

Promoting Positive Solutions

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Dr. Stephanie T. Machell, PsyD 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 was a polio survivor.

Question: I found out I had polio when I was 55 years old. My Mother's explanation was that "the doctor told me not to tell anyone." Can you help me understand why this was told to parents?

Response from Stephanie T. Machell, PsyD:

Your experience is not an unusual one. I've had many clients who didn't remember having had polio and were never told that they did. While there can be many reasons for this, what your mother was told by the doctor points to one of them: the stigma attached to polio and those affected by it.

At that time, polio was viewed much as HIV/AIDS is now. Polio survivors and their families were often shunned, even after the risk of contagion was past. Polio was considered to be highly and indiscriminately contagious (think closed swimming pools and movie theatres), and the polio survivor and his or her family were often viewed as dangerous.

I have heard stories of homes being burned by neighbors and of doctors and dentists whose practices closed because patients were afraid of being infected by a parent who might be carrying the disease. These beliefs persist in many who lived through the epidemics. For example, a few years ago, I was told by a well-educated person that it was a miracle that my brother and I didn't catch our father's polio. (The person making this statement knew that I was born two years afterwards. My brother was born six years later!)

Apart from fear of contagion, there was fear of disability itself. In the mid-20th century, and even now, many people subscribed to the moral model of disability, in which the person who has the disability (and by extension his or her family)

must have done something to deserve this fate. The polio survivor would be viewed as morally flawed or bad, and the possibility that such badness could be as contagious as polio itself makes others reluctant to associate with “carriers.”

It is also possible that the doctor was trying to be helpful. If you recovered well enough that you had no need to be aware that you had had polio, you were most likely able to “pass” as non-disabled. Your lack of knowledge that you were a polio survivor would have helped you to pass. Because children with disabilities often were excluded from schools and other opportunities, this might have been seen as positive. And because it was widely believed that children would suffer no ill effects and might actually benefit emotionally by not being told about their polio experience, parents were often advised not to discuss polio with their children, even those old enough to remember what had happened.

Your parents’ own shame and guilt over what happened to you may also have factored into their willingness to go along with what the doctor advised. Because of the way polio was viewed, parents often had these feelings when their children were afflicted. They may have felt responsible for your polio because of something they allowed you to do, or for something they failed to do (like not vaccinating you soon enough if the vaccine was available). The doctor’s message would have reinforced their shame and guilt, further reinforcing the secrecy around what happened.

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

Question: I am 66 and widowed for five years. My wife was highly attuned to my needs with polio. We had a loving relationship for 25 years. I am anxious about dating again, specifically meeting and trusting someone and also relying on someone again with my disability. My wife had a heart of gold and it’s hard to imagine anyone being able to replace her.

Response from Rhoda Olkin, PhD:

First, I am sorry about the loss of your obviously beloved wife; my condolences. And second, I can relate to your trepidations about dating again – it is not easy as an older person, nor as a person with a disability. (I happen to fit both of these descriptions.) But rest assured, it is not easy for those without disabilities either! You have to know that nothing replaces 25 years of building a loving and trusting relationship one that started when you were younger. Thus,

it is important as you date that you not be looking for the same things that you found in your wife. You were in your mid-30s when you married her, and what you wanted and needed then are probably different from what you want and need now. Additionally, the life tasks and goals we have in our 30s, 40s and 50s are different than our life tasks in our 60s and beyond.

I would suggest you begin by making a list of what is important to you now, individually, as a 66-year-old man. Second, what would you like in a partner? Is it to live with someone or to see someone on weekends, to have someone to watch movies with but then go home, for sexual encounters or for snuggling in the middle of the night, for intimate chats or occasional dinners?

Third, look hard at the items on this list. I cannot help but wonder if some of the things you want are about basic assistance or security as a person with a disability. Are you worried you might fall and no one will there to help you? Do you have trouble with daily household tasks? Do you get fatigued and want someone else to do some of the driving?

I understand the fragility some of us polio survivors feel about living independently, especially as we age. But as you look for a partner, make sure you are not really looking for an assistant. Partners provide assistance because they have a meaningful history and years of love to fortify their assistance. New partners do not bring this to the table and shouldn't be expected to.

So basic assistance needs have to be met other ways. For example, start a phone buddy system of someone to check in on you (and you on that person). If at all possible, hire someone to do laundry, clean, grocery shop; outsource whatever you can afford.

At any age, we do better at dating if we have confidence in ourselves and our ability to be alone. From this position of strength, go find a partner. And love can come at any time, at any age. It won't be like the last time, but it can still be rewarding, fulfilling and special.