

Haematology Department

Transition from Paediatric to Adult Services for Adolescents with Red Cell Disorders

Information for patients

Introduction

This leaflet is designed to explain about the transition process from Alder Hey Children's Hospital to the Royal Liverpool University Hospital. If you have any questions about transition after reading it please speak to your nurse specialist or haematology doctor.

What is transition?

Transition is a purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult-orientated health care systems. It is a process that will enable you to take responsibility for your own health, by making informed choices and decisions about your health and well being, both now and in the future. Transition is one of the greatest challenges for the young person and their family and we want to aim for it to be a problem free event.

What is the transition process?

You will be introduced to the transition process when you are about 12-13 years old. The transition process takes time and is done over a number of years, with the aim of increasing your independence over that time. Firstly, you will be given a self-assessment questionnaire, the aim of which is to identify your needs. This will form the basis of your personal transition action plan. The transition action plan will help you become more knowledgeable, confident and competent in understanding and managing your condition. It will help to clarify current and future health needs and allow for us to have clinical services in place when you move from children's to adult services. You will be involved at all stages of your transition plan. The self-assessment questionnaire will be carried out again when you are between 14-15 years old, and when you are over 16 years old. You will also be given a red cell workbook. This will be an educational tool to be worked through with your nurse specialist and doctor to help increase your knowledge about your condition.

Transition clinic

From the age of 13 you will be attending a clinic that the adult consultant haematologist attends. This gives you the opportunity to meet the adult team, and for the adult team to meet you and your family. When you first attend clinic your parents will be involved, but as you get older we will encourage you to do the clinic appointment by yourself. You will be supported in doing this, and we will only encourage you to do clinic appointments by yourself when you are ready to do so.

Transfer to adult services

Before you transfer to adult services we will give you the opportunity to go and visit the adult hospital and meet the adult team. This will be done with your nurse specialist, your parents and other teenagers with blood disorders who are part of the transition process. We will also give you a booklet about services at The Royal Liverpool Hospital, how to access them and contact numbers.

Between the ages of 16-18 we will transfer your care to The Royal Liverpool University Hospital. The age you go to the adult hospital will depend upon your transition action plan. Everyone is ready to go to adult services at different ages. Don't worry if you do not feel ready at 16 to move to adult services. We will work with you to support you.

When you are ready for transfer, a referral letter will be written by the paediatric doctors to the adult doctors. When they receive this, you will be sent a clinic appointment. Until you attend your first clinic appointment you will still come to Alder Hey for your treatment and clinics.

Your first clinic with The Royal Liverpool University Hospital

At your first clinic appointment a full medical history will be taken. You will have to tell the doctor about any problems you have had, what your current medical treatment is and you will be given the opportunity to discuss any fears or concerns that you may have about coming to adult services. You will also have some blood tests done. The doctors will also make sure that you know who to contact for advice, and when and where to come if you are worried or unwell. They will also check that you have all the relevant contact numbers.

The nurse specialist from Alder Hey will attend your first clinic appointment with you.

Further information

If you need any further information please contact the nurse specialist on 0151 252 5070

Useful websites

www.alderhey.co.uk

www.rlbuh.nhs.uk

www.ukts.org.uk

www.teenagehealthfreak.co.uk

www.connexionslive.com

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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Review Date: May 2024

PIAG: 0085

