

Employment Rights of People with Diabetes: Changing Technology and Changing Law

John W. Griffin Jr., J.D.

Abstract

Though the treatment of diabetes has advanced remarkably, the law and many employers have not always kept pace. New insulins, delivery systems, and monitoring systems give people with diabetes exceptional control over their blood sugar and virtually eliminate serious complications such as hypoglycemia and hyperglycemia. Changes in the law, particularly the Americans with Disabilities Act and its 2008 amendments, give people with diabetes greater rights and employment opportunities than ever before. Despite these advances, many employers continue to use blanket bans or ill-considered standards to bar people with diabetes. Efforts to break down these remaining barriers are ongoing through employee litigation and through the American Diabetes Association's collaboration with entities that set occupational standards.

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There has been a dramatic expansion in employment opportunities for people living with diabetes, and many legal and attitudinal barriers to employment for this group have been removed. Both improvements in diabetes management technology and changes in the legal framework have contributed to this progress. Today, people with diabetes hold jobs throughout our nation's economy, including many safety-sensitive positions that were once off limits to them. This article examines how federal laws, coupled with better diabetes management, are helping to overcome ignorance and the stereotypes that cause much discrimination against people with diabetes.

In the years after insulin was discovered in 1922, many employers, often with very limited understanding of diabetes, simply banned workers with diabetes, especially those managing diabetes with insulin. In the 1980s, many of these bans were still in place. Of course, as late as the 1970s, the disease was much more difficult to manage than it is today, and treatment options were much more limited. The many types and mixtures of insulin available today were unknown then and the large-gauge needles that were used then, which were boiled and filled with insulin, are long since obsolete. For those with type 2 diabetes not using insulin, the oral drugs available then (sulfonylureas) are rarely prescribed today. Prior to the development of blood glucose meters and test strips, careful monitoring of daily blood glucose levels was impossible, leading to poorer control and more frequent hypoglycemia and hyperglycemia.

The advances in diabetes care are nothing short of revolutionary. And many of the inflexible rules that kept all people with diabetes out of certain jobs are gone too. Individuals with diabetes now have access to jobs that they were previously banned from holding. This is the result of legislative changes and advocacy that have eliminated most blanket bans, technological changes that allow for glucose monitoring, and increased awareness among employers.

Author Affiliation: Marek, Griffin, and Knaupp, Victoria, Texas

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Corresponding Author: John W. Griffin Jr., J.D., Marek, Griffin, and Knaupp, The McFaddin Building, 203 N. Liberty St., Victoria, TX 77901; email address jwg@adamember.org

A key factor in this change was the passage of the Americans with Disabilities Act in 1990. That monumental civil rights law made it unlawful to discriminate against “qualified” workers with disabilities such as diabetes. Workers with diabetes have a covered disability under the Americans with Disabilities Act. Before the passage of amendments to the act in 2008, employers often questioned whether diabetes was a disability, because court decisions had narrowly construed what qualified as a disability, leaving many with diabetes and other disabilities without protection. However, the 2008 amendments broadened the act’s coverage by, for example, requiring that conditions that substantially impair the functioning of the endocrine system (as diabetes obviously does) be considered disabilities. As a result, they are protected from discriminatory treatment because of diabetes.

In addition, the act requires that blanket bans or other standards that screen out people with disabilities such as diabetes be based on the best available medical evidence and must be “consistent with business necessity.” If an employer determines that a worker is dangerous (a direct threat to self or to others), the burden of proof is on the employer. While blanket bans remain in force by law in very few areas (the military and commercial airline pilots), the trend is unquestionably toward individualized assessment for all.

The act protects only people who are able to do the job with or without an accommodation. An accommodation is a modification of the work environment or of work rules that will allow a worker with a disability to successfully perform the job.

There are two components of being able (“qualified”) to perform a job. One is having the necessary education, background and experience. The other is the actual ability to perform the essential functions of the job.

If the worker is qualified and the employer still refuses to allow them to work because of safety concerns, then the employer must prove this through objective medical evidence using the most current medical data and information.

Discrimination against people with diabetes was common in 1990; legal bans existed on pilots, commercial drivers, Federal Bureau of Investigation agents, scuba divers, air traffic controllers, fire fighters, and police officers who had diabetes or used insulin. Many employers also enforced bans for other jobs that required driving or carrying a firearm or otherwise impacted public safety because of generalized fears about unpredictable swings in blood glucose levels or the possibility of an accident. The passage of the Americans with Disabilities Act required a reevaluation of these standards. A key provision of the act is its requirement that rules that screen out or classify workers with disabilities such as diabetes because of safety concerns be based upon reasonable, objective, and up-to-date medicine. Congress recognized the need for individualized assessment of an employee’s capabilities rather than reliance on inflexible rules. What followed during the 1990s were many legal challenges to blanket bans—using that law as a foundation and improvements in diabetes care as evidence.

Courts in the early 1990s still approved such bans.^{1,2} Courts accepted the notion that *all people* with diabetes were an unacceptable safety risk—and therefore could be banned. One court did, however, note its hope that there would be a point in time when diabetes management would improve so that people could be judged individually instead of being lumped into a group.

Volunteers with the American Diabetes Association vigorously opposed these bans. Led by eminent scientists such as Edward Horton with the Joslin Center, Ralph DeFronzo with the Texas Diabetes Institute, and Chris Saudek with Johns Hopkins Medical School, the association helped litigate cases against employees with blanket bans. The association is unique in that it utilizes health care professional groups as well as a group of lawyers who comprise its Legal Advocacy Subcommittee.

The tide began to turn with the case of Jeff Kapche and his exclusion from a law enforcement position. Mr. Kapche has a law enforcement degree and was hired as a police officer, only to be rejected for one reason: he had type 1 diabetes. Dr. DeFronzo helped the courts to understand that all people with diabetes are not the same and that some are clearly qualified to be police officers. The legal proceedings in Mr. Kapche’s case took 7 years, but the courts ultimately

concluded that he was entitled to a meaningful individualized assessment of his ability to be a police officer. The courts acknowledged that new developments in diabetes care undermined the traditional view that people with diabetes could be automatically excluded.³

As these developments have unfolded, there has been a marked increase in advocacy efforts on behalf of individuals who are successful in diabetes management.⁴

The changes in diabetes care that the Kapche court used to justify its rejection of a blanket ban are immense. Of course, the cornerstone of diabetes management is glucose monitoring. Early in the history of diabetes management, there was no way for individuals to make any measurement of blood glucose levels at all. Then there was the urine dipstick check, which was a poor predictor of blood glucose levels.

Until the advent of portable blood glucose monitors, patients could learn of their blood glucose values only by obtaining expensive laboratory testing. And even then, those results reflected the amount of glucose in the bloodstream at the moment the blood was drawn. It did not disclose the blood glucose values for the other 364 days of the year or the values of the patient after the main meal of the day.

So people with diabetes did not have the tools to carefully manage blood glucose levels—the key to avoiding long-term diabetes tragedies (complications such as blindness, kidney dialysis, amputations, and fatal heart attacks).

They also did not have good insulins for proper glucose regulation. These early insulins were grossly imperfect, originating from dogs at first, then pigs, before the advent of modern insulins. Even when the absorption of insulin became more consistent, many insulins such as neutral protamine Hagedorn, the standard insulin in the 1980s and 1990s, had facets such as peaking, meaning that their hypoglycemic (glucose-lowering) properties were concentrated during part of neutral protamine Hagedorn's mechanism of action. Hence patients were required to eat meals at these specific times or face high blood glucose during non-peak hours.⁵

Then came a real game changer: introduction of Humalog and Novolog insulins. These two insulins have relatively flat absorption and are fast acting, meaning people could inject while eating. They have relatively short duration, mostly less than 3 h. They were available in pens.⁵

Coincidentally, as these insulins were being rolled out, insulin infusion pumps began to appear on the market, allowing patients to forgo shots, syringes, and insulin pens. These pumps can constantly infuse Humalog and Novolog insulin at rates chosen by the patient and can be used to administer insulin to cover meals and to correct high blood glucose values. This option is yet another advancement in diabetes care.⁵

Then there was another improvement: the introduction of basal insulins that can be injected once a day and that have virtually no peak.⁶ This means a patient can have an insulin that simulates the human body's background insulin that is produced constantly by the pancreas. These insulins, Levemir and Lantus, are now utilized by many workers. This means workers can choose to be protected for a full day without serious risk of diabetic ketoacidosis or insulin delivery problems.

Last but not least, workers now have accurate, real-time methods to monitor blood glucose values and to act on them as appropriate. Meters now produce accurate results within 5 s and can store the results, make recommendations, and be linked to diabetes management software. Self-monitoring of blood glucose is critical to achieving good control of diabetes.⁷

Because diabetes care and technology have advanced so far, it is much more difficult for employers to justify bans on people with diabetes. While some bans persist, it is often because many employers utilize contract physicians who may not have experience with or have the most current information on diabetes care. Only experts in diabetes care should begin conducting such reviews.

These dramatically improving methods of managing diabetes and monitoring blood glucose values have prompted the United Kingdom to end its decades-long ban on commercial airline pilots with insulin-treated diabetes in August 2012. Canada has permitted more than 25 pilots with insulin-treated diabetes since the 1980s, and those pilots have had no diabetes-related issues on the job. Given that such pilots have the ability to monitor and control blood glucose successfully, there is no longer any medical or legal justification for banning all of them, regardless of their ability. Protocols for Canada and the United Kingdom have strict requirements that ensure pilots maintain good blood glucose levels at all times. These developments have strengthened employment laws that protect workers with diabetes, because the potential diabetes-related risks are all preventable by knowing blood glucose values and acting on them.

As those who live with and treat diabetes have educated courts and employers about these new diabetes management methods and their impact on safety, attitudes and standards have begun to change. Since the 1990s, doors have been opened through collaborations between the American Diabetes Association and the Professional Association of Diving Instructors, the American College of Occupational and Environmental Medicine, and the National Fire Protection Association. Each of these groups collaborated with the American Diabetes Association to develop more up-to-date protocols for people with diabetes and eliminate blanket bans. Likewise, the association worked with the U.S. Department of Transportation to develop a protocol for allowing those who use insulin to get an exemption from federal rules restricting them from getting medical clearance to drive commercial vehicles, allowing many of these individuals to keep their jobs.

Collaboration, by itself, was not always enough, and litigation has sometimes been necessary. Lawsuits involving the United Parcel Service, the Internal Revenue Service, the Federal Bureau of Investigation, and the State Department have opened new doors, eliminated blanket bans, and secured more medically appropriate protocols. Of those, bans at the Internal Revenue Service and the Federal Bureau of Investigation were ended by jury verdicts, while the State Department actually engaged the president of the American Diabetes Association in order to formulate a case-by-case protocol for foreign service officers and end the prior existing ban. Litigation is ongoing with the Central Intelligence Agency, but leading association medical professionals hope for a collaboration with the agency that will allow special agent candidates with diabetes to be assessed as individuals.

As the law has come to recognize and take into account the developments that have occurred in diabetes care and technology, the rights of workers with diabetes have never been stronger. That said, for every breakthrough, there is another employer that still bases its employment decisions on either outdated medicine or, worse yet, uninformed medical opinions. Illustrative of this are rules banning anyone, whose hemoglobin A1c (a measure of average blood sugar) is higher than a certain value, from employment in certain jobs. Some employers run afoul of the law by adopting bans against workers with hemoglobin A1c greater than 8.0 or 9.0. Though arguably well meaning (since patients will do better over the long term with hemoglobin A1c less than 7.0), these values nonetheless have little to do with short-term complications and virtually nothing to do with the day-to-day ability to perform a job.⁸

In conclusion, while diabetes care and technology have progressed significantly, there is still work to be done in educating employers and those who conduct their medical evaluations who still need improved awareness of diabetes care. Medicine and technology do not stand still and neither does the law. These two considerations have dramatically opened opportunities that did not exist for workers with diabetes in the 1980s, and as medicine advances, this trend will inevitably continue.

Acknowledgments:

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