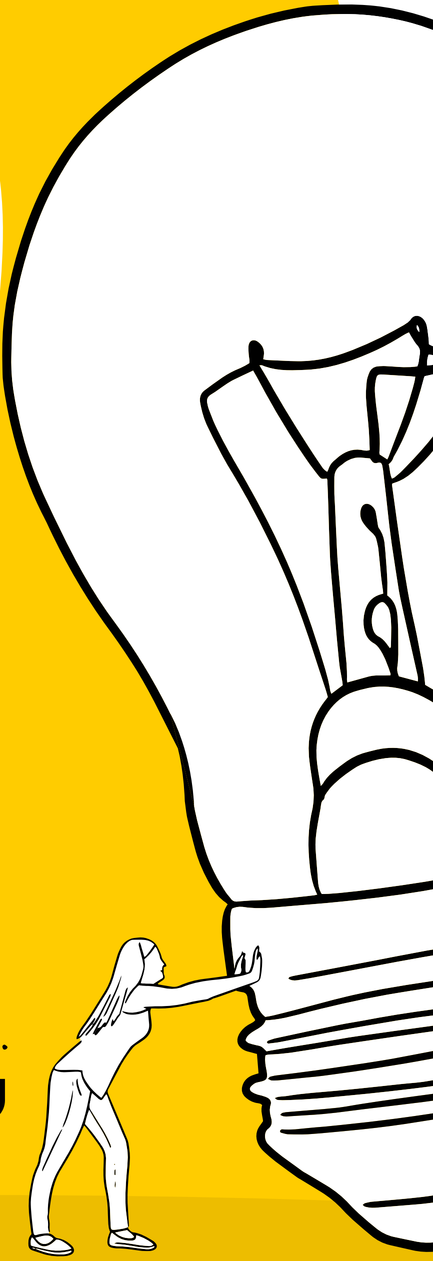
Cystic Fibrosis
a lifelong challenge

Support your child's next step

Fighting for a Life Unlimited

Content

> “We have to let them try – be positive, not critical but help get out the safety net if needed.”
>
> \- Parent



Support your child's next step

Information for parents

Of all the life stages and transitions children go through as they age, growing into adulthood can be the most exciting, eventful and, for parents, stressful time of all!

As your child approaches adulthood and begins to explore their options beyond secondary school, you may have concerns about how their further education/training will be affected by their cystic fibrosis (CF) and perhaps even more worried about how their CF may be impacted by their chosen path.

Sometimes young people with CF and their families understandably focus on the here and now, not knowing what the future will bring. But for many young people with CF, their future is brighter than ever before, so thinking about their life plans, including a career, is really important. While your child must reach their own decisions and take ownership of their life plan, parents can play a vital role in supporting them to plan for their future.

"It's really important for young people to engage and plan for their future. When there's no clear plan, and no real reason to get up and out in the day, sleep patterns and routines go out the window, which can have a knock-on effect on treatment and the potential to impact on mood and motivation." - CF psychologist

Of course, CF can present challenges, and initial plans may have to be altered or sometimes even completely rethought, but that shouldn't stop young people engaging with their future and ambitions; you both may need to be creative or flexible in achieving the end goal.

This booklet is designed to help parents support their child's plan for their future, providing information about education and training options and detail on how CF may factor in their decisions and experiences.

"A short-term plan is better than no plan. Try to plan for the first three to six months after school finishes, emphasising the positive and exciting possibilities now that the final days of school are over. It's time for them to spread their wings and create a life that fulfils and motivates them; having a life to stay well for." (CF psychologist)

What are their options?

It's important for your son or daughter to really think about and research what training or qualifications are needed to enable them to pursue their chosen career or interest. Many young people do go on to college or university after school, which of course is a fantastic opportunity, but it isn't always necessary, or indeed desirable, for all careers. In considering the following options, it's helpful to keep in mind what their ambition or end goal is.

Going into employment

Some young people will want to leave school at 16 to go straight into employment, although in England young people will still have to undertake some form of education or training until they are 18 years old. For more information, please see **www.gov.uk/know-when-you-can-leave-school**. Our factsheet on employment contains information about applying for jobs, talking about CF with an employer and discrimination. This may be useful if your child is going straight into a job after school. You can download the factsheet at **www.cysticfibrosis.org.uk/publications** or request a printed copy from our helpline by calling **0300 373 1000** or emailing **helpline@cysticfibrosis.org.uk**.

Other young people may opt for a combination of part-time study and work, perhaps as part of an apprenticeship. There are many options for young people to combine studies with paid or unpaid work experience. The following websites have more information about apprenticeships and part-time study options:

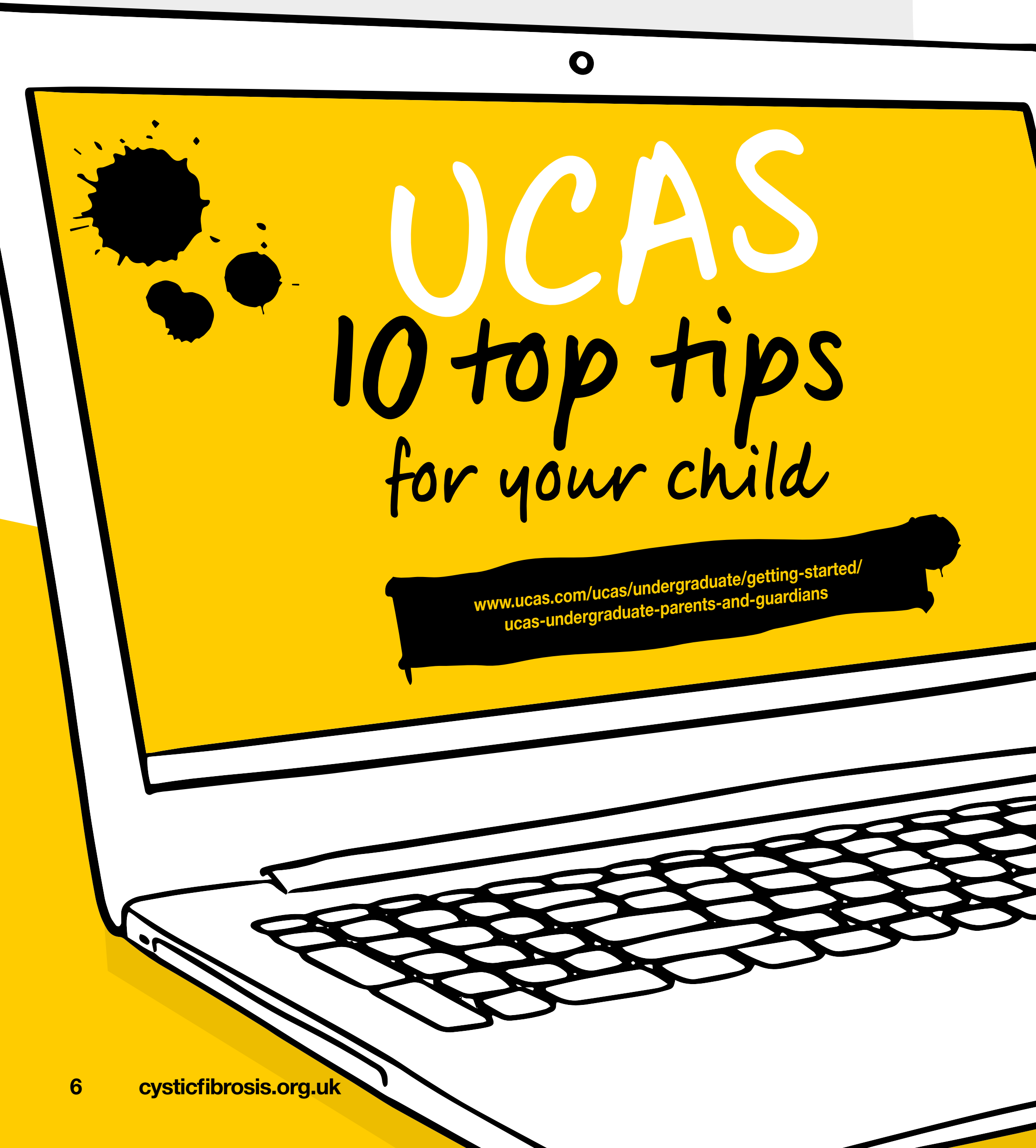
www.notgoingtouni.co.uk/apprenticeships-223

www.ucas.com/ucas/undergraduate/getting-started/distance-learning-and-part-time-study


Employment
College
Training
Sixth form

Staying on at school or sixth form college

Many young people decide to stay on at school or go to sixth form college to do A-levels, Highers, Advanced Highers or similar qualifications. These qualifications are usually required to progress to higher education. Your child's school or college will be able to give you details on the qualifications and courses on offer.



Further education and training

The education and training options after school are almost endless and your son or daughter may already have ideas about what they'd like to do. If not, you might find it helpful to direct them to **www.allaboutschoolleavers.co.uk**, which is a comprehensive careers site designed for young people. The National Careers Service is also useful – **www.nationalcareersservice.direct.gov.uk** – or they can speak to a careers advisor at school.

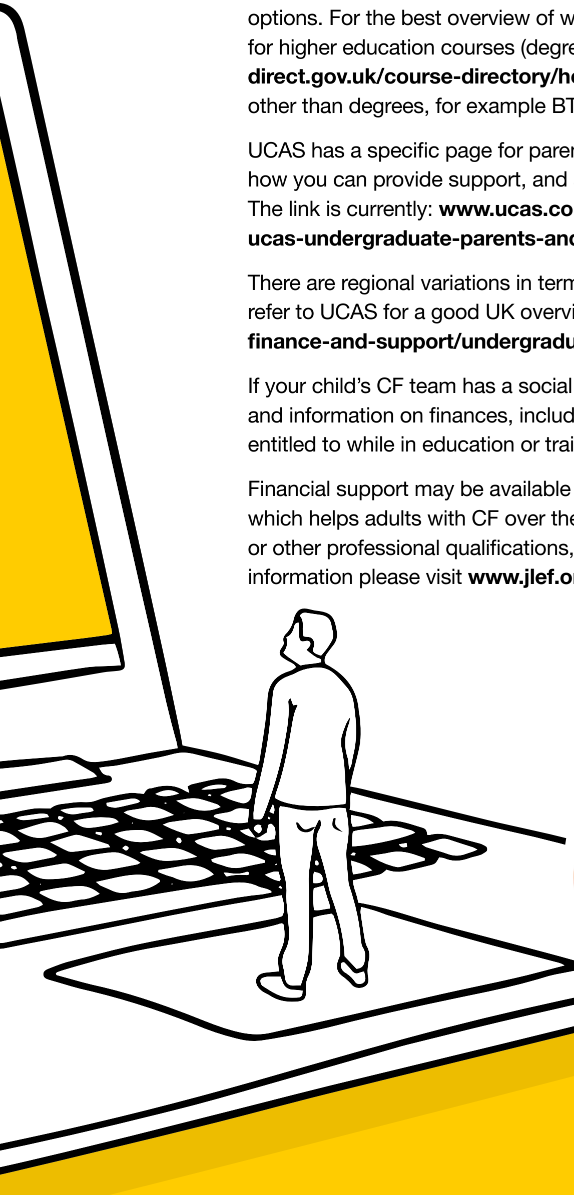
Colleges and universities offer a huge range of courses, qualifications and study options. For the best overview of what's on offer, have a look at **www.ucas.com** for higher education courses (degree courses) or visit **www.nationalcareersservice.direct.gov.uk/course-directory/home** for further education courses (qualifications other than degrees, for example BTECs and HNCs).

UCAS has a specific page for parents that includes 10 top tips for your child, how you can provide support, and an option to sign up for a parent newsletter. The link is currently: **www.ucas.com/ucas/undergraduate/getting-started/ucas-undergraduate-parents-and-guardians**.

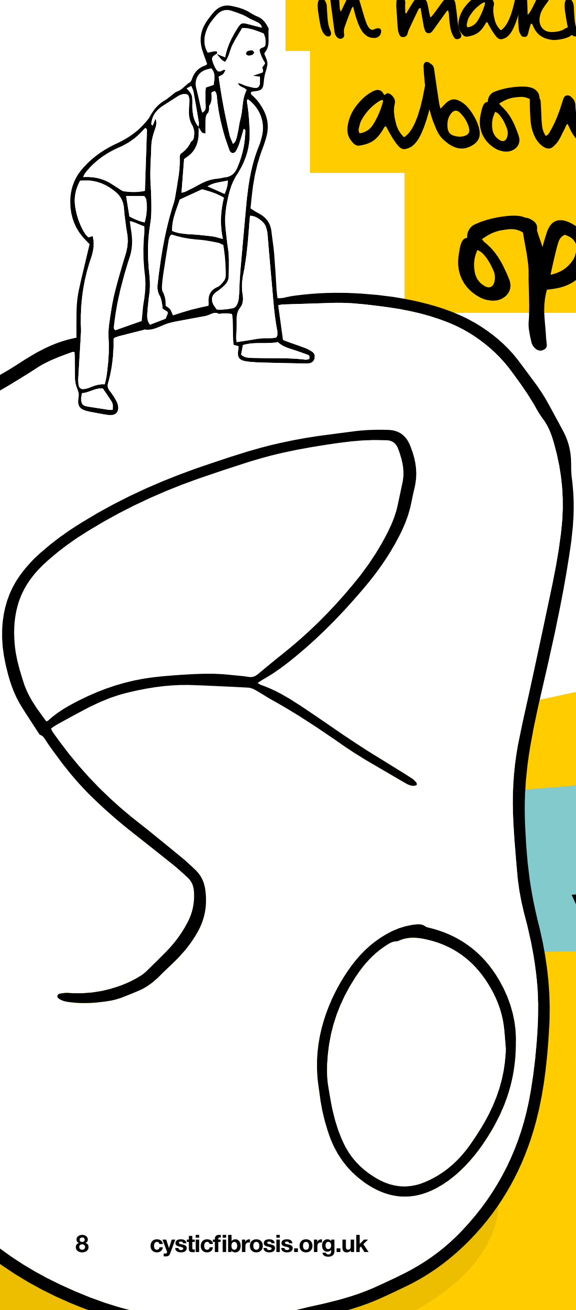
There are regional variations in terms of cost and access to funding, so please refer to UCAS for a good UK overview: **www.ucas.com/ucas/undergraduate/finance-and-support/undergraduate-tuition-fees-and-student-loans**.

If your child's CF team has a social worker, they may be able to provide advice and information on finances, including any benefits that your child 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. For further information please visit **www.jlef.org.uk**.



Supporting your child in making a decision about their options



If you are involved in your child's decision-making about further education or training, the following sections might be useful to you.

Useful website!

www.careersadviceforparents.org

Are there any CF-related risks or restrictions associated with their area of interest?

For the most part, people with CF can pursue any career. However, there maybe a few **possible** exceptions including the fire service and careers in diving. There may be other careers that could be difficult for your son or daughter, depending on their health.

As well as current health status, it's worth considering the possible infection risks associated with some training or courses – for example, veterinary studies. That's not to say that people with CF shouldn't undertake such training, only to highlight areas of possible infection risk so that reasonable adjustments can be made.

For some young people with CF, long hours and stress can be tiring and difficult to sustain, so the nature of the course or career should be taken into account and, again, reasonable adjustments sought where practical.

> "I've never said, 'you can't do that'. I've tried to encourage my daughter to consider what would make her life easier and be enjoyable. I'm really pleased that she has chosen a career in the fitness industry, she's good at it, enjoys it and it's good for her cystic fibrosis. I think it's important that she doesn't put all her eggs in one basket though, so I've really encouraged her to do qualifications or pick up experience wherever possible so that she has other career options."
>
> - Parent

Staying on at school?

If your child is unsure whether to remain at school or move onto other things, you might be able to support them in making their decision.

Working with them to identify their next steps and talking it through, rather than just expressing your view, can be a useful approach. You might find that there are underlying concerns that are driving them in a particular direction, for example worries about the stresses of A-level/Higher revision and exams might be discouraging them from staying on at school. Working through possible solutions to ease the stress and pressure could help broaden their options.

> “My daughter chose BTECs over A-levels. BTECs are based on coursework whereas with A-levels we both were concerned that a lot of the grade might come down to one exam, and what if she wasn't feeling great that day? She got three distinctions in her BTECs as well as obtaining additional qualifications.”
>
> - Parent

Your son or daughter’s CF team or school might also be able to help by identifying how treatments could fit in around study regimes and vice versa. The school may also be able to advise on how to reduce the pressure, perhaps through subject selection and flexibility. Some subjects may be graded on a higher proportion of coursework than others, thus reducing the pressure to be on top form for that one exam. There may also be the option to extend the period of study, for example doing A-levels over three years rather than two. It’s worth asking how the school can help accommodate your child’s ambitions.

It may be that leaving school is the best option for your child, depending on their chosen career path.

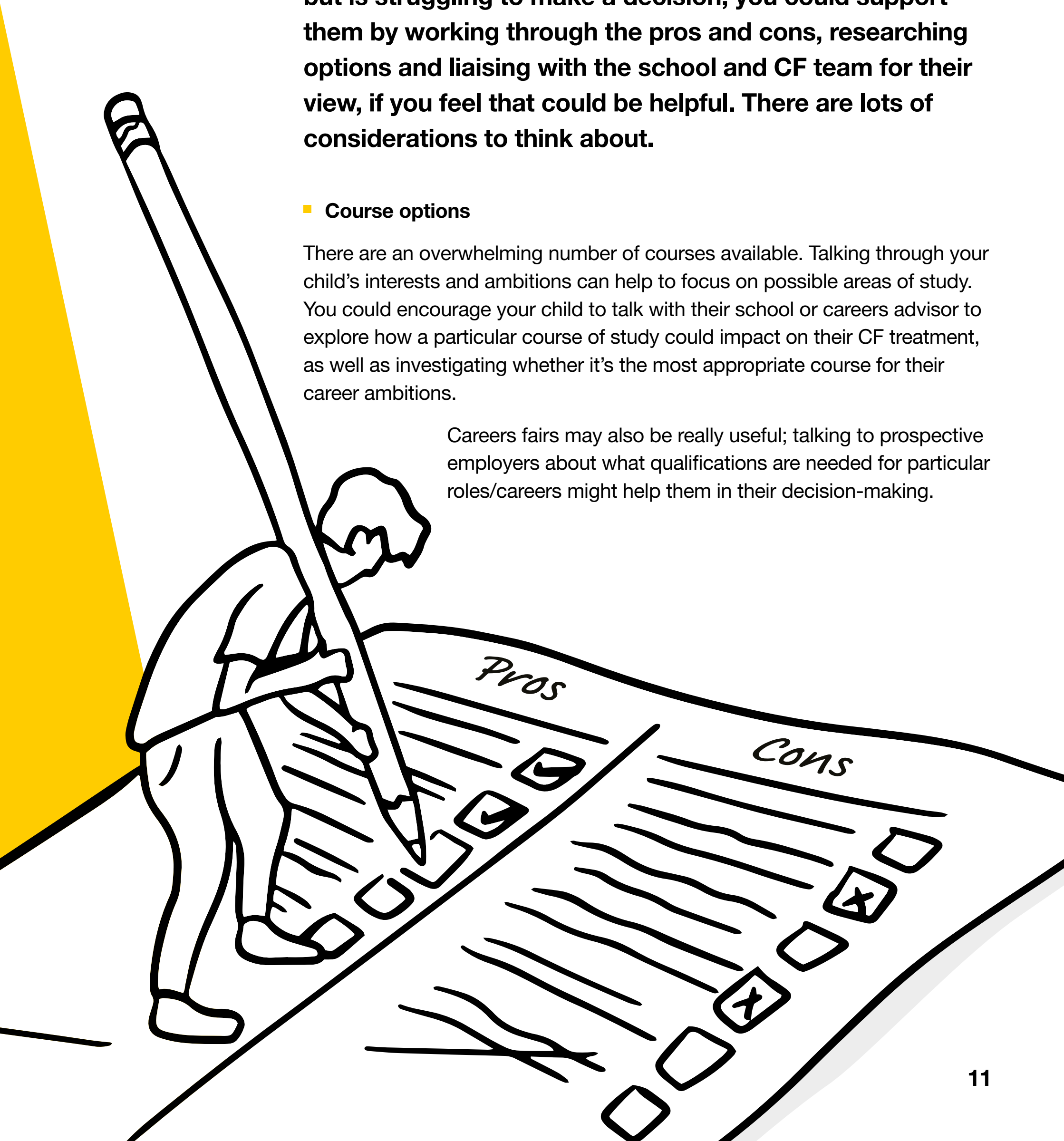
Going to college or university?

If your child is interested in further or higher education, but is struggling to make a decision, you could support them by working through the pros and cons, researching options and liaising with the school and CF team for their view, if you feel that could be helpful. There are lots of considerations to think about.

- **Course options**

There are an overwhelming number of courses available. Talking through your child's interests and ambitions can help to focus on possible areas of study. You could encourage your child to talk with their school or careers advisor to explore how a particular course of study could impact on their CF treatment, as well as investigating whether it's the most appropriate course for their career ambitions.

Careers fairs may also be really useful; talking to prospective employers about what qualifications are needed for particular roles/careers might help them in their decision-making.



- **Location of education/training provider**

It's useful to consider the practicalities around your child's choice of college, university or other training provider. Will they continue to live at home? If moving, will they transfer their CF care to a new clinic? How far will they have to travel? Is that realistic, particularly if early starts or late finishes are required? There's also a possible cost implication of public transport or running a car.

These are particularly relevant questions to ask if your child does have periods of poorer health, where practical logistics could really impact on their health and on their studies.

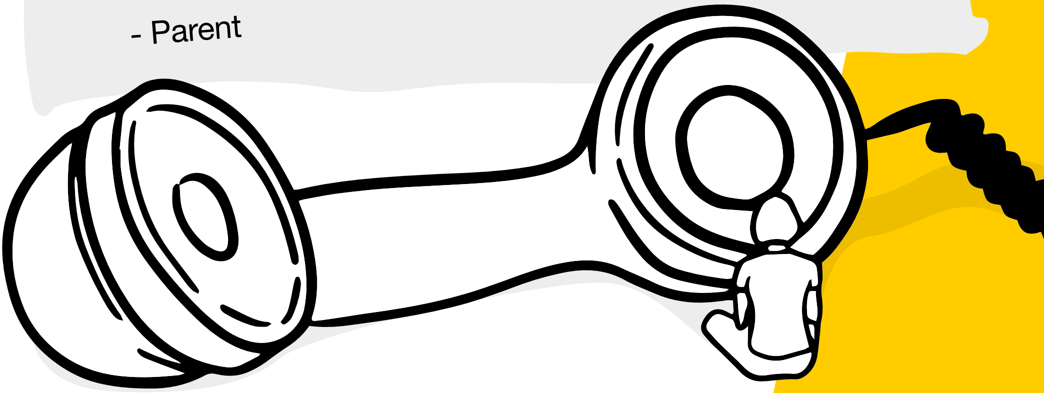
Remember, the location may be less important if there can be some flexibility in the course or training.

- **Flexibility**

The possibility of flexibility in arrangements has already been mentioned regarding A-levels. It's also possible to study or train flexibly, so look out for part-time courses, home-based study or courses where there's a good proportion of graded coursework.

As CF can be so variable, it's quite possible that your child could have a spell of poor health during their studies or training. Flexibility in deadlines and other adjustments may be possible, providing the university or college are aware of your child's condition.

> “I said to my daughter that I'd be happy to liaise with the lecturers and college staff about her CF if she'd like. She hasn't needed me to do this, but it felt good to be there as a backup. It's really about the young person having confidence to talk about their condition when they want to or need to and being able to communicate their own needs.”
>
> \- Parent



Communication

It's likely that throughout your child's life you'll have been central in communications about CF with the school, CF team and many other people that are involved in your child's life.

Over time, of course, the balance starts to shift, with your child taking more of a lead in the management of their care and life overall. If your child has transitioned to adult care, you might find that they are already proactive and comfortable taking the lead in talking about their care and expressing their needs.

However, for some young people going off to college, university or work, it might be the first time they've had to manage these conversations independently. It's important for young people with CF to be able to ensure their needs are met, so encouraging and supporting your child to communicate with their college, university or employer about any specific needs or adjustments can be beneficial. Promoting this confidence and ownership of their condition helps prepare them for adult life, although they may appreciate knowing you are there for 'backup' if needed.

Cystic fibrosis:

an invisible disability

The words ‘disabled’ and ‘disability’ can spark a lot of discussion within the CF community, and some people feel that these are not words that should be used when describing cystic fibrosis. Some people may not feel that the nature of their individual condition warrants use of the word ‘disabled’.

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 in different aspects of life, including education and employment. If such challenges arise, it’s important that you and your child know about the legal rights relating to discrimination and how to access support.

The law is designed to ensure that people aren’t discriminated against because of their disability and that they can study and work in their chosen areas where possible. The specific legislation that provides this protection is the Equality Act (2010), which 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.”

The Act also protects people who have progressive conditions, even if they are currently able to carry out normal day to day activities.

In the vast majority of cases, universities, colleges and employers will be very accommodating and help your child if they do need any additional support. For young people going to university or college, it can be helpful and reassuring to speak with support staff prior to beginning a course, or even prior to applying. You may also find the UCAS page on supporting students with disabilities useful:

www.ucas.com/support-disabled-students-your-questions-answered

If you feel that your child is experiencing discrimination because of their 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. 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 to 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. You can call the helpline on **0300 373 1000** or email **helpline@cysticfibrosis.org.uk**.

Staying well

While your child might be preoccupied with their A-levels, new apprenticeship, job or college studies, for many parents the main concern is that CF treatment isn't neglected and that health is maintained as well as possible.

Financial issues

Your child may be able to access funding to help with health-related costs including travel. If your team has a social worker, ask for more information about this. If you don't have access to a social worker, search online for 'Form NC1' for help with healthcare costs.

Pre-payment certificates (PPC) are a way of saving money on prescription charges by purchasing a 'season ticket' at a fixed cost. The certificate covers the cost of all NHS prescriptions. To find out more, take a look at **www.nhs.uk/NHSEngland/Healthcosts/Pages/PPC.aspx**. Additionally, the Cystic Fibrosis Trust's grants programme may be able to fund a one-off PPC for people who are struggling with prescription costs. To find out about the available grants and how to apply, please contact our helpline on **0300 373 1000** or email **helpline@cysticfibrosis.org.uk**.

Treatment adherence

Parents have told us that they really worry about their child managing their own treatments. This isn't necessarily a reflection on the young person's ability to do the treatments, but often founded in a concern about adherence. This is the case whether the young person stays at home or not.

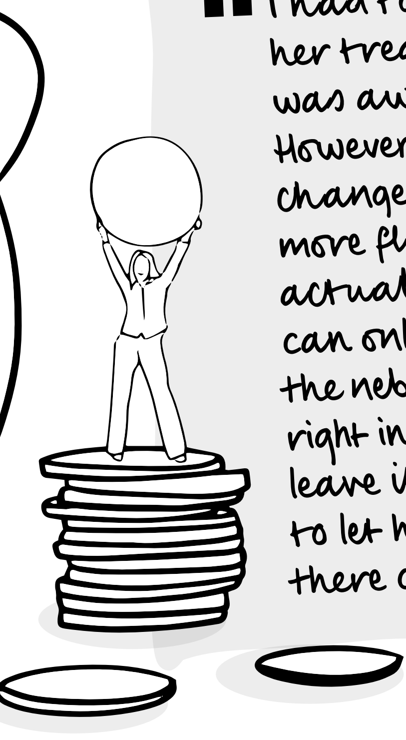
Some young people with CF are fully independent in their care from early teenage years, but for others it can be much later. This varies from family to family, circumstance to circumstance.

Your child may have already transitioned into adult care, in which case adherence is likely to have been raised in discussions with their adult CF team. Adherence to treatment can change over time and may correspond to other life events, extent of treatment burden and state of health. So it's not something that is fixed or 'dealt with'.

We know from research studies and from families' experiences that adherence to CF treatment can be challenging. One study (Bregnballe et al, 2011) suggests that 60% of adolescents reported that they experienced barriers to treatment adherence, with the key blockers being:

- difficulty in finding the time to do treatments;
- forgetting to do treatments;
- choosing to be with friends instead;
- too tired to do treatments; and
- not wanting to do treatment in public.

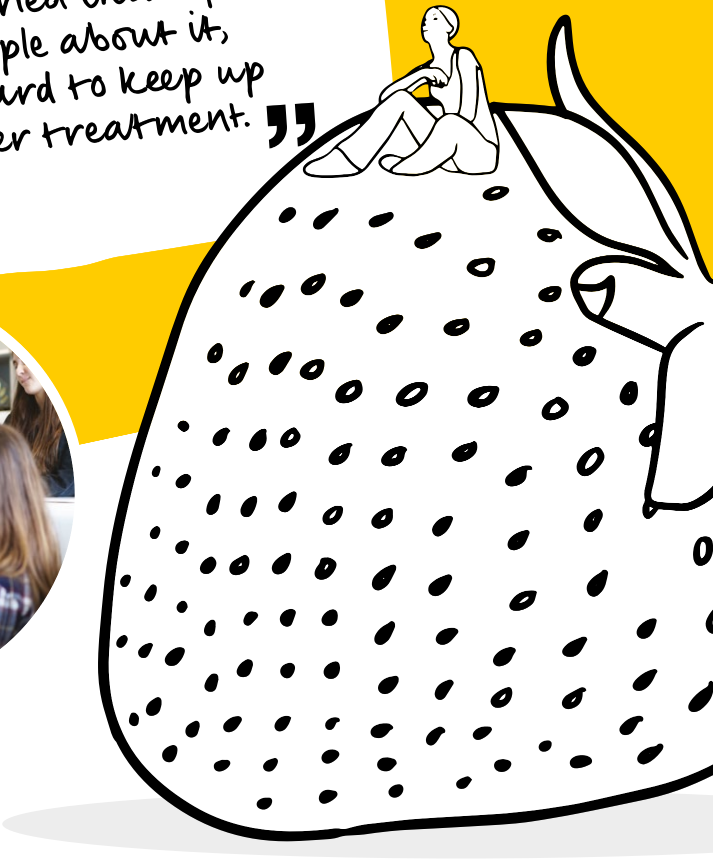
The excitement and change of schedule that can come with moving on to college, university or other training can impact your child's routine and ability to fit in the treatment as they've previously done. So treatment adherence may (or may not) be an issue for young people going through this significant transition.



> “I had to remember that she had managed her treatments over the seven months she was away and didn't have me nagging! However, now she's home her routine has changed and there's less structure and more flexibility, which sometimes actually makes adherence harder. But I can only nag so much! Sometimes I will get the nebuliser ready and literally put it right in front of her. My motto is 'say it and leave it'. I know, hard as it is, that I have to let her go, stand back and accept that there could be a decline in her health.”
>
> - Parent

This is a possible worry for some parents but it’s important to remember that this isn’t something you can ‘fix’. Research and expertise from CF teams are clear that just repeatedly telling a young person that their treatment is very important is unlikely to improve adherence, no matter how earnestly this information is shared. Teenage brains function differently to adult brains, and as a result teenagers have different perceptions of risk and priority, which helps to explain why many teenagers (regardless of medical condition) experiment with risky behaviours including drug use, drink driving and excessive alcohol consumption.

> “I was concerned about the possibility of my daughter going off to uni or college. She'd never been open about her CF and I was worried that if she didn't tell people about it, she'd find it hard to keep up with all of her treatment.”
>
> - Parent



> “Young teenagers will mainly believe what they can see or have experienced and, thus, they cannot fully appreciate the long-term or unseen consequences of not taking their medicine.”
>
> - From Taddeo (2008) study

“Preparing your child for the day they leave home is very important, particularly ensuring they have confidence in managing their treatments but also in planning and cooking meals. Ideally responsibility is shared and then handed over from you to your child in a gradual process. Having open discussions about planning and sharing responsibility, perhaps starting a couple of years before they leave home will give you time to pace yourselves and identify areas where additional support might be needed.”
(CF psychologist)

If you do think that adherence is a problem for your child, you could suggest that they develop a treatment plan in partnership with you, or their CF team, that takes account of their needs and priorities. This allows them the independence and control to assert what their priorities are and to find ways of fitting treatment around this.

Diet

This may be the first time that your child will have to plan meals and shop for food. They may be perfectly capable of pulling together a three-course meal, or may be at the other end of the spectrum! There is a Cystic Fibrosis Trust 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/meals, budgeting advice and ideas for key items to keep in the cupboard.

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

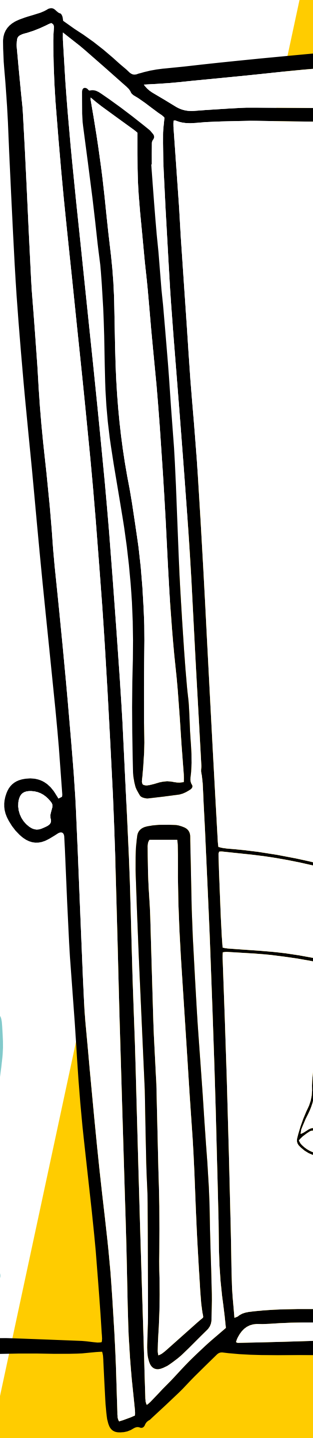
They might also find this website useful: **www.cfcooking.org**

Moving away from home

If your son or daughter is moving away from home to pursue training, studies or employment, it can feel particularly exciting, or perhaps realistically for many parents, a bit worrying. It can also be a very emotional time, not only do parents have to deal with 'letting go' of a child, but they also potentially have to deal with a change of CF team as their child transitions to adult care, or to a new CF centre. Your child's CF team, in particular the social workers and psychologists, may be able to offer you some support with coping with this transition.

Accommodation

Your first concern might be the availability of suitable accommodation – there's lots to consider here and it could be useful to sit down together and go through some of the following points.



For college or university accommodation

- Would a catered or self-catered hall work best? The benefits of catered are that your son or daughter doesn't have to worry about buying or cooking food – however the food at the halls might not always be to their taste or may not meet their nutritional requirements.
- If you're looking at a catered hall, would your child have access to a fridge for their medicines?
- Are en suite facilities needed? It's probably a good idea, so that your son or daughter has day-to-day access to private, clean facilities, but also if they require IVs.
- Do the rooms in the halls have enough plug points (for any equipment)? Do the windows open (for nebulised antibiotics)?
- Think about whether your child needs, or is likely in the future to 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 your child to make for clinic visits or admissions?

Private rented accommodation

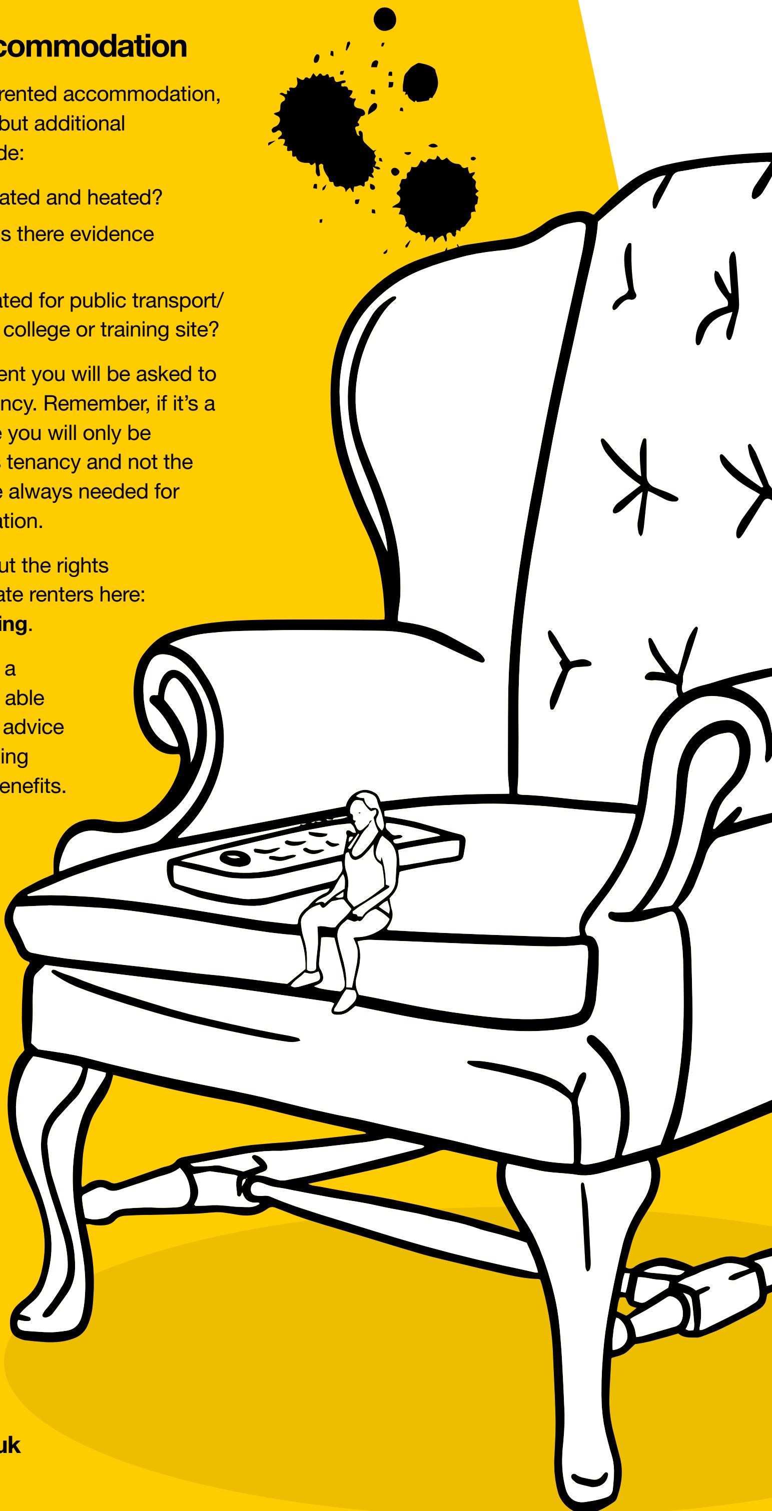
If you're looking at private rented accommodation, much of the same applies but additional considerations could include:

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

It's very likely that as a parent you will be asked to be a guarantor for the tenancy. Remember, if it's a shared property, do ensure you will only be responsible for your child's tenancy and not the other tenants! Deposits are always needed for private rented accommodation.

You can find out more about the rights and responsibilities of private renters here: **www.gov.uk/private-renting**.

If your child's CF team has a social worker, they may be able to provide information and advice on accommodation, including possible housing-related benefits.



Conclusion

The transition from school to the next stage of life can be exciting and challenging for lots of families, including those who are not affected by cystic fibrosis. However, CF adds an extra dimension to proceedings. The experience will be different for all families, so there is no checklist or right or wrong approach, but there are some key things to bear in mind.

- Where possible, try to support your child in planning for their future. People with CF are living longer and with better health than ever before and this improvement should continue. So it's really important that young people engage with their ambitions and options.
- Cystic fibrosis can interrupt or completely change plans, so it can be helpful to think about getting to the 'end goal' in a flexible way.
- There are lots of practicalities to consider – it could be useful for your family to sit down and go through the pros and cons of different options and see how these will fit with your child's treatment schedule.
- If you haven't already done so, encourage and support your child to make their own decisions and to manage their own CF treatment.

We can't cover everything in one booklet, so please do contact us if you need further information. You can contact our helpline on **0300 373 1000** or by emailing **helpline@cysticfibrosis.org.uk**.

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The Cystic Fibrosis Trust is very grateful to the parents and CF professionals who helped with the development of this booklet.

Thank you!