

Talking to children and young people about ADPKD

This article is a general guide for parents or carers of children and young people (up to age 18) who are at risk of or have been diagnosed with autosomal dominant polycystic kidney disease (ADPKD). It contains advice and tips to help you explain ADPKD to children and young people.

It does not cover the medical aspects of ADPKD in children and young people, how it is diagnosed and monitored, symptoms and complications, and how the disease might progress.

If your child is the first person in your family to have ADPKD, which happens in around 1 in 10 people, you may find it helpful to read more about ADPKD from other information on the PKD Charity website (www.pkdcharity.org.uk) or contact the PKD Charity for support (0300 111 1234).

Advice on and tips for talking to your child about ADPKD

Many parents find the prospect of talking to their child (or children) about ADPKD difficult and distressing. Your first instinct is likely to be to protect your child from knowing about ADPKD and its risks. If you also have ADPKD, you may find it difficult to know what and when you should tell your child.

It is likely you're dealing with your own concerns about your health and future wellbeing. It's not unusual to feel a sense of guilt that your children are at risk from carrying a gene that causes ADPKD. But remember, no one is responsible for the genes they inherit or pass on to their children.

What helps children and young people?

In most cases, children cope better when their family is more willing to discuss what is happening to different family members. Talking to children helps them feel valued and respected. It helps them cope better than when they are left feeling confused and unsure how or what to ask.

Children get information from many places including school, television, friends and the Internet. By talking to them you can help them understand what is happening in the family and be clear on the facts. You can clarify things they are not sure about.

Children are likely to already have some knowledge about genes and how diseases can be inherited. However, this will vary according to their age and development.

Children will probably be more worried about their parent with ADPKD, and what will happen to that parent, than their own health. In some cases, children will need reassurance and reminders that having a faulty gene that causes ADPKD does not always result in the disease occurring in the same way as for other family members who have ADPKD.

You may have to explain things several times. It can sometimes take children several explanations before they begin to understand, even though they may have asked the same questions previously. Similar to adults, children need time to process information and think it through.

You can provide reassurance that knowing you carry a gene that causes ADPKD means that you can monitor your health and have tests. This means that - if the disease arises - it can be detected very early on and suitable treatments started to control symptoms.

Younger children do not have experience to recognise and anticipate the fuller implications of situations. Therefore, your child will have a gradual realisation of the implications of your ADPKD if you talk to them as they grow up. Finding out about ADPKD for the first time when older can be a shock to young people. They can ask difficult questions, yet not be emotionally prepared for the answers.

When is a good time to tell your children?

There is no 'right' age, but try not to keep too much information back from your child. Children place great emphasis on trust and honesty from parents. They often observe changes in their parents' behaviour and may try asking questions or be waiting for you to discuss what is happening. Watch for any changes in your child's behaviour - it may indicate that they are worried or concerned about what they have observed or overheard.

By the age of 8 years, children learn not to ask difficult questions unless you give them permission, because they fear upsetting you. Therefore you may have to prompt your

child, and let them know you're willing to talk with them about what is happening in the family and with your (or their) ADPKD. This applies to older children too.



What are children likely to know about genes and inheritance?

Below age 8: Your child is not likely to have a basic understanding of inheritance yet. However, if there is information your child wishes to know about ADPKD, you may want to give simple explanations from age 2 onwards. For example, if your child asks what a scar is or why you had to go to hospital, you could explain that you had poorly kidneys and the hospital helps make them better. This may help your child to feel encouraged to ask questions in the future.

8-11 years: Your child is likely to have a very basic understanding of inheritance. They may know that they share characteristics with their parents. They may talk about genes but not fully understand what they are. Often children of this age cope with simple explanations in response to their questions and are not easily upset. However, you may have to reassure them that having the ADPKD gene is not always the same as having the disease. Children and young people can easily confuse this, so it often needs repeating throughout development into adulthood.

12-14 years: Your child is beginning to develop more insight about inheritance. Young people will begin to recognise that you having the gene may have implications for them. They will usually cope well if you explain there is a 50% chance of them carrying a gene fault (mutation).

15-17 years: Your child is likely to recognise the risks to you, themselves and often their future children. They can begin to consider screening if they have not been diagnosed. By this age, young people will be learning about hereditary diseases in school.

Most children are quite pragmatic in response to learning about genetic risk in families affected by inherited genetic conditions, and the genetic condition itself. Children and young people are often focused on living their lives, developing friendships, schoolwork and their personal interests, so do not dwell on the disease or its risks.

What information do you give children?

Try to respond to your child's questions, using language appropriate to his or her age. Providing small amounts of information gradually is likely to help them understand and cope best. Check on the question being asked, so that you find out what your child actually wants to know.

You may find it helpful to look through the PKD Charity website www.pkdcharity.org.uk for information on ADPKD that you could use as a basis for your conversation. You may need to reword or simplify information for your child. For young children, you may wish to use props, such as a teddy, to help explain where the kidneys are, for example.

Explain and provide the name - Autosomal Dominant Polycystic Kidney Disease (ADPKD)

Children cope better when given a disease name. Naming the disease takes some of the fear away, especially if they see you struggling with symptoms, it gives them a sense of control. It also allows them to discuss the disease more easily with you. You can place a positive emphasis on the importance of knowing about ADPKD, because it means there will be improved screening and perhaps treatment options available to your child when they grow up. When children become adults, there may also be even better treatments available, which you can explain to your child.

Communication tips

- Children and young people think it is most important that it is their parents who discuss ADPKD with them first. They then might wish to speak to health professionals or other families after you have told them.
- If you want to start a discussion, try to take naturally occurring opportunities, for example a TV programme or something your child has told you.
- Try not to use upsetting or dramatic language when explaining ADPKD.
- Children and young people prefer informal discussions about ADPKD, often whilst doing other things together e.g. driving, cooking or gardening.
- Check their understanding, because children worry about upsetting their parents and so may not always ask.

- Talking about ADPKD is an ongoing discussion rather than a one-off conversation. Like adults, children probably need information given to them more than once. They may need time to digest information and then want to come back and discuss it with you.
- Discuss information young people find on the Internet or in newspapers.
- Discuss emotions - provide reassurance they are not alone in how they might feel.
- Explain your behaviour if you're anxious or upset.
- Being with peers e.g. cousins in similar circumstances might be helpful.
- Support and guide your child in making decisions, especially with young people. Young people usually like to make their own decisions but with advice from parents.
- If you do not know the answer, explain that you'll try to find it out for your child or explain why some questions do not have answers.
- Agree a future appropriate time to discuss ADPKD if your child asks questions at inopportune moments.
- Try not to let ADPKD dominate your lives. Recognise there are other aspects to family life that ADPKD is part of but not central to.

What helped parents talk to their children?

The following points have helped some parents to talk to their children:

- Knowing that children and young people can feel valued when parents talk to them about what is happening in the family.
- Belief in a child's right to know.
- Not feeling pressurised to talk by an upcoming event, e.g. a school science lesson or a genetic test.
- Taking the conversation as an opportunity to be a role model for young people - giving them insight into how to cope with risk and health conditions.
- Not being afraid to discuss their own feelings and emotions about ADPKD, so their child could learn from example.
- Recognising that siblings may have different needs.
- Getting support from other family members, friends and health professionals.

- Attending support groups, which can give a focus to regular discussions between children and young people and their parents.

Preparing to talk to your children

It might be worth considering the following benefits and drawbacks when preparing to talk to your child.

Benefits	Drawbacks
<ul style="list-style-type: none"> • Makes family closer. • Provides support for children. • Gives insight and can help your child realise that you being upset about your genetic condition is not down to them or their behaviour. • Can reduce your child's worry in the longer term about what's happening. • May give your child the confidence to talk to close friends. • Can help children and young people feel valued by their parent(s). • Allows discussion of ADPKD and its risk without centralising it to life. • A shared reality and understanding helps children and young people cope. • Reduces risk of children getting inaccurate information from elsewhere. 	<ul style="list-style-type: none"> • It can be emotionally taxing for you to deal with questions. • Children and young people can remind you about the genetic condition when you don't want to be reminded. • Questions can arise at inopportune moments. • Your child may want to talk to peers but have a limited network. • New knowledge can affect a child's schoolwork for a short time.

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Visit www.pkdcharity.org.uk

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The PKD Charity Helpline offers confidential support and information to anyone affected by PKD, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years.

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