



# NephU™

Improving Awareness  
& Patient Outcomes

## Caring for Yourself While Caring for a Loved One With ADPKD

### A Resource for Caregivers

Because ADPKD is a chronic, genetic disorder, its impact is often felt throughout family life. As a family, together, you can celebrate triumphs and face any challenges that may come to members managing ADPKD.

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## Make yourself a priority also

When you are caring for someone with autosomal dominant polycystic kidney disease (ADPKD), it may be difficult to focus on your needs as well as those of your loved one. Balancing both can be difficult. Here are some tips:

- **Establish personal health goals** such as:
  - Being physically active
  - Maintaining healthy sleep patterns
  - Eating healthy
  - Keeping up with your routine health exams
- **Stay informed** about ADPKD. Knowing what to expect now and in the future can help you plan.
- **Set limits** so you can lessen the stress you can control.
- **Set realistic goals** for how you spend your time.
  - This includes taking a break from caregiving make a date with a family member or friend to get out.
- **Communicate** openly and honestly about how you are feeling.
- **Create a support system.** This could be spending time with friends, joining a support group (in person or online), and/or accepting help.



**“I am also reminded that I have to take care of myself, because if I don’t, I can’t be there for my family when they need me. I would tell other caregivers to learn as much as you can about the disease, focus on your health, and get involved.”**

— Caregiver to son and husband with polycystic kidney disease.

## Caregiver stress is the emotional and physical stress of caregiving and is common.

Watch for signs of caregiver stress such as:

- Getting too much sleep or not enough sleep
- Loss of energy
- Feeling tired often
- Difficulty concentrating
- Headaches
- Muscle or back aches
- Stomach aches

**If you find yourself feeling some of these signs, get support consider reaching out to a friend for support or a healthcare professional if the symptoms become troubling.**

## Goal setting is one strategy to help you take care of you

Setting goals or choosing some things you would like to accomplish is one approach for taking care of yourself.

### Examples of goals you might set:

- ✓ Find help preparing meals or doing other chores like housework.
- ✓ Set aside time each week to take a break from caregiving.
- ✓ Engage in activities you enjoy and that help you maintain your social life.
- ✓ Regularly plan activities with your loved one.

Gradually working on your goals may make them more enjoyable and less stressful. Take it step by step.

## Spend time with your loved one

If your loved one is in the early stages of ADPKD, they may have few symptoms or signs. You can support them with things that help their condition, like preparing healthy meals and physical activities. You can also help them maintain their regular routine and make time for activities you both enjoy. This may help strengthen your bond and help you both maintain normalcy.

## Take care of you

It is possible to cope with the stress we face in our daily lives. As someone who provides care for a person with ADPKD, taking care of yourself is an important part of the job. Now and then, check for the warning signs of stress listed on the previous page, and, when you are feeling stressed, use these tips to help lessen it. You may also want to contact your healthcare provider for additional support and coping strategies.

**Effective communication is an important tool for caregivers. Clear, firm, and constructive communication can help you be heard. It can also help you get the support you need.**



## Questions? Concerns?

**Never hesitate to ask. You have a right to know everything about your health and your care.**

If you have any questions or concerns about your condition or your care, ask your doctor or a member of your treatment team right away. They are there to help you.