

PHI Columnists Weigh In on Future Life with a Polio Survivor

The following question has come to Post-Polio Health International a number of times via phone, email and letter. We asked our regular Post-Polio Health columnists Frederick M. Maynard, MD; Rhoda Olkin, PhD; and Stephanie Machell, PsyD, to comment on it for our readers.

QUESTION: I am dating a woman who had polio, but if you didn't know it, you could not tell it. We are both in our late 20s and I am very interested in her. I have heard about post-polio syndrome and am wondering what I may expect in our future years if I marry her.

Dr. Maynard's response: People with a history of polio in childhood who “pass” as normal and able-bodied in their 20s are at risk of developing new health problems during their middle-age and later life. These problems are known as the late effects of polio and include post-polio syndrome (PPS), which is a slow weakening of affected muscles many years after the polio infection and recovery.

Other common problems are excessive fatigue and musculoskeletal pain problems. The likelihood of developing symptoms and their severity are both related to the extent and severity of initial paralytic polio and to one's personal lifestyle and health behaviors.

In general the late effects of polio do not significantly shorten a person's expected life span, nor should they cause one to avoid a long-term commitment to someone they love because of fear of excessive disablement in the future. There has been a lot written about the late effects of polio, and by learning about them one can often postpone, prevent or minimize their occurrence and can make timely lifestyle adaptations to them in order to prevent their significant interference with having a high quality of life.

Please read about the late effects of polio and discuss them with your friend. By having an honest and supportive attitude about her history of polio, you will gain a special intimacy and will be in a great position to assist her in maintaining optimal health and function into your older years.

Dr. Olkin's response: Good for you for being honest about your concerns! No one can tell you what the future will be for her, whether she will develop any post-polio symptoms (pain, fatigue, new weakness) or not. Of course, marrying anyone brings the possibility that the person will develop future infirmities, which is why there is the whole “for better or worse, in sickness or in health” part of vows.

What is possible for the woman you are dating is that she had a mild case with few aftereffects. There may be some weakness that is not very apparent, which could be more apparent with age, as nerve axons naturally die off. But given that she is starting from a place of relative strength, it might not be that noticeable. She might get a bit more fatigued than peers without polio, but again it won't be too intrusive on activities of daily living.

But predicting what will happen is not the right question, since the future with any partner brings unknown risks. So, you have to ask yourself: “If in twenty to thirty years ... would I still want to marry her?” What goes in the missing spot could be:

- ♦ She develops sufficient leg weakness that she uses a cane, or crutches, or a scooter or a wheelchair.
- ♦ Her fatigue means she naps every day.
- ♦ She is unable to work and take care of children due to fatigue, so you make hard choices about income levels, or number of children to have, or using income to hire help.

Suggested readings:

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (www.post-polio.org/edu/handbk/)

Post-Polio Health Care Considerations for Families and Friends (www.post-polio.org/edu/healthcare/)

Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome by Lauro S. Halstead, MD

Traveling without a Spare: A Survivor's Guide to Navigating the Post-Polio Journey by Wenzel A. Leff, MD

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- ◆ She loses balance and falls more easily, and breaks bones, and you have to take care of her intensively for a couple of months.
- ◆ You have to modify your house for thousands of dollars to put in ramps and grab bars and wider doors and lower counters.
- ◆ She develops a circle of friends with disabilities, and you find that disability topics become a major topic in your household.
- ◆ She becomes an activist in disability rights.
- ◆ She needs to, but refuses to, use assistive technology such as a scooter, and thus you no longer go to museums or large stores or shopping malls or walks together.

Are any of these likely? No one knows. But if you are not able to think about a future in which you could handle any of these scenarios, then don't sign up. You would be doing both of you a favor by being honest with yourself.

Dr. Machell's response: All you can know with certainty is that having had polio she is eligible to develop post-polio syndrome. I've known polio survivors whose polio was all but invisible in their late 20s who went on to develop severe PPS. I've known others who were always more visibly disabled but whose PPS was relatively mild.

Some polio survivors I've known developed PPS relatively early. Some developed it later. Some never developed it at all. And some developed another disabling or chronic condition in addition to or instead of PPS.

And some polio survivors' spouses become chronically ill or disabled. Or die young.

At any moment of any day of our lives all of us, including yourself or any woman you might marry, are eligible to develop a disability or a chronic illness. Whether or not we become disabled, all of us will

age. As we do, our appearance will most certainly change, along with some or all of our physical and cognitive abilities.

Some of us will age well. Some of us won't. Some of us won't live long enough to find out.

Marriage is a leap of faith into a great unknown. However happy, well-matched, and/or in love you may be, all marriages face challenges. A spouse's disability is a major challenge for any marriage. Some marriages, often but not always the ones that are already troubled, end as a result. Some, often but not always the ones that are already strong, come through the crisis stronger. And some, often but not always the ones that are neither great nor dreadful, continue as they always have.

No matter how much you know about the possibilities, the future is uncertain. And no matter who you choose to marry, you may regret your choice. To make the best decision possible it helps to be aware of your own feelings, values and beliefs.

Does knowing that this particular woman might someday develop PPS overshadow your current feelings about her and the life you could have together? For just a moment, imagine your future if she does develop PPS. Imagine living with a wife who has less energy and more pain, one that needs to use a brace, or crutches, or a wheelchair or scooter. Imagine that she can do less in the home, that she can no longer work, that she is less able to engage in active leisure activities. That she can no longer pass as temporarily able-bodied.

Still interested in her? If not, better you know now, when you both have the opportunity to make different choices. If so, you may have realized that no matter what your futures hold, you can't imagine yours without her in it – which is the best reason to marry anyone.

Whatever you decide, I wish you, and her, all the best. ■