
2. Patient Engagement and Self-Management

The Importance of Self-Management Support

Because diabetes is a largely self-managed illness, diabetes education has long been viewed as an essential component of care.

In the past, the success of patient education and support was judged by patients' ability to be compliant with their treatment program. Education was largely content-driven, and the primary educational strategy was lecturing to patients. The view was that patients would learn what to do and then adapt their lives to fit the recommendations of their health-care professionals.

In recent years, the emphasis has shifted from didactic education to programs that are oriented toward empowerment. An empowerment-based program is patient-centered rather than content-driven and is designed to provide patients with the knowledge and skills they need to make informed choices. In addition, patients are helped to identify and achieve their own goals rather than goals chosen by health-care professionals. This approach acknowledges the expertise of the patient in knowing his or her own values and abilities. Within the empowerment framework, diabetes self-management education is designed to meet the needs identified by the patient or group of patients so that they can become informed, active participants in their own care.

Does outcomes evidence support the value of diabetes self-management education?

The answer to this question is yes. Several meta-analyses have shown that diabetes education is

effective for improving metabolic and quality of life outcomes. Research has also shown that whereas no one program is more effective than others, education that incorporates behavioral and affective aspects along with information have better outcomes. The results of the Diabetes Attitudes Wishes & Needs (DAWN) Study showed very clearly that people find their diabetes distressing and difficult, even when they are able to effectively manage the metabolic and other self-care aspects. The respondents in that survey also indicated they wanted more help with these issues from their health-care professionals.

How can I incorporate self-management education and support into my practice?

To be effective, diabetes self-management education and support need to be viewed as part of care and incorporated into each routine visit. Specific strategies for incorporating self-management support into a practice include:

- Using a team of professionals within a practice, system, or community
- Implementing case management
- Using interactive technology to enhance self-management education and support
- Using group or cluster visits
- Using standardized instruments or electronic medical records

These strategies are discussed more fully in Chapter 1, Improving the Quality of Care in Your Practice—A Team-Based Approach.

Patients with Newly Diagnosed Diabetes

Principles of Diabetes Self-Management Education

- Patients may be overwhelmed, frightened, angry, or depressed, and unable to process information. These psychosocial concerns need to be assessed before beginning care and education. A list of possible questions to ask patients to assess these and other concerns is provided in **Table 2-1**.
- Initial education is based on the patient's concerns and questions.
- If barriers to treatment are identified during the assessment of concerns (for example, paying for medications, fear of complications), address these concerns initially.
- Ask more than advise; listen more than lecture.
- Repetition is important.
- Initially, patients need enough information to be safe and to feel safe at home (survival skills).

One model for successful implementation of self-management education and support is Glasgow's "5 As" model (assess, advise, agree, assist, arrange). Because patients with a new diagnosis of diabetes require a great deal of information and support, this model can help the clinician provide and evaluate different components of the interaction. Tips for using the 5 As model with a patient with newly diagnosed diabetes are presented below.

The 5 As for Self-Management in Patients with Newly Diagnosed Diabetes

Assess

The questions you ask in the initial assessment of the patient can inform the ensuing discussion

Table 2-1. Self-Management: Assessment Questions

<p>Approach to the Patient</p> <p>What language do you prefer to speak? To read? What is your favorite way to learn (e.g., reading, discussion, videos, computers, group class, individual teaching)? Where do you get most of your information about health and diabetes? Do you have difficulty with your hearing or vision, such as reading regular-size print? How far did you go in school? Do you have any cultural or religious practices or beliefs that affect how you care for your health and diabetes? Do you have trouble remembering things?</p>
<p>Emotional State</p> <p>Have you ever known other people with diabetes? How did it affect them? How much stress are you experiencing in your life? Have you felt sad and blue most of the time for the past two weeks? Two months? What were your thoughts and feelings when you first learned that you had diabetes? What are your thoughts and feelings now?</p>
<p>Support Network</p> <p>What kind of support do you receive from your family and friends to care for your diabetes? Who helps you the most to care for your diabetes? What kind of support do you want and need from your family and friends to care for your diabetes?</p>
<p>Readiness and Strategies for Change</p> <p>Do you have health problems that you manage other than diabetes? What helps you manage them? Have you ever lost weight or increased your physical activity? What helped you make those changes? What got in your way? What are you currently doing to manage your diabetes at home? On a scale of 1–10, with 10 being the most important, how important is managing diabetes in your life?</p>
<p>Concerns and Areas to Address</p> <p>Do you ever have difficulty paying for your diabetes supplies or medicines? What aspects of diabetes are you most interested in learning about? What is your greatest concern about your diabetes? What is the hardest thing for you in caring for your diabetes? What is the easiest? How can I be most helpful to you?</p>

and provide guidance in the areas listed below (see Table 2-1):

- How the patient prefers to receive information
- How the patient is coping with the diagnosis
- What kind of a support network is available
- How ready and able the patient is to implement strategies to manage the disease
- Whether there are barriers to self-management or change

Advise

- Address the patient's fears and concerns before addressing diabetes care and education.
- Address any misconceptions about the disease with respect and cultural sensitivity.
- Teach the patient about his or her role in the care of a chronic disease such as diabetes; discuss your role as well.
- Teach survival skills (e.g., for type 1 diabetes, blood glucose/ketone monitoring, dealing with hypo/hyperglycemia).
- Acknowledge that negative feelings are common and provide reassurance (and information regarding counseling/treatment if appropriate).
- For type 2 diabetes, discuss the “continuum of care” and expected treatment changes over time.

Agree

- Plan a return visit and initial education and self-management support.
- Identify when and whom to call if there is a problem or if additional help is needed.

Assist

- Identify a resource for getting questions answered between visits.
- Identify a resource for addressing barriers and problems if any are identified as concerns during the assessment.
- If the primary intervention is lifestyle changes, use community resources and referrals to assist with the “how”—not just the “what.”

Arrange

- Arrange a referral for diabetes self-management education and/or medical nutrition therapy.

What education do patients with newly diagnosed diabetes need in their first visit?

The following “take-home concepts” should be discussed with any patient with a new diagnosis of diabetes:

- Diabetes is serious but manageable.
- Negative feelings—fear, anger, sadness—are common. If the feelings become overwhelming or negatively affect self-care abilities, additional help is available.
- Patients have a role in the self-management of their disease and so need to learn as much as possible about it.
- For type 2 diabetes, there is a continuum of treatment—lifestyle changes, then oral medications, then injectables. The point is to use what works and is needed to manage glucose levels.

In addition, depending on their medical status and treatment plan, patients should be provided with clear (preferably written) instructions regarding the following points:

- What to eat until you see the dietitian
- Blood glucose monitoring
- Acute issues (e.g., hyperglycemia)
- Insulin administration with demonstration and practice
- Hypoglycemia (type 1 diabetes)
- Ketone monitoring (type 1 diabetes)
- When to next contact the office for both routine follow-up and urgent/emergent problems

Ongoing Care of Patients with Previously Diagnosed Diabetes

Because diabetes is a chronic illness, a one-time educational intervention is not adequate. Several meta-analyses have shown that although diabetes education is effective for improving metabolic and quality of life outcomes, traditional knowledge-based programs are not enough to help participants sustain the type of behavioral changes needed for diabetes self-management. Patients need initial diabetes self-management education followed by ongoing diabetes self-management support. The goal is to facilitate patients' self-care and behavior change efforts so that patients become effective daily managers of their diabetes. Ongoing self-management support is important for:

- Helping patients initiate and sustain behavioral changes
- Addressing barriers, concerns, and psychosocial issues
- Screening for depression or anxiety
- Helping patients to continue to learn about diabetes and new treatments as they are needed

Although the initial, comprehensive education may best be done outside the practice setting, the office setting is ideal for ongoing diabetes self-management support, including education and goal-setting to achieve behavior change.

How can I help my patients set self-management goals that they can achieve?

An effective strategy for behavior change is helping patients to establish self-management goals based on their own needs, priorities, and values. The empowerment-based 5-step goal-setting process is an effective strategy for setting goals *with* rather than *for* your patients:

1. What is it about your diabetes care that is causing you the most distress at this time?
2. How do you feel about this issue?
3. What do you want to do about this issue (long-term goal)/how important is it to you to address the problem?
4. What will you do this week (short-term goal)/how confident are you that you can achieve the goal you set?
5. How did it work/what did you learn?

A key to the success of this approach is to encourage patients to think of their short-term goals as a series of behavioral experiments. Experiments provide information and feedback regardless of their success or failure. Therefore, the critical question is not “Were you a success?” but “What did you learn and what will you do or not do differently next time?”

All of these five goal-setting steps may not be possible for many providers within the context of a busy office visit and thus can appropriately be the role of other professional staff members. However, providers can begin each visit by asking patients what concerns they need addressed today and end by asking what they plan to work on between this visit and the next. For strategies to help you support behavior change by your patients, see *Tips for Encouraging Behavior Change*.

The “AADE 7” are the seven critical self-care behaviors identified by the American Association of Diabetes Educators (**Table 2-2**). Worksheets for setting self-management goals



provided in the *Diabetes Care Guide Toolkit* include *Setting Your Self-Management Goal* and *Your Self-Management Workbook*.

Principles of Ongoing Diabetes Self-Management Education

- Successful self-management education programs are patient-centered and aim to provide education for informed decision making and behavior change. Goal-setting is a patient-directed, rather than a clinician-directed, activity.

Tips for Encouraging Behavior Change

ONE STEP AT A TIME

Changes are easier to make and more likely to last if patients make them one at a time. A series of small changes can ultimately result in a major change in the patient's self-management and lifestyle.

EASY DOES IT

Focus on changes that your patients believe will work. Changes that are likely to work are ones that your patients feel enthusiastic about and believe strongly that they can carry out.

TAKE SMALL STEPS

For example, if you have patients who drink whole milk and want to try drinking fat-free milk, advise them do it in a series of small changes. They can start by switching from whole milk to 2% milk, then change from 2% to 1%, and then from 1% to skim milk. Making changes like these in steps is a way to help your patients gradually adapt to a larger change.

DON'T GO IT ALONE

Advise your patients to ask for support when they need it. It is hard to make long-lasting lifestyle changes without the support of other people. Often patients think those close to them should know what they want in the way of support without having to be told. If your patients are making changes for their health and want the help of their friends, family, or co-workers, advise them to ask for it. Have them tell the people from whom they want support what they are doing, why it is important, and specifically what they want in the way of help.

PLAY TO WIN

Help your patients identify the behavior changes that will be the most meaningful to them personally. Start with these changes even if as a health-care provider you believe different changes would have a greater positive impact on your patients' health. Patients are more likely to succeed in making changes that are important to them personally than in making changes that the provider thinks are important. After the patient has succeeded in making some personally meaningful changes is when to discuss the changes the provider thinks are important.

Source: Anderson RM, Funnell MM. Tips for Encouraging Behavior Change. Copyright © University of Michigan. Used with permission.

- Programs should be flexible according to the learning styles and needs of the patient. For example, a patient may prefer to read on his or her own rather than attend a class or may prefer one goal-setting tool over another.
 - Effective programs are based on the principles of adult education and problem-based learning and integrate psychosocial, behavioral, and clinical content.
 - Patients whose providers are positive about education (rather than using it as a punishment) are more likely to participate and benefit.
 - Depression is common in diabetes and negatively affects patients' ability to manage their diabetes. Screening for depression and other psychosocial barriers to care is an important component of ongoing support.
- Self-management interventions can occur either in group or in individual sessions. Practices with a large number of patients with diabetes can create innovative arrangements with local diabetes self-management education providers in the area. For example, one day a week can be scheduled for bringing in a diabetes educator for


Table 2-2. AADE 7 Key Self-Care Behaviors

Healthy eating Being active Monitoring Taking medication Problem-solving Healthy coping Reducing risks
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Developed by the American Association of Diabetes Educators. Adapted with permission from Mulcahy K, Maryniuk M, Peebles M, Peyrot M, Tomky D, Weaver T, et al. Diabetes self-management education core outcomes measures. *Diabetes Educ.* 2003;29:768–70, 773–84, 787–8 passim.

all patients with diabetes. (For other strategies for using a team-based approach to incorporating diabetes self-management education into your practice, see Chapter 1, *Improving the Quality of Care in Your Practice—A Team-Based Approach*.) Reimbursement for diabetes self-management education has become more widely available in recent years, particularly for programs recognized by the American Diabetes Association. Practices are also learning strategies for obtaining reimbursement for diabetes self-management support (for example, through group or cluster visits) or using personnel other than the provider.

What topics need to be addressed in ongoing self-management discussions with patients?

It is important to enable patients to take the lead in voicing their concerns and questions  about managing their disease. *Identifying Your Concerns* in Chapter 2 of the *Diabetes Care Guide Toolkit* is a questionnaire your patient can fill out before an appointment to help frame the discussion of self-management and clinical issues.

The 5 As model can guide you in providing effective ongoing self-management support.

The 5 As for Ongoing Self-Management Support

Assess

As for newly diagnosed patients, the questions you ask your patients will inform the ensuing discussion.

- What are your greatest concerns at this time about your diabetes? What is hardest for you in caring for your diabetes right now? What questions do you have today? How can I be most helpful to you? What are your thoughts and feelings about diabetes at this time?
- How well do you think your treatment plan is working to manage your diabetes? What do you think would help to improve the situation?
- Have you ever received diabetes self-management education? What was your experience? Are you interested in receiving diabetes self-management education?

Advise

- Explain that negative feelings (fear, anger, sadness) are common but if the feelings become overwhelming or negatively affect self-care abilities, additional help is available.
- Provide information about new therapies and issues as they arise (e.g., starting insulin).
- Provide specific information about the patient's test results.
- Establish priorities for teaching that are based on patient-identified concerns and treatment.
- Use teachable moments and opportunities during the visit for education (e.g., during monofilament testing, point out areas of the foot for which particular attention is needed).

Table 2-3. American Diabetes Association Content Areas for Diabetes Self-Management Education

Describing the diabetes disease process and treatment options
 Incorporating appropriate nutritional management
 Incorporating physical activity into lifestyle
 Using medications (if applicable) for therapeutic effectiveness
 Monitoring blood glucose level and urine ketones (when appropriate), and using the results to improve control
 Preventing (through risk-reduction behavior), detecting, and treating chronic complications
 Goal setting to promote health, and problem solving for daily living
 Integrating psychosocial adjustment into daily life
 Promoting pre-conception care, management during pregnancy, and gestational diabetes management (if applicable)

Adapted from Mensing C, Boucher J, Cypress M, Weinger K, Mulcahy K, Barta P, et al. National standards for diabetes self-management education. Task Force to Review and Revise the National Standards for Diabetes Self-Management Education Programs. *Diabetes Care*. 2000;23:682-9.

Address the diabetes self-management education content areas identified by the ADA (**Table 2-3**) either through a formal program or an informal program. (A curriculum titled *Life with Diabetes: A Series of Teaching Outlines* is available from the ADA at: www.diabetes.org/for-health-professionals-and-scientists/recognition/resources.jsp.)

- Content areas need to be addressed in order of patient interest and assessed need.
- Not all patients need all content areas.
- Written materials should reflect the culture and literacy level of the audience.
- Written materials need to be reviewed and discussed with patients.

Additional or more specific content areas that may arise include:

- Psychosocial issues
- How to make behavioral changes
- The meaning of numbers (e.g., blood pressure, A1C)

Sick Day Recommendations

KEY MESSAGES FOR PATIENTS ABOUT SICK DAYS INCLUDE THE FOLLOWING RECOMMENDATIONS:

1. Never omit diabetes medication.
2. Self-monitor blood glucose every 3 to 4 hours and perform ketone testing when two blood glucose readings are greater than 250 mg/dL.
3. Drink 6 to 8 ounces of fluids each hour while awake.
4. Call a health-care provider if vomiting or diarrhea persists more than 8 hours, the ketone value is moderate to large, blood glucose values greater than 250 mg/dL do not decrease with extra insulin, blood glucose values are low, or the appropriate action is unknown.

- Standards of care and annual testing
- Moving from pills to insulin (patient decision making)
- Injection techniques
- Hypoglycemia (type 1 diabetes)
- Strategies for remembering to take medications
- Sick day management (see *Sick Day Recommendations*)
- Foot care
- Sexual health
- Simple meal-planning strategies
- Stress management
- Wearing diabetes identification

- Financial resources
- Resources in the community

Agree

- Schedule a return visit and a plan for diabetes self-management education and support.
- Patients should establish self-selected short-term goals, which are followed up at or between visits using the 5-step goal-setting model.
- Establish target metabolic goals and times when a patient is to contact office staff.

Assist

- Identify a resource for getting questions answered between visits.
- Assist patients to identify barriers/problems and identify strategies to address these problems.

Arrange

- Ongoing support through visits, support groups
- Method for follow-up education or support

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