Healing by letting emotions be heard

When a child is diagnosed with Type 1 diabetes, it is important to let the initial adjustment difficulties run their course and to let all emotions be heard, writes Claire Crowe



earning that a child has been diagnosed with Type 1 diabetes can leave parents feeling powerless. Those of us who are parents would willingly take this burden on ourselves if we could. At the very least we want to mitigate any emotional distress our child may experience.

In this regard, a magic wand to vanquish the upset has a certain appeal. And in the absence of such an item, a psychologist specialising in diabetes is fittingly high up on the wish list, however, research does not support specialist psychological intervention in the immediate aftermath of diagnosis.

Dealing with a diagnosis

In fact, early psychological intervention can detract from existing coping strategies and disempower the child and family. Parents are a child's best advocate and best therapist. A diagnosis of a chronic illness was not what was envisaged for any child's future. Adjustment difficulties in the first few months post diagnosis are not just normal, they are

necessary. It is not easy for the young person with the diagnosis or their family.

The first task of parents and those caring for the newly diagnosed is to validate the child's feelings whether that is anger, sadness, injustice, or something else. Validating is a popular buzz word, but knowing what it means in reality can be difficult to ascertain.

The animated film 'Inside Out' has a particularly good scene that can be watched on YouTube (Bing Bong talks to Sadness) to explain this abstract term. In the movie, the character Joy tries to cheer Bing Bong up by rushing to reassure him, then to distract him, to humour him, to cajole him – anything to help stop him from feeling sad. These are ineffectual strategies and actually serve to heighten his distress.

The character Sadness simply listens to what has made Bing Bong sad and repeats back to him what he has said: "you're sad because you lost something that was important to you".

There's no reassurance, no tyranny of positivity, but that's what makes him feel heard. In the same way, with a child with diabetes, it is important that a parent does not rush to reassure and do things like promise that future research will fix the pancreas.

It's not helpful to highlight the seemingly positive: "At least it isn't cancer"; "at least you weren't too young when it happened"; or "at least we found it early". Nor is cajoling helpful: "We needed something to happen to help us eat healthily as a family".

Instead, stay with the emotion: "I hear you saying that this is unfair" and "I hear you saying how angry you are that this happened to you. That must be hard for you feeling all that anger". Not fixing it is exactly what a child needs because in truth it can't be fixed. Allowing a child to experience their emotions — as difficult as that may be — allows them to reach a point of emotional healing more readily.

Sometimes, there may be concern that

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the child isn't actually distressed, seems to be coping fine, and must therefore be holding it all in, with disastrous consequences for the future. However, some young people take on their diagnosis readily. Research shows that those who adjust best at the time of diagnosis actually tend to have an advantage over their peers who struggle. Having said that, it is only human to have moments of crisis along the way.

Psychological safeguard

An important psychological safeguard to put in place is to ensure that family life doesn't become dominated by the diagnosis. It can be a terrifying prospect initially, but allowing the child with diabetes to go to parties, school tours, matches and sleepovers, independent of parents, is essential.

Of course that means that the responsible adults need to be upskilled on how to manage the situation, but more crucially, it means that parents need to allow themselves to trust in others to care for the child. If diabetes becomes a scapegoat for why a child cannot do things, the risk is the child will learn to hate their diabetes and it can be difficult to care for something that you hate.

Another relevant psychological stance is to ensure that we as parents see our

child first, not their diabetes. Tempting as it may be for us to ask "what were your blood glucose readings in school today?", better questions are: "How was your day? Did you get much homework? What did you do in art?"

Diabetes should come lower down on the agenda. Of course, this can be significantly aided if parents keep a phone synced to the child's scanner so that the necessary information is to hand.

The teenage years

The teenage years represent a particularly challenging phase in terms of diabetes management. The psychology of adolescence necessitates that a young person spends increased time with their peer group and that fitting in becomes the dominant goal.

Anything that marks the young person out as different can often be hidden. In this instance, it can be useful to set out the medical team's ground rules so that the teenager's friends know about diabetes and how to respond in a crisis.

Sharing information about the condition can be very helpful in the teen and young adult years. We know that the frontal lobe of the adult brain is not fully formed until the age of 24. This part of the brain addresses behaviours such as the capacity to plan, organise,

self-monitor, and assess risk and impulse control.

These attributes are all vital if a young person is to care for their diabetes by themselves. Meanwhile, parents should bear in mind that a young person will continue to need help, monitoring and support.

Parents and self-care

Parents should also consider their own self-care. Talking to others and contacting support groups can be helpful. While there is no magical solution, from my experience, members of the paediatric diabetes team are pretty magical in the commitment and care they give these young people. Where there is a psychologist on the team, parents can ask for a consultation if and when they need it.

When it is safe to do so following the Covid pandemic, there will be events available through Diabetes Ireland, including camps for young people with Type 1 diabetes and their families. These can offer a fun way to recognise that children are not alone. In the absence of magic, there is still lots to be hopeful for.

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