

The Diabesties Foundation: Supporting the sapling to grow

The diagnosis of type 1 diabetes is often abrupt, jarring and comes out of nowhere. It affects every single area of your life, and while you were slowly trying to figure things out, none of your past experiences prepare you for what comes next. It is as if someone has pushed you off a cliff into an unknown and unfamiliar ocean and you must learn how to swim. When a similar event occurs in other aspects of your life, there is typically a lot of literature and practical first-hand experience you can learn from. The same cannot be confidently said for living with type 1 diabetes.

Support at diagnosis

Immediately after a person is diagnosed with type 1 diabetes, they may feel their most vulnerable and will probably be in need of maximum support. At least that's how I felt. When I was diagnosed, it was an immediate declaration of my condition, a stating of fact, an objective conclusion. "She has type 1 diabetes" – that was it. I speak from a place of privilege when I say I was fortunate enough to have a doctor who sat me down for 30 minutes to explain about living with this condition. The conversation focused on all the clinical things I would have to do, all the mechanical protocols that I had to learn, repeated until it was second-nature.

What happens sometimes, however, due to a overburdened healthcare system in India, where I received my diagnosis, is that healthcare professionals get little to no time to explain what life with type 1 diabetes actually looks and feels like. Therefore, the consultations are clinical, concise and often one-sided with very little counselling, and almost never on a regular basis. And so an unclear mind searches for alternatives, falls for fake news and is left in an unpleasant limbo.

Having lived with this condition for 12 years, I know now that what is needed for a good quality of life is not just knowing how to stay alive, but how to live – and thrive – with type 1 diabetes. If only I had

been introduced to peers who were given the same diagnosis, my journey to where I am now would have been a lot different.

Introducing peer support

Consider this: what if, when someone is newly diagnosed, along with all the clinical guidelines and information, he or she is introduced to someone who has been living and thriving with the condition? When I was diagnosed at 13, it would have been extremely valuable to meet someone my age who was also going through this and had similar struggles and successes. Someone who could teach me the lessons they had learned from making mistakes, someone who I could share my tips, tricks and hacks with. Together, we would have significantly improved each other's physical as well as mental wellbeing. Not only would we feel less afraid, and more confident, but we would also get to the "thriving state" much more quickly given that we would share our insights.

Being diagnosed with a chronic condition can also bring with it an overwhelming sense of loneliness. You are often the only one in school to have to inject insulin, or go to the nurse's office regularly, or consider your sugars before enjoying your favourite dessert. You find yourself adding an extra step before uninhibitedly jumping into doing some common things. However, when you meet people who are facing the same things as you are, it brings comfort knowing that you are not the only one going through this journey. Somehow it normalises taking that extra step tied to type 1 diabetes management, and allows you to be more free and secure in your being.

Having a support system when you live with a difficult and persistent condition is crucial. I often like to use the analogy of a tiny sapling to explain the importance. When we are born, we are all tiny seeds that grow into small saplings with the nourishment of our parents' support. We are given the right food, the right shelter and a lot of love and comfort. When we are diagnosed, however, it is like a storm with strong



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Citation: Sethi J (2021) The Diabesties Foundation: Supporting the sapling to grow. *Diabetes Care for Children & Young People* 11: DCCYP078

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winds and a downpour of rain that makes our stems weak and our leaves wither. At this time, you normally would insert a tiny stick to hold the tree straight.

This tiny stick in the world of type 1 diabetes management is peer support. With this, the sapling gets the strength to lay down more roots and grow taller and stronger. With this support, a person with type 1 diabetes gets hope and agency.

Family support

Type 1 diabetes never affects only the person diagnosed. An entire group of family and friends face uncertainty around what comes next. So a newly diagnosed family, along with this kind of support, also needs access to quality type 1 diabetes education. I have always believed that it is not enough just giving insulin: the person needs to know what to do with it. It is in the early days that the right kind of information and education is needed, delivered with compassion, empathy and care. This helps ensure that the person and family affected has a 360-degree understanding of the technicalities, as well as the subjective elements such as the mental support required to deal with what is coming.

The Diabesties Foundation

The Diabesties Foundation started in 2018 in Ahmedabad, India. The foundation works closely national and international bodies such as Research Society for the Study of Diabetes in India, Diabetes India, Diacare Trust, Dream Trust, the NHS

and JDRF. Our mission and vision is to ensure that everyone living with type 1 diabetes is heard, supported, understood and celebrated. We work with the core understanding that type 1 diabetes is not a “disability”, but “this ability” to take charge of your life and create change.

In India, we face unique issues that make living with type 1 diabetes slightly more challenging. From disturbing myths and taboos to false promises of cures, from misdiagnosis to lack of access to insulin, we have witnessed heartbreaking stories of people living with this condition. We do not have a 360-degree type 1 diabetes support system in India, as our health sector is already overburdened.

The Diabesties Foundation provides peer support for people with type 1 diabetes through several ways, and education is a key method. We understand that not all children learn alike. Using the research of Howard Gardner’s Multiple Intelligence Theory (Gardner, 1987), we have designed quality education modules that cater for different learning styles. For example, for the linguistic and verbal learner (who learns by reading), we have a pocket book littered with images and helpful illustrations. For the kinaesthetic learner (who learns by doing), we have designed interactive games and activities. With thought and care, we have created something for everyone. Each material is translated into regional languages in India so that it reaches the unreachable.

While education serves as a strong base, we also go beyond this. Along with educational resources, nothing can be more helpful than time and an ear to listen, by being on the ground in the middle of it all. Our Back To Basics (B2B) project is an effort to bridge the gap between the overburdened health sector and quality diabetes education.

Back to Basics

During the COVID-19 pandemic, since face-to-face consultations were physically impossible, we launched the B2B project. This is an educational project by Diabesties where we recognise the importance of the one-on-one model, and share our undivided time and attention with our peers. It was highly necessary to provide support, grounded in fact, so our B2B team comprises of a panel of diabetes educators, healthcare professionals, mental health experts and people living with type 1 diabetes for over 10 years. Since the



The Diabesties Foundation was established in July 2018 in India.

start of the project, we have scheduled over 400 calls regarding newly diagnosed cases, diabetes distress, carbohydrate counting, and basics of management and techniques.

Our B2B Team is set and trained using a basic person-centered philosophy and approach. Each team member inputs their area of expertise and languages they can converse in. Using these criteria, they are cross-referenced with B2B participants for providing the most appropriate and targeted care and support. We have set up a WhatsApp B2B business account where scheduling takes place. The B2B trainer is informed about the session and given details of the person they will be supporting. Repeat sessions are scheduled with the same trainer, fostering a sense of belonging and comfort.

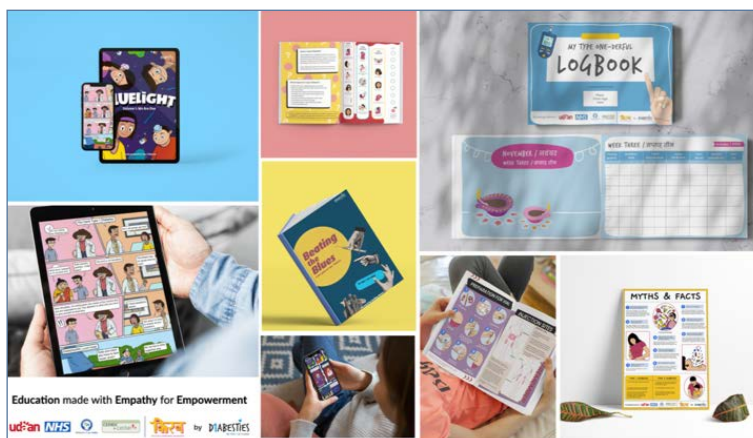
At Diabesties, we value the feedback loop, so anything the participant mentions is considered and acted upon during future sessions. This continuous improvement model has warranted some very gratifying testimonials regarding the support we provide:

“The session was great. I was feeling bad about myself and the anxiety was there for the future; however, I am feeling really confident for the same. Thanks for the same. Keep doing the good work. Also please introduce me to the group.” – Anonymous

“It was an amazing B2B session. Your advice and care helped ease our pain. Please accept our heartfelt appreciation for your support during this time. Thank you so much for caring” – Anonymous

Support can be given in multiple ways. It could be through a one-to-one consultation or it could be organising a “diaMeet”, where so many subconscious myths about this condition are broken just by participating in heartfelt group activities. Support could also be standing up for someone with the condition on social media and defying stereotypes, or it could just be a smile shared with someone in a hospital waiting room, showing that you care.

Moving past targeted support, as a community at large, we need to be mindful about the messages we put out, both verbally and visually. The biggest example of this is failing to mention the “type” of diabetes. When a newly diagnosed person with type 1



The Diabesties Foundation has partnered with other national and international bodies.

diabetes suddenly sees a poster for the “reversal of diabetes” without knowing that it refers to type 2 diabetes specifically, it sends out a misleading and potentially fatal message.

The language we use when talking about diabetes needs to be accurate, and while a slogan may seem catchy to hear, we need to ensure it is factual. Let’s not propagate “clickbait” content for more views while compromising on the science, because the language – whatever the language we use – does matter. All of this circles back to the peer support Diabesties provides as a foundation, and what people with type 1 diabetes subconsciously respond to.

Living life with type 1 diabetes is difficult, but with enough education, attention and care, it can be made easier. Peer support, quality education, factual messages and awareness can act like that plant guard, and give the distressed sapling enough support and sunlight to make it flourish into a strong, beautiful tree.

I have personally never thought the work we do is “giving back” to the community, for we **are** the community. The people with lived experience are the ones who must rally together to support each other, because if not us, then who? And if not now, then when? ■

Gardner H (1987) The theory of multiple intelligences. *Ann Dyslexia* 37: 19–35

The Diabesties Foundation

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