

Autosomal dominant polycystic kidney disease (ADPKD) and pregnancy



This information sheet is about pregnancy in women with autosomal dominant polycystic kidney disease (ADPKD). It is intended as a general guide for women and their partners about planning for pregnancy, what to expect during pregnancy, and what to do if you are already pregnant. We will briefly cover fertility issues for men with ADPKD too.

Before you become pregnant

Can women with ADPKD get pregnant?

Your level of kidney function greatly affects your ability to conceive and to go on to have a successful pregnancy. If your kidney function is normal, your fertility is also likely to be normal. If your kidney function is severely impaired, the levels of reproductive hormones that your body produces may be considerably reduced, meaning that it could be harder to conceive [1].

Miscarriage early on in pregnancy - i.e. before 12 weeks - occurs in 2 in 10 women (20%) in the general population. One study has suggested that the risk of miscarriage in women with ADPKD who are on medication to treat high blood pressure increases slightly to 3 in 10 (30%) [2]. If you have difficulties conceiving, you should contact your GP or kidney doctor to refer you to a fertility specialist.

Can men with ADPKD father children?

Men with ADPKD usually have normal fertility, unless they have low kidney function [3,4]. Men with severe ADPKD, but who have had a transplant are usually fertile soon after transplantation [4]. ADPKD can cause cysts in the reproductive system, but it's uncommon for this to affect fertility [3,4]. If you would like advice on your fertility, speak with your GP or kidney doctor.

What is the risk of my baby inheriting ADPKD?

If you or your partner have ADPKD, there is a 1 in 2 (50%) chance of your baby also inheriting a faulty gene and developing ADPKD sometime during their life [5].

Pre-implantation genetic diagnosis (PGD)

If you are particularly concerned about having a baby with ADPKD, you may wish to talk to your GP or kidney specialist about being referred to a specialist centre for genetic counselling. If either prospective parent has ADPKD, it may be possible to undergo specialised *in vitro* fertilisation (IVF) with testing of the embryos beforehand to select one unaffected by ADPKD. This is called pre-implantation genetic diagnosis (PGD). An unaffected embryo is transferred into the womb. It is essential that the prospective parent with ADPKD has already had genetic testing to identify the gene causing their ADPKD, so this can be searched for in the embryos.

PGD is only offered in a few centres [6]. Funding may be available through the NHS under certain conditions. For more information, ask your genetics centre and see the [Human Fertilisation and Embryology Authority website](#).

You can find out more about how ADPKD is inherited in our information sheet 'How did I get ADPKD?', which is available to read and download from our website (www.pkdcharity.org.uk). You will also find a link to a directory of all the UK genetics centres at the end of this guide.

What should I do if I am planning a pregnancy?

Ideally women with ADPKD should be offered pregnancy planning with a GP, midwife, obstetrician or other pregnancy specialist [7]. This is so that you understand before you become pregnant how your kidneys will affect your pregnancy, and how being pregnant may affect your kidneys.

Pregnancy planning is also very important to make sure, where possible, that you are not on any medication that might affect the developing baby. Any other medical problems that might change with pregnancy are monitored too.

If you are thinking about becoming pregnant, it is advisable to talk to your GP or kidney doctor before you start trying to conceive. You may be referred to an obstetrician specialising in medical problems in pregnancy.

It is recommended that you use a reliable form of contraception before you start trying for a baby. It's important to be aware that contraceptive pills that contain the hormone oestrogen may not be suitable for some women with ADPKD, as they can increase blood pressure [8].

Some common drugs taken by people affected by ADPKD are unsafe in pregnancy, because they may affect the developing baby [9]. The most common drugs that should be changed if you become pregnant are listed in the following table.

Angiotensin converting enzyme inhibitors (ACE inhibitors)	Angiotensin receptor blockers (ARBs)
<ul style="list-style-type: none"> • Benazepril • Captopril • Enalapril • Fosinopril • Lisinopril • Moexipril • Perindopril • Quinapril • Ramipril • Trandolapril 	<ul style="list-style-type: none"> • Candesartan • Eprosartan • Irbesartan • Losartan • Olmesartan • Telmisartan • Valsartan

If you're taking any medication and wish to become pregnant it's important that you discuss your medication with your doctor. You may need to plan to switch to an alternative medication. **Remember that it is inadvisable to stop taking any medication unless your doctor has suggested that you do so, because this may put you and your baby at risk of complications.** In particular, good blood pressure control is important for a safe and successful pregnancy.

Like all women who are planning to become pregnant, it's recommended that you take folic acid every day for 3 months before you begin trying to conceive, and for the first 12 weeks of pregnancy. This helps to reduce the risk of problems affecting

the neural tube, tissue that eventually develops to form the baby's spine and nervous system [10]. These problems are known as neural tube defects, and include spina bifida, in which the spine does not form properly. Some specialists may advise you to take a higher dose of folic acid.

If you are overweight, it is recommended that you lose weight before planning to become pregnant [10]. This will improve your chances of conceiving and of an uncomplicated pregnancy.

If pregnancy is not possible for you, or you feel it is too risky, alternatives include surrogacy (another woman carrying your and your partner's baby) or adoption.

Once you are pregnant

What should I do when I become pregnant, or if I am already pregnant?

You should inform your GP, who will refer you to appropriate maternity services. Alternatively, you can contact a midwife directly. If possible, inform your kidney doctor straight away that you are pregnant.

If you are taking any of the medications listed earlier, see your GP or kidney doctor as soon as possible. Under their medical supervision, you can stop taking those medications safely and switch to an alternative.

What care will I receive when I become pregnant?

Like all pregnant women, you are likely to see a midwife at your first antenatal (meaning 'before birth') hospital appointment for a 'booking visit', where your personal details and medical history are recorded. Your subsequent care is likely to be with a specialist team of obstetricians and midwives with experience of looking after women with medical problems. Later in your pregnancy you may have more hospital visits than in standard antenatal care, to monitor you and your baby more closely.

When you become pregnant, your doctor may suggest that you take aspirin at a low dose (75 mg) [11]. Aspirin is safe to take in pregnancy and reduces the risk of pre-eclampsia. This is a condition characterised by high blood pressure, protein in the urine and fluid retention (see the section on blood pressure, below) [12].

You will be offered the same ultrasound scans and blood tests as other women in the UK. If there are concerns about how your baby is developing, or about your blood pressure, you may also be offered extra scans later in pregnancy to assess the baby's growth.

What can I do to improve the outcome of my pregnancy?

Good blood pressure control is very important for successful pregnancies. To achieve this, it is recommended that you [13]:

- Continue to take the medication recommended by your doctor for your pregnancy (if listed in the table, please see your doctor).
- Avoid excessive weight gain before or during pregnancy.
- Exercise regularly, unless advised not to by your doctor or midwife.
- Attend all your appointments as scheduled.

How will having ADPKD affect my pregnancy?

It is important to remember that most women with ADPKD have safe pregnancies and healthy babies. It is likely that you will be closely monitored to pick up any complications, in particular blood pressure problems.

The outcome of your pregnancy is partly dependent on your level of kidney function and blood pressure control before pregnancy. If your kidney function is normal or only mildly impaired, you are very likely to have a successful pregnancy.

The risk of complications in pregnancy increases as kidney function declines, but everyone is different. Your kidney doctor and/or a specialist obstetrician should be able to advise you about how your pregnancy might be affected.

Blood pressure

Women with ADPKD are more likely to develop high blood pressure in pregnancy than women who don't have ADPKD [2,14], particularly in later pregnancy. If this happens you may be advised to start taking medication or increase your current medication to control your blood pressure. Remember - any changes to your medication should only be made under close medical supervision.

Women with ADPKD are also more likely to develop pre-eclampsia [2,14]. This is a condition in which women have protein in their urine, fluid retention and high blood pressure. Pre-eclampsia is a serious condition for both the mother and the baby. Approximately 1 in 10 women with ADPKD with normal or mildly reduced kidney function develop pre-eclampsia [2,14]. You could be more likely to get pre-eclampsia if you already have blood pressure problems or poorer kidney function [14]. To reduce your risk of developing pre-eclampsia your doctor may suggest that you take aspirin at a low dose (75 mg) [12].

The most common complications of pre-eclampsia are poor growth of the baby and early delivery [9]. The condition can also cause seizures in the mother [9], and can make existing kidney problems worse [2], although usually only temporarily.

Rarely, pre-eclampsia causes the mother to have a stroke or to deliver a stillborn baby [9,15].

Some of the earlier signs of pre-eclampsia to look out for are [9,15]:

- visual disturbances, such as blurring or flashing lights
- sudden swelling of the hands, feet or face
- a severe headache that does not get better with standard painkillers
- sudden vomiting or stomach pain
- severe pain just below the ribs

If you experience any of these symptoms, seek immediate advice from a healthcare professional [9]. If left to escalate, seizures may occur in a small number of women [9].

If your midwife or doctor suspects you have pre-eclampsia, you are likely to be admitted to hospital for monitoring. Once pre-eclampsia has been diagnosed, you may be asked to stay in hospital until you give birth. Although your blood pressure will be controlled with medication, the only treatment for pre-eclampsia is delivery of the baby [9].

The timing of the birth will depend on how severe your pre-eclampsia is, balanced with the risks to your baby of being born early. The doctors will consider the risks to both you and your baby of prolonging the pregnancy or delivering your baby early. If your baby is going to be born prematurely (i.e. before 37 weeks' gestation) you may be offered a course of steroids before the birth to help your baby's lungs to develop [9].

Your obstetrician will discuss with you the timing of the birth and whether it is advisable to be induced or have a caesarean birth.

Problems with the placenta

High blood pressure or pre-eclampsia may mean that the placenta does not work as effectively; this can prevent the baby from growing properly [9]. This is more common in women with blood pressure problems, and with more severe kidney disease [16].

If your obstetrician is concerned about your baby's growth or the blood supply to baby, they may discuss with you whether it would be best for the baby to be born earlier than its due date.

Very occasionally, the placenta may detach before the birth of the baby. This is very serious. If this happens, you will usually feel severe and constant abdominal

pain and may have some vaginal bleeding [17]. You will need urgent medical attention and your baby will need to be delivered [11,17].

Kidney function

During pregnancy, your kidneys need to work up to 50% more to get rid of waste [18]. Usually, your kidney function is calculated using estimated glomerular filtration rate (eGFR). This is a measurement of how much waste fluid (in ml) your kidneys can filter from the blood in 1 minute. However, eGFR is inaccurate during pregnancy so will not be used [19]. Instead, your blood creatinine levels will be measured throughout pregnancy to check that your kidney function is not being affected [19]. These levels tend to fall in early pregnancy and rise again towards your due date [19].

You are more prone to urinary tract infections in pregnancy, and they're more likely to affect your kidneys [20]. If you develop symptoms of a bladder or kidney infection (pain, stinging or burning while passing urine) you should seek medical advice. Your doctor and midwife will regularly check your urine for signs of infection. If you develop a urinary tract infection, you will need to take antibiotics to treat it [20].

The growth of your kidney cysts is not likely to be affected by pregnancy [2].

Liver cysts

It is possible that pregnancy hormones may cause an increase in growth of liver cysts (but not kidney cysts) [21]. These may cause abdominal discomfort or pain, but they are no risk to the baby and do not affect your liver function [21].

You should contact your midwife, kidney doctor, obstetrician or GP if you are concerned about anything during your pregnancy.

Planning the birth

You'll be supported in your decision to give birth in the location of your choice, but most healthcare professionals will recommend that you have your baby in hospital [9,22]. This is because of your ADPKD and the possibility of developing blood pressure problems or pre-eclampsia during or after delivery.

You may be offered monitoring of your baby in labour [22], which is likely to be 'continuous foetal monitoring' or cardiotocography (CTG). This means the midwives and doctors will be able to listen to your baby's heart rate through labour. This will probably be advised because women with any kidney impairment or high blood pressure have a slightly higher chance that the placenta will not work as well as it should. Continuous monitoring means any changes in baby's heart rate in labour are

picked up and can be closely monitored and acted upon by the midwives and doctors.

If you have had good kidney function and normal blood pressure during pregnancy, midwives will look after you during your labour [22]. However, your midwife will continue to check your blood pressure and keep a close eye on your baby's heart rate. If you have had complications during your pregnancy, you may be advised to have your baby in a specialist centre, so you and your baby can be carefully monitored by specialists.

Having ADPKD does not mean you will need a caesarean delivery. Your doctors may advise you that your baby needs to be delivered a little early (usually 1 to 2 weeks early). They will discuss the appropriate method of delivery with you.

You will be able to have all forms of pain relief in labour including [13]:

- transcutaneous electrical nerve stimulation (TENS machine), which uses a mild electric current to reduce pain signals
- strong pain relief injections (pethidine and diamorphine)
- gas and air (Entonox®)
- an epidural, which is an injection of anaesthetic into the spine

If your kidney function is more severely reduced, the dose of pain-relieving injections may need to be reduced to minimise side effects [23].

After delivery, you should avoid non-steroidal anti-inflammatory drugs (NSAIDs), such as diclofenac and ibuprofen if you have reduced kidney function [23].

Alternative painkillers, such as paracetamol (which can be used safely if you are breastfeeding) or codeine (which should not be used if you are breastfeeding [24]), can be prescribed for you instead.

After your baby is born

What will be the long-term effects of the pregnancy on my kidneys?

Unless your kidney function is very poor, your pregnancy is unlikely to cause damage to your kidneys. During pregnancy, your kidney function will be very closely monitored. A temporary fall in kidney function may occur in some women, which usually recovers after the baby is born [2].

If your kidney disease is severe, pregnancy may cause a permanent reduction in kidney function. This may need to be treated with dialysis to keep you and your baby well [18].

If you develop high blood pressure during pregnancy, you are more likely to go on to have blood pressure problems after delivery and in later life [25]. This can be controlled with medication prescribed by your GP or kidney doctor.

If you are concerned about your health affecting your ability to be a parent, discuss this with your GP or kidney doctor. They will be able to discuss possible symptoms you may experience in the future.

How can I find out whether my baby has ADPKD?

If either you or your partner has ADPKD, the risk of your baby inheriting a faulty gene and having ADPKD is 1 in 2 (50%). Occasionally, abnormalities that show a baby might have ADPKD are seen on antenatal scans [26]. More usually, people with ADPKD develop cysts later in life, either in their teens or adulthood [26].

Until recently, testing for ADPKD was not generally advised in babies and children unless they showed symptoms. If your child is diagnosed with ADPKD before they have symptoms, this takes away their right to choose whether they want this knowledge. It may cause them distress growing up. However, there is growing evidence that some children with ADPKD develop high blood pressure - about a third have high blood pressure at night [27]. So many doctors now think it is useful to test children at risk of ADPKD for increased blood pressure, and to also look for signs of kidney problems using urine and blood tests [5]. Early diagnosis can allow treatment to prevent progression to be considered.

More information from the PKD Charity

- [How is ADPKD diagnosed?](#)
- [Talking to children and young people about ADPKD](#)
- [Genetic counselling and testing in ADPKD](#)

Useful information from others

- The [Human Fertilisation and Embryology Authority \(HFEA\)](#) has useful information on fertility and fertility treatments, including pre-implantation genetic diagnosis (PGD) (Tel: 020 7291 8200; email: enquiriesteam@hfea.gov.uk; Opening 9:00-17:00 Monday to Friday)
- [Guy's and St Thomas' Centre for Preimplantation Genetic Diagnosis](#) explains how PGD works, including preparation, risks and stages of PGD
- The [British Society of Genetic Medicine](#) has a list of UK Genetics Centres
- [NHS Choices](#) has general information on many health topics, including [pregnancy](#), [high blood pressure \(hypertension\)](#) and [pre-eclampsia](#)

- [Action on Pre-eclampsia](#) provides support and information for women with pre-eclampsia and their families (01386 761848; info@apec.org.uk)

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Published by the PKD Charity

The PKD Charity is a registered charity in England and Wales (1160970).
A company limited by guarantee. Registered company in England and Wales (9486245).

Information Product Ref No ADPKD.IP.2017.V2.0

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First published May 2017

Due to be medically reviewed May 2020

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With thanks to all those affected by ARPKD who contributed to this publication.

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