

# POLIO NETWORK NEWS

## IMPROVING QUALITY OF LIFE: HEALING POLIO MEMORIES

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**AUTHORS' NOTE:** *People who live with the residual effects of polio experience varying levels of fatigue, weakness, and pain. For many, managing these challenges involves re-organizing their lifestyles to adjust to changes in health. Individuals unable to make the necessary lifestyle adjustments usually encounter difficulties in their jobs, recreational activities, daily routines, and/or relationships. In addition, some may experience intense reactions to these difficulties, causing upheaval in their lives and those of loved ones.*

*In this article, we invite polio survivors to consider how polio memories of various types can affect present day responses to changing health needs. We focus on the value of resolving polio memories that may consciously or unconsciously interfere with survivors' ability to make positive life choices.*

*If you find this article unsettling, we encourage you to read it in sections or with the support of a counselor, psychotherapist, or trusted friend.*

While it is common for individuals to experience frustration or discouragement with the loss of physical function, unresolved memories from the original polio experience may amplify the intensity of their emotional responses. Some individuals live with traumatic memories of physical, emotional, or psychological injuries that have impaired their view of the world (Hale, 1996). Others may not have specific polio memories or traumas, but acknowledge the ongoing stress of coping with disability as a child, and now as an adult.

### PROTECTIVE COPING PATTERNS

Over the past decade, health care professionals have studied the coping patterns of individuals with chronic pain and the fears that block their taking steps to manage it (Asmundson, 1999). Such studies may shed light on the coping patterns of polio survivors. Though they report symptoms related to the late

effects of polio, many are reluctant to consult specialists. A post-polio specific study reports that even when they do consult physicians, 50% of surveyed survivors had complied with their doctor's recommendations to use assistive devices (Thoren-Jonsson & Grimby, 2001).

The reasons for avoidance vary and they are important to understand. Some survivors experience anxiety as they approach a medical facility or attempt to wear a nasal mask. Some individuals are unaware of the cause for their feelings of inaction; others are reluctant even to discuss their reactions.

Survivors may cope with past polio experiences by not thinking about that period of their life. Blocking out memories is a common way of protecting against uncomfortable feelings such as sadness, anger, or disappointment. Survivors may unconsciously avoid certain

thoughts, feelings, people, or places through distractions such as:

- Overworking or taking care of others to the detriment of their own health;
- Overeating or unhealthy eating;
- Depending on or overusing alcohol or prescription or non-prescription drugs to reduce pain, relieve anxiety, or to sleep;
- Excessively watching television, spending time on the computer, sleeping, reading, or talking;
- Neglecting responsibilities (e.g., routine health care, medical claims) because these may trigger unconscious painful reactions.

Schiraldi points out that continually blocking out memories requires enormous energy that can leave one fatigued and irritable (Schiraldi, 2000). He adds, "trying to avoid or forget traumatic memories does nothing to neutralize them. In fact, the more we fear and flee them, the more negative energy we give them (Schiraldi, 2000)."

The energy spent avoiding uncomfortable thoughts and feelings

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can strain a person's physiology and immune system, increasing fatigue and susceptibility to other illnesses.

Another reason survivors may avoid questioning the effects of early polio experiences is that they may feel protective of the loved ones who sacrificed a great deal to care for them. The intent of reviewing polio memories is not to criticize or blame others, but to enlighten survivors about how their polio histories affect their present day choices.

Schiraldi says that traumatic memories may continue to pursue us much like a little barking dog chases a person until that person stops, turns, and faces it. "Facing the dog" is often the first step in finding healthier ways to deal with intense reactions and uncomfortable feelings.

"I was in my late 30's when my leg muscles began to weaken and I needed to wear a leg brace again. I remembered that as a child, I disliked wearing a brace because the only shoes that fit it were 'brown boy's shoes.'

"As an adult, I was surprised that I would not wear my new brace in professional and social settings. I was anxious about how management would react to my physical weakness, and how that might affect my job during a period of significant staff reductions. As a single woman, I feared further rejection from men since my disabilities already appeared to be an obstacle. Nevertheless, I was disturbed about my reluctance to wear a brace when it protected me from tripping and helped to conserve my energy. As an advocate for people with disabilities, I was ashamed that I could not easily accept using equipment that identified me more prominently as a person with a disability.

"In psychotherapy, I worked through my grief about losing muscle strength and feelings about cultural attitudes that impacted my self-esteem. I learned how to forgive myself for fearing the reactions of others. I also uncovered valuable memories. I had not realized how hurt I felt when peers avoided or excluded me."

This example illustrates how past experiences contributed to the survivor's feelings of anxiety and shame when she faced the current day decision about wearing a brace.

It also highlights the benefits of personal permission giving – allowing oneself to acknowledge reality, accept one's needs, and take the steps needed to initiate purposeful changes. For polio survivors, personal permission giving is key to making emotionally healthy changes related to the late effects of polio or other chronic health conditions (Kennedy, 1998).

While the idea of permission giving may sound obvious, it acknowledges the complex dilemmas survivors may face in order to:

- accept the reality of their physical condition;
- acknowledge feelings and express them in healthy ways;
- adapt lifestyles to match their abilities and needs;
- use assistive devices and adaptive equipment;
- seek emotional and practical support; and
- consult effective treatment professionals.

Some survivors have benefited from using psychotherapy to explore the impact of their early polio memories.

"I remember painful experiences during puberty that would further explain my 'shame anxiety' (Bieniek, 2001). I realized that when my schoolmates went to the Boys and Girls Club, I felt excluded.

"In the Masters and Johnson's Trauma Program, I learned to value such memories as 'gifts.' Although painful, they explained reasons for my reactions to current day situations and provided me with hope of resolving social inhibitions that still limited my ability to experience deep intimacy (Westbrook, 1996). Resolving other memories has increased my ability to breathe more deeply, concentrate, exercise, and assert myself in social situations."

In her last two explanations, the survivor illustrates "facing the dog." She faced her reactions to present day dilemmas, and the limiting effects from adolescent social situations.

## MEMORIES OF HAVING POLIO

Experiences of having had polio differ. Many survivors experienced supportive responses from their families, medical communities, and school systems. For some, a sense of community developed in hospital units, leading to life-long friendships. For others, new bonds of support have developed over the last 20 years through post-polio support groups and related organizations.

While many people had supportive experiences, others encountered negative situations including bullying, emotional alienation, humiliation, or even physical abuse.

Because polio is a contagious disease, children were usually hospitalized in isolation, some in iron lungs. Often, they endured lengthy hospitalizations



and subsequent surgeries involving further separations from their families.

Until the early 1960s, little was known about the impact of these experiences on child development. The medical field functioned with an authoritarian approach that did not always take into account the emotional and psychological needs of the child. The system had not yet learned about the important support role that family members could play in the hospitalization and medical rehabilitation of young children.

Today, we know that when children are separated from their primary caretakers, they are at risk of developing attachment difficulties that may affect their ability to maintain healthy relationships in adulthood. Some of the factors that may determine the impact of a separation are the age of the child, what is communicated at the time, and the quality of support in the parents' absence (Lieberman, 1987). Attachment difficulties in adulthood relate to problems forming and maintaining long-term intimate relationships as in the following example.

A survivor reported that, as a child, she was hospitalized for polio far away from home. Her parents were unable to travel the distance, so she rarely saw them. When she would cry for her parents, the staff labeled her crying as being "weak." As an adult, she fought similar feelings of intense loneliness. Through psychotherapy, she identified the impact of the staff's mistreatment and the separation from her parents on her present difficulties of consulting health professionals,

expressing emotions, and developing intimate relationships.

Painful medical procedures, unsuccessful surgeries, discrimination, abuse, and the loss of friends who died from polio are all examples of disturbing experiences that may, consciously or unconsciously, deter individuals from pursuing medical and emotional assistance.

Many people have forgotten much of their polio experience; some were too young to remember. When they understand the possible reasons for feeling anxious or avoidant, survivors may find it easier to seek the assistance they need. The following questions may help survivors remember how they perceived what happened to them.

- How did you and your family respond to your having polio?
- Was it openly acknowledged, a "family secret," or avoided?
- How did you and others respond to your physical pain?
- How did others react towards you after your initial recovery?
- Did any event leave you feeling disappointed or abandoned by family, friends, medical professionals, educators, or God?

As individuals deal with the late effects of polio, they may encounter smells, sights, tastes, sounds, or experiences that cause emotional reactions, reminding them of when they had polio. Memories are often repressed until an unconscious trigger takes the survivor back in time. Triggers are cues coming from either the external environment or internal unconscious reactions related to past trauma (Napier, 1993).

For example, an adult survivor recently reacted with pleasure to the smell of the plaster when having a leg brace fitted. It reminded her of when she was eight years old and was able to walk with a leg brace after a successful surgery. For her, the smell of plaster represented a positive association.

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## **International Polio Network**

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Triggers, however, are often unconscious cues that can cause intense negative reactions out of proportion to the current reality. The association may be obvious or subtle (Schiraldi, 2000). For example, grief triggers often relate to dates, seasons, holidays, memories relating to the age of a child in one's life, rituals, or music (Dayton, 1997). As the following example illustrates, a trigger may take the form of a bodily reaction, even though the person may not understand the reason (Napier, 1993).

"As an adult, when I would get into a swimming pool or lake, I would tense up, get short of breath, and, at times, have an anxiety attack. In therapy, I began to look at early polio memories and realized that my intense reaction stemmed from a hospital experience. When I was five years old, my polio treatment involved hot baths. One evening, a nurse left me alone in a bathtub, suspended on a net with water up to my chin. I was unable to move and had no way to call for the nurse, who had closed the door. I remember praying that I would not drown.

"Once I worked through the feelings and beliefs associated with that terrifying experience, I was able to get into a pool of water and breathe freely. Since then, exercising in warm water has become my most valuable form of exercise and a great source of comfort and energy."

Triggers are opportunities for survivors to understand the sources of their internal reactions, especially those that create obstacles in their health and relationships. However, even when triggers are not completely resolved, recognizing their sources can help in identifying ways to protect one's vulnerabilities.

## EFFECTS OF TRAUMA

Distressing events or experiences, whether subtle (e.g., a child's interpretation of a parent's facial expression) or blatant (e.g., terrorism that kills thousands), can have traumatic effects when they threaten basic needs to be safe, to trust, to feel some control over one's life, to be valued, and to feel close to others (Saakvitne & Pearlman, 1996).

People react differently to threatening events or experiences. For some individuals, their polio experiences may feel as traumatic as living through a war or natural disaster. The aftereffects can result in clinical conditions. On a continuum, the effects can range from mild anxiety and/or depressive symptoms to panic attacks, obsessive/compulsive behaviors, chronic and/or severe depression, post-traumatic stress disorder, and dissociation. When reactions are severe they can result in feelings of helplessness or being stuck, and an inability to function in certain areas of life.

Post-Traumatic Stress Disorder (PTSD) is a medical condition that can arise immediately after a trauma or perceived threat, or be triggered many years later. PTSD frequently takes the form of intrusive thoughts or memories (e.g., nightmares, recurrent dreams, flashbacks), hypervigilance, isolation and withdrawal, and numbing of feelings (DSM-IV, 1994).

A common example of dissociation is how children block out distressing events from their conscious minds in order to cope. For survivors, dissociation often takes the form of blocking physical pain to avoid overwhelming

feelings such as helplessness and hopelessness.

Stephen Levine recognizes that "... Accidents, falls, illnesses, and surgeries that the body unconsciously perceives as threatening are often not consciously regarded as outside the range of usual experience. However, they are often traumatizing (Levine, 1997)."

In working with a therapy client who suffered from panic attacks, Levine discovered that the cause was a disturbing childhood memory. The experience resurfaced in the form of intense physical and emotional reactions to being in a crowded room while taking a graduate exam.

"When she was three, she was strapped to an operating table for a tonsillectomy ... Unable to move, feeling suffocated (common reactions to ether), she had frightening hallucinations. This early experience had a deep impact on her ... (Levine, 1997)."

Over time, in her therapy sessions, Levine helped this woman to remember and discover the reason for her panic attacks. Gradually, she noticed her anxiety decrease and she was able to learn constructive ways to manage what remained of it.

Each individual will respond uniquely to a traumatic experience based on factors such as personality, self-esteem, level of emotional support, and past experiences of trauma. For this reason, responses to threatening experiences or the perception of a loss of safety can differ, even to the same event. While learning from others' experiences is useful, judging and comparing oneself with others can undermine self-esteem and relationships.



Individuals need to approach themselves compassionately in order to resolve traumatic memories effectively. The very fact that individuals have survived having had polio reflects the depth of their inner strength.

### **MAKING SENSE OF TRAUMA**

Earlier interpretations of events, especially those formulated during childhood, can result in traumatic perceptions. When the facts are explored, some individuals have discovered that their perception of an experience was different from the original intent, as in the following example.

A six-year-old boy who was hospitalized for one year due to polio perceived that his mother had abandoned him and carried this sense of abandonment with him into his adult life. In therapy as an adult, he learned that at the time of his polio his father was serving in the military overseas. His young mother lived six hours from the hospital without a vehicle and was parenting two small children with no family support.

He eventually realized that his mother had, in fact, done the best she could during that difficult time. Through counseling, he was able, over time, to express and process his feelings of grief, hurt, and abandonment. This allowed him to connect with the truth of the original situation and to begin to build trust in intimate relationships.

While previous examples have revealed actual mistreatment and incompetence that have caused great distress to survivors, the above situation points out how even a perceived threat or loss can have a traumatic impact.

"Children can be traumatized by events that might not be overwhelming to an adult because children's minds, especially in the very young, lack the capability to process the experiences. Many of our traumas remain hidden from us until our minds or bodies give us hints that something is wrong. Scientists have found that we not only store traumatic memories in our minds, but in our bodies as well. As adults, people may have totally forgotten the trauma they experienced as children, and start therapy because they are having nightmares or flashbacks of events they do not recall, or because they are feeling depressed (Finney, 1995)."

From these examples, we can see that even well-intentioned actions can result in harmful long-term consequences. The

goal of exploring past memories is to gain insights that lead to concrete solutions for resolving complex difficulties in life.

### **RECOGNIZING THE NEED TO SEEK PROFESSIONAL ASSISTANCE**

Psychologist Gary Schoener, an international expert on professional boundaries, recommends the use of behavioral health professionals just as we consult specialists in other fields. Schoener suggests seeking professional assistance from a competent, ethical therapist when:

- facing personal difficulties that appear unresolvable;
- feeling emotionally stuck over a long period of time;
- reacting intensely and out of proportion to the reality of present day situations;

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**LINDA L. BIENIEK, CEAP**, is a Certified Employee Assistance Professional, whose knowledge of trauma issues stems from over 15 years of professional training as well as from participating in Master and Johnson's Trauma Programs. As a CEAP, she assesses, counsels, and refers clients with a wide-range of conditions including depression, post-traumatic stress, dissociation, and chemical dependency.

Bieniek previously worked for a major corporation, managing its Employee Assistance Program and often negotiating accommodations for employees with and without disabilities. Bieniek is a polio survivor, ventilator user, and disability advocate who serves on GINI's Board of Directors.

**KAREN KENNEDY, MSW, RSW**, is a registered medical social worker who, for the past nine years, has worked in the Post-Polio Clinic at West Park Healthcare Centre in Toronto, Ontario. West Park Healthcare Centre is a regional rehabilitation centre and offers rehabilitation, complex continuing care and long-term care services.

As a member of the Post-Polio Clinic team, Kennedy provides assessment, counseling, education, management recommendations, and referral for individuals and families of those who have previously contracted poliomyelitis. Kennedy holds a Masters of Social Work degree from the University of Toronto.

*The authors recently co-presented at the Ontario March of Dimes Post-Polio Wellness Retreat.*



- having difficulties making changes that would improve an aspect of life such as physical or emotional health, cognitive abilities, relationships, or sexuality;
- becoming aware of unhealthy coping patterns such as compulsive eating, shopping, smoking, gambling, cybersex, or depending on alcohol or medications to relax or to sleep;
- receiving feedback from others that reveals difficulties adjusting to health changes.

Consulting professionals is especially important when a person recognizes any of the following signals:

- increased pain, weakness, and fatigue due to increasing distress (Westbrook, 2000);
- persistent feelings of frustration or irritability;
- isolation and withdrawal;
- loss of interest in pleasurable activities (including sexual intimacy)
- increased difficulty functioning in the workplace;
- feelings of worthlessness or hopelessness (Bieniek, 1999);
- overwhelming feelings of anger, sadness, fear, despair, shame, or guilt;
- nightmares or recurrent distressing dreams;
- anxieties, panic, phobias, and fear responses that interfere with functioning;
- acting or feeling as if a previous disturbing event were recurring (DSM-IV, 1994);
- persistent avoidance of thoughts, feelings, or topics that remind you of a distressing time in your life.

Always obtain regular medical evaluations to rule out the possibility that other medical conditions are causing your symptoms.

### TAKING STOCK

Survivors may want to ask people they trust for their perceptions with questions like these:

- How do you think I am functioning and adapting to my changing physical needs?
- How would you describe my ability to accept assistance from others?
- How do you think I respond to my physician's recommendations?

One essential and healing component of revisiting past memories is that it provides survivors with an opportunity to tell their story, sometimes for the first time.

In *Healing the Blues*, polio survivor Dorothea Nudelman and her therapist described her struggle for wholeness. Dorothea wrote:

"We often resist the pure telling of our story. We want to tell the story as we think it should be and edit out the parts that make us uncomfortable. But this doesn't work. We must be honest and complete. We must acknowledge even the parts we don't like. In fact, where we have the most resistance is exactly where special attention is needed. Our resistance signals where we may discover the most important things about ourselves. There is no part of ourselves we can afford to discard. Every part is crucial for wholeness and has value to us. When we review our life thoroughly, we return to the present

with a renewed sense of meaning and possibility. We catch up with time, as it were, by finishing what is past (Nudelman & Willingham, 1994)."

**AUTHORS' END NOTE:** We have focused on how exploring polio memories may reveal reasons that survivors have avoided seeking help or following up with medical recommendations.

We encourage readers to use the aspects of this article that apply to their lives. We believe that understanding the effects of early experiences can provide insight that offers hope of making positive changes in current life situations. These changes, in turn, may lead to reductions in pain, healthier personal relationships, less stress, and greater ability to experience comfort and joy.

A future *Polio Network News* article will provide suggestions for seeking and evaluating professional assistance to look at and learn from polio experiences. ■

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## CONFERENCE ON RETHINKING CARE

Joan L. Headley, MS, Executive Director, International Polio Network

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In April 2001, I spent three days in Oslo, Norway, at a conference sponsored by the World Health Organization's Disability and Rehabilitation Team. The Norwegian Ministries of Health and Social Affairs, along with the Norwegian State Council on Disability, the Norwegian Association of the Disabled, and the Norwegian Federation of Disabled People, organized the event.

I struggled with how to report on the experience, and the job was not made easier when I recently received the final report (authored by Professor Colin Barnes, University of Leeds, United Kingdom) of 30 pages with six appendices. I decided to explain why we were there, to extract a few comments in an attempt to portray discussions, and to reflect.

### Why were we there?

The conference – "Rethinking Care from the Perspective of Disabled People" – was convened in recognition of the fact "... that health and disability can no longer be understood in purely medical terms and that a more holistic approach is required." This universal challenge to orthodox thinking about medical, rehabilitative, and support services has its roots in the independent living and self-advocacy movements that emerged in the late 1960s. People with disabilities "... began to demand not only greater participation in the organization and running of disability services, but also to develop their own."

The challenge before the group of 100 from all over the world, both disabled and nondisabled, was to rethink how care for

people with disabilities should be provided.

The background papers stated that the terminology of the conference would be of the social model of disability. In the model, impairment refers to an individual's biological condition. Disability denotes the collective economic, political, cultural, and social disadvantages encountered by people with impairments. In other words, going in we were dumping the "... unhelpful assumption that the only way to overcome the disadvantage of disabled people is to change the individual and not society."

### Excerpts from individual presentations

"The concept of care is changing, from being a matter of charity to one of human rights and equal opportunities for all."

– Guri Ingebrigtsen, Norwegian Minister of Social Affairs

"The magnitude of chronic conditions and injuries has increased in all regions of the world, but at the same time, the old problems of poverty, malnutrition, and wars continue to be an important cause of morbidity and mortality."

– Dr. Ala Alwan, Director, Management of Noncommunicable Diseases, WHO

"The beginning for every disabled person is very much the same. It starts with the emotional shock, together with news about 'the disability.' The way this new life starts will affect the future. The notice may be given by an insensitive professional who is discriminative or may be

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