What Price Activism?

Coping with the fight for change

May 20, 2019 By Mark S. King

Wanda Brendle-Moss arrived at the 2018 United States Conference on AIDS (USCA), in Orlando, in a car. She departed soon after in an ambulance.

“I fell in the shower at the hotel one morning,” Wanda explains to me. She has a friendly North Carolina drawl and a sunny face framed by an avalanche of silver hair. Her motherly affections make her a favorite among the many younger advocates on the scene who surround her.

When Wanda hit the floor of the bathtub, she heard a crack. It took her a full 30 minutes, wincing in pain, to crawl out of the bathroom.

She eventually made it downstairs to the conference and tried to keep her physical agony to herself. “I was there on scholarship,” Wanda tells me. She takes such opportunities seriously because her USCA attendance depends on financial support. Wanda doesn’t have money. If a scholarship did not provide meals, she probably wouldn’t eat. But, she says, she would still go.

After someone noticed her distress and questioned her, Wanda consented to an ambulance, leading to hours in the emergency room and a diagnosis of fractured discs. She longed to return to USCA. By midafternoon, she had made it back, walking slowly down the long hallways to attend workshops, propped up by painkillers and pure grit.

“I know, I know—it sounds crazy,” Wanda responds, when I warn her that her level of commitment might sound extreme when I write about it. “But I felt compelled to be there. I am doing this work because I need to be.”

Need. Compulsion. I wonder to myself whether these are the healthiest motivations for HIV advocacy. “And,” Wanda adds, with only a hint of defensiveness in her Southern lilt, “I finished that conference.”

There is something familiar about Wanda’s story to this long-term survivor, something about fighting the good fight at any cost, and it strikes a satisfying chord, like a favorite old disco song playing again.

Liz Defrain

Larry Frampton, an advocate from Tennessee, knew better than to travel to the 2016 HIV Is Not a Crime conference in Huntsville, Alabama. He was feeling sick and fatigued from working day and night on needle exchange legislation. But he made the trip to Alabama anyway. When Larry was transported to the emergency room mere hours after arriving, he was unconscious. He didn't leave the hospital for 10 days.

"I was embarrassed to back out of the conference because I was scheduled to be on a couple of panels," Larry admits now. "I know that sounds fucked up. That's where my thought process was at the time. After the dust settled, I thought, God, you were stupid."

Beware how you judge these activists. They are our community role models. We created this culture and this work ethic. We set the bar and keep lifting it up and up, to a place beyond healthy

personal boundaries.

In 2018, as Olga Irwin was returning home from Washington, DC, where she had been protesting changes to the Affordable Care Act, she suffered a stroke. Using her voice as a woman living with HIV had taken precedence over remembering to take her blood pressure medication. Olga's husband was too concerned for her health to let her watch the protest coverage while in the hospital, but that didn't keep Olga from tracking developments on her phone and teaching the nurses around her how to organize a perfect demonstration.

Olga returned to DC for another protest three weeks later. In a wheelchair.

There are more stories like these, more than we might realize. For every extreme example among activists that ends with dehydration and IV drips, there is a case manager slipping his or her own money to a client for bus fare or a volunteer taking vacation days from work to staff yet another resource table. There are late nights and forgotten meals and overlooked family members.

There is Zee Strong, speaking out on social media as a straight man living with HIV, manic from sleep deprivation after weeks working on his Digital Living Quilt project. There is Thomas Davis before he found a paid position at the Black AIDS Institute, who did it all for free, who valued his volunteer projects more than rent, who once spoke at the National HIV Prevention Conference without mentioning he was sleeping in his car.

And now that satisfying disco tune has begun spinning again, and I understand its meaning. Our instinct to work without guardrails is part of our history, baked into our DNA as activists from the earliest years of the AIDS crisis.

Self-care was a luxury in the 1980s. It often felt like we were all going to die, so we made a karmic deal to fight until that time came. What's the point of pacing yourself in a world that is ending?

We attended protests in wheelchairs, like Olga. We were taken away by ambulance, like Wanda and Larry. Our very sickness—the body wasting and lesions, the suffering and the mourning—was used as a tool for our activism. We fought until we died and then even beyond, our ashes thrown onto the White House lawn in a final gesture of spite and fury.

We were taught that our survival was linked to our willingness to get empowered and get busy. Many long-term survivors are a testament to that. But the equation isn't absolute. AIDS has stolen the lives of people who were the very personification of empowerment. The epidemic can be random in its brutality, and that only adds to the guilt of surviving at all.

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You can't help but wonder what is driving our frenzied lives of activism today. Are we doing this work for our own survival? For a piece of glory? Are we seeking forgiveness?

"I feel like, as a newer advocate, I haven't suffered enough," Julio Fonseca admits, even though he

was diagnosed with AIDS 10 years ago. “I don’t bear the physical battle scars of the early years.” Julio mentors newly diagnosed people at Whitman-Walker Health in Washington, DC, and is a program manager at AIDS United, but it has taken him years to recognize his contributions as worthy.

“In the past,” he says, as his voice lowers, “I sometimes thought if I pushed myself to the point of illness, it legitimized my contribution somehow.”

It is a troubling admission, but I don’t have to break that news to Julio. He knows. “I had late-stage symptoms when I was diagnosed,” he explains. His initial hospitalization was harrowing. “I don’t think I ever processed it emotionally. I jumped into all kinds of volunteer work without having dealt with the pain of my diagnosis.”

Julio believes that HIV advocacy can become escapist behavior, obscuring unresolved distress. “I think anyone who has tested positive and wants to get into this movement should explore trauma-informed therapy first,” he says. “If you haven’t dealt with your stuff, there’s almost no opportunity for self-care.”

It might also explain why some newly diagnosed people immerse themselves in the HIV arena to an unhealthy degree, racking up multiple obligations and unrealistic expectations. It’s as if their original trauma keeps trying to express itself by returning to the scene of the crime.

“Overcommitting can be a natural reaction to complex trauma,” Katharine Campbell, PhD, LCSW, tells me. Psychological trauma care is her specialty. “But our reaction to trauma is only negative if it is dysfunctional to us. It could be healthy too. This is not one size fits all. If I am not taking my medications or getting enough sleep, then clearly that is not healthy anymore.”

Working within a movement that lacks strong societal support is also a factor, Campbell believes. “Microaggressions about HIV, those constant demeaning statements and experiences, impact your brain. There’s no way we are not impacted, even if we don’t believe them. You have to figure out how to respond to those messages. For some people, the response is to be hypersensitive and use advocacy to channel their feelings.”

This environment can have an effect on our HIV-negative allies as well, a condition known as vicarious trauma. “You cannot witness a story and not be affected by it,” Campbell cautions. “For instance, before I worked with domestic violence survivors, I never thought twice about people walking too closely behind me. So if I am working as an advocate for long-term survivors and hear those stories or I deliver test results in an HIV clinic, it impacts how I think and react to the world.”

Campbell urges advocates to do the one thing we usually do terribly: take care of ourselves. “As a clinician, I include self-care as part of my ethical mandate,” she says. “Am I taking care of me? Am I modeling what I expect others to do? You might be able to do this on your own, or you might need outside guidance. Self-care doesn’t have to mean going on a vacation. It is different for everyone. Self-care is as complex as human nature.”

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The HIV/AIDS epidemic isn't so unique in this regard, despite our tribulations as a community facing a devastating new illness. It's possible to look toward more mature social and racial justice movements to find wisdom about how to cope with fighting for change in a largely inhospitable atmosphere.

For Larry, who has stepped away from several of his volunteer commitments since his hospitalization, self-care has meant listening to his body. "I'm more relaxed now," he says, although he can't resist taking a victory lap for the very thing that physically clobbered him. "But that needle exchange legislation we were working on in Tennessee?" he mentions proudly. "We got it passed!" There is constant tension in our work between our triumphs and the price we pay for them.

Olga has become more discerning about which events she attends. "There's a workshop coming up about domestic violence and HIV," she tells me, the excitement swelling in her voice. "I'll get to be a presenter for the first time." There's another conference only weeks later, but Olga won't be there. "Before my stroke, I wouldn't have given it a second thought. I would have done both.

"I wish I had listened more closely to the people around me," Olga admits, thinking about the ordeal that nearly killed her. "They tried to warn me I was running myself down."

Olga has not, however, ruled out marching back to Washington, DC, for another round of protests. "If something really scares me," she says, providing an admittedly low threshold given our current landscape, "then I will go back. Definitely."

"Is it worth my T cells?" Julio asks. It has become his self-care mantra, demonstrating how far he has come in valuing himself. "I don't have time for interpersonal bullshit. If you hear somebody say something ignorant about HIV at Starbucks," he advises, "it's OK to walk away. You don't have to provide a full educational moment. It might not be what you need right now."

Julio is still learning to heed his own advice. "I feel guilty when I say I can't do something or when I see a phone number calling and don't answer because I'm at dinner. I'm still trying. It's hard."

Wanda will be 65 years old this year, and the milestone has her thinking about some changes. "I am pacing myself," she claims. "Sometimes, less is more." She doesn't intend to leave another conference in a vehicle with a blaring siren.

Wanda's son wants her to move in with his family. He admires her advocacy but wants to keep a closer eye on his mom. Wanda is willing to consider it—but not just yet. She has another timetable in mind.

"After 2020, maybe," Wanda says. Just the mention of the year makes me shudder with exhaustion. Looming ahead of us are months of grueling politics and intensive organizing and voter drives and protests and town halls, all of it requiring an army of committed volunteers.

It is an irresistible and dangerous brew for any HIV advocate who can’t say no.

Mark S. King is a writer and long-term HIV survivor. His blog, My Fabulous Disease, has been nominated for a 2019 GLAAD Media Award. In April, he checked himself out of the hospital—against doctor’s orders—and flew to Minneapolis for an HIV-related speaking engagement and workshop.

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