

The background of the entire page is a photograph of a family—a mother and two children—sitting together and reading a book. The image is overlaid with a semi-transparent orange filter. The mother is in the center, smiling, holding the book. A young boy is on the left, also smiling, and another boy is on the right, looking towards the camera.

Peritoneal dialysis

Information for families

Name

Hospital number

Great Ormond Street Hospital
for Children NHS Foundation Trust

This leaflet contains information about peritoneal dialysis (PD) at home. It includes information about what happens next and gives you an idea of how our training programme works. The management of PD care is specific to each patient and varies according to your child's needs and underlying condition.

This booklet will not answer all your questions but covers the points raised most often by parents of children starting PD. Please ask us any questions or concerns. It may be useful to keep a notebook and write questions down as you think of them. You will receive another booklet that has detailed step-by-step instructions on how to set up the dialysis machine and other practical issues. This will be used when your child is admitted to Great Ormond Street Hospital for training.

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Renal team contact details

Urgent calls to clinic Monday to Friday 8am to 5.30pm	020 7813 8172 If nurses are not available, please leave a message on the answer phone
Clinical administrator Monday to Friday 9am to 3pm	020 7813 8276 to change or book an appointment
Out of hours – Eagle Ward Before 8am, after 5.30pm or at weekends and bank holidays	020 7829 8815 020 7405 9200 and ask for extension 5103 If you have difficulty contacting Eagle Ward and need to speak urgently to a member of the renal team, please call 020 7405 9200 and ask to speak to the 'on call renal registrar'

Other useful numbers

Pharmacy Medicines Information	020 7829 8608
Renal Dietitians	020 7405 9200 and ask for extension 5362

What is PD?

Dialysis is needed when a child's kidneys stop working properly. This can be for several reasons. Your child's doctor will have discussed with you what has happened in your child's case. If you would like more information on this, please see our separate leaflet on kidney failure.

Dialysis does the job that is normally performed by the kidneys - that is, it removes waste products from the blood and excess water from the body.

There are two methods of dialysis: peritoneal dialysis, where a catheter is inserted into the abdomen, and haemodialysis, which involves filtering out waste by passing blood through an artificial kidney machine. This leaflet explains peritoneal dialysis.

When your child starts peritoneal dialysis you will have a lot of new skills to learn. Your child will also need to be prepared for dialysis, both physically and mentally.

Peritoneal dialysis works by using the lining of the abdomen (peritoneum) as a filter. There are three stages to a dialysis cycle (or exchange):

- **FILL** – The abdomen is filled with dialysis fluid (dialysate). The amount of fluid varies but is usually worked out according to your child's weight.
- **DWELL** – The dialysis fluid stays in the abdomen for a period of time, which varies from child to child and depends on the type of peritoneal dialysis used. During this time, waste products and chemicals pass from the tiny blood vessels next to the lining of the abdomen into the fluid.
- **DRAIN** – The 'used' dialysis fluid is drained from the body and discarded.

Preparing for PD

One of the PD nurses will come to see you at home to discuss the practical issues of home dialysis. For instance, where your child will have dialysis, where the machine will go, where you will set up the dialysis and storage of fluid and equipment. It is also a time for you and your family to ask practical questions, discuss the implications of PD and get used to the idea of PD at home.

The home visit ideally occurs before insertion of your child's dialysis catheter. However, sometimes this will take place following the event, for instance, after insertion for acute illness. The day and time of the home visit will be negotiated with you and the PD nurse specialists.

What is a PD catheter?

The dialysis catheter is a soft tube that is put into the peritoneum (in the abdomen) under general anaesthetic. The operation normally takes place on a Tuesday afternoon and your child will be admitted to Eagle Ward on the morning of the day before. Your child will need to take laxatives in the week before the operation as it is safer to make sure the catheter is in the correct place if your child's bowel is empty. The operation itself lasts between one and two hours. You will be given more detailed information about the operation and will have the opportunity to speak to the nurses, doctors, anaesthetist and play specialist.

After the PD catheter has been inserted

Your child will come back from the operating theatre with a dressing over the site and will be given pain relief as discussed with you before the operation. The new catheter will be 'flushed' when your child comes back to the ward. This involves the catheter being attached to the dialysis machine so that fluid is flushed in and out of the peritoneum. This is done to stop the line blocking and usually lasts between two and six hours.

Children often stay in hospital for two to three days but this can vary from child to child, depending on his or her pain level, mobility and kidney function. Before you are discharged home, the nursing staff will explain how to look after the catheter and what to do if you have problems at home. The checklist below should be completed before you go home.

For the following few weeks, before starting dialysis, the dressing must be left on covering the exit site. Do not remove or change the dressing. It will be changed at your weekly clinic appointment. If the dressing comes off or is soiled, please contact the clinic. The PD nurse specialists will also flush the catheter during the clinic appointment. These weekly clinic visits will take one to two hours.

If your child has any problems, such as pain, a high temperature or catheter problems or is at all unwell, you must contact the PD nurse specialists or Eagle Ward immediately.

Checklist	Date and signature of nurse discharging
Date PD catheter inserted	
Date to return to clinic	
Take home spare clamps, gauze, caps, alcohol wipes, Tubigrip® and dressings	
Understand what to do if problems occur with the dialysis catheter (if the cap comes off)	
Understand what to do if problems occur with the dressing	
Understand medication diary	

Peritonitis

One of the potential problems with your child's dialysis is the risk of peritonitis. Peritonitis is an infection affecting the lining of the peritoneum (the location of the PD catheter). It is very important that you are aware of the signs and symptoms of peritonitis so that your child can be treated as soon as possible.

Peritonitis can make your child become very unwell very quickly so it is essential that you report any signs and symptoms immediately, so that your child can be admitted for monitoring and to receive antibiotics.

Signs of peritonitis

During your training, you will be given more information about peritonitis, learn how to check for symptoms and be taught what to do if your child has any of the symptoms. When your child is established on PD, you will automatically check for symptoms of peritonitis as part of your routine.

The main symptoms of peritonitis are:

Cloudy dialysis fluid

- This is checked every morning when your child has finished dialysis
- The fluid should be a clear or straw-coloured liquid
- Please contact us immediately:
- If the fluid is cloudy or has any lumps of fibrin in it
- If the fluid looks different to normal
- If the fluid is blood stained

Pain

- If your child complains of abdominal pain, please contact us

Temperature

- This is checked before and after dialysis
- It should also be checked if your child feels unwell or has any of the other signs of peritonitis
- A normal temperature should be between 36 and 37°C
- If your child has a temperature of 37.5°C or more, please contact us

Nausea and vomiting

- If your child is feeling and/or being sick, please contact us

Feeling unwell

- If your child generally feels unwell, please contact us

If your child has any of these signs, you must telephone the PD nurse specialists or Eagle Ward immediately, regardless of the time of day or night.

You will be given advice on what action to take. Remember that peritonitis can mean that your child becomes very unwell very quickly. In severe cases, the dialysis catheter has to be removed. If you have any worries, please contact us. The sooner we know, the sooner we can act and start treatment.

PD and fluid balance

Fluid balance is very important when your child has kidney failure. Your child is likely to make less urine than before and will need to be restricted in how much they can drink each day.

Fluid overload

Fluid overload means that your child has too much fluid in his or her body, which they cannot get rid of (excrete). This may be because they have drunk too much fluid or they may have not got rid of enough through passing urine or dialysis. If you think your child may have fluid overload or has any of the symptoms below, please contact us.

- Weight increase
- High blood pressure, which may show up as headaches
- Puffiness, especially around the ankles and eyes
- Breathlessness

Dehydration

Dehydration means that your child does not have enough fluid in his or her body. This may be because they have not drunk enough fluid or they may have got rid of too much fluid through passing urine or dialysis. If you think your child may be dehydrated or has any of the symptoms following, please contact us.

- Weight decrease
- Low blood pressure, which may show up as feeling faint or lethargic
- Dizziness
- Dark rings under the eyes
- Dry mouth

When does PD begin?

After insertion of the catheter, ideally the plan is to 'rest' the catheter for three weeks to allow it to heal. However, there are times when your child's blood results indicate the need to start dialysis earlier.

What happens during training?

You will work with the PD nurse specialists and ward staff so that you feel confident and have a good understanding of your child's needs on PD. Some of the things you will learn include:

- How to monitor and record your child's weight, blood pressure and temperature
- How to set up for overnight dialysis including connecting and disconnecting your child to and from the machine
- Gaining understanding of your child's dialysis programme
- Troubleshooting
- Recognising the signs of peritonitis
- Recognising signs of fluid overload and dehydration
- Exit site care
- Hand washing
- Fluid balance

Training will involve you and your child being admitted to Eagle Ward for approximately ten to fourteen days. Admission for training is usually on a Monday and your child will start dialysis that night. During this time you will be expected to stay overnight so you can gain experience and become comfortable with your child on overnight dialysis.

You will also be expected to be available for teaching during the day. The importance of this is to ensure that you have the opportunity to understand and learn the practical skills that you will need to carry out PD at home. The aim is that you will be attending to all your child's care, initially with support and then independently before you are discharged home.

What happens when we go home?

Once your child is established and stable on dialysis, plans for discharge will be made. This will only take place once you and the medical and nursing teams are confident that you are fully trained and able to care for your child's dialysis independently. On the day of discharge, one of the PD nurse specialists will meet you at your home to support you while you set up the dialysis machine for the first time.

When you are at home, you will be seen in the dialysis clinic regularly, weekly at first, then every two weeks and eventually every month. Your first appointment date will be given to you before you go home. The clinic is held every Monday from 9.30am to 1pm in the Royal London Hospital for Integrated Medicine (RLHIM) next door to GOSH. Please report in to the receptionist on the 4th Floor.

Your child will have blood taken and his or her catheter exit site swabbed and dressed, before seeing the doctors, PD nurse specialists and dietitians to address any concerns or make any changes needed. Please bring your dialysis sheets with you to each clinic appointment.

We appreciate the commitment that is involved both for training and carrying out dialysis at home. Please talk to us if you have any specific concerns or worries regarding your child's dialysis. Remember that you can access 24-hour support by phoning the dialysis clinic or Eagle Ward out of hours. If you have any questions, queries or concerns, please ring us.

The team are here to support you and help you throughout your training, transition home and ongoing management of your child on PD.

Possible problems with the PD catheter

It is important that you or your child carries with them an emergency pack of supplies at all times. This will enable you to temporarily repair your child's PD catheter, should a problem happen to it, while you travel up to GOSH for treatment.

Line contamination

If the dark blue end of the PD catheter becomes exposed, for example, if the cap comes off accidentally, or you touch it by mistake, you should:

- Attach a new cap – if possible ensuring hands are clean
- Call the clinic or Eagle Ward immediately
- We will need to take a sample of PD fluid for checking. We may also need to do a 'line change' where we change the outside section of the catheter. You will need to come to Eagle Ward for this as soon as possible.
- Your child will need antibiotics in his or her PD fluid bags for at least 48 hours. If your child is well, this can be done at home, or your child may need to be admitted for longer if the contamination results in an infection. Please note, if your child has not yet started PD, he or she will need to be admitted for assessment and intravenous (IV) antibiotics.

Line breaks or hole in line or line is leaking

If you notice that there is a problem with the PD catheter itself, for example, it has developed a hole, the line is leaking or the line extension becomes detached, you should:

- Clamp the line using a blue clamp above the problem area, for example, above the hole. If the line extension has become detached, do not try to reattach it.
- Wrap an alcowipe around the exposed end of the line or hole – if possible ensuring hands are clean.
- We will need to take a sample of PD fluid for checking. We may also need to do a 'line change' where we change the outside section of the catheter. You will need to come to Eagle Ward for this as soon as possible.
- Your child will need antibiotics in his or her PD fluid bags for at least 48 hours. If your child is well, this can be done at home, or your child may need to be admitted for longer if the contamination results in an infection. Please note, if your child has not yet started PD, he or she will need to be admitted for assessment and intravenous (IV) antibiotics.

PD and medication

Most children with chronic renal failure who are on dialysis will need to take a number of medicines. Make sure that you understand exactly how and when to give your child medicines before you leave the hospital or pharmacy. If you have any questions, please ask your doctor, nurse or pharmacist.

Most medicines now come with a patient information leaflet. This gives information about what the medicine is for and how it should be taken. It will also list all of the reported side effects, although this does not mean that your child will get these side effects. Sometimes medicines are used for conditions not listed in the patient information leaflet and/or at different doses. The leaflet may state that a medicine should not be used for children, although its use in children may be well established. If you are concerned about any medicine prescribed for your child, please speak to your doctor, nurse or pharmacist.

The medicines your child will need to take may include:

Phosphate binder

The dietitian will give you advice to help your child's dietary phosphate intake. They will probably also need to take a phosphate binder such as calcium carbonate, calcium acetate or a newer one called sevelamer (brand name Renagel®). They work better at binding the phosphate in food or drink if they are taken before a meal or feed. If this is not possible, have your phosphate binder during the meal or feed. Do not give afterwards, as they will not work properly. If your child cannot chew or swallow them, the tablets can be crushed and mixed with a little water or added to feeds if mixed thoroughly. Calcium carbonate 250mg dispersible tablets are a 'special' medicine, which means that your local pharmacy will not usually keep them in stock so will have to order them especially for your

child. If your child cannot chew or swallow them, the tablets can be crushed and mixed with a little water or added to feeds if mixed thoroughly.

Iron preparation

This is available as tablets (ferrous sulphate or ferrous fumarate) or syrup (brand names Fersamel® or Sytron®). Iron preparations should not be taken at the same time as the phosphate binder, as the absorption of the iron is reduced. Please leave an interval of about an hour.

Epoetin (EPO)/Darbopoeitin (brand name Aranesp®)

This is a replacement for the naturally occurring hormone erythropoietin, which would have been produced by the kidneys. It stimulates the body to produce new red blood cells. EPO is given as an injection under the skin (subcutaneously) once weekly, using either a pre-filled syringe for children or an injection pen. You will be shown how to give epoetin or your family doctor or community nurse may give it to your child. Always keep EPO in the fridge. Sometimes a home delivery of this medicine can be arranged.

Laxatives

Your child will also need to take a gentle laxative regularly, such as lactulose or senna to prevent constipation.

Alfacalcidol (1 alpha)

Vitamin D, which is required for healthy bones, is usually changed by the kidney to its active form. In renal impairment, the active form alfacalcidol is given instead. It is available as a capsule or as oral drops.

Vitamins

The dietitian will decide whether your child needs additional vitamins depending on your child's dietary intake. See Diet and PD section for further information.

Important information about your child's medicines

- Keep an up to date list of your child's medicines
- Learn the names of your child's medicines and keep an up to date list of the medicine names as well as the dose.
- Never miss a dose or change the amount of medicine your child takes unless your doctor or nurse tells you.
- If you accidentally miss a dose, please contact us and ask what to do. Do not decide what to do on your own. Some medicines can be dangerous if too much is taken.
- If your child experiences side effects, please contact us immediately but do not stop giving your child the medicine unless we tell you.
- Always check with your doctor, pharmacist or dietitian before giving your child any other medicines, including herbal or complementary medicines, vitamins and medicines bought 'over the counter' without a prescription.
- If you go to your family doctor (GP) or community pharmacy for other medicines, remember to tell them that your child is on dialysis. Doses of many medicines, such as antibiotics, may need to be reduced, and some medicines should be avoided altogether.
- For temperatures, aches and pains, your child can take paracetamol in the recommended dose. You should avoid any product that contains ibuprofen, such as Nurofen®, Brufen® or Junifen®, or diclofenac. Ibuprofen is widely available from community pharmacies and shops and is packaged under lots of different names so make sure you read the label carefully.
- Some of the medicines your child takes may be 'specials' so not kept in stock by your community pharmacy. You must make sure that you get a repeat prescription from your doctor and take it to your pharmacy in plenty of time before you run out of medicines.
- If you are planning to go on holiday, make sure that you have enough medicines for the trip and a few days extra, and carry them in your hand luggage. That way, if your bags go missing, your child will still be able to take his or her medicine. If you are going abroad and your child needs to take anti-malaria medicines, the dose may need to be adjusted.
- Keep your medicines in a dry place, away from heat and light. Alfacalcidol drops, epoetin injections and Ketovite® tablets must be stored in the fridge, as do sodium bicarbonate and sodium chloride solutions once opened.
- If you have any out of date or leftover medicines, please take them to your pharmacist for safe disposal. Do not throw them away or flush them down the toilet.

Diet and PD

The team of specialised renal dietitians work closely with all families. Infants and children on PD often have a decreased appetite and need to adhere to a strict fluid restriction. Your dietitian will help to make sure your child has the best nutritional intake possible to maximise their growth and development.

The dietitian will review your child's intake, weight, height and blood results and your child's diet or feed may need to be adjusted based on this.

Energy

Your child's energy (calorie) intake may need to be increased. Your child will absorb glucose from the PD fluid and this will be taken into account when working out your child's requirements.

Protein

During PD, protein is lost across the peritoneum and therefore your child may need to have extra protein from food and/or feeds or supplement drinks to make up for this.

Phosphate

This is not cleared well on PD and your child's intake of phosphate-containing foods will need to be controlled. If you or your child is unsure how much phosphate they are allowed check with your dietitian.

Salt

It may be necessary to reduce your child's salt intake if your child has high blood pressure. Your dietitian will advise if this is necessary.

Vitamins

Some vitamins are lost across the peritoneum during PD. Your child may require a supplement to replace these losses. If your child is already taking a supplement drink or feed, they may be receiving enough of these vitamins. It is important for your dietitian to know if your child is taking any multivitamin or supplement other than those prescribed, as these may be harmful.

If you want to discuss your child's diet or have any queries or concerns, the dietitians are available in the PD clinic every Monday or you can contact them by phone on the number inside the front cover of this booklet.

Family support

We have a large psychosocial team that works closely with families who have children on dialysis. You will probably have met some of the team already. They may contact you directly but you can also ask to speak to any of them whenever you want and we can help to arrange this for you. They are here to support you and your family. The members of this team include a ward counsellor, psychologist, family therapy, social workers and family support workers.

In addition to this team, we have a full time play specialist on Eagle Ward, who works Monday to Friday. You will meet her during you stay on the ward but you can also ask to meet her before your admission. She has a teddy with a PD catheter that you and your child can look at and play with before the operation. This will give you all the opportunity to know what it looks and feels like. You can ask her any questions about the operation or going home on dialysis. The play specialist also looks after the playroom on the ward and will make sure your child is not bored during his or her stay. You can ask her for things to do, such as games, videos/DVDs, computer games or arts and crafts and so on. There is also the Centre and School, which your child may be able to visit.

Frequently asked questions

Does my child need to have dialysis every night and how long will it last?

Yes, most children will need to have dialysis every night. The programmes vary but usually last for 10 to 12 hours.

Do I have to tell my child's school?

The school will need to know that your child has dialysis and what they need to do if there is a problem with the dialysis catheter. It is possible for one of the dialysis nurses to go to your child's school and explain about his or her dialysis. We will also teach them what to do if there is a problem with the dialysis catheter or if your child feels unwell.

Can my child play sports?

We encourage children to carry on with their normal activities as much as possible. There will be some sports that we do not recommend. Please discuss this with us so that you can agree a safe plan for your child.

Will my child feel tired on dialysis?

Some children do feel tired, however a lot of children often feel an improvement in tiredness while on dialysis. Please let us know if your child has extra tiredness.

Are there any other families I can talk to?

If you would like to talk to other families and children that have dialysis, we can try to arrange this for you, so please ask us.

We have a pet, is that OK?

Yes, it is fine to have a pet. However, we recommend that your pet does not go into the bedroom where your child has dialysis.

The dialysis equipment is quite heavy, should I be lifting it in a certain way?

The following advice comes from our health and safety advisors. Please be careful when you are moving and handling your child's equipment.

- Plan the move in advance
- When holding a load, carry it close to the front of your body
- Have a stable base, keeping both feet flat on the floor
- Do not stoop, twist or pick something up with straight legs and back
- Bending slightly at the knees moves your centre of gravity towards your pelvic area, making you more stable, reducing muscle strain and keeping the natural S shape of your spine.
- Always adjust the height of any equipment being used to suit the activity

General back care advice

- Maintain a good posture
- Exercise, for example, gentle stretches, walking, yoga or swimming

Can we still go on holiday?

When stable and established on dialysis, it is possible for your child to go on holiday in the UK or abroad. This takes extra planning to organise dialysis fluid to be delivered to your destination. Please discuss this with us before you book your holiday.

Will dialysis hurt?

While your child is getting used to dialysis, usually in hospital, it can be a little uncomfortable. Your child will be given pain relief if this happens and the dialysis programme may be changed. Once your child is at home, the overnight dialysis should not be painful. However, if pain is a problem, please tell us.

Are my child's medicines free?

You can get free NHS prescriptions if:

- Your child is under 16 – if your child's date of birth is on the prescription no further proof of age is needed.

- Your child is aged 16 to 18 and is in full-time education – your child will need to show further proof of date of birth and that he or she is a student.

How do I apply for financial support?

You will be automatically allocated a social worker who can provide information on benefits and other sources of financial support. Details about the Disability Living Allowance, to which all children receiving peritoneal dialysis are entitled, follows:

What is DLA?

The Disability Living Allowance (DLA) is a benefit that you can claim if your child has a long-term health problem that affects everyday activities. It needs to have lasted at least three months and is expected to last another six. The health problem has to result in your child requiring considerably more care or supervision than other children of the same age.

Your child must be at least three months old before receiving DLA, however, you can put in the claim pack before this date to ensure that you receive the benefit straightaway.

Am I entitled to DLA?

DLA is assessed only on the care needs of your child. Therefore, it does not matter if you are working, unemployed, receiving any other benefits or have savings.

Why claim DLA?

If your child has a long-term health problem, this might create many extra expenses, such as higher heating bills, taxi fares, additional laundry and special diets. The DLA can help meet these extra expenses. However, you do not have to specify what the money is going to be used for and it is up to you how you spend it.

How do I claim DLA?

You can telephone the Benefits Enquiry Line on

0800 882 200 and ask them to send you a claim pack for a child under 16 years old. Your claim form will be date stamped on the day that you requested it and therefore if successful, DLA will be paid from this date.

Alternatively, you can collect a claim pack from the Social Work department. However, the claim pack will not be date stamped so if successful, DLA will only be paid from the date the form is received by the Benefits Agency.

Help with filling in the form

Completing a DLA claim form can be a lengthy and often stressful process and unfortunately, many people are put off by the size of it. However, help is available from the family support workers at GOSH. Please ask us to contact them for you. There are also many advice organisations that can assist you in completing the forms:

- Benefit Enquiry Line – 0800 243 355
- Citizens Advice Bureau – 020 7833 2181 or www.nacab.org.uk to find your local bureau
- Independent Advice Agencies – Contact your local social services or council to find your nearest agency
- Carers' Centres – 020 7480 7788 or www.carers.org to see if there is a centre near you. Remember that they can also offer advice, information and support about caring in general.
- Free guides – www.benefitsandwork.co.uk or www.bhas.org.uk for various free downloadable guides to completing a DLA claim form.

Other sources of financial support

There may also be charities or support organisations specific to your child's condition that can offer assistance. For further information, please get in touch with Contact a Family on their free phone number 0808 808 3555 or visit their website at www.cafamily.org.uk.

Notes

© GOSH NHS Foundation Trust October 2013
Ref: 2013F0196
Compiled by the Renal team
in collaboration with the Child and Family Information Group

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