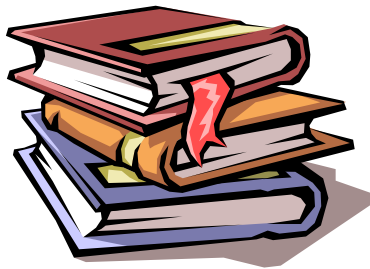


HIGHER EDUCATION

This pack is designed for adults with Cystic Fibrosis (CF) intending to go on to higher education.

It covers some points to think about before embarking on higher education courses. It also covers several issues you need to think about when you first arrive at your chosen campus/college/university or other site of further education.

We have also included two factsheets, which serve to inform people about Cystic Fibrosis. These are designed for Tutors and Accommodation Officers respectively.



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www.cftrust.org.uk

11 London Road, Bromley, Kent BR1 1BY Tel: 020 8464 7211 Fax 020 8313 0472 enquiries@cftrust.org.uk

INTRODUCTION

Going to University can enable you to realise academic potential, broaden your career prospects, secure financial independence and achieve personal satisfaction. It also offers the chance to make new friends, think differently about yourself and the world and have a great time! This factsheet will assist your thinking process. It is split into three sections:

1. *Which University?*
2. *When you have accepted an offer*
3. *At University*

Throughout this factsheet we have included comments from adults with CF who have been to University. If you have any tips that would be useful to others then please let us know.

Which University?

Many factors will come into the decision about where to apply; geographical location, the courses on offer, and the nightlife! In addition to these factors it would be useful to consider additional needs you may have in terms of access and accommodation. It is also important to consider the nearest Specialist Cystic Fibrosis Centre. There are also financial costs to consider. The importance attached to these factors will obviously vary between individuals.

a. Location and facilities

Which University?

When thinking about which University to choose consider the facilities on offer and your accommodation needs. Local libraries and your school will have books providing information on different universities. General Internet sites summarising different UK Universities are available at: [www.ucas.ac.uk](http://wwwucas.ac.uk) and www.student.uk.com. and www.push.co.uk.

The wide variation between people with CF means that some of you may not consider yourselves to have a disability. However, under the Disability Discrimination Act 1995 any 'progressive' impairment, even if managed by medication and not currently having a substantial impact on day-to-day activities, is covered.

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As part of the Act, all Higher Education Institutions are required to submit a Disability Statement. The Statement outlines University policy, current provision for students with a disability, and future plans, and is intended to give a realistic picture of the situation for students with a disability. The majority of Statements are accessible on the Internet at <http://cando.lancs.ac.uk/> to enable you to compare provision at different Universities. These Statements discuss the institutions' current policy, current provision, future activity and policy development and further information and contacts. These are a useful way of quickly assessing your chance of getting the access and accommodation you need, and give contact numbers for the person at the University responsible for disability issues. Accommodation considerations include:

- Building with “no smoking” policy.
- Ground floor.
- Self-catering as opposed to catered Hall.
- En-suite facilities.
- Facilities for intravenous equipment.
- Enough plug points.
- Security (consider all university buildings and your accommodation).
- Windows that open if you have to nebulise antibiotics.
- Fridge for medicines.

These may not all be possible to obtain, but the CF Trust has an information sheet for Accommodation Officers to explain CF and accommodation needs in more depth. The general rule when finding accommodation is to try to make things as easy as possible for yourself.

Health Considerations

It is worth thinking about where the nearest Specialist CF Centre would be to your preferred University. The CF Trust can provide you with more information if necessary, including a list of Specialist CF Centres in the UK. It may be worthwhile visiting the Centre to get an idea of the location and service provided. A very exposed campus and adverse weather will exacerbate symptoms, and is best avoided.

“A three hour train journey to the nearest CF clinic may sound OK now but could you do it when you are ill”

“Check out that there is a sick bay on campus. This is the halfway house between being bedridden in your accommodation and hospital.”

b. Course considerations

It is obviously important to choose a subject that interests you and you will be motivated to study. Another choice is whether you will study full-time or part-time. If you have found that you cope best with part-time work, it may be sensible to consider starting your tertiary studies part-time rather than full-time. Though there are some frustrations about studying part-time, and of course you will take longer than the minimum time to complete your degree, there are also some benefits. This is particularly so at the beginning of university study when you are adjusting to a new environment, encountering diverse teaching styles, developing more effective study habits, and learning time management and organisational skills. If you opt for a 'sandwich' course, the CF Trust has an information pack on various aspects of employment including letting an employer know more about Cystic Fibrosis.

A 'Modular' course is another option, which means you can repeat individual aspects if necessary rather than the whole year.

For full-time courses it is a good idea to check out the timetable and location of lectures. Consider whether the timetable is feasible for you, considering your level of fitness and dietary requirements.

“My course had lectures in two centres some distance apart, and in one building the lectures were on the second floor. We had ten minutes to travel from place to place and I would not have been able to make it if I couldn't run upstairs”.

c. Financial considerations

“Cystic Fibrosis affects people differently and you may not consider yours to be in any way disabling. However the extra cash that is available to you can prevent your CF from becoming a problem. It will allow you to ensure decent accommodation when others are living in damp flats, buy a proper meal in the bar when others are surviving on crisps and get that all important taxi four miles back to campus at 3am when others have to walk home in the rain. In other words it can allow you to maintain your current level of health so you can experience university life to the full.”

The CF Trust has a more detailed fact sheet about financial support: *A Guide to Financial Help* which can be obtained by telephoning the Welfare Grants Officer ☎ 0845 859 1020 or by downloading it from the website: www.cftrust.org.uk.

Factsheets are also available from the National Bureau for Students with Disabilities (SKILL) Chapter House, 18-20 Crucifix Lane, London, SE1 3JW.

☎ Helpline 0800 328 5050 (Mon-Fri 1.30-4.30pm) www.skill.org.uk.

Student Loans

You must contact your **L**ocal **E**ducation **A**uthority (LEA) at the beginning of the year in which you intend to go to university. They will send you the relevant forms to fill in with regard to help towards tuition fees and living costs. They will then assess your situation and tell you how much your family may need to contribute and how much they are willing to give or grant you. The LEA will also advise you on how to apply for:

Disabled Students Allowance

The allowance is intended to pay for the additional help, travel costs and equipment you need in order to study (eg. a fridge or computer or even a note taker if necessary). Further information available from SKILL National Bureau for Students with Disabilities, website: www.skill.org.uk

Benefits

Many students are able to continue to get Disability Living Allowance (DLA). In addition to this you may be able to claim Income Support (IS), Incapacity Benefit (IB), Housing Benefit (HB), depending on the hours worked and your financial circumstances. Disability Living Allowance is not means tested and does not affect other benefits. If you do not already receive DLA it is worth applying, the **CF Trust** has an information pack on how to apply, this includes a form to complete if you want a letter of support. The letter of support form is available from the **website: www.cftrust.org.uk**. To obtain the pack please contact our **Benefits Officer on ☎ 0845 859 1010**. Please note you need to contact your local benefits office or **Benefit Enquiry Line (BEL) ☎ 0800 88 22 00** to obtain the actual DLA form.

University Access Funds/Hardship Grants

All universities have their own funds to help students with special needs and you can apply to them, for example, for help with extra food costs and travel expenses.

Grants

It is possible that you could obtain a grant from The Joseph Levy Memorial Fund which gives financial assistance to adults with CF 18 years old and over for the development of their career by way of Further or University education or in pursuance of other professional qualifications. Grants will be considered to cover the cost of tuition, living expenses, examination fees or other costs of a similar nature, which are required to assist the applicant to progress his or her career. Contact: **Mrs Elizabeth Neville, First Floor, Pegasus House, 37/43 Sackville Street, London W1X 2DL**

☎ 020 7333 8118 or email: Elizabeth.Neville@shaftsbury.co.uk for further details and information on how to apply.

The Trustees meet during mid June and applications should be received by late March. It is advised not to wait for A level results before applying.

The Educational Grants Directory

Contains national and general sources of help and gives information on statutory entitlements, grants and loans, company sponsorship, career development loans. Gives sources of further information and how to make an application to an educational charity. **This is available either from your local library or from: The Directory of Social Change, 24 Stevenson Way, London, NW1 2DP.**

☎ 020 7209 5151 or email: info@d-s-c.demon.co.uk

When you are offered a confirmed place

a. Negotiating a flexible work schedule

Once you have been offered a confirmed place it can be useful to discuss your individual experience of CF with your course leader. This can be used to discuss the course requirements, provide information about CF and how *you* are affected and negotiate how *you* will work.

It can be useful to discuss that the quality of your work may fluctuate, that there may be times in the term when you are unable to work effectively and your attendance at lectures/seminars may sometimes be erratic. Discuss how you react to feeling tired and ill. Consider how you will be able to get any information you have missed. Find out the procedures around exam time and how you may be accommodated depending on your health at the time.

The following may be a useful way of negotiating a more flexible academic term:

Altering the work schedule

Deadlines for work could be extended outside full-term and attendance at non-essential lectures or classes excused, in order to lighten the workload. Deadlines for the return of library books could also be extended.

Examination arrangements

There are a number of special arrangements which may be approved by the Board of Examinations at the request of College tutors. These include taking the exam in College with extra time, rest breaks, a separate room to sit in and the use of a word processor as necessary. If College authorities require a doctor's note to support your request for special arrangements, then you should be informed in good time.

The CF Trust has a factsheet to give to Tutors if required.

b. Health considerations

Now is the time to make contact with the Specialist CF Centre near the University. You can do this through your current Specialist CF Centre or make contact yourself to organise a visit and arrange the 'transition'.

Arriving at University

a. Support within College

Make contact with the support people around the University as soon as is practicable. You will be able to pick up a list of student services / support personnel from the Students' Union office and from other locations around campus. There are a number of ways in which a College can support a student with a chronic illness; these might include:

- Ensuring that the College nurse liaises with the student.
- Ensuring College Porters are aware of the student's condition (subject of course to the student's wishes).
- Arranging help with regular tasks such as laundry.
- Arranging at least daily contact by a member of the College staff during periods when a student is bedridden.
- Advising where to get professional help if they don't provide it i.e. counselling, housing and financial advice.

At all times confidentiality should be preserved in health matters, and the wishes of the individual student fully respected.

“Combining forces (e.g. with people with asthma) may make it possible to get areas designated as non-smoking, where a lone voice is less effective. The CF Trust may be able to help you with this”.

b Health considerations

It will be necessary for you to register with a new GP and obtain a certificate so that you are exempt from prescription charges. Lists are available from University Welfare Services or from the local Family Health Services Authority.

“Some Universities have their own medical services with which you can register for GP support. This means that if you become ill the system is aware that you have a chronic health problem”.

“Butter up the GP's admin staff, that way they will be much more forthcoming with emergency appointments and repeat prescriptions you have forgotten to order”.

“Ask the campus pharmacist to keep a stock of all medication YOU CANNOT DO WITHOUT, such as enzymes, antibiotics or DNase. It doesn't matter how good you are at getting your prescriptions done with the pressure of parties, deadlines and exams you will run out of something essential at some point”.

“Take your vitamins and arrange for the flu jab the second it comes out. With these rudimentary precautions you can live like a student and get away with it.”

Obtain a copy of *Pseudomonas Aeruginosa Infection in People with Cystic Fibrosis* from the CF Trust or the website: www.cftrust.org.uk. This explains how to minimise the risks of getting other infections.

“One simple rule - ASK. The nice lady in the accommodation office may well have put someone free of chronic infection and someone with MRSA on the same corridor on the basis that CF meant you would have something in common. Do the same with your course and the university in general. If there is someone else take simple precautions and meet in the open air or communicate via university e-mail as there may be a risk of cross-infection”.

Try to ensure that treatment doesn't slide as you become more involved in university life.

c Academic considerations

A meeting halfway through the term can be used to review progress and consider any difficulties. You could contact the Disability Officer for suggestions and assistance.

If necessary it may be useful to know that it is possible to **degrade**. Leave to degrade allows a student to, in effect, repeat all or part of an academic year during which they have been ill, and take an examination in a year in which they would not otherwise have been eligible to take it. So, if you reach the Easter Term and feel that you cannot do yourself justice in the examination because of illness, degrading may be an option. This may allow time to recover from a relapse, or it may allow you to compensate for time lost owing to illness.

People should be aware, however, of the financial implications: sometimes a Local Education Authority (LEA) will not be willing to use its Discretionary Funds to fund a repeat year, or part year for a student who has been ill. The decision of the LEA must be taken into account when deciding whether or not to degrade.

Going to university is about much more than attending lectures and tutorials, completing assignments and sitting for examinations. University offers the opportunity to meet a diverse range of people, try different activities, experience a different side to life and have a good time!

Open University

Has developed a wide range of services for students with disabilities, including telephone tutorials and equipment loans, and the Government introduced a scheme waiving fees for part-time education students on benefits. The Open University website provides more information about help with money:

☎ 01908 653231 (general enquiries)

☎ 01908 653745 (students with disabilities)

www.open.ac.uk

A TUTOR'S GUIDE TO CYSTIC FIBROSIS

About Cystic Fibrosis

Cystic Fibrosis (CF) is the UK's most common life-threatening inherited disease and affects approximately 1 in every 2,500 children born. Currently there are around 7,500 people with CF in the UK; half of these are adults. Cystic Fibrosis is caused by a single faulty gene and is a progressive disease.

Cystic Fibrosis does not affect everyone to the same degree - some people are worse or better than others. Cystic Fibrosis causes the mucous glands to produce abnormally thick, adherent mucus and the sweat glands to produce excessive salt. The two main areas of the body involved are the lungs and the pancreas. The mucus is responsible for the principal complications. In CF the lungs are normal at birth but become susceptible to bacterial infection and damage. The thick mucus collects in the lungs blocking airways and resulting in damage caused by infection.

Serious symptoms and complications of CF include infection, inflammation, malnutrition, diabetes, liver failure and osteoporosis. There is currently no known cure.

Important considerations

Cystic Fibrosis is a fluctuating condition

A person with CF will experience differing levels of incapacity, sometimes within the same day. People with CF face a daily regimen of treatment. This includes physiotherapy to help clear mucus from the lungs, enzyme supplements with food to aid digestion and antibiotics to fight infections. The latter often requires a period of hospitalisation.

Cystic Fibrosis is a hidden condition

People with CF do not usually look unwell. Unless they are very ill they are unlikely to use a wheelchair or to show outward signs of illness. People with CF may look well but this is due to the time and effort required by their treatment regimen. How badly a person is affected depends on a number of factors. They may not be able to cope with the same daily demands as others.

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Cross-infection

It is important to bear in mind that people with CF are more susceptible to certain bacterial infections and at risk of infection from others, particularly others with Cystic Fibrosis. *Burkholderia Cepacia* and *Pseudomonas Aeruginosa* are common infections and it is advised that the individual does not come into close contact with other people with Cystic Fibrosis. The CF Trust has guidelines available which explain cross-infection in more depth, entitled *Pseudomonas Aeruginosa Infection in People with Cystic Fibrosis*. This would be recommended reading if the course is considering accepting more than one person with Cystic Fibrosis. For this reason it is important that any individual with CF is aware if there are other people with CF within an organisation. Other students who do not have CF **are not at risk** of contracting an infection from someone with Cystic Fibrosis.

Working with people with Cystic Fibrosis

It is important to treat each person with CF as an individual due to a wide variation between those affected. From the outset it is important that tutors have an open dialogue with individuals about questions and concerns on both sides. Due to the wide variation between people with CF, and the hidden and fluctuating nature of the condition, a recent letter from the student's hospital Consultant outlining their current condition and providing additional medical information can be extremely helpful in determining abilities. A daily treatment record can also provide information on the student's condition.

The following may be useful in working with students with Cystic Fibrosis:

- Although an adult with CF usually manages to maintain reasonable health through self-care, there may be episodes of illness that require hospitalisation. It would be useful to have support systems such as additional tutorials, notes in written form or recordings etc.
- Some adults with CF require more treatment at home, for example, physiotherapy, using nebulisers, doing intravenous treatments etc. It may mean a tight schedule fitting in all these around a normal student life. Therefore, it would require understanding and flexibility on the part of the University regarding punctuality and attendance at both lectures and tutorials.
- A student who drives will appreciate a designated parking space.

There are a number of ways in which a University or College can support a student with a Cystic Fibrosis; these might include:

- Ensuring that the University/College nurse liaises with the student.
- Ensuring College Porters are aware of the student's condition (subject of course to the student's wishes)
- Arranging help with regular tasks such as laundry.
- Arranging at least daily contact by a member of the College staff during periods when a student is bedridden.

At all times confidentiality should be preserved in health matters, and the wishes of the individual student fully respected. With a flexible approach and acknowledging that occasionally the quality of work may fluctuate, a University can accommodate individuals with Cystic Fibrosis. While this leaflet serves as a brief guide, it is best to talk to individual students with CF to find out what support they need.

A GUIDE TO CYSTIC FIBROSIS FOR ACCOMMODATION OFFICERS

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Accommodation for people with Cystic Fibrosis

The following outlines issues to consider when providing accommodation for students with Cystic Fibrosis.

1. A person with Cystic Fibrosis often coughs in an attempt to clear his/her chest. The cough can often be misunderstood by other people who may make unhelpful comments. At night, coughs may annoy other residents. A room with thickly insulated walls may help to minimise the noise caused by coughing.
2. To clear the mucus in their lungs a person with Cystic Fibrosis needs to do regular chest physiotherapy. In addition s/he may use nebulisers. A room with a mains supply is required for the use of the nebuliser.
3. A room with en-suite facilities would be desirable for two reasons. Firstly bowel problems can cause the person with Cystic Fibrosis to have diarrhoea and require the toilet urgently. Secondly, during a period of chest infection, a person with Cystic Fibrosis may need to administer intravenous antibiotics. This procedure requires the room to be as sterile as possible.
4. Compared with the average person, a person with Cystic Fibrosis may need to consume 100 - 150% more calories and 200% more protein per day to maintain normal body weight. As a result s/he may want to use the kitchen often to prepare snacks and meals. Proximity to the kitchen may be a factor to consider.
5. The availability of a lift is important if the accommodation is not on a ground floor.
6. A non-smoking and unpolluted environment is recommended.
7. Students with Cystic Fibrosis may have a car and will appreciate a designated parking space in the accommodation premises.

At all times confidentiality should be preserved in health matters, and the wishes of the individual student fully respected. While this leaflet serves as a brief guide, it is best to talk to individual students with CF to find out what support they need.