

# Information for employers about cystic fibrosis



This information has been produced for Australian employers and organisations who have an employee with cystic fibrosis (CF). It provides an overview of what CF is, how it impacts daily life and an overview of ongoing management. Our aim is to educate employers about CF, and provide ways for employers and organisations to support employees to reach their full potential.

## WHAT IS CF?

CF is a progressive genetic condition that causes persistent lung and digestive issues. Respiratory infections can result due to mucus clogging the airways and trapping germs (bacteria and viruses), leading to complications such as scarring of the lungs or lung failure.

CF is the most common genetic condition in Australia, impacting approximately 3,500 people. Due to significant advances in clinical care, treatments and medication, those living with CF can now expect to live a relatively normal life.

While people with CF may look outwardly healthy, they are living with a chronic condition that affects their body in many ways. It is a complex condition that impacts multiple organs in the body, primarily the lungs and digestive systems. Due to a variety of factors, the health and severity of symptoms vary greatly in people with CF. Everyone's journey is different.

## HOW CF IS MANAGED?

People with CF predominately manage their condition at home with very little impact during work hours. While most treatments are performed before or after work hours, occasionally nebulised medications or airway clearance techniques may be needed during the day. These can be typically undertaken in a short timeframe during normal breaks.

## WORKING AND CF

People with CF work in successful, challenging and thriving vocations all over Australia, and are fully capable of independently managing their health. Due to the health demands of living with CF, efficiency, time management, self-sufficiency, hygiene and determination become innate. An inclusive and diverse workplace provides creativity and a rewarding culture for all.

Because there is a high degree of variation in the severity of symptoms that people with CF experience, some may have minimal health concerns and others can be chronically ill.

Most people with CF have a persistent cough that increases in frequency when they have an infection. It is important to note that this daily, persistent cough is not contagious. Due to the demand on the body to breathe and function at the same capacity as someone without CF, people with CF can quickly become tired, lethargic and unwell when they have complications.



### As the employer of someone with CF, information that you may find useful includes:

- Understand that lung infections feel like having constant bronchitis. People can feel okay or really unwell.
- Stomach issues are common. Frequent short bathroom breaks may be necessary.
- Coughing is normal and helps maintain lung health. It isn't contagious or harmful to others.
- Each person with CF has a different experience. Avoid stereotyping the condition.
- Ask your employee if they are happy to disclose their health to colleagues or not.

### If you have an employee with CF:

- Ensure a private space is available in case your employee with CF needs to take nebulised medications.
- Promote the use of hand sanitiser to all employees to help reduce virus and bacterial transfer.
- Provide available space in a communal refrigerator to keep necessary medications cool.
- The quality of the air we breathe is important for everyone. Minimising exposure to smoke, dust and fumes in the workplace can be advantageous for all staff.



### WHAT ARE CF CLINICS?

Almost all people with CF have a clinical team that supports their health. Outpatient respiratory clinics are held throughout the year, about every three months, at major hospitals and regional health centres. These may change in frequency, depending on the person's circumstances.

Clinic team members include respiratory clinicians, psychologists, dieticians, social workers and physiotherapists. Due to the complexity of CF, the person must attend clinics to ensure their baseline health is monitored and maintained.

At clinic appointments, indications of reduced lung health or deterioration are addressed. Because people with CF typically need to see each specialist and allied health member, as well as conduct tests, clinics can take several hours to attend.

### You can support your employee with CF in several ways, including:

- Plan meetings around clinic appointments. Often dates are known in advance.
- Understand that waiting in a hospital environment is not 'slacking off'. Clinics are long, intense days, where people have little control over time and delays. They may not have access to technology like emails during this time.
- Support attendance. By skipping clinics, a person's health can decline, ultimately impacting their home and work life.

The CF Strong project is funded by the Australian Government.

## WHAT ARE HOSPITAL ADMISSIONS FOR?

Hospital admissions are commonplace for people with CF and can at times be planned to help maintain baseline health. They are required as a preventative measure to preserve optimum health, or when an infection is particularly difficult to control or clear.

Admissions usually involve targeted antibiotics, steroids and intense physiotherapy. Some people require the full treatment as a hospital inpatient, and others can manage using Hospital in the Home (HITH) after a shorter stay of three to five days. The frequency of admissions can range from once every few years to every few months, depending on the severity of the person's illness.

Admissions are important to recuperate energy, maintain weight and return to baseline health.

Depending on the health of the person and the complexity of their treatment, they may be able to work flexible or part-time hours during this time.

### If you have an employee with CF who is admitted to hospital:

- Understand that CF is unpredictable. Some infections are serious and require immediate treatment. If admissions to hospital are recommended, people have little choice about this.
- Discuss tasks that can be delegated while the person is offline.
- Provide IT options for working offsite, such as a laptop, tablet and phone.
- Discuss ways to secure annual, sick or personal leave.

## EMPLOYER RIGHTS

### Federal laws protect employees and employers:

- For workplace rights and responsibilities, visit Fair Work Australia: <https://www.fairwork.gov.au/>
- For information on leave, refer to Fair Work Leave: <https://www.fairwork.gov.au/leave>
- For information on Australian Discrimination Disability Laws, refer to: <https://humanrights.gov.au/our-work/employers/quick-guide-australian-discrimination-laws#disability>
- For information on Australia's Anti-Discrimination Law, refer to: <https://www.ag.gov.au/rights-and-protections/human-rights-and-anti-discrimination/australias-anti-discrimination-law>
- For more information on Leave Laws, visit <https://www.fairwork.gov.au/leave/sick-and-carers-leave/long-periods-of-sick-leave>

If you would like more information on CF or ways to support your employee, contact your state CF organisation and ask for the services team or social worker.

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