

# POLIO NETWORK NEWS

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## Polio Eradication & Rehabilitation in India

By Sunny Roller, M.A.

A team of health care professionals visited India from January 25-February 14, 1990. Frederick M. Maynard, M.D., an Associate Professor of Physical Medicine and Rehabilitation at the University of Michigan Medical School, led the group sponsored by Michigan's Rotary District 638 and Rotary International's Special Projects Program. Team members included: Celest Van Wert, PT; Hans Schaepper, CO; and Sunny Roller, Coordinator of the Post-Polio Research and Training Program. An orthopedic surgeon originally from India and past president of Rotary District 638, Mav Sanghvi, M.D., was instrumental in organizing the trip.

An estimated 12 million polio survivors are living in India today with 80,000-100,000 new cases per year. The team evaluated over 50 children with polio paralysis, lectured at the Trivandrum Medical College, visited several homes for children with polio and participated in India's Polio Eradication and Rehabilitation conference.

The national conference, sponsored by the Home for Handicapped (Polio) Children in Trivandrum, Kerala, was attended by 100 professionals who participate in polio eradication and rehabilitation programs in India.

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## "Prescription for Fatigue" from Fifth International Polio & Independent Living Conference in St. Louis

Polio survivor, Jane Dummer, Baltimore, MD, introduced the topic of fatigue as it relates to the late effects of polio. Her remarks are followed by comments and suggestions from William Waring, M.D., University Hospital, Ann Arbor, MI, Richard Owen, M.D., Sister Kenny Institute, Minneapolis, MN, and Martin Wice, M.D., St. John's Mercy Medical Center, St. Louis, MO.

**JANE DUMMER:** I am qualified to introduce the panel on fatigue because I fade right after lunch. When I agreed to speak, I realized very quickly I was going to discuss something which is global, yet something I really can't define for you.

So what am I going to say? Fatigue is a normal part of living. Perhaps I can say something about what I've experienced that would help people who don't yet know they have polio-related fatigue to see how it may be different from the fatigue that anyone who is alive has.

I had polio many years ago and did fine with a brace and cane while pursuing normal activities for about 30 years. I knew my baseline. I've always been limited in what I could do, but within the parameters of my limitation, I was able to carry on a fairly normal existence. About ten years ago, I started to develop weakness and pain. Much of the weakness was in my better leg, which started giving way on occasion. I was very concerned.

But I was not aware that I had overall fatigue until the day I was coming back from a meeting in an enormous federal complex in Baltimore. About halfway back, my better leg started to shake. I stopped

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dead in my tracks. I had to sit down; I could not move. After I rested, I limped back to my desk. I sat in a state of "zombie-ism" for about two hours, thinking, "This is it! You know you have to go to meetings in other buildings. You need a wheelchair."

I bought a wheelchair that afternoon. (I didn't buy the right kind, but that's another lecture!) The next day I rode over to the same place and back in my wheelchair, and I was absolutely amazed! I came back as rested as when I had left for the meeting. I was able to work for the rest of the afternoon. At that particular moment, I realized that over a period of three or four years, I had gradually been curtailing my activities to deal with chronic overall, unaccustomed fatigue (about which we hear so much), and I didn't even know I was doing it!

I'm a very pragmatic person. As a general rule I deal with things in a straightforward manner, but it really shocked me to think how much I had altered my life-style and didn't even know it!

In the last couple of years, it's been obvious that fatigue is my main problem. I couldn't ignore it forever. It's had an impact on my job, on my social life. I had a nap before lunch today, and that's why I'm here. I'm good for six hours. I have an eight-hour-a-day job.

What helps me the most is rest. I asked if I could take a rest period on my lunch hour at work. I was nervous because I knew they were going to think I was not doing a competent job if I couldn't stay awake for eight hours. It was hard to go and ask, but I did it. They agreed.

About three weeks later my supervisor said, "Jane, I'm just not sure this rest period is working out." I said, "What do you mean?" She said, "Before you started to take that nap you were so docile and quiet all afternoon, I didn't have to worry about supervising you. Now I don't know what you're going to stir up!"

One of the biggest things about fatigue as a polio survivor is its assault on your self-esteem. You suddenly cannot do what

you've always done. You may start an activity and can't continue it. You may have to work part-time. You may have to forego the promotion because the job might be too taxing. If you let it, these circumstances hurt your self-esteem. I think the trick is to take as much control as you can. Make your own choices and be aware that you can change them! You have to alter your life-style and see what works for you. That's what I'm doing. I'm trying things, and if they don't work, I drop them and I try something else. I'm going to look at part-time work, think about disability retirement, and look at getting some hobbies that aren't so taxing. I'm trying to focus on quality of life, retain my sense of humor, and learn. I'm trying to listen to my body, not deny what's going on, and live within it. I came here to share with people like you, to learn from you, and hopefully to help you.

DR. WARING: I'm very happy to be here because it's a chance for me to thank some of you for being my patients. You have taught me about my profession, and you are a pleasure to work with because you're so involved. You care about what's going on and want to learn more.

It is evident that from a medical and scientific standpoint, fatigue is confusing. From a clinical standpoint, the biggest challenge I face is to understand the symptom or complaint and to correlate that with what I understand in terms of the physiology.

One definition of the post-polio syndrome is based on five points.

The first point is a history of polio. The second is a period of recovery, which is followed by the third step--stability. The next step is the onset of problems, such as fatigue, weakness, shortness of breath, and pain. The last point is the exclusion of any other medical diagnosis to explain these symptoms.

One of the changes I've seen in the last few years is that there has been a change in the flexibility of thinking about these post-polio problems. We not only continue to study what might be a potential nerve

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problem, but we also now look at things that are obvious. There are symptoms that can be identified and symptoms that can be treated. That's our challenge as clinicians--find things we can treat.

From a physiological standpoint, fatigue is best studied and best understood at the muscle-nerve level where fatigue can be defined as the normal loss of maximal or sustained tension over time. In this context, all muscle will fatigue if it's asked to work hard enough. It is also true for a muscle that is already weak.

Scientists have developed a curve on a graph that compares strength and fatigue by the amount of work the muscle does. When muscles are asked to do very little work, they don't get fatigued, or it takes a very long time for that to happen. As we approach the maximal strength of the muscle, it fatigues very quickly. In fact, it can fatigue at maximal strength in seconds.

Now, with a weakened muscle, whatever the cause, the curve has the same shape, but it's in a slightly different location on the graph. The muscle fatigues earlier at lower loads and its maximal point is also less. So a muscle that's weakened from polio might do pretty well and not fatigue, as long as it's not at the maximal end of its function. If you ask the muscle to work harder, it fatigues very quickly. If there's an absolute loss of strength, the curve will move down.

Fatigue as a symptom is not as well studied or understood, because we could look at it as a perception of how you feel. It tends to be more clinical than basic science, and we have a number of conditions that have fatigue as a symptom--multiple sclerosis, strokes, pain disorders, anxiety, stress, sleep disorders, and chronic pain.

In our clinic at the University of Michigan, we have a number of patients who do not have any evidence of polio. This is determined by clinical examination, electromyography, and by screening with single-fiber electromyography. When we compare the symptoms these individuals report to those of the survivors who have

obvious weakness from polio, we find that their complaints about fatigue are about the same. I think this points out that fatigue can be a sign of a disease but is not a specific sign of anything. Because of that, we need to have an open mind and work on developing a list of possible causes.

I approach this problem in terms of what could be causing this person's fatigue. I start with a clear history. Some survivors will talk about fatigue in a very specific manner ("If I walk a lot, my foot drags") while others speak more of a perception ("I just feel wiped out"). Fatigue changes from individual to individual.

Some possible causes of fatigue include deconditioning of muscle, severe sleep disorders, and pain. Pain, the major complaint of survivors who see us, can cause fatigue because one reaction to pain is inactivity. Severe pain can also affect your sense of how you feel.

Fatigue results when muscles work harder as a result of weight gain. Fatigue can also be the presenting symptom of depression. As a whole, the post-polio population is probably less depressed than the normal population. Anxiety and stress can cause fatigue, and these two factors are very common in the post-polio population.

A cause of fatigue is the development of any progressive deformity. For those of you who have knees that are becoming unstable or giving out, the leg in effect is made shorter. It's like stepping in a hole and you use extra energy picking that leg up to walk. Any pain that might cause a limp will tend to be translated into more energy cost. (Remember the curve. If you're on the end of the curve, a little change might make a big difference, and the muscle is now fatiguing.)

I want to discuss walking and relate some of the results of a study done last summer with polio survivors and non-disabled people who were in the same age group. The people wore a pedometer, which measures how many steps you take, and if you know your stride length, you can figure distances walked.

What we found, not surprisingly, is that polio survivors walked about an average of two kilometers a day, while the controls walked about four kilometers a day or almost twice as far.

The polio survivors walked fewer steps but proportionately more in terms of distance. People with polio tend to walk slower--the average speed for polio survivors was 50 meters per minute compared to 75 meters per minute. Their stride length was also shorter--56 centimeters versus 70 centimeters. These changes in terms of walking slower with shorter strides can be very useful in terms of pain management and safety, but the price is paid with more work for the distance. Many survivors have experienced a major decrease in walking ability.

We recently had a paper published in the Archives of Physical Medicine concerning gait management with polio. The survivors who got an appropriate brace for their legs and used it daily (which was about 60%) reported not only increased walking distances, less pain, increased safety, but also less fatigue.

Another potential cause for fatigue is in terms of deconditioning of heart and lungs. The polio population shares with the normal population the fact that most of you do walk; over 90% of you learned to walk after polio. I think 90% of you are still ambulating, and that accounts for the majority of the energy you expend daily. It also is the main way people can stress their heart and lungs to get the beneficial effects of exercise. As there is a major drop in the ability to walk distances, there is a gradual loss of heart and lung conditioning.

I can't tell clinically by looking at you whether your fatigue is from heart and lung deconditioning. But certainly by taking a good history, I can get an idea whether I think you are at risk for this problem. I think that we're beginning to believe (and to practice) that we need to treat each of you separately and develop your own individualized program recommendations. It's not a case now of "use it or lose it" or "preserve it" but rather understanding which one of these is appropriate for you and which might be

appropriate at different times for the same person.

DR. OWEN: I think the more I listen to other experts, the more I'm convinced that the concept of post-polio syndrome is the process of aging in conjunction with a pre-existing disease. Yet, there are parts of us that can age more gracefully than other parts of us. Thinking about taking advantage of the difference is what led to Sister Kenny's heart and lung conditioning program.

There are some issues that I'd like to mention about our program. I feel it is very critical to establish whether or not there's any under-oxygenation in the involved musculature. There are factors about the oxygen available to muscles that have to be assessed prior to participating in our cardio-pulmonary conditioning program. (Many times labs schedule studies first thing in the morning, and they turn out normal pulmonary function. It would be very helpful to measure oxygen saturation at night time and during the day on people who experience severe fatigue. If the tests were done late in the afternoon, the result might be entirely different.)

A common error is that people talk about their "incidental exercise" as though it was good for their health. In Jane's case, she found that walking great distances was so fatiguing that it was not good exercise. Dr. Waring points out that people with polio walk so slowly that they fatigue their muscles, are worn out, and have done nothing for their health.

Two years ago in St. Louis, Northwest Orient's plane landed at a gate on the furthest concourse. Because the plane was threatening to take off, I walked very fast carrying my suitcase, and all of a sudden I lost my anterior tibia and my long toe extensor on my "better leg!" Every crack was leaping up to grab my toe and toss me to the ground. That experience is so vivid to me now and was very embarrassing then because I had just been talking about staying healthy and being wise. I had some odd pride in thinking that I should walk that distance. I came back this year and brought my wheelchair and my baggage carrier. I zip

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on and off the plane, and I pass all people who are trying to be brave!

My point is that intentional structured exercise can be beneficial to you, and that's one of the nice pieces of news from our first of three studies at Sister Kenny, Minneapolis, MN.

The question of "global fatigue" as opposed to "specific fatigue" is really a tough one. Your vulnerability to local fatigue depends on what you're doing, like the long distance walk that suddenly made Jane's "better leg" start to feel weak or my long toe extensor and anterior tibia drop out. These experiences are memorable, but they are not the "hit-the-wall" fatigue. I feel the basic mechanism is somewhat the same and that the person is experiencing degrees of under-oxygenation in involved musculature. Some of the involved musculature may well be the muscles of ventilation. Those muscles might fatigue in much the same way as my anterior tibia or Jane's quadriceps.

There's a similar experience of under-oxygenation that takes place in the bulbar innervated muscles of swallowing and speaking. People with bulbar involvement are more fatigued in the afternoon, their swallowing and speech are often weak in the afternoon. People who used to sing in the choir have had to quit, particularly after extended periods of speaking and talking.

I feel we should address the adequacy of oxygenation, and whether that comes from something you can do yourself or whether it comes from a need for supplementary oxygenation and whether that depends on your individualized status.

The one problem we've had in fatigue measurement is that we don't have good statistics. I can remember when I used to "play football" as a post-polio youngster. (I actually stood with one crutch and passed left handed or blocked with my right crutch.) And yet, if I told a physician that I used to play football, he would think that I am really wasting away. We have to have some measurements that are self-inflicted so you can establish both subjective and objective changes. Start

recording information, not in a neurotic diary system but by a once-a-month or once-a-year look at what you're able to do.

How long do you have to rest after you fatigue? I think this is very critical. I used to find that I could drop out a muscle, stop for two or three minutes, and get back up and go again. It takes longer now, and I think that would be a nice measurement for a clinician.

One of the points about muscle strengthening in general is that a lot of people think they are strengthening muscle, but often are stronger by retraining their brain to use what they have more effectively.

DR. WICE: I'd like to discuss how I approach individuals who complain of fatigue in our post-polio program. I see things both as an internist and a physiatrist. For this presentation, I'm defining fatigue as excessive tiredness after exertion which is inadequate to cause the fatigue.

I'd like to make a statement that I don't think has been made before at this conference--a dog is not a cat. People come to our clinic as a polio survivor and think that they are a polio survivor and in a state of excessive fatigue. An individual with post-polio syndrome is also in a state of excessive fatigue. Therefore, a polio survivor is an individual with the post-polio syndrome. I can use the same rationale and say, "A dog is brown. A cat is brown. Therefore, a dog is a cat." I'd just like to reiterate, a dog is not a cat!

So what is the cause for fatigue? I reviewed the different diagnoses for fatigue in a book (French's Index of Differential Diagnoses) that lists various problems and possible causes. It made it very simple, "any medical problem can cause fatigue."

From a practical point of view, how do I approach fatigue? I think the most important thing is to do a good history and physical. I also get a complete blood count, check the serum electrolytes, check blood chemistry for liver and kidney

function, and do a thyroid screen because hypothyroidism can present only with fatigue. I also check vital capacity to make sure that ventilation is adequate.

Raymond Adams, a well-known neurologist at Harvard, is one of the principle authors of a major internal medicine text (Harrison's Principles of Internal Medicine). He wrote a section on lassitude and fatigue. With hospitalized patients, it is clear that of most of the commonly overlooked diagnoses, psychoneurosis and depression, should be considered. This statement jumped out at me because many people who come to my clinic talk about fatigue and other symptoms of post-polio syndrome. They're convinced that it's in their head! Their spouses and their family members may also be convinced that it's in their head. Their co-workers or their bosses may think they're lazy. It could even be that their own physician is not so certain that they are not a little anxious or a little depressed. Whatever the cause for fatigue, the medical cause should be treated.

As a physician, I think it's important that if someone has post-polio syndrome and fatigue from it, that it be legitimized. Dr. Adams says that if there is true weakness, it's almost never due to psychological factors alone. So it's important to validate the post-polio syndrome and the fatigue from it. Polio survivors should also tell their spouses and family members, and if necessary, tell their co-workers and their bosses, and if they have to, tell social security disability and also if they have to, tell the referring physician.

The non-disabled population talks about exercise being a good way to build up endurance, strength, and energy level. That is a good way for many people even with post-polio syndrome to build up their energy level. But polio survivors have a dilemma in that if they push themselves too hard, they pay the price. The body just cannot seem to take additional stress, which is quite difficult to tell individuals who have had polio and recovered by working very hard, by pushing themselves to the point of pain and seeing positive results. The secret is to be

active enough to prevent deconditioning but not so active that they pay the price of exacerbating the post-polio syndrome.

Polio survivors should listen to their bodies. Everybody is different, and I cannot give a prescription for a whole group. As a general comment, if you do something where you feel worse for several hours or a day or two later, you are doing too much. But if you feel better afterwards, it probably is going to be OK.

The other thing to remember is that there are other causes for fatigue, and if they can be treated, treat them. If taking certain medication causes the fatigue, you may be able to stop the medication. Also, we have heard repeatedly from polio survivors with the post-polio syndrome that rest is the best treatment. Make sure you get a good nights sleep. Also be aware of the problem of hypoventilation. Another problem is excess weight because it takes more energy to move.

Braces really do work. If they are recommended for you to improve your energy reserve, your gait technique, and for safety and decreasing pain, seriously consider it.

Also consider work simplification. Think efficiently on how you plan your day so that you can do as much as possible with as little energy expenditure as possible. It's not a matter of being lazy, it's a matter of being smart. Don't do activities that will exhaust you. If you can hire out work or have other family members do work for you, do it. Also, organize work areas. Try to have everything close at hand and use energy saving devices like a mixer, a food processor. Slide objects on a countertop versus picking them up.

Don't stand if you can help it. If you have trouble going up and down steps, don't live in a three-story home! If you need a brace for walking, use a brace. If a wheelchair or electric scooter will allow you to go from point A to point B, by all means, use it! Don't be afraid to ask for a handicapped parking sticker. Everyone else seems to be using them. Why shouldn't you?