



Rhoda Olkin, PhD

Promoting Positive Solutions

QUESTION: I am not bitter because of my love of life, my family and my God, but it just gets tougher and tougher to survive and tougher on those who help me. I have children who help me and a wife who loves me but hates PPS and what it has done to her husband. How do I deal with a wife/support person who loves me but hates my PPS?

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.

Response from Rhoda Olkin, PhD:

I want to respond first to the fact that it gets tougher and tougher. I presume you mean as you age – the symptoms get more pronounced, weakness from polio combines with weakness from aging and new symptoms appear. Where maybe you could walk a city block, now it seems like a big effort to go from the bedroom to the kitchen. Perhaps you have started to use assistive technology such as a scooter or wheelchair, or now you have to use crutches all the time instead of just some of the time. Yes, these are big adjustments, not only for you but for your family.

I am going on the assumption that they love you, and would rather have you around, polio and all, than not. So, if you will forgive my bluntness, everyone needs to get over it. That is, I suspect you had polio all during your marriage, and hence all during your children’s lives. This is not a new issue for the family. But I hope the family is able to talk about it openly and honestly, perhaps with the help of a professional counselor or a church elder.

Hold a family meeting, ask everyone to be honest in how they feel. Problem-solve the areas that are emotionally and/or physically difficult. For example, does your wife feel held back because you cannot do something? Would you be okay with her going some places without you? Does she feel able to do so? Is she worried that as she ages she can no longer help you in the same ways? Do some

tasks need to be doled out (to children, neighbors, church members, hired help) or even not done at all?

I want to emphasize that we polio survivors need to be careful about ascribing any new or worsening symptoms to polio when in fact they could be due to a treatable cause. For example, I went for several years thinking I had just reached a new stage of disability. In fact my thyroid hormone levels were low, and taking thyroid medication returned me to my previous levels of energy (which, admittedly, were still low and still decline with age, but are no longer debilitating).

Second, I have to wonder about your idea that it is possible to love you but hate the polio. Imagine substituting another descriptor for “polio” and see how it sounds. For example, you could never say “my wife loves me but not my gender.” They are one and the same. You are who you are as a polio survivor. There is no you, and then on the side the polio. There is only you with polio. It’s a package deal. I suspect it may be that your wife doesn’t hate what it is doing to you, but rather what it is doing to her (e.g., preventing the two of you from taking trips, or putting more responsibility on her for household tasks).

So re-read what I’ve said above, and find out what the issues really are. And remember, those vows say “for better or worse,” even if the *worse* sucks.

Please send questions for Drs. Olkin and Machell to info@post-polio.org.

QUESTION: I am a 70-year-old woman who is on Medicare. I have gotten weaker as I age and anticipate that I will need more assistive devices in the future. All of this talk about cutting Medicare has me feeling helpless and worried sick. What should I do?

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

Your fears are shared by many, if not all, of those who depend on Medicare. And they are understandable, especially when you feel so vulnerable.

I believe that those currently on Medicare, and those about to be, have little to fear. While there may be changes made to the Medicare program, these changes would probably be phased in and affect younger people more.

I believe this because seniors are the most consistent voters in this country, and politicians are aware of this. Unfortunately, inflammatory rhetoric gets the biggest share of press coverage in this age of fear-mongering, and politicians know this as well. Some organizations aimed at seniors may also stir these fears, inadvertently or otherwise.

Listening to rhetoric won't help you feel calmer or more empowered. Turn off the news, or at least the talk shows, or limit your listening and viewing. While staying informed is helpful, the sound bites and rapid-fire delivery don't tell the whole story. You may want to identify a good resource for balanced journalism or look to more than one source. The Alliance for Retired Americans (www.retiredamericans.org) is an advocacy group that has a website and weekly email newsletter that provides accurate information about Social Security and Medicare issues. While the information itself can be concerning, it is presented with a minimum of fear-mongering.

In dealing with feelings of helplessness, it helps to have support and a plan. If you don't have one already, it

might be helpful to enlist a friend or family member as an informal medical advocate. This person can not only help you assert yourself with providers but also help you identify resources. If you don't know anyone who can do this, you might find assistance through your local Council on Aging, senior center or doctor's office. Some health insurance plans have programs for providing seniors with a case manager who might be helpful as well.

Should needs arise that insurance doesn't cover, it can be helpful to know that there are resources for seniors and people with disabilities to help pay for assistive devices. For example, Post-Polio Health International provides some small grants for this purpose. If you have ever lived in Rhode Island or have family connections there, you may be eligible for help from the Rhode Island Infantile Paralysis Foundation. You or your medical advocate can research and identify similar organizations.

Depending on your financial situation and where you live, you may also be eligible for more help than Medicare and your Medigap insurance provide. Medicaid could be an option. Your state may also have other programs that help seniors and/or people with disabilities with some medical expenses.

Provided that it wouldn't increase your fears, it may help you to become involved in political or advocacy groups that are working to keep Medicare strong or to write letters to your representatives expressing your concerns. There are many senior action groups working on this issue. Joining with others to take action can help you feel more empowered. ▲



Stephanie T. Machell, PsyD

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