

# Cystic Fibrosis *our focus*

## Employment

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# Employment

This factsheet contains six sections, which provide information about obtaining and remaining in employment, including finding a job, Government schemes, work and benefits, legal aspects and a section that you may wish to give to your employer.

## Finding the right job

Describes the stages involved in applying for a job, attending an interview, being offered a job and starting work. It discusses possible discrimination and issues to consider when telling an employer you have cystic fibrosis.

## Balancing work and changing health

Outlines some options if you need to change your contract of employment for health reasons.

## Government schemes

Provides a brief summary of the ways in which the Employment Service can help and the leaflets available from the Jobcentre.

## Work and benefits

Gives a brief overview of how state benefits are affected by employment.

## Legal aspects of employment

Describes the Equality Act 2010 and Health and Safety at Work Act 1974 in more detail.

## Factsheet for employers

Provides a brief summary of cystic fibrosis and describes the importance of flexibility and how to make adjustments. This sheet can be given to employers.

**Written by the Cystic Fibrosis Trust, reviewed and updated by Tom Royston, Barrister.**

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# Finding the right job

## The application stage

The National Careers Service, the Jobcentre Plus and specialist employment agencies have a number of useful leaflets outlining how to approach employers and complete forms. A Jobcentre should also be able to provide an assessment service and employment and benefit advice for people with a disability. There may also be specific Government schemes that will be of use to you; there is information in this factsheet that describes these in more detail. There are also many books, which offer excellent advice on how to design CVs and complete application forms; these are available from local libraries and bookshops.

It can be useful to brainstorm your skills and relate these to key aspects of the job you're applying for. Describe what you learnt from previous paid work, voluntary work or work experience, and think about how this relates to the job description. Briefly describing hobbies and interests gives a potential employer more of an idea of you as a person. As family and friends can also help identify your strengths, it may be a good idea to share your draft application with them.

There are rules restricting when an employer is allowed to ask about health problems or disability before making a job offer. See the 'Legal aspects of employment' section in this factsheet.

If you do discuss cystic fibrosis (CF) in the course of applying for a job (for example if explaining gaps in your CV due to illness), it is best to be straightforward. Consider how CF could affect your work, and how it could be managed.

**Remember you are selecting an employer, as well as potential employers selecting you. Some questions you may like to ask at the outset include:**

- Are there flexible working arrangements? These make life easier in terms of attending CF clinic appointments etc.
- What is the working environment like? Do they have a staff canteen, restroom or first aid room?
- Does the company have a Permanent Health Insurance plan? If you become too ill to work, health insurance may provide you with an income. Having CF doesn't necessarily mean you won't qualify; it depends on the company.
- Does the company display the 'positive about disabled people' logo?
- Is there an on-site Occupational Health Centre to provide medical assistance when required?

Information you receive from the company should answer all of these questions. With larger firms, you can ask their Human Resources department.

**It would be a good idea to discuss your employment aims with your specialist CF centre team. They will be able to advise on whether the role could pose any concerns or risks to your health and could also prepare a letter describing your medical fitness, which could be useful at a later date.**

## Attending an interview

Attending an interview is a great opportunity to 'sell' your skills and experience to the employer. Preparing for an interview can be really useful – it can help to research the company and the role in detail and be ready and able to talk about why you want this particular job. Employers will often ask for examples of particular skills (for example, they may ask you to talk about a time you've worked as part of a team). It's often worth preparing some examples in advance – these don't always have to be examples from paid work. They could be from voluntary work or even hobbies, especially if you are applying for your first job.

You may be asked whether you have any questions, so it's a good idea to prepare one or two questions that demonstrate your interest in the role, as well as ensuring you ask about any important day-to-day practicalities. An interview can often be a nerve-wracking time, so knowing you are prepared can be reassuring. The employer has invited you for an interview because they are interested in your application, so try to relax, take your time and listen carefully to the questions you are being asked.

## Being offered the job

Well done! Now it's time to clarify arrangements. The key word here is 'flexibility'.

### Think about exploring:

- Adjustments to working arrangements. Would it be possible to have an annual contract in hours? Would some home working be possible?
- Sick leave allowance. Would it be possible to have extra (perhaps unpaid) days if required?
- Facilities at work (eg fridge, staff room).
- Adjustments to any pension provision if you opt out of the scheme.
- Other available benefits.

## 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/line manager about how CF may affect your work. Explain how the condition may affect you in the particular work environment and always emphasise your 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. For example, is it possible for you to 'bank' your time to allow for absences? See the 'Balancing work and changing health' section in this factsheet.

The 'Employers' section in this factsheet will provide more information for the employer and should help you to negotiate satisfactory arrangements.

## Dealing with discrimination

If you do not make an employer aware that you have a disability, you may lose protection, which would otherwise be available to you under discrimination law.

The Equality Act 2010 aims to combat discrimination against people with disabilities (see the 'Legal aspects of employment' section in this factsheet).

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

- What is the company policy on disability, and how widely is this circulated?
- Does the company actively promote employment opportunities for disabled people?
- Is your potential employer a member of the Business Disability Forum or Disability Confident scheme?

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 CF, seek specialist advice (see 'further advice' on p11 for contacts).

## Summary

When looking for a job, persistence pays, so don't give up and focus on what you can do, rather than what you can't. If you encounter prejudice, you may find that the ignorance behind this can be combated by providing information when required. If necessary, seek specialist advice to ensure that your legal rights are respected.

## Useful organisations

**Citizens Advice:** provides free, independent and confidential advice to people on their rights and responsibilities. [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk).

**Disability Rights UK:** provides comprehensive advice and information relating to the rights of people with disabilities. [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org).

**The Prince's Youth Business Trust:** assists unemployed people between 18 and 30 to set up their own businesses. Provides low-interest loans and grants. All applicants must produce a viable business plan and have tried to raise the finances elsewhere. [www.princes-trust.org.uk](http://www.princes-trust.org.uk).

## 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.

All employees have a right to make a formal request for flexible working once they have completed 26 weeks' employment. However, employees with a disability will often be entitled to have this kind of arrangement considered, regardless of how long they have been working. An employer should be considering reasonable adjustments at every stage of work, even at job interviews.

**The Equality Act 2010 can require employers to make a very wide range of reasonable adjustments for people with a disability. Emphasise what you can do and concentrate on finding a solution. Be positive and creative.**

For example:

- Could adjustments be made instead of reducing hours? For example, would it be possible to have an annual contract in hours, or to do some of the work from home, or at a different time of day?
- Would a different role within the organisation make life easier?
- Would it be possible to have unpaid days (sick leave) if required?
- Could a contingency plan be established to manage absences? For example, is it possible for you to 'bank' your time to allow for absences?

## Government schemes

There is support available for people with disabilities and long-term health conditions to help ensure that their diagnosis isn't a barrier to obtaining work. Some of the Government schemes available for people with a disability may help you to find the right job. Each Jobcentre has disability employment specialists who can offer employment advice and an assessment service for people with a disability and their employers. It is a good idea to make contact with this team. They will not only help you find a job, but can also support you and your employer whilst you are in employment.

Information about some Government schemes is provided below. Further information on schemes throughout the UK is available on the Citizens Advice website at [www.citizensadvice.org.uk/work/self-employed-or-looking-for-work/government-employment-schemes](http://www.citizensadvice.org.uk/work/self-employed-or-looking-for-work/government-employment-schemes).

### The 'Access to Work' scheme

This scheme offers practical advice and support by tackling some of the obstacles that people with a disability may face at work. These can include funding alterations to buildings, providing financial help for special equipment, assisting with travel to work or funding a support worker. The Jobcentre can provide more information about this scheme, or you can visit [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work).

### The 'Work Choice' scheme

Work Choice can help you get and keep a job if you are disabled and find it hard to work. It's voluntary – you don't have to do it. The type of support you get depends on the help you need. This is different for everyone but can include:

- training and developing your skills
- building your confidence
- coaching for interviews

Visit [www.gov.uk/work-choice](http://www.gov.uk/work-choice).

**You can't get Work Choice in Northern Ireland, where different schemes operate. Citizens Advice Northern Ireland may be able to advise further.**

**For more information, visit [www.citizensadvice.org.uk/nireland/](http://www.citizensadvice.org.uk/nireland/).**

### The 'Disability Confident' scheme

Under this scheme, employers agree to interview people with disabilities if the minimum criteria for the job are met. The employers also have to agree to ensure the employee with a disability is encouraged to develop his/her skills and will ensure that the individual remains in employment for as long as possible.

## Work and benefits

### Non-means-tested benefits

If you are eligible for Disability Living Allowance (DLA) or Personal Independence Payment (PIP), these will not be affected by employment or other income.

In some circumstances, particularly if you are working only a small number of hours, you may also be entitled to claim (or to continue to receive) contributory Employment and Support Allowance or Jobseeker's Allowance.

If you have children, you may also be entitled to Child Benefit (though if your income exceeds £50,000 per year, your entitlement may be reduced or extinguished).

### Means-tested benefits

You may be entitled to Universal Credit, Income Support, Employment and Support, Jobseeker's Allowance and/or Tax Credits to supplement your work income.

These benefits can include extra amounts to take into account the extra costs of disability. It is very important that you tell the government when you are claiming these benefits whether you or anyone in your family is disabled or caring for a disabled person.

Tax Credits and Universal Credit can include amounts to help with the costs of childcare.

If you pay a mortgage, you may be able to get extra help for that cost as part of your benefit.

If you pay rent, you may be able to claim Housing Benefit from your local council.

If you pay council tax, you may be able to claim a Council Tax Reduction from your local council.

### Calculating entitlement

The information above is not comprehensive, and is not a substitute for getting proper advice about benefit entitlement, for example from Citizens Advice: [www.citizensadvice.org.uk/benefits](http://www.citizensadvice.org.uk/benefits).

You could also use an online benefit calculator to find out what you might be able to claim: [www.gov.uk/benefits-calculators](http://www.gov.uk/benefits-calculators).

**For more information about health and benefits, you can also speak to a CF team social worker, or contact our helpline on 0300 373 1000 or by emailing [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk).**

# Legal aspects of employment

## Protection against discrimination at work

Under the Equality Act 2010, it is unlawful for an employer, or potential employer, to discriminate against you because of a disability, or to refuse to make reasonable adjustments for your disability. If an employer breaks the law, legal action can be brought in an Employment Tribunal. There are short time limits: in general, legal action must be taken within three months of the act complained about though there are some exceptions. Also, there are special procedures to follow before starting a claim. All of this can be complicated to get right, so if you think you might need to take legal action, get advice immediately.

## Job applications:

The Equality Act restricts the circumstances in which employers can lawfully ask health questions before offering a person a job. If you think you are being asked inappropriate questions on an application form or in a discussion with a potential employer, seek specialist advice.

## Reasonable adjustments:

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

- Having somewhere safe and clean to keep medication, perhaps with access to a fridge.
- Not being asked to perform tasks that would expose you to a high risk of infection.
- Doing some work from home.
- Working flexible hours.
- Being allowed time off for medical appointments.
- 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 (eg under the Access to Work scheme) and the extent to which the person with a disability is willing to cooperate. Each case is individual.

## Sickness absence:

Employees with a disability are not 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 disability's sickness absence no more sympathetically than that of a person without a disability might well amount to unlawful conduct.

## Health and Safety at Work Act

The Health and Safety at Work Act 1974 sets out the general duties that employers have towards employees and members of the public, and which employees have to themselves and each other. The law requires employers to identify and assess potential risks and take sensible measures to eliminate them.

## 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.

## Employee responsibilities:

As an employee, you have a duty to cooperate with any reasonable measures that an employer takes to protect your health.

## Does this job pose a risk to my health?

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.

## Further advice

This leaflet gives a basic introduction to a complex area, and is not a substitute for seeking proper advice about the law as it applies to your particular circumstances. You should not rely on this leaflet for legal advice.

**It is important to act quickly when faced with employment problems. Deadlines for legal action can be very short.**

## Helpful sources of further advice may include:

Legal aid: free legal advice is available for discrimination law problems, under the legal aid scheme, to people on low incomes. [www.gov.uk/civil-legal-advice](http://www.gov.uk/civil-legal-advice)

Citizens Advice: a charity providing independent advice on people's rights. [www.citizensadvice.org.uk/work/discrimination-at-work](http://www.citizensadvice.org.uk/work/discrimination-at-work).

Equality and Human Rights Commission: the body responsible for overseeing and enforcing discrimination and human rights protection in the UK. [www.equalityhumanrights.com/en/advice-and-guidance/disability-discrimination](http://www.equalityhumanrights.com/en/advice-and-guidance/disability-discrimination).

ACAS: the body responsible for assisting with and resolving employment disputes. [www.acas.org.uk](http://www.acas.org.uk).



## Information for employers

Cystic fibrosis (CF) is a life-shortening, inherited condition caused by a faulty gene. You can't catch CF, or develop it later in life.

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 CF, 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 CF undertake a wide range of jobs.

### A few interesting statistics:

- One in 25 people carry the faulty gene that causes cystic fibrosis.
- More than 10,800 people in the UK have cystic fibrosis.
- Each week five babies are born with the condition.
- Diagnosis is usually at around four weeks of age.
- 61% of adults with CF are either students or in paid employment.
- The CF gene can be faulty in many different ways. In fact, more than 2,000 different faults (mutations) have now been identified.

### All about cystic fibrosis

- People with CF 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 do.
- Cystic fibrosis does not affect cognitive ability. People with CF have a condition that affects their lungs and digestive system, not their brains.
- Not everyone with CF will have exactly the same symptoms – some people can have 'milder' versions of the condition. If your workplace has had someone with CF working with them previously, please be aware that a new employee with CF could have different symptoms.
- A person with CF 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 CF's health can fluctuate, and as such, the treatment regimen may change or they may require additional hospital visits or appointments.
- People with CF 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 really supportive to people with cystic fibrosis. Usually a routine clinic visit is needed every six to eight weeks, so it's helpful if flexibility can be offered to ensure that the appointment isn't missed. If a person with CF is unwell or undertaking a course of intravenous antibiotics, working from home may help conserve energy and promote a speedier recovery.



- People with CF are prone to lung infections that can be very harmful to others with the condition. Each person with CF 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 CF are advised not to mix with each other at all. For this reason, it is important that any individual with CF is aware if there are other people with CF working within an organisation or if people with CF are likely to visit the building.
- There are some environments that can harbour bugs which are harmful to people with CF: stagnant water, mouldy/damp environments and hay/rotting vegetation can 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 CF is a relatively invisible condition; people with CF don't usually look ill unless they are very unwell, and for this reason, CF can be classed as a non-visible disability. People with CF have their own feelings on whether or not they want their colleagues to know about their condition.
- People with CF have had it all their lives and are experts in their own treatment. Employers do not need any specific medical training at all, and it's extremely unlikely that CF could result in an emergency medical situation. People with CF 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 CF could affect their work. As mentioned earlier, people with CF 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. For example, is it possible for the individual to bank their time to allow for absences?
- Provide in-house training, if your employee wishes, to other employees to help them understand the impact of cystic fibrosis.
- Consider visiting the Business Disability Forum website [www.businessdisabilityforum.org.uk](http://www.businessdisabilityforum.org.uk), which gives organisations an opportunity to understand disability issues and promote best practice.
- Contact the Department for Work and Pensions for access to the Disability Service, which can liaise between employers and employees with a disability. This service is able to provide support through use of the Access to Work Fund, which will pay for most aids or required adaptations, including personal support, vocational assessments, employment rehabilitation training courses and access to schemes that may help an employer decide whether or not to recruit a person with a disability. It is possible for a person with a disability to undertake a trial before a decision is made. Contact Jobcentre Plus for details: [www.gov.uk/jobcentre-plus-help-for-recruiters](http://www.gov.uk/jobcentre-plus-help-for-recruiters).



## Retaining people with cystic fibrosis

It's in everyone's interest that employees continue to work for you as long as possible. If you do have any concerns about an individual's performance, discuss it with them. The Equality Act 2010 establishes legal rights for people with a disability in a number of areas, including employment. Employers have a duty to not treat people with a disability less favourably. If problems with an employee are related to their CF, then there is a duty to make reasonable adjustments in the workplace. A regular appraisal of progress can be a useful mechanism in this process:

- Focus on achievements and successes, not the disability.
- Encourage the individual to assess their performance. If there have been any changes, establish why.
- If changes are due to the person's CF, consider if any further adjustments could be made, eg working part-time, working from home, or seeking medical advice, either from the company medical adviser, or the individual's hospital or specialist CF centre consultant.
- Ensure that decisions about future employment reflect mutual agreement.

With progressive and fluctuating conditions like CF, symptoms can become worse as a result of stress or tiredness. Managing workloads and tackling the cause of stress may help reduce absences from work.

**If you would like any further information about cystic fibrosis, please contact our helpline on 0300 373 1000 or email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk) (Monday-Friday 9am-5pm) or visit our website [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk).**

## Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website. Visit [cysticfibrosis.org.uk/publications](http://cysticfibrosis.org.uk/publications).



The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted on 0300 373 1000 or [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk) and is open Monday to Friday, 9am – 5pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk).

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More factsheets available at:  
[cysticfibrosis.org.uk/publications](http://cysticfibrosis.org.uk/publications)

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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# Cystic Fibrosis Trust

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