



**WHAT TO EXPECT** 

# The Transplant Journey

mtbakerfoundation.org

#### THE JOURNEY TO TRANSPLANT

The best time to explore the option of transplant is early in the course of your kidney disease. When your GFR is 20 or less, or your nephrologist recommends you consider a transplant, this is truly when the journey begins.

#### **STEP 1: A MENTOR CAN HELP!**

If you don't have a Mentor for the Transplant Journey, now's the time to connect. Mount Baker Nephrology Associates (MBNA) and Mount Baker Foundation (MBF) offer a mentorship program called Peer to Peer. Our mentors have experience with their own transplants and can share helpful tips and answer questions. To be assigned a mentor, contact a member of your care team or email <a href="mailto:support@mtbakerfoundation.org">support@mtbakerfoundation.org</a>.

#### STEP 2: FINDING A TRANSPLANT CENTER

In choosing a transplant center, your decision might be based on accessibility, support groups, and whether the Center performs living donations and participates in a "kidney paired exchange program." This means the center will match you with someone in a similar situation if your living donor is not a match. The National Kidney Registry, offers a nationwide database that can open up your options to a potential match anywhere in the country. Here in Seattle, WA there are three kidney transplant facilities to consider:

- UW Kidney Center (206) 598-3882
- Virginia Mason Franciscan Health (206) 341-0925
- Swedish Medical Center (206) 386-3660

Note: It is possible to be listed at more than one transplant center.

#### STEP 3: EVALUATION FOR KIDNEY TRANSPLANT

While guidelines for each transplant center may vary, generally your evaluation process will include:

#### A medical and surgical history

You will be asked about any illnesses, surgeries, and treatments you've had in the past, as well as your family's history.

#### A physical exam

A transplant is major surgery. You will meet with both a nephrologist and a surgeon to ensure you are healthy enough for surgery and that a transplant is your best option.

Looking for a mentor?

#### A psychosocial assessment

Completed by a clinical social worker, this assessment evaluates whether you are emotionally prepared for the surgery, post-transplant care and recovery. Your team will help make sure you and your family are prepared to deal with the physical and emotional aspects of your transplant, and ensure you have adequate caregiving support, lodging, and the financial resources to cover your out-of-pocket expenses.

#### Financial evaluation

While federal and employer insurances generally cover the majority of costs associated with a transplant, there are other expenses to anticipate. For people residing in Whatcom County, for example, you may have transportation costs, and housing costs to stay near the Transplant Center for four to six weeks after surgery. There can be significant co-pays on prescription drugs, and possibly the need to pay a caregiver.

#### **Compatibility tests**

To find a kidney that will work for you, the following tests will be done:

- Blood typing Finding a donor that matches/is compatible with your blood type
- Tissue typing Making sure that your body won't reject the donor's kidney
- Crossmatching Blood tests to ensure your antibodies won't destroy the donor kidney.

#### **Additional tests**

Depending on your health conditions, these tests may include the following:

- Blood tests
- Echcardiogram
- Cancer screenings

- Chest x-rayCT scan
- ElectrocardiogramCardiac stress test
- Dental exam

#### STEP 4: FINDING A KIDNEY

The most important step in the transplant journey is finding the right kidney. There are two sources of kidneys: a deceased organ donor, or a living donor.

#### **Deceased organ donation**

You will want to be proactive in getting on the "kidney list," which is managed by the United Network for Organ Sharing (UNOS). This system is based on a combination of blood-type and antibody matching, length of time on dialysis and/or length of time listed for transplant, medical urgency, where you live and in some cases your weight and size compared to the donor. Children and past live kidney donors are given priority.

#### Finding a living donor

Most of us are born with two kidneys, and only one is necessary. Living kidney donors are healthy people who are willing to – and want to – "share their spare." Living donors describe it as a very rewarding experience! Mount Baker Foundation offers support for individuals seeking a living donor – contact us at <a href="mailto:support@mtbakerfoundation.org">support@mtbakerfoundation.org</a>.

#### STEP 5: WAITING AND PREPARATION

Once you are on the national organ transplant list, you may receive a kidney fairly quickly or you may wait many years. It is important to be proactive and be ready for the call!

#### Take care of your health

While you are waiting, be sure to take good care of your health by staying up-to-date on cancer screening and dental visits.

#### Talk to your transplant financial coordinator

The transplant financial coordinator can share out of pocket costs you will need to pay yourself, not just for the transplant surgery but during post-transplant care. You will need to consider the cost of on-going prescription medications, lodging, transportation, etc. The important thing is to check with your transplant financial coordinator and know what to expect.

#### Figure out your lodging and caregiver during recovery

During the initial 4-6-week recovery period, you will need to be close enough to the transplant center to easily get to post-op appointments. You must have a caregiver who is generally available to stay with you 24 hours a day.

#### Visualize your life after transplantation

Think ahead to life after transplantation and where you want to be. Keeping a journal may help keep your thoughts steady as you plan for life after transplantation.

#### Have a to-go bag packed

- You'll want to take a change of clothes and undergarments, of course, and remember you will be staying near the transplant center for four to six weeks.
- You should bring your regular medications, your phone chargers, and toothbrush!
- Items to entertain yourself while in the hospital, such as books.
- Be sure to bring any educational materials your transplant center has provided you.

#### STEP 6: BE READY FOR SURGERY

#### If you are on the transplant list...

You may be one of three people notified about a kidney match but only the best match will be the recipient. If that isn't you, you will go back on the waiting list and be one step closer to getting your perfect match.

#### If you have a living donor...

If you are receiving the gift of a kidney from a living donor, your surgery will be scheduled in advance.

### SERVICES WE OFFER AT MOUNT BAKER FOUNDATION

### **MEETING FINANCIAL REQUIREMENTS**

Transplant Centers may require proof that you have cash on hand to cover post-transplant costs. You may have transportation costs and housing costs in order to stay near the Transplant Center for four to six weeks after surgery. There can also be significant co-pays on prescription drugs, and possibly the need to pay a caregiver.

Mount Baker Foundation offers a "Letter of Commitment" to cover some of these costs up to a certain amount for individuals who qualify, based on financial need.

#### PEER TO PEER MENTORSHIP PROGRAM

In collaboration with Mount Baker Nephrology Associates, Mount Baker Foundation offers a peer mentorship program. You will be paired with a successful transplant recipient who can answer questions for you as you start the transplant journey. Contact us at <a href="mailto:support@mtbakerfoundation.org">support@mtbakerfoundation.org</a>

#### FINDING A LIVING DONOR

Visit **mtbakerfoundation.org** for helpful information and support to help you be your best advocate in finding a kidney that's right for you.

#### ABOUT MOUNT BAKER FROUNDATION

## A CATALYST FOR COMMUNITY AND GENERATIONAL TRANSFORMATION.

Catalyst. Generational. Transformation. We know these are big words. But we are willing to work towards them, learning day by day, month by month, and engaging with the heart of the communities throughout Whatcom County and with expert resources here in our community, across the state, nation and the world.

We actively seek experts in these areas, whether locally, across the state or nation. And we want to learn from what other communities are doing – even on a global basis. Please visit **mtbakerfoundation.org/contact** 



#### **SHARE YOUR STORY WITH US**

While we do not accept incoming applications, we want to hear from you about our areas of focus. We believe change happens when all stakeholders are engaged in understanding the issues and considering solutions.

