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Conservative/Palliative Treatment and End-of-Life Care in Chronic Kidney Disease

Alvin H. Moss

Before You Start: Facts You Need to Know About End-of-Life Care

- Kidney supportive care should be offered to all patients with advanced CKD.
- Prognosis is an inherent issue in transitioning to end-of-life care, but there are few tools to predict outcomes in CKD patients who choose not to begin dialysis.
- Patient-centered advance care planning is an integral aspect of kidney supportive care and is based on determining a patient's goals for care.
- Nephrology clinicians need to initiate advance care planning discussions.
- Advance directives like identifying a healthcare surrogate or proxy decision-maker and medical orders like do-not-resuscitate preferences and Portable Orders for Life-Sustaining Treatment (POLST) should be determined for each patient.
- Symptom burden is high throughout CKD, including near the end of life, and systematic symptom assessment and management are therefore important aspects of supportive care for CKD patients.

36.1 Supportive or Palliative Care in CKD

The terminology in this chapter is key to understanding the nuances in the continuum of care for patients with kidney disease. In medical literature, supportive care is often used as a synonym for palliative care. In this chapter, the term "supportive care" is used because patients and healthcare professionals prefer it [1]. Supportive care refers to the care that the nephrology team provides, while palliative care refers to the care provided by specialists in palliative care. The word "palliative" has been defined as that which reduces violence associated with disease or a process of easing burdens associated with disease during the dying process that is not curative in nature. The World Health Organization defines palliative care as "An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spir-

A. H. Moss (✉)
Divisions of Nephrology and Geriatrics and Palliative Medicine, Department of Medicine, West Virginia University School of Medicine,
Morgantown, WV, USA
e-mail: amoss@hsc.wvu.edu

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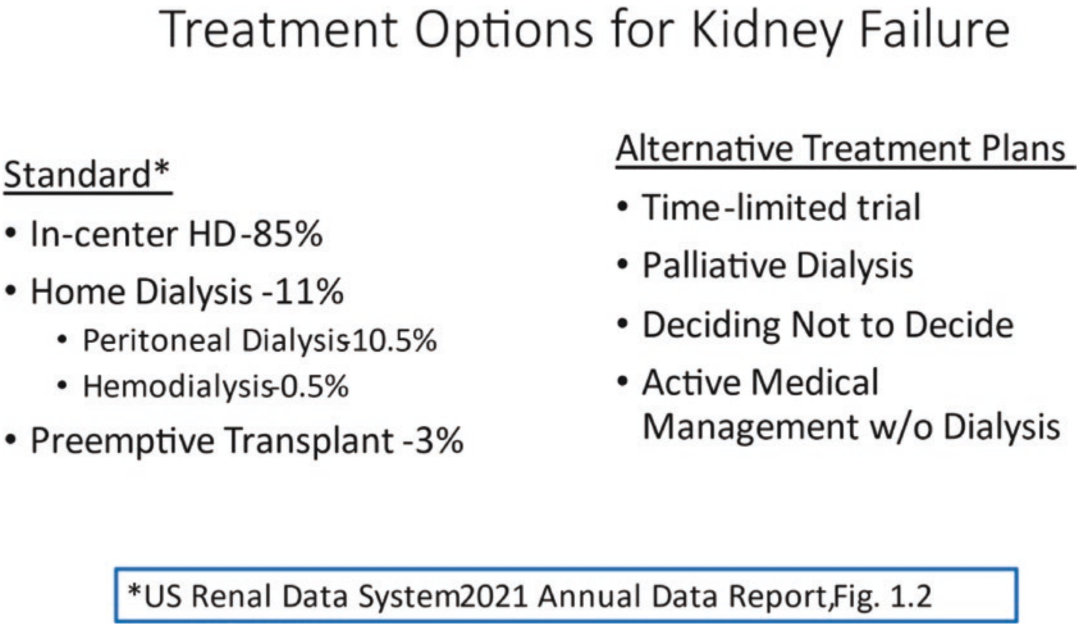
itual." Life-sustaining technology such as dialysis may provide palliation of some symptoms although the use of organ sustaining technology might be considered counter to the palliative approach. The term "active medical management without dialysis (AMMWD)" is increasingly used to describe a program of care that excludes kidney replacement therapy but encompasses management of biochemical abnormalities as well as symptoms accompanying CKD and, ultimately, the dying process. Importantly, AMMWD can be proactive and deliberate as directed by patient preferences and values and does not mean "no care." International interest in AMMWD continues to increase, particularly for those 75 years of age and over who constitute a large and the fastest growing proportion of dialysis patients in the USA and for whom the costs of care are formidable. In contrast to the 1980s–1990s and even early years of the last decade when the ability to provide life-prolonging care perhaps promoted a blind eye to the propriety of doing so, the concept that dialysis may not be the best option for every patient is growing in acceptance.

Providing informed consent requires an individualized approach and the presentation of clear expectations. In patients with CKD, the option of dialysis is ideally posed before symptoms develop, and there is need for active intervention to delay death. A patient's decision to pursue or forgo dialysis will likely be influenced by clinical information provided about prognosis, the dying process, and the quality of life on dialysis. Sharing one's expectations about the anticipated clinical course for a patient poised to die from complications of kidney failure may be helpful to patients as they contemplate their wishes informed by evidence-based information provided to them by their physicians.

Because older patients and those with poor functional status may not live long enough to need dialysis [1–3], it is reasonable to consider prognosis when deciding whether or not to proceed with dialysis. Tools for predicting outcomes in patients with advanced CKD are available [4] and useful to help patients and families decide on the best course of action. Poor functional status and the presence of frailty suggest shorter survival among older dialysis patients as do older age, poor nutritional status, comorbid conditions (especially dementia, peripheral vascular disease, and ischemic heart disease), and answering "no" to the surprise question ("Would you be surprised if this patient died within the next 6 months?") [5, 6].

Such clinical hallmarks of a poor prognosis are important factors to consider when contemplating dialysis as well as when discussing goals of care. The burdens associated with dialysis are multifaceted (social, financial, medical, and logistic), and some patients may not be willing to accept such burdens, instead favoring quality over quantity of additional life. Thus, identifying patients likely to benefit from AMMWD before starting dialysis may save them the traumas accompanying kidney replacement therapy. There are also other alternative treatment options to beginning standard in-center or home dialysis [Table 36.1]. Renal professional societies have recommended that a shared decision-making conversation in which patients are informed of all treatment options for kidney failure with their attendant benefits and burdens should precede a choice [3]. For those choosing to proceed with dialysis, repeated evaluation and ongoing conversations about quality of life and the burdens of dialysis should accompany changes in clinical, physiologic, emotional, and social functioning as such changes may prompt a patient, their family, or their nephrologist to consider withdrawal of dialysis.

Table 36.1 Options for kidney failure treatment to fully inform patients



Treatment Options for Kidney Failure

Standard*

- In-center HD-85%
- Home Dialysis -11%
  - Peritoneal Dialysis10.5%
  - Hemodialysis-0.5%
- Preemptive Transplant -3%

Alternative Treatment Plans

- Time-limited trial
- Palliative Dialysis
- Deciding Not to Decide
- Active Medical Management w/o Dialysis

*US Renal Data System2021 Annual Data Report,Fig. 1.2

36.2 End-of-Life Care in CKD

Although care at the end of life is an integral aspect of total care of an individual with CKD, we know even less about end-of-life (EOL) care in CKD than we do about EOL care in those on dialysis. There are few studies of illness trajectory in CKD patients who choose not to begin dialysis, and, thus, there is little information about dying and EOL care in this population. The most comprehensive study to date was reported from the large Kidney Supportive Care program at St. George Hospital in New South Wales, Australia [7]. They found that patients who chose not to undergo dialysis compared to those who did were older (84 vs. 74 years), more often had 3 or greater comorbidities (43% vs. 25%), lived a shorter median period of time (14 months vs. 53 months), had fewer hospital days per year (9 vs. 20), and a better symptom score (2.2 points lower).

An understanding of the tradeoffs including prognosis inherent in starting dialysis or not is key to engaging in advance care planning, an essential component of EOL (Fig. 36.1). In CKD patients choosing not to begin dialysis, principles of decision-making will rely on prognosis, including expected survival and quality of life with and without dialysis. Small studies of elderly patients with CKD who choose AMMWD show a shortened survival compared with patients beginning dialysis [8–12], Table 36.2. In these studies, as in dialysis patients, comorbidity portends a poor prognosis as do age and poor functional status. The typical illness trajectory of patients with solid organ disease (e.g., congestive heart failure or chronic obstructive pulmonary disease) is characterized by a progressive downward slope with intermittent acute episodes or sentinel events from which the patient never returns to his or her baseline status (Fig. 36.2). It is assumed that dialysis patients also follow this pattern of illness with sentinel events represented by hospitalizations, e.g., with a myocardial infarction, limb amputation, or episode of access-associated bacteremia. There is only one study of illness trajectory in CKD [13]. A small number of elderly CKD patients managed with AMMWD demon-

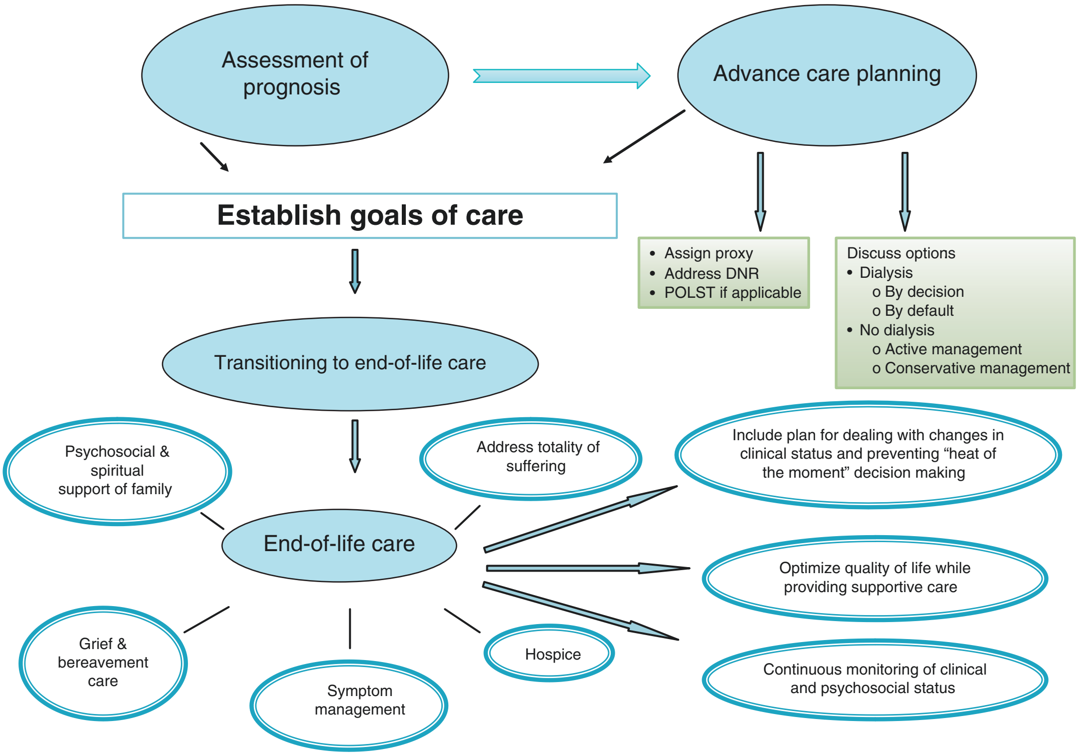


Fig. 36.1 Palliative care in CKD includes advance care planning as well as end-of-life care. This figure depicts an algorithm for palliative care in CKD. *DNR* do not resuscitate, *POLST* portable orders for life-sustaining treatment

Table 36.2 Survival in elderly patients with and without dialysis

	N		Survival			
Author	Dialysis	Conservative	Dialysis	Conservative	Age	Est GFR
Carson [8]	173	20	37.8 months	13.9 months	≥70	11[a]
Brunori [9][b]	56	56	84% 1 year	87% 1 year	>70	5–7[c]
Murtaugh [10]	52	77	84% 1 year	68% 1 year	>75	<15[a]
Joly [11]	107	37	74% 1 year	29% 1 year	≥80	<10[d]
DaSilva-Gane [12]	124	30	1317 days	913 days[e]	33–84	10–17[a]

[a] Modification of Diet in Renal Disease (MDRD) formula
[b] Diet intervention
[c] Mean of creatinine clearance and urea clearance in a 24-h urine collection
[d] Cockcroft-Gault formula
[e] Comorbidity was the primary factor

strated a fairly well-preserved functional status until shortly before death when an abrupt fall in functional status heralded a rather quick death (Fig. 36.2). Knowing the usual illness trajectory serves multiple purposes including functioning as a guide for addressing and reviewing advance care planning and goals of care, planning for future events and interventions, and completing tasks required before death. Illness trajectories are intimately entwined with illness prognosis and an understanding of each in CKD will facilitate identification of appropriate individuals for decision-making and assist in the transition to EOL care. Additional study of prognostic factors and illness trajectory in CKD is needed.

Transitioning to EOL care requires an honest assessment of prognosis, establishment of goals of care through advance care planning, and edu-

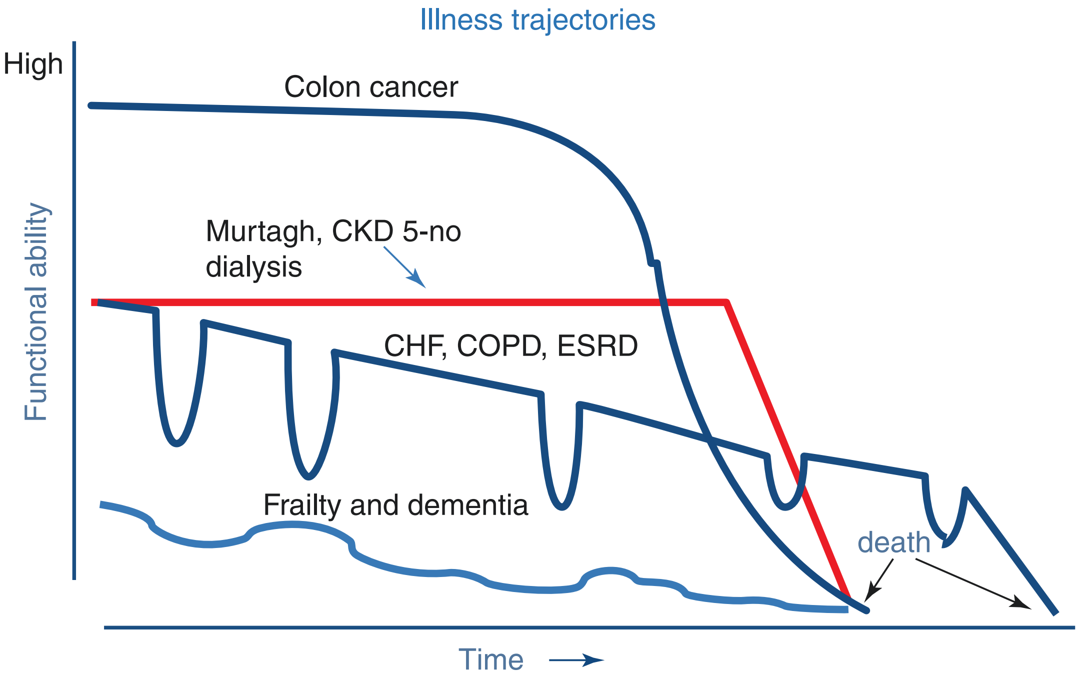


Fig. 36.2 Illness trajectories of various chronic diseases; *CHF* congestive heart failure, *COPD* chronic obstructive pulmonary disease, *ESRD* end-stage renal disease. (Reprinted from Holley [14] with permission from the American Society of Nephrology)

cating the patient and family about options for EOL care (Fig. 36.1). As with all other patient populations, ethical and cross-cultural issues will affect decision-making and EOL care in CKD patients. This is most evident during the advance care planning process where a patient and family's values will influence and direct goals of care. Useful questions for addressing values and stimulating discussion during advance care planning are shown in Box 36.1.

Box 36.1 Useful Questions for End-of-Life and Advance Care Planning Discussions

- *Addressing patient goals*
  - Given the severity of your illness and that your time is short, what is most important for you to achieve?
  - What is most important to you in your treatment? What treatments do you want and what do you want to avoid?
  - What are your biggest fears?
  - What are your most important hopes?
  - Is it more important to you to live as long as possible, despite some increased suffering, or to live with less suffering for a shorter time?
- *Addressing patient values*
  - What makes life most worth living for you?
  - Are there any circumstances under which you would not find life worth living?
  - What do you consider your quality of life to be like now?
  - Have you seen or been with someone who had a particularly good (or difficult) death?
  - If you choose to start dialysis, under what circumstances, if any, would you want to stop dialysis?

36.3 Establishing and Achieving Goals of End-of-Life Care

Assessment of a patient's wishes for EOL care is an important part of comprehensive care irrespective of whether or not a patient chooses to begin dialysis. Many choose to forgo dialysis in order to avoid prolongation of the dying process and in an attempt to assure that their desires about treatment remain under their control. Patients and families have taught us that they use advance care planning for a variety of things, to achieve a sense of control, to have treatment choices followed, to relieve burdens on family, to strengthen relationships with loved ones, to avoid inappropriate prolongation of dying, and to be at peace with God [15, 16].

Pertinent issues to address include whether the patient wishes to die at home, in hospital, or elsewhere and specifics about what symptoms are and are not acceptable. Patients who choose to forgo or even withdraw from dialysis may be offered the option of reconsidering, an act which may be emotionally helpful to some patients who fear that the dying process will be too unbearable.

Aims of AMMWD include control of symptoms such as itching, restlessness, dyspnea, confusion, and pain, as well as emotional and spiritual support. Studies have shown that patients choosing AMMWD do not have more symptoms at the end of life than those who have been treated with dialysis [7, 17]. Patients with kidney failure should be prepared for symptoms arising as a result of kidney functional decline. The close follow-up and careful symptom management accomplished by the Kidney Supportive Care program in New South Wales show that patients treated with AMMWD need not have more symptoms than dialysis patients at the end of life [7].

Chronic pain has been reported in half of dialysis patients, 82% of whom have moderate-severe pain [18] (see also Chap. 22). Pain management for patients choosing to forgo dialysis requires attention to the reduced kidney clearance of many drugs. In addition, the myriad sources of pain in patients with kidney disease also require consideration. The propensity for side effects which may be exacerbated in patients with kidney failure prompted the development of specific recommendations for managing pain and other symptoms in patients on dialysis (Table 36.3). Pain management, irrespective of whether a patient chooses dialysis or the non-dialytic route, is a key component to the care of patients with advanced kidney failure. Plans for treatment should be made in anticipation of symptoms. Neuropathic pain is common and often poorly responsive to opioids, requiring addition of adjuvant medications like tricyclic antidepressants or anticonvulsants. An important part of AMMWD is recognizing evolving symptoms of respiratory distress which may in turn cause anxiety and a patient or family member to question their decision to forgo dialysis.

Table 36.3 Treatment of common EOL symptoms in CKD patients

Symptom	Treatment options
Pruritus	Antihistamines, skin lotion with menthol, dexamethasone, difelikefalin
Dyspnea	Relaxation exercises, diuretics, oxygen, morphine
Pain	Opioids ± adjuvants[a]
Dry mouth	Artificial saliva, swabs, good local care
Nausea, vomiting	Haloperidol at 50% normal dose, Compazine
Constipation	Senokot, stool softeners, lactulose, enemas prn—avoid phosphosoda, magnesium
Respiratory tract secretions	Hyoscyamine 0.125 mg po or SL, scopolamine patch

Source: Data from Davison [18], Douglas [21], Davison [22], and Fishbane [23]

Adjuvants for neuropathic pain (e.g., gabapentin, pregabalin) require dose adjustments and slow titration of dose; avoid >600 mg daily of gabapentin

[a] If needed for more than 1–2 days, use fentanyl; active kidney-excreted, short-acting hydromorphone metabolites may accumulate without dialysis and cause opioid-induced neurotoxicity. Do not use a fentanyl patch stronger than 12 μg in opioid naïve patients. Long-term morphine, meperidine, codeine, propoxyphene contraindicated because of the accumulation of kidney-excreted neurotoxic metabolites. Use with caution: oxycodone, tramadol (avoid sustained release form in CKD)—limited data in CKD. Whenever an opioid is prescribed, laxatives also need to be prescribed because of opioid-induced constipation

Preparing the patient for such events, both emotionally and with specific plans to ameliorate the symptoms, will help avoid patient and family anxiety. The Coalition for Supportive Care of Kidney Patients has developed an Active Medical Management without Dialysis Pathway to help clinicians, patients, and families anticipate mounting uremic symptoms at the end of life and to establish an action plan that avoids patients going to the emergency department and "crashing" into dialysis [19]. There is also a chapter in the textbook *Palliative Care in Nephrology* written by leaders of the Kidney Supportive Care program in New South Wales, Australia, explaining how to care for patients who choose AMMWD with information about validated clinical tools to assess symptoms and online symptom management resources [20]. A plan to address dyspnea, itching, control of pain, (Table 36.3) and a generalized discussion of what a family might expect is the key to a smooth and acceptable course of AMMWD.

Family members of patients choosing AMMWD or dialysis withdrawal may need emotional support in addition to guidance in recognizing changes in symptoms that might warrant adjustments in the management program. The logistics of providing care must be considered if families choose not to engage in hospice. Close monitoring of clinical and psychosocial as well as emotional parameters in addition to routine symptom assessment by the health-care providers focusing on new pain, worsening chronic pain, or the development of new uremic symptoms is integral to ongoing care. For CKD patients choosing to proceed with dialysis, establishing goals of care includes plans for dealing with symptoms and changes in clinical status. It is important to continually monitor the patient's response to dialysis, their comorbid conditions, functionality, and quality of life on dialysis. The option of withdrawal from dialysis should be incorporated into the overall plan of care as the patient's preferences may change or the patient's medical status may deteriorate.

Advance care planning is best initiated in the early as opposed to late stages of CKD when a plan for EOL care can be established and tailored to a patient's prognosis, values, and preferences (Fig. 36.1). AMMWD can be proactive, deliberate, and directed by individual patient preferences and values, and patients and families should be educated that AMMWD does not mean "no care." It is care toward a different goal. Presenting clear expectations, setting contingencies, and incorporating the opportunity for withdrawal for those who choose dialysis may facilitate decision-making in times when clinical events make objectivity difficult. Discussions of prognosis and advance care planning afford patients and families the opportunity to shape the direction of life at its end and, by doing so, provide solace, comfort, and hopefully peace.

36.4 Advance Care Planning

Advance care planning is an important component of palliative care and should be addressed with each CKD patient. The purpose of advance care planning is to establish the goals of care within a care plan consistent with a patient and family's values and preferences [14]. Advance care planning requires the patient's participation and thus his or her ability and interest in the process as well as some perceived benefit and the resources to participate. Completing written advance directives may be an aspect of advance care planning, but because circumstances change and most patients make decisions about desired interventions based on their health status, values, and quality of life (as opposed to the intervention being considered), completing a written advance directive is not the goal of advance care planning. However, some written directives are useful to guide decision-making when the patient has lost the capacity to participate, and their completion should be encouraged to all patients. These include designation of a surrogate decision-maker or health-care proxy and execution of a living will if consistent with the patient's wishes. Completion of medical orders to specify the treatment limitations the patient wants at the end of life such as a do-not-resuscitate (DNR) order if applicable, or portable orders for life-sustaining treatment (POLST) or the equivalent where available can be very helpful in medical emergencies (Box 36.2). The majority of states in the USA have adopted POLST, making them legal medical orders. Orders on the POLST generally include DNR status, preferences for hospitalization, medically administered nutrition and hydration through a feeding tube, intubation and ventilation, intensive unit care, and, in some cases, dialysis. Although discussing advance directives and medical orders and engaging in the process of advance care planning may be difficult, surveys of various patient groups indicate that patients and families overwhelmingly believe their physicians should raise these issues and initiate the discussions. Focusing on the day-to-day issues raised by medical care can often prevent the setting of goals and exacerbate hopelessness, fear, and uncertainty. Helping CKD patients see future possibilities consistent with their personal values can help maintain hope [24]. Thus, engaging in discussions of prognosis and advance care planning should not be viewed by nephrologists as an act that extinguishes hope for patients and their families. Advance care planning affords patients and their families the opportunity to direct and control their care (Fig. 36.1) and requires physician input.

Box 36.2 Web Resources for Advance Care Planning and End-of-Life Care

1. Coalition for Supportive Care of Kidney patients and website is: (www.kidneysupportivecare.org).
2. The Caring Connections website offers information about advance care planning and free downloads of state-specific, legal advance directives (http://www.caringinfo.org/stateaddownload).
3. The Portable Orders for Life-Sustaining Treatment form contains patients' end-of-life wishes in an easily identifiable, portable format with reviewable medical orders. The form honored throughout the health-care system is recognized as a preferred practice by the National Quality Forum in its A National Framework and Preferred Practices for Palliative Care and Hospice Care Quality (http://www.polst.org).
4. Hemodialysis mortality predictor (http://touchcalc.com/calculators/sq).
5. The UK website for end-of-life care (http://www.endoflifecareforadults.nhs.uk/assets/downloads/EndofLifeCareAKD.pdf).

Once the goals of care are established, plans for EOL care services can be determined. In dialysis patients, we know that EOL care should be discussed whenever conversations involve consideration of prognosis, treatments with low probabilities of success, patients' hopes and fears, and if the physician would not be surprised if the patient died within the next 6–12 months. It seems reasonable to extend this recommendation to those with advanced CKD. Interdisciplinary coordinated care provides opportunities for peaceful dying and "good deaths" by addressing all the domains of suffering (physical, psychological, spiritual, functional, and social) as well as managing symptoms occurring during the end of life (Fig. 36.1).

Figure 36.3 shows the symptoms reported on the Memorial Symptoms Assessment Scale-Short Form during the last 30 days of life in 49 patients with CKD stage 5 managed conservatively and followed prospectively [25]. There are few studies of symptoms experienced at the end of life in any population. Murtagh et al. [25] is the only report of end-of-life symptoms in CKD patients who chose not to begin dialysis. In her study, the mean number of symptoms reported was 16.65 ± 4.04 SD with a range of 6–24; the maximum number of symptoms reportable on the MSAS-SF is 32. Seven additional "renal symptoms" assessed in Murtagh's study included restless legs, muscle cramps, bone/joint pain, dry skin, muscle soreness, chest pain, and headaches [25]. The total number of symptoms possible was therefore 39, and adding these additional possible symptoms, the mean reported number of the 49 studied patients was 20.35 ± 5.20. Similar symp-

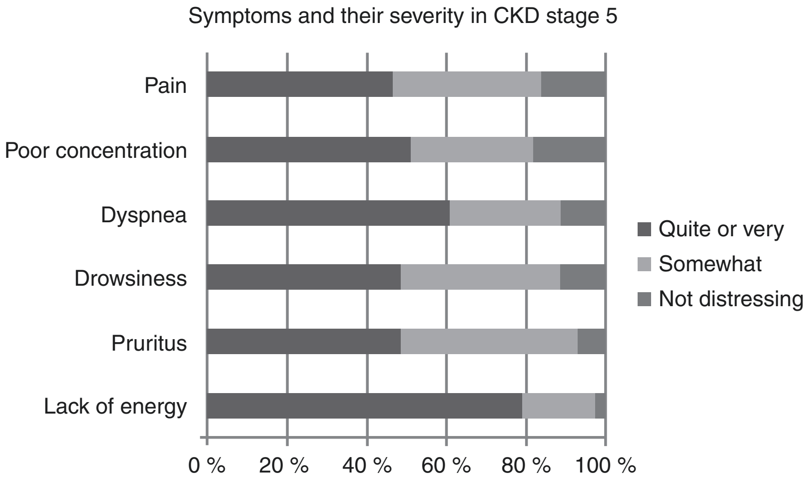


Fig. 36.3 Symptoms reported by CKD stage 5 patients undergoing conservative care. (Adapted from Murtagh et al. [25], Copyright 2010, with permission from Elsevier)

toms have been reported by patients with ESRD who discontinued dialysis with pain, fatigue, dyspnea, and anxiety commonly noted by surviving loved ones [26]. The little information available about symptoms experienced by patients at the end of life suggests that CKD patients have higher symptom distress than cancer patients, especially pruritus, drowsiness, and dyspnea. Constipation, edema, dry mouth, and fatigue were similar among the CKD patients and previous reports of cancer patients during EOL care. There is no information to determine the cause of these symptoms or whether they are due to underlying uremia or comorbid conditions. Clearly, symptoms near the end of life are common among CKD patients, and additional study is needed. End-of-life care for CKD patients forgoing dialysis should include routine symptom assessment with treatment focused on reported symptoms. Table 36.3 illustrates some treatments for commonly reported symptoms. Multidisciplinary care, including hospice and outpatient palliative medicine consultation and follow-up, should be encouraged for all patients in an attempt to alleviate distressing symptoms.

Coordination of EOL care for CKD patients may rest with the patient's primary care provider, nephrologist, or palliative medicine specialist, depending on the availability of services and the patient and family's desires. Hospice care is a Medicare benefit in the US health-care system and requires an anticipated survival of 6 months or less if the disease takes its normal course, stipulated by 2 physicians based on the usual course of the patient's underlying disease. The patient must elect hospice care which requires acknowledgement by the patient and family of the likelihood of death and the relinquishment of attempts at curative therapies. Hospice care includes nurses, aides, clergy, volunteers, and physicians (the nephrologist, the patient's own primary provider, the hospice medical director, and palliative medicine specialist if available) who work with the family to treat the patient's physical and psychological symptoms and to provide psychosocial and spiritual support to the patient and family. Most hospice care is performed in the home with the family and loved ones acting as the primary caregivers. Hospice care continues after the death of the patient through grief and bereavement care provided to the family and loved ones (Fig. 36.1). This continues for a year following the patient's death.

Although there are multiple guidelines for complications of CKD, there are no specific guidelines for EOL in CKD patients. The Renal Physicians Association clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* (Box 36.3), includes guidelines on establishing a shared decision-making relationship, informing patients about CKD, advance care planning, decisions to withhold or discontinue dialysis, resolving conflicts around dialysis decision-making, providing effective palliative care, and communicating about prognosis, treatment options, and goals of care and is the one guideline focused on aspects of EOL care for CKD and dialysis patients. This guideline also incorporates clinical tools addressing depression and cognitive capacity assessment, functional status, prognosis assessment, and communication skills [2]. In 2013, the Kidney Disease Improving Global Outcomes organization convened an international conference to provide a roadmap and make recommendations to improve kidney supportive care including at the end of life [1]. The working group subsequently published a number of papers in a Moving Points in Nephrology issue of the *Clinical Journal of the American Society of Nephrology*, October 2016.

Box 36.3 Relevant Guidelines for EOL Care in CKD

1. Renal Physicians Association Clinical Practice Guideline. Shared decision-making in the appropriate initiation of and withdrawal from dialysis. 2nd ed. Rockville: Renal Physicians Association; 2010 [2].
2. Levin A, Hemmelgarn B, Culleton B, Tobe S, McFarlane P, Ruzicka M, et al. Guidelines for the management of chronic kidney disease. CMAJ. 2008;179:1154–62 [27].
3. Douglas C, Murtagh FEM, Chambers EJ, Howse M, Ellershaw J. Symptom management for the adult patient dying with advanced chronic kidney disease: a review of the literature and development of evidence-based guidelines by a United Kingdom Expert Consensus Group. Pall Med. 2009;23:103–10 [21].

Guidelines for comprehensive conservative kidney management for CKD patients are included in the Canadian Guideline for the management of CKD (Box 36.3) but are general (recommending shared decision-making and interdisciplinary care) and, due to lack of controlled trials in this aspect of nephrologic care, are opinions rather than evidence-based recommendations. General guidelines for EOL care are available in the UK (Box 36.3). Thus, EOL and AMMWD are now recognized as topics of importance to nephrologists and the kind of care they provide. However, there is much work still to be done to develop more comprehensive evidence-based guidelines for CKD EOL care, especially in the area of symptom management.

Although decisions about initiating dialysis are among the most important made by a patient with advanced CKD, until recently, there was little discussion of prognosis and the option of AMMWD. These discussions are difficult and require communication skills and an assessment of the patient’s goals and values (Fig. 36.1). Such discussions naturally lead to advance care planning, an activity that should be initiated by nephrologists or other nephrology clinicians such as nurse practitioners alone or in conjunction with social workers for all patients and families facing advanced CKD. Resources for this aspect of clinical nephrology exist on the web (Box 36.2) and through clinical practice guidelines (Box 36.3) which will undoubtedly expand over the next several years. Figure 36.1 and the available guidelines (Boxes 36.3 and 36.4) focus on key components in EOL discussions which can be addressed whenever a clinician initiates a conversation about dialysis. Alternative treatment options [Table 36.1] are appropriate for some patients and deserve equal consideration by patients and families. It is only through clinician-initiated discussions that alternatives can be considered.

Box 36.4 What the Guidelines Says You Should Do: Key Components of End-of-Life Discussions

- Respect and assure the integrity of the informed consent process.
- Assure decision-making capacity and cognitive capacity for comprehension.

- Determine and agree on the patient's goals for both short- and long-term care.
- Recognize the importance of life experience and tailor the discussion accordingly.
- Engage the patient's family in the decision-making process.
- Distinguish informed consent for the option of dialysis from that associated with the dialysis procedure.
- Present estimate of kidney and overall prognosis with and without dialysis.
- Present anticipated changes in functional status with and without dialysis.
- Describe burdens of dialysis, including potential for both intra- and interdialytic distress.
- Explain risks of dialysis procedure, including those risks related to dialysis access.
- Make plans for dealing with symptoms that could occur should kidney failure progress faster than anticipated and/or faster than other comorbid conditions.
- Discuss desires for acute symptom management and goals to avoid heat of the moment decisions.
- Clarify that palliative care is available irrespective of their decision to pursue or forgo dialysis.
- Incorporate the option of withdrawal into practical plan and monitor patient's status accordingly.
- Consider hospice particularly for patients with additional terminal illness.

Source: RPA Clinical Practice Guideline [2].

Before You Finish: Practice Pearls of End-of-Life Care

- Initiate advance care planning early in the continuum of chronic kidney disease.
- Develop a plan for end-of-life care according to the patient's prognosis, values, and preferences and readdress these issues throughout the trajectory of CKD.
- For patients with advanced kidney disease progressing toward kidney failure, in a shared decision-making discussion present the risks and benefits of dialysis as well as those anticipated should the patient choose to forgo dialysis.
- Assure patients that AMMWD can be proactive, deliberate, and directed by individual patient preferences and values and does not mean "no care."
- On average patients who choose AMMWD may live over a year, have symptoms comparable to those who start dialysis, and spend fewer days in the hospital.
- Patients choosing AMMWD and those withdrawing from dialysis should be offered hospice care as interdisciplinary care can assist in the management of symptoms and end-of-life care for patients and families.

References

1. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, Murtagh FE, Naicker S, Germain MJ, O'Donoghue DJ, Morton RL, Obrador GT, Kidney Disease: Improving Global Outcomes. Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: developing a roadmap to improving quality care. Kidney Int. 2015;88(3):447–59.
2. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P. Survival of elderly patients with stage 5 CKD: comparison between conservative management and renal replacement therapy. Nephrol Dial Transplant. 2011;26:1608–14.
3. Renal physicians association clinical practice guideline for shared decision making in the appropriate initiation and withdrawal from dialysis. 2nd ed. Rockville: Renal Physicians Association; 2010.
4. Couchoud C, Labeeuw M, Moranne O, Allot V, Esnault V, Frimat L, et al. A clinical score to predict 6-month prognosis in elderly patients starting dialysis for end-stage renal disease. Nephrol Dial Transplant. 2009;24:1553–61.
5. Conway B, Webster A, Ramsay G, Morgan N, Neary J, Whitworth C, et al. Predicting mortality and uptake of renal replacement therapy in patients with stage 4 chronic kidney disease. Nephrol Dial Transplant. 2009;24:1930–7.

6. Cohen LM, Ruthazer R, Moss AH, Germain MJ. Predicting six-month mortality for patients who are on maintenance hemodialysis. Clin J Am Soc Nephrol. 2010;5:72–9.
7. Brown M, Chou A, Li C, Farshid S, Hoffman A. Survival, symptoms and hospitalisation of older patients with advanced CKD managed without dialysis. Nephrol Dial Transplant. 2023;38(2):405–13. https://doi.org/10.1093/ndt/gfac154.
8. Carson RC, Juszczak M, Davenport A, Burns A. Is maximum conservative management an equivalent treatment options to dialysis for elderly patients with significant comorbid disease? Clin J Am Soc Nephrol. 2009;4:1611–9.
9. Brunori G, Viola BF, Parrinello G, DeBiase V, Como G, Franco V, et al. Efficacy and safety of a very low protein diet when postponing dialysis in the elderly: a prospective, randomized, multicenter, controlled study. Am J Kidney Dis. 2007;49:569–80.
10. Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. Nephrol Dial Transplant. 2007;22:1955–62.
11. Joly D, Anglicheau D, Alberti C, Nguyen A-T, Touam M, Grunfeld J-P, et al. Octogenarians reaching end-stage renal disease: cohort study of decision-making and clinical outcomes. J Am Soc Nephrol. 2003;14:1012–21.
12. DaSilva-Gane M, Wellsted D, Greenshields H, Norton S, Chadna SM, Farrington K. Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. Clin J Am Soc Nephrol. 2012;7:2002–9.
13. Murtagh FEM, Sheerin NS, Addington-Hall J, Higginson IJ. Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. Clin J Am Soc Nephrol. 2011;7:1580–90.
14. Holley JL. Advance care planning in CKD/ESRD: an evolving process. Clin J Am Soc Nephrol. 2012;7:1033–8.
15. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA. 1999;281:163–8.
16. Steinhauser K, Chastakis NA, Clipp ED, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;248:2476–82.
17. Abdel-Kader K, Unruh ML, Weisbord SD. Symptom burden, depression, and quality of life in chronic and end-stage kidney disease. Clin J Am Soc Nephrol. 2009;4(6):1057–64.
18. Davison SN. The prevalence and management of chronic pain in ESRD. J Palliant Med. 2007;10:1277–87.
19. Coalition for supportive care of kidney patients. Active medical management without dialysis pathway. go.gwu.edu/ammwd. Accessed 29 Nov 2022.
20. Li K, Brown M. Active medical management without dialysis for patients with advanced chronic kidney disease. In: Moss AH, Lupu DE, Armistead NC, Diamond LH, editors. Palliative care in nephrology. New York: Oxford University Press; 2020. p. 136–47.
21. Douglas C, Murtagh FEM, Chambers EJ, Howse M, Ellershaw J. Symptom management for the adult patient dying with advanced chronic kidney disease: a review of the literature and development of evidence-based guidelines by a United Kingdom Expert Consensus Group. Palliant Med. 2009;23:103–10.
22. Davison SN. The ethics of end-of-life care for patients with ESRD. Clin J Am Soc Nephrol. 2012;7:2049–57.
23. Fishbane S, Jamal A, Munera C, Wen W, Menzaghi F, KALM-1 Trial Investigators. A Phase 3 trial of difelikefalin in hemodialysis patients with pruritus. N Engl J Med. 2020;382(3):222–32.
24. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. BMJ. 2006;333(7574):886.
25. Murtagh FE, Addington-Hall J, Edmonds P, Donohoe P, Carey I, Jenkins K, et al. Symptoms in the month before death for stage 5 chronic kidney disease patients managed without dialysis. J Pain Symptom Manag. 2010;40:342–52.
26. Cohen LM, Germain MJ, Woods AL, Mirot A, Burleson JA. The family perspective of ESRD deaths. Am J Kidney Dis. 2005;45:154–61.
27. Levin A, Hemmelgarn B, Culleton B, Tobe S, McFarlane P, Ruzicka M, et al. Guidelines for the management of chronic kidney disease. CMAJ. 2008;179:1154–62.