West Midlands Renal Network

NHS
Warwickshire

The Kidney Peer Supporter *Handbook*

West Midlands Renal Network

Contents

Introduction

The aim of this handbook is to provide a short practical guide on kidney Peer Support.

The guide is intended to give those kidney patients and carers who've been through the Peer Support training programme, together with staff working in kidney services an understanding of:

- What Peer Support is
- What Peer Support sets out to achieve
- The benefits of Peer Support
- The role of the Peer Supporter
- Where you can get support

It also provides some useful sources of information and contact numbers when providing Peer Support.

The handbook has been produced by a range of people involved in kidney care, including kidney patients, carers, doctors and nurses.

Peer Support

Nobody understands what people with chronic kidney disease are going through as well as people who have gone through the experience themselves.

The Kidney Peer Support service involves kidney patients helping other kidney patients who are facing similar situations. It aims to give short term practical, emotional and social support to people with chronic kidney disease, their families or carers based on common experiences. Peer Support offers an opportunity to have a one-to-one chat and share personal experiences and stories either face to face or over the telephone with an experienced kidney patient or carer.

Peer Supporters are ideally individuals who share similar life experiences, lifestyles and are approximately the same age. However, it is not always possible to match people in this way, depending on who has been trained to be a Peer Supporter, so you may find that sometimes you are asked to talk to someone who has had slightly different experiences to you. Often these people need just a friendly chat, but if you feel they need specific information that you cannot offer, please contact your Peer Support organiser.

Peer Support is intended to complement the care and education patients and carers receive from their kidney healthcare team. It is therefore an additional service which is available if wanted. It is not a substitute for the professional team and you should not be answering queries better suited to others e.g. about medication.

Benefits of Peer Support for chronic kidney disease

It is important for people with a long term condition such as chronic kidney disease to be given high quality support and information when making decisions about their treatment.

Peer Support offers benefits both for the people using the Peer Support service and for the Peer Supporters themselves.

People using Peer Support Services	**Peer Supporters**
Reassurance of knowing they are not on their own Increased confidence to make decisions and have better control over your life Sharing experiences of what works well and is helpful Good source of encouragement Can talk to someone who understands the challenges they're facing	Able to use your own personal experience to give others encouragement Positive experience by having the opportunity to contribute and give something back Draw satisfaction from supporting others to help themselves Helps you gain confidence

The role of the Peer Supporter

The role of the Peer Supporter aims to build upon an individual's experience and strengths. The following table gives examples of key experiences, skills and qualities needed, together with a list of requirements and a description of the Peer Supporter role.

Experiences	• Relevant condition and treatment experience from a variety backgrounds. This can include carers.
Skills and qualities	• Good communication • Sympathetic listener • Empathetic and non-judgemental approach • Ability to relate to and make others feel at ease • Understands and is able to explain about kidney disease, its treatments or procedures in simple terms • Ability to give encouragement • Ability to deal with possibly difficult and sensitive situations • Honest and trustworthy • Understands the importance of maintaining confidentiality and when to disclose concerns • Has knowledge of where to access other sources of information or support • Awareness of the boundaries of Peer Support
Role description	• Provide a voluntary service to kidney patients, their families or carers • Offer short-term confidential support and help to fellow patients with kidney disease and their families and/or carers • Listen to fellow patients' experiences in an open, non-judgemental and empathetic way • Share openly and honestly where appropriate own personal life experience of kidney disease, its treatments and practical knowledge of day-to-day issues • Provide practical information and signposting • Support others to care for themselves and follow medical advice, without giving medical advice • Be involved in a variety of patient education activity sessions • Discuss general questions on making treatment decisions and lifestyle • Promote the Peer Support service • Complete and maintain a Peer Support contact log • Maintain regular contact with identified Peer Support organiser/link nurse and escalate any concerns
Other requirements	• These vary depending which hospital you train in and you will be given more detailed information about this • Clearance from the Criminal Records Bureau (CRB) • Completed local Trust volunteer application form • Successful completion of the Peer Support training sessions • Local Trust induction session

What if you need support?

If you have any worries about what to do or how to deal with a situation please contact your local Peer Support organiser (see contact details at the end of the handbook) at your hospital Trust.

You may find it helpful to contact them when you feel:

- More help or specialist support may be needed
- You are unable to be honest and impartial
- Worried that the person might come to harm
- Concerned about your own circumstances
- You are not 'hitting it off' with the person you have been asked to support
- You feel that the patient being supported is not behaving in an appropriate way to you as a volunteer e.g. frequent phone calls

Your local Peer Support organiser will be able to decide on the best course of action. Please remember that if you have any anxieties about whether a person needs help from another member of the kidney team, it is important for you to refer it onto one of the kidney doctors or nurses. We as professionals can always approach the issue of concern with the patient without implicating you in anyway.

Remember that you are doing this role as a volunteer. Your unit will not be at all upset if you feel that you are unable to support or contact a particular patient. Please let them know if you feel uncomfortable or are unable to offer support at a particular period of time.

The unit will never give out your contact details to a patient requiring Peer Support: you can obviously do so if you wish to, but do not feel under any pressure to do so. If the supported patient wishes to contact you again they can always do so via the hospital Peer Support organiser.

Your unit may wish to contact the supported patient after you have had contact with them to check whether they found the Peer Support service helpful. This is not intended to check up on you but to allow collection of data (virtually always very positive) to promote Peer Support and if necessary apply for further funding to help run the service. You may also find that you are asked to take part in research about Peer Support. You obviously do not have to do this if you do not wish to.

Useful contacts

Hospital Trust	**Lead(s)**	**Contact Details**
Heart of England NHS Foundation Trust	Annette Dodds Bridget Ferris Dr Hugh Rayner	0121 424 2677 A specific email address has been created for peer support referrals. Emails will be checked Monday – Friday 8am – 4pm kidneysupport@heartofengland.nhs.uk
The Royal Wolverhampton Hospitals NHS Trust	Jean Shears	01902 695 466 (office receptionist) A specific email address has been created for peer support referrals. Emails will be checked Monday – Friday 9am – 5pm Rwh-tr.kidneysupport@nhs.net
Queen Elizabeth Hospital Birmingham	Dr Clara Day Haemodialysis Co-ordinator	0121 371 5853 (secretary) 0121 371 3006 A specific email address has been created. Emails will be checked Monday – Friday 8am – 4pm kidneysupport@uhb.nhs.uk

Useful sources of information

A range of information leaflets and fact sheets are available from your local kidney unit, Kidney Patients' Association or further kidney information can be obtained from:

Support Groups

There are a number of self help, patients' associations and support groups:

British Kidney Patient Association (BKPA)
Tel: 01420 472021/2
www.britishkidney-pa.co.uk

National Kidney Federation
Tel: 01909 544999
Helpline: 0845 601 0209
www.kidney.org.uk

Queen Elizabeth Hospital Birmingham Kidney Patients' Association
www.kidneymatters.co.uk

Transplant Support Network
Advice line: 0800 027 4490
www.transplantsupportnetwork.org.uk

Polycystic Kidney Disease Charity
Helpline: 01388 665004
www.pkdcharity.co.uk

Diabetes UK
Tel: 020 7424 1000
Helpline: 0845 1202 960
www.diabetes.org.uk

Expert Patient Programme
Tel: 01886 833186
www.expertpatients.nhs.uk

Other Useful Kidney Resources

Kidney Research UK
Tel: 0845 300 1499
www.kidneyhealth@kidneyresearchuk.org

Kidney Alliance
Tel: 01483 724 472
www.kidneyalliance.org

Renal PatientView provides online information about renal patients' diagnosis, treatment and latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world. PatientView is available to you if you wish to participate.
www.renalpatientview.org

"Living with Kidney Disease: What should you know" are two DVDs aimed at raising awareness and education to support anyone who has been told by their doctor that they have kidney damage. The first DVD is for people who have just been diagnosed with chronic kidney disease. The second DVD offers practical advice for people with advanced kidney disease. There are options to view the DVDs with subtitles in English and audio in Bengali, English, Gujarati, Hindi, Punjabi and Urdu. Copies can obtained from Kidney Research UK's health information line
Tel: 0845 300 1499
Email:kidneyhealth@kidneyresearchuk.org

Eurodial is an international dialysis organisation dedicated to the care and mobility of dialysis patients in Europe.
www.eurodial.org

The Kidney Patient Guide provides information for people with kidney failure.
www.kidneypatientguide.org.uk

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This handbook can be found on the West Midlands Renal Network's website www.wmrn.co.uk