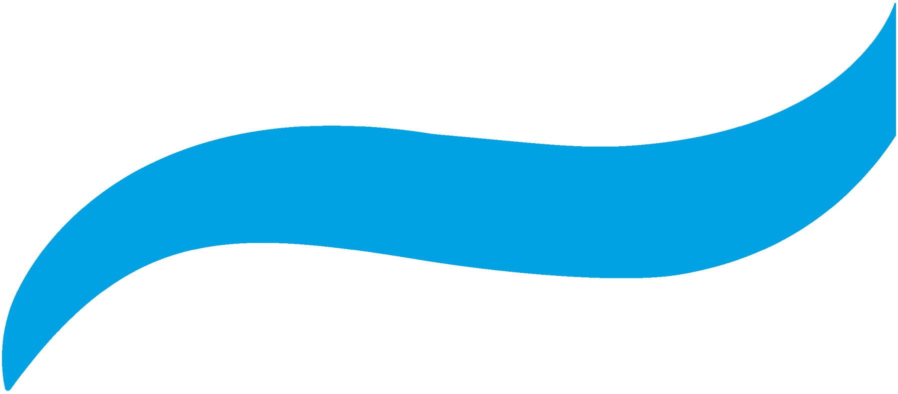
NHS
Ayrshire
& Arran

Information for Young People about Transition to Adult CF Services

Paediatric Cystic Fibrosis (CF) Service



WHAT IS TRANSITION ?

Transition is a term used by the healthcare team when we work with you and your family as you prepare to move from the care of Paediatric services to Adult services at the Queen Elizabeth Hospital Glasgow.

This process will take a couple of years, finishing around your 16th birthday; we do adjust timings to take account of exams.

Being a teenager is great in many ways but it comes with a few challenges! One of the biggest changes is taking responsibility for yourself rather than relying on your parents and carers. We know that this can be harder for you; as in addition to normal daily living activities you have the added responsibility of coping and managing your CF, your medications, treatments and hospital appointments.

We will support you to gradually take more responsibility so that you are ready to move into adult services when the time comes.

HOW WILL YOU SUPPORT ME TO DO THAT?

Your Appointment

Your clinic appointments will be a bit different from now on; we will ask your parent or carer to stay in the waiting room for the first part of your appointment. This means you will see the CF team alone and you will be able to tell us how you are doing instead of someone else speaking for you. It also gives you a chance to talk to us about things you may not want to discuss in front of your parent/carer.

The CF Team

Another change is that team who look after adults at the Queen Elizabeth Hospital will be at some of your clinic appointments, as well as the paediatric team. This allows you to get to know the adult team, so that when you make the final move to adult services there will be lots of familiar faces.

The Hospital

In addition to this, some of your transition clinic appointments will be at the Queen Elizabeth Hospital so you can get to know the place as well as the people.

Home Visits

One of your paediatric CF team will visit you at home from time to time (whoever you feel most comfortable talking with). This is to chat about your CF, growing up with CF and your CF care.

CF nurses from the paediatric and adult team will offer a joint visit at home at the beginning of the transition process and again at the end, this will give you and your parents/carers the opportunity to discuss your transition and to ask any questions you may have about adult services.

GETTING USED TO THE TRANSITION PROCESS

Most young people find they enjoy the transition process and feel ready to transition to adult services when the time comes. Your parents/carers are always invited to join in at the end of any discussions so they can get an update and a chance to ask any questions. Both paediatric and adult CF teams will work with you and your family to make sure you receive the best care and treatment throughout your transition. It is important you understand how CF influences the lifestyle choices you come across as a teenager and young adult. We have included information in this pack that other young people in your position told us would be useful. If you have any questions you can contact your CF nurses.

Their contact numbers are:

At Crosshouse Hospital 0156382566

At the Queen Elizabeth Hospital 0141 4516075

USEFUL WEBSITES FOR INFORMATION

These websites have lots of useful information on the Queen Elizabeth Hospital, cystic fibrosis and on topics related to growing up.

- **www.nhsggc.org.uk/sguh - 0141 201 1100**
  The website for the Queen Elizabeth Hospital provides campus maps, directions by car, information on parking and public transport and lots of other useful information about outpatient and inpatient visits. CF clinics are normally held on Tuesday afternoons and Thursday mornings.

- **www.cftrust.org**
  The CF Trust is the UK's only national charity dedicated to all aspects of cystic fibrosis. They fund research to treat CF and aim to ensure appropriate clinical care and support for people with CF. They also produce several booklets and leaflets which provide useful information about CF.

  The following fact sheets and booklets can be downloaded from the CF trust websites.

  Transition – A factsheet guide for young people and parents moving from paediatric to adult care.

  Cystic Fibrosis & relationships – A collection of real life experiences written by people with CF and their partners.

- **www.changing-futures.co.uk**
  New online resource for teenagers by teenagers called Changing Futures. This resource gives facts about living with CF, Gene Therapy and much more.

- **www.butterflytrust.org.uk - 0131 445 5590**
  The butterfly trust provides a variety of support services in the community for people affected by Cystic fibrosis who live in Scotland.

- **www.samh.org.uk**
- **www.seemescotland.org**
  Interactive sites for young people to explore feelings and worries and mental health.
- **www.knowthescore.info - 0800 587 5879**
  If you've got questions about drugs.
- **www.drinklinescotland.org - 0800 731 4314**
  Information, advice and support on anthing to do with alcohol.
- **www.canstopsmoking.com** - **0800 848 484**
  Advice and support on giving up smoking.
- **www.fpa.org.uk - Appointment line - 0300 3030 251**
  Information and advice on sex and contraception.
- **https://sites.google.com/site/ltcmacmillan/**

You can also contact this service by:

Telephone - **0141 2875901**

E-mail: ltcandmacmillanservice@glasgow.gov.uk

Long term conditions financial and health inclusions partnership is a free and confidential service. It is a "you only tell your story once" type of service where welfare advisers can decide on who to approach once they see what help you require. CF Trust logo is on the website. While this is a Glasgow based initiative; if you call, you can be directed to an adviser in your local authority. This project has lots of awards for excellence.

Let us know if you don't have access to the internet; we're happy to print the information for you.

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