



Caring Is Sharing



ESRD Networks 7, 13, 15, 17, 18

Kidney Talk With Family and Friends Over the Holidays

The holidays are just around the corner. This is a time to be with family and friends, to share stories, and to give thanks for the blessings we have in our lives. While everyone is gathered, it is a perfect time to discuss with loved ones your journey with end-stage renal disease. By sharing, you are helping them understand the associated risk factors, prevention measures, and how family and friends can support you.

Here are some talking points to help guide you in your conversations with family & friends:

1. I am so thankful for this time to talk with you. I want to share information with you about the leading causes of chronic kidney disease and how you can reduce your risks of getting it. If I can help you prevent end-stage renal disease, this would make me so happy.
2. Thirty-five million American adults have chronic kidney disease. The two main causes of kidney disease are: diabetes and uncontrolled blood pressure. Other factors include family history, being overweight, smoking, age (50+ years of age), and ethnic/racial minority groups.¹
3. There are five stages of chronic kidney disease. The last stage (Stage 5) means that you have kidney failure or end-stage renal disease. There is no cure, but treatment can slow the progression.²
4. Because there is no cure, I will always need treatment. Getting a kidney transplant is the most effective treatment option for this disease.³
5. A kidney transplant from a living donor will last on average, 15–20 years and a kidney from a deceased donor will last on average, 8–12 years. A transplant can occur much sooner when you have a living donor. The average wait time for a deceased donor can be 5–8 years, depending on the state and hospital.⁴
6. Donated kidneys have a kidney donor profile index (KDPI) score. A KDPI score measures how long a kidney is likely to work. The score ranges from 0% to 100%; a lower score is better and means that the kidney will last longer and was from a younger and healthier donor when they died. I have been told that it may take a long time to get a kidney with a low KDPI score and that it is possible I may not get one at all. If I decided to accept a high KDPI kidney, these kidneys typically last 7–10 years and I would receive a kidney transplant sooner.⁵
7. When I feel overwhelmed, I may need to pick up the phone and call you for help. I may need someone to talk to when I feel down and lonely. If I decide to pursue transplant, most transplant centers require the presence of a caregiver throughout the entire process from pre-transplant to post-transplant care. I will need someone to support me through this process, especially post-transplant.
8. When you have time, I would like to show you the Scientific Registry of Transplant Recipients (SRTR) website where we can explore post-transplant outcomes, the average length of wait time, and other important data for transplant centers near where we live, and across the United States. There are videos, decision aids, and other tools to help people like me who have end-stage renal disease.⁶

Resources

1. Centers for Disease Control and Prevention. Chronic kidney disease in the United States [Fact sheet]. 2023. Accessed on September 20, 2024. Available at www.cdc.gov/kidney-disease/media/pdfs/CKD-Factsheet-H.pdf.
2. American Kidney Fund. Stages of Kidney Disease. August 28, 2024. Accessed on September 20, 2024. Available at www.kidneyfund.org/all-about-kidneys/stages-kidney-disease.
3. End Stage Renal Disease National Coordinating Center (ESRD NCC). Is kidney transplant right for me? You guide to the transplant process [Booklet]. 2015. Accessed on September 20, 2024. Available at www.esrdncc.org/globalassets/patients/41-ncc-patient-toolkit-transplant-booklet_7_07_15_508.pdf.
4. National Kidney Foundation. Kidney Transplant. March 15, 2024. Accessed on September 20, 2024. Available at www.kidney.org/kidney-topics/kidney-transplant.
5. Health Services Advisory Group. Understanding KDPI Scores in Kidney Transplant. 2022. Accessed on September 20, 2024. Available at www.hsag.com/globalassets/esrd/transplant/highkdpi-handout_2022.pdf.
6. Scientific Registry of Transplant Recipients. Find and Compare Transplant Programs. Accessed on September 9, 2024. Available at www.srtr.org.