Caring for Patients with Advanced Kidney Disease at the End of Life – Ten Top Tips

For many GPs the thought of trying to manage a patient with advanced kidney disease at the end of their life can be quite challenging. GPs may be uncertain what drugs to use and in what doses. There can be a temptation to admit the patient to hospital although this may not be what they or their family wish.

The aim of these 10 Top Tips is to raise awareness about this group of patients and to signpost GPs to more information where needed. It is hoped that they will give GPs more confidence about providing good end of life care at home to kidney patients. They are written by a GP with an interest in end of life care who has been involved in providing primary care input to such renal projects.

Many kidney units are developing systems to identify this group of patients and there are a number of detailed guidelines giving information about drugs and doses available. These include a renal version of the Liverpool Care Pathway as well as guidelines produced by local renal and palliative care units – for example North Bristol Trust, which are available on the North Bristol NHS Trust website

End of Life Care in Advanced Kidney Disease: A Framework for Implementation can be downloaded from the NHS Kidney Care website

Ten Top Tips

1. Look out for patients identified by kidney team (consultant, dialysis nurses etc) as nearing the end of their life. These may be people not opting to go onto dialysis or deciding to stop dialysis, or some who may still continue dialysis. Make sure they are added to the practice Palliative Care register and that the local OOH and ambulance services are informed about them.

2. Check what conversations and advance care planning has already happened. Kidney patients often have close relationships with renal and dialysis nurses and may talk to them more than to other health care professionals. Note where the preferred place of care and death is – kidney patients are more likely to want to die in hospital than patients with other long term conditions and cancer – due to close links with hospital. However kidney units may be a considerable distance away and people may prefer to die at local hospice or at home. If so make sure you and the OOH service have good guidelines for treatments that may be needed at the end of life.

3. No dialysis option does not mean a no treatment option. There are a number of active treatments that will help improve quality of life e.g. intravenous iron and ESA in anaemia, and good symptom control is still important.

4. Kidney patients often look well and may not complain of many symptoms or needs. However they can deteriorate quickly. **They may experience many of the whole range of symptoms** of any palliative care patient, sometimes for a long period: pain, nausea and vomiting, dyspnoea, lethargy and fatigue, terminal restlessness, retained secretions.

5. Pain may be just as common as in some other illnesses at the end of life. It may also be due to co-morbidities. The **strong analgesics of choice are fentanyl and alfentanil** as these do not produce active metabolites in those with renal failure, but should still be started in low doses.

6. Avoid NSAIDs early in advanced kidney disease if you do not want a further deterioration in renal function. However **do use them at the end of life** if they ease symptoms. Clonazepam is useful adjuvant analgesia for neuropathic pain.

7. Symptoms of uraemia include lethargy (remember to correct anaemia), itchy skin (emollients, antihistamines, ondansetron), lack of appetite and nausea and dry mouth or bad taste. Address dietary needs and ensure patients have access to good nursing care and equipment at home.

8. Restless legs are common in kidney failure – they may respond to clonazepam or levodopa. Other options are amitriptylline and gabapentin.

9. Fluid overload is less common than you might think. Treat dyspnoea and pulmonary oedema. 'Usual' end of life symptomatic measures for the breathless patient are appropriate and effective including low dose opioids and benzodiazepines. Pulmonary oedema can be treated with sublingual nitrates, high dose diuretics. Ask advice about management from kidney team. Prepare the patient and family for possible symptoms.

10. Communicate throughout. Use advice from the kidney team even when you are managing the patient at home, and remember local palliative care and hospice teams. Inform the kidney team of the patient's death if this occurs at home.

With grateful thanks to Dr Jo Chambers, the palliative care and renal teams at Southmead Hospital.
*Reference: '*Supportive Care for the Renal Patient.*' 2nd Edition. (E. Chambers, Michael Germain and Edwina Brown).*

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