

Oxford Kidney Unit

What is Renal Supportive Care?

Information for healthcare professionals



People who live with chronic kidney disease often need increased help and support as their illness progresses. Some people may need help with controlling the symptoms that the kidney disease produces, others may need extra assistance with every day activities, such as washing, dressing, shopping and cleaning. Some people want more information about their illness and help to plan their future care.

Through the use of a supportive care register, the Oxford Kidney Unit is going to highlight those patients on dialysis or those patients who choose not to have dialysis, who are likely to be in need of added support.

How will patients be identified as needing supportive care?

The Oxford Kidney Unit (including the satellite units) has chosen certain staff who have become 'supportive care champions'. These champions will be working together, to highlight those people who are likely to need their help. Please ask your Unit Manager who the supportive care champion is in your unit.

All dialysis patients should be offered the opportunity to complete a supportive care assessment if they wish. The questionnaires should be completed on a yearly basis or any time deterioration is noted. Deterioration may include recurrent unplanned admissions due to frailty or a similar problem that current interventions are not addressing, for example a drop in weight despite dietetic input, a reduction in mobility, or repeated falls.

An assessment should also be completed if a patient asks to stop dialysis.

The Supportive Care assessment tool consists of the Visual Analogue Score (VAS) and the Palliative care Outcome Scale – Renal (IPOS Renal) questionnaire for the patient to complete. These are designed to be a simple reflection of how the patient is feeling about their health on a particular day. The IPOS-Renal has been designed specifically for patients with kidney problems.

Staff are then asked to consider the surprise question (would you be surprised if your patient died in the next 12 months) and complete the Charleston Comorbidity Score (CCS).

A patient information leaflet explaining the purpose of the assessments is available to give to patients and any staff involved in the patient's care. Please ask your supportive care champion if you need a copy.

What happens next?

The supportive care champion will collate all of the results and establish a baseline score. This can be discussed with the multi-disciplinary team as is explained in the supportive care criteria.

Supportive care criteria

The criteria for discussion about a patient being placed on the supportive care register includes a score of:

- less than 50 on the VAS
- more than 30 on the IPOS-Renal
- answer 'No' to the surprise question 'Would you be surprised if your patient died in the next 12 months?'
- score 2 or more on the Charleston Comorbidity Score (CCS).

What does renal supportive care look like?

All patients who meet the supportive care criteria as described on page 5 should be flagged to their consultant for review.

A conversation with the patient should take place to inform them of their scores and to ask them if they are happy to be added to the renal unit supportive care register. This may be done by the most appropriate person, such as the named nurse, doctor or supportive care champion.

The person who has had the conversation with the patient should then:

- Send a template letter to the GP.
- Liaise with GP/ district nurses/community palliative care team/ specialist nurses to ensure they are aware of the patient's concerns and agree a shared care support plan.

The patient's consultant will review and assist with managing any symptoms related to their kidney condition, such as reviewing their medications and considering reducing 'pill burden' as appropriate

It may also be appropriate to discuss DNA CPR.

Once all of this has been completed, the patient should be asked if they want to share their plans or wishes for the future. This could be with a carer or other healthcare professional.

A personalised care plan should be completed and copied onto lilac paper. This may also be shared with the GP or other community staff if the patient gives consent.

What happens if a patient decides to stop dialysis?

Sometimes patients decide to stop dialysis. An individual care plan of how this will be managed should be completed and communicated with the multi-disciplinary team.

The care plan will:

- Make sure that the preferred place of care is discussed and plans are made to support this.
- Review DNA CPR status.
- Continue to assess and manage symptoms.
- Ensure the patient and all of those involved in the patients care have renal services (24 hour) contact numbers for advice and guidance on symptoms. This will vary, depending on where the patient has dialysis.
- Provide written information for all patients, their carers and (where appropriate) community teams, on symptoms and management to avoid crises and unnecessary admissions (if the patient's wish is to remain at home).
- Liaise with GP/district nurses/community palliative care team/ specialist nurses in their preferred place of care (depending on patients wishes) to ensure seamless transition of care and to agree shared care support plan.

If you wish to know more information please contact your supportive care champion.

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 **PALS@ouh.nhs.uk**

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