

# Comprehensive conservative care for patients with advanced chronic kidney disease

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## Abstract

The number of patients given renal replacement therapy (RRT) has expanded significantly over the last few decades, but it is increasingly recognized that such invasive treatment might not offer the intended and desired quality of life for very frail, elderly people and those with multiple co-morbidities. Comprehensive conservative care is an increasingly accepted and recognized way to provide viable, high-quality treatment for patients with advanced chronic kidney disease (CKD) who are unlikely to benefit from or choose not to have RRT. Comprehensive conservative care comprises interventions to delay progression of CKD and mitigate associated risks and complications, active managements of symptoms, shared decision-making, advance care-planning and psychosocial and family support.

Use of symptom assessment tools is encouraged in clinical practice as a way to measure symptom burden and focus efforts on what matters to patients and their caregivers.

**Keywords** Chronic kidney disease; comprehensive conservative care; quality of life; renal replacement therapies; survival

## Introduction

The psychological impact of being on dialysis and the required adjustments to daily living should not be underestimated. This is particularly true for patients with multiple co-morbidities and frail, elderly individuals. The unadjusted mortality of patients on dialysis, largely resulting from cardiovascular disease, exceeds that of most cancers.

Current evidence measuring the survival advantage of dialysis in this group of patients comes from observational rather than experimental, randomized studies, because of the obvious ethical challenges around the latter. Keeping in mind the inherent limitations of observational studies, the existing evidence suggests that the survival advantage of dialysis disappears in patients  $\geq 75$

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## Key points

- Some patients with end-stage kidney disease do not benefit from dialysis
- Comprehensive conservative care is a viable alternative to renal replacement therapy and should be considered for some patients
- Comprehensive conservative care broadly includes maximizing renal survival and good symptom management, shared decision-making and advance care-planning
- Patients with end-stage kidney disease report as many symptoms as those with cancer
- Most patients with end-stage kidney disease report pain, which should be addressed
- Use of appropriate tools to measure symptom burden and physical function is strongly encouraged

years of age with high levels of co-morbidity and/or poor functional status.

The concerns of patients with advanced chronic kidney disease (CKD) are similar to those of anyone with a serious medical condition, such as ‘How long have I got?’, ‘How will I feel?’, ‘Will it hurt?’, ‘How will I die?’ and ‘Where will I die? These concerns are probably best addressed using shared decision-making, including discussion of the comprehensive conservative care approach. This article discusses the main principles of this approach, in addition to ways to manage symptoms.

## Estimating prognosis in chronic kidney disease

Most patients with advanced CKD eventually experience progressive functional decline associated with physical and psychological symptoms, but these illness trajectories can be variable and hard to predict. A very limited number of studies have attempted to transform such prognostic factors into clinically useful prediction tools. The ‘surprise question’ – ‘Would you be surprised if this patient were to die in the next 12 months?’ – is a simple and useful clinical tool to identify dialysis patients at high risk of early mortality.

Measuring functional decline can provide valuable signals indicating shortened survival. This is in addition to its great value in providing and planning for adequate care for the patient. The ability to predict disease trajectories, as best as we can, and communicate prognosis to patients and families is integral to high-quality care and decision-making. This is particularly valuable for effective planning of palliative and supportive services.

## Symptoms assessment and management

Most patients with advanced CKD identify symptom management as a top priority.

The Kidney Disease: Improving Global Outcomes (KDIGO) supportive care working group strongly recommends regular assessment of symptoms using a number of validated symptoms assessment tools, with the aim of directing treatment towards a patient-centred model of care.<sup>1</sup> It is also important to dedicate ample time to discussions about appropriate supportive care options and align treatment to the patient’s values, preferences and goals.

A number of validated symptom assessment tools now exist for use in CKD patients. These include the Edmonton Symptom Assessment System Revised: Renal, Palliative Care Outcome Scale—Symptoms Renal and Dialysis Symptom Index. They are appropriate for routine screening in renal programmes to identify patients’ common and troublesome symptoms, including in the last days of life. These tools have been translated into several languages. Patients should also be screened for symptoms of depression using standardized instruments that have well-documented evidence of validity in CKD.

Many of the recommendations concerning treatment strategies have, however, been extrapolated from those used successfully in the general population. Studies to evaluate treatment efficacy in CKD are often underpowered and typically do not address outcomes that are most relevant to patients, such as overall symptom burden and health-related quality of life.

**Pain management**

Pain is particularly common in patients with advanced kidney disease, reported in 80% of patients on haemodialysis. Pain can be a consequence of renal disease or its complications (adult polycystic kidney disease, calciphylaxis), or of dialysis treatment (e.g. post-dialysis headache, pain from vascular access complications – steal syndrome to an arteriovenous fistula). Other causes of pain include musculoskeletal, neuropathic or ischaemic.

Understanding the underlying cause of pain is usually helpful in indicating more effective treatment. Most pain can, however, be treated by following the World Health Organization (WHO) analgesic ladder, which has been modified to include the less problematic types of analgesia in patients with moderate to advance CKD and depicted with suggested doses of appropriate drugs in [Figure 1](#).<sup>2,3</sup>

If opioids are required, it is vital to monitor for signs of accumulation, such as respiratory depression, hallucinations and vomiting. Opioids that are least likely to cause toxicity are those metabolized and cleared at least partly through the biliary system, or those with no active metabolites, such as fentanyl.

In the end-of-life phase, effective analgesia is paramount and opioids should not be withheld.

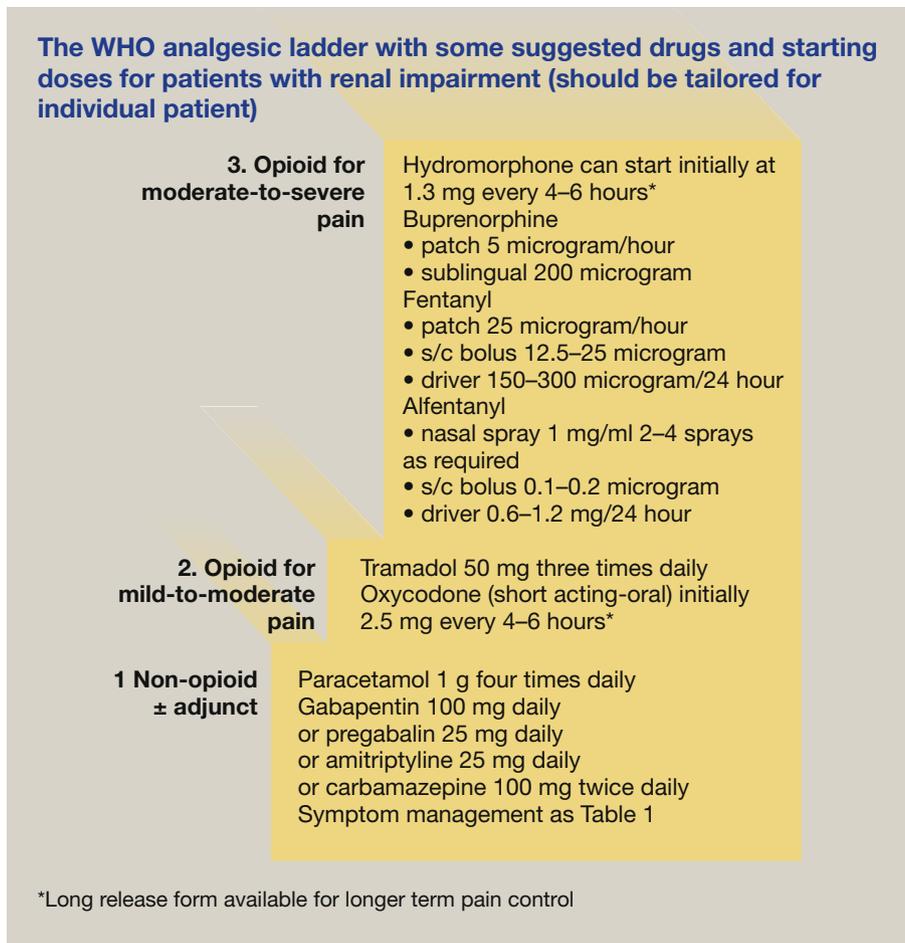


Figure 1

**Management of nausea and vomiting**

Treatment of such symptoms can be tricky. To increase the chance of success of treatment, it is important first to try to identify the possible underlying cause.

Uraemia can cause persistent nausea and is best managed by drugs acting on the chemoreceptor trigger zone; haloperidol can therefore be effective, although it should be used in greatly reduced doses to minimize the risk of adverse effects. Domperidone and metoclopramide can be tried if delayed gastric emptying is suspected, as with diabetic or uraemic neuropathy. In cases where nausea and vomiting are refractory, levomepromazine can be used given its broad-spectrum antiemetic properties.

**Management of pruritus**

Pruritus is commonly reported by patients with advanced kidney disease. The underlying pathology is thought to be multifactorial and interlinked, involving, for example, metabolic abnormalities (calcium, phosphate, parathyroid hormone), accumulation of uraemic toxins and systemic inflammation.

Evidence for various treatment options is very limited. Douglas<sup>4</sup> has made some useful suggestions, which are probably best followed in stepwise fashion:

- control of blood concentrations of calcium and phosphorus by diet and phosphate binders
- regular use of skin emollients (e.g. Doublebase™, Diprobace®) applied 2–3 times daily
- antihistamines – although these are usually ineffective in treating uraemic pruritus, a sedating antihistamine can help with sleep disturbance
- gabapentin – there is some supporting evidence for use in pruritus, although it accumulates and can induce drowsiness
- mirtazapine – selective noradrenaline reuptake inhibitors relieve itching, possibly by reducing central sensitization to itch
- phototherapy – there is good supporting evidence for use of ultraviolet B light in refractory pruritus.

**Restless legs**

Many patients report restless legs are reported as an unpleasant symptom, usually increased by rest and worse at night. There is limited evidence to suggest that treating iron deficiency anaemia and hyperphosphataemia can help. Some drugs used with variable and mostly anecdotal success include gabapentin, pramipexole and clonazepam.

Some other symptoms, including those frequently encountered in end-of-life care, are summarized in [Table 1](#).

**Shared decision-making and advance care-planning**

Shared decision-making is a process of communication by which physicians and patients agree on a specific course of action based on a common understanding of the patient’s treatment goals, taking into account the benefits and harms of treatment options, and the likelihood of achieving the outcomes that are most important to individual patients.

It is important to realize that, in many cultures, the family and even society has a large role in the decision-making process. Barriers to decision-making such as cognitive dysfunction, depression and socioeconomic factors should be recognized and addressed.

**Symptom control in maximal conservative management**

| Symptom                                      | Management  |
|--|---|
| Tiredness, fatigue, lack of libido           | Address anaemia with iron and/or erythropoietin. Dietary advice   |
| Shortness of breath, swollen legs            | Diuretics (may need high dose)  |
| Restless legs                                | Clonazepam, gabapentin, pramipexole   |
| Muscle spasm                                 | Benzodiazepines, clonidine, baclofen  |
| Pruritus                                     | Moisturizing creams, emulsifying lotions for bathing<br>Antihistamines if is affecting sleep<br>Gabapentin or pregabalin                                |
| Thirst                                       | Suck crushed ice or ice cubes.<br>Good mouth care   |
| Pain   | See <a href="#">Figure 1</a>  |
| Depression, anxiety                          | Counselling and psychological support are often sufficient<br>Antidepressants can be useful; dose should be adjusted for low glomerular filtration rate |
| Nausea and vomiting: choice depends on cause | Uraemia – haloperidol; opioids (metoclopramide); in refractory cases, levomepromazine   |
| <b>End-of-life symptoms</b>                  | <b>Management</b>   |
| Pain   | See <a href="#">Figure 1</a>  |
| Agitation                                    | Midazolam, haloperidol  |
| Excessive secretions                         | Hyoscine butylbromide   |

**Table 1**

Advance care-planning is a process that involves understanding, communication and discussion between a patient, the family (or other caregiver) and staff for the purpose of clarifying preferences for end-of-life care. Research has shown that open, honest discussions with patients with advanced CKD about prognosis and end-of-life care promote self-reliance, alleviate fear and uncertainty, and reinforce both trust and hope.<sup>5</sup>

These patients are usually frail and elderly, care should be as close as possible to home, and unnecessary hospital visits should be avoided. Teamwork and good communication between patients, carers, primary care and specialist renal and palliative care services are essential to achieve the goal of a good quality of life and death for a patient, once they have selected conservative management for their end-stage kidney disease.

**Quality of life and mode of death**

In a prospective longitudinal study of patients choosing conservative care, Murtagh (see Further reading) has shown that the symptoms and average functional trajectory are very stable until the last 2–3 months of life, when symptoms markedly increase and function declines. Conservative care patients spend considerably fewer days in hospital and are much more likely to die at home or in a hospice than those on dialysis. With good symptom management, the usual course is for the patient to become increasingly drowsy, drift into a coma and die. ◆

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**FURTHER READING**

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**TEST YOURSELF**

To test your knowledge based on the article you have just read, please complete the questions below. The answers can be found at the end of the issue or online [here](#).

**Question 1**

An 88-year-old man presented for review. He had few symptoms but had been found to have progressive chronic kidney disease secondary to immunoglobulin (Ig) A nephropathy. He also had hypertension and ischaemic heart disease. He had been assessed and deemed unfit for a kidney transplant. He was interested in having conservative care as he had decided against renal replacement therapy.

**Investigation**

- Estimated glomerular filtration rate 10 ml/minute/1.73 m<sup>2</sup> (<60)

**What is the best next plan of action?**

- A. Refer for a formal psychiatric assessment
- B. Advise a trial period of dialysis
- C. Explain that dialysis treatment will improve his quality of life
- D. He should be offered information about both dialysis and conservative care
- E. Explain that whatever decision is taken now is irrevocable

**Question 2**

An 82-year-old woman presented with severe pruritis. She had chronic kidney disease stage 5, secondary to diabetes mellitus. She had opted for conservative care of her kidney disease. Antihistamines and skin emollients had had little effect.

**What would be the best next line of treatment for her symptom?**

- A A short period of haemodialysis
- B Amitriptyline
- C Optimization of diabetic control
- D A long-acting antihistamine
- E Gabapentin

**Question 3**

A 76-year-old woman presented with increasing pain in one leg on walking that was relieved by rest. She had end-stage renal disease secondary to adult polycystic disease, was also hypertensive and had severe peripheral vascular disease for which she had previously had multiple vascular interventions to her legs. She has been taking regular paracetamol and the maximum dose of gabapentin but both have provided very minimal relief for the pain.

On clinical examination, no pulses could be palpated below the femoral arteries.

**As well as surgical referral, which drug can be added next for pain relief?**

- A. Oxycodone
- B. Modified-release morphine sulphate
- C. Non-steroidal anti-inflammatory drugs such as ibuprofen
- D. Topical opioids such as a fentanyl patch
- E. Codeine sulphate