
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 Children's Hospital at Westmead to the adult health system for their ongoing care and treatment.

The policy includes information about :

- When to transition
- How each department can implement transition planning as an integral part of each young persons 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
- What assistance is available though the Adult Transition Coordinators contacts, eg what health services are available throughout NSW
- 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
- Limited resources? Transition made easy, in just TWO steps!

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

Preparation and planning are the keys to a successful transition to adult care.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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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" (American Academy of Paediatrics).

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 providing care of young people with chronic conditions should develop a transition model for their service. All young people with a chronic condition should be supported with an individual transition plan.

Aim

This policy provides the framework for planning 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 are 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. Consideration needs to be given to education around their condition, promotion of self-management skills as well as assessment of their psychosocial needs. Preparation for transition planning should therefore generally commence from age 12 years with education towards self-management followed by active transition planning from age 16 years.

Admissions Policy

- In general, new **inpatients** will be accepted and admitted up to their 16th birthday. Patients previously treated at CHW 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 at CHW.
- New **outpatients** will be accepted up until their 16th birthday. Patients previously treated at the CHW 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.

- Young people having reached their 18th birthday can only be admitted (or accepted as an outpatient) if approved by the Director of Clinical Operations or delegate. Exceptions may be approved for young people with developmental or complex disabilities, rare conditions or palliative care or where appropriate adult services are not available.

Note: All requests for admissions of children over the age of 18 years **must** be discussed with the Director of Clinical Operations.

More information, refer to [Admissions](#) Policy

Transition planning by clinical teams

Each clinical team providing care of patients with chronic conditions should identify a transition coordinator and develop a transition model for their service, in consultation with the Transition Project Officer. 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.

Resources may include information about:

- How and when transition will be undertaken – [Transition Planning fact sheet](#)
- [Transition flowchart](#) - including who will be responsible for coordinating the process
- Age related self-management skills checklists (generic checklists may be adapted for specific conditions):
 - [Self management checklist 14 – 16 years](#)
 - [Self management checklist 16 – 18 years](#)
- [Individual Transition Plan](#) for each young person
- Lists of available adult services (services may be identified with advice from the Transition Coordinators at Westmead Hospital and RPAH where appropriate)
- Other resources for young people and their parents/caregivers – e.g. transition information kits & GMCT postcards available through AMU and OPD

The referral form to the Adult Transition Coordinator – [Transition Referral Form](#)

The transition model should be evaluated by each team annually.

The [Departmental Transition Planner](#) is available to assist in the evaluation process.

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

Clinical teams should 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 is encouraged.

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.

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'.

Issues that need to be addressed in the preparation phase include:

- Education around the illness
- Genetics / cause / risk factors
- Growth and development
- Puberty
- Medication knowledge
- Promotion of self-management skills
- Illness specific areas
- Treatment plans
- Planning and keeping appointments
 - Knowing when to seek treatment advice
- Psychosocial Issues
 - Growth/pubertal delay
 - Adherence to treatment
 - Impact on school or work
 - Changes in mood or behaviour
 - Knowing when to seek help

When necessary discuss and refer to adolescent specific services. These services are available for young people both as outpatients and inpatients.

- **Consultation or liaison with Adolescent Medicine.** The multidisciplinary Adolescent Medicine team may be consulted regarding a range of health issues, such as delayed puberty, gynaecological problems, psychosocial issues, high risk behaviour and non-adherence to management plans (refer using the Adolescent Medicine Unit (AMU) [Chronic Illness & Transition referral form](#))
- **Adolescent Outpatient Clinics:** Each sub specialty unit, where possible, should establish Adolescent Clinics for young people of high school age.
- **Adolescent Ward:** Wade Ward is a specialist adolescent unit that works in conjunction with the Department of Adolescent Medicine to provide a developmentally appropriate environment for young people who require treatment for various health issues. The young person is aged 12 years or over and/or attends high school and will benefit from an environment in which they are with their peers. Priority for the admission to Wade Ward is given to adolescents with chronic complex conditions and those needing psychosocial support through Psychological Medicine and Adolescent Medicine Teams.
- **Peer Support:** Peer support and mentoring programs aimed at supporting young people with a chronic condition are available. Contact the ChIPS Program Coordinator, via the Department of Adolescent Medicine (ext 52446), for further information.

Active Phase: 16–18yrs

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

The timing of transition to adult care is flexible according to the individual needs of the adolescent, but planning needs to be completed prior to their 18th birthday.

This usually coincides with:

- completion of growth and pubertal development
- completion of cognitive developmental tasks of adolescence
- choosing future health service based on the geographical location of university, TAFE or employment opportunities.

Exceptions to transition after their 18th birthday require approval of the Director of Clinical Operations.

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

- At the age of 16 years, provide a transition information kit to the young person and their family. (These can be requested from the transition coordinator or obtained from CHW Outpatient Department and the Department of Adolescent Medicine).
- Ensure an [individual transition plan](#) is implemented and, if appropriate, 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 CHW and can be reviewed at 6-12 monthly intervals.

- Provide written information about appropriate adult services (i.e. how to get there, who the team members are, and what happens when you attend clinic or require admission to hospital). If you are unsure of what health services are available the Adult Transition Coordinators can assist you in finding appropriate care.
- Confirm 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.
- Make sure that all allied health groups involved with the young person's care are aware of the transition and that comprehensive referrals are made to all relevant parties.
- Make sure they have information on how to make the appointment in the adult setting, or make the appointment in consultation with them.

At the time of Transition to adult care

(To assist a successful transition, a [Transition 10 point Checklist](#) may be completed.)

- The [Transition Plan](#) and Checklists ([14 – 16yrs](#) or [16 -18yrs](#)) should be completed, and the young person should feel confident to manage their care to the best of their ability.
- A [Transition Referral Form](#) should be completed and signed by the young person or their carer allowing the Adult Transition Coordinator to contact them. This is then sent to the appropriate area health Adult Transition Coordinator.
- A comprehensive transition referral letter should be sent to the adult team / treating Physician and the Adult Transition Coordinator, with a copy given to the young person.
- When appropriate, the first appointment to see the adult team should be made prior to leaving CHW.

Transition is complete when the young person is actively engaged with adult services. This is usually evident once correspondence is received from the adult physician or health care team.

When a transition referral form has been completed, follow up is carried out by the Adult Transition Co-ordinator after 6-12 months, to ensure that the young person has continued to be actively connected with the adult service and has graduated from paediatric care.

Developmental delay and major physical / cognitive disabilities

For those young people who will not manage to achieve independence and who will require the ongoing assistance of a family member and community services, it is essential that planning for their adult health care needs begin as early as possible to ensure all aspects of their future health care needs are addressed. Special consideration regarding the timing of transition should be discussed with the Director of Clinical Operations.

Each young person's transition plan will need to be coordinated by a case manager, 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 liaise with the Adult Transition Coordinators to assist with locating appropriate adult health services.

Limited Resources? Transition in 2 easy steps!

1. Complete a Transition Plan
2. Send a copy of your referral letter or referral form to the adult transition coordinator

Completing these 2 steps will ensure that the young person will have the skills to manage their care and will be followed up in the adult system.

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

- o Documenting completed individual Transition Plans, or their progress towards completion annually.
- o Documenting the numbers of patients transitioned annually from each service.
- o 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.

Individual departments can keep track of the numbers of young people transitioning and the stage they are at, by using the [Transition Planner](#).

[Transition Referral Forms](#) sent to the adult transition coordinators will help identify numbers of young people transitioning, and the ongoing service needs in the adult health care facilities.

3 monthly reports are provided to the Transition Project Officer on the number of patients admitted and seen in Outpatient Department for each Clinical Program and Specialty.

Need more information?

Go to:

- CHW internet site: www.chw.edu.au/
- CHW intranet site: http://intranet.kids/ou/transition_services/
- GMCT Website: www.health.nsw.gov/gmct/transition

Contact details for adult Transition Coordinators

Transition Coordinator

Western Area Health Service (based at Westmead Hospital)

Phone: (02) 9845 7787

email: Joanne.Brady@swahs.health.nsw.gov.au

Transition Coordinator

Northern Sydney/Central Coast Area Health Service(based at RPAH)

Phone : (02) 9515 6413

email: lif.Oconnor@email.cs.nsw.gov.au

Transition Coordinator

John Hunter Hospital (Northern NSW)

Ph: (02) 4016 4783

Email: Karen.Johnson-Dewit@hnehealth.nsw.gov.au

If you are not sure which adult coordinator to contact, send the referral on to Joanne Brady Western Area coordinator and she will direct to the appropriate person.

Links to other information

www.pdcnsw.org.au/

www.sports.org.au/

www.hic.gov.au

www.caah.chw.edu.au/

www.drlink.com.au

www.reachout.com.au

Transition Flowchart

Diagnosis to 12 years

General Clinic



12 years onwards **PREPARATION PHASE**

Adolescent Clinic (when available)

- From the age of 12 years transition should begin to be discussed with the young person and their family
- Completion of the **Self-management skills checklist 14-16yrs.** Education and evaluation of the young persons skills should begin now and be monitored 12 monthly.
- **Consultation/liaison** regarding general health issues/psychosocial issues.
- Regular liaison with adult clinical teams.
- **Team transition coordinator/ clinician** to facilitate management across paediatric/adult services and develop an individualised transition plan.



Adolescent Clinic

16-18 years **ACTIVE PHASE**

- Adolescent Clinic provides a focus on the preparation and planning for transition with the **adult team** member attending where possible
- If there is no Adolescent Clinic, an **individual transition plan** facilitated by the consultant and CNC will provide the same information and process to enable smooth transition to adult care
- Adolescents should receive detailed **information on adult services** (verbal & written, eg adult service pamphlet) 12 months prior to transition
- Where possible, the young person may **visit the chosen adult service** and meet the staff
- Prior to transition the young person should **discuss any concerns** they have with the paediatric service
- **A transition referral letter** should be sent to the adult transition coordinator prior to leaving paediatric care. This will ensure follow up.
- **Formal transition to adult service.** 1st appointment planned and made by young person with CNC or Consultant
- All young people will need to have a **local GP** who will be able to liaise with the adult health service



Adult Clinic

18-19 years **EVALUATION**

- In order to evaluate the success of transition a Follow up Questionnaire: should be completed with the adult transition coordinator after 12 months.

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