

# **Cystic** **Fibrosis** *our focus*

**Transition from paediatric to adult care**  
**A guide for commissioners, hospital**  
**and clinical teams**

Factsheet – March 2013

**Fighting for a**  
*Life Unlimited*

# Transition from paediatric to adult care – A guide for commissioners, hospital and clinical teams

## Introduction

The transition from paediatric to adult care should be a planned, collaborative process involving professional caregivers, the young person and family. This factsheet describes how you can help ensure a smooth transition for young people with cystic fibrosis.

Written by the Cystic Fibrosis Trust.

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## **Early discussion of transition**

The topic of transition should be introduced at least a year before transfer might be expected to take place, allowing time to explore feelings and resolve concerns which the young person and/or parent may have.

## **Time of transfer**

The actual timing of transfer should then be flexible, in accordance with individual needs. In order to avoid either premature moves or prolonged delays, it is, however, recommended that broad age limits for transfer be set and that these should be 14 and 18 years.

The emphasis on paediatric consultations should progressively be on the young person, but should not exclude parents prematurely or abruptly.

## **Preparation for transition**

Preparation for transfer should be thorough and well planned. The proposed procedure should be discussed with the young person and his or her parents and modified as appropriate. It should provide opportunities for the young person to familiarise him or herself with the new staff and new environment on an informal basis. This should normally include organised visits by the adult team to the paediatric centres, and by the young person to the adult centre.

## **The joint transition clinic**

Joint clinics, where the young person and family can meet the paediatrician and adult physician together, should be held. They should also include opportunities to meet other members of the adult team, along with their paediatric counterparts. The focus of the clinics should be on how the young person's care has been, and will be, managed. The transfer should be managed sensitively, with full account taken of individual needs and concerns.

## **An intermediary**

A key person from the paediatric centre, with whom the young person has a good relationship, should facilitate the young person's introduction to the adult service, and provide emotional support where needed.

## **Provision of information**

A booklet about the adult centre should be provided which includes information about clinical arrangements, in-patient facilities, the names of team members and how to get to the centre.

## **The ward environment**

In-patient facilities should be appropriate for young people, particularly in terms of sleeping and leisure facilities. Staff should be specially trained to respond to their physical and emotional needs.

## **Provision of service**

Provision should be made for the planned management of the transition from paediatric to adult care. Protocols should be drawn up which can be used to negotiate personal plans for each young person, to enable him or her to transfer from the paediatric to the adult service smoothly and with confidence.

## **Summary of guidelines**

- A planned, collaborative process.
- Early discussion about transition.
- Flexible timing of transfer, reflection individual needs but within broad age limits.
- Gradual change of emphasis from parent to young person within paediatric centre.
- Opportunities provided to meet adult team and visit adult centre.
- Joint transition clinics.
- An intermediary to facilitate transition process.
- Information booklet.
- Appropriate in-patient facilities.

## 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](http://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](mailto: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](http://cysticfibrosis.org.uk).

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[cysticfibrosis.org.uk/publications](http://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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