TRANSITIONAL CARE

POLICY©

DOCUMENT SUMMARY/KEY POINTS

This policy aims to assist staff in planning the transition of young people with a chronic childhood condition from the Sydney Children's Hospital Network (SCHN) to the adult health system for their ongoing care and treatment.

The policy includes information about:

- What is transition
- When to transition
- How to implement transition as an integral part of each young person's care
- Tools to help with preparation and planning in the group aged 14 -16yrs
- Further development of a transition plan for young people once they are in the active phase (16 -18yrs)
- What to do at the time of transition/discharge from SCHN.
- What assistance is available through Trapeze (SCHN Transition Service) and the Adult Transition Care Coordinators from the Agency of Clinical Innovation (ACI).
- How each department can begin to collect data and plan for the needs of young people transitioning and the stage they are at using the transition planner.

Transition should be seen as part of high quality health care for young people

CHANGE SUMMARY

- Minor review to update links.

READ ACKNOWLEDGEMENT

- All clinical staff, Clinical Directors and Heads of Departments should read and acknowledge this document.

TABLE OF CONTENTS

Introduction

Most children with chronic conditions now survive into adulthood. Successful transition from paediatric to adult care is therefore an important goal. The goal of transition planning should be to "maximise lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood" [1]

The transition from family oriented, developmentally focussed paediatric health services, to more independently oriented adult services, requires a planned collaborative process. The process should focus on consultation with and preparation of the young person, with the support of their family, general practitioner and other service providers.

To ensure that successful transition occurs, each clinical team should develop a transition model for their service that supports young people with an individual transition plan.

Aim

This Policy provides the framework to plan the transition of young people with a chronic condition into the adult health care system. This includes the timing of transition, the roles of clinical teams and the steps required in transition planning. A range of tools and resources to assist clinical teams in preparing young people for transition is also provided.

Transitioning a patient

Age of transition

Transition planning should be flexible in timing but should commence early in adolescence to allow the young person, where possible, time to increase their capacity for self-care. It is recognised that some young people with major cognitive and physical disabilities may not manage to achieve independence and will require the ongoing assistance of a family member and community services. In these situations, it is essential that planning for their adult health care begins as early as possible to ensure all aspects of their future health care needs are addressed.

Consideration needs to be given to promotion of health literacy and self-management skills as well as assessment of their psychosocial needs. Where possible, parents may also need support to encourage their child to take more responsibility for their health care. Preparation for transition planning should therefore generally commence from age 12 years followed by active transition planning from age 16 years.

Admissions Policy

- In general, new **inpatients** will be accepted and admitted at Sydney Children's Hospitals Network (SCHN) up to their 16th birthday. Patients previously treated by SCHN will continue to be treated and may be admitted up to and including their 18th birthday for conditions for which they have been previously treated by SCHN

- New **outpatients** will be accepted up until their 16th birthday. Patients previously treated at SCHN may continue to be treated as outpatients up to and including their 18th birthday for conditions for which they have previously been treated or which are related to their existing condition

Where coordinated adult health care services exist, patients can be transitioned at an earlier age if appropriate, as agreed by the clinical team, the young person and their family.

For all new patients, appointments must be available for them to be seen and/or admitted before their 16th birthday.

Young people who have reached their 18th birthday can only be admitted (or continued as an outpatient) if approved by the Patient Flow Medical Director (inpatients) or relevant Clinical Program Director (outpatients). Existing patients must have received prospective approval at least 4 months prior to their 18th birthday from the Patient Flow Medical Director (inpatients) and/or the relevant Clinical Program Director (outpatients) and:

- Transition is arranged and transition planning completed
- Patient is attending Year 12 in the calendar year of their 18th birthday (Note: Pathways does not extend this age limit.)
- Patients who have a minor procedure to complete a package of care

Note: Poorly managed transition is not a justification for readmission.

Exceptions may be approved for young people with palliative care arrangements in the very terminal phase of care and must be approved by the Director of Clinical Operations via a Clinical Program Director.

Patients who have reached their 19th birthday will be referred to the Director of Clinical Operations via Patient Flow Medical Director unless they are in one of the exempt outpatient categories as follows:

- Perinatal advice
- Genetic consultation around an existing SCHN patient
- Late effects follow-up oncology clinic
- New patients older than their 18th birthday are not accepted unless approved by the Director of Clinical Operations via a Clinical Program Director

For more information, refer to Admissions Policy

Transition planning by clinical teams

Each sub-specialist providing care for patients with a chronic condition is responsible for identifying a clinical team member to coordinate and develop a transition model for their service. The model details how transition will be undertaken for all young people in their care, including the role of individual team members in transition preparation, the age at which transition will begin and be completed, and the resources to be used to support the process.

Each young person's transition plan will need to be coordinated by a case manager in consultation with Trapeze, as it may require input from a variety of teams, and coordination with schools and community services. This should be decided by the primary treating team who then make a referral to Trapeze, the specialist transition service of SCHN, once the young person is 14 years old.

Individual preparation & planning between the ages of 12-16 years

Clinical teams may consider providing adolescent specific clinics for patients aged 12 years and above or when they enter high school. All inpatients and outpatients between the ages of 12 and 16 years, who will require ongoing care, are to be involved in the preparation and planning for their transition to adult health care services.

From the age of 14 years active monitoring of self-management skills and referrals to Trapeze are encouraged. All referrals for transition support in SCHN are to be made to Trapeze in the first instance.

The Self-Management Skills Checklist - 14 -16 years is a useful tool and can be used 6-12 monthly to ensure basic areas of education and self-management are covered. The checklist assesses knowledge about the condition, communication skills and understanding and use of medications. It also highlights problem areas where further input by various team members may be required (e.g. nutritionist, physiotherapist, psychologist).

As each young person progresses through adolescence an individualised transition plan should be developed so they can move to adult care with confidence. At CHW, this should be documented on PowerChart. Staff at SCH should liaise with Trapeze directly. The involvement of the young person and their family in the development of a transition plan is essential to successful transition. The young person may be required to develop new skills during the transition process, and their family or carer/s may need time to adjust to their changing role of 'primary carer' to 'support provider'.

- When necessary discuss and refer to adolescent specific services in their local area where possible. These services are available for young people both as outpatients and inpatients.

Active Phase: 16–18yrs

Once the young person reaches the age of 16 years, a transition plan, including end of life plans if appropriate, must be completed. Other tools, such as checklists, which help in assessing the young person's ability to manage their care, may be used to start discussion around transition planning.

The steps to be taken in the active transition phase are as follows:

1. At the age of 16 years, provide a Transition Information Kit (developed by Trapeze and ACI) to the young person and their family. Packs can be sourced from Trapeze, Adolescent Medicine at CHW, and Outpatient Departments at both campuses. Ensure an individual transition plan is implemented and the Transition Self-Management Checklist - 16-18 years is completed. This checklist follows on from the 14-16 years preparation phase checklist. It details the issues that need to be addressed before they leave SCHN and can be reviewed at 6-12 monthly intervals.
2. Ensure that the young person has a GP, as the GP will play a pivotal role in their ongoing care. The GP is often the single health professional who is constant during this period of change and can provide a wealth of support to both the young person and the family.
3. All allied health groups involved with the young person's care need to ensure that comprehensive referrals are made to all relevant parties.

4. A Trapeze Referral Form should be completed. At CHW, the referral form is found electronically in PowerChart through AdHoc charting and by opening the folder Trapeze Service. At SCH the paper referral form is found on the SCHN intranet at: http://chw.schn.health.nsw.gov.au/o/forms/transition_services/trapeze_transition_referral_form.pdf. The form should be scanned and emailed to trapeze.schn@health.nsw.gov.au or faxed to 02 8303 3650. .

Exceptions to transition after their 18th birthday require approval of the Director of Clinical Operation via a Program Clinical Director.

At the time of Transition to adult care

- A comprehensive transition referral letter should be sent by each treating team to the adult team/ treating Physician, a copy to Trapeze, and to the young person.
- The first appointment to see the adult team should be made prior to leaving SCHN.

Trapeze

Trapeze is the specialist transition service for SCHN supporting young people as they transition from paediatric to adult health care services. Trapeze will assist facilitate, monitor and coordinate a young person's care during transition and strengthen their links with their GPs and with their communities so they are able to better manage their conditions and stay out of hospital.

Trapeze eligibility criteria:

- 14-25 years old
- Any chronic condition
- Known to SCHN

All clinical teams are encouraged to refer patients from 14 years, so that Trapeze can prepare them well in advance for their move to adult services.

When a Trapeze Referral Form has been completed, the young person and/or their carer will be contacted for a comprehensive assessment which then determines the level and types of support required. If the young person's needs require adult tertiary services then Trapeze staff will refer to the ACI Transition Care Coordinators located in the adult hospitals for coordination.

Trapeze will provide support by:

- Liaising with subspecialty teams within SCHN to facilitate case management;
- Assisting the young person in navigating the health care system;
- Engaging a GP for the young person or strengthening their existing relationship, and arranging a GP Management Plan;
- Providing health coaching and face to face support;
- Consulting with community and hospital adult services about the transition of the young person, and at all times involving the young person in the transition process;
- Telephone, email, and SMS reminders of coming appointments;

- Linking the young person to relevant support groups such as the ChIPS program;
- Assistance through the transition process in collaboration with the ACI Transition Care Coordinators (TCC) and community services; and
- Assisting the clinical teams in implementing the SCHN Transitional Care Policy

What is the role of the ACI Transition Care Coordinators (TCC)?

The Agency of Clinical Innovation (ACI) provides three Transition Care Coordinators in NSW who are based in adult hospitals and provide a state-wide service. Their role is to ensure continuity of care for young people aged between 12-24 years of age with any chronic condition/ disability as they move to the adult health service. They provide information and support to the young person for a minimum of 12 months post transition from a paediatric to an adult health care setting. They help find appropriate health services, provide support to attend clinics and ensure young people stay engaged in adult health services.

Evaluation of the Transition Process

In order to evaluate and measure the success of transition planning, it is essential that information regarding the numbers of young people in both the active and preparation transition phase is kept. This includes:

- Updating individual Transition Plans annually.
- Documenting the numbers of patients transitioned annually from each service.
- Recording numbers of adolescents admitted over the age of 16 years

Each department should have a designated individual responsible for coordinating the active phase of transition who will work in collaboration with Trapeze. Individual departments can keep track of the numbers of young people transitioning and the stage they are at. Trapeze Referral Forms will help identify numbers of young people transitioning and their ongoing service needs in the community and in adult health care facilities.

How to contact Trapeze

Manager
Suite 2, Level 1, 524-536 Botany Rd,
Alexandria NSW 2015
Phone: (02) 8303 3600
Fax: (02) 8303 3650
Email: trapeze.schn@health.nsw.gov.au
Website: www.trapeze.org.au

How to contact ACI Transition Care Network

Contacts for the Transition Care Coordinators at ACI Transition Care Network can be found on the ACI website at: http://www.aci.health.nsw.gov.au/networks/transition-care.

All referrals from SCHN for transition support must be made initially to Trapeze.

Useful Links

- Trapeze www.trapeze.org.au
- Transition resources SCHN intranet and Adolescent Medicine intranet plus website when finalised
- ACI: http://www.aci.health.nsw.gov.au/networks/transition-care
- Physical Disability Council of NSW www.pdcnsw.org.au
- Australian Athletics with a Disability www.sports.org.au
- Medicare Website www.humanservices.gov.au
- www.reachout.com.au

Reference

1. American Academy of paediatrics, American Academy of Family Physicians & American College of Physicians – American Society of Internal Medicine (2002). 'A Consensus Statement of Health Care Transitions for Young People with Special Health Care Needs', Paediatrics, 110(6) pp1304-1306, http://pediatrics.aappublications.org/content/110/Supplement_3/1304.short