PATIENT ADVOCACY ACROSS THE AGES: Navigating Diabetes Management Challenges at School, on the Job and in Other Aspects of Life

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• Notice of Requirements For Successful Completion
  – Please refer to learning goals and objectives
  – Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours

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  – Presenter: Linda Siminerio, RN, PhD, CDE – Research grant: Becton Dickinson
  – Presenter: Gina Gavlek, RN, BSN, - No COI/Financial Relationship to disclose
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4 General Advocacy Goals

MISSION:
To Prevent and Cure Diabetes and Improve the Lives of All People Affected by Diabetes

1. Increase federal and state funding for diabetes prevention, treatment and research
2. Prevent diabetes
3. Improve the availability of accessible, adequate and affordable health care
4. Eliminate discrimination against people with diabetes

Everyone Who Has Diabetes Deserves Fair Treatment throughout their lifespan
  • at work
  • at school
  • in daycare
  • while driving
  • in jail/prison
  • in other parts of daily life

This Doesn’t Always Happen

What is Unfair Treatment Due to Diabetes?

Treatment that prevents a person who has diabetes from a normal experience just because he/she has diabetes

If it doesn’t seem fair, it may be unlawful discrimination.

Legal Protections for People with Diabetes

• Recognize that discrimination is often based on fears and misunderstandings – not always on facts!
• Diabetes is considered a disability under federal law
How Big is the Problem?

- The American Diabetes Association receives an average of 250 calls per month related to diabetes discrimination.
- In 2014, the Association’s Legal Advocacy Department provided individual guidance and help for over 1,000 of these situations.

Purpose of Legal Advocacy

Provide information, training & resources to prevent or stop discrimination:
- For people with diabetes & families
- For lawyers, healthcare providers & advocates
- For schools, employers, & correctional facilities

And to:
- Help people know their rights/self-advocacy
- Build "expert" teams
- Professional Volunteer Network Support and Expertise
- Health Care Professional Legal Advocacy Network
- Advocacy Attorney Network

4 Step Approach

Goal is to resolve problems at the earliest step possible:
- Educate
- Negotiate
- Litigate
- Legislate

Association Position Statements:

Our New Childcare Position Statement was published in October 2014

Getting Involved

- Where do you work?
- Do you work with adults or pediatrics?
- What interests you?
  - Legal or legislative advocacy- or both
  - Diabetes prevention or management
- During patient encounters…
  - Questions to ask
  - Things to listen for
- What is your employer’s position?
Dustin, a 9-yr-old with T1DM, arrives for his 4:30 p.m. appointment accompanied by his father. When asked how school is going? Both say “fine”.

The Story

- T1DM x 5 yrs. (diagnosed at 4)
- Mother quit job when Dustin was diagnosed & was the “on call” parent for school.
- A1C 8.1% (usually 6.8 - 7.1%)
- Insulin pump use x 4 yrs.
  Pt. able to accurately enter BG & carb count into Bolus Wizard
- Review of pump history
  - Missed correction doses between 9am - 4pm (weekdays)

The Problem

Father meets with principal to discuss the blood glucose problems noted during the school day. Mother died in a car accident 9 months ago – no family caregiver always available for Dustin at school.

When asked about the missed correction doses father shares the following:

- It’s not school’s responsibility to take care of Dustin’s medical needs.
- Only a nurse provides diabetes care.
- If nurse is absent, Dustin must go home OR he must come to school to test blood sugar and give insulin.
- If left unattended, 9-1-1 will be called if Dustin needs insulin or glucagon.

He thanks you for the late appt.

Last month, school sent a truancy letter.

What do you do now?

Where do you start?
Federal & State Laws - Protect All Ages

Level the playing field and ensure a safe and fair school and childcare environment for our children

Federal laws
- Americans with Disabilities Act (ADA)
- Section 504 of the Rehabilitation Act of 1973 (Section 504)
- Individuals with Disabilities Education Act (IDEA)

State laws, regulations, and guidelines vary from state to state

ADA and 504 - Civil Rights Laws
- Prohibit discrimination on the basis of DISABILITY.
- Also prohibit retaliation for asserting the right not to be discriminated against.
- NOT limited to disabilities that affect learning/academic progress.

Definition of DISABILITY - ADA & 504
- A physical or mental impairment that substantially limits one or more of major life activities
- A record of such an impairment, or being regarded as having such an impairment.
- This includes children, teens, and college students with diabetes - as well as adults at work, in public accommodations, or in police custody!

What are Major Life Activities? - ADA & 504
- Endocrine function
- Caring for one's self
- Performing manual tasks
- Eating
- Breathing
- Learning
- Working
- Speaking

NEED NOT BE LEARNING!

Limits to Endocrine Function Are Enough
- A diagnosis of diabetes is, by definition, a substantial limitation on endocrine function.
- Students with diabetes:
  - do not need to exhibit any additional substantial limitations in major life activities,
  - specifically, do not need to be limited in learning ability or educational progress.

Mitigating Measures
- ADA/504 covers students with diabetes even if they are successful in the medical management of their disease.
  - Schools cannot exclude students from eligibility because they use insulin or medication to manage their disease.
  - The law recognizes that "mitigating measures" like insulin or medication administration do not "fix" the disability.
ADA
- Covered: Public, private, schools (including charter schools), day care centers, camps and more
- Not covered: Religious institutions (unless they receive federal funds--then Section 504 applies)

Section 504
- Covered: All public schools (including charter schools) and private schools that receive federal financial assistance.

Religious Operated Schools
Must comply with federal law if federal funds are received.
May develop 504 Plans/IEPs for students.
Federal funds typically received are Title 1, IDEA, E-rate, voucher programs, USDA school lunch programs.
Case law supports obligation to provide services under Section 504, if federal funds are received.

Under 504/ADA
Schools Must:
- Identify children with disabilities
- Provide a “free appropriate public education” (FAPE) to each child with a disability
- Educate children with disabilities with other students as much as possible
- Allow parents to participate meaningfully in decisions regarding their child’s diabetes care at school
- Afford equal opportunity to participate in nonacademic and extracurricular services and activities.

Diabetes and IDEA
- Diabetes must adversely interfere with academic performance, unless another disability — other than diabetes — limits learning/academic progress.
- School must provide special education program and related services as specified in Individualized Education Program.
- Children must be educated in the least restrictive environment.
- Students who qualify under IDEA are also covered by ADA/504, but do not need a separate 504 plan.

Diabetes Medical Management Plan
Serves as the foundation for the 504 plan or IEP.
Document signed by student’s personal health care professional that sets out how student’s medical needs will be met at school.
A written document where the parents and school agree on the services & accommodations that the student needs.

Each child with diabetes has individual needs.

A Section 504 Plan must be individually developed.

Section 504 Plan?

1-800-DIABETES (1-800-342-2383)
Safe at School Online Resources
31 Diabetes Care Task Training Modules for school personnel available for FREE at: www.diabetes.org/schooltraining

Care of the Younger Child in the Child Care Setting - Laws

Like schools, ADA and Section 504 prohibit discrimination on the basis of disability in the child care setting.

Under ADA, child care providers must make reasonable modifications to enable a child with diabetes to fully participate, unless the modifications impose an “undue hardship” or cause a “fundamental alteration” to the nature of the program.

Under Section 504, federally funded entities must provide disability-related accommodations.

Under IDEA, pre-kindergarten programs must identify children with disabilities and provide disability-related accommodations.

Many states have laws and regulations impacting the provision of childcare.

Child Care Providers Must:

• Accept children with diabetes.
• Provide training to staff with the help of a diabetes professional and the parent/guardian.
• Provide prescribed care and adhere to care schedule (routine blood glucose testing, insulin administration, meals and snacks eaten on time).
• Recognize and treat hypo- and hyperglycemia including glucagon administration.
• Allow the child to participate in their own care as they are able to do so.

Post-Secondary Rights

• Compliance with Section 504 and ADA
• FAPE not required
• No identification requirement
• Must provide academic adjustments so that it does not discriminate because of student’s diabetes.
• Documentation required – letter from student’s provider.
Mary is a 49 year old female with T2DM

• She works as a customer service representative at a busy call center.
• She was referred to you by her primary care physician for diabetes self-management education (DSME).

Mary is a 49 year old female with T2DM

• She works as a customer service representative at a busy call center.
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Upon review of her medical record you learn:
- Hx: T2DM x 15 years, hyperlipidemia and HTN
- Medications: Humalog insulin before meals; Lantus at bedtime; Lipitor and Metoprolol
- Allergies: NKA
- VS: BP 136/88 – HR 64 – RR 16
  Wt. 192 lbs  Ht: 5’8”  BMI 28.9
- A1C 8.9%

PCP note from appointment last week reveals:
- Maxed out on oral diabetes meds; started on insulin injections 3 months ago
- Upon review of PCP documented blood sugar logs you find:
  - BG drops below 70mg/dL around 11:15 am several times on both the weekend and weekdays.
  - Brief mention of “patient having difficulty with diabetes management at work”; but nothing further documented.

During the appointment, Mary hasn’t mentioned the problems she’s experiencing at work.

What can you say to obtain this information?
- Her job at her job is highly scrutinized.
  - Restroom breaks are timed & monitored
  - Only allowed 5 min. No extra breaks.
  - She is “docked points” for each minute past the allotted break time.
  - Points tied to disciplinary action
  - Can result in lost pay
  - Recently spent 8 min in restroom & written up for “abusing personal time”
  - Told not to check BG at her desk because it interferes with helping customers.
Legal Protections for People with Diabetes

Americans with Disabilities Act (ADA)

- Intended to provide comprehensive protection against discrimination against “qualified individuals with disabilities.”
- Recognizes that source of discrimination is often not due to an individual’s limitations, but fears, myths and stereotypes by others.

ADA Requirements

- Prohibits discriminating against a qualified individual with a disability who is an employee or applicant.
- Discrimination includes taking an adverse action because of disability such as:
  - Failing to hire or firing
  - Reducing pay or working hours
  - Providing fewer fringe benefits
  - Failing to promote
  - Failing to provide reasonable accommodations

Reasonable Accommodations

- If employee falls under the ADA, the employer must make reasonable accommodations.
- Can typically be provided at little or no cost.
- To obtain reasonable accommodation, employee must make a request (does not need to be in writing, though good idea).
- If need for an accommodation is not obvious, employer may ask for “reasonable medical documentation.” Entire medical or mental health history not required.

Employee Request for Accommodations

- Template letter
- Online

Reasonable Accommodations: Documentation

- Patient should submit own written request.
- Health Care Provider should write letter that
  - Describes diabetes to establish coverage
  - Documents needed accommodations.
  - Emphasizes patient can successfully perform job.
  - Avoids danger words.
  - Counters safety concerns with individualized assessment.
- Sample request available at: diabetes.org/jobaccommodations.
American Diabetes Association

ADA Driving Position Statement
• Most people with diabetes do not pose an increased risk of MVA
• Individuals whose diabetes poses a significantly elevated risk...must be identified and evaluated prior to getting behind the wheel.
• At time of licensure, a brief questionnaire can be used to find those drivers....
• It is important that the identification and evaluation processes be appropriate and individualized
• Evaluation...must include an assessment by the treating physician or diabetes specialist

Covers Private and Commercial Driver’s License

Diabetes & Commercial Driving

Your patient drives a semi truck and you think he needs to go on insulin for his health. He says he'll lose his job if he goes on insulin. What do you tell him to do?

American Diabetes Association

ADA Driving Position Statement
Physicians should be asked to evaluate:
• Any severe hypoglycemia in the prior 2 years.
The events surrounding severe hypoglycemia.
Is the driver at risk for severe hypoglycemia?
Can the driver detect early hypoglycemia?
Does the driver perform adequate SMBG?
Does the driver have diabetes related complications that may interfere with safe driving?
Does the driver have a good understanding of diabetes and its management?

American Diabetes Association

Position Statement

Treatment Recommendations
• Measure BG before driving.
• Never begin driving with BG 90-70mg/dl without prophylactic carbohydrates.
• Never drive when BG is <70mg/dl.
• During long drives, treat prophylactically.
• If detect hypoglycemia while driving, immediately:
  - Pull off the road
  - Consume fast acting carbohydrates/dextrose
  - Do not resume driving until BG >90 mg/dl

American Diabetes Association

Commercial Driving

Until 2003, Federal Motor Carrier Safety Administration barred individuals who treated diabetes with insulin from being interstate commercial drivers.
• Today: federal Diabetes Exemption Program available for interstate commercial drivers: www.diabetes.org/cdl
• Exemption takes up to 6 months to receive, during which time individual may not drive a commercial vehicle.
• Many employers and occupational health clinics unaware of this program.

American Diabetes Association

Commercial Drivers
Blanket ban on insulin treated diabetes
Federal Exemption Program Criteria:
• Be operating in interstate commerce
• On insulin for > 1-2 months
• No severe hypoglycemia in prior 12 months
• No more than 2 episodes of severe hypoglycemia in preceding 5 years
• No unstable retinopathy or other disqualifying co
Federal Exemption Program Criteria - Cont’d

- Have undergone diabetes education and demonstrate willingness to manage the condition.
- Maintain driving and BG log.
- Check BG q 2-4 hours.
- Only drive if BG is between 100-400 mg/dl (5.6-22 mM).
- Submit quarterly and annual reports to DOT.
- Report MVA or adverse driving events.

New Proposed Rule!
Published in the Federal Register on May 4, 2015
- Amends the Federal Motor Carrier Safety Regulations to eliminate the ban against insulin
- Gets rid of the cumbersome Diabetes Exemption Program – all certification of insulin-using drivers done by certified medical examiners
- Treating clinician assesses diabetes
- Driver must be free of severe hypoglycemia for 12 months and be properly managing diabetes

Commercial Driving: Common Problems
- Employer fires or refuses to hire individuals who use insulin, due to misunderstanding about Diabetes Exemption Program.
- Requires Dept. of Transportation medical certification, when inapplicable.

Mechanic/ Gov’t Employee / Assembly Line Worker/ Forklift Operator/ Pick-Up Truck Driver / School Bus Driver

Requires certain A1C level.
Questions?
Contact legalAdvocate@diabetes.org

Private Driving Licenses in the USA
- Regulated by State departments of motor vehicle (DMVs).
- State DMVs collaborate in the American Association of Motor Vehicle Administrators (AAMVA).
- Guidance by the National Highway Transportation Safety Administration (NHTSA).

Private Driving Licenses
- Varies State by State (see: diabetes.org/driverslicenses)
  - New & Renewal License Questionnaire
    - Do you have any medical condition that may interfere with safe operation of a motor vehicle?
    - Above plus specific list including diabetes
  - Evaluation after a MVA
  - Referral to DMV after a severe hypoglycemic or – in some states, hyperglycemic – event (MVA)
  - Physician reporting Mandatory or Optional
    - (Varies by state)

Focus in Corrections: Improving Outcomes
The American Diabetes Association and Philadelphia Police Department created policies & procedures to make sure:

- People with diabetes have access to medication, food & medical personnel
- Police officers receive training about diabetes symptoms & care.
Advocacy volunteers—doctors, nurses, lawyers, parents, and others—work with law enforcement personnel to educate their communities.

- The Arthur Green, Jr. Act.
- New legislation establishing statewide diabetes training for law enforcement officers in Florida.
- First such legislation in the country.

These are only some examples of diabetes discrimination.

- When diabetes discrimination happens, what should the person do?
- When a patient says something to his health care provider regarding his ability to safely manage his diabetes at work or school, what can the health care professional do?
- Call 1-800-DIABETES (342-2383)

Help Get the Word Out:
Key Information to Share with Your Patients

- 1-800-DIABETES
- diabetes.org/gethelp
- Materials in Spanish

Online Training Resources


FREE Webcast from 2015 Postgraduate Course Workshop: Advocating on Behalf of the Student with Diabetes

- Workshop designed for pediatric health care providers who treat children who have diabetes.
- Provides information to help educate about students’ legal rights in the school setting.
- Webcast available for continuing education credit to primary care physicians, endocrinologists, nurses, dietitians and certified diabetes educators at http://smartbrief.com/2015PostGradCourseWorkshop.
- Webcast also available without credit at http://smartbrief.com/2015PostGradCourseWorkshop.
HCP Legal Advocacy Network

Hundreds of people call the American Diabetes Association each month because they’ve been treated unfairly due to having diabetes. Members of the Association’s Health Care Professional Network function as advisors and expert witnesses to help fight against diabetes discrimination. It’s a really interesting way to help and can also give you a chance to diversify and expand your skills. Join and you can make a real difference in people’s lives.

Business Cards to Help Recruit Members

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