Johns Hopkins Pediatric Diabetes Center Transition Program

Risa Wolf, MD and Amanda Palmer, MPH, RN, CDCES

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JHH Pediatric Diabetes Transition Components

- Transition preparation and readiness assessment
- Diabetes transition to college or the work-force event
- Transition tracking and confirmation

JHH transition policy
Based on "Got Transition" Core Principles

Begin	Transition preparation will begin at the start of high school • Provider introduces topic of Transition • Transition checklist provided to patients/families • RN/CDCES and/or provider cover topics on checklist
Prepare	Transition readiness (READDY) will be assessed in 11th grade and 12th grade • Given to patient by RN/CDCES • Reviewed by provider, BH/KKI, or RN/CDCES • Annual nutrition visits
Transition	Transition to adult care one year after high school completion (with discretion from provider on those ready sooner, or later) • Identify adult provider • Provide adult provider contact information and guidance on when to schedule appointment • Close the loop – communicate with adult provider and ensure patient arrived • Reach out to Amanda with transitioning patients and identified adult provider for tracking

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The Transition Checklist

Freshman Year

- **Begin Transition Discussion**
- Shared Responsibility (adolescent and family)
  - Does patient know medication names and doses
  - Notify parents when it is time for a refill
  - What is the patient in charge of for self-cares
- Preparing for extended time from the home
- Managing lows?
- driving with diabetes
- Effect of Alcohol on Diabetes management
- High School: how to deal with stress and diabetes
- Meet with nutrition and behavioral health at least once/ Nutrition Quiz

Sophomore Year

- Review Diabetes Health
- What is HbA1c? - does the patient know theirs?
- Complications of diabetes
- **Self Management Tasks**
  - Exercise and blood sugar
  - pattern recognition
  - sick day management
- **driving with diabetes**
- Pregnancy and diabetes; safe sex
- Meet with nutrition and behavioral health at least once/Nutrition Quiz

Junior Year

- Shared responsibility (adolescent and family)
  - **Making appointments**
  - **Refilling prescriptions**
  - Contacting diabetes team for blood sugar review/questions between visits
- Carrying insurance card
- Review knowledge of diabetes self-management tasks
  - Medication/Technology
  - Blood glucose monitoring
  - Acute management (lows, highs, sick days)
- Meet with nutrition and behavioral health at least once/ Nutrition Quiz

Senior Year

- Discuss current health insurance coverage
- Diabetes health: Eye exam, Blood pressure; Screening labs
- **Discuss Navigating Healthcare System**
- **Identify cost of medications/Maintaining/obtaining prescriptions**
- Making appointments
- Discuss differences between pediatric and adult care with diabetes team
- Patient responsibilities and expectations
- Confidentiality and parent involvement (HIPPA)
- **Future changes to living environment** (e.g., dorm, roommate, living alone)
- **Discuss risk taking behaviors** (tobacco, alcohol, sexual health and preconception care)
- Identify adult diabetes provider: name, contact information, plan to schedule appointment

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Transition Preparation

- 9th/10th grade checklist: **.64TRANSITIONFRESHSOPH**

Transfer of Care: Checklist for patients transitioning from Pediatric to Adult Diabetes Care

Freshman & Sophomore Year - Begin Transition Discussion

General Knowledge:

- What is HbA1C? What does it mean? What is the target HbA1c? What was the patient's last HbA1c? {diabetes understanding:36987}
- Does patient know medication names and doses: {Yes or No:35302}

Health Behaviors:

- Shared Responsibility – delineating roles for patient and roles for parent: {diabetes understanding:36987}
- Notify parents when it is time for a refill: {diabetes understanding:36987}
- Do you feel comfortable with recognizing and treating low blood sugars: {Yes or No:35302}
- How do you prevent lows when exercising? {diabetes understanding:36987}
- How does patient prepare for extended time away from home? {diabetes understanding:36987}
- How do you manage ketones? {diabetes understanding:36987}

Insulin and Pump Management:

- If using an insulin pump –
  - Changing infusion set: {diabetes understanding:36987}
  - Identifying when there is a problem: {diabetes understanding:36987}
  - Programming the pump: {diabetes understanding:36987}
  - Administer insulin by injection if pump is not working: {diabetes understanding:36987}
- How to deal with stress and diabetes – resources that can help when feeling overwhelmed by diabetes (BH at least once a year, diabetes camps): {diabetes understanding:36987}

Nutrition Quiz

Transition Preparation

- 11th/12th grade checklist: .64TRANSITIONJRSR

Junior & Senior Year

General Knowledge:

- Alcohol and Diabetes: {diabetes understanding:36987}
- Tobacco/Smoking/Marijuana and Diabetes: {diabetes understanding:36987}
- Driving with diabetes: {diabetes understanding:36987}
- Pregnancy and diabetes; safe sex: {diabetes understanding:36987}
- Diabetes Complications: {diabetes understanding:36987}

Health Behaviors:

- Acute management (lows, highs, sick days): {diabetes understanding:36987}
- Routine diabetes monitoring (eye exam, foot exam): {diabetes understanding:36987}
- Annual labs: HbA1c, thyroid, lipids, kidney function: {diabetes understanding:36987}

Insulin and Pump Management:

- Adjust insulin doses based on blood sugar patterns; Basal testing: {diabetes understanding:36987}
- Call pump company if not functioning or need replacement: {diabetes understanding:36987}

Navigation:

- Contacting diabetes team for blood sugar review/questions between visits: {diabetes understanding:36987}
- Making appointments: {diabetes understanding:36987}
- Knowing when you need a prescription refill, notifying your doctor or pharmacy: {diabetes understanding:36987}
- Identify a hospital for emergency care (when traveling or away from home): {diabetes understanding:36987}
- Carry your own insurance card: {diabetes understanding:36987}
- Attend Transition/Off to College event: {diabetes understanding:36987}
- Meet with nutrition and behavioral health at least once per year: {diabetes understanding:36987}
- Complete ***Nutrition Quiz***
- Complete ***READDY*** assessment once a year

Transition Preparation

Senior Year

- Identify Adult diabetes provider: {diabetes understanding:36987}
- Discuss living situation after high school: {diabetes understanding:36987}
- Discuss college environment – housing, prescriptions, dining hall, roommate: {diabetes understanding:36987}

Final Visit Before Transition

- Review responsibility for self-care and importance of family/friend support: {diabetes understanding:36987}
- Sign release/clinical summary (if needed) for transfer of medical information from pediatric to adult provider: {Yes or No:35302}
- Identify adult diabetes provider: name, contact information, plan to schedule appointment: {Yes or No:35302}

Adult Provider:_____ Clinic Number:_____ Appointment:_____

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READDY Roadmap

After administration, RN/CDCES/MD/ NP documents date of READDY administration in snapshot and scans into media

Annual Nutrition and Psychology Visits

- Nutrition quizzes
  - 6 quizzes
  - Discussion of eating in dining hall/on erratic schedule
- Psychology
  - Yearly visit
  - Focus on communication, anxiety, distress

Pictorial Nutrition Quizzes

Brief Pictorial Quizzes to Assess Carbohydrate Counting and Nutrition Knowledge in Youth With Type 1 Diabetes

Myra Waheed,[1] Tyger Lin,[1] Meredith Thivierge,[2] Maureen Seel,[1,2] Laura Prichett,[3] Elizabeth A. Brown,[1] and Risa M. Wolf[1]

-Series of 6 quizzes
-129 youth with T1D completed ~2.4(SD1) quizzes
-Median score 4.7/5
-Higher quiz score associated with lower A1c, higher parental education and income.
-Quizzes can help identify knowledge gaps and provide opportunities for education

Quiz 6 (advanced)	
Questions	Goal/Knowledge assessment
1. You are out to eat to celebrate your team at a pizza place. You check your BG and it is 141mg/dl. You are very hungry and eat the 3 slices of pizza in the picture and have a diet soda. How many carbs do you think you ate? And what would be your insulin dose?	• Capable of estimating carbohydrates without label • Demonstrates ability to calculate insulin dose based on grams of carbohydrates • Able to use arithmetic to figure out different serving size carbohydrate amount

Waheed et al. Clinical Diabetes 2023

Assessing transition readiness

- Assess transition preparedness and readiness at least annually in adolescence: READDY (**R**eadiness assessment for **E**merging **A**dults with **D**iabetes **D**iagnosed in **Y**outh)
- If poor glycemic control, consider delay of transition until stable glycemic control
- Delay transition until patient able to manage **competing demands** (college, work, etc)
- Studies suggest that 19-21 is an appropriate age for transition
  - **Recommendation for our practice: 1 year after high school graduation**

Garvey 2017, Lotstein 2013

Diabetes Transition/Off to College Event

- Yearly transition/off to college event in March
- Held on Zoom; previously held in person
- Recommend patient/families attending Junior and/or Senior years
- Notice of event distributed in January
- Agenda: 1 hr of rapid-fire talks on transition preparedness, importance of transition preparation, accommodations, nutrition, wellness, communication with parents/roommates/team, etc
- Panel discussion with college students/grads and parents

Diabetes Transition/Off to College Event

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Breakthrough T1D™ Formerly JDRF

THE DIABETES LINK Where Young Adults Thrive

Diabetes Teen Transition & Off to College Webinar

The Johns Hopkins Pediatric Diabetes Center and Breakthrough T1D invite high school students living with diabetes and their caregivers/parents to this unique opportunity to learn about and discuss the many facets of the "teen transition years," including going off to college and transitioning from pediatric to adult diabetes care. If you currently have a child in college or are currently a student in college or preparing for adult medical care, you may also find this program valuable.

This program will give you the opportunity to hear from and ask questions of health care professionals who have experience in this field, as well as a panel of young adults living with diabetes who have first-hand experience with these transition years.

Sunday, March 23, 2025
10:00 am – 12:00 pm
Webinar held via Zoom

To register and obtain Meeting ID, please contact Amanda Palmer at apalmer2@jhmi.edu

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Diabetes Transition/Off to College Event

Program Agenda

10am — ***Welcome!***
Risa Wolf, MD, Associate Professor of Pediatrics, Pediatric Diabetes Program Director, Division of Pediatric Endocrinology, Johns Hopkins University School of Medicine

10:15am — ***Focus Topic Presentations***

Finding an Adult Provider
Aniket Sidhaye, MD, Associate Professor of Medicine, Division of Endocrine, Diabetes and Metabolism, Johns Hopkins University School of Medicine

Navigating the Dining Hall
Ashley Blevins, RD, CSP, LDN, Clinical Dietitian and Diabetes Educator, Johns Hopkins Hospital

Disability Services and Accessing Prescriptions
Amanda Palmer, MPH, RN, CDCES, Diabetes Nurse Educator, Division of Pediatric Endocrinology, Johns Hopkins Hospital

Sick Days
Jacqueline Manfredo, MD, Assistant Professor of Pediatrics, Division of Pediatric Endocrinology, Johns Hopkins University School of Medicine

Drugs and Alcohol
Kristin Arcara, MD, Assistant Professor of Pediatrics, Division of Pediatric Endocrinology, Johns Hopkins University School of Medicine

Healthy Communication
Karen Dimenstein, PhD, MPH, Diabetes Psychology Fellow – Breakthrough T1D; Postdoctoral Fellow – Pediatric Psychology Consultation Program, Kennedy Krieger Institute

JDRF Resources
Jessica Allston, Development Coordinator, Breakthrough T1D Mid Atlantic Chapter

11:15 am — ***Panel and Q & A with parents and young adults***

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Off to College Event

Development and implementation of a workshop for young adults with diabetes entering college and the workforce

Margaret West[1], Aniket Sidhaye[2], Meredith Thivierge[3] and Risa M. Wolf[3*]

[1]Department of Pediatrics, Division of Endocri
Baltimore, MD, United States, [2]Department of
University School of Medicine, Baltimore, MD,
University of Maryland School of Medicine, Bal

TABLE 1 Diabetes transition and off to college workshop content.

Presentation Title	Content covered in each presentation
Welcome & Introduction	-Transition period from adolescence to adulthood -Challenges in the diabetes transition period -Importance of transition preparation and readiness
Finding an Adult Provider	-Differences in adult and pediatric diabetes care -Scheduling with an adult provider in advance
Nutrition & Exercise	-Navigating meals and eating on an erratic schedule -Considerations for carbohydrate counting in the dining hall -Planning for exercise and physical activity
Disability Services & Accessing Prescriptions	-Setting up accommodations with the Disability office -Considerations for accommodations at school and work -Transitioning management of prescriptions from caregiver to child -Prescription planning at college and identifying local pharmacies -Identifying local care for urgent issues and emergencies
Managing Sick Days, Hyper- and Hypoglycemia	-Review management for sick days and checking for ketones -Acute management of hypoglycemia review -Emergency medications and training roommates
Alcohol and Drugs with Diabetes*	-Responsible intake of alcohol and adverse effects on diabetes management -Marijuana use and effects on diabetes (in states where it is legal) *if applicable to students >21years of age
Healthy Communication	-Communications about diabetes with peers, professors and coaches -Managing communication expectations between students and parents/caregivers
Partner Organization Resources	-Invite local diabetes organizations to present and share resources (example: JDRF, The Diabetes Link)

West et al. Frontiers in Endocrinology. 2023

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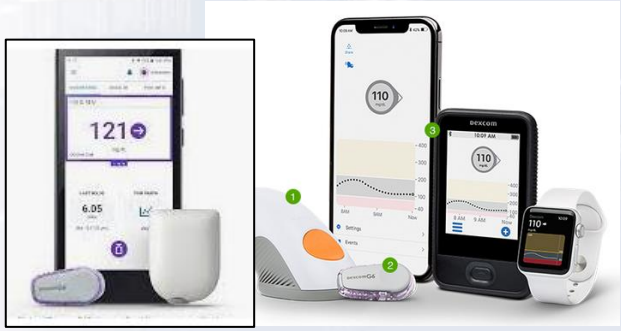
Importance of Transition Preparation for Patients/Families

- Advanced planning -> smoother transition
- Ask for a copy of the transition checklist
- Meet with nutrition and psychology in the preparation process
- Review hypoglycemia management and what to do when sick or ketones present
- Consider CGM, insulin pumps, and automated insulin pumps
- ***Make sure you feel ready***



Planning Transfer to Adult Care

- Providing **specific** adult provider or practice with contact information to make an appointment (EPIC smartphrase .64ADULT)
  - Patient needs to set up first adult visit prior to final pediatric visit
  - Includes list of area (MD/DC/VA/PA/WV) adult diabetes providers
- Review outstanding READDY topics

Final Pediatric Visit

- Provide medical summary to patient (in chart and/or hard copy for patient/MyChart)
- Pediatric provider to contact adult provider – any form of communication
- Pediatric practice tracks that patient attended follow-up appointment
  - Amanda will oversee tracking once notified of plan for transition

Tips for Success

Transition	Clear transition plan – start early
Track	Track acquisition of transition milestones
Integrate	Integrate nutrition and psychology in preparation
Assess	Assess transition readiness
Facilitate	Facilitate transition to adult provider
Follow	Follow-up to make sure patient reached adult care

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Transition team

- Risa Wolf, MD
- Amanda Palmer, MPH, RN, CDCES
- Aniket Sidhaye, MD (Adult endocrine)

References

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