



# Supporting PwT1D to be Self-Advocates

**Marissa Town, RN, BSN, CDCES**

Clinical Director, Children with Diabetes

Community Diabetes Educator, Cincinnati Children's Hospital

***DISCLOSURE*** CWD receives support from the following sponsors:

- Walgreens
- Dexcom
- Abbott
- Insulet
- Provention Bio
- Tandem Diabetes Care
- Lilly
- JDRF
- Medtronic
- Splenda
- Novo Nordisk
- Xeris





# We are all Human.



- Autonomy is one of the key aspects of being human
- When people are enabled and empowered to have autonomy related to their healthcare, odds are the outcomes will be better



# Considerations

- Would you want someone to choose your groceries for you?
  - Do they know better than you what you should eat?
  - Do they know if you know how to cook with the foods they give you?
  - You'd have to make do to the best of it
- *How do you feel about this?*





# Knowledge versus Wisdom

- Knowledge is knowing that a tomato is a fruit, wisdom is not putting tomatoes into a fruit salad.
- Healthcare providers may feel they know what is best for people with diabetes
  - When they suggest things – or worse, require things – of other people, do they truly *know* what is best for them?
  - Does someone else know what is truly best for you?
    - Perhaps they do, but will you *listen*?



# Tip #1 - Listen + Empower

- Listen to the people with diabetes and their families
- Even more, make sure you are encouraging other health care professionals to listen to the people that they are seeing for care as well
- By listening, you are telling people that their voice, their feelings, their experience matters
- “Sit down, be humble” – Kendrick Lamar



# CGM use in newly diagnosed children with T1D

**ISPAD 2023**  
ROTTERDAM, THE NETHERLANDS  
49<sup>th</sup> Annual Conference | October 18 - 21, 2023  
Pediatric diabetes in a rapidly changing world



**DIABETIC**  
Medicine

**DIABETES UK**  
KNOW DIABETES. FIGHT DIABETES.

RESEARCH: CARE DELIVERY | Full Access

**'I was ready for it at the beginning': Parent experiences with early introduction of continuous glucose monitoring following their child's Type 1 diabetes diagnosis**



## Study Protocol

Visit 1: DX

Visit 2: CGM start

Visit 3: CGM FU

Visit 4: Recent onset visit

Visit 5: CGM support

Visit 6: Standard visit

- High levels of satisfaction and reliance
- All participants recommended
- All committed to continuing using the technology if insurance covered it.

Tanenbaum, Diabetic Medicine 2022



**ISPAD 2023**  
ROTTERDAM, THE NETHERLANDS  
49<sup>th</sup> Annual Conference | October 18 - 21, 2023  
Pediatric diabetes in a rapidly changing world



# You don't know what you don't know

- “Yeah. I just got offered that recently when I went to my doctor on Wednesday. Never before, and I've had it for a year and a half. I didn't know the technology existed.”
- “I didn't really have a choice as to why I didn't get it [CGM and insulin pump]. I couldn't have it because my blood sugar was always high.”
- “He [the doctor] just said if I was a bit more responsible, if I'm getting my numbers under control, then he would see if I should get the pump or not. But then in my mind I'm like, Wouldn't you want me to get the pump anyway so I can control my diabetes and so my numbers can get better?”



## Limitations/ Future Directions

**ISPAD 2023**  
ROTTERDAM, THE NETHERLANDS  
49<sup>th</sup> Annual Conference | October 18 - 21, 2023  
Pediatric diabetes in a rapidly changing world



- There is no demographic that does not benefit
  - There is no glycemic range that does not benefit
  - **Cost and access is the real issue**
- 
- Reduce diabetes management burden while optimizing efficacy
  - Recognize the importance of family support and diabetes education
  - **Focus on wider access across the diabetes population.**



Shout out to  
Dr. Laya  
Ekhlaspour  
from UCSF and  
Dr. Sue Brown  
from UVA

**ISPAD 2023**  
ROTTERDAM, THE NETHERLANDS  
49<sup>th</sup> Annual Conference | October 18 - 21, 2023  
Pediatric diabetes in a rapidly changing world





# “Life is lived off-label” –J.H.

- Diabetes doesn't follow rules, so how can we make black and white rules for diabetes care?
  - CGM approved locations for wear
  - Insulin pump or CGM approval by age
  - Expired supplies or “Diabetes Black Market” supplies
  - GLPs + SGLTs



# Our lives are in your hands – and we know it

- Prescribing
  - Medications
  - Devices
- Support vs. Shaming and Blaming
- Accessibility
  - FMLA, Driver's License forms
  - Resources – diabetes related and general resources





## Tip #2 – Don't stand in the way

- When people ask for things, consider it, discuss it, and do your best to help them obtain it – avoid being the gatekeeper
- If there are contraindications, find an alternative that helps them achieve their goal
- If you don't know how to support them, refer them to another provider or a diabetes community – remind them that their voice matters!

# Stigma

a

83%

81%

Feel as though others believe diabetes is a character flaw or a failure in personal responsibility

38%

25%

Report that stigma has impacted their emotional life—feeling shame, blame, isolation, and guilt.

25%

27%

Report that stigma has impacted their social life.

17%

22%

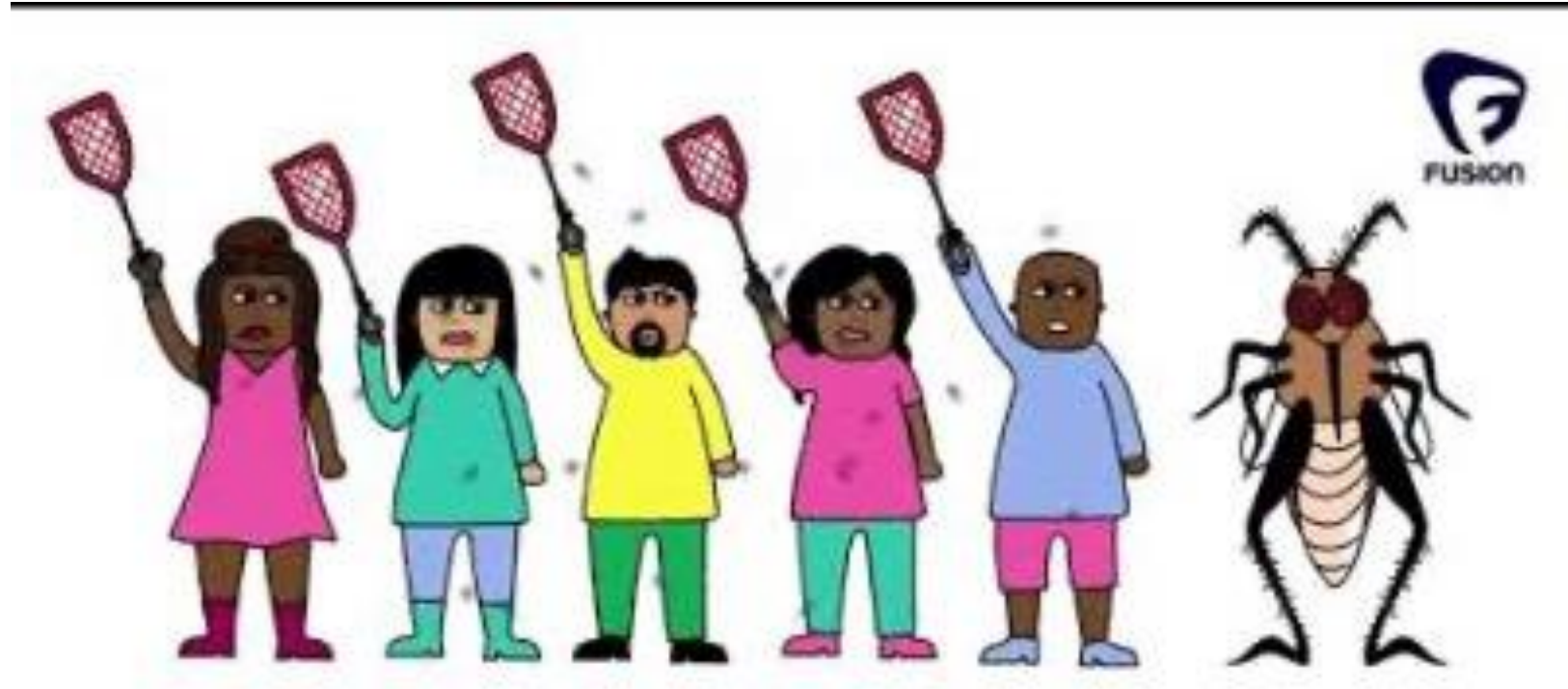
Report that stigma has impacted their diabetes management.

● Type 1 diabetes

● Type 2 diabetes



# Stigma



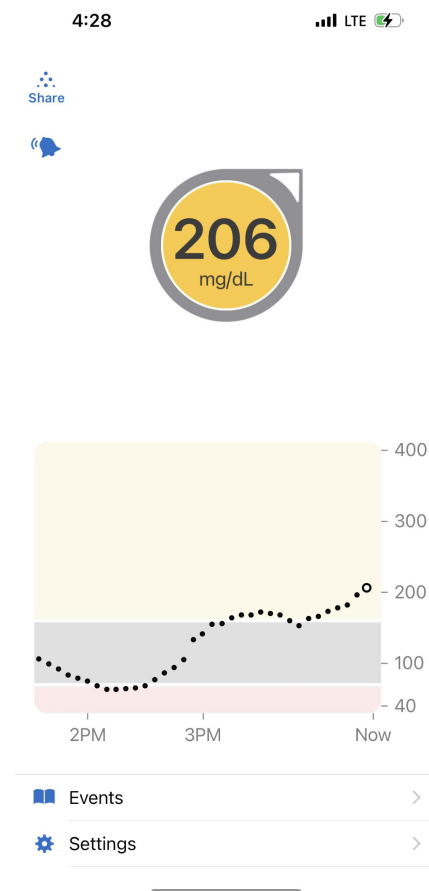
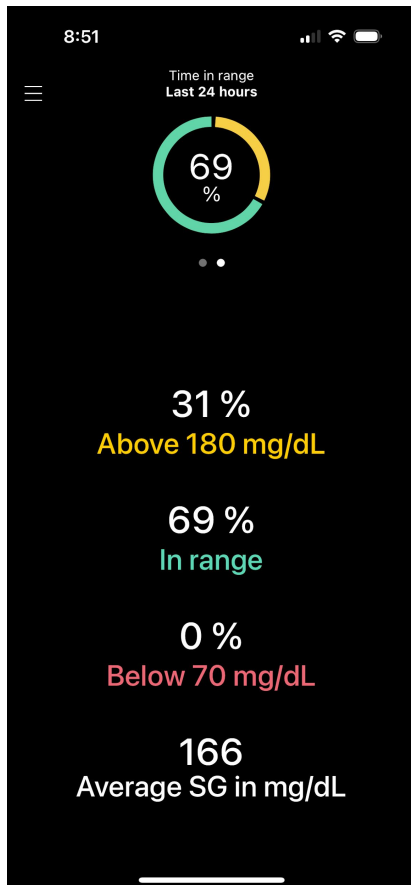
WE MEAN MICROAGGRESSIONS.

# Tip #3 - Your Language Use REALLY Matters

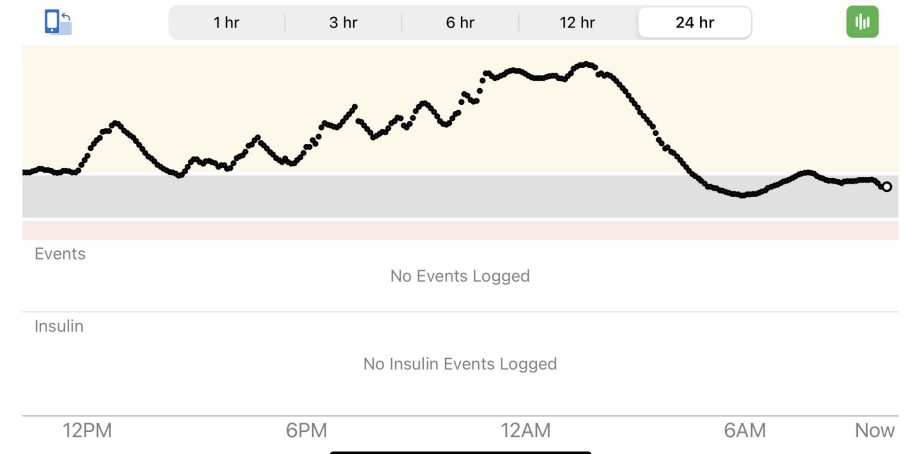


- Acknowledge the challenges with stigma in peoples' lives
- Avoid stigmatizing language, behaviors, and examine your own beliefs or biases
- Do your homework – if you are not familiar with the ADCES Language Matters tool, please visit the website and learn more
- “People will forget what you said, people will forget what you did, but people will never forget how you made them feel” – Maya Angelou

# Perfection Does NOT Exist



- Diabetes is a science experiment
- $A + B$  does not always =  $C$





Blood Sugar & Medication Record - Insulin Pump

Name: Manissa Town

Home Phone: W 400 0000

Work/Cell Phone: 539 100 081

MR#: \_\_\_\_\_

DOB: 8 131 87 GA: 16 weeks

Wilson Evans T1DM T2DM

**PREGNANCY GOALS: Before meals 50-90; one-hour after meals 90-120, before bedtime snack and 3 AM 60-90. PLEASE BRING YOU THIS RECORD AND YOUR BLOOD GLUCOSE METER TO EVERY VISIT.**

Insulin: <input type="checkbox"/> HumaLog <input checked="" type="checkbox"/> NovoLog			Insulin pump settings verified/Date:			Site change verified/Date:	
Sensitivity Factor: <u>1.65 / 6A 1.50 / 4P 1.60</u>			Active Insulin Curve: <u>2.15 hours</u>			Total Daily Doses	
Times:	<u>12A</u>	<u>9A</u>	<u>9A</u>	<u>4P</u>	<u>7P</u>	<u>9P</u>	Date: <u>3/26</u> <u>35.5</u>
Basal Rates:	<u>0.5</u>	<u>0.525</u>	<u>0.5</u>	<u>0.4</u>	<u>0.575</u>	<u>0.475</u>	Date: <u>3/27</u> <u>31.1</u>
Changes:							Date:
I:C Ratios	Breakfast:	Lunch:	Dinner:	Bedtime:			
Changes:	<u>1:8</u>	<u>1:10</u>	<u>1:11</u>	<u>1:13</u>			

**Blood Sugars - Remember to eat meals and snacks every 2-3 hours apart beginning at 8AM**

Date	3 AM	Before breakfast	1 hr after the start of breakfast	Before lunch	1 hr after the start of lunch	Before dinner	1 hr after the start of dinner	Bedtime	Others	Comments
<u>3/26/13</u>	<u>90</u>	<u>108</u>	<u>79</u>	<u>78</u>	<u>89</u>	<u>92</u>	<u>60</u>	<u>101</u>		<u>WORK 7-7p</u>
<u>3/27/13</u>	<u>48</u>	<u>102</u>	<u>143</u>	<u>99</u>	<u>108</u>	<u>50</u>	<u>90</u>	<u>104</u>		<u>WORK 7-7p</u>
<u>3/28/13</u>	<u>39</u>	<u>73</u>	<u>117</u>	<u>58</u>	<u>77</u>	<u>72</u>	<u>89</u>	<u>134</u>		<u>Easter Dinner</u>
<u>3/29/13</u>	<u>88</u>	<u>103</u>	<u>84</u>	<u>98</u>	<u>99</u>	<u>99</u>	<u>50</u>	<u>68/66</u>		
<u>3/30/13</u>	<u>101</u>	<u>90</u>	<u>98</u>	<u>104</u>	<u>52</u>	<u>75</u>	<u>143</u>	<u>91</u>	<u>3:45-45</u> <u>3:55-30</u> <u>4:15-67</u>	<u>WORK 7-3p</u> <u>-when 30 units - 10B1</u> <u>low dose glucose quick</u>
<u>3/31/13</u>	<u>62</u>	<u>106</u>	<u>122</u>	<u>35/49</u>	<u>79</u>	<u>84</u>	<u>158</u>	<u>64</u>		<u>WORK 7-7p</u>
<u>4/1/13</u>	<u>60</u>	<u>98</u>	<u>125</u>	<u>70</u>	<u>80</u>	<u>127</u>	<u>80</u>	<u>91</u>	<u>7:30 42</u> <u>7:35 41</u>	<u>WORK 7-7p</u> <u>Keep clean</u> <u>Vomiting, liquids only</u>

Please call 513.558.0738 if 2 blood sugars are less than 50 or greater than 200 in 24 hours or if your blood sugars are outside goals 3 OR MORE DAYS. Or FAX BLOOD SUGARS to 513.558.9982. Office hours are Monday through Friday between 8 and 5 PM.

4/2/13 42 70 107

After vomiting





## Tip #4 – Acknowledge the Suck

- Acknowledge that diabetes is something we are still learning about and it is impossible to achieve perfection
- Encourage people to meet others with diabetes – diabetes online communities, local support groups, camps, Friends for Life conferences, etc. – to find peer support
- Remind PWD that they may know their diabetes best and encourage them to speak up with HCPs who do not understand or are less inclined to listen



# Relationships with Diabetes



- Everyone has their own unique, individual journey with diabetes
- Changes across lifespan + duration of diabetes
  - Diagnosis
  - Burnout
- Help people "own" their diabetes so it doesn't own them



# Diabetes Advocacy

- “Each time a woman stands up for herself, without knowing it possibly, without claiming it, she stands up for all women” – Maya Angelou
- Many PWD experience challenges within the healthcare system and it propels them into diabetes advocacy
- Connections with other PWD are key to helping develop a strong sense of self related to diabetes



## Tip #5 - Empower and Support PWD

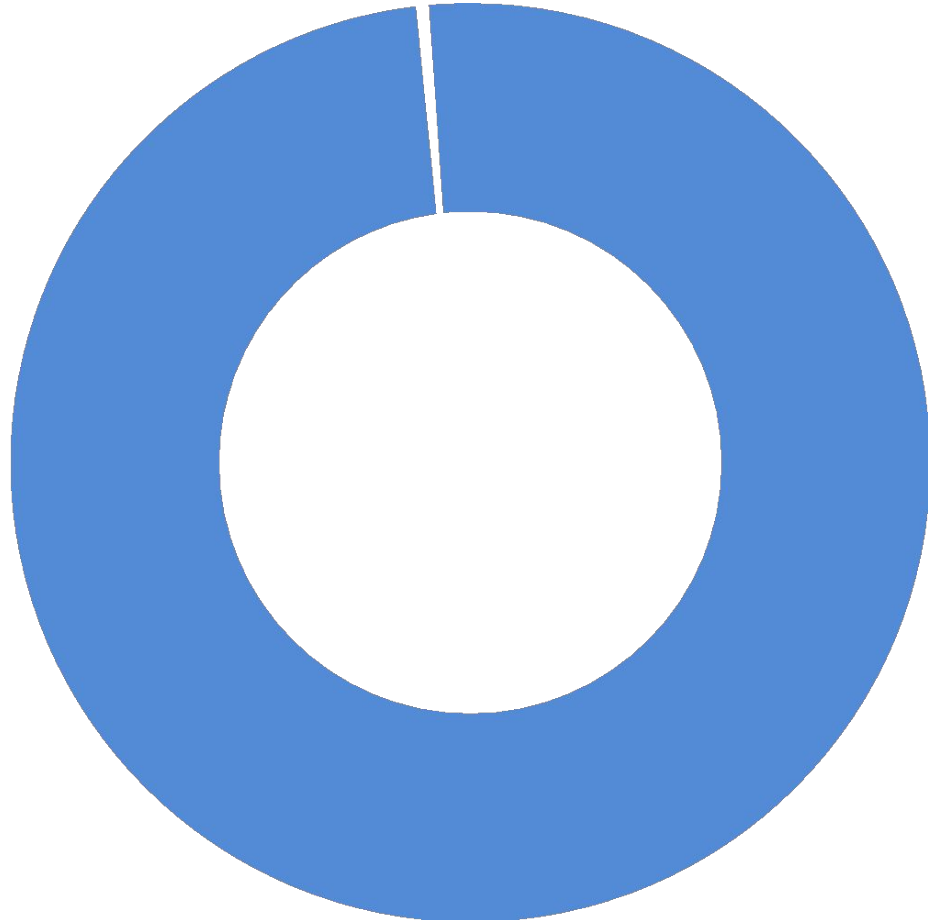
- Support PWD in their own relationship with diabetes
- Encourage them to seek out events for PWD to meet others who truly understand what living with this every day means
- Provide resources for mental health and wellness during times that they're struggling



# In Summary

- Tip #1 - Listen + Empower
  - Tip #2 – Don't stand in the way
  - Tip #3 - Your Language Use REALLY Matters
  - Tip #4 – Acknowledge the Suck/Challenge
  - Tip #5 - Empower and Support PWD
- 
- Have compassion for yourself + others

Because at the end of the day...



99.98% of the time  
PWD are managing  
their diabetes on  
their own

Thank you  
for listening!

Email:

[marissatown@childrenwithdiabetes.com](mailto:marissatown@childrenwithdiabetes.com)

