CYSTIC FIBROSIS TRUST

GROWING UP WITH CF

A guide for young people with CF aged 12-18 years

Cystic Fibrosis Trust. Registered Charity No. 1079049. Registered Company No. 3880213.

The Cystic Fibrosis Trust funds medical and scientific research aimed at understanding, treating and curing Cystic Fibrosis. It also aims to ensure that people with Cystic Fibrosis receive the best possible care and support in all aspects of their lives.

Contact details for information and other literature published by the Cystic Fibrosis Trust are given on the back cover.

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This booklet is about you, and what it is like being a teenager with Cystic Fibrosis (CF).

Teenage years are a strange time for everyone. Suddenly, you may find yourself growing up really quickly, both physically and emotionally; or you may find that everyone else seems to be growing up and nothing is happening for you. This is the same for everybody, whether they have Cystic Fibrosis or not. This booklet hopes to show you the ways that having Cystic Fibrosis might make things more difficult or just different.

One of the most important things about teenage life is getting to know yourself better and becoming more of an individual. For you, this might mean thinking about your Cystic Fibrosis seriously for the first time. Your Cystic Fibrosis will not be the same as anybody else's, you may be mildly or severely affected. Teenage years are a time to take control of your own life and for you this might mean making your own mind up about the sort of life you want to lead.

This booklet should answer some of the questions you might have. If there is anything that this booklet does not cover, or there is something in it you do not understand, do not feel like you are out there on your own. Why not talk to a member of the team at your CF Clinic. There are also people at the Cystic Fibrosis Trust who would be happy to talk to you about anything you may be having trouble with. You can find a contact number on the back page.

Chat Room

If you would like to talk to others who have the same interests or concerns as you and you have access to the Internet, you can use **TALK** on the CF Trust's website – the address is on the back page of this booklet.

Physical Changes

Puberty can be unsettling and strange and a lot of people get paranoid if their friends seem to be growing up quicker than they are. This is often true of people who have Cystic Fibrosis, sometimes it can slow things down a bit. The thing to remember is that everyone goes through puberty sooner or later, so relax! Teenagers get a lot of stick for being lazy, but there is a perfectly good reason for it. Growing up can really take it out of you and so you will feel like sleeping for longer. (Remember to tell this to your parents when they are trying to kick you out of bed!).

These things are true of both boys and girls, but in some ways, puberty is very different for the two sexes.

Changes for Girls who have Cystic Fibrosis

Some girls go through puberty from as early as 11 years old. Cystic Fibrosis might delay things for you, as your body may have to slow down to cope with all that is about to happen. This is particularly true if low weight or poor nutrition is a problem for you. If you get a lot of chest infections, this might happen to you as well.

The important thing to remember is that growing up is not a race. Do not worry if things seem slow, because sooner or later your body will start to change shape, slowly, but surely. As well as this your periods will start. They may be irregular to start off with and it might take a while before you get in to a monthly cycle. Do not let this bother you, it is perfectly normal. Remember that puberty is a difficult time for everyone. It can be confusing and you might find some things embarrassing to talk about. The best thing to do is probably to talk to a friend. They might not know what it is like having Cystic Fibrosis, but they are growing up too and will understand how you feel.

Chat Room

Don't forget **TALK** on the CF Trust's website – the address is on the back page of this booklet. Finding someone with similar interests or concerns can sometimes be a great help.

Changes for Boys

Boys take a bit longer to mature physically than girls. Puberty normally starts at around twelve, but if you get a lot of chest infections or have trouble gaining weight, your body may delay puberty until you can cope with it. Sooner or later, you will be having growth spurts, your voice will be getting deeper and hair will be growing on your body. All of these things take up so much energy that your body just has to wait until it's ready. If you ever feel worried or embarrassed by something, try talking to someone you trust. You may have found a friend via **TALK** on the CF Trust website who will lend a sympathetic ear. It is more than likely that they will know how you feel. A lot of the problems you might find with growing up will be the same for everyone else.

Some young men and women who have Cystic Fibrosis will have no problems at all at this stage, if they are well nourished and do not get too many chest infections. It all just depends on how badly your Cystic Fibrosis affects you. Remember there are people who are happy to talk to you in confidence and there is a contact number at the back of this booklet.

The main thing is just to relax. You will mature physically just like everybody else, even if it does take a bit longer to happen.

Emotional Changes

Teenage life can be a bit of a mess at times, emotions run high and life can seem confusing and unfair. The most important thing is not to let it get on top of you. You can feel on top of the world one minute and angry and upset the next. This is the same for everybody, and you will probably notice it in your friends as much as yourself.

One important thing about teenage life is becoming an individual. It is not just your body that develops, your personality does too. Pretty soon you will want to be more independent and this might mean looking after yourself rather than being looked after by someone else. For people with Cystic Fibrosis, this might cause a few problems. When you were younger, your parents probably got used to being in charge of things like your physiotherapy, your drug regime and your diet. As you get older, you might want to sort these things out for yourself and in a way, your parents will miss looking after you.

Just remember that they are on your side and that they are only human! Some people like having their parents help them with their care at this stage whereas others would rather look out for themselves. At the end of the day, it is all up to you.

When you become a teenager, you start wanting to go out and socialise more. The problem is that your Cystic Fibrosis care takes up just as much time and effort and you might have a hard time fitting everything in. You might get frustrated with all the physiotherapy, nebuliser treatments and drugs you need to keep healthy. It is not easy balancing physical needs with emotional needs, but the best thing to do is organise a sort of timetable, that fits in with your social life, but will also keep you in good shape.

Smoky Environments

Smoky atmospheres are a public nuisance but they affect people with Cystic Fibrosis the most. Nowadays, more and more places have a no smoking policy because the dangers of passive smoking have been recognised. Always try and stay out of smoke-filled rooms and whatever you do don't take up smoking yourself.

Boyfriends and Girlfriends

Going out with people can be a lot of fun, but most teenagers will tell you that it makes life a lot more complicated as well! Having Cystic Fibrosis should not really make much difference if you have found the right person, but you might find yourself asking some questions. At some point you might have to think about the same sort of things and you may have other questions too.

Questions which are often asked, and some answers are list below:-

Will anyone want to kiss me because I cough a lot?

If you're attracted to someone and they are attracted to you, your coughing is not going to make any difference. The best thing to do is just to be upfront and honest about it. Anyone, who is put off by something that is not your fault, is not really worth it anyway. The most important thing is just to try to be laid back and confident about yourself. The most snoggable people always are.

Should I tell my new partner that I have Cystic Fibrosis?
This has to be your decision, but asking yourself some of these questions might make it easier to think about.
How would I feel if they had Cystic Fibrosis and did not tell me?
Is it really important to me that they know?
Will it make things between us better or worse?
Do I tell them everything at once, or break them in gently?
What if they find out from someone else?
How will I explain things like going to hospitals for IVs?

How will I feel if my relationship ends and I do not want it to?
Getting dumped is a horrible feeling that everyone has to put up with sooner or later and this is not any different for people with Cystic Fibrosis. Things are only different for you if the relationship ends because your partner cannot cope with your Cystic Fibrosis. But it would be just as bad if they only stayed with you because you had Cystic Fibrosis, even though for other reasons they might wish to move on. Try to remember that anyone who can not accept you for who you are is not worth bothering with and that if it comes to an end, as many early relationships do, it probably has nothing to do with your Cystic Fibrosis. The best thing to do is just pick yourself up and move on.

I can not understand my feelings at the moment, one minute I am so happy, then I can be crying over the slightest thing. Is this normal?
Yes, it is perfectly normal. Teenage years is a time of ups and downs for everybody, but this booklet is all about Teenagers with Cystic Fibrosis, so lets talk about how having CF might make you feel at this time. When you are having a good time of it, Cystic Fibrosis might be the last thing on your mind, and you can forget about even having it. At other times though, when life seems to be getting on top of you, you might ask, “Why me?” and really hate the fact that you have Cystic Fibrosis. Some

teenagers with Cystic Fibrosis have started to think about how long they have to live and what the future will hold. This is perfectly natural; a lot of teenagers ask questions about their own mortality, particularly if they lose someone close to them. If you start thinking of your life in this way, do not bottle up your emotions. Talk about it with someone you trust and let them help you through it. Try to stay positive if you can; it makes life so much easier to deal with.

It was hard when I moved to an adult hospital, because I met so many people who were very sick with Cystic Fibrosis. I recently found out that one of them has died, and I was really shaken up by it. I am very well and have Cystic Fibrosis; no one really talked to me about how bad it could get.

Just remember that Cystic Fibrosis affects everyone in different ways. There are some young people who are very sick because they have Cystic Fibrosis and there are a few that die because of it. On the other hand, there are plenty of adults with Cystic Fibrosis who have a full, useful and enjoyable life and treatments are improving all the time. Hopefully, knowing this should help you stay positive about your future. If you are worried about your health and you do not know where you stand, have a word with one of your medical team. It is important that there is someone you can talk to about your fears, because having people there to support you can help a lot.

I was in a biology class at school and we were doing genetic conditions and Cystic Fibrosis was a part of it. I was quite shocked to learn that Cystic Fibrosis can make young men infertile. Where can I find out more about this?

Infertility is usually a problem for young men who have Cystic Fibrosis. It is a shame that so many people with Cystic Fibrosis do not find out about this sort of thing for so long; a lot of parents and even some doctors seem to find it very difficult to talk about. There is some good news however. The tubes that the sperm go down to leave the body to get to the egg gets blocked up with mucus, but there is nothing wrong with your sperm. This means that you could still have a baby with your future partner, using special medical techniques. Do not confuse infertility with impotence. Impotence is when you do not get an erection and cannot have sex. Men with Cystic Fibrosis do not have this problem! It is just that when you ejaculate, there are no sperm in the fluid.

Fertility can also be a problem for women with Cystic Fibrosis, if there is a thickening of the mucus around the cervix. Another thing to consider is a women's state of health at the time of considering having the baby. It could be dangerous for both you and your baby if you are suffering from poor nutritional health or have very poor lung function. Do talk to your doctor or nurse, who will understand your longing for a child, but who will explain to you the risks that might be involved.

If you want to find out more about this issue, there are people at the Cystic Fibrosis Trust you can talk to. The telephone number is at the back of this booklet.

If you are in a sexual relationship with someone, or even if you want to be, make sure that you find out about contraception. Pregnancy is not the only risk of having unprotected sex, there is also the risk of catching sexually transmitted diseases. Always make sure you use condoms properly.

School Life

School life does not have to be a nightmare; it is up to you to make it as fun and rewarding as possible. You may find your Cystic Fibrosis causes a few additional problems. A lot will depend on how understanding your school and your friends are.

You will be expected to attend school until the age of 16 at least, and there is nothing to stop you going into the sixth form and then on to university or college. The Cystic Fibrosis Trust has available a *Further Education Pack* that might help you think about these options.

Having Cystic Fibrosis might mean that you miss a lot of school because of poor health or hospital admissions. This might make your school life seem like a struggle and you might find yourself behind with work at times. If the school knows about your problems, then you will get them on your side and it will make things a lot easier.

The Cystic Fibrosis Trust has produced a *Secondary School Pack* to help you let your school know how they can help you. In it there are contact sheets, which are personal to you, so you can explain to your teachers how having Cystic Fibrosis affects you in their lesson. Contact the Cystic Fibrosis Trust if you would like a copy. **You can get special consideration at exam time if you record your own absences from school.**

Some people with Cystic Fibrosis have talked about getting bullied, so it is worth saying something about it here. Some young people say they get called 'druggies' because they take so many pills with their meals. It is things like this that can really make life hard. Others do not understand how serious Cystic Fibrosis is and think you are exaggerating to get out of lessons or to attract attention.

If something like this happens to you, do not try to put up with it on your own; why should you? Just tell someone about it. No one likes a bully and getting them in trouble for it is the right thing to do.

Cross-infection

Part of being a teenager is looking out for yourself and others; for you this means learning the facts about cross-infection. Find out what sort of bugs and bacteria you grow, like *Pseudomonas aeruginosa*, *Burkholderia cepacia* or *Staphylococcus aureus*. In hospital, you have to bear in mind that you might be carrying bacteria that could harm other people who have Cystic Fibrosis, and they could be carrying bacteria that could harm you. Here are some ways of making sure that this does not happen.

- When you are coughing, cover your mouth with your hand or a tissue. Politely ask other people to do the same.
- Do not share drinking bottles, cups or glasses.
- Do not kiss other people with Cystic Fibrosis, you could do each other more harm than good.

Some people who have Cystic Fibrosis carry a bug called *Burkholderia cepacia*. They are advised not to mix with others who have Cystic Fibrosis and this does not make it any easier for them. You can talk to them on the telephone or, if you have access to the Internet, via **TALK** on the CF Trust website (see back cover). Make sure you treat them with respect and understanding, they do not deserve anything less.

The Move to Adulthood

As you get older and move on from adolescence, you might want to find out more about things like housing, insurance, further education etc. The Cystic Fibrosis Trust has information packs about things like these that might help you out. The Cystic Fibrosis Trust also produces a magazine *CF Talk* for 16 to 25 year olds with CF who the Cystic Fibrosis Trust know about.

Another useful book is *After 16 – what's new?* If you would like a copy of this particular book please telephone The Family Fund Trust on 01904 550005.

We hope this booklet has helped you out. Teenage life can be a bit of a strange time, but there is a lot of fun to be had as well. We also hope that now you realise you are not alone with your concerns and worries, and that you are not out there on your own. If you still have any unanswered questions, why not call us at the Cystic Fibrosis Trust and talk with us about it. Also, talk to other teenagers with Cystic Fibrosis on TALK on the CF Trust Website. There are people there that want to help you out with any problems you may be having, so give it a go.

Always remember that if you stay positive, life is yours for the taking. Do not try to ignore or deny the fact that you have Cystic Fibrosis, but do not let it stop you getting the most out of life. At the end of the day, it is up to you to find a balance between your social life and your physical care, so do not let yourself down.

For further information and literature published by the CF Trust, or to talk to a trained professional, please contact:

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TALK

Introducing **TALK**. The part of the Cystic Fibrosis Trust website designed especially for anyone in their teens. This is your space – use it to meet friends, exchange information, share news and gossip. You'll also find downloadable desktops and screensavers and links to other sites.