

# Vitamin D and xeroderma pigmentosum

This leaflet explains:

- what vitamin D is and what it does in the body
- how your vitamin D levels get tested and what you can do if they are too low.

If you have any further questions or concerns after reading this leaflet, please speak to one of the doctors or nurses caring for you.

## What is vitamin D?

Vitamin D absorbs and uses calcium within the body, and maintains healthy bones and teeth. It also helps the body fight infections and keeps normal muscle function.

A small amount of vitamin D comes from the foods we eat, but most of it is made in the skin through exposure to sunlight. People with xeroderma pigmentosum (XP) usually have low levels of vitamin D because they need to protect their skin from sunlight.

## How do I know if my vitamin D level is low?

Some people who have very low levels of vitamin D in their body complain of bone pains (often in the legs), and of muscle pain or weakness. However, most people with low levels of vitamin D do not feel any different.

When you come to the XP clinic we will ask you to have a blood test to check your vitamin D level. If it is low (below 50 nmol/L), we will ask your GP to prescribe a vitamin D medicine, which may also include some calcium.

## Why should I take vitamin D medicine?

It is very difficult to achieve normal levels of vitamin D through diet alone. The best way to do it is to take regular vitamin D medicine by mouth. This medicine is available in a liquid or spray form, or as tablets. If it is difficult for you to swallow tablets or you do not like the taste of the liquid or spray, please tell us. We can suggest a different form for you to try.

## Are there any side effects?

It is very rare to have any side effects from taking vitamin D medicine. If you experience nausea, vomiting or diarrhoea, it is important to contact your doctor. They can arrange to check the level of vitamin D in your blood in case it is too high. Everyone is different and may react differently to the medicine.

## Is there anything else I need to know?

Once you are taking vitamin D medicine, it is important to check your vitamin D level with regular blood tests (the first test after three months, and if it is normal, twice a year after that). We can check your vitamin D level when you come to the XP clinic, but you can also have this blood test at your GP surgery or local hospital. Please let us know if you have your level measured locally so we can keep our records up to date.

Please remember to tell the doctor who prescribes your vitamin D about any other medicines you are taking. When you start taking a new medicine, it is important that you check with your doctor whether it may interact with your vitamin D.

Most people with XP need to take vitamin D medicine long-term. Please don't stop taking vitamin D unless you are advised to do so by a healthcare professional.

**Remember to store medicines out of the reach of children.**

## How do I get a repeat prescription?

Your GP will be able to provide a repeat prescription.

### Contact us

If you have any questions or concerns about XP, please contact the XP nurse specialists on **020 7188 6351** or **020 7188 6339** (Monday to Friday, 9am to 5pm).

If you are calling out of hours, you can either leave a message on the answerphone with your contact details, or email children's XP nurse specialist at [sally.turner@gstt.nhs.uk](mailto:sally.turner@gstt.nhs.uk).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

## Useful sources of information

### XP Support Group

It offers advice and practical help to anyone affected by XP.

**t:** 01494 456192    **e:** [info@xpsupportgroup.org.uk](mailto:info@xpsupportgroup.org.uk)

**w:** [www.xpsupportgroup.org.uk](http://www.xpsupportgroup.org.uk)

### Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

### Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

**e:** 020 7188 8801 at St Thomas'    **t:** 020 7188 8803 at Guy's    **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

### NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

**Leaflet number: 3502/VER2**

Date published: July 2014

Review date: July 2017