

## 1. Employment and cystic fibrosis

Well done, you have been offered a job and you are raring to go. Now it is time to clarify employment arrangements. The key word here is 'flexibility'.

### Preparing to start work

The appropriate stage for an employer to ask health questions will often be after a job offer is made, but before you start. Talk to your employer about how cystic fibrosis may affect your work. Explain how the condition may affect you in the work environment and always be confident and comfortable to emphasise your abilities. Cystic fibrosis does not define or limit your skills and abilities.

It is best to be straightforward (though consider seeking specialist advice if you think questions are inappropriate or unnecessary). If you are not asked about your health, the information you decide to volunteer is a very individual choice, as is identifying the right time to negotiate adjustments.

Establish a contingency plan for how any absences will be managed. Ask about flexible work arrangements and working from home.

### Dealing with discrimination

The law gives you protection against discrimination at every stage of the employment process, including recruitment. If you suspect you have been discriminated against, including being refused a job (or having an offer withdrawn) on the grounds that you have cystic fibrosis, seek specialist advice from organisations such as Legal Aid and Workcover.

### The following questions may help you assess how likely you are to encounter discrimination:

1. What is the company policy on disability and special needs, and how widely is this circulated?
2. Does the company actively promote employment opportunities for disabled people/or people with special needs?

### Balancing work and changing health

It is possible that during your employment, you will want to discuss with your employer changes to your employment arrangements for health reasons. These changes may include reducing your hours, changing your work pattern, or moving to an entirely different job. This can be a difficult conversation to have and we strongly encourage you to disclose to your employer that you have cystic fibrosis. If you are upfront and honest about your needs at the start of your employment it will be an easier discussion to have when you are seeking adjustments.

### Examples of reasonable adjustments which you might want to ask for at work include:

1. Having somewhere safe and clean to keep medication, perhaps with access to a fridge.
2. Not being asked to perform tasks that would expose you to a high risk of infection.
3. Doing some work from home.
4. Working flexible hours.

5. Being allowed time off for medical appointments.
6. Working on the ground floor of a building.

Whether it is reasonable for an adjustment to be made depends on all the circumstances, for example the practical implications for the employer, its resources and size, the availability of finances to assist the employer in implementing adjustments and the extent to which you are willing to cooperate. Each case is individual.

### **Sickness absences**

No one is allowed an indefinite amount of time off work for ill health. However, an employer does have to make reasonable adjustments, including sickness procedures. Treating a person with a cystic fibrosis' sickness absence no more sympathetically than that of a person without cystic fibrosis might well amount to unlawful conduct. Be open and honest with your employer and be sure to know your entitlements.

### **Employer responsibilities**

An employer has a responsibility to see what hazards are present, consider if they pose risks to your health and safety and take steps to manage them. By you disclosing that you have cystic fibrosis, you are making it easier for them to support you in the best possible way.

### **Employee responsibilities**

As an employee, you have a duty to cooperate with any reasonable measures that an employer takes to protect your health. You also need to question if the job poses a risk to your health due to the required tasks, which cannot be altered, to complete the job.

Ideas about risk are strongly shaped by culture and current opinion, and it is never possible to have a totally risk-free environment. However, it is possible to have a situation where you and your employer are aware of the risks and take reasonable precautions to minimise them.

Systematically discussing potential risks to your health, perhaps with input from your doctors, can help reduce an employer's anxieties.

If required, your cystic fibrosis centre should be able to provide your employer with a letter to assist any adjustments that may need to be made for your work environment or if needing to increase or decrease your hours. Your cystic fibrosis centre will support you in any way that they can to help you fulfil all your work environments.

## 2. Information for employers

Cystic fibrosis is a life-shortening, inherited condition caused by a faulty gene. You cannot catch cystic fibrosis or develop it later in life. You are born with it. There is no cure.

The faulty gene disrupts the movement of salt and water in the body's cells, causing the mucus that naturally occurs in the body to be thicker and stickier than in people without cystic fibrosis. This sticky mucus causes problems, particularly in the lungs and digestive system, but can also affect other parts of the body. The small airways in the lungs can get clogged with mucus, causing infection and, over time, damage to the lungs. For many people with cystic fibrosis, blockages in the pancreas mean a lifelong need for enzyme supplements and a special diet.

Cystic fibrosis does not affect everyone to the same degree, and people with cystic fibrosis can perform a wide range of jobs across numerous workplaces. People with cystic fibrosis are people with different personalities, abilities, hopes and beliefs. Whilst this condition has been with them all their lives, it neither defines who they are nor what they can do in the workplace.

Cystic fibrosis does not affect cognitive ability. People with cystic fibrosis have a condition that affects their lungs and digestive system. Not everyone with cystic fibrosis will have the same symptoms – some people can have 'milder' versions of the condition. If your workplace has had someone with cystic fibrosis working with them previously, please be aware that a new employee with cystic fibrosis could have different symptoms.

A person with cystic fibrosis will have a daily regimen of treatment, some of which is likely to be carried out before and after work, so flexibility around starting and finishing work could be helpful. A person with cystic fibrosis's health can fluctuate, and as such, the treatment regimen may change, or they may require additional hospital visits or appointments. People with cystic fibrosis generally cough, and sometimes may cough a lot. This is the body trying to clear the lungs of mucus. The cough is not infectious.

Flexible working can be supportive to people with cystic fibrosis. Usually a routine clinic visit is needed every few months, so it is helpful if flexibility can be offered to ensure that the appointment is not missed. If a person with cystic fibrosis is unwell or undertaking a course of medication, they may need additional time away from work.

People with cystic fibrosis are prone to lung infections that can be very harmful to others with the condition. Each person with cystic fibrosis may carry different bugs in their lungs, which can be passed on by being around each other. To avoid the risk of cross-infection, people with cystic fibrosis are advised not to mix with each other at all. For this reason, it is important that any individual with cystic fibrosis is aware if there are other people with cystic fibrosis working within an organisation or if people with cystic fibrosis are likely to visit the building.

There are some environments that can harbour bugs which are harmful to people with cystic fibrosis:

- stagnant water
- mouldy/damp environments
- hay/ rotting vegetation

These environments all present an infection risk to people with cystic fibrosis. In an office environment, most risks can be eliminated with good cleaning and hygiene practices.

Often cystic fibrosis is a relatively invisible condition; people with cystic fibrosis do not usually

look ill unless they are very unwell, and for this reason, cystic fibrosis is often called an invisible disease. People with cystic fibrosis will have their own feelings on whether they want their colleagues to know about their condition. Their personal wishes must be respected.

People with cystic fibrosis have had it all their lives and are experts in their own treatment. Employers do not need any specific medical training and it is extremely unlikely that cystic fibrosis could result in an emergency medical situation. People with cystic fibrosis mostly need employers' support to ensure they can continue to manage their treatment and care as well as fulfilling their potential at work.

### **Supporting an employee with cystic fibrosis**

Talk to the individual about how cystic fibrosis could affect their work. As mentioned earlier, people with cystic fibrosis differ in how the condition affects them, and it is important to be clear from the outset how your employee is affected.

Establish a contingency plan about how any absences could be managed and contact Cystic Fibrosis Queensland if you would like an education session about cystic fibrosis to be delivered to your staff.

### **Retaining people with cystic fibrosis**

It is in everyone's interest that employees continue to work for you if possible. Employers have a duty to not treat people with chronic illness less favourably. If problems with an employee are related to their cystic fibrosis, then there is a duty to make reasonable adjustments in the workplace. If changes are due to the person's cystic fibrosis, consider if any further adjustments could be made, e.g. working part-time, working from home, or seeking medical advice. Ensure that decisions about future employment reflect mutual agreement. All employers and employees are encouraged to consult The Fair Work Commission [www.fwc.gov.au/](http://www.fwc.gov.au/)