



Conversations with Caregivers

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It's the tug and pull of your heart strings, your anxieties, fears and hopes that when your young loved one with celiac disease leaves the house to go, well, anywhere, that they do not get sick.

In this column, I frequently discuss the difficulty of “doing for them” vs. “learning for themselves.” Initially, we have to take responsibility for reading labels, calling ahead, and talking for our children at restaurants, thereby modeling for them what is needed to become pillars of strength, of self-advocacy and confident decision makers. However, this also includes educating other caregivers who will also be helping them to make safe decisions and, more likely, making the decisions for them. It's tough not to have that over-bearing and protective response so I am hoping to give you a couple of tips to have a successful initial conversation to further discourse with caregivers, whether it be teachers, coaches, babysitters, bus drivers, friends, or family members.

Granted, this is not a one-size-fits-all approach as interpersonal dynamics and job titles warrant different methods. However, some of the following might be helpful:

Be positive and courteous: Sometimes situations can be frustrating pending peoples' willingness to understand and be accommodating to the needs of your loved one. At the end of the day though, if you remain courteous, future conversations will not be as difficult and may progress further than if the interaction ended with hostility. Also, we represent the face of the disease. If we are presenting ourselves as being demanding, needy and self-righteous, we will start to change the face of who we are for the worse.

Educate, educate, educate: I've had this disease for eighteen years now and I am still learning. There is so much that science has yet to figure out, so for someone who doesn't live in our world even remotely, they will not have the slightest clue what it means to have to avoid gluten below 20 ppm. I take the opportunity to educate people about celiac disease whenever I get the chance whether it's giving them a basic fact, providing them with websites/educational material or even having a lengthy phone conversation. It happens at the park, at birthday parties, or in the grocery store. I don't mean for it to happen, it just sort of comes up!

Regardless, for someone who is going to be a caregiver of your young loved one, you are going to want to figure out how much they already know and then give them a run-down:

- a. Basics of the disease
- b. What is gluten?
- c. Foods to avoid
- d. Concerns for cross-contamination

Depending on the nature of that caregiver's involvement in the life of your child, you will want to make sure they can demonstrate how to keep your child safe.

Do a dry-run

If possible, role-play or do a dry-run of common areas of concern. It's a scientific fact that people learn by doing and less so than by being told what to do. Have caregivers attend support groups, come to your home to see how you prepare meals or snacks, or have them watch online videos. If it's a school setting, be sure to have meetings ahead of time so the teacher is aware of the needs of someone with celiac disease. In our home, our dry-run was to have my mother take my daughters out to eat, one of whom has celiac disease and the other, a tree nut allergy. Initially, my little one with celiac disease, aged 6, did not want to dine out without me. However, we chose a safe restaurant during a quiet time of day. I prepped my mother and daughter with what to say and what to look for. I encouraged my daughter to speak for herself, but my mother was there to oversee the process. Given all of the above, it was a very successful lunch and she gained a great deal of confidence (as did my mother).

Choose the right time

This is really important! When is the wrong time? Here are a couple of examples: when someone is distracted, unprepared, in a rush, or whose attention is otherwise engaged. Obviously there is not always the perfect time to talk with someone about this, but seeing as how this is such an important subject, it's optimal to try and think ahead and make the time. We were hoping to have at least 20 or so minutes with my daughter's kindergarten teacher at least a week ahead of time before her first day of school. Despite my attempts at making that happen, our meeting didn't even occur until 2:30 in the afternoon the day before school started.

While we were waiting on the bench outside the principal's office (how scary!), we saw all the teachers rushing around getting ready and I thought, "This is not going to be a productive conversation." While it wasn't an ideal time, thankfully all parties were prepared and were cognitively present for the discussion. My daughter wasn't the first child in the school system to have celiac disease so problem-solving class and lunchroom situations was easier than expected. Also, we were quite thankful to learn that gluten was not allowed in the curriculum for the entire district, which meant no Paper Mache art projects, no cheerio necklaces and no sensory tables with gluten-related products! We left the meeting feeling quite relieved.

Know when to hold'em, know when to fold'em:

Depending on the situation, there may be a time when the risk is too great for your child or adolescent to depend on the knowledge of outside caregivers. These situations can vary greatly ranging from dinner at prom, to lunch after the basketball game miles away from home, or to a preschool teacher who really just doesn't understand. Some situations are just not safe situations to venture out and "risk it." This is when you need to have a Plan B; prepare ahead of time and be sure there are always other options for getting food, most likely prepacked food from home. We once had a preschool teacher who really just didn't understand and so, ultimately, we had to tell everyone in the class and write a note on my daughter's lunch box that under no circumstances was classroom food allowed to be given to my daughter. Only food from home would be allowed to be in front of her. In this particular event as well, it was the teacher's assistant who was the culprit so the head teacher took it upon herself to always be the one helping my daughter with her lunch. This ended up being a good solution and she was no longer exposed to gluten.

Check-in

Lastly, check-in with caregivers. See how they are doing, if they have questions or challenging situations they want to discuss. Pending the age of the child, their ability to accurately report a situation or WANT to talk to their parent might be non-existent. My six-year old hasn't always been the best reporter so when she comes home telling me she didn't eat her lunch because her friend's sandwich crumbs got in it, I question that slightly as she may not have wanted to eat what was packed (however, I have to congratulate her for making the right decision). Conversely, the teenager who may have become reserved may not be forthcoming about an upcoming event to plan for. A quick email, text or phone call can be all that is needed as a reminder for the caregiver to explain anything that might have happened or might be going on in the future.

If you are able to effectively open a positive dialog between yourself, your child and their outside caregiver, fewer mistakes will happen and eventually, a trust will build. While this is the Children's Corner, these strategies can overlap with many situations and especially for older adults as they may have hospital stays, enter rehabilitation, assisted living facilities, and long-term care homes. If you gain nothing else from this article, please take away the critical importance of positive communication with caregivers. Start there and see how it goes.

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