

Harnessing the Power of “WE”



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Objectives

- Better understanding of the burden of family/support people of PWD
- Describe the role of social support in diabetes care.
- Discover strategies of identifying stress for PWD and their family/support systems
- Incorporate psychosocial support strategies of family members/support system of PWD into their daily practice

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**Every good story shows
CHANGE...
Every. Single. One.**



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**2017 National AADE
Diabetes Educator
of the Year**

Team effort = Team award

**Montana diabetes educators
and MT DPHHS – Diabetes
Program**



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Montana ADCES shows up at San Diego!

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**What happened next
in this story?**



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Thoughts, feelings during/after this episode of hypo:

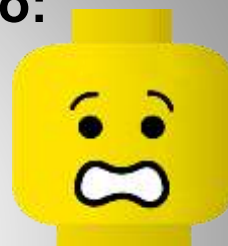
Jason

- Embarrassed
- Sad
- Angry at Marci
- Angry at himself
- “I need to get my butt back home!”
- Disappointed with himself



Marci

- Scared
- Helpless
- Angry at Jason
- Angry at myself
- “He needs to go home!”
- “I soooo don’t deserve that dang award!!!”



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Living with diabetes is a *JOB!*

Burden on daily life for the person with diabetes



“Diabetes is the ultimate DIY. It has to be – people make up to 300 decisions daily that impact their blood glucose.”

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Diabetes Distress (DD)

- Emotional toll on living with diabetes – the worries, fears and constant demands
- Prevalence: T2D = 62%, T1D = 74%
- Sources of DD:
 - Self management demands
 - Hypoglycemia
 - Shame/stigma
 - Interpersonal issues
 - Financial strain – PWD have 2.6x healthcare costs
 - Tech challenges
 - Long term health

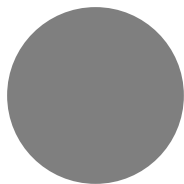
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Why is addressing Diabetes Distress important?

- Real health impacts:
 - Elevated A1C
 - Less effective medication taking
 - Missed medical appointments
 - Fewer positive health behaviors
 - Reduced energy/motivation
 - Lower QOL and confidence

Addressing DD leads to better clinical outcomes!

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**Diabetes
is not a
solitary
journey.**

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**What do we
know about
psychosocial
burden in
care
supporters?**

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**More than 63 million
Americans are family
caregivers
(1/4 of adults)**

- Health suffers
- Finances suffer
- Family members are overwhelmed & exhausted

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Caregiver burden



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Social support and care supporter burden

- Diabetes management requires engaging in a multitude of daily tasks
- Partners are uniquely positioned to experience potential burden from seeking to influence their partners' behaviors
- Spend time and effort devoted to helping PWD as well as experience adverse effects on their psychological or physical health
- Feel burden due to disrupted routines or drain of energy due to monitoring and seeking to influence partners' behavior
- How the PWD responds may play a role in whether the partner experiences burden

J Health Psychol, March 15, 2013

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When PWD respond positively to partner support ...

-
- Partners may not experience burden
 - Likely to regard time and energy invested in helping partners as worthwhile



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DAWN™ study – 2001 (published in 2006)

The DAWN™ study set out to identify the barriers and facilitators of effective self-management and to shed light on the wishes and needs of people with diabetes and their healthcare providers.

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The objectives of the DAWN study:

- Understanding of PWD perceptions surrounding diabetes
- **Develop insights into the attitudes and responsibilities of caregivers**
- Identify areas for improvement in the psychosocial management of diabetes
- Identify the most important psychosocial barriers and solutions to more effective self-management of the disease across the world
- Provide information to help decision-making and the development of national diabetes care programs
- Identify areas where it is critically important to improve collaborations between the parties involved in diabetes management

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Enable better psychological care



More than 2 in 5 PWD report poor psychological well-being.



Many PWD experience emotional stress related to their diabetes.



>1/3 of providers do not feel equipped to adequately address patients' psychological needs.

(DAWN™ study 2001)

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DAWN2™ study – published in 2013

- Advance understanding and awareness of the **unmet needs of people with diabetes and their families**
- Facilitate dialogue and collaboration to strengthen patient involvement and improve self-management and psychosocial support in diabetes care
- Establish a multi-national scientific benchmarking system for person-centered diabetes care and health policy

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Diabetes and the burden on daily life: Family Members

- 40% of family members reported high level of diabetes-related stress
- 61% are worried about the risk of hypo events occurring in the loved one
- 37% are frustrated that they don't know how to best provide help
- 39% report they'd like to be more involved in care

(DAWN2™ results)

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Diabetes and the burden on daily life: Family Members



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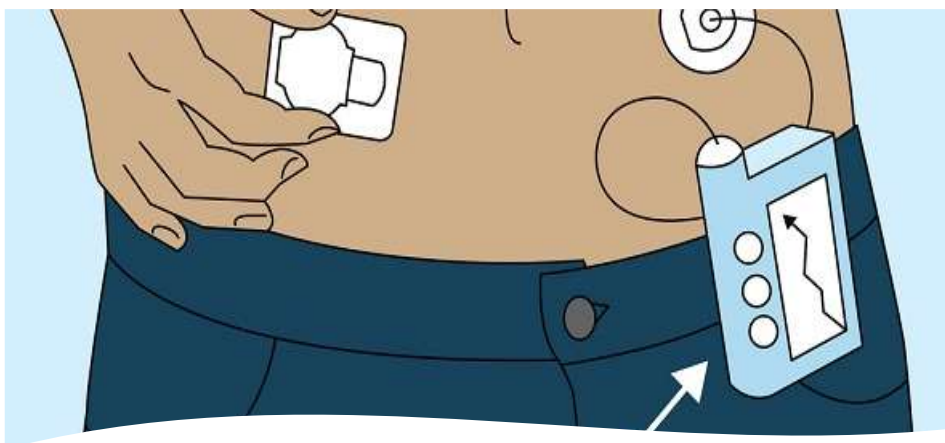
Q: Where do you place a CGM?

A: In the cupboard!



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Partner perspectives on devices

- Partners and relationships will be increasingly affected by technology innovations
 - Balance with disruptive alerts, technical issues, maintenance tasks, device size, other issues may strain relationships

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Diabetes and the burden on daily life: For Health Professionals

- Only **24%** of PWD reported they were asked by HCP how DM impacts their lives
- **75%** of family members found DSME helpful, but only **23%** participating
- Most HCPs agree that family involvement is vital to good diabetes care
- To help PWD, we must also help their family members.

(DAWN2™ results)

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How do we support PWD and their families?

- Person-centered and collaborative partnership.
- Ask how diabetes is affecting their daily lives.
- Adopt question-based approach and active listening skills to understand and explore psychosocial needs.
- Actively involve PWD and their family members in goal-setting, decision-making processes, and treatment plans.
- Be mindful that treatment options may increase burden.
- Embed QOL indicators into routine practice.
- Provide family support group or refer to community organizations and social media/online support.

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Invite the partner to the DSMES visit

- Ask how diabetes is impacting family relationships.
- Actively LISTEN...their stories *matter*.
- Encourage conversation starters to navigate the roles surrounding support.
 - How much help do you want or need?
 - Am I providing not enough or too much help?
 - What am I doing that is working, and what isn't?
 - How does it make you feel when I try to help?

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Behavioral Diabetes Institute:

Partner of Adult T1D Diabetes Distress Scale

[Scales and Measures –
Behavioral Diabetes Institute](#)

www.behavioraldiabetes.org

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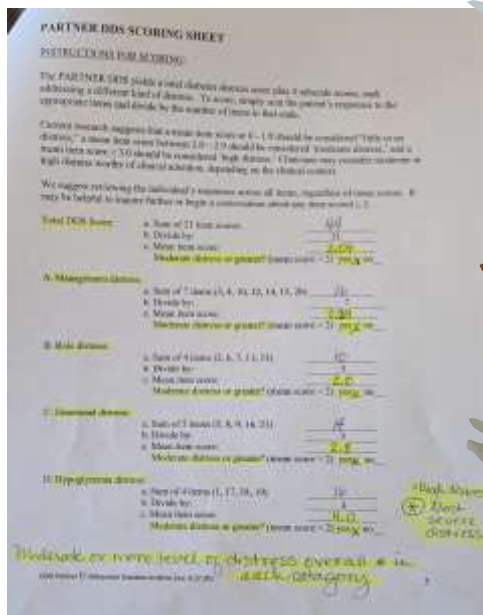
PARTNER DIABETES DISTRESS SCALE (PARTNER-DDS)

The following questions ask about how you have been feeling as a spouse or partner of someone with diabetes. For each item, circle the number that gives the best answer for you. Please provide an answer for each question.

During the past month, I have been:

	Not at all	A little	Somewhat	A lot	A great deal
1. Worrying about my partner's low blood sugars.	0	1	2	3	4
2. Feeling unclear about exactly how much I should be involved in managing my partner's diabetes.	0	1	2	3	4
3. Frustrated that my partner shuts me out of his/her diabetes.	0	1	2	3	4
4. Feeling that my partner doesn't try hard enough to manage his/her	0	1	2	3	4

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Why aren't we studying people who do well?

- We tend to look for what's NOT working, instead of looking for what IS.
- We have 'diabetes distress scales' → no diabetes SUCCESS scales
- Books on diabetes burnout/coping
- Exploring what **is working** may yield more answers than probing the problems

(Riva Greenburg)

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What enables PWD to 'do well?'

- Lots of new technology and 'hardware'
- Is "heart-ware" a tool that enables PWD to do well, or thrive?
 - Empathy
 - Collaboration
 - Interest
 - Attentive and active listening
 - Support for PWD from health team and family or other support system
 - Supporting the family/caregivers

(Riva Greenburg)

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Implementing strategies to include care supporters and helping them to flourish:

- Results in better outcomes
- Results in better relationships



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Hiking 25 miles in 11 hours!

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**Diabetes can shape families
in positive ways!**

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Harnessing the power of WE...

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Resources

- [Diabetes Distress Assessment & Resource Center](#)
- [Behavioral Diabetes Institute](#)
- [BDI DD Infographic](#)
- [BDIFinal2ndEdition.pdf](#)
- [Etiquetteonepage](#)
- [ada mental health workbook chapter 3.pdf](#)
- [ada mental health toolkit questionnaires.pdf](#)
- <https://pubmed.ncbi.nlm.nih.gov/26859072>
- [HIA-TipSheet CaregiverBurnout19.pdf](#)

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