



Family Planning for CF Partners

If you are thinking about having a baby and your partner has CF there are many things to consider including your partner's health, whether you carry the CF gene and the reproductive options available to you.

It is important that your partner discusses their health status with their CF care team as they may be able to access treatments to optimise their health before planning a pregnancy.

The CF team will also be able to provide information about your reproductive choices to help you both decide on the best option for you.

Do You Carry the CF Gene?

If you are planning a pregnancy you may want to find out if you carry a CF gene. If you do NOT carry a CF gene, then the new baby will be a CARRIER as they will inherit a CF gene from your partner but not from you. If you are not a carrier your baby will not have CF.

If your partner has CF and you are a carrier, with each pregnancy a baby will inherit a CF gene from your partner and have a 50% chance of also inheriting a CF gene from you. This means a new baby will either be a carrier or have CF.

Couples who both carry CF genes can contact their local Genetic Services to make an appointment with a genetic counsellor. All discussions with a genetic counsellor are confidential. Information will not be passed onto the CF team without your permission.



What are your Reproductive Choices?

Conceive Naturally: Many couples decide to conceive naturally. In some situations, umbilical cord blood may be able to be collected and tested at delivery of the new baby. This would need to be arranged prior to the birth of your child and discussed with your obstetrician or doctor.

Newborns may also be diagnosed through newborn screening (heel prick/ Guthrie test) or recalled for further investigations, such as sweat tests if they are found to be carriers.

Conceive Naturally and have Pre-Natal Testing: Once a baby is conceived naturally there are pre-natal tests that can be performed to see if the baby has CF.

The genotype (genetic make-up) of both parents needs to be known for pre-natal

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testing so it will be necessary for you to find out your carrier status.

- Chorionic Villus Sampling (CVS): This test can be performed from 12 14 weeks of pregnancy, with public hospitals in WA performing CVS from 13 weeks gestation. In this procedure a sample of placental cells are taken from the mother and tested for genetic conditions such as CF.
- *Amniocentesis:* This test can be performed from 16 weeks. A sample from the amniotic fluid (the fluid surrounding the developing baby) is taken and analysed by a laboratory.

Whilst these are both very safe procedures, there is a very small risk of miscarriage associated with them. Talk to your managing team about any concerns.

Pre-implantation genetic testing (PGT): PGT is performed on embryos conceived by in vitro fertilization (IVF). IVF is a process by which an embryo is created outside the body using an egg cell from the mother and a sperm cell from the father. After a few days, a cell is removed from the newly created embryo and tested for a specific genetic condition such as CF.

Only the unaffected embryos are implanted into the mother's uterus. As for all IVF procedures, there is no guarantee of a pregnancy. You will need to research the costs carefully as extra fees exist for the PGT component in addition to those associated with IVF. All couples wishing to pursue IVF in WA need to submit an application to the Reproductive Technologies Council and meet with a clinical geneticist or genetic counsellor. Your chosen fertility specialist can assist you with these applications and make any necessary referrals to a genetics service.

Donor Sperm or Egg: Although an egg donor can be used, it is much easier to use a sperm donor. The aim here is to avoid both parents being carriers of the CF gene. Artificial insemination is available through private fertility practices. All sperm and egg donors are screened for the most common CFTR genes.

Donor Embryo: Donor embryos are sometimes available. Couples undergoing IVF may choose to donate their embryos if they have more than they need.

Decision Making

Obviously, there is no 'right' choice here. People will make different choices at various times in their lives and choices are often influenced by family, relationship, medical or financial circumstance. Only you and your partner can decide which option is the right one for you both.

Useful Resources

- Fertility factsheets (CFWA)
- Genetic Services of WA (Department of Health)
- Preimplantation Genetic Diagnosis in WA
- <u>Genetic Factsheets (NSW Health)</u>

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