Understanding students with diabetes: a communication handbook for high schools

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ABSTRACT

Karen M. Ferguson
Understanding Students With Diabetes:
A Communication Handbook For High Schools
2000
Thesis Advisor: Donald Bagin
Master of Arts in Public Relations

Effective communication between students with diabetes and school personnel is essential to the well-being of the student. The author conducted this study to identify the needs, feelings, and behaviors of students with diabetes.

The author performed literature searches and conducted informal, qualitative research techniques to obtain information for the handbook. The author conducted telephone interviews with seven nurses from selected counties in Southern New Jersey. The author asked the nurses questions about diabetes management in their schools. The author also questioned 15 students with diabetes regarding communication efforts with the school, signs and symptoms of high and low blood sugars, and ideas on how to improve communication with teachers and classmates.

The author’s research revealed that school nurses, teachers, and other school personnel needed assistance in understanding and managing high school students with diabetes. The author compiled information obtained from literature research, interviews with school nurses, and surveys of students with diabetes into this handbook. This handbook can be a valuable asset for the support network of students with diabetes.
MINI-ABSTRACT

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Understanding Students With Diabetes:
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Effective communication between students with diabetes and school personnel is essential to the well-being of the student. This study identified the needs, feelings, and behaviors of students with diabetes.

A handbook was prepared to assist school personnel who need assistance in understanding and managing high school students with diabetes.
CHAPTER I

INTRODUCTION

The author sensed a need to create an awareness of diabetes within the school system. The author, like many other diabetics, went through school having to take insulin, check blood sugars, and eat snacks. Many times classmates and teachers simply stared instead of asking questions and learning about diabetes.

Students with diabetes today are more fortunate than when the author attended school. Diabetes-related information can be easily obtained from the Internet, library, or associations such as the American Diabetes Association and the Juvenile Diabetes Foundation. However, many teachers and classmates don’t take the time to learn about the disease. This, in conjunction with the diabetic student’s reluctance to share information, can cause communication barriers.

I. NEED FOR THE STUDY

Approximately 120,000 school-aged children in the United States have insulin-dependent diabetes (IDDM or Type 1 diabetes), with 14 to 16 new cases per 100,000 children under 14 diagnosed each year (American Diabetes Association, 1993).¹

Though many people may know someone who has diabetes, they fail to understand the implications of the disease. One’s failure to recognize signs and symptoms of an insulin reaction could be detrimental to the diabetic.

The February 1999 *Journal of Nursing Education* reported a study of nursing students, registered nurses, and non-nursing students who were given a Diabetes Knowledge Questionnaire. The questionnaire covered diabetes issues such as etiology of diabetes, classification of diabetes, insulin action, diet, hypoglycemia, and hyperglycemia. The study revealed that all the groups lacked diabetes knowledge. Alarmingly, practicing nurses scored only 60% in recognizing and treating hypoglycemia and only 35% in recognizing and treating hyperglycemia.²

The student with diabetes needs a support network while at school, as well as at home. The teachers, principal, classmates, school nurse, and guidance counselor make up this network. These people must have an understanding of diabetes and how it affects the student.

According to Stephanie Schwartz, a diabetes nurse specialist at “childrenwithdiabetes.com”, an Internet website, “Effective management of diabetes at school can help provide a supportive learning environment for students with diabetes; reduce absences; reduce disruption in the classroom; provide the necessary support in the event of an emergency; achieve full participation in physical activities; and foster self-esteem.”³

² Ibid
The American Diabetes Association (ADA) takes the position that school personnel must have an understanding of diabetes and its management to facilitate the appropriate care of the child with diabetes.\(^4\)

The ADA's position paper states:

Federal laws that protect children with diabetes include the Rehabilitation Act of 1973, Section 504, the Individuals with Disabilities Education Act of 1991, and the Americans with Disabilities Act of 1992. Under these laws, diabetes has been determined to be a disability, and it is illegal for schools and/or day care centers to discriminate against children with diabetes. In addition, any school that receives federal funding or any facility open to the public must reasonably accommodate the special needs of children with diabetes. Indeed, federal law requires an individualized assessment of any child with diabetes. The required accommodations should be provided within the child's usual school setting with as little disruption to the school's and the child's routine as possible and allowing the child full participation in all school activities. Despite these protections, children in the school and day care setting still face discrimination.\(^5\)

In fact “childrenwithdiabetes.com” surveyed its audience regarding where their child performed blood tests while at school. The poll was conducted from December 27, 1998 to January 3, 1999. Of the 497 total respondents, only 21% reported that their child’s school was supportive and allowed testing in the classroom. A frightening 18% reported that their children were not even allowed to test their blood sugars at school.\(^6\)


\(^5\) Ibid

II. PROCEDURE

The author obtained information regarding diabetes from journals and Internet resources. The signs and symptoms, complications, and special needs associated with diabetics was compiled into a handbook.

The author communicated with local high school nurses to learn their interactions with diabetic students. The author also surveyed students with diabetes to gather information on how they communicate about diabetes. Such information will be used to develop communication tips for the educator and diabetic student.

The author also compiled a list of relevant diabetes-related resources for inclusion in the handbook.

III. DEFINITION OF TERMS

Type 1 Diabetes: Previously called juvenile diabetes or insulin-dependent diabetes, this is a disease in which the body destroys insulin-producing beta cells in the pancreas.\(^7\)

Type 2 Diabetes: Previously called adult-onset or non-insulin dependent diabetes, this is a disease in which the beta cells still produce insulin but not enough to meet the body’s current needs.\(^8\)

Hypoglycemia: Low blood sugar that occurs when the blood sugar level is too low, due to too much insulin, too little food, or too much exercise.\(^9\)

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Hyperglycemia: High blood sugar that occurs when the blood sugar level is too high, due to too little insulin or too much food.\textsuperscript{10}

Insulin: A hormone (chemical messenger) made in the pancreas that allows glucose to enter cells and convert to energy.\textsuperscript{11}

Ketones (Ketone Bodies): Chemicals that the body makes when there is not enough insulin in the blood and it must break down fat for its energy.\textsuperscript{12}

Glucagon: A hormone that raises the level of glucose (sugar) in the blood. The alpha cells of the pancreas make glucagon when the body needs to put more sugar into the blood. An injectable form of glucagon, which can be bought in a drug store, is sometimes used to treat insulin shock. The glucagon is injected and quickly raises blood glucose levels.\textsuperscript{13}

Insulin Shock: A severe condition that occurs when the level of blood glucose (sugar) drops quickly. The signs are shaking, sweating, dizziness, double vision, convulsions, and collapse. Insulin shock may occur when an insulin reaction is not treated quickly enough.\textsuperscript{14}


\textsuperscript{14} Ibid
Blood Glucose Meter: A machine that helps test how much glucose (sugar) is in the blood. A specially coated strip containing a fresh sample of blood is inserted in a machine, which then calculates the correct level of glucose in the blood sample and shows the result in a digital display.\textsuperscript{15}

School System: The author defines school system as being the principals, teachers, school-nurses, counselors, and administrators responsible for the education and well-being of students.

IV. SCOPE OF THE STUDY

The author created this handbook to enhance communication between students with diabetes and teachers, school nurses, school administrators, and classmates. The handbook includes information pertaining to the signs, symptoms, and complications associated with Type 1 Diabetes (insulin dependent). The handbook also includes ideas on how to encourage communication about diabetes. The author also included a list of resources for information pertaining to diabetes.

Although some of this information may apply to Type 2 Diabetes as well, this handbook was designed around the student with Type 1 Diabetes. Additionally, the handbook is aimed at secondary schools.

This handbook is not intended to serve as medical advice. Any diabetes plan should be individualized and discussed with the diabetic student, parents, and healthcare provider. Also, due to the small number of students surveyed, these numbers cannot be projected to a larger population.

\textsuperscript{15} Ibid
Chapter II

Literature Review

The author used several different sources to obtain literature relevant to the thesis topic. The author performed searches using the ERIC database, WebSPIRS databases, and VALE NJ database. These searches provided articles or abstracts from Education Abstracts, Sociological Abstracts, PsycInfo and CINAHL- Allied Health.

The author also performed Internet searches for information pertaining to students with diabetes. The author used the Internet web site "childrenwithdiabetes.com."

Telephone interviews with seven local high school nurses were also conducted. The nurses provided information about diabetes management within their schools. Additionally, the author questioned diabetic students from these schools via a written questionnaire. The author also e-mailed the questionnaire to a group of teenagers with diabetes from the "childrenwithdiabetes.com" Internet e-mail list.

This chapter contains the information gathered from the literature and Internet arranged by diabetes-related topics.

Prevalence of Diabetes

According to World Health Organization statistics, in 1997 there were an estimated 14,315,000 diabetes cases. This number is estimated to grow to 21,892,000 in the year 2025. 16

According to American Diabetes Association 1993 statistics referenced in Lipman, T.H., Mahon, M.M. (1999) Nurses’ knowledge of diabetes, approximately 120,000 school-aged children in the United States have insulin- dependent diabetes (IDDM / Type 1 diabetes), with 14 to 16 new cases per 100,000 children under 14 diagnosed each year (American Diabetes Association, 1993).¹⁷

Signs and Symptoms

Type 1 or immune-mediated diabetes is a disease in which the body destroys insulin-producing beta cells in the pancreas.¹⁸ Insulin is a hormone (chemical messenger) made in the pancreas that allows glucose to enter cells and convert to energy.¹⁹

Type 1 diabetes used to be referred to as “juvenile diabetes” because it typically affected children.

Type 2 diabetes, previously called adult-onset or non-insulin dependent diabetes, is a disease in which the beta cells still produce insulin but not enough to meet the body’s current needs.²⁰

Joseph J. Fallon, M.D. stated “As of the past few years, there are more reports of students with type 2 diabetes due to weight problems than type 1 diabetes.”²¹ On

2/23/00, the American Diabetes Association (ADA) issued new guidelines to address
the alarming rise of Type 2 diabetes in children and adolescents. The ADA emphasizes,
"Early detection and treatment are key to preventing future complications." 22

It is important for school officials to understand the signs, symptoms, and
complications of diabetes to support those students already diagnosed with diabetes
and those not yet diagnosed. Many people use the terms "sign" and "symptom"
interchangeably. However, there are differences between them. According to Kemp’s
and Pillitteri’s Fundamentals of Nursing, a sign is "an observable condition of
malfunction or illness (an objective finding); whereas, a symptom is "an awareness of
disease or malfunction experienced by the patient (a subjective finding)." 23

A diabetic student could develop low blood sugars due to taking too much
insulin, not eating enough food, or exercising without eating extra food. Diabetics
may or may not feel that their blood sugar is dropping. This condition is called
hypoglycemia unawareness. Testing the blood sugar regularly with a capillary blood
glucose monitoring device is the best way to determine the blood sugar.

Hypoglycemia can occur at blood sugars less than 60 mg/dl. Even if there is doubt as
to whether the student’s blood sugar is low, it is best to treat if symptoms and/or signs
are evident. Failure to treat a low blood sugar could be detrimental, whereas giving
sugar to a diabetic that doesn’t need it will result in a temporary minor rise in blood

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22 American Diabetes Association Issues New Guidelines to Address Alarming Rise of
Type 2 Diabetes in Children and Adolescents
sugar. Endocrinologist Joseph Fallon recommends giving 15 to 30 grams of carbohydrate to increase the blood sugar.\textsuperscript{24}

According to the Internet web site, "childrenwithdiabetes.com," beginning signs of hypoglycemic (low blood sugar) insulin-reactions include shakiness, sweatiness, pallor, and increased heart rate. The student may also complain of headache and dizziness. Advanced signs include staggering walk, pale appearance, uncontrollable crying episodes, slurred speech, blank stare, and refusal to take anything by mouth. If the insulin reaction is not treated, the diabetic could become unconscious, unresponsive, and experience convulsions.\textsuperscript{25}

The behavior of a diabetic student experiencing hypoglycemia may change. These changes include acting quiet and withdrawn, being stubborn or relentless, tantrums of sudden rage, confusion, inappropriate emotional responses, and poor concentration or day dreaming.\textsuperscript{26}

Recognizing signs and symptoms of high blood sugars is also important. A diabetic may experience hyperglycemia (high blood sugar) due to forgetting to take insulin, not taking enough insulin to cover food intake, experiencing stress, rebounding from a previous low blood sugar.

According to the Internet web site "childrenwithdiabetes.com," signs and symptoms of hyperglycemia include loss of appetite, increased thirst, frequent urination, tiredness, sleepiness, rapid breathing, and fruity odor to the breath. If the

\textsuperscript{24} Fallon, Joseph J. M.D., Interview, 6/21/00.
blood sugar is higher than 240 mg/dl, the student’s urine should be checked for ketones.\textsuperscript{27}

School officials should encourage diabetic students to communicate how they feel when experiencing low and high blood sugars.

In \textit{Teaching Exceptional Children}, Malek-Rosenthal and Greenspan discussed interviews with diabetic students. The students were asked about their perspective on blood sugar “lows” and “highs.”

Pertaining to low blood sugars, one 12-year-old student stated, “Sometimes I feel horrible! I feel like I am going to fall over. I feel shaky all over. I sometimes feel nauseous. Other times, I don’t even know that I am low.”\textsuperscript{28}

Pertaining to high-blood sugars, a 13-year-old said “It feels very weird. Sometimes I don’t even know that I am high. When I do think that I am high, I feel like I’m going to throw up, and I feel like I need to drink every 5 seconds or go to the bathroom.”\textsuperscript{29}

\textbf{Complications}

According to the Diabetes Control and Complications Trial (DCCT), a 10-year nationwide study completed in 1993, people with Type I diabetes were able to

\textsuperscript{26} Ibid
\textsuperscript{27} Ibid
\textsuperscript{29} Ibid
reduce their risk of developing serious long-term complications by 50 percent or more by keeping their blood sugar as close to normal as possible.\(^{30}\)

Long-term complications associated with diabetes include retinopathy, nephropathy, neuropathy, heart disease, and foot problems.

Retinopathy is damage to the retina, the thin light-sensitive inner lining in the back of your eye. Retinopathy occurs when small blood vessels and nerves in the retina are harmed by high levels of glucose. About 90 percent of people who have had diabetes more than 25 years will experience some blood vessel changes in their eyes. Fortunately, if retinopathy is detected early, blindness is rare.\(^{31}\)

Nephropathy is a serious kidney disease. As blood flows through the kidneys, nephrons filter out waste products and other substances, passing them out in the urine. Over a period of time, high blood sugars can damage the nephrons. Once damaged, the kidneys typically deteriorate over time. This deterioration could lead to total renal failure. In these cases, the person undergoes kidney dialysis or kidney transplant.\(^{32}\)

Chronic high blood sugars can also damage the nerves. This condition called neuropathy can be very painful and affect different parts of the body. Sensory neuropathy, damage to the sensory nerves, typically affects the legs, arms, or hands.


Autonomic neuropathy affects the body's involuntary nerves. These nerves control the actions of the stomach, intestine, esophagus, bladder, and circulatory system. Studies have shown that high levels of sugar in the blood can damage blood vessels. "The link between heart disease and diabetes is convincing. Studies show that among people who have had a recent heart attack, one third to one half have had abnormal blood sugar levels, at least temporarily." Joseph Fallon, M.D. stated, "Cardiovascular risk is two-fold for diabetic men and four-fold for diabetic women."

Poorly controlled diabetes can also lead to foot problems. Foot problems can occur because of less sensation in the feet (neuropathy), narrowing of blood vessels, and increased risk of infection. Foot infections can lead to gangrene and amputation.

People with diabetes check their blood sugars with a glucometer. During this process, the diabetic lances a finger for a drop of blood. The blood is dropped on a test strip that is outside the meter. The meter will display a digital reading of the blood sugar after a varying period of time, depending on which meter is used.

Keeping blood sugars under control is the best defense against diabetes-related complications.

It is very important for students with diabetes to be able to use their glucometer freely.

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Diabetes Management in Schools

According to the Internet web site "childrenwithdiabetes.com," a diabetes management plan needs to include:

- A plan for communicating with parents and the student’s medical providers
- School policies and procedures for administering medications, and handling equipment such as meters and insulin pumps
- Specific actions for school personnel to perform in the management program
- An action plan for each student who has diabetes

The New Jersey Department of Education published Guidelines For The Care of Students With Diabetes In The School Setting in January 2000. This guideline was developed by The Task Force on Diabetes in the Schools. The guideline stipulates,

"Children with diabetes attending public schools should have an Individual Health-Care Plan (IHP). The school nurse should be involved with the initial and ongoing discussions developing the IHP, since the nurse will serve as the case manager who establishes the school treatment, emergency plans, coordinates the nursing care and educates the school staff in monitoring and treatment of symptoms. S/he has the responsibility for consulting and coordinating with the student’s parents and health care provider to establish a safe therapeutic environment."

The Taskforce on Diabetes in the Schools recommends that the individual health-care plan include the following information:

- The definition of hypoglycemia for that particular student and the recommended treatment

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• The definition of hyperglycemia for that particular student and the recommended treatment
• Frequency of blood glucose testing
• Written orders from the student’s physician outlining the dosage and indications for insulin administration and/or glucagon if needed.
• Times of meals and snacks and indications for additional snacks for exercise.
• Full participation in exercise and sports, any contraindications to exercise, or accommodations that must be made for that particular student.
• Accommodations for school trips, after school activities, and class parties, etc.
• Maintaining communications with the student, the parents, the child’s health care team, the school nurse and the educational staff.39

Communication

It is imperative to the well being of a student with diabetes that open communication be encouraged. The teachers, classmates, nurses, and parents should be aware of the verbal, as well as non-verbal communication facets of diabetes.

Stephanie Schwartz, author of *Diabetes Management at School* on the Internet web site “childrenwithdiabetes.com,” identified the following feelings associated with having diabetes.

Denial and Disbelief

- “This isn’t really happening to me.”
- “I don’t have to change, diabetes isn’t forever.”
- “It’s not that serious.”
- “I don’t have to feel anything about my diabetes.”

Fear

- “What will this mean for my life.”
- “What’s going to happen?”

Anger

- “Why me?” or “Why my child?”
- “Why do I have to do all this stuff?”

39 Ibid
• “It isn’t fair.”

Guilt
• “What did I do to deserve this?”
• “If I just hadn’t eaten so much sugar…”
• “The diabetes must have come from my side of the family.” (parent)
• “I did this to my child.”

Depression
• “I feel so sad.”
• “I just don’t feel like doing anything.”
• “I feel so alone, no one understands.”

Acceptance
• “I don’t always like watching how much food I eat, but I understand how important it is to me.”
• “I have diabetes so I guess I’m going to have to make some changes.”

Schwartz identified the following psycho-social aspects related to teenagers with diabetes.

• Massive denial is frequently manifested as omitted insulin injections, forgotten snacks, breakfast not being eaten, food binges (especially in girls), and behaviors that suggest rejection of ‘being different.’
• Diabetes is difficult to incorporate into the adolescent’s self-identity.
• Social nonacceptance of self-monitoring of blood glucose (SMBG) or being reliant on needles (like a drug addict) bring additional pressures to deny diabetes.
• Confusion of feelings during this period of physical change prevents open communication with parents and other adults.
• Anger, inappropriate sexual behavior, escapism, suicidal gestures. And depression are part of an attempt to gain self-control.
• Substance abuse let the adolescent demonstrate self-determination even though it compromises physical and emotional health.
• Growth spurts disrupt control and accentuate differences and moodiness, making it difficult to know what’s causing what.
• High blood sugars can delay puberty.

• In girls high blood sugars may alter menses, and cause chronic vaginal infections.
• Isolation from group activities (e.g. sports) can lead to peer separation and lack of social involvement.
• Sexual identity can be confused and misunderstood.
• Family confusions and frustrations with normal and abnormal adolescent rebellion may lead to loss of family support and disruption of communication patterns. 41

The school nurses and teachers must be aware of how to handle these potential psycho-social aspects of diabetes. Schwartz recommended the following preventive measures:

• Encourage family therapy to avoid and limit denial and to work through problems of appropriate control and limit setting.
• Inform parents that they have rights and powers over teenagers.
• Instruct teenagers that they should earn privileges based on responsibility for their own behavior.
• Encourage parents to enforce the rules.
• Encourage participation in leadership training to teach assertiveness skills so that teen learns how to say “no” and to develop pride and self-control.
• Develop alternate behaviors to “acting out” that rely on negotiating skills and other social skills to use in the face of peer and societal demands.
• Encourage verbalization of feelings to avoid psychosomatic patterns and somatic symptoms such as hysteria and hypochondria.
• Encourage teens to bring peers to clinic and to extend themselves to others as a means of developing a positive social identity.
• Respond directly to sexual needs by providing accurate information.
• Fully explore the meaning of insulin use, independence, food habits to help resolve emotional problems.
• Address issues of substance abuse in a nonjudgmental manner. 42

In Teaching Exceptional Children, Malek- Rosenthal and Greenspan suggested that teachers ask questions that will encourage students to talk about their

feelings. This is best done by either asking direct questions or using reflective listening.

"For instance, if the student is late for class or late getting to school, take the student aside and ask, 'Did you have a bad night?' If the student wants to talk, you have given the opening. Then give the student your full attention and use your most effective listening techniques."  

Legal Rights of Students With Diabetes

The ADA’s position paper states:

Federal laws that protect children with diabetes include the Rehabilitation Act of 1973, Section 504, the Individuals with Disabilities Education Act of 1991, and the Americans with Disabilities Act of 1992. Under these laws, diabetes has been determined to be a disability, and it is illegal for schools and/or day care centers to discriminate against children with diabetes. In addition, any school that receives federal funding or any facility open to the public must reasonably accommodate the special needs of children with diabetes. Indeed, federal law requires an individualized assessment of any child with diabetes. The required accommodations should be provided within the child’s usual school setting with as little disruption to the school’s and the child’s routine as possible and allowing the child full participation in all school activities. Despite these protections, children in the school and day care setting still face discrimination.

Some school districts have had lawsuits brought against them for unfair treatment of students with diabetes.

Loudoun County Public Schools (District) entered an Agreement to resolve Office for Civil Rights (OCR) Complaint Nos. 11-99-1003, 11-99-1064 and 11-99-

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42 Ibid.  
44 Schwartz, Stephanie. Position Statement. Care of Children With Diabetes in the School and Day Care Setting
In this agreement, the Loudoun District was required to perform the following duties:

- Designate at least three full-time ADCPs (authorized diabetes care providers) on staff in each school attended by one or more students with a Health Care Plan to provide these students with adequate diabetes care.

- Designate additional ADCPs as needed to provide students with Health Care Plans with adequate diabetes care.

- Provide an ADCP at each school attended by one or more students with a Health Care Plan during all regular school hours that a student with a Health Care Plan is on the premises.

- Provide an ADCP for each school-sponsored field trip in which a student with a Health Care Plan participates.

- Provide an ADCP for each school-sponsored extracurricular activity or program -- and for each educational extracurricular activity or program that receives significant assistance from the District -- in which a student with a Health Care Plan is a direct participant, but not when that student is an observer or an audience member.

- Complete BDDCP (bus driver diabetes care provider) training for all District full- and part-time bus drivers, or provide an ADCP on board a District bus at any time that a student with a Health Care Plan is being transported on that bus and the bus driver has not completed BDDCP training.

- Provide or arrange for the provision of DCAP (diabetes care assistant provider) training for all District staff (except ADCPs) who have responsibility for the immediate custodial
supervision or care of students with Health Care Plans.

- Maintain a location in each school attended by one or more students with a Health Care Plan to provide privacy during the care and testing of those students.  

Resources of Information

Diabetes-related information can be easily obtained from the Internet, library, or associations such as the American Diabetes Association and the Juvenile Diabetes Foundation. However, many teachers and classmates don’t take the time to learn about the disease. This, in conjunction with the diabetic student’s reluctance to share information, can cause communication barriers.

Associations

The American Diabetes Association (ADA)
1701 North Beauregard St.
Alexandria, VA 22311
1-800-DIABETES
http://www.diabetes.org

The Juvenile Diabetes Foundation
120 Wall Street
NY, NY 10005
800-JDF-CURE
212-785-9500
http://www.jdf.org

The American Dietetic Association
Headquarters: 216 W. Jackson Blvd.
Chicago, IL 60606-6995
(800) 366-1655
http://www.eatright.org

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The National Institute of Diabetes and Digestive and Kidney Diseases
9000 Rockville Pike
Bethesda, MD 20892
(301) 654-3327
http://www.nih.gov

American Association of Diabetes Educators
100 West Monroe Street, Fourth Floor
Chicago, IL 60603-1901
(800) 832-6874
http://www.aadenet.org

Internet Sites
Children With Diabetes
http://www.childrenwithdiabetes.com

Insulin Pump Information
MiniMed Inc.
12744 San Fernando Rd.
Sylmar, CA 91342
(800) 933-3322
http://www.minimed.com

Disetronic Medical Systems
5151 Program Avenue
St. Paul, MN 55112-1014
(800) 280-7801
http://www.disetronic-usa.com

Animas Corp.
590 Lancaster Ave.
Frazer, PA 19355
(877) 937-7867
http://www.animascorp.com

Books
Caring for Children with Diabetes
by Belinda Childs, R.N.
Published by American Diabetes Association, 1990
ISBN 0-945448-14-7

How to Write an I.E.P. (individual education plan)
by John Arena
Published by Academic Therapy Publications, 1989

*The Joslin Guide to Diabetes*
by Richard S. Beaser, M.D. and Joan V.C. Hill, R.D.,C.D.E.
Published by Simon & Schuster, 1995

*Teens Pumping It Up: Insulin Pump Therapy Guide for Adolescents*
By Elizabeth Boland, MSN, APRN, PNP, CDE
Published by MiniMed 1-800-933-3322

*When a Child Has Diabetes*
By Denis Daneman, Marcia Frank, and Kusiel Perlman
A Firefly Book, 1999
ISBN 1-55209-331-X

*Insulin-Dependent Diabetes in Children, Adolescents and Adults-*
How to become an expert on your own diabetes
By Ragnar Hanas
Published by Piara Publishing, 1998
ISBN 9163062615

**Magazines/Journals**

*Diabetes Self Management*
Published bimonthly by Rapaport Publishing Inc.
150 West 22nd Street
New York, N.Y. 10011
For subscriptions call (800) 234-0923
http://www.diabetes-self-mgmt.com

*Diabetes Interview-* The News Magazine for the Diabetes Community
Published monthly by Kings Publishing, Inc.
3715 Balboa Street
San Francisco, CA 94121
For subscription information call (800) 488-8468
CHAPTER III

PROCEDURES

The author began her research by communicating with Bernadette King, National Director of Communication at the American Diabetes Association. The author informed Ms. King of her thesis topic and questioned whether such a guideline was available.

Ms. King queried her colleagues via email and reported the findings to the author. The author learned that although some information was available to schools, there didn’t appear to be an available set of guidelines.

The author performed searches of the ERIC database using keywords such as “students and diabetes” and simply “diabetes”. The author viewed the articles using the ERIC microfiche located at Rowan University library.

The author also performed searches of the WebSPIRS databases using keywords such as “diabetes and communication” and “diabetes and students”. This search provided articles from Education Abstracts and Sociological Abstracts.

The author also performed searches using VALE NJ database. This search revealed abstracts from PsycInfo and CINAHL- Allied Health.

The author obtained information from http://www.childrenwithdiabetes.com, an Internet web site.

The author also conducted the following informal, qualitative research techniques to obtain information for the handbook.
The author conducted telephone interviews of seven nurses selected from the Burlington County, Camden County, and Gloucester County high schools. The author asked the nurses questions about diabetes management in their schools. The author also asked questions regarding the availability of a diabetes plan/policy, number of school-nurses, and number of diabetic students.

The author also questioned 15 students with diabetes. The author selected these students from six of the high schools where the nurses were employed and an email address book on “childrenwithdiabetes.com.” The questionnaire included 10 open-ended questions designed to obtain information about communication efforts with the school, signs and symptoms of high and low blood sugars, and ideas on how to improve communication with teachers and classmates.

After completing the literature search, interviews with school nurses, and surveys of diabetic students, the author developed an outline for the handbook. The outline, listing key content areas, was shared with five of the nurses. The author asked the selected group to review the outline for clarity and completeness and suggest any changes. The author also obtained expert opinion from a physician who specializes in endocrinology.

The author reviewed the evaluation data and wrote the handbook.
Chapter IV

Results

The author obtained the following information from the interviews with seven school nurses.

Question No.1: Does your school have an established policy for diabetes management?

- Three schools had an established policy for diabetes management.
- Four schools did not have an established policy for diabetes management.

Question No. 2- Are school personnel trained in this policy?

- None of the schools trained teachers and other school officials regarding diabetes.
- Four schools provided the teachers with a list of students with diabetes. One of these five also had a first-aid list posted in the class rooms.
- The nurse from one of the seven schools anticipated attending a diabetes seminar in the near future.

Question No. 3- What is the ratio of school nurses to students with diabetes?

- Three schools responded 2 nurses/ 5 students with diabetes
- One school responded 2 nurses/ 6 students with diabetes
- One school responded 2 nurses/ 4 students with diabetes
- One school responded 1 nurse/ 2 students with diabetes
- One school responded 1 nurse/ 0 students with diabetes
- In the seven schools there were a total of 17 students with diabetes.

Question No. 4- Where can the students check their blood sugars?

- None of the schools allowed students to check their blood sugars in the classroom. Their school policies required students to test their blood sugars at the nurse’s office due to universal precautions against contamination with blood.

Question No. 5- Who can administer glucagon in the school?
None of the schools allowed anyone other than the school nurse to give glucagon shots. The glucagon was stored at the nurse's office.
The author obtained the following information by surveying 15 students with diabetes.

**Question No.1- Briefly explain how you informed your school about your diabetes.**

- All of the students notified their teachers and/or school nurses about their diabetes.
- One student sent letters to all the teachers, guidance counselors, and coaches.
- One student’s parents spoke to and distributed a written report to all the teachers during a school meeting. This student also told new friends since they didn’t know anything about diabetes.
- One student’s diabetes nurse visited the school and educated the school-nurse about the student’s diabetes.
- One student phoned the school office and made visits with the teachers. Another mother of a diabetic provided literature. The school nurse then called the students to learn more.

**Question No. 2- Briefly explain how you felt telling others in school about your diabetes.**

- Ten students felt very comfortable discussing diabetes.
- Three students initially felt uncomfortable, but understood the importance of sharing the information.
- One student claimed not to have told anybody else in the school and still doesn’t like talking about diabetes.
- One student didn’t have any specific feeling.
- One student responded that it was no problem because the teacher told others while the student was in the hospital. Prior to the student returning to school, the teachers made a field trip to the student’s home to learn more about diabetes.
- One student responded that it’s difficult to explain diabetes to those that don’t understand it. So the student simply says that she can’t have sugar.
- One student’s parent shared that it is extremely important to make people aware because there are many misunderstandings and much fear surrounding diabetes.

**Question No. 3- Briefly explain how you feel when your blood sugar is low.**

- All of the students feel shaky.
- Nine students feel weak.
- Six students feel sweaty or clammy.
- Feelings mentioned less often include slurred speech, rapid heartbeat, difficulty concentrating, sloppy work, and emotional.
Question No. 4- Briefly explain how you feel when your blood sugar is high.

- Six students experience extreme thirst and/or going to the bathroom a lot.
- Six students feel stomach aches, headaches, and/or joint aches.
- Feelings mentioned less often included being tired, an acid taste in the mouth, moodiness, and irritableness.

Question No.5- Briefly explain how somebody could recognize if your blood sugar was low.

- Eight students identified acting out of character and/or appearing drunk.
- Seven students identified shakiness and/or paleness.

Question No.6- What should somebody do for you when your blood sugar is low?

- Seven students were non-specific and indicated that they should be given sugar.
- Five students indicated that they should be given regular soda or juice.
- Two students indicated that they should be given glucose tablets, which they carry.
- One student indicated that she should be reminded to check her blood sugar because she’s acting low.

Question No. 7- What are the most positive experiences you have had regarding communicating in school about your diabetes?

- Ten students identified the understanding and support of school nurses, teachers, or peers.
- Three students identified others’ interest in wanting to learn more about diabetes.
- Two students indicate that they didn’t have any positive experiences.
- One student identified a seventh grade project that he did on diabetes. After giving the presentation, all the students knew what he was going through. They also asked how he was feeling at times.

Question No. 8- What are the most negative experiences you have had regarding communicating in school about your diabetes?

- Four students identified the lack of diabetes knowledge by the teachers, school nurses, or athletic department.
- Two students identified the over-reaction of teachers and substitutes.
- Two students identified when they fainted and people didn’t know how to help.
- One student identified when people ask weird questions like- Are you going to die?
- One student identified being accused by the security guards for having a pager when it was an insulin pump.
- One student identified people being nosy and asking to see that insulin pump thing when it's none of their business.
- Three students indicated that they didn’t have any negative experiences.

**Question No. 9:** What advice would you give a friend who just got diagnosed with diabetes regarding communicating with classmates and teachers about his/her diabetes.

- Twelve students indicated that the newly diagnosed diabetic should be open, honest, and not be afraid to tell anyone about it.
- One student indicated that the newly diagnosed diabetic should be patient and comprehensive because there will be a lot of questions.
- One student suggested that if a public school is not cooperating, just mention the Americans with Disabilities Act or phrase “specially handicapped.”
- One student suggested that the newly diagnosed diabetic should keep a low key and not make a big deal about it.
- One student also reminds the newly diagnosed diabetic that there isn’t anything he can’t do because of diabetes. Don’t let it stop you from doing what you want.

**Question No. 10:** List some ideas that could enhance communication between students with diabetes and other school members.

- Four students suggested that students with diabetes teach others in the classroom about diabetes, glucometers, and insulin pumps.
- Four students suggested that diabetes should be taught as part of the health-class curriculum.
- One student suggested that all school workers need to learn more about diabetes and how to help out in the classroom or athletic fields.
- One student suggested that blood should be tested openly and explained to others.
- One student suggested that the student should answer peoples questions and know that they are genuinely concerned and curious.
- One student indicated that she would rather not make a big deal of it.
- One student suggested that diabetics and other school members communicate by taping a show regarding diabetes, being interviewed, or freely sharing information.
- Two students did not offer any suggestions.
CHAPTER V

Summary

The author sensed a need to create an awareness of diabetes within the school system. The author, like many other diabetics, went through school having to take insulin, check blood sugars, and eat snacks. Many times classmates and teachers simply stared instead of asking questions and learning about diabetes.

Students with diabetes today are more fortunate than when the author attended school. Diabetes-related information can be easily obtained from the Internet, library, or associations such as the American Diabetes Association and the Juvenile Diabetes Foundation. However, many teachers and classmates don’t take the time to learn about the disease. This, in conjunction with the diabetic student’s reluctance to share information, can cause communication barriers.

The author studied methods of managing high school students with diabetes. The author conducted literature searches, interviewed seven nurses regarding management of students with diabetes in their schools, and surveyed 15 students with diabetes.

Conclusion

The author’s research revealed that school nurses, teachers, and other school personnel needed assistance in understanding and managing high school students with diabetes. A majority of the nurses interviewed did not have an established policy for diabetes management. None of the schools that had a diabetes policy received training regarding management of students with diabetes.
Some of the students surveyed felt that the school nurses, teachers, and coaches lacked knowledge regarding diabetes. The students identified their feelings associated with fluctuations in their blood sugars that others should recognize for treatment purposes. The students also offered suggestions on ways to improve communication regarding diabetes in the school setting.

The New Jersey Department of Education published *Guidelines For The Care Of Student’s With Diabetes In The School Setting* (January 2000) while the author was developing this thesis. These guidelines offer recommendations pertaining to blood glucose testing, hypoglycemia, hyperglycemia, insulin, meals and snacks, exercise and sports, school trips, and bus rides. The guideline also discusses the responsibilities of various stakeholders involved with managing the student with diabetes.

For school nurses, teachers, and other school personnel to implement the requirements of the aforementioned guideline, they must effectively communicate with the student. The schools are required to develop individualized health plans for each student with diabetes. The author compiled information obtained from literature research, interviews with school nurses, and surveys of students with diabetes into a handbook titled: *Understanding Students With Diabetes- A Communication Handbook For High Schools*.

The author feels that the communication handbook can be used by school nurses, teachers, guidance, counselors, and bus drivers to better understand the intricacies associated with having diabetes.
Recommendations

The author recommends that school nurses and teachers attend seminars on diabetes awareness. The school nurse should then hold workshops to educate the guidance counselors, coaches, and bus drivers about diabetes management. These activities can be subsidized by the State Department of Education. The author also suggests that schools implement activities to encourage communication about diabetes. The schools could start a diabetes support group with the aid of a certified diabetes educator. They should also encourage classroom presentations about diabetes. The author also recommends incorporating diabetes into the health-class curriculum. This is particularly important due to the increased numbers of students with type 2 diabetes.

The author recommends that this handbook be used in conjunction with any state guidelines pertaining to managing students with diabetes.

Recommendations For Future Study

The author recommends that communication efforts between students with diabetes and school personnel be reevaluated after the schools have had time to implement the New Jersey Department of Education Guidelines. This future study could include focus groups of school nurses, teachers, and students with diabetes.

The author also recommends conducting research into these other areas regarding diabetes:
• Evaluate media’s coverage of diabetes-related issues. This can be achieved by performing content-analysis of newspapers and news video-clips.

• Evaluate whether billboard announcements outlining preventive measures of Type 2 diabetes can affect the prevalence of Type 2 Diabetes. An organization with an interest in diabetes care can sponsor the billboard. People within a certain geographic area can be surveyed about their attitudes and behaviors resulting from the billboard.
Understanding Students With Diabetes

A Communication Handbook

For High Schools

By

Karen M. Ferguson

Copyright July 2000
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INTRODUCTION

The student with diabetes needs a support network while at school, as well as at home. The teachers, classmates, school nurse, guidance counselors, and bus drivers make up this network. These people must have an understanding of diabetes and how it affects the student.

The author studied methods of managing high school students with diabetes. The author conducted literature searches, interviewed seven nurses regarding management of students with diabetes in their schools, and surveyed 15 students with diabetes. The research revealed a lack of knowledge regarding diabetes, a majority of the schools not having a formal diabetes policy, and students desiring better communication about diabetes within their schools. The author included the research data in this handbook.

The February 1999 *Journal of Nursing Education* reported a study of nursing students, registered nurses, and non-nursing students who were given a Diabetes Knowledge Questionnaire. The questionnaire covered diabetes issues such as etiology of diabetes, classification of diabetes, insulin action, diet, hypoglycemia, and hyperglycemia. The study revealed that all the groups lacked diabetes knowledge. Alarmingly, practicing nurses scored only 60% in recognizing and treating hypoglycemia and only 35% in recognizing and treating hyperglycemia.¹

The New Jersey Department of Education published *Guidelines For The Care Of Student's With Diabetes In The School Setting* in January 2000. These guidelines offer recommendations pertaining to blood glucose testing, hypoglycemia, hyperglycemia, insulin, meals and snacks, exercise and sports, school trips, and bus rides. The guideline
also discusses the responsibilities of various stakeholders involved with managing the student with diabetes. For school nurses, teachers, and other school personnel to implement the requirements of the aforementioned guideline, they must effectively communicate with the student. This guideline requires schools to develop individual health plans for each student with diabetes.

The author feels that the communication handbook can be used by school nurses, teachers, guidance, counselors, and bus drivers to better understand the intricacies associated with having diabetes. This handbook can be used in conjunction with any state guidelines pertaining to managing students with diabetes.

PREVALENCE OF DIABETES

According to World Health Organization statistics, in 1997 there were approximately 14,315,000 diabetes cases. This number is estimated to grow to 21,892,000 in the year 2025. According to 1993 statistics, approximately 120,000 school-aged children in the United States had insulin-dependent diabetes (IDDM / Type 1 diabetes). At that time, the American Diabetes Association anticipated yearly increases in diagnoses of 14 to 16 new cases per 100,000 children under age 14 (American Diabetes Association, 1993).

DIABETES MANAGEMENT IN SCHOOLS

A student with diabetes faces a daily regimen of medication, diet, and exercise. Diabetics keep a daily check on their blood sugars with the aid of a glucometer. Many diabetics determine insulin dosage based on their blood sugars. Research shows that the
best method of preventing diabetes-related complications is maintaining balanced blood sugars. For these reasons, it is very important for students with diabetes to have easy access to their medication, snacks, and blood glucose monitor.

The Internet web site “childrenwithdiabetes.com” surveyed its audience regarding where their child performed blood tests while at school. The poll was conducted from December 27, 1998 to January 3, 1999. Of the 497 total respondents, only 21% reported that their child’s school was supportive and allowed testing in the classroom. A frightening 18% reported that their children were not even allowed to test their blood sugars at school.4

According to seven New Jersey school-nurses interviewed by the author, none of the schools allowed students to check their blood sugars anywhere but in the nurses' office. The nurses claim that this is due to universal blood precautions.

**Diabetes Management Plan**

According to the Internet web site “childrenwithdiabetes.com,” a diabetes management plan needs to include:

- A plan for communicating with parents and the student’s medical providers
- School policies and procedures for administering medications, and handling equipment such as meters and insulin pumps
- Specific actions for school personnel to perform in the management program
- An action plan for each student who has diabetes5

**New Jersey and Individual Health Plans**

The New Jersey Department of Education published *Guidelines For The Care of Students With Diabetes In The School Setting* in January 2000. This guideline was developed by The Task Force on Diabetes in the Schools. The guideline stipulates,
"Children with diabetes attending public schools should have an Individual Health-Care Plan (IHP). The school nurse should be involved with the initial and ongoing discussions developing the IHP, since the nurse will serve as the case manager who establishes the school treatment, emergency plans, coordinates the nursing care and educates the school staff in monitoring and treatment of symptoms. S/he has the responsibility for consulting and coordinating with the student’s parents and health care provider to establish a safe therapeutic environment.6

The Taskforce on Diabetes in the Schools recommends that the individual health-care plan include the following information:

- The definition of hypoglycemia for that particular student and the recommended treatment
- The definition of hyperglycemia for that particular student and the recommended treatment
- Frequency of blood glucose testing
- Written orders from the student’s physician outlining the dosage and indications for insulin administration and/or glucagon if needed.
- Times of meals and snacks and indications for additional snacks for exercise.
- Full participation in exercise and sports, any contraindications to exercise, or accommodations that must be made for that particular student.
- Accommodations for school trips, after school activities, and class parties, etc.
- Maintaining communications with the student, the parents, the child’s healthcare team, the school nurse and the educational staff.7

In order for school-nurses, teachers, and other school personnel to communicate effectively with a student with diabetes, they must understand the signs and symptoms associated with diabetes.
SIGNs AND SYMPTOMS OF DIABETES

Type 1 or immune-mediated diabetes is a disease in which the body destroys insulin-producing beta cells in the pancreas. Insulin is a hormone (chemical messenger) made in the pancreas that allows glucose to enter cells and convert to energy.

Type 1 diabetes used to be referred to as “juvenile diabetes” because it typically affected children.

Type 2 diabetes, previously called adult-onset or non-insulin dependent diabetes, is a disease in which the beta cells still produce insulin but not enough to meet the body’s current needs.

Joseph J. Fallon, M.D. stated, “As of the past few years, there are more reports of students with type 2 diabetes due to weight problems than type 1 diabetes.” On 2/23/00, the American Diabetes Association (ADA) issued new guidelines to address the alarming rise of Type 2 diabetes in children and adolescents. The ADA emphasizes, “Early detection and treatment are key to preventing future complications.”

It is important for school officials to understand the signs, symptoms, and complications of diabetes to support those students already diagnosed with diabetes and those not yet diagnosed. Many people use the terms “sign” and “symptom” interchangeably. However, there are differences between them. According to Kemp’s and Pillitteri’s Fundamentals of Nursing, a sign is “an observable condition of malfunction or illness (an objective finding); whereas, a symptom is “an awareness of disease or malfunction experienced by the patient (a subjective finding).”
Hypoglycemia (Low Blood Sugars)

A diabetic student could develop low blood sugars due to taking too much insulin, not eating enough food, or exercising without eating extra food. Diabetics may or may not feel that their blood sugar is dropping. This condition is called hypoglycemia unawareness. Testing the blood sugar regularly with a capillary blood glucose monitoring device is the best way to determine the blood sugar. Hypoglycemia can occur at blood sugars less than 60 mg/dl. Even if there is doubt as to whether the student’s blood sugar is low, it is best to treat if symptoms and/or signs are evident. Failure to treat a low blood sugar could be detrimental, whereas giving sugar to a diabetic that does not need it will result in a temporary minor rise in blood sugar. Endocrinologist Joseph Fallon suggests that giving 15 to 30 grams of carbohydrate will cause a temporary minor rise in blood sugar.14

The Internet web site, “childrenwithdiabetes.com” identified the following signs and symptoms associated with hypoglycemia:

Beginning Signs of Hypoglycemia

- Shakiness
- Sweatiness
- Pallor
- Increased heart rate
- The student may also complain of headache and dizziness.

Advanced Signs of Hypoglycemia

- Staggering walk
- Pale appearance
- Uncontrollable crying episodes
- Slurred speech
- Blank stare
- Refusal to take anything by mouth
If the insulin reaction is not treated, the diabetic could become unconscious, unresponsive, and experience convulsions. In cases of unconsciousness, a student with diabetes may have to be given a glucagon injection to raise the blood sugar. Glucagon is a hormone that raises the level of glucose (sugar) in the blood. The injectable form that is used to bring diabetics out of insulin shock can be purchased in a drug store. All of the nurses surveyed by the author stated that glucagon can be administered only by the school nurse. This practice can be dangerous if a student with diabetes is found unconscious, and the nurse is not around.

The Internet web site, "childrenwithdiabetes.com" also identified the following behavioral changes associated with hypoglycemia:

**Behavioral Changes and Hypoglycemia**

- Acting quiet and withdrawn
- Being stubborn or relentless
- Tantrums of sudden rage
- Confusion
- Inappropriate emotional responses
- Poor concentration or day dreaming

**Hyperglycemia (High Blood Sugars)**

Recognizing signs and symptoms of high blood sugars is also important. A diabetic may experience hyperglycemia (high blood sugar) due to forgetting to take insulin, not taking enough insulin to cover food intake, experiencing stress, or rebounding from a previous low blood sugar.

The Internet web site “childrenwithdiabetes.com,” identified the following signs and symptoms associated with hyperglycemia:
Signs of Hyperglycemia

- Loss of appetite
- Increased thirst
- Frequent urination
- Tiredness and sleepiness
- Rapid breathing
- Fruity odor to the breath

If the blood sugar is higher than 240 mg/dl, the student's urine should be checked for ketones.\(^1\)

School officials should encourage diabetic students to communicate how they feel when experiencing low and high blood sugars.

In *Teaching Exceptional Children*, Malek-Rosenthal and Greenspan discussed interviews with diabetic students. The students were asked about their perspective on blood sugar "lows" and "highs."

Pertaining to low blood sugars, one 12-year-old student stated, "Sometimes I feel horrible! I feel like I am going to fall over. I feel shaky all over. I sometimes feel nauseous. Other times, I don't even know that I am low."\(^1\)

Pertaining to high-blood sugars, a 13-year-old said "It feels very weird. Sometimes I don't even know that I am high. When I do think that I am high, I feel like I'm going to throw up, and I feel like I need to drink every 5 seconds or go to the bathroom."\(^1\)

COMPLICATIONS OF DIABETES

To properly manage the student with diabetes, school officials must also understand the complications associated with diabetes.
Preventing Complications

According to the Diabetes Control and Complications Trial (DCCT), a 10-year nationwide study completed in 1993, people with Type 1 diabetes were able to reduce their risk of developing serious long-term complications by 50 percent or more by keeping their blood sugar as close to normal as possible.\textsuperscript{20}

People with diabetes check their blood sugars with a glucometer. During this process, the diabetic lances a finger for a drop of blood. The blood is dropped on a test strip that is outside the meter. The meter will display a digital reading of the blood sugar after a varying period of time, depending on which meter is used.

Keeping blood sugars under control is the best defense against diabetes-related complications. It is very important for students with diabetes to be able to use their glucometer freely.

Long-term complications associated with diabetes include retinopathy, nephropathy, neuropathy, heart disease, and foot problems.

Retinopathy (Eye Disease)

Retinopathy is damage to the retina, the thin light-sensitive inner lining in the back of the eye. Retinopathy occurs when small blood vessels and nerves in the retina are harmed by high levels of glucose. About 90 percent of people who have had diabetes more than 25 years will experience some blood vessel changes in their eyes. Fortunately, if retinopathy is detected early, blindness is rare.\textsuperscript{21}
Nephropathy (Kidney Disease)

Nephropathy is a serious kidney disease. As blood flows through the kidneys, nephrons filter out waste products and other substances, passing them out in the urine. Over a period of time, high blood sugars can damage the nephrons. Once damaged, the kidneys typically deteriorate over time. This deterioration could lead to total renal failure. In these cases, the person undergoes kidney dialysis or kidney transplant.22

Neuropathy (Nerve Disease)

Chronic high blood sugars can also damage the nerves. This condition called neuropathy can be very painful and affect different parts of the body. Sensory neuropathy, damage to the sensory nerves, typically affects the legs, arms, or hands. Autonomic neuropathy affects the body’s involuntary nerves. These nerves control the actions of the stomach, intestine, esophagus, bladder, and circulatory system.23

Heart Disease

Studies have shown that high levels of sugar in the blood can damage blood vessels. "The link between heart disease and diabetes is convincing. Studies show that among people who have had a recent heart attack, one third to one half have had abnormal blood sugar levels, at least temporarily."24 Joseph Fallon, M.D. stated, "Cardiovascular risk is two-fold for diabetic men and four-fold for diabetic women."25

Foot Problems

Poorly controlled diabetes can also lead to foot problems. Foot problems can occur because of less sensation in the feet (neuropathy), narrowing of blood vessels, and increased risk of infection.26 Foot infections can lead to gangrene and amputation.
COMMUNICATION AND STUDENTS WITH DIABETES

It is imperative to the well being of a student with diabetes that open communication be encouraged. The teachers, classmates, nurses, and parents should be aware of the verbal, as well as non-verbal, communication facets of diabetes.

Feelings

Stephanie Schwartz, author of *Diabetes Management at School* on the Internet web site “childrenwithdiabetes.com,” identified the following feelings associated with having diabetes.

Denial and Disbelief

- “This isn’t really happening to me.”
- “I don’t have to change; diabetes isn’t forever.”
- “It’s not that serious.”
- “I don’t have to feel anything about my diabetes.”

Fear

- “What will this mean for my life.”
- “What’s going to happen?”

Anger

- “Why me?” or “Why my child?”
- “Why do I have to do all this stuff?”
- “It isn’t fair.”

Guilt

- “What did I do to deserve this?”
- “If I just hadn’t eaten so much sugar…”
- “The diabetes must have come from my side of the family.” (parent)
- “I did this to my child.” (parent)

Depression

- “I feel so sad.”
- “I just don’t feel like doing anything.”
- “I feel so alone, no one understands.”
Acceptance

- "I don’t always like watching how much food I eat, but I understand how important it is to me.”
- “I have diabetes so I guess I’m going to have to make some changes.”

Psycho-Social Aspects

Schwartz identified the following psycho-social aspects related to teenagers with diabetes.

- Massive denial is frequently manifested as omitted insulin injections, forgotten snacks, breakfast not being eaten, food binges (especially in girls), and behaviors that suggest rejection of ‘being different.’
- Diabetes is difficult to incorporate into the adolescent’s self-identity.
- Social non-acceptance of self-monitoring of blood glucose (SMBG) or being reliant on needles (like a drug addict) brings additional pressures to deny diabetes.
- Confusion of feelings during this period of physical change prevents open communication with parents and other adults.
- Anger, inappropriate sexual behavior, escapism, suicidal gestures, and depression are part of an attempt to gain self-control.
- Substance abuse lets the adolescent demonstrate self-determination even though it compromises physical and emotional health.
- Growth spurts disrupt control and accentuate differences and moodiness, making it difficult to know what’s causing what.
- High blood sugars can delay puberty.
- In girls high blood sugars may alter menses, and cause chronic vaginal infections.
- Isolation from group activities (e.g. sports) can lead to peer separation and lack of social involvement.
- Sexual identity can be confused and misunderstood.
- Family confusions and frustrations with normal and abnormal adolescent rebellion may lead to loss of family support and disruption of communication patterns.
Communication Tips

The school nurses and teachers must be aware of how to handle these potential psycho-social aspects of diabetes. Schwartz recommended the following preventive measures:

- Encourage family therapy to avoid and limit denial and to work through problems of appropriate control and limit setting.
- Inform parents that they have rights and powers over teenagers.
- Instruct teenagers that they should earn privileges based on responsibility for their own behavior.
- Encourage parents to enforce the rules.
- Encourage participation in leadership training to teach assertiveness skills so that teen learns how to say “no” and to develop pride and self-control.
- Develop alternate behaviors to “acting out” that rely on negotiating skills and other social skills to use in the face of peer and societal demands.
- Encourage verbalization of feelings to avoid psychosomatic patterns and somatic symptoms such as hysteria and hypochondria.
- Respond directly to sexual needs by providing accurate information.
- Fully explore the meaning of insulin use, independence, food habits to help resolve emotional problems.
- Address issues of substance abuse in a nonjudgmental manner.29

In Teaching Exceptional Children, Malek-Rosenthal and Greenspan suggested that teachers ask questions that will encourage students to talk about their feelings. This is best done by either asking direct questions or using reflective listening. “For instance, if the student is late for class or late getting to school, take the student aside and ask, ‘Did you have a bad night?’ If the student wants to talk, you have given the opening. Then give the student your full attention and use your most effective listening techniques.”
The Students’ Thoughts and Feelings- Study of 15 Students With Diabetes

Communication is a two-way street. The student with diabetes is also responsible for ensuring effective communication. The author interviewed 15 students with diabetes to identify communication methods pertaining to diabetes within their schools.

Telling Your School You Have Diabetes

The research revealed that 10 students felt very comfortable informing their school about their diabetes. However, four students initially felt uncomfortable, and one student did not like talking about diabetes. Here are some suggestions on how students can notify their school about diabetes:

- Send letters to all the teachers, guidance counselors, and coaches informing them of your diabetes, signs, and symptoms.
- Have your parents speak to the school and give out written information about your diabetes.
- Have a certified diabetes educator teach the school-nurse and teachers about your diabetes.

Feelings Associated With Low Blood Sugars

The students interviewed offered the following information on how they feel when faced with a low blood sugar:

- All of the students feel shaky.
- Nine of the students feel weak
- Six of the students feel sweaty or clammy.
- Other feelings included slurred speech, rapid heartbeat, difficulty concentrating, and sloppy work.
Feelings Associated With High Blood Sugars

The students interviewed offered the following information on how they feel when faced with a high blood sugar.

- Six students experience extreme thirst and/or going to the bathroom a lot.
- Six students feel stomach aches, headaches, and/or joint aches.
- Other feelings included being tired, an acid taste in the mouth, moodiness, and irritableness.

Ways That Others Could Recognize Low Blood Sugar

Since some students experience hypoglycemia unawareness, it is important for others to recognize their signs and symptoms of low blood sugar. The students interviewed offered the following way to recognize when they need assistance:

- Eight students said others would see them acting out of character or appearing drunk.
- Seven students said others would see their shakiness and/or paleness.

Communication Experiences Regarding Diabetes

The students realized that they will experience positive and negative events regarding their diabetes. The students shared the following positive and negative communication experiences within their schools:

Positive-

- Ten students identified the understanding and support of their schools.
- Three students identified others’ interest in wanting to learn more about diabetes.

Negative-

- Four students identified the lack of diabetes knowledge by the teachers, school nurses, or athletic department.
- Two students identified the over-reaction of teachers and substitute teachers.
- One student said people ask weird questions like- Are you going to die?
- One student identified being accused by security guards for having a beeper when it was an insulin pump.
Advice Regarding Diabetes Communication

The author asked the students for advice they would give to a newly diagnosed diabetic. The students offered the following advice:

- Be open, honest, and not afraid to tell anyone about it.
- Be patient and comprehensive because there will be a lot of questions.
- Become familiar with the Americans with Disabilities Act.
- Do not let diabetes control your life. Remember there is not anything you cannot do because of diabetes.

Ways To Enhance Communication Between Students with Diabetes and Others

The author also asked the students for ideas on how communication efforts could be enhanced between students with diabetes and other school members. The students offered the following ideas:

- Students with diabetes could teach others in the classroom about diabetes, glucometers, and insulin pumps.
- Diabetes could be taught as part of the health-class curriculum.
- Students with diabetes should check their blood sugar openly so that others could learn about it.
- Students with diabetes and other school members could communicate by taping a show regarding diabetes, being interviewed, and freely sharing information. This tape can then become part of the education process within the school district.
- Students with diabetes could start a diabetes support group with the assistance of a certified diabetes-educator.

The research clearly demonstrates the need for effective communication between students with diabetes and teachers, school-nurses, guidance counselors, coaches, and bus drivers. This support network should become familiar with the students’ thoughts and feelings regarding diabetes. Open communication should be invited in the classroom setting.
LEGAL RIGHTS OF STUDENTS WITH DIABETES

Students with diabetes should not be singled out. However, they should be granted certain accommodations needed due to eating schedules and medication regimens.

American Diabetes Association Position

The ADA’s position paper states:

Federal laws that protect children with diabetes include the Rehabilitation Act of 1973, Section 504, the Individuals with Disabilities Education Act of 1991, and the Americans with Disabilities Act of 1992. Under these laws, diabetes has been determined to be a disability, and it is illegal for schools and/or day care centers to discriminate against children with diabetes. In addition, any school that receives federal funding or any facility open to the public must reasonably accommodate the special needs of children with diabetes. Indeed, federal law requires an individualized assessment of any child with diabetes. The required accommodations should be provided within the child’s usual school setting with as little disruption to the school’s and the child’s routine as possible and allowing the child full participation in all school activities. Despite these protections, children in the school and day care setting still face discrimination.30

Some school districts have had lawsuits brought against them for unfair treatment of students with diabetes.

Loudoun County Public School Case

Loudoun County Public Schools (District) entered an Agreement to resolve Office for Civil Rights (OCR) Complaint Nos. 11-99-1003, 11-99-1064 and 11-99-1069. In this agreement, the Loudoun District was required to perform the following duties:
• Designate at least three full-time ADCPs (authorized diabetes care providers) on staff in each school attended by one or more students with a Health Care Plan to provide these students with adequate diabetes care.

• Designate additional ADCPs as needed to provide students with Health Care Plans with adequate diabetes care.

• Provide an ADCP at each school attended by one or more students with a Health Care Plan during all regular school hours that a student with a Health Care Plan is on the premises.

• Provide an ADCP for each school-sponsored field trip in which a student with a Health Care Plan participates.

• Provide an ADCP for each school-sponsored extracurricular activity or program -- and for each educational extracurricular activity or program that receives significant assistance from the District -- in which a student with a Health Care Plan is a direct participant, but not when that student is an observer or an audience member.

• Complete BDDCP (bus driver diabetes care provider) training for all District full- and part-time bus drivers, or provide an ADCP on board a District bus at any time that a student with a Health Care Plan is being transported on that bus and the bus driver has not completed BDDCP training.

• Provide or arrange for the provision of DCAP (diabetes care assistant provider) training for all District staff (except ADCPs) who have responsibility for the immediate custodial supervision or care of students with Health Care Plans.

• Maintain a location in each school attended by one or more students with a Health Care Plan to provide privacy during the care and testing of those students.\textsuperscript{31}
Resources of Information

Diabetes-related information can be easily obtained from the Internet, library, or associations such as the American Diabetes Association and the Juvenile Diabetes Foundation. However, many teachers and classmates do not take the time to learn about the disease. This, in conjunction with the diabetic student’s reluctance to share information, can cause communication barriers.

Associations

The American Diabetes Association (ADA)
1701 North Beauregard St.
Alexandria, VA 22311
1-800-DIABETES
http://www.diabetes.org

The Juvenile Diabetes Foundation
120 Wall Street
NY, NY 10005
800-JDF-CURE
212-785-9500
http://www.jdf.org

The American Dietetic Association
Headquarters: 216 W. Jackson Blvd.
Chicago, IL 60606-6995
(800) 366-1655
http://www.eatright.org

The National Institute of Diabetes and Digestive and Kidney Diseases
9000 Rockville Pike
Bethesda, MD 20892
(301) 654-3327
http://www.nih.gov

American Association of Diabetes Educators
100 West Monroe Street, Fourth Floor
Chicago, IL 60603-1901
(800) 832-6874
http://www.aadenet.org
Internet Sites
Children With Diabetes
http://www.childrenwithdiabetes.com

Insulin Pump Information
MiniMed Inc.
12744 San Fernando Rd.
Sylmar, CA 91342
(800) 933-3322
http://www.minimed.com

Disetronic Medical Systems
5151 Program Avenue
St. Paul, MN 55112-1014
(800) 280-7801
http://www.disetronic-usa.com

Animas Corp.
590 Lancaster Ave.
Frazer, PA 19355
(877) 937-7867
http://www.animascorp.com

Books
Caring for Children with Diabetes
by Belinda Childs, R.N.
Published by American Diabetes Association, 1990
ISBN 0-945448-14-7

How to Write an I.E.P. (individual education plan)
by John Arena
Published by Academic Therapy Publications, 1989

The Joslin Guide to Diabetes
by Richard S. Beaser, M.D. and Joan V.C. Hill, R.D.,C.D.E.
Published by Simon & Schuster, 1995

Teens Pumping It Up: Insulin Pump Therapy Guide for Adolescents
By Elizabeth Boland, MSN, APRN, PNP, CDE
Published by MiniMed 1-800-933-3322
When a Child Has Diabetes
By Denis Daneman, Marcia Frank, and Kusiel Perlman
A Firefly Book, 1999
ISBN 1-55209-331-X

Insulin-Dependent Diabetes in Children, Adolescents and Adults-
How to become an expert on your own diabetes
By Ragnar Hanas
Published by Piara Publishing, 1998
ISBN 9163062615

Magazines/Journals

Diabetes Self Management
Published bimonthly by Rapaport Publishing Inc.
150 West 22nd Street
New York, N.Y. 10011
For subscriptions call (800) 234-0923
http://www.diabetes-self-mgmt.com

Diabetes Interview- The News Magazine for the Diabetes Community
Published monthly by Kings Publishing, Inc.
3715 Balboa Street
San Francisco, CA 94121
For subscription information call (800) 488-8468
Glossary

**Blood Glucose Meter**: A machine that helps test how much glucose (sugar) is in the blood. A specially coated strip containing a fresh sample of blood is inserted in a machine, which then calculates the correct level of glucose in the blood sample and shows the result in a digital display.\(^3\)

**Diabetes, Type 1**: Previously called juvenile diabetes or insulin-dependent diabetes, this is a disease in which the body destroys insulin-producing beta cells in the pancreas.\(^3\)

**Diabetes, Type 2**: Previously called adult-onset or non-insulin dependent diabetes, this is a disease in which the beta cells still produce insulin but not enough to meet the body’s current needs.\(^4\)

**Glucagon**: A hormone that raises the level of glucose (sugar) in the blood. The alpha cells of the pancreas make glucagon when the body needs to put more sugar into the blood. An injectable form of glucagon, which can be bought in a drug store, is sometimes used to treat insulin shock. The glucagon is injected and quickly raises blood glucose levels.\(^5\)

**Hyperglycemia**: High blood sugar that occurs when the blood sugar level is too high, due to too little insulin or too much food.\(^6\)

**Hypoglycemia**: Low blood sugar that occurs when the blood sugar level is too low, due to too much insulin, too little food, or too much exercise.\(^7\)

**Insulin**: A hormone (chemical messenger) made in the pancreas that allows glucose to enter cells and convert to energy.\(^8\)

**Insulin Shock**: A severe condition that occurs when the level of blood glucose (sugar) drops quickly. The signs are shaking, sweating, dizziness, double vision, convulsions, and collapse. Insulin shock may occur when an insulin reaction is not treated quickly enough.\(^9\)

**Ketones (Ketone Bodies)**: Chemicals that the body makes when there is not enough insulin in the blood and it must break down fat for its energy.\(^10\)


7 Ibid.


11 Fallon, Joseph J. M.D. Interview on 6/21/00.


14 Fallon, Joseph J. M.D., Interview on 6/21/00.


16 Ibid.

17 Ibid.


19 Ibid
29 Ibid.
32 Ibid.
39 Ibid.