

## Polio Survivors Ask...

Nancy Baldwin Carter, Omaha, Nebraska, [n.carter@cox.net](mailto:n.carter@cox.net)

**Q:** As I get older and accumulate more secondary conditions, it is more difficult for me to get around. Do you have any suggestions as to how to communicate my knowledge about my post-polio health to my grown children when they really don't want to "hear it"?

**A:** There may be more than one hurdle lurking in this question.

We should start with US. Some of us talked with our children about our post-polio experiences from the get-go. Others played the role of the brave soldier, quietly marching on in the face of adversity, full of pluck and certain sacrifice—and never revealing the polio reality to anyone. Which has been the approach to our disability?

Some of us have spent years nurturing a fantasy of our capabilities, always telling ourselves, "No problem. I can handle it myself." And suddenly now, just thinking of making the effort fills us with dread, exhausts us beyond measure. Have we reached the point when we can say, "Sorry, gang, I simply cannot do this anymore?"

We may have a new truth to tell ourselves about our physical status, now that polio and aging have come crashing into each other.

How can we approach the subject with our children who have a hard time considering they have a parent with increasing health issues? Think about venturing into these areas:

- **ATTITUDE.** Can we be straight-forward, truthful, accepting our role in this scenario—and not play the shame game if others don't react the way we think they should? Can we empathize with our children's feelings enough to put them at ease as we spell out what we want to say?
- **EXPECTATIONS.** Do we realize we can't realistically dictate our children's sensibilities any more than they can ours? Aren't our expectations of ourselves the only ones we can truly control?
- **SUBSTANCE.** A few essential items about our conditions are enough at first. We needn't inundate others with "homework." If our children don't seem to want more, we should thank them and move on. Truth is, while many of us may have children who can handle such details, others may not. This is a bonus—the prize in the Cracker Jack box—not a necessity.

It is important to have someone "in the know," however. Here are some things we can do:

- Find a relative or friend who agrees to serve as Durable Power of Attorney for Health Care. This person can legally speak for us if we should become incapable of speaking for ourselves (doctors determine that patients are incapable, not relatives or others) when serious health care decisions are needed. Discussing specifics extensively will give us a better chance of having our wishes carried out.

- Make a Living Will, which allows us to tell doctors and others, in writing, what we want done regarding certain life-or-death situations. Give copies to our doctors, hospitals, family members, and friends--and hope someone insists this be followed.
- Show our doctors reliable articles and participate in our own health care decisions. Ventilator users will be particularly interested in PHI's new doctor/patient worksheets "Take Charge, Not Chances."
- Choose a buddy, maybe someone in the polio support group, with whom we feel free to talk, shed a tear, have a laugh about our current polio selves. We can do the same for them. Stuffing is not a good idea.

Mainly, our health care is up to us. Getting our children involved may be helpful, but it isn't a requirement. They observe the struggle and they love us in a very special way. Sometimes that has to be enough.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

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**Q:** I have been my wife's attendant for many, many years. I am getting older and can't do what I used to do, but it is still expected of me. How I can broach this topic, without her feeling like she is a burden to me?

**A:** Our family caregivers are precious. They meet our needs perfectly. They know exactly what to do. They seem indefatigable. They never complain. And when we ask them if this or that is getting to be too much for them, their inevitable reply is "No. I can handle it." They cannot say otherwise. They don't want us to think they see us as a burden.

We, of course, don't want them to believe we think they view us that way, either. So out of guilt (she, for needing so much; he, for wishing he could do more) or love or procrastination, the right words may never get said.

But something has to give. Research shows that caregivers have higher rates of poor health, including anxiety, depression, risk of heart disease, and even higher death rates than non-caregivers. Caregivers deserve a break.

The solution could be more available than it seems. Begin the dialog. Be prepared, caregivers. A scenario: "One of the things I've always loved doing, Sue, is making healthy lunches for you. But lately, pain in my hands makes it difficult to prepare food. I wonder. There's a woman who can come over and cook up large batches of meals to freeze in individual containers. All I'd have to do is warm one up for you. Does that sound OK to you?"

Slowly, one after another, the caregiver will find ways to transfer many of his jobs to someone else. People who love each other will understand. She may even join the search. She can see his stress, and she knows his good emotional and physical health is best for them both. He may never hear a word of dissent. Like it or not, though, this must be done.

Just so we know—AARP says more than 44 million unpaid caregivers provide over \$35 billion worth of care in this country every year. We are not alone

### **THE HOW AND WHERE OF IT**

There may be more help available than many of us realize. Begin by making a list.

What do you need? Home-delivered meals? Someone to prepare meals? Housekeeping services, laundry? Help bathing, dressing, eating? Shopping? Companionship services? Respite care for caregiver? Transportation? Handyman? Nursing care? Durable medical equipment? Services coordinator? Day care centers? What else?

The search is time-consuming. Have questions at the ready and ask them all. Persist. Keep good records. Each resource is unique and there is much crossover. Call these for starters:

- Area Agency on Aging (AAA) or Office on Aging—many in-home services offered, often staffed by volunteers. Check phone book.
- State Health and Human Services office—get clues on what's available.
- Independent centers may direct us to help See (<http://www.ilri.org/html/publications/directory/index.html>)
- Home Health Agencies offer many kinds of in-home care. Staffed by paid workers. Check yellow pages.
- Headings like these in your yellow pages: Home Health Care; Aging, Disabilities, Eldercare, Churches
- Many states have a 211 help line for assistance with searching.
- AARP (<http://www.aarp.org/families/caregiving/>). Pages of good advice.

Every state is different. Learn when licensing or certification is required. Explore funding options. Medicare-certified agencies must meet certain standards set by Medicare, which will pay only for what's Medicare approved. Private insurance or pensions may cover certain services. Private payers may be charged on a sliding scale. Examine everything.

Finally: It's best to start early. Don't wait for a crisis. Work it out together. And try to stay calm--this process can make anyone tense.

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**Q:** I keep hearing about the shingles vaccination. Should polio survivors get one?

**A:** Currently there is no experimental data regarding polio survivors getting this vaccine. PHI polled nineteen doctors (experienced in treating polio survivors) about your question and received a variety of responses. The most prudent thing to do seems to be to study the information we provide below, talk with our doctors about our individual circumstances, and then each make our own decision.

**THE VACCINE:** In the year 2006 a vaccine called Zostavax was licensed to prevent shingles in people over age 60. In the clinical trial, the vaccine was successful in 51% of the participants 60 and older and was most effective in those aged 60 to 69. Shingles-related pain may also be reduced in many of those receiving the vaccine.

**PRECAUTIONS:** The Centers for Disease Control says those who should not get this vaccine are people who have had a life-threatening **allergic reaction to gelatin**, the antibiotic **neomycin**, or **any other component of shingles vaccine**. They advise those who have severe allergies to inform their doctor about this.

They also recommend certain people do not get shingles vaccine (which contains live though weakened chickenpox virus): Individuals who have a **weakened immune system** because of HIV/AIDS or another disease that affects the immune system, treatment with drugs that affect the immune system, such as steroids, cancer treatment such as radiation or chemotherapy, a history of cancer affecting the bone marrow or lymphatic system, such as leukemia or lymphoma. Those with active untreated **tuberculosis** and those who are **pregnant** or might be pregnant should not get the vaccine.

Individuals who are moderately or severely ill (including those with a temperature of 101.3° or higher) should wait to get their vaccine until they are well.

**THE DISEASE:** Approximately one million cases of shingles (also known as *Herpes Zoster*) occur in the United States each year. The same virus that causes chickenpox causes shingles. When people recover from chickenpox, the virus lies lurking in the nervous system for the rest of their lives. Certain circumstances (perhaps stress or immune deficiency or something else) reactivate this virus and cause shingles. This usually occurs after age 50.

Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain nerve on one area and one side of the body. Shingles blisters then form for a number of days before they pop and finally crust over and heal. The entire process can take several weeks.

**SYMPTOMS AND COMPLICATIONS:** Fever, chills, upset stomach, and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis, or death.

A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as postherpetic neuralgia, which occurs in more than 40%

of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

**INTERESTING FACTS:** People who've had shingles can get it again. Only people who had chickenpox or chickenpox vaccine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chicken pox or the chickenpox vaccine can get **chickenpox** from someone with shingles.

**COST:** A number of factors determine what the shingles vaccine costs individuals. For example, in Omaha, Nebraska, the vaccine is administered in pharmacies for the cash price of \$220. Plan D picks up from \$25 to the full amount, depending on the coverage one has chosen. Medicare itself won't pay for the vaccine, though it will pay a \$20 administration fee. Getting a firm price may take a few phone calls in each separate locality.

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**Q:** Is our condition—post-polio syndrome—included in new medical texts or taught to medical students?

**A:** Apparently, the answer is “yes.” PHI has been asked for photos of polio survivors with PPS for such reasons.

At first this idea sounded to me a bit like providing photos for a criminal justice class to show them what a criminal looks like. Just how does someone with PPS look, anyway?

An individual with PPS is not simply someone with recurvatum or an atrophied hand. It's a million other things, as well. What does underventilation look like? How do doctors view a likeness of someone with severely weakened throat muscles and understand that she cannot swallow solid food?

Furthermore, is there any way those same doctors could know that the deformities they see were caused by PPS and not by the original bout with polio?

Could our photos make a difference?

The task seemed impossible. We would have to develop our own huge “rogue’s gallery” if we hoped to present an even halfway useful visual means of familiarizing doctors with the various “looks” of PPS.

And yet, what a contribution this could be! How about at conferences, where medical professionals could use our photos in teaching other medical professionals about PPS and a variety of devices that provide solutions for polio survivors?

Or perhaps use the PHI website to display a certain number of relevant “before and afters” so that medical professionals could view them easily in their own offices? Or to encourage polio survivors in other countries, for instance, who aren’t familiar with what’s available in the way of braces and various other assistive devices they have never seen?

I began to warm to the idea. I talked with Joan L. Headley, PHI’s Executive Director, to discuss the issue. She loved it and suggested we devise a way to give it a try. This could be exciting!

So here’s the deal: PHI asks those of you with PPS who wish to participate in this venture to provide us with pictures. Not just any photos, mind you, but specifically a series of Before and After shots that will make your case clear through photos. Something like this:

1. If polio left you with a drop foot, for example, see if you can find an old photo of how that foot looked before you had polio and how it looked after the disability became observable.
2. If your problem was alleviated with a brace, see if you have a photo that shows the brace and how that solved the problem.
3. If, then, you encountered more problems in that same area when PPS hit you, let photos show how PPS changed that leg and then how that was corrected.

You may be one who saw no noticeable difference to, say, your arms when you had polio, but PPS changed that—then we’d need pictures of how your arms looked before PPS and how they look now. If the condition has been corrected, then a photo of that would be needed, as well. Each photo submitted must be clearly identified so we know what it represents.

Please submit these photos (with a minimum resolution of 300 pixels per inch) to PHI’s email address – [info@post-polio.org](mailto:info@post-polio.org) – with “Before and After” in the memo line by August 1, 2008. You should know that photos cannot be returned to you, so it may be best to scan them. (Scan them at 600 dpi.) If you can’t scan them and no longer want the photos, please mail them to PHI, 4207 Lindell Blvd, #110, St. Louis, MO 63108. Also, there is no guarantee anyone’s photos will be used.

Want to pull out your old albums and new digitals and join in this exciting undertaking?

Let’s go for it!

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**Q:** I'm in the market for either a power chair or a scooter and am trying to make up my mind which would be better for me. I've heard there's a stigma associated with using a power chair rather than a scooter. What's that about?

**A:** Stigma? Really? I've used a power chair for over fifteen years, and I've never heard of this. It's hard to imagine that something giving me the sense of joy and freedom my chair does could somehow brand me as unacceptable.

Is it possible others think ill of me not because I'm obnoxious or disagreeable, but simply because I use a power chair? I needed to check.

First stop: Talk with crackerjack experts. Goal: See if there is anything inherent in power chairs that could cause me shame or humiliation.

Their responses in a nutshell: Chairs are better for people with less mobility, for easier transferring, can turn on a dime, and can go places where scooters can't.

On the other hand, scooters are fine for people who require less support, they weigh less than power chairs, usually take less effort to load, and cost considerably less than chairs.

Or not. Assessments differ. It's smart to do the homework, test what's in the showroom, and then ask for a trial run at home or at work before making a purchase. Lifestyle is a determinant. Needs differ. Comfort counts. To each his own.

Still, nothing in the equipment spells STIGMA. Could the problem lie in how the polio survivor in that chair is perceived?

Time for a small, informal poll. Thirty non-polio individuals were asked three questions to determine what using a power chair rather than a scooter says about the individual using the chair.

The results: About 43% believe those using power chairs are unable to walk much or are more disabled than those using scooters—who are considered to have trouble walking or to be less disabled (46%) and also to be elderly, overweight, or in one case, lazy. About 26% say those using power chairs are the same as those who use scooters. Others think people using power chairs are interested in keeping their independence or want to be active.

Forthright and thoughtful answers. Power chair users are not characterized in a derogatory way. No attempt is made to humiliate or condemn. If there is power chair stigma here, it's not coming from these respondents.

Does this mean I'll never see a shopper at the market stare as my power chair zips me down the aisle? Of course not. People are curious—a woman wearing an Eiffel Tower hat, a street brawl—anything different draws attention. And there's a mean-spirited jerk in every crowd. But if I find stigma here, it's only in MY mind. It's merely what I THINK—it is not a FACT.

Accepting disability can be tough. Coming to terms with who we are often requires making formidable choices, dealing honestly with our very souls. In the end we must come out whole.

Why not help people understand? If they see enough of us tooling around in our power chairs, we'll no longer be a curiosity. No need for our defensiveness.

What we can't do is perpetuate this "stigma" myth. It's said that if you tell people something long enough, they'll believe it. Do we really want to play into the hands of discrimination like this? What do we expect of others, if we ourselves keep repeating such specious nonsense?

So to answer your question: There ain't nothin' to it.

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**Q:** I recently attended a banquet given to raise funds meant to help eradicate polio worldwide. Others at our table seemed to believe that this was the end of it—that once we get everyone immunized, there would be nothing more to do regarding polio. Why don't people hear as much about ongoing needs of polio survivors as they do about efforts to eradicate the disease?

**A:** The simple answer is that the CDC and Rotary International and others have spent a good deal of time and money organizing and publicizing this most successful eradication effort (and thank goodness for that). But so far nobody has approached our post-polio cause with anything close to that much vitality.

More to the point, perhaps, is what can WE do? A vigorous grass roots effort on the part of polio survivors and their families could create a domino effect, finally attracting the attention of those in an excellent position to assist us in meeting our goal.

And what is this goal? To alert health professionals, policy makers, and the general public to the fact that polio survivors are active individuals within their communities with successes to tell, and for many of us, unmet needs.

One huge need is for rehabilitation as well as re-rehabilitation. Polio survivors remember the role rehab played in taking us from polio patient to functioning member of society as we recovered from the disease initially. Worldwide, rehab efforts, although limited in some countries, still exist. And now the cause is just as

great for re-rehabilitation as those of us with the late effects of polio struggle to get back on our feet from this second blow.

We hope for doctors, therapists, medical institutions to see our plight and come pounding on our door. We look for policy makers to steer others in our direction. We dream of energizing those in our communities in the same way FDR brought them to our side all those years ago.

It all starts here, with you and me and each of us.

After a death in my family last month, someone asked where she could send a memorial. I suggested the research division of PHI, to help boost the amount of money available for promising grants. Shouldn't people know that right now we're close to finding a definitive diagnosis for post-polio syndrome—and that this could lead to breakthroughs in treatment?

A few days later she called to ask if I minded her sending the money to a homeless shelter, instead, since they have a current need. Of course the shelter is worthy. And in her mind, post-polio is so remote it presents no urgency whatsoever. That made me sit up and pay attention. What can I do to make a difference? What can I do to get others to take notice?

I've been looking over ideas various groups have proposed. Did you see the "button" suggestion? Wearing buttons with the WE'RE STILL HERE logo on them? Brilliant, I thought! I could wear one, and everywhere I go people would ask who "WE" are and why they should care if we're "STILL HERE." A Johnny Appleseed of post-polio, that'd be me. How does that quote go? If everyone lit just one little candle, what a bright world this would be!

Or I could reach lots of people at once by being part of producing the skit right here in Omaha that's offered on the PHI website this year. What a kick!

Take a look at the bright green logo at [www.post-polio.org](http://www.post-polio.org) and discover some great possibilities. You'll see. And remember this: Anything we can do is a zillion times better than doing nothing at all.

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**Q:** *I called my local Rotary Club and am scheduled to speak for 20 minutes on Wednesday, October 15, 2008, during WE'RE STILL HERE! week. There is so much to say! I need suggestions in putting together my presentation.*

**A:** Hopefully, polio survivors like you will see to it that the same thing happens in Rotary Club meetings all over the world that week. There couldn't be a much better opportunity to re-energize Rotarians, who are, as we are well aware, most interested in polio.

Let's begin with some quick PHI links to help find information for your talk:

- To check out Jan Flood Nichols' short guide for planning a speech for Rotary, click here: [Yes, You Can Speak to Rotary: Suggestions and Polio Facts](#).
- To cite the polio rate the year you got polio, or to compare the rates in this country since we got the Salk, look at this: [Incidence Rates of Poliomyelitis in US](#). If you want to mention the rate in your home state for your polio year, try contacting your state's Department of Health.
- For current updates on the global count of cases and the eradication effort, go here: [Global Polio Eradication Initiative](#).
- To search the PHI warehouse of other polio information ([www.post-polio.org](http://www.post-polio.org)), type what you're looking for in the search window and/or click on the WE'RE STILL HERE! logo, and you may be delighted with the treasures you find.

One important aspect of using statistics is to be certain they come from reliable sources. Unfortunately, we are surrounded by untrustworthy websites, listservers, chat rooms, and newsletters that pass on information so wrong it should never be repeated. Give 'em true facts, ma'am.

Nonetheless, facts are only facts. How we present them makes all the difference. Most of us become engrossed listening to speakers who weave an appealing personal story—one that pastes colorful images on the mind. Hearing a long list of statistics won't do that.

However, when we intersperse our own polio anecdotes with a few historical facts or current post-polio realities, listeners will sit up and take notice.

We don't need to explain eradication to Rotarians—they're already experts at that. But many may not know about today's post-polio struggles.

It may never have occurred to them, for instance, that even if not one more person contracts polio, there would still be up to 20 million polio survivors on this earth. As many as 70 percent of those could face the need for re-rehabilitation, help from informed medical personnel and effective peer support.

Also, a number of Rotarians may not have thought about the role polio survivors have played in their communities. When polio is mentioned, some people have an image in mind of a woman in an iron lung; a man tooling along in a bulky, wooden wheelchair; a child using crutches to walk. They may not know their third-grade teacher was a polio survivor, or the guy who painted their house. Or even the

Rotarian sitting next to them at lunch that day. It may surprise them that we ARE still here—with successes to tell and for many, with still unmet needs.

A few tips:

- Try a light touch. Include humor; avoid being a drama queen.
- Stay within the given time limit.
- Be willing and prepared for a short Q&A session after your talk.

Here's one final idea: If being a solo act doesn't appeal to you, why not get together with others from your group and produce a rousing WE'RE STILL HERE! presentation? Take a look at the "ready to go" [script](#) at the PHI site—what a lot of fun that can be!

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**Q:** I've never attended any of these conferences. What should I expect?

**A:** Expect fun! Expect excitement! Expect a conference like no other! There is nothing to compare with what you are about to experience.

Where else can you be thrust into the center of discussions of today's post-polio scene, along with around 350 other polio survivors, all of us privy to the knowledge being shared by maybe 40 doctors and other medical professionals?

You'll hear experts; you'll ask serious questions and get serious answers about serious issues—every session is participatory, interactive or followed by Q&A's. Polio survivors as well as docs and pros participate, with everyone working as a team.

You'll make life-long friends from exotic places and exchange views and laugh together. You'll breathe the pine-scented air of this historic site in Georgia, a first time location for a PHI Conference. And if you are a graduate of Warm Springs rehab, the reunion with these buildings may infuse you with the will of spirits past.

The IMPACT of being there, being caught up in the swirl of heady conversation, creating solutions, meeting goals, and doing it all as one—goodness—simply thinking about this fills me with anticipatory joy!

### **WHAT GOES ON?**

Take a look at the agenda on [www.post-polio.org](http://www.post-polio.org). So many sessions call out to me—which to choose? I want to know the secret to how our groups can be more effective. And what about boosting energy and maintaining weight? And bracing, exercising, managing fatigue, what to do about pain. There's yoga and acupuncture and dealing

with families and assisted living communities. All about breathing. And so, so, so much more. And who could resist a gathering with story telling and pizza?

There are some fascinating innovations this year. A handful of historians will paint unusual, as yet untold, pictures of the polio past for us.

Plus, because of the special facilities available at Warm Springs, a three-day Post-Polio Wellness Retreat precedes the Conference. Although enrollment to this additional feature is limited, many will be drawn to the experience.

### **TESTIMONY**

I asked a friend who has attended a number of PHI Conferences (and who is already registered for this one) why she keeps going back.

"I learn so much," she said. "I get *answers* at these Conferences. They offer an unbelievable variety of information. There's something for everyone. Not to mention this year's added incentive of the Wellness Retreat.

"I get to choose the agenda that meets my needs. I'm picking my topics for this one already. I definitely won't miss the sessions on current research, aquatics, alternative medicine, surgery, and equipment. I wonder what 'film night' is about.

"These PHI Conferences are unique. Professionals and lay people working together like this—that just doesn't happen other places. My daughter even went with me one year—family members should get in on these things. There are so many seminars, so much to learn.

"Besides, I love chatting with the people there. I like to hear how they do it. I always want in on the breakout groups. And I've made many friendships over lunch."

### **WHAT'S UP?**

PHI's current "Post-Polio Health" newsletter adds to the information. As time goes by, even more details may be revealed. Keep your eye on the website.

PHI has been doing these exceptional Conferences a long time, since the early '80's. They know how to make them work. It's all about networking, served up on the most palatable platter imaginable. That's what I'd expect, if I were you.

As the blurb says—It's an experience of a lifetime!

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**Q.** *Do you have suggestions for a person with disability during this economically difficult time?*

**A.** If you're hoping I'll offer a discourse on using generic drugs and house brands, cutting back on lattes, and turning that dream of vacationing in Hawaii into cheery tips on camping out in the back yard, you may as well stop reading right here.

Wonderful advice on living less expensively abounds on the Internet. Entire websites are devoted to solving the physical needs of those of us with disabilities who are caught in an economic crunch. There isn't a notion on this issue that isn't tackled more thoroughly there than we can do in the space of this column.

And yet, there is still much on this subject to talk about. Times are tough for many of us, no question. Some have lost their retirement nest eggs, some their homes. People are without jobs, businesses are going belly-up. We would not wish this economic climate on anyone. I'm interested in how we can get through it emotionally.

I can't help thinking that those of us who are disabled may be uniquely equipped to deal with hardship. We've done this before, big-time—we figured out how to move from a "normal" existence to one that must accommodate permanent disability. We're survivors. Surely we have an edge on understanding how to handle change in our lives. We pull out all the stops—our faith, our families and friends, that mysterious instinct that gets us where we need to go. We know how to adjust.

When I told a friend I was doing this column, she suggested I channel FDR. Good idea. Who better? Here's a polio survivor who led this country through several major crises. Could prospects have been more dire? Wall Street had crumbled, bread lines to feed the poor extended for blocks, jobs didn't exist, destitute farmers struggled through the Dust Bowl. And then the topper, World War II. We had a lot to overcome!

And yet a man in a wheelchair engendered hope, created possibility, and patched this great country back together.

Roosevelt began by calming our fears, assuring us that we could do what needed to be done. We heard the confidence in his voice on the radio, saw his friendly, unwavering smile in news reels. Nothing seemed insurmountable. Together, we could do it.

I was just a kid, but I learned from that. Don't let fear get the upper hand. Live with optimism and joy. Make opportunity work. Help ourselves by helping one another. And do it all with humor, that indescribable something that transforms anger and frustration into fun and gets us through the night.

Come to think of it, aren't these the qualities we brought with us in designing our post-polio support groups? Haven't our meetings provided a forum for discussions of

our frustrations and disappointments, a place for members to get together at crucial moments in their lives and work with each other to find peace?

Aren't these the messages we find in our best post-polio newsletters? At our conferences? Words of strength and courage as we struggle to keep our balance, hurtling through life? Opportunities to fortify our resolve?

It isn't only the name of a fine doctor or the news of a promising treatment that we get from each other, important as those are. There's a human element here that can't be found in a directory or a scientific journal. We must be here for each other, someone to touch that hand reaching out for help, someone to say, "We are not alone."

We can do this.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q.** *As I think about this joyous time of year I feel like celebrating, but many of my family and friends don't understand why I, a survivor with the late effects of polio, have a reason to celebrate. Can you help explain it?*

**A.** Sounds as if you explain beautifully how *you* feel! I, too, love this season—no doubt about it. Just makes me want to sing! There's such excitement in the air, an expectant atmosphere, as if something wonderful, delightful were about to happen.

And it does. Strangers smile and say a cheery hello as I bump my chair past them at the mall. An uncharacteristically sunny mail carrier delivers a package at the door.

Happiness bubbles out of me, and I feel compelled to give it away, in whatever form such a gift takes. Do I bake Aunt Sally her favorite cookies? Read a story to an eager kid? Whatever I can do toward infecting others with my lighthearted spirit, I'm gonna.

I'll bet you're that way, as well.

So now I ask, what has any of this to do with having the late effects of polio? I've been a polio survivor since I was eleven. Went from total paralysis to a darned good recovery to serious paralysis to a fair recovery. And never once in all those years did I fail to be filled with the jubilation of this season.

My paralysis merely exemplifies the condition of my body; what this time of year does for me speaks to my Soul. Apples and oranges.

This miserable body of mine has never gotten in the way of the essence of my life. This is how polio survivors operate, isn't it? We do what we must to get where we have to be. It's sort of like my *desperate yearning* to be a blond. What am I gonna choose—moping or Clairol? I'll take the "more fun" route, thank you. I need a chair to get around? I buy a chair. It's the "getting around" part that counts. We do what it takes.

We adapt, adjust our way through the inconveniences of disability so thoroughly that often we don't even think of ourselves as disabled. I've never had a dream in which I wasn't fully functioning. In my psyche I am whole.

Where did we polio survivors acquire our determination to enjoy life in ways certain non-disabled people cannot grasp? Perhaps it was an unconditional acceptance we received from family and friends as we began to grow into the world around us after polio.

Or how about exactly the opposite—our "I'll show you!" defiance as we struggled to find our own way amid a sea of "normies."

Or did the "You can do it" mantra repeated to us day after day by our super therapists start us down a path to believing we could have it all if we did it for ourselves.

In the end, does it matter where it came from? We're in the midst of an entire season of glorious days that add up to Friendship, Fun, and Fabulous Food (you notice I omitted Fatigue, that awful other "F," the one we have to learn to avoid in order to savor the delicious first ones). I'm ready!

As for those other folks, your family—well, let's just hope they get over it.

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
([n.carter@cox.net](mailto:n.carter@cox.net))**

**Q:** *We have known about the late effects of polio for almost 30 years. I've gotten a lot of advice during that time and wonder about other polio survivors. What's the best post-polio advice you ever received?*

**A:** I've always felt I got wonderful advice from Dr. Ann Bailey at Warm Springs. My body had hit a patch of frightening paralysis, and I called her to cry on her shoulder. After listening to my weeping and wailing for quite a while, she finally said, "Accept it, Nancy." These simple words gave me the serenity I needed to go on. No amount of teeth gnashing could help me in the way that accepting the reality of the situation did. This is lasting help—I use her words of wisdom often.

But this is a question with a million answers. I wondered what others would say. Curiosity caused me to contact a number of polio friends around the country to get their responses.

From Illinois, Jan says, "Rest. Schedule it into your day. It's as important as anything else you may do and will possibly give you the oomph! to do what you must."

"The best advice I've ever gotten is 'walk the knife edge: too much exercise can hurt you and too little exercise can debilitate you,'" says Larry in Minnesota. "Just in case you're interested, the second best advice was 'take charge of your own health care.' Certainly that does not mean ignore the advice of your health care professionals but it does mean make sure you understand their recommendations and that those recommendations fit with everything else you know. If they don't, it is your responsibility to question the provider until you do understand."

What popped into Becky's mind in Texas is "PACE YOURSELF. Conserve energy—stop along the way when we need a rest from walking; stop to admire a rose halfway up the staircase. This reminds me of a favorite quote from Georgia O'Keeffe: 'Nobody sees a flower really; it is so small. We haven't time, and to see takes time—like to have a friend takes time.' I am encouraged to enjoy the precious things in life, and that doesn't require physical energy."

Richard, in California, tells us "You must acknowledge to yourself that you have a disabling condition. Don't be consumed by that reality, but be honest with yourself. Ignoring or denying this reality leads to anger and frustration. It can also lead to counterproductive behaviors. When you make peace with your body you can begin to make appropriate adjustments. And, don't be afraid of all the things available to assist you in life. These assistive devices can be your friends, not your enemies."

"In looking back, the best advice I received was that when judging my activities and exercise, I should be aware that there is weakness from disuse as well as from overuse," says Missouri's Joan.

"Pace myself," Peggy, another Missourian, replies. "I must be a hard learner, because on the good days, I find myself trying to do more to sort of catch up with things I was unable to do on the bad days. I call it 'Hallelujah I'm healed' syndrome, on the good days, and it drives my husband nuts! I try to be good, I really do. But there is a little voice inside that says 'Go for it Peggy. You'll be able to do all of it, and then rest.' I can tell you with certainty that life at our house is not boring."

Aren't these terrific! Now I'm thinking many of you have gotten excellent post-polio advice, as well. Why not share these gems with us—send them to [info@post-polio.org](mailto:info@post-polio.org) and we will post them on [www.post-polio.org](http://www.post-polio.org).

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## Polio Survivors Ask...

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** The Obama administration has asked for our opinions on policy. If you had to pick just one issue, what would it be and what would you say?

**A:** As President Obama said in his inaugural address, "...everywhere we look, there is work to be done." Surely we all agree. Well, here's where I'm looking today, Mr. President—this is my issue:

I hope for each of us to live as independently as possible, and since statistics show 80% of us want that to be in our own homes, while 90% say they definitely don't want to live in a nursing facility, this column is about getting to live at home. Importantly, if we are legally competent, the decision must be ours to make.

Today it's possible for many of us to stay in our own homes, even with significant disabilities, and have help with such chores as housecleaning, laundry, cooking, handyman work; and personal needs such as bathing, dressing, eating, medication, therapy, maybe a ride to the doctor's office or the grocery store.

This is one of the options of community-based living: The dignity of CHOICE. You want to live in your own home? Invest in a cell phone and a "medical alert" system to keep on your person for safety. Contact your local Office on Aging and discuss the variety of help available. Get connected. Learn the system. Engage family and friends in the pursuit.

The problem isn't that living at home is a dangerous or inadequate choice. The problem is that funding and politics pretty much account for today's current lack of community-based living opportunities. Government funds that could go into community-based living are, instead, being fed to institutions.

If states keep increasing Medicaid funding to nursing facilities, we can be sure these institutions will continue to admit residents who could otherwise live in the community. More money merely encourages warehousing people in institutions who don't have to be there. In 2007, 29% of nursing facility residents had NO Activity of Daily Living impairment; another 260,000+ had only one. Over 31% had NO cognitive impairment; more than 58% had ratings of "mild" or less. Why are such individuals in institutions?

For friends and relatives who believe placing a loved one in an institution will provide the peace of mind that eludes them when they leave their loved one home alone and head to work each day, let me show you the photos of my bloodied mother after she fell more than once in a highly-rated nursing facility where she was visited at least twice a day by a devoted son. Exception? Look at the statistics online.

The point is that no one of us is perfectly safe anywhere. Merely saying institutions can keep residents safe is not a reason for stripping people of their identity and depriving them of choice. Nursing facilities are not "better"; they are simply more abundant and more costly than at-home care. If an informed and competent individual who wants to continue living at home is willing to accept the consequences

of that decision, why should others think they have the right to change that determination?

Instead of devoting ourselves to telling others how they should live, why not help the Obama administration make community-based living more available? Start Buzzin'. Do the homework. Insist on workable funding. Spread the word about new home monitoring technologies.

Communicate! Write and call Obama and Biden, Representatives and Senators, the proper state authorities and local contacts. Discuss possibilities. Let them know we're serious. We're going to have to make it happen.

If we want CHOICE, it's up to us to get out there and DO SOMETHING!

#

*Those wanting to check ratings for any Medicare or Medicaid-certified nursing facility in the USA should see [www.medicare.gov/Nursing/Overview.asp](http://www.medicare.gov/Nursing/Overview.asp). ADL (Activity of Daily Living) refers to basic tasks of living, such as bathing, dressing, eating, toileting, perhaps transferring, that are measured as a means of determining if one needs the care offered in a nursing facility. Many amazing in-home monitoring technologies are being developed, such as a bed that measures your vitals and weight as you lie in it—and transmits the information to your doctor in his office.*

Contact elected officials: <http://www.usa.gov/Contact/Elected.shtml> .

Check out the newly formed [Center for Self-Determination](#)

*The Center for Self-Determination is the primary clearinghouse, training and technical assistance source on Self-Determination in the United States and other countries. The Center is devoted to moving power and authority over resources directly to individuals with disabilities, families and allies.*

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
([n.carter@cox.net](mailto:n.carter@cox.net))**

**Q:** An important topic families tend to ignore is a discussion of those all worthwhile decisions we may have to make at the end of our lives. Knowing that we should discuss it and actually doing so are two different things. Do you have any ideas on this topic?

**A:** More often than not, we can't be certain when an "end-of-life" discussion is due. If we have serious thoughts about certain issues dealing with life and death—or even

how we want to be treated as age or disability or illness comes upon us at any point in our lives—the time for that talk is today.

It doesn't matter how resistant our loved ones may be to listening to such talk or how frighteningly ghoulish it may seem to us, we must not put it off. Tough as it may be to reveal how we feel, doing so not only removes from others the burden of decision-making, it ensures that we're going to have a better chance of being treated the way we want in times of change.

We need to be in charge of our lives. We have rights. While we are still able, we need to be the decision makers. To do this, we have to become aware of our options and take the action that puts us where we want to be.

For some of us, the day may come when we can no longer voice our desires because we have become incompetent. This doesn't mean, however, that we cannot have a say in what becomes of us. We can speak through a Living Will as well as through a person we have appointed to spell-out our health care wishes, known as a Durable Power of Attorney for Health Care.

A Living Will is nothing like a will that distributes our assets. A Living Will expresses directives we have made—such as whether or not we want our lives prolonged artificially if attending physicians have determined our condition is incurable or irreversible or terminal. It may address whether we want nutrition and hydration to be withdrawn. It may direct that we not be resuscitated; or that we be kept as pain-free and as comfortable as possible. We decide.

An attorney can draw up such a Living Will for us—or we can find one on the Internet to adapt to our needs. To be valid, this must be properly witnessed and notarized, everything according to the laws in our state.

For a Durable Power of Attorney for Health Care, we choose a trusted friend or relative we know we can count on to speak up for us to see that others follow our wishes when we are unable to do so ourselves. The appointment is made through the same route as the Living Will.

We then have the task of spreading the word. We must tell our doctors what we want and give them copies of the Living Will for our files. Tell our children, our cousins, our friends and neighbors, the butcher at our favorite grocery. Tape a copy of the instructions inside the closet door where it can be found easily. The more people who know about our intentions, the better chance we have of getting them carried out. Talking is the key here.

And while we're at it, we'll discover an even greater reward than dealing with end-of-life issues. The moments spent with loved ones, remembering our lives together, laughing, touching, letting each other know how much we care—these are the words that really count.

Better start talking.

*Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

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## Polio Survivors Ask...

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** I just remodeled my kitchen and found non-slip tile that is called "ADA tile." The label helped me narrow the possibilities, but I wasn't sure if that was a good use of "ADA." What do you think?

**A:** That's the point of having the Americans with Disabilities Act (ADA), isn't it? Now there's a standard. We're no longer forced to go whistling in the dark. Want non-slip tile on the floor? Check the ADA criteria: Coefficient of friction of 0.6 or greater on flat surfaces, 0.8 on ramps or inclines. Voila! How easy could it be! And how helpful!

We're smart to question how we use "ADA." We don't want people thinking of these letters as silly government gibberish. The ADA is not simply a meaningless pile of rules and measurements. Those guidelines translate into our freedom.

In fact, the ADA is the most comprehensive antidiscrimination legislation ever devised for those of us with disabilities. This civil rights law, our shot at equality, is our passport to accessing life in a way never possible before. We count.

For years our participation often came riddled with impossible barriers, physical and otherwise. We, society's outcasts, stood in the shadows, waiting our turn.

When President George H. W. Bush signed the ADA into law in 1990, he said "Let the shameful walls of exclusion finally come tumbling down." The ADA lets us IN—figuratively as well as literally over the curb, up the steps, through the door, into the room, down the aisle, *whatever*. We get our chance. The ADA offers us the fresh breath of spring—it brings precious ACCESS.

So when we say that something is "ADA accessible," (whether that be jobs, public accommodations, commercial facilities, government services) we know that pains have been taken to follow ADA regulations. The question isn't "Can *I* reach the credit card processing machine on the counter?" The question is "Can *everyone* reach the credit card processing machine on the counter?" The ADA shows us how to answer that question equitably.

We do not judge accessibility by what we, alone, need. The ADA has taught us to look around us and consider usefulness, workability for the *entire* disability community before we brand anything as accessible.

For instance, I don't require grab bars in order to transfer from my chair to a toilet seat. However, some folks with disabilities do. Therefore, all it takes is the absence of grab bars to make a public toilet stall inaccessible.

It's not OK to lift wheelchair users up the steps to a business establishment. Hoisting is no more a substitute for ramps than flip-flops are for winter boots. No ramp? The building is inaccessible.

It's not OK to corral wheelchair users in an isolated section of a theater or stadium, away from their companions and other spectators. Seating plan isn't integrated? It's inaccessible, not to mention unacceptable.

Let there be no excuses. Remember: We no longer have to accept the unacceptable.

Yes, yes, I know—numbers of exemptions let these groups or those buildings off the ADA hook. I've read the regs. I hope you have, too.

We must continue to focus on compliance. I'd thank that establishment for carrying "ADA tile." I'd tell others about it and encourage their doing business with that company. For those who still refuse to comply with the ADA, I'd start with a gentle reminder.

People fought a tough battle for US to be the ones to define accessibility. We do that through the ADA. I want to keep things that way; I'm going to insist on it.

How about you?

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** Every now and then I get a feeling of sadness over losses that I associate with my aging with polio. I was never taught to acknowledge my polio emotions, and that left me with a lump in my voiceless throat. Deep down, I think I should not express these feelings that make me feel so vulnerable. If I do, I am concerned I will be judged for expressing my feelings. How can I move through this?

**A:** No doubt we all feel hesitant about revealing our innermost selves to others in the beginning. There's that fear. Fear that someone will make fun of us, fear that our feelings will be trivialized, fear that people will think we're complaining, think we're whiners, that we're not tough enough. Whatever. It's a vulnerable spot to be in—must I always take a deep breath when I open myself up honestly, fearful that others will leap in to crush me?

Fears. They can be mighty. Yet, what are the consequences of silence?

Oddly, the more I stifle myself with these fears, the more I believe they are true. Soon I have stuffed myself so full of pent-up emotion that I explode in bitterness or anger or sadness or some other expression of a person I do not want to be. I've decided this isn't the way I want to live.

Much of my fear had to do with being all wrapped up in how I was viewed by others. Then one day I heard a wonderful speaker who brought me down to earth with

humor: "We wouldn't worry so much about what others think of us if we realized how seldom they do."

Suddenly I understood this wasn't about *them* at all—it was totally about me. Thank goodness for that—I can actually do something about *me*.

First up: take a look. Over time, I had lost track of my identity. I wasn't sure who I was anymore. I started searching.

What I discovered was a person who had spent a lifetime rationalizing my physical losses, pretending they meant nothing. I stayed home rather than admit I needed a chair. I even delayed getting SSDI until my time nearly ran out because I couldn't face that my considerable losses were enough to qualify me.

My days had been spent "doing." As my ability to *do* diminished, I felt myself slowly disappearing, tiny pieces of physical ability falling irretrievably to the wayside until very little was left. It was time to base my perception of my Self on *being*. I grieved the loss. I loved that other person—the whirlwind of her life, the accomplishment, the fun. I had to learn to appreciate the merits of *being*. This has to be about who I am, not who I wish I were.

I wasn't sure how I was supposed to act about my disability. My parents never mentioned it and seemed to think it would be better if *I* didn't. However, I needed to acknowledge it. I learned that while it usually isn't helpful to sally forth with a long catalog of my aches and pains, I *do* need to talk about what it does to me inside to be the person I am.

Post-polio support group discussions can be great for this, as are loved ones and trusted friends. The important thing for me is to express myself. I become stronger each time I speak up. More free.

Not every day is perfect. And of course nobody has everything. But I discovered that what I have is plenty. I take it one day at a time, and I'm still here, still intact, and still purring contentedly.

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** I have been evaluated for a basic power chair. Now my vendor tells me that Medicare will not pay for the chair unless it is intended only for home use. What does Medicare really say?

**A:** That's pretty much it. In 2003 President Bush "reformed and modernized" Medicare, and in 2005 its revisions for power wheelchair conditions for coverage kicked in. Yet some of us are still not totally aware of its ramifications.

Simply stated, any Medicare beneficiary (B) whose mobility limitations make it difficult to carry out mobility-related activities of daily living (MRADLs) such as toileting, bathing, dressing, grooming, and feeding at home is eligible for power wheelchair coverage. Well, sort of—there's more.

Other points to be considered before making this decision: Are the B's thinking and vision good enough to carry out MRADLs at home? Is a caretaker available to safely help the B needing such assistance, and is the B willing and able to comply? Does the B's home lend itself physically to the safe use of a power chair? Does the B require a power chair for any of these MRADLs or would some other type of equipment work better? Would a cane or walker do just as well? If the B doesn't have enough upper extremity function for safe manual wheelchair use, can a caretaker help with a manual chair? Is the B able to use a scooter safely—and would his home allow for that?

This doesn't mean you can't use your power chair outside the home—it merely means that getting Medicare to **pay** for that chair depends totally on your in-home MRADLs experiences. You may have a legitimate need for a power chair at work, but unless you also meet the "MRADLs at home" standard, Medicare won't pay.

Since Medicare's payment depends on a medical need, proving that need is crucial. Your doctor isn't asked only to conclude that you merit a power chair; he must provide the details that allow Medicare to draw the same conclusion:

- The B's physician, physician assistant, nurse practitioner, or clinical nurse specialist may prescribe the chair following a face-to-face examination.
- Supplier must receive the script within 45 days of the exam. It must be in writing, signed and dated by the practitioner, show B's name, exam date, diagnosis, conditions the chair should modify, description of chair, and length of time it will be needed.
- Supplier must also receive from practitioner supporting information that demonstrates relevance of the chair to solving the B's MRADLs problems. This may mean applicable "medical history, physical exams, diagnostic tests, summary of findings, diagnoses, and treatment plans." Records should also show what led to the need for the chair, what the chair will correct, that nothing else will rule out using the chair, that the chair will work in B's house, and that the B can operate a power chair.

Once all systems are "go," Medicare Part B pays 80%, and 20% of the bill is up to the B.

Finding a certified Assistive Technology Professional (ATP) might be a good move. ATPs are experts at analyzing exactly what the B needs and then helping her choose and learn to use the right equipment. Many equipment providers have ATPs on staff.

OK. So these guidelines don't seem to promote all the independence we hope for in our lives. Still, they are a start. Next step? Develop other funding sources. Medicare may not see the health benefits of having a chair mainly to pursue activities away from home, but these certainly exist. Let's just keep insisting until we get what we need.

*Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** I need to lose weight. My longtime post-polio weakness limits my choices of exercise. How can I enjoy going the nutritional route?

**A:** Want some adventure in your nutritional life? Grab a wide-brimmed hat and head for the nearest farmers' market! Warm breeze nudging you from one canopied booth to the next, baskets of intriguing produce lighting up the gourmet corner of your brain, food so fresh you can almost smell the garden it came from mere hours earlier.

Talk with the vendors. Relish this one's description of the rather thin, tapered, dark green pod he holds, the perfectly-named Chinese rat tail—and imagine chopping this kooky radish into your next salad. Laugh with that one, as he explains in mock-exasperation that his 12-year-old nephew, dutifully spritzing the collard greens (not to mention the vendor in the next booth) is, well, just a kid and whacha gonna do. People! Fun!

Here's bright pink amaranth, which dazzles up a salad a bit more than the green variety, though they both have the same spinachy taste. And arugula—dark green here, a tender leaf with a peppery bite. And spigariello, long-leafed broccoli that comes with a dainty, yellow edible flower. All of these help make salads enticing.

Get an exciting assortment: Pleasantly bitter radicchio, its beautiful magenta leaves streaked with ivory; or frilly-edged kale, with its gray-green (and even purple) leaves and slight cabbage taste; or turnip greens and their mustardy touch of sweetness; or cabbage-flavored collards, flat and green; or baby bok choy, cupped deliciousness from the mustard cabbage family; and our old stand-by, spinach.

Make salads. Shred young, tender beets into them; embellish with fresh herbs like thyme or basil or dill or rosemary. All from the market. Add chickpeas or kidney beans or Craisins or slices of mangoes or pears. You won't need more than a touch of fat-free dressing. Steaming is good, too, quick and tasty, and will retain nutrients that otherwise might leach out if cooked in water.

This isn't merely a salad story. The best book I've seen about eating the right stuff in the right way is *Everyday Cooking* by Dean Ornish, M.D. Oh yes—it has scrumptious recipes, too. Who can resist Creamy Mushroom Stroganoff or Brandied Pear Bread Pudding or Braised Brussels Sprouts and Chestnuts!

Irma S. Rombauer's classic *The Joy of Cooking* is a wonderful source of veggie information, with outstanding drawings, overflowing with tips, explanations, and recipes.

Of course, the trip to the market merely whets the appetite for the eating changes we realize we must make if we want a different outcome. We all know losing weight requires taking in fewer calories than our bodies burn up. Here's the good news: This isn't about deprivation—it's about making healthier choices. Experiment. Try new stuff. Let curiosity get the better of you!

How about taking home a handful of delightful little Yukon Gold potatoes, so new the skin comes off when you barely rub them with your fingers? Steam them with some fresh green beans and a breath of basil. Heaven!

And don't forget to check out the kohlrabi, those alien-looking turnip-y globes with weirdly shaped appendages sticking out in all directions where leaves used to hang. Great for snacks or soups or stews.

What to drink? Remember the Brewster sisters in the play *Arsenic and Old Lace*? Eccentric spinsters who treated their suitors to a sip or two of poison-laced elderberry wine? Here we have elderberry blossoms! You, too, can make your own wine. Or easier yet, brew up a pot of tea by steeping the blossoms in hot water. Or perhaps you'd prefer juicing a large, cool glass of antioxidant-packed aronia berries.

What a refreshing outing this has been!

## **A FEW TIPS**

Food has wonderful flavor, all by itself. Everything doesn't have to taste like some form of fat and salt. Food already has fat and sodium in it—adding more may only mask the unique flavor of the food. Guidelines say our bodies actually require no more than 20-25 grams of fat a day. One tablespoon of ANY oil contains 14 grams of fat. One tablespoon of butter contains 14 grams of fat.

There's no good reason to fry food in butter or oil. Ever taste a fresh mushroom sautéed in its own juice? All that delicious liquid cooks right back up into the mushroom—divine! Invest in a Teflon skillet—that's all you need. If you know a food is absolutely going to stick to the pan, toss in a spoonful of the broth on pages 18-19 in Ornish's *Everyday Cooking* for spectacular added taste. Or very lightly spray the pan with Pam. Think you need to add fat in your recipes? Try substituting plain, unsweetened applesauce or plain yogurt instead of butter or oil. Use your inquiring mind. Alter recipes to fit your needs. Spend time investigating fat-free products.

Salt's another culprit. When 140 mg is the cutoff for low sodium, eating food containing five or ten times that amount simply makes no sense.

A smart choice of juices: Low-sodium, all vegetable V-8. No fat, 140 mg salt, nearly three times the potassium of a banana, 50 calories. Check that label out! And always use skim milk. Did you know you can whip it into "whipped cream?"

Here's a good exercise: Move away from FAT and SALT!

And sugar. Do we really have to say anything more about sugar? Here's a little nugget of chocolate candy barely over an inch long. Doesn't look as if much harm

could be lurking there. How about 13 g of fat, 60 mg of sodium, 20 g of sugars, and 200 calories. What a bite! Think you can stop with one?

It's imperative to know the Nutritional Facts and Ingredients for everything we eat. Learn how to read these. For starters, they are on the back of every package of processed food. Pay attention to number of calories, amount of fat, sodium, sugar, and protein. Processed food can be riddled with things we don't even imagine. Don't ever buy any food without checking the labels to be certain you're within the nutritional parameters you've chosen for your eating style. To be clear: READ THE LABELS!

You can't beat this for canned tuna: StarKist's special Very Low Sodium Chunk White Albacore Tuna in Water—1 g fat, 30 mg sodium, 13 g protein, 60 calories. Compare that!

Eat Complex Carbohydrates—whole grains, breads, cereals, pastas, beans, which are absorbed slowly and can supply energy steadily, helping maintain an even blood sugar level. Limit Simple Carbohydrates—fruit juices, sugar, sugar products, jams, jellies, syrups, etc., which cause a quick rise in blood sugar, are easily converted into fat, and leave us feeling tired,.

For times when cooking is out of the question, keep a well-stocked freezer. It's not much more difficult to make a quantity when cooking. Store individual servings in containers in your freezer to pop out for a yummy meal on those blah days.

Chestnuts may be the only nut that doesn't contain fat. Buy them peeled and vacuum packed with no liquid if you don't want to struggle peeling fresh ones. Mind you, we're not talking about water chestnuts here. Dream of all the ways you can use these nuts in your cooking.

Make this kind of cooking a hobby. What a sensational way to enjoy a day!

As always, seek your doctor's advice before making major changes in diet.

*Want some delicious, healthful recipes? Please send a request to Nancy at [n.carter@cox.net](mailto:n.carter@cox.net)*

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
([n.carter@cox.net](mailto:n.carter@cox.net))**

**Q:** I have a significant pain problem in my shoulder and I've heard about a special taping technique used by athletes. What's the deal? Could it help me?

**A:** Kinesio® Taping is a method of using therapeutic taping to alleviate pain arising from muscular-skeletal problems. This interview with polio survivor Marlene Orton sheds light on her experiences with this process:

**Nancy:** What led you to try Kinesio® Taping, Marlene?

**Marlene:** At the PHI Conference in Warm Springs, the pain in my shoulder suddenly became almost unbearable. By pure luck, Michelle Guevin, PT, MHSc, MTC, a Conference presenter, described Kinesio® Taping, and I asked if she would tape my shoulder.

**Nancy:** I've read that Kinesio® Tex Tape is 100% cotton, and stretches to 30-40% of its resting length, so the muscle has complete range of movement at the same time it's upheld by the tape. The tape supposedly lifts the skin, reducing edema and inflammation by allowing a freer flow of body fluids. What did you notice about it?

**Marlene:** I felt it gave me more support and left me more relaxed, feeling comfortable. When my shoulder was in so much pain, I had tried to control the pain by moving more. Directly after the taping, the shoulder had a certain stability that felt good—I knew this was how it belonged. I still had some shoulder pain, but this seemed to be easing up.

**Nancy:** I know how desperate I become when nothing I do seems to help a situation. How did the taping make you feel?

**Marlene:** I had been in such awful pain that I actually cried. I was ready to head for home. The first glimmer of hope came when Dr. Maynard and Joan Headley said, "We will find something that will help you." This allowed me to believe that perhaps there was a way to lessen the pain. I thought, "OK, we're going to get this worked out." Icing and other remedies all helped, and after the taping, the pain was so much better that I didn't want to take the tape off when the three-to-five day wearing period was up. I determined by then that I wanted to have more experience with the taping.

**Nancy:** I notice that there is no certification required for Kinesio® Taping, nor is there any regulation. How did you find a capable PT to do the job when you got home?

**Marlene:** It wasn't easy. I called all over town to find someone with experience to do this. I did a lot of networking, called PTs at numerous sites, investigated sports medicine options, contacted physical therapy colleges, searched online, all with no luck. Finally someone called me back who had found a PT in private practice. She taped my shoulder differently from the way it was done in Warm Springs, but it feels just as effective.

**Nancy:** What qualifications do you think one should look for?

**Marlene:** I'd ask how the person was trained in Kinesio® Taping—if he learned from a successful practitioner, or took a continuing education course in the technique, or what. Since so much of this taping is done in sports medicine, I'd want to know if my therapist had experience with people with post-polio or other neuromuscular conditions. Also how long she'd been doing this, and if her goals for me seemed realistic.

**Nancy:** Is it true that Medicare and other insurance don't pay for this procedure?

**Marlene:** Depends. There's a pretty good chance of getting it paid for if the therapist bills for her skilled services rather than billing for "taping," which Medicare won't pay for and neither will most insurance companies. However, considering the part this process played in relieving my pain—well, I'd think twice before saying I wouldn't shell out for it.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** I am disillusioned by the US healthcare reform discussion, partly because I don't know who or what to believe. It occurred to me that it is the same problem I have sometimes when reading about post-polio issues. Do you have some advice on how to be sure I am getting the correct information?

**A:** This is a question many of us have pondered through the years. We have an essential responsibility to seek the truth and not allow ourselves to be hoodwinked. It's easy to become confused if we don't take charge, ourselves.

### **LOOK IT UP—DON'T MAKE IT UP**

Remember when the move was on to get people to use the word "disabled" rather than "handicapped"? A few proponents invented a sensationalized version of the origin of the soon-to-be-discarded "handicapped," insisting it suggested pitiful beggars standing on street corners, *cap in hand*, pleading for alms. (Thus hatching, as etymologies go, the nonsense word *capihand*.)

A quick glimpse in the *Oxford English Dictionary*, a prime source, always straightens things out. Checking here would have revealed that the word handicapped derives from *hand in cap*, a phrase referring to a complicated game of chance involving, among other things, reaching into a cap with the hand—thereby creating the word *handicap*. Its definition, befitting the game, points to a burden of some sort that makes it more difficult to have an equal opportunity. HUGE difference.

I want to be aware of that difference. I can't afford to let myself be bamboozled, misled, unfairly influenced. Do I allow others to play on my fears and emotions? Do I listen for solid truth? Have I trained myself to recognize outlandish statements, manipulations of my thinking?

### **THE REAL DEAL**

Question number one: Does what I'm being told make good sense?

True experts exist. Good solutions are available. Survivors returning from PHI's 2009 Conference expressed high praise for the excellent practical information they gleaned from their sessions. New stuff. Unusual and innovative stuff. All delivered to them by experienced pros in their field.

Often I get a clue that I'm working with experts when I'm dealing with individuals who launch ideas or document facts. These kinds of people have no vested interest in steering me wrong or leading me to an outrageous conclusion. I'll place my trust here.

There's a great difference between information found on a website featuring well-researched medical articles—and one that merely relies on the chatter of casually-cognizant polio survivors. Which should I believe? Truth only exists in the truth.

I've gotten excellent help at medical libraries, where trained librarians can guide me right where I hope to go. Sources like CNN.com's regular "Empowered Patient" feature can be enlightening. Networking works—PTs, OTs, doctors, other professionals can give us exceptional leads. PHI's website offers an enormous number of resources in a wide variety of directions. Websites of institutions of known quality, like the Mayo Clinic's [mayoclinic.com](http://mayoclinic.com) and the National Institutes of Health's [nih.gov](http://nih.gov), can be most beneficial.

### **IN THE END**

But no matter where I look, I know I'm the one who must make sense of it, the one to decide the worth of the information I'm considering, whether it refers to health care reform, polio issues, or frankly, anything else.

Emerson says that every mind is given the choice between truth and repose. Sounds about right to me. If I'm dedicated to the search—exercising my curiosity, making the effort, refusing to stop short, declining to accept someone else's easy (and often incorrect) answer—I'll know when I get to the truth.

I hear ya, Ralph! I'm crawlin' off my couch.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
([n.carter@cox.net](mailto:n.carter@cox.net))**

**Q:** A friend who had polio told me that since he uses a cane, people give him more room so he has less fear of being bumped by others. He wishes he used it a few years earlier. Me, too! How can we help people "get over" the fear of looking disabled?

**A:** Fear can be so self-destructive, can't it. Early support group organizers ran into the problem of people's not wanting to appear disabled again and again. We'd call polio survivors to interest them in attending meetings and would get this frequent response: "You know, I think I'd be so out of place there—I don't look disabled. People can't actually see that I had polio."

Then, being assured that there would be many others in that same situation, they'd show up at the meeting—with one leg two inches shorter than the other, or a withered hand, or obvious scoliosis. For whatever reason, they told themselves they didn't look disabled. Was this fear? What did "looking disabled" mean to them?

Recently a woman who, at the least, wore a short brace on one leg from the beginning said, "I didn't think I had a disability. Nobody told me I couldn't do things. The issue was whether or not I could perform, not whether or not I wore a brace."

So disability doesn't have to be a stigma. Not everyone is concerned about what others think of their using a cart or walking with a limp.

Perhaps the fear of looking disabled has less to do with how we believe others perceive us than with how we see ourselves. Will "they" think I'm odd? stupid? helpless? worthless? These are *our* fears. Do they truly reflect society's conception of who we are?

Since the advent of the ADA, many of us realize a newfound kinship with the rest of the world. Often we can get *there* now. And where physical obstructions still exist today, tomorrow they may not. Clearly others care more than before about making our surroundings serve us better. Some of them look with refreshing understanding upon disability. Can we say as much about the barriers in our own minds?

As for how we might help people "get over" the fear of looking disabled—maybe we should introduce them to this wonderfully auspicious line from polio survivor Dr. Arnold Beisser's *Flying Without Wings*: "Acceptance with dignity is surrender without a sense of capitulation."

That's what our friend above finally did, isn't it. He accepted his disability—found a way to allow himself to be OK with it. He discovered the good in using a cane, created a positive reason to go for it. That's acceptance with dignity. This is an inside job. Nobody else can do it for us.

It's a choice. Say I roll into the sexy nightie shop and the cashier pretends she doesn't see me—reaches right over my chair to wait on the guy in line behind me. What do I do? Take it personally? Get angry, bemoan my disabled state, feel ashamed, wish I'd never thought of coming into this store?

Or do I say to myself, "Poor baby—she doesn't have a clue," move in closer, read the name tag she's wearing, smile, and say in a cheery voice, "Hey, Gladys, let me help you reach these pajamas so you can ring them up more easily." I know which response is going to make me feel better. And feeling better is in my best interest.

Truth is, we all do what we want to do. Me? I think Beisser is right. I choose acceptance.

*Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

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## Polio Survivors Ask...

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** My wife, who had polio, and I are in our late 70s and have been married for 52 years. We had our interactions down pat until we both started having medical problems. Do you have any ideas on how to keep the problems from overwhelming our relationship?

**A:** Sometimes it's difficult, I know. My husband is 81 and I'm 73. Amid a never-ending parade of ailments, he's had a major heart attack and two cancer surgeries; my vigorous PPS has been peppered by a colorful variety of other health issues. We've been around since the polar ice caps froze over, and we've been through it all. For what it's worth, I can tell you what we do.

Each of us understands we have no control over the other's physical condition—nor indeed very much over our own. But as long as life goes on, we deal with it. We focus on what we *can* do. On wanting "what we have" rather than insisting on having the elusive "what we want." Acceptance. Serenity.

Start with this: He's always here when I need him—and I am here for him. He takes me to the doctor and holds my hand and opens the ketchup bottle for me when the cap won't come loose. I write a poem for him and fold his socks.

It helps that we truly like each other. I love everything he does—well, almost. Who wouldn't smile at a shelf of canned veggies arranged alphabetically by her librarian hubby? Or clothes closets in which he's made the color of each hanger match the color of the garment it holds? It's these little things that count.

We're a great team. We think a lot alike. Once I chose some dining room wallpaper that the decorator hated. "Your husband will never go for that," she declared. "Let's see," I said as I slammed shut the heavy book of samples and called him up from the basement. With no coaching whatsoever, he looked until he found the wall covering he preferred. Yes. Exactly the one I chose. He knows what books to get me; I can pick a movie he'll enjoy.

He makes me laugh. We don't just play a game, we banter our way through it. Last week he got me a terrific spelling game for my birthday. After I beat him two to one, he said, "I'm at a real disadvantage here." It *is* hard to play on this bed. The game board won't lie flat, so his playing pieces keep slipping off; he can't reach the cards from where he must sit. I thought maybe we could change something. "What disadvantage?" I asked. "I can't spell," he said.

We talk a lot. Sometimes about life or philosophy or simply some little nothing we want to discuss. Recently a friend loaned us a DVD that suggested this question: "If Heaven is a memory, what one memory would you choose?" It's long been a favorite theme of mine—that one pivotal moment that made all the difference. The two of us don't live in the past, but sometimes it's fun looking back.

We're not the two we used to be. Time and circumstances have seen to that. But what's inside draws us closer every day. We take advantage of it. "I love you," he

tells me. And I, catching the secret meaning of the phrase, respond in kind. We're who we are today. And that's enough.

We take today seriously. It's all we have, in fact. Right now. We try our best to make the most of it.

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** I am 58 years old and I attended a support group meeting recently. I will never go back. The members were friendly enough, but the message I heard over and over again was this: "You look good now, but just wait. I used to walk, too." I suppose they mean well, and I could attend and learn what I can from them, but I haven't because I can't get past their feelings of resentment. Can you alert the groups that this is a problem?

**A:** Whoa! What on Earth. . .!

Surely these polio survivors know that nobody can predict with any certainty what will happen to any other polio survivor. They can't actually make more than a wild guess about their own prognosis. Our original polio was different in as many ways as there were people who contracted it. Post-polio is the same. It's nonsense to pretend otherwise.

Frankly, I don't think it would improve the situation for anyone to notify this group that there's a problem. If their leaders haven't figured that out by now, hearing it from someone else won't change their minds. How many polio survivors does it take to pass through the revolving door of poor meetings before someone catches on? People have been offering ways to avoid the pitfalls of such meetings for years. Groups either stop the foolishness or they don't. Simply put, this group likes what they are doing; if they had wanted to change, they would have.

There has to be a different answer—and I think I know what it is. A little over twenty-five years ago, I telephoned Gini Laurie, the legendary founder of what is now PHI. I had never heard of a post-polio support group; indeed, I had never heard of post-polio. I knew nothing. But I was seeking help that I desperately needed. We talked for quite a while, and then she said to me, "Why don't you start a Nebraska post-polio support group, Nancy?"

It's as simple as that! You want a good post-polio support group? Start one yourself!

You don't have to be a veteran of the post-polio wars. All that's required is the determination to have quality meetings. Get started: get the word out. There are plenty of places to post free notices for such an organization. Polio survivors turned off by meetings like the one you describe will be waiting in line. And there will be

others, too, to get some new blood flowing. It only takes a few members to have a top-notch meeting.

Truly excellent information abounds these days. Start with this outstanding PHI link: *What Is a Support Group?* Spend time with the PHI website. Read everything they have regarding developing healthy, helpful meetings. Check out Lauro Halstead, MD's book *Managing Post-Polio, Second Edition*, and absorb the ideas about support groups in chapter 9. PHI's directory may help identify medical experts as speakers. More leads will materialize out of the blue.

Sit down with the other polio survivors and talk through what you all want for this group. What kind of meeting does it take to make members feel better when they leave than when they went in?

Most of us have learned that talking endlessly about the problem never produces a solution. And trying to one-up each other's horror stories is nothing but self-defeating. Is this what polio survivors look for?

Worthwhile support groups offer the kind of information and emotional support it takes to weather the storm. Members listen thoughtfully—and encourage one another to express themselves. We let our empathy show our loving, human, and yes, even fun sides. We discover that the support we give others is a gift to ourselves. That's what keeps us coming back.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** I attended a support group meeting recently and was very uncomfortable with the denigration of physicians. I know from experience that some health professionals are not familiar with the management of post-polio problems. However, wouldn't we all be better served if groups sought out physicians in the area and worked with them?

**A:** In a perfect world, we would all have curious doctors who listen to our every word, spend time with us during an office visit, and dedicate themselves to following the examples of post-polio experts. They'd scoff at the idea of pushing pills to mollify their patients or ordering procedures to appease their malpractice attorneys. And they'd always be pleasant.

Also, I'd be able to buy shoes narrow enough to fit my feet—and Coca-Cola would still be selling six-and-a-half ounces of pop in little glass bottles.

Clearly, this is not a perfect world.

While we may not have perfection, however, we *do* have opportunity. Is there a better setting than a post-polio support group for hatching a plan to recruit doctors and other health professionals to jump onto the post-polio bandwagon?

This, then, begs the question—why would a group choose to spend its time bad-mouthing the very individuals who could be helping them, and in the process create a negative atmosphere bound to ensure that members will leave their meetings grumbling and unhappy?

Perhaps groups don't give themselves enough credit. It may never have occurred to them that they might have the power for change that they actually do have. Think of this:

WHAT IF—

- Individual members asked specific doctors for advice on how best to recruit physicians to our cause—and then took this information back to their groups to bring it to life?
- Groups invited a small panel of doctors to a meeting to discuss their points of view on ways to interest other physicians in devoting more attention to post-polio problems? What would it take? How would it be helpful to doctors to have post-polio information? Groups would then grab that ball and run with it.
- Groups contacted their local medical associations to determine how to place a recruitment article in that association's newsletter—and ask for additional suggestions for accomplishing our enlistment goal?
- Groups arranged with local hospitals for a post-polio expert (provided at group expense) to speak at education/training sessions to pique the interest of participants in post-polio issues? (PHI has a list of experts who might help with such a project.)
- Groups conducted a mini-publicity-campaign by engaging their leading newspaper's medical columnist to write a serious plea for recruiting doctors?
- Groups regularly invited specific local doctors to speak briefly about a post-polio issue at their meetings, engaging them in positive and educationally valuable question and answer sessions (be careful—no ambush attacks) following their talks?

Sure—there are a million other ways. Start buzzin'. Get some positive energy swirling in meetings, and our fantastic post-polio thinkers will come up with a terrific game plan. Start small. Get detailed. Be fully prepared.

Next Up: Everybody follows the plan. Let there be no mavericks running around in the hills, going off on tangents that might sink carefully devised projects. Work as a team—where everyone picks roles to play that fit their capabilities and inclinations.

Then, let 'er rip! Everybody involved will gain from the effort. We may not snatch one doctor for the cause, but participating members will be whistling a happy tune come meeting time, nonetheless. And who knows, some far off doc may hear the echo and, well.... There's simply no way cooking up a little pizzazz in a group is a bad thing.

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**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** The older I get, the older my friends and families are, and it seems that they have one illness after another. Then there are the kids and grandkids, all with their hectic lives. I worry about them; I worry about the state of the world; I worry about the cost of things; I worry about my money lasting. All this worrying can't be good for me. Do you have any suggestions that are practical and realistic?

**A.** It's a bit of a double whammy to be worrying about worrying, isn't it. Our imaginations go berserk. Our fear directs us to limitless apprehension. We lose all perspective. And if anyone doesn't believe this is bad for our health, Google "illness caused by worry," and that astounding list should erase all doubt quickly.

So the question becomes what to do about all this stress.

Charlie Brown had a solid idea. Remember the cartoon where he declares he has come up with a new philosophy—from then on he's only going to dread one day at a time? That's our Charlie. He's right about "one day at a time," though.

I think I get it. These are the facts: I have only right now, today, this minute. I am never going to reach tomorrow, no matter how much I fuss and fume. Furthermore, I will never know what to expect or be able to manipulate all of life's circumstances to my satisfaction. If what I want is power over everybody and everything, I'm screwed. I'm just not capable of changing other people to make them do what I want. But there is a solution—and here's the truly big deal—I can change *me*.

Once I understood this, I found I could be in charge of my attitude and create joy where worry once resided. It's a decision I make. I can use my energy for positive ventures rather than for anxiety. I can phone people who are sick and tell them I'm thinking of them. I can allow others to determine how they want to live, understand that their frantic lifestyles are their business, not mine, and never criticize or judge them for the choices they make. I can budget my finances, not spend foolishly, and trust I'm doing the best I possibly can. Any of this is an antidote to worry.

When I was a kid my mother taped a little magazine clipping to the mirror above the bathroom sink. On it was written "God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference."\* I read it over and over.

It puzzled me at first. I thought I was supposed to be able to change everything, that I was somehow a failure if I couldn't make wrong right or bad better (or at least my version of these conditions). I was too young to understand that there are things I merely have to accept as they are. I had to learn how to do my part, how to

distinguish what I can change (mostly me) from what I cannot (mostly you) so I don't drive myself and everyone around me nuts.

Here's what I discovered: Fretting today is not going to lessen any hardship that may lie ahead. This only adds a day of unpleasantness to my life. That's not what I'm looking for.

What I do want is peace. Without a doubt, I'll continue to be faced by challenges. But I have every faith I'll be able to handle whatever comes along. That's part of the bargain.

*\*Serenity Prayer, widely attributed to Reinhold Niebuhr*

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## **Polio Survivors Ask...**

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
(n.carter@cox.net)**

**Q:** In the January 2010 column, you mentioned parenthetically that speakers' expenses should be at the group's expense. We have no source of income and I was wondering how other support groups raise money.

**A:** There may be a few misguided souls who believe that the words "disability" and "destitute" are synonymous. The rest of us know better. If a support group has members, it has a source of income.

First up: donations. Of course everyone is not in the same financial bracket. No problem. If the cause is good, those with more give more, voluntarily. Those who are blessed with wealth understand when it would help for them to pick up the slack, and they always do—as long as others are doing their part and the result is worthy.

Just to dispel any notions that those who are limited physically must also be limited in every other way: Two of the biggest polio survivor donors I have known were quadriplegics who earned every penny on their own, after polio. Great abilities—and generous hearts.

If a group has decided it's essential for them to fly-in a speaker from halfway across the country, more than likely it is going to have to reimburse expenses. Most expert polio speakers will accept a sensible honorarium. They understand our situations and do their best to make their trips affordable. Another way of doing this is to offer speakers a certain amount, explaining that this is all your group can afford. It would then be up to the speaker to accept or decline. That's it. It's a business deal. If members are enthusiastic enough about importing such a speaker, they will figure out a way.

Cash isn't always needed. The support groups I know don't pay local speakers. Pulmonologists, orthopedists, neurologists, anesthesiologists, physiatrists, physical

therapists, respiratory therapists, occupational therapists, assistive technology professionals (and on and on) are among the many professionals with a *pro bono* ethic who will not expect compensation when they understand the purpose and financial status of our groups. They gain as much from speaking with post-polio support groups as we do by having them there. Win/win.

As always, we show gratitude with a formal thank you note.

Our support groups have a history of finding ways to provide excellence at little cost. For instance, our meeting places are usually free or may ask for a token monthly fee—locations like churches, hospitals, senior centers, assisted living centers, nursing homes, public libraries, even certain office buildings. Many places have meeting rooms that are left unused at times. If deserving groups can be responsible “squatters,” they’ll find great places to meet, gratis.

When groups do need money, and donations aren’t enough, fundraisers are a sure bet. A cookbook is always a winner—members send their treasured family recipes, and a professional cookbook company produces the books. Members then must sell them to everyone in sight—their families, neighbors, church friends. They can even have a bake sale, cooking up goodies from recipes in the book to convince buyers this book is a must-have purchase.

Or maybe the group would rather get outsiders involved. Civic-minded organizations often devote time for projects to raise money for laudable outfits like ours. Or individuals (such as Tupperware or Pampered Chef salespersons) may be willing to donate part of their profit from a party. Look around—the possibilities are amazing.

Groups I know have held a zillion really terrific fundraisers. I’ll bet yours has, too. Tell PHI about it! Help us make an impressive list of ways post-polio support groups raise money. Just send it to me: [n.carter@cox.net](mailto:n.carter@cox.net). Put “PHI—MONEY” in the subject line.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

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