

## **Grappling with acceptance**

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Good morning beautiful people. What a gift for us to be here and for you to spend your Friday morning with us.

As you may know I have ALS, which according to my partner's daughter stands for Awfully Large Sickness. ALS paralyzes one's muscles including those responsible for breathing, swallowing and speaking. Which can make giving a talk rather treacherous.

### **Help**

So I need a lot of help. First, I need this ventilator to help me breathe.

Secondly, I need friends to help me give the talk. At first I thought I would give the talk and Marc would type so you can read the words when my pronunciation wanes. But when we practiced yesterday it was clear that my mouth doesn't have the stamina. Halfway into the talk my words sounds like mashed potatoes. So I called my friends and said, hey, please help me give this talk! And they said yes. So today you'll not only hear my voice but also some of my most favorite people.

And then I need your help. Many more muscles in between are becoming paralyzed too. So sometimes I am going to make gross noises or I might choke on my own saliva. So please be part of my helping team. When I make gross noises, would you be willing to be gross with me?

Can we practice? Can you make a gross noise with me? [Clear throat and soft palate.] Also, please let me know if you can't hear me. You can do this: [Cup hand behind ear.]

One more thing. I'm talking about my own prospect of dying today. So there is a 90% forecast for tears. We don't have to practice crying, but when it happens—for me or for you— let's practice feeling it, and breathing through it.

That's really great, thank you! So, you're ready for me to share some moments of grappling with acceptance with you?

Ok, let's go!

## **FORCE**

On the day my ex-husband and I agree to end our marriage, a friend calls. I anticipate a “Congratulations!” Instead she says, “This is going to hurt so much.”

“Isn’t the pain over now?” I ask.

“No,” she says, “The grieving just began.”

Confused, I google grief. I do not come from the grieving type. We have stood at graves of beloveds who died of cancer, car-crashes, murder. We didn’t grieve. We moved on.

Perplexed, I google grief and see that it’s a process: denial, anger, bargaining, depression, acceptance.

“F-that,” I say, slamming my laptop closed. “No time to be a sad sack.” Instead of going down the well of grief, I go to the coffeeshop and write a letter I never sent to my ex-husband. In the letter I say, “I accept this, I accept all of this.”

Naively, I try to white-knuckle acceptance.

After the letter, I become a fugitive, running and numbing. Running and numbing. Refusing to go down that well.

## **FURY**

When I learned that I might have ALS I listened to a guy tell his ALS story. When he learned about the disease, he fell into a deep depression. I didn’t want to do that, so I got practical.

I tried my best to fight it in some way.

I asked for speech therapy.

I asked for hand therapy.

I asked for medicine.

And all they told me is that there is nothing they can do to keep this avalanche from falling on my face.

But I am a fighter.

I am a survivor.

I am a worker.

I will break what is precious. I will walk into pain in order to get free. I’d rather hurt like hell and repair than feel so powerless.

But with this illness there is nothing I can do to make this better and nothing on earth that can make this go away. Not even Elon Musk and all his billions, nor Benny Hinn and all his prayers.

A thousand angry bees fill my chest. I walk to the edge of a snow-covered pond where I gather snow, arch backwards and toss it onto the frozen surface. Gather, arch, toss,

scream. “I hate this!” I yell with my wobbly vocal cords. “I hate this illness!” “I don’t want to be so ill!” “I hate this!”

I do this until I am exhausted and fall on the snow where the only thing left to do is punch. Punch the snow. Punch it again and again and again. Oh how I hate what is happening to me.

## **SOLVE**

My people hate the idea of me dying so young, and so terribly. They want this to be something fixable.

Amber thinks it’s the COVID vaccine and sends me a vaccine detox diet

Holly believes it’s my lack of faith and implores me to repent and seek God’s healing favor.

Dan thinks there is a spiritual cause and urges me to take his \$5,000 course as it might solve it.

Jenny believes an anti-inflammatory diet will do it.

Frank believes it is because of the lack of self-care in my life.

I too scamper through the labyrinth of my past, trying to see how I caused this damn illness, how I could be so stupid to land in this terrifying mess.

## **TERMINATE**

I live with the knowledge that I might have ALS for nine weeks before I am able to see the ALS specialist. On the day I am diagnosed, the specialist says, “This is the most terrible disease. Something you do not wish on your worst enemy.”

This. This body unhurriedly paralyzing itself over years.

I ask him, “Is life worth living with ALS?”

Later my therapist asks me, “Can we pause this inquiry and not come to a conclusion prematurely?”

Then my friend asks me, “Do you consider taking your life so you can be spared this suffering?”

I pause, and then I say unsmilingly. “No. I owe it to myself to see what happens.”

## **SHARE**

The last thing I want to do is to tell the kids that I have ALS. I am too afraid to. The space with my partner and the kids is my last refuge where I can pretend I am not dying.

The kids know I'm ill, that I have naughty-annihilating-no-neurons, that there might not be a cure. But to tell them I've been diagnosed feels like a slap in the face, a breaking of innocence, a risk that I will be hated for my illness, that I will become an embarrassment for the tweens.

My partner holds me as we get ready to tell them. I cry. Like a pig-squeal cry. When my tears subside, he asks, "Are you ready?"

"I will never be ready." I reply.

The thing that helps me to my feet are words from my partner and his mom, "Trust the kids." And those of my friend Michelle King: "Trust the devastation."

After an hour on the couch sitting together in a knotted heap, in silence and tears, we find ourselves outside smashing knotweed against the ground until our silence swings to tears and then into laughter. We end up an exhausted mess holding each other.

## **TRUST**

The first time I go cabin-camping with ALS illuminates the ways in which I am diminishing. And in this brash light, the future looks bleached-bone-brittle. All night I feel scared of this slow-motion mudslide confining me to muteness, entombing me in gravity until I can no longer lift my limbs. And how it will affect those around me.

I keep to myself at the breakfast picnic table. Then a rust-colored movement pulls me out of my story and my eyes rest on a chipping sparrow pecking at leftovers. When it flies off into the woods, the words of Jesus fill me. "If the father takes care of the sparrow, surely he will take care of you." I think about how up to this day in my life I am okay. We're okay. I am okay. We're okay.

I pivot from fear towards the possibility that, just like that tiny bird, I too am cared for by this beautiful life and I can choose to trust that it will continue. I exhale the night's worries and return to my camping companions.

## **SUPPORT**

One benefit of dying is that you feel motivated to get your affairs in order. My friends and I gather for dinner so we can reflect on our end-of-life care. We use the structure of an “advance directive” for this. It confronts you with questions like, do you still want to live if you can no longer speak, move and take care of yourself?

I tell the group that a year ago I would have said no I do not want to live in this manner. One friend cocks his head and says, “That will do us a great disservice.” Then another chips in with, “I can’t wait to bathe you!” and yet another, “Oh no, I’ll fight you for that!”

Never in my wildest dreams did I imagine a table of friends fighting over who will take care of me. Amidst the laughter, something scared inside absorbs this abundant love, exhales and settles down.

## **ACCEPTANCE?**

I would like to say that I accept what is happening to me, and by “accept” I mean welcome and embrace. But I can’t.

I don’t want to die before I’m fifty from suffocation, just like I don’t want to live in a world that devalues life—taking it with a knee on a neck, a chokehold on a train, a bullet in the back. I don’t want callous policies that place communities next to toxic sites that suffocate generations of people. I don’t want our planet’s lungs to be cut down for commerce.

I don’t want to see my body waste away, just like I don’t want species to go extinct, wetlands to be dried up for development, the bodies of glaciers to melt away. I do not want our world to keep warming, becoming uninhabitable and forcing more displacement.

I do not want to go mute and lose my ability to whisper good night to you. Just like I don’t want to live in a world where so many people need to silence their truth to avoid harm.

I don’t want my future taken from me, the one where we continue to be in community, attend all our children’s weddings and grow old together. Just like I don’t want to live in a world where creating a thriving future for everyone and every being isn’t the top priority of leadership.

And here you are too. And I know that in your life there is a litany of losses and anticipated grief. Things that happen that we cannot condone. Things that are happening that devastate you.

And yet here we are. Beautiful human beings sitting here, breathing, the precious gift of life in our hands. So how do we live, how do we feast on this precious gift amidst the pain, loss and hurt and extend that life-sustaining-force outwards? How do we say yes to the mess and co-create with it?

## **PRACTICE**

I don't know, but I do know that I wish to be in practice with you. Let us practice.

Practice noticing when we feign faux acceptance and choose to face the hurt instead.

Practice allowing ourselves all the space to rage and hate, but not get stuck there.

Practice noticing when the conversation fixates on blaming others and instead soften into the discomfort underneath.

Practice holding each other in great care when we feel hopeless and would rather opt out.

Practice bringing the devastation into community where we can co-create new rituals and new ways of caring for each other.

Practice trusting each other to hold us and resting. Resting into life's abundance and generosity.

Thank you.