

Useful information for new Peritoneal Dialysis (PD) patients

Introduction

This leaflet gives you information on how your stock, deliveries, waste disposal and holidays will be managed. It also gives you information about your care and the support available.

Together with support from your renal consultant and the Peritoneal Dialysis (PD) Nursing Team, you have started your dialysis treatment in the form of Continuous Ambulatory Peritoneal Dialysis (CAPD) or Automated Peritoneal Dialysis (APD).

Training

You will have been trained in the use of CAPD/APD by one of the PD nurses. We are a small team and are always pleased to be able to answer any of your queries. Our contact details are at the end of this leaflet.

Delivery of equipment and its storage

Your first delivery of dialysis fluid and additional items will be within the next 2 weeks. This will be enough stock for 3 to 5 weeks. The order will include 5 to 7 days of overlap stock. You should always keep your overlap stock at this level. This is to make sure that you do not run out if there are problems with your order or delivery.

We ask that you carefully check your delivery note against all the items sent before signing for them. Please tell us if anything is wrong. We are here to help you if you are unsure.

The driver will put your stock delivery where you have asked for it to be placed. The driver will also rotate your stock to make sure you use the older items first so that your bags never go out of date.

The delivery drivers are used to giving such a personal service and you should find them kind and helpful.

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Renal Services

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Patient Information

When storing your fluids, please note that they should be stored between 4°C and 30°C. This is a 'cool' to summer temperature. If storing your fluids in a cold area, please make sure you protect them with padding and bring them up to room temperature before use.

You may be offered something called a key 'holding' service which can give you freedom to go about your day on the date of your stock delivery. This is a secure service where the supplier is given a key to your property. Please ask your PD Unit for details if you are interested.

Alternatively, you may be happy for another person, such as a neighbour, to have a key to a shed or garage, so that stock deliveries can be made in the future, when you are not at home. The suppliers also offer a text messaging service to remind you that your delivery is due. This text gives you a 4 hour time slot for the delivery.

Your machine will be delivered straight to your home by the supplier.

You may be supplied with a fluid warmer box from your PD unit if you are on CAPD. This box will need regular servicing as shown by the date on the side of the box. Please bring this box to your PD unit before the expiry date and we will replace it with a newly serviced heater.

Your stock

If you notice any stock that may be going out of date, please tell the supplier when they telephone you.

This stock will be replaced when your next order is delivered. The supplier will call you 1 week before your delivery to check your stock levels on that day.

The supplier can then make sure that you have the right amount of stock delivered to you the following week.

Before this call, you will have received something called a 'stock sheet' in the post. This will show the ideal levels of stock that you need, these are known as 'target levels'. The supplier will always aim to top-up your stock to this target level, using the information you give them.

**Patient
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Running out of stock

If you feel you are under or over-stocked, please let us know so that any changes to your prescription can be made.

Keep a check of your stock levels and be careful not to let them run low. Transport may be a problem on the odd occasion for the supplier, so your overstock level may get used.

If you do find that your overstock level is running low, items can be sent by courier. This can be costly so please try to keep your stock levels up.

If you are coming to clinic before your next delivery and we can help with a small quantity of items, please telephone us and we will have these items ready for you to collect. You can email your stock list to the supplier if you wish.

Going on holiday

For your annual holiday, deliveries of your fluids can be made almost anywhere in the world.

Before booking a holiday, please note that it is your responsibility to contact your renal consultant, to check that you are fit enough to travel. You must also contact your PD Unit and let them know the name and delivery details so that your fluids arrive at your destination before you do. In regards to your holiday transport, again it is your own responsibility to let your travel agent know that you are a dialysis patient, travelling with medication.

As a guide, you need to contact your renal consultant and PD Unit:

- for UK holidays - 6 weeks before your holiday.
- for holidays in Europe - 10 weeks before your holiday.
- for other international holidays - 16 weeks before your holiday.

There are times when earlier notification may be possible, but this would need to be discussed with your renal consultant and PD Team, as well as having customs clearance.

Patient Information

Once we have given these details to the supplier, your fluids will be delivered to the address you have given, about 1 week before your arrival. Together, we will make sure that these fluids have reached your holiday address and you will be left with only your extra items to transport, along with your machine, if you are on APD.

About 1 week before travel, you will be sent contact details of the nearest renal unit and a list of the stock being delivered.

You must take all other supplies for your dialysis with you from your home stock.

Waste collection

Your waste bags will be collected by your local council, along with your normal household waste. You will need to let your local council know that you are including PD waste along with your household waste, which you will double bag and fill to only half to three quarters full. Extra waste bags may be provided by your council, but you will also receive plenty in your regular dialysis stock.

If you have a sharps bin, when full, this can be returned to your local hospital or GP surgery for incineration.

Utilities

As a home dialysis patient, you may be given priority consideration from certain companies. Your telephone company may run an 'at risk' register for home dialysis patients. This is a register of customers who are dialysis patients who can apply to have their landline repaired as a priority, due to the fact that you carry out CAPD/APD at home and need emergency contact with your hospital from home. You can contact your telephone company directly from your landline.

You may wish to contact your electricity supplier to see if they can add you to an 'emergency repair' scheme, in the event that your electricity is cut off for any length of time and to discuss your tariff.

As a PD patient, you are entitled to receive a payment towards your electricity costs as you either use a fluid warming box if you are on CAPD, or you use your APD machine overnight. Please ask your PD Nurse for details on how to apply.

Patient Information

You will need to give the same details to the company who supplies your water, as water is a vital part of your care. They may be able to 'cap' your water charges so that you do not pay more than the average person in your area.

Please note that your water supplier should provide you with bottled water if the water needs to be turned off.

Remember to run the water through your taps for up to 1 hour after your water supply comes back on, before using tap water for your dialysis.

Remember to clean your shower head once a month.

Benefits

You are entitled to a free 'Safe and well' visit by Gloucestershire Fire and Rescue Service. If you are concerned about fire safety in your home, call them on:

Tel: 01452 888 7477 or 0800 180 4140 (freephone)

You may be able to receive a reduction in your council tax due to your condition. Please contact your local council for further details.

You may also be able to claim benefits such as the Personal Independence Payment (PIP), or Attendance Allowance. Visit the website: www.gov.uk/pip for more information.

As a PD patient, you are entitled to an NHS medical exemption certificate and will not have to pay for prescriptions. Visit website www.nhs.uk/using-the-nhs/help-with-health-costs/get-help-with-prescription-costs.

You may wish to change the conditions of your home insurance now you are using dialysis at home, to cover accidental spillages.

Please remember to always have to hand an emergency lighting kit. This should include a torch in case of dim or no light during your dialysis session.

**Patient
Information**

Charitable help

Gloucestershire Kidney Patients' Association (GKPA) offers excellent support if you would like it. They are terrific fundraisers; all funds raised are used locally.

Our consultants like us to let GKPA know about you and in return they will tell you about any events coming up, newsletters and any local support available.

GKPA sponsor and donate regularly to our unit, providing equipment for your dialysis such as fluid warmers, drip stands, scales and blood pressure machines.

Renal Registry

You have the right to opt out of the national Renal Registry. This is a database of information that is held in all Renal Units in the UK. The register holds information about your condition, but is not patient identifiable. This information is shared amongst doctors to make sure they offer best practice in renal care.

If you wish to have your details taken off the Renal Registry, please ask the one of the PD Team for the appropriate form.

Contact information

Ward 7b (Inpatient unit)

Tel: 0300 422 6768

The ward-based team are available 24 hours a day, if you need any help.

If you are in doubt about any aspect of your care, please contact the Renal Out-Patients Team based in Gloucestershire Royal Hospital; made up of the following:

PD Co-ordinator/Administrator

Tel: 0300 422 6890

Monday to Friday, 8:00am to 4:00pm

E-mail: karen.williams40@nhs.net

PD Nurses

Tel: 0300 422 6761

Monday to Friday, 8:00am to 4:00pm

Email: ghn-tr.pd.nurses@nhs.net

Patient Information

Renal Access Nurse

Tel: 0300 422 6270

Monday to Friday, 8:00am to 4:00pm

Renal Anaemia Nurse

Tel: 0300 422 6766

Monday to Thursday, 8:00am to 4:00pm

Email: ghn-tr.renalanaemianurse@nhs.net

If you are unable to speak to a member of the team straight away, please leave a message on their answer phone. If your call has not been returned within 1 hour, please contact **Ward 7b**.

Reminder

- Think about the key holding service.
- Make sure you have your stock list – ask your PD Co-ordinator if you have not received this in the post from the supplier.
- Never run low of stock – keep 5 to 7 days of all stock at all times.
- Council waste collection – add your dialysis waste to your household waste which is collected every 2 weeks.
- Make sure you have emergency lighting, such as a torch, to carry out your dialysis.

Checklist

- Request an extra household waste bin from your local council.
- Apply for Council Tax reduction if you are entitled.
- Apply for your Utilities payment through your PD Team.
- Contact providers to be added to their 'At Risk' register for your landline, electricity and water.
- Apply for PIP if you are under 65 or Attendance Allowance if you are over 65 (Age Concern can help you complete the form).
- Apply for your NHS Exemption Certificate if you do not already have one.

Patient Information

- Review your home insurance.
- Think about asking for a free 'Safe and well' visit from Gloucestershire Fire and Rescue Service.
- Think about joining GKPA if you are not already a member.
- Consider joining Patient Knows Best, which is a web-based site for renal patients to gain access to their blood results. You will be given a leaflet explaining how to register by your PD team, if you have not already received one prior to starting dialysis.

Further information

Patient Knows Best

Website: www.patientknowsbest.com

Gloucestershire Kidney Patients' Association

Website: www.gloskpa.org

Kidney Care UK

Website: www.kidneycareuk.org

National Kidney Federation (NKF)

Website: www.kidney.org.uk

Kidney Patient Guide

Website: www.kidneypatientguide.org.uk

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Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<https://aqua.nhs.uk/resources/shared-decision-making-case-studies/>