

Recurring Anticipatory Grief

by Kurt Ewen

Times for grieving the loss of classmates, colleagues, pets, friends, mentors, and family are expected in any life lived. Because grief is deeply personal, there are no established norms for when, how and how long we will or should mourn. In an earlier phase of life, I worked with people needing support as they mourned – their examples guide me in mine.

My disease progression brings with it the successive loss of long-held abilities (adequately appreciated or not). Some slip away over time without much notice, others are seemingly here one day and gone the next. I often think of the experience of my dad and others as dementia took over on the way to death. Is the ability to cognitively experience and mourn all the losses that ALS affords a benefit, a burden or both? Losses to date include:

- Easily tying my shoes or a tie
- Buttoning pants and shirts unaided
- Commanding a stage as a speaker
- Speaking with clarity and fluidity
- Eating without fear
- Combing my hair
- Cooking, wood working and other hobbies
- Walking without AFOs, a cane or rollator
- Breaking a sweat from a good workout
- Driving (my truck) for pleasure
- Advancing career dreams
- Walking my (any) dog
- Opening a pickle (any) jar for the 1st time
- Carrying my briefcase to work
- Working in the yard

In isolation, each could be something to reminisce about as an age thing or shared as a proverbial “football injury” story. For the sake of independence and self-preservation, my ALS pulls from within me an outward stoic pragmatism. The disappearance of mundane abilities is hardest for the stoic and can bring the deepest frustration. In quiet moments I mourn the cumulative impact of abilities gone for good as I watch the world spin by.

In even quieter moments I am mindful that I have more to give, and this fucker will eventually take it all – if I let it. Rooted in perverse gratitude, anticipatory grief demands I live my best life now for future loss to be worthy of mourning. Anticipatory grief breeds a pessimistic concern about future abilities that recurs whenever I consider future plans. Will I be able to do X in 1 month, 2 months, 3, 4, ... from now – how far out can I reasonably speculate?

I often wonder if my grief would be more or less profound had I understood anticipatory grief earlier in life. Could my stoicism be a symptom of having not lived my best life making my current losses less worthy of mourning?