

## Patient Consensus Statement

# What People with Diabetes Want Their Caregivers to Know: Development of the TCOYD Patient Consensus Statement

Steven V. Edelman, MD  
*University of California at San Diego, San Diego, California*

Kathryn Britton, CPC, MAPP  
*Theano Coaching Service, Chapel Hill, North Carolina*

This article is about giving individuals with diabetes mellitus (DM) a voice to tell caregivers what they want from them. It is about increasing the understanding that caregivers have for patients with DM to create a stronger and more effective health care relationship.

Taking Control of Your Diabetes (TCOYD) is a nonprofit organization dedicated to educating and empowering people living with DM and their loved ones to take an active role in their own health care. This includes informing patients of the new treatments, medications, technologies, and therapies for DM and its complications, and motivating them to take control of their DM. At the 7th Annual TCOYD Conference and Health Fair in Raleigh, North Carolina, we conducted a workshop with individuals living with types 1 and 2 DM. The goal was to develop the first of its kind—a Diabetes Patient Consensus Statement. Workshop participants included people of multiple ethnicities and a wide range of ages, with a duration of DM ranging from 1 month to 25 years. We drafted the following Consensus Statement based on the points the group reported to the entire conference. It is our intention to distribute this document to as many physicians as possible around the country.

We hope that when caregivers read this TCOYD Patient Consensus Statement, they take it seriously and consider it with open minds. The best outcomes originate from effective partnerships between caregivers and their patients.

To our knowledge, an agreement such as this has never been attempted before, and it is our belief that this TCOYD Patient Consensus Statement will eventually strengthen the caregiver–patient bond and lead to better DM management.

### **What People with Diabetes Want Their Caregivers to Know**

To: Professionals Who Care for Us

From: Your Patients with Diabetes

1. When first diagnosed, we don't know what to ask you. We are also overwhelmed by the new medications, new health dangers, and lifestyle changes. We need help learning how to play the central role in our own care.
2. We want to understand the reasons why you prescribe each medication and order each blood test and examination. Many of us want copies of these results so we can keep our own histories. We need to understand in order to participate effectively in our own care.
3. We do not always understand medical terminology. You have ordered these medications/tests many times before for other patients; however, we are not health care professionals, and we therefore need you to use lay language when talking to us about our care.
4. Because we are the ones who make the daily decisions about our own care—including what to eat, when to test, when to exercise, and when and how to take medications—we need to participate in the big decisions in order to be motivated to make these daily decisions correctly.
5. When we have just received bad or disappointing news from our health care provider, many of us are too busy dealing with the shock to listen to your suggestions for treatment changes. When we calm down, we are unlikely to remember what you want us to do. We need help remembering what you suggested during our meeting. We may need to be encouraged to bring family/friends with us or, if nobody accompanies us, then we need to be given written instructions.
6. When we hear lectures telling us specifically WHAT TO DO or WHAT NOT TO DO (for example, "Never walk bare-foot!"), it can make us feel that we are being treated like children. We find it much easier to accept if you make us aware of the problem(s) or danger(s) and then make suggestions. With this information, we can make up our own minds about what is right for us.

7. We need you to listen to our concerns. When you dismiss them too quickly, we get frustrated and our confidence in our own judgment drops. We often have important ideas that can improve our health care.
8. Many of us do not like taking so many medications. It is disheartening and often makes us feel more infirm than we actually are. We worry about drug-to-drug interactions, particularly since we often have multiple doctors prescribing for us. We need to know that you have reviewed all of the medications we are taking, especially the ones other caregivers have prescribed for us. We need to see that you are treating the whole person, not just the endocrine system. We need help thinking about the medications in a positive way.
9. We sometimes have barriers to doing all of the things you tell us to do during our appointments. We do not find it helpful to be labeled as “noncompliant” if we do not satisfy your expectations of what we were supposed to do according to our last visit. Diabetes is a struggle in our lives every day. We are not perfect, but we really do want to live long and healthy lives, and sometimes need help moving past the barriers that keep us from achieving our goals.
10. We have deep emotions about dealing with diabetes. We are fearful of complications. We worry about being a burden to our families. We feel like failures when our individual blood sugar values and/or A1C are not good. This sense of failure sometimes makes things worse; we give up on taking medications, testing, exercising, and being careful about what we eat. We need help keeping our complications and numbers in perspective. If we are truly failing, we want to know. But if we are not, we need help moderating our self-blame.