

End Stage Kidney Disease Briefing Book

for State and Federal Policymakers:

A Guide to Kidney Disease Awareness and Education



About The American Nephrology Nurses Association (ANNA)

The ANNA improves members' lives through education, advocacy, networking, and science. Since it was established as a nonprofit organization in 1969, ANNA has been serving members who span the nephrology nursing spectrum. ANNA has a membership of over 7,000 registered nurses and other health care professionals at all levels of practice. Members work in such areas as conservative management, peritoneal dialysis, hemodialysis, continuous renal replacement therapies, transplantation, industry, and government/regulatory agencies.

ANNA is committed to advancing the nephrology nursing specialty and nurturing every ANNA member. We achieve these goals by providing the highest quality educational products, programs, and services. Our members are leaders who advocate for patients, mentor each other, and lobby legislators, all to inspire excellence.

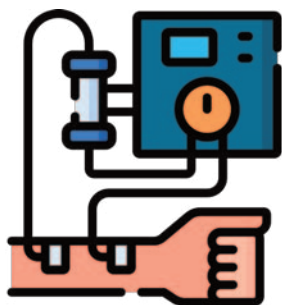
Chronic Kidney Disease

Thirty-seven million adults in the United States have chronic kidney disease (CKD) (Centers for Disease Control & Prevention [CDC], 2021). The National Kidney Foundation (NKF) (2022) estimates that 90% of those with kidney disease do not know they have it. The number of individuals with prevalent end stage kidney disease (ESKD) reached 782,818 in 2019, an increase of 40.4% from 2009 (United States Renal Data System [USRDS], 2021).

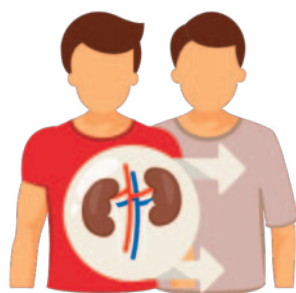


37
million

Individuals on in-center hemodialysis have poor outcomes; one in five will die in the first year of treatment (U.S. Department of Health and Human Services [NKF], 2019a) with 50% mortality within 5 years (NKF, 2019b). Without increased investment in prevention, the total number of people with kidney failure will likely exceed 1 million by 2030 (NKF, 2022).



554,000 receive dialysis to replace kidney function



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About 554,000 receive dialysis to replace kidney function and 230,000 live with a kidney transplant; however, in 2018, almost 39% of people with a new diagnosis of CKD (18-44 years) had received little or no care for their CKD (NKF, 2019).

Blacks or African Americans, Hispanics, Asians, and Pacific Islanders are disproportionately affected by CKD. Reports have shown that individuals from these racial/ethnic groups are two to four times more likely than White people to experience kidney failure.

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What Are the Causes?

The two most common causes of CKD are diabetes and high blood pressure. One in three adults with diabetes and one in five adults with high blood pressure have CKD (NKF, 2022). By medically managing both conditions, the risk of developing CKD is reduced. Social determinants of health (SDOH) also contribute to health disparities and inequities. Addressing SDOH earlier will improve outcomes. The most common causes of CKD from infancy to early teens is cystic disease, hereditary issues, or congenital diseases. The most common cause of CKD for 15-19-years of age is glomerulonephritis, which damages kidney tissue.

Kidneys perform the following functions:

- Remove waste products
- Balance fluids and electrolytes
- Release hormones that regulate blood pressure
- Produce an active form of vitamin D that promotes strong, healthy bones
- Control the production of red blood cells
- Remove drugs

People with kidney disease are at greater risk for cardiovascular disease. Kidney disease and cardiovascular disease are linked and have common risk factors, such as diabetes and high blood pressure.

The best prevention of CKD is through early detection when the disease can be slowed or stopped. Early prevention strategies include:

- Diet
- Exercise
- Medications
- Treating risk factors like diabetes and high blood pressure
- Addressing SDOH

**1 in 3 adults
with diabetes
have CKD**

(NKF, 2022)



**1 in 5 adults
with high blood
pressure
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(NKF, 2022)

What Are the Challenges?

Persons with kidney disease face numerous challenges. With the loss of kidney function, they:

- Cannot remove waste products. Toxins build up in the body and must be removed by dialysis.
- Cannot balance electrolytes, resulting in high potassium and phosphorus levels.
- Cannot balance fluid, which can result in fluid retention and swelling.
- Release hormones that affect blood pressure. Typically, they have difficulty maintaining normal blood pressure, resulting in high blood pressure.
- Are typically anemic. Anemia occurs when red blood cells (RBC) are in short supply. The kidneys make an important hormone called erythropoietin (EPO). EPO tells the body to make RBCs. With kidney disease, the body cannot make enough EPO, causing the RBC count to drop and anemia to develop.
- Are at risk for decreased bone metabolism. Healthy kidneys produce an active form of vitamin D that helps maintain stable blood and bone levels of calcium and phosphorus. When kidney function declines, the individuals typically develop bone disease.
- Have a decreased ability to remove drugs. “Normal” medication dosing is based on normal kidney function. Medications that are eliminated primarily through the kidneys may build up and become toxic or cause side effects. People with impaired kidney function may require lower drug doses (Le, 2020).
- Identifying and promoting efforts to reduce risk that focus on designated priority populations. Promoting healthy choices is essential. Partnering with health organizations to dismantle structural barriers within the healthcare systems will allow for more significant changes that address inequities.



Treatment Options

When kidneys fail, treatment requires hemodialysis, peritoneal dialysis, or kidney transplant. Since 1972, Medicare has reimbursed for the care and treatment for all persons with a diagnosis of ESKD who are currently insured by Medicare or eligible for benefits under Social Security. All individuals with kidney disease are educated on treatment options, including in-center/home therapies and transplant. In addition, they are educated on palliative care and conservative management if they choose not to initiate dialysis.



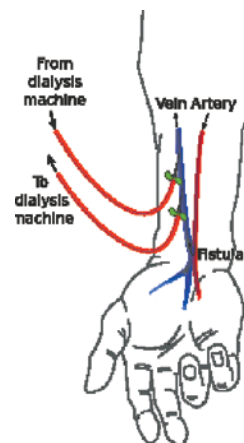
Hemodialysis

- Removes toxins and excess fluids by circulating the person's blood outside the body through an artificial kidney or dialyzer.
- In-center hemodialysis
 - Treatment is performed predominantly in freestanding in-center dialysis facilities.
 - Treatments most often are scheduled three times weekly and last 3-4 hours.
- Home hemodialysis
 - Hemodialysis may be performed at home after a person and in some cases, a care partner, undergo several weeks of training.
- Devices that increase total hours of treatment are receiving more use, such as short daily (treatment four to six times weekly for 2-3 hours) or long nocturnal dialysis sessions (three to six times weekly for 6-8 hours while the person sleeps).



Peritoneal Dialysis

- Uses a person's peritoneal membrane (abdominal lining) for dialysis.
- Requires the placement of a catheter into the abdominal cavity where sterile dialysate is instilled, which then sits in the abdomen where the dialysis occurs, until it is drained, and the process is repeated.
- Types of peritoneal dialysis:



- ambulatory peritoneal dialysis (CAPD)
 - Four to five exchanges are performed during the day, every day.
- Continuous cycling peritoneal dialysis (CCPD)
 - Several exchanges are administered by a machine (cyclor), typically every night, with one long dwell during the day.
- CAPD and CCPD can be used in combination when needed.
- Peritoneal dialysis is the dialysis modality used most often for children.

Dialysis Access

Whether hemodialysis or peritoneal dialysis is used, a route (or access) is required to perform these treatments; therefore, the access is frequently referred to as the individual's lifeline.

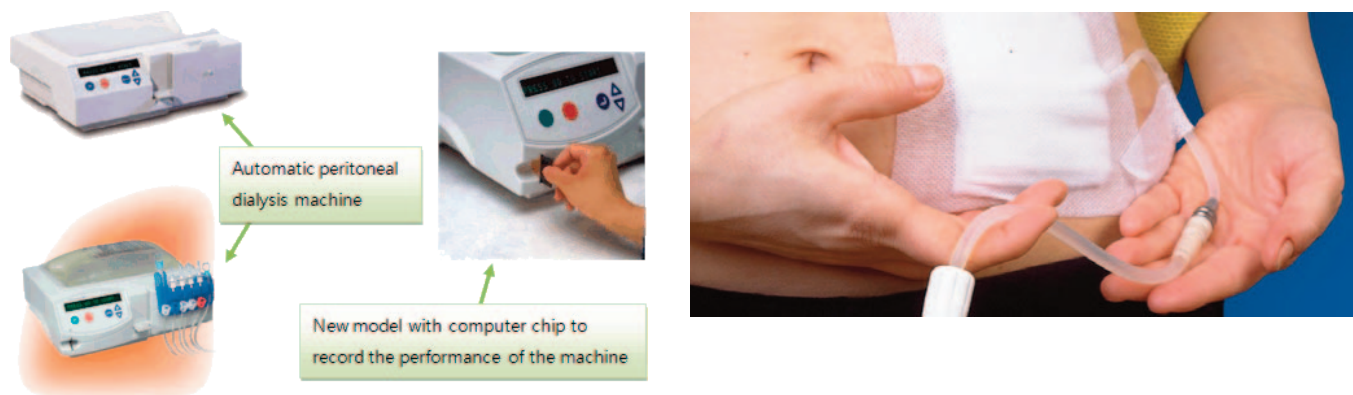
Three types of vascular access are used for hemodialysis:

- An arteriovenous fistula is created by surgically connecting a person's artery and vein.
- An arteriovenous graft is a surgically created connection between an artery and a vein using a soft tube.
- A central venous catheter (CVC) is a tube that is tunneled to the heart. It has two lumens, allowing blood to flow into and out of the body. CVCs should be avoided as they are the leading cause of bloodstream infection and have the highest rate of hospitalization and death in persons receiving dialysis (Lok et al., 2020).

For peritoneal dialysis, a catheter (a silicone tube) is surgically placed in the abdomen (Crabtree et al., 2019)

Transplantation

Kidney transplantation is a treatment for kidney failure; it is not a cure. This is an elective procedure rather than an emergency or life-saving procedure. Medical and socioeconomic factors may impact eligibility for a kidney transplant.



- Wait times for transplants vary by state. Not everyone who needs a transplant will receive one. Disparities exist in access to transplantation for vulnerable populations. Advocacy efforts are geared toward policies that improve care delivery and access for underserved and vulnerable populations.
- People with transplants must take anti-rejection medications every day during the life of the kidney to prevent rejection. These medications have side effects that may affect quality of life but are necessary to maintain the transplanted kidney.
- Many individuals struggle to pay for these medications, sometimes leading to rationing or stopping the medications, which almost always results in transplant failure and a return to dialysis.
- In December 2020, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2020 changed the coverage for these medications from 36 months to the lifetime of the transplanted kidney.
- For individuals whose coverage will expire before January 1, 2023, the NKF is available to assist by working with pharmaceutical companies, state assistance programs, and others to prevent a gap in medication coverage.
- Anyone with a transplant whose Medicare eligibility expires before, on, or after January 1, 2023, can enroll in Medicare Part B if they do not have other insurance to cover the cost of their immunosuppressant's, except for required co-pays and deductibles.

116,935 men, women, and children are on the national waiting list for organ transplants.

(NFK, 2022)

97,762 are waiting for a kidney transplant

(HRSA, 2021)

17 people die each day waiting for a transplant.

39,000 people received transplants

(HRSA, 2021)

Updated February 2022 by:

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References

- Crabtree, J.H., Shrestha, B.M., Chow, K.M., Figueiredo, A.E., Povlsen, J.V., Wilkie, M., Abdel-Aal, A., Cullis, B., Goh, B.L., Briggs, V.R., Brown, E.A., & Dor, F.J.M.F. (2019). Creating and maintaining optimal peritoneal dialysis access in the adult patient: 2019 update. *Peritoneal Dialysis International*, 39(5), 414-436. <https://doi.org/10.3747/pdi.2018.00232>
- Health Resources and Service Administration (HRSA). (2021). Organ donation statistics 2021. <https://data.hrsa.gov/topics/health-systems/organ-donation>
- Le, J. (2020). Drug elimination. Merck manual consumer version. <https://www.merckmanuals.com/home/drugs/administration-and-kinetics-of-drugs/drug-elimination>.
- Lok, C.E., Huber, T.S., Lee, T., Shenoy, S., Yevzlin, A.S., Abreo, K., Allon, M., Asif, A., Astor, B.C., Glickman, M.H., Graham, J., Moist, L.M., Rajan, D.K., Roberts, C., Vachharajani, T.J., & Valentini, R.P. (2020). KDOQI clinical practice guideline for vascular access: 2019 Update. *American Journal of Kidney Disease*. 75(4 Suppl 2): S1-S164. <https://doi.org/10.1053/j.ajkd.2019.12.001>
- National Kidney Foundation (NKF). (2019). 37 million American adults estimated to have chronic kidney disease (CKD). <https://www.kidney.org/news/37-million-american-adults-now-estimated-to-have-chronic-kidney-disease>
- National Kidney Foundation (NKF). (2022). Kidney disease: The basics. <https://www.kidney.org/news/newsroom/fsindex>
- United Network for Organ Sharing (UNOS). (2022). Waiting for your transplant. UNOS Transplant Living. <https://transplantliving.org/before-the-transplant/waiting-for-your-transplant>
- United States Renal Data System (USRDS). (2021). 2021 annual data report. <https://adr.usrds.org/2021>

Additional Resources

- Centers for Disease Control & Prevention (CDC). (2021). Chronic kidney disease in the United States, 2021. <https://www.cdc.gov/kidneydisease/pdf/Chronic-Kidney-Disease-in-the-US-2021-h.pdf>
- Couch, S. (2022). H.R.5534 – the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2020: It passed – So now what?! Renal Support Network. <https://www.rsnhope.org/uncategorized/h-r-5534-the-comprehensive-immunosuppressive-drug-coverage-for-kidney-transplant-patients-act-of-2020-it-passed-so-now-what/>
- Department of Health and Human Services. (2022). Organ Procurement and Transplantation Network data. <https://optn.transplant.hrsa.gov/data/>