

Guidance on Pediatric Transplant Recipient Transition and Transfer

Summary and Goals

Suboptimal transition and transfer processes for pediatric transplant recipients have been associated with increased risk of non-adherence with their plan of care and graft loss. The goal of the guidance is to support improvements in transplant outcomes by reducing instances of graft loss from non-adherence, and by providing guidance to transplant hospitals to improve the transition and transfer process for pediatric recipients.

Breakdowns in transition and the transfer to adult medical care may also contribute to “lost to follow-up” designations for pediatric transplant recipients on OPTN data collection forms. A secondary goal of this guidance is to reduce the incidence of lost to follow-up designations for pediatric transplant recipients. These data are used to help the transplant community develop healthcare policy (e.g.: in organ allocation) and guides their clinical decision making (e.g.: in determining acceptable travel distance and cold ischemic times for organ recovery). Additionally, transplant professionals use these data when counseling patients’ families and guardians regarding expected outcomes and to set realistic goals regarding transplantation.

By sharing effective practices for recipient transition and transfer from pediatric to adult medical care, transplant outcome data will be more complete and more representative of clinical practices.

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Guidance on Pediatric Transplant Recipient Transition and Transfer

Background

Suboptimal transition and transfer processes for pediatric transplant recipients have been associated with increased risk of non-adherence with their plan of care and graft loss. Breakdowns in transition and the transfer to adult medical care may contribute to instances of non-adherence, and also contribute to “lost to follow-up” designations on OPTN data collection forms. The OPTN/UNOS Pediatric Transplantation Committee (Committee) uses these data to examine long-term outcomes in pediatric organ transplantation. Transplant professionals use these data when counseling patients’ families or guardians regarding expected outcomes and to set realistic goals regarding transplantation.

The Committee recognized there are gaps in data reported to the OPTN that may influence their analyses. The “lost to follow-up” designation is available for a transplant program to enter on Transplant Recipient Follow-up (TRF) forms if the program is unable to obtain the recipient’s health information. This may be due to losing contact with the recipient, the recipient relocating, or being referred to another healthcare provider for post-transplant medical care.

By identifying and promoting effective transfer and transition practices, the Committee hopes to support improvements in transplant outcomes by reducing instances of graft loss from non-adherence to a recipient’s treatment plan. A secondary goal of this guidance is to decrease the number of pediatric recipients lost to follow-up after they transition to adult care, which will in turn increase the accuracy and transparency of the recipient data available to the OPTN, the transplant community, and the public.

Transition

Transition ideally begins in late childhood and early adolescence and involves many stakeholders. This occurs during a challenging stage of development, the complexities of which are well documented in medical literature.^{1, 2, 3, 4, 5, 6, 7} This is even more challenging in children with complex medical conditions, which would include transplant recipients.⁸ Further complicating this progression to autonomous care is

¹Park, MJ, et al., “The health status of young adults in the United States, *Journal of Adolescent Health* 39 (2006), <https://doi.org/10.1016/j.jadohealth.2006.04.017>. Accessed June 27, 2018.

² Keith, D, Cantarovich, M, Paraskevas, S, Tchervenkov, J, “Recipient age and risk of chronic allograft nephropathy in primary deceased kidney transplant”, *Transplant International* 19 (2006), <https://doi.org/10.1111/j.1432-2277.2006.00333.x>. Accessed June 27, 2018.

³ U.S. Government Accountability Office, *End-stage renal disease: Characteristics of kidney transplant recipients, frequency of transplant failures, and cost to Medicare* (2007), <https://www.gao.gov/assets/270/267345.pdf>. Accessed June 27, 2018.

⁴ Dobbels, F, Van Damme-Lombaert, R, Vanhaecke, J, De Geest, S, “Growing pains: non-adherence with immunosuppressive regimen in adolescent transplant recipients”, *Pediatric Transplantation* 9 (2005), doi10.1111/j.1399-3046.2005.00356.x. Accessed June 27, 2018.

⁵ Hazen, E, Schlozman, S., Beresin, E, “Adolescent psychological development: A review”, *Pediatrics in Review* 29 (2008), DOI: 10.1542/pir.29-5-161. Accessed June 27, 2018.

⁶ Giedd, J, “The teen brain: insights from neuroimaging”, *Journal of Adolescent Health* 42, (2008), <https://doi.org/10.1016/j.jadohealth.2008.01.007>. Accessed June 27, 2018.

⁷ Steinberg, L, “A social neuroscience perspective on adolescent risk-taking”, *Developmental Review* 28 (2008), <https://doi.org/10.1016/j.dr.2007.08.002>. Accessed June 27, 2018.

⁸ Andreoni, KA, Forbes, R., and Andreoni, RM, “Age-Related Kidney Transplant Outcomes Health Disparities Amplified in Adolescence”, *JAMA Internal Medicine* 16 (2013), doi:10.1001/jamainternmed.2013.8495. Accessed June 29, 2018.

the transfer to an adult medical provider when the recipient reaches early adulthood. Clear plans for transition have been identified as an effective practice across many disciplines in pediatric health care.^{9, 10}

As pediatric transplant recipients reach this vulnerable age, health professionals often find it challenging to effectively transition the recipients from pediatric to adult care. There are broadly acknowledged facts that may negatively impact transition:

- Lack of optimization in the transition process
- Many youth are ill-equipped to receive care in the adult system
- Adult providers may lack knowledge and skills to care for young adults with childhood-onset chronic conditions
- Inadequate health insurance and transition services funding^{11, 12, 13, 14, 15}

Acknowledging the linkages between less than effective transition, the challenges associated with recipient transfer during a challenging developmental time, and the impact of these on recipient data submission, the Pediatric Committee examined lost to follow-up rates for heart, kidney, and liver transplant recipients in the U.S. who were transplanted during the period 2000 to 2010, and were less than 18 years old at the time of transplant. The data showed diverse lost to follow-up rates across all organs, with the highest for kidney recipients, than liver recipients.¹⁶

Transfer

There are three common models of transfer of care to an adult provider:

- Transfer to an adult transplant physician within the same transplant program
- Transfer to an adult transplant physician at another transplant program, usually geographically closer to the recipient
- Transfer to an adult provider who is not associated with a transplant program, but geographically closer to the recipient

Responsibility for completion of the TRF forms will differ, depending on the model of transfer used. For those recipients transferred to adult providers at another transplant program, the responsibility for completion of the TRF forms will follow them to the new transplant center following an official handoff of this responsibility. For those recipients transferred to an adult provider not associated with a transplant program, the responsibility for completion of the TRF forms will continue to reside with the transplanting program.¹⁷

⁹ American Academy of Pediatrics, Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, *Pediatrics* 128 (2011), 182-200, DOI: 10.1542/peds.2011-0969. Accessed June 29, 2018.

¹⁰ Schwartz, L.A., et al., Measures of Readiness to Transition to Adult Health Care for Youth with Chronic Physical Health Conditions: A Systematic Review and Recommendations for Measurement Testing and Development, *Journal of Pediatric Psychology* 39 (2014), 588-601, doi.org/10.1093/jpepsy/jsu028. Accessed June 29, 2018.

¹¹ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016.

¹² McDonagh, JE, "Growing up and moving on. Transition from Pediatric to Adult Care", *Pediatric Transplantation* 9 (2005), <https://doi.org/10.1111/j.1399-3046.2004.00287.x>. Accessed June 29, 2018.

¹³ Rosen, DS, et al., "Transition to adult health care for adolescents and young adults with chronic conditions: Position paper for the society for adolescent medicine", *Journal of Adolescent Health* 33 (2003), https://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/2003-Transition_from_Child-Centered_to_Adult_Health-Care_Systems_for_Adolescents_with_Chronic_Conditions.pdf. Accessed June 29, 2018.

¹⁴ Watson, AR, "Noncompliance and transfer from paediatric to adult transplant unit", *Pediatric Nephrology* 14 (2000), <https://doi.org/10.1007/s004670050794>. Accessed June 29, 2018.

¹⁵ Knauth, A, Verstappen, A, Reiss, J, and Webb GD, "Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease", *Cardiology Clinics* 24 (2006), <https://doi.org/10.1016/j.ccl.2006.08.010>. Accessed June 29, 2018.

¹⁶ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017. Based on OPTN data as of August 5, 2016 and February 12, 2016 respectively.

¹⁷ OPTN Policies 18.1 *Data Submission Requirements*, and 18.2 *Timely Collection of Data*, https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf#nameddest=Policy_18. Accessed June 29, 2018.

Identification of Effective Practices

The Committee created and administered an on-line survey of transition and transfer practices. They compared survey responses to transplant programs with low, average, or better than average lost to follow-up rates on TRF forms identified in OPTN data.¹⁸ The results were stratified over what can be considered small, medium and large volume transplant programs.¹⁹ This comparison highlighted those effective practices that may promote average or better than average lost to follow-up rates.

The Committee observed the following themes from the survey results:

- A defined transfer age varied among transplant programs. Such a practice may not be in the best interest of long-term follow up. In general, the younger the recipient at transfer, the worse the lost to follow-up rate. Instead, a recipient's developmental milestones and maturity should be strongly considered to determine when to begin the transition process and when to transfer a recipient to an adult provider.
- The absence of a formalized transition process was noted at small volume transplant programs, but was not associated with higher lost to follow-up rates.²⁰ The lower case volume at these programs may inherently allow staff to focus more on recipient-centric indicators for transition and transfer readiness, and focus less on transition processes.
- Low volume centers were frequently in close association with an adult center. The transfer of care to an adult transplant physician within the same program likely contributes to the low lost to follow up rates observed at low volume centers.
- Transfer to adult providers within the same transplant program has its benefits and is associated with lower rates of lost to follow-up designation.
- Transplant programs should commit resources to diligent follow-up of those recipients who reside extended distances from the transplant program and to report these data to the OPTN.
- Transplant programs with average or below average lost to follow-up rates were more likely to transfer recipients to unaffiliated providers compared to transplant programs with better than average lost to follow-up rates.
- Physicians at small volume transplant programs are more frequently involved in the transfer discussion as compared to medium or large volume programs.
- Large volume transplant programs more frequently utilize social workers, transition specialists, or other staff members in transfer discussions.
- Reluctance to transfer care on the part of the parents was reported more frequently by medium and large volume programs, standalone pediatric transplant programs, and kidney programs with below average lost to follow-up rates.
- Large volume transplant programs cited geographic location as a challenge for transferring recipients. This may reflect pre-transplant referrals from a wide geographic area, or programs that operate outreach care clinics.
- Transplant coordinators were most frequently the individuals responsible for contacting other providers for transfer. These individuals were most frequently registered nurses.

Recommendations

Successful transition and transfer practices must balance the needs of the recipients and families/guardians, regulatory requirements, payer factors, hospital policies, transplant program resources, and OPTN member obligations. Though the highest lost to follow-up rates were observed in kidney and liver transplant recipients, the practices outlined can be applied to all types of transplant programs.

¹⁸ Transplant program performance on TRF completion: Below Average = program's 5 year lost to follow-up rate was >10%, Average = program's 5 year lost to follow-up date was between 6-10%, Better than Average = program's 5 year lost to follow-up rate was <5%.

¹⁹ Small Volume = <5 pediatric transplants/year, Medium Volume = 6-9 pediatric transplants/year, Large Volume = at least 10 pediatric transplants/year.

²⁰ See Appendix, Figure 1.

The following are the responsibilities proposed for each team:

Pediatric Transplant Team:

- Create a written health care transition plan that draws on the multidisciplinary approach to transplant care. Examples of this include cardiology, dermatology, endocrinology, pharmacy, and psychology/social work. Encourage and provide guidance to recipients' family/guardians about how they can promote independence and self-responsibility during the transition process. Emphasize that recipients must advocate for themselves and ask questions when faced with unfamiliar tests, medications, outpatient clinic practices, or if treatment plans are modified.
- Prepare both the recipient and their family members/guardians for transfer to another provider.
- Assess transition readiness to include:
 - A recipient's general preparedness for independent care
 - Knowledge and practice gaps
 - Potential threats to graft health and recipient wellness (including emotional/behavioral health), and a mechanism for addressing deficiencies
 - Critical milestones that should be achieved before transferring to adult care²¹

Transition plans should be flexible and based on the unique needs associated with each recipient, and cultural considerations to the recipient and their family.

- Stand-alone pediatric transplant programs should carefully assess if the transplant recipient is reluctant to transfer to another provider. This assessment should occur multiple times during the transition process. If the reluctance to transfer continues then the transfer to adult care should be delayed until the cause of reluctance is addressed appropriately.
- Ensure surrogate decision-makers are identified for those recipients with limited decision-making capability. This would include resolution of guardianship or formal legal arrangements, and should be completed before the recipient's 18th birthday. Formal legal arrangements may be necessary to avoid future conflicts, and ensure continuity of a stable support system.
- Should have a formalized policies and procedures for recipient transfers. Tools, such as a transfer checklist, may be helpful to standardize the process. Collaborate with adult providers on tools to have linkage/overlap to prevent communication gaps.
- Consider transfer to an adult provider within the same institution whenever possible. A multidisciplinary post-transplant transition clinics may be helpful to prepare recipients for transfer to adult providers.
- Partnerships with adult providers should be established well in advance of transfer. Multidisciplinary post-transplant transition clinics jointly staffed with by pediatric and adult teams may be considered in preparing recipients for transfer to adult providers.
- Consider payer requirements earlier in the transition period to prevent lapses in coverage that can lead to recipient noncompliance.
- Communicate each recipient transfer to the OPTN. This will allow accurate assignment of TRF responsibility to the appropriate transplant program. Guidance and frequently asked questions can be found on the TransplantPro website.²²
- Provide the transplant recipient with a portable, concise, up-to-date summary of their medical and surgical history, and detailed list of their medications. In addition to the normal scope of clinical information, the program should indicate prominently the initial reason for transplant, the type of transplant and whether not they have received more than one transplant, HLA typing, any history of rejection, copies of pathology reports (biopsies), detailed history of transplant-related complications or comorbidities (post-transplant DM, hypertension, rejection episodes & treatment, or PTLT).

²¹ See Appendix, Table 2.

²² <https://transplantpro.org/news/tiedi-enhancements-allow-for-self-service-on-recipient-follow-up-forms/>. Accessed June 29, 2018.

- If a recipient relocates or a payer requires transfer of a recipient, additional resources may be needed to effectively obtain recipient health information and submit the information to the OPTN.
- Remember that transplant programs that transfer recipients to providers unaffiliated with a transplant program are still responsible for submitting TRF forms for those recipients to the OPTN.²³
 - To improve health information sharing, the transplant programs should communicate to the accepting provider the need to be kept informed on the recipient's state of health, information required by the OPTN, and the frequency of data submission requirements prior to and at the time of transfer.
 - The originating transplant program should carefully consider the administrative burden of obtaining health information on these recipients when considering staff responsibilities and work volume.

Accepting Adult Providers:

- Provide staff education regarding childhood and adolescence psychosocial development and the impact of childhood chronic disease on development.
- Be knowledgeable about congenital conditions that lead to organ failure in childhood and that may rarely be seen in adult patients.
- Should have a formalized policies and procedures for recipient transfers.
- Multidisciplinary post-transplant transition clinics jointly staffed with by pediatric and adult teams may be considered in preparing recipients for transfer to adult providers
- Recognize that transplant recipients who are transferring into their practice may need time to fully adjust to the more rapid pace of an adult clinic, and a recipient's transition to assuming more responsibility for self-care does not stop after the transfer event.
- Collaborate with pediatric transplant programs on tools to have linkage/overlap in order to prevent communication gaps.
- Programs should consider use of a recipient mentor/coach program to ease the transfer process.
- Maintain ongoing communication with the pediatric transplant programs to improve recipient transfers and provide needed recipient health information for data reporting.

Additional Resources

Additional resources for the recipient's transplant team are available below:

- American Academy of Pediatrics – *Guidance on adolescents transitioning to adult care*²⁴
- New England Journal of Medicine – *Operational Standard for Transitioning Pediatric Patients to Adult Medicine*²⁵
- Organ Procurement and Transplantation Network –
 - UNOSConnect: *Special Considerations and Challenges in Management of Children and Adolescents Presenting to Adult Transplant Centers, and Smoothing the Path to Adulthood: A Transition Clinic for Kidney Transplant Recipients*²⁶
 - *What Every Parent Needs to Know*²⁷

In addition to this guidance for transplant hospitals from the OPTN, transition guidance specifically for transplant recipients can be found on the AST Pediatric Transition Portal.²⁸

²³ OPTN Policies 18.1: *Data Submission Requirements*, and 18.2: *Timely Collection of Data*.

²⁴ <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Helping-Adolescents-Transition-to-Adult-Health-Care.aspx>. Accessed June 29, 2018.

²⁵ <https://catalyst.nejm.org/operational-standard-pediatric-transition-adult/>. Accessed June 29, 2018.

²⁶ <https://unosconnect.unos.org/UI/LandingPage.aspx>. Accessed June 29, 2018.

²⁷ https://optn.transplant.hrsa.gov/media/2464/weparentntk_optn.pdf. Accessed June 29, 2018.

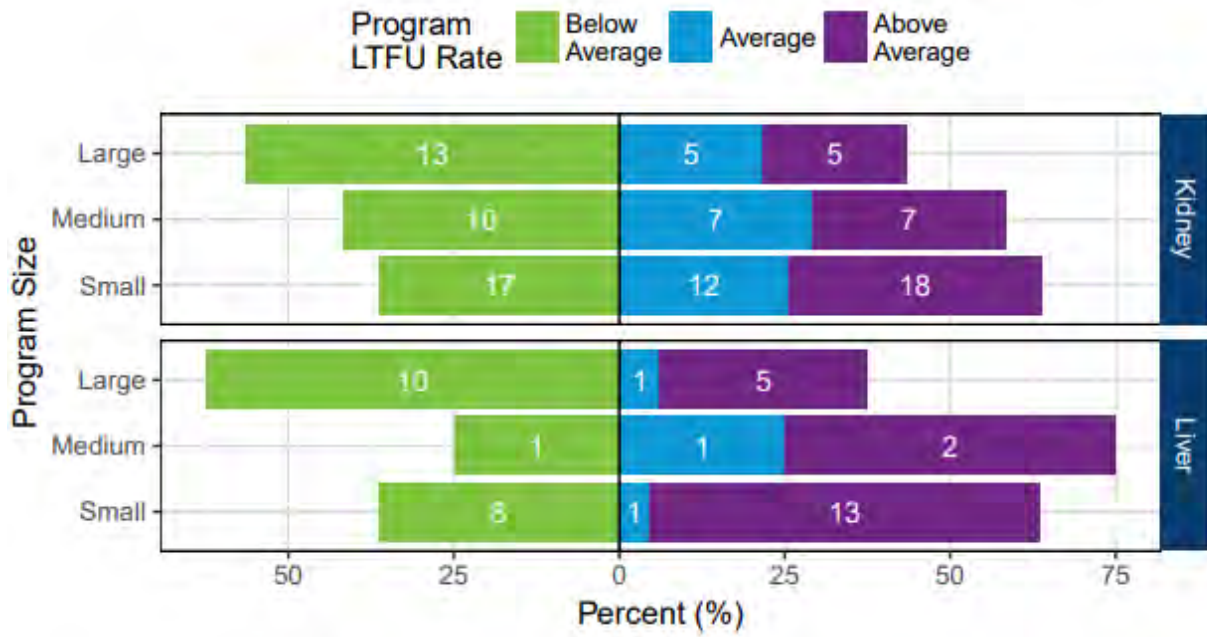
²⁸ <https://www.myast.org/education/specialty-resources/peds-transition>. Accessed June 29, 2018.

Conclusion

By sharing effective practices for transition and transfer of pediatric transplant recipients, this guidance will hopefully support improvements in transplant outcomes, and reduce the incidence of lost to follow-up designations for pediatric transplant recipients.

Appendix

Figure 1: Survey Responses by Organ Type, Program Size, and Program Lost to Follow-up Rate²⁹



²⁹ Based on OPTN Data as of March 16, 2018.

Figure 2: Lost to Follow-up Rates at 1 through 10 Years after Transplant for Kidney Transplants Performed during 2000 - 2010 by Age at Transplant³⁰

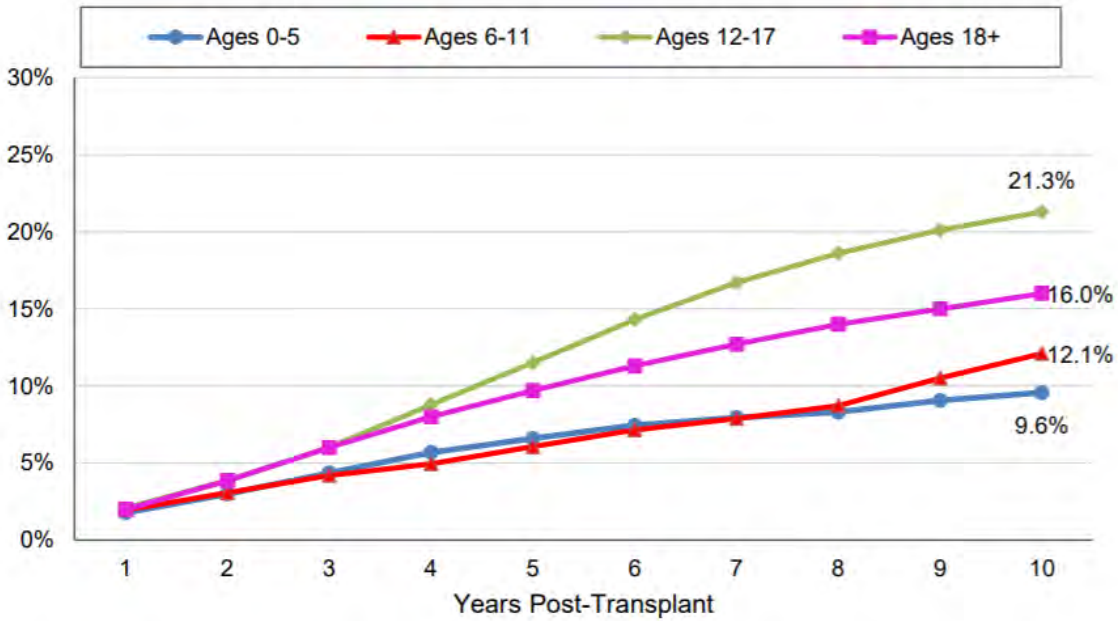


Figure 3: Lost to Follow-up at 1 through 10 Years after Transplant for Liver Transplants Performed during 2000 - 2010 by Age at Transplant²⁹



³⁰ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017.

Figure 4: Lost to Follow-up at 1 through 10 Years after Transplant for Heart Transplants Performed during 2000 - 2010 by Age at Transplant²⁹

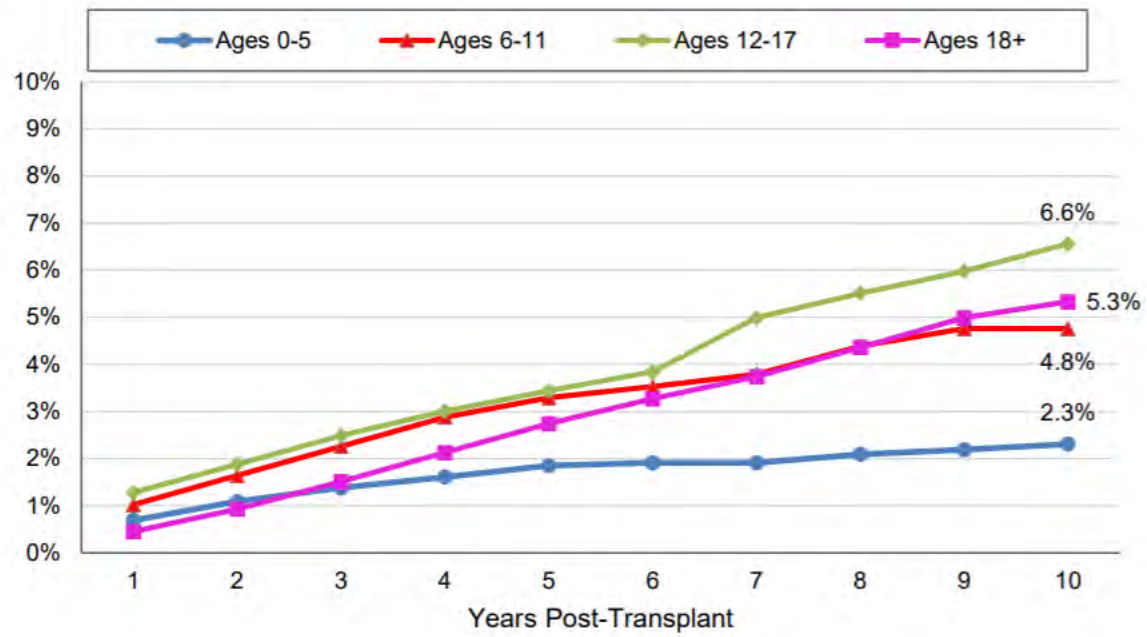


Figure 5: Critical Milestones for Patients to Achieve Prior to Transfer to Adult Care³¹

- Understanding of and ability to describe the original cause of their organ failure, need for transplantation
 - Initial education may have been primarily provided to their parents; repetition is necessary to ensure they understand their condition
- Awareness of the long and short term implications of the transplant condition on their overall health and other aspects of their life (e.g. infection prevention, cancer surveillance, academic and vocational aspirations)
- Comprehension of the impact of their illness on their sexuality and reproductive health, including
 - the impact of pregnancy on their own wellbeing
 - the effect of their medications on fertility
 - Any potential teratogenicity of their medications
 - The role of genetic counselling, and genetic risk of their disease recurrence in future offspring, if pertinent to their condition
 - their own increased susceptibility for sexually transmitted disease
- Demonstration of a sense of responsibility for their own healthcare
 - Knowledge of the names, (and shapes/colors), indications and dosages of their transplant and ancillary medications (or carry that information in wallet/purse)
 - Call for their own prescription refills and renewals
 - Prepare their own medication dose boxes, if not done by their pharmacist
 - Independently communicate their health care needs to their providers
 - Know when and how to seek urgent medical attention, including health emergency telephone number(s)
 - Ability to make, keep a calendar of, and follow through with their own health care appointments
 - Understanding of their medical insurance coverage and eligibility requirements
- Capacity to provide most self-care independently
- An expressed readiness to move into adulthood
- Ownership of their medical information in a concise portable accessible summary

³¹ Bell, L.E., et al., (2008) Adolescent Transition to Adult Care in Solid Organ Transplantation: A Consensus Conference Report, page 9.

Table 1: Developmental Stages/Milestones of Adolescence and Young Adulthood, and Suggested Clinic Visit Developmental Subjects³²

	Early adolescence ages ~10-13 years*	Mid adolescence ages ~ 14-16 years*	Late adolescence ages ~ 17-21 years and beyond*
<i>Cognitive, affective & moral</i>	<ul style="list-style-type: none"> • Concrete thinking • Beginning development of abstract thought in some • Inability to grasp long-term outcome of current decisions • Heightened emotional arousability • Sensation seeking • Early exploratory behaviors (e.g. smoking, violence) • Reward oriented • Development of early moral concepts 	<ul style="list-style-type: none"> • Increased intellectual functioning and abstract thinking • May revert to concrete thinking in confusing or stressful situations • May begin to perceive future consequences of actions but not utilize in decision making • Sense of omnipotence and invincibility • Heightened vulnerability to risk taking • May have difficulty regulating affect and behavior • Questioning of moral conventions • Development of personal code of ethics • Emergent fervent ideology 	<ul style="list-style-type: none"> • Complex abstract thinking (some may never fully achieve) • More future oriented: can act on long-term plans, delay gratification, set limits • Greater emotional stability • Idealism but sometimes absolutism, with intolerance of opposing views • May be swayed by religious and political ideology that promise answers to complex questions
<i>Self- concept/identity formation</i>	<ul style="list-style-type: none"> • Fantasy and present-oriented • Self-conscious about appearance, body image and attractiveness 	<ul style="list-style-type: none"> • Increased introspection • May question meaning of life and have intense feelings of inner turmoil and misery • Concern with attractiveness 	<ul style="list-style-type: none"> • Progression of personal identity • More stable body image; attractiveness may remain important
<i>Family and peers</i>	<ul style="list-style-type: none"> • Beginning of emotional separation from parents and early effort toward independence • Need for privacy • Beginning of strong same gender peer identification and affiliation 	<ul style="list-style-type: none"> • Further emotional separation from parents and family • Struggles and conflicts over autonomy • Strong peer identification and involvement 	<ul style="list-style-type: none"> • Separation from family emotionally and physically • Peer group / peer values begin to diminish in importance • Formation of stable relationships with increasing involvement of love and commitment

³² Bell, L.E., et al., (2008) Adolescent Transition to Adult Care in Solid Organ Transplantation: A Consensus Conference Report, *American Journal of Transplantation* (8) 11, 2230-2242, <https://doi.org/10.1111/j.1600-6143.2008.02415.x>. Accessed June 29, 2018.

	Early adolescence ages ~10-13 years*	Mid adolescence ages ~ 14-16 years*	Late adolescence ages ~ 17-21 years and beyond*
<i>Sexual</i>	<ul style="list-style-type: none"> • Examination of own sexual feelings • Progression of sexual identity development & orientation 	<ul style="list-style-type: none"> • Questions of sexual orientation • Initiation of sexual relationships (often superficial) • Sexual experimentation • Aware of risks of pregnancy and sexually transmitted diseases, but may not consistently act upon the knowledge 	<ul style="list-style-type: none"> • Consolidation of sexual identity
<i>Relationship to society</i>	<ul style="list-style-type: none"> • Adaptation to middle/early secondary school years 	<ul style="list-style-type: none"> • Assessment of skills and opportunities • Early educational and/or vocational plans • Realistic role models critically important 	<ul style="list-style-type: none"> • Career decisions central • University/college/vocational experience with increased self-responsibility • Progression of workforce capability and financial independence
<i>Suggested subjects to explore and discuss at clinic visits discuss</i>	<ul style="list-style-type: none"> • Introduce concept of private confidential visits to parents and patient • Simple directed interactive questions to patient • Straightforward interactive counselling • Discuss healthy lifestyle choices 	<ul style="list-style-type: none"> • Enquire about friends, free time activities, home life, school • Ask in non-threatening, non-judgmental manner about experimentation with drugs, alcohol or sexual activity, and about any trouble with the law • Discuss healthy living 	<ul style="list-style-type: none"> • Discuss healthy living habits and personal interventions for improving overall wellness • Identify unhealthy living habits and their consequences • Build upon questions from earlier age ranges (left of table)

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