

TAKING CHARGE OF YOUR HEALTH

A GUIDE FOR TEENS WITH CYSTIC FIBROSIS
PLANNING THE TRANSITION TO ADULT CARE



CUH

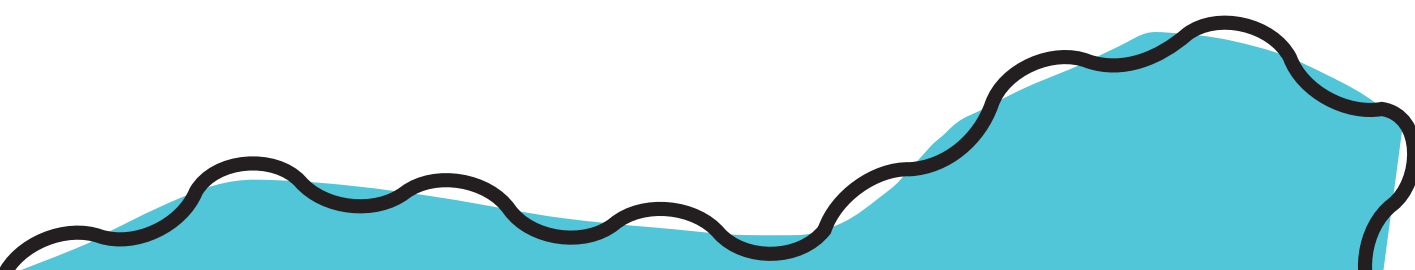
Grúpa Ospidéal Ollscoile Chorcaí
Cork University Hospitals Group

Created By:
Paediatric Cystic Fibrosis Team
Cork University Hospital
Version 1.2 July 2024



Front Cover Photo by Naassom Azevedo on Unsplash www.unsplash.com

Your guide to a smooth transition from paediatric to adult care.....	2
Growing up with Cystic Fibrosis.....	3
How do I get started?.....	4
Meeting with the CF Team on your own.....	5
Tools for transition.....	6
Talking about CF.....	7
Sexuality.....	8
How does CF affect fertility?.....	9
Smoking/vaping, drinking and taking drugs.....	10
Smoking.....	11
Vaping.....	12
Drinking.....	13
Taking drugs.....	14
Going to college or university.....	16
Transition isn't always easy.....	17
Your transfer to adult care.....	18
Important notes.....	20
Questions.....	22
Appendix 1.....	24



Your guide to a smooth transition from paediatric to adult care



CHANGE
AHEAD

In health care, the term ‘transition’ is the word used to describe the process of transferring from child to adult health care services. Transition is not a single event. It should be seen as a gradual process of thinking, planning and preparing, which ensures that you and your parents are ready for the eventual move.

Your teenage years are filled with change. As you grow up, you learn how to do new things and get better at what you have already learned. You make more of your own decisions as you take on more responsibility. Learning life skills and becoming independent happens slowly, over time.

Your health care needs change too. Gradually, you will say goodbye to your health care team in the paediatric unit and start to see the team that takes care of adults.

You, your family and your health care team share the responsibility for making your transition to adult care as smooth as possible. We will work together.

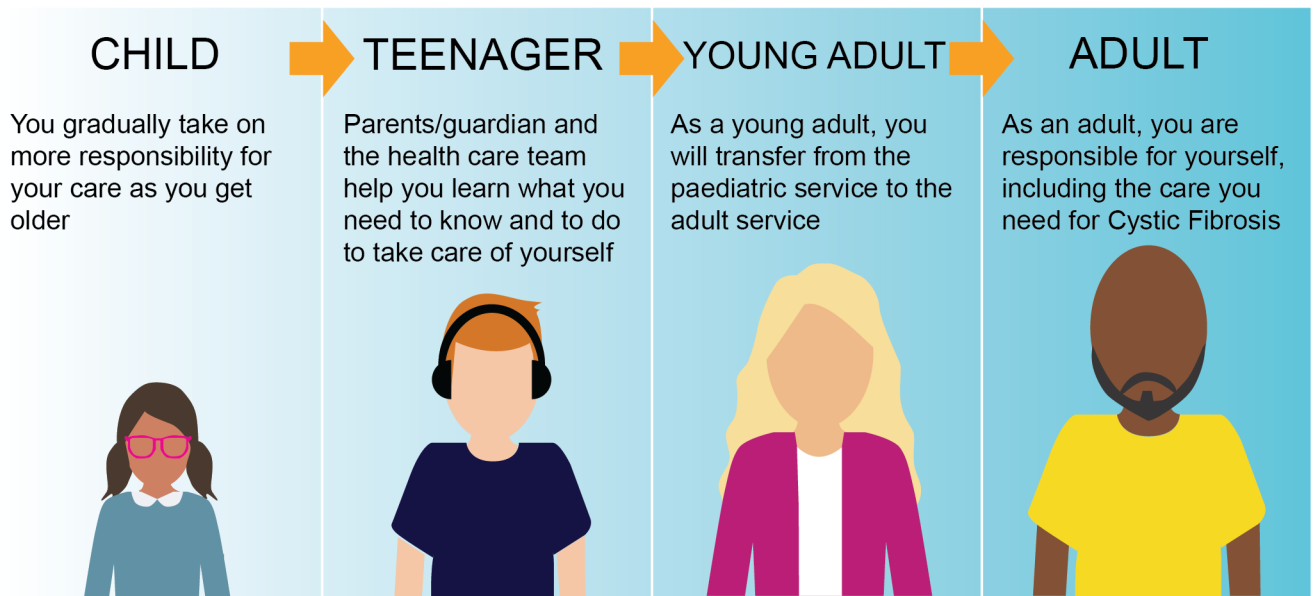
Your health care team will help by:

- Telling you what to expect
- Helping you make plans, set goals and learn what you need to do
- Making the change gradual, not sudden
- Supporting you along the way

This book can guide you through this process. We hope you find it helpful as you prepare for adult life with Cystic Fibrosis.

Growing up with Cystic Fibrosis

As you grow up, you become independent by gradually taking on more responsibility for your actions and choices in life. This includes the things that you do for your health.



Becoming an adult means learning to:

- Take responsibility for yourself and your actions
- Be as healthy and fit as possible
- Manage your own health care

This is more challenging when you have Cystic Fibrosis. There is a lot to learn about managing your health care. For example, learning to do physiotherapy and take enzymes.

It's best to take it one step at a time. The next page will show you how you can get started.

How do I get started?

7. Put a checkmark beside the things that your family does to help you stay healthy.

- Remind me to do my physiotherapy.....
- Remind me to take my enzymes.....
- Schedule appointments with my CF team.....
- Take me to my appointments.....
- Come into the clinic examination room with me.....
- Answer the questions the team asks.....
- Tell the doctor how I am feeling.....
- Order my medications.....

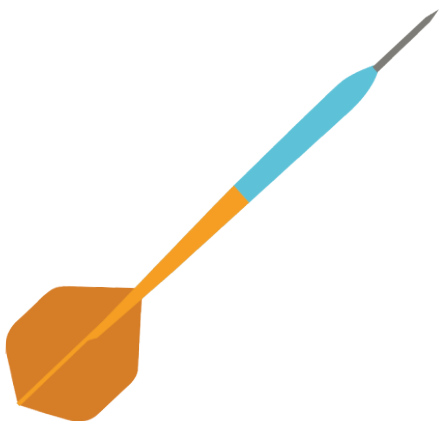
2. Now, review the list again and think of at least **ONE** thing that **YOU** could take responsibility for before your next clinic visit.

3. Let your parents/guardian know that you would like to take responsibility for this.

4. Follow through!

Staff will review this list with you at your clinic visits. We will encourage you and your family to have you assume more responsibility for your medical care.

The goal is for you to be able to do ALL these tasks by the time you have your first appointment in the adult CF clinic.



Meeting with the CF Team on your own

One step towards adult care is spending part of each clinic visit meeting with the CF team on your own.

- This gives you the chance to ask questions that you may feel too uncomfortable to ask in front of your parents/guardian.
- It may be helpful to write down questions for the team before the visit as it can be difficult to remember all of the things that you wanted to ask during the appointment.
- This shows your parents/guardian that you are maturing and taking more responsibility for your health.
- Your parents/guardian are more likely to give you more privileges when you demonstrate that you are more responsible.
- By the time you finish 1st year of secondary school you should be able to attend at least some of the appointment by yourself.

<i>1st year</i>	Parents/guardian attend at beginning and end. Able to spend 10-15 minutes talking to the team on your own
<i>2nd year 3rd year</i>	Attend up to 30 minutes alone and then joined by parents/guardian
<i>By the end of 3rd year</i>	Able to attend most or all of the appointment alone

This is just a guide, how much of the appointment you attend on your own will be up to you and your parents/guardian to decide together.

RESPONSIBILITY

Tools for transition

As you grow and get ready for adult care, you may find a transition checklist helpful. You can find this at the back of this document. Use them as often as you like. You can get more copies from the CF team. You can also use this checklist to let us know what topics you would like more information and advice on.

The adult CF team in Cork have a website which contains lots of information about the adult CF service including transitioning to the service, a virtual tour of the CF unit, and information about team members.



Cork Centre for Cystic Fibrosis (3CF)
www.3cf.ie

In the Cork service, your first visit to the adult CF service will be for Annual Assessment. This will be followed by routine clinic visits approximately 3 months apart. The adult team will contact you by phone or by letter to arrange your first visit.

The Adult CF Team in CUH

<i>Doctors</i>	Professor Barry Plant Dr. Kevin Deasy Dr. Hisham Ibrahim	<i>Physiotherapist</i>	Edel Madden
		<i>Dieticians</i>	Karen Cronin
<i>Nurses</i>	Claire Fleiming Mairead McCarthy James Dorgan	<i>Pharmacist</i>	Sarah Twohig
		<i>Psychologist</i>	Dr. Ciara Quigney Dr. Vicky Matthews

For information about other services, you can contact them directly or look on the relevant hospital website.

Adult CF centres in Ireland are located in:

- Cork University Hospital
- University Hospital Limerick
- Beaumont Hospital Dublin
- St. Vincent's University Hospital Dublin
- University College Hospital Galway

Other useful websites include:

www.steppingup.ie

www.cfireland.ie

www.cysticfibrosis.org.uk



You may find it difficult to talk about having Cystic Fibrosis. Or you may not wish to share this information with everyone. You are far more than your CF of course, but it is an important part of you. It is helpful to tell others that you have CF. Not everyone needs to know of course as it is your private information, however it is helpful for at least close friends to know. We understand that this can be hard sometimes. You may worry that others will think negatively about you or will treat you differently. However it is likely that most of them will be supportive. A few may not know how to deal with it at first, but educating them and explaining about CF to them may help to overcome this. Sharing this information tends to be good for friendships. When you have a shared understanding it lessens the burden of trying to hide or mask what is involved such as doing physiotherapy, taking medication, eating snacks, going to medical appointments etc.

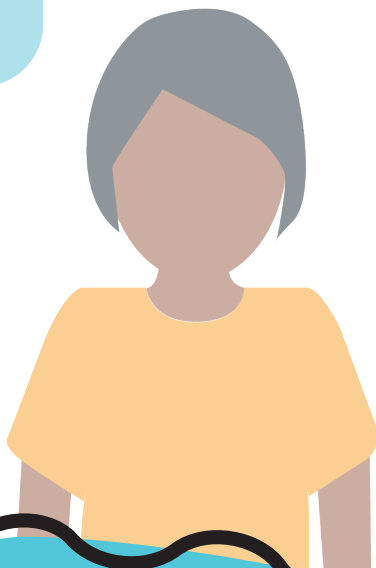
Remember how others respond is not a reflection on you. Everyone has moments when new information has surprised them and they may not have said the 'right thing'. However, people learn and good friends will always show up for you.

When and how?

When and how and if you tell others about your CF is up to you. However, it's a good idea to have an honest answer ready for when a friend asks about your health. For example, you could say: "I have a condition called Cystic Fibrosis. It can affect my lungs and digestive system so I need to take medication and do physiotherapy daily."

Sometimes people might ask more questions as not everybody knows about CF. It is up to you how much or how little you want to share about your CF. You may even prefer to say just a little and then to signpost the person to relevant websites so they can do their own learning.

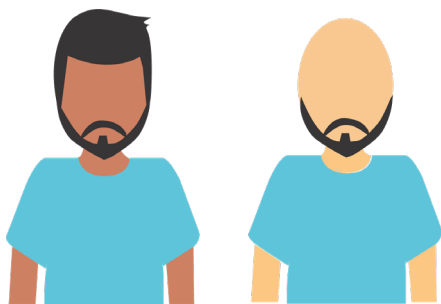
You shouldn't feel embarrassed about having a chronic medical condition, just as you wouldn't feel embarrassed about having a sore foot or a broken wrist. Remember it is always up to you if, when and how you wish to inform people about your health and your Cystic Fibrosis.



Sexuality

Sexuality is a normal, healthy part of your life.
Your sexuality includes:

- How you feel about yourself and your body
- Wanting to be intimate with someone
- Sexual feelings and sexual activity
- Protecting yourself and your partner during sexual activity
- Your desire and ability to have children in the future



Many teens may be embarrassed to talk about the topic of sexuality, but it is important to learn about sexuality and CF, and get your questions answered. This section provides general information. If you have any questions, please feel free to ask us. You can speak privately with one of the CF nurses or doctors during your visits.



Telling someone special that you have CF



It is up to you if and when you discuss your CF with someone you are dating. Talking about it will become more important as you become more committed to a relationship.

Your partner may be understanding and supportive and this may even bring you closer together. It is also possible that your partner may have a lot of questions about your condition. You can speak to the CF team if you are having difficulty answering any of these questions.

How does CF affect fertility?

It is important to be aware of how CF can affect reproduction. CF affects males and females differently. CF does not affect your sex drive or your ability to have sex, but it can affect your ability to make a baby.

Most males with CF will have fertility issues.

This is because the tube that carries sperm from the testicles to the penis (called the vas deferens) is either blocked or missing. There is nothing 'wrong' with the sperm, it just can't get into the semen. As an adult, it is possible to have a simple test of your semen to tell if you are infertile (no sperm are found).

It is still possible for men with this CF-related problem to father children through fertility treatment. Your options will be discussed with you when you are older. Until you know for sure, use contraception to prevent any unplanned pregnancy. Condoms are a good choice as they also protect you from STIs.



Women with CF are more likely to experience fertility problems than women who don't have CF. This is becoming less common with the introduction of highly effective modulator drugs such as Kaftrio. There are various fertility treatment options available if needed. However many women with CF are still able to have babies without undergoing any fertility treatment, so it is very important to use effective contraception to prevent unplanned pregnancy. If you become pregnant, your medications may need to be modified during pregnancy.



If you are sexually active or plan on becoming sexually active and you do not wish to become pregnant, talk with your family doctor about a method of contraception that is best for you. It is important to remember that hormonal contraception such as the oral contraceptive pill do not protect from STIs so it is advisable to also use condoms to protect both you and your partner.

Being pregnant can have an effect on your health. If/when you wish to have a baby, you should speak to your CF team, it is best to plan ahead and be aware of how a pregnancy could affect your body and your health.

As part of your care, we will ask you about your choices. We hope you will feel free to talk openly and be honest with us. You will not be in trouble, but it will allow us to give you better care when we are aware of the facts.

Smoking/vaping, drinking and taking drugs

As part of your care, we will ask you about your choices. We hope you will feel free to talk openly and be honest with us. Please don't worry about doing this - you will not be judged or criticised; we are simply more able to help you when we are aware of the facts.

As healthcare professionals we recommend that you never smoke, vape or take illicit drugs. If you decide to drink when you are over 18, we recommend you only drink in moderation.

All teens have heard about the dangers of smoking, vaping, drinking and taking drugs, yet many still decide to do this.

Some reasons that teenagers smoke, vape, drink or take drugs include;

- *Curiosity* - They are curious about it and want to give it a try
- *Peer pressure* - They see friends or others doing it and want to feel included or feel pressured into joining in
- *Environment* - People are more likely to smoke and drink if those around them smoke and drink
- *Stress* - Some may see it as a way to relieve their feelings of stress or anxiety

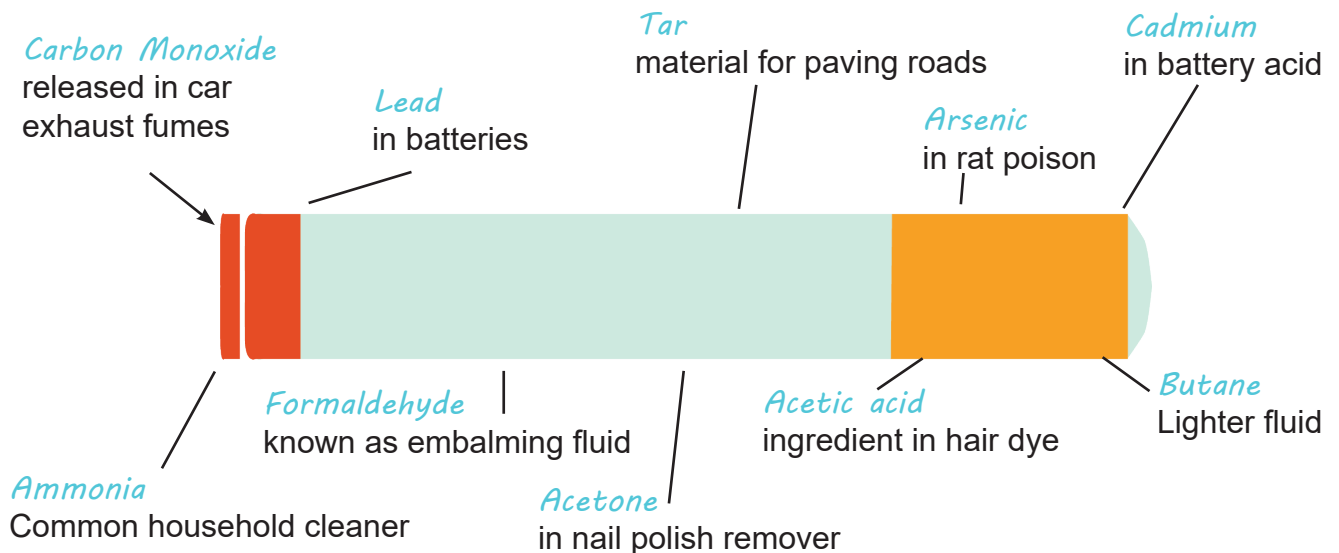
We understand that adolescence is a time of exploration, where your friends and peer groups are incredibly important to you, and where a lot of change is occurring. Experimentation is normal. However for those with Cystic Fibrosis the risks are greater.



Before you engage in smoking, vaping, drinking, or drug use, we would like to provide you with as much information as possible about how this may affect your health. And if you have already been smoking, vaping, drinking alcohol, or taking drugs, we hope that this information will help you in your choices and reducing harm. Remember the CF team is here to support you, not judge you.

Smoking is highly addictive and once you start, it can be difficult to stop! Lung damage from smoking appears sooner and more often in people with CF. You can do your body a big favour by not smoking.

Cigarette Smoke contains the following



Cigarette smoke contains over 4,000 chemicals, including approximately 69 known cancer-causing (carcinogenic) chemicals as well as over 400 other toxins. Nicotine is one of the main ingredients in a cigarette and it is a highly addictive

Many teens secretly smoke.

Please be honest with us about your smoking. We won't give you a lecture. We just want to know so that we can give you the best possible advice.

Quitting smoking can be difficult but you can get help. Talk to your family doctor or a member of your CF team.

Facts About Smoking

- Smoking raises blood pressure - a risk factor for heart attacks and stroke
- Smoking worsens lung disease
- Smoking stains your teeth and gums.
- Smokers are more likely to get cancer than non-smokers
- Smoking reduces blood and oxygens supply to the skin.
- Smokers age quicker
- Smoking alters your sense of taste and smell

For more information about quitting smoking:
www.quit.ie
Freetext QUIT 20100
Freephone 1800 201 203

Vaping

Electronic cigarettes (e-cigarettes) are battery-powered devices. They heat nicotine mixed with flavouring and other chemicals to create an aerosol that the user inhales. Using an e-cigarette is known as vaping.

Compared to cigarettes, vaping may be somewhat less harmful. But vaping is not harm-free. Emerging data suggests links to chronic lung disease and cardiovascular disease.

Here are some of the chemicals that are in e-cigarettes:

- Nicotine
- Ultrafine particles that can be inhaled deep into the lungs
- Flavorings such as diacetyl, a chemical linked to a serious lung disease
- Volatile organic compounds
- Cancer-causing chemicals
- Heavy metals such as nickel, tin, and lead

The risks and negative health effects linked with vaping include:

- Nicotine dependence
- Injuries - for example, from defective e-cigarette batteries
- Poisoning and exposure to toxins
- Changes to how your heart, lungs and other organs normally work. Over time these risks may cause diseases such as heart disease, lung disease and cancer.



You may be offered alcohol long before you're legally old enough to drink it. As healthcare professionals we recommend that you do not drink until you are 18. If you decide to drink alcohol, you should always drink responsibly. This means:

- Drinking alcohol in moderation (see guidelines below)
- Never ever drink and drive

THE LOW-RISK WEEKLY ALCOHOL GUIDELINES FOR ADULTS ARE:

- **Women: Less than 11 standard drinks spread out over the week, with at least two alcohol-free days**
- **Men: Less than 17 standard drinks spread out over the week, with at least two alcohol-free days**

While there are no specific guidelines for people with CF consuming alcohol, it is important to remember that people with CF are more at risk of the adverse effects of alcohol.

- In people with CF, the liver can be 'sluggish', which means it has to work harder to rid the body of alcohol. This puts more strain on it, and **puts you at greater risk of liver damage than the general population.**
- People with **CF-related liver disease should avoid alcohol** to minimise further damage to their liver.
- **Some medications can enhance the effects of alcohol**, causing unpleasant symptoms.
- **Some medications may also not work effectively** when taken alongside alcohol. If you are concerned about the way your alcohol intake may interfere with your medication please speak to your CF team.
- **Alcohol can also have a big effect on your blood glucose levels** if you have CF-related diabetes (CFRD). Speak to your CF team if you have more questions about this.

If you drink alcohol, consider when, where and why you drink? In those situations, could you drink something other than alcohol? Could you drink less or less often?

If you can't seem to control or stop drinking, you may need some help. Talk with your family doctor or a member of your CF team.

You can also find more information on www.drinkaware.ie

Taking drugs

You may have spent a lot of time in school learning about 'drugs' and the harmful effects they have on your body and mind.

When people talk about drugs they usually refer to illegal substances like marijuana or cocaine. These aren't the only drugs that can make you high. Some teens inhale chemicals or misuse prescription medications like painkillers. These are just as harmful.

Drugs are highly addictive and becoming dependent can spin your life out of control.

Taking drugs is risky for everyone, but the risks to someone with CF could be more serious. Drugs can change the way you think, feel and behave. If you're high, you may not take care of yourself or your CF.

If you are using drugs, consider;

- What's in the drugs you use?
- Are they safe?
- How are drugs affecting your life?
- What would happen if you were caught?



If you are concerned about your use of drugs or medications, talk with your family doctor or a member of the CF team. We are here to help and can connect you to effective treatment programs and helpful resources.

You can also find more information on **www.drugs.ie**



Remember, smoking/vaping, drinking and taking drugs are risky behaviours. It is important to know and understand the risks before you engage in any of them.

They can affect:

- Your breathing
- Your appetite and weight
- How well your liver works
- Your mood
- The effectiveness of your medications

If you have any questions, please speak to a member of the CF team.

Going to college or university

When you finish school, you may decide to further your education or get a job. To gain more independence, you may want to move away from home and try living on your own. This is an exciting time of life, but you can also expect some struggles and uncertainty.

This is yet another reason why you need to take charge

of your health and be able to manage your CF and your own health care needs independently.



When you are transitioning from the paediatric to adult CF service, you will likely still be in school and may not have decided where you will be attending college or university. If you decide to move away, speak to your CF team about how you will manage your appointments and if you need to be linked in with a CF team nearer to you.

Wanting some distance from parents/guardian and siblings is a normal part of growing up. As you become more independent of your family, you start to rely more on your friends for emotional support.

This may be difficult for your family and it is normal for them to be concerned about you and your CF.

It may help to be open and honest and tell them what you are doing to manage your health and your CF. This is reassuring and helps them accept that you are a responsible and independent young adult.

Transition isn't always easy

As they take charge of their own health and managing their CF, some teens go through a period where they stop going to the clinic, stop taking medication and stop doing treatments. It seems like they are pretending that they don't have CF. This may be because it has been difficult living with an illness and you are seeking a break from that identity. Or it can be a way to avoid feeling anxious about CF and what the future may hold.

Unfortunately, not adhering to the treatment plan does not stop the damaging effects of CF and stopping your treatment may cause damage that cannot be reversed. This is an unintended consequence of trying to cope in your own way. No matter what challenges have occurred the CF team is here to help you.

If you are struggling or overwhelmed by trying to manage your CF, please speak to your parents/guardian or reach out to a member of the CF team. We are here to help and support you.



Your transfer to adult care

In your early teen years, you will start to learn more about managing your CF. Over the next few years you will gradually take more responsibility for your health.

At around 16, most teens are ready to say goodbye to the paediatric team at Cork University Hospital. They transfer to the adult CF clinic where they begin taking charge of their health. The exact time of the transfer varies from person to person.

It is normal to feel uneasy about going to the adult CF Clinic. You may have come to our clinic and seen the same health care team for a long time. We know each other well and you're used to our routines.

Please let us reassure you. We will work with you, your family and the adult CF team to make this move as smooth as possible.

It may be helpful to fill out the "Transition list" checklist a few times over your last year in the paediatric service. This will identify areas that you need to work on, it may highlight questions that you would like to ask the paediatric team and it will hopefully reassure you that you are ready for adult care.

At the Adult CF Clinic, you are in charge of your health.

This means that you are responsible for:

- Sharing information about your health
- Taking part in planning your care
- Asking questions
- Expressing your needs, preferences and concerns
- Booking and keeping your appointments
- Calling the clinic to cancel or change an appointment

If the move to adult services feels particularly daunting and you have lots of worries or feelings of anxiety about this, you can speak to our Paediatric CF Clinical Psychologist.

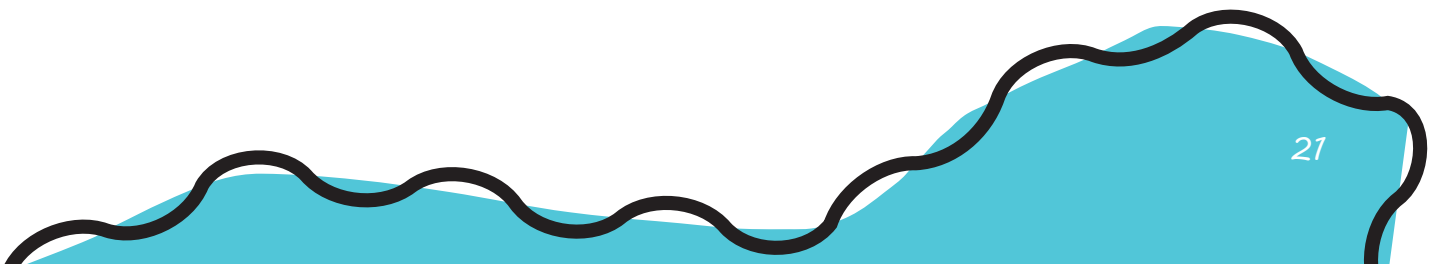
Sometimes talking about your worries and fears with someone outside of your family and friends can be helpful, and can make things clearer in terms of what you need from your CF Team and your support network to help you to manage this next step. Our psychologist can offer a safe space to explore your feelings about moving to the adult service and work with you to equip you with skills to manage this move as well as possible. They can also link with the psychologists in the adult service to make sure you get the support you need when you move.

Please let any member of your CF Team know if you would like to book an appointment to speak with our psychologist. You will also see the team psychologist when you come for regular clinic appointments and she will make sure to ask if you feel you need any extra support.



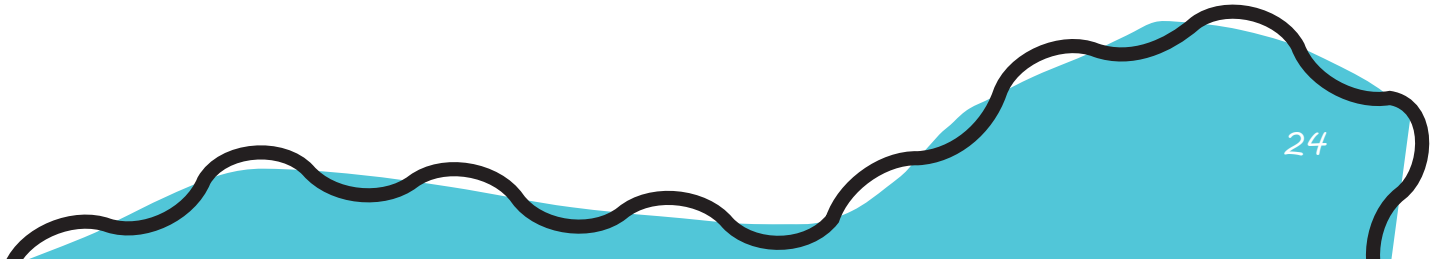
Over the next few years, we will work together with you and your parents/guardian to ensure that you start taking charge of your health and become independent in managing your CF as you grow up. We hope that this booklet will be a valuable resource for you. The next few pages are blank for you to write down any questions or concerns you may have, feel free to bring it to your appointments as a reminder of things you would like to discuss with the team.

Important notes



Questions





Transition Checklist

Read the statements below and tick the relevant box for each. This will highlight the areas you need to get some advice about. This will help you as you prepare for your transition. You should discuss any concerns with your parent(s)/guardian(s) and health care team.

Knowledge	Happy with this	Need some advice about this	Notes
I understand my medical condition	<input type="checkbox"/>	<input type="checkbox"/>	
I know about the tests that I need to have	<input type="checkbox"/>	<input type="checkbox"/>	
I know the names of my medications and what they do	<input type="checkbox"/>	<input type="checkbox"/>	
I know when and how to take my medication/treatments	<input type="checkbox"/>	<input type="checkbox"/>	
I am aware of my medical history (e.g. hospital visits, procedures, tests)	<input type="checkbox"/>	<input type="checkbox"/>	
I know the main differences between child and adult health care services	<input type="checkbox"/>	<input type="checkbox"/>	
I am happy to talk to the chemist about my medication/treatment	<input type="checkbox"/>	<input type="checkbox"/>	
I know how to care for my medical equipment (if applicable)	<input type="checkbox"/>	<input type="checkbox"/>	
I know who to call in an emergency	<input type="checkbox"/>	<input type="checkbox"/>	
Knowledge	Happy with this	Need some advice about this	Notes
I feel ready to prepare to be seen alone in the young person's/adult clinic	<input type="checkbox"/>	<input type="checkbox"/>	
I feel confident to ask my own questions in clinic	<input type="checkbox"/>	<input type="checkbox"/>	
I understand that I will have to take more responsibility for my health care as I get older	<input type="checkbox"/>	<input type="checkbox"/>	
I keep a record of my hospital/clinic appointments	<input type="checkbox"/>	<input type="checkbox"/>	

Health & Lifestyle	Happy with this	Need some advice about this	Notes
I am aware of the choices that I have to make in order to have a healthy lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	
I know how much exercise is recommended for me	<input type="checkbox"/>	<input type="checkbox"/>	
I understand the risks of taking alcohol and drugs	<input type="checkbox"/>	<input type="checkbox"/>	
I know how important appropriate eating is for me	<input type="checkbox"/>	<input type="checkbox"/>	
I am aware that my medical condition may change as I get older	<input type="checkbox"/>	<input type="checkbox"/>	
I know where to get more information about my condition and other aspects of my life (e.g. sexual health, sport, education)	<input type="checkbox"/>	<input type="checkbox"/>	
About Transition	Happy with this	Need some advice about this	Notes
I understand the meaning of 'transition' and the reasons why I have to move to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	
I understand about the transfer of my medical records/files to the adult health service	<input type="checkbox"/>	<input type="checkbox"/>	
I have found out about the challenges that I could expect during the transition process and feel ready to deal with them	<input type="checkbox"/>	<input type="checkbox"/>	

Useful links:

www.steppingup.ie
www.cfireland.ie
www.cysticfibrosis.org.uk

www.quit.ie
www.drinkaware.ie
www.drugs.ie