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Polio Did Not Beat Us—Colorado Lieutenant Governor Barbara O’Brien’s Story

By Margaret Hinman

“There’s a section from John Milton in the poem Paradise Lost that I think of probably once a week that says, ‘you can make a heaven of hell or a hell of heaven.’ Everything depends on your attitude and how you look at things. I know that our experience was not typical. Some of the other people in town who had polio were not as happy as we were. In our family, from my Mom and Dad on down, we were going to live life to the fullest and we weren’t going to feel sorry for ourselves. We were responsible for our lives. Now, that attitude was possible because we had a lot of help from friends and relatives in town. We were open to receiving help and with giving help to others. Just because Mom had polio didn’t change our sense of the give and take of a community. So that’s how we lived.” This is how Colorado Lieutenant Governor Barbara O’Brien describes growing up with her mother who was a polio survivor.

In 1955, when Barbara was five years old and her mother was twenty-eight years old, her mother, Virgene Jack, came down with polio which paralyzed her from below the neck and which confined her to a wheel chair and a respirator for the rest of her life. However, this physical setback did not stop her from raising a family of four children and from being a vital and inspirational member of her community.

The Lieutenant Governor has vague memories of the onset of her mother’s polio. She recalls her mother being in a darkened bedroom with the shades pulled and asking her to do something for her. What? She doesn’t remember.

(Continued on page 9)
In My Opinion. . .

One of the gifts my parents gave me was keeping from me their concerns about my polio. As a result, I grew up choosing what I could do or not to do and my dreams and expectations were not limited by their fears. Later, as an adult in talking with my mother, I learned how much they worried about me. By then, my “can do” attitude about life had been formed.

As I have aged, however, I have learned to exercise more physical caution than I did when I was younger. So, this exceptionally cold, snowy Colorado winter had me watching the weather forecasts, stocking up on needed supplies before bad weather hit, and spending my time reading good books, visiting via the phone and keeping snug and warm at home.

Linda Bieniek’s article discusses just those issues, namely, being aware of and caring for ourselves. Margaret E. Backman’s book, The Post-Polio Experience, reviewed in this issue, explores the emotional components of our experiences over time and in relation to others. And By the Way . . . shares how other polio survivors emotionally care for themselves.

Colorado Lieutenant Governor Barbara O’Brien’s story is an example of how her family lived with her mother’s polio. It is truly inspirational.

When I interviewed her, not only was the Lieutenant Governor gracious and open, she was generous with her time, at a time when she had just taken on her new job. Her staff, especially Eileen Sullivan, her personal assistant, was most helpful in answering my questions, arranging the interview, and facilitating my access to the State Capitol parking lot and to the handicapped access into the building, as well as cueing me in on the protocol of interviewing the Lieutenant Governor.

On a final note, Barbara O’Brien’s insights and her perceptions about her family have led me to wonder about how my children and my siblings think about my polio, something we have never really shared. I need to put this on my “to do” list. Perhaps I could learn something about myself from that experience.

Margaret C. Hinman

Donated quilt to be sold--Marilyn Baham, a post-polio survivor, has donated a quilt to our post-polio organization. The quilt is Emma’s Courtyard by Jo Morton and is a Prairie Hands Pattern. Marilyn hand cut and machine pieced the quilt and hand appliquéd the appliquéd parts. The 90” X 90” quilt in tans, reds and greens was machine quilted by Lori Housel. The quilt was started in a block of the month class at Fabric Expressions and was purchased as a kit. For information as to the sale of the quilt, contact Marlene Harmon at 303-689-7669.
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 strengthening 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 “Caretaker 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 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 (Continued on next page)
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 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 & 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 “permissive-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:
Women’s Bodies, Women’s Wisdom by Christiane Northrup, MD, Bantam Books (1998).
“Early Memories of Having Polio: Survivors’ Memories Versus the Official Myths” by Mary T. Westbrook, Ph.D.

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The Post-Polio Experience by Margaret E. Backman, Ph.D.


We feel that this is a book that polio survivors will want to read, particularly because so few books have been written on psychological insights and coping strategies for those who have had polio and for their families.

The author did not have polio; but for the past 20 years she has been treating polio survivors concerning psychological reactions to their earlier experiences and to their current struggles with the late effects of polio. Dr. Backman writes with clarity and simplicity and invites (Continued on next page)
Experience—(Continued)

the reader to put himself into situations that most polio survivors have experienced. She examines cases of people who have had polio either as a child or later, and have wondered why they were experiencing flashbacks to those earlier years, particularly if they have been diagnosed with Post-Polio Syndrome.

The chapter on personal relationships--those dealing with parents, children, spouses and friends--was particularly meaningful and applicable to most of us survivors. Also the section relating to patient-doctor relationships and to helping your doctor understand PPS was highly relevant and useful.

Dr. Backman conducted a small study in which she considered the feelings and views of caregivers. The study revealed that their main complaint was “feeling low.” Their not being able to do some of the activities they had done together before and missing doing things on their own were revealed in the study. Those with PPS compounded their relationships. Not being able to care for themselves as they had previously brought on feelings of guilt; the other spouses felt the same because they could not help their polio partners more. The author stressed the balancing of needs and interests and the importance of communicating each other’s concerns. Some guidelines for improving interpersonal relationships make the book well worth reading.

And By the Way . . .

Some members of the post-polio community share the following insights into their own self-awareness and self-acceptance:

- By getting a new brace that better fit my needs I now feel like a whole person. I walk without feeling like people are staring at me, have improved my appearance and my gait, and I can prevent further physical complications.
- As my post-polio physical condition deteriorated, I learned to accept the changes in my body and I changed my career from farming to the academic world.
- In recognizing the harmful implications of a relationship, I got out of the relationship.
- When I was 30 years old and unmarried and wanted children, I considered single parent adoption.
- As my mobility has become more limited, I now keep social by letter writing and phone calling instead of going out.

And they share examples of self-appreciation and self-nurturing by:

- Taking joy in following a passion, doing artwork and hobbies that allow use of my hands rather than using legs that don’t work so well any more.
- Using more mental skills than physical skill such as reading and writing.
- Acknowledging ones health and abilities.
- Being one’s own advocate with the medical profession.
- Listening to trusted specialists.
• Asking for help from the physically able.
• Pacing oneself.
• Budgeting money to go to the pool for exercise and therapy.
• Putting oneself first now that the children are grown.
• Hiring someone to do housecleaning.
• Moving to a one-level home with no steps.
• Getting a stair glide to ease going to the basement.
• Accepting family support, both emotional and physical.
• Attending a support group.
• Keeping up to date with the issues related to polio and post-polio syndrome.

Polio did not beat us—(From page 1)

Her mother’s doctor knew immediately that she had polio. With the help of the railroad company which diverted cars to the small farming town of Brawley, California, she was transported six hours north to Rancho Los Amigos in Los Angeles. The doctor rode with her, keeping her alive by clearing her lungs so she could breathe until she was placed in an iron lung at the hospital. There were two other seriously ill polio patients from the town on the same train.

“People did heroic things to deal with the outbreak of polio.” We had “that sense of ‘we’re all in this together. . .’ The railroad company did not have to do that.” The doctor could have put her on the train and let her travel alone. It’s “just what people would do,” she recalls, “and they would do their best.”

After her mother was hospitalized, Barbara, her younger brother, age two, and her father moved in with her paternal grandparents who also lived in town. And, for the next two years, while her mother was at Rancho Los Amigos, they went to see her. Every weekend, on Friday evening after work, her father, who was a farmer, would take Barbara, and sometimes her brother, and travel to Los Angeles, where they would spend the night with her maternal grandparents and her baby sister, who was six months old when her mother got polio. On Saturday and Sunday, they would stay with her mother at the hospital, returning home Sunday evening so that her father could go back to work on Monday and she could go to school.

When her mother returned home, dependent on a respirator and confined to a wheel chair, she needed constant care. As they lived in a small farming community, there were always people who needed steady work and who would help care for her. There were also people who were willing to help out by bringing food to the family or doing errands for them, everything from taking a child to get new shoes to picking up groceries when they were at the store.

One of the lessons Barbara learned from that experience was that, on some level, she was fundamentally on her own. But, at the same time “if you let people find ways to help, they will want to help and they will help. And, you can make those opportunities happen. . . We weren’t shy about asking for help. We knew it was up to us to let people know if we needed something. They always responded.”

Barbara attributes part of that attitude to a wonderful nurse at Rancho Los Amigos who advised her mother to “just think of other people being your arms and legs, and that

(Continued on next page)
you’re in charge of the action,” even though “it might not be your own arms that are doing the work.” The nurse gave her the idea that she was an orchestra conductor, so that even though the family sometimes needed outside help, it was their agenda.

As a result, Barbara had huge responsibilities, starting at a very young age. Although her Mom’s “brain was great,” and “she was the idea person,” she could not do the physical activities of parenting. As the oldest child, Barbara became the person who cared for the younger children, doing everything from seeing that they were dressed and doing their chores to being the person who kept the other kids in line for her mother. As a result she got the reputation in the family for being the “Marine sergeant.”

“It’s kind of the roll of the dice where you are when something like that hits your family. I was lucky that I was older.” The responsibility was good for her. “It made me be someone who always wants responsibility. That’s what feels comfortable to me.”

As she grew into adolescence, Barbara wanted to be like other kids, so at times, even though she liked the responsibility she also would resent it, especially on Sundays when she had to care for her mother, while other kids could go and do what they pleased. She describes that attitude as a “kid thing” that she outgrew in time.

Virgene and Neal Jack set the expectations for how their family was going to function. Barbara’s dad told her that “once in the early years of the polio, he just decided that HE wasn’t going to live like an invalid. Therefore, the family had to get out and do things and not let the physical labor of including her mother, her wheelchair and her respirator get in the way. He never shied away from the amount of work it took to get her (mother) someplace. We did amazing things.” The family would have dinner parties with the children doing the cooking. They went to the mountains to cut their own Christmas trees. Her mother attended most of the children’s school activities. Her parents went on a tour in Europe.

Needless to say, such activities took great planning, making sure someone had the spare battery for the respirator, the backup respirator, and that the wheel chair was securely fastened to the car, all of this in the days before vans were available for persons with disabilities.

When it was time for Barbara and the other children to leave home for college, it was considered as a normal part of growing up. Her parents never made polio “a burden. They always had great dreams for their kids. They would be heart broken if they thought Mom’s physical disability stunted their children’s lives, so they encouraged us to leave the nest and go fly our wings.”

That perspective held by her parents had a lasting impact on her own attitude. “Sometimes, denial is a great coping mechanism, and so we just ignored anything that got in the way of our family life, and to my husband’s particular dismay at times, I have carried this belief that any challenge can be met into my whole life . . . We acted as if it was perfectly normal to live as we did.”

Her mother always wanted a fourth child. And because they had a “perfectly normal family,” polio did not get in the way of that dream, either. As a precaution, her mother returned to Rancho Los Amigos for the delivery of her (Continued on next page)
Polio did not beat us—(Continued)

youngest son. As doctors feared giving her any anesthetic because of her compromised lungs, she delivered her son while instructing the nurses and doctors as to how much to adjust the oxygen levels of the respirator, as well as guiding her own labor.

The “normal family” attitude carried on to her grandchildren who don’t think about her polio when they think of her. They remember the great food that she provided and playing cards with her, and riding horses on the farm, and touring the fields with their grandfather. Riding around in the electric wheelchair was just part of the fun!

The family dealt with the polio by telling funny stories about their experiences, stories that people outside the family might find not so funny, like the time her uncle accidentally tipped over the wheel chair with her mother in it or the time that her father accidentally broke her mother’s leg when trying to get her wheel chair over a curb or the time that her mother, just learning how to use an electric wheel chair, pinned a hotel bell boy to the back of an elevator.

There was one area of their lives where her polio experience made her very vigilant. When it came to getting the newly discovered polio vaccines, Virgene made sure that her children were immunized. Barbara recalls that she had the series of three doses of the Sabin vaccines four times, every time there was an immunization clinic in town.

Virgene’s contribution to her community existed on several levels. Her home was always open to not only the women who cared for her and to her friends, but to their children. When she would see that a child had learning or other problems, she became the advocate for that child, making sure that the child was mainstreamed in the school and not isolated in a special classroom. This example influenced the Lieutenant Governor in her own work in advocacy. She focuses particularly on children’s issues, mainly related to health and education. Not only did she do this as the former president of the Colorado Children’s Campaign and also this is her focus in her position as the Lieutenant Governor.

Virgene’s home was a place where friends would come and discuss ideas, politics and literature, a place where Barbara learned to love the interactions and the ideas that set her on the road to the careers she has had since leaving home.

When Virgene died from heart failure ten years ago at the age of 70, many members of the community expressed how her mother helped them with their own personal problems. One friend said at her funeral, “Looking back, why would you go to the most disabled, most physically fragile person in town with your problems? Because she had the greatest heart and she wasn’t thinking about her own problems. Sitting there, looking at her, and hearing her advice, you could put your own problems in perspective.”

Putting her own experience in perspective, Barbara O’Brien, the Lieutenant Governor of Colorado, summarizes by saying, “The whole family history of dealing with the polio is that it did not beat us, so we were not going to give an inch. When you think about my Mom, you don’t think about her disability. I think that’s what every person with a physical problem would hope for. It’s the mind and the heart that count.”
This Is Your Newsletter-----

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at post-poliocolo@comcast.net or write to us:

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Please include your name, address, phone number and email address in any correspondence.

Our next issue will focus on diet and nutrition. We need suggestions from you on eating habits that have helped you either maintain or lose weight as a polio survivor for our “And By the Way...” column.

Disclaimer

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval by the Easter Seals Society or the Post-Polio Advisory Council. If you have personal medical problems, consult your own physician.