A guide to peritoneal dialysis

This booklet is for people who have chosen peritoneal dialysis as a treatment option. It explains the different types of peritoneal dialysis, how they work and how you can fit the treatment into your lifestyle.

As a kidney patient at Guy’s and St Thomas’ NHS Foundation Trust you will have been given some information about the different treatment choices. If you require further information about your treatment options, please ask a member of staff caring for you for a copy of the booklet ‘Your kidneys, your choice’. There is also a DVD available with the same name.

What is peritoneal dialysis?
Peritoneal dialysis (PD) is the removal of the waste chemicals and extra water from the body using the peritoneal membrane as a filter (more explanation is given below).

What is the peritoneal membrane?
The peritoneal membrane is the natural lining of your abdomen (tummy). It surrounds most of your organs in your abdomen. There are two layers to the peritoneal membrane, and between these layers is the peritoneal cavity. The peritoneal membrane has a very good blood supply and can act like a sieve or filter enabling dialysis to take place (see below).
How does PD work?
PD works as below:

- A small, soft tube (catheter) is inserted into your abdomen so that dialysis fluid can be drained in and out of the peritoneal cavity.
- The peritoneal cavity holds the dialysis fluid within your abdomen.
- Waste products are passed from your blood, across your peritoneal membrane, and absorbed into the dialysis fluid.
- When the dialysis fluid is drained out of the peritoneal cavity, it takes the waste and extra fluid out with it.
- The dialysis fluid is then replaced or exchanged with fresh dialysis fluid and the process starts again.

What is the PD catheter?
The catheter is a soft tube that allows dialysis fluid to drain in and out of the peritoneal cavity. You may hear it being called a Tenckhoff catheter after the doctor who invented it. You will need a small operation to put it into your abdomen – this usually involves an overnight stay in hospital.

Types of PD
There are two types of PD:

- Continuous ambulatory peritoneal dialysis (CAPD) which exchanges fluid during the day
- Automated peritoneal dialysis (APD) which exchanges fluid during the night

Continuous ambulatory peritoneal dialysis (CAPD)
Below is an explanation of what CAPD means:

Continuous – means you are dialysing all the time
Ambulatory – you can carry out normal daily routines whilst dialysing
Peritoneal – using the peritoneal cavity
Dialysis – the process by which waste products and fluid are removed from the body.

CAPD is carried out every day.

There are usually four exchanges of dialysis fluid during the day:

- first thing in the morning
- in the evening
- around lunchtime
- before going to bed at night.

Each fluid exchange takes about 20-30 minutes.

A fluid exchange consists of:

1. attaching the CAPD bags to your catheter
2. draining out the dialysis fluid from your peritoneal cavity (that has been absorbing the waste chemicals and fluid from your blood)
3. then draining in the fresh dialysis fluid into the peritoneal cavity.

Once the process is complete you disconnect the bags from your catheter so that you do not have to carry them with you between fluid exchanges.
Automated peritoneal dialysis (APD)
Below is an explanation of what APD means:
- **Automated** – a machine performs the exchanges overnight whilst you sleep
- **Peritoneal** – using the peritoneal cavity
- **Dialysis** – the process by which waste products and fluid are removed from the body

APD is carried out every night while you sleep and takes about eight hours:

The steps involved in APD are as below:
1. You will need to prepare the machine before you go to bed. This takes about 20 to 30 minutes.
2. When you go to bed you attach your catheter to the lines on the machine.
3. The machine drains the dialysis fluid out that you have had in during the day; it warms the fresh dialysis fluid and drains it into your peritoneal cavity.
4. After leaving the fresh dialysis fluid in to allow the waste chemicals and extra water to filter across the peritoneal membrane, the machine will then drain the fluid out again.
5. This process continues through the night whilst you sleep.
6. In the morning when the programme is finished the machine will leave fluid in your peritoneal cavity – this will stay in throughout the day.
7. You can then detach your catheter from the machine, and remove the lines and used bags of fluid.
8. Some people need to do one CAPD exchange in the early evening to give them extra dialysis.

What are the advantages of PD?
- PD is continuous. This means that usually your blood results stay constant.
- This form of dialysis is taking place 24 hours a day. Your diet and fluid allowance can be more relaxed than with haemodialysis.
- PD is a home-based treatment. Visits to the hospital are about every four to six weeks.
- PD supplies can be delivered to any address in the UK and many overseas countries, so you can go on holiday to many destinations.
- PD enables you to be independent by managing your own treatment.
- The times of the fluid exchanges usually fit in with your work, family and social life.
- Support is available via telephone day or night should you need any advice.

What are the disadvantages of PD?
- PD needs to be done daily to be effective. However, you can be flexible with the times of treatment.
  
The main risk associated with PD is peritonitis which is an infection of the peritoneal membrane. We will teach you how to reduce the risk of peritonitis and what to do if you think you have it. Usually peritonitis can be treated successfully with antibiotics at home but sometimes people need to be admitted to hospital for treatment. If the infection is very severe, PD may be stopped and you will need to swap to haemodialysis either temporarily or permanently depending on the severity of the infection.
• Occasionally you may get an infection where the peritoneal catheter exits the body (the exit site). This is usually treated successfully at home with antibiotics.

• Sometimes people experience problems with the flow of fluid – we will teach you how to deal with this should it occur.

• In a small number of cases, abdominal hernia (organs bulge or push through weakened muscle) can occur due to pressure caused by the dialysis fluid. If this happens, you will need a small operation to repair the hernia and have temporary haemodialysis whilst the scar heals.

• Very rarely PD patients can develop thickening and scarring of the peritoneal membrane, called encapsulating peritoneal sclerosis. This is thought to be related to staying on PD for a very long time. This can cause abdominal pain, difficulty absorbing nutrients, and in extreme cases can cause severe abdominal problems. To avoid this occurring we recommend that you stop PD after five years and start haemodialysis as an alternative treatment.

Questions people often ask about PD

• PD training
  How long will it take me to learn how to do my own PD?
  Two to three weeks following the catheter insertion, you will be shown how to carry out the dialysis yourself. The training takes as long as you need but on average this is about five days.

  Where will I go to do the training?
  We can offer you training at:
  o the Peritoneal Dialysis Unit
  o home
  o a training centre (which will include staying overnight).
  
  You can tell us about your preferences nearer the time.

  Will I be able to bring my carer/family member with me?
  Yes, your carer, partner or a member of your family or a friend is very welcome to join you.

  Will there be other people training at the same time as me?
  There may be other people at the hospital or training centre at the same time as you. Your privacy will be maintained at all times.

• PD supplies
  How do I get the supplies I need?
  The dialysis company delivers PD supplies directly to your home. We will give you more information about this during your education period.
Will I need to buy any supplies or equipment?
Most of the supplies and equipment will be provided by us. You may need to provide small items such as a table.

How much room do I need to store the supplies?
The supplies take up about as much room as a single bed. They can be stored in a spare room or in large cupboards. We can advise you on how to resolve storage problems so please ask the PD team about this.

- **PD schedule and visiting clinic**

  How long can I stay on PD?
  At Guy's and St Thomas' we recommend you transfer to haemodialysis after five years on PD, if you have not had a kidney transplant. This is because evidence has shown that after this time PD is less effective.

  How often will I need to come to clinic?
  You will need to come to clinic at least every four to six weeks for blood tests and assessment of your progress. Clinics are held at Borough Kidney Treatment Centre (near Guy's Hospital), Queen Mary's Hospital, Sidcup, and Tunbridge Wells Kidney Treatment Centre. You can attend at whichever site is most convenient.

### Questions people often ask about living with PD

**Will I be able to go away for day trips and on holiday?**
Using PD usually means you can continue to go away for days out and on holiday. An exchange can be done in any clean environment with a sink.

If you are planning a holiday, you need to talk to one of the PD nurses so that we can make arrangement for your fluid to be sent to where you are staying. If you are planning to go abroad, please discuss this with us as early as possible as there are some countries where PD fluid cannot be easily supplied.

**Will I be able to do any exercise?**
In most cases people find that they feel healthier after a few weeks of treatment. Following the catheter insertion, ask us about when it is safe to start exercising.

As with any exercise programme you should start slowly and gently, increasing the amount of exercise as you become stronger. You may need to drain the PD fluid out when doing any strenuous activities. Do not lift heavy objects as this increases the risk of developing a hernia.

**Can I swim?**
Swimming is a good form of exercise. However, we advise that you swim in a chlorinated pool as the sea and rivers can be contaminated. There is a special pouch that you can put over the catheter to prevent the exit site from getting wet. Please ask us for more information.
Should I stop smoking?
Yes! There is plenty of evidence to suggest that smoking greatly increases the risk of developing heart disease and other serious illnesses. The risks are greater in someone with kidney disease. Please ask for advice on how to stop smoking.

Can I drink alcohol?
Yes, but please seek advice from the dietitian and remember not to exceed your fluid allowance.

Can I still drive?
Using PD does not stop you driving. If you think there is any other medical reason why you should not drive, talk to your doctor.

Will I be able to carry on studying?
You should be able to do full or part-time study.

Will I be able to work?
Once you are established on PD, you should feel fit enough to work, depending on your job. Every situation is different but a PD schedule can fit around most jobs. Many people do a CAPD exchange during their lunch break. If this is not possible, APD may be more suitable. APD may also suit you if your job involves manual work or constant travelling. Some heavy lifting jobs are unsuitable for people using PD. Talk to the PD team if you have any questions or concerns.

Sex
Using PD does not mean you have to stop having sex. As long as you feel physically comfortable and have the desire you can continue as normal. You may find it more comfortable to drain the dialysis fluid out before you have sex. With APD you may wish to stop the machine and restart the programme afterwards.

What if I want to start a family?
Pregnancy is rare in women using PD. You would require very close monitoring and for this reason it is advisable to discuss the advantages and disadvantages with your doctor before trying for a baby. Men on PD can successfully father children but usually the sperm count is low. This will usually return to normal after a transplant.

Contraception
Although pregnancy is rare in women using PD, it is possible so it is important to use contraception to avoid an unplanned pregnancy. Various methods of contraception can be considered. Please discuss this with the PD team or your doctor.

Erectile dysfunction (difficulties getting and keeping an erection)
As a kidney patient you may have reduced interest in sex and erectile dysfunction may be a problem for men. However, once you are established on PD desire often returns. Please discuss any concerns with the PD team as it is possible to refer you to a specialist doctor or nurse for advice.
Further information

Contact us
If you have any questions or concerns about PD, please contact the PD team on 020 7188 5133 (Monday to Friday, 9am to 5pm).

A variety of support services are available from the kidney team. Help can be given throughout your treatment and can begin at any stage. This is available for you and your family.

Peer Support
Peer support aims to provide support for kidney patients and their families. It provides an opportunity to talk to an experienced kidney patient or carer on a one-to-one basis.
t: 020 7188 7924

Psychologists
Psychologists provide assessment and counselling services. They can help patients cope with and adjust to living with kidney disease. t: 020 7188 9770 / 7845

Social workers
Social workers offer advice and assistance with finance, housing, work and legal issues. They can also give you practical information about services available from your local social services department.
t: 020 7188 4023 / 5684

Support organisations

Guy’s and St Thomas’ Kidney Patients Association
Supports kidney patients at Guy’s and St Thomas’ hospitals, their families and carers
t: 020 7188 7552
e: info@gsttkpa.org
www.gsttkpa.org

National Kidney Federation
Charity providing information on kidney disease and its treatment	t: 0845 601 02 09
w: www.kidney.org.uk

Kidney Research UK
Produce a variety of free publications, leaflets and DVDs, to help kidney patients and their families get the information they need on kidney disease
t: 0845 070 7601
w: www.kidneyresearchuk.org

British Kidney Patient Association
Charity that provides support and information to people with kidney disease
t: 01420 541424
w: www.britishkidney-pa.co.uk
Carers UK
Charity that provides expert advice, information and support to carers
\textit{t:} 0808 808 7777
\textit{w:} www.carersuk.org

Diabetes UK
Charity that provides information, advice and support to help people with diabetes
\textit{t:} 020 7424 1000
\textit{w:} www.diabetes.org.uk

Pharmacy Medicines Helpline
If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.
\textit{t:} 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
\textit{t:} 020 7188 8801 (PALS) \textit{e:} pals@gstt.nhs.uk
\textit{t:} 020 7188 3514 (complaints) \textit{e:} complaints2@gstt.nhs.uk

Language Support Services
If you need an interpreter or information about your care in a different language or format, please get in touch:
\textit{t:} 020 7188 8815 \textit{e:} languagesupport@gstt.nhs.uk

NHS 111
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
\textit{t:} 111

NHS Choices
Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.
\textit{w:} www.nhs.uk

Get involved and have your say: become a member of the Trust
Members of Guy’s and St Thomas’ NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:
\textit{t:} 0800 731 0319 \textit{e:} members@gstt.nhs.uk \textit{w:} www.guysandstthomas.nhs.uk/membership