

PHI: *I have always been a fairly active person. I have a good circle of friends, and we like to meet up for various outings—nothing too strenuous, just going to plays or museums, meeting up for lunch, going shopping, etc. Like many people that had polio and are getting older, I can't quite do as much as I used to. Certain activities just tire me out. There are times (not all the time) when I'd rather just stay home and read or watch TV. I'm afraid, though, that if I start to opt out of our regular outings, my friends will start to just not ask me to things in the future assuming I don't have the energy for it. I don't want to feel excluded. How do I balance this with my need to slow down a bit?*

Response from Stephanie T. Machell, PsyD:

Regardless of age, this is a common dilemma for people with disabilities. Temporarily able-bodied people rarely understand the issues involved in living with a disability, including the need to pace oneself and conserve energy, or the way a “bad” day might mean a sudden change of plans. The more “invisible” someone's disability, or the more that person's condition seems similar to something familiar (such as normal aging) the more puzzling these needs may seem. And because most people's mental model for disability is based on what is familiar to them (e.g., acute conditions), the lack of improvement and/or cure causes further confusion.

As you fear, well-meaning friends may assume it's kinder not to invite you. Or they may feel hurt at what they perceive as rejection and stop asking to avoid more rejection. No matter the reasons, the result is increased social isolation and loneliness.

What can you do? First spend some time thinking about what kind of social life would suit you best. Being clear with yourself will help you be clear with your friends. For example, if certain activities

tire you out, maybe you'd prefer to opt out of them altogether and conserve your energy for the ones that don't. Maybe you'd rather be asked on all outings, reserving the right to say yes or no depending on how you're feeling. Or maybe you have thoughts about some new activities or ways of getting together that might be less fatiguing.

It can be awkward to discuss something as personal as your disability, especially if these are “activity” friends rather than close ones. Often people believe the only way they can justify themselves is to provide more details than they may be comfortable sharing.

Think about how much (or little) you want them to know beforehand. It can help to develop an “elevator speech,” i.e., something brief and to the point. Consider how you'll respond if your friends ask questions.

Now it's time to talk with your friends. If you're closer to one or more than the others, you could start with them. Be clear about what you want and need, how much you enjoy their company, and how important it is to you that this continue. You might discover you're not the only one who feels the way you do. Good luck!



Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.

Response from Rhoda Olkin, PhD:

I'm going to address how to make decisions about slowing down. Most of us have to do this as we age with polio. Using a mobility device is one option for energy conservation, but reading over questions from the past, it seems that many people feel it is an admission of defeat to use a scooter or wheelchair. But mobility devices are not the only option.

Let's do a thought exercise to work through how energy affects us. Suppose you had 258 pennies, each of which represents some amount of energy. Every action you do costs some number of pennies. As you go through the day the number of pennies dwindles. If you go over your allotment of 258 pennies you will start the next day with fewer pennies and need to do more things to replenish your supply. In an ideal world you would spend about 200 pennies a day, always leaving some in reserve for unavoidable events, and never going over your limit.

But the problem is this: you don't know how many pennies you have each day, and the number varies from day to day. The only way to really know how many pennies you have is to go over the limit a bit several times, and computing what the outer limits are. Furthermore, each decision to spend a penny is a decision not to spend it on something else. So slowing down is all about making choices of what we want to spend our pennies on, and what we don't feel is worth the penny.

Reserving a large portion of your pennies for socialization is one of the most important things you can do, as shown by

studies on aging well. You don't have to be a social butterfly, saying yes to everything. But I would advise doing at least one to two social activities a week. This might mean cutting down expenditure of pennies elsewhere. The times you spend reading and watching TV are also important—you are lucky in that you like time by yourself. Those times may be nurturing as well.

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Could you make a list of everything you do in one week? Now cross off at least five things. Or make trades—going to a play this week means not going out to dinner until next week. But beware of all-or-nothing thinking. Turning down a social outing or two does not mean friends will drop you.

Practice this line: "I have X on Friday so I believe I'll be too fatigued for Y on this Saturday but would love to do Z with you next Saturday." Friends should understand. ■

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.

