

Coping

by Annie

Coping: What in the world does that mean, anyway??

What is coping? For us with PPS, coping is finding ways to deal with the challenges that we face because of our disability. It is finding ways to focus on what we *can* do instead of what we *can't*.

What a novel idea! It seems totally natural, yet something that each of us must learn, if we didn't learn it as children when we had the original polio. And even if we did, that's no guarantee that we'll remember how to use them right away.

I mentioned in a previous article; *"Grieving; the aftermath of Polio and Post-Polio*, that I had done (that I remember) little grieving after the original illness. But I was a "passer". Other than a sagging and small right arm and shoulder, I could do most things others could do. I didn't spend almost a year in an iron lung, as did my dearest friend Gail. She had surgery upon surgery, spending much of her life in hospitals, and lost the ability to go to school all of her senior year after having surgery once again and spending it in the hospital. She'd managed to keep up, and to graduate, but told me recently that when she went to her class reunion, some of her classmates looked at her as if she were a ghost, because they thought she had died. She still giggles, quoting the great Author Mark Twain, and says that "The reports of my demise have been greatly exaggerated". After all she has been through, she has retained a sense of humor that is utterly delightful. She's truly an amazing gal.

There may be those of us, like Gail, who managed to develop those coping skills very young in life. Does that mean that it is easier for us when we begin having post polio? Not necessarily. Many of us, when the post polio hits; find ourselves grieving and devastated when we are forced to go back into wheelchairs, back into braces, or back into using full time vents or BiPaps. We may find that even the best of coping skills don't provide instant relief for the grief we experience during the acute phase of grieving. They will, however eventually help.

I did not have the depth of the coping skills that Gail learned early, in the aftermath of the original polio. Most of mine had to be learned later, as an adult, suddenly lying in bed and unable to do much besides, well, just lie there. It's taken me a while, but I'm finally beginning to "catch up."

What exactly are some of these “coping skills”? These are a few.

- **Learning to be an active participant in our own care.** This was a hard one for me. We who spent our lives under the care of Dr’s, respected and admired them. And depended on them. So the idea of being a participant in our own medical decisions and our own care was a foreign thing to us. We did our therapy, but didn’t question anything we were told to do. It’s been a challenge for me, but over the years I’ve learned to ask questions like; “Why?” “How will this help?” And “How much will this cost? And if it turns out to be really expensive: “Is there something I can do that is tried and true but costs less?” I’m blessed that I have an Internal Medicine Physician who appreciates me asking, and is very willing to work with me.
- **Another thing we can do:, this, too was a hard one, especially in 2004 when Post Polio struck with a vengeance.** It is: “We are not victims here. We don’t have to just sit back and take whatever happens to us. We can fight it! (I have this mental vision of delivering a lethal Karate chop to a dragon with “ Post polio” written across it’s back, but of course, can’t do that!) What I *can* do is change my focus.

We are ultimately the ones who have control over our lives, and our attitudes. Our illnesses can do that only if we allow it. Yes, there are things about our disabilities that do put limits on us. But allowing limits and allowing control are two different things. Figuring out the difference can sometimes be a trick.

Allowing LIMITS is necessary; we know we have those. It’s how we think of them that’s important. Instead of thinking of them as *limits*, think of them as *paths*, or as *forms of enabling*. Yep, the wheelchair that we may have considered a limit yesterday becomes the path to allowing us to visit all our favorite places.

Allowing CONTROL is to give up and say, “I can’t do anything I love anymore. I want to run, I want to go to the gym, but I can’t. Since I can’t do what I love, I won’t do anything. This hands over our lives to the illness. If we do this, we’ve succumbed. We’ve given up.

Okay, so how do we allow limits without allowing control? Every time we end up with the “victim mentality” pressing inward, we can make a mental list—or a physical one, for that matter.

We can:

Focus on the things we *can* do—not just to stay busy, but to feel like we can make a difference.

These are a few of the things we can do when we have very little energy:

Research online (the recliner is a friendly partner in doing this!)

Join support groups online (you may need to spend a little time weeding out the ones that are the “doom and gloom” ones, as I did.)

Keep an eye out for others who need encouragement; and if *we* need it, ask

Write about things that interest us

Read our favorite kinds of books

Keep up with friends on e-mail

Listen to music

Watch our favorite kinds of shows and/or movies; (mine are murder mysteries)

Things that require a little more energy on days when we have more:

Go to visit sick friends and relatives

Join a support group that meets in person once a month

Join a book study group

Meet friends for lunch

Volunteer, making sure that the outfit we volunteer for understands our limitations and doesn't expect more than we can do. Also, make sure we don't volunteer for more than we can do. Volunteering is a wonderful way to feel as if we're making a difference in someone else's life and to “think outside our own selves.”

Take up Hobbies that may or may not require much energy. This depends on whether you are male or female, and how much you feel you can do—And what your disabilities are. The list of available hobbies is endless; but here are some I like to do that don't require lots of energy. Make things that you can give as gifts for holidays or birthdays kills two birds with one stone!

Making jewelry

Beading

Doing needlepoint or cross-stitch (Some friends do plastic canvas as a hobby)

Make projects with woodworking (this requires more energy) A friend has a lathe and spends carefully allotted time on good days in his workshop, keeping track of the time to enable rest.

And of course, there is always the need to try to keep up with the housework, laundry, and cooking. I know that is important; however, so many of us have so little energy that we must write into our schedule the things that we enjoy. If housekeeping is something that brings you joy, by all means, do that as your hobby. If you don't enjoy it and it's a chore to you? Compromising is important. If you spend all of your energy on doing something you don't particularly like to do, and don't do things that bring you joy, life is a dreary existence. It might help to make a schedule and try to do some of both each day?

Soooo...on to the next.

3. Another way to cope?

Whatever we choose to do, appreciate the things we accomplish for what they are. They are valuable! This may be hard, but it's important for us to appreciate our own work.

***Don't fall into the trap* of saying, 'Well, I know it's not as good as it should be; if I were not disabled, it would be so much better.'" For one thing—it's very doubtful this is true! Most PPS'ers are such type A's that we insist on doing things as perfectly as possible. Don't be afraid to be proud of yourself and what you do! But that being so, it may be necessary to allow more time to do our projects.**

There are other ways to cope; and I know I've probably missed some really good ones! Each one of us is an original creation; each of us may have different ways of coping; whatever they are, it's important that they are uplifting. At the end of a day, I feel so much better about myself if I have accomplished even something very small, that was done for other people!

Put your imagination to work! These are just my ideas, and your mileage may vary. □

Annie