## **Chapter 2**

# Facing Life with Diabetes



#### **Key Messages**

- Living with diabetes involves acquiring new knowledge and developing skills to self-manage a lifelong condition.
- Responses to diagnosis can vary: some people experience a range of negative emotions (e.g., shock, grief, anger, distress, or self-blame), while for others, the diagnosis has little impact, or can bring a sense of relief after a period of uncertainty about unexplained symptoms.
- Responses are influenced by the type of diabetes diagnosed, and by the person's individual characteristics and experiences prior to diagnosis (e.g., symptoms and/or familiarity with the condition).
- The journey is different for everyone, but most people with diabetes will need support from their health professionals, families, and peers at some point.



### **Practice Points**

- Reflect on how you might feel if you had to live with diabetes. Use your insights to support the person.
- Be mindful that a new diagnosis can raise a range of emotions for a person.
- Listen empathically, assist the person, and assure them that you can support them to live well with diabetes.

### Experiencing the Diagnosis of Diabetes

The diagnosis of diabetes is the beginning of a new reality. Nobody chooses diabetes. The person is confronted with an incurable and potentially demanding condition. Life will not be the same as it was before diabetes. The person may feel that they will never return fully to their previous health state, or they may perceive they are losing their independence or control over their health.

For some people, the diagnosis of diabetes can be a shock.<sup>1,2</sup> Their initial emotional reactions are disbelief, anger, self-blame, anxiety. For others, the diagnosis may be a relief after a period of uncertainty about symptoms and consequences of hyperglycemia.<sup>1,2</sup>

I was just shocked, thinking, because I'm so healthy. And I thought, 'oh my, God, it's like the end of me,' kind of, you know, that shock.

-Person with type 2 diabetes<sup>3</sup>

[I was] jumping around from shock to denial to grief to tears to... I certainly went through that.... The reactions might go up and down for quite some time... for my first 12 months I went through lots of reactions.

-Person with type 1 diabetes

I don't think it's all that devastating. There are far worse incurable sorts of things.

-Person with diabetes<sup>4</sup>

I think it's quite good... that it's been sort of picked up.... If they hadn't done those tests... I could just have been sort of doing always what I've normally been doing... I could have been damaging myself even more.

-Person with type 2 diabetes<sup>1</sup>

How a person responds to diabetes will differ according to individual characteristics, such as age, gender, social, and cultural background; their life stage; and experiences. Reactions are likely to vary also depending upon the type of diabetes diagnosed (see **Box 2.1**), and the person's beliefs about the condition, its trajectory, and how well it can be managed.

Let was easy for me because my son had it, so I had the experience of it, I knew what it was already.

–Person with diabetes<sup>4</sup>

#### BOX 2.1 Reactions to a Diagnosis of Type 1 or Type 2 Diabetes

**The onset of type 1 diabetes** can be sudden and highly symptomatic (acute hyperglycemia). Sometimes, diagnosis follows a brief period of ill health and hospitalization due to diabetic ketoacidosis, which can be traumatic. Diagnosis of type 1 diabetes is almost exclusively considered devastating, despite the fact that people can live long, healthy, and happy lives with the condition. Thus, typical reactions can include both shock and relief.

Conversely, **the onset of type 2 diabetes** is rarely accompanied by such acute symptoms and can mistakenly be considered a "mild" condition, to be expected in older age. Typical reactions can include denial and apathy. The exception to this is when a diagnosis is made in the presence of complications (e.g., background retinopathy). In these exceptional cases, the potentially devastating consequences of diabetes are already obvious to the person and typical reactions can include anger, self-blame, and grief. A person's reaction may also depend on whether or not they expected the diagnosis. For example, someone who is experiencing symptoms that they suspect are related to diabetes or with a known family history of diabetes may feel more prepared for the diagnosis and may not be "shocked" by it. In comparison, a person who has been feeling unwell may feel relieved that the cause is now known and perhaps that the diagnosis is not something they perceive to be "worse." The reaction of a person who is surprised by the diagnosis, for example because they were asymptomatic, may be more variable (e.g., "shocked" or "grateful" that it has been revealed).<sup>1</sup>

It is crucial not to refer to type 2 diabetes as "mild" diabetes or "a touch of sugar"—these terms do not reassure the person and can do more harm than good. All forms of diabetes are serious and all can lead to complications if they are not managed well.

#### [Diabetes is]... the best thing that has happened to me for ages because it's brought around so many other changes and benefits.

-Person with type 2 diabetes1

Some people believe that diabetes will not cause much disruption to their "normal" life—and this may be true. However, the perception that diabetes is affecting very little in their life can be a sign that the person has not grasped (yet) how serious diabetes is and what they need to change/do to manage it effectively. It may take them a few weeks, months, or years to fully realize how diabetes affects their life and future. Not acknowledging the need to adopt or change certain self-care behaviors can be a sign of low self-efficacy (i.e., that the person lacks confidence in their ability to make behavioral changes) or fear of failure. A lack of confidence and/or fear of failure is typically the experience of people who need to quit smoking or lose weight—repeated failed attempts lead to avoiding the need to continuing trying.

> I don't let it worry me, nothing has been changed, even if I eat somewhat different now. Diabetes is something you can live with... or, am I wrong?

> > -Person with type 2 diabetes<sup>5</sup>

And to be honest I don't feel as if I've got diabetes... the only reason I know I've got diabetes is because the doctor told me I have... I don't feel as if I've got to do anything to correct it. Really I might as well carry on with my beer... if I... really took to mind that I'd got diabetes I'd do something more drastic about it.

-Person with type 2 diabetes<sup>6</sup>

I don't think I fully accept that [the diagnosis] happened... you have to, to continue getting on with life... I think you adjust to incorporating it or integrating it into your life.

-Person with type 1 diabetes

Not every person who has been told they have diabetes will immediately feel ready to deal with its consequences. This "avoidance" strategy can be an adaptive and effective coping mechanism. In the short-term it can serve a positive purpose, offering a way for people to adapt slowly and come to terms with change, without becoming overwhelmed.<sup>7</sup> If it continues for weeks, months, or even years, it may have negative consequences for emotional well-being, selfmanagement, and health outcomes.

> I think it was about two months later, if that, you know, and I think I still haven't got, sort of, you know, I haven't told myself that I have got it, you know, I'm still in denial... I still keep thinking 'they must have got it wrong.'

> > -Person with diabetes<sup>3</sup>

I've heard that diabetes can make you go blind, but I don't want to know. I just don't want to think about it.

-Person with diabetes8

Not engaging in diabetes self-management (e.g., not taking medication or not attending clinic appointments) may be a sign that the person has difficulties coping with the diagnosis or with self-care and, therefore, may need extra support.

Regardless of their initial reactions, for most people the adaptation process will have a natural course and they will find a way to incorporate diabetes and its management into their daily life and lifestyle.<sup>9</sup> For some, it may continue to be a struggle and they may require support from a health professional.

Apart from emotional responses and beliefs, there are many other reasons why people with diabetes have difficulties incorporating the diabetes management demands in their lives. For example, health literacy, social and cultural consequences (e.g., fear of losing their job, being isolated in their community, or stigma), and limitations related to the healthcare system and access to care.

Often, during the weeks and months following diagnosis, a person can feel overwhelmed by "information overload" and the many complex management tasks they need to learn and apply. These initial overwhelming emotions can leave a person feeling unable to cope and may disrupt their memory and capacity to retain information.<sup>1</sup> If a person believes that they need to get everything right from the beginning, it puts extra pressure on them and adds to the emotional burden of diagnosis. You can help to reduce this pressure by assuring them that it will take time to learn what works best for them and by showing confidence that they will get there. You feel a little like 'Ahh, am I too high now [glucose level]? Should I take more [insulin] or not?' Then I have to think, 'Yes, I do that,' or, 'No, I don't,' so it takes a while to learn to know myself how I react.

-Person with diabetes<sup>10</sup>

Ask, at regular intervals during the first year after diagnosis, about how they are coping, and their beliefs and feelings about their diabetes, self-management, and its impact on their daily life (see **Box 2.2**). These conversations can help you identify, at an early stage, if the person is not adapting well and may need additional support.

Strategies to identify which aspect(s) of diabetes are causing coping problems (e.g., emotional, cognitive, or behavioral) and how to provide appropriate support are included in Chapter 3 and Appendix C.

If you recognize that the person continues to struggle with feelings of denial, grief, self-blame, or anxiety associated with their diabetes several months after diagnosis, consider referring them to a mental health professional for specialist support. For information about making mental health referrals, see Chapter 9.



If there is a psychologist in your team, introduce them to the person with diabetes as early as possible. The best option is a face-to-face meeting so that they get to know each other from the start, which will lower the threshold to consult with the psychologist in the future and also "normalize" that asking for psychological support is not a sign of "weakness."

In summary, there is no single way to respond to the diabetes diagnosis. Many factors play a role in the process of dealing with this condition. Understanding the person's experiences prior to and since living with diabetes will help you to support the person effectively.

#### **BOX 2.2** Asking How a Person Is Coping with the Diagnosis of Diabetes

Here are some examples of open-ended questions you might use to enquire about how the person is coping with the news that they have diabetes:

- "How are you feeling at the moment about the news that you have diabetes?"
- "How did you react when you were told you had diabetes?"
- "How do you feel your diabetes may affect your [school/work/personal relationships/ family/ sport/hobbies, etc.]?"
- "How do you feel about telling other people that you have diabetes?"
- "How did your [close family members] react when you told them about the diagnosis?"
- > "How do you feel you are coping?"
  - "What do you expect will be the hardest part of fitting diabetes into your life?"
  - "What do you think will be easy for you to do/change?"
  - "What do you think may be more difficult?"

Acknowledging the daily challenges of living with diabetes and the efforts it takes to manage the condition can help people feel more comfortable about sharing their thoughts and feelings. You can do this by prefacing these open-ended questions. For example, *"Many of the people that I see find living with diabetes challenging,"* or, *"Finding out you have diabetes can be a lot to take in."* Comments like these "normalize" the adjustment process and help the person to realize they are not alone in thinking or feeling this way.

Explain that incorporating diabetes into their life takes time. For example, *"Living with and managing diabetes is a learning process, quite a bit can feel like 'trial and error.' Over time, you will become an expert in managing your diabetes."* 

### Diabetes Diagnosis: The Start of a Lifelong Relationship with Health Professionals

For many people, the diagnosis of diabetes is the start of a lifelong relationship with health professionals and the healthcare system.<sup>10</sup> Although the time you will spend with the person is minimal, they will value your expertise and guidance when you show genuine respect and empathy<sup>11</sup> (see **Box 2.3**).

Remaining supportive will help the person with diabetes realize you are "on their side" rather than someone they are accountable to. In doing so, you will maintain the person's trust and keep them motivated to take care of their diabetes and their overall health in the long term. The blog reprinted in **Box 2.4** describes how a person with diabetes feels, what they would like their health professional to know, and importantly, how they would like their health professional to communicate.

It illustrates that it is important to use appropriate language and not to trivialize people's diabetes management efforts and/or the challenges they face with ongoing self-care of this lifelong condition. A health professional's communication style has a significant impact on how a person copes with and manages their diabetes (see Chapter 1).

#### BOX 2.3 What Is It Like to Live with Diabetes?

It is difficult to imagine what living with diabetes is like when you don't have diabetes yourself. However, with the knowledge you have about the condition and the stories people with diabetes have shared with you, you may reflect on:

- > "How would I feel if I had diabetes?"<sup>12</sup>
- The diabetes treatment regimen is just one aspect of managing diabetes. For most people, self-management is intensive and multi-faceted. Physical daily tasks include medication-taking, self-monitoring of blood glucose, dietary changes, physical activity, and foot care. Then, there are the regular health check-ups (e.g., A1C checks, blood pressure, and eye screening).<sup>13</sup> However, effective self-management involves more than simply performing these tasks and attending appointments. It requires problem solving, decision making, healthy coping, and reducing risks.<sup>14</sup> This means developing resilience to the everyday frustrations of living with diabetes, working out how to deal with other people's reactions to their diabetes and their self-care choices, and being confident experts in their own condition.<sup>15</sup>
- > A person with type 1 diabetes:
  - who has lived with it for 40 years has done 58,400 finger pricks (average four per day) and has likely had over 4,000 mild hypoglycemic episodes and 40–60 severe hypoglycemic events.
  - typically makes over 100 diabetes-related decisions every day, feels tired of continually thinking about diabetes, and feels that their family is continually concerned about them and their diabetes.
- > A person with type 2 diabetes:
  - is typically asked to change the habits that have accrued over a lifetime; healthier eating, more exercise, and losing weight are not easy to achieve, especially when the rewards are not apparent in the short term.
  - has to make difficult and/or frustrating decisions at every meal (e.g., continually resisting their favorite foods, dealing with well-meaning family/friends who say things like "just one won't hurt," and being confused by healthy eating advice).
- Many people with diabetes describe it as "more than a full-time" job.<sup>16</sup> And so it is—but without any pay or holidays, and without assurance that your efforts will be rewarded.<sup>17</sup> How would you feel if you were asked to keep doing your job 24/7 for a year, but without vacations and without the guarantee of being paid at the end of the year?

#### BOX 2.4 Dear Doctor: An Excerpt from the Diabetogenic Blog<sup>18</sup>

I frequently give talks about how to get the most out of our healthcare professionals [HCPs]. One of the things I talk about is making sure that we find the HCPs that work best with us. I talk about interviewing doctors—something that I did years ago when I was looking for the right endo. It's a two way street. One doctor told me that he didn't think that we would work well together. He was completely right and I walked out of that appointment rather quickly!

I also talk about being really clear and upfront about things—what we need from our HCP, what we expect. And then give them the opportunity to do the same thing.

This is pretty much what I want to say to every HCP when I meet them for the first time.

#### Dear Doctor

Hi. You and I are on the same side. My side. We are both championing for me to be the best I can be with the cards I've been dealt.

I thought that we would start out by me telling you what I need from you and I would love it if you did the same.

This is a relationship that works two ways. You need things from me, and I need things from you. Let's get all that out on the table from the beginning.

Mutual respect is really important. I come with mine ready to give to you. I won't, however, be quite so generous if you don't demonstrate the same thing.

Judgment is not welcome in our consultations. That message is actually for me as much as it is for you, because I am totally judging you. I expect you to be judgmental and not understand me or my condition. Show me that I'm wrong. And then don't judge me for being such a pain in the ass!

My health condition is one that you know a great deal about. That is why I am coming to see you. I want to know everything you know that is relevant. But I need you to remember that I have a unique expertise in the field of Renza's Diabetes. I am the world expert in this field and I will impart everything I have learned and continue to learn about it to you. If you could then help me make sense of that, I'd really, really appreciate it.

I am not stupid. I have a really good understanding of the health system of which I am, unfortunately, a user. I also know a lot about the technical sides of my condition. I totally get that you need to make sure that I am clear about what you are saying, but please don't dumb it down too much for me. I promise that I don't care about looking stupid. I'll ask if I don't understand.

I use humor a lot to try to deal with what is, at times, a really scary thing to live with. Sometimes you may think that my humor is not particularly appropriate. A lot of the time you won't find me funny (but for both of our sakes, please pretend; I promise to ignore your fake laugh). I don't make fun of the situation because I am making light of it. Or because I don't care. I always care a great deal. But sometimes, it's what I need to get me through.

I'm really not good at asking for help. But I am coming to see you because I need it. I may seem to be going the long way around getting to actually ask for what I need. Feel free to ask and prompt and even push a little.

I'll say it again. I care a great deal about my health. I want to be healthy and well and on top of everything. There will be times—and they may be extended times—where it seems that I don't care. The important word there is "seems." I do care. Really. Sometimes, though, it is just overwhelming and exhausting. But I really, really do care.

I have a beautiful family and a great job and a shoe collection that may make you jealous and I really like to drink coffee. I bake a lot and love old black and white films. I have wonderful friends I spend time

with—frequently over a meal somewhere. Exercise and I are not mates. I read voraciously and should probably seek some sort of therapy for my inability to stop buying books. I have a thing for bright red lipstick and have too many handbags. I love Nutella. And bacon. And doughnuts. You may wonder why I am telling you this. It's because all of these things are part of my life. Just like diabetes. And it goes to explain why diabetes is not the most important thing in my life or the thing that I focus on all the time.

I'm terrified about my future. I am scared about diabetes complications, I lie awake at night worrying about the chance of my daughter getting diabetes and I fear becoming a burden on my loved ones. Diabetes is scary. It is not just a condition of numbers and lab results. It is (an unwelcome) part of my present and my future.

I solemnly swear that I will never, ever walk into your office asking you about some ridiculous cure I read about on the internet. Remember that bit about me not being stupid? But equally, the internet is where I get a lot of my support and information about living with diabetes. I have a support network of people living with diabetes from all around the globe. They build me up, tell me about new things, help me work through tough times. They are, to me, as important a part of my diabetes management as you are. Don't treat them with suspicion.

So, did you know that cinnamon can cure diabetes? I'm disconnecting my pump and eating cinnamon doughnuts and nothing more for a week to see how it goes. Just kidding. (Pretend laugh. Now.)

And finally. I want you to remember all the time that I am doing the best I can at that very moment. It may not be as much as you would like, but this isn't about you. It's probably not as much as I would like either. Acknowledging what I am doing makes me feel really great. And frequently then makes me want to do better.

Thanks for reading. I really do hope this is the beginning of a beautiful doctor-PWD [person with diabetes] friendship.

Best Renza

#### **Bringing Bad News**

You may be the health professional who will tell a person that they have diabetes. Some health professionals may not feel skilled or confident in bringing bad news, as the response can be overwhelming. Bringing bad news is a crucial communication skill. The words used, the content, and the tone of the message can make a big difference for a "good" start to life with diabetes. It can impact on how a person responds to the diagnosis, their reactions now and in the future, and on their relationship with health professionals. Here is one approach for delivering bad news.

The SPIKES approach<sup>19</sup> is a useful six-step protocol:

- > Setting up: prepare yourself for the conversation, including what you are going to say; create a private and quiet space; minimize interruptions; invite the person to bring a "significant other"; and establish rapport with the person.
- Perception: determine what the person already knows about diabetes and their level of

comprehension, including how much they appear to be assimilating or understand of what you are saying.

- Invitation: ask about what level of detail the person would like to receive (brief or in-depth information) and offer the option to ask questions later.
- > Knowledge: provide the information they would like to receive in a language they understand. Take into account, for example, their educational level, sociodemographic background, and emotional state. Short sentences and pauses will help the person to process the information. Give facts about treatment options, prognosis, and costs.
- > Emotions: allow the person time to express their feelings and acknowledge their feelings, and respond empathically to the person's emotional response.
- Strategy and summary: summarize what has been said; check whether the person has questions or needs clarification; develop a strategy based on the person's hopes, expectations, and specific concerns; and arrange a follow-up date and time.

#### First Principles and Philosophies for Moving Forward

As a health professional, you have expert knowledge about diabetes, its management, and potential consequences. It is important to acknowledge that only the person with diabetes has expertise about their own diabetes and their own life. It is your responsibility as a health professional to help the person with diabetes to explore their own expertise, to highlight how their diabetes fits into their lives, and where there is an obstacle that can prevent optimal management of diabetes. People are responsible for their own selfmanagement. As a health professional, you can only ever have limited responsibility and influence over this.

You are responsible for providing the person with diabetes with accurate and clear information about diabetes and its treatment options. This is especially true in the short term following diagnosis. They need basic knowledge before they can learn how to manage the condition. Understanding the condition facilitates the coping process and will help them in making sense of the new reality.<sup>10</sup> It is important for the person with diabetes to:

- > be well-informed about treatment options, the course of diabetes, and the seriousness of diabetes.
- > know that the condition can be managed effectively, and does not have to lead to complications—indeed, while "untreated diabetes is the leading cause of many complications, well-managed diabetes is the leading cause of nothing."<sup>20</sup>
- > and understand that they will experience "ups and downs" in the way they feel about living with diabetes.

Thus, as a health professional, you are responsible for providing up-to-date, evidence-based information ensuring people are aware of their risks, and then helping them to identify successful strategies for minimizing those risks. **Box 2.5** offers some guidance about how to support people in the development of their own strategies for preventing complications and living well with diabetes. However, in the real world, there are many barriers to optimal self-management that may hamper the individual's efforts to achieve optimal outcomes or change their motivational focus. As a health professional, you need to acknowledge these barriers with empathy at all times. If in doubt, "over-celebrate," "under-criticize," and "honor effort as well as outcomes."

#### **BOX 2.5** Helping a Person Make Changes to Fit Diabetes into Their Life

- When asking people to make significant changes to their lifestyle, it is important to convey a message of hope, empathy, and understanding, while being factual and informative.
- It is important to refrain from using threat or fear-based persuasion,<sup>21</sup> particularly if the person is not ready to face the reality and the consequences of diabetes for their future.
- It is more constructive to understand why a person may not be making changes that would appear to be "good" for them.
- Help the person to understand their own barriers in implementing optimal diabetes selfmanagement and ways to overcome these.
- Create a space where the person can reflect on where they are now, so they can realize their own priorities and preferences—what is it they like and don't like about where they are now, and what they like and don't like about where they see themselves in X years' time if they don't make some changes.
- Acknowledge that other issues may have greater priority for them right now; explore the person's own "roadblocks" and help them to identify how important these are to them or whether they can find ways to overcome them.
- With all this in mind, explore what options they have for making changes that would benefit their health.
- Enhance the person's confidence to undertake specific behaviors. When someone is asking for help to achieve their goals, help them reflect on their options for changing and support them to make realistic steps. This makes it more likely that they will try and succeed.
- Successful completion of one step (e.g., walking for 30 minutes once a week) increases a person's confidence in undertaking the next step (e.g., walking for 30 minutes three times a week) and so on.
- Work with the person to develop a realistic and individualized action plan, and to identify resources to aid change. Ensure that the actions you agree upon are relatively easy with few barriers.

### Resources

#### **For Health Professionals**

#### **Books**

#### > The Journey of the Person with Diabetes

**Description:** This book chapter explains the unique journey that people with diabetes take during the course of the condition, including psychological, social, and other factors that may impact upon how they think and feel about living with diabetes.

**Source:** Speight J and Singh H. The journey of the person with diabetes, in the book by Dunning, ed., Diabetes Education: Art, Science and Evidence. Oxford, John Wiley & Sons. 2013.

**URL:** <u>https://onlinelibrary.wiley.com/doi/</u> pdf/10.1002/9781118702666.ch2

#### > The Skilled Helper

**Description:** Now in its 11th edition, this book provides training in how to have conversations to help people manage "problems" and identify opportunities using a three-stage model.

**Source:** Egan G. The Skilled Helper. US, Cengage Learning. 2018.

#### **For People with Diabetes**

Select **one** or **two** resources that are most relevant and appropriate for the person. Providing the full list is more likely to overwhelm than to help.

#### Support

#### > American Diabetes Association (ADA)

**Description:** ADA offers resources through which people with diabetes and their family/friends can access diabetes information, education programs, and other events.

Phone: (800) 232-3472

URL: www.diabetes.org

#### > Juvenile Diabetes Research Foundation (JDRF)

**Description:** JDRF provides a number of resources for those living with type 1 diabetes, including educational material and in-person events related to resilience and distress. Sections include information on insurance, tool kits, and links to Type

One Nation, a social networking site for people living with type 1 diabetes.

Phone: (800) 533-2873

URL: www.jdrf.org

#### Information

#### > Learning About Diabetes

**Description:** Easy to understand teaching handouts in English, Spanish, and a variety of additional languages.

URL: http://learningaboutdiabetes.org

#### > National Diabetes Health Topics

**Description:** This section of the National Institute of Diabetes Digestive and Kidney Diseases (NIDDK) website contains much of the information originally found in the National Diabetes Education Program, which was discontinued in 2019. Topics include diabetes basics, statistics, and more.

URL: <u>https://www.niddk.nih.gov/health-information/</u> <u>diabetes</u>

#### > NIDDK School Guide

**Description:** A program of the NIDDK designed to help parents and school administrators optimize care for students managing diabetes in the school setting.

URL: https://www.niddk.nih.gov/health-information/ communication-programs/ndep/health-professionals/ helping-student-diabetes-succeed-guide-schoolpersonnel

#### > Joslin Diabetes Education Library

**Description:** The education section of the website for the Joslin Diabetes Center has a wealth of information on a variety of topics of diabetes self-care, as well as access to in-person programs.

URL: <u>https://www.joslin.org/patient-care/diabetes-</u>education-library

#### > My Glu Website

**Description:** Mobile community for people with type 1 diabetes to connect with others with type 1, learn, and contribute to research.

URL: www.MyGlu.org

#### Don't Freak Out: 10 Important Things to Know When You've Been Diagnosed with Type 2 Diabetes

**Description:** This pamphlet lists 10 important points that people with newly diagnosed diabetes should know. A PDF version can be downloaded

('previewed') for free from the Behavioral Diabetes Institute website.

Source: Behavioral Diabetes Institute.

URL: www.behavioraldiabetes.org

#### Research

For those wishing to learn more about the scientific and research advances being made in diabetes, a number of sites provide information designed with a nonprofessional audience in mind.

URLs: <u>www.diabetestrialnet.org</u>, <u>www.trials.jdrf.org</u>, <u>www.clinicaltrials.gov</u>

#### **Books**

> Bright Spots and Landmines: The Diabetes Guide I Wish Someone Had Handed Me

**Description:** A person with diabetes shares the strategies for food, mindset, exercise, and sleep that have had the biggest positive impact on his diabetes. Along the way, he argues that the usual focus on problems and mistakes in diabetes—landmines—misses the bigger opportunity—bright spots.

**Source:** Brown A. Bright Spots and Landmines: The Diabetes Guide I Wish Someone Had Handed Me. US, The diaTribe Foundation. 2017.

#### > Type 1 Diabetes in Children, Adolescents and Young Adults, 6th edition

**Description:** A comprehensive guide to type 1 diabetes in children, enabling children and their parents to become experts in control of the child's diabetes.

**Source:** Hanas R. Type 1 Diabetes in Children, Adolescents and Young Adults. Sweden, Class Health. 2019.

#### > The Everything Parent's Guide to Children with Juvenile Diabetes

**Description:** *The Everything Parent's Guide* helps readers cope with the challenges of helping their children live happy, healthy lives while controlling the disease.

**Source:** McCarthy M, Kushner J. The Everything Parent's Guide to Children with Juvenile Diabetes. US, Adams Media. 2007.

#### > Understanding Diabetes, 14th edition

**Description:** A classic title from the Barbara Davis Diabetes Center in Denver, CO, now recently revised.

Covers a variety of topics, including diabetes basics, self-care, coping, and more.

**Source:** Chase HP, Understanding Diabetes. US, Children's Diabetes Foundation. 2019.

#### > KIDS FIRST Diabetes Second: Tips for Parenting a Child with Type 1 Diabetes

**Description:** Based on the author's "D-Mom" Blog, this resource shows parents how to automate tasks, navigate challenges, celebrate achievements, establish a support group, and relieve stress.

**Source:** Calentine L. Kids First Diabetes Second. US, Spry Publishing. 2012.

#### > The Mindful Guide to Managing Diabetes

**Description:** This guide helps those with diabetes manage stress, anxiety, and depression through mindful living.

**Source:** Napora J. The Mindful guide to Managing Diabetes. US, American Diabetes Association. 2019

### References

- Peel E, Parry O, et al. Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. Patient Education and Counseling. 2004;53(3):269-75.
- 2. Beeney LJ, Bakry AA, et al. Patient psychological and information needs when the diagnosis is diabetes. Patient Education and Counselling. 1996;29:109-16.
- 3. Wilkinson E, Randhawa G, et al. What's the worry with diabetes? Learning from the experiences of White European and South Asian people with a new diagnosis of diabetes. Primary Care Diabetes. 2014;8(3):181-6.
- 4. Clark M. Understanding diabetes. West Sussex: John Wiley & Sons; 2004.
- Hörnsten Å, Sandström H, et al. Personal understandings of illness among people with type 2 diabetes. Journal of Advanced Nursing. 2004;47(2):174-82.
- Ockleford E, Shaw RL, et al. Education and selfmanagement for people newly diagnosed with type 2 diabetes: a qualitative study of patients' views. Chronic Illness. 2008;4(1):28-37.
- American Diabetes Association. Denial, 2015 [cited 12 January 2015]. Available from: <u>www.diabetes.org/living-</u> <u>with-diabetes/complications/mental-health/denial.html</u>.
- Gillibrand W, Flynn M. Forced externalization of control in people with diabetes: a qualitative exploratory study. Journal of Advanced Nursing. 2001;34(4):501-10.
- Nicolucci A, Kovacs Burns K, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2): Crossnational benchmarking of diabetes-related psychosocial

outcomes for people with diabetes. Diabetic Medicine. 2013;30:767-77.

- Kneck Å, Klang B, et al. Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus. Scandinavian Journal of Caring Sciences. 2011;25(3):558-66.
- Capehorn M, Polonsky WH, et al. Challenges faced by physicians when discussing the Type 2 diabetes diagnosis with patients: insights from a cross-national study (IntroDia®). Diabetic Medicine. 2017;34(8):1100-7.
- 12. Davies M. Psychological aspects of diabetes management. Medicine. 2014;43:57-9.
- 13. Coyle ME, Francis K, et al. Self-management activities in diabetes care: a systematic review. Australian Health Review. 2013;37(4):513-22.
- 14. Boran SA. Self-care behaviours: systematic reviews. The Diabetes Educator. 2007;33(6):866-71.
- Peyrot M, Rubin RR, et al. Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) study. Diabetic Medicine. 2005;22(10):1379-85.
- Hinder S, Greenhalgh T. 'This does my head in'. Ethonographic study of self-management by people with diabetes. BMC Health Services Research. 2012;12:83.
- 17. Polonsky WH. Diabetes burnout: what to do if you can't take it anymore. American Diabetes Association; 1999.
- Diabetogenic: real life with diabetes. Dear doctor, 2015 [cited 7 March 2016]. Available from: <u>www.diabetogenic.</u> wordpress.com/2015/08/07/dear-doctor.
- Baile WF, Buckman R, et al. A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302-11.
- 20. Polonsky WH. Engaging the disengaged patient webinar, 2015 [Accessed 10 May 2016]. Available from: www.niddk.nih.gov/health-information/ health-communication-programs/ndep/health-careprofessionals/webinars/disengaged-patient/Pages/ ResourceDetail.aspx.
- 21. Lawson VL, Bundy C, et al. The development of personal models of diabetes in the first 2 years after diagnosis: a prospective longitudinal study. Diabetic Medicine. 2008;25:482-90.