



Burden of **care**

———— *When you love someone with diabetes,* —————
— *you do all you can to keep him well.* —————
————— *And that's how the trouble begins.* —————



Family members can make the best diabetes care partners, as Sophie Clark and her husband, Alvey, have learned.

IT'S SOMETIMES HARD to tell who in the Clarks' home has diabetes. While Alvey, 74, was diagnosed with type 1 diabetes 52 years ago and checks his blood glucose levels on his own, it's his wife Sophie, 70, who frets about the results. Alvey injects the insulin, but Sophie brings his medications to the table. As the cook in the family, Sophie plans meals based on Alvey's blood glucose levels. "If they're high, I'll make a point of using foods with a lower carbohydrate content or lower Glycemic Index," says Sophie, from their farm near Moosomin, Saskatchewan.

And, oh yes, Sophie reminds Alvey when to eat.

Diabetes affects lives as much as it does bodies. With advancing age or the development of diabetes complications, the caregiver role intensifies. The spouse or adult children may be called on to plan meals, manage medications and help with a host of day-to-day functions. Add worry to the mix, and the caregiver's emotions can go up and down with the loved one's blood glucose levels.

Caregiver challenges

"MY DISEASE, MY PROBLEM," you might say, but most caregivers see it differently. "The more you care about the person, the harder it is on you," says Gail MacNeill, a diabetes nurse educator at the Tri-Hospital Diabetes Education Centre (TRIDEC) in Toronto. "Studies tell us that diabetes can stress caregivers as much as patients," she says. "Caregivers can suggest things but can't control their loved one's choices. It can be enormously frustrating to stand by and feel helpless."

Then there's what Frank MacDonald, a gerontology nurse practitioner in Calgary, calls "instrumental support." This list of caregiver tasks can include speaking with pharmacists, overseeing blood glucose testing and medications, watching and assisting in treating episodes of hypoglycemia and setting up doctors' appointments.

In the Clarks' case, Sophie has taken over sorting Alvey's medications into a pill box, which has four compartments for each day of the week. "My memory is not what it used to be," admits Alvey. As his regimen includes drugs for digestive problems, bladder control, high blood pressure and tremors, as well as metformin to stabilize his blood glucose levels, the job of medication manager calls for perpetual vigilance.

While applauding such efforts, MacDonald cautions caregivers to keep the loved one firmly in the driver's seat. "As long as the person with diabetes still has his mental faculties, he should be making the ultimate decisions about his care," he says.

The takeover syndrome

EASIER SAID THAN DONE, of course, especially when the person with diabetes isn't making what you consider "the right decisions." "I used to be a bit of a watchdog," admits Donna Epp of Brandon, Manitoba. Shortly after marrying Ed Epp, 52, who developed type 1 diabetes as a child, Donna urged him to have his eyes tested. "It turned out he needed laser treatment," Donna recalls. "For some time after that scare, I felt it was up to me to stay on top of Ed's disease."

PHOTO: DARRYL KAJATI

Donna, a nurse, decided to take diabetes management even more seriously and enrolled in classes to earn accreditation as a diabetes educator. She brought home different blood glucose monitors for Ed to try, and encouraged him to check his levels four times a day. "I didn't want to miss anything," she says.

The problem with such takeover behaviour is that it rarely works in the long-term. "Studies show that the more the environment functions like the police, the more likely the patient will act like a criminal," says MacNeill. The thousands of patients interviewed in the multinational 2002 Diabetes Attitudes, Wishes and Needs (DAWN) survey made it clear that unwanted caregiver support and pressure has a negative effect on their well-being and self-care.

That's exactly what Donna discovered. Ed wasn't

amenable to being micro-managed, she says. "I stopped for the sake of the marriage." Donna still gets frustrated when Ed has what she considers too many episodes of low blood glucose levels. But, she says, "I realize I have to let him make his own mistakes." Donna's attitude has paid off. "He's taking more responsibility, and there's less stress on me," she says.

Not everyone with diabetes, though, is intent on managing their diabetes well. "The reality is that some will never make responsible choices," says MacNeill. As difficult as it may seem, emotional disengagement may be the best strategy for caregivers in such cases, she says. "At some point, the caregiver has to protect his or her own mental health. Otherwise they'll crash and burn."

Lighten your load

KERRY ACLAND, the manager of public programs and services for the Canadian Diabetes Association's Manitoba and Nunavut region, recommends that caregivers approach diabetes as a shared learning experience. "Go out and shop *with* the person, rather than *for* the person," she suggests. "Go hiking together, do yoga together, take the opportunity to improve your connection. The person with diabetes will feel less singled out, and the caregiver will feel good about the family's improved lifestyle."

Even then, caregivers run the risk of burning out. "Caregiver depression and anxiety are big issues," says Gwen Morgan, a social worker and one of MacNeill's colleagues at TRIDEC. "Spouses of people with type 1 diabetes report more anxiety than the patients themselves." Diabetes-related depression often responds to non-drug approaches such as psychotherapy and cognitive behavioural therapy, adds Morgan.

Some diabetes centres offer workshops or support groups for caregivers. TRIDEC plans to launch a caregiver program this fall, says MacNeill, who did her Master's thesis on programs for caregivers. "We'll provide information, support and feedback," focusing on how caregivers can communicate effectively with their loved ones, she says.

Even those who can't access a caregiver program can attend some of the workshops or support groups that many diabetes clinics set up for patients, says Acland. Some clinics have counsellors or social workers who will see patients and caregivers together, she adds. At the end of the day, "the caregiver has to put on her own oxygen mask," says Acland. "Otherwise, she's of no use to anyone." **DD**



The language of caring

He's so stubborn, thinks the caregiver. She's such a nag, thinks the person with diabetes. The more the caregiver pushes, the more the person with diabetes pushes back. And everyone's health suffers.

To avoid this vicious cycle, make a conscious effort to use the language of good communication, advises Gwen Morgan. Stick to "I" statements rather than "you" statements, she advises. Avoid accusatory words such as "always" and "never."

If you have concerns about how your loved one is managing his or her blood glucose levels, for example, you might say, "I worry when I see such wide fluctuations in your glucose levels." This expresses concern, not anger, as this comment does: "You never watch what you eat. Can't you see you're killing me?"

While "I" statements may seem contrived when you first try them, Morgan says that they become natural with practice. What's more, they work. "They're your best shot at getting your point across," she says.