
October 1999

THE DISABLED: SUCH INTERESTING PEOPLE

by
Hugh Gallagher

The other night, I was living independently, using my electric powered wheelchair, happy as a clam. It had been a good day. My writing was going well. I had driven my car to the library in the afternoon, cooked myself a dinner and now I was getting ready for bed.

And then the left rear wheel fell off my wheel chair. No movement was possible: when I gave the chair power, the left axle would just grind itself into the oak floor. There I was, naked, all alone, and marooned twelve feet from the telephone.

If I were to save myself, I had to get to the telephone and to do this, I would have to "crawl." I once knew how to get safely to the ground from my wheel chair. This was done by crossing one leg over the other, turning in the chair, and sort of backing off onto the ground. This is what I tried to do the other night but I have lost strength and I just fell to the floor, all legs and arms in a tangle. Fortunately, no bones or tendons were damaged.

By lying on my stomach, I was able to drag my body, inch by painful inch, to the telephone and the help I needed. It took me an hour and a half. The effort left me badly shaken and my muscles were sore and my skin was bruised and burnt.

There are times when it is all just too much. One moment you are independent, able to deal with life, the next you are on the floor, stuck, helpless as a baby. Dignity, self esteem, all that evaporates, goes up in air. There you are, out in the world, competing with the able-bodied, kicking ass, and then of an instant, zap, you are a pathetic cripple.

It is a life of contrast: at the same time you are both a master and a wimp. You are a live, active player and, concomitantly, you are engaged in a private struggle, fending off the wily advances of disability, helplessness and death.

And even more confusing is the fact that an episode like the other night is a real life adventure. It is an unexpected test of grit and courage. My crawl across the living room floor to the phone was, in its way, as challenging, daring and dangerous as Edmund Hillary's ascent of

Everest. I will bet the sense of achievement I felt when I reached the phone was just as great. There is a rush of confidence: I will survive; I will prevail. This is a rush of pure joy at just being alive. Flowers, sunlight, loved ones are seen with a new intensity.

This is part of what makes the disabled such interesting people. We experience a harsh reality the able-bodied can only read about. We relish the adventure of disability even as we hate it. And from it all we learn to appreciate life as it is, without blinkers.

Back in the 1960s when I worked in the Senate, Hubert Humphrey was a force to behold. It was said that the effort that he and his office put into a average day's work would have been sufficient to govern a country the size of France. Humphrey had incredible energy; he was buoyant and confident. There was no problem that could not be solved and he was the one who would solve it.

Yet when I saw him in the last months of his life, he was a scared man. He knew he was dying of cancer and his eyes, once brimming with confidence, had a desperation he could not hide. Humphrey had caught a glimpse of his true helplessness in the face of approaching mortality. Clearly he could not handle this knowledge that we severely disabled people live with, day in, day out.

If we are able to live with our painful, fearful knowledge; live with it and transcend it; to have a full, productive and happy life in spite of it, then we have come to have a wisdom that is granted to very few. Oliver Wendell Holmes said once that the wisest of men is the old family doctor. He has seen all the pain and suffering life has to offer and he has seen the best and worst of mankind. The severely disabled person who makes peace with his disability is like the old family doctor.

So it is a rich, complex world for us disabled people. Our career out in the world, our private struggles, our adventures and our failures give us a "quality of life" that the able-bodied can only guess at.

And yet, strangest of all, it is the able-bodied who feel they have the right to make quality of life judgments about us.

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NEWS NOTE:

From: GINI, 14 October 1999

Update on Post-polio/MOD Committee Mtg

The expert committee to plan and conduct a symposium, entitled International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Clinical Management, to be held May 19-20, 2000, in collaboration with the Warm Springs Institute for Rehabilitation in Warm Springs, Georgia, met October 8-9, 1999.

In attendance were Lewis P. Rowland, MD, Columbia University (Chair), John Bach, MD, UMDNJ- New Jersey Medical School, Lauro Halstead, National Rehabilitation Hospital, Joan Headley, Gazette International Networking Institute, Daria Trojan, MD, McGill University, and William Wendling, Cleveland Municipal School District. Also attending were March of Dimes program staff members Christopher Howson, PhD, Director of International Programs, Michael Finnerty, Manager, International Programs, Richard Leavitt, Director of Science Information, Ellen Fiore, Associate Editor/Science Information, and Lindsey Whitcomb, Health Information Specialist.

The committee heard comments from 17 individuals on Friday morning October 8th. Many of the individuals reported the need for better training of health professionals (primary care physicians, pulmonologists, orthopedists, emergency medicine personnel, physical therapists, etc.) about the diagnosis and management of post-polio syndrome. Health professionals and polio survivors expressed a need for more research including the assessment of the effectiveness of recommended interventions.

Another frequently mentioned concern was the lack of funding for equipment and services caused by cuts in Medicare reimbursement and lack of health care insurance. The psychological consequences of having a disability and the complex issues related to experiencing post-polio syndrome later in life were also mentioned.

The committee then discussed a preliminary agenda for the May meeting. The goal of the May 19-20 meeting is to review the current information about post-polio syndrome and to critique it to identify the best practices in diagnosis and clinical management. The contents of the final document will be evidenced-based information that has been peer reviewed. The plan is to disseminate this document in hard copy and electronically and in various formats, including provider and patient guides.

The committee encourages interested parties to cite relevant data, make suggestions, voice their concerns, and provide other information for consideration.

Please e-mail your comments to jroe@modimes.org or mail them to Joan Roe, March of Dimes Birth Defects Foundation, 1275 Mamaroneck Avenue, White Plains,

NY 10605.

I would like to clarify two points.

One, attendance at the International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Clinical Management to be held at Warm Springs is open to health professionals by invitation only.

Two, Gazette International Networking Institute's Eighth International Post-Polio & Independent Living Conference to be held in Saint Louis on June 8-10, 2000 is open to polio survivors and health professionals.

Preliminary information will be published in the Fall Polio Network News (Vol. 15, No. 4). The registration form will be available in January 2000. To receive the registration materials and future updates, contact us at gini_intl@msn.com.

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THE GINI RESEARCH FUND

For Post-poliomyelitis and Neuromuscular Respiratory Research.

The one million survivors of poliomyelitis in the United States, and the 12 million worldwide, know there are consequences of living and aging with a disability. They also know that funding for research into their problems is limited.

Gazette International Networking Institute (GINI) established The GINI Research Fund in 1995 dedicated to "seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases."

The GINI Research Fund with a corpus of \$100,000 will award its first grant from the interest in the fall of 2000.

Q: What research will GINI support?

A: The initial modest grants will help support researchers, scientists, and clinicians worldwide to investigate the cause(s), treatment, and management of post-poliomyelitis and neuromuscular respiratory disease.

As it approves grants, GINI will foster new innovative research - both basic science and clinical - that will result in improved quality of life for people with disabilities, as well as support valid ongoing research.

Q: How will funding decisions be made?

A: A panel made up of peers and people with disabilities will review all grant applications that meet established requirements for respiratory research or post-poliomyelitis research. This panel's recommendations will be reviewed by the GINI Board of Directors, who will make the final funding decisions.

Q: How can contributions be made?

A: Gazette International Networking Institute is a not-for-profit 501(c)(3); Federal ID No. 34-0961952. Tax deductible contributions can be made payable to GINI. For more detailed information, contact Gazette International Networking Institute, 4207 Lindell Blvd., #110, Saint Louis, MO 63108-2915 USA (314-534-0475, 314-534-5070 fax, gini_intl@msn.com, www.postpolio.org).

Holistic Polio

Polio Biology VII
Eddie Bollenbach

On reflection, it is quite obvious that everything in the body works together. Put another way: nothing can happen inside the body without an effect on all parts of the system. After reading some recent articles on nerve and muscle function I started thinking about Post-Polio Syndrome and how closely a skeletal muscle fiber and attached nerve work together. The relationship is so close that it is quite impossible, at times, to tell what the primary cause of neuromuscular weakness is. This is particularly true when we are focusing on the synapse, the gap between nerve and muscle through which stimulant chemicals like acetyl-choline act. Without a nerve connection a muscle is an orphan and incompetent. Without a muscle a motor-nerve is useless. It is commonly understood that in Post-Polio Syndrome the end fibers of an axon (long fiber which is part of a nerve cell) break down leaving a small but effectively insulated moat between muscle and nerve. Since each nerve end fiber innervates only one muscle fiber the muscle cell is then cut from stimulation. Without stimulation we know that the receptors of stimulation on the surface of the muscle fiber are forever lost.(1)

I think most of us assume that the loss of end fibers in PPS is due to overuse. And we have a tendency to extrapolate to say that if this could only be remedied we would defeat our foe. However, during the increased neuromuscular load of exercise the earliest response of the neuromuscular system is to allow for increased efficiency of nerve stimulation. A later response is the production of muscle protein and the consequent hypertrophic growth of muscle fibers. Also, even in normal neuromuscular systems there is only one end fiber per muscle fiber. During synaptogenesis several fibers may innervate one muscle but eventually all lose touch but one.

This evolutionary competition for muscle fibers by nerves is believed to result in efficient and varied innervation of muscle because different kinds of fibers have different effects on the contraction of muscle.(2) In normals there would be a tendency toward a diversity of muscle tension strength along the length of a muscle which would be produced by the natural competition of early nerve type synapses. Polio obviously alters this process by killing neurons. This allows for secondary synaptogenetic events.

What happened to skeletal muscle fiber receptors while they were left without stimulation for months during acute polio? We know now that they break down. People hoping for cures to spinal injury must exercise their muscles with electrical stimulation to keep muscle cell receptors alive. The old maxim "Use em or lose em" applies here. We with polio are in a position of slow loss of both end fibers and muscle receptors. How can we say that polio is a nerve disease when it is also, obviously, a muscle disease? And, by the way, I'm not convinced that the "cause" of PPS is overuse. There could be a host of other reasons why these end fibers of nerves, and/or muscle receptors, lose function. When analyzed there may be more than one cause. With some of the advances appearing now in measuring and differentiating antibodies, along with similar advances in DNA and RNA cloning techniques, which have been used to identify polio virus fragments in PPS, it may not be long until we have more definitive answers. Until then we should understand that we are a system and that whatever proximately caused our PPS, reversing secondary and tertiary problems will likely prove very difficult, because we are whole.

References.

1. Akaaboune, M., Culican, S.M., Turney, S.G. et al. 1999. Rapid and reversible effects of activity on acetylcholine receptor density at the neuromuscular junction in vivo. *Science* 286(5439):503-507. (Pubmed.Abstract)
2. Introduction To Muscle Physiology and Design, University of California at San Diego, 1999. <http://muscle.ucsd.edu/musintro/Over.html>

How To Prevent Further Disability In Polio Survivors

By Julie K. Silver, M.D.

Julie K. Silver, M.D., completed her residency at National Rehabilitation Hospital in Washington, DC. A California native, Dr. Silver earned her BS at the University of California/Davis, and her MD at Georgetown University. She interned at the former Framingham Union Hospital. Dr. Silver pursues her interests in musculo-

skeletal rehabilitation and Post-Polio Syndrome as Director of the new Spaulding Neighborhood Rehabilitation Center in Framingham and is on the faculty of Harvard Medical School.

Spaulding Rehabilitation Hospital is an affiliate of The Massachusetts General Hospital and Partners HealthCare System, Inc and is associated with Harvard Medical School, Tufts University School of Medicine and MGH Institute of Health Professions. Dr. Silvers has written a new book on Post-Polio Syndrome that will be published early in the year 2000 by Yale University Press.

The thought of becoming increasingly disabled as aging progresses is something we all fear. For polio survivors, particularly those who are experiencing symptoms of Post-Polio Syndrome (PPS), the fear of not knowing what the future will bring may be overwhelming.

Although it is important to treat the symptoms of PPS, there are many other reasons why polio survivors may become further disabled. This article addresses three major reasons why polio survivors may experience further disability as they age, and how to prevent this from occurring.

Systematically addressing and Treating All Potentially Serious Medical Conditions

The symptoms of PPS (i.e.: new weakness, fatigue, pain, cold intolerance, breathing and swallowing problems, and muscle atrophy) may occur with many diseases as well as with a prior history of polio. Moreover, some of these "other" diseases may be life-threatening whereas PPS generally is not. Therefore, anyone experiencing symptoms consistent with PPS should have a thorough work-up by a physician who is a polio expert in order to eliminate other, more serious or potentially curable medical conditions that may mimic symptoms found with PPS. If all other diseases are ruled out and the diagnosis of PPS is made, polio survivors should remain alert to the onset of new symptoms or the worsening of previous symptoms. A re-evaluation is indicated with either of these scenarios in order not to mistake the onset of a new medical condition for PPS.

For instance, if a polio survivor has a long history of muscle pain in his arms and legs and is now experiencing abdominal pain, this warrants investigation. New abdominal pain may be a minor problem involving constipation or may herald the first warning signs of a life-threatening condition such as colon cancer. Therefore, despite having had a thorough evaluation by a polio doctor and being diagnosed with PPS, any individual experiencing new problems or more severe problems than initially reported, should be reevaluated.

Although PPS rarely becomes life-threatening, there are many other medical conditions that may seem like minor annoyances at first, but can escalate into disabling or even deadly diseases. Some common diseases that

are frequently underestimated include high blood pressure (hypertension), high cholesterol levels (hypercholesterolemia), and poorly controlled blood sugar (diabetes).

These are examples of diseases that should be aggressively treated in order to prevent severely disabling and potentially life threatening events such as a stroke.

Polio web sites and newsletters across the country have often contained information about medications that may exacerbate the symptoms of PPS. While this is an extremely important topic, it is imperative the polio survivors don't recklessly abandon medications they are taking to control a variety of other serious medical conditions.

Anyone who is concerned with possible drug interactions or side effects from a medication should discuss this with the prescribing physician who then has the opportunity to consider alternate treatment approaches. Certainly the goal is always to have individuals take only those medications that work effectively and cause few side effects; however, in reality this is not always possible. As with all medical treatment, it is ultimately up to the individual taking the drug to decide whether the side effects are worth the benefits. The important point here is that polio survivors need to make informed decisions about which medications they will and won't take. Medications used to treat disabling or potentially life threatening illnesses should not be discontinued even if they exacerbate the symptoms of PPS unless a reasonable alternative is available or unless the individual taking the medication fully understands what may happen without it and makes an informed decision not to use it regardless of the consequences.

Protecting the Arms

There is a direct correlation between the strength of an individual's arms and their ability to care for themselves without assistance. Thus, one can say that the arms are the keys to independence and the stronger an individual's arms are, the greater the likelihood that he or she will be independent. Think of it this way -- arms are essential for mobility (rising from a chair, transfers, etc.), dressing bathing, driving a car or even communicating by phone fax or internet. While it is true that technology is providing new types of adaptive equipment that will enable individuals with upper extremity weakness to become more independent, keeping the arms strong and injury-free is essential.

Unfortunately protecting arms and avoiding injuries to them may be easier said than done -- particularly in those individuals who rely on their arms to compensate for trunk or leg weakness. For instance, polio survivors who rely on their arms for mobility purposes are prone to having arm injuries such as rotator cuff problems in the shoulder, nerve injuries at the elbow or wrist, tendonitis and even muscle strains and ligament sprains.

For example, a polio survivor who uses a cane to walk puts pressure on the hand and arm that holds the cane. Further overuse of the arm holding the cane is very common due to putting pressure on it repeatedly in order to rise from chairs and the commodes.

The combination of using the arm during ambulation and transfers as well as for everyday activities may prove to be too much and an injury or new weakness can result. Studies have shown those polio survivors, who use wheelchairs or other assistive devices such as canes and crutches have higher than average risk of injuries to the arms.

Although injuries to the arms may be inevitable, early medical attention can do a lot to mitigate these injuries. On the other hand, ignoring pain, tenderness, swelling, numbness or tingling in the arms and hands can lead to serious permanent injuries, which may in turn lead to further disability. This is because injuries are nearly always easier to treat in the early stages and those injuries that are allowed to progress to a more advanced stage become much more difficult to cure.

The good news is that many, if not most, arm injuries are treatable and often curable. The cure may involve rest from activities that exacerbate the symptoms, splints, medications, injections, physical and/or occupational therapy, and in some cases even surgery. The earlier an injury is treated, regardless of the injury, the more likely that treatment will be successful.

In summary, for those polio survivors who have become accustomed to a variety of aches and pains, it is important to recognize that many of the symptoms that occur in the arms are treatable and potentially curable and, therefore, should not be ignored. Moreover, leaving injuries in the arms untreated may lead to significant disability that may be permanent.

Avoiding Falls

Falls resulting in serious injuries is one of the leading causes of disability in individuals as they age--regardless of whether they have a pre-existing disability. One of the most important things to remember about falls is that they are generally "preventable occurrences," rather than accidents. Common injuries associated with falls include minor bruises and abrasions, broken bones, and head trauma that may lead to permanent brain damage. Obviously, all of these injuries can be potentially disabling. However, even if an individual simply has a fear of falling (without necessarily having experienced a fall with a serious injury) this may be equally disabling by leading to social isolation because they are afraid to go out. Therefore, regardless of whether an individual has fallen or is simply worried about falling in the future, this may significantly impact their quality of life.

Preventing falls is much easier to do when one understands how and why most falls occur. Certainly there are some absolutely unavoidable situations where preventing

a fall would be virtually impossible, however, as noted above, most falls are avoidable with a little forethought and planning. Falls occur for a number of reasons, but in general they can be broken down into two categories.

The first category includes falls that occur due to a problem with the way an individual's body works. This may be due to weakness, loss of balance, problems with vision or hearing, dizziness, etc.

The second category includes those falls that occur due to a problem with the environment. This would include falls due to hazardous weather conditions, slippery floor surfaces, cluttered rooms, etc.

In order to prevent falls, both categories -- your own body and your physical environment -- should be carefully considered and changes made as deemed appropriate. Medical experts who specialize in treating polio survivors can be excellent resources for information on how to prevent falls as it applies to individual polio survivor. For instance, a polio doctor can determine whether new braces are needed, if physical therapy might improve balance and strength, etc. He can also recommend that a physical or occupational therapist visit your home or workplace in order to evaluate how to make the environment safer (and offer suggestions on how to protect your arms!). Polio doctors and other healthcare providers can offer invaluable advice on how to prevent falls and subsequent disability.

For those individuals who trip occasionally but haven't fallen (yet), it is important to remember that a trip is less than a step away from a fall. Anyone who is experiencing tripping or falling or who is concerned that they may fall, should seek medical attention. Most falls are preventable which means that serious injuries that lead to further disability in polio survivors can generally be prevented?

Preventing further disability in polio survivors is critical. Fortunately, there are a number of things which can be done to prevent further disability but to do this require a thoughtful intelligent approach by the individual as well as appropriate medical intervention from physicians and others who are experts in the care of polio survivors.

The three ways mentioned in this article to prevent further disability in polio survivors (treating all serious medical conditions, protecting the arms and preventing falls) are certainly not the only ways to prevent further disability, however, they are a good place to start. Moreover, polio survivors who take the initiative to try and prevent further disability will likely experience fewer problems in the future and in turn, this may give them a measure of comfort about what the future will bring.

*Source: Post-Polio Syndrome Central Web Directory.
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