Clinical Guideline

HNEkidshealth
Children, Young People & Families

Health
Hunter New England
Local Health District

Transition to Adult Health Care Providers for Young People with a Chronic Health Condition

Sites where Clinical Guideline applies	Children, Young People and Families Services
This Clinical Guideline applies to:	
1. Adults	No
2. Children up to 16 years	Yes
3. Neonates – less than 29 days	No
Target audience	All clinicians that provide health services to young people who have a chronic physical medical condition(s) and are 14 years or older.
Description	This document provides a guideline for clinicians to develop a transition pathway that ensures young people receive holistic transition preparation and have a coordinated transition to adult health services.

Hyperlink to Guideline

National Standards Keywords	Transition, young people, chronic, medical, condition, illness, adult, health.
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Replaces existing document?	Yes
Registration number and dates of superseded documents	HNELHD CG 17_23 Version One from 20 July 2017; JHCH 3.5 - 2011,

Related Legislation, Australian Standard, NSW Ministry of Health Policy Directive or Guideline, National Safety and Quality Health Service Standard (NSQHSS) and/or other, HNE Health Document, Professional Guideline, Code of Practice or Ethics:

- NSW Health Directive: NSW Youth Health Framework 2017-24 PD2017_019.pdf
- NSW Health Directive: Supporting Young People During Transition to Adult Mental Health Services GL2018_022
- NSW Health Directive: Healthy-safe-well-A strategic health plan for children young people and families 2014-24
- NSW Health Directive: Paediatric Service Capability Framework GL2017_010

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Note: Over time links in this document may cease working. Where this occurs please source the document in the PPG Directory at: http://ppg.hne.health.nsw.gov.au/.

PURPOSE

This guideline outlines evidence-based principles and promotes best practice for health professionals. It does not replace the need for consideration of each young person's individual needs.
Young people who have a chronic medical condition(s) and are accessing HNEkidshealth Children, Young People and Families Health Services should have a well-coordinated and seamless transition to adult health services.

Transition is the planned movement of young people from paediatric health services to adult services and should be considered a process not an event[1]. It should occur within a developmental context and should be flexible in timing. Preparation should commence early in adolescence to allow the young person time to increase their capacity to self- manage to the best of their ability.

The transfer of medical care is only one component of the transition process, consideration also needs to be given to psychosocial, educational and cultural needs. Young people should have an individual transition plan that is developed in accordance with transition pathways and reflects the individual needs of the young person.

Each paediatric clinical speciality or service should have a transition pathway which details how transition will be undertaken for young people in their care. The pathway should identify the age at which transition preparation will begin and end and the team members responsible for overseeing the process. Transition checklists, plans and Apps used should be identified along with options for young adult friendly adult services. The pathway should also identify how evaluation of the transition process will be undertaken.
Successful transition, with a smooth continuum of care requires collaboration between paediatric and adult health services.

RISK

It is estimated that 90% of young people with a chronic medical condition are now surviving into adulthood. Adolescents are transitioning to adult services in greater numbers. They outgrow the scope of paediatric services and require a well-coordinated and planned transition to appropriate adult health services.

Consequences of a poor transition can result in young people being lost to health services, poor health outcomes and increased emergency presentations to hospital.

A lack of open and transparent communication and collaboration between services can impact on a young person's confidence around self-management. It can lead to anxiety and result in adverse impacts on social, educational and vocational outcomes for young people.

Risk Category: *Communication and Information*

GLOSSARY

Acronym or Term	Definition
Aboriginal Medical Service (AMS) / Aboriginal Community Controlled Health Service (ACCHS)	Holistic, culturally appropriate and comprehensive primary health care service for the Aboriginal community they serve. Aboriginal Community Controlled Health Services are non-profit incorporated Aboriginal community controlled organisations, governed by an Aboriginal Board of Management elected by a local Aboriginal community membership.
Agency for Clinical Innovation (ACI)	The NSW Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better health care for NSW. The ACI Transition Care Network aims to improve the experience and delivery of health care for young people with chronic health conditions and disabilities as they transition from paediatric to adult health services.
GP	General Practitioner or local doctor
HNELHD	Hunter New England Local Health District
HSC	Higher School Certificate
NGO	Non-Government Organisation
SCHN	Sydney Children’s Hospitals Network, encompassing The Children’s Hospital at Westmead and Sydney Children’s Hospital, Randwick.
Primary Health Care	Health care provided in the community. First level of contact for individuals, families and communities.
Secondary Health Care	Medical health care provided by a specialist or facility upon referral by a primary care physician. Includes services provided by hospitals and specialist medical practices.
Tertiary Health Care	Medical health care provided by a specialist or facility upon referral by a primary care physician. Includes services provided by hospitals and specialist medical practices.
Trapeze	Transition service for The Sydney Children’s Hospitals Network, available to current patients of The Children’s Hospital at Westmead and/or Sydney Children’s Hospital, Randwick. The service supports young people to make a seamless transition to adult health services. Trapeze clinicians work collaboratively with ACI Transition Care Coordinators.

GUIDELINE

While not requiring mandatory compliance, staff must have sound reasons for not implementing standards or practices set out within guidelines issued by HNELHD, or for measuring consistent variance in practice.

The aim of this guideline is to assist paediatric clinicians to:

- Develop a transition pathway for young people.
- Develop an individualised transition plan in consultation with the young person, family and GP with achievable and measurable objectives.
- Achieve a planned transition that incorporates a holistic approach.
- Ensure a seamless transfer to adult health services.
- Ensure continuity of care in primary, secondary and tertiary adult health services and maintain the best health outcomes for young people.

THE KEY PRINCIPLES FOR YOUNG PEOPLE TRANSITIONING TO ADULT HEALTH SERVICES

These principles were developed by the ACI Transition Network and Trapeze, SCHN for use throughout NSW.

See Appendix 1 or view at ACI Transition of Care Principles.

CONSIDERATIONS FOR A YOUNG PERSON'S READINESS FOR TRANSITION

AGE

Each young person's readiness should be individually assessed. Preparation should commence at approximately 14 years (year 8) and focus on education and empowerment around self-management to the best of the young person's ability.
All young people should have an individual transition plan that addresses all aspects of their life.
Age of full transfer to adult health services should be individually planned and accommodate individual needs but should be completed before the young person's 19th birthday. Local paediatric admission policies and adult health service eligibility criteria should be considered. Some adult health services do not accept referrals for young people until 18 years of age.

Transition clinics or a period of shared care with paediatric and adult medical physicians/services can provide an opportunity for young people to get to know the new clinician/service and become familiar with adult health services while still accessing paediatric health services.

SOCIAL AND EMOTIONAL READINESS

Timing of the transfer to adult health services should not coincide with a young person's HSC year prior to the completion of the final examinations. Year 12 can be very stressful as the young person prepares for examinations and the life changes that will soon occur. Undertaking transfer well before this time, or delaying the transfer to adult services until after the HSC examinations is recommended.

MEDICAL STABILITY

Transition should occur at a time of medical stability and should be delayed for planned procedures or treatments to be performed by paediatric health services.

Some young people may continue to access paediatric health care services in adulthood e.g. oncology patients accessing late effects clinic or palliative care patients at end of life.

THE GENERAL PRACTITIONER (GP)

A GP is essential as coordinator of care for the young person. The GP is the first point of contact and may be the only consistent health professional at the time of transfer to adult health services. The GP should be someone the young person trusts and can talk to about any health issue.

BARRIERS FOR YOUNG PEOPLE IN RURAL AND REGIONAL AREAS

Barriers to a smooth transition and health care include difficulty obtaining timely access to a GP and limited options for local primary and specialist medical health services, particularly bulk billing services. Limited options for specialist health services can result in an increased reliance on primary health services, so a GP the young person trusts and can access is even more important.

Young people may have to travel long distances to access health services, have limited transport options and therefore incur costly travel expenses. Telehealth consultation options should be considered. Young people often have to leave rural communities to study or work so transition planning may have to be delayed until the young person knows where they will be living beyond the age of normal transition.

DEVELOPING A TRANSITION PATHWAY

Each clinical team/service should develop and follow a transition pathway that addresses the specific needs of the young people they care for. The pathway should include:

- Time frame, when preparation will commence and planned time of transfer to adult health services.
- Allocation of a paediatric clinician who will assist to coordinate transition and be the named contact for the young person/carers.
- Consultation with the GP, adult health services, Aboriginal Medical Services, case managers, NGOs and education providers as required.
- Checklists and factsheets should be available to the young person/carers. These can be generic or disease specific.
- A written transition plan should be provided to the young person and reviewed regularly. The clinician should ensure that the plan is in a format or language the young person can understand and an interpreter provided to explain to non-English speakers.
- Referral to ACI Transition Care Coordinator.
- Evaluation process.

> The ACI Transition Network and Trapeze SCHN have developed generic factsheets and checklists for clinicians, young people and carers. Access at https://www.aci.health.nsw.gov.au/resources/transition-care.

AN INDIVIDUAL TRANSITION PLAN

An individual transition plan should be developed in partnership with the young person and carers from the age of 14. All young people should have a written plan by 16 years.
Plans should be individually tailored and consider, medical, psychosocial, and cultural needs of the individual. The young person's capacity for independence, lifestyle and role of the parents or carers should also be considered.

The transition plan should be updated regularly and be accessible for the young person and clinicians. If multiple specialties provide health care to the young person communication and collaboration between clinical teams is essential and early referral to the ACI Transition Care Coordinator recommended to assist with transition planning.

The ACI Transition Network generic transition plans can be adapted. These documents are included at Appendix 2 of this Guideline.

THE ROLE OF TRANSITION COORDINATORS IN NSW

THE AGENCY FOR CLINICAL INNOVATION (ACI) TRANSITION CARE SERVICE

ACI Transition Coordinators provide a state wide service to clinicians, young people with complex medical conditions or identified transition barriers and their carers. They can support clinicians by assisting to develop transition pathways and resources and to investigate options for adult health services. Coordinators provide guidance and assistance to young people and caregivers as they prepare, transfer and adjust to new adult health services. Transition processes are evaluated and feedback is provided to paediatric clinicians. The Northern Region Coordinator is based with HNELHD Youth Health Team, Newcastle.

Trapeze Transition Service (SCHN)
Young people 14-25 years are eligible for referral to the SCHN transition service if:

- Currently receive health care services within the SCHN
- Have a complex chronic medical condition
- Do not have a clear health care transition pathway

Further information can be accessed at http://www.trapeze.org.au/content/referral-pathway.

STAFF PREPARATION

It is mandatory for staff to follow relevant Five moments of hand hygiene, infection control, moving safely/safe manual handling, documentation practices and to use HAIDET for patient/carer communication (**H**and hygiene **A**cknowledge, **I**ntroduce, **D**uration, **E**xplanation, **T**hank you).

IMPLEMENTATION PLAN

Inclusion on the HNELHD Intranet and HNEkidshealth website to achieve maximum awareness of this revised guideline. Relevant senior managers and clinicians will be advised of the Guideline's existence

via direct email. Targeted distribution to identified stakeholders will also occur. Information about the revised Guideline will also be promoted via staff forums, education days and by the Transition Coordinator when visiting rural and regional centres.

MONITORING AND AUDITING PLAN

This Guideline will be reviewed and updated every 3 years. The transition patient's medical record will be evaluated annually to assess if the young person has successfully engaged with adult health services and to monitor Emergency Department presentation rates in the year following transition to adult health services.
The results of the Clinical Audits in Appendix 4 are completed annually and transition gaps and barriers reported to the paediatric Clinical Team and the ACI Transition Care Coordinator Northern Region.

CONSULTATION WITH KEY STAKEHOLDERS

Karen Johnson Dewit, CNC Team Leader Youth Health Team, HNELHD
Rachael Havrlant, ACI Transition Care Network Manager
Dr Julie Adamson, Director of General Paediatric and Adolescent Medicine, John Hunter Children's Hospital
Dr Sharon Ryan, JHCH Co-Director Medical and Staff Specialist Palliative Care, Children, Young People and Families Services
Matt Frith, Director of Community, Partnerships and Integrated Services, Children, Young People and Families Services
Cathy Grahame, JHCH Ambulatory Care Manager, John Hunter Children's Hospital
Margaret Hayes, Community Network Manager, Child and Youth Health, Children, Young People and Families Services
Paul Widseth, Nurse Unit Manager, Adolescent Ward, John Hunter Children's Hospital
Sam Ness-Wilson, Acute Service Manager, John Hunter Children's Hospital
Dr Elizabeth Cotterell, Director of Paediatrics, Armidale Rural Referral Hospital
Gai Lovell, Service Manager, HNEkidsrehab, Children, Young People and Families Services
Dr Heather Burnett, Staff Specialist, HNEKidsrehab, Children, Young People and Families Services
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Sandra Babekuhl, Clinical Nurse Consultant, Paediatric Outreach Manning, Children's Health care Network Northern
Helen Stevens, Clinical Nurse Consultant, Paediatric Outreach Armidale, Children's Health care Network Northern

APPENDICES

1. Key Principles of Care for Young People Transitioning to Adult Health Services
2. Transition Plan example document
3. Transition Pathway example document
4. Clinical Audit

REFERENCES

1. Blum RW, Hirsch D, Kastner TA, Quint RD, Sandler AD. A consensus Statement on health care transitions for young people with special health care needs. Paediatrics 2002; 100:(6) 1304-1306

2. Brodie L, Bridgett M. Key Principles for Transition of Young People from paediatric to Adult Health Care. Agency for Clinical Innovation and Trapeze, The Sydney Children's Hospitals Network, 2014;5 & 15

3. Children and Adolescents - Guidelines for Care in Acute Care Settings

USEFUL LINKS

http://www.hnekidshealth.nsw.gov.au/site/transition
https://www.aci.health.nsw.gov.au/resources/transition-care
http://www.trapeze.org.au/content/referral-pathway

FEEDBACK

Any feedback on this document should be sent to the Contact Officer listed on the front page.

APPROVAL

CYPFS CPGAG – June 2020

CYPFS CQ&PCC - July 2020

APPENDIX ONE – KEY PRINCIPLES OF CARE FOR YOUNG PEOPLE

Key Principles of Care for Young People Transitioning to Adult Health Services

1 A Systematic and Formal Transition Process

A systematic and formal transition process is required. This should be underpinned by formal guidelines and policies outlining the transition process.

2 Early Preparation

Transition is a process not an event. Education on transition and empowerment around self-management will commence with the young person at the age of 14.

3 Identification of a Transition Coordinator/ Facilitator

A designated Transition Coordinator/Facilitator from the young person's paediatric and adult specialty teams should be identified to coordinate the transition.

4 Good Communication

Communication processes and tools will support person-centred care for the young person throughout their transition journey. Openness, transparency, collaboration and a willingness to work together underpins all good communication.

5 Individual Transition Plan

All young people should have an individualised transition plan which focuses on all aspects of their life.

6 Empower, Encourage and Enable Young People to Self-Manage

Responsibility for decision-making should be increased gradually and adolescent friendly transition services should be put in place. Where the young person has complex needs, it is particularly important to involve their family/carer.

7 Follow up and Evaluation

Follow up may be required for several years to ensure that young people have engaged effectively with adult health care services. Evaluation of the transition process must be undertaken to inform future planning and policy.

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APPENDIX TWO – TRANSITION PLAN

INDIVIDUAL TRANSITION CARE PLAN

Name: ______________________ **DOB:** ____________ **MRN CHW:** ____________ **MRN SCH:** ____________

Address: ____

Young person Email: ______________________ Young person Phone: ______________________

Parent/Carer Email: ______________________ Parent/Carer Phone: ______________________

Chronic Condition/s: ____

Trapeze Clinician: ____________ Phone/Mobile: ____________ Email: ____________

Consent to share transition care plan: YES ☐ NO ☐ ACI Transition Coordinator: ____________

Treatment Plan/Goals

1. ____
2. ____
3. ____
4. ____
5. ____

MAKE A PLAN

www.trapeze.org.au

INDIVIDUAL TRANSFER INFORMATION

	PAEDIATRIC TEAM		ADULT TEAM	
Role	**Name**	**Contact details**	**Name**	**Contact details**
General Practitioner				

MAKE A PLAN

www.trapeze.org.au

APPENDIX THREE - EXAMPLE TRANSITION PATHWAY FOR A MULTIDISCIPLINARY TEAM

KEY STAGES	TRANSITION PATHWAY
14 years	• Formal initiation and introduction of transition process • Identification of key transition clinician • Promote the importance of the GP • Promote health literacy using transition resources
14–16 years	• Promote health literacy and empowerment around self-management • Referral to ACI Transition Coordinator at 16years • Transition clinic or shared care if available • Written transition plan given to young person • Communicate plan with GP
17 years	• Promote health literacy and empowerment around self-management • Communicate plan with GP • Referral to adult health services by GP or paediatrician • ACI Transition Coordinator will be actively involved
17-18 years	• Paediatric discharge summary provided • First adult health services appointment • Optional final paediatric appointment following first adult appointment • Communicate plan with GP **Full transfer of care to adult health**
6 months and 12 months post transfer	• Key paediatric transition clinician/Transition Coordinator to contact young person • Assistance provided as required • ACI Transition Coordinator remains contact for young person • Evaluation

APPENDIX FOUR - CLINICAL AUDIT TOOL

(**National Standard 1:** 1.7.2 the use of agreed clinical guidelines by the clinical workforce is monitored)

Criterion no.	Criterion	Exceptions	Definition of terms and/or general guidance	Data source	Frequency	Position Responsible
1	Percentage of young people (residing in HNELH geographical region) who have been seen by their adult clinician minimum once (each speciality) one year following final paediatric appointment.	None.		Patient health record	Annually	Paediatric clinical team or Transition Care Coordinator
2	Number of presentations to Emergency Department HNELHD in year following transition to adult health services and comparison with year preceding transition.	None		Patient health record	Annually	Paediatric clinical team or Transition Care Coordinator
3						
4						
5						

Reference: *Electronic audit tool - National Institute for Health and Care Excellence (NICE):* http://www.nice.org.uk/about/what-we-do/into-practice/audit-and-service-improvement/audit-tools