The Art of Living in the Present

An HIV long-term survivor reflects on joining the 50-and-over club.

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Hitting the big 5-0 even for those who have experienced decent health can prove alarming. Time can drag when you are young and searching for your niche in life. By 50, months seem to pass as swiftly as weeks, and you've settled into things.

After decades of quiet little birthdays without much fanfare, half a century rolls up to you in a hearse, and the tinted window on the driver's side rolls down. You walk up and take a peek inside, but nobody's in there.

Oddly, a pair of fuzzy dice are hanging from the rearview mirror. Your favorite song is playing, so you climb in to get a better listen of the killer chorus about to drop. And wow, the extra padding in the seat sure feels nice, probably takes the edge off driving around dead folks.

As you play with the dice, you catch yourself in the mirror. You are shaken by what you see: More than half of your life behind you. Already? You are suddenly much closer to your expiration date.

My childhood navigating hemophilia provided some close calls: head bleeds, bike wrecks, all kinds of fun stuff. Contracting hepatitis B via blood product treatments resulted in a family keepsake moment. My first ambulance ride was at age 6.

Turning 50, for me, is living 40 years beyond my expiration date, which has been a moving target virtually my entire life. Those terrifyingly close calls with hemophilia felt like a warm-up act after HIV threatened to be my final curtain call.

We often hear the question “If you could go back in time, what would you tell your younger self?” Surprises make movies fun, and my movie has been a genre-hopping tale: a comedy one moment, a drama the next. A firm believer in no spoilers, I wouldn’t clue younger me in on any of the big plot twists. But I would really love to offer up a sneak preview.

However, the sight of my nightstand might make young me queasy. There’s the toe fungus salve, the pillbox, the allergy medicine, the giant UV light box for morning mood enhancement, the peppermint oil I douse under each nostril because I’m precious.

He’d recognize his alarm clock, which stays until it dies. “Hey, what’s this?” young me would ask, picking up an engraved silver disc and chain. “That’s my MedicAlert necklace.”

Young me would quickly plop the necklace back down on the nightstand. What isn’t in my nightstand would intrigue him the most: no condoms.

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After explaining U=U (Undetectable Equals Untransmittable, which means that since I’m on effective treatment, I can’t transmit HIV sexually), I’d glean the wisdom on the art of living in the present from someone (future me) who had no burden of expectations. But young me’s coping mechanism of a carpe diem lifestyle sprinkled with denial isn’t such a good fit for a 50-year-old with a normal prognosis.

I just have too many doctor appointments, medications and health goals that require diligence to stick my head back in the sand trap. And, to use another golf metaphor, there's no way I birdie a few on the back nine if I take my eye off the ball.

Lately, some of my friends have received distressing medical news, which comes with this aging business. Because I got a head start on all that, I'm positioned to help them in a way others can't. They know how comfortable I am talking about medical issues.

Not long ago, a childhood buddy reached out during a medical scare. We met, we talked, we had a beer and saw a movie. I was happy to provide calm waters in the midst of a potential medical crisis, but when another friend was diagnosed with brain cancer, I wasn't sure what I could do to help.

We talked about the special license friends and family have to share their hearts when, suddenly, the amount of time left to do so has been threatened. It's a beautiful side effect of the ugly truth that no one is guaranteed tomorrow. It forces our hand to live with and deal with and actually experience the present.

Now, do I want to dramatically flip over my prescription bottles, like Simon Le Bon in the "Hungry Like the Wolf" music video? Sometimes.

Then I remember that I'm still adjusting to this new lifestyle of facing health challenges head-on. Last year, I started treating hemophilia prophylactically. With once-a-week injections, I'm walking around with normal levels of clotting factor for the first time. I'm respecting the ADHD diagnosis I initially laughed off. Dealing with depression and anxiety openly with my wife, Gwenn, my friends and my doctors has helped me cope with early traumas.

Shawn Decker and Gwenn BarringerAri Michelson

For much of the last three decades, I've been public about my life, but lately, I've kept things closer to the vest. As an educator, I was used to having all the answers to the questions I was most likely to receive. While I wanted to talk about the realities of being a long-term survivor, I didn't want to throw a wet blanket on the proudest work of my life: I survived.

My ultimate goal was to be accepted and to find a lifelong love, and I achieved that. I didn't want my lack of confidence and uncertainty regarding my mental health challenges to be on display.

Last fall, I felt compelled to share again. After I wrote my post, however, I hovered over the delete button. It felt brave to post, doing something that once came so naturally to me.

Among the loving sentiments I received about the post was a comment from my Uncle Tim reminding me that depression is a time-honored family trait. This led to a few private messages back and forth. I was thankful he reminded me "it wasn't just me." Several months later, when I got the word that Uncle Tim had passed, I was all the more grateful that a moment of summoned courage had afforded me one last opportunity to connect with him.

Several months after that, I truly found out where being a healthy 50 puts you in the pecking order. Shortly after the sad news about Tim, I also got the incredible news that I'd be a granduncle for the first time.

Existential whiplash struck once again when at a dermatology appointment to discuss my fungal toe situation, I realized that I am now older than most—if not all—of my doctors.

After the shift in how I approach hemophilia, I got a little overzealous. With all my new clotting factor, I was less worried about injuring myself—a perfect setup for injuring oneself—which I did on day 2 of lifting 5-pound weights.

At physical therapy, as I was warming up my frozen shoulder, a woman in her 70s was riding the exercise bike beside me. "Not yet," the woman said after her physical therapist informed her it was time to move on. "I just want to be able to do things," she added, which granted her more time on the bike. I so related to her.

I wish I didn't need to add physical therapy to the mix, but I don't beat myself up over the mishap that landed me there like I would have in my youth. Negative emotions drain my battery much more than they used to, but I've never been more equipped to handle them.

Simply put? I just want to be able to do things. Like being the best partner for Gwenn. The cool uncle. The goofy godfather. The son who takes dad on a day trip to the casino. The brother who still makes you feel like a kid. The friend who is ready to provide a shoulder to cry on as well as a friend who is no longer afraid to do the crying.

So whenever the day or night comes when my own driverless hearse rolls up, I'll have only one final request: "Can I choose the song that's playing?" Because what is on file as my favorite might be as obsolete as my original expiration date.

If it is possible to make a request, here are my suggestions. "Just Like Heaven" by the Cure. That's a great one. I just wish the band's name were the Functional Cure, something a little closer to my lived experience. "Personal Jesus" by Depeche Mode? A little on the nose. Plus, I'd worry that a catchy-as-hell song invoking his name might cause Jesus to jump the line, and I'd much rather be greeted by familiar faces, clueing me in that I'm on the other side too.

Actually, I don't want to know the soundtrack that bridges this life to whatever is next, which I imagine as being somewhere over the rainbow, where the grass is greener. Or maybe I come back

as a blade of grass? Once again, a small, delicate piece of a bigger, beautiful picture.

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