QUESTION: I am worried about my father (and my mother). He is in his 70s, and for the past few years, we have had trouble getting him out of bed each day. He doesn’t use any assistive devices, but he has one weaker leg, and he was in an iron lung when he had polio. His medication for depression is being adjusted, but he has refused to see a psychologist or psychiatrist. He tells us, “You just don’t understand how I feel.” Our problem as a family is this: How much should we “encourage” him to stay active?

Response from Rhoda Olkin, PhD:

I’m sorry, I know this must be difficult for your whole family. I have several thoughts. First is something I notice about your question that has been true for previous questions we’ve received: often people ask about someone in their family rather than about themselves. Therefore, I am usually answering a question from a person who does not have polio about a family member or friend who does have polio.

*It strikes me that there is so little information available about interactions between people with physical disabilities and their family and friends, that there is a real void about how to handle day-to-day interactions, much less the deeper situations like the one you describe.

Alas, it is harder for me to answer questions about another person without hearing directly from that person. I can’t tell whether your father is significantly clinically depressed, in physical pain, fed up with disability difficulties or in early stages of dementia or Parkinson’s. Thus, I can only answer more generally.

Of course my first response has to be that he needs an evaluation. Anyone who refuses to get out of bed and needs encouragement to engage in life should be evaluated for medical complications, depression and suicidality. If he won’t see a mental health provider, his general practitioner can do an initial screening. Unfortunately, medication alone for depression is not always effective, and relapse rates are very high.

Second, I may understand a bit of what he feels. Disability is very hard work. So is depression. The two together are quite a barrier to engagement and enjoyment of life. What helps? All those things he’s refusing to use: assistive devices, distraction, good evaluation of any secondary conditions and therapy. Has the full family system been mobilized to help him make a change? For example, is everyone on board with the idea of his using assistive technology? What if a scooter just showed up in his bedroom one day? What if you announced that he had an appointment with his physician on Thursday and that you would be arriving at 11:00 AM to drive him there? In other words, are you taking him at his word, or are you taking actions?

Third, he’s not so old. My parents are in their upper 80s, and I want them to still enjoy life fully, living as if they have more time ahead of them. The 70s are too young to be giving up. He may have twenty more years in him; how does he want to live them?

Okay, suppose he wants to die. Is that an option? What would the family do differently today if they knew he might die tomorrow? Has everyone said what they needed to say? Is there a will? What would happen to your mother?

*See Page 2. “Post-Polio Health Care Considerations for Families & Friends” was developed by PHI specifically as a resource for families and friends of polio survivors.
I am really giving you two options: let him stay in bed, and stop trying to change him, or move heaven and earth to get him actively engaged in his own life. Whichever you choose, do it as a family. I wish the best for all of you!

Response from Stephanie T. Machell, PsyD:

As the child of a polio survivor, I know that family members walk a fine line in situations like this. Your father wants to have his independence, and that may mean rejecting (or seeming to reject) help from his wife and children. He may be fearful of becoming a burden – or of burdening you with his fears for the future. He wants to solve the problem his way, even though his way may no longer be working.

The simple answer to your question is, yes, of course you should encourage him to stay active. Being active would help your father’s depression. The problem is that a person who is depressed doesn’t feel like being active. And a person who is having more difficulty doing what he previously could do with little effort may avoid activities that are now more problematic. If your father feels that he can’t do what he once did, being “encouraged” may feel more like being told he is inadequate – and misunderstood.

Your father might be feeling that he is losing control of himself and his life right now.

The best way to help is by helping him find ways to feel in control again. Ask your father what help he would like from you, and encourage your mother and other family members to do the same. Offer him choices and encourage him to make them. Give him information that would help him; for example, letting him know that being active would help his depression. When he says you don’t understand, say, “You’re right, I don’t understand how you feel, but I really want to. Would you tell me about it?”

It would definitely be helpful if your father would see a psychologist or psychiatrist who understands the issues he is dealing with. If he is determined not to go, you may not be able to persuade him, and pressuring him to go would just make him feel more out of control. Is there anyone else he might trust to talk to about his concerns – a member of the clergy or his health care professional? Would he be willing to try a post-polio support group? It might also be helpful for him to see a polio doctor, if he hasn’t already. He might benefit from assistive devices and/or physical or occupational therapy if he is having more difficulty getting around and/or increased pain or weakness. Again, provide him with the information, and offer to help if he wants it.

It would be beneficial for you and your mother to get support for yourselves. Caregiving is stressful and difficult, as is living with someone who is depressed. There are support groups for caregivers, and, of course, psychotherapy is an option as well. One or both of you getting help (and sharing your experiences of doing so) might even encourage your father to do the same. Good luck to all of you!

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 was a polio survivor.

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