**QUESTION:** As a group leader I sometimes feel I come across as too “pushy” when suggesting a polio survivor try out an assistive device. How can I get someone who obviously needs to use a new device to try it without appearing to be too pushy?

**Response from Rhoda Olkin, PhD:**
Sometimes it is easier for someone else to see what a person needs than it is for that person him/herself. But what do you do with that knowledge? Let me tell you how I first went from being a crutch user to a scooter user as a way of introducing how hard this transition can be. I was teaching at a university, and one day I arrived at work to find a scooter parked outside my office. I was told, “Oh, the Dean thought you could use this on campus to get around.”

Well, it seemed churlish to refuse, so I started using the scooter. And lo and behold, I found I went places I hadn’t gone before because they were too far, and I conserved energy. But at first I limited my scooter use to on campus, that is, I was okay with being a “scooter user” in my professional life.

Then I got a scooter for home and began to use it with friends. Suddenly I could go to big box stores, museums, the park – the scooter expanded my world. The last place I used the scooter was with family. That was the harder transition – both for me and for my parents – bringing up lots of feelings in all of us. Our identity shifts when we go from being upright to a seated position; I get that, it’s hard.

But you know the moral of the story. It’s the one every new scooter or wheelchair user can recite: You don’t realize how much you have limited your world until you get wheels and expand it again. Then you feel a sense of freedom that you couldn’t have predicted, and you would never go back again to not having wheels. But how do you impart this moral to someone who is not there yet? I have a few suggestions.

Have a questionnaire for people to fill out and discuss with each other. Ask questions like: Are there stores you don’t go to because they are too big? How long can you stand in line? How active do you envision yourself being in the next five years? Have you fallen in the past six months?

Plan an outing at a place that is easy to get to by scooter, but difficult on foot. Make scooters available for those who don’t usually need them.

Have small group discussions about self-image as a person with a disability and what it means to be a crutch user, or scooter or wheelchair user.

Have timed treasure hunts in the facility where you meet. Have clues spread out in the facility so that walkies have to go all over. Offer scooters for use as needed.

Put wheelies on one side of the room and walkies on the other and have them talk about what is easy and hard about their mode of transportation.

*Remember, you can lead the horse to water, but only the horse can make itself drink.*
Response from
Stephanie T. Machell, PsyD:

Caregivers, like parents and spouses and others we love and depend on, are often taken for granted. No matter how much someone appreciates your care, in the daily routine that caregiving becomes, the person may forget the importance of expressing appreciation and gratitude.

It’s hard to be a caregiver, especially for a spouse or partner. It changes the relationship and can create inequalities and resentments. There is ambivalence for both partners about their new roles. The one receiving the care may be appreciative of what is given but fear becoming a burden and resent not being able to do what he or she once did. The one providing the care may be happy to help but resent the extra work and loss of freedom. Both may long for the carefree earlier days of the relationship.

It’s especially hard for polio survivors to receive care. Being taken care of may bring up memories of the original polio, which may include negative experiences of caregivers who were anything but caring. Or it may bring up feelings of helplessness and dependence that can be hard to handle for someone who has always believed it was essential to be fully in charge and independent. Expressing appreciation for care, even when it’s felt, might make the polio survivor feel more vulnerable.

Can you talk with your partner about how you feel? Couples often fail to discuss such sensitive issues until they come up in indirect ways or in angry and hurtful words – or until the caregiver becomes ill and unable to carry on. Such a serious and important discussion would be best held at a calm and neutral time. You might start by asking your partner how he or she feels about the way things are going in your relationship. Or you could talk first about what you value about being able to care for your partner, or ask what it’s like to receive care. You could ask your partner how he or she feels about what you are doing and if there is anything he or she especially likes or dislikes.

This may be a chance for your partner to express gratitude or appreciation for all you do. If not, you can let your partner know how you feel and see how he or she responds. If talking about it doesn’t work, or if your partner can’t or won’t do so, there may be less direct ways he or she expresses appreciation that you can observe.

For instance, he or she might look more comfortable or smile at you when you have done something helpful. You might also notice the positive effects of what you do for your partner, like having more energy. Feeling taken for granted could also be a sign that you need a break. It’s important to care for yourself so that you can care for your partner. Find a way to take time out. If no family or friends can help, there are resources available for respite care. Use them and take the time to do something that will replenish you. You will return refreshed and revived and better able to care for your partner.

Dr. Stephanie T. Machell
is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

Resources:
National Alliance for Caregiving
4720 Montgomery Lane, 2nd Floor
Bethesda, MD 20814
www.caregiving.org

Family Caregiver Alliance
National Center on Caregiving
180 Montgomery Street, Suite 900
San Francisco, CA 94104
415-434-3388, 800-445-8106
info@caregiver.org
www.caregiver.org

Because We Care: A Guide for People Who Care
Administration on Aging
Washington, DC 20201
202-619-0724
www.aoa.gov

Area Agency on Aging
For caregiver support groups, respite providers, and other caregiving services.
Eldercare Locator:
800-677-1116
www.eldercare.gov

ARCH National Respite Network and Resource Center
Call to find local respite providers.
800-473-1727
http://chtop.org/ARCH.html

QUESTION: I am a caregiver of a polio survivor. At times I feel taken for granted. How can I handle this situation without hurting my partner?

Check out
Post-Polio Health Care Considerations
at www.post-polio.org/edu/healthcare/