Recently I had the profound privilege to give a graduation lecture to a group of physicians in China. These 500 physicians had spent several years in a course organized by the China Diabetes Society. Over 12 weekends during two years they had learned the latest in diabetes care. I decided to title my talk “So you want to live to be 90!”, for I truly believe we have reached the tipping point where, with modern care, people with type 1 diabetes can expect to live as long as their peers. Regrettably such is not always the case due to two main factors. For a long life with diabetes, one must have good care as well as access to all the needed supplies for care. While the Chinese physicians now have the knowledge, their ability to provide care is limited by access to needed tools for their patients. While more acute
there and in other countries around the globe, even here in America, I am too often unable to get the needed supplies for the children I care for. That is not the point of this editorial, but it cannot be left out of the diabetes story. We must continue to work so that people with diabetes have access not only to knowledge, but also to all the essential supplies in adequate amounts to successfully manage diabetes.

As I was working on this editorial, I met a new family with diabetes. Approaching 40 years caring for children with diabetes, I still marvel at the change the diagnosis brings to a family. No one who has not lived with diabetes in a child can ever truly understand the magnitude of commitment needed to be successful. I have often said, and maybe even that isn’t enough, how much I respect the work required of people with diabetes. One of my most poignant memories comes from a young woman who I had first met at 18 months of age and followed her until after high school. She had married, and with her husband deployed for a year, asked if I would see her as she spent time at home with her parents. She reminded me that next to her father I was the

man she had known longest in her life. What a privilege, and what a responsibility! Chronic medical problems create a long-term bond between physician and patient.

I have also attended diabetes camp for over 40 years. The weeks with children as my responsibility have helped drive the respect I feel. One mother said I could never understand what it was like to put her 5 year old to bed; I told her about the 50 that I put to bed. We both worried about our charges. So I hope the reader understands that it is tough, but we still have to push for success. With diabetes, one really never is away from the disease. How I feel right now, what am I going to do in the next hour, what will I eat, and how will it all fit together? Diabetes is never just take a pill and forget about it. It truly demands 24/7 attention and accountability.

How then does a physician work with families for success? How are things different now, and what have 40 years taught me? Our medical school at Florida State University has openly advocated for patient-centered health care. Certainly this is not new in quality diabetes care. My mentor Don Etzwiler used to draw a diagram with the patient at the center. It is perfectly clear that the interaction between physician and family with diabetes is a mere speck in the overall experience with diabetes. I frequently remind parents that they, too, have a license to practice diabetes medicine for their child along with me. Part of my job is to help them learn to do that. I often tell older children that they also have jobs and I have congratulated them on doing their jobs well. Once, when things were not just where we wanted them, I was asked by an astute child if I was planning to do my job better because it was perfectly clear that the overall management had not achieved all the goals we had outlined.

Reflecting on families who have been successful gives me the opportunity to share some of my observations about how we made it so. First of all, these families have made it a point to come to see me. More than half the people who see me drive more than 100 miles for a visit. I know and respect that it takes time from work and time from school to keep an appointment. However, making diabetes that important is a critical variable for success. Children know what their parents consider important. Taking the time to manage diabetes, including visits to the doctor, makes a powerful statement to everyone: Parent, child, and physician.

Children grow and change. I have been told more than once that the family came to see me, we made some changes, they worked for a while, and now it is clear things need
Audience Perspectives

WE CAN NOW OFFER OPPORTUNITIES TO GROW AND REMAIN HEALTHY FOR DECADES. ■

updating. Of course, children are a moving target, growing and developing and changing. Diabetes changes with them. The management has to change too. This is all part of the need for regular care and frequent communication.

How do we interact, doctor, parent and child? First and foremost, it is collegial. Diabetes cannot be managed in a model where the doctor dictates. Why? Because the doctor simply cannot know all the details of the home life and situation. This means, then, that the physician must ask and work hard for the family to be open and forthright. It is never them against me. I need to hear what is possible and what is not possible. I need to hear what they can and cannot do, or even what they are unwilling to do. I do not live with them and share their daily activities, stresses, and burdens. Maybe, however, with all this time and experience, I have seen a similar situation and can offer advice about how others were successful. Sometimes I just have to listen, and I have no good solution.

Figuring out how to communicate that the physician perhaps knows more about the condition in general, but not necessarily about this individual person, can be a delicate dance. That is why one has to create an atmosphere of give and take, talking and listening, teaching and learning, in every encounter. Over time, the patient comes to trust that he will be seen and helped, but not judged. Because I watch children grow and mature, the process is often uneven. Times come where all is not easy and the adolescent is not eager to do all or anything that we ask. As a colleague reminded me, we just wait them out and are there when they are ready for change.

I truly believe these are exciting times for diabetes. Research is racing towards better care. We can now offer opportunities to grow and remain healthy for decades. Taking this long-haul approach as we care for people with diabetes offers the best hope for success. I hope The PLAID Journal offers the reader clues to better care and a better understanding of working together -- physician and person with diabetes -- to achieve success.■