

Pregnancy and Family Planning in Autosomal Dominant Polycystic Disease (ADPKD)



It's natural to wonder how ADPKD can affect fertility and pregnancy. For people with ADPKD, the ability to conceive children and have a healthy pregnancy is not that different than the general population. About 80% of pregnancies in women with ADPKD are safe and proceed with minimal complications; however, there are some additional risks that are important to be aware of. This means that extra monitoring and care throughout a pregnancy and when the baby is being born is recommended.

Pregnancy and a new diagnosis of ADPKD

Some women do not realize that they have ADPKD until they are pregnant and undergo certain tests. While this may be surprising for some women, it's not an uncommon way that ADPKD is diagnosed.

If you would like to learn more general information about ADPKD, visit [BCRenal.ca](https://www.bcrenal.ca) ► [Health Info](#) ► [Kidney Care](#) ► [Polycystic Kidney Disease](#).



What should I do if I'm already pregnant?

If you are already pregnant, it's important to let your care team know as soon as possible, so you can discuss next steps and if any changes related to lifestyle or medical care are required. Some medications are not safe to take during pregnancy and may need to be changed.

What to Know Before Pregnancy

Fertility

Both men and women with ADPKD are able to have children. However, damage to the kidneys can affect the reproductive hormones of both men and women, making it more difficult to conceive. This means that with mild kidney damage, you are likely to experience the same fertility rates as the general population and with more severe kidney damage, you may have more difficulty conceiving children.



For people with severely damaged kidneys who receive a kidney transplant, fertility may return after surgery takes place.

For women living with ADPKD, fertility is not affected by ADPKD itself unless kidney damage is present. For men however there is some evidence that ADPKD may impact fertility even if they have normal kidney function; one study found that this is the case for about 5% of men with ADPKD and normal kidney function.¹

Inheritance of ADPKD

A common question among parents is whether their child(ren) will develop ADPKD, which is an inherited disease. Each child who has a parent with ADPKD has a 50% chance of also developing the condition. For more information about how and when to consider screening and testing for ADPKD, you can review the resource [Screening and Testing for Autosomal Dominant Polycystic Kidney Disease \(ADPKD\)](#) for more information. Visit: [BCRenal.ca](#) ► [Health Info](#) ► [Polycystic Kidney Diseases](#) ► [Managing my ADPKD](#) ► [Self-Management](#)

There is one approach that some parents choose that reduces the likelihood of their child developing ADPKD. It involves genetically screening embryos for the gene mutations associated with ADPKD. Only embryos that do not have the gene mutations are then artificially implanted into the mother's uterus (in vitro fertilization). This method is called pre-implantation genetic diagnosis (PGD).

Each individual will feel differently about this approach to conceiving a child. It's important to have open, honest and informed discussions with your partner and health care team about PGD and in vitro fertilization if you are considering this option.

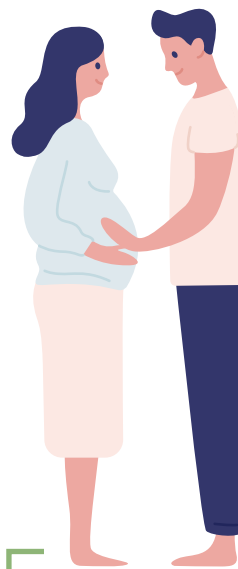
The Mother's Health: Pregnancy Risk Factors to Consider

Below are some possible health complications that can happen during any pregnancy, but which women with ADPKD may be at higher risk of developing.^{2,3,4} For each condition, general statistics are provided. However it is important to know that your individual risk may be lower or higher than the numbers listed in this resource, depending on your specific medical situation. Talk to your care team about your personal risk for complications during pregnancy.

Blood Pressure: Women with ADPKD are more likely to develop high blood pressure (hypertension) during pregnancy, and this risk is increased if the mother's blood pressure was already high before becoming pregnant.

- Pregnant women with ADPKD experience higher rates of new hypertension (15-20%) compared to the general population (5-10%);
- Pregnant women with ADPKD who already have hypertension before pregnancy experience a higher chance of worsening hypertension (10-20%) compared to the general population (1-2%);
- There is also evidence that 25% of those with hypertension also develop a hypertensive complication, such as pre-eclampsia (see the section on pre-eclampsia below).²

For these reasons, monitoring and managing your blood pressure closely both before and during pregnancy is very important.



How can I prepare myself before becoming pregnant?

Optimizing your health before becoming pregnant can help improve your chances of having a healthy and uncomplicated pregnancy. This includes making sure that your blood pressure is under control, and that any other health conditions you may have are well controlled too. Also, some medications cannot be used in pregnancy, so you may wish to adjust these before becoming pregnant. If you are thinking of becoming pregnant and want to know what steps you should take to prepare, talk to your doctor/kidney team.

Kidney Function: Evidence suggests that women with ADPKD are at a higher risk of experiencing kidney damage during pregnancy. A small but sustained loss of kidney function that persists after pregnancy occurs in approximately 10%⁴ of women with ADPKD. This scenario is more likely for women who already had impaired kidney function before becoming pregnant, who have more risk factors (e.g. high blood pressure) and those who have had multiple pregnancies.^{2,3}

Pre-eclampsia: This is a condition whereby pregnant women develop high blood pressure and lose protein in their urine. While 2 to 3 percent of pregnancies result in pre-eclampsia, one study³ found that 11% of pregnant women with ADPKD develop the condition; this risk is higher in those with other risk factors such as prior pre-eclampsia or eclampsia, uncontrolled blood pressure, lower kidney function or other health conditions such as diabetes or obesity. Pre-eclampsia can be life-threatening for both mother and child if left untreated (see treatment options further below).

Eclampsia: Eclampsia is a more severe complication of pre-eclampsia which is diagnosed by seizure in someone who has never suffered a seizure before. Women with eclampsia may be given anti-seizure medication and, if the pregnancy is advanced enough, labour may be induced early.

Miscarriages: A miscarriage is when the pregnancy is lost within the first 12 weeks. This occurs in about 2 in 10 of all pregnancies (or 20%), regardless of whether the mother has ADPKD. However, if you have lower kidney function or uncontrolled hypertension, there is a greater risk of miscarriage.

Urinary Tract Infections: All women are more susceptible to urinary tract infections during pregnancy, and those with ADPKD are at higher risk (14% in the ADPKD population vs 1% in the general population)⁴. Increased screening for bacteria in the urine is recommended, so that treatment can be given as early as possible.

Liver Cysts: Hormone changes during pregnancy have the potential to cause liver cysts, but not kidney cysts, to grow in size.

Long-term impacts: For some women with ADPKD, the changes in blood pressure and renal damage from pregnancy continue after the pregnancy is over.² Talk to your doctor about your personal risk of potential long-term complications.

Other Factors to Consider

Abdominal Fullness and Pain: With ADPKD, cysts and the enlargement of kidneys can cause the sensation of a “full stomach” or cause [pain](#), discomfort or even shortness of breath. Pregnancy may make these sensations more intense.

Mental Health: Pregnancy can not only strain people physically, but emotionally as well. This may be especially true for parents with ADPKD, who may feel the added stress of coping with their disease during pregnancy. You can visit our [mental health pages](#) for more information, and speak to your care team about any concerns related to mental health.



Medications: If you’re taking any medication and become pregnant, it’s important that you discuss your medications with your doctor. Some common drugs taken by people who have ADPKD are unsafe to take and need to be modified during pregnancy, because they may affect the developing baby.



Some commonly used medications that are not safe during pregnancy and/or breastfeeding include:

- *Blood pressure medications*
- *Immunosuppressant medications (including ‘anti-rejection’ medications after transplant)*
- *Pain medications*
- *Some over the counter medications*
- *And others*

The Baby's Health: Pregnancy Risk Factors to Consider

Just like there are possible complications for the mother, there can be complications for the baby. One study showed only a slightly higher risk of fetal complications for ADPKD pregnancies (67% of these pregnancies were completed with no complications, whereas 74% of pregnancies in the general population had no complications). Risks need to be considered on an individual basis, so it is important to talk to your care team about your baby's health.

Some examples^{2, 3, 4} include:

- Intrauterine growth restriction, which is reduced growth while developing in the uterus (this occurs in 8-10% of babies born to mothers with ADPKD, compared to 3-4% for the general population)^{3, 4}
- Lower-than-average weight at birth
- Premature birth (this happens for 11% of babies born to mothers with ADPKD, compared to 6% for the general population)⁴
- The need to be admitted to the neonatal intensive care unit for extra care and monitoring
- Stillbirth/spontaneous abortion (15–20%, which is a similar rate as the general population)²

While it's important to note that most babies born to mothers with ADPKD are healthy, these risks exist and, in general, the risk of any of these problems increases when pregnant women have more severe kidney disease.



NOTE: Importantly, rates of other birth defects are no different in babies born to mothers with ADPKD compared to the general population.

Monitoring and Care During Pregnancy

Monitoring

During any pregnancy, it's common to have many tests to monitor the health of the mother and developing baby. Even if your kidney function and medical condition is stable going into the pregnancy, by virtue of having a kidney disease your pregnancy is considered higher risk and so you will be monitored more closely. This may mean having tests done more often throughout your pregnancy, as well as during and after giving birth.



Your doctor will recommend how often these tests are done based on your personal risk for developing complications during pregnancy, and how your health progresses over the course of the pregnancy. Your doctor may refer you to specialists, including those such as obstetricians and/or maternal fetal medicine specialists who are more familiar with higher risk pregnancies, based on your health needs.

Treatment

While each person will require individualized treatment best suited for their needs, some general descriptions are below for potential health complications:

Blood Pressure: It's important that a women's blood pressure is maintained at a healthy level during pregnancy and that the appropriate blood pressure medications are used. This may mean that your blood pressure target during pregnancy is different than your usual blood pressure target and/or you may use different blood pressure medications than you have in the past.

Pre-eclampsia and eclampsia: Early in your pregnancy, your team may suggest preventative medications to reduce the risk of this complication. If these complications occur, treatment may include medications to lower blood pressure and, depending on the severity of pre-eclampsia, labour may be induced early.

Urinary tract infection: Antibiotics are used to treat an infection, even if no symptoms are showing.

Planning the Birth

Like other higher risk pregnancies, it is also recommended that your pregnancy proceed with close medical monitoring and that births take place in the hospital.



After the Birth

After giving birth, the health of both the baby and mother will be monitored. Some of these complications, like pre-eclampsia and hypertension, can affect women even after delivering their baby. Close monitoring will ensure that proper care and adjustment of medications happen if any health complications arise.

Women with ADPKD are able to breastfeed, but as is the case for all new mothers, some medications are not recommended during this time. Talk to your care team about what medications are safe to use while breastfeeding.

References

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