

Surviving the Parental Guilt Accompanying a Type 1 Diabetes Diagnosis

By Beth McNamara

Reprinted from www.MyDiabetesCentral.com

We all can remember that first time that we received our child's Type 1 Diabetes diagnosis, and how hard the dawning realization hit us.

My son's diagnosis was handed down on New Year's Eve (Happy New Year!). Although I had known deep down that my 13-year-old son had Type 1 Diabetes before we had the official diagnosis, I will never forget the ER doctor leaning over the rails of my son's hospital bed and saying, "I guess you understand what's going on. You are now an insulin dependent diabetic." He might as well have hit me in the head full force with a two-by-four.

The next few days were not much better. I, like so many other parents before and after me, put on a strong face for my newly-diagnosed child, my other children, my husband, the rest of our friends and family, our doctors, and the hospital staff. When I could, though, I'd steal away to the bathroom or car for a good hardy dose of "Why him?" or "Why us?" or "What did I do wrong?" or "I should have never let him eat his Halloween candy for breakfast." At the very least, I'd be in for a good crying jag.

Some of the first reactions we as parents experience upon receiving our child's diagnosis can run the gamut between anger to grief to everything in between. We despair for the loss of our child's "perfect health," (http://www.jdrf.org/index.cfm?page_id=106129); we are angry and can't fathom what we did wrong as parents since we followed nearly every guideline out there; we yearn for days before the fateful diagnosis.

Worse of all, many of us do endless Internet searches to learn more about the disease only to be bombarded with site after site expanding at length on the physical consequences of Type 1. Refrain, at all costs, of falling into this trap. There are good, educational sites about Diabetes and children meant to support you (please see the list below), and then there are those sites that only will scare you.

Remember that your child's Diabetes is not your fault. Our family doctor, Dr. Alan Dappen of doctokr Family Medicine (www.doctokr.com), who helped us through those particularly rough early days of diagnosis, had these reassuring words: "It is not your fault. It was in your son's genetic code and then he happened to be on the short end of the stick when the roulette wheel was spun."

Surprisingly enough, many parents often suspect that their child has diabetes before they seek medical assistance. According to another member of our primary care medical team, Dr. Steve Simmons, this is not unusual. Two weeks ago, Dr. Simmons attended the Stanford Symposium on Emergency Medicine (<http://emedcme.stanford.edu/>), where he heard Dr. Richard Cantor present a pediatric literature update, which included, according to Dr. Simmons, "findings that for the majority of children presenting with Type 1 Diabetes at the ER, the mother or father have already made the diagnosis themselves because of family history, awareness of the condition, or fear of it."

However, suspecting or even making one's own unofficial diagnosis is not the same as reality.

So what's next?

With night-after-night of 3 a.m. blood glucose checks, digesting the overwhelming amount of information needed to manage the condition, the constant watching of your child's diet, 24/7 monitoring for lows and highs, some parents move past their urges to succumb to self-flagellating guilt to total immersion in the day-to-day management of the condition.

However, this might not always be best. As a parent, you will need to step back and evaluate the impact of the diagnosis on not only yourself, but your diabetic child, his or her siblings, your spouse and your family unit as a whole. Life just has changed, significantly, and it is not good to continue on as if nothing is wrong.

Don't hesitate to seek support or counseling; having the emotional strength as a family to confront Type 1 Diabetes can only make the first few months easier. Here are some places to look for resources:

1. Family, friends, neighbors, and your community: This is the first, and probably most important, place to start. Do not hide what has happened to your family and child, reach out to those who are closest to you. Send an email or letter alerting people you care about of your child's diabetes; you will be surprised at the number of family and friends who are also touched by this disease.

2. Counselors or therapists: These professionals are imperative in helping to manage feelings of guilt, anger and grief associated with the new diagnoses. If you are looking for a recommendation, you can start with your family doctor or your diabetes-related health team.

3. Diabetes organizations: These groups offer a wealth of support and assistance: The Juvenile Diabetes Research Fund (JDRF) (www.jdrf.org), complete with a mentoring program that matches mentoring families long dealing with disease with newbies; Children With Diabetes (<http://www.childrenwithdiabetes.com/>), which offers an outstanding yearly conference; and the American Diabetes Association (www.diabetes.org), which includes an online forum specifically for parents to interact and discuss life with diabetes. (<http://community.diabetes.org/n/ptx/forum.aspx?tsn=1&nav=messages&webtag=adaparents&tid=14055>).

4. Diabetes-related health team: These health professionals include your Certified Diabetes Educator (CDE), endocrinologist and family doctor.

5. Leaders or members of your faith-based community.

Does the guilt ever go away? I guess that depends on who you are. I find that sometimes it rears its ugly head, and I need to force myself to understand that these are non-productive feelings and that I am not helping myself, my child or my family. Yet there are days that this is easier said than done.

These feelings, whether you child is newly diagnosed or not, seem to be interwoven into the new fabric of life as a parent with a child with "D."