Pediatric Pharmacy Advocacy Group

Smooth Transitions: Pediatric to Adult Care of Chronic Conditions

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Objectives

- Assess common barriers to transitioning form pediatric to adult care
- Evaluate existing literature regarding pediatric to adult transitions
- Review transition program structures to help facilitate adult transitions
- Consider available resources to aid in transitions which may benefit your practice

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Background & Transition Barriers

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Background

- Definition:
  - Chronic condition
    - Health condition or disease that is persistent that may last more than 3 months
    - Examples:
      - Asthma, cancer, chronic kidney disease (CKD), congenital heart disease (CHD), cystic fibrosis (CF), diabetes, epilepsy, human immunodeficiency virus (HIV), sickle cell disease (SCD), systemic lupus erythematosus (SLE)

www.webmd.com Accessed on 28 January 2019
Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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Background

- 90% of children with chronic health conditions survive into adulthood
- ~500,000 young adults with these conditions become adults yearly
- 1/4th of 18 million adolescents in U.S. have chronic conditions
- Transition
  - "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems"

Lotstein et al, *Pediatr*; 2005
Bonnie et al, National Academies Press; 2014
Blum et al, *J Adolesc Health*; 1993

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Top 10 (11) Barriers to Transition

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#10: Socio-demographics/Culture

- Unstable living conditions (i.e. homeless)
- Lack of high school diploma
- Low parental education
- Poverty

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#9: Goals

- Transitioning patients have goals to remain in pediatric care

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#8: Neurocognition/IQ

- Cognitive/developmental delay—contraindication to transition
  - CHD
  - Cancer
  - CF
  - Epilepsy
  - HIV
  - Solid organ transplant

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#7: Development

- Developmental immaturity
- Forced to take responsibility for care too early in life—not ready
- May lead to delay in transition & non-adherence (medications, appointments, management of care)

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#6: Health Status/Risk

- Complexity/instability of patients condition
- Risk of infection exposure (CF)
- ↑ severity the disease, ↑ barrier to transition

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#5: Psychosocial Functioning

- Unstable life circumstances
- Depression, anxiety, denial of illness, life stress
- Mental health and substance abuse issues
- Re-disclosure of symptoms to new providers
- Fear of transition
- Lack of peers

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#5: Knowledge

- Medication/illness/transition process (patient/caregiver)
  - Identified by CF providers
    - Knowledge of medications that patient is currently taking
    - How to read prescription labels
    - How to refill medications
    - Awareness of drug-drug interactions/OTC meds/herbals
- Pediatric chronic conditions (adult provider)

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#4: Skills/Efficacy

- Pediatric provider/institution
  - Unable to support transition or coordinate care
  - Lack of staff/time/funding or training in transition issues
  - No established training protocol
- Pediatric patient self-management deficits
  - Poor adherence
  - Unable to be independent
  - Low health literacy leading to inability to schedule appointments, navigate the adult health system

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#3: Beliefs/Expectations

- Differences between pediatric/adult care
  - Belief that adult care quality was poorer—spend less time with patients
  - Adult providers are less caring, knowledgeable, and experienced
- Lack of expectations for moving to adult care
- Perceptions of transition process
- Perceived stigma from adult providers

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#2: Access/Insurance

- Difficulty accessing/finding adult care providers
  - Almost every chronic disease state lists this as a common barrier
- Medical costs/insurance
  - Affordability
  - "Aging-out"
  - If lose coverage, inability to find new coverage
  - Adult providers accepting insurance
  - Unable to understand insurance issues (identified by CF providers as an issue)
- May result in lack of continuity of care, delay in treatment, ↑ ER use

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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#1: Relationships

- Concerns for leaving pediatrics to adults were noted in many disease several chronic disease states
  - Anxiety and worry developed over terminating pediatric provider relationships because they were considered "family"
- Do not want to develop relationship with adult providers—due to strong pediatric provider attachment
- Pediatric providers struggle to let go of long-term relationships
- Over-protective or overinvolved parents limit self-management skill development

Gray WN, et al., *J Pediatr Psychol* 2017;43:488-502

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Successful Transitions

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Transition Theory

- Patient centered
  - Individualized
  - Early and ongoing process
- Self-management with caregiver engagement
- Shared accountability
  - Peds and adult
  - Patient and healthcare provider
- Equitable
  - Eliminating disparities
  - Cultural, socioeconomic

White PH, et al. Pediatrics. 2018;142:e20182587

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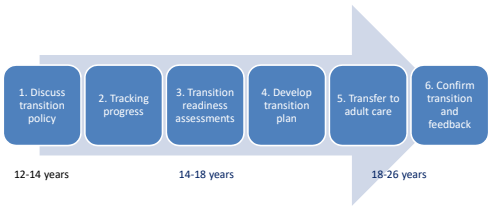
Six Core Elements of Health Care Transition



White PH, et al. Pediatrics. 2018;142:e20182587

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Six Core Elements-Key Points

Six steps for sending & receiving providers
Also for combine providers (Med-Peds, Family Med)

- Pediatric
  - Review policies starting at age 12
  - Conduct transition readiness assessments starting at age 14
  - Prepare for changes to legal requirements at age 18
  - Transfer when clinically stable
  - Compile standard transition packet
  - Follow-up with patient to confirm transfer
- Adult
  - Review polices at 1st visit & routinely thereafter
  - Create orientation for young adults to the practice
  - Address concerns about adult approach to care at 1st visit & as they arise
  - Communicate with pediatric providers as necessary

www.gottransition.org Accessed 23 February 2019.
White PH, et al. Pediatrics. 2018;142:e20182587

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Transition Data

- Limited and inconsistent
- Most publications focus on patient/caregiver or provider satisfaction and perceptions
- Areas for improvement:
  - Cost of transition
  - Systematic study design or variables measured
  - Inclusion of patients with multiple conditions, including mental health conditions

White PH, et al. Pediatrics. 2018;142:e20182587

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A Vulnerable Population

- Could it just be age?
  - Kidney transplant patients 17-24 years-of-age are at highest risk of graft failure
- Risk for worsening of disease state at the time of transition
  - A registry study of kidney transplant patients transitioned before 21 years-of-age and after found that early transition resulted in higher risk of graft failure (HR 1.57)

Foster BJ, et al. Transplantation 2011;92:1237-43.
Samuel SM, et al. Transplantation 2011;91:1380-5.

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Transition Readiness Assessment Questionnaire (TRAQ)

- Modeled off of the transtheorhetical model for change
- Validated 33-item questionnaire for patients 16-26 years-of-age
  - Tested with three groups
    - Activity limiting illness
    - Cognitive impairment
    - Mental health condition
- Not disease specific
- Separated into 2 domains
  - Self-management
  - Self-advocacy

Sawicki GS, et al. J Pediatr Psychol 2011;36:160-71.

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TRAQ Results

- Scores in self-management domain were higher in:
  - Activity limiting conditions
  - Each advancing age group
- Scores in self-advocacy domain were higher in:
  - Females
  - Activity limiting conditions
  - 19-20 & 21-26 years-of-age

Sawicki GS, et al. J Pediatr Psychol 2011;36:160-71

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TRAQ Highs and Lows

- Highest scoring topics:
  - Taking medications
  - Filing prescriptions
  - Communication with the health care team
- Lowest scoring topics:
  - Maintaining health insurance
  - Paying for medical care
  - Employment
  - Support service (community, financial)

Sawicki GS, et al. J Pediatr Psychol 2011;36:160-71

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Transition Models

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Examples of Transition Models in CF

- CF R.I.S.E (Responsibility.Independence.Self-care.Education.)
  - Transition program developed by multidisciplinary team of CF experts and Gilead®
  - Provides tools and resources for CF patients/families & care teams to help prepare for independence & future success
  - https://www.cfrise.com/

https://www.cfrise.com/

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Examples of Transition Models in CF

- University of Minnesota/Fairview Specialty Pharmacy
  - 2 pharmacists dedicated to CF/1 pharmacy technician
  - Start transition process at age 4
    - Measuring specific milestones
  - Readiness assessed at least annually
  - Do hand-off between pediatric to adult care team pharmacists
  - Documentation in EMR

Info provided by pharmacists at Fairview Specialty Pharmacy. Used with permission

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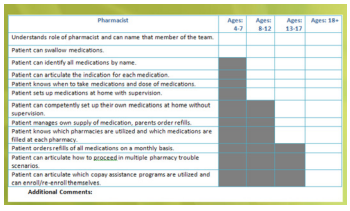
Examples of Transition Models in CF



Pharmacist	Ages: 4-7	Ages: 8-12	Ages: 13-17	Ages: 18+
Understands role of pharmacist and can name that member of the team.				
Patient can swallow medications.				
Patient can identify all medications by name.				
Patient can articulate the indication for each medication.				
Patient knows when to take medications and dose of medications.				
Patient sets up medications at home with supervision.				
Patient can competently set up their own medications at home without supervision.				
Patient manages own supply of medication, parents order refills.				
Patient knows which pharmacies are utilized and which medications are filled at each pharmacy.				
Patient orders refills of all medications on a monthly basis.				
Patient can articulate how to proceed in multiple pharmacy trouble scenarios.				
Patient can articulate which copay assistance programs are utilized and can enroll/re-enroll themselves.				
Additional Comments:				

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Examples of Transition Models in CF

- Alberta (CA) Children's Hospital
- Transition Tips (before transition)
  - Review current drug coverage options
  - Consider alternative coverage if needed
  - Complete a tax return
  - Refill all medications prior to turning 18
  - Prepare an up to date medication list
  - Ensure immunizations are up to date

Used with permission from Taryn Bomersback, B.Sc.Pharm

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Transition Programs with Online Resources

- Hospital-based:
  - Children's Hospital Los Angeles
  - Lurie Children's Hospital
  - BC Children's Hospital
  - CHEO (Children's Hospital of Eastern Ontario)
- Community/Specialty-based:
  - Washington State Medical Home Partnerships Project
  - CHAT (Carolina Health & Transition Program)
  - National Diabetes Education Program

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Intermountain Pediatric CF Center

- Pharmacist process (peds)
  - Pharmacist sees all patients at all visits
  - Annually, patients bring in all oral medications, inhalers, respiratory medications for med review/education with pharmacist
  - Review dosing, reason for taking (i.e. mechanism of action), order of respiratory meds—start with parents; start moving to patient around age 4 (usually enzymes, names of other meds); around age 8, start working on MOA of other meds

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Intermountain Pediatric CF Center

- Pharmacy Transition Packet
  - Pharmacy clinic notes
  - Inpatient Pharmacokinetics/IV antibiotics received
  - Microbiology results
  - Allergies
  - Med List
  - Immunizations
  - Insurance info
  - Pharmacies utilized
  - Copay assistance info

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Movin' On Up: Pediatric Transplant Transition Program

- Kidney, liver, and heart transplant programs
- Typically transition to 1 of 2 local transplant centers based on insurance coverage
- Process is different for each program, but strides are being made on standardization
- Not based on set age
- Special circumstances considered
  - Missionaries have care transferred to local pediatric transplant center, seen 1-2 times after return, then transfer to adult center

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Movin' On Up Structure

- Heart transplant: Driven by nurse coordinators at most visits
- Kidney transplant: Managed by child life specialist who reviews and assigns tasks to responsible members of the transplant team
- Liver transplant: 1 day boot camp where pediatric liver transplant team meets with the patient to assess readiness with combine visit with pediatric and adult hepatologists

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Movin' On Up: Pharmacist Role

- Provision of patient and family education regarding medications
  - Start small (names of medicines) and work your way up to more complex (long-term side effects)
  - Set goals regarding education and gaining more independence in the ambulatory medication use process
  - Adherence!
  - Sex, drugs, and rock and roll
    - Why does this always fall to the pharmacist?
      - Teratogenicity
      - Drug-drug, drug-disease interactions

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SickKids Resource Navigation System

- Previously Good2Go program
- Online information & resources related transition to the adult healthcare system for families
- Features:
  - Transition resources
    - Transition readiness checklists
    - Patient/caregiver centered educational material
    - General timeline for transition
  - Links to other transition websites

www.sickkids.ca/good2go Accessed 23 February 2019

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My Health 3 Sentence Summary

- Used as a tool to practice communicating with healthcare providers
  - Sentence 1: My age, diagnosis and brief medical history
  - Sentence 2: My treatment plan
  - Sentence 3: My question/concern to talk about during this visit

http://www.sickkids.ca/patient-family-resources/resource-navigation-service/transitioning-to-adult-care/index.html Accessed 23 February 2019.

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SickKids Transitions Website

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Got Transition

- Program of The National Alliance to Advance Adolescent Health
- Features resources for providers and patients/caregivers
  - Providers:
    - Links to literature surrounding transition
    - Six Core Elements of Healthcare Transition
    - Toolkits to aid in transition
  - Patients/Caregivers
    - Informational resources geared toward adolescents/families
      - Payers, insurance
      - Guardianship
    - Transition readiness quiz

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https://www.gottransition.org/index.cfm Accessed 23 February 2019.

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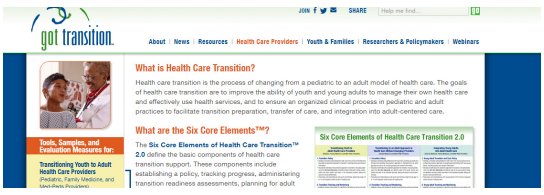
Got Transition Website



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Pediatric Transition Portal

- Provided by the American Society of Transplantation
- Resources include:
  - Readiness Assessment/Checklists
  - Action plans for providers and patients/caregivers
  - Literature regarding transition
  - Links to other websites for transition
- Grouped by age, so can grow with the patient

https://www.myast.org/education/specialty-resources/peds-transition Accessed 23 February 2019.

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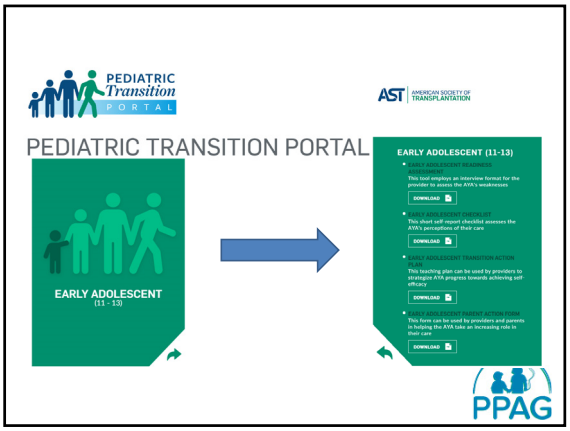

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