

**Question:** *I often attend my local post-polio support group's in-person meetings. My partner usually requests to come along in order to show his support. I really appreciate the fact that he wants to be supportive, but sometimes I'd rather go alone. There are times when I feel I can't speak freely about certain things because he is there. I want to stress that he's a great partner, and it's not like he's demanding he be allowed to go. Am I wrong to want this space for myself? How do I go about telling him without hurting his feelings?*

**Response from Rhoda Olkin, PhD:**

To your first question, no, of course you are not wrong to want this space for yourself. Your feelings are your feelings, and hence, legitimate. I can understand the desire to carve out a space that is separate from your partner, and where you can speak more freely without worrying about the effect of your words on a partner.

Your partner is showing a great willingness to have the polio be a part of the partnership, that is, not just something about you, but something that you as a couple own. I applaud this, as it seems to be a key way for a successful relationship to incorporate disability. Nonetheless, as the person who had polio, your internal experiences may have some private parts that you don't wish to share with your partner. Talking to and hearing from other polio survivors can be enormously helpful.

You might approach this with your partner as an issue around space, distance and closeness. Each person in a couple comes to the relationship with differing needs for distance or closeness. Rather than saying that you don't want your partner to attend, say that you feel you need a bit more space just for you. "I appreciate how you are so supportive of me and how you take the disability as something that we both have to manage. When the meetings have a speaker, or are about something specific, I love that you come with me. And I also want to go by myself some of the time, when it's a 'sharing and caring' time."

**Question:** *While I feel like there are a lot of resources for polio survivors, I'm curious where spouses can turn to for help? My husband requires a lot of help around the house. I'm getting older, too, and it's becoming more physically and mentally taxing. I want to be a good caregiver, but sometimes I feel burned out.*

**Response from Stephanie T. Machell, PsyD:**

Part of being a good caregiver is recognizing and respecting your limits. Trying to do it all leads to neglecting self-care and ultimately to the burnout you are already beginning to experience. Yet trying to step back and delegate some of the tasks and care you



**Dr. Rhoda Olkin** is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

are providing may make you feel guilty, especially if your husband resists the idea of “outside” help.

Before things get worse, it’s time to reassess what you’re doing. Discuss your concerns with your husband. Though it is tempting to do so, don’t minimize how difficult things are becoming for you. If he is resistant to the need for help other than yours, remind him that your ability to provide this is contingent on your own well-being and that if something happens to you, he will end up depending exclusively on others for assistance. Pointing out that studies show that partners taking on more caregiving responsibilities interferes with romantic and sexual feelings may also help!

Together, make a list of everything you both do to maintain your household, including any personal care you provide for him. Consider the time and labor involved in each task and the level of difficulty you and/or he have completing it. Discuss your preferences for doing the task yourselves versus how much you wish someone else could take it on.

Decide what you want to delegate and to whom. Family members or friends might be able to take on some tasks, but for more major or skilled assistance you may want or need to hire professionals. If there is a medical necessity for either or both of you, services such as homemakers and home health aides may be paid for by insurance when ordered by a physician.

Another essential but all too often neglected part of being a good caregiver is prioritizing your own health and well-being. This means getting adequate rest, exercising as you are able, eating (mostly) healthy meals, making and keeping medical and other appointments, maintaining your social connections, and taking time to pursue your own interests.

It is important to have supportive others who understand what you are going through. Friends and family who are also caregivers can provide support and camaraderie. Though rarely specific to spouses of polio survivors, there are support groups available for caregivers through senior centers, councils on aging, many hospitals, and some churches. If your husband attends a post-polio support group, request a parallel group for spouses. And there are mental health professionals who work with caregivers.

For more information, check out the PHI website ([www.post-polio.org](http://www.post-polio.org)). Under the Resources tab of the menu, you will find “Post-Polio Health Care Considerations for Family and Friends.” It provides comprehensive information on caring for a family member with polio and links to further information and resources, including relevant past newsletter articles and talks. It includes a navigation tool you can use to zero in on your specific concerns. ■

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.

