



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



Patient summary for transfer to an adult healthcare provider

The National Clinical Programme for Rare Diseases

The National Clinical Programme for Rare Diseases was established to ensure that the needs of people with a rare disease 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.

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 template has been developed to assist with the transfer of young adults with a rare diseases from paediatric to adult healthcare services.

Additional information and guidance

For more detailed recommendations about the transition of young people living with a rare disease 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 Clinical Programme for Rare Diseases. A number of resources for healthcare providers are also available on the website including a summary version of the model of care and a guide for planning the transition of young people with a rare diseases from paediatric to adult healthcare services.

www.hse.ie/eng/about/who/cspd/ncps/rare-diseases/resources



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. The office also provides contact details for patient support groups and information about clinical research projects and European Reference Networks. The National Rare Diseases Office can be contacted via email rare.diseases@mater.ie and by phone (01) 8545065. www.rarediseases.ie

This document is available in Word format so that it can be adapted locally. Please contact the National Clinical Programme for Rare Diseases to request a copy. ClinicalProgrammeAdmin@RCPI.IE

[Insert hospital logo]

Summary of [patient name] under the care of [Consultant name] at [department/service and hospital name].

Department contact details:

PATIENT INFORMATION:

Place patient sticker here

Patient email:

Parent/guardian/carer name and contact information:

Name and phone number for emergency contact:

Relationship of emergency contact to patient:

Name and address of school/college:

Language(s) spoken and verbal communication ability:

Name of GP:

Address:

Tel No:

Special considerations (e.g. hearing impairment, pregnant, interpreter required, safety concern to self or others):

DIAGNOSTIC INFORMATION:

Diagnosis at time of transfer:

Age at which diagnosis was made:

Presenting signs and symptoms:

Tests completed to confirm diagnosis:

Genetic testing and/or counselling history:

Medical History (symptoms, medical procedures):

-
-
-
-

Previous surgical history (symptoms, surgeries):

-
-
-

Medications:

Vitamins and food supplements:

Allergies (including food allergies):

Compliance/adherence issues with treatments:

Other Dietary information:

Supplies/equipment required (e.g. home appliances, etc.):

Please describe most recent nursing intervention:

Most recent Physio/OT/Speech/Nutritional (or other) intervention:

Other health care professionals involved: Yes No

If yes please list name of:

Consultant(s) and speciality:

Hospital(s):

Date of next OPD:

Psychosocial considerations:

General health:

Reproductive health and education received:

If the patient has cognitive delay, have sexual health issues been addressed/initiated by the Youth Health Services? www.spunout.ie Yes No

Genetic testing:

Has the patient received genetic counselling? Yes No

Details:

Medical card:

Is the patient eligible for medical card/disability allowance? Yes No

Have applications for these been started/completed? Yes No

Details:

Occupation/education:

Current occupation or education programme:

Grade completed:

Living arrangements: (circle)

- Independently
- With family
- Care facility

Details:

Community supports:

Details:

Capabilities of daily living: (circle)

- Independent
- Needs assistance (specify)

Details:

Level of independence:

Task	Rating 1, 2 or 3*	Comments
Understands disease(s)		
Understands basics of treatment		
Makes/keeps appointments		
Success with self-management		
Prepares meals		
Monitors own medications		
Does own food shopping		

*Rating scale

1. Independent, able to complete task
2. Parent support required for activity or task
3. Dependent on parents and others for activity or task

Interests/recreation:

MOST RECENT MEDICAL/DIAGNOSTIC TEST RESULTS:

Test type	Result
1	
2	
3	
4	
5	

ATTACHMENTS:

Document/report	Notes/comments
1	
2	
3	
4	
5	

GENERAL ASSESSMENT OF TRANSFER READINESS:

PATIENT SUMMARY COMPLETED BY:

Name of MDT member	Date	Signature

Name: (Lead consultant for the patient)

Signature:

Date:
