

## Dr. Henry writes about Polio Spouses

Eleanor Roosevelt is probably the most famous polio spouse of this century. She was born into an aristocratic family on November 7, 1884. However, emotional losses and low self-esteem plagued her developmental years. She was the oldest child and only daughter of Elliott Roosevelt, President Theodore Roosevelt's brother, and his beautiful and vivacious wife, Anna Livingston Ludlow Hall. At age two and a half, she was crossing the Atlantic with her parents when their ship was involved in a collision. The terror of being lowered from on high to a lifeboat left her with a fear of heights and the water. As a young child, her mother called her "Granny" because she was so serious and mature. When she was six, her mother said, "You have no looks, so see to it that you have good manners." As a result, Eleanor tried to be dutiful, compliant, obedient, responsible, and useful, but she was also independent, goal directed, and willful.

Death left her an orphan by age eight. She had two younger brothers. One of them, Elliott, died at age four from scarlet fever. When she was eight, her mother died from diphtheria. Her father had a history of alcoholism and chronic depression. He was not awarded custody of Eleanor after her mother's death. Eleanor went to live with her maternal grandmother in Manhattan. Two years later, her father died from the consequences of alcoholism. She stayed with her grandmother for five years. During this time, she grew to be a tall, but rather awkward and self-conscious teenager. She was a loner and an outsider. At the age of fifteen, her grandmother sent her to the Allenswood boarding school in England. At this school, Eleanor came under the influence of the headmistress, Mademoiselle Marie Souvestre. This school was most progressive for the Victorian nineties. The daughters of England's more liberal leaders attended this school. Eleanor excelled at Allenswood for three years. She became more self confident, versatile, and a well loved young woman. At age eighteen, she returned to New York, involved herself in social work causes, made her debut in society at her grandmother's insistence, and soon met Franklin.

In August 1921, she became a polio spouse. During her husband's acute illness, she was his bedside nurse and performed many necessary duties such as attending to his urinary catherizations. Over the next several years, despite her mother in law's opposition, she kept the hope alive in Franklin's mind that he could return to politics. Franklin did become the four times elected President of the United States. During this time, Eleanor became his conscience, promoting progressive social reform. She became his legs and traveled throughout the world as his "ambassador of hope." She was a person ahead of her times. She was a feminist. She was compassionate and idealistic. She was a friend to the disenfranchised. She was an assertive and hopeful voice for the hungry, the unemployed, and African Americans. She became a writer, a teacher, lecturer, and voluntary ambassador.

When asked about her husband's polio, she would say his polio was a "blessing in disguise." Some had argued that FDR had always been a powerful and compassionate man; she believed that Franklin's struggle with polio "gave him a strength and courage he had not had before. He had to think out the fundamentals of living and learn the greatest of all lessons --- infinite patience and never ending persistence."

Eleanor appeared on the Edward R. Murrow TV Show, "This I Believe." In response to a question about her life, she stated, "You have to accept whatever comes, and the only important thing is that you meet it with courage and with the best you have to give."

In my opinion, Eleanor Roosevelt's perceptions as a polio spouse are astute and wise. As polio survivors, most of us learned long ago about the value of patience, persistence, and trying to think through the fundamentals of living. For many of us, polio brought a precocious understanding of the perils of life. If we did not learn and exercise these lessons years ago, we certainly need to exercise them now with the realities of Post-Polio Syndrome (PPS).

There are a number of polio spouses who are quite active in our post-polio support group. From my observation, these spouses fully represent individuals who have learned "to accept whatever comes" and have met adversity with "courage and the best they have to give." No marriage is all bliss and joy. The realities of polio and now PPS can stress the best of marriages. Based on last year's survey of our group, 70% of our members are married. 51% felt that the development of PPS had had some impact on their families. The changes that might result in a marriage relationship as a result of PPS can be adverse, or can be part of the "for better or worse, in sickness and in health" definition of a committed marriage.

I think that polio spouses are often forgotten and overlooked heroes. For many of us, they are "gofers." They run errands, pick up things, and help with many details of daily living. They also get tired and moody, and have bodily aches and pains. Usually, they say "yes" more often than "no" to us, are our thoughtful personal advocates, and our loving protectors. Marriage relationships are traditionally complementary, as each spouse is expected to manage certain tasks toward the maintenance of a home and the raising of children. The invasion of PPS may alter the dynamics of that complement. As a consequence, the polio spouse may feel somewhat abandoned, needed more than loved, and less valued. This is more likely to occur when the PPSer is having greater difficulty accepting and adjusting to a life with PPS. When the PPSer is more anxious, fearful, depressed and uncommunicative, the polio spouse may be on the receiving end of irritability, complaining, and subtle rejection. Both marriage partners may well understand this process, but feel helpless in changing it. Meaningful communication is the key to working through the changes that have occurred and in establishing a new and lasting complementary relationship. If this level of communication is not possible, professional help may be an excellent next step.

As a first lady, Eleanor Roosevelt made a positive impact on the lives of many people. As a polio spouse, she must have felt the anger, fear, and uncertainty brought to their lives by her husband's polio. I feel that many polio spouses have felt and may still feel the anger, fear, and uncertainty that PPS has brought. There may be no brilliant dynamic psychotherapeutic models to resolve the realities of the impact of PPS on a marriage. Eleanor's advice is the best that I have heard.

"You have to accept whatever comes, and the only important thing is that you meet it with courage and with the best you have to give."

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