# POST-POLIO HEALTH

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### What to Eat: Revisiting the Basics

Ann Crocker, West Gardiner, Maine

What to eat? Nearly every day we may hear or read about the benefits or risks of certain foods or specific elements in foods. Sometimes, we may be tempted to try some hard-to-believe, miraculous food or food product, which later may turn out to be of little value. With so many daunting warnings about what we should eat and why, it is no wonder that many of us just give up trying to change.

I want to offer some nutritional basics and highlights that may help guide you when making food choices. As always, check with your health professional before undergoing any dietary changes, as existing health conditions or prescription medicines may restrict certain food choices.

**Food basics:** First, foods are listed in three categories which are all essential for our bodies: carbohydrates, fats

and proteins. Many foods we eat may contain more than one food category, such as milk, which is categorized as a carbohydrate but has proteins and fats, too.

Carbohydrates may be complex carbohydrates, such as whole grains, vegetables and fiber-rich fruits which are the healthiest for our bodies. Carbohydrates may also be simple, such as sugar, white flour and white rice, which are not as nutritious. All fats aren't equal, either. Polyunsaturated and monounsaturated fatty acids, such as those found in fish, nuts, avocados and olive or canola oil offer the most helpful types for our body. For proteins, consider lean meats, fish, poultry, nuts and beans as these contain the least amount of saturated fats which can clog our body with unneeded weight or other fat-related health issues.



According to Dr. Lauro S. Halstead, for muscles to have a fighting chance to maintain or increase their strength, there should be a generous amount

of protein in the diet.¹ Polio survivors have something in common with athletes – they both often exert excessive strain on their muscles and so may need extra protein to help maintain whatever level of strength they have.

Nutritionists often encourage including some protein at each meal, beginning with breakfast. Our first daily meal could include protein from an egg, nuts sprinkled on cereal, some type of nut butter on toast, lean meat and/or a milk



#### **ABOUT THE AUTHOR:**

Ann Crocker is a co-founder of the Post-Polio Support Group of Maine, established in 1986. She also serves on PHI's Polio Survivor Advisory Committee. While not a trained nutritionist, Ann has been an avid reader of nutritional books and reports for at least 50 years. In this article, she shares some of her thoughts on healthy eating.

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product which contains some protein. Guidelines for the general public include only about 5 to 6 ounces of protein per day, which is the equivalent in size to a deck of cards plus 3 or 4 tablespoons, but you may choose, as I have, to increase your intake of protein to help sustain adequate protein needs.

While carbohydrates, fats and proteins are the dietary basics, let's break down these three categories by types of food, which is how most of us shop. The main types include dairy, fruits, vegetables, fats, meats, fish, poultry, nuts, dry beans and grains of all kinds. We need to eat foods from all types. Also, it's important to eat foods containing enough fiber to maintain a healthy digestive process. We actually do need fats, too, but try to keep them around 5 to 6 teaspoons per day, as fat calories add up very quickly!



Dairy products contain muchneeded calcium, protein, vitamins, carbohydrates and other minerals. Three cups per day of low-fat milk, or

its equivalent, will provide most people with adequate dairy needs. One ounce or about 1¼ to 1½-inch cube of cheese is equivalent to one cup of milk. Yogurt also offers many probiotics that help the digestive system. Health conditions, such as osteoporosis, may necessitate working with a health professional to determine the appropriate quantity of dairy foods.



**Vegetables** 

at least five to nine servings of fruits and vegetables per day, with the total amount depending upon age, size and activity level. A serving is about ½ cup of cooked or 1 cup of uncooked fruits or vegetables. Try filling

We are encouraged to eat

up a ½ measuring cup with a cooked vegetable, then pouring it onto a dinner plate. That gives you a rough estimate of a serving size. For those over 50, consider consuming 2 cups of vegetables and 1½ cups of fruit per day for women and an additional ½ cup each for men.



Let's not leave out the importance of grains in our diet. When choosing breads, those containing whole grains and fiber are more nutritious.

If currently eating white (simple carbohydrate) pasta or rice, try gradually incorporating a fraction of whole grain pastas or rice with the white type. You may find that the taste, texture and added fiber is so beneficial that you will switch to fully whole grain carbohydrates.

The newer, white whole wheat flour has a lighter texture than regular whole wheat. Replacing about 1/3 of white flour with this white whole wheat flour in recipes will add fiber and extra nutrition, with little change in the look or texture. One serving of grains is 1 ounce, or about one cup of whole grain cereal, one slice

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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.

#### **How to contact PHI**

Executive Director Joan L. Headley, MS director@post-polio.org

4207 Lindell Blvd., #110 Saint Louis, MO 63108-2930 USA Phone: 314-534-0475 Fax: 314-534-5070 info@post-polio.org www.post-polio.org www.polioplace.org PHI sends PHI Membership Memos via email. Be sure to set your spam filter to receive emails from info@post-polio.ora.

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

of bread, ½ cup cooked pasta, rice or cooked cereal. A daily serving ranges from 5 to 6 ounces for those over 50, with an average activity level of 30 minutes per day.

Moderation and variety have been my long-standing guidelines. I avoid fads where one either gorges on certain foods or skips some kinds altogether. The importance of our body needing a large variety of vitamins and minerals has been known for a long time. To obtain them, we need to eat a large variety of foods, and while food must be at the forefront of providing these essential elements, taking vitamin/mineral supplements may help ensure our body gets adequate amounts.

Various beneficial compounds, known as antioxidants, are found naturally in food or man-made supplements and may help to protect against cell damage from harmful molecules called free radicals. Vitamins C, E and betacarotene are among the most studied dietary antioxidants.

There are many other important nutrients that can best be found only in food. Plants provide a wide variety of compounds known as phytochemicals, contributing protective or diseasepreventive properties.

For example, flavonoids are one of the largest groups of these phytochemicals, with only 1,000 of these specific flavonoids researched. One subgroup, anthocyanins, provides the deep red, purple and blue colors in foods such as in berries, radishes, red cabbage, eggplant skins, beets, red-fleshed peaches and apples. In addition to possible antioxidant properties, flavonoids offer such health benefits as aiding visual acuity, improving cardiovascular strength and acting as an anti-inflammatory.

Don't forget the herbs and spices, either! Replacing salt with these alternatives helps reduce excessive sodium intake common in our diets. Adding these extra zips to our meals is not just flavorful, but offers health benefits, too. For example, cayenne, chili powder and paprika have capsaicin,

which has cardiovascular and antiinflammatory benefits. Cinnamon can improve blood sugar levels and may lower cholesterol – try sprinkling it on toast or oatmeal. Ginger provides digestive relief and has anti-flatulence properties.

Add a little more color to your diet by including fruits and vegetables offered in the basic rainbow colors of red, orange, yellow/light green, green and blue/purple. Each fruit and vegetable contains a slightly different array of vitamins, minerals, phytochemicals and important fiber that helps protect cells from damage. For example, apples, beets, cherries, cranberries, pomegranates, red plums, tomatoes, strawberries and watermelon are some red-colored fruits and vegetables.

If you want more information on all the types and daily recommended amounts of food, you may want to check out a U.S. government website. The Department of Health and Human Services and the U.S. Dept. of Agriculture have compiled an updated food pyramid, or plate, which can be found at www.choosemyplate.gov. Specifics are broken down by age and male/female, and it also lists benefits of each type of food. Many of the specific quantities listed in this article were taken from this website.

I think we all ought to relax and occasionally enjoy something that might not be the healthiest choice, but is so enjoyable. Sometimes, it may not be possible to eat all the recommended nutrients, but don't give up trying. Just get back on track when you can. I believe that eating a nutritious diet, drinking enough water and exercising at a level compatible with your physical condition will help keep polio survivors going in the best condition we can be.

#### Reference

1. "Nutrition and Post-Polio," Lauro S. Halstead, MD, Post-Polio Health, Vol. 14, No. 1, Winter 1998.

**Note:** This is the first article about nutrition and weight loss. The next article on the topic will appear in *Post-Polio Health*, Volume 32, Number 3. The issue will also feature the next article in our series of "where to live."





#### POLIO IN AUSTRALIA

Joan L. Headley, Executive Director, Post-Polio Health International

Dancing in my Dreams: Confronting the Spectre of Polio was written by Kerry Highley, who received her PhD in the History of Medicine from the Australian National University for her thesis on the polio epidemics in Australia.

Released in November 2015, the book documents the polio story of Australia, tracing the disease throughout the country noting that the first official epidemic was in 1895.

The bulk of the book details the lives and work of two Australian women who held opposing views on the treatment of acute poliomyelitis. The well-known Sister Elizabeth Kenny championed and practiced the treatment of hot packs and movement early in recovery. Dr Jean Macnamara advocated bed rest and immobilization of affected limbs in a neutral position. As Highley explains, "In pre-Second World War Australia, the public's reverence of the medical profession entrenched Mcnamara's approach until well after most Western countries had abandoned it."

The book contains several pages of excellent historic photographs. Polio survivors are quoted in the Introduction and Chapter 2, "I'm Afraid It's Polio ...," setting the stage for the historic chapters that follow. For example, the search for the method of transmission of the poliovirus and the quest for the vaccine is told in Chapter 8, "A Tale of Brains, Guts and a Virus."

#### Post-Polio in Australia

The Annex features two charts. One was compiled by the author from Reports of the Director General of Health,
Commonwealth of Australia for 19151963. It lists the number of reported cases for those years for each of the eight states and territories, with a total of 30,977.
Australia's incidence rate per 100,000 population in 1951-1953 was 32.30.
During that same time period, Denmark recorded 59.90; Canada, 35.90; Sweden, 28.50; US, 26.00.

Polio Australia was established in 2008 when the existing support groups, some of which had been established in the late 1980s, and State networks agreed to formally incorporate. In 2010, they hired a National Program Manager, Mary-ann Liethof, who works full time today.

Polio Australia has organized six Polio Health and Wellness Retreats for Australia's survivors and have developed a comprehensive website at www.polioaustralia.org.au.

Their years of collaboration and hard work has resulted in an international conference to held in Sydney, September 22-24, 2016.









The theme of the 2016 Australasia-Pacific Post-Polio Conference is "Polio: Life Stage Matters." Because the health issues for ageing polio survivors and young polio survivors differ, the aim of the Conference is to exchange knowledge about the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life.

The Conference will provide sessions for both polio survivors and healthcare providers, emphasizing research results and gold standard evidence-based clinical practice. Since care for polio survivors involves many different disciplines, the conference will target professionals in the fields of rehabilitation medicine, virology, neurology, orthopedic surgery, allied health and students in these areas.

For more information and to register, visit www.cvent.com/events/post-polio-conference/event-summary-c063c19139614fc1967493 1eec705932.aspx or contact Polio Australia Incorporated, PO Box 500, Kew East Victoria 3102, Suite 119C, 89 High Street South, Kew 3101, Australia, +61 3 9016 7678.

Joan L. Headley, Executive Director, Post-Polio Health International

#### What are ICD codes?

The International Classification of Diseases (ICD) is a clinical cataloging system of alphanumeric designations given to every diagnosis, description of symptoms and cause of death attributed to human beings.

It means that each diagnosis a human being may be given has a code or a numbered designation that goes with it. The codes are intended as a means for every medical professional in the United States and many other parts of the world to understand the diagnoses the same. They are also used by others in the healthcare industry, such as insurance companies and manufacturers of medical equipment.

The United States implemented the ICD-10 on October 1, 2015, which was late compared to some countries which immediately switched in 1998. Most countries that use the tenth edition (ICD-10) now.

# What are the codes of significance to the health professionals of people who have a past history of acute poliomyelitis in the new ICD-10?

According to the official ICD documents on the World Health Organization and the Centers for Medicare and Medicaid Services sites, the following codes are the most relevant. The descriptions inserted below are from www.ICD10Data.com.

#### G14 - Postpolio syndrome

[Incl: postpolio myelitic syndrome; Excl: sequelae of poliomyelitis (B91)]

"Clinical Information about post-polio syndrome: A syndrome characterized by new neuromuscular symptoms that occur at least 15 years after clinical stability has been attained in patients with a prior history of symptomatic poliomyelitis. Clinical features include new muscular weakness and atrophy of the limbs, bulbar innervated musculature, and

muscles of respiration, combined with excessive fatigue, joint pain, and reduced stamina. The process is marked by slow progression and periods of stabilization. (from *Ann NY Acad Sci* 1995 May 25;753:68-80)."

#### **B91 – Sequelae of poliomyelitis**

[Excl: Postpolio Syndrome (G-14)]

"B91-B94 is a category provided for sequelae of conditions that are no longer in an active phase. B91 is a condition resulting from (sequela) the infectious disease. The description lists the following Approximate Synonyms.

- Late effect of poliomyelitis
- Late effects of poliomyelitis
- Neurogenic bladder as late effect of poliomyelitis
- Neurogenic bladder due to late effects of acute polio
- Neurogenic bladder, late effect of acute poliomyelitis
- Osteopathy after poliomyelitis
- Osteopathy from poliomyelitis
- Paresis as late effect of poliomyelitis
- Paresis, late effects of poliomyelitis
- Poliomyelitis, late effect."

M41.4 – neuromuscular scoliosis is the non-specific code, which is applicable to scoliosis secondary to cerebral palsy, Friedreich's ataxia, poliomyelitis and other neuromuscular disorders. There are eight specific codes under M41.4.

### What was the old code? Why wasn't it satisfactory?

ICD-138 was the code for the late effects of polio, i.e., any polio-related problem whether a new one or a long-existing but stable problem. In the versions of the ICD-9 manual, first established in 1979, ICD-138 was the only code available.

Many survivors in the United States were advised not to have their physicians use

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it in their records, because the survivor would then have a "pre-existing disease," which could make them ineligible for health coverage. Instead, physicians used codes that described the specific issue, e.g., low back pain, pain in right ankle, dysphagia, etc.

There was a need to define or describe the condition, i.e., establish criteria for research purposes. Differential diagnosis was discussed by Frederick M. Maynard, MD; David O. Wiechers, MD; Marinos Dalakas, MD; Richard Owen, MD; Mary B. Codd, MB, BCh, and others at the Research Symposium of the Late Effects of Poliomyelitis, May 25-27, 1984 in Warm Springs, Georgia.\*

In 1984, Dr. Dalakas and others published "Late postpoliomyelitis muscular atrophy: clinical, virologic, and immunologic studies" in *Rev Infect Dis.* 1984 May-Jun; 6 Suppl 2:S562-7. They described "late postpoliomyelitis muscular atrophy (late PPMA) characterized by focal progressive muscle weakness, wasting, fasciculations, and muscle pains affecting previously spared muscles or muscles previously affected but recovered."

Dr. Maynard also wrote about the importance of differential diagnosis in the July 1985
Orthopedics, and spoke about the problem of semantics in a presentation at the GINI (now PHI) Fifth International Polio & Independent Living Conference (1989).

He proposed definitions for the late effects of polio or post-polio sequelae as alternative synonyms, and also proposed definitions for post-polio syndrome and post-polio muscular atrophy (*Polio Network News*, Winter 1990, Volume 6, Number 1). Some presenters felt that the latter condition could be called post-polio progressive muscular atrophy or post-polio progressive muscular weakness.

Lauro S. Halstead, MD, presented criteria for a diagnosis of post-polio syndrome (PPS) in his article "Assessment and differential diagnosis for post-polio syndrome," published in *Orthopedics*. 1991 Nov; 14 (11):1209-17.

In 1991, once again, *Orthopedics* featured post-polio sequelae in the November and December 1991 issues. The series was introduced by Richard L. Bruno, PhD, who wrote in the November Guest Editorial that the issue would use the "more general term referring to late-onset symptoms," that is post-polio sequelae, which he chose to abbreviate as PPS. It is important not to confuse the two similar abbreviations that are used for two distinct conditions, ie, post-polio syndrome and post-polio sequelae.

As more research was done in the '90s, a picture of what was happening physically to individuals with previous polio developed as a "distinct clinical entity." The term post-polio syndrome and the development of specific criteria for it gained favor.

"As more research was done in the '90s, a picture of what was happening physically to individuals with previous polio developed as a 'distinct clinical entity.' The term post-polio syndrome and the development of specific criteria for it gained favor."

Individuals in the US were not having problems with the codes, but advocates in other countries who were educating about post-polio syndrome were having difficulty in getting recognition from the medical community for services without an official ICD code for "post-polio syndrome." There was a need to indicate an active neuromuscular disease with new disabling consequences, not just a past history of a disabling condition.

The criteria for post-polio syndrome were solidified at the 2000 March of Dimes Conference in Warm Springs, Georgia, and in 2006, when the European Federation of Neurological Societies (EFNS) published nearly identical criteria.

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.
- Symptoms persist for at least a year.
- Exclusion of other neurologic, medical, and orthopedic problems as causes of the symptoms.

Ultimately, the work of a team from Brazil, led by polio survivor Luiz Baggio Neto and Dr. Acary S.B. Oliveira, resulted in the G14 and B91 codes added to the ICD-10 in 2010.

## Do polio survivors in the US need to talk with their physicians about this?

No, it should not be a concern. Because of the Affordable Healthcare Act of 2010, people, polio survivors included, in the US can obtain health insurance even if they have a pre-existing condition.

Dr. Marny Eulberg, explains that if a provider uses any kind of electronic medical record for the visit notes then the "The medical community has settled on the term "post-polio syndrome" with the requirement of new weakness. The definition now used for post-polio syndrome is very similar to the 1980s definition of post-polio muscular atrophy."

computer will choose an ICD-10 code that is based on key words in the note, even if the provider did not choose a code.

Dr. Frederick Maynard comments, "The medical community has settled on the term 'post-polio syndrome' with the requirement of new weakness. The definition now used for post-polio syndrome is very similar to the 1980s definition of post-polio muscular atrophy."

- \*Lauro S. Halstead, MD (polio survivor) and David O. Wiechers, MD coordinated two scientific/research meetings about the new problems of polio survivors in 1984 and 1986. The audiotapes from those meetings are on Polio Place. Special thanks to Michael Shadix, from the Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia, for donating the files and to Brian Tiburzi, PHI, for posting all of them on Polio Place. See the links below for a list of the speakers, their topics and the audio.
- Audio from First Research Symposium on the Late Effects of Poliomyelitis (1984) www.polioplace.org/resources/first-researchsymposium-late-effects-poliomyelitis-audio
- Audio from Second Research Symposium on the Late Effects of Poliomyelitis (1986) www.polioplace.org/resources/secondresearch-symposium-late-effectspoliomyelitis-audio

## PROMOTING POSITIVE SOLUTIONS

QUESTION: As a young polio survivor, I think the hardest thing is having a disease/diagnosis that no longer has a current social context. It is like being caught in the cultural time warp. I have a condition that is relatively cured and eradicated from most parts of the world. While other diseases get a lot of media attention and have cultural support, this is not the case with polio. I find it very hard to get support, generate empathy from others and find others who have gone through similar experiences. Have others expressed this? Do you have suggestions for me?

#### Response from Rhoda Olkin, PhD:

Yes, it is true that we are a diminishing breed. But I don't agree that we lack cultural support. It depends on how we think of ourselves. If my identity is as a person with polio, then the media images are rare and public discussion of polio even rarer. But if my identity is as a person with a mobility limitation then I have many counterparts – anyone else using crutches, or a scooter, or a wheelchair. And if I think of myself as a person with a disability I have a whole community. Polio aftereffects and post-polio syndrome have symptoms of pain, fatigue and weakness. Well, that is the disability triad. People with varying conditions experience those same symptoms. I have lots in common with people with spinal cord injury, or multiple sclerosis, or even arthritis (one of the most common causes of disability).

Medical and rehabilitation literature tends to discuss us by our diagnoses. Textbooks typically have chapters on each diagnosis or cluster of diagnoses (such as autoimmune disorders). This is the medical model of disability. It defines groups by medical diagnosis or cause of disability. But in the social model of disability we are defined by the experiences we have in a disabling world, and group ourselves as a community of persons with varying conditions who have common interests (e.g., greater accessibility, pain management, more understanding of

disability by non-disabled people, better enforcement of disability-related laws).

Getting support means asking for support. Frankly, I suck at this. I wonder if vou do, too? It can be difficult to ask for help, especially since so many people with polio were raised with the idea of independence and overcoming. But of course as we age with polio things do get harder to manage, and often we need some support. Support is not only one kind of thing. There is material support (e.g., finances, building a ramp), instrumental support (e.g., cleaning the house, carrying in the groceries) and emotional support (a kind word or empathic understanding). The latter is often the hardest to ask for. But it is important to have sufficient people in our lives that provide each of these kinds of support. Take stock, and see where the deficiencies are. Then make a plan to address them.

Regarding empathy, the hard truth is that it is difficult for anyone without a disability to really understand what it is like on a daily basis, unless it is a close relationship. Even then, unless you say things like "I am in pain now" or "I can't take another step" no one will know your experience. So brave the world by saying who you are and what you feel, and keep around you only those who respond how you would like. Some of these others will be persons with disabilities, not necessarily only those with polio.



**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.

#### Response from Stephanie T. Machell, PsyD:

I've heard this from polio survivors of all ages. All of you have had the experience of feeling like survivors of a forgotten war. It is common for others to express shock and surprise over the number of people living with PPS, and to be even more surprised when they find out that cases have occurred in the recent past.

As a young polio survivor you have likely encountered this. Some might even argue that you couldn't possibly have had polio. Some might ask intrusive questions about how you contracted an "eradicated" disease. Some may not even know what polio is and put you in the position of being their "educator." All people with disabilities struggle with how much or how little to explain about their conditions. I advise my clients to develop elevator pitches and sound bites and to consider how (and if) you might answer the "FAQs" that follow. I also recommend planning how you will deal with ignorant and/or intrusive questions and comments about your disability.

As a young polio survivor you face challenges related to your age and stage in life as well as your disability (or current lack thereof). For example, previous generations of polio survivors, not knowing about PPS, could feel more comfortable with pushing themselves and being active in an age-appropriate way because the consequences weren't known. While you benefit from improved accessibility and reduction in (overt) discrimination, society's expectations and "ableism" make it hard to be a young adult with any disability, let alone one lacking a social context.

Even those with disabilities that are well known experience a surprising lack of empathy and support. Fear of rejection due to societal attitudes and your own internalized "ableism" make it feel risky to be vulnerable. Difficult as it is, communicating with others, especially those closest to you, about your experiences and needs is essential to gaining their empathy and support.

Support groups and conferences (like those PHI holds) can provide you with the opportunity to be with others who share the polio experience. It is likely that you will feel a bond with other survivors regardless of age. But because of the particular issues you face in common it would be even better if you and other young polio survivors could connect, either in person or through social media. You could start a Facebook group for polio survivors under a particular age.

You could approach organizations sponsoring major conferences and request programming aimed at your needs, as younger survivors may be more likely to attend if they see at least one session and/or a social hour specifically for them. If you find that there are enough young survivors in your area, you could develop your own support groups or join existing ones. The latter are often in need of new members who can carry on their mission.

If you are under 45 and are interested in communicating with others, contact Post-Polio Health International at info@post-polio.org.

**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.





Frederick M. Maynard, MD

## Ask Dr. Maynard

**Question:** As a young kid I contracted polio in my right leg. Apparently it was a mild case because I had no noticeable effects until my late 40s or 50s. At that time, I experienced right leg pain if I had not exercised for several days or about a week. If I exercised moderately then I had no pain. If I exercised very intensely then my right leg would end up much more sore than the left one (and recovery took longer).

I discovered this on my own, never even thinking that the polio might have something to do with it. But I came across an article about post-polio syndrome and a light came on. At that time, I learned about your organization and have followed your publications ever since.

For the past decade I've been a competitive cyclist, racing from April through August and training intensely year-round. I mostly compete in road racing, but have also participated in extreme endurance mountain bike races like the infamous Leadville 100 in Colorado.

I had my legs tested for cycling power and discovered that my right leg generates substantially less wattage (a measure of cycling power) than my left leg, at all levels of effort. Needless to say, training is problematic. I often have to reduce my training days per week because my right leg has had enough, yet my left leg could do more. If I do more, then my right leg suffers.

The best scenario for pain prevention seems to be frequent easy-to-moderate exercise. But that's not too conducive to high-performance racing, in which I've done pretty well in my age-group categories, including a New York State Championship.

The real issue is, what am I doing to my right leg with all this intense exercise? I lift heavy weights in the gym to strengthen my legs for ski racing in the winter. I realize I'm very lucky compared to many people with post-polio syndrome, and in fact I'm not even 100% sure that's what I have.

I am 64, and as the years go by the condition of my right leg gradually gets worse, and I fear for my later years. So the whole subject of exercise and pain is something I'd like to learn more about. I wonder if I should just stick to easy or moderate exercise, but that would mean giving up competitive cycling, which I'm loath to do.

**Answer:** Thank you for sharing your story of polio with later life development of leg pain and its relationship to exercise. You have basically been doing well and making good decisions.

I would like to offer you my thoughts about your current concerns about what to do now with exercising in order to best preserve your future function without pain or deteriorating strength in the involved right leg muscles. I think you should continue to focus on "easy or moderate" exercise for the right leg to maintain its strength, prevent pain and not increase the realistic risk that it will further weaken as you continue to age.

Relative to "giving up competitive cycling," I do not like to encourage people to stop doing things they enjoy and that are healthy for them to do!

However, being focused on competitiveness to the point of risking damage to yourself is a different matter. I would ask you whether you could still enjoy participating in competitive cycling without being driven to win or even being driven to push yourself to your absolute best possible performance.

If your answer is "no," then perhaps you should give it up and participate in a road biking club for "fun and companionship," or try teaching/coaching biking skills.

If the answer is "yes," then just enjoy the race experience and exercise at the level you can comfortably do it and without the right leg later "suffering."

**Response from cyclist:** From everything I've read and studied, I was afraid that is what the answer was going to be. I have not yet decided what path to choose. Intellectually, I know the path that you recommend is what I should do. Emotionally, it would be difficult to give up competitive bike racing.

Sooner or later, at some point I will likely cut back to much more moderate exercise intensity and just experience the joy of riding for fun, which is still pretty nice.

It may also be that issues with my right leg may force me to cut back. Naturally declining performance as I get older may just make it too difficult to compete with all the youngsters out there. But, I do give them a good run for their money.

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

#### Letter to editor:

"I was 100 years old November 11, 2015 – can no longer read, write or paint – macular degeneration – I can't subscribe. This old lady entered a good nursing home last summer. Can't read this after writing it."

-Celia Bell Yoder

## In Appreciation

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