



Frederick M. Maynard, MD

Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

Question: My sister who had polio in 1953 at age 17 was affected from the waist down. She also struggles with bipolar disorder. Last winter she was hospitalized on a behavioral health floor for 44 days. Her crutches were taken away because they were considered weapons. She spent the days in a wheelchair and did not receive any physical therapy. Upon her release, we found she has lost what strength she had and now uses the wheelchair all of the time and is in a nursing facility. It is difficult to convince hospitals to allow the use of the usual assistive devices or equipment, and even more so, when it is a mental health facility. Do you have any advice for the family members who are advocates?

Answer: It is very important for family members or friends to become effective advocates for polio survivors when they are hospitalized for serious medical problems, including mental health problems. One of the best ways that they can do this is to read PHI's monograph titled "Post-Polio Health Care Considerations for Guidelines for Families & Friends" available at www.post-polio.org/edu/healthcare/.

They will learn that it is an important issue for a polio survivor to minimize any major decrease in their usual daily activities, especially walking and self-care related mobility. This is because a polio survivor's strength and/or flexibility can rapidly decrease with inactivity. Most health care professionals cannot be expected to know this.

One of the basic problems your sister's unfortunate experience illustrates is the difficulty our current health care system has in treating people with "double diagnoses," such as an acute mental health condition necessitating hospitalization AND a chronic medical disability condition. Significant post-polio leg weakness requires continued physical exercise to not worsen, even if a person's usual daily walking provides sufficient exercise.

Your sister should have received physical therapy services in order to ensure that her walking would continue in a manner safe in her unfamiliar environment of a psychiatric facility. An advocate might need to explain to physicians and nurses of the psychiatric facility that continued walking with crutches and performance of other self-care activities in her usual fashion are essential for her continued capability for doing them in the future. It is important for them to understand that her daily walking is as necessary as continued insulin or chemotherapy treatments for a person with diabetes or cancer who is hospitalized in a psychiatric facility.

One of the challenges for family members or other advocates who may try to ensure that a polio survivor's need for usual activity-related exercise are met is that they must "play by the rules" of confidentiality and get written permission from the patient to speak with providers, especially when a hospitalization is for mental health problems.

This can present a formidable challenge. In addition to addressing necessary assistive device use and usual activity, one of the best things for an advocate to insist on is a consultation by a physician who is familiar with the polio survivor's usual needs for maintenance mobility and independence. This could be a primary care physician or a physical medicine and rehabilitation or neurology specialist who knows them and who is willing and able to get involved.

In summary, my best advice is to "get involved" and to not rely on or trust the "system" to do the right thing relative to addressing important special needs arising from a person's polio-related impairments and adaptations. ■