Question: If I am told, “I never think of you as disabled,” should I be complimented or insulted?

Response from Rhoda Olkin, PhD:

This question created an opportunity for discussion among some of us. Some people wanted to delete “or insulted” at the end of the question, after getting feedback from a few folks who couldn’t understand why someone might be insulted. But I wanted to keep the phrase there, because I really do get why someone (myself included) might be insulted by being told “I never think of you as disabled.” I’d like to try to explain why.

First, let’s examine what someone might mean if they tell you they don’t think of you as disabled. I believe the person means it as a compliment. S/he is saying that you seem very able, that you don’t pity yourself, that you engage in activities much like someone without a disability would, that you don’t use disability as an excuse and that you seem to have overcome your disability to the greatest extent possible. That’s a good thing, yes?

Yes. But there is a flip side. Though let’s be clear about the language: I am not a disabled person, I am a person with a disability. There is a difference. I also am a mother, female, Jewish, a psychologist and a person who had polio. It’s one of a list of things, not the main thing, so I relegate it to the background.

But imagine someone saying to me “I never think of you as Jewish.” What might this mean? Does it mean I think, behave and talk so much like a non-Jewish person that my Jewishness disappeared? And would I be complimented or insulted by this statement? I think you can see why I would be insulted. “Ahhh,” you say, “but Jewishness is something to take pride in, while disability is not.” Isn’t it?

There is a certain pride in being a person with a disability. It means I have survived, have experienced suffering and become more empathic for it, have felt the cruelty of other children and grown stronger, learned a lot about myself as I faced discrimination, learned to choose my fights wisely, became expert in disability laws and rights, joined a disability community that challenged my viewpoints, juggled my pain and fatigue and still planted a beautiful garden and raised two children. Would I have done these things without a disability? Some of them, perhaps, but not the same way.

There are no answers to the questions “who are you without a disability?” or “how does having a disability change you?” I am who I am with my disability, not in spite of it. So when you tell me you don’t even notice my disability, I hear that part of me has been disavowed.

There is another reason I might feel insulted. Disability is not a dirty word. You don’t have to lower your voice when you say it. I am not ashamed of having had polio. (I may be annoyed, fatigued, in pain, sick of it, angry, fed up, but I am not ashamed – I did nothing wrong.) So if being a polio survivor is not shameful, why would I want someone to tell me that they don’t even see that part of who I am?

Try telling another person “I never think of you as ___________” – and fill in the blank with gender, ethnicity, sexual orientation, religion or country of origin. See if s/he takes it as a compliment or an insult.

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.
Response from Stephanie T. Machell, PsyD:

There’s no “right” way to feel about anything. How you feel is how you feel. From your question, I’m guessing that you felt confused or uncertain how you felt. Or maybe you felt more than one thing at once and had difficulty sorting it out. On a subject as complicated as your disability, it would be likely that you would have mixed feelings – maybe in this case both proud and insulted.

How you feel about yourself as a person with a disability most likely influences your feelings. Are you ashamed of your disability? Were you always able to “pass” as nondisabled and now PPS makes that impossible? If so, you might be proud that the other person sees you as still able to pass. Conversely, you may be proud of your identity as a person with a disability and so you might be insulted that the other person doesn’t see or accept that part of you. If you are uncertain, it may be because you feel ambivalent and are struggling with how you feel about your disability.

How you might feel about someone saying he or she forgot you had a disability might also depend on the context, including how well you know him or her, what your relationship is, what you know about the person’s attitudes towards disability and how relevant your disability is to the interaction the two of you are having.

For example, a close friend may not think of you as disabled because for him it is not the most important fact about you. People in close relationships where there are differences of gender, race or religion – or disability – often report forgetting about the differences until a situation that makes them relevant occurs. If your friend were to take you out to dinner to a restaurant that turns out to be inaccessible, your disability would be quite relevant to both of you.

You may be uncertain how to feel because you don’t know how the person saying it meant it. She may not be a close friend, or you may not know how she views people with disabilities. Or her statement might bring up some issues or doubts for you. You could try asking this person why she said this, or (if appropriate) talking about how her answer made you feel.

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.

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

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Swallowing specifics for those with PPS

It is important that a swallowing examination be conducted periodically if any of the symptoms listed here are exhibited. Even if the problems seem minimal, swallowing should be evaluated, as people with PPS often accommodate changes that need attention, and these can become full-fledged problems when ignored. Make sure to contact a qualified clinician for treatment. A modified barium swallow study is the most complete and reliable instrumental test to examine a swallow, so be sure to follow through if it is recommended and to follow up with additional studies if any changes in swallowing occur. Swallowing is an important human function that can be preserved in those with PPS.