QUESTION: My brother, now 68, had polio in 1961. It affected his legs, and he has used a wheelchair since then. He lives alone, is very independent and has always been able to find a way to take care of himself. He just told me that he has lost the use of his (already weak) right arm and does not want to go on living. I told him I would take care of him, but he doesn’t want to be a burden. I am devastated – what can I do? Is there any way to help him?

Response from Rhoda Olkin, PhD:

First, let me acknowledge how scared you must feel that your brother is talking about wanting to die. This can arouse all kinds of emotions in you, including powerlessness, anxiety, anger and everything in between. I will let my colleague address what you can do to help. Here, I will address what might be going on with your brother.

A few studies suggest that people with polio have lower rates of depression than the general population. Perhaps the need to deal with adversity, usually early in life, provides some coping and resilience. But with your brother the opposite seems to be occurring. Thus, you need to consider the possibility that your brother is depressed.

He had polio when he was about 16 years old. That experience may have left emotional traces that reverberate now. He went from a healthy body to probably being hospitalized, probably feeling isolated in his experience. Now, as he ages and has decreased physical functioning, these feelings, dormant for many years, are reawakened. The idea of old emotions being re-triggered is not just theory. One example comes from studies of monkeys who got depressed after their mothers were removed. They recovered when reunited with the mother, but years later they were more prone to depression again. The brain chemistry seems to be ignited again when a current situation reminds us of an older experience.

It is important to keep in mind that people don’t want to die because they have polio per se. They might feel like dying because of polio’s effects on daily functioning. This might include not being able to visit friends whose houses are not accessible, or being less social due to fatigue, or finding that simple daily tasks are too taxing, or needing help with activities of daily living when one is used to independence. I wonder what your brother used to be able to do, that limited use of his right arm now might prevent him from doing. As an example, I used to do woodworking every weekend, but then as my arms got weaker, I found power tools too dangerous. This forced me to find a different (and more sedentary) hobby, which I did, but I still miss woodworking. What is different or missing in your brother’s life now?

I am guessing your brother does not have a partner. This means he has to find social support outside the house, which requires energy and mobility. Social support is one of the predictors of well-being (and even longevity) in older adults. Just today I pondered cancelling a social event for Friday night because this has been a hard week. It is easy to do this and not notice that weeks can go by without any socialization. If daily life requires too much of our energy, we start...
cutting out things that sustain and feed our emotional being. It is better to hire someone to vacuum the house to reserve energy for having coffee with a friend. Your brother is blessed to have a caring sibling such as yourself.

**Response from Stephanie T. Machell, PsyD:**
Without speaking with your brother, it’s hard for me to know if he is clinically depressed. It is clear that he is grieving a major loss – his arm, certainly, but more significantly, his previous lifestyle and independence. Saying he no longer wants to live may be more an expression of grief than a wish to commit suicide, or even to die at all. He needs the chance to experience and process this grief as well as find solutions to the problem of how he will move on with his life.

It can be easier to do this with someone who your brother doesn’t fear hurting by expressing these feelings, which is why seeing a therapist would be helpful whether or not he is clinically depressed. A therapist can help your brother deal with his grief and with thinking about and planning the future. A therapist can also assess whether or not your brother is clinically depressed and/or at risk of committing suicide.

The right therapist for your brother would be someone who understands disability issues. A therapist who doesn’t might simply assume your brother is depressed and miss the issues related to the disability. If you and he can’t find a therapist with a background in disability, someone who works in health psychology and deals with issues related to chronic illness could be a good option.

Your brother may be reluctant to see a “shrink” because he assumes it represents a failure on his part or an assumption by others that he is weak or mentally ill. Reassure him that the right therapist for him is one who recognizes his considerable strengths and is there to empower him to use these to move through the current crisis.

It might also be helpful for your brother to know that getting help and being independent aren’t mutually exclusive. A personal care attendant (PCA) is an option you can pay for either through insurance or out of pocket. Your brother would be responsible for hiring and training this person. He would have control over what the PCA does for him and how and when it is done. When this model works well it provides independence and the freedom to live in the community. Receiving such help would allow your brother to use his energy for activities he values rather than simply maintaining. Being able to do things he enjoys will serve to improve his mood and help him to feel less helpless.

Being the family member of someone struggling with these issues is difficult. It’s hard and painful to hear someone you love say he doesn’t want to live. And it’s hard to have your help rejected. You need a place to deal with your own feelings about what your brother is going through in order to be able to be helpful to him. Apart from confiding in family and friends you might benefit from speaking with a therapist familiar with these issues. Caregiver support groups are available in many different places.

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.