

Learning to Dance in the Rain

Vaneetha Rendall, Raleigh, North Carolina, vdemski@nc.rr.com

“Why do you walk like that?”

That single question haunted me for years. Young children would boldly demand an answer as they pointed at me. Adults would not dare to voice the question, but looked puzzled as they watched me walk. And I, I would ask myself that question daily as I struggled to understand why I had to be different from everyone else.



Vaneetha Rendall

When I was in elementary school, none of my classmates were familiar with polio. With the vaccine's development in the '50s, polio had become a disease that my friends had just heard about from their parents. Even in India, where I was born in 1964, the disease was almost eradicated although there were sporadic outbreaks since the vaccine was not given to infants less than 6 months old.

At 3 months of age, I contracted polio, but the inexperienced doctors assumed I had typhoid and gave me cortisone to lower my 105-degree fever. Twenty-four hours later, after the poliovirus had spread throughout my body because of my depressed immune system, they realized their mistake. But by then it was too late – I was almost a quadriplegic, with little movement in my arms or legs.

With limited medical options, my family quickly left India and moved to London, where I had my first surgery at age 2 by the renowned polio expert, Sir Herbert Seddon. Shortly afterwards, we moved to Canada where I went on to have 20 more surgeries, many at the Shriners Hospital in Montreal where I lived for months at a time throughout my childhood.

Most of my operations were muscle transfers which helped me to walk, though I always had a pronounced limp, visible evidence of my disability. Since my arms were very weak, crutches were out of the question, so I had to walk unaided or use

a wheelchair. The doctors recommended I try a special school for people with disabilities, but my parents were determined to keep me out of a wheelchair and in regular public school. I needed to learn to survive in the real world.

While hospital life was lonely, it was less painful than the constant mocking that I experienced in the “real” world. Through elementary and middle school, I buried the hurt of that teasing deep, yet it constantly whispered to me that I didn't count, that I didn't belong, that I'd always be an outsider. But at age 16, the acceptance of an unlikely friend broke through that pain, convincing me for the first time that I was worthwhile.

Finally feeling comfortable with myself, I chose to go away to the University of Virginia, to see if I could make it on my own. Virginia was not accessible, and I struggled to get into buildings with stairs without railings. Before one particular class every week, I had to find a friendly passerby to give me a hand up the countless steps.

Going to Virginia taught me to be independent; I discovered I could live on my own and survive if I had the courage to ask strangers for help. At first, it was humbling, but then it was liberating. If I didn't need to rely solely on people I knew, I could go anywhere and be okay.

continued on page 3

Promoting Healthy Ideas



PHI's 11th International Conference

St. Louis 2014

Thirty-two years! Can you believe it? PHI (then Rehabilitation Gazette) collaborated with the Education and Training Center of the Rehabilitation Institute of Chicago to organize its first international meeting in 1981 entitled "What Ever Happened to the Polio Patient?"

In subsequent years, titles of the next nine conferences included phrases such as "living independently with severe disability," "polio and independent living," "strategies for living well" and "living with polio," which mirror the evolution of disability rights and post-polio knowledge in North America. In 2014, we are

"Promoting Healthy Ideas," a theme that combines having had polio and living independently. People with disabilities can be healthy or, at the very least, strive to be healthy.

When: PHI's 11th International Conference is scheduled for Saturday, May 31 – Tuesday, June 3, 2014. Individuals attending a PHI conference for the first time will be invited to a special session Saturday afternoon. The conference will officially open with a dinner on Saturday evening. Sunday, Monday and Tuesday will feature many sessions aimed at Promoting Healthy Ideas. The program committee is developing tracks based on our Members' suggestions that include Wellness Practices, Recreating Ourselves, Minding Our Relationships, Life Decisions of Aging, Conditions of Aging and more. The closing session will end at 4:00 pm on Tuesday, June 3.

PHI's reservation form will include some questions about accessibility, diet, etc., needs. Early registration information will be available September 3.

Where: A block of rooms has been reserved at conference headquarters, the Hyatt Regency St. Louis at The Arch, 315 Chestnut Street, St. Louis, Missouri 63102. Additionally, we have contacted hotels close by and have accessible rooms available in an overflow hotel should the need arise. Individuals registered for the conference may register for a room online or by phone. As you all know, there are many people in our group who have mobility problems. PHI will make every effort to meet accessibility needs. Please understand these rooms will be assigned based on essential need, not solely on first-come, first-served. Hotel reservations will be available September 3.

Getting more information: Program and registration details will be posted on www.post-polio.org as they become available. Updates will also be featured in the *PHI Membership Memo* distributed in September, October, December, January, March and April. Individuals who do not have access to the internet may request a print registration packet by calling 314-534-0475 or by mail to PHI, 4207 Lindell Blvd., #110, St. Louis, MO 63108.

Learn and share ideas. Meet us in St. Louis in 2014!

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PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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Moving? Change of address?

Notify PHI before you move by calling 314-534-0475 or email info@post-polio.org, and tell us your old and new addresses.

Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send your newsletter.

continued from page 1

That revelation gave me the confidence to take a job in Boston after graduation, an unfamiliar city where I learned to manage on my own.

After four years in Boston, I moved to California to earn my MBA at Stanford. There I met my husband, and afterwards we settled down in North Carolina, near my parents. We had three children, two daughters and a son, who died at 2 months old. Although he was born with a heart problem, his death was the result of a doctor's mistake, which made the grieving even more difficult. I naively thought that after polio, I would not have to face more suffering; in my mind, everyone should endure only one major trauma, and I had already had mine. It only seemed fair. But as I buried my baby boy, Paul, I realized that none of us are or ever will be immune to tragedy.

About six months after Paul died, I was diagnosed with carpal tunnel syndrome. I was told that it could be a precursor to post-polio syndrome (PPS), but I was unconcerned. Surely that couldn't happen to me as well. And yet several years later, I learned that indeed I did have PPS after debilitating pain in my right arm led me to pursue treatment and an eventual diagnosis by Dr. Julie Silver at The Spaulding Clinic in Massachusetts.

Many of the changes suggested at Spaulding were helpful: electric gadgets, voice-activated computer software, assisted steering for my car, but other things were more difficult: giving up my hobbies, getting a wheelchair for community use and slowing down my pace of life. It seemed that all the things I'd worked for were crumbling before my eyes. At first, I was resistant to making any changes, but I soon realized that I needed to think long-term, if only for the sake of my daughters, who were ages 5 and 8 at the time.

I slowly made the necessary adjustments, trying to keep the activities that brought me the most pleasure. It was yet another grieving process as I said goodbye to my old way of life. Yet as with any loss, there is an opportunity for something

new to develop to fill the void created. My primary method of expression had always involved my hands, or specifically right hand, as I was an artist as a young woman and a scrapbooker as a young mother. Surprisingly, I found my new creative outlet in writing. I started writing poetry and just finished a memoir chronicling my childhood, detailing the unique yet universal struggles of growing up with a disability.

The last few years have been especially difficult, as I was recently divorced from my husband of 20 years. It has been a daunting task to raise two, now-teenaged, daughters on my own with PPS. Yet I know I can find joy as I face the next chapter in my life if I'm willing to look for it.

My faith is a big part of my life and has enabled me to weather the tempests without losing hope. I love the saying, "Life is not about waiting for the storms to pass, it is about learning to dance in the rain." I am truly grateful for my polio; it has taught me that I can overcome, that I am resilient, that I will endure.

So now, when I am asked the inevitable question, "Why do you walk like that?" I can answer, "Because I had to learn how to overcome adversity; I needed to know how to dance in the rain." ■



Vaneetha, age 2, with her mother.



Vaneetha, age 7.



Vaneetha and her daughters, Katie (left) and Kristi.

PROMOTING POSITIVE SOLUTIONS

QUESTION: *I am 81 and my wife, a polio survivor is 80. We are both in relatively good health, but it is more and more difficult to keep up with our day-to-day activities. I worry about what will happen to my wife when I die, or to me when she dies. The future looks very lonely. Our children (in their 50s) do what they can to help us and we have modified our home to make it more convenient. But, it still is too much. I would like your advice on how to approach this with my son and two daughters and their spouses, all of whom seem to have ideas about what is best for us.*

Response from Rhoda Olkin, PhD:

Let me address the issues for you and your wife. My colleague will address how it might look from the perspective of your offspring.

Much of what rightly concerns you is common to people as they age and is not unique to polio survivors. Nonetheless, the issues may be somewhat amplified by limitations associated with polio. It is fortunate your overall health is good, and long may that continue to be the case! However, you still have to plan for diminishing capabilities.

You say that everyone seems to have ideas about what is best for you. I understand how that can feel like pressure and sometimes as if people are not helping you figure out what you want. You and your wife have to decide.



Rhoda Olkin, PhD

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

She is a polio survivor and single mother of two grown children.

Here are several questions to address:

- (1) Do you want to stay in your home until the end? If so, let everyone know that.
- (2) Would you have someone come live with either of you if the other were to die?
- (3) Is there an elder community/agency that will arrange to give you a phone call every day to check on you?
- (4) Can you afford to hire more help?
- (5) Have you made end-of-life decisions together, and each is clear what the other wants?
- (6) If one of you outlives the other, would that person be able to and want to go live with your son or one of your daughters?
- (7) Do you have a life alert system or would you get one?
- (8) Are you able to ask for help, or is it hard for you to do so? When people offer, do you give them specific tasks to do?

You seem concerned about loneliness, and you are wise to pay attention to this. Socialization is one key to longevity and happiness. Research consistently underscores the importance of social support and social activity. Unfortunately, as we age we lose friends to aging, incapacity or demise. So now, while you are both in good health, increase your social activities. Make dates to go to movies; join or start a book club; have weekly meals with other people; take a class (art, scrapbooking, computer skills, cooking); take tai chi (excellent for balance – my mother, who had polio when I did, and is now 88, finds that she can do tai chi and feels better when she does); sit outside (being in nature tends to make people feel better); throw a neighborhood pot luck; host a neighborhood watch organizational meeting; go to ‘meetup.com’ to find others who like to do things you like to do. The point is that you have to work at it – friends develop from shared history and time, so start making new friends now.

Will you or your wife be sad when one of you dies? Of course! There is no antidote for the heartache of losing a partner of many years. But the more support you build now, the better it will be for the remaining spouse. This will ease the minds of your children as well, if they know you are busy and have friends.

Response from Stephanie T. Machell, PsyD:

As the daughter of a polio survivor, what I wanted most (and received least) was information about my parents' needs as they aged. They were fiercely independent and reluctant to burden us even with information about their health. It has been my experience that most polio survivors are like this. We as children often respond by being reluctant to intrude and believing that you don't need or want our help. In the absence of real information we may draw our own conclusions, which can involve stereotypes of what some archetypal "old person" needs.

There is a tendency, reinforced by the media and society at large, for children to think they should be the ones in charge when parents get older. However, unless both of you are declared incompetent, there is no reason for them to be. No matter what your children think is "best" for you, you and your wife are the ones who should decide. While you want input and possibly assistance from your children, remember that you have a right to live as you wish. That being said, if what you want is more support or to move in with your children now or if you are widowed (or if this is what your wife wants), you may have to sacrifice some independence and control.

Before you approach your children, you and your wife should discuss your needs and wishes. It might be useful to take notes so you have something to refer to and perhaps to give to your children

for reference. Think about what you need now as well as what your needs might be in the future. Clarify what you do and don't want. Obtain information about options that interest you and/or your wife. Remember that whatever you choose as a couple, each of you may want different things later as a surviving spouse. You might find it helpful consult with elder law experts and/or agencies or individuals who do elder care planning.

Once you have clarified your wishes, set a time to meet with your children (and, if appropriate, grandchildren). If possible, this shouldn't be on a holiday or other emotion-laden occasion. Everyone involved should be there so that information is conveyed as you want it to be. If distance prohibits this, you might want to consider using technology such as Skype so that everyone has the same information. Set ground rules for how the meeting will go, especially if you know that one or more of your children will have difficulty listening.

Be clear about what is happening now with your health and daily lives. Directly and nondefensively state your needs and wishes. Be open to questions. Let them know that this meeting is the beginning of a dialogue about your needs, and then keep the lines of communication open.

The more honest you are, the more comfortable your children will be with your choices. Remember that you are providing them (and their children) with a model for positive aging! ■



Stephanie T. Machell, PsyD

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.

**WE'RE
STILL
HERE!**

October 6-12, 2013

www.post-polio.org

WE'RE STILL HERE! What Having a Disability Taught Me

PHI invites you to participate in its 2013 WERE STILL HERE! campaign during the week of October 6-12 by speaking to students in your local elementary, middle and high schools.

Why would they want to hear from us? What would we want to tell them? What is the purpose of telling an experience or two from our lives? How would we decide what to say?

We want to send the message to our children and youth that having a disability is part of the human experience and that the experience taught us lessons that helped make us successful. We will be reminding them that we all have more in common than we have as differences.

Think about it. Can you synthesize what having had polio taught you that would be a good and positive lesson for our youth?

It would be a great time to show off your wheelchair, your brace, your ventilator and how equipment grants you independence. (Maybe you will inspire a future rehabilitation engineer!)

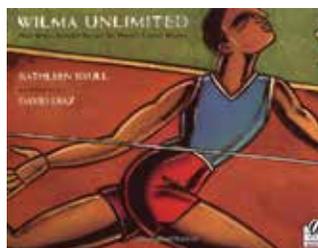
You could tell them about your education, and how important it was to your success in life. Was there a special experience during your school days that was a significant factor in your success? (Staying in school and graduating from high school is an important message.)

This is probably not the time to tell about that kid who picked on you all through high school ... unless asked. Or about the fear you experienced while in the iron lung ... unless asked.

Start with the principal. Summer is a good time to contact your local school principal to discuss a visit to one of the classrooms. Whether you choose elementary, middle or high school depends on your background and is up to you.

Here are some ideas and excellent resources for you to share with the principal and faculty.

For lower elementary

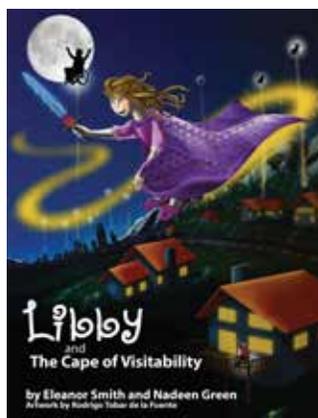
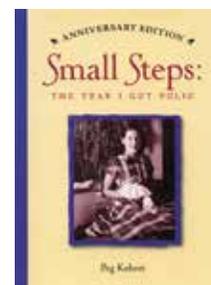


Wilma Unlimited: How Wilma Rudolph Became the World's Fastest Woman by Kathleen Krull, Deborah Halverson (Editor), David Diaz (Illustrator). This book noted for its “striking illustrations” for K-5, tells the story of Olympian Wilma Rudolph (Rome 1960), who had polio at age 5 in Clarksville, Tennessee.

For upper elementary

Small Steps: The Year I Got Polio by Peg Kehret, well-known children's book author. Kehret has won many awards and many children in grades 3-8 will have read *Earthquake Terror*, *Escaping the Giant Wave*, *Trapped* and *The Ghost's Grave*.

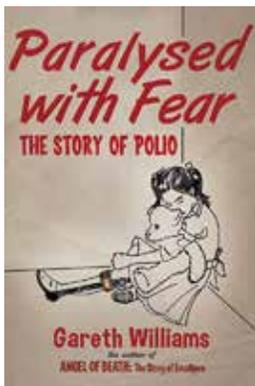
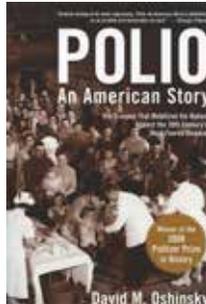
Kehret has a website – www.pegkehret.com – and a Facebook page. There are reader's guides available online for *Small Steps*. It is also available as an audio book.



Libby and the Cape of Visitability by Eleanor Smith and Nadeen Green (e-book). This book is the diary of Libby, a KWD (Kid with Disability). Written for children ages 8-13, this book raises awareness of the exclusion created when houses are not built with simple features that allow wheelchair users to visit or live in them. It provides not only a captivating story and relatable characters, but a reader's guide with discussion questions and resources as well.

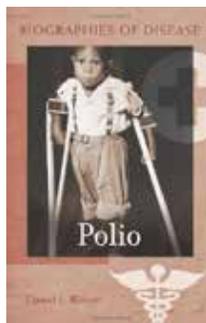
For middle and high school

Polio: An American Story by David Oshinsky “tells the gripping story of the polio terror and of the intense effort to find a cure, from the March of Dimes to the discovery of the Salk and Sabin vaccines – and beyond.”



Paralysed with Fear: The Story of Polio by Gareth Williams is the story of mankind’s struggle against polio that is “compelling, exciting and full of twists and paradoxes. One of the grand challenges of modern medicine, it was a battleground between good and bad science. He takes an original view of the journey to understanding and defeating polio.”

Biographies of Disease: Polio by Daniel Wilson “draws on recent scholarship to provide the most current portrait of polio available; written in an engaging, non-scholarly fashion to make the science of polio accessible to readers of all kinds.” *Biographies of Disease* is a series of books written specifically for high school libraries.



To find an extensive list of books about polio and the polio experience, visit PHI’s Polio Place at www.polioplace.org/resources/books. Some books are appropriate for biology and psychology classes, in addition to history.

Polio Place lists a variety of DVDs at www.polioplace.org/resources/multimedia that could be shown, including the classics *A Paralyzing Fear: The Story of Polio in America* directed by Nina Seavey and *The Polio Crusade* from WGBH *American Experience* video series by filmmaker Sarah Colt.

What Having a Disability Taught Me

Learning from Wise Elders (www.polioplace.org/sites/default/files/files/Tenth_International_Conference.pdf, pages 30-33) by Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan, revealed that post-polio mentors coping strategies included having a strong social support system, enjoying life and being optimistic. Self-acceptance, assertiveness, education and spirituality also were mentioned as beneficial to living life with polio.

Roller concluded, “Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and worked hard using their ‘lens of difference,’ a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial.

“Later in life post-polio mentors became more willing to look at their lives through the ‘lens of disability,’ more fully embracing their disability as part of their overall personal identity. In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.”

Can you identify with this? Has your perception changed? What wisdom have you acquired? Be a part of WE’RE STILL HERE! 2013 and tell a short story from your life’s “book” to the younger generation in your community. ■

PHI’s Polio Place (www.polioplace.org) is collecting Essays and Artifacts or Memorabilia accompanied by recollections. Send your “What Having a Disability Taught Me” to info@post-polio.org, so others can learn from you.

Part II

A Gentle Death

Nancy Baldwin Carter, BA, MEd Psych, Omaha, Nebraska

Surely we don't need studies to prove that planning ahead is a good idea, yet plenty of them exist, even when it comes to end-of-life issues. The goal, of course, is to assure that a patient's medical care will ensure the greatest measure of comfort and serenity possible. This requires patient power – the promise that whatever medical plans dying patients choose will be carried out. Patients treated in this manner are known to experience a more positive frame of mind, less pain and even a longer life. Helping patients examine the details of possibilities such as Hospice, Palliative Care and Death with Dignity pays off.

Hospice

As a concept of providing comfort and peace at home for those at the end of life, hospice has progressed through several centuries. It wasn't until the 1970s in this country, however, that hospice was established as what is widely known today as the most recognized program offering compassionate relief from death's pain and agony.

Hospice is surprisingly multifaceted, operating with a large variety of designs. Many of us think of receiving hospice

care in our homes. Often a hospice doctor or medical director consults with the patient's personal doctor to develop a plan of action. Other professionals, such as nurses, aides, counselors, clergy and therapists may then enter the picture.

Family and patient work with everyone on the team: What kind of hospice support does the patient want? What equipment is needed? How should pain and other medical needs be dealt with? Care must be taken not to treat the patient more aggressively than wished, thus causing unintended pain and driving up costs unnecessarily. Does the patient have Medicare, Medicaid, private insurance or other financial resources? Has everyone

discussed what to expect from hospice and how the disease proceeds? Every aspect is covered.

In addition, trained volunteers as well as family members and friends bring a great deal of comfort to the terminally ill on their final journey. Studies show that hospice volunteers, family and friends make up around 90% of those caring for the dying at home. Because of this, hospices actively recruit volunteers and provide training sessions to prepare them to be the non-medical companions so necessary to the success of this challenge.

One Family's Experience

Here's how the hospice experience worked for Janice, a teacher in a small Nebraska town, and her mother: "When we learned my mother's struggle with cancer was coming to an end, I looked for hospice help. There was none available where we lived, but I located a hospital about 65 miles away whose hospice staff met with mother and me to discuss



Nancy Baldwin Carter, a Nebraska native, contracted polio in 1948 at age 11. With BA and MEd Psych degrees, she began her career as a high school English teacher and moved on to administering adult education programs in Missouri and Kentucky. Carter founded Nebraska Polio Survivors Association in 1984 and was its initial director.

She was a contributing author to Dr. Lauro S. Halstead's *Managing Polio: A Guide to Living Well with Post-Polio Syndrome* in 1998 as well as its second edition in 2006. Carter has written three series of columns for Post-Polio Health International – "Leadership," "Polio Survivors Ask ...," and "Post-Polio Thoughts."

▷ details. They told us a nurse would visit mother's home once a week to check her physical condition. As the family member on duty, I was introduced to good ways to care for mother's daily living needs such as bathing, feeding, toilet issues, turning her in bed, administering her medications. They also explained what to expect as mother's condition deteriorated.

"A volunteer came in for two hours once or twice a week. She tended to mother's needs and often also sat and chatted pleasantly with her. This gave me respite time, which I gratefully used to go grocery shopping or merely to enjoy a restful moment to put my feet up and have a cup of tea. Occasionally she would do small tasks around the house—sweeping or washing a few dishes, for instance. She was great help."

Hospice Situations Vary

However, not all hospice care occurs in the familiar surroundings of patients' homes. In some areas, patients or the family may choose, instead, a hospice house, created especially for those who want hospice care, but prefer not to remain at home. For others, hospice care is an institutional benefit. Many patients receive hospice care in nursing homes or in certain hospitals.

While not administered to "prolong life nor hasten death," specific medications are important to bringing comfort to hospice patients. Pain medication is, in fact, the prime source of such relief. The exact kind of medication and the extent to which it is used becomes a significant early discussion between hospice doctors and their patients in determining the care they desire.

Medicare and Hospice

In 1982, Medicare benefits became available to hospice patients expected to live no more than six months. If those terminally ill patients exceed that time limit, their physicians can re-certify to allow them to continue receiving hospice care.

Medicare pays 100% of hospice costs for terminally ill hospice patients who waive the right to curative care for that

illness. At the same time, these patients may be treated for non-terminal illnesses, though expenses for this are not covered by Medicare hospice. Medicaid is also available in a large number of, but not all, states. Statistics show that most hospice patients die within two to three weeks, confirming the public view of hospice as end-of-the-line care. In 2010 alone, an estimated 1.6 million patients received services from hospice. Some 30% of Medicare resources are expended on the 5% of beneficiaries who die each year and one-third of costs in life's last year is accounted for in life's last month.

Finding Care

Hospice care is available to one degree or another in every state in our country, though it is carried out in a wide variety of ways. Knowing exactly what to expect when getting into hospice care can be quite an asset. Mayo Clinic and others provide a number of tips on what to look for when choosing a hospice program. Here are a few:

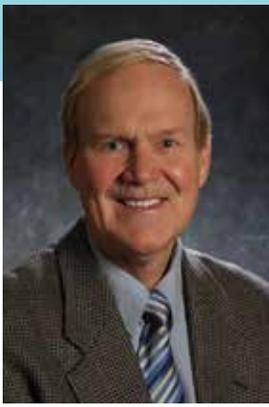
- ◆ If possible, use a Medicare-covered hospice program that, additionally, is licensed or certified by your state or is accredited by The Joint Commission, an independent evaluating organization known to inspire certain performance standards in health care organizations it certifies. Ask if hospice care teams are trained.
- ◆ Learn what services are offered and if they are available after hours.
- ◆ Find out how pain and other symptoms are managed.
- ◆ Check on which hospice services are available for family and other caregivers.
- ◆ Understand what Medicare hospice pays for and when private insurance or some other source is expected to pay.

Many Options to Consider

As it turns out, getting the medical issues settled in our thoughts may only be part of the task. Coming to terms with our intense inner feelings and the role our emotions play at this time in our lives also has much to do with the

continued on page 11

This is the second in a periodic series about end-of-life issues. While difficult to think about, avoiding the subject can result in last-minute decisions based on incomplete facts and misconceptions. Part III of this series will discuss Palliative Care.



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: I am 74 years old and had polio in 1954. My recent DEXA scan (to measure bone density) showed I had osteopenia. I have also recently suffered two compression fractures in my L1 and L2 vertebra due to an automobile accident in which I drove off the road over very bumpy terrain. My longtime physician, who is familiar with my PEG (feeding) tube, wants me to have a bisphosphonate infusion. What is this and is it safe?

Dr. Maynard: I invited Marny Eulberg, MD, Denver, Colorado, family physician and polio survivor, and Daria Trojan, MD, Montreal Neurological Institute, post-polio researcher and clinician to respond with me on your question. It is one that PHI receives regularly.

Dr. Eulberg: As you may know from past issues of *Post-Polio Health* [See Calcium, Vitamin D and Bisphosphonates, Oh My! (Vol. 27, No. 3) and More Research About Bisphosphonate Treatment in Polio Survivors (Vol. 28, No. 1)], there are some controversies about bisphosphonates (oral or injection/infusion). For you who uses a PEG tube the possibility of taking the bisphosphonate pills is not an option, and thus, the side effects of irritation to your esophagus or GI tract is eliminated.

The advantage of bisphosphonates is their ability to slow down or completely stop the process of bone becoming more brittle and decreasing the risk for fractures of vertebrae, of the hip and of the wrist. The risks are that some people have developed breakdown of bone in their jaw bones (osteonecrosis) especially after extractions or other dental work that involves the jaw bone (routine fillings, cleaning, etc., do not cause this), or in some people an increased risk of spontaneous fracture of the femur (thighbone). Therefore, if you have been advised to have any dental work done you should do it before starting the bisphosphonate.

It is now thought that people do not need to take a bisphosphonate for a lifetime. The current thinking is that a total of five years gives the best benefit with the least amount of risk.

Your insurance will likely need some extra documentation explaining why you can't take the pills and why you need the more expensive injections or infusions. The criterion they use to approve intravenous bisphosphonates is usually a diagnosis of osteoporosis not osteopenia. But, they may decide you qualify because some experts say that a diagnosis of even a single vertebral fracture is sufficient to say a woman has osteoporosis. Osteoporosis means that the DEXA scan shows a T-score of -2.5 or greater, which means your bone is about half as dense as the bone of a normal 30-year-old. Osteopenia means that your bone is less dense than a normal young adult but not bad enough yet to qualify as osteoporosis.

Dr. Trojan: With regard to the question about intravenous (IV) bisphosphonates in post-polio patients, we did not analyze data of patients treated with these medications in our published manuscript (Alvarez A et al. *PMR* 2010;2:1094-1103). See *Post-Polio Health*, More Research About Bisphosphonate Treatment in Polio Survivors (Vol. 28, No. 1). Outside of this group of patients, more recently, we have had a few patients treated with IV bisphosphonates and from our anecdotal experience with this very small number of patients, they seem to be well tolerated.

continued from page 9

end-of-life process. Many of us take time to imagine those final days, dreaming of what we can do to bring about soft clouds of serenity to waft us peacefully on, for example.

We may rely on our deep faith, the divine gift that leads us to a glorious new tomorrow. Or on moments of laughter among the tears as memories of happiness crowd our minds, and loved ones find their way to say goodbye.

Others want no part of this. Their time is here, they say – let death design the stage and pull the curtain. Their plan is not to have a plan. So be it.

But no matter what, if we want to see our intentions carried out, active or passive as they may be, we are the ones who must steer ourselves to that outcome. We are in charge of this phase of life and death. It is we who examine our options, consider where they sometimes telescope into each other – Hospice merging into Death with Dignity? Palliative Care moving into Hospice? – and how this leads us to develop our plan. Whatever we decide, however we put it together, this is the message we send to those around us. ■

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continued from page 10

Dr. Maynard: In this case, I think the dilemma is deciding if the vertebral compression fractures were a result of violent trauma, or if they were a result of osteoporosis weakening the vertebrae sufficiently that minor trauma resulted in their fracturing.

I would favor recommending treatment with vitamin D and calcium, and then a repeat of the bone scan in one year before initiating IV bisphosphonates now, because violent bouncing in a car can result in fractures regardless of bone scan scores. ■

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Inside *Post-Polio Health*

Vol. 29, No. 3, Summer 2013

- Learning to Dance in the Rain ... 1
- PHI's 11th Conference ... 2
- Promoting Positive Solutions ... 4
- WE'RE STILL HERE! ... 6
- A Gentle Death ... 8
- Ask Dr. Maynard ... 10



A guide for users of home mechanical ventilation to plan for emergency and planned visits to the hospital can be downloaded at www.ventusers.org/vume/. It is also available in Spanish.