Children's haematology

# Glucose-6-phosphate dehydrogenase (G6PD) deficiency

## Information for patients, relatives and carers

https://www.imperial.nhs.uk/childrens-haematology

## Introduction

This leaflet will help answer some of the questions you may have about G6PD deficiency. It is not meant to replace the conversation between you and your healthcare team, but will help you understand more about what you discussed together.

## What is G6PD?

G6PD is short for glucose-6-phosphate dehydrogenase. It is an **enzyme** (chemical) that exists in many cells in the body, protecting them from damage.

G6PD is important in red blood cells that carry oxygen to all parts of the body. When you're sick, take certain medicines or eat certain food, harmful chemicals can go into your body. G6PD protects cells from being damaged by these harmful chemicals, so that you don't become unwell. When you're G6PD deficient, your red blood cells don't have protection from these chemicals.

Although you might not have heard of it before, it is a very common condition in many parts of the world, particularly in people originating from around the Mediterranean, Africa, the Middle East, India, China and South East Asia.

## How did my child become G6PD deficient?

G6PD deficiency is passed on by a parent. They might have been completely healthy for most of their lives and not know they had it. It is usually passed on from the mother.

It is found in both males and females but usually affects men and boys more severely. Often when a mother passes it on to her son, she may never have had any symptoms.

G6PD deficiency can be diagnosed by a laboratory test. Sometimes people who have it can develop haemolytic anaemia. If this happens, your child's doctor will ask the laboratory to do a test so they can confirm they have G6PD deficiency.

## What is haemolytic anaemia?

Anaemia is a drop in the number of red blood cells that carry oxygen around the body. Your body is constantly making new red blood cells and each cell will usually stay in your body for 120 days.

Sometimes red blood cells are destroyed much earlier than this. This is called haemolysis. If the red cells are destroyed very quickly, your body can't make new red blood cells fast enough to keep up. When this happens, you don't have enough red blood cells and you become anaemic. This is called haemolytic anaemia.

When you have G6PD deficiency, haemolytic anaemia can be caused by drugs, certain foods and chemicals that do not usually cause any problems in other people. Getting an infection can also cause haemolytic anaemia. Knowing what to avoid can make episodes of haemolytic anaemia much less likely.

Not all people have deficiency of the same severity. People from around the Mediterranean with G6PD deficiency usually have quite severe deficiency. For people of African origin, including Afro-Caribbean people, G6PD deficiency usually isn't as severe. This means that episodes of haemolytic anaemia might be shorter. Which drugs you can take can depend on how severe your deficiency is.

## How do I know if my child has haemolytic anaemia?

Signs of haemolytic anaemia are:

- sudden loss of energy (or listlessness in a child)
- pale skin
- fast heart rate, breathlessness or dizziness
- dark urine (it may be the colour of Coca-Cola)
- yellowness of the skin or the whites of the eyes (called jaundice)

If this happens, it is important to go to your GP or to a hospital accident and emergency department quickly. The anaemia can be quite severe and your child might even need a blood transfusion.

## How can my child avoid having haemolytic anaemia?

Most episodes of haemolytic anaemia can be prevented if you follow this advice:

- do not eat broad beans, also known as fava beans (other types of beans are safe)
- do not dress in clothes that have been kept with mothballs (which contain naphthalene)
- do not take certain prescribed medication (more information in the next section). Occasionally, your doctor might have to give your child one of these medications, but the most important thing is to make sure your doctor and your pharmacist know that your child has G6PD.
- do not take herbal medicines as they haven't been tested for safe use with G6PD deficiency (this includes Chinese herbal medicine)

You can have vaccinations, and take paracetamol and ibuprofen.

## Which drugs should my child avoid?

Do not take these medicines for malaria:

- Chloroquine
- Fansidar
- Maloprim (contains Dapsone)
- Pamaquine
- Primaquine

Do not take these other medicines:

- Aspirin (large doses)
- Chloramphenicol
- Dapsone
- Nalidixic acid
- Nitrofurantoin
- Sulphonamides (some, e.g. Cotrimoxazole)
- Vitamin K
- Ciprofloxacin
- Moxifloxacin
- Levofloxacin
- Probenecid

If your doctor thinks your child might have G6PD deficiency, they might ask the laboratory to test their blood if they need to give them one of these drugs.

## Travelling advice

- If you are going to an area where there is malaria, get expert advice before you go. You can ask your GP or specialist travel clinics. If you go to a specialist travel clinic, take a copy of the clinic letter that shows that your child is G6PD deficient
- Remember that the same medications have many different names and the names can be different in different countries
- Be very careful buying medication abroad, only buy from pharmacies and ensure you check with pharmacists and tell them about your child's G6PD deficiency
- Take this information sheet with you if you are travelling

## Is haemolytic anaemia the only side effect of G6PD deficiency?

No. G6PD deficiency can also cause jaundice in newborn babies. Doctors looking after babies know about this. If your baby becomes jaundiced the doctor will make sure to get a test.

## Can I pass G6PD deficiency on to my children?

The shorter answer is:

- women usually don't have G6PD deficiency but pass G6PD deficiency onto half their sons if they are carriers
- women who are carriers of G6PD deficiency can pass on being a carrier to half of their daughters
- men can't pass on G6PD deficiency to their sons

The longer answer is to do with chromosomes and genes. Chromosomes are what make up our DNA. Genes are small parts of chromosomes. The gene that causes G6PD deficiency is on the X chromosome.

Usually only boys and men have G6PD deficiency. Boys and men only have one X chromosome so, if the G6PD gene is abnormal on that X chromosome, they will be G6PD deficient. They have another chromosome called a Y chromosome.

Girls and women have two X chromosomes. Usually, they don't get G6PD deficiency because they have only one abnormal gene on one X chromosome and the other one is normal. A woman who has one abnormal gene is called a carrier.

A woman who is a carrier will pass the G6PD deficiency gene on to half of her sons, which means they will inherit G6PD deficiency. The other half will have normal genes and won't have

G6PD deficiency. She will also pass the abnormal X chromosome on to half of her daughters, who will then be carriers.

In parts of the world where G6PD deficiency is common, girls and women can inherit two X chromosomes with abnormal G6PD genes and can have G6PD deficiency. If you would like to talk about the inheritance of G6PD deficiency, tell your doctor you want to see a haematologist (a doctor who specialises in blood disorders).

If you are the mother of a son with G6PD deficiency that means that you are a carrier. If you are pregnant again, you might want to avoid broad beans and the drugs listed on page two late in pregnancy and when you are breastfeeding. They won't hurt you but if your baby is a boy they might cause him jaundice or haemolytic anaemia. If you have a baby boy, avoid clothes that have been in mothballs until he has been tested.

## Who can I contact for more information?

**G6PD Deficiency Association**

Website: https://www.g6pd.org/

## How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

## Alternative formats

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## Wi-fi

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