

Case 1

JUNE 2006

I am an active 55 year old recently retired male. I am also a polio survivor (1952 atrophy in left leg). I exhibit no post-polio syndrome symptoms (other than normal wear and tear). Happily I can report I swim 2/3 mile everyday, bike, lift weights and have never let my handicap get in the way of reasonable normal activities.

Recently I was diagnosed with a severe compression of my right (good foot) side of the L5 nerve, I didn't even know it was happening. I have some weakness on that side. The cause seen on the MRI is I guess a normal arthritic deterioration of the disk causing the disk space to shrink and nerve to be compressed. Luckily I have as of yet no pain and it's basically a bit more than a nuisance. I'm concerned about it getting worst (drop foot etc). I have two opinions now from top level neurosurgeons here, one favors surgery to stop the situation from possibly getting worst, the second is not in favor due to what he perceives as the stress coming out of the fusion by my gait caused by my differential leg length (screws saying in position). Obviously I will have to sort this out somehow. I'm trying to get as much info from informed sources as possible.

I saw some info on the site about fusions but nothing as it relates to more of the garden variety fusion such as this. I have no curvature of my spine, it is pretty normal. Overall I am in excellent shape, weight is well within recommended levels and I have substantial lower back and upper back muscle development. How well or not well in general do polio patients do after fusion?

I am confused as I don't know if just let it run its course might be the right decision for someone of my age with a lot of life in front of me.

SEPTEMBER 2006

I completed my journey of doctors we had been discussing with what I suspected would be the outcome. No one at the end of the day thought the Spinal Fusion was the correct thing to do....basically risk and little to no reward. I've adapted to the fairly minor weakness that I developed as a result of the nerve compaction and have moved on.

I had my yearly visit with the neurologist...basically he says I'm doing great. My nerve conduction remains stable and he his belief is that my attitude and work ethic will maintain either the status quo or as he can see actually get some improvement. I have been able to get back most of the atrophy to my calf muscle on my good leg and improve my walking, endurance, and strength. I've basically evolved to swimming, water walking, and stationary bike as the cornerstones of my exercise program with I think good results. My neurologist agrees that post- polio can achieve a plateau if one does the right things as far as lifestyle, exercise, work ethic, and diet. Also he does share the view that new nerve sprouts and compensation from other nerves can occur as your life goes on. Basically see him in a year and we will talk again.

Lately, I have been getting some pain on the outside of the hip/leg and sometimes in the flexors and Glut. I know the joint is in very good shape based on my yearly ortho visit and X-Ray (no arthritis, spurs, etc. I seem to remember that due to the way we walk we are perhaps prone to inflammation, bursitis, etc. Also I have noticed lately that due to the imbalance of the development of my pelvis (smaller on the left than the right) and the size of my gluts that when I sit my pelvis is at an angle I think putting further pressure on the outside. Lately I'm sticking a small pillow under my left gut to try I think to level out that side to the right. I wonder if you have any comments from either your own experience or from others. My ortho guy is more than willing to "drop in some cortisone" if I want. I haven't gone there yet. Also we have been watching my left knee which has a bowlegged windswept condition where the joint alignment is angling towards the inside. No one is recommending a knee brace as of yet, but I do wonder about if that contributes to the alignment of the hip joint. Just wondered if you have any comments?

Case 2

JULY 2006

My husband had polio when he was 2 years old. Now he is 37. He has atrophy of his right leg. He doesn't use any assistive device.

When he walks, he uses his right hip muscle. He uses his left leg to support his body weight. His right leg is very thin and the muscles are very weak. When he lies on the bed, at anti-gravity position, he can not lift his leg up; at gravity eliminate position, he can move his right leg parallel to the floor with slight resistance. His right leg is 5 cm shorter than the left one; his right knee can not be stretched straight. The passive range of motion on the right knee joint is 0-170.

He is doing exercise by his own to increase his left leg strength, but the result is poor. His left leg is normal, even stronger than normal because he uses his left leg most in his daily activity. His other parts of the body are normal except his right side leg. He is walking for 15-20 minutes in the gym every day, and also he often plays Ping Pang ball. His goal is to make his right leg stronger, at least to keep his current situation when he gets older.

We met two physicians, who gave us opposite suggestions. One told my husband that the more he uses his right leg, the worse his right leg would be; the other asked him to do moderate exercise on right leg. We don't know whose suggestion is right.

Case 3

JUNE 2006

I was born in 1954 age 52 now and at the age of 1+ years diagnosed with polio/infantile paralysis at the first onset on symptoms that included total collapse and was hospitalized. I am very fortunate with now only partial paralysis to left leg, foot drop and a mild case of scoliosis.

At the age of 2+ years, I had somewhat successful corrective orthopedic surgery to my left leg with Z incisions to release ligaments and I think tendons behind my left knee and heel.

My parents were very supportive and took me to every medical specialist available at the time. After my surgery, I had constant medical follow-up which included the usual treatment plan of orthopedic shoes, supports, corrections, braces and the never ending home physical therapy regiment of stretching and exercises with my parents to try and build up more muscle tone and strength to my left leg.

At the age of 12 years old I said that is enough. If I haven't developed more muscle tone, strength and range of motion I never will and stopped wearing all supports used now only corrective shoes and stopped the physical therapy. My parents were in agreement.

With adolescents growth and as a young adult and mother, I experienced some periods of flare-ups of symptoms usually generalized to left leg and lower back, aches, pains, spasms, muscle fatigue and actual weakness, muscle tremors with a long period of years without any more symptoms or problems.

In the last few years, I have noticed more symptoms returning with measurable atrophy to left leg and a new form of weakness to my left leg and entire body. At this time I also experienced problems with swallowing especially with certain foods (rice, etc.) that became stuck and with choking. Doctor's diagnosed me with Barrett's Esophagus including a possible ring and dilated my esophagus. At this time I also developed problems breathing with asthma-like symptoms with no medical history of asthma.

I had a total Placenta Abruption at the age of 22 years 30 years ago prior to delivering my daughter. The doctors miraculously saved both our lives but I was given massive blood transfusions that resulted in giving me a very chronic case of Hep C from the tainted blood supply at that time.

I have a co-viral infection of HCV/polio. My Hep C wasn't diagnosed until late stages and I was already into Stage 3 liver disease. I was a failed responder to Interferon/Ribavirin treatments twice pre and post transplant and with the latest form of pegalated Pegasys/Copegus meds 2 years ago.

I developed ESLD and on March 4, 2001 I received a life saving liver from a young clean HCV free male cadaver donor of 18 years. This was also a medical 1st because he was my own nephew that sustained a fatal brain injury from a 1 car auto accident all his vital organs were untouched and he was my cadaver directed liver donor.

With having 2 very serious life altering and life threatening progressive diseases HCV/polio both viral incurable with little know about both by medical science is very frustrating for me and also all my treating physicians.

My doctor's and I find it very interesting and not coincidental the similarities and patterns of both HCV and polio viral diseases in one medical case study and also with interferon also tried and failed for PPS.

Which virus is causing my symptoms? Which one is primary and at any given time? How has my having polio being viral affected my Chronic HCV viral infection? From having polio since age 1 has this contributed to my severe case of Chronic Progressive HCV and again immediately Post Transplant? Has polio contributed by means of a weaken immune system and a much more severe case of Chronic HCV and as a failed responder to interferon?

The most significant question of them all to me is....

With no previous medical history of other serious medical diagnoses of heart, lung, kidney, cancer diseases, a clean lifestyle, etc., did my medical history of having polio contribute to or have a factor in my very serious complications during my liver transplant of total arrest, respiratory arrest and prolonged respiratory therapy and lung infections post transplant? Will this be a factor again if listed and if I receive a second liver transplant to hopefully save and prolong my life again ?

I am now again in Stage 3 Liver Disease but have been very stable lately and with stable monthly complete lab profiles.

All my medical specialists are all in agreement. Medically speaking we don't know the answers.

In the last few years I have experienced general muscle fatigue, weakness, actual muscle wasting, full extremities EMG with abnormal findings especially my left leg and all becoming slowly worse in time.

I have measurable atrophy now to my left leg with periods of more weakness a worse foot drop and just recently with episodes of total weakness to my left leg including total collapse from normal use and a fall from steps when my left leg gave out completely resulting in an extreme case of a sprained left foot, ankle, strained left leg and lower back but fortunately no broken bones.

How has this trauma and injury to my left leg and lower back affected my polio case? Will I regain former strength in my left leg or not? Will physical therapy help or hurt? Did this trauma trigger a more aggressive form of PPS? Is PPS now aggressive and progressing in stages?

I am still having many complications from my fall on April 16, 2 months ago to my left leg with it healing very slowly more measurable atrophy, swelling, still unable to stand on it and use my foot with my total weight, bruising, more and different types of pain, sharp, burning and unexplained poor circulation to left foot and leg turning red than blue than purple, cold to touch, all medically documented when I was evaluated for physical therapy with slight pressure applied for measurements with my Cam Walking Brace off and this also happens when I stand for a short time and do not have the brace on.

I was sent to the ER to rule out a blood clot and thankfully the test was negative. I maintain a pulse in my left foot but experiencing symptoms of poor circulation.

It seems to me the fixed stationary cam brace is keeping my left leg and foot aligned without being able to move or bend improving the spasms, swelling and circulation in my left leg and foot. I have less pain with the cam brace on and it has greatly improved my balance and the ability to walk.

My medical care and treatment of my injured left foot and leg with partial paralysis from polio and strained lower back is now at a standstill with treating Physicians and physical therapists not knowing what to medically do next.



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Post-Polio Clinics Directors
Network September 19, 2006

Points of Discussion:

Case 1

- Question how diagnosis was made if there was no pain, any sensory loss. Because there is a compression on the MRI screen doesn't mean that is what is causing the problem.
- Case points out you have to be careful about the history you get from the patient.
- In a situation like this, the role of EMG in terms of differentiating old vs. new denervation is important.
- It is not clear if the person has atrophy or not.
- Be cautious to see that everything is from the root. EMG may help out.
- If it was fairly recent, we would see some changes. But if it has been going on for awhile, we probably would not be able to differentiate if it was part of PP or something self-imposed.
- Interesting that two top level neurosurgeons thought the L5 root was causing the symptoms and one wanted to do surgery.
- Be very cautious.
- Surprised at the reason for a fusion as opposed to a less invasive spine surgery.
- Let's say we have a patient with a history of polio and spinal stenosis and fusion is recommended ... question ... how do polio patients do after fusion?
- I'm sure I have seen post-polio patients with lumbar fusions and none that I can remember have had complications.
- If you have someone with limited mobility to begin with, chances of them having osteoporosis and bone not as workable, that might be a complication.
- I have not seen any one. I do not know if they could benefit from the surgery but have not had any more complications.
- If an individual has a history of polio and proximal weakness and gait abnormalities, the known risks of having disk problems above and below the fusion would probably be higher. I assume there would be some increased risk because there would be increased motion in the spine. I have never seen anything to support this.

- Patient goes on to say at the end of the day no one thought he should have a fusion. A little confused that he says he has atrophy in his calf and is relating that to the L5 nerve compression. That makes me wonder if he has a decrease in strength from PP and the MRI findings are incidental.
- Next paragraph he goes on to talk about his pelvis is smaller on the left than on the right and he sits on a small pillow. I guess an orthopedic would "drop in some cortisone" and he was not sure where he would inject him.
- I see a lot of sacroiliac problems and always think about the fact that muscular weakness leads to decreased support but I do not think about the pelvis itself.
- If people have significant weakness on that side, the pelvis could be smaller
- Does anyone recommend that someone look at a J cushion with an extra buildup on one side to address that instead of just a pillow?
- Have done foam – the challenge is to figure out something the right height. A J cushion is expensive.
- Toward the end of the paragraph, the individual asked whether or not the valgus of the knee might be contributing. My answer is yes. I wonder if he might have significant sacroiliac problems going on.
- Another question – did not sound like there is a mention of bracing. That would be appropriate to look at to decrease his back pain. I think of anti-inflammatory medications and muscle relaxants.

Case 2

- Would suggest doing some exercise – do it, but don't overdo it. I think doing activity is very important.
- How do we define that? Here one physician said to do "moderate" exercise.
- Case-to-case. If the individual can only take 10 steps before he gets tight, he should only do eight. You have to feel your own parameters. He has to be his own control. But if he can, walk or swim or whatever he can do. If he can take 10 steps without pain or fatigue, he should do eight steps. If he can lift one pound of weight without any problem he should do it for eight times.
- If he does it too long and has pain and fatigue for two days, he should not overdo it.
- Other ways to educate patients on levels of exercise?
- Feeling is that this person has somehow taken himself through a little bit of excessive exercise. We have to ask how do you feel at the time of the exercise period and do you exercise on the weekends? If you do exercise on the weekends and feel less pain and fatigue, then it could be the exercise.
- I think he was given too much confusing info on building up weak muscles.
- It needs to be individualized and people should not be told to exercise for exercise sake.

- Dr. DeMayo's approach the last few months – everyone comes from their own place on what they think is the role of exercise. If they are couch potatoes or if they could run a marathon, people with polio are like others.
- Telling someone not to overdo it means different things to different people. I ask them to do a check. But most people are fatigued after exercise. I usually tell them – no studies to support. If 15 to 30 minutes after you are done with your exercise you feel that the exercise will limit your ability to function – you cannot walk as far or dress yourself -- you have probably overdone it. Or if your body is telling you you are paying the price or have increased pain or fatigue, then you have probably overdone it.
- We all have our threshold or limit and this is where I would like to get feedback – I think it is important that people do not overdo or under do it either. The only way they will know where their limit is, is to go passed it now and then. The folks who exercise in a conscious way...in a few weeks go a little further. If your body tells you you overdid it, then stop. If your body doesn't tell you you overdid it, then you can go a little further in a few more weeks.
- For normal people when they exercise they increase it. That is the whole purpose of exercise. Once in awhile it doesn't do any harm to test your limit.
- I don't think there is any disagreement with your advice. I indicate to them that the neuron affected in the acute stage and recovered is a weak neuron, that could lead to some problems.

Case 3

- One question: This individual describes a first presentation as total collapse. I have had a couple of individuals come to the clinic and when I ask about their initial onset of polio they describe being completely fine, no fever, no illness. One was seven years old at the time and reported he was walking home from school with his buddies and then it hit him – an acute case of bulbar polio and he collapsed.
- Have you had patients that claimed to have a very acute onset like that and you believe they had polio as their original neurological illness?
- The majority of those who suddenly had polio, when you inquire, they relate problems the day or two before or they did heavy exercise. No recall of a sudden case of polio.
- The reason I hesitated though is that he said he had bulbar polio. Is it possible he had a brain stem encephalitis and may have ignored other symptoms? I have never seen or heard of this before. This individual alludes to a sudden onset of symptoms which is not typical of polio.
- Patient moves on to talk about a very complicated case of polio and hepatitis and required a liver transplant.
- Is anyone aware of any reason why other than possibly weakness? Patient goes on to talk about respiratory problem after liver transplant.
- Liver transplant is major surgery and that could be a difficult thing for a person with PPS. I do not think the fact that the person had polio is worse. I believe that we are dealing with two separate events, one unrelated to the other.

- Would like to hear from the transplant team as to whether this case is outside the norm. In the middle of the next page, she says "...I have experienced general muscle fatigue, weakness, actual muscle wasting, full extremities EMG with abnormal findings especially my left leg and all becoming slowly worse in time."
- Question as to whether people's experience – independent of major illness triggering PPS and this seems to be what she is describing and it has been measurable. Much of what she has to say is consistent with PPS.
- What are people's thoughts on this major surgery, the role of the illness in actually triggering PPS?
- Consider it an aggravating factor. I remember one person who said she had an accident and she developed PPS and one who had major surgery. But people seem to feel that some event – some physical event – caused it.
- Some people had major surgery and soon after that had the onset. The family members said there was marked atrophy after the surgery; then there was progressive atrophy.
- I wonder whether or not there was some type of positive effect there. Think about a transplant and drugs that might be administered that might have an effect on peripheral nerves.
- Is it possible that someone would have minimal effect but someone with PPS who has neurons already taxed, it might trigger PPS?
- On the last page the individual talks about a Cam Walking Brace used after her liver transplant. She doesn't say anything about being treated with AFO and I wonder if she had proper management of PPS and bracing ahead of time.

Consensus of the group was that going through some cases are interesting from the academic standpoint. It might be interesting to do some of the cases which are particularly interesting or perplexing to get the opinions of the other directors.

Dr. DeMayo will determine the best way to structure a discussion on case studies.

Barbara Duryea suggested a topic for the October call to be the Post-Polio Wellness Retreat which is going on in Michigan this week. She will follow up with Dr. Maynard.