



A guide to cystic fibrosis
for employers





About this guide

This guide is for New Zealand employers and organisations who have an employee with cystic fibrosis (CF). It provides you with an overview of what CF is, how it impacts on an adult's life and how you can best accommodate your employee to reach their full potential at work.

Included in the guide are quotes from New Zealand adults with CF that offer an insight into how they're successfully managing CF alongside their careers.

Because CF is a life-long condition, adults with CF are experts in managing their health.

They've spent their life focused on staying well, eating well and balancing their treatments with school, study, work and generally living a normal life.

An employee with CF doesn't need help from employers to manage their day to day health and work; what they do need is an understanding of CF and how it impacts their life.

Understanding cystic fibrosis

Cystic fibrosis (CF) is New Zealand's most common life-limiting genetic condition. It mainly affects a person's lungs and digestive system.

CF affects the way salt and water move in and out of the cells in the body. It's caused by a faulty gene passed down from both parents and is usually diagnosed soon after birth. CF isn't contagious and doesn't affect a person's intelligence or mental ability.

There is no cure, but new research and medications focusing on ways to repair or replace the gene that causes CF are promising.

How CF affects the body

When we don't have CF, our body makes mucus that is thin and slippery and works as a lubricant to help protect us from infections and to keep the inside of our body working well.

If we have CF, our mucus becomes thick and sticky and blocks the tiny tubes of many of our organs.

In the lungs, the sticky secretions are difficult to cough up and viruses, bacteria and fungus can become trapped under the mucus. This can cause inflammation and infection, making it harder to breathe, and it often causes a chronic cough and repeated chest infections.

In the digestive system, thick secretions can block the flow of digestive enzymes from the pancreas to the duodenum (top part of the intestine), where they're needed to help break down food. Without these enzymes, fats and vitamins can't be absorbed and people with CF can find it hard to put on weight.

CF can also affect other parts of the body such as ears, nose, sinuses, liver, bones and joints and can cause CF-related diabetes.



Treating the symptoms of CF

People with CF maintain their health with daily chest physiotherapy, nebulisers and exercise. This aims to keep their lungs free from mucus and infections.

They take medications daily and most people with CF need to take pancreatic enzymes when they eat to help their bodies absorb nutrients from their food. Often a person with CF eats foods that are high in fat and salt to help maintain a healthy weight and stay hydrated.

People with CF spend between 1–2 hours every day doing treatments and if they become unwell they may need extra medications or other treatments.

Treatment with antibiotics, either oral or intravenous, is common for people with CF as they have a greater risk of developing serious complications from bugs that are generally harmless to people without CF.

"As my cough is generally consistent, as soon as someone suggests that I might have a cold or a flu, I let them know not to worry and that I have CF which means I cough almost out of habit but they can't catch it.

People are generally interested for five minutes, and then it's status quo for them. People often tell me they knew I had arrived, or where to find me in the office, because they heard my cough. It feels welcoming that people feel they can make those jokes."

Talking with colleagues about CF

How much your employee with CF wants, and needs, to tell colleagues is a personal choice.



Because many people with CF look well and maintain their health, they may choose not to tell their work colleagues for many different reasons. As long as it doesn't impact on their work their decision should be respected.

Often people with CF are very open about their condition and are happy to answer your questions.

"I'm pretty relaxed regarding telling work colleagues about my CF. Disclosing CF is something I let happen naturally as people get to know me. There are people in the office who don't know about my CF but colleagues who I work closely with will generally find out in the first 3-6 months of starting a new job. I hope people would feel that they can come and ask me about how CF affects me directly if they're curious."



"I personally like to go under the radar and only tell people about my condition when necessary. I would also rather be the one to bring my health up with the boss instead of them constantly focusing on it. I like that work is somewhere I can escape the hassles of CF and is with people who haven't seen the struggles throughout my life (which can be a bit harder to hide during school years when you're still learning the ropes of dealing with differences)."

"I personally have no issue discussing CF and its impacts on my life, however I've found work colleagues take the information differently. Once they know they begin to listen to my coughing with worry for my life rather than a standard illness. Therefore, I feel sometimes it's best to keep colleagues in the dark."

"For me, I've worked as a teacher in a couple of early childhood centres and have been selective about the people I tell about having CF, just because I know that some people do not really understand. I do let any prospective employer know about having CF up front, particularly so that they can ensure that no child with CF is or will be enrolled at the centre I am working in, as this would be a cross infection risk for us both."



"At work we manage our own diaries and days, so when I get a clinic letter I put it in my calendar, allowing travel time, and then it's booked. My work know I go to my appointments and come back afterwards. They trust me not to abuse the freedom to go, and in return, I don't take liberties."

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"A person with CF is adept at identifying the need to slow down. It's not their employer's responsibility to manage workloads and stress, but we need open communication when we do identify it."

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"My employer allowed me to change my work schedule to work between antibiotic infusions while I was an inpatient. He understood my health was more important than the job and ensured there was no extra stress on me."

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"I usually want my employer to let me do me, rather than do something for me."

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Supporting your employee who has CF

People with CF work in diverse areas of employment – advertising, accounting, early childhood, farming, business, teaching, building and many other professions.

As an employer, there are some key ways you can accommodate your employee with CF to ensure they stay well and reach their full potential at work:

- Communication is key. Talk with your employee about how CF affects them and any questions you have. People with CF who are working are motivated to stay well and keeping communication channels open benefits both employers and employees.
- Every person with CF is under the care of a specialist CF team. Adults with CF usually have an outpatient clinic appointment every few months, more if unwell. It's important they attend appointments to maintain their health. Appointment dates are often known well in advance, allowing employees and employers time to organise workload cover if needed.
- Sometimes people with CF need a course of intravenous antibiotics. Most adults learn how to do these themselves and can manage them around their work schedule after a short time in hospital (usually 3–5 days) to establish the IV treatment and plan. The option to work from home, if possible, during this time can be helpful when managing any extra demands to maintain their health. Enough time to rest when unwell usually means people recover faster and return to work quicker.
- Be open to considering temporary part-time work arrangements, working from home or flexible hours if a person with CF becomes unwell.
- The symptoms of CF can become worse with ongoing tiredness or stress. Encouraging manageable workloads and minimising stress can help to reduce the amount of time off work.
- Mutually agree on a plan to cover any time off from work outside of usual sick days. Can your employee accrue leave for unexpected time off work? Does your company have a policy to apply for more sick days or discretionary leave or can your employee take time off without pay?
- CF affects every person differently. If you've worked with someone with CF in the past, it's important to know your employee or colleague may have different symptoms.



Having an employee with CF doesn't automatically mean they'll be off sick more often than other employees. The majority of time off is usually for clinic appointments and is known well in advance.

"My direct report and the CEO understand I need to go to appointments on certain days. It's understood I will make up any time I've missed or can use sick, annual or unpaid leave if I don't work the extra hours."

"Last year I successfully introduced a paper towel dispenser in the lunch room so people would use those rather than having lots of dirty tea towels lying around. I also introduced hand sanitisers (some pumps on desks and permanent dispensers on walls) around the office. The management team was more than happy to oblige."

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"I once went on a site visit with my boss where we were invited into a house with a floor completely covered in mould. My boss insisted I stay outside and understood this situation's impact on my health without speaking."

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"It's helpful for employers to know people with CF should avoid people with colds and flu in an office environment and encourage people to stay at home if they're sick so as not to spread illness around. Encourage good hygiene practices for all staff and have bottles of hand sanitiser around especially over the winter months, when they have someone with CF in the office."

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Work environment

Having an employee with CF doesn't require your organisation or colleagues to complete any additional medical or first aid training other than your company's policy, as CF is unlikely to cause any need for urgent medical treatment.

Stagnant water, damp and mouldy environments, compost and rotting vegetation can contain 'bugs' that can make people with CF unwell. Most adults with CF are experts at understanding the risk of infection and most risks can be minimised.

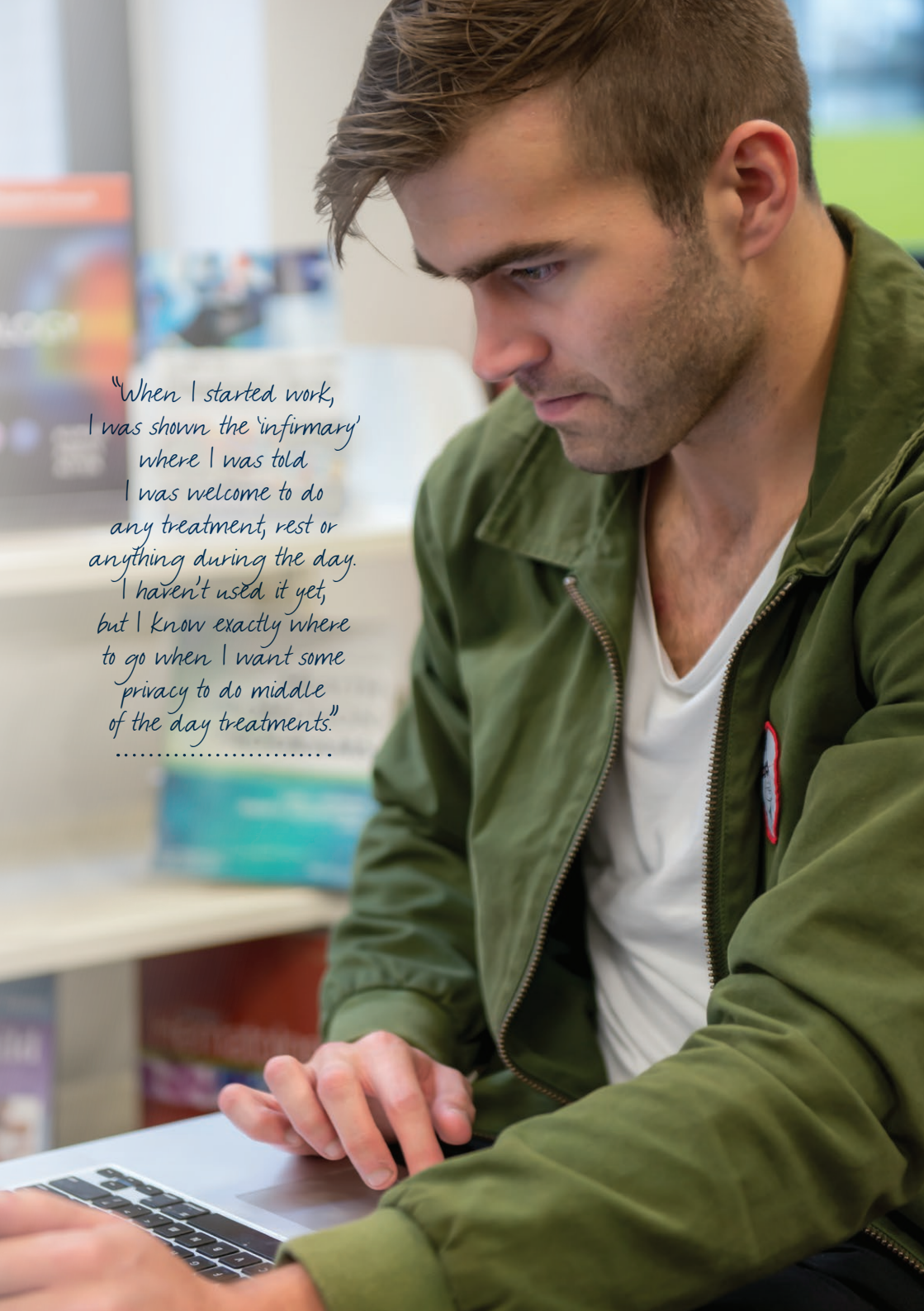
Every person with CF carries different 'bugs', or bacteria in their lungs that can potentially be passed on to other people with CF so it's recommended people with CF don't have close physical contact with other people with CF.

People with CF are more susceptible to catching 'bugs' than people without CF and are pretty aware of other people around them who are sick. A workforce that encourages people not to come to work if they have the flu or are quite unwell is beneficial for not only people with CF, but also for other work colleagues.



"When we went away on conference one year, I requested my own room instead of sharing, and it was granted. This allowed me to unpack my equipment, do my treatment and look after myself, without having to explain or hide anything. It's the only time I've requested special treatment and it was unquestioned."

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*"When I started work,
I was shown the 'infirmery'
where I was told
I was welcome to do
any treatment, rest or
anything during the day.
I haven't used it yet,
but I know exactly where
to go when I want some
privacy to do middle
of the day treatments."*

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Employment law

Under the Human Rights Act 1993, employers are required to introduce reasonable changes to work the employee will do, or the workplace where the employee will do the work to meet the needs of someone with a disability.

What is reasonable will be different for each employer and organisation.

For example, for CF it could include minimising cross infection risks, having a clean and safe place for keeping medications (such as a separate fridge), being able to work from home at times, not having your employee with CF go to certain job sites or take on certain tasks and having flexible hours and time off for hospital appointments.

Candidates for jobs and employees are protected against discrimination in employment due to disability by the Employment Relations Act 2000.

In addition, the Employment Relations Act 2000 allows all employees (not just those with disabilities) to request a variation to their working arrangements, often known as a flexible working request. Employers can only refuse these requests on limited grounds, set out in the legislation. Visit the Employment New Zealand website www.employment.govt.nz for more details.

As an employer you may be eligible for government subsidies for employing someone with a disability, such as wage subsidies or modification grants to help make adjustments to your workplace. Visit the Employment New Zealand website www.employment.govt.nz to find out more about the eligibility criteria.

"I like to be treated the same as everyone else in terms of ability, but also have that extra bit of implicit understanding when I need to duck away. I do everything at work to my best ability, and this has helped show management and my team that I am reliable and passionate about doing a good job, as well as prioritising my health."

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About Cystic Fibrosis New Zealand

Established in 1968 as a volunteer support group for parents, we dedicate ourselves to shaping a brighter future for everyone with CF.

As people with CF live longer and have a better quality of life, there are many life transitions, milestones and challenges to manage along the way. We offer personalised support through emotional guidance, practical advice and financial assistance to individuals and their families.

Our team of fieldworkers visit and support families, provide information packs, cover the costs of essential medical equipment, hospital allowances, welfare assistance and other means of support. We also fund CF research and advocate on behalf of the community for better access to services and care.

As well as our national office, based near Auckland Hospital, we have regional branches run by CF families for CF families. The branches provide invaluable friendship, advice and a caring support network.



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FIBROSIS NZ

If you would like to
know more,
please get in touch.

www.cfnz.org.nz

info@cfnz.org.nz

0800 651 122



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This publication has been written as a general guide for employers of adults with cystic fibrosis in New Zealand.

While Cystic Fibrosis New Zealand (CFNZ) has consulted with healthcare professionals and adults with cystic fibrosis to ensure the information is accurate, it does not substitute specialist medical and employment advice.

CFNZ will not be held liable for inaccuracies or omissions.