

PHI: *Recently a woman contacted PHI to ask for advice about how to communicate with her spouse that their current living situation was no longer suitable for her. She felt that she was forcing him into assisted living—something he doesn't want—and was experiencing guilt about this. We asked our regular columnist, Dr. Machell, what advice she would offer.*

Response from Stephanie T. Machell, PsyD:

I commend you for recognizing your limitations as a caregiver. As you have experienced, caregiving takes a toll on the caregiver. Rather than feeling guilt over what you can't do, think of how awful you (and your husband) would feel if you overextended yourself and became ill and/or resentful. Knowing your limits preserves your ability to provide the most important thing a spouse can provide—your companionship and love.

It sounds like both of you feel forced into choosing assisted living. Have you explored other options? Because most people prefer to age in place, a range of services exist to facilitate this. Depending on your husband's (and family's) needs, there are programs that provide everything from personal care to nursing care to various therapies.

If home renovations are needed there are even some programs that will help defray the costs and/or provide low or no interest loans. And even if renovations are needed, aging in place may be less expensive than assisted living. Insurance (including Medicaid) may cover some or all of the cost. Your local council on aging or other elder service program can provide information and help you consider the options.

If assisted living is the best (or only) option in spite of your husband's objections, or your husband is also against having home care provided by someone other than you, communicating honestly about how best to meet your needs and his is usually the best approach. Be clear but empathic, provide concrete examples of needs he has that are difficult for you to meet, and emphasize the benefits of these being provided by someone more skilled than you, including allowing you to enjoy each other's company and preserving your health. Be prepared that no matter how diplomatic you are he may be angry and that you may feel even guiltier than you do right now.

If having this conversation feels too overwhelming, you might enlist others to help. Choose those whose opinion he (and you) respect. If you have friends who have made this transition (especially if they are happy with their choice) you might encourage him to speak with them.

No matter where it's provided, your husband's need for increased levels of care likely brings up many feelings about aging with a disability, including grief and fears about loss of independence. It might even trigger memories of his polio experiences. It will help if he feels empowered to make as many choices about this as possible. And if he (or you) feel overwhelmed by the process or feelings it evokes, support groups and/or psychotherapy can help.



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.

QUESTION: *I had bulbar polio when I was three years old. My parents told me I spent time in an iron lung. I am now 70 years old. I don't currently have any breathing problems. But because of my history, I know it's a possibility in the future. I know PHI has a whole website dedicated to breathing problems, but I just can't bring myself to research the issue. I don't even like seeing an article on the topic in my inbox or when searching for post-polio information. I would rather not deal with the stress and worry until it's bad enough to have to see the doctor. Am I being foolish?*

Response from Rhoda Olkin, PhD:

No, you are not being foolish. In fact, you are being wise. I suspect that if you are not having breathing problems by age 70 there is a chance you won't ever have them, barring another medical condition (and absence of history of smoking).

I am chuckling a bit, though, remembering how I “developed” breathing difficulties every time I read an article about breathing problems! So, I stopped reading the articles about breathing and swallowing difficulties.

Avoidance is a problem when it prevents us from taking necessary actions. Researching something you actually have could be important information seeking. Researching something there is a slight chance you might get in the future doesn't make sense unless (a) there is a high risk of the problem, and (b) there are preventive measures you should be taking now.

Ask yourself if there is anything you might do differently if you knew you would have some breathing difficulties in the future. I suppose you might practice deep breathing, go for walks, maybe try to build up some muscle. And if you knew you would not have any breathing issue in the future? Those walks, deep breathing and muscle building are all still good ideas.

When we have the flu, we don't tend to research the flu. Instead we focus on rest and getting better. But okay, flu passes. What about something more permanent or serious, like emphysema? Personally, I would research treatment options, including both Western and Eastern medicine (often called complementary and alternative medicine) approaches. But this is after I got the diagnosis, not before.

Ask yourself if there is anything you might do differently if you knew you would have some breathing difficulties in the future.

Life's too short to spend time reading things that make us more anxious when there is no compelling reason to do so. Go sit under a tree and read for fun, keep on breathing, and may you live happily to a ripe old age. ■

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.

