Empowering Our Patients through Language

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THANK YOU!

Lifelong thanks to my colleague and mentor

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Objectives

- Define patient empowerment for diabetes care and education
- Explain the impact of diabetes related-distress, depression and stigma on diabetes outcomes
- Discuss the recommendations for changing the language of diabetes by healthcare providers and educators
- Review AADE resources for diabetes language

Empowerment- How do you define it?

- Empowerment means authority and power is **given** to someone to do something
- Usually includes a concept of getting stronger, control, confidence

Patient Empowerment for Diabetes

- empowerment is not something one does to patients.
- empowerment begins when HCPs acknowledge that patient are in control of their daily diabetes care.
- Empowerment occurs when the HCPs goal is to increase the capacity of patients to think critically and make autonomous, informed decisions. Empowerment also occurs when patients are actually making autonomous, informed decisions about their diabetes self-management.
    - Anderson RM, Funnell MF. Patient Educ Couns. 2010 Jun; 79(3): 277–282.

Empowerment

- Helping people discover and use their own innate ability to gain mastery over their diabetes
- “Diabetes is self-managed and I am the self”
- “You can teach me, but you can’t make me. I have to make myself.”

Empowerment fundamentals

- Patients are responsible
- Patients are therefore the final decision-makers
- Knowing what is best for diabetes, is not the same as knowing what is best for that patient
- Goal of DSME is to make informed decisions

Empowerment

- Based on the theory of self-determination, a theory of motivation.
- Person-centered educational, support and healthy coping strategies (empathy, compassion, respect, and informed decision-making).
- Patient-directed behavioral goal setting.
- Effective for improving clinical and psychosocial outcomes.

Funnell MM. *Patient Education and Counseling 2016;* 99:1921-1922

Empowerment and Language

- Root word is Power
- Language conveys the recognition of power
- Language that supports empowerment focuses on patient generated goals
- People hear words, translate them to meaning, and can affect how a person views himself.

Patients were labeled as non-compliant, non-adherent and unmotivated

Patients were blamed for poor outcomes

Expected patients to view diabetes as their top priority and change their lives in order to manage diabetes

Diabetes-related distress

- Fearful
- Frustrated
- Overwhelmed
- Anxious
- Guilty
- Angry
- Powerless
- Discouraged

Undesirable outcomes

Perceived stigma is associated with:

- Increased A1c independently
- Increased blood glucose variability
- Increased feelings of diabetes related distress
- Social life impacted

Liu NF 2017, Dickinson 2017

Depression vs. Distress

- Diabetes-related distress has a significantly higher prevalence and incidence than clinical depression, and is significantly more persistent over time.
- Different “conditions”; over 70% of type 2 adults with high distress are NOT clinically depressed.

Fisher L, et al., *Diabetes Care*. 2010;33:23-28. Fisher L, et al., *Diabet Med*. 2009;26:622-627.
Fisher L, et al., *Diabet Med*. 2009;25:1096-1101. Fisher L, et al., *Diabetes Care.* 2007;30:542-548.

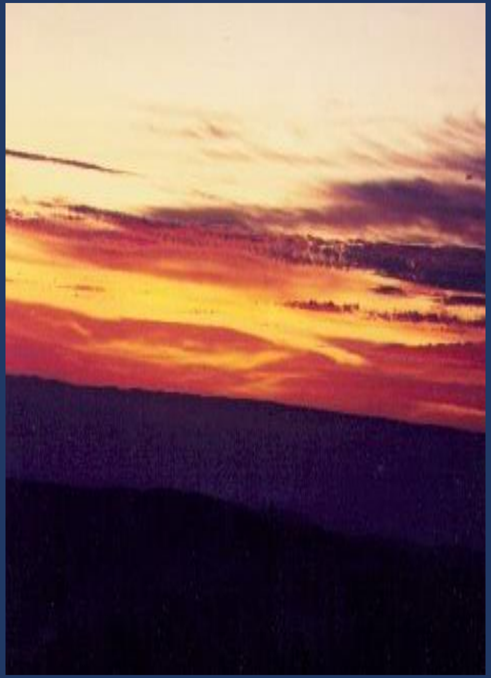
Stigma adds to Stress

- Living with diabetes is challenging 24/7
- Guiding principle #2:
  - Stigma attached to diagnosis of diabetes
    Diabetes is perceived as resulting from a character flaw
  - Stigmatizing words like nonadherent is associated with negative perception of not caring
  - Stress coupled with shame, self judgement and/or blaming by others
- Marion Alex, 2013, stigma is a form of violence

DAWN

(n=>5,000 patients; 13countries)

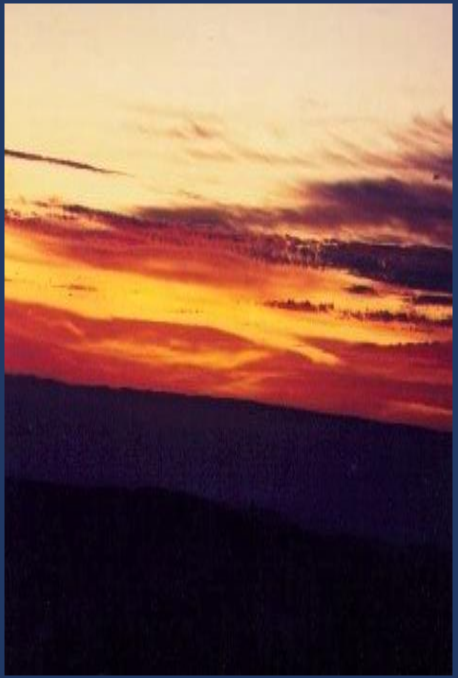
DAWN1



- Diabetes self management is less than optimal
- Self-management problems are due in large part to psychosocial problems which are common but rarely treated.
- **85% reported severe distress at diagnosis; 43% continued to experience these feelings (mean=15 years**)
- Access to team care and communication between patients and professionals is associated with better outcomes
- Initiatives to address psychosocial needs must have a high priority in order to improve outcomes

Skovlund SE, Peyrot M. *Diabetes Spectrum.* 2005;18(3):136-142.

DAWN2 (n=8,596; 17 countries)



Diabetes-related distress reported by 44.6%, but only 23.7% reported that their healthcare team asked them how diabetes impacted their life.[1]

Other studies show prevalence of 18-35% and an 18 month incidence of 38-48%.[2]

2. Fisher L, et al. *Diabetes Care.* 2012;351. Nicolucci A, et al. *Diabet Med*. 2013:30:767-777. :259-264.

Summary: Psychosocial Differences in DAWN2 Ethnicity Data

- The ethnic minority groups were generally similar in their results and all varied signficantly from the white non-Hispanic PWDs.
- African Americans the highest level of overall self-management and white non-Hispanics reported the lowest overall self-management
- African Americans and Hispanic Americans reported larger diabetes support networks
- Minority ethnic groups had more positive psychological well-being and better QoL, reported less negative impact from diabetes and were more empowered related to diabetes
- There is a substantial amount of diabetes distress among both PWD and FM, and PWD in minority groups reported more diabetes distress than non-Hispanic whites
- Perception of need for major improvements in social conditions and stigma regarding diabetes by people with diabetes and their family members is greater in ethnic minority groups

Peyrot M, et al. *Diabetes Res Clin Pract*. 2013;99:174–84

Patient centered language

Language has an impact on :

- Motivation
- Behavior
- Outcomes

Dickinson, 2017

History

- AADE and ADA convened an expert panel to discuss language used in diabetes care and education
- Language movement involving several disciplines
- International attention to language – publications
- American Psychological Association- guidelines for nonhandicapping language
- ADA Standards of Medical Care 2017- patient centered communication
- AMA Manual of style- avoid labeling people with their disabilities

Nonhandicapping Language

- Respects the person by maintaining the integrity of the whole person.
  - The person as a whole is not disabled
  - The person is not reduced to being addressed as their condition, i.e. amputee
  - The person is not referred to as unmotivated or suffering from (negative)
  - The person is not judged using labels like poorly controlled or noncompliant

Key Definition #1

Word/Phrase	Definition
Strengths-based language	Opposite of a deficit 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.
Compare: Lee takes her insulin 50% of the time because of cost concerns.	Lee is noncompliant/nonadherent.

Dickinson, 2017

Key Definition #2

Word/Phrase	Definition
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.
Compare: Lee has diabetes	Lee is a diabetic

Dickinson, 2017

Five recommendations

- Language is neutral, nonjudgmental
  - Use facts actions or physiology to discussing plan or problem
- Language is stigma-free
- Language includes strengths, is respectful, inclusive and imparts hope
- Language fosters collaboration
- Language is person centered

  - Dickinson, et al. 2017 The Use of Language in Diabetes Care and Education. *The Diabetes Educator*, 43(6):552-564.

Our Words Matter

Our Words Matter

- The words we use in diabetes education and care has an impact on people with type 2
- Choose words that empower rather than judge, criticize, blame and stigmatize.
- Avoid:
  - Diabetic
  - Uncontrolled
  - Compliance, adherence
  - Let, negotiated, allowed, got to, motivated, got to agree
  - Lifestyle disease

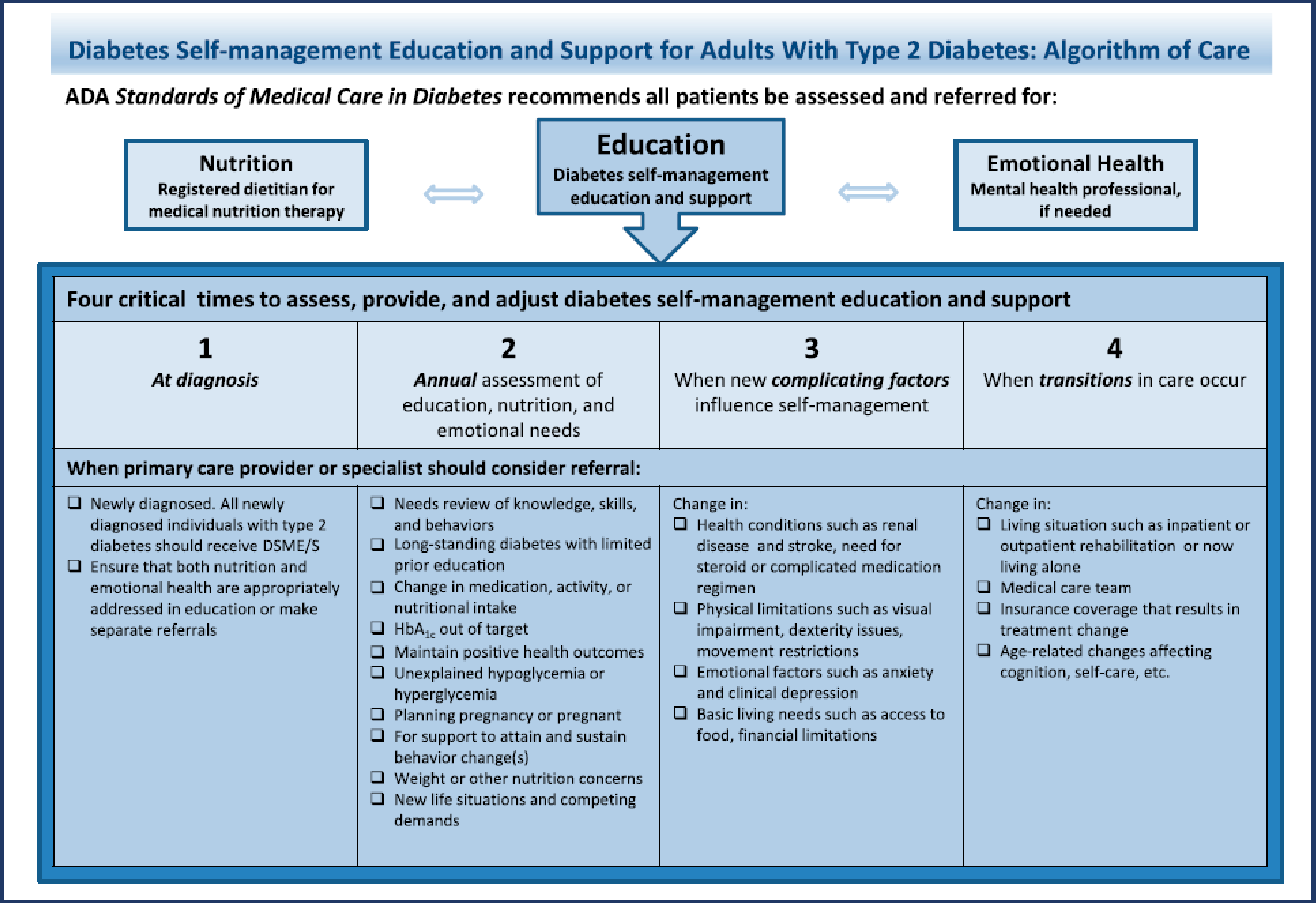
Dickinson J, et al. *The Diabetes Educator* 2017; 43:551-564

What can we do to support empowerment and healthy coping?

- Recognize that self-management behaviors are not problems, but are symptoms
- Need to start with identifying the problem and strategies if we want to help patients improve behaviors and coping skills
- Need to integrate psychosocial and behavioral aspects into the clinical content

Funnell MM, Piatt GA. *The Journal of Nurse Practitioners* 2017; 13:468-474

DSME/S Algorithm of Care



Diabetes Self-management Education and Support for Adults With Type 2 Diabetes: Algorithm of Care

ADA *Standards of Medical Care in Diabetes* recommends all patients be assessed and referred for:

Nutrition
Registered dietitian for medical nutrition therapy

⟺

Education
Diabetes self-management education and support

⟺

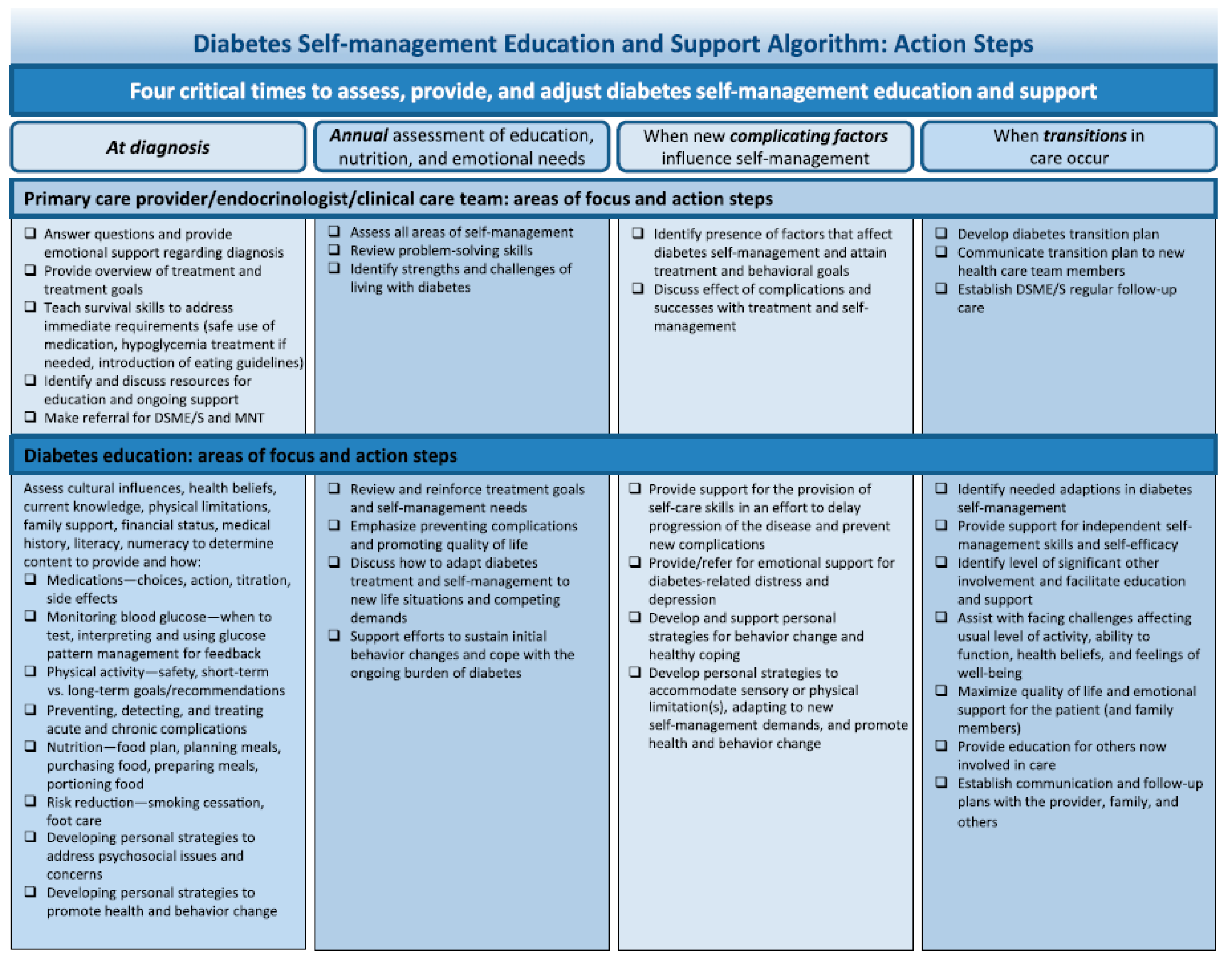
Emotional Health
Mental health professional, if needed

Four critical times to assess, provide, and adjust diabetes self-management education and support

1	2	3	4
At diagnosis	***Annual*** assessment of education, nutrition, and emotional needs	When new ***complicating factors*** influence self-management	When ***transitions*** in care occur
When primary care provider or specialist should consider referral:			
☐ Newly diagnosed. All newly diagnosed individuals with type 2 diabetes should receive DSME/S ☐ Ensure that both nutrition and emotional health are appropriately addressed in education or make separate referrals	☐ Needs review of knowledge, skills, and behaviors ☐ Long-standing diabetes with limited prior education ☐ Change in medication, activity, or nutritional intake ☐ HbA_{1c} out of target ☐ Maintain positive health outcomes ☐ Unexplained hypoglycemia or hyperglycemia ☐ Planning pregnancy or pregnant ☐ For support to attain and sustain behavior change(s) ☐ Weight or other nutrition concerns ☐ New life situations and competing demands	Change in: ☐ Health conditions such as renal disease and stroke, need for steroid or complicated medication regimen ☐ Physical limitations such as visual impairment, dexterity issues, movement restrictions ☐ Emotional factors such as anxiety and clinical depression ☐ Basic living needs such as access to food, financial limitations	Change in: ☐ Living situation such as inpatient or outpatient rehabilitation or now living alone ☐ Medical care team ☐ Insurance coverage that results in treatment change ☐ Age-related changes affecting cognition, self-care, etc.

Powers MA et al. DSME/S Position Statement. *Diabetes Care, The Diabetes Educator, Journal of Academy of Nutrition and Dietetics;* July 2015

DSME/S Algorithm of Care: Action Steps



Diabetes Self-management Education and Support Algorithm: Action Steps

Four critical times to assess, provide, and adjust diabetes self-management education and support

At diagnosis	***Annual*** assessment of education, nutrition, and emotional needs	When new ***complicating factors*** influence self-management	When ***transitions*** in care occur
Primary care provider/endocrinologist/clinical care team: areas of focus and action steps			
☐ Answer questions and provide emotional support regarding diagnosis ☐ Provide overview of treatment and treatment goals ☐ Teach survival skills to address immediate requirements (safe use of medication, hypoglycemia treatment if needed, introduction of eating guidelines) ☐ Identify and discuss resources for education and ongoing support ☐ Make referral for DSME/S and MNT	☐ Assess all areas of self-management ☐ Review problem-solving skills ☐ Identify strengths and challenges of living with diabetes	☐ Identify presence of factors that affect diabetes self-management and attain treatment and behavioral goals ☐ Discuss effect of complications and successes with treatment and self-management	☐ Develop diabetes transition plan ☐ Communicate transition plan to new health care team members ☐ Establish DSME/S regular follow-up care
Diabetes education: areas of focus and action steps			
Assess cultural influences, health beliefs, current knowledge, physical limitations, family support, financial status, medical history, literacy, numeracy to determine content to provide and how: ☐ Medications—choices, action, titration, side effects ☐ Monitoring blood glucose—when to test, interpreting and using glucose pattern management for feedback ☐ Physical activity—safety, short-term vs. long-term goals/recommendations ☐ Preventing, detecting, and treating acute and chronic complications ☐ Nutrition—food plan, planning meals, purchasing food, preparing meals, portioning food ☐ Risk reduction—smoking cessation, foot care ☐ Developing personal strategies to address psychosocial issues and concerns ☐ Developing personal strategies to promote health and behavior change	☐ Review and reinforce treatment goals and self-management needs ☐ Emphasize preventing complications and promoting quality of life ☐ Discuss how to adapt diabetes treatment and self-management to new life situations and competing demands ☐ Support efforts to sustain initial behavior changes and cope with the ongoing burden of diabetes	☐ Provide support for the provision of self-care skills in an effort to delay progression of the disease and prevent new complications ☐ Provide/refer for emotional support for diabetes-related distress and depression ☐ Develop and support personal strategies for behavior change and healthy coping ☐ Develop personal strategies to accommodate sensory or physical limitation(s), adapting to new self-management demands, and promote health and behavior change	☐ Identify needed adaptions in diabetes self-management ☐ Provide support for independent self-management skills and self-efficacy ☐ Identify level of significant other involvement and facilitate education and support ☐ Assist with facing challenges affecting usual level of activity, ability to function, health beliefs, and feelings of well-being ☐ Maximize quality of life and emotional support for the patient (and family members) ☐ Provide education for others now involved in care ☐ Establish communication and follow-up plans with the provider, family, and others

Powers MA et al. DSME/S Position Statement. *Diabetes Care, The Diabetes Educator, Journal of Academy of Nutrition and Dietetics;* July 2015

Communications

Providers are to:

- Discuss adaptations of treatment
- Discuss effects of complications
- Identify strengths
- Teach skills
- Provide support

Reference: The Use of Language in DCE

Negative meaning:	Replace with:	Why
Compliant/compliance/noncompliant/ noncompliance Adherent/nonadherent/adherence / nonadherence	“He takes his medication about half the time.” “She takes insulin whenever she can afford it.” “He eats fruits and veggies a few times per week.” Engagement Participation Involvement Medication taking	The words listed in the first column are inappropriate and dysfunctional concepts in diabetes care and education. Compliance and adherence imply doing what someone else wants (ie, 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.

Dickinson, 2017, p. 554

Reference: The Use of Language in DCE

Negative meaning:	**Replace with:**	**Why**
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 is supposed to do. Use words/phrases that focus on what the person is doing or doing well. Focus on intent and good faith efforts, rather than on “passing” or “failing.” Focus on physiology/biology and use neutral words that don’t judge, shame, or blame.

Dickinson, 2017, p. 554

Reference: The Use of Language in DCE

Negative meaning:	Replace with:	Why
Diabetic (as a noun) “Are you a diabetic?”	“Do you have diabetes?” Person living with diabetes Person with diabetes Person who has diabetes	Person-first language puts the person first. Avoid labeling someone as a disease. There is much more to a person than diabetes. When in doubt, call someone with diabetes by their name.

Dickinson, 2017, p. 554

Reference: The Use of Language in DCE

Negative meaning:	**Replace with:**	**Why**
Imperatives Can/can't, should/shouldn't, do/don't, have to, need to, must/must not	"Have you tried . . ." "What about . . ." "May I make a suggestion . . ." "May I tell you what has worked for other people . . ." "What is your plan for . . ." "Would you like to consider . . ."	Words and statements that are directives make people with diabetes feel as if they are being ordered around like children. They can inflict judgment, guilt, shame, and blame.
Regimen, rules	Plan Choices	Use words that empower people, rather than words that restrict or limit them.

Dickinson, 2017, p. 555

Key Messages for DSMES

- Can be managed
- Patients role (Decision-making)
- Complications are not inevitable
- How to make changes in behavior
- Emotional responses to diabetes
- Progressive nature of type 2 diabetes
- Diabetes is an insulin problem, not a sugar problem
- It’s not easy, but its worth it

Know Yourself

Know your illness

Know how to make changes and get support

AADE resources

American Association of Diabetes Educators has developed the following:
Two-page handout • for patients, families, friends, students, colleagues, members of society
Media guide • writers
www.diabeteseducator.org • click on *practice* then *educator tools*

Dickinson JK, Johnson & Johnson webinar, 2018

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