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Polio Regina Incorporated

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Season's Greetings



My Polio Story

Clara Wiese is one of our newest members. The following is Clara Wiese's Polio Story.

Clara Wiese

The first seven years of my life story are the events as told to me by my parents.

I was born in 1924 on a farm 14 miles north of Regina called the Foxleigh District.



One day when I was four years old, I complained that my neck hurt and also had a headache. Shortly after I began running a fever. My mother treated me with the usual home remedies, but instead of improving, my condition was getting worse.

I was taken to the family doctor. After examining me, he said he would need to take a blood test to find the reason

for my symptoms. He took a blood test and sent me home and told my parents he would call them with the test results.

When the doctor called with the results, he said I had Infantile Paralysis but not to bring me to the hospital as they could do as much for me at home as they could in the hospital. (Later, after I recovered the doctor told my parents he did not believe I would survive).

My parents knew very little about Infantile Paralysis except what they had heard about the disease, that it usually was fatal. So they decided to contact the Mayo Clinic in the USA. The Clinic was very helpful in the steps to take to bring me through the ordeal. One of the things they advised (which I believe saved my life) was to apply cold to my back and heat to my feet to draw the disease to my legs and keep it from the upper part of my body. With the continued help from the Clinic and dedicated work of my parents, I did recover.

However, by drawing the disease to my legs it caused havoc to some of the muscles in my legs. The foot on my right leg turned outward and the knee muscles on my left leg had weakness, which caused me to fall a lot.

When I was seven years old I spend three months in the hospital. Dr. B.D. Martin, who worked with the Veterans of the First World War, operated on me. He first operated on my right foot to straighten it and when it had healed, he operated on the left leg to correct the knee problem. By the time I went home, the only evidence of Polio was a slight limp and the scars on my legs.

I do not remember being sick but I do have recollections of being in the hospital - such as the big heavy casts on my legs and going to school in the hospital.

I went to a country school when I came home from the

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My Polio Story - Clara Wiese continued

hospital and then to Balfour Tech where I also took a Business Course.

In 1944 I began working for the Dept. of Agriculture and worked there until 1958. Lou and I got married in 1952 and our first daughter was born in 1959. In 1961 I began work with the Association of Rural Municipalities. In 1963 our second daughter was born and a few months later I went back to work for the S.A.R.M and stayed there until I retired in 1989.

Except that I was not able to do a lot of things because of lack of strength in my legs, I was fortunate to enjoy good health.

In 2002 I fell and broke my left hip. After the operation I spent three weeks at the Wascana Hospital. While there, I worked with both Occupational and Physiotherapists, mainly to strength my arms and do leg exercises. However, they advised me having polio and breaking my hip had caused those muscles affected by the polio to lose their strength. Therefore it is necessary that I use a wheelchair.

We moved into Broadway Terrace in Regina from our house in 2004.

I have been using a wheelchair for eight years and am thankful for strong arms and no pain related to polio.

High Tech Breathing

By David Cotcher

Breathing is fundamental to life. If we do not take in sufficient oxygen or get rid of carbon dioxide (CO₂) it affects every part of our body. I had polio at about 18 months and at seven I started to have a curvature of my back that developed into a double curvature called kyphoscoliosis. As I grew my muscles were weaker on one side than the other causing my back and rib cage curvature. This restricts my lung volume. Muscle weakness also affects my breathing. The problem is worsened when laying down and I was not breathing deeply enough when sleeping. I was prescribed supplementary oxygen usage starting in 1995 after I had pneumonia. This allows me to get sufficient oxygen with less effort, but this can compound the problem of my lungs not getting rid of the CO₂ build up in my blood. More about the effects I had from polio are told in My Polio Story in the May 2009 Polio PostBox.

In 2007 I ended up in hospital about 10 days in January, another 10 days in early February with worsening

respiratory condition, and then back in hospital with respiratory failure from high CO₂ in my blood later in February. I was in critical condition with my oxygen level down to 31% and my CO₂ level 3 to 4 times the limit. High CO₂ leads to being incoherent, then unconscious, and then to death. I had been getting more incoherent over the previous weeks and was slipping into unconsciousness. I ended up with a tracheostomy and on a respiratory ventilator to help keep my CO₂ level under control. I was there recovering until mid April. I improved quite well and was able to go back to work part time by June. I still have a trach and use the ventilator at night to improve my breathing while I sleep. Follow up tests show that my CO₂ level is still under control.

For this reason I have continued using a respiratory ventilator at night to keep a proper balance of oxygen and CO₂ in my system. I used a BIPAP (Bi-level Positive Airway Pressure) machine for a while in January/ February 2007 but my condition continued to worsen and I need the extra support of a volume ventilator. The ventilator I used for 5 years is called a Phillips Respironics PLV 100. It is called a volume ventilator because it gives a measured volume of air on each breath. At night it is connected through a hose to my trach tube. It is set to give me 0.37 liters of air on each breath for a minimum of 10 breaths per minute. Room air is about 21% oxygen, but extra oxygen is added to the ventilator air to bring it up to 30%.

The first picture shows with me in bed connected to the



David with old ventilator PLV100



David with new ventilator PB560

old PLV 100 ventilator. The ventilator is on a bed side table (with a lamp sitting on top of the ventilator) as seen in the picture. I used this same model of ventilator each night for five years starting when I was in the hospital in 2007. The PLV 100 ventilator model is out of date and no longer supported by the manufacturer. It is a simple and reliable machine, sometimes with a

High Tech Breathing - continued

few clunks, honks and rattles, but it just keeps puffing along. The family says I sounded like a steam engine when using it. It is a pretty rugged machine and I told the respiratory therapist it looks like it was designed to mount in the back of an army truck.

Then earlier this year we got the news that the provincial health department had approved the purchase of new ventilators. The respiratory therapist brought mine in mid May to get me going using it. The new machine is a Covidien Puritan Bennett 560 ventilator which is the latest technology. The second picture shows me in bed connected to the new PB 560 ventilator. The heated humidifier behind the ventilator is the same one I used with the old machine.

When I used the new ventilator for the first night, I woke up after sleeping one hour and then had some trouble getting used to it before sleeping and waking several more times. After being used to the feel and sound of the old machine it takes some getting used to sleeping with the new one. The old ventilator we called a “steam engine” with the sound of a large piston cycling back and forth with each breath. The new machine has a variable speed micro turbine (like a tiny “jet engine”) that has a varying higher pitched whirring sound with each breath. The feel of the breathing cycle is different as well. The following nights were still more difficult sleeping and I would wake feeling like I was not getting my breath. But night by night there was some improvement in being more relaxed and comfortable to sleep with the new ventilator. Now I have been using the new ventilator for about 5 months and I am getting used to sleeping with it, although it still takes a little while at the start of each night to relax and not think about the sound or feel of the machine.

One big advantage of the new ventilator is that it is much lighter to take with us when we travel. It just has a zippered soft case with a shoulder strap for carrying. The old one had a large heavy steel framed shipping case. The PLV 100 machine weighed 12.8 kg (28 lbs) and over 18 kg (40 lb) with the shipping case. The new PB 560 ventilator is only 4.5 kg (11 lb) with a light carrying case. Not having to take the old heavy ventilator in and out when we travel made my wife Elaine very happy. We did try out traveling with the new ventilator when we went away for some weekends as well as a 10 day trip and all went well.

It took some time to get used to my new ventilator. But I am thankful I can sleep comfortably at night now with my “hi tech” breathing assistance.

Heath Sparrow

July 1, 1934 – October 19, 2012

Heath was called home on October 19, 2012 to be with his parents, one sister, and one son-in-law. He leaves to cherish his memory, his loving wife Marjorie, daughter Tammy and son Jason. He will be greatly missed by his friends and family. A private graveside service will be held at a later date.

The following is an article about Heath that was published in the PostBox in April 2004. We extend our sympathies to Marjorie and family.

Heath & Marjorie Sparrow, Members from Bulyea, Sk.



A promising career as an electrical lineman was cut short in 1952 for Heath Sparrow of Bulyea when the dreaded polio virus attacked his body. He worked for SaskPower for three and a half months.

Heath was working up a power pole east of Prince Albert “tying-in” a line, and was having a bad day. He was racked with a severe headache and weakness in his legs and arms muscles and had to climb-down or fall down. When the rest of the crew came to his work site at noon, they quickly bundled him up and took him to hospital at Prince Albert.

At around eight or nine o’clock that evening, Heath was experiencing severe pains and was rushed to the isolation ward at the Catholic Hospital in Prince Albert. After two weeks of isolation and a further 48 days of treatment, Heath was told he wouldn’t be able to walk. Polio severely affected his back and legs.

“I give a lot of credit to Ray Chadwick who was my chiropractor. He helped me to walk again and he was amazing even by today’s standards” Heath recalls.

“When I was able to work again, I did work which I could manage which meant doing a variety farm jobs. Later I worked as a utility person for a municipality which lasted 17 years”. Heath farmed for 20 years (1969-88). He retired from work in 1999.

Heath and Marjorie met at Edmonton and were married in 1968. They have a daughter, living in Victoria and a son living at home.

Heath and Marjorie are active members of Polio Regina Inc. They are a great asset to the club.

At the Meetings

May 2012 – Our May meeting was our spring picnic which was held at the home of Dr. Mavis Matheson. David Cotcher received a request from Public Health in Assiniboia, who would be giving vaccinations at the Assiniboia School, requesting a speaker to talk to them about the effects of polio and the importance of receiving the vaccine. David contacted Polio Regina member Diane Berggren, who lives in Assiniboia, and she said that she would be glad to talk to the students.

Jim Allonby reported on the “Living with a Disability Conference” and “Wellness Retreat” that he and Gail Frederick had attended. Both events were presented by the March of Dimes. The conference was held on May 24th at the Hilton Garden Inn in Calgary. It included workshops and breakout sessions on various subjects such as Living with Disabilities, Emergency Preparedness, Self-Advocacy and Respiratory Workshop. The cost was only \$10.00 per person. The Wellness Retreat was held at Camp Ursa outside of Calgary from May 25th through May 27th. It was a relaxing weekend with massage, stress management, crafts, yoga, nature, campfires and games. The cost was only \$20.00 per person which included meals and accommodation.

Spring Picnic: Our annual spring picnic was enjoyed by everyone with lots of great food and conversation. The weather was pleasant and we were able to spend the evening on the deck. (Photos are included on the back cover of this issue.)

September 2012 - We discussed asking the candidates that are running for mayor and city council in the civic election about various issues concerning mobility such as the handicapped parking at the Pasqua Hospital and city services for assisted services for garbage removal and snow removal. We agreed to draft a letter to the new mayor and council expressing our concerns about accessibility in Regina.

Our president and vice-president were no longer able to attend our regular meetings at 7:00 p.m. on the last Thursday of the month. We decided to try to hold the meetings in the afternoon instead. Ivan would book the meetings and report at the next meeting.

Open Forum: Our guest speaker was Mr. Lindsay Tolley of the Regina Fire Department. He spoke informally about on fire safety, procedures, smoke and carbon monoxide detectors and common causes of fires as well as answering questions.

October 2012 - Room booking for 2013. Ivan Jorgensen presented a list of the dates that have been booked for next year’s meetings. We were unable to get the days and times that we had requested. The dates are as follows: Wednesday February 13, 2013 at 3:30 p.m., Wednesday March 20, 2013 at 3:30 p.m., Thursday April 25, 2013 at 3:30 p.m., Wednesday September 18, 2013 at 3:30 p.m. and Thursday October 24, 2013 at 3:30 p.m.

Carole and Wilf Tiefenbach will be speaking at the Rotaract Dinner November 3rd 2012.

Open Forum: Diane Lemon led the open forum. Diane spoke briefly about advocacy for accessibility and gave several examples of buildings in Regina that are not accessible.

Diane then reported on the Pain and Pain Management Conference that was put on by Post Polio Network Manitoba. The Keynote speaker was Dr. Carol Vandenakker-Albanese. Some of the issues that were discussed were: weakness without pain, chronic pain, muscle pain, micro trauma, deep or superficial pain, nerve pain, bone pain and methods of dealing with pain and weakness. (A similar presentation by Dr. Vandenakker-Albanese is printed in this issue.)

New Meeting Dates for 2013

Please note that our meeting days and times have been changed for 2013. The dates are as follows:

Wednesday February 13, 2013 at 3:30 p.m.

Wednesday March 20, 2013 at 3:30 p.m.

Thursday April 25, 2013 at 3:30 p.m.

Wednesday September 18, 2013 at 3:30 p.m.

Thursday October 24, 2013 at 3:30 p.m.

All regular meetings are held at in room H203 at the Wascana Rehabilitation Centre.

Our Spring Picnic and Christmas Party dates and times will be determined at future meetings.

POST-POLIO PAIN: CAUSES AND MANAGEMENT

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May 18, 2002 presentation
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 oversteering, 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 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 its 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 its 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, its 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.

4. Alternative treatments (use caution)

I also wanted to mention just a few of the alternative treatments that are around. With all of these, I would say "Use Caution". They are not well studied as far as risks or benefits. Logically thinking about them, certain ones have fewer risks than others. But don't make the mistake of when you hear something is a natural treatment that it's automatically safe for you because a lot of the things that occur in nature can be very destructive. Almost all our medication comes from naturally occurring substances. So if you're taking a health food supplement, it may actually be as dangerous as taking a prescription medication or more dangerous because the supplements aren't controlled by the FDA and the amount of the substance in tablets or capsules is not regulated. Be careful with those and don't over do.

Acupuncture

One of the more accepted alternative treatments would be acupuncture. Acupuncture actually can be

very, very helpful and there have been a number of studies done on acupuncture. It can be very helpful for pain management. It can be very helpful for some of the tendonitis, muscular-skeletal pain.

Acupuncture is one of those things that, depending on whom you go to, you may have a completely different experience. My feeling in general is that if you are going to try acupuncture, go to an Asian-trained acupuncturist and not a western doctor that has taken a six-week course to learn where the points are because the whole theory behind medicine is totally different from Western medicine.

I don't think just taking a little piece of it and trying to apply it is helpful; it's like sticking needles in the dark. It would be like me sticking needles in a voodoo doll. You might have a Westerner that has really studied acupuncture and knows what they are doing, but it's not one of those things you really know with a little quickie course we can all take through the university now a days. So if you are really serious about trying acupuncture, I would find somebody who really has trained extensively and knows Eastern medicine.

Yoga

Yoga is one of those things that also varies. You have your strict yoga, which includes all the meditations; and then you have a lot of exercise trainers' therapists that use yoga techniques for stretching. With yoga I'm not sure it makes that much difference. We're not talking about doing anything invasive in the body, but really more stretching techniques. And a lot of times because stretching and improving range of motion is helpful, doing yoga may be helpful.

Again, use caution. There are a lot of yoga positions that if you don't have normal joints or you have problems in a joint put way too much stress on a joint. So if you are giving yoga a try, listen to your body. If something hurts, don't do it. You might only be able to do half of the exercises the leader is doing, but that's OK. You don't have to stretch as far as the person in front. Be careful with that.

Biofeedback

Biofeedback is one of those things that some people like, some people don't. It certainly can't hurt you. Biofeedback is simply using your mind to control the body. There's a lot more mind-body interaction going on than we can really identify or test for or have control of. It's an interesting area. I think if that's your bent, and especially if you are one of those typical

polio type-A people, it might not be a bad idea to help yourself relax to learn some biofeedback techniques. How much of it you use is up to you, but certainly there are ways of using your mind to help take stress off muscles, relax your body, tolerate pain, and that sort of thing.

Chiropractic

Some people wouldn't even list that under alternative treatment. It's relatively conventional although not considered conventional by the medical community in this country. Chiropractic treatment can be very helpful for localized spasms, that sort of thing, but be cautious. Like with any profession, you have your chiropractors that are conservative and pay attention to a person, and then you do have your ones that really aren't very good practitioners and try to do way more than they should be doing because your muscular-skeletal system is not as strong as a person who has never had polio. Beware of letting a chiropractor work on any areas that were affected by the polio. Certainly, if you have significant osteoporosis in your spine, avoid all chiropractic treatment. The risk of the manipulation causing a fracture is too great. But for someone who has a strong spine and is experiencing a lot of soft tissue problems around the spine, it can be very helpful.

Massage therapy.

Pretty much the same guidelines apply. Again, it can be very helpful for sore muscles or muscles that are in spasms, but you don't want a masseuse who is overly aggressive. Don't use the really deep tissue massage technique unless it is in a very strong area of your body. In general, you would want more of the light massage. So again, you have to know your therapist and they have to understand you and the differences of your body as opposed to a non-polio patient they see.

Vitamins/supplements

There are a ton of vitamin, mineral, herbal supplements. I'm not going to attempt to get into all of them. I'm just going to mention a few that actually may be helpful for some of the polio-related problems. The vitamins have been well studied. Some of the other substances to a lesser extent we know a little bit about.

- Vitamin B1, B12, Folic acid, Multivitamin
The B vitamins, especially B1, B12, folic acid, all help with nerve growth and nerve healing. Because

a big part of PPS is felt to be failure motor neurons to continue to be able to supply the amount of muscle that they have been for years, it's certainly not a bad idea to take a supplement or at least make sure you're getting the minimum daily requirements of the B vitamins and folic acid in your diet.

Often this can be accomplished with a multivitamin. A multivitamin will give you your basic daily requirements.

- Calcium, Vitamin D

The multivitamin will also have the calcium and vitamin D, which are important for the osteoporosis prevention. The vitamin D alone with the calcium is to help you absorb it better. In California nobody is vitamin D deficient because your body makes it from sun exposure. That's a problem for people in the northern climates with limited sun exposure.

- Magnesium, Potassium

Some of the minerals important to muscle function are magnesium and potassium. Again, you'll find those in a multi-vitamin. You don't have to take them specifically. They are something that it's not common to be low in, but it can happen. Certainly if you are on a diuretic for blood pressure you can be low in potassium. That can impact muscles, really aggravate muscle cramping and that sort of thing. Have a good supply of those vitamins and minerals in your diet.

- Coenzyme Q and Creatine

Although not studied a whole lot, Coenzyme Q has some anti-oxidant properties that seems to help with muscle tissue repair. Creatine is also one of those supplements that is used to build muscle.. The results certainly have not been proven, and have not been studied to polio survivors specifically. If you are one of those people who want to take supplements just in case they might help, then Coenzyme Q and Creatine are the ones to probably put on your list because they may help.

- Glucosamine chondroitin

The last one I want to mention is glucosamine chondroitin. Of the recent supplements you keep hearing about, this is the one that's been probably studied the most. Some very well designed studies have shown that it is helpful for more than 50% of people who take them for joint pain, maybe in the 60-70% range. That doesn't mean it rebuilds or slows the degeneration of cartilage. We don't know that. There haven't been tissue studies looking at cartilage over

time. But it does seem to help with joint pain in a fair amount of people.

What I find interesting is a lot of veterinarians are starting to use it for dogs or cats with arthritis and it seems to help the animal. If it helps animals (and they don't have psychological interactions going on), there may really be something to it. Certainly it's not something that will hurt you. It's not a risky supplement to take. So for most of my patients who have any joint pain, I say at least try it.

For a fair trial you should take it for three months. and then you determine whether it makes a difference or not. If it seems to do absolutely nothing, it's probably not worth spending your money. But if it does seem to help even a little bit, it may be worthwhile. It's so widely available now that it's not as expensive as when it first came out, so it may be worth a try.

D. Avoiding the "Pain Cycle"

(Pain → inactivity → increased weakness and loss of flexibility → frustration and depression → over-exertion → increased pain → eventual damage to relationships)

Last thing we are going to talk about is avoiding the pain cycle. Often what happens when you have pain on a regular or chronic basis is it turns into this whole cycle of *I'm in pain, Don't do any activity, then you get weaker and you lose flexibility and you lose function and now you're even more frustrated and you get depressed and then you say you're just going to do it anyway and you go out and over-exert because you are even weaker and it's easier to over-exert and you have more pain.*

And this cycle can go on and on and on, and lead to a lot of damage to your relationships with your family and your friends. You end up being like a hermit and dwelling on your pain all the time and getting more and more miserable.

Learn to accept your condition; Learn to relax; Let your feelings and needs be known; Continually problem solve - find new ways of remaining involved and active in relationships; Find a physician partner to work with you.

You have to mentally learn to accept the pain and really work at learning to control it. Learn what you can do (don't do nothing; do what you can do). Learn to rest (relax, take those breaks, don't over-push). Let the people around you know what's going on (know

what you need; don't get pushed into doing things you really can't do).

On the other hand, don't complain and talk about your pain all the time or people won't want to be around you. It's always an ongoing process of problem solving - "Ok, let's try this; let's see if this will relieve that." Things change all the time in your body, so it's always a challenge to find what works and what doesn't. Remain really involved in life and be active. If you don't play golf any more, you can go with my friends, go to lunch, or do other activities. Don't give up your social life or your relationships.

From a medical perspective, find a physician who's willing to work with you and problem solve with you. None of us know everything, but if your physician's willing to do some research, to read up on things, to at least give you advice, not tell you "you do it my way or forget it; I won't treat you". I can't stand physicians that do that. It's not fair. It's your body, your ultimate decision about what you're going to do or not do, You are responsible for your health. You are the primary person responsible, but find that physician who will help you and work with you.

Thank-you.

Questions & Answers:

1) *When you do a bone density test for osteoporosis, do you do a specific limb?*

Yes, you can. In Miami we have started to chart a study comparing a polio limb to a non-polio limb. There is a huge difference. What you want to be aware of, though, say your doctor just wants to know your over-all bone density, they should not test a polio-affected limb. It will come out severely osteoporotic, and the rest of your limbs might be just fine. If they test a polio limb, then it is important that they test your most normal limb as well. Routinely what they usually do is test one in the hip and one in the thigh. Those are your typical sites.

2) *In a blood test, my muscle enzyme was very high.*

That means you're breaking down a lot of muscle.

~ What would cause all that?

Over stressing the muscle. Did they differentiate the muscle enzyme as to which enzyme it was coming from? If you have a number of viral illnesses will cause muscle breakdown. There's also a disease known as polymyocitis, which is inflammation

of the muscle which you can get after a viral illness which breaks down muscle and you can get the very high muscle enzyme also.

A lot of the viruses affect muscle tissue and even for a non-polio survivor, someone with all normal muscles, it's very important not to go and over-exert right after flu or a bad cold. That's because you can break down muscle, and that's especially true for you who have weak muscles. You want to be very careful if you've had a viral illness to not over-exert.

~How do you overcome or treat high muscle enzyme?

If it's very bad and it's something like the myocitis, they use Prednisone actually, steroids to calm down the inflammation. If it's just breakdown from a viral illness, it'll get better over time. If it's from you over-doing, it sounds like in your case with levels that high there was more going on, if it's just a little high from you over-doing it, you have to learn to curtail your activity.

3) *Other than swimming, what exercises are good for cardiovascular?*

While the conditioning exercises are a very individual thing up to what you can do. It depends on which limb, which muscles are involved, how much. So it's something I can't answer specifically for a person until I have examined them. In general, swimming is the one thing that works for most people, as long as you have access to a pool, can get in and out of the pool, don't mind the water, and don't have skin problems. There are things that keep you from swimming.

An exercise we've done with people, especially with lower body involvement, is an upper extremity ergometer for cardiovascular conditioning. If there is just one weak limb, something like an Aerodyne stationary bike will work the arms and legs but you can put one leg off to the side and not use it. There are some other things that can be done besides swimming.

4) *If you are on anti-inflammatory medication, is it advisable to take something like glucosamine chondroitin?*

There's no interference, so you can use them together.

5) *I had bronchitis in April and bronchitis made my good leg useless, so I can hardly walk. I had antibiotics for the bronchitis, but it weakened it a lot. I had hip surgery in July, and worked with good physical*

therapists for months to be able to walk. But now I can't walk.

Sometimes it can just be a matter of deconditioning, and you'll get better with the therapy. But there may be something new going on as well. Sometimes with bronchitis if you're coughing a lot you can get herniated discs causing a nerve problem. There are other possibilities, but the most likely is just deconditioning.

Whenever you're in bed for even a day, it has serious consequences for polio survivors. If you're in bed for a week, you lose a significant amount of strength. The rule of thumb for a non-polio survivor is if you are in bed for a week, it takes two weeks to recover that strength. For a polio survivor it takes more like six or eight weeks to recover the strength you lost from one week in bed.

5) *For alternative therapy, is marijuana helpful for the post-polio related problems?*

No, it does not help muscles at all. In fact, I would be leery of people using it because there is probably an increased risk of falling. Falling is one of those things we work very hard in preventing.

6) *I tore my rotator cuff and it never recovered fully. My doctor said being a post-polio that I was not a good surgical risk, surgical candidate, so I accepted that although there is some occasional pain. What do you think about this automatic refusal of surgery?*

I don't think it should be automatically dismissed. I think your doctor should have you come back and have an MRI done and then determine the appropriateness of surgery.

7) *Regarding medication side effects –*

The side effects, and they have to warn you about all the side effects, are fairly uncommon. Certainly, people who are more sensitive to medication tend to get more side effects. A lot of the anti-inflammatories don't produce side effects in people. So I wouldn't be too afraid of trying them. Remember, with any medication it only stays in your system for a limited amount of time. You can stop it at any time too. If you have side effects you just stop it and they go away. It's not a permanent thing. But everybody's individual and you just have to work with your physician and relay the sort of symptoms you have.

The newer inflammatories I believe are safer as far as risk of gastritis. We don't know all the risks

long-term because they've only been out a couple of years, like are Vioxx and Celebrex.

8) *Are there certain drugs polios should stay clear of because contraindicated?*

It's all relative contra-indication. In general you should stay away from the muscle relaxants because they work centrally. They actually tend to weaken all the muscles. In general, that's a very bad idea unless you have very mild polio residuals. Valium, the same sort of thing, you can actually over relax the muscle. And again, any of the medications that affect alertness and cognition be very careful with because of that increased risk of falling. If you're not real steady on your feet, being just a little off you might take a serious fall.

World Polio Eradication

Pakistan is one of the three countries, with Afghanistan and Nigeria, where polio is still endemic. Many challenges exist in those countries. First, the **geography** makes access to the high-risk populations difficult. The **religious** factors add more difficulties. In Pakistan, it is reported that healthcare workers have had to call the police to assist in the administration of the polio vaccine to twenty children, as their parents were refusing the vaccine because of their religion. Finally, **war**, the Taliban want to prevent the vaccinations as long as the Coalition forces continue sending military drones over their territory.

President and Vice-President Speak at Rotaract Dinner

President and Vice-President Carole and Wilf Tiefenbach spoke at the Annual Rotaract Polio Awareness Dinner on November 3, 2012. They each talked about their experience with Polio and how it had affected their lives. They also talked about Polio Regina; how it is organized as a support group and its goals and objectives.

Rotaract is the young Rotarians branch of Rotary International. They put on a fund raising dinner every year to raise funds for the Polio Plus Initiative to eradicate Polio in the world. The dinner raised \$3,000, all of which was donated to the Polio Plus Initiative.

You Are Invited

Polio Regina is inviting people who have had poliomyelitis and are now experiencing new symptoms such as fatigue, muscle weakness and cold intolerance, to join our self-help support group to learn how they can cope with post polio syndrome. Spouses and partners of polio survivors are also welcome. Polio Regina Inc. was formed to help people from southern Saskatchewan.

Our Objectives:

- To develop, promote and increase awareness of Post Polio Syndrome.
- To disseminate information concerning research and treatment pertaining to Post Polio Syndrome.
- To provide support to survivors of polio, other than financial aid.

Where to meet

Our Polio Regina group meets in room H203 at the Wascana Rehabilitation Centre 2180-23rd. Ave., Regina, SK. Enter the main doors of the Wascana Rehabilitation Centre and turn left and take the elevator that is across from the information desk. Push button "2" (not 2R) on the elevator. When you leave the elevator turn left and go past the information desk, through a recreation area, past the pool table to room H203 which is the first meeting

room. Our group should be in there. There are no meetings in January, June, July, August or December. The following are the dates of our 2013 meetings: Wednesday, February 13; Wednesday, March 20; Thursday, April 25; Wednesday, September 18 and Thursday, October 24. All meetings are at 3:30 p.m. We usually have our Spring Picnic in May at a private residence and our Christmas Party in November at a different location.



Web Site:

Check out our website for more information on Polio Regina and links to other useful related information at: <http://nonprofits.accesscomm.ca/polio/> or you can just Google **Polio Regina**. Our email address is: polio@accesscomm.ca

Disclaimer

Information published in the Polio PostBox may not represent the opinion of Polio Regina. It is not to be regarded as Polio Regina's endorsement of treatment, products or individuals. If you have or suspect you may have a health problem, please consult your health care professional.

MEMBERSHIP APPLICATION POLIO REGINA Inc.

Name _____
Active () if you had polio Associate () New () Renewal ()

Address _____

Postal Code _____ Phone: _____

Annual membership fee: (Jan.- Dec.) *Membership Fees are due January 2, 2013*

\$10 Single; \$15 family \$ _____

My donation to Polio Regina Inc. :* \$ _____

Total \$ _____

(If you require sponsorship for your fee, inform our membership chairman)

Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:
Polio Regina Inc., 825 McDonald St. Regina, Sk. S4N 2X5

*(Official receipt of donation for income tax purposes will be mailed.)

Spring Picnic

Our annual spring picnic was held at the home of Dr. Mavis Matheson. The weather was great and we were able to spend the evening on the deck. There was lots of good food and socializing. Thank you Mavis for hosting us in your home and thank you to tireless Carole for getting and setting out the food.

