

Center to
Advance
Palliative Care
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NATIONAL KIDNEY
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The Case

for Palliative Care
in Kidney Care

"The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick."

Eric Cassell, MD

Founding Fellow, Hastings Center on Bioethics

Advanced kidney disease is a complex condition—often with co-occurring illness, and always with a significant impact on patient and family quality of life. In addition to the physical effects of the disease, patients and family members face challenging decisions about treatment and grapple with profound emotional and existential issues.

The nephrology team can relieve this suffering by incorporating palliative care.

Palliative care is a clinical specialty that focuses on improving quality of life for people living with a serious illness. Palliative care specialists partner with the nephrology team to:

- ✓ **Clarify patient values, preferences, and goals, and support shared decision-making**
- ✓ **Manage pain, fatigue, pruritus, and other physical symptoms**
- ✓ **Address emotional and spiritual distress**
- ✓ **Counsel and coach family caregivers with anticipatory guidance**

Palliative care is appropriate regardless of prognosis and at any stage of illness. Basic palliative care can be delivered by the kidney care team with additional training, while more complex cases will benefit from consultation with a specialty palliative care team.

The evidence shows that palliative care has a significant positive impact on patient outcomes while strengthening financial performance for health care organizations.

A Substantial Need for Palliative Care Services

Since 1972, when people with end-stage kidney disease (ESKD) were added as Medicare beneficiaries, the population has changed significantly. In 1978, only 25% of people on dialysis were older than 65 years. Today, more than 50% of the dialysis population is over 65 and generally comes to dialysis with more comorbid conditions and complex social needs.¹

People living with advanced kidney disease also face considerable physical and psychological symptoms.¹



SYMPTOM	PREVALENCE IN PATIENTS ON HEMODIALYSIS IN U.S. ¹
Fatigue/Weakness	68%
Pruritus	54%
Pain	50%
Insomnia	44%
Restless Legs	29%
Worrying/Anxiety	28%
Nausea	26%
Sadness/Depression	24%
Constipation	21%
Dyspnea	19%

The prevalence of some symptoms, especially pain, depression, and dyspnea, climbs to 54%, 61%, and 63%, respectively, in retrospective studies of decedents. These are the exact problems where palliative care has a solid evidence base for improvement, with the positive impact lasting for months.^{2,3}

While symptom burden in this patient population is significant, patients with kidney disease are much less likely to receive pain and symptom management than patients with other diseases, such as cancer.⁴ More can be done to relieve unnecessary suffering for these patients.

Compounding the physical burdens, patients with advanced kidney disease face complex treatment decisions. Patients and families require skilled discussions regarding prognosis, the pros and cons of each treatment option, and clarification of their values, goals, and cultural and spiritual beliefs so care can be aligned accordingly.

Fewer than 10% of people on dialysis report having conversations about their goals of care.

And even at this low rate, Black patients are less likely than White patients to report having supported decision-making conversations.⁵ As a result, more than one in five people on dialysis regret the decision to start dialysis, and more than 20% of older patients withdraw from dialysis each year.^{7,8}

Palliative care addresses these exact gaps to improve care delivery and quality of life—resulting in better outcomes and improved patient satisfaction.

Shared Decision-Making Conversations Are Particularly Necessary for Older and Complex Patients with Advanced Kidney Disease

In some older patients with comorbidities, dialysis and conservative kidney management have small differences in survival—but large differences in patient quality of life.⁶ Skilled conversations to explain the benefits and risks of all treatment options and clarify patient values and goals are recommended in the clinical practice guideline and are essential to effective patient care.

Palliative Care Consultation Improves Outcomes

While specialty palliative care consultation and co-management for people living with kidney disease is not yet common, those nephrology teams that do collaborate with palliative care teams—particularly for patients with multiple comorbidities—see tremendous impact.

When palliative care specialists talk with patients about their prognosis and goals of care, dialysis regret decreases and quality of life improves.^{8,9}

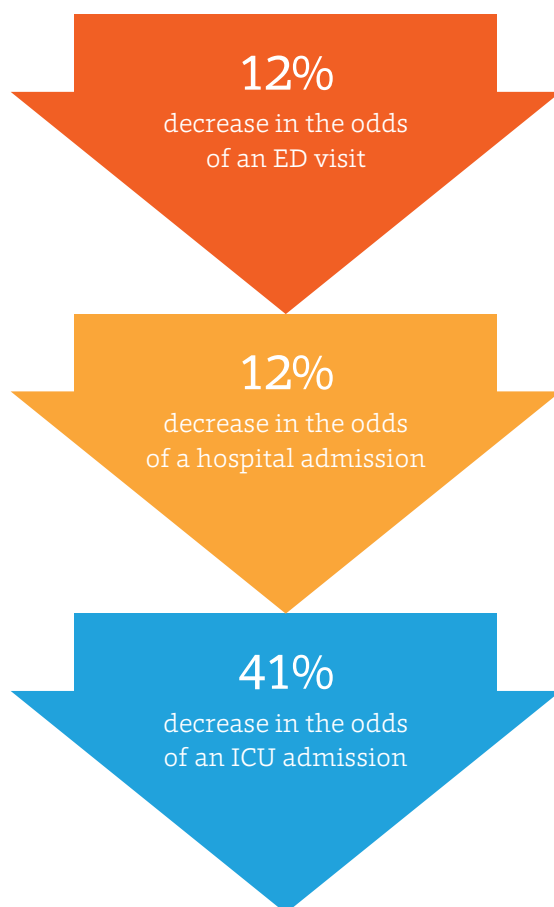
Inpatient palliative care consultation for patients on dialysis results in significant improvement in symptoms, even after a single visit, as well as reductions in length of stay, hospital costs, and readmissions. For decedents, inpatient palliative care was associated with a 21% shorter length of stay and a 14% reduction in hospital costs.^{10,11}

"Inpatient palliative care is associated with a 14% reduction in hospital costs for decedents with ESKD."

Integration of palliative care into specialty clinics is standard practice in the Veterans Health Administration (VA), and patients may elect to receive hospice concurrently with dialysis; in fact, 40% do.¹² As a result, VA patients are less likely to receive high-intensity care at the end of life and experience fewer emergency department (ED) visits, fewer hospitalizations, and fewer intensive care (ICU) admissions when compared to Medicare beneficiaries.^{13,14}

A Canadian study found that decedents with ESKD who received care from specialty palliative care teams in the prior six months had lower odds of health care utilization compared to those who did not receive any palliative care visits.¹⁵

Reduced likelihood of health care use following receipt of palliative care: decedents with ESKD¹⁵



Not only is this good business, it's the professional standard. The **Renal Physicians Association's clinical practice guideline** includes Recommendation No. 9, "To improve patient-centered outcomes, offer palliative care services and interventions to all AKI [acute kidney injury], CKD [chronic kidney disease], and ESKD patients who suffer from burdens of their disease." The guideline observes that palliative care specialists should be involved in managing the physical, psychological, social, and spiritual aspects of treatment for these patients, including end-of-life care.¹⁶

Palliative Care Skills Training for Nephrology Clinicians Strengthens Quality of Care

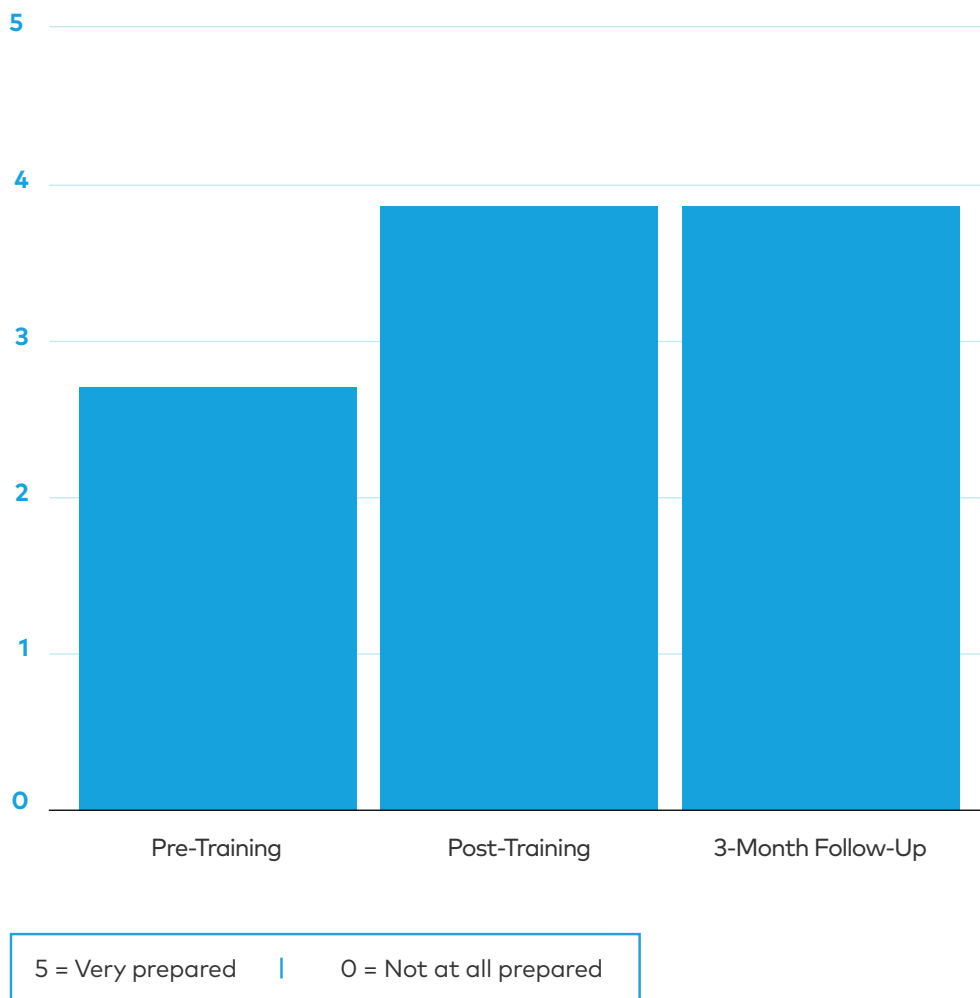
Most practicing nephrology clinicians report trepidation about discussing prognosis, goals of care, quality of life, symptom relief, and alternatives to dialysis, and yet the vast majority recognize the value.¹⁷

“[Palliative care] helps align what choices they face with the kind of person that they are. And that’s sort of where the joy really is.”

Amar Bansal, MD, FASN
Assistant Professor, University of Pittsburgh

In a large academic medical center, the NephroTalk communication skills training for nephrology fellows resulted in improved ability to identify patients in need of goals of care discussions, and increased confidence in their abilities to have meaningful conversations.^{19,20}

How Well-Prepared Are You to Hold Conversations?



In addition to communication skills, continuing education programs in core palliative care skills—including pain and symptom management—have been shown to build confidence and result in practice change.²¹

Benefits to Dialysis Centers

Incorporating palliative care skills and specialists into care for people with kidney disease and high medical complexity has profound benefits not only for patients and families, but also for dialysis providers.

- **Fewer Missed Sessions** — Symptom distress is responsible for a significant portion of hospitalizations, and with symptoms well-managed, crises and hospitalizations are avoided.²²
- **Reduced Rates of Withdrawal from Dialysis Therapy** — Strong patient-led decision-making for dialysis will reduce rates of withdrawal, particularly for those with complex comorbidities.²³
- **Improved Clinician Satisfaction** — Fewer than 5% of clinicians working in dialysis centers believe they are providing high-quality support for their older and complex patients, leading to moral distress, burnout, and turnover.^{24,17}
- **Alignment with Future Quality Measures** — Looking ahead, there is movement toward weighing patient-reported outcome measures more heavily and advocacy efforts to expand the palliative care exclusion to more quality measures.^{25,26} Additional advocacy is ongoing to exclude patients receiving palliative dialysis from Medicare's End-Stage Renal Disease Quality Incentive Program (QIP).

A Call to Action

Given these findings, it behooves nephrology practices and dialysis centers to improve their palliative care capabilities, and several organizations provide support for such care transformation. The following resources can help in your care transformation:

- 1 **The Center to Advance Palliative Care (CAPC)** has tools, resources, and [online clinical training](#) in both communication and symptom management skills, with continuing education credits across all disciplines, and ABIM maintenance of certification (MOC) credits for physicians.
- 2 **The Coalition for Supportive Care of Kidney Patients** offers a trove of educational resources specific to nephrology and palliative care practices, and provides a community for clinicians to learn, research, and advocate for kidney supportive care.
- 3 Find palliative care specialist teams in your area for consultation and collaboration via [CAPC's Palliative Care Provider Directory](#).
- 4 Learn more about integrating palliative care approaches and specialists in nephrology care:
 - Renal Physicians Association, [Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis: Clinical Practice Guideline, Second Edition](#)
 - [Palliative Care in Nephrology textbook](#)
 - [Pathways Project Change Package](#)
- 5 Access resources for patients and families:
 - [GetPalliativeCare.org](#)
 - [National Kidney Foundation](#)
 - [Resources | Coalition for Supportive Care of Kidney Patients | The George Washington University](#)

"Kidney supportive care merges palliative care into nephrology, emphasizing a holistic, patient-centered approach that honors each individual's values, wishes, and preferences while prioritizing symptom management and spiritual, psychosocial, and emotional support. We must ask the right questions and then listen to our patients."

Christine Corbett, DNP, CNN-NP, ACHPN

Assistant Research Professor, The George Washington University, and Executive Director, Coalition for Supportive Care of Kidney Patients

"At the end of the day, it's our job to be a guide for our patients and families. Ultimately, they make the decision with our guidance and our help, and it may be different from what we expected or what we might choose for ourselves."

Jane Schell, MD

Associate Professor and Section Chief of Palliative Care and Medical Ethics, University of Pittsburgh

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About the Center to Advance Palliative Care

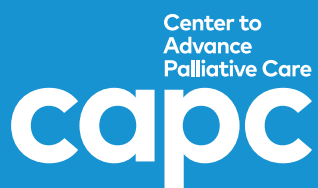
The Center to Advance Palliative Care (CAPC), established in 1999, is a national nonprofit organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness. As the nation's leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively redesign care systems that meet this need. CAPC is part of the Icahn School of Medicine at Mount Sinai in New York City. capc.org

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About the National Kidney Foundation

The National Kidney Foundation (NKF) is revolutionizing the fight to save lives by eliminating preventable kidney disease, accelerating innovation for the dignity of the patient experience, and dismantling structural inequities in kidney care, dialysis, and transplantation. kidney.org

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