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In Control

Living with a chronic disease requires a different focus than the immediacy of an acute illness. Rather than dealing with the diagnosis as the start of a closed loop of symptoms and treatment and cure, the diagnosis of a chronic illness is an open-ended event that influences the person's day-to-day life from that point on. The first few weeks are a flurry of recovery, if the diagnosis was spurred by ill-health, and in-depth learning about the disease and the current recommended management protocols.

In our case, my youngest child Michael got quite ill the day after we returned home from the Live & Learn Unschooling Conference in September 2008. At the hospital that night we discovered he had developed type 1 diabetes. He was in the hospital for four days as they brought him out of diabetic ketoacidosis (DKA); or more rightly we were at the hospital, as I stayed with him throughout. During our stay the educators at the hospital's Diabetes Education Centre started giving us the information and accompanying medical paraphernalia we'd need when we went home, as well as an initial schedule of clinic appointments to check on progress, discuss the disease in more depth, and answer our questions as they arose.

After a few weeks things settled down as we began to understand the disease and felt a growing competence with the daily management. At this point a shift in focus became essential: away from the disease and toward my son. Focusing on the medical issues over the long-term can leave the child feeling powerless and at the mercy of the disease as it looms large in how he approaches each day. Instead, it is important to bring the rest of the child's life back into focus: management of the disease is just a small, albeit essential, part of his bigger day-to-day life. The key is to follow the child's lead – the medical issues will flow in and out of focus as they intertwine with all the other fun and interesting aspects of the child's life.

At some point the child will want to start taking some control over his day-to-day medical care (eleven at diagnosis, Mi-chael was fully involved from the start). This can be a huge issue of trust for parents of children living with a chronic dis-ease, so sure that they need to stay in control of their child's medical decisions, citing their child's best interest. But ap-proaching day-to-day life from a position of fear is very stressful, particularly long-term. I know that's the picture that fundraising paints – instilling fear of the disease and its "devastating impact on the victim and their family" in an effort to convince people to spend their charity dollars with their cause – but it's a damaging perspective from which to live day-to-day. My experience with unschooling quickly showed me that this is yet another area where trust is warranted, and I think quite essential, to my son learning how to manage his disease directly.

I wrote about this trust in making choices before my son developed diabetes (Life Learning March/April 2006, "Whose Goal is it, Anyway?"), but I think it applies here just as importantly: "I don't want to be that nagging voice in my child's head as she gets older. I want spend time with her now helping her analyze situations, possible outcomes, likely out-comes. And supporting her decision, helping her figure out how to make choices, not what choices to make."

Michael will best learn effective self-management of his disease by doing: making choices, seeing the results, and incor-porating that experience the next time a similar situation arises. Working together we discuss upcoming situations, antici-pating the possible effects they can have on his blood sugar and considering his options for dealing with them both proactively and reactively, and he chooses the path forward that he thinks will work best. We work well as a team but he has one advantage that I never will: he's living in his body and knows how it feels at the moment.

Imagine the flipside. If I instead told him what to do, that learning would not be as effective: he'd learn what I would do in that situation (parent-management) but may or may not remember the next time the situation arises and I'm not around to remind him. And when conflict would inevitably arise over my decision my enforcement would negatively affect our relationship and erode our trust in each other. Over time that can develop into rebelliousness where the child may make medical decisions specifically in reaction to parental control, not in his own best interest. And without the time and freedom to learn self-management growing up, it could be a lonely crash course when he moves out on his own, which he may do before he feels truly ready just to escape the controlling environment.

Looking back now I am not surprised to see that we have not had to compromise any of our unschooling principles to adjust to life that includes day-to-day diabetes management. In fact, it seems our lifestyle been a distinct advantage in several areas. One of the most important is that we continue working together as a team. We learn and figure things out together, me in support of him. Here are some of our experiences over the past year with an eye to sharing how I supported Michael and ensured that he was involved in and in control of his own care.

The day following his diagnosis an educator from the hospital's Diabetes Education Centre came to his room to introduce herself. The diabetes educators at the hospital were, and continue to be, careful to address Michael or both of us together, not just me with him hanging around. They have been careful not to overwhelm us with information up front but always answer our questions. They see their role as supporting the patient in their decisions, not as an authority figure whose job it is to get you to do what they say. If you find yourself in similar circumstances one of my first suggestions is that if the health care team working with you and your child are not treating him as a full partner in his medical evaluation and treatment, start insisting they do. For example, when a paediatric ward nurse would come into our room and direct their questions to me I'd politely redirect them, or say "What do you think, Michael?" to ensure he was a full participant.

If this is not possible it's worth taking the time to find a health care team that focuses on supporting the patient's health goals, not enforcing their own. I have found the goals of our local hospital's Diabetes Care Program align well with mine: "We believe the Diabetes Care Providers role is: to act as coach and cheerleader; listen, reflect and respect the person's experience with diabetes; support the choices the person with diabetes makes without judgement; build a trusting relationship that empowers the person with diabetes to care for themselves to the best of their ability; provide hope."

Question what you are told. My favourite question is still a politely asked "Why?" If you don't get a satisfactory answer, keep digging. In my experience health care professionals can be tempted to summarize their knowledge and generalized experience with a short-cut answer and can be too busy to explain their reasoning in detail. If your child balks at a directive do some research together regarding the logic behind the recommendations and brainstorm some ideas. And after some research you will be better prepared to ask the doctor, nurse, or educator direct questions that they can answer quickly so you and your child can continue to learn more about the issues and make better informed choices.

If there are lifestyle changes involved, try hard to see it through your child's eyes and support them through the process instead of becoming a gatekeeper. Share information with your child, don't process the information, make a decision, and just pass along "the answer". How will your child learn to live day-to-day with his or her disease if they aren't involved in the decision-making?

There were a couple of food-related issues we worked on together when he first came home from the hospital. The educators warned us that after coming out of DKA he would likely be ravenously hungry for a few weeks as his body adjusted and suggested we might want to stock up on carbohydrate-free snacks so he could eat between meals without requiring an insulin shot.

We encountered this with drinks as well since he now needs to take insulin for any drink with carbohydrates (and fruit juice and milk were regular drinks of his). So we focused on the discovery of what new things he could drink. Not a fan of plain water, we tried all sorts of sugar-free water flavours and diet sodas (he's not a big soda drinker to start with). I just browsed the drink aisle and brought home anything

that looked relatively interesting for him to try out. And realistically we didn't need to dump his favourites altogether, we just shifted them to mealtimes and accounted for them in his insulin dose. And sometimes he really wanted a glass of fruit juice and just gave himself a shot of insulin.

If something seems like a no-brainer to you but not to your child try again to see it through his eyes. Work together so you don't feel like you're in a position where the only options you see involve parental enforcement of rules. Research the issue and share what you find just like you would with any other of your child's interests. Talk with him about his body, how it's affected by the disease, and ask how he feels physically when things are going well, and not so well. Not necessarily in big, sit-down talks, but in passing conversation as things come up.

Michael and I have lots of conversations about his body and diabetes that only last a minute or two; a few sentences. We haven't yet ventured into talking about dire complications or death - though possible, they really have no useful impact on good day-to-day management. He is fully in control of his life and is very conscientious about managing his diabetes. He doesn't want to get that ill again, it's not fun. And I am his trusted adviser: he knows I have useful thoughts to share and have his best interests at heart (versus what I may think his best interests should be). I support him as I always have: if he's busily engaged I bring his testing supplies and needles to him, prep it all and hand it to him ready-to-go. He knows he can wake me up in the middle of the night if he had a bad dream or for food or drink if his blood sugar is getting low. He knows I'll help with any of them. The relationship is the key. The relationship comes first because he is a person first; the disease is just one small part of who he is.

Another advantage to unschooling with a chronic disease is that there is no need to accommodate a school schedule. In the case of diabetes we were free to follow a flexible insulin management process, allowing Michael to eat when he was hungry and take insulin accordingly versus having a more rigid insulin schedule and needing to eat to it. Yet another advantage comes from the extension of life learning into daily care. For years this has given Michael the freedom to eat according to his body's cues and as a result he quickly learned what approaching low blood sugars feel like and he catches them before they get far enough along to produce hypoglycaemic symptoms.

This past summer Michael decided to move to an insulin pump. Up until this point he was comfortable staying with the needles. Even though using progressive technology in support of his diabetes had seemed like a logical step to me since his diagnosis, I hadn't pushed it: he had good blood sugar control with the needles, was content with the process, and life had reached a comfortable sense of routine. And because he wasn't in school he was already using a flexible insulin management protocol so many of the advantages of lifestyle flexibility touted by the pump manufacturers just didn't seem to apply to his situation - he saw no compelling reason to make the move. If I had tried to convince him to use the pump earlier than he was interested I would have likely created resentment, and fed it each time he had the pump in hand "and seeing as he would be wearing it constantly and using it multiple times a day, that would build a lot of resentment!

But after six months or so he decided the needles were getting annoying and decided to learn more about insulin pumps. We went through the company information packages, watched the various DVDs, and browsed their websites. He chose a pump and we attended a series of preparation appointments at the clinic, learning the reasoning behind the changes in routine it would entail. It was a pretty big day when one of the pump company's educators came to our house to go through the final information and hook him up.

Another example of following his lead came soon after. Having had his pump for little more than a month, the manufacturer came out with a new model with no warning or suggestion to us when we started to wait those few weeks. I felt a bit cheated and wanted to "get our money's worth" by getting a free upgrade. Michael, much less jaded and defensive, took a look at the additional features, evaluated the upheaval of the change process and decided to stay with the pump he had. It's his pump and he's the one who uses it - it's his decision.

And recently I signed up for an advanced pumping workshop and the organizer asked whether Michael would be coming too, to which I replied no, he didn't want to miss his karate class. I was not bothered by his choice at all: he knows I don't think any less of him for choosing karate. He trusts me to go, learn

anything new, and share it with him later.

It has been incredibly interesting to see the decisions Michael makes in his day-to-day diabetes management – he'll run his thoughts by me, I'll run mine by him, we may have a quick discussion on the best approach for the moment, but ultimately he's the one who decides what goes into his body: both food and insulin. And each time he puts his own health at the forefront of his decisions. It is so important that the child living with a chronic disease be fully involved and in control of their health management as much as possible. This environment of trust gives them the freedom and the tools to learn how to best care for themselves over their lifetime.