

Common Questions

Will CF affect a person's day to day life?

CF does not affect a person's intellectual ability and most people are able to go to school, play sport, travel, have families, work and do all the things that other people can do.

The main issue for people with CF and their families is keeping on top of the treatment which is required on a daily basis. The treatment can be time consuming and expensive. Admissions to hospital and clinic appointments are sometimes required so it is necessary to have time off from work or school.

How many people have CF in Australia?

More than 3000 people have CF in Australia and approximately 330 have CF in Western Australia.

Is there a cure for CF?

Currently there is no cure for CF. However there are promising research developments in the areas of genetics and new treatments.

Although CF is a life-shortening condition, improvement in the understanding of CF and treatments has resulted in children being able to survive well into adulthood. Currently over 50% of the people who have CF in Australia are adults, which was not the case thirty or more years ago.

Is CF contagious?

You cannot catch CF. You have to be born with it.

Can CF be diagnosed before birth?

Yes, if there is already a child with CF in the family then testing can be carried out at 10 weeks of pregnancy. Parents of a child with CF are encouraged to have genetic counselling before planning a further pregnancy.



What is Cystic Fibrosis?

Cystic Fibrosis Western Australia (CFWA) is a not-for-profit organisation, which relies heavily on the support of the community, to deliver essential services to people living with CF in Western Australia.

CFWA provides a number of services including education, advocacy, counselling, social networking opportunities, community nursing and home support services. We work to create more awareness about CF in the public arena and contribute fundraising funds to medical research.

If you or your family are affected by CF and would like to find out more about how CFWA can provide support contact:

Services Manager

Email: servicesmanager@cysticfibrosiswa.org

Telephone: 08 9346 7348

If you would like to find out more about how you can support CFWA or contribute to the cause contact:

Marketing Manager

Email: marketing@cysticfibrosiswa.org

Telephone: 08 9346 7336

About CF



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What Is Cystic Fibrosis?

Cystic fibrosis (commonly known as CF) is a genetic condition which affects each individual differently. Many years ago babies born with CF did not have a strong chance of survival. Today, with earlier diagnosis, greater understanding and improvements in treatments, medication and research, the majority of babies born with CF are able to live well into adulthood.

People with CF are missing an essential protein from their cells, preventing salt from being properly transported across the cell membrane. This causes the mucus in the body to become thick and sticky and build up in organs such as the lungs and pancreas.

How is Cystic Fibrosis Diagnosed?

Since the year 2000, all babies born in Australia are tested three to five days after birth for the most common genetic mutations of CF and other conditions, using the Guthrie Heel Prick test. If the test comes back positive then a sweat test will be done to measure the amount of salt in the sweat.

A diagnosis of CF will be made depending on the results of the sweat test. Most babies born in Australia now, who have CF, are usually diagnosed within the first two months of life.

What Are the Symptoms?

People who have CF can be affected differently by the condition however some common symptoms are:

- Persistent cough
- Some difficulty breathing or wheezing with effort
- Tiredness/ lethargy
- Frequent trips to the toilet
- Poor appetite
- Increased risk of dehydration
- May be underweight

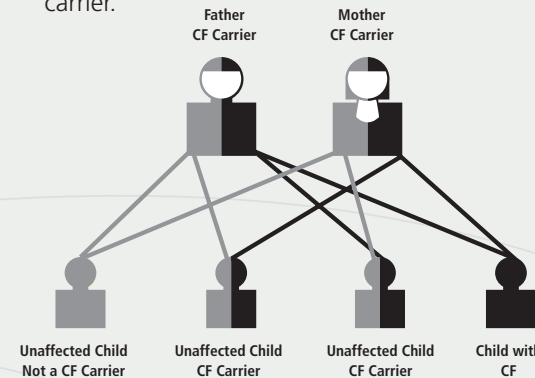


How Do You Get Cystic Fibrosis?

CF is not contagious, it is an inherited, genetic condition. In the Caucasian population 1 out of 25 are carriers of the CF gene except for in some population groups, for example in Ireland, where the incidence of genetic carriers is 1 in 19. If a person has two CF genes they will have CF.

If two people are carriers of the CF gene and they have a child there is with each pregnancy the following possibilities;

- A 1 in 4 chance they will have a child with CF
- A 2 in 4 chance they will have a child who is a genetic carrier but does not have CF
- A 1 in 4 chance the child will not have CF or be a genetic carrier.



There are over 1500 different genetic mutations of CF.

How Does Cystic Fibrosis Affect the Body?

Lungs

The build-up of thick and sticky mucus in the airways of the lungs leads to infection and inflammation and can also cause airway and lung damage over a period of time.

Regular physiotherapy airway clearance helps to remove the mucus from the lungs. Oral or intravenous antibiotics are often used to control infections and some people who have CF also use a nebuliser to inhale their medications.

Regular exercise also helps clear mucus from the airways and lungs, builds up muscle mass and strength, improves posture and slows lung function decline.

Sweat glands

People with CF do not sweat more than other people but they do lose more salt and potassium in their sweat.

The main diagnostic test for CF is the sweat test which measures the level of salt in the sweat.

The sweat glands are also affected by mucus, so as a result people with CF can lose about two to five times more salt in their sweat. If the salt loss is not replaced with salt supplements and additional fluids there can be a risk of dehydration. More salt supplements and fluids are required in summer and in warmer climates.

Reproductive system

CF can also affect the reproductive system in males and to a small degree in females.

97% of males who have CF are missing their vas deferens but are often able to have children with assisted reproductive techniques.

Digestive system

Approximately 85% of people who have CF suffer from malabsorption (difficulty in digesting food) due to mucus blocking the pancreas. Malabsorption can lead to low levels of vitamins being absorbed, poor weight gain and compromised health and lung function.

To assist with digestion, enzyme replacement capsules are consumed with most foods and some drinks. Individuals may require vitamin supplements due to vitamin deficiencies.

A high energy diet which is well balanced and provides an extra 20% to 50% more calories is required to assist in counteracting the effects of malabsorption.

Other complications

- Some people with CF experience sinus problems.
- The liver can be affected.
- Diabetes can develop during the teenage years.
- Low bone density can occur.
- Some people will have weakened pelvic floor muscles.

