

Being an Active Participant in Your Health Care

By Dorothy Woods Smith, R.N., University of Southern Maine School of Nursing, Portland, ME

At this point in the conference, I would suggest that we pause, and ask ourselves the question, "What does all this information mean to me?" For the health professionals in the audience, that is probably fairly straightforward--to integrate the new insights and information into an existing practice. I suspect it is less clear-cut for the people who came as polio survivors, and it is especially to this group that I would like to speak.

We who have had polio are part of a unique group. We are a population whose health care needs were once fully met regardless of income and insurance. From the mid-'40s on, the diagnosis of poliomyelitis meant that all medical and rehabilitation expenses would be paid for by the National Foundation, popularly known as the March of Dimes. The health care assured was so comprehensive that some infants with neurological problems were knowingly "misdiagnosed" as having polio in order to enable them to receive the needed services.

The National Foundation has moved on to other causes, and now we need to learn about health care in the '80s, how to access the system, and who and what may be available to help meet our needs. Many of us also have to make attitudinal changes: giving up the false comfort of magical thinking; no longer empowering the doctor, nurse, and therapist to make our choices for us; learning instead to join with health care professionals as partners in our care.

I would like to share a personal experience that led me to exchange wishful thinking--that I would be taken care of--for the realization

that I needed to participate actively in my own health care. I had been in a back brace for seven years, since the birth of our fourth child, and was experiencing increasing pain and spasms. Despite (or because of) increasingly high doses of valium for the spasms and codeine for the pain, I grew less and less able to function, until I was admitted to a hospital under the care of a rehabilitation physician I had never met--a gruff, dictatorial man who gave orders and expected compliance.

I remember telling him one morning that my pain had intensified and asking whether I should go to physical therapy as scheduled. His reply was a brusque pat on the shoulder and the comment, "Raise your pain threshold." I had had it. I rallied energy I didn't know I still had! I went to the physician's office and engaged in a "sit-in," refusing PT, stating that I would wait as long as necessary to see him.

I can still picture the startled secretary as she reported this mutiny over the phone and remember how she followed his orders to make me comfortable in his office. I ate lunch seated in his big leather chair as I waited! This act of rebellion, refusing to go along with my treatment until I knew what was going on, proved to be the beginning of a warm and supportive relationship with a physician I had formerly viewed as unapproachable. It also marked the beginning of my feeling like I was treated as an individual, having my sense of self worth restored, and taking an active role in my own health care.

As a nurse, I am attracted to the work of Dr. Elizabeth Barrett of N.Y.U., who believes that nurses should work with people to help them participate knowingly in change...to make them aware of the power they have in terms of influencing the nature and direction that changes take in their lives.

Barrett's concept, which she calls power-as-knowing-participation, has four components, each of which has meaning for us: awareness, choices, involvement in creating changes, and freedom to act intentionally.

AWARENESS: By attending this conference, by listening to the speakers, and by networking with one another, we are increasing our awareness not only of change, but of some ways in which we can respond to it.

CHOICES: We are certainly faced with choices and are involved in making choices regarding our therapy, our life-styles, and our priorities. We can choose to seek help or not, to listen or not, to conserve our strength and ration our muscle function...or to go on a major energy-spending spree, flaunting and enjoying what we can do while we can do it. We can also choose whether or not our experiences will lead to personal growth.

INVOLVEMENT IN CREATING CHANGES: One of the important changes we can be involved with is how we respond to what happens in our lives. Maslow described self-actualization as the process of selecting the "growth choice" over the "fear choice" many times. He also noted that the most holistic levels of human consciousness seemed most frequently found in "heroic" people who had been strengthened, rather than weakened, by adversity.

FREEDOM TO ACT INTENTIONALLY: According to psychologist Al Siebert, people who take an active role in responding to personal trauma are among "life's best survivors." We are free to act intentionally, selecting health professionals to work with us as we make choices about our rest and exercise, eating habits, use of orthotic aids, ways to minimize our pain, and maximize our energy, and our physical abilities. And it seems to me that many of us are indeed among the group called "life's best survivors."

As knowing participants in change, each of us is empowered to participate in changes in the manner and direction we value. I urge my friends who have also had polio to take an active role in your health care. Be aware. Become knowledgeable. And make the choices that work for you, reflecting your own values and priorities.

I would like to close with a plea to my fellow health professionals to hear us. We are trying to learn to swallow our pride and ask for help. We are working to overcome years of conditioning that we are "the lucky ones," that others need help more than we do, and that to ask for help is to admit failure. When we do realize that we need help and finally reach out to you, please hear us, believe us, and work with us. Together we can find a way for us to continue to enjoy meaningful, productive lives with our sense of self-esteem intact.

NEUROLOGICAL RESEARCH *

By Raymond Roos, M.D., University of Chicago, Chicago, IL

I want to discuss three research directions we are involved in at the University of Chicago. I'll very briefly describe: analyses of the neuromuscular junction (the nerve and muscle junction) in post-polio individuals; studies looking for immunological or virological abnormalities in post-polio individuals; and molecular studies of the poliovirus and related viruses to learn more about why motor nerve cells die.

But first, let's review a previous study that tried to answer questions still very much on our minds. What laboratory studies differentiate post-polio syndrome individuals from post-polio individuals who have no new weakness or functional disturbance? How can we make the diagnosis of post-polio syndrome from a laboratory point of view?

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