

2019

Kidney Transplant Toolkit

Developed by the Forum of ESRD Networks' Medical Advisory Council (MAC)

This toolkit for dialysis clinic staff is a reference tool that gives information about the transplant referral process and guidance to help patients prepare for receiving a kidney transplant.

Tell us what you think!

Please take a moment to complete a short questionnaire about this Toolkit. We appreciate your insight and suggestions to make our resources better.

<https://www.surveymonkey.com/r/ForumResEval>



This publication is the product of a workgroup under the auspices of the Forum of ESRD Networks, Inc., a non-profit organization of volunteers dedicated to improving the quality of care to patients with end stage renal disease (ESRD). This toolkit was conceived of and sponsored by the Forum of ESRD Networks' Medical Advisory Council (MAC). The toolkit committee was a multidisciplinary group of volunteers who generously contributed their time and expertise to this effort. The Forum would like to acknowledge the hard work of these individuals.

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Introduction

Author: Stephen Pastan, MD

Kidney transplantation is the preferred therapy for End Stage Renal Disease (ESRD). Patients who undergo a transplant have an increase in their life expectancy and also their quality of life. Patients become eligible to be placed on a kidney transplant list when their percentage kidney function, as measured by estimated GFR, is less than 20%. Therefore, many patients can be or are listed before they start dialysis. (It is important to ask the patient if they are already listed.) Some patients will receive a transplant before they need to start dialysis. Of patients who reach dialysis, a large number are eligible to receive a kidney transplant. However, only 16% of dialysis patients are currently on the waiting list. For dialysis patients who are placed on the waitlist, only about 40% receive a transplant within 5 years; 25% are still on the waitlist, and approximately one third will have died or been removed from the waitlist over the 5-year period.

Living donor transplants are the best choice if available. Living transplants can be arranged within a few months; they work faster after the transplant operation, and last longer than a renal transplant from a deceased donor (DDRT). Deceased donor transplants last about 8-10 years on average, where living transplants can average over 15-year longevity. Data from the Scientific Registry of Transplant Recipients (SRTR) registry are displayed in the two figures below. This first figure shows the 5-year (60-month) graft survival for DDRTs. You can see it ranges from about 70% in diabetic kidney disease to about 80-85% in patients with glomerulonephritis (GN) or cystic kidney disease (CKD); grafts placed in patients with hypertensive ESRD fall in the middle with about a 75% 5-year graft survival.

OPTN/SRTR 2016 Annual Data Report: Kidney

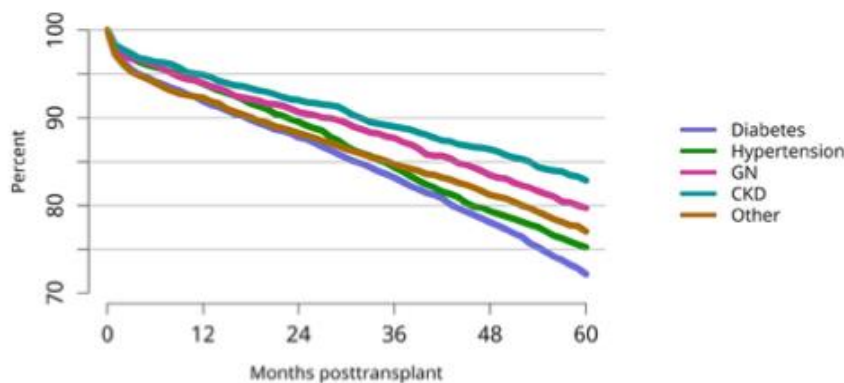


Figure 1: Graft survival among adult deceased donor kidney transplant recipients, 2011, by diagnosis. OPTN/SRTR 2016 Annual Data Report. HHS/HRSA.

The next figure shows the 5-year (60-month) graft survival in living donor transplants (note the scale is different from the graph above). You can see 5-year graft survival is somewhat better: 80% for diabetic kidney disease, 88-90% in patients with GN and CKD; patients with hypertension as their cause of ESRD fall in the middle with about 85% 5-year graft survival.

OPTN/SRTR 2016 Annual Data Report: Kidney

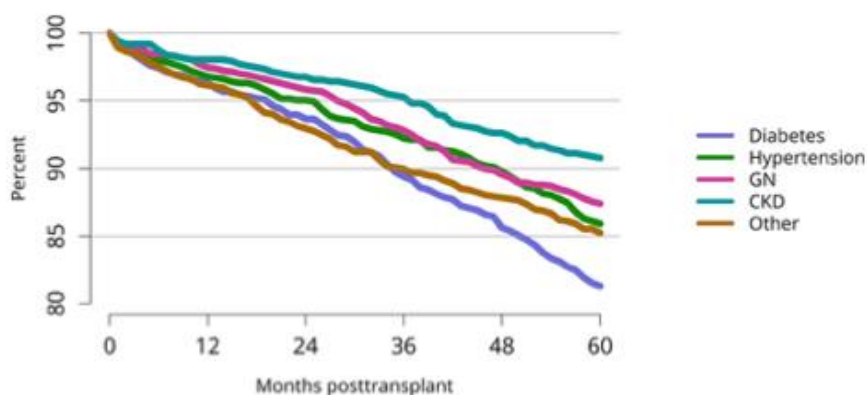


Figure 2: Graft survival among adult living donor kidney transplant recipients, 2011, by diagnosis. OPTN/SRTR 2016 Annual Data Report. HHS/HRSA.

Patient survival is somewhat better than graft survival, as patients can return to dialysis and in many cases be eligible to receive a second (or even third) transplant. It is important to note that patients with living donor transplants have somewhat longer graft survival, as well as patient survival. However, in general, eligible patients undergoing any kind of kidney transplant have better survival and quality of life than those remaining on dialysis, regardless of the cause of kidney failure.

The dialysis unit is an important part of the transplant team. The dialysis team is required by the Centers for Medicare and Medicaid Services (CMS) to educate patients about renal transplantation. Patients are referred for transplant from the dialysis unit, if they have not already been referred. The team can help patients complete the steps needed to be placed on the waitlist by encouraging and helping the patients finish required testing, such as colonoscopies, PAP smears, mammograms, and outpatient cardiac testing. Not only can the dialysis team arrange the patient's dialysis schedule to be able to visit the transplant center and complete the testing, but also can help by giving the patients vaccines and by sending timely blood samples to the HLA lab. The dialysis clinic can give the transplant center important feedback on a patient's social situation, drug or alcohol use, or lack of adherence to medical therapy, which can impact their candidacy for transplantation. Once on the waitlist, the dialysis clinic can help make sure the patient maintains a stable state of health, and can notify the transplant center if the patient develops a change in their medical condition with a severe illness, such as cancer, chronic severe infection, or congestive heart failure which will affect their transplant candidacy, and also notify the transplant center when the illness has resolved, so that the patient can be activated on the list again. They can let the transplant center

know if the patient's social situation becomes unstable – for instance if they become homeless, go into a nursing home, or lose their transportation – which would impact their ability to have a successful transplant.

We don't know the percentage of patients in a dialysis unit who are eligible to receive a kidney transplant – this may vary based on the location, demographics, and medical profile of a given dialysis clinic. However, evidence suggests that over 50% of dialysis patients are actually eligible to receive a transplant. The best data we have, from the Southeastern US, reveals that only about 25% of ESRD patients are referred for a kidney transplant in their first year on dialysis. As mentioned above, only 16% of dialysis patients are on the kidney transplant waitlist.

Recently CMS has directed the ESRD networks to develop quality improvement programs for dialysis units with the goal to increase the number of patients who are referred for transplant and placed on the kidney transplant waitlist. The quality initiatives have usually involved dialysis clinics with low referral and transplant waitlisting rates. This transplant toolkit was developed in order to provide information regarding kidney transplantation that will be useful for dialysis clinic staff. The chapters are written for clinical staff who are trained in dialysis but are not trained in transplant medicine. We also believe nephrologists will also find the chapters informative. It is not a comprehensive textbook on transplantation, but a series of chapters that covers basic information; this information should be beneficial to those helping patients prepare for receiving a kidney transplant. We hope you find this toolkit useful and welcome your feedback for ways we can improve it in the future.

Chapter 1: Selecting Patients to be Referred to a Transplant Center and the Transplant Evaluation

Author: Carlos Zayas, MD

Despite modern improvements in healthcare, Chronic Kidney Disease (CKD) currently affects approximately 14% of the American population. In some patients, progression of CKD leads to terminal loss of renal function, requiring one of three forms of renal replacement therapy: hemodialysis, peritoneal dialysis, or renal transplantation.

Transplantation confers a survival advantage over dialysis and appears to improve the quality of life of most patients by providing them with a lifestyle free of dialysis constraints, minimizing their dietary restrictions and decreasing the incidence of dialysis-associated complications including cardiovascular death, progression of their renal bone disease, correcting anemia and improving the patient's overall wellbeing.

Unfortunately, renal transplantation is not a treatment alternative for all patients with End Stage Renal Disease or those with CKD Stages III and IV not yet on dialysis. In general, any patient on any type of dialysis (hemodialysis or peritoneal dialysis), or anyone with sufficient loss of kidney function to qualify, could be referred to a transplant center to determine whether or not the patient is a suitable candidate (see below).

When is the best time to refer a patient to a center?

As soon as it is documented that a patient's estimated glomerular filtration rate (eGFR – a measure of renal function) has declined to 20 ml/min or less, he or she is technically eligible to be placed on a waiting list for a kidney transplant. Many transplant centers will evaluate patients early when the eGFR is less than 25-30 ml/min.

What is necessary for a successful referral?

A nephrologist, primary care physician, dialysis unit social worker or nurse, on behalf of the primary care physician or nephrologist, can refer a patient. Patients can also refer themselves to many transplant centers. Every transplant center has a specific referral form, which can be submitted by fax or electronically. Most centers will require the submission of the form, a recent clinical note or history and physical, the CMS-2728 form (if the patient is on dialysis already) and copy of the insurance card. Required information at the time of referral differs by transplant center, but requested information may include: CKD diagnosis, age, height, weight, BMI, type of dialysis, dialysis schedule and specifics about the need for oxygen, a wheelchair, a translator or sign language interpreter, and mode of transportation.

What are the contraindications for renal transplantation?

There are medical, psychological, psychosocial and financial reasons not to accept a patient as a potential transplant candidate. Some of the conditions are temporary or reversible or are considered relative contraindications. Some other conditions are permanent or irreversible and are called absolute contraindications. Further details are given below.

What is a transplant evaluation?

A transplant evaluation is the process by which a potential transplant recipient is evaluated by a multidisciplinary transplant team housed at a transplant center, designed to determine if the patient can be relatively safely given a transplant organ. Many centers will invite the potential candidate to attend a

preliminary educational session, after which the patient will visit to complete the testing process. Some centers provide online education or incorporate education into the initial evaluation visit. The patient and family will be educated about the process, complications and long-term care post-transplant.

Evaluations may occur in one day or more, depending on the center's protocol and the patient's medical conditions. Some centers take several weeks to months to complete the assessment. The patient will be evaluated and examined by a transplant surgeon, transplant nephrologist, or both depending on the center. Often Advanced Practitioners such as Physician's Assistants or Nurse Practitioners will assist with the evaluation. Transplant Nurse Coordinators are in charge of arranging the visit and making sure the correct testing is completed; they also participate in presenting the patient's evaluation to the transplant team in a multidisciplinary conference to determine the patient's eligibility. Each patient is assigned an individual transplant coordinator, who is the best point of contact for communication with the transplant center to receive information on the status of a patient's transplant evaluation. In addition, the candidate will be interviewed by the transplant financial counselor, social worker, dietitian, living donor coordinator (if applicable), and by a mental healthcare professional. The exact tests that will be ordered differ between transplant centers. A typical evaluation will include laboratory testing, electrocardiogram, cardiac echocardiogram and often cardiac stress testing, chest X-ray, and abdominal imaging which may include a CT scan, MRI scan, or abdominal ultrasound. Some patients will be scheduled to undergo pulmonary function studies or vascular studies depending on their medical condition. Most centers will include a serum drug screen, nicotine screen and sickle cell screen when appropriate. This valuable information will be necessary for the patient's assessment by the Transplant Selection Committee. Individual transplant center protocols are reviewed and approved by the national United Network for Organ Sharing (UNOS), which is one of the government regulatory bodies that oversee transplant centers.

Medical contraindications account for more than half of the denials issued by transplant selection committees. Common absolute medical contraindications include: active infection, cancers under treatment or diagnosed within the last 2-5 years, depending on the type of cancer (see below), cirrhosis or advanced liver disease (unless the patient is also a candidate for a simultaneous liver transplant), severe cardiovascular disease including coronary disease non amendable to surgery or coronary artery stenting, severe or irreversible peripheral vascular disease, severe pulmonary disease including emphysema and need for home O₂, and smokers who also have diabetes and are therefore at high risk for vascular complications. Absolute contraindications also include active psychiatric disorders, advanced dementia, or debilitating neurological or neuromuscular disorders.

Patients who are mentally disabled, such as with Down's Syndrome, may be candidates for kidney transplantation if they have good social support.

The above partial list includes some of the most common causes for not being eligible for transplantation. The coexistence of multiple significant medical conditions will make an individual patient's selection and acceptance less likely; in such cases the procedure and medication-related risks will outweigh the benefit of transplantation.

Regarding cardiac contraindications, the reality is that a diagnosis of coronary disease, which is very prevalent among dialysis patients, is not necessarily a contraindication unless there are signs of irreversible cardiac damage including: advanced heart failure with LVEF less than 30%, recurrent coronary disease after CABG, symptomatic angina after CABG, recurrent and multiple coronary artery stenting, end stage heart disease or active cardio-pulmonary syndromes.

Any active bacterial, viral, protozoan or fungal infection should be treated and eradicated before attempting transplantation with few exceptions.

Patients are not transplant candidates if they have an active malignancy that has been recently diagnosed, is being actively treated, or has metastatic disease. Patients with non-melanoma skin cancer that is not metastatic are candidates for transplantation. Patients with cancer that is in remission who have a long enough life expectancy to benefit from transplantation (typically a minimum of about 5 years) are acceptable to be referred and may be transplant candidates. After a cancer is in remission by surgical removal, or chemotherapy, patients may become eligible to receive a kidney transplant, depending on the long-term prognosis of their cancer. Different transplant centers have different waiting periods depending on the individual patient's clinical situation. Waiting times vary -- for instance a patient who undergoes a nephrectomy for a small renal cell carcinoma may be able to be listed for transplant immediately after recovering from surgery. However, most cancers, once treated will have a 2-5 year waiting time including: colon, prostate, cervical and lymphoma/leukemia. Breast Cancer, pancreatic cancer and ovarian cancers could have a longer surveillance waiting time that is center specific, usually between 5 to 10 years. Other cancers such as Multiple Myeloma are a contraindication unless the patient has undergone a stem cell transplant and has been in remission for several years. If the patient is interested in transplantation, it is better to refer the patient for evaluation and let the transplant center determine if the patient is a candidate at the current time. They will state when the patient can be referred back in the future.

As mentioned above, patients with end stage liver disease and cirrhosis may be eligible for a combined liver and kidney transplant.

Patients who have lost their kidney function due to active autoimmune diseases, such as Systemic Lupus Erythematosus or systemic vasculitis, will be asked to delay transplantation until their autoimmune disease becomes inactive.

In general, unless a patient has a clear contraindication for renal transplantation, it is appropriate to refer a patient for evaluation; the transplant center will make a determination of the patient's eligibility.

Recipient weight considerations

Obesity is a serious healthcare issue and its medical consequences are multiple and in certain cases life-threatening. Obese patients have more complications post-transplant, including a higher risk of surgical wound infections and transplant rejection. Most Transplant Centers now include BMI guidelines and limits to the selection process. Typical centers will not transplant a patient with a BMI above 35 kg/m², although many will allow a patient to be placed on the waiting list at a higher BMI, in anticipation of weight loss. There are centers that will transplant patients with higher BMI, above 35; please check with your center regarding their specific requirements before you send the referral.

Psychological contraindications

Patients with a psychiatric diagnosis should be referred for pre-transplant evaluation. Most centers will include a psychiatric or psychosocial evaluation as part of the initial visit. A previous psychiatric disorder doesn't constitute by itself a contraindication, as long as the patient's condition is stable and free of acute episodes, appropriately treated, and the patient is compliant with the treatment and pharmacologic regime as documented by the treating or supervising mental health professional. Patients with active Bipolar Disorder, Schizoaffective Disorders, Schizophrenia or severe anxiety or depression disorders will need appropriate care before they could be accepted as candidates and will need close psychiatric or psychological follow up post-transplant.

Financial, support and transportation requirements

Besides the obvious medical and psychological contraindications, there are other serious considerations that could negatively impact the longevity and wellbeing of the transplanted organ and the patient. The social worker and the financial transplant coordinators will discuss in detail the insurance coverage,

patient's deductibles and patient's financial responsibilities. Depending on an individual patient's financial situation, many patients will be required by the transplant center to set money aside to cover the out-of-pocket expenses and copayments related to the transplant episode; different centers have different requirements. In addition, given the imperative need to follow the patient often in clinic, particularly in the first post-transplant year, a reliable transportation plan and family support plan should be available as a prerequisite for acceptance. Medication adherence is critical for the success of the transplant, and plans will be required to ensure that the patient will be able to afford the medication deductibles.

Recreational drug use

Most renal and pancreas programs will accept patient who consume alcohol in moderation, as long as the patient has no evidence of liver disease or a diagnosis of alcoholism. All other recreational drugs are usually prohibited by most centers, although some centers do not consider casual marijuana use to be a contraindication. During the initial screening, a comprehensive drug screen will be performed and that patient with a positive test for cocaine, other illegal drugs, and narcotics not prescribed by a physician won't be accepted until the agent in use is discontinued and proof of cessation, rehabilitation, and relapse prevention is completed and certified by a mental health professional or drug rehabilitation program. Drug use is associated with an increased risk of medication non-adherence, increased risk of rejection, increased risk of some infections and subsequent multi-substance abuse.

Medication and medical care non-adherence

Every member of the transplant selection team will assess the patient's history of compliance with physician visits, medications, dietary restrictions, and the dialysis prescription. Lack of compliance as demonstrated by poor attendance to dialysis sessions, or early termination of the sessions as per patient request, could be seen as lack of compliance and poor insight; both adherence to a complicated medical regimen and insight into a patient's own medical condition are necessary for a successful transplant outcome. Such patients will with all likelihood be viewed unfavorably as a transplant candidate by the transplant selection committee.

Age limitations, physical performance, and candidacy

Chronological age is not by itself a contraindication to transplant. However, an elderly patient with multiple medical conditions who has poor physical capacity, or is in a frail state, is likely to be denied listing. Patients who are 75 years old or older may receive extra scrutiny to be sure they have the physical stamina to undergo the transplant procedure, and tolerate common post-transplant complications, such as infection or rejection. The expected waiting time until transplant must be considered: a 75-year-old patient who does not have a living donor is likely to be 80 years old or older when they receive a transplant offer and is likely to be in a worse medical condition than when they were first listed. Patients over age 80 may not experience a survival advantage from a renal transplant; however, every patient must be evaluated as an individual. It is important to see elderly patients back at the transplant center on a regular basis, typically yearly, to assess their current state of health, and to decide if the patient should be removed from the waitlist.

Re-transplantation after prior transplant

20% of the ESRD patients listed in the UNOS Renal Wait List have a history of a previously failed graft. The reasons for transplant loss vary, but three common reasons are:

1. Chronic allograft dysfunction resulting in kidney failure, especially after many years of chronic immunosuppression use;
2. Failed graft secondary to medication non-adherence;
3. Recurrence of the primary renal disease, or occurrence of a new kidney disease such as a glomerulopathy

There is no absolute contraindication for a referral for re-transplant, as long as the patient meets the same medical and psychosocial criteria of any patient being considered for a renal transplant. If the patient has lost a graft due to non-adherence with medications, or poor follow up with the transplant center, they may or may not be a candidate for repeat transplantation. It is usually a good idea to let a period of time go by before re-evaluation. Such patients must have undergone a change in their situation such that they have insight into how their previous actions resulted in the loss of their previous transplant. For instance, it is not uncommon for teenage transplant recipients to lose a transplant due to non-adherence with their medications. Many of these patients become much more responsible as they grow up into adults. If the patient is medically stable, has good psychosocial support, and is expected to be adherent with their transplant regimen in the future, they may be considered for repeat transplantation.

Smoking history

Recent literature and clinical observations have linked chronic smoking to progression of atherosclerosis and renal disease in humans, which is worse among diabetics. Even the alternative use of electronic cigarettes or marijuana is associated with similar health risks. Smoking alone is associated with an increased risk of transplant rejection, as well as a decrease in transplant and patient survival. Most centers will strongly recommend tobacco cessation but may still consider smokers for transplant listing. Because of the increased health risk, diabetic patients who are actively smoking are likely to be denied access to renal transplantation.

Health maintenance studies

Most transplant centers follow national guidelines for disease prevention as established by consensus groups from the American College of Physicians, the Center for Disease Control and Prevention, and the American Society of Transplantation. Transplant candidates are required to follow some basic recommendations:

1. Recommended Vaccinations: Hepatitis B series, Pneumococcal vaccinations (both pneumococcal conjugate vaccine 13 and pneumococcal polysaccharide vaccine 23), Herpes Zoster, Tetanus with diphtheria, and for those who are not immune, hepatitis A.
2. Dental care: Recommend assessment by an oral health provider to assess for cavities and severe periodontal disease
3. Dermatology Screening: Basic screening to exclude skin cancer
4. Colonoscopy for patients over age 50 or who are at increased risk.
5. Females: Mammogram and Pap Smears as per standard guidelines
6. Males: Prostate examination and PSA as per standard guidelines
7. Cardiac Screening: 2D Echocardiogram, and Stress test or equivalent if clinically indicated (Cardiac testing practice varies by transplant center; some centers require cardiac testing to be done at the transplant center).

Referral to multiple transplant centers

Due to the size of the UNOS list and the lengthy waiting times to receive a deceased donor transplant, referring nephrologists and patients may consider multicenter referrals. According to UNOS guidelines, patients may be evaluated and listed at as many centers as they like. As long as the patient chooses to list at transplant centers which operate under different organ procurement organizations (OPOs), that practice may have a benefit, as the each OPO procures its own kidneys; multiple listing may therefore increase a patient's chance of being offered a kidney.

Living donation

The number of patients on the kidney transplant waiting list continues to grow, but the number of deceased donors has been relatively unchanged. Most centers recommend that a potential candidate bring at least one family member to the transplant evaluation, to educate the family and other members

of the patient's support system about the benefits of living donation and the living donor evaluation process. Patients are strongly encouraged to seek out living donors, as living donor transplants have the best outcomes for transplant recipients.

Chapter 2: Deceased Donor Transplantation, The Kidney Transplant Operation, and Transplant Complications

Author: Ron Parsons, MD

Kidney transplantation is the best available treatment for end-stage renal disease. A kidney from either a deceased or live donor has been shown in numerous studies to have superior patient survival rates, and improved quality of life, compared to dialysis therapy. Successful kidney transplantation requires finding a compatible donor, surviving an abdominal surgery, and maintaining successful levels of immune suppressing medication to avoid rejection. We will review these topics below. The five-year survival rate after deceased donor kidney transplantation is approximately 75%.

Kidneys from living donors can be more quickly identified and transplanted than a deceased donor kidney. Wait time on average for a deceased donor kidney is approximately 5 years in the United States but is longer in many regions. Patients should be encouraged to actively seek live donors through discussion with family and friends, as these individuals are most likely to donate. Please see the Living Donor Transplant chapter for details on this process. The successful outcome of a deceased donor renal transplant requires that both the donor and the recipient have undergone adequate evaluation and selection. These processes strive to identify which organs and which patients will be best suited for the endeavor of transplantation.

Recipient Selection

Patients who undergo deceased donor renal transplant have by definition failed to secure a living donor for renal transplantation. Deceased donor candidates are referred for renal transplant and depending upon the transplant center's evaluation process will undergo a variety of medical tests to determine the patient's relative fitness for transplantation. See the chapter on recipient selection and the evaluation process for more details.

What can patients do to receive a kidney transplant sooner?

Kidneys are procured from a variety of donors with a variety of medical backgrounds and social situations. For instance, recently the opioid epidemic has resulted in an increase in drug related deaths and an accompanying increase in the availability of deceased organ donors. Patients on the kidney transplant waiting list may potentially shorten their waiting time by consenting to accept kidneys from a variety of donors.

1. Some deceased donors are designated Public Health Service (PHS) increased risk. PHS increased risk is assigned to donors that have a possible risk of acquiring an infection as a result of their lifestyle or their mechanism of death (e.g., from a drug overdose). Any donor considered to have a risk of infection from hepatitis B, hepatitis C, or HIV will be defined as PHS increased risk. Such donors may have a sexual history that increases their risk of infection, or have been incarcerated, or have used IV drugs. These donors undergo nucleic acid testing to rule out infection with viruses; the tests are not perfect, but they are extremely sensitive. After testing negative, these patients are still at higher risk of transmitting a viral infection than a donor without that history, **however the risk of transmitting infection is still extremely low**. The infectious risk is much lower than the health risk of staying on dialysis. We encourage patients to consent to receive a PHS increased risk kidney, which may shorten their time on the waitlist.

2. Most kidneys are procured from brain dead donors, but an increasing number are being procured from donors whose heart has stopped beating before procurement, called deceased after cardiac death (DCD) donors. Kidneys from DCD donors have an increased risk of delayed graft function (continuing dialysis within one week after the transplant), but overall have good outcomes. Accepting DCD kidneys can increase the number of patients transplanted.
3. High KDPI kidneys. Although transplant professionals cannot predict with certainty which procured kidneys are likely to do better than others, there are ways to estimate the outcome of patients who receive different kidneys. For instance, we expect a kidney from an 18 year old that died in a car accident is more likely to last longer than a kidney from a 65 year old that died of a stroke. The Kidney Donor Profile Index (KDPI) is a score assigned to each individual kidney that predicts the organ quality. The score ranges from 1% (the best) to 100% (the least good). Factors determining the score include donor age, race, history of hypertension or diabetes, cause of death, creatinine, and if they are a DCD donor. The majority of kidneys with KDPI between 0 and 20% function for over 11 years, with KDPI 21-85% about 9 years, and with KDPI over 85% more than 5 ½ years. For some patients, such as those who are older or who have comorbidities that make them at higher risk for continuing on dialysis, it may be advantageous to consent to accept a high KDPI kidney which will shorten their waiting time and get them off dialysis sooner. It has been shown that receiving a high KDPI kidney confers a survival advantage over staying on dialysis for such patients. Patients will be asked to give consent to receive a transplant with a kidney having a KDPI greater than 85%.
4. Patients with untreated hepatitis C may receive a kidney from a donor who died and also had a hepatitis C infection. The hepatitis C can then be treated after the patient has received a kidney transplant. If a patient's hepatitis C is treated before transplantation, they are not eligible to receive a hepatitis C positive kidney. It is important that each ESRD patient makes an individualized decision with his nephrologist, liver specialist, and transplant center regarding the decision to treat hepatitis C before or after transplantation. Receiving a hepatitis C positive kidney can shorten a patient's time on the waiting list, as hepatitis C kidneys may otherwise go unused.
5. Patients with controlled HIV may undergo successful renal transplantation. Some transplant centers are participating in a research study to transplant HIV positive kidneys into HIV positive patients, rather than discarding them. This kind of transplant was legalized by passage of the HIV Organ Policy Equity (HOPE) act in 2013. Receiving an HIV positive kidney can shorten the waiting time for patients with HIV.

Organ Acceptance Phase and Pre-Transplant Preparations

After a potentially acceptable deceased donor kidney offer is received from the United Network for Organ Sharing (UNOS), the center will enter a provisional "yes" until further information is obtained. There are two categories of deceased donors, those that have undergone brain death but whose hearts are still beating (donation after brain death DBD), and those whose organs are procured only after the heart has stopped beating (donation after cardiac death, or DCD donors).

After a kidney donor and potential recipient are identified the transplant center will need to confirm that the ABO blood types are compatible, and that there are no concerning HLA (human leukocyte antigen) antibodies in the recipient against the donor's kidney. The reason for the antibody test is to determine if the kidney can be safely transplanted; if there are circulating antibodies present, they can immediately bind to the kidney and cause a severe "hyperacute" rejection, graft thrombosis and graft loss. The transplant center may often receive HLA information regarding the transplant donor, including a blood

sample, before the kidney is removed from that donor in a procurement operation, which will allow time to complete the HLA compatibility testing.

If HLA testing and information about the procurement are acceptable, the transplant center will “accept” the offer and the patient will be prepared for surgery. Transplant centers will typically prepare the patient for surgery well before the organ is “accepted.” The patient is admitted to the transplant center’s hospital and the confirmatory HLA testing is obtained. The patient’s recent history will be reviewed, a physical exam performed, and blood and x-ray testing performed. Sometimes the patient is found to have an active medical issue and cannot be transplanted on that day; if so, the operation will be cancelled and the next patient on the list will be offered the kidney. The patient may require dialysis prior to transplantation depending on the patient’s dialysis schedule, and the physical exam and lab results. For instance, if the patient has signs of fluid overload, or a significantly elevated potassium level, urgent dialysis will be performed. If the patient is found to be healthy enough to undergo the procedure, the patient will not be permitted to eat within six to eight hours before surgery. The risks of kidney transplantation are always discussed with the patient, and informed consent is always obtained prior to the transplant surgery.

Kidney Transplant Surgery

Pre-Transplant Kidney Preparations and Cold-Ischemia Management

Most deceased donor kidneys are stored using a cold storage solution, which is instilled into the kidney at the time of the procurement operation, before the kidney is placed inside a cooler for transportation. Sometimes kidneys are also placed on a perfusion pump. A perfusion pump is used by some transplant centers to reduce the risk of delayed graft function (DGF). DGF means that the patient requires dialysis after the transplant surgery, since the kidney has not yet started to work well enough to allow the discontinuation of dialysis therapy. The practice of using perfusion pumps to prevent delayed graft function varies across the United States.

Common risk factors for DGF are kidneys with greater than 18 hours of cold ischemic time (the time the kidney has been stored cold since being removed from the donor’s body), kidneys from older donors, kidneys from deceased after cardiac death (DCD) donors, and kidneys transplanted into patients who have been on dialysis for many years. Delayed graft function occurs in about 25-30% of all recipients of deceased donor kidneys (and about 2-4% of living donor kidneys). Patients who experience delayed graft function will usually go on to have a kidney that functions well.

Transplant Surgery

The nursing team and the transplant teams will confirm that the patient and the kidney have the correct identifying information, including blood types and results of the final crossmatch. The patient will be placed on the operating table, and intravenous and intra-arterial catheters will be placed, as will be a catheter into the urinary bladder. General anesthesia is required for this surgery. An antibiotic will be given to address possible skin bacterial contamination. The surgical incision is in the lower abdomen, either on the right or the left. The peritoneal sac is pushed to the side, and the artery and vein going to/from the leg (usually the external iliac artery and vein) are identified. The kidney is placed, the artery and vein are attached, and then the vascular clamps are released, so that the kidney receives blood and it is assured that there is no leaking of blood. Then the ureter is sewn into the wall of the bladder. Many surgeons leave a temporary stent in place to protect the ureteral implantation. The incision is then closed, layer by layer.

Recovery from Kidney Transplantation

After kidney transplantation, the patient may be in the hospital 3-7 days, or longer if complications occur. Kidney function and other lab work will be measured daily, and ultrasound of the kidney will likely be performed. If there is concern about the blood flow to the kidney, other tests may be needed. Urine output will be carefully monitored. About 25-30% of deceased donor transplant recipients will need to continue dialysis for a period of time after the surgery because of delayed graft function (DGF). In spite of this delay in function, most of these kidneys will recover and have good function in the coming months and years.

Before discharge, the patient must have return of bowel function (have a bowel movement), adequate pain control with oral medications, financial and social support for taking all prescribed medications, good blood pressure control, and acceptable laboratory studies.

Complications After Kidney Transplantation

Kidney transplantation is generally a safe procedure with one-year patient survival rates greater than 95%. Given the co-morbid conditions from which renal failure patients suffer, these good outcomes cannot be assumed; complications do happen, even in apparently healthy recipients.

Common Complications

Pain: Almost all recipients of renal transplants will experience postoperative pain. Patients will receive a combination of intravenous and oral pain medicine after transplantation, and almost all patients will continue to require some amount of oral pain medicine after discharge from the hospital, but usually only for 1-2 weeks.

Gastrointestinal problems: This complication is manifested commonly as nausea and constipation; vomiting is much less common. Bowel rest, anti-emetics, and time will help restore bowel function. Upon return of bowel movements, bouts of diarrhea are not uncommon. Diarrhea is often a side effect of the immunosuppressive medications, especially mycophenolate mofetil. Provided infectious sources are excluded, diarrhea can be controlled with anti-diarrheal medications.

Delayed Graft Function (DGF): Approximately 30% of deceased donors and 2-4% of living donor renal transplant recipients will require dialysis in the first 7 days after transplantation. DGF does not dramatically impact the long-term function of the transplant, however, careful medical management is important as the kidney recovers function.

Acute Rejection: Approximately 10-20% of kidney transplant recipients will experience acute rejection in the first post-transplant year. Acute rejection may be asymptomatic, or patients may experience fever and/or pain over the transplant. If acute rejection is suspected a transplant biopsy is necessary.

Social and Medication Access Challenges: The sudden nature of the call for transplantation may make it harder for the patient to adjust to their new situation and to get their medications, including the prophylactic antibiotics and immunosuppressive medications which can be very expensive. The patient's social support, such as their family, must also suddenly adjust their lives to help care for the patient. In addition, in the first year, the knowledge that someone died to give them a kidney may commonly lead to depression.

Exacerbations of Co-morbid Conditions, Especially Cardiac Events and Diabetes: Up to 30% of kidney transplant recipients can newly develop diabetes after transplant due to the side effects of immune suppressive medications. These medications can also cause hyperlipidemia and hypertension,

which must be treated. Also, the risk of myocardial infarction and congestive heart failure are higher in the months following renal transplantation.

Infectious Complications: Infections happens more commonly after transplantation, in the setting of immunosuppression. Re-activation of cytomegalovirus (CMV), pneumonia from *Pneumocystis* and other opportunistic infections are a risk, prompting most centers to prophylactically treat patients with antimicrobial medications post-transplant, usually for a period of 3-6 months. The risk of bladder infection is approximately 10%. Skin infection and surgical site infections can also occur.

Less Common Complications

Vascular problems: Recipients may experience hemorrhage around and/or clotting involving the transplant kidney. These problems often require prompt re-operation and blood transfusions. Patients with a known hypercoagulable state will require anticoagulation during surgery. A thrombosed kidney that cannot be salvaged will be removed. Patients who lose their transplants in the immediate post-operative period will maintain their original place on the waiting list, if they recover well and are still an acceptable candidate for transplant.

Malignancy: Transplant recipients are at increased risk for cancer when taking immunosuppression. The risk of cancer is slightly greater than the general population. Non-melanoma skin cancer, such as squamous cell or basal cell carcinoma, are common. Transplant patients should have regular screening examinations by a dermatologist. Lymphoma occurs in about 2% of kidney transplant patients. However, any other cancer can happen, necessitating regular surveillance. It is recommended that national cancer screening guidelines be followed.

Chapter 3: Living Kidney Donation

Author: Sumit Mohan, MD, MPH

Approximately one third of kidneys that are transplanted in the United States today are from living donors and include both donors who are related and unrelated to the transplant recipient.ⁱ In 2015, 5626 living donor kidney transplants were performed in the United States. While this was a slight improvement over 2014, living donation rates remain below the peak of 6647 transplant performed in 2004 – despite a rapidly growing number of people waitlisted for kidneys.

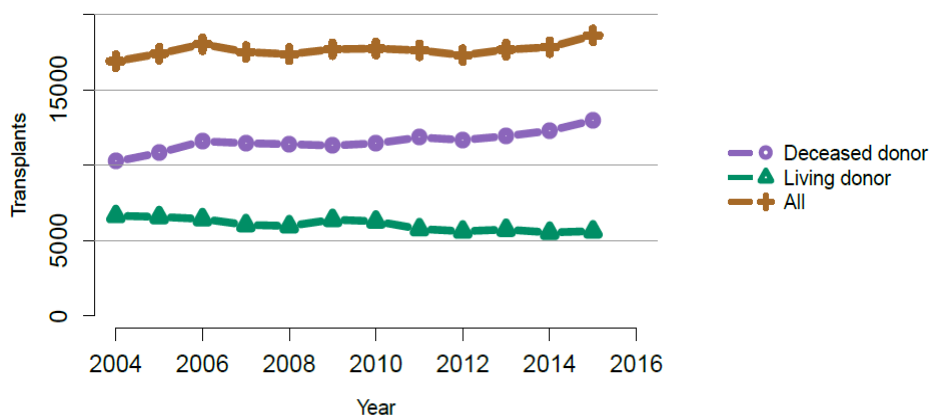


Figure 1: Number of kidney transplants over time in the United States (source: OPTN/SRTR 2015 Annual Data Report. HHS/HRSA.)*

Living donor transplants are the preferred form of kidney transplantation because of the significantly better outcomes for patients. Patients who receive kidneys from living donors tend to do much better than those who receive kidneys from deceased donors.

Who can donate?

Most healthy individuals in the United States have two kidneys and are potential kidney donors. Currently, more than half the donors across the country are women and the number of older individuals who are donating has been increasing steadily.

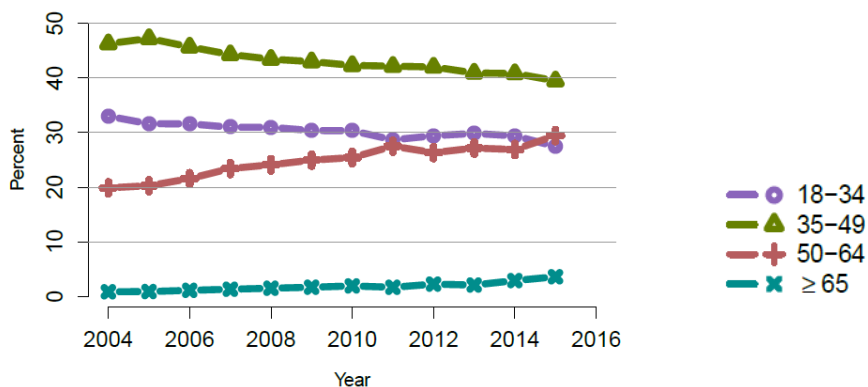


Figure 2: Number of donors across different age groups in United States (source: OPTN/SRTR 2015 Annual Data Report. HHS/HRSA.)*

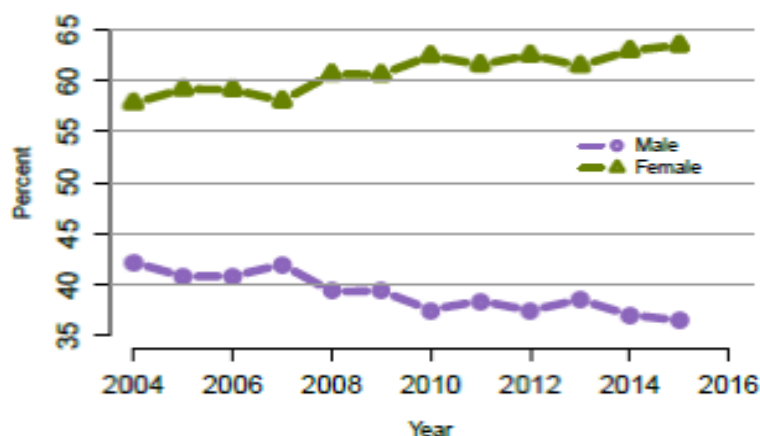


Figure 3: Number of male and female living kidney donors in United States (source: OPTN/SRTR 2015 Annual Data Report. HHS/HRSA.)*

Donor Nephrectomy (or kidney removal from a donor)

Donor nephrectomy is an extremely safe surgical procedure. One measure of complications following surgery is the need for readmission to the hospital after surgery within 30 days. Readmission rates following kidney donation in the first 30 days are lower than those seen following cholecystectomies, appendectomies and even surgery where a kidney is removed for other reasons, such as kidney cancer. Currently 97% of all donor nephrectomies are performed using laparoscopy that results in a small incision and quick recovery times. Compared with donor nephrectomy using a flank incision, which was used in the past, laparoscopic surgery is generally associated with less pain/discomfort in the immediate post-operative period, shorter hospitalizations and a much more rapid recovery for the donor. Most living donors can expect to be discharged 2-3 days after surgery and can return to work in approximately 4 weeks – and sometimes sooner depending on the type of work.



Figure 4: Types of living donor nephrectomy in the United States over time (source: OPTN/SRTR 2015 Annual Data Report. HHS/HRSA.)*

Loss of Kidney Function

Assuming that both kidneys of a potential donor are equal in size, the left kidney is preferentially removed. The blood vessels to the left kidney are longer, making it easier for the surgeon to remove and transplant this kidney. Sometimes donors may have unequal size kidneys or may have more than one set of blood vessels supplying a kidney. In these cases, the smaller kidney is usually removed (to allow the donor to keep the larger kidney) or the kidney with fewer blood vessels. In individuals with equal size kidneys, compensatory increase in filtration in the remaining kidney results in an increase in the glomerular filtration rate (the measure of kidney function) thus resulting in a loss of only approximately 25-30% of kidney function after donation, rather than 50% of kidney function. Individuals who donate a kidney also do not have an increased rate of decline in renal function over time.

Types of Living Donor

Living kidney donors do not have to be related to the potential recipient. As a result, donors can be biologically related (parent, child, sibling, etc.) or biologically unrelated (spouse, friend, acquaintance such as a fellow church member). Occasionally individuals may step forward to donate a kidney without knowing a person who needs a kidney. These individuals are referred to as “altruistic” donors.

Compatibility and Donor Swaps

In the majority of transplants performed in the United States, both the recipient and the donor have the compatible blood types. In cases where the donor and recipient have different blood types, transplantation can still move forward in one of two ways. Blood group incompatible transplants are performed at some transplant centers for low risk individuals. For the majority of cases where the blood groups are different, a donor swap is the recommended approach. In a donor swap, two donor-recipient pairs that have different blood groups come together and exchange donors. For example, the donor from the first pair will donate to the recipient from the second pair, while the donor from the second pair will donate a kidney to the recipient from the first pair. This exchange results in both donors donating a kidney and both recipients receiving a compatible kidney transplant and is thus sometimes referred to as a “paired donation” or “paired exchange” transplant. There has been a dramatic growth recently in the number of transplants that have resulted from donor swaps in the United States.

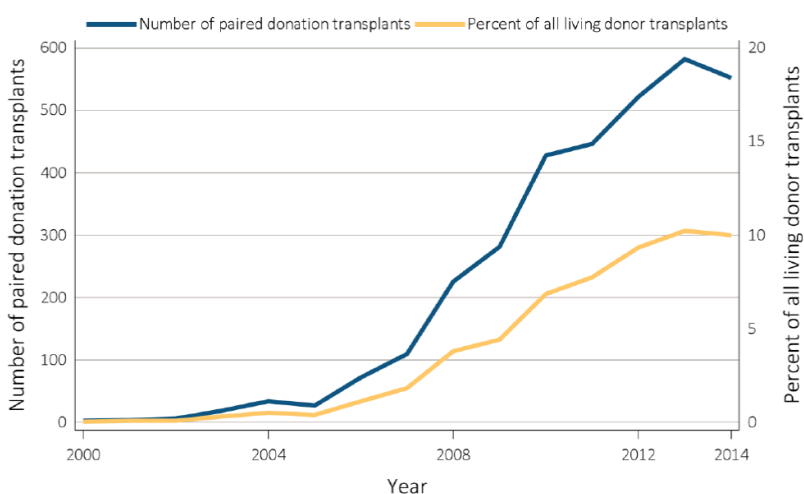


Figure 5: Increasing Number of living donor swaps in the United States (source: OPTN/SRTR 2015 Annual Data Report. HHS/HRSA.)*

Screening Living Donors

Most transplant centers have center specific guidelines that attempt to identify individuals at an increased risk of developing kidney disease in the future in order to keep them safe and preclude them from donation. In order to be considered a candidate for donation, individuals must be able to provide informed consent. In addition, several other factors are considered in the evaluation of an individual prior to donation

1. Renal Function

Individuals with > 90 mL/min/1.73m² are considered candidates for donation while those < 60 mL/min/1.73m² are not. For those with renal function between these two levels, an individual clinical decision needs to be discussed with the transplant center. Renal function used in the assessment needs to be measured at least once given the wide variation noted with current GFR estimates.

2. Protein in the urine (proteinuria)

Patients with significant proteinuria are not considered candidates for donation. Individuals with very small amounts of albumin in the urine may be considered acceptable donors at some transplant centers

3. Hematuria (blood in the urine)

The presence of microscopic hematuria i.e., blood in the urine that is not visible to the naked eye, is usually considered as acceptable for a kidney donor, especially if a reversible underlying etiology can be identified. A kidney biopsy may be done on a donor with microscopic hematuria to rule out significant underlying kidney disease.

4. History of kidney stones

Individuals with kidney stones who want to donate should be evaluated in the context of the likelihood of recurrence of kidney stones and its attendant complications. A single isolated instance of a kidney stone in the distant past, for example, would not be a reason to rule out a potential donor, if medical evaluation shows that they are at low risk for developing another stone. Individuals who have previously had bariatric surgery need to be screened for the risk of recurrent nephrolithiasis.

5. Hypertension

The presence of hypertension is not an absolute contraindication for organ donation at this time at most centers. However, hypertension that is difficult to control, associated with end organ damage, or occurs in individuals with an elevated lifetime risk of ESRD can rule these individuals out as potential donors. For example, African Americans are at increased risk for kidney disease; African Americans with hypertension are usually not candidates to be organ donors.

6. Obesity

Given the increasing prevalence of obesity and overweight individuals, this is a common consideration when evaluating donors. Obesity is not considered an absolute contraindication. However, there is an independent association between obesity and ESRD prompting most transplant programs to decline organ donation from individuals with a body mass index (BMI) of > 35 Kg/m². Some centers may choose stricter criteria. Transplant centers often require obese potential donors to lose weight prior to organ donation based on the total lifetime risk of ESRD.

7. Glucose intolerance

Diabetes is an absolute contraindication for kidney donation. Individuals, particularly those who are overweight or obese, should be screened for glucose intolerance which would be predictive of developing diabetes in the future. Individuals with an elevated risk of developing diabetes are

ruled out at most centers. Occasionally, these individuals may be counseled on the increased risk of diabetes and a decision to allow donation taken in the context of their overall long-term risk of ESRD, or after they are able to lose weight and improve the results of their glucose tolerance.

8. Smoking

Given the association of smoking with progressive renal injury, cardiovascular disease and peri-operative complications, potential donors should be strongly encouraged to quit smoking for an extended prior to organ donation. Some centers require donors to complete stop smoking prior to donation.

9. High Risk Behavior

Individuals who have been approved for organ donation should be screened for high risk behaviors that increase their risk of acquiring transmissible infectious diseases such as HIV, Hepatitis B, and Hepatitis C. Individuals who engage in high risk behavior should at the very least abstain from these behaviors prior to organ donation for an adequate duration, to allow nucleic acid testing to be performed prior to transplant and adequately rule out the transmission of these viruses.

10. Cancer

Individuals with active malignancies are precluded from donation. Individuals with certain cancers that are at high risk of transmission (e.g. malignant melanomas) even after treatment are also precluded from donation, while those that are low risk (e.g. squamous or basal cell carcinoma of skin) can donate after adequate treatment.

11. Genetic testing

Some centers will offer genetic testing on a case by case basis for individuals who are thought to be at increased risk of having a predisposition for genetic forms of kidney disease or may be carriers for mutations that increase their risk of kidney disease. Individuals with ApoL1 risk variants may be at increased risk for end stage renal disease following donation, but currently there are no definitive agreed upon data on the magnitude of this risk.

Long Term Consequences of Living Donation

Kidney donation is considered to be quite safe for most individuals with few, if any, long term risks. Major complications post donation are relatively rare events. Concerns for potential donors include:

1. Risk of end stage renal disease

The risk of end stage renal disease following donation remains very small. For example, the 15-year risk of ESRD for a 40 year old varies by race and gender (table 1).

Table 1: 15-year projection of ESRD risk for a 40 year old donor

40 year old	Risk of ESRD without donation
Black male	0.24%
Black female	0.15%
White male	0.06%
White female	0.04%

Lifetime risk of ESRD decreases among older donors on account of the shorter periods that these individuals are at risk. Black individuals have a significantly higher risk of developing end stage renal disease.

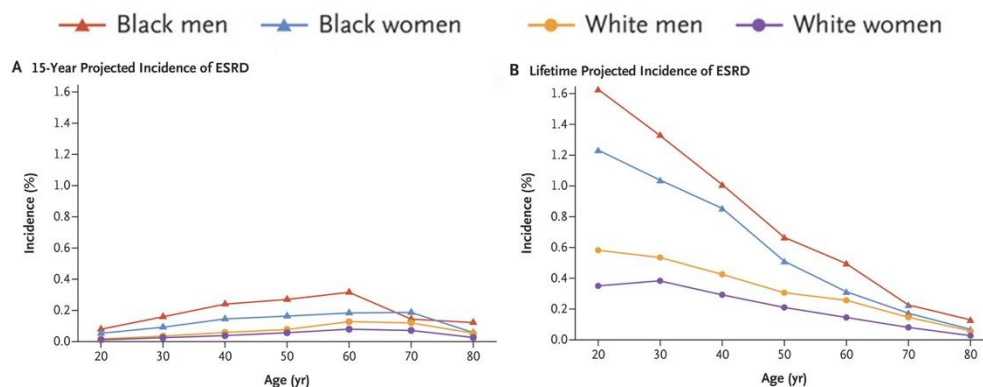


Figure 6. 15-year (A) and lifetime (B) projections of ESRD incidence in the United States by age, race, and sex.

From *New England Journal of Medicine*, Grams ME, Sang Y, Levey AS, Matsushita K, Ballew S, Chang AR, Chow EK, Kasiske BL, Kovesdy CP, Nadkarni GN, Shalev V, Coresh J, Lentine KL, Garg AX; Chronic Kidney Disease Consortium. *Kidney-Failure Risk Projection for the Living Kidney-Donor Candidate*. 2016 Feb 4;374(5):411-21. Copyright ©2016 Massachusetts Medical Society. Reprinted with permission.

2. Proteinuria

After kidney donation there appears to be a small increase in protein excretion over time, but this proteinuria appears to be associated with the hemodynamic consequences of the increase in filtration seen in the remaining kidney and does not appear to have the same adverse consequence of proteinuria seen in individuals with chronic kidney disease.

3. Hypertension

The development of hypertension appears to be common after kidney donation with approximately 50% of donors developing hypertension approximately 40 years after donation in one cohort. Hypertension after donation is often also associated with the development of trace urinary albumin excretion.

4. Gout

Kidney donation appears to increase the risk of gout in susceptible individuals. In a recent retrospective study from Canada, there was a 1.6 fold increase in the incidence of gout compared to healthy controls (3.4% vs 2% of individuals) after 8.4 years of follow up.

5. Gestational hypertension and pre-eclampsia

A recent study of a small cohort of Canadian women who donated a kidney were found to have a small increase in the risk of gestational hypertension or pre-eclampsia, particularly if the donor did not have a prior pregnancy or were older than 32 years of age at the time of the pregnancy. Of note, the majority of the study participants reported a significant family history of kidney disease and there was no adverse impact on the duration of pregnancy or on birth weight.

6. Life expectancy

Kidney donors do not appear to have a decrease in the overall life expectancy or quality of life.

7. Becoming a living donor

Patients who have relatives or friends who are interested in becoming a living donor should ask the prospective donor to contact the transplant center directly themselves. Traditionally contact is by phone, but many transplant centers are using a website that the prospective donor can use. The web site may ask questions regarding medical history to screen for eligibility. Transplant centers keep the donor evaluation confidential and separate from the recipient evaluation.

8. Further reading

For more detailed information regarding screening living donors for transplantation see Locke JD and Sawinski D. Evaluation of Kidney Donors: Core Curriculum 2018. Am J Kidney Dis. 71(5):737-747, 2018.

*The data and analyses reported in the 2016 Annual Data Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients have been supplied by the United Network for Organ Sharing and the Minneapolis Medical Research Foundation under contract with HHS/HRSA. The authors alone are responsible for reporting and interpreting these data; the views expressed herein are those of the authors and not necessarily those of the U.S. Government.

Chapter 4: Educating Dialysis Patients Optimally About Transplantation and Living Donation

Amy D. Waterman, PhD, John D. Peipert, Amanda F. Lipsey, MFA, Christina Goalby, MSW, Catina O'Leary, PhD

There are more than 500,000 patients who receive dialysis for kidney disease in the United States,¹ and each of these patients deserve to know about all their end-stage renal disease (ESRD) treatment options and have the help they need to make the best decisions for themselves. It is particularly important for them to learn about renal transplantation. Deceased donor kidney transplant (DDKT) and living donor kidney transplant (LDKT) offer much better length and quality of life compared to remaining on dialysis.¹⁻³ It is now widely accepted that LDKT is the ideal treatment option for most kidney patients. Relative to DDKT and dialysis, LDKT yields superior graft, patient survival, and improved quality of life.^{1,3,6}

Patients not informed about transplant in dialysis centers are over 50% less likely to get on the transplant waitlist or receive an LDKT.⁸ Research has shown that many dialysis patients never pursue transplant at all or discontinue the process once started⁷ due to difficulties in completing the transplant medical work-up or finding potential living donors.

To adequately educate all kidney patients about transplant, information should be provided as early as possible in their chronic kidney disease (CKD) trajectory.⁹ Deciding about whether to get a transplant is very complex. Transplant discussions should include the patient, their family and friends, and any potential living donors. Kidney patients who are less ready to pursue transplant¹⁰⁻¹² and who have poorer transplant knowledge¹³ may particularly benefit from starting education earlier.

Thus, to ensure that all eligible dialysis patients make informed transplant and LDKT choices, this chapter will examine challenges to education and pursuit of transplant in dialysis centers; make recommendations on how best to educate patients using established best practices in behavioral change, health literacy, and cultural competency; and provide a list of transplant resources to use when creating educational programs within dialysis centers.

Challenges to Education and Pursuit of Transplant in Dialysis Centers

There are many challenges to delivering transplant education in dialysis centers today. First, significant racial and socioeconomic disparities in transplant remain. Despite a higher prevalence of CKD in Black and Hispanic patients, they are less likely than White patients to receive transplants, especially LDKTs.¹ Also the annual number of living kidney donor transplants in the United States has recently declined, with a more pronounced rate of decline for non-White, low-income, and older transplant candidates.¹

Compared to White patients, Black patients:¹

- Are 3.1 times more likely to develop ESRD
- Have a 40% lower overall transplant rate and a 75% lower LDKT rate

Compared to Non-Hispanic patients, Hispanic patients:¹

- Are 1.3 times more likely to develop ESRD
- Have an 8% lower overall transplant rate and a 25% lower LDKT rate

There are also many issues affecting whether dialysis patients receive transplant education, begin evaluation for transplant, or whether they successfully receive one. Studies have shown that patients feel very uncomfortable asking others to be living donors.^{14,15} Mistrust of healthcare providers is also more

common for Blacks than Whites,¹⁶ which may affect their trust in physicians' recommendations for LDKT and cause suspicion of LDKT itself.¹⁷ Additionally, Black kidney patients are more likely to have illnesses that run in families like diabetes and hypertension, reducing the likelihood of locating potential living donors within their families.¹⁸ Hispanic and Asian patients may face language barriers that prevent them from completing the transplant evaluation process or receiving transplants.¹⁹ More broadly, many socioeconomic factors have been demonstrated to impede progress toward transplant; one study found that patients of higher socioeconomic status were over 75% more likely to receive LDKTs than their lower socioeconomic status counterparts.²⁰ Specific socioeconomic barriers include less comprehensive health insurance,^{10,21,22} lower educational attainment,²⁰ higher rates of poverty and unemployment,^{20,21,23-25} and greater distance to the transplant center from the patient's home.^{20,25}

Patients also face many barriers to learning what they need to know to make an informed decision about transplant. These barriers can include not having enough time or information available or not understanding the information they have.³³ In addition, while transplant discussions should include the patient, their family and friends, and any potential living donors, all these individuals are not usually present in dialysis or transplant settings.

Finally, providers in dialysis centers have reported not having enough time to educate or educational resources to distribute to their patients.²⁶

Readiness Challenges and Recommendations for Delivering Transplant Education

In addition to general challenges to delivering transplant education, individual patients also vary in how interested and ready they are to pursue transplant evaluation or living donation. For example, one dialysis patient might be very motivated to get a transplant as soon as possible and sees dialysis as an interim step in care, while another is only slightly curious about transplant because they have made dialysis work for their lives. These two patients will respond differently to a health educator discussing DDKT or LDKT as possible treatment options.

Currently, most providers educate these patients in the same way, taking an action-oriented approach to discussions by recommending that all patients "start transplant evaluation" or "find a living donor." Depending on their level of readiness, some patients can hear these recommendations for actions as very stressful, even impossible to do, and need other types of educational support.²⁷

However, there is an evidence-based approach to guiding conversations related to health care decisions that honors all patients and can be applied to decisions surrounding renal transplantation. The Transtheoretical Model (TTM) of behavior change holds that not all patients are immediately ready to pursue changes, such as transplantation, and that educational interventions must be targeted to a patient's individual Stage of Readiness, addressing their fears, increasing their perceptions of the benefits of change and their self-efficacy to do so.²⁸

Research based in the TTM has found that patients move through distinct Stages of Readiness in their decision-making about whether to get a DDKT or LDKT over time. For example, a patient who is just thinking about whether to get an LDKT when first starting dialysis, a stage called Contemplation, might become more or less motivated to get an LDKT based on how well dialysis is going over the next year and whether a family member expresses interest in donating to them. Tailoring communications to a patient's Stage of Readiness allows providers to engage the entire population of eligible kidney patients, particularly those of racial or ethnic minority groups and at-risk patients who are less likely to have received transplant education in the decision-making process. It also ensures that patients are not pressed to take actions before they are ready, which is key to reducing resistance and compliance issues. Patients

who receive educational messages tailored to their readiness stage have twice the chance of taking a health behavior in the following six (6) months compared with patients receiving general health recommendations.^{28,29}

A Guide to Discussions and Resources about Transplant and Living Donation

To know which stage of change for DDKT and LDKT each patient is in, you first will need to have the patient complete a validated assessment of readiness and interest in taking small transplant action-oriented steps. Table 1 outlines the questions to ask and the answers that define a patient's Stage of Readiness for pursuing DDKT and LDKT. Note that patients may be in different stages of readiness for the two different transplant options. For example, they may be in Action for DDKT but in Precontemplation for LDKT. The table lists these stages in order from the earliest levels of readiness (Precontemplation) to the latest (Action/Maintenance). It is important to notice that LDKT does not have a Maintenance stage. An assessment of an individual patient's willingness to take a variety of smaller transplant-oriented actions towards DDKT and LDKT should also occur, as shown in the table.

Table 1. Measuring Stages of Readiness for DDKT and LDKT

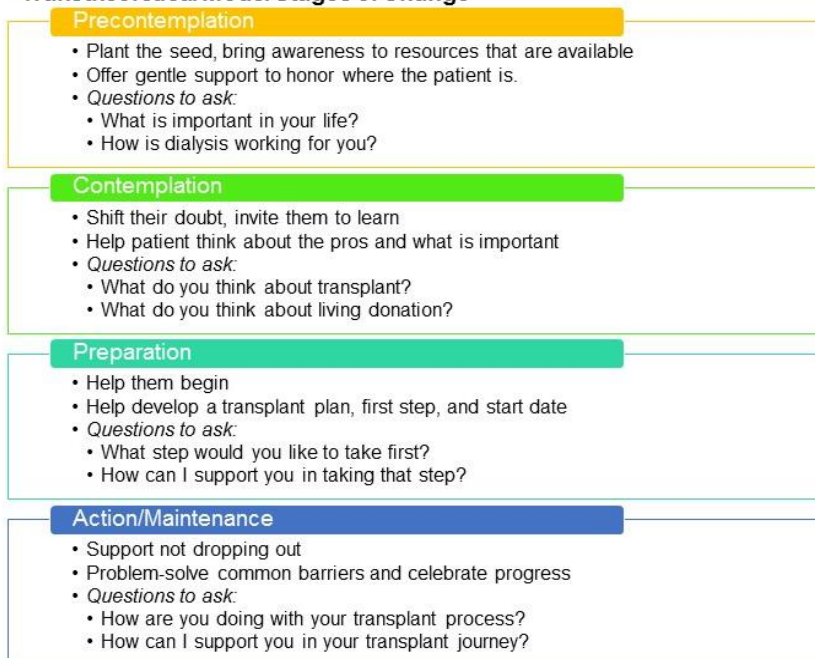
Readiness Measure Questions to Ask	Deceased Donor Kidney Transplant	Living Donor Kidney Transplant
	To get a deceased donor transplant a person needs to be: (1) willing to accept a kidney from a deceased donor, and (2) evaluated and eligible for transplant. Based on this, how ready are you to get a deceased donor transplant?	To get an LDKT a person needs to be: (1) willing to accept a kidney from a living donor, (2) evaluated and eligible for transplant, and (3) have identified a matching, eligible donor. Based on this, how ready are you to take actions to pursue living donation?
Stage of Readiness Patient is in:	Patient Answers which Statement Below is Most True for Them	
Precontemplation	I am not considering getting a deceased donor transplant in the next 6 months	I am not considering taking actions in the next 6 months to pursue living donation
Contemplation	I am considering getting a deceased donor transplant in the next 6 months	I am considering taking actions in the next 6 months to pursue living donation
Preparation	I am preparing to get a deceased donor transplant in the next 30 days	I am preparing to take actions in the next 30 days to pursue living donation
Action	I am undergoing transplant evaluation to get a deceased donor transplant	I am taking actions to pursue living donation

Maintenance	I am listed and waiting to get a deceased donor transplant	-
Interest in Small Steps toward Transplant Questions to Ask	For each action, tell me if you have: already done this, are planning to do this, or don't plan to do this. Do you plan to...	
Small Steps Patient May be Interested in Taking <i>*This step may be taken for either DDKT or LDKT.</i>	<p>Read information/watch videos about getting on the deceased donor waiting list</p> <p>Share educational materials about deceased donation with people in your life</p> <p>Generally, talk to people you trust about whether to get a deceased donor transplant</p> <p>Call the transplant center to pursue evaluation*</p> <p>Complete and mail back the transplant center's new patient medical forms*</p> <p>Invite someone to come to evaluation with you</p> <p>Come to the transplant center to complete medical tests*</p> <p>Follow-up with transplant coordinator until transplant evaluation is complete*</p>	<p>Read information/watch videos about getting a living donor transplant</p> <p>Share education materials about living donation with people in your life</p> <p>Generally, talk to people you trust about whether to get a living donor transplant</p> <p>Make a list of people who might be a living donor for you</p> <p>Ask another person to tell others about your need for a living donor transplant</p> <p>Ask potential donors to be tested</p> <p>Give potential living donors the transplant center phone number</p> <p>Share my need for a living donor with a large community (e.g., Facebook, Twitter, etc.)?</p>

The assessment at the start of a transplant educational session allows you to individually tailor what you say and do next to honor where a patient is in their readiness and empower them in learning or taking transplant actions. Figure 1 gives examples of general educational approaches and questions to ask for patients at each Stage of Readiness.

Rather than being action-oriented and recommending that all patients pursue transplant, in this approach, you would recommend different actions based on where a patient is in their Stage of Readiness. For example, if you know that a patient is in Contemplation, then the focus of discussion should be on the advantages of transplant (e.g., the pros) and whether these would add anything to the specific patient's quality of life. In contrast, a patient in Preparation would need support in calling the transplant center to begin evaluation and completing the transplant medical forms.

Figure 1. Transplant Education Approaches for Each Transtheoretical Model Stages of Change



For patients in all Stages of Readiness, assistance with taking any transplant-related actions they plan to do, as indicated in the assessment, is also recommended. This could take several meetings. For patients who are more interested in pursuing transplant, especially LDKT, continued support and counsel over time is required to help overcome challenges to finding the right transplant center, completing transplant evaluation, potentially locating a living donor, and figuring out how to manage the costs associated with transplant. Even if a patient does not express immediate transplant interest, repeating this readiness assessment at least yearly is necessary to monitor whether there are any changes in DDKT and LDKT interest since the previous assessment.

Finally, it is important to encourage the patient to share transplant educational resources with anyone who helps them make important health decisions. Providers should help them identify who those people are and recommend that these individuals learn about DDKT and LDKT with the patient. In this way, one or more potential living donors may be located and educated as well.

Health Literacy Challenges and Recommendations for Delivering Transplant Education

In addition to honoring a patient's Stage of Readiness and interest in taking specific transplant actions, it is critical that patients have the opportunity to make an informed decision after learning all the facts about the risks and benefits of DDKT and LDKT. This is a complex task. In addition, different dialysis centers use different combinations of transplant educational resources. Patients learn most effectively when they have access to many different sources and types of educational resources, including websites, brochures, videos, and discussions with providers and people who have received transplants.

The American Society of Transplantation (AST) recommends that transplant education programs include:

- Multiple transplant education meetings for kidney patients over the course of their disease

- Standardized content that includes risks and benefits of living donation, fears and concerns, and stories about real-life donor and patient transplant experiences
- Support for LDKT as the best option for most transplant candidates and reflect this philosophy in educational processes
- Training for kidney candidates and their caregivers on how to find living donors
- Discussion of alternative LDKT programs such as paired exchange and desensitization.
- Discussion of financial costs of transplant and donation and resources available to assist if needed
- More culturally tailored education to racial/ethnic minority patients, with historically lower LDKT rates, and their support systems
- Phone numbers of all transplant centers in their referral area

Regardless of which program or resources are used, an important way to help combat the barriers to patients learning about transplant is to make the information as health literate as possible. The definition of health literacy is an open debate in the field,³⁰ as many factors play into any given health situation and can affect someone's ability to understand, remember, and act on the information they get. A useful way to think about health literacy is as an intersection of factors that affects the capacity of people to find, understand, evaluate, communicate, and use health information.

Decades of research have helped health communicators build a set of evidence-based strategies to use when communicating verbally or developing written material. These strategies extend into ways to simplify the processes and spaces where health communication takes place. While health literacy was once thought of as an individual's inability to understand, we now know that health care systems and professionals have a large part to play in health literate communication around transplant.

For example, the complexity of the U.S. health care system and health insurance system places a variety of demands on a person, such as the need to follow complicated policies and procedures, navigate the health care environment and physical space, and understand health information that constantly changes. These barriers can be reduced by designing information, forms, and signs to help kidney patients know where to go for care and how to navigate the transplant process. Even decorating the dialysis or transplant center space in ways that contribute to patient well-being may help lower stress that makes understanding more difficult.

Health care professionals often communicate both verbally and nonverbally in ways that make understanding more difficult, whether it is because they use complex language or do not focus on the most important pieces of information first. Providers can contribute to better understanding by using simple verbal and written strategies, such as explaining medical terms in simple language, focusing on only three main points, having a specific piece of information they want a patient to walk away with, and having patients "teach-back" information in their own words to help check for understanding.

People also vary greatly in their capacity to process the information they receive and may face a variety of barriers related to their reading skills, verbal communication, confidence, emotions and attitudes, and knowledge of health and kidney disease. The average American reads at only a 7th grade reading level (about the level of a Harry Potter novel), while most health education is written at a 12th grade level or above. This is compounded by the fact that our reading levels and ability to understand information is lower when we are under large amounts of stress, such as when we are diagnosed with a chronic and potentially life-threatening disease. One way to help people access information is to provide information in multiple formats, including videos and other multimedia formats. Another strategy is to increase provider awareness of the challenges that patients have around health literacy and improve verbal communication during healthcare appointments, including responding with empathy to patients' emotions and helping to lower a broad spectrum of communication barriers.

An additional consideration is the influence of cultural barriers on understanding. A culturally competent organization is “one that acknowledges and incorporates—at all levels—the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs.”³¹ Many patients need certified translators and educational resources in other languages. They may also need special attention to cultural health practices and beliefs that may influence their access to services or ability to engage in self-care. These influences may be even more profound in settings that involve outside people, such as asking someone to be a living donor or to care for them after transplant. The most important takeaway for providers about cultural competence is that they need to work to understand the cultural needs of the populations they frequently serve and how those practices or beliefs may influence health care conversations. They also want to make sure that they have access to educational resources and content in multiple languages for all their patient communities.

A recent AST Consensus Conference recommended that LDKT education be repeated at multiple points throughout the kidney disease progression.³² It was also recommended that the field produce simple, well-validated, engaging educational tools, build patients’ and potential living donors’ knowledge, readiness, and actions taking small steps towards LDKT over time, and disseminate education widely.

Three examples of health literate programs that honor these recommendations and that have been previously endorsed by the Forum of ESRD Networks are the Explore Transplant-Explore Living Donation programs (<https://exploretransplant.org>),³⁴ the UNOS Kidney Transplant Learning Center (<https://transplantliving.org/kidney/about-the-kidney-transplant-learning-center/>), and My Transplant Coach (<https://mytransplantcoach.org/#/>).³⁵ These programs have undergone multiple rounds of health literacy review to ensure that the content:

- Is modular and structured in a way that builds both comprehension and motivation to act
- Includes a balanced representation of the risks and benefits of DDKT and LDKT
- Uses language that is clear, simple, and conversational
- Integrates simple design elements using technology to aid in comprehension
- Includes videos and animation for patients with low health literacy
- Contains fully-vetted, evidence-based health information with the most current research available
- Provides decision aids to help patients make the right decision for themselves

Explore Transplant is a series of education programs that has helped tens of thousands of kidney patients nationwide make an informed choice about their treatment options. The centerpiece of the program is a series of four videos that guides patients through their transplant decision-making process. The Explore Living Donation Education Program helps kidney patients and healthcare providers make informed decisions about whether to receive a living donor kidney transplant and offers practical strategies to find a living donor. It also educates potential living donors and recipients about the risks and benefits of donating a kidney. Both programs include print materials, medical information presented by transplant professionals, and video storytelling sharing recipient and donor experiences with transplant and LDKT. Both programs are available in English and Spanish.

The UNOS Kidney Transplant Learning Center is a national collaboration of experts from leading universities, hospitals, and organizations, including the Forum of ESRD Networks, who have shared their clinical expertise and educational content. The online educational tools include a series of modules to allow patients, donors, and their social networks to move from learning more basic facts about transplant to specifics about how to find a living donor. This online education resource has different modules for both kidney patients and potential living donors.

My Transplant Coach is an interactive, online, video-based decision aid to help patients and families learn about dialysis and kidney transplant. It uses animated videos and personalized graphs to help patients understand what treatment options are available, so they can make informed renal replacement decisions that are right for them.

In addition, a comprehensive list of free online kidney and transplant educational resources for patients and donors is included in Table 2.

Table 2. Kidney and Transplant Online Resources

Kidney Disease Websites		
American Association of Kidney Patients	www.aakp.org	Provides advocacy, education, and interaction for kidney patients
Centers for Medicare & Medicaid Services (CMS)	www.cms.gov/Center/Special-Topic/End-Stage-Renal-Disease-ESRD-Center.html	Provides resources to compare dialysis facilities and learn about Medicare coverage for End-Stage Renal Disease (ESRD)
Kidney School	www.kidneyschool.org	Features educational models for patients and providers about kidney disease and its treatments
National Kidney Foundation	www.kidney.org	Official website of the National Kidney Foundation, a U.S. organization dedicated to the awareness, prevention and treatment of kidney disease
PKD Foundation	www.pkdcure.org	Offers comprehensive information about polycystic kidney disease
Renal Support Network	www.rsnhope.org	Provides non-medical services to those affected by chronic kidney disease, including education about transplantation
General Kidney Transplant Websites		
Explore Transplant	www.exploretransplant.org	Supports patients and kidney care providers with education programs and training seminars
Transplant Recipients International Organization	www.trioweb.org	Provides education about transplantation in general, as well as financial issues around transplantation
United Network for Organ Sharing (UNOS)	www.unos.org	Provides information and data about transplants, the waiting list, and transplant centers

UNOS Kidney Transplant Learning Center	www.transplantliving.org/kidney/about-the-kidney-transplant-learning-center/	Leaders from leading universities and hospitals share their clinical expertise and educational content with the public to help patients and potential live donors make informed decisions
U.S. Dept. of Health & Human Services	www.organdonor.gov	Provides comprehensive information about organ donation and transplantation
Ascent to Transplant	www.ascenttotransplant.org	Patient stories regarding transplantation and Staff education regarding transplantation and the Kidney Allocation System
iChoose Kidney	www.ichoosekidney.emory.edu	Calculator to compare patient survival with kidney transplant or with dialysis
My Transplant Coach	https://mytransplantcoach.org/#/	An interactive decision aid to deliver tailored transplant education that's optimized for mobile devices
Living Donation Websites		
Alliance for Paired Donation	www.paireddonation.org	Links transplant candidates with matching potential living donors and provides education about paired donation
Living Donation California	www.livingdonationcalifornia.org	Provides education designed for potential living donors who have not identified a specific recipient
Living Donors Online	www.livingdonorsonline.org	Provides information related to living donation for patients, medical professionals and the public
National Kidney Registry	www.kidneyregistry.org	Links transplant candidates with matching potential living donors and provides education about paired donation
Renewal	www.life-renewal.org	Provides education, referrals, and logistical support to Jewish patients seeking and receiving living donor transplantation or living donors
UNOS Kidney Paired Donation Pilot Program	https://unos.org/donation/kidney-paired-donation/	Provides information about kidney paired donation and about the Kidney Paired Donation Pilot Program

Living Donation Storytelling Library	www.explorelivingdonation.org	A library of video stories about living donation in the voices of donors, patients, and family members.
Help Finding a Transplant Center		
Organ Procurement and Transplantation Network (OPTN)	https://optn.transplant.hrsa.gov/	Provides a Member Directory that allows patients to search for nearby transplant centers
Help Paying for a Transplant or Living Donation		
American Living Organ Donor Network	www.helpivingdonorssavelives.org	Provides resources to help people make informed decisions about living donation; provides financial and informational support for living donors
American Kidney Fund	www.kidneyfund.org	Educates patients about financial support for treatment, medication, and surgery costs
American Transplant Foundation	www.americantransplantfoundation.org	Financially assists with lost wages post-surgery and lack of access to essential medications
National Foundation for Transplants	www.transplants.org	Assists transplant candidates and recipients in raising money for costs not covered by insurance
National Living Donor Assistance Center	https://www.livingdonorassistance.org/Home/default.aspx	Provides financial assistance with travel costs and expenses associated with living organ donation

Conclusions

While transplant education programs within dialysis centers differ, educators will be enabled to have beneficial and effective conversations with patients when they have: (1) access to health literate educational materials and (2) an understanding of the unique Stage of Readiness of each dialysis patient to pursue DDKT and LDKT. This report provides an evidence-based strategy for helping kidney patients access excellent transplant educational resources, make informed treatment decisions, and take actions that are right for them.

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Chapter 5: Financial Toolkit for Dialysis Centers

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Kidney transplantation success is highly dependent on adherence to immunosuppression and follow-up visits, as well as undergoing hospitalizations and interventions to maintain health. However, receiving the kidney transplant and subsequent medical treatments require maintaining insurance premiums, and paying deductibles and co-pays, the cost of which varies widely depending on insurance type. This toolkit was developed with the aim of providing patient-optimized insurance recommendations that will allow patients to receive a kidney transplant and the post-transplant care they need with the lowest patient cost. Since this toolkit was developed to help dialysis staff help patients, our recommendations are aimed at patients who are already on dialysis.

At the time of kidney transplantation, approximately 60% of recipients are covered by Medicare, 30% of patients have private insurance, and 6% have Medicaid.¹ Almost 100% of ESRD patients will eventually enroll in Medicare when their coordination of benefits ends. (When two insurance plans work together to pay claims for the same person, that is known as the Coordination of benefits period or the COB. The COB begins the first month that the individual is eligible for Medicare, even if he/she has not enrolled.) The best time to enroll in Medicare will depend on each individual. There are many contributing factors that could influence the time a patient enrolls in Medicare. A flow chart of insurance coverage plan recommendations is provided in Figure 1. The rationale for these recommendations, and tips for enrolling in Medicare (when the time comes) is written below. When discussing health coverage with a potential dialysis and or transplant patient, it is imperative that the patient be realistic about their current financial situation. By comparing their current out of pocket cost for their health care premium, and co-pays for services and medications, the patient must decide what plan is most affordable, while offering them the most complete effective coverage.

Patients with Medicare Only

ESRD patients with Medicare only, should obtain Medicare A, B, D and a supplemental plan before transplantation for the best coverage. If the only reason a patient has Medicare is because of ESRD, their Medicare coverage will end 3 years after the kidney transplant. If a patient is 65 or older, or has another qualifying disability, their Medicare will continue as long as they meet Social Security criteria.

What the Different Parts of Medicare Cover

Medicare Part A:

- Covers inpatient needs.
- Is free to those who have paid taxes for a minimum amount of time.

Medicare Part B:

- Covers outpatient needs. For ESRD patients, it could include immunosuppression medications for life if Medicare Part A was in place, or retroactive prior to the transplant date, if the transplant occurred in a Medicare-approved facility, and if the patient was enrolled in Part B at the time the immunosuppression claim was processed. If Part B criteria are not met for immunosuppression coverage, then Part D is the responsible payer; however, coverage is not guaranteed, depending on the insurance carrier and plan chosen.
- In 2019, monthly premiums for Part B are \$135/month, as long as the income in 2016 was less than \$107,500 for a single person, more for a married person. Premiums are billed quarterly and can be

paid directly to the Social Security Administration by those patients that are not receiving Social Security benefits or deducted from monthly Social Security benefits of eligible patients.

Medicare Part D:

- Covers prescription drugs.
- In 2019, the monthly premium ranged from \$13-\$92/month. Medicare.gov provides a program for patients to research plans in their region of the country based on their zip code. The website will provide information on available prescription drug coverage, carriers and monthly premiums for each.

Supplement Plan:

- Depending on plan chosen, a supplemental plan could cover copays under part A and B, and deductibles. This may include Medicare Part B copays such as the 20% co-insurance for immunosuppressive therapy, skilled nursing facility care copays, Medicare Part B excess charges, foreign travel emergency services, and Hospice care.
- Supplemental coverage plans or “MediGap” plans are only available to patients enrolled in Original Medicare A&B (Medicare Advantage members cannot enroll in a supplemental plan).
- Supplemental Plans consist of A, B, C, D, F, G, K, L, M, and N.
- The cost of a Supplemental Plan will vary depending on the county and state in which the patient resides. Medicare.gov provides a simple program for patients to research plans in their region of the country based on their zip code. The website provides plan choices and carrier contact information. For example, in Erie County, the cost of a supplemental plan can vary from \$51 to \$356/ month depending on the plan chosen and the carrier. It is important to note that all the plans within the plan type have the exact same coverage, but the carrier cost can vary.

Medicare Advantage Plans

Patients that have enrolled in a Medicare Advantage Plan could have been enrolled through their former employer, as a retirement plan, or by their own choice. Medicare Advantage Plans follow Medicare guidelines, and cover everything original Medicare covers. For many patients, a Medicare Advantage plan is a financially sound decision. However, Medicare Advantage plans are not always the best insurance choice for ESRD patients. Often the plans have high office visit, dialysis, testing, and inpatient copays. It is also important to keep in mind that since Medicare Advantage plans follow Medicare guidelines, post-transplant patients will incur a 20% co-insurance for their transplant immunosuppression medications. This 20% is the undiscounted retail cost of the medications, which a transplant patient needs in order to maintain their new organ. These medications alone could cost hundreds of dollars on a monthly basis. Unlike straight Medicare, a Medicare Advantage holder cannot acquire a supplemental plan to offset these Part B medication costs. Medicare Advantage plans may also have limits on which hospitals or providers are considered to be "in-network".

The decision to keep the Medicare Advantage plan, or change to straight Medicare A, B, D, and a supplemental, will need to be weighed by each patient individually. Open enrollment to change to straight Medicare usually runs from the middle of October to the beginning of December. Note that the straight Medicare plan will not become effective until January 1st, after open enrollment ends.

Retiree Medicare Advantage Plan:

- If a patient has a Medicare Advantage plan, as a retiree benefit, there is usually no monthly premium. As a result, it may not be advantageous for these patients to drop the free policy, and in turn have to pay out of pocket for Medicare B, D, and a Supplemental. Again, each policy needs to be looked at individually, and a decision needs to be made based on cost and services. The monthly

20% out of pocket cost for immunosuppression medication is something the patient may be able to afford since they are not paying monthly premiums, or could financially prepare to pay, for example by fundraising.

Patient's Choice to have Medicare Advantage Plan:

- Individuals who choose a Medicare Advantage Plan generally choose them because of the lower monthly premium. The Advantage Plan covers everything Medicare covers, as previously mentioned, however, these plans usually have higher overall copay costs, which becomes evident for ESRD and post-transplant patients. Insurance premiums, dialysis, physician, and inpatient copays, as well as monthly 20% co-insurance copays for immunosuppression medications and other prescription copays, could run hundreds of dollars a month. For these reasons, an ESRD patient should be urged to switch to straight Medicare A, B, D, and a supplemental during open enrollment. The total monthly premiums for straight Medicare coverage will be higher, but the overall out of pocket cost for services and medications will be less.

No Insurance Coverage

If an ESRD patient has no insurance at the time they go on dialysis, a patient will need to enroll in Medicare A, B, D, and a supplemental plan, or apply for Medicaid. If they have worked sufficient quarters with Social Security withholdings on their pay (the number of quarters varies with the age of the patient), they will qualify. However, if they have not worked sufficient quarters, Medicare will be denied.

Commercial Insurance

Patients may have commercial insurance through their own, or their spouses' employer. Commercial coverage will sufficiently cover inpatient needs (like Medicare Part A), outpatient needs (like Part B) and prescriptions if there is a prescription plan (like Part D). A patient can sign up for Medicare any time after the 1st day of the fourth month they started dialysis, or in the case of peritoneal dialysis, the month of starting peritoneal dialysis. The decision to sign up with Medicare immediately, or wait until the coordination of benefit period ends, is a decision the patient will need to weigh. Every commercial policy has its own unique benefits, and coverage information should be verified. Important questions to ask a carrier include: possible annual deductible, co-pays for dialysis treatments, inpatient stays, office visits, and medications, as well as limits to in-network providers, facilities, and pharmacies. Please note that if a commercial plan has high prescription copays, there may be copay cards available to assist patients with non-Medicare coverage. (Prescription copay assistance cards are prohibited by Federal regulations for use by Medicare patients). It would also be beneficial to have a patient speak to their employer to see if there is a possibility to up-grade coverage to a better plan. All in all, a commercial policy is usually sufficient for ESRD patients. There would be no need to apply for Medicare immediately, and endure additional coverage costs for Part B.

Eventually, after 30 months of dialysis, a patient will be required, by their commercial carrier, to enroll in Medicare. After the coordination of benefits period is over, the commercial insurance will see themselves as secondary payer, and Medicare will become the primary insurer. As secondary payer, the commercial insurer has the right, and almost always will, *only* cover the 20% copays that Medicare does not cover. When the coordination of benefit period ends, it is highly recommended that the patient sign up for both Medicare Part A and B. Even though B will have a monthly premium fee, it is best to enroll in A and B at the same time to avoid gaps in coverage, and a late enrollment penalty in the future. Medicare Part D is not needed if the commercial plan has pharmacy benefits. It is important to note that adding Medicare coverage only changes the enrollee's benefits. Other family members covered under the commercial policy, will not be affected.

There are 3 reasons to consider enrolling in Medicare A&B before the coordination of benefit period ends. If the copays for the commercial insurance are more than \$135 per month, if the commercial insurance is a Cobra plan, and if the patient has a living donor, then an ESRD patient should consider enrolling in Medicare early. Enrollment in Medicare is not automatic. On the 1st of the 4th month of dialysis patient's become eligible for Medicare coverage, and patients can enroll at any time before their enrollment period ends.

High co-pays:

- If an ESRD patient has commercial insurance, and their copays are more than \$135 a month, they should strongly consider immediately signing up for Medicare A and B as a secondary coverage. Medicare will assist with the cost of copays, deductibles and co-insurance. Again, there is no need for Medicare Part D, if the commercial plan has a prescription coverage. The commercial insurance will remain primary payer until the coordination of benefits period ends. After that, Medicare will flip to become primary, and the commercial become secondary automatically.

Cobra:

- Cobra is a temporary extension of an employee's health coverage. For example, if a patient loses their employer sponsored health benefits, they may qualify for Cobra. Cobra costs are high, and the insurer will be responsible for 102% of the premium, which includes the 100% of the cost of the coverage, plus 2% administration fee.
- Due to high premium costs and a limited time of coverage, dialysis patients, who are the sole beneficiary of the policy, are strongly urged to enroll in Medicare A, B, D, and Supplemental Plan as soon as possible. The cost of Medicare B, D and supplemental would be less than the cost of their Cobra plan. In addition, the patient will not need to worry about running out of benefits. The patient will be entitled to Medicare, as long as payments are made, the whole time they are on dialysis, and up to 3 years post-transplant.
- If the Cobra plan covers other family members, the patient may want to keep the Cobra plan as primary and add Medicare A and B as secondary. In this case, the patient would continue to pay the monthly Cobra, and part B premium. Medicare would be seen as secondary payer. It is important to note that an employer can terminate Cobra coverage, after they learn that Medicare has been acquired. If this occurs, the patient will need to add Medicare Part D, a supplemental plan, and find coverage for the family. The other option currently available is to find an affordable plan on the state's health coverage exchange website. It is important to keep in mind to seek out the best affordable coverage which provides manageable copays.

Living Donor:

- If a patient has a living donor, they will need to acquire Medicare A&B prior to transplant. The Medicare coverage will cover their donor for any donor related complications for the rest of their life.

Medicaid

A patient with Medicaid should continue with the Medicaid only for as long as possible. It will cover all inpatient and outpatient copays at 100%, and patients are only responsible for a copy of up to \$1 for generic medications, and up to \$3 for brand prescriptions. Of course, the state would prefer the patient to enroll in Medicare as soon as possible, alleviating the state's responsibility for medical payments. However, when the patient enrolls in Medicare, they will then incur fees for Medicare part B, and D. At the end of the 30 month coordination benefit period, a patient will have no choice, and will need to sign up with Medicare part A, B, D. If they are able to keep Medicaid as a secondary, a supplemental plan is not needed. Patients with low incomes may be eligible for state assistance to pay for Medicare part B, D.

In New York State there is a NY Qualified Medicare Beneficiaries program, and an Elderly Pharmaceutical Insurance Coverage program. Other states may have similar programs. More information can be found on the Medicare.gov website.

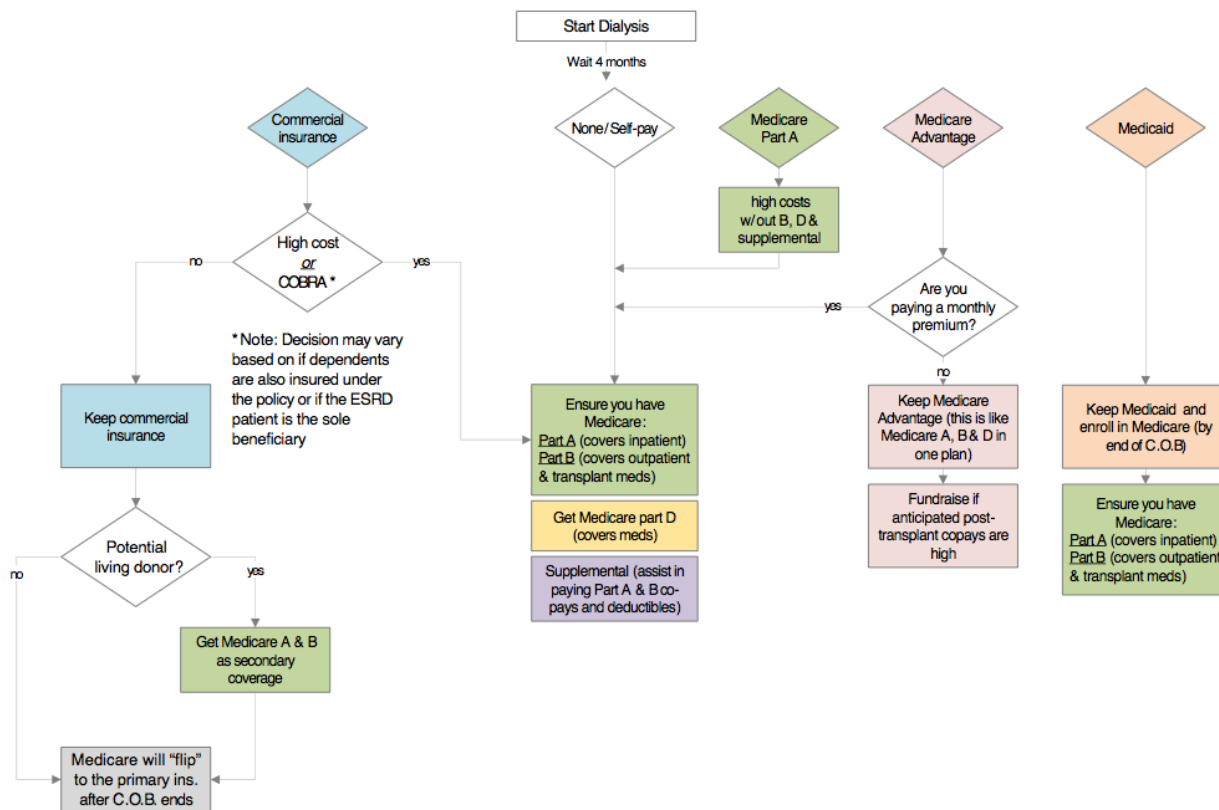
This guide is meant to assist ESRD patients in choosing the best insurance coverage available, with the least out of pocket expense. Maintaining a transplant could prove to be financially devastating. It is our hope that these suggestions could ease their financial burdens and maintain a healthy organ.

Endnotes

1. ScientificRegistryofTransplantRecipients.2015AnnualDataReport.
<http://www.medicare.gov/pubs/pdf/10050-Medicare-and-08.pdf.Pages58-59>. Accessed June 13, 2017.

Insurance Coverage Recommendations

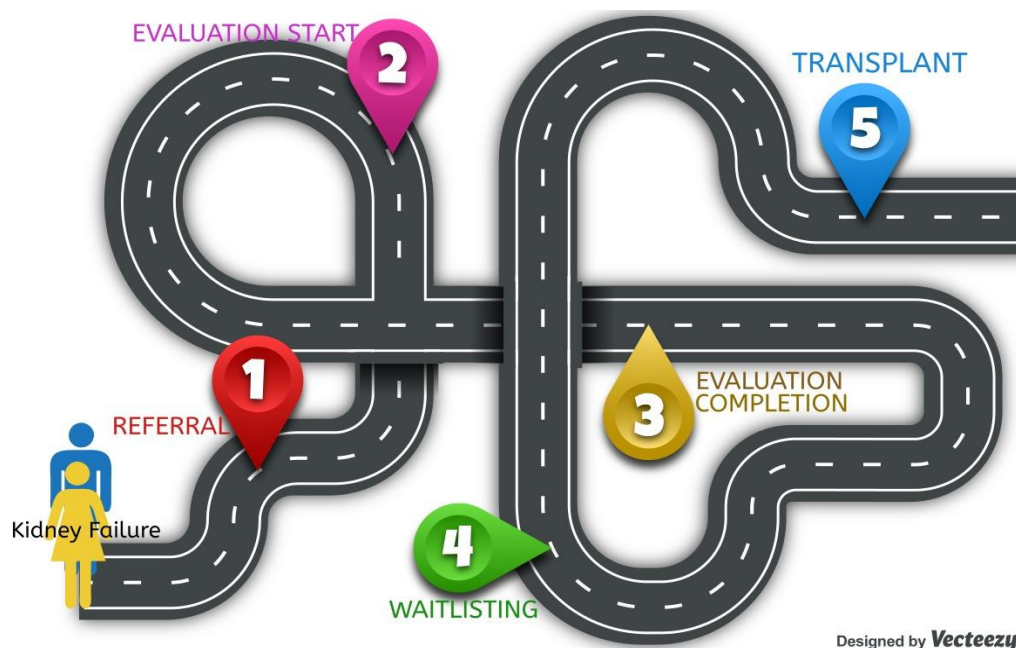
for people who are pursuing transplant and are likely to get listed and transplanted



Chapter 6: The Role of the Dialysis Unit Beyond Education: Successful Care Coordination to Achieve Success in Transplant

Author: Jennifer Gander, PhD, MPH

The road to kidney transplantation can have many twists and turns, with patient-specific barriers. The road to kidney transplantation can be confusing for the patient, their caregiver, and anyone assisting them along the way. The following chapter provides a guide on how you can help your patients overcome their barriers and achieve a kidney transplant.



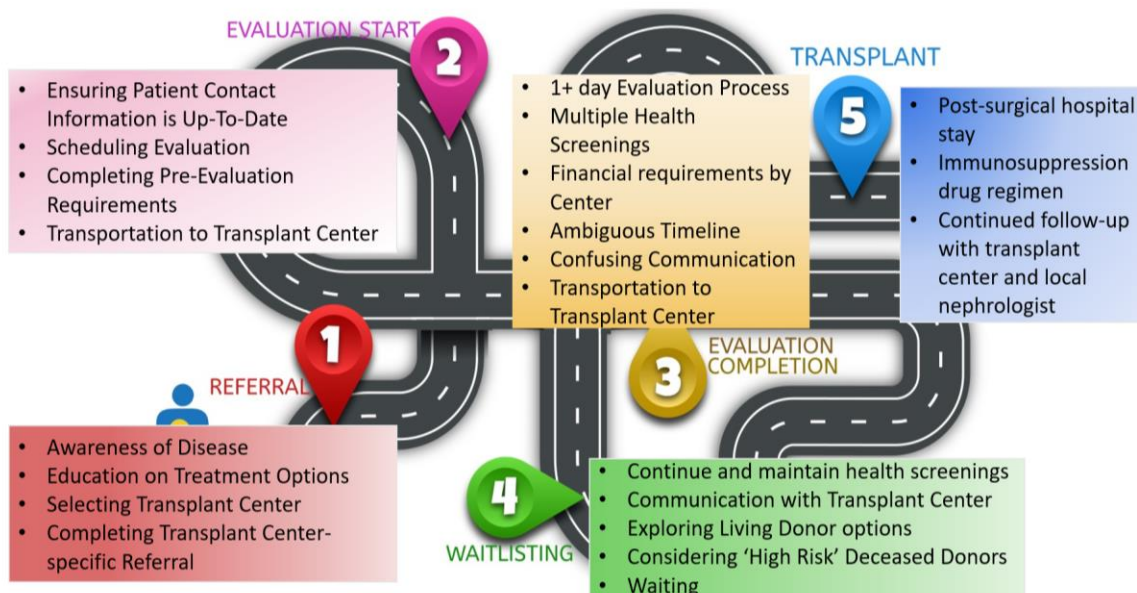
How You Can Help Your Patients Achieve a Transplant

Dialysis units have been frequently described as an ESRD patient's "medical home". Most dialysis patients receive their renal replacement therapy within dialysis facilities and spend more than 12 hours a week in their dialysis facilities.

Although kidney transplantation decreases patient mortality and hospital costs, and CMS requires treatment modality education for all dialysis patients, one in three new dialysis patients report not having had education about renal transplantation.

Your role in a patient's care coordination goes beyond education on transplant. Transplant is a complicated and (usually) long journey for a patient. There are several steps, shown below on the road map, that a patient must complete before progressing to the next step. Each step has its own requirements and challenges.

The (rocky) Road to Kidney Transplantation



Possible Barriers to Kidney Transplantation that Create a (Rocky) Road to Transplant

Consider yourself a very important source of support that helps a patient navigate the kidney transplantation process. Your roles may include:

- Discussing eligibility for transplant with the patient and nephrologist
- Choosing a transplant center to refer the patient for evaluation
- Sending blood to the transplant center's HLA lab
- Ensuring patient insurance is up-to-date
- Certifying the patient's vaccinations are current
- Assisting with transplant evaluation and pre-transplant testing
- Helping the patient maintain overall good health prior to transplant through preventive medicine and adequate dialysis

In a recent report from a focus group of 40 ESRD patients, 2 themes emerged that patients were asking for:

1. Patients were requesting more comprehensive information on kidney transplantation that is easy to understand
2. Patients look to dialysis unit staff for encouragement and advocacy related to their treatment options

Everybody Needs a Cheerleader

The following sections will review available resources that dialysis unit staff can use to help their patients through the transplant process, while providing encouragement to pursue the treatment option that is best for them. While we acknowledge that this chapter does not provide a comprehensive list of patient and staff resources on transplant, we prioritize the transplant resources that could provide the most benefit to your patients and minimize the time burden placed on you and your staff.

Kidney Transplant Education Video for Dialysis Unit Staff

The ASCENT (Allocation System Changes for Equity in kidney Transplantation) Project is intended to educate patients, their families, and dialysis staff about kidney transplantation.

Researchers have developed a short, 10-minute video that walks dialysis unit staff through the process of kidney transplantation while providing some suggestions of common barriers to kidney transplantation. While the video does not offer a detailed account for the kidney transplantation process, which may vary between transplant centers, the video does provide a step-by-step overview for transplant. The short video can be viewed during a 'Lunch and Learn' or could be shown during staff's annual review. We encourage all dialysis staff to watch the video.

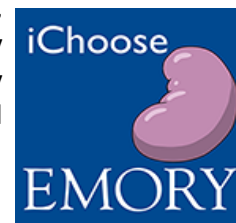
<http://ascenntotransplant.org/for-dialysis-facility-providers-and-staff/#staff-video>



iChoose Kidney: Helping healthcare providers communicate ESRD treatment options

iChoose Kidney is a patient-specific risk calculator that can be used by physicians, social workers, nurses, or the dialysis units Transplant Champion. iChoose Kidney assists healthcare providers in discussing the benefits and risks of kidney transplantation and living donor kidney transplantation compared to dialysis and deceased donor transplantation.

Free for download and use: <http://ichoosekidney.emory.edu/>



How to use iChoose Kidney

1. Download iOS app or website
2. Select to display patient survival or patient mortality risk
3. Healthcare provider enter in the patient's characteristics
4. iChoose Kidney will display the chance for patient survival between:
 - dialysis vs transplant
 - deceased donor vs living donor transplantation
5. iChoose Kidney will display the risk for graft failure between
 - deceased donor vs living donor transplantation
6. Interpret the benefits and risk for each treatment option
 - On screen prompts, pictographs, and interpretations are offered to help the healthcare provider accurately interpret the risks to the patient

Please enter patient information at dialysis start

SEX

Male
 Female

AGE AT DIALYSIS START

64 Years

RACE

White
 Black or African-American
 Other

ETHNICITY

Hispanic
 Non-Hispanic

DIALYSIS TYPE

In-center Hemodialysis
 Peritoneal Dialysis
 Home Hemodialysis
 No Dialysis

TIME ON DIALYSIS

< 6 months 6—12 months
 > 1—2 years > 2—3 years
 > 3—5 years > 5—7 years
 > 7—10 years > 10—14 years
 > 14 years

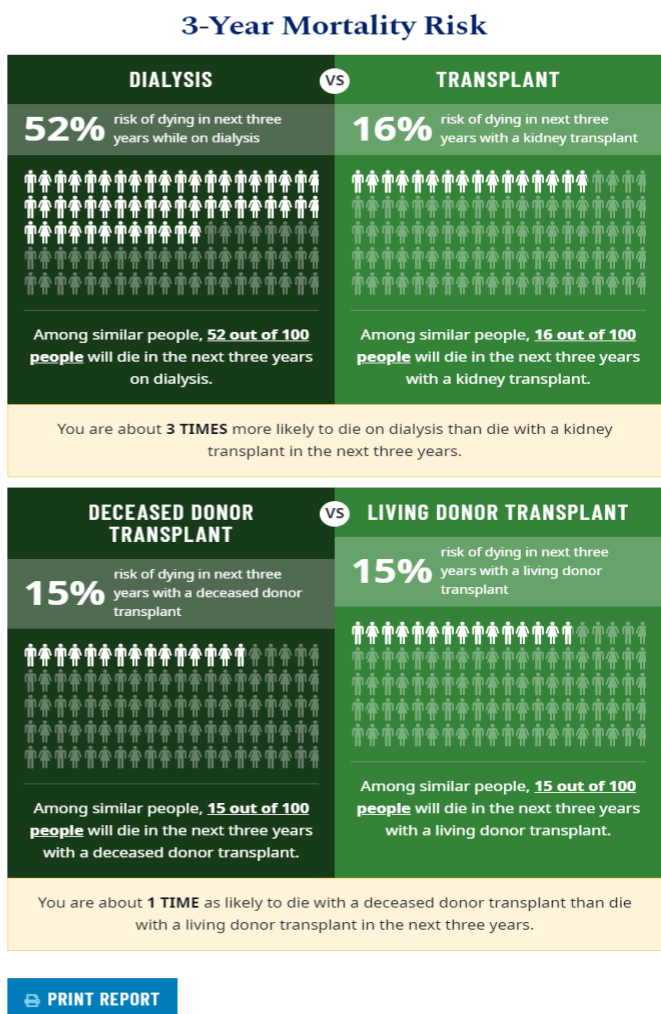
PATIENT HISTORY

Select all that apply:

Hypertension
 Diabetes
 Low Albumin (Less than 3.5 g/dL)
 Cardiovascular Disease

VIEW AS

Mortality Risk
 Survival Benefit



Transplant Champion and Patient Tracking Tool

Dialysis facilities can appoint a Transplant Champion! Although many patients will be the first ones to admit that you have to be a good self-advocate to successfully manage their healthcare, patients also want an empathetic and informative advocate for their healthcare. In the dialysis clinic, a Transplant Champion can be a dialysis facility social worker, nurse, dietician, or patient care technician.

A Transplant Champion is responsible for educating the staff and patients about the benefits of transplant and transplant process. The Transplant Champion would work closely with their local transplant center staff to ensure the ESRD patients in their dialysis unit are progressing through the transplant process

ESRD Network 8 (Tennessee, Alabama, and Mississippi) has developed a [Transplant Champion Handbook](#). The 30-page handbook discusses what a transplant champion is, discusses patient engagement, recent policy changes that may improve a waitlisted patient’s possibility of receiving a deceased kidney, and the option of multiple waitlisting. The handbook can be found here:

<https://esrdnetwork8.org/sites/default/files/TP-3-transplant-champion-handbook-2018.pdf>

Transplant Champions are encouraged to use a **Patient Tracking Tool**. The Patient Tracking Tool can help staff ensure their patients interested in transplant are progressing through the transplant process. The Transplant Champion can periodically update their patients' status and can easily sort by 'Action Needed'

Sample Transplant Tracker

Patient Name	Status	Action Needed	Transplant Center
Patient A	Listed	needs stress test and colonoscopy	Piedmont
Patient B	Listed	active since 12/14/2012	Emory
Patient C	Pt Declines	satisfied with modality	
Patient A	Listed		Piedmont
Patient B	Not Eligible	will refer once insured	
Patient C	Pt Declines	age/hx of cancer	
Patient A	Declined	Needs SARP	
Patient B	Listed		Piedmont
Unit Contacts			
Piedmont Contacts			
Cheryl Manley (A-L)	404-605-4600	404-605-2252	Cheryl.Manley@piedmont.org
Laureen Dame (M-Z)	404-605-4930		
Rochelle Williams	404-605-4284	waitlist coordinator	
Denise Neal	404-605-5360		
Georgia Health Sciences			
Emory Transplant	706-721-2888		
UAB	855-366-7989		
	205-975-9200		

Transplant-Oriented Nutritional Guide

A common contraindication for kidney transplantation is increased body mass index. However, just because a patient may not meet the body mass index criteria when they attend the transplant evaluation appointment, patients can begin a diet plan to achieve the weight loss needed to qualify for a transplant. Transplant centers may offer some information on weight loss, but it may be most effective for the dialysis dietician to follow-up with these patients.

The dialysis dietician is uniquely positioned because the dietician has:

1. An established relationship with the ESRD patient
2. Comprehensive understanding of the patient's history and stability of lab values
3. The opportunity to regularly follow-up with their ESRD patients to ensure the patient is meeting their goals and to trouble shoot any frustrations the patient may be facing.

The dietician is a skilled staff member that can help the patient establish a weight loss plan that will allow the patient to safely achieve their weight loss goals and pursue transplant.

The Transplant-Oriented Nutritional Guide may work best in conjunction with the patient tracker tool. Once the Transplant Champion has alerted the dialysis dietician to a patient's status, the dietician can begin working more closely with the patient on specific weight loss goals

Family and Patient Advisory Councils

A Patient and Family Advisory Council is a formal group of patients, families, and healthcare providers that work together to make policy and program decisions to:

- Enhance quality of care
- Improve patient outcomes
- Increase patient satisfaction

Patient and Family Advisory Councils can alter the expectations of the healthcare professionals based on the patients' expectations. The Council offers a great resource to dialysis staff for ongoing patient and family feedback.

The Nuts and Bolts of the Council Membership: Consists of 8-25 members

1. Members can be...
 - a. Patients
 - b. Family members
 - c. Dialysis staff such as social workers, dietician, technician
2. Should be representative of the patient population based on demographics and clinical characteristics
3. Recruitment
 - a. To recruit patients and family members, post signs on bulletin boards, provide handouts to patients, ask for recommendations from other patients

Meetings

1. It should be noted at the inception that Patient and Family Councils serve as a connection between the patients, families, and staff. The meetings should allow each of the members to be open and honest, while respecting others' experience
2. Structure: Once the Council has been formed, decide how often and the duration of each Council meeting
3. Establish the roles and responsibilities of each Council member
4. Have each member complete Confidentiality Training (HIPAA)

Example Family & Patient Advisory Council from ESRD Network 14 (Texas):

http://www.esrdnetwork.org/sites/default/files/content/uploads/2013/10/PFAC_Facilities.pdf

Dialysis Facility Peer Mentor Program (available as part of the Transplant Toolkit)

The Dialysis Facility Peer Mentor Program is a patient service program. The purpose is to provide confidential, individualized, and one-on-one support for dialysis patients considering kidney transplantation. Peer Mentors are kidney transplant recipients who provide encouragement to dialysis patients and their families considering transplant.

The Peer Mentor Program Toolkit is a 38-page booklet that is intended for dialysis staff to establish their own Peer Mentor Program within their dialysis facility. The Peer Mentor Program Toolkit is available online as part of the Transplant Toolkit.

The Peer Mentor Program Toolkit guides dialysis staff through a

- a. Program description
- b. Successful strategies to recruit, screen, and train a transplant recipient to serve as a peer mentor
- c. Educational resources that the staff can educate the peer mentor, and also that the peer mentor may use with their mentees

Inspirational Patient Video on the Journey to Transplant

The journey to kidney transplantation can feel long, difficult, and lonely.

"I would encourage people to work toward transplant because it is a better life. You still have to take medications to maintain your kidney, but you don't have as many restrictions as you have on dialysis. You get a lot of your life back."



Brenda - Patient

Patients want someone who is empathetic to their struggles. ESRD patients want to know they are not alone and that other people, with similar experiences, have been able to get off of dialysis and improve their life! The ASCENT (Allocation System Changes for Equity in kidney Transplantation) Project developed a 10-minute patient video that provides 5 different patient stories and how they got to transplant. The website also has other resources available for patients, and patient stories to read and share!

The patients' stories are as varied as their demographics. The patients discuss the kidney transplant process and the barriers they faced throughout. The patients offer solutions and encouragement to overcome these challenges. The video is available online for free viewing! See the "For Patients" tab on the Ascent to Transplant Website: <http://www.ascenttotransplant.org>.



DONALD



FRED



DORIS

Have the video playing in the lobby or treatment area so they can watch segments while they wait! Provide the link for patients to watch while they dialyze! Dialysis staff can also schedule a movie night for patients and their families to view the video; consider inviting a transplant recipient to come to this informal support group meeting to share their experience and to answer questions. Patients can also share the link with their friends and family to watch on their own.

"I believe as African Americans, we do not understand how much it means to our community to be a donor. Because we are the ones that have the highest number of kidney disease. Why take these parts with you? There are other people who are waiting to start a new chapter in their life."



Cynthia - Patient

Resources

Attachment A: Transplant Peer Mentor Program: Dialysis Facility Toolkit

Created by Emory University, The Georgia Transplant Foundation, The Southeastern Kidney Council Inc., and the University of South Carolina College of Social Work. Funded through NIH U54 Pilot 2014-1-TCC Pilot

Attachment B: Hall, L., Gore, S., & Witten, B. (2009) Vocational rehabilitation: Is your facility on track? NN&I, Dec 2009, 22-27.

Annotated links:

A comprehensive list of transplant resources is available in Chapter 4, Table 2, pages 29-31 of this Toolkit.

Patient Education CHECKLIST (Coordinated Health EduCation / Kidney LISTing for Transplant): The following Patient Education Checklist has been developed by the Emory Transplant Center and The Southeastern Kidney Transplant Coalition. It contains a list of kidney transplant topics to discuss with patients, with web links to resources available on line. Most of these resources are of general interest to a national audience. A few of the resources, related to The Georgia Transplant Foundation, are only available in Georgia.

<https://med.emory.edu/education/vme/TransplantCoalitionChecklist/index.html>

SSA Publication Red Book, A Summary Guide to Employment Supports for Persons with Disabilities Under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) Programs: This resource serves as a general reference source about employment related provisions on SSDI and SSI for educations, advocates, rehabilitee professionals, and counselors who service individuals with disabilities.

<https://www.ssa.gov/redbook/>

United Network of Organ Sharing Patient Learning Center. UNOS has partnered with leading health education organizations to provide peer reviewed, accurate health information on kidney disease and treatments, including dialysis and transplantation options.

<https://transplantliving.org>

Shared decision tool to educate patients and providers on the survival benefits of transplant compared with dialysis, and of living donor vs. deceased donor transplants.

<https://ichoosekidney.emory.edu>

The Big Ask The Big Give. National Kidney Foundation program to educate patients regarding living donation. Includes videos with patient stories, and resources to help patients learn to ask potential donors for a transplant.

<https://www.kidney.org/transplantation/livingdonors>

Ascent To Transplant website. Provides educational information and videos, for dialysis unit staff and patients, regarding the benefits of transplantation. Discusses the revised kidney allocation system for patients receiving kidneys off the waiting list.

<http://ascenntotransplant.org>