Cystic Fibrosis our focus

Transition from paediatric to adult care
A guide for parents

Factsheet – March 2013

Fighting for a Life Unlimited

Transition from paediatric to adult care – A guide for parents

Introduction

Transition from paediatric to adult cystic fibrosis care is a normal part of your child's care. The age at which this happens will depend on a number of factors. This factsheet explains why transition is necessary, the differences between paediatric and adult care, the changes you and your child can expect and what your role may be in the process.

Written by the Cystic Fibrosis Trust.

Last updated 2010.

Contents

Why does my child need to transfer to an adult centre?

The care of patients with cystic fibrosis has changed considerably in a relatively short period of time. It is no longer a condition that only affects children. People with cystic fibrosis are living longer, and there are now more adults with cystic fibrosis than there are children.

However, the care of adults is increasingly complex and requires a specialist adult CF multidisciplinary team with experience of the long-term nature of the condition.

There is a need to respond to the growing maturity of young people with cystic fibrosis. They need to become more involved in decisions about their care and treatment. This should start as early as possible in the paediatric centre and continue after transfer to an adult centre.

Young people do not always see the need for this to begin with but it becomes more relevant to them as they mature, become more independent and find interests and relationships with others outside the family home.

They will eventually have to balance the demands of health and treatment against conflicting demands of education, career, social life and relationships. It is important that they begin to understand that their feelings, opinions and attitude towards their health and treatment will have a significant impact on their future wellbeing.

What are the differences between the paediatric and the adult CF centre?

In the paediatric centre the CF team works very closely with parents. Parents are given responsibility and taught how to care for their child and how to manage treatment routines. The CF team encourages the parents to explore how best to integrate care and treatment into their personal and family life.

Parents may look to the CF team for emotional support in addition to that given by friends and family. The CF team's relationship with the young child is a parental one where decisions are made for the child rather than with them.

This changes as the young person matures. They will be encouraged to participate in making decisions about their care. This process will continue after transfer to adult care.

In the adult centre the CF team works directly with the patient. The relationship is more of a partnership. Patients are encouraged to be more closely involved in making decisions about their care and treatment. The CF team tries to ensure that treatment fits in with the patient's lifestyle.

Patients are encouraged to ask questions and to discuss their care with the CF team. The CF team may also provide emotional support for the patient when difficult situations arise. Patients make their own decisions about care and treatment in consultation with the CF team.

Most parents continue to be involved although their role may change gradually to a more supportive one where their views may be sought but not always heeded.

What will happen when my child transfers to the adult centre?

Children do not turn into adults overnight. They begin to change and mature long before the time of transfer and will continue for some time afterwards. There is a need for paediatric and adult CF teams to offer services which reflect this change. Preparation should begin prior to transfer.

Specialist CF centres adopt a number of different ways to handle the transition. Some hold special young people's clinics run by the paediatric CF team. They are organised along adult lines with greater emphasis on the young person's participation. Others hold special transition clinics at which the adult and children's teams are present. These try to introduce the young person and their family to the adult CF team and to answer any questions they may have.

Following the transfer of care, the adult CF centre should offer services in a way that makes young people comfortable. If they wish to have a parent with them in consultations this should be accepted. The views of parents and carers should also be considered.

What changes can I expect as a parent?

Young people gradually learn to handle more mature relationships and begin to relate to other adults as equals. They become more emotionally independent, and want to make decisions for themselves. They will continue to need help and support from others, especially when making difficult decisions.

There are many important decisions to be made at this time. What kind of education or career to choose and whether to live independently for the first time. They may also have to cope with the intense feelings that go with starting a relationship, having sex and falling in love.

They may also have to make difficult decisions about medical treatment, such as weighing up the pros and cons of a particular treatment or giving consent to surgical intervention.

If you have been closely involved in your child's care up to this point it is likely that you will feel uncertain at times how to react. Your opinions may be sought but disregarded. This happens to all parents as their children grow up. Your reminders to do treatment may be resented or ignored.

It's a good idea to be willing to step into the background at times. Check with your child what they want. They may still want to talk about health issues but without being told what to do. They might want you to remind them about treatment in spite of getting annoyed when you do. You will find that your relationship will change from that of protector and advisor to that of consultant and counsellor.

As you start to think of your child as more of an adult, try to respect their views, even though you may not always agree with them. This can be very hard and raises many difficult thoughts and feelings for parents. You may need support at this challenging time. Most adult centres are familiar with these issues and will be able to help you find reassurance and support, as you need it.

What is my role likely to be?

Parents are almost always the people to whom young adults turn when they need help and support.

It is important to allow your child to make their own decision even if it differs from the decision you would have made for them. This can be hard for parents and you may need help and reassurance from the CF team. Please discuss any doubts or anxieties that you have with them. Although they must respect the young persons' need for confidentiality it does not mean that you cannot raise your anxieties with them.

Young adults can be very challenging in their behaviour. This can affect parents and healthcare services. They can become irresponsible in attitude towards their health and show little understanding of their condition or of the effects of treatment. They may fail to accept adult responsibilities and simply hand over responsibility for their health and lifestyle to others.

It is important that parents give positive support and encouragement to the young person when he or she is ready to start taking more responsibility. They need to start involving and informing them about the things that affect them at an early stage. With health care this should happen before transfer and with the help and support of the paediatric CF team.

Remember you have been a key figure in your child's life up to this point. However as they mature, friends and other adults such as teachers, employers, colleagues, and members of the CF team may all be asked to give their opinion and advice. They need to be able to access specialised advice independently as they start to move into the adult world. Parents and families are still needed to provide practical and emotional support especially when there are difficulties, but it takes a different form.

What is the role of the adult CF team?

- The adult CF team is there to give expert advice.
- To listen to what the patient has to say and to support the patient and their family.
- To help patients make decisions about their care and treatment.
- To respect the patient's decision whatever that may be.

What if there's a problem?

Change can be difficult for everyone involved and there may be some problems particularly in the early stages of transfer. If you have any doubts or anxieties talk to someone at the adult centre and ask for help if necessary. Try to communicate directly with those members of the CF team who are providing care for your child. They are there to help and advise you.

Going back to the paediatric team for advice isn't a good idea however comfortable this may feel, as they no longer have any direct input into your child's care. It will take time for a new relationship to develop and requires a willingness to work through difficulties together and to understand and respect each other's roles.

The process of transition can seem daunting to both parents and young people. However, once begun, most seem to adapt quickly and find that the change is a positive one. Young people benefit from the increasing confidence they gain by making their own decisions and parents can begin to feel more confident in their child's ability to cope.

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.

Cystic Fibrosis Trust
2nd Floor One Aldgate
London
EC3N 1RE
020 3795 1555

cysticfibrosis.org.uk

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

Cystic Fibrosis Trust, registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE