



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

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 York 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

Website: 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.

We provide advice on benefits and care, working and caring, supporting someone with mental ill health or someone with an addiction, and we carry out carers' assessments, offer counselling and run a number of support groups. Our newsletter gives details of all our activities.

The telephone lines are open Monday to Friday 9.30am to 4.30pm (4pm on a Friday) for information and advice. We have an evening Advice Line on Wednesdays from 5 to 8pm

Carers Plus Yorkshire

96 High Street, Snainton, Scarborough, YO13 9AJ
Telephone: 01723 850155
E- mail: admin@carersplus.net

The Adult Carer Service

Provides impartial information, helps maximise your income, offers a listening ear, signposts and refers on, gives guidance to navigate obstacles, social opportunities, family & bubble support and provides carers with a voice.

The Young Adult Service

Provides impartial information, helps maximise your income, offers emotional support, helps overcome personal barriers, provides training, learning and work opportunities, enables you to meet others like yourself and offers 1:1 support.

Home From Hospital

Offers helps with shopping, prescription collection, telephone/home visit support, liaison with health and social care professionals, helps to set up services and support for the future and provides emotional support for family and friends that are caring for a person that has been recently discharged from hospital.

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

Website: 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 Carers Service

Cross Street, Beverley, East Riding of Yorkshire,
HU17 9BA

Telephone: 01482 396500

Email: Ercarers@eastriding.gov.uk

Open Monday – Friday 9.30 – 4.30

The Carers Support Service is available to provide advice, information and services to recognise, value and support carers. If you need support with your caring responsibilities, we can find ways that may help you by discussing this with you and completing a carer's assessment. All carers receive a quarterly newsletter, which includes details of drop in sessions, legal clinics and money and benefit advice clinics and peer support groups across the East Riding.

Carers' Resource Selby District

Community House, Portholme Road, Selby. North
Yorkshire, YO8 4QQ

Website: www.carersresource.org/

Telephone: 0808 5015939

Opening Hours: Monday – Friday 9am- 5pm

Carers' Resource exists to support unpaid carers. We provide information, advice and support to carers, to the people they care for and to professionals who work with them. Our services include carers' identity and rights, health and wellbeing, planning and coping, money and benefits, events and groups, young carers, employment and education, Carers' Time Off and Home from Hospital.

Carers Plus Yorkshire

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

Email: admin@carersplus.net

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

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Carers' Resource Harrogate

Unit 3, Grove Park Court, Grove Park Terrace,
Harrogate, HG1 4DP

Email: info@carersresource.org

Website: www.carersresource.org

Telephone: 0808 5015939

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We can offer a wide range of services, including personal care, emergency cover, traditional home help (cleaning/shopping), personal assistants, hospital visiting, accompanied hospital appointments, accompanied outings, holiday cover, befriending, Individual Service Funds, carers' breaks and supported living care.

Counselling with York Carers Centre

If you are interested in accessing carers counselling through York Carers Centre, your first step is to register with us. You can do this online or contact our reception on 01904 715 490 who will be able to assist you with this over the phone. Please mention when you register that you are interested in carers counselling.

If you are already registered with us, and would like counselling specifically around your caring role, please email enquiries@yorkcarerscentre.co.uk or ring 01904 715490

Our website gives a list of local counselling providers, including on-line options.



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

By landline: 01904 422437 (+ answer machine)

By text and WhatsApp: 079 3939 4556

By e-mail: yorkcarersforum@yahoo.co.uk

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 the links on the York Carers Centre webpage:

<https://yorkcarerscentre.co.uk/young-carers/young-carers-revolution/> to find details of their publicity material designed to highlight the role of young carers and educate others.

Carers Connect, Carers UK's Online Community

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

<https://www.carersuk.org/get-involved/join-us/our-forum/>

Forum for adult carers; includes sections for young adult carers, ethnic minority carers and former carers.

Renal Team- Contact Details

Kidney care specialist nurses

Telephone: 01904 721325 or 725486

PD nurses

Telephone: 01904 726329

Home haemodialysis nurses

Telephone: 01904 721851

Renal admin

Telephone: 01904 725370

Haemodialysis unit nurses

Telephone: 01904 725371 (York)

01904 724800 (Easingwold)

01423 554513 (Harrogate)

01723 357810 (Scarborough)

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 yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:
www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

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