

The ROYAL MARSDEN

NHS Foundation Trust

Transition: Moving from
child to adult healthcare services

**Information for parents and carers of
young people aged 13–18 years**

Oak Centre for Children and Young People

Patient Information



NHS

Introduction

This booklet explains what transition is, how you will be involved in the process, and what you can do to support your child as they move towards adulthood and adult healthcare services. The aim of transition is to make sure your child's move to adult services is as smooth as possible.

A separate booklet for young people 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 young people aged 13–18 years*

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

What is transition?

As your son or daughter is getting older, you will be thinking more about their future. You may have heard people talking about '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 your child and everyone involved in your child's care, time to get ready to make the move.

It's best to start transition early, usually soon after the young person's 14th birthday and at least 3–6 months before moving to adult healthcare services. This gives everyone involved time to ensure that they feel prepared and ready without feeling rushed or unsupported.

When does the move to adult services happen?

The exact timing of the move from children's to adult healthcare services varies from person to person but for most young people it happens soon after their 18th birthday. By this stage, we hope that both you and your child will feel confident and ready for your child's 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.

It is important that both you and your teenager are comfortable with the transition and the new service. There may be a choice of which young adult or adult service your teenager can transfer to. Your team will be able to tell you more.

You and your teenager should receive information about the adult service, contact details for staff there, how the service is organised and how the adult services differ from our services. It might be possible for your team to arrange an informal visit to the adult service or organise other ways for you and your teenager to meet the new team and start getting to know them.

Who organises transition?

We want to make the transition as easy as possible for you and your teenager. To help this happen, every teenage 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 both you and your teenager 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 child's Paediatric Oncology Shared Care Unit (POSCU) and the adult team so that everyone works together to support the transition.

Usually, the clinical nurse specialist or consultant takes the Transition Key Worker role although other members of staff may be involved. You can discuss any queries or concerns with any member of your teenager's healthcare team.

Preparing for transition

In children's services, parents are given the responsibility for managing young people's health care, communicating with healthcare professionals and making important decisions. This

is different to adult healthcare services, where the responsibility is usually given to the patient rather than the family.

We know that approaching a move to adult healthcare services can be a scary time in a young person's life and that this can be difficult for parents as well. We will work with you and your teenager to ensure that you have the support and information you need.

Families often have an important role in supporting young people in gradually developing independence and becoming more involved in their health care. Parents and carers are often able to give young people tips on how to organise appointments, find out information, remember medicines and treatments and advise which questions to ask during admission, ward rounds and clinics.

Topics for you and your teenager to think over and discuss might include:

- learning the names of regular medicines, why they need them, how much to take and how often
- asking and answering questions about their health and treatments
- seeing their doctor or nurse on their own, for part of clinic appointments or consultations
- keeping track of hospital appointments and storing health information
- learning the ways their doctor or nurse can help them feel ready to move to adult healthcare services.

Some support groups and charities can offer valuable support to young people and their families who are going through the transition process. It may also be useful to speak with other families of teenagers who are getting ready for adult services.

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 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.

Fill in this questionnaire with your parent/carer to 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 would like to know more about this	Comment
KNOWLEDGE			
I can describe my condition			
I know when to take my medications, tablets, drops, how often, etc.			
I know what to do in the medical and nursing team			
I know when to contact if I have any concerns about my health			
I know about medicines 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 - i.e. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/often or as often as I can			
I understand what appropriate eating means for my general health			
I understand the effect of smoking, drugs and alcohol on my condition and general health			
I can assure that my condition can affect how I feel and function (e.g. mood, function, fatigue, fertility)			
I know when and how I can access information about mental health			

*See <http://www.nhs.uk/healthcareprofessionals/the-ask-3-questions-ask3/>

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.

Fill in this questionnaire with 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 would like to know more about this	Comment
KNOWLEDGE			
I understand the medical treatments and procedures relevant to my condition			
I understand what each of my medications are for and their side effects			
I am responsible for my medications at home			
I order and collect my repeat prescriptions and book my hospital appointments			
I ask the hospital myself if there is a query about my condition or condition therapy			
I know what each member of the medical team can do for me			
I know when to contact if I have any concerns about my health			
I know about medicines that offer support for young people and adults with my condition			
SELF-ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own for part/all of each 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 - i.e. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/often or as often as I can			
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 can assure that my condition can affect how I feel and function (e.g. mood, function, fatigue, fertility)			
I know when and how I can access provider for accurate information about mental health			
I understand the implications of my condition and drug on my pregnancy/breastfeeding			

*See <http://www.nhs.uk/healthcareprofessionals/the-ask-3-questions-ask3/>

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.

Fill in this questionnaire with 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 would like to know more about this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what to look to happen with my condition in the future			
I understand what each of my medication/ treatment is for and their side effects			
I book and collect my repeat prescriptions and book my own appointments			
I know when to contact if I have any concerns about my health			
I ask the hospital myself if there is a query about my condition or treatment			
I know about medicines that offer support for young people and adults with my condition			
SELF-ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team - i.e. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/often or as often as I can			
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 can assure that my condition can affect how I feel and function (e.g. mood, function, fatigue, fertility)			
I know when and how I can access provider for accurate information about mental health			
I understand the implications of my condition and drug on my pregnancy/breastfeeding			

*See <http://www.nhs.uk/healthcareprofessionals/the-ask-3-questions-ask3/>

At each stage the doctor or nurse gives the young person and the person accompanying them a questionnaire to fill out before they come into their appointment. Each questionnaire is designed to get you and your teenager thinking about transition and some of the things that matter to you both.

Stage 1: Ready

Usually, we introduce the idea of transition between the age of 14 and 15 and ask the young person to fill in the first of the questionnaires, *Getting Ready*.

Stage 2: Steady

At 15 to 16 years, we start talking about transition and moving to adult healthcare services in more detail. We aim to help the young person understand their cancer diagnosis, treatment and care, and what they can do to help themselves now and in the future.

Stage 3: Go

At 17 to 18 years, we ask the young person to complete the *Go* questionnaire. By this stage we hope that the young person has all the information they need about their cancer, its treatment, the follow up care and where to find help if needed. The aim is for the young person to feel ready to move to adult healthcare services.

Stage 4: Hello

The adult team may use the *Hello* questionnaire to check how your teenager is feeling about moving to adult healthcare services and to review the transition plan.

Talking to healthcare professionals on their own

Young people have told us they value spending time on their own with their healthcare team. They said that they sometimes have questions but are too embarrassed to ask them with their parents in the room. We know they are also more likely to be honest about things such as whether they sometimes forget to take any medicines.

Remember – everything your child says in the appointment on their own is kept confidential unless we are concerned for their safety.

Legal and financial changes when young people turn 16

Young people legally become responsible for things relating to their health care once they are 16. Special rules apply if the doctors think, for any reason, that a young person is not able to make decisions on their own.

Consent – Legally, once they are 16, your child should be the main decision maker for any treatment. They do not have to make decisions about any treatment on their own – you, their doctors and nurses and anyone else who usually supports them would be able to help as they have always done.

If you and your child disagree, there are people at The Royal Marsden who can help.

Hospital communications – After their 16th birthday, health communications such as clinic or discharge letters should be addressed directly to your child. We will ask them if they want you to carry on receiving letters as well. If they lack the capacity to agree to your receiving copies of letters, they will continue to be sent to the person or people with ‘parental responsibility’.

Making appointments – Your child should be the one to make or change the date or time of any of appointments unless they have given permission for you to do so.

Benefits – You might be receiving a Disability Living Allowance (DLA) payment to help with any additional costs of caring for your child. When they are 16 they will need to be reassessed to see if they qualify for a different payment called a Personal Independence Payment (PIP). The Department for Work and Pensions will contact you before their 16th birthday to explain how to claim for a PIP.

Details are available at the *Contact for families with disabled children* website (see page 8) or from your local Citizens Advice Bureau.

Changes related to 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 your child becomes unwell or you need advice, you can contact your POSCU and be admitted directly to the POSCU children’s ward if necessary. The age that POSCU services finish and adult health services start varies depending on where people live. In some areas, adult healthcare services start at 16 years and in others they start at 18 years.

If your cancer care team has not talked to you about how your teenager’s shared care might change, ask them about it at their next appointment. You might find it helpful to ask what support

and advice is available for your teenager if they become unwell, once they are too old to access the POSCU for inpatient care.

Treatment summary and follow up care plan

Every young person should be offered an end of treatment summary and care plan within six months of completing cancer treatment. It contains a summary of their cancer treatment, recommended follow up care and sources of further support and information. This document can be accessed when needed to help your child and the people looking after your child manage their health now and in the future.

Long-Term Follow Up

The Long-Term Follow Up Service is specifically for people who have finished their cancer treatments and do not need close monitoring for disease recurrence; this is usually from about 5 years after finishing treatment. Follow this link for more information about long term follow up:

<http://patientinfolibrary.royalmarsden.nhs.uk/long-term-follow-up-service>

After moving to adult services



The most difficult thing for some families is to break contact with the children's service. While you can stay in touch with the children's team, it is important for your teenager's continuing health that any questions or concerns are discussed with the adult team and they are the first point of contact in all matters related to their own 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 continue to offer your teenager support until they turn 25. This is regardless of where they have had their care or which team manages their care. Further information and contact details 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 your teenager 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 your teenager.

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

Contact for families with disabled children

Support with benefits, tax credits, education and social care. Contacts also offers Listening Ear telephone appointments with a family support advisor.

www.contact.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

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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

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