

New to PKD

GETTING FAMILIAR AND COMFORTABLE WITH IT ALL

What the patient should know

I deserve to have the best care that I can. I am my own best advocate.

Remember that you have the power to get optimal care in partnership with your healthcare team so you can live your best, healthiest life with PKD.

- ❑ Have I been referred to a nephrologist (kidney specialist)?
- ❑ Does my nephrologist have some familiarity and/or experience with PKD?
pkdcure.org/find-a-clinic
- ❑ Does my relationship with my doctor feel comfortable and open?
resources.pkdcure.org/resources/communicating-with-your-health-care-team
- ❑ Do I need to interview more than one nephrologist to find the right fit for me?
- ❑ Am I comfortable asking questions?
- ❑ Have my most important questions, concerns or issues been addressed to my satisfaction?
- ❑ Are there clinical trials I may be eligible for at this time?
- ❑ Are there other specialists I should be seeing?
pkdcure.org/living-with-pkd/working-with-your-doctor
- ❑ How often should I be seen by my providers?
- ❑ What support is available to me if needed?
connect.pkdcure.org

What the doctor should address

Initial evaluation by a PKD nephrologist should be comprehensive, reflecting multisystem effects of ADPKD.

- ❑ What are the patient's manifestations of ADPKD?
Kidney size and symptoms • Kidney function: GFR (glomerular filtration rate) or progression • Hypertension (high blood pressure) • Presence or absence of protein in the urine (proteinuria) • Brain aneurysm risk and management • Liver cysts
- ❑ Assess total kidney volume (TKV), at least once; determine Mayo Imaging classification
resources.pkdcure.org/resources/understanding-your-risk-for-adpkd-progression
- ❑ What are potential treatments and interventions for general and cardiovascular health?
LDL cholesterol below 100 • Healthy diet; caloric restriction, optimal weight • Avoid smoking • Regular exercise
- ❑ What are potential treatments and interventions for ADPKD?
Refer to an appropriate clinical trial (clinicalstudies.pkdcure.org) • Consider tolvaptan in patients at risk of rapid progression, discuss risk or benefit (pkdcure.org/tolvaptan)
- ❑ What are potential treatments and interventions for psychosocial function and well-being?
Counseling • Family planning • When or if to diagnose children