

Post-Polio Thoughts

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

Nancy Baldwin Carter is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

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Why We're Here

A while back a nutritional product's flyer, filled with impressive success stories, made the rounds. One of its claims had to do with a polio survivor, unable to lift her legs for 60 years—until she regularly began taking the product. Because of this miracle elixir, the ad says, she can now lift her legs to her chest. Say Hallelujah!

The week after that, the *New York Times* featured an article about the late effects of polio in which it mentioned that a certain polio survivor found her deteriorating breathing muscles so debilitating that she was forced to take early retirement. She now uses oxygen most of the time to help with her breathing.

We all get a good feeling when others discover solutions. Let's hope that's happening for these two survivors.

One wonders, though.

A magic potion that brings to life muscles that have lain dormant over half a century? Does that have the ring of plausibility to it?

And oxygen therapy for what very well could be respiratory muscle weakness? When we know that individuals who are developing progressive respiratory failure risk death unless the condition is treated with *ventilation*—not oxygen?

Enter now dynamic post-polio support groups.

Let's say these two survivors find their way to our doors. Other members welcome them and gently guide them down the path to good decisions. The group directs them to reputable materials they can read about their conditions, and they hear about appropriate doctors to talk with and learn what questions to ask.

If it turns out that what they need are secret formulas and oxygen, wonderful—they already have them. They should feel reassured. On the other hand, we may, at the very least, save one of them some money in snake oil fees, and perhaps even stumble into the happy circumstance of helping to save a life.

Amazing power, put to healthful use.

Think of it—what a history for responsible service our post-polio support groups have! More than twenty-five years of newsletters featuring reliable research and current post-polio information. Of advocacy, spotlighting member needs in every direction. Of support, providing personal assistance, encouragement, referrals, and meaningful group discussion. And all of this through reaching out the hand of

friendship to provide take-it-to-the-bank-trustworthy and right-on-the-button-accurate help and inspiration.

Sometimes our groups don't hear enough cheers from the sidelines. The tremendous job we've done gets lost in each day's mundane routine, lost in the haze of time. Groups may hit a momentary snag and begin to wonder about their viability.

Then the mail comes—and with it messages like this one recently received by a support group leader: "Seeing your latest newsletter brings a flood of so many memories, dating back from the time I met one of the most helpful persons on my road to learning all I could about post-polio. That person is you, my dear friend. I don't know if I would be in nearly the same place as I am now, both physically and emotionally, without your strength of purpose, and the knowledge you are always there, so eager to share about what is happening to us as we continue through this mysterious journey."

And with that heartening boost, we know it's time to get back to work. The good we do sustains us. We know we cannot stop now.

THIS is why we're here.

Building Bridges

At first she irritated me. A relative newcomer to a literature study group I attend was heading my way, and I didn't want to deal with her. The previous week she had given me a condescending pat on the head as she threw a bit of baby-talk at me, a common reaction of some folks when they first encounter a person with a disability, and I didn't want any more of that.

But she was rushing toward me full-tilt, and I couldn't see a way to escape her this time, either, so I gritted my teeth and smiled.

"Oh, it's like a miracle!" she gushed. "I can't believe it! I didn't know you can walk."

Of course she didn't know I can walk; she didn't know me at all. Clearly she knew nothing about polio, either. From the very beginning, she had been making a lot of unwarranted assumptions about my capabilities.

That day she had seen me rise from my power chair during the meeting to hand out some pamphlets, not realizing I use the chair mainly for going distances and, since I cannot sit in regular chairs, for sitting. The last thing I need, I thought, is some irritating ratchet-mouth trying to engage me in a conversation about faith healers or wheelchairs.

I was building quite a case for being unpleasant to the woman when it struck me: Wait a minute! I didn't know her, either. I had no idea who she is, and already I'd decided she's some addlepated airhead without a clue. To be honest, I had no hint what she wanted—or even if she wanted anything at all.

Immediately I thought of a little plaque my grandmother used to have hanging in her kitchen: Presume Goodwill. A fine place to start.

Quickly it became essential for me to see how the woman and I are alike. My philosopher husband calls this "Immersing yourself in the 'what is'—joining the cosmos."

And so we chatted. She was a kind woman with lovely eyes. Her family came from Italy, and she had learned their secret to making the best biscotti in the world, she said—and offered to bring me some. The recent death of a loved one weighed heavily on her. She was reaching out the only way she knew how.

Over time, searching for the inner value of the woman led me to realize something else: When my focus was on finding her, I was no longer touchy about me or how she viewed my disability. I made an effort to see her positively and to see things from her vantage point. This was not simply a lesson on tolerance; we were becoming friends.

Amazingly, the more I found to appreciate in her, the more I saw to appreciate in me, too. In spite of my initial opposition, the more I knew of her, the more alike we seemed—and that's what I was looking for. My willingness to view her in a new light changed me for the better.

The experience made me realize, once again, how easy it is to be wrong about people. And how ill-served I am by not being open-minded enough to give the other guy a chance, not taking the time to build relationships. It doesn't matter whether it's a stranger on a park bench or Aunt Suzie. The smallest effort can make a huge difference.

It's a clear path to serenity and happiness. Puts a smile on my face, just remembering.

Whose Life Is It, Anyway?

My friend Mary called with what she termed a dilemma: She has a friend whose mother won't take a bath. "It's been three months," she said. "The woman refuses to bathe. Her daughter promises her a night out at her favorite restaurant if she'll clean up, but she won't do it."

"So?"

"What do you mean, 'so'? She *stinks*. She's a health hazard."

"A health hazard? To whom? Is putrid stench catching?"

"She's dirty. Maybe she could die from her own filth, I don't know."

"Good for her! I love it when people have creative ideas about their own death, don't you? How many folks do you know who have died from personal malodorousness? Here's an inventive mother with spunk!"

"Stop joking around. This is serious. She shouldn't be allowed to go without bathing. I'm telling you—she *reeks!*"

"What you mean is her gaminess repulses her daughter."
"Well, it certainly does."

"Is she incompetent? Under guardianship?"

"No."

"Does she live with others where there are covenants about bathing?"

"No. She lives alone."

"Does she have a job that has 'offensiveness' rules?"

"She's retired."

"Then leave the poor soul alone. If she wants to stink, let her stink."

"She's not going to have a friend left."

"If that's true, then she has a choice to make, doesn't she. Either she hops into the tub before getting together with pals—or she doesn't. But this is for sure: I ain't makin' that decision for her."

When did this country turn into such a nation of do-gooders? Outright busybodies? When did it become O.K. to make other people's personal business *our* business? What is wrong with us!

Of course we want to offer a hand to those who ask for assistance. We want to be there for the disabled woman who's seeking an affordable power chair so she can get to her doctor's office or to the mall. We want to be on call for the elderly man who's looking for someone to change the sheets on his bed and vacuum his carpet. We even want to give aid to a mother who requests help taking a bath.

I'm talking about people who are mentally alert and quite capable of making up their minds. They know what they need—and what they want. Some may simply require a little outside help. What they do NOT need are wildly opinionated, totally uninvited pushy "supporters" who believe they have the right to determine how others should live. If individuals happen to choose a path detrimental to themselves, fully cognizant of the consequences, why should it be up to any of us to force them onto a different route?

What's next? How big a leap is it for some self-appointed saint to decide the solution for a guy requesting help changing his sheets is to pack him up and trot him off to a nursing facility? Do we have a prayer of convincing such meddlers that health care changes now encourage our having the freedom to get the help we want and need, even in our own homes?

Let's be sure independent living involves independence.

Oh, by the way—Mary called back. Things changed with her stubborn friend's stubborn mom. Once everyone got off her back, she grabbed a bar of soap, filled the tub for a steamy, bubbly bath, and started soaking. Hmm...

The Doctor Is In

No sooner do we find ourselves rejoicing over the promise of affordable health care for everyone, than up pops the brilliantly diamond-studded temptation called concierge medicine.

You may have seen a version of this—the TV show where a former ER doc and his accountant brother head for a posh life in the Hamptons, setting up a glittering medical practice out of their mansion, treating the wealthy wherever they might be. High-priced adventure. Chic clientele. Unexpected, 24-karat excitement. And this is not necessarily all fantasy.

Pot-of-gold medical care has been lurking on the sidelines for at least the past dozen years, yet for most of us, it's still a concept way beyond our wildest dreams.

Many polio survivors have longed for these concierge medicine miracles:

A doctor who . . .

- 1). . . personally returns phone calls and faxes.
- 2). . . spends enough time with us during an office visit to listen to what we have to say and to discuss our condition with us.
- 3). . . schedules office appointments exactly when we need them.
And the greatest plum of all—maybe even a doc who . . .
- 4). . . makes house and office calls!

Think of it. Chances are, we'd get to see a real physician every visit. Examining rooms could be large and comfortable. Pristine, even. Maybe hardly any need for a waiting room. The staff might be smiling, relaxed, trained to leave medical decisions up to the doctor. And the doc—perhaps he'd come in, sit down, breathe easy, and relate. The possibilities are dizzying.

All it takes is money.

Got \$2,500? In Omaha (it varies from city to city, practice to practice), you can buy your way to a primary care physician with maybe 300 or 400 patients, rather than the usual 2,000 to 4,000. It's as simple as paying that basic annual fee.

If you up the ante to \$4,000, an Omaha patient gets an expanded level of care (things such as your doctor's oversight while you're hospitalized). In certain areas, depending on the circumstances involved and what services are provided, some memberships could cost a whopping \$20,000 a year.

Without question, primary care docs making the average approximately \$200,000 annually in a standard practice could find the concierge medicine concept mighty appealing—the perfect incentive needed to keep them satisfied personally and professionally.

And while nothing suggests that these doctors are better qualified than any others, at least they're likely to be available 24/7 and have more time for their patients.

Some concierge medicine docs don't accept insurance and may institute other office practices to cut down on administrative overhead. Don't worry—if you ask all the right questions you'll understand what you get for your money. Things work out.

So hey—you want special care? It's as easy as pulling out your checkbook!

Maybe it's the "designer car" complex: While my little yellow Volkswagen may take me where I need to go, getting there in the luxury of my own Maybach Zeppelin could be irresistible.

Know what I mean?

Changes of Heart

"You just don't get it," she said.

My friend was accusing me of having "no idea what it's like to be handicapped." No milk of human kindness coursing through my veins, apparently. No empathy.

In a sense, she's right. Never mind that I spent a year in hospitals, fighting my way out of total paralysis when I was a kid. Haven't raised my right arm since. Haven't had a neck that could hold up my head. Never mind. And post-polio paralysis increasingly riddling my body for the past four decades. Never mind.

When the high school principal at my first teaching job, unaware that he was being politically incorrect, told me I was the most normal cripple he'd ever seen, I knew he meant to compliment me. Odd, I thought, that he would think of me as a cripple. I saw me as a teacher. A good one, too. And a daughter, a sibling. And a friend. But I never thought of myself as a cripple—or even a person with disabilities.

Of course I know I have physical limitations. Nobody with a body as erratically functional as mine could miss the fact that often it's not working well. So what? I always get the job done. One way or another.

The thing is, we don't all think alike. Certainly not my friend and I. My disability seems *normal* to me; it's simply the way I am—it's me. Not non-disabled, but *me*. So my arm doesn't work. How does that feel? Well, after sixty-two years of this, it feels *normal*. Does my disability seem normal to *her*? Probably not. Am I in denial merely because I don't think of me as she does? Hardly.

So what *is* it like to be handicapped? Our answers are shaped by our personal experiences, our philosophies—to her it's one thing, to me, another. Both valid. How I feel inside about disability does not necessarily have to reflect the condition of my body.

Years ago I had a doctor who berated me for suggesting that my pain and weakness could be polio-related. "Nonsense," he said. "I had polio when I was in medical school and nothing like that is happening to me." He wrote the name of a shrink on a prescription pad and said, "Here. This will help you." Adios, doc.

Some time later, he ran into my husband at the library. He was retiring, he said, stepping down because he was undergoing symptoms of post-polio syndrome. He

apologized. He had seen the light. A bit of revised thinking when it became *his* dysfunction. Was he learning what it's like to be handicapped?

Obviously having had polio did not make this man a better "polio" doctor. But I cannot forget that the most amazingly knowledgeable and wonderfully understanding polio doctors in my life were not polio survivors. Did *they* know how it felt to be handicapped? Does it matter?

Here's what matters to me: I want independence. I want to be the one to decide. I want to do what I can do. I want to accept me as I am and love the life I live. It's an attitude. A state of mind.

Do I know what it's like to be handicapped? Define handicapped.

Movin' On

We're talking civil rights here. Big Time. "Our crowning achievement of the 20th Century," as Justin Dart, Jr. called it—the passage of the Americans with Disabilities Act—the ADA. On July 26 we celebrated its anniversary. Twenty years of freedom.

Immediately after the ADA went into effect, it became clear that this Act would alter more than the law. Attitudes all across the country began to change, as well.

People everywhere began to see us in a different light. A much-loved comic strip suddenly featured a popular teacher who used a wheelchair. Individuals with disabilities began popping up in TV commercials. Smiling strangers held a heavy door for us—or realized we had a place in line. We became visible.

Of course challenges followed. Many of us remember the goofy Catch-22 court decisions that limited the ADA definition of disability to its most useless extreme. More than one piece of outrageous nonsense belched up by official detractors even left us concluding that the only people eligible for ADA protection against job discrimination would be those too disabled to work. Obviously, we needed to clarify.

So Congress moved in to tighten up the language in the ADA, making it harder to misinterpret, more difficult to distort. On September 25, 2008, the Amendments to the Americans with Disabilities Act was signed into law.

The purpose of this Act is "to restore the intent and protections of the Americans With Disabilities Act of 1990." No more twisting what Congress meant out of shape by Supreme Court rulings or others' wrong interpretations.

To begin with, the definition of disability remains the same ("an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment"), except in the Amendments, Congress makes it clear that this is to be understood in the broadest way possible.

Let there be no doubt. If I'm disabled because I have only one leg, but my loss has been corrected by the use of a prosthetic device—guess what? I'm still disabled. Some people's idea that my impaired body is no longer disabled because I'm wearing a brace or because glasses improve my myopic vision, simply will not wash anymore.

Take a look at these Amendments online. Or perhaps better yet, start by clicking onto the PHI website's informative article, "[The ADA Amendments Act of 2008.](#)" A word here, a phrase there—now nobody can miss the teeth in this Act. Look all the way through. Think about what we know about discrimination on the basis of disability. See how we view a "reasonable accommodation."

Oh no, we're not home free yet. There will still be those who try to ignore what's right for those of us who are disabled. We have more changes to make, many roads left to travel. But we're on our way.

Today the contest is different—we have the ADA to fight for us. Look at the outcome when a U.S. District Court reminded the State of Florida of the ADA-guided Olmstead decision (the Supreme Court's 1999 integration mandate). When that state tried to install a quadriplegic into a nursing home instead of providing her with the required services allowing her to live at home, they lost the battle. ADA to the rescue.

The ADA has a way of convincing people of our mutual and equal worth, and that each one of us has a role to play in achieving this equality. Today we have ADA power to count on—thanks to legions of contenders from the disability world and our fighting, caring friends.

Opportunity Knocks

Have you heard? Rotary International (yes, the same wonderful service organization that has already contributed over \$600 million to polio eradication worldwide) is taking a look at the late effects of polio! Much of the September issue of their magazine, *The Rotarian*, is devoted to post-polio. [Take a look!](#)

That's you and me they're talking about—and some of *them*, too. A certain number of Rotarians are polio survivors, remember. All of us are hopeful that this glimpse into the critical needs of polio survivors in developed countries, such as the United States, will give us the boost we've been longing for.

More good luck: Some Rotarians are also doctors. Perhaps more than anyone else, they understand the need for post-polio research to unlock the puzzles of this condition; they realize the importance of training knowledgeable health professionals.

Their magazine sets the scene perfectly for PHI's current WE'RE STILL HERE! project. It's this easy: First, Rotarians read all about the late effects of polio in *The Rotarian*.

Then, polio survivors arrange to address members at a Rotary meeting. We give our personal touch to the story by mentioning a little bit about our own post-polio journey. They can learn from our experiences, and we can paint a thoughtfully beneficial picture for them. We thank Rotary for all they've done so far and congratulate them for deciding to continue down the post-polio path.

We describe what having more doctors and therapists trained in post-polio issues would mean in our lives, personally, and to others like us. We mention the need

many have for equipment, like braces and wheelchairs and chair lifts and other assistive devices. We emphasize the worth of research in finding a reliable diagnosis, with the further hope of then discovering dependable methods of treatment for post-polio conditions.

We answer questions in a short Q&A session, if Rotarians want this, and invite them to take a stroll through the PHI website (www.post-polio.org), with special attention to the Advocacy tab.

And finally, of course, we have the [donation form](#) for groups or individuals who care to contribute. For decades, PHI has played a vital role in effectively reaching out, dedicated to educating health professionals and polio survivors as well, always serving those in need. Here's an opportunity to ensure the future through PHI's continued research projects, dissemination of information, advocacy, and support.

Voila! Rotarians get new ideas through this collaboration—they see how they can continue to improve the lives of many polio survivors, at home and abroad, struggling with a myriad of post-polio problems.

Those of us participating can be sure our words are heard when we present our talks to a group of Rotarians. This is an interested audience. They've been working in this field for fifteen years. If anyone is caught up in the story we have to tell, Rotarians are.

It's up to us. This is the time and the place. What could be easier? We have only to dash to the phone and book a speaking date with a local Rotary meeting. They're waiting to hear from us. They all want the message behind WE'RE STILL HERE!

That's the white pages. Under Rotary.

Part I — Opening the Door

The subject doesn't come up much. Not many in the post-polio community seem to want to talk about it.

...Even though the American Medical Association declared it a disease well over forty years ago, in 1966.

...Even though the prestigious medical journal, JAMA, published the results of a two-year study that says it's a "primary, chronic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations."

...Even though this disease is often progressive and fatal.

By now you may have guessed—the subject here is ALCOHOLISM.

Sounds serious, doesn't it. Knowing this, would we still rather not talk about it? Would we prefer to pretend there is no problem? Are we so steeped in ancient myths of shame and secrecy that we can't bear the thought of facing the alcoholism reality?

Of course not!

We're talking about it because the U.S. Department of Health and Human Services says that people with disabilities have an even greater likelihood of having alcoholism than the general population's risk of at least 10%—perhaps as much as two to four times greater. That includes *us*—nearly 800,000 U.S. polio survivors, as many as 20 million worldwide.

We're talking about it because the alcoholics among us are our spouses, our children, our parents, our siblings, others we love—maybe even you and me—all people with a treatable illness who can find help.

Turns out alcoholics aren't necessarily people who end up lying dead drunk in the middle of the street—or bums living under the bridge. Could be they're doctors or carpenters or waitresses or men of the cloth. Some only drink periodically. Others don't drink in public. Alcoholism doesn't seem to care. Alcoholics are unlike in so many ways. But the one thing they all have in common is an obsession for drink that eventually leaves them afflicted in mind, body, and spirit.

Alcoholics, perhaps unaware of all the consequences of excessive drinking, may be ruining more than relationships and self-esteem with their boozing. Alcohol takes a terrible toll on the body. It is, for starters, an irritant and a depressant. The list of medical conditions caused or worsened by alcohol is alarming. How about anemia, cancer, heart problems, diabetes, epilepsy, liver disease, kidney disease, pancreatitis, esophagitis, bleeding disorders—plus a long catalog of others. We're talking major physical illness here.

PHI's *Handbook* tells us that certain non-alcoholic polio survivors, who might otherwise drink socially with little problem, should avoid drinking alcohol because of potential problems with swallowing and breathing. Those with post-polio weakness should know that drinking alcohol can impede judgment and coordination, increasing the possibility for accidents.

A lot of denial runs through an untreated alcoholic's head—in fact, denial and its partner, distorted reality, are outstanding symptoms of alcoholism. Such alcoholics find themselves torn apart inside, as A.A.'s basic book, *Alcoholics Anonymous*, puts it, left to face "the hideous Four Horsemen—Terror, Bewilderment, Frustration, Despair." They may be consumed with feelings of sadness, guilt, and uselessness. Often the disease takes a frightfully hopeless turn.

We're way beyond thinking of alcoholism as a "moral weakness"—we simply don't buy that nonsense anymore. Alcoholism is an incurable disease that can be managed, offering alcoholics who are serious about recovery a life of freedom from alcohol. There is hope. There is a way.

Today over two million recovered alcoholics live productive, fulfilling lives through using the principles of Alcoholics Anonymous. They made the decision to seek sobriety on their own and discovered the same path followed successfully by millions of others over the past 75 years.

A.A. is here to help.

MORE ABOUT ALCOHOLICS ANONYMOUS

Interested in knowing if A.A. is for you? Click onto [Is A.A. For You?](#) on the official A. A. website and answer questions that will help you decide.

For much more information, click here: [Official A.A. Website](#)

To find an A.A. meeting, click here: [How To Find an A.A. Meeting](#) or turn to Alcoholics Anonymous in your local yellow pages.

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)

PART II—THE REST OF THE STORY

“It was one of the most popular displays we ever had,” the librarian said. “People couldn’t pass it by. They were drawn by a framed round mirror a local Al-Anon group hung in our tall glass case. In an arc at the top of the mirror were the words ‘YOU CAN SEE WHAT THE DRINKING IS DOING TO THE ALCOHOLIC.’ And at the bottom it read, ‘BUT CAN YOU SEE WHAT IT IS DOING TO YOU?’ Many stood quietly looking at their image in the mirror for a long time. I wondered what they were thinking.”

Al-Anon—the flip side of the Alcoholism coin. Al-Anon is not about the drinker. People in Al-Anon are those whose lives have been deeply affected by someone else’s drinking. That “someone else” may still be drinking or longtime sober; a family member or a friend; drinkers now in their graves or someone in the kitchen this morning. What matters is that this individual still suffers from contacts had with the drinker, regardless of when they occurred. And this individual could be any of us—polio survivors are not exempt.

Sometimes it’s difficult for people to recognize that we, ourselves, need help. Answering the following questions can give us a clue to what the face in the mirror reveals: Do you search for hidden alcohol? Do you pour alcohol down the sink? Do you cancel plans because the drinker is unable to participate? Do you make excuses to cover up for problems caused by the drinking? Do you have money problems from behavior caused by the drinking? Do you think that if the drinker stopped drinking, your other problems would be okay?

Any of this ring a bell? Those answering “yes” to even one of these questions usually find themselves easing comfortably into chairs at an Al-Anon meeting.

“I was slow to talk myself into trying Al-Anon,” says one member. “I thought if the drinker in my life cared enough about me, he’d stop drinking and everything would be fine. I thought I was the *sane* member of the household. Why would I need help? I couldn’t convince myself that my upset stomachs and feelings of anxiety were connected to my husband’s drinking. But others kept suggesting I try Al-Anon, so even though I wasn’t exactly sure why, I finally decided to give it a shot. How could it hurt? Guess what I found there—*me*. And with that, a life of blessed serenity. I never would have dreamed this could happen.”

Another member speaks up: "I tried counseling, therapy, treatment—I was still a mess. Al-Anon was my last resort. Right off I saw that this wasn't happening solely to *me*, that I wasn't the only one without a perfect life. Al-Anon showed me I'm not a victim. I have a right to be happy and have a good life no matter what else is happening around me. I like feeling better about myself. I love the new-found freedom. I will never forget one day, after I'd been in Al-Anon a few months, when I was driving my six-year-old daughter to school. She looked over at me for a minute and then asked the most joyful question: "Mommy, why are you smiling?" How long had it been!

If you're still wondering about you, drop in at your local library and read merely a chapter or two of Al-Anon's basic book, *How Al-Anon Works for Families and Friends of Alcoholics*. If you don't see yourself on these pages, Al-Anon may not be for you. But if you're there, well. . . .

MORE ABOUT AL-ANON

For more questions designed to help decide if Al-Anon is for us—click here: [IS AL-ANON FOR ME?](#)

To learn more about Al-Anon—click here: [HOW WILL AL-ANON HELP ME?](#)

Click here for [AL-ANON FACES ALCOHOLISM 2011](#), a marvelously informative publication provided in its entirety on the official Al-Anon website.

Many more insights on the Al-Anon program can be found on their website. Click here: [OFFICIAL AL-ANON WEBSITE](#)

To find a meeting, click here: [HOW TO FIND AN AL-ANON MEETING](#), or look in your local Yellow Pages under Al-Anon.

RACKING UP SUCCESS

A few years ago Hubby's dentist gave him a scruffily pathetic Christmas cactus that wasn't doing well under her tutelage. He brought it home, put in on his desk under the desk lamp, in front of an east window, next to the room's heating duct, and here it is kept throughout the year.

"Wrong, wrong, wrong!" shriek the experts. "These are tropical plants. No artificial light at night. . . keep them strictly at in a 50 degree temperature half the year. . . water them way less in fall and winter or they'll never bloom. . . stay away from heat ducts. . . place in total darkness 12 to 14 hours each day. . . ." On and on they go with their endless, impossible rules.

But Hubby has a special gift. As a librarian, he may know nothing about growing the Christmas cactus, but he and this plant understand each other. At various times throughout the year, lush green foliage bursts forth with voluminous and gloriously red blossoms. Simple as that.

Who knows. Maybe the plant recognizes Hubby's sincere desire for it to do well, and not wanting to disappoint such an ardent admirer, it does. Whatever it is, Hubby's Christmas cactus cannot be surpassed.

So, experts can be wrong. The road to success may not always be paved with what we've been led to expect.

Each of us can say what we believe it takes to be a success. *We* decide. Intelligence? Relentless pursuit, inventiveness? Good luck? Maybe always getting the job done well signifies success, or coming in at the top of the heap. Does being the chief of staff, the CEO, the hall-of-fame inductee do it?

Maybe genuine success is more complicated; maybe we should also mix in a heavy dose of an often elusive and somewhat mystical element. Let's add possessing the ability to leave others feeling better for having been in their presence.

I think of my Warm Springs doctor, Robert Bennett, M.D., and much later my Rancho Los Amigos doctor, Jacquelin Perry, M.D. Top of their professions, no question, but these are not simply doctors who knew what they were talking about. Beyond that they exhibited a certain touch of humanity that others didn't seem to have. In their hands, patients felt valued, appreciated, unique. With doctors like this, the *patient* comes out feeling like a success.

There are those who believe that having great wealth and power spell success. Others say nobody can be a bona fide success without being kind, caring. Do we have to like ourselves? See the worth in others?

Maybe we should examine how success looks through the eyes of eight-year-olds. Where do they rank the elderly neighbor whose sweet smile always says to them, "I'm glad you're here"? She, who fills the neighborhood with the aroma of her scrumptious chocolate chip cookies every morning, beckoning enthusiastic cookie-lovers to her door. She, who teaches us all to treat others the way we want to be treated.

How about you and me? Who among us is a success? I wonder what the requirements would be.

Perhaps all it truly takes to be a success is a loving man with an uncommon talent for helping a Christmas cactus thrive.

MAY HIS TRIBE INCREASE!

Did you see it? That two-panel *New Yorker* magazine cover? Sort of a cartoon. Here's a little boy in the first panel, red knit scarf around his neck, with matching cap pulled snugly down over his ears. His dad holds him tightly by the hand, moving swiftly on through Rockefeller Center as snowflakes fall around them. The boy stops, turns back, gazes up with concern at a huge bronze statue of the mythical Greek, Atlas, holding up the world.

Panel Two: Same little boy, now skipping happily to keep up with his father. But what's this? The scantily clad Atlas now wears the boy's red cap on his head, the scarf folded warmly around his neck.

No deep metaphorical inferences here. Just a thoughtful kid dancing through winter with his dad. Leaves ya smiling.

Such compassion. Innocent children are good at this. They may not even know us, but they want the best for us. If they think we're hurting, they come rushing to help.

No vituperate outbursts. Not from these little kids. No railing in anger. No spewing of hatred, attempts to incite to violence. No inflaming others to the point of rage or leaving them seething, dangerously close to vicious rancor. That's only adult behavior.

Little kids' minds haven't been corrupted to that point yet. They haven't been twisted by evil circumstance, taught by marginally unstable thinkers around them. They still see goodness and react in kindness.

A few years ago a youngster stood watching me in the lobby of a mall as I sat in my power chair waiting while Hubby got his hair cut. Before long the boy sidled over. "What's wrong?" he asked, leaning in, close to my face, touching his fingers to the arm sling on my brace. We chatted for a moment. I reassured him, and then he was silent, pushing his shoulder against me, tentatively brushing his hand over mine as he pondered the situation.

"Is someone coming to get you?" he asked. I said my husband would be there before long. "OK, then. Bye." And off he ran, satisfied that he didn't need to save me.

We all know adults, as well, who possess such a sense of caring. People who look for the good in others, who appreciate rather than loathe. These are folks who are glad when a country singer is honored at the Kennedy Center for his years of dedication to his art, even though he never was their favorite. Or are delighted when a former president is given the nod for decades of exceptional service worldwide by the Nobel Peace Prize committee, though politically they might not always agree.

It's exciting to see polio leaders being recognized by their peers after their endless willingness to work their extraordinary magic for the rest of us. And it's just as inspiring to see a newcomer rewarded for remarkable efforts on whatever little polio outreach project we're into this year. We all seem to understand there's no room for hostility or mean-spiritedness among *us*. We have some super groups—and outstanding members.

When I was a kid, my mother often read a favorite poem to me at bedtime. It's Leigh Hunt's *Abou Ben Adhem*. I still remember some of the words, one line especially: "Write me as one that loves his fellowmen."

Well—why not?

COME HEAR THE MUSIC PLAY

The words kept running through my mind: "What good is sitting alone in your room?" Da dah da dah dah. Yes. That song from *Cabaret*. What was I thinking? Then it hit me. Exactly! How many polio survivors have said similar words as they explain their interest in a very special kind of volunteering—working with children.

Take Jan, a retired realtor who has struggled with post-polio issues for years. Jan works with two-and-three-year-olds at a Florida child development center. Once a week she spends half a day at the center dealing with English-as-a-Second-Language children, in small groups or individually.

She's experienced amazing breakthroughs. Imagine this: "One day, Diego and I had a wooden puzzle with cutout places in which to insert seven different dinosaurs," Jan says. "Diego loves dinosaurs. A little girl ran over and asked what Diego was doing. To my surprise, he took each piece out of the puzzle, lined up the dinosaurs along the edge of the table, and then, pointing carefully, said, 'This is a dinosaur,' seven times, once for each dinosaur. This was the first time Diego ever spoke, in English or in Spanish, at school or at home. What an amazing moment that was!"

There are so many ways to assist teachers. In Colorado, Anna and her gentle chocolate Labrador both became certified to help elementary children improve their reading skills. The kids loved reading to Koko in the classroom. Again, there was that special child, this time little Angie, who had never been heard to speak in school. Never, that is, until finally one morning, when she saw the Lab trotting in for their session, she shouted, "There's Koko! There's Koko!" She rushed over to her pal and began chattering as she had never done before. Had a polio survivor and her affable dog brought new life to Angie?

Not every post-polio volunteer works in schools, however. Mentors often have a different goal. Here in the Omaha Boys and Girls Club, mentors work with students on character and leadership development, as well as on effective communication. Mentors and mentees get together around pizza to discover what individuals might have in common. If a mentor is good at photography, and a Club member finds that fascinating, for instance, it's a match.

"We have a shortage of mentors," says the Club's Regina. "We have so many excellent ones—people who are patient and have outgoing personalities. Good communicators. We just don't have enough."

All their applicants go through background checks and three hours of training. Mentors devote one hour a week for a minimum of eight months with their mentees (all in the 6 to 18 age group) in order to establish a viable relationship. They meet only at the Club, for the safety of both individuals. Other mentoring organizations may have different guidelines.

In yet another program, Betty mentors elementary students from affluent homes. "The emphasis is on academic success," she says. "These are kids who are not keeping up with their peers." Once a week they meet, one on one, in locations set up by the family. "Relationship is extremely important," says Betty. "Kids thrive on the extra individual attention and respond beautifully."

O.K., so a lot of polio survivors aren't simply sitting at home watching the dust gather. We're busy folks, often driven, they tell us. Still, many of us have time for one more gig. As Betty says, "I want to give back instead of just taking. Makes me feel better about myself."

And helping kids find their way—well that's music to our polio-survivor ears, isn't it.

Wanna hum along?

SEGWAY INTO SPRING

Spring. Soft, warm breezes. Blue skies teeming with sparkling sunshine. Birds chirping. Freshness in every breath. Gentle showers coaxing crocuses from the earth. Polio-survivor-driven Segway® Personal Transporters (PTs)* rolling forth on city sidewalks.

Yes, Segway PTs. And yes, driven by polio survivors.

Consider Dodie Briskey, a realtor in Naples, Florida, where Segways bloom year 'round. Dodie has had a Segway PT since soon after they hit the market in 2001. "We were watching *Good Morning America* when in rolled the host, demonstrating a Segway. I knew from the beginning this was for me. My Segway is a Godsend—an innovative means of transportation that's absolutely life-changing."



Several surgeries had left Dodie unable to walk as she had before, even when wearing the left leg brace she had counted on since contracting polio at age four. She was ready for help. "My Segway has been a blessing. I was at the point of preferring to stay home rather than making the effort. And it's fun. It's almost sinful for something so useful to be such fun, too. It gives me such a sense of freedom."

The Segway PT is the two-wheeled, gyro-balanced, battery-powered means to mobility invented by Dean Kamen.

"Segways are effortless," says Dodie. "If people have the ability to step up onto the machine, they can use it. You get yourself grounded, balanced. Then, if you want to go forward, for example, you lean forward; to turn right, move the LeanSteer frame right. That's the way you propel yourself."

A gauge on the machine shows if the battery is low. If so, plug it in—it goes up to 24 miles on one charge. Next to no maintenance. Zero pollution emissions. Quiet. Small. And some people insist—nearly perfect.

"It's a wonderful thing," says Dodie. "It's not for everybody with a mobility issue, though. You do have to be able to take that step up and stand for the distance. It's very easy to operate if you pay attention. However, if you're not paying attention,

you will fall. I have a little scar on my face to remind me. I feel safe on it, though. You know, you can have an accident riding a bicycle, too. You just have to use common sense.”

Dodie started with two hours of required training and learned about the machine’s built-in safety features. An online study at SegwaySafety.com offers videos and a variety of other material to make using the Segway PT a safe experience. Wearing a helmet is suggested. A number of independent studies conclude that the Segway PT can be operated at an impressive level of safety and is compared most favorably among bicycle and pedestrian traffic area users.

Segway PTs ordinarily run on sidewalks or on certain roads designed for slow traffic. Various models of the machine (check out Segway.com) perform well on a variety of terrains. Laws regulating use of the Segway PT vary from state to state, even from county to county or town to town. Licenses are not required. Not FDA approved as a medical device, the Segway PT costs in the \$7,000 range.

Dodie is rarely without her Segway PT—she hoists the machine onto the specially-made bumper lift on her car, and off she drives, often to her Naples post-polio support group meetings. “I use mine mainly inside buildings. But I take it with me wherever I go. On a recent trip to Alaska, we went by plane and ship, and I used it everywhere there. By the time I got home, my fellow passengers were asking ‘Where do I get my Segway!’”

**Segway is a registered trademark of Segway Inc. in the United States and/or other countries.*

HOME SWEET HOME?

FACT: 90% of Americans polled said they definitely do not want to live in a nursing facility.

FACT: 80% of Americans polled want to continue living in their own homes until the end.

With the total of elderly citizens on the upswing, innovative choices are beginning to pop up, attempting to offer new ways to allow us to live where we want to as age and disability continue to do their number on us.

Now comes PACE (Programs of All-inclusive Care for the Elderly), one more entry in community-based living that may keep many of us out of institutions. PACE is a government-inspired program, decades in the making, and now individually operated by a variety of non-profit companies throughout the country. Check www.npaonline.org to see if your state is one of the 30 currently involved.

Who Can Join? Those of us who are 55 or older and living in a PACE-served area can join if we meet our state’s Medicare and Medicaid nursing home level of care guidelines. This is determined by the 11-member Interdisciplinary Team in each local PACE area.

How Does This Work? Participants sign a contract allowing PACE to provide services. PACE is Medicaid and/or Medicare funded on a per person basis, rather than on a fee-for-service basis. Participants not on Medicaid would have to make up the difference, paying a monthly charge, plus a hefty Part D fee. Joining PACE dis-enrolls us from other health insurance, and PACE becomes our health and Part D insurer.

PACE also provides doctors, nurse practitioners, therapists, and other participants of a health-care team to work with us, rather than using the health professionals we had before. Members are free to leave PACE at any time, and PACE social workers will help with the transition of finding a doctor, health and medicine insurance, and other care and services.

What Do We Get? Most of us get to live in our own homes. A large part of PACE activity centers around an Adult Day Center, to and from which participants are regularly transported by PACE. Here we might find a chapel, TVs, a coffee bar, and a dining facility, all comfortably arranged for maximum sociability. Also at the Center is a Health Clinic, designed to provide primary care, dental and podiatry care, therapists, and all the exam rooms and equipment necessary at that facility.

Certain types of in-home care and services are provided, as determined necessary by the Interdisciplinary Team on a person-to-person basis. They decide what is needed according to the impact this has on our health. Participants requiring more care (about 7% now) go into nursing facilities, still under the auspices of PACE.

And Others? Family caregivers are not forgotten. At the Center, PACE offers support groups and even training in how best to deal with us in our homes. Overworked caregivers appreciate a much-needed break during the day while members are at the Center.

PACE presents an option. If we like it, it's ours. If this isn't our cup of tea, we move on to the next possibility.

Many of us who have spent a lifetime with disability might hope for more independence than I see in PACE. Personally, I'd like to be the one who decides what I do with my day—and with whom I do it. I want staying in my home to mean more than merely sleeping here—I want to *live* here. Eat here, Watch TV here. Get my laundry done here. I want my regular doctor and my usual pals. Give me my phone and my computer and let me soar. I don't want to be left to rely upon the kindness of volunteers among my family and friends to get my house cleaned or my personal needs met. There must be a way.

We have tough choices to make. You know: "Old age ain't no place for sissies."

TOUTING SOLUTIONS

How did we miss these two—the pulmonary doctor and his polio survivor patient? For years we've been sending the message, and yet this week, more evidence that it wasn't always received.

Here's what happened: A good friend called. She had gotten the results of her sleep study. Underventilation, she said—great lungs, but her diaphragm is weak and can't deliver the necessary oxygen to her lungs, she said; oxygen saturation at 77%, well below the acceptable 90-95%; also, sleep apnea—stopped breathing an average of 19 times each hour in the night. She was happy enough with this and felt relieved that her doctor had not suggested her using some form of ventilation. Instead, the doctor put her on oxygen.

That's the problem. We've heard time and again that treating a patient with oxygen who has respiratory muscle weakness is like trying to inflate a balloon by blowing over its mouth instead of into it. If our muscles aren't strong enough to get the air into our lungs, we end up with too little oxygen and too much carbon dioxide in our systems. This can turn into a deadly combination. The answer to these kinds of neuromuscular breathing difficulties is always mechanical ventilation.



Breathing difficulties came as a bit of a surprise for my friend. She was left unprepared. Post-polio educators have harped away on this subject for years, yet she didn't hear any of this. How many others missed the message?

I suggested she do some reading, discuss the issue with her doctor. Hear it from the experts in International Ventilator Users Network's wonderful [TAKE CHARGE, NOT CHANCES](#), and learn how a polio survivor sees it in "[My Journey Through the Basics of Post-Polio Breathing Problems](#)," on IVUN and PHI's websites respectively. We should all take a look. It's too easy for us to imagine "This could never happen to me!"

But the pulmonologist—how do we account for his lapse of knowledge? Perhaps the problem has not been discussed enough at professional meetings. Maybe the number of patients with neuromuscular problems is so small that it seems less crucial to some. Who knows.

Makes one wonder, though. What about all the doctors in various other medical disciplines who deal with those of us who have post-polio issues? Are they satisfied they've absorbed all they need to learn about polio's late-effects? Is all that's new and valuable being brought to their attention?

Goodness knows, many have tried. PHI has been at the forefront. Are you aware that once a month for the past seven years, PHI has collaborated with a leading neuroscience institute to provide educational conference calls for physicians all over the country? Doctors experienced in the late-effects work with willing medical professionals on topics vital to people like you and me. So far, so good.

Let's keep pushing. Why not expand these efforts in the most practical way, so that more doctors will become involved in learning about treating post-polio issues? What should it be? A series of CEU Webinars? Some sort of online interactive model to educate health professionals? DVDs designed for the purpose of informing, educating, training medical personnel about issues that are uniquely tailored to polio survivors? All of the above?

This mission is alive and well at PHI. They recognize, as all of *us* do, too, that we can't simply leave this work to others. Every effort that PHI has made, everything that you and I have done in the past in this direction, every little step we take—it all

has an impact. Now we must keep moving on—become more visionary, more inventive, more effective.

How would this pay off for others like my friend? Maybe one day we'll get so good at spreading the word that every polio survivor will understand that oxygen is not a substitute when mechanical ventilation is the absolute answer. And maybe by then, all doctors will be prepared to tell us that.

WHAT'S A PATIENT TO DO?

Let's say we're doctor-shopping. Maybe we've moved to a new city or our long-time doc is retiring—for whatever reason, we need a different doctor. Question is—where to start? How to choose?

We all want the best. Someone who knows what he's doing, who can get the diagnosis right. Someone reliable, respectful, trustworthy. We want more than a good listener—we want a doc who understands, who acknowledges that our concern is real. We realize not all physicians have special post-polio expertise—still, the best are curious, interested. They don't miss a beat. They ask all the right questions, answer every one of ours as fully as possible—and they keep searching. How do we find this special person?

Top of the list? Check qualifications. Here's some great advice: Start with Board Certification.

This one's important. While being licensed to practice medicine assures that a doctor holds certain minimum requirements, board certification goes way beyond this. Doctors who choose to be board certified do so voluntarily to demonstrate skill in their particular area of practice. While every specialty and subspecialty has its own certification, some boards may not be very exacting. Clearly, some are better than others. What we must look for, then, is board certification that has been approved by the American Board of Medical Specialties (ABMS).

The ABMS carries out a rigorous standard of testing and evaluation. In addition to strict initial certification, doctors must go through a recertification process every six to 10 years. They must also keep their certification current with the ABMS Maintenance of Certification (MOC) program, which requires more testing and proof of continuing education and experience throughout their period of certification.

How can we learn that a doctor is board certified with ABMS approval? One place is www.healthgrades.com. It's easy. Go there. Enter your doc's name. Details pop up before your eyes. His specialties are listed, and if he's board certified, a mark following each of these indicates ABMS approval. (If your doctor is not specified here, try CertificationMatters.org.)

Beyond certification, notice the state where the doc is licensed; details concerning his education; and a background check that shows any malpractice, sanction history, and board action history in the past five years. General guides. This is good stuff.

Maybe not so reliable are patient evaluations. While the criteria rated can be of interest, this may be biased, bearing no resemblance to accuracy. It's merely one patient's word.

Other things can make a difference, too. Ever notice the initials after doctors' names? Does it matter whether the amorphous "Dr." Mary Smith diagnoses my underventilation, or whether this is left to Mary Smith, M.D.? Better yet, could I feel even more secure if my pulmonary problem were in the hands of Mary Smith, M.D., FCCP? Education, staying current, searching for excellence, earning the best credentials—all of this matters.

Even so, looking good on paper isn't all there is. What else counts?

Our interaction with the doctor, for one thing. If we've done our part—handed her the list of our meds, our allergies, and a complete history, discussed every issue we meant to, asked every question and open-mindedly heard every response—we can begin to assess the situation. Are the two of us developing a healthy rapport? Are we becoming partners in pursuit of wellness?

These days we expect doctors to believe us when we say we have a problem. We expect them to search in every direction for answers, to keep at it until we find relief.

If this doesn't happen, we move on. No need to pull out the voodoo doll. Simply get a second opinion, find another doctor. Ask around for referrals—and then begin, again, by checking qualifications. Remember—we deserve the best.

A BETTER LIFE

It's time we got this straight: palliative care is not the same as hospice.

As Karen Rafinski put it in June's AARP Bulletin, "Palliative care is about making the most of life with a serious illness, whether the disease is terminal or not." While this could mean patients with life-limiting illnesses, it means those who may be recovering from grave conditions such as cancer or stroke, as well.

And guess what: It can also be us—certain polio survivors, perhaps still living at home but not necessarily bedridden, who simply want a better life. They may be severely affected by pain, for instance, or chronic weakness or stress—survivors using ventilators or those losing more muscle mass—others additionally affected by complications of aging. A better life. We're talking quality here (not to mention quantity—at least one study shows patients living longer for having been involved in palliative care).

Todd Sauer, MD, Medical Director at Nebraska Medical Center's three-year-old Palliative Medical Service in Omaha, says, "We are experts at helping to manage symptoms. We bring comfort to patients far earlier than they would find by merely seeking end-of-life care. We also offer help in making decisions. We meet with families and patients to discuss options, to open their lives to a variety of possibilities."

Traditionally, palliative care programs use a team approach. Teams are often made up of a physician (probably different from our primary care doctor, though the palliative doctor does work with others to coordinate care), nurse practitioners, social workers, and chaplains, as well as patients and, at times, family members. Such teams cover a wide range of symptoms by addressing physical, emotional, and spiritual issues.

A holistic approach to one of our major concerns, pain management, may be used. In addition to medication, it's possible to try massage therapy, acupuncture, or any of an assortment of relaxation techniques, such as yoga and other meditation methods. Much attention is paid to the type of pain involved. Emotional pain is far different from a nagging rotator cuff, yet both kinds of pain must be tended to. Many patients undergoing standard treatment for their specific disease discover that palliative programs add an amazingly helpful layer of support.

In Omaha, members of the palliative care team make home visits at any stage of a patient's illness. "While a doctor can't be available to visit people in their homes 24/7," says Dr. Sauer, "we do the best we can. We also make every effort to help families caring for their loved ones at home." Check with your doctor about what Medicare covers.

Not all palliative care programs are alike—and neither are all patients. We need a good fit. Shop around—[check out the list](#) of what's available in your locality at getpalliativecare.org (see Step 2) or ask your doctor for a referral.

What to look for? As an example, Dr. Sauer is board certified in Family Medicine with a subspecialty in Hospice and Palliative Medicine. He's Fellowship trained, comes into the picture with outstanding credentials. Here's a family physician who liked treating families enough to move on to devote time and effort to becoming skilled in the world of palliative care. Those all have to be clues.

Today you and I may believe we don't have a reason for palliative care—could be we're not sure, or we're thinking maybe later it would be a good idea. How could it hurt to get in touch with a palliative care doctor and discuss options?

O.K. Have you looked it up yet? The word "palliative"? Alleviation of symptoms. To mitigate. To reduce the severity.

Sweet, sweet sounds to my ears. What do you think...

PLAYING A NEW TUNE

Have you noticed? Change is in the air!

It's the sweet, comfy feel of *caring* wafting in on the breeze from certain previously impersonal doctors' offices.

Exhibit 1: Recently my curmudgeonly ophthalmologist suddenly turned friendly, asked if I am interested in art, said he has a Norman Rockwell collection, and wondered which is my favorite Rockwell painting.

Exhibit 2: As he left the examination room, my overworked internal medicine doc put his hand on my shoulder, actually touching me for the first time, and muttered, "These polio issues can be puzzles."

Exhibit 3: My pulmonary doc admitted he didn't have a solution, and in a moment of concern, said, "I wish I knew how to help."

Exhibit 4: Curiosity got the better of my colon/rectal surgeon, who asked, "How affected was your body when you contracted polio? What residuals were you left with in recovery? How much longer was it before you began noticing symptoms of PPS? What was your profession?"

What's happening? Clearly, we have doctors trying to learn new ways to communicate, attempting to engage! Good for us!

Truth is, more and more medical schools are spotlighting communication—and not simply doctor/patient communication, but that involving others in the medical community, as well.

One of the newest admissions processes being used to choose the best 19,000 med school students (out of over 42,000 applicants in this country) is the multiple mini-interview (MMI), developed by researchers at McMaster University in Ontario. Used extensively in Canada, MMI is now found in a growing number of the 134 medical schools in the USA.

Gone are the days when good grades and a firm handshake are all it takes. In addition, with MMI, aspiring doctors must also spend a short amount of time with each of a number of interviewers, answering questions that lead to evaluations in non-traditional areas such as critical thinking, ethical decision making, cultural sensitivity, and empathy. The idea is for medical schools to be able to produce more quality doctors who exhibit the much-wider range of skills that we find in all outstanding physicians. Compassion and communication top the list—what most of us think of as excellent bedside manners.

Today we see more and more doctors working in TEAMS. The MMI process helps identify the most likely candidates—future doctors capable of working well with those from a variety of disciplines to provide the finest possible integrated treatment for patients. That's teamwork.

Electronics already brings us to a marvelous level of communication. The pulmonologist sent us off for a lung X-ray? It pops onto the examination room computer screen before we're back in the room. Almost instantly our medical records reach the specialists our docs refer us to—allowing them plenty of time to study our cases before we show up in their offices.

And who would have dreamed of this: certain health systems now make it possible for us to communicate directly with our doctors, who personally return our e-mail and telephone messages. Even where staff members still field our calls, they seem to have gotten the message not to attempt to give us medical advice, but instead pass our questions on to doctors and then get back to us with the doc's response.

Gotta say—things are looking up.

THAT OLD FEELING

It got their attention—our friend Mac wheeling along in his power chair, lugging three two-by-fours and a standard toilet stool into the City Council meeting.

He'd been there before, our friend Mac, and had made no headway trying to describe why the city government building restrooms made it impossible for people like him in wheelchairs to use those facilities.

This night he *showed* them. Plopped down his two-by-fours to square off the dimensions of a stall, arranged the toilet stool in the center, and proceeded to demonstrate, tastefully, why this does not work—and then made clear what needed to be done. By the end of Mac's show, he had a unanimous vote for change, and the city government building had accessible restrooms within weeks.

Lesson One in Making the ADA Work For You.

But that was 20 years ago. Enthusiasm ran high among those of us with disabilities back then. We saw a world of freedom beckoning. Suddenly there were buildings we could get into, pathways we could sail through, reachable drinking fountains. We spread the word, touted the universal importance of accessibility. We talked with city planning directors, property owners, parents watching children frolic in the park. We shared our vision, and it became theirs. We showed them how—and why. What spectacular results!

But time marched on. As with other initiatives to great social change, after outstanding bursts of accomplishment, efforts began to wane, and today public response to the ADA remains "a work in progress."

A local polio survivor serves on a committee dealing with housing units being built in a retirement community. "Management" tells her they want to comply with ADA regulations. Only, apparently, not too often—a pitiful one in fifty of the independent living apartments currently under construction is accessible. Could they possibly believe that those of us with disabilities cannot also be independent?

They say budget concerns cause ADA cuts; they can adapt later if they need to. Besides, they say, people are turned off by apartments that look as if the purchasers, themselves, might be disabled some day.

Indeed, the retirement village's resort-like ads project, through appealing photos, the image of a mecca for active aging folks. The relatively affluent. The non-disabled. Nary a wheelchair, scooter, or walker in sight. Can it be this describes the typical retiree?

Who are "the disabled," anyway? Our fathers, putting up with debilitating arthritis all these years? Niece Amy, living with MS since she was 35? Beloved Uncle Ralph, using a walker after recovery from a stroke? Our sweet old neighbor, still baking cookies as she did when we were kids, in spite of her frequent need for oxygen?

Thousands of veterans returning home scarred and maimed from defending us in wars? These people couldn't possibly be independent?

Surely we have not become so outrageously biased as to suggest relegating them all to an invisible society. Who today would be offended by the sight of a wheelchair? A brace? An artificial limb? Are there actually those who do not accept people who are disabled as viable members of a community?

Let's find out. Get people's attention again. Let's remind them of the tune they danced to twenty years ago when they began to embrace the ADA. The kindness in their hearts. The way they felt when they made room for one more imperfect soul in their world. Let's start shouting from the rooftops as we did before. Only this time the message is: WE'RE STILL HERE!

Let's see how it goes. I'm betting on *us*.

CLOSE ENCOUNTERS OF THE POST-POLIO KIND

It's not as if we polio survivors never run into a glitch or two in a day. Let's face it—dealing with the unexpected has become part of everyone's routine. Developing the finesse to do that smoothly and successfully—well, that may be a different matter.

Consider Alice, a former nurse with serious arm weakness. Alice just returned home from two weeks at a rehab center where she was evaluated by a PT, an OT, and her personal physician, all of whom concluded that she needs a power chair.

Congestive heart failure and weakness in her legs make it difficult for Alice to walk around the house, and she finds it impossible to be independent when it comes to such things as getting to the bathroom. She needs the power chair.

So the rehab center folks contact a power chair supplier and arrange for them to meet with Alice to work out the details for finding the right chair.

Meantime, Alice (now home and renting a power chair) engages a home health agency to provide the PT her doctor orders. And herein lies the problem.

The PT, seeing Alice only once, decides he will be a miracle worker, says he'll have her up and walking in no time, and puts the kibosh on the power chair. Without consulting anyone, he calls the power chair outlet, switches them to his own questionable evaluation of Alice's condition, and declares that only a manual chair is indicated for our weak-armed Alice. Trouble ensues.

Time for Alice to jump into action.

We all have options. We do not have to sit passively and watch others take over our lives. This doesn't require shouting angrily in indignation, loudly stirring the pot with wild demands or accusations. A calm, quiet, "I'm in charge here," will do.

Alice could:

1. Start by firing the PT (if not the home health agency) and hire one that will honor the perfectly acceptable existing evaluations already attained. Check the qualifications of workers sent by any agency and be clear on job descriptions. Everyone must understand that our health care decisions are up to us—we do not casually hand over our authority to every individual who stumbles into the picture.
2. Speak up. If we have already been through a certain process and have no intention of doing it again, we have merely to say so. If someone insists on our participation when we know this to be wrong for us, we refuse. The word “NO” comes to mind. And if this is more than we can handle, then we’d best find ourselves a “NO-man” to carry along with us to utter the word.
3. Work with experts. For instance, see an assistive technology professional to get exactly the fit and the kind of chair needed. Don’t settle for anything less. Discover what works for us. Don’t allow a salesman with extra scooters in his inventory to decide that would make a better purchase than the chair we want. Who knows our bodies better than we do?

Of course it isn’t just Alice. Lots of people need to realize it’s OK to act on the courage of their convictions. You know how it is. Jack makes an appointment with his doctor. When he arrives at the office, he learns he will be seen by a nurse only. Fine, if that’s what he wants. If not, he needs to say so. Firmly, but calmly, he must insist a pinch-hitter is not acceptable. Next time he can avoid this situation by confirming this when calling to get on the schedule. Nothin’ to it.

Easy enough—no whining or complaining. We simply gather up our polio pluck and make our lives work for us. What could be better than that!