

A Sister Remembers

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When Joan Headley, PHI Executive Director, asked me to be on a panel of family members of polio survivors at the conference in St. Louis, I was hesitant to do so as it was, and still is, difficult to talk about my life with my sister who contracted polio at the age of 6 – and even more so to speak about her death four years ago at the age of 64. Yet, I thought it might be helpful to others who are survivors and those who love them. And so I gathered some thoughts on the topic and went to the conference. I soon found myself in a room at the hotel with two other members of the panel, one was the daughter of a survivor and the other was the husband of a survivor.



As the polio survivors, their spouses, siblings and adult children began to fill the room, I became aware of enormous amounts of fatigue, pain and confusion in the air. And this was not among those using wheelchairs. This was among the significant others of those who had survived polio. After the three of us spoke, questions were asked that revealed puzzlement, mixed messages, anger and hurt. Some of the survivors had overcome many of the physical limitations they had experienced at the onset of the disease and were now experiencing what seemed like a recurrence.

Who wouldn't be angry? Spouses may not have known the person when he or she contracted polio originally, and they were now puzzled at what was happening. Some survivors appeared to be reacting out of resentment and anger that they were now losing the independence they had fought so hard to achieve, and sometimes they expressed feelings of hostility toward their significant others who didn't seem to GET IT. For example, a husband said, "If I ask her if she needs help she says, 'no,' then, she blames me for not seeing that she does need more help."

I can relate to this reality as my own sister was fiercely independent, yet as she became more dependent on assistive devices, oxygen and ventilator, her rage was sometimes vented toward those with whom she felt most safe – her family. Understanding this helps relieve some of the sting, but is not the whole answer.

Outside Help May Alleviate Stress

My sister and I learned through trial and error that we needed outside help to enable us to negotiate the treacherous waters of the post-polio world; she needed to hire a lot more done for her along the lines of physical help, domestic duties, transportation and home health aides so that we could be sister to each other, and I would not be in the role of nurse, cleaning lady or chauffeur whenever we were together. Cost was an issue, of course, but eventually there was no other choice and with some assistance (albeit minimal financial help from government programs like Independent Living), the stresses were alleviated – somewhat.

From the very beginning, our relationship was one of big sister (me) and little sister (her) as I was 9 years old and she just 6 when in 1952, polio dropped into our family's life like a bolt out of the blue. We have three brothers who were part of the picture – each of them coped with the

family dynamics in his own way; but that is a story for them to tell.

My parents were heartbroken as they watched their darling, red-haired, lively 6-year-old struggle to breathe and move and live. And we, the siblings, were baffled completely. In that day and time and place, children were not told much of anything and we were left to figure it out for ourselves.

My own response was to try to make it up to my sister that she could not and would never walk again. I felt guilty for walking and doing things she could not do. I always looked out for her and tried to flatten the bumps and smooth the way. Although we each came to lead our own very productive and fairly happy lives, I still to this day survey new terrain for accessibility. Nice restaurant! Hmm. Steps at the front entrance. No ramp. How does a person in a wheelchair get in?

Eventually, I learned that I could not make it up to her, but I could be her sister. I could walk beside her even if I could not be the fixer-upper and the problem-solver – although I must say I can leverage a wheelchair just about anywhere and coax a reluctant battery to kick in when the wind chill is well below zero.

Counseling and Support Groups Are Useful

I think in some cases, a family systems counselor could have helped all of us negotiate this terrain, and support groups for both relatives and survivors could be useful in airing the emotional baggage and strategizing on how to make life better for all concerned.

Polio doesn't happen to one person; it truly does happen to an entire family. In fact, in the 1940s and 1950s, it happened to our entire nation, and that has had its effects too. Those who **survived** the polio epidemic tended to be lionized as heroes (millions had died over the decades), and of course President Franklin D. Roosevelt was the epitome

of the polio hero who pulled the nation through the great depression and never appeared the least bit stressed. Hugh G. Gallagher's story, *FDR's Splendid Deception*¹, is a well named book as it depicts the intense efforts he, his family and staff took to conceal his disability from the public.

But lionizing a survivor can be an added burden. Polio survivors are not lions, nor victims, nor heroes, nor saviors – neither are their significant others any of these things. We are people, interdependent, sometimes loving, sometimes really pains in the back sides of one another.

My sister had a favorite poem which I would like to quote here as it is just two sentences in length, but captures much of our lives together then and even now in this new day and way of being family. ■

*We sat talking
in the summer sun,
lazing on the swing
and as it swung,
we moved from light to shadow,
weaving strands
of memories and plans.*

*And so we added length
and strength and color
from the varied fiber
of our lives,
knowing that the parts
may fray and ravel,
but the fabric
of our family survives.²*

1. Hugh Gregory Gallagher. *FDR's Splendid Deception: The Moving Story of Roosevelt's Massive Disability and the Intense Efforts to Conceal it from the Public*. Vandamere Press, 1999.

2. Genevieve Smith Whitford. "Reunion" from *Queen Anne's Lace and Other Poems*. Harp Press, Madison, Wisconsin, 1982.