

The Benefits of Being in a Support Group



Mornington Peninsula Post Polio Support Group

It is important to be amongst self minded people. A few years ago I was working full time and felt unable to attend a Polio support group, because I couldn't make the time. Then one day I attended one of Polio Network Victoria's "Polio Days" and was motivated by the people who attended. They were all busy living their day to day lives but still found time to go to meetings in their areas.

The meetings in my area had unfortunately stopped. I had personally hoped that this group could be re-instated and here we are 12 months down the track! We are up and running again with the strong help from very enthusiastic colleagues who share the workload and offer their encouragement at every turn. We are now meeting on a monthly basis, have had a variety of speakers, i.e. physiotherapist, Feldenkrais practitioner, Arthritis Foundation, gardening advice, Scooters Australia and, most importantly, we have had time to just sit around and talk to each other, giving to each other the time to listen and share our stories and the strength of community.

Shirley – Bayside Polio Support Group

I have been with a polio support group for approximately 7-8 years. Our group has a total of 55 members and meetings are held once a month. I attend all meetings because I gain so much from the group. We can discuss matters that non polio survivors just do not understand. One has a 'fellow feeling' speaking to another 'Polio'. We have a good laugh as well as discussing matters that may concern us. A Polio who does not have a support group can spend years worrying about what is happening to him/her. It is at these meetings where we find out that others have the same concerns. **IT DOES PAY TO BE IN A SUPPORT GROUP!**

Owen – Geelong Polio Support Group

I almost take their support for granted now. I have to go back to about 1984-5 when I was living in Pascoe Vale. I received an invitation to attend the first meeting of a polio support group in Essendon, in the home of the late Chris White. Chris was so much appreciated by all she came in contact with. I can still remember the extreme feeling of relief as I listened to the roomful of 'old polios' present. We each shared about the strange new symptoms of extreme fatigue, legs and arms suddenly exhibiting new weaknesses, reduced concentration and memory capabilities, swallowing difficulties under stress, etc. that we were encountering. I can remember thinking, "I am not going mad, I am not imagining these symptoms. We 'old polios' all have the same types of problems." I could not get home quick enough to tell my family.

Harry – Hume Polio Support Group

I was not aware that the Post Polio Support Group existed until I read about it in the local paper. I was intrigued that such a thing could happen to Post Polio patients. I contacted the phone number listed and spoke to this welcoming voice who suggested I attend their meeting. I was a bit skeptical as I thought it would be conducted in the same manner as an AA meeting with me standing up repeating "I am a polio victim". Instead, I was introduced to a friendly group who did not have self pity but talked about their experiences with post polio, whether it affected them or some acquaintance. I am happy I have found this group as I feel I am one of the lucky ones (so far) as I do not show any evidence I have contracted post polio. But I know if it does happen I will be steered in the right direction for the assistance I need and that is very comforting to me. I now know Post Polio Syndrome exists. It is a pity that the support group is not widely known, as I am sure it could help a lot of people to cope with Post Polio should it happen to them. It would be sad for any one to have to face that news without proper treatment and support.

Tom – Mornington Peninsula Polio Support Group

One of the ways to better manage life with a disability is to join a support group. In the Knox-Yarra Ranges Polio Support Group, we have gained wide access to information through invited speakers and setting up a resource library – both things you can't do on your own. We are a very positive group providing a lot of support to each other, sharing strategies and social activities with others who don't need to explain limitations. It has also provided valued information to my family when I felt loathe to talk about my own situation. In fact, we always encourage partners / families to join all activities and that gives opportunities for 'carers' to gain support from each other as well.

From a more individual perspective, I have found great satisfaction in using my previous career skills to assist others – I can still be a giver and helper, as well as needing to accept help for myself. I've been challenged to undertake workshops, write submissions, conduct information sessions to other clubs and groups, and collate newsletters, to name a few. So I see the support group as a chance to contribute as much or as little as each person feels able to. It is not just a sit around and 'feel sorry for ourselves' group. We have new friends to share new experiences and new learning.

Joan – Knox-Yarra Ranges Polio Support Group

I am not sure who recommended me to contact Post Polio Support Group but at that stage of life I desperately needed help to untangle my personal, confused attitude about my disability.

As an engineer, I understood the problems of stress and strain and, subsequently, was under the misconception that some muscles would be dramatically overused through life and consequently could fail, thus shortening my life span. Therefore, I didn't expect to live beyond 50 years of age. At that stage of life, I was introduced to Beth Brodribb, Co-ordinator of Polio Network Victoria. From her newsletters I learned there were many polio victims in their 70's plus age group who had lived very difficult and tough lives.

Beth suggested I join the Western Post Polio Support Group and because I had a holiday house in Rosebud, I also joined Mornington Post Polio Support Group. From these groups I found friendship and compassion. But having a common denominator – polio – it was very satisfying to be able to share knowledge on this subject with people who understood the problems associated with daily life.

The main attribute from the polio support groups was the effective way they were organised by a competent and compassionate Polio Network Co-ordinator. Polio Network Victoria is essential to represent and co-ordinate the polio support groups with various associated service organisations such as Polio Services Victoria, for improvement of the health conditions for the polio community.

Up to this date I am personally satisfied with the support group, but like all organisations there is always room for improvement. Such improvement would be dramatically enhanced by the involvement of State and Federal Governments in supporting this largest body of disabled people in Australia to cope with this dreaded old virus that damaged a large section of the public 60 years ago. It's unquestionable, that if the governments had contributed and recognised the problems of Post Polio Syndrome many years ago, the increase in health problems of these 60 year oldies today would have resulted in a vastly reduced individual health burden.

Graeme – Mornington Peninsula Polio Support Group

With our support group there is the benefit of being able to meet each month, also able to make contact with members at any time, to discuss our problems, regarding our situation. It is a comfort to know that we are not imagining our pains and aches. It can also become a social outlet for members who are not able to venture out often.

We have the occasional Guest Speaker, not always involving our problems, which gives members something else to reflect on.

In our area, we also have a combined group of Chronic Health Support Groups who have the one aim of learning how other groups operate and support their members. We also join these groups at their functions and hold two combined social functions a year - one being a B-B-Q the other a luncheon. This brings a mix of members together for a very social and informal get together.

Anne – Warrnambool Polio Support Group

A support group brings one in touch with a variety of people who are all dealing with the same situation. The benefit comes from observing how different people manage their lives around whatever the disability or condition is.

At a support group meeting, there's often a lot of information exchange; helpful hints and tips on how to manage, what remedies work, where there's a good supply of product/help/support or whatever that may be useful.

A good, chatty meeting when people are talking about things other than their particular ailment and just sharing a social experience, can also be beneficial. It reminds members that they are people first, not solely defined by their disability or condition.

There's an 'old soldier' bond among members of a support group. Just as the rest of the community respects the shared experience of those who have gone through war as being something that only the veterans can fully share, likewise, in many ways, those who are members of a support group - particularly due to a condition that has been life-threatening - have a special bond. Many, such as those in polio epidemics, have gone through the experience in childhood years with those who may turn up as support group members. In the Australian polio experience, many of these relationships go back decades. Members have kept in touch over the years and gain a special benefit in keeping in touch at meetings with their old 'comrades', with so many shared memories. Annual Christmas get-togethers with these group members are special and especially poignant when some pass on.

Rosslyn – Northern Region Polio Support Group

To our new friends we can't pretend

To our support group friends
we cannot hide behind
our inability.

"I know I could yesterday,
but today I just can't.
OK."

We've all been bound hand and foot
knew the splints and hot plasters
injection, dejection, infection, subjection,
and the ultimate resurrection.

Our support friends understand
the autumn sun, to shed our pain
to hold on
rest a while
take a breath and try once more.

We've shared the pain of other's cries
Shared years of forlorn looks and terrifying
physio
hours and hours of
you can
you can do it
just a little more . . .

Our support friends understand
our dissent
and
why we try ever so hard not to be
noticed
different
clumsy
difficult

No more
 No more
 No more

To our support friends
we can't pretend
that we're just friends.

Our support group friends understand
the push of others desires.
Our kindred spirits all live the indignity
of

Peter – Bayside Polio Support Group