Empowering People With Diabetes

An Honors Thesis

By

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Abstract

Diabetes is one of the most common diseases in the United States, affecting nearly 16 million people. However, the majority of the population has only a small amount of knowledge about the disease—and much of that knowledge is based on incomplete or false information gained through media and second-hand exposure to the disease. This is a problem not only for the 10.3 million people that have been diagnosed with Diabetes, but also for the 5.4 million people who have the disease and have not been diagnosed yet. Perhaps one of the most difficult aspects of this lack of Diabetes information has to be the effect that Diabetes has on the social and emotional aspects of life for the people who have been diagnosed. Although people often feel free to speculate and discuss the physical aspects of Diabetes such as medication, diet, and exercise—they seldom, if ever, take a look at what effects Diabetes has on the daily life of people who are trying to cope with it. The purpose of this thesis is to give people general information on the social and emotional aspects of Diabetes in order to encourage and empower people who are living with this chronic condition. The first section is a word document covering the main content of the thesis. The second section is a hard copy of the actual website, http://www.bsu.edu/web/mmpierron and its various parts. There is also a CD included, which has the website on it as well as links to many other Diabetes related websites.
Acknowledgments

I would like to thank Dr. Lisa Huffman for the time and effort she put into helping me get through this thesis. I would also like to thank her for the numerous meetings she had with me, through which she helped me gain a better understanding of what I want out of life. Her enthusiasm about the future has greatly influenced how I look at the future. Thank you Dr. Huffman—without you the future definitely would not seem as bright and exciting! I would also like to thank the friends who have encouraged me throughout my last semester to work on my thesis, especially those of you who have Diabetes and were willing to sit down and talk about the frustrations related to our disease. Most importantly of all, I want to thank my Mother. She has been such a great source of strength and support throughout my life—especially during the time of my diagnosis and now that I am at college—and I want to let her know that I appreciate all that she does for me. Thanks mom for loving me like no one else could!
Empowering people with Diabetes

There's more to Diabetes than blood tests and needles!

Diabetes is one of the most common diseases in the United States, affecting nearly 16 million people. However, the majority of the population has only a small amount of knowledge about the disease—and much of that knowledge is based on incomplete or false information gained through media and second-hand exposure to the disease. This is a problem not only for the 10.3 million people that have been diagnosed with Diabetes, but also for the 5.4 million people who have the disease and have not been diagnosed yet. Perhaps one of the most difficult aspects of this lack of Diabetes information has to be the effect that Diabetes has on the social and emotional aspects of life for the people who have been diagnosed. Although people often feel free to speculate and discuss the physical aspects of Diabetes such as medication, diet, and exercise—they seldom, if ever, take a look at what effects Diabetes has on the daily life of people who are trying to cope with it. The purpose of this website is to give people general information on the social and emotional aspects of Diabetes in order to encourage and empower people who are living with this chronic condition.

What is Diabetes?—A General Overview

The main function of the pancreas is to help the hormone insulin change the food we eat into energy. However, in people with Diabetes the pancreas either does not produce the appropriate amount of insulin or produces no insulin, which causes the food we eat to build up in our blood stream. The major distinction between Type 1 and Type 2 Diabetes is the type of insulin production. In people with Type 1 Diabetes little or no insulin is produced—this type of Diabetes requires the use of daily insulin injections and
occurs most often in childhood and adolescence. It does have a genetic component, but this component is complex and not clearly understood. People with Type 2 Diabetes on the other hand, produce some insulin but not appropriate amounts for their daily food intake, so they are forced to take medicines or injections to compensate for this lack. Type 2 Diabetes occurs most often in people over the age of 40 who are overweight and runs in families even more frequently than Type 1 does.

Doctors are unsure of what causes Diabetes but they have found that Type 1 Diabetes is often triggered by a virus in the body. In this situation the immune system, which usually fights the virus, begins to fight the beta cells that create insulin because it mistakes them for the virus. People with Type 1 Diabetes may have this happen many times over a period of years before they actually see the direct results in the form of Diabetes symptoms. People with Type 2 Diabetes do not have any of these problems—for them Diabetes is most often caused by being overweight. Despite the different causes, the symptoms of both Type 1 and Type 2 Diabetes are similar and may include:

- extreme thirst
- excessive urination
- feeling very tired
- feeling very hungry
- loosing weight without trying to
- having sores that are slow to heal
- dry, itchy skin
- tingling or numbness in the feet or hands
- blurry eyesight
Where to find more information on Diabetes

There are hundreds of places to look for information on Diabetes depending on what you are looking for. Two of the best places for general information are the American Diabetes Association Website and the Joslin Diabetes Center Website. Both of these sites provide in-depth information about Diabetes symptoms, complications, and treatment as well as information on how to deal with Diabetes on a daily basis. Both websites also give information on Diabetes programs and clinics in your area. These sites are great for people who have Diabetes and people who are trying to learn more about Diabetes. If you are looking for information specifically on Type 1 Diabetes then you might try the Juvenile Diabetes Foundation Website or the Children with Diabetes Website. These websites are the perfect place for parents of children with Diabetes to look for information pertaining directly to their families and children. There are also some wonderful books that provide a more in-depth look at Diabetes and can be found at any local public library such as:


The Emotional side of Diabetes

There are many feelings associated with Diabetes—some are positive and help us to cope with the chronic condition that we are facing, but others are negative and hinder our physical health because of their effects on our behavior. The only way to truly cope with and master your physical health is to first understand and master your feelings. This is definitely one of those things that is easier said than done, but simply being aware of and communicating about your feelings is the first step to mastering them!

When people are first diagnosed with Diabetes there are many feelings that may arise such as shock or denial. Many people just do not believe that it is true, nor do they believe that it can or did happen to them. They may also feel guilt and anger as they wonder, “Why me” or “Why my child?” Another common feeling is fear—newly diagnosed patients are afraid of what effects Diabetes is going to have on their daily lives as well as their futures. They also worry about how others will react and whether or not they will be able to go on to lead normal lives. Some other common feelings people have when they are first diagnosed are:

- Isolation
- Sadness
- Helplessness
- Embarrassment
- Hopelessness
- Resentment
- Grief
- Bitterness
- Confusion
- Stress
- Irritation
- Threatened
- Overwhelmed
All of these feelings are natural reactions to learning that your life will change due to a newly diagnosed chronic illness. It is very important that people who are dealing with Diabetes for the first time are assured that their feelings are normal and that they are encouraged to openly share their feelings. Without acknowledging and sharing their feelings after diagnosis it makes it difficult for people to accept and learn to cope with Diabetes, which is one of the most important factors determining how well they will live with Diabetes.

Coping with Diabetes is a complicated issue. There has to be a compromise between all areas of Diabetes care and your daily lifestyle in order to make Diabetes management a reality. It is not only adjusting your life to your Diabetes but it is also adjusting your Diabetes to your life. This is really the area where you have to strike some sort of balance between the things that you have to do in order to live a healthy physical life and the things you have to do in order to live a healthy mental life. Allowing one aspect of Diabetes care to rule your thoughts and decisions can be frustrating and stressful. One example of this would be the person who constantly obsesses over their Blood Sugar Readings and is frustrated because they eat healthy, exercise at every available opportunity, and still can not get their levels to read like they want them to because they are too focused on one aspect of Diabetes care. The same can also happen when people are so focused on how angry and sad they feel about Diabetes controlling their life that they end up skipping meals or injections because they want to live a "normal" life. Both of these situations can lead to serious future consequences, which is why Balance is a key aspect of Diabetes care.
Stress management can also be an important part of Diabetes care. People with Diabetes have the normal everyday stresses plus the stress associated with taking care of a chronic illness added onto them so they often have more stress to deal with than their peers. Having a child or spouse with Diabetes can cause similar stress-related effects on the family. Managing this stress is necessary for the person with Diabetes because it can affect their blood glucose level by either raising or lowering it. There are two reasons why this happens. The first is that stress can directly affect blood glucose levels by causing hormone levels to change, which makes the body absorb food differently. The other way stress affects blood glucose levels is indirectly through changing behaviors. Some examples of this indirect change might be skipping meals or insulin injections due to conflicting time schedules or drinking and smoking more. People who are under a lot of stress need to be aware of negative ways of coping and try to use positive coping methods instead to maintain control. Another way of dealing with stress is to learn some relaxation techniques such as breathing exercises or progressive relaxation therapy. However, there are millions of other ways of dealing with stress that anyone can do without training or instruction like exercising, positive thinking, and keeping a journal.

Stress management is important because people with high levels of stress tend to be more susceptible to psychological problems such as denial and Depression. Researchers have found that nearly 20 percent of people with Diabetes suffer from Depression. This is another way in which psychological problems can cause problems with Diabetes care and management so it is important to watch for the signs of depression and to get help if they are persisting for more than two weeks. Support Groups and Therapy Sessions with a trained counselor can be a great first step!
There are many ways to make Diabetes a part of your life without it running your life. Here are some suggestions on how to BALANCE your physical and mental health:

- Don’t let Diabetes dominate your life—make life your priority
- Get support—from friends, family, support groups, or counselors
- Be open and flexible to changes in Diabetes Care
- Talk about your feelings and emotions—it is okay to hate Diabetes—as long as you acknowledge your feelings then you can move past them
- Reward yourself for the good things in your life—all of them!
- Educate yourself and others—this is a great way to make everyone feel more comfortable around Diabetes
- Think Positively—don’t dwell on the negative it will only bring you down
- Accept some help from others—make it a family affair
- Help others—which can be one of the best ways to help yourself
- Prepare ahead of time for things so you can relax and enjoy them when they occur
- Be assertive—communicate clearly and don’t let people push you around or force you into bad decisions
- Develop your interests—take up a new hobby or revive an old one
- Laugh!!!—This can do wonders for your mood and your health
- Develop your spiritual side, whatever beliefs that may be
- Be PRO-ACTIVE instead of retroactive—you have a lot of power and you can make things happen so don’t just sit back and wait for them to happen to you!!!!
If you are interested in finding out more about Diabetes and feelings then try the American Diabetes Association Website. They deal with all kind of issues facing people with Diabetes such as Stress, Bad Feelings—Denial, Depression, and Anger, and Parenting a Child with Diabetes.

Effects of Diabetes on Children’s Social and Emotional Health

Sometimes finding out that a child has Diabetes can be even more frightening and overwhelming for the parents than for the child. Parents are often overcome with feelings of guilt as they try to comprehend what they are hearing and also try to answer the question, “Why my child?” Every parent naturally feels responsible for the health of their child and throwing Diabetes into the situation only makes parents feel more guilty that somehow they are responsible for their child’s illness. However, it is absolutely necessary that every parent realize this is a NORMAL reaction to finding out about a child having Diabetes. It would be unrealistic and inhuman to think that we would not blame ourselves for the health of our children—no matter how inaccurate that belief may be—but that is the truth of the situation, it is completely INACCURATE!

The first couple of days after the diagnosis most parents will spend in the hospital with their child. At this time there are a lot of new things to learn and a lot of new emotions to deal with. First of all, understand that you are not going to remember everything that the doctors and nurses tell you, and you are probably going to end up going home with just the basic knowledge that you need in order to live with Diabetes at home. This is fine, do not get so overwhelmed with the information that you forget about the reason you are learning it, instead remember the most important things and write
down questions you have so you can ask the doctor or nurse later when you are able to concentrate more. Second, realize that it is going to take you awhile to adjust to having a child with Diabetes, but it is important for you to accept your emotions at this point because most children will initially adopt their parents’ feelings and beliefs toward Diabetes. Try to set a good example for your child and show them that although Diabetes is not the best situation in the world, it is not the worst either, and it is definitely a situation that you, as a family, can deal with. Try to be supportive of your child and listen to his or her fears and encourage sharing because you are both trying to cope with the new diagnosis and it makes it easier if you both share the experience together.

Coming home from the hospital can be another challenge for families of children with Diabetes. All of a sudden you are placed in the same old surroundings with a new challenge to face, and it is going to take some time to adjust. Even though it will be difficult initially, do not give up!!! Instead try to make life as normal as possible by starting a new routine as soon as possible. This is also the time when the real education begins—all sorts of new situations are going to arise and you will have to figure out how to handle them without the aid of a doctor or nurse. There are no clear cut answers for dealing with Diabetes, so you have to realize that some things will have to be sacrificed both in terms of physical and emotional comfort and in terms of Diabetes control—this is when the period of trial and error learning starts and it never ends! This can be difficult for parents because they feel they are hurting their children by denying them sweets or forcing them to do blood glucose tests and insulin shots, but it is important to remember that what you are doing is what is best for your child. Even though it may feel like you are punishing them, you have to realize that what you are really doing is giving them life!
Suggestions and Activities to Empower Kids with Diabetes

- Treat kids as individuals not as “Diabetics”
- Make life a priority—and a Family Affair!!!
- Include them in taking care of their Diabetes—give them responsibilities that are appropriate for their age and understanding
- Encourage independence and try to avoid being overprotective—build a relationship on trust because you cannot be around 24 hours a day 7 days a week to take care of them
- Educate your children and encourage them to teach friends, family, and peers about the reality of living with Diabetes in order to educate others and help end discrimination
- Help your kids express their feelings through conversations, drawings, and play opportunities
- Get involved in activity groups and support groups with other families of children who have Diabetes—this is great for both you and your child!
- Think before you criticize
- Be supportive of both the physical aspects of Diabetes and the Emotional aspects of Diabetes
- Try to learn new coping skills and strategies
- Make life as “normal” as possible for everyone in the family
- Praise success—no matter how small it is!
- Be optimistic and enthusiastic and teach your child to be the same way
- Encourage your child to write his or her own story of Diabetes
• Take your children out for a treat
• Before you tell your child to do something, try to do it yourself
• Try to come up with creative ways to handle problematic situations instead of just
  avoiding them—(check out the book Trick-or-Treat for Diabetes for a great example
  of a creative way to handle Halloween)
• Do Not completely remove all sweets and candy from the child’s life—instead allow
  them to have some in moderation—completely removing them often makes kids eat
  them more when they are away from home
• Use terms with neutral meanings instead of value judgements—for example try to use
  the terms high or low blood glucose reading instead of good or bad reading—kids
  often internalize good or bad readings to mean that the child is good or bad too
• Foster a sense of confidence in your child—children who are confident tend to take
  better care of themselves and their Diabetes
• Keep an open mind about things—be flexible!
• Take control of Diabetes—Don’t allow it to control you!!!!
Diabetes Resources

Internet Links of fun places for kids with Diabetes and kids who want to learn more about Diabetes:

www.diabetes.org/wizdom

This is the American Diabetes Association website for children under the age of thirteen to learn more about Diabetes and how to take control of it through information, discussion with other children with Diabetes, games and activities.

www.thehumanelement.com/courage

This is an online comic about Courage--the Diabetic Superhero.

www.kidshealth.org/teen/health-problems/diseases/diabetes.html

This website is written for teens and has all kinds of information about dealing with Diabetes.

http://www.angelarose.com/FamousDiabetics/

This website is all about famous inventors, politicians, actors, and movie stars that have Diabetes and the many other famous people who have Diabetes. It also has a place for all of the “soon to be famous” kids out there with Diabetes to add their names to the list!

http://www.diabetes.dyndns.info/diabetes/

This website was made by kids for kids to learn about Diabetes. It’s one of my favorites!

http://www.jdf.org/kids/index.html

This is the Juvenile Diabetes Foundation’s website just for kids to learn about Diabetes and to get a chance to meet other kids who have Diabetes.

http://www.starbright.org/
Starbright foundation is all about empowering kids with chronic and serious illness. They have an amazing CD-ROM that is free to kids with Diabetes and is tons of fun. It is a game you play with Xylo the little alien guy whom you have to help through the day by managing your Diabetes.

http://www.insulin-pumpers.org/pkids.shtml

This is a website dedicated to kids with Insulin Pumps—it also tells you where to find out more information about pumping and gives lots of examples of the many activities that insulin pump users can do every day.

http://www.pumpgirls.com/

These are three teenage girls who all use insulin pumps to control their Diabetes—and they sing to educate people about Diabetes and the pump. Check out their website to hear some of their songs.

Books for children about Diabetes:

Chase, H. Peter. *Understanding Insulin-Dependent Diabetes, 9th edition.* Childrens Diabetes Foundation, 2000. This is one of the most comprehensive books about Diabetes for children. Doctors and nurses at the hospital often use it in order to teach children who are newly diagnosed with Diabetes. (Recommended for children of all ages, however younger children will need an adult’s help in order to understand many subjects because of the high reading level it was written for)

Peacock, Carol A., Gregory, Adair, & Gregory, Kyle C. *Sugar Was My Best Food: Diabetes and Me.* Morton Grove, IL: Whitman, 1998. This is a wonderful book in which Adair tells all about being diagnosed with Diabetes and the changes that he and his
family had to go through. He shows how he can do all of the same things he did before he got Diabetes, just with a little adjustment. He also talks about how he and his family try to help others who have Diabetes. (Recommended for ages 8 through 13)

Betschart, Jean. *A Magic Ride in Foozbah-Land: An Inside Look at Diabetes.* Minneapolis: Chronimed, 1995. This book explains to kids with Diabetes how their bodies use food and insulin in order to show them the importance of eating good food, taking insulin shots, and exercising. (Recommended for ages 3 through 7)

Beatty, Monica Driscoll. *My Sister Rose has Diabetes.* Sante Fe, MN: Health Press, 1997. This is the story of James and his sister Rose who has Diabetes. First he tells us about how things have changed since his sister was diagnosed with Diabetes and she tells us all about what it is like to live with Diabetes every day. This is a wonderful book for siblings of a diabetic child! (Recommended for ages 6 through 14)

Pirner, Connie White. *Even Little Kids Get Diabetes.* Morton Grove, IL: A Whitman, 1991. This is the story of a two-year-old girl who has Diabetes. It shows how young children deal with Diabetes as well as how frustrating it can be for parents. (Recommended for ages 2 through 6)

Mulder, Linnea. *Sarah and Puffle: A Story for Children about Diabetes.* New York: Imagination Press, 1992. Tells the story of Sarah who feels angry and frustrated because she has Diabetes. But after she has a dream in which her stuffed animal Puffle comes to life and helps her to understand that it is okay to be a little different than other kids, she feels better and tries to help her cousin learn more about Diabetes. (Recommended for ages 5 through 12)
Gosselin, Kim. *Taking Diabetes to School*. St. Louis: JayJo Books, 1994. This is an informative book meant to educate the classmates of child with Diabetes. It shows how important it is to learn about Diabetes in order to understand that people with Diabetes just want to be treated like everyone else. (Recommended for ages 6 through 11)

Gosselin, Kim. *Rufus Comes Home: Rufus, the Bear with Diabetes*. Valley Park, MO: JayJo Books, 1998. The story of Brian who is diagnosed with Diabetes and wishes that he could have someone to share his special thoughts about Diabetes with. His mom understands and she gets him Rufus, the bear with Diabetes, and he feels like he has someone to share his feelings with. (Recommended for ages 3 through 10)

Gosselin, Kim. *Trick-or-Treat for Diabetes*. Valley Park, MO: JayJo Books, 1999. Tells the story of Sarah, who has Diabetes and how she is unhappy about Halloween since she can not have much candy. Her mother ends up creatively solving the problem and showing that Diabetes does not have to be a setback for children and their families. It shows a wonderfully creative way to overcome Diabetes at Halloween. (Recommended for ages 5 through 12)

Block, Jed. *The Best Year of My Life, Book 1: Getting Diabetes*. Block, Jed, 1999. Caitlin tells about the year that she was diagnosed with Diabetes and how close she grew to her dad because of it. She also tells about how frustrating and scary it can be when you leave the hospital and has to figure out how to live every day with Diabetes. She does a great job at encouraging other children with Diabetes. (Recommended for ages 4 through 10)

Betschart, Jean. *It's Time to Learn about Diabetes: A Workbook on Diabetes for Children*. Minneapolis: Chronimed, 1991. This is a workbook telling about the basics of Insulin, Food, Exercise, and Special Occasions. It also tells how to deal with Diabetes at
school, managing feelings, and telling friends about Diabetes. (Recommended for ages 7 through 12)

Bergman, Thomas. Meeting the Challenge: Children Living with Diabetes. Milwaukee: Gareth Stevens, 1992. This book tells the story of Jonny, a boy with Diabetes who goes to Diabetes camp and gets to do all sorts of fun and new activities. Jonny also learns to give himself Insulin shots and he becomes more confident in himself and his Diabetes. (Recommended for ages 6 through 12)

Silverstein, Alvin and Virginia B. Runaway Sugar: All About Diabetes. New York: Lippincott, 1981. This book explains what may cause Diabetes and what happens to the body when it occurs. It is very explanatory and great for classmates of a diabetic child to learn the more physical aspect of Diabetes. (Recommended for ages 6 through 10)

Betschart, Jean & Thom, Susan. In Control: A Guide for Teens with Diabetes. Minneapolis: Chronimed, 1995. A great book for teens with Diabetes! It is funny but also gives you the bottom line on Diabetes care and management. It also talks about subjects like sex, alcohol, smoking, and dating and how they affect Diabetes. (Recommended for ages 12 through 18)

Books for parents of children with Diabetes:

McAuliffe, Alicia. Growing Up With Diabetes. New York: Whiley, 1998. This book gives parents an opportunity to look at Diabetes through the eyes of a child or teenager growing up with the disease. A twenty-one year old student who has had Diabetes since she was eleven-years-old and now hopes to help other families who are dealing with Diabetes wrote it. I love this book because it provides people with information beyond
the facts and statistics of Diabetes—it goes straight for the emotional and social aspects of the disease.

Betschart, Jean. *Diabetes Care for Babies, Toddlers and Preschoolers.* New York: J. Whiley, 1999. This book tells you everything you need to learn about taking care of your child’s Diabetes. It goes beyond the normal information and shows pictures of things such as how to give an insulin shot to a squirming child or how to deliver Glucagon to a child. It also gives suggestions for dealing with the daily aspects of Diabetes care.


Page Brackenridge, Betty & Rubin, Richard R. *Sweet Kids: How to Balance Diabetes Control and Good Nutrition with Family Peace.* Alexandria, VA: American Diabetes Association, 1996. This book tells all about dealing with a child with Diabetes in a realistic and humorous way—such as comparing Diabetes to a Gorilla at the Symphony—sometimes we pay so much attention to the Diabetes that we forget about the child. It focuses on many common topics and gives the bottom line on how to deal with issues that arise without loosing control and without loosing hope!

Peurring, Victoria. *Living With Juvenile Diabetes: A Practical Guide for Parents and Caregivers.* New York: Hatherleigh, 2001. An easy to read book focusing on the ins and outs of caring for a child who has Diabetes—from a parent of a diabetic child. It has an excellent chapter about Diabetes at school in which she explains how she helped the faculty of her daughter’s school to understand her needs as well as her rights.

Indiana Diabetes Resources:
Additional References


Empowering people with Diabetes

By Michelle Pierron

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My Own Story of Diabetes

What is Diabetes?—Click here for a General Overview

http://www.bsu.edu/web/mmpierron/

4/24/02
The Emotional side of Diabetes

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Effects of Diabetes on Children’s Social and Emotional Health

(Click here to see a Child Development Chart)

Sometimes finding out that a child has Diabetes can be even more frightening and overwhelming for the parents than for the child. Parents are often overcome with feelings of guilt as they try to comprehend what they are hearing and also try to answer the question, “Why my child?” Every parent naturally feels responsible for the health of their child and throwing Diabetes into the situation only makes parents feel more guilty that somehow they are responsible for their child’s illness. However, it is absolutely necessary that every parent realize this is a NORMAL reaction to finding out about a child having Diabetes. It would be unrealistic and inhuman to think that we would not blame ourselves for the health of our children—no matter how inaccurate that belief may be—but that is the truth of the situation, it is completely INACCURATE!

The first couple of days after the diagnosis most parents will spend in the hospital with their child. At this time there are a lot of new things to learn and a lot of new emotions to deal with. First of all, understand that you are not going to remember everything that the doctors and nurses tell you, and you are probably going to end up going home with just the basic knowledge that you need in order to live with Diabetes at home. This is fine, do not get so overwhelmed with the information that you forget about the reason you are learning it, instead remember the most important things and write down questions you have so you can ask the doctor or nurse later when you are able to concentrate more. Second, realize that it is going to take you awhile to adjust to having a child with Diabetes, but it is important for you to accept your emotions at this point because most children will initially adopt their parents’ feelings and beliefs toward Diabetes. Try to set a good example for your child and show them that although Diabetes is not the best situation in the world, it is not the worst either, and it is definitely a situation that you, as a family, can deal with. Try to be supportive of your child and listen to his or her fears and encourage sharing because you are both trying to cope with the new diagnosis and it makes it easier if you both share the experience together.

Coming home from the hospital can be another challenge for families of children with Diabetes. All of a sudden you are placed in the same old surroundings with a new challenge to face, and it is going to take some time to adjust. Even though it will be difficult initially, do not give up!!! Instead try to make life as normal as possible by starting a new routine as soon as possible. This is also the time when the real education begins—all sorts of new situations are going to arise and you will have to figure out how to handle them without the aid of a doctor or nurse. There are no clear cut answers for dealing with Diabetes, so you have to realize that some things will have to be sacrificed both in terms of physical and emotional comfort and in terms of Diabetes control—this is when the period of trial and error learning starts and it never ends! This can be difficult for parents because they feel they are hurting their children by denying them sweets or forcing them to do blood glucose tests and insulin shots, but it is important to remember that what you are doing is what is best for your child. Even though it may feel like you are punishing them, you have to realize that what you are really doing is giving them life!

Suggestions and Activities to Empower Kids with Diabetes

http://www.bsu.edu/web/mmipierron/ 4/24/02
• Treat kids as individuals not as "Diabetics"
• Make life a priority—and a Family Affair!!!
• Include them in taking care of their Diabetes—give them responsibilities that are appropriate for their age and understanding
• Encourage independence and try to avoid being overprotective—build a relationship on trust because you cannot be around 24 hours a day 7 days a week to take care of them
• Educate your children and encourage them to teach friends, family, and peers about the reality of living with Diabetes in order to educate others and help end discrimination
• Help your kids express their feelings through conversations, drawings, and play opportunities
• Get involved in activity groups and support groups with other families of children who have Diabetes—this is great for both you and your child!
• Think before you criticize
• Be supportive of both the physical aspects of Diabetes and the Emotional aspects of Diabetes
• Try to learn new coping skills and strategies
• Make life as "normal" as possible for everyone in the family
• Praise success—no matter how small it is!
• Be optimistic and enthusiastic and teach your child to be the same way
• Encourage your child to write his or her own story of Diabetes
• Take your children out for a treat
• Before you tell your child to do something, try to do it yourself
• Try to come up with creative ways to handle problematic situations instead of just avoiding them—(check out the book Trick-or-Treat for Diabetes for a great example of a creative way to handle Halloween)
• Do Not completely remove all sweets and candy from the child’s life—instead allow them to have some in moderation—completely removing them often makes kids eat them more when they are away from home
• Use terms with neutral meanings instead of value judgements—for example try to use the terms high or low blood glucose reading instead of good or bad reading—kids often internalize good or bad readings to mean that the child is good or bad too
• Foster a sense of confidence in your child—children who are confident tend to take better care of themselves and their Diabetes
• Keep an open mind about things—be flexible!

Take control of Diabetes—Don’t allow it to control you!!!!

Click below for more Diabetes Resources

Internet Sites
Books for Kids and
Books for Parents of Children with Diabetes

Additional References Used for this Website

http://www.bsu.edu/web/mmpierron/ 4/24/02
My Own Story of Diabetes

This Website was developed as a part of my Undergraduate Honors Thesis at Ball State University. I had a difficult time deciding on a topic because as a Psychology major there are millions of things I am interested in, but few topics that I have much indepth knowledge about. I decided to write about the emotional aspects of Diabetes because that is one area where I do have some knowledge and a lot of experience.

I was diagnosed with Type 1 Diabetes when I was sixteen. I was a junior in High School and our school was on a new program where if you maintained a grade of C or higher and had perfect attendance you could opt out of taking your finals. I tried my best to opt out—I went for about two and a half weeks with Diabetes before I ever actually went to the hospital to find out what was wrong. My mother and her friend had to take me to the emergency room because I had Ketoacidosis so bad that I was kneeling over in the bathroom after vomiting and I could not stand up because of the pain in my stomach. I remember the trip to the hospital, but I do not remember anything that happened once I got there. My mom says that I was delirious, and at that point I was telling everyone that I was fine and that I was ready to go home. (I have to admit that I dislike going to the doctor, and the hospital definitely is not fun if you are the one being admitted!)

The next day I remember waking up in the hospital room. I cannot remember who told me I had Diabetes, but I do remember the look on my mom’s face—like she felt so sorry for me. I just started crying. At that time I accepted the fact that I had Diabetes but I wasn’t ready yet to try to deal with the consequences—emotionally or physically. Those four days in the hospital were some of the most challenging days of my life, but they were also some of the most meaningful days of my life. It was during that time that I got to see how loving and supportive my mother was. She stayed at the hospital the entire time I was there and when she did leave temporarily to take care of the house and our dogs, she always made sure that someone else was there to stay with me. That meant a lot because even though I was sixteen, I was still scared out of my mind about what the future held and even about what the day held.

During those four days the hospital staff tried to educate us to the best of their ability—but they gave us so much information that everyone felt overwhelmed. My mom said that her biggest fear at that

http://www.bsu.edu/web/mmpierron/mystory.htm 4/23/02
time was that either she or I would not be able to adapt to all of the changes that they said we had to make. Now she admits that we all adapted fairly quickly—although not very smoothly at first. I still remember her trying to stick exactly to the new diet they gave us, so she went out and bought every possible kind of spray or squeeze butter imaginable in order to make the new healthier food taste a little better. Before long we were all back into a routine and life became normal again. It was a different kind of normal, but it was normal nonetheless and Diabetes just became a part of our lives.

In the time since my diagnosis, I have graduated from High School, graduated from Ball State University with a Bachelor of Arts Degree in Psychology, and I am now pursuing a Masters Degree at the University of Michigan in the field of Social Work. Life is still caotic at times—and it always will be—but now Diabetes has moved to a position a little lower on my priority list. I am still trying to learn about it and trying to make changes and adjustments because of it. I think in some ways I am still trying to come to terms with it completely, but that is one reason that I did this Thesis—to prove to myself and other people that having a chronic condition like Diabetes affects more than just your physical health. There is definitely more to Diabetes than just blood tests and needles—there are life changes, social responsibilities, emotions, and most important of all there is an individual who has to face Diabetes every day. My hope is that people will realize that it is okay to be sad, angry, and irritated about Diabetes and all that it entails—but it is not okay to keep those feelings bottled up inside! Let your feelings come out to someone you trust and respect and you will realize that the center of your life does not have to be Diabetes. Life is what you make it—and despite adversity, you can make it wonderful!!!!!
What is Diabetes? - A General Overview

The main function of the pancreas is to help the hormone insulin change the food we eat into energy. However, in people with Diabetes the pancreas either does not produce the appropriate amount of insulin or produces no insulin, which causes the food we eat to build up in our bloodstream. The major distinction between Type 1 and Type 2 Diabetes is the type of insulin production. In people with Type 1 Diabetes little or no insulin is produced—this type of Diabetes requires the use of daily insulin injections and occurs most often in childhood and adolescence. It does have a genetic component, but this component is complex and not clearly understood. People with Type 2 Diabetes on the other hand, produce some insulin but not appropriate amounts for their daily food intake, so they are forced to take medicines or injections to compensate for this lack. Type 2 Diabetes occurs most often in people over the age of 40 who are overweight and runs in families even more frequently than Type 1 does.

Doctors are unsure of what causes Diabetes but they have found that Type 1 Diabetes is often triggered by a virus in the body. In this situation the immune system, which usually fights the virus, begins to fight the beta cells that create insulin because it mistakes them for the virus. People with Type 1 Diabetes may have this happen many times over a period of years before they actually see the direct results in the form of Diabetes symptoms. People with Type 2 Diabetes do not have any of these problems—for them Diabetes is most often caused by being overweight. Despite the different causes, the symptoms of both Type 1 and Type 2 Diabetes are similar and may include:

- extreme thirst
- excessive urination
- feeling very tired
- feeling very hungry
- losing weight without trying to
- having sores that are slow to heal
- dry, itchy skin
- tingling or numbness in the feet or hands
- blurry eyesight

Where to find more information on Diabetes:

There are hundreds of places to look for information on Diabetes depending on what you are looking for. Two of the best places for general information are the American Diabetes Association Website and the Joslin Diabetes Center Website. Both of these sites provide in-depth information about Diabetes symptoms, complications, and treatment as well as information on how to deal with Diabetes on a daily basis. Both websites also give information on Diabetes programs and clinics in your area. These sites are great for people who have Diabetes and people who are trying to learn more about Diabetes. If you are looking for information specifically on Type 1 Diabetes then you might try the Juvenile Diabetes Foundation Website or the Children with Diabetes Website. These websites are the perfect place for parents of children with Diabetes to look for information pertaining directly to their families and children. There are also some wonderful books that provide a more in-depth look at Diabetes and can be found at any local public library such as:


http://www.bsu.edu/web/mmpierron/general.html


Positive and Negative Patterns of Coping with Diabetes

Potentially Negative Coping Patterns:

- Seclusiveness—Isolating yourself or withdrawing from the company and help of others
- Aggression—Acting out in violent ways
- Bravado—Boastfulness or Having the attitude that you can do whatever you want without consequences
- Self-blame—Shame or Guilt—Feeling like you caused the Diabetes
- Open Resentment and Rebellion—Continuously refusing to take the treatments necessary for caring for your Diabetes—such as faking Blood Glucose Readings, not taking medications, or disregarding your diet
- Meticulousness, Perfectionism, and other Obsessive-Compulsive Reactions
- Distancing—Acknowledging Diabetes but failing to deal with its emotional significance
- Fantasy or Wishful Thinking—Hoping that your Diabetes will magically change or go away
- Denial—Refusal to Accept that you have Diabetes
- Mental and or Behavioral Disengagement—Giving up either physically or emotionally on yourself and your Diabetes
- Substance Use or Abuse—including Alcohol, Drugs, Smoking, Eating, or any other type of excessive behavior

Positive Coping Patterns:

- Active Coping—Actively trying to change the situation or its effects—trying to take control over your life and your Diabetes
- Planning—Looking ahead and coming up with ways to deal with situations that may arise in the future
- Searching for Social Support
- Accepting Reality—Accepting you have Diabetes
- Positive Reappraisal—Reappraising the situation in positive terms and looking for ways you can use Diabetes to grow—this may involve making downward comparisons or comparing yourself to people who you feel are in a worse situation than you are
- Searching for Alternative Rewards—look for other activities that make you feel happy
- Relying on Religion
- Catharsis—Focusing on and venting your emotions
- Tension Reduction—such as exercising, using relaxation techniques, or doing Yoga
- Humor
- Self-assertion—making your needs and wants known
- Distraction—trying to keep your mind off of the situation that is bothering you
- Information Seeking
- Creativity—figuring out new ways to handle old or frustrating situations


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Symptoms of Depression

When looking at the warning signs of Depression it is important to remember that some of these symptoms are simply natural reactions to Diabetes—such as waking early in the morning due to a low blood sugar or irritability associated with Hyperglycemia. However, if you are having three or more of these symptoms and they last for more than two weeks then you need to get help from a professional—especially if you are feeling like you want to die or hurt yourself.

- Feeling unhappy or sad for most of the day
- Loss of interest in activities that you usually enjoy
- Inappropriate feelings of guilt, worthlessness, or inadequacy
- Poor or increased appetite or weight gain or loss in a short amount of time
- Changes in your sleeping patterns—such as sleeping more than usual or not being able to fall asleep (insomnia)
- Feelings of hopelessness
- Trouble thinking, concentrating, and making decisions
- Feeling tearful or crying a lot
- Having less energy or feeling tired all of the time
- Frequent thoughts of suicide or death—if so get help IMMEDIATELY
**Typical Child Development:**

(Adapted from Understanding Insulin-Dependent Diabetes, 9th ed. By H. Peter Chase, pg 163)

<table>
<thead>
<tr>
<th>Age: Below Age 3</th>
<th>Social/Emotional Development:</th>
<th>Diabetes-related tasks:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Communicates nonverbally</td>
<td>Parents do all Diabetes care</td>
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<tr>
<td></td>
<td>Developing speech</td>
<td>Child accepts Diabetes as a normal part of life</td>
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<td></td>
<td>Learning to trust—shows</td>
<td>Inconsistent eating patterns—choices and amounts vary</td>
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<tr>
<td></td>
<td>strong parental attachment</td>
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<td></td>
<td>Shows basic emotions</td>
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<td>Uses social referencing</td>
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<td>(determines emotions by</td>
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<td></td>
<td>watching parent’s reactions)</td>
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<tr>
<td>Ages 3 to 7</td>
<td>Imaginative/concrete thinker</td>
<td>Parents do all Diabetes care</td>
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<tr>
<td></td>
<td>Self-centered and egocentric</td>
<td>Child cooperates with blood glucose tests and insulin shots</td>
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<td></td>
<td>Develops complex emotions—</td>
<td>Learns to recognize hypoglycemia</td>
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<tr>
<td></td>
<td>shame, guilt, jealousy, and</td>
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<td>envy</td>
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<td>Describes causes and</td>
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<td>consequences of emotions</td>
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<td>Socialization occurs mostly</td>
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<td>with family members</td>
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<td>Increased responsiveness to</td>
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<td>changes in family relationships</td>
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<td></td>
<td>Develops friendships</td>
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<td>Displays prosocial play and</td>
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<td></td>
<td>caring actions</td>
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<td>Ages 8 to 12</td>
<td>Concrete thinker—logical</td>
<td>Can do blood glucose tests</td>
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<td></td>
<td>More curious</td>
<td>Begins to draw up and give their own shots but still needs supervision</td>
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<td></td>
<td>More responsible</td>
<td>Makes own food choices</td>
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<td></td>
<td>Can mask or fake emotions</td>
<td>Can recognize and treat hypoglycemia</td>
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<td></td>
<td>Increased interaction with</td>
<td>Older kids can remember snacks and snack times</td>
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<td>peers and decreased interaction with parents</td>
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<td></td>
<td>Forms intimate friendships</td>
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<td></td>
<td>Desire to conform to peers</td>
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<td></td>
<td>Increased understanding of</td>
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<td></td>
<td>other people’s perspectives</td>
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<tr>
<td>Ages 13 to 18</td>
<td>Abstract thinking—</td>
<td>Does majority of Diabetes care but still needs parental support and involvement</td>
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<td></td>
<td>hypothetical thinking</td>
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<tr>
<td></td>
<td>Behaviors vary—due to</td>
<td>Knows appropriate food choices</td>
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<td></td>
<td>hormonal changes</td>
<td>Recognizes the importance of good control in order to prevent complications</td>
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<td></td>
<td>More responsible</td>
<td>More willing to do multiple injections in order to gain more freedom</td>
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<td>Body image is important</td>
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<td>Spend more time away from</td>
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<td></td>
<td>Interested in Dating</td>
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<td>Good at perspective taking</td>
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<td>Identity Development</td>
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<td>independence</td>
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Diabetes Resources:

Internet Links of fun places for kids with Diabetes and kids who want to learn more about Diabetes:

www.diabetes.org/wizdom

This is the American Diabetes Association website for children under the age of thirteen to learn more about Diabetes and how to take control of it through information, discussion with other children with Diabetes, games and activities.

www.thehumanelement.com/courage

This is an online comic about Courage--the Diabetic Superhero.

www.kidshealth.org/teen/health-problems/diseases/diabetes.html

This website is written for teens and has all kinds of information about dealing with Diabetes.

http://www.angelarose.com/FamousDiabetics/

This website is all about famous inventors, politicians, actors, and movie stars that have Diabetes and the many other famous people who have Diabetes. It also has a place for all of the "soon to be famous" kids out there with Diabetes to add their names to the list!

http://www.diabetes.dyndns.info/diabetes/

This website was made by kids for kids to learn about Diabetes. It’s one of my favorites!

http://www.jdf.org/kids/index.html

This is the Juvenile Diabetes Foundation’s website just for kids to learn about Diabetes and to get a chance to meet other kids who have Diabetes.

http://www.starbright.org/

Starbright foundation is all about empowering kids with chronic and serious illness. They have an amazing CD-ROM that is free to kids with Diabetes and is tons of fun. It is a game you play with Xylo the little alien guy whom you have to help through the day by managing your Diabetes.

http://www.insulin-pumpers.org/pkids.shtml

This is a website dedicated to kids with Insulin Pumps—it also tells you where to find out more information about pumping and gives lots of examples of the many activities that insulin pump users can do every day.

http://www.bsu.edu/web/mmipierron/resources.htm 4/23/02
These are three teenage girls who all use insulin pumps to control their Diabetes—and they sing to educate people about Diabetes and the pump. Check out their website to hear some of their songs.

Books for children about Diabetes:

Recommended for all ages:

Chase, H. Peter. *Understanding Insulin-Dependent Diabetes, 9th edition*. Childrens Diabetes Foundation, 2000. This is one of the most comprehensive books about Diabetes for children. Doctors and nurses at the hospital often use it in order to teach children who are newly diagnosed with Diabetes. (Recommended for children of all ages, however younger children will need an adult’s help in order to understand many subjects because of the high reading level it was written for)

Recommended for ages 3 through 6:

Betschart, Jean. *A Magic Ride in Foohbah-Land: An Inside Look at Diabetes*. Minneapolis: Chronimed, 1995. This book explains to kids with Diabetes how their bodies use food and insulin in order to show them the importance of eating good food, taking insulin shots, and exercising.

Pirner, Connie White. *Even Little Kids Get Diabetes*. Morton Grove, IL: A Whitman, 1991. This is the story of a two-year-old girl who has Diabetes. It shows how young children deal with Diabetes as well as how frustrating it can be for parents.

Gosselin, Kim. *Rufus Comes Home: Rufus, the Bear with Diabetes*. Valley Park, MO: JayJo Books, 1998. The story of Brian who is diagnosed with Diabetes and wishes that he could have someone to share his special thoughts about Diabetes with. His mom understands and she gets him Rufus, the bear with Diabetes, and he feels like he has someone to share his feelings with.

Recommended for ages 6 through 13:

Peacock, Carol A., Gregory, Adair, & Gregory, Kyle C. *Sugar Was My Best Food: Diabetes and Me*. Morton Grove, IL: Whitman, 1998. This is a wonderful book in which Adair tells all about being diagnosed with Diabetes and the changes that he and his family had to go through. He shows how he can do all of the same things he did before he got Diabetes, just with a little adjustment. He also talks about how he and his family try to help others who have Diabetes.

Beatty, Monica Driscoll. *My Sister Rose has Diabetes*. Sante Fe, MN: Health Press, 1997. This is the story of James and his sister Rose who has Diabetes. First he tells us about how things have changed since his sister was diagnosed with Diabetes and she tells us all about what it is like to live with Diabetes every day. This is a wonderful book for siblings of a diabetic child!

Mulder, Linnea. *Sarah and Puffle: A Story for Children about Diabetes*. New York: Imagination Press, 1992. Tells the story of Sarah who feels angry and frustrated because she has Diabetes. But after she has a dream in which her stuffed animal Puffle comes to life and helps her to understand that it is okay to be a little different than other kids, she feels better and tries to help her cousin learn more about Diabetes.

meant to educate the classmates of child with Diabetes. It shows how important it is to learn about Diabetes in order to understand that people with Diabetes just want to be treated like everyone else.

Gosselin, Kim. *Trick-or-Treat for Diabetes*. Valley Park, MO: JayJo Books, 1999. Tells the story of Sarah, who has Diabetes and how she is unhappy about Halloween since she can not have much candy. Her mother ends up creatively solving the problem and showing that Diabetes does not have to be a setback for children and their families. It shows a wonderfully creative way to overcome Diabetes at Halloween.

Block, Jed. *The Best Year of My Life, Book 1: Getting Diabetes*. Bloc, Jed, 1999. Caitlin tells about the year that she was diagnosed with Diabetes and how close she grew to her dad because of it. She also tells about how frustrating and scary it can be when you leave the hospital and has to figure out how to live every day with Diabetes. She does a great job at encouraging other children with Diabetes.

Betschart, Jean. *It's Time to Learn about Diabetes: A Workbook on Diabetes for Children*. Minneapolis: Chronimed, 1991. This is a workbook telling about the basics of Insulin, Food, Exercise, and Special Occasions. It also tells how to deal with Diabetes at school, managing feelings, and telling friends about Diabetes.

Bergman, Thomas. *Meeting the Challenge: Children Living with Diabetes*. Milwaukee: Gareth Stevens, 1992. This book tells the story of Jonny, a boy with Diabetes who goes to Diabetes camp and gets to do all sorts of fun and new activities. Jonny also learns to give himself Insulin shots and he becomes more confident in himself and his Diabetes.

Silverstein, Alvin and Virginia B. *Runaway Sugar: All About Diabetes*. New York: Lippincott, 1981. This book explains what may cause Diabetes and what happens to the body when it occurs. It is very explanatory and great for classmates of a diabetic child to learn the more physical aspect of Diabetes.

Recommended for ages 13 through 18:

Betschart, Jean & Thom, Susan. *In Control: A Guide for Teens with Diabetes*. Minneapolis: Chronimed, 1995. A great book for teens with Diabetes! It is funny but also gives you the bottom line on Diabetes care and management. It also talks about subjects like sex, alcohol, smoking, and dating and how they affect Diabetes.

Books for parents of children with Diabetes:

McAuliffe, Alicia. *Growing Up With Diabetes*. New York: Whiley, 1998. This book gives parents an opportunity to look at Diabetes through the eyes of a child or teenager growing up with the disease. A twenty-one year old student who has had Diabetes since she was eleven-years-old and now hopes to help other families who are dealing with Diabetes wrote it. I love this book because it provides people with information beyond the facts and statistics of Diabetes—it goes straight for the emotional and social aspects of the disease.

Betschart, Jean. *Diabetes Care for Babies, Toddlers and Preschoolers*. New York: J. Whiley, 1999. This book tells you everything you need to learn about taking care of your child’s Diabetes. It goes beyond the normal information and shows pictures of things such as how to give an insulin shot to a squirming child or how to deliver Glucagon to a child. It also gives suggestions for dealing with the daily aspects of Diabetes care.

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Page Brackenridge, Betty & Rubin, Richard R. *Sweet Kids: How to Balance Diabetes Control and Good Nutrition with Family Peace*. Alexandria, VA: American Diabetes Association, 1996. This book tells all about dealing with a child with Diabetes in a realistic and humorous way—such as comparing Diabetes to a Gorilla at the Symphony—sometimes we pay so much attention to the Diabetes that we forget about the child. It focuses on many common topics and gives the bottom line on how to deal with issues that arise without losing control and without losing hope.

Peurring, Victoria. *Living With Juvenile Diabetes: A Practical Guide for Parents and Caregivers*. New York: Hatherleigh, 2001. An easy to read book focusing on the ins and outs of caring for a child who has Diabetes—from a parent of a diabetic child. It has an excellent chapter about Diabetes at school in which she explains how she helped the faculty of her daughter's school to understand her needs as well as her rights.

Additional References:


http://www.bsu.edu/web/mmpierron/references.htm