

Type 1 Diabetes Mellitus Explained: An Engaging and Informative Guide for Kids

By

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Introduction

Type 1 diabetes mellitus (T1DM) is an autoimmune disorder affecting millions, which the International Journal of Pediatrics recognizes as the most common type of endocrine metabolic disorder for pediatrics worldwide¹. This disease affects the pancreas' ability to produce insulin and regulate blood glucose levels, thus requiring insulin injections to sustain life². Unfortunately, despite its severity and widespread prevalence, no cure or prevention is currently available. The peak age of diagnosis for T1DM is between four and seven years old³. Thus, patients with T1DM and their family members have the task of managing a lifelong disease that can be fatal if left mismanaged, since there is no cure.

Like many other children worldwide, my little brother was diagnosed with T1DM at six years old. It all happened on a typical day when he was having a good time at the lake with my father. Unfortunately, he became ill quickly and needed medical care. The emergency room doctors stated that my brother was in diabetic ketoacidosis (DKA) and, if left untreated, would pass away. Luckily, the doctors could quickly diagnose and restore his blood glucose levels. After this traumatic 24 hours, he and my parents met with an endocrinologist in the hospital to discuss the implications of this diagnosis and what that would mean for the rest of his life. Luckily, diabetes is a manageable disease; however, the treatment and management can be complex, and grave repercussions can occur if not done correctly.

Daily management and proper care of a T1DM can be daunting as it requires constant monitoring, many insulin injections, and lots of doctor's appointments. Yet, this management can be incredibly stressful for newly diagnosed patients, typically young developing children and their families. Therefore, education becomes necessary to encourage proper management and teach children how to happily coexist with a disease they must live with for their lifetime. In addition,

education can help build confidence and awareness, give the child some sense of bodily autonomy, and give the parents peace of mind that their child will be okay when they are not around to help.

Child-based education is something that my brother and our family have become familiar with. For example, after my brother's diagnosis, he felt terrified since he had just suffered a traumatic event and was now tasked with a lifelong disease that required ongoing management. However, few resources or representations of his illness were aimed toward him, which only exacerbated this fear of his new life and furthered my parents' responsibility and worry. The current education available aims toward the parents, leaving them responsible for teaching their child and other adults how to properly manage the disease to keep their child alive. Incorporating child-based education into diagnosis would encourage the child to learn how to take care of their body best and relieve some of the parental stress allowing for a more normal childhood.

Prevalence of Type 1 Diabetes Mellitus

Diabetes prevalence has become a matter of great concern nationwide and worldwide. This increase in concern is partially due to the rise in T1DM incidence, with a 30% increase in prevalence since 2017⁴. Currently, 8.7 million people worldwide⁵ and 1.6 million in the USA alone suffer from T1DM⁶. The most frequently diagnosed age is between 5 and 14 years old, with 27% of all diagnosed cases being between 5 and 9⁶. The United States has the highest number of these new cases, followed closely by India and Brazil⁷. The rise in prevalence has come with a hefty annual price tag of \$16 billion in T1DM-associated healthcare expenditures and lost income⁸. However, this price tag is only rising, with 17.4 million people expected to be diagnosed with T1DM by 2040.

Diagnosis of Diabetes

If a child exhibits excessive thirst, frequent urination, increased appetite, unexplained weight loss, fatigue, irritability, headaches, and blurred vision, consulting a healthcare professional about suspected T1DM is crucial⁹. If these symptoms go unnoticed and the child does have T1DM, they are susceptible to diabetic ketoacidosis, which, if untreated, can be fatal. Despite the severity of diabetic ketoacidosis, it is relatively common, with nearly one-third of T1DM diagnoses presenting with diabetic ketoacidosis. Once a healthcare professional decides T1DM may be possible, they will run tests to confirm and begin the next steps. The most common test is a random blood glucose test, where the patient gives a blood sample, and glucose levels are determined. If this test results in 200 mg/dL, or 11.1 mmol/L, or higher, along with any of the above symptoms, this indicates diabetes⁹. Another standard diagnostic tool is the glycated hemoglobin (HbA1C) test, which can determine their average blood sugar for the past three months. To be diagnosed with diabetes using the HbA1C specifically, one must have two separate HbA1C readings of 6.5% or higher⁹. However, to determine whether this is T1DM or T2DM, an additional blood test looking for antibodies will be performed¹⁰.

Pathophysiology of Type 1 Diabetes Mellitus

T1DM is an autoimmune disorder, thus meaning the immune system begins to attack one's body (i.e., the beta cells of the pancreas) as it believes it is foreign and possibly a dangerous matter. Research suggests that environmental factors, such as viruses or bacteria, trigger the autoimmune destruction of the pancreas¹¹. The environmental trigger weakens the body and activates the patient's immune system to fight it off. One consequence of this is the thymus releasing

autoantibodies, which target the beta cells of the pancreas and start the autoimmune reaction that leads to T1DM¹¹.

Once the activation of autoantibodies occurs, they destroy the beta cells of the pancreas, which controls the synthesis and release of insulin. Insulin is a crucial hormone that regulates blood glucose by keeping it at homeostatic levels throughout the body. Without these beta cells, there is no insulin release resulting in little to no control of one's blood glucose, leading to hyperglycemia episodes. This is where one begins to notice the signs of diabetes; as more beta cell destruction occurs, the blood glucose control is lacking, and the more severe the symptoms and damage to one's body become¹¹.

Hyperglycemia is when glucose builds up in the body and is over the homeostatic levels of an average, healthy individual. In patients with T1DM, this occurs whenever they eat a meal as their body cannot release the insulin to properly uptake the glucose within the foods. This leads to a buildup of glucose in the bloodstream. When there is a buildup of glucose, typically with a blood glucose level over 200 mg/dL in one's body, one will experience frequent urination, increased thirst, blurred vision, and feeling weak or unusually tired. However, when left untreated (i.e., via an insulin injection), in that case, it causes health problems that affect the eyes, kidneys, nerves, and heart, and ketones accumulate in the blood and urine, leading to diabetic ketoacidosis or DKA. DKA can cause fruity-smelling breath, dry mouth, abdominal pain, nausea, vomiting, shortness of breath, confusion, loss of consciousness, and, if left untreated diabetic comas or death¹².

Hypoglycemia is when the blood glucose levels are too low. T1DM patients experience hypoglycemia when they receive too much exogenous insulin or consume insufficient glucose. For example, suppose the blood glucose level is under 70 mg/dl. In that case, it can lead to looking pale, shakiness, sweating, headaches, hunger, nausea, an irregular or fast heartbeat, fatigue,

irritability, anxiety, difficulty concentrating, dizziness, tingling or numbness sensations of the lips, tongue, or cheek. If left untreated via the administration of glucose either through high carbohydrate or sugar-filled foods or specific glucose gels, one can become confused and begin exhibiting unusual behavior such as the inability to complete routine tasks, loss of coordination, slurred speech, blurry vision or tunnel vision and can even become unresponsiveness and have seizures¹³. Hypoglycemic events have been the cause of 10% of diabetic-related deaths¹⁴. This means that regulating blood glucose within homeostatic levels is crucial to the survival of these patients with T1DM, who otherwise are unable to.

Lastly, there is a strong genetic association with T1DM. Research shows that 6-7% of children with a sibling diagnosed with T1DM and 1-9% with a diagnosed parent are at risk of also developing T1DM¹⁵. Many studies have concluded that this genetic correlation is due to two human leukocyte antigen (HLA) class 2 haplotypes involved in antigen presentation¹⁵. These haplotypes associate with gene expression in the thymus, regulation of T-cell activation, and viral responses involved in the manifestation of T1DM¹⁵.

Importance of Education in Type 1 Diabetes Mellitus

Since T1DM is a lifelong disease without a cure, it requires ongoing management and monitoring. Properly managing the condition requires one to be highly educated on the condition and how to remedy events such as DKA and other life-threatening effects of diabetes. Not only must one manage and monitor their blood glucose level and provide proper medical interventions, but they must also upkeep a healthy lifestyle that supports regulating blood glucose by eating healthy and intentionally and routinely exercising. Without this vigilance, the child may have extreme effects on their overall health, which could lead to tragic events such as comas or death.

Thus, educating the caregivers, such as parents, guardians, teachers, coaches, babysitters, friends' parents, and the child, is critical for proper management and, ultimately, the affected ones' life. While ensuring a responsible adult is in charge of this management, it is also crucial to empower and educate the affected child as this is a lifelong disease they will eventually have to manage independently.

Child-focused education can be highly beneficial for the child. Involving them in their care encourages proper management, empowers their confidence and ability to care for themselves, gives them some sense of bodily autonomy, and helps them articulate and understand their needs while preparing them for a future where they are their own primary caregiver. Child-focused education can also be beneficial for the guardians as well as their family unit as a whole. Constantly managing, monitoring, and educating a child through a life-threatening disease is no easy task. Recent studies have shown that parents with children diagnosed have a much higher incidence of mental health issues such as depression, anxiety, and post-traumatic stress disorder¹⁶. Child-based education could relieve some of this parental stress and workload by helping the parents educate their children, encourage self-management, and decimate potential worries about them being able to properly care for and advocate for themselves when they are older.

Providing education that is accessible to young children can help build awareness and decrease the stigma around T1DM. It could make the child feel more confident in their ability to explain to their peers and let them know what others out there are going through and living with the same condition. As a T1DM child, you may have a pump or a continuous glucose monitor and require insulin injections at school. Some children may feel embarrassed or ashamed to do this in front of their classmates as there could be a stigma around diabetes. Despite the widespread effects of T1DM, there is still little to no representation. So, having an education guide or tool that the

T1DM child can share with their friends can create a culture of inclusivity and support. Increasing awareness and support for these children can also lead to additional funding and research to find cures or better treatment options and advocacy for more affordable and accessible treatments.

Current Type 1 Diabetes Mellitus Education

To provide the right level of care for an individual, one must be adequately educated and have access to tools and resources to support them. Unfortunately, current educational resources for T1DM are limited. Most resources aim to educate and support an older population, such as the parents or guardians, rather than the affected children. Also, the primary source of education on T1DM is from the endocrinologist to the parents or guardians and the children in their office or the hospital directly after diagnosis. However, after this initial in-person education, the parents or guardians are responsible for undertaking this management and monitoring and educating the other loved ones in the child's life to ensure their health.

One excellent educational resource is a website called Juvenile Diabetes Research Foundation (JDRF), which gathers resources, research, and tools for T1DM free of cost. They have documents, videos, and guides on properly caring for your newly diabetic child; they also have links to find support groups for other parents and their children with T1DM to help those affected support one another. However, once again, these resources are mainly aimed towards the parents or older diabetics, not newly diagnosed children. A few children's books also aim to educate newly diagnosed T1DM patients, such as "A First Book for Understanding Diabetes" with Pink Panther or "Shia Learns About Insulin." While these resources are a great start, there is room for improvement and a need for a more diverse selection.

Education Guide for Type 1 Diabetes Mellitus Education

My goal is to create an educational guide that helps children ages four to seven who have recently been diagnosed with Type 1 Diabetes Mellitus. This guide will be in the form of storybook so it can be easily read and understood by this age group. The storybook can be read to the child by their parents or even brought to school to be read aloud to the class to help educate their fellow classmates and help the child feel a sense of normalcy among their peers. In this guide it will include a definition of Type 1 Diabetes, what insulin is, who gets type 1 diabetes, diabetic tools, doctors they will need to see, what to do if they are going high or low, what it looks and feels like when they are going high or low. By providing them with this simple yet informative and engaging guide I hope to encourage confidence and a sense of belonging in newly Type 1 diabetes diagnosed children.

Conclusion

T1DM is a lifelong disease requiring immense management that directly impacts the lives of many families worldwide. This management is crucial to the survival of the child. It demands that one be highly knowledgeable on diabetes and how to best support their child mentally and physically during this time. Empowering the child to be confident within their management can improve their overall well-being, raise awareness for the issue, relieve some parental stress, and ultimately support and encourage proper management. To achieve these goals, current educational tools must be updated and have a child-based focus. As such, I created an engaging and informative guide for children explaining T1DM.

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A Tale of Highs and Lows

A diabetic adventure set in the
wild west



An educational story by
Emma Harbour



What is diabetes

Diabetes is an autoimmune disease that stops our body from turning food into energy.

If you are diabetic like me, you use insulin to help your body with this process.

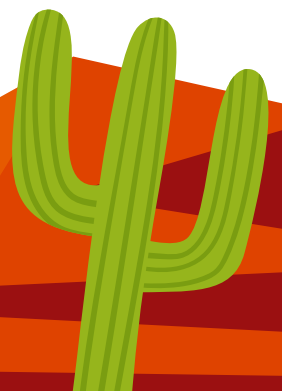


Howdy friends! My name is Lonestar Logan!

Me and 8.7 million people from around the world have diabetes. Diabetes is not contagious and can not be spread from friend to friend. You may already know people with diabetes. There are teachers, athletes, singers, scientists, doctors, and so many others who share this autoimmune disorder.



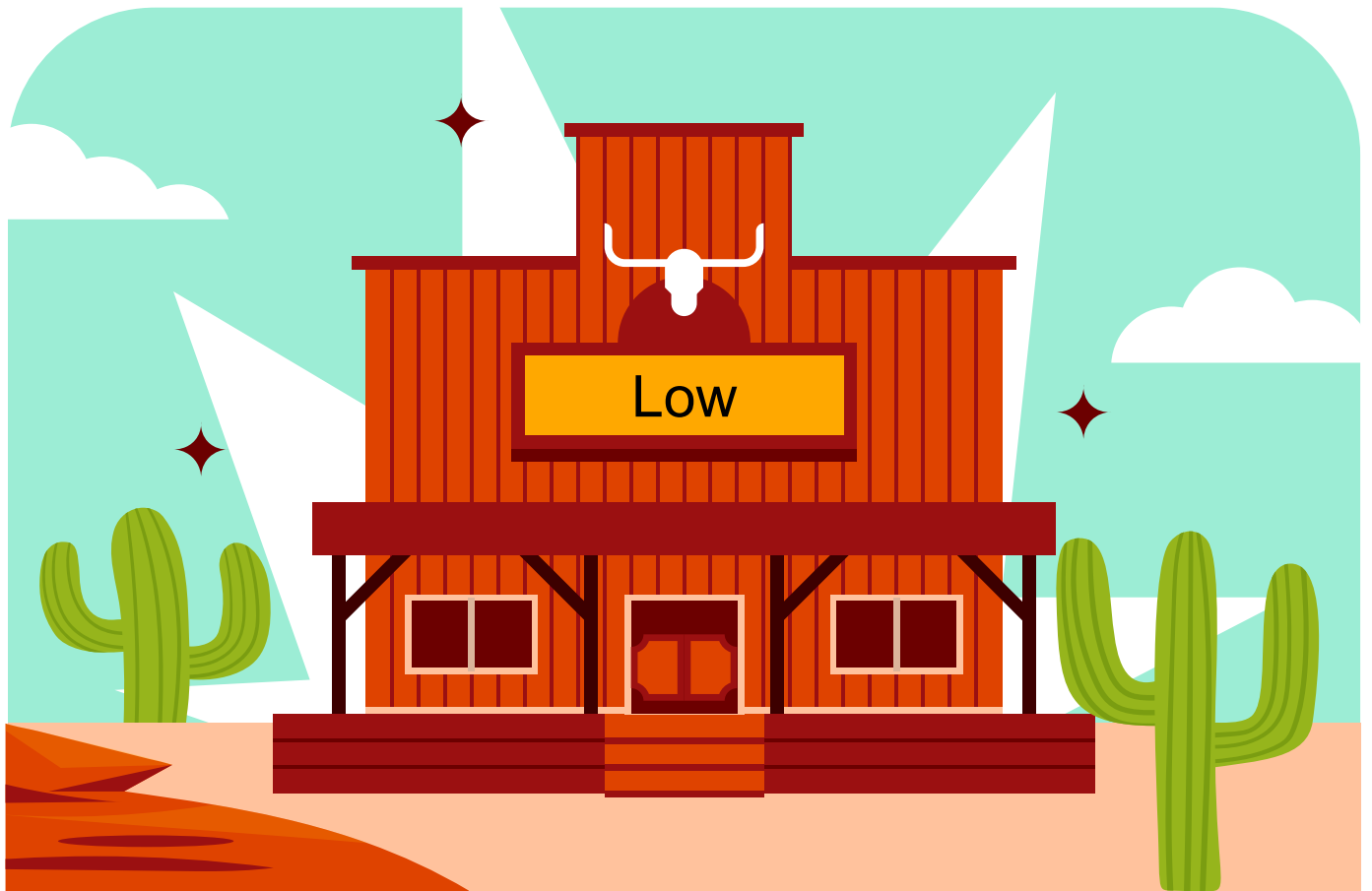
Out here in the wild west there is one thing extra I need to survive, it is called insulin. My friends without diabetes make their own insulin already. Diabetics have little to no insulin being made in our bodies so we add it using a shot or a device like a pump.



There are many different tools and devices to help diabetics monitor their blood sugars and receive the insulin we need.

Doctors and scientists are always hard at work making cool devices to help us.



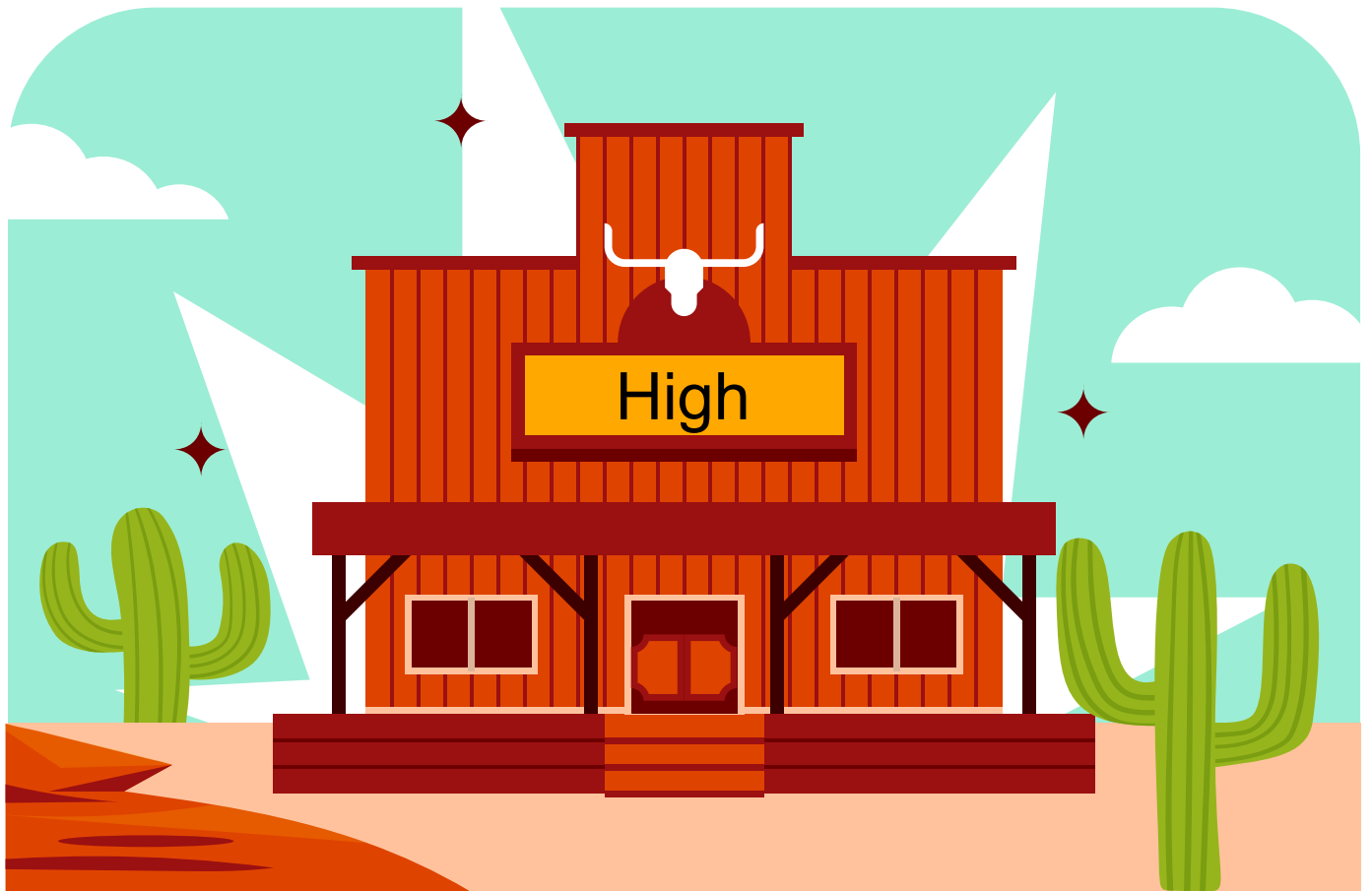


Lows:

If my diabetic friends don't have enough sugar or food in our body they will go "low" which is called hypoglycemic. Hypoglycemic means low blood sugar and when this happens we might start to feel sick, confused, and act a little silly.

When this happens we or a friend need to find an adult and tell them they are going low. We will need to eat or drink something with glucose like fruit snacks, orange juice, or sugar gel to raise our blood sugar.

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Highs:

If my friends have too much sugar in their blood this is called going “high” which is called hyperglycemic. Hyperglycemic means high blood sugar and when this happens we might start to feel very tired, have to go potty more often, get headaches, and want to drink a lot of water. When this happens we need to find an adult and tell them we are going high and need to take an insulin shot or adjust our pump.

The Round up

There are many devices and medications designed to make our days out on the range easier to manage. With a simple routine and the help of medical technology , the wild west is ours to explore!

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Rodeo Routine

Following a routine helps us keep a close eye on our blood sugar levels.

- ★ Routine exercise
- ★ Blood sugar checks
- ★ Doctor visits
- ★ Sleep schedules
- ★ Meal planning

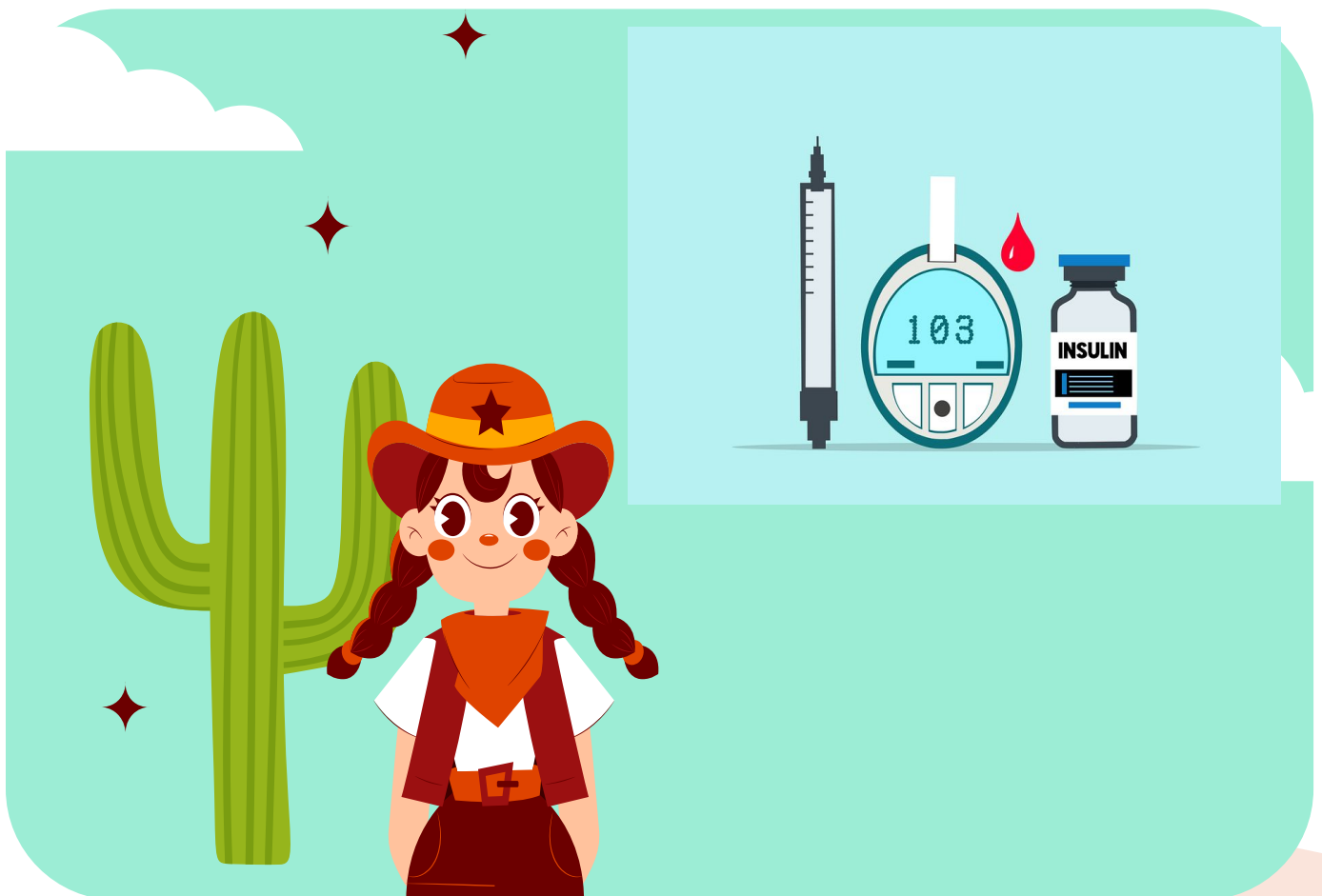
These are all great ways that Lonestar Logan and friends keep their blood sugar levels within range while riding the range!



Tools Of The Trade

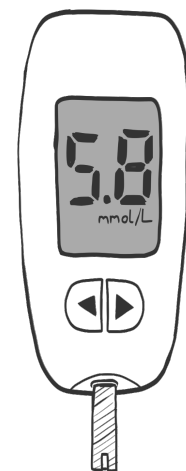
Not all of our diabetic friends use all of these neat devices. Some friends may not have access to all these devices or they have different tools that work better for their bodies. These are some of the devices or tool we may use!

- ★ **Insulin pump** - this device has a little tiny plastic tube that goes in their skin that measures the sugar in their body and gives insulin when they need it or alerts them when they need food and stays on them all the time.
- ★ **Insulin pen**- this is the insulin shot we need to take after we eat or when our blood sugar levels go high.



Tools Of The Trade

- ★ **-Continuous Glucose Monitor-** this device has a little tiny plastic needle that sits in our skin and measures the sugar in our blood and alerts their phone or their parents.
- ★ **-Blood glucose monitor and test strips-** a little tiny needle pricks our finger and you drop the blood on the strip and the monitor measures the sugar in our blood or a CGM that uses technology to read blood sugar levels every 5 mins and reports them to a device.





**“I am a
courageous
cowboy”**