Renal Support Network
RSNhope.org

Service to those affected by chronic kidney disease

August 23, 2022

The Honorable Xavier Becerra
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

From: Lori Hartwell
Founder/President of Renal Support Network

Dear Secretary Becerra and Administrator Brooks-LaSure,

RE: CMS–4203–NC: Medicare Program; Request for Information on Medicare Advantage

We appreciate the chance to comment on Medicare advantage these from the patient's perspective.

Renal Support Network (RSN) empowers people who have kidney disease to become proactive in their care, and to work with healthcare professionals and all stakeholders to get the best care and health outcomes possible. I have been dealing with kidney disease since age two (1968), and spent 13 years on dialysis, with ten years on successful home dialysis, both hemodialysis and peritoneal dialysis. I'm currently doing well with my fourth kidney transplant. I founded RSN in 1993 to provide hope to my peers and advocate for the best care. RSN reaches hundreds of thousands of people who have kidney disease and their families through our many patient programs.

Across the industry, there has been a major push to provide more options for patients with chronic kidney disease. We at RSN are always promoting ways to make the lives of people living with chronic kidney disease easier. Thank you for the opportunity to comment on Medicare Advantage (MA) as it impacts people living with ESRD.

Part of the reason ESRD patients were originally excluded from MA is because they are the only disease-specific form of Medicare recipients, making it difficult territory to navigate. Given that we are a small, specialized population, we don't have as many options for providers. Patients with ESRD require substantial and immediate health care and need adequate networks to receive quality care. There is a very specific complexity to living and dealing with ESRD. To provide the most benefit, understanding those needs with as much accuracy as possible is vital. A network of qualified providers is critical.

Managed Care plans are on the rise among people who have ESRD, because of the fact they are being priced out of accessing “wrap around care” since the vast majority do not have access to Medigap secondary insurance coverage or don’t have access to it at all due to state laws. It’s not that patients are choosing Managed care as the best option it’s the only option they have or that they can afford.

Currently, people on dialysis enrolled in MA plans are suffering from inadequate networks and long wait time for appointments. Limited access to vascular surgeons is a situation that is dire. MA plans are also more cumbersome to navigate as the provider network can change, leaving the patients to start all over again to build a partnership with a provider. Yet, for dialysis patients’ continuity of care is essential to survival.

We’ve seen that in many cases private health plans have incentives to underprovide or create obstacles when people get sick. One of our members was told they had a hefty copay for each dialysis treatment. We need to prevent insurance companies from cherry-picking and thereby making their prices unreasonably high, which only hurts patients and further exacerbates health equity.

We need a sufficient network of appropriate and available providers for the ESRD population. CMS needs to assess the adequacy of each MA network. They must maintain enough specified providers/facilities to ensure that beneficiaries have access to at least two of each specialty type within published maximum time and distance standards.

It's also important to factor in the needs of people on dialysis who live in rural and rely on family/friends to get to providers and necessary treatment like dialysis centers. There are fewer plan providers in rural areas, and transportation issues in both rural and urban areas are rampant. If patients don’t like one provider, they should have the ability to choose another that they can get to.

Whenever I hear a presentation about managed care, the phrase “value-based care” is mentioned. We agree with this in concept, but managed care and value-based care are different things entirely. Managed care focuses on care coordination, case management, and utilization controls, which can help dialysis patients, but as currently delivered, it has some deficiencies when managing a serious chronic illness. The phrase is also contrary to patients receiving innovation. We all know if payment drives practice, the lowest cost treatment will be given even if a better option is available for a patient. It begs the question: how much choice does the patient and doctor have?

Value-based care focuses on paying for care that results in the delivery of high-quality care with a demonstration of improved patient outcomes. Of course, patient centered meaningful measures are the only way to know if quality is performed. We have yet to define a measure that allow the patients to share how they perceive their treatment. Traditional Medicare has the ESRD QIP that supports moving in this direction, but more work needs to be done with that program as well.

Right now, only traditional Medicare has any type of pathway to support innovation. Innovation provides hope and better outcomes. The Transitional Drug Add-on Payment Adjustment (TDAPA) and the Transitional Add-on Payment Adjustment for New and Innovative Equipment and Supplies (TPNIES) provide reimbursement for new products. Currently, two medications have been awarded TDAPA and one device is receiving TPNIES. MA plans are not providing the same level of care as Medicare fee for service as they are not providing access to these products. We understand that MA plans have not provided the TDAPA or TPNIES add-ons to contracted facilities. MA plans needs to correct this. MA plans are required to provide at least the same items and services available in the Medicare FFS program. The innovation payment structures were put in place to allow new therapies to be created and available.

Also, there should be oversight and penalty for managed care companies who use aggressive marketing campaigns to recruit ESRD patients and “bait and switch” with services the beneficiary was promised and not delivered.

Medicare will start covering kidney transplant patient’s medications for life of the kidney starting in 2023. It’s imperative MA plans hit the ground running when this policy takes effect.

Medicare Advantage plans for people living with ESRD can be a positive if they have the proper networks and provisions in place to ensure continual optimal coverage.

Thank you for allowing RSN to express our concerns and suggestions on behalf of people who have kidney disease.

Sincerely,

Lori Hartwell

Lori Hartwell
President/Founder