

QUESTION: *Regarding the Promoting Positive Solutions column in the last issue of Post-Polio Health, Vol. 29, No. 4: I can identify with the person in the question. I also had polio as a teenager, and, like him, I am still on my own with assistance but concerned about what will happen to me if my situation worsens. I don't think the columnists understand the problem. Loss of independence is a heavier problem than is reflected by their answers; they see this problem only on the surface. It is depressing to think about transitioning from being autonomous to depending on strangers as caregivers who then become dependent on you for their livelihood. If you are a polio survivor – you have the right to be depressed!*

Response from Rhoda Olkin, PhD:

It is good to get feedback about a previous column. I am sorry my answer seemed too superficial. I can assure you I do understand the psycho-emotional turmoil that accompanies decreases in independence, as I too age with polio and find my abilities declining and my need for assistance increasing.

Let me address the two key aspects of your comments. The first aspect is about what you call “loss of independence.” Why put this in quotes? Because I want to reframe it. Having someone help you with tasks or even doing them for you is not the same thing as loss of independence. I have someone who does my laundry, changes the sheets, goes grocery shopping, vacuums, cleans, runs errands, changes light bulbs and scoops up the dead mice my cats bring me as gifts, but I still consider myself independent. That’s because I ask her to do those things, and because doing or not doing these tasks myself in no way defines who I am. Independence is not an either/or – either you have independence or you don’t – but a matter of degrees of independence.



Rhoda Olkin, PhD

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She is a polio survivor and single mother of two grown children.

As I notice changes in my functioning, I have to make adjustments. For example, I use a wheelchair more in the house than I used to, and walking the few steps from stove to sink with a pot full of boiling water and noodles became scary. So now I have a microwave container for making noodles that allows me to make them myself. Or sometimes I ask my assistant to make a big pot of noodles at the beginning of the week. But neither the change in how I do things nor the assistance in making noodles affects the essence of me: I am not defined by the noodles I make! But let’s think of a harder example: At one point I had to give up using woodworking tools, hence letting go of a major hobby of mine. Of course this was a harder adjustment than the noodle-making problem. I had to find different hobbies, and truthfully, the new hobbies were not as satisfying as woodworking, so this change required more personal readjustment than I would have wanted. Yes, I was sad, but not depressed.

Which brings me to the second point, about depression, and your assumptions: (a) that depression will accompany changes in independence, and (b) that polio survivors have a right to be depressed. I take issue with both of these points. And I say that as someone who has had more than my share of depression in my life. Depression is not a necessary or even usual response to changes in functioning. It should not be expected, it should not be thought of as typical, and it should be aggressively treated. Generally it is not the decrement in functioning per se that is the root of any depression, but the loss of socialization and activities that lead to a depressed mood.

Longevity is most associated with continued socialization, so work on that aspect of life. And if living alone, I recommend cats – they don’t need walking, there are automatic feeders and litter boxes and they cuddle!

QUESTION: *At a recent meeting, someone found it fun to mock me as she spoke. My body is quite misshapen and the brace makes me appear to look stiff and odd. She focused on me in a friendly, humorous way as if seeking my approval for doing her performance so well. Earlier, I saw another member go through a similar act mocking a woman who is not disabled, but does have a unique way of speaking. There will be more meetings and I haven't decided the best way to handle this. How would you suggest I respond?*

Response from Stephanie T. Machell, PsyD:

Even children know that mocking others in this way is unacceptable. Though some people have conditions that prevent them from understanding how their behavior affects others it seems unlikely there would be two people in the group with such conditions. More likely the mockers think they are funny. But their behavior makes them bullies. And bullies thrive on reactions – the group's as well as the target's.

If the group enjoys the performance or is fearful of confronting the bully, and/or the target has an interesting reaction, the mocking will continue. You don't indicate how the rest of the group or the other woman who was mocked reacted. But because two members of the group mocked two other members, and because the member who mocked you seemed to think you should have enjoyed her performance, it sounds like mocking others is part of the group's "culture" and acceptable for at least these two members.

Depending on your personal style there are many ways of dealing with the situation. If you are comfortable with confrontation you can bring the issue up in the group. Be prepared that if this really is part of the group's culture, the members may support the mockers, and that if they do, you may be scapegoated in some way. If not, the group may be glad you spoke up!

You can talk to the mocker outside the group and tell her you find her behavior hurtful and offensive. Maybe she really doesn't know this is wrong and will give you a sincere apology and never do it again. Or she may become defensive and blame you for your reaction to her "humor."

You can wait for a repeat performance. When the mocker looks for a reaction, you can say something. For example, "I never cared for that sort of humor." Or, "Was that supposed to be me?" Or, "I wonder why you would do that?" Or, "Imitation is the sincerest form of flattery." Or, "Isn't that interesting? Can you do Cagney?" Or, as Miss Manners used to recommend, just look at the person without reacting.

Or you could say, "Good thing this isn't a workplace. You could be fired for doing that!" Remember, if it is a workplace or somewhere else where rules exist about bullying you can report the mocker to HR or whoever else enforces the rules. Or if this is a group you can leave, you could decide you don't want to be part of a group that has this culture.

Is the other woman who was mocked someone you feel comfortable speaking with? Two people confronting a bully – or a culture of bullying – may be more effective.

Whatever you decide to do, the most important thing is to remain calm and non-defensive. The less reactive you are, the less interesting you are as a target, and the less likely it is that the bully can interpret your response as defensive or hurt so the show can go on. ■



Stephanie T. Machell, PsyD

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Her father was a polio survivor.