

## Transition to Adult Healthcare Services Work Group Guidelines for Transition from Paediatric to Adult Care

The Transplant Centre at The Hospital for Sick Children developed “*Guidelines for Transition from Paediatric to Adult Care*”, a checklist for health care providers to use to make sure all steps are covered regarding preparing youth/families for the transition/transfer to adult care.

SickKids

Transplant Centre


### Transplant Centre The Hospital for Sick Children Guidelines for Transition from Pediatric to Adult Care\*

#### Definition

Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-centred health care systems (1).

#### Guiding Principles (2, 3, 4, 5)

- Transition planning should begin at an early age and focus on increasing independence over time. This should take place both within the hospital setting (i.e. clinic/outpatient and during In-patient stay) and in the home
- Transition planning helps to ensure uninterrupted, coordinated health care.
- Involvement of the adolescent, family, pediatric and adult health care providers is crucial to and optimizes successful transition.
- Parents/carers and adolescents may have different needs regarding the transition process, therefore transition planning should be individualized; taking into account the specific developmental and physical needs of the adolescent.
- Plan for transition to an adult care facility by age 18 yrs.

	Age & time	Provider	Parent/family	Young person
	Early	Major responsibility	Provides care	Receives care
	Increasing Age	Support to parent/family & child/youth	Manages	Participates
	Increasing Age	Consultant	Supervisor	Manages
	Adult	Resource	Consultant	Supervisor/CEO

**Transition Intervention Menu: Good2Go Program (6)**

<http://www.sickkids.ca/Good2Go/What-we-do/index.html>

### **Transition Process**

#### **Very Early (diagnosis -10 yrs)**

- Give parents 'Ready, Set... Good 2 Go Timeline' (6).
- Encourage parents to make a 'MyHealth Passport' (7) for their child.

#### **Early (10-13 yrs)**

- Include age-appropriate discussion of medications, tests and treatments at each interaction
- Employ strategies for the young adolescent to assist with medications under parent's supervision.
- Discuss with patient and family the role of Adolescent Medicine at age 12 yrs (may be younger or older based on maturity or other factors) during a routine clinic visit or during inpatient stay, and facilitate a referral, as appropriate.
- Discuss the importance of seeing adolescent patients alone with parents and gain their support for this strategy.
- Begin seeing the adolescent alone for part of each clinic visit at age 12 yrs.
- Ensure the adolescent and family are aware that care will be transitioned at age 18 yrs and determine to which adult care facility care will be transitioned.
- Begin discussing the clinic's plan to help prepare patients for transition (i.e. more independent management of health). Discuss any concerns regarding this transition process.

#### **Middle (14-16 yrs)**

- Review medications / tests and plan of care with adolescent at each interaction. Adolescent should know names and doses (or pill colours / shapes).
- Discuss strategies to promote increasing independence with medication administration and tracking health care appointments with the adolescent and parent.
- Continue with Adolescent Medicine visits annually or as appropriate.
- Continue to see the adolescent alone for part of each interaction.
- Explore family plans for drug coverage once the adolescent turns 18yrs.
- Attend a "Transition Information Day" (recommend age 15 yrs or older)
- Explore / acknowledge any parental concerns regarding their child's increasing independence.
- Have patient update 'MyHealth Passport' with parents or clinic team member, and if necessary, discuss knowledge gaps with member of transplant team

#### **Late (17-18 yrs)**

- Continue with all of the above strategies
- Older adolescent should know names and doses of all medications and have primary responsibility for administering and re-ordering their medications.
- By the time adolescents transition to adult care they should understand their health history and current conditions; have an appreciation of the importance of long and short-term complications; and be aware of the impact of transplant on sexual health and reproduction (5). In addition, they should have knowledge about how to identify the symptoms associated with a clinical exacerbation (i.e. medical 'red flags'), what to do and who to ask for help in these circumstances.

**Late (17-18 yrs) (con't)**

- Confirm mechanism of drug coverage as an adult.
- Facilitate application for adult disability benefits, as appropriate.
- Review previously completed 'MyHealth Passport' with a member of the transplant team, and update as necessary.
- Secure adolescent / guardian consent for transfer of health information to the adult centre.
- Schedule a "transition visit", transition clinic or contact with adult health care provider, at least 6- months prior to the adolescent's 18<sup>th</sup> birthday (please see caveat below).
- Sick Kids will continue as the primary contact for Transplant Care until the patient is seen by a physician at the adult care facility.

**Transition Referral Package**

Provide a written summary and copies of relevant reports to the receiving adult centre prior to transition. Useful information to include; referral letter, contact information for family MD/Pediatrician, most recent clinic visit summary and most recent imaging or pathology (CD).

**Additional note**

This document is designed to provide general guidelines regarding the transition process, and can be utilized with most patients / families. However, there will be a small percentage of children / adolescents who present with complex developmental, sensory and/or physical limitations who due to their disabilities will not be able to proceed through the stages as described; in these instances, additional modifications and support may need to be provided by the health care team and family/carer, in order to facilitate successful transition.

**Resources**

- (1) Blum RWM, Garell D, Hodgman CH, Slap GB, (1993). Transition from child-centred to adult health care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14, 570-576.
- (2) Canadian Paediatric Society Adolescent Health Committee (2007). Transition to adult care for youth with special health care needs. *Paediatrics & Child Health* 12(9): 785-8.
- (3) American Academy of Pediatrics (2002). A consensus statement on health care transitions for young adults with special health care needs: *Pediatrics*, 110(6): 1304-6.
- (4) Anthony SJ, Kaurman M, Drabble A, Seifert-Hansen M, Dipchand A, Martin K. (2009). Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation*, 9, 614-19.
- (5) Costanzo MR et al, (2010). The International Society of Heart and Lung Transplantation guidelines for the care of heart transplant recipients. *The Journal of Heart and Lung Transplantation*, 29 (8), 914-956.
- (6) Good2Go Transition Program (Sick Kids) <http://www.sickkids.ca/Good2Go/What-we-do/index.html>
- (7) MyHealthPassport <http://www.sickkids.on.ca/myhealthpassport/>

\*This document is an amended version of the Sick Kids Heart Transplant Program document (Dec 2010). Revised version completed by members of the Sick Kids Transplant Clinical Committee – Transition subgroup (3<sup>rd</sup> May 2011).