



**York and Scarborough  
Teaching Hospitals**  
NHS Foundation Trust

# **A carer's guide to living with kidney failure**

Information for families and carers

**Hospital Social Work Team**

① For more information, please contact:

Renal Social Workers

Telephone: 01904 721900

The York Hospital, Wigginton Road, York, YO31 8HE

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Having a relative with kidney failure can affect everyone in the family, and this leaflet is designed to focus on the help that is specifically available for informal carers.

## **What is a carer?**

Many people see it as their duty to support those closest to them and so would not recognise themselves as carers. The care you provide may be in the form of help with personal care (washing, bathing, dressing, feeding), and/or with medication, cooking, shopping, housework and giving emotional support. Carers can be any age. They are parents, grandparents, children, partners, friends or neighbours who are doing what needs to be done to maintain the quality of life for someone close to them, and many areas offer services specifically for young carers.

The Care Act was introduced in 2015 and is designed to ensure that carers are in control of the support they receive. If you provide a substantial amount of care to a family member or friend on a regular basis, even if you do not live with them, you are entitled to a carer's assessment from your local authority and support from your renal social worker. This assessment will look at your needs and how you can be supported as a carer to maximise your well-being as well as that of the cared for person. This will include ensuring that you are claiming all the benefits and receiving all the practical help you are entitled to, looking at how to support you to stay in work and the services available to offer emotional support.

## **Being a carer has its ups and downs...**

Many carers enjoy supporting someone who is important to them and often coming to terms with kidney failure together brings people closer to each other than ever before.

However, being a carer is not always easy. As well as the practical work of being a carer, which can be very tiring, there are emotional consequences that can be very difficult to deal with.

Carers may worry about the future, but having more understanding of the symptoms that may be experienced by the person you are caring for can help.

The symptoms associated with kidney failure can change over time and no two people will be affected in exactly the same way. Some people have only a few symptoms and others may have more, but they may be able to find ways of managing them. The symptoms may include:-

- tiredness
- feeling out of breath
- feeling sick
- having difficulty sleeping
- cramp and restless legs
- finding it harder to think and concentrate

Some people of working age will find that they can continue working, whereas others will need to reduce their hours or may need to change jobs if their current post involves working long hours or spending extended periods of time away from home. Help may be available from the Jobcentre to keep a person in work as employers are legally obliged to make reasonable adjustments in order to enable a person with health problems to continue to work.

The type of dialysis a person has will also impact on when and where they are able to work.

**Haemodialysis** usually takes place in hospital on alternate days and treatment sessions generally last four hours. Some people arrange to work on their dialysis-free days and others opt to have their dialysis in the evening and work during the day. However, dialysis treatment has to remain as a regular weekly pattern. It should be possible to fit the person you care for into their preferred shifts, although this may not happen immediately. Some people can be trained to carry out their **haemodialysis** at home, and treatment times can then be more flexible to enable them to fit around work commitments. Home treatment can be more daunting for carers, but they will be involved in the training and there is always a specialist nurse on hand to offer advice in the event of difficulties.

**Peritoneal dialysis** is an alternative form of treatment that involves placing dialysis fluid into your peritoneal cavity through a plastic tube in your abdomen. It is often preferred by people of working age as it is more flexible and usually takes place at home. Treatment often takes place overnight via a machine (**Automated Peritoneal Dialysis**), or it can be carried out manually either at home or at work (**Continuous Ambulatory Peritoneal Dialysis**). The fluid exchanges take between 20 and 30 minutes and usually need to be carried out three to four times a day.

Carers are likely to be more involved in helping with home dialysis and will be given training where necessary. The PD nurses are always on hand to help with any problems including being on call overnight in the event of urgent problems. As well as assisting with clinical tasks, in the case of PD carers may need to move heavy bags of fluid into storage and help dispose of clinical waste.

Some carers feel frustrated because the person they are caring for can no longer do as much as they used to. This may mean that they become isolated because they no longer feel able to leave their loved one for long periods and so have to give up hobbies, and it may be hard to go out socially as a couple when patients have fluid and dietary restrictions. Nearly everyone feels angry and resentful at some point. And then they may feel guilty or selfish about having these kinds of emotions.

It may be difficult for you to discuss your feelings with the person you are caring for, but it is important that you make sure others are aware of your responsibilities.

**Tell your GP that you are a carer** - they will record this on your notes and they may be able to offer you extra support.

**Talk to your friends and family** – they may not be aware of the level of care you provide. Don't try to cope alone. They may be able to support you and help you take a break. As well as help from the social worker, the renal service includes psychologists who are there to support family members as well as patients, and there are dedicated counselling services for carers as well as helplines and support groups organised through local carers' centres.

**Watch your stress levels** - Taking regular exercise and learning relaxation or meditation can help to reduce stress and make you feel better able to cope with being a carer. Some carers' centres organise special sessions focusing on health and well-being as well as giving opportunities for carers to share their stories with other people in similar situations.

**Speak to a renal social worker** – For City of York residents, we can complete a carer's assessment and set up care packages for the cared -for person. For both City of York residents and residents in other local authorities, the renal social work team can help you and the cared-for person with a number of practical and emotional issues that might be impacting your wellbeing, such as: supporting you with finances, work-related and housing issues, applying for charitable and holiday grants, liaising with other agencies, providing information about other organisations and supporting you with planning for the future. Contact details can be found at the end of this guide.

### **'Carers Credit' – help with your pension if you are caring for someone**

If you have given up work to care for someone, your pension may not be your first concern. However, if your working life is interrupted because your paid job ends it can impact on your pension longer term.

'Carers Credit' helps build National Insurance contributions for those taking time away from work including carers. Recent Department of Work and Pensions figures show that 95% of eligible carers don't claim it.



Full information about this and how to help maximise your pension if you have given up work to care for someone can be found on the **Carers UK website** <http://www.carersuk.org/help-and-advice/financial-support/help-with-your-pension>.

## **Carers' centres**

### **York Carers' Centre**

17 Priory Street York

Telephone: 01904 715490

Email: [enquiries@yorkcarerscentre.co.uk](mailto:enquiries@yorkcarerscentre.co.uk)

Website: [www.yorkcarerscentre.co.uk](http://www.yorkcarerscentre.co.uk)

We work in partnership with carers, statutory and voluntary organisations to ensure carers throughout York have access to confidential information, advice and support. We work with carers to influence positive change in service delivery with local government, employers and health providers.

The telephone lines are open Monday to Thursday 9am to 5pm and Friday 9am to 4.30pm for information and advice.

We have an evening Advice Line on Wednesdays from 5 to 8pm

## **Scarborough and Ryedale Carers' Resource**

96 High Street  
Snainton  
Scarborough  
YO13 9AJ

Telephone: 01723 850155

E- mail: [staff@carersresource.net](mailto:staff@carersresource.net)

Text: 07527 678172

We provide advice and information, assistance to maximise your income, a listening ear, information on volunteering and employment and a young carers' service.

## **Ryedale Carers' Support**

The Old School  
Tinley Garth  
Kirkbymoorside  
York  
YO62 6AR

Telephone: 01751 432288 (please leave a message if no-one is in)

E-mail: [enquiries@ryedalecarers.org.uk](mailto:enquiries@ryedalecarers.org.uk)

Website: [www.ryedalecarers.org.uk](http://www.ryedalecarers.org.uk)

We offer practical and emotional support for carers, the people they care for and older people living on their own.

We have volunteers who can visit weekly, fortnightly or monthly for a couple of hours or so. We provide a free sitting service to give carers a break, a visiting service for elderly people with few social contacts who would welcome company, and we run monthly support groups for carers throughout the area.

## **East Riding**

18 Wednesday Market,  
Beverley  
HU17 0DJ

Telephone: 0800 917 6844 or 01482 396500

Email: [Ercarers@eastriding.gov.uk](mailto:Ercarers@eastriding.gov.uk)

## **Selby District Carers Count - carers' resource and support**

Community House  
Portholme Road  
Selby  
North Yorkshire  
YO8 4QQ

Email: [selbydistrict@carerscount.org.uk](mailto:selbydistrict@carerscount.org.uk)

Website: [carerscountselbydistrict.org.uk](http://carerscountselbydistrict.org.uk)

Telephone: 0300 012 0415 (local call rate)

Opening hours: Monday – Friday 9am – 5pm

This service is run by Cloverleaf Advocacy, delivering focused support to adult carers across the Selby area, including practical advice; emotional support; carers activities and support groups; benefits advice; advice on health and social care services; referrals to other support organisations; advice on employment and training; and carers assessments.

### **Hambleton and Richmondshire Carers' Centre**

2 Omega Business Village, Thurston Road,  
Northallerton, DL6 2NJ

Our office is open for you to call in: 9.00am till 5.00pm  
Monday to Friday

Telephone: Our telephone line is open: 9.00am till  
5.00pm Monday to Friday.

Telephone number: 01609 780872

Text: 07443980375

### **Harrogate Carers' resource**

11 North Park Road  
Harrogate, North Yorkshire  
HG1 5PD

Email: [info@carersresource.org](mailto:info@carersresource.org)

Website: [www.carersresource.org](http://www.carersresource.org)

Telephone: 01423 500555

Fax: 01423 507777

Harrogate carers' resource is an independent Yorkshire charity which gives tailored information and support to carers, those in need of care and support and the professionals who work with them. Its services support people to remain independent and have choice and control to improve their lives or situations.

It provides quarterly bulletins, runs a careers service for those seeking employment or learning opportunities and also offers access to a range of social groups and activities.

### **Carers' counselling service – York Mind**

This is a service specifically developed for people who care for others with any mental, physical or other disability, and offers emotional support and counselling. We ask that those accessing the service contribute a minimum of £10 per session to help ensure the continuation of the service for everyone.



Caring for someone can be emotionally demanding, no matter how much you love and care for them.

Sometimes when caring for others it may feel like you are neglecting your own emotional needs. The Carers' Counselling Service provides a space for you to talk about the issues that are important to you in order to help you cope. There is a time limit with this service, which is currently set at 12 weeks.

Contact us if you would like more information about the Counselling Services at York Mind: Tel 01904 643364, email: [counselling@yorkmind.org.uk](mailto:counselling@yorkmind.org.uk)

### **York Carers' Forum**

York Carers Forum offers support to all unpaid carers over 18 living or caring in the City of York area and:

- provides a focus across all care groups
- promotes carers needs
- gathers and shares information for carers
- identifies carers' needs
- works with agencies to develop appropriate services

York Carers Forum meets regularly and holds many social events for carers.

## **Get in touch with York Carers Forum**

**write:** Katie Smith, York Carers Forum, c/o 15, Priory Street, York, YO1 6ET

**email:** [yorkcarersforum@tiscali.co.uk](mailto:yorkcarersforum@tiscali.co.uk)

**phone:** 01904 422437

## **Young Carers Revolution**

Young Carers Revolution (YCR) provides empowerment and influence to young carers and young adult carers (8 to 25 years) in York. Its purpose is to be proactive in influencing services provided for them by statutory and voluntary organisations.

For more information please visit their blog:

<https://ycryorkuk.wordpress.com/> or follow them on

Twitter: [twitter.com/YCRyork](https://twitter.com/YCRyork)

## **Online community**

Join up for support, information, friendship and chat with other carers.

<https://www.carersuk.org/forum>

Forum for adult carers; includes a section for young adult carers aged 18-35

## **Renal Team – Contact Details**

### **Pre-dialysis/conservative care nurses**

Telephone: 01904 721325 or 725486

### **PD nurses**

Telephone: 01904 726329

### **Home haemodialysis nurse**

Telephone: 01904 721851

### **Renal admin**

Telephone: 01904 725370

### **Haemodialysis unit nurses**

Telephone: 01904 725371 (York)

01904 724800 (Easingwold)

01423 554513 (Harrogate)

### **Renal social workers**

Telephone: 01904 721900





## **Tell us what you think of this leaflet**

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

Renal Social Workers, Hospital Social Work Team,  
City of York Council, York Hospital, Wigginton Road,  
York, YO31 8HE or telephone 01904 721900.

## **Teaching, training and research**

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

## **Patient Advice and Liaison Service (PALS)**

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email [pals@york.nhs.uk](mailto:pals@york.nhs.uk).

An answer phone is available out of hours.



# Leaflets in alternative languages or formats

Please telephone or email if you require this information in a different language or format, for example Braille, large print or audio.

如果你要求本資 不同的 或 式提供，電  
或發電

Jeżeli niniejsze informacje potrzebne są w innym języku lub formie, należy zadzwonić lub wysłać wiadomość e-mail

Bu bilgileri değişik bir lisanda ya da formatta istiyorsanız lütfen telefon ediniz ya da e-posta gönderiniz

Telephone: 01904 725566

Email: [access@york.nhs.uk](mailto:access@york.nhs.uk)

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