BUZZ CHRONICLES > HEALTH
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Twitter Thread by Martha Crawford

Martha Crawford
@shrinkthinks

A request for comment from people living with life-limiting diagnoses:

I am developing a workshop for the general population on creating a healthier relationship to mortality- and I want to amplify the voices of those engaged in the confrontation.

If there is something that you feel you want the wider culture to understand about living with life limiting illness, but is hard to get others to hear or withstand,

and you want me to share it in workshop- please contact me here or through my website

https://t.co/nFdzkoyWLx

What do you feel the culture does not understand about the labors of confronting mortality? What do you have to protect others from about your experience? What do you have to edit away from people who think this will never happen to them?

So much of what is talked about in these space, is offered by people who are vicariously impacted, or who are trying to stay near

What would you want your wider community to integrate and understand about your experience that they turn away from?

I will attribute your comments to you in the workshop, or I can keep them anonymous if you prefer.

I know what my own experience was like living post-diagnosis- I know that I learned to hide things and edit and protect myself and others from the way I now saw the world and the medical and existential tasks that preoccupied me. But I am one person, with my own viewpoint.

“Nothing about us without us” doesn’t often extend into explorations of death and dying. Because we are sick, fatigued, or need to protect our energies by not wasting our breath

Or because we die and others may posthumously edit or misperceive what we wanted them to understand

You can tweet, DM (I’ll open my DM’s for the day) or email me:

https://t.co/nFdzkoyWLx

For example: I found the binary notion that I was either “dying” and my life was over or seemed “just fine and cured” completely exhausting.

Almost no one could grasp that I was living on chemotherapy for 3 years , with attending limitations, with no clear prognosis.

People who had been told repeatedly that I was on chemo would be stunned when I turned down a drink and reminded them I was on chemo yet AGAIN.
“oh! But I thought you were all done with that!”

Or chemobrain, I would sometimes want to scream at people who wanted me to remember trivial details or process information quickly or who simply did not seem to ACCEPT that I was cognitively altered by the meds

“You seem fine! Your writing is so clear”

Anyway: my DMs will be open for a day or two for those who want to share privately.

And cancer isn’t the only life-limiting experience, just the one I’ve experienced.

Here is another one:

“WOW! You look great!” is more about the relief of your own fears than any comfort to me.

You were just bracing yourself to see me as gaunt and wasting.

Also: this is no criticism, just truth. I have absolutely done this to others even post-diagnosis.

I catch myself now and say: “I just feel so happy to see your face- its been too long.”

In case you are confronting a life-threatening diagnosis and seeing this and don’t follow me and are thinking: “why should I tell this stranger anything?” I am living in the in-between too:

https://t.co/F81qjskepY

I'll add one more. This one is dicey- because I don't mean to negate anyone's pain or suffering - here goes:

The voices of caretakers & the bereaved unwittingly drown out the voices of the potentially dying.I know because I've been a caretaker and survived many loved ones.

and I realized that once I was diagnosed myself, that my fear of losing my loved one, and the responsibility I felt for protecting them was important and excruciating -

but not the same labor as preparing to say goodbye to everything and everyone, including my own identity.

My attempts to share my own process would often stir up absolutely understandable grief in those who were mourning their own losses.

But too often, the tables would turn to my needing to comfort them, and my own work would have to continue in isolation.

Both sides of the experience of loss are important - and I don't mean to minimize anyone's grief.

I just think that the work of mourning one person and the work of mourning every one and everything are similar but different.

And I know that I absolutely could not see this distinction clearly for my loved ones as they died.

There are things we share standing at the edge of the abyss.

But there are things that only those preparing to actually go over the edge contend with.