



Things Patients Wish They Knew Before Transplant Surgery **Prepared by Patients for Patients**

The following list of tips, talking points, and questions to ask of your transplant team were compiled in late 2021/early 2022 from over two dozen Alport syndrome patients of varying ages and backgrounds who previously received the Gift of Life in the form of a living or deceased donor kidney transplant.

After communicating as a group, it became readily apparent many practical aspects of renal transplant were not addressed in advance, brought to patients' attention at the last-minute, or only mentioned in passing. In addition, important decisions and preparations for surgery are often required when patients are experiencing fatigue and/or brain fog caused by end-stage-renal failure.

We hope this document, intended for Alport patients ages 18+ approved as a candidate for kidney transplant surgery, helps you best prepare and-reduces the number of "unknowns." Feel free to print and bring this tip sheet with you to your transplant clinic to ensure your individual needs are addressed.

Preparation for Surgery

Surgery Requirements:

Am I compliant with my transplant clinic's policy on COVID and all other vaccination requirements for potential organ recipients? Note: Clinic policies regarding COVID vaccination may potentially change due to updated recommendations from the CDC.

Additional Pre-Surgery Questions to Consider Discussing with your Medical Team:

What is a realistic assessment of how long I'll wait for a deceased donor (cadaver) kidney in my part of the country? Should I pursue "multiple listing" (evaluation and approval at more than one transplant center) to potentially receive an organ sooner?

What is the HLA match of my living or deceased donor organ? How strong of a match is it and will this influence the level of immunosuppressant medication I will need after surgery?

What is the induction method used for my transplant surgery? Are there different options available to me?

Which immunosuppressant medications will I be placed on after surgery? Do I have options?

If I don't immediately produce urine after transplant surgery, will I require temporary dialysis to help "wake up" my new kidney?

In the case that I go into acute rejection after a living donor gift, what can be done to preserve my newly donated kidney?

If applicable, discuss personal history of reaction to anesthesia in prior surgeries. Discuss potential inclusion of anti-nausea medications with your surgery anesthesia team.

Am I at risk for Cytomegalovirus (CMV) infection after surgery? If so, how will I be treated to mitigate risk?

Am I at risk for anti-GBM (glomerular basement membrane) disease following my transplant?

Are there any food items or medications I should avoid before surgery?

Will a ureteral stent be placed during my transplant surgery? If so, please provide some expectations around what I may physically feel and when/how the stent will be removed post-surgery.

Preparation for Immediately Post-Surgery

Note: Having a support network is critical during the first few weeks after surgery. You will likely not be allowed to drive on your own. You will be required to identify a primary caregiver who will participate in transplant education meetings, accompany you to all post-surgical follow up appointments, help manage your medications, and more for at least the first month post-transplant. It's important to thoughtfully select who this person will be for you during this time. It's also important to understand your role as a caregiver to others will be affected by your surgery and recovery time.

Who exactly is my follow-up care team (and for how long), especially if my surgery is performed a great distance from home? How often will I need to meet with this team after surgery and what will that schedule look like (once weekly/twice weekly and for how long)?

What is a realistic surgery recovery time frame? What is the projected length of my hospital stay? Can a caregiver stay overnight in the hospital with me – can I advocate with the hospital to approve this? (Can be even more important if hearing loss is a part of your Alport experience).

How long until I can drive, exercise, return to my job?

How can I improve my comfort level right after surgery?

Will I require placement of central venous catheter or central line (used for blood samples, medications)? Is this necessary if I already have a hemodialysis permacath in place?

Will I leave the hospital with a document outlining my exact medications, dosages, and required times to take them? Will I leave the hospital with important medications or be expected to get my initial doses from a pharmacy? *Note: It takes time to regulate immunosuppressant medication doses – it is common to experience frequent adjustments to medications and*

potential changes to creatinine value for the first few weeks/months post-surgery...this can be stressful!

What are the common signs of acute renal rejection I should be aware of and what do I do if I experience them? Call my transplant care team? Visit the ER?

Are there any alarming short-term medication side effects I should tell my care team about if I experience them?

Will I go home with a foley catheter to continuously collect urine? If so, please provide detailed care instructions.

Which supplements or over-the-counter (OTC) drugs should be avoided after-surgery?

What over-the-counter or prescription medications can be safely taken to help with irregular bowel movements, insomnia, indigestion, ureteral stent removal discomfort, and other symptoms post-surgery? Which pain management medications are safest and best for me?

Discuss after-care for kidney transplant surgical wound: Can I get it wet when showering? Do I need to change the dressing myself? What potential signs of infection should I look for?

How can I adhere to my schedule for taking medications? *Note: Common patient solutions include setting cell phone alarms for pill times, using a weekly pill box organizer, and using mobile apps that include a reminder and tracking of dosing/refills.*

What do I do if I miss a dose of immunosuppressant medication? Should I skip the dose/wait until next dose or try to ingest immediately when realizing my mistake?

Will I need to take and record my weight or blood pressure daily after surgery?

Surgery Discharge Day:

During the final 24 hours in the hospital prior to surgery discharge, it is helpful to keep a log of all the medications given to you by your nurses/care team, including dosage, and times administered. You can write these down on paper or take notes in your cell phone. This will help guide you on what time pain medications were last given and what doses of medications have already been administered on this day to avoid confusion or double dosing.

Ask your care team to go through the medication list with you to be sure you understand which medications to take and when. Some medications may be referred to by one name in the hospital setting but referred to as another name on the label of the bottle from the pharmacy.

Other Short-Term Care Items to Discuss with Your Medical Team:

Will I be on prednisone? Can you explain common side effects of this medication?

Will I require a prescription mouthwash to prevent potential oral infections when severely immunocompromised in the first weeks after transplant?

What if I experience prolonged insomnia in the initial days and weeks after surgery? What can be done to help?

Can I speak to a renal transplant dietician to better understand realistic diet guidelines for the short-term?

What resources does my clinic offer to help educate me about life as a transplant recipient?

Long-Term Transplant Care

Reminder: You are an active part of your care team! Never be afraid to ask questions or voice concerns you may have!

Familiarize yourself with your medications. Research information regarding the various brands of immunosuppressant medication, their potential availability/cost, and the clinical data behind each to help make informed care decisions along with your transplant team. Ask if you have flexibility in your post-surgery medication protocol, or if all transplant patients have to be on the same medications due to the hospital's research/clinical study commitments.

Long term immunosuppressant side effects can include increased cancer risk, bone health issues, and thyroid, cardiac, and neurological complications. Ask your care team about the long-term side effects associated with your particular medications and what you can do to mitigate potential risks.

Your team should be able to connect with a renal dietitian to maintain optimal long-term health post-transplant. Ask: What foods truly need to be avoided vs. which foods are "risky?"

If you feel your needs or concerns are often not adequately addressed by your care team, consider a second opinion from another transplant clinic (telehealth or in person).

Long-Term Care Questions for Your Team

Should I be taking any supplements, such as calcium or vitamin D?

Do I require prophylactic antibiotics for dental work?

As someone who is immunocompromised during the COVID pandemic, what additional steps should you take to maintain optimal health?

Does the transplant hospital offer mental health resources for transplant patients? Do they have an in-person or virtual support group?

Long-Term Insurance and Financial Considerations:

Costs of surgery and subsequent immunosuppressant drugs should be discussed with your transplant center's appropriate staff such as the social worker or finance coordinator, and your insurance provider(s). These talks are often pre-requisites to surgery approval. As most kidney transplant patients will be on immunosuppressant medications indefinitely, the following questions are important to consider for long-term care:

General questions: Am I still eligible for Medicare, if so, how do I apply? Does it matter if my transplant center is “out of network” with my insurance plan? Will this affect the cost of follow up visits?

Drug Coverage: Will my private insurance cover immunosuppressant costs if I change medications? What happens if my employment status/insurance changes post-surgery? What do I do if I’m self-employed or lack employer-provided insurance in the future? Those under age 26: What happens when I am no longer part of my parents’ insurance coverage?

Note: Starting January 1, 2023, eligible individuals may receive expanded Medicare coverage for immunosuppressant drugs beyond the current 36-month period. Learn more about [End-Stage Renal Disease Medicare coverage on their website](#).

Alport Syndrome Foundation would like to acknowledge Alport patient and transplant recipient Miriam Gabai who was instrumental in virtually convening Alport transplant recipients to share experiences and discuss gaps in care. Thank you to all those who generously volunteered their time and input to help craft this document. Additional transplant resources can be found [on the Alport Syndrome Foundation website](#).

There are some new innovations in kidney transplantation including clinical trials that are evaluating STEM cell therapy during the transplant process. The end goal of these studies is to avoid the need for kidney recipients to take immunosuppressant drugs for the rest of their lives. These studies often remove financial barriers by taking care of costs for travel and transplant surgery. During your transplant evaluation, consider asking your care team about potential research opportunities that may be available at your hospital/clinic. You can learn more about clinical trials, for patients pre-and post-ESRD, [on the ASF website](#).

Interested in connecting with other Alport transplant patients and/or contributing to future transplant resources? Email ASF Staff: info@alportsyndrome.org