Transitions of Care in Adolescents with Diabetes

November 17th, 2021 DISH presentation M. Tracy Bekx, MD Associate Professor Pediatric Endocrinology





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Checking blood glucoses Counting carbs Dosing insulin Treating highs/low Filling prescriptions Making appointments Calling Diabetes Team Driving and Diabetes ETOH and Diabetes Reproduction and Diabetes Long term complications



shutterstock.com · 638396365 Checking blood glucoses Counting carbs Dosing insulin Treating highs/low **Filling prescriptions** Making appointments Calling Diabetes Team **Driving and Diabetes ETOH and Diabetes Reproduction and Diabetes** Long term complications



Transition of Care in Adolescents with Type 1 Diabetes:

Teaching patients "The Keys" to Drive their Diabetes

American Diabetes Association *Clinical Practice Recommendations For Transition*

- Time of frequent lapses in care:
 - moving out of home
 - moving away from "medical home"
 - moving to an adult provider/new team

Diabetes Care, Vol 38, January 2015 Diabetes Care 2011 Nov; 34(11): 2477-2485 **WHealthKids**

Time of Emerging Stresses:

- Erratic eating patterns-work, school
- Time constraints: work, school, relationships
- Finances/Food/insurance
- Absence of social support-changes in relationships
- Mental health
- Alcohol



Time of Emerging Chronic Complications *Studies looking at young adults ages 18-30 years*

- Retinopathy: 12%-47%
- Nephropathy: 7.3-14.8%
- Hypertension: 30-33%
- Neuropathy: 8.2% of teens+

James et al, BMC Research Notes, 2014: 7:593

Jaiswal et SEARCH Study, Diabetes Care, 2013 WHealthKids

Why important to address: ADA guidelines

- "Pediatric health care providers, working collaboratively with the patient and family, should prepare the developing teen for the upcoming transition in health care delivery beginning at least 1 year prior to the transfer to adult health care providers, and likely during the **early** adolescent years."
- "Preparation should include a more directed focus on diabetes selfmanagement skills for the teen/emerging adult and his/her parents"

When to start the Transition Process?

- The average age of transition for patients with T1D is 19–20 years old
- American Academy of Pediatrics (AAP) suggest that transition planning should begin as early as age 14, including regular assessments to identify self-care needs and goals
- AFCH: Can start as early as age 8-10 years



How to carry out Transition



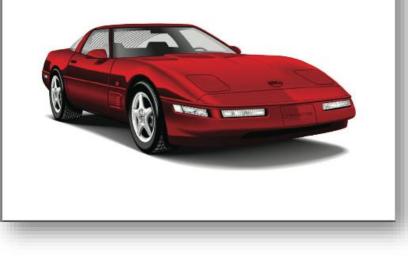
IDENTIFYING TOOLS FOR ASSESSMENT

IMPLEMENTING IN CLINIC



Keys To Independence...

Transitioning from the Pediatric to the Adult Care Team



 <u>https://www.uwhealth.org/files/kids/d</u> ocs/pedsdiabetes/peds_diabetes_key s_independence.pdf



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Acknowledgements

A special thanks to Cheryl, Ashley and Natalie Eklund. Copyright © 2007

Stage 1 Ages 8-10

The diabetes team begins to ask you (instead of your parents) questions about your health. We help you understand how food, insulin, and exercise affect your blood sugars.

Checklist

Explain what it means to have diabetes.

Understand why some people have diabetes and others do not.

- Begin to learn how your body uses the food you eat.
- Understand why checking your blood sugar is important, and learn to check your blood sugar.
- □ Begin to learn how to give yourself insulin.
- □ Begin to identify foods that contain carbs. (Carbohydrates)
- Begin to learn how to make healthy food choices that are part of your food plan.
- Begin to understand the causes, symptoms, and treatment for low blood sugars. (Hypoglycemia)
- Understand that insulin is going to be part of your daily life even when you are sick.
- □ Name insulin types and simple reasons for taking them.
- Begin to understand how sports, play, and exercise affect your blood sugar levels and insulin sensitivity.

Begin to understand how your school day affects diabetes.

Stage 2 Ages 10-12

We continue to ask you questions about your health and diabetes. Try to answer questions about your health on your own. We will help you to understand your diabetes and how to recognize changes in your control. When you begin to notice these changes, you can start to take charge of your own care. This helps you be more independent.

Checklist

□ Continue steps from stage 1.

- □ Remember (most of the time) to check blood sugars on your own.
- Choose foods that are healthy for you and fit your meal plan. Discuss ways to make healthy choices at school, eating out with friends, and other special occasions.
- Begin to understand how an illness like a cold or flu can affect your body and blood sugar.
- □ Begin to answer questions in clinic.
- Understand why you come to clinic every three months.
- □ Begin to understand the importance of A1C values and target goals.
- Begin to name insulin types (use proper names), reasons for taking them, and the proper doses.
- Continue to understand how sports, play, and exercise affect your blood sugar levels and insulin sensitivity.
- Continue to understand how diabetes affects your school day.
- Begin to make choices about friends, drinking, and smoking that keep you healthy.
- Discuss effects of growth, puberty, and sexual development on diabetes.



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Stage 3

Ages 13-15

The diabetes care team gives you and your family the option of seeing you alone for a portion of the visit. We will ask your parents to join you for the remainder of the visit to review information, talk about the health care plan, and answer any questions or concerns. This helps you to be more independent and to build confidence that you can take care of your health.

Checklist

Continue with steps from the previous stages.

- Answer questions independently in clinic.
- I Mix insulin and give all injections with minimal reminders.
- Parents review blood sugar logs, help you to think through and double check insulin doses.
- \square Let parents know when you need medications or supplies.
- □ Understand the significance of A1C, how the choices you make affect it, and how you can change the numbers of your A1C.
- □ Introduce the option of attending a teenage clinic.
- Begin to understand ketones, what they are, what they do, and how to check them.
- Begin to understand the tests that we do each year and why.
- Discuss effects of growth, puberty and sexual development, sexual activity, and reproduction on diabetes.
- Begin to understand the impact of diabetes on driving and the importance of checking blood sugar levels prior to driving.

Stage 4 Ages 16-17

This is a time when you, instead of your parents, begin to talk directly with the diabetes team over the phone when there are changes in your health. We will begin talking about your plans for after high school and how your career choice or school may impact you and your health. We will talk about when to transition to the adult care team. You and your family will have a chance to meet with adult team members during a clinic visit. (See more detail about this clinic visit under, "Common Questions And Concerns About Transition.") You may have already done this if you have attended the "Teenage Clinic" held throughout the year.

Checklist

□ Continue with steps from the previous stages.

- □ Independent with monitoring and recording blood sugars.
- □ Independent with all insulin doses without parents reminding you.
- Begin to call the diabetes team and speak directly with staff if there are changes in your health. (See Keys to Independence Resource Roadmap.)
- Understand the impact of diabetes on driving and the importance of checking blood sugar levels prior to driving.
- Know your health history including major illness, surgeries, allergies, and health care providers.
- Begin to think about the impact of college, work, and career choices on diabetes management.



Stage 5 Ages 18-21

We expect you to call the diabetes team independently if there are changes in your health. You will manage your own insulin and diabetes related medications and supplies and call when refills are needed. We will continue to talk about how school, work and lifestyle choices impact your health. We will talk about and help facilitate transition and link you with the adult diabetes care team.

Checklist

(10)

- Continue with steps from the previous stages.
- Routinely call the diabetes team and speak directly with staff if there are changes in your health.
- Understand reproductive choices and the impact on your diabetes and overall health.
- Understand Advanced Directives and complete if desired.
- Discuss long-term complications of diabetes, the need for routine follow up and tests, and the importance of glucose control into adulthood.
- Review the American Diabetes Association guidelines for managing and controlling diabetes. (See Keys to Independence Resource Roadmap.)
- D Explore "Off to College" course offered by the Pediatric Diabetes Team.
- Establish care with an internist or family practice physician and with an adult diabetes team.

Pros:

Cons:

- Existing document to use as tool and provide guidance
- Paper as well as electronic version
- Complete and thorough

- Challenging to address during clinical visit
- Long list can be overwhelming
- No standard implementation
- Age does not always match listed skills
- Tracking in EMR

Base Knowledge:

What type of diabetes do you have?

What is an A1c? Goal A1c?

What are your goal blood glucoses?

How do your insulins/pump settings work?

What is your sick day plan?

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Daily Management

How often to you check blood glucoses on own?

Dose Insulin on own?

Change pump site?

Adjust for exercise?

Treat a low blood sugar?



Transition and Logistics:

What are the longterm complications of DM?

How does ETOH effect your blood glucoses?

What do you need to know about driving and DM?

Pregnancy and DM?

Filling prescriptions?

Contacting DM team?



How to carry out Transition



IDENTIFYING TOOLS FOR ASSESSMENT

IMPLEMENTING IN CLINIC



Diabetes Transition Clinic at AFCH

The AFCH DM TC began in 2016, lead by a pediatric and adult diabetes team member. The purpose of the clinic is to have a conversation with the young adult, focusing on current readiness for transition, listening to patients needs and concerns in moving to the Adult Diabetes Clinic, and communicating differences and expectations of the Adult Diabetes Clinic.

From 2016-2018, had a total of 24 patients seen in the TC, average age 19 years, average A1c 9.2%



	No Transition clinic n=32	Transition clinic n=24	p-value
Loss to follow up; % (n)	31.2 (10)	16.7 (4)	0.110
Months from last pediatric to first completed adult visit; mean (sd)	10.5 (7.6) ^a	6 (4.2) ^a	0.026*
Months from referral to first completed adult visit; mean (sd)	5.0 (3.7) ^a	4 (3.2) ^a	0.303
ED visits or hospitalizations during transition; % (n)	9.1 (2) ^a	10.0 (2) ^b	0.461
Change in A1c during transition; % (sd)	+0.51 (1.1) ^a	+0.16 (2.0) ^b	0.480

a total *n*=22 subjects who completed transition b total *n*=20 subjects who completed transition

Mann et el, PES 2020 Annual meeting

What happened next? Staffing and Covid

- •2019=0
- •2020 n=9

- "Need to make 2021 a better year."
 - Organize TC dates, staff and campaign
 - Work with the Adult providers on a Transfer Letter



2021 Transition Clinics

provider	Number of pt seen in TC	Number of pts with Peds NP only	Transfer letter	Number with Adult appt made	Number of those attended adult app	
East	5	3	8	7	5	
West	6	6	12	9	3	
Total	11	9	20	18	14*	

*Pt not being seen yet either due to future appointment (2) or no show (2)

Breakdown by age

Age	Ν	TC/TL
Age 18	74	2
19	38	7
20	14	7
21	11	1
22	5	3



What about 2022?

- Continue promoting and improving the TC
- Identify patients going to outside providers and provide Transfer Letter visit prior
- Look how to implement a standard Transition Curriculum



Role of School RNs

- Frequent interaction with students, sometimes daily
- School orders-opportunity for discussion
 - Assess DM knowledge
 - Assess DM Self Care
 - Assess Transition Readiness



Additional Tools for Transition Specific to Diabetes:

- Endocrine Society Transition Assessment
- National Diabetes Education Program



Endocrine Society Transition Assessment

Basic knowledge of your diabetes:		
	DATE	INITIALS
Describe what insulin does		
□ If you take oral medications, describe how they keep blood glucose in range		
Describe what happens if you don't take your medications		
Describe the meaning of HbA1c		
Describe the link between HbA1c level and the risk of diabetes complications		
Describe how nutrition/diet affects blood glucose and cardiovascular (heart and blood vessel) health		
 Describe the effect of exercise on blood glucose (right after exercising and overnight) 		
Describe how to drive safely		
Describe how to drink alcohol responsibly and reduce risk of low blood glucose levels		
Describe importance of excellent blood glucose control before & during pregnancy to support the development of a healthy baby		
Describe risk for other autoimmune diseases and symptoms to look for (for type 1 patients)		
Describe the need for and recommended frequency of routine check-ups		
Describe the need for annual lab work to assess kidney, eye, and cardiovascular health		
Describe the need for routine dental care exams		

						Experience in the followin	a skills:	DATE	INITIALS							
						Accurately measure and give yo	urself insulin injections									
					1	(even if you're on insulin pump Calculate correct dose of insulin	according to both blood glucose level									
						and carbohydrate intake										
						Monitor blood glucose										
						Monitor ketone levels (urine or t blood glucose levels are persisted	blood) during illness, stressful times or when antly elevated	n 		0						
						Log or download blood glucose r	readings									
						Be able to state target blood glu	cose levels/range and goal HbA1c level									
						Show how to program date/time any other devices you may use	e into blood glucose meter and									
						Be able to count/estimate carbo	hydrates									
						For those on fixed dosing, state at each meal/snack	number of carbohydrates to eat									
						Describe the reasons for changing	ng/rotating injection/infusion sites									
						Wear a medical alert identification										
							therapy/continuous glucose me	eter:								
						Demonstrate how to insert infus										
						 Demonstrate how to check diabe order new supplies 	etes supplies and when it's time to									
						Demonstrate how to access insu	ulin nump basal and bolus settings									
						and how to alter them	party bases and bolds sectings									
						Demonstrate how to download p	pump/glucose monitor information									
						 Demonstrate how to share pump diabetes care provide 	p/glucose monitor information with the									
						Demonstrate how to program th	e pump (date, time, correction dose,									
						carb dose, insulin on board, typ	es of boluses, basal rates and									
						temporary basal rates)	n injections and monitor for ketones									
						to prevent diabetic ketoacidosis										
						channah ilita da anna a fa	and the state of t									
						Show ability to arrange fo	or medical care:									
						Be able to make appointment										
					L.	Identify what insurance you hav										
							have when you are over 18 years of age									
						Be able to keep track of insuran										
						 Be able to maintain prescription before you run out 	s and obtain medications/supplies									
						Identify the name and phone nu	umber of pediatric endocrinologist									
						Identify the name, phone numb	er, and office location of adult endocrinologi	st								
						Confirm contact information for					1		T			
	29)				weekends, holidays						UV	VF	16	311	hKid
														_		

	Describe what to do in emergency situations or when ill:	DATE	INITIALS
	Create a list with names and numbers of people who should be contacted		
	Describe how to reach your doctor's of ¿ce		
	Describe when you should be calling your doctor's of ¿ce		
	State what information you will need to tell the diabetes care provider		
	Identify a nearby emergency room/hospital if ever needed		
⇒	Create an emergency plan for high blood glucose, low blood glucose, and illness		
	State how to manage high blood glucose levels (insulin, glucose, ketone monitoring, drinking sugar-free liquids/water)		
	State how to manage low blood glucose levels (carbohydrate intake, low dose glucagon)		
	State how to manage diabetes when sick (monitoring glucose, insulin adjustments)		
	Review the signi¿cance of vomiting and the need to check glucose and ketone levels, give insulin, and call healthcare team.		



Date completed

— Making appointments — Refilling prescriptions

— Making insurance claims — Carrying insurance card

Review the above topics

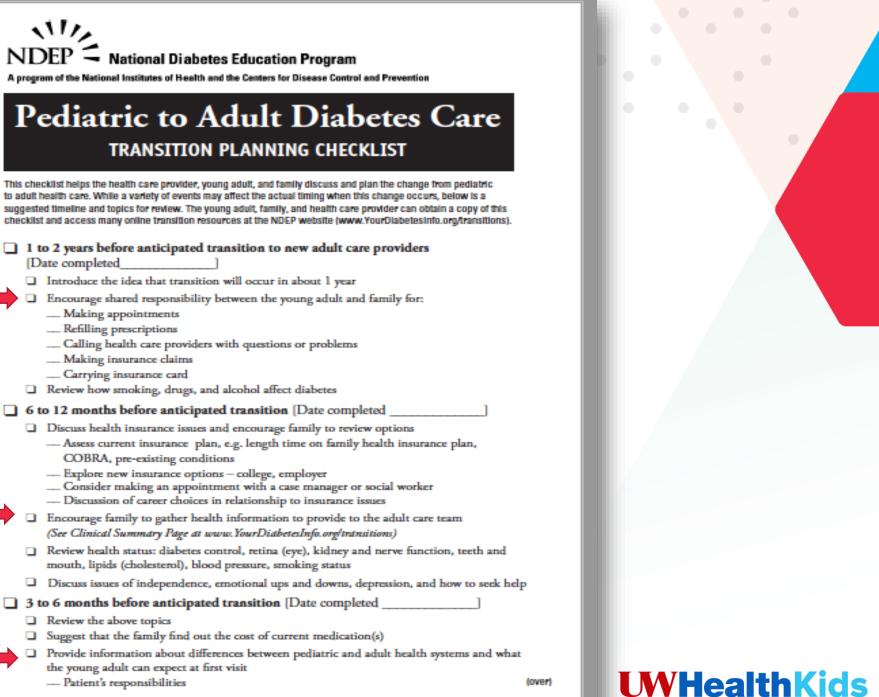
— Patient's responsibilities

Review how smoking, drugs, and alcohol affect diabetes

Explore new insurance options – college, employer

COBRA, pre-existing conditions

the young adult can expect at first visit



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Pediatric to Adult Diabetes Care Transition Planning Checklist Continued

- Other possible health care team members
- Confidentiality/parental involvement (e.g., HIPAA Privacy Act and parents need permission from young adult to be in exam room, see test results, discuss findings with health care providers)
- Help identify next health care providers if possible or outline process (See online resources)
- Discuss upcoming changes in living arrangements (e.g., dorms, roommates, and/or living alone)

Last few visits [Date completed _

- Review and remind of above health insurance changes, responsibility for self-care, and link to online resources at www.YourDiabetesInfo.org/transition
- Obtain signature(s) for release for transfer of personal medical information and for pediatric care providers to talk with the new adult health care providers
- Identify new adult care physician
 - --- If known request consult (if possible) and transfer records
 - If unknown ask teen to inform your office when known to transfer records and request consult
- Review self-care issues and how to live a healthy lifestyle with diabetes
 - Medication schedules
 - ---- Self-monitoring of blood glucose schedule
 - ---- Meal planning, carb counting, etc
 - Physical activity routine and its effects on blood glucose
 - Crisis prevention-management of hypoglycemia (low blood glucose), hyperglycemia (high blood glucose), and sick days
 - --- Need for wearing/carrying diabetes identification
 - Care of the feet
 - Oral/dental care
 - Need for vision and eye exams
 - Preconception care (preparing for a safe pregnancy and healthy baby)
 - ___ Immunizations
 - ---- Staying current with the latest diabetes care practice and technology
- Suggest options for a diabetes "refresher" course

To learn more about living well with diabetes contact NDEP: 1-888-693-NDEP (6337), TTY: 1-866-569-1162 or www.YourDiabetesInfo.org



Lune 2013

Role of School RNs

- Frequent interaction with students, sometimes daily
- School orders-opportunity for discussion
- Develop a system of Transition Assessment and education through the school?
 - What Assessment tools to use?
 - How to implement?
 - How to measure?
 - If interested in working to pilot a project, reach out to me at mtbekx@wisc.edu



Team Members

- Dr. M. Tracy Bekx, MD and Whitney Beaton, Peds Diabetes CNS (Peds Endo Diabetes/Project Leaders)
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