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Sixth International Post-Polio and Independent Living Conference
JUNE 1994

Coordinating Post-Polio Treatment: You, Your Primary Physician, and Your Expectations

***You ... Dorothy Woods Smith, RN, PhD,
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School of Nursing, Portland, Maine***

Before addressing the topic of our panel I'd like to briefly address how those of us who are polio survivors, especially people who are attending their first G.I.N.I. conference, can sort through the vast amount of information being presented at this conference in a way that will enable us to become empowered rather than overwhelmed.

I would like to share Dr. Augusta Alba's advice to me when we first met in 1986. The reason to attend the International Post-Polio and Independent Living Conferences is not just to obtain information, which most of us can do through reading, viewing, or listening to the conference proceedings. We come here in person to meet other people who share similar experiences, questions, and interests, and to have fun in the process. This is a my third such conference. Experience has shown me that she was right!

We should apply all our knowledge about living as polio survivors to this conference. That means making choices. It means being clear about what we want to do or learn most, and what we can let go. It means pacing ourselves, taking breaks, paying attention to our body positions, and providing our bodies with nourishment and rest. This will allow us to be fully present when the issues of greatest importance to us are discussed. We can fill those nice gray bags with information of interest to our post-polio support groups, our physicians, and therapists — and be generous in distributing it to them when we get home. And we can take home for ourselves information, ideas, insights, and inspiration.

Now, to our discussion of what we can and should expect of our primary physician. I think all of us would like to have what Gini Laurie, the founder of G.I.N.I., referred to as an "R.D." — a real doctor — available to us at all times, and if not in person, then at the other end of the phone. It would also be nice if that person were an expert in all aspects of post-polio syndrome: a specialist in the areas of neurology, orthopedics, pulmonary function, rehabilitation, and psychology. It

would be even nicer if that physician was also a nurturing, caring human being who treated you as a favorite patient. It would be nearly perfect if the physician was always available within a few hours of being called, and had an easily affordable fee.

Most of us here are adults, and have set aside magical thinking. But we can still dream. And it is reasonable to look for a network of health professionals and friends who can collectively provide some of the expertise, guidance, and therapy that we need.

As a polio survivor and a nurse, I want a primary physician who cares enough to listen to me, and who treats me as a believable, reasonable, intelligent human being. This physician does not have to be an expert but does need to know people who are, and be able to arrange for me to see them when it is appropriate. This person needs to be someone I can share information with when I return from the conference, and who will read and/or save the information that I bring.

The person whom I have chosen for my primary physician is an internist whom I see about once a year for an overall check-up. The primary physician has "the big picture" and serves as coordinator of all my health-related needs. I am referred to a neurologist for polio-related symptoms; we have been learning together about my post-polio sequelae for seven years. This year I was also referred to a physiatrist, a rehabilitation specialist new to our area. Reports from the specialist go to my primary physician, and they occasionally consult with one another by phone.

After the physicians diagnose the underlying cause of the symptoms and recommend treatment, they make referrals to the other health care professionals who will carry out the treatment plan. In my case this year I was sent to a physical therapist for treatments to relieve tightness, to a nurse practitioner for strategies for dealing with chronic pain, and to an occupational therapist who devised a program of gentle stretching and energy conservation.

In closing my remarks, I want to add that I believe that we as patients share responsibility for the patient-

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physician relationship. We owe it to ourselves and to them to be direct and honest, to ask questions about what we do not understand, and give timely feedback about our responses to medications and treatments they prescribe.

Your Primary Physician...

**Marny Eulberg, MD, Mercy Medical Center,
Denver, Colorado**

I have a dual role of being a polio survivor and a primary care physician.

As I have gone through life, I have realized that part of the reason I went to medical school was because of some treatments I received as a child and as someone who had polio. I want to say, first of all, that I had very appropriate medical care. But I felt like a lot of things were done TO me instead of for me and without my permission. And as I have gone through therapy and learned more about myself, I realize that one of the reasons I went to medical school was never again would that happen to me. I wanted to have the knowledge, the recognition, and perhaps the peership, so that I could be an active partner in my own health care.

I do not necessarily advocate that all of you go to medical school, or complete a residency. It is a significant price to pay, and I think there are other ways you can be a partner in your health care these days.

Times of medical care have changed. Patients can, and a number of patients do, interview doctors. You are hiring a physician just as you hire other people to work for you. What you are seeking from a health care provider is a determination of what is wrong if you do not know, or some reassurance after your annual physical that a lot of things are very right. You also seek advice about what can be done to take care of problems, or to keep you healthy. And, you seek assistance to perform certain technical procedures that you cannot do yourself.

The whole process of hiring a physician should not be unlike that of hiring an accountant, a lawyer, or a mechanic. And it is fraught with some of the same problems. When I take my car in to be fixed, they can tell me a lot of things about alternators and generators and TVC valves and other things I have no idea about. In my relationship with my mechanic, I have to have some trust, and you have to have some trust with medicine.

These days, however, the process of hiring a physician gets a little muddled, or sometimes very muddled, by insurance restrictions, particularly HMO's (Health

Maintenance Organization) that have closed panels of physicians and are very stingy about out-of-plan referrals.

It appears to me that sometime within the next few years we are going to have some kind of national health insurance here in the United States. It also appears that it will be an HMO model. If it becomes a reality, all of you here in the United States are sooner or later going to have your care coordinated by a primary care physician. (Some of you may already be in that situation.) If you have enjoyed the option of calling and making an appointment with any specialist in the past those days may be limited. In the future, you may need to develop a relationship with a primary care physician.

Primary care physicians, by most HMO's, are defined as either a family physician, general internal medicine physician, a pediatrician, and in some cases an obstetrician-gynecologist for women's health care.

There are differences among the physicians and their training. Family physicians have, in general, a little broader training because they take care of children, adults, sometimes pregnant women, and generally have had some training in some minor surgery. It is said that they can handle 90% or 95% of the problems that come in their office.

Internal medicine physicians mostly have had training with diseases of adults, generally have had less gynecology training, and less surgical experience. They may not be able to take care of quite as many things in the office.

As you all know, not all primary care physicians know about polio or post-polio. Some are willing to learn and some are not.

I have heard from many polio survivors in the past of the frustrations with physicians, but I never experienced it until last summer. I gave a 20-minute talk at a musculoskeletal conference for primary care physicians in Breckenridge, Colorado, and when the comments came back from the audience at least half of the comments were, "I don't know why you put polio on the program; I am never going to see polio. It was a total waste of my time." These represent the physicians who are not willing to listen and learn.

As a primary care physician, I know that primary care physicians cannot know it all. At least 50 different high blood pressure medicines, about 100 different antibiotics, and 40 different birth control pills are now available. I know most of the names, generally what they are for, and a couple of the side effects, but I cannot even come close to knowing all of the details. And that is true in a lot of other areas of medicine.

Please value a physician who says, "I do not know" and who, in front of you, gets out the books and looks it up or gets on the phone and asks someone else. A physician who knows it all is lying.

Primary care physicians, as well as all physicians, have good and bad days just like you. There are also physicians you will work well with and others with whom you will not. And some of the physicians with whom you do not work well will be deemed great by others.

It is possible that a physician may have just entered the office after having had a terrible fight with a teenaged son, or may have just told the patient before you that they have a terminal disease. There will be days that your physician is struggling to keep things together and may not be there for you. If this happens all the time, start wondering. If it is unusual, your physician may be showing some of his/her human side.

Physicians also sometimes make mistakes. One of my professors in medical school told us that we should not be in medicine unless we could live with the fact that some day we would kill a patient because of something we did or we did not do. So far I do not think I have had to live with that, but it is reality.

Most physicians will not make mistakes intentionally or maliciously, although there are physicians who have problems themselves, such as drugs. As a profession, we need to weed them out.

Most primary care physicians schedule a patient every 10 to 20 minutes. If you have many issues to deal with and lots of questions schedule more time. Do not expect that they can spend an hour going over your problems. If they do, the other scheduled patients in the waiting room are getting very angry.

Try not to save your most important issues for the end. Try not to talk about the sunspots on your skin that bother you along with the fact that you do not like it that you are balding, and then at the very end, mention that you are very depressed and have considered suicide. The "oh, by the way" at the end are difficult for most physicians because we realize their importance. It has bothered you a lot which is why you had a hard time bringing it up and saved it to the end. When it is an "oh, by the way" and I know I am a half hour behind, you may not get the appropriate evaluation and care that you need immediately. I may do a quick short and sweet evaluation that could miss some important things.

Also understand that most physicians have "work-in" appointments for emergencies. If you call with a temperature of 104, you need to be seen that day. Those appointments are for emergencies or single acute problems. It is not the time for you to bring up 10 or 12 concerns and complaints. Physicians cannot do all of those problems justice in a "work-in" appointment.

If you have special problems, like difficulty getting on or off the exam table, it is useful to tell the office in advance. Most primary care physicians, or a number of them, do have a procedure room with a table that will go up and down. They usually only have one and it is

just more efficient for everybody if the staff knows ahead of time.

If you are coming for a problem, do not also bring along other sick family members. Do not expect indirect or direct assistance by saying, "Oh, by the way, my granddaughter has a sore throat. Could you just take care of that while I am here?"

Write down your questions and concerns. It is also helpful for you to bring a list of your medicines and dosages. Telling me that you are taking a little pill for your heart is not very helpful. I used to know the high blood pressure medicines by color. But with the number of generics, and the fact that they do not have any identifying marks on them, I cannot look them up and find out what they are. Bring in your medicines; bring in the facts.

It is also useful for you if you have had a number of orthopedic surgeries, when you are seeing the physician for the first time, to bring a list of the surgeries and the approximate dates.

And lastly, it is helpful when you call a physician, to give the office an idea of how urgent the problem is. If I have a list of 10 phone calls, and I have no idea how to prioritize, I start at the top of the list and go down. Usually the first call in the morning is at the bottom of the pile. If you are having chest or abdominal pain, you should tell the office staff that it is urgent, and then I know whom to call first.

Additionally then, be available for a return call or specify with the original message when you are available. I

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am fairly patient and will keep trying up to nine, ten times. A number of physicians will only give people one or two tries, and if you have not answered they throw the message away and wait for you to call again.

And lastly, if every time I call you I know I am going to be on the phone for 30 minutes, I will not return your call until the end of the day. If I know that I can talk to you in a few minutes, I will call while someone is getting undressed or dressed or after I have seen a well child and sent in the nurse to give the shots. In other words, make sure that you keep phone calls brief if possible.

Your Expectations ...

Stanley K. Yarnell, MD, St. Mary's Medical Center, San Francisco, California

I am not a polio survivor. I have a visual impairment due to recurrent optic neuritis. My expertise regarding relationships between patients and physicians is based on personal and professional experience.

First of all, relationships between physicians (all health care professionals) and patients have evolved as medicine has evolved. Polio survivors have been part of that change. Originally there was the apostolic model in which the physician was the healing priest. Information was handed down from on high. The relationship has evolved to a more collaborative model with the health care professionals and the patient working together.

A good collaborative physician-patient relationship — and that includes the primary care physician, specialist, and the patient — is truly a team effort and fundamental concepts of effective team building are applicable.

Any really productive relationship requires effective communication, and, above all, listening. As a patient, sitting across from a health professional, listening is very important. You should be able to repeat what your physician has to say. If you can not repeat it, you have not understood it. From my perspective as a physician I know listening is important and that if I listen hard enough the patient will tell me the diagnosis. I just have to take credit for it and bill!

Sharing information among a team such as the primary care physician and the specialists (neurologist, physiatrist, orthopedic surgeon) is an important part of communication. Frequently, it falls disproportionately on the shoulders of patients. Physicians need to work at communicating. With managed care expanding, we will all be compelled to communicate more effectively.

As health care professionals giving out information, we need to minimize the jargon. We learn jargon to feel important, but the major benefit is the way it streamlines speech.

For patients, it is important to get to the point and be succinct. Many of my patients write things down ahead of time so they do not forget their questions or all of the points they need to make. Remember, as a physician, I can get the diagnosis from you by listening.

As I talk to polio support groups, I repeatedly hear, "My physician's an idiot. He doesn't understand. He doesn't listen." And many physicians have said, "They just go on and on. They come in and expect me, in 45 minutes, to be able to solve all of their problems which they have not taken care of for the last 30 years."

Everyone is angry, and I think we need to be aware of it. It is easier to talk about than it is to solve. But one thing we can all do, whether we are sitting on the physician's side or the patient's side, is not to let things brew and stew and turn into anger. If there is conflict it should be dealt with. If you feel that you do not want to, or cannot deal with it face to face, or have not figured it out during your appointment, write a letter or telephone. And if you cannot talk directly to your physician, or the physician has some issue, it is important to communicate somehow whether it is with the dreaded phone mail technology or with someone else in the office. Issues of conflict need to be resolved so the therapeutic relationship does not get bogged down.

It is important that this collaborative team share goals and expectations. My perspective and expectation as a physician of what I can do for polio survivors in a clinical situation is to help them feel healthy and as functionally independent as possible — doing those things they want to do. Some polio survivors who come to me may have a completely different expectation. They may be searching for a cure to get rid of this new disability, so they can do the same old things they have always been doing. These are two completely disparate goals. Unless there is a shared goal — a mutually-agreed-upon expectation — there will be conflict.

It is absolutely crucial to have honesty and trust and that takes work and is a two-way street. You expect your physician to be straightforward and honest and not hold back anything about your prognosis. At the same time, your physician expects you to be completely honest and to share, for example, if you are seeing a post-polio specialist or admit that you are taking certain medications.

And finally, we all need to acknowledge and compliment each other's positive qualities. I am probably most effective in relationships where patients give me some strokes as well. □