

What I tell families about haemodialysis in children

Kidney disease in children is rare, but when a child does have a problem, it is important that they are cared for in a children's renal (kidney) unit. The Children and Young People's Kidney Unit in Nottingham is one of only 13 units in the UK that provide this type of care.

These units are staffed by teams of professionals who understand the special physical and psychological needs of children. They include: your child's nephrologist (kidney specialist), specialist children's nurses, dietitians, social workers, play specialists, schoolteachers, youth workers and psychologists. Their roles will be explained later.

It is important that you have enough information to make decisions about the most suitable treatment for your child's chronic kidney failure. You will be able to make this decision in partnership with the team at the children's renal unit. We have a number of booklets and videos to offer help and advice, and members of the renal team will usually visit you at home before dialysis begins to explain the treatment choices to all members of the family.

What is dialysis?

'Dialysis' describes the removal from the body of the waste products and extra fluid that build up when the kidneys do not work properly. We can remove the waste and water directly from the blood using haemodialysis, which is the technique described in this article.

Is there an alternative treatment to haemodialysis?

The alternative to haemodialysis is chronic peritoneal dialysis (CPD), which is usually performed at home. CPD is carried out over six to seven days a week, while your child is asleep at night. All types of chronic dialysis in children are seen as a temporary measure before a kidney transplant is available. Increasingly, we are able to offer a kidney transplant before dialysis is needed (this is called a 'pre-emptive transplant').

Haemodialysis

Haemodialysis is carried out at the hospital, usually for four to five hours at a time, three times a week. It uses a special machine to do some of the work that your child's kidneys usually do.



Having a central venous line means that children have both hands free to take part in enjoyable activities during dialysis

The machine uses an artificial kidney called a dialyser to remove waste and fluid that isn't needed. The machine itself helps blood to be pumped through the dialyser safely through specially designed plastic tubes. Trained and experienced nurses are always present to ensure that dialysis is performed safely.

How do you reach the bloodstream?

To dialyse your child successfully we need to take some of the blood out of their body temporarily (less than 10% of the body's total blood supply at any time) and put it through the tubes and dialyser on the machine. We, therefore, need good access to the bloodstream to ensure a steady flow of blood. In our unit, we use two main types of access: central venous lines and fistulas. These are described below.

Central venous lines

A central venous line is a special tube inserted by a surgeon under general anaesthetic, usually into a large jugular vein in the neck (hence the common term 'neck line'). The tube comes out from the chest wall and is covered with a dressing to keep it clean. This is called the 'exit site'. Having a central venous line means the child will have both hands free to do school work, play and eat normally.

The neck line remains in place until dialysis is no longer needed. When it is not in use, the line is flushed with a drug called heparin, which helps to stop it from getting blocked. Each time the line needs to be used, a nurse will clean it

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carefully, take the heparin out and flush it with saline (salt water). It is then ready to be used. This is a very simple procedure and is not painful because it is only the line we are touching, not your child. Once in place, the line can be used to obtain blood for all regular blood tests. This means that no needles are necessary.

The nurse will change the dressing over the exit site every week. You will also be given instructions on what to do if there are any problems when you are at home. Neck lines can last for months or years if properly cared for.

Fistulas

A fistula is an artificial passage between an artery and a vein. When this connection is made, the vein is exposed to the higher pressure and increased blood flow in the artery. This develops the walls of the vein until it becomes capable of withstanding access for haemodialysis treatment three times a week.

Fistulas are used much less frequently in children than in adults, but they may be preferred by older children or young people who are likely to spend a long time on haemodialysis, and who find that neck lines restrict activities such as swimming. After the operation to make the fistula (which is made at the wrist or higher up the arm), the fistula needs time to develop before it can be used. During this time a central line will be used.

When the fistula is ready for use, special needles are inserted into the vein at every dialysis session. It doesn't sound very pleasant but children do get used to it. Our play specialists and nurses will help your child prepare for this.

Preparation for haemodialysis

As a specialist children's renal unit, we understand the need to prepare children, using methods appropriate to their age, for everything they will have to face. To reduce their anxiety and to encourage participation in their own care, children need to understand their treatment.

One excellent way to achieve this – particularly with younger children – is through play preparation. Hospital play specialists are important members of our team. They work very hard to prepare children for dialysis, and to prepare their brothers and sisters.

Whenever possible, the play specialist will meet you and your child in the outpatient clinic before dialysis begins. They will also visit you at home to begin the preparation process, accompanied by one of the dialysis nurses. They

use videos, photo albums and dolls to explain how procedures work and what to expect. For older children, we provide computer packages and booklets, which address many of the questions that young patients ask.

We try to ensure that the same play specialist will be with your child when they are admitted to hospital to have their access line put in or their fistula created, and for their first dialysis session. The presence of a familiar face from previous meetings is reassuring for the child.

For those children who find it very difficult to understand the procedures, or who are feeling particularly anxious about the treatment, we have a child psychologist to offer additional support.

Use of a central venous line means that no needles are needed when taking regular blood tests

For preschool children, our play specialist or nursery nurse will devise a play programme that will aid your child's development while they are on dialysis





Supervision of haemodialysis

Specialist children's nurses carry out haemodialysis treatment in the hospital. Your child will be appointed a named nurse who will co-ordinate their care both in the hospital and at home. They will carefully monitor your child's progress, adjusting their treatment as they grow.

Children adapt very quickly to their treatment routine. They learn that they need to go to the hospital on certain days, and they know what will happen when they arrive (their weight and blood pressure will be taken, and then they will be connected to the dialysis machine).

The blood results will tell us how well the dialysis treatment is clearing the blood. Your child will also be seen by the nephrologist once a month, just before one of their dialysis sessions, to review their overall progress and to make any necessary adjustments to their treatment.

Will my child's schooling suffer?

Your child may spend three out of five school days on dialysis, so our school education department works closely with the haemodialysis unit to ensure that their education does not suffer.

As soon as a child starts haemodialysis, their nurse will arrange a visit to their school, accompanied by a hospital schoolteacher, dietitian and social worker. This meeting will ensure that the staff at school understand what is happening to your child in terms of their diet, blood flow access and so on. Further visits are made if anything changes – for example, if your child is placed on the transplant list.

The hospital schoolteachers will keep in touch with the school to ensure that they have work for your child to do on dialysis days. The dialysis area becomes a classroom during the school term. At other times of the year, activities and games are arranged by the play specialists or youth worker.

Preschool children

For younger children, a play programme is devised by our play specialist or nursery nurse. One-to-one input not only aids your child's development, but also provides an enjoyable distraction. Your child will not be able to get up and walk around when they are connected to the machine, and they can get bored very quickly. If your child attends a nursery or child minder, we will visit them to provide information and support, just as we do with schools.

Youth work

Older children and young people are offered support by our youth worker. Many young people take the opportunity to work towards the Youth Achievement Award. Our youth worker also holds

youth clubs and arranges activities, which your child can choose to become involved in.

What can I do to help my child?

Follow dietary advice

Diet and fluid restrictions tend to be stricter on haemodialysis than on CPD because, on haemodialysis, your child does not dialyse every day. We, therefore, have to be careful that waste and water do not build up excessively between treatments. Your child's renal dietitian will provide ongoing advice, as described below.

- Some foods will need to be limited in your child's diet as they are more likely to be harmful if they are allowed to accumulate in the body. These include, in particular, foods containing potassium, salt and phosphate and protein (the dietitian will advise you which foods you will need to avoid).
- If your child does not pass much urine, they may be given a fluid limit. Again, this reduces the build-up of fluid between dialysis sessions, which, in the short and long term, can be harmful to the heart.
- It can be difficult to make sure that your child eats enough of the foods that are rich in energy and nutrients. There are special drinks that you can give your child to help this. Some children need even more help than this and may receive special milk feeds overnight through a tube into their stomach (this is called 'gastrostomy').

Your child will be appointed a named nurse who will co-ordinate their care

Medication

Your child will need to take medication regularly, as well as undergoing dialysis. This may include tablets to help blood pressure, vitamin supplements and medication that aids the balance of phosphate in the diet, which can affect bones and growth.

The combination of medicines, dialysis and diet will keep your child well. All are equally important, and every effort must be made to follow the advice you are given. We appreciate that it can be difficult to follow these restrictions, so do discuss any problems with us.

No treatment can be completely perfect. The common advantages and disadvantages of haemodialysis are listed in Box 1 (overleaf).

For how long will my child need to have dialysis?

Children do very well on dialysis for a number of years, but we hope that most will have received a renal transplant within six to 18 months. We do sometimes transfer young people on haemodialysis to adult services nearer to where they live, when both they and the team



Box 1. Advantages and disadvantages of haemodialysis

Advantages

- Specialist children's nurses carry out haemodialysis treatment at the hospital, which many families find easier than learning to carry out peritoneal dialysis at home.
- On non-dialysis days, children and their families have more freedom for other activities (although, unfortunately, there is no escape from medicines and dietary issues).
- Children and their families have close contact with each other when attending the hospital three times a week. They can get a great deal of support from each other this way. They also see other members of the team frequently if they have any concerns.

Disadvantages

- Even if you have transport arranged for you, your child must be accompanied if they are under 16 years old. You may have to travel long distances three times a week and this can be a strain. Many families share this responsibility, and grandparents and other family members often help out. We will do everything we can to help you. Our social workers specialise in supporting families like yours, and can give you advice on all manner of issues.
- Children miss out on time at school and among their peers. However, they do receive input in hospital with our teachers who have a lot of experience in assisting children on dialysis. Children can, and have, taken their GCSEs on dialysis days at the hospital.
- As this type of dialysis is only offered in hospital, this places certain restrictions on your activities. Holidays overseas are not usually an option for children on haemodialysis, but we do have a reciprocal arrangement with other children's dialysis units and we can arrange for your child to dialyse elsewhere in the country if we are given enough notice. As there are few units available, it can restrict your choice of location so this should be discussed with your named nurse. Every year, we endeavour to give children and their families a break by organising a holiday week away from the unit.

feel the time is right with regard to completing growth and schooling.

Haemodialysis at home is very rare these days, but it may be considered if the child is unlikely to have a transplant for some years, and the home situation and support is favourable.

Some children can change to CPD if complications arise on haemodialysis, and if CPD is possible. This can only be judged on an individual basis, and your nephrologist will discuss this with you if appropriate.

Transplantation

As a treatment, transplantation has many advantages. Your child may already be waiting for a transplant. If not, you will be given information about this by our children's transplant nurse. Two options may be possible:

- A good match via the national list. Children under 18 years of age have a higher priority on this list, so do not tend to wait as long as adults.

- Living related donation. It is sometimes possible for a parent to donate one of their own kidneys to their child. Other close relatives are also sometimes considered. Not everyone is suitable for this, but it is something you can discuss.

Whatever long-term choice you make, our specialist team will provide support and advice to guide and help you ■

Key points

- Haemodialysis removes the waste and water that build up when our kidneys do not work properly.
- Children's haemodialysis is provided in a specialist unit that can cater for all the physical and psychological needs of a growing child.
- Most children can be successfully dialysed using a chronic jugular venous catheter that provides 'no needle' haemodialysis.
- Successful dialysis is one part of a whole treatment that includes your child taking regular medication and your family co-operating to make changes to what your child eats and drinks.

For more information about fistulas, see: Palmer J. What I tell my patients about haemodialysis. *BJRM* 1999; 4(1): 12-15.



If you would like to receive a copy of the Palmer article or additional copies of this feature, please send your request to BJRM Patient Information, Hayward Medical Communications, Rosalind Franklin House, The Oaks Business Park, Fordham Road, Newmarket CB8 7XN.