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sent with problems that are purely medical, purely social, or (for a large group in the middle) caused by a mixture of medical and social factors. The aim of social prescribing is to give physicians access to interventions that should reduce unnecessary prescriptions and referrals and encourage patients to take responsibility for



An audio interview with Dr. Roland is available at [NEJM.org](https://www.nejm.org)

their health by giving them the capacity and opportunity to use their personal resources and those in their families and communities. Social interventions could also reduce disparities in health — particularly interventions that focus on socially disadvantaged communities where

patients' medical problems are especially likely to be compounded by social difficulties.

Social prescribing has the potential to change the consultation in ways that have profound implications for medical practice and medical education, but physicians need reliable information on what interventions work best and for whom and how social prescriptions can best be integrated into conventional medical practice.

Disclosure forms provided by the authors are available at [NEJM.org](https://www.nejm.org).

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1. NHS England. Social prescribing and

community-based support: summary guide. January 31, 2019 (<https://www.england.nhs.uk/wp-content/uploads/2019/01/social-prescribing-community-based-support-summary-guide.pdf>).

2. Bickerdike L, Booth A, Wilson PM, Farley K, Wright K. Social prescribing: less rhetoric and more reality — a systematic review of the evidence. *BMJ Open* 2017;7(4):e013384.

3. Chatterjee HJ, Camic PM, Lockyer BL, Thomson LJM. Non-clinical community interventions: a systematised review of social prescribing schemes. *Arts Health* 2018;10:97-123.

4. Moffatt S, Steer M, Lawson S, Penn L, O'Brien N. Link Worker social prescribing to improve health and well-being for people with long-term conditions: qualitative study of service user perceptions. *BMJ Open* 2017;7(7):e015203.

5. McNally L. Tackling loneliness with a well stocked community. *BMJ* 2018;362:k2953.

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## Ensuring Choice for People with Kidney Failure — Dialysis, Supportive Care, and Hope

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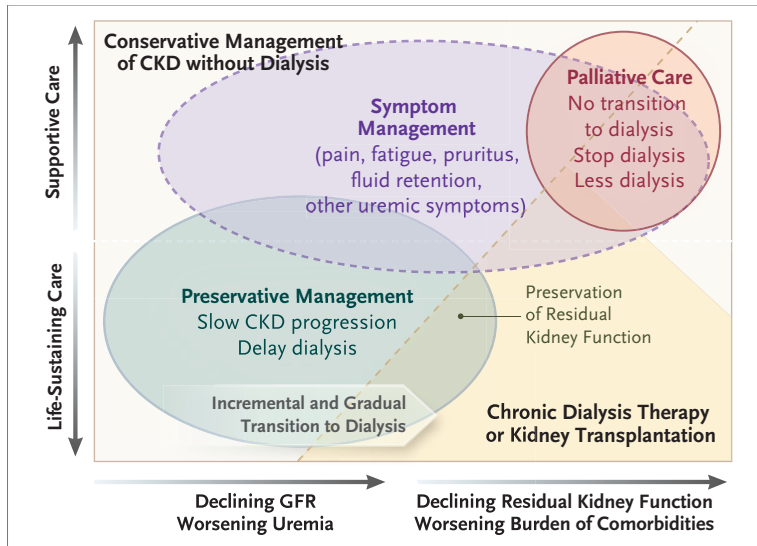
Each year in the United States, approximately 120,000 people with kidney failure choose to start dialysis therapy — an arduous, life-sustaining treatment — and more than half a million patients already receiving dialysis continue their treatment. More than 80% of these patients receive hemodialysis therapy three times per week in an outpatient dialysis clinic, which involves frequent travel that can be particularly challenging for elderly people and frail patients with unstable conditions. Because of the lack of kidneys available for transplantation, less than 5% of patients who have been receiving dialysis undergo transplantation each year.<sup>1</sup>

In a July 2019 executive order, President Donald Trump called

for increased utilization of home dialysis and kidney transplantation; moreover, the Department of Health and Human Services hopes to achieve a 25% reduction in the incidence of end-stage kidney disease by 2030. Many potentially beneficial changes could come out of this executive order, including the expansion of conservative and preservative management of chronic kidney disease (CKD) without dialysis and more effective symptom management (see diagram). There is also an emerging perception among physicians and other experts that palliative and supportive care without renal replacement therapy may be increasingly leveraged for many current and prospective dialysis recipients.

Dialysis treatment prolongs life, but it can be burdensome for patients and their care partners. It has physical, psychosocial, and financial impacts similar to those of chemotherapy for advanced cancer, and patients starting dialysis will live an average of less than 5 years more. Given these burdens, palliative medicine specialists may be engaged in providing guidance for current and prospective dialysis recipients and their caregivers. Supportive care can address symptoms such as pain, fatigue, anxiety, and depression and can promote understanding of prognosis, discussions about goals of care, advance care planning, and consideration of compassionate, conservative care.

However, involvement of pal-



**Conceptual Model of the Conservative Management of Advanced Chronic Kidney Disease (CKD).**

GFR denotes glomerular filtration rate.

liative care specialists may also lead to avoidance or cessation of dialysis therapy and referral to hospice (in which case dialysis is often not permitted), since many patients requiring dialysis have multiple coexisting conditions, are subject to frequent and prolonged hospitalizations and readmissions, and are perceived as terminally sick.<sup>2</sup> In an effort by policymakers to control health care costs and increase the efficiency of patient care, the Affordable Care Act altered health care policies and payment models and implemented financial incentives and penalties to reduce the length of hospital stays and prevent readmissions within 30 days. The Centers for Medicare and Medicaid Services reported that in 2018, more than half a billion dollars of payments to hospitals were withheld as a result of these policies. Such penalties have created serious financial challenges for hospitals, which benefit from transitioning many sicker patients

— such as those receiving dialysis treatments — to hospice care or long-term care facilities that don't offer dialysis, thereby shortening hospital stays and preventing readmissions.

When patients with advanced CKD are hospitalized for an acute illness, including Covid-19 infection, or the worsening of a pre-existing problem, a palliative care consultation often takes place. Goals of care may therefore be discussed when patients are at their sickest and without the participation of their primary internist, pediatrician, or nephrologist. During these discussions, initiation or continuation of dialysis is frequently presented as the opposite end of the treatment spectrum from comfort care, with no integrated option offered as a middle course.<sup>3</sup> Given the perceived rush to get patients out of the hospital and the importance of reducing costs and readmission rates, a transition to hospice care with an abrupt withdrawal of

dialysis therapy or termination of dialysis transition plans may be presented as the preferred option. Furthermore, when hospitalized patients choose to stop dialysis treatments, they may have little opportunity to revisit that decision, since death could follow fairly quickly (after a median of 10 days in adults 80 years of age or older, for example).<sup>4</sup> Indeed, dialysis withdrawal is among the leading causes of dialysis-associated deaths.<sup>4</sup> Complex financial and family considerations could confound decisions about dialysis withdrawal, but physicians may overlook these factors in their rush to streamline discharge plans.

Evidence suggests that overtreatment of patients whose lives might not be extended by dialysis — such as frail, elderly patients and those with multiple coexisting conditions — is common.<sup>5</sup> However, the process of reviewing goals of care should give patients and their care partners the opportunity to reconsider the fundamental reasons why they chose dialysis in the first place. The 1973 Medicare expansion allowed nearly all Americans with terminal kidney failure access to life-sustaining dialysis. It permitted patients to choose dialysis not just to survive, but also to maintain hope: hope of continuing valued relationships, hope for rehabilitation, and hope of achieving life goals and pursuits.

To overcome the perceived dichotomy of dialysis therapy versus palliative care without dialysis, especially for hospitalized patients, and to mitigate the pressure to reduce hospital lengths of stay and prevent readmissions, alternative treatment options can be used.

A first option is conservative

and preservative management of CKD to delay dialysis initiation, including use of diet and lifestyle modifications, conventional and new pharmacotherapies, and proactive management of symptoms such as pain and fatigue, as well as mental health issues.

Second, patients could make a gradual transition to dialysis, perhaps initiating once- to twice-weekly hemodialysis or less-than-daily peritoneal dialysis at home, each of which may preserve residual kidney function longer than conventional dialysis.

Third, there could be expanded use of palliative care. For instance, instead of having a one-time palliative care consult during an inpatient hospitalization, a dialysis patient or potential candidate for dialysis could be evaluated for concurrent palliative options and symptom management as an outpatient and then during each hospitalization, independent of the severity of the person's illness.

A final option is for clinicians to offer palliative dialysis with a gradual decrease in frequency and intensity so that patients and caregivers can choose less-stringent dialysis therapy with a goal of improving comfort. Dialysis could be combined with hospice care, and home dialysis could be offered at nursing homes or skilled nursing facilities. In these contexts, a focus on symptom management — rather than aggressive clearance or rigorous fluid removal — is prudent.

To minimize the influence of perverse financial and regulatory incentives, decisions about dialysis therapy should be made thoughtfully and after multiple

discussions over a reasonable period, before an acute hospitalization occurs. During this process, some patients may choose to receive comfort care and have ongoing dialysis withdrawn or avoid dialysis initiation, whereas some may choose to try certain palliative options such as less frequent or shorter dialysis treatments than is standard and others may choose to continue life-sustaining treatment.

We believe that all patients with imminent or existing kidney failure should be afforded the opportunity to benefit from palliative care and dialysis treatment and to receive continued care from their primary care provider or nephrologist, with whom they have often had long-standing relationships. Hospitals shouldn't receive incentives for adopting policies that encourage dialysis withdrawal, and clinicians shouldn't feel pressured by 30-day readmissions policies, by the recent executive order, or by current or future pandemics or other extenuating circumstances. Efforts to shift palliative care consultations from the hospital to outpatient services for patients receiving dialysis and those who could soon transition to dialysis should be encouraged, supported, and expanded.

Dialysis has been a treatment choice available to all patients facing end-stage kidney disease (or their guardians) in the United States for more than four decades. Despite its flaws and burdens, dialysis prolongs life for many people — people who choose to start or continue this therapy to maintain hope in the face of organ failure. Although

patients may ultimately choose to avoid dialysis or withdraw from treatment, decisions to initiate or continue it should also be respected and protected. We call for increased support for collaborative efforts and amended policies so that patients may have a better range of options for their care; enjoy improved quality of life, including better management of pain and other symptoms; and have their goals supported and realized.

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1. Saran R, Robinson B, Abbott KC, et al. US Renal Data System 2018 annual data report: epidemiology of kidney disease in the United States. *Am J Kidney Dis* 2019;73: Suppl 1:A7-A8.
2. Lam DY, Scherer JS, Brown M, Grubbs V, Schell JO. A conceptual framework of palliative care across the continuum of advanced kidney disease. *Clin J Am Soc Nephrol* 2019; 14:635-41.
3. Ladin K, Pandya R, Kannam A, et al. Discussing conservative management with older patients with CKD: an interview study of nephrologists. *Am J Kidney Dis* 2018;71: 627-35.
4. Ko GJ, Obi Y, Chang TI, et al. Factors associated with withdrawal from dialysis therapy in incident hemodialysis patients aged 80 years or older. *J Am Med Dir Assoc* 2019;20:743-750.e1.
5. Wong SP, Vig EK, Taylor JS, et al. Timing of initiation of maintenance dialysis: a qualitative analysis of the electronic medical records of a national cohort of patients from the Department of Veterans Affairs. *JAMA Intern Med* 2016;176:228-35.

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