

Cystic **Fibrosis** *our focus*

Transition from paediatric to adult care
A guide for young people

Factsheet – March 2013

Fighting for a
Life Unlimited

Transition from paediatric to adult care – A guide for young people

Introduction

This factsheet provides information about the transition from paediatric to adult clinical care for young people with cystic fibrosis, including what the process involves, when transition usually occurs and how to prepare.

Written by the Cystic Fibrosis Trust.

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What should happen when I transfer to the adult CF centre?

It is important that you are fully involved in what is happening as you move from the children's to the adults' CF centre.

The doctors and other members of the team should be making plans with you, not about you, and your parents should be included provided that is what you and they want.

The transition from paediatric to adult care is a gradual, planned process – not a one-off event. Time should be taken to make sure you are fully prepared and ready for the move to the adult centre.

When should my doctor and I start talking about transition?

Your paediatrician should start talking to you about moving to the adult centre at least a year before he or she thinks you may be ready to go. If you feel ready to discuss it and it has not been brought up, ask your doctor to explain the procedure to you. You should have the opportunity to ask questions and be given plenty of time to think things over and talk about how you feel about moving.

When should I transfer?

Not everyone wants to move to an adult centre at the same age. However, we suggest that it is probably best if you do so sometime between the ages of 14 and 18, so that you do not find yourself with adults too early or find it hard to move because you have waited too long.

The important thing is that your views about when you move are listened to and that you feel it is the right time for you.

It is also important to check out the centres for adults with CF in your region.

How should I be prepared for the transfer?

Your paediatrician should start to talk more to you, rather than to your parents, about your CF and treatment as you get older. You should have the opportunity to talk to him or her by yourself as the time for transfer approaches, but this should be discussed so that both you and your parents feel comfortable with the new arrangement. Besides taking more responsibility for your treatment, there may be matters that you would like to discuss privately.

You should have the opportunity to get to know members of the adult team and become familiar with the adults' centre before moving. How this happens should be discussed with you. It could involve the adult team visiting you at the paediatric centre and/or your going to look around the adult centre informally and meeting the staff there.

You should be able to take part in a joint transition clinic where both the paediatrician and the physician who will be responsible for your adult care are present. You should also be able to meet other members of the adult and paediatric teams together. The purpose of this is to discuss your clinical care and for you to feel confident about how this will be managed by the adult team.

What else should I consider?

Hospital admission

Someone from the paediatric team, with whom you get on well, should act as your key person to help make your move easier. This person should arrange your visit to the adult centre and accompany you, if you wish. They should also be able to help with any worries or concerns you may have about moving.

You should be given an information booklet about the adult centre which explains how to get there, who the team members are, and what happens when you attend the clinic or are admitted to hospital.

If admitted, the ward you stay on should be appropriate for you as a young person, particularly in terms of where you sleep and the leisure facilities available. The staff who look after you should be trained and able to respond sensitively to your physical and emotional needs.

Checklist for transition

- Early discussion about moving
- Time to talk and ask questions
- Full involvement in plans for transfer
- Meet the adult team
- Visit the adult centre
- Joint transition clinic
- Key person
- Information booklet
- Reassurance about in-patient care

Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website or ordered using our online publications order form. Visit cysticfibrosis.org.uk/publications.

The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted on 0300 373 1000 or helpline@cysticfibrosis.org.uk and is open Monday to Friday, 9am – 5pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website cysticfibrosis.org.uk.

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More factsheets available at:
cysticfibrosis.org.uk/publications

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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