



## Summary

# Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases

## The National Clinical Programme for Rare Diseases



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

  
**ROYAL  
COLLEGE OF  
PHYSICIANS  
OF IRELAND**

Building a  
Better Health  
Service

Seirbhís Sláinte  
Níos Fearr  
á Forbairt

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## 1. INTRODUCTION

This document has been developed to assist healthcare professionals who provide care for young adults with rare diseases. It focuses specifically on guiding principles to support the successful transition of young adults who are living with a rare disease from paediatric to adult healthcare providers. This document is a summary of the key recommendations from the Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases which was published by the National Clinical Programme for Rare Diseases in July 2018.

## 2. DEFINITIONS & KEY CONCEPTS

### 2.1 RARE DISEASES

A rare disease is defined in the EU as a disease or disorder affecting fewer than 5 in 10,000 of the European population. There are an estimated 6-8,000 known rare diseases affecting up to 8% of the total EU population, representing up to 300,000 Irish people during their lives. Estimates suggest that around 50-75% of all rare diseases affect children.

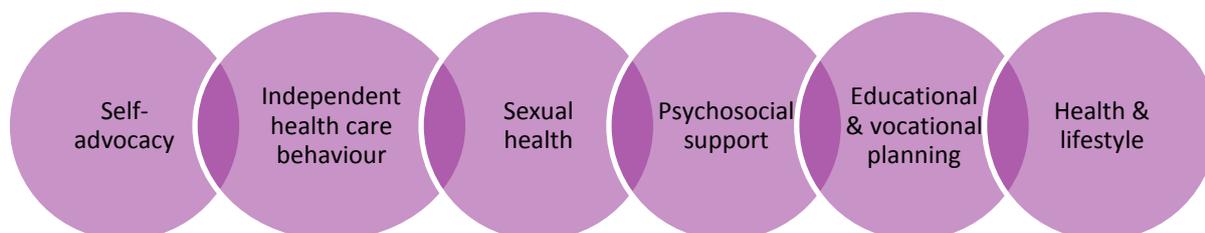
### 2.2 TRANSITION

The concept of transition is defined as the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems. In the context of rare and ultra-rare diseases transition has added and unique challenges. Three groups with broadly different needs should be considered in the planning process:

1. Those with a rare chronic but relatively stable condition for which normal or near-normal life expectancy is anticipated.
2. Those with a rare life-limiting condition.
3. Those with a rare condition associated with complex needs - intellectual and/or physical disability.

For successful transition to occur a developmentally appropriate transition plan should be developed in collaboration with the young person and their family. The transition plan should address not only the young person's specific health issues but 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 adolescent and their families.

These are:



Collaboration across various healthcare settings is vital for successful transition given the nature of national services and expertise. This requires solutions which address the alignment of healthcare providers in multiple settings, with facilitated communication, record sharing, capacity building and related audit and clinical research.

### 3. GUIDING PRINCIPLES FOR TRANSITION IN RARE DISEASES

For additional information on these guiding principles please refer to the Model of Care for Transition to Paediatric Healthcare Providers.

#### Hospital documents

- Hospitals should have a transition policy which is publically available.
- Both paediatric and adult hospitals should share common care pathways and guidelines. This documentation should be publically available.
- The care pathway/medical summary/emergency care plans should be available in a developmentally appropriate format.
- The transfer package including medical/surgical, nursing and HSCP summary and care plans should be transferred to adult healthcare provider at least four weeks in advance of the young person's first adult OPD appointment.
- Regular audits of the transition process should be carried out. This should include feedback from young adults and their families. Clinic attendance rates should be evaluated on a regular basis.

#### Service & workforce planning

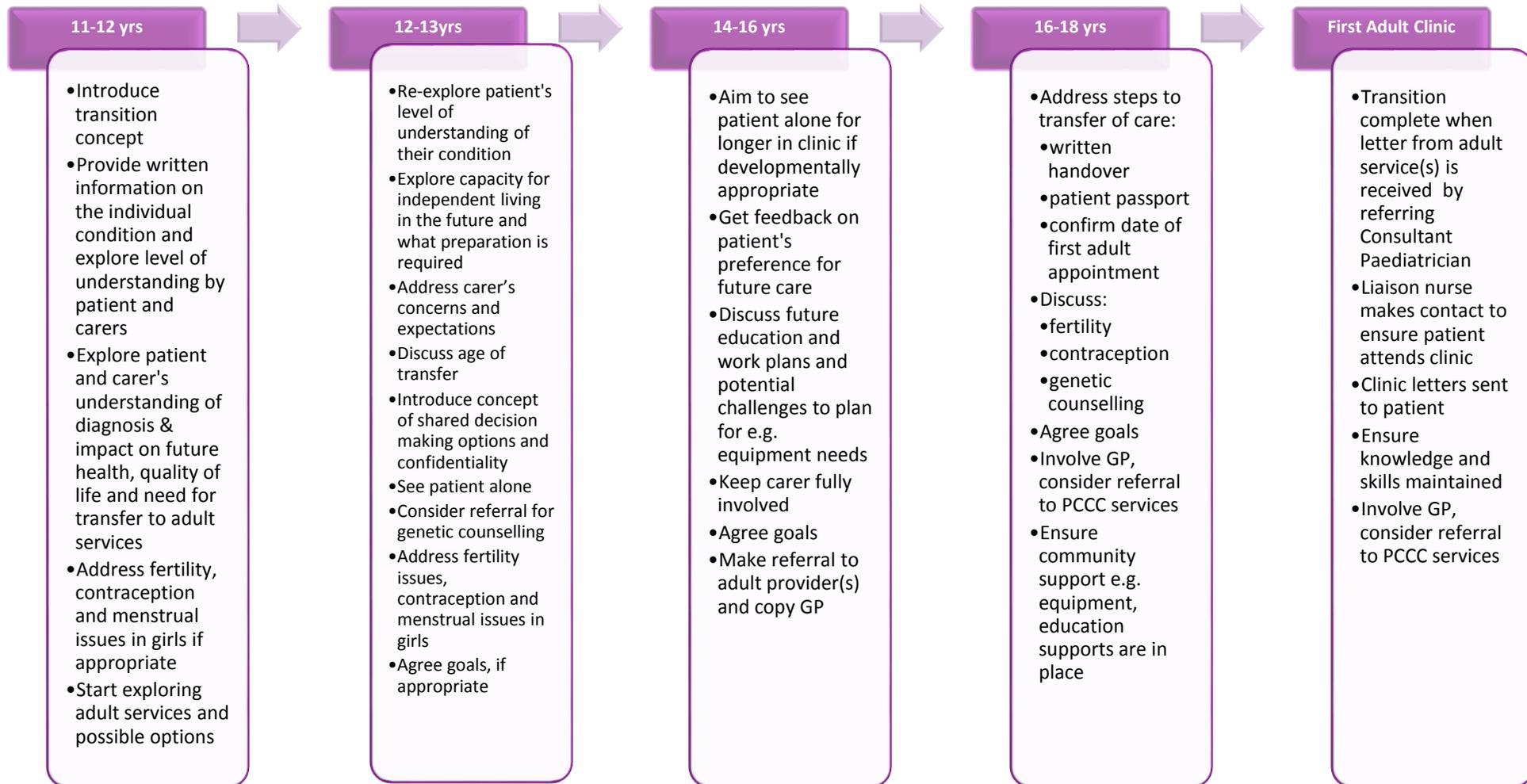
- A dedicated transition coordinator should be appointed as a point of contact for each centre. This person should be an experienced health professional (with experience in the particular therapy area or services available) who will have the responsibility for co-ordinating/facilitating transition of care in liaison with the individual clinical teams within the speciality, region or hospital group depending on the condition.
- Adequate genetic counselling should be provided to the young person and their family.
- Once the adult healthcare provider is agreed, costs associated with the transfer of patients into the service should be included in business and operational plans.
- Transition clinics should be held in a paediatric rather than adult setting (if feasible).
- Outreach services from centres of expertise should be established/supported so that patients can be offered the best possible care and expertise as close to home as possible.
- Emergency admissions of young people to adult healthcare providers does not constitute successful transition. Once stabilised, the transition pathway should be completed.
- Care should be provided at, or in conjunction with, a nationally recognised centre of expertise. A shared care model between a tertiary and primary care is recommended.
- All cases of rare diseases should be registered with a national centre of expertise.
- Transition usually occurs between 16-18 years of age but should occur at a developmentally appropriate time. The time/age of transfer should be agreed with the young person and their family, in agreement with the adult healthcare provider. The appropriate adult healthcare provider should be identified by the paediatric provider.
- If the patient has a multisystem condition, agreement should be reached as to what is the main system affected and the appropriate clinician to manage that system should be the coordinator of the ongoing care into adulthood.

#### Information for young people

- A service-specific transition booklet should be available for young people and their families.
- Young adults should be given developmentally appropriate verbal and written information.
- Young adults should be encouraged to participate in their own self-management and setting of realistic treatment goals.
- Specific and developmentally appropriate discussion about sexual and reproductive health should be offered to all young adults prior to and during the transition period.

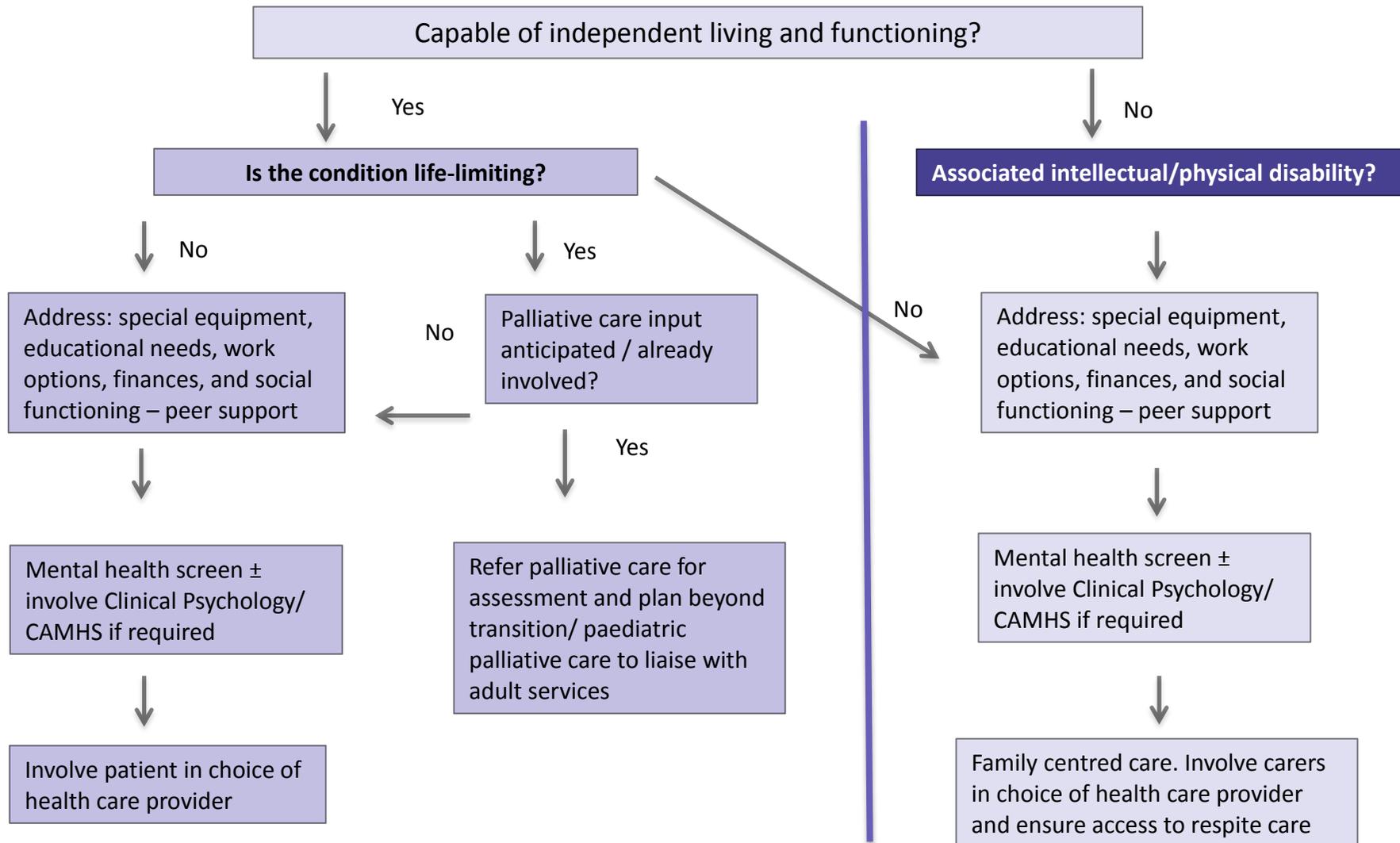
## Flowsheet 1

Guiding principles for transition of young people with a rare disease according to age.



## FLWSHEET 2

Issues to consider in rare disease transition for a young person with complex needs. This may be useful as the multiplicity of healthcare needs is particularly challenging in rare diseases where a defined care pathway may be lacking.



## 4. USEFUL LINKS

### Ireland

Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases: [www.hse.ie/eng/about/who/cspd/ncps/rare-diseases/resources/model-of-care-for-transition-in-rare-diseases.pdf](http://www.hse.ie/eng/about/who/cspd/ncps/rare-diseases/resources/model-of-care-for-transition-in-rare-diseases.pdf)

HSE National Clinical Programme for Rare Diseases: [www.hse.ie/eng/about/who/cspd/ncps/rare-diseases](http://www.hse.ie/eng/about/who/cspd/ncps/rare-diseases)

National Rare Diseases Office: [www.rarediseases.ie](http://www.rarediseases.ie)

Orphanet Ireland: [www.orpha.net/national/IE-EN/index/homepage/](http://www.orpha.net/national/IE-EN/index/homepage/)

Stepping Up: <http://steppingup.ie>

Rare Diseases Ireland: <http://rdi.ie>

Irish Platform for Patient Organisations, Science & Industry (IPPOSI): [www.ipposi.ie](http://www.ipposi.ie)

Medical Research Charities Group (MRCG): [www.mrcg.ie](http://www.mrcg.ie)

### UK

Unique- Understanding Rare Chromosome and Gene Disorders: [www.rarechromo.org](http://www.rarechromo.org)

Together for Short Lives Transition Hub: [www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services](http://www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services)

Northumbria Healthcare NHS Foundation Trust and Newcastle University Transition Programme: <https://research.ncl.ac.uk/transition>

### Europe

Orphanet: [www.orpha.net/consor/cgi-bin/index.php](http://www.orpha.net/consor/cgi-bin/index.php)

EURORDIS-Rare Diseases Europe: [www.eurordis.org/about-eurordis](http://www.eurordis.org/about-eurordis)

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