Information for parents

Your teenager and cystic fibrosis

Most of us remember our teenage years as a time of excitement, challenge and, above all, change. Perhaps the most significant change is learning to take responsibility for ourselves and mastering skills that ensure we become healthy, independent young adults.

During the next few years your teenager will need to learn how to look after their own health and how to get on in the adult world. We call this process "**Transition**". We have created this pamphlet for you to work alongside your teenager and help them master self care and gain a good understanding of cystic fibrosis. We have produced **checklists of tasks** to achieve for different ages so that this becomes less daunting and a gradual process over time

We recommend that **you help your teenage**r and support their efforts in achieving the skills outlined in the checklists. It is fine if your teenager wants to pick and choose from the different checklists or delay completing certain skills.

There may be certain things on the checklists that you do not feel happy or confident about discussing or assisting with. You might struggle with **"letting go"** and promoting your teenager's independence. These feelings are understandable and our role at PMH CF clinic is to help support you and your teenager throughout this exciting time of **transition**

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Getting to grips with cystic fibrosis

Transition information for teenagers

Teenagers and Cystic Fibrosis

Being a teenager is a busy and exciting time with lots of changes. **Getting to grips with CF** and learning how to look after your health can prevent CF getting in the way of life and makes the move on to adult care a lot easier.

We call the time between age 12-18 years '**Transition**' and at the end of this you will be moving on to the adult clinic. Moving on is called '**Transfer**'. By the time you transfer you will need to know about CF and how to look after your health.

This pamphlet is to help you (and your parents!) through your transition. It contains checklists for different ages of skills that you need to learn to help you look after yourself and make the move to adult care. A good way to start is with the list that suits your age now. You can work up to other skills on different lists as you get older and as you feel able to.

A couple of points:

- This is much easier if you have a go at the skills in the lists with your parents' help. You don't have to do it alone
- Feel free to choose the skills you would like to start getting to grips with. You don't have to stick to the check lists for your age group.
- Don't worry if you don't feel up to certain skills at the moment or don't complete them all. It is not a test!

Have a look at the list for your age group and tick where you think you are now with each skill. Then a little later on after some practice you can put in the date when you think you have got to grips with that skill

Good luck!

Useful info *(fill in the blank spaces)*

Telephone numbers	
PMH respiratory department	9340 8830
The CF Nurses at PMH	
PMH social work department	9340 8290
PMH pharmacy	
Kids helpline	www.kidshelpline.com.au
GP surgery	
Cystic fibrosis WA	9346 7333
My CF Consultant is called	
My GP is called	
My GP surgery address	
My medicare number is	
I am allergic to	

Check list 17-18 years

	Not just yet but I am thinking about it	I need a bit of help but I am getting there	No worries
I look after my CF care myself at home			
I know when I am sick and what to do			
I have written a summary about my health to give to other doctors			
I make my own clinic appointments and can order medicines myself			
I know about transfer to adult care and have met /have a date for meeting the team			
I have talked about Centre-link & entitlements with the CF social worker			
I know about my fertility, pregnancy planning and contraception			
I have a good group of friends and people I can depend on who know I have CF			
I have a GP I like and am comfortable with			
I have plans for my future education and employment			
I know how CF may affect my mental health and how to get help with this			

The three stages of learning to care for yourself:

Stage 1

Working out what you need to know

- You haven't started to learn the skills yet but are learning what you need to know for your future

Stage 2

Learning the skills you need to care for yourself

- You know what you need to learn and are practicing the skills for later life with some help

Stage 3

Looking after yourself with confidence

- This is the advanced stage where you know what you need to know and have learnt the skills to do things on your own with confidence

Check list 13-14 years

	Not just yet but I am thinking about it	I need a bit of help but I am getting there	No worries
I am seeing my CF doctor on my own for a short time in clinic			
I know I have CF and know some of the ways it affects my body			
I have started learning about my medicines and their names			
I can take some of my medicines on my own			
I can tell when I am sick			
I know about the way puberty affects my body			
I know about the way smoking and drugs can affect my health			
I have told important friends and other people that I have CF			
I have a GP and I know their name			
I do regular exercise and know why it is important for my health			
I can list the right foods that I should eat			
I can talk about my moods and feelings easily			

Check list 15-16 years

	Not just yet but I am thinking about it	I need a bit of help but I am getting there	No worries
I see my doctor on my own and ask questions in clinic			
I know about CF and how it affects my body			
I know all about my medicines and why I take them			
I can take most of my medicines on my own			
I know when I am getting sick and what to do about it			
I have started practicing how to make an appointment & ordering medicines			
I know about the way smoking and drugs can affect my health			
I know about my fertility and about safe sex and contraception			
I have a GP that I like and I visit			
I have a group of mates and important people in my life who know I have CF			
I have plans for education and work in the future			
I have people I can talk to if I am feeling down or worried			