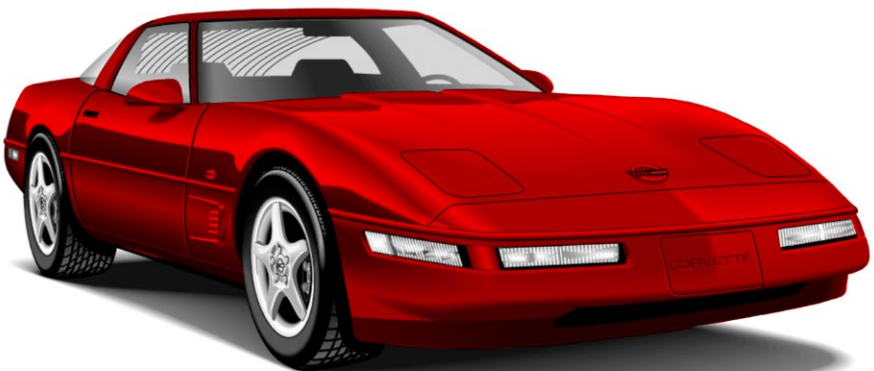




Keys To Independence...

*Transitioning from the Pediatric
to the Adult Care Team*



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A Special Note to You and Your Family:

As a way to help make a smooth transition from pediatric to adult care, we have created this booklet to help you learn more about diabetes and to take charge of your diabetes and health.

The age at which you were diagnosed with diabetes will determine how much help you need in managing your diabetes. This book will serve as a tool for you and your family along with your health care team to help you reach your goals. As time goes on, we hope that you will start to use this booklet on your own. This is a great way to build confidence in yourself, and also to let your parents know that you are learning to take care of yourself.

As you grow and develop, you may find it helpful to refer back to the “Pink Panther” Understanding Diabetes book*. This is a great source for information about diabetes, ketones, standards of care, and long-term complications. Chapter 18 explores responsibilities of children at different ages.

As you learn more about diabetes, you can take charge of your life and your health.

We wish you well on your journey...

* *H. Peter Chase, M.D.*
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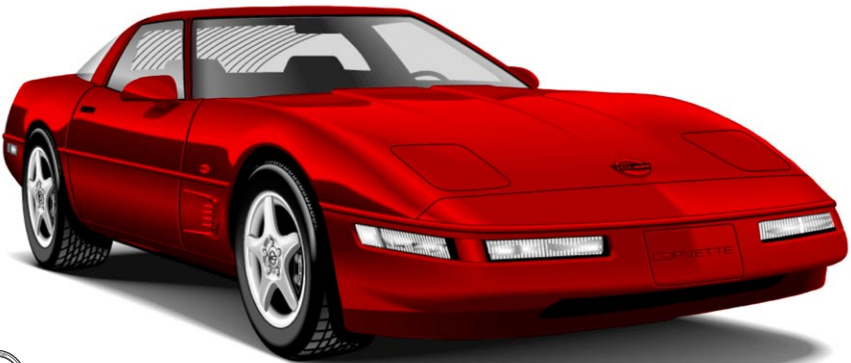
What Is Transition?

To get started, we look to our “Old friend” Webster’s dictionary. According to Webster, transition is “the passage from one state, stage, or place to another.” At the University of Wisconsin Diabetes Program, we see it as moving from pediatric to adult care in a way that feels safe and smooth to you and your family.

What Is Our Philosophy Regarding Transition?

We are committed to caring for people with diabetes across their lifespan. Helping young adults and their families move to the adult care team is a big part of our commitment. We believe transition is a rite of passage or a milestone that you and your family will experience. This is a big change. We want you to know that you are not alone and we will be here to help you with this change. We’ll help you throughout your journey and promise to take good care of you along the way.

Just like school prepares children for the future, we hope our pediatric diabetes program prepares you and your family for life as an independent, healthy adult. Our goal for all young adults is to learn about and manage their diabetes effectively and successfully.



What Is The Diabetes Care Team's Policy On Transition?

The diabetes care team has a policy that states that all young adults under the age of 18 will be cared for in the Children's Hospital. It also states that we can provide care up to the age of 21. Both the pediatric and adult diabetes care teams expect that you will transition by the age of 21. To help you make a smooth transition, we have developed a program to help you learn more about how to manage your diabetes as you move from pediatric to adult care.

Stages Of Transition

Just as you had to roll over before crawling, crawl before walking, and walk before running, there are times when you are ready to learn new things and take on more responsibilities. Your diabetes management is built on skills you will learn along the way. We have broken down these skills into five stages. We have given you an overview of what to expect during each stage.

Our philosophy is that your parents need to be involved in your diabetes management at least until you are 16 years old. We choose the age of 16 based on the fact that you can't drive a car until you are 16 years old. We also realize that not everyone is ready to be independent at the age of 16 and some may require more family involvement.

We included a checklist to help you learn more about diabetes. Learning the specific skills in each list will help you to take charge of your life and your health.

Our experience shows most young adults are successful when they have help from their parents throughout their adolescence.



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.



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.
- Mix insulin and give all injections with minimal reminders.
- Parents review blood sugar logs, help you to think through and double check insulin doses.
- 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

- 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.)
- 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.



How to Prepare for Transition

What adult family members can do...

1. When your child is age 8, begin talking to him/her about the changes that will happen in clinic. Explain that we will start to ask questions directly to him/her. This will allow your child to get comfortable answering questions while they have a “safety net” of a parent in the room.
2. Work with your child at home to take an active role in his/her care. You can use the checklist that we have provided as a guide. Gently encourage independence, but know that it will take time.
3. When your child is 14, encourage him/her to see the Diabetes team independently for the majority of the visit. You can join your child and care providers at the end of the visit to review information and ask any questions or concerns you may have. This will help your child become independent and form a relationship with his/her health care providers. This can also help him/her learn how to form future relationships with the adult care team. You may also encourage your child to attend the teenage clinic as a way to increase independence.
4. Find out about the age limit and terms of coverage under your health insurance policy.
5. Find out how your insurance company handles referrals to an adult diabetes care team.
6. If it would be helpful to you, ask to speak to another parent who has a child who has transitioned to the adult care team.
7. Remember, you are not alone and we will be here to help you with this change.



How to Prepare for Transition

What adolescents / young adults can do...

1. As you get older, take on more responsibility for your diabetes.
2. Keep a list of your health care providers and other information about how you manage your diabetes.
3. Keep a log of blood sugars, insulin doses, and other medications.
4. Learn how to obtain and maintain an appropriate weight through good nutrition and exercise.
5. If it would be helpful to you, ask to speak to another young adult who has recently transitioned to the adult care team.
6. Find out how your health insurance coverage works.
7. Make a list of questions to ask your future health care practitioner.
8. Work through the checklists for each of the five transition stages.
9. Remember you are not alone... your parents, and the pediatric and adult care teams will help you with this change.

How to Prepare for Transition

What the health care team can do...

1. Encourage you to meet the adult care team.
2. Encourage you to come to clinic prepared to talk about your health, medication and supplies.
3. Remind you that you are not alone and will help you with the move to the adult care team.
4. The adult care team will answer your questions and ease you into their system.



How Do You Know When It Is Time to Transition?

1. Do you take responsibility for your diabetes most of the time? Are you independent with your blood sugar testing and medication administration? Do you choose and make your own meals? Do you know how these choices affect your diabetes?
2. When you give the diabetes team your health history, does it sound the same as what your parents tell the team? Does your health history match with the diabetes team's view of your health and diabetes control?
3. Do you speak directly with the diabetes team?
4. Do you know when you need refills for your medication and supplies? Do you call the pharmacy?
5. Do you have a plan for your future, such as college or work?
6. Have you met the goals in each checklist?

If the answer to all the questions is “YES,” then you are ready for transition.

If the answer to any of the questions is “NO,” then a plan will be made to help you be more independent with that part of your diabetes management. However, answering no to any of the above does not stop you from transitioning to adult care. The adult care team is experienced in helping young adults become independent.



How Does Your Information Transfer To The Adult Care Team?

- A Medical Summary Transfer Form
- Medical Records will be sent upon your request
- Release of Information Forms to allow medical records to be sent to adult providers
- Bring patient and Family Notes to the Adult Care Team



Glossary

“Off to College” class – A one day course offered at the UW for high school graduates planning to attend college. It provides information regarding meal planning with college cafeterias, insulin adjustments, exercise on campus, sick days, and special accommodations available to students.

Annual labs/tests – Blood and urine tests done once a year to detect early signs of diabetes complications. These tests generally include thyroid studies, cholesterol screening, and urine microalbumin screening.

Diabetic Ketoacidosis (DKA) – What happens in the body when not enough insulin is available. The blood sugar is usually high at this time but can be normal. Moderate or large ketones are present in the urine and then build up in the blood. The ketones make the blood acidic resulting in total body acidosis.

Family Practice Physician – A doctor who specializes in the general care of children and adults.

Ketones – Acids that build up in the blood. They appear in the urine when the body doesn't have enough insulin. Ketones can poison the body. They are a warning sign that the diabetes is out of control or that a person is getting sick.

Ketostix – Test strips which are dipped into the urine to detect ketones.

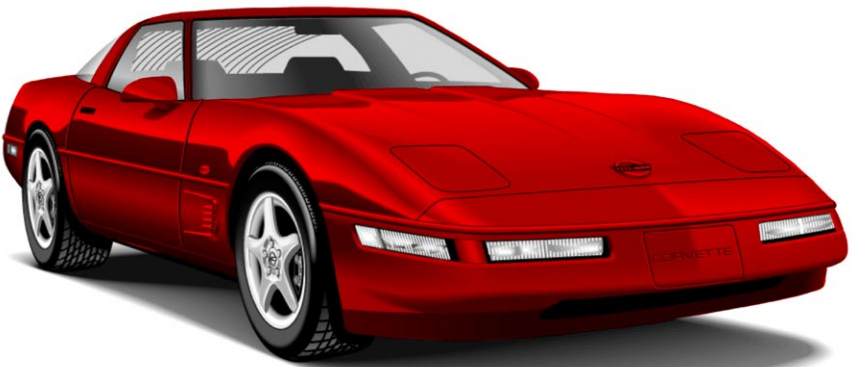
Medical records – Documents that contain one's health history, medical diagnoses, and treatments; cannot be shared without the individual's written permission.



Medical Release form – the document that provides permission to release all or a designated portion of the medical record. The individual or legal guardian must sign it.

Medical summary transfer form – a document outlining a person's health history; utilized to ease his or her transition to another provider.

Teenage clinic – a UW pediatric diabetes clinic offered specifically for teenagers with the goal of assisting teens to become more independent in the care of their diabetes. The clinic focuses on issues of particular interest to teens.



Phone call “cheat sheet” for sick days or high blood sugars

1. What is your glucose reading right now?
When did you last check it?
Is this outside of your normal range?
2. Have you been nauseated, vomited or had diarrhea in the past 24 hours? What are you doing to manage your symptoms?
3. When was the last time you took any insulin?
What type was it?
How many units did you take?
If you are using a pump, what are your settings?
4. How old is the insulin you have been using?
Is it older than one month?
5. How do you usually correct a high sugar?
Do you use a correction scale?
Did you do this?
6. Do you have urine ketone sticks?
Have you checked your urine ketones?
7. Do you rotate your injection sites or do you use the same site all the time?
8. What pharmacy do you use?
What is the phone number and/or the fax number of the pharmacy?





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