



The Supportive Care Register

Information for patients with chronic kidney disease and their families

What is supportive care?

People who live with chronic kidney disease, often need increased help and support as their illness progresses. Some people need help with controlling the symptoms that the kidney disease produces. Others need more help with every day activities such as washing, dressing, shopping, and cleaning.

Some people want information about how their illness is likely to progress and help to plan their future care, including care at the end of their life.

What is the Supportive Care Register?

The Supportive Care Register is a way of highlighting those people who are likely to be in need of added support, whether they are on dialysis, have had a transplant, or have chosen not to have dialysis.

The aim of the Supportive Care Register is to make sure that those in need of help are recognised and put in touch with the most appropriate services to help them - for example a dietitian, renal counsellor, social care manager, physiotherapist, GP, community nurse, or other specialists depending on their needs.

- Every four months staff will review the needs of everyone attending for haemodialysis.
- You will be asked to complete a questionnaire which will capture information about your symptoms. This can be done whilst you are on dialysis.
- Any symptoms which show that your general health is declining, will be discussed with you.
- The kidney doctor or nurse may recommend that your name be added to the Supportive Care Register.



How might I benefit from the Supportive Care Register?

- Part of a regular review of your health and any specific symptoms will be identified and addressed.
- Other needs that you may have can be identified and referrals will be made to the services who can best meet them.
- Your GP and community nurse will receive a letter updating them about your condition and make sure you have access to extra support at home, should you need it.
- You may want to think about aspects of your future health that are important to you. You will have the opportunity to discuss these with your kidney doctors and nurses.

With your consent, these discussions and any preferences you express for your future care will be clearly recorded and shared between the doctors and nurses in the kidney unit and those working in the community. Everyone involved in your care will be fully aware of your wishes, whether they are seeing you at the hospital, at your GP surgery, or in your own home.

Discussing preferences or decisions with your family and those who are important to you is called Advance Care Planning.

What happens now?

Key healthcare professionals will be nominated to coordinate services for you; they may be from kidney services, community care, or palliative care.

References and further information

- **NHS: End of Life Care**
Web: www.england.nhs.uk/eolc/
- **Kidney Care UK: About kidney health**
Web: www.kidneycareuk.org/about-kidney-health
- **East Kent Hospitals: What happens if I choose not to have dialysis? leaflet**
Web: www.ekhuft.nhs.uk/renal-patient-leaflets/

Contact details

- Renal Satellite Unit, Wiliam Harvey Hospital Ashford Telephone: 01233 65 18 72
- Renal Satellite Unit, Buckland Hospital Dover Telephone: 01304 22 26 95
- Alan Squirrel Renal Satellite Unit, Queen Elizabeth the Queen Mother Hospital Margate Telephone: 01843 22 55 44
- Alan Squirrel Renal Satellite Unit, Medway Hospital Gillingham Telephone: 01634 82 51 05
- Renal Satellite Unit, Maidstone Hospital Telephone: 01622 22 59 01
- Home Therapies Unit, Kent and Canterbury Hospital Telephone: 01227 86 40 11
- Thomas Becket Renal Unit, Kent and Canterbury Hospital Telephone: 01227 78 30 47
- Marlowe Ward, Kent and Canterbury Hospital Telephone: 01227 78 31 00
- Conservative Management Team Telephone: 01227 86 41 42
- Renal Counsellor Telephone: 01227 86 43 80

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation