Cystic
Fibrosis
a lifelong
challenge

School's out...
What's Next?!

Fighting for a Life Unlimited

Content

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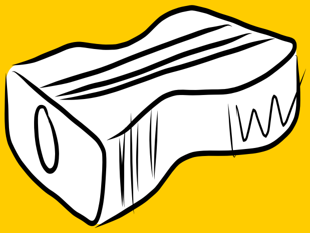
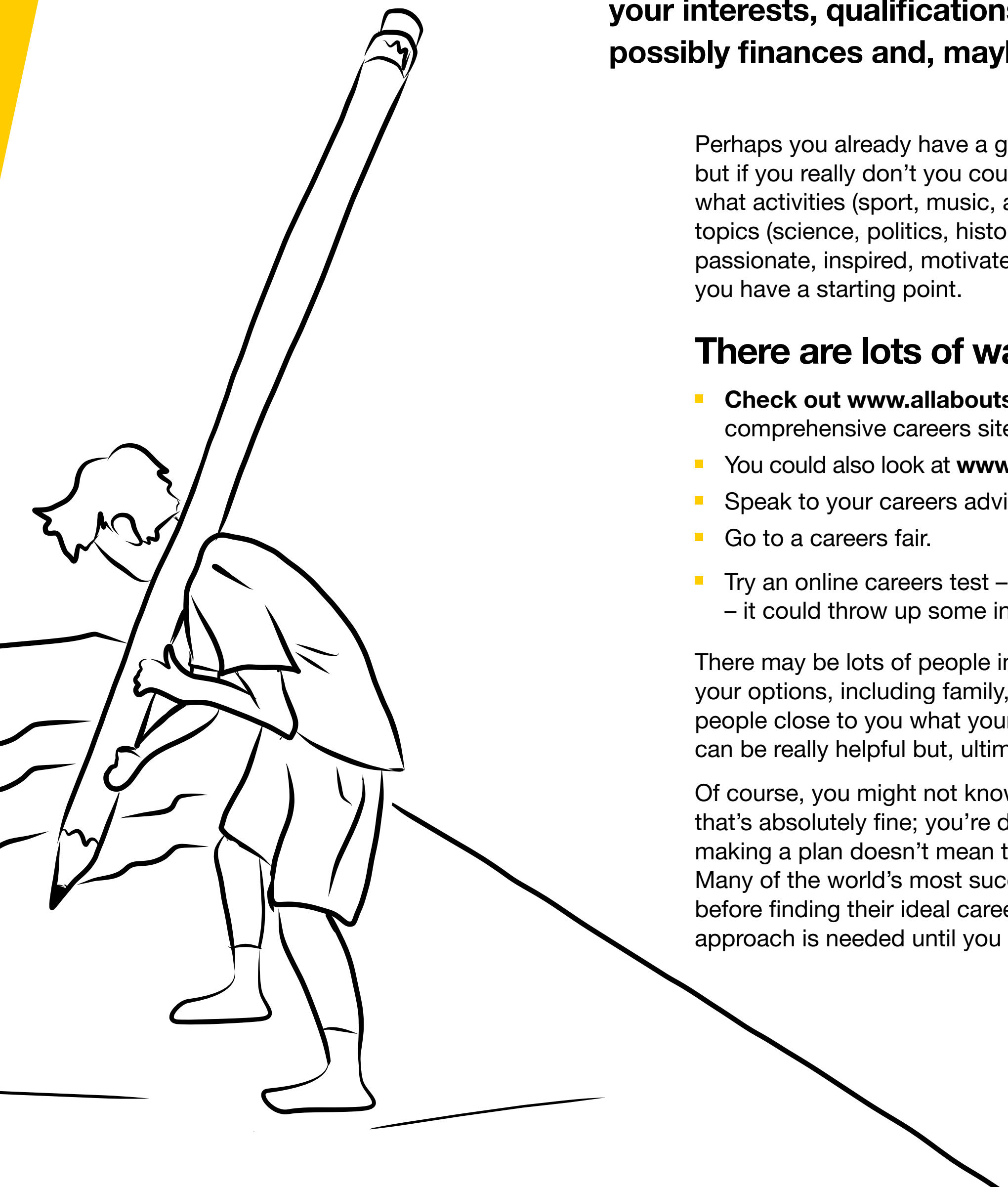


Your future. Your Call...

Choosing what to do after school can be overwhelming. What you do next will depend on a number of things: your interests, qualifications, strengths, weaknesses, possibly finances and, maybe, your condition.



Perhaps you already have a good idea of what you want to do, but if you really don't you could try to start off by thinking about what activities (sport, music, art, drama, writing, design) or topics (science, politics, history, languages) make you feel happy, passionate, inspired, motivated and interested. Write this down - you have a starting point.

There are lots of ways to build on this:

- **Check out www.allaboutschoolleavers.co.uk**. It's a totally comprehensive careers site, designed for young people.
- You could also look at **www.nationalcareersservice.direct.gov.uk**.
- Speak to your careers advisor at school.
- Go to a careers fair.
- Try an online careers test – there are lots of free ones out there – it could throw up some interesting ideas and might be fun.

There may be lots of people in your life that can help you explore your options, including family, friends and teachers. Maybe ask people close to you what your best qualities are. Talking it through can be really helpful but, ultimately, it's your call.

Of course, you might not know what you want to do just yet and that's absolutely fine; you're definitely not alone. Bear in mind that making a plan doesn't mean that you can't change your mind later. Many of the world's most successful people did lots of different jobs before finding their ideal career. You may find that a trial and error approach is needed until you find a path that works for you!

Did you know...?

Leaving school

The rules around leaving school at 16 vary across the United Kingdom. In Northern Ireland, Scotland and Wales you can leave school at the age of 16, but there are some differences around exactly when you can leave, depending on your birthday. In England, the law is different - if you were born after 1 September 1997, then even though you can leave school at 16, you must stay in some form of education or training until you are 18.

For full details look at www.gov.uk/know-when-you-can-leave-school.

What are my options?

There are loads of options, and cystic fibrosis (CF) may or may not play a role in narrowing your focus. You could talk to someone from your CF team about the pros and cons of different study and career options, exploring how you might organise your treatment in different scenarios. People with CF work in a huge range of different jobs, including doctors, artists, actors, teachers and entrepreneurs.

It is possible that some careers won't be open to you because of the potential risk to your health, for example careers in scuba diving or firefighting. But if you experience any unreasonable barriers in the way of your chosen path, it's important that you know that there are laws in place to protect people with CF from discrimination. We hope that you'll never need to worry about this, but just in case...

Did you know...?

There is a law in place designed to ensure that you aren't discriminated against because of your condition and that, where possible, you can study and work in your chosen area. The specific legislation that provides this protection is the Equality Act 2010 and it defines disability as:

> "A physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities."

You are also covered by the Act if you have a progressive condition, even if you are currently able to carry out normal day to day activities.

But I'm not disabled, am I?

The words 'disabled' and 'disability' can spark a lot of discussion amongst the CF community, and some people feel these are not words that should be used when describing cystic fibrosis.

However, there are times when a lifelong condition like CF, which brings a burden of treatment, times of ill-health and the need for regular specialist hospital care, can bring challenges. This is when your legal rights are important in many aspects of life, including at work and in education.

Sometimes your CF might mean that you would appreciate a few adjustments to enable you to fully take part. For example, if you've been struggling with your health but really want to get those A-levels done, explore the possibility of doing them over three years, rather than the usual two years. You might also be able to get extra time for exams or sit in a separate room. Your CF shouldn't lead to you being excluded or having barriers put in your way where reasonable adjustments are possible.

In the vast majority of cases, universities, colleges and other training providers will be very helpful and accommodating if you need any additional support. You might find it useful and reassuring to speak with support staff at the university or college that you're interested in, even before you apply. College and university disability advice services can provide 'study needs assessors' including wellbeing advisers and counselling services, support with applying for Disabled Students Allowance and provision of reasonable adjustments and equipment, including liaising with the accommodations team.

You may also find the UCAS page on supporting students with disabilities useful: **www.ucas.com/support-disabled-students-your-questions-answered**.

If you do feel that you're being discriminated against because of your CF, there are a number of organisations that could help, including:

Citizens Advice provides lots of useful information about discrimination, disability and the Equality Act 2010. They also signpost to other useful websites and organisations that can provide support and advice. Visit **www.citizensadvice.org.uk**.

Equality Advisory Support Service (EASS) offers support and advice to people who have experienced discrimination. They don't provide legal advice, but can assist with resolving issues informally, without the need for a tribunal or other formal legal action. Visit **www.equalityadvisoryservice.com** or call **0808 800 0082** (Monday–Friday, 9am–7pm and Saturdays 10am–2pm).

You can also call our helpline. Our friendly, trained staff can't provide legal advice but can talk through your concerns and signpost you to other organisations if you need more specific advice. Contact the helpline on **0300 373 1000** or email **helpline@cysticfibrosis.org.uk**.

Staying at school

> “Sixth form college is a great place to find out who you are and meet people you have things in common with. It's a good bridge between school and the 'real world'.”

A-levels, Highers, Advanced Highers, BTECs and Welsh Baccalaureate are the main qualifications offered in secondary schools or sixth form colleges across the UK. If you want to go on to university, get onto many college courses or pursue certain careers, you’re likely to need these qualifications. Staying on at school and studying in a little more depth also gives you the chance to explore your interests and gives you space to think about what you might want to do in the future.

Most people find A-levels, or similar qualifications, full on. Having CF can add an extra challenge, especially if time at school is missed through illness, but many young people with CF do A-levels (and similar qualifications) very successfully. Your school or college should be able to support you if you do have difficulties managing your studies during periods of poorer health.

“The school did what they could to support me going to uni. There was another person with CF at my school, so I think they were used to it. My doctor always used to say that ‘you’re not taking three A-levels, you’re taking four, CF counts as an A-level!’”

“I had a difficult time at GCSE, I was very unwell and ended up not sitting the exams. My results were upsetting, because I’d worked so hard. So, after speaking to my team, parents and head-teacher, we decided to take a different approach for my A-levels and I did them over three years instead of two. I didn’t even know that was an option! When my friends started to leave for uni, I felt a bit left behind but I just focused and had more time to look after myself and get prepared for university.”

“I didn’t really think about doing anything other than A-levels and that wasn’t really anything to do with CF. All my friends were doing A-levels and the school were very insistent that you needed them if you wanted to progress in life. I studied Drama, English combined, Media and Psychology. I did have to get some extensions for Media coursework because I was ill but my teacher was really supportive.”

If you want to do A-levels or similar qualifications and you're worried about fitting the coursework and revision in with your treatments, speak to your CF team and your school – compromises with your treatment schedule or flexibility with your study plans may be possible. For most people, with or without CF, exams are a stressful business. So it's a good idea to plan it out as much as possible beforehand. Here are some things to consider:

- What will you do if you have to miss school? It might be useful to have a chat with someone from your school about planning for absence. You could always ask your friends to help out by sharing notes and other info too.
- Are there courses where there is more emphasis on coursework and your grade won't largely rely on one exam?
- You might find it helpful to draw up a study/treatment schedule. There are loads of apps out there to help you manage your study schedule or for general time management.
- Also, remember to look after yourself, not just from a CF point of view, but also in terms of your general wellbeing! Find some time to chill, be with friends and relax. You might find some exercise, meditation, mindfulness exercises, yoga or other relaxing activities help you to unwind.

"I was quite anxious about transitioning into adult care so I agreed with my team that we'd put off transition until after my A-levels. I had a pre-conception that the adult centre would be less helpful or supportive but that wasn't the case at all, I felt really cared for in adult services."

"I started out doing four A-levels at sixth form, but after two months in I realised that the work load was too intense and it was having a profound effect on my health. I spoke to the teachers and we agreed to drop one which definitely made things easier! If I was off ill, one of my classmates let me look over her notes when I was back and the teacher sometimes put the PowerPoint presentation online so I could read it."

> "I stayed at school post-16 to do three A-levels. I was at the stage where I didn't want to do my physio but I started doing it after realising that I had to take responsibility for my health, that nobody else would do it for me."

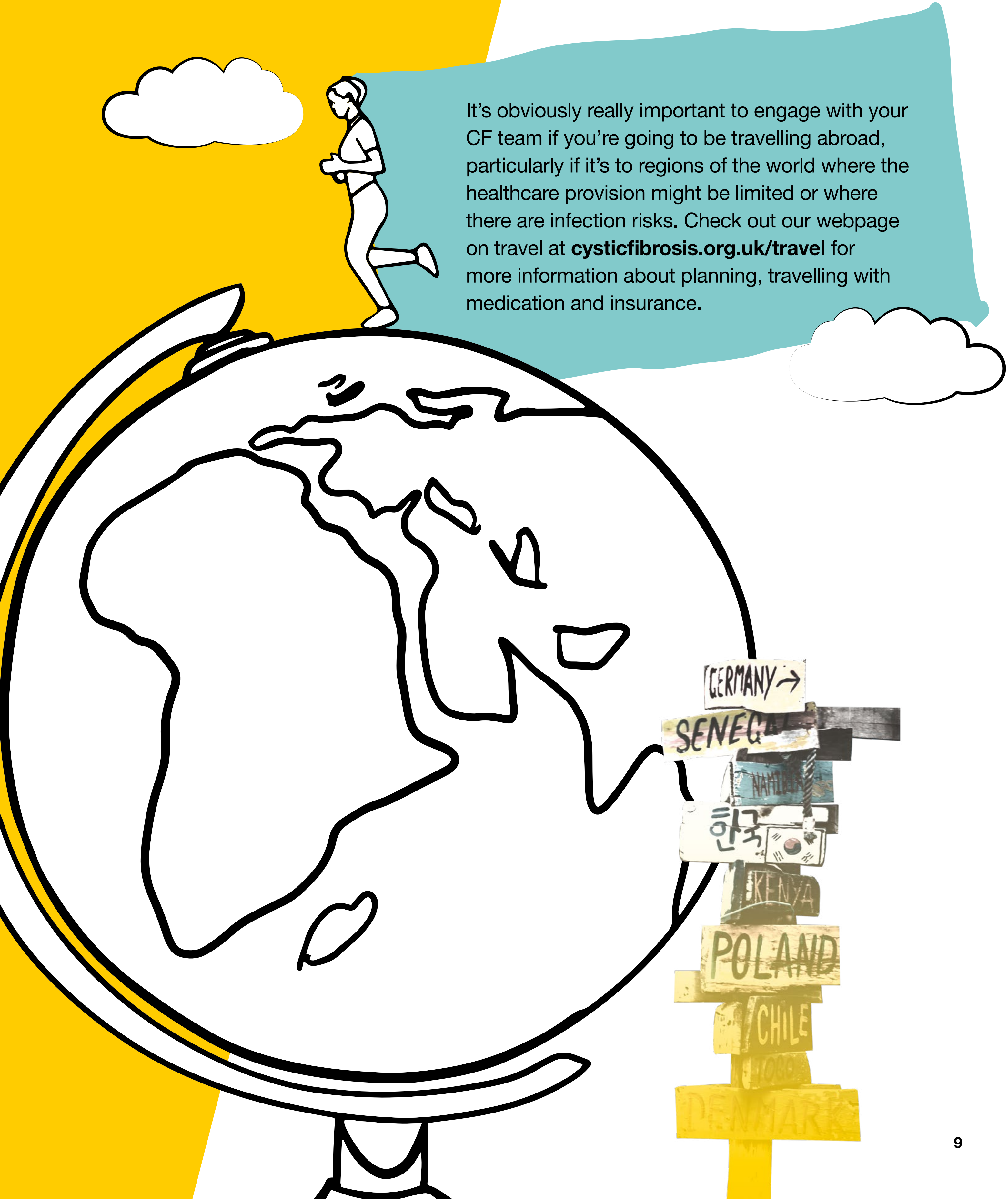
Gap year

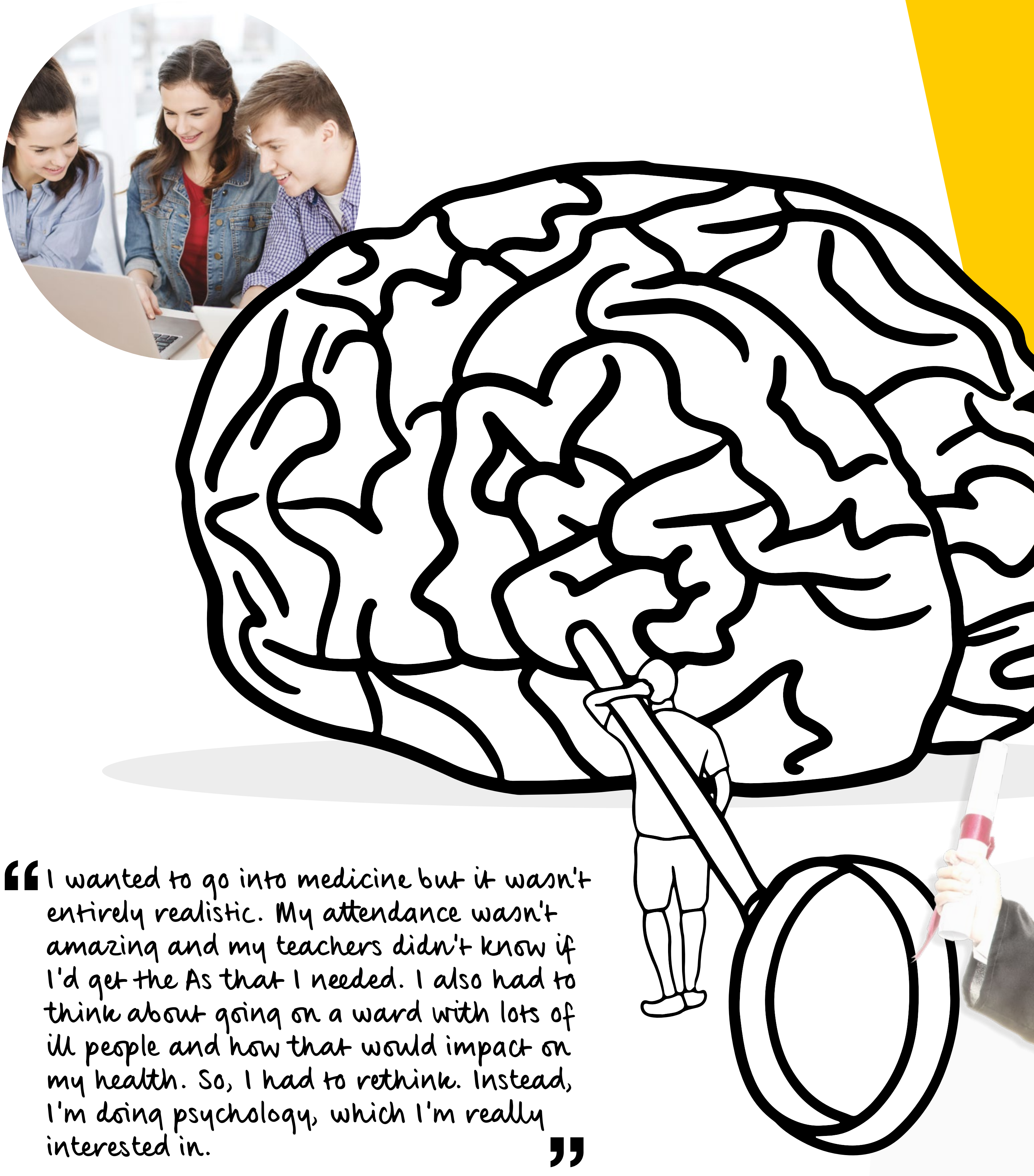
The possibilities for a gap year are endless – interrailing in Europe, helping build schools in developing countries or chilling in Australia are all well-trodden paths. If you are thinking about taking a gap year you might find the following websites useful:

www.prospects.ac.uk/jobs-and-work-experience/gap-year

www.ucas.com/ucas/undergraduate/getting-started/alternatives-higher-education

It’s obviously really important to engage with your CF team if you’re going to be travelling abroad, particularly if it’s to regions of the world where the healthcare provision might be limited or where there are infection risks. Check out our webpage on travel at **cysticfibrosis.org.uk/travel** for more information about planning, travelling with medication and insurance.





“I wanted to go into medicine but it wasn't entirely realistic. My attendance wasn't amazing and my teachers didn't know if I'd get the As that I needed. I also had to think about going on a ward with lots of ill people and how that would impact on my health. So, I had to rethink. Instead, I'm doing psychology, which I'm really interested in.”

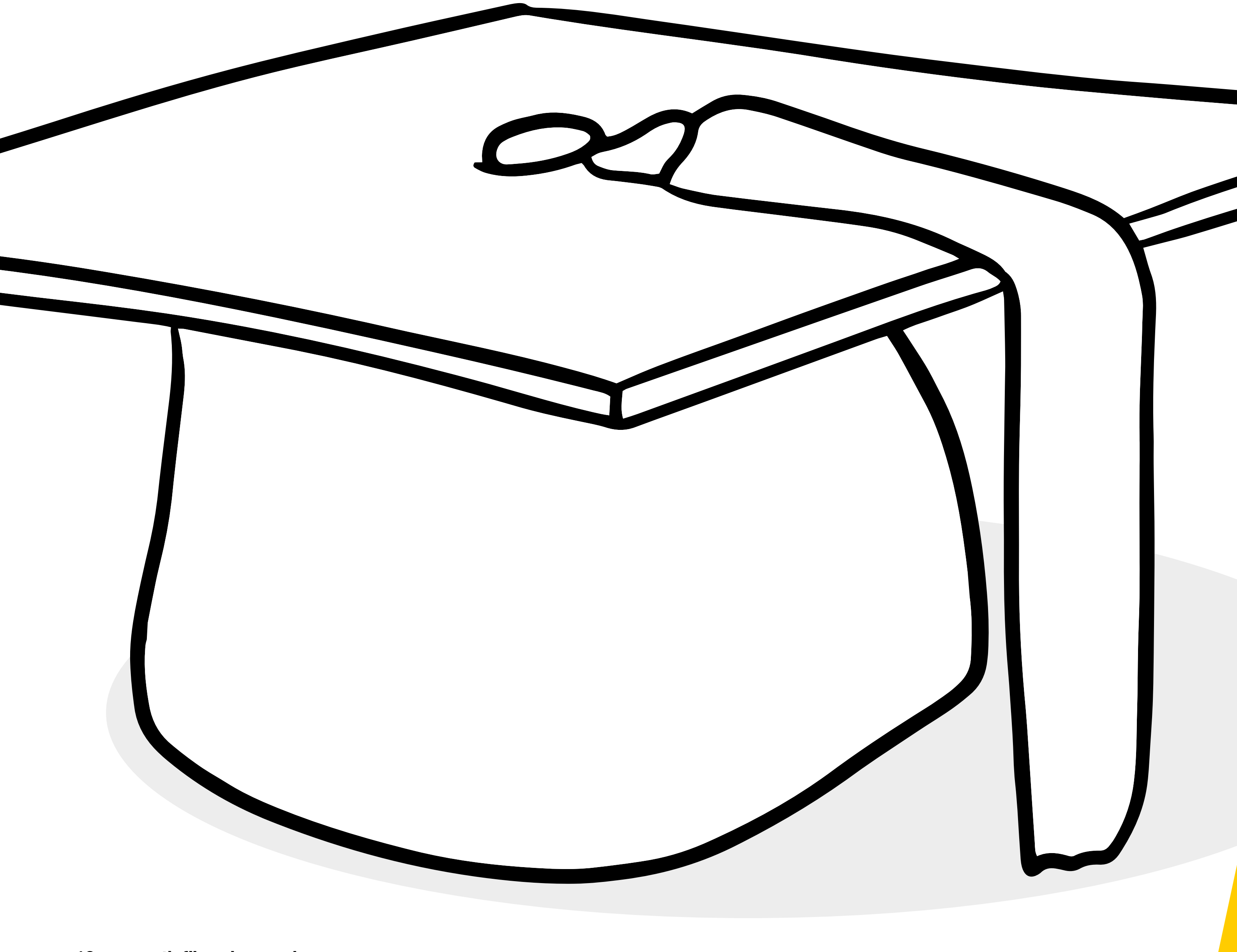
Uni or College

If you want to go onto higher education (university or college) - to study for a degree or diploma – you will usually need to have certain qualifications, for example A-levels, Highers or the International Baccalaureate (IB). The UCAS website provides lots of information about course options, required grades and funding at www.ucas.com.

You might want to think about a few things when choosing your preferred college or university.

- **Location.** How will you get there – is it a long or difficult journey? If you need to move, is there suitable student accommodation and where is the closest CF centre?
- **Course timetable.** Are there lots of early starts or late finishes? Is there flexibility? Is there a lot of graded coursework or is the assessment mainly exam-based?
- **Are there other course requirements,** i.e. a work placement, and does it involve travel or awkward hours?
- **Are there any infection risks that you need to consider?**

> “I did a four-year IT course, with a year's placement as IT support in a primary school. To save money, I commuted every day, which was daft for me. It was far too tiring, I'd have to get up early to get my meds done and when I got home in the evening I was too tired to exercise or do my physio. So I moved to be closer to my course.”



> “I stayed at home for college and uni as it was much easier for me to have that family support. We're a close-knit family. Moving out would have required a lot of responsibility and a level of independence that I don't think I was ready for! I think it was 50/50 between it being a desire to stay with my family and also to manage my health.”

You might like to contact the university or college before you even apply if you have any concerns about how your CF may impact on your studies or if you have any specific needs. Institutions offer a wide range of services to support you with any problems you may face, including those of an academic or personal nature. Services will vary depending on campus size and funding, but may include access to a disability liaison officer with whom you can discuss your requirements.

You're not obliged to tell anyone about your CF, but it may help if you need support later down the line, for example if you require an extension to an assignment due to poorer health or if you need some adjustments to enable you to fully participate in the course. It also enables the university or college to liaise with programme leaders and amend timetables if necessary, to prevent cross-infection if there is someone else with CF on your course or at your place of study.

Being at uni or college is going to be different for everyone so there's no point trying to pre-empt everything that may or may not happen with regards to your condition. Perhaps just try to find out from the start who you should go to if your health deteriorates and you need extra support, whether that's with extensions to coursework, flexibility with your timetable or changes to your accommodation. Even if you're very well, know who to go to just in case.

You might find it useful to share the Cystic Fibrosis Trust's factsheet specifically for universities, colleges and other training providers to help them understand the possible implications of CF and how they might be able to support students with cystic fibrosis. You can download it here **www.cysticfibrosis.org.uk/whatnext** or order a free copy from our helpline by emailing **helpline@cysticfibrosis.org.uk** or calling **0300 373 1000**.

You might also find these websites useful:

www.cff.org/CF-Community-Blog/Posts/2015/10-Things-I-Wish-I-Knew-Before-Coming-to-College/

www.nus.org.uk

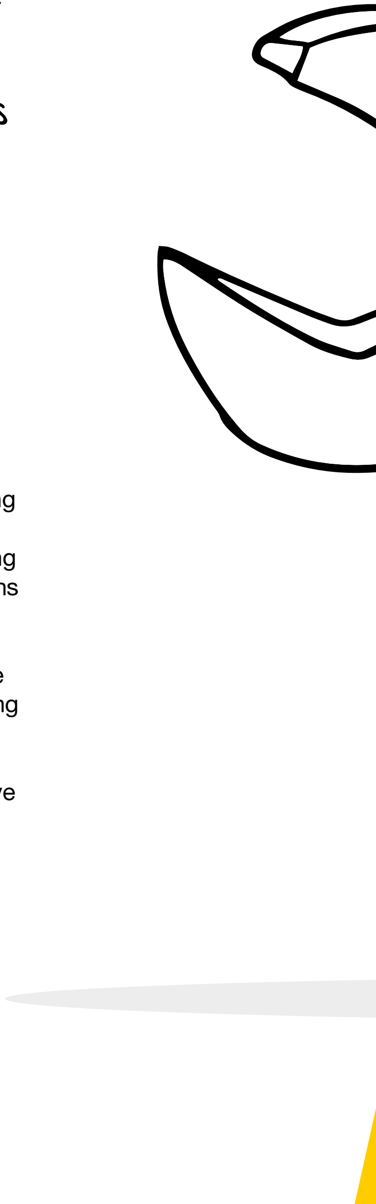
But I don't want to go to uni!

> “I knew that I wanted to be an actor but thought it was best to have A-levels as a back-up in case I wanted to go to uni. Once I'd finished my A-levels I decided not to go to uni and pursue acting instead and CF was definitely an influence in my decision making.”

“After my A-levels I was adamant that I didn’t want to go back to the stress of studying again, especially as I didn’t know what I wanted to do! So I applied for jobs and through each one I’ve not only gained experience but I’ve also come to realise what my strengths are and what I want to do as a career. Cystic fibrosis has played a prominent role in each job I’ve had, and the most important thing I’ve learned from work and CF is to always put your health first, no matter what.”

University isn’t for everyone and, for many careers, isn’t necessary at all. It’s important to really think through what you want to do and from there work out what study/training is required. Depending on your health, your CF may be a factor in deciding what options to pursue.

Try not to be influenced by what other people are doing. Sometimes it seems that university or college is a natural follow-on from school, but that’s not always the case. The next step following school is whatever you need it to be to take you where you want to go. Thinking it through, planning it out, asking questions – that’ll help you find your successful route, rather than feeling any external pressure to pursue university or college education. There are lots of study/training options that can lead to successful careers – Zoella, David Karp (founder of Tumblr) and Sir Richard Branson have all done pretty well without university or college qualifications!



Take a look at these options, which schools, colleges and other training providers can offer:

- **Apprenticeships** are an opportunity to do on-the-job training. There are loads of different types of apprenticeships available, from joinery to accountancy, hairdressing to plumbing.
- **Vocational qualifications** like NVQs, BTECs and TechBacs can be a great way of combining hands-on work with learning technical skills. These are specialist courses that relate to particular jobs or subject areas such as food technology, engineering, beauty therapy and hospitality.
- **Traineeships** help with preparation for an apprenticeship or other job, providing work experience and support in literacy and numeracy, which are essential for most careers.
- **Working or volunteering while studying part-time** allows you to combine training or studying for a qualification and work (paid or voluntary). Many training courses can be part-time, including A-levels and work-related qualifications.

You might not want to do any further education at all and go straight into work after your A-levels/Highers or after leaving school at the age of 16, in which case you might find our factsheet on employment helpful. You can download it from **www.cysticfibrosis.org.uk/publications**. (Remember! There are some restrictions in England for young people under the age of 18 who wish to leave school and go straight into work).

For more information on this, check out www.gov.uk/know-when-you-can-leave-school.

continued...

> “I left school in January of my AS year. I'd been in hospital and had been struggling to keep up – the worry of keeping up was making me ill. My brother had been to uni and I thought it was what was expected of me and couldn't think of not doing it myself.”

“I spoke to my drama teacher who pointed out that I had an agent and a CV and that maybe I should consider just getting on with my acting career as I already had a lot of experience. Not everyone is cut out for uni and if you know what you want to do then you can go and do an apprenticeship or, like me, get on with working.”

“Of course it isn’t easy and I have to figure out how I can fit my meds around each job and get up ridiculously early some days if I have an early call, but for me because it isn’t every day I know I can get some rest when I’m not working. It is possible with portable nebulisers and freezer bags to do your meds pretty much anywhere if you put your mind to it. My health improved the minute I took the stress of school away, so for me it was the right decision.

There are all sorts of jobs out there, you just have to find one that’s right for you.”

As with going to college or uni, you’ll need to give some thought to practical considerations including:

- **Location and travel** – how far will you have to travel to get to the college or workplace? Is there public transport? Will you need to drive?
- **Flexibility** – are there options to work or study flexibly? How will you catch up on any missed coursework or placements? Have you spoken to your employer about your condition? Is there an option to work from home if necessary?
- **Managing your treatment** – is there space in your day to ensure you keep up with your treatments? Are there risks associated with the course or job you’re doing?

You can download a Cystic Fibrosis Trust information sheet for colleges and employers to help them understand a little about CF and how it may impact on their employee or student, from **www.cysticfibrosis.org.uk/whatnext**.

The following websites give a comprehensive overview of study, training and volunteering options that you might find useful:

www.notgoingtouni.co.uk

www.nationalcareersservice.direct.gov.uk

www.careerpilot.org.uk

www.successatschool.org

www.ucas.com/ucas/16-18-choices/getting-started/what-are-my-options

www.do-it.org

New friends, new experiences

Whatever you decide, moving on from school is an exciting step – there are likely to be a lot of changes!

Alongside the business of meeting new friends, going to new places and learning new things, you've still got to keep your CF treatment on track. It's up to you, maybe with some help from your CF team or family, to work out how best to do this. Have a think about:

- **whether you want to tell your new friends about your CF;**
- **how your treatments fit with your timetable;**
- **if there are sports/activities on offer that you'd enjoy and could also be helpful for your CF; and**
- **who your support network are.**

> “Sometimes, if I'm meeting a friend of a friend or something, I'll just tell them that I have asthma because it's easy but once I get to know someone better, I'll tell them, 'yeah, I've actually got CF'. My friends knew and I would answer any questions people had if they asked but I didn't make a big deal out of it and even friends didn't always know why I was going into hospital.”

> “I wasn't particularly open about my CF at sixth form, only my close friends knew and even they didn't know everything. I had a couple of teachers that I felt comfortable talking to. It's up to you how you want to deal with it, if you feel a bit shy about it you could talk to one teacher and ask them to tell others, or you could ask your parents to talk to your teachers.”

> “All of the people in my flat at uni know about my CF. They sit with me while I do my physio sometimes.
> You don't have to party at uni if you don't want to, the people in our flat don't go out much. We prefer to stay in, have wine nights, that sort of thing. Sometimes I come back to the flat between lectures to have a nap or rest, it's okay to do that if you need to.”

What about the social side of student life?

You might already be all over the party scene but for some young people, moving on from secondary school is also the start of a new found social freedom! Alcohol, smoking and drugs are nothing new, they're readily accessible everywhere and have been for years.

You already know that smoking is obviously an absolute nightmare for your CF – you know it, but we still have to say it. There's loads of information about drugs and alcohol out there (check out **www.talktofrank.com**) and this is as relevant to you as it is to young people without cystic fibrosis.

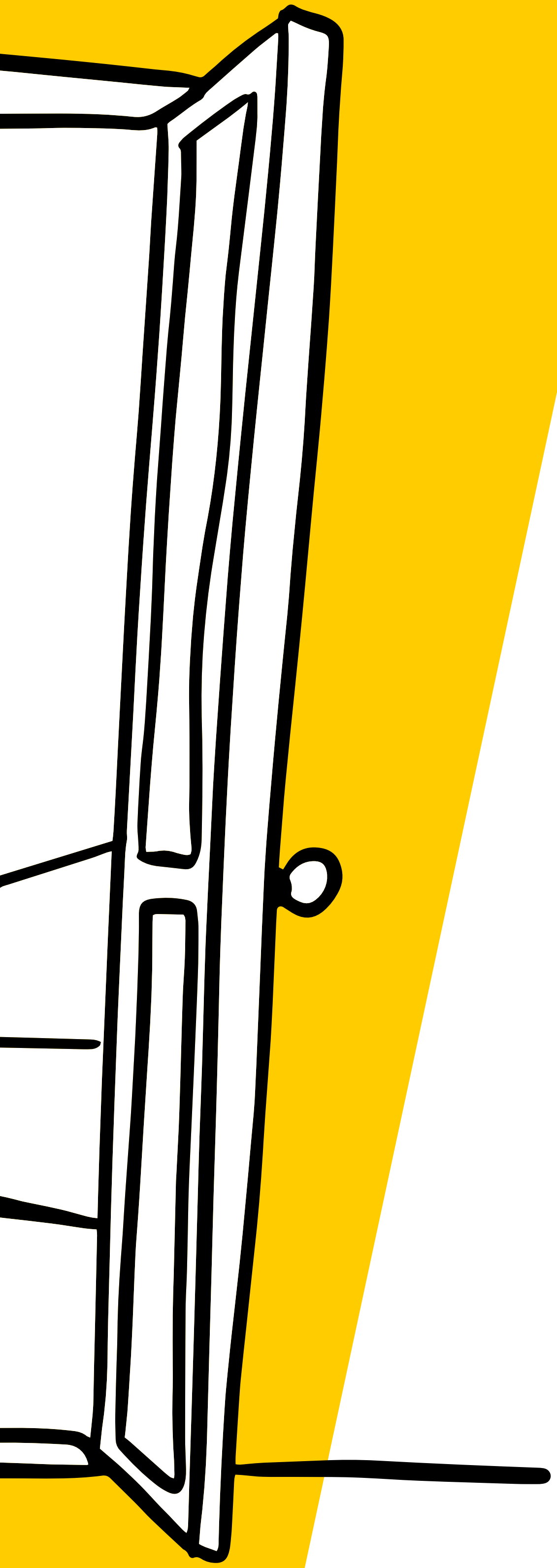
However, because of your CF you do need to be aware that drugs and alcohol can have specific effects on you, both directly through altered absorption of your CF meds and indirectly if use interferes with your treatment schedule.

Talk to someone in your CF team about it - they were young once too. Your team won't judge you, they're looking out for your health.

Leaving home

If your studies or job take you away from home, there will be lots to think about! If you have a social worker in your CF team, they may be able to offer information and advice about finances and housing, including any benefits that you might be able to access.

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



Accommodation

Your first concern might be the availability of suitable accommodation. If you're looking at student accommodation, you might like to think through some of these questions and maybe discuss it with your CF social worker or other team members, parents or friends.

- **Would a catered or self-catered hall work best?** One benefit of catered is that you don't have to worry about buying or cooking food – however the food in halls might not always be to your taste or meet your nutritional requirements.
- **If you're looking at a catered hall, is there access to a fridge for your meds?**
- **Do you need en suite facilities? I**t's probably a good idea, so that you have day-to-day access to private, clean facilities, but it could also be useful if you require IVs.
- **Do the rooms in halls have enough plug points for you to use your equipment?** Do the windows open for when you're taking nebulised antibiotics?
- **Do you need, or think you might need, a room on the ground floor?** Or access to a parking space?

In addition to these specifics, you might want to take into account how far away the nearest CF centre is. Would this be a reasonable journey for clinic visits or admissions? You may need to think about transferring your care to a more local centre, which is something you could chat to your team about. It might be possible to visit the nearest centre and find out more about their service before making a final decision about transferring.

If you're looking at private rented accommodation, much of the same applies but additional considerations could include:

- if the property is well insulated and heated;
- if it is well ventilated, and if there is evidence of damp/mould; and
- if the property is well situated for public transport or access to the university, college or training site.

It's likely that you'll need a parent or guardian to act as guarantor for your tenancy and a deposit will always be required. You can find out more about the rights and responsibilities of private renters here: **www.gov.uk/private-renting**.

Diet

This may be the first time that you will have to plan your own meals and do your own food shopping. You might be perfectly capable of pulling together a three-course meal, or may be at the other end of the spectrum! Chat to your dietitian, they'll be able to provide tailored advice and point you in the right direction for cookbooks and recipe sites.

Check out the Cystic Fibrosis Trust's leaflet on diet, especially for young people leaving home for the first time. It offers tips on how to maintain a high-calorie diet, suggestions for snacks and meals, budgeting advice and ideas for key items to keep in the cupboard.

You can download the leaflet at www.cysticfibrosis.org.uk/publications or order a free copy from our helpline by calling **0300 373 1000** or emailing **helpline@cysticfibrosis.org.uk**.

You might also find this website useful: **www.cfcooking.org**.

Physical activity

It can be hard to fit everything into a day, and of course even more so when you have lengthy CF treatments to contend with. As you already know, physical activity can really help with your CF, so continuing with sports you did at school or finding new sports or activities to do is great for your health and also a really good way to meet new people.

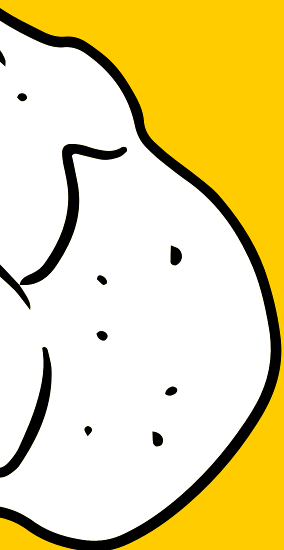
If you're going to university or college, you are likely to have more gaps in your timetable than you did at school, so you might be able to squeeze in a quick gym session or swim. It can be harder when you're working, depending on your hours, but it's worth investigating what your options are at lunchtimes or seeing if colleagues have any sporting groups - squash ladders or yoga groups for example. Some employers also offer their staff benefits, including reduced rates at gyms or schemes to help you buy a bike.

Pactster is an online exercise website that hosts a range of workout videos made by fitness trainers who have CF themselves, as well as trainers who have a background in cystic fibrosis. Pactster also offers the facility to join in group classes online, and has chat facilities, so you can train with other people with CF at the same time without the risk of cross-infection. Membership is free for people with CF, and if you want to train with a friend or family member they can join for free too.

www.pactster.com/cystic-fibrosis

Funding for further/higher education

There are regional variations in terms of cost and access to funding for further and higher education.



If you have a social worker in your CF team, they may be able to provide helpful advice on accessing funding or benefits that you could be entitled to while in education or training. Financial support may be available from the Joseph Levy Education Fund, which helps adults with CF over the age of 18 with the costs of higher education or other professional qualifications, including vocational training. You can find out more at www.jlef.org.uk.

You might also find the following websites helpful.

- **www.ucas.com/ucas/undergraduate/finance and-support/undergraduate-tuition-fees-and student-loans** gives a good overview of tuition fees and loans.
- **www.gov.uk/browse/education/student finance** provides a comprehensive overview of possible financial support for students.
- **www.gov.uk/student-finance-calculator** gives a useful rough guide of how much in tuition and maintenance loans you might be able to get.
- In England may be able to apply for the bursary fund. Young people aged 19 and over may also be eligible in certain circumstances, including if they have an Education Health and Care Plan (EHCP). The bursary is to help with costs around transport and books.
- **www.gov.uk/disabled-students-allowances-dsas** has information specifically about disabled students' allowance (DSA).
- **www.gov.uk/student-finance/extra-help** gives information about extra help for low income families/DSA/dependants.

Need more information or support?

We can't cover everything in one booklet, so if we've missed something – give us a call **0300 373 1000** or drop us an email **helpline@cysticfibrosis.org.uk**

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Thank you very much to all the young people in the Youth Advisory Group who've supported this project. By sharing your experiences and views, you've helped guide the development of this booklet - thank you very much! We're also very grateful to the CF professionals who assisted with the development and review of this booklet.