

Advocacy



A diabetes diagnosis comes with many lifestyle changes, including a community of people with diabetes who can help you find your advocacy voice. Advocating can take many forms and can help yourself or others in your community. Learning about resources, legal protections, and types of advocacy is the beginning of your diabetes advocacy journey.

Self-Empowerment Advocacy

With Healthcare Professionals

Your advocacy begins when you select the healthcare professionals that will become your trusted medical team. When possible, research whether they have specialized training in diabetes management (look for the term “diabetologist” or a designation of CDCES, which stands for Certified Diabetes Care and Education Specialist). These days most medical practices have websites where you can review their training and get a sense of how progressive or conservative the office may be in managing diabetes. You may also ask for recommendations from other medical professionals whom you trust, such as asking your endocrinologist, internist, or CDCES whom they would choose as their own podiatrist or cardiologist.

Review your insurance plan to confirm that medical professionals are covered, and hopefully in-network. If they aren’t covered by your plan or are out-of-network, you may pay significantly higher prices than those who are covered. For some patients with diabetes, the choice to pay for out-of network physicians with whom they have established long-standing relationships is important.

Being a responsible and proactive advocate for yourself allows you to be prepared for your healthcare appointments. If you are a new patient and transferring your medical records from another healthcare office, make sure they are sent over well before your appointment day. In some instances, you may be able to pick up your previous labs or records and take them with you.

As an established patient, have any laboratory tests completed well enough in advance to be available for your appointment.

Use a notebook to help structure your appointment (or photocopy the sheet at the end of this chapter).

By having these items written down to review during the appointment, the conversation becomes a two-way dialog and is more productive and actionable.

- What is the reason you are spending time today receiving care from that medical professional? (Is this a checkup? Do you have a specific health concern?)
- How do you feel your daily diabetes management has been? Do you need extra education or guidance in a particular area?
- Are you having issues or challenges with your current diabetes management? (Are you having negative side effects from a medication or treatment? Are you skipping medications because you can't afford the copayment?)
- What does success for this appointment look like to you?

Tip: Medical offices can be busy, and often healthcare professionals are given only a few minutes for each appointment. When individual patients have complex needs, those healthcare professionals must take care of them and may run late for the appointments that follow. While it may be frustrating to wait in the front area or in an exam room for longer than you expect, remember that health care providers may also share your frustration with delays and time limits. You want them to take time to help you, too — and you may take longer than expected.

During the appointment, be truthful in your answers.

Telling a medical professional that you took your prescribed medication as directed when you stopped taking it several months ago, or that you exercise every day when you have not, makes it difficult to make good future decisions about your daily management. When you have written down the challenges of your existing management before your appointment, discussion can help you and your provider find solutions together, rather than wasting your valuable time working on a program that is not attainable when you leave.

Don't accept general statements without concrete, small steps toward a solution.

If the medical professional says: "Exercise more," you can respond with: "What type of exercise do you recommend for me to get the best results? How much time per day or per week should I exercise?" If a member of your healthcare team says: "You need to lose some weight," you can ask: "How much weight would be reasonable for me to lose between now and our next appointment? What tools or resources can you recommend to help me achieve this goal?" Always ask about the side effects of medications prescribed and what the medication is supposed to do for you. Offices may also be able to see if a recommended medication is covered under your insurance plan (or provide information about copay cards or patient assistance programs if you are having difficulty paying for medications).

Speak up.

This is your health. If you don't understand something that the healthcare professional says, you have the right to ask for more explanation. When you feel that a member of your healthcare team isn't listening to you, sharing healthcare information that could help you, or they dictate rather than discuss your management plan, it's up to you to address that in a non-confrontational manner. For instance:

- "I'd like to step back and discuss the symptoms I have been having while taking this medication again."
- "I'd like some clarification on your recommendation on exercise. You told me to get more. Can we discuss how to achieve that?"
- "Let's discuss the goals you'd like to set with me in greater detail so that I can understand more clearly."

Write it all down.

This will provide you with information while it's fresh in your mind and make sure that you've heard everything correctly. Go over what you've written before you leave the appointment so that you don't have to wonder later if you've missed anything. If you are comfortable, you may even want to bring a family member or a friend into the exam room with you; they can take notes or ask questions on your behalf.

With Language & Awareness

There has been a recent movement to shift the way the public and health professionals identify and describe you and discuss your treatment related to diabetes. In the past, some discussions were stigmatizing or disease-specific, such as "uncontrolled" or "suffering from diabetes." Today, the recommendations published in the Association of Diabetes Care and Education Specialists (ADCES) The Diabetes Educator and American Diabetes Association's (ADA) Diabetes Care give recommendations on how to have positive conversations with you about your care. There is even a guide for journalists and the media:

<https://www.diabeteseducator.org/docs/default-source/practice/educator-tools/diabetes-language-media-guide.pdf?sfvrsn=2>. You can choose how you want them to describe or refer to you: "a patient with diabetes" or "a person with diabetes." Share with those around you the positive words to use in relation to diabetes and diabetes management.

Tip: Download the guides and recommendations and share them with your medical professionals and friends. Use your advocacy muscles to change the language used and the conversations with both the public and your healthcare team.

Our community relies on awareness advocacy to educate the public, especially when it comes to fundraising for research or correcting misinformation. Regardless of the type of diabetes you may have, all of us need to provide non-stigmatizing, accurate information on the differences between the types of diabetes and where people can learn more. For instance, it can be frustrating to see yet another meme or social media post saying that a dessert causes diabetes or making others living with a different type of diabetes feel bad simply because you have a different type of diabetes from theirs.

Use your knowledge of the signs and symptoms and ways to learn more rather than telling the person who posted an uninformed statement. For instance, if someone posted: "I ate so much sugar today, I'm going to get diabetes," you can respond with: "Did you know that eating too much sugar does not cause any type of diabetes? You might think it's funny but knowing what really causes diabetes can help you and others. Learn more at: [insert trusted sources of information here, such as: www.diabetes.org, www.jdrf.org, www.diabetessisters.org, or even <https://www.cdc.gov/diabetes/basics/diabetes.html>]."

Tip: It's hard not to get angry at people for spreading misinformation. Explaining and raising awareness as a diabetes advocate means taking the higher road — a lot of the time.



Legal advocacy

With Employment

Whether you are applying for a new position or have been employed for several years at one location, you may find that diabetes can present complex situations that need legal advocacy.

Diabetes is a disability under U.S. law, which provides discrimination protection and certain rights. Thanks to the Americans with Disabilities Act, you cannot be fired or denied a promotion because of diabetes, nor can you be denied a “reasonable accommodation” for completing your daily tasks at work.

That being said, accommodations you may feel are reasonable may be different from what your employer sees as reasonable. Only being allowed to check your blood glucose levels or inject insulin in a utility closet rather than at your desk, or not being allowed to take a break to treat hypoglycemia, are examples of unreasonable accommodations.

When you apply for a position, you are not required by law to disclose your diabetes diagnosis. However, in order to ask for reasonable accommodations or protections under anti-discrimination laws, you must let your employer know you have diabetes.

Navigating legal issues related to diabetes can be difficult. The American Diabetes Association has a wide array of information and resources, as well as a hotline if you have legal issues related to workplace discrimination. You can call them at 1-800-DIA-BETES or visit: <https://www.diabetes.org/tools-support/know-your-rights/discrimination>.

When Traveling

Traveling with diabetes involves preparation: packing enough supplies, making sure you have enough medication, having current copies of prescriptions, and even learning how to ask for help in foreign languages. But nothing is more frustrating than encountering misinformation at a security checkpoint or customs.

Before you travel by air:

The U.S. Transportation Security Administration (TSA) hires agents who may not interact with or understand diabetes or the devices and medications we carry. It’s important to know your diabetes legal rights at a TSA checkpoint and use the resources that TSA provides to help make the process easier.

- Call TSA Cares at 1-855-787-2227 approximately 72 hours before your flight. This program is a special helpline for individuals with disabilities (including diabetes) to expedite the screening process. They can provide answers to common screening questions and can even assign you a passenger support specialist at the TSA checkpoint.
- Let the TSA officer know if you are wearing an insulin pump or a continuous glucose monitor before you begin the screening process.

- You have the right to request — and they must comply with — a pat-down or personal screening (in public or private) to bypass the x-ray or millimeter wave machines that may affect electronic equipment. Check with the manufacturer of the devices you wear or carry to learn about the safety aspects of device screening.
- You have the right to have your diabetes supplies hand-checked before you begin the screening process, rather than placed through the x-ray machine.
- If you have an issue or feel you have been treated unfairly, ask for a supervisor immediately. You can also follow up by filing an official complaint with TSA online at: <https://www.tsa.gov/contact/contact-forms>

Before You Visit Customs:

While you may hold a U.S. passport, when you travel to other countries you are subject to the laws of the country you are entering. It is recommended that you carry a medical letter from your physician that includes your diabetes diagnosis, treatment plan, and information about the supplies and devices that you carry. Likewise, upon reentry into the United States, if you have purchased a large amount of medication or other supplies while visiting you may be subject to additional screening and potential confiscation.

Policy advocacy

Policy advocacy efforts ensure policymakers understand that laws and other protections are needed for people with diabetes. Some people may feel like advocating for policies to protect people with diabetes is too complicated or overwhelming for them to get involved. However, with social media and the internet, it's never been easier to let your government representatives know what's important to you.

Whether it's speaking out on a federal or state bill related to diabetes or giving your opinion to the Food and Drug Administration (FDA) through regulatory comments, many diabetes nonprofit organizations have ways to connect with officials making important decisions. To learn more and take action, you can visit:

- American Diabetes Association at www.diabetes.org
- Diabetes Patient Advocacy Coalition at www.diabetespac.org
- Diabetes Leadership Council at www.diabetesleadership.org

These diabetes organizations provide lobbying opportunities to citizens through grassroots or direct advocacy. It doesn't matter if you've never advocated for policy; these organizations will teach you!

Much as our diabetes treatment plans are individualized to meet our specific needs, your choices of ways to advocate are based on what you need — and what you want to do. Our community has many resources and programs to help explore what you can do to help yourself and others.

Self-Advocacy: Before Your Appointment

Below are some questions to ask yourself before you see any health care provider regarding your diabetes. Bring a copy of this sheet with the questions and your responses with you to the appointment.

Question	Your response
What is the reason you are spending time today receiving care from this medical professional? (Is this a regular checkup? Do you have a specific health concern?)	
How do you feel your daily diabetes management has been? Do you need extra education or guidance in a particular area?	
What issues or challenges do you have with your current diabetes management, and which one is most important to you? (Does a medication you are taking have negative side effects? Are you skipping medications because you can't afford the copayment?)	
When this appointment is over, how will you know it was successful?	

Advocacy Type	What changes would you like to see?	Next steps (Who to contact, What to say)
Self-Advocacy		
Awareness		
Legal		
Policy		
Advocacy		