

The ROYAL MARSDEN

NHS Foundation Trust

Transition: Moving from
child to adult healthcare services

Information for young people aged 13–18 years

Oak Centre for Children and Young People

Patient Information



NHS

Introduction

This booklet will explain what transition is, how you will be involved in the process, and what changes happen as you grow older and become an adult. The aim of transition is to make your move to adult healthcare services as smooth as possible.

A separate booklet for parents and carers who want to know more about transition is available on The Royal Marsden patient information library via (link). The booklet is called *Transition: Moving from child to adult healthcare services. Information for parents and carers of young people aged 13–18 years*

<http://patientinfolibrary.royalmarsden.nhs.uk/>

What is transition?

In healthcare, we use the word ‘transition’ to describe the process of preparing, planning, and moving from child to teenage and young adult or adult healthcare services. Transition is a gradual process that gives you, and everyone involved in your care, time to get ready to make the move.

Each family takes a different approach to how much you, as a young person, are involved in taking care of your health. As you move to becoming an adult, we will work with you and those closest to you, to grow your confidence and independence in managing your own health and wellbeing.

It’s best to start transition early so everyone has plenty of time to prepare. If you are over 14 years old and your team hasn’t mentioned transition to you yet, ask them about it at your next appointment.

Why do I have to move?

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 you. 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 and leaving the staff that you have got to know over the years can be difficult. 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.

Before moving to adult healthcare services, we will offer you plenty of opportunities to talk about transition. We'll also give you information about what might change and the people and places that might be involved in your care as a young adult. When possible, your team will schedule a joint appointment for you to meet the team taking over your care, and visit the facilities.

When will I need to move?

The timing of the move to adult healthcare services varies from person to person but for most people it happens soon after your 18th birthday. By this stage, we hope that both you and your family feel confident and ready for your care to be transferred to the adult team. The adult team may treat patients aged 18 and over, or may be specialised in treating teenage and young adults (TYA) aged 16–25.

Who organises transition?

We want to make the transition as easy as possible for you and your family. To help this happen, every patient is allocated a member of staff who is responsible for organising their transition, known as the Transition Key Worker. The Transition Key Worker is responsible for ensuring that you are supported throughout the process and receive all the preparation needed to feel ready to move to adult services. The Transition Key Worker will link with your Paediatric Oncology Shared Care Unit (POSCU) and the adult team so that everyone works together.

Usually, your clinical nurse specialist or consultant takes the Transition Key Worker role, although other members of staff may be involved.

Talking to healthcare professionals on your own

Now you are older, we will offer you some time alone with your doctor or nurse. Other young people have told us that they find this useful. It gives you the chance to talk about the things that matter most to you, to practise asking your own questions and to get to know your doctor or nurse better. You could start by spending just a few minutes on your own either at the beginning or the end of your appointment.

If your team does not suggest this, let them know this is something you would like and they will happily arrange it for you.

What can I do to get ready to move on to adult healthcare services?

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 such as 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 healthcare services makes you feel. You should make plans with them about how you can practise getting involved in looking after your health and taking responsibility. As you get older your parents will still be able to support you and be involved in your healthcare. It will be up to you to decide how much you would like your parents to be involved.

If you know any other young people that have already finished their transition, it might be useful to ask them for tips on how to get ready. You could also ask them questions about the adult healthcare service. The *Further support and information* section on page 8 has information about opportunities for meeting other young people who have experienced cancer.

It might be helpful for you to practise doing the following things to help prepare you for adult care:

- practise asking and answering questions during clinic appointments so you can learn about your health and treatment
- take more responsibility for remembering your medicines and learning what they are called, what they are for, how much to take, when to take them and how to get more supplies
- practise arranging appointments with your consultant, family doctor (GP), physiotherapist or dietitian and learn how to cancel if you can't attend
- keep important phone numbers and appointment dates in your mobile phone, calendar or diary
- find out about any changes in your condition that mean you should get urgent help
- find out who to contact in an emergency.

Confidentiality

What you say to a healthcare professional is private and stays private. The exceptions to this are if you and/ or other people might be at risk of harm. If this is the case, the member of the team will discuss with you what parts of the information might need to be shared, who with, why it might be shared and how. They do not have to tell your parents what you have said in an appointment and would only do this with your permission. If there is something you are finding difficult to share with your parents, they can help you with this if you want.

As we work as a team, it may be necessary for individual staff to discuss your issues with other team members. If you do not want information to be shared, please let one of the team know.

Changes after your 16th birthday

Your 16th birthday may seem a long way off but there are important legal changes relating to your health that happen then. We need to make you aware of them so that you have plenty of time to get ready.

Consent – After your 16th birthday you will be the one asked to decide about treatments or operations. This will sometimes involve signing a consent form. There's no need to do this on your own – you can still discuss your options with your family, doctors or nurses. There are special rules that apply if the doctors think someone cannot understand information well enough to make a decision on their own.

Hospital communications – Once you are 16 years old, communications about your health should be addressed to you. This includes appointment letters, discharge summaries, clinic letters and test results. You can decide who can receive copies of letters or look at your medical notes after this age.

Arranging appointments – We encourage you to make appointments for yourself after you are 16. Your parents will only be able to make, cancel or change your appointments if you have given the hospital permission for them to do so. Booking and keeping track of appointments is an important skill to learn. You may want to ask your family how they make your appointments and keep track of dates and ask them to help as you learn to do it for yourself.

Changes related to your shared care

Children with cancer normally have shared care with a hospital nearer to their home, known as a Paediatric Oncology Shared Care Unit or POSCU. This means if you become unwell or need advice you can contact your POSCU and be admitted directly to the POSCU children's ward if necessary. For most people this will change when you turn 16 or 18. This means that if you become unwell after this age, you will need to go to A&E (Accident and Emergency) rather than the children's ward.

Speak to your POSCU or hospital nurse specialist about how shared care might change for you and what to do if you become unwell or need advice.

Ready, Steady, Go, Hello

At The Royal Marsden, we use the Ready, Steady, Go, Hello programme to help us support children, young people and their parents as they move to adult healthcare services. The aim of the programme is to help young people to take more control of their lives and manage their own health care.

The Ready Steady Go transition programme - Getting Ready

The medical and nursing team aim to support and help you develop the confidence and skills to take charge of your own healthcare.

Helping in this questionnaire will help the team create a programme to suit you.

Please answer all questions that are relevant to you and **ask** if you are unsure.

Name: _____ Date: _____

Knowledge and skills	Yes	I need to be supported with this	Comments
KNOWLEDGE			
I can describe my condition			
I know when to take my medications, names, doses, how often, etc.			
I know who works in the medical and hospital team			
I know who to contact if I have any concerns about my health			
I know about resources that offer support for young people and adults with my condition			
SELF-ADVOCACY (speaking up for yourself)			
I feel ready to start preparing to be seen alone for part of the clinic visit			
I ask my own questions in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team (e.g. Ask 3 Questions*)			
HEALTH AND LIFESTYLE			
I consider regularly having an active lifestyle			
I understand what appropriate eating means for my general health			
I understand the effects of smoking, drugs and alcohol on my condition and general health			
I am aware that my condition can affect how I feel and function (e.g. sexual function, fertility, contraception and how I can access information about sexual health)			

*See NHS.uk at <https://www.nhs.uk/healthcare-professionals/ask-3-questions/>

The Ready Steady Go transition programme - Steady

The medical and nursing team aim to support and help you develop the confidence and skills to take charge of your own healthcare.

Helping in this questionnaire will help the team create a programme to suit you.

Please answer all questions that are relevant to you and **ask** if you are unsure.

Name: _____ Date: _____

Knowledge and skills	Yes	I need to be supported with this	Comments
KNOWLEDGE			
I understand the medical terminology and procedures related to my condition			
I understand what each of my medications are for and their side effects			
I am responsible for my own medication at home			
I can read and collect my repeat prescriptions and know my own appointments			
I call the hospital myself if there is a query about my condition or/and therapy			
I know each member of the medical team can do for me			
I know who to contact if I have any concerns about my health			
I know about resources that offer support for young people and adults with my condition			
SELF-ADVOCACY (speaking up for yourself)			
I feel confident to speak up for the interests of both clinic visit and to ask my own questions			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team (e.g. Ask 3 Questions*)			
HEALTH AND LIFESTYLE			
I consider regularly having an active lifestyle			
I understand the effect of smoking, drugs and alcohol on my condition and general health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I feel and function (e.g. fertility, sexual function, fertility)			
I know where and how to access providers for accurate information about sexual health			
I understand the implications of my condition and drug on my pregnancy planning			

*See NHS.uk at <https://www.nhs.uk/healthcare-professionals/ask-3-questions/>

The Ready Steady Go transition programme - Go

The medical and nursing team aim to support and help you develop the confidence and skills to take charge of your own healthcare.

Helping in this questionnaire will help the team create a programme to suit you.

Please answer all questions that are relevant to you and **ask** if you are unsure.

Name: _____ Date: _____

Knowledge and skills	Yes	I need to be supported with this	Comments
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what is likely to happen with my condition in the future			
I understand what each of my medications' treatment is for and their side effects			
I can read and collect my repeat prescriptions and book my own appointments			
I know who to contact if I have any concerns about my health			
I call the hospital myself if there is a query about my condition or treatment			
I know about resources for young people or adults with my condition			
SELF-ADVOCACY (speaking up for yourself)			
I feel confident to speak up for the interests of both clinic visit and to ask my own questions			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team (e.g. Ask 3 Questions*)			
HEALTH AND LIFESTYLE			
I consider regularly having an active lifestyle			
I understand the effect of smoking, drugs and alcohol on my condition and general health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I feel and function (e.g. fertility, sexual function, fertility)			
I know where and how to access providers for accurate information about sexual health			
I understand the implications of my condition and drug on my pregnancy planning			

*See NHS.uk at <https://www.nhs.uk/healthcare-professionals/ask-3-questions/>

Stage 1: Ready

Usually this happens between the ages of 14 and 15 years, later if you are diagnosed after this age. We introduce you and your family to the idea of transition and what it might mean for you.

Stage 2: Steady

At 15 to 16 years, we help you to understand your cancer treatment and care, what you can do to help yourself, and how transition works. We do this by talking about it in more detail.

Stage 3: Go

At 17 to 18 years, we hope that you understand cancer treatment and care, what you can do to help yourself now and in the future, and where to find help if needed.

Stage 4: Hello

The adult team may use the *Hello* questionnaire to check how you are feeling about moving to adult care and review the transition plan.

At each stage your doctor or nurse will give you and the person accompanying you a questionnaire to fill out before you come into your appointment. Each questionnaire is designed to get you started thinking about transition and some of the things that matter to you. Some of the questions may not seem important and it is ok to leave those spaces blank. In your appointment the doctor or nurse will talk to you about the questionnaire and answer any questions you or your family might have.

Treatment summary and follow up care plan

Every young person finishing cancer treatment should be offered an end of treatment summary and care plan within six months of completing treatment. It contains a summary of your cancer treatment, recommended follow up care and sources of further support and information. It's a good idea to keep this document somewhere safe so that you can access it when you need it to help you and the people looking after you manage your health now and in the future.

After moving to adult healthcare services



It can be difficult to leave behind the people you have got to know in the children's service. It is important to know that you

can stay in touch with the children's team, but your new adult team will be your first point of contact in all matters related to your treatment and health.

The Teenage and Young Adult (TYA) service including the TYA Nurse, TCT Youth Support Worker and Young Lives vs Cancer worker are available and will offer you support until you turn 25, regardless of where you have your care or which team manages your care. Contact details and further information the TYA service can be found here:

www.royalmarsden.nhs.uk/your-care/children-and-young-people/patients-aged-16-24-teenagers-and-young-adults

Transition will be slightly different for each person. By talking about transition early and leaving plenty of time for discussions and questions, we hope that when the time comes for you to move to adult healthcare services you will feel fully prepared. If you have any further questions after reading this booklet, please speak to a doctor or nurse caring for you.

Further support and information

Children's Cancer and Leukaemia Group

CCLG provides information and support about childhood cancer. They offer publications specifically aimed at younger children, teenagers, siblings and grandparents.

www.cclg.org.uk

Ellen MacArthur Cancer Trust

This charity focuses on sailing and outdoor adventure, helping young people aged 8–24 build confidence and make connections.

www.ellenmacarthurcancertrust.org

Teenage Cancer Trust

TCT offers information and support designed for and with young people. They also run events for young people with cancer such as comedy nights, exercise challenges and concerts.

www.teenagecancertrust.org

TeensUnite

This charity brings young people aged 13–24 together, whether they have recently been diagnosed or are years into remission. They hold regular events such as days out at theme parks, and masterclasses from beauty to videography.

www.teensunite.org

Young Lives vs Cancer

This charity helps to support young people and their families to lessen the emotional and financial impact of cancer. They offer information for employers and schools as well as parents, grandparents and siblings.

www.younglivesvscancer.org.uk

Alike

The Alike app provides an inclusive space for young people with cancer to connect, chat online and to create a community.

www.alike.org.uk

References

This booklet is evidence based wherever the appropriate evidence is available.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

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No conflicts of interest were declared in the production of this booklet.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

The patient information service is generously supported by The Royal Marsden Charity.

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Registered Charity No.1095197



Published March 2023. Planned review March 2026
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Radiotherapy and
Chemotherapy Services
F538021 & F538022

