

Cystic Fibrosis Association of New Zealand

How we 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

The 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

Cystic Fibrosis

Late Diagnosis Guide



If you would like more information about the Cystic Fibrosis Association of New Zealand and its work in the CF community, please return this slip to our office

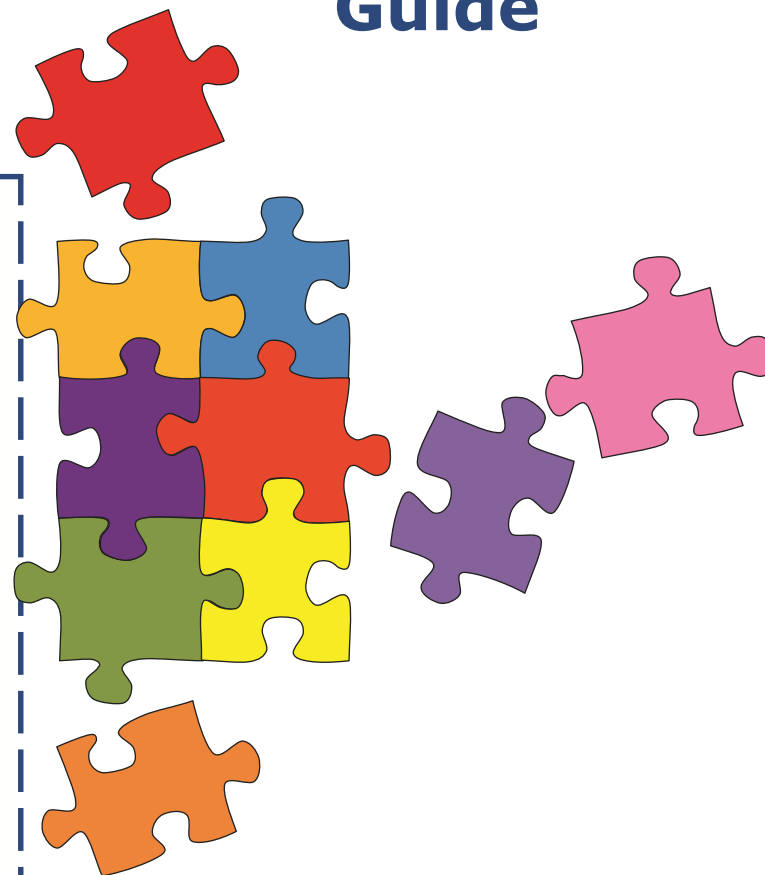
Name:

Address:

Postcode:.....

Please send me further information on the following:

- The CF Association and its work in the community
- How to make a donation
- How to contact my local branch
- I would like to receive quarterly CF newsletters



**Cystic Fibrosis Association
of New Zealand**

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Late Diagnosis Guide

What is Cystic Fibrosis?

Cystic Fibrosis (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. CF affects primarily the lungs and digestive system. It does not affect everyone equally.

Please refer to the Cystic Fibrosis Information Guide from the Cystic Fibrosis Association of New Zealand for more information regarding CF and the Association.

Diagnosis

CF is usually diagnosed before three years of age. A 'late diagnosis' – one in adolescence or adulthood – may indicate

that the person has a milder form of the condition, or their symptoms are atypical (not the usual symptoms).

While a late diagnosis can be traumatic, there can also be relief that a definitive diagnosis has been made after a period of uncertainty.

Diagnosis of CF after childhood maybe the result of investigations for other health problems such as recurrent bronchitis, atypical asthma or allergies, colitis, fertility or gastro intestinal problems or a sudden respiratory illness.

As CF is an inherited genetic condition, it is not contagious and it isn't something you have just acquired. Acknowledging that you have CF may take some time and you might be reluctant to

think about how CF will affect your lifestyle and plans, but CF is an important factor in your life, one that will take on a greater or lesser significance depending on the particular features of CF that you have.

Impact of CF on your Daily Life

Some people with CF find it difficult to do all that is recommended or expected to keep you well. CF is a condition that needs consistent attention. It is hard to go unexpectedly from little or no treatment to a program of daily medication and therapy. Finding time for these new treatments can be challenging, but your healthcare team will help you develop routines that suit your lifestyle.

Once a diagnosis of CF has been made, various medications and treatments may be prescribed. Regular exercise is also strongly recommended.

At some point, hospitalisation to treat a chest infection may be required. The challenges of being away from your home, family and routines should be discussed with your healthcare team so that you can identify people and strategies that can help you.

Impact of Late Diagnosis on Your Family

Talking to your immediate and extended family about CF can be an emotional time. You may just be coming to terms with the condition and the changes it has made in your life, or you may still be seeking the answers yourself. Your healthcare team and the CF Association can assist with information and counseling and help

you to give the right information to those you care about.

Importance of your CF Healthcare Team

CF clinics in New Zealand provide a team of professionals who are specialists in the care of people with CF. Your team may consist of a Specialist Doctor, CF Nurse Specialist, Physiotherapist and a Dietitian. These professionals have access to other services such as Genetic Counselling, Psychologists or other Specialist Doctors if required.

You will be required to attend CF clinic on a regular basis, with frequency of visits depending on your current status and symptoms.

Resources and Educational Materials

In addition to the material in this brochure, there are a number of educational materials available. Your clinic will have access to information on most CF topics and further information is available from the Cystic Fibrosis Association of New Zealand, our website: www.cfnz.org.nz, or our lending library.

See over for more information about the Association

