

## LEADERSHIP

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**QUESTION:** “I was shocked, but I have come to learn that people in our group who can walk expressed at a recent meeting their opinion that the people in wheelchairs and less mobile have limited the activities of the group. They want to go downtown, for instance. Also, they say they are sick of hearing about polio. Has this ever been a problem in other groups? How was the issue resolved? What recommendation would you give to other groups, so it doesn’t happen to them?”

**ANSWER:** Whoooooa! What on earth...! We’d all be screaming bloody murder and calling in the ADA police if we heard this kind of discrimination coming out of the mouths of “outsiders,” wouldn’t we? A polio support group with a prejudice against polio survivors who find it difficult to get around? Think about it.

Here’s the deal: You have a polio support group, you’re going to offer support to polio survivors—ALL of them. And you’re going to talk about the polio condition and solutions. You want a group for ambulatory members who only go shopping or out to lunch? Start The Walking-Mall-Lovers Club or Lunchin’ Ladies Afoot—but don’t call it a polio support group.

Most groups have operating charters that spell out the mission of the organization. Goals usually include objectives like support, information, advocacy. The idea is to bring polio individuals and their loved ones together with others who have questions, concerns, even fears, about what’s happening now that PPS and aging have entered the picture—and then deal with these issues.

Membership often creates bonding. Words like camaraderie, friendship, fellowship, compassion, empathy, tolerance, understanding come quickly to mind. If members aren’t there for each other as well as for themselves, that group’s in trouble. It’s an almost magical thing: A certain amount of healing comes from one person’s helping others get through the same experiences he has been through. We share our stories, our knowledge, our regard for our fellow survivors. The process itself makes us feel better.

A successful polio support group is not simply a social gathering. There’s room for socializing, of course, and an occasional social outing can be a lot of fun. Many members might relish the opportunity to prove they have no intention of tempting the fates with an ungenerous attitude toward the less mobile, lest they themselves be next in line. Groups could ponder the advantages of checking out accessible venues ahead of time and learning from those in chairs the “ins and outs” of negotiating the streets with that limitation. Not a bad project, actually.

But polio support groups exist primarily so that survivors can examine serious polio concerns. We see newcomers seeking this kind of relief every day. Many people are just beginning this search. They are not looking for lunch. It’s essential to live up to our “polio support group” billing and address their needs. Oldtimers face new uncertainties as their conditions progress into unfamiliar territory. They, too, deserve the relevance of polio support.

What to do:

- Rotate leadership before meetings begin to smell like rotting fish.
- Bring in a breath of fresh air by actively encouraging new membership.
- Wake members up with variety and exciting ways of presenting information—listen to their ideas, allow them to participate, put their solutions into action.
- Look to reliable sources for new information—and there IS new information. Let a committee's curiosity and expertise get to work on it.
- Nip divisiveness in the bud with shared decision-making and an open mike at business meetings. Talk about problems out loud and up front.
- Discuss reasons for the group's existence, goals, how everyone can help. Discuss attitudes, the big picture. Get out your crystal ball.

There's an abundance of diversity among polio support group members. Some folks use chairs, others walkers or crutches. Still others walk freely. Sally's shoulder doesn't work; Phil has trouble breathing. This one is a size 42; that one wears a hearing aid. Doesn't matter. What unites us is that we're a group of polio survivors reaching out for support. It doesn't take much. A friendly smile. A hopeful word. A little information to keep us afloat as we try to figure out how to bring balance back into our lives. We do this for each other.

What we don't do is forget about why we're here.

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