What to Expect

A Guide for Young Adults and Loved Ones Facing Kidney Care

Created by NW Kidney Connection

Support. Clarity. Community.

NW Kidney Connection - What to Expect Packet

Packet Contents

Welcome Letter

Dear Friend,

If you're reading this, or someone you love may be facing one of the most overwhelming times in the kidney journey. Whether you're starting dialysis, preparing for transplant, navigating the healthcare system, or supporting a spouse or partner through it all, we want you to know this:

You are not alone.

This packet was created by people who've been where you are. We're patients, spouses, caregivers, and advocates who know how hard it can be to find clear information, supportive community, and practical guidance especially as a young adult.

Inside, you'll find simple explanations of what to expect during common kidney care experiences, tips from peers who've been there, space to write down your questions, and information about programs available through NW Kidney Connection. Use what helps, skip what doesn't. This is your space.

We believe every person deserves to feel seen, prepared, and supported. And we're here to walk beside you--step by step, side by side.

With care,
The NW Kidney Connection Team
Email: nwkidneyconnection@gmail.com
Website: https://sites.google.com/view/nwkidneyconnection/home

What to Expect: Starting Dialysis

What Is Dialysis?

Dialysis is a treatment that helps your body do the work your kidneys can no longer do like removing waste, extra fluid, and toxins from your blood. There are two main types:

In-Center Hemodialysis (HD)

What It Is:

Hemodialysis uses a machine to filter your blood. It's usually done at a dialysis center: - 3 times per week

- Each session lasts 3-4 hours
- Blood is filtered through a machine using a fistula or catheter

What Might Feel Hard:

- Sitting for long periods
- Feeling drained or crampy afterward
- Adjusting to a new routine
- Seeing mostly older patients and feeling out of place

Tips from Peers:

- Bring a hoodie, headphones, and a charger as your go-to comfort kit.
- Be honest about side effects. They can adjust your treatment.
- Ask if you can shift your schedule to work around school or work.

Peritoneal Dialysis (PD)

What It Is:

PD uses the lining of your belly (peritoneum) to filter your blood. A special fluid is cycled in and out through a tube (catheter) in your abdomen. PD is usually done at home:

- Every night (automated with a machine), or several times a day (manual)
- Allows more flexibility with school, work, or travel
- Requires training and keeping supplies at home

What Might Feel Hard:

- The learning curve in the beginning
- Cleaning your space and supplies to prevent infection
- Fear of complications like peritonitis
- Feeling isolated or responsible for your own care

Tips from Peers:

- You get more control, but it takes some setup and getting used to.
- Stick to the sterile routine it gets easier.
- Make a supply station and keep it organized. It helps with stress.

Questions You Can Ask Your Care Team:

- Which type of dialysis is best for my lifestyle?
- What will training for PD or HD look like?
- What are signs something might be wrong and what do I do? - Can I travel? Will I still be able to work or go to school?
- Is there anyone I can talk to who's been through this?

What to Expect: Hospital Stays

What Is a Hospital Stay?
A hospital stay means getting care when your health needs extra attention. This could be for surgery, an infection, or a change in your kidney care.

What It Is:

- Regular check-ins from doctors and nurses
- Tests like blood work, X-rays, or scans
- Medications given on the hospital's schedule
- Possible changes to your dialysis routine

What Might Feel Hard:

- Being away from home and your normal routine
- Getting interrupted at night for checks or tests
- Feeling like you don't have much privacy or control
- Missing friends, family, or work/school

Tips from Peers:

- Bring a few comfort items (blanket, headphones, favorite snacks if allowed).
- Write down questions so you don't forget them when doctors come by.
- Ask a spouse, partner, or friend to help keep track of what's said.
- Use small items (like a book or coloring supplies) to pass the time

What to Expect: Transplant Evaluation

What It Is:

A kidney transplant evaluation is a series of appointments, tests, and conversations that help your transplant team decide:

- If you're healthy enough for surgery
- What your risks are
- Whether a transplant is the right option now

This process often includes labs, imaging (like an EKG or chest X-ray), meetings with social workers, a dietitian, a financial coordinator, and a nephrologist or surgeon.

It can take a full day or be spread over several appointments depending on your hospital.

What Might Feel Hard:

- The volume of appointments and medical questions
- Talking about mental health, finances, or social support
- Being unsure what happens next, or how long the wait is
- Feeling overwhelmed or unprepared for what's expected of you

Tips from Peers:

- Bring a notebook. It helped me remember which doctor said what.
- Ask if you can bring someone with you. Two sets of ears are better.
- Some questions caught me off guard, like who would care for me after surgery. Think about that ahead of time.
- Even if it feels scary, it means you're getting closer to something better.

Questions You Can Ask:

- What tests will I need?
- What does the transplant waitlist process look like?
- What does the recovery time look like?
- Where can family/care team locate me after surgery
- How will I be notified if I'm approved?
- What happens if I'm not approved? Can I try again?
- Can I talk to someone who's been through it?

What to Expect: Receiving a Kidney Transplant

What It Is

A kidney transplant is a major surgery where a healthy kidney from a donor is placed into your body. This can come from:

- A living donor (like a family member or friend)
- A deceased donor (through the waitlist)

Once transplanted, your new kidney may start working right away—or it might take a few days. You'll begin a lifetime of follow-up care and immunosuppressant (anti-rejection) meds.

What Might Feel Hard

- Fear before surgery or waking up afterward
- Waiting for the kidney to "wake up" and start working
- Adjusting to strict medication schedules
- Worrying about rejection or infection
- Balancing the joy of freedom with the anxiety of "what now?"

These are normal feelings, and you don't have to process them alone.

Tips from Transplant Recipients

- "Set alarms for your meds. Don't skip, not even once."
- "Your emotions might surprise you. Talk about them, even the good ones."
- "Ask your team every question. There are no dumb ones."
- "You're not instantly cured, give your body and brain time to adjust."
- "Celebrate the wins. Shower without tubes? That's a win."
- "Prepare yourself for the temporary tubes you will have after surgery"
- "Listen to what your Doctor says"

Questions You Can Ask

- What are signs of rejection or infection?
- Who do I call if I feel sick after hours?
- What's the plan for follow-up labs and appointments?
- Can I return to school or work, and when?
- Can I talk to someone else who's had a transplant?

What to Expect: Transitioning to Adult Nephrology

What It Is:

When you age out of pediatric kidney care (usually between 1821), you'll transfer to an adult nephrology team. This shift often includes:

- A new doctor and clinic
- Less involvement from parents or caregivers
- More responsibility on you to manage appointments, medications, and communication. Transition doesn't happen overnight and you deserve support along the way.

What Might Feel Hard:

- Losing the familiar team you trusted for years
- Feeling unprepared to handle medical decisions on your own
- Confusion around insurance, prescriptions, or who to call
- Worry that you won't be taken seriously in adult care spaces

Tips from Peers:

- Write down your meds and bring that list everywhere.
- I started practicing calling in my own refills before I transferred.
- Its okay to ask your new team to go slow or explain things twice.
- Bring someone to your first few appointments if you can.
- You can still include your parents or caregivers in decisions just let your new team know how you want them involved.

Questions You Can Ask:

- When exactly will I transfer to adult care?
- Can I meet the new doctor ahead of time?
- Who can help me get set up with insurance, pharmacy, or a MyChart account?
- What happens if I feel lost or overwhelmed?

What to Expect: Supporting a Spouse or Partner

What It Is:

When your spouse or partner is living with kidney disease, your relationship becomes part of the care journey. You may find yourself taking on new rolescaregiver, advocate, coordinatorwhile still wanting to be their partner first.

It's okay if this feels complicated. You are not alone.

What Might Feel Hard:

- Worrying constantly, even when things seem stable
- Feeling unsure of how to help (or when you're doing enough)
- Balancing emotional support with your own stress
- Navigating medical conversations you weren't prepared for
- Feeling like the healthy one means you shouldn't struggle

Tips from Partners:

- Ask your partner how they want you to support them, don't guess.
- Go to appointments together, even just to take notes or be a second pair of ears. - Make space for your own feelings. Get support for you, too.
- Being there emotionally means just listening, not fixing everything.
- We set aside one night a week to talk about us not kidneys.

Questions You Can Ask:

- How can I support you without taking over?
- What signs should I watch for when you're not feeling well?
- Can we meet with a social worker or counselor together?
- Who can I talk to about caregiver burnout or relationship stress?

What to Expect: Navigating an ER Visit

What It Is:

Kidney patients sometimes need emergency care for infections, fluid overload, access issues, or complications from treatment. An ER visit can feel chaotic, especially when you're trying to explain a complex medical history to someone new.

Being prepared can make a big difference.

What Might Feel Hard:

- Repeating your history to multiple people
- ER staff not understanding dialysis or transplant-specific needs
- Long wait times, fear, or pain
- Feeling dismissed because of age, disability, or chronic condition
- Worrying about cost or insurance

Tips from Peers:

- Bring a printed med list and a short summary of your condition. It helped me avoid repeating myself. - Say clearly: I'm on dialysis, or I have a transplant right up front.
- Have your emergency contact, nephrologist's name, and dialysis center info in your phone or wallet.
- If you're not being listened to, ask to speak to a charge nurse or patient advocate.

Questions You Can Ask:

- Can you please document that I'm a kidney patient and list my dialysis schedule? - What tests are you running, and what are you looking for?
- Can someone from my nephrology or transplant team be contacted?
- Will this affect my transplant listing or regular treatment schedule?

What to Expect: Insurance & Financial Questions

What Is Insurance?
Insurance helps cover the costs of dialysis, transplant, medicines, and doctor visits. Coverage can come from different places, like government programs or private insurance.

What It Is:

- Most people use a mix of insurance types
- Coverage usually helps with treatments, but not always everything
- Hospitals and clinics often have staff who can explain your benefits
- Financial help programs may be available if costs get overwhelming

What Might Feel Hard:

- Getting bills from different places at once
- Not knowing what part of the bill you're responsible for
- Long calls with insurance companies
- Worrying about how changes in school, work, or family may affect coverage

Tips from Peers:

- Always ask for a clear breakdown of charges
- Don't be afraid to ask about financial assistance or payment plans from both the hospital and the insurance company
- Social workers and patient advocates can help with confusing paperwork
- Keep a folder for bills, letters, and insurance notices so nothing gets lost

Helpful Resources

NW Kidney Connection

Website: www.nwkidneyconnection.org

Email: info@nwkidneyconnection.org

Emergency Planning

- National Kidney Foundation Emergency Resources: www.kidney.org/help

- Know your dialysis centers emergency contact info and hours

Center: _____ Hours: _____

Phone: _____ Email: _____

Peer Support

- NWKC Peer Mentorship: Side by Side Program (ask us how to join!)
www.nwkidneyconnection.org/side-by-side

- Young Adult Renal Support Groups: Ask your clinic social worker

Medical Knowledge

- MedlinePlus Kidney Disease: medlineplus.gov/kidneydiseases.html

- American Kidney Fund: kidneyfund.org

Mental Health & Caregiver Support

- NAMI (National Alliance on Mental Illness): nami.org

- Dialysis Patient Citizens Patient Support and Advocacy: dialysispatients.org

Social Work & Legal Help

- Northwest Kidney Centers Social Work: www.nwkidney.org

- Disability Rights Washington: www.disabilityrightswa.org

- Disability Rights Oregon: www.droregon.org

- Disability Rights Idaho: www.disabilityrightsidaho.org