

New Beginnings: Managing the Emotional Impact of Diabetes – Module 2

ALEXIS (AW): Welcome to New Beginnings: Managing the Emotional Impact of Diabetes. I'm Alexis Williams.

MICHELLE (MOG): And I'm Dr. Michelle Owens-Gary.

AW: The purpose of the New Beginnings audio programs is to introduce you to the important role that emotional coping and family support play in helping a person with diabetes manage their condition. In the first program, we talked about the emotional impact of diabetes and helpful coping strategies. In this program, Michelle and I will talk about the role of family and social support in helping a person with diabetes manage their condition. The New Beginnings Discussion Guide has resources and activities to help you incorporate the strategies we'll discuss into diabetes education and support groups.

Let's begin by listening to Terry and LyCynthia talk about how they learned to manage LyCynthia's diabetes together. As you listen, think about the roles family members play in providing support to a person with diabetes.

Terry: Well, I can say it's a learning experience year in and year out from the very beginning when we first married. It was all about learning about diabetes from the beginning, genetically how it affects the body itself, and emotionally how it affects the whole family. I knew nothing about it and when I started, LyCynthia and I had to sit down and she had to help me understand what was going on with her blood sugar, the danger signs and, I'm not going to say I'm a quick learner, but I do learn. And at that moment, I guess after two years I started watching very intently what she was doing, how she's doing because she has to apply the shots in various places like in her legs and arms, and it helps me to understand exactly what was needed. And then there was the time where we had to both understand exactly what she could eat because we are restaurant frequenters. We do go to a lot of restaurants and we do love to eat various types of food. But then that had to change in my life to help her. There have been many nights that she wakes up in the middle of the night and I have to look for the signs, you know. Whether it's high or low blood sugar and then immediately, after so many trainings and after so many understandings, I know what to do and how to do it.

LyCynthia: This is why communication in the family is just so important. You got to know not only just verbal communication but non-verbal communication. If the person is experiencing a low blood sugar and not able to communicate there may be signs there that you could recognize – a person could recognize –letting you know that there’s a problem. But you also must have been the wisdom and the knowledge as to what you need to do. You first have to determine what it is – low or high – and then do the right thing. This is why, again, diabetes education is essential to maximizing that person’s quality-of-life. If it were not for my husband attending diabetes education classes with me and the rest of my family, then he would not have known what to do when those lows occurred. He would not know what to do as far as my diet or anything regarding my care. Communication is so important in the entire family because, again, diabetes affects the entire family.

I’ve had diabetes a long time. 29 years, 30 years, oh, I’m sorry, 40 years...

LyCynthia: and through those years I’ve developed complications as well. As different complications begin to develop such as kidney failure, again, I had to communicate to them exactly what was going on and they also learned how to help me deal with the kidney failure. I started out with peritoneal dialysis, which is just doing dialysis at home. They also had to learn how to do that. When I developed nerve damage they didn’t understand that. But again through education and remembering what they heard in diabetes education, they knew that if I had a tingling sensation in my hands or my feet it was because of that. So communication and talking to each other and talking about the emotional part of living with diabetes helps to alleviate some of the frustration and the denial. A lot of us get to the point that will be just don’t believe that we have it and don’t want to deal with it, but it’s something that we all have to deal with, whether we like it or not, it’s there. But it’s easy to manage if you take the responsibility and you don’t see it as a problem but an opportunity to better yourself, educate yourself, and do the best that you can do to live a long and healthy life with diabetes. It’s not something to be afraid of. I think I’ve been pretty successful because of my family in dealing with the disease and I think that to live with it for 40 years means that what I’ve learned I’ve applied successfully and I expect to live 40 more years successfully. So diabetes is not the end but the beginning of a new life, just learning how to live it a little bit differently.

AW: I think this is a good example of how diabetes affects the whole family, not just the person with diabetes, and the important role family can play in helping a person manage their diabetes.

MOG: Families can be a real support to people with diabetes by helping them cope emotionally, helping them with the tasks of managing diabetes, and providing care in an emergency.

AW: I can also see how family might be a source of stress. For example, Terry mentioned that they both like to go out to eat. Image what would have happened if he didn't understand the important role that diet plays in managing LyCynthia's diabetes.

MOG: If he hadn't been willing to work with LyCynthia on changing her eating habits, it might've made it hard for her to change, and that could cause additional stress for the family.

AW: Michelle, are there ways family members try to help that are actually not that helpful?

MOG: It's not helpful when family members are controlling, nagging, or critical. People might mean well, but these types of behaviors don't help the person with diabetes learn to feel confident in their ability to manage their diabetes.

AW: And you can't really *make* another person change their behavior.

MOG: Right. A person has to decide for herself that she's ready to change. This can be frustrating for family members who don't want to see a loved one sick or suffering and just want to help. But family members can wear themselves out pushing a loved one with diabetes to make changes that she's not ready to make. It can also be frustrating for the person with diabetes who might feel that the well-meaning family members just don't understand what they're going through.

AW: Avoiding discussions about diabetes is probably not helpful either.

MOG: Pretending the diabetes doesn't exist won't make it go away. Family members may avoid talking about the disease because they're worried about what it means for their loved one or what it might mean for their own health. They might be afraid of upsetting the loved one by talking about the diabetes. LyCythia talked about how communicating with the family can help relieve some of the frustration and denial the person with diabetes might be feeling. If families can talk openly about diabetes and its impact on the family, it can help take away some of the fear and anxiety and together, they can plan for the future.

AW: What kind of family support is helpful?

MOG: Family support is most helpful when it's encouraging, helps the person with diabetes feel good about herself, and focuses on solving problems.

There are three types of support family members can provide to someone learning to cope with an illness like diabetes: informational, practical, and emotional support.

Informational support is when a family member helps the person with diabetes find and understand information about the disease and how to take care of herself.

AW: Like finding reliable websites or figuring out what the information in a diabetes brochure means.

MOG: Right. A family member might also go to diabetes education classes with the loved one. They can be an extra set of ears to help remember instructions or information. They can also help remember questions or information the person with diabetes wanted to share with the educator.

AW: It was helpful that Terry went to diabetes education classes with LyCynthia, because they got a lot of information and he could help her remember what they learned.

MOG: It can also be helpful to have a family member go to health care appointments with someone who has diabetes. There can be a lot of information shared during these appointments that needs to be understood and remembered. Family members can help the loved one with diabetes sort through the information, ask the provider questions, and remember what was shared. Sometimes, people get upsetting news from the provider which can make it hard to remember information. For example, the doctor might tell the loved one that she has developed a complication.

AW: If you're in shock or upset, it can be hard to focus on what the health care provider is trying to tell you.

MOG: At times like this, it can be helpful to have a family member at the appointment. When LyCynthia had complications, it was helpful to have Terry there to help her understand the information.

AW: It also sounded like he helps her manage her diabetes. For example, he helps when she has low blood sugar.

MOG: That's the second type of support – practical support. This is help managing day-to-day tasks. This can include things like running to the drug store to pick up a prescription or watching the kids so the person with diabetes can get some physical activity.

AW: What about emotional support?

MOG: That's providing comfort and emotional care the person with diabetes needs to make it through the ups and downs of living with the disease. This could mean being a good listener, helping relieve stress, providing encouragement, or making the person with diabetes feel good about herself.

AW: So family support is helpful when it's encouraging, helps the family member feel good about themselves, and is focused on problem solving. It's not helpful to nag, criticize, or try to control the loved one. It's also not helpful to avoid talking about diabetes altogether. Instead,

family members can provide informational, practical and emotional support. Michelle – Tell us about some steps family members can take to provide positive support and improve communication with their loved one who has diabetes.

MOG: The first step is to learn about diabetes. Terry talked about how he would not have known what to do about LyCythina's low blood sugar if he hadn't taken the diabetes education classes with her. Learning about diabetes can also ease some of the fears that family members might have about the illness. Family members can go to diabetes education classes, join a support group, or go to doctor's appointments with the loved one. They can also learn more about diabetes by going to the NDEP website at your-diabetes-info-dot-org.

The second step is to talk to their loved one about coping with diabetes. Find out what makes it hard for them to manage their diabetes, what helps, and what goals the person has set.

AW: LyCynthia talked about how family communication was so important in helping her live with diabetes. Not just in terms of the day-to-day tasks, but in providing emotional support so she could have a good quality of life.

MOG: As she said, the whole family is affected by diabetes so they have to learn to talk about all parts of living with it – the physical and the emotional.

The third step is for family members to find out what they can do to help. Sometimes we think we know what's best, but it helps to let the person with diabetes tell us what they need.

AW: In LyCynthia and Terry's story, it sounded like he watched her and talked with her and took his cues from her about ways he could help, instead of deciding on his own what he would do.

MOG: Right. The idea is for the person with diabetes to take control of managing her disease. She have to take the lead and let her loved ones know what kinds of support she needs. At the same time, family members should recognize that they can't do everything for the loved one with diabetes. So the fourth step is for the person with diabetes and the family member to

discuss specific goals for how they will provide support. For example, goals could be once a week they will walk with the person who has diabetes for 30 minutes. This way, the person with diabetes can be clear about what she needs, and the family member can be clear about what kinds of help they can provide. Relationships tend to be smoother when everyone is on the same page, but the only way to get everyone on the same page is to *talk* about what's going on, and *be specific* about what support is needed and what support people are able to provide.

AW: So there are four steps family members can take to provide support to a loved one who has diabetes. First, learn more about diabetes. Second, talk to the loved one about coping with diabetes. Third, find out what the loved one needs and fourth; find specific ways to help – by discussing and establishing support goals.

MOG: When a person has diabetes, the people closest to her are also affected and the whole family has to learn to live with the disease. When family members provide helpful, positive support, it can make a difference in how the loved one with diabetes learns to manage her condition.

AW: So far in these programs, we've discussed the emotional impact of diabetes, helpful coping strategies, and the role the family plays in providing support. Helpful family support is encouraging, helps the loved one with diabetes feel good about herself, and focuses on helping her solve her own problems. Families can provide informational, practical, and emotional support. Open communication about what the person needs to manage their condition can help family members set specific goals about ways they can help.

In the final audio program, we'll talk about some cultural considerations around these issues and storytelling as a strategy for diabetes education and support groups.