

Overcoming Diabetes Burnout: Helping patients live well with diabetes

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The Faces of Diabetes Burnout

Meet Frank

- Frank is a 54 year old engineer who has had type 1 diabetes for 47 years.
- Until about 5 years ago, Frank's diabetes had been well-managed. Over the past 5 years, Frank has gone through a divorce and has developed several diabetes complications.
- Recently he has felt so helpless about diabetes, that he only checks his blood glucose every couple of days.



Meet Cindy

- ➤ Cindy is a 58 year old retired nurse who was diagnosed with type 2 diabetes 4 years ago.
- Cindy knows she needs to change her diet and exercise more, however she worries that no matter how hard she tries, any change she makes will not be good enough.
- She recently said that she feels angry and frustrated that diabetes has so much control over her life.



Meet Blake

- ➤ Blake is a 21 year old college student who has had type 1 diabetes for 14 years. He has never met another person with type 1 diabetes.
- ➤ Blake recently moved home from college after being hospitalized twice with DKA. He does not check his blood glucose regularly and he takes prandial insulin only sporadically.
- ➤ He knows the risks of not managing diabetes, but states that living his life now is more important than the inconvenience of diabetes management.





"Think about how discouraging it is to fail at something you really wanted to do. Then consider what it must feel like to have diabetes and be failing at something you never, ever, wanted to do in the first place."

- Joan Williams Hoover

What is Diabetes Burnout?

A state in which patients with diabetes grow tired of managing their disease and then simply ignore it for a period of time, or worse, forever.





What does diabetes burnout look like?

- Having strong negative feelings (e.g., overwhelmed, anger, frustration) about diabetes
- Feeling controlled by diabetes
- Feeling isolated, or alone with diabetes
- Avoiding all or some diabetes management and self-care activities
- Being unmotivated or unwilling to make efforts to change this behavior



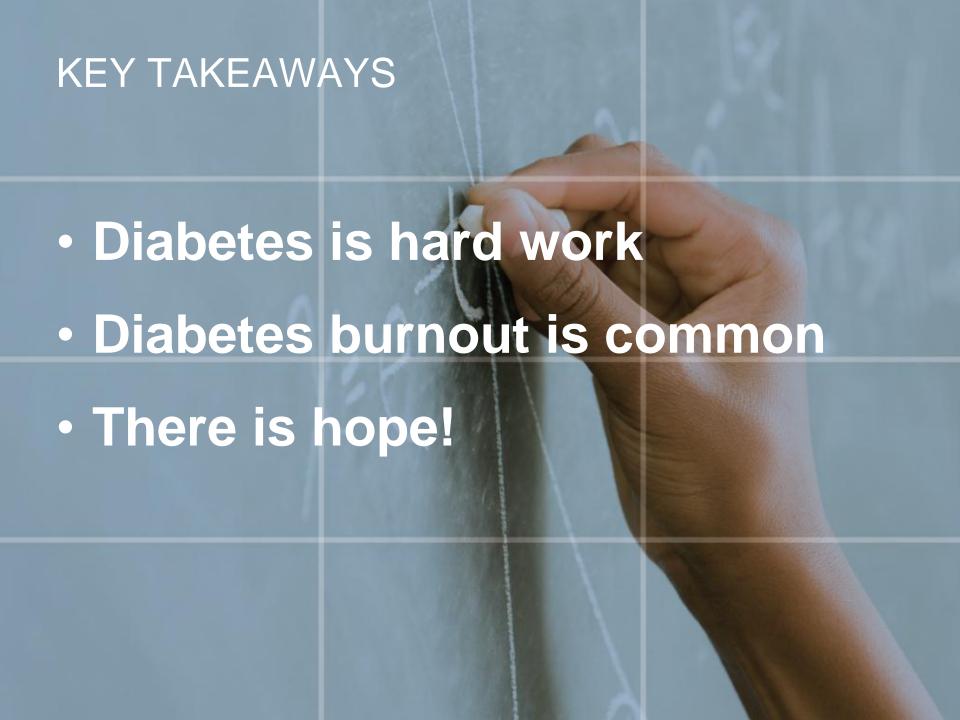




What Diabetes Burnout Is NOT:

- Laziness
- Depression
- Lack of concern about health





POLLING QUESTION

According to a study published in 2015, what percentage of patients with type 1 diabetes reported at least moderate levels of diabetes distress?

A. 11.3%

B. 24.7%

C. 32.8%

D. 41.6%



Assessment Tools

- Diabetes Distress Scale (DDS)
- Problem Areas in Diabetes Scale (PAID)
- Open communication with patients





Diabetes Distress Scale (DDS)

DDS2 is a 2-item screening instrument that asks respondents to rate the degree to which they are (1) feeling overwhelmed by the demands of living with diabetes, and (2) feeling that they are often failing with their diabetes regimen

DDS17 is 17-item scale measuring diabetesrelated emotional stress in 4 areas:

- Emotional burden
- Physician-related distress
- Regimen-related distress
- Interpersonal distress





Diabetes Distress Scale-2

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6



Diabetes Distress Scale-17

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ш		Not a Problem	A Slight problem	A Moderate	Somewhat Serious	A Serious Problem	A Very Serious
1		Froniem	problem	problem	Problem	Froniem	Problem
1.	Feeling that diabetes is taking up	1	2	3	4	5	6
١	too much of my mental and		_		,		
	physical energy every day.						
2.	Feeling that my doctor doesn't	1	2	3	4	5	6
2.	know enough about diabetes and		_ *	,	'	,	
	diabetes care.						
3.	Feeling angry, scared, and/or	1	2	3	4	5	6
٥.	depressed when I think about	١.		3	, ,	,	0
	living with diabetes.						
4.		1	2	3	4	5	,
4.	Feeling that my doctor doesn't give me clear enough directions	1	2	3	4	,	6
	on how to manage my diabetes.						
<u> </u>							
5.	Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6.	Feeling that I am often failing	1	2	3	4	5	6
	with by diabetes routine.						
7.	Feeling that friends or family are	1	2	3	4	5	6
	not supportive enough of self-care						
	efforts (e.g., planning activities						
	that conflict with my schedule,						
	encouraging me to eat the "wrong" foods).						
						_	_
8.	Feeling that diabetes controls my life.	1	2	3	4	5	6
9.	Feeling that my doctor doesn't	1	2	3	4	5	6
	take my concerns seriously						
	enough.						
10.	Not feeling confident in my day-	1	2	3	4	5	6
	to-day ability to manage diabetes.						
11.	Feeling that I will end up with	1	2	3	4	5	6
	serious long-term complications						
	no matter what I do.						
12.	Feeling that I am not sticking	1	2	3	4	5	6
	closely enough to a good meal						
	plan.						
13.	Feeling that friends or family	1	2	3	4	5	6
	don't appreciate how difficult						
	living with diabetes can be.						
14.	Feeling overwhelmed by the	1	2	3	4	5	6
	demands of living with diabetes.						
15.	Feeling that I don't have a doctor	1	2	3	4	5	6
	who I can see regularly enough						
	about my diabetes.						
16.	Not feeling motivated to keep up	1	2	3	4	5	6
L	my diabetes self management.						
17.	Feeling that my friend or family	1	2	3	4	5	6
	don't give me the emotional						
	support that I would like.						





Problem Areas in Diabetes Scale (PAID)

PAID is a 20-item scale that describes common problematic situations for people with type 1 or type 2 diabetes, each representing a unique area of diabetes-specific emotional distress.



Problem Areas in Diabetes Scale

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
Not having clear and concrete goals for your diabetes care?	0	1	2	3	4
Feeling discouraged with your diabetes treatment plan?	0	1	2	3	4
3. Feeling scared when you think about living with diabetes?	0	1	2	3	4
4. Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)	? 0	1	2	3	4
5. Feelings of deprivation regarding food and meals?	0	1	2	3	4
6. Feeling depressed when you think about living with diabetes?	0	1	2	3	4
7. Not knowing if your mood or feelings are related to your diabetes?	0	1	2	3	4
8. Feeling overwhelmed by your diabetes?	0	1	2	3	4
9. Worrying about low blood sugar reactions?	0	1	2	3	4
10. Feeling angry when you think about living with diabetes?	0	1	2	3	4
11. Feeling constantly concerned about food and eating?	0	1	2	3	4
12. Worrying about the future and the possibility of serious complications?	0	1	2	3	4
13. Feelings of guilt or anxiety when you get off track with your diabetes management?	0	1	2	3	4
14. Not "accepting" your diabetes?	0	1	2	3	4
15. Feeling unsatisfied with your diabetes physician?	0	1	2	3	4
16. Feeling that diabetes is taking up too much of your mental and physical energy every day?	0	1	2	3	4
17. Feeling alone with your diabetes?	0	1	2	3	4
18. Feeling that your friends and family are not supportive of your diabetes management efforts?	0	1	2	3	4
19. Coping with complications of diabetes?	0	1	2	3	4
20. Feeling "burned out" by the constant effort needed to manage diabetes?	0	1	2	3	4
PAID • © 1999 Joslin Diabetes Center					





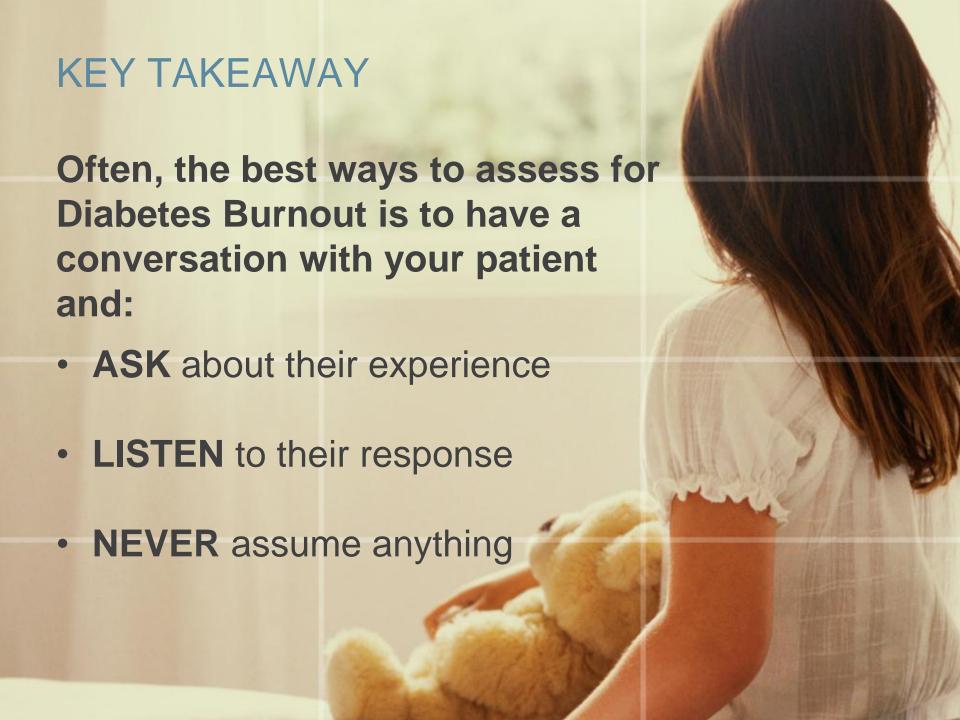
Open Communication with Patients

Often, the best way to assess diabetes burnout is by asking open-ended questions and really listening to their answers.

- Tell me about what makes living with diabetes hard for you.
- What has been the most challenging part of managing your diabetes recently?
- What word(s) do you use to describe diabetes?
- What about living with diabetes takes the most energy?







POLLING QUESTION

In the DAWN2 study, what percentage of healthcare providers said that they would like more training in communication and motivation strategies to support long-term behavior change?

A. 8%

B. 39%

C. 56%

D. 83%



Where should we focus our efforts?

- Behaviors
- Expectations
- Relationships





Behaviors

People with diabetes generally know what they **should** do to manage their diabetes, but they often struggle anyway.

- Help patients identify barriers to diabetesmanagement behaviors
- Identify the behaviors that will have the biggest impact
- Work with your patient to set goals that are specific, measurable and realistic







Expectations

Many people with diabetes believe that they have to manage their diabetes perfectly, setting themselves up for failure.

- Normalize that it is impossible for anyone to be perfect all the time
- Help patients understand that even with good management, diabetes is not always predictable
- Work with patients to help them set reasonable expectations for themselves around diabetesmanagement behaviors and glycemic control





Relationships

Many people with diabetes feel that they do not get enough support and they are struggling with diabetes alone. People with diabetes need support from people in their life including:

- Their health care team
- Their friends and family members
- Others with diabetes





POLLING QUESTION

In a survey of people with type 2 diabetes, over 75% of respondents reported that they:

- A. Are not sticking closely enough to a good meal plan
- B. Are not sticking to a good exercise plan
- C. Are not motivated to keep up with their diabetes self-management
- D. All of the above

KEY TAKEAWAYS

- Help patients identify and overcome barriers to treatment
- Help patients set reasonable expectations for their diabetes management
- Help patients develop a support system
- Refer to behavioral health treatment when appropriate

What happened to Frank?

- Frank found a new endocrinologist who listened to his concerns.
- ➤ He recognized that even though he had developed complications, there were still things he can do to engage with his health.
- ➤ He opened up to his family and friends about his struggles.



What happened to Cindy?

- Cindy learned to break down her diet and physical activity goals into manageable pieces.
- ➤ She came to realize that she did not have to be perfect all the time. Just because she was not perfect one day did not mean that she had lost everything she had gained.
- ➤ Cindy found a group of others dealing with similar issues. This group celebrates members' successes and supports them in their struggles.



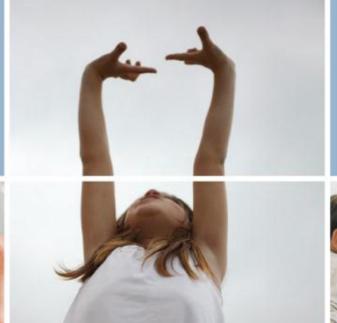
What happened to Blake?

- ➤ Blake is still having trouble overcoming his diabetes burnout.
- Some days he checks his blood sugar and takes prandial insulin, but other days he decides it is too much trouble. This continues to cause conflict in his family.
- Blake's endocrinologist will not prescribe insulin pump therapy until his diabetes management is more consistent.



Diabetes is a fulltime job that no one applies for and no one wants. If you get the job, you can't turn it down, there is no pay, no vacation time, and no matter how bad it gets, you can't quit.

Questions?







THANK YOU



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