

Polio Network News

Emotional Bridges to Wellness

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Survivors who live with the recent or late effects of polio often need to make lifestyle changes in order to manage physical symptoms such as fatigue, weakness, and pain. For many of us, gaining the ability to adjust our lifestyles requires a great deal of inner strength and emotional support. Numerous authoritative studies have documented how our minds, bodies, and emotions affect each other. These findings offer us insights into how we can support ourselves and maximize our satisfaction with life by making wellness-oriented changes.

To experience wellness, we need to balance and integrate the physical, emotional, mental, social, sexual, and spiritual aspects of our lives. Obtaining reputable information will equip us in making informed wellness-oriented choices. Most importantly, we need to consciously weigh the benefits and risks of various lifestyle options. Rather than making choices based on rigid attitudes, habits, reactions of others, or our own anxieties, we need to ask, "How can I best take care of myself?" As survivors, many of us take pride in being self-responsible, and making responsible decisions about our lifestyles is one way to maintain our independence.

In this first article in a series, we will focus on "how we treat ourselves." While making adjustments is difficult, this article offers possibilities for strength-

ening our internal resources or developing emotional wellness. By approaching ourselves with self-acceptance and self-appreciation, we can increase the likelihood of making self-nurturing choices that contribute to our overall health and well-being.

Looking at our various "selves"

At a recent Ontario March of Dimes Wellness Retreat, Karen Kennedy, MSW, West Park Healthcare Centre, Post-Polio Clinic, Toronto, Canada, presented "Setting the Stage for Wellness." She described various personality characteristics that Drs. Hal and Sidra Stone refer to as "selves" in their book, *Embracing Our Selves*. Kennedy identified how certain "selves," or parts of oneself, may interfere with a survivor's ability to make healthy choices.

For example, the authors refer to the "Perfectionist Self" as the part that demands the highest level of performance from oneself and others, no matter the cost. They name the part that is attentive and dedicated to the needs of others, sometimes tuning out one's own needs, pain, or fatigue, as the "Care-taker Self."

Their term "Pusher Self" represents the self that helps people achieve the levels of success they aspire to in their life. Some people operate with a small "Pusher Self," while others appear to

have a Mack truck driving them to unrealistic and unhealthy ends. While the "Pusher Self" enabled many survivors to recover from their initial polio, the Mack truck is dangerous when it propels individuals with chronic health conditions to overdo and increase their physical and mental fatigue. The Stones contend that this self may not discriminate between what is damaging and what is constructive.

Depending on the situation and how intensely each part is expressed, each "self" has the capacity to be either beneficial or harmful. For example, our "Communicator Self" is beneficial when we express thoughts, feelings, and needs responsibly by being honest, open-minded, direct, and appropriate. This part also can address conflicts sensitively and effectively, and can share humor and hope in relationships. However, when the "Communicator Self" is demanding, insensitive of other people's feelings, or refuses to ask for assistance, then it can distance others and even cause feelings of shame or remorse.

Kennedy encouraged self-awareness when she asked, "Which of

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the selves is in the driver's seat of your life?" and introduced another self, that she calls the "Permission Giver." She defined the "Permission Giver" as the part of oneself that says, "It is good to set limits, to take care of yourself, and to be compassionate towards yourself."

Personal permission-giving means allowing one to acknowledge reality, to accept one's needs, and to take the steps to initiate purposeful change. It is key to making changes related to the late effects of polio or any chronic health condition.

Permission-giving encourages us to think about ways we can take responsibility for our health and the quality of our lives. It offers a compassionate frame for making decisions to accommodate new weakness, pain, fatigue, and breathing problems.

Kennedy's permission-giving invites us to assess how we can respond to ourselves as we make changes. This process involves learning about ourselves and understanding what we each need. The following sections highlight how this process can work and include examples from my own life (*italicized quotes*).

SELF-AWARENESS

Self-awareness is the foundation for making healthy changes. In order to create a gratifying life, Robert Fritz emphasizes that people need to be honest and clear about their needs. He contends that too often people set goals, yet are unrealistic about what they need to move from their present situation to their desired state (Fritz, 1991).

Self-awareness helps us identify our feelings and needs (Masters &

Johnson, 1986). When we are aware of them, we can respond responsibly, and make healthy decisions. Self-awareness provides us with the freedom to be our "true self" rather than exerting energy striving to fill the unrealistic expectations of others or ourselves (Masters & Johnson, 1986).

Self-awareness does not mean being obsessed with our own needs to the exclusion of caring about others. On the contrary, self-awareness strengthens our ability to be intimate with others, and equips us to choose whom to confide in, and how to discriminate between healthy choices and unhealthy coping patterns.

Self-awareness also involves understanding. Understanding the reasons for one's feelings and attitudes is important for making decisions that impact one's health. For example, *"At one of the early GINI post-polio conferences, a ventilator user announced that he sometimes felt 'anti-social' when in reality he did not have the energy to talk. His sharing helped me understand the effect that my respiratory limitations had on my relationships. Even though I wanted to be sociable, fatigue and shortness of breath limited my ability to extend myself to others. This man's awareness helped me accept my own reality and deal with my feelings about my respiratory limitations."*

Finally, self-awareness includes listening to one's intuition. Intuition is that inner voice or body-felt sense that can be a guiding force in making wellness-oriented choices. We can become aware of our intuition by paying attention to our feelings, our reactions to experiences, and messages conveyed through dreams (Northrup, 1998).

Asking "What do I need right now?" can provide clarity when we are feeling fatigued. Paying attention to the feelings and ideas that surface when we ask ourselves this question, can uncover valuable solutions. Journaling or drawing can tap our intuition for insights about how we can take care of ourselves amidst the many demands in life.

Northrup encourages us to discover what we do want and to learn to say "no" to what is not supportive of our needs and values.

SELF-ACCEPTANCE

Self-acceptance involves appreciating one's strengths – those parts of one's personality that others value, such as a sense of humor, intelligence, or organizational skills. Equally important is accepting one's limits, such as an inability to dress oneself, or the need to take breaks during the day. Rather than abandoning enjoyable activities or taking on a fatalistic attitude, self-acceptance implies accepting and expressing the feelings related to a loss. It also means finding alternate ways to satisfy needs or desires.

Many survivors can still participate, but need to adjust their ways of gaining access to activities. For someone who enjoys boating, but cannot step into the boat anymore, it may mean using assistive devices. The good news is that, in many areas, there are increased opportunities for recreation for people with disabilities.

Adapting to new methods of functioning takes self-acceptance. A recent study revealed that about 50% of survivors follow

Editor's Comments

their physicians' recommendations to use assistive devices (Thoren-Jonsson & Grimby, 2001). The reasons the remaining 50% of the participants choose otherwise may relate to self-acceptance, including self-image, self-worth, and the reactions of others.

"One of my successes in self-acceptance involved my 'Communicator Self.' When I was on a first date with a man who wanted to walk three blocks to show me his office, I asserted that I would need to take a cab. Rather than apologize, I offered to meet him at the destination. In years past, I would have felt anxious about his responses. This time, I realized that how he responded would tell me if he could accept my physical limitations and whether developing a relationship with him was of mutual interest and a realistic possibility."

SELF-APPRECIATION

Self-appreciation is an attitude or feeling of caring about oneself. When we appreciate ourselves, we increase the likelihood of treating ourselves in caring ways and ensuring that others treat us respectfully.

In contrast, feelings of shame or anxiety are especially distracting and draining of energy. Mary Westbrook, PhD, has researched the impact of "shame anxiety" on polio survivors' ability to ask for help and to maintain intimate relationships (Westbrook, 1996). She found that various forms of anxiety are associated with survivors' early polio experiences (Westbrook, 1996).

People are apt to isolate themselves when they are ashamed or dissatisfied with life and may go to excessive means to prove their worth or to gain recognition or acceptance (Masters &

Twenty years ago in October 1981, our organization hosted its first conference on new problems facing the survivors of polio. Held in Chicago, this important meeting brought together survivors, health professionals, leaders in the ventilator industry, and policy makers. The candid discussions ended the isolation of many and began a collaborative effort that continues today. We salute our founder, Gini Laurie (1913-1989), for her foresight and perseverance.

October is also the time the popular press promotes the flu vaccine for the season that runs from November through April. The Centers for Disease Control and Prevention suggests that those people who will benefit the most from the vaccine – those over 64 years old and those with chronic (long-term) health conditions – get their shots as soon as vaccine becomes available, which is now. Every year we receive calls from panicked polio survivors saying that they heard that polio survivors should not receive the flu vaccine (most often, after they had).

According to our Medical Advisory Committee, there is no reason why having had polio should preclude a survivor from getting the flu shot. To the contrary, physicians urge their patients to get the vaccine, especially if they have respiratory muscle involvement due to polio.

This fall, I had the opportunity to visit a few post-polio groups and discussions were held, formally and informally, about change. Why do we? Why don't we? Why is it so hard to do? Can we learn to change? This issue offers two honest and related articles. The cover article sets the stage for change by focusing on how we treat ourselves, and the other (page 5) encourages us to try change.

Other discussions and observations from the fall meetings necessitated the inclusion of an addendum to our Breathing Problems of Polio Survivors (Volume 17, Number 3). One article describes the Equipment (page 9) and the other clarifies Oxygen Use (page 10). These articles are coupled with cogent comments from a cardiologist about our need, as aging polio survivors, to be aware of cardiovascular disease.

— Joan L. Headley, MS,
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Johnson, 1986). When depressed or anxious, people are inclined to block their feelings and self-awareness by overeating or drinking alcohol, or to distract themselves by watching television or overworking.

"Westbrook's research motivated me to look at how my early polio memories affected my ability to ask for help. Years ago, I avoided asking for help. I would struggle, walking in the wind, rather than ask a colleague to drop me at my destination. I learned I had a distorted view of needs and dependency. After working through my feelings about past experiences in therapy, I understood the reasons for my feelings – the beliefs behind them – and how these affected my inability to be responsible about my health. This process freed me to become capable of asking for assistance in a self-responsible way."

In contrast to shame and anxiety, self-appreciation strengthens our ability to respond to ourselves in nurturing ways.

SELF-NURTURING

Self-nurturing is a way we show that we care for ourselves. We nurture ourselves when we take in adequate nutrition, get enough rest, and discriminate about taking on a new task or commitment.

To nurture means to soothe, ease, refresh, invigorate, and develop resilience (Louden, 2000). Louden describes nurturing as fuel that compels us to live life fully and keeps us going when life gets tough.

Nurturing involves tenderness, comforting, gentleness, and pleasure. Examples include affirming auditory messages; tender, pleasurable touch; enjoying beauty through nature, the arts, or one's environment;

surrounding oneself with comforting fragrances from fresh flowers, candles, or aromatherapy; and eating luscious, nourishing foods.

"Self-nurturing is more than pampering. It is about becoming powerful" (Louden, 2000). Jennifer Louden explains, "Comforting yourself is about strengthening yourself, becoming ... more durable ..." (Louden, 2000). Far from encouraging self-absorption, this concept means that taking time to nurture oneself will increase resilience to discomfort and fears. For polio survivors, self-nurturing is a useful skill to develop since discomfort and fears can result from making lifestyle changes associated with declines in our ability to physically function.

"For me, exercising in a warm water pool (over 90°) is a therapeutic source of self-nurturing. Stretching and breathing in the water reduces the pain in my limbs and shoulders. It increases my energy, deepens my breathing, and stabilizes my gait. The freedom and mobility I experience in the water is pleasurable and leaves me with a valuable sense of wellness."

In reflecting on my article, you, too, can gain clarity about what you need to do by asking:

- Will this activity or person energize me or deplete my energy?
- Which activities do I need to say "no" to because they deplete my valuable energy?
- How can I listen to my intuition and face myself in a caring and responsible way?
- How can I use "permission-giving" to strengthen my ability to accept my needs and nurture myself?

These are tough issues and many of us would prefer to avoid them as long as we can. My experience has taught me that my body forces me to notice what it needs. I have learned that the sooner I pay attention and consciously make a change that adds ease to my life, the more energy and peace of mind I experience.

Many resources are available to support us in developing personal skills and insights that can equip us as we continue through this journey of adjusting to the effects of polio and life's unpredictability. You may want to read some of the books listed as references for this article. I hope you will benefit from my explorations and will discover ways to experience a sense of overall wellness and satisfaction with your life. ■

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Transitioning to a Wheelchair: An Exploration of Our Fundamental Fears

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When actor Christopher Reeve sustained his spinal cord injury in a horse riding accident, he went immediately from Superman to Man in Wheelchair. In contrast, some polio survivors, myself included, go through a lengthy, angst-ridden decision-making process before we plunk ourselves down in a wheelchair.

We listen to the recommendations of our physicians, and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and surely would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

Let's go back to our beginning. Does this sound like you? You contracted polio as a baby, child, or young adult and endured a long hospitalization. You were separated from your family at a tender age and may still have some psychological wounds from that trauma. You emerged using braces and crutches for mobility. However, in many cases, your medical professionals gradually eliminated those aids.

You made an impressive recovery, walking unaided for many decades. Then years after onset, you began to experience weakness, fatigue, and pain. You were diagnosed with post-polio syndrome.

You now use a cane for support in walking; possibly, you were fitted for a brace and/or forearm crutches, and you find that

motorized shopping carts at the grocery store are of colossal help to you. But, life is still much more difficult with the late effects of polio.

Did you once adore concerts in the park? Now you decline to go because walking on that uneven grass is far too difficult for you. You stay home.

Did you once savor the fun of cruising the mall with your daughter-in-law? Now you decline to go because that much weight-bearing and walking is far too painful. You stay home.

Did you once thrill to walking the boardwalk at the beach, absorbing the sights and sounds of the ocean atmosphere? Now you decline because the length of that long, winding boardwalk is too much to manage. You stay home.

You and your polio medical professionals recognize that the time has come for you to use a wheelchair for most of your mobility needs. However, the thought of appearing in public in a wheelchair fills you with dread. The key phrase is "appearing in public." Alone in your home, you love the way you can move smoothly, gracefully, and without pain and fatigue. But the image of using your wheelchair out in public terrifies you. Why? You realize on a rational level that using a wheelchair would be very liberating. But that rational base is overpowered, indeed almost buried, by the negative emotions that shout: "No! No wheelchair for me!"

Let's examine some of the contributing factors for this resistance.

As a child, you received considerable praise for your attempts to walk unaided.

Much of your self-esteem is wrapped up in the fact that you are still able to walk.

Society places an inordinately high value on walking.

The wheelchair makes it virtually impossible to be a "passer," that is, to pretend you are non-disabled.

It is the image of a wheelchair that is, indeed, the universal symbol of disability.

These are only surface reasons. The deeper, overriding reason for your reluctance stems from a negative association of ideas. Think of an algebraic equation: YOU are on one side of the equation and DISABLED is on the other. That association of ideas is laden with shameful emotional overtones. Why? Because, historically, people with disabilities are stigmatized. They occupied a low rung on society's "A List."

I remember the various social cliques in high school. Teenagers were ranked in hierarchical order as "preppies, jocks, greasers, and nerds." Very few kids with disabilities landed in the most popular crowd, and we absorbed that message like water into a sponge. Although those classifications have undergone various transformations over the years,

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I have a sense that we still long to belong to the "popular crowd."

Our resistance to using a wheelchair is intimately connected to our unwanted view of ourselves as disabled. We are influenced by a deep-rooted prejudice in society that it must be better to be ambulatory than to be in a chair. For example, there may be no greater medical triumph than getting someone "up out of a chair."

How my heart pounded with dread and self-consciousness the first semester I wheeled into the faculty meeting. That wheelchair gets the credit for "outing" me. I now had to admit to the world that I was, indeed, a Person with a Disability. Ever since that day, the liberation has been mine!

It is an important healing step to act on the belief that it is okay to be YOU and to know that the consumerist driven, stereotypical images of "attractive" and "popular" are oppressive falsehoods rather than the truth. It is stunningly appealing for a person with a disability to exhibit confidence and self-acceptance. People are not used to seeing this. When you perceive others' positive responses and you realize these responses are to YOU, as you are, you will be freed. When you receive positive reactions to the real you, not despite your disability, nor because they are unaware of your disability, but to YOU, you will shed a burden you may have carried around since adolescence.

If you love the comfort and ease of using your chair in private but dread the thought of using it in public, you can use the power of your human consciousness to

restructure your perceptions and free yourself. You were paralyzed by polio; don't be paralyzed by society!



Linda, being fitted for her first power wheelchair, at Gaylord Rehabilitation Hospital in Wallingford, Connecticut.

Are you still suffering from antiquated tapes playing incessantly on your internal tape recorder? If so, it is time to erase those old tapes. You can trade in your negative thought patterns for powerful new positive beliefs. You can liberate yourself and claim your rightful place in society.

Think about sitting proudly, head held high, in your sleek manual chair or perhaps zipping around in your sporty, power-chair. Visualize yourself maneuvering gracefully over the grass at the concert in the park. How lovely the grounds look when you are no longer fearful of tripping. How sweet the evening air as the melodic musical sounds touch your heart.

Picture yourself on a swift mobility scooter at the shopping mall with your favorite friend, scooping up bargains. You can "shop

'til you drop" and still have energy to go out to dinner.

Envisage yourself traveling the length of the boardwalk at the ocean. Your senses overflow with the ambiance of the seashore. Since you have no pain or fatigue, you are much more free to hear the seagulls scream, to smell the salty sea breeze, and to celebrate the sheer joy of this outdoor experience.

I know that this is still a difficult decision. Generally speaking, I think we are in a climate in which the mobility-limited person has to swim upstream against self-imposed inner conflict, as well as from family and friends who are caught up in the "use it or lose it" mantra. If we are to make optimal advantage of wheelchair mobility, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate. Won't you join me in the swim?

Dread of using a wheelchair is based on old emotional baggage. Toss that baggage out. Wheel with pride and flaunt your self-acceptance. You will be a role model to all who encounter you. ■

CORRECTION A reader informed us that the **National Odd Shoe Exchange** IS in business. To find out more about their services or to register with the exchange, call 480-892-3484 or write to National Odd Shoe Exchange, PO Box 1120, Chandler, AZ (Arizona) 85244.

CLARIFICATION The **Post-Polio Support Society NZ, Inc.** contacted us to say that the Polio Course at Queen Elizabeth Hospital in Rotorua is currently available only to North Island survivors. The Society is working hard to make the hospital a center of excellence with services available to all of New Zealand's survivors.

Cardiovascular Issues of Polio Survivors

Remarks at GINI's Eighth International Post-Polio and Independent Living Conference, June 2000

Rupert D. Mayuga, MD, Assistant Professor of Clinical Medicine/Cardiology, Northwestern University Medical School, Chicago, Illinois

Cardiovascular disease (CVD) is the leading cause of death in both men and women in the United States. One of every 2.4 deaths is attributable to CVD. However, the incidence of CVD in individuals diagnosed with post-polio syndrome is not known.

CVD is often a "silent" disease without significant symptoms until its life-threatening or catastrophic sequelae appear suddenly. All too often, the first manifestation of CVD is sudden death, stroke, or heart attack. The need to identify individuals at increased risk early enough to alter its catastrophic course cannot be overemphasized.

◆ *Are there reasons to suspect that polio survivors who are experiencing post-polio problems might be at increased risk for CVD?*

Yes, certain features such as generalized fatigue, generalized and specific muscle weakness, and joint and/or muscle pain may result in physical inactivity – deconditioning, obesity, and dyslipidemia. Polio survivors with respiratory difficulties may develop hypoxemia (low levels of oxygen). Any of these circumstances – deconditioning, obesity, dyslipidemia, and hypoxemia – can increase the risk for cardiovascular disease.

Furthermore, most polio survivors are at an age when CVD becomes increasingly more likely.

◆ *What are the common signs and symptoms of CVD?*

CVD signs

Enlarged heart
Swelling of the ankles or legs
Unusual/excess weight gain
Wounds that do not heal well

CVD symptoms

Chest discomfort (pain, pressure, squeezing, heaviness, etc.) especially if brought on by exertion and relieved by rest
Shortness of breath with minimal exertion or upon lying down
Palpitation or irregular heart beats
Severe dizziness or loss of consciousness
Sudden weakness or paralysis of one part of the body
Sudden slurring of speech or loss of vision
Frequent nocturnal urination
Unusual and progressive fatigue
Leg pain/discomfort with walking

A WORD OF CAUTION: The symptoms of CVD overlap with common symptoms of post-polio syndrome. This presents a problem because individuals diagnosed with the syndrome may not recognize cardiovascular symptoms and think that these may just be a progression or altered manifestation of the post-polio symptoms. The resulting delay in diagnosis can be costly.

◆ *What tests should I have if I experience some of the above symptoms?*

One study, of practical importance to polio survivors, evaluated the cardiovascular autonomic function of individuals who had polio (Borg, 1988) and concluded that there was no significant dysfunction of autonomic nerves despite the presence of progressive muscle atrophy.

This finding becomes important when one considers that many current methods for assessing cardiovascular function and fitness include evaluation of parameters – such as heart rate, blood pressure, heart rate variability, valsalva response, etc. – all of which require an intact autonomic system. The study results suggest that polio survivors in general can use any of a number of standardized tests for cardiovascular risk assessment such as the exercise stress test without a decrease in test sensitivity, provided that due consideration of the presence of muscular dysfunction is made.

For example, an arm ergometer may be used instead of a treadmill as the method of providing the exercise in individuals with lower extremity weakness. There are also non-exercise types of cardiovascular stress testing such as pharmacologic, vasodilator perfusion stress tests (dipyridamole or adenosine stress tests) used in conjunction with nuclear imaging, or a dobutamine stress echo test. These are the preferred tests for those who cannot perform significant exercise.

Also, make certain that blood pressure, cholesterol/lipid profile, fasting blood sugar (FBS), body weight, and an ECG are included in your annual physical examination. A chest x-ray would also be useful periodically to determine heart size and the status of the lungs. More frequent testing as well as additional specific tests (stress tests, echocardiograms, coronary angiograms, etc.) may be needed.

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Although there appears to be no large scale studies evaluating whether individuals experiencing post-polio syndrome are at increased risk for CVD, it is probably safe to assume that there may be increased risk in certain individuals who have the traditional risk factors mentioned above. A study of 64 post-polio individuals (Agre, 1990) found that 66% of the men and 25% of the women had hyperlipidemia (high lipid concentration) with men also having low HDL (the "good") cholesterol. These findings underscore the need to actively screen for dyslipidemia and/or hypercholesterolemia (excess cholesterol in the blood; less than 200 total cholesterol is desirable). In addition, deconditioning and obesity was found to be strongly associated with the presence of dyslipidemia. Therefore, it is important to address these issues.

◆ *Since CVD is described as a "silent" disease without significant symptoms, what are some of the risks factors that are of major importance to everyone with or without a history of polio?*

Risk factors include cigarette smoking, hypertension (high blood pressure), elevated LDL cholesterol (the "bad" cholesterol; less than 100 is optimal), low HDL cholesterol (the "good" cholesterol; 60 or more is optimal), diabetes, male gender, post-menopausal women, family history of premature coronary heart disease, the presence of peripheral arterial occlusive disease, and, last but not least, obesity and physical inactivity.

The presence of multiple risk factors results in more than just additive risk.

◆ *How can I avoid physical deconditioning and becoming overweight?*

In individuals with identified post-polio symptoms consistent with cardiovascular deconditioning, there has been some hesitation in prescribing an exercise program to improve conditioning because of fears that traditional exercise regimens may lead to further loss of muscle from overuse. The prospect of safely and effectively training PPS subjects was evaluated by a number of investigators. All

investigators found that a carefully designed exercise program, which avoided excessive muscle fatigue was able to provide positive results.

Consult your health care professional for appropriate recommendations. In general, exercise has to be started very gradually and at a lower level individually tailored to each individual's physical status and needs. Care should be taken not to over-exercise. Nutritional counseling is also a useful resource. ■

"If we don't know the disease, we don't know that we are at increased risk, and we might not do anything about it."

— Rupert D. Mayuga, MD

SIGNS AND SYMPTOMS OF A HEART ATTACK OR IMPENDING HEART ATTACK:

Continuous chest and/or throat discomfort/pressure/pain/heaviness lasting more than 15 minutes even with rest and even after sublingual nitroglycerin. This may be associated with shortness of breath, sweating, dizziness, and palpitations. Discomfort may radiate to the left arm or jaw.

Immediately proceed to the nearest emergency room or call the paramedics (911).

If you have no severe allergies to aspirin, chew one tablet of regular 325 mg. aspirin. This can help immediately by preventing or delaying further accumulation of blood clot in the arteries of the heart. In the emergency room, you can be given powerful clot dissolving medications or, if the facilities are available, emergency coronary angioplasty (a means of re-opening a blocked artery using a small balloon at the tip of a catheter) can be performed. These procedures can prevent an impending heart attack or reduce the size of a heart attack that has already started, thus reducing significantly the risk of dying as well as the risk of future complications.

Remember, emergency coronary angioplasty is only effective if the blocked coronary artery causing the heart attack can be opened within the first few (preferably less than three) hours of the onset of chest discomfort.

Do not delay in getting to the ER!

Addendum to Breathing Problems of Polio Survivors

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EQUIPMENT

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Polio survivors and people with other neuromuscular diseases may need help with breathing because respiratory muscles are paralyzed or weakened. The chest walls of polio survivors may be stiff and inelastic, and, if they have scoliosis (curvature of the spine), breathing may be more difficult.

Problems with breathing usually are noticed first during sleep and can be due to underventilation, to sleep apnea (obstructive, central, or mixed), or to a combination of both. To determine the best equipment for treatment, it is important to determine the correct diagnosis, either through pulmonary function tests, pulse oximetry during the night, and/or a sleep study.

The following descriptions may be helpful when considering assisted breathing options.

INTERFACE

An interface is what connects the circuit or tubing from the equipment to the person using it. This connection can be invasive through a tracheostomy, or noninvasive via nasal or facial mask, a lipseal, or a mouthpiece.

CPAP – CONTINUOUS POSITIVE AIRWAY PRESSURE

When using a CPAP machine, air flows continuously into the airways via the nose with the use of a nasal mask to keep the airways open. CPAP does NOT assist inspiratory muscle activity directly NOR does it assist gas exchange in the lungs. John

Bach, MD, describes it as “breathing with one’s head out of the window of a car going 60 mph.” CPAP is primarily used to treat obstructive sleep apnea and is normally used only at night during sleep. CPAP units are not ventilators and will not be useful if the sleep or breathing problem is due to underventilation.

Newer units, known as auto-titrating positive airway pressure units, automatically adjust the pressure and provide varying levels of pressure throughout the night based on the individual’s needs. They may also be used diagnostically. The pressure is generally lower than that of standard CPAP units. The AutoSet® T from ResMed (www.resmed.com) is an example.

BiPAP – BI-LEVEL POSITIVE AIRWAY PRESSURE

BiPAP machines continuously deliver air, as do CPAP machines, but the inspiratory pressure can be adjusted separately from the expiratory pressure. These respiratory assist devices are usually prescribed for people with mild to moderate inspiratory muscle weakness and underventilation. It is recommended that the initial inspiratory pressure be set at 8-10 and gradually increased if necessary. The expiratory pressure on set-up should not be higher than 3-4, but may be adjusted lower. Like CPAP, BiPAP units are used with a face or nasal mask or nasal pillows, mainly at night. BiPAP units also compensate for mask leaks better than volume ventilators (*see following*).

There are many other bi-level positive airway pressure venti-

lators on the market, but the only one that can be truly called BiPAP® is registered to Respironics, Inc. (www.respironics.com).

VENTILATORS – VOLUME

Volume ventilators deliver a pre-set volume of air via nasal/face mask, nasal pillows, or tracheostomy tubes. These machines can deliver much more air than BiPAP units, and thus enable deeper breaths for improved breathing, coughing, and air stacking. Volume ventilators may be the most beneficial equipment for people with more severe respiratory muscle weakness, poor lung elasticity, and stiff chest walls. Volume ventilators, though larger, heavier, and more expensive than bi-level ventilators, are quieter and have more alarm features. The most commonly used volume ventilators in the USA are the LP6 Plus, LP10, and Achieva® series from Puritan Bennett (www.mallinckrodt.com), and the PLV®-100 and PLV®-102 from Respironics.

VENTILATORS – NEXT GENERATION

A new generation of ventilator technology has produced the LTV™ series from Pulmonetic Systems, Inc. (www.pulmonetic.com). This new ventilator is “compressorless” and is run by turbines. It is very small – about the size of a laptop computer – and lightweight, about 13 pounds, but more expensive than volume ventilators. Some models provide both pressure and volume modes, while the latest and simplest model (LTV800™) provides only volume ventilation.

CONTINUED ON PAGE 10

ASSISTED COUGHING

Most often the lungs of polio survivors are healthy. However, the inability to produce a good cough can lead to an increased incidence of respiratory tract infections and pneumonias. Thus, clearing secretions is extremely important. Manually assisted coughing involves

another person administering a thrust to the chest and abdomen of the individual immediately after that individual takes a big breath. Mechanically assisted coughing can be performed with the CoughAssist™ from J.H. Emerson Co. (www.coughassist.com) that applies positive pressure to provide a

deep breath in, then shifts rapidly to negative pressure to create a high flow out, as with a normal cough.

References

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- Hill, N.S. (2001). *Long-Term Mechanical Ventilation*. New York, NY: Marcel Dekker, Inc.

OXYGEN USE

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Are there circumstances when oxygen use might be appropriate for a person with respiratory muscle weakness due to neuromuscular or musculoskeletal disease?

There are at least six situations in which using supplemental oxygen is warranted.

FOR PEOPLE WHO ARE NOT USING ANY TYPE OF VENTILATOR:

1. Oxygen might be used if the individual does not want to use any type of assisted ventilation but wishes to have symptomatic relief without improving survival; this is often called palliative care.
2. Supplemental oxygen is justified if the arterial carbon dioxide (CO₂) is repeatedly not elevated, indicating that there is no hypoventilation, but the oxygen saturation (SaO₂) is 88% or lower and the arterial oxygen (PaO₂) is 55 mm Hg or less. Adjusting the added oxygen to achieve oxygen saturation of 90-95% should be on the advice of one's physician. He or she may prescribe it only at night or whenever the oxygen saturation is 88% or lower. Sometimes the cause for this is difficult to iden-

tify but can occur more often at higher altitudes, such as Denver or Mexico City, than at sea level. At higher altitudes, atmospheric pressure is reduced and this decreases the availability of oxygen.

FOR PEOPLE WHO ARE USING A VENTILATOR (NONINVASIVELY OR VIA TRACHEOSTOMY) TO SUCCESSFULLY TREAT HYPOVENTILATION RESULTING IN NORMAL ARTERIAL CO₂:

3. Oxygen might be needed if there is also a chronic lung or heart problem such as COPD, pulmonary fibrosis, or heart failure.
4. Oxygen might be needed if there is an acute lung problem, such as pneumonia, until this resolves.
5. Oxygen might be needed if one is living (or visiting) at higher altitudes. If the ventilator is adjusted properly so the arterial CO₂ is normal, but the high altitude causes the oxygen saturation to drop to 88% or lower and the arterial PaO₂ is 55 mm Hg or less, then supplemental oxygen is justified – again, adjusting the added oxygen to achieve an oxygen saturation of 90-95% following the advice of one's physician.

A variation of this, often at high altitudes, might be that the night-

time adjustment of the ventilator, despite all attempts, is not optimal (perhaps due to leaks), so the physician may suggest adding supplemental oxygen rather than considering tracheostomy.

6. In air travel, the airplane often flies at about 30,000 feet, with the cabin pressure adjusted to between 5,000 to 8,000 feet. This is equivalent to being at high altitude. The arterial oxygen would drop by at least 16 mm Hg, compared to the sea level value. A person who usually only uses night-time ventilation may need supplemental oxygen during air travel. A physician would need to advise, arrange this, and determine the oxygen flow (usually available either with 2 or 4 liters per minute). Some people need to be sure a small portable oxygen tank will be available in order to leave one's seat and use the toilet.

The general guideline is true – oxygen is not the right treatment for hypoventilation due to respiratory muscle weakness. In fact, using oxygen rather than assisted ventilation can result in serious complications. However, in the situations described above, using oxygen can be quite reasonable and important. Each individual needs to discuss this with a physician to get the best advice. ■

UPDATE: Outbreak of Poliomyelitis – Dominican Republic and Haiti, 2000-2001

From July 12, 2000, through September 18, 2001, a total of 21 cases of poliomyelitis (including two fatal cases) were reported from the Caribbean island of Hispaniola, divided between Haiti and the Dominican Republic.^{1,2}

This outbreak was the first in the Americas since 1991 and was associated with the circulation of a type 1 OPV-derived virus, having substitutions affecting 1.8% to 4.1% of nucleotides encoding the major capsid protein (VP1). The circulating vaccine-derived poliovirus associated with the outbreak recovered the capacity to cause paralytic disease and widespread person-to-person transmission and was biologically indistinguishable from type 1 wild poliovirus.

In response to the outbreak, health authorities in both coun-

tries conducted house-to-house vaccination with OPV. Three rounds of mass vaccination campaigns were conducted in the Dominican Republic in December 2000, and February and April 2001.

Haiti conducted two rounds of mass vaccination in February and March 2001. However, these campaigns were hampered by logistic difficulties and heavy rains and reached an estimated 40% of the 1.2 million children aged <5 years. During May-July 2001, a door-to-door and school-based campaign among all 2.3 million children aged <10 years was conducted sequentially in all of the country's departments. Preliminary results suggest that 2.4 million OPV doses were administered, and a second door-to-door campaign is underway.

Travelers to the Dominican Republic and Haiti who are not vaccinated adequately are at risk for polio. Travelers should have received poliovirus vaccination according to national vaccination policies³. ■

References

1. CDC. Outbreak of poliomyelitis – Dominican Republic and Haiti, 2000. *MMWR* 2000;49: 1094-103.
2. CDC. Outbreak of poliomyelitis – Dominican Republic and Haiti, 2000-2001. *MMWR* 2001;50:147-8.
3. CDC. Poliomyelitis prevention in the United States: updated recommendations of the Advisory Committee on Immunization Practices (ACIP). *MMWR* 2000;49 (no. RR-5).

EXCERPTED FROM: *Morbidity and Mortality Weekly Report*, October 5, 2001, Vol. 50, No. 39, pp. 855-856.

Acute Flaccid Paralysis Associated with Circulating Vaccine-Derived Poliovirus – Philippines, 2001

Three cases of acute flaccid paralysis (AFP) associated with circulating vaccine-derived poliovirus (cVDPV) isolates were reported in the Philippines during March 15–July 26, 2001.

Following cVDPV outbreaks in the Dominican Republic and Haiti (Hispaniola) during 2000-2001¹, the global polio laboratory network implemented additional testing requirements for all polioviruses under investigation, prospectively and retrospectively. Both an antigenic-based (ELISA) and a molecular-based test (probe hybridization) are used to determine whether a poliovirus is wild or derived from vaccine (i.e., intratypic differentiation [ITD]). Divergent ITD results (one test showing vaccine-derived and the

other wild-type virus) for any poliovirus isolate now require genomic sequencing of the suspect isolates. Retrospective testing of >2,000 vaccine-related isolates from AFP cases globally has revealed no additional cVDPVs, although testing results of other isolates in the laboratory network are pending. The cVDPVs from the Philippines were detected after the implementation of new testing requirements for prospective virus investigations.

Wild poliovirus was last reported in the Philippines in 1993², and national vaccination rounds were last conducted in the Philippines in 1997 followed by sub-national immunization days in 1998 and 1999. Coverage did not extend to the three provinces

now reporting cVDPV cases. Routine coverage with 3 OPV doses has been approximately 80% nationwide since the early 1990s; however, coverage gaps are likely, particularly in slum areas.

Travelers to the Philippines should ensure that they are vaccinated appropriately against polio according to national recommendations³. ■

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2. CDC. Progress toward poliomyelitis eradication – Western Pacific Region, January 1, 1996–September 27, 1997. *MMWR* 1997;46:1113-7.
3. CDC. Poliomyelitis prevention in the United States: updated recommendations of the Advisory Committee on Immunization Practices. *MMWR* 2000;49 (no. RR-5).

EXCERPTED FROM: *Morbidity and Mortality Weekly Report*, October 12, 2001, Vol. 50, No. 40, pp. 874-875.

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Capital Area Association of Polio Survivors
New Jersey Polio Network
Post-Polio Connection of San Mateo County
(given in memory of Sharilyn Kimura)
Polio/Post-Polio Resource Group
of Central Florida

Post-Polio Support Group of
the Lehigh Valley
Sacramento Post-Polio Support Group
Toledo Post-Polio Connection

Time Line for The GINI Research Fund Call for Proposals

Deadline for Phase 1 application
March 1, 2002

Deadline for Phase 2 application
(if invited by GINI)
May 15, 2002

Announcement of recipient
October 15, 2002

Payment of \$15,000
January 15, 2003

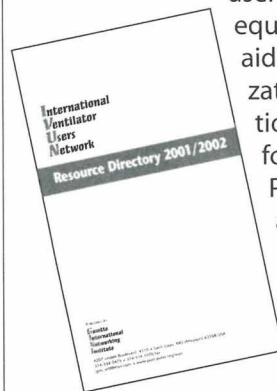
Payment of \$10,000
July 15, 2003

To receive a copy of the guidelines,
contact the GINI office or log on to
www.post-polio.org/gini/grf-1. ■

GINI Directories

The *IVUN (International Ventilator Users Network) Resource Directory 2001/2002*, published by GINI, has been updated and is "in the mail." The 26-page compilation lists health professionals, ventilator

users, ventilator equipment and aids, and organizations, associations, and foundations. Printed copies are available for \$5 (USA);



\$6 (Canada/Mexico & Overseas surface); \$7 (Overseas air) or for continual updates, visit www.post-polio.org/ivun.

The first week in January is the time we confirm and update the information for International Polio Network's *Post-Polio Directory – 2002*. Published since 1985, it lists post-polio clinics, with select details; health professionals and their specific medical specialty; and support groups with their general meeting information.

Watch for your listing via email, fax, or postal service after the first of the year, and return it immediately. Many people use the print copy and the online version and we need your assistance to make it as accurate and complete as possible. Printed copies are available for \$5 (USA); \$6 (Canada/Mexico & Overseas surface); \$7 (Overseas air) or for continual updates, visit www.post-polio.org/ipn. ■

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