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Life without sax? Oh, no!

I haven't been able to play my baritone saxophone for a few weeks. I'm bummed and worried. I often speak about my health goals: progress as slowly as possible, don't fall, don't mess with my pathological optimism, and continue playing the baritone saxophone. I haven't been able to play due to issues with my back, decreasing mobility, and the weight of the big 25-pound horn hanging around my neck. I've been playing an average of an hour a day for the past 18 months. The more I play, the more equipment I accumulate and lug around. One place I rehearse weekly has 2 flights of steep steps. It's been getting more difficult and riskier to climb those stairs. I know that I could get band mates to haul equipment for me. That's not the problem. I haven't been able to stand and play for 15 years. I sit. But I spent the last couple of weeks not able to sit for more than 15 minutes at a time. If I can't sit and hold the sax with a shoulder harness, I can't play. What are my options? I could play a smaller instrument – clarinet or alto sax, but I love the bari. Playing the bottom resonates in my soul and in my bones. My sax teacher pointed me to a bari sax stand made in Germany that will hold the sax while playing without a strap. Hopeful that works, but it's more equipment to lug around.

Acute pain, chronic pain, which? 02:34

Sarah Anne Shockley of <u>The Chronic Pain Companion</u> blog and website fame published a nice six minute <u>video this week</u> with nine approaches to managing chronic pain. Timely for me. Is this new thing acute pain on top of chronic pain or new chronic pain? Too soon to tell, yet these experiences allow me to self-examine, re-examine my approach to managing pain. I'm disturbed that none of the tools in my toolbox seem to work. No, that's not true. Massage, chiropractic, and acupuncture focused the pain that started as a debilitating cylindrical trunk pain and transformed it to a more localized mobility interrupting pain. Ice helps more than heat. Owning the pain, becoming 'friends' with the pain, work the edges of the pain, resting when able, keep moving, etc. etc. Good news I have tools, but I do need some new ones.

Face and adjust to changing abilities 04:15

How do we adjust as our abilities diminish – with pain or without pain? How do we put a value on doing what we love? Can I put a value on playing the bari sax? Can a runner put a value on marathons when exercise tolerance lessens? Will problems playing the sax impact my pathological optimism? I'm fortunate that I live with an occupational therapist and have a top-notch physical therapist. They help



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me adjust and adapt as my MS progresses. I'm wired for adapting. It's my superpower – accept what is and adapt. Still – it sucks.

It's interesting to watch my wife and I alternate freaking out about these changes in abilities. Is this temporary or a permanent progression? What does it mean for my independence, our plans? Thank goodness we don't often freak out at the same time. I can see that additional caregiving is a stressor for my wife although she appears to go with the flow in pretty good humor. Occasionally, that stress leaks out. I learned from a grief counselor the importance of managing the stress you can manage so you can handle the stress you can't manage, like grief, like progression, like pain.

Now a word from our sponsor, Abridge. Use Abridge during your visit with your primary care, specialist, or any clinician. Put the app on the table or desk, push the big pink button, and record the conversation. Read the transcript or listen to clips when you get home. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations.

Right sizing virtual and in-person primary care 06:37

I'm trying to find a cause for my pain and lessened mobility? Is it neurological, MS, or is it musculoskeletal? I'm fortunate I can count on my PCP to dog this until we have a cause, a diagnosis. Yet, so far, we've only met about this via portal chat and virtual visit. Nothing in person. I will be meeting with one of her colleagues this week for a physical exam since she alternates weeks for virtual and inperson visits. We still experiment with virtual, a double-edged sword, when to use virtual and when not? I continue my amazement at the range of issues family practice clinicians contend with while low specialist on the totem pole – less time allotted, less reimbursement, less recognition.

Maintaining spirit, pathological optimism 07:45

Lechuga Fresca, the Latin Band I play with rehearsed on my patio a few days ago. I played percussion - claves and maracas. My mates exclaimed that I still smiled and laughed despite the pain and not playing my horn. My superpowers endure, most of the time!! May that continue. May this be temporary. May this be acute, not chronic. If not, may I adjust. Onward.



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