

Case 6

On his fifth birthday, a month before starting kindergarten, Justin Jones was diagnosed with Type-1 (insulin-dependent, or "juvenile") diabetes (T1D). T1D is a genetically inherited disease in which the pancreas fails to produce insulin, a hormone needed to metabolize sugar. As a result, blood sugar levels become dangerously high; extreme elevations of blood sugar can cause coma and death.

With careful management, diabetics can live near-normal lives, provided they check their blood sugar levels several times each day. If the level is too high, the person with diabetes injects insulin; if the level is too low, the person has a snack to get more sugar into the body. If the level is dangerously low, an injection of glucagon (a naturally-occurring peptide that stimulates the liver to release stored sugar) is given.

Most diabetics test their own blood sugar and, based on the results, decide how much insulin, food, or glucagon (if any) to take. Very young diabetics typically need adult assistance for blood testing and administration of insulin or glucagon. Their parents assist at home, but other arrangements must be made to carry out these activities when the child is at school.

Ideally, a school nurse would oversee blood sugar testing and administer any drugs Justin might need. But Justin's school has no nurse. As a result, Justin's parents taught him to test his blood sugar. Justin, now in second grade, leaves his classroom twice a day and goes to the principal's office where he pokes his finger, places a drop of blood on a chemically-treated paper, and puts the paper into an instrument that reads his blood sugar level. If he needs either insulin or glucagon, he calls his mother who leaves work, gives Justin his medication, and waits with him until he is able to return safely to his classroom.

Ms. Jones typically must leave her job twice each week to care for Justin. Her employer's patience has worn thin over the last three years. Further, Ms. Jones is not paid for the time away from her job; some weeks she loses a full eight hours of pay. At the beginning of this school year, Ms. Jones met with Justin's principal to request that Justin's teacher be trained to oversee testing and treatment. Ms. Jones volunteered to teach Justin's teacher everything she needs to know about the disease, warning signs of complications, blood sugar testing, and medicine administration.

The principal and Justin's teacher seriously considered the request, but chose not to accept this responsibility. They agreed that, however well-intentioned, Ms. Jones is not a health care professional trained to educate others about diabetes or its management. Both worried that important information could be missing or misunderstood, jeopardizing Justin's welfare. (In fact, the principal contacted the California Nurses Association and was informed that insulin is a "high-alert" medication that requires two licensed nurses to check the dosage before the drug is administered.) Furthermore, testing and injections

are medical procedures that neither feels comfortable performing. Indeed, the teacher stated that blood and needles make her squeamish. The principal added that assuming responsibility for these tasks could place the school in a precarious position regarding liability, should Justin have a serious problem while at school.

Ms. Jones replied that neither procedure is especially complicated. She pointed out that Justin can do his own testing, so all she is really asking is that the teacher (or some other adult) give any injections he needs. She noted that Justin's teacher needs to understand his disease and warning signs of crisis in any event, since Justin is in her care 6 hours each day. She added that she is concerned about losing her job, given her repeated absences.

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