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Outgrowing the Child Neurologist: Transition in Tourette Syndrome

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Road Map

- Why is transition for Tourette syndrome so challenging?
- What are the important considerations in transition planning?
- How can we improve the situation?

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First: a few facts about Tourette Syndrome

- Changes in DSM V Criteria vs DSM IV
  - Multiple motor and ≥ 1 vocal tic at some time
  - Clusters of different tics, daily or intermittently for >1 year, with no tic-free period ≥ 3 months
  - Onset < age 18 years
  - Tics cause significant distress or impaired functioning (school, social or occupational)
  - Not caused by direct effect of substance abuse, stimulants or general medical condition

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A few more facts about Tourette Syndrome

- Best estimate of Tourette prevalence somewhere between 0.1-1.0%
- Lower bound includes estimated 600,000 children with impairment
- Upper bound includes all cases of multiple tics
- Tics are more common in boys
- Isolated tics occur in 20- 25% of all children

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And even more facts about Tourette Syndrome

- Symptoms often begin with ADHD then motor tics followed by verbal tics and OCD
- Cephalo-caudal spread and simple to complex progression of tics
- Maturation of circuitry in basal ganglia may explain tendency for tics to diminish with puberty
- Even latest DSM V definition of Tourette syndrome is limited to tics and does not include co-morbid conditions

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Natural History of Tourette Syndrome

4-6 years	ADHD symptoms
6-8 years	Simple motor tics
7-9 years	Obsessive-compulsive behaviors
8-10 years	Complex motor tics
10-11 years	Simple verbal tics
12-14 years	Complex verbal tics
Late Adolescence	Improvement/resolution

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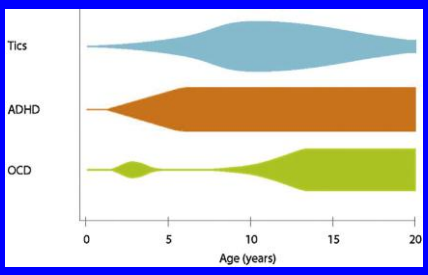
Common sequence of symptoms associated with Tourette Syndrome



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Common Neuropsychiatric and Developmental Co-Morbidities with TS

- ADHD 60-75%
- Obsessive-compulsive Disorder 20-30%
  - 50-60% have OC symptoms
- Anxiety disorders 20-30%
  - Separation anxiety, panic attacks, generalized anxiety
- Intellectual disability and specific learning disabilities 20-25%
- Autism 5%
- Mood disorders, emotional lability, aggression, rage attacks – near 100% at some point

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Why emphasize developmental disabilities and co-morbidities in TS?

- Tics define the disorder, but co-morbidities often more disabling and longer lasting
  - Only 12% have isolated tics, according to survey of 3500 patients by the Tourette International Consortium
  - Tics are often outgrown while other symptoms often persist

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ADHD in Tourette Syndrome

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Treatment of ADHD in Tourette Syndrome

- Behavioral/educational interventions
- α-adrenergic antagonists
  - Guanfacine, clonidine
- Atomoxetine
- Stimulants
  - Methylphenidate, dexmethylphenidate
  - Amphetamines (Adderall, Vyvanse)
- Antidepressants
  - Imipramine, buproprion
- Neuroleptics + stimulant as last resort

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Potential Impact of Untreated ADHD

Low self-esteem | **Academic limitations** | **Smoking and substance abuse** | **Legal problems**

Injuries | **Impaired family and peer relationships** | **Motor vehicle accidents** | **Occupational/ vocational difficulties**

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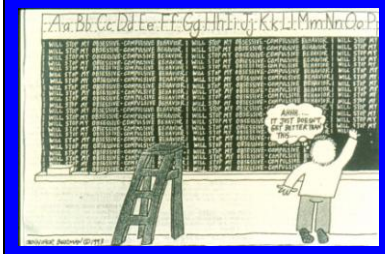
OCD in Tourette Syndrome



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Treating OCD

- Cognitive Behavior Therapy (CBT)
- SSRI
  - Fluoxetine (Prozac)
  - Sertraline (Zoloft)
- Combination of CBT and SSRI
- TCA
  - Clomipramine (Anafranil)
- Consider adjunctive atypical neuroleptics

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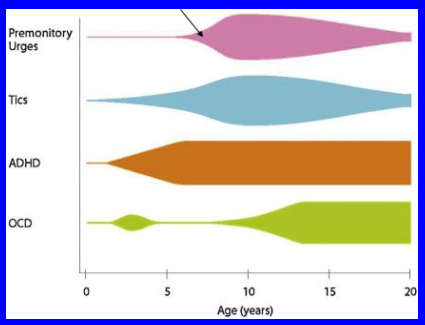
Importance of Premonitory Urges



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Strategies for Managing Tourette Syndrome

- Develop a team to address **all** of the child's needs
  - Medical (primary care, specialist), psychological, educational, family, community
  - Insist upon open communication between all members of the team
- Involve the child in any treatment plan
  - He/she must understand, participate and "own" the plan, especially by adolescence
- Always maintain optimism
  - Remember the natural history of waxing and waning symptoms plus tendency to improvement over time

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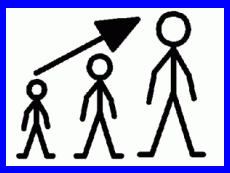
What do we mean by Transition?

- The process beginning in childhood to prepare children with chronic illness and their families for adult care
- Transition must be distinguished from transfer - the formal act of handing over care from pediatric to adult health system



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As a neurologist, I must remember that for parents, caring for a child with Tourette syndrome can seem like traveling through a long tunnel….

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As a neurologist, I must remember that for parents, caring for a child with Tourette syndrome can seem like traveling through a long tunnel….

…. but there is always daylight at the other side.

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The child neurologist is as skeptical about transition as the patient and family

- We have often been working with the family for years, and we have bonded with the child and family

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The child neurologist is as skeptical about transition as the patient and family

- We have often been working with the family for years, and we have bonded with the child and family
- The culture of pediatric care is different from adult medicine – we see ourselves as comprehensive and collaborative vs narrow and focused
- Few adult practitioners seem interested in our complex and behaviorally challenging patients (especially if they are intellectually disabled with limited insurance)

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Not all transition is bad

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Not all transition is bad

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Not all transition is bad

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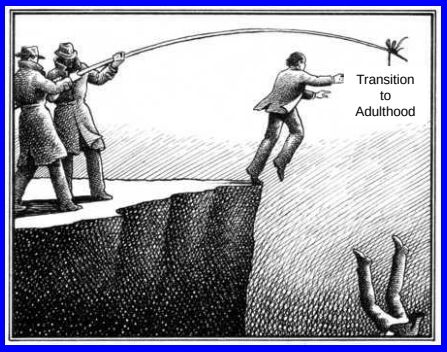
Transition is a necessary fact of life that should not be like falling off a cliff



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Goals of Medical Transition

- To prepare young adults with ability to understand and take responsibility for management of his/her chronic disorder
- To achieve maximal independence in activities of daily living including educational, vocational and social relationships
- To transfer to adult medical providers and ancillary supportive services

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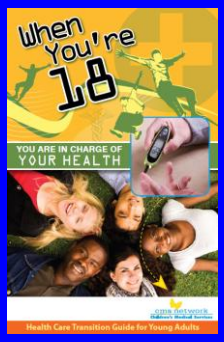
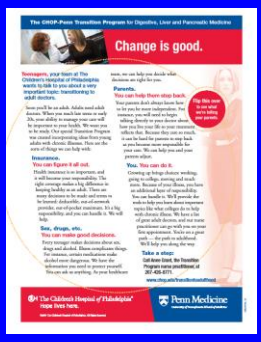
Transition has become a part of pediatric care





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Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes ***your*** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level. **Check here** if you are a parent/caregiver completing this form. ☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					

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Core Developmental Issues to Address in Adolescence

- Personal responsibility
- Autonomy (Independence)
- Personal identity
- Body Image

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How does Tourette syndrome impact these issues?

- Personal responsibility
  - "Why do I have to take medication? nobody else does."
- Autonomy
  - "I am not supposed to do most of the things that my friends do—drinking, drugs, sex."
- Body Image
  - "The pills will make me fat."
- Personal identity
  - "No one will go on a date with me."

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Transition takes planning

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Transition: General Concepts

- Transition planning should start by age 12-16, and should include:
  - Preparation for higher education, vocational support, employment and maximal independence
  - Awareness of available resources and how to access them for on-going support
  - Recognition that adult services can be limited (especially for those with intellectual disability or behavioral disorders)

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Transition in Tourette Syndrome

- Most teens outgrow tics, but persistent are common with complex Tourette syndrome (i.e. ADHD, OCD and anxiety disorders)
- Even if tics and behavior are under control, must anticipate risk of sub-threshold problems leading to academic challenges, difficulty maintaining job, substance abuse

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Perceived Barriers to Successful Transition

- Patient and/or family unwilling to transition (72%)
- Adult providers lack experience (71%)
- Not enough adult providers (68%)
- Multiple Providers (Fragmented care) (62%)
- No time to discuss transition (58%)

Goldberg B, Unpublished 2008

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Other barriers to successful transition

- Lack of knowledge of community resources
- Difference in pediatric vs adult culture
- Aging out from pediatrics, but patient unready to take adult responsibility
- Funding changes
- Transportation
- Lack of reimbursement for transition services

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How can we overcome perceived barriers to successful transition?

- Develop explicit transition policy
  - goal as part of lifelong preparation for successful adult life (not "kicking to the curb")
- Discuss differences between pediatric and adult model of care starting at early age
  - Shift from family to individual
  - Youth as decision-maker

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My personal Transition advocacy agenda: What can be done to improve the process?

- Identify barriers to transition
- Establish a local transition program
  - Develop collaborations with adult neurology, primary care providers, disability services
- Create national transition resources under auspices of Child Neurology Foundation
  - Transition Consensus Panel

Brown, LW, Roach ES. Outgrowing the Child Neurologist: Facing the Challenges of Transition. JAMA Neurology 70, 496-497, 2013.

Brown, LW et al. Neurologist's Role in Supporting Health Care Transition from Adolescence to Adulthood: A consensus statement. Submitted for publication.

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CHOP Neurology Transition Model

- Clinician referral
- Review of medical chart and preparation of detailed summary by transition specialist
  - Diagnosis, evaluation including past medications, most recent psychoeducational evaluation or school records, if available
- Assessment of readiness for independence
- Identification of appropriate adult resources within Penn system and in local community

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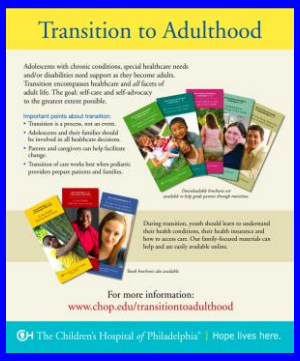
CHOP Transition Program



(www.chop.edu/transitiontoadulthood)

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REACH and REACH for College

(Rapport, Empowerment, Advocacy through Connections and Health)

- Self-care
- Self -advocacy
- Care coordination
- Wellness
- Relationships
- Eligibility for insurance and federal/state programs
- Navigating the medical system
- Advocating for support services

Opportunity for young people and their parents to gather information, network and socialize.

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Behind the Scenes

- Transition Special Interest Group
  - Representatives throughout the hospital from every department
  - Partnership with the electronic medical record
- Chair's Initiative on Transition
  - Development of hospital wide policies tailored to needs of individual programs
  - Utilize EMR to reduce time factor and facilitate compliance
  - Empower patients and families to pursue transition

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Initial Collaborations with UPenn

- Epilepsy
- Neuromuscular program
- Movement disorders
- ADHD
- Autism
- **Tourette syndrome**
  - Adult neurologist at CHOP
  - Penn Adult Developmental Disabilities program

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Transition is very gratifying when it works

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Slide 47

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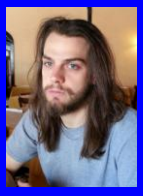

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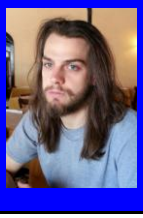
Transition is very gratifying when it works







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…and even though it seems that transition can be an impossible feat…

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…it is necessary, all patients deserve to graduate to adulthood…

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…it is necessary, all patients deserve to graduate to adulthood…

…and we must remember that the goal is **TRANSITION** – NOT JUST **TRANSFER**

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With appreciation to all of my wonderful, challenging patients....

.... in the hope that they will all grow to their full potential