

Sitting with Suffering: Part 2

Adjusting to a Chronic Disability – Seven Steps

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After a tour in Vietnam I thought that all I would have to deal with were the hippies yelling anti-war sentiments. Here it is decades later and I discover that the progressive neurological symptoms I am dealing with are likely due to Agent Orange exposure. I was in country during one of the heaviest spraying times and the effects on my body are those that I have tracked now for more than 30 years. Initially my neurological symptoms would flare up one week every 2 years. Now, as of 2011, they are a persistent everyday occurrence with only the intensity changing over time.

I have been trained with a Ph.D. in rehabilitation counseling but nothing replaces real world experience that is also deeply personal. Over the decades there has been this continual process of dealing with loss. It is the loss of functioning, of things that were so easy to do once, of “fun” things that were much a part of my sanity in a hectic world. It has been a walk through the stages of grief associated with these losses. I have had to “give up” doing several things that I loved and was “proud of”. There were many days of angst and tears along the way.

The choice I faced was to either become disabled in mind and spirit as well as body or to reframe my life. Reframing my life so that it had a new definition of quality was not easy, and it took many years. But I replaced the old list of “fun” with other things that were more in line with my progressive condition. I built a new quality of life plan for myself. This is something that most anyone can do. The steps are easy and simple to understand:

Step 1 – Recognition: The first step in the rehabilitation process is to acknowledge you have a disability and to recognize where the issues are. It seems that you are in the middle of step one, although it is hard for me to believe that you did not know what was going to be in the letters you asked people to write. Maybe you were still holding on to the hope that it would all get better – I know I held on to that hope for a long time.

Step 2 – Quality of Life: Once you have admitted to yourself the nature of your disability then you need to take charge of your own quality of life. No one else is going to do it. Exactly what is quality of life is something that is self determined and self actualized.

Step 3 – Day by Day: Every day presents itself with issues, limitations that get in the way of functioning. An important part of quality of life is to design life so that decisions can be made daily about what is going to be accomplished that day. This means that you will have on your plate hard things, medium things, easy things and what I call “routine tasks” (which are even more simple than the easy tasks). All of these tasks can be part of a larger picture you have painted that fits your image of

what is quality of life. You will need to be flexible to accommodate the “day”, accepting what the day brings, and be willing to accept that things may not go as planned.

Step 4- Building Mental Stamina: In order to put the quality of life plan into place you need to work on mental stamina. It used to be that physical stamina was available at our command. Know that is no longer the case. It is imperative that mental stamina be worked on in the same way that one would exercise to get the body in shape for a marathon. The marathon now is one of mind and not the body. Quality of life is quite difficult when stamina of mind is present. It is one of the key ingredients to a long and productive life. But no matter where you are in the process, stamina of mind can always be increased.

Most of the success I have had has come from improving mental resilience and stamina. How to do this? Well that is individually defined. I doubt I can come up with any specific “tricks” for you without actually being in your life. I do know that there is a kind of catch 22 and it goes like this: “I need to have more mental stamina. I am tired today and I don’t feel like doing things. But I need to have more mental stamina so I can get things done. But I don’t feel like doing anything.....” and it continues on and on. I find that this is the first block to building mental stamina. The physical pain issue can be dealt with AFTER the above block. The pain is dealt with by engrossing oneself in daily activities which are connected to building a quality of life, and hopefully making a difference.

Step 5 – Keep it Going: Let us assume that you have a general plan for what is quality of life, that you have a day-by-day plan, and an exercise schedule for mental stamina. Now the hard part – putting it all in place and keeping it going. There is a simple mantra – “Every day I will do something” and at the end of the day as you head to bed you do not look at all the pain and problems but you take pleasure in what was done regardless of how small.

Step 6 – Do What You Can: Because of the progressive physical disability, and the pain, it is important to continually do what you can to lessen the effects of this in your life. This includes, but is not limited to, the following: adjusting diet, adjusting medications (pay special attention to side effects and the risk of abuse), changing the nature of daily physical activity, weight management, decreasing any addictive patterns and changing your thought patterns so that they are positive – every day! Remember that you will have “internal resistance” to change so you battle this with mental stamina. Also be aware that there is a long distance between the lip and the cup. Talking is not the same as walking the walk.

Step 7 – Bad/Good Day Adjustments: It is important to use your quality of life plan to make adjustments to both good days and bad days. On good days work on those hard tasks. On bad days work on easy tasks and routine ones. But always keep in mind your quality of life plan.

All of these steps can be done within an overall framework of “it is all within God’s plan for me” and truly believing in that. It will all come to the “good” if we allow ourselves the time and space to reframe it in that way.

If you are struggling, I pray that this brief article finds you well during this difficult time in your life.