

# In the Beginning: Setting the Stage for Effective Diabetes Care

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One of the most difficult aspects of a clinician's job is delivering bad news to patients. Although there is worse news than a diagnosis of diabetes, the Diabetes Attitudes, Wishes, and Needs (DAWN) study showed that 85.2% of patients experienced negative emotions at the time of diagnosis.<sup>1</sup> Even symptomatic patients, who may be initially relieved that the news is not as bad as they feared, are likely to experience distress as the daily realities of caring for diabetes hit home.

Patients often ask, "What does this mean?" Trying to understand this question from the patient's perspective will ultimately make your task easier. Although it is tempting to provide a complete explanation of diabetes, the underlying questions patients are really asking are, "Why is this happening to me?" and "How will diabetes affect my life?" At the time of diagnosis, most patients do not really want a comprehensive review of the "pancreatic mechanics" or the pathogenesis and other clinical aspects of diabetes. Offer a simple explanation of diabetes and relate it to the patient's particular situation, both clinically and environmentally. Describing diabetes as an insulin deficiency or defect (and not as a "sugar problem") will help to set the stage for future treatment.

Admittedly, there is no one best way to provide this news. However, there are seven key messages that patients need around the time of diagnosis that may make it easier for

them to incorporate diabetes into their lives and help you to create a working (and more successful) partnership with them.

## 1. Diabetes is self-managed.

Although most health professionals expect that patients will actively manage their diabetes, we rarely discuss the fundamental importance of their self-management role with them.

Patients who are mostly accustomed to dealing with acute illnesses may be expecting that the illness will go away if they follow simple recommendations from their provider. Point out that diabetes is different. Help them understand that diabetes is a lifelong condition and that the decisions they make every day will have a great deal to do with the outcomes they achieve in the short term and for their future health and well-being.

A fundamental reality of diabetes is that the patients will always be in charge of its daily management.<sup>2-4</sup> At the same time, discuss your role in the treatment dynamic with them. Let them know that as much as you would like to be able to manage diabetes for them, you cannot. The daily burden of diabetes management is largely in their hands. What you can do is to be their partner and an expert counselor and collaborator who can provide valuable guidance and assistance. Let them know that you will be with them as they make this journey. Point out that it will work best if they let you know how you can be most helpful, what their

concerns and questions are, and what they are willing and able to do to care for their diabetes.

Let them know you understand that hearing this diagnosis and accepting the tasks of diabetes self-management is not easy. At the same time, build their sense of self-efficacy by conveying the positive message that you have confidence in their ability to successfully manage diabetes and to live a meaningful life by working with you. Let them know that there are times they may struggle, but they *can* do it.

## 2. Take your diabetes seriously.

The American Diabetes Association and the National Diabetes Education Program have campaigned strongly through the years to alert the public that diabetes is serious. This message has been well received and understood by the public, people with diabetes, and health professionals. However, a key message that also needs to be conveyed is that patients need to take *their own* diabetes seriously and do what they can to manage it. Remember, also, when conveying this potentially frightening message to provide hope that there is something that can be done to lessen the severity of the consequences of diabetes. Without hope, patients are less inclined to take action. Let them know that you will take their diabetes seriously as well and that you will work closely with them to manage it effectively.

**3. Learn all you can.**

Diabetes education is the cornerstone of effective self-management.<sup>5</sup> Offer a referral for diabetes education and medical nutrition therapy. Let your patients know that you believe that diabetes education is an essential component of their care that can help them move from just *being* in charge to *taking* charge. Explain that with a strong knowledge base, they can control their diabetes rather than letting their diabetes control them. They will also learn ways to make behavioral changes and receive support. Because your patients may need some time to incorporate the initial diagnosis into their view of themselves, you will need to help them gauge when they are ready to attend and benefit from an education program.

An important aspect of diabetes education is that patients not only need to learn about diabetes in general, but also need to learn about themselves and how diabetes affects them.<sup>6,7</sup> Although you and their other health care professionals are experts about diabetes, patients need to become the foremost experts about their own diabetes. They need to learn what does and does not work for them both in their lives and in their treatment.

Because of the lifestyle changes that a diagnosis of diabetes often precipitates, it is a family affair. Let patients know that family members are generally welcome to attend diabetes education programs and appointments with the dietitian if they believe this will be helpful to them. Family members who not only understand diabetes but who know their family member's goals and treatment plan can offer more effective support and may be less likely to become the "diabetes police."

Although initial diabetes education is important, diabetes is a lifelong condition that will present new questions, feelings, and

challenges along the way. Patients will need to continue to receive education and support to live well with their diabetes and sustain the changes they make through their initial education and efforts.<sup>5</sup> Tell them that you will continue to provide information and discuss targets, therapies, and their concerns and questions as you go forward. Encourage them to find a good listener and to seek support from you, other members of their diabetes team, their families, clergy, and others with diabetes.

**4. Treatment will change over time.**

One of the first questions patients often ask is what can be done about diabetes. Let them know that type 2 diabetes is treated in stages, and then outline the steps for them. Point out that changes in treatment are not a result of their failure to manage their diabetes effectively and do not mean that their diabetes has worsened. Explain that these changes result in large part from the progressive nature of type 2 diabetes and that you may have to try several different therapies until you find the one that works best for them. Although it is common to use insulin as a threat to encourage weight loss and exercise,<sup>8</sup> keep in mind that sending negative messages or making patients feel that they have failed may actually increase your patients' resistance to insulin therapy when the time comes.

**5. Negative emotions are common.**

Coping with diabetes is difficult. Feelings of anger, guilt, fear, and sadness are common.<sup>1</sup> It is helpful to normalize these negative emotions by letting patients know that they are common and can be expected to come and go and vary in degree from day to day. There is no timetable for these emotions. The DAWN study<sup>1</sup> showed that many years after diagnosis (mean 15 years), 43.8% of patients

were still experiencing negative emotions related to their diabetes. In addition, these negative emotions often interfered with many patients' self-management efforts.

Let them know that you are here to help and that it is important for them to let you know if their emotions are getting in the way of managing diabetes or functioning in their daily lives. In addition, offer them information about other resources, including professional counseling when necessary, for support.

Patients with diabetes are about twice as likely to experience clinical depression.<sup>9</sup> Let them know the signs of depression for which they need to be alert and that they can always discuss these issues with you. In the appropriate circumstances, provide a similar message to their families or other caregivers because it is often easier for others to detect symptoms of depression than for depressed patients to see it on their own.

**6. One step at a time.**

Diabetes often involves making lifestyle and behavioral changes. This can quickly become overwhelming, causing patients to become frustrated and abandon their efforts. Let them know that they are more likely to be successful if they make these changes one at a time and incrementally.<sup>10</sup> Suggest that they start with a problem or area that has meaning and importance for them and try to make small changes each day. They will probably need to try different things and make adjustments along the way. Stress the experimental nature of their efforts.<sup>2,3</sup> Not achieving the desired results should not be characterized as a failure, but rather as a learning opportunity. Using these experiences to evaluate past efforts and design new options will actually increase the likelihood for long-term success. Remind them that perfection is not

the goal. It is what they do most of the time that counts.

### 7. Complications aren't inevitable.

Most adults have some understanding of diabetes and its consequences. They may have seen the negative toll of the long-term complications of diabetes among their family members or friends. Reassure them that these are not inevitable and can be delayed or prevented by keeping their blood glucose and blood pressure levels in the target ranges. Although there are no guarantees, they can greatly reduce their risks through your combined efforts.

### Creating a plan: The LIFE Approach

One method to help your patients incorporate these messages into an easily understood framework is the LIFE approach,<sup>5,6,11</sup> consisting of four distinct, but very fluid steps:

- Step 1: **Learn** about your diabetes, your health care team, your personal life circumstances, and your feelings about diabetes.
- Step 2: **Identify** your three guiding principles: your role, how much flexibility you need in your life and diabetes plan, and the blood glucose and other targets toward which you are working.
- Step 3: **Formulate** your personal self-management plan, including both clinical care and your self-management strategies.
- Step 4: **Experiment** with and **Evaluate** your plan based on both your achievement of target levels and your ability to sustain this plan given your life circumstances and other priorities.

### Conclusion

Although there is no one best way to deliver a diagnosis of diabetes, it is important to stay focused on the patients and to try to understand the message from their point of view. Although it is tempting to launch immediately into a physiological explanation of the disease, be sensitive that your patients are probably not ready to digest all of the details involved. Instead, they need to understand that much of the treatment responsibility will be theirs, but that you and their other health care providers will always be there for them to provide guidance and support. Throughout the initial visits, as well as subsequent appointments, offer opportunities for them to ask questions and raise concerns. Keep in mind that, although you will go home to resume your regular life and routine, your patients' and their families' lives will have irrevocably changed with this news.

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### REFERENCES

- <sup>1</sup>Skovlund SE, Peyrot M, on behalf of the DAWN International Advisory Panel: The Diabetes Attitudes, Wishes, and Needs (DAWN) program: a new approach to improving outcomes of diabetes care. *Diabetes Spectrum* 18:136–142, 2005
- <sup>2</sup>Anderson RM, Funnell MM: *The Art of Empowerment: Stories and Strategies for Diabetes Educators*. 2<sup>nd</sup> ed. Alexandria, Va., American Diabetes Association, 2005

<sup>3</sup>Funnell MM, Anderson RM: Empowerment and self-management education. *Clinical Diabetes* 22:123–127, 2004

<sup>4</sup>Weiss MA: Empowerment: a patient's perspective. *Diabetes Spectrum* 19:116–118, 2006

<sup>5</sup>Funnell MM, Brown TL, Childs BP, Haas LB, Hoseney GM, Jensen B, Maryniuk M, Peyrot M, Piette JD, Reader D, Siminerio LM, Weinger K, Weiss MA: National standards for diabetes self-management education. *Diabetes Care* 30:1630–1637, 2007

<sup>6</sup>Funnell MM, Weiss MA: Empowering patients with diabetes. *Nursing* 39:34–36, 2009

<sup>7</sup>Funnell MM, Weiss MA: Patient empowerment: the LIFE approach. *Eur Diabetes Nurs* 5:75–78, 2008

<sup>8</sup>Peyrot M, Rubin RR, Lauritzen T, Skovlund SE, Snoek FJ, Matthews DR, Landgraf R, Kleinbreil L, the International DAWN Advisory Panel: Resistance to insulin therapy among patients and providers: results of the cross-national Diabetes Attitudes, Wishes, and Needs study. *Diabetes Care* 28:2673–2679, 2005

<sup>9</sup>Anderson RJ, Clouse RE, Freedland KE, Lustman PJ: The prevalence of comorbid depression in adults with diabetes: a meta-analysis. *Diabetes Care* 24:1069–1078, 2001

<sup>10</sup>Bodenheimer T, MacGregor K, Sharifi C: *Helping Patients Manage Their Chronic Conditions*. Oakland, Calif., California Healthcare Foundation, 2005

<sup>11</sup>Weiss MA, Funnell MM: *The Little Diabetes Book You Need to Read*. Philadelphia, Pa., Running Press, 2007

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