

CARE PARTNERS:

A Powerful Team of Love and Support

Hello. I'm Bob. I am 62 years old, I'm a husband, father, brother, grandfather, and "care partner". I have Parkinson Disease. At first my life went on pretty much as usual, except that I was a little unsteady, and my leg muscles would "freeze" sometimes. Little by little this disease robbed me of most of the activities I used to love, not to mention the dream vacation I had planned with my wife Linda. Now I need Linda's help to do even simple things like buttoning my shirt. That's what makes us "care partners." We both do what we can to look after the other's wellbeing. I do everything I can for myself, and I try to show Linda my love, appreciation, and concern every way I can. Some days that's not much. Then I get pretty grouchy. It's humbling to accept help going to the bathroom! Sometimes I actually feel angry with Linda and say unkind things to her. Then I see her cry and notice how tired she looks, and I feel terrible. I'd like to be able to help her more with all that she has to cope with. After all, this disease has happened to both of us.

I am Sadie. I'm 89-year-old, a retired piano teacher. I have rheumatoid arthritis and diabetes. My granddaughter lives in my house and takes care of me. She does all the cooking, laundry, and cleaning, checks my blood sugar, gives me my medicine, and helps me with my bath. She quit her job to come and take care of me. She's taking online college classes, and I can see that she is overwhelmed a lot. She "talks" to friends on her computer, but she never gets to spend time with people her own age. Sometimes she gets cross with me. I wish I could put a little fun in her life.

These stories demonstrate an often-overlooked part of the family caregiving situation: the person needing care has many difficult feelings to deal with, and there may not be any appropriate time or place to express them. A person who receives care may feel embarrassed, guilty, inadequate, angry, and betrayed by life events. If feelings are not recognized for what they are, they may come out as unkind words to the caregiver, stubbornness, and drawing in to one's own troubles with blinders to anyone else's needs. Even though the caregiver is doing most of the physical work, the care receiver can be a partner in the relationship by offering appreciation, emotional support, and encouragement. After listening to many caregivers over the years, I've noticed several ways in which they feel supported by the person needing care, and it makes a huge difference.

Here are a few suggestions:

- Keep doing whatever you can.
- Be a good listener. Be interested in your caregiver's stories and feelings.
- Show affection and gratitude – Just say "Thank You" – often.
- Be willing to compromise and problem-solve with your care partner.
- Accept help from outside sources, even though it isn't exactly what your family member would do. This affords your caregiver some time to rest, do errands, get together with friends, or something else special and return to caregiving duties refreshed.
- Attend day programs and activities so your caregiver can have time off and you have some socialization. These programs afford you opportunities to be with others who are experiencing some of the same symptoms and feelings. There is conversation and laughter and good food, and by the time you come home, both you and your care partner will feel renewed. Trying a day program is a wonderful gift you can give to your partnership.
- When making decisions about your care, remember that those choices may affect others profoundly. Sometimes what you want most just may not be possible right now.
- Nevertheless, you and your care partner will continue to have moments of joy as long as you appreciate each other.

Bob and Linda join the local Parkinson's Support Group together. They decide to enroll Bob in the Parkinson's Exercise Program at the YMCA. And with Bob's encouragement Linda attends one of the ADRC Caregiver Support Groups and takes a class called Powerful Tools for Caregivers. Together they are a strong team!

Melissa reads about family caregiver support offered at the ADRC. She calls, subscribes to the Family Caregiver Newsletter, and hears about Harmony Club, a day respite program with activities for people who need care at home. Sadie agrees to go, and she actually plays the piano there for a sing-a-long! Melissa has lunch with a friend. By the time they return home, both are animated and re-energized. Both Sadie and Melissa develop a new outlook on their care partnership!

A Note to Caregivers: The person(s) you care for may not be able to follow through on all or any of these suggestions. Thank your loved one for whatever sign of appreciation and love is offered. Remember that he or she is experiencing a lot of difficult emotions, as you are. Appreciate and thank yourself for what you are doing. Don't be afraid to set limits and claim your right to self-care. That's what the person who needs care would want if he/she could see the big picture. And that's what will help you continue to be a good family caregiver as long as needed.

Hats Off to Racine County's Family Caregivers!!

By Marilyn Joyce RN
Caregiver Support Specialist