in the blood (13). This is significant as levels of this serum's presence in the blood are used as a reliable indicator of vitamin D deficiency by clinicians.

More information

Our 'Diet and Supplements' Choices booklet offers further information about the many different diets that have been created to help people manage the impact of MS. Some of these include vitamin D supplementation. Visit www.ms-uk.org/vitamin-d-and-multiple-sclerosis-choices-booklet/

Vitamin D levels and dosage

Vitamin D levels

Your vitamin D levels are mostly measured in nanomoles per litre (nmol/L) of blood. According to NICE an individual is deemed vitamin D deficient if they have a serum 25-hydroxyvitamin D level under 25 nmol/L. They go on to advise that, particularly with respect to good bone health, serum levels of at least 50 nmol/L are sufficient for most people (14).

Regarding vitamin D blood serum levels in people with MS, there is no standardised approach. Many neurologists like their MS patients to be within the range of 50 and 200 nmol/L (12).

The Overcoming Multiple Sclerosis (OMS) programme, a holistic lifestyle approach that is designed to help people manage the impact of MS, recommends vitamin D serum levels of over 150 nmol/L (15).

You can ask your GP, MS nurse, or neurologist for a blood test to check your vitamin D levels. If they are low, you may be prescribed a supplement that will elevate them. Your blood should then be monitored periodically to ensure that levels are kept within a desired range.

Dosage for adults

As mentioned earlier in this booklet, during the darker months our bodies do not get sufficient exposure to the sun's UVB rays to convert into sufficient levels of vitamin D. We therefore need to bolster intake using a combination of diet and supplements.

To understand vitamin D and dosage levels, particularly regarding supplements, it is important to be aware of how these are measured. Amounts of vitamin D in supplements are usually expressed in international units (IU). You may also see vitamin D amounts shown as micrograms (mcg). For clarity, one mcg of vitamin D is the equivalent to 40 IU.

For the general adult population, the NHS recommends supplementing with a daily dose of 400 IU. This amount is suggested to be suitable during pregnancy and for mothers who are breastfeeding. They also suggest that taking a daily dose in excess of 4,000 IU could be harmful (1).

The recommended daily amount is in relation to supporting good general health and is not specific to people with MS. Some neurologists advise their MS patients to supplement their vitamin D intake by 2,000 IU to 5,000 IU daily, with regular monitoring

of blood serum levels dictating whether future amounts are decreased or increased (12). The OMS programme recommends supplementing via a daily dosage of 5,000 IU in summer and 10,000 IU during winter. Their guidance states that the most vitamin D an individual can take daily, without risk of serious side effects, is 10,000 IU per day (15).

Given the NHS guidance on maximum daily vitamin D intake, it is important that supplementing over the recommended amount is only conducted under the advice and supervision of healthcare professionals. This will help to prevent a potentially harmful build-up of vitamin D in the body that may lead to health issues such as hypercalcaemia, which occurs when the blood contains too much calcium. Hypercalcaemia can cause damage to organs such as the heart and kidneys and can weaken the bones (1).

Dosage for family members of those with MS

As we mentioned earlier in this booklet, studies have shown that low levels of vitamin D are linked to MS onset and could play a part in genetic susceptibility. So, it makes sense that people diagnosed with MS may wish to encourage their family members to supplement with vitamin D, not least as a potential preventative measure to diminish their risk of developing MS.

We have referred to the OMS programme previously in this booklet. Part of their guidance includes what they term as 'The Family Health pillar' which looks at ways which could potentially prevent the development of MS in blood relatives. One suggestion is that close relatives of people with MS supplement their diets daily with vitamin D, with adults taking 5,000 IU of vitamin D3 daily during darker months (16). They also state that in children dosage should be reduced and amended accordingly.

Dosage for children

The Department for Health and Social Care recommend that children up to one year old should be given a daily vitamin D supplement of between 340 to 400 IU. This can be adjusted for children who are formula-fed given it is already fortified with vitamin D (1). They continue to state that children between the ages of one to four years old should be given a daily supplement of 400 IU.

For reasons already given, some people with MS may wish to give their children higher doses of vitamin D supplements than those officially recommended. A conversation with your child's general practitioner (GP) is advisable prior to going ahead with larger dose supplementation.

The Great Ormond Street Hospital for Children (GOSH) has published guidance on vitamin D supplementation for children with a diagnosis of MS. They test a child's vitamin D levels upon diagnosis and advise all of their patients to supplement their levels with 1,000 IU per day (17).

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About MS-UK

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

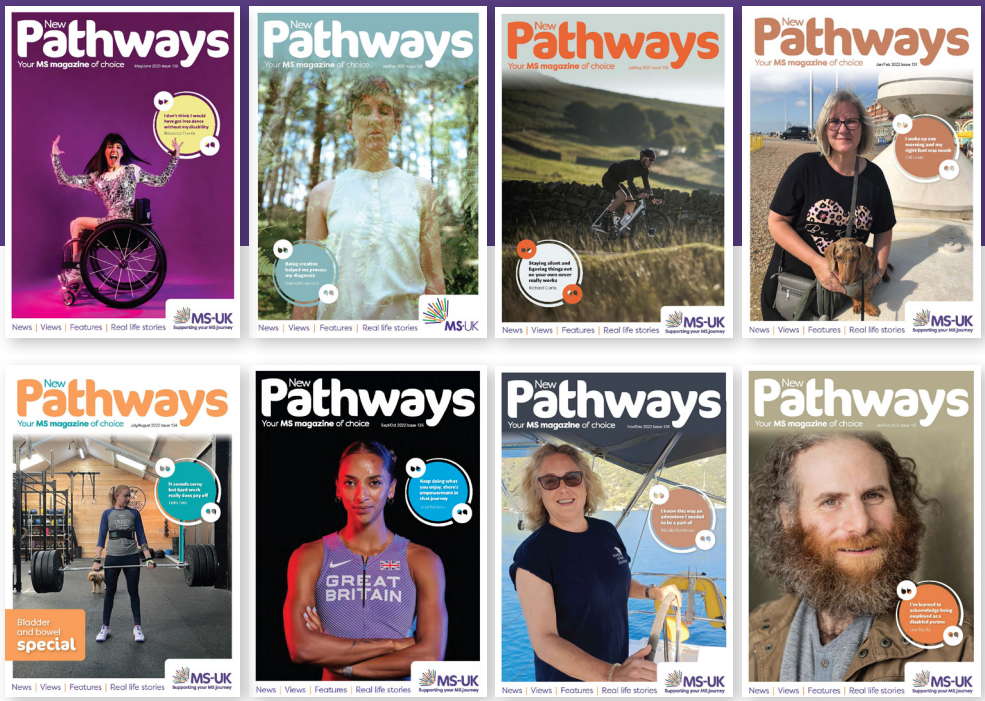
MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

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

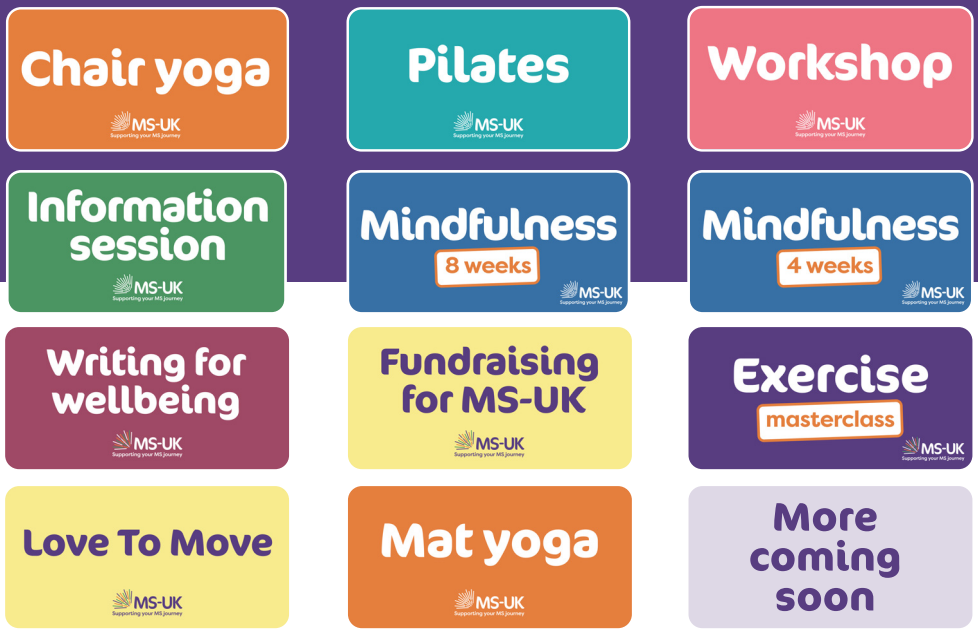
Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

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.



MS-UK's 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.

MS-UK 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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