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Transition in Tourette Syndrome: The Role of the Family and the Child Neurologist

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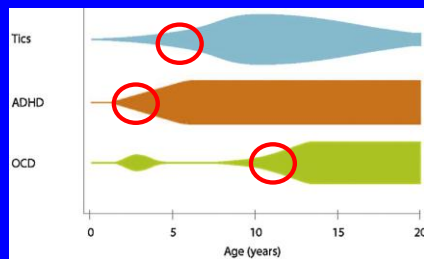
Outline

- Brief review of natural history of Tourette syndrome
- What is transition?
- What are the core principles of good medical transition
- How can we apply these principles to Tourette syndrome
- What can parents do to improve the situation?



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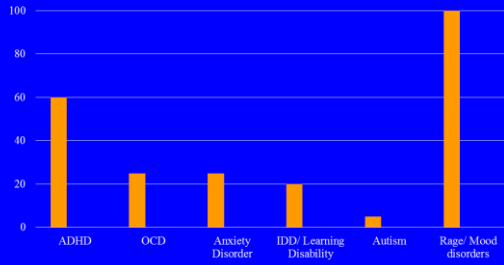
Progression of symptoms associated with Tourette Syndrome



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ADHD and OCD are Not the Only Co-Morbidities in Tourette Syndrome



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Importance of Associated Features in TS

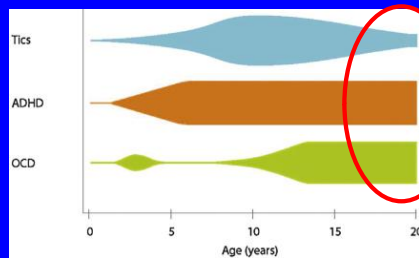
- Tics define the disorder, but co-morbidities often more disabling and longer lasting
 - Only 12% have isolated tics, according to survey of 3500 patients by the Tourette International Consortium
 - Tics are often outgrown while other symptoms often persist



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What Happens to Individuals with TS as they Approach Adulthood

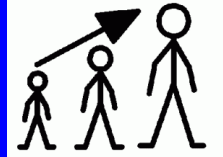


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What do we mean by Transition?

- 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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Goals of Medical Transition: The Neurologist's Version

- 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 ancillary supportive services



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Goals of Medical Transition: The Parent's Version

- To develop a person who can make decisions and advocate for himself
- A mature person with a positive vision for the future
- A person prepared to work, learn, make friends, live as independently as possible
- Where appropriate, a person with access to supports and accommodations
- In essence, a family that is ready to move forward and pass decision making to their emerging young adult



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Transition takes planning...



...although guidelines for success have been lacking

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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group
Pediatrics 2011;128:182; originally published online June 27, 2011;

Six Core Elements of Health Care Transition

- Transition policy
- Transition tracking and monitoring
- Transition readiness
- Transition planning
- Transfer of care
- Transfer completion



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Recommended Medical Transition Timeline

Age 12:

Make youth and family aware of transition policy

Age 14:

Initiate health care transition planning

Age 16:

Prepare youth and parents for adult model of care and discuss transfer

Age 18:

Transition to adult model of care

Age 18-22:

Transfer care to adult medical home and/or specialists with transfer package

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

Which leads to my current project in Transition

- It all started with an initial goal of establishing a local transition program
- Grew into initiative to develop national transition resources under auspices of Child Neurology Foundation



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Primary Goal of CNF Transition Project

- *"...to outline the responsibilities, describe the challenges and provide practical mechanisms to support child neurologists in planning and coordinating medical transition of patients."*

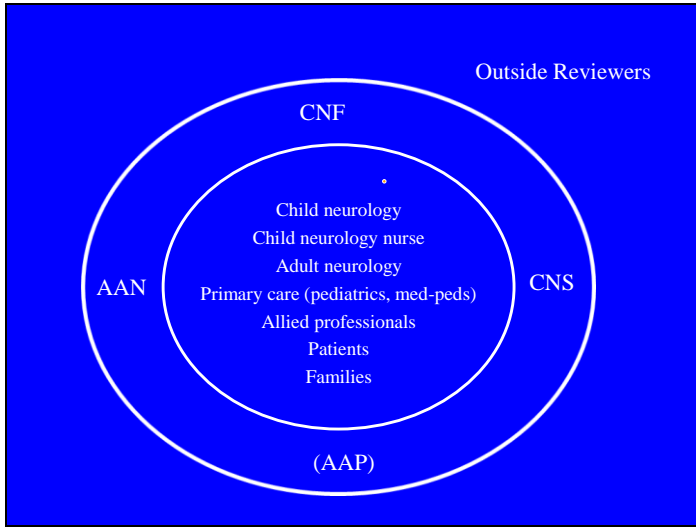


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Methodology

- Interdisciplinary team representing major stakeholders
- Consensus based on literature review and expert opinion
- Development of common principles and vignettes to show generalizability across diverse conditions
- Peer review
- Final guideline

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The child neurology team discusses with the youth and caregiver(s) the expectation of the future transition to the adult health care system.

This discussion should be initiated early and documented no later than the youth's 13th birthday

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Transition Begins with Clear Vision of Adulthood

- Explicit transition policy
 - Early awareness that patients will not stay in pediatric care forever
 - Goal as part of lifelong preparation for maximal independence and successful adult life
- Discussion of differences between pediatric and adult models of care
 - Shift from family to individual
 - Youth as decision-maker

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The child neurology team assures that an assessment of the youth's self-management skills begins at age 12 and continues on an annual basis.

Assessments should be documented in the medical record and communicated to other health care providers.

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Self Management is a Gradual Process that Occurs over Time

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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The child neurology team engages each youth and his or her caregiver(s) in phased transition planning, patient education, and transfer readiness at least annually at scheduled visits, beginning at age 13 years.

- Youth's medical condition
- Current medications and potential side-effects
- Signs and symptoms of concern
- Genetic counseling and reproductive implications
- Issues of puberty (e.g. sexuality, driving, alcohol substance use)
- Psychological concerns and wellness.

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Transition Planning as Annual Responsibility

- Ideal setting unclear
 - Separate annual appointment vs incorporated into non-acute visit
- Age-specific concerns
 - Unrealistic to cover all areas
 - Discussion of increasing self-management skills, disease knowledge, expectation of risk-taking behaviors
- Recognition of patient drift
 - Neurologist is responsible until transfer completed
 - Consider transition summary for youth and family



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The child neurology team initiates discussion by age 14 years with the caregivers regarding the youth's expected legal competency. If unclear, reassessment should be made annually.

Additionally, the team supports interventions to maximize the youth's decision-making ability and assists caregiver(s) to address the legal implications of the assessment.

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By age 14, the child neurologist develops a transition plan in collaboration with the youth, parents, other health care providers, school personnel, vocational professionals, and legal services (as needed) to meet the comprehensive needs of the youth.

The plan should address primary and specialty health care, finance and legal concerns, education to employment, and community services.

The adequacy of the transition plan is reviewed annually.

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Importance of Incorporating a Team for Youths with Tourette Syndrome

- Although most youths outgrow (interfering) tics, persistent problems are common with complex Tourette syndrome (i.e. ADHD, OCD and anxiety disorders)
- Even if tics and behavior are under good control, must anticipate risk of persistent sub-threshold areas of vulnerability which can lead to academic challenges, substance abuse and difficulty maintaining jobs or relationships

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The child neurology team is responsible for developing and verifying the neurological component of the transition plan of care and should update it annually.

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The child neurology team, in collaboration with the youth and caregiver(s), identifies appropriate adult provider(s) for the neurological condition(s) before the anticipated time of transfer. The child neurology team coordinates the transfer utilizing a transfer packet.

**Suggested time frame 1-2 years*

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Treatment Comfort of Adult Neurologists in Childhood Onset Conditions

M. Oskoui, C. Wolfson Can J Neurol Sci. 2012; 39: 202-205

Table 2: Reported comfort level in treating patients with selected neurological disorders: Adult neurologists

Neurological disorder	n	Completely comfortable n (%)	Somewhat comfortable n (%)	Not comfortable n (%)	Impossible n (%)
Autism	98	1 (1%)	10 (10%)	57 (58%)	30 (31%)
Chromosomal or metabolic disorders	98	1 (1%)	25 (26%)	61 (62%)	11 (11%)
Cognitive or Behavioral disorders	98	16 (16%)	33 (34%)	46 (47%)	3 (3%)
Depression	98	14 (14%)	43 (44%)	25 (26%)	16 (16%)
Tourette Syndrome	98	21 (21%)	39 (40%)	34 (35%)	4 (4%)
Anxiety disorders	99	19 (19%)	53 (54%)	18 (18%)	19 (19%)
Multiple Sclerosis	94	56 (60%)	19 (20%)	18 (19%)	1 (1%)
Epilepsy	98	54 (55%)	37 (38%)	7 (7%)	0 (0%)
Headaches	97	67 (69%)	26 (27%)	4 (4%)	0 (0%)
Cerebrovascular disease	97	68 (70%)	25 (26%)	3 (3%)	1 (1%)

83% of adult neurologists find patients with Tourette syndrome difficult or impossible to accept

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Why Don't Adult Neurologists Typically Treat Tourette Syndrome?

- Adult neurologists rarely treat any neuropsychiatric issues (i.e. Tourette syndrome as well as ADHD, OCD, autism, mood disorders, aggression)
- Even adult movement disorders specialists who treat tics may refer to psychiatry for ADHD or OCD management
- Lack of enthusiasm for accepting any new patients with severe behavior challenges or inadequate insurance

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The child neurology team directly communicates with the appropriate, identified adult provider(s) to ensure that the identified provider agrees to accept the patient and an appointment is made and kept. The child neurology team documents the youth's transfer into the medical record.

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Or as the philosopher once said...



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How does this work in the real world?
A hypothetical case



Age 12



Age 21

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Age 12

- Healthy male with Tourette syndrome, ADHD, OCD, sleep difficulties
- A/B student in gifted program with IEP
- Active in sports, band, church group
- Currently on Intuniv, Prozac, melatonin
- Occasional severe tics, but no interfering features
- Neurologist provides transition policy and encourages patient to be responsible for taking medication

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Age 14

- Parental concern that he is unwilling to take medications
- Doing well at school, but increased tics, withdrawn and sulky at home
- Youth's concern that he is different and does not like how he feels on medication, but no real concerns (does not like idea of medication)
- More discussion on self management
- Intuniv increased, referred for counseling

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Age 16

- Academic decline, rage reactions, admits to 2-3 cigarette daily and marijuana 2-3 times monthly
- Neurologist invites youth to identify goals
 - Driver's license, basketball team, college
 - Motivational counseling to identify how treatment adherence can lead to success
- Referral for CBT to address anxiety and self-esteem (which can reduce self-medication)

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Age 18

- Increased tics and insomnia with stress of college application
- Neurologist recommends talking to pediatrician about finding adult primary care provider
- Neurology social worker explores health care and academic support at college
- Neurologist reviews risks of independence
- Medical summary prepared so youth has printout of diagnosis, treatment, emergency plan

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Age 22

- With impending college graduation, further discussion about transfer to adult providers
- Since no neurologists in community treat complex Tourette syndrome, refer to psychiatry
- Neurology team updates medical summary to include previous medications, psychoeducational results, psychological treatment
- Transfer completed and confirmed

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Why Neurologists May Not be Helpful in the Transition Process

- Transition was not taught in medical school or residency
- It is hard to raise issues and not know how to respond to questions
- Neurologists are often uncomfortable with discussions of sexuality, drugs and alcohol
- Feeling that transition is responsibility of school or PCP
- There is nobody on the neurology team with expertise
- Transition care is rarely reimbursable

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What can parents do to help prepare for medical transition?

- Encourage teen to speak for himself
- Encourage him to participate in making appointments, refilling prescriptions, etc.
- Start looking for adult medical services to replace pediatric providers
- Explore funding for adult medical services

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What parents can do to help prepare beyond medical transition

- Home
 - Encourage personal responsibilities such as chores, summer jobs or volunteer work
- School
 - Participate in school evaluations and IEP meetings
 - Insist on educational transition plan by age 14
 - Choose vocational or academic track
 - If in special education, determine timing of graduation

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A Few Questions to Ask Yourself

- Does my child see a neurologist on a regular basis?
- Do I have a partnership with him?
- Am I prepared for appointments with a list of questions and concerns and pertinent reports?
- Does the neurologist have a transition policy?
- At any age, does he talk directly to my child as well as to me?
- Does he talk privately with my teen?
- Am I networking with other parents to learn from others who have gone through similar issues?

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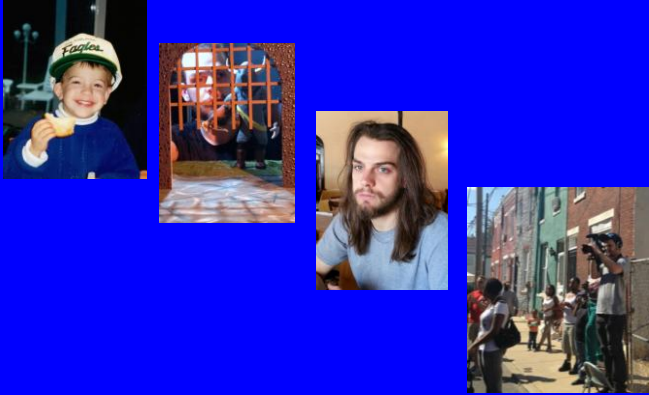
Transition is very gratifying when it works

“Thank you so much. I know you have always been proud of S.... Last year he was in the University of Florida marching band, he went to Israel with UF Hillel, he is taking pre-med classes and he plays his guitar and sings on Sundays at the hospital. I appreciate all you have done these 12 years to help make all this possible.”



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Transition is very gratifying when it works



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Even though transition can seem impossible...



...all patients deserve to "graduate" to adulthood

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*With appreciation to all of my wonderful, challenging TS patients....
.... in the hope that they will all grow to their full potential....*



....and don't forget www.gottransition.org

