

# Later stage PKD to ESKD

OPTIMAL PLANNING FOR THE CHANGES AHEAD

## What the patient should know

By anticipating and planning for ESKD, I can have a major impact on my ongoing well-being.

- ❑ What changes or symptoms have I noticed since my last visit?  
*resources.pkdcure.org/resources/kidney-failure-what-to-expect*
- ❑ What do the changes in my labs mean?
- ❑ What changes do I need to make to my lifestyle (diet, exercise, etc.) to preserve my best health?
- ❑ What might be the approximate timeframe to end-stage kidney disease (ESKD)?
- ❑ What ESKD options am I and my family comfortable with?  
*living vs. deceased donor transplant • hemodialysis vs. peritoneal dialysis*
- ❑ When do I need to act and how?  
*resources.pkdcure.org/resources/transplantation-from-evaluation-to-transplant-surgery*
- ❑ How often will I need to be seen by my nephrologist now?
- ❑ How are any clinical trials I may be participating in affected by my PKD progression?
- ❑ What other support do I need at this time?

## What the doctor should address

Optimal preparation and education for a safe and smooth transition to ESKD.

- ❑ Manage symptoms and complications of advanced kidney dysfunction
- ❑ Refer to kidney dietitian
- ❑ Psychosocial support
- ❑ Planning for kidney replacement therapy including dialysis and transplant  
*Transplant surgeon and nephrologist • Transplant social worker • Transplant pharmacist • Pre-transplant evaluation of general and cardiac health • Education regarding appropriate dialysis access in advance of needing to start dialysis*
- ❑ Timely referral to transplant center to allow both recipient and donor evaluation to be completed in advance of need for transplant
- ❑ Preemptive live donor kidney transplant is optimal therapy; planning with extended family for potential family donation
- ❑ Placement, when eligible, on kidney transplant waiting list for deceased donor transplant
- ❑ Refer for appropriate clinical trial, likely fewer options with low GFR
- ❑ Planning with extended family for future living kidney donation

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.