

Gleanings

October Gathering

Nebraska Polio Survivors Association will be holding its Fifth Annual Polio Survivors Reunion on Sunday, October 3, 2010. It will be held at the Field Club of Omaha, 3615 Woolworth Avenue. Our schedule is as follows:

- 12:15-12:45 Registration
- 12:45-1:00 Introductions and current announcements
- 1:00-2:00 Dinner
- 1:45-2:15 Musical entertainment by Tom and Jana, possibly followed by a short talk on health and wellness
- 2:15-2:45 Pat Meirhenry will give us some helpful and enlightening words
- 2:45-4:00 Visiting and goodbyes

We hope many of you will be able to attend. There is no charge for the meal, but you do need to RSVP by Sept. 30.

Please RSVP, indicating your choice of entrée (marinated chicken breast, Atlantic salmon or roast pork w/cranberry chutney) to

Millie Lill

214 S. 20th St., Apt. 215

Denison, IA 51442

NAME

CHICKEN

PORK

SALMON

Bouncing Back Without Guilt

BOUNCING BACK WITHOUT GUILT

Wendy Clyne PsyD.

Transcribed from the Colorado 1993 Educational Conference

Today, I'm going to be talking about some of the factors that may hinder you from becoming your own medical advocate. Some factors may be related to your experience of having polio, or to anyone attempting to cope with medical problems, such as chronic pain, fatigue, weakness, loss of function.

Even though there's an attempt now to educate professionals and the general public about the existence of post-polio syndrome, many of you began to have your symptoms at a time when there wasn't much information about this condition. Not only did you not understand it yourself, but the symptoms often went unrecognized by the health professionals working with you. Or they may have been misdiagnosed as depression, as hypochondriasis, or as frightening diseases such as ALS.

When you were recovering from polio no one said to you, 'You're doing a great job but down the road, twenty, thirty, forty years from now you might have some problems'. To have to deal with the unpredictability of having symptoms returning or other symptoms coming back is extremely unsettling. Whenever someone feels like they've gotten sideswiped in life like this, feelings of being helpless, feelings of being out of control, feelings of vulnerability

are very normal. Feelings of denial, anger, and frustration are also normal in these situations.

It's important to check if the intensity of your reaction to your physical limitations may not seem to match the level of physical problems that you're experiencing. This can be a source of self-criticism for people because they are thinking, 'Why am I having such a reaction, it's not that big of a deal, I'm just having some weakness'. But your reactions are coloured not only by the physical limitations that you have, they're also coloured by your memories from the past. They're coloured by how much interference those physical limitations caused in your lifestyle, in your sense of self, and in your coping strategies.

Intense emotional reactions are a normal response to remembering catastrophic illnesses such as polio. Even if you've made a very good recovery, some of the things you had to go through to make that recovery were anxiety producing and stressful.

There is a condition called Post Traumatic Stress Disorder, which includes flashbacks, nightmares and feelings of re-experiencing the

trauma. Many of you first heard of this disorder with Vietnam veterans. Returning veterans did not have the opportunity to talk about their experiences. From that experience psychologists have gained knowledge covering the problems related to not being able to talk about and work through a traumatic experience. Today however, there's a real recognition of the need, the importance, of having an opportunity to talk about what people go through (like plane crashes or earthquakes). Talking about feeling wasn't acceptable or 'in' until the late 60's or early 70's and that was a long time after most of you went through your illness.

The people who seem to have the most difficulty with emotionally letting go of a traumatic event are the ones who either don't have an opportunity to talk to other people about what they've gone through, or even if they have someone there they feel like they aren't able to regain a sense of control about their experience.

PTSD symptoms can be set off by a lot of things; by sensory input, by thoughts, by feelings. Some people walk into a hospital and they smell the odour that reminds them

of the things they smelled as kids when they were in hospital, and they start getting rattled. They start thinking about what they went through, they start thinking about the doctors. Actually smell is one of the strongest triggers for memory because it has got the shortest route to the brain. Smells are very powerful and sometimes we don't always recognize that it's setting off some memories.

Flashbacks and re-experiencing the trauma can happen on a couple of different levels. Sometimes very concrete; you have a visual memory, you can see the doctors, you can see the hospital, you're very clear on the memories you are having. But sometimes the memories are more unconscious, something called emotional memories or physical memories. Going back to the example of the breathing problem, you might start having trouble breathing and start to panic; you're not reacting just to the current situation of breathing trouble, you're reacting to that situation plus being flooded with memories of having trouble breathing and wondering if you were going to survive when you were a child. You may not be aware of it, it may be happening unconsciously.

Another example is sometimes people may experience some pain in their legs. They know it's not a huge pain but they have this intense sense of anxiety and panic. They are asked, 'Why are you getting so upset? You say it's not bad pain.' But there's this intense emotional reaction. Part of what may be going on is an unconscious remembering of all the feelings that went with that particular pain. This is especially true for people who experienced their polio when they were very young. Real young kids remember more on an emotional level or kinesthetic level. They don't have the words to encode their memories on a verbal level. For those who had polio at ages, one two and three you might have more emotional reactions that are hard to make sense out of.

During the 30's, 40's 50's most people did not talk about feelings; doctors didn't want to hear it and our parents said 'Just be quiet and do what the doctor says'. Intellectually, people understand that it's good to talk about their feelings, but when it comes to talking about post-polio syndrome this big wall comes up and they beat themselves up about the thought they can't talk about polio. Other people criticize by saying, 'Why can't you talk about it? You can

talk about everything else'. But that pervasive feeling of 'I'm not supposed to talk about it' comes up. You're dealing with strong prohibitions that you grew up with.

Another experience on a behavioural level is that many of you were quite young or young adults when you had your polio. Even though you may be 60, old enough to be the parent or grandparent of this doctor that you're talking to, you're dealing with your polio, you're experiencing being young again, in the sense you're supposed to be quiet, you're supposed to listen., be good and do what the doctor says.

How do you confront or disagree with a doctor when you are feeling like a kid and he is the adult and you are supposed to listen and do what he says? A lot of this occurs on a more unconscious level so the more conscious you can be of this process, the more you can say, 'I'm not just reacting because I think I'm not supposed to question him.' The more conscious you can be of that process the more in control you can be and make choices about how you want to have it.

At the time you were experi-

encing polio there was not a glimmer of an accessible world. People who were disabled were not out in public, you did not see them around. So, as you're re-experiencing symptoms, there may be a sense of shame that seems totally out of context with what you're going through now. There might be a feeling that people won't want to be around me, I shouldn't be out there. The daily living begins to feel monumental as you worry about how you're going to get around. How you will be accepted.

Many of you were separated from your families. If you were out in the country, a long way from a medical establishment, your family had to stay where they lived while you were shipped off to a hospital. Some hospitals didn't allow visiting. That sense of isolation, of being cut off from your family, can also come up now even if it's not realistic for our current situation. The more you are aware of his process the more you're going to be able to manage those feelings.

Another area that I think is complicated for people with post-polio syndrome is coping strategies. Now the line is 'No pain, no gain'; back then what was pounded into you by physical therapists was 'use it or lose it' or 'push till it hurts - then push a little harder'. The way you learned to cope after polio was to push hard, to have a hard work ethic. The statistics show folks with polio have a

sense of self-esteem. If you were praised and recognized for overcoming your obstacles and for your productivity and suddenly you're no longer able to produce, many people start to devalue themselves. You need to value yourself outside your accomplishments. Recognize that you are loved for who you are and not for what you do. Focus on what you can get done, not what you can't get done. Not constantly compare yourself and evaluate yourself based on what you were able to do ten or fifteen years ago.

How do you do this? Write down the tasks you've accomplished that day. You might think you've accomplished nothing until you write it down and see what you've done. Simple tasks can feel monumental when you're dealing with chronic pain and fatigue. It's important to give yourself recognition for what you accomplish. Give yourself credit for your rest time. You're taking care of yourself - a novel concept for those who are always pushing themselves hard. Nurturing yourself one day maybe a greater accomplishment than getting the dishes done.

To regain a sense of control, learn to monitor yourself. The biggest key to that is having realistic expectations for yourself. Dr. Frederick Maynard said that folks with post-polio may take two to ten times longer to recover than someone not experiencing PPS from things like fractures, flu, - which cre-

ates a ripe opportunity for self criticism. Be realistic about how long it takes you to bounce back and you'll not cause so much stress for yourself. You have to have health care specialists who also have realistic expectations. Ideally find health care specialists who know about PPS - who understand the medical condition. If that's not possible because of insurance or location, find health care specialists who are willing to learn from you. You need people who'll remind you 'Remember this is going to take longer than you expect'. When you have realistic expectations for yourself, you have more opportunity to feel successful. Unrealistic expectations are a guarantee to make you feel like you're falling.

Other ways to increase your sense of self control are through choices; predictability, and information. One of the strengths of support groups is the information sharing. If somebody is a little further along in the process and can help you understand what he's going through, you can then prepare yourself for what might be ahead. Pay attention to your thinking. Everybody has little voices, little tape recorders in their head (things you've heard your parents say that you thought you'd never say) saying things like 'I'm not working hard enough, I should be over this'. You're buying into 'old tapes'. It's important to stop that think-

ing and say, 'Wait a minute! That was before, it's not true now and I need to let go of that.' The more you're aware of your thinking the more you can deal with the things coming your way.

Psychotherapy can be helpful. It's not for everybody and it's another area where it's important to be a good consumer. You need to see if it fits with everything I'm saying today, see if the pieces fit with your experience; some pieces will and some won't. If you're looking for a psychologist or a psychiatrist find someone you feel comfortable with, someone who's trustworthy, treats you with respect and seems to really listen to what you have to say. Sometimes people benefit from short term marital or family therapy just to help those people you are living with understand better what you're going through and improve some of the communications.. Learning to cope with PPS is a process. Things begin to get clearer as you go along.

A lot of folks are labelled 'non compliant'. It's difficult for individuals who have experienced polio and are now experiencing PPS to be encouraged to do things differently from the way you learned to cope with them.. You're asked to use a walker, or use a brace (you proudly discarded years

ago); to shirt (sic.) the way you are dealing with your situation. This brings up a lot of old polio memories. When you are stressed and anxious is the worst time to make big changes. A better way is to make changes with minor interventions at first. A way of gaining a sense of control is by being aware of your own reactions and trying to understand them. When someone is saying to you that you need to do something very differently, you'll be able to have more ability to advocate for yourself, deal with health care professionals and not be labelled as non compliant.

Some other things to help with the treatment of some of the symptoms of post-polio are antidepressants - even if you're not clear if you are depressed. Make sure you take it in appropriate doses. Folks with post-polio syndrome often require small doses to receive the positive effects without the negative side effects. Other helpful things; Relaxation, Biofeedback, Meditation, Self-Hypnosis, Holistic approaches can be helpful as an adjunct, not replacement for our medical therapy. Acupressure, Acupuncture, Massage, Healing Touch. Ways of gaining a sense of control; social activism; getting in-

involved in a support group network; distractions - such as music crafts and hobbies, reading or listening to books-on-tape; humor is a very adaptive way of coping with stress.

Lastly take care of yourself as you would someone you very much love,

Be nurturing and accepting of yourself.

GIVING IN

By Millie Malone Lill

So often I hear my fellow polio survivors say, I refuse to give in. That usually means that they refuse to use the adaptive aids that are so necessary to their continued independence. I'll never use a wheelchair, not till I cannot walk a single step. What will my neighbors say if they see me using a walker/cane?

I was thinking about that today as my dog and I were out for our morning stroll. She walks, I roll. Robert E. Lee came to mind. Don't ask me why. My mind, early in the morning, tends to roam around untethered, leaping from idea to idea like an antelope.

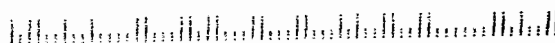
Robert E. Lee, by all accounts an honorable and proud man, nevertheless had to give in. At some point in that awful war, he real-

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ized that to continue would cost more than it was worth. He cut his losses and gave in as graciously as he could. He could not justify the losses, knowing that the end result would not be victory.

We could think of it that way, too. Our little motor neuron soldiers are dying. To stubbornly refuse to allow them rest is similar to continuing a winless war, no matter the cost. Perhaps this struggle is seen in a romantic light. Perhaps we think it is nobler to fight on to the bitter end, never letting up, even knowing that we will be defeated in the end. We may have a picture of ourselves going out in a blaze of glory, a hero to the end.

Reality is somewhat different, I'm afraid. There is no glory in fighting to the bitter end. There is ignominious defeat or there is honorable surrender. Post polio will win. It had a head start, after all, in the blitzkrieg that wiped out half our motor neurons or more in the opening sally of the conflict. Continuing to battle will only deplete our forces, leaving us with nothing as we leave the field.

There is a victory of sorts. We can call in help from canes, walkers, wheelchairs, whatever is available to us. We can leave the field bloody but unbowed. We can save our remaining battalions for other pursuits. We are still heroes. We fought the good fight. Now we can put our wounded soldiers to good use as we retire from combat. Retirement is not so bad. Now we can rest, enjoy our retirement from the battle, become civilians, wearing our battle scars proudly. There is no shame in giving in. Like old soldiers, we recognize each other and form a bond that others will never know.

Marian Barnett Retires

Marian Barnett, who has served as Nebraska Polio Survivors Association's Executive Director for 19 years, is retiring as of September 1, 2010. We wish to thank her for her many years of loyal service, and hard work. Marian put together several polio conferences, set up meetings and speakers, and got the newsletter done. She is an inspiration to many polio survivors, although she herself has not had polio. Thank you, Marian.



Mr Stentford, most people claiming Disability Benefits use the front door, some even use the wheelchair ramp!