

# Transition

## Definition

Transition is the purposeful, planned process whereby children with chronic medical conditions move from child-centred to adult-orientated health care systems.

Transition is not simply the transfer of care between services but involves systematically addressing the medical, psychosocial and educational/vocational needs of young people with chronic health issues; it begins in early adolescence and is an ongoing process throughout teenage years and is completed when the young person moves to adult services.

## Background

Historically, patients have had a poor understanding of their medical condition as they grow up. Loss to follow up is common in teenage years, occurring in up to half of cases, and can have disastrous consequences in terms of morbidity and mortality. Poorly planned transition increases the risk of this loss to follow-up and non-adherence to treatment. It can also result in adverse social and educational outcomes for the young person.

## Aim

The aims of successful transition are:-

- to facilitate smooth transfer of care between child-orientated and adult services;
- to educate patients about their medical condition and support them in taking over the responsibility for their health from their parents or caregivers;
- to educate patient about any medication they may be taking and its purpose;
- to recognise when their condition may be changing and to know what to do if this occurs;
- to provide a point of contact for medical, psychological or social support;
- to support the patient in achieving their maximum potential socially and educationally; and
- to educate about lifestyle issues such as smoking, pregnancy and contraception.

Transition should be individualised and issues discussed as soon as appropriate for each patient. Patients are encouraged to make informed choices. Written information should be given where possible to support verbal information.

## Patient Education

Issues which need to be addressed as part of transition are:-

- specific medical information, enabling them to understand their cardiac condition, including medication and the importance of compliance;
- pregnancy and inheritance;
- endocarditis prevention and prophylaxis;
- employability and insurability; and
- support with learning disabilities;
- lifestyle issues, diet, smoking, safe alcohol limits/drugs and exercise;
- psychological support;
- information about websites and support organisations.

### **Specific medical information, including understanding of medication and compliance**

Less than 50% of patients can explain their diagnosis by the time they reach adulthood. Time spent with diagrams and appropriate information about the defect and possible changes in the condition (particularly arrhythmias, heart failure and secondary pulmonary hypertension) should be part of an ongoing process. Information should be given at an appropriate level, in jargon-free language, and repeated and expanded upon as the teenager is able.

It is important to establish what the patient understands about their medication and how often they actually take it. If they only take medication less than half the time, identify the most important medication with them, for example warfarin, why they need to take it, and the implications for them if they do not take it. Compliance is also improved by explaining possible side effects.

### **Psychological support**

Support may be needed by patients with complex conditions and reduced life expectancy. Anxiety disorders are common, especially needle and hospital phobias. Support may be provided by the patient's own team or local psychology or liaison psychiatry services. CBT can be very helpful. The "feeling of being different" emerges in adolescence when physical performance and appearance are important; patients often require support around body image in their teenage years. Families may need support to enable them to allow their child to begin to manage their own condition.

### **Support with learning disabilities**

Learning disabilities are common in patients with congenital heart disease. Any information given to families and patients will need to be at an appropriate level in an appropriate format. Involvement of the community learning disability team, from the patient's home area, is valuable. Psychological or psychiatric assessments may be required for issues around informed consent and early onset dementia. Capacity assessments will be required and Best interest meetings necessary if the patient does not have capacity.

## **Lifestyle issues**

Encouraging teenagers to adopt a healthy lifestyle is crucial in patients with pre-existing cardiac disease. Unhealthy lifestyle choices will predispose them to acquired heart disease and the importance of avoiding this must be emphasised.

### **Exercise**

A significant proportion of patients with congenital heart disease have been inappropriately advised not to exercise in childhood and many are afraid that they will damage their heart by doing so. Therefore it is especially important to encourage each individual patient to be physically active and exercise within safe limits for their particular heart condition. The majority of patients can exercise aerobically completely safely, though competitive or endurance sports and weight lifting are advised against in some patients.

### **Smoking**

Patients should be strongly advised of the dangers of smoking, with particular reference to acquired heart disease. The concept of cardiovascular risk factors for heart attack and stroke need to be introduced so that the patients know how to reduce their risk of acquired heart disease by adopting a healthy lifestyle.

### **Alcohol and Stimulant Drinks**

Many young people are unaware what safe drinking is. Advice on safe alcohol consumption should be given, with particular reference to drugs that may interact with alcohol, such as warfarin. The medical and social effects of excessive alcohol should be discussed. Many patients suffer from arrhythmias secondary to binge drinking and excessive consumption of energy drinks, which contain stimulants. Patients need to be educated about the risk of consumption of these products. Stimulant drinks should be avoided.

### **Recreational Drugs**

Recreational drug use carries increased dangers for young people with congenital disease, depending on the substance taken. Dangerous effects on blood pressure, heart rate, arrhythmias, stroke and damage to cardiac muscle can occur together with serious respiratory, neurological, gastrointestinal and psychological problems and patients need to be educated on these risks.

### **Diet**

Information on healthy eating should be given to all patients and a healthy BMI should be encouraged.

## **Pregnancy, contraception and inheritance**

### **Pregnancy**

During pregnancy the workload on the heart increases considerably. However, most patients with congenital heart disease can safely undergo a pregnancy; few women advised not to become pregnant. Pre-pregnancy counselling is advised for all women with pre-existing heart disease and this should be done by cardiologists and obstetricians with experience in caring for pregnant women with heart disease. Issues discussed include how well a pregnancy would be tolerated, complications that may occur, how often the patient will need to be seen, the effect of pregnancy on the cardiac condition, the type of delivery to expect and how any medications taken by the patients might impact the pregnancy. Inheritance will also be discussed. An echo or exercise test may be performed to help inform the discussion. Medication needs be reviewed, particularly ACE inhibitors and warfarin, which are not safe in pregnancy. During pregnancy, care should be managed in a joint obstetric/cardiology antenatal clinic with input from obstetric anaesthetists and specialist midwives. Vaginal delivery is advised for most women with cardiac conditions.

### **Contraception**

Contraceptive choices should be discussed with all patients, as well as the importance of using condoms to reduce the risk of sexually transmitted infections. Most contraceptives are suitable for the majority of patients. However some patients, for example those with venous baffles, patients with mechanical valves and those who are cyanosed, should avoid the combined oestrogen-containing pill, due to the increased risk of thrombosis. Generally, progesterone-only methods are safe for all cardiac conditions. If compliance with an oral contraceptive is thought to be an issue, depot injections or the contraceptive implant can be helpful.

### **Inheritance**

The issue of passing on congenital heart disease to offspring should be discussed with all patients. The overall risk varies depending on the individual lesion but ranges from 4-10%. Some single gene defects are inherited in an autosomal dominant fashion and this needs to be discussed if applicable. Fetal echocardiography is offered to all patients. Referral to genetic counselling can be made in certain circumstances.

## **Endocarditis prevention and prophylaxis**

Most patients with congenital heart disease are at increased risk of endocarditis, especially if they have prosthetic valves or have had previous endocarditis.

Micro-organisms enter the blood stream as a result of poor dental hygiene, dental intervention, piercings, tattoos, acupuncture, poor nail and skin care, and minor injuries. Enabling the patient to recognise the symptoms of endocarditis so that they can seek appropriate intervention as soon as possible is important. Patients should be told that flu-like symptoms with fever and night sweats lasting more than five days need to be investigated and that blood cultures should be taken before any antibiotic treatment is commenced. Patients should be advised that treatment is four to six weeks in hospital on intra-venous anti-biotics.

## Employability and Insurability

Many patients with chronic medical conditions, particularly those that will reduce their life expectancy or ability to work, experience problems with employability and insurability. Patients with complex or palliated lesions are disadvantaged in employment and discrimination can occur. Patients undergoing a period of cardiac investigation and intervention are also at risk of employment difficulties. Obtaining life insurance can be difficult. Many patients do not declare their cardiac condition or remain uninsured. Advice can be given on companies who insure those with cardiac conditions more readily than others.

## Information about support organisations

There are many groups providing support to adult patients with congenital heart disease. It is important to make patients aware of these and provide them with published literature. Young people appreciate appropriate website information. Patients are often warned that, though much information on their condition may be available on the internet, many websites are not vetted by medical personnel and some information may be erroneous.

The clinical nurse specialist service is key in supporting patients and providing education and information in all the above areas.

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