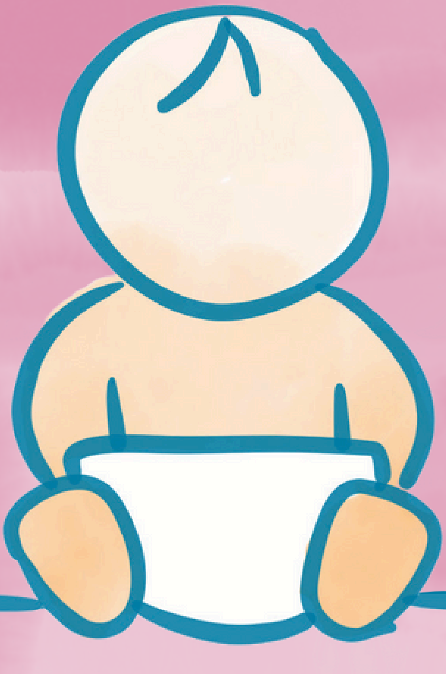
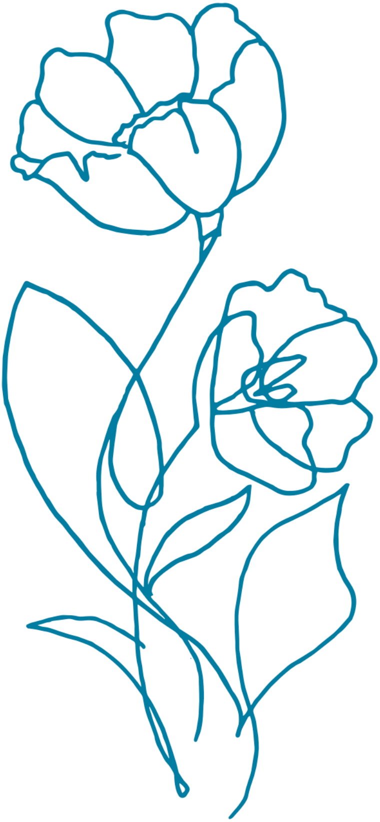
CYSTIC
FIBROSIS NZ

FAMILY PLANNING





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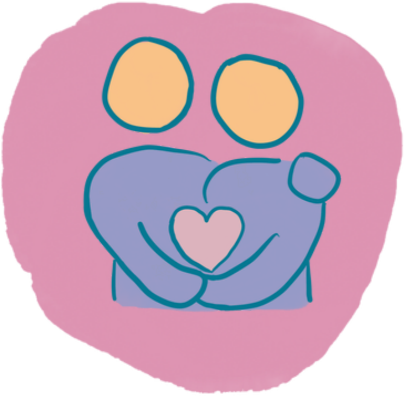
FAMILY PLANNING

DECIDING TO START A FAMILY IS A BIG DECISION FOR MOST ADULTS. HAVING CYSTIC FIBROSIS MEANS THERE'S MORE TO THINK ABOUT, AND IT CAN TAKE MORE PLANNING, BUT BEING A MUM OR DAD IS A REALITY FOR MANY KIWI ADULTS WITH CF.



THE CYSTIC FIBROSIS TRANSMEMBRANE CONDUCTANCE GENE AND YOUR BABY

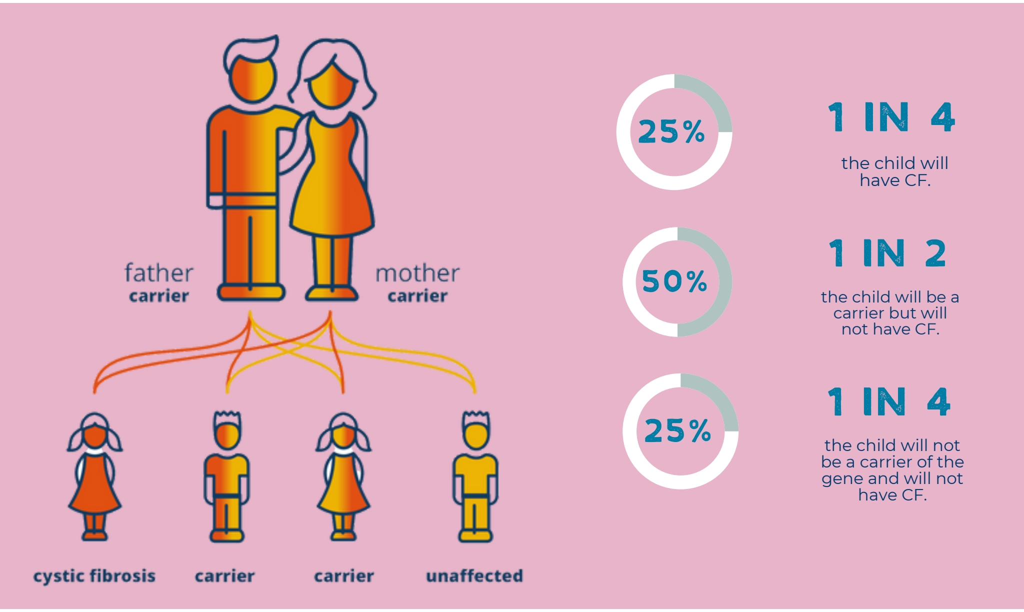
As a person with CF, you'll pass on the mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene that causes CF, to any children you have. If your partner doesn't carry the CF gene this means your child will be a carrier of the CF gene but won't have CF.

If your partner also carries a mutation in the CFTR gene, each child you have together has a

- 50% chance of having CF
- 50% chance of not having CF but will carry the CF gene.

About 1 in 25 Kiwis carry the CF gene, however most people don't know they're a carrier because being a carrier doesn't affect their health.

Your partner can find out if they're a carrier through a simple blood test. It's important to know though that not all CF genes can be tested for. Your partner may have a negative test but there's a very small chance your child with have CF.



UNDERSTANDING YOUR OPTIONS

It's a personal decision whether you decide to find out if your partner carries the CF gene. Cystic fibrosis carrier screening is available if you want to find out if your partner carries the CF gene.

CYSTIC FIBROSIS CARRIER SCREENING

CF carrier screening can be done during pregnancy, though often people chose to do it when they're planning to start a family. If you chose to have CF carrier screening before pregnancy, you'll be offered genetic counselling to discuss your reproductive options.

If you decide to wait until pregnancy, one options is to have a test at about 11–12 weeks' gestation vis chorionic villus sampling (CVS). This test looks for genetic conditions by taking a sample of the placental tissue using a small needle. The other option is an amniocentesis at around 15–16 weeks' gestation which diagnoses chromosomal abnormalities from amniotic fluid.

Testing during pregnancy can tell you before your baby is born if they have cystic fibrosis. It can also tell you if they're a carrier only. CF carrier screening identifies the majority of CF carriers. However, the screening test is designed to identify only the most common

CF mutations and may not identify all of the 2,000 mutations.

PREIMPLANTATION GENETIC DIAGNOSIS

Preimplantation genetic diagnosis (PGD) is another option if you found out your partner is a CF carrier before pregnancy. PGD can help you conceive a baby not affected with CF. This is done using in-vitro fertilisation to create embryos. In PGD, females take medications to stimulate her ovaries to produce a large number of eggs. These eggs are then fertilised with the male's sperm.

Three to five days later, either a single cell or a number of cells are removed from each embryo and tested for their specific gene changes in the CFTR gene. Only embryos without CF are chosen for transfer into the female partner's womb. These embryos will be carriers of CF.

In New Zealand, only one embryo is transferred at a time and any other unaffected embryos are frozen for later use.
Some couples who have IVF treatment have great success with few obstacles.

However, some couples face numerous challenges and may not be successful after many attempts. The same is true for PGD.
At the start of a PGD cycle, there's about a 25% chance that you'll conceive from that cycle. The further you get through the cycle, the greater the chance for success. If a healthy embryo is transferred, the chance of having a baby increases to about 35-45%.

Before starting PGD you'll need to meet with a genetic counsellor at a Genetic Services Hub at either Auckland City Hospital, Wellington Hospital or Christchurch Hospital. Your GP or CF team can send a referral for an appointment. Your appointment is publicly funded so you don't need to pay anything. There are also private options for genetic testing.

During your appointment the genetic counsellor will discuss CF genetics, genetic testing, PGD process and what the best options are for you. You'll then be referred to a fertility clinic.

There is some public funding available for PGD and includes the cost of IVF. However, there is a waiting list and you must meet certain criteria including females being aged under 40 a BMI less than 32.

If you're eligible you can receive 2 cycles of publicly funded PGD, unless you have a baby following the first cycle.

You can pay privately for PGD but the cost of a cycle starts from approximately $16,500.

Pre-implantation genetic diagnosis is 95-98% accurate for each embryo. This means that there is a small chance that an embryo transferred could be affected with CF.

“If you decide you want to have a child, the process until you start IVF takes a while. First, your partner needs to do a carrier test, then wait for an initial consultation, then there is a minimum 1 year waiting list to begin the IVF process. Budget at least 1.5 years from when you decide you want kids until you actually begin.

We found IVF quite an emotional time. Neither my partner or myself are emotional people, but from 20 eggs harvested we ended up with 2 viable eggs. This was very difficult for us both. Since become a dad, I've found it hard to balance my health routine and look after a baby. The baby keeps you awake so much that outside of work, all I want to do is sleep.

Exercise is often pushed down the priority list. I haven't got a great system sorted out yet (our baby is 6-weeks-old), but I've .found I'm far more likely to do exercise straight after work, and before I get home, because the moment I walk in the door there are chores to be done and a baby to look after.”

MAKING THE DECISION TO START A FAMILY

It's your decision whether you'd like to have children. It's important to talk with your CF team as they can discuss and plan for any impact your CF has during pregnancy and for parenthood.
These may include:

- How pregnancy will affect your general health.
- Any impact of pregnancy on your lung health.
- A healthy weight to support a health pregnancy.
- Current medications and any changes to your medications during pregnancy.
- Family support.
- The practicalities of life as a new parent.
- Pregnancy post organ transplant.
- Breastfeeding.

"Before deciding to have children, my partner had genetic testing to see if he was a CF carrier, which he wasn't, and that helped give us confidence in our decision.
I felt confident in my CF team and discussed having a family extensively with them. At one stage, my CF nurse and dietitian discussed with my partner that it was okay for us to have kids, so right throughout I felt like they really had my back, which was a huge support.
We ended up going through IVF, which was a long and difficult process though I'm sure it is for everyone regardless of CF. I was diagnosed with CF related diabetes part way through so that slowed us down while I got on top of that. Setbacks were really upsetting and frustrating.
We only have one child and recently decided to give up two embryos still on ice. Primarily, we felt so lucky to get one baby and he was hard fought, with lots of effort going into IVF then diabetes management and being premature. My health had declined in the time since and it felt like the right thing to do, stopping at one healthy child and maintaining my health as much as possible. It was a decision we spent at least a year, if not two, making. If you can, don't rush these decisions."

"I actually never thought I would have the opportunity to become a parent and when I met my husband, he knew kids would possibly be off the cards due to my health, I had also accepted this.

After I had a transplant, we decided to meet with a fertility specialist and find out what our options were. We decided to go down the avenue of fostering a child. Choosing to have a child has always been a difficult decision, as we know our health is so fragile and takes a lot of energy and time to manage it well. But I do believe no one is guaranteed a set amount of time on this earth so any time I could give our beautiful child/ren would be a blessing and would forever make a positive impact on them.

Five and a half years later, we have two beautiful children who are siblings. It's been an absolute privilege to be able to experience parenthood, to love our beautiful children and to experience the world through their eyes. Juggling motherhood, work, health, relationships, housework etc takes a lot of balance, awareness of self-care and the importance of asking those close to you for help when you need it. It really does take a village to raise a child/ren and for someone with an illness like CF, it takes a really big village, but it is possible!"

"We wanted a family so did the tests and found out we needed IVF. They had me on good drugs so I was quite woozy and don't remember much about it. My wife doesn't like needles much but did what she had to do and it worked first time. We were pleasantly surprised."

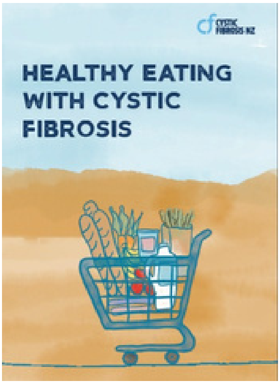
DOCUMENTS IN THE ADULT GUIDE SET:

Click on icon to below to view other resources.

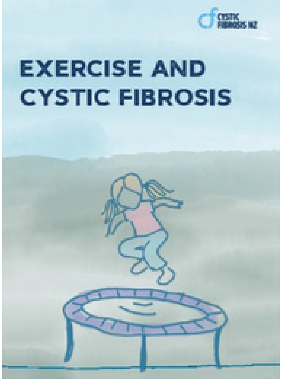
SUPPORT FROM CYSTIC FIBROSIS NEW ZEALAND

TRANSITIONING FROM CHILD TO ADULT SERVICES

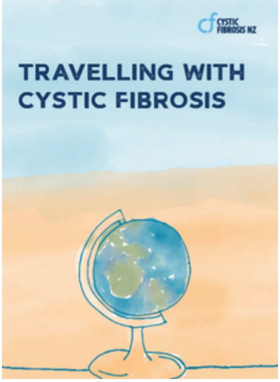
MENTAL HEALTH AND WELLBEING



HEALTHY EATING WITH CYSTIC FIBROSIS



EXERCISE AND CYSTIC FIBROSIS

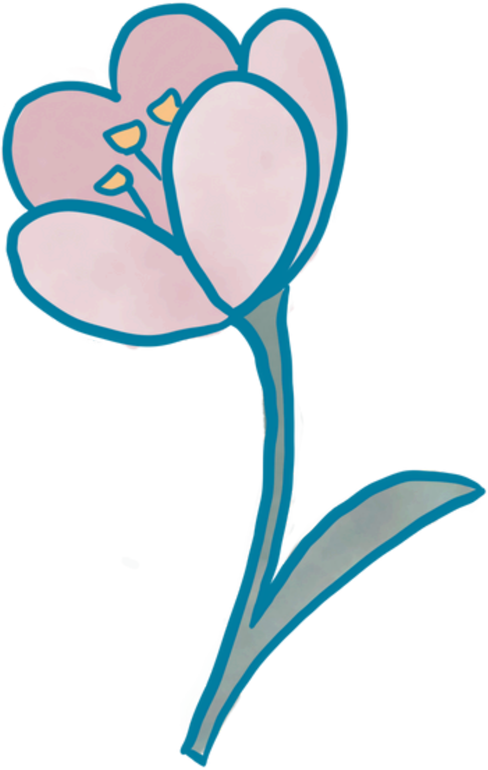


TRAVELLING WITH CYSTIC FIBROSIS

FERTILITY AND SEXUAL HEALTH

FAMILY PLANNING

MANAGING DAILY LIFE WITH CYSTIC FIBROSIS



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