

A practical guide for the care of patients with end-stage renal disease near the end of life

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Abstract

Most patients who rely on dialysis for treatment of end-stage renal disease (ESRD) never receive a kidney transplant. Therefore, it is important for nephrology providers to feel comfortable discussing the role of dialysis near the end of life (EOL). Advance care planning (ACP) is an ongoing process of learning patient values and goals in an effort to outline preferences for current and future care. This review presents a framework for how to incorporate ACP in the care of dialysis patients throughout the kidney disease course and at the EOL. Early ACP is useful for all dialysis patients and should ideally begin in the absence of clinical setbacks. Check-in conversations can be used to continue longitudinal discussions with patients and identify opportunities for symptom management and support. Lastly, triggered ACP is useful to clarify care preferences for patients with worsening clinical status. Practical tools include prognostication models to identify patients at risk for decline; ACP documents to operationalize patient care preferences; and communication guidance for engaging in these important conversations. Interdisciplinary teams with expertise from social work, palliative care, and hospice can be helpful at various stages and are discussed here.

1 | INTRODUCTION

Over 2 million people worldwide are treated with dialysis with a majority never receiving a kidney transplant.¹ Hence, dialysis is a “destination therapy” for most patients with end-stage renal disease (ESRD). These patients often have unrecognized symptom needs, multimorbidity, and frailty; all of which further impact their experience and mortality.²⁻⁵ Nephrologists should then feel comfortable providing patient-centered care especially at the end of life (EOL). However, substantial improvement is needed in EOL care for dialysis patients. Compared to patients with chronic conditions such as cancer and heart failure, patients with ESRD are more likely to undergo an intensive EOL experience characterized by hospitalization, invasive procedures, and in-hospital death.⁶ These EOL outcomes differ from what most adults define as a good death.⁷

Nephrology providers are well positioned to address the EOL experience for dialysis patients given the frequent interactions

during dialysis rounds and continuity over time. There are certainly systemic barriers affecting the nephrology workforce’s ability to deliver high-quality EOL care that includes a lack of communication training to have EOL conversations, clinical demands, cultural barriers, and financial incentives to continue dialysis.⁸ These realities challenge nephrology providers’ ability to deliver patient-centered care and may lead to provider burnout.⁹ Despite these challenges, we believe nephrology providers can succeed in providing EOL care in the dialysis setting. Our longitudinal relationships with dialysis patients make us uniquely situated to not only understand their physiology, but also use our frequent encounters to guide decision-making for EOL care.

Although clinical practice guidelines on shared decision-making for dialysis initiation and withdrawal exist, how these guidelines are incorporated into practice is variable.^{10,11} This is a practical guide that will help nephrology providers better incorporate advance care planning (ACP) into routine care for dialysis patients. We present a

framework for how to introduce early ACP as well as triggered ACP discussions for patients who are declining. This review includes practical tools and phrases for addressing ACP needs in dialysis patients throughout the disease course, including dialysis withdrawal. A clearer understanding of ACP can enable nephrology providers to work more seamlessly within interdisciplinary care teams and develop thresholds for when palliative care consultation could be beneficial.

2 | ADVANCE CARE PLANNING—A CONTINUOUS PROCESS WITH POSITIVE EFFECTS

Advance care planning (ACP) is a continuous process through which providers engage in discussions with patients and their families to learn their goals and preferences toward future medical treatments. Advance care planning is especially important for patients with ESRD as a substantial percentage of dying dialysis patients do not have decision-making capacity near the EOL and are unable to express care preferences.¹² Patients who have engaged in ACP are more likely to receive EOL care aligned with their preferences.¹³ Furthermore, the benefits of ACP extend beyond patients to include caregivers. Studies suggest that timely ACP can improve caregiver confidence in EOL decision-making, improve the quality of EOL care, and positively impact psychological symptoms in bereaved caregivers.¹⁴ One study of bereaved families rated the quality of EOL care better in cases with cancer or dementia as compared to ESRD.¹⁵ This difference was attributed to aspects of ACP, such as discussions on limiting escalation of care, addressing code status, and consultation with palliative care.

In our experience, ACP is a skill that can be taught and practiced much in the way physicians are accustomed to learning other skills.^{16,17} Initial conversations often build trust and rapport, thus leading to subsequent conversations that feel more fluid. Optimally, timing these conversations can be difficult, especially as making accurate predictions about future clinical developments is essentially impossible.

2.1 | Prognostication for patients with ESRD

Patients with kidney disease experience an illness trajectory similar to other chronic illnesses characterized by acute declines followed by incomplete recovery (Figure 1). Although these illness trajectories oversimplify clinical reality, they highlight the need for integration of ACP *throughout* the course of a chronic illness, regardless of which specific trajectory a patient follows.¹⁸ They also highlight the challenges of predicting which patients would benefit from goals of care discussions. The goal of identifying high-risk patients is not to necessarily predict impending mortality, but to gain an understanding of which patients are likely to have setbacks and therefore enable providers to have timely conversations. Using validated prognostication

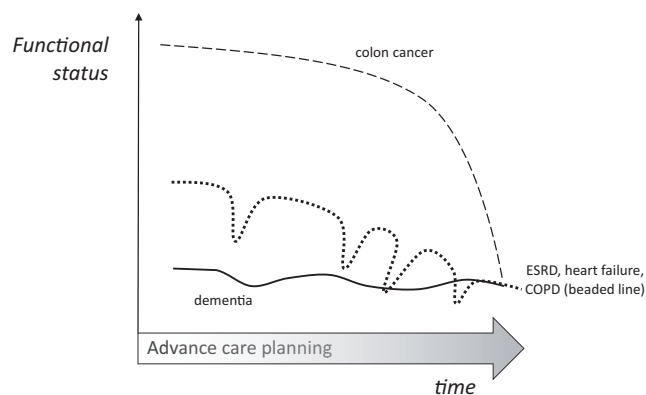


FIGURE 1 Illness trajectory diagram showing hypothetical changes in functional status over time in a variety of chronic conditions. Advance care planning should be integrated throughout the course of chronic conditions

models or findings from prior studies can add valuable objectivity to clinical judgment.

A well-known prognostication model estimates 6-month survival for patients receiving hemodialysis (HD) using 4 clinical variables associated with increased mortality: advanced age, hypoalbuminemia, and the presence of peripheral vascular disease and/or dementia.¹⁹ These variables, combined with the provider's response to the "surprise question" (*Would I be surprised if the patient died in the next year?*), can estimate the percent chance that a patient will be alive at 6 months. The model can be accessed at <http://www.qxmd.com/calculate/>. Interestingly, the "surprise question" has prognostic utility on its own. Compared to "yes," responding with "no" has been shown to be associated with a 3.5 times higher risk of death in 1 year (odds ratio 3.5, 95% 1.4 to 9.1).²⁰

Other triggers to predict patients at risk for declining include demographic and clinical characteristics. The overwhelming majority of patients with ESRD who are also residents of nursing homes have a decline in their functional status and over 50% die within 12 months of initiating dialysis.²¹ While age alone is typically not predictive enough of impending mortality, patients who are over 75 with any combination of frailty or ischemic heart disease with reduced ejection fraction are a high-risk group.^{22,23} Patients who have other life-limiting comorbidities such as metastatic cancer or end-stage liver disease without a transplant option, regardless of age, are also high-risk subgroups. Lastly, the presence of geriatric syndromes such as functional and/or cognitive impairment can also identify patients at high risk for death.²⁴

Advance care planning may involve sharing prognostic information with patients and families. Providers often feel a tension to balance honesty with the notion of "preserving hope." Data from Canada suggest that an overwhelming majority of dialysis patients want to discuss prognosis and difficult topics such as dialysis withdrawal with their nephrologists, but fewer than 10% report having these conversations.² While a review of specific techniques on how to share difficult news is outside the scope of this article,²⁵

nephrology providers should feel comfortable *asking* patients if they are interested in discussing prognosis.

2.2 | Early ACP

Early ACP is defined as discussions that occur during a time of clinical stability. These early conversations allow patients to reflect on their care preferences to inform decision-making in future times of decline or acute illness. Evidence shows that among nursing home residents with ESRD, those who engaged in early ACP by completing an advance directive and naming a surrogate decision-maker had fewer hospitalizations, less intensive care, and fewer invasive procedures compared to those who lacked both.²⁶ Furthermore, the high prevalence of cognitive impairment in ESRD reinforces the need to engage in early goals of care conversations.²⁴ Early ACP includes bringing up the conversation, incorporating preferences for dialysis decisions near end of life, and ACP documentation. An overview of the ACP framework in this article is shown in Figure 2.

2.2.1 | Bringing up ACP

Many providers may worry that talking about ACP will evoke strong emotions of fear and worries that death may be near. For early ACP, we suggest introducing the conversation as an expected part of routine nephrology care: “*These are questions I like to ask all of my patients*”. Other phrases intended as examples rather than an exhaustive list are included in Table 1. An additional way to introduce these conversations is to ask about prior ACP experiences as many patients have had previous conversations or completed ACP documents. This approach also normalizes the conversation by helping patients realize that the topic can be important to multiple physicians, not just the nephrology team. Providers are encouraged to also ask patients to identify a surrogate decision-maker who can speak on the patient’s behalf if decisional capacity is lost: “*In case your health worsened and you weren’t able to speak for yourself, is there someone you trust to make healthcare decisions for you?*” Initially,

patients may feel unprepared or hesitant to engage in these discussions. This response is normal and expected. Hence, these conversations should be described as an ongoing *process* or *dialogue* and that responses can evolve and change over time.

2.2.2 | Discussing dialysis-specific ACP

Advance care planning can also inform current and future preferences about dialysis decisions. In a retrospective study of hemodialysis patients, almost 50% of patients completed an advance directive; however, only 10% explicitly outlined dialysis preferences at EOL.²⁷ Yet, 1 in 5 dialysis deaths follows a decision to discontinue dialysis. These decisions are often informed by critical illness rather than patient preferences.²⁸ Therefore, outlining dialysis-specific ACP can enhance patient-centered decision-making at EOL.

Dialysis-specific ACP involves learning what *priorities* the patient *hopes* dialysis can help to achieve as well as the *concerns* or situations in which the patients would want to continue life-sustaining treatments such as dialysis (discussed more in section on withdrawal from dialysis). Table 2 contains examples of general questions to elicit these patient values and priorities. Understanding these dialysis-specific preferences can inform immediate treatment goals as well as guide future decision-making. For example, asking “*What are your concerns about dialysis*” could result in a variety of useful insights. An elderly patient may worry about being a burden on family as she nears the EOL. By asking this question, the patient can articulate these worries to family and inform future situations that may serve as opportunities to revisit dialysis decisions (see section on withdrawal from dialysis below). It is important to clarify that patient values and priorities can change over time, thus highlighting the need to revisit conversations and previous decisions. In addition, these conversations are most successful when they include family members, an endeavor that is challenging due to the lack of privacy typical of an outpatient dialysis setting. More specific guidance on having conversations during a spectrum of dialysis-related events can be found in the literature.²⁹

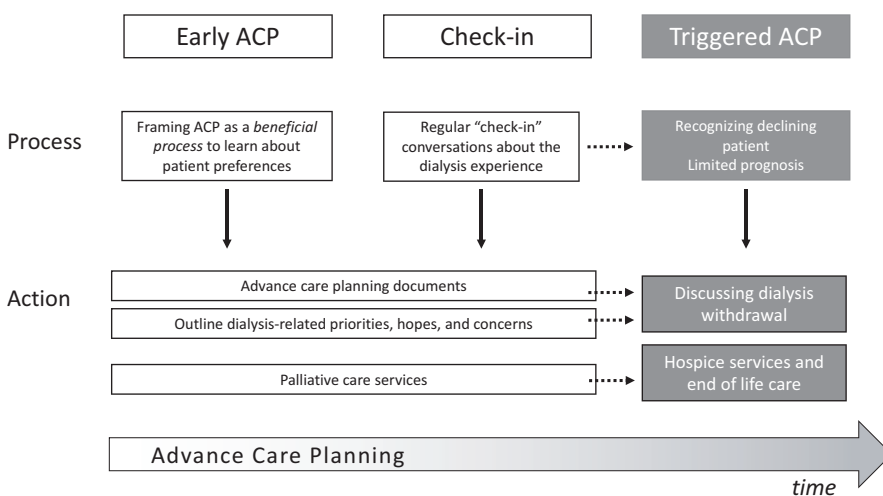


FIGURE 2 Framework for advance care planning that includes early, check-in, as well as triggered conversations. Although the tools are not limited to specific phases of chronic illness, for simplicity, they are shown as discrete tools over the course of time. ACP; advance care planning

TABLE 1 Phrases that can be useful for 1) normalizing advance care planning, 2) framing it as a process, and 3) discussing values and preferences. These are not an exhaustive list, and providers should expect to repeat these conversations over time

Phrases to DISCUSS advance care planning

I want to understand how you would like us to care of you if you got sicker. What would you like us to prioritize?

Talking about how to take care of you now can help your family know what would be important if you were too sick to tell us. Are you willing to talk about this with me?

It is important for us to be able to respect your wishes about your healthcare if you were very sick. Have you discussed this with someone?

Would it be ok if we talked about how you would like to be cared for if your health worsened?

Are there situations you would like to avoid if you became very sick?

Getting to know what is important to you will help us take better care of you. How do you like to make decisions about your healthcare?

Phrases to NORMALIZE advance care planning

These are questions I like to ask all of my patients

These conversations are an important part of every dialysis patient's care

Many people find these conversations difficult. That is normal

I want you to know that you can talk to me about your preferences

Phrases to convey that advance care planning is a PROCESS

Over the course of your time on dialysis, talking about this will help me understand your preferences

If there is family that helps you make decisions, it can be useful to involve them in these discussions

I would like to have an ongoing conversation about these topics. Getting to understand your priorities is a process

TABLE 2 Phrases that can be useful for asking about dialysis-specific hopes and concerns

Values and priorities	Open-ended questions to outline dialysis goals
Explore patient hopes	What do you hope dialysis will help you do? or How do you think dialysis can improve your life?
Explore patient concerns	Are there situations when you would not want to continue treatments like dialysis? or What concerns about dialysis do you have?
Check-in on patient experience	Now that you have been on dialysis for a while, is there anything you are worried about?

2.3 | ACP "Check-in" conversation

Patient preferences can change over time, and so ACP conversations should be revisited. We recommend having a deliberate "check-in" conversation to reassess the dialysis experience.³⁰ "Now that you've been on dialysis for a few months, how are things going?" This open-

ended question allows a patient to share concerns and needs that may inform the care plan. Having this conversation during a time of clinical stability enables a proactive and exploratory discussion rather than a reactive one after acute setbacks. Patients can then reflect on their preferences without the emotional apprehension that can accompany episodes of clinical decline or illness. In addition, these conversations often uncover unmet needs and symptoms which may prompt consultation with palliative care services. Palliative care is interdisciplinary care for patients living with serious illness including those who are pursuing life-prolonging care such as dialysis. Palliative care providers work alongside the dialysis team to address distressing symptoms, provide support, and assist with ACP and goals of care conversations.

2.4 | Advance care planning documents

Advance care planning conversations can be operationalized into documents that outline care preferences.¹⁸ Common documents such as healthcare power of attorney, physician orders for life-sustaining treatment (POLST), Five Wishes, and do not resuscitate (DNR) are reviewed in Table 3. An important difference between POLST forms and the traditional advance directive is worth highlighting. POLST forms are medical orders that are signed by a physician and patient with clear wording and actionable plans for providing EOL care. They are short (1 sheet, front and back) and are

TABLE 3 Documents commonly used to document healthcare preferences

Document	Description
Healthcare power of attorney	<ul style="list-style-type: none"> Enables a patient to grant healthcare decision-making authority to a person of their choice.
Advance directive (also referred to as a "living will")	<ul style="list-style-type: none"> A declaration of preferences regarding healthcare to be used as a guide when a patient lacks decisional capacity. More often drafted with legal help than with medical input.
Physician Orders for Life-Sustaining Treatment (POLST)	<ul style="list-style-type: none"> A standardized form signed by a physician that clarifies care preferences. As the name suggests, it is a medical order and is intended to be portable across healthcare settings. It is available in most states (see http://polst.org)
Five Wishes	<ul style="list-style-type: none"> An explanatory/narrative form designed to encourage patients to think about and declare EOL care preferences. It meets legal requirements for an advance directive in most states. https://www.agingwithdignity.org
Do Not Resuscitate (DNR)	<ul style="list-style-type: none"> An inpatient medical order that restricts the use of cardiopulmonary resuscitation in the event of cardiac arrest. It is sometimes referred to as an Allow Natural Death (AND) order

intended to be portable. However, traditional advance directives are most often drafted with legal help, may be difficult to interpret, and are usually several pages long.

It is important to note that while each of these documents has its own emphasis, there is substantial redundancy within the five that are shown. For example, in most states, a POLST form is legally usable as an advance directive and information regarding code status is contained within it. Therefore, additional completion of a DNR form is not necessary.

Providers should also outline dialysis-specific ACP information because the documents shown in Table 3 are all designed to be applicable to the general population. They do not help patients with ESRD clarify the role of dialysis at the EOL. Some advance directives may mention dialysis, especially if they were drafted prior to the patient having ESRD. Therefore, it is important for nephrology providers to be aware of the contents of these directives and provide guidance on updating them, if necessary. For example, a patient with ESRD may have an advance directive mentioning that he/she would “*want dialysis in the event of kidney failure.*” This is a common scenario, and we recommend that nephrology providers be involved in an effort to clarify these kinds of advance directives to also include dialysis-specific ACP information. For example, revised language could say, “*I would not want to continue dialysis if I wasn't able to interact with my family or friends.*” When completing any advance directive documents, it is often useful to involve a dialysis social worker to help ensure compliance with state regulations and policies of the dialysis unit, especially in the case of large dialysis organizations.

2.5 | Triggered ACP

While early ACP is beneficial for all patients, it is equally important to address ACP in patients who are declining or at high-risk for death. Prior to sharing these concerns, it is important to clarify prognostic worries with other providers involved in the patient's care and clarify prognostic misunderstandings. For example, a patient may have worsening dementia, downtrending albumin, and repeated failed attempts at arteriovenous fistula creation. At the same time, cardiac evaluation may show a preserved ejection fraction and a normal stress test. This scenario can lead to a cardiologist not having the same prognostic concerns as a nephrology provider. Thus, discussing prognosis as an interprofessional team can better guide ACP conversations for patients who are declining.

2.5.1 | Bringing up dialysis withdrawal

When having discussions about stopping dialysis for high-risk patients, it becomes important to revisit previously outlined patient priorities, hopes, and concerns (see Table 2). For example, if “being independent” was articulated as an important patient priority when starting dialysis, a dialysis withdrawal conversation may start with discussing setbacks such as functional dependency or concern for future skilled nursing needs.

TABLE 4 Phrases that can be useful for bringing up dialysis withdrawal and responding to requests to stop dialysis

Rationale and framing	Useful phrases
Gain patient perspective. This step helps to determine whether they are also worried.	<ul style="list-style-type: none"> • How are things going on dialysis? • Are your other doctors worried about your condition? • How are you doing this month compared to, let's say, six months ago?
Gently frame your own concerns and explore further.	<ul style="list-style-type: none"> • Given the setbacks you've experienced, what's most important to you? • I am concerned you have declined in the past few months. Do you think so also? • I am worried dialysis is not making your life better. Do you see it this way?
Suggest how dialysis may not be optimizing quality of life based on patient's stated goals.	<ul style="list-style-type: none"> • When you started dialysis, it helped you recover and regain strength. That was important to you. Now I believe it could be making you weaker. (Expect and acknowledge emotion)
Responding to a request for dialysis withdrawal.	<ul style="list-style-type: none"> • I am grateful you brought this up with me. Can you tell me more about why you want to stop dialysis?
For patients at risk for dying in weeks to months, flexibility is important. ^a	<ul style="list-style-type: none"> • Many people in your condition would say that dialysis may not be helping them anymore. • Do you feel this is true for you? You are very sick. It is ok for you not to come to dialysis if you feel too weak.^b

^aFor these situations, coordination with the family, other care providers, and consultation with palliative care may be helpful.

^bGiven the risk of death from uremia or electrolyte abnormalities, we recommend a do-not-resuscitate (DNR) order in this circumstance.

While there is not a “preferred” or evidence-based approach to these discussions, we recommend being comfortable *bringing up* dialysis withdrawal as well as *responding to requests* for dialysis withdrawal. Table 4 has some suggestions on how to frame the conversation, gain patient perspective, and use this information to help guide decision-making around dialysis withdrawal. For example, intentionally framing a conversation by mentioning recent setbacks enables the provider to acknowledge how they adversely affected the patient as well as ensure that the patient also perceives recent occurrences in a similar way.

3 | WITHDRAWAL FROM DIALYSIS

Withdrawing dialysis for a patient with ESRD is a transition from reliance on life-sustaining treatment to a situation in which death is

usually imminent. In a cohort study involving patients with ESRD who withdrew from dialysis and then enrolled in hospice, mean survival time after enrollment was 7.4 days.³¹ From the same study, survival time for patients who enrolled in hospice for nonrenal diagnoses was 54.4 days. Interestingly, estimates indicate that many patients who die after dialysis withdrawal do not receive hospice services. These trends exist despite the fact that hospice enrollment can have statistically significant effects on lowering hospital deaths and costs of EOL care for patients with ESRD.³²

In addition to a mean survival time of 1 week, most patients who die after dialysis withdrawal also experience distressing symptoms.³³ Hospice can improve the EOL experience for patients stopping dialysis and their families through specialized EOL care and bereavement services after death. The referral can often be initiated through the social worker in the dialysis facility. Ideally, the timing should be such that the patient receives a clear explanation of hospice benefits and has an opportunity to enroll in hospice *before* withdrawing from dialysis. This sequence of events enables preparation for logistics and durable medical equipment so that the hospice team can be ready to meet the needs of the patient and caregivers.

In settings where it is available, consultation with palliative care can also be helpful when dialysis withdrawal is being considered. This is especially true if there are concerns about decisional capacity, psychiatric conditions such as depression affecting judgment, or unmet symptom needs. However, it is important to emphasize that palliative care consultation can also be helpful in situations aside from dialysis withdrawal. Aggressive symptom management, assistance with complex medical decisions, and enhancing communication to better elicit patient goals and values are all aspects of palliative care that are not reserved for EOL situations.

3.1 | Conclusion and future directions

Dialysis patients benefit from early and frequent discussions about goals of care and future care preferences. This review presented ACP across the disease trajectory as early, check-in, and triggered ACP discussions with phrases to guide the conversation. As we envision the future of dialysis care, it is clear ACP will be best delivered through a team-based approach. Similar to the interdisciplinary care involved in managing dialysis, ACP requires a diverse skill set that no one person can deliver alone. Hence, successful ACP must be viewed as a collective responsibility. With the creation of ESRD Seamless Care Organizations (ESCOs), dialysis organizations are testing innovative care models to deliver team-based care that includes ACP. The future of patient-centered dialysis care will involve defining team roles, learning ways to effectively work together as a team, and collaborating with supportive services such as palliative care and hospice.

CONFLICT OF INTEREST

The authors declared that they have no conflict of interest.

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