

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

CONTINUED ON PAGE 2

Inside this issue

Cardiovascular Issues of Polio Survivors	7
Addendum to Breathing Problems of Polio Survivors ...	9

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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CONTINUED ON PAGE 4

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). Loudon 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 Loudon 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. ■

References

- Embracing Our Selves: The Voice Dialogue Manual* by Hal Stone, PhD, and Sidra Stone, PhD, Nataraj Publishing (1989).
- "Permission Giving: Emotional Adjustment and the Late Effects of Polio" by Karen Kennedy, MSW, PoliOntario, Ontario March of Dimes (January, 1998).
- Creating* by Robert Fritz, Fawcett Columbine (1991).
- Sex and Human Loving* by William H. Masters, Virginia E. Johnson, & Robert C. Kolodny, Little, Brown and Company (1986).
- Women's Bodies, Women's Wisdom* by Christiane Northrup, MD, Bantam Books (1998).
- "Ability and Perceived Difficulty in Daily Activities in People with Poliomyelitis Sequelae" by A.L. Thoren-Jonsson and G. Grimby, *Journal of Rehabilitation Medicine* (January, 2001).
- "Early Memories of Having Polio: Survivors' Memories Versus the Official Myths" by Mary T. Westbrook, PhD. Paper presented at the First Australian International Post-Polio Conference (1996).
- The Comfort Queen's Guide to Life* by Jennifer Loudon, Harmony Books (2000).