

The Polio Perspective
June 2014

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Medicare's Wheelchair and Scooter Benefit

If your doctor submits a written order stating that you have a medical need for a wheelchair or scooter for use in your home, Medicare will help cover any of the types listed below. Generally, Medicare will pay 80% of the Medicare-approved amount, after you have met the Part B deductible. You pay 20% of the Medicare-approved amount. Wheelchairs (both manual and power) and scooters are also known as "mobility assistive equipment." Medicare will help cover your wheelchair and scooter, if you meet **all** of the following conditions:

- You have a health condition that causes difficulty moving around in your home.
- You're unable to do activities of daily living (like bathing, dressing, getting in or out of a bed or chair, or using the bathroom) even with the help of a cane, crutch, or walker.
- You're able to safely operate, and get on and off the wheelchair or scooter, or have someone with you who is always available to help you safely use the device.

Also, the equipment must be usable within your home (for example, it's not too big for your home or blocked by things in its path).

Types of Mobility Assistive Equipment:

Manual Wheelchair

If you can't use a cane or walker safely, you may qualify for a manual wheelchair. The manual wheelchair you choose can't be a high strength, ultra-lightweight wheelchair that you could buy without renting first.

Rolling Chair/Geri-chair

If you need more support than a wheelchair can give, you may qualify for a rolling chair. These chairs have small wheels that are at least 5 inches in diameter. The rolling chair must be designed to meet your medical needs due to illness or other impairment.

Power-Operated Vehicle/Scooter

If you can't use a cane or walker, or can't operate a manual wheelchair, you may qualify for a power-operated scooter.

Power Wheelchair

If you can't use a manual wheelchair in your home, or if you don't qualify for a power-operated scooter because you aren't strong enough to sit up or to work the scooter controls safely, you may qualify for a power wheelchair.

Before you get either a power wheelchair or scooter, you must have a face-to-face exam by your doctor. The doctor will review your needs and help you decide if you can safely operate the device. If so, the doctor will submit a written order telling Medicare why you need the device and that you're able to operate it.

Remember, you must have a **medical need** for Medicare to cover a power wheelchair or scooter. Medicare won't cover this equipment if it will be used mainly for leisure or recreational activities, or if it's only needed to move around outside your home. Also, in some areas, you may need to get your power wheelchair or scooter from specific suppliers approved by Medicare.

Visit www.medicare.gov/supplier or call 1-800-MEDICARE (1-800-633-4227) for more information. TTY users should call 1-877-486-2048.

Note: If you don't need a power wheelchair or scooter on a long-term basis, you may want to rent the equipment to lower your costs. Talk to your supplier to find out more about this option. Some

wheelchairs must be rented first, even if you eventually plan to buy them.

Fraud

Most doctors, health care providers, suppliers, and private companies who work with Medicare are honest. However, there are a few who aren't. For example, some suppliers of medical equipment try to cheat Medicare by offering expensive power wheelchairs and scooters to people who don't qualify for these items. Also, some suppliers of medical equipment may call you without your permission, even though "cold calling" isn't allowed. Medicare is trying harder than ever to find and prevent fraud and abuse by working more closely with health care providers, strengthening oversight, and reviewing claims data.

★★How to Spot Fraud and Abuse★★

You can help Medicare stop fraud and abuse by watching for the following examples of possible Medicare fraud:

- Suppliers offer you a free wheelchair or scooter.
- Suppliers offer to waive your co-payment.
- Someone bills Medicare for equipment you never got.
- Someone bills Medicare for home medical equipment after it has been returned.

What to Do if You Suspect Fraud and Abuse

If you suspect billing fraud, contact your health care provider to be sure the bill is correct. If your doctor, health care provider, or supplier doesn't help you with your questions or concerns or if you can't contact them, call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

For More Information

Medicare is here for you 24 hours a day, every day. To get more information, visit www.medicare.gov or call 1-800-MEDICARE. For more information about Medicare's fraud and abuse activities, visit www.stopmedicarefraud.gov.

KNOWLEDGE IS...CONFUSING. POLIO SURVIVORS AS CONSUMERS OF MEDICAL "RESEARCH."

The gold standard always has been the peer-reviewed, 'randomized controlled prospective clinical trial,' not an article in USA TODAY written from drug company press release...

THE RECORD
MARCH 30, 2014
BY JOHN PETRICK

Did you hear about the latest study?

Long-term exposure to social media outlets like Facebook could raise your risk of serious health problems by reducing levels of face-to-face contact, a doctor claims.

Just because a study comes out saying something is good for you, bad for you, or ineffective doesn't necessarily mean you should blindly listen. Here's a quick study in how to evaluate studies:

Size matters: "Usually, the sample size should be mentioned," said Celine Gelinas, senior associate dean for research at Rutgers Robert Wood Johnson Medical School in New Brunswick. "If it's 15,000 samples, or in the thousands, versus 15, the data will obviously be more reliable. Also, it should be longitudinal – done over time."

Get a dose of perspective: "I think it's very important to consult with your physician. They have the expertise to advise," Gelinas said.

Follow the money: Gelinas said that if the study is funded by, say, a federal agency, it probably has some credibility. "That's not to say that a study funded by Merck still can't be reliable and legitimate, too," she said. "But the source of the funding might be something for you to explore before you come to a conclusion."

And if you like to peruse Facebook with a nice glass of red wine before bed (because remember there was that study that said one glass a day can be good for your heart?), not so fast. Another study claims that drinking just a small glass of wine a day can more than double the risk of mouth and throat cancer. Cheers.

Speaking of cancer: Remember all those mammograms you faithfully got after a certain age, because they said early detection is crucial? Now comes a study that says it doesn't appear to make much, if any, difference.

Put it all together with the study that came out this year saying constant cellphone use may give you cancer, and why not just break out the cyanide-laced Kool-Aid now and call it a day?

"You can drive yourself crazy," said Jamie Ketas, director of Englewood Hospital and Medical Center's Clinical Research Center, of the myriad studies, reports and findings that seem to emerge almost on a daily basis on the Internet, on television news and in print media. "The problem is that patients have become consumers – they are looking for a quick and convenient answer. The public, in general, doesn't have a way to discern what is a true scientific study and what is simply an anecdote."

Before the Internet became part of everyday life, studies that made headlines generally underwent a "peer review" before getting the American Medical Association Journal's stamp of approval. Carol Byrd-Bredbenner, professor of nutrition at Rutgers University, explained: "To get it published, peers conduct a blind review by reading my paper and questioning me on it: 'Why did you do this, shouldn't you have done that?' And if I can stand up to their scrutiny, it is accepted and published."

While studies published in, say, the Journal of the American Medical Association still undergo that scrutiny, the study that concluded Facebook may be bad for you – well, who knows? Reports of the study were headlined on the British news website Daily Mail, which attributes the findings to psychologist Aric Sigman, as quoted in *Biologist*, the journal of the Institute of Biology.

Increased isolation could alter the way genes work and upset immune responses, hormone levels and the function of arteries, the report stated. This could increase the risk of problems as serious as cancer, strokes, heart disease and dementia, the report attributed to Sigman's statements in *Biologist*.

Details about how the doctor reached these conclusions were not spelled out in the Daily Mail's report – which could be another complicating factor in how to figure out whom to listen to, and whom to ignore, experts said.

"I know the media have a job, and it is to get a message out," said Byrd-Bredbenner. "But sometimes they take a single study out of context. They need to put these latest findings within the context of the overall findings."

Ketas added, "No offense to the media, but they want the catchy headline. There's a sensationalism to this. The public doesn't always know the quality of these studies. You can call anything a 'study.' The bottom line is: You have to know the source of the information."

Byrd-Bredbenner explained what makes for a good study: "The gold standard always has been a 'randomized controlled perspective clinical trial' – you take patients that meet certain criteria, define a patient population, they all have to be a certain kind of patient, then you randomize them to one thing or another and follow them prospectively, going forward. That's what the Food and Drug Administration looks for – what anybody should really look for – if you want to prove something,"

For professionals, that's fine. But it sounds a little complicated for the average consumer. What should the everyday person look for? "Peer-reviewed journals publish data from well-designed studies," Ketas said. "Everything else has to be taken with a grain of salt."

Even when the source is credible, people may cherry-pick findings that confirm their beliefs or reject a study if it says something that contradicts years of conventional wisdom or prior studies, according to experts.

Last month, controversy flared over follow-up data from a long-term study on mammograms. Researchers with the Canadian National Breast Screening Study conducted a 25-year follow-up with their participants and concluded that "annual mammography in women aged 40 to 59 does not reduce mortality from breast cancer beyond that of physical examination or usual care when adjuvant therapy [treatment given after surgery] for breast cancer is freely available."

The results were published in the peer-reviewed British Medical Journal. But several professional associations and experts have questioned the authors' findings.

"Research has found that when people are confronted with contradictory health and nutrition information, it breeds confusion and ambiguity, and that in turn leads to a backlash against any kind of information," said Lauren Feldman, professor of journalism and media studies at Rutgers University. "People become frustrated, they develop a general mistrust, and they wind up not following any guidelines."

Feldman's own research points to what she terms "motivated reasoning" when people are confronted with a deluge of conflicting messages.

Her ultimate findings? "People believe what they want to believe."

POST-POLIO PAIN: CAUSES AND MANAGEMENT

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to San Francisco Bay Area Polio Survivors meeting

[Transcribed and edited by Phyllis Hartke, SFBAPS Pres.]

Introduction: This presentation may not cover every type of pain you may experience. A polio survivor can have other kinds of pain associated with other medical conditions that don't have anything to do with polio, as you all are aware. As far as the things that seem to be related to the fact you had polio (the changes in muscle and body mechanics and the pain syndromes that are the result of that), that's what we are going to cover today.

Symptoms of Post-Polio Syndrome

As you all know, pain is one of the three major symptoms of PPS - the classic triad of fatigue, new weakness, and then pain in either muscles or joints. You don't even have to have the "PPS" as far as the whole blown syndrome to be experiencing pain related to polio. Obviously, as a physician, one of my goals if you are complaining of pain is to work on decreasing and managing that pain because that will subsequently increase your comfort level, your functional level and overall quality of life.

A. Causes of Pain in the Polio Survivor

There are a number of different causes of pain. I broke these up into four different categories: post-polio muscle pain; the different soft tissue or overuse syndrome type of pain; biomechanical or pain due to degenerative changes; and, bone pain. We are going to start with the post-polio muscle pain.

1. Post-Polio Muscle Pain:

Pain in polio-affected muscles

This is the pain people experience in the muscle tissue itself. It is most-commonly in polio-affected muscles. If you are experiencing this type of pain in a muscle that was not polio-affected, there's a good chance that muscle actually was polio-affected but to a lesser extent and you may not have been aware of it. In a lot of people as they get older, we note some subtle weaknesses in muscles that you always thought were normal but in fact were not completely normal.

Deep or superficial

The pain may be experienced as either a very deep pain deep in the limb or a more superficial sensation. May be similar to pain of acute polio

A lot of patients will describe it (pain) to be very much like the pain they had with acute polio, if they remember that. Of course, people that had it (polio) as infants don't really recall that; but, the ones that had it a little bit older remember the pain associated with the acute polio infection.

Associated with muscle cramps, twitching, or crawling sensation

Along with the muscle pain, there is also muscle cramping or twitching or a sort of crawling sensation where the muscle seems to be doing things that you can't control. Often increased at night or end of day. Often people experience this at rest, not while they are doing something but later in the day or at night, especially when they get into bed. Then they start feeling all those muscles they've been stressing.

Exacerbated by physical activity, stress, and cold

These symptoms are definitely aggravated by physical activity, specifically excess physical activity, and also are increased with stress and cold. Caused by overuse/excess stress on weak muscles resulting in tissue damage.

2. Overuse syndromes and soft tissue pain

Caused by injury or inflammation of soft tissues: muscles, tendons, bursa, and ligaments

This pain is what happens to a weak muscle when you are stretching it beyond its capability of strength or endurance. Most of the time it's endurance and not strength we're talking about. A weak muscle can often give, one time, a pretty good contraction or at least an anti-gravity contraction. But if you try to do that repetitively, you don't have the endurance there for that muscle to keep firing and keep doing an activity. Even a muscle that's just a little bit weak can be overused if you're doing an activity that involves a lot of repetition movement. For most people that ends up being just that you've gone somewhere and ended up having to walk a lot farther than you normally do or had planned to do. And then later on you notice the weak legs and the muscles are really acting up.

This is what happens when you overuse the muscle, and this goes for all muscles - normal and those affected by polio that have lost some of the muscle fibers -- but anytime you stress a muscle what happens is you damage some of the muscle fiber. That's actually the concept behind strengthening exercise when you see these body builders and weight lifters working on building muscle. What they do is actually work the muscle to the point that there is some damage to the tissue and then the muscle, as it heals, hypertrophies and enlarges, and you actually can kill tissue. But if you have a muscle that you're overusing and really stressing all the time, your body may not have the chance to do that rebuilding in between. Especially in a polio-affected muscle it takes longer to do that rebuilding process. So if you have a little bit of muscle damage, if you don't get that muscle wrapped for two, three, four days afterwards and go out and then do the same activity the next day or two days later you may just tear down the muscle further and become weaker.

Early on before post-polio syndrome was really recognized that happened to a lot of polio survivors. And to be honest, it still happens now when polio survivors are sent to physical therapists that don't know anything about polio. The therapists do the traditional "ok, let's try to strengthen that weak muscle, let's do lots of reps, let's stress it." But they are overstressing, so instead of seeing strength gains as you would see in a normal muscle, you're tearing down the muscle and you have a lot of tissue damage. And that's a big part of what causes that pain when you're later on resting and you realize "Hey, I really overdid it and this muscle is now very painful." That's a symptom you all need to be aware of, even if it is not especially painful.

Even if you are getting only a little bit of cramping, twitching, crawling sensation at night in certain muscles that means you've been overusing the muscle that day or possibly the day before. It's a sign to you to think back, "ok, what did I do involving this muscle and how can I change that or cut back a little bit so that I'm not getting these symptoms later on."

It's a good thing to learn to know so that you can listen to your body as far as what for you is too much. Those random sorts of jerks that occur when you first relax, that's a nerve impulse that causes that. That's not what I am referring to. I am referring to where it's more continual and the muscle is actually kind of fluttering.

Moving on to the soft tissues other than muscle in the muscular skeletal system. The muscles are connected to bones by tendons. The bones are held together by ligaments. There's bursas or sacks of fluids around all your joints. All of these are part of the soft tissues of the body. In somebody who has polio these soft tissues are also very much at risk of having injuries.

Strains, sprains, tendonitis, bursitis, myofascial pain

The body is really amazingly designed as far as the whole anatomy and how it functions. If you have one muscle that's weak or a group of muscles that are weak, then the area of the body or the limb, the

whole biomechanics of that limb change. Often you use substitution to do certain movements. Often a joint has more pressure or tension on one side than another because one muscle may be strong and the opposing one may be weak. The normal biomechanics of different joints can be significantly altered and this leads to a real propensity to having different types of sprains which are stretching or tearing of ligaments, strains which are injuries to muscles. That, of course, can even happen to a good muscle because of the muscle imbalances. It is very common to see bursitis or inflammation around joints, again because of altered mechanics.

I know for a lot of people who have scoliosis that you may not connect this right away. A lot of polio survivors do end up with scoliosis if they have trunk weakness. It affects the position of the pelvis. The pelvis will be rotated and twisted, and that translates into different degrees of stress in the hips. A lot of people with scoliosis develop bursitis around the hip because now the hips aren't really balanced; one may be turned in a little bit. It may be very subtle but over time inflammation around weak joints develop.

In addition, you can have myofascial pain, which is chronic pain in a muscle where there's a degree of muscle spasm, which is that muscle trying to do more than its able to. You get trigger points and have a constant tightness and pain in certain muscles, which is different from pain that occurs after overuse.

If you are using crutches to ambulate or have a medial tear, you might develop overuse syndromes or tendonitis in the upper extremities, not from the altered mechanics so much, but from the repetitive use. These are the sorts of things we see in the general population with overuse, but you are at a special risk if you are, say, using your upper extremities a lot for mobility. The upper extremities really weren't designed to take all your weight the lower extremities were, so over time people often develop tendonitis in the shoulders, specifically the rotator cuff. Often if those are chronic they end up being tendon tears.

You can get inflammation around the elbow from using grip and having to use both the wrist extensors and flexors all the time. You get inflammation where those muscles connect at the elbow. You can get tendonitis around the hand as well as around the thumb. It is an area that often gets over stressed, and you start to get a lot of pain in that area.

Often affects strong limb

Related to body mechanics, positioning, posture

Worsens with time if not treated

These kinds of chronic inflammations in the soft tissue tend to get worse over time. They often start out as just a minor bothersome little "my shoulder's kind of bothering me." If you keep doing what you've been doing and continue with the overuse or the overstrain to that area, that inflammation will get worse over time.

May lead to more serious tissue injury

This often leads to a more serious condition where there's either tearing of the tendon because it's been inflamed and weakened for so long, or subsequent degeneration to the actual joint itself and destruction of cartilage.

These are things to certainly pay attention to, and pay attention to early even though most of us reason "oh, as I get older I'm going to have more aches and pains". The more you know about why you are having those aches and pains and which one of them can be corrected or reversed and treated early, the better it is for you. It is much easier to control these aches and pains earlier than when you get to a point that it's been a chronic thing and you've torn a tendon. It may not be repairable at that point, and then we have to really change a lot of how you are doing things. In addition, we want to get into the

degenerative changes that subsequently occur.

3. Biomechanical/degenerative disease pain

Changes in normal joints due to wear and tear

Those soft tissue symptoms are usually the earlier symptoms you see, and then over time with wear and tear on joints there develops biomechanical degenerative disease conditions. This can be just the normal wear and tear on joints.

Excess stress of joints due to altered body mechanics

For example, if you have one strong leg and one weak one, you tend to favor that strong one all the time. Whenever you're standing, you're standing on that strong one. Whenever you are going upstairs, you're leading with that strong one. Well that strong leg is getting basically twice as much work out as I put on my leg. So, if I was going to get arthritis at 70, you might be developing it at 50 just from that daily wear and tear on the joint.

Stretching/tearing of ligaments

In addition, if any of the joints aren't balanced and protected the way they were designed to be by the muscles that surround them, there's going to be abnormal stresses to the joints. Often you then see degeneration in part of a joint.

For example, if you have a knee that bends back and you rely on that for stability in the leg, over time you are going to get degeneration in the front of the knee where those bones are pressing together more than what they normally should. And the ligaments in the back of the knee start to stretch so you're extending further and further back and pretty soon the front of that knee is losing all the cartilage and you're starting to get pain.

Joint deformity

I saw an extreme example of this in Miami where I saw a gentleman, big muscular guy with very weak legs. He had worked as a boat mechanic for years. Never wore braces, just used crutches, because he could back bend his leg and maintain stability. He could back bend his weaker leg 90 degrees backward. It's amazing the things that can happen over time with stretching the joints day after day after day. These joint deformities, certainly at some point, start to cause pain. Most people will experience it well before that degree of deformity.

Degeneration in spine-disks, joints and increased curvature

With the deformity in joints, not only do you get the arthritis and loss of cartilage and pain from that, but also you can get degeneration in the joints in the spine. Especially if you don't have strong top muscles there's more stress to the spine than what is normal. And if you have scoliosis, even more so because you have a curvature that goes this way rather than straight up and down.

Secondary nerve compressions

Whenever you are bearing weight through the spine, there's more stress on the inside of those curves. Just think of a "C". If you put pressure here, pressure is running through the inside of that rather than straight through everything as if the spine were straight. So what happens over time is you get degeneration on the inside of that curve; all the joints on the inside start to compress more toward the side of the curve and those curves can get worse over time. That is if it is not fused. If you have spinal fusion with scoliosis it eliminates a lot of that because the fusion will take the stress off of those bones.

But even with fusion you can get degenerative changes above and below the areas that were fused. As you start to get this narrowing in the spine or sometimes in other joints, you can get compression of nerves. A lot of times, especially with a spine where nerves exit between all of the vertebral bones and there's a little space between them, if that's getting tighter and tighter, at some point you're going to put pressure on the nerve.

That can also occur in other peripheral joints, say the elbow, if you are developing arthritis there. Your ulnar nerve passes right behind the bone there, that's your "funny bone" called that because the nerve is so superficial. You have arthritis there and can start to impinge on the hand and start to lose grip strength.

The thing to really be aware of, as far as the secondary nerve entrapment, if any of you are starting to experience sensory loss, numbness, tingling, change in sensation, that is not purely due to polio changes in muscle. That means a nerve is involved - a nerve that contains both sensory and motor fibers. Remember, the poliovirus only attacked the motor neurons. So if you've got sensory changes, there's something going on in addition to post-polio changes. I think you better check it out because often these things can be corrected and the pressure taken off of it, especially if talking about the nerves in the upper extremities and you're losing grip strength and you rely on your arms for everything you do. You don't want to risk losing strength in your arms which really enable you to function each day.

4. Bone pain

Lastly we are going to talk about bone pain. Bone pain can be very severe pain; it can be kind of a deep ache.

Osteoporosis: loss of bone matrix with weakening of the bone

A kind of achy bone pain often is due to osteoporosis. Unfortunately, with the acute polio if you have any limb that is significantly weak, that limb has osteoporosis. Even if you are still 40 years old, that limb that is weak has osteoporosis.

Bone builds because of muscle tension and stresses to the bone. If you have a weak limb that doesn't have that muscle tension on it and you can't use for a lot of activities, the bone has not developed to the strength that it normally would have or to the strength that you're trying to get. Often if you had polio as a child you'll note also the weak limb is smaller because those bones don't grow as much as you're growing through childhood and adolescence. For that same reason there's lots of stress to the bones so they don't grow in the normal pattern.

In addition, there's the neurologic loss. There are many studies done on what happens when people have neurologic injuries or neurologic diseases. With an acute loss of nerve function the bone releases automatically a lot of the calcium. We don't know exactly why, but there are apparently factors in the nerve that keep the bone stimulated. Even with a full-grown adult with normal bone density, if there occurred a stroke or a spinal cord injury or something at this point, that would cause new weakness. The bones would lose calcium as well and would have secondary osteoporosis within a few months.

Other things affect osteoporosis, of course, such as immobility or limited mobility. This is especially true of people who have been in chairs their whole life. Even with the osteoporosis that started with the polio, it worsens faster because of the immobility. You have to just assume that a polio-affected limb, if it's significantly affected where you have muscles that barely work, has osteoporosis there.

With all my polio patients, we look at rib fractures and falls. It is very important especially when you get older that you do as much as you can to prevent osteoporosis and even more so to prevent falls. Osteoporosis in and of itself doesn't always cause pain or problems until it becomes very severe. You want to know if it is there. You want to try to keep the bones as strong as possible.

Fractures: traumatic or spontaneous

You won't usually have acute pain unless you have a fracture. With osteoporosis that is very severe you can have spontaneous fractures without falling, without doing anything. Very commonly the bones in the spine will just compress. They can't hold it anymore. Instead of being these nice little rectangular blocks, they compress down into pancakes. You can imagine that can cause all sorts of secondary

problems in the spine and the nerves that exit from the spine.

In addition, if you are involved in any trauma, you can have severe fracture, compound fractures and multiple breaks that are very difficult to fix and very difficult to heal. I had one woman who had severe fracture in the distal femur and some orthopedic surgeon who really didn't think too much tried to put in hardware. It just shattered the bone. She ended up losing the limb. That was the best thing we could do for her because she was more functional just losing the limb rather than having a fracture that couldn't heal and was in constant, constant pain. She wasn't able to bear weight on the limb anyway. You want to be very, very careful with those weak limbs especially to protect them.

So those are all the different types of pain that can be specifically related to polio. Now, what do we do about it? Well, like I said with the soft tissue thing, the thing you can do is if you are experiencing pain somewhere go in and get it checked out by somebody that understands at least body mechanics, the differences that occur with a polio to the body.

B. Evaluation of pain

1. Assessment of pain history

(Pain drawing often helpful)

Typically when I see somebody with a complaint of pain, the first thing I like to do is have them do what I call a pain drawing or a pain diagram. It's just an outline of the body and I have you mark on there where is the pain. There's different symbols or different colors for how you describe that pain -- whether it's an aching, a burning, a sharp pain, that sort of thing. It's very interesting what happens the more you use these pain diagrams. A lot of the time I can look at the diagram and know what's wrong with somebody. This is because the pain patterns for certain problems are so unique a lot of times.

When you go to the doctor, the more specific you can be about the pain and the faster you can relay the information, the easier for the doctor. Some people come in and just say "I hurt all over". It's really hard to help somebody like that because it's real hard to say "well I don't know why".

Be very specific about the pain, even if there are very different types of pain in different areas. Be able to isolate the pain: I have this pain here. I describe it as an ache, a sharp, or burning. Is it there all the time or does it come and go? If it comes and goes, what seems to bring it on? If it's there all the time, what things make it better, make it worse? When did it start? Has it changed since it started? Has it gotten worse? Has it gotten better? Has it spread to other areas? Are there other symptoms along with it? How does it impact you life? What does this pain mean in your day-to-day life? Does it keep you in bed for days at a time? Or does it mean you're not able to work in the yard anymore? Or does it not impact your activities at all?

There are all sorts of different pain and degrees of pain. Any tests you've had in regards to the pain, any treatments you've tried, or medications you've tried we want to know. What's been tried? What works? Not work? What's made you worse? and then go from there. Then, of course, once you're able to get a whole picture of the pain and all. Sometimes when people have a hard time getting specific about pain, I have them go home and keep a journal for a week or so to see if you can pick out a pattern of when the pain occurs.

2. Appropriate physical exam and diagnostic studies to identify etiology of pain symptoms:

Anyway, what I would do is the physical exam. In general what we look at are the muscular skeletal system, all the major muscle groups - which ones are strong, which ones aren't, how does that attach, the body mechanics, what condition are your joints in, how is the range of motion, how's your

circulation to that joint, how are you moving, what are the activities you are doing and how do you do them, how do you get around, what's your means of mobility.

I always assess gait of somebody who is ambulatory. In addition, depending on the type of pain, we might check other things. We might check cranial nerves. we might check heart function. And we might check the abdomen. Not every pain experience is going to be related to the polio and the muscular skeletal system. So we always have to keep in the back of our minds, that there are other possibilities. If something doesn't fit for musculoskeletal pain or post-polio pain, we've got to look at other sources of pain. And especially a lot of these internal organs can give referred pain to other areas.

Everybody knows about how a heart attack causes pain down the left arm. If someone comes in with pain down their left arm you always have to think, especially if it's coming and going, does this person have risk of heart disease and is it following the pattern of heart disease rather than a nerve problem or musculoskeletal problem. Those internal problems can often cause symptoms that appear to be muscular-skeletal but aren't.

Once the physical exam is done we usually pinpoint the problem a little more specifically when it appears to be etiology-based. Other special studies come in as far as providing better evaluation. We may need to get x-rays, MRI scans, and bone scans if a fracture is suspected or an infection in the bone is suspected, and bone density studies if it's a question of osteoporosis. So a lot of times further studies are needed to help pinpoint the exact origin of the pain symptoms.

In addition, if there appears to be nerve problems that are different from your original polio we often need nerve studies and EMG testing. It used to be that they required EMG testing for the diagnosis of PPS, but that got dropped as far as the criteria for making the diagnosis, which is good news to you guys because it's a nasty test. We stick needles in a lot of your muscles. Initially they wanted practitioners to do that test to document that someone really had polio. Over time we realized that for most people really by history and exam you can be definite you had polio. So now we only use it for post-polio diagnosis if the original diagnosis of polio was in question. But we still do use it when there are new nerve problems that we need to identify where it comes from.

C. Management of Pain

What do we do about these pain syndromes that can occur? Well, the more specific we can be with the diagnosis, the more we can really get at what's causing the pain, the more likely we are able to treat the pain and help you if not completely alleviate it, at least to manage it.

Certainly if the pain is because you have severe arthritis in the knee, and it's your polio leg, there's not a lot we can do to fix it. We can't do a joint replacement in the polio limb because you run the risk of shattering the bone and not having a stable joint. If it's severe arthritis in the good limb, surgery might be an option. Even if it's not a fixable problem, there are ways to manage it most of the time and at least make it tolerable and enable you to do the things that are important to you to do in life.

1. Specific conditions

Post-polio muscle pain: protection of muscles, modification of activities, pacing activities, learn to know your limits and LISTEN to your body. As earlier discussed, post-polio muscle pain is due to really over stressing a polio-affected muscle. Sometimes it's as simple as limiting the amount of distance you walk in a day or eliminating some of the real high stress activities. But for other people, it's the muscle that's bothering them or group of muscles that are very weak. If even just regular day-to-day activities cause pain every day in that muscle, then we have to be a little more creative as far as

maybe changing how you do some of those activities - using the other arm or the other leg, or protecting that leg with a brace. Instead of making the muscle do all the work to get around, now the brace is helping in taking a lot of the stress off the muscle. Don't worry. I don't put everybody in braces immediately. I have enough experience with polio survivors to know that mostly you want to try everything short of that and usually we do. But there are times when the brace is well worth using and can make such an improvement in life that you don't mind using it.

As far as that muscle pain, that's something I want *everybody* who had polio to learn to identify and pay attention to. That is the "*Listen to your body*" symptom. That should be the thing that you really key in on. If those muscles are bothering you there is something you've done, something to really over stress them. And that's the one thing we want to really avoid because over using those weak muscles makes them weaker.

Overuse pain: change body mechanics, alleviate excess stress, protect affected areas, rest, ice, anti-inflammatory medication, injections, and surgery.

Now with the overuse pain syndrome, these are more of the soft tissue tendonitis, bursitis and that sort of thing. Like we talked about, they're usually the result of either body mechanics or over-using a certain area of the body. So again we have to look at how are you doing these things, how can we change those body mechanics. It might just be using a cane when you're walking a long distance, straightening out the trunk and taking the weight off the hip that's developed this terrible bursitis where you can hardly use the leg any more. It's often a very simple thing.

Again, we might have to protect a certain area, sometimes just temporarily. Let's say it's around the ankle. We can often use an ankle support for a period of time, get the tendonitis to swell down and its gone and you can go on without using anything as long as you don't over do.

The traditional approach to an inflammatory condition is: rest, that's either complete rest or relative rest (which means taking the stress off the affected area); using ice or if its a chronic condition heat, but for the more acute pain ice almost always works better; using anti-inflammatory medication part of the time.

I know a lot of you don't like using medication but sometime we just have to use it for a couple weeks to get an inflammatory process under control. I don't like to put people on anti-inflammatories long-term unless they have significant arthritis where you've got to use it really just to keep those joints fluid and movable. Some of the newer anti-inflammatories aren't as risky as far as causing GI problems. So, if it is going to be long-term use, we go with one of the safer anti-inflammatories. But in fact, the older anti-inflammatories are more effective and work faster if you have an acute condition and can tolerate the medication as far as the stomach.

And then, worst case scenarios, at times surgery is needed. That would tend to be more in the good limb or good joint that has developed an over use problem such as a rotator cuff, a serious rotator cuff tendonitis or tear. We may have to repair that before it gets completely torn and can't be repaired because that's an important limb for day-to-day function.

The surgery risks and benefits always have to be weighed specifically for an individual - will this surgery give enough benefit that it's worth the risk to go through a surgery. Certainly for a lot of people surgery means a lot of planning and arrangements ahead of time because you may be totally immobilized by immobilizing a shoulder; whereas, for a person without polio it would not be a big

deal. But if you rely on that solely to get around, obviously there's a lot of planning and additional assistance that has to be arranged before any kind of surgical procedure.

Biomechanical pain/joint:: protect or strengthen joints, regain range of motion, unweight, bracing or assistive devices, surgery in select cases.

With the joint pain, if it's a joint that can be strengthened just with regular physical therapy often that helps significantly. When it's a key of just contracture around the joint without changing body mechanics, often regaining full motion of a joint will enable you to use it and take that abnormal strap off of it and the pain can go away. But when you get to the more advanced stages of degeneration in the joints you're going to have to take some of the weight off the joint, unweighted either through bracing, splinting, using an assistive device. Sometimes it's a matter of I tell you to lose twenty pounds. The truth is, especially with arthritis in the lower extremities, how much extra weight you're carrying around makes a big difference.

In selective cases surgery might be an option for the degenerative disease. That is very carefully evaluated and the whole picture looked at before we make a decision for surgery. For any of you who develop a problem and have an orthopedic surgeon really gung ho on doing surgery on something, if you're not sure it's not the right thing, please see someone like myself who knows polio and will evaluate from a non-surgical perspective and discuss with you and really make a decision with you whether surgery is the right option for you. I've seen too many people railroaded into the surgery that was a big mistake.

The thigh pain, again very similar to the joint pain.

Biomechanical spine pain: exact diagnosis, modify body mechanics/position, injections, orthotics, surgery if appropriate.

The spine is more complicated than a lot of the other joints. And again, it's one of those areas where you want to see someone who really knows spines and can identify what it is in the spine that is causing problems. Is it just arthritis in the spine? Sometimes we can manage very nicely with some injections in the joints or something to modify position. Or are there pinched nerves that are a little more serious and require a little more aggressive treatment. Because the spine is a complicated area, we felt surgery is one of those options of last resort. Often times for you it isn't even an option. This is because it would make you worse rather than better.

One of the other primary things I do clinically at UC Davis spine evaluations is conservative treatment of spine. So I happen to do a lot of the overlap cases of polio survivors with spine reactions. I did a talk on that at the conference in St. Louis because there are a lot of conditions that mimic post-polio symptoms. Often a polio survivor who's having problems, say in the lower extremities, it could be due to post-polio where in reality it's due to a spinal problem that can be corrected. It is always a good idea to get the spine checked out. More often than not, when we check out the spine it's OK; it's PPS that is causing you the lower extremities problem. But when there is something there, we need to know it and be able to treat that for what it is.

Biomechanical/nerve entrapments:

alleviate by change of activities or positioning, splints, medications or injections, surgical release.

Nerve entrapment often can be alleviated by altering positioning of joints, altering the way you are doing things, using splints. Sometimes medications or injections will just calm down a nerve inflammation and that takes care of the problem. But again, if there's a significant nerve entrapment and you are losing functioning of a peripheral nerve that can be corrected surgically we may choose that option if appropriate for you.

Bone pain: assessment of bone strength, treatment of osteoporosis, immobilization of fractures, bone stimulation.

Every one of you should know what your bone density is, whether you need to be on treatment for that. Certainly, whatever age you are, however strong or weak your bones are, you need to get adequate calcium. It's a mistake a lot of people make thinking "unless I have osteoporosis, I don't need to take calcium." Well, the truth is the typical American diet, unless you're a real dairy fiend and drink three cups of milk a day, especially for adults, we don't get enough calcium.

The body needs calcium. The heart needs calcium to contract; all your muscles need calcium to work. If you're not taking that calcium in your diet, your body is not going to do without and let your heart stop. Your body is going to take it out of your bones even if you are 20 years old and not getting enough calcium. They've made it pretty easy these days to get calcium in your diet. They have a lot of things that are fortified with calcium. Those are the specific ways we target those types of pain.

2. Basic principles

The basic principles are the kinds of principles for preventing overuse, pain control and pain prevention.

Improve body mechanics

You really want to optimize body mechanics. Unfortunately, a lot of physicians don't know body mechanics very well. I think it's only rehab medicine, which I do, and orthopedists that even study body mechanics as far as the muscular skeletal system. But your body mechanics has a lot to do with the stress and the risk to certain parts of the body as far as developing problems.

Correct or minimize postural and gait deviations; protect and support weak muscles and joints.

As much as possible we try to correct those mechanics early, minimize the deviations you have, and try to protect those weak areas (the weak muscles, the weak joints). Adjust workload on muscles and joints to match capacity. You want, and this is a good point to keep in mind, to try to keep the workload to a muscle or joint as matching the capacity to that area. Of course your good limb you're going to stress more, use more, because it can take it and the weak limb can't. Don't try to do things with the muscle or joint that it's not able to do. If you're barely able to do it, you're over using it. So, keep that in mind.

Control inflammation and muscle spasm.

As soon as you see signs of inflammation or spasm, get those under control as much as possible.

Alleviate nerve impingements.

Try to alleviate any nerve impingements or nerve impairments. Again, if there are sensory changes, start thinking that there may be something else going on with the nerves, that this may not be post-polio now.

Promote lifestyle modifications.

As all of you know, just life style modification is often a big key to avoiding that over-use, over-stress.

Pace activities.

Take rest breaks. I know you've heard that for all the post-polio symptoms. Really learn your limits and how much you can do in a day, how can you space that to be most effective and most comfortable.

3. Conventional treatments

The conventional treatment we talked about with the different issues earlier discussed. But also consider the following:

Medications: anti-inflammatories, anti-depressants, neurotropic medications, pain medications.

There are a number of different medications we use - the anti-inflammatories, the anti-depressants - a

lot of the time both for nerve pain. The anti-depressants are very effective.

But also a lot of people with chronic pain develop a secondary depression, which then makes it even harder for them to function and to live their life. Sometimes the anti-depressants can just help as far as your over-all feeling of well-being and being able to relate to the family and not being upset or irritable all the time or crying all the time. So it's not infrequent that I use anti-depressants for depression even though it's not the primary diagnosis but secondary to the problem. Because the depression is secondary, it's really something we're just going to use for that period of time you need it. You need not necessarily be on this for the rest of your life if you don't have an inherent depression problem as far as brain chemistry. But it can be very helpful in managing post-polio symptoms.

In addition, some of the other neurotropic medications, some of the anti-seizure medications, can work quite well for bone pain. It's some of the other central nervous system acting medications we use, like anti-seizure meds and some of the Parkinson's meds. There are different ones that we'll use for nerve pain or for myofascial, fibromyalgia-type pain.

Sure, with pain medications, like the narcotic pain medications, you'll read in a lot of places "avoid them at all costs" sort of thing. I tend to run a little bit less emphatic line than that. There are some people that need low dose pain medication just to keep pain under control so they can function. But with narcotic medication you have to be very aware of the side effect and very careful to watch for that. Those side effects are that they can interfere with breathing, depress some of that pulmonary response and drive to blood oxygen and CO2 levels. They can cause constipation, and that's a significant problem for some people.

They can tend to make you do more than you should given that what they do is cover your pain. Some of that pain we want you to experience so you'll know when you are doing damage to your body. You don't want to be on doses of a narcotic that "oh, it enables me to do everything", but five years from now you might be a total wreck and there's nothing we can do for you. So a lot of the pain your body has is actually not a bad thing. It's your body telling you, "Hey, there's something wrong here; hey, you're doing something you shouldn't be doing."

Interestingly, leprosy, which we don't really see in this country anymore, is a disease that destroys nerve endings and pain is gone. Do you know what happens to people with leprosy? They lose fingers. They lose their nose. They burn themselves and not know it. They basically abuse their body because they can't feel it and end up with much worse complications. So, remember that pain is uncomfortable but it's not always a bad thing either.

We are very careful in using any sort of narcotic pain medication, and it has to be for a specific reason and specifically helps you function better in a constructive way and not doing damage to you body. Be careful of doctors who want to give you pain medication without really knowing what's causing the pain. That's usually not the right approach.

Trigger point injections, spray and stretch; joint injections; nerve blocks

With muscle problems often you use spray and stretch type techniques, trigger points, injections, joint injections or nerve block can be done a lot of times.

Physical therapy: modalities, therapeutic exercise

Your traditional physical therapy can be very helpful if you are working with a therapist who knows about polio. Unfortunately, I'm in a position here relatively new to the area. I have not really identified the therapists throughout this San Francisco area or even the Sacramento area that knows polio and

how to treat a polio survivor.

Back in Miami I had two wonderful therapists who were a big part of my clinic and for people who lived out of the area would make sure and talk to the therapist that was going to treat those people, the polio patients, and make sure the therapist knew exactly what to do or not to do.

Because of that problem with some therapists knowing and some not, it is very important for all of you to be aware of that or signs of over doing things or over stressing muscles so that you can tell if the therapist knows what they're doing or not, and you can report back to the therapist. If the therapist is willing to know about post-polio, (learn from you, do some reading) there's no problem in staying with that therapist. But if it's somebody that has the approach of "Oh no. This is the way we do it." and is not paying any attention to you, get out of there. They'll probably do you harm.

Appropriate therapy with modality includes therapeutic exercise. Stretching would be very helpful in eliminating a lot of the pain problem. Modalities are things like ultrasound, heat packs, the TENS. A lot of them work for stimulating blood flow to an area to help it heal. Spray and stretch technique is one of the techniques for muscle spasm where you use a topical coolant, a spray, and then stretch the muscle and it enables someone to tolerate the stretching more and relax the muscle.

Occupational therapy: adaptive Equipment; Behavior modification; Psychological counseling
Occupational therapists may be helpful as far as prescribing adaptive equipment, teaching you to do certain health care things in a different way to unstress joints, and sometimes psychological counseling for just relaxation techniques and management techniques. Or if you have a pain that is really aggravated by stress, they can help you work with some of those stress levels.

Weight loss

Like we talked about earlier, it is very important to maintain ideal body weight. Unfortunately, the more immobile you are, the harder it is to take that extra weight off. Because it is such a big problem, we're actually starting a study at UC Davis to do with obesity, not just in polio survivors, but polio survivors would be part of the group with all people with disabilities. From the medical perspective I think we need to do a better job of helping some of you to get some of that weight off, but you need to do your part too. Everyone is in control of what you put in your mouth, so you have to be careful there.

Conditioning exercise

General conditioning, cardiovascular exercise, is almost always helpful. As you improve circulation in the body, you help your body to be able to deal with problem areas - inflammations, tissue damage. Your body is actually very good at repairing itself in a lot of ways, but you have to enable the body to do that.

Surgical intervention

Intervention surgery is in the back of our minds, usually not in the forefront.

Reprinted from Rancho Los Amigos Post-Polio Support Group, June 2002 with special update by Phyllis Hartke.

INSPIRATION PORN

By Millie Malone Lill

The other day, on Facebook, I saw a video of a woman in a wheelchair giving a speech to an audience of mostly non-disabled people. She said she lived a normal life, like everyone else, but that a charitable group approached her, wanting to give her some kind of achievement award. "For what?" she wanted to know. "I haven't done anything!" When they told her she was being given the award for just doing what everyone else was doing but from a wheelchair, she got a bit incensed.

This is the part that is hard to explain. She did not want to be an inspiration. She feels that this attitude toward people with disabilities objectifies them. I agree. Anyone who regularly reads my column knows how I feel about labels, about being 'cute' and about pigeonholes. I just didn't know how to express it as well as she did. She calls this kind of thing "Inspiration Porn."

People have asked me how I can remain so cheerful. I know they mean well, but exactly why should I not be cheerful? I use a power chair instead of walking, but many of them play golf using a golf cart instead of walking. My life is good. It would not necessarily be better if I'd not had polio. In fact, although polio can be and often is a pain in the neck and points south of there, it is through my association with polio survivors that I have become a writer, have done the traveling I so loved, met people who are now my family of the heart.

I don't know about you, but I have no desire to be a poster child for Don't Let This Happen To You. I don't want people to look at me and think, "Oh, poor thing. She's so brave." True, I have had moments of bravery, but they had nothing to do with my having had polio. I think it was pretty brave of Carolann and me to travel as we did, camping in the van, cooking at rest areas, seeing so much of both our countries and meeting so many online friends in person. That would be a brave thing to do for anyone, don't you think? Okay, maybe foolhardy is a better description, but still...It might be considered brave of me to get up in front of a group of people and speak. It is said that most people are more afraid of public speaking than of death. That is "most people," not just people with a disability or able bodied people. Again, nothing to do with my wheelchair.

There are challenges in life for everyone, with or without a disability. In fact, when you look at the word "disability," it simply means an inability to do something. I'm here to tell you, everyone has an inability to do something. Some people cannot sing, some can't dance, some cannot spell, some people cannot even read. These same people, however, can do many other things. I think I speak for most of us when I say that I do not want to be an inspiration.

There was a cute meme on Facebook today. It said, "Do not follow in my footsteps. I walk into walls."

Web Corner

The CIA Says It Will Stop Doing Fake Vaccination Campaigns:

<http://www.vox.com/2014/5/19/5731834/the-cia-says-it-will-stop-doing-fake-vaccination-campaigns>

Chronic Fatigue: a polio by a different name

<http://www.anapsid.org/cnd/diffdx/polio1.html>

The race to eradicate polio:

<http://www.vox.com/2014/5/19/5732400/the-race-to-eradicate-polio>

Museum receives rare footage of FDR walking:

http://articles.philly.com/2014-05-17/news/49900796_1_roosevelt-family-new-footage-ken-burns#ocSKElh1M7riBmQL.01

Polio resource list:

<http://www.i-sites.net/ppsr/reslist.html>

Loss of motor unit size and quadriceps strength over 10 years:

[http://www.clinph-journal.com/article/S1388-2457\(13\)01172-3/abstract](http://www.clinph-journal.com/article/S1388-2457(13)01172-3/abstract)

Experimental technique coaxes muscles to regrow:

http://www.npr.org/blogs/health/2014/04/30/308395528/experimental-technique-coaxes-muscles-destroyed-by-war-to-regrow?utm_source=facebook.com&utm_medium=social&utm_campaign=npr&utm_term=nprnews&utm_content=20140501

The new bionics that let us run, climb and dance:

http://www.ted.com/talks/hugh_herr_the_new_bionics_that_let_us_run_climb_and_dance

The role of exercising in post polio:

<http://www.blogtalkradio.com/voice-aerobics/2014/03/14/the-role-of-exercise-in-post-polio-syndrome-limbs-speech-and-swallowing#.UzECzAayNLw.facebook>

The Atlanta Post Polio Association newsletter:

<http://www.blogtalkradio.com/voice-aerobics/2014/03/14/the-role-of-exercise-in-post-polio-syndrome-limbs-speech-and-swallowing#.UzECzAayNLw.facebook>

A Little Bit of Humor

Age Takes Its Toll...

Three older ladies were discussing the trials of getting older. One said, "Sometimes I catch myself with a jar of mayonnaise in my hand in front of the refrigerator and can't remember whether I need to put it away or start making a sandwich."

The second lady chimed in, "Yes, sometimes I find myself on the landing of the stairs and can't remember whether I was on my way up or on my way down."

The third one responded, "Well, I'm sure glad I don't have that problem, knock on wood." She raps her knuckles on the table, then she, says, "That must be the door, I'll get it."