

USEFUL LINKS:

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#2 | FEB 6 2023

BUTT HURT? PARK THE BIKE AND TAKE A BREAK AT

Keithbob's Village

COPING SKILLS:

I GET BY WITH A LITTLE HELP FROM MY FRIENDS

I'm often asked how I maintain a positive outlook as ALS slowly shuts me down. To be honest I really don't know for certain, but I have some ideas.

Many will want to know "when were you diagnosed?" (August 2020) but I don't consider the actual date important. After learning I had ALS, I was able to look back two years and understand why I was having those muscle twitches, leg cramps and shortness of breath. I have been feeling ALS since at least 2018. Once I understood all the symptoms, I could start to deal with the ALS.



PASTRAMI IS A JOYOUS THING

Upon diagnosis, I could still do everything, except grip a hammer driving multiple nails. My right hand lost grip after a few nails. And my right leg was a little weak. I limped some. For the next 18 months or so I concentrated on *what I could still do*, and that method seemed to work. For a while. But that attitude contains a hidden dichotomy, a kind of yin and yang. I might be thinking about what I could still do, but deep down in my brain lurked the underlying pairing of what I could no longer do, and that dragged my attitude down. While I believed I was thinking positively, I was simultaneously grieving my loss of abilities, which were starting to pile up. With the help of a therapist, I discovered a new way, the Yoda Way.

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"DO, OR DO NOT"

The Yoda Way applies to whatever choice is directly in front of me right now. I can choose to do something, or choose to forgo it. I give myself permission to select either option. Having made the choice, I can move on. I stay in the present and there is little regret over not doing something. Of course there are times when I will be sad about choosing Do Not. But it's far better to make the choice and then move forward with life than to sit around moping about how bad things are.

DON'T TAKE ANYTHING PERSONALLY

I don't have the energy to take ALS personally. Nobody pointed their finger at me and said "Keith gets ALS." Yeah it sucks that this happened but I'm stuck with it, and no matter how angry or bitter I let myself get, I can't fix it. Trying to get around in a wheelchair is frustrating. Trying to do anything with my hands is frustrating. The day I could no longer kick-start the Husqvarna (my beloved dirt bike) was a really bad day for me. But I'm not going to waste my energy on anger toward ALS. It's not going to change anything. Better I put that energy toward some fun or useful or meaningful activity.

RUN TOWARD LIFE

Let's face it, ALS is a bitch. It makes everything harder. And things continue to get tougher every day. But guess what? There is a lot of fun and satisfaction to be had even as your body falls apart. There are wonderful people around me. Yes, there will come a time when I'm ready to say I've had enough. But until then I'm still living. There are wonderful things to see and experience, and I keep this in mind when I choose to Do or Do Not. I have no intention of missing out on cool things while I can participate in this world. No, I can't ride motorcycles anymore but guess who's helping to host the Canal Creek BMW campout this coming August? Guess who is going to the One Moto Show this spring? Yeah, that's right. Me. I don't intend to lay back and slouch toward death. I try to keep running toward life.

"WHAT'S THE MEANING OF ALL THIS?"

It was always bad when we heard this out of Mom. Now I'm the one asking about the meaning of living. Finding what gives me agency today is very important for maintaining my self-worth. What can I do for Jalene today? I can't make or fix much anymore, but maybe I can buy the supplies for the emergency kit she has wanted me to put together for years. Maybe I can help everyone I know by writing this newsletter. If you have never read Viktor Frankl, I strongly suggest you do so. His slim book *Man's Search For Meaning* will set you straight about the importance of meaning in your life. I'll loan you my copy.

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WHAT DO I DO NOW? ASK FOR HELP!

As things get harder, the choice to Do or Do Not is sometimes taken away from me. I think the next six months are going to be a time of vast and significant change. I will lose the ability to handle utensils. I will lose the ability to turn the bidet on and use it. I will probably have a catheter every day. These are not pleasant things to look forward to. How will I handle it psychologically? Will I still find meaning in life? Will I be able to keep a positive outlook?

I have always avoided complainers. I also hate to complain myself. Because of this mindset I often don't ask for help nearly soon enough. And so - in the future when I find myself complaining, *I will know that I didn't ask for help soon enough.* And I think help is going to be key to keeping a positive outlook as things get harder and harder.



THE WORLD'S BEST HELPER

CAREGIVERS NEEDED!

We could really use your help! We have a neighbor who is an amazing care giver for me three mornings a week for 2-3 hours a day. This frees up Jalene to work uninterrupted during the morning. Jalene is my care giver in the evenings and on weekends. Here's where you come in — we need a care giver on Thursday and Friday mornings from about 8 or 8:30 to 10 or 10:30. Jalene has been checking with all the local agencies for the last few months and they don't have any openings.

Would you, or someone you know, be interested in volunteering or being paid \$25 per hour as a care giver? Jalene has learned how to do it and can train a caregiver, so for the right person no experience is necessary. Jalene is often (not always) nearby. Here's the basic morning routine: wake me up, help me with dressing, get me out of bed using a lift system (no manual lifting involved), put me in the wheelchair, put on my shoes, and help me get breakfast. If the person is being paid they could help with some light housework. Please share our contact info directly with anyone you know: jalene-case@gmail.com or 541-272-2337. We are grateful for whatever you can do to help.