

# Cystic Fibrosis *our focus*

**Employment**

Factsheet – October 2013

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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 the job and starting work. It discusses possible discrimination and issues to consider when telling an employer you have cystic fibrosis.

### **Keeping your job**

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 leaflets available from the Jobcentre.

### **Work and benefits**

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

### **Legal aspects of employment**

The Health and Safety at Work Act 1974 and the Disability Discrimination Act 1995 are described in more detail.

### **Factsheet for employers**

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

Written by the Cystic Fibrosis Trust.  
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# Finding the right job

## The application stage

The Careers Advisory Service, the Jobcentre Plus and specialist employment agencies will have a number of useful leaflets outlining how to approach employers and complete forms. A Jobcentre will also have a Disability Employment Adviser (DEA) who provides an assessment service and employment and benefit advice for people with a disability, for example, the Supported Employment Scheme “Work Step” – which provides a progression from supported employment into open employment. DEAs can provide further information. There may also be a specific Government scheme 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 fill in application forms; these are available from local libraries and all good bookshops.

Consider whether you want to work full-time or part-time. Make the most of your abilities. It can be useful to brainstorm your skills and relate these to key aspects of the job you are applying for. Describe what you learnt from previous paid work, voluntary work or work experience and consider how this relates to the job description. Briefly describing hobbies and interests can give a potential employer more of an idea of you as a person. As family and friends can also help identify your strengths it maybe a good idea to photocopy the form and show them a draft application.

If the application form asks about health problems it is best to be honest, but explain how cystic fibrosis could affect your work and how it could be managed.

If you do not reveal your condition to an employer, then you are not covered by the Disability Discrimination Act 1995 and there is no redress.

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

- 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, rest-room or first aid room?
- Does the company have a Permanent Health Insurance plan? If you become too ill to work an index-linked retirement pension is paid for life. Having cystic fibrosis doesn't mean you won't qualify; it depends on the company.
- Is there a no-smoking policy?
- 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, or you can ask their Human Resources department.

It would be a good idea to discuss your employment aims with your specialist CF centre consultant. Be specific about the job you want, and ask for a letter describing your medical fitness. This could be useful at a later date.

## Attending an interview

You've got an interview! This is your opportunity to sell your abilities and skills to the employer. Use the first part of the interview to do just that when answering the employer's questions. Find out about the organisation beforehand and where appropriate include relevant information in your answers. It is a good idea to ask one or two pertinent questions about the job or organisation. Listen carefully to questions and try not to rush answers. Be positive and emphasise what you can offer the organisation.

## Being offered the job

Well done! The hardest part is over; now is the time to clarify arrangements. The key word here is flexibility.

Consider:

- Whether adjustments could be made to working arrangements. Would it be possible to have an annual contract in hours?
- Sick leave allowance – would it be possible to have unpaid days if required?
- What facilities are there at work (eg a fridge, staff room)?
- Could adjustments be made to any pension provision if you opt out of the scheme?
- Are other benefits available instead?

## Starting work

Talk to your employer / line manager in more depth about how cystic fibrosis may affect your work.

Establish a contingency plan about how any absences will be managed. For example, is it possible for you to 'bank' your time to allow for absences? – see the Keeping your job section in this factsheet.

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

## Dealing with discrimination

When do I disclose that I have cystic fibrosis?

This is a very individual choice, as is when is the right time to negotiate adjustments. If you are asked whether you have a health problem or disability, answer in a straightforward way.

Make the distinction between a health problem and a disability. If necessary, explain how cystic fibrosis would affect you in a work environment. Emphasise your abilities and why you feel you are the right person for the job. If you do not mention you have CF when appointed, you may lose some legal rights relating to the Disability Discrimination Act 1995 and relating to unfair dismissal.

The Disability Discrimination Act 1995 aims to combat discrimination against people with disabilities (see Legal aspects of employment section in this factsheet). Now that this legislation is in place, disability organisations are recommending that if you work for an organisation that has 15 or more people (the minimum number to ensure the legislation is applicable), you should disclose your condition.

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 Employers Forum on Disability?

## Summary

Focus on what you can do rather than what you can not. When looking for a job, persistence pays; so don't give up. You may encounter prejudice along the way, but the ignorance behind this can be combated by providing information when required.

## Useful organisations

### The Prince's Youth Business Trust

18 Park Square East, London NW1 4LH  
0800 842842 Textphone 020 7543 1374

[www.princes-trust.org.uk](http://www.princes-trust.org.uk)

Assists unemployed people between 18 and 30 to set up their own businesses. It provides low interest loans and grants. All applicants must produce a viable business plan and have tried to raise the finances elsewhere.

### Jobability

[www.jobability.com](http://www.jobability.com)

Initiative of Leonard Cheshire, to give disabled people access to a wide variety of jobs as well as career advice.

### Shaw Trust

Shaw House, Epsom Square  
White Horse Business Park, Trowbridge  
Wiltshire BA14 0XJ

0300 3033111 [www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)

Shaw Trust is the UK's largest third sector provider of employment services for disabled and disadvantaged people.

## **Remploy Ltd**

Stonecourt, Siskin Drive, Coventry CV3 4FJ

[www.remploy.co.uk](http://www.remploy.co.uk)

Aims to expand employment opportunities for disabled people. A network of services helps people find work either within Remploy or provides support to facilitate employment in another company.

## **Disability Rights UK**

12 City Forum, 250 City Road, London EC1V 8AF

020 7250 3222 [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

## Keeping your job

It is possible that during your employment you will want to discuss with your employer changes to your contract of employment for health reasons. These changes may include reducing the hours worked, changing your work pattern, or moving to an entirely different job. The key word here is flexibility. The Disability Discrimination Act 1995 requires employers to make reasonable adjustments for people with a disability. Emphasise what you can do and concentrate on finding a solution. Be positive and creative.

For example:

- Before reducing the hours worked consider whether adjustments could be made to working arrangements instead? For example, would it be possible to have an annual contract in hours?
- Would a different job within the organisation make life easier?
- Sick leave allowance – would it be possible to have unpaid days if required?
- Could you establish a contingency plan about how any absences could be managed? For example, is it possible for you to ‘bank’ your time to allow for absences?
- See the Work and benefits section in this factsheet for information on how benefits are affected if you adjust your hours of work.

## Government schemes

Although you may not consider yourself to have a disability, cystic fibrosis can sometimes be 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 a Disability Service Team, which offers employment advice and an assessment service for people with a disability and their employers. It is a good idea to make contact with the Disability Employment Adviser (DEA), who is part of this team. The Adviser will not only help you find a job, but will 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 Bureau website [www.adviceguide.org.uk/](http://www.adviceguide.org.uk/).

### Access to Work

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

### Employment assessment

This involves an in-depth interview to identify strengths and plan how to obtain a job. The impact of cystic fibrosis on the type of work or training you are aiming for will also be discussed. This does not affect benefits and travel expenses can be claimed.

### Work Choice

Work Choice can help you get and keep a job if you're 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
- interview coaching

You can't get Work Choice in Northern Ireland - they have different schemes instead.

Work Choice replaced WORKSTEP and Work Preparation. The Job Introduction Scheme has not been replaced and has now stopped.

Visit <https://www.gov.uk/work-choice>.

### The disability symbol

This leaflet outlines the role of the Disability Employment Adviser and advantages of Government schemes for employers.

When an employer displays the 'positive about disabled people' symbol it means they have agreed to interview people with disabilities if the minimum criteria for the job are met. The employers have also agreed to ensure the disabled employee is encouraged to develop their skills and will ensure that the individual remains in employment for as long as possible.

## Work and benefits

### Non-Contributory, Non Means-Tested Benefits

If you are eligible for Disability Living Allowance (DLA)/Personal Independence Payment (PIP) and/or Child Benefit these will not be affected by having a job.

### Non-Contributory Means-Tested Benefits

From April 2003, Disabled Person's Tax Credits are part of: Working Tax Credits and Child Tax Credits.

These are tax credits for people who are in paid work (including self-employment) for a required number of hours. You may be eligible if:

- You are a single person or lone parent.
- You are a married couple living together.
- You are a man and woman living together as if you are married.

You must be aged 16 or over to apply and the amount you receive will depend on your annual income and savings.

#### Elements of Working Tax Credit

- A basic adult element which is paid to you if you meet the above criteria.
- An extra element which is paid to lone parents and couples.
- An extra element which is paid if you and your partner, (if you have one), work a total of 30 hours or more a week.
- An extra element which is paid if you (or your partner) are working and have a disability.
- A childcare element which is paid to help households who are working and have to spend money on childcare.

If you receive the childcare element of Working Tax Credit, this will always be paid, together with your Child Tax Credit, directly to the person who is mainly responsible for caring for the child or children. It does not have to be paid to the person who receives Working Tax Credit.

Working Tax Credit Helpline 0845 300 3900

Northern Ireland 0845 603 2000

Website: [www.inlandrevenue.gov.uk](http://www.inlandrevenue.gov.uk)

The Enhanced Disability Credit introduced in April 2001, provides additional help for severely disabled adults and families with disabled children in receipt of the higher rate care component of Disability Living Allowance.

The Enhanced Disability Credit is paid at two different rates and will be paid in addition to the basic credit as follows:

- Higher rate payable to a couple (or either partner), or a lone parent.
- Lower rate payable to a single person with no dependent children.

The Child Enhancement Disability Credit is payable instead of Disabled Child Tax Credit and is payable for each child within the household.

## Other Benefits

Income Support, Housing Benefit and Council Tax Reduction are also paid depending on your level of income.

Income Support is extra money you may be able to get if:

- you have no income or a low income
- you're working less than 16 hours a week
- you haven't signed on as unemployed

See [www.gov.uk/income-support/overview](http://www.gov.uk/income-support/overview). Help with mortgage interest payments may also be included.

Housing Benefit is paid to help with rent. You could get Housing Benefit to help you pay your rent if you're on a low income.

See [www.gov.uk/housing-benefit](http://www.gov.uk/housing-benefit).

Council Tax Reduction replaced Council Tax Benefit in April 2013. If you qualify for Council Tax Reduction, you will get money off your Council Tax bill. See [www.gov.uk/council-tax-reduction](http://www.gov.uk/council-tax-reduction).

# Legal aspects of employment

## Health and Safety at Work Act

The Health and Safety at Work Act 1974 sets out the general duties which employers have towards employees and members of the public, and 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's responsibilities

An employer has a responsibility to see what hazards are present, and consider if they pose risks to your health and safety.

### Employees responsibilities

As an employee you have a duty to cooperate with any 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 these.

Systematically discussing potential risks to your health can help allay an employer's anxieties.

## The Disability Discrimination Act

The Disability Discrimination Act 1995 (DDA) requires employers to make reasonable adjustments for people with a disability when considering employment, promotion, transfer, training or other benefits. Examples of adjustments which may have to be taken are:

- Making adjustments to premises (eg widening doors). However, if the building complied with building regulations when it was built they are exempt from further duty.
- Allocating some of the individual's duties to another person.
- Transferring the person to fill an existing vacancy.
- Being flexible about working hours.
- Assigning a different place of work.
- Allowing the person with a disability to be absent during working hours for rehabilitation, assessment or medical treatment.
- Training.
- Acquiring or modifying equipment.
- Providing supervision.

However, whether it is reasonable for the adjustment to be made depends on several factors:

- The practicalities for the employer.
- The resources of the employer (financial and other).
- The financial costs weighed against other costs to carry out the activity.

- The availability of finances to assist the employer in implementing the step (e.g. under the Access to Work Scheme).
- The extent to which the disabled person is willing to co-operate.

Employers must be made aware that you have cystic fibrosis to utilise this legislation.

To summarise, each case is individual and reasonable is a subjective decision. This legislation does not apply to employers with less than 15 employees. There are also other exceptions eg Armed Services, Emergency Services or employment on a ship, hovercraft or aircraft.

### **Sick pay and ill health**

The interaction between the DDA and an employer's sickness procedures is not straightforward. It is not the case that employees are allowed an indefinite amount of time off work for ill health or as a result of sickness. However, an employer does have to make reasonable adjustments. In practice this will mean that an individual case will ultimately be determined by case law.

## Information for employers

Cystic fibrosis (CF) is a life-shortening genetic condition and affects approximately 1 in every 2,500 people. Currently there are nearly 10,000 people with CF in the UK; half are adults. Cystic fibrosis is caused by a single faulty gene and is a chronic progressive disease.

Cystic fibrosis does not affect everyone to the same degree and people with CF can undertake a wide range of jobs including nursing, secretarial work, teaching, office work, doctors, engineers and builders.

Cystic fibrosis causes the mucous glands to produce abnormally thick, adherent mucus affecting mainly the lungs and pancreas. The lungs are normal at birth but the thick mucus collects and blocks some airways and they can become susceptible to bacterial infection and damage.

### Cystic fibrosis is a fluctuating condition

A person with cystic fibrosis will experience differing levels of incapacity and face a daily regimen of treatment. Some people with CF may need to carry out physiotherapy at work and may require some time off for routine antibiotic treatment.

### Cystic fibrosis is often a hidden condition

People with cystic fibrosis do not usually look unwell. Unless they are very ill they are unlikely to use a wheelchair or to show outward signs of illness. For this reason CF can be classed as a non-visible disability. However, some people with CF may find it hard to climb stairs or walk for any distance.

### Cross-infection

People with cystic fibrosis are more susceptible to certain bacterial infections and at risk of infection from others, particularly others with cystic fibrosis. Because of the dangers of cross-infection, the Cystic Fibrosis Trust recommends individuals with CF should not come into close contact with other people with cystic fibrosis. 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.

Other employees who do not have CF are not at risk of contracting an infection from someone with cystic fibrosis.

Cystic fibrosis is not infectious.

### Negotiating with an employee with cystic fibrosis

- Talk to the individual about how CF could affect their work. As noted 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?
- Ensure that other employees are aware of the impact of CF through in-house training if the person with CF wishes.
- Contact the Business Disability Forum (020 7403 3020) and ask for a copy of their briefing paper 'A practical guide to employment adjustments for people disabled due to progressive or fluctuating conditions'.

- Consider visiting their website: <http://businessdisabilityforum.org.uk/> which gives organisations an opportunity to understand disability issues and promote best practice.
- As part of New Deal for Disabled People, The Department for Work and Pensions: [www.dwp.gov.uk](http://www.dwp.gov.uk) (Helpline 0800 137177) has a Disability Service, delivered by Disability Employment Advisors (DEAs) who can liaise between employers and disabled employees. This service is able to promote and support, through use of the Access to Work Fund, which will pay for most aids, or adaptations, required including personal support, vocational assessments, employment rehabilitation courses, training and access to schemes which, may help an employer decided 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 your local Employment Service for details or: Jobcentre Plus: [www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk).
- **Shaw Trust** – 0300 3033111 [www.shaw-trust.org.uk](http://www.shaw-trust.org.uk). This is a national charity helping people with disabilities find and retain work. It also provides a wide range of advice and support to employers on disability and employment issues.

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

It is in your mutual interests that all employees continue to work for you as long as possible. It is important that any concerns about an individual's performance are discussed with them. The Disability Discrimination Act 1995 established new rights for people with a disability in a number of areas including employment. Employers of 15 or more people now have a duty to not treat people with a disability 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. 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 e.g. part-time working, working from home, or whether medical advice is needed, either from the company medical adviser, or the individual's hospital or specialist CF centre consultant.
- Try to ensure that decisions about future employment reflect mutual agreement.

The key word here is flexibility. However, it is important to remember that reasonable adjustments mean reasonable; if someone is almost permanently absent then they are clearly not fulfilling their contract. With progressive and fluctuating conditions like cystic fibrosis, 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.

## Further information

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

Most of our publications can be downloaded from our website ordered using our online publications order form.

Visit [cysticfibrosis.org.uk/publications](http://cysticfibrosis.org.uk/publications).

Alternatively, to order hard copies of our publications you can telephone the CF Trust on 020 8464 7211.

If you would like further information about cystic fibrosis please contact:

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11 London Road  
Bromley  
Kent BR1 1BY

T 020 8464 7211

[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)  
[enquiries@cysticfibrosis.org.uk](mailto:enquiries@cysticfibrosis.org.uk)

Helpline 0300 373 1000

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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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