PKD FOUNDATION
Polycystic kidney disease

What to Do When Your Child Receives a PKD Diagnosis

Receiving a new PKD (Polycystic Kidney Disease) diagnosis for your child can be confusing. In challenging moments like this, understanding the key steps to take can be overwhelming. Here are tips to empower caregivers and parents to tackle the journey ahead.

UNDERSTAND PKD: PKD is a genetic disorder affecting the kidneys, leading to the formation of cysts. It may present with various symptoms such as enlarged kidneys, high blood pressure, urinary tract infections and liver problems.

THERE ARE TWO MAJOR FORMS OF PKD:

ARPKD (AUTOSOMAL RECESSIVE POLYCYSTIC KIDNEY DISEASE):

- Inherited in an autosomal recessive manner, requiring both parents to carry the defective gene.
- Symptoms typically appear in infancy or early childhood, characterized by kidney and liver cysts, varying in severity.

ADPKD (AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE):

- Inherited in an autosomal dominant manner, requiring inheritance of one defective gene from one parent.
- Symptoms usually manifest in adulthood, featuring kidney cysts leading to progressive kidney dysfunction, with variable severity.

BUILD A SUPPORT SYSTEM:

- Reach out to family, friends, and support groups to share your feelings and concerns.
- Connect with the PKD Foundation and the PKD Parents Community for additional resources and support.
- Research and engage in discussions with nephrologists and pediatricians from the PKD Foundation Centers of Excellence network.

EDUCATE YOURSELF:

- Learn about PKD through reputable sources and literature provided by your healthcare team.
- Stay informed about the latest research and treatment options.

COLLABORATE WITH HEALTHCARE PROVIDERS:

- Establish open communication with your child's healthcare team.
- Discuss treatment options, potential complications, and create a comprehensive care plan.

EMOTIONAL WELL-BEING:

- Acknowledge and manage your own emotions. Seek professional help if needed.
- Encourage open communication with your child, providing age-appropriate information about their condition.

FINANCIAL AND PRACTICAL CONSIDERATIONS:

- Explore financial assistance programs and resources available to families with children diagnosed with chronic illnesses.
- Plan for practical aspects like transportation to medical appointments and school accommodations.

MONITOR AND MANAGE SYMPTOMS:

- Keep a record of your child's symptoms, medications, and appointments.
- Follow prescribed treatments and medications diligently.

CREATE A ROUTINE:

- Establish a daily routine that includes medication schedules, dietary restrictions, and regular medical check-ups.

ADVOCATE FOR YOUR CHILD:

- Be an active advocate for your child's needs within the healthcare system and educational institutions.
- Stay informed about your child's rights and available support services.

SEEK A SECOND OPINION:

- When managing PKD, seeking a second opinion can provide valuable insights and perspectives on your treatment plan. Consulting with another healthcare professional can offer additional clarity and options to ensure you make informed decisions about your care. It's important to note that while researching information about PKD online may be tempting, it's best to rely on trusted healthcare professionals rather than solely relying on Google or the internet for accurate advice.

CELEBRATE SMALL VICTORIES:

- Acknowledge and celebrate milestones, no matter how small. Focus on the positive aspects of your child's life.

LEARN MORE BY VISITING THE PKD FOUNDATION WEBSITE AT WWW.PKDCURE.ORG.

RESOURCES

» Community
- PKD Parents Community
- Find Your Community
- Voices of PKD
- PKD in Children
- ARPKD
- ARPKD Angels
- Now I Lay Me Down to Sleep
- PKD Foundation Centers of Excellence Network
- PKD Hopeline (**844-PKD-HOPE** or **844-753-4673**)

» Recordings
- Your Child Has been Diagnosed with PKD – Now What?
- How to Navigate the Emotions of Having a Child Diagnosed with PKD
- Networking: Finding mentors and Building your Village
- Disease Management for Children with ADPKD and ARPKD

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