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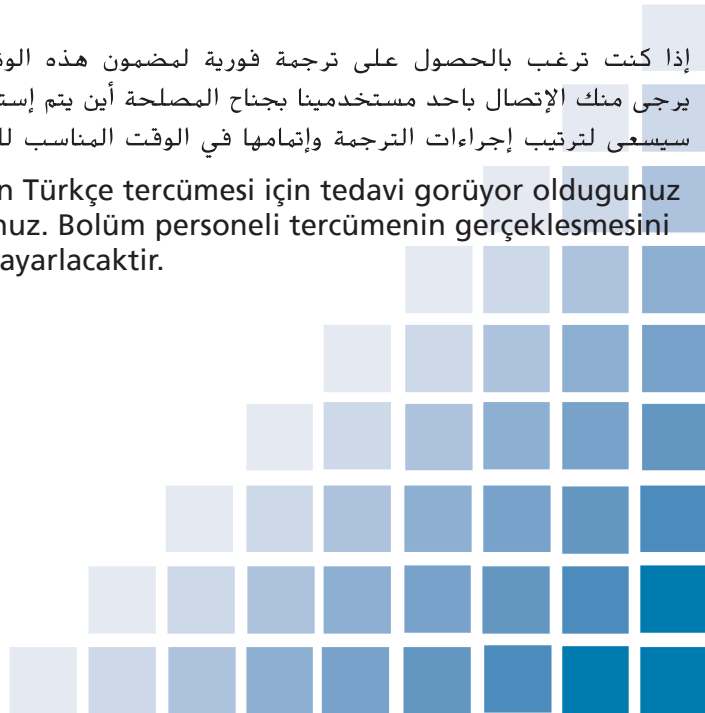
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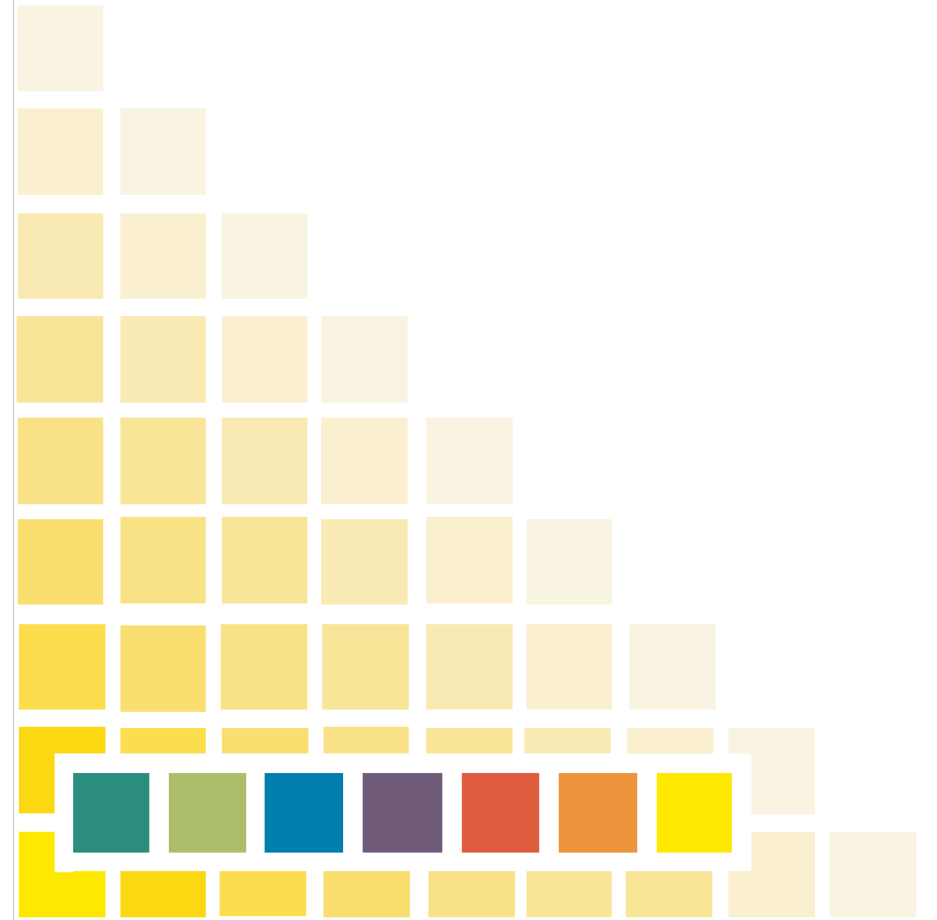
November 2007

إذا كنت ترغب بالحصول على ترجمة فورية لمضمون هذه الوثيقة الى اللغة العربية، يرجى منك الإتصال باحد مستخدمينا بجناح المصلحة أين يتم إستشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosürteki bilginin Türkçe tercümesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercümenin gerçekleşmesini en kısa zamanda ayaracaktır.



Transition: information for young people growing up with congenital heart disease



Welcome to the congenital cardiology transition service!

We have written this leaflet to give you information on a process called "transition". This is the time during which you move from the paediatric (children's) cardiology service, which has cared for you since you were diagnosed with a heart condition, to the adult service. The leaflet does not replace explanations given to you by our staff but we hope it will be a useful guide for you to use as you move from the paediatric to the adult service. If you have any questions or need any further information please just ask.

What is transition?

Transition is the term we use to describe moving from the paediatric (children's) cardiology service to the adult service. It is a period during which you will become more involved in dealing with your heart problem and more responsible for your own health.

When does the transition process start?

When you turn thirteen, you will start to come to our young persons' congenital cardiology clinics. These are still run in the paediatric outpatients department and the majority of the patients attending will be teenagers (sometimes we see younger patients at these clinics if they require emergency appointments).

The clinics have been set up to help you become more independent and to understand your condition better. At the young persons' clinic the emphasis will be on you and on helping you look after yourself. The more you know about your condition, its treatment, and how to take care of your health the more prepared you will be when it is time to move over to the adult service.

Who can I contact with comments or if I want further information?

If you have any questions or queries or would like any further information, please contact the specialist transition nurse.

Lynda Davies Shaughnessy
BHF cardiac nurse specialist (transition)
Tel: 020 7352 8121 bleep 1129
Mobile: 07974 184268
Email: l.shaughnessy@rbht.nhs.uk

We are always pleased to hear any comments or ideas that you may have about our services – please just get in touch.

If you have concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call Patient Advice and Liaison Service (PALS) on 020 7349 7715 or e-mail pals@rbht.nhs.uk. This is a confidential service.

What is the adult department like?

Our adult congenital heart disease (ACHD) unit is one of the largest specialised centres in the world. It provides a full range of outpatient and inpatient care for patients with a variety of congenital heart conditions. Our ACHD team works closely with doctors from the paediatric cardiology team that has looked after you over the years. Our transition nurse can answer any questions you may have about the adult unit – just ask.

An important part of the work at our Trust is research. We are working to find new ways to diagnose and treat heart disease, and also train new doctors and nurses to become specialists in this area. We may sometimes ask you to take part in research. If we do ask you we will give you full information on the study at the time and it will be your choice as to whether or not you would like to take part.

Will I still go to Rose Ward if I have to be admitted?

If you are 15 or under and need to come into hospital you will be cared for on Rose Ward. If you are 16 years or older you will generally stay on Paul Wood Ward but will be looked after by your paediatric consultant until you have officially transferred to the adult department.

What happens if I move or go away to university when I get older?

The most important way of looking after your health is to have regular check ups and so it is really important that you let us know if you change your address or go away to university. Some patients with simple congenital heart problems can be discharged from regular care but others need to be seen regularly – although this may only be every couple of years. As you get older you will become responsible for making and attending your outpatient appointments. Remember that it is very important to let us know if you are unable to attend an appointment you have booked.

Who will help me through the transition process?

Here at Royal Brompton & Harefield NHS Trust we have a specialist nurse to help you through the transition process. She will help to prepare you for living as an adult with congenital heart disease.

You will have a chance to meet this nurse at the young persons' clinic. She will talk to you about your condition, and will use pictures to explain it to you. She will also talk to you about issues around growing up with congenital heart disease, including exercise, employment, insurance, and sexual health, and will give you information on support groups. You can ask this nurse any questions you may have about moving into the adult cardiology service. She regularly attends the adult clinics and the hospital wards and so can answer any questions you may have about either of these.

Will I see my usual doctor and nurses at the young persons' clinic?

Yes, as well as seeing the transition nurse specialist you will see the same consultant and doctors as before and will stay under the care of your children's cardiac liaison nurse, who will communicate between your local hospital team, community medical team, and our hospitals. The transition nurse specialist sees you in addition to the doctors and nurses you usually see – not instead of them.

Will I be expected to see the doctor alone at the young persons' clinic?

Whether or not your parents come into your doctor's appointment with you is entirely up to you. When you first start coming to the young persons' clinic you may want your mum, dad or guardian to see the doctor with you. It is often useful to have someone with you during clinic. Sometimes you may forget some of the things you discuss with the doctor – things that the person who was with you may remember.

As you grow older and get used to attending these clinics you may take the decision to talk to the doctors by yourself. An important part of transition and the young persons' clinic is preparing your whole family for your move from a child patient to an adult patient.

Whether or not your parents are with you during your appointment, your doctor will talk directly to you and you can ask any questions directly to him or her.

What if I want to discuss an issue with the doctor that I don't want my parents to know about?

This is absolutely fine. You could start the appointment with your parents in the room and then have time alone with the doctor at the end of the appointment if you would like. Or you could see the doctor with your parents but see the nurse specialist alone. It is entirely up to you. Remember that whatever you say to our doctors or nurses is treated in confidence – this means it will not be discussed with anyone else without your permission.

When will I stop going to the paediatric outpatients department and move to the adult department?

Different people are ready to move on at different times – some people move on at 16, some at 18. Part of the role of the transition nurse specialist is to suggest when you are ready to move on and make sure you are comfortable with the decision.