

Promoting Positive Solutions



Stephanie T. Machell, PsyD

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 is a polio survivor.

QUESTION: Although all couples face challenges and adjustments due to age and health, how can people diagnosed with post-polio syndrome (PPS) make sure that the “health” issues don’t become the main focus in the relationship?

Stephanie T. Machell, PsyD:

Communication is key for keeping any relationship in balance. Even though it may seem counterintuitive, talking about health issues is the best way of keeping them in perspective and finding solutions that work for the couple.

Polio survivors’ independence is one of their greatest strengths. However, this independence can make it difficult to discuss physical changes, especially those that might mean that assistance is needed. All too often, what *isn’t* discussed takes up far more space in the relationship than what is, and health issues can easily become the “elephant in the room.” Needs that are clearly expressed can be met. Unspoken – and thus unmet – expectations create resentment that can erode the relationship.

This is especially important when issues of mobility or energy and fatigue create the need for the person with PPS to accept help from their temporarily able-bodied (TAB) partner. If this assistance involves personal care, it can affect the romance in the relationship. If the couple is aware of this and other issues that might come up, they can work together to consider whether it would be better to hire outside help, such as a personal care attendant or “bath person,” or if there are ways to use this as an opportunity to deepen their intimacy.

When the TAB partner has to take over tasks that were previously the responsibility of the partner with PPS,

the balance of the relationship shifts, and resentments can arise in either or both partners. A reexamination of tasks may be needed. Are there tasks that the polio survivor could take over that require less energy and/or mobility to complete? If possible, it may be helpful to look for outside assistance, such as hiring a housecleaner or landscaper. Taking a fresh look at tasks could turn into a positive experience, with each partner finding new interests and strengths.

The biggest concern I hear from those with PPS in terms of their relationships is how energy issues affect activities with their partners. They worry that they are holding their partner back, even when the partner protests that this is not the case. It is helpful to find ways that the person with PPS can either continue to participate in valued activities (perhaps by giving up an activity that is less essential or valued) or to find new activities that both can enjoy together while encouraging the TAB partner to continue to pursue more strenuous activities with others.

Another concern that often comes up is the fear of being or becoming a burden to those around them. Again, communication is key in addressing this, but in my experience all too many polio survivors suffer in silence with these and other fears. Simply talking with the TAB partner about this will often reduce this fear. It is a good idea for this to be an ongoing conversation, as these fears tend to recur with real or perceived changes in the polio survivor’s functioning, as well as when the TAB partner takes on any new responsibilities.

If the couple is having difficulty communicating about health concerns, or

if it seems that health concerns have already taken over the marriage and neither party can see a way to change this, it may be helpful to see a couples counselor. An objective third party can help sort out concerns and provide the freedom to bring up difficult subjects.

Finally, I strongly believe that humor, including black or gallows humor, can help in most situations. Couples that can laugh together can get through almost anything.

QUESTION: *I heard about the late effects of polio about 10 years ago. I am 65-years-old now and, admittedly, I fret about my current and future health. My children have suggested I stop reading post-polio newsletters. Do you think this is good advice?*

Rhoda Olkin, PhD:

I had to laugh – I stopped reading about breathing problems in persons with post-polio because every time I read them I had trouble breathing! But I don't mean to make light of your question, because it's a good one, one that confronts many of us.

When is information helpful and when might it be harmful? When does reading about others' experiences feel validating and when does it create fear? How do I plan realistically for my future as an older person with a disability without making myself crazy?

So I suggest that you ask yourself a few probing questions: 1. How is your health other than polio/PPS? 2. Are you someone who will fret anyway, whether you read about polio or not? 3. Is worry about the future preventing you from experiencing pleasure in the present?

What's the importance of these questions? The first one, about your general health, is important because other health issues, rather than polio per se, are probably a better predictor of future problems. Polio/PPS might make you feel tired, slow you down, even contribute to falling, but you can go about your life anyway. The second and third questions relate more to your mental and emotional health. Those need tending as much as your physical health.

I recommend two questions to use before deciding whether to read something about polio: 1. Is this information new to you? 2. If you knew this information, would you need to take action?

Let's take an example. Suppose you see an article that says swimming laps improves breathing. Is this new information? It might be to you. Does the information mean you need to take action? It could – it might encourage you to go swimming, or it might mean you swim even though it fatigues you or it might lead you to increase the number of laps slowly over time. On the other hand, if you don't have access to a pool, or it hasn't stopped snowing yet or you don't even own a bathing suit, then probably the article won't be meaningful for you. Stop reading!

And if the article makes you feel guilty or creates new anxiety then *really, really* stop reading!

So next time you see an article, ask yourself those two questions. If you can't answer YES to both questions, move on. You are not required to be an expert in polio. When was the last time at a dinner party someone asked you whether there was a statistically significant correlation between swimming and breathing for people with polio/PPS? ▲



Rhoda Olkin, PhD

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