

“ Our family is very open about CF and everyone’s carrier status so I never felt it was something I had to sit down and discuss with my son, nor has it ever been something to be ashamed of. To us being a carrier is nothing to feel guilt about - it is just the way it is. ”

“ My sister has CF but I never really thought about finding out my carrier status until I was planning to have a family. Even then we discussed it and decided that knowing my carrier status would make no difference to the decision we made together to have our child. ”

“ Everyone should have access to enough information to make their own informed choice about carrier screening. To me it was important to know my carrier status and make my own choice. With CF in my family I have always known about CF and known there was potential for me to be a carrier so when I started to think and talk about having a family with my husband we decided to both find out our carrier status. ”



KNOWING YOUR OPTIONS

CYSTIC FIBROSIS CARRIER SCREENING

CF & GENETICS

SOME FACTS

- 1** Approximately 1 in 25 Australians of Caucasian ancestry are carriers of the CF gene changes that cause cystic fibrosis.
- 2** Being a carrier does not mean you have CF but that you have the gene changes that can cause CF.
- 3** Both parents need to be carriers of a gene change that cause CF in order for a child to be born with CF.
- 4** Over 95% of children born with CF have parents who did not know they were carriers of the CF gene change.

There are thousands of gene changes that could cause CF. General CF carrier screening can tell you if you have one of the more common CF causing gene changes.

Knowing your carrier status can help inform the life choices you make for yourself or your family.

Q. WHAT DOES IT MEAN TO HAVE A CHILD WITH CYSTIC FIBROSIS?

Everyone's experience with CF is unique.

CF is not infectious and it does not impact on a person's intellectual ability. There is no cure for CF and there is no way to tell whether a child will have a severe experience of the disease. The most common cause of death of people with CF is impaired lung capacity.

The symptoms of CF are due to excessive salt in the cells. This causes the natural mucus in the body to be very thick, sticky and to build up in the lungs and digestive system which can create difficulties with breathing, immunity and digestion.

A person with CF can experience a lot of symptoms but some of the most serious are a persistent cough (including coughing up blood), difficulty breathing, susceptibility to infections and being underweight. Frequent hospitalisation, daily physio sessions and taking up to 40 tablets a day are also part of living with CF.

Treatment of CF has improved over the past 30 years, but reduced life expectancy is still a reality for the majority of people with CF. Coming to terms with this, as well as dealing with the day to day of chronic illness, is a big part of living with CF.



Q. HOW DO I KNOW IF I AM A CARRIER?

People who are carriers of CF typically do not have any symptoms and approximately 94% of carriers have no family history. The only way to know you are a carrier is to have a genetic test for the gene changes that cause CF.

WHERE CAN I GET CARRIER SCREENING DONE?

Carrier screening is available in Australia. For more information about CF carrier screening services in your area talk to your GP or go to:

www.cysticfibrosis.org.au/vic/carrier-screening

WHAT DOES CARRIER SCREENING INVOLVE?

Carrier screening can be done either as a saliva or blood screen. Blood tests are becoming the most common form of screening. Different service providers will have different costs, methods and screen for a different number of gene changes. It is best to talk to your doctor and also to a genetic counsellor about your screening options.

IS CARRIER SCREENING COVERED BY MEDICARE?

Carrier screening is not covered by Medicare and there is a cost. The cost varies depending on the service provider but expect to pay no less than \$150.

WHAT DO THE SCREENING RESULTS MEAN?

The screening results will tell you if you are a carrier for the most common genetic changes that cause cystic fibrosis. It is important to remember that the current tests do not look for rarer forms of the CF causing genes. Ask your genetic counsellor any questions you have about your results and the small risk of carrying a rare CF causing gene change.

WHAT ARE MY CHOICES?

Making the decision to know your carrier status is a choice only you can make. Be sure to ask questions and discuss in detail what the options and potential impacts are with a genetic counsellor or your doctor.

Some people will choose to know their carrier status and some may choose not to. What is important is that you feel you have made an informed choice about how CF may affect your decisions for you and your family.

WHAT ELSE CAN I DO?

Some things that people have found helpful:

- 1 Include history of **CF and carrier status in the family tree** so that future generations know and have a record of a family history of the condition. It is very helpful to take any family history to your doctor to help inform the screening process.
- 2 Think about how, or if you want to talk about CF and carrier status with your extended family and children. Every family is different but it has been found that the more **talking about CF and carrier status** is normalised the easier it can be for people to understand what they can choose later in life.

Cystic Fibrosis Victoria's vision is for a world where lives are unaffected by CF by increasing the well-being and quality of life of people living with CF.

CFV supports cystic fibrosis carrier screening as an opportunity for people to make informed life and reproductive choices in relation to CF.



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What is Cystic Fibrosis (CF)?

CF primarily affects the lungs and digestive system and is the most common, life shortening, recessive genetic condition in Australia. With improved medication and treatment most people living with CF are able to lead normal and productive lives on a day to day basis with an average life expectancy now extending into the late 30s.

Who gets CF?

CF is an inherited condition. There is a 1 in 4 chance a child will be born with CF if both parents are carriers of the gene changes that cause CF. Therefore both parents carry the gene changes that when combined can cause CF but they do not have CF, or show symptoms of CF themselves.

How common is CF?

1 in every 2,500 babies (male or female) will be born with CF each year in Australia.

If two people are genetic carriers for CF and they have a child, with every pregnancy there is:

- 1 out of 4** chance that the child will have CF.
- 2 out of 4** chance that the child will be a genetic carrier for CF.
- 1 out of 4** that the child will not have CF and will not be a genetic carrier for CF.

