

How to Make Life Better for People with Kidney Disease



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In the spring of 2008, Mike Guffey became ill while visiting his parents in Arizona. Thinking that he had a bad case of the flu, Mike headed to an urgent care center. Little did he know, he would be hospitalized as a result of kidney failure. And just like that, Mike’s life changed overnight.¹

Mike was diagnosed with End-Stage Renal Disease (ESRD) and began receiving dialysis, which is a type of treatment that filters waste, salt, and fluid from the blood like well-functioning kidneys. For nearly four years, he took multiple trips each week to a dialysis center while continuing to work full time as a vice president at a bank. He also had to arrange for medical evaluations and financing to be eligible for the kidney transplant waiting list. Then, in early 2012, Mike received a transplant.

Patients with ESRD like Mike must not only learn about managing their kidney failure, but also about managing multiple and compounding complications like diabetes, bone disease, and heart disease—all while making efforts to stay healthy and remain eligible for a kidney transplant. As if ESRD wasn’t hard enough, a fragmented care system and

complicated coverage makes this nearly impossible for people to handle on their own. It's no wonder many patients do not fare well and end up needing additional medical care, like trips to the emergency room, for complications that could have been prevented with comprehensive care.

Innovative dialysis providers and health plans are offering patients a better way—providing coordinated care for people with ESRD, including personalized support for all of their health care needs. Expanding these innovative models throughout Medicare could improve the lives of people living with ESRD and save Medicare money.

This idea brief is one of a series of Third Way proposals that cuts waste in health care by removing obstacles to quality patient care. This approach directly improves the patient experience—when patients stay healthy, or get better quicker, they need less care. Our proposals come from innovative ideas pioneered by health care professionals and organizations, and show how to scale successful pilots from red and blue states. Together, they make cutting waste a policy agenda instead of a mere slogan.

What Is Stopping Patients from Getting Comprehensive Quality Care?

People with ESRD face three major barriers to accessing quality care: managing their treatment regimen, getting the right care for other health care problems, and navigating a fragmented system of care driven by fee-for-service payments.

Managing a treatment regimen

ESRD is the final stage of chronic kidney disease, when the kidneys can no longer remove enough waste and excess water from the body to support daily living. It is most commonly caused by diabetes and high blood pressure.² Patients facing an ESRD diagnosis do not have many treatment options—without dialysis or a kidney transplant, ESRD can lead to

death.³ In terms of survival, quality of life, and health care costs, transplant is the preferred treatment option.⁴ Unfortunately, kidney transplant rates have not improved in recent years, and while the kidney transplant waiting list for dialysis patients has recently declined, this improvement is primarily due to a policy change that reduced the incentive for providers to wait-list patients before they were actually ready for a transplant.⁵ As of January 2016, more than 100,000 Americans await kidney transplant, and the average wait time for a kidney transplant is 3.6 years.⁶ In 2014, 4,761 people died waiting for a transplant, and 3,668 people experienced a decline in their health status that made them too sick to receive a transplant.⁷ Without health care coverage, costs can also be a barrier to a kidney transplant, with billed charges in the first year following transplant averaging nearly \$263,000.⁸

Patients ineligible or waiting for a kidney transplant face other choices in their dialysis care. The majority of dialysis patients go to a *hemodialysis* center about three times per week for a 3–5 hour visit.⁹ Hemodialysis uses a machine to filter waste and extra fluid from the body, mimicking the work of functioning kidneys.¹⁰ Dialysis patients require a “connection” that allows blood from an artery to flow into a vein and provide access for dialysis.¹¹ An arteriovenous fistula, in which a surgeon connects an artery directly to a vein (usually in the forearm), is considered the “gold standard” given overall performance, fewer infections that can lead to hospitalizations, durability, and allowance for increased blood flow, relative to other types of “connections.”¹²

Regular dialysis treatments are life sustaining for patients with ESRD. Unfortunately, patients do not always attend their scheduled treatments. One study found that ESRD patients miss an average of 7.1 in-center dialysis treatments per year. Missing one treatment over a three-day period increases the risk among ESRD patients for a hospitalization, an emergency room visit, an intensive care or cardiac care unit admission, and death.¹³ Patients, who often depend on family or

caregivers for support, may miss treatment due to transportation issues, inclement weather, holidays, and/or unforeseen issues during the normal course of a week.

In-home dialysis is also an option for many patients and is more flexible and convenient than in-center treatment.¹⁴ Patients may choose home dialysis so that they can continue employment or other regular activities and avoid multiple trips to a dialysis center each week. They may also prefer home dialysis because it allows for fewer dietary restrictions and may require fewer medications.¹⁵ A small portion of in-home dialysis patients use home hemodialysis, but the vast majority—about 84%—use home-based *peritoneal* dialysis. For peritoneal dialysis, patients get a surgically implanted tube into the thin membrane lining the inside of the stomach (the peritoneum) to deliver cleansing fluid that soaks up waste and then drains about 30 to 40 minutes after the filtering process is complete.¹⁶ Patients do peritoneal dialysis several times per day at work or at home, or they use a cyclor machine while they sleep.¹⁷

While the most appropriate kind of dialysis varies for each patient, the use of home dialysis is on the rise, with an 82% increase from 2007 to 2015.¹⁸ Even more patients might choose home dialysis if they were fully informed about their treatment options during early discussions with their care providers. Research has shown that patients who are fully educated on their treatment options will select home dialysis almost as often as in-center dialysis.¹⁹ Medicare has a kidney disease education benefit, but it is greatly underutilized according to the U.S. Government Accountability Office.²⁰

Other health problems

ESRD patient care is complicated because people with kidney failure typically have a number of additional medical conditions. For example, ESRD patients are at high risk for cardiovascular disease, and cardiovascular disease contributes to more than half of all deaths among ESRD patients.²¹ Seventy-eight percent of ESRD patients also have

diabetes and 98% have hypertension.²² Because of their complex health care needs, ESRD patients are often treated by multiple health care providers and follow multiple treatment plans. In the absence of care coordination services, this can be challenging for people to manage on their own, particularly when they spend 12-15 hours per week connected to a dialysis machine. Dialysis clinics, where the majority of ESRD patients receive treatment three times per week, are in the best position to help patients manage these additional medical conditions and complications along with their regular treatment for kidney failure. There is an opportunity for dialysis clinics to bring other services to the patient in order to address all types of complications, like medication conflicts, and keep patients healthy and out of the hospital. Though hospital admission and readmission rates have improved since 2011 for ESRD patients, they remain far higher than for patients with similar conditions but who do not have ESRD.²³

In addition to these health-related challenges, ESRD patients face behavioral, social, and socioeconomic challenges too. They often need to make a number of lifestyle, dietary, and fluid intake changes to manage their disease well and have to adjust to the notion of depending upon a machine to continue living.²⁴ Furthermore, patients must maintain these lifestyle changes for the rest of their life or until they receive a kidney transplant. Because of that, it should not be surprising that psychosocial problems, including depression, dementia, and substance use disorders, are common among ESRD patients, who are at higher risk for hospitalization due to these conditions.²⁵ In addition, lower socioeconomic status (as measured by income, education, and occupation) as well as limited access to care are associated with higher incidence of ESRD and with lower quality of life among ESRD patients.²⁶ All of these social determinants of health combine to impede access to care and increase costs, illustrating the need for a targeted, integrated system of care for patients with ESRD.

Fragmented care system

Our current fee-for-service payment system creates a series of barriers that make it very difficult for patients with kidney disease to receive the care that would prevent the onset and progression of the disease, improve medical conditions that accompany the disease, and improve a person's quality of life while on dialysis. In some patients, kidney function may slowly decrease for 10-20 years before their kidneys fail. In contrast, patients like Mike Guffey (mentioned above) can have acute kidney failure without warning.²⁷ Despite that often slow, steady progress of chronic kidney disease over months or years, 36% of patients diagnosed with ESRD receive little or no specialized care from a kidney specialist (nephrologist) before their ESRD diagnosis.²⁸

As recently as the late 1960s, ESRD was a fatal disease. Though the development of dialysis helped alter patients' prognosis, the lack of insurance coverage became the main barrier to accessing this expensive, life-saving treatment.²⁹ In order to address issues around equitable access to treatment for ESRD, Congress passed legislation in 1972 extending Medicare coverage to individuals diagnosed with ESRD. Nearly all ESRD patients are eligible for Medicare (no matter their age) if their kidneys no longer work, they need regular dialysis or have had a kidney transplant, and meet other requirements.³⁰

If eligible for regular dialysis treatments, Medicare entitlement usually begins on the first day of the fourth month of regular dialysis, meaning patients must rely on existing coverage, get coverage through insurance exchanges during open enrollment, apply for Medicaid coverage, or go without coverage for the first three months of treatment.³¹ For the first 30 months of Medicare eligibility, Medicare is the secondary payer to any group or employer-based coverage the ESRD patient has, after which it becomes the primary payer.³² So, in addition to learning how to manage a life-altering chronic illness, patients newly diagnosed with ESRD must also navigate multiple types of insurance coverage, including Medicare supplemental coverage known as Medigap.

ESRD care is expensive because of the conditions that accompany ESRD and frequent complications, in addition to the life sustaining dialysis treatment. Medicare spending averages nearly \$73,000 per year for ESRD patients who receive dialysis, about 8.5 times more than the average spending for all Medicare beneficiaries.³³ High health care utilization drives this spending, as ESRD patients are hospitalized nearly twice each year, spending an average of 11 days in the hospital with a readmission rate of 35%. Their medication burden is also significant as ESRD patients take more than 19 pills every day.³⁴

Stable health care coverage is crucial for patients with ESRD and also for patients before they develop the disease. Low-income Americans are most at risk for developing ESRD.³⁵ They often lack coverage for critical services like the treatment of hypertension, which can slow the progression of initial kidney disease to full-blown ESRD.³⁶ Medicaid coverage helps fill that gap and slows the development of ESRD.³⁷

Given the complexity of coverage for kidney disease, the challenges of dialysis treatment, the prevalence of additional medical conditions, and the impact of social determinants of health, ESRD patients would likely benefit from the enhanced coordination of services available from many Medicare Advantage plans or third-party organizations that offer such services. In addition, because Medicare Advantage plans receive a predetermined capitated rate, the plans and providers who work with them have an incentive to manage care, keep patients healthy and use the cost savings to improve benefits and beneficiary savings while offering high-quality care.³⁸ The *21st Century Cures Act*, enacted in 2016, allowed ESRD beneficiaries to enroll in Medicare Advantage after their diagnosis.³⁹

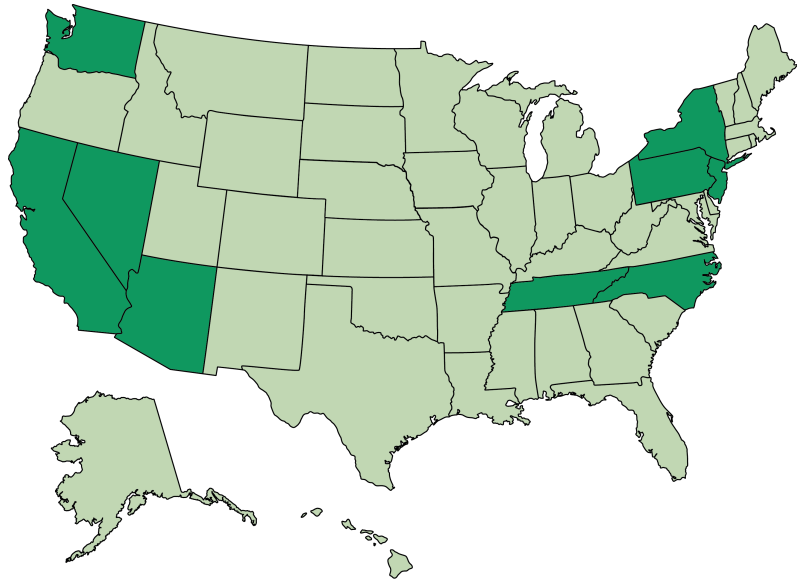
Still, too few ESRD beneficiaries have access to coordinated care. Nearly all beneficiaries entitled to Medicare due to an ESRD diagnosis are enrolled in fee-for-service Medicare, with only about 15% of all ESRD beneficiaries enrolled in Medicare

Advantage plans.⁴⁰ (ESRD beneficiaries can be in a Medicare Advantage plan only if they developed kidney disease after they enrolled in the plan.) An even smaller percentage of ESRD beneficiaries have access to coordinated care specifically targeted toward their condition. Medicare Advantage Chronic Condition Special Needs Plans (C-SNPs) are available to individuals with certain severe or disabling chronic conditions, including ESRD. However, only 10 of these ESRD-focused C-SNPs are available throughout the country, with a total enrollment of just 3,400 beneficiaries.⁴¹ ESRD patients can also get coordinated coverage through a Dual Eligible Special Needs Plan, but only if they qualify for Medicaid. The adequacy of payments to Medicare Advantage plans including C-SNPs for ESRD patients as mentioned above may well be a factor in the limited availability of special needs plans.

Therefore, the vast majority of Medicare beneficiaries with ESRD receive health benefits through the fragmented fee-for-service system. In a fee-for-service system, providers generally do not receive payments or incentives to coordinate a patient's overall care. Rather, they receive more payments for providing more services. In 2011, Congress partially solved this problem by bundling payment for most of the dialysis care that patients need, including dialysis drugs, lab tests, and other ESRD items and services.⁴² Then, in 2012, these outpatient dialysis facility payments were linked to quality of care measures, ensuring that dialysis facilities were early innovators in the adoption of bundled payments and pay-for-value arrangements. These two payment changes maintained beneficiary access to care while reducing costs and improving quality across several measures.⁴³ Dialysis providers now offer comprehensive care within the dialysis facility by a team that includes nurses, nephrologists, dialysis technicians, social workers, dietitians and others. However, the bundled payment does not cover the care and coordination patients need for non-dialysis services. This often results in inefficient and unnecessary use of costly health care services.

Where Are Innovations Happening?

Despite these challenges, innovative care coordination and disease management efforts to improve health outcomes and quality of life for ESRD patients are occurring throughout the country. Below, we look at three of these efforts: two different Medicare Advantage Chronic Condition Special Needs Plans and Medicare's Comprehensive ESRD Care Model.



VillageHealth Special Needs Plan

Medicare Advantage Chronic Condition Special Needs Plans (C-SNPs) restrict enrollment to individuals with certain severe or disabling chronic conditions. One of the ESRD-focused C-SNPs is a partnership between VillageHealth, the renal population health management division of DaVita, Inc., and SCAN Health Plan, operating in San Bernardino and Riverside counties in California. This plan grew out of a demonstration created by the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, which encouraged partnerships between Medicare Advantage plans and dialysis organizations to coordinate care for ESRD beneficiaries.⁴⁴

VillageHealth refined its existing ESRD model of care to better serve the Medicare Advantage population, starting

with a care management team consisting of nurses, social workers, dietitians, specialists, and the dialysis center staff working with the local nephrologists.⁴⁵ These care team members received specialized renal care training, and care protocols were designed to address the specific clinical needs of renal patients. VillageHealth built its own ESRD-focused technology and analytics platform, allowing for risk stratification and forecasting of patients at highest risk for hospitalization so that care managers could engage with patients to prevent admissions.⁴⁶ The plan's model of care depends on collaboration with dialysis center staff and physician engagement through outcomes reporting and performance-based agreements.

Overall, the SCAN VillageHealth C-SNP reduced non-dialysis costs compared to a Medicare fee-for-service sample. These cost savings were driven by population health improvements, including hospitalization and readmission rates that are 26% and 31%, respectively, lower than the national average for ESRD patients receiving dialysis. The VillageHealth plan increased fistula placement, which lowers infections and allows for increased blood flow, to 79% in 2013, an increase of 9 percentage points in three years.⁴⁷ Finally, and perhaps most importantly, the VillageHealth plan achieved extremely high patient satisfaction, ranking among the top three California SNPs for patient satisfaction from 2014 to 2016.⁴⁸ VillageHealth built on the success of this plan and subsequently launched four additional ESRD C-SNPs.

CareMore Special Needs Plan

CareMore Health System, a subsidiary of Anthem, Inc.—an integrated health care company offering Medicare Advantage plans, including special needs plans—offers another innovative example of ESRD care coordination.⁴⁹ CareMore's ESRD C-SNPs received a four-star rating from Medicare and are available in parts of Los Angeles and Orange counties in California.⁵⁰ CareMore aims to improve each ESRD patient's experience and health outcomes through several initiatives, including improving health literacy about kidney disease,

increasing the proportion of patients with well-planned kidney replacement therapy, addressing and improving functional status, reducing the need for acute care utilization, and integrating and streamlining outpatient care. To achieve these goals, CareMore utilizes a care management and coordination model in which a primary care provider assumes responsibility for members' care coordination, in close concert with a nurse practitioner-led interdisciplinary care team.⁵¹ Members of the interdisciplinary care team also include an internist, nephrologist, vascular surgeon and vascular access providers, dialysis center, case manager, fitness trainer, ophthalmologist, social worker, registered dietitian, podiatrist, and mental health professional.⁵²

One example of CareMore's care redesign efforts involves hospital admissions. Before redesigning its model of care, CareMore found that half of ESRD patient admissions were the result of poor hygiene, poor diabetic control, or vascular access limits.⁵³ When dialysis center staff encountered these problems, they generally referred the patient to the emergency room, which often resulted in admission. CareMore established a dedicated case manager and nurse practitioner team to receive referrals from dialysis centers.⁵⁴ In addition, all patients enroll in a diabetes disease management program and receive focused monthly access care as needed. CareMore's ESRD inpatient admission rate dropped to 22% below the national average, inpatient bed days fell to 73% below average, acute average length of stay was 33% lower than average, and its readmission rate was 17% below average.⁵⁵ Overall, its patients with chronic kidney disease have a projected 24 years on average until they have to use dialysis as opposed to less than six years under other forms of care.⁵⁶ These results are possible because patient, provider, and payer incentives are aligned.

New Medicare Initiatives

Finally, Medicare, through the CMS Innovation Center, is testing ways to improve payments, care delivery, and ultimately outcomes for ESRD beneficiaries. Under the

Comprehensive ESRD Care (CEC) Model, CMS partners with groups of health care providers and suppliers, called ESRD Seamless Care Organizations, who assume clinical and financial responsibility for all care, not just ESRD-related care, provided to Medicare beneficiaries.⁵⁷ The model started October 1, 2015, with 13 locations comprised of only four different dialysis organizations participating, and an application process is currently underway for another round of participants.⁵⁸ In the second round, CMS aims to entice smaller dialysis providers to participate in the model by giving them the option of accepting downside risk with a higher upside potential, or choosing an upside-only model with a lower rate of return.⁵⁹ Despite this and other modifications to increase participation, some model design elements may preclude large-scale participation in the CEC model. For example, ESRD Seamless Care Organizations are required to have at least one nephrologist or nephrology group practice as participant owners, limiting participation to clinicians that can make an initial capital investment.⁶⁰ In addition, ESRD Seamless Care Organizations that participate in a two-sided risk model must provide a financial guarantee to demonstrate ability to repay any shared losses, requiring an additional capital investment.⁶¹

The CMS Innovation Center has also funded a three-year pilot study to look at the use of telemedicine for peritoneal dialysis patients, and evaluate the impacts on both clinical outcomes and costs of care.⁶² Telemedicine and remote monitoring technologies may enable practitioners to effectively assess and manage certain patients on chronic home dialysis, without patients requiring frequent in-person clinic encounters. These technologies enable clinicians to see their patients' treatment data in real time, and make adjustments or intervene more frequently to avert problems or ensure compliance with a treatment regimen.

How Can We Bring Solutions to Scale?

The key to coordinating care for people with chronic kidney failure is to let providers and plans take full responsibility for the quality and cost of all the health care each person needs along with engaging patients as full partners in the decisions and responsibility for their care. This means having Medicare pay providers and health plans an all-inclusive amount for each person's care instead of piecemeal payments. It also means ensuring that providers and plans deliver high-quality care by measuring their performance and reporting the results publicly. Medicare already pays a complete amount to private plans under the Medicare Advantage program, which can serve as a foundation for payment and delivery innovation. This innovative payment methodology can be expanded in four ways:

1. *Test paying providers a complete payment for all of the health care needs of people with ESRD.* Reps. Jason Smith (R-MO), Earl Blumenauer (D-OR), Cathy McMorris Rodgers (R-WA), and Tony Cardenas (D-CA) along with Sens. Todd Young (R-IN) and Bill Nelson (D-FL) have introduced the Dialysis Patient Access To Integrated-care, Empowerment, Nephrologists, and Treatment (PATIENTS) Demonstration Act of 2016.⁶³ This legislation would create a demonstration program for testing a completely bundled payment to providers for ESRD patients. It would build on the existing payment for dialysis services, which were converted from a fee-for-every-dialysis session to a bundled payment for all dialysis-related services.⁶⁴ The new payment would cover all of an ESRD patients costs under Medicare Parts A and B (except for a kidney acquisition, which would be funded as a pass-through cost) and allow the provider to offer prescription drug coverage through a Part D plan. It would also automatically enroll current patients with the opportunity to opt-out at the start, annually, or when they experience a change in their health status. Patients would continue to receive all of Medicare's traditional benefits. They could also reduce their out-of-pocket costs for services by using a network of providers for their care. At the same time, they could choose to see any non-network provider without penalty. Patients could also save money by dropping supplemental Medigap coverage during their participation in the demonstration program while retaining the right to return to Medigap coverage afterwards. With the opportunity to enroll a large number of beneficiaries and receive a payment for all of their care, this legislation would ensure providers have the resources to invest in care coordination activities that provide patients with improved outcomes and a better experience.

2. *Expand successful models.* The Dialysis PATIENT Demonstration Act allows the Secretary to expand the program nationally if it improves the quality of care for people with ESRD without increasing costs. Such expansion would also make sense as part of the Secretary's larger effort to move Medicare payments away from fee-for-service and toward value-based payments. This effort is key to reducing the excess costs from the wide variation in health care spending in a variety of areas—including the costs for ESRD patients. CMS should also expand the successful model for engaging patients as full partners in the decision about in-home vs. in-center dialysis by ensuring providers offer the Kidney Disease Education benefit and by using patient surveys to measure whether patients are truly informed about their options.

3. *Permanent authorization of Medicare Advantage Special Needs Plans.* These plans serve people with a variety of conditions, including kidney disease. Congress has authorized only temporary extensions of these plans since their enactment in 2004. A permanent authorization would let plans make a long-term commitment to serving people with special needs and ensure they will continue to receive the customized benefits and services for their condition. Under a permanent authorization, Congress should give CMS additional authority to ensure that plans are held accountable for delivering high-quality care and measurable improvements in patient outcomes particularly for C-SNPs, which include ESRD patients. The House of Representatives Committee on Ways and Means has announced a bipartisan package of Medicare provision that includes a five-year extension of special needs plans, which, while not a permanent authorization, would nonetheless go a long way to create more stable coverage for beneficiaries with special needs.⁶⁵

Potential Cost Savings

Care coordination and additional benefits to beneficiaries with ESRD will not cost Medicare any additional money in the short term, and those investments may produce federal savings in the long term. Under the Dialysis PATIENTS Demonstration Act, the complete Medicare payment would be the same as the payment to Medicare Advantage plans for ESRD patients. The Congressional Budget Office has determined that the complete Medicare Advantage plan payment is equivalent to all the individual payments under the existing bundled dialysis payments plus non-dialysis fee-for-service payments on average.⁶⁶ That means as ESRD beneficiaries shift to the Dialysis PATIENTS Demonstration program or to a Medicare Advantage plan, Medicare will not incur any extra costs.

Long-term savings could come from care coordination that keeps ESRD patients healthy and reduces their trips to the hospital, reduces length of stay when they do have to go, and prevents problems that may cause them to have to return to the hospital. The promising initial results from innovations described above show the potential for reducing costs that can cover not only the care coordination and extra benefits, but also an overall reduction in Medicare's costs for ESRD beneficiaries. Congress should monitor the exact level of savings from expanding the use of a complete payment in order to determine the potential for long-term savings.

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