

Cystic Fibrosis Association of New Zealand

How you can help

The aims of the Cystic Fibrosis Association of New Zealand are to ensure increased life expectancy and improved quality of life for people with Cystic Fibrosis and their families; and through research to achieve better control and ultimately a cure for the condition.

About the Association

The National Office in Christchurch coordinates a network of Branches (support groups) and regional contact people throughout New Zealand. Reporting to an elected Board of Trustees.

Branches exist in most regions to provide local support for CF families e.g. experience and information sharing, social functions, fundraising and financial assistance.

The Association's activities include:

- Providing an information service about Cystic Fibrosis (CF)
- Providing support for people with CF and their families, e.g. welfare assistance, fieldworkers, physical activity grants, conference registration fees, tertiary study grants, scholarships and achievers' awards
- Publishing books, brochures, print material and other media about CF and maintaining a library of this material
- Communication and coordination through newsletters, conferences, and our website
- Promoting public awareness of CF through Awareness Week, media stories and other activities
- Providing educational opportunities for people with CF, their families and health professionals to learn about management of and therapies for CF
- Providing an effective lobby to government and social service agencies on behalf of the CF community
- Encouragement and funding for CF research
- Raising funds to ensure that our important services for the CF community continue into the future

Share in Life Trust

The Association established a research fund in 1993. Research funds are managed by the Share in Life Trust.

Anyone can contribute to the research fund by occasional donation, bequest or payment by direct credit.

For further information, visit our website:

www.cfnz.org.nz

How you can help

The Cystic Fibrosis Association needs your help to conduct its vital family support: information, education, research and other services.

Options include:

- A personal donation or business sponsorship
- Asking your local service club, community group, workplace or other organisation to donate funds
- Giving to our work in your will. Legacies and bequests are thoughtful ways of giving continued support
- Offering your time and expertise as a volunteer for fundraising or other activities
- Your assistance to the Cystic Fibrosis Association can be directed to the National Association or to your local branch



Donation enclosed. Please send my receipt to:

Name

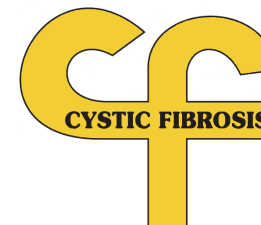
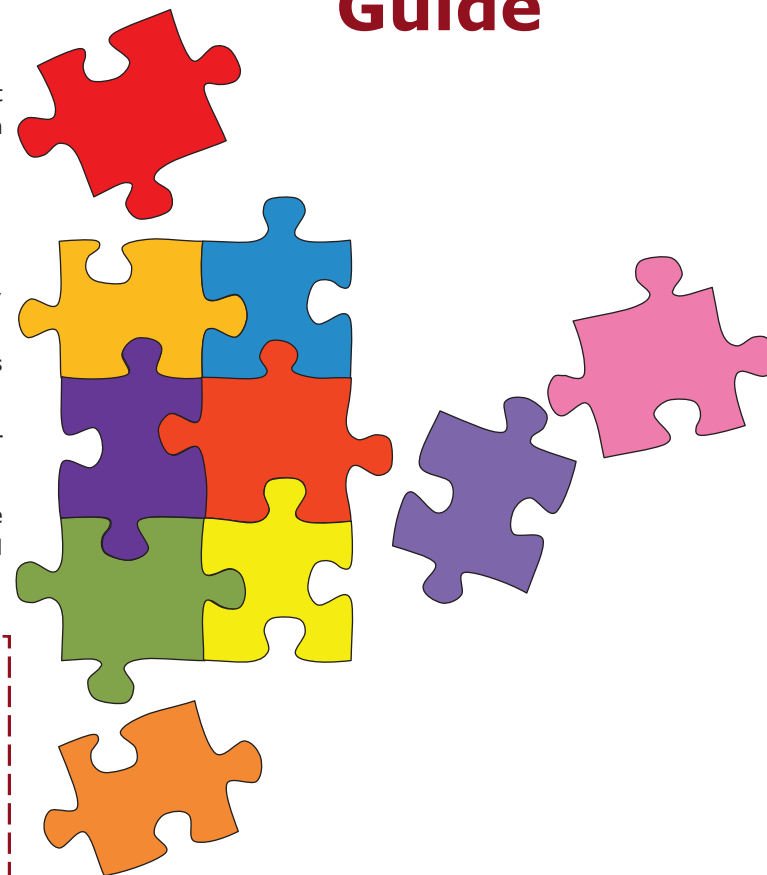
Address

Telephone

- I would like to assist the National Association (Please tick if your support is to be allocated to research)
- I would like to assist my local branch
- Please send information about how to help through leaving a gift in my will
- I would like to receive regular CF newsletters

Cystic Fibrosis

Information Guide



**Cystic Fibrosis Association
of New Zealand**

PO Box 8241, Riccarton,
Christchurch 8440
Phone 03-341-8024
Freephone 0800 651 122
Email: info@cfnz.org.nz
www.cfnz.org.nz



Question & Answer Guide

What is Cystic Fibrosis?

Cystic Fibrosis (CF) is the most common life-threatening, genetic condition affecting New Zealanders. CF affects primarily the lungs and digestive system. It does not affect everyone equally. Life expectancy has been extended considerably with improved medication and treatment.

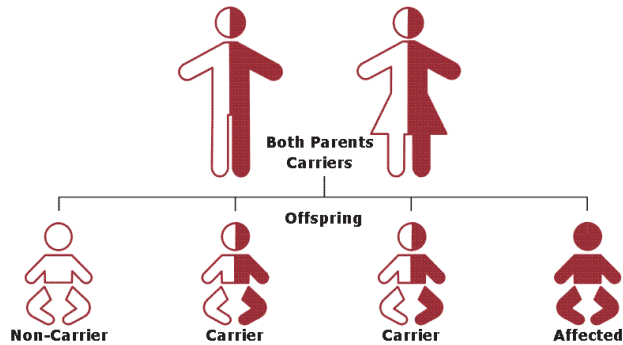
Who gets CF?

CF is an inherited condition. For a child to be born with CF both parents must carry the CF gene. Carriers of the CF gene do not have any symptoms of the condition. In families with a known history of CF it is possible to determine the carrier status of most relatives.

How common is CF?

1 in 25 people in New Zealand is a carrier of the CF gene. If two people carry the gene with every pregnancy there is:

- a 1 in 4 chance that the child will have CF
- a 2 in 4 chance that the child will not have CF but will carry the gene
- a 1 in 4 chance that the child will not have CF and will not be a carrier



One in every 3500 babies, born in New Zealand, will be born with CF. There are more than 500 people in New Zealand with CF and life expectancy is increasing all the time due to management therapies and advances in medical knowledge.

How is CF diagnosed?

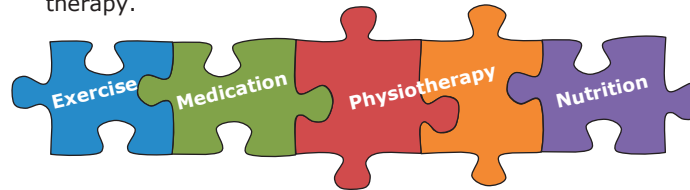
In New Zealand all babies are screened at birth for CF. A Guthrie Heel Prick test is applied and if this test proves to be positive, a sweat test will be done which measures the amount of salt in sweat and it is with this test that a final diagnosis is made.

Occasionally adults are diagnosed with CF later in life, but this is not a common occurrence.

Effects of CF?

CF is a multi-system condition which means it affects many organs in the body.

In Cystic Fibrosis the mucus glands in the body secrete very thick sticky mucus. This mucus clogs the tiny air passages in the lungs and traps bacteria. Repeated infections and blockages can cause irreversible lung damage and lead to death. The pancreas can also be impaired, preventing the release of enzymes which are needed for the digestion of food. This means that people with CF can have problems with nutrition and need help to digest their food with synthetic enzyme replacement therapy.

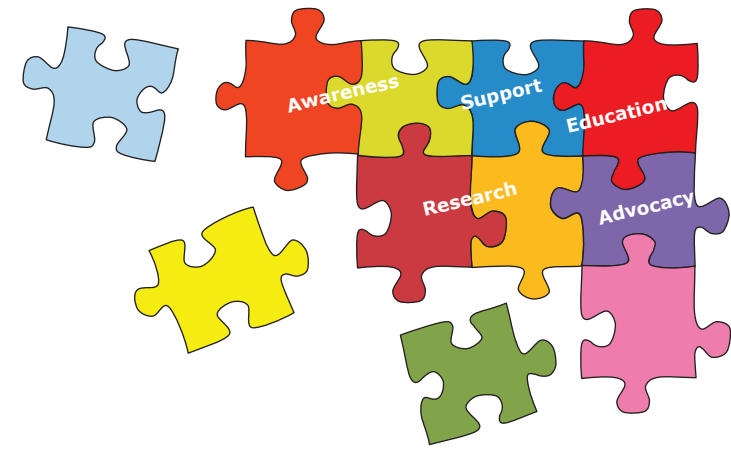


How is CF treated?

The identification of the defective CF gene in 1989 was a major step toward developing a carrier test, improving treatment and eventually better control of the condition.

Currently people with CF must have intensive daily chest physiotherapy to combat the build-up of mucus in the lungs. Most people with CF will also take up to 30 enzyme replacement tablets each day to aid digestion. They must also follow high energy diets with added vitamins and salt.

Regular visits to CF clinics, hospitalisation and antibiotic treatment are common for people with CF.



What are the symptoms of CF?

CF is often accompanied by the following symptoms:

- Persistent cough, particularly with physical effort.
- Wheezing or breathlessness with physical effort.
- Tiredness, lethargy or an impaired ability to exercise.
- Increased salt loss in hot weather.
- Frequent lung infections

Is there a cure for CF?

Cystic Fibrosis is not curable at this time. However, with today's improved treatment most people with CF are able to lead longer, productive lives. A great amount of time, energy and money is being directed toward finding new and improved ways of treating CF and ultimately finding a cure.

Where can people get help or further information about CF?

Practical help and information can be obtained from the Cystic Fibrosis Association of New Zealand. The Association exists to increase knowledge of the condition and to give advice and support to people with CF and their families. It funds research into improved treatment, and ultimately, prevention and cure.

The Association has 12 voluntary branches throughout the country.

See over for more information about the Association.