Management File

by Dr Charles Shepherd, medical adviser to The ME Association

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Vitamin D deficiency and ME/CFS

INTRODUCTION TO 'THE SUNSHINE VITAMIN'

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 theoretical reasons why vitamin D could have a role 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 wide range of important functions – particularly involving bone, muscle, brain and immune system function.

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 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.
- Fresh meat.

But it's difficult to get enough vitamin D by 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.

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. 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.

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.

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 adequate regular exposure to natural sunlight.

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 indicating significant vitamin D deficiency. Concentrations up to about 40 nmol/l may be associated with adverse effects. The level that is required to maintain optimal bone health remains uncertain.

The blood level of phosphate and calcium may be reduced and alkaline phosphatase increased – these investigations form part of the 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 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.

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 (ie 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 D 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. But there is growing evidence to show that a daily supplement (eg calcium and ergocalciferol tablets) containing 800 iu (20 micrograms) of vitamin D is safe and free from side-effects.

RESEARCH INTO VITAMIN D

The ME Association believes that this is yet another area where good quality research is required. 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.

FURTHER INFORMATION

The Hammersmith Hospital Calcium and Bone Clinic has produced some useful guidance for general practitioners on the investigation of vitamin D deficiency. This is available on-line at: hammersmithendocrinology.co.uk/ and type 'Vitamin D deficiency' in the search box.

Medical information contained in this leafletis not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or healthcare professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor.