



# How to manage the transition: psychological aspects

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The journey from adolescence into adulthood is a challenging time for all young people from a biological, social and psychological perspective. For those with long term health needs this is made even more difficult



# Guidelines

- Dept. of Health –Transition; moving on well
- RCN –Lost in Transition ;moving young people between child and adult health services
- CQC 2014 -Children's transition to adult services
- NICE guidelines- Transition from children's to adult health and social care services



# CQC report 2014

Found only 50% of young people and their carers had received help from a lead professional during the transition process

Many families found it caused stress and anxiety ,

“ from the pond ,you are picked up and put in the sea “



**Transition is a process that takes place over a period of time and is not a single event .**

It is dependant on a flexibility that takes into account the young persons wishes ,needs ,and developmental readiness .



The key factors are;

Person Centred Care

Holistic approach involving a multi-disciplinary -team

A key worker can play a very important role in this process .

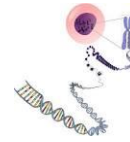


# Diagnostic Categories

For individuals and families at risk of, or affected by, inherited cardiac conditions and Sudden Cardiac Death.

Clinically affected  
Screening  
Gene positive - asymptomatic

Cardiomyopathies - ARVC, Dilated, Hypertrophic, Restrictive



Arrhythmias - Brugada, Long Q-T, CPVT

Connective Tissue and Vasculopathies

Marfan Syndrome, Dominant Aortic Aneurysms,  
Ehlers-Danlos IV, Primary Pulmonary Hypertension, Loeys-Dietz

Chromosomal and Genetic Syndromes

These conditions are of different modes of Inheritance, Heterogeneous and Variable penetrance and expression



# Emotional issues

- ♥ Survivor guilt
- ♥ Uncertainty of diagnosis
- ♥ Asymptomatic but affected
- ♥ Over protection of family members
- ♥ Restrictions on lifestyle
- ♥ Family relationships
- ♥ Genetic testing – child's autonomy for future care
- ♥ Lifestyle changes
- ♥ Affects of treatment
- ♥ Mortality
- ♥ Perception of world as a dangerous place
- ♥ Fear, Anxiety, depression, isolation
- ♥ Grief
- ♥ Loss/changes to life as they know it
- ♥ Adapting to Role changes
- ♥ Cause of death - uncertainty
- ♥ Anger at misdiagnosis
- ♥ Employment- childcare issues
- ♥ Financial



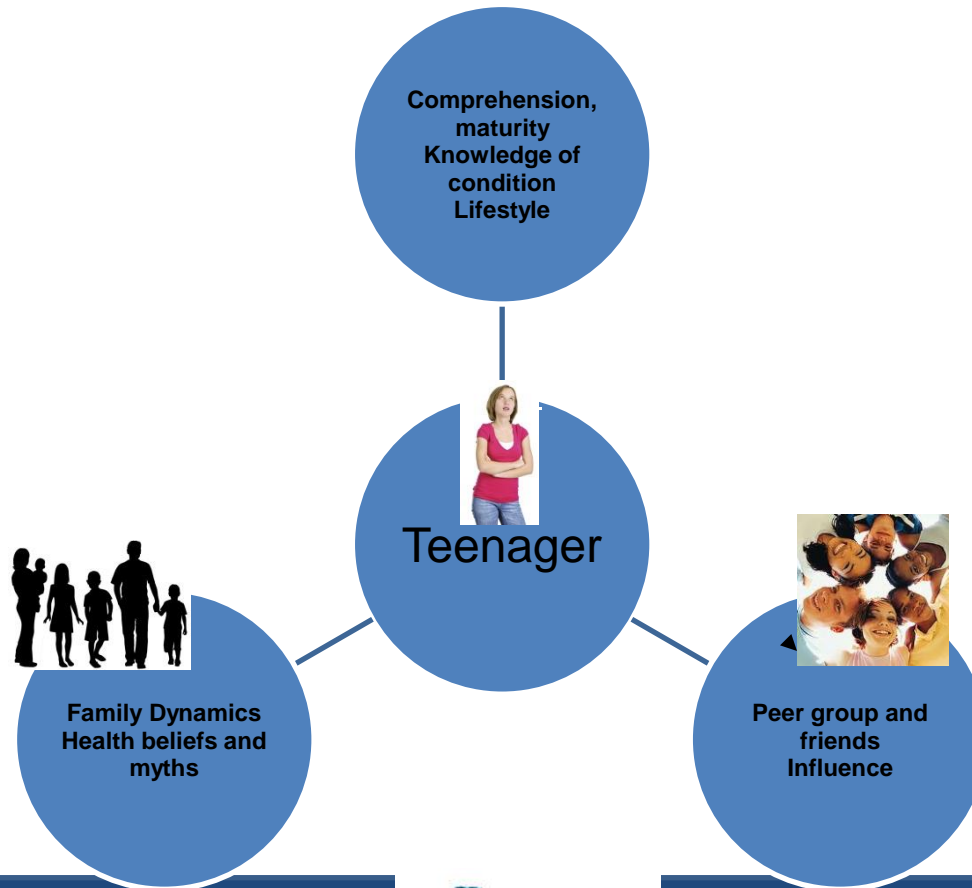
Appreciate the emotional ,ethical ,legal and social impact of an inherited cardiac condition may have on the young person and their family ,when assessing needs

- Stage of life and experience of the condition
- Family dynamics and myths
- Coping strategies and social support
- Personal History. Early loss, early trauma, relationship with parents, ability to confide ability to make and sustain relationships
- Grief and loss
- Guilt and fear
- Transcultural issues





# Assessment



# Working with the young person

Building a relationship with the patient –Listening to their concerns ,fears anxiety .

Empowering them to manage the situation and acknowledging that the relationships change as they become an adult .

Learn about family dynamics ,accept they may not change, but have to find a way to help them manage the transition .



# Working with Parents and Carers

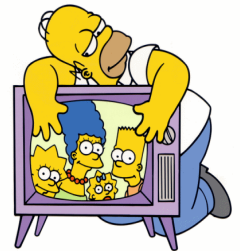
Young persons rights should be respected and protected(right of autonomy)

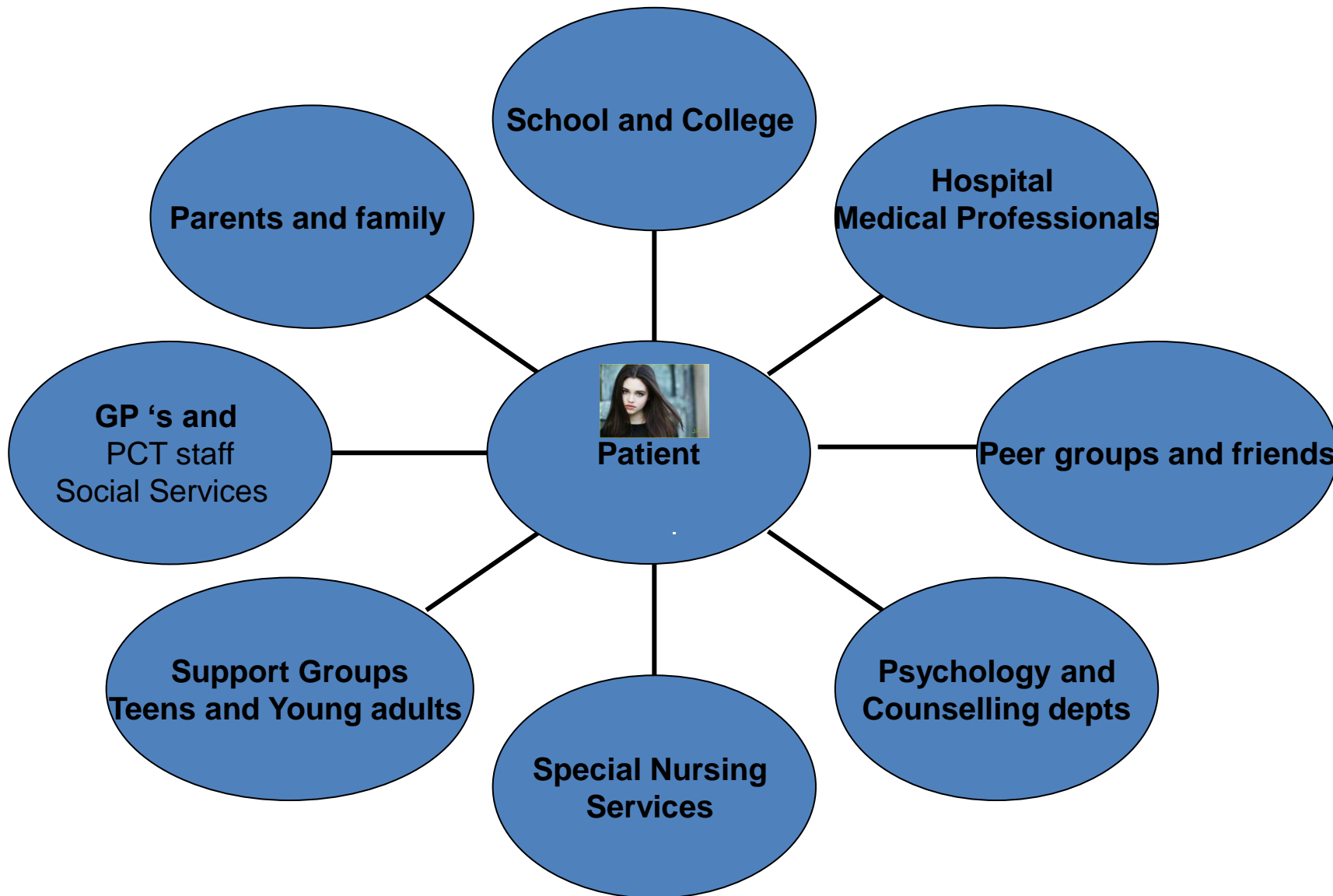
But ...Parents and carers also need support as the teenager becomes more independent .

They are still involved in their child's care throughout the transition process .

They may be over protective ,secrecy ,have different views and opinions .

Avoid collusion , remain impartial





# Thank you for your attention

## Any Questions



