Hyperphosphataemia in chronic kidney disease

Information for the public
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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about hyperphosphataemia in chronic kidney disease (CKD) that is set out in NICE clinical guideline 157.

All of the treatment and care that NICE recommends is in line with the NHS Constitution (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961). NICE has also produced advice on improving the experience of care for adults using the NHS. For more information, see 'About care in the NHS' on our website (www.nice.org.uk/nhscare).

Does this information apply to me?

Yes, if you are a child, young person or adult with advanced chronic kidney disease (referred to as stage 4 or 5 CKD) whether or not you are on dialysis, because you may be at risk of hyperphosphataemia (high phosphate levels in the blood).

It does not apply if you have early chronic kidney disease (referred to as stage 1, 2 or 3 CKD).
Hyperphosphataemia in chronic kidney disease (CKD)

Chronic kidney disease

CKD is divided into 5 stages ranging from the mildest form (stage 1) to the most severe (stage 5). If you have stage 4 or 5 CKD, it means that your kidneys are not working well and they have lost their ability to filter the blood properly. Stage 5 CKD is sometimes called established renal failure, end-stage renal disease or chronic renal failure. Some people with stage 5 CKD may be on dialysis, on the waiting list for a kidney transplant, or receiving conservative care (this means they have chosen not to go on dialysis but are still having treatment).

What is phosphate?

Phosphate is a mineral in the blood that gets into our bodies through food and drink. The kidneys control the amount of phosphate in the blood and pass excess phosphate out of the body in the urine.

Hyperphosphataemia

People with stage 4 or 5 CKD often have high levels of phosphate in their blood; this is called hyperphosphataemia. When the kidneys are not working as well as they should, phosphate is not passed out of the body in the urine. Instead, it builds up in the blood and hyperphosphataemia develops.

How do I know I have hyperphosphataemia?

Hyperphosphataemia is usually diagnosed by blood tests, but it can cause symptoms such as itching, most commonly around the torso and back, red eyes, joint pain and, in the long term, it can damage your bones. It can also affect your blood vessels and heart, leading to 'furring' up of the arteries.

Your healthcare team

The various types of treatment described may be provided by a range of healthcare professionals who specialise in different treatments. These could include doctors, specialist nurses and dietitians who specialise in kidney problems. The medical name for kidney problems is 'renal' so, for example, a dietitian who specialises in kidney problems is a renal dietitian.
A member of your healthcare team should discuss hyperphosphataemia with you and explain the tests and treatments for it in detail. You should have the opportunity to ask any questions you have – there is a list of questions you might like to ask to help you with this.

Some treatments described may not be suitable for you, depending on your exact circumstances. If you think that your treatment or care does not match this advice, talk to your healthcare team.

**Diet**

**Changing your diet**

A change of diet is the first step to take if you have hyperphosphataemia or are at risk of developing it. Reducing the amount of phosphate-rich foods and drinks in the diet can help to control the level of phosphate in the blood.

A renal dietitian, supported by a team of healthcare professionals, should look at your diet and give information and advice, relevant to your own needs and preferences, about how to manage the amount of phosphate in your diet. The advice should include how to control the amount of phosphate-rich foods and drinks you consume, while still making sure you get all the nutrition you need.

**Nutritional supplements**

If a child or young person needs a nutritional supplement to make sure they are getting enough protein, the dietitian should offer a supplement with a lower phosphate content and take into account what the child or young person prefers, as well as their nutritional needs.

**Phosphate binder treatment**

Changing your diet may not be enough to lower the levels of phosphate in your blood. So, as well as making changes to your diet, you should be offered a drug called a phosphate binder. Phosphate binders stop phosphates in food and drink from being digested and absorbed into the bloodstream. You need to take phosphate binders with food for them to work properly.

Phosphate binders can be calcium-based (which are preferred for children and young people, who need extra calcium for growing bones) or non-calcium-based. They can be taken separately or in combination and your healthcare team will take into account which type you prefer, how easy they are to take, and other factors when deciding which is the most suitable for you.
If a combination of phosphate binders is used, your healthcare team will adjust the dose to control the level of phosphate in your blood, while also checking the effect that any calcium-based binders are having on your calcium levels.

**Phosphate binders for children and young people**

For children and young people, a calcium-based phosphate binder is preferred (as well as following a low-phosphate diet). This is because calcium is important for growing bones. If the levels of calcium in the blood are getting too high, the healthcare professional should discuss combining the calcium-based binder with a non-calcium-based binder called sevelamer hydrochloride. Before changing phosphate binders, they should take into account any other reason for rising blood calcium levels – for example, if the child or young person is taking vitamin D supplements or getting too much calcium from their dialysis.

At the time of publication (March 2013), although sevelamer hydrochloride is only licensed for use in adults and not in children, doctors often prescribe it for children. The healthcare professional should explain the treatment and discuss the possible benefits and harms with the patient (or their parent/carer) so they have enough information to decide whether or not to have the treatment. This is called giving informed consent. You can find more information about licensing medicines from [NHS Choices](http://www.nhs Choices).

**If the phosphate levels are still too high**

Sometimes, phosphate levels are still too high even after the child or young person has taken the phosphate binders as prescribed. If this is the case, and if their blood calcium levels are also above the normal limit for their age, then the healthcare professional may discuss either combining the calcium-based phosphate binder with, or changing to, sevelamer hydrochloride.

**Phosphate binders for adults**

For adults, your healthcare professional should offer a phosphate binder called calcium acetate first. If you can't take calcium acetate for any reason, they should talk to you about taking a different binder called calcium carbonate.

**If you have stage 4 or 5 CKD (and you are not on dialysis)**

If you have stage 4 or 5 CKD, you are not on dialysis and you are taking a calcium-based binder such as calcium acetate or calcium carbonate but you are having problems taking the calcium-based
binders, your healthcare team should talk to you about changing to a non-calcium-based binder. If your calcium levels are too high (and other possible causes of raised calcium have been explored), or if blood tests show that you have low levels of a hormone called parathyroid hormone, your healthcare team should talk to you about taking a non-calcium-based binder, either instead of, or as well as, the calcium-based binder that you are already taking.

If you have stage 5 CKD (and are on dialysis)

If you have stage 5 CKD, you are on dialysis and your phosphate levels are still too high, even though you are taking the maximum dose of calcium-based binders exactly as prescribed, your healthcare professional should talk to you about taking a non-calcium-based binder, either instead of, or as well as, the calcium-based binder that you are already taking.

If you are taking a calcium-based binder and your phosphate levels are under control, but blood tests show that either the level of calcium in your blood is too high, or the level of parathyroid hormone in your blood is too low, your healthcare professional should talk to you about taking either sevelamer hydrochloride or lanthanum carbonate either as well as, or instead of, the calcium-based binder that you are already taking.

Reviewing your treatment

During your follow-up appointments with your healthcare team, your phosphate control should be assessed. Your healthcare team will look at how well the changes to your diet and your medication are working, and also take into account any changes that could affect your phosphate levels, such as if you start on dialysis or start taking vitamin D supplements.

Questions to ask about hyperphosphataemia in chronic kidney disease

These questions may help you discuss your condition or the treatments you have been offered with your healthcare team.

About your condition

- Can you tell me more about hyperphosphataemia? What are the risks?
- Why is it important to me?
- Are there any support organisations in my local area?
• Can you provide any information for me and my family/carers?

**Treatments**

• What food and drinks are high in phosphate? Is there an information leaflet I can have?

• Can you tell me why you have decided to offer this particular type of treatment?

• Why is dialysis sometimes not enough to remove all the phosphate?

• What are the pros and cons of this treatment? What are the risks?

• What will the treatment involve and what will it do for me?

• How long will the treatment last?

• How long will it take to have an effect?

• Is there some other information (like a leaflet, DVD or a website I can go to) about the treatment that I can have? Can I have a summary of the treatment plan?

• Are there any long-term effects of taking this treatment?

**For family members, friends or carers**

• What can I/we do to help and support the person with hyperphosphataemia?

• Can we have a diet sheet?

• Is there any additional support that I/we as carer(s) might benefit from or be entitled to?

**Sources of advice and support**

• Kidney Research UK, 0845 300 1499
  [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

• National Kidney Federation, 0845 601 02 09
  [www.kidney.org.uk](http://www.kidney.org.uk)

• Polycystic Kidney Disease Charity, 0300 111 1234
  [www.pkdccharity.org.uk](http://www.pkdccharity.org.uk)

• Welsh Kidney Patients’ Association
  [www.wkpa.org.uk](http://www.wkpa.org.uk)
You can also go to NHS Choices for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

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