Cystic Fibrosis our focus

Higher education

Factsheet – March 2013

Higher education

Introduction

This factsheet 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 place of further education.

It also includes information for tutors and accommodation officers who have a student with cystic fibrosis. You may wish to pass on a copy of these factsheets to the relevant people when you start your higher education.

Written by the Cystic Fibrosis Trust.

Last reviewed March 2013.

Sections

A guide for young people with cystic fibrosis considering enrolling at a college or university

Introduction

Going to college or 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 college / university?
2. When you have accepted an offer
3. At college / university

Throughout this factsheet we have included comments from adults with CF who have been to college / university. If you have any tips that would be useful to others then please let us know (see contact details on back page).

Written by the Cystic Fibrosis Trust.

Last reviewed March 2013.

Contents

Which college / university?

When considering a college or university, many factors will come into the decision about where to apply, such as geographical location, the courses on offer, nightlife etc. In addition to these factors it would be useful to consider additional needs you may have in terms of access and accommodation, and the location of the nearest specialist CF centre. There are also financial costs to consider. The importance attached to these factors will obviously vary between individuals.

Location and facilities

When thinking about which college / 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. Internet sites summarising different UK universities include **www.ucas.com**, **www.student.uk.com** and **www.push.co.uk**.

The wide variation between people with cystic fibrosis means that some people with the condition may not consider themselves 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.

As part of the Act, all higher education institutions are required to submit a Disability Statement. These statements discuss the institution's current policy, current provision, future activity and policy development and further information and contacts. These are a useful way of quickly assessing your chances of getting the access and accommodation you need, and can be found on the websites of most institutions.

Accommodation considerations may include:

- Self-catering as opposed to catered hall
- En-suite facilities
- Facilities for intravenous equipment
- Enough plug points
- Security (consider all college / university buildings and accommodation)
- Windows that open if you have to nebulise antibiotics
- Ground floor
- Fridge for medicines

These may not all be possible to obtain, but when finding accommodation 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 college or university. The CF Trust can provide you with more information if necessary, including a list of specialist CF centres in the UK (this is also available on the CF Trust website). It may be worthwhile visiting the centre to get an idea of the location and service provided. A very exposed campus and adverse weather may exacerbate symptoms, and is best avoided.

Some tips we have received from students include:

"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."

Course considerations

It is obviously important to choose a subject that interests you and will motivate you 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 course part-time rather than full-time. Though there are some frustrations about studying part-time, and 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 your studies 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, which includes a work placement, 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. Assess whether the timetable is feasible for you, considering your level of fitness and dietary requirements.

One student said:

"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."

Financial considerations

We have a more detailed factsheet about financial support, A Guide to Financial Help, which you can obtain by calling our helpline on 0300 373 1000 or by downloading it from **cysticfibrosis.org.uk/financehelp**.

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)
Website www.skill.org.uk.

One student offers this advice:

"Cystic fibrosis affects people differently and you may not consider your CF 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 3:00 am 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 college or university life to the full."

Student loans

You must contact your Local Education Authority (LEA) at the beginning of the year in which you intend to go to college / university. They will send you the relevant forms to fill in for 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, www.skill.org.uk.

Benefits

Many students are able to continue to get Disability Living Allowance (DLA) or as of 8 April 2013, Personal Independence Payment (PIP). In addition to this you may be able to claim Income Support (IS), Employment and Support Allowance (ESA), Housing Benefit (HB), depending on the hours worked and your financial circumstances. Disability Living Allowance/ Personal Independence Payment is not means-tested and does not affect other benefits. If you do not already receive DLA/PIP it is worth applying; the CF Trust has an information pack on how to apply, which includes a form to complete if you want a letter of support. The letter of support form is available from cysticfibrosis.org.uk/benefits. To obtain the pack please contact our helpline on 0300 373 1000. Please note you need to contact your local benefits office or Benefit Enquiry Line (BEL) on 0800 88 22 00 to obtain the actual DLA/PIP form.

College / 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 aged 18 years and over for the development of their career by way of further or college / 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

T 020 7333 8118
E 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
T 020 7209 5151
E info@d-s-c.demon.co.uk

When you have accepted an offer

Negotiating a flexible work schedule

Once you have been offered a confirmed place it can be useful to discuss your personal 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 affected by cystic fibrosis. 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.

We have a factsheet to give to tutors if required.

Health considerations

Now is the time to make contact with the specialist CF centre near the college / 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 college / university

Support within your institution

Make contact with the support people around the college / university as soon as is practicable. You will be able to pick up a list of student services and support personnel from the Students' Union office and from other locations around campus. There are a number of ways in which a college or university 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.

Health considerations

It will be necessary for you to register with a new GP and obtain a certificate which will entitle you to exemption from prescription charges for one year. Lists are available from your college or university Welfare Services or from the local Family Health Services Authority.

Tips from students include:

"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."

"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."

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

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 period of ill health, or it may allow you to compensate for time lost due 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.

It should be remembered that going to college / university is about much more than attending lectures and tutorials, completing assignments and sitting for examinations. Higher education 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

The 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 students on benefits. The Open University website provides more information about help with money:

T 01908 653231 (general enquiries)
T 01908 653745 (students with disabilities)
W www.open.ac.uk

A guide for tutors

Introduction

This factsheet is intended as a guide for tutors and lecturers who have a student with cystic fibrosis (CF) at their college or university. It contains information about CF and the impact this can have on the lives of those with the condition, particularly with respect to education and living away from home.

If you have any questions not answered in this factsheet, please contact the Cystic Fibrosis Trust for more information (contact details can be found on the back page).

Written by the Cystic Fibrosis Trust.

Last reviewed March 2013.

About cystic fibrosis

Cystic fibrosis is a life-shortening genetic condition that causes the lungs and digestive system to become clogged with sticky mucus. This causes lung infection and damage, digestive difficulties and a range of other symptoms.

There are almost 10,000 people with cystic fibrosis in the UK; over half of these are adults. The faulty gene that causes cystic fibrosis is carried by 1 in 25 of the population, most of whom have no idea. If two carriers of the gene have a child, it will have a 1 in 4 chance of having cystic fibrosis.

Cystic fibrosis is caused by a faulty gene and is a progressive disease. It does not affect everyone to the same degree – some people have it worse or better than others and many people with CF experience periods during which their condition worsens (called ***exacerbation***s), but can then improve again.

There is no cure for cystic fibrosis; half of those currently living with the condition will survive past 41 years of age.

Important considerations

Cystic fibrosis is a fluctuating condition. A person with cystic fibrosis will experience differing levels of incapacity, sometimes within the same day.

People with cystic fibrosis have to undergo an intensive daily regime of treatment. This includes physiotherapy to help clear mucus from the lungs, enzyme supplements with food to aid digestion, tablets or inhaled treatments to help clear the airways and antibiotics to fight infections – the latter often requires a period of hospitalisation.

Cystic fibrosis is often a hidden condition. People with CF may not look unwell. Unless they are very ill they are unlikely to use a wheelchair or to show outward signs of illness. How badly a person is affected depends on a number of factors, and someone with CF may not be able to cope with the same daily demands as others.

Someone with cystic fibrosis may have a persistent or troublesome cough. This cough does not pose an infection risk to others, but can be a source of embarrassment for those affected.

Cross-infection

It is important to bear in mind that people with cystic fibrosis are more susceptible to certain bacterial infections and at risk of infection from others, particularly others with cystic fibrosis. As such it is advised that two people with cystic fibrosis do not come into close contact with one another.

For this reason it is important that any individual with CF is aware if there are other people with CF within an organisation, including a university or college. 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 cystic fibrosis as an individual. 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 cystic fibrosis, 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 in place for such periods, for example 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 with CF 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 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 factsheet serves as a brief guide, it is best to talk to individual students with CF to find out what support they need.

A guide for accommodation officers

Introduction

This factsheet is intended as a guide for accommodation officers who have a student with cystic fibrosis (CF) at their college or university. It contains information about cystic fibrosis and the impact this can have on the lives of those with the condition, particularly with respect to education and living away from home.

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Provision of accommodation for students with cystic fibrosis

The following outlines issues to consider when providing accommodation for students with cystic fibrosis:

- 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.
- 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 (inhalation devices). A room with a mains supply is required for the use of the nebuliser.
- 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.
- Compared with the average person, a person with cystic fibrosis may need to consume more calories and 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.
- The availability of a lift is important if the accommodation is not on a ground floor.
- A non-smoking and unpolluted environment is recommended.
- 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 factsheet serves as a brief guide, it is best to talk to individual students with CF to find out what support they need.

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 **www.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:

Cystic Fibrosis Trust
11 London Road
Bromley
Kent BR1 1BY

T 020 8464 7211
cysticfibrosis.org.uk
enquiries@cysticfibrosis.org.uk

Helpline 0300 373 1000

We would welcome your feedback on this or any other of our publications. Please email publications@cysticfibrosis.org.uk.

More factsheets available at:
cysticfibrosis.org.uk/publications

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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