Living with Huntington’s Disease: A Conversation on Advocacy, Mental Health, and Self-Care

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I recently had the privilege of sitting down with Lauren Holder, Producer and Host of the Help 4 HD podcast, who is also a caregiver, advocate and person living with Huntington’s Disease (HD). Lauren is someone whose work in the HD community has not only been transformative for so many others, but also deeply personal. From navigating the mental health challenges associated with HD to advocating for more and better resources, she shared her journey, struggles, and the ways she’s found resilience and strength to continue her work. Lauren has participated in two Patient Focused Drug Development (PFDD) Listening Sessions with FDA, a clinical trial, and numerous national and international advocacy conferences—working closely with researchers and academicians studying the disease.

Lauren and I focused on mental health and wellness because it is a core component of good self-advocacy and a common thread across many different advocacy journeys and diseases. Here’s our conversation:

Q: Tell me about your organization and its mission. How did you come to be connected with it, and how has it shaped your advocacy work?

Help 4 HD International is an incredible organization. It started as a podcast and radio show, and when I first connected with it years ago, I was actually the very first guest on the show. It wasn’t even called Help 4 HD back then, but I’ve seen it grow into something truly vital for the HD community. Now, I not only produce but also host the podcast.

The organization’s mission really speaks for itself: “Help 4 HD envisions a world where everyone knows what Huntington’s disease and Juvenile Huntington’s disease are, and where compassion is a normal response to the devastation this disease causes.” That’s the vision we strive toward, and it resonates with me deeply, especially as someone who lives with the disease and has seen its impact firsthand.

My personal connection to Help 4 HD came at a time when I was really struggling. In 2015, I had to step back from my advocacy work to become my dad’s primary caregiver and legal guardian. A year later, my mom had a heart attack, and I was juggling both of them. During that time, I lost my job and felt like I was in a really bad mental space. The work I had done in advocacy before had been a coping mechanism for living with HD, and when I didn't have that anymore, I just didn't know how to manage it.

Help 4 HD Podcast host Lauren Holder

Then, in 2018, I got a call from Katie Jackson, asking if I would be interested in producing the Help 4 HD podcast. It felt like a lifeline. I jumped at the chance, and now, being involved again has been a real blessing. It's been a godsend for me and I'm incredibly grateful for the opportunity to still be part of this work.

Q: What sort of experiences with mental health are the most common for people from HD-impacted families? Does a genetic test impact that?

It's definitely a mixed bag. Anxiety is probably the most common mental health challenge for people living in HD-impacted families, whether they're at risk themselves or have already chosen to test. Just living in a family affected by HD can trigger anxiety—whether it's the fear of becoming symptomatic or watching a loved one deteriorate. Many of us become caregivers at a young age, which only adds to that stress.

We're also facing a mental health crisis around grief. It feels like we're always in a state of grief—whether it's anticipatory grief for ourselves or our loved ones, or actual grief after a loss. We often find ourselves cycling through the stages of grief over and over again, but there aren't enough resources to help us navigate it. Social anxiety, depression, bipolar disorder, and other mental health issues are also common, especially for people who are symptomatic with HD. And sometimes, these mental health issues are the very first signs of HD itself.

Q: What do your self-care practices look like?

That's a tough one for me because I'm naturally a caregiver. I cared for my dad for years before he passed away in 2021. Being a caregiver makes it difficult to focus on self-care, but I'm working on it. Right now, it looks like simple things—like leaving my phone inside when I go outside so I can be present with my kids. Whether it's playing a game of "Green Light, Red Light" or doing a craft together, I try to be fully in the moment.

I also take time every day to sit outside by myself and just watch the birds, squirrels, and a chipmunk—I actually named him Chippy, he's a frequent visitor– that come by. It's grounding for me. I even tried gardening once, but I'm not great at it, so instead, I created a fairy garden with my kids, which ended up being really fun.

Sometimes, self-care is as simple as taking a bath with Epsom salts and bubbles and allowing myself to have a good cry. Other times, it's about simplifying my evening routine—letting my kids hop into bed with me so I know they're safe, and I can fall asleep without anxiety. It's all about finding those moments of peace, even if they're small.

Q: Self-advocacy can be tough, but you do such an incredible job of it! How do you manage it? Do you have some red lines or topics you don't dwell on?

Thank you! I learned a lot about self-advocacy through caring for my dad. I was his legal guardian, and it was incredibly important to me that he continued to have a voice throughout his illness. I made sure he could speak during doctor appointments and made decisions as long as he was able. Even when his abilities were limited, I worked hard to maintain his autonomy because I knew how much that mattered.

That experience really taught me the importance of advocating for myself. I learned that I have to speak up for my needs just like I did for my dad’s. As for topics I avoid, I don’t really have any. I try to feel it all—whether it’s anger, sadness, or frustration—because only by feeling it can I truly process and move forward.

Q: There’s a lot written and studied about stigma in mental health. How do you see stigma in the HD space, and how do you address it?

There’s a major mental health crisis within the HD community. As I mentioned earlier, many of us live in a constant state of grief, and tragically, the suicide rate in our community is up to 10 times higher than the national average. This crisis is exacerbated by a lack of resources. While we do have some support systems—traditional support groups, online communities, and even newer initiatives like Game Over HD, a gaming club for young adults impacted by HD—there’s still a long way to go.

Stigma is a huge barrier in addressing mental health in the HD community. We’re often so focused on the physical symptoms of the disease that we overlook the psychological toll it takes. In my work, I try to create spaces where people can openly talk about their feelings and experiences, without fear of judgment. By acknowledging the mental health aspects of HD, we can begin to destigmatize it and build the support structures we so desperately need.

That’s such an important point—that quality of life is really tied up with mental health in many ways. One reason C-Path works with advocates is to gather and include the perspectives of people living with the disease. This improves the quality of the work and ensures that their experiences, needs, and perspectives are actively incorporated into the drug development process.

Q: Any thoughts on mental health best practices for the HD community?

There are a few key tools that have helped me—and that I think can benefit others in the HD community. Peer support is crucial. Connecting with others who understand your experiences can be a lifeline. In addition, compartmentalization—learning how to separate your emotions from immediate tasks—can help manage overwhelming feelings.

Talk therapy is invaluable for processing everything we go through, and medication, when needed, can provide necessary support. It’s about finding the right combination of tools that work for each individual. But ultimately, creating a community where people feel safe to share their mental health challenges is one of the most important things we can do.

Thank you so much, Lauren, for speaking out and your continued engagement with us and the community. This conversation sheds light on the complexities of living with Huntington’s disease—not just the physical symptoms but the emotional toll it takes on families. This sort of information will help researchers and clinical trial designs in the future as they are able to understand the context of a participant’s experience and areas where they may need support to successfully participate.