

Chronic Kidney Disease (CKD) – an introduction

Overview

This infoKID topic is for parents and carers about children's kidney conditions.

This leaflet has the overview only.

Go to www.infoKID.org.uk to find out more about this topic or other topics

Chronic kidney disease (CKD) is a lifelong condition. The kidneys gradually stop working as well as they should. This usually happens over many years.

There are five stages of CKD – the final stage is kidney failure, when the kidneys can no longer support the body. However, some people with CKD do not go through all stages.

CKD is quite common in older adults with other illnesses, but very rare in children. It is caused by different conditions that affect the kidneys. Some of these are present at birth, and others start later in childhood.

A team of healthcare professionals who specialise in treating and caring for babies, children and young people with kidney conditions will support you and your family. They will make sure your child gets the right tests and treatments at each stage of the disease.

→ CKD is a complicated disease. You and your child will learn more over time about how to help manage the condition, and what to expect. While it is not possible to recover from CKD, specialist care will help your child live as full and healthy a life as possible.

This topic introduces CKD. For more information about what happens in later stages of CKD, go to the infoKID topic **Chronic kidney disease – stages 3b to 5**.



About the urinary system

The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

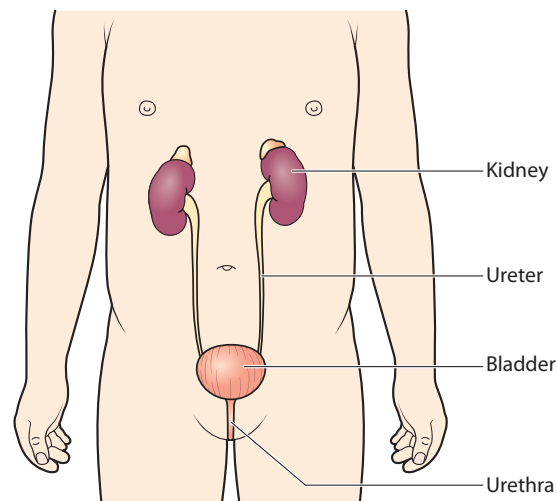
The **kidneys** are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

The two **ureters** are long tubes that carry urine from the kidneys to the bladder.

The **bladder** is a bag that stores urine until we are ready to urinate (have a wee). It sits low down in the pelvis.

The **urethra** is a tube that carries urine from the bladder to the outside of the body.

» **More about the urinary system and kidneys**



Stages of chronic kidney disease

The word **chronic** in CKD means that the kidney disease lasts a long time and does not disappear completely. The term **kidney function** is used to describe how well the kidneys work – especially how they clean blood and make urine.

CKD used to be called **chronic renal failure (CRF)**. This is because, in the final stage of CKD, the kidneys have failed.

Stages of CKD

There are five stages of CKD. Stage 3 is often split into two – stages 3a and 3b. However, many children with CKD do *not* progress through all stages. Some children progress through all stages, but how quickly this happens is different for each child.

- **Mild or early CKD** – stages 1, 2 and 3a. At first, the kidney function is normal, but there are other signs of kidney disease – one or both kidneys may be small or different than normal, or the kidneys may leak protein in the urine (wee). The kidney function may slowly get worse if both kidneys are affected, though there are usually no symptoms.
- **Late CKD** – stages 3b, 4 and 5. The kidney function continues to get worse, and children may start having symptoms. In stage 5, the kidneys can no longer support the body and have failed. This stage is sometimes called **end-stage renal failure (ESRF)** or **established renal failure (ERF)**. See **Chronic kidney disease – stages 3b–5**.

Symptoms and complications

Symptoms in stages 1 to 3a

In the early stages of CKD, there are generally no **symptoms**. If your child has CKD caused by an underlying health condition, he or she may, however, have symptoms from that condition. Many of these conditions are described in detail on the infoKID website.

Symptoms in stages 3b to 5

In later stages of CKD, there are more symptoms. Your child's healthcare team will speak with you about treatments to help these symptoms. These include:

- changes in urinating (weeing) – some children pass a large amount of urine, and need to drink lots of water; others pass only a small amount of urine
- too much water in body (**fluid overload**)
- swelling in different parts of your child's body (**oedema**)
- high blood pressure (**hypertension**)
- poor appetite, feeling sick (nausea) or being sick (vomiting)
- low energy levels and feeling tired

- bones are less strong and healthy (**renal bone disease**)
- problems in the blood that may cause children to feel weak and tired, and look paler than usual (**anaemia**).

Complications in stages 3b to 5

In later stages, children may be at risk of complications – rare health problems associated with CKD.

A serious complication is **cardiovascular disease**, diseases of the heart and circulation (blood going round the body). In severe cases, children are at risk of **cardiac arrest**, a life-threatening emergency in which the heart suddenly stops pumping blood. Other complications include more severe problems in the bones or muscle cramps.

Your doctor will speak with you about how to reduce the risk of these complications. If your child follows the treatment plan, including changes to his or her diet and medicines, he or she is less likely to have complications.

Causes

In CKD, the kidneys may gradually stop working as well as they should. This means they are less able to clean the blood, so waste products and extra water and salts can build up in the blood. They are also less able to do other jobs of the kidneys as well – such as controlling blood pressure, keeping bones healthy and strong, and making **red blood cells**, which carry oxygen round the body.

CKD is very rare in children. It is caused by a number of conditions that affect the kidneys. Some of these are present at birth, and others start later in childhood. Not all kidney conditions cause CKD, and not all children with CKD progress to later stages.

Diagnosis and tests

Stage 1 CKD is **diagnosed** (identified) when a child has a **chronic** kidney condition or anomaly. If your child has certain symptoms or signs, or if your baby had problems before birth, your doctor will speak with you about the symptoms, examine your child and arrange some tests. Your child will usually need tests to diagnose the specific kidney condition that is causing CKD.

→ **Your child will need to return to the clinic or hospital for follow-up appointments. It is important to go to these even if your child feels well. If you cannot go to an appointment, please speak with your child's healthcare team to arrange another date.**

These will measure the kidney function – to find out the stage of CKD – and check for any complications. They may include:

- measuring your child's height and weight – to find out whether he or she is growing well
- measuring your child's **blood pressure** – to check for hypertension (high blood pressure)

- **blood tests** – to measure your child's kidney function to find out the stage of CKD and check for other substances in his or her blood, such as minerals, sugar and fats (including cholesterol)
- **urine tests** – to check for blood, protein and other substances in his or her urine
- **imaging tests** (scans) – these use special equipment to get images (pictures) of the inside of your child's body.

Treatment

The treatment depends on the stage and the symptoms that your child has.

Mild CKD: stages 1 to 3a

In early stages of CKD, your child will probably be monitored by a **paediatrician**, a doctor who treats babies, children and young people with different conditions, who may be based at your local hospital or in another healthcare setting. Your child may also have some appointments with your family doctor, or **general practitioner (GP)**.

You will be given advice on how your child can live healthily to protect his or her kidneys. Some children need to take medicines to help control their blood pressure.

Late CKD: stages 3b to 5

Those children who reach later stages of CKD need more specialist treatment to manage the symptoms. At stage 5, when the kidneys are in failure, your child will need specialist treatment, including dialysis and/or a kidney transplant.

These children are normally referred to a **paediatric renal unit**, a specialised unit for babies, children and young people with a kidney condition, which may be in a different hospital. A team of healthcare professionals supports these children and their families throughout these stages.

Questions to ask the doctor or nurse

- What treatment will my child need, and when?
- How will the treatment help my child?
- How can I help my child prepare for tests and treatments?
- How will you know whether my child is likely to go into later stages of CKD?
- How will I know if we need to go back to the hospital or see the doctor?

Supporting your child

This can be a difficult and stressful experience for your child and the whole family, including other children. You and your child will learn more over time about how to help manage and live with CKD.

Your child's healthcare team is there to help you. They can provide support with your child's education, accessing financial benefits and planning holidays around tests and treatments. There may also be help available from a team social worker and/or psychologist.

Speaking with other families of children with CKD can also be a huge support.

→ If you have any concerns or need additional support, speak with your doctor or nurse.

Medicines at home

Speak with your doctor, nurse or pharmacist before giving your child medicines, including herbal or complementary medicines. Some medicines called **non-steroidal anti-inflammatory drugs (NSAIDs)**, such as ibuprofen (e.g. Brufen, Motrin or Nurofen) and **diclofenac**, can further damage kidneys.

Transition to adult services

When your child reaches adolescence, he or she will prepare to transfer from paediatric services (for children) to adult services. The timing is different for each person – though many will start being looked after by an adult nephrology unit by the time they are over 18 years old.

Many units have a **transition programme**, which starts some years before the transfer, to help adolescents to prepare.

Impact on adult life

Your child will need to take care of his or her health throughout life. As an adult, he or she will be supported by a new team. He or she should be encouraged to live a full and fulfilling life and go on to further education, work and having a family.

» Read more about CKD and stages of CKD on www.infoKID.org.uk

Your notes and contact information

www.infoKID.org.uk



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