

“So Your Child Has Diabetes”

A Step by Step Plan for You and Your Child

For Parents Of Children
Newly Diagnosed With Type 1 Juvenile Diabetes

By Russell Turner

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Legal Statement

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Forward

First a little bit about us. My name is Russ. I have two daughters Kari and Kristin.

Kari is 10 and Kristin is 8. Kari was diagnosed with Type 1 Juvenile Diabetes May 25th 2002. She was 8. I am not a doctor, or a healthcare professional. I'm Kari and Kristin's daddy.

I'm writing this from the perspective of a parent. When Kari was diagnosed I jumped on the Internet to find all the information I could about this disease. As you have probably found, there's tons of it. Hypoglycemic, Hyperglycemic, A1C Hemoglobin, all kinds of stuff. But nothing that really tells you "how does this disease affect my child, our family, brothers and sisters, our lives".

In this book I will tell you of the problems and situations that we faced. How we overcame them and how we are dealing with the ones we haven't overcome yet.

Chapter One: The Dreaded Diagnosis

If you are reading this book your doctor has just told you that your most prized possession has an incurable disease that will affect them for the rest of their life. Take as long as you feel you need to panic, cry, ask God why, and generally stomp around alternately angry, distraught, and guilty that this has happened to your “baby”. That’s just what I did. That’s what everybody does!

Diabetes doesn’t care how much you already have on your plate or what else is going on in your life. Diabetes is a huge amount of stress for the first few weeks for your entire family. Fortunately the stress is right up front where you can recognize it and deal with it. Later on it gets sneakier, but we’ll talk about that later. Right now just remember, millions of people have been where you are right now. Frightened for the future of our children, not wanting to believe this has happened, and sometimes looking for someone or something to blame. THERE IS NO ONE TO BLAME! It’s not your fault, it’s not your child’s fault, and nobody is being punished for some past transgression. Diabetes happens.

The experts can give you some indicators but they don’t hold true for everybody. Nobody knows why a child develops Type 1 Juvenile Diabetes. Rest assured the emotions you are feeling and the thoughts racing through your head are perfectly normal. I promise it will get better. I was an emotional wreck. Our adventure started about a week before the actual diagnosis. Kari was thirsty all the time and the poor kid had to pee constantly. She drove me nuts. “Daddy I have to go to the bathroom, Daddy I have to go to the bathroom”. She couldn’t make it through dinner without having to get up to go.

We were at a carnival and she was so thirsty she was crying. She can be a bit of a drama queen at times so I was more annoyed than concerned. Looking back, I’ll feel guilty about that for the rest of my life. The next morning she came to me and said “daddy I think I have a mosquito bite on my vagina, it itches”. I had her show me and it looked like she had a yeast infection. Being a complete diabetes ignoramus my first thought was some kind of urinary tract infection. I called the doctor that morning and made an appointment for later that afternoon. I was told to bring a urine sample.

We showed up, handed over the sample and were shown to an examining room. I hadn’t even opened my magazine when a nurse popped her head in and asked if I had used a clean container for the sample. Duh! I almost told her that except for a little left over salsa it was pretty clean. I’m glad I kept my mouth shut for once. Almost immediately the doctor came in and said “I want you to take her to the Children’s Hospital Emergency Room. I think your daughter may have diabetes. I’ll call and tell them you’re coming”.

That was the beginning of the panic.

We got to the emergency room and her blood sugar level was somewhere in the 800’s. They couldn’t figure out why she was still on her feet. We got out of the emergency room around midnight with instructions to report back to the Endocrinology Department first thing the next morning. I went to the hospital for the first day of diabetes training with my hair standing on end. I had trouble understanding the million or so pieces of information that they were trying to teach me. Add to that everything began with “H”. Mix this “H” with that “H” but first charge this “H” with air, then draw this “H” first followed by that “H” but make sure you roll this “H” between your palms and for crying-out-loud don’t shake that “H”. I hit an all time low when they tried to teach me how to draw up the insulin.

My head was so full of the dire possibilities that nothing was getting through. I went home that evening after about eight hours of training convinced I would never get it. Since my daughter had been diagnosed in the emergency room around midnight and I had just spent the next day at the

hospital starting at 8:00am, I hadn't had an opportunity to call anyone. So I called my cousin first. He and I are very close and he loves my kids. I was pouring out my panic to him. All of a sudden I found myself explaining to him step by step how to charge the different types of insulin vials, in what order, and everything else I thought I would never be able to grasp. I was stunned. I could do this! All I had to do was quit worrying about the disease (and quit feeling sorry for myself) and start taking care of Kari. In other words, I'm the tall one. I'm the parent. It's my responsibility to care of her.

From that point on I was able to approach this entire problem with a positive attitude. Right there is the secret. Your lives are not coming to an end. They will be changed but it's not over. Everything you used to do together as a family will still happen. Favorite foods, favorite activities, school, dancing, scouting, all of these things will still be part of your child's life. Your doctor probably told you all of this. If you're like most of us your first thought was, "How can that be?" Well, I'm here to tell you that what they told you was all true. However, in this book I will try to help you integrate that knowledge into your daily lives.

Chapter Two: The Day They Turn You Loose

Okay, take a deep breath. You have all of the emergency phone numbers for the doctor on call. The direct line to your doctor, and probably a big box full of literature and information. If you're like me all of that information in the box will be invaluable, just not right now. You have enough to remember. The time will come for that. If they didn't give you one, ask your doctor for a second meter. The meter salesmen often give these things to the doctor for free. If they are able, they will gladly give you one. You'll want one for home and for school. If your child isn't in school yet store it at grandma's house for the day you forget to bring your regular one when you visit. Ask your doctor for a couple of vials of saline. It comes in the same type of vial as insulin. It's a great way to practice charging, drawing, and injecting insulin.

Practice on yourself and your spouse. Have other family members who may be responsible for watching your child practice with it. This will give you at least a tiny idea of what your child will be going through and it's a good way to get used to the type of addition you will need for figuring insulin doses. The first thing to remember is to **take your meter and supplies with you everywhere you go!** The first dosages of insulin that your doctor tells you to use are estimates based on your child's age and weight. I'm sure your doctor has told you this. He's not kidding. It takes a little while to get them as close to right as they are going to get. During this period your child's blood sugar levels may surprise you both high and low.

Another thing to remember. Listen to your child. It usually takes them no time at all to know what it feels like to be high or low. They are your best early warning system.

The body gives a warning when low blood sugar or insulin reaction is developing. DIFFERENT PEOPLE GET DIFFERENT WARNINGS. These signs are common warnings of low blood sugar:

- Hunger: the person may either feel hungry or have an upset stomach (nausea)
- Shakiness: the person's hands or body may feel shaky
- Sweatiness: the person may sweat more than usual (often a "cold" sweat)
- Color: the face may become pale or red
- Weak, anxious feeling
- Headache
- Confusion: the person may feel or look "spacey" or may appear "dazed"
- Drowsiness: the person may yawn, feel sleepy, or may have trouble thinking clearly; preschoolers frequently get sleepy

- Behavioral changes: changes in behavior are quite common; often the person may cry, act intoxicated, or act angry
- Double vision: the person may "see double" or the pupils may get bigger; the eyes may appear glassy
- Loss of consciousness
- Seizure or convulsion: both loss of consciousness and convulsions occur late in the reaction; they are the result of not treating a reaction quickly enough

These are some of the symptoms of high blood sugar:

- Upset stomach and/or stomach pain
- Vomiting
- Sweet (fruity) odor to the breath
- Thirst and frequent urination (if the blood sugar is high)
- Drowsiness Deep breathing (indicates need to go to the emergency room)
- If not treated, coma (loss of consciousness)

I don't know how many times we went somewhere for just a couple of minutes only to discover we had to go somewhere else and the timing was going to fall into "test time". Or we got invited to stay for lunch and couldn't because we didn't have Kari's insulin or syringes. This is the fastest way to allow diabetes to upset your family's normal lifestyle.

Put together a travel kit that includes a meter, lancets, test strips, ketostix, insulin, your daily log, some alcohol swabs, and at least a roll of glucose tablets. Glucose tablets taste like chalky candy and have 4 grams of carbohydrate each. They come in a fairly small package and you don't need to refrigerate them like orange juice. They're a great way to regulate emergency carbs when your child goes low, and they will go low. Buy a tube of "oral glucose gel". Buy several. Have one at home, one in your travel kit, one at grandma's, one at aunty's etc. they go under different trade names, we use Glutose 15. This tube looks like the stuff you use to write on birthday cakes. You can even use the birthday cake tubes. It is for emergencies.

We went for a year without having to use it but when we needed it, boy was I glad I had it. More on that later. You will also want to get at least one Medic Alert id. Notice I said at least one. The first one will get misplaced once in a while. There are a lot of different styles available. Some are actually cool enough that your child won't mind wearing it so much. The best way to keep your family life as normal as it can be is to be prepared.

Travel Kit Checklist:

- Meter
- Insulin
- Syringes
- Lancets
- Test Strips
- Ketostix
- Daily Log
- Glucose Tablets
- Glutose 15 (or suitable substitute)
- Alcohol Swabs

Chapter Three: Regiment, We're In the Army Now!

If your child is diagnosed during the school year this will be a little easier on your family than summer vacation. The regime; Get used to it. The sooner you accept that certain things have to happen within a certain time frame, meals, finger sticks, injections, the sooner it all becomes part of your normal family life. Normal is what we're looking for here.

Your doctor gave you a little booklet that is a daily log for writing down meal times, test times, insulin amounts etc. This is a great tool if you use it properly. Ask if they have more. If they are able they will give you a couple. They only hold about one month's worth of information. They print them in a variety of formats. Find the one you like and stick with it, especially if your child is old enough to share the responsibility of keeping it accurate. Some parents opt for a notebook. It allows for a little more customization. Speaking of your child sharing responsibility, this is a great way of giving your child some feeling of control over their destiny. I suggest that in the front of your log you write down all of your dosages. It's just too handy this way. They are always on hand wherever you are. Also, write them in pencil. You will be changing them fairly often for a while and it will become unreadable very quickly if you use a pen. It's important to keep an accurate log.

When you go for your scheduled doctor appointments they will tell you to bring the meter so they can download the numbers. Bring the log with you as well. Invariably the dates or the times on the meter will get changed somehow and won't be accurate. This is where all that attention to detail you paid in keeping your log will pay off. Just hand it to them and they have a perfect record of dates and times. They use these numbers to calculate your child's A1C reading. The more accurate the numbers, the more accurate the calculation. It's also a good idea to check the log once a week. It's a great way to spot trends early. You may notice that your child is trending high or low at certain times of the day. Call your doctor with this information. This way any changes in dosage they may suggest will happen quickly before your child has a chance to really feel lousy. It's hard to live a normal life if you don't feel good all the time.

We were lucky, Kari was still in school when she was diagnosed. So bedtimes and mealtimes were about the same every day. Weekends start out a little tricky because a lot of times your children are allowed to stay up later. Ask your doctor about extra carbohydrate requirements when your child stays up past their normal bedtime. I found out about this well after the fact. It may make a difference so ask now. Also be aware that activity levels and temperature effect blood sugar levels. When your child is playing hard they burn more carbohydrates. You need to be on guard against low blood sugar levels. Also heat, summer time, a hot bath or shower also cause insulin to be absorbed faster than usual. Again, be on guard for low blood sugar levels. This may sound like a lot to grasp. I promise it will become second nature for you in no time.

Chapter Four: "Daddy, Can I Sleep Over Grandma's?"

A normal part of every child's life is sleeping over at a friend or relative's house. This will be scary not only for you but also for whoever will be responsible for your child. For a while your answer will probably be no. That's likely a good idea until you, your doctor, and your child, have a better handle on insulin dosages. The time will come for this but it will take a while. This is a change from normal that can't be helped. However, visits during the day to grandma's, birthday parties, and play dates can be accommodated with a few preparations. First write everything down. Times for finger sticks, carb counts for meals and snacks. Pay particular attention to symptoms, both high and low and what to do about them. A list of acceptable foods if you use one. Phone numbers, yours, the doctors, the restaurant where you will be, you get the idea. Then make a bunch of copies.

You'll spend half your life writing this list over and over if you don't. For a while until everyone is more comfortable leaving your child during insulin shots, time it so you give the shot while you are there as everyone is sitting down to eat. That gives you the best chance at a couple of free hours. If your child is spending the night you will have to come back to give the bedtime shot. You will also have to come back in the morning to give the breakfast shot. This may seem like a lot of back and forth. It is. But until your child can administer their own insulin this is the best way to keep their life normal if not yours. If you cannot avoid being gone during an insulin injection and someone else has to give it, follow up! Kari was at her aunt's house and was given her nighttime shot. Over the phone I asked what she had been given. It turned out they gave her the correct dosage of insulin. Unfortunately, they gave it from the wrong bottle. She had been given a very large dosage of short acting insulin by mistake.

When something like this happens you will be glad you have the emergency number for the doctor on call at the hospital. Use it. Never be shy. In this case it turned out to be Kari's lucky day. She got to eat all of the ice cream and soda she could stand. She also got to stay up extra late for the hourly blood tests her aunt had to monitor. Her Aunt on the other hand was mortified. Who could blame her? Don't assume everything will be just fine. Follow up. Then spend all the time you need calming the aunt down. If you don't she'll be too scared to keep your child over night again.

Birthday parties are a different story. You have no control over times. Do the same thing with the list. Write everything down: Times for blood tests; carbohydrate requirements; times for meals and snacks. Include the signs of hypoglycemia and what to do. If the activity falls into a time where an injection is needed explain that you will be there to give it. Most parents will be comfortable having your child over if they have instructions and they know that you will be available. Knowing that they can reach you at all times is usually enough to reassure most parents.

Educating the parents of friends will probably be ongoing, as your child makes new friends and as her social life expands as she gets older. You will be surprised how many people will be comfortable with your child's situation if they just have instructions. You may also be surprised at how many people have a diabetic niece or nephew. They may be more familiar than you are with how everything works. Remember, a normal life is what you are striving for.

Always ask whoever will be responsible if they are comfortable with the responsibility. Some people may just nod their heads while you are explaining all this then be panicked the entire time you are gone. This isn't good for them and especially isn't good for your child. They pick up on these feelings. It makes them feel even more different. When you ask make sure you get a yes or no answer. If it's no make other plans. How old your child is and how much responsibility they can realistically be expected to take is also a big consideration. No one knows your baby better than you do.

You and your child may get a lot of different responses to your child's Type 1 diabetes diagnosis - some positive and some not so positive. Sometimes people react fearfully just because they are ignorant about juvenile diabetes. When my daughter was diagnosed (she was 8) She knew more about diabetes than I did because a character in a book she had read was diabetic and it was discussed. If you find this happening, the first step is to take the time to educate others. This discussion is very important, not only for others but also your child. They need you to help them realize that having diabetes doesn't make them different. Special maybe, but they are the same person they have always been. Usually, just having more understanding of diabetes and its treatment will help people respond better to your child and her needs.

Chapter Five: School

Remember that extra meter I suggested you request? This is where it comes in real handy. First, make an appointment with the school nurse, the teacher, the gym teacher, and if your school has one the school psychologist. Before you go in get a big Tupperware box. Put the extra meter, test strips all of the stuff that you already have in your travel kit in it. Make sure you get a signed statement from your doctor that gives the nurse permission to administer medication. Don't forget the one for aspirins. Your child will need them for the headaches she may get when she goes high. In my state the schools are very sticky that the milligrams per dose on the aspirin or Tylenol, or whatever you choose, match exactly what the doctor has given permission for. Don't have the doctor give permission for 200mg per dose and walk in with a bottle that's 250mg per dose. Now, take a magic marker and write your child's name on the box. The nurse will kiss you if you show up prepared.

Your child may not be the only child in the school with diabetes, but if they are the nurse will be really appreciate these preparations. The timing worked out so Kari only had to have a finger stick during school hours. Your situation may be different but the procedure will be the same. After you make arrangements with the nurse and have given her the box go see the teacher. Explain the situation. Give the teacher a copy of the same instructions you left with grandma. Make sure she understands how important your child's snack time is! If it doesn't coincide with her schedule she must make an allowance! Make sure the teacher understands that there will be times when your child will feel lousy and need an unscheduled blood test. Make sure they will allow your child to go to the nurse when this happens no matter what the class is doing.

It is also a good idea for the teacher to assign another student to accompany your child to the nurse just in case. I doubt you will get any argument. If you do check with you're state's laws concerning people with disabilities.

There are three federal laws that cover your child. These are:

- **The Rehabilitation Act of 1973, Section 504**,
<http://mychildhasdiabetes.com/articles/legal/federal-laws.htm>
- **The Individuals with Disabilities Act of 1991**, and the **Americans with Disabilities Act of 1992**.
<http://mychildhasdiabetes.com/articles/legal/Americans-with-Disabilities-Act.htm>

You may have to call for a formal "504" meeting (they used to call these PPT meetings).
http://www.jdrf.org/files/Life_with_Diabetes/sample504plan.pdf

Call the principal to schedule this if necessary. After the teacher go see the gym teacher. Give him or her a copy of the list. Have a similar conversation as you had with the teacher. You will be pretty good at it by now. Finally, introduce yourself and your child to the school psychologist. The time will come when she can probably help. Kari had a couple of occasions and the psychologist is just down the hall. A lot closer than you can be during the school day.

One thing to watch out for. After a little while Kari found that if she had to do something in class she didn't like, all of a sudden she didn't feel good and had to go to the nurse. Nice try. Any work she missed in class due to a sudden onset of convenient symptoms had to be made up at home in addition to regular homework. It didn't take long for her to become miraculously cured!

Remember that your child may have diabetes but they are still a kid.

Chapter Six: “Daddy, I Don’t Want to Take Any More Shots”

Depending on your child this may come sooner rather than later but it will come. Let’s face it, shots and finger sticks hurt. Imagine having 4, 5, 6 or more holes poked in you every single day. Day in day out, week after week, month after month, you get the picture. This would be difficult for us as adults. We can’t really imagine what this must be like for our child.

Pain is a funny thing. As an adult if we cut our finger we feel the pain, cope with it however we choose, and then forget about it. Sounds pretty simple right? Well it’s not that simple at all. It’s pretty complex. We all experience pain differently and react to it differently. Pain is not only different from person to person, but for each of us the same pain can be different depending on a variety of circumstances. Watch your kids when they are playing with their friends. They’re fully absorbed in what they’re doing and having a blast. They stub their toe. They yelp once hop once and continue running without another thought about that dumb toe. Now watch your child when they’re tired or mad at you because you called them in from play to clean their room. On the way in they stub the other toe. They drop to the ground and scream and cry like they’ve been shot. It’s the same pain but it’s a lot more painful and upsetting because of their mental state. The same thing will happen with shots.

Some days Kari will take them all in stride giving them no more attention than the time it takes to poke the needle in. Other days it’s a battle. Pay attention to your child’s overall emotional state. Usually your hospital or medical center has a social worker or a psychologist on staff. We have Stacy. She’s a Licensed Clinical Social Worker. Kari loves her. Since I’m not having any more children at this stage of my life I’m going to name my next goldfish after her. Your child will go through all kinds of phases with diabetes. I don’t want to take any more shots will be one of them. Like everything else, be prepared. Know who to call for help when this happens. Be aware that it will happen. Have plenty of hugs, kisses, and sympathy ready and waiting. This too is now a normal part of your life.

Chapter Seven: Real Low Blood Sugar Levels

I’ll warn you now. At some point no matter how careful you are about diet, blood tests, and insulin injections your child’s blood sugar level will go low. You come back from your scheduled doctor visits and your child’s A1C has been 7. You have done everything right! You’re going to get a reading in the 50’s, or 40’s, or even the 30’s. Kari woke me up around 3:00am one morning. She says to me “daddy I have a headache”. Okay, no big deal we’ve dealt with headaches before. I told her to go get an aspirin while I start to drag myself out of bed.

On my way to her room I stopped in the bathroom to get her a glass of water. Spread out on the bathroom floor is a thousand aspirins. My old friend panic starts to stir. “Stay calm” I tell myself as I go into her room. She’s kind of whimpering because her head hurts a lot. I try to hand her an aspirin and the glass of water. She turns in the wrong direction, away from me and toward the wall, reaches out and is upset because she can’t find the aspirin. Okay, she’s still half-asleep. I call her name and she turns back towards me.

Now I notice her eyes are completely unfocused, she doesn’t have a clue where she is and is generally in Neverland. Panic is really starting to make a nuisance of itself now. “Let’s check her blood” I decide. Remember it’s 3 o’clock in the morning I’m not at my sterling best. I walk her into the kitchen and hand her the meter. She has no more idea what’s in her hand or what to do with it than the man in the moon. She had been responsible for checking her own blood for months. I hadn’t touched the meter in all that time.

Here’s some advice, stay in practice with everything pertaining to your child’s diabetes.

You never know when you will have to do something for them. I fumble around and I finally get a reading, it's 38! How did this happen? I grab some glucose tablets and hand them to her. "Eat these". As you can see I don't catch on very fast. She has no idea where her mouth is or even how to open it. Remember that cake frosting stuff I told you to buy. Now is when you'll be glad you have it. Ours sat in the medicine cabinet for almost a year. I run and grab it, rip off the top, stick the nozzle between her cheek and teeth, and start to squeeze. The effect was very fast. In about ten minutes she was completely lucid and her headache was gone. She could talk to me and she knew where she was.

About ten minutes after that the vomiting started. They don't tell you that a side effect of that fast a blood sugar rise is nausea. That lasted for quite awhile but I could deal with that. I had my baby back. To this day Kari has no recollection of this little episode. The moral of this story is, you guessed it, be prepared. Your child's symptoms may be different. Your doctor can give you a list of possibilities. My point is there isn't always an obvious reason for it. Nor does it always happen during business hours. Prepare for it.

Chapter Eight: When Do I Take My Child to the Emergency Room?

The answer to this question is whenever you are faced with a situation that you do not feel prepared to handle. Or when you don't think you should wait for the doctor to call you back. If you think it's an emergency, it's an emergency. Don't be shy. This is your baby.

We've had one instance. Kari went real low again. She had similar symptoms to the first time. It was the last day of school this past year. She woke up and couldn't come up with the word "toothbrush" or the word "part" for her hair. She couldn't check her own blood. She was fairly lucid other than some slight confusion. Although when I checked her blood she tested low normal, around 70, I couldn't get rid of the symptoms. I sent her younger sister Kristin (you'll meet her later) off to school and Kari and I headed to the emergency room. They couldn't give me a definitive answer as to why but after a couple of hours on an IV drip she didn't look like Uncle Fester anymore and was up and being her old self again. She made it back to school for the last half-hour and was able to say goodbye to all of her friends for the summer. Remember that an emergency is whatever you think it is.

Another thing along these lines you should plan for is when your child gets sick. If your child is in school it's almost guaranteed they will bring home some sort of bug. Be prepared before it happens. Your doctor or diabetes educator has probably already warned you about this. Follow their instructions. The following information is from the American Diabetes Association. Check with your doctor first! Check with your doctor first! Check with your doctor first!

To take care of your child's diabetes along with her current illness, follow these general principles:

Continue Insulin Treatment

Your intuition might tell you to reduce or stop your child's insulin, especially if she is not eating very much. Younger or newly diagnosed children could need reduced insulin depending on their blood glucose level, but other children need just the opposite-extra insulin. Ask your doctor for guidelines for insulin treatment on sick days and call the doctor anytime you're not sure how much insulin to give.

Stay Close to the Meal Plan

You may want to substitute soup and other comfort foods for the usual fare. Be sure to maintain about the same meal times and number of carbohydrates at each meal and snack as you would on a normal day. If your child has an upset stomach and can't eat,

give her clear liquids that contain carbohydrates (sports drinks, juices, gelatin, broth, frozen fruit bars).

Give Plenty of Liquids

Encourage your child to drink as much water and other non-caffeinated beverages as she can.

Choose Medications Wisely

Many over-the-counter medications contain sugar and/or alcohol. Although there might not be too much glucose in one dose of cough syrup, it can add up if your child takes it every four hours. If you can't find a glucose-free version or if it's more expensive, just account for the medicine's carbohydrates in the meal plan. Medicines that contain alcohol can lower blood glucose levels. If you choose a medicine that contains alcohol, have your child eat something when she takes it in order to prevent hypoglycemia. You may wish to choose alcohol-free medicines.

In addition, certain medications can affect your child's diabetes. Many decongestants can raise blood glucose levels. And ibuprofen is not safe for anyone with kidney problems. Ask the doctor what over-the-counter medications he or she recommends for your child.

Check Blood Glucose and Ketone Levels Frequently

Diabetic ketoacidosis (DKA) is a danger whenever your child is sick. DKA occurs when a person with diabetes has too little insulin in their system. If left untreated, DKA can lead to coma. To prevent DKA or catch it early, check your child's blood glucose levels often (every few hours) while she's sick. Also, check her urine for ketones several times a day. If she is vomiting or has diarrhea, check ketones even more frequently (maybe even every time she urinates, depending on the severity of the illness).

Foods for Sick Days

When your child is not feeling too well, she may not feel like eating a lot of the foods she normally loves. For example, if her belly is doing somersaults, she's probably not craving a big, spicy plate of nachos. But it's important for her to eat in order to keep her body from burning fats for fuel (and making ketones) and to keep her body energized so it can get better fast. Here are a few flu-friendly food ideas for when a bug has your child down.

- Liquids
- Fruit Juice
- Jell-O
- Milkshakes
- Popsicles
- Soups & Broths (try bouillon, chicken noodle soup, or plain hot broth)
- Solids
- Fruit
- Ice Cream or Sherbet
- Hot Cereal
- Toast
- Crackers

SOURCE: American Diabetes Association

<http://www.diabetes.org/for-parents-and-kids/diabetes-care/surviving.jsp>

Chapter Nine: “I Feel Different from Everyone Else”

The hospital that is treating my daughter has a wonderful program about four times a year. It's called Super Saturday. Pretty much any of their juvenile diabetes patients can sign up. It's a half-day of activities, games, socialization, and kids talking to kids about being diabetic. That morning my girls and I were all in the bathroom brushing our teeth. I off-handedly asked Kari if she was excited about attending her first event. She absolutely lit up. “Oh yes daddy” she says. “I'll be with a whole bunch of kids just like me”. “I won't feel different from everyone else”. I will admit that took me by surprise.

Somewhere during the preceding months things had settled down. We were no longer making what seemed like weekly insulin adjustments. We had reached a comfort level with the regime. And we didn't have to tell everyone everywhere we went that Kari was a diabetic. I had stopped only seeing a diabetic every time I looked at her and started seeing her as my precious little girl again. Well guess what? Just because I had stopped seeing one didn't mean she had stopped being one.

I had made the mistake of becoming a little complacent about the whole situation. Your child doesn't have that luxury. This little episode gave me a whole new perspective on what my daughter was going through. It will be amazing to watch when your child meets another with diabetes. There is an instant bond that says we're both in the same boat, we need to stick together. It's very important to allow your child to express their feelings both positive and negative. My first response to negative feelings is sympathy. “There there it's not that bad”. Well that doesn't help. Diabetes is that bad. It's unfair, it's difficult, and it sets them apart. You need to acknowledge that. You also need to reassure your child and let them know that you will always be there to help.

So don't make the same mistake I did. Encourage your child to talk. Make it as easy as possible for them to let you know about their worries and feelings of being different. Our diabetic children feel different because they are different. Insulin shots, blood glucose monitoring, and carbohydrate counting all becomes routine for us and we begin to move it away from the front of our minds. Our children don't have that luxury. We as parents may be comfortable with the thought of administering everything associated with diabetes but it's not us this is all happening to. It's actually happening to our kids. We need to maintain not only a healthy perspective for our own emotional balance, but we also can't forget to see diabetes through the eyes of our children. When you are young you don't want to stand out. You seek acceptance by being one of the crowd. This is especially true during puberty. Our diabetic child's perspective will be very different from ours. We must keep those critical lines of communication open.

If we make sure to be aware of our children's view of what has happened to their lives we can be there to reassure and help them through these difficult periods.

Chapter Ten: Be Prepared for Emotional Times

The last chapter was sort of the tip of the iceberg. In this chapter I am tiptoeing very close to advice you should seek from a Mental Healthcare professional. I cannot stress enough how important this is. I'm here to give you a heads up.

You and your child have gotten onto an emotional roller coaster and you may not even know it yet. We've spoken about how your child's emotions can affect their pain tolerance. It will also affect their tolerance to brothers and sisters as well as their tolerance of you. If you haven't come across this scenario yet you soon will. Your family is out somewhere and your child's blood sugar levels are dancing. You've got it pretty much under control and some well meaning friend or

relative offers everybody candy or ice cream. If your child is in pretty good shape emotionally they will understand that if they have any they will feel lousy and it's not too hard to pass up. However, if things aren't so rosy emotionally they don't care how they might feel. They only care that everyone else is having ice cream and they're not. It's pitch a fit time.

You need to prepare your child ahead of time for these possibilities. This is an ongoing process. Don't wait until they're dishing out the ice cream. Your child has a much better chance of a positive reaction if you have been talking with them as part of your daily routine. Pay attention when siblings argue. Many times you will notice that your diabetic child is just being contrary because they are depressed. Depression! Keep a sharp eye out for this. Learn everything you can about it. We all experience it at some point in our lives. Your child will probably experience it a lot earlier because of having to deal with this disease. It can wreak havoc on family life. There goes normal right out the window. Start looking for ways to deal with it now. Don't wait until you're in the middle of it to react. Be prepared.

There is a lot of useful information out there on the subject. Familiarize yourself with it. Talk to a psychologist or social worker now to find out what to watch for. You should spend at least as much time learning and preparing for this as you do learning about the medical aspects of diabetes.

These are some symptoms of depression. Trouble sleeping, irritability, apathy, less interest in friends, and less interest in activities they used to enjoy are just some of the signs that our child may be depressed. They may just seem generally sad. Other symptoms to watch for may include temper tantrums, low self-esteem, or maybe they stop doing well in school. Adjusting to life with type 1 diabetes is tough. It strikes at a time in life when children really don't have any experience in dealing with these types of emotions. If any of these symptoms are present in our children we must not ignore them.

It can't be overstated; depression should be treated by a mental health professional

Chapter Eleven: “An Apple or a Coma Those Are Your Choices”

In case you thought you were going to be immune from some emotional ups and downs of your own let me set the record straight. WRONG! You may not have the disease but you have all of the responsibility.

This is a burden that unless someone has experienced it they can never fully understand it. The title of this chapter is a direct quote of something I once said to Kari. She wanted a soda or some chips for a scheduled snack and I wanted her to have something healthy. When I think back, I can't believe I really said it. The point is the pressure and the emotional strain that you will find yourself under at times dealing with diabetes is tremendous. You will need a break. If you are a single parent it can be even tougher. Be prepared. If it hasn't dawned on you yet it soon will, you are the one giving the shots. You are the one inflicting this pain on your baby. Even though it's absolutely necessary it's a huge burden to carry. At first there's no way around it. You have to be there. But as time goes by and you and your family get a better handle on how to keep your life normal.

Allow yourself a break once in a while. Indulge in your hobbies. Learn a new hobby. Do something that doesn't involve diabetes. Don't let diabetes win. You will be a lot less help to your child if you are all tied up in knots about it. Keep in mind your own emotional state when you are dealing with your child. Especially when you're not having a storybook day. Be careful what you say. The off hand remark that you throw out when you're hot under the collar can do a lot of harm even if you didn't intend any. It's a lot more likely that you will be part of the solution if you make time for your own mental health rather than contributing to your child's emotional problems. It's like when you are traveling on an airplane. The stewardess is telling you about the oxygen

masks. They say “if you are traveling with a child, put your own mask on first then help your child with theirs”.

Take care of your own mental health so you can be there to take care of your child's. Adaptation or adjustment to the diagnosis of diabetes takes a long time. Often you may have stronger feelings about diabetes than your spouse, or vice versa. It helps to talk and share feelings within your family and with members of your diabetes healthcare team. As your child and family live with diabetes, they become more used to it. They will feel more sure they can manage it. Fears that have no reason will go away. Sadness and anger may still come and go at times. You may feel sadness when your child is hospitalized or when you see a picture of your child before the diagnosis. Sometimes you may feel very sad for a moment, like when kissing your child at bedtime. These feelings decrease with time. The continued love for your child is the most important feeling and does not change.

As your family adjusts, everyone begins to feel more hopeful. They may want to help in diabetes research studies or help diabetes support groups raise money. It is important not to look at diabetes as the end of the world. If everyone in your family has a positive attitude, life with diabetes will be much easier. Fitting diabetes care into as normal a lifestyle as possible is what it's all about.

Chapter Twelve: Your Other Children

Kari has a younger sister Kristin; she's 8 now. She was 6 when Kari was diagnosed. She's still a little young for me to just turn loose and allow to write a chapter. It might start out on subject but would quickly move to finger knitting, Care Bears, and Barbie. I wrote out a list of questions for her to answer. They surprised me. As it turns out this is one more situation you need to prepare for. I have written this next section incorporating Kristin's answers. These are Kristin's thoughts about being the younger sister of a diabetic.

“My name is Kristin. I am 8 years old. I am going into third grade. When I first found out my sister had diabetes I was very scared that Kari would get all the attention. I didn't think I would catch it. It's hard being the sister of a diabetic because Kari is getting all the attention. Yes I get mad when she gets extra attention when she doesn't feel good. I am annoyed with Kari this, and Kari that, I am annoyed with her!”

Wow! Just when you think you have a pretty good handle on things. Do you see a theme here? I can't tell you how sad it made me to find this out. Even though you think you have created a good balance between the attention you have to pay your diabetic child and the rest of the family that's not always the case. At least that's not how it's perceived. As you know children have a different way of looking at the world. They don't see it the same way we do. They're children not just short adults. Perception is reality! The way they perceive a situation is the way it really is for them. You must be very aware of this.

If you find you really are being uneven in the amount of attention you are giving your children admit it. Sit down with your other child and explain why. Then together try to come up with ways to improve the situation. I handled this in a couple of ways. The first action I took was to set aside some time just for Kristin and me. Actually I set aside some more time. Obviously what I thought was enough and what she thought was enough were two different enoughs! Now I'm not saying give up all of your time just so your children think they are getting what they think they need. We all know as far as they're concerned you will never be able to give them enough of your time right up to the point where they've had enough of you. You do the best you can. You can't do more than that.

The second action I took was to holler for Stacy. You remember Stacy, I named a goldfish after her. A mental health professional may be able to help your other child realize she's not as left out

as she may think. One of the keys of adjusting to diabetes is to keep your family routine as close to normal as possible. In most cases, diabetes care should fit into your lifestyle -- not the other way around. It's natural to be very focused on diabetes for the first weeks and months after diagnosis, but with proper preparation you and your family can live healthy normal lives.

The point is you must be aware. Your children won't always tell you what they are thinking in so many words. They will usually tell you by their actions. Be prepared.

Chapter Thirteen: And Now A Word from Kari

"Hi, my name is Kari and I have diabetes. I'm 10 ¼ years old and going into 5th grade. At first diabetes made me feel depressed and different all the time. Now it's just part of my daily life. I wake up, go to school, come home. My life is perfectly normal.

When I got my first low I basically freaked out. I always felt sick. When I'm high I get this weird feeling like I'm just sitting somewhere for no reason. It's really odd. Right now my life is awesome. I get along with my friends. The word trouble is not in my vocabulary. I'm laid back and casual. I have a mom and a dad and a younger sister Kristin who is 8. I have the same birthday as my sister. When I wake up on the morning, the first thing, I think about events and plans I may do. When I go to sleep or I'm lying in bed I always think about things. Anything really, it doesn't matter. It sort of depends on my mood.

When the doctor first told me that I had diabetes I thought "oh gosh! What am I going to do? What about school? What about my friends"? Well, as it turned out nobody cared really. They treated me the same as always. Today diabetes is so simple I don't care about it. Well, I still pay attention to it and all but it doesn't affect me as much anymore. Soon I'll go on the pump. Now I'm on Lantus. If your child just found out that they have diabetes they're probably feeling some sort of emotion. For me I was depressed. You should remember no matter how often you tell your kids to tell you all of their problems they aren't going to spill. During this time they will probably feel pretty depressed. When I get that feeling I stretch or draw or just read a book. Tell your kid to do one of their hobbies and that might help them relax."

That is a couple of years of diabetes in a nutshell. The range of effects on your child, your family, and yourself are mind-boggling. You will go up, down, and round and round. Hang on! Be prepared.

Chapter Fourteen: Let's take A Vacation!

A lot of this information is available on the Internet or from your doctor so I won't beat it to death. These are a few things to keep in mind. It depends on where you are going and of course for how long. If you are going in a long trip see your doctor before you go. Just to be sure everything is as it should be.

If you are going overseas or anywhere your child may need immunization shots get them early. If they make your child sick they will need time to recover before you leave. Get an extra prescription for insulin and syringes. If you leave the insulin in the car by mistake while you are at the beach or out sightseeing and it cooks, replacing it won't be such a disruption to your vacation.

Pack about twice as much medication and supplies as you think you will need. Better to have it and not need it. If you are flying put half in your carry on bag. Insulin purchased in the United States is all of the same strength U-100. In foreign countries it will vary. U-40 or U-80. You will also need different syringes that take into account the difference in dosages.

Finally, pack snacks. Don't assume that you will always find food whenever you need it while you are away.

Traveling with diabetic supplies

http://www.diabetes.org/advocacy-and-legalresources/discrimination/public_accommodation/travel.jsp

Due to increased airport security measures in response to September 11, 2001, the American Diabetes Association is providing information about diabetes-related equipment, medication, and supplies to airline passengers with diabetes.

For a little more in depth information visit

<http://mychildhasdiabetes.com/articles/parenting/Traveling-With-Diabetes.htm>

Chapter Fifteen: The Wrap Up

So there you have it. This crazy little thing called diabetes will change certain aspects of your world. It can affect you and your family in ways that if you aren't prepared can throw everyone for a loop. However, since you are now armed with all this information in addition to what your doctor sent you home with you can start preparing today.

A diagnosis of diabetes doesn't mean your life and your child's life as you have known it up to now has to stop. It's just the opposite. Your lives can and should go on as before. All the things that make life great can still be enjoyed. Your child doesn't have to lose any part of their childhood. With your guidance your child's life will be enriched.

When you approach diabetes by being prepared and together as a family it becomes an addition to your life not a hindrance. You may become even closer to your child and as a family than before diagnosis. When you maintain a positive attitude nothing brings a family together like the journey you are about to begin. The Boy Scout Motto is Be Prepared. The boy scouts have it right. By preparing yourself, your child, and your family ahead of time you can avoid those situations that make living a normal life next to impossible.

Nobody knows your child better than you do. No one loves your baby more than you do. Nobody is in a better position to prepare your child to be able to laugh, play, and continue to shine than you!