

FROM THE DESK OF HENRY: THE MARK OF POLIO

By Henry Holland

SCRIBBLE

*To be crippled
To sit in a twist
Unable to be straight.*

*To reach out and topple over into the bend.
No balance at all.*

*Scoliosis
The mark of polio
Uneven as a scribble
No way to unwind and rest.*

An American female polio survivor wrote the poem above. The author prefers to remain anonymous. She had polio at age two and she suffered significant paralytic damage from the neck down. Like so many severely damaged polios, she spent much of her childhood trying to walk with two braces and crutches. She was unable to attend school away from home until her high school years. She eventually earned an undergraduate and masters degree and worked until Post-Polio Syndrome (PPS) ended her career. She had no choice but to commit to a wheelchair as a teenager and a power chair as an adult woman. For years she drove her own van equipped with hand controls. Like many confined to wheelchairs, she drank almost no fluids during the day in order to avoid using non-handicapped restrooms while at work. PPS has taken its toll on her. She is essentially quadriplegic. She has a lifting apparatus to lift her from her bed to her wheelchair and back as well as to lift her from her wheelchair to the toilet seat and back. As a result of polio, she has scoliosis. Recently when she was sitting in her bed, she fell over because of her weakened back muscles and could not get upright again. During this time of helplessness, she thought of the words for her poem. She was successful in getting one of the lift straps under her chin and with some struggle, was able to return to a sitting position. In regard to the poem, she explained, *"The poem poured out of me because the minutes I was unable to sit up – I kept falling over to the right. I felt like a corkscrew. The left side of my back has no muscles, so those on the right, when used, pull me over."*

Much has been written about the pain, new weakness, and fatigue of PPS. Much has been written about the changes in lifestyle that PPS demands and much has been written about the various modalities of treatment and recommendations to help PPSers. I have written my share of articles on these topics. Many polio survivors, who were fortunate to achieve good recoveries, now have to deal with PPS. Many writers refer to these PPSers as "passers" because for so many years they "passed as normal." From my perspective the "passers" conquered polio, but were caught off guard by PPS and were often misjudged by medical professionals because they had no visible marks of polio.

I would like to write a few words about the many polio survivors who were left with some mark of polio. They were left with a deformity as a result of acute polio. "Scribble's" author is one of them. I am one of them. I use the word deformity because that word captures the shame, the horror and the emotional pain of a perception that is real. There are countless deformed polio survivors around the world. Many are too disabled to attend support group meetings. Many do not have computers. I know that these people are out there and hopefully are on the mailing list of some Post-Polio support group's mailing list. If you are on this group's mailing list, then hopefully you are reading this newsletter. This group of survivors has overcome incredible obstacles at a time when most cripples were kept out of the public eye. And even when one managed to achieve an entrance to the public eye, one can never forget the stares, the reactive expressions of fear, and the desire to avoid such encounters. Most of us learned the almost automatic reflex

to present an outer expression contentment and joy. Many of us developed wit and humor to distract others. One had to smile because tears were not a possibility. Tears invited pity and being crippled was bad enough. The author of "Scribble" wrote the following to me:

"Yes, you must write about deformity. It makes no sense to me, but a withered arm or leg is enough to crush some people. A deformed face is the worst of deformities. And number two is the back. Both are impossible to hide. I am not consoled to understand it is inborn, a survival mechanism that keeps others away from the sick and possibly harmful. I couldn't have married the elephant man, but it would have taken years to see the beauty in his eyes. But he wouldn't have had beauty in his eyes because he would have been defensive and frightened. He would anticipate the gasps – involuntary gasps – from those who saw him without extensive preparation and maybe a good shot of whiskey. I understood this, and when I got out in the world, I realized I had to be personable, funny, smart, kind, and funny again. I had to be on, all the time. It was my part of the social contract. It was exhausting, especially in the early years when I was scared to death of people's reactions to me. These reactions were uniformly negative. I got it together in the 70s, but that was my hippie time, but it also was the times, as the times – they were a-changing."

We have all benefited from "the times a-changing." But most of us with the mark of polio had adapted to an unchanged world long before the social revolution of the late sixties and seventies. The ADA law of 1990 found most of us in middle age. We can now go to many restaurants, hotels, concerts, plays, parks, malls, and even airplanes because of the ADA and greater accessibility. Modern technology has made life easier for us. Mobile power chairs, scooters, vans with lifts, and hand-controlled vehicles give us greater mobility and freedom. Ventilators have both prolonged lives and retained some quality of life. A ventilator has prolonged my life for thirty-five years. Many PPSers are now using C-pap, Bi-pap and volume ventilators and these machines are prolonging livable lives. Many of us have bolstered the business of power wheelchair and scooter manufacturers. We often can use the help of advocates in finding ways to financially afford necessary modern technology.

"And the Lord put a mark on Cain, so that no one who came upon him would kill him. Then Cain went a way from the presence of the Lord, and settled in the land of Nod, east of Eden. (Genesis 4:15b – 16)

As children or young adults many of us found our own inner lands of Nod. Nod was an inner lonely world where total understanding was absent and an explanation for the "why me's" was silence. Many of us may have sought and found spiritual comfort where others perhaps felt unnoticed or forgotten by God. I do not believe that God is responsible for the mark of polio nor do I believe that God has abandoned the deformed. The ministry of Jesus of Nazareth included much healing, including the healing of the deformed. Two verses in Matthew address and summarize his healing ministry:

Great crowds came to him bringing with them the lame, the maimed, the blind, the mute, and many others. They put them at his feet, and he cured them, so that the crowd was amazed when they saw the mute speaking, the maimed whole, the lame walking, and the blind seeing. And they praised the God of Israel. (Matthew 15:30 – 31)

Before I conclude these thoughts, I often think about, remember, and hope I never forget those many polio victims who have already died from polio. There were many who died from the acute disease. They never had a life beyond polio. There were others who died from complications of polio in the early decades after polio. Their lives were shortened and often incomplete. If you have a mark of polio, try to move away from your inner land of Nod and return to Eden, but be sure to tell the people in Eden about your experience in Nod. Otherwise they will never know. □

References:

1. Poem "Scribble," author anonymous and excerpts from E-mail, May 2002
2. Meeks, Wayne A., Editor, Harper Collins Study Bible, New Revised Standard Version, Harper Collins Publishers, New York, 1993

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SACROILIAC PAIN: A PHYSICAL THERAPY PERSPECTIVE

Cynthia Henley, PT, Miami, Florida, and Kathryn Wollam, PT, Coral Springs, Florida

Most people experience low back pain at some point in their life. There are many possible causes of back pain, and it is important to find the correct source so that proper treatment can occur successfully. One common cause of low back pain in post-polio survivors is sacroiliac dysfunction.

The sacroiliac (SI) joints are located on each side of the lower back at the top of the buttocks, connecting the sacrum (base of the spine) to the ilium (hips/pelvis.) The SI joint is a true joint, connected with cartilage and strong ligaments to support the structure. It has very limited mobility and functions to provide stability between the spine and pelvis, to distribute the load from the legs to the torso, and to provide shock absorption for the spine. There are many muscles in the trunk and legs that affect the spine. There are many muscles in the trunk and legs that affect the SI joint and can contribute to pain in that region.

Sacroiliac pain is often one-sided, caused by either hypermobility or instability (too much movement), or hypomobility or fixation (too little movement). The pain may be of sudden or gradual onset and may radiate from the low back to the buttock and back of the thigh. The pain can be described as sharp and stabbing or as a dull ache. Twisting, extended sitting or standing with a sway back can aggravate the pain. SI joint dysfunction can result in stiffness with getting out of a chair or bed. The pain often results in limitations with functional activities such as turning in bed, donning shoes and socks, getting legs into a car, and driving long distances.

The most common causes of sacroiliac joint dysfunction explain why it can be a source of back pain in post-polio individuals. These causes include, but are not limited to, the following:

- Leg length discrepancy or legs of unequal length often seen in polio survivors can cause asymmetric forces on the pelvis resulting in pain, usually in the shorter limb.
- Muscle imbalance in the legs or unilateral weakness of lower extremity muscles affected by polio can lead to abnormal transfer of stress and load through the torso in an asymmetric posture, increasing stress on one or the other side of the pelvis.
- Poor trunk and abdominal muscle control can lead to increased stress on the ligaments, causing laxity over time and sacroiliac joint dysfunction.
- Weight gain, especially around the area of the trunk, adds stress.
- Structural pelvic asymmetry is a result of the underdevelopment of the affected lower extremity and pelvic structure following polio. This can cause an abnormal transfer of load through the torso that can lead to SI joint dysfunction.
- Scoliosis (curvature of the spine) can cause asymmetrical movement, leading to an abnormal load transfer and SI joint dysfunction.
- An altered gait pattern can increase the stress on the SI joint.
- Poor postural awareness and habits in sitting, standing and daily activities can load the sacrum incorrectly.
- Trauma or injury from a fall onto the buttocks, a blow to the side of the pelvis, or a motor vehicle accident can strain the ligaments around the SI joint, creating instability. Most polio survivors experience falls, often leading to traumatic SI joint dysfunction. Women are at greater risk later in life for developing SI joint problems, especially when coupled with the above-mentioned causes. Anatomically, women have a wider pelvis and the effect of the hormones that are released to relax the

pelvis for childbirth may cause them to develop “hypermobility” SI joints. This eventually can lead to wear-and-tear arthritis.

While most sacroiliac pain comes from benign causes such as arthritis, the pain can also be caused by inflammatory disease, infection, stress fractures, irritable bowel syndrome and malignancy. A proper medical examination and an accurate diagnosis is critical to successful treatment.

Treatment of sacroiliac pain is usually multifaceted and individualized based on the cause of the pain. The physician may prescribe medication to control pain and inflammation.

Physical therapy is often prescribed by physicians with therapists receiving referrals from physiatrists (physical medicine and rehabilitation specialists), rheumatologists (consulted for inflammatory disease), osteopathic physicians or orthopedists. It is important that the treating physician and physical therapist are aware of the patient’s history of polio as this affects the treatment plan.

Physical therapy treatment for SI joint dysfunction depends on the cause of the pain and focuses on trying to restore normal motion in the joint. *Two completely different treatment options – manipulation or stabilization – are considered.*

In some cases, it appears that the joint is “too stiff” or “locked” and needs to be more mobile to function correctly. In these cases, the pain seems to decrease in response to mobilization of the joint. Mobilization of the joint includes stretching exercises and manual therapy. This type of therapy is directed to loosening up the joint ligaments, allowing the joint to move in a normal fashion.

Polio survivors more commonly experience the opposite problem. Long-standing laxity or biomechanical stress can be the source of arthritic changes in the SI joint. Exercises that are directed by the physical therapist will reduce the mobility of the joint by stabilizing the region, thereby decreasing the pain. Stabilization of the joint occurs by muscle strengthening and pelvic stabilization exercises that reduce movement in the joint. A sacroiliac belt that wraps around the hips to squeeze the SI joints together can help to accomplish this stabilization.

Specifically, in polio survivors, the therapist must attend to the cause of the SI joint dysfunction. A wedge seat is a simple solution to correct the SI joint pain. A shoe lift compensates for a leg length discrepancy. Weight gain should be addressed with diet and exercise. Altered gait patterns are modified with bracing and assistive devices. Poor postural habits can be corrected with postural retraining. Fall prevention is essential to reduce the risk of traumatic SI joint injury.

Pain can then be addressed in physical therapy with modalities such as ultrasound, heat and cold. Manual techniques, such as deep tissue massage and myofascial release, decrease the tightness of the muscles surrounding the SI joint. Stretching of the tight musculature in the neutral spine position is often helpful. Activities and postures that aggravate the condition should be avoided.

As the condition becomes less acute, physical therapy is beneficial to strengthen the weak muscles. Muscles affected by polio that are graded less than 3/5 on a manual muscle test cannot be strengthened and stabilization with a belt should be considered. The therapist should follow the exercise guidelines for strengthening a polio survivor. Muscle cramping or twitching following the PT session is an indication of overuse.

It is best to start strengthening exercises slowly, progressively building the resistance and repetitions. Isometric exercises and trunk stabilization techniques are useful. Aquatic exercises are a valuable tool in reconditioning and balance retraining. Patient education is a priority and a commitment to a home exercise program is essential. Some less traditional therapies such as Pilates, tai chi and yoga can improve core stability.

If the pain does not respond to PT and medications, other treatment options exist. A qualified physician can perform a cortisone-based injection into the joint under an x-ray fluoroscopy screen. Alternative treatments such as prolotherapy,* acupuncture or neuromuscular massage can help in chronic cases as well. Surgery is not usually helpful in cases of chronic SI pain.

Sacroiliac pain in polio survivors is often due to the long-term biomechanical stressed placed on the body. Successful management is achieved with proper evaluation of the cause, medical management and physical therapy, and active involvement of polio survivors in the treatment plan. □

* Prolotherapy is a non-surgical injection procedure used to treat connective tissue injuries of the musculoskeletal system that have not healed by either rest or conservative therapy in order to relieve back pain. The injections promote a healing response in small tears and weakened tissue, with the goal of alleviating back pain and improving function. Prolotherapy is also referred to as sclerosant therapy, sclero-therapy, regenerative injection therapy, "proliferative" injection therapy and non-surgical ligament reconstruction.

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Resources: Sacroiliac Joint Syndrome www.spineuniversity.com/public/spinesub.asp?id+89

A SHORT HISTORY OF MEDICINE

"Doctor, I have an ear ache."

2000 B.C. - "Here, eat this root."

1000 B.C. - "That root is heathen, say this prayer."

1850 A.D. - "That prayer is superstition, drink this potion."

1940 A.D. - "That potion is snake oil, swallow this pill."

1985 A.D. - "That pill is ineffective, take this antibiotic."

2000 A.D. - "That antibiotic is artificial. Here, eat this root."

ONE PSYCHOLOGIST'S PERSPECTIVE ON THE POLIO EXPERIENCE: SOME FINAL THOUGHTS ON MEMORY

By Margy Hull

I've noticed an interesting phenomenon in writing this series of articles about memory. The same processes I have been describing are occurring in parallel abundance in my own brain. Chewing over one novel leads off to vivid associations of my childhood with polio. That leads to thoughts of other people's accounts of their polio experience, and that leads me to thoughts about what I've been taught, what I've read, what I have seen on TV in documentaries about memory. Then on I go to some pivotal and some ordinary conversations with friends and family, with support group peers, with professional colleagues, with clients about memories and how memory works for them. Then it goes around and around and back and forth some more. Then I see in my mind's eye a diagram I've seen somewhere of all the neuronal connections that can occur in all different parts of the brain. And then I remember, with satisfaction, the things I've heard about there being some preventive effect from Alzheimer's disease for people who have a lot of associations in their brain. Parenthetically, I also remember reading that there seems to be a lower incidence of Alzheimer's disease in people who have had polio. Hmm. And on it goes.

Having talked about how memory is key in forming our sense of self, and helping us to maintain a sense of continuity throughout our major life transitions, I would like to go on with another point of view on how our

memories can be developed and given shifts in perspective for the benefit of our own mental health, without risking accuracy or authenticity. This line of thought arises from another meandering memory. One of the interesting things that happens in psychotherapy occasionally is that, as people begin to feel less depressed, more self-confident, and more positive toward the world in general, they seem to tap into new sources of memories. For example, a man has gone on at great length about how devaluing and abusive his father was toward him as a child. As he begins to make progress, he may suddenly recall about how close he felt toward his father when the father took him fishing in Alaska one time. After that, more positive memories may flood back, in addition to the ones about being scolded and shamed.

I thought long and hard about what could account for this change. One of the theories about it arose from another book called *The Structure of Magic I: A Book About Language And Therapy* by Richard Bandler and John Grinder. The underpinnings of this book were based on the idea, common in psychology, that everyone has a unique view of the world that is based on their own unique personal history and how they have interpreted it. They call it a representation, or a map, which then becomes the basis of their expectations of what will happen in the future, and determines their preferences and tendencies toward different kinds of responses. It establishes the categories that a person uses to organize his memories.

Sometimes people are able to establish maps that are very detailed, with many different roads they may travel, with many choices for how they may act in the world depending on circumstances. Sometimes people's maps are more constricted and limited with few choices and little freedom of movement possible. The authors believe that all good psychotherapy boils down to helping people differentiate and expand their maps, so that they have new ways of describing where they have been, and more productive and satisfying paths of travel through life and destinations for the future.

The authors choose to focus on ways of expanding people's maps that are based on exploring their use of language. There are three basic ways that people can constrict their maps without even realizing it. Having them brought to our attention with the help of a therapist, or hopefully some insightful self-examination, we may be able to find new options for action and feel a greater sense of completion as people. The significant things that we tend to do with language to our detriment are **generalizations, deletions, and distortions**. Because the experience of polio has been such a major force in the lives of us polio survivors, how we interpret that experience and its effects on us can be a key part of our map. I would like to give an example of a portion of my map that I have had to struggle with, that may illustrate how each of these uses of language can constrict our view of life and its choices. I have been known to think to myself: "as a teenager I got left out of everything."

The first constriction of my map in this area is the generalization that I was left out of 'everything.' I am aided in my challenge to this generalization by the fact that I am a compulsive 'journaler', and I recently reread a diary from my 14th year and was amazed by the number of times I got out and about and the various places I went to. Maybe it wasn't 'everything'. It turns out the 'everything' was after school activities and bopping around informally with friends. I did get to go to some games, movies, organized parties, and church youth groups. The second constriction comes in the form of a deletion. There is an implication if I was 'left out', there must have been somebody that left me out. Was there a person or more who deliberately 'left me out'? Come to think of it, there were those sorority girls who asked me to join them and I chose to politely refuse. In my sixties liberal zeal, was I the one that left them out? The other thing that has been deleted is recognition of some of the factors that limited my social life somewhat in those years, namely that I only went to school half a day and could not be there for after school activities, and that travel by bus or other people's cars was very difficult for me. The inherent danger of these deletions is that they can lead to a distortion with serious consequences: they could have led me to the belief that people just don't feel comfortable around those with disabilities, they don't really accept them, and that's why I was left out of everything. That belief could have haunted my life as I tensed up around people anticipating the rejection, thereby making them uncomfortable around me, leading to the classic example of a self-fulfilling prophecy.

I'm suggesting that we develop the habit of getting suspicious when we hear words in our memories like 'all', 'everything', 'nobody', 'never'. Start looking for the exceptions and what you are leaving out. Be open to your memories that will pop up at odd times in response to the memories of others, to documentaries of the times of your youth, to biographies and autobiographies, conversation, a walk in the park, anywhere.

For my own well being, I'm not going to worry too much about becoming one of those oldsters who is always reveling in memories of the past. (Hopefully, I will be somewhat selective about who I share them with and careful to not go over the same things again and again.) Not only will I be protecting myself against Alzheimer's disease, but I will continually be expanding my sense of who I am, where I have been, and what choices I have for the future. ☐

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MY FIFTY YEAR JOURNEY WITH POLIO

By Addie Warns

My journey with polio began 50 years ago in July of 1956 when I was eleven years old. I can remember how sick was as if it were yesterday. I made the Marion county newspaper this year under what happened 50 years ago.

I grew up on a farm just a few miles west of Lost Springs, Kansas and loved to be outside. I became ill during harvest time and was sicker than I had ever been in my life. I had to beg my mother to take me to the doctor. She was so busy that time of year and she just didn't realize how sick I was. I couldn't even swallow my own saliva and at that point she realized that she needed to get me to the doctor. I hated going to the doctor so she really knew that something was wrong for me to beg her to take me!!! I couldn't move my neck and was so weak when we got there. The doctor immediately told my parents what he suspected and that I needed to get to St. Francis Hospital in Wichita fast.

They took me there themselves. The doctors did a spinal tap and indeed it was polio and it was bulbar. They gave my parents not much hope of my survival and, if I did survive, that chances were that I would be in an iron lung for the rest of my life. They were surely not happy with that diagnosis and began to call home and tell everyone to pray for me.

I made the front page of the Wichita newspaper with my dad beside my bed and I was listed as critical. They had me in some kind of machine that helped clear out my throat because my muscles were paralyzed and it was impossible to even swallow.

I had not had the polio vaccine and my mother felt so bad about that. My parents took turns staying at my bedside. After several weeks of being fed intravenously and critically ill, I started to have terrible leg pain and the polio was starting to attack my legs. When the virus finally left my body they inserted a tube down my throat and fed me that way. I can remember how I would have given anything to be able to eat and taste real food! I kept telling everyone what I was so hungry for. After at least a month when I could swallow, my family remembered and they kept bringing me all of my favorite foods! My sister made cream puffs for me and I counted them before I let the nurses put them in their refrigerator. I was not very happy when I came up short! Evidently someone else loved cream puffs as much as I did! They just said that I must have miscounted.

They treated me so well and I received cards and gifts from people all over Wichita that we didn't know. I was in St. Francis Hospital for about two months. After a few weeks in therapy to learn how to walk again and being lowered into a large water bath, I was able to go home in time for my 12th birthday! My parents' prayers were answered and I was able to walk out of the hospital with help. Little did I know then that my journey with post-polio hadn't even begun yet!

It was a long recuperation period, but I rebounded fast after a year. What bothered me most was that I could no longer jump rope that was the love of my life and I was beginning to realize what polio had taken from me. I overheard my mother telling my sister that the doctor had told her that I wouldn't be able to have any children. Of course, then that didn't mean much to a 12-year old! As a teenager, not being able to wear

high-heeled shoes was devastating. My left leg stayed very small and my right leg became extra large because of its extra duties. I walked with a limp because my left foot was paralyzed.

I did not know that I was a miracle child to have even survived this dreaded illness and was very thankful to God. I had hated my brother before I became sick because he was always so mean to me. He told God that if He would let me live that he would never be mean to me again and he truly kept his word! He was five years older than me and we became friends for life!

Another miracle was that I was able to have two beautiful daughters and have been married for 45 years. I retired from the Postal Service four years ago with 31 years of service. As I got older, especially in my late fifties, I could definitely see that my energy level was limited. My right leg was tired of the extra duty and of course that affected my whole body. I listen more and more to what my body is telling me, pace myself and take each day one at a time. I cherish each day and focus on what I can do and not what I cannot do.

I expected to be in a wheelchair by now, but instead my husband, who was always the picture of good health, was diagnosed with MS eleven years ago. He is now in a wheelchair and paralyzed from the mid - chest down. So I've learned to completely put my trust in God and whatever will happen, will happen and that we have no control over it. We can just be the best that we can be and with His strength be thankful for what we have and learn to take one day at a time.

I am also a cancer survivor of seventeen years. Even though I do wish that life would be easier for my husband and I, I also know that without the hardships that life has handed us, I truly don't believe that I would be the person I am today without what I've had to go through. I have a personal relationship with God that keeps getting stronger with each trial I've had to go through. For that reason alone I wouldn't change anything about my life. I am so thankful for my family and friends and just knowing that whatever I have to face in this life that God is with me and that life is just a short journey to what we have to look forward to in eternity. There won't be any pain or sorrow there! Keep positive and God bless you all. ☐

Addie Warns lives in Salina, KS

TRY BEING ACTIVA

In a recent issue of *New Mobility* it reported that Activa is a relatively new yogurt made by Dannon to help those with difficult digestive systems. It contains Bifidus Regularis, a live bacteria only available in Activa. A reader wrote that after an injury, she developed an ileus and had been plagued with problems since. After using Activa she got relief from constipation and bloating. For more information go to: www.activia.com.