



Considerations When Seeking a Living Kidney Donor

This document is largely intended for patients who have already been approved as candidates for renal transplant and who are currently searching for a living donor. However, all the information below can still serve as an important educational tool for caregivers and all those interested in learning more about this topic.

Asking someone to be a living donor can be one of the most challenging conversations a potential transplant recipient will face. Living donors, in particular, allow a potential recipient to bypass the long wait times that exist to receive a deceased donor kidney.

The following resource was written with the direct input of both living kidney donors and Alport patient recipients and reflects their shared experiences regarding living donation.

Encouraging Transplant Data

According to [a research article](#) authored by Dr. Clifford Kashtan of Alport Syndrome Foundation's (ASF) Medical Advisory Committee, preemptive kidney transplantation (receiving a kidney donation before the need for dialysis) "is the treatment of choice for ESRD [end stage renal disease] resulting from Alport syndrome." He goes on to note that while "Alport patients who require chronic dialysis exhibit relatively good outcomes," preemptive kidney transplantation remains the "preferred mode of therapy" for Alport patients approaching ESRD.

More recently, in a 2022 layman's summary of [Racial disparities and trends in kidney transplant outcomes in patients with Alport syndrome](#), co-author Dr. Kashtan noted to ASF, "There are two major reasons for the superior outcomes of kidney transplantation in people with Alport syndrome. First, people with Alport syndrome usually have good heart function when they are transplanted." This is not necessarily always the case with other chronic kidney disease patients. "Second, Alport kidney disease does not come back in the transplanted kidney, unlike some other important causes of kidney failure," said Dr. Kashtan.

Preparing for Preemptive Transplant

Despite positive outcomes for patients, the challenge remains that preemptive transplant requires considerable preparation. Most transplant centers will begin a transplant workup on a patient with an estimated glomerular filtration rate (eGFR) of less than or equal to 20. Sometimes patients must self-advocate for referral to a transplant clinic if they feel their lab values are quickly trending toward renal failure and their routine nephrology visits are relatively infrequent.

Dialysis may be required when a patient reaches an eGFR of 15 or lower, known as stage 5 chronic kidney disease or ESRD. Listening to your body and being in tune with any changes you may feel is imperative. Unfortunately, due to [the “carrier” misconception](#), some female (birth sex) Alport patients may not expect abrupt changes in renal function and find themselves especially unprepared for the need for dialysis or transplant. Additionally, common symptoms of ESRD, such as fatigue, nausea, and leg cramps, can be misinterpreted as other health conditions by members of either birth sex.

When researching medical centers with kidney transplant programs, you are making an informed decision for both your and your potential donor’s health. This research can begin at any time – there is no downside to early preparation. To quickly find centers near you, visit the [Organ Procurement and Transplant Network website](#).

Transplant Surgery Following Dialysis

Despite one’s best efforts, it is not always possible for patients to avoid dialysis. ASF asked transplant nephrologist Alexander Wiseman, MD (AdventHealth Porter hospital in Denver, CO) to comment on the number of patients undergoing transplant workup and nearing “the finish line” (living donor surgery day) but for one reason or another, find themselves on temporary hemodialysis for a few days or even weeks.

According to Dr. Wiseman, “This usually is due to concerns from the transplant surgery team regarding safety of the surgical procedure itself. Some concerns are fluid overload or high potassium levels going into a transplant, so very often a brief period of time of dialysis may be necessary to stabilize in preparation for surgery. This is usually a precaution rather than an emergency. It is unfortunately sometimes uncomfortable to have a dialysis catheter placed and is a time commitment to start dialysis, delaying what is of course the best treatment option (transplant). It is not always easy to manage and avoid this scenario, but the best strategy is to be very diligent about a renal diet, and monitor and manage fluid intake as closely as possible with your nephrology team.”

Patients and families often ask if there are any adverse effects on the living donor transplanted kidney for those that have been on short- or long-term dialysis. “There really is no significant risk to long-term success (or even short-term success) with pre-transplant dialysis exposure for a brief period of time. Those of us who care for patients before and after transplant would like to avoid dialysis mostly for the increased infection risks associated with dialysis catheter placement, but short periods of dialysis in general do not portend worse outcomes following transplant,” notes Dr. Wiseman.

Short-Term Dialysis After Transplant Surgery

While many transplanted kidneys begin producing urine immediately, it is sometimes the case that a newly transplanted kidney (from a living donor or from a deceased donor) is slow to function. The term “sleepy kidney” is used to describe this occurrence. Dr. Wiseman noted sleepy kidneys can especially occur in settings of kidney paired donation when kidneys are donated from one location, placed in cold preservation fluid on ice, and flown across the country for transplant at another center. “After transplant, most transplant programs will employ a ‘wait and see’ approach, and use dialysis sparingly, particularly in the first week. If the kidney takes longer than 1 week to begin to show signs of function, then typically a more routine dialysis schedule will be used until urine output increases and labs show kidney function,” says Dr. Wiseman.

Disqualifications for Living Donors

As Alport syndrome is a genetic disease, it is worth noting affected family members in the immediate and extended family are ineligible to donate. In particular, female (birth sex) family members/relatives experiencing hematuria (and especially proteinuria) should not be considered as donor candidates, as some transplant clinics may be unfamiliar with Alport syndrome and the misinformed notion of female “carriers.” It is also important to mention the genetic component of our disease to unrelated potential donors to dispute the common misconception that it is easy to find donors among relatives. Family members with an unclear health history are advised to be genetically tested to screen for Alport syndrome. As previously noted, one silver lining of Alport syndrome is that it will not manifest in or “attack” the donated organ.

Besides the presence of Alport syndrome, common living kidney donor disqualifications include uncontrolled high blood pressure, diabetes, a history of cancer, and the presence of certain infectious diseases.

Preparing for “the Conversation”

Patients seeking a kidney donor commonly note “suffering in silence” and internally struggling with their need. This time of grief and acceptance of one’s health situation can vary in severity from patient to patient. While many kidney recipients are quick to express the critical importance of working through these feelings (potentially with the assistance of a mental health professional), these same patients often note, in retrospect, how much valuable time was lost prior to going public with their awareness efforts.

When talking directly with potential donors, it is most important to “put yourself out there.” There is no need to feel ashamed or embarrassed. Try not to place expectations on others. Approach the subject with vulnerability and humility, no matter how difficult. If someone is unable or unwilling to donate, try not to take their decision personally. Living donation is a very emotionally-charged subject. Respect and validate your feelings but try to avoid denial and resentment.

Sharing Accurate Information During Your Ask

It is important to share accurate information, while also combating misinformation concerning living donation. Be honest with your potential donor about the workup process, physical surgery, recovery time, and potential complications along the way. The donor workup process is tedious to ensure that donation is the safest option for the potential donor. The donor will even have their own team of doctors separate from the recipient’s team. Donors go on to live very full lives, as the one remaining kidney takes over the function of the original two. If for some unforeseen reason the donor were to need a kidney transplant in the future, donors are “bumped” to the top of the transplant list.

Despite active legislative efforts to protect donor rights, there can be financial hardships for donors, including having to potentially take substantial time off work to recover. Even though the recipient’s insurance will fully cover things such as the donor’s pre-surgical testing, surgery/hospital stay, and follow-up visits, clinics still require the potential donor to have their own insurance in place. It is vital to not shield potential donors from the realities of transplant surgery.

Encourage the potential donor to do their own research on living donation and carefully weigh the pros/cons. One vetted source of information is the [Organ Procurement and Transplant Network website](#). There are many misconceptions about organ donation that can only be

challenged through continued education. Additionally, potential donors should educate their friends and family on their decision to include them in the process. If the potential donor is interested in being tested, share the transplant coordinator's contact information. Be sure to only do so with this professional's explicit permission.

Conversation Starters & Donor Testing

When entering into difficult conversations about donation, it is crucial to approach the subject with openness and vulnerability. Start by sharing about yourself and what led to your decline in kidney function. Disclose whatever information you are comfortable with, but keep in mind donors may be more inclined to donate the more familiar they are with you and your story. It can be helpful to use phrases like:

- "I need help..."
- "This is my reality..."
- "Consider this..."

Some patients find it easiest to ask:

"Would you be willing to take a simple blood test to see if you are a match?"

Following a series of general health inquiries directed at the potential donor by a transplant coordinator (typically over the phone), a blood test ordered by the transplant clinic is a relatively simple first step and does not imply the expectation of follow-up testing or the actual act of donation. The blood test ascertains the potential donor's blood type and also reveals details about the presence of antigens; all of this information is required to assess donor/recipient compatibility.

After a blood test, the potential donor may be ruled out or, conversely, would have the opportunity and time to consider moving forward with additional testing. Follow-up tests include, but are not limited to, urinalysis, chest X-ray, electrocardiogram, and psychological evaluation. If the donor is ruled out as a blood/antigen match but is willing to donate, you might be able to propose the idea of a paired exchange program. These programs, available at certain transplant clinics, allow donor/recipient pairs who are not matches to "swap" kidneys with other compatible pairs.

Why Donors Choose to Give

People choose to donate a kidney for a variety of reasons, including, but not limited to: altruism, an allegiance to the person in need, being inspired by someone else who donated, faith-based reasons, and even wanting to check a box off of their bucket list. A psychiatric evaluation of the donor is a routine part of the extensive donor testing to ensure a true willingness to give. It's important to note the donor has the option of backing out at any time, even right before surgery.

Widely Sharing Your Patient Story

What channels of communication can you use to voice your need for a kidney transplant? Social media is the most prominent and accessible tool for spreading the word. Facebook, Instagram, X, Youtube, etc. have all proven effective in allowing one's health journey to reach a widespread audience. In addition to social media, other common modalities for broadcasting the need for an organ include direct emails to one's personal network, newspapers, TV news segments, online blogs, faith-based bulletins, t-shirts, and even car decals. You can [visit the ASF website](#) to view

some email and social media phrasing suggestions – these can help you begin to craft your messaging.

It's important to be prepared to speak about your need for a kidney at any given time. If you think it will be helpful, you can keep a list of important conversation points stored in your phone or on a piece of paper in your wallet/purse etc. Numerous Alport patients report chance encounters with individuals at work, at a public gathering, or even in line for coffee that resulted in positive donor leads.

Lastly, connecting with living kidney donor recipients about their success stories is an excellent way to brainstorm ideas and find kinship during the transplant workup process. If you would like to be connected with fellow patients and families who have experienced living donation, please email ASF Staff at info@alportsyndrome.org.

For additional resources, including transplant surgery considerations, educational video interviews, and more, please see [the transplant page on the ASF website](#).

Alport Syndrome Foundation extends heartfelt gratitude to transplant nephrologist Dr. Alexander Wiseman for his expertise and to the numerous kidney recipients/donors who shared their journeys with us to help prepare this document.