

Life in a Post Polio Support Group

Around our country and the world there are numerous post polio support groups. Most of these groups were founded in the decade between 1985 and 1995. Some were founded some time after 1995. I am a member of the Central Virginia Post Polio Support Group (CVPPSG). The CVPPSG, which was founded in 1986, as most support groups has four primary reasons for existing. One is to provide mutual support for the members of the group. Another is to provide education in regard to Post Polio Syndrome. Still another is to provide advocacy in regard to the rights of polio survivors in our society, particularly regarding issues related to the American Disabilities Act, our civil liberties and our medical well being. Lastly we exist for social inaction involving the shared joy of meals, parties and even trips together.

Post polio support groups are subject to the dynamics of any group. Issues that may arise with any group are splitting, petty jealousies, leadership problems and burn out. Theoretically the people experiencing PPS should be about equal between the sexes. The only difference on average is that women have a longer life span than men in the general population of the USA. This writer has observed that many male PPSers do not have the staying power for a support group that many women have. Often men simply want the information that a support group may offer and are not interested in social interaction. Also, men often are less comfortable with sharing their feelings and are more likely to still be in denial regarding what is happening to them. Generally, women are more comfortable in expressing their feelings and talking about what is happening to them and find it therapeutic. Men often prefer to hide in a cave when emotions are involved and simply want to know the way to fix a problem. The male PPSers that become involved in support groups usually become effective members of the group. Spouses, family members and significant others are active in our group. Several times during the year our group holds @partner meetings# for the benefit of the spouses or partners of the PPS members. This is also therapeutic because many of these people have a common interest. They love and care about someone who has PPS.

Another unique aspect of PPSers is that no two members have exactly the same physical problems with PPS and situations may vary significantly between members. A crisis for any member can occur at any time. Unexpected problems with fractures, infections, cardiovascular conditions and cancer can occur to PPSer and cause even greater stress. Our group has experienced more deaths among members in recent years than in earlier years. We are all getting older and aging has its own difficulties for anyone with a chronic condition.

Some Post Polio support groups have diminished in size and even stopped meeting. This can result for many reasons. If meetings become more complaining and less supportive in nature, some members simply get tired of this and stop coming. Good leadership is important. A flexible leader who has an active board or a team of leaders who willingly share responsibilities will ensure a healthy support group. Also a newsletter that is written and edited well is essential in communicating valuable information to members who may have great difficulty in attending meetings or simply live too far away to make travel practical. Our group has been fortunate to have a great editor for over a decade. Newsletter articles are often shared with other newsletters around the world. Without a newsletter it is difficult to maintain a support group.

As members can experience fatigue; thus a support group can experience fatigue as part of a group process. Splitting can occur if a clique within a group seems to control all decision making or seems to capture more attention during a meeting. Dominant personalities can affect group dynamics for the whole. The best approach for such situations is for the leaders to try to address the problem on an individual basis or in by inviting those who feel left out to be included in leadership or areas of responsibility on a voluntary basis.

A common psychological defense that polio survivors have utilized for years is denial. It is difficult for us and some groups to cope with surrendering this defense. Another defense that is often used is projection. This simply means that some individuals with problems find it easier to blame someone else for problems than to do some self examination. Often anger is the underlying emotion that provokes the defense of projection. Support groups can listen to complaints, but if complaining becomes a pattern for an individual or a group, some type of therapeutic intervention would often be helpful. For support groups that may be in decline an independent consultant who is trained in group process might be helpful.

Most support groups are doing well and meeting their goals. It is a reality that Post Polio Support Groups will cease to exist at some time in the future. This will occur as our generation of polio survivors passes on and the disease will hopefully be eradicated from the planet earth. The Post Polio support group movement has been remarkable as we have never had a national organization to solicit funds, provide education, invest in research and provide advocacy. Some organizations have been helpful, but we have never had an organization similar to the Multiple Sclerosis Society or the Muscular Dystrophy Society to work for us. The March of Dimes remembers us, but that is the extent of it. We as individuals have done well to accomplish a lot on our own. Many support groups have done the same thing; that is accomplishing a lot on their own. So often the individual experience parallels the universal.