



University of California
San Francisco

2019 UCSF Mini Medical School

Speaking the Language of Diabetes

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Faculty

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Ms. McGrath has over 25 years caring for youth with type 1 and type 2 diabetes. She helped found UCSF's first pediatric diabetes clinic in the mid-1990s. A 1995 graduate of the UCSF School of Nursing's Advanced Practice Pediatric Nurse program she returned as faculty in 2012 to begin the nation's first minor in diabetes for advanced practice nurses. She oversees diabetes projects in Haiti, Chiapas, and Navajo Nation. For the past 35 years she has been involved in diabetes camps. In 2015, the Masters class awarded her with the Excellence in Teaching award. In 2016, she received the UCSF SON Excellence in Teaching Award for Educational or Curricular Innovation for the Behavior Lab she designed.

Disclosure to Participants

- Notice of Requirements For Successful Completion
 - Please refer to learning goals and objectives
 - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours
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 - Presenter Maureen McGrath has no COI/Financial Relationship to disclose.
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- Off-Label Use:
 - Participants will be notified by speakers to any product used for a purpose other than for which it was approved by the Food and Drug Administration.

Standards of Medical Care in Diabetes—2016: Summary of Revisions

Diabetes Care 2016;39(Suppl. 1):S4–S5 | DOI: 10.2337/dc16-S003

GENERAL CHANGES

In alignment with the American Diabetes Association's (ADA's) position that diabetes does not define people, the word “diabetic” will no longer be used when referring to individuals with diabetes in the “Standards of Medical Care in Diabetes.” The ADA will continue to use the term “diabetic” as an adjective for complications related to diabetes (e.g., diabetic retinopathy).



The Use of Language in Diabetes Care and Education

<https://doi.org/10.2337/dci17-0041>

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<http://care.diabetesjournals.org/content/40/12/1790>



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Speaking the Language of Diabetes

New Language Guidance for Diabetes-related Research, Education, and Publications

[AADE's resources](#) and the HCP handout on the AADE website



INTERNATIONAL DIABETES FEDERATION
LANGUAGE PHILOSOPHY
TECHNICAL DOCUMENT





diabetes australia

Position Statement

A new language for diabetes

Improving communications with and about people with diabetes

Summary

- Diabetes is the fastest growing chronic condition in Australia, affecting 1.7 million Australians. It is a progressive condition, which can reduce both quantity and quality of life, and requires daily self-care. On average, people with diabetes have higher levels of emotional distress than those without diabetes. Distress can continue throughout life with diabetes.
- The way language is used – both verbal and written – reflects and shapes our thoughts, beliefs and behaviours. Language has the power to persuade, change or reinforce beliefs, discourse and stereotypes – for better or for worse. Words do more than reflect people's reality: they create reality.
- Language needs to engage people with diabetes and support their daily self-care efforts. Importantly, language that de-motivates or induces fear, guilt or distress needs to be avoided and countered.
- Diabetes Australia believes optimal communication increases the motivation, health and well-being of people with diabetes; furthermore, that careless or negative language can be de-motivating, is often inaccurate, and can be harmful.
- The aim of this position statement is to encourage greater awareness of the language surrounding diabetes, and identify potential improvements.

***“Words are, of course, the most
powerful drug used by mankind”***

Rudyard Kipling

Guiding principles for communication with and about people living with diabetes

- Diabetes is a complex and challenging disease involving many factors and variables
- Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment
- Every member of the health care team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach
- Person-first, strengths-based, empowering language can improve communication and enhance the motivation, health, and well-being of people with diabetes

Key Definitions

- Strengths-based language

- Opposite of deficits approach; emphasizing what people know and what they can do
- Focusing on strengths that can empower people to take more control over their own health and healing



- Person-first language

- Words that indicate awareness, a sense of dignity, and positive attitudes toward people with a disability/disease. Places emphasis on the person, rather than the disability/disease



Recommendations

Use language that:

- is neutral, nonjudgmental, and based on facts, actions, or physiology/biology
- is free from stigma
- is strengths based, respectful, inclusive, and imparts hope
- fosters collaboration between patients and providers
- is person centered



Avoiding Judgment

- Camp policy re: campers showing BG on meter
- School RN accepting verbal report from student
- Meter download reconcile with written log (1995 clinical)
- Use of control solution or checking friends' or pets' BG
- Mother of one of my patients “taking off 100 points” of BG
- All of the above are examples of protective behaviors to avoid
 - Judgment, punishment, shame, feelings of failure

Adolescent Management

- 29% of the 144 subjects reported fabricating BGs to give lower numbers
- 25% of the subjects reported forgetting injections/boluses
- Belief that certain injections are not needed
- Teens fabricated blood tests because of perceived pressure from family and physicians to produce good results
- Skipped blood sugars so as to appear in better control

Qualitative Study

- Primary author of language paper
- Conducted focus groups (live and virtual)
- Virtual was done in the DOC- Diabetes Online Community
- Adults with type 1 and type 2 diabetes

Qualitative Study



1. What diabetes-related words have a negative impact on you?
2. How do you feel when you hear those words?
3. What particular experiences do you recall that involved words and diabetes?
4. If you could ask your diabetes care professionals to stop using one word, what would it be?
5. If there is another word(s) that you'd like them to stop using, please share it (them) as well.
6. How do you think not using those words would affect your diabetes experience?

Qualitative Study

- Question 1 & 2- What diabetes-related words have a negative impact on you? How do you feel when you hear those words? Six themes emerged from analysis of question 1 and 2
 - **Judgement** - “non-compliance”, “uncontrolled”, “good/bad”, “can/can’t”, “should/shouldn’t”
 - **Fear and Anxiety**- “seizure”, “complications”, “DKA”, “blindness”, “death”
 - **Labels, reminders, and assumptions**- “diabetic”, “disease”, “brittle”, “suffer”

Qualitative Study- Quest 1 & 2 themes

- Question 1 & 2- What diabetes-related words have a negative impact on you? How do you feel when you hear those words?
- Themes continued:
 - **Oversimplification and directives-** “you”ll get used to it”, “at least it’s not”, “exercise more”
 - **Misunderstanding, misinformation, or disconnection-** “reverse”, ”you’re fine”, “are you still using insulin?”
 - **Body language and tone-** “I felt like a lot of it was my fault”

Qualitative Study

- Question 3- What particular experiences do you recall that involved words and diabetes?
- Three themes emerged from this question
 - **General public** (friends, colleagues, family, teachers, and strangers)- “food police”
 - **HCPs**- seeing “uncontrolled” in the medical record
 - **Media**- perpetuates stereotypes

Qualitative Study

- Question 4 & 5- If you could ask your diabetes care professionals to stop using one word, what would it be? If there is another word(s) that you'd like them to stop using, please share it (them) as well. Three themes emerged:
- **Stop Judging-**"anything that begins with 'should'", "sigh, control. I think that's just an illusion"
- **Stop labeling-** "diabetic", "noncompliance"
- **Stop discussing complications-**"I don't want to hear about the complications at EVERY visit. I totally heard it the first time"

Qualitative Study

- Question 6- How do you think not using those words would affect your diabetes experience?
- Three themes emerged:
- **Suggestions for HCPs-** “focus on the person, not the diagnosis. You’ll treat both more effectively that way”
- **These words will be replaced with other words-** “people use words to pigeonhole us instead of actually seeing and listening to the person”
- **If HCPs stopped using these words-** increase feelings of respect or being listened to, relief, supported, and comfortable...

Qualitative Study

“I would have more faith in my health care providers if they didn’t use words that I think convey a lack of information, sensitivity, or understanding of my experience.”
(Participant 1)



“Better language would help shift the shame, blame, and self-loathing from the person to the disease. Allows for hope.”
(Participant 25)

“. . . could get to meaningful conversation more quickly with less emotional obstacles and baggage.” (Participant 23)

What to do?

■ Interventions

- Blood Glucose is data by which therapies can be adjusted
- Reinforce self-management behaviors, not results
- The only “bad” number is one that doesn’t exist
- There are no “good” or “bad” blood glucoses
- Use “in range”; “above range”
- Use “check” BG, instead of “test” BG

Problematic

Preferred

Rationale

Compliant/compliance/
non-compliant/
non-compliance

Adherent/non-adherent/
adherence/non-adherence

Engagement
Participation
Involvement
Medication taking

*"She takes insulin whenever
she can afford it."*

- Compliance and adherence imply doing what someone else wants, i.e., taking orders about personal care as if a child. In diabetes care and education, people make choices and perform self-care/self-management.
- Focus on people's strengths – what are they doing or doing well and how can we build on that?
- Focus on facts rather than judgments.

Control (*as a verb or an
adjective*)
controlled/uncontrolled,
well controlled/poorly
controlled

Manage

*"She is checking blood glucose
levels a few times per week."*

*"He is taking sulfonylureas, and
they are not bringing his blood
glucose levels down enough."*

- Control is virtually impossible to achieve in a disease where the body no longer does what it's supposed to do.
- Use words/phrases that focus on what the person is doing or doing well.
- Focus on physiology/biology and use neutral words that don't judge, shame, or blame.

Control (*as a noun*)
glycemic control; glucose
control; poor control; good
control; bad control; tight
control

A1C
Blood glucose levels/targets
Glycemic target/goal
Glycemic stability/variability

- Focus on neutral words and physiology/biology.
- Define what **"good control"** means in factual terms and use that instead.

Problematic	Preferred	Rationale
<p>Diabetic (<i>as an adjective</i>) diabetic foot diabetic education diabetic person</p> <p><i>"How long have you been diabetic?"</i></p>	<p>Foot ulcer; infection on the foot Diabetes education Person with diabetes</p> <p><i>"How long have you had diabetes?"</i></p>	<ul style="list-style-type: none"> • Focus on the physiology or pathophysiology. • "Diabetic education" is incorrect (education doesn't have diabetes). • Put the person first. • Avoid using a disease to describe a person.
<p>Diabetic (<i>as a noun</i>)</p> <p><i>"Are you a diabetic?"</i></p>	<p>Person living with diabetes Person with diabetes Person who has diabetes</p> <p><i>"Do you have diabetes?"</i></p>	<ul style="list-style-type: none"> • Person-first language puts the person first. • Avoid labeling someone as a disease. There is much more to a person than diabetes.
<p>Non-diabetic; normal</p>	<p>Person who doesn't have diabetes Person without diabetes</p>	<ul style="list-style-type: none"> • See above. • The opposite of "normal" is "abnormal"; people with diabetes are not abnormal.

Diabetes Minor Cohort 2019



The Diabetes Minor at UCSF SON

- N296A- Advanced Clinical Management of Pediatric Diabetes (2 units)
- N296B- Behavioral Approaches to Diabetes Across the Lifespan (1 unit)
- N301.5- Lab to N296B (1 unit)
- N296C- Advanced Clinical Management of Adult Diabetes (2 units)

Diabetes Youth and Family (DYF) Family Camp 2015



Diabetes Nurse Fellows (2015-16) Piloting an In-service for School Nurses





PUMP TIME: Peds Class







Diabetes Minor Students-Camp 2014

DIABETES MINOR CLASS OF 2016



***“Words are, of course, the most
powerful drug used by mankind”***

Rudyard Kipling