

2017

January 8th, 2017

Feel the best since early December. Sleeping better last few nights. Gut has started feeling better on Wednesday. Seemed to have a big diuresis that day as well. Ankles are much less swollen.

January 10th, 2017

Officially back. Gut feeling back to baseline...no strong urge.

On a more savory topic, I had my strongest, best buzz yoga ever!!! Did 30 standing breaths tall, one leg forward then the other. Ankle stretches. 300 kapalabati breaths with no early SOB and maintained the same snap and depth and cadence the whole time. Strongest ever and I did it in my room.

January 17th, 2017

Wow!! Run of amazing yoga. Went to the ALS clinic and performed at a high level. My weight was 184# and my VC was up from 82-88%!! Then Jane and Marcy came for a visit. My yoga was strong and enjoyable. Had a number of days in the last week that equaled my strongest day ever and had the best yoga buzz ever yesterday. Crushed my kapalabati breath record with 725 and form is pretty quality throughout. My pace is faster and the snap is quicker. ***I am also discovering parts of my body that I never knew. I can now feel lordosis in my upper thoracic spine.*** Tomorrow morning is my colonoscopy. Hopefully they find something to fix.

January 18th, 2017

A few texts I wrote yesterday:

Sarah: Thank you & congrats on your breathing and perseverance with your practice. It's a testament to you! Yes, enjoying the space of growing with Kaia.

Me: The mother-daughter bond is such a beautiful thing to witness. ***As to perseverance, that was required for the first 18 months or so. Now my practice is a necessary part of my life and the source of mind and body inspirations from which all good things come 😊***

Me: Hi Michelle. Just read your Grow Wise newsletter. You write beautifully with great feeling and connection. ***I thought I would share my 2017 goal: Explore the depths of my yoga practice from which all good things and energy comes 😊***. Here's my yoga journal entry from today: "Wow!! Run of amazing yoga....."

So, all is good with me. How about you? 🙄

Michelle: This made my day yesterday! Such great news from you and all I can say is I am completely impressed by your determination and commitment to your well-being. I am so glad you texted, you have been on my mind and I would love to connect with you over the phone sometime soon let me know what your availability is and we can set something up. Have a beautiful day!

January 23rd, 2017

So, ***best ever*** is losing its impact if I say it every day. But there is no question that my endurance and strength continue to improve. I need to pursue some way to measure it. ***So, 3 years ago my core was out of my normal reflex motor loop that functions in the subconscious background to keep us upright.. I was holding my trunk up with my arms. Didn't even know it. In retrospect, it was if I had a stroke and my motor strip had lost the connection to the core musculature. In the early days of yoga, I was fearful of losing my balance when sitting unsupported by my arms. When I would get slightly off balance, I would just go that way. The righting reflex was absent. My yoga has forced a reconnection and retraining of the core. My reflexes have started to return. Pretty amazing.***

January 27th, 2017

Best ever!!! Feeling really good, really strong. Have the thought that this is for real. One yoga thought: I had my strongest kapalabati breath session today. Did a record 1001 in 3 contiguous sets. Really good form. I also had an insight into the form...when my form is best, I feel the breaths emanating from the entire circumference of my lower torso. Particularly the low flanks. Also, I'm in a really good headspace. Here is a text I wrote to Michael Trujillo about the Winemaker's dinner with Tim Carr:

"So, I gave you 10 days...no reply 😞. Had my best day of yoga ever today 😊. Feeling amazingly good. ***A few years ago, I was hoping to see spring. Now I'm pretty sure that I will***

be around for awhile which makes making good on commitments a bit more important 😎. So I ask you to help me honor this commitment 🙏. I can't promise you a lot of wine sales, but can promise a good time with really good people. And the knowledge that you helped me check off one important item in my "bucket list". And an added bonus, Dianas's birthday is May 24th. She's going to be in great party form 🥳 🥳 "

Hope it works 😊

January 30th, 2017

Yoga is great. Feeling so strong. Accomplished a bunch of stuff. On a roll. Did 849 kapalabati breaths without a pause. Only stopped when I had to swallow. Great form. I feel my breath all the way to C8. Seems like the more stoned I am, the stronger my yoga is. Am standing longer and it is better tolerated.

February 4th, 2017

Thursday. Not too inspired. Friday was great. 90' with 2 sets of 400 kapalabati breaths. Today 60' with 1 set of 650'. Strong!!

February 9th, 2017

Had a temporary setback. Unsure of the reason. Bladder and bowel urgency markedly reduced today.

During yoga, aches and pains disappear. Righting reflex enhanced. Meditation comes in bursts triggered by a set of yoga. Very strong enhancement of clarity and creativity of very positive thinking. That in itself is pleasurable.

So, after a week of uninspired yoga, the last 2 days have been stellar. Really strong. I feel powerful. Best performance of a number of the poses. Breathing so comfortable. Buzz is pretty dependable. 1'21" with 750 kapalabati breaths. Feeling good.

February 10th, 2017

Amazing day of yoga. Best buzz ever. Yoga buzzes come multiple times following poses. Seems the harder the pose the better the buzz. Being good and stoned doesn't hurt either.
1111 kapalabati breaths. New record.

Yoga thought. I realized and felt early on that improving the pose was a focus. That's maybe the first thing I really felt.

February 11th, 2017

Finding the breath is almost instantaneous. Shakeout cruise of the new dab rig. Toasted. Strongest arm day ever!!

February 15th, 2017

Used to find the breath. Now the breath finds me. Last few days have been uninspired. A lot of things to wrap up. Need Diane's help. Don't know how to ask. Same old thing. My yoga always perks me up. Just a matter of what degree.

February 16th, 2017

So, it's not that easy. I am getting complacent and a bit cocky. Uninspired yoga is part environment and part lack of focus. Today, I didn't take the breath for granted and worked for it. Much better session. Maybe I learned something. Breath is earned, not given.

February 25th, 2017

Dear Yogini Sarah. As I aspire to a deeper understanding of my practice, I have a favor to ask. I am designing a yoga station in our Miami condo. I am in need of a mat. Thought...would you have a spare mat infused with your yoga energy that I could buy? Happy to replace it. I'm starting to get it

Enclose Endorphin article.

February 26th, 2017

One of the hidden blessings of this is the yoga buzz. It has a narcotic character. Practicing enhanced yoga involves cannabis. Here is my proposed mechanism on a pharmacologic basis related to receptor density: Endocytosis of endorphin receptors from reduced stimulation increasing sensitivity.

Yoga thought. Dictate into a voice recorder and have it transcribed.

Last few days of yoga have been very very rewarding. Have Introduced standing into my practice and am gaining stability and noticing less sensory discomfort. Less auditory disturbances and less brown out sensation. In fact, the auditory and brown outs that used to be permanent with my yoga have decreased as I have gained endurance. I am capable of more output before they appear. Also, the more I push my yoga, the more intense the buzz. The buzz and the sensory disturbances seem very closely related.

March 7th, 2017

Didn't do yoga today for the first time in I can't remember how long. I have had a good week of yoga. Really strong kapalabati breathing. Also standing more and noticing improvement in stability and walking.

March 12th, 2017

Erin and Pablo here. Stool's pretty normal. Had PT Friday. My sigmoid colon was unhappy. ?Hernia. Better today.

Yoga really does it for me. I feel a bit out of sorts and yoga turns it around. My mind is hyper alert interspersed with nothingness. The nothingness feels wonderful. It grows in intensity as the session lengthens. Afterward I have a period of deep relaxation followed by incredible energy that lasts all day.

Today was 1 hour 30 minutes with a liter of water and 600 kapalabati breaths. Strongest day ever.

March 15th, 2017

Good yoga. Reduces my urinary urgency. Makes my gut happy.

March 19th, 2017

Was enjoying my daily yoga practice and, in my mind surfing thought of home, yoga and you. Hope you are weathering this winter in good health both physically and spiritually. Tomorrow at 10:28 AM the sun passes the equator on its way north. The annual cycle of renewal begins.

March 21st, 2017

Had PT at 11:00. On the parallel bars, I was marching to 90 degrees. 3 sets of five. Felt good at the end. Remarked to Chris that my legs felt awake. Came home and had the best yoga ever. Strength, buzz, everything. Was feeling a little dull after lunch. Was thinking negative thoughts about me in the future before I started. Yoga turned that around powerfully in the first three minutes. I woke up feeling like I didn't expect much out of today and it was awesome.

March 22nd, 2017

PT. Better early. 10?? I am developing routines that marry nicely with my yoga. Maybe better to focus on the lower body one day and upper the next. I think stretching immediately following motion might be more effective.

March 23rd, 2017

I live in compression. My practice combats that. Shoulder range of motion. Some exercise in the chair. Neck traction. PT plan built around how I live.

Board with scale or yardstick to measure sun angle.

Feeling progressive increases in strength and endurance over the long haul, but comes in bursts followed by plateau. Best kapalabati breaths ever, 500 with good form. Belly is nice and warm after the Breath of Fire. Also the orthostasis and brown out feeling is gone. Less toe curling. The buzz lasts all day. Also my mind is crazy active during yoga. I have some almost brilliant thoughts.

March 25th, 2017

Great shoulder ROM: hold a glass with both hands in a drinking position. Slowly move the shoulder girdle through extremes of position while keeping the glass stationary. Reverse direction.

Stretching/exercise apparatus.

April 2nd, 2017

To Adam: I had an amazing yoga experience yesterday. The buzz was so intense I felt like I was tripping. My mind was electric and my body had this intense buzz of pleasure. It seemed to last a long time, but it was only five minutes. That must be what meditation is like?

So I had a really good run of yoga. The mental component keeps getting better. I am incorporating the PT instruction into my practice. Pooping great. Feeling good.

Both Fred and Millie are afraid of sitting in my lap. Reasons why.

- I can't physically handle them. I think they sense my insecurity. All the other people in their lives are capable of picking them up. They see me as different.
- Wheelchair. Lots of no touch buttons. Tough to walk next to.
- Male.
- Can't visit their home.

April 13th, 2017

Going home soon. Miami is good for my health. Really hard to leave.

April 16th, 2017

Easter. Flow. ***When I'm flowing I'm either thinking about my body, my breath or nothing at all. Really internal.***

Amazing yoga today. Lots of flow. I do a set of something and start to think just about my body or breathing and my body buzzes all over. Then I come out of that into mind surfing and finally back to the present.

Toe curling and auditory distortion is minimal and it takes more to provoke them. Conditioning is producing tolerance to these side effects.

April 20th, 2017

To Spike and Jenny: Morning friends. Last day for you guys 😞. I have an idea. How about instead of the party we have an early dinner at Mike's Irish pub, the kids and I watch a movie and you go to the Standard for cocktails? Besides, I have a big day tomorrow with the ALS clinic and want to be at my best. A wine tasting isn't the best preparation. Sounds good??

April 21st, 2017

Wow!! I was tripping really intensely for what seemed to be a long time. It feels like you're going to pass out. It used to scare me. I let it go today and wow. My gut feels sooo much better. Had PT at 10 followed by the ALS clinic. Got home at 4:30. Went straight into yoga. So, when I checked the time it had been 11 minutes. I feel powerful. I had a great PT. Am stronger. Look forward to the gym. VC was 1 point lower at 87% but I felt better. Need to find a spirometer.

To Adam: Was intensely tripping today. Then, right as I finished yoga 3 international flights flew by my balcony really low. 2 were A-330s followed by an A-380 which was doing 230 kts at 1500 feet. It was so cool. I'm naked on the balcony. Hope someone saw me 🙈

April 25th, 2017

Strongest day. Best buzz. Felt so powerful. Had an aggressive PT upper body today. Worked out for 30' and then got stretched out for 20'. Was in an amazing flow when westley barked. It brought me back but was a demonstration of how many layers below I was. Really deep.

No doubt in my mind I am benefiting from PT. Tangible progress is my breathing is more powerful, and walking is more stable. The feeling of losing my balance is much less, lifting my right leg is possible with less collapse of my left hip. Also, my gut is feeling great for the first time in recent memory. I feel better than I have in a long time. I feel great!!

April 27th, 2017

Last PT day. Feel stronger and my measurements confirm. My flexibility is way better. I was statistically significantly improved in all but 2 measurements.

Today's yoga is really mature. I just feel immersed in it. Best ever. Funny how the best yoga follows PT.

I've noticed that my default motion is sloppy and unnatural. If I consciously think about the body mechanics of reaching or sitting, I have been able to do the maneuvers and improve the strength and range and performance impressively. I'm capable of rehab!!

April 29th, 2017

This disease creates lazy muscles. If I would have given in to the pull of the disease, I would have been a blob. Movements are sloppy and imprecise if I don't think about it. My movements are not coordinated. For example: starting yoga. Getting my water and timer. Getting the chair in just the right spot lining up with the tile. Then getting positioned on the chair. Lots of shit. If I just get to it, I end up with no base to support me. I'm leaning at an awkward angle totally unsupported. It's like I start the movement with my hand and work backwards. That's my natural coordination with my disease and it feels right to accept it. This is the insidiousness of ALS. It lulls you into a sense of confusing inevitability. I realized that if I consciously plan the movements, I can do it with better form. Over time the movements become more natural with less conscious thought. What PT has taught me is that I'm capable of improvement. It seems that the rate of improvement accelerated with PT. I feel great 🧐

April 30th, 2017

Had an amazing day. Forgot to mail the taxes. Found a self service usps in coconut grove. Took 3 hours to get there. Metro mover out. Lots of other impediments. Felt great and didn't feel fatigued. Arrived back home and immediately did yoga. Was in the flow big time. Seems like the harder I push myself the better the yoga is. This last week has seen the steepest rate of improvement ever. My core is alive!!

May 3rd, 2017

My Birthday. Just turned 64. 6 years from diagnosis. Wasn't sure I would make it this long, especially feeling so well. Grateful for yoga and the miracle of finding it.

Got back from Miami yesterday. Miami was magical. I'm in a really good place both physically and mentally. The PT opened up a world of possibilities. Very excited to pursue that.

My email to Ned, Lex and Adam about flow and the flow genome project:

Alright. Just finished the podcast. It affirms what has happened to me over the last 2 years. The last week my yoga was so intense that I have seriously never been that high. My body is filled with pleasure and my mind is hyper alive. It is real!!

So, I am a curious skeptic by nature. It keeps me busy looking for proof and am unwilling to accept something as truth unless I have assured myself that it is proven. That leaves a lot of unanswered important questions, but I am particularly good at not knowing. In fact, it's almost deflating to answer a question, because the real joy is in the search. Fortunately there are plenty of questions that I will never answer in my lifetime:)

With respect to my disease, I accepted the diagnosis as fact but elected not to read anything about ALS as it is about as well understood as the Big Bang and far less interesting. My skeptical nature protected me somewhat by not having me buy into the system. The literature and neurologists basically tell you all the horrible things that happen and nothing me or anyone else could do to change the inevitable. Not my idea of something I wanted to think about in my last days so I just got busy living. I was not certain of the direction I was going until I found yoga. When I got the first glimpse of flow, the skeptic in me said is this real. That was July 19th, 2015 on Dan Murphy's dock. It took me until this February to finally become a believer.

It's all about the journey. Very glad you're on it with me. Can't wait to read the book.

Dr. Scott

May 6th, 2017

So, the most profound day in my yoga practice ever. Feeling pretty out of sorts before. Feeling like I had to pee. Took a few hits of the new bubble hash. What followed was incredible. Felt the pull of flow before I even started breathing. My body was actually flowing. I felt incredibly strong and discovered a neck stretch that was so intense. I had a few buzzes when I felt like I might pass out but reduced the intensity and was able to work through them. The flow that followed was the best ever. I finally came out of it to drink water and put a tickler to describe neck rolls and only 11 minutes had passed. Nuts!!!

Side bends: both arms outstretched palms up. Lean to one side with contra lateral arm coming over head. Repeat for the other side. Thought: like a ballerina.

Figure 4: neck roll.

May 11th, 2017

Yoga has been somewhat disjointed but really strong. I'm distracted by all the stuff to do in a good productive way, but the deep flow is fleeting. One additional physical thing I notice is my strength and stamina increase with each set. I need 5 minutes recovery. Notice my strength improves a little each day. Need to get a trainer. Btw, did 1000 kapalabati breaths with good form in one set. Best ever.

May 12th, 2017

Hi Sarah. How are you doing? We're back in Pennsylvania and it's really cold. Doing my yoga mind-surfing and came to this realization...You got to me just in time 🙏.

May 13th, 2017

I take my breath for granted.

May 14th, 2017

It's been a week of transformation in my practice. The length and intensity are increasing. No doubt that pushing myself yields more rapid gains. The gym is next.

Today I had the realization that I didn't feel as heavy. I felt light in the saddle. I have felt leaden in my feet for years. Never realized that what was happening in my legs was happening in my trunk as well until today. It's the insidious nature of the disease. Your body readily accepts and succumbs to the process. It's like you don't remember what it felt like before. Nothing is natural. But, by working at it I am seeing gains. And oh does it feel good 🥰.

Neck stretching is killer. Making gains. Also, finally figured out a hamstring stretch. Having one foot on the floor and one leg on the chair. Next, heel cord stretch and walking.

May 16th, 2017

Last 2 days were mediocre. This morning was worse. Diane got mad when I tried to communicate on moving the chair in my bedroom. Can't believe how we ever sailed. Then she left for breakfast with Shelia and the grocery store. Jan was supposed to come spray. I was on subconscious alert. Never showed. Trying to use the applesauce. Spoon in a big jar. End up getting applesauce all over and dropping 2 pills. Cluster. Then I have no shorts because they're still in the closet. Finally get to yoga. No water.

So, start in a bit of a funk. As a worshiper of routine, this showed the limitations of my disease at every step.

The silver lining...once I started yoga everything brightened. Amazing 🤗

Hands definitely less spastic during yoga. Able to grasp a glass more completely with my thumb.

May 18th, 2017

Can endorphins be measured?

May 22nd, 2017

Adam. A somewhat personal question that I would appreciate your guidance on. I am finding talking progressively more difficult and physically taxing. I am also conscious of it to the degree that I have started avoiding phone calls, conversation and have avoided coming to TAIT. Feeling pressure to speak makes my speech worse. Kinda like a stutter. 😬. Need to figure out a way to take the pressure off.

So, we have the Winemakers Dinner on Wednesday, plus it's Dianas's birthday. I love everyone who's coming. I'm nervous about talking. I thought I would send an email to all the attendees saying basically this and letting them know that my silence doesn't mean I'm not having a great time. What do you learned gentlemen think about my plan? Thanks, Dr. Scott

Monica. You stated, "A simple pose but there's lots in there". I always feel that way. Get inside the pose and then constantly tweak it.

I just had the best flow ever. Felt kinda shitty before. Lots of stuff. Have the Winemakers dinner Wednesday. Got a call from Victoria. Hung up and wow 🤩. Powerful. Light on my seat. Mind crazy good.

May 23rd, 2017

Hi friends.

As my mother said, "good things come to those who wait". We are all soon to be rewarded:) Michael has his fabulous wine and stories to share while we enjoy the fabulous food chef Tim has prepared.

Please allow me to share the principals at this soirée as a preliminary introduction:

- *Michael Trujillo, winemaker extraordinaire from Napa.*
- *Tim Carr, chef extraordinaire and owner of Carr's restaurant.*
- *Jane Fairorth and Carla Stull, friends extraordinaire.*

And us, the lucky recipients:

- *Jan and Tom Bergen*
- *Katy and Troy Clair*
- *Beth and Jeff Cope*
- *Tracey and Adam Davis*
- *Ann and Ray Foley*
- *Diane and Scott Stieber*

A little about me. I have come to the realization that surviving with a disability is a work in progress. Ultimately you have to own it. It took me a few years to understand that. Now, I have to remind myself that I'm in a wheelchair. I have found my way to a place of happiness and contentment that is profound. Yoga is the pathway to the place. I truly feel great.

So, on to my next challenge. I have noticed my speech changing for a few years. Over the last 6 months I have found talking progressively more difficult and physically taxing. I have tried to concentrate on speaking clearly, but the harder I try the worse my speech becomes. I'm currently searching for ownership of this challenge.

Why am I telling you all this? So, when I'm sitting silently at the table with a shit-eating grin, that's my excuse:)

Really excited for this celebration.

Dr. Scott.

- Does sodastream carbonation neutralize stomach acid? SIBO?

May 25th, 2017

Dinner at Carr's with Jane and Carla with Tim at the table and my wine.

Honoring the organization that made my practice possible, LGH. I thank all of you for supporting a cause I feel a personal attachment to. We didn't recognize it last night, so please allow me to do it here.

House is quiet. Michael just left. Reflecting on the night doing enhanced yoga mind surfing and arrived at today's intention: 'it's good to be home':)

May 28th, 2017

Last week was uninspired. Felt out of sorts. Yoga has been distracted. Amazingly though I was able to find buzz and feel much better afterwards. It's real. Yesterday I really didn't feel well. Headache frontal, gut not happy, fatigued, yoga with mild auditory wah wah. Weak upper body. Thought about stopping. Then started kapalabati breathing. Had to push through the early sense of SOB but 150-400 were pure and best ever and the lower body was the strongest ever. Maybe all the wine Wednesday night had an effect?

June 2nd, 2017

So, my back was stiff on the 29th. Not sure how it happened but same old thing. Made my standing much more challenging. Took a total of 3 naproxen and took it easy and today I'm 96% better. My first thought was how long it had been since my back had bothered me 😊. Monica came for the second time and it was good. It's been a while on this plateau. Waiting for the next period of growth.

June 4th, 2017

Fred, Chelsea and Michael came yesterday. Yoga for the last 2 days was good. My back is 110%. Doing cobra comfortably. **It is amazing how my back is holding up.** Another blessing. Core is the strongest ever. Notice it most with Boris's toilet assist device and getting out of the armchair in the great room. Feet are much less slippery. Concentrate on my quads bearing weight. I can honestly say that I'm able to accomplish them better than a year ago. A definite marker to measure my progress. Struggle to get off the toilet without the device being

forward and using my calfs against the bowl. Now the device is back and I'm more stable getting up.

June 9th, 2017

ALS is a neurological disease. Is it possible that by using the muscles you maintain and even rehab the neural pathways? Neuroplasticity?

June 15th, 2017

The last week's yoga has been consistently good. Arrived at the lake yesterday. Today Best yoga ever. Back has been less twitchy and minimal spasm. Had a record number of kapalabati breaths, 901 and only stopped to make the next record achievable. Leg lift and figure 4 strong. Two years ago Diane had to roll me over in the Murphy bed. Now I am comfortable rolling side to side. It's all about the core which is much stronger.

Yoga thought. Why do I get the impressive buzz I do so easily? Maybe because the bar is so low? 😊.

June 20th, 2017

The lake was good. But not the best for yoga after day 1. Instructed Phil on yoga. Didn't do yoga yesterday for the first day in months. Today I did 1 hour and 30 minutes at 09:30. Really awesome. Then Monica came for an hour in the afternoon. She's going to be good for me. Was the best mind surfing ever but I can't remember all the themes. 😊

- Out of bed early. I am wasting the morning lying in bed.
- Early yoga. Yesterday I did yoga at 9:30 and had lots of time in the morning.
- Writing my book. Start with fleshing out topics. Don't worry about how it fits together.

June 21st, 2017

John was helping me with the irrigation system. In resetting Zones 1 & 8 boxes, I gave John my dad's pick and said "dig here". On the first pass, he hit the mainline and necessitated an expensive repair. John is 15 and I am 64. Who's the adult in this interaction? I said "Giving John the pick was the ultimate expression of faith."

Elam: I'm honored that you trust your boys with me.

June 22nd, 2017

My mind is on fire. After 2 tough yoga practices, today has been sloppy. I think I'm too stoned. My mind surfing, on the other hand, has been 20' waves. Below is a smattering of locations I could remember surfing to. Really stoned.

Debby listened to our last session together and talked strategy.

Todd and Mike. How to compensate?

Compression and socks.

Discuss with Jake how to build the tomato deck.

Amish text. Hand deliver the statement below as a computer printout.

June 25th, 2017

Really good session today. Strongest ever. Back feels great. Nothing hurts. Mind surfing is incredible. My mind is not blank. I get lost in the pose and find my mind touching base with different parts of my body and informing improvement in the pose. The buzz I have while lost is ecstatic. Very similar in character to an orgasm but lasting much longer, maybe 3-4 minutes. I have 5-10 in a session of varying intensity with the strongest one typically the first. In between I come back to reality and do the power part of my practice. When I do my hamstring stretch I have one foot on the floor and the other leg on the chair. Get a good Stretch. After I notice less spasticity in my Achilles.

Need to work on my legs. Slant board comes next week. It is going to have the same finish as Elton John's piano bench.

June 26th, 2017

- Core is circumferential. Feel powerful. -Never felt this strong. Less to absent toe curling.
- Body never felt this good.
- ***ALS makes you lazy. Each movement is rendered cheaply. I can make them rich but have to concentrate and develop the muscle groups I ignored.***

- Way less yawning.
- I feel my weight in my heels.

June 27th, 2017

Yesterday was amazing. Starting at 08:30 with picking up John. Lancaster irrigation came around noon and fixed the break caused by a pick (my bad). We got a lot done. Then the Tait guys came and raised the canopy on the trees. Then Tim and Marcy came and Tim did some exercises with me. It was a great day and I felt great. Then today I had the absolute best yoga buzz ever and right at the end of that buzz Sarah texted me. The power of positive energy demonstrated again!! Then Monica came. Another amazing day.

Then I crashed. I wanted to get my tomato fertigation running and the butts on for the overnight cook and I came face to face with my disabilities...my hands don't work and I can't talk. Diane and I bumped through both of them with my frustration showing and choice words about me from her. I have to own this part of my disability too. I can't do it myself. I need help. For my help to participate most effectively, I need to be an effective leader. Need to have a plan 😊.

July 9th, 2017

Can't remember. I had a period of the best ever yoga and then kind of talked myself silly over 2 parties in 2 days. Too much on my mind...assessment, projects, car, ??other stuff.

Had the family here for the entire holiday. Parties Saturday with the English and Amish Monday. Had great yoga during the baby's nap time. I carved out my quiet time better but it was still a lot of disruption to my routine. Wonderful and worth it!! Had a bit of a let down after they left. They left Tuesday morning and I didn't do yoga Tuesday or Wednesday, the 4th and 5th. Took naps and felt sluggish. Thursday was good but somewhat distracted.

Friday was a doozy. Felt awesome and powerful. Near the end I was marveling at how strong I was in the one leg lift. I was doing my left leg and the next thing I saw was the floor coming at me. I hit on my left forehead, jarred my neck and skinned my forehead but was otherwise unhurt. Suddenly I realized I was on the floor naked and Diane wasn't home. I couldn't reach my phone and couldn't get up. I laid there for about 20 minutes and then heard a voice from the porch. It was Marcy bringing me the MRI of her shoulder. I was presented with a Sophie's choice, should I have her come in and help me accepting the fact that I'm naked or wait for Diane? I chose to bite the bullet and she came in. We then spent an hour figuring out how to get me off the floor. Lots of giggles.

July 13th, 2017

Monica yoga day. Have been pushing for the last few days. John yesterday and worrying about the reassessment for a few weeks and Chris. Have way too much on my mind. Miami will be great.

- Slower pace. Hold each pose for 3 breaths while continuing to tweak. Have Monica give corrections.
- Jesus on the globe pose. Mary?? Rotate arms by concentrating on the shoulders. Feel shoulders go through complete rotation, lock to lock.
- Learn routine and have her run me through it.

July 15th, 2017

Skipped yoga yesterday. Outing with Dave and Annie to Daniel and Mary's. Then to the Ritters. Felt like I was running late since Wednesday. So, today was amazing. Did 20' of continuous yoga. Great stamina and strength. Have really explored this in the last few weeks. Definitely a noticeable improvement.

Stamina.

Back stronger than before First symptoms.

Mind surfing.

Life is busy. I thought I was dying.

Thinking about Chris led me to Fernando. I never said "you should thank me". Instead, I acted like I was hurt. Was pissed but...didn't resolve the issue. Typical.

July 16th, 2017

Amazing yoga. Best ever. I have real stamina. Amazing how it reboots my being. Whether a physical or mental funk, I come out feeling fantastic and the feeling lasts.

I have a fear of talking on the phone. I avoid callers and have Diane call for me. Like RICK must have felt with his stuttering, but I theoretically have better tools to deal with it. 🙏

July 18th, 2017

Traveling to Miami. No yoga.

July 19th, 2017

Was in a funk this morning. Just fatigued.

July 25th, 2017

My absence from writing in this for 5 days says a lot. I don't transition well. Ted and Dan were here and we accomplished a lot. Busy. No sense of routine. GI tract unsettled. Lots of rich food. Yoga unsettled as well. Felt fatigued and less strong. I pushed myself in the beginning but then got a good workout. My head just wasn't into it. Then today, after Ted left I had wonderful head yoga. Best sun salutation ever. Felt super strong.

Letter: this is our government. We are the best experiment in democracy the world has ever seen. It's a work in progress. Democracy is fragile and we need to respect this fact. We can do better than this.

July 29th, 2017

Hurt my back on the 25th. Can't remember any strain but it's really stiff at bedtime. Hard to bear weight when standing. Had very powerful yoga that day (best ever sun salutations), pushed it hard and was noting how good my back felt. Maybe punishment for cockiness? 😊. The next day I only did gentle yoga. My back was stiff and sore. The 27th felt better and progressively better each day. Amazing how yoga turns the day around!!

July 30th, 2017

Back still not 100%. I had one of those tweaks getting out of bed this morning where it just lets go. I got up and it was noticeably stiff. Not as bad as earlier in the week. I started my yoga around 11:30. Back sore. I then found a routine where I didn't force the lower lordosis and concentrated only on having my lower back happy while concentrating on shoulders and thoracic lordosis. Miraculously, my lower back felt progressively better and had a wonderful practice. I was able to work through my pain with yoga and finish feeling much better. The pain relief lasted for the rest of the day. Amazing!!

July 31st, 2017

Amazing. Back feels 99%. Started yoga. Got in that back-friendly posture and felt all of the pose in my T6 region. Stretching in a lordotic direction. Back feeling super strong. Then had the most perfect buzz which lasted forever. Did 5 reps of my modification of sun salutation with total power and checked the timer...6 minutes 🙏. Time stood still 😊

Can feel the pose throughout my entire body.

Neck finally feels 90+%. Took a jolt when I fell.

Strongest leg sequence ever.

Just noticed that my acoustic neuroma symptoms of auditory hallucinations and feeling like I was going to pass out are gone.

August 1st, 2017

Got home about 16:00 from Miami. Trip was not too bad. Left the condo at 6:45. Westley in my lap. Way too late. Metro mover to rail to Airtrain to the gate scrambling is an hour and a quarter. Scramble to the gate. There, just getting ready to board. I cut in front of the line. Diane has 2 dogs, 2 carriers and a backpack. I get seated and on the wheelchair cushion and feel pretty good. Midway through the flight I decide to pee. Under a towel, bottle in place and we hit turbulence. Can't start. Takes 15 minutes to find smooth air.

Westley handled the trip great. Came home. Ate. Belched. Had his way with his bed. Chewed on a dry old bully stick. And then passed out. Pics.

My lumbar spine and pelvis feel solid like an oak stump. Feel totally connected from the waist down. Really solid.

August 5th, 2017

Amazing how much yoga turns the day around. Was reading back in this yoga journal. Have really made progress in the last month. Both in strength and stamina. Fell July 7th. Marcy to the rescue. Hurt my neck. Had a wonderful run of yoga before. Next period of time was amazing but consumed with stuff...Chris, reassessment, Diane, Miami. Had a lot of writing about that stuff. Started writing about how yoga was rebooting my day. Then we traveled to Miami on the 18th. Ted and Dan, projects, distractions from a routine, Walter all served to interfere with establishing a routine. Travel is a routine buster. Coupled with the condo projects and Walter made for a pedestrian yoga practice. A workout but no flow. Ted left on

the 25th. Had the best yoga ever and felt super strong. Really pushed the sun salutation pose. By that evening my back was in spasm. Struggled to get to bed. Erin Pablo and Millie came the next day and it was a wonderful visit. Did gentle yoga the next few days and recovered quickly. Then I discovered the back friendly pose that felt strong and solid and very comfortable. By the time I left my back felt awesome. The trip home is well detailed in the post below. ***What is remarkable is how the yoga I did after my nap totally re-energized me. Unquestionably the deepest and most meaningful ever. Magical. There's no doubt. It's for REAL!! Even a skeptic like me has been convinced. The next 4 days have been incredibly profound. My mind is alive and my body feels great. Continues to evolve. My yoga practice is life sustaining 🙏.***

August 6th, 2017

Best ever. Am strong and the acquisition of strength has accelerated over the last few months. My body feels really good. ***Interesting that I never get sore.***

Lumbar spine feels comfortably fused. Torso moves on hips.

August 8th, 2017

I believe I'm entering a new phase in my yoga practice. Monica came today. I did an hour of yoga before she came. Body feels great and strong. The feeling of power is now continually present and assumed. During my session with Monica, she led me through 15' of intense upper body poses and I finished wanting more. This new phase is marked by endurance. It will allow me to accelerate my physical training. I used to feel fatigue with modest exertion and have to stop. I persisted and noticed slow progress in strength and endurance. ***Progress is encouragement to a person with ALS who feels the steady decline of the disease. At first I was cautious of believing that improvement was possible. I'm a realist and a skeptic by nature. I am optimistic and positive, but never embraced false hope. In Miami 2016 I started to be convinced that yoga was making improvement physically and encouraging a meditative state. The thought that I could actually improve was reinforced frequently by my practice. I would have periods of revelation followed by periods of consolidation but the trend was always improvement. I first noted feeling 'powerful' on 09/04/16. That was "an 'almost'". I had noted feeling stronger for many months, but feeling powerful is a sensation of a more holistic nature. Now I feel powerful much of the day. It's become natural and has been incorporated into my daily living. Woohoo 🙏***

August 16th, 2017

Last 8 days have been consistently excellent. I feel strong and my endurance keeps getting better. Yesterday was my ALS clinic appointment. Dr. Simmons did my entire exam with me seated on the end of my chair unsupported. My VC was 77%. I feel better than that.

August 20th, 2017

Why do eclipses travel west to east? At the lake. 8 hour trip down. Horrible traffic. Really impressive yoga after we arrived. Revived me. Today fantastic. ***Feeling powerful is when you feel your physical space. Solid and grounded. What I notice now is my ability to flow through 10-15 minutes and have my body ready to go some more. My endurance is responding to pushing through the first sense of fatigue. I'm developing a strong second wind.*** My trunk feels like it's sitting on a pedestal. I feel light. My back feels amazing. I'm finally feeling sore. Pretty measurable improvement over the last few months.

August 21st, 2017

At the lake. Solar eclipse at 14:40.

Phil is a really decent human being.

I drove off the ramp going from the garage into the house. Ejected from my wheelchair. My yoga may have cushioned my fall. Remember my head whacking off the kitchen stools but not the landing. Landed on my left side. Must have landed softly. Other than my two eyes, zygoma and jaw I feel fine. Neck is perfect. Woohoo. Have a scrape and bruise right abdomen and a rug abrasion left knee. ***Should be more injured.***

Is repeatedly being lucky purely random? I have had numerous falls where I could (should) have been more injured. Like something is cushioning my landing.

- This fall.
- My fall into the garage from the front hallway stair where bottles o

August 22nd, 2017

2 hours 9 minutes and 500 kapalabati breaths. Absolutely the strongest, best buzz ever. The second wind is dependably there. I am linking various poses together in 10-15 minute intervals. Body feels fantastic.

The second wind is active on many levels. On a micro level in my actual practice, on a mini level on the day and on a macro level on life.

I guess I should wonder how I could possibly feel this good after a fall like I had on Sunday. Onto concrete from my chair on a ramp 6" above the floor. But I don't wonder because I know it's my yoga. I feel great.

August 25th, 2017

Most yoga like neck stretch ever.

Feet and knees together.

Strength has increased noticeably but progress is slow. What may be more available is endurance. I can't move fast and I'm not that strong but I seem to be on a steeper curve with conditioning. Obviously slow twitch muscle fibers. Duh 🤔.

Amoeba golf.

Unplugged with Steve Howe. Fundraiser to benefit downtown Lancaster wheelchair accessibility.

August 26th, 2017

Most intense ever. I think I'm significantly stronger than 2 weeks ago. Seems like the more stoned I am the better it is. So I'm pretty buzzed and take 5' to get going. I then do an intense powerful set of sun salutations followed by.

We have to take our country back through the democratic process.

August 28th, 2017

Unbelievably solid leg exercises. It continues. Definitely feeling soreness now. Body feels great. Amazing that I don't have any auditory distortion or lightheadedness. I feel like I'm going to pass out kinda but it's super pleasurable and if I back off a little bit it clears.

August 31st, 2017

I'm in kind of a rut. I'm too lazy in the morning and end up wasting a couple of hours reading about the trump train wreck. I also have days when I have to rush to the bathroom. Time for a reboot. No news. Establish a routine.

September 6th, 2017

Had an amazing run since the last entry. Then I tweaked my back being disrespectful of my body and careless with my poses. Have to travel to Colorado on Friday. Not smart 😬.

September 10th, 2017

So, my back was 90% better by the wedding. The travel was easy and I was strong and comfortable. No comparison with January 2016 where my hip hurt, I was miserable on the plane and blubbering on the jetway as they loaded the plane for the next trip. That was 21 months ago 😊. I've really improved quite a lot by any measure.

Observations:

- My back recovers quickly and I seem stronger after the recovery than before.
- I was very strong and vibrant the entire time. ***I felt almost "normal". That is a statement I haven't made before. I slept great and moved well in bed. Compare this with my experience in DC after Millie was born. I was miserable and had to have Diane roll me over and was super unstable on the edge. Big difference.***

September 11th, 2017

No yoga today. On the plane back from David and Sarah's wedding in Colorado. The trip went smoothly and I feel great. I was able to hold on to a routine and my yoga was good. My endurance continues to evolve. I fatigue to a certain level and then my fatigue plateaus which allows me to continue for longer. My strength continues to increase and the plateau period lengthens. Also, I was in a rut but broke out of it in the last week.

I had energy and felt great the entire weekend. I slept and ate well. Pooping like a champ. I amazed my family and looking back it is amazing. My body and my mind are in a really good

place. I am on to something. People asked me about my yoga. Got me thinking. I feel my yoga to my core. My body feels electric and alive 5 seconds into my breathing. That sensation is intensified with routines. After completing a series of poses I lapse into a period of sensual stupor. I am in a blissful state of Euphoria. ***My yoga is deeply personal. It is breath based. I move slowly and spend minutes exploring a pose. I am very aware of how the pose is affecting my body and use that awareness to tweak the pose.*** My mind surfing is based around this awareness and I return to exploring my body in the pose. I guess this anchors my mind surfing. That is the essence of my practice. My increased strength, stamina and improving sense of well being are natural byproducts of my practice.

September 12th, 2017

Feel so strong. A different feeling from two weeks ago. I did every exercise better and with ease. I trust my body. For the single leg lift I interlocked my fingers and easily grabbed my knee. Effortless. I'm eating well. Sleeping ok. Have plenty of energy. Wedding was fun and I was able to have enough of a routine. Actually I just need some quiet time and an hour of yoga. I am definitely rehabilitating my body and it feels great. The yoga is so alluring. My muscles come alive and my core has a delicious warmth. I feel incredible.

Almost normal.

September 16th, 2017

The last three days have been amazing. ***Made a huge leap when I started pushing myself.*** Stronger for longer and a buzz to match.

- Yoga awakens my body.
- I go into a trance.
- My neck doesn't have that exhausted feeling.
- Feel very solid.
- The normal feeling.

Dog trainer. I need some kind of electric signal that doesn't involve a collar. I need to get their attention when they run off.

September 17th, 2017

I get stoned, the more the better. I fiddle around with the chair, water and complete the undercarriage drying with the fan. I finally am done, step up to the plate and my entire body

energy changes. My body feels great. I feel physically fit. It's a real transformation that happens in five seconds.

September 18th, 2017

An exceptionally good back day!

Man, I'm feeling really good, check the time and it's 13 minutes. I am stunned and then think I have 90 minutes left. I am joyous 🙏

I just think a lot.

First time I really felt my legs under me. Had the chair seat tilted a bit. Felt like I was sitting proud.

September 20th, 2017

- ***Like a stroke. The communication is off.***
- ***You don't know what you lost. It's like your memory of what is normal is erased and you just accept what is happening.***
- ***Yoga is unlocking the rooms where the memories are hidden.***

September 21st, 2017

Wedding: I had great plans to write to each other individually but time is slipping away for that.

September 22nd, 2017

Wow. What a wonderful week of yoga. So energized and productive. Working on the WHG catalog. Organized. Reaching out for donations. Wrote Kevin an email about forgiveness. It was just a great week.

September 23th, 2017

Funny how I said best yoga for a year? Now I am letting my performance say that for (to?) me. ***I am on a journey and it is for real.*** I feel great, sleeping well, pooping great, eating well and my gut is feeling the best I can remember. My yoga is becoming very intense.

It's amazing how good my back feels. During yoga it cracks up to mid-thoracic.

September 27th, 2017

- Purposeful water consumption.
- Linking numerous poses together.
- Holding long.
- Notice strength and endurance increasing daily.
- ***Monica asked if I counted breaths or how I knew how long to hold it.***
- ***I only count kapalabati breaths. The rest I just use my inner clock. My Yoga body informs.***

October 4th, 2017

Getting stronger by the day. Body feels great. Can do the one leg lift with good form and rotate the up leg forward. Feeling really solid. I also think I have answered the more is better question. Yes to a point 🙏

October 5th, 2017

Just amazing. Over the past week or so, I have noticed a measurable increase in strength and stamina. The buzz has taken on a different character too. I did 30 minutes without my hands touching my lap. I just kept going and maintained a pretty respectable form to the end. I spent lots of time reconnecting with parts of my body.

October 7th, 2017

Wow. Noticeable improvement every day.

October 15th, 2017

Fell on the toilet.

October 26th, 2017

Pain level: 8.

Fell on the 15th on the edge of the toilet bowl. Had to poop and didn't call anyone to help. Was standing with my walker over the bowl trying to get my shorts down. Lost my balance, sat down awkwardly with my butt sliding the toilet seat off and landing directly on the edge of the porcelain bowl. **Severely traumatized my coccyx.** Monica came on Tuesday. Was so painful we had to stop. Burning. Painful to sit and yoga made it worse. Tried to rest it. Missed 3 days and the rest of the day's yoga was short, limited and uncomfortable. WHG was on day 6 and was tough. Chelsea came with the Shirks and Clairs. Traveled to Miami on day 9. Aisle chair was bad. Now day 11. Second day in Miami. I love my bed. Have slept great. Finally had meaningful yoga. Still hurts but worked on poses that didn't aggravate it. It seems to be getting better. Slowly. It has the character of chronic pain. Need to head that off.

Boys are really happy to be back. No adjustment period. They knew that it was home.

October 28th, 2017

Pain level: 7.

Day 13. Now the pain is less intense. I can finally sustain the yoga intensity I had before I fell. Didn't lose any strength and maybe a little conditioning. Still burns but it's likely not fractured. That's a relief. **On the positive side I have been taking my coccyx for granted. It has become a focal point and now I have discovered poses that stretch it out. Body exploration 🙏**

October 29th, 2017

Maybe the most intense yoga day ever. Still hurts but the pain was a focus for my yoga.

October 30th, 2017

Pain level: 5.

Pain absent during parts of my practice.

October 31st, 2017

Pain level: 6.

Worse than yesterday.

November 1st, 2017

Pain level: 5.

Better but still nagging.

November 2nd, 2017

Pain level: 3-4.

Took a Naproxen.

November 3rd, 2017

Day 19: Took a naproxen before. Pain level 1-3. Have had a few days of great yoga.

November 4th, 2017

Pain level: 0-3.

Wow. Mind surfing. Strongest ever.

- ***Water is an integral part of my yoga. I drink 1-2 bottles of soda stream during each session. It has multiple positive effects. I practice swallowing. My GI tract gets a flush and feels great. I have great belches. It seems to fuel my body.***
- Deep.
- Grumpy. Was in pain.
- Introspection. And change.
- Injury and yoga. Focus and exploration. Forward fold.

November 5th, 2017

Day 21. Pain level: 0-2.

I feel stronger than I ever have. My back feels awesome. The coccyx pain was dominant until the last day or so. I didn't appreciate how good I felt before I fell. Took 3 weeks. Amazing how I persevered. Couldn't do much for twelve days and it hurt constantly while I was in the chair. Once I could tolerate yoga I discovered poses where it felt better. That became the focus and my yoga explored that part of my spine. I believe yoga had a significant influence on healing. It was neural in character and sitting made it much worse. I could imagine that, if I was beached in my chair, it would have become chronic in nature. ***Amazing that today was my best yoga practice ever and I came out of the 21 day detour stronger than when I went in.***

Hi guys from sunny, gorgeous Miami. I have had a challenging 3 weeks. I fell in the bathroom during our family's "Thanksgiving" weekend on October 15th. I was trying to get on the toilet and landed with the edge of the porcelain bowl resting in my crack and fracturing my coccyx.

November 6th, 2017

Pain level: 0-2.

Maybe a little worse? Definitely hurt yesterday. It's lingering.

Feel super strong. Mentally as well. The stream of consciousness I call mind surfing is on fire. I am thinking about things very vertically. And quick. I'm very curious.

- Cannabis is a great analgesic.
- Miami goals: Dog class. Learn to use a wheelchair computer.
- Me. Moral and ethical. Not religious but my beliefs mirror religious teachings. I try to be non-judgmental, but cannot when I see darkness in someone's heart. One of my strengths as a physician was my ability to read people's inner thoughts, fears and intentions. This is a blessing, but also a curse when I see bad intent. I know Matthew preached "judge not lest thee be judged", but it is hard.

November 7th, 2017

Finally a yoga routine. The last few days have been the best ever in strength and buzz. The pain is present and annoying but yoga can override it.

I'm in an amazing place. I'm able to heal my body with yoga. My mind is electric. I feel good. All the negative stuff is far away. I really feel alive.

I can heal my body through yoga.

November 8th, 2017

My pain was nagging today. I was uninspired. I had pain affecting my poses.

November 9th, 2017

Another more painful day. Feel movement down there. Might be fractured 🤔

- ***I suffer well.***

November 11th, 2017

ALS is disarming. You don't know what you have lost. Before I started to practice yoga, I was in a bewildering state of physical deterioration. My sensation was completely intact as was my proprioception (ability to sense your body's position in space), but I had lost the ability to control my physical movements. I had no idea how it happened, how to reverse it, or even remember how it used to feel! ***I had LOST my BODY.***

November 12th, 2017

ALS lulls you into acceptance. You're lazy. You accept what is without a motor memory of what was.

November 13th, 2017

Dear Dr. Dan. Day 29. Still hurts. It has a neural character. Episodic. The kind of pain that becomes chronic. Have a better day followed by a worse day. Trend seems upward. Slow. Can feel something moving and point tenderness. ***Probably fractured.*** Question: Is it bad to do yoga poses that make it hurt more?

I'm working on the theory that it won't. Here's my thinking. It will likely heal as a nonunion. I want a flexible nonunion. Plus, increased blood flow aids in healing. So, I ignore the pain and push through and it gets better or at least the character changes. Then I ice the shit out of it. Thoughts?

One more observation. Cannabis is an effective analgesic 🤖. That is all.

- I never think what it would be like to be me. Looking at me from outside. Wow, I'm toasted.

November 14th, 2017

- ***ALS is like dying in slow motion*** 🙏

Finally cleaned my pipe. It took us an hour and a half. It was full of goo. Smoking really runny concentrates. Now it was wide open. Problem #1 solved. Problem #2 was that I had just gotten a new preparation that I had been smoking and didn't think was very good and Problem #3 was I was completely out of my routine and really wanted to do yoga. I took 2 hits and was toasted. Had to wait 30 minutes for me to come down before I could start my practice.

November 15th, 2017

- ***The joy of rediscovery. Like losing your sight and gaining some back.*** I had lost my body. Now I have found a way to find it again. ***EXHILARATING.***
- Congrats Molly... Send her a fruit basket.
- Tyler. Complementary shapes that are proud to the wall. Deconstructed photo, abstract painting, wallpaper? Color. Complementing the media panel.

November 17th, 2017

Day 33. 90% better.

- I think that I know what my disease mechanism is. Yoga has revealed a key to unlock it. Breeds hope.
- Back stronger now than before I fell. Yoga allowed me to explore that area
- Westley territorial.
- I'm not so much liberal as I am against the politics of the right.

November 18th, 2017

- ***Blessing: My coccyx. I am much more aware of my entire spine. It still hurts but the pain lets me concentrate and focus my energy right at the problem area. As a result my pelvis is more familiar to my practice.***
- Prolific writing day.

November 19th, 2017

Water is an integral part of my practice.

- Drinking freshly poured soda stream and having an epic belch.
- An activity to do during breaks that involve coordination including drinking practice.
- Gives the upper GI a good flushing. My mouth feels awesome.
- My gut is super happy.
- Seems to flush my body.

Absolutely the best day ever. Strong of mind and body. I feel very solid on the end of my chair.

November 20th, 2017

Have noticed a full feeling in my right upper lip for about a week. Today I had the acute onset of numbness over the entire trigeminal nerve distribution.

November 21st, 2017

Strongest day ever. My endurance is amazing. Balancing in boat pose is comfortable and precise. I can float down.

Coccyx is much better. Did yoga for 50' before it hurt. Then it flared up for 15' and now it doesn't hurt. Weird.

Acoustic neuroma. Symptoms about a week and intensifying. Trigeminal distribution numbness as prominent as yesterday. Also I have noted an increase in the ringing and the feeling of fullness over the last week. Seems to be worse with yoga. I am experiencing auditory distortion and mild headache symptoms again.

- Need to talk to Wally 😊

November 22nd, 2017

My most meaningful yoga ever. I didn't go too hard and didn't get the auditory effect or headache. I was in the zen for the entire time and was really strong throughout the poses.

Acoustic Neuroma Symptoms abruptly changed starting 11/15. My right upper lip tingled for a few days before the entire right side of my face went numb. Temperature sensation is gone. Pain is blunted and touch is intact. Don't think I have any weakness, but my right eye feels weird. Cornea is numb? Right side of my teeth and tongue are numb. The density of numbness has increased. Have an increased sense of fullness and fleeting pain in my right ear. If I push my yoga, the sense of auditory distortion and lightheadedness grows stronger.

Brief History of my Right Acoustic Neuroma:

- Diagnosed during ALS workup. Asymptomatic except for ringing which was mild.
- Gamma knife when it became symptomatic with pressure. 06/2013.
- Headaches and auditory distortion with yoga starting 02/2016. Building in frequency and intensity.
- Impressive hypertension noted in April. Diastolic bp 120's.
- MRI in May suggested minimal change. Referred to Dr. Lee at Penn for a surgical opinion. By my appointment 3 weeks later my bp was under control and my symptoms were negligible.
- Dr. Lee was less than enthusiastic to operate on an asymptomatic patient with ALS and I concurred. At that time I was only admitting to myself that I was really getting stronger with yoga. It took 2 years to convince the skeptic in me that this was real.
- In the intervening 18 months I have practiced every day and have improved in strength and endurance. The improvement seems to be accelerating. When I fractured my coccyx on October 15, I couldn't do yoga for 12 days. I feared that I would lose a lot of what I had gained. To my surprise I came back stronger.

Blessings

- Blessing. That I moved to Miami with world class medicine.
- Blessing. That a former chairman of the department of Neurology lives in my building, is my friend and is a really kind person.

November 24th, 2017

Day 40. First day I am close to pain free.

Day 10. Been a stable level of hypesthesia for 5 days. Primarily temperature and sharpness.

What a wonderful thing yoga is. My coccyx is finally healed enough to be forgettable during stretches. Now replaced by trigeminal numbness which doesn't hurt but is annoying. Gate theory of pain?

Headache avoidance yoga.

Since I started not pushing so hard, I have found a new facet to my yoga. I'm holding my leg poses and the upper embrace for minutes and exploring the deeper layers. I feel my body so deeply. I notice my traps have increased endurance. No burning or trigger point pain.

- Surgical risk. Anesthesia risk level.
- Analemma breathing.
- Letter to Wally et. al. Academic. Mangeshkumar. Increased ICP.
- I'm thankful for clouds.

November 26th, 2017

Still hurts. Worse than yesterday.

- Forward fold. Since my coccyx injury, my yoga has been informed by my coccyx.
- Dinner at the Beiler's.
- Send political letter to my Amish friends.
- Dear friends. Over the past few days of this Thanksgiving holiday, I have spent meditating on what I am thankful for. You were in there.

November 27th, 2017

I think I have it. My yoga practice is continuing to evolve. My coccyx still is present in my consciousness but not in a physically dominating way. I have incorporated the coccyx friendly stretches into my practice. ***I now have mobilized my entire spine. The poses connect my spine to my pelvis in a more meaningful way.***

My back feels great. Strong and powerful. I had at least 15 cracks today. They come during intense parts and feel liberating.

I think Ashok is on to something. ***My yoga is breath based. It supports the poses. My core has become quite strong. Despite air always moving, my intra-abdominal pressure is elevated the entire time. I have lower extremity venous engorgement. That contributes to my lower extremity swelling.***

Blessing. Breaking my coccyx.

- Academic group to include Mangeshkumar.
- Posters in the basement. Alex
- Condo art album covers.
- Golf memorabilia.

December 1st, 2017

- Trump is trying to dismantle government. Constructive government is the best expression of democracy.

December 2nd, 2017

- Very excited for the Christmas holidays.

December 3rd, 2017

Coccyx still hurts. Worse than yesterday. Yesterday barely hurt. Facial numbness is about the same. Yoga is good.

- Scheduling. I'm struggling to schedule my MRI. I originally worked through the existing process by calling MRI scheduling. The first available was in 18 days. I believe it was ordered "stat". I emailed the triumvirate of Ashok, Wally and Ginna and Ginna arranged for the next day. I was scheduled for 2:00. I was called to reschedule and assumed it was for another day and didn't call back. Missed opportunity. I called back 2 days later and the next available appointment was 16 days later. I then emailed the triumvirate and Ginna will work her magic tomorrow. Frustrating!!

- Issues:
 - I need insider help to accomplish a timely test. What about the average patient without knowledge or connections?
 - I don't have a doctor advocating on my behalf. I need help navigating through the maze of radiology. It seems that the process puts the onus on the patient to make it happen.
- At home, our Radiology scheduling is better, but insider connections are valuable. I know the system. Secretaries. Unknown to many.
- Radiology. Appears to be the least responsive of all Hospital based physician specialties. The physicians are too insulated from patient contact.

December 7th, 2017

Most meditative day of yoga ever. Going really deep.

Yoga.

- Interesting. I've been pretty distracted by my recent trigeminal nerve issue as witnessed by my paucity of journaling.
- I have done yoga every day. Chelsea and Fred were here for 3 days. It continues to amaze how yoga resets both mind and body.
- I continue to gain strength. It's like I reconnected to my body. Movements are more natural and reflexes are back.
- My coccyx still hurts mildly. My yoga was so informed by that injury. My core is significantly stronger than before. My boat pose balance is precise and my single leg lift is a very meditative pose.
- Yoga performs a realignment of my spine. I have many joint pops and they feel liberating.

To the girls 🧘

- Dana and Dan are here. Dana is napping. Yogaing. First thought. 'It's Pearl Harbor day. I envision a day when we respectfully celebrate what it took to bring peace to the world 🙏'

December 8th, 2017

- Erin and Millie arrived. Pablo later today. Diane is really sick with the flu. In bed.

December 10th, 2017

Yoga continues to be a very special part of my day. It seems I'm stronger each day. The auditory distortion is present but if I respect it and warm up I'm good.

- Acoustic neuroma. Face numb. About the same. Ear feels full and a twinge of pain occasionally. White noise louder and higher pitched. No other obvious symptoms. MRI tomorrow.
- Coccyx is still noticeable. Amazing how my cat/dog is more complete. I now feel it all the way to the bottom of my spine.

December 11th, 2017

No yoga today. Had my MRI this morning. Tumor much larger and pushing on my trigeminal nerve against the brainstem. As expected, a central cause of the Trigeminal dysfunction. Needs to be debulked.

December 12th, 2017

It is real. I had a tough morning and yoga just turned everything around. My core is crazy strong. It recenters my mind and brings practical clarity to life.

So, starting with Chelsea, we have had people here since the first. Surge got here this morning and overlapped with Erin and Millie by 4 hours. I don't know him from Adam. He is a college friend of Diane's. He hasn't stopped talking. Nice person, but weird. Definitely not chill. He must meditate to quiet his mind. Not properly vetted by Diane and it was a stretch to think that a perfect stranger would be a good idea. I know that she is just trying to be nice. Not to mention the stress of my Acoustic neuroma.

December 13th, 2017

Dear Dr. Morcos.

Here's a short history of my ALS.

- 10/2010. Noticed some weakness in the quads while using a hydraulic log splitter.
- 02/2011. Had a sense of imbalance on a ski trip in Utah.
- 05/2011. Started to feel symptoms of imbalance on a golf trip to Scotland.

- 10/2011. Diagnosis. My Acoustic Neuroma picked up incidentally during the work up.
- 11/19/2012. Retired.
- 06/2014. Gamma knife when Acoustic Neuroma became symptomatic.
- 08/2014. Fell and fractured Left hip.
- 11/2014. Started yoga. At this point I was pretty wheelchair bound.
- ~05/2015. Was able to sit unsupported.
- 07/19/2015. Had my first memorable yoga session. Early Sunday morning at Smith Mountain Lake, Virginia on the dock of my best friends lake house. Just a glimpse into the wonder of yoga.
- 08/2015. Started a daily yoga practice.
- 02/2016. Headaches and auditory distortion with yoga. Building in frequency and intensity.
- 04/2016. Impressive hypertension noted. Diastolic bp 120's.
- MRI in May suggested interval change of a few mm. Referred to Dr. Lee at Penn for a surgical opinion. By my appointment 3 weeks later my bp was under control and my symptoms were negligible.
- Dr. Lee was less than enthusiastic to operate on an asymptomatic patient with ALS and I concurred. At that time I was only admitting to myself that I was really getting stronger with yoga. It took 2 years to convince the skeptic in me that this was real.
- In the intervening 18 months I have practiced every day and have improved in strength and endurance. The improvement appears to be accelerating.
- Today was unquestionably my strongest practice ever. My body feels great.

December 17th, 2017

- Preserving quality of life.
- Recent history.
- Yoga increases intra abdominal pressure.
- Used to tell patients "We are all good at giving help, but not so good at taking it".

December 20th, 2017

- Returned home yesterday. Uneventful trip. We seem to be getting better at airline travel.
- Ady Barkan.
- *Coincidence is not a Random Event* to Marcos.
- Girls email about my end of life.

Weird Acoustic Neuroma symptoms.

I have a sensation in the right tonsillar pillar that makes me want to cough, tear and increase mucus. It predates my diagnosis by a number of years. Are they related?

December 21st, 2017

First time I am really having to face my mortality. I have never thought deeply about it. I lived in the moment. Now I need to weigh the pros and cons of the surgery.

- ***Life without yoga? It will happen eventually in the course of this progressive disease. My Acoustic Neuroma is not fatal, but the symptoms produced during yoga will curtail and eventually make the practice untenable. I believe that will hasten my demise.***

Need to do a whole body assessment.

- Feet worse. Bit of neuropathy. Hammer toes. Slow to heal.
- Muscle strength in legs is about the same. Think I'm more stable transferring, but I'm still a fall waiting to happen. If it does and is bad I will transition to the no yoga track.
- Hip feels great. No pain when I sit. Strong during yoga.
- Core is unquestionably stronger. The strongest ever today? My balance and reflex to fine tune are really precise. My spine feels great.
- Neck is worse. The left C5-6 is sore.
- Dr Rico email to the Anesthesia department.
- Dr Morcos. Recovery? Until I'm doing yoga? Not getting cold feet. 7th nerve (Facial nerve) injury with/without surgery. Progression of the tumor growth.

December 23rd, 2017

Body feels great. Neck a bit uncomfortable. Hip feels like my own. Monica came yesterday and was impressed by my yoga. She last saw me 2 months ago and noticed significant improvement. I followed that up with an equally intense one today. Haven't noticed the headache or dizziness the last two days either. Face still numb but I'm getting used to it. Still have not made a final decision. If the PFTs confirm how I feel, that will help. Need Dr. Morcos's post-op information too. Also his prediction on future growth.

- ***Went from not feeling well and feeling the weight of life to feeling better and solving problems in one hit and 5 minutes of meditation.***
- Boris and Tanya's party.
- Adam.
- Email to sibs.
- Family.

- Need mom to slow down a little bit.
- Fruit smoothie to help Fred with pooping 🍌

Dr. Morcos.

- Weather. Minnesota.
- Coincidence.
- Surgical specifics.
- You appreciate the practice of medicine as much as I did.

December 24th, 2017

- BCC family on my communication with Morcos.
- Back feels awesome.
- Feet don't look good.

December 25th, 2017

- Merry Christmas. Entire family is here.
- ALS and length of anesthesia. I don't believe that this is a major factor in predicting outcomes. The type and location are more important predictors.
- Coccyx still hurts. I was ignoring it and not doing the yoga that focuses on the area. A reminder.

- ***Yoga is definitely getting stronger at a measurable and still at an accelerating rate.***
- ***Need to imagine life after yoga. It will happen.***
- ***Need to plan surgery based on an estimate of yoga life. The physical leads to meditation and the goal of improving is a part of the buzz.***

December 26th, 2017

Absolutely the best practice ever. 1 hour 45 minutes non-stop with only water breaks. Drank 1 1/2 liters of water. Much stronger core than a month ago.

- Tough decision. Really evaluating life.
- Mom is part of the equation. Unloaded on Molly last evening.

- I was nervous about what the PFTs would show. When they were good, then the decision was made real.
-

December 28th, 2017

- Taller. Lighter. Endurance. Buzz.
- Don't feel like I'm dying.
- Letter to Amish.

December 29th, 2017

Definitely feel the effects of the tumor. Haven't had a headache in 5 days. My head feels increasingly full and the trigeminal sensory changes are becoming more intense. Have twinges of pain in the ear canal and a metallic taste on the right side of my mouth.

Just finished 20' of continuous yoga and it was intense. I'm more capable than last week!!.

While I'm not looking forward to the recovery, it's the right thing to do. Made up my mind.

Had my first headache in a while just after yoga. Yup, right thing to do.

- Anesthesia really matters. Alcohol bad. Cannabis good.
- ***Wonder if I'll miss the ringing in my ear. It has been a constant in my yoga from the beginning. Does the tumor act like Samson's hair? I have such a terrific buzz.***

December 31st, 2017

Yesterday was a travel day. 30" of yoga at home and a little at the airport. In Miami there was a wheelchair snafu and I sat in an aisle chair for 45". My coccyx hurts today but I did amazingly well considering. Yoga is more tired today and the exacerbation of the fullness in my head, the twinges of pain in my ear and the auditory oscillation was pronounced. Didn't have that for a few days.

- Very aware of my physical orientation in space.
- Musings.
- Enhanced yoga.
- Coincidence.
- My greatest fear.

- Auditory oscillations.