SickKids | **Transplant & Regenerative Medicine Centre**

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

PROCESS

Very Early (diagnosis -10 yrs)

- Go to About Kids Health[6] for further information on early transition preparation.
- 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 18 yrs.
- 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.
- Confirm mechanism of drug coverage as an adult.
- Facilitate application for adult disability benefits, as appropriate.
- Review previously completed 'MyHealth Passport'[7] with a member of the transplant team, and update as necessary.
- Secure adolescent/guardian consent for transfer of heath 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 18th birthday (please see caveat below).
- SickKids 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). Perception s 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] About Kids Health (SickKids)
https://www.aboutkidshealth.ca/transitionadultcare

[7] MyHealthPassport
http://www.sickkids.on.ca/myhealthpassport/

* This document is an amended version of the SickKids Heart Transplant Program document (Dec 2010). Revised version completed by members of the SickKids Transplant Clinical Committee – Transition subgroup (3rd May 2011). Reviewed and updated March 2021 by Anna Gold (Psychologist) and Angela Williams (NP).