

What Polio Survivors Had to Say – What Families Had to Say

These are the results of a workshop session, which followed a talk by Drs. Susan and David O'Grady on the Psychological Issues and Family Relations in Post Polio Survivors. Reprinted from the Mt. Diablo Post Polio Network Newsletter, Vol. 6.

The group was divided into polio survivors and family members. Each group was asked one question, with discussion lasting 45 minutes. They then reconvened to summarize and discuss what the two groups said. The question posed to each group was:

“What part of the experience of post-polio syndrome is most difficult to communicate to your spouse/family?”

The Polio Survivors: By all accounts, this turned out to be an intense discussion. Strong feelings were stirred up. Many were moved, some cried. It was clear that the process of confronting the emotions surrounding the experience of post-polio is difficult and painful. Similarly, communicating about these feelings to family and even to other polio survivors can sometimes feel overwhelming.

Paraphrased, here are some of the areas of concern:

- We are afraid of what the future holds. In fact, sometimes the future seems so scary we can't allow ourselves to think about it.
- We are afraid that our physical needs will place such demands on our families that they will grow weary and resentful and withdraw support. We wish we had reassurance that we will not become so burdensome that others will leave us.
- We want families and friends to not judge us by our appearance. Appearances can be deceiving. More often than not, we look much better than we are. Weakness, fatigue and pain are less visible than braces and wheelchairs, but no less real.
- When we are tired, we mean it. In fact, it usually means we are exhausted and a short rest may not remedy it. Don't overestimate how much we can do. We struggle enough as it is, to figure out our own limitations.
- Sometimes we need to put ourselves first, which is difficult for most of us to do – this is a major shift for us. We would like you to help us do this by cooperating when we say we need something. We know the difference between a need and a whim. It is hard for us to ask for help; it doesn't come easily.

Conflict within the group emerged when some participants expressed fear and frustration while others reacted with anger. It seemed that both fear and anger were central and universal experiences, but that people cope differently. The anger expressed seemed to grow out of a need to fight feelings of vulnerability and helplessness and instead, maintain a sense of control and a positive attitude. Worried that their fears and sorrow will pull them down, some people use anger to protect against feeling fear. Other people are afraid of how intense their anger can become, so they suppress it.

Partners and Families: All expressed a deep commitment to their partner and a readiness to be a part of their lives, regardless of changes in physical status. This commitment was not naïve or superficial, but seemed founded on genuine love and respect for the challenges their partners have faced and will continue to face.

They acknowledged that coping with PPS involves a series of compromises, but they adapt by remaining flexible and tolerant. Within this group there was much commonality, but when differences of experience emerged this group was quite respectful and compassionate.

Partner and family expressed the following concerns:

- It is difficult to see our partners in pain. We feel helpless to ease physical suffering. Therefore, we would like our partners to listen to their bodies, slow down and not be such perfectionists.
- It is hard to see our partners reject changes that would help them cope (e.g. –using a wheelchair or a scooter). We do not view use of adaptive devices as failure, but as an increase in functionality and freedom to enjoy life together.
- Sometimes our partner’s anger is hard to deal with. When they are feeling tired and frustrated they get irritable. If we say the wrong thing, they get upset. We sometimes have to ignore what they are saying, so we don’t take it too personally.
- The lack of predictability of the illness is frustrating and frightening. We don’t know what our partners will be able to do in the future. Therefore, we feel it imperative to live for today and not postpone doing things that give us pleasure.
- Over time, our role in household responsibilities is getting larger. We accept this. Still, your comment of appreciation is very welcomed.
- Some of us feel concern about our own physical ability to provide care for our partners as we, ourselves, age and contend with our own aches and pains. We worry about the possibility of not being able to give necessary help.
- It is difficult to know when to be the cheerleader, when to be comforting and soothing and when to confront anger or passivity. We’d like to feel we have permission from our partners to express our feelings about this.

In conclusion, there was a broad agreement that life is all about challenge and response; that amidst the hardship, post-polio represents an opportunity for personal growth for both survivors and family, if the challenge can be faced with flexibility, acceptance and openness.