

Transition from Pediatric to Adult Care

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Disclosures

None



Objectives



Define health care transition and transfer



Understand why transition of care is important



Know the key steps in a planned transition



Identify patients who are at high risk for increased transition needs

What is Transition of Care?

A planned transition “to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring high-quality, developmentally appropriate health care services are available in an uninterrupted manner as a person moves from adolescence to adulthood.”

AAP 2011

Transition vs. Transfer of Care

TRANSITION

- Purposeful, planned preparation for moving adolescents from child-oriented to adult care
- Begins ~age 12, ends with transfer of care and when patient is comfortable with self-management
- Ensuring medically and developmentally appropriate care

TRANSFER

- Physical change of care from pediatric to adult providers
- Happens when pt will receive more appropriate care in adult setting (usually ~18-21)
- End point, but not entire process
- Not appropriate for all situations!

Transition education helps patients understand how to

- Describe their medical history
- Refill medications
- Make doctor's appointments
- Take their medications and what they are for
- Utilize health insurance
- Create emergency plans
- Balance their medical comorbidities with creating a successful and balanced adult life
- Speak up for themselves in a medical setting



Transition: a new Need

- Medical and surgical advances have improved quality and quantity of life for many pediatric conditions
- Earlier detection of chronic diseases leads to more young adults with medical diagnoses
- 90% of children born today with a chronic health condition will live more than 20 years (Reiss, 2002)
- Around 500,000 children with special health care needs turned 18 in 2002 (Reiss, 2002)



Current Life expectancy of “Childhood diseases”

Disease	Estimated life expectancy (years)	Source
Autism spectrum disorder (with cognitive disability)	36	(Guan, 2017)
Cerebral palsy	55	(Coppus, 2013)
Complex congenital heart defect	35-40	(Reid et al., 2006)
Cystic fibrosis	44	CF Foundation
Down syndrome	60	NADS
Sickle cell disease (HbSS)	42-48	(Platt et al., 1994)
Type I Diabetes	67	(Huo et al., 2016)

Barriers to Successful Transition

System barriers:

- Lack of funding
- Lack of evidence as to best way to do transition
- Loss of other services (ex: CHIP)

Provider barriers:

- Perceived lack of time
- Lack of ownership (should be done by primary care or specialist?)
- Assumption patient has necessary knowledge already

Patient barriers:

- Developmental needs create different timelines
- Disinterest of patient or family
- Other life transitions happening simultaneously

Why is transition of care important?

- Only 47% of young adults (age 19-21) with complex congenital heart disease had successful transitions, and more than 25% had not seen a cardiologist since age 18 (Reid et al., 2004).
- 40% of individuals with ASD lost support services (mental health, case management, speech therapy) after graduating high school (Shattuck et al., 2011)
- High ER utilization in 20-29 year-olds for non-urgent medical issues, especially in the “medically homeless” (Fortuna, 2010)

Why is transition of care important?

- Most deaths in young adults with sickle cell disease happened soon after transfer of care to adult provider (Quinn et al., 2010)
- Only 21% of children with special health care needs transfer care successfully (Oswald et al., 2013)
- Evidence that transition of care can improve clinic attendance and A1c in T1DM (Cadario et al., 2009, Gholap et al., 2006)
- As patient ages, at higher risk for adult comorbidities and need screening pediatricians will not be familiar with

Difference between pediatric and adult medical care

Pediatric

- Family centered
- Diverse support system to help patient achieve goal
- More frequently insured
- Developmental focus
- “Friendlier” environments, more familiarity with system and providers



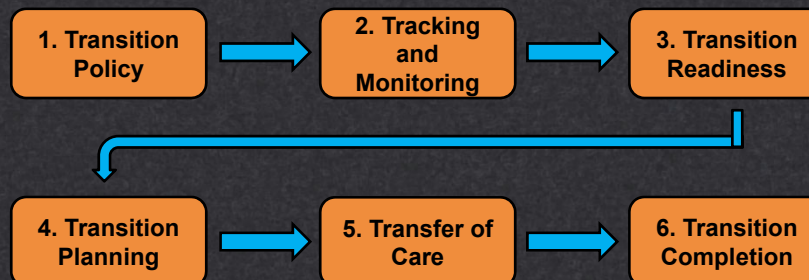
Adult

- Individual centered
- Largely requires patient initiative to achieve goals
- Higher rates of uninsured patients
- Expect similar understanding from patients

Acknowledgment of importance

- Consensus statement on importance of transitional medicine by AAP, AAFP, and ACP
- Got Transition: online resource for patients, families, and providers created by Maternal and Child Health Bureau with the National Alliance to Advance Adolescent Health
- Title V Program: federally funded resource for specialized medical services for children with significant medical conditions

Steps of transition



As outlined by GotTransition.org



1. Transition policy

- Transition Policy is practice's unique approach to transition and why it is important
- Identify "stakeholders", or people who are invested in process (nurses, social workers, family advocates)
- Should include privacy and consent information, as well as that will start doing interviews with patient alone
- Make policy available to family and patient and discuss



2. Transition tracking and monitoring

- Establish how/when will start transition education and how to identify them, start around 12-14 years
- Some EMRs have ability to build in transition SmartPhrases
- Have transition "goals" for all patients to meet (meet with Pharmacy, appointment on their own, etc.)
- Apply to all patients, but identify patients who are at higher risk for difficulty transitioning

3. Transition readiness

- To help decide when patients AND families are ready for transition education
- Focus on self-management and self-advocacy
- Some questionnaires (like TRAQ) can be given to patient and help guide where/when discussions are started

Transition Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to prepare for/change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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How confident do you feel about your ability to prepare for/change to an adult doctor?

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My Health *Please check the box that applies to you right now.*

	Yes, I know this	I need to learn	Someone needs to do this... Who?
I know my medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain my medical needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my symptoms including ones that I quickly need to see a doctor for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do in case I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my own medicines, what they are for, and when I need to take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines and medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how health care privacy changes at age 18 when legally an adult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care

I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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4. Transition planning

- Transition education
- Health care transfer plan
- Emergency care plan
- Portable medical summary
- Discuss legal and insurance changes
- Determine if guardianship needed
- Discuss optimal timing



5. Transfer of care

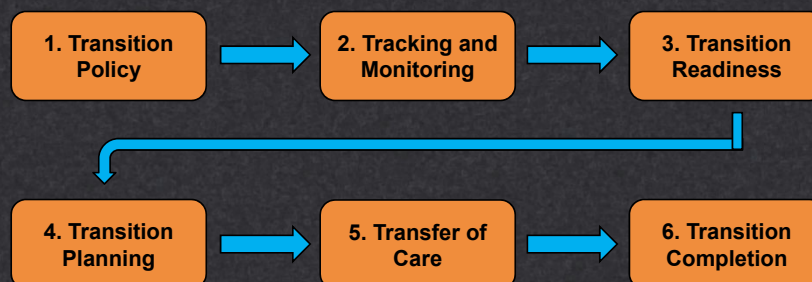
- Confirm date and which providers
- Meeting with adult provider- if possible, prior to transfer
- Transfer when stable and well managed
- Transfer package with medical summary, plan of care, any necessary legal documents, additional records
- Are there providers it makes sense to not transfer?

6. Transition completion

- **CONFIRM** transfer of care, either electronically or by reaching out to family or provider with documentation as such
- Adult provider to confirm what patient knows and what transition education patient and family would still benefit from
- High five- you did it!



Steps of transition



As outlined by GotTransition.org

Reimbursement for Transition

- Got Transition has resource created with AAP that lists codes for transition care
- Includes health risk assessments, medical team conferences, telephone services
- Associated ICD-10 Z71.89 if not for specific medical diagnosis
 - Persons encountering health services for other counseling and medical advice, not elsewhere classified

Who is at high risk during transition of care?

- Racial minorities
- Developmentally delayed individuals
- “Medically homeless”
- Children with special health care needs: 12.8% of children under age 18 (or about 9.4 million people in the US) estimated by US Dept of HHS

Defining children with special health care needs (CSHCN)

“Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

- Department of Health and Human Services

CSHCN

- **Genetic conditions: Cystic Fibrosis, sickle cell disease, Down syndrome**
- **Congenital conditions: congenital heart defects, cerebral palsy**
- **Acquired conditions: diabetes, IBD, organ transplant, history of pediatric cancer, asthma**
- **Learning disabilities and developmental delay**
- **Vulnerable populations: foster children, mental illness, substance use disorders**

Why are CSHCN challenging to take care of in adult setting?

- Limited understanding of history of their disease
- Normalization of illness
- Power dynamic of medical care and parental involvement
- Younger age than average internal medicine patient brings developmental challenges
- Generally have less self-management skills
- Only 16% of CSHCN receive services necessary to make transitions to adult care (NSCH 2016)

Conditions likely to be lost to follow up in pediatric care

- Congenital heart defects
- Childhood cancer survivors
- History of epilepsy
- Learning disabilities

Are you prepared to help these patients?

- Congenital heart disease and pregnancy
- Pediatric cancer survivors and adult cancer screening
- Recurrent seizures in a history of pediatric epilepsy
- Learning disabilities in college
- Diabetes and self-management

Congenital heart disease & pregnancy



A 24 year-old woman with a history of unrepaired VSD comes to primary care office to discuss preconception planning and discussion of safety of pregnancy.

GUIDANCE

- Scoring systems for risk of pregnancy: WHO, CARPREG II
 - WHO Class IV (EF < 30%, prior postpartum cardiomyopathy with HFrEF, PAH, Fontan with complication, vascular Ehlers-Danlos, severe MS, severe symptomatic AS) NOT recommended to become pregnant
 - Updated Echo important for risk stratification
- Have been told their entire life they may die, difficult to discuss risk with
- Progesterone-only contraception safest for CHD (due to estrogen's thrombosis risk), although IUD can lead to vaso-vagal syncope

Pediatric cancer survivors



A 30 year-old woman with a history of pediatric Hodgkin's lymphoma at age 7 comes to establish care. What cancer screening does she need?

GUIDANCE

- Look at COG and/or NCCN for secondary cancer guidelines
 - Ex: if this pt had radiation of neck/chest, would need annual mammograms starting 8-10y after therapy completion, annual TFTs, consider Echo to determine if any cardiotoxicity
- American Cancer Society has patient-friendly versions
- Pediatric providers can fill out ASCO Treatment Summary and Survivorship Care Plan form for adult providers

History of epilepsy



A 27 year-old man with a history of previously well controlled epilepsy has had recurrence of his seizures, and wants advice on how to deal with it at work.

GUIDANCE

- Decide whether should tell employer or not
- Discuss who will disclose to and should have seizure response plan
- Should be seizure free (range from 3-12m, depends on state) prior to driving
- Lifestyle and work should be discussed with neurologist when deciding medication

Learning disabilities in college



A 19 year-old with a history of ADHD comes to his primary care doctor's office for refill of Adderall, and he discloses that his grades have been dropping without extra time for tests like he had in high school.

GUIDANCE

- Develop wish-list and ask for it
- Determine if there is an Office of Disabilities Service
- If had 504 plan in high school, can use to develop accommodations
- Can provide letter as physician if no ODS
- Legal resources: Council of Parents Attorneys and Advocates (COPAA), Association for Higher Education and Disabilities, National Disability Rights Network, Equal Employment Opportunity Commission

Diabetes and self-management



An 18 year-old girl with a history of type I diabetes is excited to go to college, but her parents are nervous about her managing diabetes on her own. What anticipatory guidance can you give her and her family?

GUIDANCE

- Determine necessary resources before pick school: student health services (need it open on weekend?), close to ER, fridges in rooms for medications, size of campus if physical impairment
- Physician can provide letter
- Have educational appointment with only patient soon before leave for college to answer questions
- Decide who needs to be told about diagnosis
- Have plan in place for risk-taking behaviors (ex: if going to drink, wear medical bracelet, have CGM on, be with a friend who knows about diagnosis)

Pediatric providers for successful transition need

- Anticipation
- Preparation
- Discussion of expectations
- Flexible timeline
- Communication with adult provider
- Development of coping skills for patient

Adult providers for successful transition need

- Awareness of patient/family concerns
- Flexible expectations
- Anticipation of ongoing parental involvement
- Understanding that coping and self management skills may be limited
- Collaboration with pediatric team
- Understanding of special considerations of young patients with chronic conditions
- Development of coping skills for patient

Importance of Provider Training

- Internal medicine residents were significantly less comfortable than pediatric residents with the management of autism, cerebral palsy, congenital heart disease, Cystic Fibrosis, Down Syndrome, epilepsy, sickle cell, and spina bifida
 - Less than 10% of IM residents comfortable with autism or spina bifida management
 - Less than 30% of IM residents comfortable with CP, congenital heart disease, or Down Syndrome
- IM and Peds residents were equally as likely to care for patients with epilepsy and sickle cell
- Only 13.8% of medicine residents (compared with 73% of pediatric residents) had formal educational session on transition of care



Patel, 2010

Resources

GotTransition.org

Most subspecialty organizations have specific transition guidance

Health Services for Children with Special Needs

The Catalyst Center- for insurance/financial support for CSHCS

National Resource Center for Supported Decision Making- on state-specific guardianship information

Med-Peds colleagues! 😊

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