THE SIDE OF **DIABETES** 10 THINGS YOU NEED TO KNOW

3rd EDITION







The Emotional Side of diabetes.

Living well with diabetes takes emotional strength. Why? Because this is a tough disease. Diabetes is more than just a simple matter of eating right and taking your medications. Staying strong emotionally is the key to keeping stress under control and your blood glucose, blood pressure and cholesterol levels where they belong. Unfortunately, people with diabetes as well as doctors often neglect these "real life" aspects of the disease.

How can you manage diabetes while also giving proper attention to your own thoughts and feelings? What follows are the most important things you need to know about the emotional aspects of diabetes, including:

the personal side the social side the behavioral side

we help you gain **CONTRO**.



Finally... there are **Solutions.**

You can succeed with diabetes through knowledge, good medical care and emotional strength. We hope this booklet will serve you as a first step towards gaining the strength and skills you need.

To learn more, visit us at www.behavioraldiabetes. The Behavioral Diabetes Institute (BDI) is the world's first organization to tackle the unmet psychological needs of people with diabetes. It is a non-profit corporation founded in 2003 and headquartered in San Diego, CA. Through direct clinical services, innovative research and training for health care providers, BDI staff works to help people overcome the emotional and behavioral obstacles to living well with diabetes and to achieve a more hopeful, confident outlook on life.

At www.behavioraldiabetes.org, you can:

- · download free copies of this booklet and other BDI educational materials
- view our educational videos
- learn about BDI programs and services

The President and Co-Founder of the Behavioral Diabetes Institute is Dr.William H.Polonsky, licensed clinical psychologist, certified diabetes educator and associate clinical professor in psychiatry, University of California, San Diego. A nationally-renowned, Yale-educated expert in behavioral diabetes, he has served as Chairman of the National Certification Board for Diabetes Educators, senior psychologist at Joslin Diabetes Center and faculty at Harvard Medical School. He has authored several books on diabetes, including *Diabetes Burnout:* What to Do When You Can't Take it Anymore, published by the American Diabetes Association.



THE PERSONAL SIDE

1.

Harnessing Your Fears

With good care and attention to your diabetes, odds are good you can live a long, healthy life. Many people think they are doomed to suffer terrible complications, but this is not true! Yes, diabetes is a serious disease and many people do develop severe long-term complications, but most of these problems are preventable if you have good medical care and take good care of yourself.

Feeling a little frightened by diabetes is not necessarily a bad thing, BUT when your fears get so big that you feel helpless and hopeless, it's time to take action. You need to harness fear to help you manage diabetes. "I thought complications were inevitable.

Learning about my numbers and what they mean helped me know how to stay safe and feel more in control of my destiny."

- Fight fear with knowledge. Now in the 21st Century, more and more people are living long and healthy lives with diabetes. Learn about the powerful benefits of good diabetes care by talking to your doctor or enrolling in a diabetes education program.
- Know the real odds. Ask your doctor what your real odds for developing complications might be, and what you can do to improve those odds.
- Stay informed. Ask your doctor about medication changes or cool new technology (like continuous glucose monitors) that might really help. Subscribe to any of the popular diabetes magazines, websites and blogs to keep informed about how to avoid or slow complications. See the BDI website for more resources.
- Worried about low blood glucose? If you are anxious about hypoglycemia, ask your doctor about medication changes that can help. Fear of hypoglycemia is about losing confidence in your body. It can lead to chronically high blood glucose, eating problems and an overly restrictive lifestyle. With treatment, these problems can be resolved.
- Stay in charge. Remember that your own self-care actions can make a big difference to your health. You are not helpless! After all, it's not diabetes itself that typically causes serious problems, it's poorly-managed diabetes. With good care, you can live a long and healthy life.



THE PERSONAL SIDE

2.

Overcoming Depression and Distress

Depression is a serious and common problem that can wreck your life, and it can make it harder to manage diabetes. Sometimes what seems like depression is not depression, but a reaction to the stresses and strains of living with diabetes—what is known as "diabetes distress".

And we do know that living with diabetes can get you down. Why? Because managing diabetes is a full-time job that you never wanted, can't quit, and the pay stinks! At times, this "job" can be discouraging, frustrating and seem like it is not worth the effort. Many people describe having tough feelings about diabetes such as anger, fear, guilt and even depression.

The good news is that there are effective strategies to help you recover from depression and from diabetes distress. As you start feel better, this can free up your interest and energy to become more active in managing your diabetes. "Depression felt like my 'give a damn' was broken and it was hard for me to care about my diabetes."

- Watch for the warning signs. Is it diabetes distress or depression? Feeling down and discouraged about diabetes is not necessarily the same thing as depression. Depression is often all about feeling down and hopeless about many areas of your life and can make it tough to even keep yourself going every day. Diabetes distress is also about feeling miserable, but it is being miserable specifically about diabetes, not life in general.
- Take action to avoid depression. Exercise regularly, schedule a "fun" activity every week, and spend time with people you like. Include activities in your daily life that are personally rewarding and meaningful, like taking an interesting class or volunteering. If you are feeling down most of the time, have lost your "get up and go", or have less interest or pleasure from the things you used to enjoy, then talk to your doctor. We do have effective medications and different forms of counseling that can help people recover from depression.
- Take action to avoid diabetes distress. Tackling distress about diabetes may require taking a closer look at your specific concerns (ideally, with your healthcare professional) and developing new ways to: make your selfcare efforts more effective, respond more effectively to hypoglycemia, and be more kind and compassionate with yourself.
- Have hope and don't just sit there! Don't suffer needlessly; read the rest of this booklet and speak with your doctor about getting help now.



THE PERSONAL SIDE

3.

Don't Ignore Diabetes

Many people believe that if they ignore diabetes, then it can't hurt them. They say things like, "I'll start worrying about diabetes when it starts to give me problems, or maybe when I have more time."

And that's the problem! You may not feel bad when your blood glucose is running high year after year, so you may think you don't need to worry about it. But diabetes ignored and left unmanaged can cause damage to your body, even though you cannot feel it.

Odds are good that you can live a long, healthy life with diabetes, but only if you are working to control it now, not sometime later. "When I finally decided to learn about diabetes, I found out that I didn't have to give up everything I loved."

- Learn the important facts about diabetes. Attend a diabetes education class or support group in your area. You need to know that:
 - a. diabetes is a serious disease that can harm you when it is not adequately controlled, even if you feel fine.
 - b. ignoring diabetes is likely to cause more serious health problems.
 - c. paying attention to diabetes can help you to live a longer, healthier life.
- Stay informed about your own health status. See your doctor regularly and complete all of the recommended medical tests (such as AIC, blood pressure and cholesterol). Know the results of these tests and what the results mean. When you are well informed, you feel more able to manage diabetes with confidence.
- **Don't do diabetes alone.** Share your thoughts and feelings about diabetes with a friend. Confiding in someone you trust can help you to gain the support and perspective you need to make sense out of your own emotions, knowledge and attitudes.







Giving Up the Guilt

You are not a bad person because you developed diabetes. It is not your fault.

You are not "bad" because you didn't exercise today or because you ate more than you intended last night.

Nobody can manage diabetes perfectly. Guilt is common when you are living with diabetes, and it is hardly ever useful.

Because of guilt, people often establish tough, sometimes impossible rules about how to manage diabetes ("I must NEVER eat even a bite of junk food ever again"). Since you can never be perfect, rules like these can make you feel like you are failing and can promote depression. Enough already! "I have been so mad at myself, but now I understand that needing insulin doesn't mean I have failed."

- Remember that you didn't give yourself diabetes. As people around the world grow heavier and heavier, it almost seems like everyone is trying hard to develop type 2 diabetes. Yet most "fail" to do so. Obesity and a sedentary lifestyle are contributors to type 2 diabetes, but if you don't have the genes for it, you can't develop it. For type 1 diabetes, your own actions played no role at all. It wasn't all those sweets you ate as a child, or anything else you did.
- With your doctor's help, make sure your diabetes expectations are achievable. Stop beating yourself up when you eat more than you planned, forget to exercise or skip a blood glucose test. You don't have to be perfect to reach the level of control that can keep you healthy. Develop a reasonable action plan that can help you achieve those goals, then relax!
- Get perspective. Instead of criticizing yourself for the occasional lapse, give yourself credit for all of your positive efforts to manage diabetes. Everyone needs a pat on the back, and you probably deserve one right now!



THE SOCIAL SIDE

5.

Appreciating the Power of Pals

Diabetes is easier to manage when you have people in your life who are cheering for you. When you feel alone with diabetes, it is harder to handle. Imagine the meaningful ways that loved ones could support you or help you feel less alone:

- when family members join you in having healthier meals each night,
- when a good friend shares your anger or disappointment with a high blood glucose reading,
- when your spouse offers to help you with your next insulin injection,
- when your neighbor agrees to join you for a brisk walk each morning.

Just having one person in your life who cares can go a long way. So are you ready to make that happen?

"I thought I was the only one who felt so bad, but then I attended this wonderful group program and now I know I'm not alone."

- Ask for the help you need. Many of your loved ones want to support your efforts, especially when you are trying to change habits, but they may not know how to do so in a manner that fits your needs and respects your independence. So think of a small, specific way in which a friend or family member can be helpful, then ask for that help.
- Be a pal to your pals. Ask for support in a kind, considerate way. If you are too demanding, your loved ones may be unwilling to cooperate. Thank your loved ones when they do offer support. Everybody appreciates positive feedback!
- Seek out new friends. Sometimes, friends and family just aren't as supportive as you had hoped. So make some new friends who can understand the hassles of diabetes. Join a diabetes support group in your community or online. Your doctor or diabetes educator can help you find one that is right for you. Talking to other people with diabetes can help you feel less alone.



THE SOCIAL SIDE

6.

Arresting the Diabetes Police

Friends and family may sometimes think it is their right to help you manage your diabetes, whether you like it or not.

Sometimes too much "support", especially if you didn't ask for it, can feel like nagging. Your loved ones are probably acting out of concern and worry, but it can leave you feeling angry, hurt, frustrated, and alone.

When loved ones are bugging you about what to eat or what to do, you may tend to do the opposite of what has been suggested. "Don't think I should eat that piece of cake? OK, then I'll have two pieces!"

Though they mean well, they have become the Diabetes Police, and you've become a Diabetes Criminal.

"Since I convinced my family that I can have sweets on occasion, they have really made an effort not to tell me what I shouldn't eat."

- Start a conversation. Because they care about you, it may be impossible to stop your loved ones from trying to be helpful. So instead of telling them to stop "policing" you, redirect their caring in a way that can work: Thank them for their concern, explain that their actions are not helpful (if they are not), and let them know specifically how they can be of real help. A heartfelt conversation can help you all feel like you're on the same team, with no police and no criminals.
- Consider your own role. Your loved ones may be nagging because they worry you aren't managing diabetes well enough. If they are wrong, let them know how well you are doing by inviting them to your next medical visit, sharing your AIC results, or having them join you at a diabetes education class. If they are right, consider how you might improve your diabetes care and recognize that your loved ones are scared for your health and feel helpless that they can't change it for you.
- Use the BDI's Diabetes Etiquette card (for those who don't have diabetes) as way to start a conversation. You can download one from the BDI website.



7.

From Discouraged to Encouraged

THE BEHAVIORAL SIDE

Are you letting diabetes get you down? Diabetes can be a lot of work and sometimes even your best efforts don't seem to pay off. For example:

- when you follow your doctor's recommendations exactly, but still your blood glucose numbers are elevated.
- when you've begun make many healthy changes, but now learn that you must take even more medications.
- when you've been carefully following a new exercise program, but discover that you haven't lost a pound.

This is understandably frustrating, but don't blame yourself. There are ways to make diabetes care encouraging rather than *discouraging*. "What a surprise. Bit by bit, I have lost over 50 pounds. I now realize how important it is to let the little changes count because they can turn into big changes over time."

- Measure your diabetes progress in a realistic manner. You can never be perfect, nor do you need to be. So measure your progress with your results (for example, AIC, blood pressure and cholesterol), not your day-to-day behavior.
- Know your AIC. Blood glucose levels rise and fall, sometimes for no obvious reason. So learn about the AIC test, a blood test that measures your average blood glucose over the previous 10–12 weeks. Your AIC result can help you to determine how you are really doing and can also help you handle the frustration of those wacky numbers. For most people, if their AIC result is in a healthy range, then they are doing fine overall, even if their blood glucose readings are sometimes erratic.
- Don't let blood glucose readings determine your self-esteem. Blood glucose results may be important, but they are neither "bad" nor "good". They are just information. To help you remember, place a small piece of masking tape on your meter and write on it, "It is just a number".
- Set clear, specific, short-term goals for action. If you just have a vague sense that you should be "eating better" or "checking blood sugars more often," you might think you are never doing enough. With your doctor, determine what your most critical self-care tasks should be, and get specific. For example, exactly how much exercise each week? Or what type of dietary changes at dinnertime over the next month? By clarifying your action plan, you can tell when you are successful.





8.

Keeping Diabetes in its Place

Diabetes is an important part of your life, but it doesn't have to run your life.

For many people, diabetes seems like a prison cell—no more enjoyable foods, no spontaneity, no fun, and constant attention to the clock. Some get so angry they decide to ignore diabetes altogether.

If you find yourself thinking this way, it is time for an attitude change.

Diabetes care in the 21st century means almost everyone can live their lives fully and take care of their diabetes successfully. Sure, some compromises will be necessary, but diabetes shouldn't be allowed to box you in. "When my diabetes was out of control, my whole life seemed consumed with all that I should be doing better.

Now that I have taken some action, I realize that while diabetes is a tough job, I can do it without it controlling my life."

- Feel like you are only allowed to eat birdseed? Eating well with diabetes doesn't mean you must limit yourself to certain foods or only eat at certain times. There are no forbidden foods. Meet with a diabetes-knowledgeable dietitian to develop a personalized meal plan that fits your needs.
- Is the clock running your life? Because of your medications or frequent problems with low blood glucose, the clock may be determining when you eat, exercise or check your blood glucose. In most cases, you don't need to live your life like this. Talk with your doctor about switching to alternative medications and/or trying out one of the cool, new diabetes devices (like an insulin pump) that can give you more control over your life.
- **Build a realistic plan.** You can't take care of diabetes perfectly and you don't have to. With your health care team, develop an overall plan so that diabetes can fit into your life, rather than your life having to fit into the constraints imposed by diabetes.



THE BEHAVIORAL SIDE

9.

Taking Control of Your Environment

Your environment, whether you notice it or not, influences your ability to manage diabetes. Having willpower isn't enough. You need to harness the power of your environment to support, rather than hinder, your diabetes care.

Think about it: how well you eat is affected by the number of tempting foods in your house and the size of the portions on your plate. How faithfully you take your medications is influenced by how many you have and whether you keep them in a convenient, easy-toremember spot each day.

When you take back control of your environment, it no longer controls you. Diabetes becomes easier to handle.

"I've made some simple changes in how I eat, like using a smaller plate and not eating in front of the T.V., and that has really helped me manage my weight."

- Select a convenient place to exercise. Pick a gym, park or road that is close to your home or work. If it is too far away, you probably won't go.
- Keep it ready. If you have home exercise equipment, make sure it is always set up and ready to go. The more effort required to set it up when you need it, the less likely you will use it.
- **Put it away.** Make sure that tempting, unhealthy snacks are out of the house or put away in cabinets out of sight.
- **Start small.** At meals, start with smaller portion sizes. Don't worry, you can always go back for more later.
- Keep things close. Keep your medications, blood glucose meter and supplies in a good spot, like the kitchen counter or dining room table, where you are most likely to see them and use them.
- **Read a book.** For more ideas, take a look at Mindless Eating, a wonderful book by Brian Wansink (Bantam Books).



THE BEHAVIORAL SIDE

10. Taking a Diabetes Vacation

Diabetes can be a lot of work, and it demands your attention every single day. Yes, taking good care of your health is worth the effort, but it is a tough job. All that effort can wear you down, especially if you never get a break. And you can never take a break from diabetes... or can you?

In reality, everyone takes "vacations" from their diabetes. When done poorly, this can be a dangerous thing to do. But when done well, a break from diabetes—an opportunity to not have to think about it for a period of time-- can be a big relief. And you can take good care of your diabetes and overall health without having to think about it all the time. You deserve a break from time to time, but please make sure your diabetes vacations are safe. And "safe" means they should be planned ahead of time, time-limited, and carefully arranged so that your health isn't compromised. Like any good vacation, they should help you to feel rested, and then ready to tackle your diabetes "job" again. "I treat myself with a hot fudge sundae once in a while. I know I will have a higher blood sugar later and don't beat myself up over it. I make sure to take a walk afterwards."

- Work with your health care professional to arrange for healthy, regular breaks from diabetes. A safe vacation doesn't last too long and involves planning ahead so your diabetes control isn't compromised. This doesn't mean quitting your diabetes care altogether. You might, for example, decide to take a night off each week from your diabetes-friendly way of eating, while learning how to adjust your medications ahead of time. A good vacation can restore your energy for managing diabetes.
- Get help if you are taking "unsafe" vacations from diabetes. An unsafe vacation is rarely planned, can go on for a long time, and may threaten your health. Perhaps you have been ignoring everything about diabetes for years, or you take your medications faithfully but decided you didn't want to ever check your blood glucose again. Develop a more practical diabetes plan with your doctor that can help you get back on track and still provide you with occasional safe vacations from diabetes.
- Everyone needs a diabetes vacation, so don't be afraid to take one. But think ahead, and collaborate with your health care providers to build safe and healthy vacations into your life. Enjoy the break!



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