

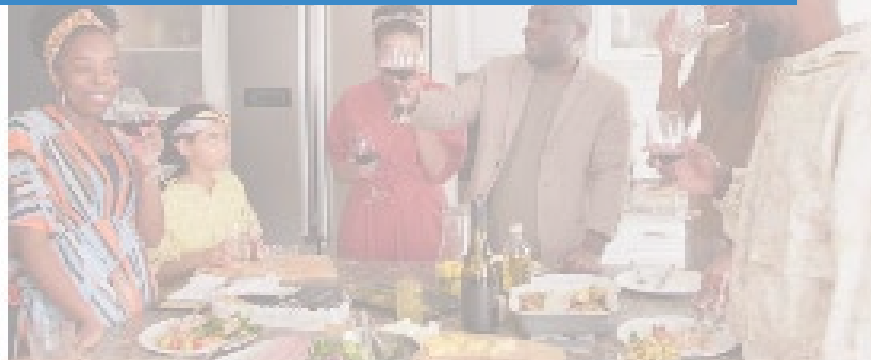


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# Guide to Organ Transplantation:

What to expect once you have received your kidney transplant

A collaboration between Mark Hardy, MD, PhD (Hon), FACS, Auchincloss Professor of Surgery, former Vice Chairman and Residency Program Director of the Department of Surgery, and Director Emeritus and Founder of the Transplantation Centre, Columbia University College of Physicians and Surgeons and NewYork-Presbyterian Hospital and Lyfebulb.



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# Introduction

Congratulations on your new transplant! This guide aims to help you take good care of your new organ and get ready to THRIVE!

Organ transplantation is part of a long journey with many steps that often include a long period of decline in organ function requiring new medications and/or dialysis in case of kidney failure, which sometimes leads to an anxious waiting period before a donor organ is found. However, the journey doesn't end with a successful operation. That is only the beginning. To take good care of this precious donated organ, either from a deceased or a living donor, it is important to understand and permanently commit to a few **guidelines outlined below**:

- 1 Care plan:** seeing your doctors regularly, on a preset schedule, and taking part in continuous learning to better understand why and how to support your new organ;
- 2 Medications:** taking the drugs your doctor prescribes exactly as directed and understanding their function, their side effects, as well as their interaction with each other; and
- 3 Monitoring:** taking notes and tests to track what is going on with the new organ, as well as with your overall health, both physical and mental.

Your transplant team includes a) your coordinator; b) your nephrologist; c) your surgeon; and d) psychiatrist, social worker, nutritionist, and financial coordinator; they are all there for you at all times. Do not hesitate to reach out to them immediately if you experience any of the following\*:

- Chest pain or shortness of breath
- Temperature over 100.2
- New or worsening swelling, pain or redness around the incision site
- Change in urine output or color - any significant blood should be reported immediately
- Vomiting or repeated diarrhea
- Missed medication dose
- Exposure to or diagnosis of COVID/Influenza or any infection
- Change of insurance coverage
- Frightening or disturbing dreams
- Social (family, work, or school) discrimination
- Headaches, dizziness, tremors, or loss of consciousness

\* <https://columbiasurgery.org/kidney-transplant/follow-visits-after-kidney-transplant-surgery>

It is also important to think about your quality of life and how you feel emotionally. Additionally, it can be expensive to manage your transplant even with insurance. Read below to learn about what to expect and how to use your new transplant most efficiently, successfully, safely, and for the longest possible time.

# Care Plan

After transplant surgery, the hospitalization time is variable, from 4 days to almost never more than one month, depending on your age, progress, kidney function (which may be delayed) and your overall health. Following discharge, the transplant clinic will be your primary source for direction on all upcoming visits for the next 6-12 months. **Below is one example of how frequently you will visit the transplant center over the first year, but each transplant center has its own system for how it manages patients.**

## Example: Transplant Center Visit Frequency (Year 1)\*

	Appointment frequency	Blood work frequency	Other Recommendations
Month 1	Every week	Twice a week	Identify prescription delivery services.  Can start driving 2-4 weeks after transplant (or when off pain meds and when movement is not restricted by discomfort from the surgery).
Month 2	Every week	Weekly	
Month 3	Every 2 weeks	Every 2 weeks	Average return to work or school is after 3 months although many patients can return earlier if their job doesn't involve manual labor or extensive travel by public transportation.
Month 4-5	Monthly	Monthly	

\* Columbia NY Presbyterian Renal & Pancreas Transplantation Service

<b>Month 6</b>	Monthly	Monthly	<p>Can travel within the US, although many patients travel earlier.</p> <p>Travel is discouraged to underserved countries with poor public health services and lack of transplant services.</p>
<b>Month 7-11</b>	Monthly	Monthly	
<b>Month 12++</b>	Monthly	Monthly	<p>Can travel internationally, although many patients can travel earlier as long as the destination has been screened by the transplant team and a transplant service or physician is identified in case of an emergency.</p> <p>An adequate supply of needed medications should accompany the patient without reliance on local medications which may have different names and sources.</p>

At routine clinic visits, any symptoms you may be experiencing (change in urine color) or quantity, swelling in the body (especially ankles, feet, and face), fever (100.2 F or greater) or general feelings of malaise may be early signs of rejection, so it is very important to keep notes of any persistent (2-3 days) changes you experience between visits and report them. It is also critical to know what changes would be important enough to require an immediate call or visit to the transplant center. The care plan is in place to oversee organ function and monitor for side effects of medications and of rejection.

Over time, the care plan will broaden to include additional specialists and specific screenings for other than renal function. Your transplant team will prescribe drugs and laboratory visits that are part of the care plan and described more specifically below.

# Medications

The immune system is critical to protecting from infections and cancers, while also serving many other important functions every day. When you receive a transplanted organ, your body sees this new organ as a “foreign invader” and activates a strong immune response to remove the threat, which would result in rejection of the organ without modern transplant medications.

One of the critical aspects of post-transplant care is the use of immunosuppressants. These medications are vital in preventing the body’s immune system from rejecting the new organ. Understanding the types, functions, and importance of these medications, as well as the challenges in managing them, including their side effect and interaction with other medications that the patient may have to take, is crucial for transplant recipients.



## Types of Transplant Medications and Their Functions\*

Transplant medications fall into several broad categories. The overarching purpose of all transplant medications is to prevent rejection of the transplanted organ by your immune system. They may also be used along with other methods to treat rejection and stop it from progressing. These medications work by either directly preventing the activation of certain immune cells or by preventing the growth and spread of many cells, but especially the immune cells.

However, these drugs also cause common side effects. The most important and serious side effects are infections (especially viral or fungal, rather than bacterial) and allowing malignancies (cancer) to develop more easily. Some of other side effects are described below:

\* <https://health.ucsd.edu/care/transplant-programs/medications/and-Lyfebulb>

Commonly used medication	Function	Common side effects
<p>Calcineurin inhibitors (CNIs)</p> <p><b>Example: cyclosporine, tacrolimus (Prograf, Envarsus)</b></p>	<p>Inhibits the activity of calcineurin, a protein that activates T-cells, a critical part of the immune system that adapts and attacks “foreign invaders”</p>	<ul style="list-style-type: none"> <li>● Headaches and tremors (Tacrolimus)</li> <li>● Hair loss (Tacrolimus)</li> <li>● Hair Overgrowth (Cyclosporine)</li> <li>● Anxiety, confusion, nightmares and other neurological side effects</li> <li>● Insulin resistance and diabetes (Tacrolimus)</li> <li>● Long-term kidney damage</li> </ul>
<p>Antiproliferative agents</p> <p><b>Example: mycophenolate mofetil (MMF), (CellCept, Myfortic), azathioprine (Imuran)</b></p>	<p>Inhibits the proliferation of many cells, including immune cells</p>	<ul style="list-style-type: none"> <li>● Nausea, vomiting, and dose-related diarrhea (MMF)</li> <li>● Low levels of immune and blood cells (may cause increased risk of bacterial infection and rarely bleeding)</li> <li>● Transient Liver damage (often self-resolving) (Imuran)</li> </ul>
<p>mTOR inhibitors</p> <p><b>Example: sirolimus, everolimus (Rapamycin)</b></p>	<p>Inhibits mTOR, a protein involved in cell growth and proliferation</p>	<ul style="list-style-type: none"> <li>● Acne</li> <li>● Edema (swelling of the arms or legs)</li> <li>● Diarrhea and nausea</li> <li>● Low levels of immune and blood cells (may cause increased risk of infection and bleeding) and anemia</li> <li>● Decreased wound healing (should be stopped briefly(2 weeks - before and after any surgical procedures)</li> </ul>
<p>Steroids</p> <p><b>Example: prednisone</b></p>	<p>Reduces inflammation and suppresses the immune system on a DNA level. This is a very powerful, effective, and initially commonly used anti-inflammatory and immune</p>	<ul style="list-style-type: none"> <li>● Acne or skin atrophy</li> <li>● Weight gain and changes to the face (“moonface”)</li> <li>● Mood or cognitive disturbances</li> </ul>



	<p>suppressant. It is also used to treat rejection</p>	<ul style="list-style-type: none"> <li>● Hypertension</li> <li>● Insulin resistance and diabetes</li> <li>● Osteoporosis</li> <li>● Stomach ulcers and bleeding (need prophylaxis when taking this)</li> </ul>
<p>Belatacept (Nulojix)</p>	<p>A fusion protein, crucial in the regulation of T cell co-stimulation, selectively blocking the process of T-cell activation. It is intended to provide extended graft and transplant survival while limiting the toxicity generated by standard immune suppressing regimens, such as calcineurin inhibitors.</p> <p>It is given intravenously, initially weekly and then once a month, under nursing supervision.</p>	<p>It suppresses the immune system and has a black box warning concerning post-transplant lymphoproliferative disorder (PTLD), in patients who were EBV negative.</p>
<p>ATG (Thymoglobulin)</p>	<p>Anti-human thymocyte immunoglobulin preparation made of purified polyclonal antibodies derived from rabbits. While these antibodies have a variety of specificities, their main mechanism of immunosuppression is through depletion of T cells.</p> <p>It is given intravenously during and for about 4 days after transplant and may be also used at other times to treat rejections. It is always used with steroids and Tylenol to avoid a major problem with fever and occasional shortness of breath.</p>	<ul style="list-style-type: none"> <li>● Initially may have high fever episode and shortness of breath («Cytokine Storm»)</li> <li>● Rare allergic reaction with fever, and rash usually prevented by steroids and thymoglobulin itself</li> </ul>

These immunosuppressive drugs are often prescribed as a regimen (many drugs simultaneously) and patients have reported psychological fatigue from taking multiple medications daily. Lastly, these medications may interact with other drugs or food, so nutritional or dietary changes may be necessary. Grapefruit and pomegranate are not permitted in patients on CI medications. It is very important to notify your transplant team of any new drugs or vitamins you might have been prescribed by other providers.

## Other Medications

Patients may be maintained on various medications before and after a transplant for diabetes, hypertension, heart disease, cholesterol, lung disease, and others. The doses of the various medications before the transplant may have to be changed, especially blood pressure and diabetes medications.

**SCAN ME**  
to learn more about introduction to transplant medications from a patient

**Jeanmarie Ferguson**  
TransplantLife's Community Manager and Kidney Transplant Recipient

## Prevention of Serious Side Effects

The most concerning side effect of immunosuppressant therapy is infection. Therefore, upon initiating immunosuppressive therapy, patients take antibacterial, antibiotic and antifungal therapies for the initial period to work to avoid these common infections\*:

Timing of infection	Most common type of infection
Early-onset infection, defined as within 1 month after transplantation	Hospital-associated infections, like surgical site infection or urinary tract infection, are most common
1-6 months after transplantation	You are more susceptible to viral and fungal infection that don't normally affect healthy people. These infections can be severe in patients on immunosuppressant therapy. Examples: <ul style="list-style-type: none"> <li>● CMV (cytomegalovirus) EBV (epstein-barr virus, which causes "mono")</li> <li>● Candidiasis (the cause of yeast infections)</li> </ul>

\* <https://emedicine.medscape.com/article/430550-overview>  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7151835/>

6-12 months after transplantation	You are similarly more susceptible to viral and fungal infections than the general population, since these particularly affect patients that are immunosuppressed.
>12 months after transplantation	The types of infections are relatively similar to those in the general population. However, these infections may be more severe, spread more quickly, and last longer given the long-term effects of immunosuppression.

How to prevent these infections?

- 1 Hygiene Practices:** Regular handwashing, avoiding crowded places, and wearing masks when necessary. Transplant recipients are not only more likely to get infections, but also to have more severe infections. Avoid people, especially infants and school children, who have active infections (e.g., those with cough or unknown rashes). In the immediate period after transplant, avoid contact with birds, cat litter, and limit exposure other pets.
- 2 Prophylactic Medications:** All patients are prescribed daily antibiotics, antivirals, or antifungals to prevent infections in the first period (up to one year) after the operation.
- 3 Vaccinations:** Keep up with recommended vaccines, though some live vaccines may not be suitable\*. See here for a guide to vaccination after kidney transplantation. To note, as many vaccinations as possible should be done prior to surgery, since the immune response to vaccinations will be reduced after the transplant. Booster vaccination should be done in a standard fashion, using the highest available dose (for elderly) regardless of age.
- 4 Routine blood and urine tests,** as well as kidney function and immune suppressant blood levels, and clinical evaluations need to be performed on an assigned schedule. Immunosuppressant medications can cause very low levels of red blood cells (anemia) and white cells (immune cells) while high levels can cause kidney damage and increase unfavorable side effects. Regular monitoring can also help to detect infections and rejections early.

\*<https://www.kidney.org/atoz/content/vaccinations>  
 Krueger KM, Ison MG, Ghossein C. Practical guide to vaccination in all stages of CKD, including patients treated by dialysis or kidney transplantation. American Journal of Kidney Diseases. 2020 Mar 1;75(3):417-25.



 **SCAN ME**  
to learn more about screening and prevention of infections from a provider

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# Monitoring (Screening for Rejection)

Over time, if the immune system is not adequately suppressed by transplant medications, this will cause rejection and potential destruction of the transplanted organ. This progression may be relatively asymptomatic until it is too late, therefore don't be fooled by feeling fine if by chance you skip the medication (this is never allowed except with instructions by your team). If by chance you skip or forget a dose, call the unit immediately for instructions and don't try to «catch up» because it may cause harm. Screening for rejection varies based on the organ and your transplant team. Some general screening measures are listed below\*\*:

Screening	Purpose	Description
Self-monitoring vital signs (temperature, blood pressure, pulse, weight, blood sugar, fluid intake (approximate), urine output (approximate), pain and swelling), sudden decrease in urine output or marked change in color (pink to red)	Similar to monitoring for symptoms, reporting any changes to your transplant team as soon as you notice them can be important in catching early signs of rejection or side effects of the drugs	Depending on the transplant team, they may ask you to monitor your temperature, blood pressure, pulse, weight and blood sugar daily at home. In the first number of weeks after a kidney transplant, it is also common to monitor fluid intake and urine output and its characteristics. It is not uncommon for urine to stay pink initially after transplant because clots in the bladder are dissolving and are mixed with the new urine. Any pain or swelling over the transplanted organ as well as unusual swelling in other parts of the body are significant to note and report.
Blood test	Test the function of the transplanted organ (kidney, liver, pancreas, lung) and identify problems early	Consult your medical team for specific scheduled blood work and other tests, as they have a better understanding of your transplant needs. Key blood tests and what they measure are listed. Other blood tests that may be checked regularly include:
Complete blood count	White blood cells are the immune cells. If they are	

\*\* <https://medlineplus.gov/ency/article/000815.htm>

	<p>high it may indicate an active infection. If they are low, it indicates a lowered defense against infections. Key blood tests are the levels of creatinine and blood urea nitrogen (BUN), measuring waste products that are removed by the kidney and reflect kidney function</p>	<ul style="list-style-type: none"> <li>● Levels of transplant medications to avoid levels that are too high or too low. If levels are too high, the dosage may</li> <li>● Worsen the side effects and even damage the kidney. They need to be reduced to prevent side effects. If levels are too low, dosage may be adjusted to prevent rejection</li> <li>● Cholesterol levels are elevated by many and may need to be treated with other medications (statins). Certain transplant medications can produce a diabetes-like condition and elevate the blood glucose.</li> </ul>
<p>Electrolytes</p>	<p>This test measures the dissolved levels of naturally occurring electrolytes (potassium, sodium, calcium, etc..) which are monitored and replaced when necessary. They reflect kidney function, nutrition or point to other problems more generally. Certain transplant medications also affect the level of electrolytes</p>	
<p>Imaging (renal ultrasound)</p>	<p>This is a non-invasive diagnostic test that uses sound waves to image the organs. It can be used to check the main blood vessels around and going to the organ, and visualize any abnormal fluid build-up, any obstruction, or to help guide future biopsy</p>	<p>Imaging is not always a part of routine screening. It is performed soon after the operation to make sure that all blood vessels are flowing to and from the kidney. It can be used to help diagnose rejection, but a biopsy with ultrasound guidance is required for definitive diagnosis. It is often used when there are changes in the routine blood tests that need further workup and explanation.</p>
<p>Scheduled protocol kidney biopsies</p>	<p>During a kidney biopsy, a small sample of the transplanted kidney tissue is taken with a small needle, and tested for signs of rejection, recurrent disease, medication damage, infection, or even poor blood flow or obstruction. Biopsies are considered the gold standard for evaluating any damage to the transplanted organ. However, biopsies can only detect rejection findings that are present at that moment, so it is important to consult your transplant team if you</p>	<p>In some centers 3-6 months post-transplant, and 1 year post-transplant, and if there are concerning rejection symptoms or laboratory findings. Not all units perform protocol kidney biopsies. Heart transplants always have protocol biopsies, most frequent in the first 6 months. Lung biopsies are performed less frequently while pancreas biopsies are performed only rarely.</p>

	experience any symptoms of kidney rejection or abnormalities between scheduled visits.	
Cell-free DNA testing	Donor-derived cell-free DNA ( <b>dd-cfDNA</b> ) is a noninvasive test of your transplanted kidney that may enable more frequent, quantitative, and safer assessment of rejection and/or injury status which needs to be confirmed by biopsy if treatment is contemplated	Is most often used when there is suspicion of rejection. In some centers, it is used regularly as part of screening in the routine follow up of patients and if they undergo a rejection episode. It is most helpful in knowing if the rejection was fully reversed so that medications may be reduced.



A callout box with a blue background and a white line pointing to the table above. It contains a yellow circular icon with a QR code symbol, the text "SCAN ME" in yellow, and "to learn more about supportive care in transplant from a provider" in white. Below this is a circular portrait of a man, the text "Syed Huzain, MD" in yellow, and "Assistant Professor of Medicine, Columbia University Irving Medical Center" in white. A QR code is located on the right side of the box.

# Long-term Care Plan

At some point in or just after the first year after transplantation, a patient is generally referred back to a community provider, for example a nephrologist experienced in management of transplant recipients, or your primary care doctor to oversee care. This provider will continue to order tests used to monitor the function of your organ, side effects and signs of rejection. It is commonly agreed that the results of all the tests are immediately forwarded back to the patient's transplant center where they are reviewed by the team which assumes the role of an expert consultant to the local provider. However, the role of the local provider broadens when he/she becomes the «conductor» of the care for organ recipient. Additional local and/or transplant center experts are invited to make sure you are screened properly for your overall health care beyond your transplant. As with the transplant center visits, it is also important that the local provider visits be scheduled every 2-4 months and that the patient notes and reports any changes that he/she sees between visits and that the report of the visit is forwarded for review by the Transplant Center team.

It should be emphasized that many of the immunosuppressive drugs cause side effects that may affect and alter recipient's metabolism. There is therefore both a need and an important benefit to also paying special attention to diet and exercise. Consultation with a dietician and a rehabilitation service may in many instances be of great benefit to fully successfully recover and stabilize with the new functioning organ. Mental health is of course also a very important aspect of any chronic illness/management. Professional support by a psychiatrist or a psychologist in some instances may be required and/ be of great benefit. This is common sense and is not cause for shame.

## Specialists

The transplant team (sometimes together with your local provider) should be able to recommend other specialists who have experience managing transplant recipients. These include cardiologists to monitor the functioning of your heart, pulmonologist if you have asthma or COPD or any respiratory difficulties, gastroenterologist if you have gastric, esophageal or intestinal diseases or persistent gastrointestinal symptoms or problems, endocrinologist if you have diabetes or thyroid/parathyroid disease, and dermatologists to monitor for skin cancers, etc. Screening on a regular basis (at least annually, and frequently more often depending on the situation) should include:



Screening	What they do	How often to go
<b>Dermatologist (skin doctor)</b>	<p>Skin cancer screening</p> <p>Provide medications for acne, rosacea, eczema and dry skin</p>	<p>At least annually* for skin cancer screening AND if you have issues with acne or dry skin</p> <p>*More frequently (can be 4x/year) if skin cancer is discovered or depending on personal characteristics and profession.</p>
<b>Ophthalmologist (eye doctor)</b>	<p>Monitor for cataracts or changes in vision, including glaucoma, and retinopathy in diabetes</p>	<p>Annually, starting 6 months after transplant or when prednisone dose is 10mg per day, whichever is earlier. Diabetic patients should be examined more often, at least 3x/year if there are no progressive changes.</p>
<b>Dentist (teeth)</b>	<p>For overall dental hygiene</p>	<p>Annually, starting 6 months after transplant OR if you experience any dental or gum pain. Hygienist visits should be at least 2x/year.</p> <p>*Note: patients are advised to take antibiotics in advance of any dental cleaning or procedure (1-2 hrs before the procedure).</p>

## Cancer Screening

In recent years, with major progress in organ transplantation, as well as immune biology, immunosuppression, and monitoring, organ transplant recipients are living much longer with functioning grafts. With that comes an increased risk of developing cancer, with studies showing multiples of increase in risk of some cancers: 100 times higher risk in skin cancer\*\*, and 20-120 times higher risk in lymphoma\*\*\*. It is well known that factors that change the immune system, such as immunosuppressant medications, can facilitate the development of some cancers, especially those associated with viruses, such as lymphomas, cervical and skin cancers. The most common cancer to develop is non-melanoma skin cancer (basal cell or squamous), which can be treated successfully with excision through surgery. However, the risks for more serious skin cancers (cervical) and

\*\*Organ Transplant and Skin Cancer Risk | UCSF Health

\*\*\*Risk of lymphoma subtypes after solid organ transplantation in the United States | British Journal of Cancer

excision through surgery. However, the risks for more serious skin cancers (cervical) and lymphomas (blood cancers) are also elevated and need to be screened for with annual Pap smears in all women and with blood tests and excision biopsies of suspicious lymph glands or masses found unexpectedly on radiologic tests. Early screening and detection of cancer is critical to initiate early treatment to lead to a successful outcome.

Screening guidelines may vary, so you should consult your transplant team for cancer screening recommendations that may vary with age and many other factors. Many of these recommendations are similar to cancer screening guidelines in the general population, but with accelerated schedules appropriate for high-risk patients. General recommendations for cancer screening are listed below\*:

Type of cancer	Screening recommendation	Timing
<b>Breast</b>	Mammogram	Every year for women older than 45 years of age. These guidelines are different in those with a family history among nearest blood relatives.
<b>Colorectal</b>	Fecal occult blood test (FOBT)  OR	Annual or biennial for everyone over 50 years of age.
	Colonoscopy	Every 5 years for everyone over 50 years of age. More often (1-2 yrs) among those with nearest relatives younger than 45 yrs of age with gastrointestinal cancer or if a polyp(s) is found on an examination.
<b>Cervical</b>	Cytological screening (Pap smear)	Every year in women over 21 years of age.
<b>Prostate</b>	Lab test for prostate specific antigen (PSA), an early marker for prostate cancer AND a digital rectal exam	Annual in all men over 50 years of age.
<b>Hepatocellular (Liver)</b>	Lab test for alpha-Fetoprotein, a marker for hepatocellular	Every 6 months in high-risk individuals (heavy alcohol

\*Acuna SA, Huang JW, Scott AL, Micic S, Daly C, Brezden-Masley C, Kim SJ, Baxter NN. Cancer screening recommendations for solid organ transplant recipients: a systematic review of clinical practice guidelines. American Journal of Transplantation. 2017 Jan 1;17(1):103-14.

<p><b>Carcinoma of the lung (history of smoking)</b></p>	<p>carcinoma AND a liver ultrasound</p> <p>CT of the lung</p>	<p>use, cirrhosis, chronic liver disease, history of hepatitis)</p> <p>Chest X-ray every 1-2 years.</p>
<p><b>Skin</b></p>	<p>Self-skin examination</p> <p>AND</p>	<p>Every month after receiving transplant.</p>
	<p>Total body skin examination by expert physician or dermatologist</p>	<p>Every 6-12 months after receiving a transplant.</p>

# Quality of Life

Many organ transplant recipients experience a significant difference in quality of life after transplantation. Transplantation can be life-changing, with commonly noted positives such as enhancing physical wellbeing, freedom from dialysis or frequent hospital visits, and extended, close to normalized lifespan. However, the journey does not end with surgery. Many factors such as mental health and social support contribute to post-transplant recovery and quality of life, and need to be monitored, understood, addressed by graft recipients and their families and close friends, as well as professional caregivers, and treated when problems are recognized.

**It is helpful to understand what you might experience in your journey ahead. Read below for a summary of common changes people experience and report, and find other transplant patients who are further along in their journeys to learn about their experiences at [TransplantLyfe.com](https://www.transplantlyfe.com):**

## Physical Health and Well Being

### Exercise

Exercise recommendations will vary, and some patients may require physical rehabilitation or physical therapy. However, in all transplant recipients, a gradual return to a healthy exercise routine is strongly recommended for overall health. In many instances, particularly in patients who have been sedentary by habit and/or because of illness for more than 6 months, initial assistance in starting or resuming an exercise program may be necessary and, in all instances, would be very helpful.

- 1** Generally, a healthy level of physical activity is 2-3 hours a week of moderate-intensity activity (walking, biking, dancing, gardening) or 1-2 hours a week of high-intensity activity (running, swimming, jumping rope). Walking in place in front of a TV or on a treadmill for 30 to 60 minutes each day (3,000 – 5,000 steps) may be an easy way to start the program with gradual progression to that level.
- 2** Discuss with your transplant team what a healthy return to exercise looks like for you, especially early after the transplant surgery. A rehabilitation facility in your neighborhood may be a good way to initiate supervised training (and it is supported by Medicare if in an approved facility for the first 60 days).

## Nutrition

After an organ transplant, your diet still plays a large role in your overall health. Since you are immunosuppressed, there are certain foods that are basically off-limits, such as uncooked fish (sushi), meat (meat tartare) and shellfish (raw oysters). One should avoid salad bars and be sure that any raw vegetables or fruits are washed properly. See [Foods to Avoid After Transplantation | National Kidney Foundation\\*](#).

Following transplantation, many patients continue to restrict their fluid intake (dialysis schedule) and this habit must be broken quickly; after transplantation they should drink sufficiently to avoid thirst and dehydration (especially in warm weather and after exercise) and maintain good urine output. Many people also report improved appetite after transplantation, which may cause unwanted weight gain. Furthermore, diet can affect absorption and levels of transplant medications. On the flip side, transplant medications affect your body and the levels of blood fats (such as cholesterol), blood sugar, and minerals such as calcium, magnesium or potassium.

While dietary recommendations vary depending on type of organ transplanted, reason for transplant, age and overall condition, some general principles apply:

- 1 Limit processed foods, sweets, pastries, and sugary drinks. High calorie foods and weight gain can cause problems such as heart disease, diabetes, and high blood pressure.
- 2 Increase protein intake soon after surgery, with a gradual return to normal protein intake: protein helps to build and repair muscles and tissues, which is important in healing after major surgery.
- 3 Supplements and vitamins: Your transplant team may recommend certain supplements and vitamins. Do not start any supplements on your own, as these may interfere with medications and may be injurious to you and to your transplant. Review everything you are taking outside of your prescribed medications with your transplant team, including any herbal remedies or over the counter supplements and vitamins.

## Other Recommendations\*

- **Hair care:** some of the immunosuppressive medications (Tacrolimus) can weaken your hair or cause hair loss, usually initially and temporarily. Other medications (particularly cyclosporine) can cause increased male pattern hair growth. Before using any hair products (hair dye, bleaching, facial hair remover), it is best to check with your transplant team as your hair and skin are more sensitive than usual.

\* <https://www.kidney.org/kidney-topics/foods-to-avoid-after-transplantation>  
\*\*<https://columbiasurgery.org/kidney-transplant/resuming-life-after->

- **Smoking:** after transplantation, smoking dramatically increases your risk of developing pulmonary infections and cancer and reduces your ability to heal. Quitting smoking is highly recommended for your overall health and especially for maintenance of your newly transplanted organ! Professional assistance may be required to stop smoking, even hypnosis.
- **Sexual activity:** a person's sexuality is seriously affected when they have kidney disease. Kidney transplantation can significantly improve some aspects of sexual function. Men may be able to attain / maintain an erection while they were previously frequently unable to do so because of many antihypertensive medications and because of kidney failure. Urological consultation may be helpful following transplantation. Following successful renal transplant, women may resume menstruation, and pregnancy may also become possible while it is unlikely while on dialysis. However, some of the medications, especially some blood pressure medications, may affect sexual function. If you are sexually active, speak with your doctor and /or gynecologist about the safest and best birth control and review safe and healthy practices, including monitoring for sexually transmitted infections.

People using immunosuppressive medications may have a higher rate of urinary tract infections (UTI). If you experience symptoms of a UTI, such as burning with urination, change to the color (cloudy, pink, or red) or smell of urine, frequent urination with or without burning, or fever, contact your transplant team or primary physician to obtain a urine culture. Sometimes, you must obtain an ultrasound of the kidney to rule out kidney infection and/or obstruction (transplanted kidney has no active nerves and therefore does not manifest pain other than that in the surrounding tissues) and if there is a UTI, get treated with appropriate antibiotics. Sometimes you may need to be admitted and receive intravenous antibiotics if the UTI is severe.

- **Pregnancy:** even without regular menstrual periods, it is still possible to become pregnant after transplantation. Family planning is an important part of quality of life. If interested in becoming pregnant after transplantation, it is important to discuss potential risks and medication adjustments with the transplant team and with the gynecologist. It is best to be followed by a gynecologist experienced in management of renal transplant recipients. Some of the common medications preventing rejection are damaging to the fetus and will need to be modified or changed to others. Pregnancy is not recommended in the first year after transplantation when the risk of rejection episode is highest and its treatment with higher doses of special immunosuppressives may be dangerous to the fetus.

## Mental Health and Wellbeing

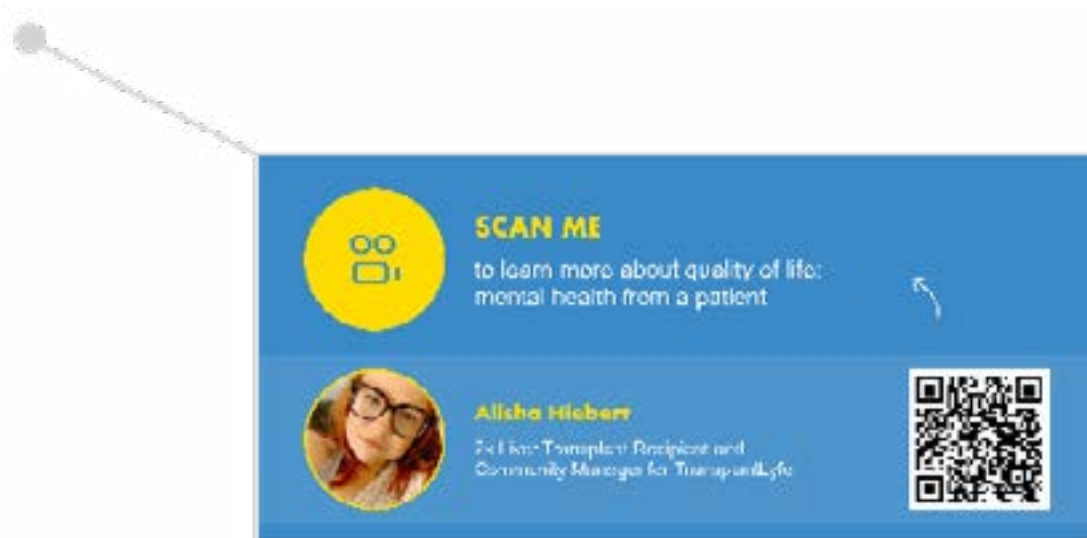
### What to Expect

- **Emotional response:** patients experience a range of emotions, from relief or gratitude to survivor's guilt, anxiety or depression. Additionally, you may feel a sense of guilt/obligation to the donor or donor's family and your care partner. Hallucinations and fantasies about the donor are not unusual, especially in dreams. Emotional support from family, the transplant team, and sometimes professional psychiatrist/psychologist is vital for navigating this critical period of recovery from a transplant, and you should seek professional help if you and/or your family feel it is needed.
- **Freedom from the hospital and constant dependence on doctors:** a commonly quoted positive change is freedom from frequent doctor's visits or dialysis sessions that can be a burden on mental health. The break from the social setting of a dialysis unit may also offer a mental challenge for lonely patients and needs to be addressed following transplantation. Relatively frequent hospital readmissions for various reasons are also a significant burden which is relieved by a transplant.
- **Return to function:** for some patients, transplant can improve physical wellbeing such that they can return to daily activities, hobbies, or work. This can provide a sense of normalcy, independence, improved self-worth, and satisfaction with happiness.
- **Pill fatigue:** some patients report that numerous complex post-transplant medication regimens can cause anxiety or fatigue, called "pill fatigue", especially given that you need to take many of the pills on a daily scheduled basis without omissions, for the duration of the transplant. Deviation from such a schedule usually bears the heavy price of rejection of the graft which may become irreversible and be lost. With kidney loss, there is the option to return to dialysis and with pancreas loss there is return to daily insulin, but with heart and lung allograft losses, there is usually loss of life (lungs and hearts rarely have been retransplanted). In case of liver transplant this may be sometimes avoided by re transplantation of the liver. Consult your transplant team and pharmacist as needed, to help simplify or address these feelings about medications and use all available means to remember to take them as instructed and not forget to take adequate numbers of pills when traveling. Also try asking other experienced transplant recipients how they manage to adhere strictly to their schedule of taking their medications. You are not alone!

### Tools for You

Transplant recipients can experience a dramatic change and improvement in their daily routines and quality of life as compared to their life while waiting for a transplant organ. Adjusting to these changes can be stressful and difficult. Mental health professionals,

such as psychologists or counselors, can help address anxiety, depression, or emotional challenges.



## Social Support and Wellbeing

### What to Expect

- **Importance of support networks:** Support from loved ones can significantly impact quality of life after transplantation. Transplant recipients often find that after transplantation they have more time and/or energy to interact with their loved ones. It is valuable for family members to become familiar with the advantages and problems with transplantation so that they can participate effectively and intelligently support their loved one. Positive relationships provide emotional and practical support especially during early recovery but also throughout the life of the graft and of the patient afterwards.
- **Care partner burnout:** Transplantation is a journey that early on requires logistical and emotional support from a caregiver(s), such as transportation to appointments or help with daily activities such as cooking or cleaning. This can be physically and emotionally taxing for a caregiver. Temporary outside help from family, friends, or, if affordable, from professional caregivers may be needed to achieve a successful outcome.

### Tools for You

In the journey to transplantation and afterwards, you are not alone!! It is important to rely on your support network of loved ones, healthcare providers, and even, in some instances, selected peers and friends:



- **Family and friends** provide emotional support and practical assistance. This support is essential for maintaining mental health, and coping with both immediate and long-term challenges, as they arise. And don't forget to ask for help with basic things, like grocery shopping or pet care, when you need it. Pets, such as dogs and cats, may provide comfort (birds and rodents, as carriers of diseases, should be avoided).
- Other **transplant patients** can be very helpful and comforting. Many transplant recipients have joined support groups (consider trying - [TransplantLyfe's Support Groups](#)) where there is a strong community of recipients and donors with experiences similar to yours. In these settings, people often feel better understood and validated. Furthermore, these may be safe spaces where recipients find solutions for challenges with which they are struggling which are similar or identical to those previously faced and conquered by others.
- Social support can come from other, different avenues. Many transplant recipients report that returning to work, school, or community activities after transplantation has had a positive effect on their mental health and recovery.

**Communication with your healthcare providers:** open communication is essential and welcome. You know your own body best, so your experience of any changes to your physical or mental health should be communicated without hesitation and promptly to your transplant team and to your local provider. Ask your transplant center for the best way to reach them for urgent issues.

# Insurance and Financial Access

After receiving a transplant, managing medications, navigating insurance and pharmacy demands, and keeping up with follow up appointments, are a critical part of recovery and long-term care. As of January 1, 2023, kidney transplant recipients qualify for lifetime Medicare coverage of their immunosuppressive drugs if they do not have other insurance coverage. For more information and to see if you are eligible, visit this page\*.

## Medication Coverage - Formularies and Prescription Coverage

### What is Prescription Coverage?

Prescription coverage describes what and how much your insurance plan will cover of the many drugs that you have been prescribed. Below are listed certain details (NOT ALL) that need to be understood:

- **Coverage Tiers:** medications are often categorized into tiers that determine the cost to the patient. Higher-tier drugs might have higher co-payments while lower-tier drugs (typically generics) might have lower co-payments. The co-payment is what you, the patient must pay, in addition to what the insurance pays.
- **Prior Authorization:** some medications may require prior authorization from the insurance provider before they are covered. This process can ensure that the medication is necessary and cost-effective. This is a process that your transplant team may help with.
- **Appeals Process:** if a necessary medication is not covered, patients can appeal the decision. This involves working with their healthcare provider to supply evidence for the absolute need for the specific medication to maintain the patient's wellbeing.

### What is a Formulary?

A formulary is a list of medications that are covered by a health insurance plan. These lists are created based on the efficacy, safety, and cost-effectiveness of the medications. Transplant recipients need to ensure that immunosuppressive drugs and other essential medications are included in their insurance plan's formulary. In order to find the formulary, go to the insurance plan's website and search for "find drugs" or "covered medications".

\*<https://www.kidney.org/kidney-topics/expanded-medicare-coverage-immunosuppressive-drugs-kidney-transplant-recipients>

## How Do I Get My Medications?

While your preferred local pharmacy may be an option, transplant patients often opt for specialized pharmacies or medication delivery systems given the relatively low supply and complexity of the medication regimen. Sometimes the health plan mandates that certain drugs come from certain pharmacies, such as specialty pharmacies which offer home delivery services and other support.

## This is Still Expensive!

What can you do if the cost of your medications are still too much for you to manage on your budget? Medications can be expensive and navigating insurance plans can be complicated. The first step would be to notify your transplant team, who may provide you with options, such as changing medications to one that is covered by your insurance, or help you to apply for either Medicare coverage or for available special plans provided by the pharmaceutical company. However, there are other options for medications at a reduced cost or even for free for eligible patients.

Source	Programs offered	Where to find more information
Patient assistance programs (PAPs)	Many pharmaceutical companies offer PAPs to provide medications at a reduced cost or even for free to eligible patients who cannot afford them	The pharmacist or transplant team may provide information on PAPs for which you may qualify, or you can contact directly the pharmaceutical company that produces the drug to find if PAP exists and if you qualify for it.
Non-profit organizations (NPOs)	<ul style="list-style-type: none"> <li>● <b>Grants and Scholarships:</b> Various NPOs offer financial assistance in the form of grants or scholarships to help cover the cost of medications and other medical expenses.</li> <li>● <b>Support Services:</b> These organizations may also provide additional support services such as transportation to medical appointments and access to support groups.</li> </ul>	<p>There are a number of national transplant organizations such as the National Kidney Foundation or the American Liver Foundation that offer drug discount cards and consolidate NPOs offering support.</p> <p>Social Service should assist you in finding any needed support services.</p>

<p>Pharmaceutical manufacturers</p>	<ul style="list-style-type: none"> <li>● <b>Co-pay Assistance Programs:</b> These programs help to cover the cost of copayments for medications, making them more affordable for many patients.</li> <li>● <b>Discount Programs:</b> Some manufacturers offer discount cards or coupons to reduce the out-of-pocket cost of medications.</li> </ul>	<p>The transplantation team or your primary care provider may be aware of discount programs for your specific medication regimen. Contacting the Manufacturer directly (Marketing or Public Relations sections) may also be effective.</p>
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# Notes and Questions

It is important to always be prepared to ask questions of your provider about your concerns and new problems (both physical, social, and mental) that may have arisen between visits. It is also wise to write and keep notes about the answers and to maintain a journal about how your body has been performing (symptoms) since your last visit and report those observations to your provider. It is best not to rely on memory alone, since it is frequently incomplete and therefore fails to be as informative as necessary to result in appropriate interventions to maintain the best possible outcome.

Things to bring to all provider visits:

- Appointment calendar: confirm your upcoming appointments
- Medication list (include name, dose, frequency), medication bottles, pill box
- Blood pressure, weight and temperature logs
- Blood sugar log (if appropriate)

Bring your notes about any symptoms or changes that you have noticed in your body. Be certain to ask questions at each visit about future events that you have planned, including travel plans and contemplated life or work changes, to prepare you for the next few days, weeks or months:

- **Ask about medications**

- Bring up anything that you have issues with, such as need for continuation, management of side effects, timing of medications, cost of medications, interaction with any new foods or other drugs.

- **Ask about other doctor visits**

- Who else should I see (primary care, a kidney doctor aka nephrologist, a heart doctor aka cardiologist, brain and nerve doctor aka neurologist, etc...)?
- When should I start cancer screening, and what cancer(s) should I get screened for?
- Vaccines, flu shots, COVID boosters, shingles and other recommended yearly health checks

- **Ask about nutrition**

- What new foods that you want to try may interact with your medications?
- What is a good diet for recovery at this stage of my journey?
- What foods should I avoid to protect my transplanted kidney?
- What is a healthy diet and weight for my overall health?

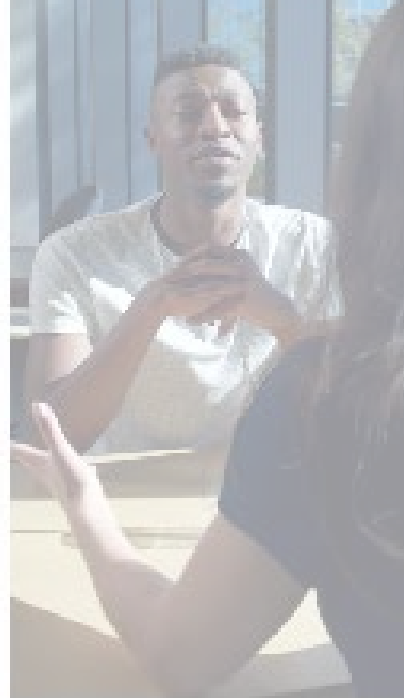
**● Ask about exercise**

- When can I start exercising?
- What kind of exercise do you recommend, and how often?
- What exercise or sports to do or to avoid? One should generally avoid contact sports (boxing, football, lacrosse, ice hockey) sudden jolts (e.g. trampoline, moguls in skiing) bungee jumping, horse jumping or galloping. Ask about specific sports that interest you. Acceptable sports include swimming (not diving from any height), walking, running, (but not pole vaulting or high jumping), golf, tennis, basketball (with protection over the kidney if competitive or professional) soccer (not as a goalie), skiing (no moguls), and many others.

**● When can I do other things such as**

- Socializing (with adults versus young children)
- Lift heavy items (including children)
- Go to work / school
- Travel (specify countries with well developed health care systems and public health vs. low and middle income countries with no transplant services and underdeveloped public health system.) Stay vigilant regarding food inspection, contaminated water, unvaccinated domestic animals, unapproved fertilizers for vegetables and fruit.
- Take care of pets. Appropriate pet vaccination is mandatory. Most birds should be avoided.

You made it to the end of this lengthy document. You should be better informed about what is ahead in your journey and how to make the most success out of it. Remember – it is time to THRIVE with your new organ!



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