

**ACP DECISIONS**

# **Building A Comprehensive Kidney Care Model**

**A Guide to Adding Medical Management  
Without Dialysis to Your CKD Care Model**

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## Abstract

This White Paper examines current issues surrounding the care and treatment options for patients with advanced renal disease and explores the underutilization of medical management without dialysis, a treatment approach that may better align with patients' goals of care and offer better quality, improved patient experience, and reduced costs. It also offers a checklist for initiating a new care delivery model that includes medical management without dialysis.

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## Overview

**Chronic kidney disease (CKD)** is one of the largest public health challenges the U.S. health care system faces today. Not only is it the ninth leading cause of death<sup>1</sup>, the rate of Americans who have **end-stage renal disease (ESRD)** ranks among the highest in the world and continues to rise.<sup>2</sup> The CDC's latest statistics show that about 90 percent of the estimated 37 million adults who have CKD are unaware they even have it.<sup>3</sup>

**Despite the substantial prevalence and costs associated with kidney disease, the prevention, treatment, and management of the condition have changed little over the past several decades.**

An aging population as well as increasing rates of diabetes, hypertension, heart disease, and obesity contribute to the growing prevalence of this often-silent disease. Medicare spends more than \$114 billion on patients with CKD and ESRD, which is only the tip of the iceberg when it comes to the financial burden. Kidney disease is considered a “cost multiplier,” due to the added costs of caring for patients who have chronic diseases that accompany CKD, such as diabetes and heart failure.<sup>2</sup>

Despite the substantial prevalence and costs associated with kidney disease, the prevention, treatment, and management of the condition have changed little over the past several decades. In fact, CKD and ESRD have not been a focus in major health promotion and public awareness campaigns until the recent launch of the **Advancing American Kidney Health** initiative by the U.S. Department of Health and Human Services.<sup>4</sup>

### The Challenge of Caring for Patients with Advanced Kidney Disease

Patients with CKD fall into five stages of kidney damage, from very mild damage in Stage 1 to 5 and complete failure (ESRD). As patients progress to the later stages, care becomes less preventive and oriented more towards managing complications, preparing for ESRD, choosing a type of dialysis, and/or preparing for kidney transplant.



Medicare spends more than **\$114 billion** on patients with CKD and ESRD.



**ESRD, which impacts approximately 760,000 Americans, is growing by 5 percent each year.**

Advanced kidney disease (Stages 4 and 5) is significantly more complex to manage, resulting in poorer outcomes with greater costs of care. End-of-life care for patients with ESRD is marked by high rates of hospital and ICU admissions, more intensive procedures, and greater inpatient deaths. ESRD, which impacts approximately

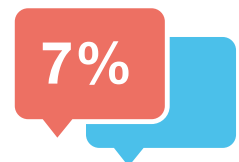
760,000 Americans, is growing by 5 percent each year. **While Medicare beneficiaries living with ESRD make up just 1 percent of this population, they account for 7 percent of the Medicare budget.<sup>2</sup>**



**Current treatment options** for individuals with advanced kidney disease include **kidney transplant, hemodialysis, peritoneal dialysis, and medical management without dialysis**. None of these treatment modalities is a cure, and each comes with some possibility of complications.

While timely kidney transplantation has the best prognosis, there is an acute shortage of donor kidneys. There are distinct advantages and disadvantages to each form of dialysis; however, the use of in-home dialysis (for both hemodialysis and peritoneal dialysis) has lagged despite clinical and quality-of-life benefits of in-home options.<sup>5</sup>

Medical management without dialysis is a palliative care approach that forgoes dialysis and focuses on the medical management and treatment of symptoms related to late-stage kidney disease. It aims to deliver medical care and psychosocial support for issues ranging anywhere from pain to depression. **Due to various factors, such as a lack of patient education, fragmented care, and clinician perceptions<sup>6</sup>, many older patients choose hemodialysis even when this treatment option does not increase life expectancy or quality of life.**



Medicare beneficiaries living with ESRD make up **7% of the Medicare budget**.





**For most individuals with ESRD, kidney transplantation is the treatment of choice.**

**All too often, older patients who would benefit from medical management without dialysis are not aware such an option exists.**

Patients perceive that they have no choice but to initiate dialysis, and most are not told of the option of medical management without dialysis.<sup>7</sup>

## Managing Advanced Kidney Disease: Maintaining the Status Quo?

### Review of the Recognized Care Options

As CKD progresses to Stages 4, 5 and ESRD, a nephrology team typically takes a more active role in the patient's care and medical decision making. Medical care in the earlier stages centers on slowing progression and addressing related medical issues, while renal replacement options become the focus in advanced renal disease. As health care providers guide patients through the transition to ESRD, **there are generally three recognized treatment options in the U.S.: kidney transplant, hemodialysis, and peritoneal dialysis.**

### Kidney Transplant

For most individuals with ESRD, kidney transplantation is the treatment of choice.<sup>8</sup> A successful transplant improves quality of life and life expectancy and is considered the most cost-effective modality of renal replacement.

Ideally, patients who are eligible to receive a kidney transplant do so before ever starting on dialysis. Although studies have shown better outcomes for these patients<sup>9</sup>, less than three percent of patients receive a preemptive kidney transplant.<sup>2</sup>

**The largest issue surrounding this treatment option continues to be a shortage of available organs.** Most candidates for transplantation must go on a waiting list and undergo dialysis until a kidney is available. **Currently, there are close to 100,000 people waiting for a kidney transplant,<sup>10</sup> and the median waiting time to transplant is 4 years.<sup>2</sup>**



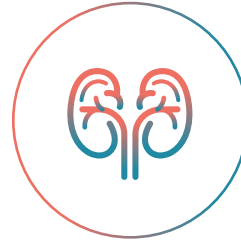
**Ideally, patients who are eligible to receive a kidney transplant do so before ever starting on dialysis.**



### Some Interesting Statistics:



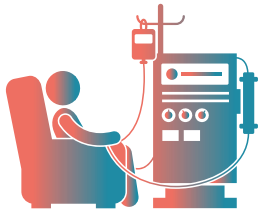
Medicare spent almost **\$35,000 per transplant patient** vs. **\$89,000 per dialysis patient** in 2016.<sup>2</sup>



In 2016, **30% of ESRD patients** had a functioning kidney transplant.<sup>2</sup>



**21,167 kidney transplants** were performed in the United States in 2018.<sup>10</sup>

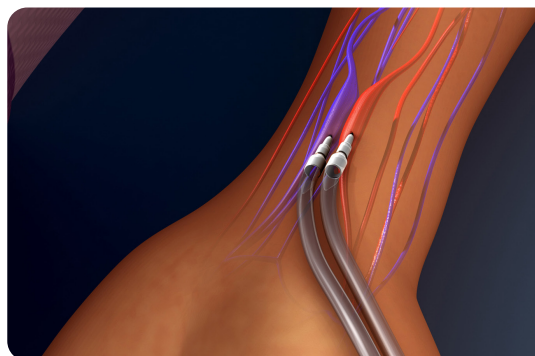


### Hemodialysis

Hemodialysis is the most common form of treatment for ESRD in the U.S. In 2016, a reported 63% of all ESRD patients were receiving hemodialysis, and 87% of patients who received a transplant began hemodialysis prior to the procedure. The mortality rate for hemodialysis in 2016 was 166 per 1,000 patient-years.<sup>2</sup>

**Prior to initiating hemodialysis, stable venous access is established via one of the following methods:**

**Arteriovenous fistula (AVF)** is the preferred method of access. Although AVFs have the least risk of complications and higher long-term patency rates, only 17% of patients have AVF access at hemodialysis initiation.<sup>11</sup>



**The mortality rate for hemodialysis in 2016 was 166 per 1,000 patient-years.<sup>2</sup>**

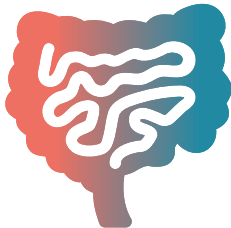


**Evidence suggests that longer and/or more frequent sessions offered by in-home dialysis may improve outcomes and enable patients to lead more independent lives.**

**Arteriovenous (AV) graft** is the best option for patients whose vascular anatomy does not support an AVF; however, it has a higher long-term complication rate than AVF. At the initiation of hemodialysis, only about 3% of patients use an AV graft for vascular access.<sup>2</sup>

**Central venous catheter** is commonly used for vascular access, despite being the most prone to infection and increased risk of blood vessels clots or narrowing. About 80% of patients use a catheter when starting hemodialysis.<sup>2</sup>

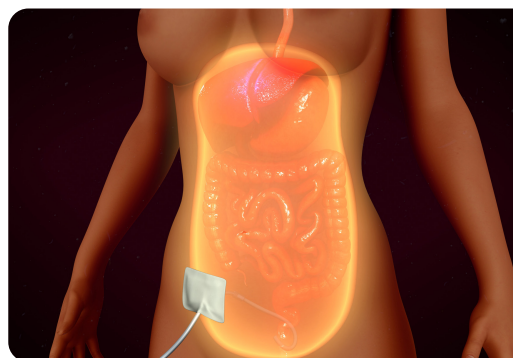
Hemodialysis can be done at a dialysis center or at home. In-center hemodialysis usually requires a visit to a dialysis center three times a week for three to four hours. In-home dialysis is often done more frequently and for shorter periods of time. Evidence suggests that longer and/or more frequent sessions offered by in-home dialysis may improve outcomes and enable patients to lead more independent lives compared to traditional in-center dialysis.<sup>12</sup> However, in the U.S., about 98% of hemodialysis patients use traditional in-center hemodialysis.<sup>2</sup>



### Peritoneal Dialysis

Peritoneal dialysis is often reserved for patients who cannot tolerate the rapid volume shifts associated with hemodialysis. Although it is considered the more cost-effective and patient-centered dialysis modality with better early survival rates<sup>13</sup> and improved health-related quality of life<sup>14</sup> than hemodialysis, **only 7% of patients with ESRD receive peritoneal dialysis treatment.**<sup>2</sup> The mortality rate for peritoneal dialysis in 2016 was 154 per 1,000 patient years.<sup>2</sup>

**Peritoneal dialysis is performed at home by patients,** giving them greater



**The mortality rate for peritoneal dialysis in 2016 was 154 per 1,000 patient years.<sup>2</sup>**



lifestyle flexibility, convenience and independence. It may be done manually four to six times per day (**Continuous Ambulatory Peritoneal Dialysis**), automatically with a cyclor machine while sleeping (**Continuous Cycling Peritoneal Dialysis**), or with a combination of the two methods.

Because dialysis occurs more frequently with peritoneal dialysis, **it also offers the benefits of less fluid and dietary restrictions**. Potential complications of peritoneal dialysis include peritonitis, infection at the catheter insertion site, weight gain and hernia. In addition, over time peritoneal dialysis can become ineffective necessitating a change in therapy.<sup>15</sup>

## Medical Management without Dialysis: The Forgotten Choice in Kidney Care

Medical management without dialysis is a treatment option that is poorly defined and often misunderstood. **Variably referred to as “active medical management without dialysis”, “conservative care”, “conservative kidney management care”, “maximal conservative management”, “renal supportive care”, “palliative care”, and “supportive care”,** it is no wonder there is much confusion surrounding this provision of care.

With the current lack of clarity and consensus as to how to define medical management without dialysis as a standard of care, experts have been able to agree that there should be an option for medical care that excludes renal replacement therapies such as hemodialysis or peritoneal dialysis. **Medical management without dialysis has been identified as an appropriate treatment option for patients who have ESRD** and are unlikely to benefit from dialysis, and/or choose to forgo dialysis.<sup>16</sup>



**Medical management without dialysis should be an option for medical care that excludes renal replacement therapies. The primary focus is to control uremic symptoms.**





Patients who decide to forgo dialysis are treated with the intent to control and manage the symptoms related to their condition, while optimizing quality of life. **Medical management without dialysis should include routine follow-up by a nephrologist and a multidisciplinary team. The primary focus is to control uremic symptoms**, which can be achieved through interventions that include dietary measures, blood pressure and fluid management medications, anemia management, and psychological support.<sup>17</sup>

**Beyond the routine nephrology care, a team of multidisciplinary professionals works toward the overarching goal to honor patient wishes. This team may be comprised of advanced practice providers, nurses, social workers, dietitians, geriatric physicians, physical therapists, and palliative medicine clinicians.**

**Despite its potential benefits, many are not made aware of the option of medical management without dialysis.<sup>6</sup> As a result, this treatment approach may not be utilized nearly as much as it could be.**

Although there is still limited research on the benefits of utilizing medical management without dialysis as a standard of care, adding it as a treatment option can potentially help patients and health care systems by enhancing patient-centered care<sup>18</sup>, reducing costs, improving quality of life, increasing patient satisfaction, and promoting shared decision making. **Medical management without dialysis is more common in older than younger people.**

Despite its potential benefits, and even though dialysis may not result in longer survival for older patients with kidney failure, many are not made aware of the option of medical management without dialysis.<sup>6</sup> As a result, this treatment approach may not be utilized nearly as much as it could be.

### The Need for a Care Model that Includes Medical Management without Dialysis

Advances in medical technology and treatment options are transforming how medical care is delivered in the U.S. Rising health care costs, ethical implications of excess care, increasing consumer demands, and government initiatives to improve access to care are all factors driving the need for change. **Newer value-based care models emphasize quality of life, prevention, and the social and emotional well-being of patients in addition to treating disease.<sup>19</sup>**





In the nephrology community, outcomes suggest that dialysis does not always have the intended effect of restoring health or extending life.<sup>20</sup> In fact, some CKD and ESRD patients experience high rates of health care utilization with increasing symptom burden. Additional factors such as decreased health literacy and limited knowledge of disease status further contribute to less patient satisfaction, poor transitional care, and diminished quality of life.



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**Both CKD and ESRD care consume over 114 billion dollars, 23% of the total fee-for-service spending.**

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**Looking to improve outcomes and lower costs, an Executive Order mandating the alignment of patient preferences with treatment modality choices was signed in July 2019.**

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**Exorbitant costs and suboptimal outcomes for patients in late stage CKD and ESRD are accelerating the demand to routinely include medical management without dialysis as a valid treatment pathway.** ESRD patients account for an estimated 7% of the total Medicare budget, yet account for only 1% of the total population.<sup>2</sup> Both CKD and ESRD care consume over 114 billion dollars – 23% of the total fee-for-service spending. The presence of CKD and ESRD with co-existing conditions quickly becomes a disease complicator and cost multiplier.<sup>2</sup>

**Unfortunately, treatment decisions do not always align with individuals' goals, representing a failure to identify an appropriate patient-centered care delivery model for shared decision making.**<sup>21</sup> While professional societies and medical guidelines recommend the incorporation of shared decision making, there is little evidence to suggest that the treatment choices offered to advanced kidney disease patients include medical management without dialysis. In fact, medical or palliative care utilization has yet to be reported by United States Renal Data System.<sup>2</sup>

The unsustainable trajectory of CKD and ESRD care has the attention of the U.S. federal government. Looking to improve outcomes and lower costs, an Executive Order mandating the alignment of patient preferences with treatment modality choices was signed in July 2019.<sup>4</sup> **The inclusion of medical management without dialysis as a treatment option delivers upon the intent to deliver patient-centered care, transparency, autonomy, and distributive justice.**



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**Teams must consider how the delivery of such care necessitates cultural transformation in medicine, change management, and the development of best practices to support the creation and distribution of a new care delivery model.**

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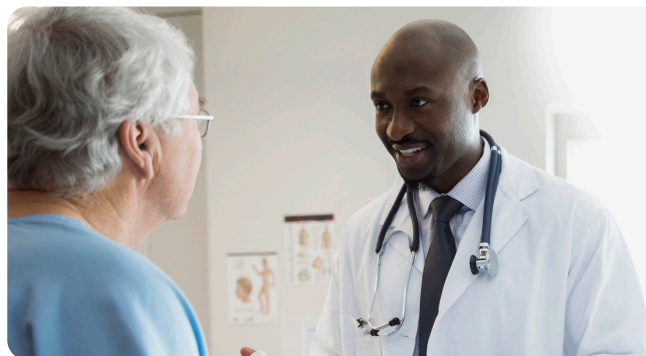
## Your Strategy Playbook for Implementing a New Kidney Care Model

As the need for medical management in CKD and ESRD emerges, teams must consider how the delivery of such care necessitates cultural transformation in medicine, change management, and the development of best practices to support the creation and distribution of a new care delivery model.

The Renal Physician Association guideline for shared decision making describes **best practices for offering the option of medical management without dialysis to patients who meet specific criteria**, which include:<sup>22</sup>

- *Establishing a physician-patient relationship for shared decision making*
- *Fully informing patients about all treatment options*
- *Providing a realistic prognosis estimate*
- *Facilitating advance care planning*
- *Opting out of dialysis when appropriate*
- *Resolving conflicts regarding dialysis treatment*
- *Providing effective palliative care*

The transition from best practice standards to the implementation of a new care delivery model is complex. It is time and resource intensive; however this task is not impossible.



**The transition from best practice standards to the implementation of a new care delivery model is complex.**



**Here is a 10-step “Strategy Playbook” you can follow to facilitate the successful implementation of a new care model within your organization:**

- 1.** Deploy a broad communications campaign that includes all internal stakeholders and works to ensure clarity and consistency of message surrounding the need for change.
- 2.** Invest in change management to establish a compelling vision for change. Leaders should promote the vision through engagement, frequent communication, and consensus building with internal stakeholders.
- 3.** Examine your resources and use objective financial data and subjective experiential data to facilitate planning.
- 4.** Build a multidisciplinary team and identify internal champions to guide and drive the implementation of the new care model.
- 5.** Stratify and identify the target populations to ensure that the most appropriate patients are included in the new clinical program.
- 6.** Incorporate new care delivery processes into the clinical workflow to facilitate care coordination and consistency in care.
- 7.** Support shared decision making by incorporating high-quality, certified patient decision aids and skills training for clinicians.
- 8.** Include advance care planning in the clinician workflow to support the individual needs of each patient and to ensure proper utilization of care.
- 9.** Identify key metrics and outcomes and apply a quality improvement approach. Develop and maintain a performance dashboard or scorecard to help track outcome data.
- 10.** Ensure transparency throughout the process by routinely reporting on the performance of the initiative to providers, staff members, leadership, and patients.





### The Bottom Line

The growing and aging population of CKD and ESRD patients is demanding a change from the status quo and driving the need for comprehensive care that supports informed patient consent and shared decision making. While the widespread adoption of medical management without dialysis as a valid treatment pathway has yet to be realized, professional societies have long supported its emergence.<sup>20</sup> For patients, this can have profound medical, financial, social, and psychological implications. When conversations with providers fail to include the medical management of late-stage CKD without dialysis, patients perceive the initiation of dialysis as their only treatment option.<sup>6</sup> By incorporating medical management of chronic kidney disease without dialysis into routine nephrology care, high-quality, patient-centered care can become a reality.

### About the Authors



**Candice Halinski, MBA, MHCDS, MSN, NP-C** is an Adult Nurse Practitioner at Northwell Health. She is the service line Clinical Director for the Division of Nephrology. For over 19 years, she has served renal patients in the capacity of LPN, RN, Nurse Manager, and Nurse Practitioner. Her experience has been in both chronic and acute settings. In her most recent role, Candice functions as the clinical lead on an innovative care management program that works to transition late-stage CKD patients to renal replacement therapies, transplant, or supportive care.



**Angelo Volandes, MD, MPH** is a physician researcher, Associate Professor at Harvard Medical School, and Co-Founder of ACP Decisions. He is an internationally recognized expert on the use of video decision support tools, decision science, and ethics and leads a recognized group of innovators and video artists who create video support tools to better inform patients about their options for medical care.



### About ACP Decisions

ACP Decisions is a mission-driven healthcare technology nonprofit that provides shared decision-making principles and evidence-based video support tools for patients and their families, so they can make informed decisions about end-of-life care. Our technology platform and video support tools help health systems, insurers, and hospitals improve the quality of end-of-life care while reducing its associated costs.

### How ACP Decisions Can Help

A shared decision making approach is essential to patient-centered care. Incorporating high quality evidence-based patient decision aids can facilitate the success of a new care model initiative for patients with advanced kidney disease like our videos entitled **“For Older Adults Making Decisions About Dialysis”** and **“CPR: Advanced Kidney Disease”**.

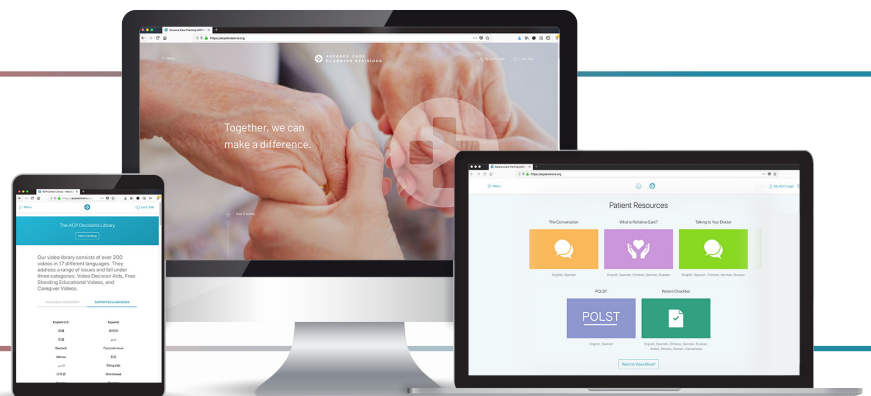
The ACP Decisions Video Library consists of over 300 video-based decision support tools in over 20 different languages. They address a range of issues and fall under four categories: Certified Video Decision Aids, Free Standing Educational Videos, Caregiver Videos, and Training & Implementation Videos.

Over ten years of research shows patients make better-informed decisions after viewing a relevant ACP Decisions video, because they see procedures and interventions with their own eyes and can thoughtfully review video content at their own pace. Data from a statewide implementation in Hawaii found that using the ACP Decisions Video Library led to increased ACP documentation, lower hospital death rates, more hospice referrals, and lower costs in the last month of life.

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