

VOICES OF TYPE 1 DIABETES: taking type 1 diabetes to school

Taking type 1 diabetes to school is the subject of the second instalment for our *Voices of type 1 diabetes* series which features first person accounts of people living with either type 1 or type 2 diabetes and their perspectives on managing the conditions in our world today.

The child who has been diagnosed with type 1 diabetes depends upon school policies and a supportive environment to help manage the rigours of an individualised self-management regimen. In order for every child with diabetes to thrive, collaboration between the student, teachers, parents, school administrators, and health care providers is critical to ensure the condition is managed appropriately and safely.

All children living with type 1 diabetes require the freedom to manage diabetes in a school

setting by monitoring their blood glucose, eating the necessary or appropriate foods, and administering insulin. At a minimum, having access to medically necessary devices and medicines such as needles, insulin pumps and pump supplies, insulin vials or pens, glucose, and various types of monitors in school is essential for health. The right to convey the seriousness of diabetes to others, manage the condition properly, resolve misunderstanding or discrimination firmly, and progress academically is key for success. No child should shoulder the burden of diabetes alone.

In the following features, students from four very different regions – Tanzania, India, USA and Brazil – speak out to discuss the ups and downs of what it's like to take type 1 diabetes to school.

Self-acceptance is key

Anita Bulindi is an 18-year-old living in Dar es Salaam, Tanzania who has one more year of high school before she graduates.

Anita has been an IDF's Life for a Child (LFAC) Programme beneficiary since 2002 and is eager to share her journey about living with type 1 diabetes. Here she talks about life with diabetes at school and how it wasn't until she accepted her condition that things started moving in the right direction.

'In 1999, I was diagnosed with type 1 diabetes at the Hindu Mandal Hospital in Dar es Salaam at age four. I started school when I was three years old, so I was already going to school when I was diagnosed.'

In 2002, I moved from the Hindu Mandal clinic to Muhimbili National Hospital diabetic clinic where I received insulin, a glucometer and all the necessary glucose-monitoring facilities free of charge, through IDF's Life For a Child (LFAC) Programme. I am most grateful for this Programme.

It was very difficult to manage diabetes when I was younger and at school. I didn't want to take care of diabetes. I wanted to eat biscuits like all the other children. So I kept the disease to myself. Only one or two friends knew about my condition and they scolded me when I ate treats. Once I had a hypoglycaemic episode in class and I wasn't aware of what I was doing. It was quite embarrassing. When I was nine years old, I got malaria and it was so bad that I went into diabetic ketoacidosis (DKA). I

used to miss school a lot during that time, but I don't anymore.

I had a hard time with diabetes until I was in seventh grade because that's when I started opening up about my condition. When I began to accept diabetes, I was able to better learn how to control it. Opening up to people made a huge difference, and around the same time, education, awareness and access to better doctors and clinics improved for me.

All my classmates began to understand my disease when I finally told them about my diabetes and afterwards, they became more supportive. Now, friends and classmates can recognize the signs of hypoglycaemia and they help me. My teachers at school are very supportive and everyone understands that I have a serious but manageable condition. My friends always accompany me to the nurse if I need help and have since I was in primary school.

Today, I am in form six at Shaban Roberts Secondary School and next year I will graduate. Currently, I take four injections a day and sometimes more especially when I need to correct a high glucose. I am able to snack as much as I want at school and I eat my lunch at home, so most of my injections are done there and not at school. I test my blood glucose with a blood glucose meter at my desk. I am usually aware of hypoglycaemia or high blood sugar because of the symptoms, like when I am feeling weird, weak, sweaty, cold, shaky, dizzy, have a bad headache or feel nauseated. My last HbA_{1c} result was 8.1%, but my doctor says it should be better. I'm working on it! I have my own meter so I can test before and after

I swim or play football. I test whenever I need to.

'My parents trust my ability to make decisions on my own now but they will never stop worrying about me.'

My parents have always been worried about me and questioned everything about my day at school. When I was in ninth grade they finally allowed me the opportunity to stay overnight with girlfriends or to going out for fun. They trust my ability to make decisions on my own now, but they will never stop worrying about me. For my future, I am looking forward to independence, continuing my education and studying law at university. Law has been in my family for many years led by my grandfather who was a Tanzanian judge.'





It can be hard to resist junk food from peers

Vivaan Thawani is a spirited boy who has been living with type 1 diabetes for nearly eight years. He was diagnosed with type 1 diabetes when he was four years and four months. Frequent urination was the first obvious symptom and subsequent preliminary tests revealed very serious diabetes. After a brief hospitalization, Vivaan's parents recovered from the initial shock and became aware of their son's diabetes management requirements at home as well as at school. Vivaan currently lives in Mumbai, India and will celebrate his twelfth birthday in October 2013. On a rainy day, Vivaan agreed to take some time off his busy school vacation to discuss a typical school day with type 1 diabetes.

'My day begins with the routine blood sugar test done by my mother when I am half asleep. This blood glucose testing is done four times a day prior to every meal. The insulin injections were most dreaded initially but now I am comfortable doing it on my own. After a healthy breakfast at home, I look forward to the school bus ride with my friends although it is very crowded.'

'I love eating candies and French fries, but I try to avoid them.'

At school, the teachers and my friends are well aware of my diabetes and I am fine discussing anything about my medication and dietary pattern. Snacks and lunchtime are difficult as my friends get a lot of treats, which are mostly denied to me because I have type 1 diabetes. Once or twice a week, my friends and I have a bus party on the way back from school which makes my mother worried as everyone gets junk food. I am aware that it's no good but I need to admit that I sometimes indulge! The outcome of such indulgence is that the next blood sugar test will show a high reading. I love eating candies and French fries, but I try to avoid them as living with diabetes doesn't allow me to have my favourite snacks. My aunt has taken notice of this and makes excellent almond or other healthy cookies, which are highly nutritious and tasty.'

My mother used to come to school every day to check my blood sugar level and give me insulin injections but for some time now, I have been managing it on my own. I take note of the blood sugar reading and inform my mother every day. At school, we have a nurse who takes care of medical emergencies and she is aware of my condition and knows that I must take special care of myself. My parents make sure I eat sensibly at home, but snacks and different kinds of food my friends offer me at lunchtime become a great challenge due to peer pressure at school.'

'My dream is to become an aeronautical engineer.'

My favourite sport is cricket. I also play football, tennis and I am excellent at skateboarding. Friends meet me at a recreational club near my house and we have loads of fun cycling, skateboarding, playing cricket and other games. I attend school picnic trips during which time my diabetes is monitored well and I always take my insulin injections on time. During my current vacation, I attended aero-modelling class and flew a plane. My dream is to become an aeronautical engineer.'

No one should ever be refused assistance



Rachel Brown developed type 1 diabetes just before her second birthday. She had to learn to navigate school lessons and socialising from the start and it hasn't always been easy. Today, Rachel is eagerly approaching her final year of high school in Beverly, Massachusetts (USA) where she plays flute for the marching band. Rachel believes her friends and teachers understand diabetes because of the educational opportunities for awareness facilitated by her high school. She hopes that everyone living with diabetes will never have to face some of the trouble she experienced in school. In her own words, she tells her story.

'My Name is Rachel and I have lived with type 1 diabetes for 15 years. I was diagnosed with diabetes when I was just 21-months-old, which means my family and I had to learn to deal with many challenges at school from the very beginning.

My first memory of diabetes at school was when I was five and in kindergarten. It was late in the year and the weather had turned warm. My teacher told the class that because we had been so good that we earned extra playtime. I remember running around with my friends and playing and when we came back into the classroom I didn't feel right, but I couldn't explain my symptoms adequately. I told the teacher my feet felt like jelly with pins and needles, but she didn't understand how this was related to diabetes. She yelled at me, accused me of telling lies and told me to go sit in the corner.

That's all I remember because I became unconscious and my mom told me the rest. My blood sugar dropped so low that I passed out on the floor as if I was taking a nap. Fortunately, the school nurse walked by and rushed in yelling to my teacher to call 911. The kindergarten teacher wouldn't help, but the nurse picked me up and ran me to her office where my extra supplies were kept. She administered glucagon while she waited for my mom and the paramedics. I recovered fully from the hypoglycaemic episode, and was fine thanks to the nurse's quick action.

I remember going back to school the next day and the kids were afraid to be around me. My mother and I were not allowed time to explain to the class that it was diabetes that had caused the problem. After that year, my mom insisted that all school staff receive training from the American Diabetes Association (ADA) or a nurse educator from Joslin Diabetes Center. For the past seven years and even today, a professional visits my school every September to talk about diabetes to the entire school staff so what happened

to me in kindergarten will never happen again to another person who attends my school and lives with diabetes.

'Diabetes is just a part of me, not the whole of me.'

The second most memorable diabetes experience at school was in fourth grade when I remember feeling so excited for the first day of school that my nerves made my blood sugar drop. I went low really fast! My teacher, Mr. Clark, picked me up and ran me straight to the nurse where I drank juice until I was OK. When I got back to the classroom a half hour later Mr. Clark decided to introduce a new topic and asked the class to think about characteristics that make everyone unique. He told us that he was 'good at sports' but that he also lived with a chronic illness called Crohns disease. He explained to us that if he ate something that wasn't on his diet he could get really sick. He then invited each of us to talk about ourselves. When it was my turn, I talked about my love for dance and music, and also informed my classmates that I lived with a condition called diabetes. I explained how my blood sugar had gone so low in the morning that I needed some juice to help elevate it to a safe level so I wouldn't pass out. I also pointed out how no one was at risk of catching diabetes from me. From that moment forward, friends and classmates understood that diabetes is just a part of me, not the whole me.

I hope my experiences and how my family developed a strategy to educate the school will help others as they move forward in their diabetes journey.'

Diabetes doesn't stop me

Eduardo da Silva is relatively new to type 1 diabetes, but he is already a Pro at managing the condition with total preparedness for his seventh grade class. Checking his blood sugar five times a day, especially before he plays football, is meaningful for Eduardo because he dreams of becoming a professional football player right in his home town of São Paulo, Brazil. In this feature, Eduardo takes a break from the field and talks about the discipline evident in his daily life – a necessary sacrifice in order for him to achieve his goals.

'My name is Eduardo, and I am 12 years old. Two and a half years ago, I found out that I have type 1 diabetes. At first it was difficult to accept the changes. I joined the ADJ Diabetes Brasil and as time passed, I realized that other people also have diabetes and live well. I have two brothers, but no one else in my family has diabetes.

'I always carry everything I need for diabetes with me.'

I lead a normal life. As with everyone who has diabetes, my blood sugar sometimes changes, but when the numbers get too high I make corrections. I also give myself insulin injections and test my blood glucose at least five times a day in order to know how my numbers look.

I am in seventh grade and my teachers and friends all know that I have diabetes. When I have a hypo (hypoglycaemic episode or low blood glucose), they help me. At one time there was another boy in my school with diabetes, but he no longer attends.

Every school day, I wake up at 5h30 am, tidy up my stuff, and do my blood glucose test before I eat breakfast. I leave home and wait for the bus to pick me up for the

ride to school that is in Vila Guilherme. I am in school full-time from 7h00 in the morning to 4h10 in the afternoon, which is just over nine hours.

I always carry everything I need for diabetes with me like my insulin, glucose meter, test strips and I always make sure I have snacks. At school, we have a snack in the morning and one in the afternoon. Sometimes I get hungry and eat a muesli bar, which is no problem because I do carbohydrate counting. The school prepares lunch and the food is good. Usually we have rice, beans, salad, and meat. My favourite food is rice, beans, and chicken breast. Yum! If there is a party, my doctor says I can eat a thin slice of cake if I count the carbohydrate amount and take extra insulin.

'Diabetes does not stop me from anything – my dream is to be a footballer.'

I always do my blood glucose tests before meals or snacks, but I also must do them before physical activity. When I am at school playing volleyball and basketball in physical education classes, I must check to make sure my blood glucose is OK. My mother always supports me and notices symptoms of hypoglycaemia (low blood

glucose) and hyperglycaemia (high blood glucose). She always reminds me that I should never hide anything from her.

At home, in my spare time I like watching TV, and playing video games. I also like going to the movies and I love comedies. Another thing I like to do is read books, especially books about sports.

My dream is to be a footballer. I cheer for the team from São Paulo Futebol Clube and my idol is the goalkeeper Rogério Ceni. Pretty soon, I'll start training the Portuguese Football Club.

Diabetes does not stop me from anything.'

