



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - February 2018

A Review of Polio and Post-Polio

by Richard Daggett and Mary Atwood

A few weeks ago, on a polio email list, a person asked an interesting question about constipation and the vagus nerve. The vagus nerve is one of the twelve cranial nerves. It extends from the brainstem to the abdomen by way of multiple organs including the heart, esophagus, and lungs. This nerve forms part of the involuntary nervous system and commands unconscious body procedures, such as keeping the heart rate constant and controlling digestion. It is sometimes impaired by bulbar polio.

The discussion which followed that question suggested there might be less knowledge of how polio affects our internal organs. So in this issue we review polio and then post-polio.

Polio Review

Poliomyelitis, often called polio or sometimes infantile paralysis, is an acute, viral, infectious disease spread from person to person, primarily via the fecal-oral route.

The polio virus enters the body and incubates in the intestinal tract. In most cases, the virus leaves the intestinal tract through the stool and causes no visible damage to the host. In some cases, the virus multiplies and enters the blood stream. From the blood stream the virus can cross into the nervous system.

Even a mild infection can extend into the brainstem and higher brain structures, resulting in polioencephalitis. This can affect breathing, swallowing, and other vital functions.

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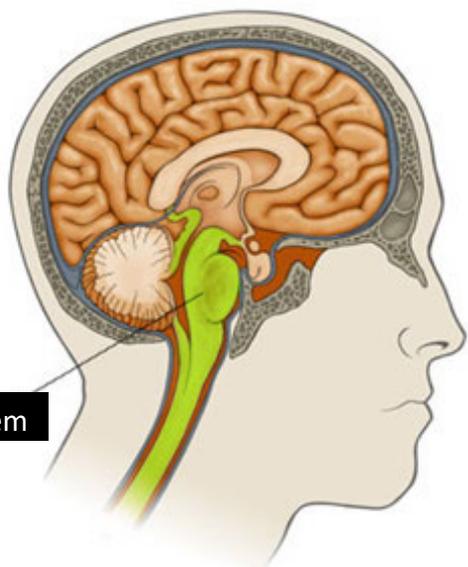
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Polio autopsy reports following the epidemics of the 1940s and 1950s showed signs of acute polio infection throughout the body and was not just restricted to the spinal cord. There were changes found in upper motor neuron pathways and in central brain structures that control alertness, central fatigue, and autonomic functions such as temperature regulation, heart rate, etc. There were also many changes seen in the brainstem itself.

Those same autopsies indicated that at least 50% of motor nerves needed to be damaged before any weakness was visible to the patient or the doctor. Probably greater than 90% of a polio survivor's motor neurons were affected to some degree during the acute stage and had some damage, even if not apparent. It is estimated that during the first few days of an acute attack as few as three percent of the motor neurons remained intact.

Although most polio infections cause no “apparent” symptoms, affected individuals can exhibit a range of symptoms that might appear later in life. This may lead to muscle weakness and paralysis. Different types of weakness may occur, depending on which nerves were involved. **Spinal polio** is the most common form. A person will usually have asymmetric muscle weakness that most often involves the legs.



Bulbar polio leads to weakness of muscles innervated by cranial nerves. It occurs when the virus invades and destroys nerves within the bulbar region of the brain stem, which is the pathway that connects the cerebral cortex to the brain stem. The destruction of these nerves weakens the muscles supplied by the cranial nerves, producing symptoms of encephalitis, and causes difficulty breathing, speaking, and swallowing.

Just as in spinal polio, bulbar polio can vary in severity. One person might have trouble forming words. Another person cannot swallow. A third person seems to sleep all the time.

The nerves that originate in the brain stem (bulb) control:

- Breathing
- Heart rate
- Chewing
- Swallowing
- Moving food through the gut
- Sleeping
- Arousal or concentration and many other functions.

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Some polio survivors might have few if any visibly “apparent” bulbar symptoms but, we need to remember, about 50% of neurons must be damaged before there is any visibly apparent weakness. Also note, many polio survivors were infants. They might not remember if they had bulbar involvement.

Bulbospinal polio is a combination of bulbar and spinal paralysis, and is often the most severe.

The nervous system comprises the brain and various types of nerves which carry impulses from all parts of the body to the brain. Motor nerves carry impulses away from the brain and to the muscles and are the primary target of the polio virus. Sensory nerves are not affected. However, directly or indirectly, the virus can affect nearly all of the organs of the body.

The somatic part of the nervous system has both sensory and motor components, which convey messages from the eyes, the nose, and other sensory organs to the brain. That is where most of the impulses reach our awareness, and motor components transmit impulses from the brain to the skeletal muscles in the limbs and trunk, allowing voluntary control of movements.

The autonomic nervous system regulates the functions of our internal organs, such as the heart, stomach, and intestines. We are often unaware of the autonomic nervous system because those functions are involuntary or by reflex.

For example, we do not usually notice when things are working well or are adjusting to minor changes. Sometimes these changes are more noticeable. For example, if our blood vessels change size, we may feel cold or we might faint. If our intestinal tract is not working as it should we might have constipation. The autonomic nervous system can also influence bladder emptying.

Post-Polio Review

Since some post-polio symptoms are more evident as we age, we may not realize that the polio infection many years ago is a contributing cause. Few hospitalized polio patients were ever told that post-polio was facing them as they got older, but that was known almost one hundred and fifty years ago.

In 1875, a polio case was presented to the Society of Biology in Paris about a nineteen-year-old patient who had polio when he was six months old. It paralyzed his left side. The young man had recovered partial use of his left arm and leg and became a tanner, which required him to use his arms to pull heavy, wet hides out of vats of acid. By the time he was seventeen, this young man reported fatigue and a feeling of heaviness in his right arm, the arm that had apparently not been affected by the polio virus. His right arm and leg both became weaker and smaller. Known as “the French patient”, this appears to be the earliest case of post-polio studied in detail. From 1875 to 1900, twenty-four articles appeared in European medical journals describing 30 additional polio survivors experiencing new weakness and atrophy.

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We now know that polio can change our body in many different ways. Bulbar polio can do things to our body that are not always outwardly evident. Here are some of the late effects:

Breathing

Do you wake often during the night, feel tired, even if you think you slept well? Do you experience:

- Frequent yawning?
- Talking is tiring for you?
- You sleep better with your head elevated?
- Poor concentration?
- Morning headaches?

Morning headaches are a sign that you are not breathing well enough to eliminate carbon dioxide from your blood. Carbon dioxide can build to a level that inhibits oxygen exchange.

If you experience any of these breathing symptoms it is time to have a pulmonary function test or sleep study. These tests require a physician's order. Some physicians are not familiar with breathing problems caused by the late effects of polio. If you have a lowered oxygen level those physicians might prescribe oxygen. This is usually not the recommended treatment. Extra oxygen can mask a more serious condition. Using a bi-pap unit at night is often more helpful. Don't be fearful of these lifestyle changes. You will probably feel better and have more energy.

Swallowing

The nerves that lead to the swallowing muscles originate in the bulbar region. If the muscles in your esophagus are affected, you may have problems swallowing (dysphagia), which in turn may cause weight loss and malnutrition.

Research indicates that swallowing problems can occur even though no problems were apparent at onset. Swallowing problems can be aggravated by breathing problems and fatigue. Difficulty swallowing may also cause you to inhale food or liquids, including saliva, into your lungs (aspiration), which can lead to pneumonia.

When you are chewing and swallowing you should be doing only that. You should not be talking or laughing. Many people have learned to turn their head to one side when they swallow. Many also keep a glass of water within reach to help the passage of food through the throat.

Post-Polio Fatigue

Post-polio fatigue can be divided into three areas. **Muscle fatigue** is when your muscles feel

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very tired and heavy, particularly after physical activity. **General fatigue** is when you feel an overwhelming sense of physical exhaustion, as if you have not slept for days. **Mental fatigue** is when you find it increasingly difficult to concentrate, have problems remembering things, and make mistakes that you would not usually make.

Post-Polio Mental Fatigue

The reticular activating system is also located in the bulbar region of the spinal cord, at the base of the brain. It controls the transition from sleep to wakefulness, and the ability to focus attention on something. It acts as a gate keeper, dampening the effect of unwanted stimuli, such as loud noises, which can overwhelm the senses. To some extent it also regulates response to the stimuli received from outside and helps to pinpoint a specific fact through detailed thought. Coordination of actions related to eating, walking, and even urinary functions are also carried out by the reticular activating system.

Mental fatigue is aggravated by physical fatigue. Learn to pace yourself. As we age we have fewer reserves. It is better to do a few things well than it is to exhaust yourself with too many tasks.

Try to link with another person experiencing similar issues. A post-polio support group is excellent, but many of us live far from any organized group. Reach out by telephone or mail or electronically. There are several good polio groups on the Internet.

Post-polio is only part of the equation. All of us are getting older. Some of us have additional medical issues, or the after-effects of injuries and other life altering situations. Just because you had polio, this does not make you immune to other diseases or conditions! Don't assume the pain in your side, or the ache in your leg is polio related. Don't neglect the headache, the tingling in your arm, or the tightness in your chest.

We are all different. Don't let any doctor scoff or belittle your symptoms by telling you, "I know it hurts but, after all, you did have polio." In addition, if anyone says to you, or you read an article that states, "All polio survivors should do this ...or do it this way." Or, the opposite, "No polio survivor ...needs this ... or should ever do this," it is wrong! Every polio survivor is different, and every polio survivor has unique needs.

The late Dr. Jacquelin Perry, one of the first physicians to identify and publish articles about post-polio, would advise her patients to be intelligent hypochondriacs. She wanted her patients to be aware of their body and how it functioned. If something felt different, or functioned less well, she expected her patients to learn why the change was happening. That is still excellent advice.

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Positive Attitudes

A positive attitude about health and wellness is maintained by becoming an active participant in one's health care, planning an individualized program, accepting the fact that some aspects of life will change with age, and believing one can control one's health.

Attributes relevant in maintaining a positive mental attitude include:

- Optimism and hope. Believe that things can be better and hope for relief or improvement in the future.
- Control and self-direction. Take control over the disability experience and willingly direct one's life. Plan ahead for the future.
- Commitment. Commit to something, such as religious groups, civic duties, hobbies, family, work. Stay involved and curious.
- Closeness or intimacy. Engage in personal and group relationships.
- Good health. Tend to a proper diet, appropriate exercise, and rest. Avoid excessive drinking, smoking, and other potentially dangerous social habits.
- Feelings and perceptions. Avoid guilt, anger, hostility, fear, anxiety, and the feeling of low self-esteem. Perceive life and life events as challenges rather than threats.
- Flexibility and adaptability. Be willing to reorder priorities.
- Humor. Look for humor, especially in one's own situation.
- Openness. Accept whatever comes along in life without blame and by forgiving people and oneself.

Excerpt from Post-Polio Health International's "Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors." © 1999

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A positive attitude fosters constructive thinking. Instead of dwelling on things lost, you think about solutions and believe that you can find them. It means being active about solving new problems. It is not enough just to believe that things will turn out okay, you need to actively work toward that goal.

Looking at life and situations with a broader vision will foster creative solutions. With a positive attitude, you are not afraid to look for new ways of doing things.

2017 Donors

Listed below are the names of the generous donors who contributed funds in the past twelve months to help both the Rancho Los Amigos and the Orange County post-polio support groups. All donations are shared equally between the two groups.

Thank you very much. These generous donations will allow our continued support to polio survivors near and far.

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Support Group Meetings

Rancho Los Amigos Post-Polio Support Group

Saturday, February 24, 2018 - 2:00 p.m. to 4:00 p.m.

Annual Anniversary Potluck

Please join us and bring a favorite dish to share. Finger food is the easiest to eat and is preferred because of the ease in clean-up. We have covered parking. A map with directions is available at www.ranchoppsg.com. For meeting information, please call Diane at (562) 861-8128. For newsletter comments, send an e-mail to ranchoppsg@hotmail.com

Saturday, March 24, 2018 - 2:00 p.m. to 4:00 p.m.

Preparing for Disasters

Southern California has had fires and floods in the past few months. Are you prepared for more of these, or “the big one”? A presentation by the City of Downey will help us with the important issues.

Saturday, April 28, 2018 - 2:00 p.m. to 4:00 p.m.

Improving our lives with gadgets, home improvements, and helpful ideas.

Post-Polio Support Group of Orange County

Saturday, March 10, 2018 - 2:00 p.m. to 4:00 p.m.

Disaster Preparedness for People with Disabilities

Sunday, May 6, 2018 - 2:00 p.m. to 4:00 p.m. (tentative)

Presentation by Dr. Perlman. This date is tentative, but mark your calendar anyway. These presentations by Dr. Perlman are always informative, and always helpful. If the time or date changes you will receive a notification. Also note ... this is a Sunday meeting!

For additional information, please call Aleta at 949-559-7102