

TRUST POLICY AND FRAMEWORK FOR THE TRANSITION OF YOUNG PEOPLE WITH LONG TERM CONDITIONS FROM PAEDIATRIC TO ADULT SERVICES

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	1	20/3/2017	Dr Zamaan/Lisa Martin	New policy (Burton only)
	1.1	26/05/2021	Nina Heighington	Updated policy UHDB trustwide, based on updated practice and NICE guidance
	2	March 2022	Nina Heighington/ Margaret Phillips/ Vanessa Cox	Updated policy UHDB trustwide, based on updated practice and NICE guidance. Includes new governance practices
Intended Recipients: For all healthcare professionals working with children and young people (11-25 years) within the Trust				
Training and Dissemination: Publicised on Intranet, disseminated by Trust Transition team				
To be read in conjunction with: Consent – including the Mental Capacity Act POL-CL/1903/02, MCA consent process for patients without capacity MCA-3032/2018, Patient Access policy POL-COR/2284/2018, DNA/WNB children POL-CL/1887-233/2011, Privacy and Dignity CL-OP/2010/028, Safeguarding adults POL – RK/1795/2004, Safeguarding children POL – CL/3755/21				
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1. Introduction

A young person with a long term condition (LTC) requiring paediatric input on a regular basis will need some degree of transition to the GP or a specialist adult service for their ongoing healthcare.

Both paediatric and adult services recognise that transition to adult services is a major milestone in the life of the young person and their family. There are significant differences in the way services are provided between paediatric and adult health care. Careful planning can reduce the impact of this transition and address the potential risks associated with it, empowering young people to navigate their healthcare with confidence.

2. Purpose and Outcomes

Transition to adult services (Transition) should be a purposeful, planned process that addresses the medical, psychosocial and educational/ vocational needs of young people with long term conditions as they move from child-centred to adult-centred health care systems¹. This should occur in collaboration with the young person and their family. The discussions about the transition process should be developmentally appropriate and focussed on the individual's strengths. This will inevitably involve several healthcare professionals (HCP) and need coordination with social and educational services.

With increasing numbers of children with LTCs now living into adulthood, ensuring equitable and sustainable transition planning requires a systematic approach that sits within a clinical governance framework in the Trust. This Transition Framework will ensure smooth, positive transitions into adult settings, followed by continuation of a high standard of care in adult services.

The principles in this framework are based on NICE guidance² for transition. The overall transition process in the Trust is outlined in Appendix 2. We follow the 'Ready, Steady, Go, Hello' framework³ for most patients. If there is medical complexity, the '10 Steps to Transition' framework⁴ could be more appropriate.

3. Definitions

Transition: A purposeful, planned process to prepare young people moving from a child-centred to adult-centred healthcare environment. It should address the medical, psychological and educational/vocational needs of adolescents and young people with LTCs as they move from child-centred to adult centred health care system.

Developmentally appropriate healthcare: An approach to supporting young people that recognises them as a distinct group, subject to constantly changing circumstances. Developmentally appropriate care and support considers the young person as a whole, addressing their biological, psychological and social development in the broadest terms⁵.

Young person: For the purpose of this policy, the term is used to describe a person between the ages of 14 years (Year 9) – 25 years.

Parent/Carer: A mother, father, carer, close friend (older than 18 years) who have been involved in caring for the young person.

Named Key Worker/Lead Professional: This person is responsible for developing good working relationships and coordination of care of the young person. It could be any professional – for example (but not limited to) a community nurse, Clinical Nurse Specialist or AHP who has the responsibility for collaborating with other professionals within their own and other services.

Markers for complex transition: Transition may be defined as complex when there are more than three specialities or services involved, or if there is no clear pathway for transition into adult services and gaps in provision are apparent. Cases with gaps in provision should be referred to the Complex transition register (see Appendix 1).

Transition plan – A regularly updated summary of information on the details of the young person's transition to adult services and how, in partnership with the young person and families, we are going to achieve a successful transition to adult services.

Transfer to adult services: The point at which the young person's care will become the responsibility of adult services.

4. **Key Responsibilities/ Duties**

Chief Executive/Chief Nurse has the responsibility for ensuring that appropriate processes are in place for the transition of young people from children's to adults' services.

Paediatric and Adult Consultants have a responsibility for ensuring that the process agreed, in line with this policy, is followed robustly to ensure effective transition between services for young people.

The Transition Team is responsible for: developing, embedding and monitoring this Framework; supporting teams at UHDB to follow best practice, develop equitable, sustainable clinical pathways and highlight and action plan for areas requiring improvement. They report to the senior management and executive teams

Trust Board should identify an Executive Lead for Transition. Ensure there is an effective transition policy within the Trust and the voice of young people is heard and acted upon in relation to transition.

Executive Lead for Transition

Member of the Trust Executive team with overall accountability for transition to adult services within the Trust. Chairs the Trust Transition Steering Group. Provides senior level outward-facing representation with regard to transition for the Trust.

Trust Clinical Leads for Transition – Paediatric and Adult

Provide senior clinical leadership for transition within the Trust working as part of the Trust Transition Team.

Trust Transition Lead Nurse

Provides senior nursing leadership for transition within the Trust working as part of the Transition Team.

Divisional Transition Leads

Provide formal link between the division and Trust with regard to transition. Ensure governance and prompt escalation of any risks, issues or concerns.

UHDB Transition Champions are an innovative, informal group of staff providing an informal link between individual teams and services to the Division Transition Leads and Trust Transition Team. They raise awareness of good practice, as well as raising risks / issues concerning transition to the Trust Transition Team.

5. The key elements for an effective transition from paediatric to adult services

5.1 Identifying young people needing transition

Transition planning is relevant to all young people, aged 14 and over, who have long term conditions (LTCs) or disabilities where the healthcare needs related to those conditions are expected to continue into adulthood. This policy is also relevant to young people of transition age diagnosed with a long term condition during the transition period. The transition process includes transfer from paediatric services to GP care alone, as well as to adult secondary or tertiary care.

The process of transition can start at any time but needs to take into account the patient's developmental stage. Transition planning is recommended to commence at age 14 (Year 9), ideally before the young person's 15th birthday.

Expected standards:

1. All young people with LTCs and their carers are made aware of the need for transition to adult services around their 14th birthday – clinicians should start to complete the 'Ready' stage of the transition plan in clinics or at professional encounters and document this.
2. Consultants caring for young people with LTCs identify cases with complex or difficult transition before the young person's 15th birthday. If gaps in provision are a concern, they should complete the Complex Transition Register referral (Appendix 1).
3. Transfer to adult services should occur between 16-18 years of age, but the process may take longer for those with complex needs.

5.2 Empowering young people and supporting parents

Education, empowerment and development of self-management skills for LTCs begin in childhood and set lifelong habits. Healthcare professionals should work with young people and their carers to support them to gain the knowledge and skills to stay healthy, including giving the opportunity to talk about how their health needs may impact on:

- Education and employment;
- Living independently;
- Sexuality and relationships; and
- Social, recreational and leisure activities.

Expected standards

1. All young people with long term conditions have access to developmentally appropriate information and advice regarding their condition, its management and wider holistic issues before their 15th birthday.
2. All young people with LTCs should receive personal clinic letters, together with opportunities for explanation and discussion of its contents.
3. The young person should be given the opportunity to have at least part of a healthcare consultation unaccompanied. This can be offered depending upon the developmental stage of the young person from around the age of 13 years. A chaperone should be considered for examination.
4. The parent or carer should play an active part in transition planning with their views and needs being taken into account.

5. Consent and capacity discussions must be undertaken by the age of 16, as decisions made by the young person will mostly fall under the Mental Capacity Act (2005) from that age – please refer to Trust policy on Consent.

5.3 Starting a Transition plan

Professionals should work in partnership with young people and their carers to create and document a personal transition plan. This should be tailored to their health needs and strengths, co-ordinating with other aspects of transition as necessary eg. education. At UHDB, we use 'Ready, Steady, Go, Hello' for most transition plans. For young people with medical complexity, the '10 Steps to Transition' framework would be appropriate. Both are available electronically on UHDB IT systems.

Expected standards

1. All young people contribute to the development of their personalised transition plan before their 15th birthday. This is documented in their health records that is regularly reviewed and updated. They should be offered a copy of this plan.
2. The young people and their families move through the various stages of a transition programme over a number of years completing the 'Ready, Steady, Go' or '10 Steps' stages before transition to adult services.
3. Issues, concerns and progress should be documented in the transition plan by the healthcare team or named key worker.

5.4 Reviewing the multidisciplinary team

Professionals should clearly outline all the members of multidisciplinary team of professionals supporting the young person. One of these people should be nominated to take over the role of named key worker when the young person has transitioned to adult services.

Expected standards

1. All young people with long term conditions who are supported by three or more specialties should have a clearly identified Lead Consultant before their 15th birthday.
2. Young people of transition age (14 – 25 years) with long term conditions have access to a named key worker to support them through transition.
3. The young person's GP is actively consulted and involved in the young person's transition including for routine prescriptions, reviewing minor illnesses and planning the young person's route into urgent care.
4. Health professionals should identify whether the young person has social care involvement and involve the social worker in transition planning. If no involvement, they must ensure it is identified whether they require social care input for preparing for adulthood.

<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-2-who-is-entitled-to-public-care-and-support>).

5.5 Joint reviews: children's or adult services leading

Transition should be a coordinated process between children's and adult services, with professionals and services communicating effectively between clinical teams, the young person and their carers.

Expected standards

1. Every young person with a LTC has at least one joint review with a member of the new adult team with children's services leading prior to transfer to adult services.

2. Professionals from adult services introduce themselves to the young person and their family, explaining their role prior to the young person moving to adult services.
3. Attendance of young people at transition clinics is actively monitored and non-attendance is followed up by contacting the young person and their GP, referring to Trust policy for 'Was Not Brought' and safeguarding policies if necessary. Another joint appointment should be offered before transfer to adult clinic.

5.6 Referring on to the Lead Adult Service

All teams should know who their adult/paediatric counterparts are in order to plan transition together.

Expected standards

1. Every young person with a LTC requiring management in secondary care is referred to adult services between the ages of 16 - 18 years.
2. When a young person is supported by more than one speciality, a mutual decision is made to appoint one paediatric consultant as Lead Consultant. That person will liaise with others involved to plan referral to adult services.
3. Onward referral happens when the young person and family are feeling confident to move into adult services, at the latest by their 18th birthday. Referrals after that age are notified to the Complex Transition Register (NB an exception to this will be if the young person is finishing a course of treatment).
4. Professionals in the adult sector should provide information about the services they provide for the young person and their family.
5. A route into urgent care should be clarified with the young person and family during the transition period and after the young person has moved into adult services, as these will differ from paediatrics.
6. Young people and their families should have the opportunity to visit the relevant adult department/ ward/ service.
7. All roles and responsibilities of both paediatric and adult teams during this transition period should be clear to the young person, their family and the professionals involved.
8. All complex patients should have at least 1 MDT case discussion with all paediatric and adult services involved in the care of the young person invited, including the GP, to ensure all aspects of holistic care will be met in the adult service.

5.7 Settling into adult services

Before their 19th birthday, the young person should be settling into adult services and children's services should have discharged them. The young person should understand how they can be supported in adult services.

Expected standards

1. A specified date should be set by the MDT, and agreed by the young person and their family, for handover of care to adult services. After this date the young person will receive all healthcare from primary healthcare and adult services, including admission for urgent care.
2. All young people will be in adult services before their 19th birthday unless they are completing a course of treatment and then will be discharged to primary care.
3. A 'Hello' to adult services plan should be completed at the first adult appointment.

4. Young people should have the opportunity to feed back on their experience of transition.
5. If a young person requires adult secondary care and there is no service at UHDB that will meet their needs this should be included on the risk register for the adult service that comes closest to meeting those needs and on the risk register for the UHDB transition team.
6. Non-attendance at first adult clinic should be followed up by contacting the young person and their GP. Another appointment should be offered.

5.8 Administrative Support

Transition of care involves many processes other than the initial referral between consultants. It requires organised administrative processes and engagement of administrative staff.

Expected standards

1. Young people must be formally referred and accepted into the adult service, with the young person and their family being aware of this referral.
2. The interval before the first adult appointment should be agreed at the transition handover clinic. If there is no handover clinic the preferred interval should be stated in the referral letter.
3. Specialities should develop their own transition checklists to ensure administrative processes are completed.

5.9 Primary Care Involvement

Transition planning must involve GPs as they may be the only healthcare service providing continuity for young people and their families during transition. <https://healthtalk.org/seeing-gp-advice-and-tips-young-people/overview> is a useful link that tells young people about primary care.

Expected standards

1. Young people should be encouraged to see their GP as the first point of contact for healthcare advice during transition.
2. GP's should be copied into transition planning letters and correspondence, including copies of the young person's personalised transition plan.
3. Young people should be clear around the role of the GP in their care.
4. GP's should be invited to any MDT meetings that discuss the holistic transition needs of a young person.
5. It should be made clear at an early stage to the GP, multidisciplinary team and to the young person/family if transition from paediatric secondary care will be solely to the GP and not adult secondary care.

6. The Complex Transition Register

The Complex Transition Register is a formal Trust record of young people whose care needs are likely to still be most appropriately met in children's services at the age of 18 or older. This may include inpatient/ outpatient/ community care based on availability of resources and risk assessment by the young person's consultant(s) and multidisciplinary team. This may be because an effective pathway for transition to adult services has not been identified and requires escalation to resolve, or required treatment is being completed by paediatrics before transfer to adult services.

The Register provides assurance for the young person and their carers that their healthcare needs will be met in the most appropriate setting, It identifies young people who remain in

paediatric care after the age of 18 years and their current plan of care, route of admission etc to avoid confusion on attendance to paediatric services at age 18 years+.

The register will also provide a method of identifying and actively managing transition for patients who currently do not have an effective pathway. Diagnosis of a life-threatening or life-limiting condition does not automatically mean a young person shouldn't transition to adult services as, increasingly, young people with such conditions are living into adulthood.

Eligibility Criteria for Complex Transition Register

1. All young people aged 14 years or over, with LTCs whose transition to adult services is at risk of delay beyond their 18th birthday unless an effective pathway or closing of a gap in service occurs meanwhile.
2. All young people aged 14 years or over with LTCs, where it is known that a gap in provision will exist in adult services and intervention prior to transfer will be needed (such as training or service development) in order to meet the needs of the young person.
3. Patients will only be eligible for inclusion on the Complex Transition Register if there are specific reasons why the young person cannot be safely transitioned to adult services – Appendix 1 outlines the referral form.
4. Cases on the register will be reviewed by the Trust Transition Team and appropriate escalation and clinical governance will be actioned to ensure the needs of the young person and similar patient cohorts are met and addressed. An alert may be put on the EPR with appropriate setting of care if registered on the complex transition register.

7.Safeguarding

Any concerns raised during the transition process which affect or do not meet the young person's care needs should prompt early involvement of appropriate support services, following local safeguarding procedures where necessary, and sharing information appropriately with other agencies.

For children with complex needs who are already known to social care, their named Social Worker will also need to be involved in the process of the transition.

8.Transition of young people with Special Educational Needs (SEND)

Transition for a young person with SEND or complex needs may involve multiple professionals and services. A transition in one service may have implications for their wider care such as consumables and care packages etc.

The '10 Steps to Transition' plan is a good alternative to 'Ready, Steady, Go' to facilitate transition planning for this group of young people. Collaboration with the parents/carers will be essential for a successful transition. The '10 Steps' plan allows flexibility to empower young people and support the parent/carers. Young people and their families should be encouraged to complete a UHDB hospital traffic light form.

Consider discussion/referral to the adult learning disability liaison nurse within the acute trust in addition during this period.

9. Staff Training

Professionals need to be confident in their knowledge and skills in working with young people, taking into consideration the biology and psychology of adolescence; communication and consultation strategies; multidisciplinary and multi-agency teamwork; and an understanding of the relevant individual conditions and disorders and their evolution and consequences in adult

life. There are regular ‘Transition Champion’ workshops available in UHDB to facilitate this and the NHSE Framework sets out expectations – this will be mandatory training going forwards.

A multi-collegiate e-learning package is available to all staff so they can develop the necessary skills to help young patients make necessary changes to lead a healthier and more active life. This can be found at: <http://www.e-lfh.org.uk/programmes/adolescent-health/>.

There is also a toolkit available to support staff and organisations to provide ‘developmentally appropriate healthcare’ for young people, promoting health and ensuring healthcare provided meets their specific needs⁵. [Developmentally Appropriate Healthcare – Northumbria Healthcare NHS Foundation Trust](#)

10. Monitoring Compliance and Effectiveness

The key requirements will be monitored in a composite report presented on the Trusts Monitoring Report Template:

Monitoring Requirement :	At a minimum this needs to be compliance with/performance against the criteria identified at L3 in the NHSLA standards but should also include other key elements of the policy
Monitoring Method:	Complex Transition Register and risk register management Regular audit of expected standards Mandatory training compliance when embedded
Report Prepared by:	Transition Team
Monitoring Report presented to:	UHDB Quality Committee UHDB Children’s Board
Frequency of Report	Annual to Quality Committee Standing item at monthly Children’s Board

11. References

1. Department of Health (2006). ‘Transition: Getting it right for young people’. London HMSO
2. NICE NG43 (2016) ‘Transition from children’s to adults’ services for young people using health or social care services’
3. Nagra et al (2022) ‘Ready, Steady, Go, Hello’ programme available at: www.readysteadygo.net. Accessed: 14th July 2022
4. Rogers J, Brooks L, Alder Hey Childrens Hospital Foundation Trust (2017), ‘10 steps to Adult services: Transition plan’.
5. Northumbria Healthcare NHS Foundation trust (2017) Making Healthcare work for young people: A toolkit to support the delivery of ‘Developmentally Appropriate Healthcare in the NHS’ Available: [Developmentally Appropriate Healthcare – Northumbria Healthcare NHS Foundation Trust](#) Accessed: 13th July 2022

Appendix 1 – Complex Transition Register referral form

University Hospitals of Derby and Burton Complex Transition Register Application		Date:	Please email: uhdb.transitionteam@nhs.net	Entered on Database (office use only)
Patient details	M <input type="checkbox"/> F <input type="checkbox"/>	Hospital No:	(CCG Code (To be completed by transition team):	
Forename :		Surname:		Date of birth :
Interpreter needed? Yes <input type="checkbox"/> No <input type="checkbox"/>		Have young person/parents/carer agreed to referral to Transition Team? Yes/No		Have you discussed Transition with the young person/ parents/carer? Yes/No
Referrer details				
Referrer name:			Job title:	
Telephone & email:			Specialty:	
History of illness/diagnosis				
Main diagnosis:				
Date of diagnosis:				
Relevant history/ other problem:				
Key professionals/ services involved in care				
Professionals/services involved:				
Lead Specialty:		Transition Keyworker childrens:		
Lead Consultant childrens:		Transition Keyworker adults:		
Lead Consultant adults (if able to identify):		If not able to identify adult lead consultant why?		
Who does the young person/family feel fulfils the role of key-worker for them?				
Optimum age for transfer, if adequate transition preparation and appropriate target adult services are available:				
Reasons why transfer may be delayed or inadequate:				
Level of GP involvement:		<input type="checkbox"/> Occasional involvement		<input type="checkbox"/> Regular involvement
<input type="checkbox"/> Transition plan	Date commenced:		Transition plan location:	Does patient have copy?
<input type="checkbox"/> Personal Resuscitation Plan/ ReSPECT form		<input type="checkbox"/> Education Health & Care Plan		<input type="checkbox"/> Hospital Traffic Light/ All About Me form

Appendix 2 – Transition process

