



EASING INTO END-STAGE KIDNEY DISEASE

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In the United States, approximately 130,000 people progress to end-stage kidney disease (ESKD) each year, and the number has been growing steadily since the early 2000s.¹ The majority of these individuals, 40% – 60% according to most studies, begin dialysis in an unplanned fashion, with only 30% – 40% having seen a nephrologist in the year prior to starting dialysis.^{2,3} Despite the increasing use of home dialysis modalities and kidney transplantation, these preferred options remain significantly underutilized compared to in-center hemodialysis, particularly among racial and ethnic minority groups.^{1,4}

The magnitude of these statistics often evades human comprehension; many individuals tend to perceive them somewhat abstractly and cannot adequately grasp their significance.⁵ In reality, a person progressing to ESKD experiences myriad symptoms that affect both their behavioral and physical health, a fact that recently received attention in a publication by ***Kidney Disease: Improving Global Outcomes (KDIGO)*** that focused on symptom burden management among those receiving maintenance dialysis.⁶ These symptoms commonly include fatigue, sleep disturbances, difficulty concentrating, hair loss, pain or achiness, and many others. While experiencing these symptoms, an individual is undergoing physically taxing dialysis treatments that last hours and occur multiple times per week. Considering that they are also learning to manage a fistula or catheter for the first time, and are juggling multiple medications and healthcare appointments, it is not surprising that anxiety and depression affect up to half of all individuals with ESKD, particularly around the time of transition to ESKD.^{7,8} When present, both anxiety and depression can negatively impact adherence to diet, medications, and dialysis treatments, as well as a person's quality of life.⁶

The purpose of this paper is not to present well-described statistics of the chronic kidney disease (CKD) and ESKD population, nor is it to review established side effects of dialysis. Instead, Healthmap Solutions (Healthmap) would like to highlight five success stories from members* in our Kidney Population Health Management program who found themselves transitioning to ESKD. In each instance, the member was struggling with some aspect of their transition, and a Healthmap Care Navigator (a registered nurse dedicated to the member who works as part of a greater multidisciplinary care management team) was able to listen, provide support and care coordination, and ultimately ease the member's transition to ESKD.

George (member) and Judy (Healthmap Care Navigator)

George had been feeling extremely tired for many weeks. He was 57 years old at the time, and the sole breadwinner for his family. For weeks, he had been pushing through symptoms such as lower extremity swelling, loss of appetite, and fatigue, but when he had trouble breathing one night, he went to the nearest Emergency Department. What the emergency physician told him came as an absolute shock. He was told that his kidneys had failed and that if he didn't start dialysis immediately, he was risking his life. Left with no choice, George had a dialysis catheter placed in his chest. He started dialysis treatments in the hospital and was eventually transitioned to a dialysis unit near his home.

"I did not like that [dialysis] catheter. Every time I saw it, it reminded me that I was on dialysis and that I could no longer go to work every day. It was a reminder that I was sick."

When George first spoke with his Healthmap Care Navigator, Judy, they had many long conversations. "What I appreciated about Judy is that she listened to me. We talked a lot about my dialysis catheter and dialysis treatments. She taught me that a fistula is usually safer for dialysis because there is less risk for infection than a catheter. I worked with my dialysis team to obtain a fistula. Because of Judy, I knew to ask about a fistula that can be created without surgery. As a result, I went in for a procedure, left the same day, and didn't have to worry about healing from surgery. I love that my fistula is not noticeable, and I no longer have a catheter."

George's Care Navigator also helped educate him about the kidney transplant evaluation process. She helped coordinate his first appointment in the transplant clinic and ensured he kept his multiple follow-up appointments. A few months later, George was listed for a kidney transplant and is now on the waiting list. He is also working with his church to look for a living donor.

"At first, I didn't want to talk about my medical condition with anybody. I didn't want to burden my friends and family with my disease. I couldn't imagine asking somebody for a kidney."

"Judy helped me understand that it is okay to talk about my medical condition. We talked about different ways I could do this. I ended up submitting an anonymous letter to my church newsletter. It talked about my experience with kidney failure and the benefits of a living kidney donor. Since it was published, five people have come forward as interested donors. I never thought people would be willing to donate a kidney to somebody they don't know. This never would have happened without Judy's encouragement."

The Healthmap Difference

George's Care Navigator, Judy, realized George was going through a stressful transition to dialysis. She realized his dialysis catheter was a visual reminder of the health changes he was experiencing, and she helped educate him about alternative dialysis access options that wouldn't be as triggering. She also provided care

coordination and support throughout his transplant evaluation process and empowered him to reach out to his trusted spiritual community about living kidney donation.

Beatrice and Ben

Beatrice is a lively woman who describes herself as 52 years young. She works as an accountant, enjoys gardening and quilting, and has two grown children. Prior to meeting her Healthmap Care Navigator, Ben, she had been living with CKD Stage 5 for two years. She had learned about dialysis through her nephrologist's office. Despite this, she was not yet ready to "choose" a type of dialysis.

When Ben first met Beatrice, he worked to better understand her hesitation about choosing a type of dialysis.

"I was scared. I knew I would progress to kidney failure, but I didn't want to think about it. Ben helped me understand that everybody feels this way. No reasonable human being wants to start dialysis. But he helped me reframe how I thought about dialysis. I realized that I planned for everything else in my life: vacations, my children's education, my retirement. All that planning has always resulted in positive outcomes. When I approached dialysis with that mindset, the fear went away. I felt back in control of the situation."

Ben also helped Beatrice recognize a few things: 1) She did not want to stop working yet; 2) She wanted to continue enjoying hobbies like quilting, traveling, gardening, and spending time with her children. Together, they determined that peritoneal dialysis would be the best option for her. When Beatrice spoke to her nephrologist about this possibility, she agreed.

"Ben also had different questionnaires, which we completed together. My test results showed me that I had a good understanding of home dialysis. This helped me realize I was ready for the next steps."

Approximately six months after deciding on peritoneal dialysis, Beatrice developed symptoms of ESKD. She had a peritoneal dialysis catheter placed and began training shortly afterward.

"The training process was faster than I thought it would be. My nurse was great. I feel very confident about doing dialysis at home. Every night, after connecting to my machine, my husband and I will watch a movie together or talk or read. We make it fun, and it can be a healthy distraction. The best part of the process has been spending more time together."

Ben also helped Beatrice and her husband learn about transplant options, and Beatrice's husband is now being evaluated to see if he is a match to donate his kidney

to Beatrice. In the event that he is not a match, they've also started looking into a kidney swap program, also known as a kidney paired donation or paired exchange, which involves two living donors and two recipients. In these programs, the recipient from an incompatible donor/recipient pair is matched with a compatible donor from another pair, and vice versa, allowing two simultaneous transplants.

"Overall, my outlook is totally different now. I feel much more positive about my future. One of my highlights of this whole process was being able to fly out for the birth of my first granddaughter. Being on peritoneal dialysis made that possible. I even stayed to help my daughter for a month after her baby was born. Being able to be there in person for both of them meant so much to me."

The Healthmap Difference

Beatrice's Care Navigator, Ben, helped her reframe her fears surrounding dialysis initiation. Together, they identified peritoneal dialysis as the best option for her because it allowed her to remain engaged in her work and hobbies while also remaining as active as possible. Healthmap's home dialysis knowledge and readiness assessments helped give her the confidence she needed to know she was ready to initiate dialysis when the time came. Perhaps most importantly, their discussions helped Beatrice thrive through what might have been an otherwise difficult transition to ESKD.

Manuel and Alicia

Manuel was six years old when he was diagnosed with type 1 diabetes. He remembers being hospitalized various times as a child due to uncontrolled blood sugar. When he was thirteen, his family moved to the United States from Mexico. He recalls the transition being difficult at first, but he quickly acclimated to the American way of life. As a teenager, he struggled to manage his diabetes. He found a diabetic diet to be too restrictive and remembers eating at fast food restaurants with his friends to fit in. He was too embarrassed to bring his insulin, syringes, and needles to school, so he only checked his blood sugar and took his medication at home. He started smoking after school with his friends and eventually dropped out of high school. "As a kid, you worry about being cool. You don't think about the effects those decisions will have on your life in the long run."

Manuel is now 48 years old. He is married and has two kids of his own and works as a custodian at a school near his home. His diabetes is now well controlled, but he suffers from elevated blood pressure, morbid obesity, and Stage 5 CKD. He was told his CKD was due to years of uncontrolled diabetes.

"It took a long time for me to wake up and realize I had to turn my health around. Really it was when I learned that my eyesight and my kidneys were bad that I decided to change things."

Manuel took advantage of a benefit through his insurance that connected him with Healthmap's Care Navigator, Alicia. They worked together to identify ways he could lose weight, quit smoking, and incorporate a diet that was appropriate for both diabetes and Stage 5 CKD. Manuel learned about "SMART" goals, or goals that are Specific, Measurable, Achievable, Relevant, and Time-Bound.

The Healthmap Difference

Through his Care Navigator, Alicia, Manuel learned how to set achievable health goals. He lost a significant amount of weight, which has improved his blood pressure and slowed his CKD progression. Alicia helped coordinate appointments and referred him to a Registered Dietitian to improve his understanding about how to stay healthy with diabetes, high blood pressure, and advanced CKD.

Emmert and Jennifer

Emmert is an 86-year-old retired farmer from western Illinois. Having been born in the late 1930s, he can tell a lot of stories - anything from how to fix a tractor to how to make coffee when you've run out of beans. He enjoys fishing, reading the newspaper, and playing card games with his friends. He resides happily in Illinois with his high school sweetheart and wife of 65 years. Last year, at the recommendation of his nephrologist, he attended a class to learn about CKD and dialysis options.

"I remember walking out of that class thinking, 'I don't really want to start dialysis, but if I don't, then I'm going to die.' Don't get me wrong, anybody who's been around 86 years has thought about death, and I'm okay with it. I've had a great life, watched my children and grandchildren grow up. I'm lucky to still be around. It was the dialysis part that made me nervous. I didn't want it to make me feel old and weak, because that's not how I feel now. And that's where Jennifer comes in..."

Jennifer is Emmert's Healthmap Care Navigator. Emmert and Jennifer hit it off right away.

"What I liked about [Jennifer] is that she let me talk. She listened while I talked to her about my life, my kids, all the different jobs I've had. She even let me play a song for her on my ukulele. Of course, we talked about my health too. I told her the idea of dialysis made me nervous. I didn't want to feel sick."

Those in Emmert's situation typically must choose a dialysis access type and start preparing for treatments or decide to forgo dialysis and opt for conservative care instead. Jennifer understood that Emmert was not yet ready to make those decisions, so she and Emmert discussed a "time-limited trial of dialysis." Instead of requiring individuals to make decisions regarding long-term dialysis care before they progress to ESKD, a time-limited trial allows one to wait until they reach kidney failure, try

dialysis treatments for a set period, and then choose whether they wish to continue their treatment.⁵ At the end of the trial period, the nephrologist and individual discuss the experience thus far, along with various clinical and quality of life goals.⁶ Patient autonomy is at the heart of this option and offers individuals the choice to make an informed decision about continuing with dialysis.

After learning about the time-limited trial of dialysis, Emmert spoke to his nephrologist about it.

“My nephrologist loved the idea. We decided to wait to see how I felt on dialysis before making any decisions about more permanent dialysis access. Knowing that I can try dialysis out and stop it if I don’t like it has lifted a huge weight off my shoulders and has made me less nervous about the process in general.”

The Healthmap Difference

Emmert’s Care Navigator, Jennifer, listened to him. She understood that he wanted to transition to dialysis with dignity. By identifying a time-limited trial of dialysis as an option, Emmert now has peace of mind that when the time comes, he will be able to make a decision about dialysis that is right for him.

Jose and Diane

Jose is a 65-year-old man who immigrated to the United States from Guatemala in his 20s. He had been receiving hemodialysis for 20 years when Diane, his Healthmap Care Navigator, first connected with him. Diane described Jose as one of the most adherent members she’d ever met. He said he had missed fewer than five dialysis sessions in those 20 years. When asked about why he hadn’t received a transplant, Jose said he did not know. He recalled an evaluation approximately ten years ago, but he did not recall why he wasn’t listed. Diane encouraged him to ask about this at his next dialysis session.

As it turned out, Jose was eligible for a transplant. Ten years ago, he had undergone surgery to remove a cancerous renal tumor, which had temporarily placed his evaluation on hold. However, this did not preclude him from receiving a transplant going forward. After learning this, Jose was referred to a nearby transplant center and completed the necessary evaluations within six months. Shortly thereafter, he received a kidney transplant.

Typically, individuals have to wait many years on the transplant list prior to receiving a kidney. However, in 2014 the United Network for Organ Sharing (UNOS), the organization that manages the list of all people in the United States awaiting an organ transplant, changed its rules so that wait time for kidney transplant candidates was backdated to the date a person started dialysis.

This rule was in part enacted to address ongoing inequities in transplant referrals affecting racial and ethnic minority groups such as Jose’s. As a result, when Jose was listed for a transplant, the 20 years he had spent on dialysis were added to his wait time, and he jumped to the top of the kidney transplant waitlist.

Per his Care Navigator, Diane, Jose is as adherent with his transplant appointments and medications as he was with his dialysis sessions. He now spends his time coaching his grandson's soccer team and traveling to Guatemala to visit his mother, who still lives there. Jose asked that his story be shared with others in case it might help somebody currently struggling with dialysis.

The Healthmap Difference

Following the removal of a malignant renal tumor ten years ago, Jose did not recall being re-referred for transplant. Care coordination by his Care Navigator resulted in clarification of his transplant eligibility and ultimately a quick transplant evaluation and listing. Most importantly, Jose received a kidney transplant and is now enjoying dialysis-free time with his family and loved ones.

EASING THE TRANSITION

Although these five members' experiences are very different, they share a common theme: transitioning to ESKD is not always easy and is often fraught with uncertainty and apprehension. Healthmap's program eases these concerns by facilitating smooth care transitions and supporting members every step of the way. By sharing these member stories, Healthmap hopes they will bring a sense of confidence and optimism to individuals facing similar transitions to ESKD.

In addition, these stories serve as an important reminder that behind every number there is a person. Healthmap is committed to working with each of its members and their healthcare providers to ensure transitions to ESKD are clinically optimized and that our members feel valued as people and supported throughout the process.

We thank the members in our program and all of the Healthmap team that contributed to their successful outcomes.



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John Danziger, MD currently serves as Healthmap's National Medical Director. He received his undergraduate degree at the University of Pennsylvania, his medical degree from the Southwestern Medical School of the University of Texas, and a Master of Philosophy from Cambridge University in England, before completing his nephrology fellowship at Beth Israel Deaconess Medical Center in Boston. He is an

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Howard Shaps, MD, MBA is a board-certified emergency medicine physician with more than 15 years of healthcare management experience and currently serves as Healthmap's Chief Medical Officer. Additionally, he has extensive experience leading Quality, Care Management, and Utilization Management teams. He previously served as Deputy Chief Medical Officer at Centene Corporation, where

he had direct oversight of medical management and supported the policy, vendor management, and clinical strategy teams. Prior to joining Centene, he was Deputy Chief Medical Officer for WellCare Health Plans, responsible for medical management, policy, and value-based care programs. Howard earned his bachelor's degree in Psychology from the University of Michigan, his Doctor of Medicine from the Boston University School of Medicine, and his MBA, with distinction, from the University of Louisville College of Business. He is also a diplomat of the American Board of Emergency Medicine.

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REFERENCES

1. United States Renal Data System. 2022 *USRDS Annual Data Report: Epidemiology of kidney disease in the United States*. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2022.
2. Hassan R, Akbari A, Brown PA, et al. Risk Factors for Unplanned Dialysis Initiation: A Systematic Review of the Literature. *Can J Kidney Health Dis*, 2019.
3. Purnell TS, Bae S, Luo X, et al. National Trends in the Association of Race and Ethnicity with Predialysis Nephrology Care in the United States from 2005 to 20015. *JAMA Netw Open*, 2020.
4. Shen JI, Chen L, Vangala S, et al. Socioeconomic Factors and Racial and Ethnic Differences in the Initiation of Home Dialysis. *Kidney Med*, 2020.
5. Barrio PJ, Goldstein DG, Hofman JM. Improving Comprehension of Numbers in the News. *Proceedings of the 2016 Chi Conference on Human Factors in Computing Systems*, 2016.
6. Mehrotra R, Davison SN, Farrington K, et al. Managing the Symptom Burden Associated with Maintenance Dialysis: Conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. *Kidney Int*, 2023.
7. Murtagh FEM, Addington-Hall J, Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Adv Chronic Kidney Dis*, 2007.
8. Goh ZS, Griva K. Anxiety and Depression in Patients with End-Stage Renal Disease: Impact and Management Challenges - A Narrative Review. *Int J Nephrol Renovasc Dis*, 2018.
9. Lok CE, Huber TS, Lee T, et al. KDOQI Vascular Access Guideline Work Group. KDOQI clinical practice guideline for vascular access: 2019 update. *Am J Kidney Dis*, 2020.

**The names and details have been changed to protect the privacy of our members and employees.*