Do We? How Can We Improve? Annie Barber, R.N., Charleston, IL Linda Bieniek, CEAP (retired), La Grange, IL

Why is **communicating effectively** especially important for polio survivors and family members? Because as human beings, we each need acceptance, respect, love, and support to thrive. Communicating provides us with opportunities to express and accept these invaluable gifts. Most importantly, our connections can support and energize us to enjoy life's beauty during both good and difficult times.

When polio survivors experience losses of physical abilities, lifestyles, careers, connections, and financial resources, these changes often impact family members' lives as well. Each of us needs to communicate honestly, clearly, and sensitively about our needs and desires to make sure that our relationships are supportive and respectful of each other.

As a polio survivor and daughter of a polio survivor, we share examples of our communication challenges and offer strategies for gaining awareness of communication styles and improving our relationships with our natural or chosen family.

Communication Challenges That We Have Faced

"Speaking up about my physical limitations and needs when I developed post-polio syndrome was one of the greatest communication challenges that I have faced. Although in my job, I was assertive at intervening for other employees with disabilities, I was shocked at my own self-consciousness with men and my inability to ask for assistance at work. I grew anxious, depressed, and self-critical about my avoidance and the changes that my physical condition forced me to make in my life. By practicing what I professionally promoted, I invested in very effective psychotherapy! By working through feelings and limiting beliefs from early polio and family experiences, I learned to face myself with compassion and to communicate honestly about my needs. This also enabled me to ask my mother questions about my childhood--in non-accusing ways. Recently, while we watched the documentary on "Polio: An American Experience," she cried throughout the program. Afterwards, when I asked about her sadness, she revealed that she felt guilty about that period. I am grateful that I was able to thank her for all the ways she supported me and to encourage her to forgive herself for her limitations."

Linda Bieniek, Polio Survivor & Ventilator User, Life & Career Coach

"My father had polio when he was 12. I believe polio comprehensively influenced almost every moment of his life afterwards. As I was a nurse, sometimes Dad chose to allow me to partner with him to seek healthcare solutions. We experienced some very challenging times as we changed roles and he became more dependent and needy. He vacillated between appearing as a rigid, demanding, in-control man and a needy, frightened young boy. Neither of these were the strong, loving, devout, passionate, overworking Dad familiar to me. I found that communicating with my Dad had become, now more than ever, extremely important and yet extremely complex. The more Dad revealed to me about his experiences as a boy, the more I understood the reasons for his strong reactions. Then I was able to provide him with comfort and support through his devastating days of being bedfast again. If I had known some of the strategies we share, they might have eased some of the tensions during that period. I know they are helping me with my children."

Annie Barber, R.N., Daughter of Polio Survivor, Post-Polio Support Group Leader

"Communication, both verbal and non-verbal, is the' stuff' that initiates, builds, maintains, and destroys relationships,....Effective communicators attend to the nonverbal aspects of space, energy, and time as well as to their choice of words and actions as they move from situation to situation, building and strengthening relationships."

Connecting with Self and Others, S. Miller et al

What Are Your Relationship Goals?

The first step to becoming aware of how to improve your communication with a specific person is to clarify your goals: What kind of relationship do you WANT with this person? What do you WANT to change in your relationship? What do you WANT to gain from communicating with this person?" Respond to these questions using positive words that apply to you. Remember, you only have control over what you can realistically do--how you communicate, listen, and respond to the other person. You cannot control how the other person responds. You can, however, use your insights and the approaches described in this article to plan how to deliver your messages and gain the best results possible.

Do You Communicate Honestly and Directly?

In some families, communicating honestly and directly is or was not considered appropriate. In other families, such as when a parent had an addiction, family members may not have felt safe speaking the truth for fear of reprisals. Now, as adults, we have the opportunity to express ourselves honestly with trustworthy individuals and also to recognize when to be discreet with a person. In order to understand your ability to express yourself honestly, take a few moments and note "yes" or "no" to these questions:

- 1. Do you say "yes" to requests when you want to say "no?" Do you avoid expressing your opinion when it differs from that of others?
- 2. Do you request what you need without feeling guilty?
- 3. When you get frustrated by a person's behavior do you communicate your needs to the person? Do you avoid the person? Criticize the person doing the behavior? Or complain to someone else?
- 4. When someone offends you, do you tell the person? Or do you get angry and either avoid the person or say nothing, but feel resentful inside?

Using an approach known as HODSA, the acronym for **honest, open, direct, sensitive, and appropriate,** will enable you to decide how, where, and when to communicate to gain the results you want. The following questions are a checklist for ensuring that your messages reflect these qualities:

- ➤ H--Honest: Is what you plan to say the truth about what you think or feel?
- ➤ O--Open: Does your message and body language invite dialogue? What level of openness do you want to share with this person? Is he/she trustworthy? What does your intuition say?
- ➤ **D--Direct**: Are you stating your message clearly and concisely?
- > S--Sensitive: Is what and how you plan to communicate sensitive to the person's feelings, circumstances, and limitations? Will it strengthen the relationship or hurt it?
- ➤ **A--Appropriate:** Are you choosing an appropriate moment and place to address this subject? Will the message, timing, or setting cause distress for the listener and interfere with your goals or relationship? Are your feelings appropriate to express or better to work through privately?

In addition, nothing can replace the value of seeking feedback. Whenever you want to verify or confirm that you are getting your point across, request feedback from your listener. Ask open-ended questions such as, "Please tell me what you think I am saying;" "Please tell me what you think I mean by that;" or "How is this coming off to you?"

Does Your Body Language Reflect Your Good Intentions?

Most people can tell whether we are sincere about what we say by how we look and sound. Body language offers us another way to communicate our positive intentions. When we reflect honesty, openness, sincerity and sensitivity, we build trust and encourage cooperation. Does your eye contact, body posture, gestures, tone of voice, pace of speaking, and facial expressions invite openness? Seek feedback from a trustworthy friend to learn if your body language matches your verbal messages.

How Intimately Do You Share With Others?

Awareness provides us with insights about ourselves, others, and our interactions. Examining the terms below may help you become aware of the different levels of communication that you engage in. When you share information only on the sensory level that means you are revealing very little personal information. People who engage with each other only on this level are not very intimate with each other. On the other hand, if you are able to consistently express what you want and then use that information to enact changes that meet your needs and desires, you are achieving a high level of intimacy, and often greater satisfaction in relationships.

Becoming familiar with these levels can help you to become attuned to your own comfort level and also can challenge you to share yourself with more depth, detail, and clarity. The more comfortable you become with expressing thoughts, feelings, and wants, the more courage you can gain for creating positive changes in your life.

Sensory Information: Verbal and non-verbal data based on the five senses of sight, smell, sound, touch, and taste. *I observed, sense, heard, etc. "I see you have a red face."*

Thoughts: Thoughts are the meaning that we give to information and experiences. For example: "I believe, perceive, think, expect, interpret, and see possibilities for...." "I think you look angry."

Feelings: Emotional reactions, often to the differences between what we expect and what we actually experience. "I feel sad, mad, afraid, glad, disappointed, etc "I'm worried that I disappointed you."

Wants: Are what you want to DO, to BE, or to HAVE. "I intend, desire, need, value...." Hidden agendas such as retaliating or gaining control are negative objectives. "I want to show you my gratitude."

Actions: What we do are our behaviors---in the past, present, or future. "I plan, achieved, will solve, resolved, will negotiate, am developing...." "I plan to listen more carefully next time."

At what level of this awareness spectrum do you find yourself most comfortable? Do you share deeper levels of awareness with anyone? With whom do you communicate intimately and want to?

Do You Take Responsibility For Your Needs By Being Assertive?

Communicating assertively means taking ownership of our thoughts, feelings, and experiences while respecting the feelings of others. Beginning a statement with "I" rather than "you" is a straightforward approach that invites open and direct exchanges. Saying, "I disagree," rather than, "You're wrong" is not blaming or accusatory, and as a result, can reduce defensiveness and conflicts. If you have a hard time turning down requests, respond by simply saying, "No, I can't do that now" instead of giving a long explanation of the reasons that you can't fulfill the person's request before saying "No."

As humans, we all have needs which may conflict with another person's behavior. When this happens, asking the person to change a specific behavior is important for protecting the well-being of each individual and integrity of the relationship. If we avoid communicating directly and honestly about our feelings and needs, we risk revealing them indirectly, perhaps even passive-aggressively, impacting both parties negatively.

Use the four-step framework below to compose a clear and direct request for an individual to change a behavior. The above section on awareness offers useful terms that you can use to fill in the blanks:

"I feel ______ when _____ because _____. I need _____."

Step 1: *I feel.* Take ownership for how you feel about the person's behavior by saying: "*I feel frustrated...*

Step 2: *When.* Concisely state the person's specific behavior that interferes with your needs. "...when you keep talking while I am reading..."

Step 3: Because. Describe the effect of the person's behavior on you. "...because I feel ignored."

Step 4: *I need*. State what you want the person to do or change. "*I need quiet time to relax and read*."

Do You Listen With an Open Mind and Heart?

How we listen is also essential to communicating effectively. Paying attention to the other person's verbal and non-verbal messages with an open mind and heart contributes to understanding, respect, and trust in our relationships. The questions below reveal traits of *ineffective* listening. If you answer "yes" to any of these, consider this an opportunity to change that pattern and to learn to listen attentively!

- ➤ Do you have definite opinions and need to be "right?"
- > Do people say that you talk too much or get defensive?
- > Do you interrupt others when they are speaking? Or finish their sentences?
- > Do you change the subject when you are uncomfortable with a topic or person?
- ➤ Do you fully focus on what a person is saying? Or do you let your mind drift off and think about the subject or to another unrelated subject or person?

How Do You Come Across with Family Members?

Next, we encourage you to be honest and CIRCLE all the words in the table below that describe how you have communicated with different family members. Often, we express ourselves differently depending on the individual, circumstances, topic, and sometimes, how we feel that day! Also, take a minute to place an "X" over words that others might use to describe the way you communicate with them. Insights that you gain can equip you to consciously decide how you WANT to interact in the future.

Communication Styles				
Direct	With Avoidance	Expressive	Playful	Inconsistent
Irreverent	Aggressive	Passive	Kind	Sporadic
Abrupt	Inquisitive	Passive-Aggressive	Sensitive	Minimal
Humorous	Respectful	Indirect	Sarcastic	Effusive
Honest	Open	Humble	Patronizing	Overwhelming
Bossy	Demanding	Critical	Accusing	Flooding
Clear	Concise	Verbose	Defensive	Compulsive
Cynical	Diplomatic	Emotional	Sincere	Need-To-Know
Cold	Dramatic	Apologetic	Loving	Patient
Annoyed	Angry	Gentle	Haughty	Timid/Hesitant
Vulgar	Childlike	Cocky/Smart	Oppositional	Encouraging

For polio survivors: How do you communicate with family members about the following issues?

- ❖ Your needs and feelings related to changes caused by the late effects of polio?
- ❖ How your current condition and having had polio has affected your life?
- How your early polio experiences have impacted your life?
- ❖ Their (family members') present day needs and feelings and/or their own past experiences?

For family members: How do you communicate with the polio survivor about the following issues?

- ❖ Your own needs, feelings, and life experiences?
- The effects on your own life of the person contracting polio and/or developing its late effects?
- ❖ Your reactions to what the person has shared about past and present polio-related issues?
- ❖ What you want to know about the person's early polio experiences or present condition?

For polio survivors and family members:

- * What do you do to become aware of your own feelings, needs, and desires?
- What "hot button" issues trigger intense reactions such as anger, anxiety, hurt, defensiveness, or avoidance? Have you considered seeking professional assistance to resolve them?
- ❖ How do you stay calm and focused when another person overreacts?
- Who is/are a trustworthy person(s) that you can turn to for constructive feedback and support during stressful family situations?

How Can You Plan To Express Yourself?

We recommend that you take time to note your answers to the questions below before approaching a family member to gain the results that you WANT. Your answers can assist you in deciding how to best communicate with the person. For complex and sensitive issues, also use the questions in the next exercise to plan your approach. These questions are all worth spending your time on!

- 1) With whom do you WANT to communicate?
- 2) What kind of relationship do you WANT with this person? What do you want to change?
- 3) What do you WANT to communicate? What is your message?
- 4) What do you WANT to gain from communicating with this person? For example: What do you want to change, have happen, or know?
- 5) How does this person usually communicate with you? Select descriptions from the "Communication Styles" box on Page 4.
- 6) What obstacles may interfere with your ability to gain a successful response from this person?
 - This question can help you recognize what you can change and what factors are out of your control. Possible obstacles include but are not limited to addictions; depression and other behavioral health conditions; cognitive limitations; unresolved fears, traumas and "hot button" issues; and also mean-spirited, manipulative, abusive, or controlling personalities.
- 7) How, when, and where will you approach this person to gain the results that you WANT after considering his or her communication style, listening skills, "hot button" triggers, and possible ways he or she may react? (See #6 on worksheet for list of defensive behaviors.)

How Can You Respond To Challenging Personalities?

Some individuals have personalities that will not only interfere with communicating effectively but also may cause conflicts within the family (See question #6 on "obstacles" above). The reasons for their personality patterns vary. Some behaviors relate to medical conditions such as having a bipolar condition or an addiction. Even with these conditions, individuals can change many of their behavior patterns. However, they must want to make changes and be willing to seek professional assistance. Your role is not to diagnose or fix the person. Instead, you can use the strategies in this article along with the following suggestions to take care of yourself and your family:

Gain Knowledge

Understanding a person's condition and behaviors and your own reactions is especially important when interacting with a challenging personality. For example, a person who was abused or lost a parent as a child may have difficulty trusting others. Your understanding of this pattern can help you recognize that when the person criticizes you, this may be his or her way of creating distance and is not meant to attack you. Learn what triggers you, the other person, and the reasons. Identify what contributes to conflicts or unproductive exchanges. The same advice holds for a medical condition such as bipolar condition. Likewise, if a polio survivor has not worked through anger and fears from early polio experiences, the person may use alcohol to numb uncomfortable feelings. Learning about the effects of traumas and chemical dependency can help you understand the person's behaviors and find effective ways to encourage the person to seek therapeutic resources to improve his or her relationships patterns.

Focus On Your Positive Goals and Values

Set positive goals about how you want to interact with this person. Be clear about your priorities. Think of the person in compassionate terms, for example, "ill" versus "crazy" or "self-destructive" versus "cruel." This can help you approach the person with understanding versus anger and defensiveness. Remind yourself of your values and affirm your good intentions. Focus on what you can do and say—what is in your control. Know that you have options of how to respond. Consider imagining yourself sending the person kind wishes or blessings (HeartMath approach). Imagine a protective clear shield between you and the other person to deflect any name-calling or accusations from feeling like a personal assault. Stay objective in absorbing what the person says. Pray for yourself and the person.

Use Good Judgment in What You Say and Do

Communicate clearly and specifically. Choose your battles and your words carefully. State your boundaries: "No, I will not be able to...." "I can do this, but not that." Stay calm and focused so that you do not fall into the trap of criticizing the person or resorting to saying the person is "crazy" or a "burden." Be discreet about what you share with the person and with others about the person. Avoid using generalizations and judgmental words. Affirm the person's good behaviors. Ask the person to be specific about what he or she wants. Limit contact and time to necessities. Be clear about roles, responsibilities, and consequences. Feed back what you understand he or she wants. Take time outs if the conversation becomes too heated or unproductive.

In all situations, gain support from trustworthy individuals. Consider joining a support group on-line if you can't attend in person. Make sure that you eat, sleep, and exercise (as much as you are able) well. Find ways to relieve stress and boost your energy. Use laughter, a good cry, movies, books, music, art, yoga, relaxation techniques, meditation, time outside and in Nature, playful games, and simple pleasures to calm and energize you. Be resourceful and seek assistance from volunteers at local churches, organizations, and college programs. Face yourself with kindness and forgiveness. Seek beauty and goodness. Use spirituality and humor to gain perspective of your situation within the big picture of life!

What Else Can You Do?

If after practicing these strategies, you still experience distress and difficulties gaining positive results from communicating with family members, consider exploring the following resources:

- ➤ Books, DVDs, websites, workshops on: communication skills, relationships, resolving conflicts, stress management, polio memoirs, and living well with the late effects of polio: www.post-polio.org/edu/aboutpol/books, Interpersonal Communications, Inc., HeartMath.
- Coaching: Obtain referrals from <u>coachfederation.org</u> or The NLP & Coaching Institute: 1-800-767-6756. Interview coaches by phone to find the professional who matches your needs.
- Counseling & Therapy: Assess website profiles and interview therapists over the phone: GoodTherapy.org; PsychologyToday.com; NetworkTherapy.com. Check backgrounds.
- ➤ Call Linda Bieniek, Life and Career Coach and retired Certified Employee Assistance Professional, at 708.354.3640 for professional "assessment and referral" services. She will interview you and match your needs with suitable resources such as counselors or therapists.
- Read What Psychotherapists Should Know about Disability by Rhoda Olkin, Ph.D., and ask a coach, counselor, or therapist whom you work with to read it.
- Interfaith (Community or Care) Partnerships in the US provide visitations and assistance to individuals with chronic health conditions and support for caregivers.

In conclusion, as polio survivors and caring supporters our lives are full of subtle and difficult changes, fears, opportunities for personal growth, disappointments, role reversals, and unexpected triggers. In these relationships, communication is paramount, yet very complex. We hope these suggestions will equip you to tend to your own and each other's needs to maximize the beauty of being people who really listen, love, and care for each other. May your interactions enrich your relationships and lives!

References and Resources

Backman, M. (2006) The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families.

Bernstein, A. (2001) Emotional Vampires: Dealing with People Who Drain You Dry.

Bieniek, L. Emotional Bridges to Wellness. Post-Polio Health. Vol. 17, No. 4. Fall, 2001.

Bieniek, L. & Kennedy, K. Healing Polio Memories Series. Post-Polio Health. Vol. 18, No. 1, 3, 4. 2002.

Black, K. (1996) In the Shadow of Polio: A Personal and Social History.

Bolton, R. (1979) People Skills: How To Assert Yourself, Listen To Others, and Resolve Conflicts.

Bruno, R. (2003) The Polio Paradox: What You Need To Know.

Canfield, J. & Hansen, M. (1995) The Aladdin Factor.

Dayton, T. (1997) Heartwounds: The Impact of Unresolved Trauma and Grief on Relationships.

Dayton, T. (2007) Emotional Sobriety: From Relationship Trauma to Resilience and Balance.

Evans, S. & Choen, S. (2000) Hot Buttons: How To Resolve Conflict and Cool Everyone Down.

Halstead, L. (Ed.) (2006) Managing Post-Polio: A Guide to Living Well With Post-Polio.

Jakubowski, P. & Lange, A. (1978) The Assertive Option: Your Rights and Responsibilities.

Kehret, Peg. (2006) Small Steps: The Year I Got Polio.

McKay, M. & Fanning, P. (1987) Self-Esteem: The Ultimate Program for Self-Help.

McKay, M et al. (1989) When Anger Hurts: Quieting the Storm Within.

Mee, C. (1999) A Nearly Normal Life.

Meyer, R. (1989) Listen to the Heart: Creating Intimate Families.

Miller, S. et al. (1992) Connecting with Self and Others.

Pearsall, P. (1990) The Power of the Family: Strength, Comfort, and Healing.

Satir, V. (1976) Making Contact and (1988) The New Peoplemaking.

Silver, J. (2001) Post-Polio Syndrome: A Guide for Polio Survivors and Their Families.

Stone, H. & Stone, S. (1989) Embracing Our Selves: The Voice Dialogue Manual.