

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.

Before you become pregnant

Will I be able to 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 two 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 three in 10 (30 per cent) [2]. If you have difficulties conceiving, you should contact your GP or kidney doctor.

What is the risk of my baby inheriting ADPKD?

If you have ADPKD, there is a one in two (50 per cent) chance of your baby also inheriting the ADPKD gene and developing ADPKD sometime during their life. 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.

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 the Polycystic Kidney Disease Charity 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, pregnancy planning should be offered to women with ADPKD [3]. This is so that you understand before you fall pregnant how your kidneys will affect your pregnancy, and how being pregnant may affect your kidneys.

It's also very important to make sure, where possible, that you are not on any medication that might affect the developing baby, and that any other medical problems that might change with pregnancy are monitored.

If you are thinking about becoming pregnant it's advisable to talk to your GP or kidney doctor before you start trying to conceive. You may be referred to an obstetrician with an interest 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 [4].

Some common drugs taken by people affected by ADPKD are unsafe in pregnancy, because they may affect the developing baby [5]. The most common drugs that should be changed before pregnancy are listed below.

Angiotensin converting enzyme inhibitors (ACE inhibitors)	Angiotensin receptor blockers (ARB)
<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 are taking any medication and wish to become pregnant it is important that you discuss your medication with your doctor, as you may need to be switched to an alternative. Remember that it is inadvisable just to stop taking any medication unless

your doctor has suggested that you do so, because this may put you and your pregnancy 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 fall pregnant, it is recommended that you take folic acid every day for three 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, a tissue structure that eventually develops to form the baby's spine and nervous system [6]. These problems are known as neural tube defects, and include spina bifida, in which the spine doesn't 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. This will improve your chances of conceiving and of an uncomplicated pregnancy.

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 that you are pregnant straight away.

If you are taking any of the medications listed above, it is recommended that you see your GP or kidney doctor as soon as possible, so that you can stop taking them safely under medical supervision 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 will be recorded. Your subsequent care is likely to be with a specialist team of obstetricians and midwives with experience looking after women with medical problems. Later on in your pregnancy you may have more hospital visits than in standard antenatal care in order to monitor you and your baby more closely.

When you become pregnant your doctor may suggest that you take aspirin at a low dose (75mg). Aspirin is safe to take in pregnancy and reduces the risk of pre-eclampsia, a condition characterised by high blood pressure, protein in the urine and fluid retention (see the section on blood pressure, below) [7].

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:

- Continue to take the medication recommended by your doctor for your pregnancy (unless it is listed above).
- Avoid excessive weight gain before or during pregnancy.
- Take regular exercise, 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 the majority of women with ADPKD have safe pregnancies and healthy babies, but it is likely that you will be closely monitored in order 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], 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]. In pre-eclampsia, women have protein in the urine (proteinuria) and fluid retention (oedema), as well as high blood pressure. It is more common in women who have pre-existing blood pressure problems, and those with poorer kidney function.

Pre-eclampsia is a serious condition for both the mother and the baby. The most common complications are poor growth of the baby and early delivery. The condition can also cause seizures in the mother, and can make existing kidney problems worse, although this is usually only temporary. Rarely, pre-eclampsia causes the mother to have a stroke or to deliver a stillborn baby.

Some of the signs of pre-eclampsia you might notice are:

- Visual disturbances, such as blurring or flashing lights
- Sudden swelling of the hands, feet or face
- Severe headache
- Vomiting
- Severe pain just below the ribs

If you experience any of these symptoms, seek immediate advice from a healthcare professional [5].

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. The only treatment for pre-eclampsia is delivery of the baby.

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 take into account 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 you may be offered a course of steroids before the birth to help your baby's lungs to develop.

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 doesn't work as effectively or does not develop fully, preventing the baby from growing properly. This is more common in women with blood pressure problems, and with more severe kidney disease.

Occasionally the placenta may detach prematurely, causing bleeding. If this happens your baby may need to be delivered urgently.

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

Kidney function

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

You are more prone to urine infections in pregnancy, and they are more likely to affect your kidneys. 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.

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

Liver cysts

Pregnancy hormones may cause an increase in growth of liver cysts (but not kidney cysts), which may cause abdominal discomfort or pain, but are no risk to the baby and do not affect your liver function. If you have more than two pregnancies, an increase in the size of liver cysts is more likely [8].

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

Planning the birth

You will 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, 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, which is likely to be 'continuous foetal monitoring' or CTG. This means the midwife will be able to listen to your baby's heart rate through labour. This may be necessary because in women with any kidney impairment or high blood pressure there is a slightly higher chance that the placenta will not be working as well as it should be. Continuous monitoring will mean that any problems in labour are picked up early.

If you have had good kidney function and normal blood pressure during pregnancy midwives will look after you during your labour. However, your midwife will continue to check your blood pressure and keep a close on your baby's heart rate.

Having ADPKD does not mean you will need a caesarean delivery but your doctors may advise you that you need to be delivered a little early (usually one to two weeks early).

You will be able to have all forms of pain relief in labour including epidurals, but after delivery you should avoid 'non-steroidal anti-inflammatory drugs' (NSAIDS), such as diclofenac and ibuprofen. Alternative painkillers, such as paracetamol or codeine, 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, and a temporary fall in kidney function may occur in some women, which usually recovers after the baby is born [9].

If your kidney disease is severe, pregnancy may cause a permanent reduction in kidney function, which may need to be treated with dialysis to keep you and your baby well [9].

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 [10]. This can be controlled with medication prescribed by your GP or kidney doctor.

How can I test if my baby has ADPKD?

If either you or your partner has ADPKD the risk of your baby inheriting the gene and having ADPKD is one in two (50 per cent).

Occasionally abnormalities are seen on antenatal scans but children more usually develop cysts later in life, either in their teens or adulthood.

You can find out more about testing for ADPKD in children born to a parent with the condition by visiting the Polycystic Kidney Disease Charity website (www.pkdcharity.org.uk).

Useful sources of information

- Human Fertilisation and Embryology Authority (HFEA)
www.hfea.gov.uk
- Guy's and St Thomas' Centre for Preimplantation Genetic Diagnosis (PGD)
www.pgd.org.uk/home.aspx
- UK Genetics Centres
www.bshg.org.uk/genetic_centres/uk_genetic_centres.htm
- NHS Choices (general healthcare information)
www.nhs.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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For the latest version including a version with references, please visit

www.pkdcharity.org.uk/about-adpkd/living-with-adpkd/adpkd-and-pregnancy



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