

## **Motivating and Enabling Self-care in Diabetes**

### **David Spero RN**

Diabetes educators say that 90% of diabetes care is self-care.<sup>1</sup> Physical movement, healthy eating, self-monitoring and relaxation are far more important than anything the medical profession can do for diabetes (or for most other chronic conditions). But self-care has a social context, and in this society, that context is mostly negative.

Self-care is not something people see on TV or learn in school. People have few role models for it, since most parents are too busy and stressed to give their bodies any attention. In fact, self-care goes against everything the dominant culture believes our lives are about and our bodies are for, which is mostly to produce and consume. Time not spent productively is considered time wasted.

We even learn a story about this as kids, about the ant and the grasshopper. The ant worked and slaved all through the year, while the grasshopper goofed off. As a result, the ant had plenty to eat in the winter, while the grasshopper starved. But that ant probably had chronic back pain and high blood pressure at the very least. They never tell you that part, because some elements of our society want us to endorse the ant's work ethic.

So it's not surprising that we take our bodies – the most precious gifts we will ever be given, and the most valuable assets we will ever have – for granted. We treat them like used cars: we drive them to do all our work and other demands and even our entertainment, without putting much effort into them. And when they break down, we take them to a mechanic (with a medical degree) and say "Here, fix this."

But when you get a chronic illness like diabetes, you find out they can't fix you. All of a sudden your life is supposed to revolve around self-care. You're supposed to do it 24/7. But you're on your own with it, because our society is not set up for healthy living. Most people get little self-care support. Families may not want to change to healthier eating. Jobs may enforce sitting or standing all day, wearing you out without allowing any exercise. Employers may not let workers test their sugar or take breaks they need. (It may not be safe to let the boss know you have diabetes at all.) Wherever we are, we're surrounded by toxic food. Stressors are everywhere, and eating comfort food is the easiest way to deal with them.

Taking the path of least resistance, eating and living as society and media urge you to do, gives people diabetes (and other chronic illness). We can sum up the essence of self-care in two words: Get Active! If you stay passive, the environment will roll you in sugar, fry you in oil, and have you for lunch. So we need to approach self-care with a fighting spirit. We need to claim the right to care for ourselves. Self-care can be a political act, an act of rebellion that says we are worth taking care of, that our lives have value, even if society seems to deny it.

### **Power and Self-care**

Succeeding at self-care requires addressing the issues of power that affect one's health. To eat right when surrounded by toxic food, to move one's body off the couch, to relax in an environment full of stresses and dangers; these things take power. So does strengthening a family or community when the culture pushes isolation and individualism.

Getting active starts with physical activity, and the more of that we get, the better. It also means people deciding for themselves what's important and what's unnecessary. It means you decide what's good for you to eat rather than reaching for what's at hand or what the TV is pushing. It means paying attention to your body when society treats your body as only a means of production or a source of shame. A political approach also includes allying with other people and changing our environments.

For most people, self-care won't be enough to handle diabetes, but without it, nothing else will work. And self-care can be a turning point that makes people more effective in their families and communities. It makes them assertive; it makes them strong. They can become catalysts who help others value themselves, and that can lead to communities fighting to change their social environment. And that kind of fight can prevent diabetes and a lot of other problems, too.

### **The Power to Change**

Self-care requires personal and social power. Sources of personal power include external resources: money, social status, education, living in a good neighborhood. Internal resources are also crucial: self-confidence, emotional security, knowledge, positive reasons to live, and an assertive fighting spirit. (Social power is just as important and gets its own chapter in my book.)

The one indispensable thing people need for self-care is a willingness to change. Change is hard<sup>2</sup>, especially for people who haven't felt much control over their lives or don't have a history of successful change to draw on. But we know that it can be done. We know how to do it, and we have seen what the benefits can be. It all starts with self-confidence.

Alfred Bandura, a great social psychologist from Stanford University, developed the concept of self-efficacy (SE), which is self-confidence applied to a particular area of life. SE is the belief that you can do the things you set out to do and is the best predictor of behavior change. "People tend to try activities they believe they can accomplish," says Bandura, "and avoid activities where they feel less confident."

Most professionals treat SE as a psychological construct, something inside an individual's brain or personality, but that is not accurate. The same confusion dogs other related constructs such as "locus of control"<sup>3</sup> and "stages of change"<sup>4</sup>. Locus of control (LOC) refers to who you think controls what happens to you – you or outside forces.

Generally, an “internal locus of control,” is thought to promote behavior change and better health, and an external locus promotes fatalism and inhibits change. “Stages of change” refers to the priority a person gives a behavior change like stopping smoking or beginning to exercise. In these concepts, the health professional should use counseling and teaching techniques to help people move to a more internal LOC or a higher readiness to change.

But if you think about it a moment, you see that these are not primarily psychological factors at all. They mostly reflect life circumstances and histories. If you have never had the power to make much of anything happen, what will that do to your SE? If you haven’t had much control in your life, where will your locus of control be? If you believe you have no control over your body because of early abuse or neglect, why would you think you could control your health, your eating or your exercise behaviors? If you are worried about losing your job, paying your rent, or taking care of a zillion other people, how high a priority would you give diabetes management? By ignoring these factors, professionals can cause a lot of frustration and add to patients’ sense of failure, the opposite of what is intended.

The great breakthrough of Bandura and other SE theorists has been breaking self-confidence down into specific areas and developing strategies for building SE around particular activities. And SE often generalizes to other activities<sup>5</sup>, so people wind up feeling more powerful and more in control of their lives. In an early study of people with snake phobia, Bandura found that, in conquering their fear of snakes, people gained the confidence to try a number of things they had been scared of before, such as public speaking. People who increased their SE around maintaining an exercise program might do things like get their high school diploma or cut back on their drinking.

### **Building Self-efficacy**

This is incredibly powerful stuff. Another Stanford researcher, health educator Kate Lorig, RN, DPH, started the Arthritis Self-Management Program (ASMP), a six week class/support group run by lay people with arthritis.<sup>6</sup> Participants reported less pain, more ability to carry out their daily lives, and less need for medication or doctor visits. But what was causing the benefit? Was it the knowledge students learned, or the exercises they did, or the relaxation techniques, or what?

When Lorig checked, the answer was none of the above. It turned out that people whose *self-efficacy* had gone up the most were the ones who got the benefit, whether they practiced the new behaviors or not.<sup>2</sup> They felt they had more control, and feelings of control reduce stress, and they got better. Lorig’s program is now given around the world and used for many other conditions, including diabetes.

Lorig and Bandura agree that a key to ASMP’s success has been the use of lay leaders instead of health professionals. One reason is that “vicarious accomplishment” is one of the best ways to build self-efficacy. When people see others like them having success with a behavior or a program, they tend to believe they can do it too.<sup>7</sup>

Lorig has fought for decades to get the lay leaders accepted by the medical profession. Many doctors and professional educators have been extremely reluctant to give up the power or to believe that lay people can do effective education. What do they know, anyway? All they have is their years of experience and accumulated knowledge. Where are the PhDs and MD degrees? But Lorig believes in people power. She keeps saying that, “Professionals are experts on an illness, and patients are experts on their lives,” and the two groups need to respect each other’s expertise. This approach is gaining acceptance in the arthritis world, but only very gradually in diabetes. A small minority of people with diabetes have access to such programs. (Many programs that are called “self-management programs” really aren’t. They lack the crucial focus on building self-efficacy.)

### **Experiencing Success**

An even better way to build SE is actually accomplishing a goal. Most people give up on a behavior change when they feel they are failing. Let’s say somebody agrees that he needs to exercise, and his doctor tells him to walk an hour every evening after dinner. He says OK, but his favorite show comes on after dinner, he needs to help the kids with their homework, the neighborhood isn’t safe, and his feet are hurting. He only walks two days out of the week, he feels like a failure, and his health providers call him “noncompliant” (medicalese for “disobeys our orders.”) His SE around exercise will be very low, and it may be years before he tries it again.

What would be an SE-based way of approaching this problem? Someone from Dr. Lorig’s program would probably ask the patient how he wanted to exercise, what he wanted to do, maybe give him a menu of choices. The best changes are things that people WANT to do, not something somebody else tells them to do. Most people are tired of being ordered around, and the key to building “internal locus of control” is to give them more control.

But how do you know they’ll actually do it? In the self-management programs, people decide for themselves how many times they’ll do something and how much of it they’ll do. They determine their “confidence level” on a scale of 1 – 10 of completing the assignment. Experience shows that the confidence level has to be at least 7; otherwise the change won’t get done. The important thing is to succeed. It’s better to say you’ll walk three days this week and actually do it, than to say you’ll walk five and do four. The first way builds SE and paves the way for more changes. The second way makes you want to give up.

Other ways to build SE include getting positive feedback (like keeping a log sheet or noticing blood sugar readings coming down), and persuasion (remembering past successes and reframing past experiences to highlight the successful elements.) Knowledge also helps build confidence.

SE sometimes generalizes to other areas of a person's life and sometimes doesn't. One key factor seems to be similarity – SE generalizes more easily to behaviors similar to the ones you have already mastered.<sup>8</sup> For example, if someone learns to keep to a daily exercise program (a “self-regulatory” skill), she may feel confident about going back to school or getting a job, where self-regulation is required. If someone learns to speak up to his doctor about medications, he might speak up to politician or developer who impacts his community, or challenge a convenience store owner to put some healthy food at the front of the store instead of the candy and soda pop.

**“You have to love yourself.”**

Self-confidence is a big part of personal power, but people also need to believe that they are worth taking care of, that their bodies' needs are as important as their other responsibilities. I got a striking statement of this truth when I interviewed James Ratliff, an African-American sales consultant in Pleasanton, California, who was diagnosed with T2D at age 46. He had a demanding job and a growing family, but he had one key asset – he believed in himself. “At that time,” he told me, “I was maybe 30 or 40 pounds overweight. So I changed my diet to eliminate sugar completely, and not eat a lot of carbohydrates. They had this little gym where I lived, and I started getting up at 5 o'clock every morning to work out. Now my sugars are pretty normal.”

As simple as that? I really couldn't believe it. I asked Mr. Ratliff how he was able to quickly make such changes, when many other people never get there. I will never forget his answer. “I love myself,” he said. “I think that's the best thing I can do. Once you love yourself, then you're going to take every resource possible to extend your life. That's not being selfish. Sometime you have to do things for yourself before you can do things for anybody else. If I don't care about myself, how can I care about anybody else? These things are important to understand, that if you want to continue to stay on this planet and breathe this air---you have to love yourself.”

I'm not sure how many people, with or without diabetes (especially discriminated-against ethnic groups or heavy people in fat-phobic America) could say that they love themselves. How do people love themselves when society does not seem to love them? When all around them is physical evidence that nobody outside their community cares? Or when a person feels unlovable because of absent or damaged parents, or a history of trauma, or because their life doesn't measure up to the images they see on TV or to what they think they should have been?

But if you don't love yourself, why and how are you going to succeed at diabetes self-care? Why watch your carbs or check your blood sugar or get up in the morning to exercise like James Ratliff does? And if you don't love yourself, why expect your children to love themselves, or others in your community to treat each other well? These issues can determine quality of life and health generation after generation. So what do we do?

### **Self-love, family, and community**

Self-love is not selfish. It can spread to other people who desperately need it. James Ratliff has been able to inspire many friends and neighbors to eat well and exercise, and has gotten his children to live healthier lives than most kids. But it doesn't stop there. His son can pack water with him to school instead of soda, and tell his friends, "That cola stuff made my Dad sick. I don't want that for me, and you shouldn't either."

Self-love starts in early childhood. Parents are best placed to build children's sense of self, but they are often too stressed to do it. So one of the most important things we can do as a society or community to improve health is to support parents and young children.

Getting social support can strengthen people's sense of self. Professionals such as therapists or clergy can help people reframe their stories to feel more optimistic and less judgmental.<sup>9</sup> Families, friends and communities can build people's sense of self or tear it down.

### **No More Nice Girl!**

Canadian Dr. Gabor Mate wrote an excellent book called *When The Body Says No: The Effects of Hidden Stress*<sup>13</sup>. The idea is that if you can't say "No," your body will say it for you, by getting sick or even dying. Some people are in a better position to say no than others. Obviously, if you're a slave, you can't say no. But many people feel powerless to refuse any demand, request or offer. Life, in the form of social conditions, family dynamics or trauma, has taught them to be helpless, but they think they're being "nice."

People with diabetes and other health problems can't afford to be nice. Say Inga has diabetes and goes to a family gathering, where her cousin Joan offers her a big piece of homemade cheese cake, "just the kind you love." Joan says or implies her feelings will be hurt if Inga doesn't eat. People do this kind of thing all the time for some reason, and Inga can't afford to be nice in this situation. Or say, Marcus gets offered a double shift at work, and the boss implies that he'd be very grateful, and Marcus knows his family can use the money. However, he also knows he needs to rest, he needs to exercise, and he needs to eat at a proper time. And he knows he will be best off not telling his boss about his diabetes.

In situations like these and many others, you don't want to be nice. That's why I carry a bag of buttons that say, "No more nice girl!" and "No more nice guy!" Buy a book, and I'll throw in a button. But many times, people just want the buttons, because this message is so important.

A good self-management or health promotion program will include assertiveness training. Too many people feel they have to do everything for everybody all the time. Such people may be nice to have around, but they're usually not as helpful as they think. They're tired; they're impaired, and they're resentful, even if they aren't aware of it.

They and everyone else will be better off when they learn to say, “No” and speak up about their real needs and desires. In situations where the power relationships make it difficult to speak up – for example, at work or in the doctor’s office – it may help to have other people with them for support.

People have to fight for their health. This doesn’t mean fighting diabetes – illness is just our bodies’ trying to cope with toxic conditions. It may mean fighting some of the conditions that cause diabetes. And it doesn’t usually mean combat. Some of our strongest weapons are acceptance of ourselves, and of others, forgiveness of those who deserve to be forgiven, and love (for ourselves and the people around us). The best way is to accept with a fighting spirit.

### **Reasons to Live**

Professionals and media usually tell people self-care is all about exercise and food. In reality, our health flows from our lives, and anything people do to make their life better, easier, or more meaningful contributes to better health. That’s why preventing and managing chronic illness often has to start with making people’s lives better, not just focusing on health. If parts of people’s lives get in their way, we have to deal with those parts.

We had a patient named Rita in a 4-week class who would never agree to do anything about her diabetes. She said her kitchen was too disorganized and needed cleaning. She wouldn’t discuss exercise, eating, or other “self-care behaviors,” but she did get her kitchen clean. Two month later, we brought everyone back for A1C tests to see how well the program had worked. Rita’s blood sugars had gone down more than anyone in the class! Maybe it was dealing with the stress, maybe it was building her SE by succeeding in the kitchen, but she got better.

William Polonsky, PhD, author of *Diabetes Burnout* says everyone decides about self-care based on a cost/benefit analysis.<sup>11</sup> If the benefits of healthy behaviors don’t seem worth the discomforts, trouble, and expense, people won’t do them. The most commonly cited benefits of diabetes self-care are longer life and avoidance of complications. But the value of those benefits depends on how highly people value their lives.

If you don’t have a reason to get out of bed in the morning, it won’t matter how healthy you are. If one’s life is filled with stress and pain and has little pleasure or love, why should that person check his blood sugars or avoid donuts, or stop shooting heroin for that matter? Finding reasons to live (and reducing the things that make us miserable, which I call reasons to die) can make a huge difference in health.

In a famous study,<sup>12</sup> Drs. Ellen Langer and Judith Rodin divided residents in a Connecticut nursing home into two groups. Each group got a cheap house plant. One group was told, “We’re giving you this plant to make your room look better. The staff will take care of it. Enjoy.” The other group got to choose which plant they wanted, and

was told something like, “This is your plant. You can take care of it or not, as you choose. It’s up to you whether the plant lives or dies.” This group was also encouraged to make some other choices, for example, about the arrangement of furniture in their rooms. Eighteen months later, Langer and Rodin were shocked to find that residents in the “just look at the plant” group had died at twice the rate of the group who were taking care of their own plant.

Now, taking care of a cheap house plant is about as minimal a reason for living as you can imagine. But in a nursing home, and in many people’s lives, reasons might not be that easy to come by. Imagine a homeless person, sleeping on a cold street, with few friends, no love, and no idea how things could ever get better. Why would this person care about controlling their diabetes? So they could live longer? In some communities, large sections of the population live in situations where the costs of self-care far outweigh the benefits, so the first self-care step is getting some more reasons to live or losing some reasons to die.

Finding reasons to live frequently involves other people. Studies show that isolation is perhaps the biggest reason to die,<sup>16</sup> and loneliness is the biggest risk factor for death among seniors. People’s health and health behaviors usually improve dramatically when they become more involved with family or community.

Unemployment devastates people’s health, mainly because of the stress of not contributing anything or having much to do. However, some unemployed people manage to stay healthy. These tend to be people who get involved in some way, by volunteering and helping others, or who keep life interesting, say by going back to school or getting politically active. Engaging in self-care and helping others do so, so helping protect one’s community, can be a way of engagement and a reason to live all by itself.

## **RESOURCES and REFERENCES**

### **BOOKS**

- Bandura, A. (1997) *Self-Efficacy: The exercise of control*: W.H. Freeman  
Langer, E. (1983) *The Psychology of Control*: SAGE Publishers  
Lefcourt, H. (1982) *Locus of Control: Current Trends in Theory and Research*: Lea  
Maté Gabor (2003) *When the Body Says No*: Wiley  
Polonsky, W. PhD (1999) *Diabetes Burnout: Preventing It, Surviving It, Finding Inner Peace*: American Diabetes Association.  
Lynch, J. MD, (2000) *A Cry Unheard: New Insights into the Medical Consequences of Loneliness*: Bancroft Press

### **ARTICLES**

- Lorig, K, Gonzalez Virginia 1(992) “The integration of theory with practice: a 12-year case study” *Health Education Quarterly* 19(3):355-68 Fall  
Bandura A, Jeffery RW, Gajdos E (1975) “Generalizing change through participant modeling with self-directed mastery” *Behav Res Ther.* 13(2-3):141-52 Jun

Lorig K.R. Sobel D.S. et al (1999) "Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial." *Med Care* 37(1):5-14 January

Spero, D. (2004) "How Stories Can Heal" *Diabetes Self-Management* April-May

Langer, E. and Rodin J. (2004). Long-term effects of a control-relevant intervention with the institutionalized aged *Journal of Personality and Social Psychology* 37(11):2003-13.

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Although the subject is diabetes, the ideas apply to any chronic condition or wellness promotion area. Please feel free to download and disseminate, as long as you keep the identifying information.

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*Mr. Spero remains active in nursing and alternative health organizations. He inspires hope and provides paths over the obstacles that keep so many of us from taking care of ourselves. He has worked closely with people with heart disease and hepatitis, leads Chronic Disease Self-Management groups, and has co-written educational programs for people with arthritis, asthma, allergies, chronic pain, insomnia, and other conditions.*

*David's new book **Diabetes: Sugar-coated Crisis – who gets it, who profits, and how to stop it** is available in bookstores, on-line, or from the author. Learn more about David's work, including workshops, seminars, lectures, and writing at [www.davidsperorn.com](http://www.davidsperorn.com). Contact [Nurse@davidsperorn.com](mailto:Nurse@davidsperorn.com) 415-585-9851*