

## Marriage: A Two-Way Street

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*I'm going to tell you a story of a marriage — my marriage. In telling this story to myself as I was preparing for this speech, I created some axioms (page 4) about how polio affects my marriage. I don't know how universal these truths are, but as you read my story, compare your life with mine. I've learned a lot from having polio. It has been, and still is, my best teacher.*

When Phil, my husband, and I met back in the mid-1970s, we were in our early 30s. I had polio when I was nine and was stabilized in my health. I had been working as a social worker at a mental health clinic for eight years. The year we met I decided to leave the clinic, my first job, and open my own private practice.

My health was stable; my career was established. It was a good time to take a risk in my professional and personal life. I was tired of having short-term relationships and decided that it was better to be alone. Having an independent spirit, I was not afraid to spend a lot of time by myself. In fact, the opposite was true. I wasn't sure I could live with another person or handle the closeness that marriage demanded.

Phil and I developed our relationship slowly. Divorced after only one tumultuous year of marriage, he was not ready to make a commitment. His job was sending him to Michigan for six months in the dead of winter, and he wanted to write to a friend. I liked him and the idea of getting to know him from a distance. Besides that, I was busy building my practice and did not need to be distracted from my professional goals.

After five months of letters and phone calls, he invited me to Michigan for my birthday, which started the romance part of our relationship. When Phil moved back to Dallas and continued to travel with his work, we developed the habit of spending the weekends together.

As with all relationships, we had a lot to work out the first few years when the infatuation wore off. We were very different in many ways, but had similar values. I'm a tidy housekeeper. He likes books and papers in precarious piles. I have a greater need for control and like to be physically active. He is more even-tempered and likes to be physically comfortable. (Sitting in his easy chair for hours with a good book is his idea of a perfect afternoon.) I'm more emotional. He's more intellectual.

We both believe in not escalating arguments beyond a certain point. We never walk out on each other or call each other names. We solve our differences before the end of the day. Over an eleven-year period, we worked out a comfortable arrangement of just the right amount of closeness balanced by a good amount of independence. We were afraid that getting married would ruin our relationship. I felt that I would rather yearn for Phil than be sick of the sight of him.

A combination of things tipped the scale towards getting married. Around 1985 when I was in my early 40s, I noticed increasing episodes of extreme fatigue. I saw an article in the newspaper about a polio support group for people who were having similar problems. I went to one of the meetings and felt awkward about hav-

ing to think about polio again. All these years it had been in the background of my life. It had not kept me from living a full life, and it made very little difference to Phil, which was one of the reasons I liked him. He recognized how polio had shaped my character and was a major part of who I was as a person. He didn't treat me like an invalid.



Phil Hughes and Joyce Ann Tepley

I started to research post-polio and was evaluated by a physical therapist. I got lightweight leg braces and bought a three-wheeled scooter. The next year I had my breathing evaluated and started using a ventilator to rest my breathing muscles at night. Even with all these changes, I was still having trouble maintaining my health and my private practice. Phil was worried about me and was helping me financially.

CONTINUED ON PAGE 4



## JOYCE ANN TEPLY'S Marriage Axioms Involving a Partner with Post-Polio

1. No matter how hidden, polio is the third entity in the marriage.
2. The non-disabled partner must be able to identify with disability.
3. The effects of polio cannot be integrated into a marriage if the experience of polio is not integrated in the polio survivor.
4. It's not just the physical effects of polio that adds extra stress on a marriage. It's how the partners deal with the emotional and mental effects.
5. Disability tends to exaggerate all the ordinary issues of marriage.
6. When post-polio syndrome enters a marriage, "for better or for worse, in sickness and in health" must be dealt with sooner rather than later.
7. The partner with polio will most likely be an over-achiever.
8. When post-polio syndrome enters a marriage, the partner with polio must begin to do less and, consequently, the non-disabled partner must begin to do more.
9. For a healthy marriage, the non-disabled partner must have a degree of unselfishness and the disabled partner must have a degree of ego strength.
10. A good marriage is based on monotony (routine) and familiarity with occasional change. Too much change, too quickly makes the relationship unstable.

At that time, my grandparents and mother were in failing health, and I was going back to Ohio as much as I could to be with them.

Phil was also facing several changes. The company he worked for went bankrupt, and he had to look for another job. We had talked about marriage over the years, but always concluded it wasn't for us. But with the older generation of my family dying off, and his parents getting older, family was becoming very important to me.

With that thought primarily on my mind, I got down on my knees, literally, on Phil's birthday in 1987 and asked him to marry me. After many delays, we wrote our vows and set the date. I'll never forget my surprise during the ceremony when I heard Phil promise to be my "helper." Over the last ten years of our marriage, he has kept that promise.

We have essentially been together now for 22 years and over that period of time, as a counselor of relationships and a student of my own, I have observed certain truths.

Over half of all marriages end before seven years. We expect a lot from a marriage; marriage is not easy to maintain. It's complicated enough without adding disability.

I wondered why people stay together against the odds, and I came up with Axiom #10. I think you have to have a high tolerance for routine and find starting all over with someone new abhorrent. It took me several years to teach Phil how to hold his arm just right so I could hold onto him comfortably when we walk together. Now he automatically waits and sticks out his elbow.

(A friend of mine who has polio is staying in a less than satisfying

marriage partly for that reason. Her husband knows just how to help her transfer in and out of the wheelchair and car.)

Phil already knew and accepted me as a polio survivor. As in Axiom #3, I had worked long and hard to emotionally accept myself as "different" growing up. When he met me, he was impressed with my confidence. Polio was not just a life-altering experience I had in my past, but a part of me. I saw myself as a healthy person emotionally and physically. But when I became weaker physically, it shook my confidence, and I was challenged again — how to again integrate polio into my life in another way.

We had to adjust our lives around my health problems. Phil had to assume most of the financial burden since I could not work full-time anymore. We started proving Axiom #8. There were days I stayed in bed grieving the death of my mother. He would come home from work and handle all the household chores. The physical things were hard enough, but the greater dilemma for him was handling my emotions.

As in Axiom #4, I believe that physical problems are more easily solved than emotional ones. Emotions are tied to perceptions, attitudes, one's character makeup, or how one's family of origin handled feelings. I've been fortunate. I picked a partner who could identify with disability. (Axiom #2.) He was a fat child growing up, and he knew what it was like to feel different. His family taught him to accept people as they are. He never felt threatened by people who were different unless they were malevolent.

I'll conclude with Axiom #9. In our marriage, the line between who is disabled is getting thinner. We're both getting older, and



Phil is developing his father's disease of arthritis. Neither one of us is "doing more" any more. We're starting to plan for the day when we'll both need more physical help than we can provide each other.

Phil has been my faithful caregiver, and I have learned to accept help without feeling diminished. I have been his faithful companion, giving him support through all the changes in his life. He has learned that he could live comfortably with another person without compromising his integrity. What more could one ask of a marriage? ■

## Post-Polio Bibliography

◆ Kemp, B., Adams, B., Campbell, M. (1997). Depression and life satisfaction in aging polio survivors versus age-matched controls: relation to postpolio syndrome, family functioning, and attitude toward disability. *Archives of Physical Medicine & Rehabilitation*, 78, 187-192.

This investigation compared depressive symptoms and life satisfaction scores between people aging with polio and an age-matched sample of non-disabled individuals, as well as among polio survivors by change in symptoms; and assessed the role of family functioning and attitudes towards disability in mediating the relationship between post-polio syndrome and outcome measures of depression and life satisfaction.

The average depression scores for both samples were within the normal range, and were not significantly different with mean values of 5.5 and 4.2 for polio survivors and controls, respectively. The percentage of persons scoring in the highest category of "probable major depression" also did not differ between groups. It was only for the middle category of "significant symptomology" that polio survivors outnumbered controls with 22.2% of the sample falling into this range com-

pared to only 12.5% for the non-disabled group.

The biggest differences in depression scores were observed within the polio sample rather than between groups. Polio survivors meeting the criteria for post-polio syndrome had an average depression score of 6.5 ( $n = 66$ ), which was significantly higher ( $p < .05$ ) than the average score of 4.2 observed for those in the combined non-symptomatic and physical-symptoms-only subgroups.

*This study found no overall differences between people with polio and age-matched nondisabled persons on either the mean level or the percentage of persons with high scores on a standardized depression questionnaire.*

Nevertheless, over one-quarter of post-polio persons had scores high enough to warrant consideration of some treatment or intervention. A separate assessment by clinical psychologists using standard diagnostic criteria further supported these findings. Also, certain subgroups of persons with polio were at higher risk of depressive disorder. *Those with more post-polio change, lower attitude scores and lower family functioning had higher depression scores. Even more important than post-polio change was the person's attitude toward disability and family functioning, especially when both were low.* Under these circumstances, the average depression score jumped to a high of 10.8.

Of special concern is the fact that treatment of any kind for people with probable depressive disorder seemed non-existent. Among those with high scores, not a single person was in counseling or taking an antidepressant medicine even though several seemed like obvious candidates on clinical examination.

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*Dr. Campbell will be leaving the Rehabilitation Research & Training Center on Aging with Disability at Rancho Los Amigos Medical Center to pursue other challenges.*

◆ Agre, J., Rodriguez, A., Franke, T. (1998). Subjective recovery time after exhausting muscular activity in postpolio and control subjects. *American Journal of Physical Medicine & Rehabilitation*, 77(2), 140-144.

This study demonstrated that the subjectively determined time to complete recovery after the performance of exhausting muscular exercise was greater in unstable postpolio than in stable postpolio or control subjects. The stable postpolio and control subjects did not differ in subjectively determined recovery time. The cause for these findings is unknown and requires further investigation. ■

## international polio network

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