Chronic Kidney Disease (CKD) – an introduction

infoKID
Information for parents and carers about children's kidney conditions

This infoKID topic is for parents and carers about children's kidney conditions. Visit www.infoKID.org.uk to find more topics about conditions, tests & diagnosis, treatments and supporting information.

Each topic starts with an overview followed by several sections with more information.

» **Links to sections** in topic | **Other topics** available on website

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.

Overview

About the urinary system

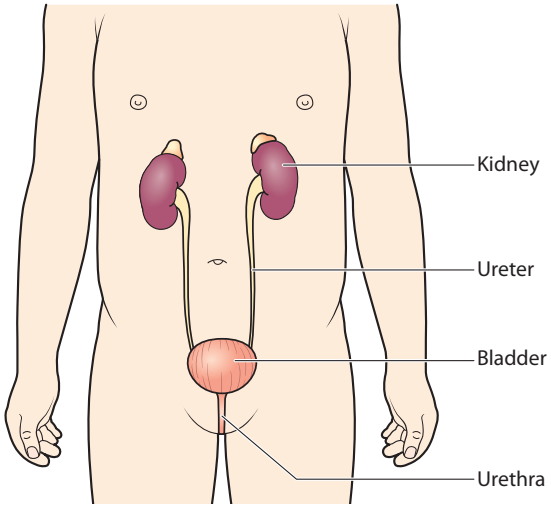
The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

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**.

» More about stages of CKD

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.

» More about symptoms and 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.

» More about causes

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.

» More information about tests and diagnosis

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.

» More information about treatment

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.

Stages

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. Other children progress through all stages, but how quickly this happens is different for each child.

Stages 1 and 2 (mild CKD)

In stage 1, 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 into the urine (wee). In stage 2, the kidney function slowly gets worse, though there are usually no symptoms.

Children need to go to follow-up appointments to find out whether their kidney function changes. They may need to take medicines or make small changes to their diet to manage any symptoms and, sometimes, to help prevent or slow down the progression to later stages of CKD.

Stage 3a and 3b (moderate CKD)

In stage 3a, the kidney function gets a little worse. In stage 3b, children may have more symptoms that are associated with the worsening kidney function.

Children need to go to follow-up appointments for tests. They often need to change the types or doses (amounts) of medicines as they progress through these stages. They may need to eat less of some types of foods, and sometimes drink fewer fluids, including water and juice.

Stage 4 (severe CKD)

In stage 4, the kidney function is severely reduced. Children continue to receive treatment for symptoms as needed.

Stage 5 (kidney failure)

In stage 5, the kidney function is *very* low, and the kidneys can no longer support the body – this is called **kidney failure**. This stage is sometimes called **end-stage renal failure** (**ESRF**) or **established renal failure** (**ERF**). It usually takes years for a child with CKD to reach stage 5. However, this varies among children. Stage 5 occasionally happens when a child is young, but is more likely to occur later in life, especially during puberty when children's bodies grow quickly, or in adulthood.

Children with stage 3b to 5 CKD need specialist treatment. Many children need **dialysis**, which uses special equipment to remove waste products and extra water from their body. The best treatment is a **kidney transplant**, in which a healthy kidney from another person is transplanted into a patient's body. After a successful kidney transplant, children can live full and healthy lives, but will need to take medicines to look after the new kidney.

Summary

Table 1: Summary of the stages of CKD

Stage	Kidney function	What this means
1	Normal	Normally no symptoms
2	Mildly reduced	Normally no symptoms
3a	Moderately reduced	Normally no symptoms
3b	Moderately reduced	Children may start to have symptoms of CKD
4	Severely reduced	Many children have more symptoms of CKD Start to plan for treatment options for next stage
5	Very severely reduced and cannot support the body	This is also called **end-stage renal failure** (**ESRF**) or **established renal failure (ERF)** Children are started on treatment options, including **dialysis** and **kidney transplantation**

Symptoms and complications

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. Other children progress through all stages, but how quickly this happens is different for each child.

Symptoms in stages 1 to 3a

In early stages of CKD, there are generally no symptoms. Most symptoms that are associated with worsening kidney function start in later stages.

Your child may have symptoms associated with the underlying health condition that is causing the CKD. Many of these conditions are described in detail on the infoKID website.

» Kidney conditions

Symptoms in stages 3b to 5

In later stages of CKD, many children start to develop symptoms. Your child's healthcare team will speak with you about treatments to help these symptoms.

Changes in urinating (weeing)

Some children with CKD are unable to make concentrated urine (wee). This means they pass a large amount of weak urine. They often need to drink lots of water to make up for the water they are losing in urine.

Other children with CKD are unable to make much urine. This means they pass only a small amount of urine.

Fluid overload

If the kidneys are unable to make much urine, water and salts may build up in your child's body – this is called **fluid overload**. This may cause swelling in his or her body (**oedema**). Medicines may be used to reduce the swelling.

High blood pressure

The kidneys become less able to control blood pressure, which may lead to high blood pressure (**hypertension**). Eating a no-added salt diet or taking medicines may help control blood pressure.

Poor nutrition and growth, and low energy

Children may develop a poor appetite, and not be able to eat as much. They may also feel sick (nausea) or be sick (vomit) because of the effects of CKD and/or the medicines they need to take. They may also feel more tired than usual and have low levels of energy.

Feeding devices may be used to help make sure children get all of the nutrients they need to grow.

Renal bone disease

The kidneys are less able to control the levels of calcium and phosphate and to activate vitamin D – these are all needed to keep bones healthy. Children may develop **renal bone disease** (**renal osteodystrophy**) – the bones become less strong, and may not grow normally. Some children have no symptoms, but some have pain in their bones or joints, and are at risk of bone fracture.

This is a very rare complication, and does not normally happen if your child follows medical and dietary advice.

Anaemia

Children may develop **anaemia** – a condition in which the blood has fewer **red blood cells** or less haemoglobin, a substance that is in red blood cells. Because red blood cells and haemoglobin carry oxygen around the body, children often feel weak and tired, and may look paler than usual.

Changes in amounts of electrolytes

Electrolytes are important chemicals in the body, which are also found in foods. We need the right balance of these to stay healthy. The kidneys help control the amounts of electrolytes. They include the following:

- **sodium** – helps balance the amount of water in the body
- **potassium** – is needed for the muscles, including the heart muscle, to work properly
- **bicarbonate** – balances the amount of acid in our body, or the **pH balance** (also called the **acid–base balance**)
- **phosphate** – helps keep bones, teeth and muscles healthy
- **calcium** – is important to keep bones and teeth healthy, helps blood to clot and also helps the muscles, including the heart muscle, to work properly.

» Chronic kidney disease – stages 3b to 5

Complications in stages 3b to 5

In later stages, children may be at risk of **complications** – other health problems associated with CKD. Although these are very rare, it is important to be aware of them.

➔ **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.**

Diseases of the heart and circulation

There is a risk of developing **cardiovascular disease** (**CVD**), a group of diseases of the heart and circulation (blood going round the body) – especially in adulthood. In children with CKD, this may be associated with:

- high blood pressure (**hypertension**) – this can affect the heart, as well as speeding up the loss of kidney function

- an imbalance (wrong amounts) of calcium and phosphate – after many years, this can cause the blood vessels to get stiff and develop problems with the blood circulation.

Potassium levels

Many children need to follow a diet with a low amount of potassium. If there is too much potassium in the blood, this is called **hyperkalaemia**.

In serious cases, hyperkalaemia can affect the way the heart beats. If this is severe, it can cause a **cardiac arrest**, a life-threatening emergency in which the heart suddenly stops pumping blood.

Calcium and phosphate levels

Many children need to follow a diet with a low amount of phosphate and take medicines that stop phosphate from working. If there is too much phosphate in the blood, this is called **hyperphosphataemia**.

This can lead to muscle cramps, numbness around the mouth or a tingling feeling. In serious cases it can cause problems in the bones (**renal bone disease**). This may include **rickets** (the bones become painful, soft and weak) and deformities such as bowed legs or a curved spine.

Hyperphosphataemia can also lead to imbalance of calcium in the blood. Calcium can get trapped in the walls of blood vessels and cause the blood vessels to get stiff, which leads to cardiovascular disease.

» Chronic kidney disease – stages 3b to 5

Causes (of sypmtoms)

What healthy kidneys do

To understand what happens in CKD, it is helpful to know what healthy kidneys do. They clean blood – waste products and extra water and salt are removed from the body in urine. They also make hormones, chemicals that are carried in the blood to send messages to other parts of the body, which help with other body functions.

This allows the kidneys to:

- remove waste products that are no longer needed or that may be harmful
- balance the levels of water, salt and minerals, which are needed for good health
- ensure the **pH balance** (or **acid–base balance**) stays the same
- control **blood pressure**, the force that helps blood flow round the body
- help keep bones and teeth healthy
- help make **red blood cells**, living parts of blood that carry oxygen round the body.

Remove waste and control the amount of water and chemicals

Kidneys remove waste products and some water and chemicals from the blood into urine (wee). This allows the body to have the right balance of water, acid and important minerals, including sodium (salt), potassium, calcium and phosphate. These minerals are in the foods that we eat.

The kidneys also make sure the body keeps blood cells and proteins in the blood.

» Read more about how kidneys make urine on the next page

When kidneys are not working properly, they are less able to make the correct amount of urine. This can lead to one of two situations.

- Some children with CKD are unable to make concentrated urine. This means they pass a large amount of weak urine (almost all water with little other substances, such as wastes and salts). They often need to drink *more* water than usual to make up for the water they are losing in their urine.
- Other children with CKD are unable to make much urine at all. This means they pass only a small amount of urine, which may be very concentrated (less water with lots of other substances). They often need to drink *less* water than usual, to avoid water building up in their body (**fluid overload**).

In either case, the kidneys are less able to remove the right amount of some important chemicals. These include sodium (salt), phosphate and potassium. Your child may need to change his or her diet and/or take some supplements to help get the right balance of these chemicals.

Control blood pressure

Blood pressure is the force that helps blood flow round the body. Kidneys regulate (control) blood pressure in two ways:

- controlling the amount of salt that is in the blood, by removing some of it in urine
- making a hormone called **renin**, which affects how much of a chemical called **angiotensin II** is made, which can make blood vessels narrower and increase blood pressure.

When kidneys are not working properly, they are less able to regulate blood pressure. At later stages of CKD, children may have high blood pressure (**hypertension**). Children may need to eat foods with less salt and take medicines to help control their blood pressure.

» More about blood pressure

Keep bones and teeth healthy

Vitamin D, which we get from sunlight on the skin and from some foods (such as oily fish, eggs and breakfast cereal with added vitamin D), helps keep bones and teeth strong and healthy. The kidneys turn the vitamin D from sunlight and food into an active form that the body can use.

When kidneys are not working properly, there is less active vitamin D and too much of the mineral phosphate. The bones become less strong, and children may feel pain in their bones or joints – this is called **renal bone disease** (**renal osteodystrophy**).

Help produce red blood cells

Red blood cells are one type of living cell in the blood, which carry oxygen round the body. The body needs to keep making new red blood cells because they die after some time. Kidneys make a chemical called **erythropoietin** which helps make new red blood cells.

When kidneys are not working properly, the body may not have enough new red blood cells. This can lead to a condition called **anaemia** – children may feel tired and weak, and look paler than usual. Treatment includes medicines and blood transfusions.

Causes of CKD

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

Your child may need further tests to find out what has caused CKD. Your doctor will give you more information.

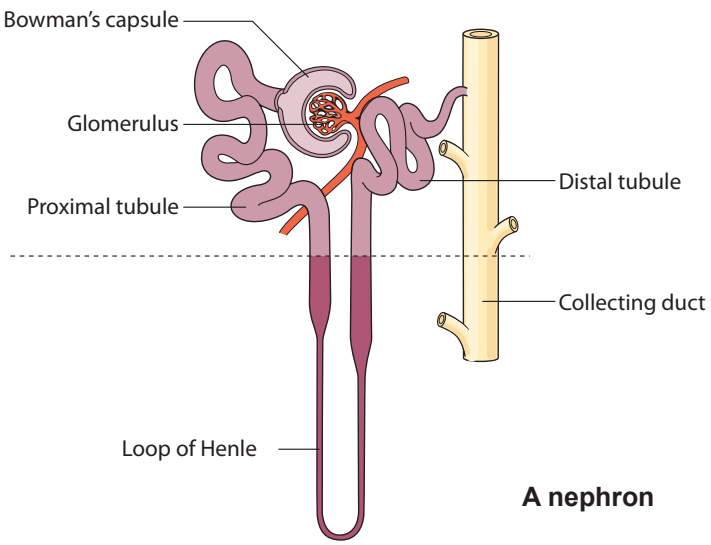
➔ **Only some kidney conditions cause CKD, and only some children with CKD progress to later stages.**

Causes: Read more about how the kidney makes urine

How the kidney works

Inside each kidney, there are about one million **nephrons**. These tiny units make urine by removing some water, chemicals and waste products from the blood. The urine is collected in the kidney before it leaves through the ureters into the bladder. Each nephron is made up of a **glomerulus** (when we talk about more than one glomerulus, we say glomeruli), and a **renal tubule**.

- Each glomerulus acts like a sieve, helping to remove extra water and waste from the body, and holding on to blood cells and protein, which the body needs.
- Blood flows into the kidneys and to each glomerulus.
- Most of the water and some other substances in the blood pass through the glomeruli.
- This liquid flows into the renal tubule. Most of this liquid moves back into the bloodstream. The rest of it becomes urine.
- The urine leaves the kidney by the ureters and goes into the bladder, where it is stored until we are ready to go to the toilet.



A nephron

» More about what the kidney does

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Tests and diagnosis

Stage 1 CKD is diagnosed (identified) when a child has a chronic kidney condition or anomaly (that lasts a long time). If your child has certain symptoms or signs, or if your baby had problems before birth, during pregnancy, your doctor will speak with you about the symptoms, examine your child and arrange some tests.

➔ **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.**

Glomerular filtration rate and stages

Your doctor can measure your child's kidney function (how well his or her kidneys are working) by measuring the **glomerular filtration rate** (**GFR**). This helps to work out the stage of CKD.

Inside the kidneys are many tiny filters called **glomeruli**, which help clean blood. The GFR is the volume of blood that filters through the glomeruli. If the GFR is lower than normal, less blood is passing through the glomeruli. The kidneys are not working as well as normal.

Measurements

The GFR measures the volume in millilitres (mL) that the kidneys filter each minute (min). This is adjusted for your child against a standard adult body size, which has a surface area of 1.73 metres squared (m2).

- The GFR for kidneys that are working at 100% (healthy kidneys) is 90 mL/min/1.73m2 or higher.
- The GFR for kidneys that are working at 50% (half as well as healthy kidneys) is 45 mL/min/1.73m2.

Stages

Table 2 below shows the stages of CKD with the GFR.

How GFR is measured

The GFR is measured by finding out how quickly the kidneys remove a substance from the blood into urine. There are two main methods of measuring GFR in children. Both of these use needles – a special gel or cream can be used to help your child stop feeling any pain.

- Blood test – this finds out the **estimated glomerular filtration rate** (**eGFR**). A small amount of blood is taken from a vein, with a needle and syringe. The amount of a waste product called **creatinine** is measured and used to calculate the eGFR. This is not an accurate measurement, but it is very close and is good enough for many children.
- **Radioactive tracer** – this is a more accurate measurement of the GFR, and is needed in some children. A small amount of a chemical that gives out **radiation** (a form of energy) is injected into a vein in your child's arm. Several blood samples are taken over a period of time. This finds out how quickly your child's kidneys filter the chemical out of the blood.

» More about these tests to measure GFR in Blood tests

Blood tests

Other **blood tests** may be used to check for other substances in the blood. These include:

- **electrolytes** – important chemicals in the body that are also found in foods
- **urea** and **creatinine** – waste products made by the body
- **full blood count** – to count the number of types of blood cells, and **iron** and some **vitamins**, to check for a problem in the blood called **anaemia**
- protein levels
- **parathyroid hormone** (**PTH**) and other hormones – to check for problems with bone development and growth
- sugars
- fats (including cholesterol).

Table 2: Summary of GFR against the stages of CKD

Stage	GFR	Kidney function	What this means
1	90 or higher	Normal	Normally no symptoms
2	60–89	Mildly reduced	Normally no symptoms
3a	45–59	Moderately reduced	Normally no symptoms
3b	30–44	Moderately reduced	Children may start to have symptoms of CKD
4	15–29	Severely reduced	Many children have more symptoms of CKD Start to plan for treatment options for next stage
5	Less than 15	Very severely reduced and cannot support the body	This is also called **end-stage renal failure** (**ESRF**) or **established renal failure** Children are started on treatment options, including **dialysis** and **kidney transplantation**

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Urine tests

Urine tests may also be used, especially to check for protein or blood in the urine (wee), which are signs of kidney disease. You, or a nurse, will need to collect some of your child's urine in a small, clean container. A **dipstick** will be dipped into the urine – this is a strip with chemical pads that change colour depending on what substances are in the urine. The sample may also be sent to a laboratory for more accurate tests.

Imaging tests

Some children need imaging tests (scans). These use special equipment to get images (pictures) of the inside of their body.

Types of imaging tests

- **Ultrasound scan**: A small handheld device is moved around your child's skin and uses sound waves to create an image on a screen.
- **DMSA scan**: a chemical that gives out a small amount of radiation (energy) is injected into one or your child's blood vessels. This chemical is taken up by healthy parts of the kidney and a special camera takes pictures. These show how well the kidneys are working and whether there are any scars.
- **MAG3 scan**: like the DMA scan, a chemical that gives out a small amount of radiation is injected into one or your child's blood vessels veins and travels into his or her kidneys. A special camera takes pictures, which show how much blood is going into and out of his or her kidneys and looks at how well the kidneys are draining urine.
- **MCUG** (or **VCUG**): a thin tube is placed in your child's urethra and a dye is put through to reach his or her bladder. An X-ray machine takes a series of images of your child's bladder while he or she is passing urine. This can see whether and how far the urine refluxes (goes back up the wrong way up the ureters, towards, and sometimes into, the kidneys).
- **CT scan**: your child lies on a bed that moves into a large tunnel. This takes a series of X-ray images at different angles. This builds up a detailed picture of their kidneys.

Kidney biopsy

Your doctor may recommend a **kidney biopsy**. A tiny piece of one kidney is removed from the body with a needle, and examined under microscopes. Special medicines are used so your child does not feel any pain or can sleep through the procedure.

A kidney biopsy can give more information about how much damage there is in your child's kidney. It can take a few weeks to get the results.

Tests: Read more about blood tests in CKD

Electrolytes are important chemicals in the body. We need the right balance of these to stay healthy. Some important electrolytes include the following:

- **sodium** helps balance the amount of water in the body
- **potassium** is needed for the muscles, including the heart muscle, to work properly
- **bicarbonate** balances the amount of acid in our body, or the pH balance (also called the acid–base balance)
- **phosphate** is important for bones, teeth and muscles
- **calcium** is important for bones and teeth, helps blood to clot and also helps the muscles, including the heart muscle, to work.

Urea and creatinine

The body makes some chemicals after it uses energy. **Urea** is made from the protein we eat, and **creatinine** comes from our muscles. These are waste products (not needed by the body). The kidneys remove them from the body into **urine**.

If the kidneys are not working as well as they should, there may be a higher amount of urea or creatinine.

Anaemia

A **full blood count (FBC)** – counts the numbers of types of **blood cells**, the living parts of blood. Children with late stage CKD may develop **anaemia**. This means that the blood has fewer **red blood cells** or less **haemoglobin**, a substance that is in red blood cells.

Because red blood cells and haemoglobin carry oxygen around the body, children often feel weak and tired, and may look paler than usual.

The level of **iron** and some **vitamins** are also measured – these help to prevent anaemia. If these are low, your child may be given supplements.

Protein in the blood

Some children with CKD have more protein than usual in their urine (**proteinuria**). This happens when the kidneys leak protein. In some cases, enough protein is lost in the urine to cause a drop in the levels of protein in the blood.

Albumin is one type of protein. Because it is small, albumin is more likely to be leaked.

Hormones for bone development and growth

A **hormone** called **parathyroid hormone** (**PTH**) is released into the blood stream by the parathyroid glands, which are in the neck. Both PTH and vitamin D work with minerals such as calcium and phosphate for bone development. In later stages of CKD, some children have too much PTH. If this happens, your child may need medicines to keep PTH at the right level.

Other hormones called **growth factors** help the body grow. In CKD, the levels of growth factors may be normal, but may not be producing normal growth. Some children with more severe CKD may need extra growth hormone.

Treatment

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

Where is my child treated?

Mild or early CKD: stages 1 to 3a

In early stages of CKD, your child will probably be monitored by a **paediatrician**, a doctor who looks after babies, children and young people with different health conditions. Your paediatrician may be in your local hospital or another setting in your area, such as a community clinic.

In very mild cases, your child may be monitored by 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. They are normally referred to a **paediatric renal unit**, a specialised unit for babies, children and young people with kidney conditions, which may be in a different hospital to your own.

You will be introduced to a team of healthcare professionals who will support your child and family, particularly in the later stages of CKD. The team may include a:

- **paediatric nephrologist** – a doctor who treats babies, children and young people with kidney problems
- **renal nurse** – a nurse who cares for babies, children and young people with kidney problems
- **paediatric dietitian** – a professional who advises what your child should eat and drink during different stages of a kidney condition
- **renal social worker** – a professional who supports you and your family, especially with any concerns about money, travel and housing related to looking after your child with kidney disease
- **renal psychologist** – a healthcare professional who supports your child and family, especially with emotional stresses and strains from having or looking after a child with kidney disease
- **play specialist** – a professional who uses dolls and other toys to help your child prepare for procedures, such as blood tests and dialysis.

Depending on your child's health, some of the clinic appointments and monitoring can still be done partly by your local paediatrician working closely with the paediatric renal unit.

About treatment: stages 1 to 3a

Most children do not need any treatment in the early stages of CKD.

Controlling blood pressure

It is important that your child's blood pressure is controlled so it is in the healthy range. Even at early stages, children are at risk of **hypertension** (high blood pressure), which can also cause further damage to their kidneys and may speed up progression to later stages of CKD. Your child may need to eat a no-added salt diet and/or take medicines.

» More about Hypertension – treatment

Reducing protein loss in urine

If your child has a high level of protein in his or her urine (proteinuria) he or she may need to take a medicine to reduce the amount of protein in his or her urine. This is usually a medicine called an **ACE inhibitor (angiotensin-converting enzyme inhibitor**) or **angiotensin-II reception blocker** (**ARB**).

Doctors understand that, in some children, these medicines will reduce the risk of long-term kidney problems.

➔ **It is important that you follow your doctor's instructions about when and how much to give. Do not stop the medicine suddenly.**

Living healthily

Your child can help protect his or her kidneys by leading a healthy lifestyle. This includes:

- eating a healthy diet – with at least five servings of fruit and vegetables a day, taking care not to eat too much salt, sugar and fats (especially saturated fats)
- getting plenty of exercise
- not smoking
- not taking the medicines ibuprofen (e.g. Brufen, Motrin or Nurofen) or diclofenac as this can further damage his or her kidneys.

About treatment: stages 3b to 5

Those children who reach later stages of CKD have more symptoms that are associated with the worsening kidney function. They will need treatment to manage the symptoms.

Eating and drinking

As the kidneys work less well, they are less able to control the amount of water, salts and nutrients in the body. Children often need to make changes to how much they drink and what they eat. Some children and babies develop a poor appetite and may feel sick (nausea) or be sick (vomit). They can be fed through a tube to make sure they have the nutrition they need to grow.

» Feeding your baby or child with CKD

Medicines

Children will need to take medicines to treat symptoms and/or to try to slow down the progression to kidney failure. Often, the types or doses (amounts) of medicines change as children progress through these stages.

About treatment: kidney failure

In stage 5, when the kidneys are in failure, children usually need specialist treatment, such as dialysis and/or a kidney transplant. Children start preparing for one or both of these treatments in stage 4. Plans are made so that, if at all possible, children have a kidney transplant in time to avoid having to start dialysis.

» Chronic kidney disease – stages 3b to 5

Further information

This is the end of the introduction to chronic kidney disease. If you would like to read more about other later stages of CKD, tests and diagnosis, treatment or supporting information, you can find a list of topics covered on the infoKID website at **www.infoKID.org.uk**.

Your notes and contact information

BAPN British Association for Paediatric Nephrology

Kidney Care UK

Health & care information you can trust
The Information Standard Certified Member