National Clinical
& Integrated Care Programmes
Person-centred, co-ordinated care

ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND

Guide for planning the transition of young people with a rare disease from paediatric to adult healthcare services

The National Clinical Programme for Rare Diseases

Version 1.1 February 16 2021

Building a
Better Health
Service

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Introduction

The National Clinical Programme for Rare Diseases was established to ensure that the needs of people with rare diseases are recognised, understood and addressed in a coordinated and patient-centred way. The programme is a partnership between the HSE and the Royal College of Physicians of Ireland. As of September 2020 the functions of the NCPRD was operationalised and transferred to the National Rare Diseases Office (NRDO) within Acute Operations, HSE governance structures.

In July 2018 the programme published a Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases. Leading on from the publication of this document, this guide has been developed to assist with the transition of young people with rare diseases from paediatric to adult healthcare services. This guide contains a number of prompts and guiding principles that can be considered when planning the transition of care for a young person.

Additional information and guidance

For more detailed recommendations about the transition of young people living with rare diseases please refer to the Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases, which is available on the website of the National Rare Diseases Office. A number of resources for healthcare providers are also available on the website (www.rare.diseases.ie), including a summary version of the model of care and a template for writing a patient summary in advance of transfer to an adult healthcare provider.

The National Rare Diseases Office provides current and reliable information about genetic and rare diseases to patients, families and healthcare professionals. The office was established in 2015 by the HSE and is staffed by healthcare professionals who have significant experience working with people affected by rare diseases. The office can help to identify national and European experts in the management of specific rare diseases and also provides contact details for patient support groups and information about European Reference Networks and clinical research projects. The office can be contacted via email (rare.diseases@mater.ie) and by phone on (01) 8545065.

Principles of transition

For successful transition to occur a developmentally-appropriate transition plan should be developed in collaboration with the affected young person and their family. The transition plan should address the young person's specific health issues as well as their wider physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial needs. Six key areas have been identified as the core issues for discussion throughout the transition process to ensure a comprehensive and holistic encounter for the participating young person and their family (Figure 1).

This is also available as a Microsoft Word document so that it can be adapted locally.
Please contact the National Rare Diseases Office to request a copy (rare.diseases@mater.ie).

Thematic area	Prompts and guiding principles	Circle as appropriate	
Diagnosis	Does the patient have a confirmed diagnosis? If no; consider options e.g. MDT discussion, referral to genetics, further expert involvement via European Reference Networks etc.	Yes	No
	Does the patient have access to a genetic consultation?	Yes	No
	Does the patient have access to genetic counselling?	Yes	No
	Has the patient and parent/guardian been informed of and understand the diagnosis?	Yes	No
	Do various methods of communication need to be considered for the patient?	Yes	No
Treatment pathways	Are there recommended treatment guidelines for the rare disease?	Yes	No
Collaboration	Has the 'primary' speciality been identified? Details:	Yes	No
	Identify all specialities involved in the care of the patient, e.g. acute care specialities, primary care and centres of expertise Details:		
	Identify the multidisciplinary team, e.g. Physiotherapist, Occupational Therapist, Speech Therapist, Dietician, Psychologist, Medical Social Worker, etc. Details:		
	Appoint a key worker to coordinate with all stakeholders.		
Age of transition	Consider the chronological and/or developmental age in transition planning. Chronological age of the patient: ___ Developmental age of the patient: ___		
Patient and family	Is there a shared understanding of the need to transition?	Yes	No

Thematic area	Prompts and guiding principles	Circle as appropriate	
preparedness	Is transition planning/goal setting offered to and agreed with the patient?	Yes	No
	Is the patient able to self-treat?	Yes	No
	Are local shared-care arrangements available?	Yes	No
	Consider means of collaboration with parents/guardian, carers and adult healthcare providers, including primary care.		
	Consider the impact of the patient's intellectual/physical disability (if applicable) on transition.		
Support groups	Contact the National Rare Diseases Office for assistance in identifying the most relevant patient support group for the young person and their family.		
Adult healthcare provider	Is there a designated and agreed adult service provider? Contact the National Rare Diseases Office to identify national and international centres of expertise.	Yes	No
	Has the age for final transfer been agreed with the adult healthcare provider?	Yes	No
Biological and social aspects of adolescence	Consider the behavioural and social differences between teenagers and adults. Adapt communication methods and style and consider clinical psychology input if available. Collaborate by working together and support all aspects of transition (see figure 1 below).		
Education	Inform and involve schools/teachers/educators.		
Mobility	Are there mobility requirements to consider and plan for?	Yes	No
Medical interventions	Have acute or emergency treatments been identified and agreed? Details:	Yes	No

Thematic area	Prompts and guiding principles	Circle as appropriate
Notes:		

Figure 1: Principles of transition

Young person in transition

Self-advocacy: can describe own conditon, understands differences between paediatric & adult services. Able to access information about condition, can ask questions about own condition or treatment.

Psychosocial support: parental/carer concerns understood & discussed, YP understands benefits of supportive relationships, future goals set, assisstance identified. Named/key worker identified.

Sexual & reproductive health:

understands puberty changes, sex & sexuality capabilities, consent, possible fertility & genetic issues.

Independent health care behaviour: understands own medication & treatment, how to access emergency help, confidentiality, met with adult HCPs, records & tracks own health care information.

Educational & vocational planning: Discussion re. educational, vocational and employment options, understands any possible restrictions. life skills discussed

Health & lifestyle: smoking, alcohol and recreational drug use implications are discussed. Body image issues and mental health issues discussed, associated technology needs discussed