

**JDRF**  
**typeone**  
**nationsummit**  
IMPROVING LIVES. CURING TYPE 1 DIABETES. **T1D**



THE EMOTIONAL BURDEN OF DIABETES  
AND HOW WE CAN HARNESS TECHNOLOGY  
TO HELP

## PSYCHOSOCIAL BARRIERS

# Outline

- Common challenges in diabetes
- Ways to address distress/burden
- How technology can impact wellbeing
- Harnessing the benefits of technology



# PSYCHOSOCIAL BARRIERS

## Diabetes Can Be Tough!

- Treatment takes both physical and mental energy
- Time-consuming
- Can disrupt daily life and activities
- No breaks
- No end



# Burden of diabetes



# Invisibility of diabetes



# Real world example

What do you see?



# People with type 1 diabetes see this...

**PROBLEM:** Starting the Day

Diana Betes wakes up at 6:30 AM With a Blood Glucose (BG) level of 60 mg/dL. She plans to have a cup of coffee with 4 oz milk on her 1/2 mile walk to work.

A) How many glucose tablets does Diana need to correct her BG level?  
 B) How many units of insulin does Diana need?

**GIVENS:**

- Normal BG = 70-120 mg/dL
- 1 carb ↑ BG 5 pts.
- 1 Glucose Tablet = 4 carbs
- 6 carbs = 1 unit of insulin
- 1 unit of insulin ↓ BG 60 pts.
- 1/2 mile walk ↓ BG 60 pts.
- 8 oz Milk = 12 carbs
- The Dawn Phenomenon is a hormonal occurrence which ↑ BG upon arising; 1 unit is required by Diana.

**A) Target BG = 120 mg/dL.**  
 Current BG = 60 mg/dL. (LOW!)

needs to  $\overset{0}{\cancel{120}}$   
 ↑ BG by  $\rightarrow \frac{120}{60} = 2$  pts

$\frac{1 \text{ carb} \pm 5 \text{ pts}}{x \text{ carbs } 60 \text{ pts}}$

$\frac{5x}{5} = \frac{60}{5}$

$x = 12 \text{ carbs}$

$\frac{1 \text{ GLUCOSE TABLET}}{y \text{ GLUCOSE TABLETS}} = \frac{4 \text{ carbs}}{12 \text{ carbs}}$

$\frac{4y}{4} = \frac{12}{4}$

$y = 3$

**Diana needs 3 Glucose Tablets**

**B) Current BG = 120 mg/dL.**

- Correction dose = 0 units . . . . . + 0 units
- Dawn Phenomenon = 1 unit . . . . . + 1 unit
- Coffee with 4 oz milk  
 coffee = 0 carbs  
 8 oz milk = 12 carbs  
 4 oz milk = x carbs

$\frac{8x}{8} = \frac{48}{8}$   $x = 6 \text{ carbs}$

6 carbs = 1 unit insulin . . . . . + 1 unit

- 1/2 mile walk ↓ BG 60 pts.  
 1 unit insulin ↓ BG 60 pts. . . . . - 1 unit

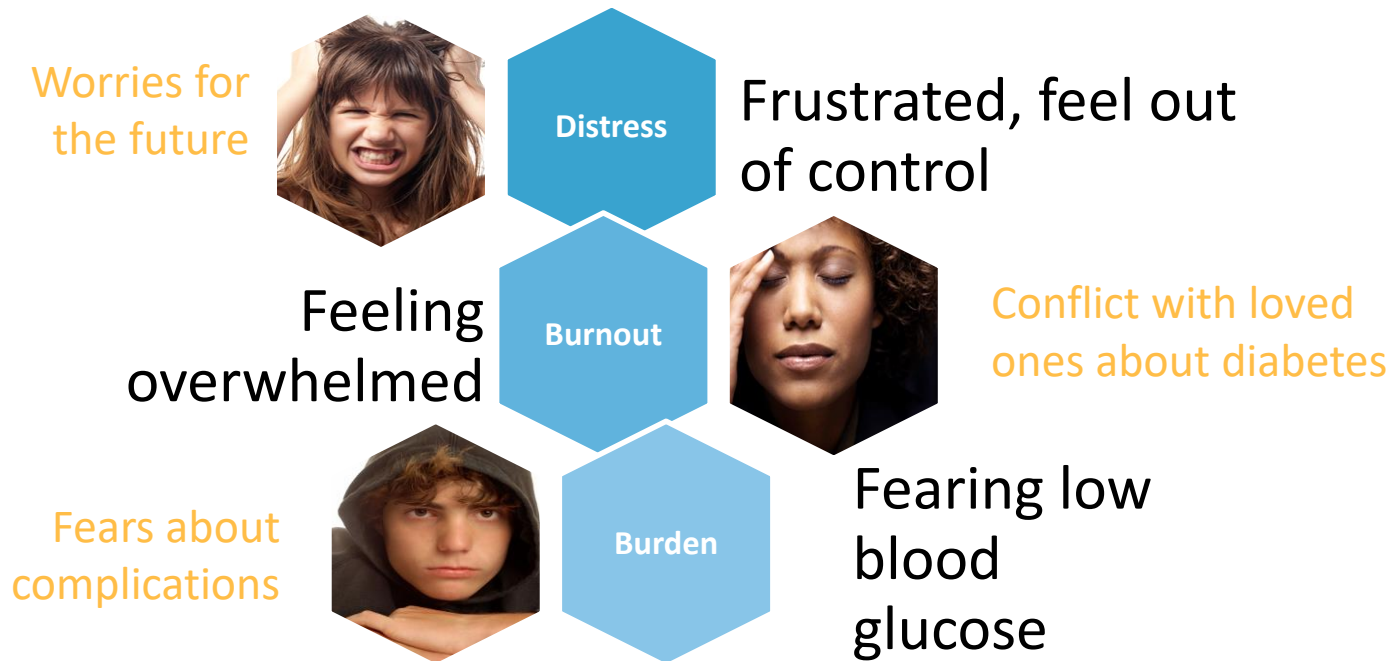
**Diana needs 1 unit of insulin to start her day!**

www.d  
 77

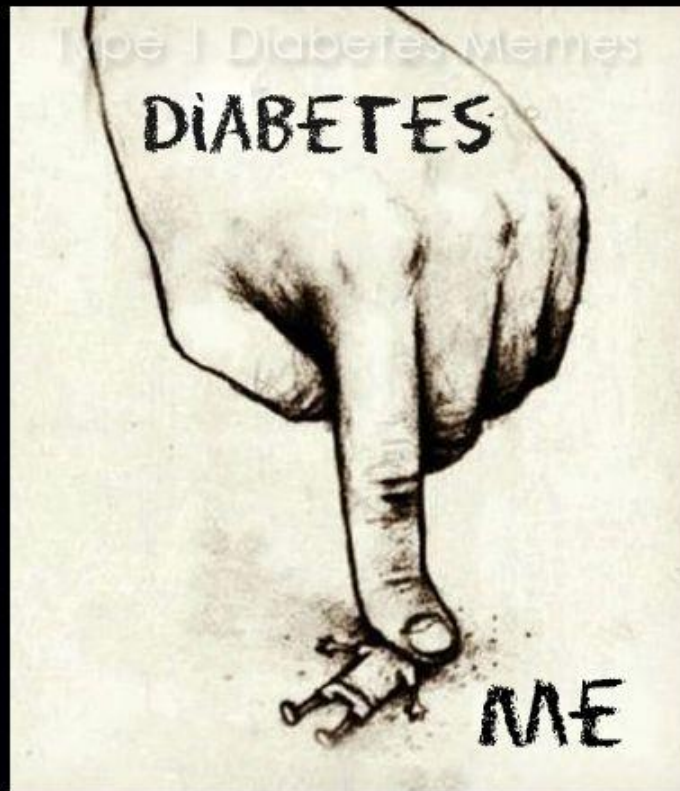




# The demands take a toll.



SOME DAYS...



# WAYS TO EASE THE BURDEN

## PSYCHOSOCIAL BARRIERS

# Go Easy on Yourself

- Emotions around numbers/tasks can make diabetes feel harder
  - Numbers can feel like grades rather than data points
- There is no failure in diabetes
  - Nothing is perfect every day
  - Treat each day like a new chance to engage



## PSYCHOSOCIAL BARRIERS

# Eliminate Blame and Shame

- You are allowed to feel: angry, upset, sad, overwhelmed, overworked, tired, bored, irritated, and more.
  - All your emotions are valid!
- Emotions that can be concerning: ashamed, blamed, and hopeless
  - Never feel bad about asking for help
  - Give yourself credit for all the hard work you do



## PSYCHOSOCIAL BARRIERS

# Finding Positives

Finding benefit in an illness can help with acceptance of the illness and self, while improving physical and mental health.

TELL ME SOMETHING POSITIVE THAT CAME OUT OF HAVING  
DIABETES, BIG OR SMALL.

## PSYCHOSOCIAL BARRIERS

### Remember...

- Small goals build up to long-term habits
- Be flexible and find what works for YOU
- Empower yourself and give yourself credit
- Eliminate blame and shame
- Find positives and reframe diabetes
- Accept who you are as a person with diabetes

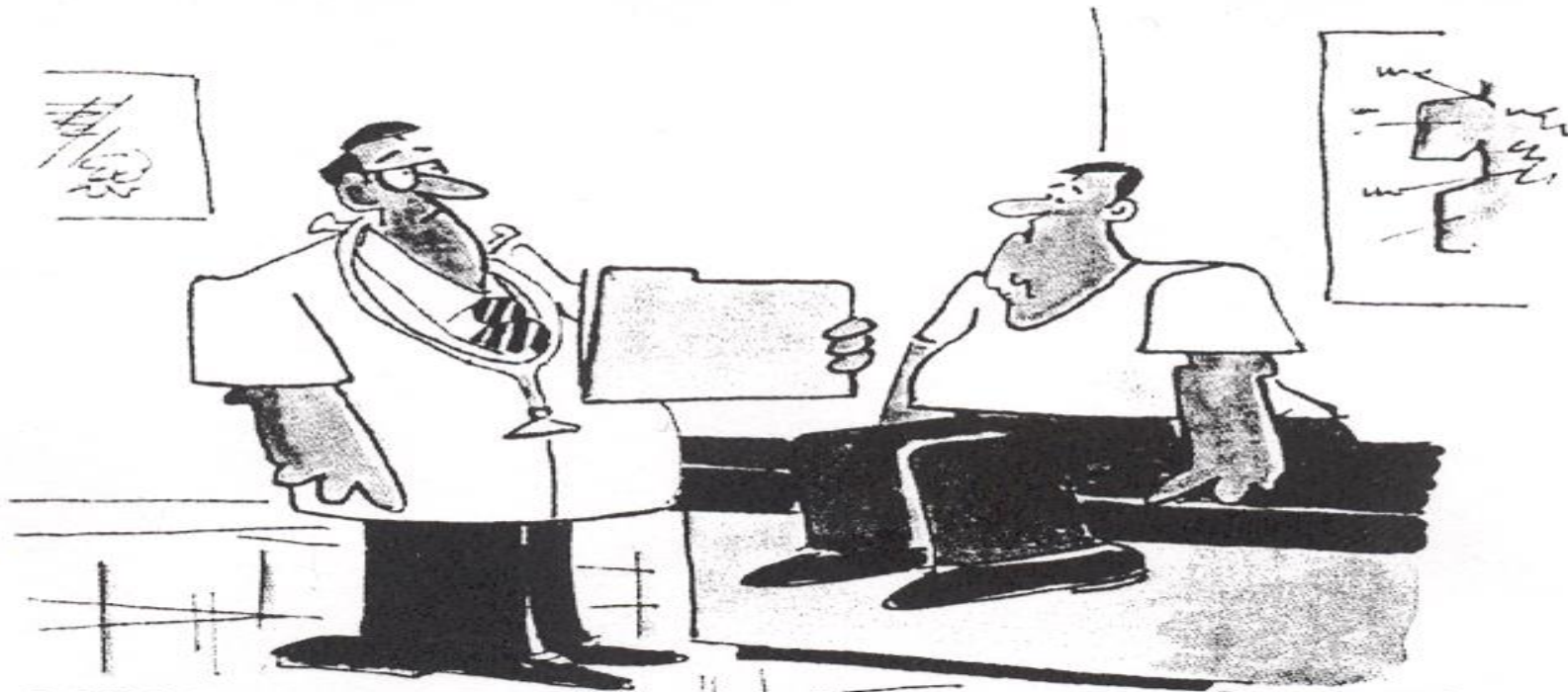




# HOW CAN DIABETES TECHNOLOGY HELP?

AND WHEN MIGHT IT GET IN THE WAY?

# A1 Chuckles



© 2003 Diabetes Interview

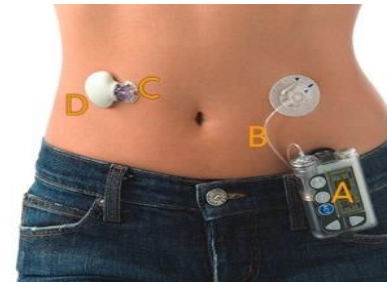
"Be honest with me, Doc. How much longer can I go on ignoring your advice to keep checking my blood glucose?"

# 3 ERAS of GLUCOSE MONITORING

Urine Sugar →  
(pre-1977)

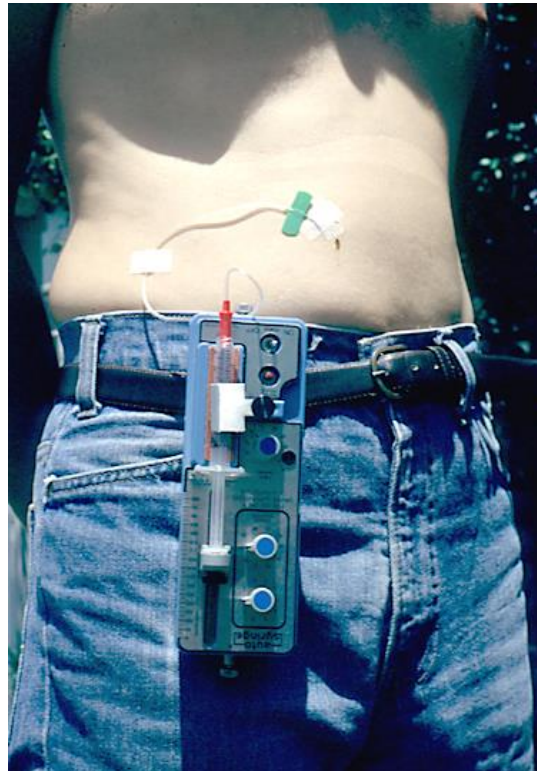
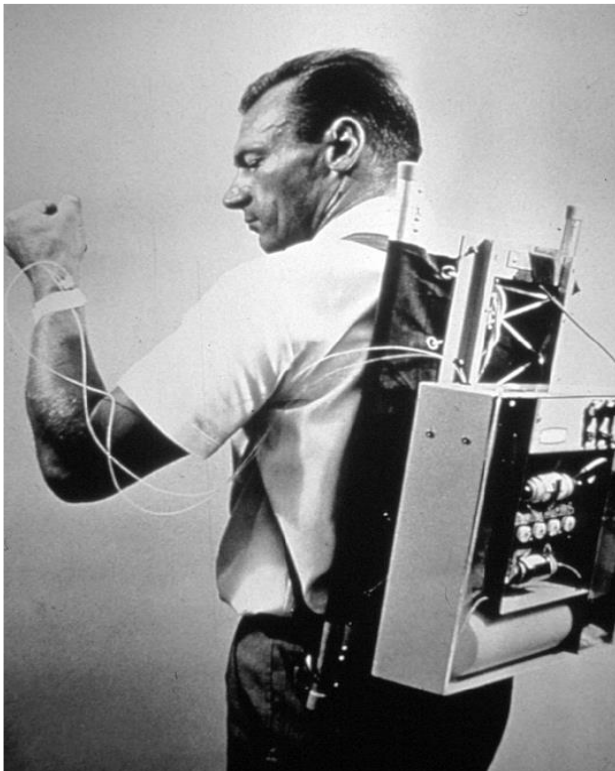


Blood Sugar → CGM/AP  
(1980s) (2003-



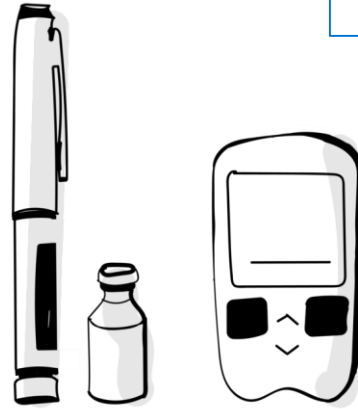
↓  
**Artificial  
Pancreas**

# Eras of INSULIN PUMPS



# Get Your Insulin

Vial and syringe  
or  
Insulin pen



# Know Your Glucose

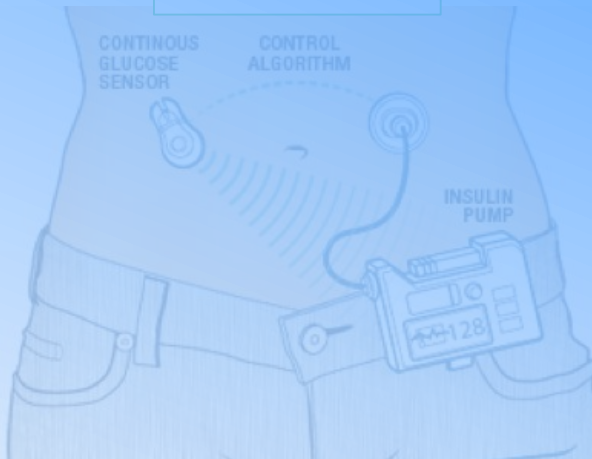
Blood glucose  
meter

## Advanced

## Continuous glucose monitoring

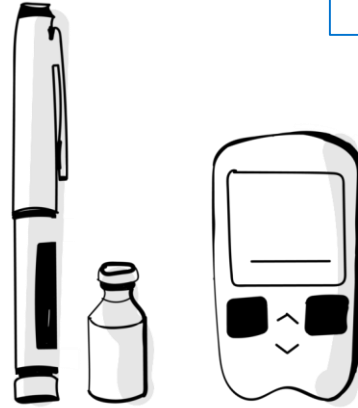
Insulin  
Pump

Closed  
Loop



# Get Your Insulin

Vial and syringe  
or  
Insulin pen

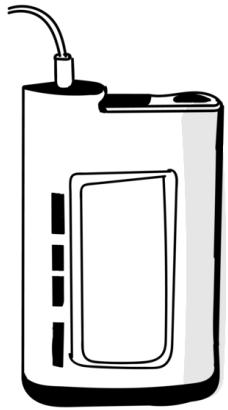


# Know Your Glucose

Blood glucose  
meter

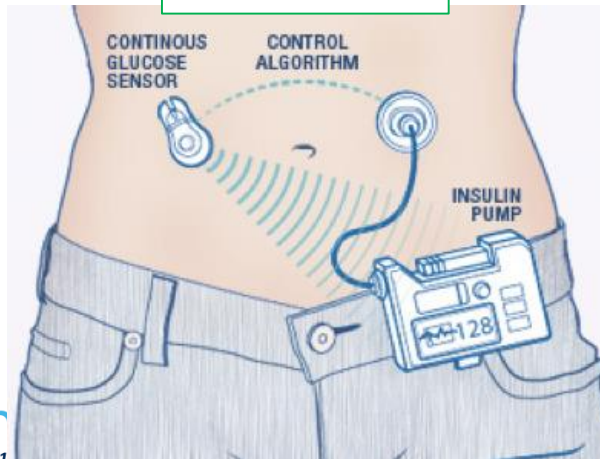
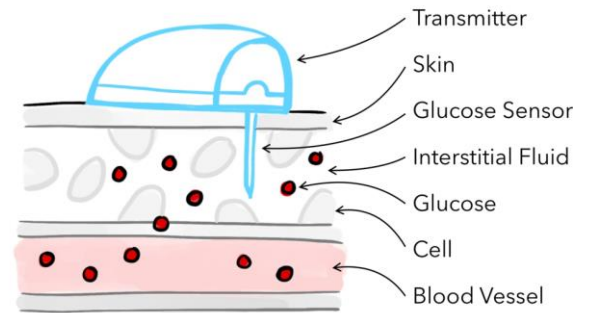
## Advanced

## Continuous glucose monitor (CGM)



Insulin  
Pump

Closed  
Loop



# Psychosocial Benefits of CGM and Pumps

- Improved quality of life
- CGM
  - Increased hypoglycemia awareness
  - Reduced diabetes distress
- Insulin pump
  - Flexibility and freedom
  - Enhanced experience in social situations
  - Improved daily management routines
- Both CGM & Pump
  - Can increase time in range
  - Can lower A1C



Polonsky et al., 2017; Payk et al., 2017

# Diabetes Device Use in Adults With Type 1 Diabetes: Barriers to Uptake and Potential Intervention Targets

*Molly L. Tanenbaum,<sup>1</sup> Sarah J. Hanes,<sup>1</sup>  
Kellee M. Miller,<sup>2</sup> Diana Naranjo,<sup>3</sup>  
Rachel Bensen,<sup>1</sup> and Korey K. Hood<sup>1</sup>*

*Diabetes Care 2017;40:1–7 | DOI: 10.2337/dc16-1536*



**Table 1. Barriers to Device Use Reported by Study Participants (n=1503)**

	Barrier	% Yes
Non-Modifiable	Cost of supplies	61.3
	Cost of device	57.4
	Insurance coverage	57.3
Modifiable	Hassle of wearing devices all of the time	47.3
	Do not like having diabetes devices on my body	34.8
	Do not like how diabetes devices look on my body	26
	Nervous that the device might not work	20
	Do not want to take more time from my day to manage diabetes	17.5
	Nervous to rely on technology	17
	Worries about what others will think about you	10.5
	I do not like diabetes devices because people notice them and ask questions about them	10.4
	Too busy to learn how to use a new technology or device	9.2
	My diabetes care team has never talked with me about diabetes technology options	4.5
	Do not understand what to do with the information or features of the devices	4.5
	Not able to get your diabetes care team to write you a prescription	4.4
	Not enough support from your family	3.7
Not enough support from my diabetes care team in using devices	2.9	
Do not want to have more information about my diabetes	2	
My family does not think diabetes devices are important for taking care of my diabetes	0.9	

**Table 2.**

*Top responses to questions “Why did you stop using your CGM?” and “Why did you stop using your insulin pump?”*

Reasons for discontinuing CGM (n=249)	% Yes
Cost of supplies	35.3
There were too many alarms	32.1
It wasn't accurate	30.1
Don't like diabetes devices on my body	29.7
Wearing a CGM took too much time and effort	28.9
It was uncomfortable or painful	28.1
Too hard to get it to work right	22.1
Cost of device	21.7
Made it hard for me to sleep	20.1
Didn't trust it	18.1
Reasons for discontinuing pump (n=72)	% Yes
Don't like diabetes devices on my body	45.8
It was uncomfortable or painful	44.4
Cost of supplies	20.8
Didn't trust it	20.8
Too hard to get it to work right	16.7
Cost of device	13.9
Caused other people to ask too many questions about my diabetes	12.5



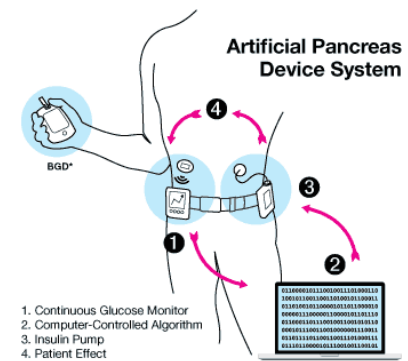
# What End Users and Stakeholders Want From Automated Insulin Delivery Systems

*Diana Naranjo,<sup>1</sup> Sakinah C. Suttiratana,<sup>1,2</sup>  
Esti Iturralde,<sup>1</sup> Katharine D. Barnard,<sup>3</sup>  
Jill Weissberg-Benchell,<sup>4</sup> Lori Laffel,<sup>5</sup> and  
Korey K. Hood<sup>1</sup>*

<https://doi.org/10.2337/dc17-0400>

## Three Primary Themes:

1. Considerations of trust and control
2. System features
3. Concerns and barriers to adoption



Naranjo et al., 2017

# Differing Priorities

- **Children:** concerns about device use in specific social situations and settings, such as school and with friends.
- **Adolescents:** focused on physical features, wearability, and comfort of devices.
- **Adults and parents:** predominantly concerned about device safety and reliability.
  - **Partners** also raised concerns about trust and control.



Naranjo et al., 2018

# Common technology worries

Fear of low BG

Will my devices work?

Fear of needles

Social embarrassment

Interference with daily life

Anxiety about complications

Dependence or burden on family

Worries about taking insulin

# Why people stop using devices



- Overall, people stop using when the balance tips toward more burden and little added-value.
  - Discontinued CGM and insulin pump use are associated with cost of supplies, bother from alarms, device inaccuracy, and not liking wearing them (Tanenbaum et al., 2017).
  - Discontinued hybrid closed-loop related to sensory issues, problems obtaining supplies, and fear of hypoglycemia (Lal et al., 2019).
- In an open protocol ecosystem, it is possible to prevent discontinued use by selecting a system that minimizes burden.

# IMPROVING ENGAGEMENT AND EMPOWERING THE PERSON WITH DIABETES

# Pathway to device/system use

Aware	Understand	Trust	Commit	Adopt	Use
Become aware of device/combo /system options	Understand how they work and advantages/disadvantages	Feel safe relying on the technology	Make a decision, obtain components and resources	Initiate initial use	Engage in continued use





## ADDRESSING THE BARRIERS

### Be Flexible

- Many options for treatment
  - Different pumps, different insulins, CGM, etc.
  - Consider what works best for YOU
  - Don't be afraid to try new treatments
- Engage with your diabetes care team to help find the most effective treatment for you
  - And remember: mental and emotional health are important and substantial parts of physical health and diabetes care



# ADDRESSING THE BARRIERS

## Mission & Objectives

- Create a digital space to promote uptake and optimal use of devices
- Do so **with people with diabetes**
- Unbiased, free, straight talk that **engages**, nudges, and improves outcomes
- Explore the options for treatment
  - Different pumps, different insulins, CGM, etc.

# DiabetesWise.org



@DiabetesWise

@hoodkore

#diabeteswise



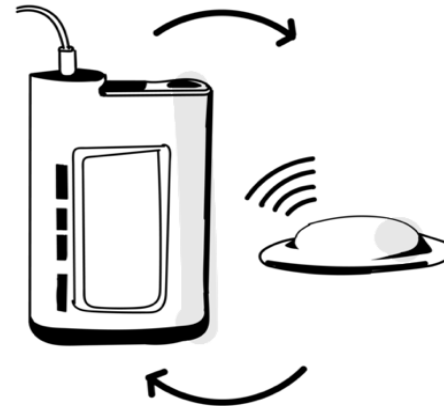
Helping You Find The Right Diabetes Devices For Your Life.

**CHECKUP**

DO YOUR DEVICES  
STILL WORK FOR YOUR  
LIFE?

Take a quick quiz to see what might be your next diabetes care upgrade.

[Check Up](#)



# Check Up Results

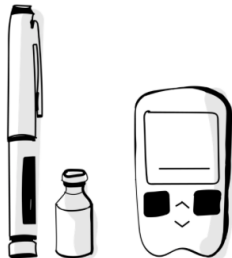


IT'S SERIOUS AND CHALLENGING TO HAVE DIABETES. LETS TAKE A LOOK IF THERE IS A DEVICE THAT WOULD HELP AND NOT CAUSE ANY NEW STRESS.

Because you said that your top priority when choosing diabetes devices is **avoid lows** and your top concern is **relying on technology** we are recommending that you consider switching your combo to **Meter & Pump**.

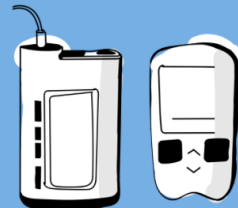
## CURRENT COMBO

NO BELLS, NO WHISTLES  
Meter & Injections



## COMBO TO CONSIDER

FEWER INJECTIONS  
Meter & Pump



## WHY WE SUGGESTED THIS

Diabetes is tough, sounds like you're in the thick of it, don't forget that it comes in waves and the tough parts don't stay that way forever. An insulin pump may be a helpful device to consider. With an insulin pump you can have different settings during the each part of the day to match your body's needs. Things have come a long way since the first pumps, some are now tubeless and waterproof.

Check out the wisdom below if you're interested in how others use a Meter and Pump, maybe you'll find a new tip or trick that someone else with the similar combo and concerns has discovered that would be helpful.

# Wisdom



CHOOSING YOUR DEVICES IS AN INCREDIBLY PERSONAL DECISION. HERE ARE THE STORIES OF OTHER PEOPLES' PRIORITIES AND CHOICES.

Different people choose different devices to fit their lifestyle, budget, and health needs. All of these stories are from real people. Learn from others and find out what's right for you.

## FILTER WISDOM BY PRIORITIES & CONCERNS

- All
- Avoiding Lows
- Cost
- Ease of Use
- Comfort
- Advanced Tech
- Unwanted Attention
- Trusting Tech
- Data Overload



# Summary

- Diabetes distress is common, expected, and needs to be addressed
  - Eliminating blame/shame, finding the positive, focusing on specific achievable and small goals can help
  - Seeking support from others (family, friends, providers) is also important
- Many believe technology is the “cure all” and there is a lot of benefit
  - Better quality of life and overall better health outcomes
- However there are still limitations
  - Overall, people stop using when the balance tips toward more burden and little added-value.
  - Discontinued CGM and insulin pump use are associated with cost of supplies, bother from alarms, device inaccuracy, and not liking wearing them (Tanenbaum et al., 2017).
  - Discontinued hybrid closed-loop related to sensory issues, problems obtaining supplies, and fear of hypoglycemia (Lal et al., 2019).
- Focus on access, realistic expectations, and supporting ongoing use

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QUESTIONS?

# Stanford Pediatric Endocrinology

[www.stanfordchildrens.org/en/service/endocrinology](http://www.stanfordchildrens.org/en/service/endocrinology)

<http://med.stanford.edu/pedsendo.html>

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