



Supporting Your Loved One With ADPKD

Caring Communication

Talking about ADPKD is a personal decision and may be difficult for your loved one struggling with ADPKD. Not knowing what to say can add to your stress and add difficulty in caring for him/her.

- Be gentle, but let your loved one know that you are there for him/her if he/she does want to talk.
- Help your loved one prepare for doctor's visits — this may help open up communication.
- Remind your loved one the more you know, the more you can support him/her.



Helping prepare for appointments

As a caregiver for someone with ADPKD, you may be asked to go to doctor's appointments. You can help prepare for appointments so that you and your loved one get the most out of appointments. Remember, being open and honest is important. Discussing concerns and accurately reporting what is going on may help providers more fully understand. They can then offer the help and support needed.

Keep track of questions or concerns before the appointment and bring them to the appointment. This can help keep you focused on what is important.

Helping prepare for appointments (cont.)

Consider keeping a journal to track symptoms between appointments. Tracking how your loved one feels, any symptoms, and how both are affecting him/her in daily life can help your loved one, you, and the healthcare team make collaborative and supportive treatment decisions.

Know the medical history. Bring notes if you need so that you can discuss them with the doctor.

Ask questions if you do not understand. Don't be afraid to ask until you and your loved one have the information you need.

If your loved one asks, be involved in treatment discussions and decisions.

Work with the treatment team to **ensure appropriate monitoring of health changes.**

Help your loved one follow any instructions and recommendations.

Take notes on key details so that you can review them later — in case you forget something.

Ask if there are websites or resources available to find more information if you feel it is needed.

Remember, a little preparation can go a long way in making interactions with the healthcare team more effective.

Questions? Concerns? Never hesitate to ask.

You have a right to know everything about your health and your care.

Keep communication open with your loved one managing ADPKD.
