

BEYOND DIAGNOSIS

MODULE 4

Instructor Notes

SLIDE 1

WELCOME BACK to the Beyond Diagnosis Diabetes Education program. We are excited to have you return for more great information about diabetes. Today we will be talking about how to build a support team that understands your journey with diabetes. This can be a personal network of friends and family, a professional network of diabetes experts, and/or a community of others who live with diabetes themselves and understand living with diabetes from a personal lens. The important part is to remember- you don't have to do diabetes alone!

You'll remember that I am **[INSTRUCTOR NAME]** and I work with **[INSERT ORGANIZATION NAME]** as a **[INSERT ROLE NAME]**. I am your instructor for today's course on Building Your Support Team. Just as in the previous class, please feel free to ask questions, share stories, and connect with others in the group. Our goal is to learn together from the course materials, but most importantly, from each other.

Let's re-introduce ourselves.

Thank you all for your introductions. Let's get started building our support networks!!

SLIDE 2

As we go through our presentation today, you can follow along in your BT1/Bt2 toolkits in the “Building Your Support Team” section.

- ◆ BT1 Toolkit: p.42-49
- ◆ BT2 Toolkit: p.41-48

As we learn about best practices for managing blood sugars today, here are some of the topics we will discuss:

- ◆ Building Your Healthcare Support Team
- ◆ Taking Care of Your Mental Health
- ◆ Emotional Check In
- ◆ Tap Into Community and Thrive Together

Give participants a minute or two to locate their toolkits and navigate to Section 2. If participants need a new toolkit, please distribute additional toolkits.

SLIDE 3

Introduce the group to the Beyond Diagnosis Ambassadors, Dex and Alysse, by sharing the linked videos.

MEET Dex (PW T1D)

MEET Alysse (PW T2D)

Thank you to Dex and Alysse for bravely sharing their stories and advice with us.

SLIDE 4

If you are new to diabetes or have been living with diabetes for a while, you may be overwhelmed, exhausted, or scared of what your future looks like.

First, take a deep breath and know that—while it may not feel like it right now—you will get through this, you will learn what you need to learn to stay healthy, and this will get more manageable over time.

Second, know that you're not overreacting and you're not alone...But since you're on a steep learning curve, it's a good idea to get support to help you manage. Remember—Beyonce? LeBron? Oprah? Nick (Jonas)? They have teams. You don't need to do this alone.

SLIDE 5

“Most people think of diabetes as a physical condition and have never really thought about the mental aspects of living with the condition. Diabetes involves making frequent, sometimes life or death decisions under sometimes stressful and physically uncomfortable circumstances. In addition, diabetes management is constant and can feel overwhelming. If you or someone close to you has diabetes, take a minute and think about all of the steps you take in your diabetes management everyday. What to eat, how much insulin to take, when (or whether) to exercise, how to interpret a glucose reading, how many carbs to take to treat a low, the list goes on. Decisions, and resulting behaviors (and their consequences) are critical aspects of diabetes management. However, doing everything necessary to manage diabetes can become overwhelming.”

Some people with diabetes have a mental health condition (that may or may not be related to having diabetes). Being diagnosed with diabetes can be a traumatic event, and living with diabetes can increase your risk for stress, diabetes distress and burnout, disordered eating patterns, anxiety and depression.

We also know that the behavioral demands of taking care of your diabetes every day is overwhelming. Maintaining healthy blood sugars is enormously complex, with many changing variables and factors to consider. Diabetes self-care demands are constant, and you can never really get a break. Diabetes is unforgiving and often uncertain. Others in our support network may not fully understand diabetes, diabetes self-care, or may try to be supportive but choose a manner which is not successful. Continued exposure to diabetes stigma and discrimination can further make it difficult to complete daily self-care activities.

As we talk about creating a support team to help us navigate our journeys with diabetes today, these are some of the reasons it's so important to have a tribe around you that feels supportive. Living with diabetes is tough- you can do it- and doing it with others who “get it” can make a big difference.

SLIDE 6

We have already talked a lot about what is involved in taking care of your diabetes on a daily basis. We've covered the importance of checking blood sugar regularly, taking medication, eating well, getting the right amount of movement, and staying in touch with your health care team as you have questions or as your circumstances change. But, who really should be part of your diabetes team?

Having a physician (or prescribing provider like a nurse practitioner or physician assistant) on your team is essential. Primary Care physicians are trained in a wide domain of medicine and can be a valuable resource. Your primary care doctor's primary specialty may be family medicine or internal medicine, though most PCPs are knowledgeable in some aspects of diabetes management. PCPs can help you by keeping an eye on your annual lab work and serving as a local check up for diabetes care such as foot exams, A1C checks, medication refills, and general health and wellness guidance. PCPs care for a wide variety of conditions, not just diabetes, and can offer a wider variety of guidance, not just diabetes. PCPs often refer you to other specialist doctors or teams when there is a need for further speciality guidance or evaluation. There should be multiple PCP providers available in your geography, and you may even be able to work with someone virtually through telemedicine, too.

Endocrinologists are specialist doctors who have extra training and expertise in the body's hormones such as insulin. Many endocrinologists are diabetes experts and work exclusively with individuals who have diabetes. Endocrinologists offer specialised expertise, tools, and resources tailored to your diabetes, overall health, and metabolic goals. Many people with T1D and T2D prefer to work with an endocrinologist because of their specialized knowledge and training specifically in the area of diabetes and blood sugar management. It is common that many endocrinologists utilize diabetes technologies to help their patients achieve the best health outcomes and quality of life. Endocrinologists can also provide foot exams, A1C checks, diabetes medication refills but also offer a wider set of tools like diabetes technologies, intensive insulin treatment programs, diabetes education and guidance, and additional staff to assist with diabetes-related questions and teaching. If you are not able to find an endocrinologist in your area, consider making a telemedicine appointment.

SLIDE 7

Having a physician champion on your diabetes care team is a great start! But, there are many other experts who manage other aspects of health and wellness that can be beneficial to add to your diabetes care team. Creating a diverse diabetes care team is essential as it involves caring for your entire body.

- ◆ Diabetes care and education specialists are your essential partner in managing diabetes care. They troubleshoot issues, identify health patterns, teach about and assist with diabetes technology, find cost-saving programs, and help answer any question you may have about diabetes or its impact on your body.
- ◆ Clinical pharmacists help with medication management and navigating side effects or cost-saving drug programs, while dietitians are experts in food and nutrition and provide guidance on meal planning, carb counting, and nutrition.
- ◆ Exercise physiologists specialize in developing personalized fitness plans to improve cardiovascular health, flexibility, and body composition. Mental health providers help manage the initial shock of adjusting to a diagnosis of diabetes, the ongoing mental and emotional challenges of diabetes self-care, and provide counseling for specific mental health concerns like anxiety, depression, distress, and disordered eating. Your endocrinologist or primary care provider—whomever is helping you manage your diabetes—is a great resource to ask for a referral. They may have a mental health provider who works with their practice, which can make coordination of care much easier. (<https://beyondtype1.org/diabetes-diagnosed-mental-health>)

Have you heard of any of these diabetes experts before? Have you met with any of these as part of your diabetes care team? We will meet more on the next slide.

SLIDE 8

Here are even more diabetes care experts that you might encounter during your diabetes care journey:

- ◆ Neurologists are nerve specialist doctors who can be included as needed to treat nerve problems like extremity pain (from neuropathy) in your limbs.
- ◆ Podiatrists are foot specialist doctors who can be included as needed to take care of foot issues like ulcers or infections. Your primary doctor or diabetes doctor should perform a preventative foot exam once per year.
- ◆ Optometrists are local primary care eye specialists that can examine your eyes, check your vision, and identify any diabetes-related eye concerns.
- ◆ Nephrologists are kidney doctors that can be included as needed to treat kidney problems like diabetes-related kidney disease. Your primary doctor or diabetes specialist should perform annual lab work to look after your kidney health.
- ◆ Dentists are experts in tooth, gum, and mouth health. Visiting your dentist is very important for oral health. Visit your dentist twice per year for cleanings and examinations.
- ◆ Ophthalmologists are specialist eye doctors who evaluate eye health and treat any vision problems, including any that require laser therapy or surgery. It is common to see the eye doctor to monitor your eyes once per year for changes related to diabetes.

Have you heard of any of these diabetes experts before?

SLIDES 9-10

Let's play some diabetes care team trivia!

1. Which diabetes expert can prescribe diabetes medications and review annual lab work?

PRIMARY CARE PHYSICIAN

2. Which diabetes expert is a specialty doctor with additional training in diabetes and hormones?

ENDOCRINOLOGIST

3. Which diabetes expert can help navigate side effects from medications, assist with teaching you about new diabetes medications, and refill your diabetes medication?

PHARMACIST

4. Which diabetes expert can help troubleshoot diabetes care challenges, identify health patterns, teach about and assist with diabetes technology, and help you learn about any aspect of diabetes care or living well with diabetes?

DIABETES CARE AND EDUCATION SPECIALIST

5. Which diabetes expert can help identify which foods affect your blood sugar the most, plan balanced meals and snacks that are satisfying without restrictions, and ensure your relationship with food stays positive and balanced?

REGISTERED DIETITIAN NUTRITIONIST

6. Which diabetes expert can help develop personalized fitness plans to improve cardiovascular health, flexibility, and body composition?

EXERCISE PHYSIOLOGIST

7. Which physician expert can help keep your heart healthy by keeping an eye on your cholesterol, blood pressure, and family heart history?

CARDIOLOGIST

8. Which physician can help identify and treat any problems with your eyes?

OPHTHALMOLOGIST

9. Which specialist doctor is a specialist in kidney health or kidney disease?

NEPHROLOGIST

10. Which medical professional looks after oral health and your teeth

DENTIST

11. Which specialist doctor is an expert in nerve function such as nerve pain?

NEUROLOGIST

SLIDE 11

We are just beginning to learn about the impact of unhelpful comments, cultural stigma and misinformation on the journey with diabetes. For years, people with diabetes have known how difficult it is to overcome many of the misconceptions about their condition and how society treats them as a result of having diabetes. Diabetes stigma refers to exclusion, rejection, prejudice, or blame that people unfairly experience as a result of having diabetes. It affects people with every diabetes type, and can also affect their family members, too. There are stigmas that surround T1D and T2D. They can be reinforced from anyone and anything such as medical professionals, friends, family and even ourselves. Misinformation about diabetes can contribute to the belief that something you did caused you to get T1D or T2D. However, it is no one's fault if they have diabetes.

IT IS VERY COMMON: 4 of 5 adults with diabetes experience diabetes stigma and 1 in 5 experience diabetes discrimination

- ◆ Stigma can be associated with diabetes self-care activities, body size, lab values, and many other misconceptions, fears, perceptions or disgust about diabetes. Unfortunately, there are many aspects of diabetes which are misunderstood in a cultural sense and these inaccuracies are harmful and hurtful to people with diabetes.
- ◆ Diabetes stigma and prejudice may result in worse self-care which can increase the risk for higher stress and worse health outcomes for people with T1D or T2D.
- ◆ It occurs in many settings like hospitals and doctors offices, schools and workplaces, places of worship and recreation, and social or personal environments, too.

Taking care of diabetes is already a lot of work. Unfortunately, diabetes stigma makes it harder to take care of diabetes. Remember that you are not alone. Having diabetes is NOT your fault, and you do not deserve to be treated worse because you have diabetes.

Being aware of diabetes stigma and diabetes discrimination is helpful because you will encounter it during your journey with diabetes. Knowing about diabetes stigma before it happens to you can help you identify what is happening as it occurs, how to respond, and how you feel about it. Having strong emotions when you encounter diabetes stigma and discrimination is reasonable, and if this begins to take a toll on you during the course of your journey with diabetes, reach out to your support team or mental health expert to help

SLIDE 12

SLIDE 13

What are unhelpful things that others have said to you about diabetes or living with diabetes?

What are the things that others have said to you that have HELPED make it easier to live with diabetes?

SLIDE 14 (1/3)

We understand that living with diabetes is complex, stressful, and can feel never-ending. It is important to check in on your stress, your emotions, and lean on your support network when you need help. We all need help, and there are many different ways to get help- from friends, from family, from health care providers, from mental health experts, from the diabetes community... there is no wrong way to get help... as long as you get help when you need it!

Diabetes has a big impact on our daily lives. Taking care of the many different self-care items that diabetes requires of us can be demanding. There can be added pressures from the outside world. There can be struggles with health insurance. There can be interruptions to our plans, work, and relationships. Diabetes can cause us stress and as stress increases, it is common for self-care to decrease. However, when stress becomes so overwhelming that it interferes with our ability to function and take care of ourselves, this is a good point to take action. It's never a good idea to stop taking care of yourself, no matter how stressed or busy you feel. This is an example of when our emotional health needs to take priority because if it doesn't, our physical health can start to suffer the consequences.

Quality of life is the balance of stress and well-being, but living with diabetes makes that even a little bit tougher. It's of no surprise that diabetes increases our risk for mental and emotional health concerns like anxiety, depression, diabetes distress, burnout, disordered eating, and shame/denial. These are all responses to the incredible stress that it is to live with diabetes, to navigate the complexities of life while taking care of yourself, and to be resilient in the face of a chronic, lifelong illness. Needing help to support you at different stages of the journey is healthy, and building the right support network can help you every step of the way. It is often easiest to hide some of the challenges when life gets tough, but sharing those challenges and connecting with others who understand or can support us typically helps us feel better.

Here are some of the mental and emotional areas that diabetes increases our risk for. Be on the lookout, and if you start to struggle with any of these, find a mental health professional to help you. The American Diabetes Association has a database of mental health providers with additional training and expertise in diabetes management. These are experts who understand the demands of life with diabetes and how to navigate along the many challenges that diabetes can provide along the journey in addition to the challenges in just life itself.

SLIDE 14 (2/3)

ANXIETY: Diabetes and anxiety go hand-in-hand. Anxiety is worry that becomes overwhelming. Research finds that it's very common in those who live with T1D and T2D. 36% of people with diabetes struggling with anxiety will ever receive treatment and support.

- ◆ One in six people with type 1 diabetes (T1D) is affected by moderate-to-severe anxiety symptoms.
- ◆ One in five people with type 2 diabetes (T2D) who use insulin is affected by moderate-to-severe anxiety symptoms.

WHAT DOES ANXIETY FEEL LIKE? Nervousness, restlessness, or feeling tense; Feelings of dread; Rapid heart rate; Fast breathing; Sweating; Trembling; Weakness; Difficulty focusing; Trouble sleeping; Strong desire to avoid things that trigger anxiety. Take this quiz to see if you are experiencing anxiety.

DEPRESSION: Research shows that if you have diabetes, your risk of developing depression more than doubles. In fact, some studies show that it could be as high as four times more likely to develop depression. People with depression have a higher risk of developing type 2 diabetes, and people with type 2 diabetes are more likely to develop depression after diagnosis.

Levels of depression are highest in the months and the year immediately following the diagnosis. Depression is also a huge predictor of whether a person would develop diabetes-related complications. And the diagnosis of a diabetes-related complication then increases a person's risk of developing depression. Everyone at some stage of their life will experience "feeling down." Depression is more than feeling "bummed out." It's a persistent feeling (lasting more than two weeks).

- ◆ **THINGS YOU MAY DO:** Stop doing things you used to enjoy; Have trouble getting things done; Are unable to focus; Remain in your home for long periods of time; Pull away from loved ones; Use alcohol or sedatives excessively
- ◆ **THINGS YOU MAY FEEL:** Guilt + Anger + Frustration + Unhappiness + Indecisiveness + Disappointment + Sadness
- ◆ **PHYSICAL THINGS YOU MAY EXPERIENCE:** depressed mood; loss of interest in usual activities; low energy; sleep changes; changes in weight and/or appetite; feelings of guilt, worthlessness, and low self-esteem; difficulty concentrating.

Take this quiz to see if you are experiencing depression

SLIDE 14 (3/3)

DIABETES DISTRESS: Stress from the demands of taking care of diabetes can be powerful and disrupting. Those experiencing diabetes distress have strong negative feelings about their diabetes care; Feeling overwhelmed, angry, frustrated about diabetes; You may feel controlled by diabetes; isolated; a need to avoid necessary diabetes management behaviors; or feel a complete lack of motivation to take care of diabetes because it all seems like too much.

Take this quiz to see if you are experiencing diabetes distress

DIABETES BURNOUT: When diabetes distress builds to an untenable amount, burnout happens. Have you ever felt like you are just “done” with diabetes? Diabetes burnout is a state in which someone with diabetes grows tired of managing their condition, and then simply ignores it for a period of time, or worse, forever. Unfortunately, diabetes burnout is common, and most people with type 1 diabetes (T1D) have experienced it at some point in their lives. It’s extremely important to work with a mental health specialist to navigate diabetes burnout. Like we talked about earlier, not taking care of yourself or your diabetes is not a sustainable plan and can become dangerous. Work with your care team closely if you are feeling completely burned out from the demands of diabetes self-care.

DISORDERED EATING: Disordered eating behaviors are common in those with T1D and T2D and it is estimated that up to 20% of those with diabetes have some form of disordered eating. Eating nutritionally, balanced meals that provide adequate nutrition and maintain healthy blood sugar levels are important to all ages. Though, sometimes this can result in severe dietary restriction of certain foods or food groups, eating unusually large quantities of food (binges), eating too much during sleeping hours, feeling a loss of control over eating, becoming addicted to certain foods, or using unhealthy measures to lose weight quickly. Eating disorders are serious and need treatment. They can lead to poor health outcomes for those who experience them. Work closely with your health care team and a mental health expert to navigate disordered eating behaviors.

Take this quiz to see if you are experiencing disordered eating behaviors that need help and attention.

Let’s all pause and take a minute to inventory our own emotions. Please navigate to the Emotional Check-in reflection page in your toolkits (page 48 on the T1D toolkit and page 47 on the T2D toolkit). Know that it’s okay to experience these emotional challenges, and it’s common for many people with T1D and T2D to experience these strong emotions during the course of their diabetes journey. Use this reflection page to check in with yourself and begin planning a path forward. In the next slides, we will learn more about ways to find support for the challenges you are experiencing. For now, we will take a few minutes to journal independently about our own experiences.

SLIDE 15

Thanks for taking a moment to check-in with yourself and your emotional health. It's a good practice to schedule time to do this to take inventory of your feelings, your stress, and how it is impacting you.

If you notice that you are experiencing some challenges, consider mental health counseling or therapy as a way to support yourself through a difficult time. Talk therapy or “therapy” is all about helping you feel better emotionally and mentally. It's a collaborative effort between you and the counselor. You and your therapist work together to see progress over time. Therapy can be life-changing.

Some people hesitate to go to therapy because they believe it's expensive or that they don't “need” it because they should be able to work through challenges independently. There is also a stigma that you have to be “broken” to go to therapy, but that's just not true! Preventative mental health care is just as important as preventative physical health care.

Therapy is a support tool you can use to help address messy and sometimes painful parts of your life. Going to therapy will help you start understanding the science behind what's happening, why you may feel the way you do, and help you unravel all the tools and pieces of what's to come next. Keeping an open mind to learn more about yourself will give you the chance you deserve.

Therapy can be done in-person or virtually through telehealth. If you have health insurance, find your mental health or counseling appointment copay amount—the amount you will pay for each appointment. You can find this by calling the customer support number on the back of your insurance card, or logging into your insurance company's website and looking at a document called your Explanation of Benefits (EOB). It will list in-network and out-of-network costs for mental health providers. In-network providers indicate healthcare providers that have a lower payment deal with your health insurance; mental health copayments for in-network providers typically range from \$0-\$75 per appointment, with a \$30 copay being fairly standard. Whether you have insurance or not, to find a mental health provider, you can ask for a referral from your doctor or you can go through a variety of directories to find a mental healthcare provider you like, then double check with their office to see if they are covered by your insurance or what their self-pay rate is. Many mental health providers offer sliding scale payments, i.e. a lower payment for those with less resources to pay.

If you need help finding a mental health expert, you can ask your healthcare team for a referral, check the American Diabetes Association for a Mental Health Specialist with additional training in Diabetes, or find a provider through your health insurance network. Many local health departments have access to discounted or free mental health counseling services, too.

- ◆ ADA Mental Health Directory: <https://my.diabetes.org/health-directory>
- ◆ Some additional FREE therapy options:
 - [Stanford Medicine Pause a Moment](#)
 - [National Black Justice Coalition Mental Health Support Program](#)
- ◆ [NAMI Local and Virtual Support Groups](#)

SLIDE 16

Though seeing a mental health provider is part of the self-support journey, the rest of your care happens at home. Making sure to build your support network of friends and family will help you do this. To further build your network of other individuals with diabetes who “really get it” and understand the challenges of living with diabetes, check out many of the Beyond T1D and Beyond T2D communities. There are online communities, facebook groups, and social media pages you can follow to get the latest.

SLIDE 17

There may be times where you need immediate help and waiting for appointments or support groups may not be possible. You are not alone. Here are some crisis and emergency resources for you:

SLIDE 18

What are these communities all about? You can find a community of people living with T1D or T2D through the Beyond Type 1 and Beyond Type 2 community platforms. In-person community meetups are often posted on each community platform. You can find opportunities to become an ambassador, share your story, create a meetup, or host a fundraising event to raise awareness for diabetes in your community.

SLIDE 19

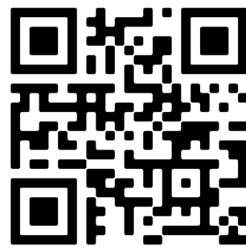
We've talked a lot today about the challenges of living with diabetes and the impact that has on our mental health and emotional wellbeing. Not everyone feels comfortable talking to their doctor about their diabetes, and not everyone knows what questions to ask. As hard as it can be, advocating for yourself is a big part of your diabetes self-management. Simply put: for your needs to be met, they must first be heard! Having an "Action Plan" with your healthcare team can help prepare you for appointments– and make the most of them.



DOWNLOAD THE TYPE 1 APP
Apple Store



DOWNLOAD THE TYPE 1 APP
Google Play



DOWNLOAD THE TYPE 2 APP
Apple Store



DOWNLOAD THE TYPE 2 APP
Google Play

SLIDE 20

On page 49 of the T1D toolkit and page 48 of the T2D toolkit, you will find a discussion guide that you can use to prepare for your next healthcare visit with your care team.

SLIDE 21

Thank you for your attention and group participation today. I hope you enjoyed our session on Building Your Support Team and are feeling confident in all you have learned about mental and emotional health as it relates to diabetes. Don't forget, there are many places where you can look for support- friends, family, others with diabetes, and your health care team.

Although our time together as a group has come to an end, get ready to dive in and learn more ways to connect with others in your community who understand your journey with diabetes and ways you can raise awareness in your local community.

Scan this QR code to join the Beyond Type 1 conversation on living with diabetes.