

# Feeding your baby or child with chronic kidney disease

This infoKID topic is for parents and carers about children's kidney conditions. Visit [www.infoKID.org.uk](http://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

This information is designed to help parents and carers feeding a baby or child with chronic kidney disease.

It should be used alongside specialist advice from individual healthcare professionals.



## Overview

### About chronic kidney disease and feeding

The kidneys filter blood and remove extra water, salt and waste in urine. However, babies and children with chronic kidney disease (CKD) have poor kidney function – their kidneys do not work as well as they should.

It is important that your baby or child with CKD feeds or eats well. Good nutrition is essential for their growth and healthy brain development. It gives them strength to fight illness and infections.

Some children with CKD struggle with eating. They will need extra support to make sure they get the energy and nutrients they need to grow and stay healthy.

» [Chronic kidney disease \(CKD\) – an introduction](#)

### About your child's care

Your child will probably be referred to a paediatric renal unit, a specialised unit that treats babies, children and young people with kidney conditions and may be in a different hospital from the one you would normally visit.

The renal team, a group of healthcare professionals who specialise in treating and caring for babies, children and young people with kidney conditions, will support you and your family. The team will include:

- A **paediatric nephrologist** – a specialist doctor who treats children with kidney problems.

- A **paediatric renal dietitian** – a healthcare professional who advises on what to feed your child to help control the effects of poor kidney function, and to ensure your child thrives.

### Feeding your baby

Babies need to go through stages of feeding. This starts with milk. Breast milk is best for most babies, but some will need a special formula milk. They then move on to solid foods, often starting with pureed (mashed up) foods, and then on to lumpy foods. This is called weaning.

Your baby's healthcare team will check that he or she is getting enough milk or food to meet his or her needs.

» [More about feeding your baby](#)

### Coping with feeding problems

Some babies and children with CKD struggle with feeding or eating. Children are more likely to be happy feeders if they sense that their parent is calm and relaxed.

You may wish to talk to someone – a family member, friend or healthcare professional – to help manage your anxiety away from your child. This will help you to stay calm and in control, without leaving you feeling that you will raise your voice or force feed your child.

» [More about coping with feeding problems](#)

## Feeding devices

Some babies and children cannot eat and drink the amount they need for their growth and development. If needed, they can be fed through a tube.

All or some of their nutrition – and water and medicines, if needed – can be given through a nasogastric tube, a gastrostomy tube or gastrostomy button.

» [More about feeding devices](#)

# Feeding your baby

This information covers feeding babies who are in the first year of life.

## Normal stages of feeding

All babies need to go through stages of feeding – starting with taking milk (usually breast milk, but sometimes a formula is used), and then **weaning**, or starting to eat solids, often starting with pureed (mashed up) foods, and then on to lumpy and finger foods, before moving on to family foods.

There are key 'windows' of time when a baby can start weaning. The following is normally recommended for healthy babies:

- about 6 months – to start eating pureed (mashed up) foods
- about 8 or 9 months and after they have regularly eaten pureed foods – to start eating lumpy foods.

## Monitoring feeding and weight gain

Your healthcare team will check that your baby is getting enough milk to meet his or her needs. They will weigh your baby at each appointment, or as regularly as needed.

If your baby's weight gain is slow, your dietitian may make formula milk more concentrated so it is higher in energy.

If there are concerns about your baby's feeding, it may be helpful to keep a diary. You can include:

- the date
- the type of milk (breast milk or formula)
- the amount of milk your baby has taken
- any comments – including whether your baby is well, or has reflux or is vomiting.

## Milk

Breast milk is *best* for most babies.

However, some babies with CKD need a special renal formula milk as the kidneys become less able to clean blood.

If your baby needs special renal formula milk, your renal dietitian will design a recipe, and show you how to make this up at home. This recipe will change as your baby's needs change – your dietitian will check this regularly.



A nasogastric tube

You may need to:

- give this renal formula milk on its own
- mix it with breast milk – you will need to express your breast milk with a pump, or
- mix it with standard formula.

## Weaning

CKD does not change the time of weaning. Solids provide extra energy. It is usual to introduce solids when babies are about six months of age. In some cases, the dietitian may encourage it after four months. Babies should not be weaned before four months of age.

### Tips for weaning

Start with smooth pureed food.

Your baby may not swallow the food at first. New experiences of taste and a variety of flavours and textures are just as important as quantity. Don't worry if your baby does not eat much – just work on his or her acceptance of tastes.

Let your baby be independent, get messy and really enjoy the feeding experience, regardless of what actually reaches the stomach.

Encourage progress with lumpy textures if you can. It is important your baby develops chewing skills at this stage. This will help him or her to develop tongue and jaw movement and speech. All babies gag (find it difficult to swallow) on lumps from time to time. Don't see this as a sign that your baby is trying to be sick. Try again, giving the lumpier texture for a few mouthfuls. Try the same approach with finger foods.

» [More information about weaning to solid food \(NHS Choices\)](#)

» [Booklet about weaning / starting solid food \(NHS\) \(PDF download\)](#)

## Special diets for older babies

Some babies with CKD need a special diet as well as special formula milk. This is usually only needed for babies who are eating a significant amount of food (more than a few tastes or spoonfuls).

If your baby needs a special diet, the dietitian will give you advice on which foods to choose or avoid.

It is very important not to add salt to any baby's food. Ready-made or convenience meals often have a lot of salt. Speak with your dietitian before giving these foods to your child.

# Coping with feeding problems

Some babies and children with CKD struggle with feeding or eating. Even if your child's CKD means he or she is ill for a long time, it is important that he or she still develops feeding skills.

## Why does my baby or child have feeding problems?

Your child may find that food tastes different. This may affect which foods he or she prefers.

- Your child may not want to eat much because poor kidney function has an influence on appetite.
- **Gastro-oesophageal reflux** (also called **acid reflux**) – when what is eaten comes up from the stomach and back into the food pipe (oesophagus) – is very common in babies and children. It may be more severe in those with CKD. Reflux can lead to regurgitating (bringing up the food into the mouth) or vomiting (being sick).
- Your child may feel nauseous (sick) or vomit. You may like to offer different foods to see which ones your child can tolerate.
- Your child may have unpleasant early experiences linked to eating. For example, if he or she repeatedly vomits, has gastro-oesophageal reflux or takes medicines that do not taste pleasant, your child may not enjoy eating.
- Your child may gag when you use feeding tubes, oral syringes or unpleasant tasting medicines. He or she may develop a fear of placing anything in their mouth.

**Illness and feeding problems can mean there are fewer opportunities to offer the right types and textures of food.**

## What you can do

Feeding a baby or child with feeding problems can be a difficult and challenging experience. It is natural that this may cause anxiety.

It is important to access the right support. You may wish to talk to someone – a family member, friend or healthcare professional. This will help you to stay calm and in control, without leaving you feeling that you will raise your voice or force feed your child.

**Providing a calm, safe and happy environment when feeding your child will allow him or her to develop positive associations with food.**

**Avoid distractions such as the phone or television, and take your time.**

## General tips

Keep calm and comfort your baby or child as he or she feeds or eats. This gives the message that feeding times can be happy and safe. Reassure your child if he or she is finding this difficult.

- Eat as a family as often as possible. Give your child lots of attention during feeds. If he or she is older, your child can learn by watching others.
- Praise your child, even if he or she just touches, licks or has a small taste of foods. Children respond much better to praise than they do to bribes, threats or punishments.
- Allow your child to get messy and have fun at mealtimes. Feeling and touching food is a great learning process. Try using foodstuffs such as dough, mashed potato, a coloured cornflour and water slimy mix, wet and dry pasta, chocolate finger painting. When this is mastered, your child may be ready for some basic cooking!
- Encourage an older baby or toddler to feed themselves while you supervise – so that he or she grows in confidence and control.
- Give your child an amount of food that is right for them and that has a texture (smooth or lumpy) he or she can easily manage. For chopped or finger food, give your child pieces that are a sensible size. Speak with your doctor or renal team if you are unsure, or if a problem arises when feeding.
- If your child can manage pureed food, make this thicker. Lumpy foods of mixed texture may not be easy to start with. 'Bite and dissolve' foods can really help. Your dietitian can give you more ideas for your child.
- Once some food is accepted, it is important to try to move forward with new tastes and textures – even if the amount of food eaten is tiny. However, if your child really dislikes a certain food after several tries, do not force it. A toddler may need to try a food up to ten times before he or she decides whether they like it or not, so just give your child plenty of opportunity to try the same food, but with no pressure.
- Avoid hiding new foods within a food that your child will eat. Your child needs to trust you – this approach could stop him or her eating foods that he or she does like.
- Try not to worry about what your child is eating at this stage. Your dietitian will make sure that your child's nutritional needs are met, according to their stage of development.

## Gastro-oesophageal reflux and vomiting

If your child has gastro-oesophageal reflux or vomits, tell your doctor. Treatments are available and may include:

- medicines to help with gastro-oesophageal reflux – these may need to be adjusted over a few weeks, so always report back to your child’s healthcare team if things do not get better
- using a feed thickener
- smaller, more frequent feeds
- positioning changes – for example by propping up the head of the cot
- keeping your baby upright for a short time after feeding
- giving the feed slowly through a **feeding tube**.

## Support

**Healthcare professionals are experienced and trained to help you manage your child’s CKD and will support you if you have any problems.**

### Renal team and health visitors

The renal team can offer you support and will link in with your local team so that you have help nearer to home. It is useful to involve health visitors, nursery or school staff, and speech and language therapists.

Regularly offload any worries and discuss issues with your health visitor and/or renal team.

### Teachers and nursery staff

You can speak to professionals – such as teachers or nursery staff – about your child’s eating difficulties and needs. Your renal team can also share feeding plans and recommendations with them. They may be able to encourage food experiences (like messy food play) in pre-school or school settings.

### Speech and language therapist

If your child has problems with chewing and swallowing foods, you may need advice from a speech and language therapist. The therapist can use techniques to encourage your child to develop eating skills, so that he or she can be given small amounts of food successfully.

Some children will find it difficult to manage certain textures – chewing skills take time to develop. Toddlers need time to gain confidence with new textures. The speech and language therapist can also give advice around how to help your child with this.

### If your child does not eat normally

Despite such help, some children with CKD do not eat normally until they have a kidney transplant. Keep up messy play and involvement at mealtimes, even if no food is eaten.

## Tube feeding

**If your baby or child is unable to eat and drink all he or she needs to grow and develop, he or she may need a feeding device. All or some of your child’s nutrition, and water and medicines if needed, can be given through a tube or button.**

**This is often called tube feeding. It is different from oral feeding, which is by mouth. Your child’s dietitian can discuss this with you in more detail.**

## Types of feeding devices

There are two main types of feeding devices.

### Nasogastric tubes

**Nasogastric tubes** are normally for short-term use. They are long, thin tubes that are placed through the nostril, down the throat and into the stomach. The feeds are given through the tube to get to the stomach.

Most tubes need replacing about once a month – or more often if they are dislodged or pulled out. After training, some parents and carers choose to replace the nasogastric tubes themselves.

Occasionally, **nasojejunal tubes** are used. These are long, thin tubes that are placed through the nostril, down the throat and into the small intestine (just past the stomach).

### Gastrostomy

If your child needs tube feeding on a long-term basis, it may be better to consider a gastrostomy. In this procedure, a small hole (called a stoma) is made through the tummy’s skin and into the stomach.

Feeds are given through a feeding device – there are two types. These have different advantages and disadvantages. Your doctor will discuss these with you before a decision is made.

- **A gastrostomy tube (or a PEG)** is a long tube that fits in the stoma and is held in place with a soft plastic disc. The gastrostomy tube can stay in for years if needed and does not become easily dislodged



A gastrostomy tube

- A **gastrostomy button** may otherwise be used – this is a smaller, neater devices that is held in place in the stoma by a water-filled balloon. Gastrostomy buttons generally need to be replaced every few months.

## Types of feeds

There are two ways to feed your child using a nasogastric tube or gastrostomy: by bolus or by pump. You may need to use both methods at different times of the day.

### Bolus feeds

**Bolus feeds** are done at regular times of the day. A syringe is attached to the feeding tube or button. The feeds flow by gravity into your child's stomach, for 15–20 minutes each time.

### Pump feeds

**Pump feeds** are done for longer periods of time and at a slower rate. An electric pump is attached to the feeding tube or button, and the right amount of feed is slowly given over the set time – this may be overnight.

## Effect on appetite

Many children start using feeding devices because their appetite is already reduced. Some children need continuous pump feeds because of excessive vomiting (being sick). The tube feeding will make sure they have the nutrition that they need to develop and grow.

Speak with your dietitian if you are concerned. Your dietitian may be able to change the feeding regimen – when and how your child feeds – so that he or she feels more hungry at mealtimes and is more likely to eat.

## Oral feeding with tube feeding

- **Remember it is important that eating skills that have been learnt are not forgotten. Keep some oral feeding going if possible and continue to encourage variety, even if it is just with small tastes.**

Tube feeding can be a very positive step towards making sure your child gets the nutrition and fluids he or she needs to stay healthy. It can be reassuring to know that there is no need to worry if your child does not eat anything.

However, it is very important that your child keeps and develops feeding skills wherever possible. Remember that eating is generally an enjoyable pleasure and is a chance for a child to socialise and communicate, as well as develop skills.

## Babies

Your baby can still breastfeed, bottle feed and wean while being tube fed.

If you find a dummy (pacifier) helpful, offer this – it can be dipped in milk. You can also give small amounts of milk from a breast, bottle or feeding cup. Doing this at the time of a tube feed helps your child to associate sucking with a feeling of fullness.

## All children

If possible, tube feed your child at meal times to keep a normal routine. Try not to be too busy or distracted, and enjoy the time together.

You can help your child associate food with a nice feeling of satisfaction, even if it is just by sight, smell and touch. If your child takes even small amounts or tastes of food, this will help to accept tastes and textures. This will also encourage your child to accept food later on.

## Tube feeding after a kidney transplant

After a kidney transplant, your child may feel more hungry. You may be able to slowly reduce the tube feeding, which can encourage eating.

Speak with your dietitian or doctor before doing this. Ask whether it is okay for your child to have a period of slower weight gain while they are gaining their appetite for eating.

Feeding tubes are not 'forever'. The majority of children take enough food and drink for their needs within a year of having a kidney transplant.

## Further information

This is the end of the information about feeding with CKD. If you would like to read more about tests and diagnosis, treatment or supporting information, you can find a list of topics covered on the infoKID website at [www.infoKID.org.uk](http://www.infoKID.org.uk).

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# Your notes and contact information

[www.infoKID.org.uk](http://www.infoKID.org.uk)



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For details on any sources of information used in this topic, please contact us through our website [www.infoKID.org.uk](http://www.infoKID.org.uk).

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