

# Diabetes Distress

Regional Diabetes Symposium Breakout Session

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## **CME Disclosure**

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# Objectives

- Understanding and Assessing Diabetes Distress
- Describe commonly held problematic attitudes and beliefs about diabetes and how they can impact patient engagement
- Demonstrate the major strategies for addressing diabetes-related emotional distress
- Case Studies



Regarding people living with diabetes, which of the following is true?

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1. Depression is more common than diabetes distress
2. Diabetes distress is more common in T1D than T2D
3. The prevalence of depression in diabetes is near 50%
4. The prevalence of diabetes distress is less than 10%
5. Diabetes distress rarely occurs in T2D

# Your Difficult Diabetes Patients

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How many of you have seen at least one:

1. Noncompliant patient?
2. Patient who is in denial?
3. Patient who is unmotivated?



# Top 5 complaints about patients with diabetes by physicians / health professionals:

1. Patients say they want to change, but are not willing to make the necessary changes
2. Not honest/Only tells me what they think I want to hear
3. Don't listen to my advice
4. Diabetes not a priority/Uninterested in their condition/ "In denial"/Don't care/Unmotivated
5. They do not take responsibility for self-management

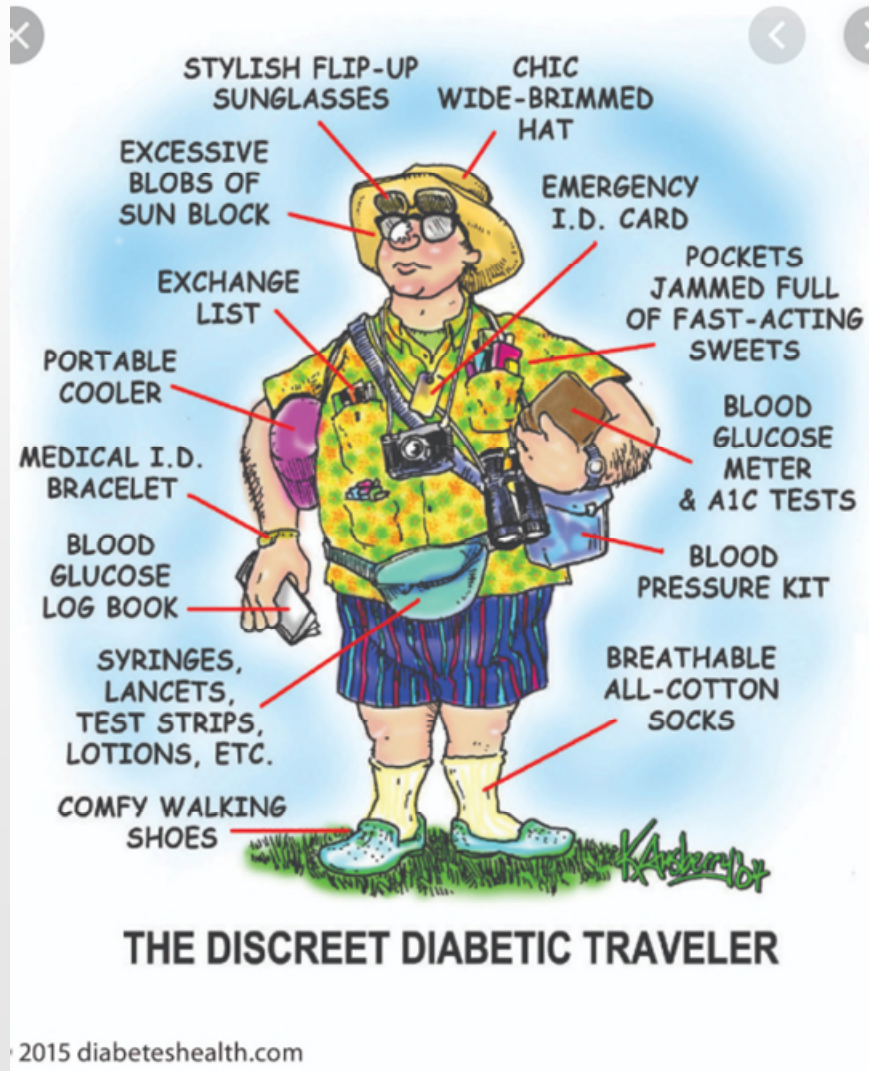




**What is life like living  
with Diabetes??**

# The Ideal

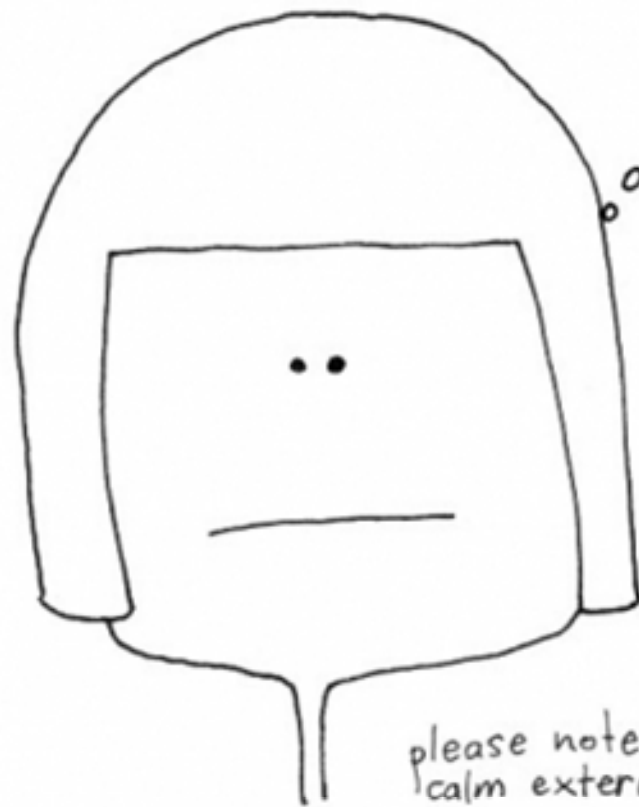
## Be Prepared and Organized— motto for anyone living with DM



A Pumper's Supplies



# what goes on in a diabetic's head:



please note the  
calm exterior

When did I last eat? Where's my  
meter? What's my blood sugar?  
How many carbs in that cookie?  
Salad? Do I need to pee? Are my feet dry?  
How long until lunch? Who will attend my funeral?  
How will people know I died? Any doctor's appointments today?  
I shakey? Am I nervous or is my blood sugar low?  
Is my blood sugar low or am I just a bitch?  
Is there sugar nearby? Am I doing my best?  
What does the clock say? What does the meter say?  
What does the pump say? What does the A1C say?  
What will my friends say? Am I acting normally?  
Am I pale? Can I make it to lunch?  
Am I ok to drive? Do I have enough test strips?  
Does he know I'm diabetic? Am I hungry or am I full?  
How many Oreos make a serving?  
Do I have bad genes? Can I afford health care?  
Why does my head hurt? Who's...

# The Reality

**Stressful** - A constant balancing act & multi tasking



# Diabetes Distress

- **Distress:** The felt burden of living with a tough demanding disease
- **Burnout:** When exhaustion and discouragement becomes too great, the individual may begin to care less and do less



# Diabetes Distress: A Sampling

Despair: “I will end up with serious long term complications, no matter what I do.”

Discouraged: “I am often failing with my diabetes regimen.”

Overwhelmed: “Diabetes is taking up too much of my mental and physical energy every day.”



# Diabetes Distress Prevalence

## Diabetes Distress

- Type 1 Diabetes (n=224) 42%
- Type 2 Diabetes (n= 36,998) 36%

## ***In Contrast***

## Depression

- Type 1 Diabetes (n=6127) 4.6%
- Type 1 Diabetes (n=305) 3.5%
- Type 2 Diabetes (n= 503) 3.6%

***Important to screen for depression with PHQ9 if clinically indicated***

***Depression may impact glycemic control and overall mortality in diabetes***

# Diabetes Distress

**5.35** Routinely monitor people with diabetes for diabetes distress, particularly when treatment targets are not met and/or at the onset of diabetes complications **B**

Diabetes distress (DD) is very **common** and is **distinct** from other psychological disorders. DD refers to significant negative psychological reactions related to **emotional burdens and worries specific to an individual's experience in having to manage a severe, complicated, and demanding chronic disease** such as diabetes. The constant behavioral demands (medication dosing, frequency, and titration; monitoring blood glucose, food intake, eating patterns, and physical activity) of diabetes self-management and the potential or actuality of disease progression are directly associated with reports of DD. The prevalence of DD is reported to be 18–45%, with an incidence of 38–48% over 18 months. **High levels of DD** significantly impact medication-taking behaviors and are **linked to higher A1C, lower self-efficacy, and poorer dietary and exercise behaviors. DSMES has been shown to reduce DD.**

# Measuring Diabetes Distress

- PAID (Problem Areas In Diabetes Scale)
  - 20 items, 5- point Likert scale, no subscale
- DDS (Diabetes Distress Scale)
  - 17 items, 5- point Likert scale, four subscales
- Reliability and Validity are well established
- Linked to Self-Care and Glycemia Control

# Two questions DDS Screener

Each item is rated on a 6-point scale  
from (1) “not a problem” to (6) “a very significant problem.”  
(3) or higher means significant distress

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



# Diabetes Distress Scale: 17 questions survey

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
4. Feeling angry, scared and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
6. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
7. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
8. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
9. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6
10. Feeling that diabetes controls my life.	1	2	3	4	5	6
11. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

# www.diabetesdistress.org

Diabetes Distress Assessment & I x +

diabetesdistress.org/access-dds

Apps Hormone Health Clin Lib FreeT Cal LabNet Lexicomp Imported From IE College Bookmarks rzim.org T connect Other bookma

## Access the Diabetes Distress Survey

Below you can print a copy of the DDS or T1-DDS in English or Spanish along with scoring instructions.

You may also ask patients to complete the DDS or T1-DDS in English or Spanish online. The total, subscale and item scores will be computed automatically and summarized in an accompanying report, available for download or printing.

### CAUTIONS

The resulting DDS or T1-DDS report can be copied and pasted into an electronic health record.

If the patient completes the DDS or T1-DDS on a phone or tablet, however, the report cannot be copied and pasted directly into another device - please email the report from a phone or tablet to a desk - or laptop to complete the copy-paste function.

TO PROTECT PATIENT CONFIDENTIALITY, PLEASE NOTE THAT NO DDS or T1-DDS ITEM OR SUMMARY REPORT DATA WILL BE RETAINED OR STORED ONCE THE RESPONDENT LEAVES THE WEBSITE!

English

Spanish

DDS

Print

Take online

Print

Take online

T1-DDS

Print

Take online

Print

Take online

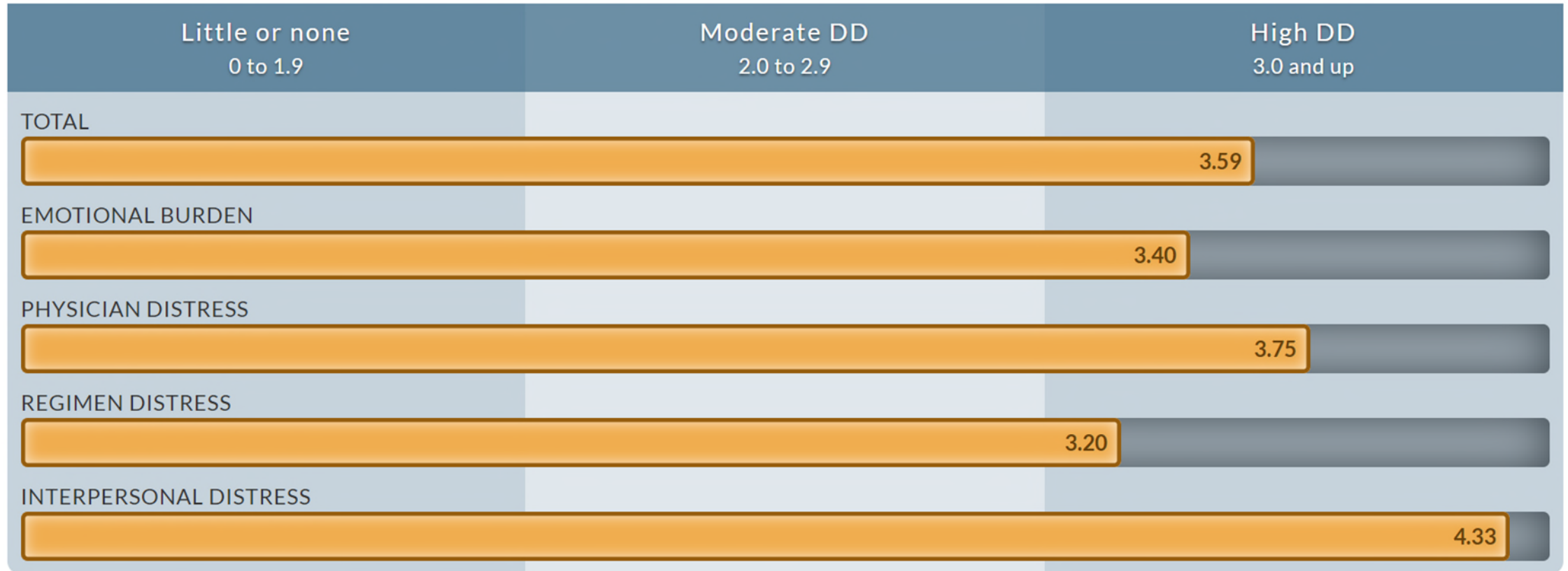
# Diabetes Distress Scale Scores

- Scores between 1.0 and 1.9 reflect little or no distress.
- Scores between 2.0 and 2.9 reflect moderate distress.
- Score 3.0 and higher reflect high distress.
- Any score 2.0 and higher is considered significant distress.

## 4 areas of diabetes distress are:

- **Emotional Burden:**
  - feeling overwhelmed, frightened or fearful about managing the demands of diabetes over time.
- **Regimen Distress:**
  - feeling that you are failing by not managing their diabetes well, e.g., meal plan, exercise, etc.
- **Interpersonal Distress:**
  - feeling that you are not receiving enough support and understanding about your diabetes from family and friends.
- **Physician Distress:**
  - worries about health care and obtaining sufficient expertise, support and direction from health care providers.

## Your DDS Summary Report (page 1)



A score of 2.0 or higher on any scale suggests significant diabetes distress.



# The Fundamental Premise

## No One

- Is unmotivated to live a long and healthy life
- Prefers to feel miserable in the face of diabetes

## The Real Problem

- Living with diabetes can be tough



# Addressing Diabetes Distress

## 1. Assess the problem

- Don't try to fix your patients' difficult feelings
- Instead, ask, acknowledge, and normalize
  - “What one thing about diabetes that's driving your crazy?”
  - “Given the nature of diabetes, feeling this way is perfectly reasonable and many others feel the same.”

# Addressing Diabetes Distress

1. Assess the problem

2. Despair...provide a sense of realistic hope

- Share the good news (not just inducing fear)
- “With good care, odds are good that you can live a long, healthy life with diabetes.”

# Joslin Diabetes Center's 50-Year Medalist Study Update

Winter, 2018

Greetings from Joslin Diabetes Center's 50-Year Medalist Program! We are writing to thank you for your continued participation and support of the Medalist Study and to update you on happenings in the program and some of the many exciting developments related to our research.

**Medalist Celebration and Grand Opening of Medalist Study Center**





# Addressing Diabetes Distress

1. Assess the problem
2. Despair...provide a sense of realistic hope
3. Discouraged....Make success possible
  - Providing appropriate medical solution may be key: the power of “perceived treatment efficacy”

# Promoting Success Experiences

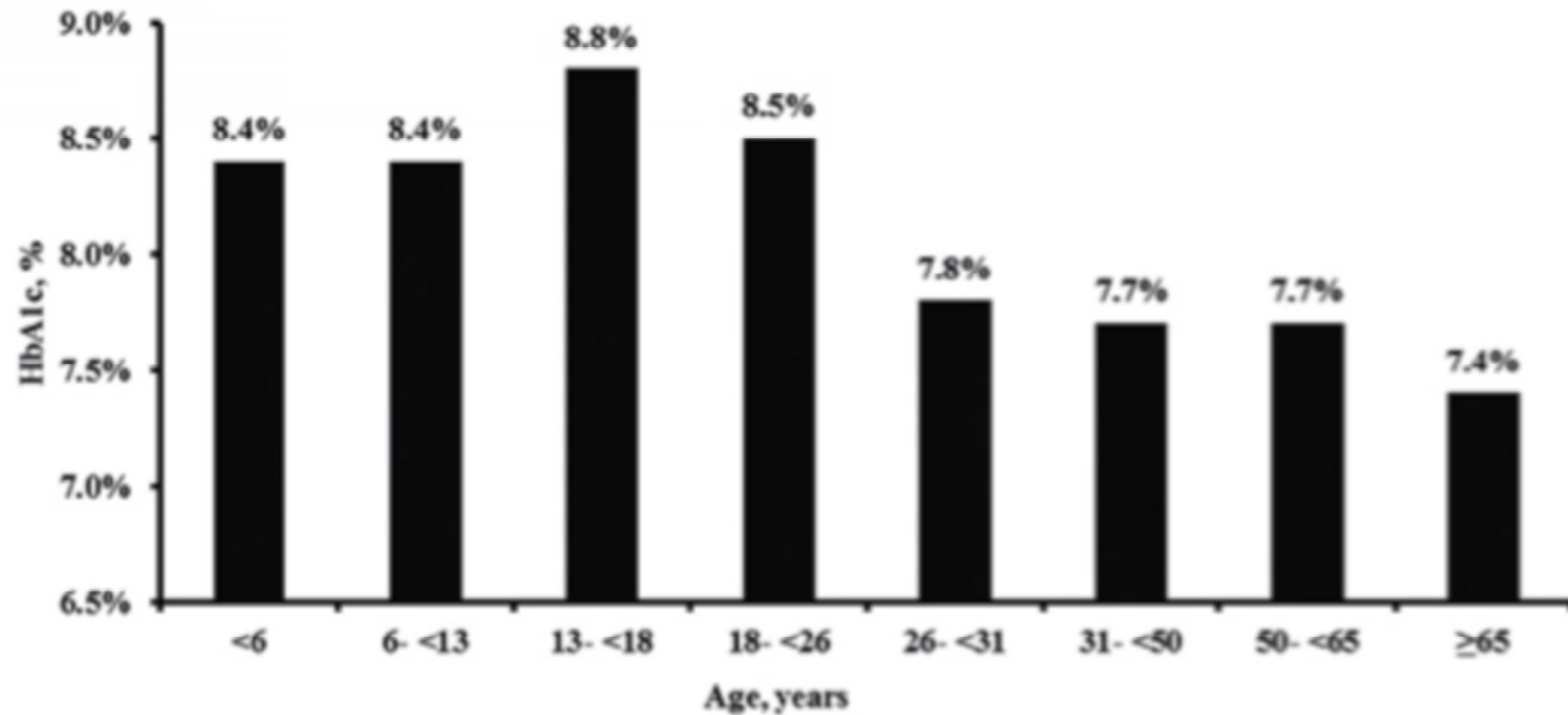
*Look for ways to congratulate. So consider:*

“This is great you brought in your BG record.”

VS

“Your numbers are still too high. What have you done wrong this time?”

# T1D Exchange: Mean A1C Values



n = 25,833; Beck et al, 2012

# Addressing Diabetes Distress

1. Assess the problem
2. Despair...provide a sense of realistic hope
3. Discouraged....Make success possible
4. Overwhelmed...Promote a doable plan
  - Help to show self-care actions can make a difference
  - A doable plan is specific, efficacious, and not too much

# Use of Empowering Language

Five key consensus recommendations for language use:

1. Use language that is neutral, nonjudgmental, and based on facts, actions, or physiology/biology;
2. Use language that is free from stigma;
3. Use language that is strength based, respectful, and inclusive and that imparts hope;
4. Use language that fosters collaboration between patients and providers;
5. Use language that is person centered (e.g., “person with diabetes” is preferred over “diabetic”).

# Case #1

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Age 31 married male no children

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Stated type 2 but actually has type 1 diabetes

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Chronically elevated A1c 11.1-17.9% with multiple complications (retinopathy, previous osteomyelitis, hospitalization for DKA)

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Poor clinic follow up

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Stopped taking meds for 1 year



# Case # 1 (Con't)

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## Components of Distress

Assessment with pt and wife revealed difficulty affording co-pay, difficult alternating work schedule

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Wife of 2 years did not know about what pt needed to manage DM or about the extent of his non-compliance

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Pt feels that diabetes has been unmanaged for so long that increasing compliance wouldn't make a difference in his future

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Also feels guilty and responsible for not being able to bear children

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Pt denied depression

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# Case #1 (Con't)

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## Intervention

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Increased wife's knowledge and involvement

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Wife started meal prepping and making pt's lunches

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Linked with Financial Aid Program

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Reviewed suggestions for gentle reminders

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Educated about relationship between mood and DM control

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Recent Ophthalmology appointment showed significant improvement which was validating for pt

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Wife states pt's mood improved and she remains involved

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# Case #2

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Age 43 male married no children

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DM1 since age 17

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Referral for "DM denial"

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A1c's in 9-10% range

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Complications includes Charcot Arthropathy, Erectile Dysfunction

## Case #2 (Con't)

### Components of distress

- General Anxiety
- From an African American military family: guilt about being unable to join arm forces due to diabetes, counseling thought to be a weakness
- Age of onset: management wasn't convenient
- Pt was reactive vs. proactive
- Father is ill, pt is only boy of 4 children and recently taken on caregiving for father and father's role as patriarch
- Travels an hour to work, works out in the field supervising youth with little downtime.

## Case #2 (Con't)

### Intervention

- Reviewed components of distress and acknowledged recent willingness to make changes
- Pt decided to focus on carb counting and planning meals
- Took 2 weeks off work to focus on management and make changes
- He was started with a CGM based on his hectic work schedule and time in the field and continued to meal plan
- Started exercising again
- A1C reduced from 9.1% to 8.2%

# Case #3

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Age 55 male married 2 kids

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Diagnosed with DM1 during his 30's

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Supportive wife, little other support

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Has arthritis in hands that significantly impairs function

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Developed fear of low blood sugars in 2015 after hospitalization for hypoglycemia



# Case #3 (Con't)

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Components of distress

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Fear of lows

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Difficulty testing and injecting at times due to pain and deformity in hands

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Completed DDS with highest scores in "Powerlessness and Hypoglycemia distress"

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Also noted very high Anxiety and possible Bipolar with no actual diagnosis or treatment.

## Case #3 (Con't)

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### Intervention

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Provided with CGM to assist with ease of testing and lessen anxiety about lows at night

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Referred to Psychiatry for assessment of Anxiety, Bipolar and medication management

# In Conclusion

Addressing diabetes distress is all about reducing powerlessness and regaining a sense of personal control over diabetes



# Regarding people living with diabetes,

Diabetes distress (DD) is more common than depression

DD is common in both T1D and T2D

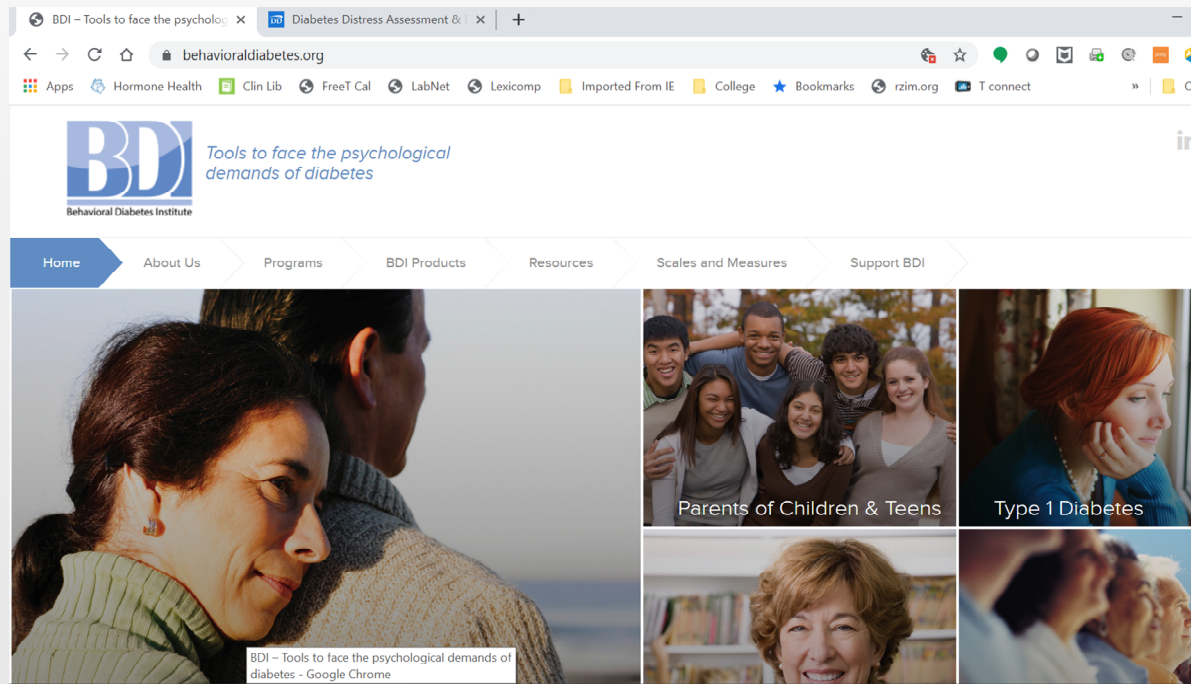
The prevalence of depression in diabetes is ~10%

The prevalence of DD is up to 48%

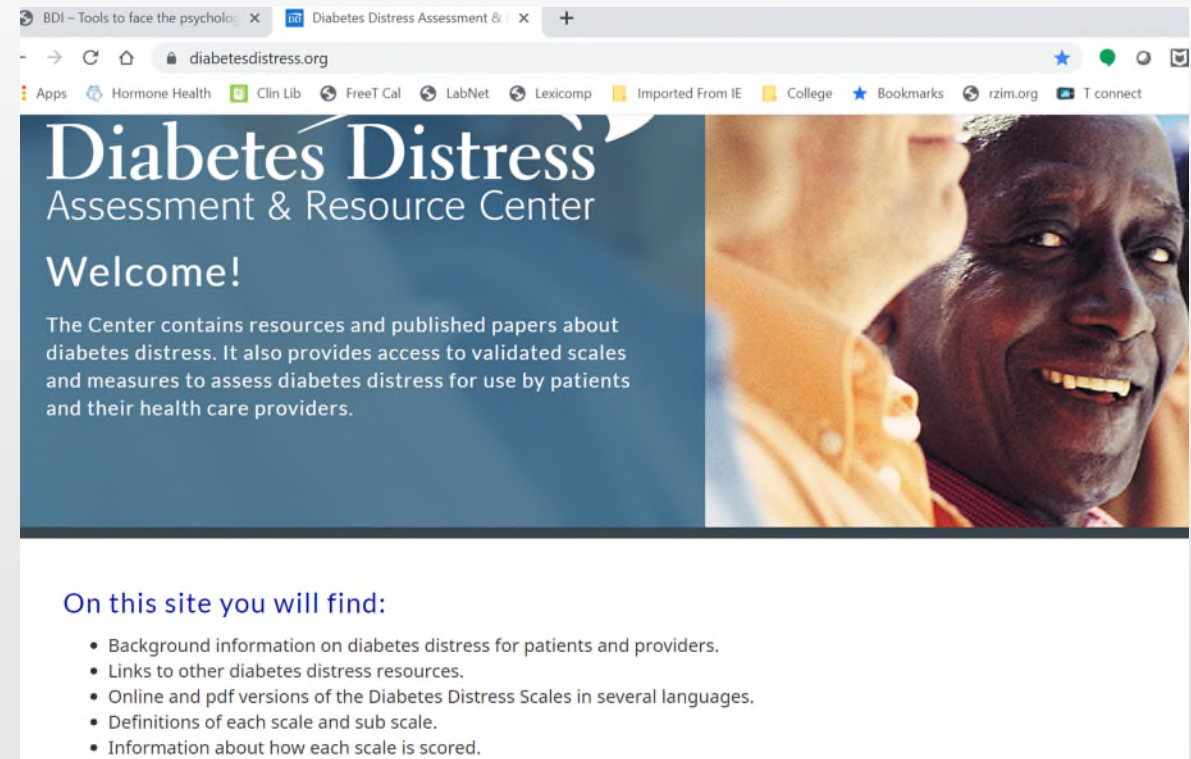
Consider screening for DD using DDS or simply asking: "What one thing about diabetes that drives you crazy?"

# Additional Resources

[Behavioral Diabetes Institute](https://behavioraldiabetes.org)  
<https://behavioraldiabetes.org>



<https://diabetesdistress.org>







Questions?