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February 24th, 2025

I am writing this letter on behalf of Kenzie Okeefe. Kenzie is currently under my care for the management of type 1 diabetes. Type 1 diabetes is an autoimmune condition where the body attacks and destroys cells in the pancreas. These cells are responsible for the production of insulin, without them, the body is unable to manage glucose or energy, which is vital for survival. This speaks to the complexity of the management of type 1 diabetes and the small margin for error in that management. In patients like Kenzie, with a combination of type 1 diabetes and developmental delay, this small margin for error significantly adds to the burden and complexity of their care.

As previously stated, people with type 1 diabetes are not able to produce any insulin. This means that at a minimum, in order to prevent severe complications related to poor glycemic control, patients are often asked to administer multiple daily injections. These injections typically are a combination of long acting, basal insulin, and short acting, meal time insulin. As stated, these insulins function very differently. Mix ups in the administration of insulin can lead to hospitalizations and even death. Patients must be able to recognize the differences between the different insulin types, even though insulin pen devices often look very similar. Unfortunately, insulin errors are not uncommon in people with diabetes. This minimal requirement can be even more difficult for people like Kenzie with underlying developmental disabilities.

The above minimal requirement may keep patients with type 1 diabetes out of the hospital but it does not prevent future complications unless we are able to keep blood sugars under tight control. This is done by more specific management of meal time insulin. Meal time insulin should be given about 20 to 30 minutes before meals. The concept of time can be difficult in people with development disabilities and they often need constant reminders and help. These pre-meal injections are also calculated based on the meals. For instance, if a person wanted to eat a BLT sandwich at lunch. Ideally, they would plan to inject the insulin 20 to 30 minutes before the meal and they would need to calculate the amount of carbohydrates in that sandwich. For instance, an average BLT on bread has about 42 grams of carbohydrates. In order to calculate the insulin dosage, patients use an insulin to carbohydrate ratio. Let's say our patient's insulin to carbohydrate ratio is 1 unit for every 10 grams of carbohydrates. That would mean that they would take 4 units to cover the 42 gram sandwich. However, before they are about to eat, they check their blood glucose level and their glucose is already elevated. They would then need to add extra insulin to the meal time dose based on something called a correction scale. We'll say their glucose reading is 250 mg/dl, so they add 3 extra units to correct for the higher reading. Now they are up to 7 units of meal time insulin. Now imagine that they are also going to have a small side salad and some juice, or that they are planning on going on a bicycle ride right after lunch. It is not hard to see that these calculations become difficult, very quickly. From the outside

it may seem like simple arithmetic but patients with advanced college degrees miscalculate dosing, all the time. Also take into consideration that these calculations need to be done, throughout the day, every day. In people with type 1 diabetes, there are no simple snacks or simple activities. Everything must be viewed through the lens of total insulin needs throughout the day.

There have been advances in technology that have led to the development of insulin pumps. Kenzie is fortunate that she has been able to use insulin pump therapy to help manage her daily insulin needs. This does make the day to day calculations a bit easier. Insulin to carbohydrate ratios are entered into the device along with correction factors. They have also developed continuous glucose sensors that are integrated with insulin pumps. These sensors “speak” to the insulin pump which allows the pump to adjust insulin dosing throughout the day based solely on a person's blood glucose levels. There are no daily insulin injections and there is no risk of confusing different insulin pens but patients still must be able to understand the carbohydrate content of their meals and snacks. They still must plan ahead and time the insulin dosing, appropriately. Exercise and activity can still lead to drops in blood glucose and there is still a very real risk of hypoglycemia if too much insulin is administered at any given time. While insulin pumps make insulin administration easier, they do very little to impact the mental burden of diabetes.

Lastly, insulin pump infusion sites have to be changed every 3 days. This task is complicated. The pumps have to be filled with the appropriate amount of insulin. The insulin pump must be paired with the continuous glucose sensor, in order for the sensor to give the insulin pump information regarding the person's glucose levels. The infusion sites may fail or the tubing may become blocked or occluded. When this occurs, the insulin pump is not working, which means the patient is not receiving insulin. This is a life threatening condition that can lead to severe hyperglycemia, or something known as diabetic ketoacidosis. This is condition that requires hospitalization and can lead to death, if not treated quickly and appropriately. Kenzie would need to be able to recognize that her blood sugars are increasing, trouble shoot the issue and then correct the issue, all within a short amount of time. Again, when an insulin pump is not working, the person is not receiving any insulin and their blood sugars are becoming dangerously elevated. These insulin pump site fails can occur at any time. When this occurs, the sensor will often alert and while Kenzie can hear a sensor alert, she does not have any grasp of the potential severity of the situation. She needs constant monitoring in order to prevent both severe hypoglycemia and hyperglycemia. Even with the use of a sensor integrated insulin pump, Kenzie does not have the capacity to manage her condition without significant assistance.

This is just a brief overview of day to day life with type 1 diabetes. As you can see, it is no easy task. Even with our technology, people with type 1 diabetes still have to troubleshoot various issues throughout the day, they need to be able to recognize the dietary content of meals, they need to plan ahead, and they need to be able to recognize a possible life threatening emergency. As previously stated, there is no small snack or small change in activity, that doesn't need to be constantly accounted for. This all requires a higher level of thought and processing that people with developmental disabilities, do not possess. Kenzie will always need assistance and constant monitoring throughout the day. If you have any questions, please feel free to reach out to my office.

Thank you,

Sarah Lane, PAC

Patient Name: Kenzie K Okeefe

DOB: 8/6/2001

PAGE: 1/1