

# Transition:

getting ready  
to move on to  
adult cystic  
fibrosis services



This information sheet explains a little about the transition process and what it will mean for you. Remember that if you have any questions about transition, please talk to your clinical nurse specialist, your consultant and/or your local Paediatrician.

Information for young people and families

## What is transition and when does it start?

In health care, we use the word “transition” to describe the gradual process of planning, preparing and moving on from children’s health care to adolescent and then adult health care. Transition gives everyone time to talk about issues related to this exciting but also challenging time of becoming a young person and to make sure you are ready to make that move.

We usually start talking about transition when you start secondary school. We invite you to attend cystic fibrosis (CF) transition clinics when you are around 14 years old. Most young people transfer to adult CF services when they have completed their GCSEs and have been in college for a year or two. Our aim is that most young people have moved on to adult CF services by their 17<sup>th</sup> birthday.

## How do I choose an adult CF service?

Most young people transition to the adult CF service nearest where they live or study. There are three adult CF services in the London area:

- Barts and the London
- The Royal Brompton Hospital
- King’s College Hospital

There are also adult CF services at Papworth Hospital in Cambridge and the Churchill Hospital in Oxford. The CF team at GOSH can tell you about all of these centres and we also encourage you to visit the centres to see what you think.

In choosing your adult centre, there will be many factors that will influence your decision, such as whether you plan to stay at home or go to college. We can discuss these factors with you and your family in clinic.

## Why do I need to move on?

As you grow into a young adult, an adult service will be the best place for you to get the care that is right for your needs. The staff in children's services are expert in caring for babies, children and teenagers, and the staff in adult services are the experts in caring for young adults, adults and older people. By the time you are at the end of the transition process, you may feel that you have grown out of children's services and be glad to move on to a more grown-up setting.

The thought of moving to a new hospital and leaving the staff that you have got to know over the years can be difficult. But we know from experience that it is a good idea to think of this change as a sign that you are growing up and moving on with your life. You might have felt the same way when you moved from primary to secondary school. Once you get used to the adult hospital, you should settle into your new routine and get to know the staff there.



## How do I meet the adult CF teams?

The CF team at GOSH holds joint clinics with some of the adult services so you can meet them informally. The teams from the London Chest Hospital, Royal Brompton Hospital and Papworth Hospital come to these joint clinics regularly so that you can get to know them, ask any questions you want about their service and they can get to know you as well.

After discussion with the CF clinical nurse specialist, we will invite you to attend a joint clinic with any of these adult CF services. You can come to one joint clinic or all three – it is your choice. You can come along with your parents or a friend but you will get chance to speak to the teams on your own too.

Unfortunately, only a few young people transition from GOSH to King's College Hospital and Churchill Hospital each year so we do not hold joint clinics with these adult centres. We can organise an informal visit to the teams there if you would like so please ask us.

## What do I need to talk about at the joint transition clinic?

The clinic is an opportunity to ask any questions or discuss any issues you want about moving on to adult CF services. You could ask where the clinic is held, what services they offer and what differences there are to the CF service at GOSH. You could also ask about inpatient stays and home care services offered by the adult CF service. The way that shared care is organised has changed so the adult CF service will explain how shared care works for them.



## How do I get ready to move on to the adult CF service?

When more formal discussions take place when you are around 14 years old, we will help you to prepare for your move.

Your parents have been really important in looking after your health and will be able to give you lots of helpful advice. They will have plenty of experience of things like taking you to the hospital, making appointments, asking questions and making sure you get your medicines or treatments. It is a good idea for you and your parents to talk about how moving to adult hospital makes you feel. You should make plans with them about how you can practise getting involved in looking after your health and taking responsibility. While you are preparing to move on, your parents will still be involved in your health care and still have an important role.

If you know any other young people that have already finished their transition, it might be useful to ask them for any tips on how to get ready. You could also ask them questions about the adult service.

It will be helpful for you to practise doing the following things to help prepare you for adult care.

- learn about your conditions and treatments
- practise asking and answering questions during ward rounds and clinic appointments
- try to take some responsibility for remembering what your medicines are called, what they are for, how much to take and when to take them
- learn how to get more supplies of your medicines
- practise arranging appointments with your consultant, family doctor (GP), physiotherapist or dietician
- keep important phone numbers and appointment dates in your mobile phone, calendar or diary
- when you agree to treatment plans, make sure that you follow them properly
- try spending time without your parents for part of clinic appointments, then when you feel ready try spending the whole appointment on your own.

## Transferring your clinical information

- find out any changes in your condition that mean you should get urgent help
- find out who to contact in an emergency

For more ideas, please see our transition checklist.

Before you move on to adult CF services, we will ask your permission to transfer all the relevant clinical information to your new CF team. This will include information from the previous two years, such as annual reviews, blood and respiratory cultures and results of any other tests. It is important that the adult CF service have an up to date picture of your health so tests are not repeated unnecessarily.



## Further information and support

The CF Trust has produced a booklet on transition, available from their website at [www.cysticfibrosis.org.uk/about-cf/living-with-cystic-fibrosis/transition](http://www.cysticfibrosis.org.uk/about-cf/living-with-cystic-fibrosis/transition)

### **London Chest Hospital**

Website: [www.bartshealth.nhs.uk/our-hospitals/the-london-chest-hospital](http://www.bartshealth.nhs.uk/our-hospitals/the-london-chest-hospital)

CF service: 020 7377 7000  
or 020 3416 5000 bleep 1960

### **Royal Brompton Hospital**

Website: [www.rbht.nhs.uk/patients/condition/cystic-fibrosis](http://www.rbht.nhs.uk/patients/condition/cystic-fibrosis)

CF service: 020 7351 8065

### **Papworth Hospital**

Website: [www.papworthhospital.nhs.uk/cli/cli\\_cystic\\_fibrosis](http://www.papworthhospital.nhs.uk/cli/cli_cystic_fibrosis)

CF service: 01480 364 761

### **King's College Hospital**

Website: [cf.kch.nhs.uk](http://cf.kch.nhs.uk) [note: no www]

CF service: 020 3299 4934

### **Churchill Hospital**

Website:

[www.ouh.nhs.uk/hospitals/churchill](http://www.ouh.nhs.uk/hospitals/churchill)

CF service: 01865 225 713

## Notes

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