

Transition: getting ready to move on from paediatric to adult cancer services

Paediatrics

What is this information about?

This information explains the transition process from paediatric (children's) services to adult services, and what it will mean for you.

Why have I been given this information?

Moving to an adult service may seem worrying. It might help you to read more about the move and what you can do to feel prepared.

This information includes a list of useful things you can do to help you prepare; it also includes the names of the doctors and nurses you will meet in adult clinics and contact details of people you can talk to.

You can read this information when you feel ready to and keep it to refer to when you need it.

What is transition?

This describes the process of planning, preparing and moving on from children's health care to adult health care.

Transition is a gradual process. It gives everyone time to talk about what health care you will need as an adult and make sure you are ready to make the move.

It is a sign that you are growing up and moving on with your life.

When does this happen?

Most young people move on to an adult hospital when they are between 16 and 18 years old. You can ask your parents or your consultant about when you will be making the move.

Whatever your plan, you will have time to make sure you feel ready.

If you were a teenager when you began treatment you will meet the Teenage and Young Adult Clinical Nurse Specialist, Julia Dahlstrom, who will help you bridge the gap between children and adult services.

Why do I need to move on?

The staff at the Children's Hospital are expert in caring for babies, children and teenagers: the staff in the adult services are experts in caring for young adults, like you, and older people.

The thought of moving to a new hospital and leaving the staff you have known over the years can be difficult but once you get used to the new adult hospital you will soon get to know the staff there.

You may already have met some of them at clinics in the Children's Hospital when they see patients as part of the transition process.

How will the adult service be different?

One of the main differences is the amount of independence you will be given.

Although this may seem scary, it is good to have more control over your health and the care you are given. This means you will need to learn about your condition, so that you can be more involved in your care and making decisions with the team overseeing your care.

Your parent, carer or close friend is still welcome to come with you if you want. Many adults bring someone with them to hospital appointments for support. You can still ask your parent or carer for advice if you want.

What can I do to prepare for transition?

- Learn about your condition and treatments.
- Practice asking and answering questions during your clinic appointments. Writing down any questions you have and bringing them with you is always helpful.
- Try to remember what your medicines are called, what they are for, how much to take and when to take them. Keeping a list with you can be helpful.
- Learn when and how to get more supplies of your medicines.
- Know if you are allergic to any tablets or medicines, and what kind of reaction you had.
- Practice arranging your appointments.
- Keep important numbers and appointment dates in your mobile phone, computer, or diary.

- When you agree to treatment plans, try to follow them carefully.
- Try spending part of your clinic appointment without your parent or carer. This may give you the opportunity to ask your doctor more personal questions without feeling embarrassed.
- Find out about any changes in your condition that mean you should get urgent help.
- Find out who to contact in an emergency.
- For some conditions or treatments, it may be helpful to wear
 a Medic Alert bracelet or necklace, so that if anything
 happened to you and you were by yourself, the ambulance
 team would know what to do.

Where are the adult follow-up and late effects clinics held?

These clinics take place in the Medical Outpatients' Department of the Royal Sussex County Hospital, opposite to the main hospital entrance, on Eastern Road.

When you arrive, you need to book in at the main Reception Desk and you will be shown where to wait for your appointment.

Who will I see?

Doctors you may meet include:

- Dr Ros Johnston, Consultant Haematologist.
- Dr Anna Crown, Consultant Endocrinologist.
- Dr Ed Kingdon, Renal Consultant.
- Dr Sabine Hippolyte, Respiratory Consultant.

You may also meet the nurse specialists:

- Sam Voss (Endocrine Nurse Specialist).
- Diane Fitzgerald (Haematology Nurse Specialist).
- Sophie McGoldrick (Late Effects Nurse Specialist).

Who can I talk to about my transition?

The nurse specialists will be able to help you by answering your questions, giving you information, offering advice and support, and helping you organise your move.

Julia Dahlstrom: Teenage and Young Adult Cancer Clinical Nurse Specialist. Mobile (working hours only)

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Nikki Huxter: Paediatric Clinical Nurse Specialist.

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Sarah Schnellmann-Smith: Paediatric Clinical Nurse Specialist.

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This information is intended for patients receiving care at Brighton & Hove, Worthing, Haywards Heath and Chichester St.Richard's hospital.

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