

POST-POLIO PAIN UPDATED:

CAUSES AND MANAGEMENT

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I. INTRODUCTION

Today we're going to talk about post-polio pain. I'll start with a little background on acute polio and what happens when you have a viral infection with polio.

II. POLIO VIRUS INFECTION

It is an RNA enteral virus and what that means is that it enters through the Gastro Intestinal tract, through the nasal pharynx, or oral. It's not body fluid, blood born like some of the other viruses. For most people, it's just a benign viral illness like the flu. The body fights it off; it passes; they never really knew they had polio. But in about five percent of the people, the virus gets into the central nervous system and that's when we see the additional symptoms of the headaches, stiff neck and in about two percent of people, it actually invades cell bodies and kills off some of the nerve cells in the central nervous system. Specifically, that is the anterior horn cells or the cell

bodies of the muscles. It's the nerves that go to skeletal muscle that are affected by polio. The virus does not affect sensory nerves.

For some reason, the makeup of this virus only attacks motor nerves. Some of the nerves that are infected by the polio virus become sick but don't die and later recover. A lot of them do die. When a nerve dies that innervates muscle tissue, the muscle tissue that is normally innervated by that nerve also atrophies and dies unless there is another nerve nearby that can send out little branches to that muscle tissue and form new nerve connections so the tissue can be maintained. It's those two things that actually happen during recovery from the initial loss of nerves in the acute infection and why a lot of you who are initially very weak, regain strength.

The first period of recovery is, a couple months, and then there is a longer period of over a few years that strength is re-gained. In that first part of rapid recovery, regaining strength, those nerves that were sick but didn't die, start working again. The second phase is those adjacent nerves that are sending out extra branches to re-innervate some of the muscle tissue that was not working. Then the muscle tissue that is left without any nerve connections does die. A lot of polio survivors have muscles that have a reduced number of the normal muscle fibers and we know from other studies that the polio patient has to lose about 40 percent of their muscle fibers before they clinically or practically notice that they are weak.

So you have muscles that may have been affected by polio that you never realized when you were young. Everybody as they get older, gradually lose about one percent of the motor nerves per year. So every year for all of us, our muscles are becoming smaller. You're going to notice that a lot sooner. In those muscles that you've already lost a fair percentage of motor neurons because you're going to drop below the level where it's perceptible as far as how well the

muscle is functioning. That's part of the reason the post-polio occurs and that polio survivors see the new weakness much earlier in life than somebody who did not have polio.

III. POST-POLIO SYNDROME

Post-polio Syndrome, as I am sure you all know, is what occurs 15 or more years after Polio with new symptoms of weakness, fatigue, and often pain. Those are the most common symptoms. Less commonly, there is swallowing issues, cold intolerance. Those not everybody gets so we're going to focus on the big ones and today that is going to be pain.

Polio-related pain is not the same thing as Post-Polio Syndrome. You can have Post-Polio Syndrome and not have a lot of pain; you might just be noticing new weakness and fatigue. You can have a lot of pain and not have post-polio Syndrome, that's because a lot of the residual effect of having paralysis in muscles causes other types of painful conditions as well and a lot of those are related to wear and tear on muscles, ligaments, joints, nerves. Other painful conditions can develop related to the muscle imbalance and weakness but not necessarily classified as Post-Polio Syndrome.

IV. PAIN (GENERALLY)

We described pain as an unpleasant sensory and emotional experience. You will note that emotional is included in there, which is interesting. Pain is not necessarily a bad thing. Pain is an important protective mechanism in the body. Pain is your body telling you something is wrong and people who have conditions where they do not experience pain such as in some of the peripheral neuropathy secondary to diabetes, infectious disease such as leprosy where sensation is lost. You see a lot of tissue loss and damage that people often can't control because they

are not feeling it and they end up losing limbs, losing digits. So pain is actually protection. If you think about it, if you touch something really hot, it's the pain that triggers you immediately jerking your hand back. It's a warning to you. As you are doing something, if you're starting to get muscle pain, that is a warning; okay, you're overdoing, this may not be a good thing. If you break your leg, the pain keeps you from using that limb, putting any weight on it. Again it's forcing immobilization to protect the area.

I think one of the first steps in learning to manage pain is to learn not to be afraid of it. Realize why it's there and what it means. Learn to look at questions like: How do I work this with this? What is it telling me? Are there things I need to avoid? Do I need to go and get this checked out?

V. PAIN SOURCE

Pain starts with stimulation of peripheral pain receptors in our skin, muscles, joints. There are many pain receptors throughout the body. That signal is transmitted up through the spinal cord to the brain and the brain interprets the pain. There are different types of pain depending on different types of pain receptors and on the brain's interpretation.

Also, other chemical systems and reactions can modulate or change the perception of that pain. Your body has natural endorphins that can dampen pain and make it less intense. A good example of the body releasing endorphins is, if you're in an extremely dangerous situation, like war, and you're shot but your life is in danger, your body is kicked into high gear with all this adrenaline and endorphins and you won't even feel the pain until you get out of danger because your body is just shutting down that signal because it's not the most important thing going on at the time. That's an extreme example.

As to mood, your emotional response to pain can affect the intensity of that pain and how much it actually bothers you or how much you will suffer from it. Emotional states such as depression or anxiety can heighten or increase the perception of pain.

When we talk about acute pain, it's often a different thing than chronic pain. Acute pain is often an immediate threat of maybe an injury. People often have an easier time dealing with acute pain than chronic pain. Pain that may not be as intensive as acute pain but is chronic and just goes on and on and on wears out people and is much more difficult to deal with. Chronic pain can be from ongoing damage to tissues or it can be from damage to nerves, which maybe there is nothing to do to really correct that, it may be old scar tissue or damage to nerve from other conditions.

VI. PAIN TYPES

In polio, we see five different types of pain or that's the way I like to break it down. We see muscle, soft tissue pain (which is more the bursa end, tendons and ligaments), joint pain (from changes in the joints themselves), nerve pain, and bone pain. I also added to the list psychologic pain, because that is pain as well. I am not going to go in depth on the psychologic pain because that is not my area of expertise.

A. Muscle Pain

Muscle pain, I think you're all familiar with it. You may not remember your acute polio if you had it as an infant but those of you who do remember the polio will remember having muscle pain because there was damage to muscle tissues and muscle tissue death. There is a whole spectrum of muscle pain and damage.

Muscle pain is from damage or impending damage. Sometimes it's from chemical build up in the muscle that is irritating things and the tissue hasn't been

actually damaged yet and often is due to excessive load on a muscle that causes disruption of muscle fibers. Often the pain is most intense later on so there is delayed onset. Often a day or two later, the pain is most severe.

The concept of disrupting or tearing down some muscle tissue is actually used in a mild to moderate degree in muscle strengthening. When muscle tissue is damaged, muscle is one of the tissues in the body that can regenerate and regrow so minor trauma to the muscle, the body will heal and make it stronger to withstand more the next time. It is the whole concept behind strengthening exercises; the bodybuilder is actually doing micro damage to the muscle to rebuild it stronger. The other extreme is severe muscle damage when muscle groups...multiple muscle groups are damaged and to a large degree. You release some of that myoglobin, one of the substances in muscle into the blood stream and that can cause kidney damage and death.

In polio affected muscles, the muscle pain can feel similar to that of Acute polio. That would be an indication you're having a pretty significant damage to the muscle. It's more than just the kind of mild chronic damage. It can feel deep or superficial because different muscle groups are at different places within the limbs. It is often associated with cramping of the muscles, twitching or crawling sensation.

When a muscle is damaged and the membrane becomes more irritable, it starts firing spontaneously so you get this kind of the muscle moving without you moving it and kind of that crawling, twitching sensation. Often it's most noticeable at the end of the day or at night when you get in bed and getting a delayed onset is very common and in polio muscles can be even more delayed than what we see in normal muscle and it's usually aggravated by physical activity, stress, and cold.

The muscles that were mildly or moderately affected by polio are at the greatest risk. In a severely affected muscle, there is not muscle tissue to use; you don't overuse it very commonly. That muscle is pretty much gone and not going to cause a lot of muscle pain. It's those partially innervated ones that are at risk of overuse. In those muscles, again they may seem strong but they may not have the same reserve as a normal muscle so it's very easy to overuse them and cause damage in the muscle. In those partially innervated muscles also healing is slower so they don't recover from that stress as fast. Body builders may be doing the stressing of muscles to rebuild at every other day to gain strength. A polio muscle usually would need two to three days maybe longer after being stressed to recover.

So if you are continually overusing the muscle or doing an activity that overuses a muscle, that will actually present as the muscle getting weaker rather than stronger or staying the same if that muscle cannot recover in between, you've broken down some muscle, it hasn't recovered, you're breaking down more, you're just going to see a gradual decline. So one of the things that we do with pacing activities is try to give those muscles a break in between to recover so you're not causing that ongoing weakness.

B. Soft Tissue Pain

Soft tissue pain is usually in the connective tissue, the tendons, the bursa. Often we see this in what you would call your strong limb or the normal limb but it can be in either one. It's usually related to body mechanics, using a limb or a joint in a position that is not mechanically ideal, stressing a joint that doesn't have the normal muscle strength around it for protection, repetitively using ligaments. All these things can cause inflammation and wear and tear that cause soft tissue pain.

Often it's a chronic thing, it may start relatively mild but if you kind of ignore it and keep going and don't change what you're doing, it will gradually get worse and can lead to tears in tissues, tears of tendons, and a bigger mess down the line. So you should pay attention to it. It usually starts with inflammation and there are some common examples that we're just going to run through because probably half the people in this room have experienced one or more of these, if not everybody.

Some common ones are rotator cuff tendonitis around the shoulder, trochanter bursitis at the hip, and patellofemoral syndrome at the knees. I am just going to give you these as examples so you kind of know what I am talking about with the soft tissue. Again, these are things that occur in non-polio survivors as well when there is muscle imbalances or a lot of stress on a joint.

This first one, the *shoulder joint* -- if you are a crutch walker or use your arms a lot to assist with weight bearing or putting more stress to the shoulders so pain is more likely to occur. Rotator cuff tendonitis -- the rotator cuff is a group of muscles around the shoulder girdle that connect the arm to the trunk basically. They stem from the trunk and scapular area attached to the upper bone of the arm and there's different muscles that provide all the different motions we have at the shoulder, which is a lot because it's a ball joint that has a lot of movement and that is completely held in there by those muscles and tendons.

Because there is so much movement at the shoulder, if the movement starts in the wrong plane or is restricted in one motion, it's very possible that the tendons that are passing under the joints there start to get pinched and then they become inflamed. If the bone also becomes inflamed or is arthritic, you get bone spurs. That increases the chance of inflaming the tendons and all of a sudden, movement is really

painful because you are pinching off those inflamed tendons. If they are chronically inflamed, they can start to tear (partial tears or full tears) and that is a painful condition. We will talk in a minute about how we treat these sorts of things.

Hip trochanter bursitis is a similar sort of inflammation that occurs around the hip but this just occurs in the cushioning fluid sacs that sit around the hip joint to maintain smooth motion and the trochanter bursa is on the outside of the hip. You've got your hip extensors and abductors that attach there and again, the hip is a joint that moves a lot and is controlled by the muscles. Well, if you have scoliosis or leg length difference and one hip is higher or crooked, if that hip didn't form normally because you don't have normal strength around there, if the muscles are weak, if your gait pattern isn't straight, all of these things add stress to the hip and rubbing at that area and cause inflammation. So I just picked trochanter bursitis here because this is one of the ones we see early but you can also get bursitis within the hip and around other of the major muscle connections in the hip and pelvic girdle.

The *knees* are another area that is commonly painful. One of the big reasons for that is falls. The knee joint only bends one way; it's a hinged joint rather than the ball and socket joint like the hip. Often you fall forward, that's the way the knee goes, and you bang those knee caps. If you don't fall straight forward, you can tear ligaments and do other things because the knee isn't going to bend other directions so then you start straining the connective tissues on the sides of the knee.

The patellofemoral syndrome refers to degeneration or pain underneath the patella because it doesn't track straight up and down across the bone of the thigh, the femur. Again, there's some lining behind there. In non-polio survivors, we see patellofemoral syndrome commonly in young woman who don't have

real strong quads. The patella is fairly lacking contact laterally. In a polio survivor, many of your knee caps aren't in the normal center to start because of muscle imbalances. Often it doesn't track normally at all. If the muscle is real weak, you often don't have this problem so much because it's actually the muscle pulling on the knee cap that pushes it into the other bone. So if the muscle is very weak, you may not have this but a partially weak muscle especially if part of the quad is functioning and the other part is not this commonly is seen and when the patella is tracking abnormally for years, you get degeneration under the patella and eventually arthritis in the knee.

C. Joint Pain

Which leads us to the next category of pain, which is joint pain, which is really due to altered joint mechanics often and just wear and tear. The stress...so in able bodied people, we just see arthritis, it usually takes quite a long time to develop although there are some genetics factors and people who have had injuries tend to have arthritis develop in a joint. Pretty much for a polio survivor, any of your joints in a polio affected limb are pretty much like those injured joints where the mechanics of the joint are altered so things aren't moving in a normal fashion so you get areas that rub and wear faster.

Also, if the muscles aren't strong and you're dependent on the ligaments for stability rather than muscle, they start to stretch. So if you back bend the knee to stabilize the knee when you're standing on a weak leg, over time, if the hamstring is not very strong, those ligaments will stretch further and further, allowing the knee to go further and further back, allowing more and more pressure on the front of the knee and that then wear and tear, changes in the bone, inflammation in the bone and in the fluid surrounding the joint and a lot of pain. So the degeneration of ligaments or the cartilage that covers the end of the bones and in some of the joints like in

the knee, there's an actually a cushion of cartilage between the bones. All of those start to wear out. This definitely gets worse as you get older; it doesn't get better.

Cartilage does not heal very well. So as the cartilage wears down and the bones start to rub together, you get a lot of pain going on. Bone is more painful than just cartilage degeneration. The bones develop bone spurs; they get stiff, the muscles get weaker, from the stress of the problem.

The same type of degeneration can occur in the *spine*. Again, if you start with having some scoliosis because of trunk weakness or imbalance or abnormal gait pattern where you are putting a lot of stress on your back to walk, that will just exacerbate the wear and tear in the spine. You can get very similar conditions to the joints in the legs or arms but in addition because the spine is the protective structure around the spinal cord and the major nerves that go to our arms and legs. When you get degeneration there, things start to settle and you get bone spurs that start pinching on nerves and you get a different type of pain, nerve pain, in that case, nerve root pain but there's different types of nerve pains. So the spine kind of sits between the joints and the nerve pain because it can produce both.

D. Nerve Pain

Nerve pain tends to be a different sort of pain than what you have in muscles and joints. Muscle and joint pain can be very painful but nerve pain has a different quality to it. Often more electric, burning, when you have nerve pain from peripheral or small nerves, which are irritated because of the local inflammation or pressure or damage to them or you can get nerve pain from the big nerves. The plexus, where a bunch of nerve bundles are passing through from the neck to the shoulder and intertwining. These are the nerves that branch out and go to the entire

arm, the nerve roots that come off the spine are bigger nerves that serve a number of muscles and when they become pinched or affected, that's pretty often pretty significant pain.

So you can have acute nerve pain from pressure on the nerve. You can have chronic nerve pain from scarring or from chronic wear on the nerve with degeneration. Chronic nerve pain is not as severe as the acute nerve pain but again still has that sort of burning quality a lot of times.

E. Bone Pain

The last one I want to talk about is bone pain. Bones also can be affected from the polio, primarily in people who had polio very young. As we grow our bones grow and strengthen. They become more dense as we stress them. A young child doesn't have real dense bones. The bones aren't even completely formed or fused because the bones have to grow as the child is growing. As you're growing, for all us, it's activity and nutrition that helps build good bone mass.

In a polio affected limb the bone doesn't develop as normally because there is not the same amount of muscle tissue pulling on the bone. That's why that limb is often smaller; the bone hasn't grown to the full length. But somebody who had polio as an adult may lose all the muscle in a limb but the limb is the same length as the other one because the bones have grown to the same length.

So a polio limb has weaker bone to start with and then again like with the muscle tissue, all of us as we get older, you lose bone mass. Bone density peaks in your early twenties and then it's a gradual decline from there.

Women in addition have this sudden decline around menopause; as women's hormones change, there's a more sudden drop and then continuing. Often women are ahead of men on the osteoporosis curve because:

1) usually their bone mass isn't as high to start, and 2) they have a more rapid drop around menopause. As the bone loses bone mass, it becomes more brittle, more fragile, and more likely to fracture.

A weak bone doesn't necessarily cause pain unless there's fractures occurring. This can be a very weak bone; it can be micro fractures which are small fractures within the bone matrix. More common are stress fractures from repeated stress to a certain area where suddenly the bone collapses or trauma fractures, falling. We always emphasize reducing the number of falls as you get older and the main reason is those bones just aren't going to be quite as strong to resist fracturing. Then fractures can also occur if there's something wrong within the bone including things like tumors, infections, or something else but that doesn't apply so much to polio.

So when we're talking about the osteoporosis and the increased fractures, we can actually see what seems to be essentially spontaneous fractures or very little impact causing fractures. These are fairly common in the spine. If you look at the picture of the lady that gets more and more curved over, that is due to osteoporotic compression fractures within the spine, mostly in the thoracic spine. All of our thoracic spines have a little bit of a curve to start. If those vertebrae start collapsing, they tend to collapse in a wedge because there is more pressure at the front and each one will bring you more and more forward, so you end up hunched over.

The other real vulnerable areas to stress and fracture are the hip and the wrist. In the hip bone, there is a relatively narrow area from the main shaft of the bone connecting it into the pelvic girdle. That's an area that if you fall wrong, twist that leg, it is a vulnerable part of the bone that can fracture. The wrist is vulnerable because many of us when we fall, the first instinct is get your hand out there to break the fall but that means the wrist snaps. So when a bone does have

osteoporosis or is weak, again just like with weak muscle, the healing process is slower. So that's something that has to be considered as well.

VII. PAIN MANAGEMENT

What do we do about pain? The reason I spent the time going over different types of pain is the more we can identify what is causing pain, usually the more we can do about it. A lot of the things that I talked about are related to too much stress, overuse, altered body mechanics causing pain and if we can intervene in some of what is causing the pain, the pain is easier to manage.

So first they want you to see somebody, a physician that is going to ask you about your pain. Where does it hurt? What does it feel like? When does it hurt? When did it start? Has it changed? Is it getting better? Is it getting worse? What makes it worse, what makes it better? How much does it impact your activities? What have you done and tried as far as medications?

Often with polio related pain the history and physical examination with a physician who knows what they are looking at in a polio survivor can usually pinpoint what's causing the pain because it's often related to the body mechanics. Matters reviewed are: which muscles are strong, which are weak, how are the joints moving, how much degeneration is in the joints, how are you stressing different areas when you sit, when you stand, when you do different activities? Sometimes we may need radiographic imaging to further evaluate joints, spine, and things like that. Used are MRIs, x-rays, dexa scan to assess bone density and occasionally if it's more of a nerve pain presentation, we may need to get nerve tests, EMG.

A. Joint pain

A lot of times those extra studies aren't even needed because it's pretty apparent from body mechanics

what's going on with the muscles and joints. So then we start looking at how do you manage the pain? If it's primarily muscle pain, muscles are the movers of the body so we have to figure how to either modify how you are using them or how frequently, giving them the opportunity to rest between activity. If you are repeatedly tearing down muscle and not giving it a chance to regenerate, you need to work on pacing that. Be more aware of listening to these muscles and knowing when to stop, when to cut back, when to take a rest. I know that's a difficult thing to do because we are all busy and important and have to get things done. But sometimes your body is more important because if you keep abusing your body, pretty soon nothing is going to get done. So I think Mary Ellen is very wise to work very little at this point so she can do things that are important to her.

The other soft tissue symptoms often associated with inflammation may take a little more intervention. Our first line approach to any inflammatory condition is rest, ice, compression, elevation, trying to get the inflammation down. Often we add to that medications. But again, the inflammation is usually related to body mechanics and how you're using joints. Look at how are using this joint, what are you using it for, can we modify how you are doing that, can we change or eliminate how you are doing certain activities, can we add some sort of protective brace, a system device, cane or something like that, that modifies that mechanics and changes those stress points. It's really all about getting the stress off those areas that are becoming inflamed.

Physical therapy can often help with this because it's often a combination of changing mechanics, working on maybe stressing certain areas, strengthening certain areas or just adapting different ways of doing things. Often that's a difficult thing to do on your own especially with an inflamed area that's just screaming at you. With the soft tissue problems physical therapy

is often my line of approach to treating those. If with therapy and modifications they continue to be inflamed, there are injection procedures we use that can help calm things down by putting steroid in the joint and at times surgery might be indicated.

Joint pain is similar to soft tissue pain in that it is also often related to body mechanics. Sometimes you have to work on balancing the structures around the joint by stretching or strengthening. Often getting the weight off the joint can help. If it's a low extremity joint, a weight bearing joint that might require using an assistive device, it might require a brace. If it's an upper extremity joint, it might be to stop using the upper extremity so much for weight bearing so you may actually have to use a scooter more or power mobility.

Sometimes it's a matter of joints carrying too much weight around and you need to pear your weight down a little bit. With those lower extremity joints, you definitely notice if you gain ten pounds or 20 pounds. With joints injections or surgical procedures may be needed at times.

B. Nerve Pain

Nerve pain can be more difficult to manage. Nerve pain from acute compression, which is the most severe nerve pain, quite commonly requires surgery. If you have that type of nerve pain, it's so severe, no matter what you're qualms are about surgery, it's like, "Cut me open, I don't care, get the pressure off this nerve because it's that bad" pain. The more chronic pain from nerve degeneration is not so easy to treat and there are a number of different medications, I am going to talk about a few. Medications work for some people and they don't work so well for other people. Sometimes it's a matter of just lessening the pain, learning to live with it and manage around it.

C. Bone Pain

As we discussed bone pain often relates to fractures. It may mean treat osteoporosis, trying to get the bone stronger. If there is an area of fracture supporting or immobilizing it is needed.

Now that does not have to occur with spine fractures because most of those don't move; they just collapse down and don't move at all so they don't require bracing or casting. But a limb certainly would.

Sometimes when bone is not healing well, there are techniques of bone stimulation to stimulate bone growth. With fractures in the spine, there are cementing procedure to solidify a fracture; that does have drawback too though. So usually we try to let the body heal itself as much as we can.

D. Summary

With Polio pain management, the most important message is don't just treat pain. Just taking pain medications is not the answer. That means you're suppressing your body's warning signals and you're likely to do more damage.

Body mechanics and improving or minimizing gait deviations is huge. We really want to focus on protecting and supporting the weak areas of the muscles and joints and adjust the work load you're putting on those weak areas. If there's acute inflammation, we treat that. If there's nerve impingement we relieve those, and then you want to look at kind of lifestyle and optimizing your body's ability to heal.

VIII. PAIN MEDICATIONS

The pain medications I do use relatively commonly are the anti-inflammatories, common ones being Ibuprofen and Naproxen. Aspirin is an anti-inflammatory although we don't usually use it that way because it's pretty tough on the stomach. Your stronger anti-inflammatories but not something for

ongoing use are steroids, oral steroids like prednisone. They can be a wonder drug but if you take them for very long they cause a lot of other side effects including diabetes and tissue breakdown. Those are only for acute short term use. There are some topical steroid and anti-inflammatory creams that can be quite effective for more peripheral problems.

There are medications that are just straight pain medications, Tylenol would actually fall in that category, which is a milder analgesic as compared to your opiates, Hydrocodone, Oxycodone. Again, when we get to those stronger pain medications, we tend to shy away from them in a Polio survivor unless it's treating a specific condition we know we can do nothing more for.

Opiate medications in general do not work well for muscular skeletal or nerve pain. Often what I see, if someone has been started on Hydrocodone by their primary doctor for nerve pain, they just go up and up on the dose until it knocks them out and that's how it helps for the pain, but it really doesn't do anything to the pain. The problem with the opiates is your body gets used to them so you end up often getting higher and higher on the dose and when you get in on those higher doses, it can cause respiratory depression and people die from opiate overdose. In somebody who is at risk of having reduced respiration to start, they can end up to be quite risky. Those are medications that certainly have to be used with caution.

Some of the nerve pain responds better to things like anti-depressant or anti-seizure medications. In that case where there is maybe some depression, anxiety associated with the nerve pain, often the anti-depressant medications are very helpful for the whole picture, both the pain and somebody's attitude or ability to handle the pain. We have three main groups of anti-depressants that we use for pain. The SSRIs are targeted toward depression and anxiety primarily.

The more selective SSRI, which is serotonin and norepinephrine reuptake inhibitors, not only affect depression and anxiety but also do have indications through the FDA for peripheral nerve pain and fibromyalgia. Cymbalta would fall into that category. The seizure medications are designed to stabilize nerve membranes. The thought is that a nerve that is irritated, not just in the brain where it might cause seizures but in the peripheral where it is causing pain, may respond to these and in fact, we do see fairly good nerve pain relief with medications like Gabapentin, which is Neurontin and Pregabalin, which is really the newer version of Neurontin with a little less side effects but cost more which is Lyrica until it gets old enough and then it will be cheap too. That's the way things go.

IX. INJECTIONS

There are the injection procedures we can use. Sometimes just trigger point injections into the muscle can help if there's localized areas of spasm. The joint injections, as I mentioned, use steroid if there is acute inflammation. For a joint that has degeneration and it's more of an arthritic picture, there's disco supplementation. It's a substance that helps stimulate cartilage growth and lubricate the joint. It's a newer approach for treating early to moderate arthritis.

Question: Is that what Synvisc is?

Dr. Vandenakker: Yes. that's what Synvisc is. Synvisc, Hyalgan, there's a bunch of them. Spine injections, depending on if it's more bone pain, nerve pain, there are steroid injections or nerve blocks and there are other nerve blocks that can be used peripherally including Botox, sometimes when there is an irritable muscle. What Botox does is block the transmission from the nerve to the muscle. This is not something we see commonly in Polio muscles because most of the problems in a Polio muscle is from that loss of nerve muscle connection. But in

some of the other neurologic disorders when there's too much irritability there, Botox is helpful.

X. THERAPY

Physical therapy we commonly use for a lot of the muscular skeletal conditions and can be very, very useful. Occupational therapy if there is more problems with doing self-care activity with daily living, need for adaptive equipment for those of you who have more upper extremity involvement. You've probably worked with OTs over the years to try to figure out how to do certain things.

For Polio survivors with bulbar involvement, speech therapy to evaluate speech and swallow can be very useful. Of course psychology when there's just problems dealing with the chronic pain or the increasing disability, the changes in life. Aging is not easy for anybody. For somebody who has Polio and/or Post-Polio Syndrome and additional problems on top of that, sometimes getting somebody to talk through things with you and help you sort things out and kind of reestablish priorities is very important. We use psychologists actually quite a bit for most chronic illnesses, which I consider Post-polio a chronic illness.

XI. MISCELLANEOUS MANAGEMENT TECHNIQUES

Bracing

Bracing is a whole lecture in itself but they are often very useful for changing those body mechanics, protecting those weak areas and minimizing or preventing joint deformities. Often just getting the stress of an area can make a big difference in the pain and if we can do that early before it's completely impossible to take the stress off, that is often helpful.

Surgery

Surgical intervention for specific conditions can be very helpful. Like I talked about for a nerve, for severe nerve compressions, definitely surgery is helpful. For joint problems, yes I can provide relief but you have to be careful with surgery on a Polio affected limb because again, the surgeons are going in and cutting tissue. If the ligaments aren't normal, if the bone mass isn't normal, they can cause more problems than they are fixing so we have to carefully evaluate that before any sort of procedure on a Polio affected limb. For limbs that are really not or minimally affected by Polio then it's very similar to the general population and orthopedists know what to do with it. But when it's a Polio limb I would advise caution.

Well lists

Can we ever say enough about well lists? Exercise is a whole other talk on appropriate exercise program for a Polio survivor, but exercise is very helpful in maintaining function and wellbeing. Healthy diet. Good sleep, again a whole other topic for Polio. Weight control, stress reduction, and trying to avoid those unhealthy things like smoking.

There are a number of alternative treatments that can be helpful as adjuncts to conventional treatments. I know a number of people in this group have tried acupuncture; it's something that's relatively readily available in the Bay area that's more or less true in other areas of the country but certainly can be helpful for painful conditions. Yoga can often be a good form of exercise that included sort of mental relaxation, meditation as well as kind of slow gentle exercise. But often yoga would have to be modified for a Polio survivor as far as what positions you could or couldn't do but there are a number of yoga classes adapted to people with medical conditions or disabilities and those are often a good resource.

Massage

Where there's a lot of imbalance around a joint and there's muscle groups that tighten up a lot, massage can be very useful. Again, chiropractic can be useful in certain situations. I do caution people against chiropractic often as they get older especially if there is a fair amount of joint deformity that it starts to become more risky. In a younger person, relatively straight spine, not a lot of degeneration then it...there's a lot of to chiropractic that can be helpful.

Dietary supplements

Then there's some dietary supplements which have some proof as being helpful for anti-inflammatory purposes. These are fish oil, topical capsaicin, which is the hot pepper cream, and glucosamine. There are many others touted as being good for pain, inflammation, and muscle strength, but all with little to know proof that they actually work so I am avoiding that topic today.

Avoiding pain cycles & be adaptive to as condition changes over time

Pain can lead to a cycle that is very important to avoid. Often when there is pain, you stop doing activity or significantly decrease it. When you decrease activity, you become weaker and stiffer and gain weight. Then any activity is harder to do and it's easier to over exercise, so then the pain is worse, so then you do even less and become very frustrated, depressed, and go in a hole and hide from people. Obviously, the cycle doesn't happen all at once but that is the spiral that can occur. I would encourage you to pay attention to what's bothering you and start early to figure out ways around it, ways to modify what you are doing. Continue to stay active and involved with people. Don't not do anything because you don't feel well; try to find a way of doing it. If it means getting in a scooter so you can go out to eat or

go out with your friends, that's better than sitting at home because you don't want to be seen in a scooter (unless you are the home body and that's a perfectly happy place to be.

You have to face the fact that certain things can't be fixed. Certain things you are going to have to learn to adapt to. You want to try to work those things into your life so you can continue with what's important to you. There are a number of tools out there. If what you can do or can't do changes, it may be time for a reassessment, another trip to the therapist, try some other intervention to keep you more functional and really work on partnering with your doctor, your healthcare providers.

Post-polio is a condition and you are it for the long haul. You may be doing well now but somewhere down the line, something's going to change. You may be doing poorly now but that doesn't mean that you can't improve at least to the point that you're not in pain all the time and you're functioning better and satisfied with your life again. So there is hope. It's livable. I know a lot of you are happy and still doing a lot of things so I am proud of you as a group. I think you are a great group to work with. So thank you.

Question: At the end of an email just this morning, somebody's little quote, it said that "pain is inevitable but suffering is optional".

Dr. Vandenaeker: Right. I'd agree with that.

Electro-stimulation

Question: You didn't mention something I am curious about. I have encountered it both in physical therapy and chiropractic medicine. The use of electro stimulation energy. Is that simply masking the pain or is it really doing something to correct the underlying situation?

Dr. Vandenaeker: It doesn't do anything to correct the underlying situation. It interferes with the pain signal to the brain so you're just feeling the electric stems. It's a good tool for chronic pain from nerve damage or muscle damage that we have nothing more we can do for it. I certainly prefer using something like heat, ice, all of those topical things over popping pills every time you have pain but it doesn't correct anything.

Prolotherapy

Question: Have you heard of prolo and do you advise it?

Dr. Vandenaeker: Yes, I have heard of it. I think in my case, the jury is out on how effective it is.

Question: Is this a drug?

Dr. Vandenaeker: No, it's actually injection with a high concentrate sugar water and the idea is to scleros tissues to make them stiffer.

Question: At the same time I am taking epidurals.

Dr. Vandenaeker: I don't know. The answer is I don't know.

Dr. Vandenaeker: In the SI joint, I think it's a relatively safe thing to try. If the SI joint is hypermobile because of weak muscles from Polio and poorly formed ligaments because of Polio, I don't know that the prolo would do enough to really correct it. But again, it's relatively safe depending on where the injections are done so I wouldn't tell you not to try it.

Question: What's a side joint?

Dr. Vandenaeker: A side joint is the joint between the sacrum and the ischium so it's at the lower part where the spine attaches to the pelvis.

Question: I am sorry, can you say a little bit more of what's the theory behind this? I have never heard of it before...is it prolo?

Dr. Vandenakker: Prolotherapy. It's injection of sugar water usually into ligaments. But I am not going to talk more about it because I don't perform it. I don't know a lot about it.

Question: It's a strengthening mechanism?

Dr. Vandenakker: Correct. As an idea. It's not a normal fashion of strengthening. You can strengthen ligaments with exercise and tension. Prolo is more to form scar tissue to make them stronger and stiffer.

Medications reactions

Question: Are we, as Post-polio patients, more apt to get a reaction from certain medications than other people? For instance, I can't take Celebrex, Lipitor, or Gabapentin because I get very bad muscle pain.

Dr. Vandenakker: You named three very different medications. I will give you two parts to the answer. Lipitor falls in a different category. Statins are known to have a possible side effect of muscle inflammation. When the drugs first came out, everybody was told that is very rare. We almost immediately noted in the Polio population that a lot more than what was expected people have problems with muscle pain on Statin drugs. It's now come out now that everybody across the whole population, there is the muscle pain incidence is higher. I think it's just more bothersome in a lot of Polio patients. There are some different Statins that have lower risk, there's other ways of controlling cholesterol but that's a known side effect of that drug that I think Polio patients might have been more sensitive to because you already have muscle pain.

Metabolism of medications may be different in some Polio survivors and that would often depend on how extensive the Polio involvement is. When you have loss of muscle tissue due to Polio, the fat muscle ratio changes and so often certain medications aren't metabolized as quickly and so there's more side effects with them. Which is also what occurs with some of these anesthetic agents. Anybody can react to any medication. Celebrex is an example. A fair amount of people are allergic to it because it's related to sulpha drugs, which a lot of people react to. Any new medication should be started with a low dose, to see how you respond. If you are somebody who has quite a bit of Polio involvement and don't weigh a whole lot, definitely talk to your doctor about starting you on a low dose whenever you start a new drug. If you take a full dose and have a reaction, that's going to be a whole lot worse than if you can start low.

Massage

Question: As alternative treatments, massage is recommended. Deep tissue massage, soft tissue, are really great. But I haven't found a masseuse that takes medical insurance.

Dr. Vandenakker: Most of them don't. You have to have a really good insurance for it to cover massage.

Question: I had Aetna and they do cover it but I don't know any masseuse who actually takes insurance. You have to re-coop it

Question: I see a masseuse through my chiropractor and it's covered that way. But now that I'm on Medicare, it isn't covered.

Dr. Vandenakker: I would say most masseuses don't want to deal with the whole insurance billing thing. That takes an extra person you have to pay in your office to play the insurance game. That's why they make you re-coop the checks.

Question : At physical therapy they do some massage but they don't want to focus on massage because it's expensive. So if you're going through a therapy session, you will get maybe ten minutes of massage and anything else after that.

Dr. Vandenaeker: When you are seeing a physical therapist, insurance will only pay for so much of those modality type of approaches and often in therapy the focus is more on teaching you to do things, gaining range of motion, focusing on motion more. So massage is often used as an adjunct in physical therapy because it's more function focused. If you're somebody who needs ongoing massages that's better handled by someone who just does massage.

Mary Ellen Brown, PT: In my experience, they call it soft tissue mobilization. Done carefully to get the tissue more relaxed and you have a lot better shot at re-corrective exercise.

Dr. Vandenaeker: I completely agree with you and I think what Mary Ellen is referring to is a lot of insurance companies have gone the other way where they pay very little for the modality, So the therapists are forced to get somebody in teach them some exercises, throw them out the door which is not nearly as effective as using the different techniques to first mobilize, relax tissue so you can then do the stretching or strengthening so it all works together.

Soap bar for treating leg cramps

QUESTION: I wanted to make a suggestion. It's a very old grandma type of remedy. Nobody knows why and where it comes from but for people who really suffer from cramps in the legs, it works. Get the small bar of soap that you find in a hotel bathroom and put it under the mattress cover and every time you feel the cramp coming, just put your leg on top of the bar of soap and the cramp goes away.

Dr. Vandenaeker: We've got a pretty large group here. Let's try it. Then report back to me how many people the bar of soap system worked for. We could have a new solution for leg cramps.

Atrophy

QUESTION: I'm experiencing some atrophy in my muscles. Is it from overuse or underuse or could it be both.

Dr. Vandenaeker: It could be from natural loss of muscle with getting older. You see atrophy from underuse or de-conditioning. If you are not walking as much, using the muscles as much, they will atrophy. However, if the atrophy was from overuse, I would expect a fair amount of pain with it.

Number of hours worked

QUESTION: As far as my work schedule, is it better to work five eight hour days or work two ten hour days then have a day of rest in between, then work two more days?

Dr. Vandenaeker: That depends on you. If the ten hour day is too long a period of time for you to work without fatiguing then you can't go to the ten hour days. That's often an individual thing. Sometimes if your commute is very long, the longer days make it easier because then you can eliminate those commute hours. You are working four days instead of five. But if you can't tolerate those ten hour days then it's not recommended.

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