

Transitions for the “Emerging Adult”

Transition of Care from Pediatric to Adult Endocrinology
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 - For successful completion, participants are required to be in attendance in the full activity and complete the program evaluation at the conclusion of the educational event.
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Objectives

- Define Transition of Care
- Describe the need for effective transition of care to the adult world
- Discuss challenges and barriers faced by emerging adults
- Review overview of strategies and clinician views in transitioning care
- Identify key factors that can improve successful transition from pediatric to adult care
- Provide resources for transitioning care and program development

Transition - defined

- Transition is defined as the overarching process of development, from adolescence to adulthood, encompassing a time period of preparation and practice to become a high functioning patient in adult care¹
- Transfer is defined as the distinct point within transition at which care is shifted between pediatric and adult systems.¹
- Who are we talking about?
 - Adolescents, young adults, adults
 - Many patients with family support, some without (or limited)
 - Special needs populations (Down syndrome, autism, mental health, T2D, others)
 - Moving spectrum of emotional maturity
- Emerging Adulthood – defined as the post adolescence age range of 18-30.



Who is the “Emerging Adult” of post adolescence?²

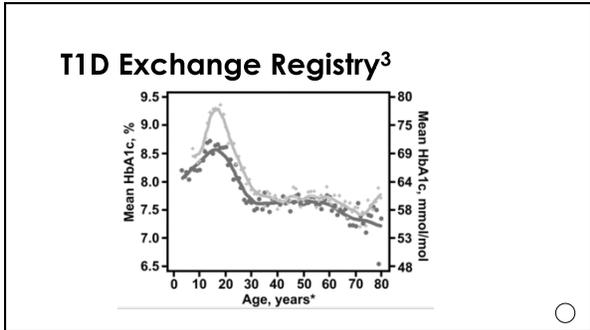
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| Early Phase (ages 18-24) | Later Phase (age 25-30+) |
| <ul style="list-style-type: none">• Headed to college or trade schools• New employment• New relationships• Social lives/media priority• Moving out/away... or NOT?• Invincible, invulnerable• Questionable choices in life• Generation Z? | <ul style="list-style-type: none">• More maturity in decision making• Increased sense of identity• More stability in employment, education, relationships• Making plans for investing in the future• More recognition of diabetes care importance• Support from peers, significant others |



What are the benefits of effective transition?

- Improved glycemic control
- Increased attendance to medical appointments
- Successful utilization of the system, navigating insurance and pharmacies
- Reduction in severe hypoglycemia events
- Improved access to new diabetes technologies and therapies
- Reduced hospitalizations for diabetic ketoacidosis (DKA)
- Reduced incidence of both acute and chronic complications
- Improved sense of psychosocial well being, autonomy





What does the ADA have to say?

- 2011 ADA Position Statement lists eight areas of importance to address when transitioning from pediatric to adult care.⁴
 - Differences between delivery of pediatric and adult care
 - Poor glycemic control, different definitions, other risk factors
 - Loss to follow up
 - Increased risk for acute complications
 - Psychosocial issues
 - Sexual and reproductive health issues
 - Alcohol, smoking and drug abuse
 - Emergence of signs of chronic diabetes related complications
- 2017 ADA Medical Standards continue to emphasize that these areas are still very relevant to date for programs to address

Results of patient surveys^{5 6 7...}

Barriers to care, or reasons for not following through on transition:

- Lack of named specific adult provider or contact information
- Lack of adult provider options, less flexibility with scheduling
- Competing life priorities (school, jobs, bills, social)
- Challenges getting an appointment in timely fashion
- Upset at leaving pediatric relationship, trust (less contextual care)
- Insurance problems (navigation, access to, lack of)
- Costs of co-pays, deductibles, medications, labs
- Patient communication with adult clinic staff and provider
- Differences in care approach between pediatric and adult providers

View from ped endos⁸...

- 2017 survey of 164 pediatric endocrinologists
 - Primary reason for transfer were age (49%) and glycemic control (18%), high self-management skills (12%)
- Barriers to transition
 - Ending long-term therapeutic relationships with patients (74%)
 - Lack of transition protocols (46%)
 - Perceived deficiencies in adult care (42%)
 - Lack of transition training (74%)
- Confirms a large degree of variation in transitioning care despite recommendations



View from adult endos⁹...

- 2016 survey of 418 adult endocrinologists:
 - Only 36% reported reviewing pediatric records
 - 11% reported receiving summaries from pediatric endo offices
 - Very few had direct communication from pediatric providers, joint pediatric-adult provider visits, or patient participation in a transition program
 - Most reported easy access to diabetes educators and dietitians in their clinics
 - Limited access to mental health professionals, a resource barrier (42%)
 - 47% endorsed having patient's parent at the first adult visit
 - Perception that they take more time (45%) and more resources (45%) compared to older adults with diabetes
 - Challenges with adherence to and acceptance of diabetes (30%)
 - Divergent approaches to care between pediatric and adult providers (18%)



What can we do to improve outcomes in our patients?

- Have a transition policy or standard of practice in place
- Utilize a multi-disciplinary team approach (if available)
- Include adult endocrinology as part of a transition clinic (if available)
- Begin early with discussion, with patients as young as age 12-14, and their parents/caregivers
- Document transition checklist topics as they are covered; utilize your electronic medical record if possible for data tracking
- Provide packet of educational handouts and resources, that will be discussed and reviewed along the way
- Teen transition clinics (group discussion, education)
- Provide follow-up after transfer of care



Preparing the Emerging Adult

In Pediatric Endocrinology, this process and education should begin as early as age 14. Topics that need covered may include (not limited to):

- Making and keeping own appointments
- Refilling prescriptions locally and with specialty mail order pharmacies
- How to call healthcare provider with questions or concerns
- Carrying insurance card
- How to call insurance re: issues or claims, or how to obtain insurance
- How to fill out medical forms and get referrals
- Knowledge of own medical condition, needs, symptoms
- Knowledge of current medications, allergies
- Status of health screening (BP, cholesterol, kidneys, etc)
- Mental health, depression screening, resources
- Medical release of information, consents for parents/caregivers
- Discuss differences in pediatric vs adult care



The Hand-off (Transfer)

- Completion of objective patient readiness assessment tools and checklists
- Readiness of patient and parent/caregiver
- Plan for interim care (college, gap years, moving away, etc)
- Plan for identifying a new adult primary care provider
- Identify adult endocrine provider and set appointment date
- Completion of medical summary and emergency care plan
- Status/stability of medical condition
- Medical summary letter to send to the adult practice with referral
- Follow-up by phone (or in some cases another pediatric appointment) after the first adult visit, to confirm transfer and elicit feedback with process



Receiving the Emerging Adult¹⁰

In the Adult Endocrinology setting, here are some suggested guidelines:

- "Welcome to the Practice" guide
 - Clinic hours, location, after-hour contact, phone numbers
 - Who to contact for scheduling, records, billing, insurance or urgent health matters
 - Policy on confirming appointments, cancellations, or no show appointments
 - Communication policies or methods with the clinic (i.e. MyChart)
 - What do I need to bring to my appointments
- Confirm receipt of referral or clinical summary letter and records from pediatric office
- Introductions to key staff, nurses, educators, other providers as able
- Understand that the first few visits may require additional time and resources
- Recommend parent/caregiver attend first visit for completeness of information (if patient allows or prefers)
- Confirm all contact information



The First Adult Visit¹⁰ ...

- Team approach if possible; helpful to include CDE on first adult visit!
- Know that they are establishing trust and rapport with a new provider/team; focus on relationship, not necessarily perfecting the A1c
- Review HIPPA and consents for communication
- Review pediatric clinical summary or records, and recommendations
- Assess for any mental health concerns or needs
- Brief review of crucial hypoglycemia and hyperglycemia treatment, sick day and ketone management plans
- Review of other medical or mental health conditions, medications
- Need for supplies or refills or additional education
- Discuss care plan for ongoing follow-up, expectations, after hours resources



Resources for Transition

You can build your own program or standard of practice. Some resources include:

- Endocrine Society
 - www.endocrine.org/guidelines-and-clinical-practice/transitions
- Got Transition / Center for Health Care Transition Improvement
 - www.GotTransition.org
- <https://collegediabetesnetwork.org/>
- <https://beyonddiabetes.org/>
- <http://myt1dhope.msu.edu/milestones/college-leaving-home>
- Families can use community resources as well, such as local/regional FaceBook support groups



Summary

- Communicate early and often; it isn't ever too early to bring up the idea of transitioning into the adult world
- Look for barriers and challenges, address them as you see them
- Understand that pediatric care and adult care approaches are different
- Implement a transition program or standard of practice for best results; a transition coordinator, or at least a multi-disciplinary team approach is best
- Pass out those emerging adult resources as you see the need
- Have patience!



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Q&A

Endocrinology and Diabetes Health Care Providers simply cannot do diabetes care justice without your expertise and knowledge as Certified Diabetes Educators!

I thank you!