

Diabetes Distress

Dealing with the Weight of Diabetes



The unpredictability in blood sugar, daily schedules and life can make this disease frustrating. Whenever our actions have unpredictable outcomes, we can become distressed. In this case it is specific to diabetes, so it is referred to as diabetes distress.

Having diabetes is like someone handing you four balls and telling you to juggle perfectly. Then it's telling you that once you acquire that skill you will now juggle every day for the rest of your life and that there are variables that are going to influence your ability to juggle, you just don't know what and when. If you stop doing this, you will get sick and the people who care about you will become upset and tell you to start juggling again.

Those who have diabetes know this scenario far too well. You have been given a disease to manage that requires daily attention to aspects of life that never seemed manageable even before the diagnosis. In addition to these behaviors, you are often expected to look at numbers as a judgment of your success and go to frequent healthcare appointments that evaluate you and your skill in dealing with this juggling act. Oh, by the way your family and friends get in on the act, because they know you have diabetes and you not only feel judged by them, you feel judged by yourself.

This wouldn't be such a big deal if you could get it right, but the unpredictability in blood sugar, daily schedules and life can make this disease frustrating. The emotional ups and downs add to the daily burden.

How does diabetes distress impact me and the disease?

Whenever our actions have unpredictable outcomes, we can become distressed. In this case it is specific to diabetes, so it is referred to as diabetes distress. We develop tension, fatigue, a sense of being overwhelmed and experience "burnout." This burnout sometimes pushes us to quit or at least not pay close attention to the things that are causing this distress. You may think "I just won't check my blood sugar," or "I'll skip that medication since it doesn't seem to do much anyway." The unfortunate result is diabetes goes unmanaged, leaving you with a high A1C, not feeling well and possibly developing complications.

Friends, family and co-workers are all likely to be concerned about you and may seem to be monitoring your activities. You have the right to ask people to give you space if they are too close, but keep in mind they are usually doing this because they care, so express appreciation for their attention, then offer them ideas for how you would like them to be involved and how you don't want them involved. It's clear you are the one with diabetes, but you also have the responsibility to help those who love you be involved in appropriate ways.

What can I do if I think I have this distress?

First find out. If you think this is happening to you, don't be surprised as it happens to many people who live with diabetes.

- Talk with your diabetes care and education specialist they can ask relevant questions.
- Get an assessment. There are simple tests that can help such as a diabetes distress questionnaire.
- The results from the test will help you identify what area in diabetes is most distressing.
- Based on those results you can develop a plan.

Diabetes doesn't go away, so what can I do to ease my distress?

- Find someone who understands your feelings surrounding living with diabetes and talk to them.
- Talk with another person who has diabetes, a diabetes support group offered by your local hospital or your diabetes care and education specialist, family member, or a mental health professional. Someone who knows diabetes will ease the burden and you won't feel so alone.
- If you feel judged by others, express your concerns and find a way to ask for their help rather than their judgments.
- The medical system can sometimes make you feel that if your health is not improving, then it is something you are doing wrong. You need their support, which is different than their judgment. Tell your healthcare team and family if and how supportive they are, because they often feel helpless as family members often do not know what to say or do to help their loved ones manage diabetes.
- If you are worn out by the daily tasks and the feeling of failure, give yourself a reasonable break from the routine.
- Realize no one gets diabetes right 100% of the time. Doing diabetes tasks well will not assure you of getting the numbers you want. Take some time off. Plan it, make it safe and perhaps ask someone to help you. Do this intentionally, not out of anger.
- If you feel bothered by others or have the sense they are monitoring your behavior, ask them to stop.

Diabetes is not easy. When you feel burned out, you may not want more responsibility, but this is probably the time you most need to ask for help and let others join in the way that works best for you.

For more information on healthy coping and diabetes, visit DiabetesEducator.org/mhealth.