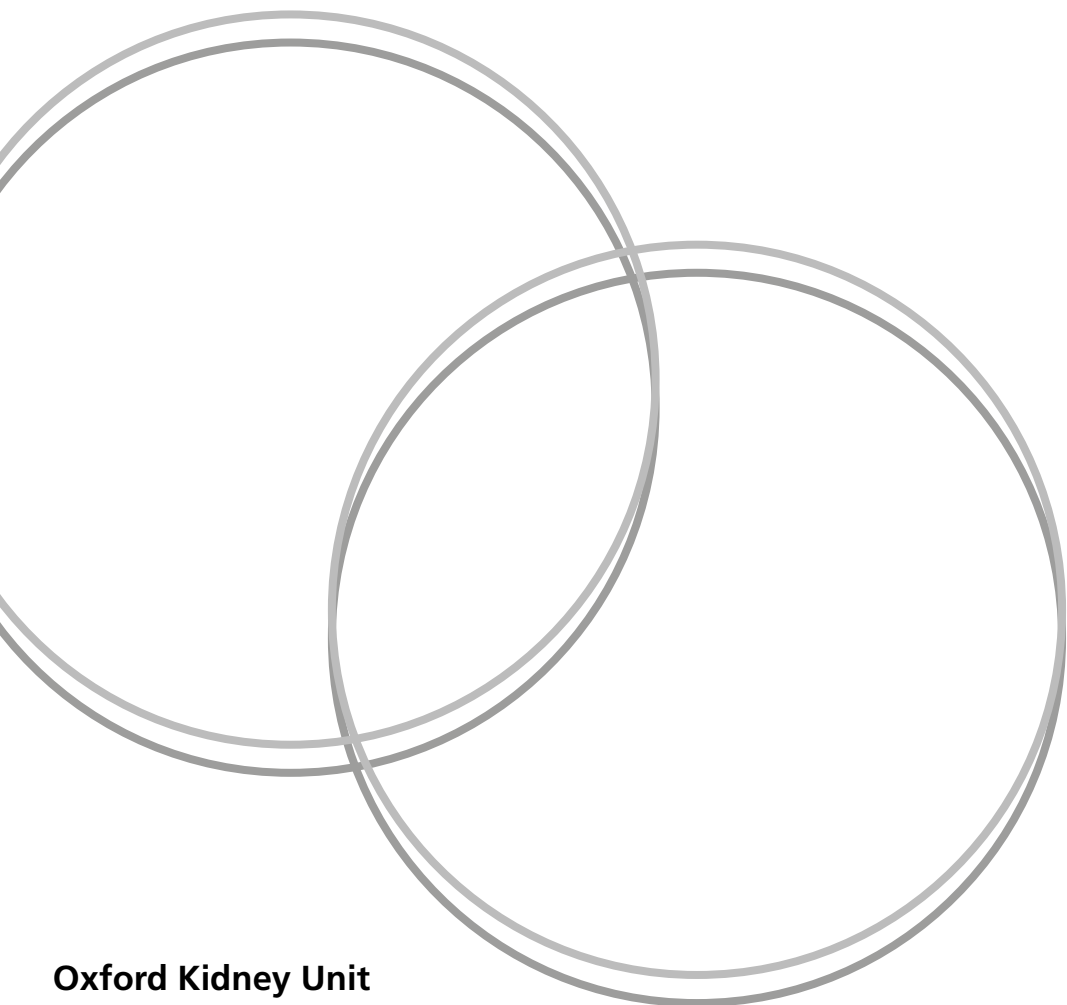




Oxford University Hospitals  
NHS Foundation Trust

# I'm thinking of stopping dialysis

Information for patients



Oxford Kidney Unit

If you are receiving dialysis treatment (peritoneal dialysis or haemodialysis) and you or your family or friends would like information about considering stopping dialysis, then this leaflet is for you.

Some people find dialysis very difficult to cope with.

This may be because:

- You have other long-term conditions that are getting worse and there are no treatments that can improve these.
- Your quality of life is no longer giving you pleasure.
- Dialysis is making your life unbearable, such as always experiencing a low blood pressure.

Some people in this situation decide they want to stop dialysis. If you are depressed this can make dialysis feel overwhelming and difficult. Depression can often be treated. If you are experiencing any symptoms of depression it is important that you discuss these with your kidney team before you make a decision to stop dialysis.

# **Who should I talk to if I'm thinking of stopping dialysis treatment?**

The decision to stop dialysis treatment is a personal one. Your kidney doctors and nurses will help you decide what is important for you and if stopping dialysis is the right decision.

You don't have to make a decision straight away. Talk to someone who makes you feel comfortable and who may be able to help you decide what to do. This may be your named nurse, your kidney doctor or someone outside of the kidney unit.

Talking about stopping dialysis can be very difficult. You may experience lots of emotions. You may also find it a relief to be able to talk about the end of your life. It can provide an opportunity for planning and sharing your wishes. Your kidney doctor will answer your questions openly and honestly.

# What will happen to me if I stop dialysis?

Everyone is different. Most people who stop dialysis die from kidney failure. For some people this happens quite quickly (within days to weeks after stopping dialysis), while occasionally some people may not develop symptoms from their kidney failure for a few weeks after stopping dialysis (especially if you have not been on dialysis for very long).

If you stop dialysis you may experience some of the following symptoms:

- **You may feel sick** – we can give you some medication to help stop this.
- **You may feel itchy** – try to keep your skin moisturised by using an emollient. We may also be able to give you some medication to help with itching.
- **You might not feel like eating** – If you do feel like eating and drinking don't worry about what you eat, you won't need to follow any renal diet. If you find it difficult to swallow your tablets we can give you medication in other ways.
- **Your breathing may change** – If you no longer have dialysis you might find that fluid builds up in your body. This can make you feel short of breath. Your doctor or nurse can give you medication to help with this.
- **You may become sleepy** – Once you stop dialysis you are likely to become more tired and spend longer amounts of time sleeping. Towards the end of life, people tend to spend more and more time asleep. When they are awake they are often drowsy and show less interest in what is going on around them.

We will work closely with you to make sure that you are comfortable and any symptoms are well managed.

## **Will I have any pain?**

You are unlikely to have any pain; if you do, it is usually because of other problems you might already have, such as arthritis. Your doctor or nurse will offer you painkillers, so that you are comfortable.

## **Who will support me if I stop my dialysis treatment?**

If you decide to stop dialysis we will discuss with you when you want to stop and will organise the right support for you. It may take a few days to arrange the care you need. You may wish to give some thought to where you would like to be cared for.

If you remain at home, your GP will be responsible for your care and will work closely with the community nurses to make sure you are supported.

If your kidney team or community team feel you need additional help and support then you may be referred to the Palliative Care Team. They can help support you wherever you are being cared for. They can offer treatment for your symptoms and psychological support for your family and carers.

Although other teams will be responsible for your care, your named dialysis nurse and Patient Support Advisor from your local dialysis unit may also be in contact with you and your family.

If you would like to talk to a member of the Pastoral Care team we can arrange this for you.

# Where can I find more information?

## Useful contact telephone numbers

### **Oxford Peritoneal Dialysis (PD) Unit**

Tel: **01865 225 792**

(8am to 6pm, Monday to Friday)

Email: [pd.team@ouh.nhs.uk](mailto:pd.team@ouh.nhs.uk) (between 8.30am and 4.30pm)

### **Wycombe PD unit**

Tel: **01494 426 349**

(8am to 6pm, Monday to Thursday)

### **Swindon PD unit**

Tel: **01793 605 288**

(8am to 6pm, Monday to Friday)

### **Milton Keynes PD unit**

Tel: **01908 996 465**

(8am to 4pm, Monday to Friday)

The PD nurses may be visiting people at home, so all units have an answerphone telling you who to contact if no one is available.

## **Main Dialysis unit, Oxford**

Tel: 01865 225 780

## **Tarver Dialysis Unit**

Tel: 01865 225 695

## **Milton Keynes Dialysis Unit**

Tel: 01908 996 496

## **Stoke Mandeville Dialysis Unit**

Tel: 01296 316 996

## **Banbury Dialysis Unit**

Tel: 01295 229 811 or 01295 224130

## **High Wycombe Dialysis Unit**

Tel: 01494 426 347

## **Swindon Dialysis Unit**

Tel: 01793 605 286

## **Renal Ward Churchill hospital**

Tel: 01865 225 780

24 hours, including weekends and bank holidays

## **NHS website**

A guide for people who are approaching the end of their life.

Website [www.nhs.uk/conditions/end-of-life-care](http://www.nhs.uk/conditions/end-of-life-care)

## **Oxford Kidney Unit**

The website has lots of information about the Oxford Kidney Unit for patients and carers.

Website: [www.ouh.nhs.uk/oku](http://www.ouh.nhs.uk/oku)

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

*Making a difference across our hospitals*

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

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[www.ouh.nhs.uk/information](http://www.ouh.nhs.uk/information)

