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## PHI Remembers Gini Laurie on the 30th Anniversary of Her Death



Gini Laurie

This June marks the 30th anniversary of the death of PHI's founder, Virginia "Gini" Grace Wilson Laurie. Sometimes referred to as the "grandmother of the independent living movement," Gini worked tirelessly for more than three decades as she campaigned against the institutionalization of people with disabilities, and for the rehabilitation and personal

assistance services that would make an empowered life possible for them in their communities. Gini worked to develop international networks of polio survivors and other people with physical disabilities, healthcare professionals in the field of rehabilitation, policymakers and disability rights activists. To mark this occasion, PHI asked those associated with the organization during her time and others that knew her to recount a memory or write some remarks on her considerable legacy.

### **Mickie McGraw**

I was 11 years old and a patient on the Toomey Pavilion polio ward at Cleveland's City Hospital when I met Gini Laurie in 1953. I will always remember that first meeting because, as I would later come to know, Gini was a unique, charismatic individual who made a lasting impression on those she met: I was lying in my bed waiting for afternoon therapy, when I heard a strange noise in the hallway outside of my door—I couldn't believe it, but I was sure I heard the crowing of a rooster and it was getting louder as it came closer to my room. Suddenly a tall, stately woman in a bright yellow volunteer uniform appeared in my doorway, where she finished off a rooster crow that would have wakened anyone within hearing!

The "rooster" turned out to be Gini Laurie. She introduced herself and told me about all the fun things we could do together, interspersing her introduction with a series of other animal calls, including a wonderful, barking, clapping seal. I didn't know it then, but my life changed from that day forward. Gini opened up a world of possibilities for me at a time when polio seemed to have temporarily set limits on my future. She helped me "see" a new self and to experience alternative ways of "being" that new self. Step by step, day by day, year by year, she mentored me and nurtured my gifts at the same time that she showed me ways to move through any challenges.

Gini was dedicated to her "Toomey" friends—she came in costumes, brought us colorful toys and games, cooked us pancake breakfasts, and seemed to know how to lift each of us up on those days we were down. And she was in it for the long haul—when we were discharged, she began the *Toomey Gazette* newsletter so we could keep in touch and support each other. Over the years in a variety of forms, the *Gazette* expanded to include all disabilities and thousands of related topics and is now the highly-respected Post-Polio Health International organization.

Though she had no guidebook or special training in rehabilitation or disability issues, Gini listened, learned and led. She opened her home and her heart and touched the lives of one person at a time. And through her publications, conferences and international outreach, she also significantly improved the lives of tens of thousands more through her positive impact on the disability rights movement. I am just one of her many "kids" as she called us—because of her, we are living productive lives around the world. I can still hear that crowing rooster and know she is urging us to carry on her good work!

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*Mickie McGraw is an Artist/Therapist, Co-Founder of Art Therapy Studio in Cleveland, Ohio and a founding member of early Rehabilitation Gazette Board.*

### **Joyce Tepley**

It was July of 1952. Cleveland, Ohio. The last polio epidemic was raging its way across the United States. I was nine years old and my brother was eight months old. We both got it, paralyzing his right arm and my back and legs. In the initial stage, we were treated at City Hospital. Polio wards were set up and hundreds of us were slowly recovering some of our muscles. After a month, my brother was sent home with care instructions. I could breathe on my own and regained enough strength to be transferred to a children's rehabilitation hospital for nine months of intense treatment learning to walk again.

I did not know it at the time, but while at City Hospital, I was put on a list by Gini Laurie to receive

a newsletter containing stories of children who got polio just like me. When I finally got back home, that newsletter, compiled and written by a woman who lived near me, became a major source of support. Like so many of us who got polio, we tried hard to live a normal life but felt isolated and not quite good enough. That newsletter helped me feel less alone because of our common experience.

I never met Mrs. Laurie until the late 1980s when she organized a polio conference addressing the new health problems people with polio were having. It was an honor to meet her and tell her how much a little girl appreciated her generous kindness that made a huge difference in my life.

*Joyce Tepley, LMSW, is retired from a forty-year career in social work and is the author of Thriving Through It – How They Do It.*

### **Allen Goldberg, MD**

As a young physician, I was given the assignment by Dr. C. Everett Koop, MD to find solutions for children who were “living” in an acute ICU on long-term mechanical ventilation with no place to go. I was led to a number of mentors who lovingly encouraged me (and my wife Evi) and guided our path. They included persons with disability from the polio era who were also dependent on long-term respiratory support (such as Margaret Pfrommer in Chicago). They were all inspired by Gini (and Joe) Laurie who shared their insights and knowledge and expanded our network of experienced leaders and mentors.

Gini was a loving person of the highest integrity with enormous ability to inspire all who knew her and were given the privilege of working with her. Our first partnering was the historic 1981 International Year for Disabled Persons Conference, “What Ever

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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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and new addresses.

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

Happened to the Polio Patient?”, held with the sponsorship of The Rehabilitation Gazette, National Foundation-March of Dimes, The Rehabilitation Institute of Chicago, and Care for Life. This was followed by many other events and initiatives to provide consumer-directed information that has fostered the partnership between very special doctors (she called them “real doctors”) and disabled persons and their families.

My last meeting with her was with Dr. Augusta Alba. We talked about the future of our efforts. I remember most her energy and commitment and her encouragement to continue and expand our efforts. This was the beginning of many initiatives still going on today by many dedicated people around the world. I have been committed to keep the promise and am grateful for the partnership of Post-Polio Health International, including International Ventilator Users Network and the CHEST Foundation, which is focused on education of health professionals to promote the understanding of the principles we all learned from Gini.

*Allen Goldberg, MD, Master FCCP, Pediatric Home Health, Loyola University Medical Center (retired), is an honorary board member of PHI.*

### **Audrey King, MA**

It was 1980 and many Ontario, Canada post-polios were experiencing increasing health problems. We didn’t know where to turn. Since the advent of the polio vaccine it seemed like all medical interest and professional expertise in helping people with polio paralysis had disappeared. My search for answers led me to the Rehabilitation Gazette which featured a news item about an upcoming conference—“Whatever Happened to the Polio Patient?”

I telephoned the number and found myself talking to Gini Laurie. I wanted to find out what this conference was all about and whether or not it would be helpful. I discovered that post-polio people all over the world were having the same difficulties and this is why such a conference was being convened. About a month later I received the conference program brochure. Imagine my shock and horror in discovering that my name was on the program, as I was supposedly going to be talking about the situation in Ontario, Canada.

My first reaction was one of shock. Then I was angry. I had not been asked to do this and even if I had I would not have necessarily agreed. My third reaction was, “I will darn well show them.”

I began researching the topic. I phoned the Ministry of Health. I talked to the March of Dimes, who had

been very involved in the early epidemic days but, since the vaccine, was no longer involved in this area. I searched out and interviewed retired nurses. And, I tried to survey as many post-polio individuals as I could find in the Toronto area to get a better picture of the difficulties people were having.

I did attend that conference, and I did speak. I came back filled with important knowledge and information. I approached the Ontario March of Dimes and challenged them to pick up the ball and start supporting polio people—because they were the only disability group that had no organization to assist them. And they did, making me the first chair and establishing post-polio support groups across the province. We held several conferences, and Gini Laurie came up, stayed at my place, and addressed the audience as a keynote speaker.

It was only later that I began to realize how Gini worked and why she was so effective. She challenged people. She threw out the gauntlet which many of us picked up, going back to our various corners of the world and establishing much-needed support groups.

She was the glue that held us polio people around the world together.

*Audrey King, MA, is a polio survivor and retired psychologist from Toronto’s Holland Bloorview Children’s Rehabilitation Hospital. She has authored several books in addition to writing and lecturing internationally on a broad range of disability issues.*

### **Martin B. Wice, MD**

I met Gini Laurie in 1987 shortly after I moved back to St. Louis. Gini was a force with which to be reckoned. Her prior correspondence with polio survivors led to the realization that there were late effects from prior poliomyelitis. She was instrumental in helping me develop my post-polio clinic. From her kitchen table, her telephone, her manual typewriter, and with the mail service, she produced newsletters, organized international post-polio conferences, and most importantly, advocated for those who had polio and other physical disabilities along with home ventilator users. Her concern for the physically disabled was infectious. She inspired countless polio, home ventilator survivors and their families to have as fulfilling a life as possible. She helped educate health care professionals and community leaders to better meet the needs of the physically disabled. When she required more resources for her “GINI” organization, she would put out calls to her loyal supporters and

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“brown bags” with financial aid would appear. Her legacy continues not only with Post-Polio Health International but also with the Independent Living Movement. Her spirit lives on supporting the new generation of all physically disabled individuals, even those who never had the privilege to have known her.

*Dr. Wice, past President of PHI, currently serves on its board of directors.*

### Gayla and Arthur Hoffman

Gini Laurie changed my life. My husband Arthur and I bought the house next door to Gini and Joe Laurie in the Central West End of St. Louis in 1976. Thirty years or so younger than they, we were told they were a nice older couple. Then we met them. We discovered the irresistible force that was Gini and her charming partner Joe, who was devoted to her.

Could we kids help, Gini asked. Of course. There was no other answer.

We soon heard about her family’s personal history with polio, her volunteer activities in Ohio with polio survivors in iron lungs and her founding of the *Toomey J Gazette*. By 1976, this had expanded into the *Rehabilitation Gazette*, a publication that encompassed people with all disabilities. But her first love was polio survivors and their stories of accomplishment. Her philosophy was that if you had a brain, that was all you needed.



In the process of helping, we learned so much. And we met wonderful people. Yes, most had disabilities, but as Gini said, they had their minds and more, and that is what mattered.

It wasn’t long before we were invited to dinner, the first of many gatherings, that over the years included people with all manner of disability: polio survivors, of course, but also people with spinal cord injuries, blind people, deaf people, a McArthur Genius award Fellow, people who started the first Independent Living Centers in America; medical professionals including the Surgeon General of the United States (the one who got health warning labels on cigarette packs) and many more.

Long before HGTV popularized the “open concept” style of living, the Lauries were practicing it. They had combined their large living and dining rooms and added a galley kitchen at the end. Their table expanded to accommodate however many folks were there. Dinner was usually a soup (often vegetable/lentil), followed by a salad and some kind of sweet for dessert, and always free-flowing wine. It was not unusual to have a half a dozen, or more, people using wheelchairs in attendance.

We were enriched by all of these experiences. For example:

- The scholar from Germany who was blind. We put him up in our house (second floor) and were concerned about it. After his first visit with his dog, he knew our house as well as we did.
- The Japanese gentleman who came to America to meet Gini. He also stayed with us. As he left, he walked about 10 paces, turned and bowed. We returned the gesture. He walked a bit further, turned and bowed. Again, we returned the gesture. By the time he got out of sight, we were exhausted.
- The deaf group for whom Gini gave a cocktail party. We arrived to find the guests engaged in animated, but silent, conversations—using sign language. Gini beamed as she surveyed the room.

We have never forgotten the things we learned from her, or the fascinating, amazing, interesting people to whom she introduced us. Gini has had a profound influence on our lives and remains, every day, an inspiration.

*Gayla Hoffman is a former editor of Post-Polio Health and Ventilator-Assisted Living.*

## Joan Headley

I started working with Gini Laurie on August 17, 1987. She was diagnosed with esophageal cancer at Thanksgiving 1988 and died in June of 1989. She was seriously ill seven of the 22 months that I knew her.

Her notable reputation in the post-polio and independent living communities was well established when we met.

We were invited to dinner one evening where she happily engaged everyone in conversation. She was quiet on the way home, and I let her be so. When I dropped her off, I said, "You asked about all of them, but no one asked about you." "Sweetie, how nice of you to notice," she replied. Our relationship was closer after that exchange.

When she was diagnosed with cancer, we discussed how we would handle it. She decided that if people asked how she was, she would tell them. Many, who called wanting something of her, never asked.

I had driven her to the dinner because her van had been ransacked one night. She took one look, cried and sold it. Her tears were a result of seeing the desecration of the vehicle that held so many pleasant memories of traveling with her husband, Joe.

The second time she teared up was during a meal she had invited me to eat with her. At dinner she told me it was the anniversary of Joe's death in 1985 and she did not want to be alone.

The third and final time I witnessed her tears was at the kitchen table while we were discussing an article about hypoventilation in polio survivors. She wanted it to be on the cover and issued as a "warning."

She shared the memory of her beloved brother Bobby, a survivor of polio, who she watched die in his early 20s struggling to breathe.

During her final months of her life, we planned and executed the fourth GINI conference. Opinion was divided as to whether she should attend because her weakness required the use of a gurney.

She called me to her bedside and asked permission to go to the hotel. I thought, "You are asking me!" Without hesitation I said, "These are your friends; this is your organization. If you want to go, by all means go." She did.

Many people with disabilities remember her for encouraging them to live.

I remember her for teaching me how to die. Her choices of how to face serious illness and death

confirmed that our final days can be lived peacefully and with dignity.

*Joan Headley, MA, served as Executive Director of PHI until her retirement in 2017.*



## Fred Maynard, MD

Everyone who knew Gini Laurie experienced her passionate energy and enthusiasm for improving the lives of people with physical limitations after paralytic polio. Sometimes called the "Grandmother of the Independent Living Movement," she strove to create a world in which people with physical disability were not impeded from reaching any goal they chose through personal and societal adaptation and/or accommodation. She admired achievements, little and big, and also knew that life needed to be fun. I can never forget the playful abandon of ballroom dancing with people in motorized wheelchairs or using crutches and braces as everyone spun together after banquet dinners on the last day of those early GINI Conferences. She also had a deeply spiritual Christian faith that led to conferences including panel discussions on the ethical issues around death and dying for people with severe disabilities, as well as Sunday morning church services.

Who can forget seeing her attend the 5th International Conference on Polio and Independent Living while in a reclining chair on oxygen as she was dying of terminal cancer? I will always remember the pride I felt when she informally granted me her "Honorary RD" (Real Doctor) degree. She surrounded herself with authentic people and always related to the most severely impaired polio survivors as 'real people' who deserved equal opportunity for having the full range of human emotions and experiences. May her spirit live on to inspire others with special challenges!

*Dr. Maynard, past President of PHI, currently serves on its board of directors. ■*



# Mona Randolph

Mark Randolph, Kansas City, Missouri

**M**ona Jean Randolph passed away February 18, 2019 from long delayed effects of polio. Polio had left Mona with minimal use of her right arm and hand, none of her left, little leg strength, and very little vital capacity. She was in a wheelchair during the day and an iron lung at night. So, summing up 82 years of a rich, full life in 50 words:

1. Mona survived polio.
2. She was an energetic and effective advocate for the disabled (see a curb cut, think of Mona).
3. She married a husband, to whom she gave great joy, and who loved her dearly in return.
4. She lived independently for 46 years, while continually ministering to others.

How did she do that?

## Onset, Recovery and a New Normal

In 1956, Mona was 20 years old and on the cusp of womanhood, but on one September afternoon that year, she had a headache. When she got home, the headache was worse. She went right to her room. Light hurt her eyes, so her mother drew the blinds. Three days later, returning from the bathroom, she had trouble walking. That afternoon, she had trouble breathing. She was rushed to St Luke's hospital. It was polio. They put her in an iron lung. They saved her life.

Six months later, in the Spring of 1957, Mona was sufficiently recovered to travel to Warm Springs, Georgia. She described her state of mind as "numbed bewilderment." She thought if she followed doctor's orders, worked hard, and with persistence and determination, she would be able to resume her life.

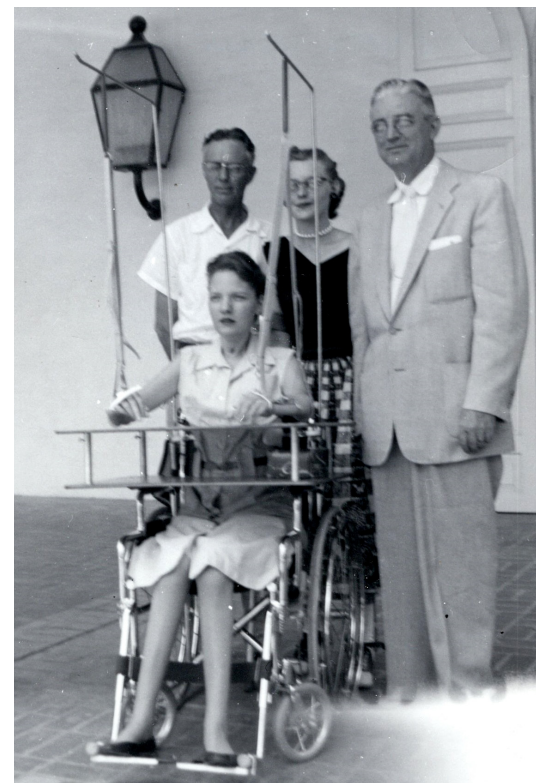
Warm Springs had tremendous experience with those stricken with polio, and all they knew was invested in Mona. She worked hard, and regained much, but no one at Warm Springs promised a full recovery. After seven months at Warm Springs, Mona had grown homesick, so she persuaded the review board of her progress, reminding them that on arrival she could only scratch her nose. They were impressed. They released her to her new life.

For a decade and a half, Mona lived with her family and they found a "a new normal." Fortunately, her family was stable, well-rooted in church and community, so they had abundant support. Her mother was a dynamic person with many friends. Her father was a devoted provider and faithful caretaker. Her brother Dick was best friend and confidante, someone she could depend on for understanding and good humor.

Mona attended friends' showers, weddings, baptisms and funerals. She worked at small part-time jobs: TV monitoring, a greeting card and invitation business, entering advertising contests (and winning a few). She also read and studied with limitless curiosity. She enjoyed going where her mind took her—no assignments, no tests, no grades, just the satisfaction of unbounded, independent, unstructured learning. Her most active life was imagining her own apartment and transportation, a meaningful career and marriage. She thought these nothing but daydreams, but they whetted an appetite for a larger purpose driven life.

## A Search for Faith

A dear friend entered her life, and with his help, Mona confronted the truth of her reality. This emotional stimulation, and subsequent emotional confusion when he left, catapulted Mona into a search for meaning and purpose. Mona began wrestling with her faith, what to believe about God. Her background had prepared her for this search. She had an active Church life growing up. In college, she had courses on comparative religions. Her broad reading had exposed her to wider philosophies and thinking.



Mona at Warm Springs, 1956.

This search culminated in a crisis. A pulmonary infection caused her to choke, and in that moment, she turned to God, “If you are real, you had better do something or I am going to die.” She took a tiny sip of air, discovered she was clear, and gave herself over to God completely.

## Advocacy

Mona had shunned others who were disabled, but that changed. In the mid-1960s, Mona found a funky little rehab newsletter called the *Toomey J. Gazette* filled with stories of people like her doing improbable things like running businesses from an iron lung. Mona then met other disabled people—and on fire

for the Lord—began to prod them. “We can do better than drink beer, chat and play games,” she insisted.

They contacted the National Paraplegic Foundation and became a chapter. Within five years, they achieved two goals: compiling and distributing a guide on accessibility to architects and obtaining a city ordinance requiring curb cuts. The chapter evolved into The Whole Person, a dynamic organization which still exists as an advocate for all individuals with disabilities in Kansas City. Subsequently,

Mona served on the board of the Coalition for Independence which coordinated direct assistance to the disabled, and she volunteered at Abounding Love, a church-sponsored ministry to the developmentally disabled.

## Her Life’s Work

In 1972, Mona would lose the only provider she had ever known—her father—to cancer. The family home would be sold. Mona and her mother would move into a co-op, with consequent distancing from the church and community of which they had always been a part. Soon thereafter, her mother received a marriage proposal and wrestled with how to care for a daughter she thought forever dependent.



Mona in her iron lung, 1980s

Mona perceived an opportunity. Paraphrasing her thoughts, “After much consultation with God, and counting the personal cost as realistically as possible, I determined to stay in Kansas City and establish a household of believers as an experiment designed both to meet resident’s needs and to demonstrate the desirability of Christian precepts for healthful, peaceful living.” She would live independently.

This was not met with universal family acclaim.

Mona’s ability to care for herself was limited to self-feeding and brushing her teeth. Tasks like writing, typing or telephoning required help. It took a month of negotiation with her mother, with supposedly good friends advising, “She should be put in a nursing home,” “She can’t possibly do it,” and “It will never work.” In the end, Mona’s mother would get married, and Mona would buy a house at 55th and Oak in Kansas City, two blocks from a vibrant church named Agape.

That first year had times when Mona did not know where her next bedpan would come from (one morning, a stranger appeared out of a snow storm to help), but God always provided, such that “It was sometimes hard on my nerves, but that year was good for my faith.”

## God’s Promise

And then, she got married! Early on, the Lord had told Mona she would have a husband. She did not understand how that could happen, but was obedient, and began practical reading and study to prepare herself if it came to pass, which it did.

God gave Mona a life partner, a soul mate, someone she could cherish, and nurture, and comfort, and uplift, and love with all her heart. Someone who would love her with all his heart, and cherish, and nurture, and comfort, and uplift. Someone to care for her all the days of her life.

In Mona’s words, “All that the locusts had eaten, had been restored. God is faithful. God keeps his promises.” ■



At home in Kansas City, 1970s.



**QUESTION:** *I know it's really important to have end-of-life discussions sooner rather than later, but I'm a procrastinator by nature and that's not exactly something I want to have to think about. Where do I even start? Do you have any ideas on how I should approach this?*

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

As no lesser authority than Hank Williams observed, we'll never get out of this world alive. Most of us would prefer to live longer and die more gently than he did. Had he been given a choice it's likely he would have, too.

We don't get a choice. Few of us know when or how we will die. It would make sense for everyone to have end-of-life plans in place at an early age, especially if we have dependents and/or beliefs and wishes we want respected.

Yet most people don't. We procrastinate and avoid. Our families collude with us because they don't want to think about our death, let alone their own. Our culture encourages us to speak in euphemisms, as if the "d-word" is somehow obscene.

Whether we say the word or not, talking about death makes just about everyone uncomfortable. Even for those who have unquestioning faith about what does (or doesn't) happen, death is the ultimate unknown. We may be afraid it will involve suffering, be frightened of the loss of control it represents, or of no longer existing. And thinking about death brings up other deaths, those losses we've failed to fully grieve.

A surprising number of us procrastinate out of superstition. I'm not proud to admit that this is part of my own procrastination. It's irrational, yet some part of me fears that getting things settled will hasten my own death, in spite of knowing people who died never having completed

a will or advance directives, and many more who lived for years after putting them in place.

I share this to let you know that while our reasons may not be the same, I understand your resistance. How are you (and by "you," I really mean "we") going to get past this? By dealing with what is in your way. Identifying the reasons you're procrastinating may mean acknowledging that thinking about your eventual demise makes you afraid or sad or otherwise uncomfortable. Or recognizing that it's "just" one more thing you procrastinate over.

Procrastination doesn't really make you feel better. It keeps whatever you're procrastinating over present in your thoughts. Set a date and use Dr. Olkin's excellent checklist to get it done. If you're not sure what your wishes are, take the time to clarify them. If you're afraid of having an uncomfortable discussion with those who will carry them out, remember that doing so models the importance of having such conversations.

Your significant others have likely thought about what you will want and may be relieved that you brought it up first. And because you've taken the time to decide what you want, all you will need to do is make sure the person(s) you name are comfortable carrying out your wishes *as you want them carried out*.

I wish you success in completing this necessary task. And now that I've written this column, I'm out of excuses for not calling the attorney I was going to call last year!



**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.



### Response from Rhoda Olkin, PhD:

This is one of those tasks that most people dread. The problem is that the task requires thinking about our own demise, and of course we'd rather not do that!

The good news is that when you finally do tackle the issues the decisions you need to make can be completed in about twenty minutes. There are many forms online, and each state has different forms, but no one form that you must use. You really could finish all the major decision making in the time it takes to answer the questions in this column:

1. Do I want to be buried (Where? Paid for?), cremated (Where? Paid for?) or donate my body? If donating, is it okay for the donation to go to (a) education; (b) donor organ; (c) for-profit; (d) overseas?
2. Who do I trust to make end of life decisions for me should I be unable to make them myself? Who is my back up for this person?

Name 1 \_\_\_\_\_ Name 2 \_\_\_\_\_

3. Have I given someone a list of who is to be notified in case of my death?
4. Do I have a will?

I'm going to make this as easy as possible for you. Fill out the form below and give it to your primary care physician.

A. Regarding life prolonging measures, I would like my agent to approve:

	Yes	No	Agent to use own judgment
Breathing tube in the nose	_____	_____	_____
Intubation	_____	_____	_____
IV nutrition	_____	_____	_____
Urinary catheter	_____	_____	_____
Dialysis	_____	_____	_____

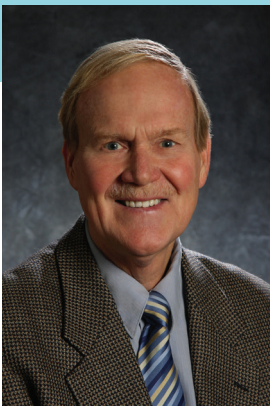
B. I would consider that I did not have sufficient quality of life and would not want my life prolonged in the following circumstances:

	Yes	No	Agent to use own judgment
Unable to breathe on my own indefinitely	_____	_____	_____
Unable to take in nutrition orally	_____	_____	_____
Unable to control bladder and bowels	_____	_____	_____
Unable to communicate orally	_____	_____	_____
In pain indefinitely, unmitigated by non-narcotic medications	_____	_____	_____

If you answered the questions 1 to 4, and completed the form, you have done 90% of the work you need to do. Making a will is the other 10%. No you can go back to not thinking about it. ■

**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.





Frederick M. Maynard, MD

## Ask Dr. Maynard

Send your questions for Dr. Maynard  
to [info@post-polio.org](mailto:info@post-polio.org).

See other questions at  
[www.post-polio.org/edu/askdrmay.html](http://www.post-polio.org/edu/askdrmay.html).

**Question:** *I am 83 and had polio when I was 6, affecting my right leg. I received the Sister Kenny treatment in St Michael's Hospital in Newark, NJ in the spring of 1942. My leg is 1/2 inch shorter and one of my quad muscles and my calf atrophied. I have led a pretty normal life with one weak leg.*

*I started singing in a choir as a Boy Scout and continued in church choirs and in later years a community chorale. While singing I have found that I cannot walk and sing like most of the other singers. I run out of breath. Nevertheless, I have had lung capacity tests that have shown good capacity, and it is only trying to sing and walk that gives trouble. My other activity was as a scout leader for 35 years where I hiked and swam with the boys over the years.*

*As I have aged, I discovered my left arm and hand also have some palm atrophy. I have no opposing muscle strength with the thumb on the left hand. I am also short of breath when I walk uphill. Is it possible that some of the lung muscle was also affected and is causing the shortness of breath and how can it be checked? I do have a cardiologist. He diagnosed a dilated aortic root, an artery that is 70% blocked and a leaky valve that he is watching. I had the breathing and walking problem prior to the heart problems.*

**Answer:** You pose a difficult diagnostic challenge because your heart problems AND/OR post-polio involvement of your breathing muscles might be responsible for your symptoms of SOB (shortness of breath) on exertion. If it was from the polio, the fact that you are noticing some new atrophy in your left hand/arm suggests that you may be having some weakness involving the left diaphragm because its motor nerve supply is located adjacent to motor nerves to the left arm/hand in the spinal cord where the polio virus caused myelitis and cell death. You could be evaluated by a pulmonologist with expertise in neuromuscular diseases affecting breathing and with testing involving not only breathing capacities, such as Forced Vital Capacity in standing and lying down positions, but also fluoroscopy (moving picture X-ray) of the diaphragm in full inspiration/expiration to see if the left side is weakened/paralyzed. You could show this recommendation to your local doctors as appropriate. If all breathing tests prove normal, your heart problems may be sufficient to explain your symptoms. This could be confirmed with exercise capacity testing on a treadmill with monitoring of your cardiac output. Although your heart problems were only recently diagnosed, they could have been present for a longer time.

**Question:** *I was diagnosed with a mild case of polio in 1952 when 12 years old. The polio affected my neck and upper back, and both recovered to the point where I didn't have any visible physical problems. Over the years I have encountered a lot of stiff neck and back problems and was treated at pain management facilities. The pain was not alleviated, but they provided enough relief that I could tolerate the pain and maintain a livable life. In 2010, I was diagnosed with autoimmune chronic hepatitis and have been receiving treatment. The treatment means I cannot take any pain medication that goes through my liver, thus I live with a lot of pain.*

*Last December, I was sitting at the table addressing Christmas cards and when I finished, I had a stiff neck and back pain below my neck. The pain worsened and I went to see my primary. He thought the pain was caused by muscle spasms. He gave me medication for muscle spasms which had very little effect on the pain. They did a CAT scan with dye but could not determine the problem. I went to the ER with severe pain. They ordered blood and urine lab work, an EKG and ultrasound on my abdomen—all came back negative. One of the doctors suggested trying a pain medication that is made at the hospital pharmacy. After approximately 30 minutes, the pain subsided somewhat, and I was released to go home. I apply the pain medication as*



*needed. Since this existing problem occurred, I am experiencing more pain and weakness in my arms and shoulders. What can be done for my condition?*

**Answer:** Based on the detailed description of your medical history and recent symptoms, I would agree that it is likely that your pain and increasing weakness through the neck and shoulder are related to your past history of polio involvement with these same muscles. Given your history of a full initial functional recovery of strength in these muscles which lasted for >20 years, unremarkable imaging of your neck for serious anatomical conditions and the trigger of recent pain symptoms in these muscles after unusually prolonged or strenuous use, you are most likely experiencing persistent pain because of ‘myofascial trigger points’ in these muscles. These can usually be alleviated and sometimes resolved with several therapeutic techniques including message therapy and gentle stretching, followed by some toning and gentle strengthening exercises provided by a physical therapist and/or massage therapist through a physician’s prescription. Use of a pain relieving cream or rub (such as the one from your local hospital pharmacy), as well as use of heat and/or cold therapy, use of TENS (Transcutaneous Nerve Stimulation) or acupuncture, can all be helpful adjuncts to controlling the pain levels and permitting the most important aspects of treatment (message, stretching, exercise) to be tolerated long enough to result in satisfactory resolution of symptoms, albeit with a possibly reduced level of activity tolerance or capacity.

To ensure that this approach is optimal, it should be based on a full examination. I would encourage you to obtain a “Neuromuscular Evaluation” by a polio expert in your area, as you have suggested. The Physical Medicine & Rehabilitation Department at Ohio State University in Columbus has a long history of expertise in evaluation and treatment of polio survivors and pain problems. It would be an excellent place to be seen for an individualized treatment plan and for recommended local therapy providers. ■

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