



Osteogenesis Imperfecta (OI) and vitamin D: information for families

Vitamin D is an essential nutrient needed for healthy bones, and to control the amount of calcium in our blood. Most people get little Vitamin D in their diet – it is found in oily fish, liver, eggs and dairy food. This information sheet from Great Ormond Street Hospital (GOSH) explains how to increase your child's level of vitamin D.

Sunshine is the main source of Vitamin D. However, Vitamin D can only be made in our skin by exposure to sunlight when the sun is high in the sky. Therefore, in most of the UK from November to February, and in Scotland from October to March, Vitamin D cannot be made from sunshine. (Royal College of Paediatrics and Child Health, 2013)

Low Vitamin D levels are common in young people in the UK. This can occur for a number of reasons including low levels of sunlight, darker skin colour, use of sunscreen or concealing clothing, obesity, malabsorption and poor diet, renal and liver disease and certain prescribed medications.

Osteogenesis Imperfecta (OI) is a defect where collagen (the protein that is responsible for bone structure) is missing, reduced or of low quality, so is not enough to support the minerals in the bone. This makes the bone weak, which in turn makes the bones easy to fracture. Vitamin D can strengthen your child's bone.

Vitamin D dosage is discussed in clinic in International Units. This usually ranges from 400IU to 1000IU depending on your child's condition. It will also be included in your child's clinic report.

Vitamin D is available as a tablets, syrup or spray as various brands (including own label brands).

Multivitamins, such as DaliVit® and Abidec®, contain Vitamin D as well as other vitamins and minerals. Please do not give multivitamins and as well as extra vitamin D supplements as the dose may be too high for your child.

You can buy Vitamin D tablets, syrup or spray over the counter in your local pharmacy without a prescription or in supermarkets or health food stores, as well as online. Whichever preparation you choose is up to you and which you think your child will take best.

- Tablets come in strengths of 200IU, 400IU, 600IU, 800IU or 1000 IU. They are usually smaller in size than paracetamol or ibuprofen tablets.
- Vitamin D syrups come in small volumes and is oil based often with fruit flavouring. It comes in 200IU, 400IU, 600IU, 800IU or 1000 IU strengths.
- Sprays are given once per day and most bottles contains 100 sprays. They can be lemon flavoured and in different strengths such as 1000IU or 3000IU.

If your child has any allergies or special requirements for medicines, please ask for advice before buying.

If your child is having bisphosphonate treatment, vitamin D is especially important. Before we can start these medications it is important we know your child's vitamin D level is above 50nmol/l. Blood samples will usually be taken either after your clinic appointment or if your child has a central venous access device, when this is flushed – usually on a monthly basis.

If your child's vitamin D level is too low (under 50nmol/l), we will ask your family doctor (GP) to prescribe some higher strength vitamin D that is only available on prescription.

Further information and support

At Great Ormond Street Hospital (GOSH), contact the OI Team via our Administration Coordinator on 020 7405 9200 ext 5293. If you have a clinical question, please contact our Clinical Nurse Specialist (CNS) for OI on 020 7405 9200 ext 5824.

There are four national services commissioned by NHS England for children with OI. GOSH is one of these and the others are Birmingham Children's Hospital, Bristol Children's Hospital and Sheffield Children's Hospital.

The Brittle Bone Society offers support and advice to parents of children with all types of OI. Telephone them on 01382 204 446 or visit their website at www.brittlebone.org