I’m thinking of stopping dialysis treatment
Information for patients
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. They might feel unwell during or after dialysis or just feel that day to day living is a struggle. Sometimes these symptoms can be improved by changes to medication or the dialysis treatment, but it is not always possible to make life easier.

Some people in this situation decide they do not want to continue life prolonging treatment. However, sometimes being depressed can make people feel like stopping dialysis. If you are thinking about stopping dialysis, it is important you and your kidney doctor discuss whether you have any symptoms of depression, as these might respond to treatment and may affect your feelings about dialysis.
Who should I talk to if I’m thinking of stopping dialysis treatment?

The decision to stop dialysis treatment is a personal one made by you. Your kidney doctors and nurses will support your decision and will talk to you and your family about what will happen if you stop dialysis.

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, such as fear, crying and sometimes anger. 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 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. You may need some medication to help stop you feeling sick. If you find it difficult to swallow your tablets then 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 sensation.

• **You may become sleepy** – If you stop dialysis you are likely to become more tired. 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.

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 Advisors 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?

If you are thinking about stopping dialysis, or would just like to talk about it, please speak to your named nurse. They will arrange for you to see your kidney doctor.

**Useful contact telephone numbers**

- Oxford Haemodialysis Unit 01865 225 807
- Tarver Dialysis Unit 01865 225 695
- Milton Keynes Renal Unit 01908 996 496
- Stoke Mandeville Renal Unit 01296 316 997
- Wycombe Renal Unit 01494 426 352
- Horton Dialysis Unit 01295 229 811
- Swindon Renal Unit 01793 605 291
- Oxford Peritoneal Dialysis (PD) Unit 01865 225 792
- Milton Keynes Peritoneal Dialysis (PD) Unit 01908 996 495
- Swindon Peritoneal Dialysis (PD) Unit 01793 605 288
- Wycombe Peritoneal Dialysis (PD) Unit 01494 426 349
If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

Author: Nadine Merson
Reviewed by Renal PIL Group
May 2016
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Oxford University Hospitals NHS Foundation Trust
Oxford OX3 9DU
www.ouh.nhs.uk/information