



## **BOUNCING BACK WITHOUT GUILT**

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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 kinaesthetic 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 experiencing 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 higher level of education than the general population and are four times more likely to be employed than any other disability group in the United States. This is a hardworking, highly motivated group of people.

You've worked very hard to get where you are. Now suddenly, people are telling you to slow down, don't push so hard, don't work so hard. This goes against everything you've learned to do to overcome your disability. It's stressful. People tell me they worry because if they don't push they will feel like they are giving up.

The absolute worst time to try to change your coping strategy is when you're worried and stressed. That is the worst time to find another way to deal with what's going on, and that's exactly what people are telling you to do. You have symptoms, you don't know what's ahead for you. There's no way you cannot be worried and stressed.

Another complication, for those of you who had minor residual physical problems, success meant hiding your limitations. Suddenly you no longer hide your limitations so there is the feeling of re-experiencing those limitations and that can add to the stress. Your whole way of coping has been built on hiding your limitations. Overcoming your physical limitations has become a strong source of pride and personal gratification. When you overcame all the troubles related to polio and then see the things you've accomplished start to crumble it can be devastating.

One of the things I need to say to spouses or professionals; unless you are also experiencing polio pain and fatigue, you don't know what it's like. Even if you have a chronic pain syndrome where you are dealing with arthritis, back injury etc., you don't have all the memories, all the old stuff that's coloring your experience with the pain. For those of you who are experiencing the pain and fatigue it's important for you to understand that, when someone says, 'Oh, yes I understand what you are going through', you can say, 'No, you do not understand what I'm going through, you may have some ideas about that, but you don't really know what it's like.'

When I talk about pain I'm not talking about ten on a scale of one to ten, which is the most intense pain you can have. People who experience the two, three, four levels of pain still experience the problems that go with chronic pain. In some ways some of those folks are more self-critical because they think they should toughen up and get past that. Sometimes the pain is always there so they can't quite get comfortable and are unaware why they are feeling irritable and uncomfortable.

I've never met a person who has chronic pain who also doesn't have sleep deprivation. They go hand in hand; you cannot sleep well if you have chronic pain. Most of us learn to live with the chronic levels of sleep deprivation, even though we can cope we pay a price. There's a lot of research literature in psychology about the consequences of chronic pain and sleep deprivation in terms of our cognitive functioning such as; Attention and Concentration; Memory; Problem Solving. There is something called information processing - speed and capacity. One of the things that happens with pain and sleep problems are both speed and capacity of information processing go down. Even if you were someone who could always take in a lot of information, now you might take in less information and process it slower. For some it's more noticeable than for others.

Other things commonly seen in people with pain and sleep deprivation, especially with post-polio problems, is staying awake - it's hard to take in information when you're having a hard time staying alert. Thinking clearly, even word finding can be affected by chronic pain and sleep deprivation.

Going back to the statistics, the level of formal education for people experiencing polio is higher than the general population. That means many people with polio took jobs that involved thinking, using your brain, being on top of things, being able to problem solve. Suddenly those capacities may not be working so well. Maybe subtle difference other people don't notice, but you do. Even if you function in the normal range, if you're not where you're used to functioning, it's a loss. A loss not supported by other people who when you say 'I just can't remember names anymore', they say, 'Ah I do the same thing,' but their situation may be a lot different than yours.

If you've used your mind to cope and live with the world, then on top of losing physical function there's also the sense of losing cognitive function. This adds to the stress. Sometimes people try to attribute pain to anxiety or depression. Anxiety does not cause pain. It can increase it by being tense. Tensing your muscles can increase pain. Depression does not cause pain. It can make it more difficult to deal with the pain. Stress does not cause pain. Many doctors don't like to say, 'I don't know', so they might attribute your symptoms to being depressed.

One of the difficulties with ruling out depression is that when a psychiatrist, a psychologist or social worker is trying to do an assessment as to whether you are depressed or not, most of the symptoms are things that are common in post-polio syndrome and very common in chronic pain and sleep deprivation.

Let me go through the list of things a psychiatrist might check out if she/he were checking for depression; Social withdrawal - if you have a lot of pain, not functioning well, and you're not sleeping well, you tend not to be as active. Social withdrawal often goes with PPS. Eating disturbance - if you hurt and don't feel well you don't have the energy to eat, especially if you must fix it. Depressed or irritable mood - not enough sleep can make you irritable. Diminished interest or pleasure - it's hard to get excited about anything when anything you do takes effort. Insomnia or hypersomnia - meaning you're trying to sleep all the time or you're not sleeping enough. Fatigue and loss of energy - again very common in PPS. Diminished ability to think and concentrate.

You can see how difficult it is for people to rule out depression or rule in depression. There's a significant overlap in terms of some symptoms of depression and symptoms of PPS. People will come in and ask me 'Am I depressed?' I don't know if we can sort that out. We can take care of some of the stresses and see if that helps, but the reality is that so much of this can be part of depression and part of what you're going through as a result of your post-polio. To sort it out may not be that important.

What do you do about the problems that go with experiencing PPS? How do you get on with your life? One of the ways is to get started grieving and getting rid of the loss. Unfortunately, for some [people] that

means going back and dealing with 'junk' you didn't have time, or opportunity, or permission for dealing with when you first had polio. I'm not saying to feel sorry for yourself, be down all the time, or blame the world. That's not grieving and loss. Everybody deals with it in a different way. For some it means getting angry, for everybody it means acknowledging that your life has changed - not changes you're happy about but changes you must deal with.

A piece of grieving and loss is trying to redefine your sense of self, regaining your 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 creates 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 thinking 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 thing; 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 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.**

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