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.
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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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Resources
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.

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

![Graph showing graft survival](image)

**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 removed, 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 Erythematosis 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 and 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 happen 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. 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.)*](image)

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.)*](image)
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.
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 perioperative 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>
<thead>
<tr>
<th>40 year old</th>
<th>Risk of ESRD without donation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black male</td>
<td>0.24%</td>
</tr>
<tr>
<td>Black female</td>
<td>0.15%</td>
</tr>
<tr>
<td>White male</td>
<td>0.06%</td>
</tr>
<tr>
<td>White female</td>
<td>0.04%</td>
</tr>
</tbody>
</table>
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.


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**

*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, 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. 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.

Patients not informed about transplant in dialysis centers are over 50% less likely to get on the transplant waitlist or receive an LDKT. Research has shown that many dialysis patients never pursue transplant at all or discontinue the process once started 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. 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 transplant and who have poorer transplant knowledge 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. 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.

Compared to White patients, Black patients:
- 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:
- 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. Mistrust of healthcare providers is also more
common for Blacks than Whites, which may affect their trust in physicians’ recommendations for LDKT and cause suspicion of LDKT itself. 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. Hispanic and Asian patients may face language barriers that prevent them from completing the transplant evaluation process or receiving transplants. 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. Specific socioeconomic barriers include less comprehensive health insurance, lower educational attainment, higher rates of poverty and unemployment, and greater distance to the transplant center from the patient’s home. 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. 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.

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. 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.

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

<table>
<thead>
<tr>
<th>Readiness Measure Questions to Ask</th>
<th>Deceased Donor Kidney Transplant</th>
<th>Living Donor Kidney Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>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?</td>
<td>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?</td>
</tr>
<tr>
<td>Stage of Readiness Patient is in:</td>
<td>Patient Answers which Statement Below is Most True for Them</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am not considering getting a deceased donor transplant in the next 6 months</td>
<td>I am not considering taking actions in the next 6 months to pursue living donation</td>
</tr>
<tr>
<td></td>
<td>I am considering getting a deceased donor transplant in the next 6 months</td>
<td>I am considering taking actions in the next 6 months to pursue living donation</td>
</tr>
<tr>
<td></td>
<td>I am preparing to get a deceased donor transplant in the next 30 days</td>
<td>I am preparing to take actions in the next 30 days to pursue living donation</td>
</tr>
<tr>
<td></td>
<td>I am undergoing transplant evaluation to get a deceased donor transplant</td>
<td>I am taking actions to pursue living donation</td>
</tr>
<tr>
<td>Maintenance</td>
<td>I am listed and waiting to get a deceased donor transplant</td>
<td>-</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>----------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td><strong>Interest in Small Steps toward Transplant Questions to Ask</strong></td>
<td><strong>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…</strong></td>
<td></td>
</tr>
<tr>
<td>Small Steps Patient May be Interested in Taking</td>
<td><strong>Read information/watch videos about getting on the deceased donor waiting list</strong></td>
<td><strong>Read information/watch videos about getting a living donor transplant</strong></td>
</tr>
<tr>
<td></td>
<td>Share educational materials about deceased donation with people in your life</td>
<td>Share education materials about living donation with people in your life</td>
</tr>
<tr>
<td></td>
<td>Generally, talk to people you trust about whether to get a deceased donor transplant</td>
<td>Generally, talk to people you trust about whether to get a living donor transplant</td>
</tr>
<tr>
<td></td>
<td>Call the transplant center to pursue evaluation*</td>
<td>Make a list of people who might be a living donor for you</td>
</tr>
<tr>
<td></td>
<td>Complete and mail back the transplant center’s new patient medical forms*</td>
<td>Ask another person to tell others about your need for a living donor transplant</td>
</tr>
<tr>
<td></td>
<td>Invite someone to come to evaluation with you</td>
<td>Ask potential donors to be tested</td>
</tr>
<tr>
<td></td>
<td>Come to the transplant center to complete medical tests*</td>
<td>Give potential living donors the transplant center phone number</td>
</tr>
<tr>
<td></td>
<td>Follow-up with transplant coordinator until transplant evaluation is complete*</td>
<td>Share my need for a living donor with a large community (e.g., Facebook, Twitter, etc.)?</td>
</tr>
</tbody>
</table>

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.

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, 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.” 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. 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), the UNOS Kidney Transplant Learning Center (https://transplantliving.org/kidney/about-the-kidney-transplant-learning-center/), and My Transplant Coach (https://mytransplantcoach.org/#/). 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

<table>
<thead>
<tr>
<th>Kidney Disease Websites</th>
<th>General Kidney Transplant Websites</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Association of Kidney Patients</td>
<td>Explore Transplant</td>
</tr>
<tr>
<td><a href="http://www.aakp.org">www.aakp.org</a></td>
<td><a href="http://www.exploretransplant.org">www.exploretransplant.org</a></td>
</tr>
<tr>
<td>Provides advocacy, education, and interaction for kidney patients</td>
<td>Supports patients and kidney care providers with education programs and training seminars</td>
</tr>
<tr>
<td>Centers for Medicare &amp; Medicaid Services (CMS)</td>
<td>Transplant Recipients International Organization</td>
</tr>
<tr>
<td><a href="http://www.cms.gov/Center/Special-Topic/End-Stage-Renal-Disease-ESRD-Center.html">www.cms.gov/Center/Special-Topic/End-Stage-Renal-Disease-ESRD-Center.html</a></td>
<td><a href="http://www.triouweb.org">www.triouweb.org</a></td>
</tr>
<tr>
<td>Provides resources to compare dialysis facilities and learn about Medicare coverage for End-Stage Renal Disease (ESRD)</td>
<td>Provides education about transplantation in general, as well as financial issues around transplantation</td>
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<tr>
<td>Kidney School</td>
<td>Renal Support Network</td>
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<tr>
<td><a href="http://www.kidneyschool.org">www.kidneyschool.org</a></td>
<td><a href="http://www.rsnhope.org">www.rsnhope.org</a></td>
</tr>
<tr>
<td>Features educational models for patients and providers about kidney disease and its treatments</td>
<td>Provides non-medical services to those affected by chronic kidney disease, including education about transplantation</td>
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<tr>
<td>National Kidney Foundation</td>
<td>United Network for Organ Sharing (UNOS)</td>
</tr>
<tr>
<td><a href="http://www.kidney.org">www.kidney.org</a></td>
<td><a href="http://www.unos.org">www.unos.org</a></td>
</tr>
<tr>
<td>Official website of the National Kidney Foundation, a U.S. organization dedicated to the awareness, prevention and treatment of kidney disease</td>
<td>Provides information and data about transplants, the waiting list, and transplant centers</td>
</tr>
<tr>
<td>UNOS Kidney Transplant Learning Center</td>
<td><a href="http://www.transplantliving.org/kidney/about-the-kidney-transplant-learning-center/">www.transplantliving.org/kidney/about-the-kidney-transplant-learning-center/</a></td>
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<td>U.S. Dept. of Health &amp; Human Services</td>
<td><a href="http://www.organdonor.gov">www.organdonor.gov</a></td>
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<tr>
<td>Ascent to Transplant</td>
<td><a href="http://www.ascenttotransplant.org">www.ascenttotransplant.org</a></td>
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<tr>
<td>iChoose Kidney</td>
<td><a href="http://www.ichoosekidney.emory.edu">www.ichoosekidney.emory.edu</a></td>
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<tr>
<td>My Transplant Coach</td>
<td><a href="https://mytransplantcoach.org/#/">https://mytransplantcoach.org/#/</a></td>
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<tr>
<td><strong>Living Donation Websites</strong></td>
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<tr>
<td>Alliance for Paired Donation</td>
<td><a href="http://www.paireddonation.org">www.paireddonation.org</a></td>
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<tr>
<td>Living Donation California</td>
<td><a href="http://www.livingdonationcalifornia.org">www.livingdonationcalifornia.org</a></td>
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<tr>
<td>Living Donors Online</td>
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<tr>
<td>National Kidney Registry</td>
<td><a href="http://www.kidneyregistry.org">www.kidneyregistry.org</a></td>
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<tr>
<td>Renewal</td>
<td><a href="http://www.life-renewal.org">www.life-renewal.org</a></td>
</tr>
<tr>
<td>UNOS Kidney Paired Donation Pilot Program</td>
<td><a href="https://unos.org/donation/kidney-paired-donation/">https://unos.org/donation/kidney-paired-donation/</a></td>
</tr>
</tbody>
</table>
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.

References


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. 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

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

Start Delays

- Wait 4 months

Commercial insurance
- High cost or COPPA

- No

- Yes

- Note: Decision may vary based on if dependents are also insured under the policy or if the ESRD patient is the sole beneficiary

- Keep commercial insurance

- Potential living donor?

- No

- Yes

- Get Medicare A & B as secondary coverage

- Medicare will "flip" to the primary ins. after C.O.B. ends

Medicare Part A
- High cost w/out B, D & supplemental
- None/Self pay

- Yes

- Keep Medicare Part A (covers transplant)
- Fundraise if anticipated post-transplant costs are high

- No

- Keep Medicare Advantage (this is like Medicare A, B & D in one plan)

- Ensure you have Medicare Part A (covers transplant)
- Get Medicare Part D (covers meds)

- Supplemental (assist in paying Part A & B, pre-pays and deductibles)

- Ensure you have Medicare

- Medicaid

- Medicaid and enroll in Medicare (by end of C.O.B.)

- No
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.
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 are 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://ascenttotransplant.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
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

<table>
<thead>
<tr>
<th>Patient Name</th>
<th>Status</th>
<th>Action Needed</th>
<th>Transplant Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient A</td>
<td>Listed</td>
<td>needs stress test and colonoscopy</td>
<td>Piedmont</td>
</tr>
<tr>
<td>Patient B</td>
<td>Listed</td>
<td>active since 12/14/2012</td>
<td>Emory</td>
</tr>
<tr>
<td>Patient C</td>
<td>Pt Declines</td>
<td>satisfied with modality</td>
<td></td>
</tr>
<tr>
<td>Patient A</td>
<td>Listed</td>
<td></td>
<td>Piedmont</td>
</tr>
<tr>
<td>Patient B</td>
<td>Not Eligible</td>
<td>will refer once insured</td>
<td></td>
</tr>
<tr>
<td>Patient C</td>
<td>Pt Declines</td>
<td>age/sex of cancer</td>
<td></td>
</tr>
<tr>
<td>Patient A</td>
<td>Declined</td>
<td>Needs SARP</td>
<td></td>
</tr>
<tr>
<td>Patient B</td>
<td>Listed</td>
<td></td>
<td>Piedmont</td>
</tr>
</tbody>
</table>

**Unit Contacts**

- **Piedmont Contacts**: 404-605-4600
  - Cheryl Manley (A-L): 404-605-2252 Cheryl.Manley@piedmont.org
  - Lauren Dunn (M-Z): 404-605-4930
  - Rochelle Williams: 404-605-4284 waitlistcoordinator
  - Denise Neal: 404-605-5560
- **Georgia Health Sciences**: 706-721-2888
- **Emory Transplant**: 404-355-7989
- **UAB**: 205-934-9200

### 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 troubleshoot 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):

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
Transplant Peer Mentor Program

Dialysis Facility Toolkit

Who Will Use This Toolkit:

This toolkit is intended to assist in the creation of a Peer Mentor Program at dialysis facilities in Georgia, North Carolina, and South Carolina and is intended for use by:

- Dialysis facility leadership with their peer mentors
- Peer mentors with their respective peer 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.

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


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

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

United Network of Organ Sharing Patient Learning Center. UNOS has partnered with leading health education organizations to provide peered 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://ascenttotransplant.org
Transplant Peer Mentor Program

Dialysis Facility Toolkit
Kidney Transplant leads to:

1. Longer survival
2. Improved quality of life
3. Decreased Hospitalizations

Dialysis patients are interested in transplant but don’t feel they have been given the adequate resources to explore this as a treatment option

Patients wants/needs:
- a sympathetic ear to listen to their dialysis specific problems
- a peer to help them consider the transplant process

Dialysis facility staff want what’s best for their patients but already feel overburdened

Staff wants/needs:
- more free and easily accessible educational resources
- more follow-up with patients
- clear and simplified referral process

The Peer Mentor Program can help with both patient and staff wants/needs

The Toolkit can help your dialysis facility implement your own Peer Mentor Program!
Who Will Use This Toolkit:

This toolkit is intended to assist in the creation of a Peer Mentor Program at dialysis facilities in Georgia, North Carolina, and South Carolina and is intended for use by:

- Dialysis facility leadership with their peer mentors
- Peer mentors with their respective peer mentees

Structure of the Toolkit:

The toolkit is divided into sections that help the facility staff and peer mentor navigate the material.

Chapters 1-3 are meant for the dialysis facility leadership. These chapters will introduce you to the Peer Mentor Program (Chapter 1) and provide strategies to recruit (Chapter 2) and screen (Chapter 3) peer mentors. Chapter 4 contains peer mentor training material and should be reviewed by both the facility leadership and peer mentor. The remaining chapters (Chapters 5 and 6) are to be used by the Peer Mentor to help them plan and report their activities as a peer mentor.
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Program Description
What Is the Peer Mentor Program?

**Overview:** The Mentor Program is a patient service program offered by the Southeastern Kidney Transplant Coalition in which facilities match dialysis patients that are interested in the transplant process to a mentor who is living successfully with a kidney transplant.

**Mission/Purpose:** To provide confidential, individualized, one-on-one support for people at all stages of transplantation through personal contact with a trained mentor. Program participants will share specialized knowledge gained from personal experience and provide information to potential kidney transplant patients to help them navigate the transplantation process.

**Who are Peer Mentors:** Transplant recipients who previously received in-center dialysis at facilities in Georgia, North Carolina, and South Carolina.

For dialysis patients, learning they need a transplant, going through the evaluation process, waiting for the call, having the surgery, recovering, and then adjusting to “chronic wellness” (life after transplant) can be a wonderful, yet emotional, and stressful time. Support from friends, family and the transplant facility team can certainly help, but talking to someone who has been in the same situation is often the best way to calm nerves and realize positive outcomes.

That’s where the **Peer Mentor Program** comes in. The program will create opportunities for transplant recipients (mentors) to be matched with people interested in transplant (mentees) at various dialysis facilities in Georgia, North Carolina, and South Carolina to form bonds and facilitate discussion.
Introduction: Before initiating the Peer Mentor Program in your dialysis facility, it is important to understand the roles and responsibilities of a peer mentor. This section discusses the differences between mentors and mentees.

Definition of “Mentoring” in the Peer Mentor Program:
A relationship between two people in which one individual invests time, expertise, and effort in enhancing another person in the areas of growth, knowledge, and skill formation (mentor). The mentor will respond to the needs of the mentee in order to encourage his/her productivity in the future.

Definition of a “Mentor” in the Peer Mentor Program:
Someone who provides guidance to an intended kidney transplant recipient through support and information in various areas, including: knowledge, growth, and skill formation regarding the transplant process.

Definition of a “Mentee” in the Peer Mentor Program:
Someone who receives guidance from another person to advance their lives in the area of kidney transplant, from referral to post-transplant, including advice on transplant preparation.
What are the Peer Mentor Program’s Short and Long-Term Objectives?

**Introduction:** This toolkit is designed to provide the patient and facility staff with a guide for developing a Peer Mentoring Program. Peer Mentoring has been shown to be a significant source of information on the transplantation process for the dialysis patient while also offering the dialysis patient enhanced social support. For the program to be successful in your facility, it is important to have clear and concise short- and long-term objectives for your Peer Mentor Program. This worksheet allows you to create objectives for your Peer Mentor Program and helps you discuss them with the peer mentor, as well as other facility leadership and staff.

**Directions for Completing the Objectives Worksheet:** You and your staff should develop 3 short-term objectives and 2 long-term objectives. Each objective should meet the SMART criteria (Specific, Measureable, Attainable, Relevant, Time based).

The “Peer Mentor Program - SMART Objectives Worksheet” is found on the next page.
### Peer Mentor Program - SMART Objectives

<table>
<thead>
<tr>
<th>Specific</th>
<th>~ Example ~</th>
<th>Increase dialysis patients’ interest in transplantation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Measurable</th>
<th>Number of dialysis patients that discuss (or have requested to discuss) transplantation options with facility Medical Director</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Attainable</th>
<th>4 additional dialysis patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relevant</th>
<th>Medical Director and dialysis patients should discuss transplantation options and then decide the next steps</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time Based</th>
<th>Within 2 months of starting the Peer Mentor Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>
## Peer Mentor Program - SMART Objectives

### Specific

<table>
<thead>
<tr>
<th>~ Example ~</th>
<th>Increase the percentage of dialysis patients referred for kidney transplantation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

### Measurable

<table>
<thead>
<tr>
<th>Increase the percentage of patients referred for kidney transplantation by 15 % (ie: from 20% to 35%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
</tbody>
</table>

### Attainable

<table>
<thead>
<tr>
<th>15 percentage point increase in referral (current: 20%, goal: 35%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
</tbody>
</table>

### Relevant

<table>
<thead>
<tr>
<th>Referral is an early and necessary step in the transplantation process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
</tbody>
</table>

### Time Based

<table>
<thead>
<tr>
<th>Within 12 months of starting the Peer Mentor Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
</tbody>
</table>
Recruitment of Peer Mentors
Recruitment Strategies

Introduction: This chapter of the Peer Mentor Toolkit is designed to assist dialysis facility leadership in the recruitment of peer mentors. Please review the following strategies and recruitment materials. The recruitment materials are just templates and may be altered to specifically relate to your dialysis facility.

- Look back in to your records to see which of your patients have received a transplant. There is no time limit to this. As long you know the individual is exemplifying a ‘healthy transplant’, you can recruit them to be a mentor.

- Ask your facility’s Medical Director to determine which patients received a transplant and who they believe would serve as a great peer mentor.

- Reach out to your local community’s nephrologists who are caring for transplant recipients. You might not be able to contact their patients directly, but you can send the nephrologist the recruitment flyer and let them reach out to their patients.

- Recruit multiple transplant recipients. Everyone has a busy schedule. If you recruit and train multiple peer mentors, you can ensure that more of your dialysis patients are meeting with and learning from the mentors.
Recruitment Materials

Page 10 is the **Peer Mentoring Recruitment flyer** that you can mail to the transplant recipient from your facility.

1. Print out as many flyers as you need!
2. Write in your facility’s name and address in the space provided.
3. Be sure to include your contact name (so the mentor knows who to ask for) and the facility’s phone number.

Page 11 is the **Mailer to Your Local Nephrologist** that you can mail to your community’s physicians that are caring for transplant recipients.

1. Discuss with your facility’s Medical Director which physicians to whom you should send the mailer.
2. Print out one letter for each provider.
3. Fill in the date and physician’s last name at the top of the letter.
4. Be sure to include your name and contact information in the space provided.
5. Sign the bottom of the letter.
6. Mail the letter along with 15 copies of the Peer Mentoring Recruitment flyers.
Help Others with ESRD…Become a Mentor!

The Southeastern Kidney Transplant Coalition and local dialysis facilities are working together to help educate patients with end stage renal disease (ESRD) about the option of transplant and we are looking for volunteers to train as Mentors.

- On your journey to transplant, were you ever on dialysis?
- Are you successfully living with your gift of a kidney?
- Do you want to give back to those currently facing ESRD?

As a Mentor you will be trained and partnered with our dialysis facility to offer a ‘face of hope’ to those on dialysis and in need of a kidney transplant. You can make a difference by volunteering to become a Peer Mentor!

To become a Peer Mentor, please contact our facility:

**Facility Name:**
**Facility Address:**
**Staff Contact:**
**Phone:**
Dear Dr. ____________________,

We are writing on behalf of the Southeastern Kidney Transplant Coalition (SEKTC), a multidisciplinary group of transplant and end stage renal disease (ESRD) professionals and patients, to ask if you provide follow-up care for any kidney transplant recipients who would be willing to volunteer as a peer mentor through the SEKTC Peer Mentor Program.

The Peer Mentor Program’s goal is to help dialysis patients learn about and navigate the transplant process, by establishing a partnership between peer mentors, dialysis staff, and dialysis patients. The Peer Mentor Program offers routine and structured visits with patients in their dialysis facility to provide education and support for transplant. Our facility will provide mentor training and will connect the mentor with our dialysis patients.

The Peer Mentor Program is seeking highly motivated transplant recipients to volunteer as peer mentors. Mentors should be healthy transplant patients who are willing to share their personal transplant stories. Our dialysis facility should be convenient to the peer mentors because we will be asking the peer mentors to visit our dialysis facility on a regular basis, agreed upon by the facility and the mentor. Peer mentors provide dialysis patients with valuable, unbiased information that helps patients form realistic expectations about the transplantation process.

The SEKTC is also committed to improving access to kidney transplantation. Currently, there are significant barriers to transplantation for the more than 600,000 ESRD patients in the United States. These barriers are the most pronounced in the Southeast where the burden of kidney disease is the highest, yet transplant rates are the lowest, in the nation. Through the Peer Mentor Program, SEKTC aims to improve rates of kidney transplantation by giving a living example of transplant success to patients in North Carolina, South Carolina, and Georgia.

If you know of any patient who would make a great Peer Mentor, please refer them to ______________________________(phone: ____________________________).

Name of dialysis facility and/or staff member

We have also included several copies of a recruitment flyer that can either be handed out to specific patients or placed in your waiting room for general distribution. Thank you for your help in our effort to improve access to kidney transplantation in the Southeast.

Sincerely,
Screening of Peer Mentors
Introduction: Peer mentors play a major role in providing support to potential transplant candidates to help them with the transplant process. Given the mentor’s important role in the mentee’s transplant process, selecting potential peer mentors can seem like a daunting task; but, it does not have to be! The following criteria will help you select the most efficient mentors that can effectively contribute to the development of the program at your facility.

Checklist for Peer Mentor Requirements:

- The mentor underwent a successful transplant and is therefore an example of a “healthy transplant recipient”
- The mentor is familiar with the kidney transplant process, including the evaluation steps, donor options, and potential financial concerns
- The mentor is able to visit the dialysis facility on a regular basis, as determined by the facility and mentor
- The mentor is familiar with additional educational resources that may be helpful for the mentee
- The mentor possesses knowledge of potential barriers that dialysis patients may face during the transplant process and becoming listed for transplant
- The mentor reports dialysis/transplantation concerns and challenges to staff

Checklist for Personal Characteristics of a Good Peer Mentor:

- Interested in building a relationship with the mentee
- Willing and able to share information, personal experiences and struggles while undergoing transplantation (aka: the patient’s “Transplant Story”)
- Willing and able to provide others with constructive feedback
- Exhibits a positive working relationship with others (including staff and other patients)
- Sets and meets his/her own personal and professional goals
- Exhibits a generally positive outlook on the kidney transplant process but is also willing to dispel transplant myths and misunderstandings

Peer Mentor Monitoring: The dialysis facility leadership should maintain a file/record of all recruited and screened peer mentors. The file for each peer mentor should contain their completed training material, planned activities, and monthly mentor log.
Training of Peer Mentors
Peer Mentor Program Toolkit

Introduction: The following agenda, materials, and activities serve as a guide for the dialysis facility leadership and the mentor. The purpose of the training is to define the objectives, roles and responsibilities of the mentor. (Please allow 2 hours to complete the outlined training).

Training Materials: All completed training materials should be kept in a peer mentor specific file.

Agenda and Activities

What Do the Terms “Mentor” and “Mentee” Mean? 5 minutes
Quick Tips for Effective Peer Mentoring 5 minutes
What are Your Short- and Long-term Objectives as a Peer Mentor? 30 minutes
Peer Mentoring Golden Rules and Red Flags 5 minutes
What are the Peer Mentor’s Roles, Responsibilities, and Expectations 20 minutes
Dialysis Facility Staff and Peer Mentor Communication 10 minutes
Dialysis Facility Staff and Peer Mentor Agreement 20 minutes
Planned Monthly Peer Mentoring Activities 25 minutes
What Do the Terms “Mentoring”, “Mentor”, and “Mentee” Mean?

**Introduction:** The dialysis facility leadership and peer mentor should discuss what it means to be a mentor and mentee. What are the differences between these roles?

**Definition of “Mentoring”:**
A relationship between two people in which one individual invests time, expertise, and effort in enhancing another person in the areas of growth, knowledge, and skill-formation. The mentor will respond to the needs of the mentee in order to encourage his/her productivity in the future.

**Definition of a Mentor:**
Someone who provides guidance to an intended kidney transplant recipient through support and information in various areas, including: knowledge, growth, and skill formation regarding the transplant process.

**Definition of a Mentee:**
Someone who receives guidance from another person to advance their lives in some way, including but not limited to, his/her professional career, extracurricular projects, and academic projects.
**Quick Tips for Effective Peer Mentoring**

**Introduction**: This list provides tips for the peer mentor to establish and maintain a positive relationship with their mentees.

1. **Positive attitude without judgement**: be enthusiastic and accepting of others
2. **Values**: analyze personal beliefs and ideals in an effort to establish values
3. **Open-mindedness**: be open to alternative ideas
4. **Effective communication**: be an attentive/active listener and pose questions
5. **Strengths**: recognize individual strengths and build on them
6. **Confidence**: encourage self-confidence/self-efficacy and growth
7. **Awareness**: be aware of your delivery (how you are “coming off” to others)
8. **Flexibility**: be flexible, empathetic, and adaptable with regard to attitudes and actions
9. **Commitment**: keep your commitment to your mentee and take the initiative to reach out to her/him on an agreed-upon routine basis
10. **Operate with Confidentiality In Mind**: adhere to appropriate boundaries for a mentoring relationship
What Are Your Short and Long-Term Objectives as a Peer Mentor?

Introduction: The training materials are designed for dialysis facility leadership and the peer mentor to determine the activities for the Peer Mentor Program. Peer mentoring has been shown to be a significant source of information on the transplantation process while offering the dialysis patient enhanced social support. For the program to be successful, it is important for the staff and peer mentor to develop clear and concise short- and long-term objectives. This worksheet allows you to create these objectives so you can effectively communicate them with the peer mentor and other facility leadership and staff.

The peer mentor should be given a photocopy of their completed “Peer Mentor’s Short- and Long-Term SMART Objectives” for their records and monthly monitoring.

Directions for Completing the Objectives Worksheet: The Peer Mentor and facility staff should develop 3 short-term objectives and 2 long-term objectives. Each objective should meet the SMART criteria (Specific, Measureable, Attainable, Relevant, Time based).

The “Peer Mentor - SMART Objectives Worksheet” is found on the next page.
# Peer Mentor - SMART Objectives

<table>
<thead>
<tr>
<th>Specific</th>
<th>~ Example ~</th>
<th>Increase dialysis patients' awareness about the Peer Mentor Program</th>
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<tbody>
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<table>
<thead>
<tr>
<th>Measurable</th>
<th>Number of dialysis patients that I, the peer mentor, have met with each month</th>
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</thead>
<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Attainable</th>
<th>Month 1: 2 patients; Month 2: 3 patients</th>
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<tbody>
<tr>
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<td></td>
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<table>
<thead>
<tr>
<th>Relevant</th>
<th>Peer Mentor Program is a new program that can provide potential transplant patients with useful information on transplantation</th>
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</thead>
<tbody>
<tr>
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<td>1</td>
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<tr>
<th>Time Based</th>
<th>Within the first 2 monthly visits</th>
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</table>
### Peer Mentor - SMART Objectives

<table>
<thead>
<tr>
<th>Specific</th>
<th>Measurable</th>
<th>Attainable</th>
<th>Relevant</th>
<th>Time Based</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Example</em></td>
<td>HAVE A DIALYSIS PATIENT ACTIVELY WAITLISTED FOR TRANSPLANT</td>
<td>2 PATIENTS</td>
<td>HEALTH RISKS INCREASE AS TIME ON DIALYSIS INCREASES, SO IT IS IMPORTANT TO BE WAITLISTED AS SOON AS POSSIBLE</td>
<td>WITHIN 12 MONTHS OF STARTING THE PEER MENTOR PROGRAM</td>
</tr>
</tbody>
</table>
**Peer Mentoring Golden Rules and Red Flags**

**Introduction:** The Golden Rules and Red Flags are items the Peer Mentor should constantly consider each time they are interacting with a dialysis patient and potential mentee. (A copy of the Golden Rules and Red Flags is provided in Chapter 5: Mentor Materials).

---

**Golden Rules for Mentors**

1. Do not give medical advice.
2. Listen more than you speak.
3. Speak from your experiences.
4. Keep all information confidential.
5. Be open-minded.
6. Take care of yourself.
8. You do not have to become friends with your mentee.
9. You have the right to turn down an assignment for a new mentee.
10. The mentee has the right to refuse mentor services.

---

**Red Flags for Mentors**

Red Flags include anything that can interfere with the patient’s health before or after transplant. It can be a medical, mental, emotional, or physical issue. Once a Red Flag is identified, it should be reported to the dialysis facility leadership and/or a staff member responsible for the Peer Mentor Program.

1. Missing medication doses.
2. Reports of feeling so good they are not going to follow medical advice.
3. Abusing alcohol or drugs.
4. Ignoring physical symptoms.
5. Family dynamics are negatively impacting decision-making capability.
What Are the Peer Mentor’s Roles, Responsibilities, and Expectations?

Introduction: The purpose of this activity is to determine concise roles and responsibilities for the peer mentor and facility staff. The Peer Mentor Program emphasizes the partnership between dialysis facility staff and the peer mentor. Together, the facility staff and peer mentor should develop the roles and responsibilities of the peer mentor.

The staff and mentor should also determine the peer mentor’s expectations for the Peer Mentor Program. These expectations should be for the following relationships:

1. Dialysis Facility Staff and Peer Mentor
2. Peer Mentor and Mentee (dialysis patient)

The completed form should be photocopied and provided to the Peer Mentor for their records.

Peer Mentor Role and Responsibilities:

Example: Call mentee every Wednesday at 12 pm to discuss preparation for transplant on July 7

---

Dialysis Facility Staff and Peer Mentor Expectations:

Example: Facility staff introduce peer mentor to dialysis patients interested in transplant for the first 4 months

---

Peer Mentor and Mentee Expectations:

Example: Peer mentor creates a welcoming environment for mentee to ask questions regarding the mentor’s transplant experience

---
Dialysis Facility Staff and Peer Mentor Communication

**Introduction**: Effective communication is necessary to build and maintain a healthy peer mentoring relationship between participants. Oftentimes, many barriers can get in the way of effective listening for both parties, such as not actively listening. Consequently, these actions may impede on the speaker’s feelings that his/her concerns are being understood. In order to prevent this, it is important to practice active listening, or listening attentively, with your mentor/mentee.

**What is Active Listening?**

A way of communicating that involves the listener re-stating the information just given by the speaker to ensure that the speaker is aware that the listener received the information.

1. Peer Mentor, provide your one Active Listening RESPONSE to the scenario below in the space provided.
2. Dialysis Facility Staff, provide your one Active Listening RESPONSE to the scenario below in the space provided.

<table>
<thead>
<tr>
<th>Dialysis Facility Staff</th>
<th>Peer Mentor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example</strong></td>
<td></td>
</tr>
<tr>
<td>Speaker: <em>I would like you to visit the dialysis facility once a month.</em></td>
<td>Response: <em>I understand that you would like me to visit one time per month and I am happy to do that. Let's discuss both of our schedules and availability to make that happen.</em></td>
</tr>
<tr>
<td>Speaker: <em>I will not be able to constantly monitor your visits with patients each time.</em></td>
<td>Response:</td>
</tr>
<tr>
<td>Response:</td>
<td>Speaker: <em>I am not sure of all the resources available to me to provide patients.</em></td>
</tr>
</tbody>
</table>
Dialysis Facility Staff and Peer Mentor Agreement

Introduction: Taking into consideration the previously completed materials, both the dialysis facility leadership and peer mentor should contribute to the development of an agreement. The dialysis facility staff and peer mentor agreement should include contributions from both parties to help clarify how each role will positively contribute to the success of the Peer Mentor Program. Each party should sign in the designated area once the agreement is complete.

Both parties should maintain a copy of the ‘Dialysis Facility Staff and Peer Mentor Agreement’. The facility staff should photocopy the completed and signed agreement and provide a copy to the peer mentor for their records.

As the dialysis facility leadership, I will contribute to the success of the Peer Mentoring Program by:

1. 
2. 
3. 

As the peer mentor, I will contribute to the success of the Peer Mentoring Program by:

1. 
2. 
3. 

DIALYSIS FACILITY STAFF PRINTED NAME: __________________________________________________________

DIALYSIS FACILITY STAFF SIGNATURE: _____________________________________________________________

PEER MENTOR PRINTED NAME: _________________________________________________________________

PEER MENTOR SIGNATURE: _________________________________________________________________
**Planned Monthly Peer Mentoring Activities**

**Introduction:** The dialysis facility staff and peer mentor should complete this activity together to ensure cohesion between activities and reduce scheduling conflicts. A copy of this schedule should be made and given to the Peer Mentor for their records.

<table>
<thead>
<tr>
<th>Month</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>~ Example ~</td>
<td>Conduct a “lobby day” to determine how many patients are interested in hearing about my transplant process</td>
</tr>
<tr>
<td>1</td>
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<td>11</td>
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<td>12</td>
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</tbody>
</table>
Peer Mentor Materials

The materials in this chapter are intended for the Peer Mentor to receive their own copy and review. Some of the material will be duplicates of the Peer Mentor Training Material.

The material should be kept in a 3-ring binder in the order in which it is presented in the toolkit.

NOTE: There were several activities completed during the Peer Mentor Training that the Peer Mentor will need for their records to ensure they are meeting their set objectives and completing the agreed upon activities. These materials should be included directly after this introduction page. The materials include:

- Peer Mentor’s Short- and Long-Term SMART Objectives
- Peer Mentor’s Roles, Responsibilities, and Expectations
- Dialysis Facility Staff and Peer Mentor Agreement
- Planned Monthly Peer Mentoring Activities
What Are the Benefits of Being a Mentor or a Mentee?

**Introduction:** The dialysis facility leadership and peer mentor discussed the differences between these two roles during the mentor training. This page offers a more detailed definition for the peer mentor to review.

**Definition of “Mentoring”:**

A relationship between two people in which one individual invests time, expertise, and effort in enhancing another person in the areas of growth, knowledge, and skill-formation. The mentor will respond to the needs of the mentee in order to encourage his/her productivity in the future.

**Benefits of being a “Mentor”:**

As a peer mentor, you provide guidance and leadership to a patient that has little or no prior experience with dialysis and transplantation. You may be able to prevent another person from experiencing some of the hardships you struggled with regarding kidney transplant or dialysis.

You can cultivate a new relationship that is intended to be beneficial for both people, while providing advice on experiences related to dialysis and kidney transplant.

**Benefits of being a “Mentee”:**

Mentees can receive guidance and leadership from another person to advance their lives in some way, including but not limited to, his/her professional career, extracurricular projects, and academic projects.
Peer Mentoring Golden Rules and Red Flags

**Introduction:** The Golden Rules and Red Flags are items you, as the Peer Mentor, should constantly consider each time they are interacting with a dialysis patient and potential mentee. (A copy of the Golden Rules and Red Flags was provided and discussed in Chapter 4: Training Peer Mentors).

---

**Golden Rules for Mentors**
1. Do not give medical advice.
2. Listen more than you speak.
3. Speak from your experiences.
4. Keep all information confidential.
5. Be open-minded.
6. Take care of yourself.
8. You do not have to become friends with your mentee.
9. You have the right to turn down an assignment for a new mentee.
10. The mentee has the right to refuse mentor services.

**Red Flags for Mentors**
Red Flags are anything that can interfere with the patient’s health before or after transplant. It can be a medical, mental, emotional, or physical issue. Once a Red Flag is identified, it should be reported to the dialysis facility leadership and/or a staff member responsible for the Peer Mentor Program.

1. Missing medication doses.
2. Reports of feeling so good they are not going to follow medical advice.
3. Abusing alcohol or drugs.
4. Ignoring physical symptoms.
5. Family dynamics are negatively impacting decisions being made.
Peer Mentor’s Personal Presentation

Introduction: It is important to engage the dialysis patient and to create a positive relationship that can be developed over time. A constructive way to initiate conversation with dialysis patients is to create a very short story that reflects your own journey with dialysis and/or transplantation.

Peer Mentor Activity: Create a 30-second story that describes who you are, your experience with dialysis and kidney transplant, and your involvement in the Peer Mentor Program. Write down quick notes to yourself that will make presenting this information easier for you.

Hints for Peer Mentors creating their 30-second story:

- Introduce yourself as a volunteer with the Peer Mentor Program, including what you aim to achieve with your involvement in the program.

- Before launching into your story, pay attention to the mentee. Ask the mentee whether this is a good time to visit.

- Set a friendly tone to encourage conversation among other participants.

- Keep the information you are discussing at a high level (just general facts about yourself), and avoid diving into intimate details regarding specific life experiences—you can do this one-on-one with your mentee later.

- If you are making a phone call, it’s a good idea to ask, “Is this a convenient time to talk?” Call back later if there is any doubt.

- Limit your talk to only the highlights. Let them ask for the details. This is MOST important. Remember: it’s not about you; it’s about THEM.

- Watch your body language...not too close...not too far...look them in the eyes. Be prepared to listen. Avoid touching the patient or bed, if visiting in person.

- Share your story in a way that allows your mentee to relate to your struggles, experiences, etc.

After you have shared your story, offer the mentee a copy of the Booklet “Your Life, Your Choice – Stories from Kidney Transplant Patients and Donors”, found at the end of this Chapter.

Let them know this is a good resource to share with their family.
What Are the Peer Mentor’s and Mentee’s Roles, Responsibilities, and Expectations?

**Introduction:** The purpose of this activity is to determine concise roles and responsibilities for you, as the peer mentor, and mentee, together. The Peer Mentor Program emphasizes the partnership between the peer mentor and mentee. Together, you and mentee should develop shared roles, responsibilities, and expectations.

*These characteristics may differ by individual. Therefore, the peer mentor should complete this form for EACH dialysis patient (mentee) they are mentoring. You, as the peer mentor, should periodically review this form with your respective mentee, update as needed, and ensure expectations are being met.*

<table>
<thead>
<tr>
<th><strong>Peer Mentor</strong></th>
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<tbody>
<tr>
<td><strong>Roles</strong></td>
<td><strong>Responsibilities</strong></td>
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<tr>
<th><strong>Peer Mentee</strong></th>
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<tbody>
<tr>
<td><strong>Roles</strong></td>
<td><strong>Responsibilities</strong></td>
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Peer Mentor’s Activity Log

Introduction: You should complete the activity log at the conclusion of each visit to the dialysis facility. You should detail each visit, including the date/time, number of patients you spoke with, topics discussed, and successes/failures.

A photocopy of the Activity Log should be turned in to the dialysis facility leadership at the end of each visit.

<table>
<thead>
<tr>
<th>Date</th>
<th>Activity</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 November 14, 2015</td>
<td>Today I spoke with 3 dialysis patients I have not met with before. I presented my '30-second story' and discussed with them my transplant experience and answered their questions about my transplant process. One patient was interested in being referred for transplant and I discussed this with the facility social worker before leaving.</td>
<td>1:30-3:00pm</td>
</tr>
<tr>
<td>2 December 19, 2015</td>
<td>I met again with a patient that I talked with November. In November, he/she was not ready to be referred for the transplant process but did take home information on deceased and living donor transplant. Today we discussed my experience on the deceased donor waitlist and what the recovery was like. I also met with two new patients I did not meet with last month. They seemed interested to hear about my story and my improved quality of life! We said we would talk more after the Holidays.</td>
<td>10:00-11:00am</td>
</tr>
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</table>

The “Peer Mentor Activity Log” is found on the next page.
<table>
<thead>
<tr>
<th>Date</th>
<th>Activity</th>
<th>Time</th>
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Vocational rehabilitation: Is your facility on track?

By Lisa Hall, MSSW, LCSW, Sally Gore, MSW, MBA, CPHQ, and Beth Witten, MSW, ACSW, LSCSW

Abstract
Background: The Conditions for Coverage for End-Stage Renal Disease Facilities require that facilities evaluate each patient for referral to vocational rehabilitation (VR) services, assist the patient in achieving and sustaining an appropriate level of productive activity, and develop a plan that reflects individual patient preference. Though research shows that people on dialysis who keep working feel better, data collected in the 2008 USRDS Comprehensive Dialysis Study indicates that only half of dialysis patients continued to work after starting treatment.

Objectives: A review of the data and the reasons dialysis patients do not work provides an opportunity to identify resources and strategies to address barriers. FMQAI: The Florida ESRD Network (Network 7) initiated a quality improvement project in June 2008 to increase the percentage of Florida ESRD patients, aged 18 through 54, who were receiving VR services, attending school, or employed.

Methods: Using the 2007 ESRD Facility Survey (CMS-2744A) data as a baseline, Network 7 employed a two-pronged approach using both statewide spread efforts and focus group interventions with a targeted group of providers. All facilities identified in the focus group began the project with a baseline of 0% of patients ages 18-54 either engaged in VR, working, or in school. Quality improvement plan (QIP) workshops, conference calls, tracking tools, individualized facility data reports, educational materials, and technical assistance were utilized to improve VR rates in Florida.

Results: As of December 31, 2008, Network 7 increased their statewide results (patients aged 18-54 either engaged in VR services, attending school or working) by 2.5% over the 2007 baseline. For the focus group, as of June 30, 2009, results indicate that 40% of patients are either engaged in VR, working, or in school.

Recommendations: By including VR in facility quality assessment and performance improvement (QAPI) activities, facilities can demonstrate outcomes-driven practice and enhance the independence and quality of life for ESRD patients.

Introduction
Research shows that people on dialysis who keep working feel better. They are more physically able, have less pain, and have better general health and energy. Better physical functioning predicts fewer and shorter hospital stays—and a longer life. People with CKD who work are also significantly more likely to have a health plan through work.

The Conditions for Coverage for End-Stage Renal Disease Facilities require that dialysis clinics:
- evaluate each patient for referral to vocational and physical rehabilitation services.
- assist the patient in achieving and sustaining an appropriate level of productive activity, as desired by the patient, including the educational needs of pediatric patients.
- make rehabilitation and vocational rehabilitation referrals as appropriate.

Evidence of interdisciplinary assessment, education, assistance with barriers, and referral should be documented in an individualized plan that reflects each patient’s preferences.

Barriers to rehabilitation
The 2008 U.S. Renal Data System Comprehensive Dialysis Study collected data on physical activity level, health-related quality of life, and work/disability. The data showed that while 50%-60% of people on dialysis under age 55 with a college degree worked prior to starting treatment, fewer than 25%-30% were still working after initiating dialysis.

The Conditions for Coverage require social workers to assess and document reason(s) why dialysis patients are not interested in VR. Some commonly stated “reasons” and interventions to address these barriers are listed in Figure 1.

Other barriers the team can address include social isolation, transportation, lack of self-confidence, others’...
attitudes about work, fear that health will fail, lack of financial resources, unemployment rate, VR program budget cuts, etc. Education and resources can help to dispel real or perceived barriers, fears, and myths.

Strategies for successful VR outcomes

Providing more treatment options may improve employment. Research published in 2008 analyzed factors that predicted employment among working age dialysis patients associated the following with higher employment:

➤ Availability of evening dialysis shifts
➤ Home dialysis (peritoneal dialysis or home hemodialysis) training
➤ More frequent dialysis

Support patients’ pursuit of rehabilitation goals by:

➤ Assessing each patient’s current status and expectations regarding:
  ➤ Productive activity
  ➤ Employment
  ➤ Education/job training
  ➤ Treatment modality
➤ Documenting a rehabilitation plan to:
  ➤ Provide education, training, and referral
  ➤ Help set personal goals for rehabilitation that reflect the patient’s preferences
➤ Following up by:
  ➤ Asking patients to inform you about VR activities, barriers, progress, and need for help (e.g., communication with counselors, current or potential employers, care coordination)

Collaborate with community resource groups:

➤ Contact and build a relationship with VR counselors
➤ Meet with VR counselors in their office or in the dialysis facility
➤ Educate VR counselors about kidney failure and patients’ ability to work
➤ Hold “VR Days” for patients and families with successfully rehabilitated patients and VR counselors

➤ Provide facility staff and physicians with education on vocational rehabilitation
➤ Post VR materials and profiles of consenting rehabilitated patients in facilities’ public areas
➤ Advocate at the facility for home dialysis referrals and prioritizing treatment around patients’ work schedules

Take advantage of work incentive programs. SSI/Medicaid recipients can benefit from a long-standing work incentive program called Section 1619. Under Section 1619a, individuals can work and keep their SSI check with a sliding scale reduction based on earnings. The publication Understanding Supplementary Security income / SSI Work Incentives explains how this works (http://www.socialsecurity.gov/ssi/text-work-ussi.htm). Under Section 1619b, individuals can keep Medicaid at a much higher income than someone who is not working (http://www.socialsecurity.gov/disabilityresearch/wi/1619b.htm).

The Red Book—A Guide to Work Incentives explains many work incentives that could benefit patients, including the Plan to Achieve Self-Support (PASS) program (http://www.socialsecurity.gov/redbook/). A 2007 report on the Ticket to Work program provides data on how many of those eligible had heard of and used specific work incentive programs.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Intervention</th>
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<tbody>
<tr>
<td>Is the person not interested due to health?</td>
<td>Change treatment regimen to improve health.</td>
</tr>
<tr>
<td>Is the person not interested due to depression?</td>
<td>Screen and treat.</td>
</tr>
<tr>
<td>Is the person not interested due to dialysis scheduling?</td>
<td>Review candidacy for home dialysis and scheduling options.</td>
</tr>
<tr>
<td>Is the person not interested because he/she believes myths about working and losing benefits?</td>
<td>Provide information on work incentive programs and use patient mentors.</td>
</tr>
<tr>
<td>Is it because the patient is not working age?</td>
<td>Encourage age appropriate activities that enhance engagement and sense of worth.</td>
</tr>
<tr>
<td>Is it because the individual prefers not to work?</td>
<td>Assess reasons, explain benefits of working, and costs of not working on physical/emotional/social functioning, and insurance/financial status.</td>
</tr>
</tbody>
</table>

Figure 1. Reasons for a lack of interest in VR
work incentives (www.socialsecurity.gov/disabilityresearch/ttw3/ttw_report3.pdf). Of the 17,696 SSI recipients surveyed, 13% have heard of PASS and only 0.6% had used it as of 2004 nationally. A PASS allows SSI (and some SSDI) recipients to designate income or resources to pursue a work goal while Social Security continues to pay their full check. A PASS can be used for such things as tuition, books, uniforms, and even a car if public transportation is not available for school or work.

**Network 7’s VR Quality Improvement Project**

The ESRD Facility Survey (CMS-2744A) collects data on patients ages 18 through 54 who are receiving VR services, attending school full/part time and/or employed full/part time.

FMQAI (the Florida ESRD Network) analyzed 2007 VR Annual Survey data, and found that, in Florida, only 25% of patients aged 18 through 54 were receiving VR services, attending school or employed. To improve VR rates in Florida, Network 7 collaborated with the Vocational Rehabilitation Advisory Committee (VRAC) to initiate a quality improvement project, “Vocational Rehabilitation: Getting Back on Track,” during June 2008.

**Goal for improvement**

The VR project goal is to increase the percentage of Florida ESRD patients, ages 18 through 54, who are receiving VR services, attending school, or employed. The objectives include:

- promoting VR awareness.
- engaging facilities in conducting CQI.
- demonstrating outcomes-driven social work practice.
- enhancing independence and quality of life for ESRD patients.

Using the 2007 VR Annual Survey data as a baseline, the Network set a statewide goal of 30% (a 5% increase over the baseline), by December 2009. The Network set a stretch goal of 35.7% of patients receiving VR services, working or employed (based on the top 25% of facilities during 2007).

A separate goal was set for the focus group (a group of facilities with the greatest need for improvement.) The goal for the focus group participants was to achieve 18.7%, which represented a 75% gap reduction between the facility baseline (0% in 2007) and the Network rate for 2007.

**Methods/activities**

Network 7 employed a two-pronged approach using statewide efforts and focus group interventions with a targeted group of providers.

**Statewide Spread.** Data were extracted from the SIMS database to identify the top 10% facility performers for each of the six Florida VR regions. Forty-three top performers were identified. A conference call was conducted to collect best practices and brainstorm ideas. Best practices were incorporated into Network 7 VR education activities, including:

- holding a statewide conference call with social workers about Social Security work incentives and VR.
- sharing articles from patient and provider newsletters.
- sending educational fax-blasts on VR to all Florida providers.
- posting new VR educational materials online.
- distributing the VR Annual Toolkit Material to all Florida providers.
- providing handouts on VR to medical directors during Network onsite visits.

**Focus Groups.** The Network identified 28 low-performing facilities representing each of the six Florida VR Regions as the focus group. In addition to including the facility social workers, administrators were also included in the focus group to engage them in reinforcing utilization of VR tools. Focus group activities included:

- a conference call to introduce the project goals, objectives, activities, and timelines.
- an in-person workshop hosted by the Network and VRAC to help each focus group facility develop its own facility-specific quality improvement plan (QIP) to improve its overall VR rate.
- quarterly conference calls to allow for facilities to report on QIP activities and data on patients receiving VR services, working, or in school using a new user-friendly Network-developed tracking tool.
- technical assistance between quarterly calls via fax-blasts, emails, and sharing of lessons learned.

**Statewide results**

As of December 31, 2008, 27.5% of Network 7 patients aged 18 through 54 were receiving VR services, attending school, or working, an increase of 2.5% over the 2007 baseline.

**Focus group results**

VR outcomes data for October/December 2008 indicated that:

- 79% of focus group facilities met the
18.7% project goal.
▶ 55% of focus group facilities met the 35.7% project goal.
▶ overall, 40% of patients in the focus group were receiving VR services, employed, or attending school full/part time.

Due to this initial success, the following changes were made to the project goals:
▶ The previous stretch goal (35.7%) is now the project goal, and the new stretch goal is now 48%. How this goal was determined:
► The top performing 10% of facilities statewide were at 57%
► The top 25% of statewide facilities were at 38.4%
► The average of these two points is 48%

As of June 30, focus group facilities were continuing to make impressive improvements, such as:
▶ 54% of Focus Group facilities have met the 35.7% project goal.
▶ 46% of Focus Group facilities have met the 48% stretch goal.
▶ overall, 40% of patients in focus group facilities are receiving VR services, employed or attending school full/part time.

A post-evaluation survey of the QI workshop was conducted. One hundred percent of facility respondents said that the workshop was effective and 85% indicated they had implemented or revised processes in their facility as a result of what they learned.

**Next steps**

One of the primary lessons learned with this project is that many facilities provided inaccurate data (that is, 0% of patients, aged 18 through 54 receiving VR services, working, or attending school) on the 2007 VR annual survey. On the 2008 VR annual survey, 60 facilities (18%) reported 0% of their patients aged 18 through 54 are receiving VR services, working or in school. The Network provided VR tracking tools/instructions to these facilities. Use of the user-friendly tracking tool that allows easy monitoring of patients receiving VR services, working or in school will be promoted through a statewide conference call, Network Web site, and fax-blast. Using the tool enables facilities to easily review their outcomes in Quality Assessment and Performance Improvement (meetings and adjust team VR goals, activities, and interventions).

**Summary**

Promotion of vocational rehabilitation not only improves facility and statewide outcomes, but ultimately makes a difference in the quality of life for kidney patients. The diagnosis of CKD is life changing. Evaluation, education, referral, and continued active involvement by the interdisciplinary team can serve to reduce the impact of kidney disease on patient lifestyle, income, and overall adjustment to care. Encouraging patients to take an active role in setting and working toward goals can provide a win-win situation for all.

**References**


![Figure 2. Percent of network patients engaged in VR, attending school, or working](image-url)
VR success story
Anthony Brooks: Getting back to work

When Anthony Brooks was diagnosed with kidney disease at age 32, he was a self-employed business owner. “I stayed pretty active,” he says, “but I was in denial about kidney failure. I didn’t really do any treatment until I was hospitalized three years later in 2005. At that point, I had no choice. I started hemodialysis.”

Dealing with ups and downs in his health and personal life (Anthony was divorced not long after he started dialysis) had a big impact on Anthony. When he decided to move to Florida in 2007, he was an unemployed single father. But, he was determined to get back on his feet.

“I heard about voc rehab at my dialysis clinic so I asked my social worker about it,” he remembers. Maria Alvarez, the social worker at RAI Care Centers in Haines City, Fla., helped Anthony connect with a vocational rehabilitation counselor. From the start, Anthony knew what he wanted to do. “I had a 10-year-old at home,” Anthony said. “I couldn’t do a job that was 8 to 5 because I had to do my dialysis during the day. Night shifts didn’t work for me because you can’t leave a 10-year-old at home alone at night.”

So Anthony researched a career that would give him flexibility—home inspector. He found an online program where he could earn his certification, and he worked with his VR counselor to get the costs covered. “They give you aptitude tests and screening exams to make sure they’re not wasting their money on you,” he joked, but Anthony passed with flying colors and VR approved the funding he needed. “They paid for my tuition, and they bought me a laptop computer so I could take the online course, and they even bought me a handheld PC that I can use on job sites,” he reports.

Anthony completed the six-week program in just four weeks and set up his own home inspection business. He does home inspections after dialysis or on nondialysis days. “The business was doing pretty good until the economy went down,” he says. “Now things are slower.” To help make ends meet, Anthony took a full-time, night shift job. He and his wife also have a networking business called TVI Express to help do part-time work online.

With a motivated attitude and a connection to vocational rehabilitation, Anthony was able to move ahead with his life. He is proud to be a husband and father who works to support his family. “As far as I know, I am the only person in my center that works,” he notes. “The clinic sets up times for people to talk to Voc Rehab but no one signs up; it seems like they like to get disability.”

For Anthony, working is a much better choice. “I make more money than I’d get on disability,” he says, “and working keeps me busy. If you just sit around and do nothing, I think it makes you sick. I plan to work until I can’t. I am taking care of my family.”

Anthony is currently being worked up for a transplant. “With the help of Jesus Christ, I will get the transplant. I have a lot to live for,” he says, “I have a new, 7-month-old baby girl, and I want to stick around to see my kids get married.” Staying active and productive—and employed—can help.

VR Success stories from Florida social workers

“I referred three patients to VR. All were assigned to a VR counselor, but were on a long wait for services. I then referred them to the local Work Incentives Planning and Assistance (WIPA) organization. All three patients received individual counseling regarding career development and employment. Additionally, the WIPA coordinator came to my dialysis center to provide education to other patients, and assist with their questions.”

“I referred an ideal candidate to VR, and was invited to provide an in-service on transplantation to the area VR office.”

“I informed a patient, who was on Medicaid, that he could continue to keep his Social Security benefits and work. He followed through with VR, and now has a part-time job as a security guard.”

“I referred a patient to VR. They funded a six-month training and licensing as a Home inspector; provided a personal computer and printer; and now he works full-time.”
A look at VR data from the USRDS

The U.S. Renal Data System is the national data registry that collects, analyzes, and distributes information on kidney disease patients in the United States. The 2009 Annual Data Report includes a report of the Rehabilitation/Quality of Life Study Center. The Comprehensive Dialysis Study (CDS) included patients ages 19-94 from 295 randomly sampled facilities. The CDS data showed the following for patients in their first year of treatment:

- Working for taxable wages (12%), and working patients reported these occupations:
  - Clerical & sales workers or technicians—23.7%
  - Semi-skilled workers, machine operators—19.1%
  - Administrators, small business owners, semi-professionals—19.1%
  - Business managers, lesser professionals—15.4%
  - Executives of large businesses, major professionals—8.8%
  - Skilled manual workers—8.2%
  - Unskilled workers—5.7%
- Employed patients covered by employer group health plan—66.7%
- Working patients receiving disability benefits—29%
  - And working full-time—5%
  - And working part-time—9.8%
- Unemployed but say they are able to work—7.3%
- Patients with a higher Human Activity Profile (HAP) survey were significantly more likely to report ability to work

Resources

- Social Security’s Web site provides links to state agencies at https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate
  - Social Security’s Work Incentives Planning and Assistance (WIPA) Organizations
  - Rehabilitation providers evaluate work history/interest, education/job training needs, needs for work-related home modifications (Rehabilitation Provider)
- Ticket to Work information—www.yourtickettowork.com
- Maximus, Social Security’s contractor for Ticket to Work—866.968.7842
- Finding and keeping a job—www.AAATakeCharge.com
- CareerOneStop—http://www.careeronestop.org/
- Protection and Advocacy Programs—http://www.napas.org/

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